

Testing PCORnet's Research Functionality

PCORI funded the development of PCORnet, the National Patient-Centered Clinical Research Network, to address an urgent national need to conduct patient-centered outcomes research faster, more efficiently, and at lower cost than previously possible. It does so by leveraging the power of health data and unique patient partnerships.



PCORI also funded several PCORnet demonstration studies that aim to test PCORnet while answering key questions to help patients and those who care for them make better-informed health and healthcare decisions. The results from these studies will inform the future of PCORnet by highlighting opportunities for improvement and enhancement.

We face many important unanswered questions about health care.



"What type of chemo is best for a breast cancer patient diagnosed at age 82?"



"My son was diagnosed with ADHD. What risks does he face if he goes on meds?"



"What can my hospital do to reduce readmission rates?"



"How can I help my patient with chronic back pain decide on the best treatment?"

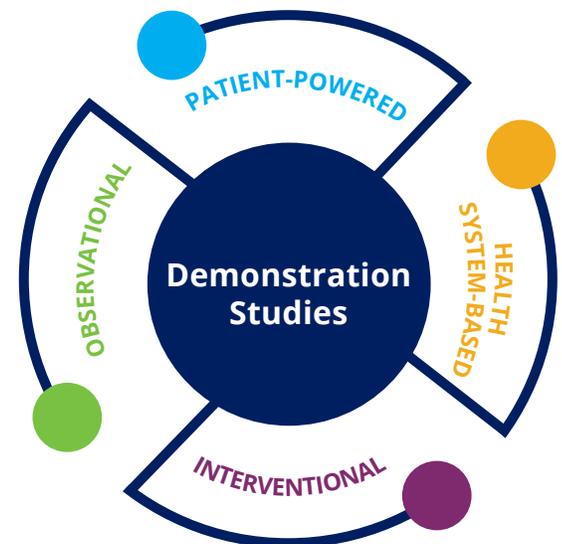


DEMONSTRATION STUDIES

PCORnet's demonstration studies fall under one of four initiatives:

- Interventional studies
- Observational studies
- Health systems studies
- Patient-powered research network (PPRN) studies

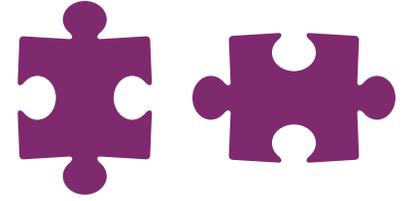
All of these are designed to answer important patient-centered research questions and uniquely designed to test key aspects of PCORnet functionality.



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Interventional Study

This initiative is composed of the ADAPTABLE aspirin study, PCORnet's first pragmatic randomized controlled clinical trial. ADAPTABLE integrates with routine clinical care and healthcare delivery. The study uses data from electronic health records (EHRs) to identify patients for participation and recruitment. ADAPTABLE is embracing a new paradigm of patient engagement in clinical research. The ADAPTABLE patient partners—Adaptors—work alongside researchers in all aspects of the trial, including designing the protocol, consent form, study portal, and study materials.



Research Under Way

- ADAPTABLE (Aspirin Dosing: A Patient-Centric Trial Assessing Benefits and Long-Term Effectiveness)

Observational Studies

These studies employ an observational design and test the technical and operational aspects of PCORnet's Distributed Research Network. They also test standardized capture of a wide range of claims, EHRs, and prescription data in PCORnet's Common Data Model (CDM).



Research Under Way

- PCORnet Bariatric Study
- PCORnet Obesity Observational Study: Short- and Long-Term Effects of Antibiotics on Childhood Growth

Health Systems Studies

These studies test PCORnet's ability to engage health systems leaders and clinicians across Clinical Data Research Networks (CDRNs); to do focused and agile research that leverages the CDM and new health system data; and to do analyses rapidly and iteratively to facilitate development of learning healthcare systems. Learning healthcare systems, as defined by the National Academy of Medicine, emphasize a collaborative approach that shares data and insights across boundaries to drive better, more-efficient medical practice and patient care.



Research Under Way

- Automating Quality and Safety Benchmarking for Children: Meeting the Needs of Health Systems and Patients
- Identifying and Predicting Patients with Preventable High Utilization
- The Impact of Patient Complexity on Healthcare Utilization
- Variation in Case Management Programs and Their Effectiveness in Managing High-Risk Patients for Medicare Accountable Care Organizations

Patient-Powered Research Network (PPRN) Studies

These test the ability to conduct research that addresses the concerns of patient network members. The studies use patient-identified research questions that have been prioritized by PPRN community stakeholders and other participants. PPRN studies include both observational and randomized controlled trials.

Research Under Way

- Comparative Effectiveness of Specific Carbohydrate and Mediterranean Diets to Induce Remission in Patients with Crohn's Disease
- Harnessing PCORnet to Study Comparative Effectiveness and Safety of Biologic Therapies
- Healthy Hearts Healthy Minds
- Healthy Mind Healthy You: A Study of Mindfulness
- Monitoring and Peer Support to Improve Treatment Adherence and Outcomes in Patients with Overlapping Chronic Obstructive Pulmonary Disease and Sleep Apnea via a Large PCORnet Collaboration (O2VERLAP)
- Resiliency Education to Reduce Depression Disparities
- Using Single Subject (N-of-1) Designs to Answer Patient-Identified Research Questions

