

ABSTRACT ID # P26

Title: Patient and Stakeholder Engagement in PCORI-Funded Research: Initiating and Fostering Partnerships

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The Patient-Centered Outcomes Research Institute (PCORI) was established in 2010 to fund comparative clinical effectiveness research (CER) that helps patients and caregivers make informed healthcare decisions. To achieve its mission, PCORI requires researchers to engage with patients, caregivers, clinicians, and other healthcare stakeholders in the planning and conduct of its funded CER studies. In this study, we describe the communities who are engaged in PCORI-funded studies, how these research partnerships were initiated, and strategies for fostering research partnerships. Principal investigators (N=187) and patient/stakeholder research partners (N = 302) from seven PCORI funding cycles responded to a voluntary online survey regarding their experiences with engagement. Responses to open-ended items were analyzed for qualitative themes. Patient/stakeholder partners most commonly identified their primary community as: patient (23%), advocacy organization (19%), clinician (18%), caregiver/family member (13%), or clinic/hospital/health system (5%). Half (50%) of patient/stakeholder respondents reported having a relationship with the researcher(s) prior to the PCORI-funded study. For new partnerships, researchers and partners described a number of strategies through which researchers initiated the relationship, including community outreach (e.g., through senior centers, community centers, and community leaders), outreach to patient/family support groups, a competitive application process, and recruitment from existing institutional advisory councils. Researchers and patient/stakeholder partners also described strategies for fostering positive research partnerships, such as creating a welcoming environment and explaining how partners' input will be used. Examples of ways PCORI awardees and their community partners initiated and fostered partnerships will be presented to inform others interested in conducting or promoting community-engaged research.