Patient and Stakeholder Engagement in Research

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Welcome!

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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

<table>
<thead>
<tr>
<th>Patient-Centeredness:</th>
<th>Patient and Stakeholder Engagement:</th>
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<tbody>
<tr>
<td>Does the project aim to answer questions or examine outcomes that matter to patients/caregivers?</td>
<td>Are patients/caregivers and other stakeholders involved as partners in research, as opposed to being merely study participants?</td>
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## Show Your Work
The Rubric

- Why develop a rubric?
- What is the rubric?
- How will the rubric be used?

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
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.

<table>
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<th>Potential activities include</th>
<th>Examples of how to demonstrate this in your proposal</th>
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| • Identifying partner organizations for dissemination  
• Planning dissemination efforts | • 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

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<th>Examples of how to demonstrate this in your proposal</th>
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<td>• Describe the roles and decision-making authority of all research partners, including patient and stakeholder partners</td>
<td>• Explaining how decisions are made within your research team, including the decision-making authority that patient and stakeholder partners have and in what circumstances</td>
</tr>
<tr>
<td></td>
<td>• 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</td>
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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

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<td>• 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.</td>
<td>• 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.</td>
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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

Since our establishment, PCORI has been committed to funding research that includes meaningful involvement by patients and other stakeholders at 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.

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Engagement Webinars

- **Observing PCORI-Funded Engagement in Action**
- **Partnering With Patients to Drive Shared Decisions, Better Value, and Care Development**
- **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:

- Eager to participate in capacity building to partner in research
- Interested in sharing PCOR efforts with their networks
- Have previously participated in a PCORI activity and/or initiative

Ambassadors by Stakeholder Group

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

- Asian (Not Hispanic or Latino)
- Black or African American (Not Hispanic or Latino)
- Hispanic or Latino American
- Native Hawaiian
- Prefer Not to Answer
- Two or More Races

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

Contact us: ambassadors@pcori.org

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

Launched in February 2014

$15.5 Million (FY 2014)
Pipeline to Proposal Awards

- **Tier 1**: Up to $15K, up to 9-month term
- **Tier 2**: Up to $25K, up to 12-month term
- **Tier 3**: Up to $50K, up to 12-month term
- **PFA**: Or submissions to other PCOR/CER Funders

Researchers who unsuccessfully submitted a PFA and need to improve proposal

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

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twitter

Questions?
Thank You!

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