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The Development of the Bronx Community Research Review Board: A Pilot Feasibility Project for a Model of Community Consultation

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Abstract

Background: The Bronx Community Research Review Board (BxCRRB) is a community–academic partnership (CAP) between the Albert Einstein College of Medicine and The Bronx Health Link (BHL). Rather than asking clinical investigators to create their own individual process de novo, we have developed an innovative, structural approach to achieve community consultation in research planning, implementation, and dissemination that involves and educates the public about research.

Objectives: To collaboratively develop (1) an independent research review board of volunteer community residents and representatives that tests a model of community consultation, dialogue, and “community-informed consent” by reviewing community-based research proposals; and (2) to increased understanding of and participation in clinical research in the Bronx.

Methods: (1) Recruiting members from the Health and Human Services committees of community boards, focus groups, and community health events; (2) interviewing and selecting members based on community involvement, experiences, availability, and demographics of the Bronx; (3) training

members in bioethics and research methods; and (4) facilitating meetings and discussions between clinical researchers and the BxCRRB for research review and consultation.

Results: There is substantial interest among Bronx residents in participating in the BxCRRB. The BxCRRB provided feedback to researchers to ensure the protection of participants’ rights, to improve research design by promoting increased accountability to the community, and expanded its scope to include earlier stages of the research process.

Conclusion: The BxCRRB is a viable model for community consultation in research, but more time for implementation and evolution is needed to improve its review practices and ensure community input at all stages of the research process.

Keywords

Community–academic partnership, community research review, community consultation, community informed consent, community-based participatory research, health disparities

Traditional research ethics in the United States have largely been individually focused, narrowing the broad concerns of traditional ethics to the immediate problems of individuals, isolating them from family and community. This is detrimental to ethical deliberations, because it minimizes these influences, as well as social traditions, shared values, and environments.¹ Many believe that communities may be affected by research in different ways than individuals.² Although moral complexities emerge when

attempting to establish “group and community rights” or define “community-informed consent,” Quigley has developed guidelines based on Native community case studies.³ If communities share enough in common to enable them to claim certain rights, then researchers are obliged morally to respect the structural and cultural integrity of the group they study and would be breaching their duty if they disrupt existing solidarity or intrude on communal life without obtaining the community’s informed consent.

This report describes the development of the BxCRRB, a pilot research project in community-based research review and participation in New York City. The BxCRRB is a program of volunteer Bronx residents who have been trained in bioethics and clinical research design by the staff of BHL, a community-based health advocacy and education organization. There are two major objectives for this project: (1) To develop an independent research review board of volunteer community residents and representatives that will test a model of community consultation, dialogue, and “community-informed consent” by reviewing community-based research proposals, and (2) to increase understanding of and participation in clinical research among residents of the Bronx. The BxCRRB seeks to ensure that clinical researchers address the needs of and protections due to Bronx residents who participate in research, build trust between the Bronx community and clinical researchers, and ensure that the Bronx community shares the benefits of clinical research.

In recent decades, many communities across the United States have sought increased ownership of health research projects, and there are several models to achieve this. The BxCRRB can be contrasted with both traditional academic institutional review boards (IRB) and community advisory boards (CAB).⁴⁻¹⁰ CABs generally advise researchers for community engagement in recruitment and retention of participants, as well as interpretation of results. CABs may occasionally review research proposals. Academic IRBs review research proposals and ensure there are adequate protections for individual participants. The BxCRRB reviews proposals from researchers assessing risks and benefits for the entire community, not just individual study participants. The BxCRRB also reaches out to and educates the community about their rights and the pros and cons of participation in research, thereby creating a feedback loop between communities and research institutions. Because the latter portion of the BxCRRB is still in development, this article concentrates on the research review process.

WHY CAP?

With 1.4 million residents, the Bronx suffers from health disparities in many areas. In 2010, it was the poorest urban county in the United States, with one third of adults and 51.4% of children and adolescents living below the federal poverty

line.^{11,12} Our community had the lowest median income and lowest median age of all NYC boroughs in 2011, and one third of residents did not graduate from high school.¹³ Of people living in the South Bronx, 66.5% are Latino and 35.6% are of African descent.¹⁴ According to the Robert Wood Johnson Foundation’s County Health Rankings, the Bronx ranks last among New York’s 62 counties in both health factors and outcomes, including diabetes, infant mortality, and mental health.¹⁵

In part because of its large population and relatively poor health outcomes, there are many community-based organizations (CBOs) in the Bronx addressing local needs and increasing access to services, as well as a large concentration of academic health centers. Taken together, these factors indicate potential for CAPs. Studies have shown that CAPs can increase trust and community input in designing, implementing, and disseminating the results of effective health interventions.^{16,17} The BxCRRB is the result of a CAP between BHL and the Albert Einstein College of Medicine (Einstein).

METHODS

The BxCRRB is itself a research study funded by the National Institutes of Health (NIH) that is intended to evaluate the feasibility of this model of community-engaged research (CEnR). For this project, Einstein and BHL are the academic and community partners, respectively. BHL’s Executive Director and Einstein’s Assistant Dean for Community Engagement, Hal Strelnick, were Co-Principal Investigators (Co-PIs) of a 2-year NIH Partners in Research award in 2008. BHL has provided meeting space and staff support for recruitment, interviewing, and training of new members; note-takers for each meeting; preparation of forms; and stipend distribution. The academic partner provided both technical assistance for training and research projects for the BxCRRB to review.

This study required the participation of human subjects. Therefore, BxCRRB members are provided stipends (\$50) and a roundtrip Metro Card (\$5.00) for every meeting and training that they attend. The Co-PIs also secured an external evaluation of the study design, a collaborative effort between BHL and the Institutes for Clinical and Translational Research (ICTRs) of Einstein and Columbia University, respectively. The Einstein Committee on Clinical Investigation (IRB)

approved the study design in December 2008 (CCI #2008-330), and as of January 2013 the Co-PIs have annually renewed IRB approval and participant consent.

Designing the BxCRRB Model

After the NIH funded the grant proposal, BHL's Executive Director, Joann Casado, along with BHL Coordinator of Community Research Initiatives, Jocelyn Camacho, designed the BxCRRB model. They asked other CABs about their processes for research review, conducted their own literature review, and investigated Bronx community beliefs and attitudes about research (Joann Casado, written correspondence, January 21, 2013). BHL had conference calls with directors and staff members of other CABs and conducted one site visit in Hartford, Connecticut (Joann Casado, written correspondence, January 21, 2013). BHL learned how these organizations had recruited members and that members had required additional training in IRBs, informed consent, bioethics, and research vocabulary. These findings helped BHL to design a structure for training new members and a process for reviewing research proposals.

BHL's research into other models of community research review occurred alongside a series of six focus groups conducted by BHL that investigated Bronx community perceptions of and attitudes about research. Focus groups participants said that, for them to participate in a clinical research study, they would need to know concrete details about the research design, background information about treatments that are already available, and more details about the risks and benefits of participation. Other participants stated that they already had enough trust in researchers and health care institutions to participate in a study. During the last two focus groups, participants frequently said they perceived discrimination in health care settings against ethnic minorities and people on public health insurance, resulting in substandard care and a lack of respect for their humanity, even when the discussion was specifically oriented toward research (Pelto D. Beliefs and attitudes about health research in The Bronx, New York City. Unpublished manuscript. 2010; Joann Casado, written correspondence, January 21, 2013).

BHL also conducted a literature review of minority trust in healthcare providers and researchers and models of community research review.^{18–20} The literature supported

the findings of BHL's focus groups that many community residents distrust researchers, which can negatively affect health outcomes. For models of community research review, BHL investigated Native American models in addition to the aforementioned CABs. The Co-PIs followed the research guidelines as outlined by Dianne Quigley, which included the following components: (a) Determining whether the investigator's goals and community's needs are compatible; (b) developing the collaboration or partnership with the community (including Community Advisory Committees, collaborative agreements and compacts, equity issues, and cultural sensitivity); (c) informed consent issues (including education on risks and benefits, individual and community autonomy, and "voluntariness"); (d) community knowledge collection; (e) research data management (including confidentiality, control and ownership, interpretation, dissemination, and publication); and (f) sustainability of research efforts.²¹ Many tribal governments hold regulatory authority over research, which is a form of "community consent." Other tribal councils rely on voluntary participation by both researchers and tribe members, which is "community consultation."^{22–37} Because the Bronx is a highly heterogeneous urban community, the latter model of community input seemed more feasible.

Implementing the BxCRRB Model: Year One

Once the design of the board was completed in early 2010, BHL recruited and interviewed potential members in November and December of the same year. BHL required that applicants be at least 18 years old, speak and read English, and live in the Bronx. BHL staff presented to 7 of 12 Bronx Community Boards (particularly to their Health and Human Services Committees), seeking applicants interested in health research. BHL also recruited at its health education events and other focus groups and advertised in its E-Communication newsletter. After the first round of recruitment, BHL interviewed applicants according to whether they represented the demographics of the Bronx, their community networks, interest in health research, and lived experiences. Of 19 applicants, BHL selected 13 Board members and 2 alternates. (Recruitment materials used by BHL are in Appendix A; interview guides and candidate rating sheets are in Appendix B: see http://muse.jhu.edu/journals/progress_in_community_health_partnerships_research_education_and_action/v007/7.3.martin-del-campo01_supp01.pdf)

After making final selections in December 2010, BHL hired Esperanza Martell (Professor, Hunter School of Social Work) as a consultant and facilitator for trainings and researcher meetings. Every training session began with BHL serving lunch and members dedicating the training to persons in their lives. The exercise was for team building and for building member solidarity. The trainers used educational strategies modeled after the work of Paulo Freire, emphasizing participation and community empowerment. BHL assigned newspaper articles for members to read before training, and some sessions included guest speakers from research institutions. Each session closed with a written evaluation and members identifying what they liked and what they would like to have seen done better, which helped BHL to improve the quality of subsequent sessions. BxCRRB members received a transportation reimbursement for each session, and stipends at the end of every third session. (Samples of BHL's Evaluation and Stipend Acknowledgment forms are in Appendix C: see http://muse.jhu.edu/journals/progress_in_community_health_partnerships_research_education_and_action/v007/7.3.martindelcampo_supp01.pdf)

After completing the training sessions, members from the first cohort reviewed six research proposals between March 2011 and February 2012. In preparing for proposal reviews, Joann Casado created an application form for researchers seeking to present to the BxCRRB and a research review checklist for BxCRRB members. In addition to questions about the research methods and individual risks and benefits, the application requests information on recruitment methods, community partnerships, funding sources, and community-level risks and benefits, along with the informed consent form and the researcher's curriculum vitae. The checklist for BxCRRB members measures the quality of community partnerships and risks and benefits for the community (the application form and checklist are in Appendix D, see http://muse.jhu.edu/journals/progress_in_community_health_partnerships_research_education_and_action/v007/7.3.martin-del-campo01_supp01.pdf). BHL conducted all communication and coordination, and during review sessions BHL both hosted and acted as timekeepers. Each session closed with BxCRRB members providing recommendations to the researchers (as recorded in the minutes), and Joann Casado emailed those recommendations to the researchers.

The Einstein-Montefiore ICTR has a Clinical Research

Training Program (CRTP), which provides a master's degree in clinical research methods to physicians and other doctoral-trained health professionals. CRTP agreed to require its masters' candidate scholars conducting clinical research on human subjects to present to the BxCRRB, and this later expanded to junior faculty with ICTR Career Development Awards. The academic co-PI, Hal Strelnick, asked investigators to make brief oral presentations followed by discussion and questions for about 1 hour. Both the founder and director of the CRTP observed one BxCRRB review each of their scholars' research projects, whereas the academic co-PI has observed all its reviews. After the first four presenters, subsequent investigators learned about the BxCRRB by word of mouth.

Implementing the BxCRRB Model: Year Two

By January 2012, BxCRRB membership had dwindled to five. Some who left had wished to remain on the BxCRRB but had other obligations. BHL asked other members not to return after a summer break, because they were not preparing for or participating during meetings. BHL began recruiting a second group of BxCRRB members at community board meetings, health fairs, and related events in the Bronx. BHL received 17 applications from individuals living in nine of the Bronx zip codes. BxCRRB members participated in the majority of interviews and approved the selections of all nine new members, evaluating each by the same criteria as BHL did for the first round (e.g., community networks, lived experiences).

After final selections, BHL and Einstein again designed a training syllabus that built on the first round training sessions. BHL scheduled six sessions during May and June of 2012, and each session lasted 3 hours (including half an hour for serving lunch). The subjects of trainings (bioethics, research methods, etc.) remained the same, as did the meeting structure for each session. However, much of the content differed during the second round of trainings, and Figure 1 contains a flow chart with tools and lesson plans that BHL used. For these sessions, trainers emphasized the distinction between clinical trials and other research designs and the historical development of federal IRB protocols.^{28,29} Using the Tuskegee Syphilis Study and forced sterilization laws as examples of abuses, trainers also discussed the distinction between observational research and clinical care.³⁰⁻³³

Francisco Martin del Campo facilitated the second round

Figure 1. BxCRRB Training Flow Chart

of trainings and used a participatory approach that emphasized equal roles as co-learners and co-teachers. Herein we have provided details on one training to demonstrate how facilitators used this teaching-learning strategy. During the training session on IRBs, BHL moderated a group activity that discussed different models of CEnR, specifically the Galveston Island Community Research Advisory Committee, West Harlem Environmental Action Network's Ethical Research Review Board, Special Services for Groups' Community IRB in Los Angeles, and the Native Hawaiian Health Care Systems IRB.³⁴ The facilitator distributed short descriptions of each model that were based on a report from the New York City Community Partner Forum in March 2012, and members divided into small groups and discussed strengths and weaknesses for each model. Participants then regrouped and reported their findings.

After a short break, Mr. Martin del Campo facilitated a discussion on reading assignments regarding the history of IRBs in the United States and Kennedy Krieger Institute's controversial lead paint study.³⁵ For the history of IRBs, Mr. Martin del Campo argued for greater context beyond the Tuskegee Untreated Syphilis Study when considering the National Research Act of 1974. Specifically, the facilitator pointed to the Helsinki Declaration of 1964, a 1966 Public Health Service internal memorandum disseminated to researchers, and Henry Beecher's 1966 article in the *New England Journal of Medicine* as evidence that the Tuskegee controversy was partially a result of victories achieved by the Civil Rights Movement.³⁶⁻³⁸ For the lead paint study, the facilitator asked BxCRRB members why they believed this seemingly unethical study received IRB approval, and members' responses raised larger questions about social and economic inequality and all-too-pervasive maltreatment of working-class people in the United States. Like the other sessions, the overall goal for this training was for BxCRRB members to participate and to relate IRBs and research ethics to their own lives.

After new BxCRRB members completed the training sessions, they met with two researchers at the end of 2012. However, the BxCRRB's priorities temporarily transitioned from meeting with researchers to developing itself as an organization. The BxCRRB has held two retreats, created a mission, vision, and values statement and is developing bylaws and a strategic plan for the future. (Appendix E contains the

BxCRRB's current mission statement. See http://muse.jhu.edu/journals/progress_in_community_health_partnerships_research_education_and_action/v007/7.3.martindelcampo_supp01.pdf) This internal development includes community outreach and research education, which is an essential part of the BxCRRB model of community engagement. In April 2013, BxCRRB hosted two standing-room-only workshops at the Bronx Health Summit, sponsored by the Bronx Borough President.

RESULTS

External Evaluation

In 2011, Alejandra Aguirre, MPH, with Columbia's ICTR, evaluated the first year of the BxCRRB. Her methods were personal interviews with BxCRRB members, BHL staff, and Einstein faculty and a focus group with researchers who presented to the BxCRRB. During the first round of recruitment, Ms. Aguirre reported that some members initially lacked a clear understanding of the purpose of the BxCRRB. Some had believed they would be promoting community health and access to healthcare, not reviewing research proposals. Members also expressed concern over the group's readiness during meetings and whether researchers respected them. Some members perceived that others were not doing their "homework" and that it was affecting their responses (or lack thereof) during meetings.

One researcher was unclear about the purpose of the meeting, and some members and researchers were concerned about antagonistic attitudes toward researchers among some BxCRRB members. On the positive side, both members and researchers expressed increased awareness of CEnR. Some BxCRRB members also said they felt responsible to the community and were more inclined to become community members of an IRB. Ms. Aguirre delivered an oral presentation with PowerPoint slides based on her preliminary and final evaluation to the BxCRRB: a full written evaluation is anticipated in 2013.

Recruitment

As discussed, BxCRRB members were highly involved in the second round of recruitment and selection of new members. Table 1 contains demographic data on the first and second

group of applicants, respectively. A larger percentage of applicants in the second group held graduate and/or professional degrees, with several having experience working with Bronx health organizations. This indicates that professionals may have had more access to information on the BxCRRB than nonprofessionals before and during BHL's recruitment drive. BxCRRB members from the first cohort selected several professionals from the second round of applicants if and only if the applicants had a history of volunteering or working with CBOs.

Training

For the training sessions, participant evaluation forms were an important tool for improving the quality of each workshop. BxCRRB members also provided input informally by calling BHL staff and providing suggestions on how to improve the sessions. Suggestions included sending agendas

out in advance, better time management, and allowing more time for questions. Indeed, during each workshop members had many questions about research methods, the history of ethical abuses, and the clinical research process. Equally important was the suggestion by several members that trainers use real examples of research studies for each method discussed during training.

The Research Review Process

During the first year of research review sessions, the BxCRRB conducted reviews at roughly the same point in the research process. Table 2 summarizes these review sessions. Members reviewed proposals either immediately before or after researchers received IRB approval to conduct their research, with one exception for a BHL focus group where IRB approval was not required. Beginning in February 2012, BxCRRB members began meeting with researchers at earlier points in the research process. One doctoral candidate requested a meeting with the BxCRRB before having a formal proposal to receive community input on the HIV-positive population that she was studying, and she returned in late 2012 to discuss how she changed her "syndemic model" to include feelings of "self-worth" as a result of their meeting. The BxCRRB also met with researchers who were designing a research ethics training curriculum for community health workers in the Westchester Square Project to obtain informed consent in their native language (Bengali/Bangla).

After BHL sent BxCRRB recommendations to investigators there were few attempts to ascertain how they changed their research projects. The community partner had little input in deciding which researchers would meet with the BxCRRB.

Sustainability

Without adequate funding sources, the cost of maintaining a structure like the BxCRRB is prohibitive for many CBOs. Table 3 contains budget information for sustaining the BxCRRB model, and it excludes costs such as traveling and accommodation for conferences and community outreach events. The most expensive items in the budget are the salary for a full-time staff member and meeting stipends. Stipends were effective in retaining some members on the BxCRRB, whereas others said they cared little about compensation.

Table 1. Applicants to Bronx Community Research Review Board, 2011 and 2012

Category	2011	2012
Applicants	19	17
Selected	13 (36%)	9 (53%)
Alternates	3 (16%)	8 (47%)
Age (y), mean (range)	45.4 (20–85)	50.2 (28–74)
Gender		
Male	5 (26%)	5 (29%)
Female	14 (74%)	12 (71%)
Race/ethnicity		
White	0	2 (12%)
African American*	11 (58%)	11 (65%)
Latino**	8 (42%)	3 (18%)
Asian	0	1 (6%)
Community board member	6 (32%)	8 (47%)
Zip Codes represented (of 24)	10 (40%)	8 (33%)
Education		
Some high school or less	2 (10%)	0
High school diploma/GED	0	1 (6%)
Some college or vocational	9 (47%)	3 (18%)
College degree	5 (26%)	2 (12%)
Graduate/professional degree	3 (16%)	13 (76%)

* Includes West Indians from Jamaica and Trinidad & Tobago.

** Includes Argentinian, Cuban, Dominican, Honduran, and Puerto Rican.

Table 2. Results of Research Review Meetings until June 2012

Date	Level of Investigator	Subject of Review Session	Results	Outcomes
March 15, 2011	Physician master's degree candidate, Institute of Clinical and Translational Research (ICTR) at Einstein	Clinical trial: Buprenorphine treatment for people who abuse heroin.	Answered questions about funding, community risks and benefits, and received feedback.	Researcher said it was helpful but sensed feelings of antagonism and mistrust among BxCRRB members. He said researchers would come out of the goodness of their heart but they are not community savvy.
April 26, 2011	Physician master's degree candidate, ICTR	Survival analysis for Latinos living with liver cancer based on data collected by Montefiore Medical Center.	Answered questions on the purpose of the study, level of community involvement, etc.	Because this study was retrospectively analyzing data that was already gathered, the researcher did not believe there was much room for community involvement. Board members offered this researcher their assistance with current or future research projects.
May 17, 2011	Physician Career Development Award (KL-2) from Einstein, ICTR	Focus groups and personal interviews on brain aging research with people over 50 who live in Co-Op City.	Received feedback on how to tailor questions to the South Bronx community.	Board members suggested the researcher shorten the questions and offered to review survey or organize focus groups for the South Bronx.
June 7, 2011	Physician KL-2, ICTR	Clinical trial for sodium bicarbonate as a viable treatment for acidosis and kidney disease.	Received feedback on how to involve community partners and disseminate results.	There was a lack of mechanism for community involvement this particular study. Researcher said they planned to inform the community by sending study results to participants and providers and publishing reports on medical journals.
October 25, 2011	Consultant for The Bronx Health Link	Focus groups on community perceptions and levels of knowledge about genetics among people in the Bronx.	Answered questions about risks, benefits, and methods of recruitment.	The principal investigator said the research team will share findings with study participants, hospitals, and researchers, and TBHL will use the results for internal programming.
February 14, 2012, and June 19, 2012 (including follow-up meeting)	Research staff at Einstein	Survey of people's levels of interest in participation in research in the Bronx.	Answered questions, received feedback on recruitment locations, and disclosed the results of the study.	Researcher said she would inform participants about study results and would make announcements at a library or another public forum. She clarified that the term "people of color" refers to minorities and people who are underserved. BxCRRB members requested the researcher return to discuss the results.
February 14, 2012; May 15, 2012; December 11, 2012; March 19, 2013 (including first follow-up meeting)	Doctoral candidate at Einstein	Study of risky sexual behaviors among women in the Bronx (concentrating on HIV risk) to design a syndemic intervention model.	Received feedback on her target populations and returned for clarifications.	Some board members said that the researcher was not considering feelings of low self-worth in the syndemic model and that sexual abuse is just one of many forms of violence that can cause such feelings. The researcher incorporated BxCRRB recommendations into the intervention model and returned to continue the discussion on December 11, 2012.
May 15, 2012	Faculty member and research fellow	Training curriculum on bioethics and informed consent for non-English-speaking community health workers.	Received feedback on levels of comprehension and readability.	One board member suggested that trainers should complete sensitivity training before going into the field.

DISCUSSION

The BxCRRB’s experience raised the following issues for practitioners of CEnR to consider:

1. Recruiting and training BxCRRB members, as well as designing methods for measuring community input in clinical research, is iterative and takes time to develop. It was challenging to perfect this model of CEnR in just 2 years, which was the length of the original NIH grant for this study.

2. It is important to develop effective evaluation measures, which can provide feedback to staff about how to improve the project. BHL staff found responses to the open-ended questions “How could this workshop been improved?” and “Do you have any other comments or suggestions?” especially helpful.

3. Another theme that emerged during the BxCRRB’s first 2 years is the value of participation at different stages in the research process, from developing a valid research question to disseminating the results of a study in the community where researchers recruited participants. Figure 2 summarizes those stages. Minkler et al.³⁹ argue that CBPR must entail partnership at all stages of the research process in which communities are willing to partner with researchers. BxCRRB members are willing to partner during all stages of a research project, starting with creating a valid research question that addresses
- community needs and concerns. Thus far, no Einstein researchers have asked the BxCRRB to collaboratively develop a research question.

4. Another issue is how active the BxCRRB should be in seeking researchers to meet with them. Thus far, the BxCRRB has waited for researchers who are interested in meeting with them. Is it better practice to actively seek out researchers who are willing to meet or to wait for those who choose to contact the BxCRRB, or to do both? An assessment of organizational capacity and the health concerns of the community are important when answering this question. There are too many clinical research projects in the Bronx occurring at a given time for the BxCRRB to review by itself. A consensus has emerged that BxCRRB should schedule follow-up meetings to ascertain whether researchers are implementing their recommendations, to evaluate the BxCRRB’s success in influencing research designs and improving research. The academic partner (Einstein) could have better informed the community partner (BHL and BxCRRB) on who was eligible and how researchers were recruited for review sessions.

5. Another theme is maintaining clear and timely communications and role expectations between the community and academic partners. Assuming they have a similar mission, vision, and core set of values, partners must agree to a set of

Table 3. Bronx Community Research Review Board: Program Costs					
Expense	Unit	Number of Units	Unit Rate (USD)	Total Costs (USD)	Explanation
Meetings With Researchers					
Stipends for BxCRRB members	Per meeting	10	708.5	7,085	13 members × \$54.50 each (including Metro cards) = \$708.50 per meeting
Food	Per meeting	10	150	1,500	10 meetings with researchers per year
Subtotal for meetings with researchers				\$8,585	
Meetings With Community					
Stipends for BxCRRB members	Per meeting	5	708.5	3,543	13 members × \$54.50 each = \$708.50
Food	Per meeting	5	150	750	5 meetings with community per year
Subtotal for meetings with community				\$4,293	
Administrative Costs					
Staff salary	Per year	1	35,000	35,000	
Indirect costs	Per year	1	2,576	2,576	Total for meetings (\$12,878) × 20% = \$2,576
Subtotal for administrative costs				\$37,576	
Grand Total					
				\$50,454	

overarching goals for building trust, modifying traditional research practices, and improving health outcomes. It is helpful for partners to meet regularly to ensure that they both know what to expect during meetings and be mutually accountable. It is insufficient for avenues of communication to merely remain open, as both partners can easily become preoccupied with the work of their own institution.

6. For the community partner, what tools and resources are needed for a CBO to successfully launch a project using the BxCRRB model? First, it is important for an organization to have strong community networks, and ideally the organization would regularly serve vulnerable members of the community. Through these networks, the community partner can recruit new members to the BxCRRB, educate to the community about research, and provide suggestions to researchers on how to disseminate their research findings. Small organizations such as BHL (with only eight staff members) would also benefit from more training in qualitative and quantitative research methods. Last, it is clear that the community partner must be efficient and well-organized, because developing a board such as the BxCRRB is an extensive undertaking, which requires staff time and resources that are often scarce for otherwise ideal community partners.
7. For the academic partner, other issues have arisen. Einstein has several CABs for different research centers (e.g., genetics, HIV/AIDS). Should the BxCRRB have a formal role within Einstein's research review process, as the director of its IRB has offered? As a corollary, are there specific kinds of clinical research that the BxCRRB should concentrate on, or should it remain open to any clinical researcher requesting BxCRRB's review and feedback? Because there is a large amount of research occurring

in the Bronx, it would be helpful if academic partners assessed their internal needs for community input.

8. What kind of regulatory authority should the BxCRRB have? Unlike an IRB with a Federal-Wide Assurance (FWA), the current BxCRRB model has no legal authority and can only communicate its concerns to an investigator's own academic IRB. As it engages in strategic planning, the BxCRRB is debating whether becoming an IRB with an FWA, whether independent or within Einstein's IRB system, could ensure that researchers would adequately listen to and respect their voice. The BxCRRB model is not simply meant to train community members to review research proposals, but also reach out and educate the Bronx and Einstein communities about local health and clinical research needs. Whether BxCRRB decides to obtain a FWA or not, community outreach is an essential strategy for this model.
9. Einstein has offered to continue funding this project after the NIH grant ends, yet is it the best practice for the BxCRRB to continue as an independent entity? If the BxCRRB were funded by an academic institution that at the same time is sending researchers for research review, there may be conflicts of interest. Accepting such funding could make the BxCRRB reluctant to "bite the hands that feed." Should the BxCRRB accept funding from one single research institution, multiple institutions in New York City, or no academic institutions whatsoever? If it is the latter, what funding sources are available outside of academic institutions? If they do accept funding from academic institution(s), can they remain an independent entity?

CONCLUSION

The BxCRRB model has both strengths and weaknesses. Strengths include the face-to-face discussions between com-

Figure 2. BxCRRB Training Flow Chart

munity members and researchers, with both parties having equal roles as both learners and teachers. As a result of their work on the BxCRRB, some members are more interested in participating in research studies and serving as a community representative on an IRB. Last, through community education and participation, the BxCRRB model addresses issues of community mistrust of researchers and care providers, and provides a confidential mechanism for community members to discuss their feelings about and experiences with research.

In its development the BxCRRB has encountered unique problems that may or may not be generalizable. First, there was much attrition among both BxCRRB members and BHL staff. Second, the BxCRRB has only existed for just over 2 years (as of May 2013), so there is still much work to do to perfect the model. Third, people with graduate or professional degrees are currently overrepresented on the BxCRRB compared with the general Bronx population. Last, the BxCRRB did not begin following up with researchers until May 2012, well over a year after the BxCRRB began reviewing proposals. This makes it difficult to evaluate the BxCRRB's impact on research and individual researchers.

Although there remains much work to be done, the BxCRRB has made progress in providing an innovative model of community input and feedback to clinical researchers in the Bronx. Throughout the development of the board, a number of questions have emerged regarding its shape, areas of focus, and future direction. The BxCRRB model holds great promise for strengthening CAPs and providing a feasible and sustainable model for community consultation. With adequate funding and an engaged

academic partner, CBOs can recruit, train, and support board members using this model of community consultation.

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