



# **PCORI's Role in Creating a Research Agenda to Reduce Disparities and Improve Health Outcomes**

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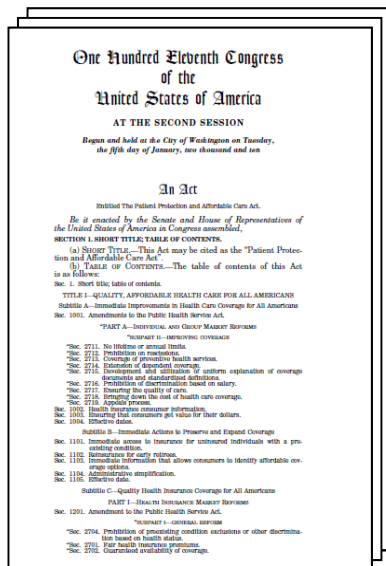
*October 28, 2013*

Patient-Centered Outcomes Research Institute

# Origins of PCORI



## Purpose Of PCORI



“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** that considers variations in patient subpopulations **and the dissemination of research findings** with respect to the relative health outcomes, clinical effectiveness, and appropriateness of medical treatments, services.

Source: Affordable Care Act. Subtitle D—Patient-Centered Outcomes Research.

PUBLIC LAW 111–148—MAR. 23, 2010.

# About PCORI

- An independent non-profit research organization authorized by Congress as part of the 2010 Patient Protections and Affordable Care Act (ACA).
- Committed to continuously seek input from patients and a broad range of stakeholders to guide its work.

# Our Mission and Vision

## Mission

The Patient-Centered Outcomes Research Institute (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.

## Vision

Patients and the public have the information they need to make decisions that reflect their desired health outcomes.



## PCORI's Board of Governors Represents the Entire Health Care Community



*PCORI Board Members at March 5, 2012, public board meeting in Baltimore, Md.*

- Patients/consumers
- Caregivers
- Physicians, nurses and clinicians
- Hospitals and health systems
- Health plans
- Health services researchers
- State and federal health officials
- Pharmaceutical, device, and diagnostic manufacturers
- Private payers
- Employers

# PCOR defined

Patient-Centered Outcomes Research (PCOR) **helps people and their caregivers communicate and make informed health care decisions**, allowing their voices to be heard in assessing the value of health care 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?”

# What is Patient-Centered Research?

- Does the proposed research compare the effects of treatment options that matter to patients?
  - Are these realistic choices faced by patients or other decision-makers?
- Does the research focus on outcomes of interest to patients and their caregivers?
  - Outcomes of interest might include: health, health-related quality of life, functioning, symptoms, safety from medical harm, survival and satisfaction with care.



# Engagement as a path to rigorous research

## Patients and Stakeholders

### Tell Us What PCORI Should Study

What questions are most important?  
(research prioritization)

What outcomes should be studied?  
(topic generation)

### Review Proposals and Partner in Research

Review research proposals for impact and patient-centeredness

Participate in conducting research

### Tell Us How We Are Doing

How can we improve on what we are doing and how we are doing it?

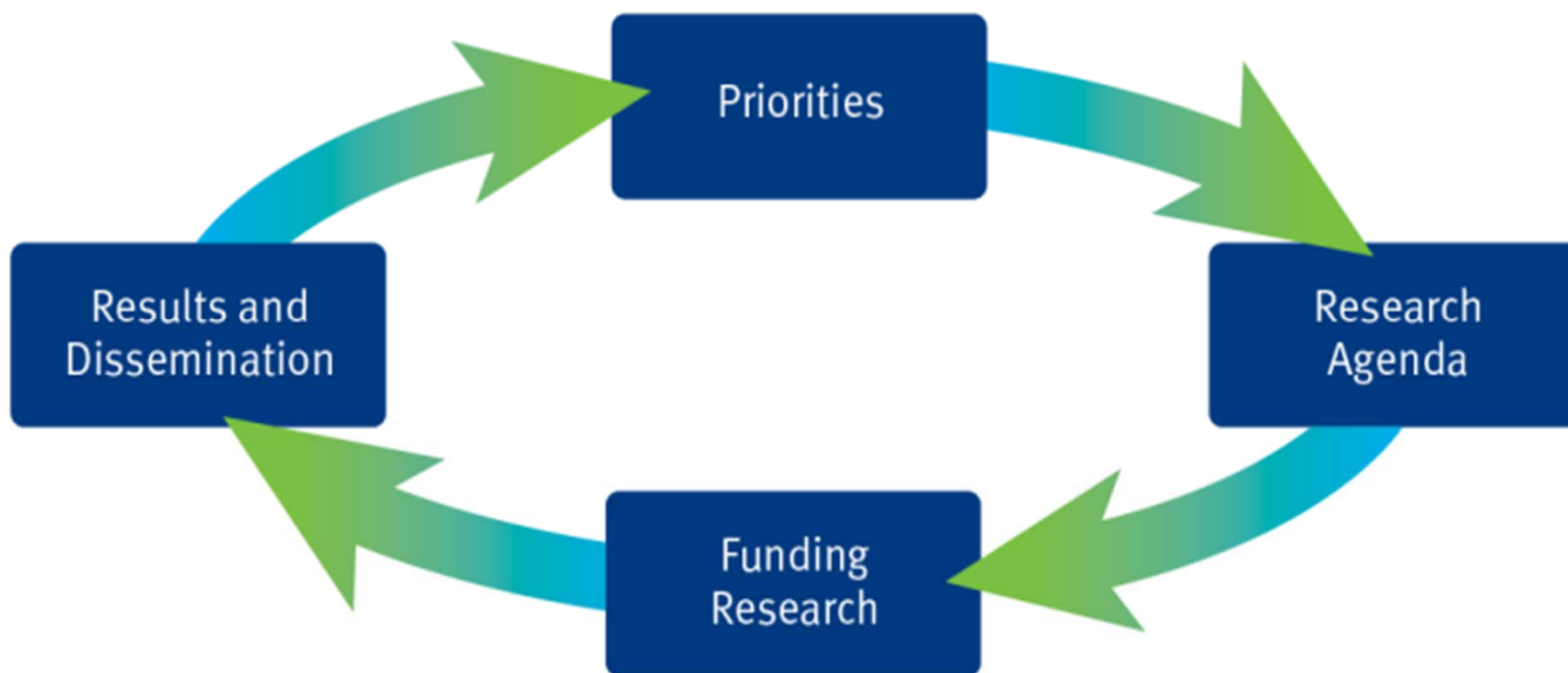
### Help Us Share the Findings

How do we best communicate important research findings?

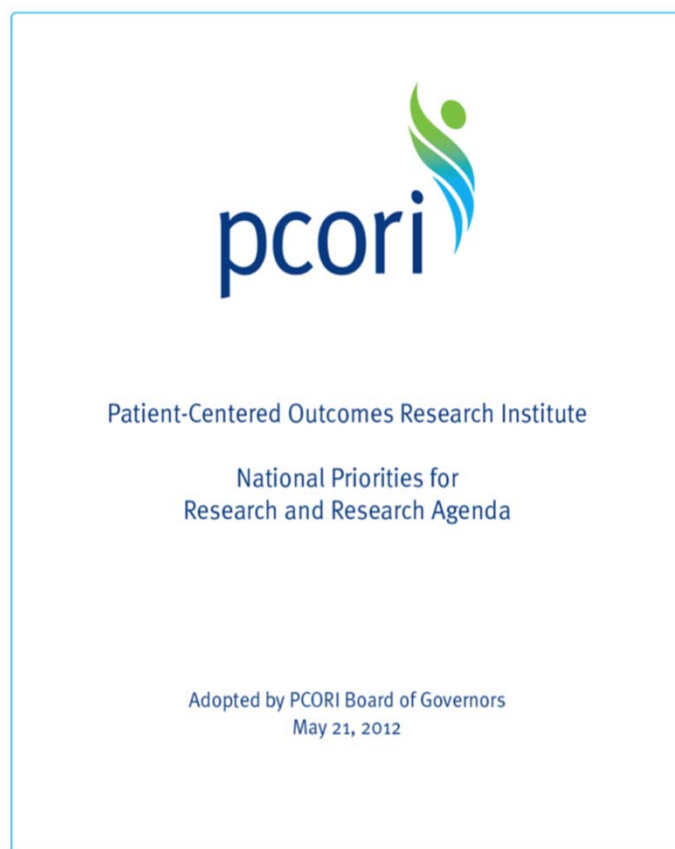


# From priorities to research patients can use

PCORI's Path from Priorities to Research Patients Can Use



## National Priority Areas



- 1. Addressing Disparities**
- 2. Communication and Dissemination**
- 3. Assessment of Prevention, Diagnosis, and Treatment Options**
- 4. Improving Healthcare Systems**
- 5. Infrastructure and Methods**

# Addressing Disparities Program's Mission Statement

## PCORI's Vision, Mission, Strategic Plan



### Program's Mission Statement

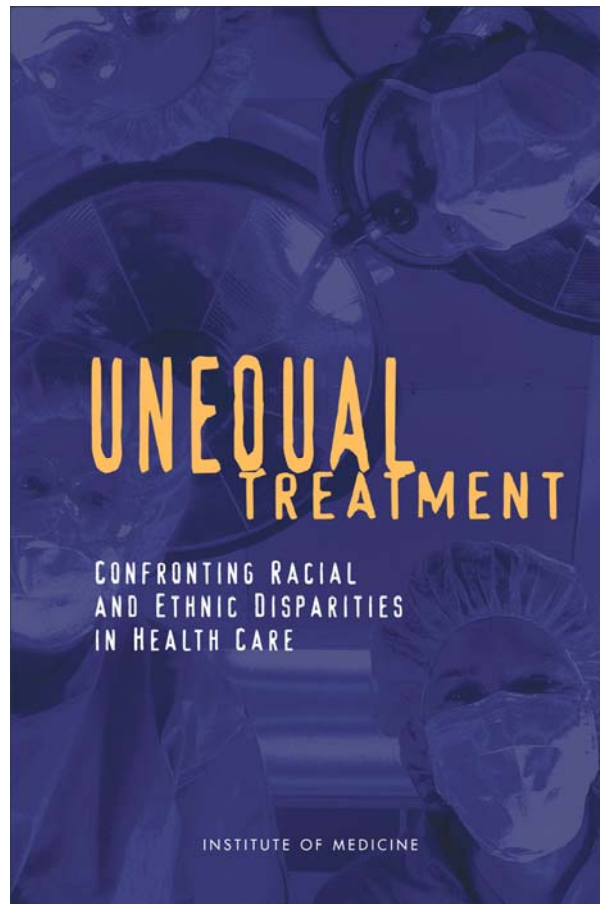
To **reduce disparities** in healthcare outcomes and **advance equity** in health and health care

### Program's Guiding Principle

PCORI is not interested in studies that describe disparities; instead, we want **studies** that will identify best options for **eliminating disparities.**



# 2002 (IOM) Plenty of Evidence that Disparities Exist



Patient-Centered Outcomes Research Institute

# ACA and Addressing Disparities

## *Patient Protection and Affordable Care Act March 23, 2010*

...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**; the potential for new evidence to improve patient health, well-being, and the quality of care...

...review the extent to which research findings are used by healthcare decision makers, **the effect of the dissemination of such findings on reducing practice variation and disparities in health care**...

\*Patient Protection and Affordable Care Act, Pub. L. No. 111-148, §2702, 124 Stat. 119, 318-319 (2010).

# Evolution of Disparities Research

- From minority health to disparities in health; describing the problem
- Understanding the Causes
  - Social Determinants
  - Healthcare Determinants
- Intersection of Disparities and Quality
- Place Matters

# Now What?

**Time to move beyond describing the problem to eliminating disparities in health and health care.**



Patient-Centered Outcomes Research Institute



# Addressing Disparities: Program Goals

## Identify Research Questions

- **Identify** high priority **research questions** relevant to reducing long-standing gaps in disparate populations

## Fund Research

- **Fund research** with the highest potential to address healthcare disparities

## Disseminate Best Practices

- **Disseminate** and facilitate the adoption of research and **best practices** to reduce healthcare disparities

# Addressing Disparities Program Goal



# 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

# What if we thought about better communication as a target for QI?

## Dyad focused (technical skills):

- Motivational interviewing
- Teach-back
- Clear language
- Cultural competency
- Etc.

## Systems focused

- Appreciative inquiry
- Community engagement
- Team-based care
- Build teach-back into forms and processes
- Provide resources to respond when pts fail a teach back
- Provide educational materials, videos, interpreter services

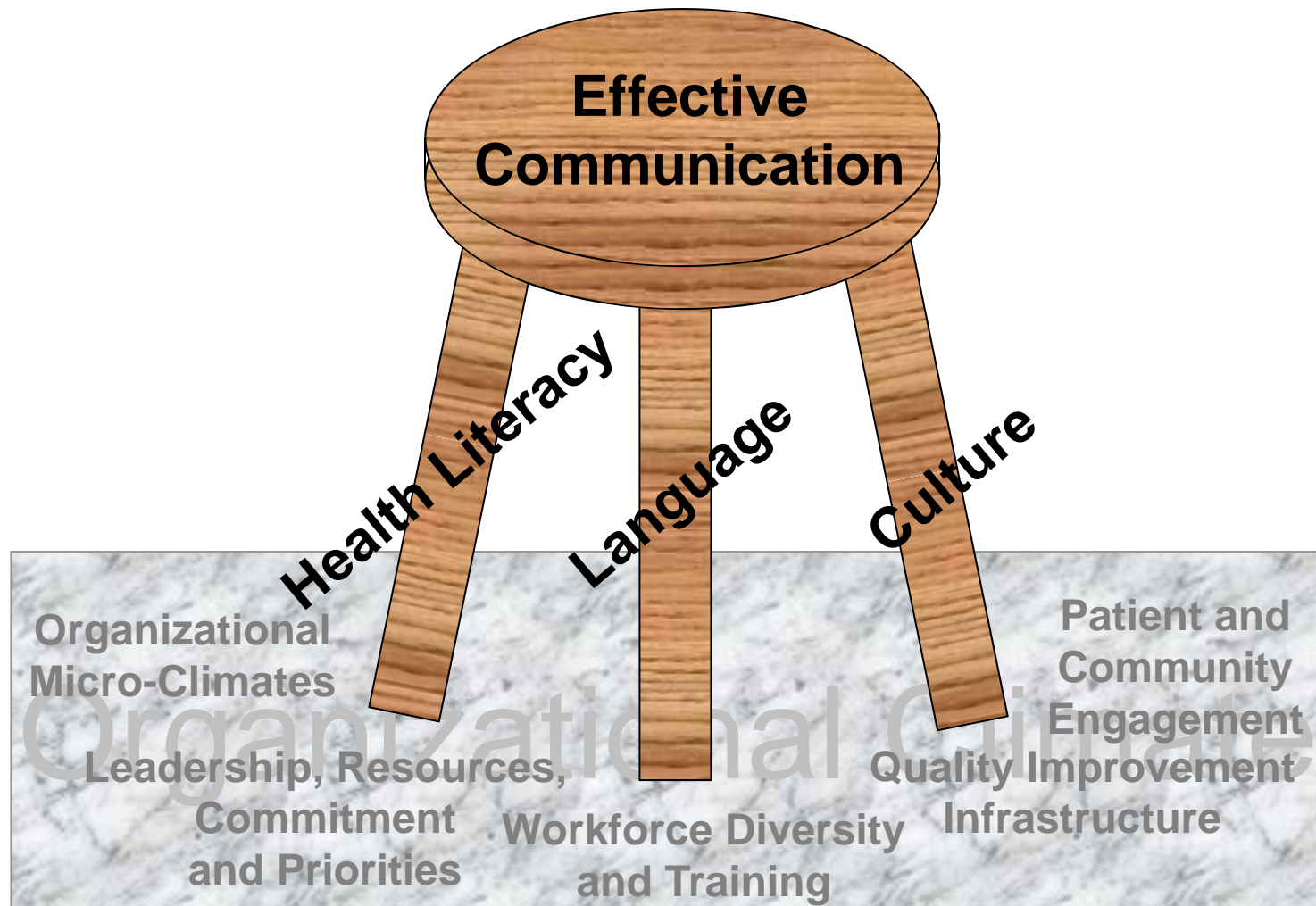
Citation: Matthew K Wynia. Making it easier to do the right thing:

A modern communication QI agenda. *Patient Educ Couns.* 2012; 88:364-6.

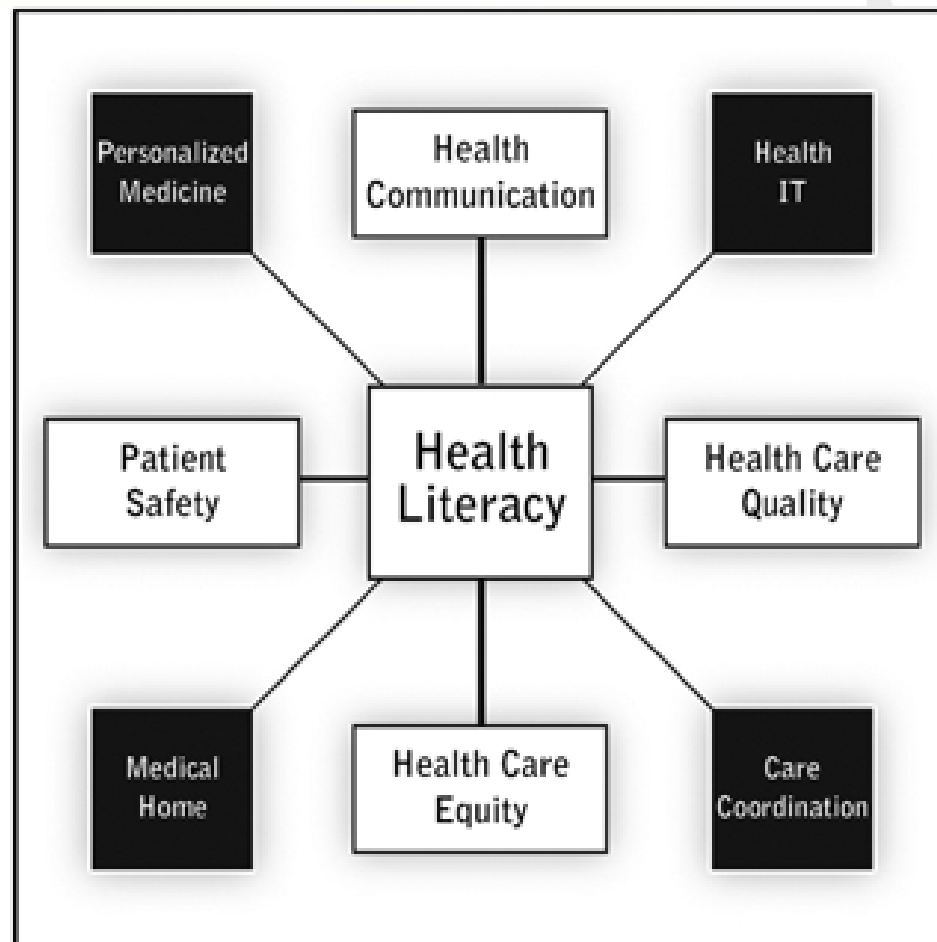


# Patient-Centered Communication Conceptual Framework

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# The Intersection of Health Literacy with Health Care Improvement



Hasnain-Wynia R and Wolf MS (2010)  
*Health Services Research*

# Addressing Disparities Program Advisory Panel Prioritized Topics

Rank	Short Name	Topic
FIRST	Health communication associated with competing treatments	Compare the effectiveness of clinician/patient and organizational health communication models on improving outcomes in minority populations, patients with low literacy and numeracy, people with limited English proficiency, underserved populations, and people with disabilities.
		Compare the effectiveness of community health worker and community health team and organizational health communication models on improving outcomes in minority populations, patients with low literacy and numeracy, people with limited English proficiency, underserved populations, and people with disabilities.
		Compare the effectiveness of interventions on reducing disparities in lower extremity amputations in racial and ethnic minorities.
FIFTH	Reduce lower extremity amputations in minorities	Compare the effectiveness of interventions on reducing disparities in lower extremity amputations in racial and ethnic minorities.



# Addressing Disparities Program: Progress Toward Goal

## **Broad PFAs:**

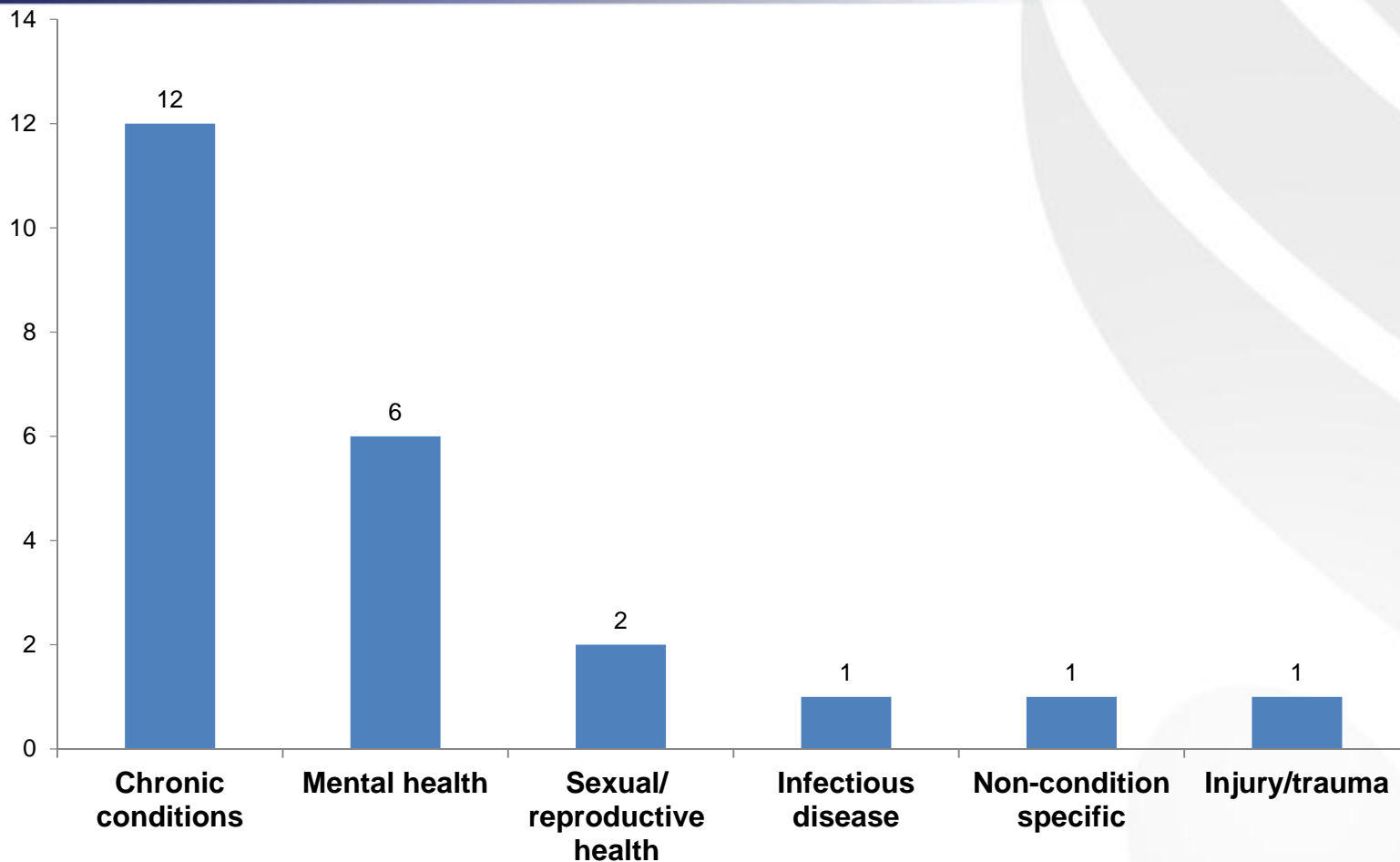
- 23 funded research contracts (Cycles I-III)
- 71 new applications awaiting review (11/21/2013)

## **Targeted Topics:**

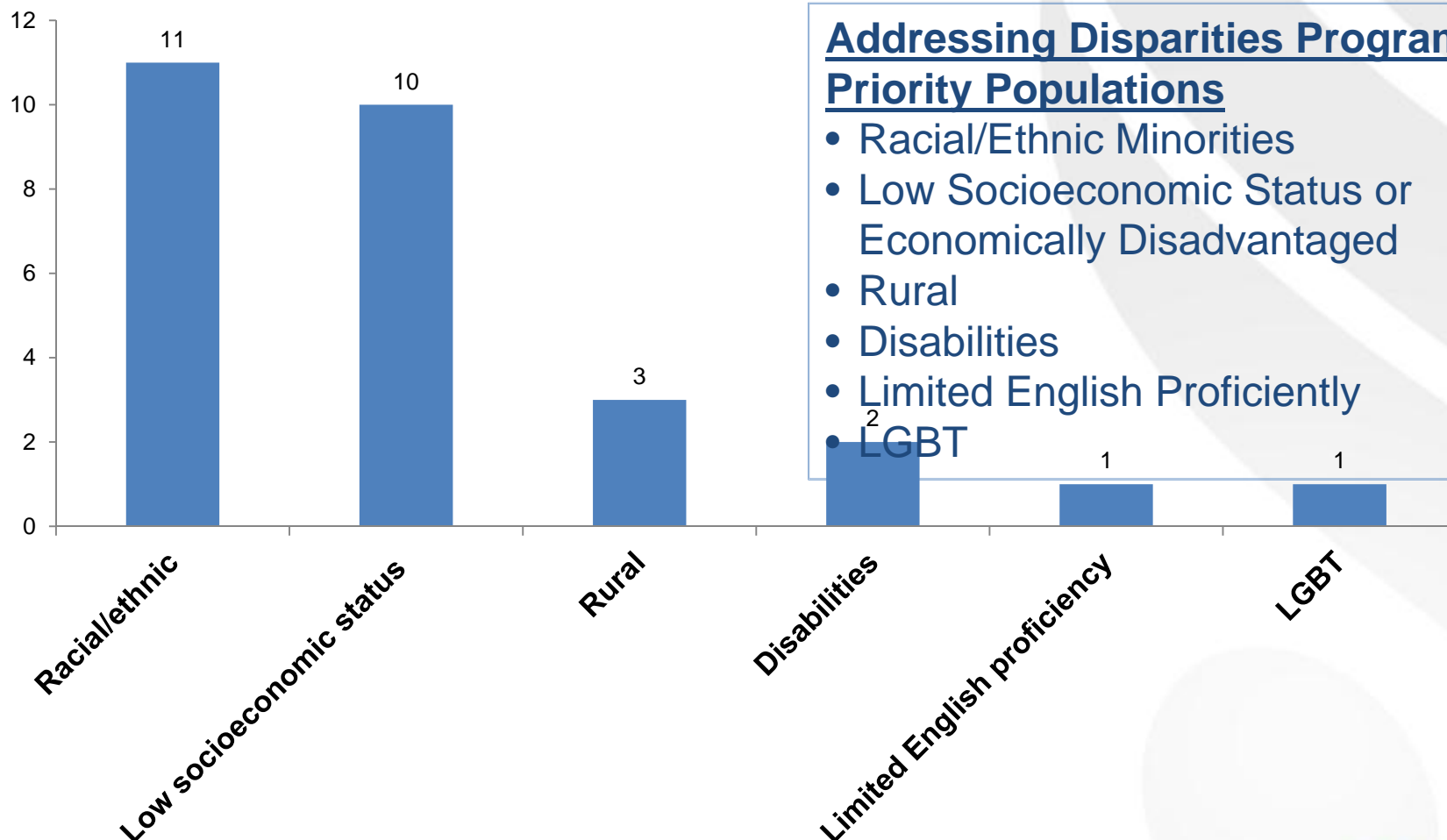
- Treatment Options for Uncontrolled Asthma in African-Americans and/or Hispanic/Latinos: Review 11/11/2013
- Three topics being refined:
  - Obesity Treatment Options. PFA development
  - Perinatal Care (in collaboration with IHS). Workgroup 10/24/2013
  - Hypertension. Collaboration with Million Hearts Initiative. Workgroup Dec 2013.

## **Overarching topic:** Compare the effectiveness of clinician/patient and organizational health communication models on improving outcomes

# Conditions and Diseases: Cycles I-III



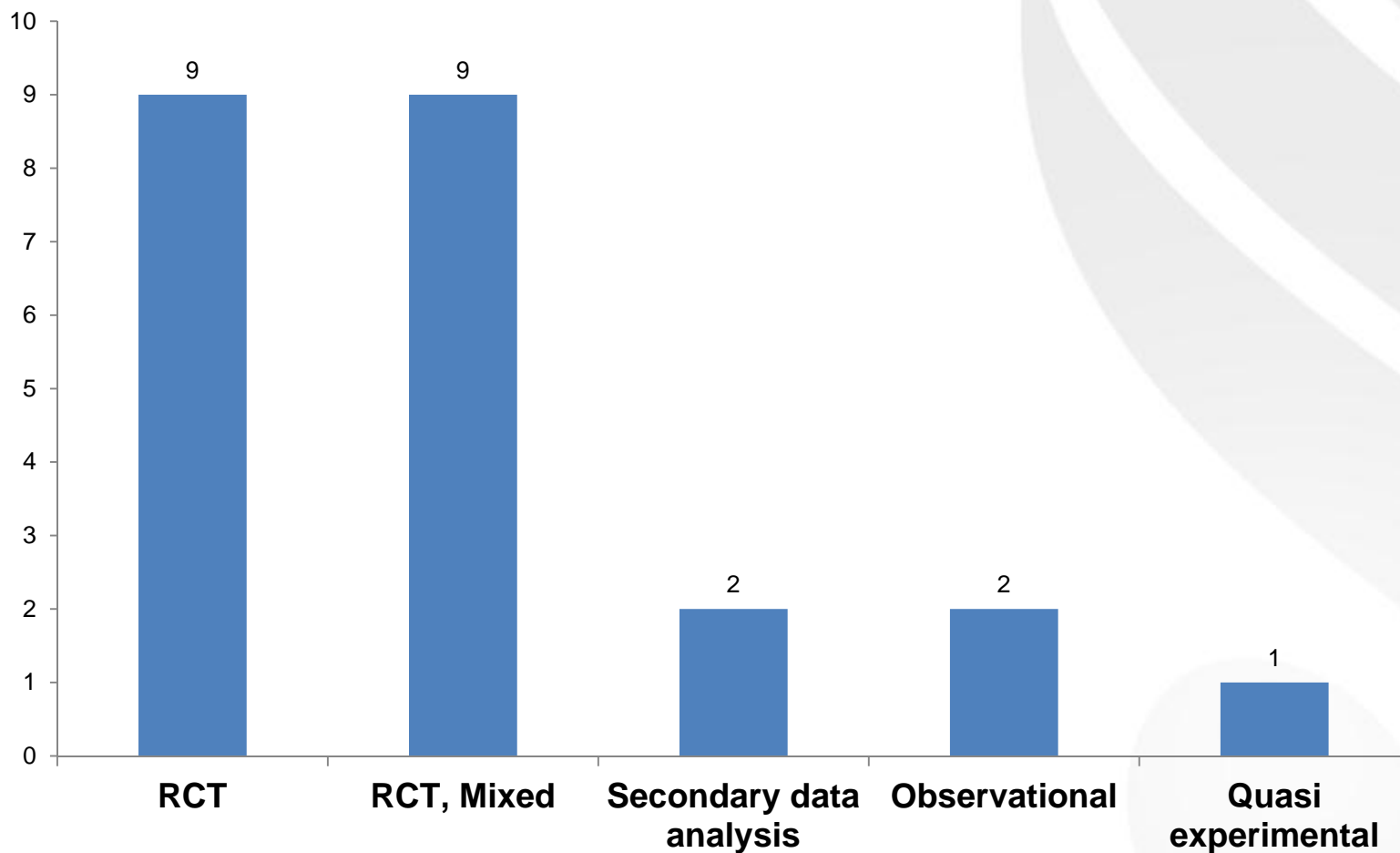
# Disparities Population: Cycles I-III (Not mutually exclusive)



## Addressing Disparities Program Priority Populations

- Racial/Ethnic Minorities
- Low Socioeconomic Status or Economically Disadvantaged
- Rural
- Disabilities
- Limited English Proficiency
- LGBT

# Study Design for Main Analysis: Cycles I-III



# Addressing Disparities Portfolio: Examples

- **Culturally-adapted decision aid**
  - Help Latina's decide whether to get the HPV vaccine.
- **Language-appropriate mobile app**
  - Educate Asian Americans about Hep B and C
- **Telemedicine**
  - Increase access when in-person visits are difficult
- **Literacy-adapted CBT group therapy**
  - Help low literacy patients with chronic pain.
- **Integrative medicine group visit model**
  - Address chronic pain among low income patients
- **Group therapy for cancer survivors AND their caregivers**
  - Improve QOL, stress and family conflict.

# Reducing Disparities with Literacy-Adapted Psychosocial Treatments for Chronic Pain: A Comparative Trial

## Engagement

- Intervention and materials will be guided by patient, provider and expert feedback, and a Research Board will provide study oversight.
- Community members will recruit participants.

## Potential Impact

- Could change practice by providing intervention for reducing pain and depression in chronic pain patients with low income and low health literacy.

## Methods

- Research is completed through a mixed methods approach and a randomized controlled trial.

Conducts a community-based randomized controlled trial comparing three treatments for chronic pain among patients at Federally Qualified Health Centers : 1) usual care, 2) pain education, and 3) health literacy-adapted cognitive-behavioral group therapy.



*Beverly E. Thorn, PhD  
University of Alabama-Tuscaloosa*

*Addressing Disparities Research Project,  
awarded December 2012*

# Nueva Vida Intervention: Improving QOL in Latina Breast Cancer Survivors and Their Caregivers

## Engagement

- Patient and caregiver focus groups will inform design and help refine intervention.
- Academic institutions and patient advocacy groups will collaborate on dissemination.

## Potential Impact

- Could change practice by providing an intervention that can close the established quality of life gap between Latina and non-Latina breast cancer survivors.

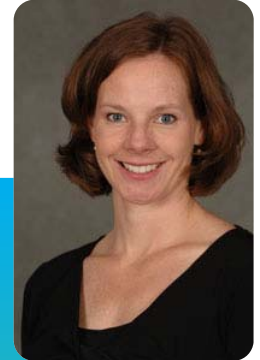
## Methods

- Research is completed through a randomized controlled trial.

Studies the use of group support sessions for Latina cancer survivors and their caregivers. Survivors and caregivers assigned to intervention group will attend separate group sessions twice a month to discuss different quality of life issues such as side effects, stress management and impact on family.

*Kristi Graves, PhD*

*Georgetown  
University*



*Addressing Disparities Research Project,  
awarded May 2013*



# Cultural Tailoring of Educational Materials to Minimize Disparities in HPV Vaccination

## Engagement

- Seeks input from a Community Advisory Board (CAB) comprised of parents of Latina adolescents and young adult Latinas.

## Potential Impact

- Could change practice by increasing HPV vaccination rates among Latinas, and creating a blueprint for improving vaccination rates among underserved communities.

## Methods

- Mixed methods including focus groups followed by a randomized controlled trial.

The project focus is to increase HPV vaccination rates among Latinas, who have the highest risk for developing invasive cervical cancer. The long-term aim is to compare three different approaches to helping Latinas make decisions about the HPV vaccine.

*Amanda Dempsey, MD, PhD, MPH,  
University of Colorado-Denver*

*Addressing Disparities Research Project,  
awarded December 2012*



# A Patient-Centered Intervention to Increase Screening of Hepatitis B and C Among Asian-Americans

## Engagement

- Patient/provider focus groups to create and pilot test app.
- Patient Advisory Councils, community advocacy groups and hospital administrators to serve in advisory roles

## Potential Impact

- Could change practice by expanding our understanding about how to use technology-based interventions to improve quality of care in diverse patient populations.

## Methods

- Research is completed through a randomized controlled trial.

Develops and tests an interactive mobile app to increase the rate of Hep B and C screening among Asian Americans. Trial will test effectiveness of app by comparing its use in combination with a physician panel notification vs. the physician panel notification only.

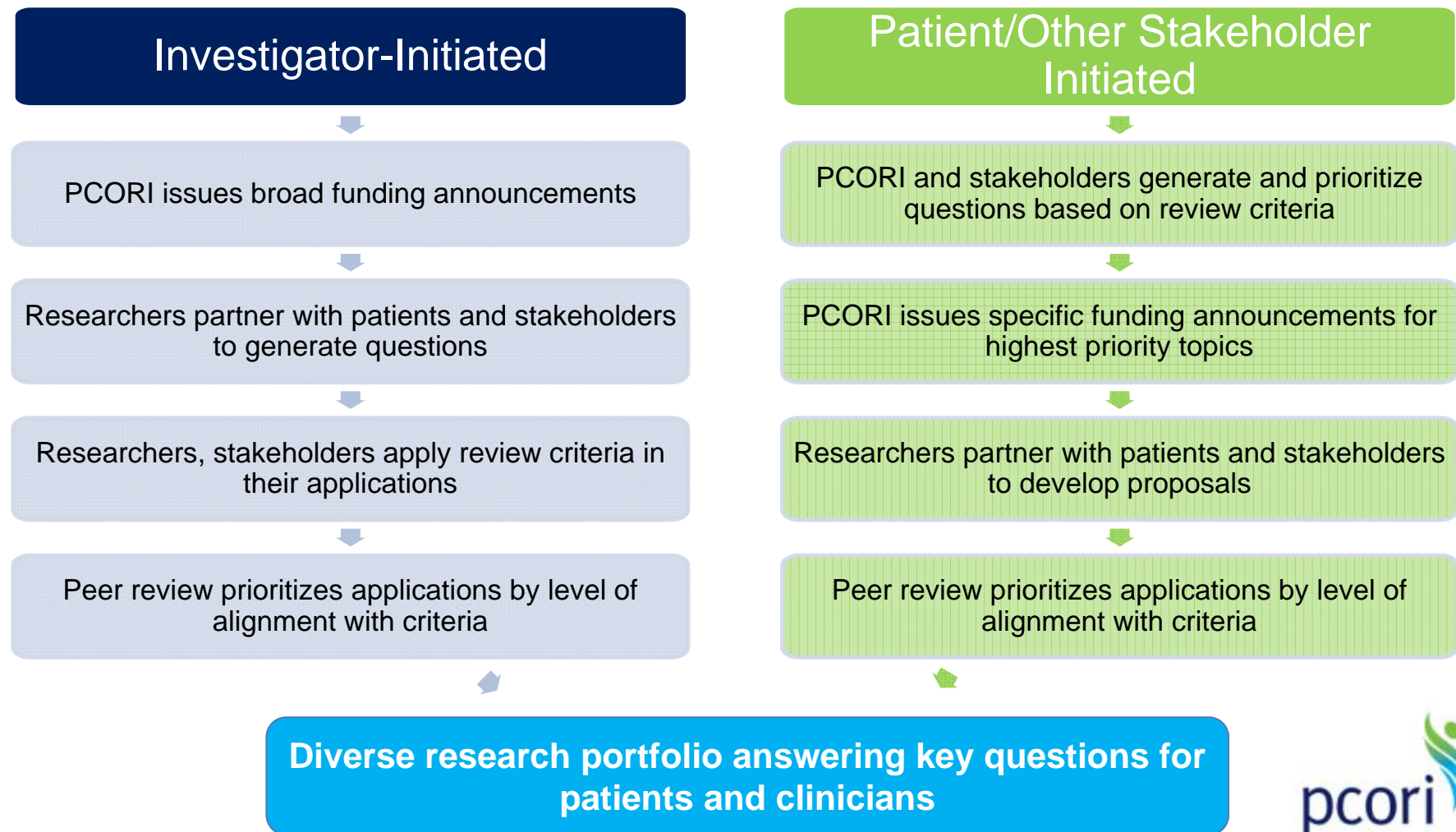
*Tung Nguyen, MD*

*University  
of California San Francisco*



*Addressing Disparities Research Project,  
awarded May 2013*

# Two Paths to Research Funding

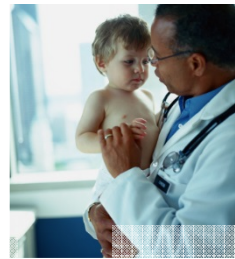


# PCORI Merit Review Criteria

*Applicants must respond to the five PCORI Merit Review Criteria within the **Research Strategy**.*



**1. Impact of the condition on the health of individuals and populations**



**2. Potential for study to improve healthcare and outcomes**



**3. Technical Merit**



**4. Patient-centeredness**



**5. Patient and stakeholder engagement**





# Suggest a research question

We want to know what health care question you may be facing



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[Opportunities for Public Comment](#) | [PCORI Reviewers: Help Us Evaluate Research](#)  
[Suggest a Patient-Centered Research Question](#)

## Suggest a Patient-Centered Research Question

Every day, patients and people who care for them must make health care decisions. They may have to choose between two or more options for preventing, diagnosing or treating a health condition. Or, they might need to decide between doing, or not doing something. For these situations, the Patient-Centered Outcomes Research Institute (PCORI) was created. PCORI funds research to help patients make the best decisions about their health care.

We at PCORI want to know what health care question or decision you may be facing. We want to hear from you. Your input can help us refine our research agenda.

Whether you are a patient with a health condition, a caregiver for someone with a health condition, someone who wants to improve care for your patients, or a researcher, we invite you to share your questions about options faced by patients, we also are interested in questions about health care delivery, address disparities in health care, or improve the community's health. For more information, please see PCORI's National Priorities for Research).

Suggesting a research question is the first step in a five-part process for funding. We will carefully consider each question and, along with public input, decide which ones we will study as part of our portfolio of patient-centered research.

This will be an ongoing feature on the PCORI website. So, please feel welcome to return to this page and suggest additional research questions in the future.

Is your question about a certain disease, behavior or health condition?

If yes, please name the disease, behavior or health condition. If no, leave blank and continue.

Your input can help us refine our research agenda

Share this page



PCORI community as a whole. We're looking for health care professionals and non-scientist stakeholders (patients, caregivers, payers, industry, and community group representatives, etc.) to review research questions submitted in response to our funding announcements!

[Get Involved →](#)

### News Room

Patient-Centered Outcomes Research Institute Names Johns Hopkins Professor and CMS

Patient-Centered Outcomes Research Institute

# Help determine what we fund



Advisory Panels & Working Groups

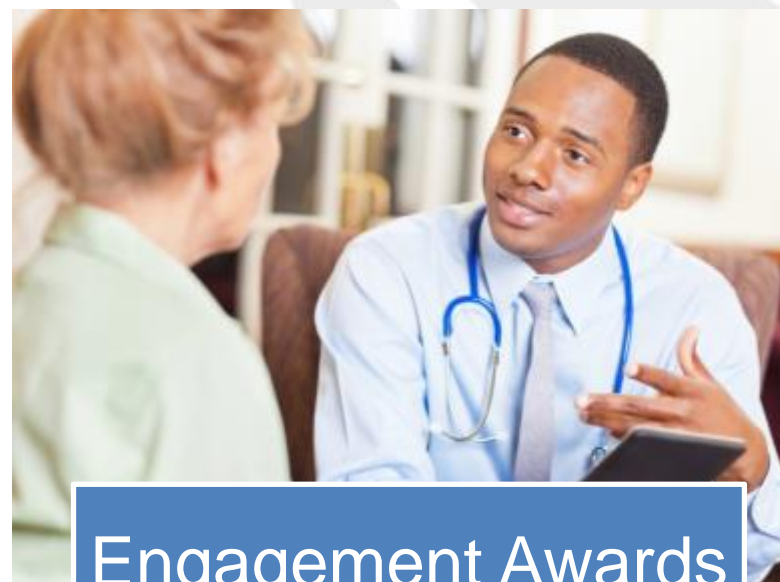


PCORI Reviewers

# Facilitating patient partnership in research



Ambassadors



Engagement Awards



# Tell Us How We're Doing



- Public Comment Periods
- Roundtables and Workshops
- [info@pcori.org](mailto:info@pcori.org)