

**Strengthening Clinical Research Network Collaboration and Participation in PCORnet[®] Studies
Hosted by the PaTH Clinical Research Network**

Pittsburgh, PA

September 11, 2025

EXECUTIVE SUMMARY

BACKGROUND

On September 11, 2025, the PaTH Clinical Research Network (CRN) hosted an event that highlighted the capabilities of PCORnet[®] through information sharing and case studies. The event included a focus on three disease-specific populations that provided opportunities for researchers to think more deeply about how PCORnet resources can support their work. Of note, these highlighted topics aligned with Patient-Centered Outcomes Research Institute[®] (PCORI[®]) 2025 Research Project Agenda [Topic Themes](#).

Overall, 68 individuals attended the event in-person and 54 joined virtually. Attendees represented a variety of perspectives including clinicians, community engagement experts, patients, caregivers, representatives from the Coordinating Center for PCORnet[®], and researchers new to PCORnet. In-person participants were affiliated with five of the PCORnet[®] CRNs, including PaTH, STAR, Greater Plains Collaborative (GPC), INSIGHT, and ADVANCE.

WELCOME AND OVERVIEW

The event began with outlining the meeting goals of fostering connections between researchers and CRNs and providing insights into PCORnet[®] resources and processes for multi-site, patient-centered health research. Participants briefly shared their affiliations and research interests, highlighting the diversity of expertise and institutions involved. Seating was arranged so that researchers who were new to PCORnet could have experts on hand to answer questions about working with the network, including representatives from CRN teams, the Coordinating Center for PCORnet[®], and Patient Partners or engagement experts.

The PaTH team shared selected results from the pre-meeting survey, in which participants were asked what they hoped to take away from the day's meeting. The most common responses were gaining a better understanding of PCORnet and connecting with other investigators. Attendees were also asked if they planned to develop a new proposal within the next 18 months, and 32 out of 49 total responses had indicated either "yes" or "perhaps."

MEETING OBJECTIVES

1. To help researchers and patient partners learn about PCORnet and processes for multi-site patient-centered health research
2. To build connections across PCORnet[®] Clinical Research Networks

Three broad topic areas were identified before the meeting including cancer, metabolic and endocrine health, and substance use. Researchers with an interest in each of these topics who had not worked with PCORnet in the past were included among participants. For each of the highlighted topics, a group of facilitators representing researcher and patient partner perspectives led conversations that included:

- Reviewing brief preparatory-to-research data to provide an idea of the scope of patient populations accessible via the PCORnet infrastructure;
- Reviewing general sub-topics of interest that had been identified through the pre-meeting survey;
- Brainstorming aspects of prevention or treatment that need to be improved, from patient,

- Highlighting how the PCORnet infrastructure could facilitate research in these topic areas

Robust conversations ensued. Online participants were able to ask questions and share comments in the videoconferencing chat feature; an in-person facilitator then brought those comments into the conversation.

DISCUSSION

Overview of Working with PCORnet[®]

Keith Marsolo presented an overview of working with PCORnet. Participants learned about how the PCORnet[®] Front Door can provide information to investigators and facilitate connections within the PCORnet community. He also noted that investigators affiliated with a participating CRN should also reach out to their local team for help navigating the process of accessing PCORnet resources (e.g., developing a data query scope of work and budget). Dr. Marsolo explained that receipt of study feasibility data is valued by many PCORnet users; having clear shell tables and defined code sets can facilitate timely access to such [data](#). Other resources that were discussed included the PCORnet[®] Common Data Model (CDM) which is a key resource, storing a variety of curated discrete electronic health record (EHR) data elements (e.g., data on diagnosis, procedures, vital signs, prescribing, and health service utilization). Also, the PCORnet[®] Population Insights Reports Tool can provide a broad understanding of the available data, and PCORnet[®] team members can help research teams understand if the data they need are routinely available through the CDM.

PCORI Perspective

Most of this session centered on PCORI priorities and funding opportunities. For example, the PCORI Broad Pragmatic Studies funding announcement includes a specific option (Category 3) for developing PCORnet[®] Studies. Components of a PCORnet[®] Study were explored by the group; PCORnet[®] Studies are national in scope; include two or more PCORnet[®] CRNs; implement patient engagement throughout the project lifecycle with a commitment to broad dissemination of findings; leverage PCORnet resources to improve the efficiency of patient-centered comparative clinical effectiveness research; and help build learning systems by sharing progress and lessons learned.

PCORnet[®] Study Use Cases & Discussion

Raj Shah discussed the PREVENTABLE Study, including its approach to recruitment of older adults, often using low-touch approaches. Elizabeth Chrischilles laid out how the NETPRO study is analyzing electronic health record (EHR) data linked with tumor registry data. Michael Kappelman focused on how to leverage PCORnet[®] resources to overcome challenges in pragmatic research as he discussed the development of the COMPARE Study, an observational study focused on pediatric inflammatory bowel disease. The effective engagement of patient partners was a cross-cutting area of interest in the use of care discussions.

Focus on Cancer

This portion of the meeting emphasized that PCORnet data resources can provide relevant insights relevant to cancer research. Yet, there are documentation gaps in EHR data such as discrete data on family history and genomics data. Potential avenues for overcoming these challenges were discussed, including the potential for linking CDM data with cancer registry data. The group also expressed interest in research to promote more effective personalized treatment. Participants noted considerable interest in opportunities for primary care research related to cancer but also felt that primary care providers are often unaware of PCORI and PCORnet resources and may benefit from outreach and education. The group endorsed the value of patient and caregiver engagement, including the need for having avenues

for maintaining partner relationships beyond a study's end. The [Story Booth](#) narrative archive, a PCORnet resource developed by the PaTH CRN, and the [PCORI ambassador program](#) were identified as programs that could be leveraged by research teams aiming to amplify patient voices.

Improving Metabolic and Endocrine Health

In this discussion, participants raised multiple salient clinical dilemmas that could benefit from PCORnet resources, such as the need for comparative clinical effectiveness research on treatment options for weight loss, including identifying which treatments are best for which individuals. Participants highlighted the need for better evidence about how to optimize care for metabolic and endocrine health with aging. Conversation highlighted the fact that patient-reported medications (e.g., ones obtained without a prescription) are often missing from structured datasets, but that an ongoing initiative is working to improve access to these data in the PCORnet[®] CDM. The discussion also addressed how PCORnet[®] Network Partners can support the development of multi-site research teams, for example, by helping researchers and clinicians identify collaborators with shared interests. PCORnet[®] CRN team members also shared ideas for working efficiently with PCORnet resources, such as through re-use of code lists for identifying covariates and outcomes. The group also made suggestions for enhancing the PCORnet[®] CDM's ability to support research in endocrine-metabolic issues. For example, they suggested more focus on the integration of behavioral and physiological data into the PCORnet[®] CDM, such as the inclusion of data from continuous glucose monitors and other wearable trackers.

Focus on Addressing Substance Use

This discussion opened with a focus on data of relevance to research on substance use disorders (SUD), which could be accessed through PCORnet. Participants were enthusiastic about the ability to examine patterns of care. Stigma was also identified as a topic of interest. While stigma itself is typically not well-documented in discrete EHR data, the group noted stigma-related studies could leverage a combination of EHR data and primary data collection (e.g., survey data), using recruitment approaches such as those discussed for the PREVENTABLE Study. One researcher shared findings from a recent analysis of patient and caregiver narratives about SUD in which participants expressed frustration with SUD treatment in healthcare systems; these findings highlighted the need for research to identify ways for improving care. The group suggested PCORnet[®] CDM improvements that would facilitate research related to substance use. For example, they advocated for better avenues for quantifying the use of behavioral interventions, such as a PCORnet[®] CDM table that captures provider referrals. They also acknowledged ongoing efforts to expand the PCORnet[®] CDM on social determinants of health and suggested that further work in that area would be of value.

KEY TAKEAWAYS

Participants in this event left with an enhanced knowledge of PCORnet resources. Participants learned about the available resources, the types of studies that these resources can support, and some of the funding opportunities available to support research using real-world data. Furthermore, they gained an understanding of who to ask for help, such as the PCORnet[®] Front Door and their local PCORnet[®] CRN, and an appreciation of how patient and community engagement can enhance the research process. Researchers also made connections with colleagues at other institutions who share their interests.

A brief feedback survey was completed by 67 individuals; 97% of respondents reported that they were very satisfied (60%) or satisfied (37%) with the event. Aspects that respondents found most helpful included:

- **The educational presentations and study use cases.** For example: *“The presentations were great. Got a sense of data available, study design, community engagement. V good.”*
- **Discussions about the three targeted content areas,** e.g., *“The open discussion was a really meaningful part to hear priorities and opportunities to advance research via PCORnet.”*
- **The opportunity to network with other researchers and the PCORnet community,** e.g., *“Networking opportunities and time for ad-hoc conversations.”*

Strengthening Clinical Research Network Collaboration and Participation in PCORnet[®] Studies

September 11 | 8:00 AM – 4:15 PM | Pittsburgh, PA

Join us for a day of collaboration, learning, and advancing
patient-centered research!

[University Club](#), Ballroom B
123 University Place
Pittsburgh, PA 15213

AGENDA

Event Goals:

- Help researchers and patient partners learn about PCORnet resources and processes for multi-site patient-centered research
- Build connections across PCORnet[®] Clinical Research Networks (CRNs)

All sessions will be livestreamed with a moderated chat

8:00-9:00	Breakfast and Networking	
9:00-9:20	Welcome, Overview, Sharing of individual goals	PaTH Team
9:20-10:20	Overview of Working with PCORnet [®]	Keith Marsolo Duke Clinical Research Institute Coordinating Center for PCORnet [®]
10:20-10:35	Break	
10:35-11:00	PCORI [®] Perspective	Nik Koscielniak PCORI
11:00-12:00	PCORnet [®] Study Use Cases & Discussion	11-11:15 Betsy Chrischilles, University of Iowa, GPC CRN 11:15-11:30 Raj Shah, RUSH University Medical Center, PaTH CRN 11:30-12:00 Mike Kappelman, UNC Chapel Hill, STAR CRN
12:00-12:50	Lunch	Participating Clinical Research Networks
12:50-1:50	Focus on Cancer	Betsy Chrischilles, University of Iowa, GPC CRN Kathleen McTigue, University of Pittsburgh, PaTH CRN Greg Merritt, University of Michigan, PaTH CRN
1:50-2:50	Focus on Improving Metabolic and Endocrine Health	Bill Adams, Boston Medical Center, PaTH CRN Jon Arnold, University of Pittsburgh, PaTH CRN Crispin Goytia, Mount Sinai, INSIGHT CRN
2:50-3:00	Break	
3:00-3:55	Focus on Addressing Substance Use	Raj Shah, RUSH University Medical Center, PaTH CRN Les Lenert, Medical University of South Carolina, STAR CRN Megan Hamm, University of Pittsburgh, PaTH CRN
3:55-4:05	Brief Feedback Survey	
4:05-4:15	Wrap Up & Next Steps	