EXPERIENCE REPORT

Stakeholder engagement infrastructure to support multicenter research networks: Advances from the clinical research networks participating in PCORnet

Elizabeth L. Cope[1] | Kathleen M. McTigue[2] | Christopher B. Forrest[3] |
Thomas W. Carton[4] | Alecia M. Fair[5] | Crispin Goytia[6] | Joseph M. Harrington[7] |
Susan Lowe[8] | J. Greg Merritt[9] | Elizabeth A. Shenkman[10] |
William J. Stephens[11] | Anna Templeton[12] | Neely A. Williams[13] |
Nadine Zemon[14] | Sarah Millender[1] | Rebekah S. M. Angove[15]

[1]AcademyHealth, Washington, DC, USA

[2]Department of Medicine, University of Pittsburgh, Pittsburgh, Pennsylvania, USA

[3]Applied Clinical Research Center, Children's Hospital of Philadelphia, Philadelphia, Pennsylvania, USA

[4]Louisiana Public Health Institute, New Orleans, Louisiana, USA

[5]Meharry-Vanderbilt Alliance, Department of Medicine, Vanderbilt University Medical Center, Nashville, Tennessee, USA

[6]Department of Population Health Science and Policy, Icahn School of Medicine at Mount Sinai, Institute for Health Equity Research, New York, New York, USA

[7]CAPriCORN Patient Community Advisory Committee, Chicago, Illinois, USA

[8]ADVANCE Clinical Research Network, OCHIN, Inc., Portland, Oregon, USA

[9]Patient is Partner, LLC, Brighton, Michigan, USA

[10]Department of Health Outcomes and Biomedical Informatics, College of Medicine, University of Florida, Gainesville, Florida, USA

[11]Great Plains Collaborative, One Hospital Drive, Columbia, Missouri, USA

[12]OCHIN, Inc., Portland, Oregon, USA

[13]Community Partners Network, Inc., Nashville, Tennessee, USA

[14]OneFlorida Clinical Research Consortium, Clinical and Translational Science Institute, University of Florida, Gainesville, Florida, USA

[15]Patient Advocate Foundation, Hampton, Virginia, USA

Correspondence
Elizabeth L. Cope, AcademyHealth, 1666 K Street NW, Suite 1100, Washington, D.C. 20006, USA.
Email: elizabeth.cope@academyhealth.org

Abstract

Background: The evidence based on the inclusion of patients and other stakeholders as partners in the clinical research process has grown substantially. However, little has been reported on how stakeholders are engaged in the governance of large-scale clinical research networks and the infrastructure used by research networks to support engagement in network-affiliated activities.

Objectives: The objective was to document engagement activities and practices emerging from Clinical Research Networks (CRNs) participating in PCORnet, the National Patient-Centered Clinical Research Network, specifically regarding governance and engagement infrastructure.

Methods: We conducted an environmental scan of PCORnet CRN engagement structures, assets, and services, focusing on network oversight structures for policy development and strategic decision-making. The scan included assets and services for supporting patient/stakeholder engagement. Data were collected by searching web-based literature and tool repositories, review of CRN Engagement Plans, analysis of previously collected key informant interviews, and CRN-based iterative review of structured worksheets.

Results: We identified 87 discrete engagement structures, assets, and services across nine CRNs. All CRNs engage patients/stakeholders in their governance, maintain workgroups and/or staff dedicated to overseeing engagement strategies, and offer one or more services to non-CRN researchers to enhance conducting engaged clinical research.

Conclusions: This work provides an important resource for the research community to explore engagement across peers, reflect on progress, consider opportunities to leverage existing infrastructure, and identify new collaborators. It also serves to highlight PCORnet as a resource for non-CRN researchers seeking to efficiently conduct engaged clinical research and a venue for advancing the science of engagement.

1 | INTRODUCTION

Over the past 15 years, momentum has been building for greater inclusion of patients and other stakeholders (e.g., clinicians, payers, and policymakers) throughout the clinical research lifecycle, particularly in the context of learning health systems. Partnering with these groups across the research activity continuum—from defining research questions through study design, conduct, and dissemination—may help ensure that findings are more relevant, complete, ready for uptake, and trusted by key individuals and communities.[1] Moreover, the literature describing engagement models and practices related to different stages of research is expanding, offering examples of successful, replicable strategies.[2,3] Methods vary substantially from discussion groups[4] and modified Delphi processes[5] to patient panels[6,7] and engagement studios,[8,9] to fully embedded patient/stakeholder investigators,[10] highlighting that there is no single approach best suited to meaningfully including these vital perspectives.

Although opportunities to work with research networks have expanded considerably,[11] the literature lacks systematic information on how patients/stakeholders are engaged in the governance of large-scale research networks.[12] Less is published on the infrastructure research networks use to promote engagement in network-affiliated activities.[13,14] These are the primary mechanisms through which the research community can be held accountable for serving and protecting the interests of the people and communities research networks comprise. Furthermore, they represent an array of sustainable assets and services for promoting efficient and effective engagement in ongoing and ad hoc network activities. With initiatives such as PCORnet,[15] the National Patient-Centered Clinical Research Network, and the All of Us Research Program (AoURP)[16] calling for robust patient/stakeholder engagement, there is an opportunity to learn more about promising engagement practices in the context of network governance and infrastructure.

PCORnet is a large-scale, network of networks with a rich set of engagement case examples, particularly for meaningful engagement of patients/stakeholders into network governance and infrastructure. PCORnet is funded by the Patient-Centered Outcomes Research Institute (PCORI) with the aim to build the nation's capacity to more quickly and efficiently conduct patient-centered outcomes research (PCOR) at a lower cost than had previously been possible. PCORnet Clinical Research Networks leverage diverse sources of health information and multi-stakeholder partnerships to pursue rigorous, high-impact research.[17] A key emphasis of PCORnet participants has been the incorporation of engagement of patient/stakeholder partners throughout network activities across three topical areas: governance, infrastructure, and research projects. This infusion of diverse perspectives in strategic decision-making as well as tactical implementation is a signature feature of the PCORnet community.

At the time of our work, PCORnet included nine Clinical Research Networks (CRNs) partnering with care delivery systems that provide electronic health record data. Clinical Research Networks serve as rich data repositories, offer an array of research-related services to investigative teams, conduct their own PCOR, and support health-care delivery improvement efforts.[18] The nine CRNs represent diverse health system settings and patient populations. Each has developed engagement practices and resources in response to constituent input. Cataloging the scope of these modalities potentiates (a) better

understanding of how to engage patients and other key stakeholders in network governance; (b) detecting recurring approaches and emergent themes related to building engagement-related infrastructure; and (c) identifying stakeholder engagement resources/approaches that are value added in the clinical research context. PCORnet governance and infrastructure provide a foundational culture of robust patient/stakeholder engagement with opportunities for growth and development across affiliate networks and studies. PCORnet Network Partners are uniquely poised to learn from these experiences and enrich the literature of engagement in patient-centered outcomes research. Accordingly, this study aimed to document engagement activities and practices emerging from the CRNs, specifically as they relate to governance and engagement-related infrastructure, laying the foundation for future evaluations of comparative effectiveness.

2 | METHODS

Between June 2020 and February 2021, we conducted an environmental scan of CRN engagement activities and practices related to network governance and engagement infrastructure. Governance was considered patient/stakeholder partner involvement in CRN oversight structures responsible for policy development and strategic decision-making. For infrastructure, we examined the specific assets and services used to engage patients/stakeholders in network activities. Data collection included searches of the literature and tool repositories made available by PCORI and the PCORnet community, review of CRN Engagement Plans, secondary analysis of existing key informant interviews, and iterative review of structured worksheets by the CRNs.

2.1 | About PCORnet

As of May 2020, the nine CRNs participating in PCORnet comprised 337 hospitals, 169 695 physicians, 3564 primary care practices,

338 emergency departments, and 1024 community clinics serving medically underserved populations. The total cohort of nearly 80 million patients[15] is widely distributed across the United States (Figure 1).[19] PCORnet governance included a 16-member Steering Committee (SC), which included one representative from each of the participating networks (including two health plan research networks not discussed in this article), two from the Coordinating Center, and three patient representatives. An Executive Management Team led by the SC chair includes the vice-chair, one representative from the Coordinating Center, and one patient representative who prioritizes topics for the SC.[15] The chair and vice-chair are selected by a SC vote, after a call for nominations from among SC members. Additionally, an engagement workgroup advises the SC by providing recommendations on patient/stakeholder engagement opportunities, priorities, and practices across the network and in PCORnet-designated research studies. The workgroup comprises one patient representative or engagement staff member from each CRN and three PCORI representatives. Throughout all governance proceedings, steps are taken to ensure a level playing field by giving each SC member one vote, including multiple stakeholder voices, and applying meeting norms and communication support to ensure meeting materials are developed using plain language and discussions are grounded in a shared understanding of the salience of all decision-making.

2.2 | Data sources

2.2.1 | Literature and tool repositories

To identify existing publicly available descriptions of CRN engagement activities and practices, we searched four repositories:

- **PCORI Engagement in Health Research Literature Explorer:**[20] a PCORI-hosted, curated searchable list of publications on engagement in health research updated monthly using

Number of Participants

50   100,000
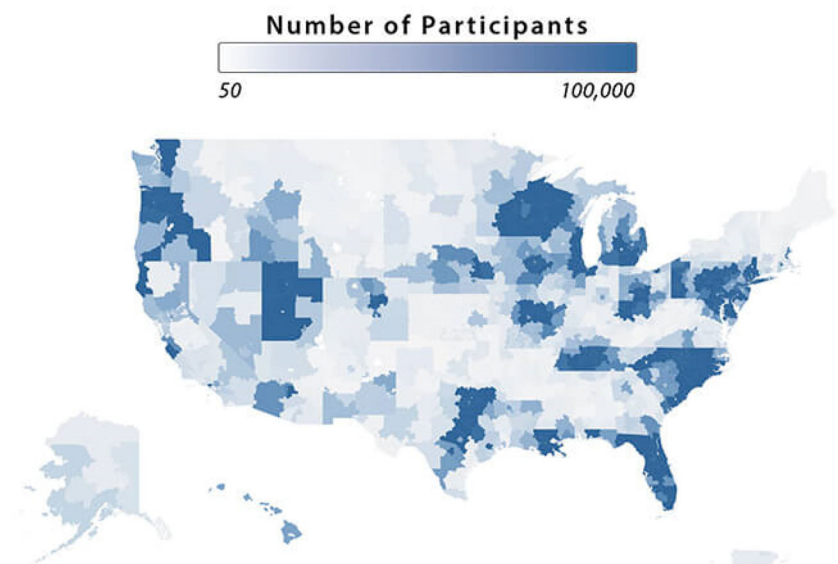
FIGURE 1 Geographic distribution of patients represented in CRNs participating in PCORnet[19]

PubMed/MEDLINE searches and reviews of relevant journals not yet indexed in PubMed (e.g., *Research Involvement and Engagement*).

- **PCORI in the Literature:**[21] a PCORI-hosted, searchable list of papers and commentaries stemming from PCORI-funded work.
- **PCORI Engagement Tool and Resource Repository:**[22] a PCORI-hosted, curated searchable list of engagement-related tools and resources developed and used by PCORI awardees to support peer-to-peer awareness and uptake of resources, and implementation of engagement practices and methodologies in the broader health-care research community. Example resources include committee charters, engagement policies, patient partner recruitment materials, and engagement evaluation surveys.
- **PCORnet Resource Repository:**[23] a curated searchable list of submitted engagement-related tools and resources specifically developed and used by PCORnet Network Partners. The repository includes resources related to engagement, research, and data. This analysis focused explicitly on engagement resources.

Keyword searches were conducted using the search terms outlined in Table 1, and results were compiled and deduplicated. Inclusion criteria for literature and resources are below

Published or documented between January 1, 2014 and February 15, 2021

- Described current/ongoing engagement in CRN governance and/or engagement-related infrastructure
- Included descriptions of either:
  - ○ Engagement activities—specific structures, assets, and/or service networks developed to foster and/or facilitate patient and stakeholder engagement *as partners* (instead of research participants/subjects)

TABLE 1   Literature & tool repository search terms

PCORnet	NYC-CDRN**
Clinical Research Network	LA CDRN***
Clinical Data Research Network	Carton T
ADVANCE	Forrest C
CAPriCORN	Haynes K
Greater Plains Collaborative	Kaushal R
GPC	Kho A
INSIGHT	McTigue K
OneFlorida	Nair V
PaTH	Puro J
PEDSnet	Rothman R
REACHnet	Shenkman E
STAR	Waitman R
Mid-South*	

Notes: *Former name of STAR; **Former name of INSIGHT; ***Former name of REACHnet.

- ○ Engagement practices—generalizable tactics, approaches, or processes that are essential to the success of engagement activities and/or tool implementation

Exclusion criteria for literature and resources were as follows:

- They described engagement activities or practices in initiatives/networks that are not current PCORnet participants
- They described engagement in research (vs. governance and infrastructure)
- The description did not contain information on the nature, purpose, and scope of the activity
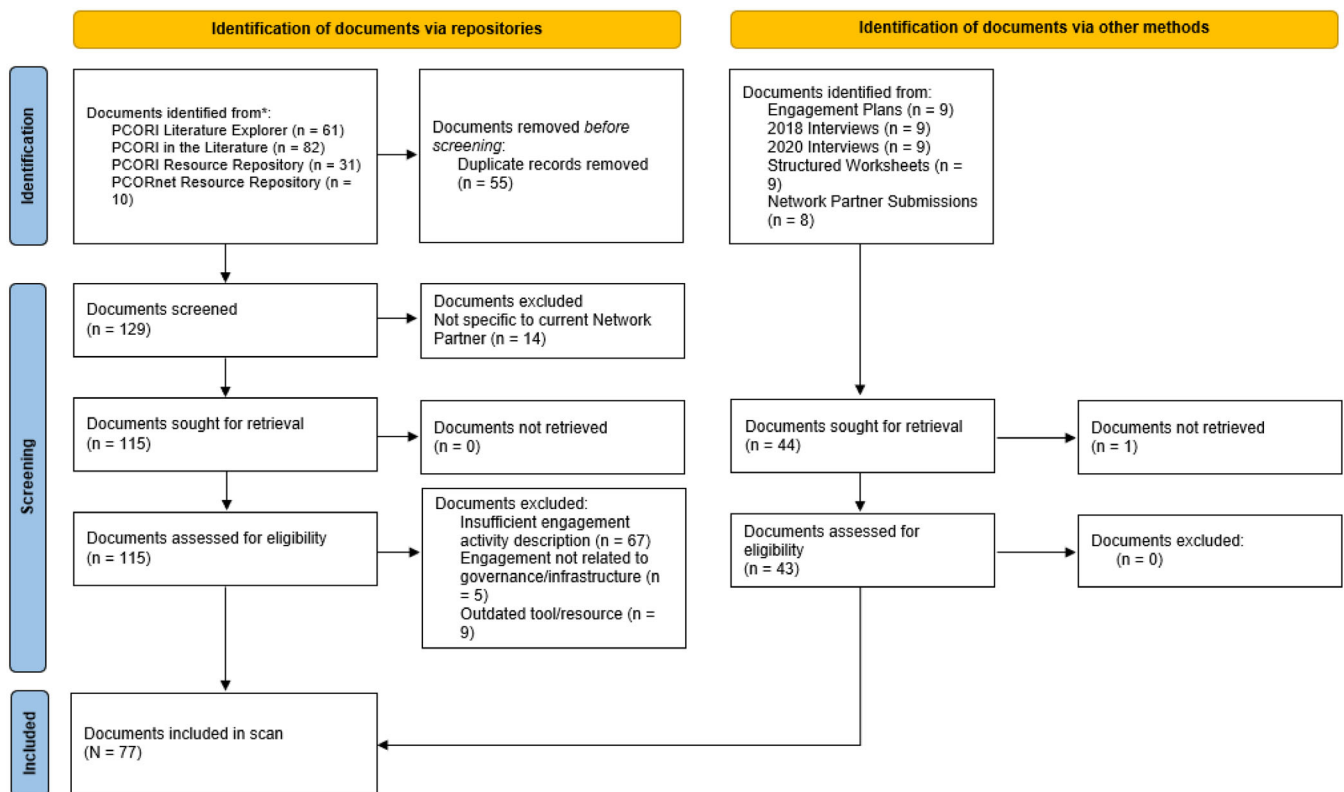- The description was related to activity planned for future implementation

2.2.2 | Engagement plans

Each CRN developed Engagement Plans designed to provide a comprehensive description of each CRN's approach to patient/stakeholder involvement and did not follow a uniform format. CRNs were also required to submit quarterly reports describing progress on all proposed engagement-related activities, which were appended to the original Engagement Plan. Written permission to include Engagement Plans and appended progress reports from November 1, 2018 to December 31, 2019 was sought from each CRN. Eight of nine CRNs agreed to share their Engagement Plan. Documents were obtained directly from PCORI for all consenting CRNs.

2.2.3 | Semi-structured interviews

Qualitative data from two sets of semi-structured interviews for separate studies exploring engagement work among CRNs were obtained and examined.

- **Engagement Evaluation Interviews:** In 2018, one semi-structured interview was conducted with each CRN to explore the scope, structure, intensity, and impact of engagement initiatives (see Document, Supplemental Digital Content 1, which provides the interview guide). Interviewees consisted of CRN leadership and engagement faculty and staff (including patient partners and representatives) via teleconference. Interview transcriptions were made available by PCORI to include in our document review.
- **Spotlighted Engagement Activity Interviews:** Between August and October 2020, semi-structured interviews were conducted with each CRN via video conferencing to support a more in-depth understanding of select engagement activities and explore perspectives on the role of engagement at the PCORnet level (see Document, Supplemental Digital Content 2, which provides the interview guide). CRNs self-selected team members (2–8 members per CRN) to participate in 90-min group interviews. All groups included the principal investigator (PI) and the engagement lead

Identification of documents via repositories

Documents identified from*:
PCORI Literature Explorer (n = 61)
PCORI in the Literature (n = 82)
PCORI Resource Repository (n = 31)
PCORnet Resource Repository (n = 10)

Documents removed *before screening*:
Duplicate records removed (n = 55)

Documents screened (n = 129)

Documents excluded
Not specific to current Network Partner (n = 14)

Documents sought for retrieval (n = 115)

Documents not retrieved (n = 0)

Documents assessed for eligibility (n = 115)

Documents excluded:
Insufficient engagement activity description (n = 67)
Engagement not related to governance/infrastructure (n = 5)
Outdated tool/resource (n = 9)

Identification of documents via other methods

Documents identified from:
Engagement Plans (n = 9)
2018 Interviews (n = 9)
2020 Interviews (n = 9)
Structured Worksheets (n = 9)
Network Partner Submissions (n = 8)

Documents sought for retrieval (n = 44)

Documents not retrieved (n = 1)

Documents assessed for eligibility (n = 43)

Documents excluded: (n = 0)

Documents included in scan (N = 77)

FIGURE 2 Flow chart of the document inclusion process for the engagement activity and practice scan

and/or project manager (PM); eight groups included patient partners. Each interview was led by an experienced researcher (EC or RA) and included a thematic notetaker. Interviews were recorded and transcribed in preparation for content analysis. In follow-up to interview responses, the effort was made to collect referenced materials to supplement our document review, including additional publications, tools, and/or resources.

2.2.4 | Structured worksheets

In November 2020, each CRN was asked to review a structured worksheet containing the comprehensive listing of network-specific engagement activities identified through the other data collection activities. CRNs were asked to remove activities that had been discontinued, update activity names and descriptions as needed, and add any missing current activities. For a new activity to be added, supporting documentation was requested in the form of publications, tools, and/or other resources for inclusion in our document review. Worksheet review and finalization was an iterative process, allowing CRNs two additional reviews of revised versions in January and February 2021. Typically, worksheets were completed by CRN team members including the PI, PM, lead engagement staff, and one or more patient/stakeholder partners. The research team performed a content analysis of free-text data from the worksheets to categorize

updated/new activities using a framework developed during the literature/tool review and interview transcript analysis.

2.3 | Data analysis

Relevant text excerpts were extracted from 77 documents (Figure 2) and imported into a database for analysis. Additional metadata also were captured, such as CRN source, document date, document type (publication, interview, etc.), document source (specific journal, repository, etc.), and other relevant details. Coding followed the principles of grounded theory.[24] Text excerpts were hand coded independently by two team members. Coding results were reviewed and compared. Any coding discrepancies were discussed and resolved through consensus (EC, RA, and SM).

3 | RESULTS

Document, worksheet, and interview transcript review resulted in the identification of 87 discrete engagement structures, assets, and services across CRNs. In addition to these activities, the thematic analysis revealed several practices that are supportive of, or foundational to, the identified engagement activities. These are described separately below.

TABLE 2 Summary of CRN structures, assets, and services that foster engagement of patients and other non-research stakeholders in network activities

	ADVANCE	CAPriCORN	GPC	INSIGHT	OneFlorida	PaTH	PEDSnet	REACHnet	STAR
Engagement structures									
Primary oversight structures with patient/stakeholder members									
Steering/oversight committees	P/C/H*	P*	P	P	P/C/H/Pa*	P/C/H	P	P	P/H/Po
Patient/stakeholder advisory structures									
Blended stakeholder models		P/C		P/Po/R	P/H/Pa				
Single stakeholder models	P		P/H						P
Workgroups/subcommittees with patient/stakeholder members									
Communications		P							
Data/Informatics		P	P		P/C	P/C/H	P		C/H
Engagement		P	P	P	P	P/C/H/IRB	P		
Operations		P				P/C/H/IRB			P/C/H
Regulatory/Ethics		P	P/IRB			P/C/H/IRB	P/IRB		
Research topics/Proposal review		P	P	P		P/C/H/IRB	P		
Engagement assets									
Engagement support teams/Programs	P	P/C/R	P		P	C		P	P/H*
Partner networks/Databases		C/R			P	P/C		P	
Blended research groups/Teams		P/C/R		P/C/I/Po/R	P/C	P/C/H/IRB		P/C/H/R	
Proposal/Project review panels & studios	P	P/C/R/IRB	P		P/C	P/C	P/C	P	P
Patient/Stakeholder prioritization process		P			P/C	P	P		P/C
Engagement services									
Engaging research partners	X	X	X				X	X	X
Proposal/project review panel/Studio access	X	X	X		X		X	X	X
Research design/Implementation consults	X	X	X		X	X			X
Research translation consults	X	X			X				

Abbreviations: P: Patient/Family/Community; C: Clinician; H: Clinic/Hospital/Health Systems Representative; IRB: IRB Representative; Pa: Payer; Po: Policymaker/Government; R: Researcher (non-CRN Team); X: Indicates the CRN provides the service to external researchers.

*Patient/stakeholder partners engage in research request/proposal review as part of this structure (vs a designated workgroup/subcommittee).

3.1 | Engagement structures, assets, & services

Engagement structures, assets, and services describe the core, enduring mechanisms, and supports for patient/stakeholder engagement in network activity. Specific subcategories, the presence of activities by CRN, and the stakeholder types involved are outlined in Table 2.

Structures relate to incorporating patients/stakeholders in strategic oversight, policy development, proposal review, and other decision-making for the network (i.e., what we define as network governance). Every CRN incorporated some types of patient/stakeholder into governance, with all including patients on Steering/Oversight Committees. The majority of CRNs established standalone Patient/Stakeholder Advisory Structures (67%; 6 of 9), using either blended (multiple stakeholder types in the same body) or single patient/stakeholder models, and included patients and/or other stakeholders in their Workgroups/Subcommittees (78%; 7 of 9).

We conceptualized network assets and services as infrastructure. Assets include the resources and models related to coordinating and managing partner engagement efforts. Examples include dedicated teams and staff that coordinate network engagement activities, patient networks, or patient/stakeholder databases that can be used for engagement needs,[25,26] the maintenance of blended research groups inclusive of patients/stakeholders and address multiple research topics over time,[27] mechanisms (such as panels or group sessions called studios) for reviewing engagement activities in projects and proposals,[9,10] and standardized approaches for facilitating patient/stakeholder prioritization of research topics.[28] All CRNs had one or more examples of engagement-related infrastructure that had been built to serve the needs of the network.

Some CRNs also offer services to support research teams in their design and execution of engaged research. These include assistance with identifying and onboarding patients/stakeholders as research partners; access to patient/stakeholder panels and studios for input on projects; and engagement-related consultation services for study design, implementation, and/or translation of findings. Nearly all (89%; 8 of 9) offered some type of formalized engagement service to external researchers.

3.2 | Supportive engagement practices

Throughout the analysis of documents, worksheets, and interviews, we noted that as networks described their activities, tools, and resources, they also included many principles and practices they deemed as essential to undertaking the work of engagement. These data are categorized into eight themes, described below, and summarized in Table 3.

3.2.1 | Supportive infrastructure

Creating and maintaining infrastructure that is supportive of engagement encompasses both how networks are built and run, as well the logistics pertaining to the use of this infrastructure. For example,

TABLE 3 Supportive engagement practices identified with descriptions and examples

Supportive practice	Brief description	Example
Supportive Infrastructure	Creating and maintaining infrastructure that is supportive of engagement	Developing clear policies around stakeholder roles and compensation
Supportive Environment	Creating and maintaining environments that are supportive of engagement	Implementing processes to eliminate jargon in meetings
Flexibility and Adaptability	Ability and willingness to adapt and improve engagement approaches	Build flexibility in processes that can incorporate stakeholder feedback in real time
Continuity and Longevity	Engaging stakeholders early in an initiative and maintaining relationships between initiatives	Creating a newsletter to help sustain connections with the stakeholder community
Stakeholder Leadership and Participation in Decision-Making	Fostering stakeholder leadership roles with meaningful decision-making authority	Deferring the most appropriate or impacted stakeholder group to make final governance decisions in cases of disagreement
Attention to Stakeholder Characteristics	Ensuring that partnerships are made with the appropriate stakeholder groups and individuals	Using stakeholder recruitment tactics that pay attention to diversity and representation
Relationship Building	Investing time, skill, and effort into building and maintaining meaningful relationships with stakeholders	Hiring engagement staff with interpersonal skills such as warmth, availability, and connectedness
Creating Value, Buy-in, and Enthusiasm for Engagement	Identifying value propositions for each stakeholder group and conducting activities, training, and outreach with this in mind	Facilitating conversations between stakeholders and researchers around shared goals

including engagement as part of network mission, policies, and projects; ensuring network leadership champions engagement; and appropriately funding and staffing engagement. Specific tactics that were shared include integrating stakeholder review of projects as part of the decision-making process,[29] developing clear policies around patient/stakeholder roles and compensation, providing formal patient/stakeholder training/onboarding,[30,31] and developing formal approaches for patient/stakeholder partner recruitment.

3.2.2 | Supportive environment

Creating and maintaining environments that are supportive of engagement was seen as key to the success of engagement and team dynamics. This includes awareness and mitigation of power dynamics, cultural sensitivity, promoting mutual respect, establishing a shared goal and inclusive group dynamics, and level-setting engagement expectations. Specific tactics that were shared include actively eliminating the use of jargon in meetings and having protected time for engagement topics in meetings and conferences.[32]

3.2.3 | Flexibility and adaptability

Flexibility was mentioned as an important part of responsive engagement and central to the iterative learning process that engagement requires. This was described as the ability and willingness to pivot when something is not working and having the flexibility to adapt and improve approaches. CRNs talked about the flexibility to change and adapt programs or training to meet patient/stakeholder needs and described this flexibility as the ability to change to incorporate patient/stakeholder feedback.

3.2.4 | Continuity and longevity

At what point patients/stakeholders are engaged in the research process was important to CRNs. In their view, engaging patients/stakeholders early and throughout the life cycle of the initiative support meaningful engagement. Additionally, interviewees noted that keeping patients/stakeholders engaged between initiatives ensures ongoing relationships and involvement that can be tapped when specific new projects arise. Several CRNs developed community newsletters and outreach strategies to keep patients/stakeholders informed in an ongoing manner.

3.2.5 | Stakeholder leadership and participation in decision-making

Our results indicate that patient/stakeholder leadership goes beyond having a patient partner or a stakeholder on a governance board. It is also about ensuring opportunities for patients/stakeholders to hold positions of leadership and meaningfully participate in decision-

making; with processes in place to support these efforts. This is linked to timing, as it is a key that patients/stakeholders are involved throughout the entire project/process like other members of the team. A tactic related to this category includes developing a process that provides patients/stakeholders authority in decision-making. For example, deferring to the most appropriate or impacted patient/stakeholder group to make a final decision if there is disagreement.

3.2.6 | Attention to stakeholder characteristics

Interview participants underscored that including patient/stakeholder members in activities was not sufficient on its own. Rather, they indicated, attention must be paid to having the right patient/stakeholder groups represented, with the right balance of expertise, skill, influence, diversity, and representation within patient/stakeholder groups. This can mean including community leaders and gatekeepers, bringing in patients/stakeholders in positions of power who can influence change, having a mix of novice and expert participants, including clinician stakeholders, and using recruitment tactics that pay attention to diversity and representation.

3.2.7 | Relationship building

Interviewees also stressed the importance of relationships, specifically having the skills and effort required to identify, build, and maintain meaningful relationships with patients/stakeholders. This includes strategically building alliances with selected organizational partners, as well as attending to interpersonal skills like warmth, availability, and connectedness to develop and maintain relationships. Interviewees suggested attention needs to be paid to investing in relationships with patients/stakeholders beyond the efforts specifically related to a project or task. The time this takes, and the value of long-standing relationships was acknowledged.

3.2.8 | Creating value, buy-in, and enthusiasm for engagement

Finally, interviewees noted identifying value propositions for each patient/stakeholder group and conducting activities, training, and outreach with this in mind can help build relationships, keep them engaged long term, and support buy-in from the wider research team. One strategy CRNs talked about was facilitating discussions between patients/stakeholders and researchers around shared goals.

4 | DISCUSSION

To our knowledge, this is the first comprehensive scan of engagement activities emerging from a distributed network of large clinical research networks. Focused specifically on governance and infrastructure at the CRN level, results provide evidence that CRNs

participating in PCORnet have developed structures, assets, and services related to engagement. The commitment to engagement, evidenced by the breadth and nature of these activities, is apparent across CRNs and suggests that infrastructure designed specifically to support engagement with patients and other stakeholders is a distinguishing feature of PCORnet. While the engagement of patients in governance was a requirement of PCORI funding for all CRNs, specific tactics including mechanisms, breadth, and intensity were all left to the individual networks to determine. Our analysis revealed that many of the activities documented have shared characteristics. For example, all CRNs include patients on Steering/Oversight Committees as well as in the review/approval process of research projects; maintain either an engagement subcommittee/workgroup or engagement staff dedicated to overseeing their respective engagement strategies; and offer at least one engagement-related service to support external researchers interested in collaborating with the CRN. These approaches are consistent with what has been reported in prior CRNs,[33,34] as well as among the Patient-Powered Research Networks that previously participated in PCORnet.[35,36,37]

Individual CRN engagement models and approaches did vary, likely owing to the diverse settings and populations served by each of these networks. Results suggest that without an explicit roadmap to follow, each CRN was left on its own to invent, adopt, or borrow strategies. For example, we observed varied governance configurations that included patient/stakeholder partner membership reflective of the specific types of assets and services maintained by each CRN. Our findings indicate the observation that there is no singular approach to engagement in research that extends to governance and infrastructure.

Results of this scan indicate an emphasis on both the infrastructure necessary for the incorporation of patients and other stakeholders into network governance and operations and on the processes and nuances required for meaningful engagement. This includes patient/stakeholder and team training, effective recruitment, partnership development, compensation, monitoring and evaluating engagement quality, and building strong relationships. It also includes some of the more intangible, softer skills of creating supportive infrastructures and environments, navigating power dynamics, promoting diversity and inclusion, and generating enthusiasm for engagement. These findings are consistent with several studies examining these factors in the context of research study (vs. network) engagement,[38,39,40,41] including those specifically examining other bodies of work in PCORI's science of engagement portfolio.[42,43] They also highlight two important opportunities for the field at large.

First, time and funding for engagement are two of the most cited barriers impeding researchers in the conduct of engaged PCOR.[39,40,43] Our scan shows that CRN infrastructure to help connect researchers to and foster relationships with patient/stakeholder communities is broadly available. The availability of standing engagement infrastructure, established patient/stakeholder relationships, and formalized consulting services could substantially reduce the time and resource investment needed to meaningfully include these important voices in the research process.

Second, the quantity, diversity, and richness of engagement activity identified among CRNs present an opportunity for the PCORnet

infrastructure to serve as a venue for advancing engagement science as well as PCOR/CER. As with their clinical research, CRNs participating in PCORnet are committed to developing and implementing engagement practices with a strong evidence base. Network Partners have already published work related to their engagement in research on such topics as community engagement studios,[8,9] patient engagement panels,[10] methods for prioritizing research topics,[28,44] citizen scientist programs,[45] and blended research teams.[27] The breadth of research engagement work coupled with the results of the scan showing the range of activities being undertaken to provide engagement infrastructure suggests that PCORnet resources could support research examining the comparative effectiveness of different engagement practices and methodologies as well as strategies for supporting institutional learning and quality improvement. In light of PCORI's recent publication of its National Priorities for Health,[46] which includes the goal of enhancing infrastructure to accelerate PCOR, additional work evaluating and leveraging the rich engagement infrastructure landscape available through CRNs participating in PCORnet could be a powerful contribution to the institute's recently released Research Agenda.[47] The authors note that there are also rich opportunities for cross-learning and collaboration with other initiatives beyond PCORnet, such as the All of Us Research Program (AoURP),[16] that centers on patient/stakeholder engagement in their design and approach. Studies highlighting the comparative effectiveness of engagement infrastructure methods and strategies across diverse initiatives could make important contributions to the evidence base.

This study is not without limitations. These results are limited to CRNs participating in PCORnet with active funding during the project period (June 2020-February 2021) and did not capture the historical experiences of past members, including previously funded CRNs, Health Plan Research Networks, and Patient-Powered Research Networks. This scan did not attempt to capture or evaluate the quality or effectiveness of engagement across CRNs. We acknowledge that the presence of activities does not indicate which activities are more or less effective than others and for what reasons. Rather, this study aimed to lay the foundation for future work focused on evaluating the effectiveness of different engagement approaches undertaken by the networks. We also caution readers that the number of activities discovered within networks should not be interpreted as correlating with engagement investment, intensity, quality, or impact. In addition, while we attempted to be as comprehensive as possible, it is possible that some were missed, so this may not be a complete picture of every engagement-related structure, asset, and/or service currently in operation across the CRNs.

The wider research community has had limited awareness of the range of engagement approaches pursued across governance and infrastructure among the CRNs participating in PCORnet. This limited awareness is a problem, as it impedes the field's ability to learn from and/or leverage the engagement work of the CRNs. The wide selection of activities identified provides rich opportunities for adoption, replication, and/or adaptation based on their strengths, limitations, and acceptability/feasibility in large-scale network contexts. Specifically, this work provides an important resource for research networks,

participating in and external to PCORnet, to explore work across peers, reflect on their own progress, consider opportunities for new engagement activities that leverage work from their peers, and identify others with whom they might collaborate. It also serves to highlight PCORnet as (a) a potential resource for external researchers seeking to conduct engaged PCOR with greater efficiency than has previously been possible, and (b) a prominent resource for advancing the science of engagement.

5 | CONCLUSIONS

The varied approaches that CRNs took to integrate patient and caregiver perspectives into network infrastructure and decision-making provide an opportunity to explore how engagement is developed to meet unique project and partnership needs. While each CRN took a slightly different path to achieve the objectives of patient and stakeholder engagement, common strategies and promising practices emerged. We present a diversity of engagement approaches that were necessarily embedded in a wide range of local and regional contexts. This identification and categorization of engagement strategies provide foundational information that new research networks or multisite research projects could adopt and adapt to inform a successful engagement strategy. Future research assessing their effectiveness should also aim to result in guidance on how best to match engagement strategies with known contextual factors.

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