

This document is intended for researchers who are considering doing community engagement, particularly those who intend to establish a longstanding relationship with a community group or patient partner. It presents tips and advice gleaned from engagement experts, researchers, and patient partners in the PaTH CRN. Researchers are encouraged to bear the following thoughts in mind as they embark on a new partnership:

Community Partnerships are Reciprocal Relationships

- They require give-and-take from both parties.
- Interactions with researchers that are not reciprocal are viewed as extractive – i.e., taking rather than giving. Historically, some researchers have “taken” ideas, time, and data from community members and research participants without any apparent change to care or practice, and sometimes without even letting participants and community members know the results of the research. This is one of the reasons research and researchers are sometimes mistrusted.

Start your Relationship with Respect

- Approach community and engagement collaborators with appreciation, humility, and respect, as all collaborators deserve.
- Ask for help, don’t demand it.
- Consider community and engagement collaborators as comparable to methodologists on your project, and compensate accordingly by level of involvement. Community co-investigators should be compensated comparably to other co-investigators. Board members should be compensated at a generous hourly rate. Who is funding the project?
- If asking an engagement specialist, community member, or other researcher for help/introductions in engaging a community, group, or individual, let that person lead the interactions and listen to what they tell you. Your behavior can strengthen that relationship, or jeopardize it.

Build the Relationship Over Time

- As with other collaborations, you get to know each other over time and by working with one another. Explain what you are offering, how they might benefit, and how you will work together over time. Be open to suggestions they have about how the collaboration should go. This is a bi-directional relationship where both parties need to learn from one another to be effective.
- If community partners suggest something for your study that seems unfeasible, try to work towards a solution where it could be incorporated; if you can’t incorporate it, explain why. This should be treated like any other disagreement between co-investigators regarding study focus, design or methodology. Treat community collaborators like any other professional collaborators.
- If a community partner says something you don’t understand, respectfully ask more about that. If you are frustrated by their suggestions or behavior, or if they seem to be frustrated with you, that is a time to stop, pay attention, listen, and use the same conflict resolution skills you would use with other collaborators. This conflict is not bad; it is a time to pay attention because it is when you can learn the most. Glossing over it can create a false sense of community buy-in that can lead to project failure.

- Effective, transparent communication is key! If you are trying to rush the relationship because of an external deadline, acknowledge the unreasonableness of the timeframe and apologize for the constraint. Be humble, and do not act as though you assume they can or will help you with no notice.

Set Clear Expectations

- Clearly define the roles you are asking for community members. Don't ask them to "join an advisory board"; instead, explain what that means: How many meetings? During what hours are the meetings likely to be held? How often? What topics will they address? What will you do with their input? What will compensation be?
- Clearly define YOUR role in the project, and how and when you will interact with them.
- If you need them to submit a biosketch, explain what that is and help them write one. Writing a biosketch with a community partner can often be easily accomplished in a 30-60 minute virtual meeting.
- Make sure you can make the case for why your research might matter: (1) to science and society in general, (2) to the community or individual you are approaching. Make your case in terms that you would use to explain it to a friend or family member. Bear in mind that you are probably already pretty good at explaining point 1, but may struggle with point 2. What benefit will they gain from partnering with you? What benefit might their community gain? Be sure to seek community member input on this, instead of simply assuming.

Build in Feedback Loops

- As your relationships progress, make sure there is a process and routine time to find out how community partners are thinking and feeling: This can be a quick conversation, a survey, or a check-in from other team members.
- Act on the feedback community members give you. Your processes might need some adjustments. If you can't act on their feedback, explain WHY you aren't doing so. If you do act on their feedback, be sure to let them know.

Create a Plan Together

- After you've started to build your relationship and have started working together, work together to identify specific engagement goals for the group. For example, community partners can help with the following, among other tasks:
 - Question formation
 - Study Design
 - Identifying Outcomes that Matter
 - Design or recruitment and study materials
 - Interpretation of results
 - Considering the implications for patients and communities
 - Disseminating findings outside of academic journals

Draw on Existing Resources

- Review PCORI guidelines on engagement.
- Find the engagement resources in your research community and utilize them. Good places to look are your CTSA and any other community research advisory boards.
- Look for community groups that have a history of successful research collaboration or patient advocacy.