

PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE (PCORI)

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**The Patient-Centered Outcomes Research Institute:
Research Foundations and Priorities**

6th Annual Nursing Quality Conference

January 25 - 27, 2012



Objectives

1. Explain history, mission and vision of the Patient Centered Outcomes Research Institute (PCORI) to include the foundational work to date and national research priorities.
2. Identify resources available through the Patient Centered Outcomes Research Institute (PCORI) to include networking and funding.

Who is PCORI?



- Patient representatives
- Caregivers
- Physicians, nurses and providers
- Health services researchers
- State and federal health officials
- Pharmaceutical, device, and diagnostic manufacturers
- Private payers
- Employers



PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

PCORI's Mission

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.

The Promise of PCORI



Understanding the choices patients face



Aligning methods and data with patient needs



Providing patients and clinicians information for better decisions

PCORI's Core Duties

- Establish national research priorities
- Establish and carry out a research project agenda
- Develop and update methodological standards
- Provide a peer-review process for primary research
- Disseminate research findings

Methodology Committee

Methodology Committee

Co-Chairs: Sherine Gabriel, MD & Sharon-Lise Normand, MD

Patient-Centeredness

Methods to incorporate the patient perspective into all phases of PCOR

Research Prioritization

Methods to inform prioritization of new research studies

Research Methods

Methods for using data, design, and statistical analyses to conduct PCOR

Report Assimilation

Working Definition of Patient-Centered Outcomes Research

Patient-Centered Outcomes Research helps people make informed health care decisions and allows their voice to be heard in assessing the value of health care options.

This research answers patient-focused questions:

1. "Given my personal characteristics, conditions and preferences, what should I expect will happen to me?"
2. "What are my options and what are the benefits and harms of those options?"
3. "What can I do to improve the outcomes that are most important to me?"
4. "How can the health care system improve my chances of achieving the outcomes I prefer?"

To what extent will PCOR be CER?

- Incorporating a stronger patient focus will help ensure that:
 - Research questions are practical, and usually comparative
 - The variety of outcomes important to patients are not overlooked
 - Patients studied come from relevant settings and are representative
 - Possibilities of heterogeneity in effectiveness are examined

PCORI Timeline

PCORI's Establishment
September 2010 – January 2011

Organizational Development
January 2011 – December 2011

Setting Initial National Research Priorities
July 2011 – June 2012

Establishing PCOR Agenda, Generating Knowledge, Disseminating Findings, and Updating Priorities
July 2012 -

PCORI's Establishment

Sep. 2010 -
Jan. 2011

- Mar. 2010 – Created by Patient Protection and Affordable Care Act (Subtitle D, Sec. 6301)
- Sep. 2010 – GAO Appoints PCORI Board of Governors
- Nov. 2010 – PCORI Incorporated as Independent Not-For-Profit Entity
- Jan. 2011 – GAO Appoints Methodology Committee

Organizational Development

Jan. 2011-
Dec. 2011

- Mission Defined
- Governance and Financial Systems Established
- Standing Committees Created
- Public Board Meetings
- Stakeholder Engagement
- Annual Operating Plan and Budget Approved
- Methodology Workgroups Created
- Executive Director and COO Hired
- Website expanded: www.pcori.org

Setting Initial National Research Priorities

Jul. 2011 -
Jun. 2012

- Priorities informed by:
 - Stakeholder Engagement
 - Landscape Reviews
 - Pilot Projects
 - Conference Grants
 - Methodology Committee Report
- Extensive public comment
- To be approved by Board of Governors

Research Agenda,
Generating
Knowledge,
Disseminating
Findings, and
Updating Priorities

Jul. 2012 –

- Full research arsenal
- Informed by national priorities
- Methodological standards defined and updated
- Collaboration with AHRQ, NIH, and others
- Close gap between availability of information and uptake
- Stakeholder engagement throughout
- Extensive public comment
- To be approved by Board of Governors

PCORI Pilot Projects Grants Program

Purpose:

- **National Priorities** – provide information to PCORI that informs future iterations of national research priorities for patient-centered outcomes research.
- **Research Agenda** – support the collection of preliminary data to advance the field of patient-centered outcomes research, providing the platform for an evolving PCORI research agenda.
- **Methodologies** – support identification of research methodologies that advance patient-centered outcomes research.

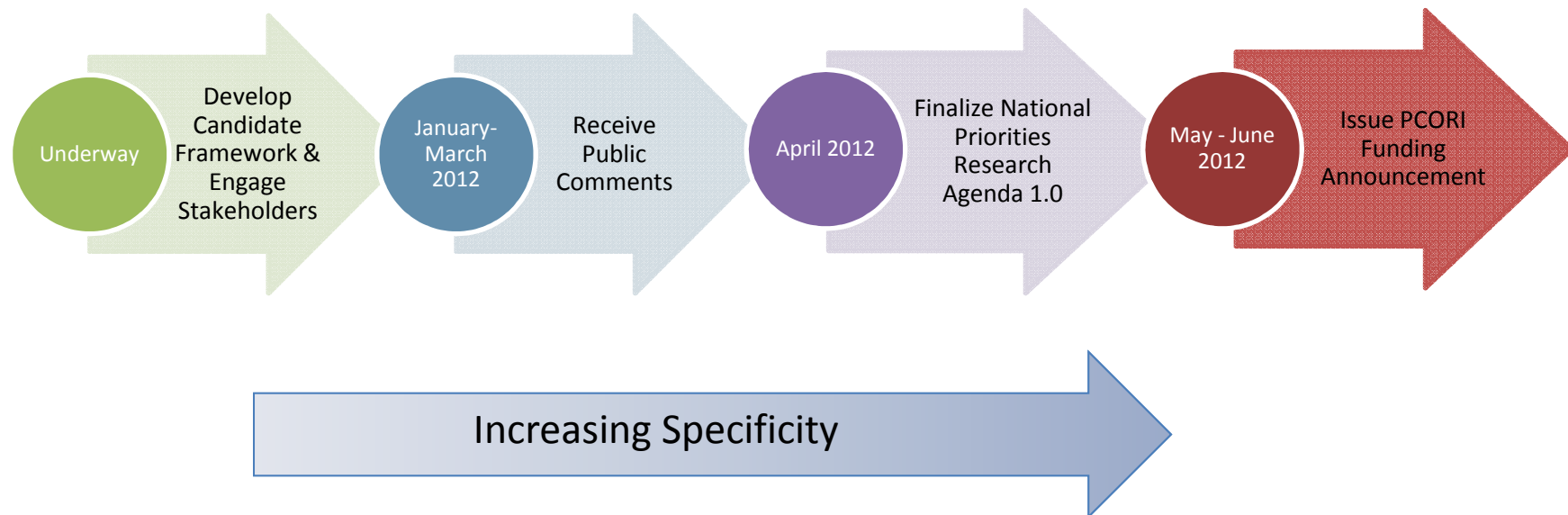
Pilot Projects Process

- Expect to commit approximately \$13 million in FY 2012 to support up to 40 projects.
- Applicants can propose project periods of up to two years. Second year funding is subject to noncompetitive review by PCORI staff.
- Direct costs are limited to \$250,000/year with an additional 40% of salary and fringe allowable as indirect costs.
- NIH will conduct review process, all other aspects of grant awards and management handled by PCORI. Award notification and funding will occur in May 2012.

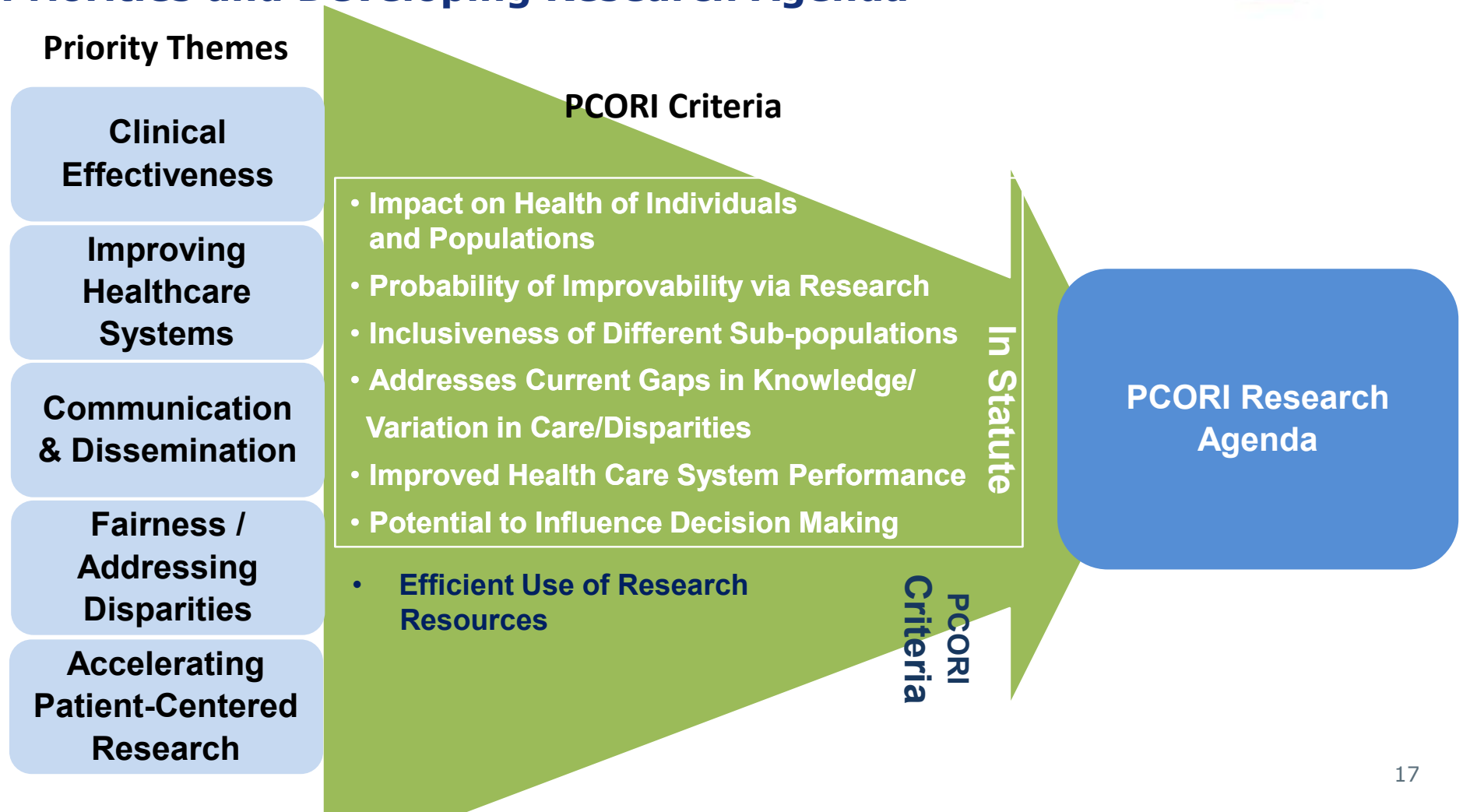
Pilot Projects by the Numbers

850	People who registered for webinars
1375	Letters of Intent received
350	Patient/Stakeholder reviewer applications received
498	Scientific reviewer applications received
800	Number of applicant questions answered

Proposed Timeline for Setting National Priorities



Framework for Refining PCORI National Priorities and Developing Research Agenda



Developing PCORI's Research Agenda

Priority Themes



Comparative
Clinical
Effectiveness

Accelerating
Patient-Centered
Research

Communication
&
Dissemination

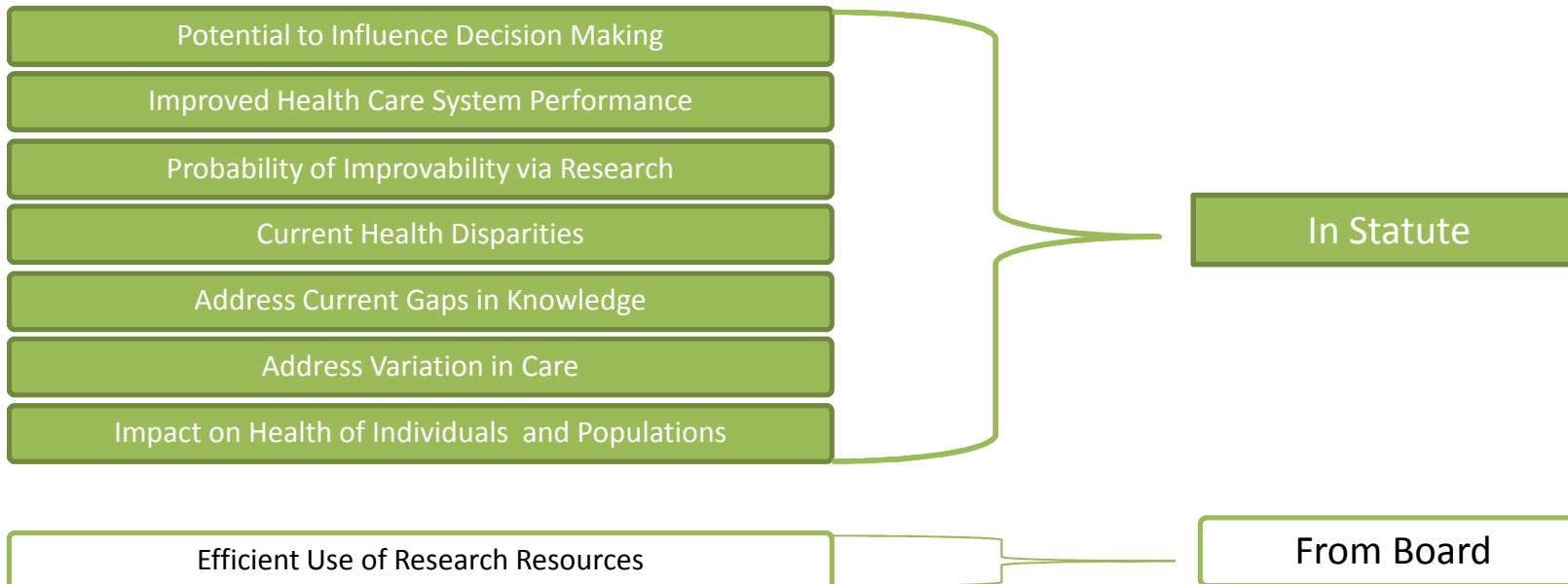
Improving
Healthcare
Systems

Fairness /
Addressing
Disparities

Developing PCORI's Research Agenda



PCORI Criteria



PCORI Research Agenda



April 2012 release

Agenda Will...

Be tied to the National Priorities and filtered through the criteria

Demonstrate a commitment to a diverse research portfolio with respect to patients, geography, health care professionals, investigators, and organizations

Promote patients as partners, with a role in the design, governance, review, and dissemination of research

Be a living document that is updated and revised according to stakeholder input.

Guiding Principles for Engaging Stakeholders

Balanced Representation

- Obtain feedback from a diverse and representative range of patients, health care stakeholders and the general public

Transparency

- Enable an open engagement process that makes clear how participants can get involved and how their input will be incorporated

Facilitate Participation

- Provide easy, accessible forums for participants to provide feedback equitably

Work in progress...



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- Analysis of Input Received on Working Definition of “Patient-Centered Outcomes Research (PCOR)”
- Review and Synthesis of Evidence for Eliciting the Patient’s Perspective in PCOR
- Expert Stakeholder Interviews to Identify Evidence for Eliciting the Patient’s Perspective in PCOR
- Methods for Setting Priorities in Research
- Review of Guidance Documents for Selected Methods in PCOR





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Request for Information

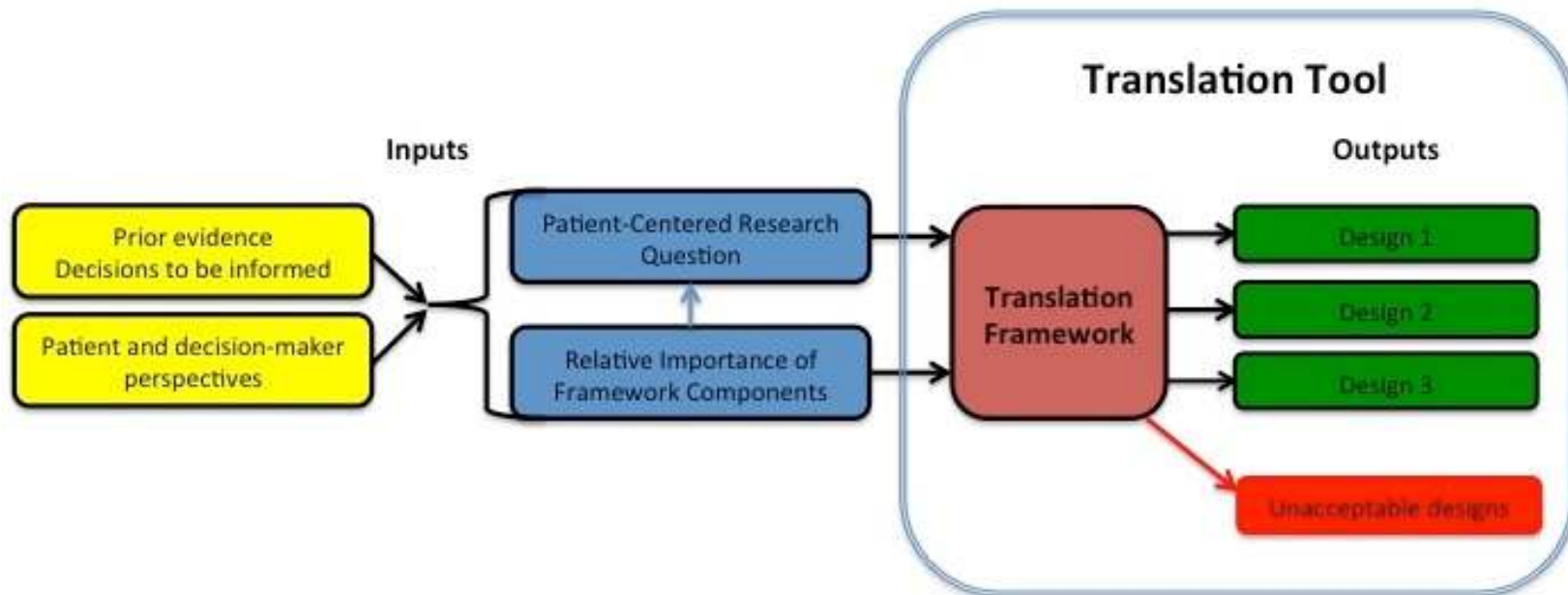
Draft Translation Table Framework

Available at:

<http://www.pcori.org/provide-input/translation-table/>

Due: February 17, 2012 at 5:00 PM ET

Translation Tool Structure





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PCORI National Priorities

1. Comparative Assessments of Prevention, Diagnosis, and Treatment Options
2. Improving Healthcare Systems
3. Communication and Dissemination
4. Addressing Disparities
5. Accelerating Patient-Centered and Methodological Research

Public comment period will remain open until 11:59 p.m. EST on March 15.

Connect with PCORI

Website: **pcori.org**

Email: **info@pcori.org**

- Provide feedback
- Submit inquiries
- Subscribe to PCORI's mailing list

Live webcast and teleconference provided for all Board meetings.



The screenshot shows the PCORI website homepage. At the top, there is a navigation bar with links for Home, Subscribe, Contact Us, and Search. Below this is a main navigation menu with links for About Us, Patient-Centered Outcomes Research, Funding Opportunities, Meetings & Events, Provide Input, and Employment. The main content area features a video player with a "Download This Video" button. The video shows Joe Selby, MD, MPH, Executive Director of PCORI. To the right of the video is an "Overview" section with text describing PCORI's mission and commitment to transparency. Below the video are three main content blocks: "Provide Input" with a sub-image and text about soliciting public input; "Funding Opportunities" with a sub-image and text about a \$25 million pilot project grant program; and "Meetings & Events" with a sub-image and text about the next meeting. At the bottom, there are three more blocks: "Employment Opportunities" with a sub-image and text about current opportunities; and "Executive Director's Corner" with a sub-image and text about a recent update from the Executive Director. The footer contains links for Sitemap, Contact Us, and Privacy Policy.