The National Patient-Centered Clinical Research Network

PCORnet is a PCORI initiative designed to empower people to make informed healthcare decisions by enabling clinical research that is faster, easier, less costly and, most importantly, more relevant to their needs. At the same time, it is engaging stakeholders from across the healthcare community in productive research partnerships.

PCORnet offers the means for researchers to securely access information on the health experiences of tens of millions of patients across hundreds of healthcare organizations. It is tapping resources such as electronic health records (EHRs), insurance claims, and outcomes reported by patients to power robust, real-world clinical research. Patients have a strong voice in determining what topics will be studied and how.

Accomplishments to Date

PCORnet has created a distributed research network that unites patients, clinicians, health systems, and health plans in an effort to expedite research that can improve health care and patient outcomes.

PCORnet represents:
- About 100 million patients who have had a medical encounter in the past five years*
- Engaged and collaborating partner networks
- 130+ partnerships with health systems and patient groups
- 150+ common and rare conditions
- $50 million in PCORI-approved funding to support demonstration projects

*Some individuals may have visited more than one network partner

Engagement

Patients
PCORnet empowers patients’ involvement in all phases of research, making sure projects focus on what matters most to patients and caregivers. PCORnet allows often-ignored conditions and populations to be studied.

Clinicians
PCORnet research drives for high-quality insights to inform clinical best practices and empowers clinicians and their patients to make informed, evidence-based healthcare decisions.

Researchers
PCORnet’s Front Door allows researchers to access its data and resources, including submitting queries to plan future research projects.

Health Systems
PCORnet enables health systems to conduct agile research that leverages EHR data and other health systems-based data sources.
PCORnet’s Partner Networks

PCORnet is primarily made up of three kinds of partner networks: Clinical Data Research Networks (CDRNs), Health Plan Research Networks (HPRNs), and Patient-Powered Research Networks (PPRNs).

13 Clinical Data Research Networks*

CDRNs are networks that originate in healthcare systems, such as hospitals, health plans, or practice-based networks, and securely collect health information during the routine course of patient care.

- Accelerating Data Value across a National Community Health Center Network (ADVANCE)
- Accessible Research Commons for Health (ARCH)
- Chicago Area Patient-Centered Outcomes Research Network (CAPriCORN)
- Greater Plains Collaborative
- Kaiser Permanente & Strategic Partners Patient Outcomes Research To Advance Learning (PORTAL) Network
- Research Action for Health Network (REACHnet)
- Mid-South Clinical Data Research Network
- PEDSnet: A Pediatric Learning Health System
- New York City Clinical Data Research Network
- OneFlorida Clinical Data Research Network
- Patient-Centered Network of Learning Health Systems (LHSNet)
- Patient-Centered SCAlable National Network for Effectiveness Research (pSCANNER)
- PaTH: Towards a Learning Health System in the Mid-Atlantic Region

20 Patient-Powered Research Networks*

PPRNs are operated by patient groups and their partners, and are focused on a particular condition or population.

- American BRCA Outcomes and Utilization of Testing Patient-Powered Research Network (ABOUT Network)
- ARthritis Patient Partnership with Comparative Effectiveness Researchers (AR-PoWER PPRN)
- Collaborative Patient-Centered Rare Epilepsy Network (REN)
- Community and Patient Partnered Research Network (CPPRN)
- Community Engaged Network for All (CENA)
- COPD Patient-Powered Research Network
- DuchenneConnect Registry Network
- Health eHeart Alliance
- ImproveCareNow: A Learning Health System for Children with Crohn’s Disease and Ulcerative Colitis
- IBD Partners
- Interactive Autism Network
- Mood Patient-Powered Research Network
- Multiple Sclerosis Patient-Powered Research Network
- National Alzheimer’s and Dementia Patient and Caregiver Powered Research Network (AD-PCPRN)
- NephCure Kidney Network
- Patients, Advocates, and Rheumatology Teams Network for Research and Service (PARTNERS)
- Phelan-McDermid Syndrome Data Network (PMS_DN)
- PI Patient Research Connection (PI CONNECT)
- Population Research in Identity and Disparities for Equality Patient-Powered Research Network (PRIDEnet)
- Vasculitis Patient-Powered Research Network (V-PPRN)

2 Health Plan Research Networks (HPRNs)

HPRNs are health plans that cover significant numbers of patients in one or more of the PCORnet CDRNs.

- HealthCore-Anthem Research Network American
- HUMnet: Humana

*Approved July 2015

Collaborative Research Groups

PCORnet’s Collaborative Research Groups (CRGs) foster multi-network partnerships focused on developing new research questions that are highly-relevant to specific health topics, such as research methods, health care utilization, health conditions, or patient populations.

- Autoimmune and systemic inflammatory syndromes
- Cancer
- Cardiovascular health
- Diabetes and obesity
- Health disparities
- Health services research
- Kidney health
- Pediatrics
- Pulmonary health

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