Patient Engagement in Research

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Advisory Panel Kickoff & Training
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How PCORI Engages Patients in Research

- Identifying and Selecting Research Questions
- Reviewing Research Proposals for Funding
- Conducting PCORI-Funded Research
- Matching Patients and Stakeholders with Researchers
- Disseminating Research to the Community
- Evaluating PCORI’s Patient and Stakeholder Engagement Programs

Patient-Centered Outcomes Research Institute
PCORI’s October 2012 workshop included five breakout sessions to help PCORI implement a patient-centered research agenda through sustained and meaningful engagement.

PATIENT ENGAGEMENT WORKSHOP VIDEO
Identifying and Selecting Research Questions

How should PCORI identify and select specific research questions for funding that are patient-centered?
Identifying and Selecting Research Questions

- PCORI Web site
- Roundtables
- Workshops

- PCORI Methodology Report
- Advisory Panels

1. Identifying Specific Topics that Matter to Patients
   Patients, stakeholders and the broader health care community identify topics to consider

2. Ensuring Topics Address a Research Gap
   Current research and evidence thoroughly evaluated to avoid duplication

3. Assessing Topics Based on PCORI Criteria
   Proposed topics must meet PCORI’s patient-centered criteria

4. Ranking Topics for the Board’s Approval
   Patients and the health care community prioritize which topics PCORI should fund

5. Creating Funding Announcements for Selected Topics
   Targeted funding announcements issued to address specific topics
How can PCORI effectively engage and use the real-world experience of patients to help evaluate research proposals we receive?
Reviewing Research Proposals for Funding

Building a community of informed stakeholder reviewers

- Training patients and stakeholders on PCORI review criteria, process, and instructions on how to score PCORI Funding Applications
- Identifying Reviewer Mentors
- Matching expertise with research priority area
- Equalizing voices at the reviewer table
Conducting PCORI-Funded Research

- PCORI Methodology Report
  - Standards Associated with Patient-Centeredness

- Review of PCORI Funding Applications
  - Patient-Centeredness

- Exemplary models of patient engagement in research
  - High Plains Research Network - *Boot Camp Translation for Patient-Centered Outcomes* (Dr. Westfall & Maret Felzien)
How can PCORI connect patients and stakeholders with researchers for collaborative work that ensures studies reflect patient perspectives?
Matching Patients and Stakeholders with Researchers

Video Clip: Ming Tai Seale
Matching Patients and Stakeholders with Researchers

The PCORI Challenge Initiative

- Developing a patient/research “matching” system that will effectively connect potential partners interested in seeking funding from us for rigorous patient-centered outcomes research
How do we ensure that patients and those who care for them can access and use PCORI’s research to make more-informed decisions?
Disseminating Research to the Community

🌍 Speeding the implementation of and use of PCOR
🌍 Becoming a trusted resource for information
🌍 Engaging stakeholders from across the healthcare community to include PCORI research in training, practice, and standards
Evaluating PCORI Engagement Activities

How can PCORI measure the effectiveness of its programs to involve patients and stakeholders throughout its work?
Evaluating PCORI Engagement Activities

- Maximizing engagement activities to inform programs and understand the impact
- Building trust in PCORI through transparent communication of the results of engagement efforts