

**A**lthough careful planning and preparation can minimize barriers to engagement, challenges may still emerge for stakeholders and researchers. Understanding what kinds of challenges could come up in advance – and how other teams have dealt with them – can help to ensure meaningful engagement by all team members. This resource presents insights from PCORI-funded research teams. Researchers and stakeholders note in their own words how they successfully addressed challenges to engagement. Their insights, which are organized by key message, illustrate how teams may address common barriers to full participation and the benefits of doing so.

1

**Research teams must be flexible when scheduling meetings** and other activities to be responsive to stakeholders' needs, such as health status or work obligations, that could be barriers to engagement.



**B**e flexible, patients are intimately concerned with the medical conditions they experience, but they have other concerns as well, e.g., jobs, family, etc. It is very helpful to ask patients when they have time to provide input, what kind of input they want to provide, and where and when they would like to provide it.

– PCORI-funded Researcher

**I**t was very important to our team that all those who held stake in the project's success be able to attend this meeting. We found that no one time worked, so we in turn decided to schedule the meeting at two different set times, alternating between those two times every other month. Using this tactic, each and every study team member is able to attend the calls bimonthly.

– PCORI-funded Researcher

**I**t is important to highlight that the team has remained nimble and adaptable to the needs of the patient partners. For example, patient partners who had to miss the group call were asked to meet one-on-one via telephone to ensure they were informed and to maintain the contact and rapport needed to retain their commitment and participation. This modification to planned patient/stakeholder engagement activities introduced additional time and coordination but resulted in 100% retention of patient participants on the project.

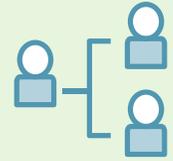
– PCORI-funded Researcher

**M**embers of our *Patient Advisory Board* have many physical challenges. In order for all members to participate, we decided to conduct our meetings as phone conference calls.

– Caregiver/Family Member

2

**Meaningful stakeholder engagement requires thoughtful planning** by and adequate resources from the research organization, including time and personnel, to address barriers to engagement.



**W**e did experience challenges with developing a way to pay patient partners. Our institution required complex consultant agreements which were not well suited for non-professionals and were very off-putting. Over time, we did develop simpler language that was still acceptable to the institution. This will facilitate similar arrangements for our investigative team as well as other investigators in the future.

– PCORI-funded Researcher

**O**ne challenge continues to be supplying manpower for the coordination efforts of stakeholder engagement. Scheduling, preparing for, and attending meetings is time consuming for stakeholders from outside organizations. We regularly offer assistance in scheduling meetings and travel off-site to accommodate those individuals and groups assisting us in this study.

– PCORI-funded Researcher

**T**he investigators planned for bilingual staff and separate English and Spanish sessions and held a session in both Spanish and English to accommodate as many patients as possible.

– PCORI-funded Researcher



3

Research organizations believe that an investment in – and commitment to – **addressing barriers to meaningful stakeholder engagement is beneficial to the research team and study.**



Investigators felt that having a patient representative more involved in the day to day activities of the project would have been helpful. For example, having a patient attending regular project meetings and calls would have provided not only immediate patient feedback regarding issues and decisions, but also would have given the *Patient Advisory Council* more insight into the research process.

– PCORI-funded Researcher

We have had ongoing engagement at multiple levels with various stakeholders including patients for more than a decade. The work with these groups in this project affirms the importance of this investment. Resources are needed to ensure ongoing communication. This would ideally be at least a half time equivalent to maintain communications through newsletters, calls, and other means of keeping constituent groups informed.

– PCORI-funded Researcher

