

Learning to Work Together: Developing Academic and Community Research Partnerships

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Abstract

Background: Community-based participatory research (CBPR) has been promoted as an important collaborative methodology for addressing local health concerns. However, academic physicians and researchers usually are not trained to work with communities as partners.

Methods: Key characteristics of effective community-academic partnerships are examined based on experiences with 2 CBPR projects in Wisconsin.

Results: These 2 projects increasingly have involved the respective communities and researchers in a collaboration. The steps they have taken illustrate the qualities of successful CBPR partnerships: ongoing development of joint community and researcher analysis, communication, and mobilization to search

for relevant solutions to important community health problems. To sustain this kind of partnership, it is critical for researchers using the CBPR approach to understand how their academic-scientific perspective differs as well as converges with the community members' practical-experiential perspective.

Conclusions: Health care researchers can effectively make use of partnerships with communities by following defined CBPR steps for developing mutually agreed upon research agendas, timelines, and goals. This, in turn, builds the capacity of communities to initiate and engage in future collaborative research projects concerning health issues.

Introduction

Much attention has been given to the benefits of community-based or participatory research in the past 5 years.¹⁻⁵ Additionally, there has been a recent push by national funding organizations (National Institutes of Health, Centers for Disease Control and Prevention, and Robert Wood Johnson) as well as local funding initiatives (Wisconsin Blue Cross/Blue Shield initiative, The Wisconsin Partnership Fund for a Healthy Future at the University of Wisconsin-Madison Medical School and the Healthier Wisconsin Partnership Program at the Medical College of Wisconsin) to fund community-

based research between academic and community partners. Thus, it is important for academics, physicians, and communities to learn to understand each other so that research partnerships can come to fruition.

In this paper, we describe briefly the principles of community-based participatory research (CBPR), and we examine 2 CBPR projects in Wisconsin and some of the issues these partnerships face. We also propose a framework on which future successful partnerships can be developed.

CBPR has been described as a mutually respectful partnership between academic researchers and the community that allows for the establishment of trust and community participation in research design, data collection, analysis, and dissemination of results.^{2,3,6,7} However, researchers and physicians are often trained in traditional scientific methodologies and find it difficult to share control with a community. Historically, this has caused significant distress and has led to mistrust and misunderstanding of research within communities.² Thus, researchers need to understand the participatory research process and be able to identify the resources necessary to interact with different communities.

Members of the North American Primary Care Research Group (NAPCRG) published an excellent

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Table 1. Community-Based Participatory Research Principles

Based on a mutually respectful partnership between researchers and community
Equitably involves all partners in all phases of research
Builds on knowledge, strengths, and resources within the community
Involves a cyclical and iterative process
Educates both researchers and communities
Results in action based on results obtained from the research

policy statement detailing the principles of CBPR.³ This document suggests that researchers and communities should negotiate the research goals and objectives, the project's methods and duration, partnership terms, confidentiality issues, data control issues, methods of resolving disagreements, incorporation of new collaborators, and joint dissemination of results. Participatory research is important in enhancing the relationship between the researcher and the community, acknowledges that community involvement is essential and beneficial in the research process, and sees direct community benefit as a desirable outcome of the study. Table 1 lists some key CBPR principles.^{1,4-6}

Community-Based Participatory Research Examples

Many excellent CBPR projects have been described in the literature.^{5,6,8} Two such projects in Wisconsin are described below. Both involve Tribal organizations and communities working with academic institutions, but the lessons learned from these partnerships may be applied to a number of partnership types.

Great Lakes Native American Research Center for Health
Tribal communities have mis-

trusted academic institutions and research in general. In the past, Tribes had little input into research agendas, and scientists from outside the American Indian (AI) culture directed the research. The Great Lakes Native American Research Center for Health (GLNARCH) is a National Institutes of Health (NIH)/Indian Health Service-funded national center that systematically addresses these issues by drawing on the strengths of the Wisconsin Tribes, the Great Lakes Inter-Tribal Council (GLITC) organization and the partnering academic institutions: the University of Wisconsin (UW) and the Mayo Clinic. The GLNARCH project was initiated by the Wisconsin Association of Tribal Health Directors (WTHDA) in collaboration with GLITC and the academic partners. WTHDA is made up of the tribal health directors from the 11 Wisconsin Tribes. Three goal areas for GLNARCH include:

Goal 1: Encourage cooperative research linked to reducing health disparities. One large research project—a childhood obesity prevention project (WINGS)—and 3 pilot research projects—cancer surveillance, reproductive health and benefits of traditional diets—make up the research component of the center. The research projects each address issues of specific concern to the Tribes.

Goal 2: Increase the number of AI students, scientists, health professionals, and organizations engaged in biomedical, clinical, and behavioral research. This is being accomplished using 3 strategies. (1) Student Development: The 4-phased GLNARCH Student Development Program focuses on AI students at multiple stages of their academic careers. The intent is to encourage them to participate in AI health disparities research through various training and men-

tored activities. (2) Tribal Staff as Research Assistants: Research activities for 3 of the 4 research projects occur within the tribal communities. Tribal staff contract to serve as research assistants. (3) Tribal CBPR Training: Three, 3-day training sessions were developed and held to provide an overview of the principles and tools used in CBPR.

Goal 3: Build capacity of academic institutions and GLITC to work to reduce distrust of research by AI people and communities. Strategies include the following: (1) memorandums of understanding have been implemented with the academic institutions; (2) the development and implementation of Community and Scientific Advisory Committees (all partners represented), which meet quarterly and have been very active; (3) returning research findings to the tribal communities in a timely fashion.

The process began with the WTHDA identifying research priority areas. This was followed by an invitation to potential researchers within the partnering academic institutions to submit research ideas for tribal consideration. The potential projects were reviewed and prioritized by the Tribes. Five project ideas were selected, and the respective project principal investigators were invited to submit full proposals that were then incorporated into the overall research center proposal.

The GLNARCH project equitably involves academic and community partners in all aspects of the research process, promotes capacity building among all partners, emphasizes local public health problems, involves systems development through a cyclical and iterative process, involves all partners in the dissemination process, and involves a long-term commitment. This process should allow integra-

tion of the knowledge gained to improve the health and well-being of the communities involved.

Wisconsin Nutrition and Growth Study

The Wisconsin Nutrition and Growth Study (WINGS) grew out of community and academic concerns about the increasingly earlier onset of diabetes and cardiovascular disease in Wisconsin AI communities, which have the highest rates of cardiovascular disease and the fourth highest rate of diabetes among AIs nationwide. The epidemics of these diseases are directly related to pediatric obesity, an increasing problem of special significance in AI communities. WINGS began as a small pilot project and expanded into a full-scale NIH- and GLNARCH-supported project. Data from the first small project with 1 Tribe showed a high prevalence of obesity and related co-morbidities of high blood pressure and abnormal lipid levels in children ages 5-18.⁹ This data was shared with the community, and the Tribal leaders expressed a desire to partner with UW researchers to design solutions to this problem. Shortly after the project's completion, the Request For Application for the Native American Research Centers for Health (NARCH) was released. Meetings were held with Tribal health directors statewide, and 3 Tribes chose to participate in the study that eventually became WINGS.

Each participating Tribe has overall concerns about pediatric obesity and the concomitant issues of diabetes and cardiovascular disease in their communities. Presentations of pilot study data and the proposed new project were made to various organizations in each community, including Tribal legislature, health boards and school boards to obtain input and

approval for the project. The research was then planned and funding was applied for from NARCH. The project was begun at 1 site prior to receiving federal funding because of local interest. Funding was obtained from Tribal funds and a State Division of Public Health grant.

In the current WINGS study, 3 Wisconsin Tribes are working to determine the prevalence of pediatric obesity, cardiovascular risk factors, and glucose intolerance in their communities. The elders and community leaders are anxious to develop appropriate intervention projects to reduce the disease burden in their communities. The overall goal of this research is to understand and model risk factors for childhood obesity in American Indians and to design interventions to reduce morbidity and mortality from obesity and its sequelae—cardiovascular disease and diabetes. Communities are partners in this process. Tribal clinic personnel function as community-based research teams that work with the academic researchers to plan data collection, gather data at each tribal site, and assist in communicating results back to their communities. The research is designed to enhance the relationship between the Tribal communities and university researchers, culminating in intervention design.

This project will be completed over 4 years and is divided into 3 phases. During phase 1 baseline data was gathered on obesity prevalence, cardiovascular and obesity risk factors, and glucose intolerance in Wisconsin AI children ages 0-7. Phase 2 is modeling factors associated with obesity. Phase 3 will utilize a participatory research framework to work with each Tribal community to develop a culturally acceptable childhood obesity prevention project aimed at

Table 2. Basic Steps of Community-Based Participatory Research

1. Determine mutual concerns and research priorities
2. Define the problem and collect background data
3. Do a pilot project
4. Return results to the community and assess response
5. Find funding and do the project
6. Return results to community and collaboratively interpret data
7. Assess health outcomes and re-cycle through process

reducing future morbidity from obesity-related diseases. Some Tribes have already initiated programs, having been motivated by the preliminary research conducted. The data compiled and model developed through this research will also allow for evaluation of these efforts. At the study's close, Tribes will be ready to implement and evaluate newly designed programs based on the data. Program resources can then be targeted to the age range where risk factors are most amenable to intervention. Figure 1 illustrates the steps of this ongoing CBPR process. Table 2 summarizes the basic steps needed for CBPR.

Discussion

The approach used in CBPR projects differs from that used in conventional research in a number of important ways. First, the process of initiation is usually reversed. In the conventional approach, a researcher designs the study, applies for and receives funding, and then recruits subjects and communities to participate. In CBPR projects, the community may initiate the study, including pulling together academic and other research resources. Second, whereas conventional research tends to be quite linear, CBPR projects can often

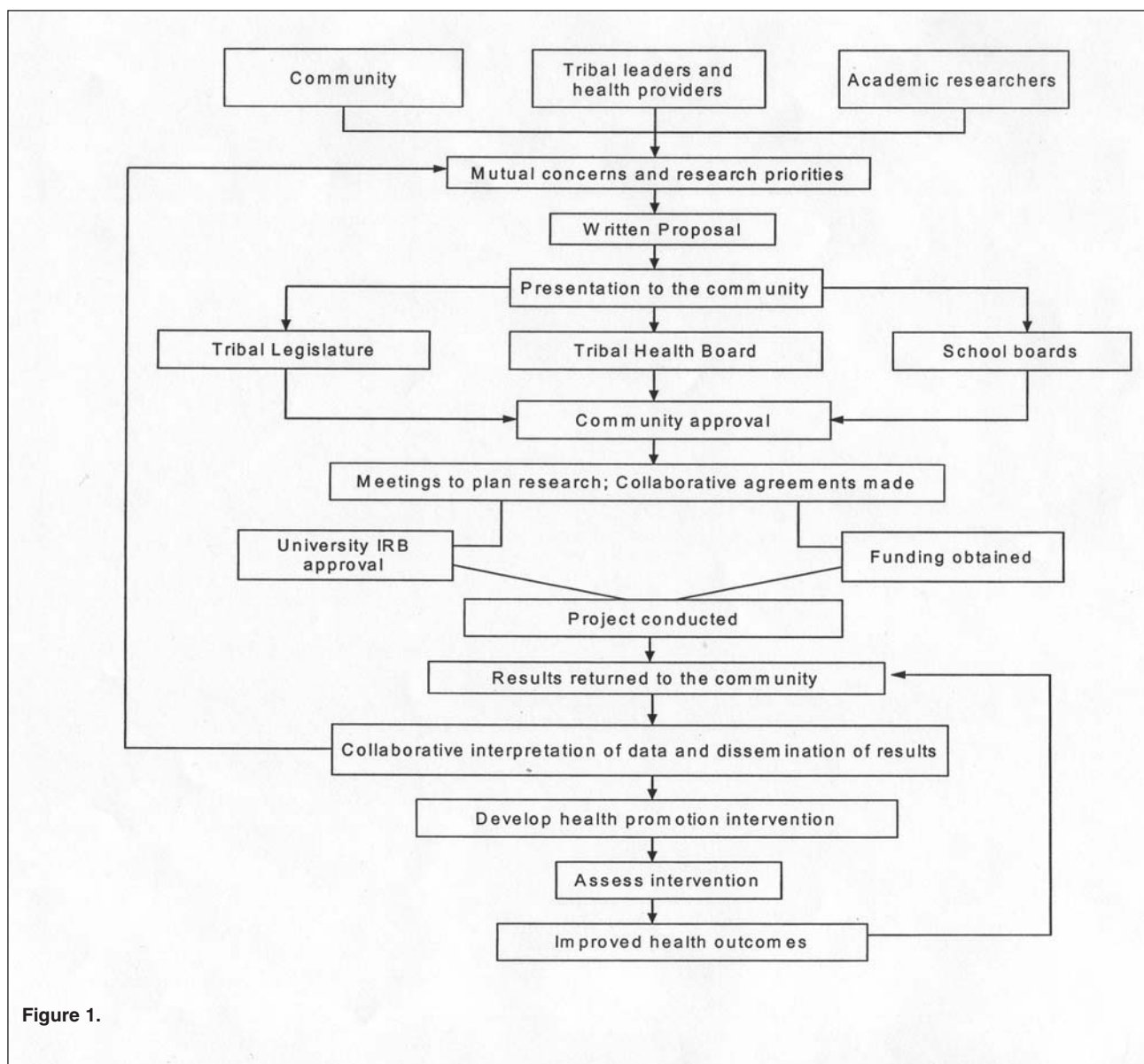


Figure 1.

have iterative processes in which research findings and practical objectives are continually revisited. Finally, CBPR projects are distinctly collaborative, involving an ongoing mutual process of research planning and data interpretation. Thus, collaborations become mutually beneficial partnerships.

Lessons learned from both the larger GLNARCH project as well as WINGS are similar and apply to most community-based research. Key factors are to (1) understand common goals as well as conflicting ones, (2) have continuing and frequent ongoing communication in

person as well as via phone, e-mail, etc, and (3) continually build on small successes to sustain community interest and involvement. Building community interest and support is essential to the project as is its endorsement by formal or informal local leaders. Building community capacity by empowering the people to do research is achieved through student mentoring, local hiring and training, and joint data analysis, dissemination and writing. Academics must view their job as educator, learner, partner, and advocate.

Challenges that need to be over-

come in CBPR are the issue of community trust/mistrust of researchers and involving the community in seeing the big picture and building solutions together. It is important to ensure that the community has the capacity to do the project, i.e. interest, staff, ability to increase workload, and baseline data. Frequent changes in local leadership and structure can be challenging and may differ between sites. There is also a risk to community members in becoming involved in research, both socially and professionally as they must remain in and be accountable to the

community long after the project ends and despite its outcome. Finally, the time involved in CBPR can impact academic advancement as well as community interest. Both the GLNARCH and WINGS projects took 2 to 3 years to fully implement.

Conclusions

Researchers must consider that community-based participatory research is more challenging in some ways than traditional research, even if the project involves a local community and utilizes community resources.¹⁰ What have we learned from our experience to date? (1) It takes additional time to build trust and to develop a sufficient understanding of local issues and politics—especially if you are not from the community. (2) Volunteering expertise for other related community needs is very helpful and fosters a basis for reciprocity. (3) Using local media and community leaders to promote the project is essential. (4) The interest of the community and health workers in the project must be high or it will not succeed. (5) The challenge is to be flexible and able to capitalize on available opportunities without as-

suming a high level of control over the project. (6) Prevention projects will be more successfully accepted and implemented, and will have greater potential for impact, when they are both community- and data-driven. Effective partnerships between communities, community researchers, and academic researchers are critical to this end.

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