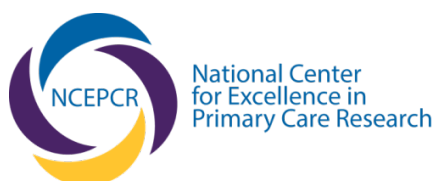


The Agency for Healthcare Research and Quality's Initiative to Identify and Support the Needs of Primary Care Practice- Based Research Networks (PBRNs)

Final PBRN Technical Expert Panel Results

September 2025



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This report was developed by Econometrica, Inc., under contract from the Agency for Healthcare Research and Quality (AHRQ), U.S. Department of Health & Human Services.

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Table of Contents

Preface	iv
Executive Summary	1
1. Introduction	1
1.1. Background	1
1.2. Overview of Contract and Purpose of TEP Engagement	1
2. Methods	2
2.1. TEP Outreach and Recruitment	2
2.2. TEP Meeting Planning and Execution	4
2.3. Post-TEP Meeting Comprehensive Review and Summary	5
3. Results: Key Findings From TEP Meetings	6
3.1. Meeting 1	6
3.2. Meeting 2	10
3.3. Meeting 3	13
3.4. Meeting 4	17
3.5. Meeting 5	19
4. Considerations for Continued Support of PBRNs	21
Appendix A. Outreach Materials	A-1
Appendix B. Selected TEP Members	B-1
Appendix C. New TEP-Led PBRN Resources	C-1

Preface

The Agency for Healthcare Research and Quality's (AHRQ) mission is to enhance the quality, appropriateness, and effectiveness of health services, and access to such services, through the establishment of a broad base of scientific research and through the promotion of improvements in clinical and health system practices, including the prevention of diseases and other health conditions. AHRQ's National Center for Excellence in Primary Care Research (NCEPCR) supports transformative primary care research, develops tools and methods for implementation, and encourages the next generation of primary care researchers to improve the delivery of primary care. As part of this work, NCEPCR has allocated resources to better understand the needs of Practice-based Research Networks (PBRNs) and develop useful resources.

Over the past 25 years, AHRQ has supported PBRNs by providing grants and infrastructure funding and hosting a PBRN resource library. In 2013, AHRQ began providing funding for the North American Primary Care Research Group (NAPCRG) Practice-based Research Network Conference, which offers a platform for PBRNs to share their research successes and learnings as well as network with their peers. In 2023, AHRQ awarded a 2-year contract to Econometrica, Inc., to reinvigorate its support of PBRNs. This report discusses the activities completed through this contract to convene a Technical Expert Panel (TEP) and summarizes the overall findings related to PBRNs' experiences, needs, and areas of support.

Executive Summary

In efforts to identify and support the needs of Practice-based Research Networks (PBRNs), the Agency for Healthcare Research and Quality (AHRQ) allocated resources to convene a Technical Expert Panel (TEP) and develop new PBRN tools and resources. PBRNs leverage the insights and experiences of practicing clinicians by identifying and addressing pertinent research questions while improving access to innovative, evidence-based primary care. The report describes the process of assembling the PBRN TEP, provides the findings from the TEP meetings and offers consideration for AHRQ to continue supporting PBRNs.

The purpose of convening a PBRN TEP was to gain a clear understanding of current PBRN experiences and needs. The TEP met for a total of five meetings between February 2024 and April 2025. To assemble the TEP, a thorough outreach process was developed to ensure adequate PBRN representation. The selected members participated in virtual meetings designed to be mutually beneficial to both AHRQ and the selected PBRNs. In order to keep the TEP engaged with meaningful content, the agenda and content reflected any identified needs throughout the span of the meetings. Each meeting was retrospectively evaluated, and emerging themes were shared with AHRQ.

This report describes the key findings from each meeting. The overall themes identified were that PBRNs believe their work is integral to their communities and that they need support to remain sustainable in their communities. The areas covered through the meetings included [AHRQ PBRN website](#) improvements, collaboration and learning needs, sustainability, and dissemination of tools and resources. The TEP offered valuable input regarding PBRN website improvements, including a sustainability plan for the [PBRN Registry](#). The TEP agreed that the PBRN website and Registry should be kept updated and offered suggestions for target audiences. The TEP provided input on collaboration, including the importance of building long-term infrastructure to support collaboratives. The TEP concluded that PBRNs need support to build successful collaborations and more opportunities to build relationships. The TEP determined that sustainability is complex and that processes are not replicable for every PBRN due to unique organizational and infrastructural factors. Finally, the TEP strategized about the best ways to disseminate PBRN research, including the PBRN synthesis report, so that the greatest impact is achieved. The TEP agreed that the PBRN synthesis report findings should be disseminated to a broad audience. The TEP concluded with final suggestions of ways they can continue to support other PBRNs as well as future considerations for AHRQ's support.

1. Introduction

1.1. Background

Practice-based Research Networks (PBRNs) are groups of ambulatory care practices “devoted principally to the primary care of patients and affiliated in their mission to investigate questions related to community-based practice and to improve the quality of primary care.”¹ The Agency for Healthcare Research and Quality (AHRQ) has supported PBRNs over the past 25 years through grants and infrastructure funding, hosting a resource library website ([PBRN website](#)) and [Registry](#) for PBRNs, and providing funding for the annual North American Primary Care Research Group (NAPCRG) [Practice-based Research Network Conference](#). Since 2022, AHRQ’s NCEPCR has served as the home for PBRNs, providing resources for PBRNs and managing a listserv for the PBRN community. Recognizing the need to update the offerings to the PBRN community, in 2023, AHRQ’s National Center for Excellence in Primary Care Research (NCEPCR) allocated resources to identify and support the needs of PBRNs by conducting a Technical Expert Panel (TEP) and renovating needed tools and reference materials.

1.2. Overview of Contract and Purpose of TEP Engagement

Contract Overview

In 2023, AHRQ awarded a 2-year contract to Econometrica, Inc., to undertake an initiative to identify and support the needs of PBRNs. The contract consisted of the following primary tasks:

- Convene a TEP to identify areas of need for PBRNs and gather feedback to improve AHRQ’s web-based resources.
- Update the [PBRN Registry](#) and develop a sustainability plan for continued maintenance.
- Conduct an environmental scan to gather PBRN research, tools, and resources from the past 10 years. As a result of the scan:
 - a. Develop the ***Primary Care Practice-Based Research Networks and Publications, 2014–2023: Synthesis Report*** to describe the landscape of primary care PBRN research and publications over the past 10 years and demonstrate the impact of primary care PBRNs through publications.
 - b. Write a scientific manuscript for publication based on elements of the synthesis report: ***A Decade in Review: Scan of Primary Care Practice-Based Research Network Publications (2014–2023)***.
- Develop a three-part [PBRN Learning Series](#) that consists of two recorded webinars and a self-paced e-learning course to support and promote the work of PBRNs.

¹ Agency for Healthcare Research and Quality. (2013, July). *Primary Care Practice-Based Research Networks (PBRN)*. <https://www.ahrq.gov/professionals/prevention-chronic-care/improve/pbrn/index.html>

Purpose of the TEP

The purpose of the TEP was to engage the primary care PBRN community to get a better understanding of PBRN needs and develop useful tools and resources. Specifically, AHRQ wanted to gather feedback on how to update and improve the content and functionality of the [PBRN website](#) and [Registry](#) and develop a learning series based on the current educational needs of PBRNs. The TEP meetings were intentionally designed to provide feedback on these items, as well as the environmental scan and manuscript as described above.

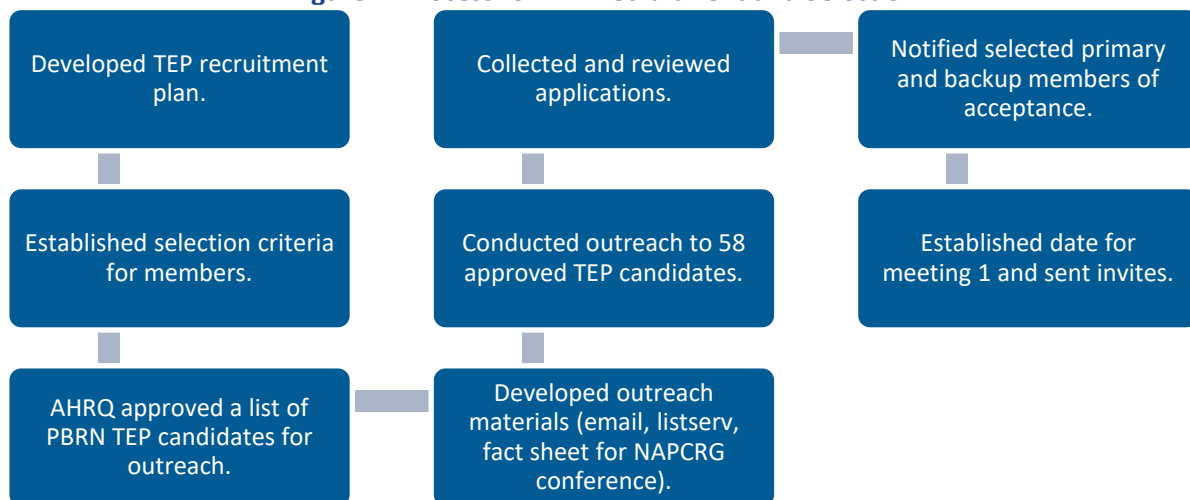
This report describes the activities completed to recruit the TEP and plan and execute five TEP meetings. It also outlines key findings from the five PBRN TEP meetings. At the end of this report, we provide considerations that AHRQ may reflect on for its continuation of PBRN support.

2. Methods

2.1. TEP Outreach and Recruitment

To ensure that the PBRN TEP included members with a variety of experiences and perspectives and from a diverse group of PBRNs, we created a structured recruitment process. The process included an assortment of recruitment materials and outreach techniques to ensure that we reached a wide PBRN audience. This section describes each step conducted during the outreach recruitment process, from developing the recruitment plan to sending the first meeting invites. Figure 1 provides a high-level overview of the process followed to establish the PBRN TEP.

Figure 1. Process for TEP Recruitment and Selection



TEP Recruitment Plan. Before the official launch of TEP outreach and recruitment efforts, we first established the TEP’s objectives, goals, TEP selection criteria, and outreach and recruitment strategies, which are outlined in Appendix A.

TEP Member Selection. TEP selection criteria were developed to ensure a representative group of PBRN TEP members. The selection criteria included:

- Be currently affiliated with a PBRN, with a minimum of 1 year of experience at a PBRN.
- Be currently engaged in research and/or practice at PBRN.
- Be available to participate in at least two TEP sessions, each lasting approximately 4 to 5 hours.
- Have a history of publication of findings within the past 10 years (preferred but not required).

AHRQ Approved a List of PBRN TEP Candidates for Outreach. A list of TEP candidates for direct email outreach was developed using the [Registry](#) and AHRQ connections for approval by AHRQ.

Developed Outreach Materials. Outreach materials (see Appendix A) included a listserv announcement providing notice of upcoming outreach for PBRN TEP recruitment; targeted recruitment emails to approved candidates; and a PBRN TEP fact sheet outlining the TEP’s goals, criteria, and recruitment information. This flyer was distributed at the NAPCRG PBRN conference.

Figure 2. Approved Outreach Materials

Listserv	Targeted Emails	PBRN TEP Fact Sheet
Approved announcement posted on the PBRN one-way listserv.	Two email attempts for recruitment of AHRQ-approved candidates for outreach.	A fact sheet and QR code were made available for distribution at the PBRN conference in October 2023.

TEP Outreach. Following the listserv announcement and advertising at the PBRN conference, targeted recruitment emails were sent out to 58 approved candidates. Interested applicants replied to emails and were provided with the TEP application link.

Applications. In order to assemble a representative group, the TEP application included 16 questions to collect information about each TEP member applicant and their PBRN. Answers were obtained through Microsoft Forms, and applications were collected and reviewed by AHRQ. The questions can be found in Appendix A, along with the other outreach materials. Participants who attended at least one meeting are listed in Appendix B.

Notification of TEP Acceptance. Thirty-four applications were received with attached curricula vitae (CVs). Each applicant was reviewed against the selection criteria established to create a diverse TEP. In total, 20 primary members and 12 backup members were selected for participation (see Appendix B). The two applications that were not accepted did not meet the criteria of being actively engaged with a PBRN.

Meeting 1 Date Established. Chosen participants were notified via email, and tentative meeting dates for participation were shared. A date for the first meeting was established, and all primary

participants were invited. Primary participants were given the opportunity to delegate a team member to attend in their absence for the first meeting.

2.2. TEP Meeting Planning and Execution

Executing the virtual TEP meetings involved careful planning and coordination to ensure that the meetings elicited the feedback needed to meet the goals set by AHRQ, as well as to provide the TEP members with an enriching experience of collaborating, solutioning, and networking. For these reasons, the first TEP meeting served as a platform to introduce the TEP members and AHRQ and to establish TEP member goals.

Planning. Prior to each meeting, the overall plan and agenda were revisited and updated to align with AHRQ's goals before developing the detailed meeting agenda. Meeting objectives were created and refined to ensure that AHRQ and the TEP members were experiencing mutually beneficial meetings. An AHRQ-approved agenda and accompanying slide deck were developed prior to each meeting and shared with all attendees.

Pre-Work and Post-Work. Any pre-work or post-work was sent to the TEP members in between each scheduled meeting. Pre-work was used to prepare for the next meeting, and post-work was for follow-up to the previous meeting. Pre- and post-work were optional and consisted of a variety of materials, including Word documents, Microsoft Forms, PowerPoint decks, and email communications. Participants were sent at least one reminder to complete each assignment. At the start of each TEP meeting, attendees were asked to participate in a poll asking whether they were able to complete the pre-work. For all meetings, at least half of the participants were able to complete the pre-work. Pre- and/or post-work for each meeting is described in Section 3.

Meeting Invites. Once the date, time, and general attendance of each meeting was established, a Zoom meeting invitation was sent to the TEP at least 1 month prior to the date, followed by reminders to RSVP at 2 weeks and 1 week. The virtual meetings were designed to last from 4 to 5 hours, taking time zones, dates, and general availability into account. The meetings required attendance by a minimum of 12 TEP members. Anticipated attendance was provided to AHRQ 1 week prior to each meeting.

Meeting Execution. Each Zoom meeting followed a scheduled agenda of presentations, activities, facilitated group discussions, and small-group conversations. The facilitators kept the group engaged using an array of techniques, including the trading off of facilitators, an interactive whiteboard (Mural), polls, breakout rooms, and TEP member presentations. All meetings were recorded and transcribed using Zoom transcription and manual examination for AHRQ review. At the conclusion of each meeting, TEP members were given time to network and have unstructured conversations with one another. Figure 3 outlines the techniques used to keep the TEP members engaged in each meeting.

Figure 3. Meeting Engagement Techniques



2.3. Post-TEP Meeting Comprehensive Review and Summary

Meeting Summaries. Within 6 weeks of each meeting, a summary of the key takeaways and discussion points was developed and submitted to AHRQ. These summaries also included a meeting transcription for AHRQ to reference. Summaries were then provided to TEP members via email 2 to 3 weeks prior to the next meeting. As part of pre-work for the next meeting, members were asked to review and provide any feedback.

Midpoint Review. Following the third TEP meeting, a comprehensive review and update of the highlights and key takeaways was conducted to ensure that the final two TEP meetings addressed the issues important to the TEP. Based on the review, a decision was made to create a series of TEP outcome products, which are highlighted in Section 3. The outcome products, or new resources for PBRNs, were a direct result of the TEP members' identification of resource needs, desire for additional resources, and their willingness to be active in the development. Meeting 4 was subsequently adapted to include these documents during the meeting, along with pre- and post-work.

Meeting Feedback. In the last 5 to 10 minutes of each meeting, the TEP was asked to complete an exit assessment in Microsoft Forms that was used to gather information about what was going well and what needed to be improved for future meetings. These exit surveys were provided via a QR code embedded in the slides as well as a direct link provided in the chat during the meeting, and they were left open for approximately 1 day after the meeting. The overall feedback was positive after each meeting, with comments mentioning that the format was engaging and the content was relevant. Recommendations included improvements such as taking down the slideshow during discussions to encourage face-to-face interactions and scheduling breaks that make sense for the different time zones.

3. Results: Key Findings From TEP Meetings

This section presents the main findings of each of the TEP meetings as related to the established focus and objectives. For each meeting, we provide the key meeting information, a meeting summary, and completed actions. Table 1 provides the established meeting objectives for the five TEP meetings.

Table 1. TEP Meeting Objectives

TEP Meeting	Date	Meeting Objectives
TEP 1	2/13/2024	<ul style="list-style-type: none">Establish overall goals for the TEP.Elicit feedback from the TEP regarding the current content and functionality of the PBRN website and PBRN Registry.
TEP 2	5/16/2024	<ul style="list-style-type: none">Build collaboration among PBRNs and between PBRNs and other entities.Identify learning and training needs of PBRNs and whether/how to update existing curricula.Increase awareness of PBRNs on the PBRN environmental scan.
TEP 3	8/14/2024	<ul style="list-style-type: none">Identify a set of best practices for PBRNs in addressing Institutional Review Board (IRB) challenges (TEP-identified topic).Develop recommendations for PBRNs to become operationally sustainable.Identify ways to increase awareness of webinars and e-learning.
TEP 4	3/26/2025	<ul style="list-style-type: none">Elicit feedback about new draft resources that resulted from prior TEP meetings to improve and finalize these products and discuss a dissemination strategy.Obtain feedback and recommendations about the PBRN synthesis report findings to inform the report recommendations and the manuscript.
TEP 5	4/30/2025	<ul style="list-style-type: none">Elicit input from the TEP regarding actionable items for PBRN website content and design, learning/training, and collaboration.Finalize input regarding the dissemination of current and future tools, resources, and research relevant to and/or produced by PBRNs.

3.1. Meeting 1

The first TEP meeting focused on providing an overview of the TEP's purpose and established goals, as well as on obtaining feedback regarding the PBRN website content, resources, and functionality and PBRN Registry improvements. TEP members were asked to assess current PBRN tools and resources hosted on the PBRN website and to recommend useful enhancements. The meeting also included brainstorming webinar topics. Table 2 outlines further details about meeting 1.

Table 2. Meeting 1: Key Information

Meeting 1: Key Information	
Date	February 13, 2024
Objective(s)	<ul style="list-style-type: none">Establish overall goals for the TEP.Elicit feedback from the TEP regarding the current content and functionality of the PBRN website and PBRN Registry.

Meeting 1: Key Information	
Pre- and Post-Work	Complete a questionnaire with items regarding PBRN website use and feedback.
Summary of Findings	<p>The TEP agreed that the PBRN website and Registry should be kept updated. The members offered insight into how the PBRN website and Registry can be enhanced for use by PBRNs:</p> <ul style="list-style-type: none"> • More up-to-date resources specific to PBRN needs and an updated Registry would be the most beneficial improvements. • Potential useful PBRN tools and resources should consider multiple audiences, as should the learning series; consider including new PBRNs, established PBRNs, primary care clinicians/practices, the public/patients, policymakers, funders, and health system leaders.
Completed Follow-Up Actions	<ul style="list-style-type: none"> • Enhancements were made to the Registry and PBRN website to improve content and functionality. • The TEP input was used to inform the development of the PBRN webinars and e-learning.
Next Steps	For further enhancements to the Registry, consideration should be given to including the addition of a “last updated” date field, an option for “rural” in the geographic coverage field, definitions for differences between the geographic coverage options, and information or links to patient or community advisory boards.

Summary of Meeting 1

As part of an overarching goal to ensure that member challenges and barriers aligned with planned TEP discussions, TEP members were asked to share general barriers and challenges impacting their ability to succeed in various aspects of their work. The members shared that their main challenges were funding, infrastructure, networking, marketing, turnover, and learning.

The TEP was asked to specifically discuss their experiences with the AHRQ PBRN website and Registry. In preparation for this discussion, the meeting’s pre-work included a questionnaire about PBRN website usage, with 86 percent of respondents reporting that they rarely or never access the website. Once the results were shared, time was used to better understand the TEP panelists’ website challenges and barriers to access, which included outdated reports and nonapplicable information on the PBRN website and Registry. A sample of comments from TEP members is provided below.

The TEP concluded that the PBRN website would be most useful to their PBRNs if it contained updated resources and an updated Registry. They also agreed that the PBRN website would be most beneficial for reaching audiences beyond PBRNs themselves, such as policymakers. The TEP discussed potential useful PBRN tools and resources, with a focus on considering multiple audiences, including new PBRNs, existing PBRNs, the public, policymakers, funders, and health system leaders. TEP members agreed that it is important to tailor the information and resources on the website to specific audiences, as they all have differing roles, interests, and understandings of PBRNs that can influence policy, funding, participation in PBRNs, and more. Key takeaways from the discussions are outlined in Table 3.

The TEP was asked to provide input regarding the learning series and identify topics that would be beneficial for PBRNs. They discussed the needs of newer versus established PBRNs and

identified some of those differing needs. Multiple TEP members agreed on the benefits of having resources to help establish PBRNs and detailed instructions for setting up a new PBRN. One TEP member expressed that template agreements for research sites would be a valuable resource. Multiple members concluded that an active PBRN website that provides updates on recent publications, grant opportunities, and other PBRN-related resources and collaborations would be ideal. A sample of comments from TEP members is provided below:

- **AHRQ PBRN Website Discussion:**
 - “Need pictures/icons, not just all words.”
 - “Need better marketing of the usefulness of it.”
 - “Seems mainly historical and not designed as a resource for tools.”
 - “Inform PBRNs of events, webinars, collaborations of PBRNs, etc.”
 - “Links to other sites outside of AHRQ.”
- **PBRN Registry Discussion:**
 - “Update profile information.”
 - “Map search function that shows PRBNs.”
 - “FAQ sheet.”
 - “Highlight research findings possible because of PBRNs.”
- **Learning Series Topic Brainstorm:**
 - “Resources for new PBRNs.”
 - “Different models of PBRN and governance structure.”
 - “Engaging under-resourced practices in research.”
 - “Conducting PBRN research with limited practice impact/burden.”
 - “How PBRNs can collaborate and resources that would support such collaboration.”
 - “Panel of different ways to support PBRN infrastructure.”
 - “How to diversify funding.”
 - “How PBRNs can improve clinical trial work.”
 - “How PBRNs can support workforce redesign/primary care survival/implementation science — more directed to health systems/institutions.”

Table 3. Key Takeaways from Meeting 1 Discussions

Key Takeaway	Opportunities to Support PBRNs
AHRQ PBRN Website	
Historical information should be reviewed.	<ul style="list-style-type: none"> ● The TEP reported that the PBRN website contains a lot of historical information. ● They agreed that while history is useful, the website should focus on useful resources. ● The historical information should be updated to emphasize why PBRNs are valuable and how PBRNs meet AHRQ’s primary care agenda.
Functional enhancements are needed.	<ul style="list-style-type: none"> ● The TEP would like to see more PBRN tools and resources. ● They would like to see the web pages look more balanced and more focused on categories and resources. ● Suggestions on improving the functionality of the PBRN website included the addition of easy features to search the website, splash pages, vignettes to illustrate things, and inclusion of more pictures and less text-heavy material.

Key Takeaway	Opportunities to Support PBRNs
Tools and resources are insufficient.	<ul style="list-style-type: none"> The TEP discussed ideas such as access or links to funding opportunities, more opportunities to be engaged, and inclusion of resources such as a frequently asked questions (FAQ) document.
AHRQ PBRN Registry	
General improvements should be made.	<ul style="list-style-type: none"> The general request was to simplify the Registry. Make the Registry useful to non-PBRNs as well. The group agreed that there are multiple people who can benefit from learning about PBRNs through the PBRN website, and this can have potential for policymakers to drive funding opportunities.
A sustainability plan is necessary.	<ul style="list-style-type: none"> The TEP discussed that a sustainability plan could include yearly reminders to update Registry listings and a portal where PBRNs could self-update their listing.
Needs Specific to Newer PBRNs	
General AHRQ PBRN website updates would be helpful.	<ul style="list-style-type: none"> New PBRNs would like a website that is clear and engaging, saying that the website is text-heavy and not user-friendly. They agreed that the general updates would allow the website to be easier to navigate and more useful for new PBRNs.
Website content can be enhanced.	<ul style="list-style-type: none"> The group identified many tools and resources, including template agreements with sites, memoranda of understanding (MOUs) with larger participating sites, starter toolkits, webinars, peer-to-peer guidance, and a community function board for collaboration and questions.
Tools and Resources	
A wide variety of audiences should be considered.	<p>The following target audiences were discussed:</p> <ul style="list-style-type: none"> The public, including information about why PBRNs are important to their healthcare. Other researchers. New PBRNs. Existing PBRNs. Policymakers (State-level, public health officials, payers, institutional leaders). Students/trainees and new/junior investigators. Practices. Patients/community (more on-the-ground than public audience). Funders (e.g., nonprofits, other non-AHRQ Federal agencies). Health system leaders.
Tools and resources to consider.	<p>The following ideas for resources were discussed:</p> <ul style="list-style-type: none"> IRB information specific to the PBRN experience. TED Talks for PBRNs. FAQ.

Completed Follow-Up Actions From Meeting 1

Substantial updates were made to both the PBRN website and Registry, including improving the overall look and functionality of design elements. TEP members provided a significant amount of insight and feedback for items related to improvement of the Registry, much of which is reflected in the current updated version. The Registry was updated using targeted outreach to confirm and revise information for active registered PBRNs throughout the United States. The fields and search tools were simplified to improve navigation. Online registration and updated forms were made available for PBRNs to ensure that their information remains accurate. Additionally, the

[PBRN Registry Map](#) was also updated based on newly updated Registry data. A sustainability plan was developed that includes recommended guidance and actions for conducting future Registry outreach and maintenance. The TEP was used to inform AHRQ of desired features and enhancements for the Registry.

The following enhancements were made to the Registry:

- Updates to listings and contact information available within the Registry.
- Enhanced search function using keywords.
- Simple registration and update forms available online.
- Updated [PBRN Registry Map](#).
- A sustainability plan for future updates.

TEP members made further suggestions for future Registry enhancements, including the addition of a “last updated” date field, an option for “rural” within the geographic coverage field, definitions for differences between the geographic coverage options, and information or links to patient or community advisory boards.

Finally, input from the TEP was used to inform the content of the learning series, which included two webinars and an e-learning course. The TEP provided ideas regarding topics important to PBRNs and where gaps in learning existed. Additionally, some TEP members participated in providing content for the series.

3.2. Meeting 2

The second TEP meeting, divided into two segments, focused on collaboration between/among PBRNs and other relevant entities and on training or learning needs of PBRNs. In the first half of the meeting, a TEP member provided a presentation on how to build collaboration among PBRNs and between PBRNs and other entities, which focused on discussing types of partnerships and identifying and addressing the barriers for successful partnerships. The second part of the meeting sought to understand existing training and desired training for PBRNs, including shared learning experiences between PBRNs and their collaborators. Table 4 outlines further details about meeting 2.

Table 4. Meeting 2: Key Information

Meeting 2: Key Information	
Date	May 16, 2024
Objective(s)	<ul style="list-style-type: none">• Build collaboration among PBRNs and between PBRNs and other entities.• Identify learning and training needs of PBRNs and whether/how to update existing curricula.• Increase awareness of PBRNs on the PBRN environmental scan.
Additional Activity	Discuss the environmental scan being conducted.
Pre- and Post-Work	Review the draft agenda, review the TEP meeting 1 summary, and answer questions about webinar/Registry.

Meeting 2: Key Information	
Summary of Findings	<ul style="list-style-type: none"> • The TEP discussed the elements needed to build collaboration among PBRNs. Building long-term infrastructure to support collaboratives is a priority for PBRNs. • PBRNs have challenges working with their IRBs, which increases their burden. • The TEP provided input on the learning needs of PBRNs and the type of support they need from meaningful tools and resources. • PBRNs need support for communication and connections. • PBRNs want more learning and educational opportunities to be made available to them and their collaborators.
Completed Follow-Up Actions	The agenda for meeting 3 was adjusted to include time to further discuss IRB challenges and solutions.
Proposed Next Steps	<p>Consider ways that AHRQ can support efforts to improve collaboration, with a goal of enhancing PBRN and non-PBRN networking and relationships. Specific areas of support mentioned by the TEP include:</p> <ul style="list-style-type: none"> • Providing resources and funding for PBRNs to create and maintain policies for collaboration, including with non-PBRN collaborators. • Continuing to facilitate discussions about TEP challenges regarding IRBs. • Helping develop a learning community for PBRNs.

Summary of Meeting 2

The TEP was asked to discuss how their PBRNs build collaborations with other PBRNs and the challenges faced during the process. The TEP offered several thoughts about the elements needed to build collaboration among PBRNs, noting that work is needed to build long-term infrastructure to support collaboratives, including resources like standing MOUs and Data Use Agreements (DUAs). More specifically, the TEP chose to discuss IRB processes and identified challenges about IRB approval as a major hurdle for PBRNs, including internal/external confusion and inconsistencies. Panelists reported that their institutions do not have established policies/procedures for collaboration, highlighting financial constraints that limit internal abilities.

The TEP member presentation covered the history of PBRN collaboration, its key elements, and examples of successful multi-PBRN projects, concluding that there needs to be a reason for collaboration and that PBRNs should aim to have working relationships across networks. The TEP also discussed successes and challenges with non-PBRN collaborators, such as academic institutions and potential funders. Other areas of the discussion included:

- PBRNs would like to be engaged in the development of grants.
- Collaboration with Clinical and Translational Science Awards (CTSAs) is critical for sustainability to understand the value and interests of individuals in a research capacity. This collaboration also allows for shared resources and institutional support for staff.
- Relationships with academic centers and small community hospitals vary and can be improved, highlighting that large institutions often have more administrative hurdles.

The TEP also discussed that learning/training should be inclusive and relevant to anyone involved in PBRN research. Examples include types of research being conducted, best practices, and basics of grant writing. Highlights from the learning and training dialogue include the following:

- Community practices struggle with clinician burnout, and training should take that into consideration. Physician-focused training should be centered around data and research.
- A TEP member shared that, in their experience, it can take more than 12 months to train an experienced researcher to become qualified in primary care PBRN research.
- Training needs to include specific materials for principal investigators and information about early involvement and how to engage with PBRNs.

The TEP also discussed learning and resources for PBRNs, and there was agreement that this area needed improvement, including shared learning and resources among PBRNs. Table 5 provides specific information from the discussions about collaboration and learning, including ways AHRQ might help improve them.

Table 5. Key Takeaways From Collaboration and Learning Discussions

Key Takeaway	Ways AHRQ Can Help
Collaboration	
PBRNs do not have set policies in place regarding collaboration.	<ul style="list-style-type: none"> • Resources and funding would be necessary for PBRNs to create and maintain collaboration policies. • Non-PBRN collaborators would benefit from more outreach and education regarding PBRNs. The TEP specifically discussed academic institutions and potential funders as needing increased outreach and education about PBRNs. It would be beneficial for the TEP to discuss this topic in greater depth.
Efforts to enhance PBRN and non-PBRN networking and relationships can improve collaboration.	<p>Opportunities to connect PBRNs for collaboration:</p> <ul style="list-style-type: none"> • Keep the Registry up to date so it can be used to find PBRNs with similar interests (but this can be burdensome for PBRNs to individually maintain). • Continue supporting conferences, where many collaborations informally begin. • Continue to support PBRNs by offering opportunities to connect with each other and build trust. • Provide education to funders and external investigators about PBRNs. • Provide collaboration opportunities and status updates to PBRNs through a listserv, community board, social media platforms, or website. • Establish a control center that helps connect PBRNs for collaboration. • Support ways to simplify data-sharing among PBRNs. • Find ways to involve PBRNs more in grant writing.

Key Takeaway	Ways AHRQ Can Help
Learning	
PBRNs do not believe there is enough education available for them.	<p>Education is needed for individual roles as well as for specific projects. Learning community ideas include:</p> <ul style="list-style-type: none"> • Create a community chat board for discussing ideas and troubleshooting. • Connect PBRNs with similar interests, and support the development of a central collaboration center that provides outreach efforts, including blast messages and coordination of in-person events. • Share non-AHRQ educational opportunities with PBRNs. <p>The TEP mentioned that educational resources, including webinars or TED Talks, to PBRNs and stakeholders would be helpful. Educational topics can include:</p> <ul style="list-style-type: none"> • Study types. • Grant writing. • Role-specific education. • Best practices for PBRNs. • Guidance for non-primary care researchers (e.g., a list of do's and don'ts), prior to them reaching out to primary care providers.

Completed Follow-Up Actions From Meeting 2

As a response to the TEP's interest in discussing IRB challenges, the agenda and objectives for meeting 3 were adjusted to include the topic of IRBs, allowing the panelists time to discuss it further.

3.3. Meeting 3

The third TEP meeting was reserved for topics identified in previous TEP meetings and for continued assessment of PBRN resource needs, including sustainability and funding. During the third meeting, the TEP members were tasked with discussing their individual PBRN resource needs, with a focus on how they remain sustainable and secure funding for infrastructure. They were asked to share tips and strategies for sustainability, including business models and strategic planning. The meeting also included a TEP-driven focus on IRBs, as this was brought up by the TEP during the first two meetings. Time was allocated for further discussion of IRB challenges and how the TEP can address those challenges during their time together. The TEP concluded that PBRNs need assistance with building partnerships for non-Federal infrastructure funding, and PBRNs need continued engagement with AHRQ as their resource needs evolve. Table 6 outlines further details about meeting 3.

Table 6. Meeting 3: Key Information

Meeting 3: Key Information	
Date	August 14, 2024
Objective(s)	<ul style="list-style-type: none"> • Identify a set of best practices for PBRNs in addressing IRB challenges (TEP-identified topic). • Develop recommendations for PBRNs to become operationally sustainable.
Additional Activity	Identify ways to increase awareness of webinars and e-learning.
Pre- and Post-Work	Review the draft agenda, review the TEP meeting 2 summary, and complete a questionnaire to provide input about the IRB experience.

Meeting 3: Key Information	
Summary of Findings	<ul style="list-style-type: none"> • The TEP-identified topic of IRBs was discussed in a solutioning session, with members sharing tips and strategies. IRB processes vary among sites and continue to be a challenge for PBRNs, and PBRNs could benefit from sharing ideas. • A review of the Common Rule was provided to ensure that the panelists were current on Federal policy for protection of human subjects in research. • The TEP offered significant insight into the challenges and barriers for sustainability. TEP members discussed operational sustainability and its complexity, as processes are not replicable at every PBRN due to unique organizational factors. Sustainability requires people, time, and money, which are often in limited supply.
Completed Follow-Up Actions	A comprehensive review of the key takeaways was completed following meeting 3, leading to the decision to use the TEP's input to create new PBRN resources for dissemination.
Next Steps	<p>Based on TEP input, a valuable tool for PBRNs would be the creation of a control center where PBRNs can interact and ask each other questions, which could help PBRNs address challenges like IRB approval.</p> <p>Additional support actions for AHRQ to consider:</p> <ul style="list-style-type: none"> • Support the sharing of tips and strategies among PBRNs. • Provide more resources that PBRNs can use for marketing, such as the environmental scan synthesis report, highlighting PBRN impact on healthcare and their communities. • Support business model strategies and share adaptations to remain sustainable based on TEP input that marketing PBRNs is essential for sustainability.

Summary of Meeting 3

TEP members were asked to discuss their challenges in working with IRBs for approval. They reported that PBRNs face both internal and external challenges when working with IRBs, which can impact their ability to start research in a timely manner. The discussion around IRBs turned into a solutioning session, with TEP members offering advice and strategies to one another. Topics covered included:

- Identification of an appropriate IRB.
- Understanding of IRB requirements.
- Training for PBRNs on submitting materials to IRBs.
- Unique PBRN challenges associated with obtaining IRB approval.
- Communication with IRBs.

To begin the discussion, the TEP was given a review of IRB regulations from the Common Rule. The TEP emphasized the importance of PBRNs supporting each other to build processes that enhance IRB approval experiences. With the support of AHRQ for dissemination, the TEP was interested in sharing its IRB tips with a larger audience. The TEP members were also asked to discuss sustainability and their unique challenges in remaining sustainable, which led to the sharing of common experiences and hindrances to sustainability. Table 7 outlines the challenges and barriers discussed.

Table 7. TEP Input on Sustainability Barriers and Challenges

Sustainability Topic	Sustainability Barriers and Challenges
Lack of Infrastructure Funding/Protective Time	<ul style="list-style-type: none"> • Lack of infrastructure funding and protected time is a key barrier that directly impacts all other sustainability challenges.

Sustainability Topic	Sustainability Barriers and Challenges
Recruitment and Growth	<ul style="list-style-type: none"> • Inability to develop infrastructure early to support ongoing development activities. • Inability to allocate time and funding to support PBRN member recruitment and engagement, and a lack of time and availability from clinical practices to engage in PBRN research. • High clinic turnover, which challenges PBRNs to keep clinics engaged, as increasing membership is difficult when so much effort is required to maintain the existing membership. • Community engagement activities—like phone calls, newsletters, and outreach—often cannot be covered by grants and add to overall costs.
Data Management	<ul style="list-style-type: none"> • Lack of understanding of the work PBRNs do by biostatisticians and data analysts. • The level of technical expertise needed by PBRNs for data cleaning, analysis, and management (e.g., extracting data from small practices can be difficult because they often have different systems). • Navigation of challenges when working with various electronic health records (EHRs), including the constant challenge of data extraction across settings. Health information exchanges can be helpful. • Challenges in creating processes for regularly updating data on practices, especially when health systems add practices.
Strategic Planning	<ul style="list-style-type: none"> • Commercialization of primary care practices, which has impacted the ability of PBRNs to engage them in research • Leadership not always matching its vision with research, which is especially challenging because research can be a burden on primary care practices.
Study Development and Implementation	<ul style="list-style-type: none"> • Engaging practices early enough in the grant process to identify appropriate funding for research and to conduct research that is beneficial to practices and supports the needs of their patient populations. • Lack of understanding about the importance of PBRNs. Funding does not support the effort it takes to sustain ongoing communication with sites, including in-person visits.

The TEP determined that sustaining a PBRN is complex and that processes are not replicable at every PBRN due to unique organizational and infrastructural factors. Sustainability requires people, time, and money, which are in limited supply. In addition, member engagement, common goals, and protected time are essential to building a path forward for PBRNs. The TEP offered activities that may be beneficial to share with PBRNs for sustainability efforts. Multiple funding sources are available to PBRNs besides typical grants and academic funding, but they require resources (e.g., research and time) to be accessible. Marketing and outreach are essential to building relationships. Most importantly, PBRNs need more support from their own administrations to remain sustainable. The TEP suggested that PBRNs should:

- Work to match institutional leadership goals.
- Focus on building strategic relationships and improving communication.
- Continue to market themselves to their own institutions and offer creative solutions, such as endowments.

Table 8 includes the TEP's ideas for activities that support PBRN sustainability.

Table 8. TEP Input on PBRN Sustainability and Supporting Activities

Sustainability Topic	Sustainability Opportunities and Activities for PBRNs
Administrative Support	<ul style="list-style-type: none"> PBRNs should prioritize gaining support from professional or administrative leadership. They should work to align with institutional goals and demonstrate their value to the organization.
Strategic Relationships	<ul style="list-style-type: none"> Build strategic relationships with entities such as the Clinical and Translational Research Network (CTRN), CTSA, university departments, State health departments, and other State organizations. Identify and attend regular convening activities, such as local professional society meetings.
Engagement in CARD Studies	<ul style="list-style-type: none"> A CARD study is a low-cost and low-burden study used to identify shared research interests informed by the prevalence of conditions in the practice patient population. This rapid-feedback study can be used to emphasize the value PBRN research can bring to the practice, thereby supporting recruitment efforts.
Communication of Needs	<ul style="list-style-type: none"> PBRNs need to identify and communicate the research needs of clinical practices to set proper expectations. PBRNs can also voice their need for administrative funding in research grants.
Match Institutional Leadership Goals	<ul style="list-style-type: none"> Changes in leadership's goals and initiatives can reduce their support. PBRNs should try to find ways to engage in research that is mutually beneficial to leadership and the PBRN. Demonstrate value to the larger organizations. Be inventive and find creative ways to engage and activate large health system leadership.
Marketing and Outreach	<ul style="list-style-type: none"> PBRNs should diversify their research portfolios. PBRNs should have individual grant-funded projects. Tie specialized research (e.g., cancer research) to other types of research. PBRNs with a narrow focus can align it with other research and develop a reputation for their specialty that is well supported by partners. Have a "face" that collaborators associate with research, such as an official network coordinator or manager. Develop creative strategies to find the face of the PBRN. Finding someone in the institution who already has ties to community outreach can be a way to get this started. Develop a marketable service that the PBRN can provide.

Completed Follow-Up Actions From Meeting 3

A comprehensive review of the key takeaways was completed following meeting 3, leading to the decision to use the TEP's input to create new PBRN resources. This decision was based on consistent feedback that the TEP was eager to provide more resources and tools to their PBRN community. The following TEP outcome products were agreed upon:

- **IRB Tip Sheet:** A Section 508 compliant PDF disseminated by AHRQ as a peer-to-peer support document.
- **PBRN Impact Profile mock-up:** A Section 508 compliant PDF to be used for highlighting individual PBRN work to increase recognition and enhance networking.
- **PBRN FAQ:** Allot time in future TEP meetings to discuss the target audience and focus of a PBRN FAQ for future development, a plan for which would be provided to AHRQ for future consideration.

3.4. Meeting 4

Meeting 4 served as a forum to discuss newly produced drafts of the TEP-led PBRN resources as well as dissemination of existing and new PBRN research, tools, and resources. The TEP also strategized the best ways to disseminate PBRN research, including the PBRN synthesis report, to achieve the greatest impact. The TEP agreed that the PBRN synthesis report's findings should be disseminated to a broad audience. Table 9 outlines further details about meeting 4.

Table 9. Meeting 4: Key Information

Meeting 4: Key Information	
Date	March 26, 2025
Objective(s)	<ul style="list-style-type: none">• Elicit feedback about new draft resources that resulted from prior TEP meetings to improve and finalize these products, and discuss a dissemination strategy.• Obtain feedback and recommendations about the PBRN synthesis report's findings to inform the report recommendations and the manuscript.
Additional Activity	Review of proposed FAQ document.
Pre- and Post-Work	Review IRB Tip Sheet and complete MS Forms questionnaire for FAQ document.
Summary of Findings	<ul style="list-style-type: none">• The TEP discussed how the synthesis report can be used by AHRQ and PBRNs to continue to validate the impact of PBRN research. Capturing PBRN impact is the main challenge to making the PBRN synthesis report's findings the most impactful.• The TEP provided input and feedback related to the three outcome documents: PBRN IRB Tip Sheet, PBRN Impact Profiles, and FAQ document. The TEP supported the finalization of the documents for publication on the PBRN website.
Completed Follow-Up Actions	<ul style="list-style-type: none">• Pilot PBRN Impact Profiles were developed and made Section 508 compliant for display on the PBRN website.• A PBRN IRB Tip Sheet was completed and made Section 508 compliant for posting on the PBRN website.• An outline for a PBRN FAQ was developed using the TEP's input.
Next Steps	<p>The following platforms were discussed for dissemination of the PBRN synthesis results:</p> <ul style="list-style-type: none">• Annual NAPCRG conference or Society of General Internal Medicine (SGIM) meeting.• AcademyHealth Conference on the Science of Dissemination and Implementation in Health.• Association for Clinical and Translational Science (ACTS) or CTSA conference.• Fact sheet for large-scale dissemination at conferences or through the listserv.

Summary of Meeting 4

The TEP was asked to discuss the challenges of making the synthesis report's findings impactful. They concluded that capturing PBRNs' impact was the main challenge, especially considering that PBRNs often play a role in published research but are not always cited or acknowledged. PBRNs also play a significant role in their communities and their impact through unpublished research, which is especially difficult to capture.

The TEP supported the development of the new PBRN resources and reflected on each one to improve content and/or dissemination. The [IRB Tip Sheet](#) was presented and reviewed by the TEP. The TEP discussed its content, dissemination, and formatting, and the members agreed that the IRB TIP Sheet would be most useful on the PBRN website.

The [Impact Profile](#) mockup was shared with the group. The feedback was positive, and volunteers for being profiled were identified. Dissemination was discussed, including recommendations to post it on the PBRN website, attach it within the Registry listings, and use it at conferences.

The intent of the FAQ was explained to the TEP, with focused development discussions on two options:

- **Option 1:**
 - *Audience:* The FAQ is intended for use by PBRNs and will consist of peer-to-peer questions and answers.
 - *Focus:* The FAQ document should be developed by the TEP and focus on topics relevant to PBRNs.
- **Option 2:**
 - *Audience:* The FAQ is intended for use by PBRNs as a resource to educate and support non-PBRN collaborators.
 - *Focus:* The FAQ document should be developed by the TEP with a list of common questions they receive about PBRNs.

The TEP provided equal support to both options, leading to a decision to create an outline for both FAQ versions.

The TEP was given a presentation on the synthesis report's findings and recommendations. The TEP was provided with a summary of the synthesis report's goals, which included the focus of PBRN research topics, methods, and results. The report also highlights gaps in current PBRN research and presents actionable steps that AHRQ can take to support PBRNs. Members discussed dissemination and offered input for reaching a large audience.

The TEP discussed how the synthesis report can be used by AHRQ and PBRNs to continue to validate the impact of PBRN research. Panelists reiterated the importance of including funding information in the synthesis report. It can be difficult to capture the impact of PBRNs and their level of involvement in published research, and it would be beneficial to understand which PBRNs are responsible for the majority of publications. The following are a sample of quotes from the TEP discussion about the synthesis report and how it can be used to measure PBRN Impact:

- "It's a real difficult issue that we don't have a universal way of flagging ... various levels of impact or involvement of a PBRN on a publication other than if you have it in a title or in the description."
- "I strongly advocate that we figure out ways to go to the PBRN's membership, the clinicians themselves, and their communities and figure out ... how they view the impact and value of PBRNs."
- "How are we actually doing programmatic evaluation each year and holding ourselves accountable for the research we're also disseminating to our clinical partners? And then what are they doing with those findings in their own clinical practices?"
- "I think another aspect of this ... is focused on understanding the reach of the PBRN research in terms of what populations are represented in these studies."

Completed Follow-Up Actions From Meeting 4

The development of new TEP-led PBRN resources was completed after meeting 4.

- Pilot PBRN [Impact Profiles](#) were developed using TEP volunteers for future display on the PBRN website as an effort to continue to support PBRN connections. Section 508 compliant versions were completed for display on the PBRN website.
- A Section 508 compliant PDF version of the peer-to-peer [IRB Tip Sheet](#) was completed for posting on the PBRN website.
- An outline for a PBRN FAQ was created to use for potential future development by AHRQ and included information and ideas generated by the TEP.

3.5. Meeting 5

During the fifth and final TEP meeting, the objectives were to obtain input on actionable items discussed during prior TEP meetings regarding website content (including tools and resources) and design, learning/training, and collaboration. For the final TEP meeting, we compiled all the TEP's input and ideas and provided a review of all discussions from previous meetings. The TEP was given time to reflect on past meetings and offer any further input to AHRQ for reinvigoration of PBRNs. The TEP members would like to continue to support one another and would benefit from continued AHRQ support. Table 10 outlines further details about meeting 5.

Table 10. Meeting 5: Key Information

Meeting 5: Key Information	
Date	April 30, 2025
Objective(s)	<ul style="list-style-type: none">• Elicit input from the TEP regarding actionable items for PBRN website content and design, learning/training, and collaboration.• Finalize input regarding the dissemination of current and future tools, resources, and research relevant to and/or produced by PBRNs.
Additional Activity	Discuss dissemination of PBRN publication database.
Pre- and Post-Work	Review of meeting 4 summary.
Summary of Findings	<ul style="list-style-type: none">• The TEP discussed the overall TEP findings and the benefits to them and their PBRNs, highlighting the connections and support they received from the group.• Input was offered for how AHRQ may be able to support these connections, including the citation database.• The TEP provided final input to AHRQ regarding the ongoing support that PBRNs need and ways that help can be provided.• The TEP agreed that PBRNs need advocacy for the development of standard Medical Subject Headings (MeSH) terms for PBRN research.
Completed Follow-Up Actions	<ul style="list-style-type: none">• A TEP member contacted the U.S. National Library of Medicine (NLM) and submitted a request for the MeSH term "PBRN."• TEP input regarding ways AHRQ can continue to support PBRNs was summarized for AHRQ's review.

Meeting 5: Key Information	
Next Steps	<p>Table 11 provides the TEP's input on the next steps regarding AHRQ's resources for support. The ideas for AHRQ are categorized based on the following summarization points:</p> <ul style="list-style-type: none"> • PBRNs should develop or adjust business models to promote sustainability while aligning with their mission and strategy. • Continued dissemination of PBRN resources may also occur through partnerships with professional organizations (e.g., NAPCRG, World Organization of Family Doctors (WONCA)). • AHRQ can continue to help support PBRN communication and connections.

Summary of Meeting 5

The TEP was provided with a review of the key findings from meetings 1 through 4. Members agreed to the key findings presented and provided further input regarding recommendations for AHRQ to continue supporting PBRNs. The TEP discussed alternative organizations and websites that can be used to rehome all PBRN resources currently housed in the [PBRN website](#). Suggested organizations and websites that were mentioned currently work in the PBRN space and have large audiences.

The members discussed the benefits of this TEP to their PBRNs, highlighting the connections and support they received from the group, with one member stating that she learned valuable information from this TEP that she would not have received otherwise. The members discussed informal mentoring as a way to build connections and support other PBRNs. They mentioned that the [Registry](#) is a good starting point for building these connections. They suggested that AHRQ may consider adding a mentor notifier within the Registry listing for PBRNs to easily identify mentorship interest. Table 11 further elaborates on the key takeaways from meeting 5 discussions.

Table 11. Key Findings From Meeting 5 Discussions

Key Finding	Opportunities to Support PBRNs
PBRNs should develop or adjust business models to promote sustainability while aligning with their mission and strategy.	<ul style="list-style-type: none"> • Conduct business model consultations with PBRNs to brainstorm ideas for how they can rethink their mission and strategies given recent changes in U.S. Department of Health & Human Services (HHS) agencies. • Foster or share opportunities for PBRN-to-PBRN mentoring programs, or encourage informal mentorships within the PBRN community.
Continued dissemination of PBRN resources may also occur through partnerships with professional organizations (e.g., NAPCRG, WONCA).	<ul style="list-style-type: none"> • Consider alternative organizations to create new resources and provide updates to existing ones. • Connect with NAPCRG and WONCA for support on an international level (e.g., an international PBRN Registry).
AHRQ can continue to help support PBRN communication and connections.	<ul style="list-style-type: none"> • Use LinkedIn as an established networking platform for AHRQ to engage with PBRNs and for PBRNs to engage and collaborate with one another. • Create ways to connect PBRNs to CTSAs. • Support data sharing, such as mentoring and DUAs. • Disseminate the publication database to facilitate research connections. • Continue to support the current Registry, where PBRNs can easily update their listing. • Develop tools and resources for PBRNs, including tailored resources for new and existing PBRNs as well as the public.

Completed Follow-Up Actions From Meeting 5

As a result of the discussion around identifying PBRN impact, one TEP member contacted NLM and submitted a request for the MeSH term “PBRN.” The TEP discussed the importance of MeSH terms for yielding more comprehensive results, thus increasing the recognition of PBRN citations. The TEP believed that increasing the recognition of PBRN work is essential to their sustainability.

4. Considerations for Continued Support of PBRNs

This section summarizes considerations for ways AHRQ can continue to provide PBRNs with support.

Throughout the initiative to reinvigorate AHRQ’s relationship with PBRNs, the TEP provided essential information for understanding the challenges and barriers that PBRNs face. TEP members gave insight into their current needs and identified ways AHRQ support can help them succeed. Some discussions led to actions being completed during this project, such as the new TEP-driven PBRN resources and [Registry](#) enhancements. Long-term support that PBRNs need from AHRQ includes assistance with facilitation and communication. Following the TEP meetings, AHRQ should consider ways to continue maintaining their relationship with PBRNs. The following considerations are based on a synthesis of information collected throughout the TEP meetings:

1. Continue to update and improve the PBRN Registry for ongoing sustainability.

- The Registry remains essential for PBRNs to make connections. Continue to support the current Registry so PBRNs can easily update their listing. Strengthening connections with NAPCRG and WONCA could bolster support on an international level (e.g., an international PBRN Registry).

2. Provide updates to improve the [PBRN website](#) to include useful tools and resources.

- Consider using the PBRN website to provide ongoing support to PBRNs through fostering connections and providing tools and resources.
- Create ways to connect PBRNs to Clinical and Translational Research (CTR) and CTSA grants through the website, as PBRNs engage with both of these mechanisms, depending on their location and affiliations.
- CTSAs support research-intensive institutions to develop infrastructure and expertise for translational research.
- The Institutional Development Award (IDeA) CTR program focuses on building research capacity in states with historically low levels of National Institutes of Health (NIH) funding.
- Support the sharing of resources, such as data sharing and agreement templates, mentoring opportunities, and other useful tools.
- Consider PBRN community sharing through the website, social media, or email.
- Ensure that resources meet PBRN community needs by engaging them in resource development.
- Consider future focus groups for identification of resource needs and subsequent development.

- 3. Provide opportunities for connections and collaboration with PBRN and non-PBRN entities.**
 - Create ways to connect PBRNs to research opportunities that match their interests by building connections at conferences or through individual outreach.
 - Disseminate the publication database to facilitate research connections. Highlight the value of the database to build connections with shared research interests.
 - Use social media such as LinkedIn to share information and messaging, and encourage PBRNs to access the platforms for updates.
 - Connect PBRNs with philanthropy groups that can provide funding for shared interests.
- 4. Provide support to PBRNs by sharing their importance and impact with a large audience.**
 - Share the message that health systems and medical schools can benefit from supporting PBRN infrastructure.
 - Assist PBRNs in developing language to use for marketing themselves within their own organizations.
 - Support messaging for PBRN funding, such as endowments. For example, a PBRN named after a donor would be mutually beneficial.
 - Provide education about PBRNs tailored to funders and investigators, such as study types and grant writing.
- 5. Disseminate the findings of the PBRN synthesis report to a large audience.**
 - The PBRN synthesis report contains a significant amount of information about the impact PBRNs have had over the past 10 years. AHRQ should consider disseminating it to a wide audience beyond PBRNs, highlighting their work and importance in the communities they serve.

Appendix A. Outreach Materials

- *PBRN TEP Recruitment Plan*
- *PBRN TEP Recruitment Listserv Language*
- *PBRN First Attempt TEP Email*
- *PBRN TEP Application*
- *PBRN TEP Factsheet*

A.1. PBRN TEP Recruitment Plan

ECONOMETRICA, INC.

Identifying and Supporting the Needs of Primary Care Practice-Based Research Networks

Contract No.: GS-00F-101CA

Order No.: 75Q80123F80012

Project No.: 1927-000

Technical Expert Panel Recruitment Plan

Objective

Econometrica, Inc., is assembling 20 Technical Expert Panel (TEP) members from a variety of Practice-Based Research Networks (PBRNs), practice contexts, geographic areas, and roles in their PBRNs. The TEP will meet virtually a total of five times over a 2-year period, beginning in February or March 2024. The goal of the TEP is to obtain insight into approaches and strategies for supporting the work of PBRNs and guidance in the development and maintenance of web-based tools and resources.

Econometrica plans to execute this proposed Recruitment Plan to successfully recruit 20 TEP members by December 13, 2023. The team will keep AHRQ updated on its progress throughout November and December. The proposed Recruitment Plan includes a comprehensive research and screening process to identify potential members, a multiple-method outreach plan, and a detailed selection process.

Set TEP Goals (Provided by AHRQ)

The Agency for Healthcare Research and Quality (AHRQ) provided the TEP with goals for establishing a TEP of 15 to 20 members from functional, active PBRNs:

- TEP participants should represent:
 - A diverse group of primary care PBRN community members, such as PBRN Directors, leaders, coordinators, researchers, and representatives from PBRN practices (e.g., primary care physicians, nurses, research project managers, site study coordinators, practice managers).
 - Diversity in geographic representation (i.e., PBRNs operating in different states and with different levels of reach).
- Overall goals of the meetings:
 - The first meeting will elicit feedback regarding the current website content (including tools, resources, and the PBRN Registry) and functionality and will assess specific PBRN resource support needs that would enable PBRNs to function optimally.
 - The subsequent meetings will continue to assess PBRN needs, focusing on specific support components raised by the TEP, to elicit further detail and input on how to design, implement, and disseminate these elements; what topics to include in a webinar series; and/or other topics approved by the COR.



Set TEP Selection Criteria (Approved by AHRQ)

AHRQ and Econometrica collaborated on the following TEP Selection Criteria, which most recruited TEP members should meet:

- Be currently affiliated with a PBRN, with a minimum of 1 year of experience at a PBRN.
- Be currently engaged in research and/or practice at a PBRN.
- Be available to participate in at least two TEP sessions, each lasting approximately 2 to 6 hours.
- Preferred: Have a history of publishing findings within the past 10 years.

Outreach Preparation

Econometrica will conduct multiple outreach preparation activities to ensure a seamless and extensive outreach and recruitment process. The following outlines the steps that Econometrica will take during the preparation process:

- Scan the AHRQ PBRN registry.
 - Collect contact information.
 - Check website links.
 - Research contacts and confirm that information is up to date.
 - Identify diverse/unique characteristics listed in the TEP goals.
- Scan the internet for potential PBRNs that are not listed in the AHRQ registry.
 - Historically Black Colleges and Universities (HBCU) and Hispanic institutions.
 - Clinical and Translation Science Award (CTSA) Centers.
 - State academic institutions.
- Outreach material preparation.
 - Prepare email scripts.
 - Prepare TEP recruitment flyer.
 - Prepare TEP bio/application.
- Initial TEP outreach announcements.
 - Create PBRN listserv announcement.
 - Approved listserv announcement will be posted on PBRN one-way listserv.
 - Create TEP recruitment flyer.
 - Subject Matter Expert (SME) Maureen Boardman, M.S.N., FNP-C, FAANP, will distribute the flyer at the North American Primary Care Research Group (NAPCRG) conference.
- Response email to interested parties to request bio. Example language includes:
 - Please reply to this email with a brief bio outlining your professional background, reason for joining the TEP, and how you meet each qualification listed:
 - Be currently affiliated with a PBRN, with a minimum of 1 year of experience at a PBRN.



- Be currently engaged in research and/or practice at a PBRN.
- Be available to participate in at least two TEP sessions, each lasting approximately 2 to 4 hours.
- Have a history of publishing findings within the past 10 years. (Preferred but not required.)

Outreach Steps

Econometrica plans to conduct outreach and recruitment using a structured timeline that includes emails; phone calls; and interviews, if requested:

1. Send the recommended participant list to AHRQ for approval.
2. Conduct outreach to prospective members. An Excel spreadsheet will be used to track contact attempts and data for reporting.
 - a. Email or call identified PBRNs on the screened list.
 - i. Confirm the main contact for outreach.
 - b. Send email using the first attempt language.
 - i. Wait 7 to 10 business days.
 1. If interested, email bio request outlining qualifications.
 2. If not interested, remove from contact list.
 - a. Track reason, if offered.
 - c. Send email using the second attempt language.
 - i. Wait 3 to 5 business days.
 1. If interested, email bio request outlining qualifications.
 2. If not interested, remove from contact list.
 - a. Track reason, if offered.
 - d. Make phone call using written phone language if no response to emails is received.
 - i. If interested, email bio request outlining qualifications.
 - ii. If not interested, remove from contact list.
 1. Track reason, if offered.
 3. Outreach received from prospective members. An Excel spreadsheet will be used to track contact attempts and data for reporting.
 - a. Email received from interested parties. *Note: May be from listserv announcement or conference attendees.*
 - i. Respond within 2 to 5 business days.
 - ii. Email bio request outlining qualifications.
 4. Conduct introductory interviews, as requested.



- a. Interested parties may request that a virtual or phone interview be set up within 10 business days. Invites will be sent via email.
- b. Time will be used to answer questions and discuss qualifications for TEP.

Selection Process

The selection process for TEP members will be divided into a minimum of two tiers and will be conducted on a rolling basis, guided by the priorities listed below. Recruitment will continue until a diverse group of participants has been gathered. *Note: In the event that multiple applicants have similar qualifications and represent similar PBRNs, Econometrica will discuss tier placement with AHRQ.*

- Tier 1.
 - 20 to 25 participants.
 - Will have first choice of meetings to attend.
 - Have committed to a minimum of 2 to 3 meeting dates.
 - Have met all the TEP participant criteria *and/or* represent a unique or underrepresented PBRN perspective. This includes diversity in setting, background, experience, and/or role.
- Tier 2.
 - Up to 20 participants.
 - Will be used as a second contact to reach meeting capacity.
 - Have met most but not necessarily all TEP participant criteria.
 - May meet criteria but lack a unique or underrepresented PBRN perspective. This includes diversity in setting, background, experience, and/or role.
 - May not have committed to 2 to 3 meetings in the initial interview call.
- Notification.
 - The notification to selected Tier 1 members will be sent out via email in December and January.
 - Confirmation of selection.
 - Notification of upcoming dates.
 - Potential topics.
 - Next steps.
 - Notification to selected Tier 2 members will be sent out via email in December and January.
 - Confirmation of selection.
 - Notification of potential upcoming dates.
 - Potential topics.



- Next steps and process for notification if presence is requested at TEP meeting.



A.2. PBRN TEP Recruitment Listserv Language

On behalf of the Agency for Healthcare Research and Quality's (AHRQ) National Center for Excellence in Primary Care Research (NCEPCR), Econometrica, Inc., is seeking members for a Technical Expert Panel (TEP) for Primary Care Practice-Based Research Networks (PBRNs). The goal of the TEP is to obtain insight into approaches and strategies for supporting the work of PBRNs and guidance in the development and maintenance of web-based tools and resources. We will be contacting prospective TEP members from the PBRN community over the coming weeks via email and phone. If you are interested in participating and would like to be contacted, please email Melissa Carbone, AHRQ PBRN TEP Lead, at AHRQ_PBRN@Econometricalnc.com.

A.3. PBRN First Attempt TEP Email



Dear XXXXXX,

My name is Melissa Carbone, M.S.N., R.N., and I am writing on behalf of the Agency for Healthcare Research and Quality's (AHRQ) National Center for Excellence in Primary Care Research (NCEPCR) to request your participation in a Technical Expert Panel (TEP) for Primary Care Practice-Based Research Networks (PBRNs). Econometrica, Inc., where I am employed, will be supporting AHRQ in its efforts to gain a better understanding of PBRN needs and provide meaningful web-based resources to support the work of PBRNs.

We hope that you will consider applying to join the TEP to share your subject matter expertise, insight into approaches and strategies for supporting the work of PBRNs, and guidance in the development and maintenance of web-based tools and resources with AHRQ. The panel will also serve as a platform for collaborative and diverse brainstorming on how to address the challenges that PBRNs face. These discussions will be critically important to assisting AHRQ with developing useful, relevant, and effective tools and resources for PBRNs.

We are seeking 20 TEP members from a variety of PBRNs, practice contexts, geographic areas, and roles. We will meet virtually a total of five times over a 2-year period, beginning in February or March 2024. Econometrica is pleased to offer an honorarium for each meeting attended.

If you are interested, please reply to this email and we will send you a request for information about you and your PBRN. Please reach out if you have any questions. I look forward to discussing this further.

Sincerely,

Melissa Carbone M.S.N., R.N.

AHRQ PBRN TEP Lead

Clinical Staff Associate

MCarbone@EconometricaInc.com

(860) 485-4014

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www.EconometricaInc.com | 301.657.9883 | 7475 Wisconsin Avenue, Suite 1000 | Bethesda, MD 20814

A.4. PBRN TEP Application



PBRN TEP Application

Thank you for your interest in joining the Primary Care Practice-based Research Network (PBRN) Technical Expert Panel (TEP). Please complete the following questionnaire as part of our screening process to build a TEP of individuals from a diverse group of PBRNs. If you are currently affiliated with a larger network of PBRNs, please answer the following questions in relation to your network.

1. Please type your full name below:

2. How long have you been affiliated with a PBRN (or larger network of PBRNs)
 - a. 0–2 years
 - b. 3–5 years
 - c. 6–10 years
 - d. >10 years
3. Which PBRN are you currently affiliated with?

4. Are you or your PBRN affiliated with a larger network of PBRNs?
 - a. Yes
 - b. No

If Yes, which larger network?

5. When was your PBRN established?

6. Is your PBRN affiliated with a Clinical and Translational Science Award (CTSA) or a Clinical and Translational Research (CTR) award?
 - a. Yes
 - b. No
 - c. I do not know
7. Approximately how many practices are engaged with/enrolled in your PBRN?

8. Is your PBRN currently registered with AHRQ? A link can be found here:
<https://www.ahrq.gov/ncepcr/communities/pbrn/registry/index.html>
 - a. Yes
 - b. No
 - c. Not sure



9. What is your role at your PBRN?

10. Are you currently engaged in the conduct of research at a PBRN?

- a. Yes
- b. No

11. If you answered “Yes” to item 7, what is your current research focus? (If “No,” skip to 9).

12. If you answered “No” to item 7, please explain more about your role at a PBRN and specific responsibilities.

13. Do you have a history of publication of findings within the last 10 years?

- a. Yes
- b. No

14. Are you able to commit to a meeting of at least 4 hours?

- a. Yes
- b. No

15. Anticipated meetings will be in February 2024, April 2024, July 2024, October 2024, and February 2025. Are you able to commit to at least three of these meetings?

- a. Yes
- b. No
- c. I can commit to at least two
- d. Not sure

16. What goals do you have for the TEP?

17. Please tell us anything else about your PBRN that will help us build a diverse TEP (about the patient population reached, geographic distribution, clinician types, practice types/settings, types of research conducted, types of clinicians engaged, etc.).



AHRQ PBRN TEP FACTSHEET



Agency for Healthcare
Research and Quality

On behalf of the Agency for Healthcare Research and Quality's (AHRQ) National Center for Excellence in Primary Care Research (NCEPCR), Econometrica, Inc., is seeking members for a Technical Expert Panel (TEP) for Primary Care Practice-Based Research Networks (PBRNs). The goal of the TEP is to obtain insight into approaches and strategies for supporting the work of PBRNs as well as guidance for the development and maintenance of web-based tools and resources.

TEP Criteria

To be eligible for the TEP, a potential member must:

- ✓ Be currently affiliated with a PBRN with a minimum of 1 year of experience at a PBRN.
- ✓ Be currently engaged in research and/or practice at a PBRN.
- ✓ Participate in 2 (of 5) TEP sessions lasting 4-5 hours.
- ✓ Have a history of publication of findings within the last 10 years. Preferred not required.



Time Commitment

- The TEP will convene virtually five times over a 2-year period with an anticipated first meeting in February or March 2024.
- We are pleased to offer an honorarium for TEP participation.

Reach out
to us via
email!



Recruitment

If you are interested in joining the TEP, please reach out to Econometrica at the following email address: AHRQ_PBRN@EconometricaInc.com. We will be recruiting individuals via email and phone throughout November 2023.



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Appendix B. Selected TEP Members

The following list contains all TEP members who attended at least one meeting and/or assisted with the development of any TEP-related activities during this contract. The table includes self-reported information about the PBRN's location, year established, size by number of enrolled practices (small, <25; medium, 25–100; large, >100), and any reported research interests.

Names/Credentials	PBRN Affiliations	State	Year Est.	Size	Specialty or Research Focus
Steven J. Atlas, M.D., M.P.H.	Massachusetts General Hospital Primary Care PBRN	MA	2006	Small	Oncology & cardiovascular disease prevention
Kavita Batra, B.D.S., M.P.H, Ph.D., FRSPH	University of Nevada, Las Vegas (UNLV)	NV	2023	Small	N/A
Maureen Boardman, M.S.N., FNP-C, FAANP (Subject Matter Expert)	Northern New England (NNE) CO-OP Practice- & Community-Based Research Network (PCBRN); Dartmouth Health Department of Community & Family Medicine	NH	1972	Large	Primary care
Ellie Brent, M.P.H.	Kansas Patients & Providers Engaged in Prevention Research (KPPEPR)	KS	2002	Medium	Cancer survivorship, colorectal cancer screening, precision medicine (All of Us Program), COVID mitigation
Sarah Brewer, Ph.D., M.P.A.	Colorado Children's Outcomes Network (COCONet)	CO	2011	Medium	Vaccination (infant series, HPV, flu, COVID), mental health
Lauren A. Cafferty, M.A.	Military Primary Care Research Network (MPCRN) at Uniformed Services University of the Health Sciences (USUHS)	National	2008	Small	Military health, new military parent education
Michelle A. Chui, Pharm.D., Ph.D.	Pharmacy Practice Enhancement & Action Research Link (PearlRx) – Wisconsin's Pharmacist PBRN	WI	2013	Unknown	Medication safety in the outpatient setting in collaboration with pharmacists and primary care physicians
Kim Coley, Pharm.D., FCCP	Pharmacy Innovation Network	PA	2018	Medium	Implementation and provision of enhanced patient care services provided by community pharmacists
Katrina Donahue, M.D., M.P.H.	NCnet, North Carolina Network Consortium (NCNC)	NC	2001	Large	Primary care
Kim Fulda, Dr.P.H.	North Texas PBRN (NorTex)	TX	2005	Large	Medication errors in the elderly, health disparities

Names/Credentials	PBRN Affiliations	State	Year Est.	Size	Specialty or Research Focus
Mary Fisher, M.P.H.	State Networks of Colorado Ambulatory Practices & Partners (SNOCAP); Colorado Research Network (CaReNet)	CO	1998	Large	Primary care
K. Allen Greiner, M.D.	KPPEPR	KS	2002	Medium	Cancer survivorship, colorectal cancer screening, precision medicine (All of Us Program), COVID mitigation
Jacqueline Halladay, M.D., M.P.H.	NCNC	NC	2001	Large	Advancing outcomes in highly prevalent chronic diseases in youth and adults
Finie Hunter-Richardson, Ph.D., M.P.H.	District of Columbia Primary Care (DC PrimCare) PBRN	D.C.	2005	Unknown	Primary care
Mari Katundu, M.S.	Alabama PBRN	AL	2000	Medium	Diabetes management, cardiovascular disease, obesity and weight management, mental health care, healthcare disparities
Niel Korsen, M.D., M.S.	NNE CO-OP PCBRN	ME	1970's	Medium	Primary care
Alex Krist, M.D., M.P.H.	Virginia Ambulatory Care Outcomes Research Network (ACORN)	VA	1996	Large	Primary care (opioid use, risky drinking, cancer screening, guidelines)
Claudia Lechuga, M.S.	New York City Research & Improvement Networking Group (NYC RING)	NY	2003	Medium	Social determinants of health and impact of social risk on health outcomes
Christy Ledford, Ph.D.	HamesNet	GA	2012	Medium	Racial and geographic disparities in cardiovascular outcomes
Joy Lewis, D.O., Ph.D., FACP	A.T. Still University School of Osteopathic Medicine in Arizona (ATSU-SOMA) PBRN	AZ	2011	Small	Social determinants of health for vulnerable populations, Million Hearts project
Tapan Mehta, Ph.D., M.S.	Alabama PBRN	AL	2000	Medium	Diabetes management, cardiovascular disease, obesity and weight management, mental health care, healthcare disparities
Zsolt J. Nagykaládi, Ph.D., B.Th.	Oklahoma Physicians Resource/Research Network (OKPRN)	KY	2000	Large	Guideline implementation, screening, prevention, chronic disease management, community-engaged research (tribal, rural, underserved)

Names/Credentials	PBRN Affiliations	State	Year Est.	Size	Specialty or Research Focus
Donald E. Nease, M.D.	SNOCAP	CO	1992	Large	Testing of best ways to introduce innovations into primary care practice
Wilson D. Pace, M.D.	AAFP National Research Network Collaboration with the DARTNet Institute		1978	Large	Primary care
Karen L. Roper, Ph.D., M.S.	Kentucky Ambulatory Network (KAN)	KY	2000	Large	Implementation and dissemination, racial and geographic disparities in cardiovascular outcomes
Andrew Telzak, M.D., M.Sc.	NYC RING	NY	2003	Medium	Social determinants of health and impact of social risk on health outcomes
Sebastian Tong, M.D., M.P.H.	WWAMI region Practice & Research Network (WPRN)	WA	2008	Large	Health equity, behavioral health (substance use, loneliness), chronic pain
Annette M. Totten, Ph.D.	Oregon Rural Practice-Based Research Network (ORPRN)	OR	2002	Large	Advance care planning, management of chronic disease, aging
Daniel Walker, Ph.D., M.P.H.	Central Ohio PBRN/Ohio Primary Care Innovation Network	OH	2012	Small	Care transformation in Federally Qualified Health Centers (FQHCs)

Appendix C. New TEP-Led PBRN Resources

- *PBRN IRB Tip Sheet*
- *Impact Profile Template*
- *PBRN FAQ Outline*

Institutional Review Board (IRB) TIP SHEET

Peer-to-peer tips about working with IRBs for Primary Care Practice-Based Research Networks (PBRNs)



By working together, PBRNs and IRBs can protect human subjects and make the research process more efficient

PBRNs often conduct multisite research studies and thus have unique challenges and needs when it comes to working with the Institutional Review Boards (IRBs). This document is intended to offer tips and support to the PBRN community to successfully work with IRBs throughout the research process. Each PBRN and study is unique, and these recommendations should be carefully considered for their application to individual studies.

Important Definitions and Concepts

- **Cooperative research** projects are those projects covered by §46.114 Cooperative Research and that involve more than one institution. In the conduct of cooperative research projects, each institution is responsible for safeguarding the rights and welfare of human subjects and for complying with this policy.
- **Exempt from review** means the research is human subjects research but fits an exemption category under Federal regulations.
- **Human subject** means a living individual about whom an investigator (whether professional or student) conducting research:
 - (i) Obtains information or biospecimens through intervention or interaction with the individual, and uses, studies, or analyzes the information or biospecimens; or
 - (ii) Obtains, uses, studies, analyzes, or generates identifiable private information or identifiable biospecimens.
- **Non-jurisdictional** means the project is not considered human subjects research and IRB has no authority over it.
- **Quality improvement (QI) projects** are projects designed to improve the quality of care for patients. Most efforts are not considered research and are not subject to the HHS protection of human-involved regulations.
- **Research** means a systematic investigation, including research development, testing, and evaluation, designed to develop or contribute to generalizable knowledge.
- **Research Site:** PBRNs may recruit multiple clinical sites for research. In general, the PBRN leading the research project will use its IRB as the single IRB for all clinical practices involved.
 - When large health institutions are involved, additional research approval steps may be required.
- **The Revised Common Rule** requires that all institutions located in the United States that are engaged in cooperative research conducted or supported by a Federal department or agency rely upon approval by a single IRB for the portion of the research that is conducted in the United States.

IRB Review Cycle



Institutional Review Board (IRB) TIP SHEET

Providing PBRNs with peer-to-peer tips about working with IRBs



Tips For Working With An IRB On PBRN Studies

- Develop processes that determine what will serve as the single IRB site and communicate with recruited clinical sites and academic institutions involved early in the collaboration.
- Explain your study design and the role of the sites carefully. Remember that most research conducted in/by PBRNs is not a traditional clinical trial and that the IRB may not be familiar with your forms, processes, methods, and engagement approaches.
- If possible, assign dedicated PBRN research staff to manage regulatory requirements on behalf of the practices and network members.
- Develop a relationship with the IRB and request that the IRB dedicate a person to review all of the PBRN's projects.
- Ask other PBRNs to share templates and examples of approved protocol submissions (e.g., card studies).
- To improve the process of adding study sites, consider contracting with external agencies to carry out the Federal Wide Assurance (FWA).
- Ensure PBRN investigators understand that language, procedures, and questions can impact or change the level of IRB review.

Considerations For Community Partner Human Subjects Protections Training

- Use available HHS resources (e.g., [Training Checklist for Someone Working with IRBs](#)).
- Consider a training process that enables practice providers to avoid lengthy or complex trainings that may not be relevant to their role in the study.
- Consider the use of the Community Partner Research Ethics Training (CPRET) for community partners engaged in PBRN research.
- Use human research training specific to community organizations, such as [CIRTification](#).

Considerations For PBRN Network Infrastructure

- Predetermine how your IRB will cover clinical sites that are not a part of your institution.
- Consider reciprocity agreements that allow one IRB to have oversight while the others accept the review and decisions of the lead IRB to enhance efficiency.
- Establish a Memorandum of Understanding (MOU) with an IRB that may allow it to extend coverage to unaffiliated practices.
- Establish a relationship with an accessible commercial single IRB willing to take on your PBRN's projects.

Institutional Review Board (IRB) TIP SHEET

Providing PBRNs with peer-to-peer tips about working with IRBs



Tips For Meeting IRB Requirements

- Submit your project to the IRB as a request for determination and allow it to determine whether the project qualifies as human subjects research. Clearly separate research and non-research activities in the design of any project.
- Be sure to understand the requirements for filing and renewing Federal Wide Assurance (FWA), especially when adding clinical sites.
- When possible, create protocols that can trigger an expedited approval process instead of full-board review (e.g., by studying practices and professionals instead of patients).
- In randomized trials, consider designs where the control group receives usual care, and the intervention group receives usual care plus the intervention to ensure ethical requirements are met.
- Consider a low-risk study design whenever possible.
- For survey-based research, add an item at the start of the survey to allow participants to provide consent easily.
- Be sure to consider all factors when determining whether individuals are participants or subjects in research, such as surveys and secondary research, because this may change the exemption status with an IRB.




Communication Tips from PBRNs to PBRNs

- Engage with the IRB **early** and **often** to help navigate potential barriers or miscommunications. Speak on the phone or through a web portal, if available.
- Establish bidirectional relationships with the IRB chair and staff to discuss PBRN research to promote understanding of how the work is done and how PBRN research is different from traditional clinical trials.
- Consider serving on an IRB to provide a PBRN-affiliated investigator perspective.
- Recruit a culturally experienced individual from the study population to work with your team (e.g., American Indian or Alaskan Native to work with Tribal IRBs) on consent protocols, if possible, and reflect that in your IRB submission.
- Consider external organizations that may be able to provide practice oversight on the study, and outside experts to help with effective communication with study participants (e.g., writing consent forms).
- Create templates for different types of protocols and share resources with other researchers.

Helpful Links for Understanding IRBs

- ▶ [AHRQ PBRN Website](#)
 - ▶ [E-learning course with module on IRB](#)
- ▶ [U.S. Department of Health and Human Services \(HHS\) IRB Tip Sheet](#)
- ▶ [Common Rule \(HHS 45 CFR\)](#)
- ▶ [Office for Human Research Protections IRB Tip Sheet](#)
- ▶ [Canadian Primary Care Research Network](#)

C.2. Impact Profile Template

<div data-bbox="228 291 350 411"></div> <div data-bbox="383 296 1060 426"><h1>PRACTICE-BASED RESEARCH NETWORK X</h1></div> <div data-bbox="383 447 540 478"><p><i>Anycity, U.S.</i></p></div> <div data-bbox="383 480 1005 514"><p>Affiliates: Organization, Organization, Organization</p></div>	<h3>CONTACT</h3> <p>Dr. Director</p> <p>Email@emailaddress.org</p> <p>(555) 555-5555</p>
<h3>RESEARCH</h3> <p>This section will list important research and any relevant links.</p> <h3>INTERESTS</h3> <p>It will also list any research interests for networking.</p> <h3>FUNDING SOURCES</h3> <p>It may include any funding sources that the PBRN would like to call out.</p>	<div data-bbox="643 585 1128 982"></div> <p>PBRN X was founded in 2012 and... (insert mini bio/history). It began with practices in Y geographical area or specialty who had a common interest in something, (... and as more organizations saw its value, it continued to expand or give example of the PBRN impact or value).</p>
<div data-bbox="217 1106 350 1176"></div> <div data-bbox="367 1106 584 1182"></div>	<p><i>"This section will have direct quotes from a representative of the PBRN. They can offer a tip or fun fact about the PBRN, such as why _____ PBRN loves what they do..."</i></p> <p>— Dr. Doctor, PBRN X</p> <div data-bbox="1240 1024 1377 1159"></div>

C.3. PBRN FAQ Outline

Based on Primary Care Practice-based Research Network (PBRN) Technical Expert Panel (TEP) members' feedback, the need for a Frequently Asked Questions (FAQ) document was indicated.

The overall goal of the FAQ would be to develop a list of questions and answers related to supporting, elevating, and promoting the work of PBRNs.

The TEP discussed two types of FAQ documents with the following audience and focus:

- **Option 1:**
 - *Audience:* The FAQ is intended for use by PBRNs and will consist of peer-to-peer questions and answers.
 - *Focus:* The FAQ document should be developed by the TEP and focus on topics relevant to PBRNs.
- **Option 2:**
 - *Audience:* The FAQ is intended for use by PBRNs as a resource to educate and support non-PBRN collaborators.
 - *Focus:* The FAQ document should be developed by the TEP with a list of common questions they receive about PBRNs.