

Patient and Stakeholder Engagement in Research

Jean Slutsky

*Chief Engagement and Dissemination Officer and
Program Director for Communication and Dissemination Research*
June 23, 2015



PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Welcome!



Jean Slutsky, PA, MSPH

*Chief Engagement and Dissemination Officer
and Program Director for Communication and
Dissemination Research*



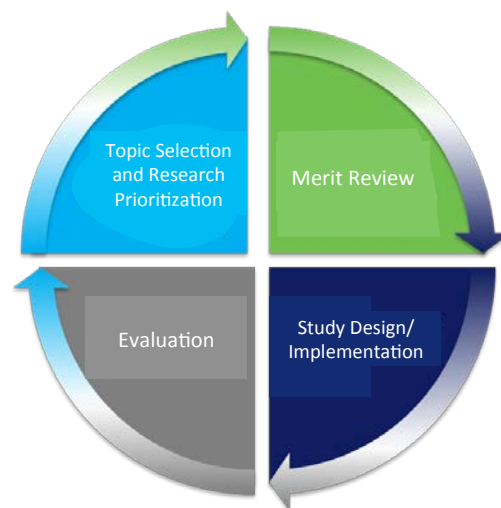
PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

In This Session

- Discuss the difference between patient-centeredness and patient engagement
- Provide an overview of PCORI's Engagement Rubric
- Discuss the role of the Engagement Officer at PCORI
- Review additional engagement resources available through PCORI



We Engage Patients and Other Stakeholders at Every Step



Our Review Criteria

During a rigorous merit review process, proposals are evaluated to assess:

Impact of the condition on health of individuals and populations

Potential for improving care and outcomes

Technical merit

Patient-centeredness

Patient and stakeholder engagement



What are Patient-Centeredness and Patient Engagement?



Patient-Centeredness vs. Patient and Stakeholder Engagement

Patient-Centeredness:

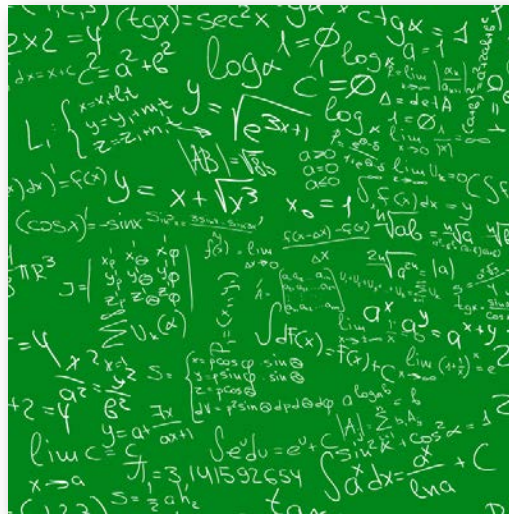
Does the project aim to answer questions or examine outcomes that matter to patients/caregivers?

Patient and Stakeholder Engagement:

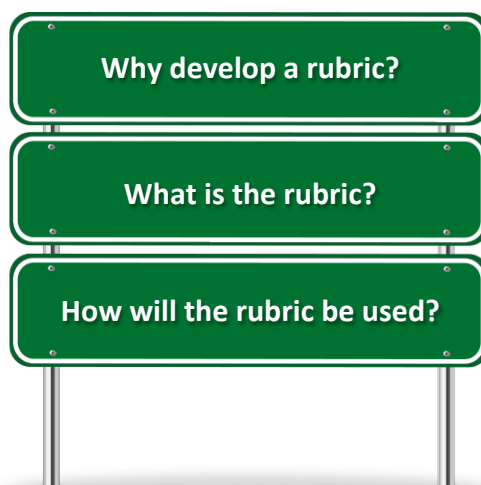
Are patients/caregivers and other stakeholders involved as partners in research, as opposed to being merely study participants?



Show Your Work



The Rubric



Overarching Rubric Principles

The rubric is a collection of examples, intended to provide guidance to applicants, merit reviewers, awardees, and Engagement/Program Officers.

The examples provided are from real PCORI-funded projects.

Applicants can choose to include some (but not all) activities illustrated, and they can include additional innovative approaches not included.

The rubric is not intended to be comprehensive or prescriptive.



Elements of the Rubric



1. Planning the Study



Describe how patient and stakeholder partners will participate in the study.

Potential activities include

- Identifying the topic and developing the research question and comparators to be studied
- Defining the characteristics of study participants

Examples of how to demonstrate this in your proposal

- Providing letters of support from patient and stakeholder partners that clearly describe the origin of the study topic and the role of the patient and stakeholder partners in defining the question, outcomes, comparators, goals and outcomes, and so on

Planning the Study—Real World Examples



Mental health study:

Patient partners and community members helped craft the study name and materials to reduce the potential for stigma and to reframe the goal of the study as a movement toward emotional well-being rather than away from a mental health challenge.



Diabetes study:

Clinicians who reviewed the initial study design indicated that clinical practice is quite variable and suggested that a three-arm approach would be more appropriate for the study. The study design was revised accordingly.



2. Conducting the Study



Describe how patient and stakeholder partners will participate in conducting the study.

Potential activities include

- Drafting or revising study materials and protocols
- Assisting with the recruitment of study participants

Examples of how to demonstrate this in your proposal

- Providing letters of support from patient and stakeholder partners that clearly describe the role of these partners in conducting and monitoring the study
- Clearly articulating in the application the roles of the patient and stakeholder partners in each component of the conducted study (e.g., helping draft survey tools and focus group questions and reviewing participant materials for readability), including the dissemination and implementation assessment



2. Conducting the Study: Real World Examples



Chronic pain study:
The informed consent document was developed with patient partners to make it understandable to study participants.



Preeclampsia study:
The study team is recruiting via a national network of local health departments and community health centers, as well as through a preeclampsia advocacy group's website and Facebook page.



Asthma study:
Clinicians and patients both provided guidance on who should deliver the intervention, when it should be provided during the process of care, and how it should be delivered.



3. Disseminating the Study Results



Describe how patient and stakeholder partners will be involved in plans to disseminate study findings and ensure that findings are communicated in understandable, usable ways.

Potential activities include

- Identifying partner organizations for dissemination
- Planning dissemination efforts

Examples of how to demonstrate this in your proposal

- Clearly identifying the role of patient and stakeholder partners in planning the dissemination of the study's findings
- Including patient and stakeholder partners on a project committee that will oversee dissemination



Disseminating the Study Results— Real World Examples



Trauma study:

The research team is convening a policy summit with relevant professional societies during the third year of the study to focus on identifying ways to speed the implementation of findings into practice.



Neurology study:

The research team presented at a neurology patient advocacy conference to inform the community that this research was ongoing and to stay tuned for future results.



4. PCOR Engagement Principles: Reciprocal Relationships



Reciprocal Relationships

- Describe the roles and decision-making authority of all research partners, including patient and stakeholder partners

Examples of how to demonstrate this in your proposal

- Explaining how decisions are made within your research team, including the decision-making authority that patient and stakeholder partners have and in what circumstances
- Including patient and stakeholder partners as key personnel, with biosketches illustrating how the skills and experiences of the patient partners prepare them to function effectively in this role



4. PCOR Engagement Principles: Co-Learning



Co-Learning

- Describe plans to ensure that patient and stakeholder partners will understand the research process and that researchers will understand patient and stakeholder engagement and patient-centeredness

Examples of how to demonstrate this in your proposal

- Providing training and educational opportunities, such as patient and stakeholder partner training in human subjects protection
- A narrative version of this document (not in table format) is included as an appendix in the PFA Application Guidelines
- Incorporating training that is provided by patient advocacy organizations, patients/survivors, and clinicians/caregivers for the researchers providing the intervention (e.g., training in better communication with patients led by patient instructors)



4. PCOR Engagement Principles: Partnership



Partnership

- Describe how the time and contributions of patient partners are valued and demonstrated in fair financial compensation, as well as reasonable and thoughtful time commitment requests

Examples of how to demonstrate this in your proposal

- Including compensation for patient partners in the budget at an appropriate level
- Holding meetings at a time and in a location that accommodates patient and stakeholder partners
- Providing compensation for transportation and related expenses
- Making accommodations to encourage the full engagement of a range of patient and stakeholder partners and to ensure that the research team includes a diverse set of members (e.g., a project that focuses on Latino health should consider including Spanish-speaking individuals on the research team and may wish to conduct patient and stakeholder meetings in both Spanish and English)



4. PCOR Engagement Principles: Trust, Transparency, and Honesty



Trust, Transparency, and Honesty

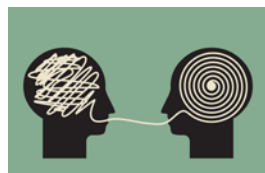
- Describe how major decisions are made inclusively and information is shared readily with all research partners, including patient and stakeholder partners; how patient and stakeholder partners and research partners express commitment to open and honest communication with one another; and how the study team commits to communicate study findings to the community studied in a meaningful and usable way

Examples of how to demonstrate this in your proposal

- Describing how the research team—including patient and stakeholder partners—will communicate with each other, the frequency of this communication, the roles of each member of the research team, and the decision-making authority of each member of the research team



Putting the Rubric to Work



Greater
understanding
of engagement

Stronger
engagement
in proposals

Strong
engagement
during
research



Engagement Officers

Engagement Officers, working closely with Program Officers, will support active portfolio management by



- Helping Awardees to outline engagement milestones
- Participating in the Awardees' kick-off and interim phone calls, as well as in separate calls with key patient and stakeholder partners
- Facilitating communication between Awardees to troubleshoot engagement challenges
- Gathering promising engagement practices from the portfolio to feature in webinars and for use in updating or expanding the Engagement Rubric



PCORI's Commitment to Engagement in Research

Get Involved

ENGAGEMENT IN RESEARCH

PCORI'S STAKEHOLDERS

SUGGEST A PATIENT-CENTERED RESEARCH QUESTION

PROVIDE INPUT

REVIEW FUNDING APPLICATIONS

Engagement in Research

Since our establishment, PCORI has been committed to funding research that includes meaningful involvement by patients and other stakeholders in all steps of the process. Bringing together all healthcare stakeholders to help set research priorities—with patients at the center—is our formula for ensuring we fund and conduct the most relevant research possible. We believe that including patients and other stakeholders in the research process will lead to trustworthy and usable information more likely to be taken up in practice, and we pick the proposals we fund accordingly.



Engagement Resources

[PCORI Applicant FAQs \(Engagement\)](#)

[PCORI Sample Engagement Plans](#)

[PCORI Town Halls](#)

- PCORI will host Town Halls for applicants on Patient and Stakeholder Engagement; these sessions will be recorded and archived as resources for current and future applicants.

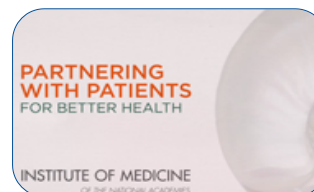


Engagement Webinars



Partnering With Patients to Drive Shared Decisions, Better Value, and Care Development

Observing PCORI-Funded Engagement in Action



Transforming Patient-Centered Research: Building Partnerships and Promising Models



Ambassador Program

PCORI has created a volunteer initiative that aims to unite individual and organizational health and healthcare stakeholders around the promise of PCOR while offering opportunities for training, research partnerships, and knowledge sharing with other Ambassadors, PCORI staff, and other external partners that support PCORI's mission.



PCORI Ambassador Program Highlights

PCORI Ambassadors:

- Have access to PCORI Ambassador Training
- Have their names and profiles posted on PCORI's website for potential research partnership opportunities
- Are connected with various PCORI activities as well as other healthcare agencies seeking skilled patient-centered representatives to:

Serve on technical expert panels

Participate in conferences and panels

Be involved in topic refinement working groups

Review scientific abstracts

Participate in funded research projects

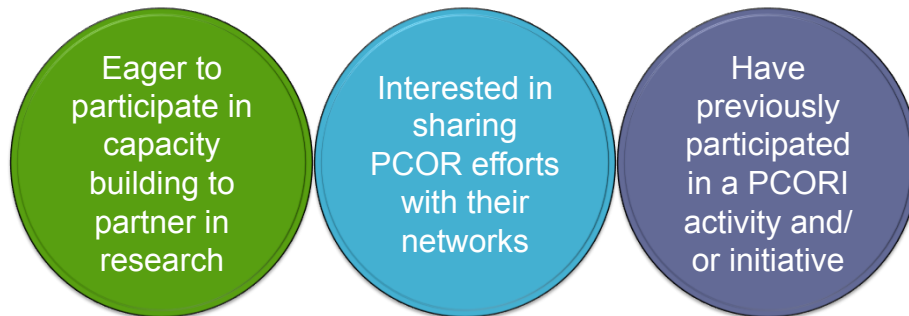
- Have access to an online community to connect with fellow Ambassadors and PCORI staff



Ambassador Program

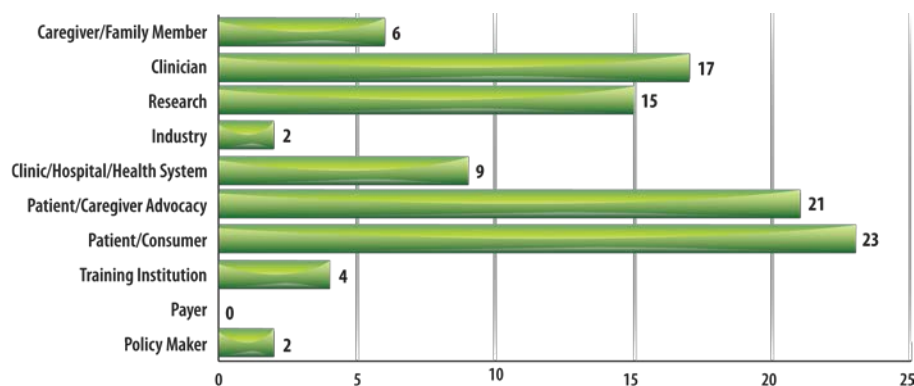
Who should join?

Individuals and advocacy, health, or healthcare organizations interested in PCOR who are:

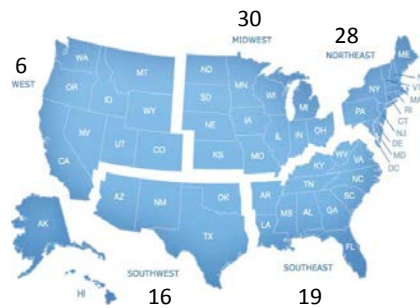
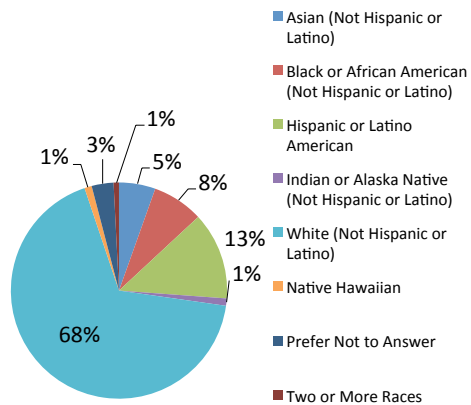


Ambassadors by Stakeholder Group

To Date: 99 stakeholders have completed the Ambassador Training
(82 individual and 17 organizational)



Ambassadors by Ethnicity and Region



Learn more and submit an interest form
pcori.org/ambassadors

Contact us
ambassadors@pcori.org



PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

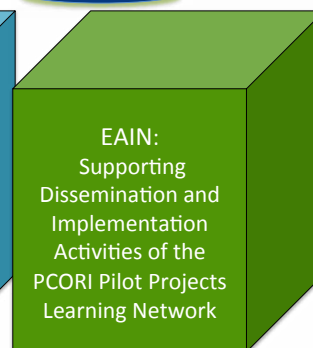
31

The Engagement Awards Program

- Provides a platform to expand the role of all stakeholders in research and to support PCORI's Engagement Priorities
- Awards up to 2 years, \$250,000

\$15.5 Million (FY 2014)

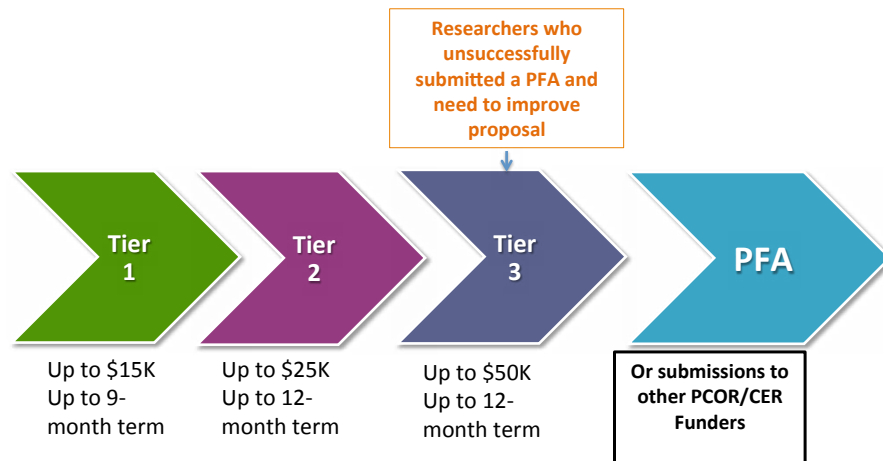
Launched in February 2014



PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

32

Pipeline to Proposal Awards



Engagement ACTivity (ENACT) Inventory

- Who is engaged
- Partnership characteristics
 - How formed, length, frequency of engagement, etc.
- Level of engagement
- When in the research process they are engaged
- Perceived level of influence of partners
- Perceived effects of engagement on research questions, study design, study implementation, and dissemination of results
- Challenges and facilitators
- Lessons learned for engagement
- PCOR principles—respect, co-learning, etc.



Learn More

www.pcori.org

info@pcori.org

[twitter](#) 

[You Tube](#) 



PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

35

Questions?

PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Thank You!

Jean Slutsky, PA, MSPH, Chief Engagement and Dissemination Officer and
Program Director for Communication and Dissemination Research



PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE