

Metrics and Measurement in Community Engaged Research

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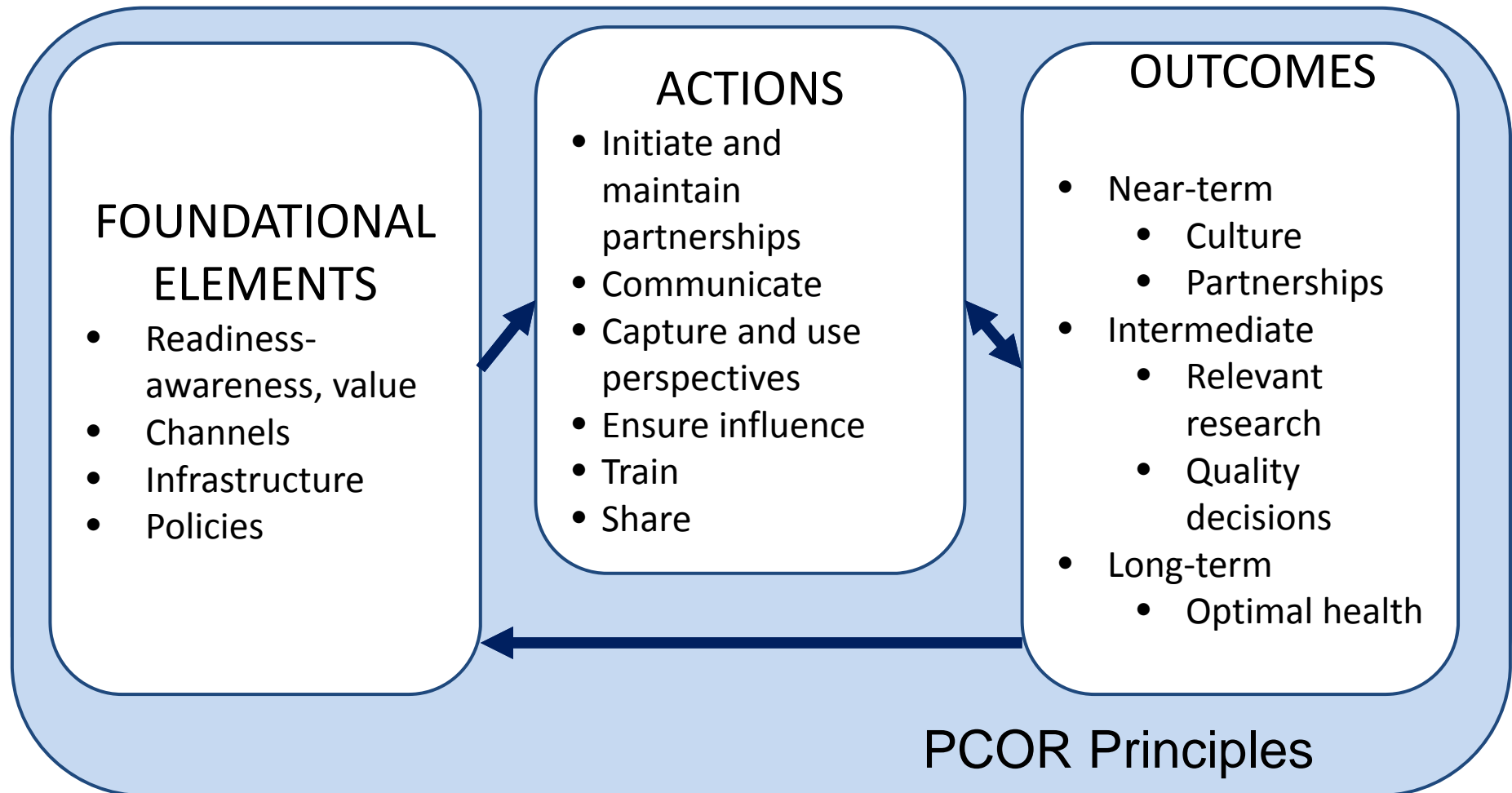
About Us

- An independent research institute authorized by Congress in 2010
- Funds comparative clinical effectiveness research (CER) that engages patients and other stakeholders throughout the research process
- Seeks answers to real-world questions about what works best for patients based on their circumstances and concerns



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Conceptual Model of PCOR



Questions about the Impact of Engagement

What is the effect of Engagement in Research on...?

- Relevance of research questions for end-users
- Study design, processes, and outcomes
- Recruitment and retention rates
- Proportion of studies that complete data collection
- Time to study completion
- Study quality

- To whom and how research is disseminated
- Time to dissemination
- Trust in results
- Understanding of findings
- Use of findings in health decision-making

Studies that
matter to
patients

Studies used
by patients

What is the effect of PCOR principles on engagement processes and outcomes?

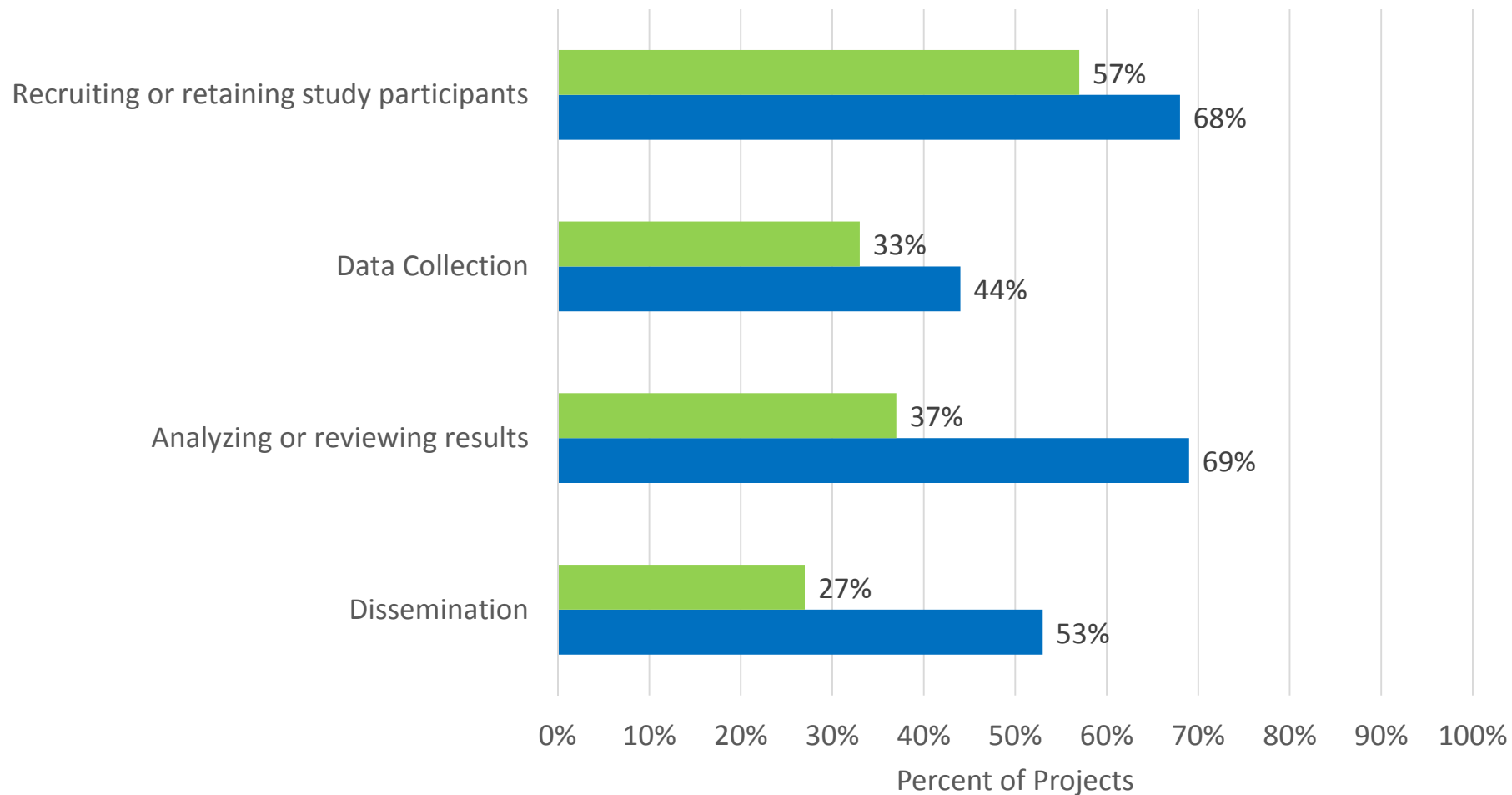
PCORI Collection of Information on Engagement

- PCORI collects information on research engagement from:
 - Research teams as part of regular project reporting
 - Partners via the Ways of Engaging- Engagement Activity Tool (WeENACT)
- Closed and open-ended items; quantitative and qualitative analysis
- <http://www.pcori.org/research-results/evaluating-our-work/how-we-evaluate-key-aspects-our-work>

When are they Engaged?

Researchers reported on when in the research process partners engaged

Conducting the Study and Dissemination



Examples of Partner Influence on PCORI Studies

“The entire study is framed around the hypothesis -- which **we helped generate**” (Patient/Stakeholder)

“**We ended up with different research questions** and framing than I would have initially thought specifically because of input from stakeholders.” (Researcher)

“Our patient co-investigators emphasized the importance of days alive and out of the hospital after stroke. **As a result, we made this one of our primary outcomes.** We also [included] fatigue, depression, functional status, and quality of life in addition to more traditional clinical outcomes.” (Researcher)

“Outcomes reflected in the study included some of the things that **I had expressed were important to me.**” (Patient/Stakeholder)



Challenges for Measuring Research Engagement

1. Measuring the observable vs. unobservable
2. Transactional vs. relational approaches to engagement
3. Heterogeneity in approaches to engagement
4. Timing for effect detection
5. Incorporating multiple perspectives
6. Recognizing the contributions of diverse partners
7. Meeting the needs of multiple audiences for learnings about engagement

Thank you!

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