EDITORIAL

Moving the Frontiers Forward: Incorporating Community-Based Participatory Research Into Practice-Based Research Networks

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Practice-based research networks (PBRNs) were developed in North America more than 20 years ago to study the health and health care events that are common in everyday primary care practice.[1-3] During the past 2 decades, the numbers of PBRNs have increased, and they have made major contributions to the science base of health and health care.[4] We believe that PBRNs can push the frontiers of research and knowledge even further by incorporating community-based participatory research (CBPR). Expanding the researcher-clinician partnership in PBRNs to include community members would greatly strengthen the research enterprise of family medicine and, in so doing, may offer new opportunities to address some of the most intractable problems in health care, including disparities in access and outcomes[5,6] and poor translation of results into practice. CBPR is increasingly recognized as a highly effective methodology of adding value and relevance to research in primary health care.[7-12] This method brings researchers and communities into partnerships for "systematic investigation, with the collaboration of those affected by the issue being studied, for purposes of education and taking action or effecting social change."[7] CBPR is different from other community research that views community as a setting or location. Rather, CBPR recognizes community as a social entity with a sense of identity. Working with rather than in communities, CBPR attempts to strengthen a community's problem-solving capacity through collective engagement in the research process.[13] CBPR recognizes the community as a unit of identity, builds on strengths and resources within community, facilitates collaborative partnerships in all phases of the research, promotes a co-learning and empowering process that attends to social inequalities, involves a cyclical and iterative process, and addresses health from multiple perspectives.[9] The equally important goals of CBPR are to benefit the community where the research is taking place and developing valid knowledge that is applicable to other settings.[8]

A CBPR approach brings the knowledge and expertise of persons affected by the health condition, disability, or issue under study into full participation in each phase of the work. In its fullest expression, researchers and communities are in an active and continued partnership throughout the research process, from generating the research question, to developing the instruments and collecting the information, analyzing and interpreting the data, developing conclusions, and jointly disseminating the results.[7,8]

In a study published in this issue of the *Annals*, Westfall and colleagues[14] describe the early experiences by PBRNs in incorporating some of the elements of CBPR. Westfall et al note this change as a natural progression of the tradition of PBRNs to partnering actively with practicing primary care clinicians and their staff in generating

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research ideas and conducting research in everyday practice settings. With the growing support for community involvement, Westfall et al are challenging PBRNs to expand their research by developing partnerships with community members—the patients of the practice who, as individuals or as family members, experience the diseases and practice patterns under investigation.

This study[14] is the first important and timely evaluation of how 2 fundamental research partnerships are coming together: the partnerships of researchers and clinicians, and the emerging partnerships of researchers with communities of patients. This partnership approach will inevitably lead to new relationships between clinicians and their patients, forming the potential for 3-way partnerships of researchers, clinicians, and patients. The advantages of formally strengthening these partnerships include not only expanded diversity in perspective and expertise but also shared learning as research projects are jointly designed, conducted, analyzed, and disseminated. In the future, closer 3-way partnerships could blur the distinctions that have separated the 3 parties in practice-based research and limited the scope of learning.

If the Westfall et al sample is representative, their data suggest that approximately one half of the PBRNs in the United States have incorporated their patients to varying degrees in the research process.[14] Some PBRNs have community advisory boards or committees of only patients, as is the case for their own research network, whereas others have invited patients onto advisory boards, which include key stakeholders, such as physicians, insurers, and public health care groups, with meetings varying from monthly to annually. The article by Westfall et al outlines the different degrees of community involvement and concludes that, to date, none of the partnerships has reached the level of power sharing and decision making throughout the research, as recommended in the full CBPR process. The key to successful partnership research, however, is likely in the ongoing development of relationships and in the individual agreements of the partners. We support others who say that no single set of principles will be applicable to all partners, that there is a spectrum of partnerships, with full partnership as the ideal for which to strive.[15]

Westfall et al also outline the ways and the degree to which CBPR has been incorporated into the research process in different PBRNs, as well as some of the benefits and challenges. Those not using CPBR describe their concerns about adding community members to the research team, especially at the beginning when researchers are engaged in team building and developing trust with clinicians, and struggling with the difficulties of practices in large geographical areas, patients speaking different languages, and concerns of inviting community members to the table in case their voices are not heard.

The early experiences with incorporating elements of CBPR into PBRNs need to be documented to offer examples and inspiration, as well as to provide guidance to other researchers, some of whom are quite fearful of loosing control by adopting this research method and moving into uncharted territory. In the online supplemental case report, the High Plains Research Network Community Advisory Council offers an enlightening view of how a community advisory committee has developed and what this collaboration has accomplished in their PBRN.[16] This article provides real-world examples. It shows the importance of exciting and highly relevant community input, how it strengthens research, as well as the Community Advisory Committee's need for support in time and funding expenses. This case study illustrates how to network over huge geographical distances, the needs and expectations of university and community members, and the dedication of volunteer members to improving local health. We encourage other descriptions of PBRNs working to address these challenges to promote an active discussion among the pioneers in adding CBPR to PBRN. (The *Annals* online TRACK discussion provides an easy opportunity to start this exchange). Honest reporting of both successes and setbacks will ground the method in reality of the benefits and challenges. Documentation of experiences will inspire some, reassure others, allow researchers to decide whether they wish to adopt the method, and show that rigorous scientific objectivity can be continued within the partnership.[13] We also encourage other research, also in its infancy, to evaluate the partnerships and level of community influence and ownership.[17]

At their inception PBRNs in North America grappled with some of the principles of CBPR as they worked to create meaningful partnerships between researchers and practicing clinicians. Although the relationships in many PBRNs have evolved in different directions, nearly all networks have attempted to balance bottom-up research (studies important to clinicians) with top-down research (studies important to researchers and/or funders).[18] As networks expand using CBPR to include patients and their social communities, the challenges and opportunities for innovation will increase geometrically. Deciding who are the relevant communities of clinicians and patients and how to engage them in the research process will inevitably lead to a variety of intriguing and widely different models. These models may also include virtual communities of geographically disparate individuals who can develop a strong sense of community without face-to-face interaction.[19] Teams will be strengthened by acknowledging power differentials of education, sex, politics, and culture, and by promoting a democratic research environment with goals of shared power and decision making with community capacity building and sustainability beyond the end of research funding. There is clearly no blueprint for developing 3-way partnerships, and we encourage research teams to experiment by expanding the team in meaningful ways and avoid the paralysis caused by uncertainty around such questions as "Who is community?" and "Who represents community?"[16]

We recommend that the partners develop written guiding principles[7,20,21] or codes of research ethics,[22,23] that include the framework for the partnership and the protection of community[24] in addition to protection of individual research subjects. CBPR teams can review current guidelines and use the principles to develop their project-specific codes to reflect local culture, political issues, needs, and interests, and to maximize close collaboration between the researcher(s), clinicians, and community partners. The experience of many teams is that the process of developing guidelines can strengthen both the partnership and the proposed research.

Increasing CBPR in PBRNs requires support and changes in many key spheres of influence, including funding, academic support, and ethical review process. In recent years leading North American funding agencies that include the National Institutes of Health (NIH), Centers for Disease Control and Prevention, Agency for Healthcare Research and Quality, and Canadian Institutes of Health Research, as well as such organizations as the North American Primary Care Research Group, have promoted CPBR by offering funding and clear guidelines for the degree of partnership expected from the researcher-community teams. The NIH Roadmap,[25] while not explicitly naming either PBRNs or CBPR, calls for the application of the principles and infrastructure developed by both. It is incumbent upon PBRN and CPBR researchers to make their work known to such funding agencies, as these agencies are crying out for the engagement of those on the front lines, exactly what CBPR and PBRNs already do with little support. Granting agencies can support CBPR not only by funding planning grants to provide the lead time for the development of research ideas and consensus among researchers, clinicians, and community, but also by funding full grants with project durations required to build trust and true partnerships, undertake the research, and disseminate results to the physicians, practice staff, communities, and individual patients.

Universities need to acknowledge and support researchers developing multidisciplinary teams and community partnerships to undertake CBPR, and taking the time to nurture relationships that transcend an individual study should be especially valued. CBPR will benefit from faculty who can offer mentoring in this research method and can influence institutional review boards (IRBs), faculty development, and promotion and tenure committees. Faculty promotion, frequently tied to publish or perish, may be difficult for CBPR junior faculty, especially if they are the pioneers in their university. Partnership research requires sufficient time to develop and maintain the partnerships, publications may be slower because of research questions and time to evaluate community interventions. Universities should review their promotion guidelines to reflect the realities of CBPR compared with traditional academic pathways.[26,27]

PBRNs face a number of challenges in navigating the often confusing issues associated with protection of human subjects and IRB approval.[28,29] For example, clinicians may share roles as researchers, clinicians, and even research subjects, sometimes in the same study. Clinicians participating in PBRN studies may face situations that stress their dual roles as researcher and patient's advocate. As patient communities become involved in CBPR projects, the parallel issues must be identified, sorted out, and addressed. Relationships among 3 parties to the research (researchers, clinicians, and patients) will be more complex and will likely create new local relationships between clinicians and their patients' communities.

In their effort to protect human subjects, the consent language and requirements of some IRBs take on an adversarial and legalistic tone that may not enhance an emerging partnership. As PBRNs engage patient communities in the research endeavor, there may be a need to attempt to educate more systematically the local IRBs to the special challenges of CBPR, which include modification of consent forms to be more community appropriate. Ethical guidelines should promote protection of communities[24] in addition to the protection of individuals, which raises such questions as how to facilitate ethical review by both the IRB and the participating communities. The members of an IRBs need to have some knowledge of CBPR, appropriate community members should be included, and they should know how to review an application for which the researcher may need to finalize the proposal with the community. Communities face the challenges of how to review a proposal. If a community review and approval process is in place, what power does it carry in light of an IRB decision?[29]

CBPR in PBRNs will likely support more-rapid dissemination of results, not only to clinicians but also to patients and the community at large! Substantive exchange by partners during all phases of research infuses the entire research activity with bilateral transfer of knowledge and wisdom across all partners. Many PBRNs are expanding their vision of research and purposefully blurring the boundary between research and quality improvement[30] in an attempt to bring the results of research into practice more quickly. CBPR can increase the rate of knowledge translation and shorten the loop between the research activity and adoption of the results by the participating physicians and community. CBPR can also ensure that research results are relevant to a wider audience and thus hasten adoption beyond the immediate communities.[31-33]

We believe that incorporating principles of CBPR in PBRNs is a huge challenge but one with distinct advantages for improving knowledge development and dissemination. If we can rise to this challenge, the effect on primary care research will be as profound as that achieved 2 decades ago when PBRNs took the initial bold steps to create researcher-clinician partnerships.

Researchers from all disciplines can learn from the partnerships of both PBRNs and CBPR.[34] Clinicians and community members will bring new perspectives and new research questions, gain new skills in the process, and use their expertise to be active participants in the generation and application of new knowledge. Unforeseen solutions will begin to emerge to many of the problems in health and health care that currently seem insurmountable.

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References

1. Green LA. The weekly return as a practical instrument for data collection in office based research. *Fam Med.* 1988;20:182-184.
2. Green LA, Miller RS, Reed FM, Iverson DC, Barley GE. How representative of typical practice are practice-based research networks? A report from the Ambulatory Sentinel Practice Network Inc (ASPN). *Arch Fam Med.* 1993;2:939-949.
3. Green LA, Hames CG, Sr., Nutting PA. Potential of practice-based research networks: experiences from ASPN. Ambulatory Sentinel Practice Network. *J Fam Pract.* 1994;38:400-406.
4. Nutting PA, Beasley JW, Werner JJ. Practice-based research networks answer primary care questions. *JAMA.* 1999;281:686-688.
5. Smedley BD, Stith AY, Nelson AR. *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare.* Washington, DC: National Academies Press; 2002.
6. Institute of Medicine. *Crossing the Quality Chasm: A New Health System for the 21st Century.* Washington, DC: National Academy Press; 2001.
7. Green LW, George MA, Daniel M, et al. *Study of Participatory Research in Health Promotion.* Ottawa: Royal Society of Canada; 1994.
8. Macaulay AC, Commanda LE, Freeman WL, et al. Participatory research maximises community and lay involvement. North American Primary Care Research Group. *BMJ.* 1999;319:774-778.
9. Israel BA, Schulz AJ, Parker EA, Becker AB. Review of community-based research: assessing partnership approaches to improve public health. *Annu Rev Public Health.* 1998;19:173-202.
10. Minkler M. Using participatory action research to build healthy communities. *Public Health Rep.* 2000;115:191-197.
11. North American Primary Care Research Group. Responsible Research with Communities: Participatory Research in Primary Care - A Policy Statement. 1998. Available at: http://www.napcrg.org/exec.html.
12. de Gruy F, III. Depression research in primary care: pushing the field forward. *Ann Fam Med.* 2005;3:3-6.
13. Agency for Healthcare Research and Quality (AHRQ). Community Based Participatory Research: Assessing the Evidence. Evidence Report/Technology Assessment. 2004. Available at: http://www.ahrq.gov/clinic/epcsums/cbprsum.htm.
14. Westfall JM, VanVorst RF, Main DS, Herbert C. Community-based participatory research in practice-based research networks. *Ann Fam Med.* 2006;4:8-14.
15. Israel BA, Parker EA, Rowe Z, et al. Community-based participatory research: lessons learned from the Centers for Children's Environmental Health and Disease Prevention Research. *Environ Health Perspect.* 2005;113:1463-1471.
16. Westfall JM, Van Vorst RF, Main DS, Herbert C. Community-based participatory research in practice-based research networks. Supplemental case report [The High Plains Research Network Community Advisory Council. Community involvement in a practice based research network]. Available at: http://www.annfammed.org/cgi/content/full/4/1/8/DC1.
17. Cargo M, Levesque L, Macaulay AC, et al. Community governance of the Kahnawake Schools Diabetes Prevention Project, Kahnawake Territory, Mohawk Nation, Canada. *Health Promot Int.* 2003;18:177-187.
18. Thomas P, Griffiths F, Kai J, O'Dwyer A. Networks for research in primary health care. *BMJ.* 2001;322:588-590.
19. Lipnack J, Stamps J. *Virtual Teams: People Working Across Boundaries With Technology.* 2nd ed. New York, NY: John Wiley and Sons; 2000.
20. Green, L. W. Guidelines and Categories for Classifying Participatory Research Projects in Health. Available at: http://lgreen.net/guidelines.html.
21. Gibson N, Cave A, Doering D, Ortiz L, Harms P. Socio-cultural factors influencing prevention and treatment of tuberculosis in immigrant and Aboriginal communities in Canada. *Soc Sci Med.* 2005;61:931-942.
22. Macaulay AC, Delormier T, McComber AM, et al. Participatory research with native community of Kahnawake creates innovative Code of Research Ethics. *Can J Public Health.* 1998;89:105-108.
23. Indigenous peoples & participatory health research: planning & management; preparing research agreements. Geneva: World Health Organization; 2005. Available at: http://www.who.int/ethics/indigenous_peoples/en/index.html.
24. Weijer C, Emanuel EJ. Ethics. Protecting communities in biomedical research. *Science.* 2000;289:1142-1144.
25. NIH Roadmap: Re-engineering the Clinical Research Enterprise - Overview. NIH Roadmap. Washington, DC: National Institutes of Health; 2005. Available at: http://nihroadmap.nih.gov/clinicalresearch/index.asp.
26. Nyden P. Academic incentives for faculty participation in community-based participatory research. *J Gen Intern Med.* 2003;18:576-585.
27. Ahmed SM, Beck B, Maurana CA, Newton G. Overcoming barriers to effective community-based participatory research in US medical schools. *Educ Health (Abingdon).* 2004;17:141-151.
28. Wolf LE, Walden JF, Lo B. Human subjects issues and IRB review in practice-based research. *Ann Fam Med.* 2005;3(Suppl 1):S30-37.
29. Hueston WJ, Mainous AGI, Weiss BD, et al. Protecting participants in family medicine research. A consensus statement on improving research integrity and participants safety in educational research, community-based participatory research, and practice network research. *Fam Med.* In press.
30. Mold JW, Peterson KA. Primary care practice-based research networks: working at the interface between research and quality improvement. *Ann Fam Med.* 2005;3(Suppl 1):S12-20.
31. NIH Roadmap: re-engineering the clinical research enterprise - translational research. NIH Roadmap. Washington, DC: National Institutes of Health; 2005. Available at: http://nihroadmap.nih.gov/clinicalresearch/overview-translational.asp.
32. Knowledge translation (KT). Ottawa: Canadian Institutes of Health Research (CIHR); 2003. Available at: http://www.cihr-irsc.gc.ca/e/8505.html.
33. Aaron KF, Stryer D. Moving from rhetoric to evidence-based action in health care. *J Gen Intern Med.* 2003;18:589-591.
34. Leung MW, Yen IH, Minkler M. Community based participatory research: a promising approach for increasing epidemiology's relevance in the 21st century. *Int J Epidemiol.* 2004;33:499-506.