

Patient-Centered Outcomes Research Institute National Priorities and Research Agenda

April 25, 2012

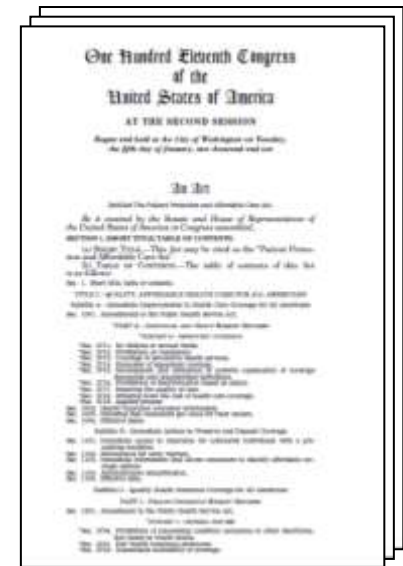


- Review Genesis of National Priorities and Research Agenda
- Review Public Comment Process
- Share Public Comment Findings
- Recommend PCORI Response
- Board Vote on Recommended Changes

The What and Why of National Priorities and Research Agenda



- Mandated in the legislation (including Public Comment period)
- Pre-requisite for releasing funding announcements
- Preliminary roadmap for PCORI research activities
- Envisioned as a living document



Development of Draft National Priorities and Research Agenda



Initial Stakeholder feedback

Reviewed initial stakeholder input advising us to not “reinvent the wheel”

Environmental scan of existing priorities and criteria

Reviewed prior CER frameworks (e.g., IOM, FCCCER, National Priorities Partnership, and NQF)

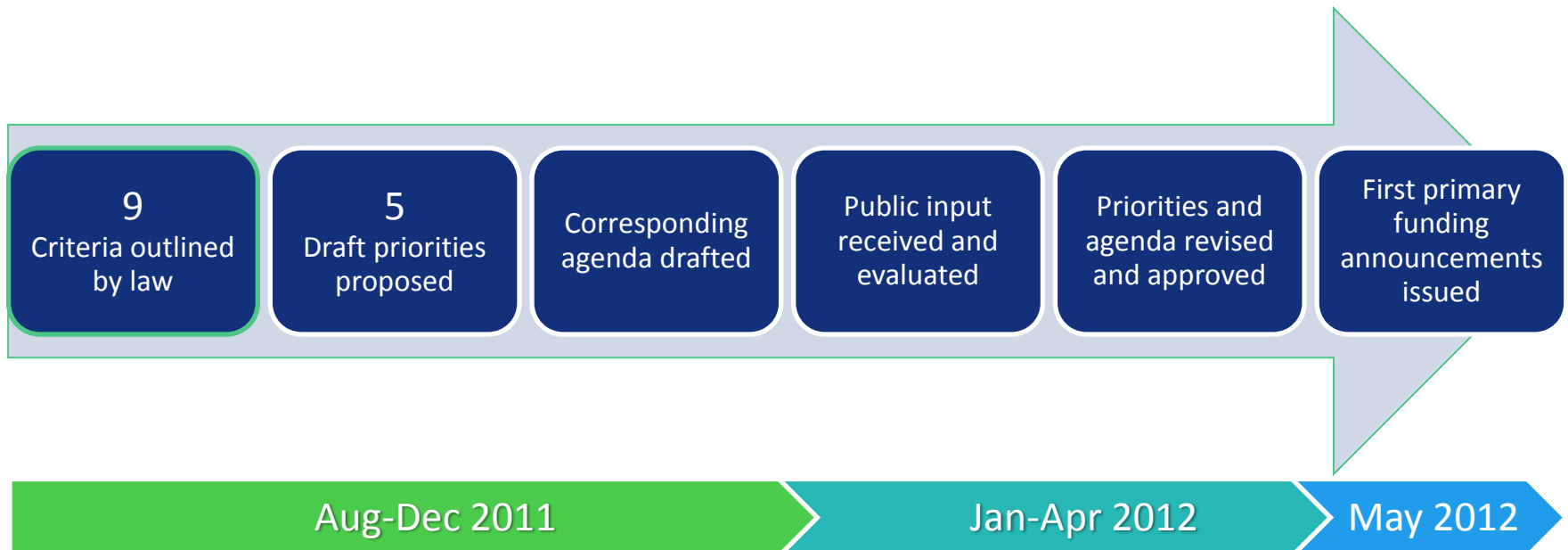
Candidate priorities and criteria identified

Identified broad priorities from prior frameworks and the statutory criteria for PCORI

Framework to inter-relate Priorities and Criteria

Developed Framework to be used for refining priorities and for determining Research Agenda and funding announcements

Establishing PCORI's First National Priorities for Research and Initial Research Agenda



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 cities across the US
 - Philadelphia
 - Birmingham
 - California
 - Chicago
- Four groups of physicians and four groups of nurses
- Behavioral Health Professionals
- Physician Assistants

A commitment to public engagement

Formal 53-day Public Comment Period

- Nearly 500 comments received through website, e-mail or postal mail
- All comments will be posted at pcori.org



Additional Forums

- National Patient and Stakeholder Dialogue
- Patient, caregiver and clinician focus groups
- Individual meetings with diverse mix of stakeholders



Public Comment Yielded Diverse Array of Input and Feedback



301 Web survey (64%)



116 Email/ letter (24%)

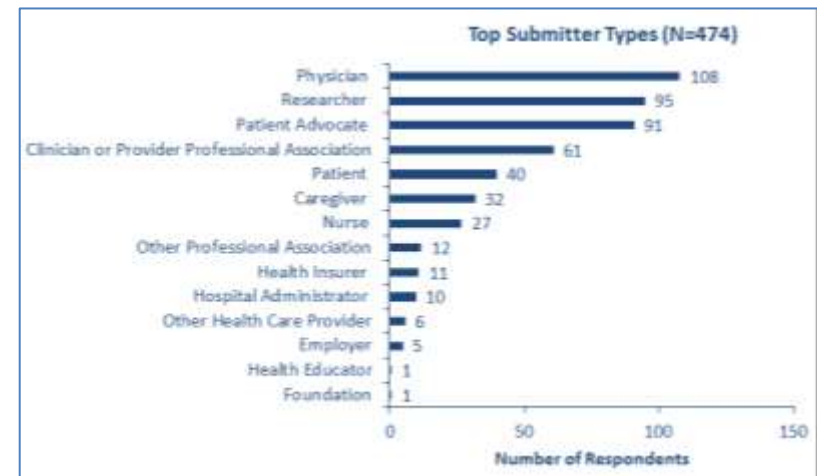


57 Stakeholder event (12%)



474 Total Comments

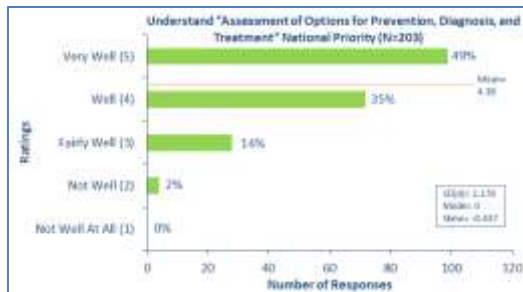
Broad range of comment sources



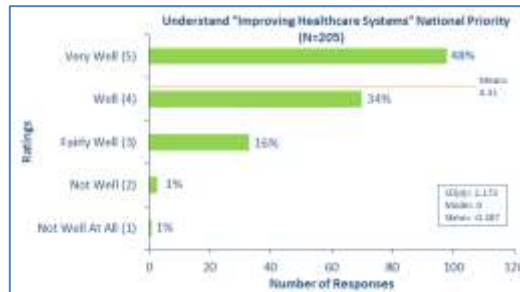
Those Who Commented Said They Understand the National Priorities...



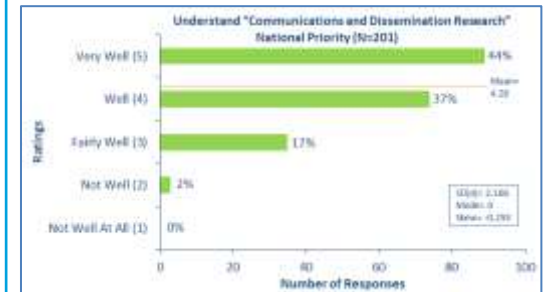
Assessment of Options



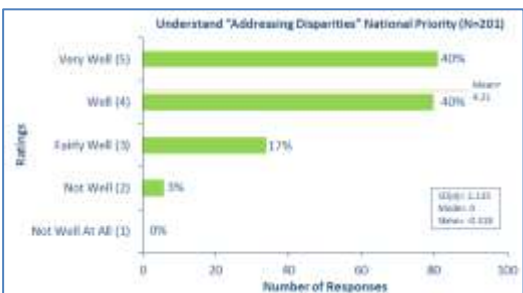
Improving Healthcare Systems



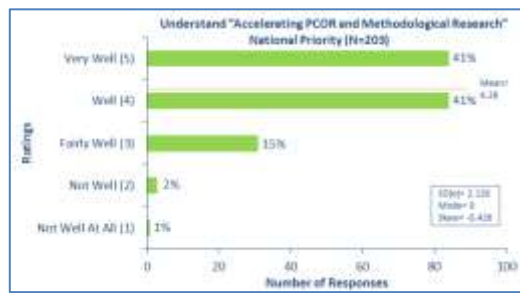
Communications and Dissemination Research



Addressing Disparities



Accelerating PCOR and Methodological Research



“How well do you understand the National Priorities?”

Rigorous, Systematic Review and Analysis of Comments



Computer algorithm to identify key terminology

Each narrative comment reviewed and analyzed by 3 people

Stakeholder comments aggregated to 15 key themes

Themes compared to National Priorities and Research Agenda to identify gaps

Gaps reviewed to determine options for PCORI response to themes

- Change Language Within the Research Agenda
- Embed in PCORI Operations and Processes
- Address in Summary Document
- Future Consideration

PCORI Response to Key Themes-1



Recommends that PCORI choose a specific condition, disease area, or other issues in the Research Agenda and National Priorities	PCORI has proposed a condition-neutral Research Agenda and has introduced specificity through its comparative nature and emphasis on patient centeredness. While future funding announcements may specify conditions, the overall mission of PCORI is not served by excluding any conditions if there is compelling reason for a patient centered, comparative clinical effectiveness study. We added language to elaborate on our position.
Recommends that PCORI partner with organizations and stakeholders to carry out its mission	PCORI is committed to efficient use of its research investments. Where appropriate, PCORI will partner with other organizations after a transparent decision-making process and consideration of conflicts of interest. This theme impacts PCORI processes, rather than funding subjects, so no specific language changes were made to the document.
Recommends greater focus on the patient, with particular attention to methods of engagement	PCORI has fully endorsed and appreciates the centrality of patient engagement to its mission. The National Priorities and Research Agenda reflect the patient centered focus of PCORI and include many of the themes from the public comments. Language has been added to the Agenda to specifically reflect the need for study of self care and to more clearly define personalized medicine.
Recommends a greater focus on care coordination	PCORI appreciates the need to study care coordination and has expanded the language in the Research Agenda to reflect its importance.
Recommends funding towards improving patient and provider health literacy and education	Improving communication between patient and provider is one of the five PCORI National Priorities for Research. Language has been added to the Research Agenda to reflect the importance of health literacy to achieving this goal.

PCORI Response to Key Themes-2



Recommends funding for and use of health IT infrastructure, networks, tools and patient data acquisition efforts in and outside the practice setting

The foundation for performing comparative clinical effectiveness requires substantial health IT and data infrastructure. The National Priorities and Research Agenda contain substantial language about this infrastructure. Therefore, no additional language was added to the document. PCORI will support reusable infrastructure for comparative clinical effectiveness research.

Recommends that PCORI pay greater attention to the role of caregivers and other stakeholders in the patient decision making process

PCORI appreciates the role of caregivers in patient centered care and has mentioned them in the document and included studies of caregiving in the Research Agenda. Therefore, no additional language was added to the document.

Recommends that PCORI pay greater attention to access to care, including the social and environmental determinants that determine access and use of care

Access to care is a key issue for patients. Language has been added in both the comparative assessment and the healthcare systems Research Agenda topics to include the comparative study of access as a determinant of health.

Recommends that PCORI provide greater rationale and transparency in the public comment, grants, and research evaluation processes, as well as the performance measurement process for PCORI as a whole

PCORI is committed to fully transparent processes as it works towards achieving its mission. The Research Agenda articulates the ongoing engagement that will occur continuously as PCORI evolves and funds research. Therefore, no additional changes were made to the document. PCORI intends to roll out a comprehensive communications and engagement plan that will clearly define when and how stakeholders can provide input into PCORI decision making.

Recommends that PCORI's research and funding should impact the practice setting, with particular attention to patient and provider behavioral change needed to obtain true shared decision making

PCORI is fully committed to the idea that its research should improve decision making and help patients at the point of care. Language has been added to the section "Establishing the Scope of the Research Agenda" to emphasize the importance of using the evidence developed through PCORI research to change the way medicine is practiced.

PCORI Response to Key Themes-3



Recommends that PCORI place stronger emphasis on patients with multiple conditions, especially chronic conditions	PCORI understands the difficulty of managing multiple chronic conditions when most evidence is generated in trials that exclude these patients. Language has been added to emphasize this in the Research Agenda.
Recommends that PCORI study new and expanded roles for allied health professionals	PCORI recognizes the diverse health professionals involved in patient centered care. In the Research Agenda, the description of allied health professionals has been expanded to be more inclusive of all of potential members of a health care team.
Recommends paying attention to international models	PCORI recognizes the significant achievements of many countries in developing the methods and practices of patient engaged comparative clinical effectiveness research that may inform investigators as they seek PCORI funding. As this is not central to PCORI research, no change is proposed to the priorities or agenda.
Recommends exploring novel methods to obtain patient centered focus	PCORI supports the approach of exploring innovative methods for focusing on the patient. The fundamental basis of PCOR, however, is the science of evidence-based medicine. PCORI will support and promote approaches that seek rigorous, scientific results; therefore no changes were made to the document.
Recommends that PCORI study rare diseases	PCORI recognizes the challenges faced in studying rare diseases. In the Research Agenda, language about rare disease has been expanded.

Discussion

Vote on Changes Outlined in Slides 13-15

- PCORI Stakeholders
 - Thank you for your thoughtful input into the first version of the PCORI National Priorities for Research and Research Agenda
- PCORI Program Development Committee
 - Thank you for all your hard work in the development and refinement of these documents
- The detailed Summary Document of changes to the National Priorities and Research Agenda will be posted on pcori.org by April 30, 2012