

# Patient and Stakeholder Engagement in Research

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## Welcome!



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## Session Objectives

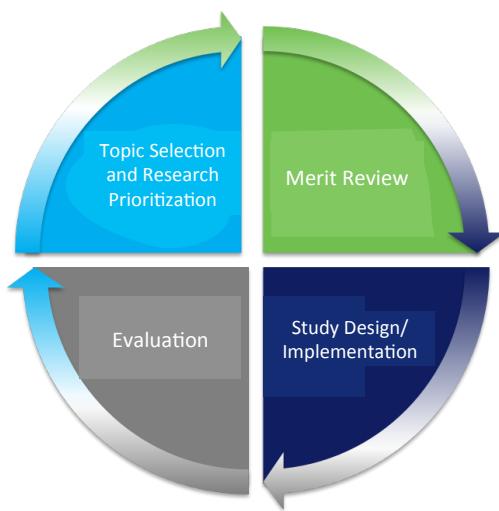
- Discuss the difference between patient-centeredness and patient engagement
- Provide an overview of PCORI's Engagement Rubric
- Discuss the role of the Engagement Officer at PCORI
- Review additional engagement resources available through PCORI



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## We Engage Patients and Other Stakeholders at Every Step



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## Our Review Criteria

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

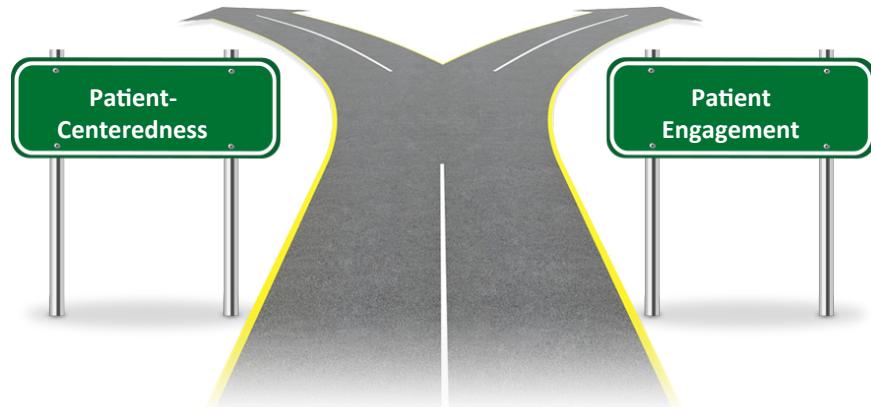
- Impact of the condition on health of individuals and populations
- Potential for improving care and outcomes
- Technical merit
- Patient-centeredness
- Patient and stakeholder engagement



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## What are Patient-Centeredness & Patient Engagement?



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## 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 study participants?



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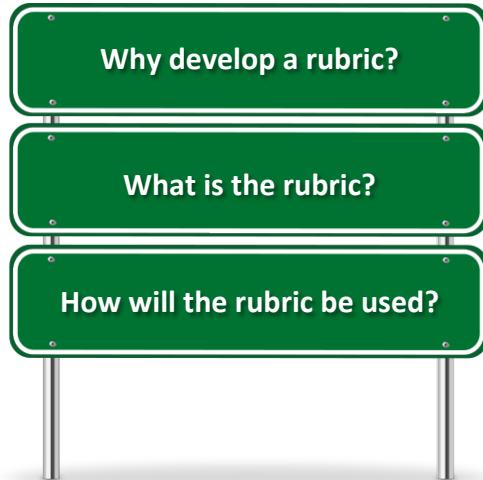
## Show Your Work



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## The Rubric



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## Overarching Rubric Principles

- The rubric is a collection of examples, intended to provide guidance to applicants, merit reviewers, awardees, and engagement/program officers
- It is not intended to be comprehensive or prescriptive
- Applicants can choose to include some (but not all) activities illustrated, and they can include additional innovative approaches not included
- The examples provided are from real PCORI-funded projects



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## Elements of the Rubric



### Planning the Study



### Conducting the Study



### Disseminating the Study Results



### PCOR Engagement Principles



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## Planning the Study

1. Describe how patient and stakeholder partners will participate in 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



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## Planning the Study (Cont'd.)

### 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.



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## Conducting the Study

### **2.** Describe how patient and stakeholder partners will participate in the study conduct.

#### Potential activities

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

#### Example 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 study conduct (e.g., helping draft survey tools and focus group questions, reviewing participant materials for readability), including the dissemination and implementation assessment



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## Conducting the Study (Cont'd.)

### 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.



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## Disseminating the Study Results

3. 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



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## Disseminating The Study Results (Cont'd.)

### 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.



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## PCOR Engagement Principles

### 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



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## PCOR Engagement Principles

### 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.

#### Example 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)



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## PCOR Engagement Principles

### 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 diversity 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)



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## PCOR Engagement Principles Cont'd

### Trust, Transparency, 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



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## Elements of the Rubric



### Planning the Study



### Conducting the Study



### Disseminating the Study Results



### PCOR Engagement Principles



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## Putting the Rubric to Work



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## 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 with research team members including 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



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## 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.



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## Engagement Resources

### PCORI Applicant FAQs (Engagement)

### PCORI Sample Engagement Plans

### PCORI Town Halls

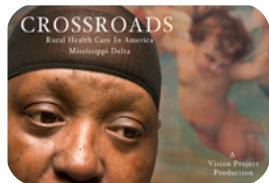
- PCORI will host Town Halls for applicants on Patient and Stakeholder Engagement; these sessions will be recorded and archived as resources for current and future applicants.



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## 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**



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## Ambassador Program

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

### *Program Highlights:*

- Ambassadors have access to PCORI Ambassador Training
- Ambassadors are connected with various PCORI opportunities such as;
  - Serving on technical expert panels,
  - Participation in conferences and working groups
  - Reviewing scientific abstracts
  - Participating in funded research projects
- Ambassadors have access to an online community to connect with fellow Ambassadors and PCORI staff
- Ambassadors are committed to the PCOR engagement principles of reciprocal relationships, partnership, co-learning, trust, transparency, and honesty

Who should join? Individuals with a personal interest in PCOR and health or healthcare entity representatives who are eager to share PCOR efforts with their networks, who have previously participated in a PCORI activity and/or initiative



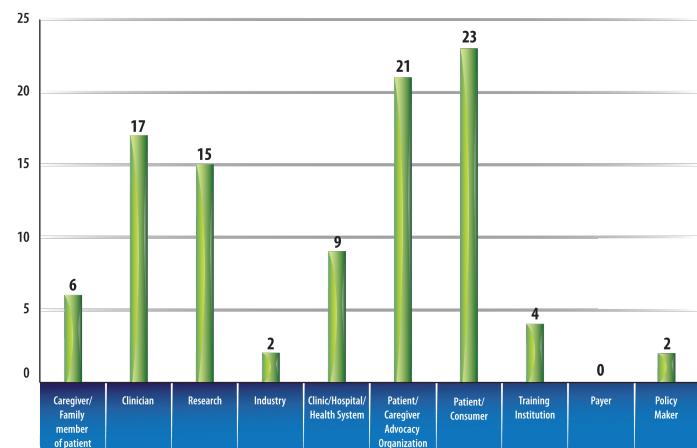
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## Ambassadors by Stakeholder Group

To Date: 99 have completed the Ambassador Training

- 82 individual and 17 organizational



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## Ambassadors by Ethnicity and Region



Learn more and submit an interest form [Contact us](#)  
[pcori.org/ambassadors](http://pcori.org/ambassadors) [ambassadors@pcori.org](mailto:ambassadors@pcori.org)

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## Engagement Awards

- Provides a platform to expand the role of all stakeholders in research and to support PCORI's Engagement Priorities
- Launched in February 2014
- \$15.5 Million (FY 2015)
- LOIs are required for each project, except those for meetings and conference support; reviewed January 2, April 1, July 1, and October 1
- Awards up to 2 years, \$250,000
  - Knowledge, Training and Development, Dissemination Awards
  - EAIN: PCOR/CER meeting and conference support



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## Pipeline to Proposal Awards



Up to \$15K  
Up to 9  
month term

Up to \$25K  
Up to 12  
month term

Up to \$50K  
Up to 12  
month term

Or submissions to  
other PCOR/CER  
Funders



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## 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, facilitators
- Lessons learned for engagement
- PCOR principles – respect, co-learning, etc.



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## Learn More

[www.pcori.org](http://www.pcori.org)

[info@pcori.org](mailto:info@pcori.org)



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# Questions?

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# Thank You!

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