ARTICLE

Infrastructure

Practice-Based Research Networks: Asphalt on the Blue Highways of Primary Care Research

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In response to the National Institutes of Health (NIH) Roadmap 2 decades ago,[1] "Blue Highways" was used as a metaphor describing the need to create and translate evidence to and from practices and communities where most individuals live and seek medical care.[2] Practice-based research was identified as a key method and infrastructure needed to support the Roadmap's translational aspirations. Practice-based research networks (PBRNs) might be thought of as the "asphalt" paving the roads for essential practice and community-based engagement. T3 translation, or translation into real world practice, quickly became a common part of the NIH Roadmap and subsequent Clinical Translational Science Awards.

PBRNs grew out of the counterculture ethos present during the birth of Family Medicine in the 1970s[3] as a reaction to the promulgation of recommendations and guidelines derived from the highly selective denominator of academic health care centers. Kerr White's identification of the "ecology of primary care" highlighted the mismatch between the source of the vast majority of health research and where people actually lived and sought care.[4] White's prescient review of the need to move research into the community served as a landmark on the road to greater involvement of primary care clinical practices in medical discovery and translation. These developments in the United States mirrored work going on in Europe where Frans Huygen in Nijmegen[5] and Henk Lamberts in Amsterdam[6] began systematic recording of primary care visits to establish a basic epidemiology of primary care. In the US, the Virginia Project led by Maurice Wood had similar goals with Wood and Lamberts subsequently leading the development of the International Classification of Primary Care.[7] As a result of this need for practice-based evidence to inform evidence-based practice, PBRNs emerged to address this gap. Two early PBRNs, the Ambulatory Sentinel Practice Network (ASPN) hosted at the University of Colorado and the Dartmouth CO-OP, began their work as largely bottom-up enterprises with inquiry driven by questions arising out of everyday practice. They were hosted by Departments of Family Medicine, which provided minimal but critical infrastructure support, and the ability to address local issues on a national scale. They additionally pioneered PBRN methods such as card studies,[8] and published

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important results that challenged the conventional wisdom of management of common problems like headaches, miscarriage and otitis media.[9–11] While the PBRN approach has spread beyond Family Medicine, this commentary focuses on their relevance for the discipline of Family Medicine and academic Departments of Family Medicine.

As the PBRN movement grew, they continued to be hosted by Departments of Family Medicine. This fostered an important symbiotic relationship between Departments and PBRNs. PBRNs provided access for many early investigators in Family Medicine to a source of topics for inquiry as well as a relationship-based infrastructure to hone their skills. For community practices, Department researchers provided a way to access methods expertise to address their questions. This partnership or bidirectional highway also provided an important link between the academic Departments and community practices, especially where Departments had missions to address regional workforce needs and quality of care. As recently as 2019, 48% of responding Departments of Family Medicine reported use of a PBRN.[12]

With the emergence of the Agency for Health Care Policy and Research (now the Agency for Healthcare Research and Quality or AHRQ), a federal agency with an explicit mission to support primary care research was established. It was natural for AHRQ to recognize PBRNs as an effective way to achieve this mission. During the late 1990s and early 2000s, AHRQ provided crucial highway infrastructure and began to release Task Order contracts to PBRNs followed by R03 grant opportunities. Both of these provided the first federal funding for many PBRNs and fostered the founding of many more networks. AHRQ additionally funded a PBRN Resource Center that hosted a listserv for PBRN investigators and supported the development and sharing of knowledge about PBRN requirements and methods.[13] AHRQ convened an annual conference for PBRN methods and research, now hosted by NAPCRG with AHRQ conference grant support. During the 2010s, AHRQ funded broad PBRN consortia through a P30 mechanism. These were designed to answer questions that required a larger scale than local PBRNs might access, leading to the formation of regional consortia. Unfortunately, only 1 targeted R18 emerged for funding to address self-management support,[14] yet relationships developed in these consortia generated other larger grant proposals and successful funding.[15–18] While there are examples of PBRNs receiving NIH awards focused on the priorities of disease specific institutes, these remain all too few, with Departments of Family Medicine receiving 0.2% of total research funding dollars from 2002-14.[19]

Most recently, PBRNs began to take up the need for more patient and community input and involvement in shaping research agendas and questions.[20] Because PBRN practices are often tightly embedded in communities, networks began to establish patient and community advisory boards to address how the needs of community, patient and practice align.[21] This active patient engagement led to PBRNs being well positioned to take advantage of a new funder, the Patient-Centered Outcomes Research Institute. In addition, the National Institutes of Health have begun to advocate for PBRN engagement support within Clinical and Translational Science Awards via the National Center for the Advancement of Clinical and Translational Research and Clinical and Translational Research awards via the National Institute of General Medical Studies. Some of the newer initiatives now require PBRN involvement, putting PBRNs on the radar of academic leaders outside of primary care who might otherwise be unaware of the existence or value of PBRNs.

Despite these successes, challenges remain for PBRNs going forward. Like any research infrastructure, support is needed to bridge individual projects. For PBRNs whose "labs are in the community"[22] indirect cost recovery dollars from large, federally funded projects fail to provide equitable support in contrast to campus-based basic science or clinical trial infrastructure. PBRNs rely on other sources, such as core Departmental support and grant direct costs, and are therefore vulnerable to the budgetary pressures faced by academic primary care where clinical revenue alone is insufficient to provide research infrastructure support.

Additional challenges have emerged as community practices have transitioned from independently owned entities to hospitals and health systems-owned practices. Decisions about PBRN participation may be restricted by these larger structures where leaders have limited understanding of the value of practice-based research and community engagement. Participation may be additionally impacted in systems with their own Institutional Review Boards and systems for legal review that now apply to previously independent practices.

Finally, primary care clinicians and staff were severely impacted by the pandemic and in many

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cases have yet to fully recover.[23] While PBRNs strive to reduce burden and research costs for practices and foster professional connections that can improve job satisfaction, the growing rates of burnout and moral injury in health care may limit the ability of practices to fully engage in PBRN activities and projects.

Opportunities for PBRNs remain robust despite these challenges. PBRNs continue to be important and necessary laboratories for translational and implementation science, without which the adoption of new clinical methods and therapies into routine practice remain reliant on "if we build it, they will come" academic wishful thinking. Well into the age of the electronic health record (EHR), because of ongoing challenges to make use of EHR data,[16,24] the early promise that the EHR would be the only tool necessary for practice-based research has not delivered, despite notable efforts and gains by groups like the DARTnet Institute and PCORnet. We now know that their transactional nature and lack of interconnectivity are insufficient for primary care practice-based research. The relational nature of PBRNs can continue as that well-worn road between clinical questions and answers, providing tools for robust research that matters to patients and practice. PBRNs remain key players in how we learn to bridge the worlds of clinical and community-based organizations, including the role of these partnerships in addressing social determinants of health and advancing health equity.

New approaches and methods are vital to the future of PBRNs. Advances in the use of distributed information technologies to connect practices with disparate EHRs provide 1 avenue of enhancing our understanding and surveillance of community incidence and prevalence of both chronic and acute illnesses. Partnerships with state Extension for Community Health Outcomes (ECHO) programs also provide a meaningful way for PBRNs to inform programming and continue to translate knowledge out to practices. Clinical and Translational Research Programs in IDeA states, funded by the National Institute of General Medical Sciences, are now required to support PBRNs or start them if there is no existing 1. This represents a new opportunity that has spawned new growth in PBRNs in these states. PBRNs were well poised to collaborate on AHRQ's anticipated Health Extension program that aligns with the long history of agricultural extension for community support, however despite being named in the Affordable Care Act, this was never funded.[25]

The April 5, 2024 announcement by the NIH Director of a major Common Fund initiative to support primary care research and research networks represents a potential game-changing opportunity for Departments of Family Medicine and PBRNs.[26] After initial investments of $5 and $25 million dollars in fiscal years 2024 and 2025, the Director anticipates $50 to 100 million dollars of annual funds being made available after assessing feasibility and budget requirements. While specifics remain to be ironed out, there is a voiced commitment to leverage existing, successful networks and to broaden the scope of networks to bring primary care research to increasing numbers of practices and communities.

PBRNs proved to be a novel approach to bringing academic medical centers and community practices together to solve the most pressing clinical questions of the day. The idea of using primary care clinicians as catalysts for research was not simply innovative, it was transformative. Today, PBRNs are foundational to community engaged research and implementation science, and play a key role in research seeking to improve health equity in the communities we serve. PBRNs continue to provide important working laboratories for Departments of Family Medicine, whose faculty need a place to pursue inquiry and advance their portfolios for promotion, while continuing to enhance relationships between academic Departments and community practices that are critical for patient care and workforce training. Throughout their history, PBRNs have benefited from their close relationships with Departments, and Departments have benefited from their association with PBRNs. Many, if not most, senior investigators in Family Medicine owe at least a part of their development to work with PBRNs. Continuing to ensure that the pavement, signage and ramps are well-maintained will ensure that the Blue Highways of research served by PBRNs continue to thrive and benefit Departments of Family Medicine and the communities they serve.

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