Networks and Partnerships to Advance Health Equity

PRACTICE-BASED RESEARCH NETWORKS: STRATEGIC OPPORTUNITIES TO ADVANCE IMPLEMENTATION RESEARCH FOR HEALTH EQUITY

John M. Westfall, MD, MPH¹; Rebecca Roper, MPH²; Anne Gaglioti, MD³; Donald E. Nease, Jr, MD⁴

While the vast majority of people receive their medical care in community primary and specialty care clinics, most clinical research is performed in academic tertiary care hospitals and hospital clinics. Practice-based research networks are most commonly collections of primary care practices that work together to ask and answer health questions for their patients and communities and are an integral part of the translational pathway from discovery to practice to community health. Community primary care practices are at the front line of health equity issues; equity in clinical care, equity in community health, equity in social determinants of health, and equity in health outcomes. Practice-based research networks can gather and combine data from dozens of communities, hundreds of practices and thousands of patients to address health equity and disparities across the full spectrum of community and public health to clinical and primary care. This article will briefly outline the history of PBRNs, types of PBRNs, locations, topics, and patient outcomes over the past 25 years. Current PBRN efforts to address health disparities and improve health equity will be described. New PBRN opportunities to address health disparities and approaches to advance implementation research for health equity in the practice and community will be described. Readers will be challenged to consider ways to engage practice-based research networks in their health equity efforts. Ethn Dis. 2019;29(Suppl 1):113-118; doi:10.18865/ed.29.S1.113.

Keywords: Practice-based Research; Practice-based Research Network; Health Equity; Primary Care

¹ Farley Health Policy Center, University of Colorado School of Medicine, Aurora, CO

DEDICATION

This article is dedicated to our friend and colleague, David Meyers, MD, who, while being a staunch supporter of health equity and practice-based research at the Agency for Healthcare Research and Quality, has also been a mentor and professional advocate for disseminating and implementing our best discoveries into primary care. While testifying to the AHRQ National Advisory Council, Dr Meyers stated that current implementation and dissemination work should focus on, "most importantly, communities that serve underserved communities including those in inner city areas."1 He is, and will remain, an inspiration to all of those working to improve health equity in primary care and the communities they serve.

Address correspondence to John M. Westfall, MD, MPH; Department of Family Medicine; Anschutz Medical Campus; 12631 East 17th Ave; AO1, 3rd Floor, Room 3601; Aurora, CO 80045; 303.724.9716; jack.westfall@ucdenver.edu

HISTORY OF PRACTICE-BASED RESEARCH NETWORKS

In 1960, Dr. Kerr White described the ecology of medical care and brought to light the mismatch between where patients get their health care and where the vast majority of health care research is conducted. Most people obtain their health care in the community setting: home remedies, ambulatory care, community hospitals. Yet, the bulk of research is conducted in the tertiary, academic hospital where patients may not truly reflect the broad community diversity.²⁻⁴ The fact that the academic health center remains the primary venue for conducting health care research is a potential cause of health inequity. Findings from health care research conducted in academic settings are often broadly applied to communities and populations that are dissimilar in race, ethnicity, culture, language, socioeconomic status, rural/urban status, health care coverage, health care access, health care infrastructure, and health literacy. Dr. White called on the scientific community to consider methods to expand research to the ambulatory setting where most of the people get most of their care.

National Heart, Lung, and Blood Institute, National Institutes of Health, Bethesda, MD
 Southeast Regional Clinicians Network, Morehouse School of Medicine, Atlanta, GA
 Department of Family Medicine, University of Colorado School of Medicine, Aurora, CO

Soon after, primary care physicians began getting together to discuss ways they might pool their own clinical care into large enough numbers to conduct medical research. They felt that moving research away from the tertiary academic institution would make the research more relevant to primary care and their patients. Early researchers like Will Pickles⁵ and Sir John McKenzie used their own office notes to identify disease outbreaks, natural history of illness, and treatment effects both good and bad.6 Often, these early practicebased researchers worked in underserved communities without collaboration from academic health centers.

While there were fits and starts in local practice collaborations, the emergence of the practice-based research network occurred in the 1970s in the United Kingdom and Netherlands, and in the United States with the Dartmouth CO-OP Project. Network growth continued in North America with the bi-national Ambulatory Sentinel Practice Network (ASPN) in 1981. ASPN members were practicing community physicians engaged in primary care clini-

cal work, their communities, and, now, through the innovation of the ASPN, the discipline of clinical research. ASPN research challenged the consensus-based guidelines of the day and led to changes in health care including management of headache and early miscarriage. In the early 2000s, ASPN became the National Research Network of the American Academy of Family Physicians.

In the intervening 40 years, more than 150 local, regional, and national Practice-Based Research Networks (PBRNs) have emerged. PBRNs are a crucial component of the translational research pathway. PBRNs are in every state and have engaged thousands of physicians and advanced practice providers, who have provided care for more than 100,000,000 patients throughout the United States, North America, and around the world.

WHAT AND WHERE?

Because PBRNs are situated in the community, their structure represents the diverse nature of the communities where they exist.¹⁰ PBRN infrastruc-

tures adapt to the geographic footprint of the network, the community health issues present, and the specific needs of the providers and people it serves. Practice-based research implies health care research conducted in the practice of health care, rather than in the rigid environment of the academic clinical research unit. PBRNs have variable governance structures – from a centralized leadership within a university to collective governance with a board of directors and executive who is also a practicing health care provider. Table 1 provides the typical core elements that define a PBRN.11

PBRNs conduct the full range of research studies including: qualitative and quantitative research, survey research, randomized controlled trials, and pragmatic trials. Practice based research is a component of community-based participatory research and many PBRNs include active engagement of community members and patients in the design, implementation, analysis, and dissemination of their research. ^{10,12} This infrastructure acts as a gateway for underrepresented communities (ie, those that exist outside of the confines of a clinical

Table 1. Practice Based Research Network Infrastructure 38	
Component	Common examples
Minimum of 15 ambulatory practices and/or 15 primary care clinicians	Membership roster, list of practices
A formal statement of the PBRN's purpose and mission	Mission statement, vision, strategic plan
Leadership who oversee administrative, financial and strategic planning	PBRN director, research director
At least one support staff	PBRN coordinator, deputy director, research assistants
A mechanism for soliciting input and feedback from the PBRN clinicians and their communities	Board, advisory council, patient advisory board
Organizational structure independent of any single study	Core funding from department or other non-study source
2-way communication with providers	Annual convocation, emails, newsletters, practice site visits
Research and/or quality improvement infrastructure	Institutional review board, statistician, data management

research unit at an academic health center) to participate in research. This not only includes the broad range of patient and geographic communities that PBRNs serve, but also includes the practicing primary care clinician researcher who is grossly under-represented in traditional research spaces like NIH study sections and as principal investigator on NIH awards. 13,14 Having a seat at the table of health care research is the first step on the path to equity for populations that have been traditionally under-represented in research. PBRNs meet these under-represented communities where they live and where they receive health care.

Practice-based research networks often explicitly address health equity. In 2015, 96 of 173 PBRNs registered on the AHRQ site reported a commitment, "to produce research applicable to improving the care of vulnerable populations living in their communities."15 As of 2015, nearly half of PBRNs included federally qualified health centers (FQHC), 16 which comprise the backbone of the country's primary care and provide comprehensive primary care, dental, and mental health services to a disproportionately poor, minority, and medically underserved population. According to the National Association of Community Health Centers,¹⁷ FQHCs care for more than 28 million people in the United States and with these centers represented in such a large proportion of PBRNs in the United States, the capacity of the PBRN research extends to populations that bear the greatest burden of health inequities in research and allows translation of findings back to those communities to advance health equity.

Over time, the number of Primary Care PBRNs in the United States has grown substantially, from 28 in 1994¹⁸ to 141 as of January 2017.¹⁹ In the late 1990s, federal contract and grant support emerged for Primary Care PBRNS. Funders recognized the critical importance of implementation strategies being designed and evaluated in health care settings since they are representative of contemporary clinical workforce, patient populations, and community-based resources and priorities. AHRQ provided modest infrastructure support for the establishment of more than a dozen individual PBRNS and catalyzed a PBRN community of learning by concurrently sponsoring the PBRN Resource Center. The PBRN Resource Center provided technical support for the organization and governance of PBRNs, which led to the development of recognized PBRN infrastructure requirements.²⁰

AHRQ's PBRN Resource Center's role in providing technical expertise began as an in-house research methods resource for primary care PBRNS. Over time, the PBRN Resource Center transitioned to serve as resource for administration of domestic and international primary care PBRNs, as well as supporting the development of PBRNs in other settings.²¹ The on-line PBRN Resource Center served as an active platform or PBRN leadership to share their prowess in research methods, practice facilitation, application of implementation frameworks, cultural competency, and other implementation research strategies that contribute to success.²² The PBRN Resource Center also supported annual in-person meetings, where PBRN leadership would gather to exchange research ideas, findings, and formulate formal research partnerships and informal collaborations.

In 2014, with the anticipated ending of AHRQ contract-supported PBRN conferences, the North American Primary Care Research Group (NAPCRG) successfully competed for AHRQ conference grants to host an Annual PBRN meeting. As evidence of the

The AHRQ PBRN
registry (https://pbrn.
ahrq.gov/pbrn-registry/
advanced-search), provides
an excellent opportunity
to learn about the areas
of research interest and
experience from registered
PBRNS from across the
country.

PBRN community's commitment to health equity, the 2018 conference theme was, "Addressing Health Disparities in PBRN Research."

In 2012, AHRQ established 8 PBRN Centers of Primary Care Practice-Based Research and learning, known as PBRN P30 Centers.²³ More than one-third of the registered PBRNs were members of at least one PBRN P30 Center. All were funded

to stimulate research advancements in the delivery and organization of primary care, nurture partnerships, conduct research, and disseminate knowledge. The PBRN P30 Centers provided unique infrastructure support for multiple PBRNs to assemble into formalized centers of research and learning for primary care PBRNs.

In 2014 leaders from Meta-Network Learning and Research (MetaLARC) Center and Collaborative Ohio Inquiry Network P30 Centers invited leadership from other PBRN P30 Centers to create a PBRN Research Methods Certificate Program (PBRM). The PBRN P30 Centers' leadership created curriculum, matched mentees and mentors, and delivered a highly valued training experience to in-thefield clinicians and researchers. The certificate program has provided training to 50 new PBRN investigators. Benefits of the program continue to accrue. For example, two of the participants at the 2018 NHLBI's Saunders-Watkins Leadership Workshop in Health Disparities and Implementation Research for Early-Stage Investigators were graduates of the PBRM Certificate program and other participants have obtained funding and published papers as a result of the mentorship and capacity building provided by the program.

HEALTH EQUITY WORK IN PBRNs

Early PBRN work revealed the power of the disseminated clinical research network through several important studies. The Ambulatory Sentinel Practice Network conducted a study on headaches that led to a new understanding of a safe, effective approach to new onset headache in primary care.²⁴ The ASPN study on care and management of spontaneous abortion also led to practice changes, making a "weight and watch" approach in the ambulatory care setting rather than immediate dilation and curettage the standard of care for spontaneous abortion in the United States.²⁵ Recent studies in PBRNs have addressed care and treatment of asthma, 26 COPD, 27 and cardiovascular disease risks.²⁸

PBRNs are ideally suited to both rapidly assess issues of health equity and study interventions designed to reduce health disparities. Because of their direct linkage to and relationships with practices that serve diverse communities and populations, PBRNs provide an opportunity to investigate the impacts of race, ethnicity and social determinants on health. PBRNs are also an ideal laboratory for studying interventions to address health equity issues, particularly those that are well suited to delivery in primary care settings. Finally, it is important to emphasize that PBRN practices can often serve a sentinel function, alerting investigators to the presence of important health equity issues while also providing a laboratory for the investigation and confirmation of suspected health equity issues.

A recent example of a PBRN study that has health equity implications was done in the ACORN and SNOCAP networks in Virginia and Colorado.^{29,30} The focus of this project was to assess the prevalence of loneliness in patients and de-

termine the associations of loneliness with sociodemographic and health status measures. Over several months, both networks conducted a card study³¹/waiting room survey capturing data from 1,246 patients in 16 practices with a rich mix of urban, rural, racial, and ethnic groups. Examining the statistical relationship of loneliness with rurality, race or ethnicity yielded no

By moving research into the community, PBRNs offer the opportunity to identify and research health issues relevant to the community and patient.

significant findings. However, when examined from the standpoint of zip code location of patients who participated, those residing in zip codes with higher social deprivation index scores had higher loneliness scores.

SERCN is a PBRN of FQHCs in eight southeastern states (Georgia, Florida, Mississippi, Alabama, North Carolina, South Carolina, Kentucky, and Tennessee). 32 SERCN is administered at the National Center for Primary Care at Morehouse School of Medicine, a historically Black school of medicine that was ranked number one in social mission in the country and whose mission is to "lead the creation and advancement of health equity." 33 SERCN also explicitly prioritizes

health equity in their mission statement: "The Southeast Regional Clinicians Network exists to improve health and advance health equity in the southeastern US via practice-based research in the primary care safety net...". Previous work focused on high-disparity conditions that disproportionately impact minority populations like asthma, diabetes, and heart disease³⁴⁻³⁶ In a recent network-wide needs assessment and agenda setting effort funded by PCORI, SERCN network stakeholders explicitly defined promoting equity in medically and socially complex patients served by FQHCs as a priority. A current study in the network is focused on understanding Black-White breast cancer mortality inequities from the perspectives of patients and primary care providers to inform interventions to reduce breast cancer mortality disparities.³⁷

Because PBRNS exist in the community, they can often address community needs as well as clinic-based research. The Los Angeles Community Health Resource Network is a collaboration of federally qualified community health centers and local community organizations.³⁸ Their focus on reducing health disparities in southern California within clinic and community led to a unique parenting program that uses community promotoras called Madres a Madres. Research conducted in PBRNS supports the promotoras' importance and capacity to address their community's health care priorities as they conduct research to address sources of health disparities and identify opportunities to leverage community-based resources to improve health equity in their communities.

Conclusion

Practice-Based Research Networks were born into the diverse clinics in communities throughout rural, urban, inner city, and suburban primary care. By moving research into the community, PBRNs offer the opportunity to identify and research health issues relevant to the community and patient. PBRNs are a vital component of the translational research pathway from discovery to implementation and dissemination. PBRNs are poised to forge a path to health equity and overcome the current inequities in health research participation and health outcome problems faced by patients, providers, and community members.

Conflict of Interest
No conflicts of interest to report.

AUTHOR CONTRIBUTIONS

Research concept and design: Westfall, Nease; Acquisition of data: Nease, Roper, Gaglioti; Data analysis and interpretation: Westfall, Nease, Roper, Gaglioti; Manuscript draft: Westfall, Roper, Nease; Supervision: Westfall

References

- Meyers D. Testimony before the National Advisory Council (NAC) Meeting. Last accessed January 4, 2019 from http://www.webconferences.com/ahrq/2345487.html
- White KL, Williams TF, Greenberg BG. The ecology of medical care. N Engl J Med. 1961;265(18):885-892. https://doi. org/10.1056/NEJM196111022651805 PMID:14006536
- Green LA, Fryer GE Jr, Yawn BP, Lanier D, Dovey SM. The ecology of medical care revisited. N Engl J Med. 2001;344(26):2021-2025. https://doi.org/10.1056/ NEJM200106283442611 PMID:11430334
- Stewart M, Ryan B. Ecology of health care in Canada. Can Fam Physician. 2015;61(5):449-453. PMID:25971762
- Pemberton J. Will Pickles of Wensleydale: The Life of a Country Doctor. Exeter, UK: The Royal College of General Practitioners; 1972.
- 6. Hickner J, Green LA. Practice-based Research

- Networks (PBRNs) in the United States: Growing and still going after all these years. *J Am Board Fam Med.* 2015; 28(5):541-545. https://doi.org/10.3122/jabfm.2015.05.150227
- The Dartmouth Practice-based Research network. Last accessed January 4, 2019 from https://pbrn.ahrq.gov/pbrn-registry/ dartmouth-practice-based-research-network.
- Green LA, Wood M, Becker L, et al. The Ambulatory Sentinel Practice Network: purpose, methods, and policies. *J Fam Pract*. 1984;18(2):275-280. PMID:6699565
- Westfall JM, Mold J, Fagnan L. Practicebased research: "Blue Highways" on the NIH roadmap. *JAMA*. 2007;297(4):403-406. https://doi.org/10.1001/jama.297.4.403 PMID:17244837
- Westfall JM, Fagnan LJ, Handley M, et al. Practice-based research is community engagement. J Am Board Fam Med. 2009;22(4):423-427. https://doi.org/10.3122/ jabfm.2009.04.090105 PMID:19587257
- Green LE, White LL, Barry HC, Nease DE, Hudson BL. Infrastructure requirements for Practice-Based Research Networks. *Ann Fam Med.* 2005;3(suppl 1):S5-S11. https://doi. org/10.1370/afm.299
- Westfall JM, VanVorst RF, Main DS, Herbert C. Community-based participatory research in practice-based research networks. *Ann Fam Med.* 2006;4(1):8-14. https://doi. org/10.1370/afm.511 PMID:16449391
- Lucan SC, Phillips RL Jr, Bazemore AW. Off the roadmap? Family medicine's grant funding and committee representation at NIH. Ann Fam Med. 2008;6(6):534-542. https:// doi.org/10.1370/afm.911 PMID:19001306
- Cameron BJ, Bazemore AW, Morley CP. Lost in translation: NIH funding for family medicine research remains limited. *J Am Board Fam Med.* 2016;29(5):528-530. https://doi.org/10.3122/jabfm.2016.05.160063 PMID:27613784
- Agency for Healthcare Research and Quality. 2015. Advancing Research and Quality of Care For Vulnerable Populations. Last accessed January 4, 2019 from https://pbrn.ahrq.gov/sites/default/files/docs/page/VulnerablePopulations. pdf.
- Practice Based Research Networks. 2015.
 Last accessed January 4, 2019 from https://pbrn.ahrq.gov/sites/default/files/docs/page/2015AHRQPBRNDataSlides.pdf.
- National Association of Health Centers. Last accessed January 4, 2019 from http://www. nachc.org/wp-content/uploads/2018/08/ AmericasHealthCenters_FINAL.pdf
- Green LA, Hickner J. A short history of primary care practice-based research networks: from concept to essential research laboratories. J Am Board Fam Med. 2006;19(1):1-10. https://doi.org/10.3122/jabfm.19.1.1 PMID:16491999

Practice-Based Research Networks - Westfall et al

- Roper R. Special issue on primary care practice-based research networks: insights on innovative strategies for harnessing health information technology to help individuals, teams. *J Ambul Care Manage*. 2014;37(2):96-99. https://doi.org/10.1097/ JAC.0000000000000000030 PMID:24594557
- Green LA, White LL, Barry HC, Nease DE Jr, Hudson BL. Infrastructure requirements for practice-based research networks. *Ann Fam Med*. 2005;3(suppl 1):S5-S11. https://doi. org/10.1370/afm.299 PMID:15928219
- Agency for Healthcare Research and Quality. 2015. Application of PBRN Model to Nonprimary Care Settings. Last accessed January 4, 2019 from https://pbrn.ahrq.gov/sites/default/ files/docs/page/Affiliates.pdf.
- Agency for Healthcare Research and Quality. 2015. *Innovative Research Methods*. Last accessed January 4, 2019 from https://pbrn.ahrq.gov/sites/default/files/docs/page/methods.pdf.
- Agency for Healthcare Research and Quality.
 2015. Centers for Primary Care Practice-Based Research and Learning: Nurture Partnerships, Method Development, and Trans-Network Collaborations. Last accessed January 4, 2019 from https://pbrn.ahrq.gov/sites/default/files/ docs/page/P30-Overview_0.pdf.
- Becker LA, Green LA, Beaufait D, Kirk J, Froom J, Freeman WL. Use of CT scans for the investigation of headache: a report from ASPN, Part 1. *J Fam Pract.* 1993;37(2):129-134. PMID:8336092
- Spontaneous abortion in primary care. A report from ASPN. J Am Board Fam Pract. 1988;1(1):15-23. PMID:3414385
- Comparative Effectiveness of Asthma Interventions within an AHRQ PBRN. Last accessed January 4, 2019 from https://clinicaltrials.gov/ ct2/show/NCT01280500
- The CAPTURE Study: Validating a Unique COPD Case Finding Tool in Primary Care (Aim 3) (CAPTURE). Last accessed January 4, 2019 from https://clinicaltrials.gov/ct2/ show/NCT03583099
- Evidence NOW: Advancing Heart Health in Primary Care. Last accessed January 4, 2019 from https://www.ahrq.gov/evidencenow/ index.html
- Ambulatory Care Outcomes Research Network (ACORN). Last accessed January 4, 2019 from https://familymedicine.vcu.edu/ research/fmresearch/acorn/
- The State Networks of Colorado Ambulatory Practices and Partners (SNOCAP) and
 The Colorado Research Network (CaReNet).
 Last accessed January 4, 2019 from http://
 www.ucdenver.edu/academics/colleges/medicalschool/departments/familymed/research/
 PBRN/SNOCAP/Pages/SNOCAP.aspx
- Westfall JM, Zittleman L, Staton EW, et al. Card studies for observational research in practice. *Ann Fam Med.* 2011;9(1):63-

- 68. https://doi.org/10.1370/afm.1199 PMID:21242563
- 32. The Southeast Regional Clinicians Network Last accessed January 4, 2019 from http://www.sercnetwork.org/.
- Mullan F, Chen C, Petterson S, Kolsky G, Spagnola M. The social mission of medical education: ranking the schools. *Ann Intern Med.* 2010;152(12):804-811. https://doi. org/10.7326/0003-4819-152-12-201006150-00009 PMID:20547907
- Rust G, Daniels E, Satcher D, Bacon J, Strothers H, Bornemann T. Ability of community health centers to obtain mental health services for uninsured patients. *JAMA*. 2005;293(5):554-556. PMID:15687308
- Rust GS, Murray V, Octaviani H, et al. Asthma care in community health centers: a study by the southeast regional clinicians' network. J Natl Med Assoc. 1999;91(7):398-403. PMID:10643212
- Daniels EC, Powe BD, Metoyer T, McCray G, Baltrus P, Rust GS. Increasing knowledge of cardiovascular risk factors among African Americans by use of community health workers: the ABCD community intervention pilot project. *J Natl Med Assoc.* 2012;104(3-4):179-185. https://doi.org/10.1016/S0027-9684(15)30139-5 PMID:22774385
- Hunt BR, Hurlbert MS. Black: White disparities in breast cancer mortality in the 50 largest cities in the United States, 2005-2014. Cancer Epidemiol. 2016;45:169-173. https://doi.org/10.1016/j.canep.2016.07.018 PMID:27720130
- L.A. Net Community Health Resource Network. Last accessed January 4, 2019 from http://www.lanetpbrn.net/about