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Lessons Learned from the Evolution of an Academic Community Partnership: Creating “Patient Voices”

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Abstract

The Problem—Long-term partners received federal funding to develop the Patient Voices Network, a partnership of safety-net family practices and their patients to develop health improvement strategies. The scope and structure of the newly funded grant presented unexpected challenges that threatened the future of the partnership.

Purpose of Article—To present a case study of the evolution of an existing partnership and offer lessons learned along with recommendations for future partnerships.

Key Points—Federal funding formalized the partnership in a way that required looking at it through a new lens. Leadership, programmatic, personnel, and financial challenges emerged. Short-term and long-term strategies were applied to address evolving needs.

Conclusions—This case study demonstrates how federal funding raises the bar for academic–community partnerships and how challenges can be worked through, particularly if the partnership embraces the key principles of community-based participatory research (CBPR).

Recommendations have been applied successfully to future initiatives.

Keywords

Community-based participatory research; health disparities; academic community partnership; capacity building

The City of Buffalo has been ranked as the third poorest large city in the nation, with 29% of residents living in poverty.¹ In 2009, the poverty rate in Buffalo was approximately double state and national averages. Buffalo is 37% African American.² Two ZIP codes are 40% Hispanic (mostly Puerto Rican), and have large Iraqi, Burmese, Sudanese, and Somali refugee communities. Buffalo is an aging community with high rates of chronic disease.³ For example, Buffalo has especially high rates of diabetes (13%) and hypertension (33%) in the predominantly African-American community of the East Side. Considering the diversity and uniqueness of the Buffalo community, CBPR^{1–5} is a valuable approach to develop translational interventions that are meaningful with the greatest impact.

The Primary Care Research Institute (PCRI) is a transdisciplinary research unit dedicated to improving health, patient care, and medical education by encouraging scholarship in primary

care. The unit pursues a dynamic and diverse agenda of clinical, community, and health systems research committed to practical applications. The PCRI is housed within the State University of New York at Buffalo's Department of Family Medicine and is supported by a diverse funding stream that includes federal, state, foundation, and local sources.

Jericho Road Ministries (JRM) is a not-for-profit organization that has strong grassroots integration in the West and East Sides of Buffalo. It offers a number of distinctive programs that are making a significant difference, including a mentoring program for refugee and high-risk pregnant women, a financial literacy program for refugee families, a mentor in-home reading program for preschool children, and a walk-in center that addresses the self-identified needs of refugee clients. JRM is funded through grants and donations from numerous individuals, organizations, and churches. It is the faith-based adjunct to Jericho Road Family Practice (JRFP), which has practices on the West and East sides of Buffalo. JRM and JRFP have become a Federally Qualified Health Center and are now referred to as the Jericho Road Community Health Center.

PCRI has had a relationship with JRM since 1998, when Dr. Glick, its founder, received an award from the American Academy of Family Physicians to conduct a health risk assessment in urban Buffalo. Dr. Tumiel-Berhalter, then a research assistant, supported Dr. Glick's efforts. The PCRI worked with JRM to write service grants and to provide evaluation services on many program-related grants.³⁻⁶ For example, PCRI and JRM partnered to implement and evaluate a Diabetes Education Program that included training the first African American Certified Diabetes Educators in Western New York.^{3,4} PCRI also evaluated JRM's Priscilla Project, which provides Doula services for refugee women. The executive director of JRM and Dr. Tumiel-Berhalter decided to submit a proposal to the National Institute of Minority Health and Health Disparities (NIMHD) as co-principal investigators (PIs) to increase the voice of the patient in practice and research. The application was successful and the partnership received its first federally funded grant (NIMHD: R24MD004936). The goal of this 2-year grant (September 22, 2009, to June 30, 2011) was to develop the Patient Voices Network, a CBPR project to involve patients from both practices to 1) conduct a cross-sectional study to describe cancer prevention screening among patients with complex chronic disease, 2) design a pilot cancer prevention intervention with Patient Action Teams (PATs), and 3) conduct a pilot cancer prevention intervention among patients with complex chronic disease.

Partnership Plan for the Patient Voices to Improve Practice Project

In planning the grant, the Co-PIs envisioned an equal sharing of resources and leadership. In brief, the proposed leadership structure (Figure 1) would be co-led by the research PI and the community PI, and it would be inclusive of the community staff, practice staff, research staff, and members of the Patient Voices Network. Even though the research and community PIs had worked together on several projects and were experienced in shared leadership and responsibility, a more formal structure of shared leadership was proposed in the grant. The co-PIs felt that, through their previous experience, they could predict the best way to work together. Processes were initially developed for the co-PIs to share in the decision-making process, the communication plan, conflict resolution, and roles and responsibilities of the

partners until the patients reached a stage in the evolution of the partnership where they felt comfortable being part of the decision making process. A Memorandum of Understanding (MOU) was created to provide the foundation for co-leading the grant (Table 1).

The Decision-Making Process

The joint PIs would serve as co-chairs of the steering committee and facilitate joint decision making to help build consensus among the partners constituting the steering committee and the PATs. Specifically, the proposed plan was to work through the steering committee, with representation from all partners, for all decision making. More sensitive issues, such as employee performance and salaries, would be decided upon solely by the co-PIs.

Communication Plan

With shared oversight by the co-PIs, all communication among participants was to be coordinated through the steering committee. Anyone could add an item to the agenda.

Conflict Resolution Plan

The co-PIs intended to jointly serve as brokers of agreement and as conflict resolution negotiators. They were to engage academic and community partners equally and assist in building consensus. Their role was to highlight the strengths and value that each side brought to the table.

Roles and Responsibilities of Program Partners

The research PI would directly oversee the grant deliverables and serve as the research co-chair of the steering committee. She would be responsible for the scientific direction of the PATs. The community PI would serve as co-chair of the steering committee and share in the decision making related to budget, protocol development, and integration of community organizations and patients. The co-PIs planned to recruit both community and research staff together, making mutual decisions on hiring and firing. They would regularly assess the project budget and jointly decide on purchases, travel, and staffing. Together, the co-PIs would oversee the work of the research assistants and community health organizers and would co-lead the evaluation of the CBPR process.

The proposed plan described did not allow for the real-world issues that would arise. The team did not have a contingency plan in place to deal with evolution of the partnership and unexpected issues. As challenges presented themselves, the team identified short-term solutions that often favored the community or research site, rather than being mutually beneficial.

Purpose of the Article

This article presents the real-world experience of the evolution of our partnership after it received federal funding to develop the Patient Voices Network. This case study describes the context surrounding issues, short-term solutions, challenges remaining, and long-term strategies for moving forward. Lessons learned are offered with recommendations that were implemented.

Methods

A narrative approach reflects the experience of the Patient Voices Team. Meeting minutes and documentation of formative processes were reviewed. Standing weekly meetings were scheduled between January and June 2011 for the Co-PIs and JRM leadership (program director and chief financial officer [CFO]) to discuss challenges, what worked, what did not, and what could be done differently. Seventeen meetings were held during this time. We highlight key elements in the process that threatened the partnership as well as elements that cemented the relationship. Project leaders documented issues, developed short-term strategies to address urgent issues, and thought proactively about long-term solutions. All co-authors contributed to the discussions on how to work together most effectively. They committed to moving forward to maintain the project and participated in drafting the manuscript and gave final approval to the submitted document.

The State University of New York at Buffalo Institutional Review Board approved all aspects of this study.

Key Points

The evolution of the Patient Voices partnership encountered opportunities and challenges with receipt of federal funding. It changed the dynamic of the partnership and created a sense of urgency that did not previously exist. Four main areas were identified: leadership, programmatic, personnel, and financial (Table 2).

Leadership

Context—The executive director of JRM, who was pivotal in decision making around the submission, and the staff member assigned to the project, both left JRM at the beginning of the project, just after funding was awarded. No one else at JRM was familiar with the project at this point, nor was there support throughout the organization. It was clear that the proposed leadership structure was specific to the co-PIs and did not plan for changes in leadership. The proposed decision-making process quickly crumbled as JRM reorganized and they began planning to merge with JRFP to become a Federally Qualified Health Center. The research team was unfamiliar with the new structure and it was unclear how Patient Voices fit in with their current efforts.

Short-Term Strategy—A new community co-PI was appointed who was recently hired by JRM to work on the project and was already involved in the grant. The grant was absorbed into JRM's division of Family and Community Health. The project now had a home and a point person from JRM leadership. The co-PIs jointly created the agenda and led monthly team meetings attended by both research and community staff. Separate meetings were scheduled to address implementation details. Meetings with the Director of Family and Community Health were ad hoc and generally occurred when a problem arose.

Challenges—The new community co-PI did not have the authority to make decisions on behalf of JRM. Her role was never redefined or clarified based on the change of JRM personnel, causing confusion and miscommunication. The partnership learned they needed

to work within the JRM leadership structure, including their board. This leadership was not familiar with the project or the approach of shared leadership. This structure protected the investment of JRM, but project-related decisions were often made outside of the context of the project and without the input of the research team. The new JRM leadership required time and training to become familiar with the program. However, they were committed to working out the challenges to have a productive relationship and successful grant deliverables. Because of the quickly changing partnership, decisions often had to be made outside of steering committee, although they always included the co-PIs. The MOU that was created originally was much too general to be of any guidance during this time and was a work in progress owing to the ever-changing dynamic of the partnership.

Long-Term Strategies—Leadership changes need to be anticipated and a contingency plan should be incorporated. We recommend having a plan in place to address leadership changes. Partners need to ensure that the project is a commitment of the whole organization, rather than an individual within the organization. Expectations for shared leadership must be explicit before grant submission. The community co-PI also needs to be actively engaged in the project and have the authority to speak on behalf of the organization.

A strong, very specific MOU should be developed and implemented. It should be a living document that needs to be reviewed, edited, and agreed upon periodically. The MOU should address key shared leadership responsibilities, including decision making. A clear chain of command within and among the involved organizations is critical to successfully implementing grant objectives. Leadership should have brief but frequent interactions to maintain effectiveness and an open communication plan so that the partnership is fully collaborative and all partners are involved. Grant and organizational priorities must align. Project organization must be well-defined and outcomes important to the community partner should be agreed upon.

Programmatic

Context—With the change in leadership, the grant deliverables and program development were not a priority. The new team was not familiar with program content of the grant or what their role was. With the changing structure at JRM, the staff was stretched and taking on grant oversight was considered an added burden.

Short-Term Strategy—The research team was as supportive as possible during this time and tried to identify ways the grant deliverables could help them to meet their current needs. Project staff conducted patient satisfaction surveys and added race, ethnicity, and language data into patient records. The research team accepted more responsibility for grant implementation than was expected originally. The community PI kept the mission of JRM at the forefront of the Patient Voices Network. The co-PIs met weekly with the JRM program director and CFO to address pressing Patient Voices–related issues and strategically evolve our partnership.

Challenges—It took longer to implement certain components of the grant than planned. Priorities were shifted periodically to better align with JRM's mission. The patients

developed an intervention that had little feedback from the practice and was not sustainable ultimately. The idea of patient involvement was positively viewed by JRM staff, but it was viewed as separate from the practice. The content of the project (cancer screening among patients with multiple chronic diseases) was an interest and priority for the original executive director of JRM, but not for the organization.

Long-Term Strategy—Research teams should work closely with key leaders of the organization and decide together what areas should be focused on. The research team should understand the priorities of their community partners and let that guide the research agenda. Consideration should be given to the sustainability of the research and the impact it has on their clients. Research leadership should have regular meetings with partner EDs and CFOs.

Personnel

Context—Three community health workers were hired by JRM for specific roles in research projects. Joint interviews were held to select these individuals from the community. Staff was employed by JRM but housed with the research staff. This arrangement caused confusion about supervision structure, roles, and responsibilities. Several of the initial hires did not work out for a variety of reasons and were released from their duties at various points over the course of the grant. Because this was a 2-year grant, it was difficult to recruit, hire, and train additional staff.

Short-Term Strategy—Personnel issues were initially dealt with during weekly meetings or ad hoc meetings between PCRI and JRM when a problem became evident. Options were discussed for each of the personnel issues that occurred and an effort was made to identify solutions that would benefit all.

Challenges—The joint supervision was challenging because ultimately final decisions regarding hiring and firing were made by the JRM board outside of the context of the project and MOU. Considering the short time frame of the grant (2 years), rehiring and retraining created challenges in meeting project deliverables.

Long-Term Strategy—Clearly defined job descriptions and reporting structures for all positions should be developed. The decision-making structure, including hiring and termination guidelines, need to be discussed up front and included in the MOU. Additionally, partners should develop a clear communication plan for team members who are off site.

Financial

Context—The partnership tried to ensure “equality” among project partners by equally sharing project monies between the university and JRM. This inadvertently put JRM at financial risk. The university process for reimbursement posed real challenges for JRM. JRM was required to commit money for grant deliverables and then invoice the university for reimbursement, creating a major financial challenge. This decision was made between the two co-PIs without input from JRM's CFO. There are several hidden financial implications for small organizations, such as unemployment insurance. JRM's

unemployment insurance almost tripled as a result of new hires, turnover, and termination of staff.

Short-Term Strategy—In this case, the research team advocated on behalf of JRM to university administrators to create an expedited payment system. In brief, this allowed for some electronic exchange rather than using the traditional postal service approach. The JRM CFO met with the co-PIs regularly to discuss budget issues. There were two meetings that also involved the grants manager from UB to discuss allowable costs.

Challenges—JRM was faced with a major cash flow challenge, even with the expedited approach to reimbursement. None of the partners were aware of long-term financial implications of the systems we were working in.

Long-Term Strategy—Budgets should be constructed carefully so that new staff and other upfront funds are administered through the university. Additionally, partners need to understand system differences and discuss logistical strategies openly. This may not be an issue for partners who are institutional, such as a hospital or a health department. The more grassroots community partners are, the more extreme this challenge will be.

Partners need to understand their organizational systems and understand the leadership and reporting structure. It is more important that the partners be given equitable resources, rather than equally distributing the resources. Community subcontracts should include travel, supplies, and other funds to support specific responsibilities of the grant. It is more sound fiscally to have the academic institution hire new staff, unless there is a solid justification for having the community partner take the financial risk. The university should be responsible for research conference travel, participant stipends, and research personnel.

Conclusions

A long-term partnership faced a new set of challenges after receiving federal funding. These challenges threatened the sustainability of the partnership and the viability of the community partner. Even though the team planned for a more formalized approach to shared leadership and decision making, there were many unanticipated challenges that threatened the sustainability of the partnership. The partners needed to be reactive in many situations to preserve their relationship and have the best project outcomes. JRM was facing a new stage of their own development. The research team needed to support them and work with them rather than be perceived as an unnecessary burden. This was reinforced by adding extra initiatives that aligned with their practices that were perceived as sustainable and helpful by JRM leadership. Several of these challenges were experienced by other partnerships.^{7–13} This case study demonstrates how partnerships with a strong, trusting relationship are able to work through these challenges in the short term and are better prepared with long-term strategies. This partnership also demonstrates a continued strength and tenacity that allows for research and practice in primary care to coexist while working on translational applied interventions, capacity building, and developing new models of care. The authors shared some of the unanticipated challenges that were faced and the strategies that were used to overcome barriers in the hope that other partnerships can avoid some of these pitfalls. The

UB/JRM partnership continues to work together and has implemented the long-term strategies discussed in this manuscript. The team has successfully received additional funding from the NIMHD (R24 MD008107) and has a much deeper shared leadership plan.

The lessons learned from this academic and community partnership can be applied to other partnerships to strengthen the foundation of the CBPR model. Other partnerships are encouraged to develop a strong foundation based on the key principles of CBPR before taking on a large, formalized project so that when unexpected challenges arise, and they will, the team will be ready to adapt as necessary. In the end, the challenges that we faced together resulted in developing a stronger, more inclusive team that has a long-term vision to improve the health and wellness of underserved communities. The outcome may have been very different had there not been a foundation of trust from working together in various capacities. There will still be bumps in the road, but the partners are now able to successfully deal with those issues and create a stronger foundation to maximize impact.

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Figure 1. Community-Based Participatory Research (CBPR) Governance Structure for the Patient Voices Network

CHWs, community health workers; JRM, Jericho Road Ministries; JRFP, Jericho Road Family Practice; PAT, patient action teams; PI, principal investigator; RA, research assistant.

Table 1
Partner Roles and Responsibilities as Outlined in the Memorandum of Understanding (MOU)

Component	PCRI	JRM
Shared fiscal and project management	The PCRI will serve as the fiscal agent responsible for compliance with fiduciary terms and conditions of the NIH award.	JRM will participate fully with PCRI in the fiscal management of the award, including the hiring decisions and supervision of community-based personnel to be hired or named under this proposal.
Function in a joint PI arrangement	Participate in the CBPR steering committee as an equal partner with JRM and other community stakeholders.	Participate in the CBPR steering committee as an equal partner with PCRI and other community stakeholders.
Adherence to CBPR principles	The PCRI will incorporate community engagement and ownership at all stages of the proposed research, sharing project leadership and management with the JRM.	JRM will maintain CBPR community collaborative arrangements and community engagement in CBPR communities.
Technical facilitation plan	PCRI will administer the Plan which covers all project activities of the CBPR steering committee and the PAT's without usurping or displacing community control or ownership of the research process and data.	Oversee the technical facilitation activities administered by the PCRI. Participate in and provide organizational support and field supervision/assistance to the PATs.

Abbreviations: JRM, Jericho Road Ministries; NIH, National Institutes of Health; PAT, patient action teams; PCRI, Primary Care Research Institute.

Table 2
Description of Partnership Experience for the Patient Voices to Improve Practice Project

Aspect of Partnership	Context	Short-Term Strategy	Challenges	Long-Term Strategies and Recommendations
Leadership	Community PI left JRM and the main JRM staff person resigned.	New community co-PI was appointed that was familiar with the project.	New community co-PI did not have authority to make decisions. Role was never redefined or clarified.	Have contingency plans in place. Ensure commitment of whole organization. Community PI needs to be actively in the project and have authority to speak on behalf of the organization.
		New staff was appointed.	New team had a learning curve.	Revisit roles and responsibilities regularly. Create clear job descriptions and expectations.
		Need approval from JRM board	Extra complexity. Decisions were made without the input of the research team.	Research projects need to be a priority for the organizations Make expectations explicit. MOU needs to be set in place but needs to be a living document that adapts to the dynamics of the partnership.
	JRM was undergoing a complete overhaul in their organization.	Limited involvement from the JRM staff outside of the Community-PI	Patient Voices was a low priority	Schedule frequent but brief meetings. Identified how new grants should be organized. Identify outcomes important to the community partner that can be done as part of the research project.
Programmatic	Development of the Patient Action Teams	The research team spearheaded the development and implementation of the Patient Action Teams	Viewed as very separate from JRM and the related practice so it was conceived more as a research initiative as opposed to something that could benefit the practice as well	Align with practice priorities
	All three Patient Action Teams chose colorectal cancer screening as their topic of focus.	The project was not a priority for JRM and was designed and implemented without appropriate consideration by that practice	The intervention was not sustainable.	Become part of the quality improvement teams at both practices.
Personnel	Three community based research workers were hired by JRM for specific roles in research project. Joint interviews were held. Research staff and community staff were housed at separate office	The team tried to jointly come up with plans for staff remediation	There was confusion about supervision structure, roles, and responsibilities.	Have clearly defined job descriptions for all positions.
		We tried several different ways to jointly supervise staff.	Final decisions were made by the JRM Board and did not	Have a clearly defined reporting structure.

Aspect of Partnership	Context	Short-Term Strategy	Challenges	Long-Term Strategies and Recommendations
Financial	locations, making the organizational structure of the program confusing. Several of the initial hires did not work out. New individuals were hired and trained during a short time frame.	The grant hired a staff member that was recently laid off from JRM.	include the input of the research team. Created unnecessary paper work. The staff hired was not necessarily the best fit for the project.	Address hiring and firing guidelines up front and put in writing in an MOU. Create a clear communication plan that includes team members off-site or in the field.
	The grant budget was divided equally (50/50). The University system required JRM to front the money for grant deliverables and invoice the University for reimbursement. Considering that funds supported a portion of several JRM staff and three new hires, the reimbursement model created a major financial challenge.	Created an expedited payment system. In brief, this allowed some electronic exchange rather than the usual postal service approach.	JRM was faced with a major cash flow challenge. Staff turnover increased unemployment insurance that lasted long after the grant ended. Began to meet with CFO of JRM regularly. Often included grants administration from UB.	Carefully construct budgets to ensure that adequately conduct the work. Address cash flow issues. Clearly understand system differences and financial nuances. Include fiscal personnel early in the grant development phase. Openly discuss logistic vs. leadership strategies Provide training to community partners on fiscal management of research grants. Include fiscal agent of community partner right from grant development.
	Several staff members were terminated during the course of the project.	New staff was hired to replace terminated staff.	JRM's unemployment rate doubled.	New grant related hires will be included in the University budget. Be aware of hidden financial implications for small organizations.

Abbreviations: CFO, chief financial officer; JRM, Jericho Road Ministries; MOU, memorandum of understanding; patient action teams; PI, principal investigator; UB, State University of New York at Buffalo.