



Incorporating Patient Input into Research

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March 3, 2016

Patient-Centered Outcomes Research Institute

About PCORI

- An independent research institute authorized by Congress in 2010. Governed by a 21-member Board representing the entire healthcare community.
- 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.



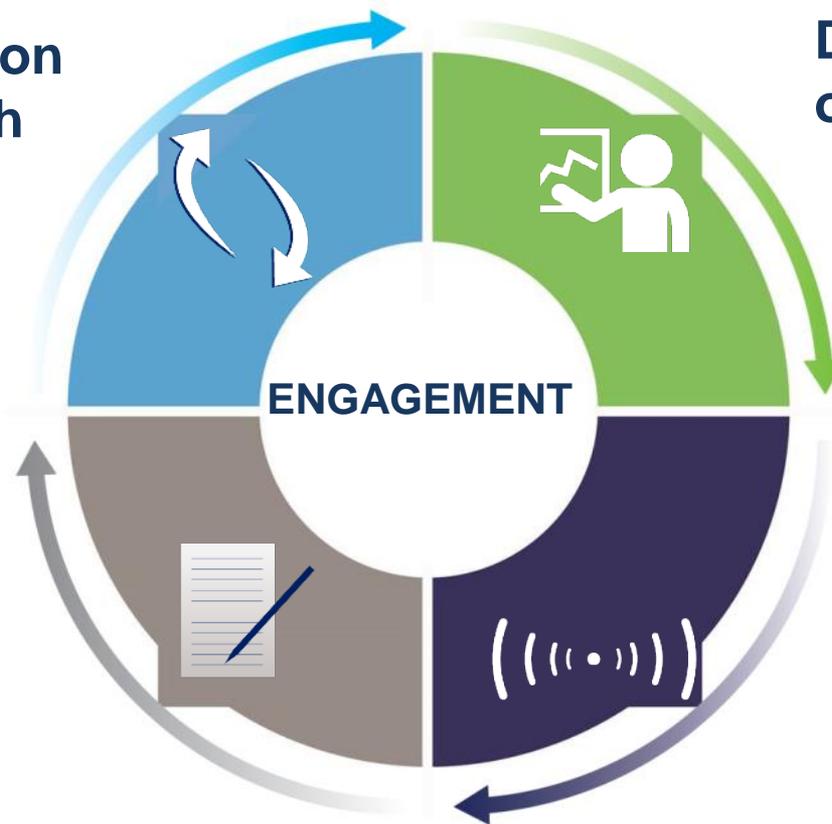
Engagement as a Path To Useful, High-Quality Research

Topic Selection
and Research
Prioritization

Design and Conduct
of Research

Evaluation

Dissemination and
Implementation of
Results



Engagement in Practice

- 🌐 Serving as co-Is, advisors, consultants, engagement bodies, or in other partner capacities
- 🌐 Identifying meaningful outcomes: PCOs vs. PROs
- 🌐 Ensuring relevant questions
- 🌐 Creating accessible patient-facing materials
- 🌐 Developing or enhancing data use/storage agreements
- 🌐 Informing (and being included in) governance structures
- 🌐 Improving recruitment and retention*
- 🌐 Encouraging active data sharing (depending on platform)
- 🌐 Ensuring transparency
- 🌐 “Personalized” dissemination, patient-engaged CME/CE

Engagement Lessons

- Compensation
- Formalized roles and agreements
- Bi-directional training
- Ask first, exclude second
- Relational, not transactional
- Takes time, energy, resource (and it is worth it)