

LEARNING FROM PCORI AWARDEES AND PARTNERS

Engagement Challenges, Strategies, and Resources

Researchers engage with patients and other healthcare stakeholders, including caregivers, clinicians, and policy makers, as partners on PCORI projects to conduct patient-centered research. PCORI collects information from partners and awardees to learn about the challenges that PCORI-funded study teams experience, and strategies they use to prevent or address these challenges. This information shows us that some challenges are shared by partners and awardees, while other challenges are unique to each group. Among partners, some challenges are more commonly described by patients and caregivers than by other stakeholders.

COMMON CHALLENGES OF PARTNER ENGAGEMENT IN RESEARCH

Patient and Caregiver Partners	Both Partners and Awardees	Awardees
<ul style="list-style-type: none"> • Understanding jargon • Feeling their perspective is understood and valued • Feeling connected to others on the team 	<ul style="list-style-type: none"> • Scheduling and other related logistics • Maintaining consistent partner participation given competing demands (e.g., managing health conditions, caregiving, other personal and professional priorities) <p><i>“Because I am the primary caregiver of my son, being able to schedule time to meet has been my greatest challenge.”</i> —Caregiver/family member partner</p>	<ul style="list-style-type: none"> • Identifying and inviting partners • Integrating diverse partner perspectives • Planning time and effort to manage engagement <p><i>“One of the largest challenges has been accommodating differing opinions.... Striking the right balance is challenging.”</i> —Awardee</p> <p><i>“Disparities in education can interfere with ability to engage all relevant stakeholders to the same extent.”</i> —Awardee</p>
<p>All Types of Partners</p> <ul style="list-style-type: none"> • Managing expectations about project delays (e.g., institutional review board approval processes, loss of momentum due to staff turnover, slow enrollment in trials) • Knowing the value of their contribution <p><i>“There were times I felt all of us couldn't understand each other clearly, which led to a little bit of frustration from both sides.”</i> —Partner representing patient, consumer, or caregiver advocacy organization</p>		

Data from annual awardee reports and partner reports collected through June 2016

STRATEGIES TO PREVENT OR ADDRESS CHALLENGES TO ENGAGED RESEARCH

Partners and awardees describe strategies that investigators can consider adopting early in the life of a project.

Nurture Partnerships	Attend to Scheduling and Logistics	Communicate and Facilitate Effectively
<ul style="list-style-type: none">Engage partners early and consistently.Draw on partners' social networks to identify other partners.Orient partners to the project and offer capacity-building opportunities throughout the project.Create a supportive and respectful environment.Be sensitive to partners' needs.Be adaptable and flexible.	<ul style="list-style-type: none">Dedicate staff time to manage engagement.Schedule meetings with partners' needs in mind.Meet or communicate frequently and flexibly (e.g., alternating meeting times, and holding some teleconferences).Meet in smaller groups if needed.	<ul style="list-style-type: none">Use plain language.Clarify roles and expectations throughout the project.Communicate with partners consistently about how their contributions shape the project.Develop group facilitation skills.

“During the first six months, we met with patient stakeholders prior to each conference call to make sure they felt comfortable with all of the information and had a strong voice. We no longer need to do this as they are truly part of our stakeholder advisory committee.”
—Awardee

“We have learned to communicate earlier and more often to help research team members internalize the key points of the study. We have developed project road maps to continually cover where we are in the project and where we are going.”
—Awardee

“Providing detailed responses to feedback so that we know our work is valued is the most important part.”
—Patient/consumer

PCORI ENGAGEMENT RESOURCES

Want to learn more? We invite you to explore PCORI's resources on engagement linked below. We can also be contacted at ppet@pcori.org.

What We Mean by Engagement Click here	PCORI Engagement Rubric Click here	Budgeting for Engagement Activities Click here
Compensation Framework for Engaged Research Partners Click here	Engagement in Health Research Literature Explorer Click here	PCORI in Practice: Webinar Series Click here

ARTICLES OF INTEREST

[The PCORI engagement rubric: promising practices for partnering in research.](#)
Annals of Family Medicine, 2017

[Conceptual and practical foundations of patient engagement in research at the Patient-Centered Outcomes Research Institute.](#)
Quality of Life Research, 2015

[Methods and impact of engagement in research, from theory to practice and back again: early findings from the Patient-Centered Outcomes Research Institute.](#)
Quality of Life Research, 2017