Getting to Know PCORI: From Application to Closeout

A Workshop for Sponsored Project Administrators

Patient and Stakeholder Engagement in Research
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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
What are Patient-Centeredness & Patient Engagement?
Patient-Centeredness

Questions to Consider…

• Is research focused on questions that affect outcomes of interest to patients and their caregivers?

• Does the research address one or more of the key questions mentioned in PCORI’s definition of patient-centered outcomes research (PCOR)?
Patient Engagement

Questions to Consider…

• Are patients and other stakeholders engaged in:
  o Formulating research questions?
  o Defining essential characteristics of study participants, comparators, and outcomes?
  o Identifying and selecting outcomes that the population of interest notices and cares about and that inform decision making relevant to the research topic?
  o Monitoring study conduct and progress?
  o Designing/suggesting plans for dissemination and implementation activities?
• Are the roles and decision making authority of all research partners clearly stated?
• Does the proposal demonstrate the PCOR principles of reciprocal relationships, co-learning, partnership, trust, transparency and honesty?
PCORI’s Commitment to Engagement in Research

Since our establishment, PCORI has been committed to funding research that includes meaningful involvement of patients and other stakeholders in all steps of the process. Bringing together all stakeholders in the healthcare enterprise to 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 in the research process will lead to trustworthy and more usable information that will result in greater uptake of the research findings. We look forward to producing evidence to that effect through our portfolio of funded projects. In response to frequent questions about what we mean by “engagement in research,” PCORI, with contributions from our Patient Engagement Advisory Panel, developed the Patient and Family Engagement Rubric to provide guidance to applicants, merit reviewers, awardees, and PCORI program staff, on meaningful engagement practices.
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.
The Rubric

Why develop a rubric?

What is the rubric?

How will the rubric be used?
Overarching Principles

► The rubric specifically focuses on patient and family engagement in research to help illustrate promising practices emerging in this relatively new area of engagement in research.

► The term “patient partners” is intended to include:
  • Patients (those with lived experience)
  • Family members
  • Caregivers
  • The organizations that represent them who are representative of the population of interest in a particular study
Although the rubric is called the *Engagement Rubric*, there is an expectation that the engagement of other stakeholders relevant to a particular study will also be evaluated, such as:

- Clinicians
- Payers
- Hospital administrators
Overarching Principles (cont’d.)

► The rubric is intended to provide guidance to applicants, merit reviewers, awardees, and engagement/program officers (for creating milestones and monitoring projects) regarding patient and family engagement in the conduct of research.

► The rubric is not intended to be comprehensive or prescriptive; instead, it provides a variety of options to incorporate engagement, where relevant, into the research process.

► Applicants can choose to include some (but not all) activities, and they can include additional innovative approaches not listed here.
Overarching Principles (cont’d.)

► The rubric is based on the promising practices identified in the first three rounds of PCORI awards.
  • It is also consistent with PCORI’s Methodology Standards for patient-centeredness and its PCOR Engagement Principles.

► The rubric is structured into four sections:
  • Planning the Study
  • Conducting the Study
  • Disseminating the Study Results
  • PCOR Engagement Principles

► The rubric provides guidance to help applicants “show their work” when describing the details of how patient and family input will be incorporated throughout the entire research process.
Elements of the Rubric: Demo

- Planning the Study
- Conducting the Study
- Disseminating the Study Results
- PCOR Engagement Principles
Rubric: PCOR Engagement Principles

- Co-learning
- Trust, Transparency, Honesty
- Partnership
- Reciprocal Relationships
PCOR Engagement Principles: Reciprocal Relationships

The roles and decision-making authority of all research partners, including patient partners, are clearly stated.
The application includes plans to ensure that the patient partners will understand the research process and the researchers will understand patient-centeredness and patient engagement.
PCOR Engagement Principles: Partnership

► Time and contributions of patient partners are valued and demonstrated in fair financial compensation, as well as in reasonable and thoughtful time commitment requests.

► When the patient partners represent unique populations, the research team proposes to accommodate their cultural diversity and/or disability.
PCOR Engagement Principles: Trust, Transparency, Honesty

- Major decisions are made inclusively and information is shared readily with all research partners.
- Patient partners and research partners express commitment to open and honest communication with one another.
- The study team commits to communicating the study’s findings back to the study community in a meaningful and usable way.
Elements of the Rubric

- Planning the Study
- Conducting the Study
- Disseminating the Study Results
- PCOR Engagement Principles
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
Engagement Resources

PCORI Applicant FAQs (Engagement):  
http://www.pcori.org/funding-opportunities/funding-center/faqs-for-applicants/#engagement

PCORI Sample Engagement Plans:  

PCORI Town Halls:  
http://www.pcori.org/funding-opportunities/funding-announcements/applicant-training/
  
  o 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

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
Questions?
Thank You!

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