

# Impact and Influence of Engagement in Research: Lessons and Findings from PCORI

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*Health Research Alliance Members Meeting  
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# Objectives

- PCORI's Approach to Engagement
- What We Have Learned
- Benefits to Organizations...and Stakeholders
- Appendix
  - Resources

# PCORI's Approach to Engagement

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# PCORI: Established (and Reauthorized!) to Meet Stakeholders' Needs

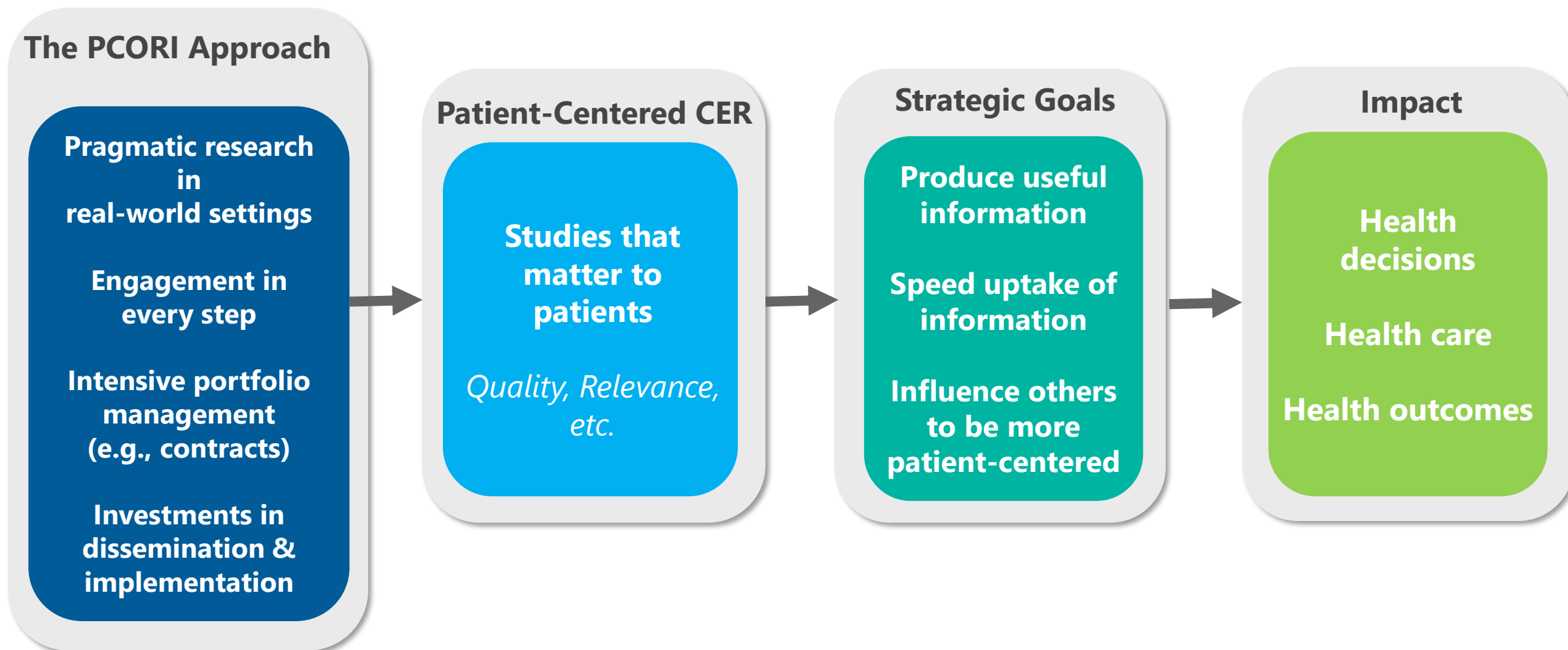


“Research shall be designed, as appropriate, to take into account and capture the full range of clinical and patient-centered **outcomes relevant to, and that meet the needs of, patients, clinicians, purchasers, and policy-makers in making informed health decisions....**”

—from PCORI’s re-authorizing legislation



# The Path to Impact: PCORI's Conceptual Model



# What we mean by...

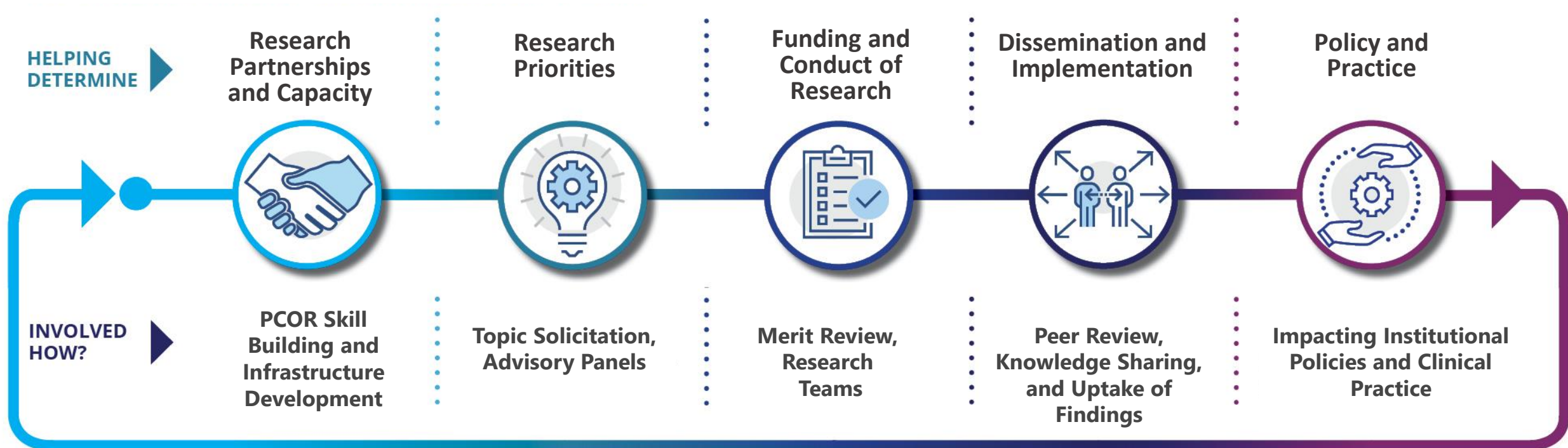
## **Patient-centeredness**

- Research reflects what is important to patients and caregivers
- Questions and outcomes that matter to patients
- Study design is low burden to participants

## **Patient and stakeholder engagement**

- Research partners vs. research subjects
- Active and meaningful partnership between scientists, patients, and other stakeholders with the purpose of improving feasibility, acceptability and relevance
- Forms: Input, consultation, collaboration, shared leadership

# Engagement: A Foundation for Everything PCORI Does



# PCORI created opportunities for Engagement at every step of the research process



## Research Partnerships and Capacity



**410** Eugene Washington Engagement Awards to build patient and stakeholder capacity to partner in research

**253** PCORI Ambassadors

## Research Priorities



**190+** stakeholders have served on PCORI Advisory Panels

**850+** unique organizations have participated in PCORI's workshops, work groups, and roundtables

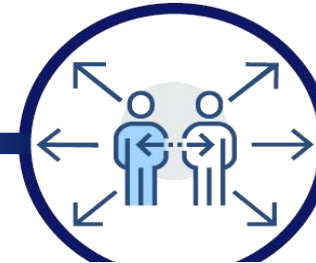
## Funding and Conduct of Research



**600+** patients and other stakeholders have served as merit reviewers

**639** research projects with unique requirements for engagement

## Dissemination and Implementation



**30** awards to actively disseminate and implement PCORI research results using approaches guided by stakeholders

## Policy and Practice



**10** stakeholder convenings to understand context for our portfolio, share findings, and get input on gaps

**13** Hill Briefings and Salons to talk with public policymakers



# PCORI Projects Engage With Partners From Many Communities

## Communities engaged in PCORI research projects: (by percent of projects, N=483)



89%

PATIENTS



65%

ADVOCACY ORGS



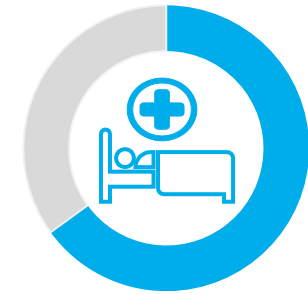
61%

CAREGIVERS



89%

CLINICIANS



65%

HEALTH SYSTEMS

**92% of projects engage with at least 1 of  
these communities**

PCORI projects also engage with subject matter experts (57%), community-based organizations (24%), training institutions (26%), policymakers (24%), payers (25%), industry (8%), and purchasers (5%)

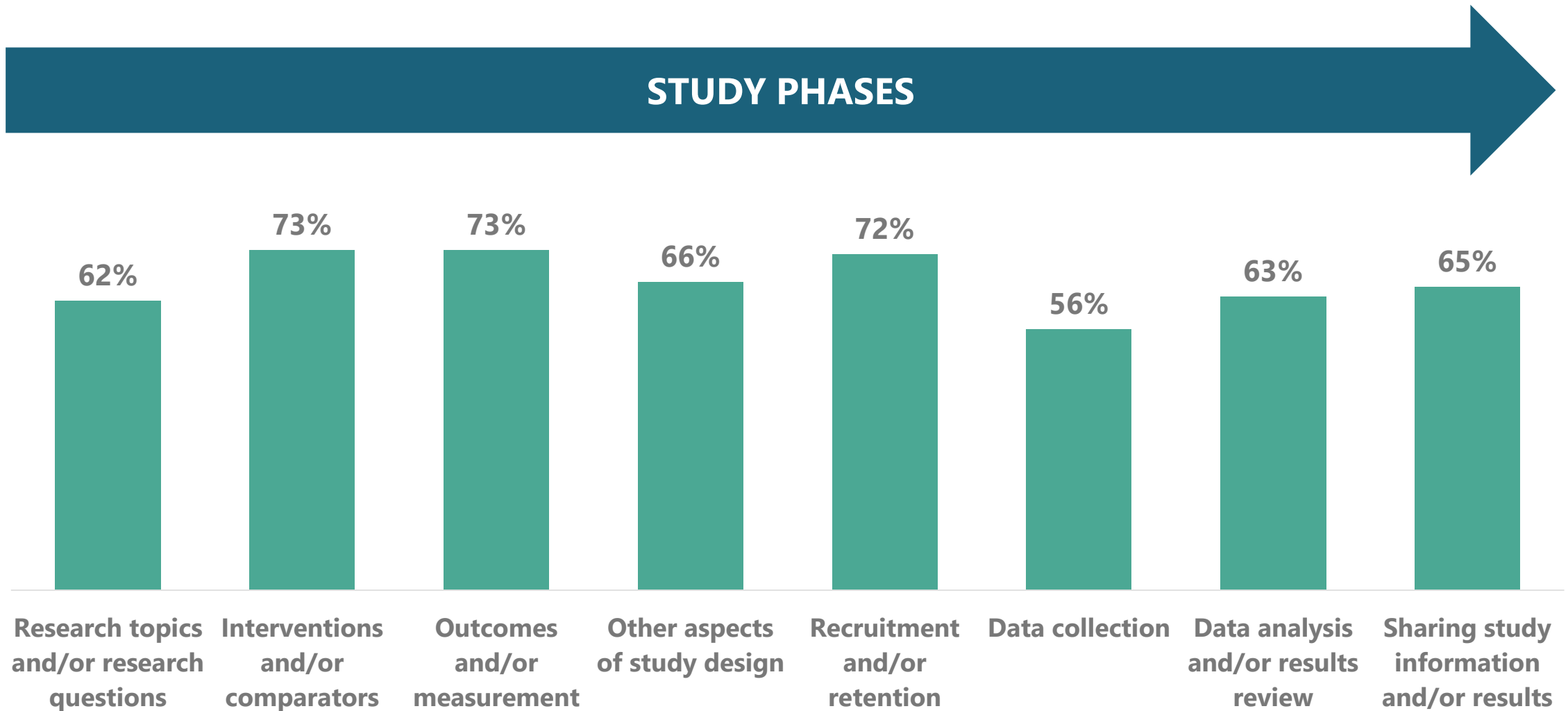
# Projects Engage Partners in Multiple Ways

**% of all projects that use engagement approach:**



# PCORI Projects Engage Partners Throughout the Research Process

Percent of projects that reported engaging partners at each study phase

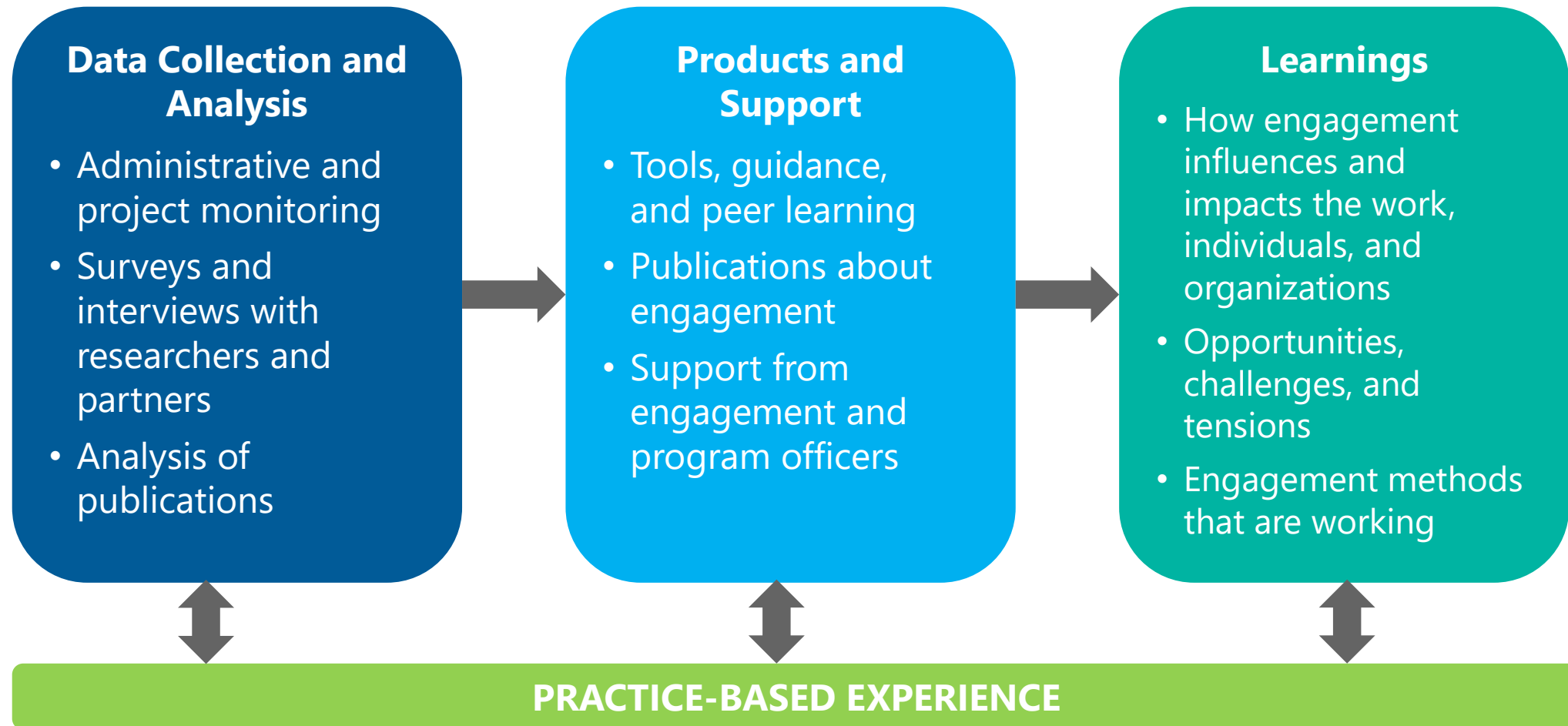


# PCORI's Findings on Engagement

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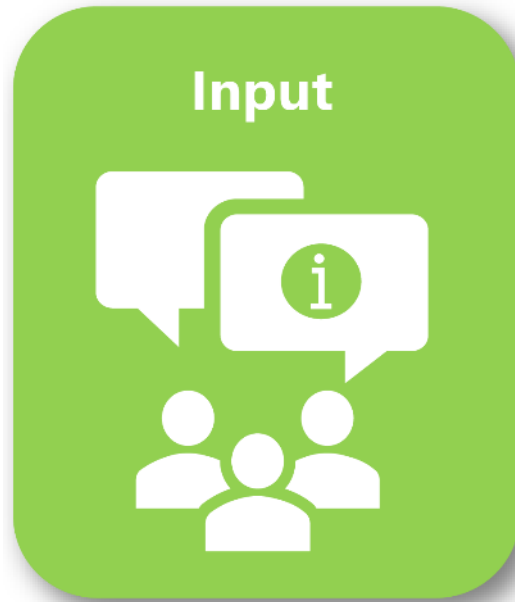
*Impact, influence,  
benefits and challenges*

## *Findings synthesized across efforts to build evidence and inform practice*



# There Is A Continuum Of Engagement Practices

Levels of partners' decision making authority for study design and implementation



EXAMPLE

**Focus Groups,  
Town Halls, Crowdsourcing**



EXAMPLE

**Advisory  
Committee**



EXAMPLE

**Patient Co-I or Multi-  
Disciplinary Executive Team**



EXAMPLE

**Patient Co-PI,  
Patient-led tasks**

Adapted from:

Hanley et al. (2004). Involving the public in NHS, public health and social care research.

Carman et al. (2013). Patient and family engagement: A framework for understanding the elements and developing interventions and policies. *Health Affairs*, 32(2), 223–231.

Arnstein, S. R. (1969). A ladder of citizen participation. *Journal of the American Planning Association*, 35, 216–24

# Ways that Engagement Shapes PCORI-Funded Research Projects



## **User-Orientation & Acceptability:**

studies in which patients and clinicians will be willing to participate based on burden, usability, and alignment with preferences, values, and needs



## **Feasibility:**

interventions, enrollment, and data collection that are more doable in real-world settings



## **Study Quality:**

study rigor, comprehensiveness, and quality of materials and products



## **Relevance:**

results applicable and important for decision-making



## **Engagement Scope & Quality:**

engagement processes are effective, and stakeholders are well equipped

# Engagement Makes Meaningful Differences in Research Projects



## *Core themes emerged across multiple studies of engagement*

### **Engagement influenced...**

- Study conceptualization, execution, materials and dissemination products
- Carrying out study tasks
- Engagement design and practice
- Researchers' understanding of patients, clinicians, and health care organizations

For example, in one recent study about engagement in PCORI-funded research projects, nearly 400 distinct examples of engagement influence were analyzed from in-depth interviews with 60 projects



## Patients & Stakeholders

- More knowledge and enthusiasm for research
- Developed skills and professional opportunities
- Improved personal health and healthcare
- New or better relationships
- Feeling of making a difference

## Communities

- Built trust
- Increased research capacity
- Strengthened relationships among stakeholders
- Increased awareness of different stakeholder perspectives

## Researchers

- Deeper understanding of real-world experiences and concerns of their study populations
- More knowledge about engagement
- Commitment to engagement in the future



# PCORI's Approach Is Helping to Influence the Culture of Research



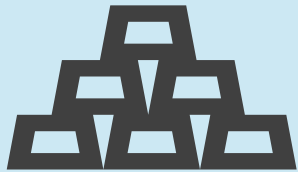
## Change at other organizations and institutions

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

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

# Engagement Can Be Challenging

## Infrastructure and Resources



- Knowledge
- Skills & Experience
- Money
- Time

## People and Teams



- Access
- Ensuring Diversity & Inclusivity
- Relationships & Communication

## Organizations



- Competing Priorities
- Contracting Policies
- IRBs

## Balancing Views and Priorities



- Differing Perspectives
- Value Conflicts
- Internal vs. External Validity

# Future Actions to Build on PCORI's Accomplishments



## Opportunities for Engagement

Expanded approaches and mechanisms to ensure participants are diverse and representative

## Guidance

Update Rubric; explore opportunities to expand standards and criteria for engagement

## Portfolio of Projects and Research

Make engagement easier and more efficient through portfolio management and support

## Science of Engagement

Implement innovative methods, including exploring new funding opportunities

Develop and use validated measures of engagement

## Culture Change

Spread learnings about engagement

# Contact Information

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 [www.pcori.org](http://www.pcori.org)

 @pcori

 /PCORInstitute

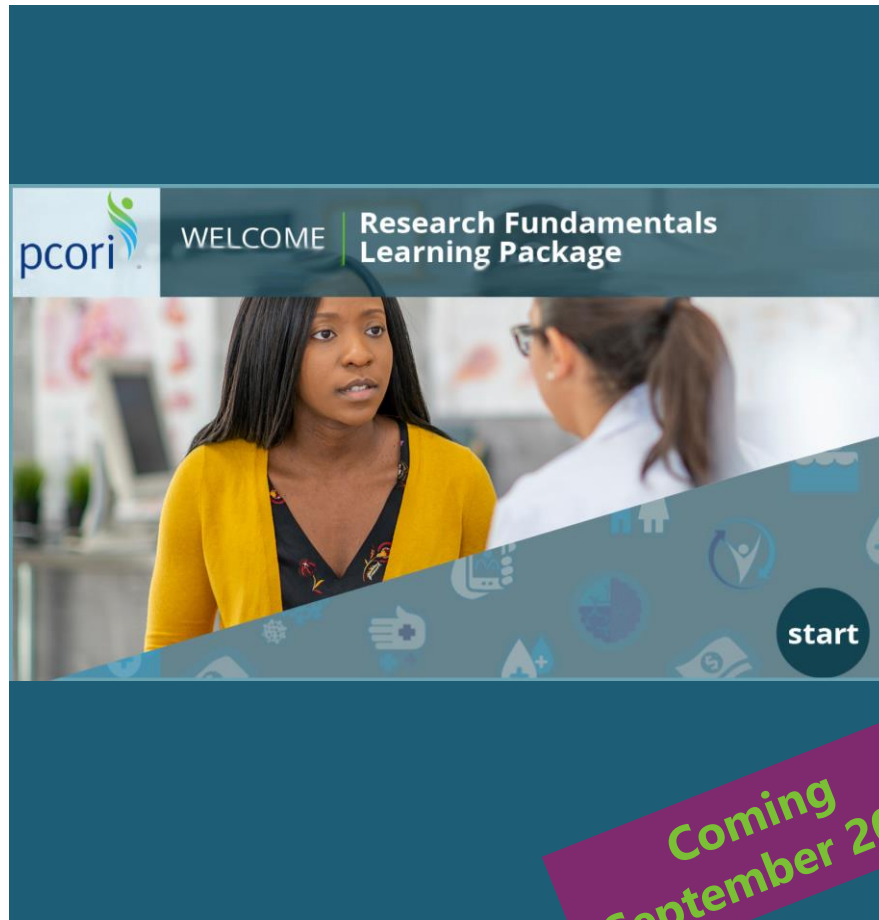
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# Appendix: PCORI Engagement Resources

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# Coming Soon: Research Fundamentals Learning Package

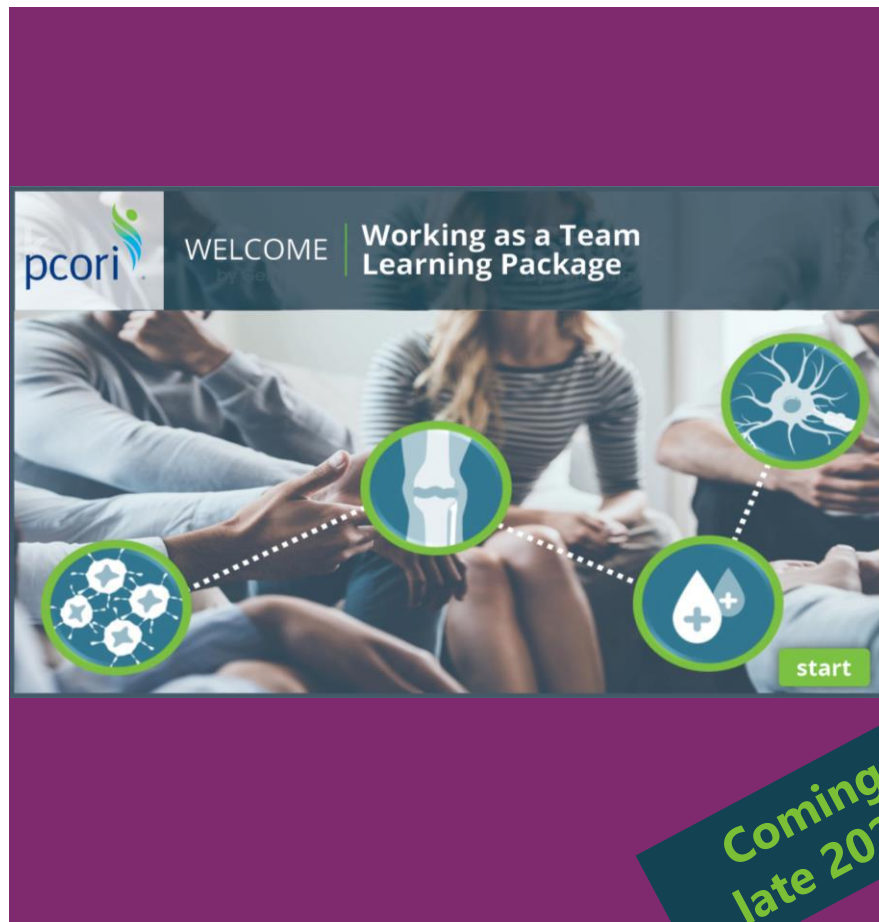


Coming  
September 2020

For **stakeholder partners** who are new to research, this package uses plain language to help learners **understand the language and logic of the research process.**

The ultimate goal is to help all stakeholders, regardless of experience conducting research, to engage with confidence and contribute individual experiences to shape studies from start to finish.

# Coming Soon: Working as a Team Learning Package



Coming  
late 2020

For **new and experienced researchers and stakeholder partners**, this package offers **practical guidance on how to work successfully as a unified team** where everyone is engaged and contributes confidently throughout the research process. From conducting meetings to resolving conflict, the package helps team members in any role to work collaboratively during a study.



# PCORI Engagement Resources

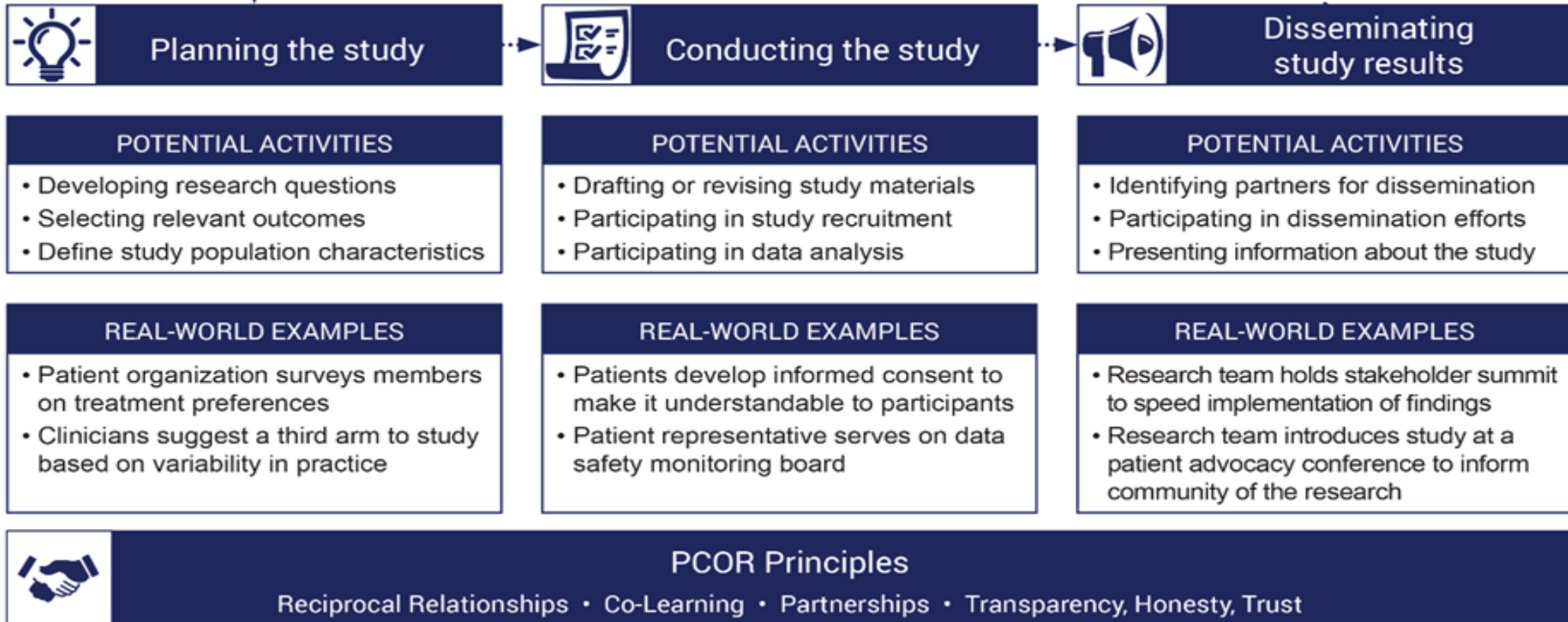


- [Ambassadors Program](#)
- [Budgeting for Engagement Activities](#)
- [Compensation Framework for Engaged Research Partners](#)
- [Engagement Rubric](#)
- [Eugene Washington PCORI Engagement Awards](#)
- [Methodology Report](#)
- [PCORI in Practice Webinar Series](#)
- [Sample Engagement Plans](#)
- [Updated Engagement Plan template](#)

**COMING SOON:**  
Guidebook on  
Engaging with  
Research Partners  
about Data and  
Analysis



# How to Engage? Engagement Rubric Overview



**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

# Engagement in Health Research Literature Explorer



- This searchable, catalogued resource for peer-reviewed literature can help identify **publications about engagement**
- It contains over 1,000 articles that include:
  - Examples of engagement in health research
  - Evaluations of engagement in health research
  - Syntheses of engagement methods and impacts
  - Frameworks, editorials, and commentaries on engagement in health research
- Articles can be filtered by communities that were engaged, phase of research engagement (e.g., study design, recruitment, etc.), and publication year
- **Link:** [Engagement in Health Research Literature Explorer](#)

Refine Your Results

^ Topic

- Example of Engagement in Health Research (528)
- Detailed Description of Engagement in Health Research (357)
- Framework, Editorial, Commentary (310)
- Evidence for Engagement (164)

∨ Stakeholder Involvement

∨ Phases of Research Engagement

∨ Year

# Engagement Tool and Resource Repository



VISIT OUR NEW PCOR  
**Engagement Tool and Resource Repository**

A searchable catalogue of work products from Research Awards and Engagement Awards to facilitate engagement in research.

Resources range from kick-off meeting agendas, to Research 101 trainings, to committee charters, and more!

**Link:** [Engagement Tool & Resource Repository](#)