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EXPERT OPINION

PCORnet's Collaborative Research Groups

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Mark J Pletcher[1,2]
Christopher B Forrest[3]
Thomas W Carton[4]

[1]Department of Epidemiology and Biostatistics, University of California, San Francisco, CA, [2]Division of General Internal Medicine, Department of Medicine, University of California, San Francisco, CA, [3]Applied Clinical Research Center, Children's Hospital of Philadelphia, Philadelphia, PA, [4]Division of Health Services Research, Louisiana Public Health Institute, New Orleans, LA, USA

Abstract: The Patient-Centered Outcomes Research Institute (PCORI) launched a multi-institutional "network of networks" in 2013 – Patient-Centered Clinical Research Network (PCORnet) – that is designed to conduct clinical research that is faster, less expensive, and more responsive to the information needs of patients and clinicians. To enhance cross-network and cross-institutional collaboration and catalyze the use of PCORnet, PCORI has supported formation of 11 Collaborative Research Groups focusing on specific disease types (e.g., cardiovascular health and cancer) or particular patient populations (e.g., pediatrics and health disparities). PCORnet's Collaborative Research Groups are establishing research priorities within these focus areas, establishing relationships with potential funders, and supporting development of specific research projects that will use PCORnet resources. PCORnet remains a complex, multilevel, and heterogeneous network that is still maturing and building a diverse portfolio of observational and interventional people-centered research; engaging with PCORnet can be daunting, particularly for outside investigators. We believe the Collaborative Research Groups are stimulating interest and helping investigators navigate the complexity, but only time will tell if these efforts will bear fruit in terms of funded multicenter PCORnet projects.

Keywords: PCORI, PCORnet, network, collaboration, infrastructure

The Patient-Centered Outcomes Research Institute (PCORI) is an independent non-profit, non-governmental organization authorized by the US Congress in 2010 to fund research and develop evidence that helps patients and clinicians make decisions about which treatment or other care option is best for them.[1] PCORI issues funding announcements several times a year that call for proposals for comparative effectiveness research,[2] and requires deep patient engagement in that research[3] to ensure that results are relevant and useful to stakeholders.

In the spring of 2013, PCORI created a National Patient-Centered Clinical Research Network (PCORnet) to support patient-centered research and learning health systems in the USA. Between 2013 and 2016, 13 multi-institutional Clinical Data Research Networks (CDRNs), 20 Patient-Powered Research Networks (PPRNs), and a coordinating center built PCORnet's infrastructure and launched a number of demonstration projects (pragmatic trials and observational studies) with funding from PCORI to demonstrate the value and productivity of the network. This large new infrastructure – designed to conduct clinical research that is faster, less expensive, and more responsive to the information needs of patients and clinicians – holds the potential for transforming the nation's clinical research enterprise.[4,5] A short glossary of PCORnet-related terminology is provided in Box 1. To fully capitalize on PCORI's vision and sustain PCORnet infrastructure into the future, PCORnet will need to entice new funders to support

Correspondence: Mark J Pletcher
Department of Epidemiology and Biostatistics, University of California, Mission Hall, 2nd Floor, 550, 16th Street, San Francisco, CA 94143-0560, USA
Tel +1 415 514 8008
Fax +1 415 514 8150
Email mpletcher@epi.ucsf.edu

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Box 1 Short glossary of PCORnet-related terms and abbreviations

PCORI	PCORnet funder
PCORnet	The National Patient-Centered Clinical Research Network – a network of networks funded by PCORI
PCORnet Common Data Model	The PCORnet Common Data Model is a way of organizing EHR data from different institutions into a standard structure (i.e., with the same variable name, attributes, and other metadata) that facilitates research queries across institutions
CDRN	Networks of health care systems that collect EHR data in a common data model format (the PCORnet Common Data Model) and support distributed research queries
PPRN	Networks operated and governed by patient groups and their partners, and are focused on particular conditions or populations
CRG	Groups that facilitate and nurture cross-network research collaboration within PCORnet, focused on broad conditions or populations
RIG	Small groups within CRGs developing collaborative research projects focused on a particular topic within the broad interests of a CRG
Computable phenotype	A computable phenotype is a phenotype defined by a data query. It can be used to define an outcome, a variable in an analysis, a set of patients to invite to join a clinical trial, and so on

Abbreviations: CDRN, Clinical Data Research Network; CRG, Collaborative Research Group; EHR, electronic health record; PCORI, Patient-Centered Outcomes Research Institute; PCORnet, Patient-Centered Clinical Research Network; PPRN, Patient-Powered Research Network; RIG, Research Interest Group.

PCORnet research and execute on large cross-network research projects.

To catalyze these efforts, PCORnet launched a pilot program in February 2016 to support formation of Collaborative Research Groups (CRGs) focused on pediatrics, cardiovascular health, health disparities, and health systems research. The CRGs were charged with forging cross-network collaborations, connecting researchers with project ideas to PCORnet networks interested in helping conduct those projects, and supporting development of successful funding applications. These pilots demonstrated early success by creating self-organizing Research Interest Groups on specific priority research topics within their broader CRG (e.g., Sexual and Gender Minorities within the Health Disparities CRG) and by soliciting interest in using PCORnet through presentations and Calls for Proposals targeting external researchers. The Cardiovascular Health CRG, for example, received 28 Letters of Intent from investigators interested in using PCORnet for a specific research project after a single presentation at a national meeting. CRGs also advanced PCORnet's data infrastructure by creating cohort selection algorithms with electronic health record data (also known as computable phenotypes) using the PCORnet Common Data Model and generating preliminary descriptive data tables focused on specific conditions for use by research teams (e.g., for cystic fibrosis, sickle cell disease, and 15 other pediatric conditions targeted by the Pediatrics CRG).

To build from and expand the success of the pilot CRG program, PCORI announced a call for proposals for additional CRGs in the fall of 2016. This structured, competitive process launched 11 CRGs in January 2017. Each was charged with creating an organizational structure to generate research priorities and launch projects, creating computable phenotypes and extending the Common Data Model, and engaging patients and clinicians in the research process. A key for success was to link clinical institution-facing Clinical Data Research Networks (CDRNs) with patient-facing PPRNs to establish a synergistic mix of data, research, and patient expertise and capacity to launch competitive projects. Additionally, each CRG was charged with engaging potential funders to explore mutual interests. To ensure that CRGs learn from one another, the PCORnet Research Committee was charged with convening CRG leaders in a learning collaborative to share best practices and co-develop strategies for overcoming challenges.

The 11 funded CRGs are varied in focus, composition, and approach (Table 1). While some CRGs address research for patients with specific disease types (e.g., cardiovascular health and cancer), others focus on particular patient populations (e.g., pediatrics and health disparities) or health care settings (e.g., hospital medicine and health systems). Most are led by CDRNs (large, multi-institutional networks that have many investigators across all specialties with varied interests); others are led or co-led by PPRNs (AR-PoWER, Health eHeart Alliance, PRIDEnet, and NKN) with interest areas that map directly to the CRG focus. The many specific Research Interest Groups supported by the CRGs are not comprehensive, but represent self-organized communities of individuals from multiple networks with common interests. Additional and updated information about the CRGs, including names of leads and co-leads and contact information for each CRG, can be found on PCORnet's website.[6]

Table 1 Characteristics and goals of PCORnet's Collaborative Research Groups

CRG name	No of networks	Lead network(s)[a]	RIGs	Goals and focus areas
Autoimmune	10 CDRNs 8 PPRNs	AR-PoWER Vasculitis	• Pathway to diagnosis • Comparative effectiveness of biologic • Reproductive concerns of patients with ASIS conditions	Focus on research areas with crosscutting relevance for people living with ASIS conditions
Behavioral health	3 CDRNs 2 PPRNs	NYC CDRN CPPRN	• Adult mental health • Addiction prevention and treatment • Child and adolescent mental health	Goal to advance patient-centered mental health and substance use research through the PCORnet infrastructure
Cancer	8 CDRNs 2 PPRNs	GPC PORTAL ABOUT	• Cancer screening and diagnostic testing • Precision cancer medicine • Cancer survivorship and outcomes • Rural cancer control • Comparative effectiveness	Special emphasis is placed on developing informatics resources (e.g., adapting the Common Data Model to support cancer research, maintaining computable phenotypes), cultivating cross-network collaborations, and stimulating and assisting efforts to obtain extramural funding
Cardiovascular health	11 CDRNs 3 PPRNs	Health eHeart alliance LHSnet OneFlorida	• Atrial fibrillation • Hypertension • Congestive heart failure • Women and microvascular disease • Central nervous system • Adult congenital heart disease • Dyslipidemia	Goal to catalyze high-quality, impactful, patient-centered research focusing on cardiovascular disease and cardiovascular health using PCORnet
Diabetes and obesity	12 CDRNs 3 PPRNs	Mid-south OneFlorida	• Obesity prevention • Obesity management • Diabetes screening and prevention • Type 1 diabetes maintenance • Type 2 diabetes maintenance	Aim to advance the evidence base to drive value-based clinical decision making in diabetes and obesity care and prevention
Health disparities	8 CDRNs 4 PPRNs	ADVANCE PRIDEnet	• Health disparities experienced by racial and ethnic minorities • Social determinants of health • Health disparities experienced by sexual and gender minorities • Health disparities experienced by people with disabilities • Health disparities experienced by the economically marginalized and/or under- and uninsured	The overall goal of this group is to promote health equity for vulnerable populations by advising on and generating proposal concepts that are of value to our patients, providers, and communities
Health systems, health policy, and public health	12 CDRNs 2 PPRNs	NYC CDRN OneFlorida	• Health systems • Health policy • Public health	Focused on the intersection of research and health care delivery, health policy, and public health
Hospital medicine	9 CDRNs 3 PPRNs	pSCANNER Mid-south	• Outcomes of transferred patients • Inpatients with acute kidney injury • Geriatric care units • Observation status assignment in acute care facilities • Post-hospital outcomes • Early warning systems	Goal to advance the care of hospitalized patients by facilitating and conducting collaborative multicenter, research studies of approaches to improve outcomes of patients with acute illness. HOMERuN's mission is to ensure that every hospitalized patient receives the best quality, safest, and highest value care from hospitalization through recovery
Kidney health	5 CDRNs 2 PPRNs	NKN pSCANNER Mid-south LHSnet	• Acute kidney injury • Chronic kidney disease progression • Glomerular disease • Kidney transplant • Polycystic kidney disease	Goal is to answer key questions about kidney disease epidemiology, practice variation, therapy, and the patient experience

(*Continued*)

Table 1 (*Continued*)

CRG name	No of networks	Lead network(s)[a]	RIGs	Goals and focus areas
Pediatrics	11 CDRNs 11 PPRNs	PEDSnet OneFlorida	• Autism • Cerebral palsy • Epilepsy • Pediatric hypertension • Sickle cell disease	Dedicated to supporting the development of multi-network research projects for children and adolescents, while advancing the sustainability of PCORnet as a research consortium
Pulmonary	4 CDRNs 1 PPRN	COPD PaTH	• COPD • Asthma • Pulmonary fibrosis	Focuses on a wide range of respiratory diseases (COPD, asthma, pulmonary fibrosis, OSA), which are highly prevalent in the US population, and is dedicated to promoting pulmonary research through PCORnet that is prioritized by both the scientific and patient communities

Note: [a]Abbreviated PCORnet network names are provided here; full names and descriptions are provided at http://www.pcornet.org/participating-networks/.
Abbreviations: ADVANCE, Accelerating Data Value Across a National Community Health Center Network; ASIS, autoimmune and systemic inflammatory syndrome; CDRN, Clinical Data Research Network; CPPRN, Community and Patient Partnered Research Network; CRG, Collaborative Research Group; GPC, Greater Plains Collaborative; HOMERuN, Hospital Medicine Reengineering Network; LHSnet, Patient-Centered Network of Learning Health Systems; NKN, NephCure Kidney Network for Patients with Nephrotic Syndrome; NYC-CDRN, New York City Clinical Data Research Network; OSA, obstructive sleep apnea; PCORnet, Patient-Centered Clinical Research Network; PPRN, Patient-Powered Research Network; PORTAL, Partners Patient Outcomes Research To Advance Learning; pSCANNER, atient-centered SCAlable National Network for Effectiveness Research; RIG, Research Interest Group.

The CRGs have had some notable successes. The CRGs have all established an internal governance structure and membership policies, research priorities, communication and patient engagement strategies, and started developing specific research projects and funding applications. Many have held in-person meetings to cement collaborative relationships and move specific project plans along. Major coordinated data analyses have described the patient population accessible through PCORnet's CDRNs by creation of computable phenotypes, validation of those phenotypes where possible (e.g., against pre-existing research datasets), and simple tabular descriptions of patients meeting those computable phenotype definitions that are currently available for analysis across PCORnet networks. These projects provide preliminary data for funding applications and demonstrate the functionality, power, and potential of PCORnet's Common Data Model and distributed research network. Twenty networks within the Pediatric CRG recently lent their support to a successful grant application to the Food and Drug Administration to establish a Global Pediatric Clinical Trials Network. CRGs have engaged stakeholders and potential funders of all types in exploratory conversations about how PCORnet might provide value. Besides traditional academic research funders such as the National Institutions of Health (which has been approached by many different CRGs), the CRGs have helped PCORnet engage with industry; other governmental funders including the Centers for Disease Control and Prevention; professional societies including the American Heart Association, American Medical Association, and American Thoracic Society; and national foundations such as the National Kidney Foundation. These budding relationships and the specific research projects arising thereof provide hope that PCORnet will attract adequate interest and funding to support its infrastructure into the future.

Some important challenges remain for CRGs. Despite having a common infrastructure and coordinating center, PCORnet remains a complex, multilevel, and heterogeneous network that is still maturing. Contracting complexity, Institutional Review Board (IRB) issues, and data heterogeneity across CDRNs pose barriers even for investigators already familiar with PCORnet. To outside investigators, who are key to bringing energy and new ideas for fundable projects (and thus potential for new funding) to PCORnet, these issues can be daunting. Investigators need to be experienced enough to lead multicenter research and have time to manage the complexities inherent to multicenter research and the special complexities of PCORnet, the knowledge and skills required of learning health system researchers who must collaborate with health systems to conduct research in real-world settings,[7] and the patience to learn enough about PCORnet to design a project that is well-suited to PCORnet's unique assets. Finding such investigators and nurturing realistic project ideas with funding potential remains a central challenge for most CRGs.

The true measure of success of the CRG program will be development of multicenter projects that are successful in garnering funds, execution of sound research, and generation of new knowledge that improves health for patients. The gestation period for large collaborative research projects is quite long, and includes not just the planning and application writing but also time for application review, start up, implementation of the project, and dissemination

of results to stakeholders. Even if the CRG program is successful in increasing the number and quality of multicenter project funding applications, the downstream benefits to PCORnet and patients will be very much delayed. An accurate assessment of the CRG program in the near term, therefore, is likely to be quite a challenge, and will have to rely on process measures (e.g., investigators convened, projects discussed, topics prioritized, pre-research queries executed, and so on) and other interim markers of possible future success.

While CRGs currently have strong support from PCORI and PCORnet leadership, the future of PCORnet will soon rest in the hands of the People-Centered Research Foundation, a new not-for-profit established in March 2017 to lead ongoing infrastructure and business development for PCORnet. Given this transition, future funding of the CRG program is uncertain, but it is hard to imagine PCORnet sustaining itself without a cross-institutional research program organized around therapeutic or other themes such as PCORnet's current CRG program. The CRGs have internal momentum – some may sustain themselves even without continued external funding – but we believe PCORnet will be stronger if the CRG program receives ongoing support. The next 2–3 years promise to be exciting as the CRG program continues to develop, People-Centered Research Foundation helps coordinate and support network and CRG efforts, and PCORnet ramps up its research portfolio and starts delivering new patient-centered research findings that benefit patients, clinicians, and researchers.

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Disclosure

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