

NETWORK INFORMATION

Patients, Advocates, and Rheumatology Teams for Research and Service (PARTNERS)

Principal investigator

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PCORI funded the development of PCORnet®, the National Patient-Centered Clinical Research Network, to make it easier and more efficient to conduct research. PCORnet is made up of Partner Networks that harness the power of large amounts of health data and patient partnerships.

Patient-Powered Research Networks (PPRNs) are networks operated and governed by patients, families, caregivers, and community members in close collaboration with clinical researchers, with the goal of shaping and conducting research to better serve their communities and improve their health outcomes. Several PPRNs, including Patients, Advocates, and Rheumatology Teams for Research and Service (PARTNERS) participated as Partner Networks in PCORnet.

PCORI funded PARTNERS' participation in PCORnet from 2015 to 2019. This report outlines PARTNERS' achievements in building its research infrastructure capacity to

1. Create ways to involve patients, families, and caregivers in decision making about the network
2. Create a way to collect and share data reported by patients for research
3. Involve patients, caregivers, families, and communities in the research process, including recruiting people to participate in research studies
4. Lead or join in research studies that focus on the community's priorities

Title	PARTNERS: Patients, Advocates, and Rheumatology Teams for Research and Service
Network design	Patient-Powered Research Network (PPRN)
Lead partner	Duke University
Other partners	The Arthritis Foundation Lupus Foundation of America Cure JM Foundation Childhood Arthritis and Rheumatology Research Alliance (CARRA) Pediatric Rheumatology Care and Outcomes Improvement Network (PR-COIN)
Participants	21,812
Area(s) of focus	Pediatric rheumatic diseases

Network at a glance

PARTNERS is a PPRN linking patients, family members, caregivers, researchers, healthcare providers, and other people interested in pediatric rheumatic diseases. Rheumatic diseases include juvenile arthritis, lupus, and other inflammatory diseases. The diseases can cause pain and affect the joints, bones, muscles, and other parts of the body. PARTNERS PPRN aimed to bring patient, family member, and other caregiver experiences to research about the diseases. Through PARTNERS, patients, family members, and other caregivers were able to share research ideas, work on proposals, and join study teams. PARTNERS PPRN

brought together five organizations: The Arthritis Foundation, the Lupus Foundation of America, Cure JM Foundation, the Childhood Arthritis and Rheumatology Research Alliance (CARRA), and the Pediatric Rheumatology Care and Outcomes Improvement Network (PR-COIN). PARTNERS included 21,812 members.

How does the network operate?

When the five organizations making up PARTNERS came together, they created a formal way to pool resources and expertise to bring patient and family perspectives into their research. They created plans to make sure studies protected patients. Plans also addressed how to use and collect data and how to enroll patients. The network also set up processes to communicate with participants and share research findings with patients, healthcare providers, and the scientific community.

Patients and caregivers served in a variety of leadership and committee positions in PARTNERS. These positions included providing overall leadership; advising on legal and ethical issues; overseeing operations; ensuring network diversity and community outreach; creating scientific priorities and the PARTNERS' research agenda; and developing and evaluating specific disease management strategies.

How did the network involve patients and other partners?

PARTNERS invited patients, family members, and other caregivers to join committees overseeing leadership, outreach, communication, research, ethics, and data quality. More than half of the Steering Committee members were patients, family members, or caregivers. For each committee, new members received training and education specific to the committee for which they worked. A buddy system gave new committee members one-on-one support from members with committee experience.

Patients, family members, and other caregivers also represented the network in teaching and speaking events and served on working groups, including data security, outreach, communication, and research. In addition, patients and caregivers also helped with specific projects that came up. An example is the PARTNERS writing group, which consisted of family volunteers trained in translating scientific reports for the general public.

Who is in the network?

As of March 31, 2019, PARTNERS PPRN included 21,812 patients and community members. All members were originally part of one of the five partner organizations.

Patient members had been diagnosed with a pediatric rheumatic disease and agreed to share health information, receive personalized communication from PARTNERS, and provide medical data.

Community members said that their lives had been affected by a pediatric rheumatic disease and agreed to share their contact information, receive communication from PARTNERS, and take part in surveys.

While a Partner Network in PCORnet, PARTNERS participated in nine studies.

Population (as of 03/31/19)

Race/ethnicity

- 71% white
- 6% black or African American
- 3% Asian
- 3% mixed race
- 2% other
- 8% no information
- 10% Hispanic or Latino

Age

- 61% 17 years or younger
- 22% 18 and older
- 14% no information

Sex assignment at birth

- 68% female
- 26% male
- <1% other
- 6% no information

Gender identity

- 21% female
- 8% male
- 69% no information

How does the network support future research?

Working with funds from CARRA, PARTNERS continues to foster patient and clinician engagement at all stages of the research process, participating in multinetwork research both as part of PCORnet and through other funding bodies, while also extending external collaborations.

To learn more about this network, visit www.pcori.org/RI-Schanberg011.

Glossary

Patient-Powered Research Networks (PPRN):

PPRNs are operated and governed by patient groups and their partners and are focused on particular conditions or populations.

PCORnet: PCORnet is a network of networks that brings together patients, clinicians, researchers, and healthcare systems to share information and participate in research.