



Insights from Researchers and Stakeholders on **Establishing and Maintaining Trust**

Trust between researchers and stakeholders can transform efforts of inclusion into strong partnerships that reflect true collaboration. This tool presents insights from researchers and stakeholders from PCORI-funded teams – in their own words – about how they have successfully established and maintained trust within their team. Their insights, which are organized by **four key messages**, illustrate why and how to establish and maintain trust.

1

Trust must be built and maintained deliberately; every interaction is another opportunity to strengthen, damage, or repair trust in the relationship.



We strongly believe that building long-term trust in relationships is one of the most critical and essential factors to ensure the success and smooth operation of the project. Without previous long-term collaboration ... and constant building/maintaining the relationship, we would not be able to achieve and surpass our proposed goals in recruitment and retention rate.

– Advocacy Organization Representative

We got together quarterly as a team, we shared a meal together and sat at a big round table where we were asked and given the opportunity to express our thoughts, ideas and opinions. Everyone was given the chance to share and respond.

– Caregiver/Family Member

I do think that we were heard for the most part. It is always a struggle on the phone calls to know who is not feeling included and when not face to face, you can't tell who isn't feeling heard. I think it would be great to have more face to face time and to have had the Blog vehicle for the entire process. I also appreciated the one on one calls to get feedback on the process and our opinion positive reinforcement that my opinion was valuable.

– PCORI-funded Researcher

Overall, we believe it is the relationships we develop with stakeholders that help people feel connected and committed to the project.

– PCORI-funded Researcher



2

Open and honest **communication** is essential to building and maintaining trust between team members.



To elicit ongoing feedback, we have begun circulating a monthly question in the newsletters to facilitate stakeholder input on project planning. Information collected is shared with the Study Advisory Committee (SAC), Study Leadership Team, Study Co-Investigators, partner practices, and other stakeholders and colleagues. These frequent contacts and sharing of study methods have led to iterative modifications to our data collection strategy.

– PCORI-funded Researcher

They were open to our input and did a **VERY** good job of making everyone **feel comfortable**. There was no coddling, but they talked to us like adults—like they would talk to anyone without mental illness. We felt like our opinions mattered . . . They made everyone feel like we were on an even plane.

– Patient/Consumer

The researchers' response to my feedback has helped me the most, as it **shows me that they really care what I think**. That makes me work even harder on the project.

– Patient/Consumer



3

Trust is strengthened when team processes encourage **diverse points of view** and respectful disagreement.



Providing an atmosphere of open discussion is key. I think critical discussion is fine, as long as there is acceptance of different ideas with the goal of productive discourse.

– Clinician

I have never had a problem sharing my opinions, but when any stakeholders or other members of the team seemed to be quiet, [the PI] would make sure to ask them what their thoughts, comments or concerns were on topic.

– Patient/Consumer

Having the round table discussions where every person’s ideas were valued equally was really important. It made it so that **everyone was more willing to share honestly because they weren’t intimidated** or made to feel that the doctors/researchers knew better than we as parents/caregivers did.

– PCORI-funded Researcher

I trusted the project leader to find and interpret the results fairly. I feel his explanations, discussions, & perspectives were based in an objective approach for the project. He/they did not put forth any influence that would have derailed an open discussion. More than a few times we had some heated discussion and it was good to have someone who can put each opinion/perspective into a focused direction, so that each idea is respected and accepted.

– Patient/Consumer



4

Team leaders and members must be aware of the **effect of their behaviors and communication style** on strengthening or damaging the trust of their teammates.



The staff works hard to maintain regular contact with the members, whether to inform them of other research opportunities that request their expertise as a Patient Advisory Group member, mail them well wishes cards, or making an unscheduled visit at the hospital if any of them have fallen ill. The team also ensures that at each meeting we have agenda items to keep members engaged and participating in a meaningful way.

– PCORI-funded Researcher

The researchers are very good at acknowledging and including comments and suggestions from me and the other patients and caregivers. There is a delightfully high level of courtesy among members of this group.

– Patient/Consumer

As the only community member involved on the core research time, I was concerned that I may be excluded for some meetings or that no one would both explaining acronyms and other tech terms for me - and that was all unfounded. [the PI] does a great job of checking in to make sure that everyone, including me, is on the same page during meetings - especially when some of us are phoning in. She's great!

– Patient/Consumer

Identifying good researchers and moderators is key when working with community members. They have to be researchers willing to concede the research question to the community. The moderators have to be willing to control the brainstorming sessions to be constructive.

– Patient/Consumer

