



# Generating Organizational Support for Patient-Centered Outcomes Research

## TIP SHEET

### Why is it important to have organizational support when partnering with patients and other stakeholders in research?

Engaging patients and other healthcare stakeholders in research can make research findings more patient centered, relevant, and useful. Having support from senior leadership at your organization can help remove barriers to stakeholder participation and foster a productive work environment for multi-stakeholder research teams.

### How can research teams generate support from their organizations?

- 1 Develop your case for engagement to clearly articulate the benefits of patient-centered outcomes research (PCOR).** Consider how engagement will benefit patients and/or caregivers in your study, how it could benefit other studies being conducted at your organization, and how it could benefit the organization more broadly.

**Try this:** Develop a short slide deck on the benefits of engagement (see the text box for sample messages). Clearly and concisely communicate how engagement could shape—and improve—specific aspects of the study such as data collection or enrollment, the acceptability and relevance of findings to the study population, and how and where to share findings. Describe how engagement efforts align with organizational plans, such as major initiatives or impending changes.

#### The following resources highlight the benefits of stakeholder engagement:

- [Better Research through Engagement](#) (PCORI fact sheet)
- [Patient Engagement in Research](#) (PCORI video)
- [Engaging in Stakeholder-Driven Research](#) (Video-based module in the PCORI [Research Fundamentals](#) Learning Package)
- The Benefits of Multi-Stakeholder Engagement\* (Sample slide deck available on the Institutional Barriers to Stakeholder Engagement webpage)

#### Stakeholder Engagement Can . . .

- Improve study conduct, including effectively recruiting participants and meeting enrollment targets
- Have substantial and positive impacts on stakeholders, patients, and communities such as improvements in personal health and healthcare and increased skills and professional opportunities
- Improve the relevance of research to help patients and caregivers make more informed healthcare decisions
- Help researchers and their organizations gain a deeper understanding of the real-world experiences and concerns of their study populations

Click [here](#) for more information on the benefits of stakeholder engagement.

\* You can use these slides to develop your own deck or use the deck as is.



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**2 Seek opportunities to educate leaders about the benefits of PCOR.** Doing so can help identify any misconceptions about PCOR.

**Try this:** Ask for time during departmental or other meetings with leaders to present your research project and discuss the role of stakeholders. Address how patient and stakeholder engagement add value to the research process and findings. Invite a patient partner or PCORI Ambassador to co-present and share their perspective on what it means to be an equal member of a research team.

**Try this:** Host a lunch-and-learn about the benefits of PCOR and stakeholder engagement using your slide deck and/or the other resources listed on page 1. Try to address any questions or concerns that attendees may have about stakeholder engagement.

**3 Identify formal and informal leaders at your organization who can help pave the way for PCOR.** Working with executives and department heads can help clear formal obstacles to stakeholder engagement such as policies, paperwork, or required trainings that could delay or prevent meaningful engagement. In addition, administrators, managers, patient advocates, clinicians, and community groups can all be important partners in generating support.

**Try this:** Reach out to leaders and individuals who influence policy and practice at your organization. Ask for some of their time to discuss how the organization supports multi-stakeholder research teams, and how support might be improved. Ask about any experiences with or perceptions of PCOR to gain insight into what might be needed to garner their support. Ask about any competing priorities, such as impending layoffs or high turnover, which could decrease interest in or attention to PCOR. Explore how PCOR could potentially address any of these priorities or concerns.

**4 Find examples of other ways stakeholders have been involved at your organization,** for example on patient advisory councils, quality improvement projects, or community benefit work. Learn from others' experiences about what worked well and how those projects navigated the system.

**Try this:** Contact someone at your organization who has conducted community-based participatory research or community outreach; these colleagues may have examples of helpful policies or be aware of others at your organization who have conducted stakeholder-driven research.



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**5 Be aware of the Institutional Review Board (IRB) requirements for PCOR. If patient partnership is new to your IRB, start working with the IRB before the research proposal is submitted.** Some IRBs may require patients who are participating as partners in research to complete informed consent processes; other IRBs may require such patients to complete research ethics training. Other IRBs may consider patients who are serving in nontraditional roles to be research subjects even when they are not enrolled in research. Try to find ways to maximize the benefits of stakeholder participation in research without creating burden for the stakeholders.

**Try this:** Meet with IRB leaders early to describe the role that stakeholders will play in planning and conducting research and whether stakeholders will have access to data. Identify and discuss any concerns that the IRB may have to foster their support early on. A [PCORI-funded study](#) (see page 48) provides guidelines and recommendations that IRBs, investigators, and patient partners can use when designing or reviewing human subjects research aspects of PCOR.

**Try this:** Encourage IRB leaders to review the interactive [PDF](#) in the [Research Fundamentals](#) Learning Package to learn more about stakeholder-driven research and how PCOR differs from traditional research.

**Try this:** Talk to other PCOR researchers to learn about potential IRB barriers.