

Patient Outcomes Research To Advance Learning (PORTAL)

Principal investigator

Elizabeth McGlynn, PhD

Institution

Kaiser Permanente Research Institute

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.

Clinical Data Research Networks (CDRNs) are one type of network supported by PCORI. CDRNs consist of two or more healthcare systems, including hospitals, integrated delivery systems, and federally qualified health centers. Each CDRN transforms data gathered from routine patient care across its participating health systems to a consistent format, the Common Data Model (CDM), to enable rapid response to research-related questions.

PCORI funded the Patient Outcomes Research To Advance Learning (PORTAL) network’s participation in PCORnet from 2015 to 2019. This report outlines PORTAL’s achievements in building its research infrastructure capacity to

1. Create ways to involve patients, healthcare providers, health plans, and health systems in the research process and decision making about the network
2. Continue building the PCORnet CDM to add new types of data, ensure data quality, answer questions and requests, link to data outside the network, and keep data secure and private
3. Create an efficient infrastructure to carry out clinical trials

Title	Patient Outcomes Research To Advance Learning (PORTAL)
Network	Clinical Data Research Network (CDRN)
Lead partner	Kaiser Permanente Northern California
Other	HealthPartners Denver Health
Population	30,010,606

4. Create rules and guidance to protect people who take part in research studies, keep participants’ information confidential, and examine the risks of proposed studies
5. Work with PCORnet partners and partners outside the network to do research studies, build information systems, and share knowledge and practices
6. Create a plan to fund the network after PCORI funding ends

Network at a glance

PORTAL collected data for more than 30 million people receiving care at the Kaiser Permanente, Denver Health, or HealthPartners health systems. Ten research centers connected with these health systems worked alongside patients, doctors, and system leaders to develop ways of working on research projects together. In addition to the general data on all eligible people in these three systems, PORTAL also compiled data for three specific groups of people: colorectal cancer survivors, people with severe

congenital heart defects, and people with obesity or who are overweight.

How does the network operate?

Three groups created the network and its policies: a steering committee made up of investigators and patient advisors, a group representing doctors and other clinicians, and a group representing patients. These groups reviewed and provided guidance on PORTAL's policies. These policies described PORTAL's purpose, how it was organized, and how it made decisions. The policies also outlined how PORTAL chose researchers to oversee studies, and how it collected and stored data. In addition, the groups established groups to work on specific issues like operations, data, governance, and science.

PORTAL set standards for network partners to store patient data securely. To answer research questions, the PORTAL network provided data that cannot be used to identify patients and followed strict security rules.

How did the network involve patients and other partners?

Patients were involved in PORTAL in two ways. First, 10 patients served on a patient advisory council. These patients took part in webinars and conferences and helped develop and work through research projects from start to end. They collaborated with researchers on studies. The patient council also created a guide for patients to learn the process of being a council member. To help patient council members become more comfortable in their role, PORTAL provided training on how to read and review research articles, grant proposals, and conference presentations.

Second, patients participated in a previously established online community called Smart Patients. Through Smart Patients, researchers could ask patients questions and get patients' feedback on research ideas. Smart Patients gave researchers the chance to learn directly from patients about how an illness affected their everyday lives.

Who is in the network?

PORTAL had more than 30 million enrolled participants as of April 29, 2019. Data were available for all three health systems from 2009 through 2018. The PORTAL network collected data from electronic health records, insurance claims and enrollment records, pharmacy and laboratory records, and other health records. The network combined and standardized these data in the PORTAL database.

Population (as of 04/29/19)

Race

- 44% white
- 19% black or African American
- 37% unknown

Ethnicity

- 26% non-Hispanic
- 29% Hispanic
- 54% unknown

Age

- 21% 0–21 years
- 63% 22–65 years
- 15% 66 years or older

Sex

- 51% female
- 49% male

How is the network supporting research?

While a Partner Network in PCORnet, PORTAL participated in 19 studies.

How does the network support future research?

CDRNs follow PCORI standards to make sure their networks continue after PCORI's funding ends. CDRNs format their data to the CDM and involve patients and healthcare providers in planning and carrying out research studies. CDRNs also take part in research with other networks in PCORnet and build relationships outside of PCORnet.

To learn more about this network, visit www.pcori.org/RI-McGlynn021.

Glossary

Clinical Data Research Networks (CDRN): 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.

Common Data Model (CDM): A CDM establishes a standard way of defining and formatting data.

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