

Accessing PCORnet's Data and Network Resources

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The National Patient-Centered Clinical Research Network

Our national clinical research system is well-intentioned but needs improvement

We are not generating the evidence we need to support the healthcare decisions that patients and their doctors have to make every day.

- + High percentage of decisions are not supported by evidence
- + Health outcomes and disparities are not improving
- + Current clinical research system faces several problems:



Too slow



Too expensive



Doesn't answer questions that matter most to people



But how can we improve?



What if we could **decrease the time it takes to get clinical insights?**



What if we could achieve **significant cost savings** over a traditional clinical study?



What if we could have at our fingertips **trustworthy, high-quality data** from health systems, people and partnerships to **bring people the real-world answers they seek?**



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PCORnet: the National Patient-Centered Clinical Research Network



PCORnet is **a large, highly representative, national patient-centered clinical research network.**

Our **vision** is to support a learning U.S. healthcare system and to enable **large-scale clinical research** conducted with **enhanced quality and efficiency.**

Our **mission** is to enable faster, more trustworthy clinical research that **helps people make informed health decisions.**

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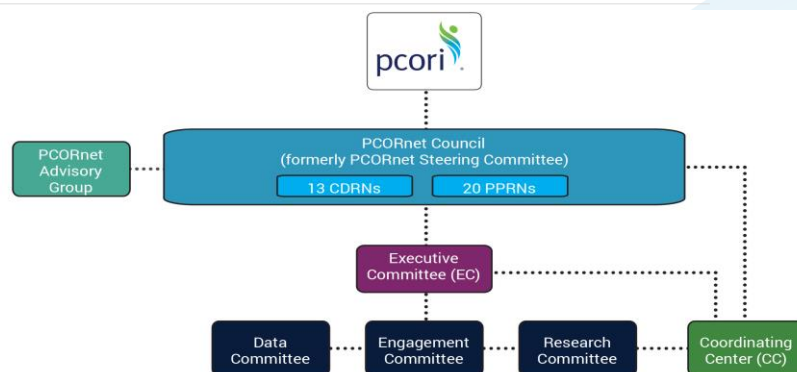
With PCORnet, we have developed a nationwide functional research network that...

- ✚ **Creates** infrastructure, tools, and policies to support rapid, efficient clinical research
- ✚ **Utilizes** multiple electronic health records, insurance claims data, data reported directly by people, and other data sources
- ✚ **Engages** people, clinicians, and health system leaders throughout



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PCORnet Structure and Decision-making Process



Role Descriptions:

Executive Committee (EC): Oversight for PCORnet operations

PCORnet Council: Representative governing body for PCORnet strategy and operations; includes PCORnet's 13 Clinical Data Research Networks (CDRNs) and 20 Patient-Powered Research Networks (PPRNs)

Coordinating Center (CC): Coordinates operational activities, maintains data infrastructure, identifies research opportunities, coordinates multi-site research



PCORnet embodies a “community of research” by uniting people, clinicians & systems















$$\begin{array}{ccccc}
 20 & & 13 & & \\
 \text{Patient-Powered Research} & + & \text{Clinical Data} & = & \text{PCORnet} \\
 \text{Networks (PPRNs)} & & \text{Research Networks} & & \text{A national infrastructure} \\
 & & \text{(CDRNs)} & & \text{for people-centered} \\
 & & & & \text{clinical research}
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Clinical Data Research Networks (CDRNs)

ADVANCE	<u>Accelerating Data Value Across a National Community Health Center Network (ADVANCE)</u> Oregon Community Health Information Network (OCHIN)		<u>National PEDSnet: A Pediatric Learning Health System</u> The Children's Hospital of Philadelphia
	<u>Chicago Area Patient Centered Outcomes Research Network (CAPriCORN)</u> The Chicago Community Trust		<u>New York City Clinical Data Research Network (NYC-CDRN)</u> Weill Medical College of Cornell University
	<u>Greater Plains Collaborative (GPC)</u> University of Kansas Medical Center		<u>OneFlorida Clinical Data Research Network</u> University of Florida
	<u>Kaiser Permanente & Strategic Partners Patient Outcomes Research To Advance Learning (PORTAL) Network</u> Kaiser Foundation Research Institute		<u>Patient-Centered Network of Learning Health Systems (LHSNet)</u> Mayo Clinic
	<u>Research Action for Health Network (REACHnet)</u> Louisiana Public Health Institute (LPHI)		<u>Patient-oriented SCALable National Network for Effectiveness Research (pSCANNER)</u> University of California, San Diego (UCSD)
	<u>Mid-South CDRN</u> Vanderbilt University		<u>PaTH: Towards a Learning Health System</u> University of Pittsburgh
			<u>Scalable Collaborative Infrastructure for a Learning Healthcare System (SCILHS)</u> Harvard University



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Patient Powered Research Networks (PPRNs)

	American BRCA Outcomes and Utilization of Testing Patient-Powered Research Network (ABOUT Network) University of South Florida		ImproveCareNow: A Learning Health System for Children with Crohn's Disease and Ulcerative Colitis Cincinnati Children's Hospital Medical Center
	ARthritis patient Partnership with comparative Effectiveness Researchers (AR-PoWER PPRN) Global Health Living Foundation		Interactive Autism Network Kennedy Krieger Institute
	CCFA Partners Patient Powered Research Network Crohn's and Colitis Foundation of America		Mood Patient-Powered Research Network Massachusetts General Hospital
	Collaborative Patient-Centered Rare Epilepsy Network (REN) Epilepsy Foundation		Multiple Sclerosis Patient-Powered Research Network Accelerated Cure Project for Multiple Sclerosis
	Community and Patient-Partnered Centers of Excellence for Behavioral Health University of California Los Angeles		National Alzheimer's and Dementia Patient and Caregiver-Powered Research Network Mayo Clinic
	Community-Engaged Network for All (CENA) Genetic Alliance, Inc.		NephCure Kidney International Arbor Research Collaborative for Health
	COPD Patient Powered Research Network COPD Foundation		Patients, Advocates and Rheumatology Teams Network for Research and Service (PARTNERS) Consortium Duke University
	DuchenneConnect Registry Network Parent Project Muscular Dystrophy		Phelan-McDermid Syndrome Data Network Phelan-McDermid Syndrome Foundation
	Health eHeart Alliance University of California, San Francisco (UCSF)		PI Patient Research Connection: PI-CONNECT Immune Deficiency Foundation
			Population Research in Identity and Disparities for Equality Patient-Powered Research Network (PRIDEnet) University of California San Francisco
			Vasculitis Patient Powered Research Network University of Pennsylvania

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PCORnet Projects (n=18)

Network Lead	PI	Title	Study Phase	Sponsor
CC-Duke	Adrian Hernandez, Matthew Roe	ADAPTABLE: Aspirin Dosing: A Patient-centric Trial Assessing Benefits and Long-Term Effectiveness	Enrolling	PCORI: \$14 million
PORTAL	David Arterburn	PCORnet Bariatric Study	Awarded, Planning	PCORI: \$4.5 million
CC-HPHC	Jason Block	Obesity-Short and Long-Term Effects of Antibiotics on Childhood Growth	Awarded, Planning	PCORI: \$4.5 million
COPD	Jerry Krishnan	RELANCE; Roflumilast or Azithromycin to Prevent COPD Exacerbations	Awarded, Planning	PCORI: \$13.7 million
University of Wisconsin-Madison	Scott Solomon Orly Vardeny	INfluenza Vaccine to Effectively Stop Cardio Thoracic Events and Decompensated heart failure (INVESTED)	Awarded, Planning	PCORI: \$1.3 million
ImproveCare Now	Michael Kappelman	COMBINE; AntiTNF Monotherapy versus Combination Therapy with Low Dose Methotrexate in Pediatric Crohn's Disease	Awarded, Planning	PCORI: \$7.8 million
OneFlorida	Bill Hogan	Surveillance for Microcephaly	Proposal	FDA/Reagan-Udall/PCORI: \$500K
CAPriCORN	William Trick	Antimicrobial Use and Reporting	Proposal	FDA/Reagan-Udall/PCORI: \$500K
CC-Duke	Sreekanth Vemulapalli	Improving Data Completeness and Expanding Available Data Elements in the TVT Registry through the use of Electronic Health Record Based Data: Linking the TVT Registry and PCORnet	Proposal	FDA/Reagan-Udall/PCORI: \$500K

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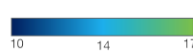
PCORnet Projects

Network Lead	PI	Title	Study Phase	Sponsor
CPPRN	Bowen Chung	Resiliency Education to Reduce Depression Disparities	Awarded, Planning	PCORI: \$2.5 million
AR-PoWER	Jeffrey Curtis	Harnessing PCORnet to Study Comparative Effectiveness and Safety Biologic Therapies	Awarded, Planning	PCORI: \$2.5 million
COPD	David Mannino	Monitoring and Peer Support to Improve Treatment Adherence and Outcomes in Patients with Overlap Chronic Obstructive Pulmonary Disease and Sleep Apnea via a Large PCORnet Collaboration (O2VERLAP)	Awarded, Planning	PCORI: \$2.48 million
CCFA Partners	James Lewis	Comparative Effectiveness of Specific Carbohydrate and Mediterranean Diets to Induce Remission in Patients with Crohn's Disease	Awarded, Planning	PCORI: \$2.5 million
MOOD	Andrew Nierenberg	Healthy Hearts Health Minds: A PPRN Demonstration Pragmatic Trial	Awarded, Planning	PCORI: \$2.49 million
GPC	Maureen Smith	Variation in Case Management Programs and Their Effectiveness in Managing High-Risk Patients for Medicare ACOs	Awarded, Planning	PCORI: \$1.4 million
ADVANCE	Scott Fields	The Impact of Patient Complexity on Healthcare Utilization	Awarded, Planning	PCORI: \$1 million
PEDSnet	Kathleen Walsh	Automating Quality and Safety Benchmarking for Children: Meeting the Needs of Health Systems and Patients	Awarded, Planning	PCORI: \$670,000
NYC-CDRN	Rainu Kaushal	Identifying and Predicting Patients with Preventable High Utilization	Awarded, Planning	PCORI: \$1.2 million

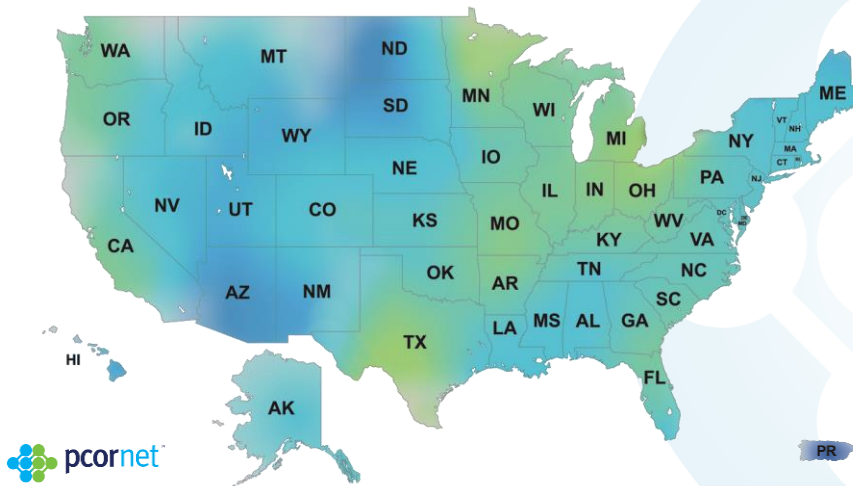


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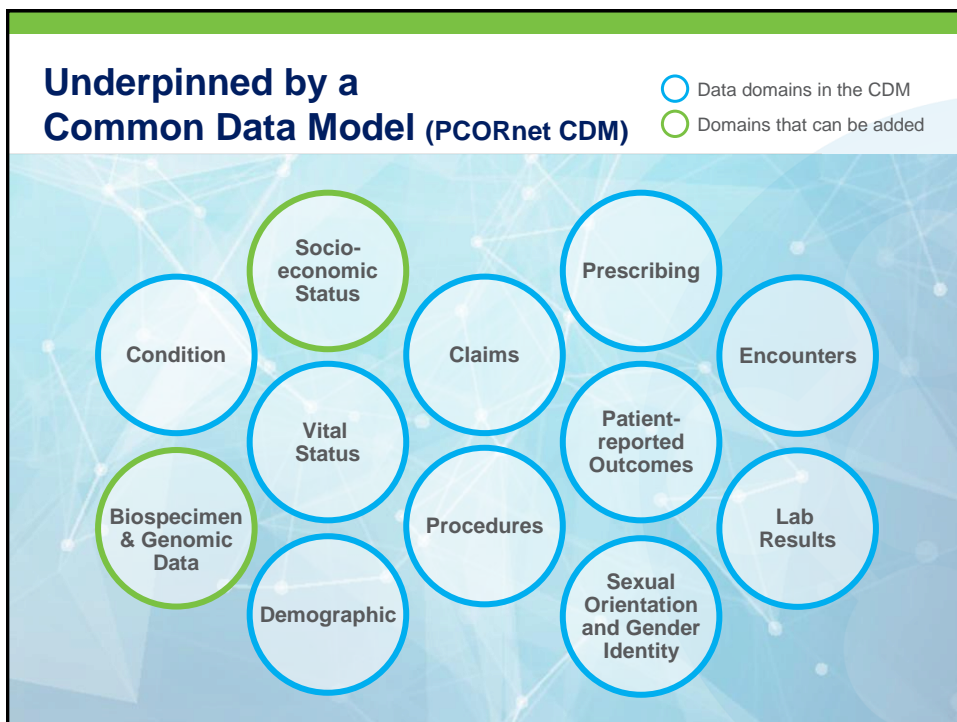
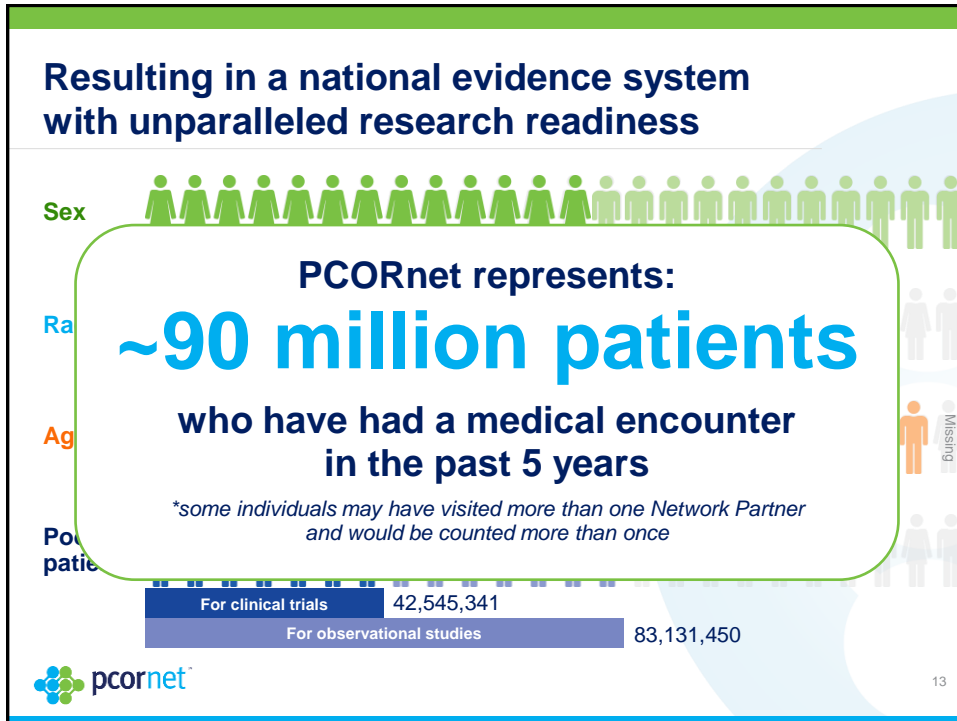
With coverage in every state — PCORnet represents thousands of conditions



This map depicts the number of PCORI-funded Patient-Powered or Clinical Data Research Networks that have coverage in each state.



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Underpinned by a Common Data Model (PCORnet CDM)

Same data are represented differently at different institutions
(e.g., Type of Encounter)

Common Data Model		
SITE 1	SITE 2	Ambulatory Visit (AV)
Social Work Visit	Office Visit	Emergency Department (ED)
Allied Health	Specimen	ED Admit to Inpatient (EI)
Office Visit	Postpartum Visit	Inpatient Hospital (IP)
Nurse Visit	Clinical Support	Non-Acute Inst. Stay (IS)
Procedure Visit	Initial Prenatal	Other Ambulatory (OA)
Employee Health		Other (OT)
Vascular Lab		Unknown (UN)
Sleep Study Visit		No Information (NI)
Social Work Visit		(null)
	SITE 3	Ambulatory Visit (AV)
	Home Care Visit	
	Office Visit	
	Therapy Visit	
	Orders Only	
	Cardiology Testing	
	Hospital Encounter	

In order to be able to trust results of an analysis, need to have consistent representations

Demographics: Initial Results that included more than 40 million persons with a 2014 encounter

	PCORnet*	2010 US Census
Age		
0-20	27.6%	27.0%
21-44	28.1%	33.6%
45-64	26.6%	26.4%
65-74	10.1%	7.0%
75+	7.7%	6.0%
Sex		
Female	57.1%	50.8%
Male	42.9%	49.2%
Other/Missing	0.0%	
Race		
Black/African American	12.1%	12.6%
White	62.4%	72.4%
Other/Missing	25.6%	15.0%
Hispanic		
Yes	14.2%	16.3%
No	61.5%	83.7%
Other/Missing	24.2%	



*Number of patients with given characteristic with an encounter in any care setting divided by the total number of patients with an encounter in any care setting (2014).

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Selected Condition: Counts of Patients (50 Data Marts)

Condition	PCORnet*
Diabetes	750,269
Pulmonary Disease	2,837,803
Any Malignancy	1,294,158
MI	354,929
Stroke	420,802
Rheumatoid Arthritis	254,803
Ulcerative Colitis	88,029
Hypertension	5,902,641
Renal Disease	1,018,729
Influenza/ Pneumonia	869,306



*Number of patients with condition of interest in any care setting divided by the total number of patients with an encounter in any care setting (2014).

**Most estimates are based on adults only.

***Prevalence of CKD

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Even more enhancements in data and expertise are coming soon



New data streams

- Claims data
- People-reported data
- Medicare data
- Registry data

More expertise

- **Collaborative research groups (CRGs)**— both organically grown and funded — in the months and years to come

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What is a Collaborative Research Group (CRG)?

- ✚ A community organized to facilitate research on health condition(s) or areas of health research
- ✚ Cross-cutting: includes CDRNs & PPRNs
- ✚ CRGs can have Research Interest Groups
 - CRG (Cardiovascular)
 - RIG 1 (Atrial fibrillation)
 - RIG 2 (Hypertension)
 - RIG n (etc.)



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What do Collaborative Research Groups (CRGs) do?

- ✚ Membership
- ✚ Leadership/Management
- ✚ Communication
- ✚ Data Science
- ✚ Study Catalyst
- ✚ Front Door
- ✚ Research Priorities



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Current PCORnet CRGs:

CRG Name	Administrative Prime	Participating Networks
Autoimmune and Systemic Inflammatory Syndromes	AR-PoWER PPRN	Vasculitis
Behavioral Health	NYC CDRN	CPPRN
Cancer	GPC CDRN	ABOUT, PORTAL
Cardiovascular Health	Health eHeart Alliance PPRN	LHSnet, OneFlorida
Diabetes and Obesity	Mid-South CDRN	OneFlorida
Health Disparities	ADVANCE CDRN	PRIDENet
Health Systems, Health Policy and Public Health	NYC CDRN	OneFlorida
Hospital Medicine	pSCANNER CDRN	Mid-South, CAPriCORN
Kidney Health	NephCure PPRN	LHSnet, pSCANNER, Mid-South
Pediatrics	PEDSnet CDRN	OneFlorida
Pulmonary	COPD PPRN	PaTH



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You can use PCORnet for many kinds of research



Pre-research

- Feasibility queries
- Engagement
- Match-making



Interventional studies

- Clinical trials
- Pragmatic randomized clinical trials
 - e-Identification
 - e-Consent
 - e-Randomization
 - e-Follow-up
- Cluster randomization



Observational studies

- Cross-sectional
- Epidemiology
- Health services
- Comparative effectiveness or safety



Administrative Efficiencies



- Common data sharing agreement
- Single IRB arrangement
- Streamlined contracting



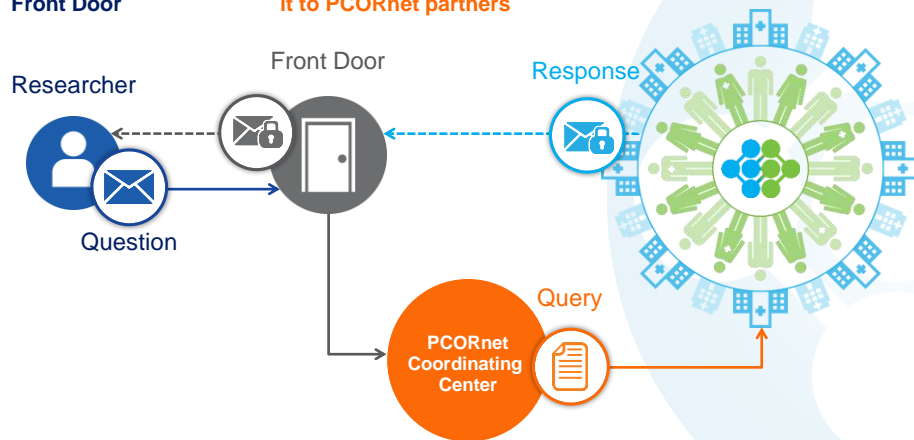
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Here's how PCORnet's distributed research network works

The Researcher sends a question to the PCORnet Coordinating Center through the Front Door

The Coordinating Center converts the question into a query with an underlying executable code, and sends it to PCORnet partners

PCORnet partners review the query and provide a response, which is sent back through the Front Door to the Researcher



Think of all the different ways you can leverage PCORnet

Faster answers to pre-research queries



SUBMIT
Data Network Request

Valuable expertise via network collaboration



SUBMIT
Request for Network Collaboration

Enhanced credibility via PCORnet study designation



SUBMIT
Request for PCORnet Study Designation



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A Front Door is opening... take your research to the next level



Through PCORnet Front Door, we invite PCORnet researchers and other investigators, patient groups, healthcare organizations, clinicians or clinician groups, government and industry scientists, and sponsors to collaborate on important patient-centered clinical research studies.

For general questions, contact us at frontdoor@pcornet.org

PCORnet and PCORI

About PCORnet

PCORnet, the National Patient-Centered Clinical Research Network, is an innovative initiative of the Patient-Centered Outcomes Research Institute (PCORI). The goal of PCORnet is to improve the nation's capacity to conduct comparative clinical effectiveness research efficiently by creating a large, highly representative network for conducting clinical outcomes research that directly involves patients in the development and execution of the research. More information is available at www.pcornet.org.



About PCORI

The Patient-Centered Outcomes Research Institute (PCORI) is an independent, nonprofit organization authorized by Congress in 2010. Its mission is to fund research that will provide patients, their caregivers, and clinicians with the evidence-based information needed to make better-informed healthcare decisions. PCORI is committed to continually seeking input from a broad range of stakeholders to guide its work. More information is available at www.pcori.org.

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Questions or Comments?

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