

PCORI's Foundational Expectations for Partnerships in Research



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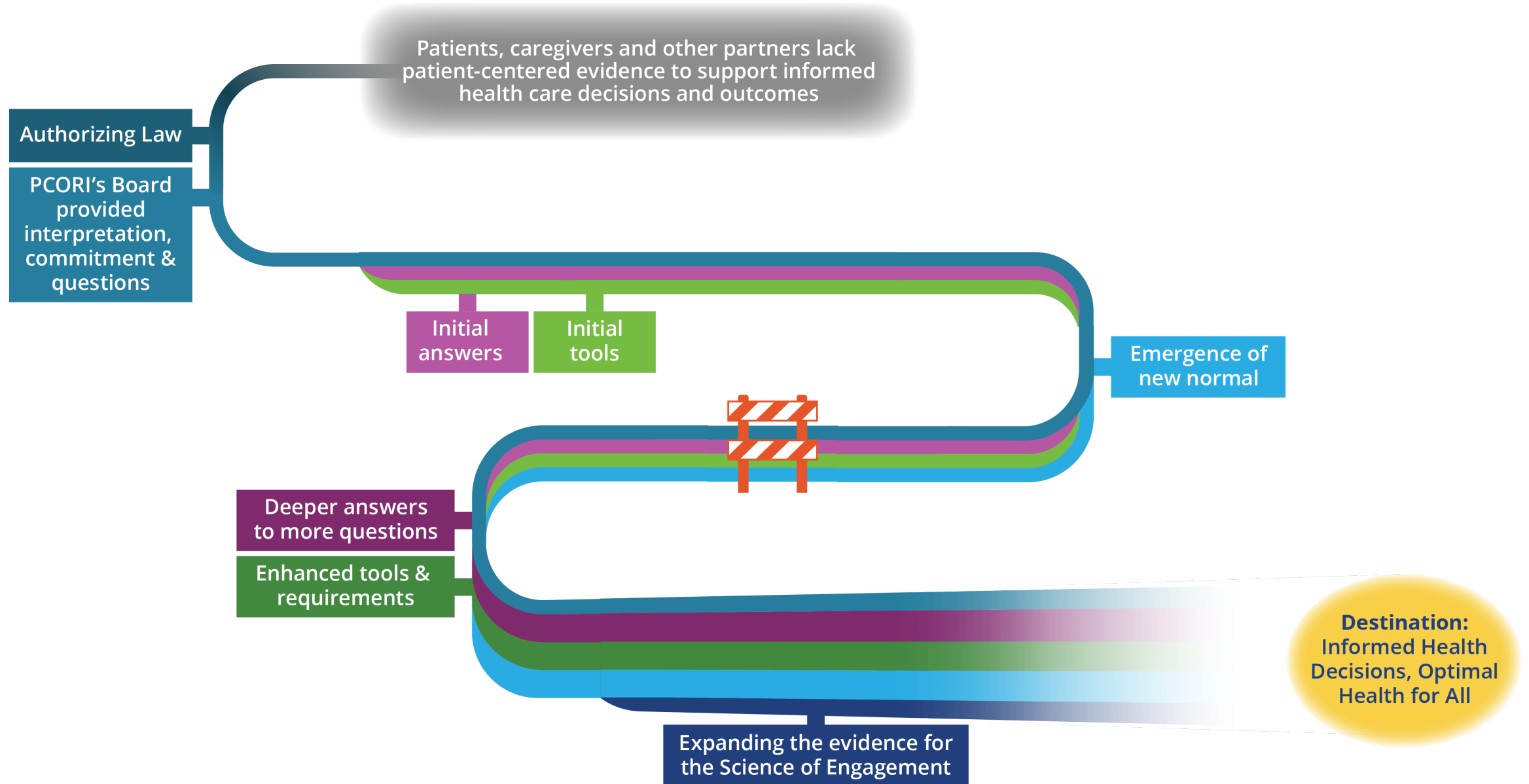
Forum on Drug Discovery, Development, and Translation

Person-Centered Clinical Cancer Research: A Workshop

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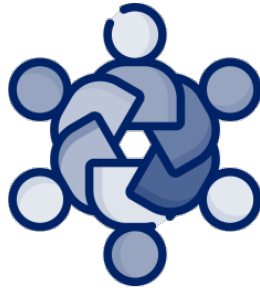
PCORI's Engagement Journey: Developing the Science and Practice



Initial Expectations: Why and How Engagement Is an Essential Element to Produce Patient-Centered CER



Research
questions &
processes
patients want



Representative
study samples
recruited &
retained



Greater
relevance
and quality



Trustworthy
information

Part of PCORI's holistic approach to CER that includes dissemination, implementation, and infrastructure

Long-Standing Goals of PCORI's Science of Engagement

- Support our awardees and engaged partners
- Improve engagement practice with individuals and organizations
- Understand what happens when you engage patients and stakeholders in research
- Develop robust evidence about the influence and impact of engagement in research on the:
 - Design and conduct of the studies,
 - Individuals and institutions involved, and
 - Use and uptake of the evidence
- Influence others in how to conduct and study engagement

Initial Answers

To Many Questions About Engagement Practices, Impact & Challenges

The Need

Many questions about engagement feasibility, practices, impact and challenges

The Step Forward

Engagement is **feasible in all phases** and with a variety of partners.

Partner involvement is **dynamic, non-linear and iterative**, taking different forms.

Trust is a lynchpin for engagement.

Engagement is **complex and has challenges** that can be addressed.

Engagement **influences the design and conduct** of research studies.

Engagement **impacts research in meaningful ways** — e.g., acceptability, feasibility, quality, relevance.

Engagement **benefits** the patient and stakeholder partners, communities and researchers involved.

The Step Forward: Initial Guidance and Tools

2014	Engagement Rubric	Initial guidance to PCORI applicants and awardees on engagement role of Engagement Officer is created
2015	Compensation Framework	Guidance on how to compensate patient partners
2017	Engagement Literature Database	Searchable database of citations for peer-reviewed articles about engagement in health research
2018	Updated Engagement Plan	Updated Engagement Plan reporting integrated into research projects
2019	Engagement Tools Repository	Engagement tools and resources developed/used by PCORI awardees made accessible
2020	Engagement Training Tools	Research Fundamentals, Building Effective Multi Stakeholder Research Teams, on-demand web-based training resources

What Measures Are Available and Appropriate?

Measuring What Matters for Engagement

The Need

Dearth of measures to assess engagement in health research

Little consensus on what engagement measures were needed by whom and for what purposes

What We Learned

Identified published instruments, few of which were validated

Developed a measurement framework to consolidate information on existing and needed measures for engagement, comprised of five domains and 27 concepts

The Step Forward

Showing the gap between what stakeholders want to measure and what they can measure with existing measures and instruments

Using the measurement framework to guide research on engagement and measure development via the Science of Engagement PCORI Funding Announcement (PFA)

How To Navigate Challenging Conversations?

Managing Different Viewpoints and Priorities

The Need

PCORI awardees repeatedly asked for more concrete guidance on navigating different viewpoints and priorities when planning and conducting their CER studies.

What We Learned

Researchers saw different viewpoints as a strength and opportunity to learn, rather than a challenge to avoid.

Teams used a variety of collaborative or consensus-based approaches to reach decisions.

Different viewpoints and priorities often emerged early and related to ethical or pragmatic issues.

No single structure was a greater facilitator or barrier to managing different viewpoints.

The Step Forward

PCORI updated its engagement guidance and resources with concrete, evidence-backed information.

Can Engagement in Research Influence CER Uptake?

Engagement and Use of CER Evidence



The Need

Unclear relationship between engagement in research and use and uptake of CER findings

What We Learned

Partners actively contributed to PCORI-funded dissemination and implementation projects in ways that were similar to partner contributions in research studies.

Partner contributions facilitated use of study findings along a pathway to uptake:

- Generation of relevant study findings
- Strategic distribution of findings
- Integration, implementation and active dissemination of findings

The Step Forward

PCORI demonstrated that engagement can influence the pathway to uptake of CER evidence and identified practices that facilitate use.

The Need: Aggregate The Body of Evidence To Date in Requirements and Resources

The Foundational Expectations for Partnerships in Research

A comprehensive engagement guidance based on current body of evidence, addressing opportunities, challenges, and tensions related to engagement in research



www.pcori.org/Foundational-Expectations

Requirements

- Enhanced requirements for engagement approaches
- Ongoing review and assessment of engagement
- Strengthen budget for engagement

Resources

- Comprehensive online guides that include definitions, benefits, and practical tools
- Practical actions for implementation
- Examples from PCORI-funded projects
- Links to specific resources for each expectation

Ongoing Need: Fill Gaps in Knowledge and Evidence About Engagement

Important gaps in knowledge and evidence:

- More reliable and valid measures of engagement (process and outcomes)
- More information about what are effective engagement activities and approaches
- More information about what works for whom, under what conditions and with what resources
- More information on how to sustain partnerships
- More evidence for engagement throughout the research life-cycle

The Step Forward: Expanding the Evidence for the Science of Engagement

Science of Engagement PFA

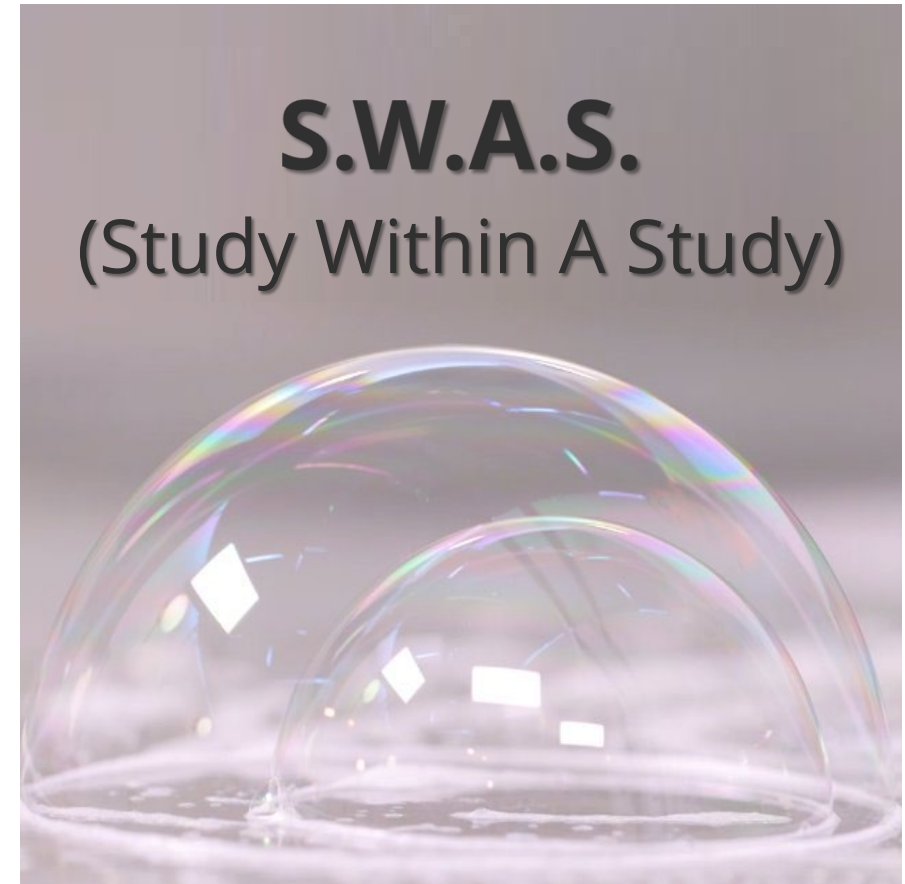
22 projects to date

9 Measures Projects

- 3 New Measures
- Improving 6 Existing Measures

13 Eng't Methods Projects

- Developing 7 New Approaches
- Comparing 6 Approaches



PCORI's Tools and Resources to Support Engagement in Research

Engagement in Health Research Literature Explorer

A searchable database of peer-reviewed article citations to help you discover best practices, lessons learned and emerging insights on patient engagement in health research



Scan Now

Find more at: pcori.org/engagement-resources

The collage features three main PCORI resources:

- Engagement in Health Research Literature Explorer:** A searchable database of peer-reviewed article citations to help you discover best practices, lessons learned and emerging insights on patient engagement in health research.
- Building Effective Multi-stakeholder Research Teams:** A guide titled "WELCOME" that discusses how PCORI has transformed research by making engagement tools available to researchers and other partners.
- Research Fundamentals Learning Package Navigator:** A video player interface with a green background and a compass rose. It includes two buttons: "I'm new here. Let's get started." and "I've been here before. Skip the Introduction." There is also an "Accessibility Instructions" link and a "Transcript" option.

The Cancer Partner PFA



PCORI seeks to fund high-impact, patient-centered CER projects **led by researcher and community partnerships** to focus on advancing care and outcomes across different phases of **the cancer care continuum**.

Goal: To inform health decisions for patients, caregivers and communities in the United States experiencing high burdens and practice variations in cancer care and outcomes

**The Cancer
Partner PFA
Preannouncement**



Thank you!



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