Research Agency Funders Panel Discussion

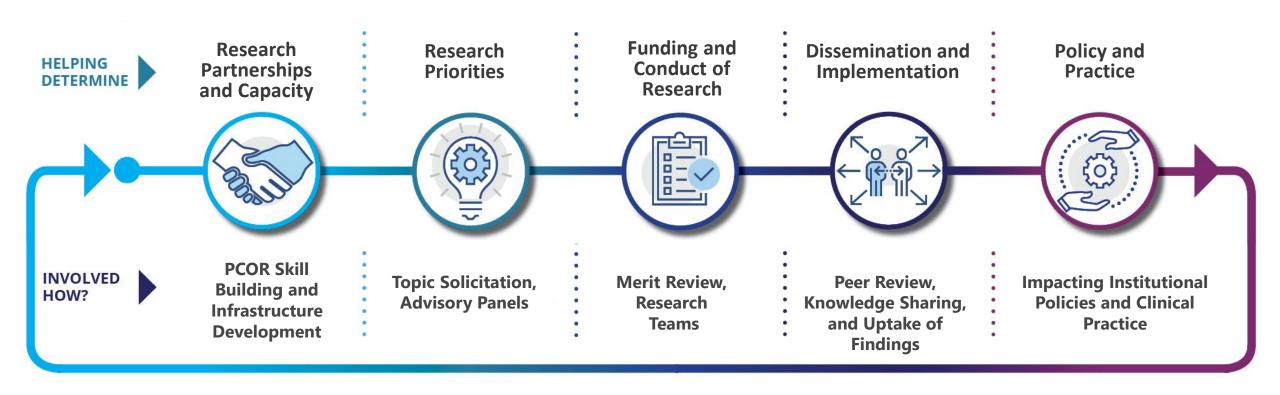
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Engagement: Foundational To Everything PCORI Does





The PCORI Engagement Rubric: Where We Began





Planning the study



Conducting the study



Disseminating study results

POTENTIAL ACTIVITIES

- · Developing research questions
- Selecting relevant outcomes
- · Define study population characteristics

POTENTIAL ACTIVITIES

- · Drafting or revising study materials
- Participating in study recruitment
- · Participating in data analysis

POTENTIAL ACTIVITIES

- · Identifying partners for dissemination
- Participating in dissemination efforts
- Presenting information about the study

REAL-WORLD EXAMPLES

- Patient organization surveys members on treatment preferences
- Clinicians suggest a third arm to study based on variability in practice

REAL-WORLD EXAMPLES

- Patients develop informed consent to make it understandable to participants
- Patient representative serves on data safety monitoring board

REAL-WORLD EXAMPLES

- Research team holds stakeholder summit to speed implementation of findings
- Research team introduces study at a patient advocacy conference to inform community of the research



PCOR Principles

Reciprocal Relationships • Co-Learning • Partnerships • Transparency, Honesty, Trust

Reciprocal Relationships: Demonstrated when roles and decision-making authority of all research partners are defined collaboratively and clearly stated

Co-Learning: Researchers help patient partners better understand the research process, and researchers will learn about patient-centeredness and patient/stakeholder engagement

Partnerships: The time and contribution of patient and other stakeholder partnership is valued and demonstrated through compensation, cultural competency, and appropriate accommodations

Transparency, Honesty, Trust: Major decisions are made inclusively and information is shared readily among all research partners

What PCORI Has Learned From Engagement



- Engagement is feasible in all phases of CER and PCOR and with a variety of stakeholders
- Engagement can influence the design and conduct of research studies in meaningful ways including acceptability, feasibility, quality, and relevance
- Engagement can benefit the patient and stakeholder partners, communities, and researchers involved
- There are known challenges to address, including those related to infrastructure and resources, people and teams, organizational policies, and balancing views and priorities

Engagement Rubric Update: Where PCORI Is Heading



- The <u>Engagement Rubric</u> was originally developed in 2014 to provide Awardees with *guidance* on **how** and **when** to engage stakeholder partners.
- The next version of the Engagement Rubric will:
 - Use knowledge developed in the natural laboratory created during PCORI's first ten years
 - Address facilitators and barriers to engagement
 - Provide guidance and tools to support engagement.
 - Reflect PCORI's **key priorities for advancing engagement** both within PCORI and in the field.

The ultimate goal of the Rubric is to promote and support meaningful and sustainable engagement in CER/PCOR, and to influence research to be more patient-centered, relevant, and useful.

What Is still Needed: SoE Potential Topic Areas for Study

What defines successful engagement, and for whom?

How can engagement be measured? What indicates that a study is patient-centered?

What are the approaches that support and achieve successful engagement?

Which approaches should be combined to achieve engagement aims?

Under which conditions do approaches work best and how should they be modified and resourced for different contexts, settings, and communities?