ORIGINAL ARTICLE

Practice-Based Research Networks

The Laboratories of Primary Care Research

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Abstract: Medical research has traditionally been based in academic centers, and the findings are frequently not applicable in community primary care settings. The result is a large gap between the possible and the practical in delivering high-quality primary medical care in the United States. Practice-based research networks (PBRNs), laboratories for primary care clinical research, are the appropriate vehicles for uniting the worlds of community primary care practice and clinical research. Although they have received little attention in the mainstream of clinical and health services research, PBRNs have already reported a variety of findings useful for primary care providers, and these networks have helped to identify key issues in healthcare delivery that affect important outcomes. In this report, we outline the rationale for and history of PBRNs. We describe the organization and work of several productive PBRNs, giving examples of their studies that have changed the standards of modern primary care practice. Finally, we describe a developing electronic process for identifying research questions obtained directly from primary care providers that can be used to focus the national primary care research agenda on questions of clinical relevance and importance. As electronic technologies are fully developed and tested, they will facilitate communication between clinicians and researchers, thereby improving the effectiveness and efficiency of practice-based research.

Key Words: practice-based research, primary care, translational research, information technology

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In their classic 1961 paper, White and colleagues estimated that only a tiny minority of Americans (approximately 0.1% in an average month) received medical care at academic referral centers.[1] However, most clinical research at the time took place in such centers. Forty years later, in finding that less than 0.1% of potential patients were hospitalized monthly in an academic medical center, Green and colleagues demonstrated that the picture had not changed significantly.[2] In contrast, 11.3% of Americans visited a primary care physician's office each month, where the spectrum of disease, its outcomes, appropriate diagnostic strategies, and optimum treatment often differ from tertiary referral care settings. To better understand the healthcare needs of most people, research must occur in primary care offices and community practice settings.

The concept of a primary care practice-based research network (PBRN) is not new, as noted in the 1999 American Academy of Family Physicians (AAFP) monograph on the history and prospects of PBRNs.[3] The Dutch Sentinel Stations, a network of general practice in The Netherlands, was established in 1970. Several regional networks were in place in the United States by the 1970s, most notably the Dartmouth Primary Care Cooperative Information Project (COOP). COOP was established in 1978 with grant funding from the Robert Wood Johnson Foundation, the Arthur Vining Davis Foundations, the W. K. Kellogg Foundation, and 2 federal agencies, the Health in Underserved Rural Areas (HURA) program and the Health Care Financing Administration (HCFA). COOP was started as a cooperative venture between Dartmouth Medical School and their community primary care preceptors, and the network was linked by a common data system using a "Superbill" encounter form.

The first national primary care PBRN in the United States was the Ambulatory Sentinel Practice Network (ASPN), established in 1981 and inclusive of both U.S. and Canadian practices.[4] Initially conceptualized as a surveillance network of primary care practices reporting on common problems (helping the U.S. Centers for Disease Control and Prevention, for example, establish a national influenza surveillance network), ASPN evolved into a research network as practices identified questions and refined data collection methods. With the publication of an ASPN overview in 1984, significant funding materialized to support this novel research laboratory.[5] In 1985, a partnership of practices in 9 countries

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modeled after ASPN formed the International Primary Care Network (IPCN). The American Academy of Pediatrics formed the Pediatric Research in Office Setting (PROS) Network in 1986, utilizing board members, policies, procedures, and projects shared with ASPN. PROS now receives infrastructure support from the Health Resources and Services Administration Maternal and Child Health Bureau.

Several strong regional PBRNs emerged in the mid-1980s, including the Pediatric Practice Research Group (affiliated with Children's Memorial Hospital in Chicago), the Wisconsin Research Network (WreN), and the Upper Peninsula Research Network (UPRNet). Entire issues of the *Journal of Family Practice* (*JFP*) in 1994 and 1998 were devoted to results from practice-based research networks.[5,6] The 1994 issue outlines the evolution of the linkage between research and medical subspecialists, with Nutting and Green addressing the "unfortunate misunderstanding" held by many that biomedical knowledge from subspecialty research is widely applicable to primary care practice. This misunderstanding "permits policymakers to assume that medical care can be made efficient and effective simply by summarizing the specialty knowledge base into 'guidelines' and coercing practicing physicians into compliance. It . . . allows the practicing physician to be perceived as a target rather than a resource and a solution."[5] In contrast, alliances between practitioners and researchers have the potential to develop evidence more relevant to guideline development and more "user-friendly" for primary care physicians.

The 1998 special issue of the *JFP* was devoted to the landmark Direct Observation of Primary Care (DOPC) studies, a research project funded by the National Cancer Institute (NCI) and conducted in the Research Association of Practicing Physicians (RAPP).[6] Using a variety of qualitative and quantitative methods, including direct observation of encounters and practice operations, Drs. Kurt Stange, Ben Crabtree, and their research team assembled a wealth of information about 84 family practice offices in northeastern Ohio. DOPC investigators have published over 50 manuscripts that shed new light on the complex, adaptive processes of primary care practices. Continued analysis of this rich dataset continues to shed new light on a host of questions about primary care practice. Publications from research networks outside of primary care also prominently emerged in 1998, including studies from a U.S. neurologic network and a North American chiropractor network.[7,8]

ASPN fell on hard financial times and dissolved in 1999, but 114 of the ASPN practices became part of the National Network for Family Practice and Primary Care Research (National Research Network) established by the AAFP in 1999. Projects of the National Research Network include studies of patient safety, alcohol screening, diabetes outcomes, pneumococcal immunizations in older adults, hepatitis C diagnosis and treatment, and bioterrorism preparedness of family physicians.[9] Staff of the National Research Network also provide support for the Federation of Practice-Based Research Networks (FPBRN), which promotes the growth and development of PBRNs. The FPBRN web site provides an extensive list of current PBRNs, with links to the individual network web sites, current projects, and contact information.[10] As of November 2003, the FPBRN has 50 U.S. network members and 5 international members.

RESULTS OF PRACTICE-BASED REARCH NETWORK STUDIES

A Sample of Publications

In addition to the papers referenced previously, there are many other examples of important publications from PBRNs. In 1988, ASPN clinicians demonstrated the safety of expectant management of spontaneous abortion, a strategy which, at that time, was contrary to recommendations in standard texts.[11] Subsequent studies have confirmed the safety of this cost-saving approach. An example of how practice networks can define the primary care spectrum of a common concern, specifically chest pain, was published in 1994.[12] Through descriptions of patients, summaries of diagnoses, and analyses of costs and services, this paper clarifies the scope of illness associated with chest pain in the primary care setting. This type of information helps to frame care guidelines in an environment appropriate for the primary care physicians. Natural histories of ill-defined conditions (eg, fatigue and dizziness) are also prime candidates for PBRN studies, as shown in a recent network study of night sweats.[13]

PBRNs have also served a valuable role in describing health and healthcare disparities within the U.S. population. In 1997 a PROS–ASPN collaborative study on the emergence of puberty in young girls indicated that signs of puberty are present in as many as 7% of white and 27% of black girls seen in practice by age 7, earlier than suggested in standard pediatric textbooks.[14] This finding led the Lawson Wilkins Pediatric Endocrine Society to revise its recommendations on the timing of referral for evaluation of precocious puberty in girls. Another recent article from a PBRN noted that smoking cessation was more likely to be discussed with privately insured patients, despite the fact that poor and underserved patients were more likely to smoke.[15] Other studies have suggested that racial disparities in healthcare delivery could be the result of barriers to access, not clinician biases.[16,17] More work in the context of primary care clinics could suggest ways to improve equity in the delivery of care across populations. International variations could also be identified by PBRNs such as the significant differences in otitis media treatment identified in the late 1980s between countries participating in the aforementioned IPCN.[18] Temporal changes in office practice have also been identified through PBRN projects; another PROS–ASPN collaborative study suggested a nearly 3-fold increase between 1979 and 1996 in psychosocial problems in children as identified by clinicians.[19]

Current Efforts to Establish Primary Care Research Priorities

PBRNs are also working to define an overall primary care research agenda. The Family Practice Inquiries Network (FPIN), for example, is a national consortium of primary care providers, librarians, researchers, and educators. The authors of this article are members of this consortium, which is committed to using electronic information technology to deliver the best available information to primary care practitioners at the point-of-care, and to integrate and generate new knowledge from practice-based research in the primary care setting. As one of its first scholarly activities, FPIN partnered with the *JFP* to publish a monthly series, "Clinical Inquiries From the Family Practice Inquiries Network," which first appeared in *JFP*'s January 2001 issue. This feature provides concise, evidence-based answers based on systematic reviews of the literature (see www.fpin.org) to questions asked by family physicians such as those collected by Ely et al.[20] These questions are all related to improving quality of care and patient outcomes.

The "Clinical Inquiries" initiative has evolved into a broader project that is one of the core FPIN research facilitation activities. This project aims to identify important clinical questions for which the available evidence is inadequate to formulate a definitive answer. Such questions could form the basis of a research agenda for PBRNs. After obtaining Institutional Review Board approval from the involved institutions in the autumn of 2003, FPIN completed a pilot-tested, web-based survey of AAFP National Research Network members. This survey asked them to rank, in order of general importance and personal interest, those "Clinical Inquiries" with currently inadequate evidence-based answers. To date, 95 AAFP Network members have participated in the survey, ranking 49 questions answered in the "Clinical Inquiries" series. Potential research topics receiving high ranks of importance (with over 80% of the responses in the highest 2 quintiles) include outcomes studies of lipid management in low-risk patients, evaluation of treatment protocols for low back pain, and development of better evidence-based indications for colposcopy.

The authors are currently refining this web-based survey process and recruiting more participants. PBRN members are receptive to ongoing participation in ranking questions for research purposes. FPIN is establishing an ongoing process of soliciting clinical questions, completing systematic reviews, and engaging a large number of practice-based researchers and clinicians to identify priority research questions for primary care practice. We hope to facilitate the work of existing PBRNs, advocate for targeted funding for primary care research in PBRNs, and to facilitate the completion of high-impact studies.

Support and Challenges

Several funding agencies have invested in PBRNs. The Robert Wood Johnson Foundation, the Kellogg Foundation, and the Rockefeller Foundation provided development funds for several networks. The Health Resource and Services Administration Bureau of Health Professions, through the Title VII programs, has provided infrastructure support to a number of family medicine departments for expanding research capacity, including research network development. Since 1999, the Agency for Healthcare Research and Quality (AHRQ) Center for Primary Care, Prevention and Clinical Partnerships has provided infrastructure support to assist the development of practice-based research networks. AHRQ also currently funds a PBRN Resource Center that is charged with evaluating and assisting primary care PBRN development. In partnership with the National Cancer Institute, AHRQ is supporting a grants program in colorectal cancer screening targeted to PBRNs. The Robert Wood Johnson Foundation Prescription for Health, a $5 million initiative in collaboration with AHRQ, currently funds 17 networks to develop methods for improving the delivery, feasibility, and reach of health behavior change interventions in routine practice.

Although the advantages of PBRNs are apparent in the studies mentioned previously, these research networks also face several disadvantages and challenges. Proceedings from the 2001 Practice-Based Research Networks Methods Conference delineate several of these challenges.[21] In an era of increasing focus on human subject protection, PBRNs must receive approval from many Institutional Review Boards to conduct research in several geographic areas and practice settings. Additionally, depending on the onsite research skills needed, projects could require team members to travel frequently to the various clinics. PBRNs must also deal with more issues of selection bias, sampling error, and data collection standardization, which are methodology aspects that are difficult to control in busy, varied practice settings.

DISCUSSION

In a recent *JAMA* special communication, the Clinical Research Roundtable of the Institute of Medicine (IOM) described 2 translational blocks in bringing new knowledge from discovery to improved health.[22] The first block is from basic sciences to human studies, and the second is from new knowledge into clinical practice and health decision-making. PBRNs overcome the second translational block. PBRNs are the only organized setting dedicated to research on clinical preventive services, the diagnosis and management of common and important medical problems, and the delivery of primary care health services. If they mature into well-established clinical research laboratories and attract sufficient funding to support investigators, practitioners, and infrastructure needs, they have the potential to help translate our rich basic and clinical science knowledge into patient care that truly improves the well-being of our population.

The IOM Roundtable sets forth 4 challenges facing the national clinical research enterprise: 1) enhancing public participation in clinical research, 2) developing information systems, 3) training an adequately clinical research workforce, and 4) funding. Internet technology can facilitate communication among the public, clinicians, and researchers (and among clinician-researchers), potentially enhancing opportunities for practice-based research among geographically distant sites. In addition, the primary care research agenda should be informed by primary care physicians. These physicians have valuable insight regarding the importance of research questions. Once the research agenda is set, the potential contributions of PBRNs do not end there. Network physicians and their patients could also participate in studies answering these questions throughout the design, data collection, and analysis phases. These networks also offer promise as efficient means through which to disseminate and implement the findings of such studies by integrating research evidence into electronic point-of-care information resources. Such a partnership between healthcare providers and researchers is an exciting approach to ensuring a central role for clinical practice in medical research.

The importance of practice-based research is clearly gaining attention in recent years. After becoming the Director of the National Institutes of Health (NIH) in May 2002, Dr. Elias Zerhouni assembled nationally recognized leaders to chart a "roadmap" for this century's medical research.[23] This NIH Roadmap includes recommendations and plans for "Reengineering the Clinical Research Enterprise." The plan includes a vision of "new partnerships of research among organized patient communities, community-based physicians and academic researchers." The plan also includes the creation of NIH Clinical Research Associates, "composed of partnerships between academic and community-based investigators . . . well trained to ensure responsible conduct of clinical research and positioned to bring research opportunities to patients and rapidly disseminate the best science-based practices."[24] Primary care PBRNs are a potential mechanism for realizing this vision. Funding mechanisms to establish cooperatives of PBRNs, analogous to NCI-funded cancer cooperative groups and maternal–fetal clinical networks funded by the National Institute of Child Health and Human Development, could accomplish for primary care what these mechanisms have accomplished for cancer and complicated pregnancy care. Such PBRN cooperatives would have biostatistical coordinating centers, data safety and monitoring committees, and other well-established mechanisms for managing large research programs. With these mechanisms in place, PBRNs will continue to evolve as the laboratories necessary to generate research from primary care practice, translate research into practice, and accelerate the flow between scientific discovery and practical clinical care.

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