

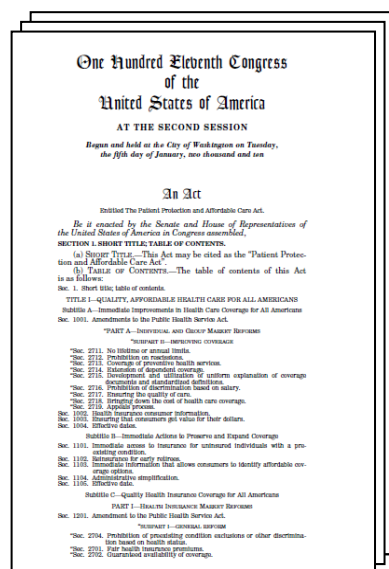


# Welcome and Overview of the Advisory Panels

*Joe Selby, MD, MPH*  
*Executive Director, PCORI*  
*Advisory Panel Kickoff & Training*  
*April 19, 2013*

Patient-Centered Outcomes Research Institute

# PCORI's Broad Mandate



## Purpose Of PCORI

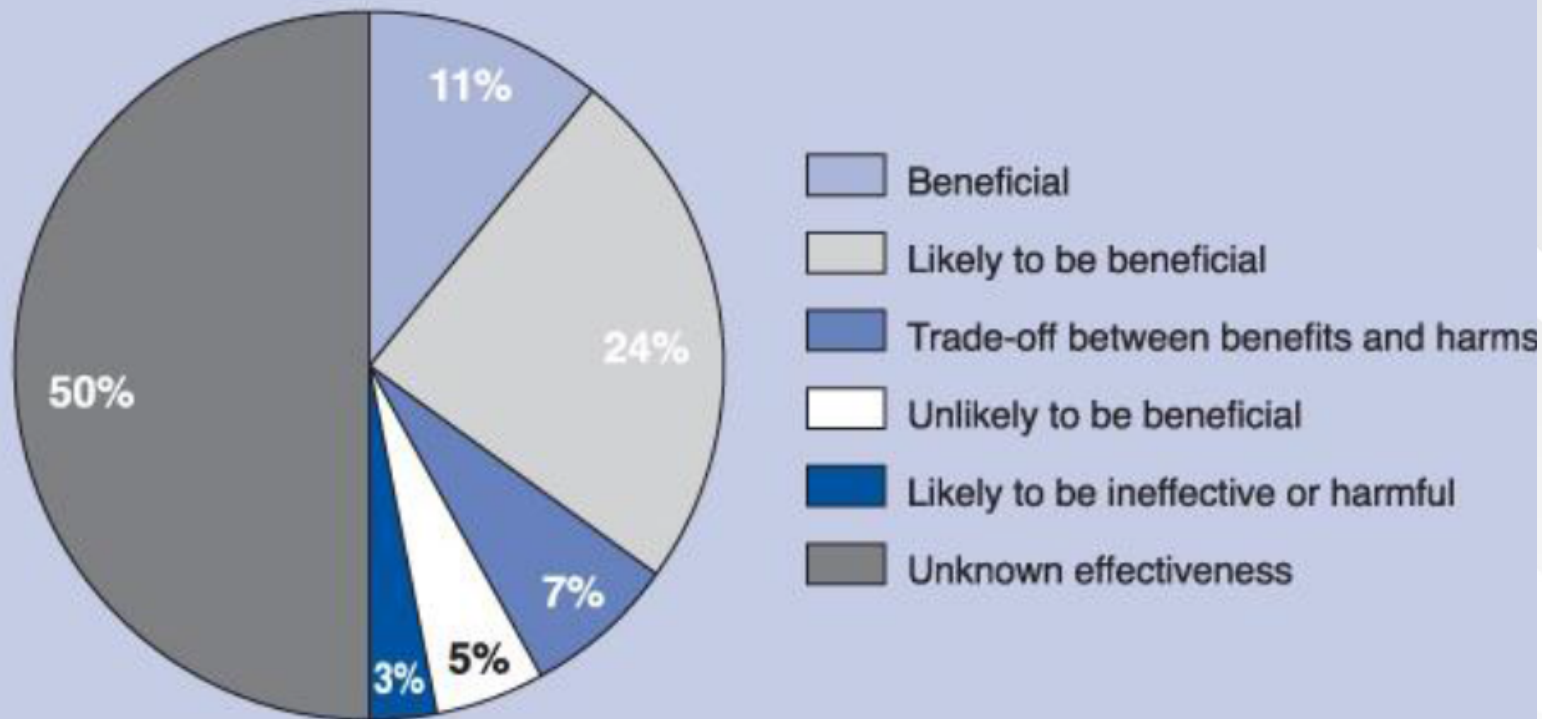
“The purpose of the Institute is **to assist patients, clinicians, purchasers, and policy-makers in making informed health decisions** by advancing the quality and relevance of evidence concerning the manner in which diseases, disorders, and other health conditions can effectively and appropriately be 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.

# Welcome to PCORI

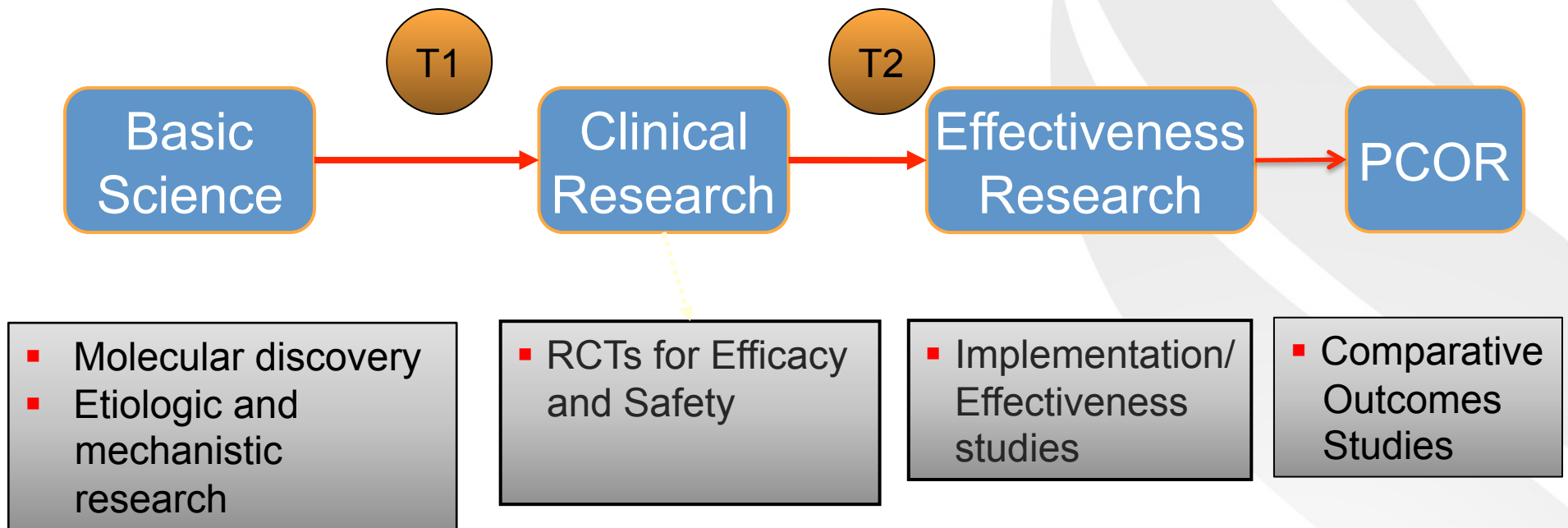
- PCORI funds research intended to provide patients and those who care for them the information they need to make better-informed healthcare decisions.
- Our core duties are to:
  - Establish national research priorities
  - Establish and carry out a research agenda
  - Develop and update methodological standards
  - Disseminate research findings

# Why PCORI is Necessary



Effectiveness of 3000 treatments as reported in randomised controlled trials selected by Clinical Evidence. This does **not** indicate how often treatments are used in healthcare settings or their effectiveness in individual patients.

# Continuum of Medical Research



KAISER PERMANENTE®



Patient-Centered Outcomes Research Institute

# National Priorities for Research and Research Agenda

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

**Improving Healthcare Systems**

**Communication & Dissemination Research**

**Addressing Disparities**

**Accelerating PCOR and Methodological Research**

# PCORI Funding – Approximate



\* 20% each year goes to AHRQ/HHS

# PCORI's Key Criteria for Funding

- **Potential for Improvement** – How likely is the proposed research to lead to changes in patient or clinician practices that lead in turn to meaningful improvement in patient health?
- **Patient-Centeredness** – Is the proposed research focused on comparisons and outcomes that matter to patients and their caregivers?
- **Patient and Stakeholder Engagement** – Have the researchers included in their team relevant patients and other key healthcare community members, representative of those who would use its information?





# Our First Topics for Targeted Research Funding

- Jump-starts our long-term effort to identify and prioritize specific research topics to study
- Leverages stakeholder input
- Ad hoc workgroup meetings recorded and available on the PCORI Web site

## Research Topics:

Treatment Options for Severe Asthma in African-American and Hispanic/Latino populations

Treatment Options for Uterine Fibroids

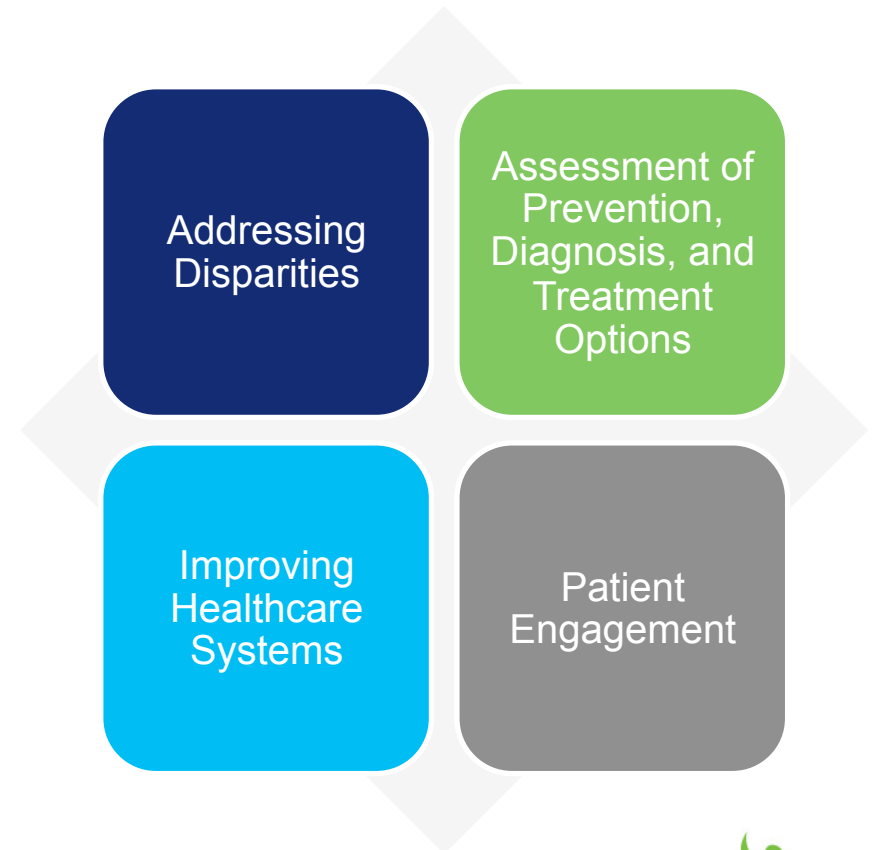
Preventing Injuries from Falls in the Elderly

Treatment Options for Back Pain

Obesity Treatment in Diverse Populations

# Long-term Approach to Targeted Research: PCORI Advisory Panels

- PCORI established the first four Advisory Panels in March 2013
- 1,295 applications were reviewed by PCORI staff, and the final panel slates were approved by the Board of Governors
- Each panel has 21 members consisting of patients, researchers, clinicians, and other experts with relevant experience and knowledge to inform PCORI's work
- Each panel has a unique charter, term duration, and clearly defined scope of work



# Overview of PCORI Advisory Panels

## Legislative Authorization

### What does the law say about advisory panels?

- PCORI can appoint permanent or ad hoc advisory panels to assist in identifying research priorities and establishing the research project agenda.
- Advisory panelists will include representatives of practicing and research clinicians, patients, and experts in scientific and health services research, health services delivery, and evidence-based medicine who have experience in the relevant topic, and as appropriate, experts in integrative health and primary prevention strategies.

## Purpose

### What's the purpose of advisory panels?

- Advisory panelists work in conjunction with PCORI staff to help identify research priorities and topics
- Leveraging members' expertise will help better inform PCORI's mission and work.

# Overview of PCORI Advisory Panels

## Conflicts of Interest

### Will panel members be eligible for future PCORI funding?

- Panel members are not making decisions on either funding or funding announcements.
- PCORI will maintain “firewalls” between Advisory Panel members and internal decisions that would convey any knowledge advantage to panel members.
- Advisory panel meetings are recorded and publicly available immediately after a meeting.
- Therefore, membership generally does not preclude eligibility for funding.

## Panel Charters

### What has been approved by PCORI's Board?

- Charters and panel slates were reviewed and approved for four panels: **Assessment of Prevention, Diagnosis, and Treatment Options; Addressing Disparities; Improving Healthcare Systems; and Patient Engagement.**
- Members will initially be appointed for a one-year term, with the possibility of reappointment for a maximum of two terms.
- Term of the charter will remain in effect for one year beginning on the day of the first meeting.
- Charter is subject to review, reauthorization, amendment, or termination by the Board of Governors or its designee.



# PCORI's Board of Governors



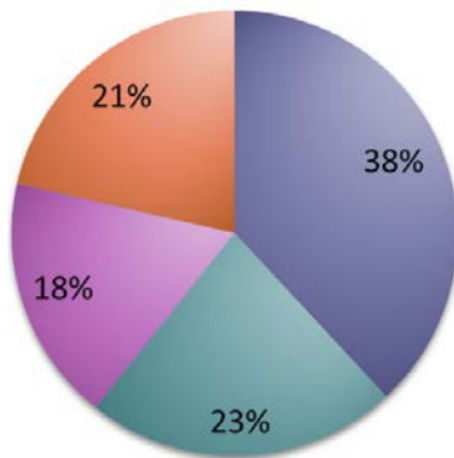
*PCORI Board of Governors, March 2012 in Baltimore, MD*

# Why PCORI Needs You

- Advisory Panels will assist PCORI in developing and refining our patient-centered comparative clinical effectiveness research portfolio and in disseminating research findings through:
  - prioritization of proposed research topics
  - provision of input and expertise on questions that arise within the Advisory Panel's focus area
  - periodic evaluation of PCORI's research portfolio
  - Ongoing two-way communication with stakeholder communities
  - Ensuring the highest patient engagement standards and a culture of patient-centeredness in both our work and the research that we fund.

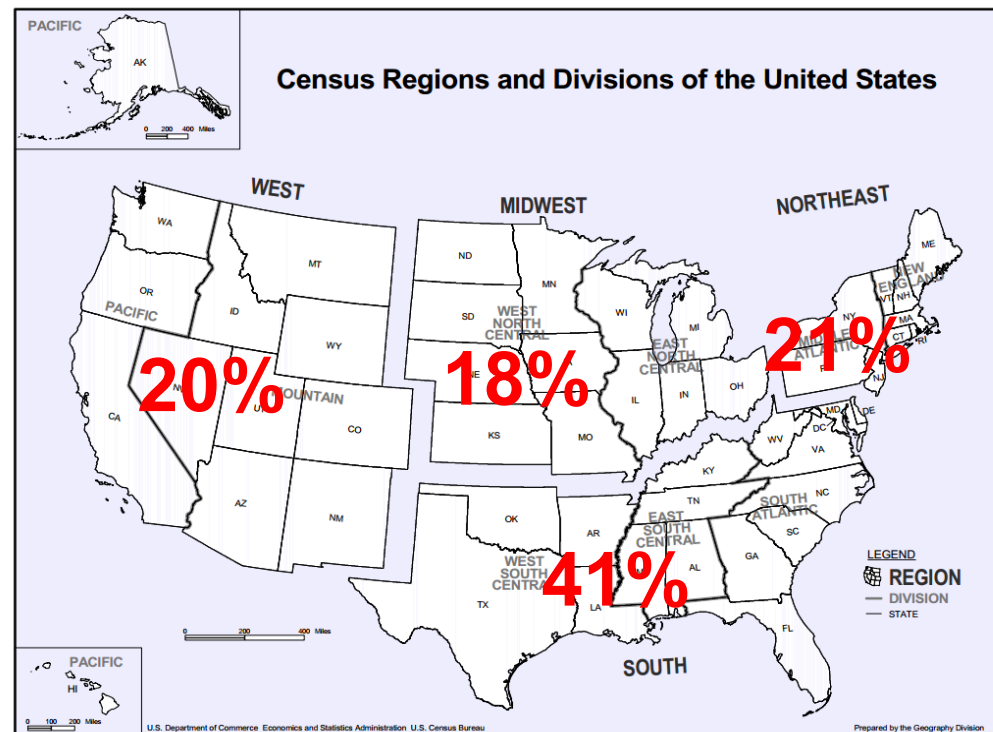
# Distribution of Advisory Panelists

**Panelists by Stakeholder Group  
(Self-Identified; N=84)**



- **Researcher** (eg., Academic, Scientist, Clinical Investigator)
- **Clinician** (eg., Physician, Nurse, Pharmacist, Dentist, Chiropractor)
- **Patient** (eg., Caregiver, Patient Advocate, Consumer, Family Member)
- **Other Stakeholder** (eg., Payer, Policymaker, Purchaser, Device or Pharmaceutical Manufacturer)

**Panelists by Geographic Location  
(Self-Identified; N=84)**



\* Map of census regions and divisions of the United States made available by the U.S. Census Bureau, U.S. Department of Commerce, Economics and Statistics Administration.



# General Session Agenda

Time	Session	PCORI Presenters
8:45-9:15	Welcome and Overview of the Advisory Panels	<b>Joe Selby</b> , Executive Director
9:15-9:35	Patient Engagement in Research	<b>Sue Sheridan</b> , Director, Patient Engagement
9:35-10	Q&A Session	<b>Anne Beal</b> , Deputy Executive Director & Chief Officer for Engagement
10:15-11:15	Research Prioritization Training	<b>Rachael Fleurence</b> , Acting Director, PCOR Methods
11:15-11:45	Software Training	<b>Kara Odom Walker</b> , Program Officer
11:45-12	Wrap-Up and Announcements	<b>Anne Beal</b> , Deputy Executive Director & Chief Officer for Engagement