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
Engagement: PCORI’s influence and system change

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

HELPING DETERMINE

Research Partnerships and Capacity

PCOR Skill Building and Infrastructure Development

Research Priorities

Topic Solicitation, Advisory Panels

Funding and Conduct of Research

Merit Review, Research Teams

Dissemination and Implementation

Peer Review, Knowledge Sharing, and Uptake of Findings

Policy and Practice

Impacting Institutional Policies and Clinical Practice
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!