PCORI's Role in Creating a Research Agenda to Reduce Disparities and Improve Patient-Centered Outcomes
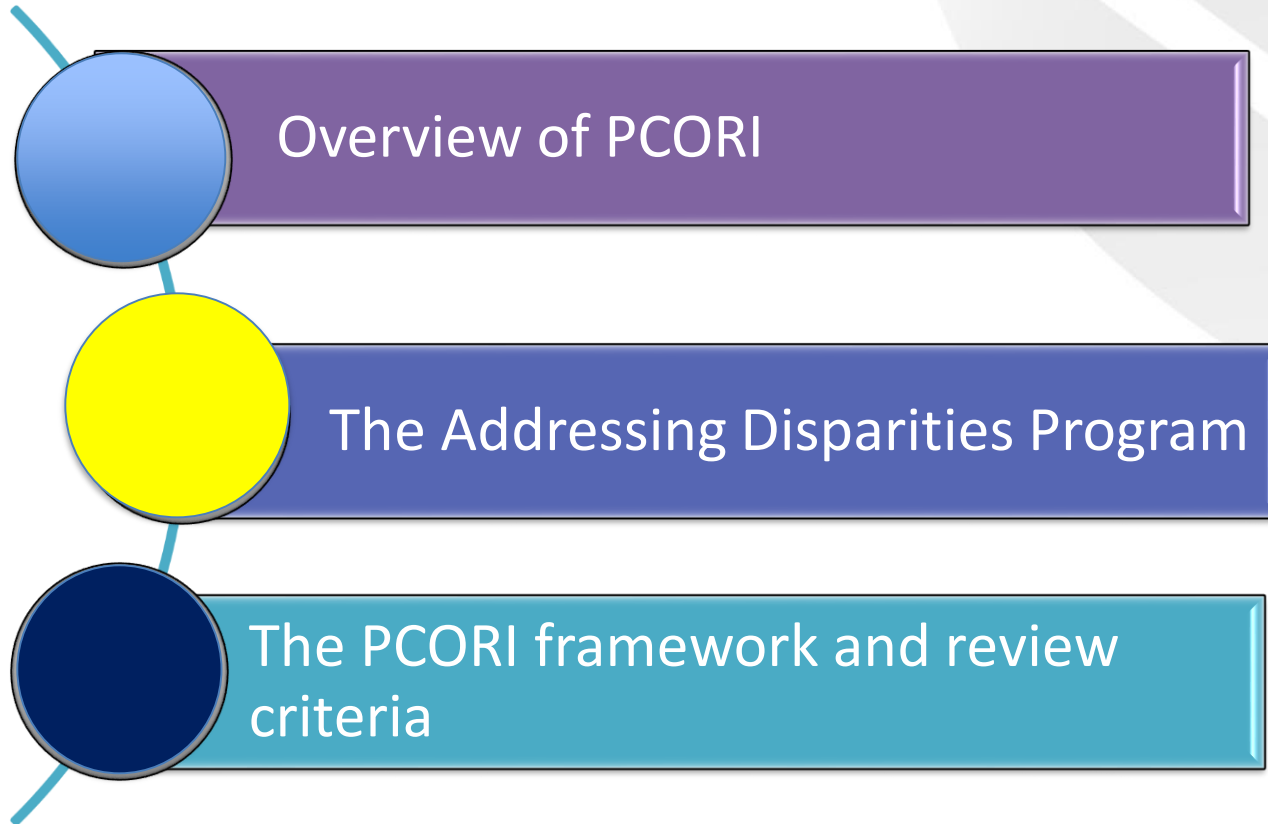
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SOAR SEMINAR: Memorial Sloan Kettering Cancer Center
Nov 11, 2014

Patient-Centered Outcomes Research Institute

For Today

Overview of PCORI

The Addressing Disparities Program

The PCORI framework and review criteria

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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.

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We Have 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*

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Mandate includes:
"....reducing practice variation and disparities"

IDENTIFYING RESEARCH PRIORITIES.—The Institute shall identify national priorities for research, taking into account factors of disease incidence, prevalence, and burden in the United States (with emphasis on chronic conditions), gaps in evidence in terms of clinical outcomes, practice variations and health disparities in terms of delivery and outcomes of care…

-- from *Patient Protection and Affordable Care Act*

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Our Mission

PCORI helps people make informed health care decisions, and improves health care delivery and outcomes, by producing and promoting high integrity, evidence-based information that comes from **research guided by patients, caregivers and the broader health care community.**

What is PCOR?

Patient-centered outcomes research (PCOR) helps people and their caregivers communicate and make informed healthcare decisions, allowing their voices to be heard in assessing the value of healthcare options.

Given my personal characteristics, conditions, and preferences, what should I expect will happen to me?"	What are my options and what are the potential benefits and harms of those options?"	What can I do to improve the outcomes that are most important to me?"	How can clinicians and the care delivery systems they work in help me make the best decisions about my health and healthcare?"

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Key Features of Our Funded Research

Studies the benefits and harms of interventions and strategies delivered in real-world settings

Compares at least two alternative approaches

Adheres to PCORI's Methodology Standards

Is based on health outcomes that are meaningful to the patient population

Engages patients and other stakeholders at every stage

Is likely to improve current clinical practices

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We Pay Particular Attention to…

Conditions that heavily burden patients, families and/or the health care system
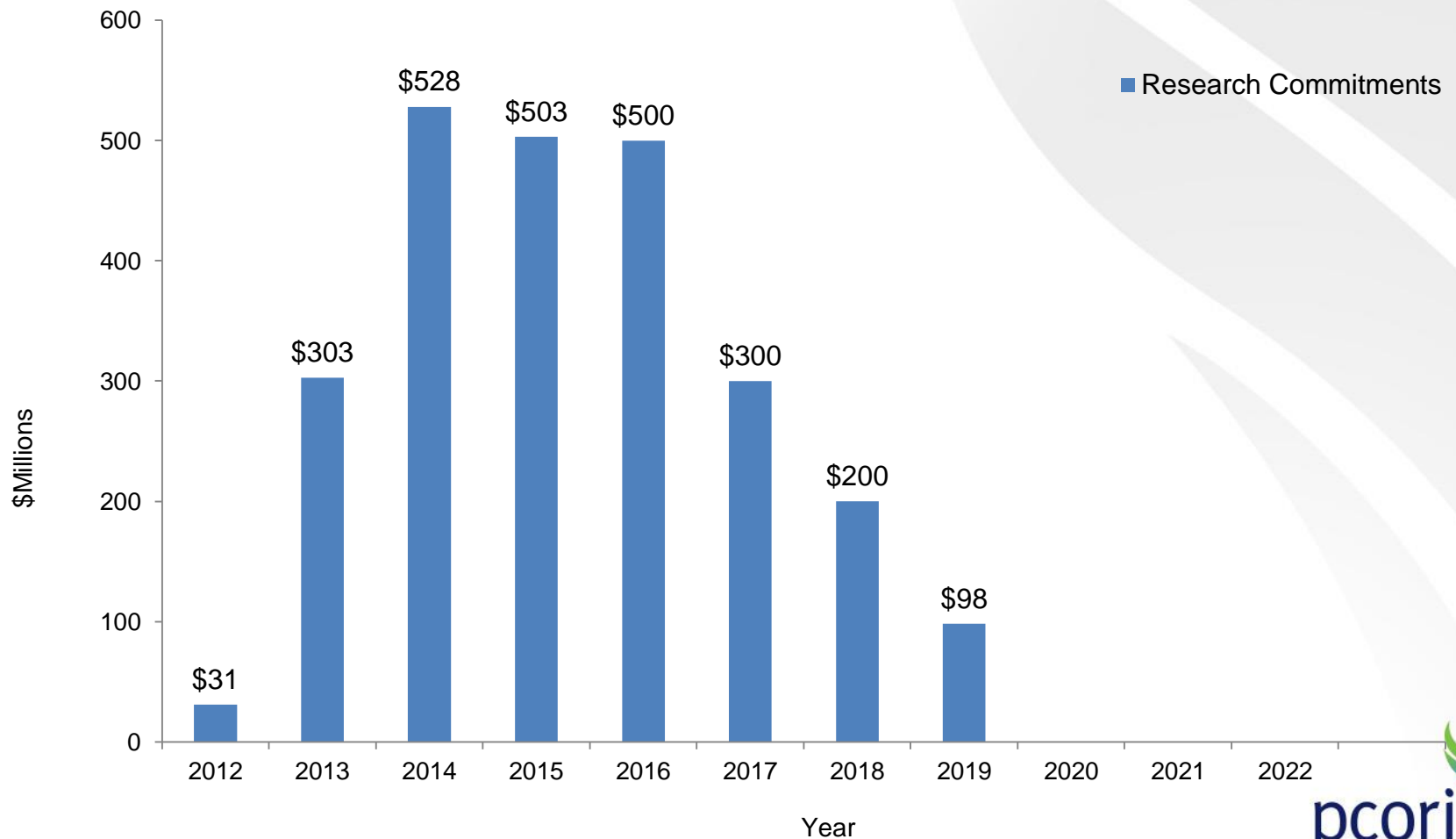
Chronic or multiple chronic conditions

Rare and understudied conditions

Conditions for which outcomes vary across subpopulations

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Our National Priorities for Research

Assessment of Prevention, Diagnosis, and Treatment Options

Improving Healthcare Systems

Communication & Dissemination Research

Addressing Disparities

Accelerating PCOR and Methodological Research

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Addressing Disparities Mission Statement

PCORI's Vision, Mission, Strategic Plan

Program's Mission Statement

To **reduce disparities** in healthcare outcomes and **advance equity** in health and healthcare

Program's Guiding Principle

To support comparative effectiveness research that will identify best options for reducing and **eliminating disparities.**

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Addressing Disparities: Program Goals

Identify Research Questions

- **Identify** high-priority **research questions** relevant to reducing and eliminating disparities in healthcare outcomes

Fund Research

- **Fund** comparative effectiveness **research** with the highest potential to reduce and eliminate healthcare disparities

Disseminate Promising/Best Practices

- **Disseminate** and facilitate the adoption of **promising/best practices** to reduce and eliminate healthcare disparities

Addressing Disparities Advisory Panel helps guide the work of our program

Addressing Disparities Program has committed $140 million in CER to reduce disparities (as of October 2014)

Investigator Initiated Projects

- 41 CER projects. $71.8 million

Targeted Projects

- Treatment Options for Uncontrolled Asthma: 8 CER trials. $23.2M
- Obesity treatment options in primary care for underserved populations. 2 comparative effectiveness research trials. $20 M
- Reducing Hypertension Disparities in collaboration with NHLBI/NINDS. Funding Announcement. Nov 2014. Up to 2 comparative effectiveness research trials. $25M

In the Pipeline

- First round of Pragmatic clinical trials, awards in January 2015
- In Development Stage (Perinatal Outcomes, Lower Extremity Amputations, and other topics)

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Conceptual Framework & Driver Model Anchors and Helps to Guide the Addressing Disparities Program

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Conceptual Framework - Barriers and Mediators of Equitable Healthcare

Barriers

Personal/Family
- Acceptability
- Cultural
- Language/literacy
- Attitudes, beliefs
- Preferences
- Involvement in care
- Health behavior
- Education/income

Structural
- Availability of appointments
- How organized
- Transportation

Financial
- Insurance coverage
- Reimbursement levels
- Public support

Use of Services

Visits
- Primary care
- Specialty
- Emergency

Procedures
- Preventive
- Diagnostic
- Therapeutic

Mediators

Quality of Providers
- Cultural competence
- Communication skills
- Medical knowledge
- Technical skills
- Bias/stereotyping

Appropriateness of care

Efficacy of treatment

Patient adherence

Outcomes

Health Status
- Mortality
- Morbidity
- Well-being
- Functioning

Equity of Services

Patient views of care
- Experiences
- Satisfaction
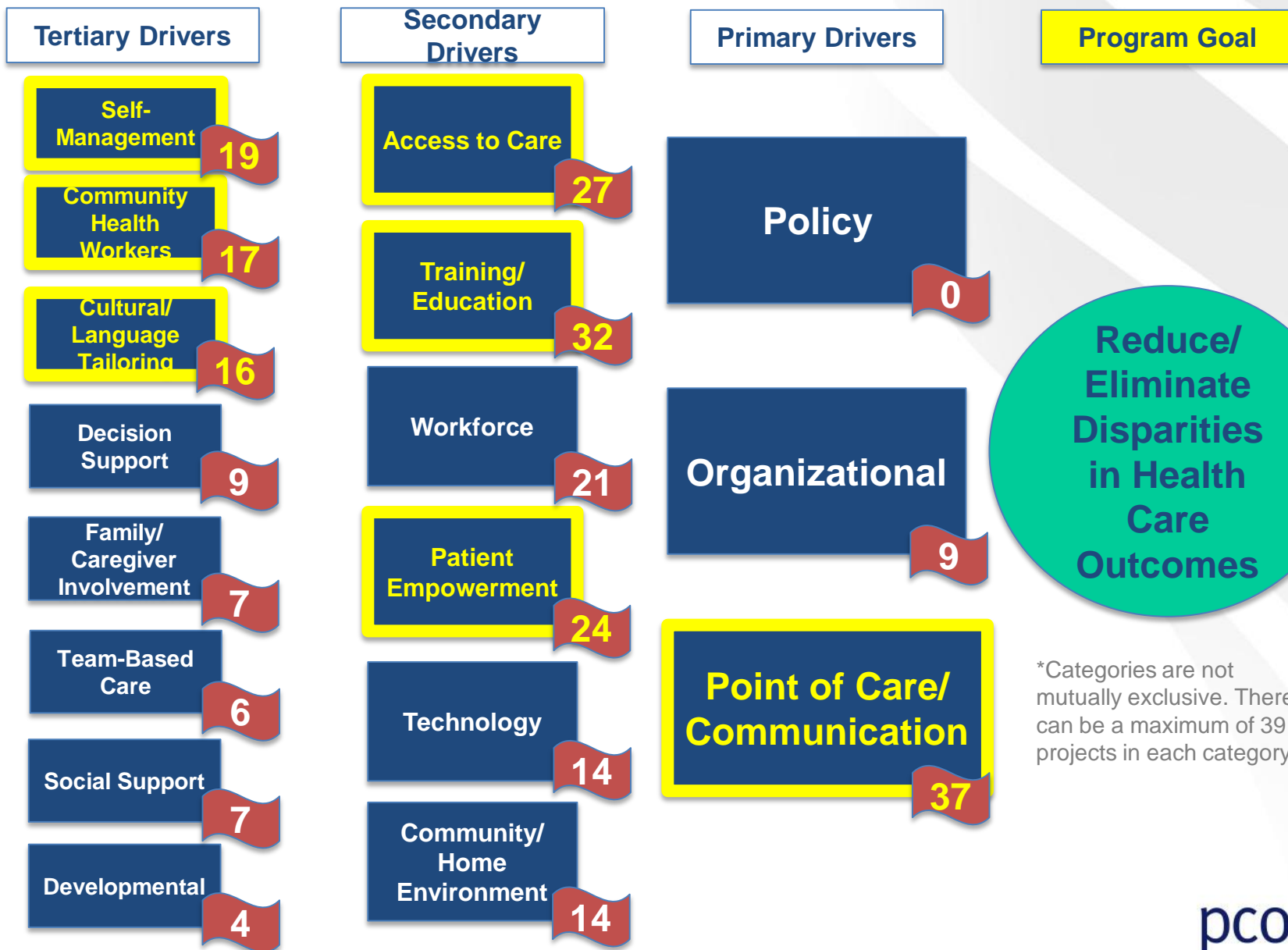- Effective partnership

Citation: Lisa A Cooper, et al. Designing and Evaluating Interventions to Eliminate Racial and Ethnic Disparities in Health Care *JGIM*, 2002

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Addressing Disparities Driver Model

🌀 The model is an *evolving* tool used to

- Evaluate where we are
- Identify where we need to go

Addressing Disparities Program: Comparative Effectiveness Research Driver Model (n=39*)

Tertiary Drivers	Secondary Drivers	Primary Drivers	Program Goal
Self-Management — 19	Access to Care — 27	Policy — 0	**Reduce/Eliminate Disparities in Health Care Outcomes**
Community Health Workers — 17	Training/Education — 32	Organizational — 9	
Cultural/Language Tailoring — 16	Workforce — 21	Point of Care/Communication — 37	
Decision Support — 9	Patient Empowerment — 24		
Family/Caregiver Involvement — 7	Technology — 14		
Team-Based Care — 6	Community/Home Environment — 14		
Social Support — 7			
Developmental — 4			

*Categories are not mutually exclusive. There can be a maximum of 39 projects in each category.

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A Look Toward Portfolio Impact

Pre-Award and Strategic Planning

Post-Award and Portfolio Management

Assessment of Impact

We are here

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Where Do We Go From Here?
Learning, Disseminating, and Implementing

- Engage patients and other end-users from start to finish (i.e., research topic generation → dissemination)

- Establish *communities* among PCORI-funded projects- EVIDENCE TO ACTION NETWORKS

  - Mechanism to foster cross-learning among project teams

  - Bring together the research community and end-users including patients, payers (e.g., AHIP), employers and purchasers (e.g., National Business Group on Health), clinicians, professional societies, policy makers, and training institutions.

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PCORI Evidence to Action Networks (E2AN)

- PCORI just launched our first Evidence to Action Network (E2AN) — learning networks with more engagement of end users

- Goals of networks are to:
  - Engage awardees and facilitate cross-learning between funded projects **across PCORI**
  - Link awardees with end users to enhance relevance of evidence and increase likelihood of uptake of findings

- Networks can be organized around:
  - Health topic or condition
  - Methodology

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How We Review Research Proposals

Who: Each proposal is reviewed by two scientists, a patient, and another stakeholder.

What: Reviewers critique and score applications, making recommendations that our Board of Governors and staff consider carefully in deciding which applications to approve.

How: We provide training so all participants are prepared and understand PCORI's review criteria.

When: You can apply at any time to serve as reviewer.

Learn more
pcori.org/reviewers

Contact us
reviewers@pcori.org

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How Are Applications Reviewed?

Applications are reviewed against five criteria:

- Impact of the condition on the health of individuals and populations
- Potential for the study to improve healthcare and outcomes
- Technical merit
- Patient-centeredness
- Patient and stakeholder engagement

- Applications are reviewed by a committee of two scientists, one patient, and one other stakeholder.

- PCORI's Board of Governors makes funding decisions based on merit review and staff recommendations.

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Advance Research Methodology

We have adopted methodology standards that all research should follow, at a minimum

Methodology Standards: 11 Broad Categories

- Formulating Research Questions
- Patient-Centeredness
- Data Integrity and Rigorous Analyses
- Preventing/Handling Missing Data
- Heterogeneity of Treatment Effects

- Data Networks
- Data Registries
- Adaptive and Bayesian Trial Designs
- Causal Inference
- Studies of Diagnostic Tests
- Systematic Reviews

How Patient-Centeredness Compares with Patient Engagement

Patient-Centeredness

- A component of what PCORI is looking for in research applications
- Does the project aim to answer questions or examine outcomes that matter to patients within the context of patient preferences?
- Research questions and outcomes should reflect what is important to patients and caregivers

Patient Engagement

- Patients are partners in research, not merely subjects
- Active engagement between scientists, patients, and stakeholders
- Community, patient, and caregiver involvement already in existence or a well-thought out plan

Patient and Family Engagement Rubric

PCORI Patient and Family Engagement Rubric

I. Overarching Concepts

The rubric is intended to provide guidance to applicants, merit reviewers, awardees, and engagement/program officers (for creating milestones and monitoring projects) regarding patient and family engagement in the conduct of research. It is divided into four segments:

- Planning the Study

- Conducting the Study

- Disseminating the Study Results

- PCOR Engagement Principles

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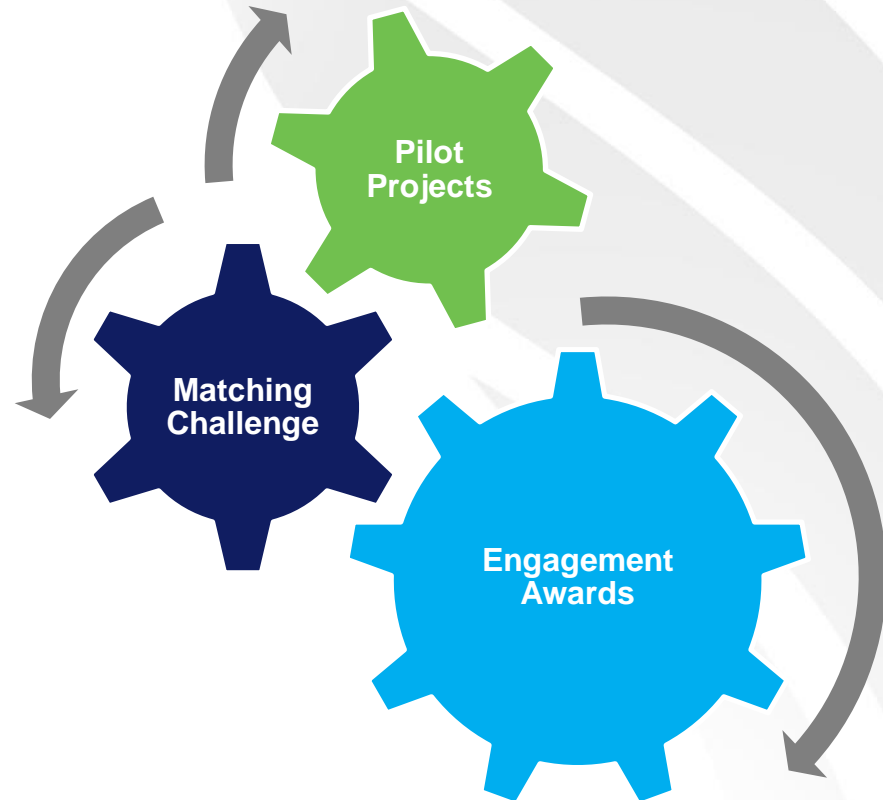
Engagement Officers

Engagement Officers, working closely with Program Officers, will support active portfolio management by:

- Helping Awardees to identify and outline engagement milestones during contract negotiation

- Participating in the Awardees' kick-off and interim phone calls as well as in separate calls with key patient and stakeholder partners

- Facilitating communication between Awardees to troubleshoot engagement challenges

- Gathering promising engagement practices from the portfolio to feature in webinars and for use in updating or expanding the Patient and Family Engagement Rubric

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How We Promote Participation in Research

- **Pilot Projects:** address a broad range of questions about **methods for engaging patients** in various aspects of the **research and dissemination** process.

- **Matching Challenge:** two challenge winners created innovative ways to **connect patients and researchers as partners** in research.

- **Engagement Awards:** Pipeline to Proposal Awards will build a national **community of patients and stakeholders** who have the expertise and passion to **participate in PCORI research. Create partnerships** between the community and academic institutions that lead to high-quality research proposals.

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