**pcori**®

PATIENT-CENTERED OUTCOMES
RESEARCH INSTITUTE

1828 L STREET NW, SUITE 900
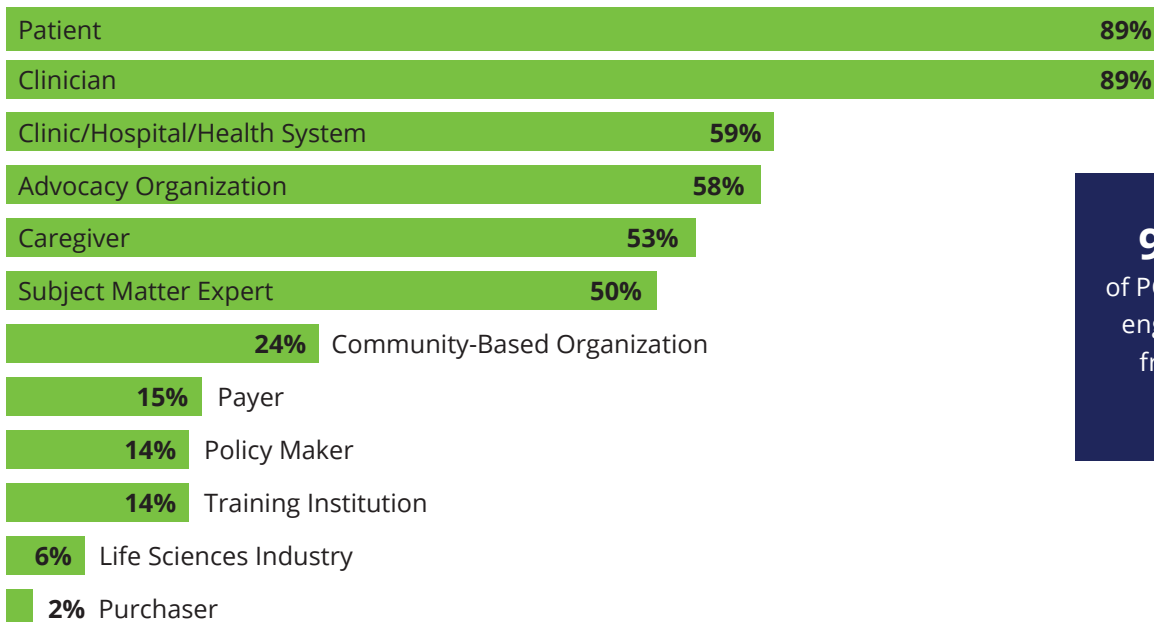WASHINGTON, DC 20036
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LESSONS FROM PCORI APPLICANTS, AWARDEES, AND PARTNERS

# Initiating Partnerships for Patient-Centered Research

Using data collected from research applicants, awardees, and partners, PCORI is sharing lessons about how researchers can engage with patients and other healthcare stakeholders to improve patient-centered research. This info sheet presents information from our portfolio about how research partnerships have formed.

## WHO ENGAGES AS PARTNERS IN PCORI RESEARCH PROJECTS?

Research partners come from many communities.

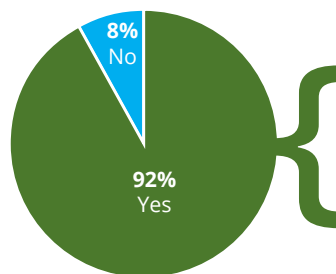| Community | Percent |
| --- | --- |
| Patient | **89%** |
| Clinician | **89%** |
| Clinic/Hospital/Health System | **59%** |
| Advocacy Organization | **58%** |
| Caregiver | **53%** |
| Subject Matter Expert | **50%** |
| Community-Based Organization | **24%** |
| Payer | **15%** |
| Policy Maker | **14%** |
| Training Institution | **14%** |
| Life Sciences Industry | **6%** |
| Purchaser | **2%** |

**95 PERCENT**
of PCORI awardees report engaging with partners from more than one community

Notes: data collected via annual awardee reports of communities engaged in past year: 112 responses about project year 1; 168 responses about project year 2; 71 responses about project year 3
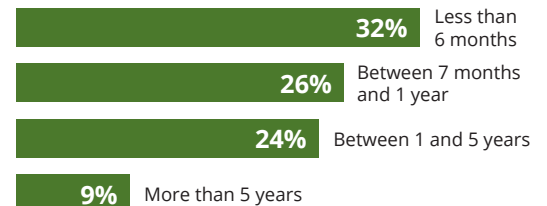
## WHEN DO RESEARCH PARTNERSHIPS BEGIN?

Nearly all applicants for a PCORI research award report forming partnerships before submitting their applications.

**Q: Did you establish a patient/stakeholder research partnership prior to applying for PCORI funding?**

8% No
92% Yes

**Q: How long before submitting your application did you establish a patient/stakeholder partnership?**

| Time period | Percent |
| --- | --- |
| Less than 6 months | **32%** |
| Between 7 months and 1 year | **26%** |
| Between 1 and 5 years | **24%** |
| More than 5 years | **9%** |

Notes: data collected via voluntary survey of applicants for PCORI research awards; N=893 applicants across 9 funding cycles; survey response rate=84% across cycles

## WHERE DO PCORI APPLICANTS AND AWARDEES FIND POTENTIAL RESEARCH PARTNERS?

PCORI applicants and awardees connect with patients and other stakeholders through outreach to a variety of sources.

### Organizations

- Patient/family support groups or advocacy organizations

- Community organizations (eg, senior centers, cultural centers, churches) and events

- Existing institutional advisory councils (eg, hospitals' patient and family advisory councils)

### Individuals

- Patients receiving clinical care and their families

- Participants or partners from previous research studies

- Patients and stakeholders recommended by colleagues or partners

Notes: data from open-ended responses to voluntary surveys of applicants for PCORI research awards (N=454), PCORI research awardees (N=179), and PCORI patient/stakeholder partners (N=246)

## LESSONS LEARNED FROM PCORI AWARDEES AND PARTNERS ABOUT INITIATING RESEARCH PARTNERSHIPS

### Engage early.

- Engage patient and stakeholder partners early, preferably before or while developing a research proposal.

- Use a variety of sources to find and reach out to potential partners.

### Plan ahead.

- Keep in mind that establishing partnerships and building trust take time. Allow for extra time to work with partners before the proposal deadline and during the study.

- Think in advance about how to financially support early engagement activities that may occur prior to receiving study funding.

### Foster positive partnerships.

- Ensure that the work is a good fit with partners' interests and abilities.

- Create a welcoming environment for partners by encouraging, listening to, and valuing their input.

- Explain the research process.

- When engaging partners during proposal development, be open about the likelihood of funding.

Notes: data from open-ended responses to voluntary surveys of PCORI research awardees (N=179) and PCORI patient/stakeholder partners (N=246)

" Patient partners are an asset to the team. It requires a dedicated effort from the research team to keep the relationship moving forward. "

**RESEARCHER**

" Trusting your researchers is hugely important...Transparency and explaining why often goes a long way in developing this trust. "

**PATIENT PARTNER**