

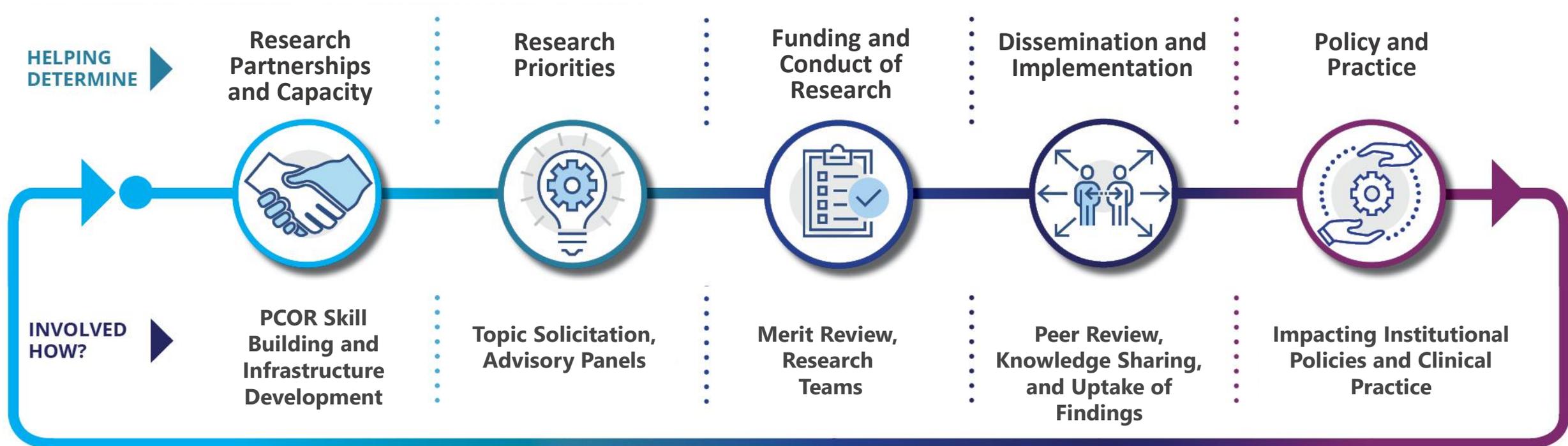
Research Agency Funders Panel Discussion

October 27, 2021

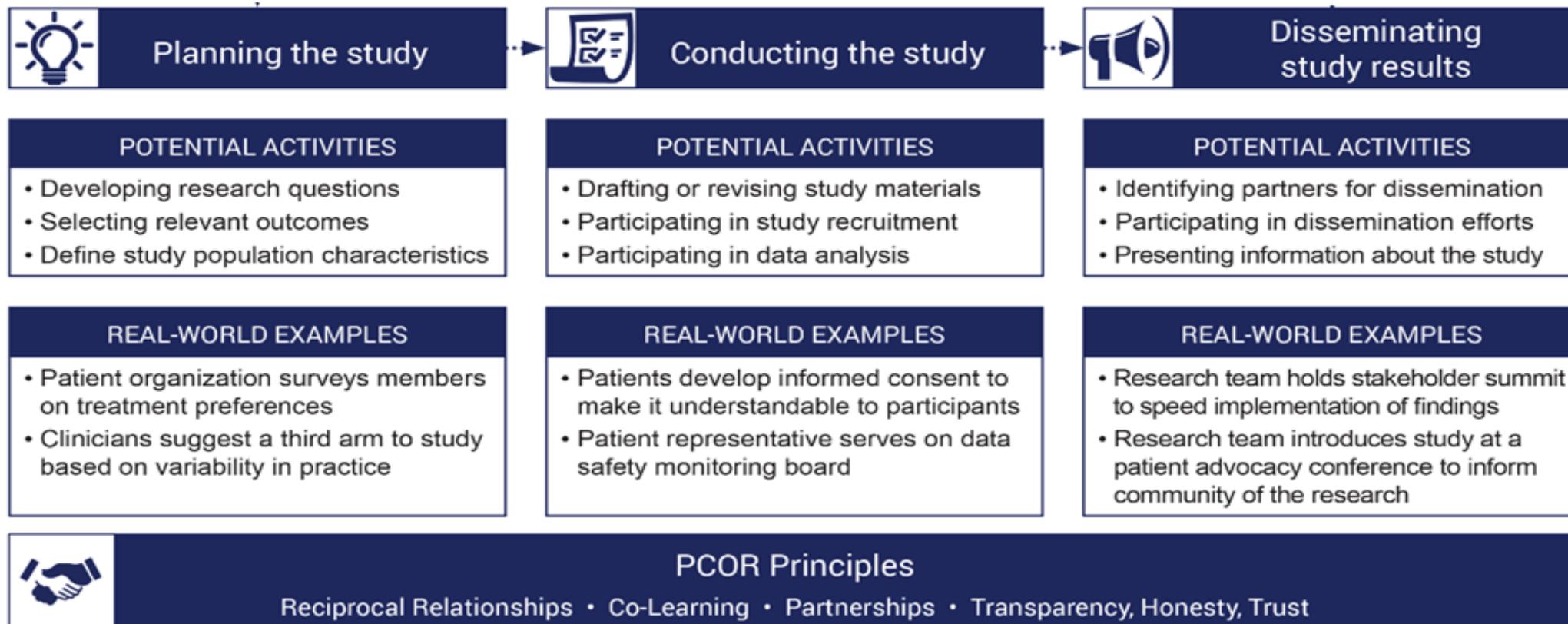
Kristin L. Carman, PhD
Director of Public & Patient Engagement
Kcarman@pcori.org



Engagement: Foundational To Everything PCORI Does



The PCORI Engagement Rubric: Where We Began



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

- The [Engagement Rubric](#) 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.

A yellow graphic element consisting of a right-angled triangle with a diagonal cut, pointing towards the bottom right, located to the left of the text.

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?