

Launching PCORnet, the National Patient-Centered Clinical Research Network

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The National Patient-Centered Clinical Research Network

PCORnet

PCORnet: the National Patient-Centered Clinical Research Network



The goal of PCORI's National Patient-Centered Clinical Research Network Program is to **improve the nation's capacity to conduct CER efficiently, by creating a large, highly representative, national patient-centered clinical research network** for conducting clinical outcomes research.

The vision is to support a learning US healthcare system, which would allow for **large-scale research** to be conducted with **enhanced accuracy and efficiency**.



Overall objectives of PCORnet: achieving a single functional research network

- Engagement of patients, providers and health system leaders
- Support of **multi-center observational and interventional CER** studies
- Openness to **external data and research partners** participating with PCORI-funded networks
- Availability to **researchers not directly affiliated** with PCORnet partners through collaborative arrangements.
- PCORnet partners will be encouraged to **use the resources created with PCORI's support** for a range of activities supported by other organizations.



PCORI

PCORnet EXECUTIVE BODY

STEERING COMMITTEE

EXECUTIVE COMMITTEE

CLINICAL DATA
RESEARCH NETWORKS

PATIENTS &
POPULATIONS

PATIENT-POWERED
RESEARCH NETWORKS

PCORnet
COORDINATING
CENTER

PROJECT
MANAGEMENT
OFFICE

TASK FORCES

GOVERNANCE

DATA PRIVACY

ETHICS & REGULATORY

DATA STANDARDS &
SECURITY

HEALTH SYSTEMS
INTERACTION

PATIENT & CONSUMER
ENGAGEMENT

PATIENT GENERATED
OUTCOMES

CLINICAL TRIALS

RARE DISEASES

BIOREPOSITORIES

OBESITY



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The National Patient-Centered Clinical Research Network

29 CDRN and PPRN awards were approved on December 17th by PCORI's Board of Governors



CDRN Partners

Goals for Clinical Data Research Networks (CDRNs)

- ❖ Extracts from **EHR data** are standardized within network
- ❖ A minimum of **1 million patients** enrolled
- ❖ Capable of implementing **clinical trials**
- ❖ Individual network's data in **interoperable format** with other awardee networks and successfully responds to **queries**
- ❖ **Patients, system, and clinicians** involved in governance and use of network
- ❖ At least **three patient cohorts** identified, characterized, and surveyed



CDRN Highlights

- Networks of **academic medical centers**, hospitals and physician practices
- Non-profit **integrated health systems**
- Networks of **low income clinics**
- Networks leveraging **AHRQ investments and NIH investments (CTSAs)**
- Inclusion of **Health Information Exchanges**
- Wide **geographical** spread
- Inclusion of **underserved** populations
- Range from **1M covered lives to 28M**



11 CDRNs

CDRN Name	Lead Organization	Principal Investigator
ADVANCE	Oregon Community Health Information Network	Jennifer DeVoe
CAPriCORN	The Chicago Community Trust	Terry Mazany
Great Plains Collaborative	University of Kansas Medical Center	Lemuel Waitman
Louisiana Clinical Data Research Network	Louisiana Public Health Institute	Anjum Khurshid
Mid-South CDRN	Vanderbilt University	Russell Rothman
NYC-CDRN	Weill Medical College of Cornell University	Rainu Kaushal
PEDSNet	The Children's Hospital of Philadelphia	Christopher Forrest
PORTAL	Kaiser Foundation Research Institute	Elizabeth McGlynn
pSCANNER	University of California, San Diego	Lucila Ohno-Machado
P2ATH	University of Pittsburgh	Rachel Hess
SCIHLS	Harvard University	Kenneth Mandl

PPRN Partners

Goals for Patient Powered Research Networks (PPRNs)

- 🌐 Target size of **0.5% of U.S population** with condition: (> 50 patients for rarest diseases; 50,000 for most common)
- 🌐 **Patient-reported data** collected for at least 80% of cohort
- 🌐 **Patients** involved in governance
- 🌐 **Standardized data** suitable for sharing with other infrastructure members and successfully responds to **queries**



PPRN Characteristics

- Variety of **stakeholders** in participating organizations and in leadership team: patients, advocacy groups, physician organizations, academic centers, PBRNs etc.
- Strong understanding of **patient engagement**
- Significant range of **conditions and diseases**
- Variety in **populations** represented (including pediatrics, underserved populations etc.)
- **50% rare diseases**
- Significant range in the **maturity** of the group in terms of data available
- Several have capacity to work with **biospecimens**



PPRNs span a number of diseases...

Organization	PI	Condition	Proposed Population Size
Accelerated Cure Project for Multiple Sclerosis	Robert McBurney	Multiple Sclerosis	20,000
American Sleep Apnea Association	Susan Redline	Sleep Apnea	50,000
Cincinnati Children's Hospital Medical Center	Peter Margolis	Pediatric Crohn's Disease and Ulcerative Colitis	15,000
COPD Foundation	Richard Mularski	COPD	50,000
Crohn's and Colitis Foundation of America	R. Balfour Sartor	Inflammatory Bowel Disease (Crohn's disease and ulcerative colitis)	30,000
Global Healthy Living Foundation	Seth Ginsberg	Arthritis (rheumatoid arthritis, spondyloarthritis), musculoskeletal disorders (osteoporosis), and inflammatory conditions (psoriasis)	50,000
Massachusetts General Hospital	Andrew Nierenberg	Major Depressive Disorder (MDD) and Bipolar Disorder (BP)	50,000
University of California, San Francisco	Mark Pletcher	Cardiovascular health	100,000
University of South Florida	Rebecca Sutphen	Hereditary Breast and Ovarian Cancer (HBOC)	17,000

... and include both common and rare diseases

Organization	PI	Condition	Size
ALD Connect, Inc	Florian Eichler	Adrenoleukodystrophy	3000
Arbor Research Collaborative for Health	Bruce Robinson	Primary Nephrotic Syndrome (Focal Segmental Glomerulosclerosis [FSGS], Minimal Change Disease [MCD], and Membranous Nephropathy [MN] Multiple Sclerosis	1250
Duke University	Laura Schanberg	Juvenile Rheumatic Disease	9000
Epilepsy Foundation	Janice Beulow	Aicardi Syndrome, Lennox-Gastaut Syndrome, Phelan-McDermid Syndrome, Hypothalamic Hamartoma, Dravet Syndrome, and Tuberous Sclerosis	1500
Genetic Alliance, Inc	Sharon Terry	Alström syndrome , Dyskeratosis congenital, Gaucher disease, Hepatitis, Inflammatory breast cancer, Joubert syndrome, Klinefelter syndrome and associated conditions, Metachromatic leukodystrophy, Pseudoxanthoma elasticum (PXE), Psoriasis	50- 50,000
Immune Deficiency Foundation	Kathleen Sullivan	Primary Immunodeficiency Diseases	1250
Parent Project Muscular Dystrophy	Holly Peay	Duchenne and Becker muscular dystrophy	4000
Phelan-McDermid Syndrome Foundation	Megan O'Boyle	Phelan-McDermid Syndrome	737
University of Pennsylvania	Peter Merkel	Vasculitis	500 (Pilot)



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