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Using Patient-Centered Research Results in the Real World

Understanding the Influence and Impact of Engagement in PCORI-Funded Studies: A Qualitative Study

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#PCORI2019

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- Has nothing to disclose.

Our research questions were

- How does engagement influence the planning and conduct of PCORI-funded studies?
- What impacts to the study result from that influence?

Who did we talk to?

- Selected 58 funded projects
- 109 hour-long telephone interviews in English
 - 58 Researchers: Principal Investigators or another member of the research team
 - 51 Stakeholder Partners, 19 identified as patients or caregivers
- Achieved diversity in
 - Study completion status
 - PCORI funding announcement types and priority areas
 - Experiences with engagement

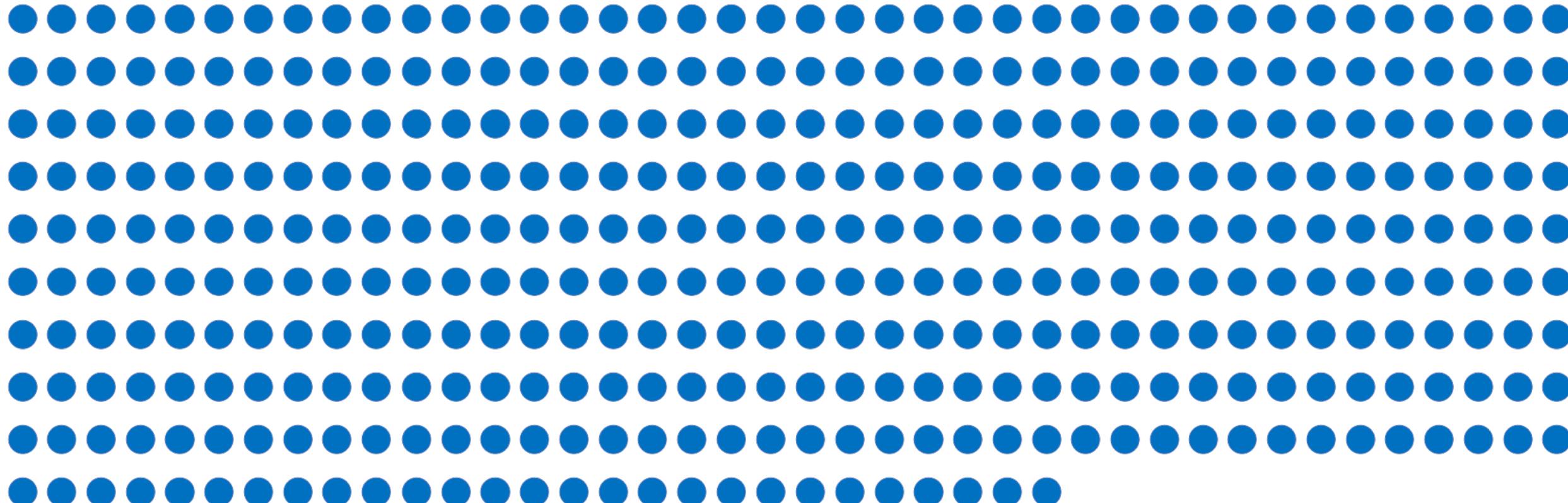
Analyzed examples reported by researchers and partners

- Catalogued examples from interviews
- Identified types of
 - Influence – how partners contributed
 - Impact – or the results of those contributions

“From the very first glimmer, I was involved. We sketched out what a trial would look like together and wrote the grant together.” (Partner)

“The providers were really critical in helping us make decisions around how the [intervention] was going to be integrated into the [clinic] work flow.” (Researcher)

Researchers and partners shared nearly 400 examples



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What did partners influence?

- Study plans and conceptualization
- Study materials and dissemination products
- Carrying out study tasks
- Engagement design and practice
- Taught researchers about lives of patients, clinicians, organizations, and health care

How did partners influence the study?

Co-producing
Partners and researchers work together or collaborate

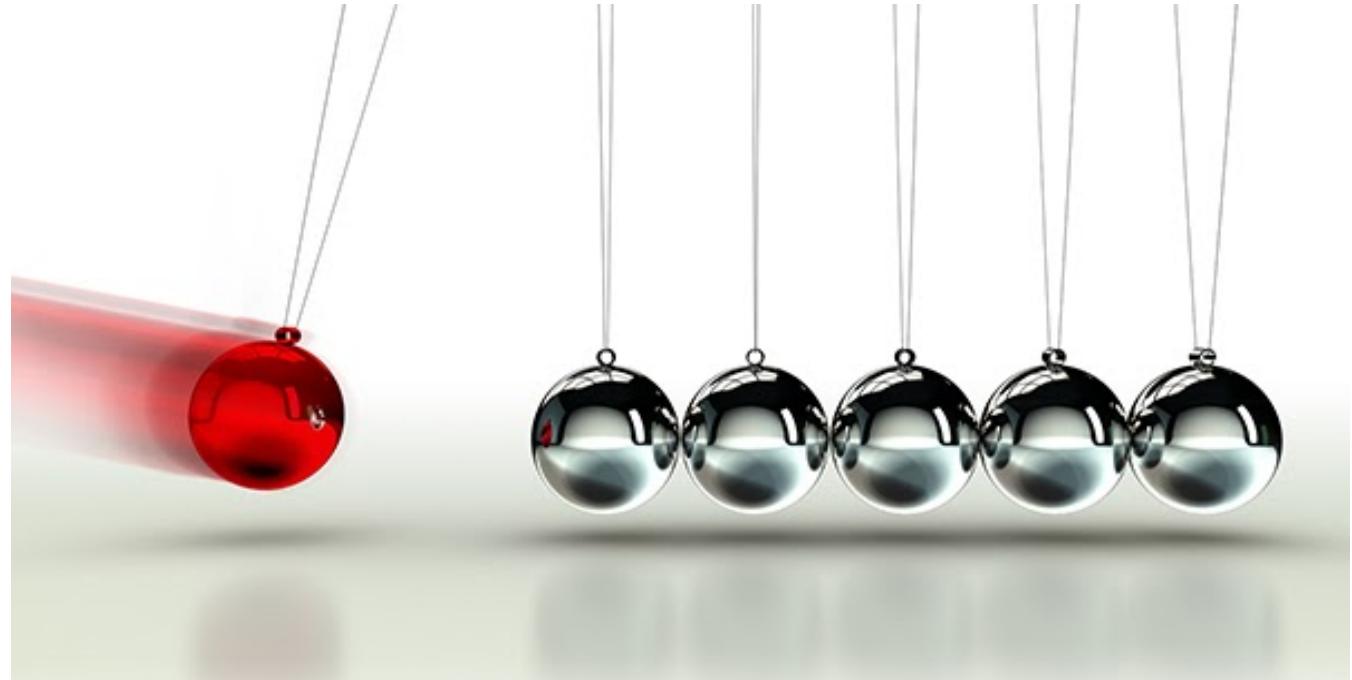
Redirecting
Partners shift the direction

Refining
Partners edit or modify

Confirming
Validate
Limited or No influence

Multiple types of influence reported within a study

Impact: Results of partner contributions



“The survey questions were coming in at a slower pace than what the researchers wanted...After we gave our suggestions, they realized a huge difference. They mentioned 80, 90 percent, up from 50 percent last year.”
(Partner)

“They gave us insights and suggestions that we probably wouldn’t have come up with on our own that in the end improved the trial design, trial implementation, and hopefully, will give us the most meaningful results.”
(Researcher)

Researcher- and partner-reported impacts

<p><i>No reported impact</i></p> <ul style="list-style-type: none">• Did not know• Could not remember• Too soon to tell	<p>How well the study reflected user needs and preferences</p>	<p>Study feasibility</p>	<p>Study quality</p>	<p>Engagement scope or quality</p>
				<p>Acceptability or Relevance</p>

Multiple types of impact reported within a study

“It’s challenging to put varied opinions together and come up with something that is scientifically sound, that addresses what the project is actually designed to do.”
(Researcher)

What are the take-aways?

- Engagement changes how studies are done - understanding of the extent and range of influence and impact
- Think about how to apply the types of influence and impact
 - Planning and supporting engagement on a study
 - Measuring engagement differently
- More to share and more to learn!

“At first we viewed it as burdensome. But over time we started to see the value in the way it was impacting the decisions we were making and how we were carrying out the study so that it would be more relevant to patients and providers on the front lines.” (Researcher)

“PCORI and this study has opened my eyes personally to how important my input is. I did not know that until I got involved with this study, how important my voice, how important a patient’s voice is in studies. (Partner)

Thank You!

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PCORI's Advisory Panel on Patient Engagement