

Update from PCORI

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National Comparative Effectiveness Summit

November 5, 2012

Patient-Centered Outcomes Research Institute



Update on PCORI

- Adopting National Priorities and Research Agenda
- Defining Patient-Centered Outcomes Research (PCOR)
- Publishing the Methodology Report
- Articulating PCORI's Engagement Strategy
- Developing a Funding Plan
- Funding Patient-Centered Outcomes Research
- Prioritizing Research Topics

PCORI's National Priorities and Research Agenda

Assessment of Prevention, Diagnosis, Treatment Options

- Comparisons of alternative clinical options; identifying patient differences in response to therapy; studies of patient preferences for various outcomes

Improving Healthcare Systems

- Improving system support of patient self-management, coordination of care for complex conditions, access to care; comparing alternative strategies for workforce deployment.

Communication & Dissemination Research

- Understanding and enhancing shared decision-making; alternative strategies for dissemination of evidence; exploring opportunities to improve patient health literacy

Addressing Disparities

- Understanding differences in effectiveness across groups; understanding differences in preferences across groups; reducing disparities through use of findings from PCOR

Accelerating PCOR and Methodological Research

- Improving study designs and analytic methods of PCOR; building and improving clinical data networks

Defining Patient-Centered Outcomes Research

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. This research answers patient-centered questions such as:

“Given my personal characteristics, conditions and preferences:

- 1. What should I expect will happen to me?**
- 2. What are my options and what are the potential benefits and harms of those options?**
- 3. What can I do to improve the outcomes that are most important to me?**
- 4. How can clinicians and the care delivery systems they work in help me make the best decisions about my health and healthcare?”**

Methodology Report Public Comment Summary

124 groups or individuals submitted comments.
There were 505 standard-related comments, 1400 total comments.

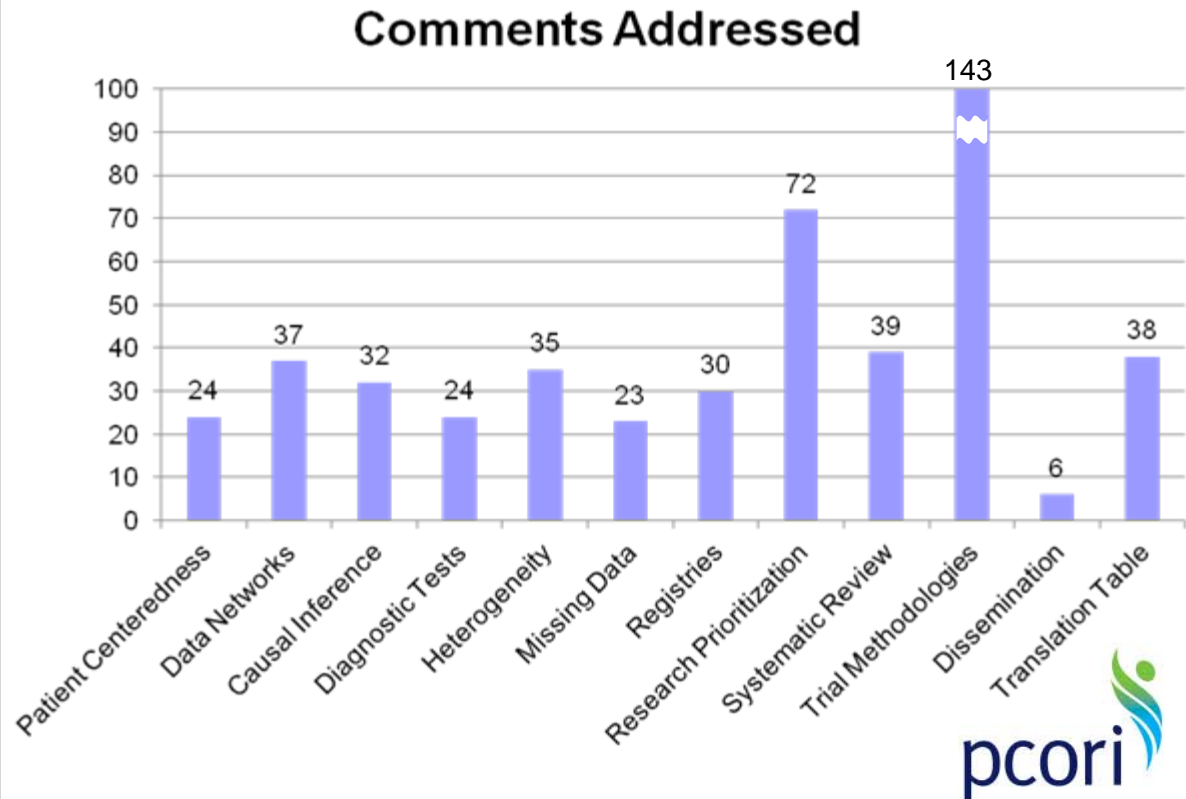
T Workman et al.



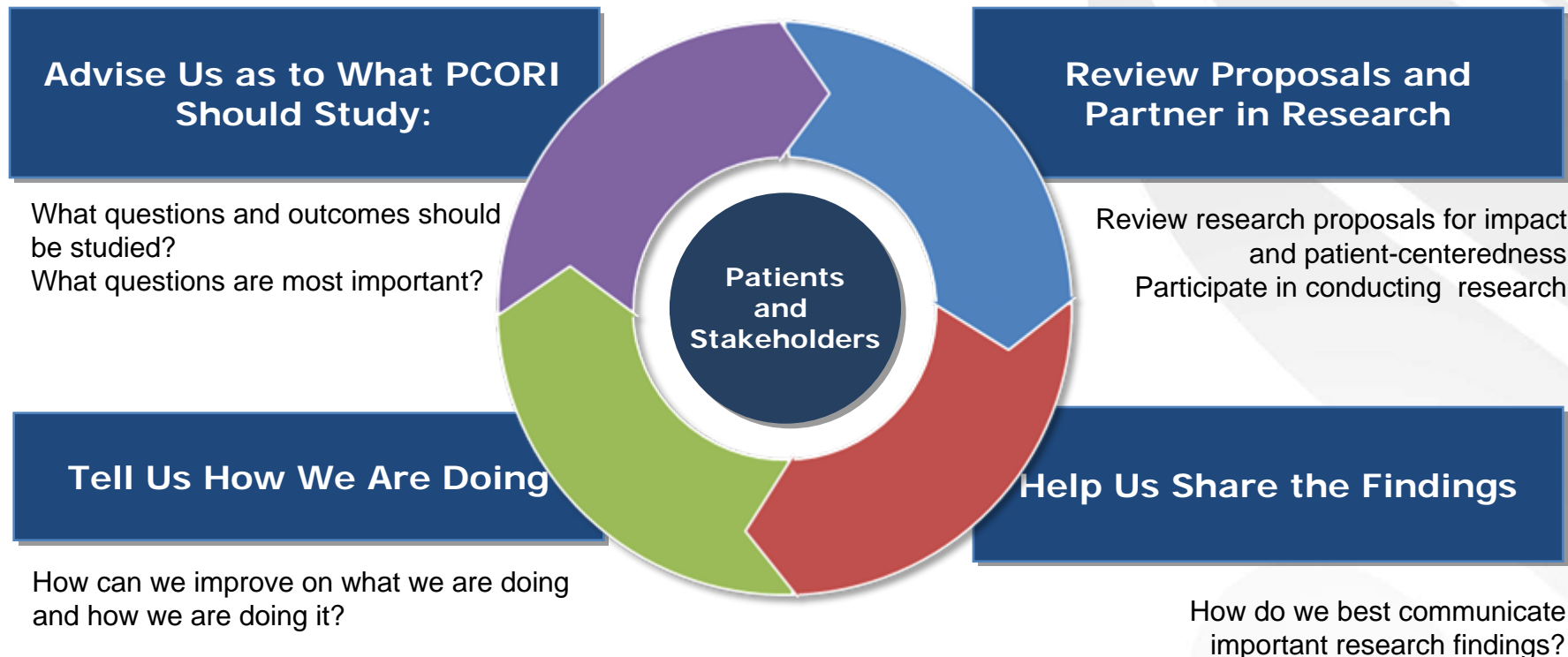
Health Policy & Research
Health Program

**Public Comment Analysis and
Revision Recommendations:
PCORI Methodology Report**

Final Report
Submitted September 28, 2012



Role of Engagement in Patient-Centered Outcomes Research

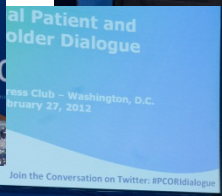


Taking Engagement Seriously

- Patients and other relevant stakeholders must be included as members of research teams and involved in all aspects of the research project - from planning to dissemination
- Applications are evaluated and scored on patient and stakeholder engagement in the review process
- At least 3 trained patient/stakeholder reviewers serve on each review committee

PCORI National Patient and Stakeholder Dialogue

Feb 27, 2012



Transforming Patient-Centered Research: Building Partnerships and Promising Models

October 26-28, 2012



170 in-person attendees
75% patients, patient advocates
40 states represented
~250 webinar attendees each day
Archived webcast is posted

Transforming Patient-Centered Research: Building Partnerships and Promising Models

Lessons Learned:

- Patient community is prepared and enthusiastic about participating with us in a transformed research enterprise
- Researchers need training to engage with patients
- Efforts and support needed to bring patients and researchers together locally
- Patients can play a stronger role in the application and in reporting/disseminating results

Upcoming Engagement Events

December 4th: Stakeholder Engagement:

What Should PCORI Study? A Call for Topics from Patients and Stakeholders

December 5th: Research Prioritization:

PCORI Methodology Workshop for Prioritizing Specific Research Topics

PCORI Pilot Projects

The pilot projects will:

- ❑ Advance the field of patient-centered outcomes research by exploring methods for engaging patients in research
- ❑ Help identify gaps to inform PCORI's future research agenda on methods

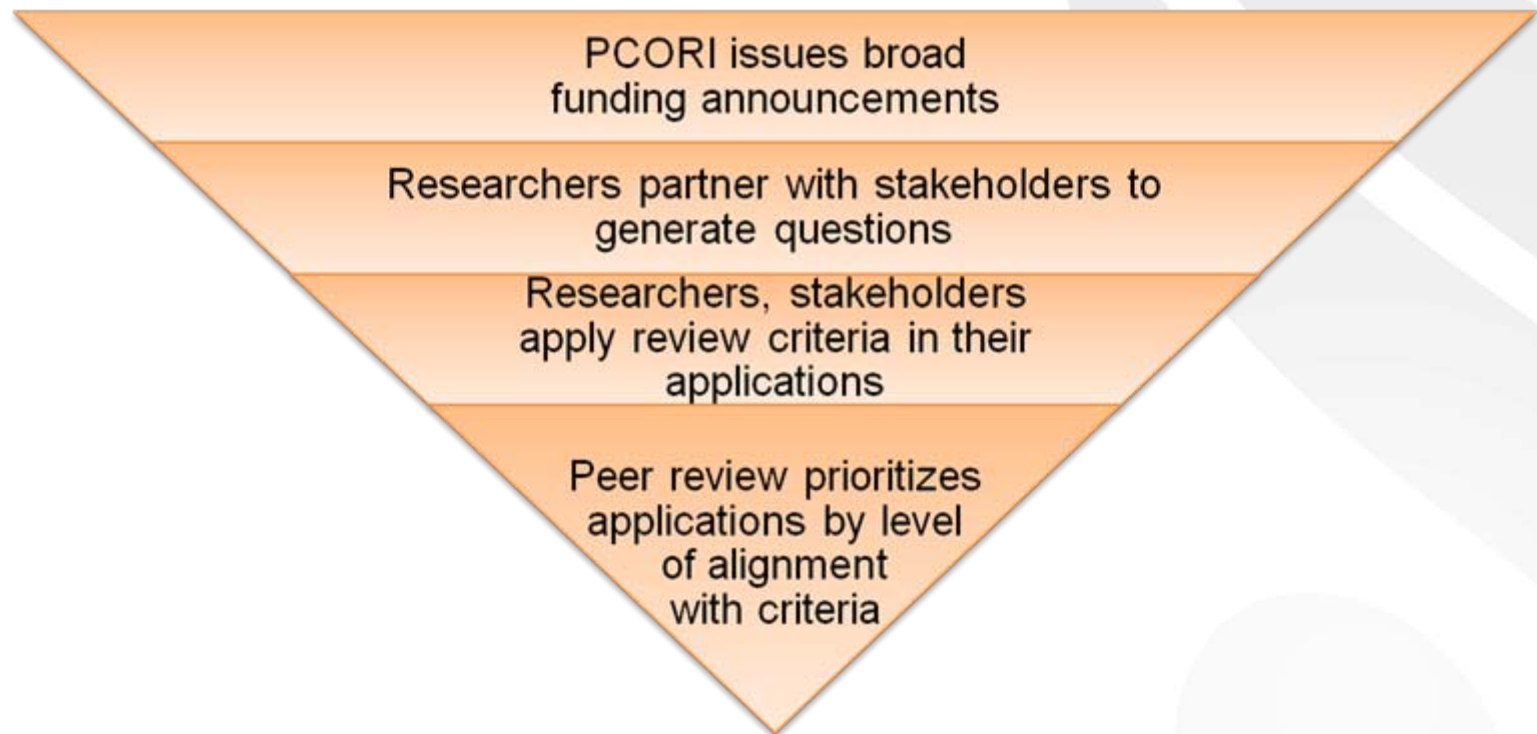
Total Awards: \$31 million over two years

Pilot Projects Areas of Interest

Area of Interest	Funded
Informing PCORI national priorities	2
Bringing together patients, caregivers, and other stakeholders in all stages of a research process	1
Translating evidence into health care practice in ways that account for individual patient preferences for various outcomes, including decision-support tools	19
Identifying, testing, and/or evaluating patient-centered outcomes instruments	11
Assessing the patient perspective when researching behaviors, lifestyles, and choices	5
Studying patient care team interactions in situations where multiple options exist	6
Analytical methods for CER	6

Two Complementary Pathways for Developing PCORI's National Research Portfolio

#1 Investigator-Generated Pathway to Research



Diverse Portfolio addressing high-priority questions

PCORI Review Criteria

1.	Impact of the Condition on the Health of Individuals and Populations
2.	Innovation and Potential for Improvement
3.	Impact on Health Care Performance
4.	Patient-Centeredness
5.	Rigorous Research Methods
6.	Inclusiveness of Different Populations
7.	Research Team and Environment
8.	Efficient Use of Research Resources

First PCORI Funding Announcements (PFAs) – May 2012

Research Agenda



PFAs

Communication and Dissemination Research

The Patient-Centered Outcomes Research Institute is accepting applications for research to <enter short synopsis of purpose for the announcement.>

Apply for a PCORI Research Grant

The Patient-Centered Outcomes Research Institute (PCORI) is an independent organization created to help people make informed health care decisions and improve health care delivery. PCORI commissions research that is guided by patients, caregivers, and the broader health care community to produce high integrity, evidence-based information.

Section One: The Application Process

If you are interested in applying for a grant under this program, follow PCORI's five-step process.



- ✓ **Review requirements.** Understand the overall requirements and timelines of the program.
- ✓ **Determine your fit.** Consider the applicant eligibility and research priorities to see if your organization and project fit this within this funding program.
- ✓ **Design the project.** Determine and document who will be involved, the research strategy, and the budget needs.
- ✓ **Inform us of your intent.** Send PCORI your notice of intent.
- ✓ **Apply for a grant.** Compile and submit your grant application.

1 Step 1: Review the Requirements
Opportunity Overview. The <Name of Funding Announcement> program calls for applications that <insert basic premise for the opportunity>. PCORI expects to award about <XXX> grants totaling approximately \$<XXX> million in <YEAR>. <Insert brief overview of the opportunity.>

System Registration. <ENTER THE PROCESS FOR REGISTERING WITHIN THE ONLINE NOTICE OF INTENT AND APPLICATION SYSTEM.>

The first four National Priorities: Assessment of Prevention, Diagnosis, and Treatment Options; Improving Healthcare Systems; Communication and Dissemination Research;

Addressing Disparities

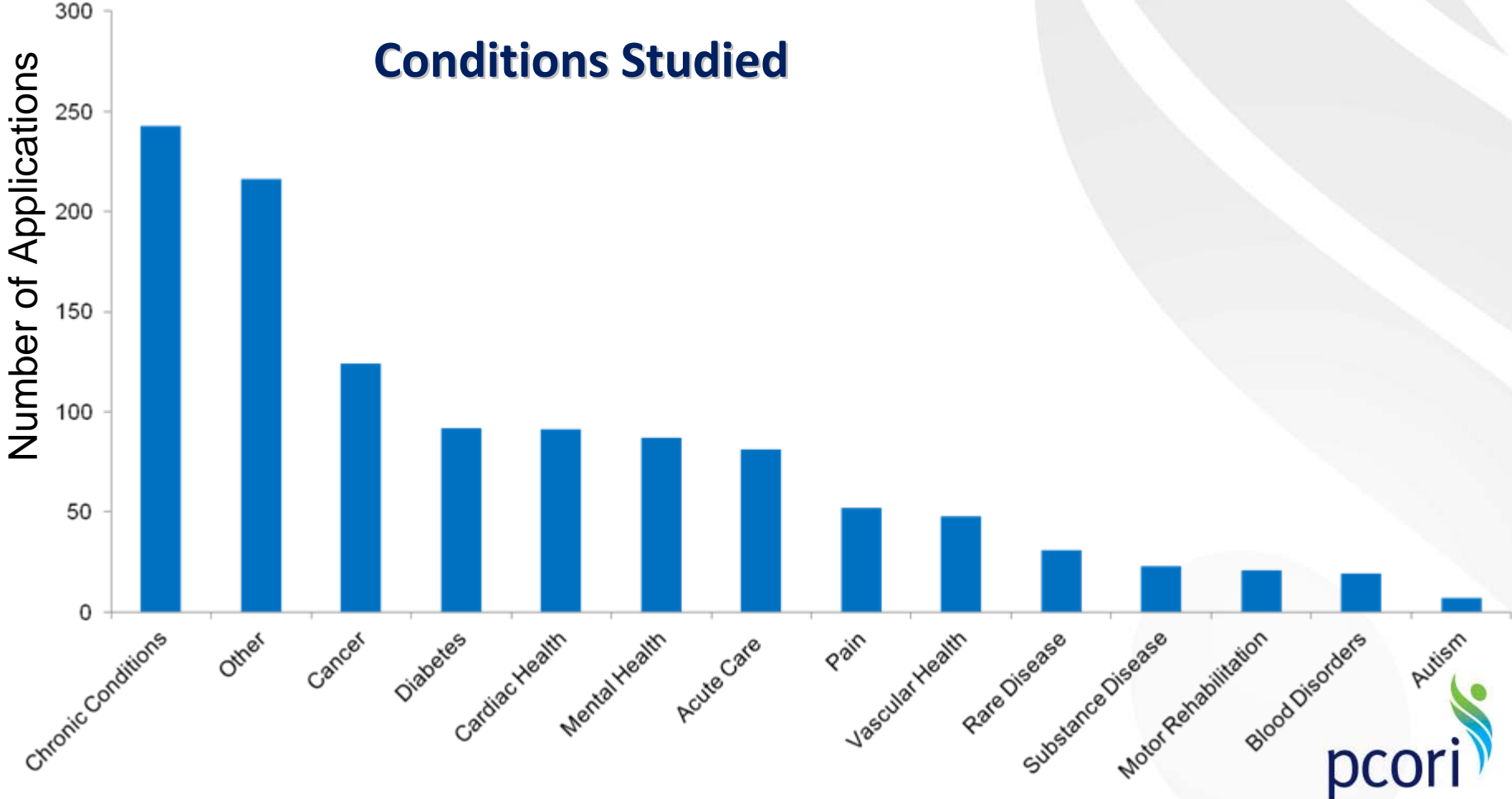
Patient-Centered Outcomes Research Institute



Requirements of Applications to Broad PFAs

- Be comparative
- Consider patient-relevant outcomes
- Assess for differences in treatment effectiveness across subgroups of study population
- Include relevant patients and other stakeholders on research team
- Discuss potential for dissemination and implementation
- NOT include cost-effectiveness analyses or treat costs of care

488 Applications in First Round Response to PCORI's Broad Funding Announcements

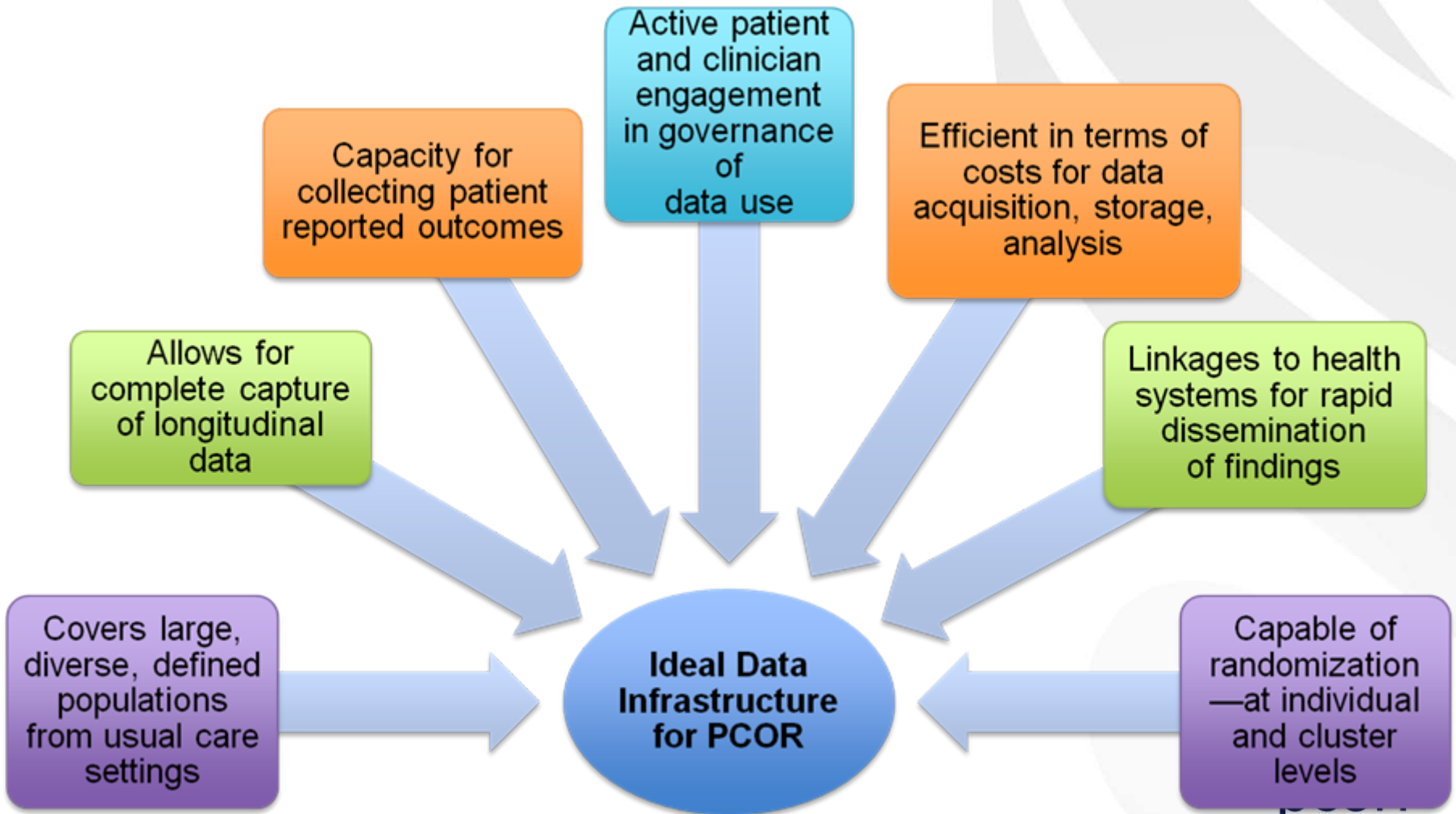


Multiple conditions and study designs may be noted in a single application

Next Steps in Research Funding

- Research Methods Announcement
- CER Infrastructure Announcement

Desirable Characteristics of a CER/PCOR Data Infrastructure





COMPARATIVE EFFECTIVENESS RESEARCH

By Harold Sox

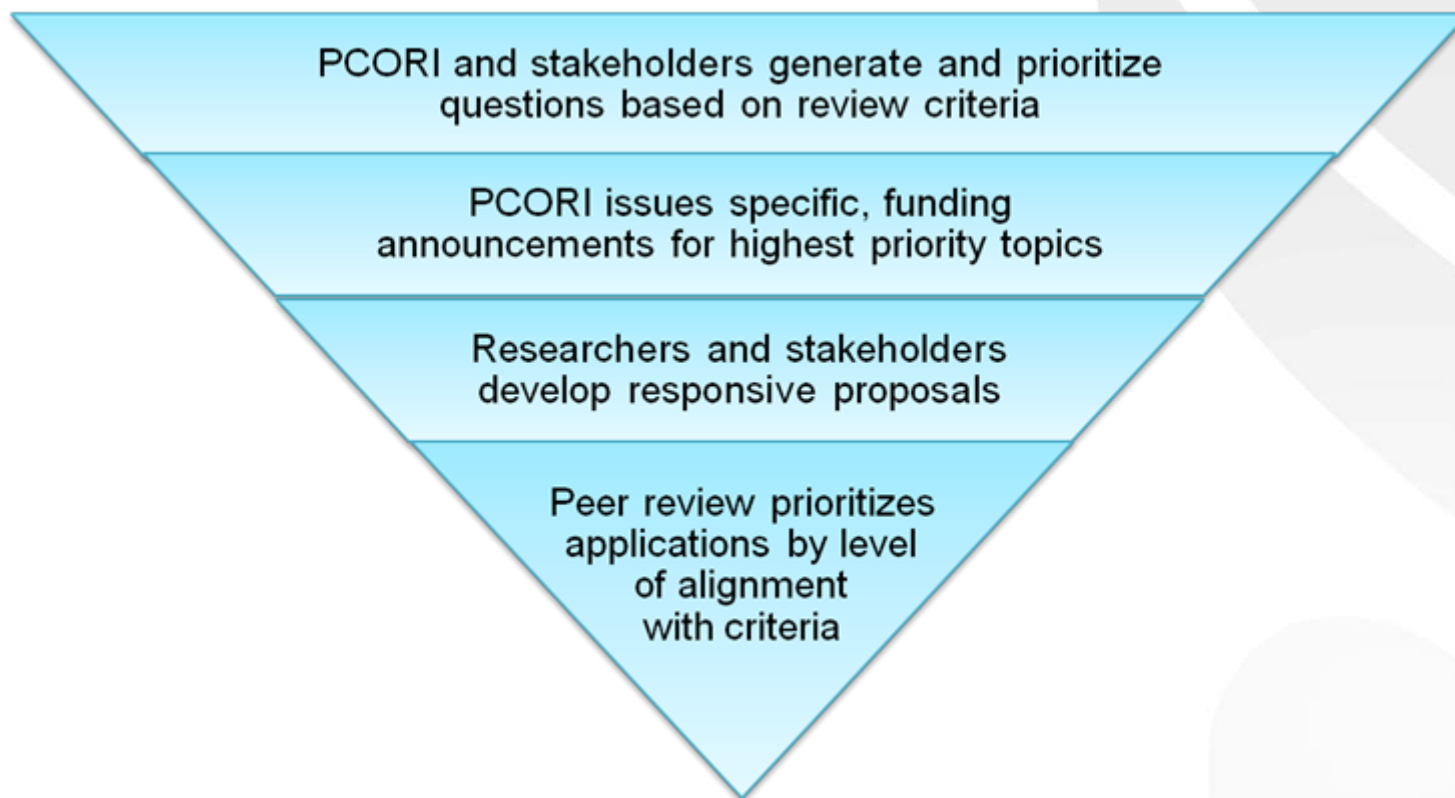
ANALYSIS & COMMENTARY

The Patient-Centered Outcomes Research Institute Should Focus On High-Impact Problems That Can Be Solved Quickly

ABSTRACT The Affordable Care Act created the Patient-Centered Outcomes Research Institute (PCORI) to help patients, clinicians, and policy makers make well-informed decisions about health care. Because its funding expires in 2019, the institute has little time in which to produce timely,

Two Complementary Pathways for Developing PCORI's National Research Portfolio

#2 Patient/Stakeholder-Led Pathway to Research



Diverse portfolio addressing high-priority questions

Developing PCORI's Research Prioritization Process

Topic Generation

Gap Confirmation

Research Prioritization

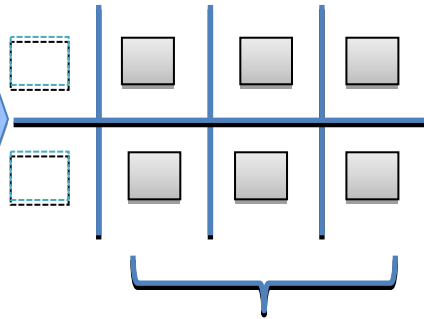
Final Selection Specific PFAs

(In Collaboration With AHRQ)

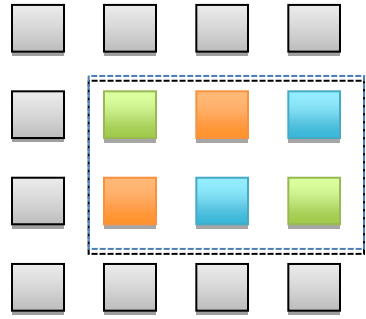
(Multi-stakeholder Advisory Panels)

(PCORI Board)

- Patients & Stakeholders:**
- Web Page
 - Social Media
 - Workshops
 - Guidelines and Sytematic Reviews
 - Direct Communication with Stakeholder Groups
- PCORI**
- Continuous Portfolio Review
- Supported by AHRQ:**
- Systematic Review Gaps
 - Future Research



Research Opportunities



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 develop our research agenda.

Whether you are a patient with a health condition, a caregiver for someone else, a health care professional who wants to improve care for your patients, or a researcher, we invite you to submit a question. In addition to questions about options faced by patients, we also are interested in questions that would help to improve health care delivery, address disparities in health care, or improve the communication of research findings (for more information, please see [PCORI's National Priorities for Research](#)).

We will carefully consider your question as we plan which questions to study.

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.

What is your question?

PCORI Advisory Panels - 2013

- Multi-stakeholder Advisory Panels will assist PCORI staff and Board in:
 - To model robust patient and stakeholder engagement efforts,
 - Identifying, refining and prioritizing specific research questions,
 - Provide other scientific or technical expertise – e.g., for clinical trials and for rare diseases
 - Other questions that may arise relevant to PCORI's mission and work – e.g., refinement of research agenda; dissemination of PCORI research findings

Join Us at PCORI.org

