

A Review of 50 Years of International Literature on the External Environment of Building Practice-Based Research Networks (PBRNs)

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A Review of 50 Years of International Literature on the External Environment of Building Practice-Based Research Networks (PBRNs)

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Background: This article is the second part of a novel scoping review of the international literature that presents those key elements that underpin the foundational activities of Practice-Based Research Networks (PBRNs). In this article, we examine the external environment and the intersection between the internal and external environment domains.

Metbods: We searched electronic databases, including MEDLINE (PubMed), OVID, CINAHL (EBSCOhost), Scopus, and SAGE for publications in English between 1/1/1965 and 9/15/2021. We also searched reference lists of selected publications, gray literature and other online sources. Inductive thematic analysis was applied to construct the main themes, subthemes, and key elements from a scoping review covering up to 10 years of reported experiences of each of the 98 PBRNs that met the inclusion criteria.

Results: In this study we present 2 main themes: "Stakeholders at the Intersection Between the Internal and External Environment" and the "External Environment." The first is linked to the subthemes "Patient and Community Stakeholders" and "Other Healthcare Stakeholders" and 11 key elements. The second relates to the subthemes "National Health System," "Institutional/Governmental Support, National/State Policy and Regulatory Environment" "Professional Organizations," "Leveraging Previous Research and PBRN Experience and Interacting with Other Networks" and "Health Information Technology (HIT) and HIT Vendors" and 21 key elements.

Conclusions: Despite variations in geography, time, and healthcare context, PBRNs shared many similar developmental experiences over the past 5 decades. Their external environment contributed significantly to their developmental trajectories during the first 10 years of their operation. (J Am Board Fam Med 2022;35:762–792.)

Keywords: Family Medicine, Practice-Based Research Networks, Primary Healthcare, Scoping Review

Introduction

Practice-Based Research Networks (PBRNs) are collaborations of academics and practitioners in the field working together as research laboratories for primary care, to generate and implement practicebased evidence and quality improvement in primary healthcare.^{1–5}

PBRNs initiated their activity over 5 decades ago in several pioneering countries. In Birmingham, UK, a group of general practitioners started collecting morbidity data systematically in their practices and developed the first primary care research collaboration in 1967.⁶ In the Netherlands, Huygen engaged 4

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Dutch family practices in the Nijmegen area in 1967.⁷ In the USA, the Family Medicine Information System in Colorado (FMIS) and the Cooperative Information Project (COOP) were developed in the 1970s to investigate problems encountered in primary care.^{8–11} Since these early initiatives, research-driven community family physicians, academics, and researchers, increasingly committed themselves to working collaboratively to improve and transform primary healthcare.^{2,12,13}

Although there is information about the development of PBRNs around the world and in specific countries, it remains unclear what characteristics they may share with regards to their developmental trajectory and what may be unique to each PBRN's own history of development. We addressed this gap in the literature by conducting a scoping review of publications and sources from as many countries as possible. We reviewed English-language publications to elucidate the broadest information about the factors that enhance or impede PBRN development. In a previous article¹⁴, we presented facilitators and barriers of the internal environment related to the creation of PBRNs. In contrast, this article explores the 2 distinct domains of the external environment that include the "Stakeholders at the Intersection between the Internal and External Environment" and the "External Environment" in terms of facilitators and barriers in building PBRNs.

Methods

We completed a scoping review of the literature following a methodological framework described by Arksey and O'Malley.¹⁵ This type of review was considered appropriate to map key elements from a broad variety of data sources and various types of evidence about building PBRNs across the world.

We followed specific analytic steps suggested by the method: (1) defining the research question, (2) identifying relevant studies, (3) study selection, (4) charting the data, (5) collating and summarizing the findings, and (6) reporting the results. The methodology was identical to what we used in a previous publication.¹⁴

Identifying Relevant Studies and Study Selection

We identified relevant publications in a 2-step process. In the first step, we searched the English literature systematically and reviewed articles

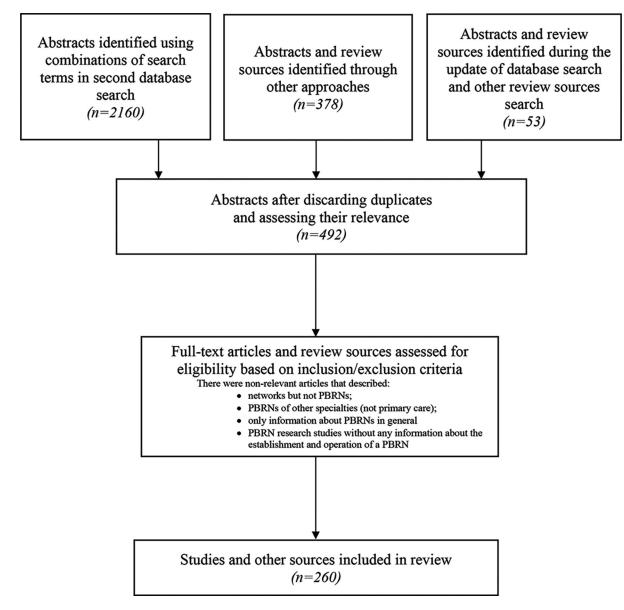
published between 1/1/1965 and 9/15/2021 in the following databases: MEDLINE (PubMed), OVID, CINAHL (EBSCOhost), Scopus, and SAGE Premier, using the following search terms: "primary care," "family practice," "general practice"; in combination with: "practice-based," "research," "network," "data," and "infrastructure." In the second step, we searched the "gray literature" for white papers, newsletters, conference abstracts, posters, proceedings, presentations, individual PBRN web sites, editorials, and online materials published by national organizations. We also assessed the references of selected articles and bibliographic lists. Google Scholar and public online sources were searched as well. Additional communications with authors and colleagues helped clarify knowledge gaps.

Three reviewers (AD, PM, and AH) scrutinized all articles separately and applied rigorous inclusion/exclusion criteria.¹⁴ (Appendix Table 1) The lead author (AD) communicated with authors and colleagues to clarify ambiguities and another reviewer (ZN) evaluated uncertainties about specific studies. The details of the review process are presented in Figure 1.

Charting the Data, Collating, and Summarizing the Findings

We examined the development of PBRNs in a period of over 50 years and we focused our study on the first 10 years from the inception of each individual PBRN. We gleaned information about each network during their first 10-year period using specific sources listed above. Some PBRNs had only 1 relevant publication, while others had multiple data sources that they produced. The data we collected were limited to those available in our selected sources. We reviewed identified sources to discover key actors, attributes, relationships between them and the nature of these relationships, resources contributed, and properties produced, using social network theory-concordant key concepts.¹⁶⁻¹⁸ Thus, we considered each network to develop relationships and interactions ("ties") with actors from the external environment ("nodes"), and we looked at the "features" of their relationships and interactions with the PBRNs, and the outcomes ("properties") that were derived from these relationships and interactions.

We applied an inductive thematic analysis approach^{19–21} using an iterative process that allowed us to group the narrative observations into components. We clustered the components Figure 1. Chart flow diagram of the process of systematic selection of articles. Abbreviation: PBRNs, Practice Based Research Networks.



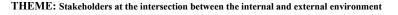
into key elements according to their relevance to specific domains of building PBRNs. Then we linked the key elements to subthemes that corresponded with groups of actors that influenced the establishment of PBRNs, considering their highlevel similarities. Finally, we connected the subthemes with the main themes, which were developed to reflect the environmental domains where the subthemes clearly belonged.

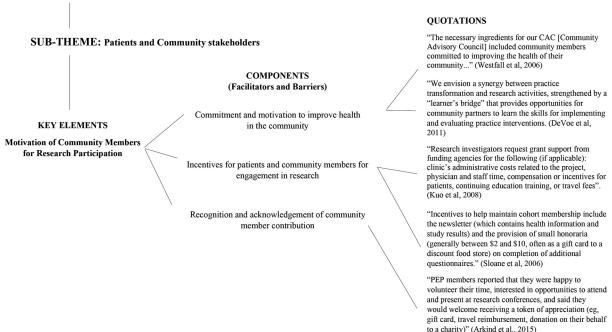
Our synthesis resulted in the conceptualization of 3 main themes, 12 subthemes and 57 key

elements. Many components captured information about the facilitators and barriers for building PBRNs, although not all components delineated facilitators and barriers. This article focuses on the 2 main themes "*Stakeholders at the Intersection between the Internal and External Environment*" and "*External Environment*," and the 8 subthemes and 32 key elements that are linked to them.

In summary, our analytic pathway from data gathering to theme development can be described as follows:

Figure 2. An example of the methodological approach in synthesizing components, key elements, subthemes, and themes from the quotations.





Note: As a methodological example, the Figure illustrates how the key element "Motivation of Community Members for Research Participation" was derived from quotations we collected from the literature

Gathering original narratives from articles (relevant quotations) > Structuring and grouping narratives > Developing components (eg, "Commitment and motivation to improve health in community") > Grouping components > Developing key elements from groups of relevant components (eg, "Motivation of Community Members for Research Participation") > Grouping key elements > Developing subthemes from groups of relevant key elements (eg, "Patients and Community Stakeholders") > Grouping subthemes > Coalescing themes (eg, "Stakeholders at the Intersection between the Internal and External Environment").

An example of the methodological approach to synthesizing components, key elements, subthemes, and main themes is presented in Figure 2.

Results

Our original database search identified 2538¹⁴ publications and the updated literature search yielded 53 publications. The inclusion/exclusion criteria were identical to the previous publication¹⁴ and applied on now 2591 publications, of which, 31 new sources met

our inclusion/exclusion criteria. Of these 31 sources, 19 came from the same PBRNs reported in the previous study¹⁴ and 12 led us to the identification of 5 new PBRNs. This resulted in 260 articles for this study.

Our review yielded 98 PBRNs, 2 of which were binational, 4 multinational, 37 from the USA, 15 from the UK, 12 from Australia, 4 from Belgium, 7 from the Netherlands, 3 from Ireland, 2 from Switzerland, 2 from New Zealand, 3 from Canada, and 1 PBRN from Finland, Germany, Greece, Italy, Singapore, South Africa, and Sweden, respectively (Figure 3).

The synthesis of our results yielded 3 main themes, 12 subthemes, and 57 key elements. The overarching thematic framework and thematic connections between its components are presented in a previous publication,¹⁴ while in Appendix Table 2 we show the key elements related to the internal environment (not included in this study; see shaded cells).

In this study, we identified 2 main themes that represented 2 groups of stakeholders. The main theme "*Stakeholders at the Intersection between the Internal and External Environment*" reflects the



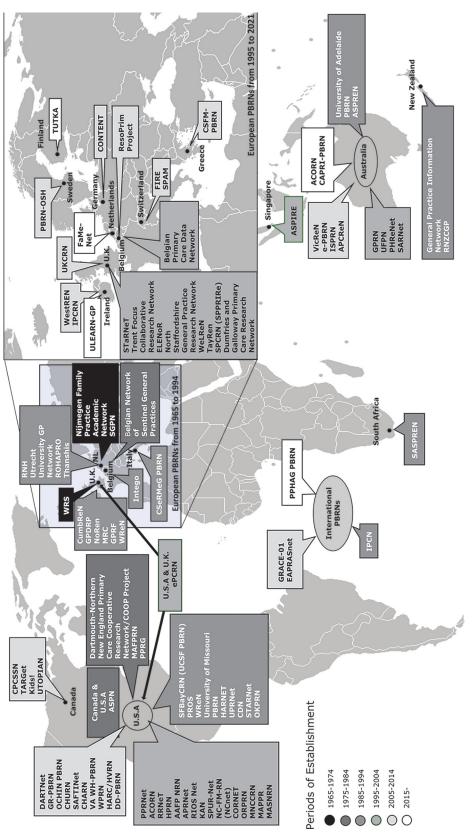
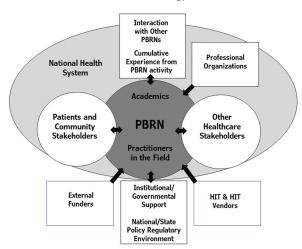


Figure 4. Stakeholders influencing the development of Practice-Based Research Networks (PBRNs). Abbreviation: HIT, Health Information Technology.



Note: The Figure is an illustration of connections between various stakeholders in relation to PBRNs (internal environment) and to the national healthcare system in which PBRNs and some of the stakeholders are situated. The directions of the arrows reflect the nature of these relationships.Relationships with "Patient and Community Stakeholders" and "Other healthcare Stakeholders" permeate the internal environment of PBRNs

group of "boundary spanners" between the internal and external environments. These stakeholders spanned both the external and internal environments in the networks we explored, which were created at various times during a period of over 50 years, and so we categorized these in a separate main theme. The other main theme "*External Environment*" includes stakeholders that, although located in the external environment,²² influenced the development of PBRNs. (Figure 4)

Main Theme: Stakeholders at the Intersection of the Internal and External Environment

We identified 2 subthemes and 11 key elements linked with the main theme "*Stakeholders at the Intersection of the Internal and External Environment.*" The overarching thematic structure of this theme (subthemes, key elements, and components) are presented in Table 1. The included components are facilitators and barriers for building PBRNs.

Subtheme: Patients and Community Stakeholders

Our review identified an increased focus on rural,^{9,22–25} nonmetropolitan,^{26–28} or disadvantaged communities^{29,30} across American PBRNs that emerged before the 2000s. A considerable number of PBRNs aimed to address health disparities among underserved, minority, or vulnerable populations in the community they served,^{30–40,41,66} or participated in consortium of PBRNs with similar missions.⁴² Australian PBRNs expressed interest in rural populations through the membership of local practitioners.^{42–46,157} We also identified several UK PBRNs that focused on rural populations.^{47–49}

A few of the early networks linked patient care excellence to patient-centeredness and community engagement,^{29,50,51} This spread across the majority of networks over time and highlighted the importance of patient-engagement to improve patient outcomes and satisfaction.^{33,40,51–58} Fundamental components of the key elements "relationships with patients and community groups" included trusting and long-standing partnerships to promote equity and address health disparities.^{25,31,34–39,48,53,57–67}

Networks with more "bottom-up" governance^{17,68,69} implemented Community-based Participatory Research (CBPR) methodologies at least in some of the steps of their research, to increase the impact of research on their community,^{25,29,31,32,40,54,59,62,70} The work of Community Advisory Boards (CABs) was essential to CBPR research.^{55,62,66,67,70,71,73} On the other hand, several networks with a more "top-down" (hierarchical) approach^{17,68,69} also established collaborative relationships, shared decision-making and research dissemination activities with patients, and incentivized patient participation in research to generate benefit for broader populations.^{58,63,74–76}

Subtheme: Other Healthcare Stakeholders

Various healthcare stakeholders such as academic institutions, health systems, public health entities, industry, insurers, health organizations, and policy advocates were involved in the activities of PBRNs.^{10,38,39,46,51–54,60,61,63,66,69,77–90} The majority of UK PBRNs started in the 1990s reported engagement of health authorities and community trusts in their partnerships,^{48,69,78,79,92} while they also integrated social care research into their activities.^{48,49,60,78,93,94}

In the past 2 decades, more emphasis was placed on the engagement of stakeholders from different levels of healthcare (national, state, and local) and educational institutions.^{37,38,52,66,68,69,71,72,77–} Table 1. Subthemes, Key Elements and Components Linked to the Main Theme "Stakeholders at the Intersection Between the Internal and External Environment"

		Sub-theme:	e: Patients and C	Patients and Community Stakeholders	olders			Sub-theme: Ot	Sub-theme: Other Healthcare Stakeholders	akeholders
			Key elements	nents					Key elements	
Patient- centeredness and community engagement in PBRNs	Relationship building with patient or community groups as an essential part of research	Quality improvement activities guided by patient feedback	Involving patients or community members in PBRN governance	Integrating CBPR and PCOR methodology into PBRN research	Community Engaged Research methodology in PBRN research	Motivation of community members for research participation	Community engagement in health policy- making through PBRN activity	Identification, engagement and contribution of healthcare stakeholders	Relationship building with healthcare stakeholders	Other aspects of working with healthcare stakeholders
			Components	ients					Components	
Facilitators	Facilitators	Facilitators	Facilitators	Facilitators	Facilitators	Facilitators	Facilitators	Facilitators	Facilitators	Facilitators
Patient care excellence linked to patient- centeredness and community engagement in PBRN research A cultural shift in the role of patients in patients in patients in patients in primary care research Setting community- based and/or based and/or patient- centered	Building collaborative relationships and shared decision- making with patients Building longstanding relationships of trust and mutual respect and gaining strong community patient groups Development of trusting community patient groups Development of trusting patient strong community Academics linking to local community	Develop patient satisfaction surveys to future QI studies Linking patient complaint to practices QI activity interaction for patient and clinician interaction for patients and with the students and patients and pa	Patient advisory board engaged in research planning Community representatives or leads engaged in the PBRN governance Involving patients or community groups in PBRN governance, even friom the network form the network form the network formation point Community group problems advocates of the community group problems some or all procedures of research activity Community	Research designed for CBPR implementation Community engagement in akared decision- making pertaining to all aspects of research through crABs that guide planning and conducting projects Community conducting projects Community members facilitate contrueach, research for the rese	Development promotion of a community engagement model Training and metings for community members <u>Barriers</u> Community engagement may entail increased costs for a study	Commitment and motivation to improve health in the community Incentives for patients and patients and patients and members for engagement in research acknowledgem acknowledgem ent of community member contribution	When the involvement in policymaking is anchored in the practice model of care, which is member of PBRN The PBRN The PBRN The PBRN tresearch impact is strengthened when the research aims are linked to community users	Identifying relevant stakeholders and establishing roles and establishing roles and responsibilities of the various stakeholders infrastructure as part of a broader effort of other healthcare stakeholders (eg., Clinical and Awards infrastructure) Multi-stakeholder engagement strengthens the infrastructure of a network, increases the potential for multidistructure of a network, increases the potential for search and enables broader collaborations with scientific assemblies broader collaboration with scientific assemblies publids on existing resources. Engaging sponsoring organizations motivated	Engaging other healthcare stakeholders in research agenda development and in research translation Barriers The research culture is not rooted in all healthcare is not rooted in all healthcare stakeholders, and if sstakeholders, and if hindered or considered not healthcare considered not necessary the different healthcare stakeholders may challenge expectations and policies within the network	Use of network data Engagement in research translation Engagement in research prioritization Development of PBRN mifrastructure as part of the effort of research infrastructure exerch infrastructure event in operations strategic planning Informing the research outcomes to various stakeholders

		Sub-the	Sub-theme: Patients and Community Stakeholders	ommunity Stakeh	olders			Sub-theme: U	Sub-theme: Other Healthcare Stakeholders	takeholders
			Key elements	nents					Key elements	
Patient- centeredness and community engagement in PBRNs	Relationship building with patient or community groups as an essential part of	Quality improvement activities guided by patient feedback	Involving patients or community members in PBRN governance	Integrating CBPR and PCOR methodology into PBRN research	Community Engaged Research methodology in PBRN research	Motivation of mmunity members for research participation	Community engagement in health policy- making through PBRN activity	Identification, engagement and contribution of healthcare stakeholders	Relationship building with healthcare stakeholders	Other aspects of working with healthcare stakeholders
			Components	ients					Components	
outcomes research agenda Patient- centered care as a priority of the network	partners through the network Patients favor practices and doctors engaged in research		in research translation Community-based organizations and community members part of network partnership	research (PCOR) methodology or integrating community engaged research methodology in PBRN research Barriers				cominuing support, both political and financial, and input into the governance of the network Building a PBRN to be an interface that fosters collaboration with other		
	Patients value their regagement in research Co-designing a PBRN with patients and community members providing strong mutual mutual (e.g., ownership of studies, use the findings, assistance in discontings, assistance in discontation is adviced orientation Batricing Balancing community advoced with the PBRN research demands			Community engagement is entraneover of turntover of community community participating either procedures Equiable partnerships with cABs muy be challengagment of cABs muy be challengagement of callengagement of callengares continuous researcher and requires continuous researcher and provernent to be bin effective and sustainable proverant to be prover to be prover to be prover to be propulation or research motivated and eligible pratents contrased cons due to CBPR vspecial propulation or research motivated and eligible pratents contrased cons due to CBPR const from inplementation				healtheater goups (eg, local hospitals, social care) Developing coalitions of interest from different parts of the healthcare system that strengthen the research impact and sastainability of the PBRN Sharing administrative assurindan research organizational research oversight and quality assurance		

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^{80,84,88,89,94–96,237,250} Shared mission between a PBRN and other healthcare stakeholders for the improvement of healthcare engendered relationships for R&D and learning in a wide array of projects.^{34,36,39,47,48,53,62,69,79,89,93,98–107} Further, a considerable number of more recently created PBRNs established such partnerships from their inception.^{39,54,55,63,72,80,88,89,97,108,109}

Main Theme: External Environment

We identified 6 subthemes and 21 key elements linked with the main theme "*External Environment*." The overarching thematic structure of this theme (subthemes, key elements and components) are presented in Table 2. These components are facilitators and barriers for building PBRNs. In addition, a condensed presentation of the subthemes is presented below.

Subtheme: National Healthcare System

Many publications indicate that PBRNs were anchored in the broader healthcare system in their country.^{7,32,35,45,58,63,67,78,81,86,89,106,116,120,121,135} A strong position of general practice/family medicine in the healthcare system positively influenced PBRN development, whereas networks reported more barriers to their development in countries with less primary care support or no requirement for patients to have a primary care/family doctor as their coordinator of health services.^{45,52,63–65,81,115–122}

In some countries, where PBRN activity was appreciated, networks were incorporated into the broader healthcare system.^{63,117,121,151} to function as research laboratories of primary care,^{63,86,102} or as organizations that conducted research that focused on the priorities of the healthcare system.^{63,86,123} In some other countries PBRNs built on their linkages to the broader healthcare system with objectives for optimizing the quality and efficiency of healthcare^{28,33,39,44,50,51,62,64,67,80,81,84–86,105,111,113,120,122–133} and for timely knowledge translation and dissemina-

tion. 25,53,55,67,70,80,85,89,95,97,114,128,129,135–139

Subtheme: Institutional/Governmental Support, National/State Policy, and Regulatory Environment

Many PBRNs provided an interface for collaborative effort with governmental bodies and institutions.^{9,38,52,89,92,97,109,136,149–152} They disseminated their results to the government and health authorities, influenced health policies and recommendations and advocated for R&D programs and practice-based and/or community-based evidence.^{29,38,40,52,57,58,70,80,81,89,92,106,109,} ^{114,120,130,149,152,153} In some countries, their recogni-

tion secured more systematic and substantial funding, via national-level initiatives.^{22,86,104,114,125,154,157}

In other cases, PBRNs were influenced by national initiatives and policies that either supported networks at their inception^{45,47–49,52,63,68,69,72,75,79,102}, 104,109,120,155-157,161,165,184,250 or later, 32,36,52,75,138,158-¹⁶² or they were linked to their transforma-tion,^{63,85,123,163,164} or to the dissolution of some PBRNs.^{165,166} The regulatory environment in different countries facilitated commitment to longterm funding to help improve evidence-based practice and research capacity in primary care,⁴⁶⁻ 49,63,68,69,72,78,79,86,102,123,149,155–159 shored up indirect support through development of agencies which became pivotal supporters of PBRNs,^{32,34,35,40}, 51,54,87,89,128,139,141,158,159,161–163,188 or positively influenced the research impact of PBRNs^{34,39,55,82,108,113}, ^{128,132,169,171,172} and reinforced the patient-centeredness of their research^{38,39,56,57,62,70,73–75,87,113,128}

Subtheme: Professional Organizations

National or local-level professional organizations identified a need for collaborative practicebased research and helped establish it as part of the development of the academic discipline.^{5,11,22,28,89,92,99,110,136,141,143,148,150,175,188} A number of networks were initiated by professional organizations^{26,92,136,141,148,166,167,176–179} alone or in collaboration with academic departments and/ or (research) institutes,^{28,64,77,82,85,92,97,109,119,130,134,178} to link PBRNs to education and professional development.

In the USA, UK and Netherlands these organizations collaborated closely with PBRNs, promoting participation in research studies among their members.^{22,56,92,110,126,141,150,175,235} In the Netherlands, professional organizations supported the development of Electronic Health Records (EHRs) appropriate for primary care practices.^{126,180} Publications suggested that international professional organizations such as the World Organization of National Colleges and Academics (WONCA), the North American Primary Care Research Group (NAPCRG), the European Academy of Pediatrics (EAP), and the European General Practice Research Network (EGPRN) played an important role in linking and motivating academics and professionals with

Table 2. Subthemes, Key Elements and Components Linked to the Main Theme "External Environment"

			The	Theme: External environment	ment			
Sub-theme: National Health System	Sub-theme	Sub-theme: Institutional /Governmental Support, National/State Policy and Regulatory Environment	ımental Support, Na Environment	tional/State Policy an	d Regulatory	Sub-theme: Professional Organizations	ssional ns	Sub-theme: External Funders
Key element			Key elements			Key elements		Key element
The impact of primary healthcare structure on PBRN development	Decision-makers	National policy	Regulatory environment	Interaction with policymakers	Community impact on public health policymakers through PBRN	National professional organization contribution and support	International professional organizations contribution	External Funders contributions
Components			Components			Components		Components
Facilitators	Facilitators	Facilitators	Facilitators	Facilitators	Facilitators	Facilitators	<u>Facilitators</u>	Facilitators
Anchoring the network	Initiative to develon	Political agenda	National initiative for	PBRN research results	Influencing healthcare	Providing official	Linked	Funding to start-un
in the national health	the general practice	supporting plans that	funding PBRN	inform policymakers	policy and legislation	endorsements and/or funding	academics and	research
morefe	Amidiaem	primary care and	National legislation	and e-health services)		building the PBRN	with common	External infrastructural
Strong position of	Assigned study to	primary care research	and subsequent		Research relevant to	5	research	funding
Family practice in the healthcare system	evaluate the research canacity in	Promotion of PBRN	initiatives for PBRN development to build	The PBRN provides the annronriate framework	community needs and effective dissemination	Linked the practice-based research to education orowth	interests	Funding for research
	primary care	development as part of	capacity and	for a national strategy or	of findings to impact		Inspired	capacity building
Integration of the			implement evidence,	initiative implementation	public health and	Identified the need for	development of	0
PBRN activity in the	Recognized need	enhancement	pull data for research		policy	collaborative research based	PBRNs	Sustainability linked to
health system	for evidence-based	Ctuotocci for DDD M	and population health,	Policymakers advocacy	Decomized need for	in the practitioner	Eacilitated	both political and
Driver for evidence-	practice in primary	reform thronohout the	health service	UII OUBIL UIC LICEMOLY	nrimary healthcare	01 gamzau1011	sunnortive	manciat support
based care and control	~ ~~~~	country	monuoring and promoting effective	Health/disease	data informing	Recognized research as part	activities for	Variability in financial
of healthcare costs	Funding allocation	1 1 1 1 1 1	research translation	monitoring needs to	population health	of the development of the	PBRN research	support for early
Transformations in the	IOT PBKIN development	with the mission of the		Inform government and health authorities		academic discipline		projects
national healthcare	mandoraan	members (practice/	INAUONAI AWATUS IOF activities nromoting			Engagement of professional		National initiatives or
system seeking more	Incentives for	clinics) of the network	community	PBRN members		organization in the research		strategies for
efficient primary	computerization of	(eg., addressing health	engagement in	represent the primary		activity of the network		developing research in
пеаннсаге	practices	disparities).	research and	formulation of the R&D		Promoting incentives (eg.,		primary care unatenuan relevant fundings
Insufficient national		Promotion of funding to	Hallslauloll	program		professional credits) for		
alignment of primary		university departments		Interconnections with		PBRN activity		Strategies for funding
may provide		to develop FDIANS	Barriers	other databases (eg.,		Supported the use of EHR		PBRN
opportunities for		Promotion of linking	civilia di la ci	hospital care) increased		with ICPC coding of		
PBRNs to contribute		academia to community-	Laws that hinder or	the value of the data for		episodes of care		International
to this leadership and		based care in primary	prohibit GPs doing	the government and				opportunities for
vision		care setting	research by setting					intrastructural funding
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Image: section with a sectio	Sub-theme: National Health System	Sub-theme	: Institutional /Governn	nental Support, N ^s Environment	ational/State Policy an	nd Regulatory	Sub-theme: Prof Organizatio	èssional Ins	Sub-theme: External Funders
Decision-malers Metional policy Regulatory Interactions with contonniety Interactions	Key element			Key elements			Key element	s	Key element
Components Components Promotion of funding for Promotion of funding for postalitomes (e.g., PRN decoprater postalitomes (e.g., PRN decoprater postalitomes (e.g., Promotion of funding for postalitomes (e.g., postalitomes (e.g., postalitimes (e.g., pos	The impact of primary healthcare structure on PBRN development	Decision-makers	National policy	Regulatory environment	Interaction with policymakers	Community impact on public health policymakers through PBRN	National professional organization contribution and support	International professional organizations contribution	External Funders contributions
Provotion of Indiating for PRN of ord optimut Individual agencies periodi Individual agencies periodi Individual agencies periodi Individual agencies detailer PRN value PRN value periodi PRN value periodi Individual professional detailer Individual professional detailer Individual professional population montholity PRN value periodicional detailer PRN value periodicional population montholity The PRN value detailer Individual professional periodicional population montholity PRN value detailer PRN value periodicional periodi	Components			Components			Components		Components
	A cultural shift towards research in the primary healthcare system Development of modern health systems that recognizes as a key foundation for a that recognizes as a key foundation for a family medicine/general practice the existence of a strong research component practice the existence of a strong research practice the existence practice the existence of a strong research practice the existence practificates are not practificates are		Promotion of funding for PBRN development PBRN development PBRN with specialized objectives (eg., the inclusion of community members or patient groups in research and procedures research and procedures for use HIT implementation of EHR implementation of EHR implementation of EHR indiatives for use HIT sharing for patient- centered care (eg., mational policies, initiatives or incentives that support the development EHRs, and/or HIT applications that may support the procedures that may support the procedures) or indirectly the PBRN infrastructure)	limitations (eg., special license for research)	national agencies decision-making The PBRN is necessary and hus a special position in the research continuum		Identified the need for Identified the need for population mobidity with either a national or state professional organization, or both Developing a PBRN as a sub-entity of a professional organization		Funders' interests and network goals are aligned and in-kind support for infrastructure development from a variety of organizations, including the national agencis and professional organizations Funding targeted to research questions ecking for more effective healthcare and patient engagement Brokering models of collaboration with experienced research grants to network Funding from industry (eg., pharmaceuticals) for research aligned to mission and ethics of the network

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			The	Theme: External environment	ment			
Sub-theme: National Health System	Sub-theme	Sub-theme: Institutional /Governmental Support, National/State Policy and Regulatory Environment	ental Support, N ² Environment	ıtional/State Policy an	d Regulatory	Sub-theme: Professional Organizations	ssional IS	Sub-theme: External Funders
Key element			Key elements			Key elements		Key element
The impact of primary healthcare structure on PBRN development	Decision-makers	National policy	Regulatory environment	Interaction with policymakers	Community impact on public health policymakers through PBRN	National professional organization contribution and support	International professional organizations contribution	External Funders contributions
Components			Components			Components		Components
National health systems where each patient is not registered with a sole FP(CP may face challenges with overlapping data or changing population, when their data derive from EHR recording The transformation of the small physician- owned practices into health systems and clinics or hospitals challenges that requests other types of membership and participation National health system with less primary care support		Barriers Reduction or elimination of government support in PBRN activity Unstable political cimate and cimate and contradictory national policies towards PBRN development						Barries Lack of stability of infrastructure funding is an instrumental problem for the PBRN development Dependence on study- specific grants to maintain the infrastructure of the infrastructure of the network network mission from industry due to conflicts of interest with network mission

(continued)

			Key elements		e erent key elements				Key elements		
International experience	National experience	Leveraging previous research expertise	Leveraging PBRN practice models	Leveraging experience from peer networks	Interacting with other networks	Developing networks of PBRNs	HIT applications sustain the infrastructure	HIT applications facilitating or supporting the PBRN operation	HIT vendors contribute to sustainability	HIT vendor in the partnershi p of the network	Challenges from the variety of EHR systems
	-		Components						Components		
					Interacting with other researchers from various countries in the context of a project	Networks of PBRNs and large-scale collaboratives of higher infrastructure and transaction costs during research	HIT changes and slow pace in applications may hinder the and evaluate data, and thus research participation Selection of an EHR vendor tHA thas not considered needs for data extraction for research when the softwore was developed		HIT vendors supporting a DBRN development, (eg., improving the EHR potential or developing effective methods of developing effective methods of developing effective methods of developing data, or creating HIT applications useful for the PBRNs or the primary healthcare) and managing data, or creating HIT applications useful for the PBRNs or the primary healthcare) and the approaches approaches approaches approaches approaches approaches and study function and translational research support Development of "big data" with increased capacity for specific big scale studies (eg. CBR) is attractive to funding organizations		

à establishment of PBRNs and belong to the main theme "External Environment". 3 575 vey cicit

Abbreviations: PBRNs, Practice-Based Research Networks; HIT, Health Information Technology; EHR, Electronic Health Record.

shared research interests to initiate international,^{11,22,112,143,181} and national^{22,48,67,145,250} or even regional PBRN^{22,67,91} activity. WONCA also facilitated the spread of the International Classification of Primary Care (ICPC) system over the PBRN registries.^{7,126,130,184}

Subtheme: External Funders

In addition to base-level funding from academic departments, which belong to the internal environment of PBRNs,¹⁴ PBRNs reported that received infrastructural financial support from a range of entities, including professional organizations, government-based funding agencies, academic and private institutions and foundations, national healthcare organizations, hospitals and other healthcare stakeholders,^{33,52,54,63,72,79,85,87,95,99,102,104,109,119,121,125, 128,138–146,250} and even HIT vendors.⁸³

A number of PBRNs reported that their early projects were conducted on small, local grants and as they matured and their methodological approaches developed, they were able to secure more substantial funding from a broader set of sources.^{22,147,148} However, we found a few networks that started their research activities with sizeable funding.^{29,63,123,136}

Some other networks used a 3-pronged mechanism to fund their research: Large-scale, externally funded projects that pooled recognized researchers, internal network-wide projects that were supported financially by the network partnerships, and smallscale projects conducted by clinician-members, which addressed their individual research interests and provided limited funding from the network.^{22,68,69,83,218}

Subtheme: Leveraging Previous Research and PBRN Experience and Interacting with Other Networks

Our findings suggest that many PBRNs were developed based on experience gleaned from previous long-standing PBRNs and by interacting with other networks on a national or international level.^{11,22,45,48,63,75,92,102,109,110,112,120,130,136,181,182,183,184} In some cases, they simply relied on literature reviews and presentations/publications by other PBRNs to translate and apply knowledge gathered from networks either from the same or other countries.^{103,120}

Some of the networks were founded to accomplish goals that were complementary to those of a previous network,^{111,127} or to leverage the research capacity of a dissolved¹ or older network,¹⁸⁵ or merging older networks,^{57,215} while others adopted specific PBRN practice models borrowed from prior networks^{48,92,112,181,187} and a considerable number tapped into previous research experience of their members and peer interaction.^{22,29,37,63,86} Federated networks could upscale research, quality improvement, and learning community activities, and provide economies of scale critical for the infrastructure of PBRNs.^{55,114,128,188}

Subtheme: HIT and HIT Vendors

Various HIT applications were used by PBRNs at their foundation phase, as early as the 1980s.^{9,11,83,116,125,126,180} Contributions of HIT sustained the development of PBRN infrastructure, either directly empowering networks to meet their growing research needs, or indirectly, when the use of a specific EHR was required for PBRN membership.^{36,38,53,73,81–83,109,130,132,133,138,146,185,191–193,197,236}

Many articles stated that PBRNs leveraged the potential of EHRs for healthcare data standardization, motivated HIT vendors to improve the quality of EHRs, and developed tools that facilitated data extraction and sharing,^{53,57,61,81,106,110,114,} ^{128,130,133,138,185,186,192–197} clinical decision-making, learning communities, and quality improvement acti-

vities. 40,51,53,55,57,61,105,106,109,114,130,133,138,197

PBRNs in collaboration with vendors, gave rise to numerous innovative HIT applications for example, technologies developed by e-PCRN,^{105,138,160,199} the shared EHR of OCHIN^{32,53,107} and the data-driven CPCSSN infrastructure.^{109,198,200,201} The expansion of EHR use facilitated "big data" aggregation and the development of Federated Networks^{87,114} and Distributed Data Networks (DDNs).^{39,128} These "big data" networks, contributed to the utilization of PBRN data by various healthcare stakeholders, including research institutes and government organizations, and advanced data-driven and policy-informing research for the benefit of wider populations.^{39,90,114,123,168,237}

Discussion

We conducted a scoping review of all discoverable literature on building PBRNs in an over 50-year period. Our analyses elucidated many facilitators and barriers for building PBRNs but our study was not limited to these exclusively. In this article, we

present 32 key-elements related to the main themes of "Stakeholders at the Intersection between the Internal and External Environment" and "External Enviro*nment.*" Some of the stakeholders that belong to the first main theme (patients, community groups and other healthcare stakeholders) gradually moved from an initially external position ("recipients" or "organizers)," toward PBRNs as "co-organizers" or "co-founders" and increasingly engaged in evidence generation, implementation, and training partnerships over time. These transitions occurred at different times for PBRNs, but they were clearly visible over the 50-year study period. Thus, the separation between the main PBRN constituents, academics and practitioner members and external stakeholder groups, has diminished over time. The main theme "External Environment" represents the social context of family medicine where PBRNs were developed, which influenced their evolution, since there was a need to adjust to new challenges, but also to leverage new opportunities and experience that emerged from each particular context. In addition, as PBRNs matured, the influence of prior experience with PBRN work and interaction with other networks increased, likewise the impact of HIT and HIT vendors.

An extensive amount of evidence from the literature that we examined suggests that there are specific processes and activities that are necessary for creating new PBRNs. The cornerstone of developing PBRNs seems to be the reciprocal relationships and trust between the actors engaged in PBRN activities.¹⁴ Other pivotal ingredients include the participation of community stakeholders and other healthcare stakeholders in PBRN activity. Just as significantly, partnerships should be developed with actors of the external environment that augment the PBRN's impact on the community that the network serves or on the broader social environment. Finally, we must note the importance of the healthcare context where PBRNs are developed and the role of infrastructural funding.

Some of our findings do not apply to all networks that are in the establishment process. For example, not all networks were shaped by all aspects of collaboration that were included in the key element "Other Aspects of Working with Healthcare Stakeholders." In addition, some facilitators and barriers we listed in the Results section may be sensitive to the context of occurrence. For example, quality improvement tends to emerge as a strong driver to engage in a PBRN,¹⁴ but it is usually curbed by the specific healthcare environment the PBRN is situated in.

This study was based on scoping review methodology which explores and assesses the available body of literature and allows the identification of key concepts that underpin the research topic.^{15,248,249} In addition, for the reasons we outlined in the Methods section, we purposefully selected social network theory to organize our data and structure our analysis, which provided our specific investigative lens. Although there may be other possible approaches to analyzing the data (eg, based on organizational theory), these were not in our scope. It may be beneficial for future studies to explore these alternative methods.

Beyond the immediate findings of this study, we also generated a repository of the international literature which may provide further information on the developmental experience of PBRNs across the world. From this repository, we also plan to create various resources that may help support the diffusion of PBRNs internationally.

Connection of Findings with Social Network Theory

Our analyses, anchored in social network theory,^{16,18} indicated that the highest density in thematic associations in our findings was identified in "relationship building," and it was expressed by the degrees of interconnections between the individuals (eg, practitioners or academics)¹⁴ and between nodes (eg, practices, institutes, stakeholder groups) and the actual number of ties between them. The most common features of these relationships (ties) were multiplexity, reciprocity and reachability and express the qualities the PBRNs were built on and sustained their ties. The ties are strongly homogenous within the network, less homogenous when they connect the network with "boundary spanners," and more heterogenous when they link the network with stakeholders of the external environment.^{16,18} These findings underscore that in addition to academic-practitioner relationships that shaped the internal environment of PBRNs, networks developed relationships with a diverse set of actors that were "boundary spanners" or were located in the external environment and they influenced the formation of networks directly or indirectly. The intensity and

density of these ties indicates that PBRNs operated as an interface for multilateral communication, interaction, and knowledge-sharing that shortened the time of spreading innovations from the "early majority" to the "late majority" of stakeholders. The first group includes practitioners and academics of the network and the second includes patients, community and other stakeholders (eg, healthcare authorities) or policymakers, who engage more actively in PBRN projects.^{202,203}

Other Interpretations on Key Elements of PBRNs

Publications indicate that each network was influenced by the timing and location of its development and many of them reported that previous experiences with healthcare systems, professionals, research policies or resources had an impact on them.^{206,214} Our review suggests that the cumulative experience gained from PBRN activity and advancements in HIT was time-dependent. The same applies to the depth of engagement of patients, community members, and other healthcare stakeholders in PBRN activity. In addition, we identified bidirectional interactions between PBRNs and health policymakers, through which PBRNs became not only the subjects of policies that supported or hindered their inception or activities, 154, 156, 158, 159, 165, 172-174, 209, ^{238–243} but they also emerged as developers of priorities that influenced health policy.^{9,10,13,28,33,37–39,51,52,67–} 69,76,79,88,91,97,110,118,119,125,128,135,150,170,183,211,216,217,237 In some situations, they acted as "conveners" who

In some situations, they acted as "conveners" who actively engaged health policymakers in the mission of PBRNs narrowing the "distance" between PBRNs and policymakers.^{9,53,85,88,89,142,237}

Through collaboration with patients, community groups and other healthcare stakeholders PBRNs paved the way for direct translation of research into practice. 29,39,48,54,67,80,86,88,89,97,109,152 policy and Some of these partnerships also became "communities of solutions"219 and were considered necessary to develop better health systems, health policies and guidelines.^{220,221} Health disparities played an important role here, through which PBRNs were able to shape a "geographic footprint" of their community to respond to the needs of their constituents and to consider the local primary care clinician as part of the community.²²² Our review suggests that a strong community and health equity focus was articulated by PBRNs by envisioning community-based research to be more pragmatic when it engages a wider variety of populations (eg, rural, uninsured, minorities) that

experienced community-based care as the only accessible care option. In addition, the interdependence we found between the pronounced motivation of practitioners to contribute to community health excellence and to serve these populations¹⁴ supports previous literature which suggests that PBRNs strengthen the ties between their internal structure and the community they serve when they embrace health equity and community engagement.^{222–224}

The Effect of National Environments

Variations in PBRN goals and pathways of network formation¹⁴ depended on specific national characteristics, of their health system over time that accentuated the role and the underlying culture of family medicine/general practice/primary care.

In our first scoping review,¹⁴ we found that most PBRNs were created either as a practitioner or academic initiative. In the current article, we show that networks were established either in the context of a national strategy that supported and defined their trajectory (a more centralized approach), or as a professional initiative that originated from groups of academics and individual practitioners, in addition to collaborations with professional organizations (decentralized or individualized approach). A decentralized approach for building PBRNs tended to be more common in the USA and the Netherlands, while a centralized (eg, national strategy-based) approach was more prevalent in the UK, Australia and Canada, in addition to the supportive involvement of the professional organizations in these countries.45,92,109

Our results suggest that the characteristics of the national environment and various approaches to building PBRNs14 influenced the structure of research governance (who is leading); the priorities of research (who decides on research topics); and the methodology of research. The literature indicates that research priorities in the UK are typically defined by the national healthcare system,86,204,237 while in the USA, emerging funding opportunities tend to direct, but do not completely define research priorities of PBRNs.²⁰⁵⁻²⁰⁸ Methodologically, Dutch PBRN data registry networks were positioned well to conduct observational studies, while many local, regional and statewide networks in the USA were designed to facilitate quality improvement activities,¹⁴ capitalizing on the understanding of the local culture, interests and closer relationships with their members and the community. In this context,

practitioner aspirations for care quality improvement created a solid foundation and strong incentive for PBRN research, while community-based participatory research (CBPR) and patient-centered outcomes research (PCOR) methodologies also found fertile ground²⁰⁹ and fostered a stronger community-based role of primary healthcare.^{31,154,156,158,189,209–213}

Collaborations of PBRNs and the Benefits of HIT

PBRNs developed various types of collaborations and "federations" to enhance their sustainability and to foster collaborations with advocacy groups.^{12,137,226} They also leveraged HIT advancements that enabled the development of large databases and HIT-driven multi-network collaborations^{57,61,114,123,128,138,168,190,197} This type of infrastructure helped extended access to a variety of populations, leveraged wider stakeholder interests, engaged in multiple types of research and focused on research topics and innovative methodologies^{190,229} leading to generalizability.^{123,168,244,245} broader These resources became more common in the late 2000s, which was expressed by the development "meta-networks" (ie, networks of networks) in USA and UK.^{14,86,123,170,189,227,228} PBRN metanetworks asked more ambitious research questions by pooling their resources and expertise and managed diversified research portfolios and business models that facilitated external stakeholders to influence PBRN research priorities and to accelerate the dissemination of research findings.^{114,189,230,231}

Financial Stability and Sustainability Models

The timing of building networks and the characteristics of the national environment defined PBRN management approaches and their funding opportunities. Early regional American and Dutch PBRNs received limited infrastructural support from professional or academic organizations. Conversely, the binational ASPN network received funding from private foundations and national organizations. Networks gradually benefited from supportive national strategies and more tangible infrastructural support from various funding bodies, as a result of recognizing the value of PBRN research and its impact on healthcare and policy.^{29,36,58,68,} 85,89,114,121,128,137,158,159,165,170,227,228 This underscores the importance of external relationships and support in the development of PBRNs,^{209,210,246} but also the risk

of becoming dependent on these relationships.^{206,246,247} In addition, research funds targeting the collection of data without much relevance to primary care, might also be seen as barrier. Some PBRNs responded to financial instability by developing either a model of limited resources^{125,153,232} or a business model that involved relationships with stakeholders in the external environment, as we reported in our previous article.¹⁴

Limitations

In this scoping review we completed the widest possible search in English-language publications and sources, and we explored a 10-year period of each network's initial development, which may have influenced our frame of reference. Therefore, PBRNs that published in other than English language or never published, although they may have substantial experience, are not included in this review. However, the parameters we used were congruent with the temporal and source-language distribution of most PBRN literature.

The list of PBRNs that met the inclusion criteria is more limited than those that ever existed in the USA,²³³ Australia,^{238,250} the UK⁴⁸, Canada,²³⁴ the Netherlands,¹⁷⁵ and in web-based sources that refer to particular PBRNs, since there was no supporting literature in every case. We also excluded articles with insufficient information on the development of PBRNs.

Scoping reviews may carry selection bias, if all available data are not identified or included in the study. Inductive thematic analysis methodology was implemented in this study, however, some a priori knowledge about PBRNs may also contributed to the development of the thematic model.

Conclusions

This analysis highlights the importance of the external environment in the development of PBRNs, in addition to the previously reported role of the internal environment. A key finding is that "internalizing" the "outside world," by involving patients, community leaders, health authorities and policymakers in their mission, makes the functioning of PBRNs more robust and the impact of their work on the health of populations more tangible. Understanding the health and social environment in which they operate is therefore a key to success in PBRN development. To see this article online, please go to: http://jabfm.org/content/ 35/4/762.full.

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Appendix

Table 1. Inclusion and Exclusion Criteria for the Scoping Review

Inclusion Criteria

- 1. Peer-reviewed journal articles published between 1/1/1965 and 12/31/2020 in English language that refer to one or more primary care PBRNs and include information about their establishment.
- 2. Articles that refer to research projects conducted by PBRNs that also provide information about their establishment.
- 3. Reports, editorials, letters, commentaries, conference papers and web pages that may provide complementary information on an already identified PBRN.
- 4. Information on PBRN establishment was included after defining primary care-linked PBRNs based on the scope of primary care in each particular region or country.

Exclusion Criteria

- 1. Articles that focus on specific research studies, data collection or database/technology development in PBRN settings, without providing information about the PBRN's establishment.
- 2. Articles in which the identity of the PBRN can't be determined (eg, due to blinding).

Abbreviation: PBRNs, Practice-Based Research Networks.

Table 2. Overarching Thematic Framework for the Establishment of Practice-Based Research Networks (PBRNs)
Focusing on the Themes of the External Environment and Stakeholders at the Intersection between the Internal
and External Environment Described in This Article

Theme	Subtheme	Key Elements
(i) Internal Environment of PBRN	(i) Foundation	(i) Setting up mission, purposes, goals, objectives and aims
	(ii) Practitioner Participation	(i) Recruitment
	and Motivation	(ii) Membership
		(iii) Levels of member engagement
		(iv) Intrinsic motivators to participate and benefits for
		practitioners (v) Extrinsic motivators to participate and benefits for
		practitioners
	(iii) Academic Participation	(i) Type of affiliation and advantages – disadvantages of
	and Attitudes	affiliation (ii) The role of academics and academic departments in
		developing, hosting and sustaining the network
		(iii) Academic contribution to governance and leadership
		(iv) Contribution of academic research expertise
		(v) Academic support for research culture development
		and practitioner empowerment
		(vi) Academic initiative to link medical students and
		residents to PBRN activity (vii) Benefits for academia from PBRN collaboration
	(iv) Network Infrastructure	(i) Initial Partnerships to Establish PBRNs and Centers
	and Operations	of Operations
	I I I I I I I I I I I I I I I I I I I	(ii) Infrastructural Funding
		(iii) Key Activities at Establishment
		(iv) Relationships Building Between Academics and Practitioners in the Field
		(v) Governance
		(v) Organizational Leadership
		(vii) Methodology of prioritizing the Research Agenda
		(viii) Topics of PBRN research
(ii) Stakeholders at the intersection between the internal and external environment		(ix) Data gathered from networks & Data management
		(x) Quality improvement (QI) activities
		(xi) Learning environment (xii) Communication
	(i) Patients and Community	(i) Patient-centeredness and community engagement in
	Stakeholders	PBRNs
		(ii) Relationship building with patient or community
		groups as an essential part of research
		(iii) Quality improvement activities guided by patient
		feedback
		 (iv) Involving patients or community members in PBRN governance
		(v) Integrating CBPR methodology into PBRN research
		(vi) Community Engaged Research methodology in
		PBRN research
		(vii) Motivation of community members for research
		participation
		(viii) Community engagement in health policymaking through PBRN activity
	(ii) Other Healthcare Stake-	(i) Identification, engagement and contribution of
	holders	healthcare stakeholders
		(ii) Relationship building with healthcare stakeholders
		(iii) Other aspects of working with healthcare
	() NT	stakeholders
iii) External environment	(i) National Health System	 The impact of primary health care structure on PBRN development
	(ii) Institutional/	(i) Decision-makers
	Governmental Support,	(i) National policy
	National/State Policy	(iii) Regulatory environment
	and Regulatory	(iv) Interaction with policymaking
	Environment	(v) Community impact on public health policymaking
		through PBRN

Continued

Table	2.	Continued
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Theme	Subtheme	Key Elements
	(iii) Professional Organizations	(i) National professional organization contribution and support(ii) International professional organizations contribution
	(iv) External Funders	(i) External funders contributions
	(v) Leveraging Previous	(i) International experience
	Research and PBRN	(ii) National experience
	Experience and	(iii) Leveraging previous research expertise
	Interacting with Other Networks	(iv) Leveraging PBRN practice models(v) Leveraging experience from peer networks
	INCLWOIRS	(v) Leveraging experience from peer networks (vi) Interacting with other networks
		(vii) Developing networks of PBRNs
(iv) HIT and HIT Vendors	 (i) HIT applications sustain the infrastructure (ii) HIT applications faci- litating or supporting the PBRN operation (iii) HIT vendors contribute to sustainability (iv) HIT vendor in the partnership of the network (v) Challenges from the variety of EHR systems 	

Note: In this Table, the shadowed part corresponds to themes, sub-themes, and key elements presented in a previous study. Abbreviation: EHR, Electronic Health Records; HIT, Health Information Technology.