What is PCORI?

- Non profit research institute
- Created by Congress (ACA) (but arms-length)
- Funded via a new trust fund
  - Some general federal revenues
  - Medicare trust fund
  - Mainly (60%) fees from...(partly)..."you" (covered lives)
  - 2014 Budget ~ $500M
Why PCORI?

Research has not answered many questions patients face (and employers pay for)
People (incl your employees) want to know which treatment is right for them
Patients need information they can understand and use
Employers want to ensure their HC $ are spent wisely
“Orzag principle”

Employers…

Provide health insurance coverage for 2/3 of the US population
Fund roughly 1/3 of all health care expenditures in the US
Fund roughly 40% of prescription drug spending

Outcomes Matter to Employers

- Productivity
- Absence
- Disability
- Work Performance

Outcomes Matter to Employees

- Effective treatments
- QoL
- Satisfaction
- Functional Status
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 the medical treatments...*

“The Institute shall establish a standing methodology committee to...develop and improve the science and methods of comparative clinical effectiveness research”

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.

* Larry Becker (Xerox) Board Member
Our 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

Our Work Answers Patients’ Questions

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?”
We Use Engagement as a Path to Rigorous Research

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
How We Pick Research Questions to Study

1. Gather Suggestions
   - Patient Stakeholder Community
   - PCORI Staff

2. Evaluate Suggestions
   - AHRQ and Academic Centers

3. Prepare Topic Briefs
   - PCORI Staff

4. Prioritize Topics
   - PCORI Board
   - Advisory Panels

5. Select Suggestions

6. Release Funding Assessments
   - PCORI Staff

Our Advisory Panels

- Leverage knowledge and experience of clinicians, researchers, patients, and other experts to help PCORI achieve its goals

- Assure meaningful patient engagement in:
  - Identifying research priorities and topics
  - Monitoring research activities
  - Conducting randomized clinical trials

Addressing Disparities
Assessment of Prevention, Diagnosis, and Treatment Options
Improving Healthcare Systems
Patient Engagement
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

Our Review Criteria

Priorities 1-4:
- Impact of the condition on health of individuals and populations
- Potential for improving care and outcomes
- Technical merit
- Patient-centeredness
- Patient and stakeholder engagement

Priority 5:
- Impact on field of patient-centered outcomes research
- Potential for the study to improve PCOR methods
- Technical merit
- Patient-centeredness
- Patient and stakeholder engagement
Our Methodology Standards

Methodology Committee (high-powered, Congressionally-mandated)

- Formulating Research Questions
- Patient-Centeredness
- Systematic Reviews
- General and Crosscutting Methods For All PCOR
- Causal Inference Standards
- Heterogeneity of Treatment Effect (HTE)
- Preventing and Handling Missing Data
- Data Networks
- Adaptive and Bayesian Trial Designs
- Data Registries
- Studies of Diagnostic Tests

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 PCOR research, and create partnerships within that community that lead to high-quality research proposals.
Our Growing Research Portfolio

Total number of research projects approved to date: 197

Number of states where we are funding research: 36 states (plus the District of Columbia)

Expected research commitment in 2013: $425 million

PCORI Pilot Projects

Advance methods for engaging patients in the research process and identify gaps in comparative clinical effectiveness research that need further development

50 Awards

$31,000,000
Improving Healthcare Systems

Projects that address critical decisions that face healthcare systems, the patients and caregivers who rely on them, and the clinicians who work within them.

By Health Topic

- Chronic Illness 26%
- Mental Health 21%
- Cancer 11%
- Care Transitions 16%
- End-of-Life and Home Services 16%
- Access to Care 10%

32 Awards
$58,978,563
Communication & Dissemination Research

Projects that address critical elements in the communication and dissemination process among patients, their caregivers, and clinicians.

By Population

20 Awards
$33,502,693

- Children 19%
- All Patients 12%
- Chronic Condition Patients 13%
- Older Adults 12%
- Racial/Ethnic Minorities 13%
- Other 31%

Some studies address multiple populations.
### Targeted Funding Announcements

#### Announced

| Prevention of fall-related injuries in older adults | $30 million |
| Treatment Options for African Americans and Hispanics/Latinos with Uncontrolled Asthma | $17 million |

#### In Development

| Treatment for uterine fibroids (with Agency for Healthcare Research and Quality) | $20 million |
| Obesity Treatment Options in Diverse Populations | TBD |
| Transitions in Care | TBD |
| Treatment Options for Back Pain | TBD |

### Methodological Research & Infrastructure Investment

Projects that aim to improve the nation’s underlying capacity to conduct patient-centered outcomes research rapidly, efficiently, and consistently over time.

**Improving Methods for Conducting Patient-Centered Outcomes Research**

- September 2013
- 19 projects, $18,045,991

**National Patient-Centered Clinical Research Networks**

- Anticipated Award Date: December 2013
National Patient-Centered Clinical Research Network

- Clinical Data Research Networks (CDRNs)
- Patient-Powered Research Networks (PPRNs)
- Data Coordinating Center
- Developmental Phase: ~ $58M over 18 months

National Patient-Centered Clinical Research Network: Our Vision

- Scientific Advisory Board
- Steering Committee
  - Awardees
  - PCORI
  - AHRQ, NIH, FDA, ONC, CMS, VA
- Special Expert Group

Coordinating Center (CC)
Potential Participants

- Patient Organizations
- Practice Based Research Networks
- Medical Groups
- Medical Centers
- Health Plans
- Integrated Delivery Systems
- Disease Registries
- Centers for Medicaid and Medicare Services
- State and Local Health Agencies

So….Why Should Employers Care About PCORI?

- PCORI can help answer health concerns of interest to employers and their employees

- Employers are (partially) funding PCORI!
  - ~ 60% PCORI funding from fees related to insured lives
How Can Employers Work with PCORI?

Guide our efforts, help define our agenda by…

- Engagement (and bring your employees!!)
- Participate in advisory panels to generate CER research questions & outcomes of interest:
  - ...to you and your employees
- Participate in our research panels to:
  - ...select research projects to fund

And…

How Can Employers Work with PCORI?

Help disseminate & translate research results into practice

- Health programs for employees
  - Risk assessments and screenings
  - Wellness and education programs, incentives
  - Behavior change programs
  - Disease management and health coaching
- Benefit design
  - Evidence-based insurance design
  - Performance incentives
  - Primary care and disease management support
Finally, You Can…

Watch us closely, evaluate how we are doing and provide constructive, real time feedback.

So, let’s talk!