



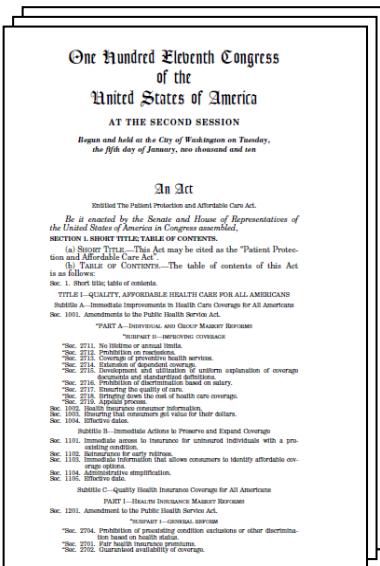
Welcome and Overview of the Advisory Panels

*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.

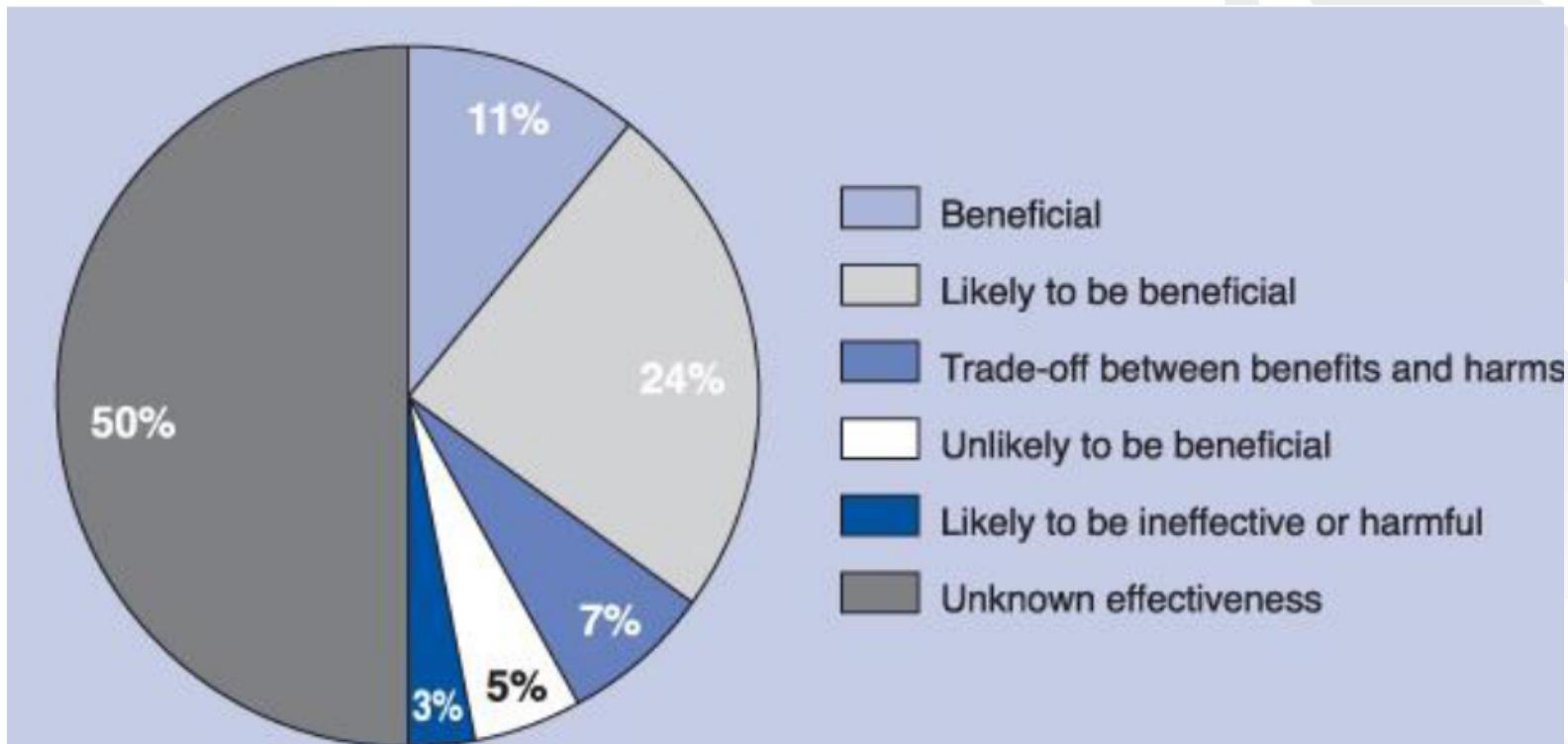
Patient-Centered Outcomes Research Institute



Welcome to PCORI

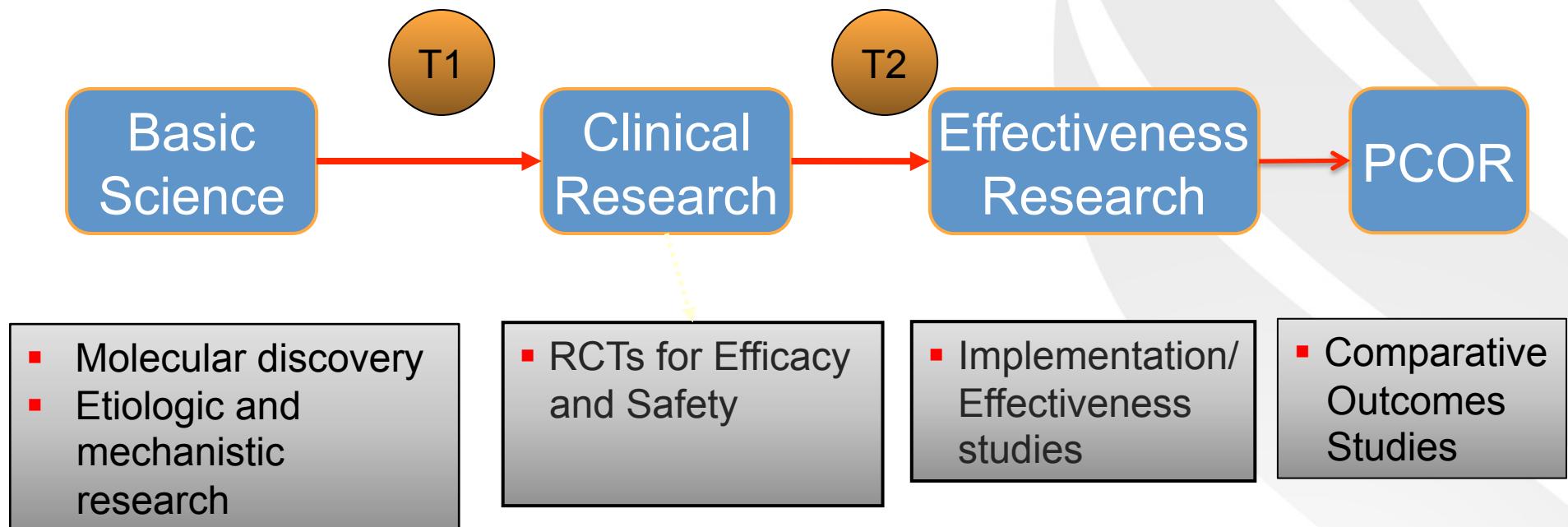
- PCORI funds research intended to provide patients and those who care for them the information they need to make better-informed healthcare decisions.
- Our core duties are:
 - Establish national research priorities
 - Establish and carry out a research agenda
 - Develop and update methodological standards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

Addressing Disparities

Assessment of Prevention, Diagnosis, and Treatment Options

Improving Healthcare Systems

Patient Engagement

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



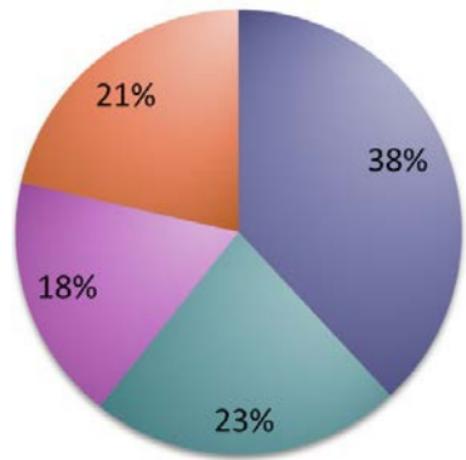
PCORI Board of Governors, March 2012 in Baltimore, MD

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.

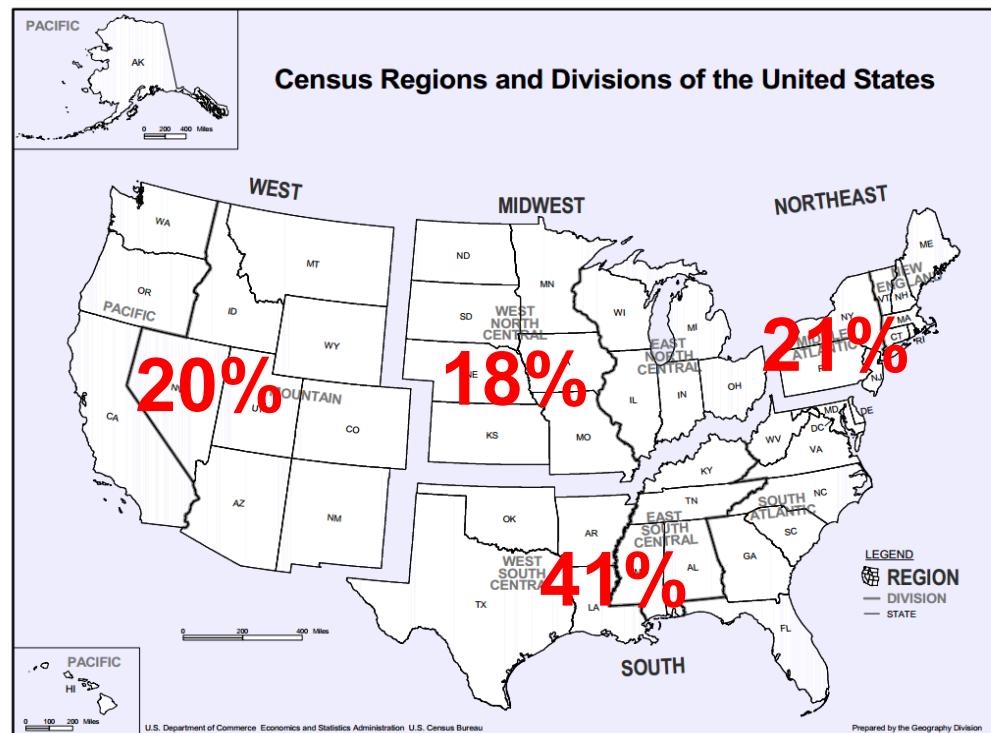
Distribution of Advisory Panelists

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	Joe Selby , Executive Director
9:15-9:35	Patient Engagement in Research	Sue Sheridan , Director, Patient Engagement
9:35-10	Q&A Session	Anne Beal , Deputy Executive Director & Chief Officer for Engagement
10:15-11:15	Research Prioritization Training	Rachael Fleurence , Acting Director, PCOR Methods
11:15-11:45	Software Training	Kara Odom Walker , Program Officer
11:45-12	Wrap-Up and Announcements	Anne Beal , Deputy Executive Director & Chief Officer for Engagement

