pcori

PATIENT-CENTERED OUTCOMES
RESEARCH INSTITUTE

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LEARNING FROM PCORI AWARDEES AND PARTNERS

Roles of Patient and Stakeholder Partners in Patient-Centered Research

Using data collected from awardees, patients, and other stakeholders who serve as research partners on PCORI-funded projects, PCORI learns how researchers and partners work together to conduct patient-centered research.

RESEARCH PARTNERS COME FROM DIFFERENT COMMUNITIES AND SERVE A VARIETY OF ROLES

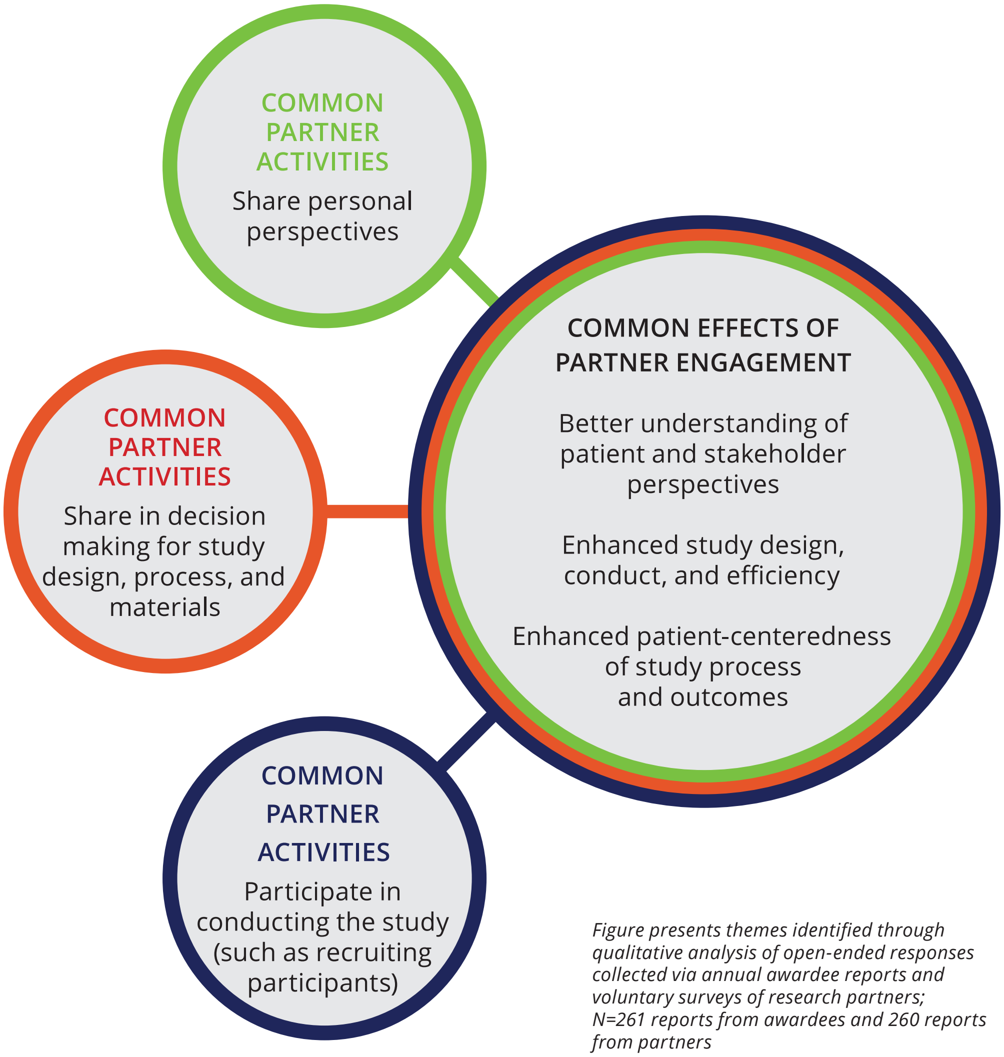
Nearly all PCORI projects (96 percent) engage with **patients, caregivers, and/or advocacy organizations representing patients or caregivers**, and most projects (92 percent) engage with **clinicians.** PCORI projects also engage with a range of other healthcare stakeholders, including **health systems, community-based organizations, policy makers, payers, training institutions, industry representatives,** and **purchasers**. Nearly all PCORI projects (98 percent) engage **with partners from more than one stakeholder community**.

Partners are commonly involved as members of the **research team** (87 percent of projects), as **co-investigators** (50 percent of projects), and/or through **advisory groups** (86 percent of projects).

Information collected via annual awardee reports; N=305 awardees: 70 projects at project year one, 116 projects at project year two, 119 projects at year three

RESEARCH PARTNERS MAKE A DIFFERENCE

PCORI awardees and research partners described ways partners get involved in the research process and the difference they make. The figure below presents common partner activities and effects of partner engagement.



COMMON PARTNER ACTIVITIES

Share personal perspectives

COMMON PARTNER ACTIVITIES

Share in decision making for study design, process, and materials

COMMON PARTNER ACTIVITIES

Participate in conducting the study (such as recruiting participants)

COMMON EFFECTS OF PARTNER ENGAGEMENT

Better understanding of patient and stakeholder perspectives

Enhanced study design, conduct, and efficiency

Enhanced patient-centeredness of study process and outcomes

Figure presents themes identified through qualitative analysis of open-ended responses collected via annual awardee reports and voluntary surveys of research partners; N=261 reports from awardees and 260 reports from partners

EXAMPLES OF EFFECTS OF PARTNER ENGAGEMENT AT EACH STUDY PHASE

	Study phase	Effects of engagement
PLANNING THE STUDY	Development or refinement of research topics and/or research questions	• Confirm the importance of research topics being pursued • Inspire the pursuit of specific research questions • Refine the research questions' relevance and alignment with patients' and/or other stakeholders' priorities
	Selection or refinement of interventions and/or comparators	• Refine interventions and/or comparators to be more patient-centered • Adapt materials or interventions to be culturally or linguistically appropriate • Modify the intervention to be less burdensome to participants
	Selection or refinement of outcomes and/or measurement	• Select primary and secondary outcomes that matter to patients and other information users • Identify and/or refine measures of these outcomes
CONDUCTING THE STUDY	Recruitment and/or retention	• Suggest changes to recruitment strategies, such as adding or changing recruitment locations, refining inclusion/exclusion criteria, and using culturally appropriate ways to recruit specific populations • Shape study materials and consent forms (e.g., simplifying or adding more information about risks and benefits) • Enhance recruitment and retention of participants by providing guidance on ways to communicate with participants, and contributing to greater perceived value of study participation among enrolled patients/caregivers
	Data collection	• Select specific modes of data collection (e.g., electronic versus phone) • Inform decisions about timing, such as appropriate follow-up periods • Inform changes to data collection as part of clinic work flow • Increase sensitivity around data collection (e.g., provide insights about why racial/ethnic minorities may be hesitant to share personal information)
	Data analysis and/or results review	• Provide input on the analysis plan • Use personal perspective to enhance interpretation of study results • Contribute to decisions about additional analyses to conduct
	Sharing study information and/or results	• Identify new ways to share results and new audiences to reach • Improve communication with different audiences • Increase credibility of the results

Data from open-ended responses collected via annual awardee reports and voluntary surveys of research partners; N=261 reports from awardees and 260 reports from partners

AWARDEE
"Our decision to pursue this study and, in particular, the patient population … was driven by requests from patients and providers who noted a clear gap in knowledge and absence of treatment guidelines for this distinct patient group."

AWARDEE
"As members of the research team, patient stakeholders were key to the development of the survivorship care plan tool and measures of effectiveness. Their involvement has ensured a truly patient-centered tool and relevance of potential findings to the patient audience."

PATIENT PARTNER
"We changed the language of recruitment materials to make it easier for the patient and family to understand what they were agreeing to."

Further information about PCORI's framework for assessing research engagement and early findings about effects of engagement:
L. Forsythe, A. Heckert, M.K. Margolis, S. Schrandt, & L. Frank. Methods and Impact of Engagement in Research, from Theory to Practice and Back Again: Early Findings from the Patient-Centered Outcomes Research Institute. *Qual Life Res.* 2017 May 12. doi: 10.1007/s11136-017-1581-x