



# Science of Engagement Initiative

## REQUEST FOR INFORMATION

RFI# SoE-2021

9/27/2021

KEY DATES	
Request for Information Released	9/27/2021
Information Due	11/19/2021

## Issued By

Patient-Centered Outcomes Research Institute (PCORI)

## About PCORI

In 2010, Congress authorized PCORI as a nonprofit, nongovernmental organization incorporated in the District of Columbia. The authorizing law establishes PCORI's purpose, significant parts of its governance structure (including the appointment of PCORI's Board of Governors and Methodology Committee) and outlines key responsibilities and requirements of PCORI. The authorizing law was amended in legislation that was signed into law on December 20, 2019.

PCORI is charged with helping patients, clinicians, purchasers, and policy makers make better-informed health decisions by "advancing the quality and relevance of evidence about how to prevent, diagnose, treat, monitor, and manage diseases, disorders, and other health conditions." It does this by funding research guided by patients, caregivers, and the broader healthcare community, which results in high-integrity, evidence-based information. PCORI's strong patient-centered orientation directs attention to individual and system differences that may influence research strategies and outcomes.

PCORI is committed to transparency and a rigorous stakeholder-driven process that emphasizes patient engagement. PCORI uses a variety of forums and public comment periods to obtain public input to enhance its work.

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## Purpose

**This notice is for exploratory purposes** to inform the development of potential future funding initiatives. In furtherance of PCORI's strategic imperative to engage patients and stakeholders, research funding opportunities to study the science of engagement could expand the evidence base on the approaches for effectively engaging diverse patients and stakeholders throughout the research process. PCORI seeks to gather information on questions around engagement that it believes are priority topics for further research. Further, PCORI requests feedback regarding factors to consider in connection with a potential funding initiative to advance research on engagement.

This request for information (RFI) should not be construed as an intent, commitment, or promise to issue funding opportunities or to fund any project. PCORI will use information submitted by respondents at its own discretion and will not necessarily provide comments to respondents. PCORI will not reimburse RFI respondents for any expenses associated with responding to this RFI, though PCORI sincerely appreciates respondents' efforts and input.

## **Background**

### **PCORI's authorizing legislation and emphasis on patient and stakeholder engagement**

PCORI was authorized by Congress in 2010 and reauthorized for an additional 10 years in 2019, as a nonprofit, nongovernmental organization. PCORI produces high-quality, reliable evidence from comparative clinical effectiveness research (CER) guided by patients, caregivers, and the broader healthcare community, in order to improve health care and patient outcomes. Engagement of patients and other stakeholders as partners throughout the entire research process is one of PCORI's five strategic imperatives for achieving its mandate, both in terms of how PCORI conducts its work as an organization and in the research we fund.

Consistent with its strategic imperative, PCORI has engendered extensive patient and stakeholder engagement in many ways, including: (a) within its own processes, (b) funding research done in partnership with patients and other stakeholders, and (c) funding Engagement Awards to support communities' efforts to build the capacity to participate in research. Due to the lack of an extensive evidence base regarding the manner to best engage patients and stakeholders at its inception, PCORI has taken a nonprescriptive, practice-based approach to engagement. By studying PCORI-funded projects, PCORI has produced salient findings about the nature of engagement, the ways engagement can affect study design and conduct, and its challenges. Although evidence on engagement approaches and ultimate outcomes of engagement is growing, it remains limited.

At this juncture, PCORI is exploring a new funding initiative to build a stronger evidence base on the approaches for engaging diverse patients and stakeholders effectively in different circumstances/contexts. The current thinking regarding this proposed funding initiative is to fund studies focused on the science of engagement—that is, the systematic study of methods for and outcomes of engagement to inform high-quality, patient-centered research—to produce evidence-based support and guidance, potentially through two complementary, interrelated funding approaches described in greater detail below.

## **Science of Engagement Overview**

PCORI engages all relevant stakeholders to identify and drive PCORI's funding priorities, to conduct and disseminate the results of PCORI-funded research, and to understand and synthesize what we are learning about PCORI's approach to engagement. This helps us inform and influence the field more broadly.

## PATIENTS AND OTHER STAKEHOLDERS ARE INVOLVED IN...



PCORI has committed to engagement in all aspects of its work (as shown in the figure above), to facilitate research that reflects the needs and values of patients, caregivers, clinicians, and other stakeholders. PCORI is also committed to improving the feasibility of doing studies in real-world settings and ensuring the relevance of PCORI-funded studies to people using the findings.<sup>1</sup> The ultimate intention is that PCORI-funded research will be more rapidly and widely used to improve healthcare delivery and health outcomes. While many definitions of “successful” engagement exist, this includes engagement that meaningfully influences study design and conduct, and engagement experiences that are beneficial to both stakeholders and researchers.

PCORI’s work has helped to stimulate the science of engagement field. In fact, since PCORI’s founding, frameworks and models for how to engage have proliferated, along with growing knowledge about the benefits of engagement. By studying its funded projects, PCORI has recently produced findings about the iterative, dynamic, and multifaceted nature of engagement; the ways engagement can affect study design and conduct; and the challenges involved in engagement, including:

- Engagement is feasible in all phases of patient-centered CER, and with a variety of stakeholders.<sup>2</sup>
- Engagement often occurs along a continuum ranging from patient and stakeholder input to consultation to collaboration or shared leadership.<sup>3</sup>
- Engagement can influence the design and conduct of research studies in meaningful ways (e.g., the content, style, and format of study materials or dissemination products) and also has downstream impacts on the research including user orientation and acceptability, feasibility, quality, relevance, and the scope and quality of engagement.<sup>4</sup>

<sup>1</sup> Engagement: What We’ve Learned. The Patient-Centered Outcomes Research Institute website. <https://www.pcori.org/sites/default/files/PCORI-Board-Meeting-Presentation-Slides-120919.pdf>. Presented to PCORI Board of Governors December 19, 2019. Accessed September 13, 2021.

<sup>2</sup> Forsythe LP, Carman KL, Szydowski V, et al. Patient Engagement in Research: Early Findings From The Patient-Centered Outcomes Research Institute. *Health Aff (Millwood)*. 2019;38(3):359-367. doi:10.1377/hlthaff.2018.05067

<sup>3</sup> Carman KL, Dardess P, Maurer M, Sofaer S, Adams K, Bechtel C, and Sweeney J. Patient And Family Engagement: A Framework For Understanding The Elements And Developing Interventions And Policies. *Health Aff*. 2013;32(2): 223-23. doi.org/10.1377/hlthaff.2012.1133

<sup>4</sup> Maurer M, Mangrum R, Hilliard-Boone T, Amolegbe A, Carman KL, Forsythe L, Mosbacher R, Lesch JK, Woodward K. (accepted for publication). Understanding the Influence and Impact of Stakeholder Engagement in Patient-Centered Outcomes Research: A Qualitative Study. *Journal of General Internal Medicine*.

- Engagement can benefit patient and stakeholder partners, communities, and researchers involved.<sup>5</sup>
- Known challenges need to be addressed, including those related to infrastructure and resources, people and teams, organizational policies, and balancing views and priorities.<sup>6</sup>

Despite the growing body of evidence on engagement practices, substantial gaps remain in the development of rigorous evidence in key areas including:

- Effective engagement methods, or how to do engagement well in general and within specific populations and settings
- The ultimate outcomes of engagement or the impact of engagement.

PCORI is considering a Science of Engagement (SoE) Funding Initiative to provide answers to critical research gaps that it believes should be addressed in order to make engagement more effective and widespread.

### **Science of Engagement Funding Initiative: Request for Information**

The purpose of this RFI is to obtain input from potential applicants, patients, and other stakeholders and organizations who participate in research or engage communities. Through the information received in response to this RFI, PCORI hopes to learn (a) the research areas that would provide information that would be the most useful to research teams for implementation of more effective engagement and (b) the resources and facilitators necessary to successfully support studies that address these research topics. The topics that could advance the science of engagement—especially in the context of patient-centered CER—are reflected in the table below. In responding to the specific questions at the end of this document, please consider these potential topics when providing your feedback.

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<sup>5</sup> Hemphill R, Forsythe LP, Heckert AL, Amolegbe A, Maurer M, Carman K, Mangrum R, Stewart L, Fearon N, and Esmail L. What Motivates Patients and Caregivers to Engage in Health Research and How Engagement Affects Their Lives: Qualitative Survey Findings. *Health Expectations*. 2020; 00: 1– 9.

<sup>6</sup> Heckert A, Forsythe LP, Carman KL, et al. Researchers, patients, and other stakeholders' perspectives on challenges to and strategies for engagement. *Res Involv Engagem*. 2020;6:60. Published 2020 Oct 7. doi:10.1186/s40900-020-00227-0

## Potential Topics of Inquiry to Understand the Science of Engagement

**What defines successful engagement, and for whom?** What outcomes demonstrate whether engagement has achieved the stated aims or goals? What impact does engagement have on longer-term aims (e.g., improving decisions and health outcomes) and how can impact be increased and sustained?

**How can engagement be measured? What indicates that a study is patient-centered?** More robust evidence also requires the development and use of validated measures of engagement, patient-centeredness, and their influence on research conduct, and impact and uptake of results.

**What are the approaches that support and achieve successful engagement?** For example, what specific tools and interventions support engagement, particularly what approaches support diversity, equity, and inclusion in both engagement and in research findings.

**Which approaches should be combined to achieve engagement aims?** PCORI knows from other fields and implementation science specifically, that many actions are often required to achieve a specific goal and that doing just one is insufficient.

**Under which conditions do approaches work best and how should they be modified and resourced for different contexts, settings, and communities?** This question focuses on the context in which a study or engagement is being carried out (e.g., the type of study, patient and stakeholder partners, history of (mis)trust, experience with research partnership).

The SoE Funding Initiative could involve two complementary, interrelated research program approaches:

- Stand-alone research awards on engagement in research
- Studies within a study (SWAS) for PCORI CER awards—the funding of an additional study in conjunction with a CER study

Many of the key evidence gaps in engagement (summarized in the table above) require a body of evidence derived from various methodological approaches and different contexts (e.g., populations, settings) to examine relationships between engagement approaches and a range of measurable outcomes. Both potential research program approaches could offer research teams the flexibility to determine the most appropriate approach (e.g., comparative, quasi-experimental, observational) based on the research question. Conceivably these complementary funding initiatives could help to address high-priority knowledge gaps that are otherwise unlikely to be addressed.

### **Funding Stand-alone Research Awards**

Stand-alone research awards on engagement could offer an opportunity for multi-stakeholder study teams to answer critical research questions about engagement using a variety of study designs, including hypothesis-driven research in more controlled settings (such as comparative experimental studies) and exploratory or developmental research in less controlled settings (such as quasi-experimental or observational studies).

Stand-alone studies that focus exclusively on learning about engagement could offer opportunities to:

- Study engagement across a wide set of research-related activities (e.g., design and conduct of CER studies, topic generation and prioritization, research application review)
- Develop and test new and existing approaches to engagement for different study types, populations, and settings
- Develop and validate a variety of process and outcome measures of engagement, including patient-centeredness, and assess their ability to capture diverse perspectives.

### **Funding Studies Within a Study (SWAS)**

Some research questions about how to do engagement or how it affects study success may be best answered in the context of a CER study. Examples include understanding which practices are (or are not) conducive for engaging diverse stakeholders and how best to engage stakeholders in supporting recruitment for a study. SWAS would involve the funding of additional studies to examine the science of engagement in conjunction with PCORI-funded CER studies. PCORI is still evaluating the manner in which SWAS could be integrated into existing studies.

SWAS could serve to:

- Capitalize on real-world settings, particularly where engagement approaches are similarly valued or where real-world application and measurement are critical
- Generate knowledge to both improve the CER project in which the study is embedded and contribute to the field of engagement research
- Enhance the relevance and applicability of the evidence about engagement generated by embedding it within clinical research.

### **Questions to Consider**

PCORI would appreciate your response to any or all the following questions:

- In reference to the table above, Potential Topics of Inquiry to Understand the Science of Engagement, do you feel these are the right topics? Are other topics or areas of inquiry missing? How would you prioritize or stage addressing these topics?
- What methods and study designs would be appropriate for producing evidence to address the areas identified in the Potential Topics of Inquiry to Understand the Science of Engagement table? Can you provide any illustrative examples?
- What innovations in research approaches are needed to most effectively produce the evidence needed?
- What outcomes are important and appropriate for studies of engagement? What measures are most important to develop, validate, and use to quantify and to understand the quality and impacts of patient and stakeholder engagement in health research?
- What challenges do you foresee for **stand-alone research studies** on engagement? What award characteristics (e.g., structures, requirements, areas of flexibility), resources, or other supports would facilitate stand-alone research studies?
- What challenges do you foresee for **SWAS** on engagement? What award characteristics (e.g., timing relative to parent study, requirements), resources, or other supports would facilitate stand-alone research studies?
- What questions do you have about the potential development of a future funding initiative that PCORI should address as we develop materials for potential funding opportunities?



- Would you or your organization be interested in pursuing this funding initiative, including as a partner, based on the above description? Why or why not? If not, please elaborate on the reasons.
- What should PCORI keep in mind to ensure that these potential research opportunities (stand-alone research awards on the science of engagement, and SWAS) are inclusive of and accessible to all types of organizations and communities? How can we best support the community to ensure high-quality applications?
- How can PCORI promote connections between organizations, communities, and qualified researchers for this potential future funding initiative if not currently available to them?
- Science of engagement research projects (stand-alone research awards or SWAS) may vary in intensity. What level(s) of funding for a science of engagement research project would you or your organization consider pursuing? Check all that apply.
  - \$250,000-\$750,000
  - \$750,000-\$1.25 million
  - \$1.25million-\$2 million
  - More than \$2 million
  - Depends on the project, but no less than \$\_\_\_\_\_
  - Depends on the project, but no more than \$\_\_\_\_\_
- Science of engagement research projects (stand-alone research awards or SWAS) may vary in length. What timeframe for a science of engagement research project would you or your organization consider preferable? Check all that apply.
  - One year
  - Two years
  - Three years
  - Four years
- Please select the stakeholder group you primarily identify with to help PCORI contextualize subsequent responses:
  - Patient, caregiver, disease or condition-based advocacy organization
  - Researcher
  - Clinician
  - Clinic, hospital, health system representative
  - Community-based organization representative
  - Purchaser (small or large employers) representative
  - Payer (public or private insurance) representative
  - Life sciences industry representative
  - Policy maker (government official)
  - Training institution (nonresearch health professions educator) representative
  - Subject matter expert—*Please describe:*
  - Other—*Please describe:*

## General Comments

We welcome your general comments on any aspect of the funding initiative as described above.

## Submission Instructions

Please submit responses to this RFI as a PDF, emailed to [SoE-RFI@pcori.org](mailto:SoE-RFI@pcori.org), by November 19, 2021. **Responses should not exceed 10 single-sided pages** (single-spaced, 12-point font minimum). Brevity and structured format, such as bulleted items, are encouraged.

All information must be furnished in writing. All proprietary information should be marked as such; responses will be held as confidential. PCORI will provide confirmation of response submission, but respondents will not receive individualized feedback.

Please submit any questions or inquiries that would help inform your response to this RFI to [SoE-RFI@pcori.org](mailto:SoE-RFI@pcori.org). PCORI will post responses to frequently asked questions at [www.pcori.org/SoE-FAQ](http://www.pcori.org/SoE-FAQ) on a rolling basis.

PCORI views this RFI as an opportunity for interested individuals and organizations to contribute information based on their knowledge and experience.

PCORI encourages participation, acknowledging that participation is completely voluntary. You may choose to answer all or some of the questions above.

## Due Date

Responses are due no later than 4 pm (ET) on **November 19, 2021**.