

# Research Partnerships and Engagement

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**Suzanne Schrandt, JD**  
Deputy Director, Patient Engagement

January 29, 2016



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## Welcome!

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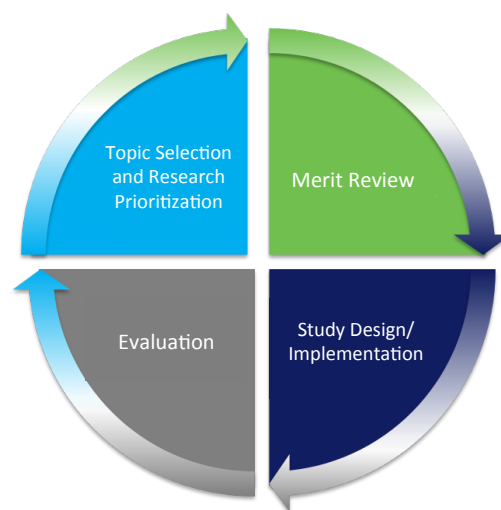


**Suzanne Schrandt, JD**  
*Deputy Director,  
Patient Engagement*

## In This Session

- Discuss the patient and stakeholder engagement requirements in PCORI funding opportunities
- Provide an overview of PCORI's Engagement Rubric
- Discuss the Engagement Team's role 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

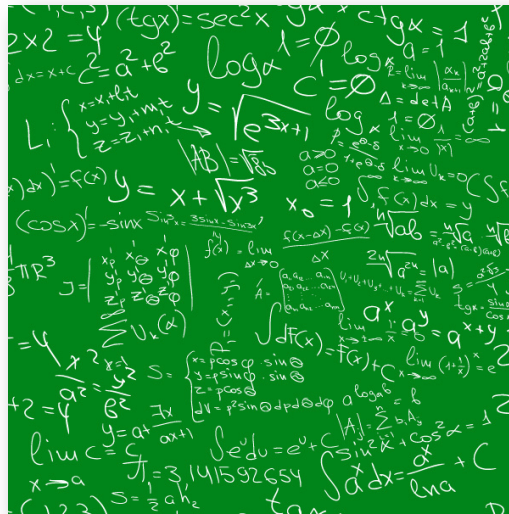
Technical merit

Patient-centeredness

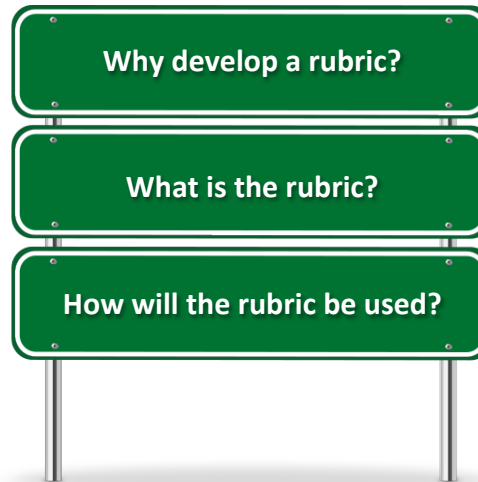
Patient and stakeholder engagement



## Show Your Work



## The Rubric



## Overarching Rubric Concepts

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

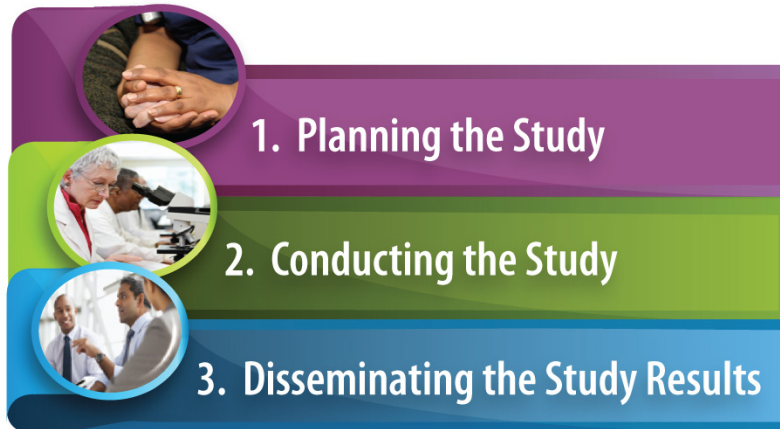
The examples provided are from real PCORI-funded projects.

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



## 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.



## PCOR Engagement Principles



- Reciprocal Relationships
- Co-learning
- Partnership
- Trust
- Transparency
- Honesty





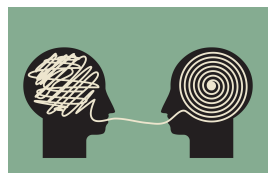
## In your application...



- Budget appropriately
  - Compensation for partners
  - Travel and meeting costs
  - Reasonable accommodations as needed
- Describe patient and stakeholder partners and their roles
- Include letters of support
- When applicable, use patient/stakeholder biosketch form



## Putting the Rubric to Work



Greater  
understanding  
of engagement

Stronger  
engagement  
in proposals

Stronger  
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



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## Engagement Resources

- 🌐 **PCORI's Engagement Rubric**  
[www.pcori.org/sites/default/files/PCORI-Engagement-Rubric-with-Table.pdf](http://www.pcori.org/sites/default/files/PCORI-Engagement-Rubric-with-Table.pdf)
- 🌐 **Sample Engagement Plans**  
[www.pcori.org/sites/default/files/PCORI-Sample-Engagement-Plans.pdf](http://www.pcori.org/sites/default/files/PCORI-Sample-Engagement-Plans.pdf)
- 🌐 **PCORI's Compensation Framework**  
[www.pcori.org/sites/default/files/PCORI-Compensation-Framework-for-Engaged-Research-Partners.pdf](http://www.pcori.org/sites/default/files/PCORI-Compensation-Framework-for-Engaged-Research-Partners.pdf)
- 🌐 **Engagement in Research Website**  
[www.pcori.org/content/engagement-research](http://www.pcori.org/content/engagement-research)
- 🌐 **PCORI's Methodology Standards PC-1 to PC-4**  
[www.pcori.org/assets/PCORI-Methodology-Standards1.pdf](http://www.pcori.org/assets/PCORI-Methodology-Standards1.pdf)



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# Questions?

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# Thank You!

Suzanne Schrandt, JD, Deputy Director, Patient Engagement



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