

# Patient-Centered Outcomes Research Institute –

## National Priorities and Research Agenda

*Cultivating Traditions of Wellness 2012:  
Advancing Community Leadership Conference*

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March 20, 2012

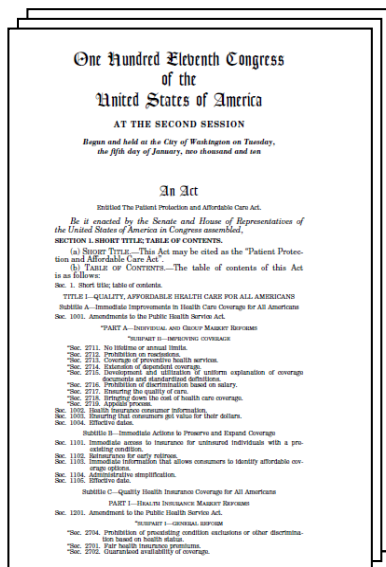


# PCORI Purpose: Defining Legislation



## Purpose

“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.



## About PCORI

- PCORI is an independent, non-profit organization created by Congress in 2010.
- PCORI's mission is to fund research that will provide patients, their caregivers and clinicians with the evidence-based information needed to make better-informed health care decisions.
- PCORI is committed to continuously seeking input from patients and a broad range of stakeholders to guide its work.

## PCORI MISSION STATEMENT

- 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.

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



- Patients
- Hospitals
- Health Plans and Systems
- Caregivers
- Physicians, nurses and providers
- Health services researchers
- State and federal health officials
- Pharmaceutical, device, and diagnostic manufacturers
- Private payers
- Employers

# Comparative Effectiveness Research - CER

The logo for the Patient-Centered Outcomes Research Institute (PCORI) is located in the top right corner. It features the lowercase letters "pcori" in a white, sans-serif font, followed by a stylized graphic of a person with arms raised, also in white.

- Addresses practical questions – especially those of interest to patients and providers – usually head-to-head comparisons
- Conducted in “typical” patients and “typical” care delivery settings
- Considers the range of outcomes of interest to patients and clinicians
- Considers possible differences in treatment effectiveness in patient subgroups – what works for whom?
- May be RCTs or observational studies

# Making Outcomes Research Patient-Centered

Patient Engagement → Patient-Driven Research → Dissemination



Understanding  
the choices  
patients face

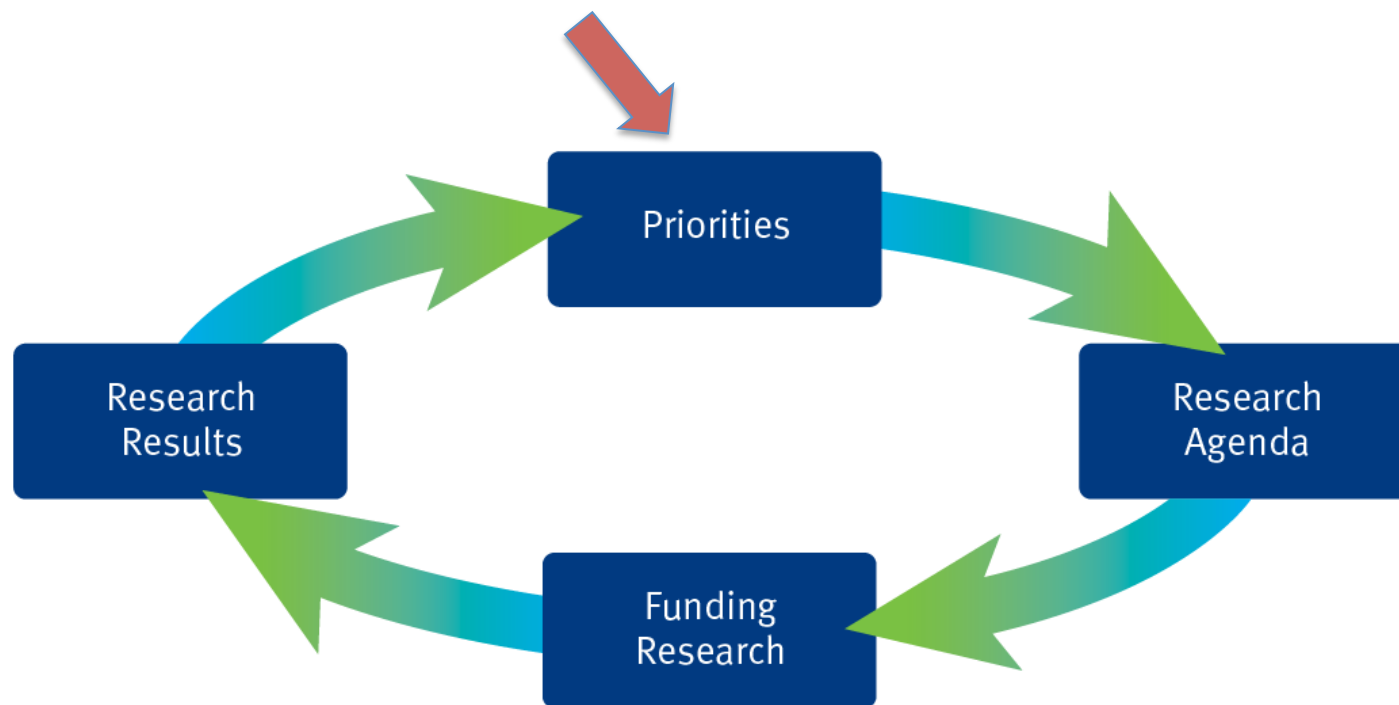


Aligning research questions  
and methods with  
patient needs



Providing patients and  
providers with  
information  
for better decisions

# PCORI's Path from Priorities to Research Patients can Use

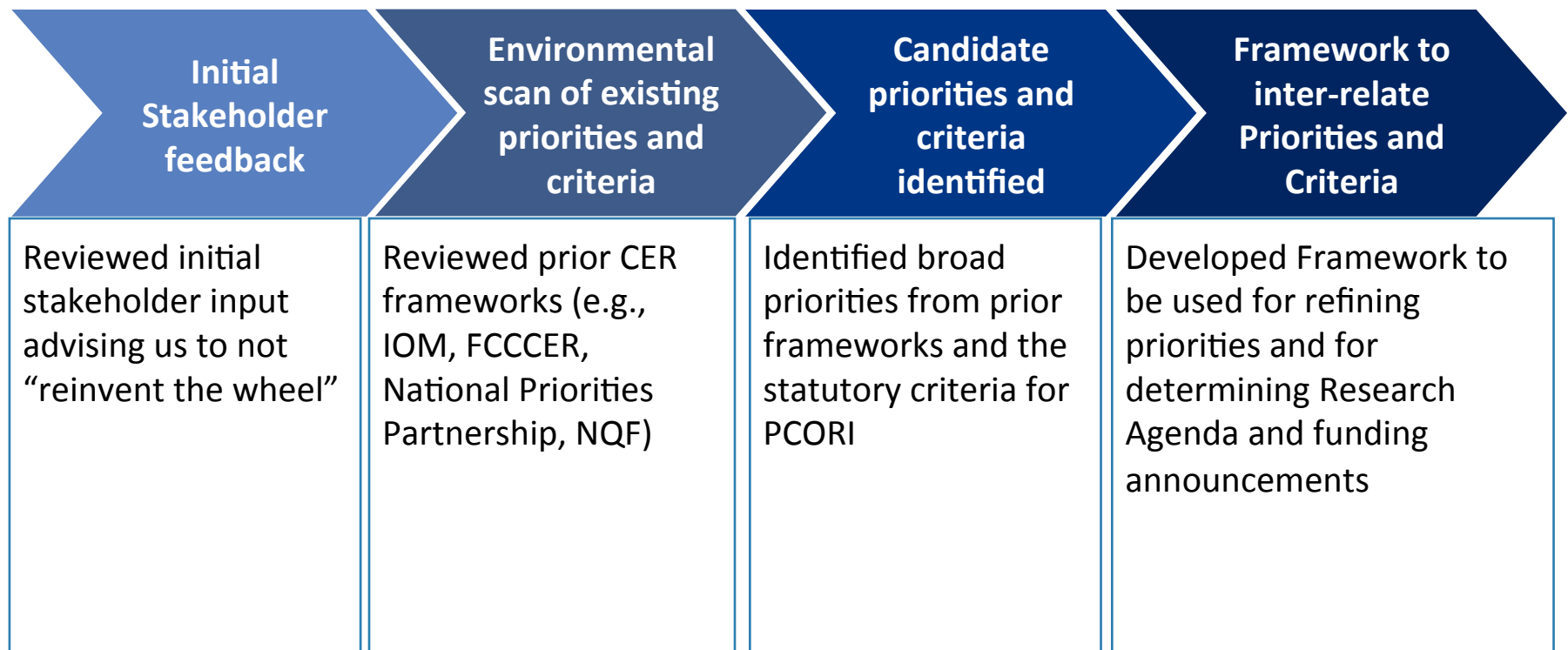


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Future priorities and agenda will be informed by the development process, ongoing stakeholder engagement, and PCORI's research results.

# National Priorities

# Development of a National Priorities Framework



# Environmental Scan



Source	Prevention	Acute Care	Chronic Disease Care	Palliative Care	Care Coordination	Patient Engagement	Safety	Appropriate Use	HIT to improve pt. experience	Impact of New Technology
IOM 2009: Priorities for CER	✓		✓	✓	✓	✓	✓	✓	✓	✓
Federal Coordinating Committee for CER	✓	✓				✓	✓		✓	
AHRQ National Quality Strategy	✓		✓			✓	✓			
AHRQ Effective Health Care Program	✓	✓	✓	✓	✓			✓		
National Quality Forum	✓	✓	✓	✓	✓	✓	✓		✓	
National Prevention Council	✓					✓				
National Priorities Partnership	✓		✓		✓	✓	✓	✓		

# National Priorities for Research

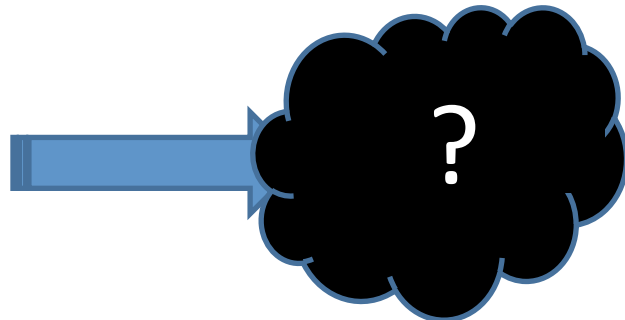


**Better Information**



**Better Decisions**

**1. Comparing  
Preventive,  
Diagnostic and  
Treatment Options**



**Better Decisions  
↓  
Better Outcomes**

# National Priorities for Research



**Producing and delivering information to support better health care decisions by individuals**



# Research Agenda

# PCORI Criteria – From Legislation



**Impact on Health of  
Individuals and  
Populations**

**Addresses Current  
Gaps in Knowledge/  
Variation in Care**

**Patient-Centeredness**

**Improvability through  
Research**

**Impact on Health Care  
System Performance**

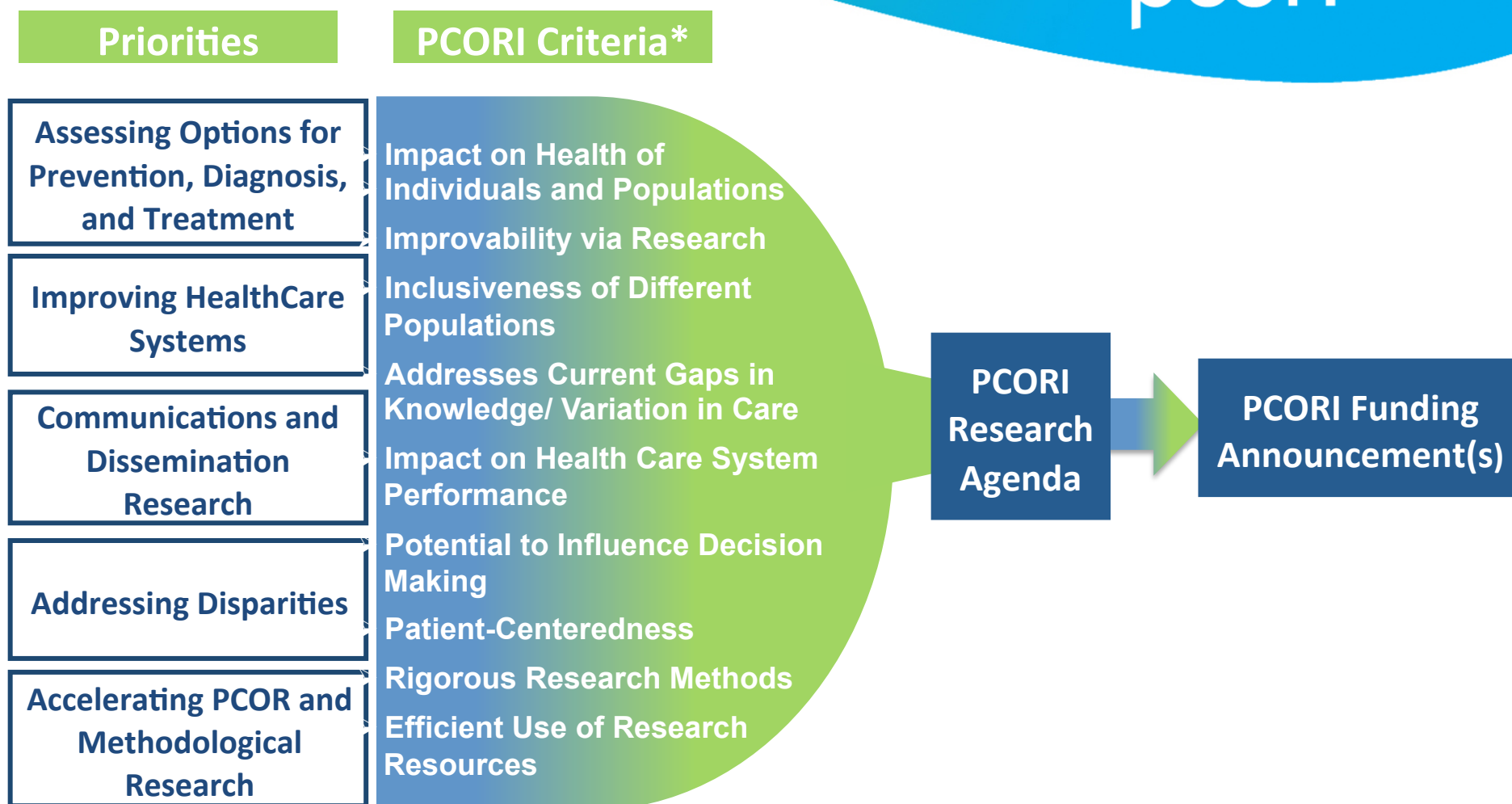
**Rigorous Research  
Methods**

**Inclusiveness of  
Different Populations**

**Potential to Influence  
Decision-Making**

**Efficient Use of  
Research Resources**

# Translating National Priorities into the Research Agenda



\* Criteria come from PCORI Statute

# Content of Draft Research Agenda



## Assessing Options for Prevention, Diagnosis, and Treatment

- Comparisons of alternative clinical options
- Identifying patient differences in response to therapy
- Studies of patient preferences for various outcomes

## Improving Healthcare Systems

- Improved support of patient self-management
- Coordination of care for complex conditions
- Improvements in the effectiveness and efficiency of care

## Communication & Dissemination Research

- Understanding and enhancing shared decision-making
- Alternative strategies for dissemination of evidence

## Addressing Disparities

- Alternative interventions/strategies to eliminate disparities
- Improvements in alignment of decisions with preferences

## Accelerating PCOR and Methodological Research

- Improving study designs and analytic methods of PCOR
- Building and improving clinical data networks
- Methods for training researchers, patients to participate in PCOR
- Facilitating the study of rare diseases

# PCORI's Draft Priorities and Research Agenda



- Draft Version 1 released for Public Comment **January 23<sup>rd</sup>**.
- Public comment through PCORI website; dialogs with key stakeholder organizations and individuals; a National Dialogue on February 27<sup>th</sup>; clinician and patient focus groups
- Priorities and agenda may be modified on the basis of this input
- Proposed initial agenda is specific with respect to study questions that will be supported, but not to the conditions (or treatments) that can be studied.
- Agenda will be expanded, become more specific and targeted over time based on ongoing, transparent stakeholder engagement and consensus – including pharmaceutical and device industry.

# PCORI National Patient and Stakeholder Dialogue


Feb 27, 2012

pcori



# Provide Formal Comment

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## Provide Input

The Patient-Centered Outcomes Research Institute solicits and receives input from the public about its work, as part of its commitment to transparency, credibility and access. PCORI encourages public input on all aspects of its work. You may provide feedback at any time by emailing [info@pcori.org](mailto:info@pcori.org) or by filling out the "Provide General Feedback" form on the bottom of this web page.

### National Priorities for Research and Research Agenda

PCORI released for public comment a first draft of its National Priorities for Research and Research Agenda, which will be used to guide funding announcements for comparative clinical effectiveness research that will give patients and those who care for them the ability to make better-informed health decisions. [Read more.](#)

[Draft National Priorities and Research Agenda](#)

[Provide Comment on the National Priorities and Research Agenda](#)

[Information on PCORI's National Patient and Stakeholder Dialogue](#)

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### Methodology Committee Request for Information


The Methodology Committee has issued a [Request for Information](#) and feedback on their draft Translation Framework Components. [Click here](#) for more information and to provide feedback.

### Policy Regarding Use and Disclosure of Public Comments

You may decide to provide personal identifying information during any public comment periods. Any comments you provide to PCORI, including, but not limited to any documents or other materials and any identifying information submitted with your comments are collected voluntarily and may be disclosed by PCORI on this website, elsewhere on the Internet, in any other public forum, or in other PCORI materials. By providing public

### Share this page



PCORI has issued its first draft National Priorities for Research and its initial Research Agenda for public comment. Click on "Provide Input" to let us know if they reflect the areas where more evidence is needed to support health care decision-making.

[Provide Input →](#)

### News Room

**Patient-Centered Outcomes Research Institute Seeks Input on National Priorities for Research and Research Agenda**

WASHINGTON, D.C. (January 23, 2012) – The Patient-Centered Outcomes Research Instit... [more](#)

## Patient and Caregiver Focus Groups

### Baltimore, MD (Nov. 9)

- Patients with Arthritis
- Parents of children with Pediatric Asthma (caregivers)
- Patients with mix of chronic conditions
  - Insured and uninsured
  - Age: 21-69

### Columbus, OH (Dec. 7)

- Parents of children with ADD/ADHD (caregivers)
- Patients with Mental Health conditions
- Patients who survived Cancer
  - Insured and uninsured
  - Age: 30-70+

### Atlanta, GA (Nov. 21)

- Patients with Diabetes
- Caregivers to Alzheimer's patients
- Patients with Chronic Pain
  - Insured and uninsured
  - Age: 21-75+

### Phoenix, AZ (Dec. 8)

- Patients with Respiratory Disease (chronic bronchitis, emphysema)
- Hispanic patients with mix of chronic conditions
- Patients with Heart Disease
  - Insured and uninsured
  - Age: 21-69

## Receiving Public Feedback on the National Priorities and Research Agenda

- **Clinician Focus Groups**

- Clinician focus groups took place in February
  - Philadelphia, February 8
  - Birmingham, February 9
  - San Francisco, February 15
  - Chicago, February 16
- Four groups of physicians and four groups of nurses
- Report will be delivered to the Board by March 1 to consider in the priorities and agenda revision process

## Next Steps

January 23-March 15, 2012	• Public Comment Period on draft national priorities and research agenda
February 8-16, 2012	• Clinician Focus Groups on the draft priorities and agenda
February 27, 2012	• National Patient and Stakeholder Dialogue
March-April 2012	• Analysis of public comment received
April 2012	• Adoption of first National Priorities for Research and Research Agenda
Spring 2012	• Issue conference grants to advance agenda specificity
May 2012	• First Methodology Report posted for public comment
May 2012	• Broad funding announcements issued
June 2012	• Brainstorming workshop to advance agenda specificity
July 2012	• Broad funding applications due
Summer 2012	• Advisory Groups formed to advance agenda specificity
August 2012	• Targeted funding announcements issued
December 2012	• Broad funding awards announced

**[www.PCORI.org](http://www.PCORI.org)**

***Questions?***