

Assessing the Impacts of Engaged Research and Its Use: Evidence and Opportunities

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PCORI is credited with inspiring change at other organizations and institutions



- Requirement to involve patients & stakeholders in strategic research planning
- Policies to support engagement in research
- Standing patient & stakeholder advisory boards
- Seed funding and capacity building for partnerships
- Training of students, fellows, and partners
- Patient reviewers in merit/peer reviews
- Adoption of patient-centered approaches by federal agencies, academic institutions, and funders
- Journal policies for person-centered language

Specific examples are described in more detail at <https://www.pcori.org/engagement/influencing-culture-research>

My Perspective on Key Ingredients

Compelling impetus

Birth of an organization – everything was new – innovation possible and necessary

Breadth and depth

Carrots and sticks

It matters

BUT: barriers are real....and solutions need to be ready to get through opportunity windows

Engagement: A Foundation for Everything PCORI Does



Summary: Findings About Engagement

- Engagement is **feasible in all phases of CER and PCOR** and with a variety of stakeholders
- Engagement **influences the design and conduct** of research studies
- Engagement **impacts research in meaningful ways** including acceptability, feasibility, quality, and relevance
- Partner involvement is **dynamic, non-linear, and iterative**, taking different forms over the course of the study
- Engagement **benefits** 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
- There is **more to learn** re: methods and impact of effective and meaningful engagement

Thank You!

