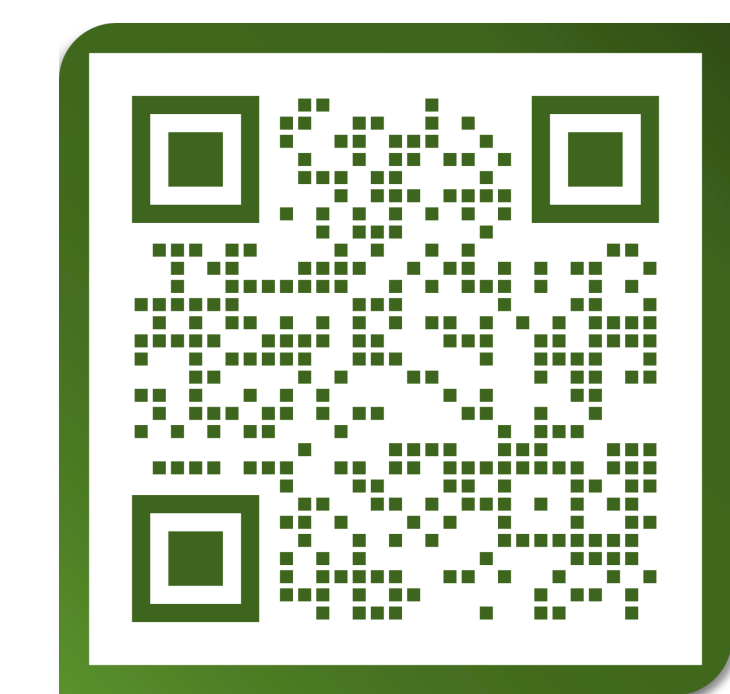




CREATING MEANINGFUL AND EFFECTIVE PARTNERSHIPS IN PATIENT-CENTERED COMPARATIVE CLINICAL EFFECTIVENESS RESEARCH: THE PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE'S FOUNDATIONAL EXPECTATIONS FOR PARTNERSHIPS IN RESEARCH



BACKGROUND

The Patient-centered outcomes research institute (PCORI) funds patient-centered comparative clinical effectiveness research (CER) which aims to produce evidence-based information to help people make informed healthcare decisions and improve outcomes that matter to patients. PCORI has created an ecosystem to support engagement in research, generate evidence about the best approaches and support needed for engagement, and the immediate impact on clinical research and more distal impacts on health care. The *Foundational Expectations for Partnerships in Research* respond to the need to **incorporate the latest evidence (see Fig. 1) on engagement from awardees and the larger research field to develop the critical building blocks of meaningful and effective engagement. PCORI systematically translated the knowledge gained over the past decade into a more cohesive framework for engagement (see Fig. 1).**

METHODS

Project activities were conducted over two years. They were iterative and included an environmental scan of engagement guidance and literature generated by PCORI, PCORI awardees and organizations other than PCORI. Focus groups and interviews with research teams and experts in diversity, equity and inclusion, and a large convening with researchers, partners, patients and other thought leaders to generate a vision and proposed content were conducted (see Fig. 2).

PCORI's Foundational Expectations for Partnerships in Research have **broad applicability, are specific and actionable, and allow for flexibility, creativity and continuous learning** around engagement.

Figure 1. Foundational Expectations for Partnerships in Research



Figure 2. Building a Body of Evidence for Engagement in Research

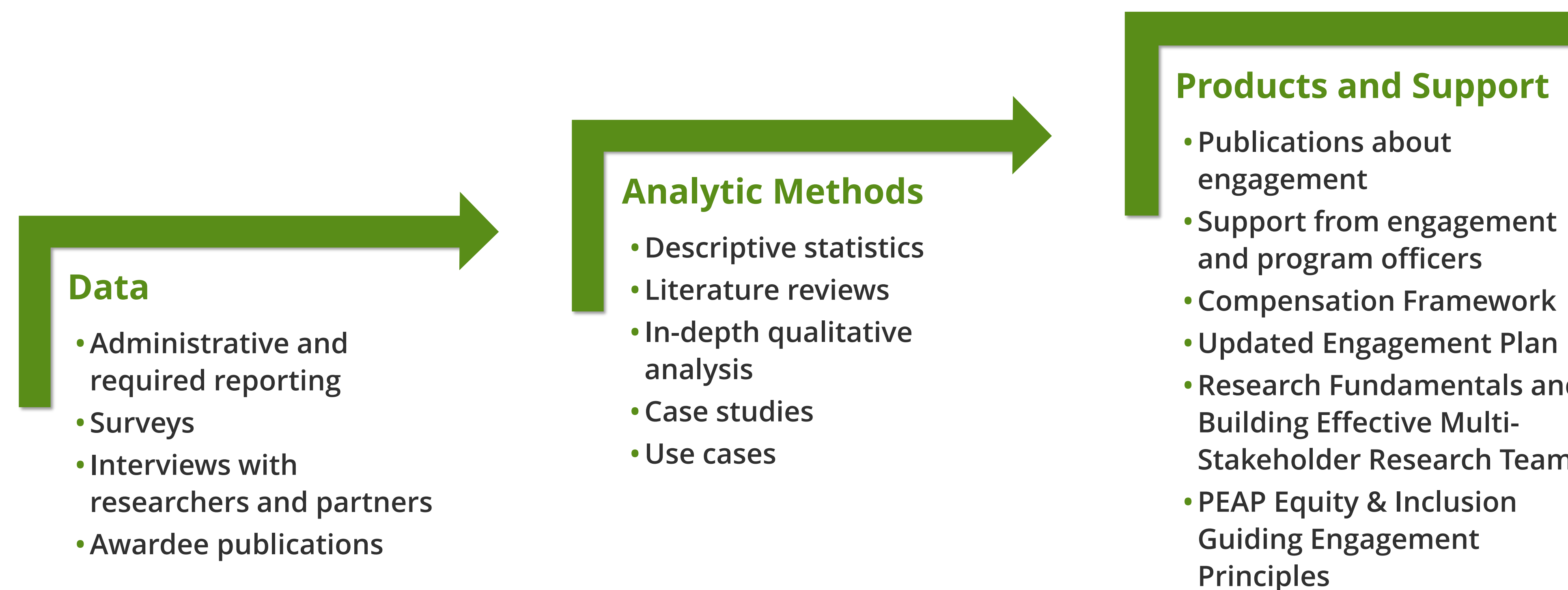
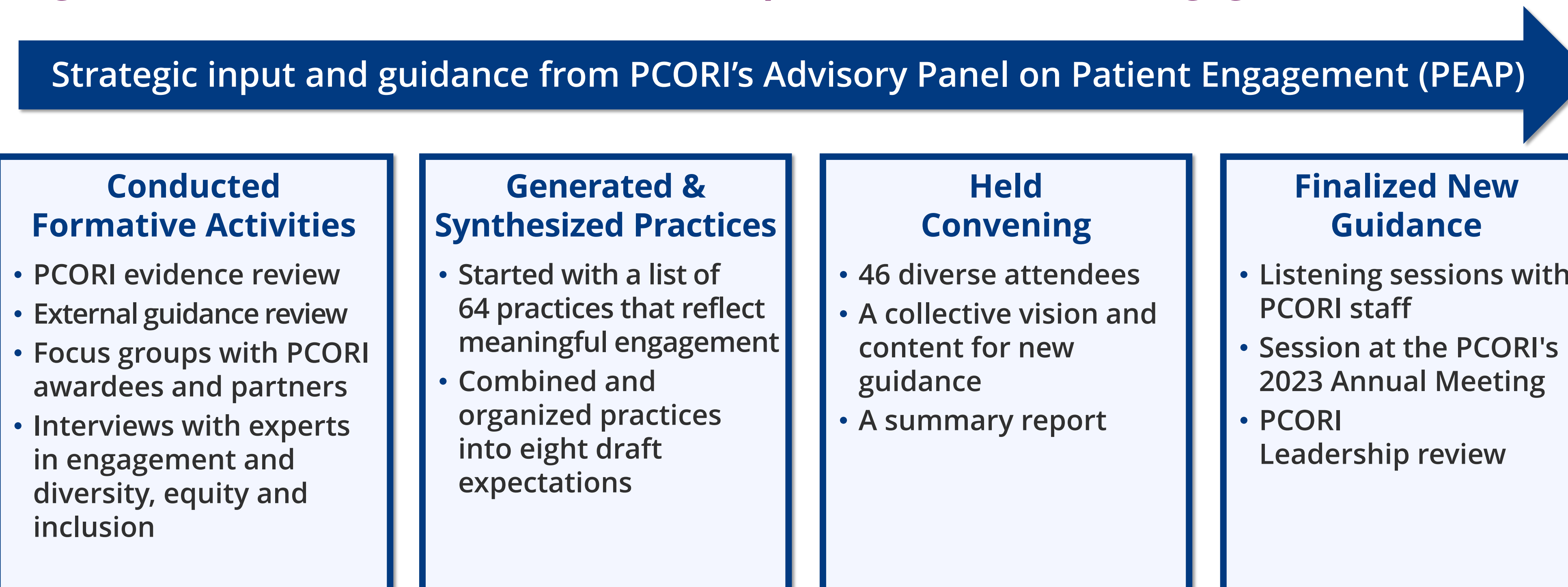


Figure 3. Collaborative Process to Develop New Guidance For Engagement in Research



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Figure 4. Brief Description of Each Expectation

Expectation	Brief Description
Diversity & Representation	Include partners, organizations, researchers, and other team members who reflect the diversity of patients and communities
Early & Ongoing Engagement	Ensure partners contribute early and throughout the study from planning to disseminating results
Dedicated Funds for Engagement & Partner Compensation	Allocate funds to support engaging with partners and compensate partners for their time, expertise and perspectives
Build Capacity to Work as a Team	Identify skills, strengths and barriers to engagement and provide team members with information, training and support
Meaningful Inclusion of Partners in Decision Making	Use engagement structures that include partners in decision making throughout all phases of the project, with consideration of the project's goals, scope and scale
Ongoing Review & Assessment of Engagement	Gather input and feedback throughout the project to identify what is working well and what could be improved, and then adjust engagement approaches as needed

CONCLUSIONS

The *Foundational Expectations for Partnerships in Research* are intended to drive support for greater engagement and diversity in research and provide critical information, tools and resources to investigators, patients, clinicians and other partners on engagement in PCORI-funded research and research-related activities, as well as the broader field.