



## Introduction to PCORI

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**PCORI Regional Workshop**

**Minneapolis, MN**

*June 19, 2014*

Patient-Centered Outcomes Research Institute

# About PCORI

[pcori.org](http://pcori.org)

# About PCORI

- An independent research institute authorized by Congress through the Affordable Care Act.
- Funds comparative clinical effectiveness research (CER) that engages patients and other stakeholders throughout the research process.
- Answers real-world questions about what works best for patients based on their circumstances and concerns.

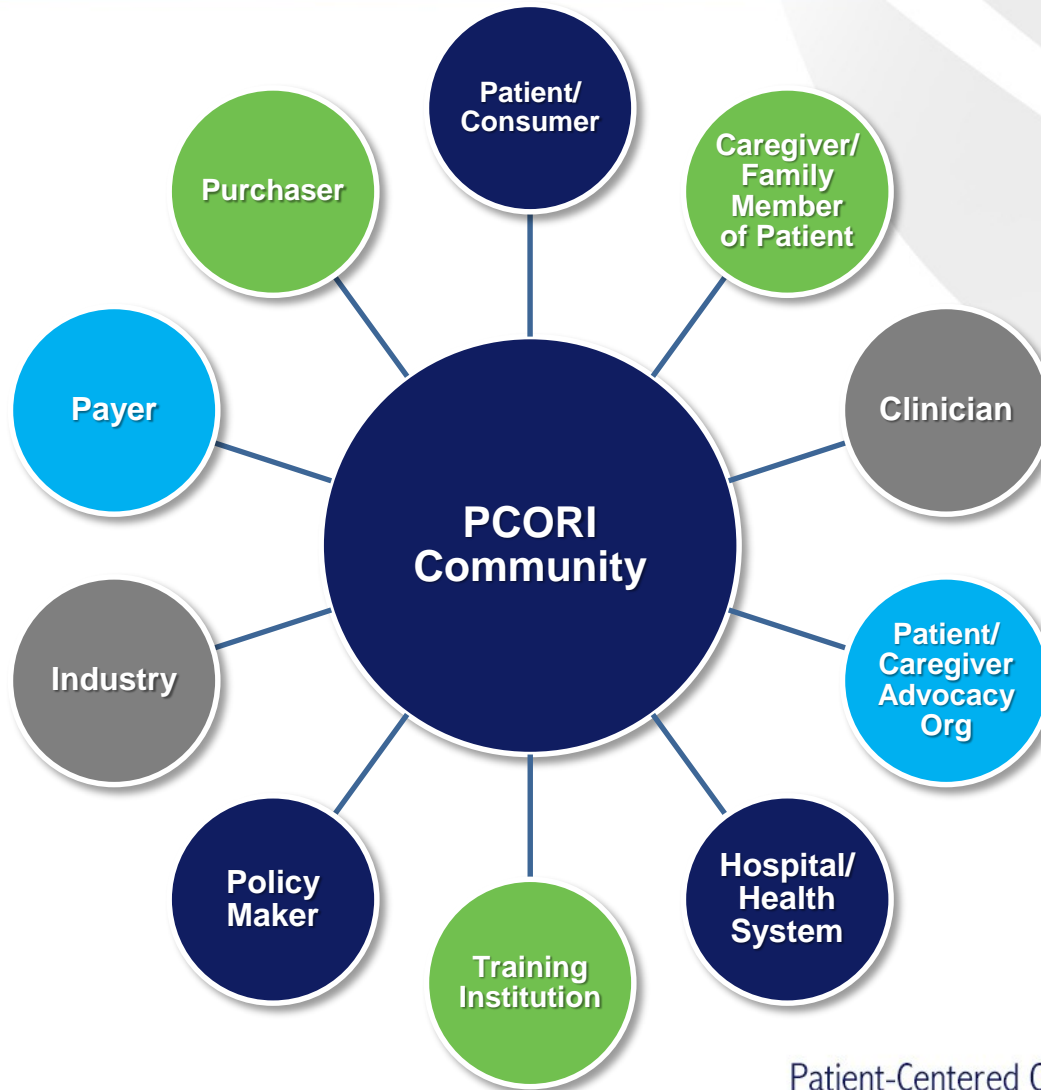


# Why PCORI?

- Research has not answered many questions patients face.
- People want to know which treatment is right for them.
- Patients need information they can understand and use.
- Many groups of patient remain not included in traditional research



# Who Are PCORI's Stakeholders?



# PCORI Has a Broad and Complex Mandate

“The purpose of the Institute is to **assist patients, clinicians, purchasers, and policy-makers in making informed health decisions** by advancing the quality and relevance of evidence concerning the manner in which diseases, disorders, and other health conditions can effectively and appropriately be prevented, diagnosed, treated, monitored, and managed **through research and evidence synthesis...and the dissemination of research findings** with respect to the relative health outcomes, clinical effectiveness, and appropriateness of the medical treatments, services...”

-- from *Patient Protection and Affordable Care Act*





# PCORI Is Accountable for Changing Practice

“(g) FINANCIAL AND GOVERNMENTAL OVERSIGHT. ...

(2) REVIEW AND ANNUAL REPORTS.

...




(iv) Not less frequently than every 5 years ... the overall effectiveness of activities conducted under this section ... such review shall include an analysis of the **extent to which research findings are used by health care decision-makers**, the effect of the dissemination of such findings on **reducing practice variation and disparities** in health care...”

-- from *Patient Protection and Affordable Care Act*



# PCORI's Focus

## Comparative Clinical Effectiveness Research

-  Patient-centered
-  Answering questions that matter to patients and other clinical decision makers
-  Comparisons of outcomes that matter to patients



# Strategic Goals

**Increase Quantity, Quality and Timeliness of Research Information**



**Speed the Implementation and Use of Evidence**



**Influence Research Funded by Others**

# PCORI's National Priorities for Research



**Assessment of Prevention, Diagnosis, and Treatment Options**



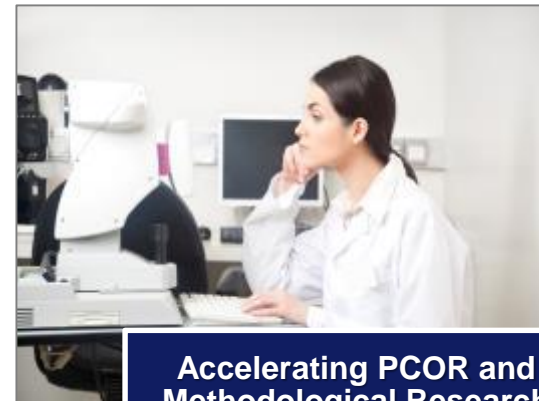
**Improving Healthcare Systems**



**Communication & Dissemination Research**



**Addressing Disparities**



**Accelerating PCOR and Methodological Research**

# Engagement as a Path To Useful, High-Quality Research

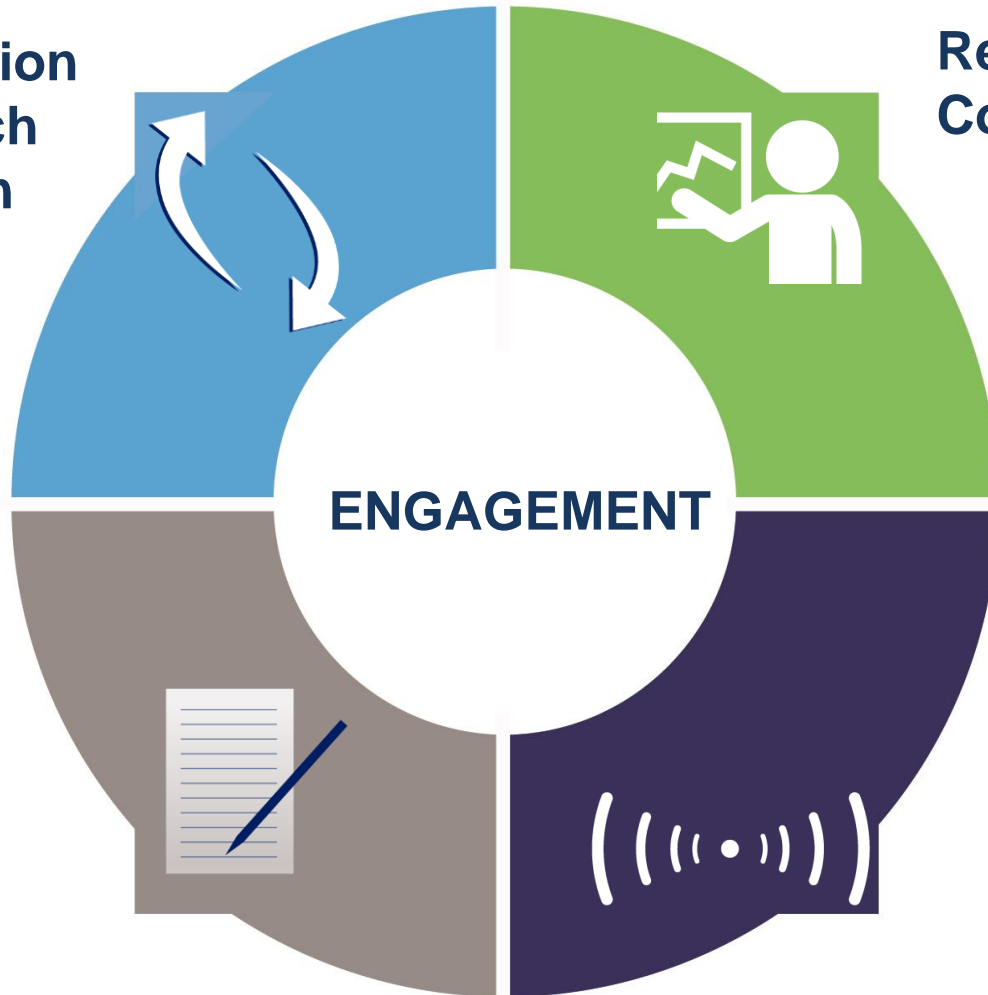
**Topic Selection  
and Research  
Prioritization**

**Review, Design, and  
Conduct of Research**

**ENGAGEMENT**

**Evaluation**

**Dissemination and  
Implementation of  
Results**



# Key Features of PCORI Research



## Research Should:

- Study the benefits and harms of interventions and strategies delivered in *real-world settings*
- Compare at least two alternative approaches
- Be based on health outcomes that are meaningful to the patient population
- Be likely to improve current clinical practices



## Special Topics of Interest:

- Conditions that heavily burden patients, families and/or the health care system.
- Chronic or multiple chronic conditions
- Rare and understudied conditions
- Conditions for which outcomes vary across subpopulations

# **Supporting Engagement as a Tool to Advance Research**

**[pcori.org/engagement](https://pcori.org/engagement)**

# Engagement Goals

**Build a Patient-Centered Outcomes Research Community**



**Engage the PCOR Community in Research**

**Promote Dissemination and Implementation**





# Patient-Centeredness vs. Patient Engagement

**Patient- Centeredness** The proposal demonstrates patient-centeredness at every stage of the research. It addresses the following questions:

- Is the research focused on questions that affect outcomes of interest to patients and their caregivers?
- Does the research address one or more of the key questions mentioned in PCORI's definition of patient-centered outcomes research?





# Patient-Centeredness vs. Patient Engagement

**Patient Engagement** The proposal demonstrates that people representing the population of interest and other relevant stakeholders are engaged in ways that are appropriate and necessary in a given research context.

- Are patients and other stakeholders engaged in:
  - Formulating research questions;
  - Defining essential characteristics of study participants, comparators, and outcomes;
  - Identifying and selecting outcomes that the population of interest notices and cares about (e.g., survival, function, symptoms, health-related quality of life) and that inform decision making relevant to the research topic;
  - Monitoring study conduct and progress; and
  - Designing/suggesting plans for dissemination and implementation activities.
- Are the roles and the decision making authority of all research partners clearly stated?
- Does the proposal demonstrate the PCOR principles of reciprocal relationships, co-learning, partnership, trust, transparency and honesty?



# Contact Us

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# Find Us Online



[www.pcori.org](http://www.pcori.org)



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