From the Schools of Public Health



On Linkages

PARTICIPATORY RESEARCH PARTNERSHIPS: ADDRESSING RELEVANT PUBLIC HEALTH SYSTEM CHALLENGES

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One measure of the effectiveness of public health research is the ability of these efforts to solve relevant health issues that affect communities and public health organizations. The shortcomings of public health research on this measure often stem from research that focuses on the internal validity of efficacious interventions without subsequent translation and dissemination to populations, interventions designed to change individual behavior rather than communities and public health systems, and research processes that reflect academic institutional requirements.^{1,2}

Participatory research approaches have been adopted as a systematic process to improve the quality and relevance of public health research.³ This process can increase the relevance of research questions; improve community participation in research, through increasing community response rates to data collection instruments and decreasing study attrition; and ensure that research questions and interventions are appropriately tailored to target populations.^{3–7}

There are several definitions and frameworks for participatory research, but most definitions emphasize that it is a collaborative approach to establish structures for participation in all facets of a research endeavor by the organizations, communities, target populations, and researchers affected by the issues being studied. Additional characteristics include co-learning and reciprocal transfer of expertise, shared decision-making power, and mutual ownership of the research process and products. $^{\rm 6}$

Examples of participatory research reveal that in implementation, there is a continuum of community participation in the various facets of the research enterprise.⁶ Krieger and colleagues⁷ recognized that there may not be one single approach to fostering participation and that community participation in research activities may vary according to the needs of the project. What is critical is that research and community partners determine the nature and degree of participation that is needed according to the needs of each project. That nature and degree of participation should ensure that research is done *with* a community not *on* or *in* it.⁸

Although participatory research processes can result in improved research quality, enhanced community capacity, and, in some cases, improved health outcomes, these processes also include a number of challenges. Israel and colleagues⁴ characterized three types of participatory research challenges: partnership, methodological, and contextual. Partnership challenges involve issues of respect, trust, and distribution of power; conflicts over perspectives, priorities, values, beliefs, and funding; and the time commitment required of both practitioners and researchers to ensure truly collaborative research. Methodological challenges occur due to tensions between assuring scientific rigor and making sure that interventions and data collection methods are appropriate for the community involved. Further, research enterprises typically move more slowly than community needs for action or service provision. Finally, contextual challenges recognize that researchers, community organizations, and individuals work in institutions with their own demands, which often compete with or take priority over the demands of participatory work. These challenges are echoed by others working in participatory research.5,9-12

While much of the focus of participatory research has been on efforts with community organizations, such as nonprofits and churches, and specific target populations, such as vulnerable communities,⁶ this approach may also provide insight into research with public

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health agencies and systems. Public health agencies are an important link in the chain of research translation, particularly for biomedical and behavioral disease prevention and health promotion discoveries. Public health systems and services research examines the organization, financing, and delivery of public health services.¹³ Much of this research has been descriptive in nature, characterizing the extreme heterogeneity in the organization and delivery of public health services.14 Like research with community organizations and individuals, it has also been hampered by low participation rates when participatory approaches are not used.¹⁵ In addition, this research may not be asking the questions that are most relevant to practitioners,^{16,17} and often it does not provide data or policy recommendations to address pressing public health issues in a timely manner.

In 1995, Baker and Tyler opined, "How can practice/ community/academic teams be created to solve urgent, practical problems in the real world of public health?"¹⁸ During the last decade, several efforts have tackled improving the relevance and timeliness of public health systems and services research through academic and governmental public health partnerships. Partnerships include practice-based research efforts at schools of public health,¹⁹ academic health departments,^{20,21} and research and teaching centers, such as centers for public health preparedness (CPHPs).^{22,23} These efforts have begun to establish partnerships by which public health agency and academic teams can collaborate to solve important public health problems.

The North Carolina Institute for Public Health (NCIPH), the service outreach arm of the University of North Carolina at Chapel Hill (UNC) Gillings School of Global Public Health (GSGPH), has participated in academic health department and CPHP efforts, and has conducted specific projects to facilitate partnerships between school of public health departmental faculty and state and local public health agencies. The UNC GSGPH has a long history of service to North Carolina (NC) communities, as well as relationships with state and local practice partners. In 1999, Dean William Roper brought together the school's many service activities to create the NCIPH. The NCIPH's first major activity was coordinating the school's response to Hurricane Floyd with the North Carolina Division of Public Health (NCDPH). Since its inception, NCIPH leaders and staff have furthered and maintained relationships with NCDPH personnel and local health directors throughout the state. Relationship-fostering activities include individual meetings between NCIPH staff and health department partners, regular meetings between NCIPH and NCDPH management teams, NCIPH staff

attendance at committee and full meetings of the North Carolina Association of Local Health Directors and the North Carolina Public Health Association, and joint projects. Additionally, two former NC local health directors have recently worked at NCIPH in senior positions. Through these activities, these partners have established working relationships from which research activities can occur.

This article examines two recent research examples in which NCIPH and its practice partners have worked to solve real-world public health problems and enrich the understanding of applying participatory research approaches to governmental public health and public health system challenges. For each project, we present a brief program description, participatory methods used, the relevance of the effort to practice organizations, data collection methods and participation rates, research challenges, and dissemination efforts. We also summarize the characteristics that have made these efforts particularly effective in addressing important public health challenges.

H1N1 LOCAL HEALTH DEPARTMENT AFTER-ACTION REVIEWS

Description

The 2009 outbreak of novel H1N1 influenza provided an opportunity to test the preparedness and response capabilities of public health agencies and to compare the responses of accredited and nonaccredited agencies. This project is part of the North Carolina Preparedness and Emergency Response Research Center (NCPERRC) housed at NCIPH, one of nine such centers around the nation funded by the Centers for Disease Control and Prevention (CDC). This center has four major research projects, one of which is examining the effects of a local health department accreditation program on preparedness and response capabilities.

Participatory processes

CDC's request for proposals for this program required an advisory committee with representatives from state and local agencies and health-care organizations. The NCPERRC created the Synergy & Translation Committee to provide oversight of the research program, facilitate communication across all four NCPERRC projects, and identify opportunities to translate research findings into practice. Committee members include the NCPERRC's principal investigators, representatives from NCDPH and the North Carolina Association of Local Health Directors, and research consultants. We specifically invited NCDPH personnel with expertise and duties in preparedness and the chair of the North Carolina Association of Local Health Directors preparedness committee to serve on the committee. Committee meetings feature the progress of center research projects and include specific discussions on the applicability and translation of project findings to public health departments.

At its May 2009 meeting, committee members discussed research opportunities and needs presented by the H1N1 influenza epidemic. From these discussions emerged a specific project to conduct targeted After Action Reviews (AARs) examining local health department response by accreditation status. In addition, staff from the accreditation research project assisted NCDPH with H1N1 influenza response analysis needs.

Relevance to practice

Although the H1N1 influenza virus was not as virulent as first anticipated, the uncertainty and publicity surrounding its progression put a strain on local health departments while these agencies were experiencing funding cuts. Simultaneously, accreditation of public health agencies has received considerable policy attention because of its potential to promote consistency, interoperability, and effectiveness in practice. While a national accreditation program was still under development, state-based programs, such as the one in NC, informed the development of the national program. This project informed a general understanding of local health department capacity to respond to the H1N1 epidemic, as well as whether accredited local health departments demonstrated greater response capacity.

Data collection methods and participation

Experts in preparedness measures and AAR methodology created a closed-form questionnaire and on-site focus group protocols, which were also reviewed by former and current directors of NC public health agencies, NCDPH staff, and investigators from the other three NCPERRC projects. Local preparedness coordinators completed the closed-form questionnaire, and on-site focus groups were held with organizations involved in H1N1 activities of each local health department. Ten agencies were invited to participate and nine agencies actually did so; the 10th agency was interested but unable to participate during the study period. Each agency identified appropriate H1N1 response partners, such as schools, hospitals, and emergency response agencies, and invited representatives from these partners to attend the scheduled focus group. Data collection for the AARs occurred in August and September 2009.

Participatory research challenges

Local health departments needed to weigh competing time and collaborative demands for both individual staff members and partners when considering the invitation to participate. This study required substantial time commitments on the part of preparedness coordinators and health department partners to participate in data collection, which is characterized as a contextual challenge.

Dissemination of findings and impact

The nine participating agencies received agencyspecific AARs in November 2009, approximately two months after data collection and in time for seasonal influenza vaccination planning. Common response strengths and challenges identified in these reviews were compiled into a research brief.24 An additional research brief examining the effects of accreditation was also prepared. NCDPH staff and two local health directors reviewed the brief and provided substantive comments for revisions. Results comparing the response capacities between accredited and nonaccredited agencies were presented at the 2009 American Public Health Association meeting, at the 2010 Public Health Preparedness Summit, and to the NCPERRC Synergy and Translation Committee. In addition, these results were shared with the North Carolina Local Health Department Accreditation program and the Public Health Accreditation Board to inform preparedness requirements in accreditation standards. Finally, several peer-reviewed journal articles are being prepared.

PRACTICE-BASED RESEARCH NETWORKS

Description

Public health practice-based research networks (PBRNs) are a partnership of public health agencies that collaborate with academic research centers to conduct rigorous, applied studies of strategies to organize, finance, and deliver public health services in real-world community settings.²⁵ The NC PBRN, housed at NCIPH, is one of 12 throughout the nation supported by funding from the Robert Wood Johnson Foundation and a national coordinating center at the University of Arkansas for Medical Sciences College of Public Health.

Since the late 1980s, NC local health departments have provided core coordination, outreach, and postpartum services to low-income women and their children, and contributed to improved birth outcomes in these at-risk populations. In October 2010, Medicaid funding for maternity care coordination and child services coordination to low-income pregnant women and their children was reduced. Through a research implementation award, the NC PBRN is examining the potential staffing and service delivery effects of this policy change.

Participatory processes

The NC PBRN was initiated through a regional partnership of local health departments interested in practicefocused research questions. Initial activities, funded by the NC legislature and supported by NCIPH staff, included identifying research questions through focus groups with local health department staff, prioritizing these questions, and identifying a joint research activity. The regional partnership received Robert Wood Johnson Foundation funding to create the NC PBRN with members that include local health directors, faculty at the UNC GSGPH, and NCIPH staff. Recently, the NC PBRN has expanded to all health departments in the state. The NC PBRN decided to respond to a PBRN research implementation award call for proposals. NCIPH PBRN partners identified and partnered with school of public health researchers who had a research interest in this area to answer the following research questions:

- 1. How will public health case-management revenue cuts and restructuring affect casemanagement service provision and outcomes?
- 2. Will revenue cuts and restructuring of public health case management affect local health department core capacity in other service areas?
- 3. What aspects of local health department capacity and coping strategies may reduce the impact of case-management funding cuts and restructuring on service provision?

Relevance to practice

Directors of local health departments throughout the state are alarmed by the potential consequences of the policy change and have communicated their concern to legislators and the governor of the state, but have little specific evidence to bolster what they see as a dire future scenario for the well-being of these vulnerable populations. It is hoped that this research will provide evidence demonstrating that this policy change is detrimental to health departments' abilities to meet their community needs.

Data collection methods and participation

To understand the context and extent of potential Medicaid cuts, project staff did the following:

- Convened and consulted with an advisory group consisting of NCDPH employees, including supervisors and/or staff from the Maternity Care Coordination and Child Services Coordination programs and from the State Center for Health Statistics.
- Met and consulted with key staff from NCDPH and other key informants (e.g., the North Carolina Local Health Director Association subcommittees and former staff).

During the summer of 2010, program staff conducted a survey of the 85 NC local health departments to measure the impact of the Medicaid cuts. A response rate of 89% demonstrated the importance of these issues to local health directors.

Participatory research challenges

Ongoing policy changes impacting maternity care and child service coordination programs have hampered the definition of the natural experiment under study. This change could be classified as a contextual challenge.

Dissemination of findings

Researchers have shared preliminary findings from the survey with the project advisory group, the NC PBRN, and the North Carolina Association of Local Health Directors. Dissemination of the final results began after completion of case studies, which occurred in spring 2011.

DISCUSSION

The examples presented are timely issues in public health. Each example demonstrates how principles from community-based participatory research can be applied to public health practice research, including identifying research questions, creating practical yet rigorous studies, and assuring that results are disseminated to participants and interested parties. These examples demonstrate that established partners can come together to address a specific need (e.g., H1N1 and Medicaid cuts).

Community-based participatory research endeavors also emphasize that long-term partnership investments, rather than one-time relationships for a specific grant, have the potential for greater benefit to both community outcomes and research efforts.²⁶ One of the most common challenges cited in conducting participatory research is the time required by both researchers and field partners to make these efforts successful. Israel and colleagues characterized this issue as a partnership research challenge.⁴ Yet, the research challenges of the studies reviewed in this article were contextual rather than partnership related. Partnership research challenges tend to stem from issues in creating relationships. Because NCIPH and state and local health department partners already had working relationships, new research efforts could readily be implemented.

A key benefit of participatory research approaches is the potential to increase participation or response rates and data quality.^{4–7} The two studies reviewed in this article had high participation and response rates. Moreover, in its first year, the NCPERRC studies fielded five data collection activities, several of which were statewide in NC, with an overall response rate of 94% (Unpublished report, NCPERRC, July 2011). This high response rate may be attributable to multiple efforts to involve health directors and state health department staff in the development and implementation of research activities, tangible participation incentives, and centralized tracking of data collection activities to minimize simultaneous and duplicative data collection.

Through our extensive work with NC state and local health departments, we recommend the following strategies to improve research relevance, increase participation in research activities, and improve the translation and dissemination of research findings.

- 1. Inform and involve state and local partners in data collection efforts and expressly ask them to review methods and measures. Use existing state and local health partner committee structures to advance support for research activities.
- Regularly attend partner meetings, with or without specific agenda items. NCIPH leaders and program directors attend local health director association monthly meetings and NCDPH management team meetings.
- 3. Be available to broker and connect state and local public health department staff with academic faculty and students.
- 4. Employ staff with experience working in state and local health departments.
- 5. Build relationships with individual faculty who are interested in this work.
- 6. Create and employ practice advisory committees as part of research enterprises.
- 7. Promptly, through multiple channels, share research results with partners and participants and offer recommendations for future action and improvement.

Despite our success in working with health departments, health directors stress that their agencies receive daily data collection requests from multiple organizations. As we implement participatory research approaches, we must be cognizant of the data burden placed on state and local health departments. Further, with these multitudes of data collection activities, we are drowning in data that we do not use well. Prior to collecting new data, researchers and public health professionals should determine if existing data will answer specific research questions or if several research efforts can be combined to streamline data collection requests.

Considerable efforts have been made to bridge public health academic and practice gaps.^{8,16,18,27} Results from a 2010 survey of the members of the 12 PBRNs indicate that 87% of participants rated steering research project questions that are more relevant to practice as very important or important benefits of participation.²⁵ The case studies reviewed in this article provide examples and insight as to how participatory research processes can be applied to public health practice research to improve research relevance, timeliness, and quality. Future efforts should monitor the PBRN and NCPERRC research outputs to see if these approaches will realize this goal. Additional research could examine how health departments use findings from these kinds of research endeavors.

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