



# Guide for Local Health Departments to Apply and Engage in Patient-Centered Outcomes Research and Clinical Effectiveness Research

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# Introduction and Overview

The Patient-Centered Outcomes Research Institute (PCORI), established via the Patient Protection and Affordable Care Act of 2010, is a leading organization in developing a program of patient-centered outcomes research (PCOR). According to PCORI, PCOR aims to “help people make better informed healthcare decisions and improve healthcare delivery and outcomes by producing and promoting high-integrity, evidence-based information that comes from research guided by patients, caregivers, and the broader healthcare community.”<sup>[1]</sup> Clinical effectiveness research (CER) achieves this goal by comparing “outcomes to determine effectiveness, including the risks and benefits, of two or more approaches to health care.”<sup>[2]</sup>

NACCHO has found that while local health department (LHD) awareness and application of PCOR and CER to their work is currently limited (i.e., data indicate that only 37% of LHDs participate in any kind of research study,<sup>[3]</sup>) a majority of interviewed LHDs felt that this information would indeed be particularly [important sources of data](#) to inform local population health decisions. Specifically, PCOR/CER helps to:



## Strengthen an LHD’s ability to effectively address community needs by:

1. Improving the ability to understand the effectiveness of a program, service, or intervention
2. Supporting identification and integration of evidence-based practices and solutions
3. Obtaining local-level data
4. Increasing awareness of and advocacy around research topic(s) and/or target population(s)
5. Informing the messaging strategy for target population(s)
6. Informing health policy at the local level

1 Patient Centered Outcome Research Institute. PCORI Methodology Report. <https://www.pcori.org/sites/default/files/PCORI-Methodology-Report.pdf>. Published January 2019. Accessed August 1, 2020.

2 Patient-Centered Outcomes Research Institute. What & Who We Fund. <https://www.pcori.org/funding-opportunities/what-who-we-fund>. Updated April 2021. Accessed August 1, 2021.

3 Feeser, K., Hall, K., Newton, S., Dekker, D., & Alford, A. 2019 National Profile of Local Health Departments. National Association of County and City Health Officials. [https://www.naccho.org/uploads/downloadable-resources/Programs/Public-Health-Infrastructure/NACCHO\\_2019\\_Profile\\_final.pdf](https://www.naccho.org/uploads/downloadable-resources/Programs/Public-Health-Infrastructure/NACCHO_2019_Profile_final.pdf). Published 2020. Accessed August 1, 2021.



## **Create a collaborative culture between different stakeholders in the community by:**

7. Forming and strengthening partnerships with existing and new stakeholders, including research or academic institutions and special populations that are challenging to reach
8. Promoting awareness in the general community and target population that the LHD is invested in their health and well-being
9. Giving stakeholders an opportunity to use research results in their own decision-making
10. Leveraging evidence to create funding mechanisms for community organizations



## **Assist with internal LHD management by:**

11. Forming and strengthening partnerships with existing and new stakeholders, including research or academic institutions and special populations that are challenging to reach
12. Promoting awareness in the general community and target population that the LHD is invested in their health and well-being
13. Giving stakeholders an opportunity to use research results in their own decision-making  
Leveraging evidence to create funding mechanisms for community organizations



## **Promote awareness of the LHD in the community by:**

14. Building a reputation for LHD as an organization that is willing to be innovative
15. Creating an opportunity for LHD to publish and share findings with others

### **Purpose of This Guide:**

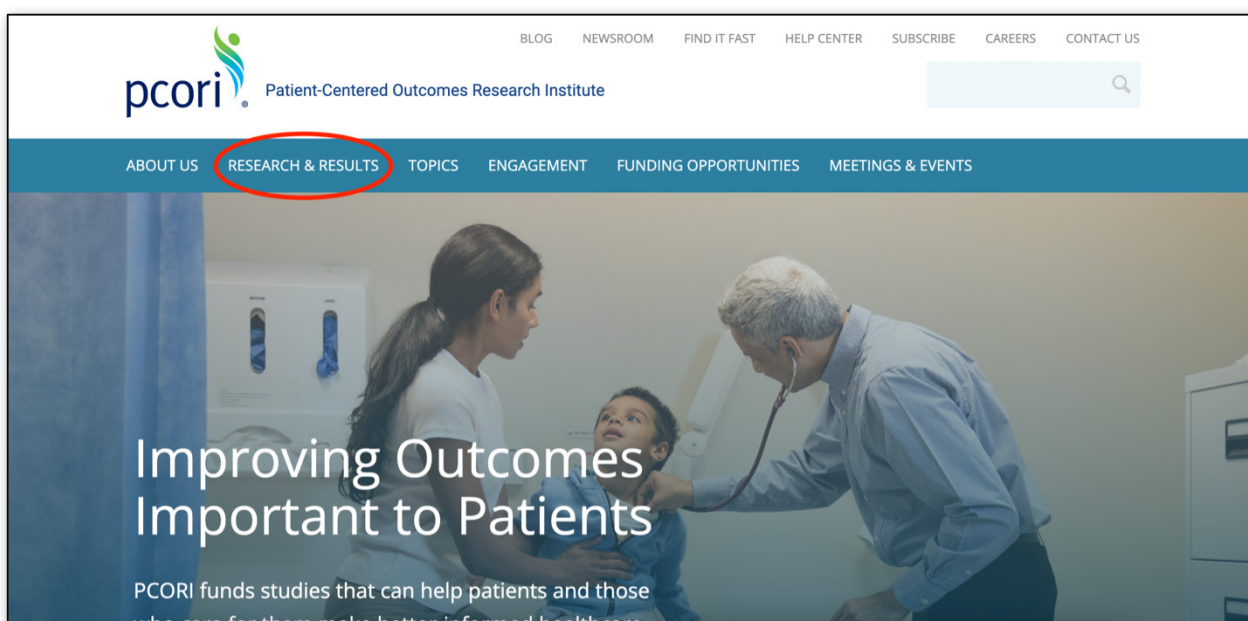
Given the value proposition of PCOR/CER to LHDs, this document will provide a step-by-step guide for how to navigate the PCORI website to find relevant data, as well as information on how PCOR/CER can be applied to community health improvement, community health education, and research.

# How to Find PCOR/CER information

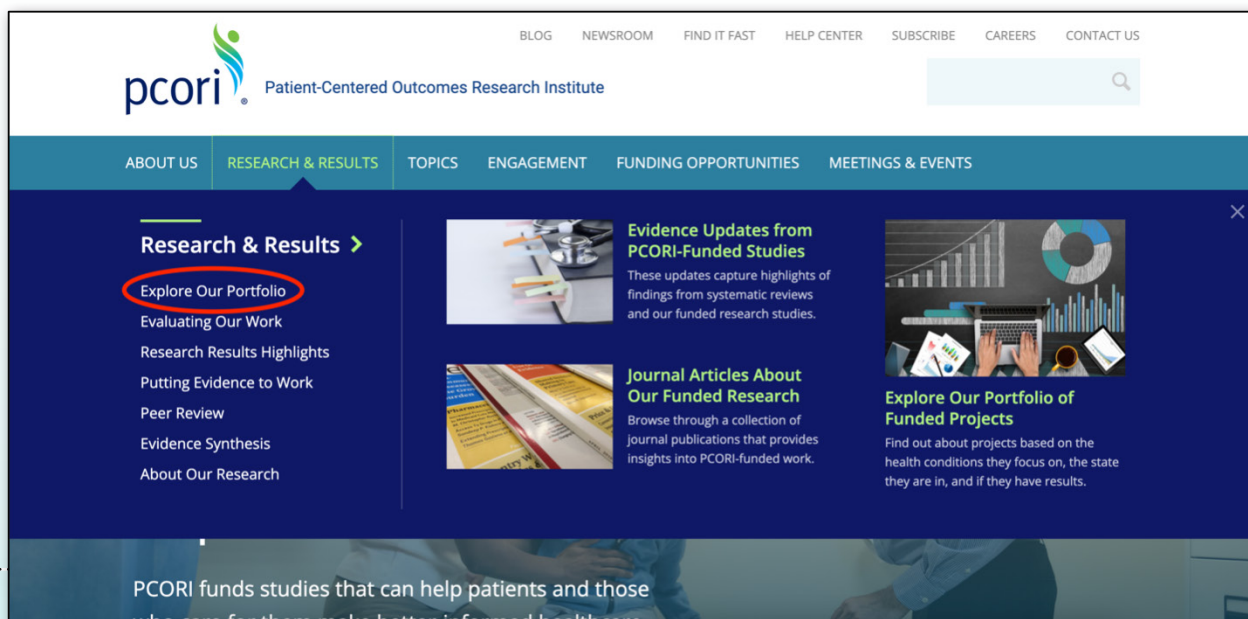
PCORI's portfolio of funded research projects can serve as a valuable source of information for LHD efforts. Data relevant to LHDs can be found by: 1) searching and filtering for a specific topic and 2) searching for information on a general topic.

## Searching and filtering for a specific topic

1. Visit the PCORI homepage at [www.pcori.org](http://www.pcori.org)
2. Click on the "Research & Results" tab at the top of the page

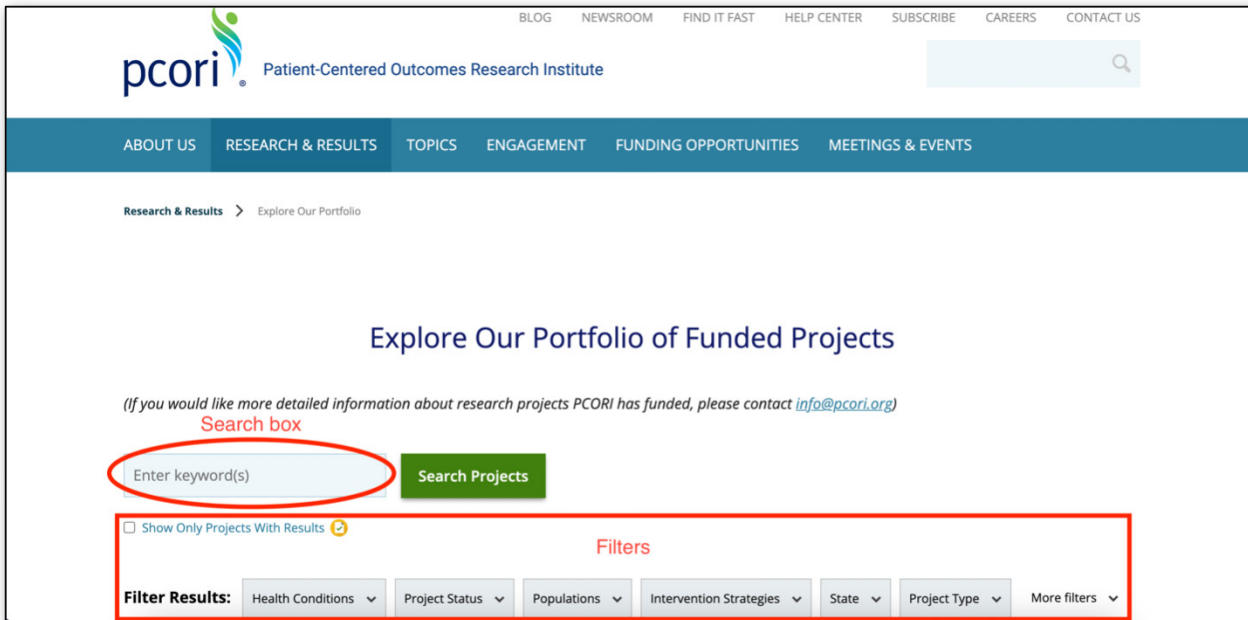


3. Click on the "Explore Our Portfolio" tab from the drop-down menu



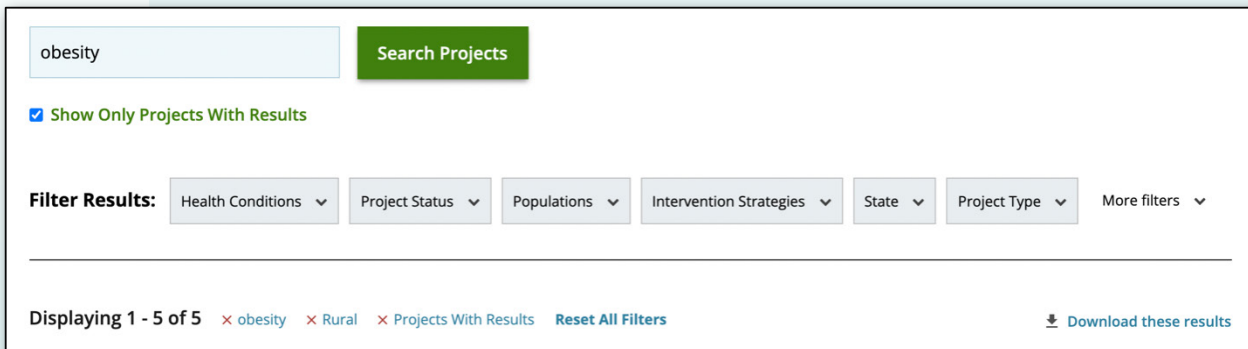
## Searching and filtering for a specific topic *(continued)*

4. Search for your topic using the search box and/or filter results by any of the following factors: if the project has results, health conditions, project status, populations, intervention strategies, state, project type, research priority area, and year awarded.



### USE CASE #1:

During its strategic planning process, an LHD in a rural setting has identified obesity as a public health priority that the organization seeks to address in the next few years. Health department staff interested in learning about the evidence behind possible interventions go to the PCORI website, navigate to the "Research & Results" tab, click on "Explore Our Portfolio," and search for "obesity" while filtering for projects with results and "Rural" under "Populations." This search yields five studies.





## Searching and filtering for a specific topic *(continued)*

### USE CASE #1: *(continued)*:

One study, [“Comparing Three Ways to Offer a Weight Management Program to Patients Living in Rural Areas – The RE-POWER Study,”](#) found that in-person group visits with 8 to 18 people per group were more effective in helping people lose weight and improve physical activity, diet, weight-related quality of life, and sleep quality compared to remote group visits by phone and in-person one-on-one visits.

With this valuable insight, the LHD staff can engage local partners, including health care and other service providers, to look at ways to safely facilitate in-person group engagement. This could inform existing efforts, including better coordinating of existing population health and clinical care/management, and/or could support a grant application to fund such services, citing the study as evidence to support their proposal.

#### Results Summary

##### What was the research about?

Primary care clinics can help patients with obesity manage their weight. To do so, clinicians, such as doctors and nurses, usually have in-person office visits with patients that last 15 minutes. But in rural areas, fewer clinic staff are available to offer these visits.

In this study, the research team compared three ways clinics in rural areas could offer a weight management program:

- In-person group visits at the clinic with 8 to 18 people per group
- Remote group visits by phone with 10 to 17 people per group
- In-person one-on-one visits at the clinic

For all three ways, the program included visits with trained staff to set goals for diet and physical activity. The first six months focused on weight loss. The next 18 months focused on maintaining weight loss. Topics included physical activity, healthy eating, and social support.

##### What were the results?

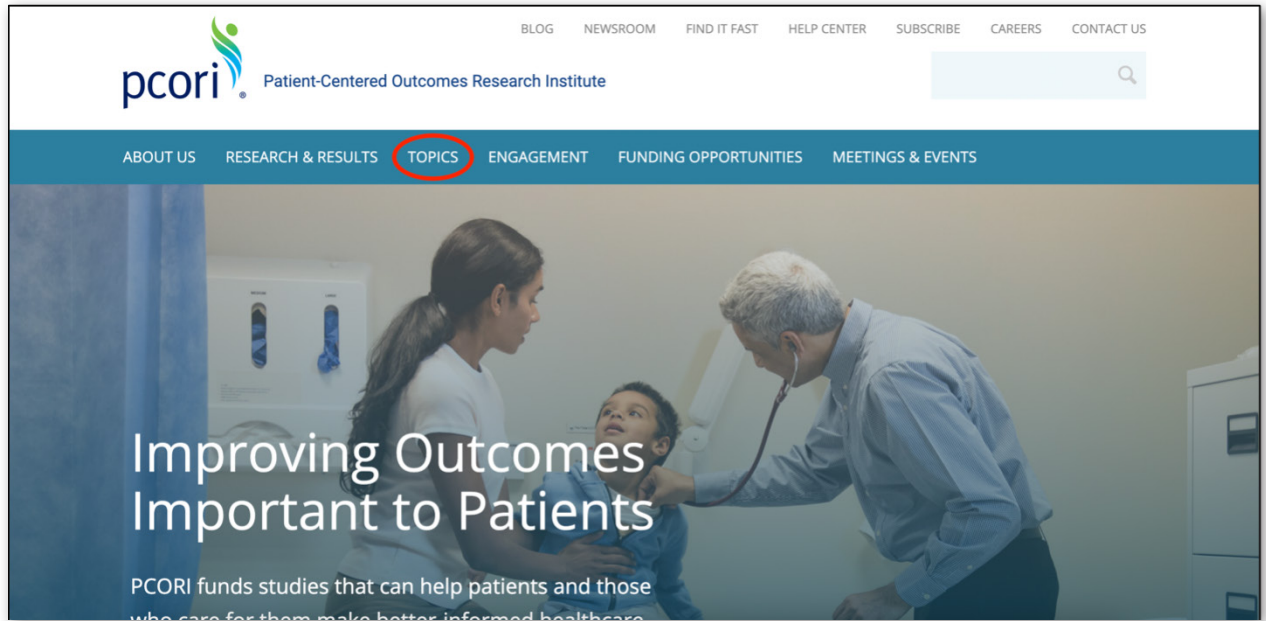
After two years, in all three ways, patients lost weight and had improved physical activity, diet, weight-related quality of life, and sleep quality.

Compared with in-person visits that were one-on-one, patients who had in-person group visits

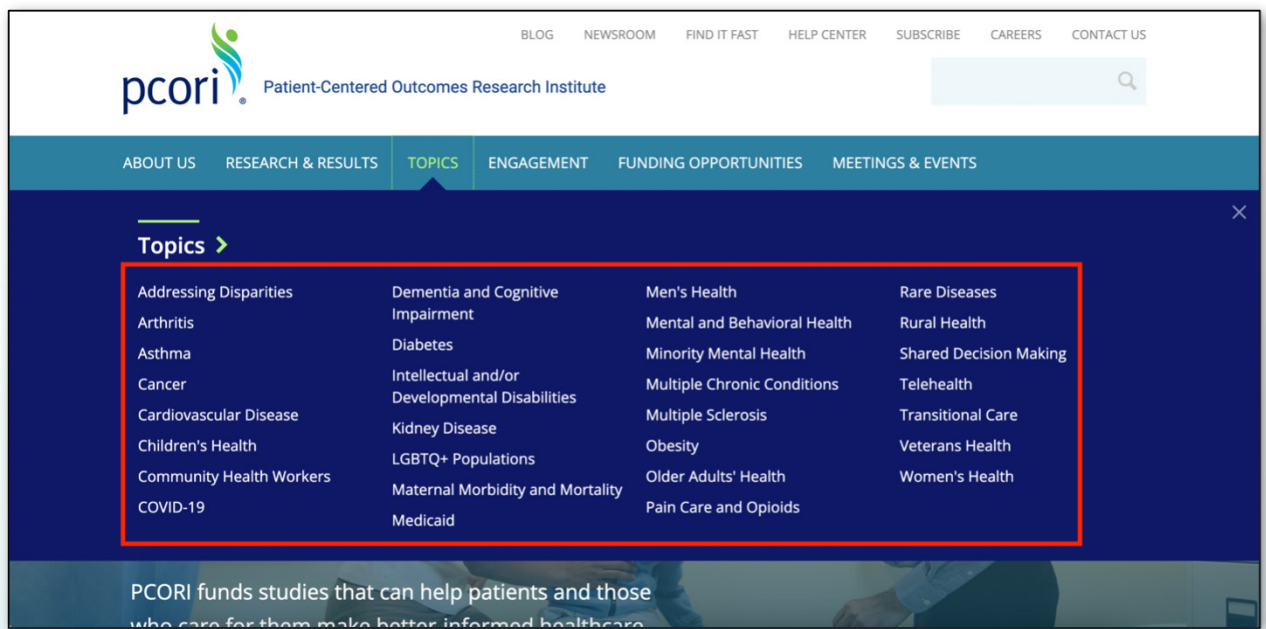
- Lost 1.9 more kilograms (4.2 pounds) and a greater percentage of weight
- Had greater decreases in triglycerides, or fat levels, in the blood
- Had greater increases in physical activity

## Searching for information on a general topic

1. Visit the PCORI homepage at [www.pcori.org](http://www.pcori.org)
2. Click on the "Topics" tab at the top of the page




3. Click on the subject matter of interest



**USE CASE #2:**

An LHD is interested in pursuing a funding opportunity to hire more community health workers. The funder is requesting more information about community health workers and how they can improve public health. LHD staff go to the PCORI website and navigate to the [“Community Health Workers”](#) topic.



TOPIC SPOTLIGHT

## Community Health Workers

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**Community Health Workers (CHWs)** are frontline public health workers who serve as liaisons between healthcare providers and consumers. CHWs promote health among groups that have traditionally lacked access to adequate care, according to the Centers for Disease Control and Prevention. By sharing the same community, or personal, cultural, linguistic, and other characteristics—sometimes including a medical condition—with those they serve, CHWs work to facilitate access to services and to improve the quality and cultural competence of service delivery. Nearly **58,000** CHWs work in the United States, according to the Bureau of Labor Statistics.

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PCORI has funded **78 active or completed comparative clinical effectiveness research studies** that use community health workers in an intervention, an investment of **\$278 million**.

As of July 2021

### Community Health Workers Study Spotlights



**The Role of Community Health Workers**

Keysha Brooker, CHW, MSW, explains how community health workers (CHWs) can help address disparities for the patients they work with by providing support and resources to help patients thrive.



**Reducing Asthma Health Disparities through Guideline Implementation**

This project compares three different approaches to implementing guidelines for people with uncontrolled asthma.



**The Bridge Between Clinics and Communities**

Lisa Cooper, MD, MPH explains the role community health workers played in her PCORI-funded project that sought to help patients from disadvantaged populations better control high blood pressure.

There, they read a brief description of the role and overview of studies that provide evidence regarding the beneficial role of community health workers in different public health contexts. Staff easily synthesize and share this information with the potential funder.

# Application of PCOR/CER to Community Health Improvement (CHI)

Community health improvement (CHI) is the process by which the health needs of a community are identified and addressed. One recommended, community-driven framework to navigate this process is called Mobilizing for Action through Planning and Partnerships (MAPP). MAPP is an interactive, community health assessment and planning (CHA/CHIP) process facilitated by health departments, nonprofit hospital systems, and community-based organizations to work with cross-sectoral partners and community representatives to collectively identify and prioritize public health issues. Those priorities then inform actions to be taken that address those health needs, including by employing social determinants of health strategies that improve health equity. The ultimate goal of MAPP is to maximize the efficiency, effectiveness, and performance of local public health systems.

The six phases of MAPP are as follows:

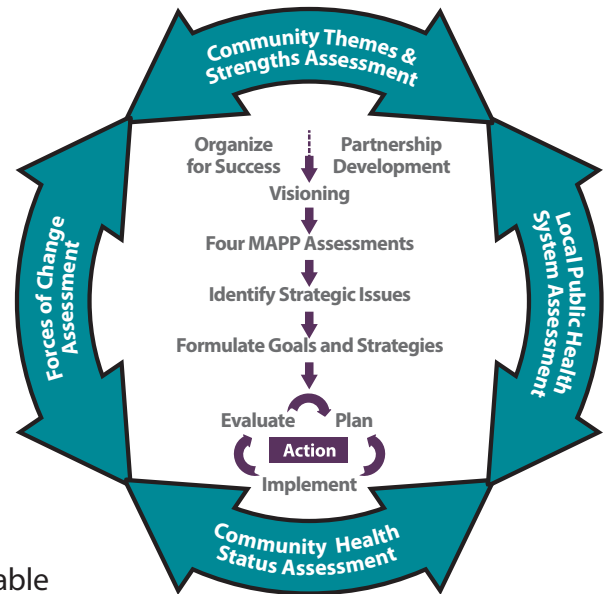
Phase	Description
<b>Phase 1: Organize for Success &amp; Partnership Development</b>	This is the first phase of the MAPP process covering how to organize for success.
<b>Phase 2: Visioning</b>	Next is a collaborative process that leads to a shared vision and common values.
<b>Phase 3: The Four Assessments</b>	Once Phase 2 is complete, you can move on to collecting and analyzing data.
<b>Phase 4: Identify Strategic Issues</b>	Phase 4 of the MAPP program helps you identify strategic issues before continuing the process.
<b>Phase 5: Formulate Goals &amp; Strategies</b>	This phase of the MAPP program will help you formulate goals and strategies to achieve them.
<b>Phase 6: Action Cycle</b>	Phase 6 of the MAPP process helps you put your strategies into action.

### PCOR and CER can play a key role in a community health improvement process in two ways by:

1. providing complementary data on identified health issues in (CHAs) for consideration for (CHIPs) and
2. informing action plan goals, objectives, strategies, and tactics.

## Community health assessments (CHA) and community health improvement plans (CHIP)

CHAs serve to provide data on public health problems, available resources, as well as policy formation, execution, and evaluation. This insight is then used to identify which issues take priority, create and execute strategies for action, and establish accountability through CHIPs. LHDs may benefit from searching the PCORI website for relevant data on identified health issues during phase 3 of MAPP. Phase 3 comprises four assessments: community themes and strengths assessment, local public health system assessment, community health status assessment, and forces of change assessment. PCOR/CER can be particularly helpful for the community health status assessment to answer questions such as, “what does the health status of our community look like?” LHDs may use these data for the CHA report to offer additional insight during the CHIP development or revision process.



### USE CASE #3:

The Baltimore City Health Department is leading Baltimore’s CHA and looks to the PCORI website for any relevant data that may inform the community health status assessment part of step 3 of MAPP. By filtering for studies in Maryland (see section II A in this guide), staff find over 45 different studies in the PCORI portfolio and by searching for “Baltimore,” staff finds over 15 different studies. They can then review the summaries of these studies and identify which ones contain additional data on health issues already identified for the CHA.

## Action planning

PCOR/CER can also be valuable during Phase 6 of the MAPP: action cycle. The three steps of this phase include: planning, implementation, and evaluation. LHDs may benefit from PCOR/CER during the planning part of this phase in which evidence from the studies can be used to inform action plans, objectives, and strategies.

### USE CASE #4:

An LHD has identified diabetes among community members with low incomes as a health priority to address. To better understand the comparative effectiveness of different interventions, staff turned to the PCORI website. By searching and filtering for the topic (see section 2 in this guide), staff came across the project, [“Comparing Three Methods to Help Patients Manage Type 2 Diabetes.”](#)

After reading the study summary, staff learn that there was no significant difference between helping patients with Medicaid manage their diabetes through daily cell phone interactive text message reminders, talking to a community health worker with diabetes, or both receiving text message reminders as well as speaking with a community health worker. Staff

share this insight with community stakeholders working on CHIP who are then able to make a more informed decision regarding which intervention they would like to pursue. For example, if the effectiveness of all three options is approximately the same, then the

#### Results Summary

##### What was the research about?

Type 2 diabetes is a long-term illness that causes blood sugar levels to rise. Diabetes causes many health problems and can be hard to manage. It is the seventh leading cause of death in the United States. Many patients use diet, exercise, and medicines to control diabetes. But less than seven percent of patients with diabetes manage it effectively.

The research team compared three ways to help patients with Medicaid manage their diabetes:

- Daily cell phone interactive text message reminders
- Talking to a community health worker with diabetes, a person trained to help others with diabetes get the health care they need
- Both daily text messages and talking to a community health worker

##### What were the results?

The study found that all three methods worked about the same to improve patients' health and encourage healthy behaviors.

At the end of the study, patients in all three groups met more of their healthcare goals. They also had lower blood sugar and cholesterol levels. In addition, patients were more likely to monitor their blood pressure than at the start of the study, and their worry about diabetes decreased. Patients had fewer hospital and urgent care visits but didn't have fewer emergency room visits.

**USE CASE #4** *(continued)*:

community stakeholders may decide to implement a multipronged approach of using a technology platform to send daily cell phone interactive text message reminders, as well as facilitate health education sessions in locations where CHA identified the highest prevalence of diabetes in neighborhoods where it cannot be assumed that impacted community members own cell phones.

## Additional CHA/CHIP resources for incorporating PCORI results

Topic	Source	Title
Community Health Assessment and Health Improvement Planning	Association for Community Health Improvement	<a href="#">Community Health Assessment Toolkit</a>
	Centers for Disease Control and Prevention	<a href="#">Community Health Assessment &amp; Health Improvement Planning</a>
	Literature	<a href="#">A Community Health Improvement Process</a>
	National Association of County and City Health Officials	<a href="#">Community Health Assessment and Improvement Planning</a>
	Patient Centered Outcomes Research Institute	<a href="#">Engaging Patients and Communities in the Community Health Needs Assessment Process</a>
Community Health Action Planning	Centers for Disease Control and Prevention	<a href="#">Action Step 8. Build the Community Action Plan</a>
	National Association of County and City Health Officials	<a href="#">Phase 5: Developing Goals, Strategies, and an Action Plan</a>

# Application of PCOR/CER to Community Health Education

Health education is a critical component of LHD's efforts. Such communication – often geared toward the public as well as community stakeholders, media, and policymakers – is used to increase education about public health topics and even inspire change.

**PCOR and CER can play a key role in these efforts in two ways by:**

1. offering insights that help inform communications plans and
2. providing high-integrity, evidence-based data that can be utilized for the content of the education efforts.

## Communications plans

When developing a health education communications plan, LHDs may benefit from searching the PCORI website for relevant studies that tested different messaging strategies.

### USE CASE #5:

An LHD is planning to promote colorectal screenings in their community. To better understand which messaging strategies would be most effective, staff turned to the PCORI website. By searching and filtering for the topic (see section 2 in this guide), staff came across the project, [“Using Numbers in a Decision Aid to Describe Risks and Benefits of Colorectal Cancer Screening Options.”](#) The high-level description provided confirms that this study is relevant, and staff quickly learn that there may be benefits to using a decision aid with numbers over words.

#### Results Summary

##### What was the research about?

Decision aids help people choose between two or more healthcare options based on what is most important to them. Decision aids may include numbers to help show benefits and risks. Researchers don't know if using numbers makes decision aids more useful or more confusing.

In this study, the research team compared two decision aids that showed risks and benefits of two ways to screen for colorectal cancer, or CRC: colonoscopy or a test for blood in the stool. The team assigned patients by chance to use either a

- **Decision aid with numbers** to describe the risks and benefits of CRC screening. For example, “Four out of 1,000 people who have a colonoscopy will have to go to the hospital due to heavy bleeding.”
- **Decision aid with words** instead of numbers to describe risks and benefits. For example, “Very rarely, people having a colonoscopy need to go to the hospital due to heavy bleeding.”

##### What were the results?

Similar numbers of patients from each group, about 29 percent, got CRC screenings in the six months after they used the decision aids.

Compared with patients who viewed the decision aid that used words, more patients who viewed the decision aid with numbers

- Planned to get a stool blood test
- Felt they were at risk for getting CRC in their lifetimes
- Answered knowledge questions about CRC and screening correctly



**USE CASE #5 (continued):**

Interested in learning more, staff go on to click on the [final research report](#) which goes over the study in significantly more detail. This report is extremely valuable to staff because it provides a copy of the tested decision aid that they can use.

	<p>Q6/V6 (General info)</p> <p>There are several advantages to having a colonoscopy. It is the most thorough colon test. Any polyps that are found can almost always be removed on the spot. If no polyps are found, there is no need to be tested again for 10 years.</p> <p>Colonoscopy also has some disadvantages. The preparation, or "cleaning out your bowel," may be uncomfortable. The test must be done in a hospital or similar facility. Because you will be given medicine that makes you sleepy, someone has to drive you home. Finally, your insurance may not cover the entire cost, so it can be expensive.</p>
	<p>Q7/V7 (General info)</p> <p>The stool test has several advantages: it is easy to do, it is done at home, And, there is no need to clean out your bowel</p> <p>The disadvantages of the stool test are that it must be done every year, collecting a small sample of stool may be unpleasant. And, if blood is found – that is, if the stool test is positive, you will need to have a colonoscopy.</p>

Furthermore, the study shared findings related to the lay public's opinion regarding what information should be included in all decision aids for colon screening, how risk information should be presented, what makes the screening

decision a good one, and what makes a decision aid and the advice it provides trustworthy. For example, study participants recommended that decision aids should be kept simple and understandable; be able to be used with and without providers present; and disclose the cost of screenings and baseline risk of getting colon cancer. LHD staff utilized all this insight to create an evidence-informed decision aid to use as part of their communications plan. They cited both the PCORI website and the peer-reviewed journal articles linked from the study project's webpage as sources in relevant documents.

**MDM**  
Medical Decision Making

Medical Decision Making  
2021, Vol. 41(5) 527-539  
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*Original Research Article*

## Layperson Views about the Design and Evaluation of Decision Aids: A Public Deliberation

**Peter H. Schwartz, Kieran C. O'Doherty, Colene Bentley, Karen K. Schmidt, and Michael M. Burgess**

**Purpose.** We carried out the first public deliberation to elicit lay input regarding guidelines for the design and evaluation of decision aids, focusing on the example of colorectal ("colon") cancer screening. **Methods.** A random, demographically stratified sample of 28 laypeople convened for 4 days, during which they were informed about key issues regarding colon cancer, screening tests, risk communication, and decision aids. Participants then deliberated in small and large group sessions about the following: 1) What information should be included in all decision aids for colon screening? 2) What risk information should be in a decision aid and how should risk information be presented? 3) What makes a screening decision a good one (reasonable or legitimate)? 4) What makes a decision aid and the advice it provides trustworthy? With the help of a trained facilitator, the deliberants formulated recommendations, and a vote was held on each to identify support and alternative views. **Results.** Twenty-one recommendations ("deliberative conclusions") were strongly supported. Some conclusions matched current recommendations, such as that decision aids should be available for use with and without providers present (conclusions 1–4) and should support informed choice (conclusion 9). Some conclusions differed from current recommendations, at least in emphasis—for example, that decision aids should disclose cost of screening (conclusion 11) and should be kept simple and understandable (conclusion 14). Deliberants recommended that decision aids should disclose the baseline risk of getting colon cancer (conclusions 15, 17). **Limitations.** Single location and medical decision. **Conclusions.** Guidelines for design of decision aids should consider putting a greater focus on disclosing cost and keeping decision aids simple, and they possibly should recommend disclosing less extensive amounts of quantitative information than currently recommended.

## Education content

When creating and compiling content for health education campaigns, LHDs may benefit from searching the PCORI website for relevant studies and resources that provide high-quality, evidence-based data in layperson language.

### USE CASE #6:

An LHD is creating and compiling content for their asthma health education campaign. To aid them in this process, staff turned to the PCORI website. By searching for information on a general topic (see section 2 in this guide), staff came across the [“Asthma” topics page](#). On this page, staff first find a high-level overview of the disease which can provide content for the introduction of their education materials.



Around 25 million Americans have asthma, including approximately 6 million children, according to the Centers for Disease Control and Prevention. The disease disproportionately affects racial and ethnic minorities. Compared with whites, African Americans and Hispanics/Latinos are more likely to have asthma, have worse health outcomes, use more healthcare services, and are at greater risk of death from asthma.

#### PCORI-Funded Research and Engagement Projects

PROJECT

**Examining Home Visits from Community Health Workers to Help Patients Manage Asthma Symptoms**

This project has results

PROJECT

**Does an Advanced Electronic Tracker Help Families Manage Children's Asthma Symptoms Better Than a Standard Electronic Tracker?**

This project has results

**Comparing Asthma Treatments: A Study Focusing on African-American, Hispanic, and Latino Adults -- The PREPARE Study for PeRson EmPowed Asthma Relief**

Scrolling down, the staff then see a sample of studies on asthma with a link to more at the bottom. Staff may choose to click on any one of these that may provide more relevant information.

PROJECT

**A Shared Decision Making Intervention for Patients with Asthma in the Emergency Room**

PROJECT

**Comparing Two Ways to Manage Asthma in African-American Children -- The ASIST Study**

This project has results

PROJECT

**Using Question Prompt Lists to Help Youth with Asthma Get More Involved in Clinic Visits**

This project has results

Staff scroll further and come across other content related to PCORI stores, blog posts, and videos on asthma. If the education campaign is geared toward parents, staff may click on the box, “Choosing the Best Option for Managing Mild Persistent Asthma in Children.”

PROJECT

**Does Type of Insurance Plan Affect Asthma Control in Adults and Children? -- AFFORD**

PROJECT

**Training Patients with Asthma to Understand and Participate in Patient Centered Outcomes Research**

PROJECT

**Comparing Two Ways to Manage Asthma in African-American Children -- The ASIST Study**

This project has results

[More Projects Related to Asthma](#)

**USE CASE #6** (continued):

On this webpage, staff have the option to view the “Evidence Update” for parents. After clicking on this link, they find a succinct, high-quality, evidence-based overview of asthma; inhaler use in children and teens; information about, findings of, and link to the PCORI-

funded study; as well as action items in the format of questions to ask the reader’s child’s doctor.

**Other Content About PCORI-Funded Projects Related to Asthma**

This section highlights PCORI Stories, blog posts, and videos on this topic.

**WEBPAGE**

**Choosing the Best Option for Managing Mild Persistent Asthma in Children**

**DOCUMENT**

**Asthma Spotlight (Fact Sheet)**

**VIDEO**

**Improving Treatment Strategies for Disadvantaged Populations**

**BLOG POST**

**Addressing Disparities in Health Outcomes of People with Asthma**

**VIDEO**

**Improving Outcomes for Asthma Patients**

**VIDEO**

**Improving Health for Children with Asthma**

**BLOG POST**

**Engaging Communities in Asthma Studies: How We Can Make a Difference**

**VIDEO**

**The Role of a Patient Partner in a Study for Latino Patients with Asthma**

Clicking on the “Download this Evidence Update” link provides staff with this information in a visually-appealing document format geared toward a layperson audience ([Evidence Update: Managing Mild Asthma in Children Age Six and Older](#)) that they can simply print and include in their campaign moving forward.

**Managing Mild Asthma in Children Age Six and Older**

Findings from a recent study can help you work with your doctor to choose the best option for managing your child’s mild persistent asthma.

[Download this Evidence Update](#)

Asthma is a common illness that can make it hard to breathe. Asthma can range from mild to severe, depending on how often symptoms occur. Children with mild persistent asthma usually have symptoms two or more days each week, but not every day. These children may experience symptoms less often if their asthma is well-controlled.

Children and teens use different kinds of inhalers to help control their asthma symptoms. Inhalers are handheld devices that push medicine into a person’s lungs. The medicine is in the form of a mist or spray. A quick-relief inhaler is used when symptoms get worse, which may happen suddenly. This inhaler usually contains a medicine called albuterol. A control inhaler helps prevent asthma symptoms. It usually contains corticosteroids. This inhaler can keep daily symptoms from getting worse.

There are two main approaches for using a control inhaler:

- **Daily use, as directed by the doctor.** Children use their control inhaler every day, whether or not they have symptoms that day. Doctors adjust the amount of medicine in the inhaler when necessary.
- **Symptom-based, or as-needed, use.** Children use their control inhaler only on days when they have symptoms and need to use their quick-relief inhaler. Children using this approach use less corticosteroid medicine overall.

The research team wanted to see if using a control inhaler as needed worked as well as using it every day for children and teens who have mild persistent asthma.

Daily use of the control inhaler may not work well if parents and children can’t visit the doctor regularly or if they often get care in the emergency room. Also, some families may prefer the as-needed approach because it doesn’t rely on repeated doctor visits. But as-needed use of the control inhaler may not work well if parents and children don’t recognize asthma flares when they happen.

**Questions to Ask My Child’s Doctor**

You may want to talk with your doctor about which treatment approach—daily or as needed—would work best for your child. Your doctor can help you create an Asthma Action Plan that best fits your lifestyle and needs. Questions to ask your doctor might include:

- Is using a control inhaler only as needed, rather than daily, an option for my child?
- Is there anything about my child’s asthma that we should think about when choosing an approach to managing asthma?
- What else should we consider when making this choice?
- If we use the as-needed approach, how can we tell if it’s working well to control my child’s asthma?

Be sure that the treatment approach you choose with your doctor is written in your child’s Asthma Action Plan. If your child has asthma symptoms, the Asthma Action Plan will help other people in your child’s life, such as other family members, school nurses, and teachers, know how to treat your child.

**About the Study**

In 2013, PCORI launched an initiative called **Treatment Options for African Americans and Hispanics/Latinos with Uncontrolled Asthma** to fund research studies on this topic. African-American children are more likely than other children to have asthma and to get sicker and die from it. In this study, the research team enrolled 206 African American children and teens ages 6-17 with mild persistent asthma. The research team assigned the children and teens by chance to use their control inhaler daily or only as needed based on their symptoms. Then the team looked at the health outcomes for the children and teens after one year.

Read more about this study at [www.pcori.org/Summo282](http://www.pcori.org/Summo282)

## Additional health education/communications resources for incorporating PCOR/CER

Source	Title
Centers for Disease Control and Prevention	<a href="#"><u>Gateway to Health Communication</u></a>
	<a href="#"><u>Health Communication Strategies and Resources</u></a>
National Association of County and City Health Officials	<a href="#"><u>Health Department Communications</u></a>
National Cancer Institute	<a href="#"><u>Theory at a Glance: A Guide for Health Promotion Practice</u></a>
	<a href="#"><u>Making Data Talk: A Workbook</u></a>
National Institutes of Health	<a href="#"><u>A Checklist for Communicating Science and Health Research to the Public</u></a>
Patient-Centered Outcomes Research Institute	<a href="#"><u>GATE Social Media Toolkit</u></a>
	<a href="#"><u>PCORI Dissemination &amp; Implementation Framework</u></a>
Public Health Reaching Across Sectors	<a href="#"><u>Tools: Resources and Expertise to Impact Public Health</u></a>
Rural Health Information Hub	<a href="#"><u>Health Communication</u></a>
	<a href="#"><u>Health Promotion and Disease Prevention Theories and Models</u></a>
The Community Guide	<a href="#"><u>Health Communication and Health Information Technology</u></a>
U.S. Department of Health and Human Services	<a href="#"><u>Making Health Communication Programs Work</u></a>

# Application of PCOR/CER to Research

## LHD benefits and role considerations

LHDs can benefit from engaging in PCOR/CER as a researcher or research stakeholder.

**Specifically, PCOR/CER can help LHDs strengthen their programs and services by aligning them to community needs and ensuring they are based in practices effective for the specific populations served.**

The role of LHDs in engaging in PCOR/CER can vary significantly depending on the organization's interests, infrastructure, and resources. When undertaking PCOR/CER, LHDs may wish to consider the issues of funding, the role it wishes to play (leader vs. participant), and potential partners.

### Funding

With a significant portion of their funding tied to grant deliverables, LHDs often do not receive funding to participate in or conduct research. While funding is not necessary to conduct PCOR or CER, it can be extremely beneficial to support the needed staff time and capacity – especially for LHDs that are smaller, understaffed, and/or have limited resources. Sources of such funding can vary widely and can be directed to a specific area, such as a particular health condition, population, or geography.

PCORI is one funder in this realm that focuses on CER as applied to vulnerable populations, conditions that affect a substantial number of people across diverse populations, conditions that are significantly burdensome, and rare diseases.<sup>[4]</sup> Notably, LHDs that have received funding from PCORI particularly appreciate the organization's emphasis on projects that meaningfully engage community stakeholders including the target population.<sup>[5]</sup> In addition, LHDs value the variety of PCORI's funding mechanisms that allow for organizations with different levels of experience with research to be able to pursue PCOR/CER.

While receiving funding to pursue PCOR/CER offers benefits, it also often comes with award management and reporting requirements that require additional staff time and experience, as well as infrastructure.

### Leadership vs. participatory role

LHDs are motivated to engage in the research process when doing so is within their scope and the research topic is important to the agency (i.e., relevant to the way LHDs

4 Patient-Centered Outcomes Research Institute. What & Who We Fund. <https://www.pcori.org/funding-opportunities/what-who-we-fund>. Updated April 2021. Accessed August 1, 2021.

5 Patient-Centered Outcomes Research Institute. What you Need to Know to Apply. <https://www.pcori.org/funding-opportunities/what-you-need-know-apply>. Updated December 2020. Accessed August 1, 2021.

function, the services they provide, or the issues important to the community they serve). If leadership sets a research vision or identifies research as a strategic priority, the effort can be planned and budgeted for financially and in terms of staff capacity. If LHDs have the necessary motivation, resources, capacity, as well as staff with relevant knowledge, skills, and experience, they may find it beneficial to lead the initiative.

However, many LHDs may not be familiar with PCOR/CER. In fact, most indirectly use research results to inform decisions regarding their programs and services by looking to federal agencies (e.g., CDC, HRSA) and national organizations (e.g., NACCHO) to provide examples of evidence-based practices that are translated from research. In addition, many LHDs may not have the staff knowledge and skills required to both conduct such research and also translate the results to their programs, services, and needs. Such LHDs may find it best to begin engaging in PCOR/CER as a research partner, with another organization – likely a research or academic institution – taking the lead or by pursuing funding opportunities that are appropriate for their circumstances. In this case, LHDs can leverage their role as trusted community entities to encourage community members with lived experiences to engage in PCOR/CER, provide important contextual knowledge about the applicability of research to their community, and support the packaging and messaging of results so they are useful and accessible to public health practitioners.

### **Partnership with academia**

LHDs may lack knowledge of the administrative aspects of forming partnerships with research and academic institutions, such as how to set up data use agreements and navigate regulatory components of research. Additional challenges may be posed by cultural differences (e.g., differences in perspectives, goals, and/or engagement) that exist between practice and research settings.

LHDs that have successfully partnered with academic institutions, such as their local university, have found the relationship to be mutually beneficial; academic institutions offered LHDs access to funding opportunities and valuable resources, such as researchers interested in publishing on relevant public health topics. In addition, they provide research infrastructure and technical expertise on the research topics and/or methodologies, which can improve the quality of the study results. Meanwhile, LHDs have valuable relationships with community partners and staff that can deliver solutions. Notably, LHDs with an [academic health department partnership](#) are more likely to consider conducting research within their scope.

With this in mind, LHDs may consider engaging in activities that establish or strengthen quality relationships with researchers. By encouraging all stakeholders to provide biographical information that includes the values that inspired them to pursue the research

project, for example, LHDs help bring to focus shared motivations. LHDs may also find understanding each stakeholder's particular strengths and communicating expectations of responsibilities at the beginning of each project helpful. This can be done by generating guiding principles for how the research team will work together throughout the project and creating a glossary of shared language that avoids jargon and represents stakeholder values.

## Checklist for LHDs seeking to lead PCOR/CER

The following checklist may be used by LHDs seeking to understand if they are prepared to initiate a PCOR/CER project.

Question	Yes	No	N/A	Comments
<b>Assessment</b>				
Have you assessed how much funding the health department has to offer the research project?				
Have you assessed how much staff time the health department has to offer the research project?				
Have you assessed health department staff experience with research (e.g., data collection methodologies, statistical analyses, regulatory procedures)?				
Have you assessed the capabilities and limitations of the health department's data management system?				
Have you assessed the health department's relationship with community stakeholders?				
<b>Preparation</b>				
Have you identified the public health decision that the research project would inform?				
Have you identified the target population(s)?				
Have you identified the relevant programs, services, and/or interventions you will compare?				
Have you decided to pursue additional funding?				
Have you decided whether you want the health department to take a leadership role or a participatory role in the effort?				

*Checklist continued on next page ...*

## Checklist for LHDs seeking to lead PCOR/CER *(Continued)*

Question	Yes	No	N/A	Comments
<b>Preparation</b> <i>(continued)</i>				
Have you identified the community stakeholders that will be invited to participate in the research process?				
Have you decided whether you want to pursue a partnership with an academic institution?				
<b>Foundation</b>				
Have you conducted a review of existing literature on the research project and ensured that you are filling a gap in knowledge?				
Have you created and documented a comprehensive research plan?				
Does it include a plan for:				
Stakeholder engagement?				
Data management?				
Sharing research results?				
Have you ensured that your research plan abides by ethical guidelines?				
Have you secured buy-in from health department leadership and staff?				



## Checklist for LHDs seeking engagement in PCOR/CER as a partner/stakeholder

The following checklist may be used by LHDs seeking to understand if they are prepared to be engaged as a partner in a PCOR/CER project led by another stakeholder.

Question	Yes	No	N/A	Comments
Have you identified how engaging in PCOR/CER as a research partner could be beneficial to your LHD?				
Is the research area relevant to your LHD's current priorities, including in your most recent CHA/CHIP process?				
Is the research area also of interest among your LHD's other (non-research) cross-sectoral partners, whose engagement may contribute to the research project's success?				
Does your LHD have a relationship with academic institution(s) or with non-academic institution(s) that conduct research on populations in your jurisdiction?				
Is this opportunity a one-off project for your LHD or is there potential for your relationship with the researcher(s) to become longer term?				
Have you identified potential roles that are feasible for your LHD to play in research projects?				
Have you identified strengths (e.g., relationship with target populations) that your LHD can bring to the research process?				
Have you identified how much staff time your LHD could contribute to supporting a research project?				
Have you identified non-staff resources (e.g., meeting space) your LHD could contribute to supporting the research project?				
Have you identified limitations of your LHD's capacity to support research?				
Do you have sufficient leadership buy-in (at the community, organizational, and programmatic levels) to help support success?				

## Additional resources

There are numerous publicly available resources that can guide LHD on various aspects of the research process. The table below is not meant to be a comprehensive list of all topics or all resources, but rather as a starting point for organizations seeking to gain additional knowledge and experience in this field.

Topic	Source	Title
Biostatistics	Centers for Disease Control and Prevention	<a href="#">Principles of Epidemiology in Public Health Practice</a>
	IBM	<a href="#">IBM SPSS Statistics</a>
	LearningStatisticswithR.com	<a href="#">Learning Statistics with R</a>
	R-Project.org	<a href="#">R Project for Statistical Computing</a>
	StataCorp	<a href="#">What's New in Stata</a>
Data Collection	U.S. Department of Health and Human Services	<a href="#">Responsible Conduct in Data Management: Data Collection</a>
	Wilder Research Foundation	<a href="#">Data Collection</a>
Data Management	Stanford University	<a href="#">Data Best Practices</a>
	Yale University	<a href="#">Research Data Management for the Health Sciences: Data Management Best Practices</a>

*Table continued on next page...*

## Additional resources *(continued)*

Topic	Source	Title
Evidence-Based Policy Making	Patient-Centered Outcomes Research Institute	<a href="#">The Road to Evidence-Based Decision Making: Steps for Using Research to Inform State Policy (Archived Webinar)</a>
	Patient-Centered Outcomes Research Institute	<a href="#">Lessons from States on Advancing Evidence-based State Health Policymaking for the Effective Stewardship of Healthcare Resources</a>
Qualitative Data	Family Health International	<a href="#">Qualitative Research Methods: A Data Collector's Field Guide</a>
Quantitative Data	Centers for Disease Control and Prevention	<a href="#">Principles of Epidemiology in Public Health Practice</a>
Research Advocacy	Patient-Centered Outcomes Research Institute	<a href="#">Research Advocacy Training</a>
Research Bias	Journal of Epidemiology and Community Health	<a href="#">Bias</a>
Stakeholder Engagement	Patient-Centered Outcomes Research Institute	<a href="#">Engagement Resources</a>
	Patient-Centered Outcomes Research Institute	<a href="#">Research Advocacy Training</a>
Research Ethics	National Institutes of Health	<a href="#">Patient Recruitment: Ethics in Clinical Research</a>
	U.S. Department of Health and Human Services	<a href="#">Ethical Codes &amp; Research Standards</a>
Research Fundamentals	Patient-Centered Outcomes Research Institute	<a href="#">Research Fundamentals: Preparing You to Successfully Contribute to Research</a>

## Example LHD PCOR/CER projects

PCOR/CER can encompass a breadth of initiatives. Below are examples of how local or state health departments have pursued PCOR and/or CER via PCORI funding in recent years.

Projects specific to a clinical diagnosis and/or treatment:

Participating Health Department Location	Research Topic
California	<a href="#"><u>Familia Unidas (United Families): Pre-diabetes Diagnosis and Treatment</u></a>
California	<a href="#"><u>University of California San Francisco Black Health Initiative (UCSF BHI) COVID-19 Response</u></a>
California	<a href="#"><u>SHARE LA: Setting HPV-Activated Research Engagement Priorities in Los Angeles County</u></a>
California	<a href="#"><u>Comparing Two Ways to Improve Pre-Exposure Prophylaxis (PrEP) Use for HIV Prevention</u></a>
Massachusetts	<a href="#"><u>Evaluating Home-Based Health Coaching from Community Health Representatives for Navajo Adults with Type 2 Diabetes</u></a>
Maryland	<a href="#"><u>Engaging Immigrant Latino Families and Community Stakeholders to Reduce Disparities in Child Obesity</u></a>
North Carolina	<a href="#"><u>Defining Unmet Patient-Centered Health Care Needs in the 4th Trimester</u></a>
Pennsylvania	<a href="#"><u>Reducing Cancer Disparities by Engaging Stakeholders</u></a>

## Example LHD PCOR/CER projects

Projects primarily focused on stakeholder engagement:

Participating Health Department Location	Research Topic
Colorado	<a href="#"><u>Creating a Patient Stakeholder Council and Patient Partner Network: Resources for Colorado Patients</u></a>
Illinois	<a href="#"><u>Collaborations for Health and Empowered Community-based Scientists (CHECS)</u></a>
Indiana	<a href="#"><u>Engaging Pregnant Women in PCOR to Improve Neonatal Outcomes</u></a>
Kansas	<a href="#"><u>Engaging Patients and Diverse Stakeholders of Color to Create Birth Equity: A Collaborative Effort</u></a>
Massachusetts	<a href="#"><u>Project ACCCES: A Collaboration to develop Capacity for Community Engaged research in Springfield</u></a>
Missouri	<a href="#"><u>Engaging Migrant and Seasonal Farmworkers in Healthcare Research</u></a>
Montana	<a href="#"><u>Building Capacity to Break Down Barriers to Complex Care Navigation in Rural America</u></a>
North Carolina	<a href="#"><u>Engaging Patients, Community, and Health System Stakeholders to Establish PCOR Priorities</u></a>
New York	<a href="#"><u>Virtual Rural Oncology Community (V-ROC)</u></a>
North Carolina	<a href="#"><u>East Carolina Partnership to Address Health Disparities through Engagement Research Training</u></a>
Washington	<a href="#"><u>Disseminating Community Health Worker Training from the Guidelines to Practice (G2P) project</u></a>

# Glossary

**Clinical effectiveness research (CER):** research that compares outcomes to determine effectiveness, including the risks and benefits, of two or more approaches to health care.

**Community health assessment (CHA):** a systematic examination of the health status indicators for a given population that is used to identify key problems and assets in a community. The ultimate goal of a community health assessment is to develop strategies to address the community's health needs and identified issues. A variety of tools and processes may be used to conduct a community health assessment; the essential ingredients are community engagement and collaborative participation.

**Community health improvement plan (CHIP):** a long-term, systematic effort to address public health problems on the basis of the results of community health assessment activities and the community health improvement process. A plan is typically updated every three to five years. (<http://www.cdc.gov/stltpublichealth/cha/plan.html>) This plan is used by health and other governmental education and human service agencies, in collaboration with community partners, to set priorities and coordinate and target resources. A community health improvement plan is critical for developing policies and defining actions to target efforts that promote health. It should define the vision for the health of the community through a collaborative process and should address the gamut of strengths, weaknesses, challenges, and opportunities that exist in the community to improve the health status of that community.

**Community Health Improvement Process:** A community health improvement process involves an ongoing collaborative, community-wide effort to identify, analyze, and address health problems; assess applicable data; develop measurable health objectives and indicators; inventory community assets and resources; identify community perceptions; develop and implement coordinated strategies; identify accountable entities; and cultivate community ownership of the process. Community health improvement is not limited to issues clarified within traditional public health or health services categories, but may include environmental, business, economic, housing, land use, and other community issues indirectly affecting the public's health.

**Mobilizing for Action through Planning and Partnerships**

**(MAPP):** community-driven strategic planning process for improving community health that provides a framework intended to help communities apply strategic thinking to prioritize public health issues and identify resources to address them.

**Patient Centered Outcomes Research (PCOR):** research that helps people make better informed healthcare decisions and improve healthcare delivery and outcomes by producing and promoting high-integrity, evidence-based information that comes from research guided by patients, caregivers, and the broader healthcare community

**Patient-Centered Outcomes Research Institute (PCORI):** organization established to fund research that can help patients and those who care for them make better-informed decisions about the healthcare choices they face every day, guided by those who will use that information.

## Summary

Local health department awareness and application of patient-centered outcomes research and clinical effectiveness research to their work is very limited. However, PCOR and CER are important sources of data to inform local population health decisions. Specifically, PCOR and CER strengthen an LHD's ability to effectively address community needs, create a collaborative culture between different stakeholders in the community, assist with internal LHD management, and promote awareness of the LHD in the community. This guide, created for LHDs, provides an overview of PCOR and CER, explains their value to LHDs, and offers tangible strategies and resources to engage in them for community health improvement, community health education, and research efforts by navigating the PCORI website.





# NACCHO

National Association of County & City Health Officials

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## About NACCHO

The National Association of County and City Health Officials is the voice of nearly 3,000 local health departments across the country. These city, county, metropolitan, district, and tribal departments work every day to ensure the safety of the water we drink, the food we eat, and the air we breathe.

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1201 Eye Street NW, Fourth Floor, Washington, DC 20005

202-783-5550

<http://www.naccho.org>