

Engagement Update

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PCORI Board of Governors Meeting
Washington, DC
September 24, 2012



Engagement: Questions to Consider

1

- What recommendations does the Board have for reaching stakeholders who may not be part of established networks and are more difficult to reach?

2

- What are the measures of success in engaging patients, caregivers, and stakeholders that the Board would like to see in the next 12 months?

3

- How do we demonstrate and lead “research done differently” for patients, caregivers, stakeholders, and the research community?

Presentation Outline

- Review of Strategic Priorities
- Engagement “Touch Points” in the PCOR Process
- Workshops

Engagement Priorities

1. To **invite, value, and use the wisdom and experience** of patients, caregivers, and other stakeholders nationwide in the PCORI research enterprise; **eliminate barriers** to participation
2. **Establish a community** of trained and informed patients and caregivers as valued partners who participate in all stages of the research enterprise
3. **Communicate transparently** and regularly about PCORI's approach and methods for prioritization, decision making, and funding to all stakeholders to create trust
4. Evaluate and refine patient engagement processes to **continuously learn** and incorporate best practices and methods for developing a robust and engaged community of stakeholders in PCORI work

- *PCORI Strategic Plan*

Patient and Stakeholder Engagement in Patient-Centered Outcomes Research

Advise Us as to What PCORI Should Study:

What questions are most important?
(research prioritization)
What outcomes should be studied?
(topic generation)

Review Proposals and Partner in Research

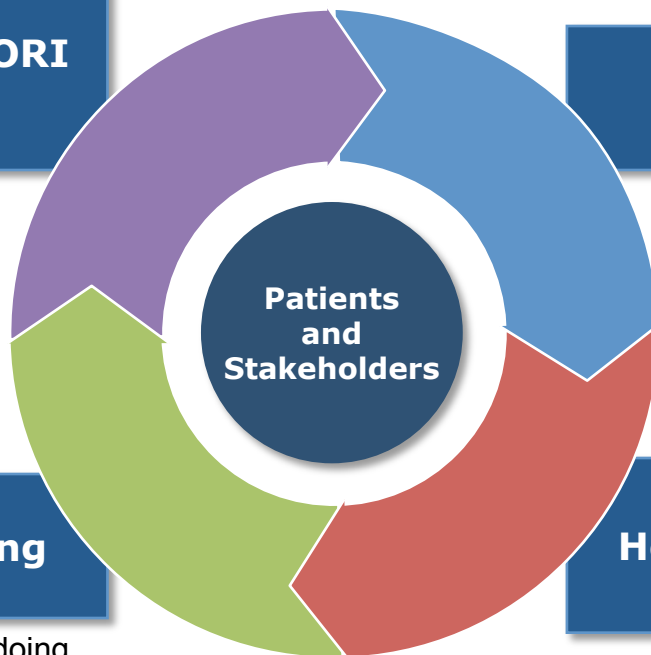
Review research proposals for impact
and patient-centeredness
Participate in conducting research

Tell Us How We Are Doing

How can we improve on what we are doing
and how we are doing it?

Help Us Share the Findings

How do we best communicate
important research findings?



Patient View on Engagement in Research





Tell Us What PCORI Should Study

- Conduct patient and stakeholder testing of content and language on topic generation Web page
- Solicit research topics in patient and stakeholder meetings and PCORI roundtables
- Host workshops
 - Patient Workshop (October 27-28)
 - Stakeholder Workshop (December 4)
 - Prioritization Workshop (December 5)

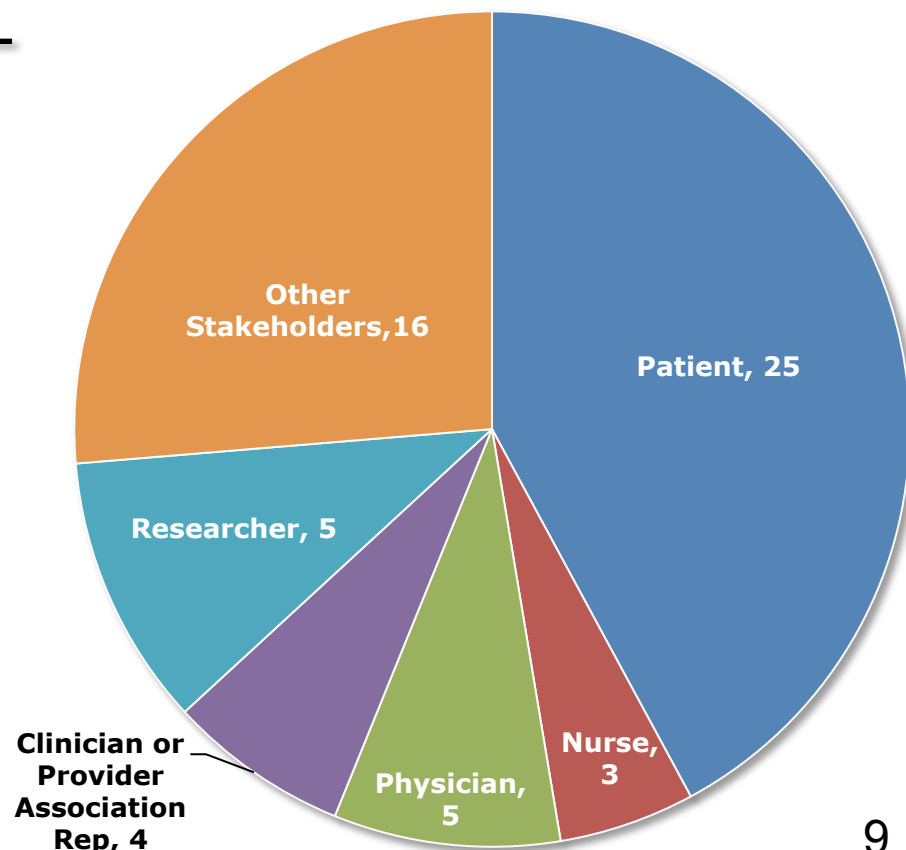


Review Proposals and Partner in Research

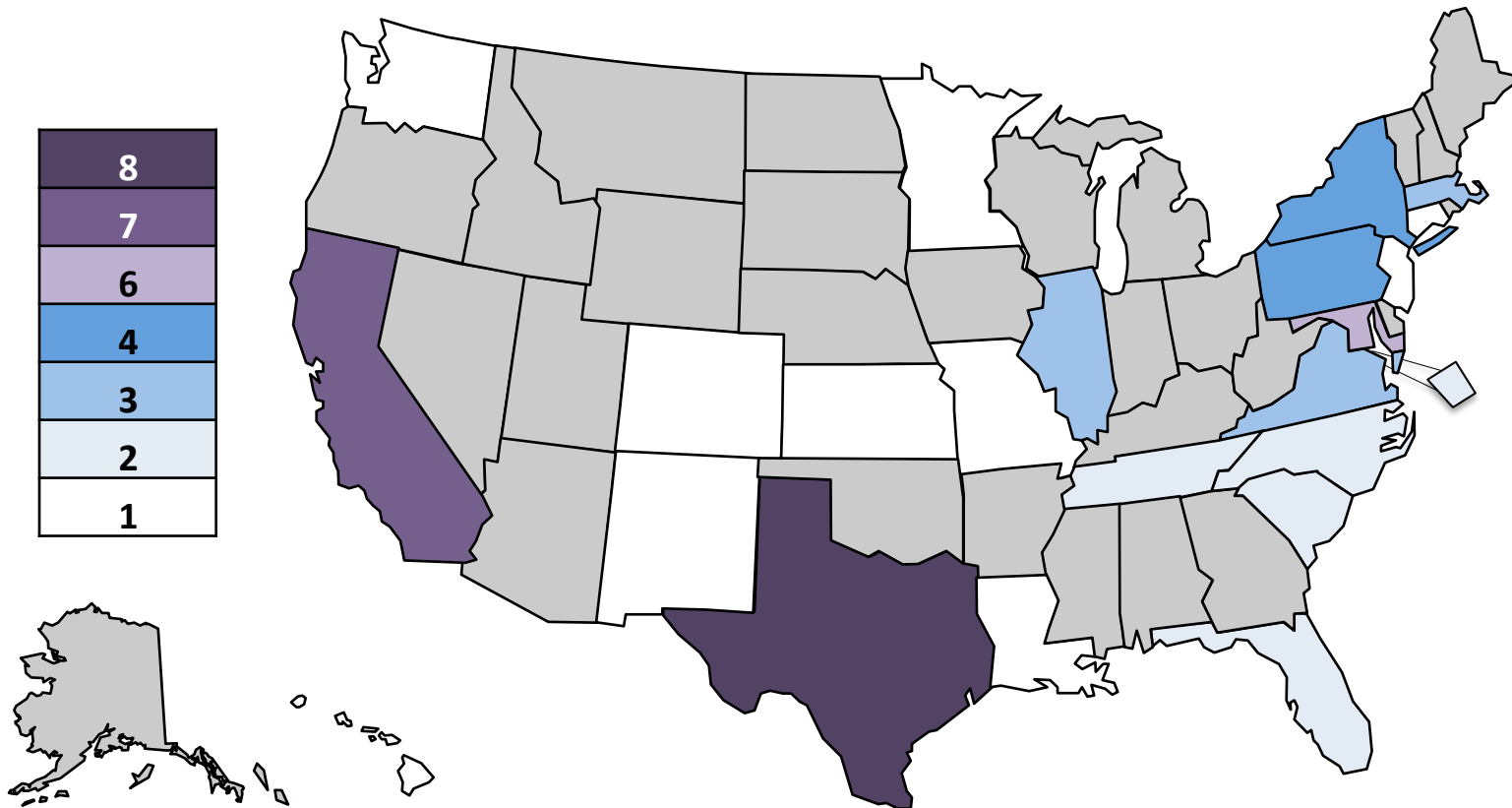
- Revamped pilot projects reviewer recruitment process
 - Created a user-friendly application and process
 - Reached out to extensive lists of key stakeholders
 - Vetted reviewer applications in-house
 - Contracted with expert vendor to develop merit review training specifically for patients and other stakeholders
 - Will engage patients and stakeholders in process improvement cycle

Patient and Stakeholder Reviewers

- Patients and stakeholders will be one-third of review panels
- 350 total applicants
- 242 with prior grant review experience
 - 102 from patient community
 - 140 from stakeholder community
- **58 selected** in final vetting
 - Based on balanced criteria
- Goal is to build a database of lay reviewers of PCORI funding applications



Patient and Stakeholder Reviewers



What We Heard From Reviewers

"This is exciting and will lead to positive outcomes."

"Need to find ways to optimize healthcare system."

"17-year breast cancer survivor and want to see an end to the disease."

"First time patient's voice is being formalized."

"It's about time this is happening in healthcare."

"Need to get patients' perspective and find ways to get them involved."

"Served as a PCORI reviewer and experience was fascinating."

"Need for more research to meet current needs of patients."

"Want to give back Expertise, and this is a great learning opportunity."

"I want do my part as a patient, and I will be honored with this opportunity."

"Stakeholder engagement is essential to relevant and useful research and evaluation: from identification of study questions to dissemination and utilization of findings."



Help Us Spread the Word

Create
Communities

Engage
Meaningfully

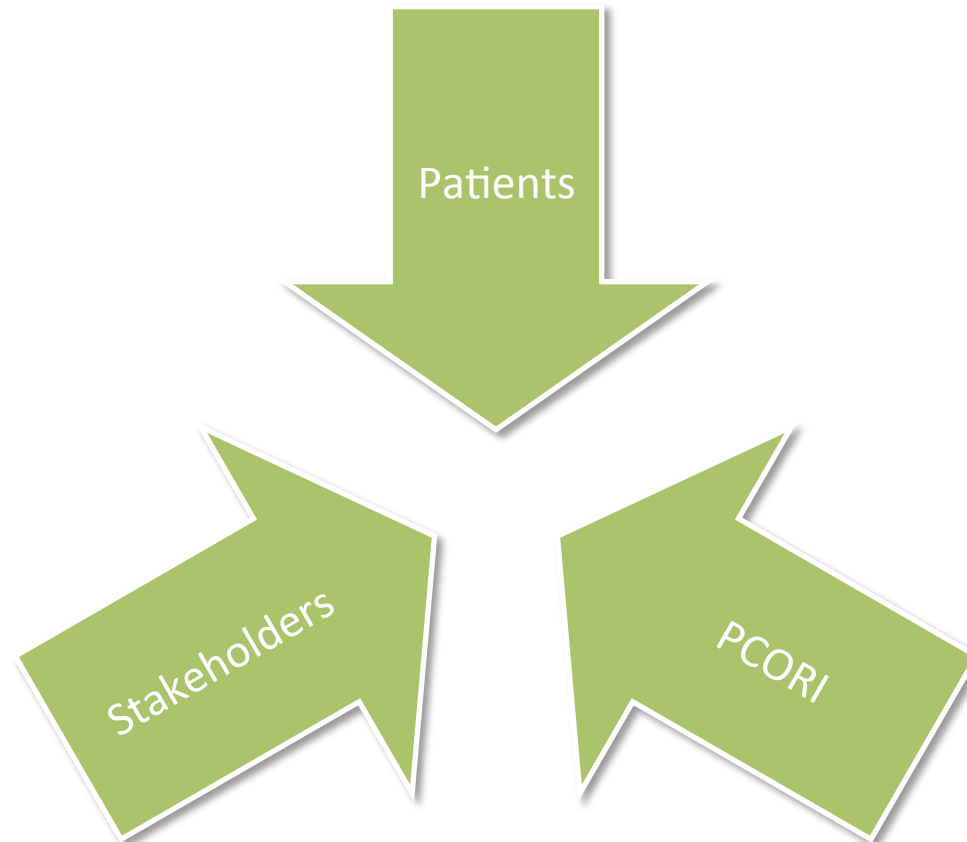
Share and
Adopt Latest
Information

Stakeholder View on Dissemination





Tell Us How We Are Doing



Patient Workshop: Objectives

Transforming Patient-Centered Research: Building Partnerships and Promising Models (October 27-28: Washington, DC)

- Launch the creation of an informed and engaged community
- Create consensus recommendations for patient engagement in
 - Generating and prioritizing research questions
 - Reviewing research proposals and the conduct of research
 - Disseminating and implementing research findings
 - Evaluating the success of PCORI's engagement efforts
- Write a "thought piece" on promising practices in patient engagement in research

Patient Workshop: Selection Criteria

- Invitation list developed with the goal of inclusiveness
- Balance sought between and among disease incidence, prevalence, burden, and disparities in the United States (with emphasis on chronic conditions)
- Total attendance will be limited to 150 participants
 - 75% of participants will be patients, patient advocates, caregivers, and individuals from patient/caregiver advocacy organizations
 - 25% of participants will be a mix of PCORI's other stakeholders

Stakeholder Workshop: Objectives

What Should PCORI Study?

A Call for Topics From Patients and Stakeholders (December 4: Washington, DC)

- Solicit research topics for specific funding announcements using breakout sessions on PCORI's priority areas and generate list
- Report on ***draft*** prioritization process (topic of December 5 workshop), allow participants to experiment with applying it to their topics, and solicit feedback on the process
- Report on Patient Engagement Workshop participants' reactions to PCORI's engagement strategies and to seek additional input

Stakeholder Workshop: Other Criteria

Specific Experience With:

- Research or work in PCORI Priority Areas
- Leadership in PCORI Priority Areas
- The health policy or research communities
- Broad membership or responsibility for health care delivery

What's Next

- Advisory Panels
- Additional Workshops
- State-Based Events

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Appendix

- Appendix A: Patient Engagement Workshop Outline
- Appendix B: Patient Engagement Workshop Timeline
- Appendix C: Stakeholder Engagement Workshop Outline
- Appendix D: Organizations Contacted