

SPECIAL COMMUNICATION

Looking Back to Move Forward: Reflections of PBRN Directors

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This article looks back on the story of the Ambulatory Sentinel Practice Network (ASPN) and its successor, the National Research Network (NRN), through the eyes of its leaders during the first 40 years. Facilitated conversations over 2 years iteratively coalesced key facts and patterns in this collective account of what they had observed. Time-durable patterns observed are distilled for interpretation and application by contemporary practice-based research network (PBRN) leaders as they move forward. Looking back is done via developmental eras. The ASPN was proposed in 1978 as a set of change strategies for primary care research, ASPN gathered momentum through efforts of individuals, institutions, and small grants that mobilized enthusiasm and commitment in the face of headwinds. The network expanded into the research mainstream from 1988, addressing large socially important questions with greater acceptance and volume of PBRN research. The ASPN is now in an era of scaling up and adapting to huge technological, organizational, and business shifts and a growing emphasis on patient and community engagement, safety, and disparities. Archetypal dilemmas and balances that emerged and re-emerged across these eras are distilled, along with ways they were addressed at the time. The authors then project their 40-year experience to future vistas they believe the PBRN value proposition can be adapted and extended; what they regard as promising directions future leaders to take. (J Am Board Fam Med 2024;37:955–968.)

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Introduction

This article looks back on the story of the Ambulatory Sentinel Practice Network (ASPN) and its successor, the National Research Network (NRN), distilling time-durable principles and patterns for use by practice-based research network (PBRN) leaders and participants. This synthesis is

from the directors of ASPN or NRN, the United States' first national PBRN, who walked a path during a 40-year period of birth and evolution of primary care PBRNs.

Beyond remembrance, this article aims to articulate patterns and balances observed in the first 40 years that these authors expect to be recapitulated

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***Dedication:** The late Dr. John Hickner was a strong, persistent leader in the invention and evolution of PBRNs, including serving as director during ASPN's transition into the National Research Network (NRN). He built multiple primary care clinical practice research networks on the national, state, and local levels to serve rural communities in addition to his larger career as clinician, teacher, and researcher. His ideas and contributions to this manuscript prior to his death in 2022 were seminal and insightful. We remaining authors express our gratitude to John by dedicating this paper to him as our co-author whom we deeply miss.

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in some form in the lives of PBRN leaders and members; lessons distilled for a contemporary audience that should not need to be rediscovered every generation. This insider view complements comprehensive, data-driven reviews of PBRN history.^{1,2,3} The authors recognize that a half century after formalizing primary care practice-based research networks, there is still keen, international interest in them as crucial infrastructure for expanding the knowledge base, improving health care, improving health of individuals and communities, and containing costs of care.⁴ Archetypal challenges and dilemmas described here can be expected to play out in different ways at different times in different places, while the value proposition (what PBRNs can do for whom) has evolved considerably since the advent of ASPN 40 years ago.

This article is the result of careful recording and synthesis of recurrent and iterative conversations during a 2-year period, with regular opportunities to read, reflect, coalesce patterns, and correct drafts intended to capture the directors' collective account of what they had been observing together.

Eras in the Spread of This PBRN Innovation

The evolution and spread of the ASPN/NRN innovation in thought, action, and relationship is shown via 3 developmental stages. An 'era' is defined as a change in the environment affecting ASPN/NRN, with the network's responses.

Era 1. Launching a Brave New Idea (1978 to 1988)

All communities, institutions, and causes have an origin story—how things came about and acquired life. In 1978, a small group of university and public health people from Colorado⁵ brought a proposal to the North American Primary Care Research Group (NAPCRG) to organize real-world, community-based practices into a national, collaborative network to provide surveillance of what happens in local practices and do research about family medicine and primary care. This was almost a decade after family medicine was established as a specialty in the United States.

The 1978 proposal was declined. Research was generally viewed as the purview of investigators in academic centers, with frontline primary care physicians a receptive vessel for research findings from elsewhere. At that time, family practice identity centered on patient care, with highly variable opinions

on the place of research.⁶ Developing a new operational infrastructure to study primary care where and as it occurred was experienced as radical because even those urging a primary care research agenda were skeptical of the feasibility of gathering scattered, independent practices into a research enterprise. "Practicing docs will not do research" was the prevailing opinion.

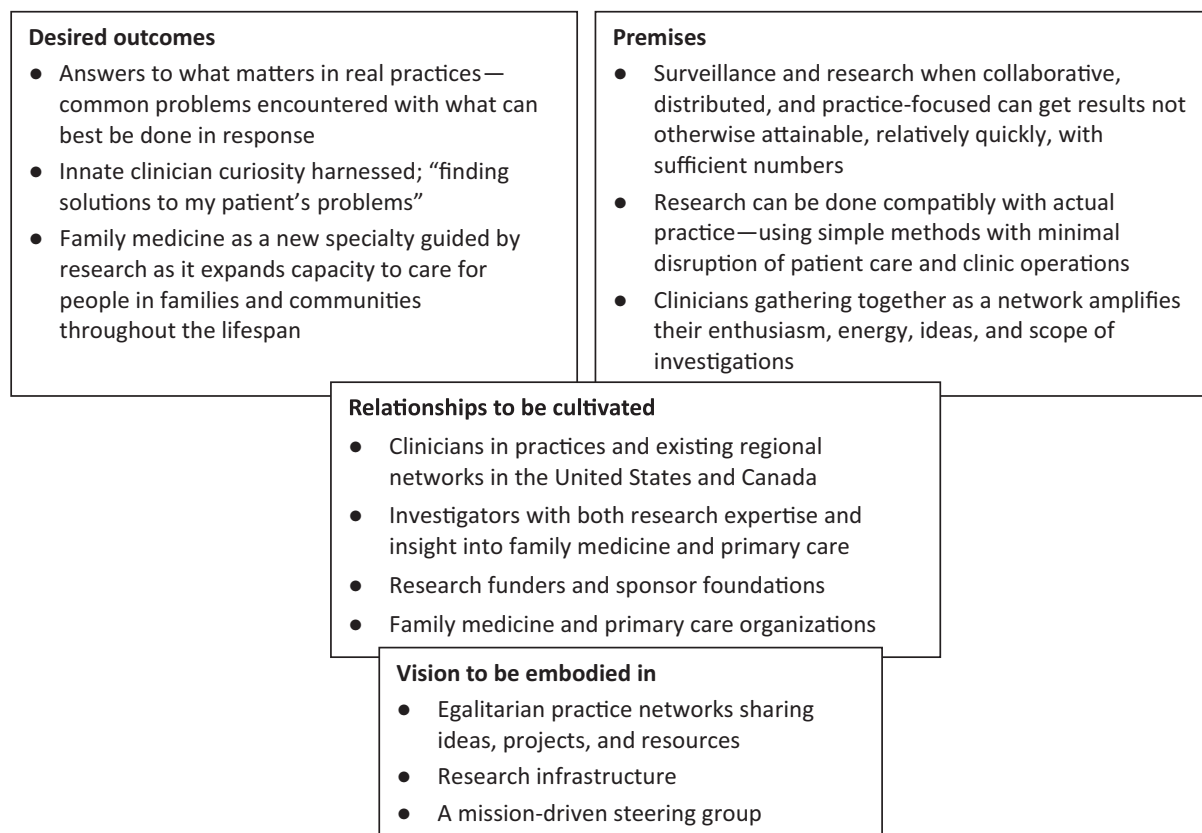
Undeterred, a small volunteer international steering committee⁷ refined the proposal, with further literature review of similar efforts and clearer description of key concepts as shown in Figure 1. In 1979, NAPCRG endorsed the revision and provided \$1,200 of initial funding. Soon after, the Rockefeller Foundation provided 3 \$25,000 annual grants-in-aid received by NAPCRG to fund the first part-time ASPN executive secretary, letterhead and business cards, newsletters, printing of pocket-sized "weekly returns" to collect practice data, and travel for planning meetings.

To guide further development and build credibility, ASPN took inspiration from historic and contemporary pioneer family physician researchers such as Sir James McKenzie (Scotland), Sir William Pickles (England), F.J.A Huygen (The Netherlands)⁸ and Curtis Hames, Milton Seifert, and Maurice Wood (United States).⁹ ASPN imported experience and methods from general practice morbidity reporting systems in the United Kingdom, influenza surveillance systems in Canada, and the sentinel stations of the Netherlands. At about the same time, a Colorado "Family Medicine Information System" demonstrated feasibility and utility of gathering clinical and billing data across practices.¹⁰ The 1961 "boxes" of Kerr White's "Ecology of Medical Care"¹¹ showed that primary care had a far greater role in care provision than specialty academic centers and became an anchoring observation for PBRN's.

Thirty-eight community-based practices across the United States and Canada were recruited by steering committee members. Many of these were rural practices and those that hosted medical students and residents to learn about real world practice. Pioneering practices exhibited defining characteristics that began to underlie a defined way of operating:

- Irrepressible curiosity, an infectious desire to "find solutions to my patients' problems."
- A shared drive to investigate and define optimal care for patients seen in community practice and how it might differ from guidelines promulgated by academic centers.

Figure 1. Change concepts in 1979 Ambulatory Sentinel Practice Network (ASPEN) proposal.



- Deep appreciation for the need to do research without disrupting or distorting the practices’ purpose—patient care—maintaining a focus on common problems encountered in practice.
- Enthusiasm for simple data collection, e.g., the “weekly return” reporting form that took no more than 60 seconds to fill it out and preserved patient and practice confidentiality.^{12,13}
- A felt need for both denominators and numerators that led to methods to develop age/sex registries and began to paint a picture of each practice’s population.¹⁴

Initial operations and early network expansion depended mostly on volunteerism. The ASPEN steering committee, generous faculty members (particularly non-physician faculty with research skills) and practice administrators supplied in-kind efforts. This volunteer action was undergirded by investment by the University of Colorado Department of Family Medicine as headquarters, and business operations initially conducted in the Department of Family Medicine at Virginia Commonwealth University. This was the beginning of ASPEN, under the aegis of NAPCRG as a binational network including US and Canadian practices.¹⁵

Regular newsletters, personalized telephone and US mail communications between ASPEN headquarters in Denver and the practices galvanized and sustained the network as the day-to-day work evolved. In the words of Linda Niebauer (first paid staff):

“People isolated in small practices had ideas to study, but inadequate time, expertise, resources or numbers large enough to implement on their own. A big accomplishment was that folks could join a network with the resources and researchers to understand their own practices in ways they didn’t know before.”^{16,17}

The new network established an annual meeting, the ASPEN Convocation. These meetings provided opportunities to review progress, formulate study ideas, and bond in common cause. A sense of renewal and important possibilities could be “felt in the room” and was “magical.”

PBRN Research About Primary Care Was Not Appreciated by Most Medical Journals
At the beginning of ASPEN, most editors did not view primary care practice as a source of important

questions and answers. Manuscripts often went unreviewed because they were not about something thought to be important or were not seen as valid when findings were contrary to prevailing wisdom.^{18,19} The *Journal of Family Practice* however was exceptionally receptive to network developments and studies.

As the volume of primary care research studies grew, several journals with a primary care focus emerged. The *Journal of the American Board of Family Medicine* (JABFM, 1988) published the first research article from ASPN concerning miscarriage and its true associated morbidity and realistic management.²⁰ In 1988, *Family Medicine* devoted an issue to ASPN methods and results including a formal 10-year evaluation of ASPN.²¹ *Canadian Family Physician* reported an update of ASPN's development in 1989, and other journals followed, such as *The British Medical Journal*, *The Journal of General Internal Medicine*, and *The Annals of Family Medicine* published articles and editorial pages receptive to the questions and answers derived in and by primary care practices.

ASPN's first funding breakthrough came in 1984 from the W. K. Kellogg Foundation as a 3-year, million-dollar grant. This fueled practice enthusiasm and enabled hiring a director from one of the ASPN practices and a data analyst. These new arrivals unleashed a period of rapid growth, a spectrum of studies using various scientific methods, and institutionalization of clarified processes. Success inspired the Kellogg Foundation to provide supplemental funding for an international practice-based study of otitis media among 4 countries with ASPN as the US/Canadian participant.¹⁸

However, in 1987, 2 weeks before a continuation award was expected, an unanticipated change in Kellogg Foundation leadership resulted in discontinuation of the programming bucket from which ASPN's grant funding flowed. This sudden loss of support from ASPN's "angel investor" during a phase of rapid growth unleashed a full-blown crisis. Word spread rapidly that the network would collapse, but it did not. Practice response was immediate: "Do not worry, we're still here." Intradepartmental budget adjustments made at the University of Colorado helped support headquarters staff. The American Board of Family Practice (now ABFM) responded to the jarring loss of funding with a 1-time grant to bridge the immediate chasm. The American Academy of Family Physicians (AAFP) committed to funding minimal essential operations via 3 1-year

grants. This bridge funding and a brief transition grant from the Kellogg Foundation reestablished an expectation of survival.

This outpouring of support allowed ASPN to continue to diversify its funding, such as a cooperative agreement with the Centers for Disease Control (CDC) to determine the seroprevalence of human immunodeficiency virus in frontline practice. Work continued to build practice capacity to do research. In the words of ASPN's first director, Frank Reed:

"We learned how to go from *curiosity* to *systematic study*; how you wrestle the nugget question down to the ground to study it. It was a time of simple methods ... an important start in building practice discipline and capacity to do research in novel community settings."

Table 1 summarizes how challenges of this era were met.

Era 2. Expanding into the Mainstream of Research (1988 to 1999)

Pressure Grew to Use the ASPN "Laboratory" to Study Problems of Interest to National Health Policy

Concern with HIV led to an HIV seroprevalence study in ASPN practices^{22,23} funded by the Centers for Disease Control and Prevention (CDC). This study marked the beginning of ASPN work oriented more to national needs than local practice interests, but the clinicians and practices endorsed this project and enabled ASPN to conduct it. Others followed. Concerns about patient safety and errors in health care,^{24,25} challenges with laboratory testing,²⁶ referral patterns,²⁷ and care of people with depression in primary care^{28–32} inspired both practices and federal research funding agencies.

ASPN Outgrew the Capacity of Its Original Institutional Home

Seizing new opportunities called for new governance and business capacities. ASPN's steering committee morphed into a founding board of directors for a new 501c3 organization with all the responsibilities of an independent organization and the capacity to collaborate widely with multiple entities.

Balancing What Practices and Clinicians Want with National Research Policy Needs Was Seen as a Key to Relevance, Independence, Financial Sustainability and Growth

ASPN began to address questions important to federal funders as a major step toward financial

Table 1. Era 1. Launching a Brave New Idea (1978–1988)

Events Calling for Something New	Developmental Response
<p>Mismatch between research and real-world needs A drive to investigate and define optimal care for patients seen in community practice and how it might differ from guidelines promulgated by academic centers.</p> <p>National doubts about the feasibility of gathering scattered, independent practices into a research enterprise PC practices not seen as places with research skills, questions, or answers. “Research starts with questions, not networks”; “Practicing docs won’t do research.”</p> <p>PBRN research about primary care was not appreciated by most medical journals. Most editors didn’t view primary care practice as a source of important questions and answers.</p> <p>No playbook for how to establish and operate a PBRN Little preexisting body of “how-tos” for running a network and studies. Processes and policies not clarified or institutionalized.</p> <p>Pressing need for early financial support to complement the energetic volunteerism Funding for the PBRN itself—to maintain the network and collaboration as well as project-specific funds With bridge funding when primary funding suddenly went away</p> <p>The opportunity to take a developmental step toward challenging studies of societal importance. The need to show success with well-funded timely important findings to pressing issues; demonstrate practice capacity to do research</p> <p>At the end of this era: ASPN was a viable, committed network of US/Canada family physicians and practices dedicated to asking and answering questions about “health problems experienced by most of the people most of the time.” Proof of concept led to larger and more diversified funding for more challenging studies and expand into the mainstream of research. ASPN was poised for growth.</p>	<p>A few leaders with words for the problem, local experience, a new idea, and a starter plan ASPN proposed in 1978; endorsed by NAPCRG in 1979</p> <p>Pull together practices already successfully doing research Initiate a binational network with operations supported by enthusiastic volunteerism and in-kind efforts. Publish early studies pertinent to frontline practice, with evaluations of data completeness and accuracy.</p> <p>Face to face visits with editors of journals to show PBRN purposes and capacities Publish in an expanding set of appreciative journals.</p> <p>Develop PBRN policies and procedures Criteria and processes were developed for developing studies, governance and decision-making, data¹⁴ requirements and protections, publication procedures, communication channels. Share widely with other PBRNs and learn from other PBRN’s experience.</p> <p>Embed network in existing departments of family medicine and NAPCRG while obtaining foundation funding When primary funding stopped, FM organizations insisted practices continue as ASPN and together with health-oriented foundations, funded development and early projects, building network expenses into project budgets. Practices and their network champions enthusiastically continued network membership and studies.</p> <p>Obtain peer-reviewed research funding for large, challenging studies. Diversify funding from other sources, such as a cooperative agreement with the Centers for Disease Control (CDC) to determine the seroprevalence of human immune deficiency virus in frontline practice.</p>

Abbreviations: PBRN, practice-based research network; ASPN, ambulatory sentinel practice network.

sustainability. ASPN responded to clinicians in practices *and* wider societal needs in a way that clinicians could identify with as also locally meaningful. The creation of the Agency for Health Care Policy and Research (AHCPR) in 1989 (now the Agency for Health care Research and Quality (AHRQ) with legislative requirements focused on primary care, was a major help to ASPN and other primary care PBRNs and networks in other disciplines. AHCPR broadened its scope to include clinical questions in addition to health services research questions.

Balancing practice and research funder needs represented a significant shift for practices. From the beginning, practices had a powerful say in what ASPN did, an inspiring and enduring principle. In the words of Paul Nutting:

“ASPN was founded on a principle that we would ask and answer questions practicing physicians were facing in their daily work; *research on the problems that most people had most of the time.*”

But recognizing larger societal need was the beginning of ASPN’s commitment to studies that *did not* derive directly from ASPN clinician interest and imagination. While ASPN continued to incorporate clinician insight into the design of all the work, this was clearly the beginning of research and methods that answered a broader set of questions. As said by Ned Calonge:

“We had to get the network to agree to draw blood and blind the results for the HIV study. This was a big deal—to test patients and not

Table 2. Era 2. Expansion into Mainstream of Research (1988–1999)

Events Calling for Something New	Developmental Response
<p>Large, nationally important health care issues compelled practice-based research Such health policy issues revealed the need for development and expansion of primary care and research about emerging primary care issues.</p> <p>Balancing what practices and clinicians want with the needs of national research policy questions was seen as key to relevance, independence, financial sustainability and growth. Some funders aligned with PBRN purposes, e.g., Agency for Health Care Policy and Research (AHCPR); now AHRQ with legislative requirements focused on primary care.</p> <p>Trends in research design and implementation emerged to challenge practice-based research. Addressing more complex clinical and public policy questions required methods not familiar to PBRNs, e.g. group randomized trials. Important questions outnumbered experienced PIs available to PBRNs.</p> <p>Growing financial challenges came with more complex projects and network As ASPN rose to meet new research challenges came increased difficulty sustaining more complex network infrastructure required for more complex projects. Need recognized for alliance with a larger entity capable of ongoing infrastructure support</p> <p>At the end of this era: ASPN had deployed a portfolio of research methods matched to different questions and published many studies, including several large ones funded by nationally recognized research organizations, e.g., AHCPR on otitis media, NIMH on Depression Care, CDC on Lab Errors, and AHRQ on Referral in Primary Care. ASPN and many other PBRNs had become an established respected source of new and timely knowledge. Many PBRNs were established as a component of the health and health care research enterprise. AHRQ championed PBRNs and enabled networks to share strategies and methods. ASPN partnered with AAFP and entered Era 3 as the AAFP National Research Network.</p>	<p>Seminal studies were published via ASPN. Examples: Otitis media, HIV seroprevalence, lab errors, depression in primary care ASPN shared its methods widely among regional primary care PBRNs and PBRNs in other specialties and urged the establishment of AHCPR.</p> <p>ASPN responded to clinicians in practices AND wider national policy questions in a way that clinicians experienced as also locally meaningful. Bring other family medicine research networks into the annual ASPN Convocation to share results and methods, build partnerships, and contemplate new studies. Help lead national PBRN conferences sponsored by the new AHRQ Center for Primary Care Research.</p> <p>Recruit experienced PIs to become familiar with PBRN practice values and the strengths and constraints inherent in PBRN research</p> <p>Overlapping sources of funding established Foundations, NIH, AHCPR, HRSA, CDC grants & contracts provided substantial funds for larger studies. Established indirect cost rates for ASPN and capture as direct research expenses those that could not be funded through indirect cost rates.</p> <p>Partner with the AAFP as the AAFP National Research Network (NRN).</p>

Abbreviations: PBRN, practice-based research network; ASPN, ambulatory sentinel practice network.

know who is positive. Yet this was a hinge to characterizing the distribution of HIV patients across the country and the path to sustainability—our transition to federal funding.”

Trends in Research Design and Implementation Challenged Practice-Based Research

Complex clinical and public policy questions required methods unfamiliar to PBRNs. For example, group-randomized clinical trials became the norm for developing and testing new strategies for delivering primary care. Over several years ASPN was able to recruit a handful of experienced researchers from related fields and successfully orient them to the principles and culture of practice-based research. With enhanced capacity and credibility ASPN was able to win several large NIH grants that addressed questions that ASPN practices believed were important and consistent

with their priorities. Practice-based research began to have a presence on NIH “roadmap”³³ and to focus the national research agenda on clinically relevant questions while identifying outcome-related issues in primary care delivery.³⁴

The Need for a Different Path to Financial Sustainability Became Clear

Despite increased funding from larger research grants, it remained difficult to cover the ASPN infrastructure necessary to conduct the research and to sustain a growing network bearing the substantial costs of collaboration. Pharmaceutical companies saw potential efficiencies in exploiting practice networks for drug trials and were prepared to pay handsomely for this kind of work, but ASPN rejected these opportunities for funding in favor of retaining control of the network’s agenda.

Table 3. Era 3. Scaling up and Adapting to Evolving Technology, Organizational, and Business Models in Health Care (2000–2021)

Events Calling for Something New	Developmental Response
<p>Dramatic growth in number and complexity of studies along with network size. Emergence of many PBRNs, partnerships with array of academic organizations and— other PBRNs, move into large grants and randomized trials. Need for scaled up infrastructure with updated governance and relationships</p> <p>The entry and rise of information technology in practices, especially widespread adoption of EHR. Clinician data entry added to non-research workload while providing a potential source of data for PBRN studies.</p> <p>Migration of local practice control to distant decision-makers and systems. Aggregations of practices; increasingly centralized, with standardized organizational processes and reduced local control. Continued rise of volume billing and the “medical industrial complex”⁴⁹</p> <p>Growing emphasis on patient and community engagement in research. An imperative to better understand and care for minority or underserved patients</p> <p>Organizational and network approaches became less local and “high touch”; experienced as remote. Organizational constraints on use of social media reduced potential for these to connect people</p> <p>The limits of traditional publication to shift practice became increasingly apparent. The gap between “what we know and what we do” remained large.</p> <p>At the end of this era: PBRNs exist on a large scale engaged in a wide range of studies providing practice-based evidence.⁵⁰ Networks of networks share infrastructure and collaborate on very large studies. The NRN provides practical know-how, mentorship, consultants, and data management services. Findings are disseminated in a wide range of professional journals and through multiple communication channels. Consistent PBRN infrastructure funding remains a challenge. Practice and clinician spirit can be maintained in an environment far less personal than at ASPN origins. Yet updating ways to sustain relationship and connectivity remains a work in progress.</p>	<p>Full-scale governance and business model through AAFP NRN supported by internal and external relationships and partnerships with funders, agencies, and many others. Respond in nimble fashion to emerging opportunities such as patient engagement, safety, and disparities in practices across the country.</p> <p>The creation of federated or combined datasets allowed multiple practice / EHR databases to function as one for research.</p> <p>Form DARTNet³⁶ as a collaboration of PBRN networks and research organizations to enable the use of new datasets emerging from practice information technology without every practice having to master that separately.</p> <p>Rapid adaptation of PBRN rules, tools, research protocols, participants, decision-makers, and decision-making processes. Emphasis on patient/community engagement Availability of large-system resources such as practice facilitation for implementing studies and other processes.</p> <p>Do PCORI-funded studies which entail by design patient and wide stakeholder engagement. Implement engagement broadly, beyond PCORI projects Often to better care for minority or underserved patients in the practice and improve trust in the research enterprise.</p> <p>Engage clinicians and practices in multiple ways Participate in remaining face-face meetings and technology-enabled ways to maintain relationship when travel and face-to-face is more difficult. Maintain the voice of network members in developing ideas, questions, proposals.</p> <p>Engage implementation science and practice improvement organizations to enhance dissemination for PBRN members, not only those in a study or reading scientific journals. Broad dissemination channels to share findings to inform action in a wider circle of communities & policy-shapers.</p>

Abbreviations: PBRN, practice-based research network; ASPN, ambulatory sentinel practice network.

During this time ASPN established overlapping sources of funding via National Institutes of Health (NIH), AHCPR (now AHRQ), Health Resources and Services Administration (HRSA), CDC, foundation grants & contracts, and sharing funded projects with universities. These projects included indirect cost rates that helped maintain infrastructure. However infrastructure costs must be met every month, and the feast and famine of grant funding made this difficult. ASPN continued to experience serious financial difficulties during dramatic growth as a

free-standing not-for-profit organization at a time when more practices, more studies, and more staff came aboard. It became evident that the network had exceeded the capacities of its independent, nonprofit organizational form.

By the beginning of 1999, ASPN had become a model for primary care practice-based research. While it had become successful in winning competitive regional and federal funding, the problem remained to assure consistent and steady infrastructure funding such as via financial backing from a

large organization. The AAFP had always been a strong moral supporter of ASPN, and ASPN leaders felt it was the organization most likely to provide it a home. AAFP leaders agreed, and ASPN became the AAFP National Research Network (NRN) in 1999. ASPN adopted a stabilizing new relationship and governance through the AAFP. Simultaneously, major shifts in the organization and financing of health care were underway, practice environments were in turmoil, and the Institute of Medicine declared that the US health care system had safety and performance problems and needed urgent attention.³⁵

Table 2 summarizes how challenges of this era were met.

Era 3. Scaling up and Adapting to Evolving Technology, Organization, and Business Models in Health care (2000 to 2021)

Dramatic Growth in Number and Complexity of Studies Along with Network Size

At the beginning in 1979, ASPN was supported by a \$25,000 foundation grant funding a network of 38 member practices of only a few individuals each. By 2021, NRN had approximately 1,800 individual members and a budget of approximately \$3 million. Scaling up meant NRN collaboration with many practice-based research networks and a wide variety of researchers, corporate systems, foundations, professional societies, universities, and medical specialties. From 2000 to 2021, NRN grew to nearly 2,300 members of different practice types in different regions. As of 2021, the research portfolio approximately doubled its previous average of 12 to 15 active studies at a given time. This meant more principal investigators (PIs), larger and greater variety in study teams, and increased visibility within the primary care research community. This growth called for rethinking the approach to cultivating research ideas, appraising partnerships, and tracking all this more systematically than before.

Growth also called for a business model for infrastructure in line with project growth. Dollars for staff and bringing people together from around the country set NRN apart from PBRNs that only occasionally had resources to enable them to build partnerships. The network developed long-range strategies and structure to retain the ability to be flexible, responsive, and innovative. For example, rapid response to funding opportunities while enlisting necessary PIs, team members and consultants for a wide variety of study designs, topics, populations, and settings.

Regular realignment of staff allocation with project needs was done throughout project life cycles while resolving emerging implementation, team or personality dynamics and conflicts. Recognizing the team-based nature of primary care, all those in the primary care environment were included as network members, not just the doctors, for example, study coordinators, nurses, physician assistants, nurse practitioners, psychologists, and clinical pharmacists.

The Rise of Information Technology in Practices

Electronic health records (EHR) challenged clinicians with profound changes in daily work, to which many clinicians took a long time to adapt. This may have distracted network physicians from research activities, but widespread adoption of standard platform EHRs helped networks rapidly aggregate good data via federated databases, such as DARTNet,^{36,37} to answer important questions quickly with large numbers—and without practices each having to master large database management.

Innovations that involved information technology often became practice requirements, for example, Primary Care Medical Home certification, documented QI activity, “meaningful use” EHR rewards, and the evolution of information technology in telehealth, e-visits, remote clinical monitoring, and applications of artificial intelligence (AI).

Migration of Local Practice Control to Distant Decision-Makers and Systems

As practices were purchased or otherwise taken over by larger medical groups and systems, practices still had their local leaders, patients, and communities but operated within larger clinical, operational, financial, and leadership systems. Payment models increasingly rewarded volume billing (further enabled by EHR), displacing most of what remained of capitation and left decreasing perceived bandwidth for clinicians to do research. Aggregation of practices into large systems brought a reduction in local control and decision making. But it also increased the sophistication of many practice systems, quality improvement, practice facilitation,^{38–40} human resources, marketing, and tools and consultants paid for by the central organization.

Large systems increasingly recognized they needed to change how they deliver care. This led to clinician or practice opportunity to become part of

research groups. Large systems began banding together to fund and do research or create internal research entities—and ultimately change what they do in practice. Part of business strategy became asking questions and plowing the answers back into practice, a “learning health system,”⁴¹ which began to be recognized by practice systems as a business advantage.

Growing Emphasis on Patient and Community Engagement in Research

This helped get at what matters to patients in practices. Systematic processes to value and obtain wider stakeholder engagement, including patient advisory councils and patient coinvestigators⁴² were encouraged with the establishment of the Patient Centered Outcomes Research Institute (PCORI) in 2010. In the words of Wilson Pace:

“While the traditional ASPN approach defined major stakeholder as primary care clinicians, with PCORI, stakeholder input markedly amplified the patient voice in project development and selection. The NRN uses a method that includes a clinician and patient dyad from practices to help guide activities.

This model evolved into the Patient and Clinician Engagement (PaCE) program sponsored by NAPCRG.⁴³

NRN priorities were influenced by a national imperative to better understand and care for patients in the practice across race, culture, languages, and social disadvantage. This led to more studies in these areas or increased emphasis on these dimensions of research, along with recognized need to increase participation and trust in the research enterprise especially among minority populations.⁴⁴ This need was amplified by the COVID-19 pandemic and the murder of George Floyd.

Organizational and Network Approaches Became Less Local and Less “High Touch.”

NRN continued the network convocation as long as it could, where clinicians and other PBRNs came together to consider projects and propose questions. AHRQ sponsors the national PBRN meeting that NAPCRG now hosts—a place to continue these conversations in a national community of interest. The growth in NRN membership created new opportunities to cultivate a sense of belonging for the practices

engaged in each particular study. For example: practices have a choice in what to participate in and how they might wish to engage (if at all); practices can be spotlighted and honored for their engagement in studies; and reasons for choices can be made visible to those in the broader network. Social media platforms used for these purposes have potential to meet needs of especially early career members at a time of increasing concern with health professional burnout.

Maintain the Voice of Network Members in Developing and Prioritizing Ideas, Questions, and Study Proposals

Network members typically do not have research training or grant-writing experience, but it is important to find strategies to cultivate member-initiated ideas within the portfolio in addition to responding to relevant sponsor-issued funding opportunity announcements. Even in a more complex research environment, the network can still ask simple questions arising from the practice setting intended to benefit the practice itself. NRN provides staff and financial support for short-term research projects led by practicing family physicians with no previous research experience through its Family Medicine Discovers Rapid Cycle Scientific Discovery and Innovation.⁴⁵ In the words of Jen Carroll:

“It is important to create “bubble up” opportunities from members and practices rather than exclusively investigator or funder-initiated projects.⁴⁶ However, this is challenging because of limited staff time to handle all the requests from even a small percentage of highly engaged network members while being still largely dependent on project-focused grant funding.”

The Limits of Traditional Publication to Improve Practice at the Frontlines of Health Care Became Increasingly Apparent

The gap between research findings and their implementation in practice has called for alternative dissemination strategies to communicate with those who can act on research findings, appealing to what matters to a broad range of stakeholders. Multiple practice improvement organizations similar to the agriculture extension service have emerged as effective agents for implementing new knowledge and technology.^{47,48} EHRs can push findings into clinical queries or embed findings into decision-support functions. NRN values moving beyond

professional journals to disseminate finding in ways and places that people hear, read, and can apply, for example, doing interviews with news services so that research results are recognized by the public and attract general media dissemination.

Table 3 summarizes how challenges of this era were met.

Balancing Archetypal PBRN Dilemmas

PBRN directors provide leadership for multiple groups having different roles, perspectives and priorities. PBRN leaders live on the edges of constantly changing clinical, academic, and business models, attempting to ask and answer research questions in ways that bring benefit to all these perspectives. This calls for balancing multiple perspectives and conflicting interests, typically without having comprehensive authority to just “make things happen.”

Because of this balancing act, along with the challenges of the studies themselves, directors can expect periodic disappointment, frustration, or discouragement among constituents. But when directors skillfully articulate and balance legitimate but competing interests, they are rewarded with study results and forged connections among curious people with common and important questions that matter.

Through multiple conversations together, the ASPN/NRN directors identified and articulated 6 archetypal PBRN dilemmas—repeating kinds of situations in which difficult choices had to be made, often among desirable alternatives. This often involved balances to strike—where actions are combined in a productive proportion that achieves enough of what most people want. The following archetypal dilemmas and balances appeared and reappeared in different forms during the first 40 years of PBRN development. A solution in one era sometimes appeared in a more advanced form in a later era. All may be expected to present themselves to future PBRN leaders, with specific form likely to vary from time to time and place to place:

1. **Tension between what practices want and what funding agencies want (on behalf of the population).**
Aligning societal and practice needs; researchers and clinicians. Keeping it meaningful and feasible for practices while appealing broadly to what matters to funders and society.
2. **Sustaining sufficient and consistent network infrastructure funding.**

Infrastructure support and costs of collaboration, not only research project funding; sustainability beyond philanthropic grants or one-off project funding.

3. **Sustaining network relationships as health care is increasingly centralized and business oriented.**
Network and clinician connectedness at times of escalating competing demands and less face-to-face time.
4. **Adapting to ongoing shifts in the technology, business and practice environment.**
For example, EHR, practice consolidation, growing emphasis on patients and communities—their engagement, safety, and disparities; use of big data and AI.
5. **The gradual evolution of what counts as a scientific question and evidence worth publishing.**
In early history, not seeing valuable questions or reliable answers in practices—low acceptance of PBRN results for scientific publication. In later history, the slow but gradual acceptance of non-traditional methodologies as legitimate science.
6. **Translating study findings to accepted practice change.**
Establishing and maintaining a tight connection between research data and wide, rapid implementation and acceptance in practice. Non-traditional dissemination not only publication in peer-reviewed journals.

These dilemmas and balances are typically inter-related drivers of change. They have stimulated design of studies that are both nationally and locally meaningful with rigorous protocols that do not disrupt patient care. They have led to methods evolved to suit wide-ranging practice environments and changing attitudes about what counts as rigorous research. Taking on this balancing act in the next era of PBRNs will require such adaptive leadership and broad, integrating perspectives of generalist leaders. Balancing these dilemmas may comprise the core job description for future PBRN leaders.

Future Horizons

Adapt Core PBRN Ideas That Are Durable and Flexible

ASPN and NRN are early examples of clinicians and practices asking and answering important questions to plow back into practice. “Future PBRN directors are well-advised to hold tight to the local practice laboratory as the source of meaningful questions and the place to best explore them.” (Frank Reed), with “clinician-generated study ideas part of every PBRNs work, even when doing large complex studies oriented to the needs of others beyond the practices.” (Paul Nutting).

But Take Up New Ideas, Skills, and Challenges

Be prepared to “engage with big data and new analytic frameworks. Work with our specialty colleagues in research that changes and improves clinical care.” (Wilson Pace). At the same time, “listen to practice partners; cultivate and respond to their curiosities and questions. Be generous and visibly grateful for the many large and small ways people participate and support practice-based research in primary care” (Jennifer Carroll).

Seek Systemic Upstream Knowledge of Particularly Complex Phenomena

Discover why people get sick when they do, social and systemic drivers of inequity in health, prognostic indicators to guide decision making, especially when diagnosis is not possible or not by itself a guiding factor. Understand the influence of societal, community, family, and individual context on interventions and outcomes. Integrate multiple types of clinical and person-centered data within and across studies. Intensify the use of patient defined outcomes and a health equity perspective to increase participation and trust in the research enterprise.

Develop classification and measures for complex phenomena such as longitudinality, well-being of whole persons, family effects on health and health care, and care that integrates behavioral health, public health, and primary care. Measure practice outcomes—systemic effects of applying principles of primary care, teams, and personal doctoring. Apply implementation science and learning health system theory, method, metrics to practice settings.

At the Same Time, Constantly Question What We Are Habitually Doing in Our Practices

“What is the value of routine vital signs? What is an “annual physical”? When is a “review of systems” needed? What situations can be managed successfully with telemedicine?” (John Hickner) How will we reduce time to translate, accept, and implement these and other findings with the PBRN tradition of addressing implementation from the outset? (Ned Calonge)

Address Large Emerging Societal Issues

Primary care PBRNs are positioned where families, communities, and medicine meet. PBRNs are already in an “Era 4” of not only new science and technology such as artificial intelligence and gene

editing, but a tumultuous period in which societal understandings about health, health care, health equity, science, professionalism, confidentiality, what it means to be a physician, what value is in relationships, what is true or real, what is an appropriate business model and what is a public good are contested, world-wide.

Distill research questions shaped by such societal tumult while answering important questions about how health is won and lost with respect to patients, communities, practices, and health systems. Use PBRNs as surveillance systems at the frontlines not only of medicine, but in the lives of families and communities. PBRN’s that are secure enough to engage these situations and opportunities with equanimity can welcome helpful new technologies and partnerships. This involves nurturing relationships among practices, networks, served communities, and funders—with enough independence that they are not overwhelmed by medical and business interests when those become too detached from practice, patient, and community realities.

Expand Collaboration Beyond Practice Networks Themselves

Move from stand-alone networks to partnerships that bring Big Data, AI, apps—with wide reach and power to implement evidence well. Make “big, bold asks” for high-impact studies of timely topics that require partners to be credibly asked, such as incorporating genetic information into frontline practice.

Routinely enable patient engagement that grounds the work in community needs, priorities, and assets. Routinely seek mutual benefit with learning health systems, implementation science, and practice transformation organizations. At the same time, maintain valuable small practice exploratory research that informs and enables networks to spot new insights that invite refinement as researchable questions.

Disseminate with Greater Reach and Power: Appeal to What Already Matters to a Wide Range of Those Who Care About Health and Care

Use direct communication, not just journals. Create impact narratives understandable to academia, financial institutions, policy makers and the public. Directly engage public and private policy makers and decision-makers. Turn findings into action among the known actors.⁵¹

“Knowledge is not a commodity that can simply be produced and dispensed. . .[it] becomes valuable only when a specific someone can act on it. Different stakeholders or actors in our health care system have different opportunities to act on knowledge and hence to use, to value, or to even notice it. One person’s knowledge is another person’s noise. . .” (Frank V. deGruy III)⁵²

Seek clearer role definition, division of labor and zones of active collaboration for primary care, behavioral health, and public health to jointly disseminate and implement findings in ways that matter for their shared work of population health.⁵³

Let PBRNs Help Improve Joy of Practice and Camaraderie

Sustain commitment to study real world practice where it happens; the problems and questions emerging from practices. Celebrate clinician and community curiosity about those questions. Make being in a PBRN a source of encouragement amid all the turmoil in health care; an agent for sustaining medicine as a profession, not just another business. Let PBRNs appeal to the clinician calling to make a difference in population health for all. At the same time, enable Continuing Certification and Organizational Quality Improvement requirements for physicians through PBRN participation.

Let networks “amplify enthusiasm, energy, and new ideas—members like-minded in pursuit of practical knowledge; an antidote for isolation.” (Linda Niebauer). Remind practices that “they have access to phenomena that powerfully influence health and well-being, for example, the earliest signals of loss of health, approaches to care over the lifespan, transitions of care among settings, and the consequences of local and global events that wash over people and enable or constrain their health where they live, work, and play.” (Larry Green). These all matter to clinicians in practices.

A Call to Service Awaits Future PBRN Leaders

As said in the earliest days of ASPN by Dr. Curtis Hames, quoting Walt Whitman:

“Sail forth—steer for the deep waters only, reckless O Soul, exploring, I with thee, and thou with me, for we are bound where mariner has not yet dared to go, and we will risk the ship, ourselves and all.”

To the participating practices and PIs who added practice-based research to their already full schedules, the authors extend

heartfelt thanks for the dedication, ideas and direction you gave us over the decades. Thank you to the thousands of patients who participated in the studies; we gratefully acknowledge that only through your willingness, trust and patience could this work be undertaken. Thanks to the original ASPN Steering Committee and subsequent leadership groups to whom we are forever grateful for your vision, leadership, inspiration and encouragement. To those who now strive to continue the work we have begun, we appreciate and acknowledge your ongoing efforts and hope some of this narrative will be useful.

To see this article online, please go to: <http://jabfm.org/content/37/5/955.full>.

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