SECTION: *ENGAGING STAKEHOLDERS*

Learning Area: *Addressing Contextual Challenges to Engagement*

▶ Challenges of Stakeholder Engagement

Engaging stakeholders as partners in research is a new and different way of doing research. Research institutions, researchers, and stakeholders may experience challenges as they implement this novel approach to research. Institutions may need to adapt policies and practices to support stakeholder engagement. Researchers may need to learn new approaches to research. And for many stakeholders, especially those who are patients and family caregivers, collaborating with researchers may be a new experience.

▶ Lessons Learned from Experience

PCORI collects information about the challenges that PCORI-funded study teams experience with engagement and the strategies they use to prevent or address these challenges.

▶ Resources on Addressing Challenges to Engagement

The following provide information and resources for organizers and stakeholders to identify and address common engagement challenges:

- **Institutional barriers to stakeholder engagement.** Research teams may encounter challenges to engagement at their institutions.

- **Individual challenges to stakeholder engagement.** Individual researchers and stakeholders may encounter their own challenges when engaging in research.

- **Solving common engagement problems.** Practical solutions and approaches can address institutional and individual challenges.

Institutional Barriers to Stakeholder Engagement

▶ What Institutional Barriers Might Research Teams Face?

Research institutions—organizations that conduct research—may have policies, systems, and norms that do not support stakeholder participation as full research partners including:

- **Leadership** that doesn't understand—or value—patient-centered outcomes research (PCOR) or stakeholder involvement.

- **Policies** that limit access to facilities for non-employees or charge fees for facility use.

- **Communications or information technology (IT)** that is restricted to institutional staff.

- **Accounting systems** that do not compensate non-employee partners.

- **Budgeting rules** that may not include compensating stakeholders for their time and expertise.

- **Institutional Review Boards (IRBs)** that are unfamiliar with multi-stakeholder teams and the concept of stakeholder partnership, or that require stakeholders to complete certification in research ethics.

▶ How Can Research Teams Address Institutional Barriers to Stakeholder Engagement?

Research teams can:

- **Identify and work with PCOR champions** in the institution to advocate for institutional changes that support stakeholder engagement.

- **Educate senior leadership** about the value of patient-centered, stakeholder-driven research and demonstrate how the institution could support it.

- **Communicate and build partnerships** with key departments such as IT, accounting, IRB, and human resources (HR) to identify and adapt systems to support stakeholder involvement.

Individual Challenges to Stakeholder Engagement

Stakeholders and researchers may face challenges engaging with each other in research.

▶ What Kind of Challenges Might Stakeholders Face?

- **Logistical challenges**, such as:
  - **Limited time** to attend meetings or other study-related activities due to work, childcare, or other commitments.
  - **Health problems or physical limitations** caused by the condition being studied for the stakeholder or the person they are caring for.
  - **Limited access** to meeting locations due to limited transportation options.

- **Limited finances** to pay for transportation to meetings and other study events, internet access, parking, or childcare.

- **Limited fluency** in English.

- **Lack of familiarity with research** concepts or terms.

- **Concerns over confidentiality or privacy** such as how their individual healthcare experiences will be protected.

- **Overwhelming demands from institutions** such as institutional training or certification.

▶ What Kind of Challenges Might Researchers Face?

Even researchers who have experience partnering with stakeholders may face challenges such as:

- **Identifying stakeholders** who have relevant experience and are a good fit with the team.

- **Limited time** to build and sustain stakeholder relationships.

- **Unanticipated costs** related to supporting stakeholder involvement.

- **Communicating study information** in a way that allows stakeholders to make meaningful contributions.

- **Balancing scientific rigor** while being responsive to input and feedback from stakeholders.

- **Sharing authority** with stakeholders who lack the credentials and experience of an academic or medical professional.

- **Being open and honest** when discussing intentions, interests, and needs with stakeholders.

- **Keeping an open mind** and recognizing that different perspectives may be helpful, for example, by offering insight into the study population to help with recruitment.

> Researchers and stakeholders can build and maintain trust with each other by being open and honest about their intentions and interests (see Establishing and Maintaining Trust in the Engaging Stakeholders section of the website).

Solving Common Engagement Problems

▶ **How Can Research Teams Anticipate or Solve Challenges and Barriers to Engagement?**

- **Ask team members what they need** to successfully participate in team meetings and activities (for example information, support, or technology).

- **Plan scheduling and logistics** to make sure that meetings are convenient for all or most team members, prioritizing stakeholder needs. Consider which meetings may not be necessary, which could be held in a more convenient location, and which could be held virtually.

- **Anticipate and plan for stakeholder costs to fully participate** as part of the team, such as transportation and parking.

- **Develop creative solutions to barriers and challenges** as a team, such as seeking resources through partnerships with stakeholder organizations and local government.

- **Set, communicate, and revisit clear goals** at study outset and throughout the study (for example, through meeting agendas and summaries).

- **Provide ongoing training and support for stakeholders in research methods**, such as plain language materials and glossaries of research terms.

- **Build support from within**, training researchers, team members, and other staff about the value of working with stakeholder partners.

- **Commit to stakeholder engagement principles** from the start, and revisit them often.

- **Identify and plan for barriers and challenges** from the earliest stages of planning.

- **Identify a liaison** on the research team to coordinate communication between team members.