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 LHSNet’s participation in PCORnet from 2015 to 2019. This report outlines LHSNet’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

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
The Mayo Clinic led LHSNet. LHSNet brought together seven other healthcare systems, as well as public health departments and health plans in 13 states. LHSNet’s goal was to help researchers find out what matters to patients and carry out comparative
effectiveness research. This type of research compares two or more treatments to see which one works better for which patients. LHSNet also wanted to share these research results to improve public health.

**How does the network operate?**
LHSNet created a Steering Committee to lead the network. The committee included LHSNet leaders and research study leads from partner sites.

LHSNet created four committees to oversee how the network operates. Each committee focused on a core area:

- Research
- Data quality and informatics
- Engaging patients and other partners
- Complying with regulations

Mayo Clinic staff led each core committee along with members from each partner site. LHSNet also created a Coordinating Committee that included all LHSNet site project managers.

LHSNet created a team of experts to improve data quality processes across sites. This helped data systems and practices work together across sites.

Network partners stored patient data securely. To answer research questions, the network provided data that cannot be used to identify patients and followed strict security rules.

**How did the network involve patients and other partners?**
The project team invited two experts on involving patients in research studies to join the LHSNet engagement core committee. These experts reviewed ways to engage participants across PCORnet projects. This review helped LHSNet partner sites engage patients.

Partner sites aimed to involve patients in the research process. Study teams at each site engaged participants in their own way. Sites taught patients about the research process. Some sites created special tools to orient patients to the research process. Other sites offered trainings for study teams to help engage faculty, researchers, and medical professionals.

**Who is in the network?**
LHSNet brought in data from 15,409,215 patients as of March 31, 2019. Data came from electronic medical records and administrative claims. Data also came from patient surveys on heart failure, weight, and other health issues.

**Population Demographics* (as of 03/31/19)**

<table>
<thead>
<tr>
<th>Race</th>
<th>92% white</th>
<th>2% black</th>
<th>6% other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td>53% female</td>
<td>47% male</td>
<td></td>
</tr>
<tr>
<td>Ethnicity</td>
<td>97% non-Hispanic</td>
<td>1% Hispanic</td>
<td>1% other</td>
</tr>
<tr>
<td>Age</td>
<td>25% 0–20</td>
<td>28% 21–44</td>
<td>27% 45–64</td>
</tr>
</tbody>
</table>

* Demographics are for a subset of the total population.

**How is the network supporting research?**
While a Partner Network in PCORnet, LHSNet participated in seven research 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-Roger030.
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.

Institutional Review Board (IRB): A group that follows federal regulations, state laws, and institutional policy to review, monitor, and approve research in order to protect the ethical rights and privacy of the subjects involved.

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