

## SPECIAL COMMUNICATION

## Practice-based Research is Community Engagement

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Community engagement has become a major contributor to medical research during the past 10 years and is an essential component of the current National Institutes of Health (NIH) Roadmap and the Clinical and Translational Science Awards program.<sup>1,2</sup> But, what is a community? And what community gets to be engaged?

Kerr White described one of the major problems with clinical research in the United States as using the tertiary academic medical center as the main location of research ideas and subject recruitment. He pointed out that the vast majority of research was conducted on the 0.1% of the population who were cared for in the academic tertiary hospital.<sup>3,4</sup> Coupled with this problem of location was the problem of the approach that did clinical research *on* subjects, ignoring their unique cultural, ethnic, and geographic identity, and which focused primarily on the interests of the researchers. As a consequence, much of the research was not readily translated into practice, nor was it reflective of clinical problems experienced in non-tertiary settings. Preceding the NIH initiative and now experienced at an accelerated tempo, many researchers have responded to these problems by moving their research enterprise into the community, directly engaging the community in their research and programs. Practice-based research provides a model

that mixes scientific inquiry and community engagement. However, practice-based research has faced growing confusion surrounding the terms community and engagement.

### Location and Orientation

What is the community? Is a community a single geographic location or region or neighborhood? Is community a single racial, ethnic, or religious group; a collection of patients with the same disease; or a population defined by multiple characteristics, such as vulnerability in relation to social and clinical characteristics? Can a community be dispersed over a larger geographic area—a state or the nation: a virtual community linked by email or the internet? Can a community be a clinic: the clinicians, nurses, staff, and patients? A significant sticking point in defining community engagement is often defining the characteristics and parameters of the community.

What constitutes engagement? There are no consistent definitions, but one definition we support states that community engagement includes, “The application of institutional resources to address and solve challenges facing communities through collaboration with these communities.”<sup>5</sup> *Community-engaged scholarship* (CES) is a recent evolution of the term *community-based research* (CBR).<sup>6</sup> The term *engaged* recognizes that the work is done *with* communities and the term *scholarship* is seen as more positive than research. However, simply using CES or CBR does not ensure full community voice in research governance. Community engagement benefits from using the participatory research principles of shared power and decision making between researchers and community members. Participatory research is the “systematic enquiry, with the collaboration of those affected by the issue under study, for the purpose of education and taking action or effecting social change.”<sup>7,8</sup> One frequently used term is *community-based par-*

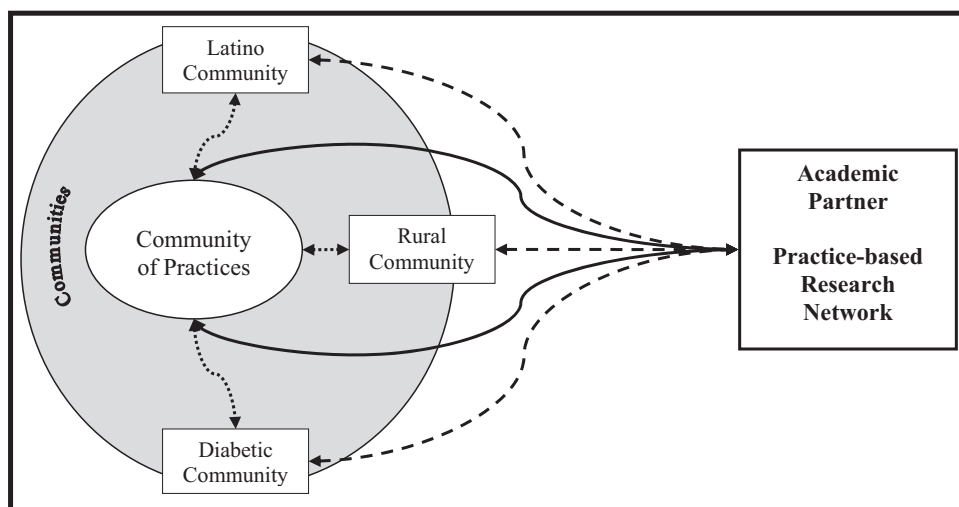
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**Figure 1. Practice-based research engaging the community.** Practice-based research networks (PBRNs) directly engage the medical practice community (*solid line*) and community members (*dashed line*). PBRNs may engage the community members through the practice (*dotted line*). A community may be geographic, demographic, disease specific, or a combination. Numerous other communities exist and may be engaged directly or through the practice (*shaded area*).

participatory research (CBPR); much of the early work in participatory research occurred in the field of health promotion and in neighborhoods and broad community locations, including public health and non-clinical settings. CBPR has become nearly synonymous with community engagement. However, is community the most important element in the community-engagement-participatory-research equation? Has the focus on the neighborhood aspects of community overshadowed the participatory aspects? Participatory research encompasses much more than just CBPR.

Participatory research is not simply about using a group of neighborhoods or community members to push forward a specific research agenda. It is really about an “orientation” to research that embraces the sharing of power. Participatory research is not a method; it is an approach to research governance that aspires to a partnership of researchers and community and a willingness to expand or reframe research questions to increase its relevance to community members, whatever that community may be. Participatory research builds long-term relationships that outlast any specific research project; these relationships form the foundation of a sustained conversation that includes 2-way communication and shared decision making. At its core, participatory research is about conducting research *with* a group, rather than conducting

research *on* a group, and *with* a community rather than simply *in* a community or *for* a community. All the above stem from—and perpetuate—the orientation that the community, and indeed participatory research itself, are not merely tools at the disposal of researchers but are the core values that drive the research endeavor.

### Engaging Community in Practice-Based Research Networks

Practice-based research (PBR) aspires to the orientation of participatory research and community engagement in 3 significant areas (Figure 1). First, PBR demonstrates the orientation to research that encompasses the participatory approach. Rather than just research *in* practices, PBR strives to do research *with* practices, with the physicians, nurses, office staff, and patients. PBR includes the principles of participatory research: trust building, long-term relationships, recognition and incorporation of local expertise and the history of local relationships, shared decision making, and identification of locally relevant clinical questions.<sup>9–11</sup> The broad spectrum of PBR recognizes 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 we strive.”<sup>12</sup> In this issue of the *Journal of the American Board of Family*

*Medicine* is an article by Parchman and Munoz<sup>13</sup> that resulted from this participatory approach. Dr. Munoz is a practicing family physician with an important clinical question. STARNet had the capacity to engage Dr. Munoz and several other practices to ask and answer this clinical question that came directly from the care of patients. Dr. Munoz was a partner for the entire project and co-author on the published manuscript.

Second, PBR engages the community of the practice. That is, each practice includes the elements of a community: collective mission and history, common time together, and a shared social identity. PBR aspires to be a collaborative partnership with practices along the whole research journey, from identification of a clinical problem to the formulation of the research question to the choice of methods, implementation, data collection, analysis, interpretation, and dissemination. In this issue, Froshaug et al<sup>14</sup> describe findings from the Prescription for Health Program. Prescription for Health supported 22 PBR networks (PBRNs) to develop unique approaches to addressing unhealthy behaviors and increasing healthy ones. Using the expertise of each practice and each network, Prescription for Health was able to evaluate multiple strategies for improving health, both within the practice and for the patients attending the practice.<sup>15–17</sup> Levy et al<sup>18</sup> and McCord et al<sup>19</sup> also describe research that engages the primary care practice in various components of the research journey.

Third, PBR occurs within the context of the broader community and neighborhoods and is directly responsive to the needs of the local community in which it exists.<sup>17,20,21</sup> The people who come to these practices may belong to the same community groups, sports teams, or schools. They may share neighborhood pride and concerns. Even in diverse communities, common concerns about children, aging parents, personal health, and economic struggles may create a shared identity. Because many practices include locally relevant clinical services that address the unique problems faced by their patients, these practices are viewed as a medical home and integral part of the community. Williams et al<sup>22</sup> describe the “marriage” of CBPR with PBRNs and list the many advantages they have experienced by involving the broader community in their PBR. They provide an excellent exam-

ple of how to engage the community of patients in the research of the practice.

PBR may be an essential step for good translational research.<sup>23</sup> As quoted widely, “if you want more evidence-based practice, you need more practice-based evidence.”<sup>24,25</sup> Networks have become a widely successful mechanism for organizing PBR within a community context. PBRNs help translate bench discovery and bedside efficacy into effective everyday clinical practice. PBR uses participatory methods to identify the problems that arise in daily practice that create the gap between recommended care and actual care, demonstrate the effectiveness or lack of effectiveness of treatments derived from randomized controlled trials, and provide the laboratory for testing system improvements in primary care to maximize the number of patients who benefit from medical discoveries. PBRNs can provide the environment to help eliminate health disparities by creating true partnerships and blurring the boundaries between clinical research and community-based interventions.

Although PBRNs are effective at communicating the practice-based nature of their research in their publications and PBR has become a successful model for translating research into practice, practice-based researchers have been less effective at communicating the participatory nature of their work. Few articles fully describe the participatory components and the community-engagement orientation of the authors’ work. We recommend that authors describe the community engagement and participatory aspects of their research in all manuscripts and editors expect this of their authors and print those portions of the manuscripts. Online supplements may provide a venue for robust description of the community engagement efforts that result in peer-reviewed publications from PBRNs.

### Practice-Based Research Supports Clinical and Translational Science

PBR is community engagement and provides an effective conduit to a population of patients and the members of the broader community in which the practice resides. PBRNs may serve as a logical introduction for academic researchers to begin collaborating with communities and engaging clinicians, patients, and community members. We believe that the host of new Clinical Science and

Translational Centers and Institutes funded by the NIH that approach research with a collaborative, bidirectional perspective will find an eager and supportive community of researchers, clinicians, patients, and community members in their local and regional PBRNs. A recent survey of PBRN Directors and the Clinical and Translational Science Award Community Engagement Directors emphasized that PBRNs provided more than just expanded access to research subjects. PBRNs also presented opportunities for the academic institution to build relationships with the community (Fagnan, personal communication, March 10, 2009). Westfall et al<sup>20</sup> reported that approximately half of the PBRNs surveyed in the United States also engaged community members in addition to clinic staff. PBRNs support the goals of the Clinical and Translational Science Awards to “effectively engage communities in the translational research process via bidirectional dialogues.”<sup>1</sup>

PBR and PBRNs have solved 2 of the major problems that have vexed clinical researchers for decades. PBRNs solved the “location” problem by moving the research into community practices, where most people get most of their care most of the time, and addressing important clinical questions with large and diverse populations.<sup>23</sup> PBR has solved the “orientation” problem by using the principles of community engagement and conducting research *with* their communities of practices, clinicians, patients, and community members so that the research is highly relevant. PBR may be an effective partner for research that truly engages the community to ask and answer those questions that are most important to the community’s members.

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