

Successful collaboration and engagement in a multi-stakeholder team requires careful planning and preparation throughout the life of the project.

This tool presents insights from researchers and stakeholders from PCORI-funded teams – in their own words – about how they have successfully planned for collaboration within their team. Their insights, which are organized around four key messages, illustrate why and how to plan for collaboration in a multi-stakeholder team.

1

Research teams must deliberately **engage stakeholders in all stages of the study**, starting from the planning to sharing the results; the process of engagement should be planned by a collaborative team including both stakeholders and researchers.



The researchers have made sure that stakeholders and patients on the project can do as much or as little as they desired based on their expertise and how it is needed for the project. They did a really good job using all of our skills and pulling from each of us what they needed without overusing one person.

– **Advocacy Organization Representative**

The institution has been able to maintain a strong and collegial working relationship between the health plan, the stakeholder board, and the institution’s research team. This strong working relationship is based on continual years of collaboration and an understanding that engaging the stakeholders during the duration of a project is beneficial and allows for the research team to maintain ongoing relationships with this cadre of stakeholders for future research projects.

– **PCORI-funded Researcher**

To accommodate varying patient preferences, it is suggested that patients and other stakeholders should have the opportunity to be involved in structured roles independently throughout the continuum of engagement (consultation, involvement, and shared leadership) rather than encouraging all patients to seek shared leadership. This approach allows patients to adjust the depth of their involvement over time to fit their own needs.

– **PCORI-funded Researcher**



2

Teams that are most successful at engagement **continually assess readiness** of their research institutions to involve stakeholders as well as assess individual team member's commitment to collaboration.



Our Institutional Review Board was initially wary of partnering with community organizations for a research project where the health center staff were actively engaged in the research process and collection of data. After many emails, meetings, and the approval of a written quality assurance plan, our IRB administrators agreed to provide oversight for the research activities conducted by the staff at the health center sites. This experience has prepared us for how to navigate the IRB system with other non-Washington University partners for future projects.

– PCORI-funded Researcher

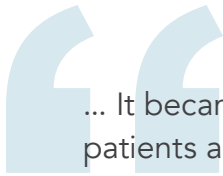
We did experience challenges with developing a way to pay Patient Partners. Our institution required complex consultant agreements which were not well suited for non-professionals and were very off-putting. Over time, we did develop simpler language that was still acceptable to the institution. This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

– PCORI-funded Researcher



3

Onboarding and training is needed for stakeholders as well as researchers to achieve successful collaboration and to establish clear expectations for the collaboration process.



... It became apparent that all of the patients and families wished to take part in the project but none of them had ever participated in a conference call. Even members who were comfortable with computer technology found this daunting, unsure of how to get on the call and were unclear as to what to say or not say. They required practice, individual support, and further explanations before each was prepared to try again. For the next scheduled conference call, it was gratifying when six out of the seven members called in on time.

– PCORI-funded Researcher

For future research opportunities, we will continue to engage the community in the research process, and we have learned through this PCORI project that a significant amount of time is required for sufficient training and preparation of the community members in research so that they are fully engaged and fully understand research before beginning activities. With improved training processes and capacity building, we will be able to have an even greater involvement and utilization of the Consumer Advisory Board to make the study better.

– PCORI-funded Researcher

There were times when medical acronyms and terms were used to quicken the pace of the discussions...I would ask one of the doctors or analysts to explain it. Without fail, they would explain it in precise detail. They invested their time in helping me understand the process. Hopefully, their investment paid dividends.

– Patient/Consumer

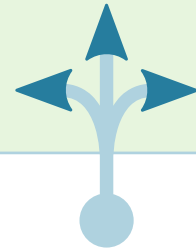
Getting information ahead of time enough for us to discuss it and make real change - because of the speedy timeline, as a stakeholder, sometimes we were only given information at the meetings which prevented us from fully digesting it and giving more in-depth suggestions.

– Patient/Consumer



4

Flexibility is an important part of planning to collaborate in a research study.



Confirming attendance for a planned discussion group and arranging transportation was time consuming, and often uncertain in guaranteeing a quorum in advance of the session. The investigators also learned that end stage renal disease (ESRD) patients' attendance could be uncertain due to variability in disease progression, symptom exacerbation, and complications. Because of this, about 25% more patients were invited than were expected to attend a given session.

– PCORI-funded Researcher

Many of our stakeholders were ill with metastatic cancer. This made in-person meetings difficult and required extra flexibility to meet patients individually or exchange ideas via phone or email."

– PCORI-funded Researcher

It 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

Be 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

