



Patient Engagement in Research

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*Advisory Panel Kickoff & Training
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Patient-Centered Outcomes Research Institute

How PCORI Engages Patients in Research

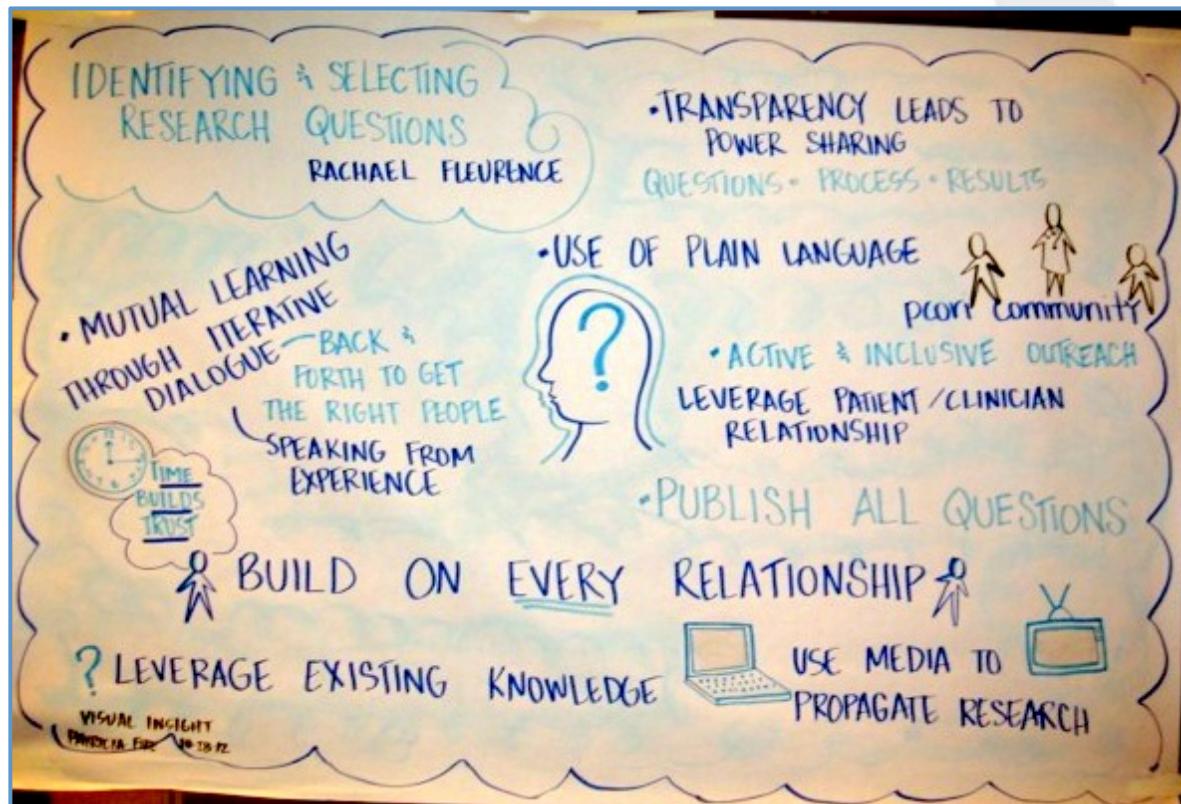
- Identifying and Selecting Research Questions
- Reviewing Research Proposals for Funding
- Conducting PCORI-Funded Research
- Matching Patients and Stakeholders with Researchers
- Disseminating Research to the Community
- Evaluating PCORI's Patient and Stakeholder Engagement Programs

Transforming Patient-Centered Research: Building Partnerships and Promising Models

- 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

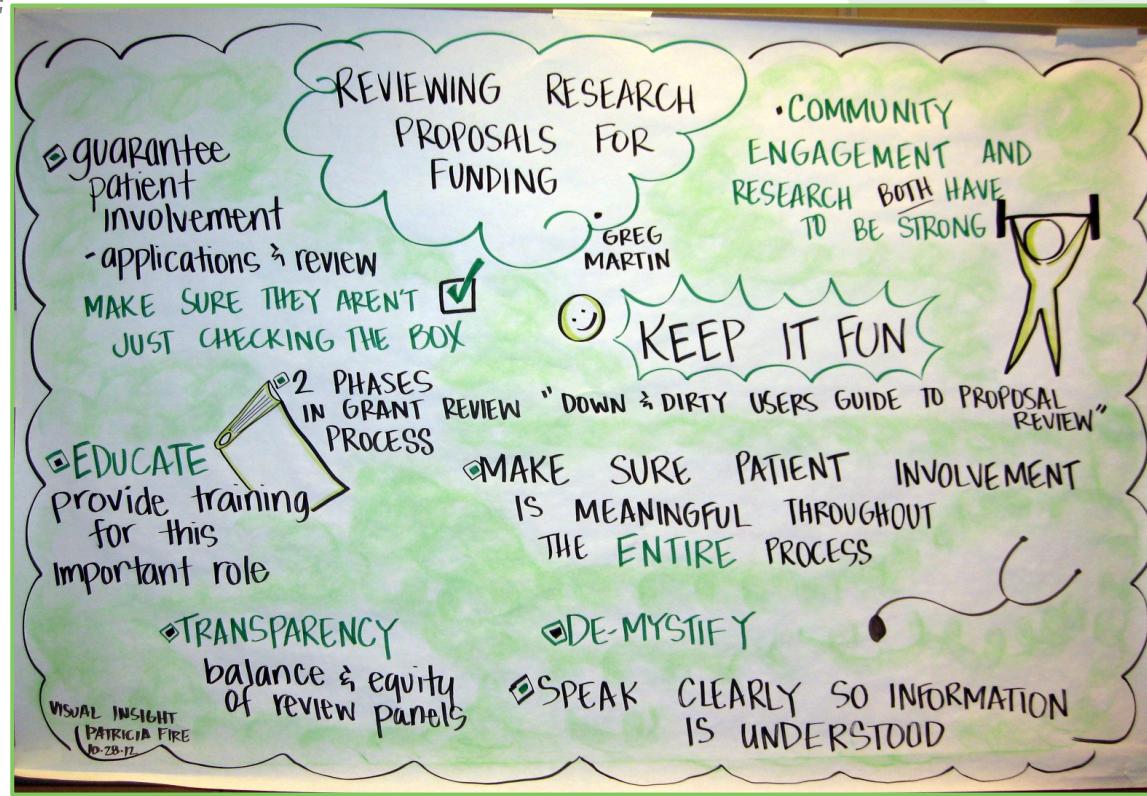
- ✓ PCORI Web site
- ✓ Roundtables
- ✓ Workshops

- ✓ PCORI Methodology Report
- ✓ Advisory Panels



Reviewing Research Proposals for Funding

- 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)*

Matching Patients and Stakeholders with Researchers

- 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](#)



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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*



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Disseminating Research to the Community

- 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



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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



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