

PCORnet[®] Playbook

MODULE 3: USING PCORnet TO POWER YOUR RESEARCH

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3.1 What to Expect

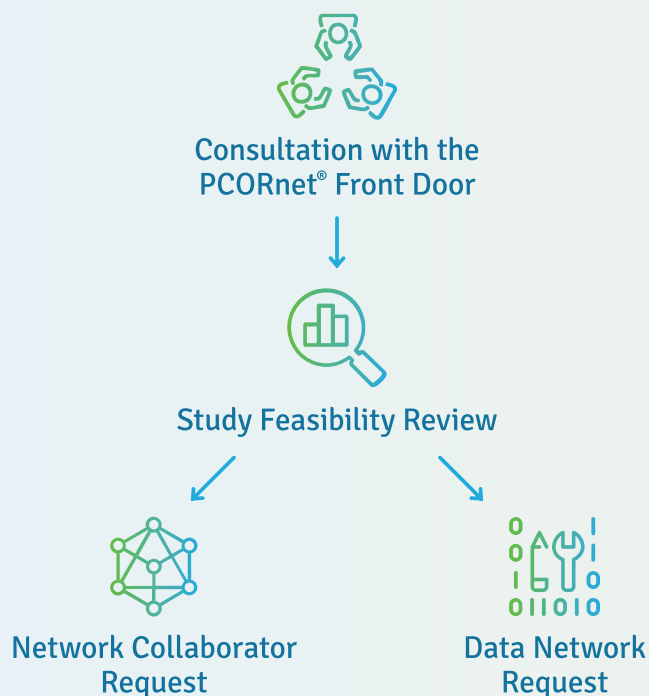
This module is an in-depth guide to accessing and using PCORnet resources to streamline your research. The PCORnet infrastructure is designed to be flexible, accommodating the different needs of studies funded by academic institutions, industry, federal agencies, and other partners. Whether you're pursuing a government-supported study or commercial research goals, the adaptable infrastructure of PCORnet helps streamline processes from planning the study through sharing of results.

When working with the PCORnet infrastructure, you will interact with the Coordinating Center for PCORnet® and its [PCORnet® Front Door](#) team. While the Coordinating Center is funded by an infrastructure award and therefore cannot directly participate in research projects, it can offer valuable guidance and support for your study. Think of the Coordinating Center and the PCORnet® Front Door team as links to the extensive resources of PCORnet such as sites participating in PCORnet, standardized data resources, and collaboration tools.

Importantly, you are not required to partner with any particular institution or funder as a collaborator; the PCORnet infrastructure includes a wide range of institutions and sites that can support your study independently of any specific partner. While PCORnet is not a funding source for research projects, services provided by the PCORnet® Front Door can strengthen funding applications submitted to variety of sponsors.

The PCORnet® Front Door team offers three core services—**Study Feasibility Reviews, Network Collaborator Requests, and Data Network Requests**—all provided at no cost and explained in detail below. Study Feasibility Reviews are part of the initial consultation with the PCORnet® Front Door team. The need for a Network Collaborator Request or a Data Network Request will depend on the specific needs of your study. These services can be tailored to help you plan your study, identify collaborators, and conduct your study within a flexible, patient-centered research framework. It is best to visit the PCORnet® Front Door as early as possible in your study planning to make the best use of the PCORnet infrastructure and resources; however, the PCORnet® Front Door team works with studies at any stage.

3 Main Service Types within a Consultation



STUDY FEASIBILITY REVIEW

A Study Feasibility Review is the first step in exploring how PCORnet can help you achieve your research goals. Offered as part of the PCORnet® Front Door consultation, this service allows you to better understand whether the data and resources available through PCORnet align with the needs of your study. This review is crucial for defining your study's scope, identifying the right resources, and determining the next steps.

When the research team for PREVENTABLE—a study on how statins impact dementia, disability, and heart disease in people 75 and older—needed to assess feasibility, they contacted the PCORnet® Front Door. The team provided aggregate data confirming that PCORnet® CRNs have the population of older adults the study needs.

Purpose of a Study Feasibility Review

- **Explore PCORnet Services and Receive Guidance:**

A Study Feasibility Review provides you with an early opportunity to gauge whether the PCORnet infrastructure—including available data types, sites, and patient populations—can support your research goals. It also helps determine if a Data Network Request or a Network Collaborator Request could benefit your study.

- **Gain Insight on Network Fit:**

During the consultation, PCORnet experts will assess your study goals and data requirements and then advise on how well PCORnet resources align with your research. They may identify specific PCORnet® Clinical Research Networks (CRNs) or sites that could be ideal collaborators based on their expertise or patient population.

When to Use a Study Feasibility Review

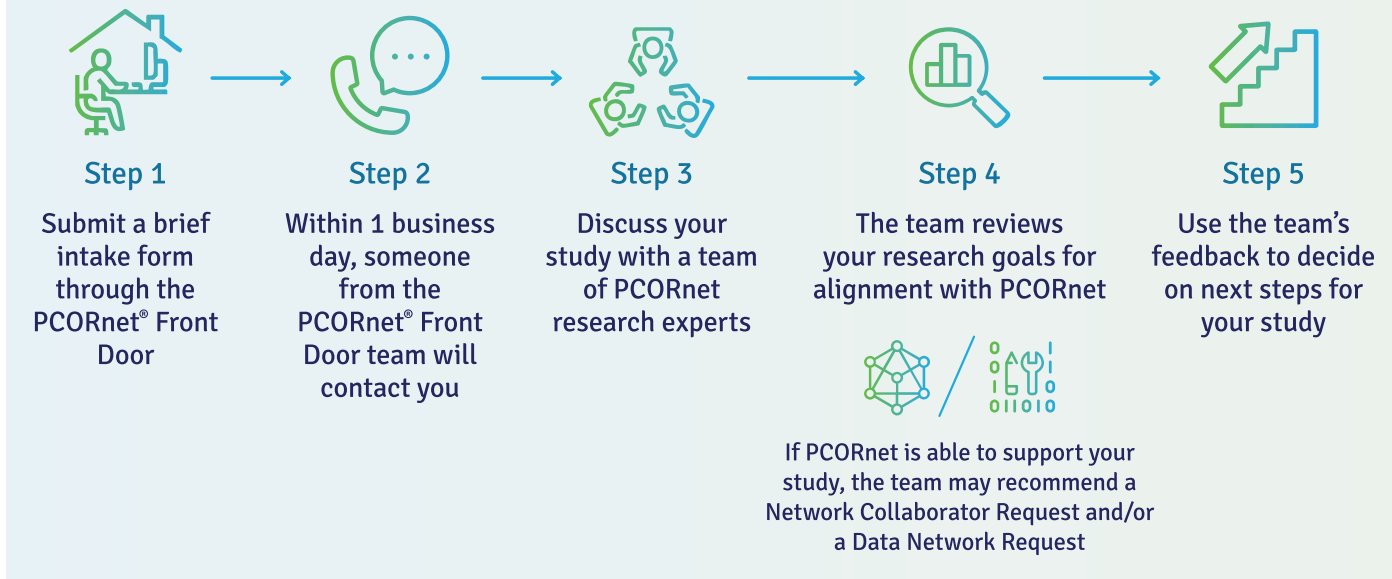
A Study Feasibility Review is useful if

- **You're in the Early Planning Stages:** If your study is still conceptual, this review helps clarify how PCORnet resources can support your research goals.
- **You Need Direction on Next Steps:** Many researchers find it useful to receive initial feedback before making formal requests, especially when they are exploring multiple study designs or they are new to distributed research networks.

We really appreciated the PCORnet® Front Door team, who explained everything to us and helped us navigate the process, including timelines (ours was short!), and connections with CRNs (regional networks) and individual sites.

— Brendan Everett, Principal Investigator, PRECIDENTD, a PCORnet® Study

Steps in a Study Feasibility Review



Process for a Study Feasibility Review

- **Request a Consultation:**

Contact the PCORnet® Front Door to request a consultation. Within 1 business day, someone from the team will follow up to request more information or schedule your consultation.

- **Discuss the Details:**

Your consultation—conducted via email or in a meeting—will focus on your study's goals, as well as any specific data or resource needs. The PCORnet® Front Door team will help you evaluate your study's alignment with the network, share insights into data availability, and answer any questions you may have about the PCORnet infrastructure.

- **Get Recommendations and Next Steps:**

Following the consultation, the PCORnet® Front Door team may recommend additional services tailored to your project. For example,

- A Data Network Request may be suggested to confirm the necessary patient population and data elements are available.

- A Network Collaborator Request may be appropriate if you're looking to build a multi-site team by identifying partner sites.

Outcomes of a Study Feasibility Review

- **Better Understand How Your Study Goals Align with the Network:**

A Study Feasibility Review is an initial assessment of how well the goals of your study align with the network, not confirmation of the availability of the data or patients needed for your study. This review is meant to help you determine if you need to refine your study design and identify next steps to effectively use PCORnet resources.

- **Determine Next Steps:**

Many researchers find this initial review helpful for decision-making, as it can highlight potential challenges and offer clarity on whether the PCORnet infrastructure aligns with their research needs. This insight can help you decide whether to proceed with additional PCORnet services, adjust your study design, or pursue other options.

NETWORK COLLABORATOR REQUEST

A Network Collaborator Request helps you identify and connect with sites interested in collaborating on your study. This service is especially valuable when seeking letters of support for funding applications, as it shows your ability to engage sites in a national research network.

Purpose of a Network Collaborator Request

- **Identify Collaborating Sites:**

A Network Collaborator Request will connect you with network sites that have relevant expertise and patient populations to ensure you are working with knowledgeable collaborators who can strengthen your study. Within PCORnet, sites are grouped into eight large PCORnet® [Clinical Research Networks \(CRNs\)](#) that may be aligned by geography or patient populations. You may select sites on your own or the PCORnet® Front Door team can recommend sites that are well suited for your study.

- **Enhance Funding Proposals:**

Having letters of support from multiple PCORnet® CRN sites can significantly strengthen your funding proposal. These letters demonstrate network-level commitment and the feasibility of your proposed study.

When to Use a Network Collaborator Request

A Network Collaborator Request is appropriate for two main scenarios.

1. **You Need Letters of Support for a Funding Application:**

Most researchers use a Network Collaborator Request to obtain site support letters and strengthen their grant applications. By including a range of committed sites, your application is more likely to secure funding.

2. **You Need Additional Sites for Your Funded Study:**

Some studies have used a Network Collaborator Request to recruit additional sites for an already funded study. If this applies to your study, you'll likely have detailed information about your project's scope, which will be helpful to engage sites that may be a good fit for your study.

For PREVENTABLE, the PCORnet® Front Door team worked with researchers to organize a webinar for the CRNs explaining the study's aims and why it is meaningful to patients. While typical requests attract interest from 10 to 25 sites, PREVENTABLE received interest from 36 sites, with 32 agreeing to participate.

Steps in a Network Collaborator Request



Process for a Network Collaborator Request

If, during your consultation, you and the PCORnet® Front Door team agree a Network Collaborator Request could benefit your study, you will work with the team to complete additional steps.

1. Complete Project Forms:

You will be asked to complete project forms to provide a brief overview of your study as well as specific details, such as patient populations, outcomes of interest, and engagement plans. The team will use this information to prepare sites for collaboration discussions.

2. Host a Webinar:

The PCORnet® Front Door team will support you in hosting a brief webinar to present your study to interested network sites. The webinar will give you the opportunity to explain the goals of your study, the expected level of site involvement, and logistics. This interactive format gives site staff the opportunity to ask questions and decide if their site is a good fit for the collaboration.

3. Receive Site Interest Forms:

After the webinar, sites have 10 business days to submit an interest form if they want to collaborate on your study. These forms, which have also been successfully submitted as letters of support for PCORI applications, capture contact details, specific expertise, and site-level qualifications that align with your research needs. The PCORnet team will compile these responses in a report so you can select sites that best suit your study goals.

Outcomes of a Network Collaborator Request

- **Receive a Report in ~4 Weeks:**

From your consultation to the completion of site interest forms, the Network Collaborator Request process takes about 4 weeks. The PCORnet team ensures this streamlined timeline by providing guidance at each stage and coordinating with sites on your behalf. At the end of the Network Collaborator Request process, you'll receive a report listing all interested sites, along with their qualifications and contact information.

- **Engage Sites Directly:**

The final report is a critical resource that provides all the information you need to directly engage with interested sites and finalize collaboration agreements.

“Our experience with the PCORnet® Front Door was incredibly valuable in the design of the study and in giving us confidence that we could pursue our goal of 20,000 participants and, importantly, that the study aim is meaningful and exciting to patients. There are so many resources PCORnet can offer to make research better, faster, and less expensive. I'd encourage anyone pursuing patient-centered research to reach out to the PCORnet® Front Door and see how the team can support your effort.

— Schuyler Jones, Principal Investigator, PREVENTABLE, a PCORnet® Study



DATA NETWORK REQUEST

A Data Network Request is a tool that helps you understand where relevant data for specific patients are available across PCORnet. This service is ideal if you need a high-level overview of data trends to inform your study's feasibility, design, or funding proposal.

Purpose of a Data Network Request

- **Assess the Availability of Patient Data:**
A Data Network Request provides insight into how many patients with specific health conditions, treatments, or outcomes appear across the network. For example, if you're studying a new medication or a rare condition, a Data Network Request can confirm if the specific patient data you need exist within PCORnet. This information is critical to understanding the potential reach and impact of your study.
- **Strengthen Funding Applications:**
A well-defined Data Network Request can strengthen your funding application by showing the availability and scope of specific patient insights available across PCORnet. It is especially useful for proposals that require evidence of a patient population that is sufficient to support your research goals.

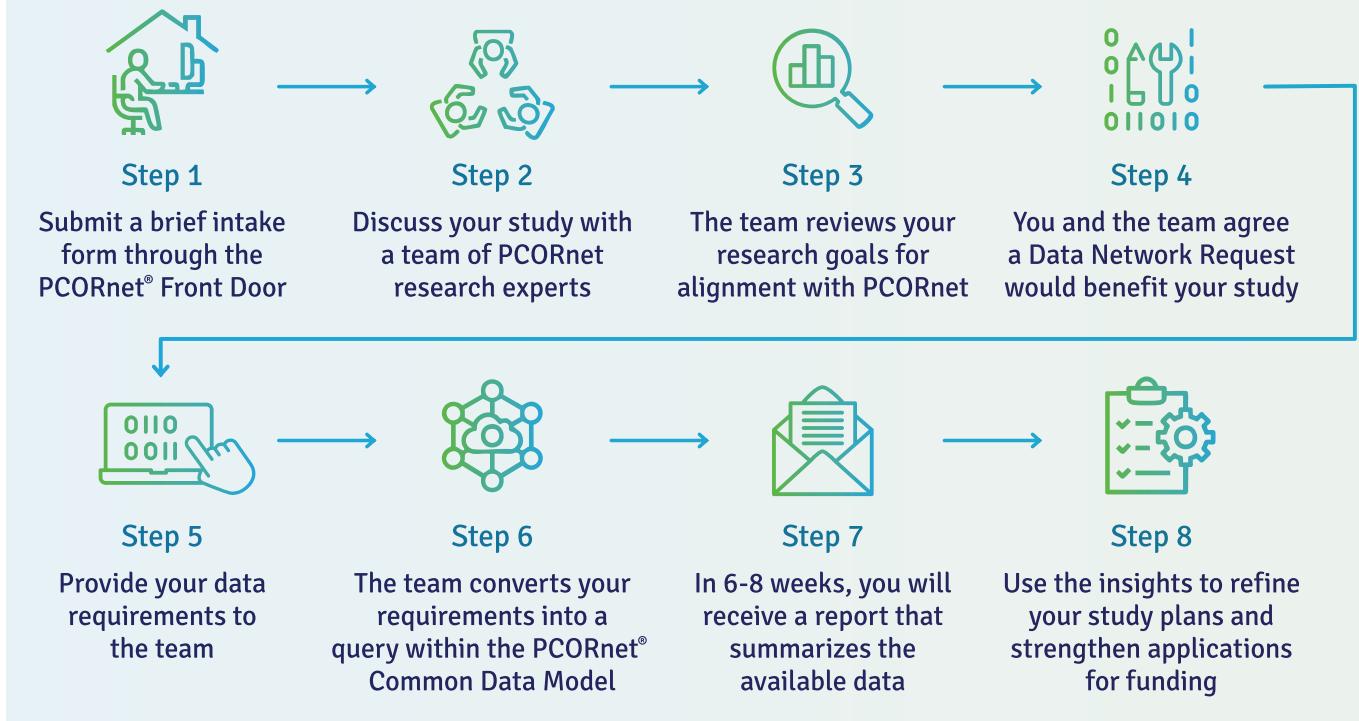
Data Reports: View snapshots of the extensive, real-world patient data collected across PCORnet® CRNs

When to Use a Data Network Request

To qualify for a Data Network Request, you must have

- **An Imminent Funding Proposal:**
In general, to perform a Data Network Request, the PCORnet® Front Door team will expect you to have a funding deadline or upcoming grant application. This requirement ensures the Data Network Request has a clear purpose in developing your study.
- **A Patient-Centered Focus:**
The PCORnet® Front Door team prioritizes requests that are meaningful to patients, which supports engagement and collaboration across sites.

Steps in a Data Network Request



Process for a Data Network Request

If, during your consultation, you and the PCORnet® Front Door team agree a Data Network Request could benefit your study, you will work with the team to complete additional steps.

1. Complete a Table Shell:

You will be asked to prepare a “table shell” to specify the data you’re seeking. This typically includes diagnosis or medication codes, demographic details, and other key criteria. The table shell helps refine the data requirements.

2. Submit Your Data Requirements for the Query:

After you provide the table shell, the PCORnet® Front Door team will translate your data requirements into a structured query within the [PCORnet® Common Data Model](#) (CDM) and begin executing the query across relevant sites.

Outcomes of a Data Network Request

• Receive a Report in 6–8 weeks:

After your data requirements are translated to the PCORnet® CDM, a Data Network Request typically takes 6–8 weeks to complete.

You will receive a report that summarizes available patient data across the network, providing insights into whether the PCORnet infrastructure has the depth and breadth of patient insights needed for your research. This report includes only site-level aggregate data and does not contain patient-specific information to ensure [patient privacy and compliance with network standards](#).

• Gain Insights to Plan Your Study:

The Data Network Request report can guide your study design and help refine your proposal or funding application by showing where the relevant data are available within PCORnet. This service can give you a clearer picture of the data within PCORnet and lay a solid foundation for your study’s success.

3.2 Administrative Simplicity

Streamlined [administrative tools](#) are available for researchers to simplify study start-up, from ethics approvals to data sharing. These tools can help reduce the time and effort it takes to start and manage multi-site studies. Note that site contracts will ultimately dictate how a PCORnet® Study will run, but these tools can serve as templates. The PCORnet® Front Door team can advise on which of these tools may benefit your study.

KEY TOOLS



Data Sharing Agreement



Clinical Research Collaboration Agreement



SMART IRB and IREx List



Data Study Flow Templates

- **Data Sharing Agreement:**

An agreement that establishes the processes for sharing de-identified and limited datasets for approved research purposes between the Coordinating Center and PCORnet® CRNs. These agreements emphasize patient privacy, data governance, and institutional oversight. However, the Data Sharing Agreement does not replace the need for institutional review board (IRB) approval or other necessary regulatory approvals required for specific studies. This structured approach ensures that data sharing

within PCORnet remains ethical, transparent, and aligned with the mission to support patient-centered research.

- **Clinical Research Collaboration Agreement:**

A pre-negotiated agreement template that accelerates contracting for PCORI-funded studies, providing a consistent framework for negotiations between investigators.

- **SMART IRB:**

A centralized, shared review system designed to simplify and expedite IRB approval processes for multi-site research studies. It allows participating institutions to rely on a single IRB to review a study, rather than requiring individual IRB approvals from each institution involved. This collaborative approach reduces redundancy, speeds up the review process, and helps ensure consistency in the ethical oversight of PCORnet® Studies of all sizes. It is especially beneficial for large, multi-site studies.

- **IREx List:**

An online platform used by sites participating in PCORnet to share IRB approval information across multiple institutions involved in a research study. It streamlines the process of managing IRB approvals, ensuring all participating sites can easily access and rely on a single, central IRB review. This helps reduce administrative burden and accelerates study start-up.

- **Data Study Flow Templates:**

These templates outline data flow processes in PCORnet® Studies, providing a standard format for IRB applications and expediting the approval process.



LEAD SITES

In the PCORnet infrastructure, a lead site is a key partner site within the network that acts as your primary collaborator and project liaison for multi-site studies. Lead sites have significant experience managing administrative processes, coordinating site-specific activities, and guiding budget requirements for multi-site research. Here's what you need to know:

- **Identification and Selection:**
If you're already affiliated with a network site, that site can often serve as your lead site. If not, the PCORnet® Front Door team can recommend a lead site during your initial consultation. Lead sites are chosen based on their expertise, familiarity with your study's focus, and ability to support your project's specific needs.
- **Role and Responsibilities:**
A lead site typically handles much of the project management and administrative workload, including IRB submissions, contracting, and coordinating across network sites.
- **Budgeting Support:**
Lead sites can provide detailed insights into potential costs, including per-site fees for study start-up, patient recruitment, and data management. Engaging a lead site early can help streamline budgeting and ensure your project is set up for success.

3.3 Pricing Guidance

All initial services provided by the PCORnet® Front Door—Study Feasibility Reviews, Data Network Requests, and Network Collaborator Requests—are provided at no cost. However, if your study progresses into using the infrastructure of PCORnet beyond these planning activities, there are costs involved.

Costs depend on the needs of a study and vary across different PCORnet® CRNs, so this module doesn't include specific amounts. However, it provides general guidance and describes the various factors that influence cost and how to account for them.

GUIDANCE FOR ESTIMATING COSTS

- **Site-Specific Activities:**

As with any study, it's essential to budget for costs associated with each site's study activities. Specific costs that vary across the PCORnet® CRNs may include

- **Site Start-up Costs:** Sites may charge initial fees for setting up the study, including administrative approvals and IRB processing.

- **Per-Patient Costs:** If your study involves participant enrollment, sites often charge a per-patient fee based on the effort needed to recruit, consent, and retain participants. These per-patient costs should come early in your study budget planning.
- **Data Query Costs:** If your study requires data from individual sites' electronic health records or the PCORnet® CDM, you should budget for the costs of running the query and collecting and transferring the data.
- **Compensation for Patient Partners:** When compensating Patient Partners in research, it's important that the compensation is fair, transparent, and reflective of the valuable time and effort they contribute. Compensation should be tailored to the type of involvement, whether it's for attending meetings, reviewing materials, or contributing to the study design.



- **Query Costs:**

While simple Data Network Requests are provided at no cost as part of the PCORnet® Front Door consultation, complex data queries may require funding. A query may be considered complex if it includes data linkages outside PCORnet, data that are not standardized in the [PCORnet® CDM](#), or multiple PCORnet® CRNs. For the best results, it is recommended to engage a network site to act as a data coordinating center and write and manage complex queries. This approach ensures

- **Efficiency and Accuracy:** Sites participating in PCORnet are familiar with the PCORnet® CDM and can tailor queries to meet study specifications.
- **Cost-Effectiveness:** A centralized approach to query development and data sharing minimizes redundant costs and helps maintain consistency across sites.

By partnering with a lead site and planning for these costs, you can create a more accurate budget, strengthen your funding applications, and set a strong foundation for conducting a successful study powered by PCORnet®.

We want to thank the [many individuals](#) who have contributed their time and valuable input to developing the PCORnet® Playbook.

Complete the [feedback form](#) to share your thoughts or suggestions to help us improve the PCORnet Playbook