



General Information for Patient Partners

The following is a list of things to consider when you start engaging with a patient-oriented research project. This guide was created by other Patient Partners based on things that are important to them.

Who is who?

- Do you have contact information for the people on your team?
- Who will help you when you have questions or challenges with:
 - technology?
 - honoraria and expenses?
 - meeting support?
 - general questions about the project?
- Is there one person who can be your main contact?



Getting to know everyone

- Introduce yourself.
- Think about your story and what made you want to join this team.
- What do you feel comfortable sharing with the group?
- Ask the other team members why they wanted to be part of the team. Find out why this work matters to everyone.
- Not all research is about formal agendas; make sure your team knows how important it is for you to get to know everyone and build trust.



Understanding each other

- Remind your team not to use acronyms.
- Ask for a glossary or list of terms that will be used often during your project.
- Don't be afraid to ask people to explain things in the meeting; it will help remind them to be inclusive.
- If you need to follow up on something you don't understand, ask for a one-on-one conversation with the researcher or email them your questions if that is more comfortable for you.



Hearing from everyone

- Your lived experience is valuable to a patient-oriented research project. Share your opinions and perspective during meetings.
- Ask the team to send the meeting agenda out beforehand. This will ensure you know what the meeting is about and have enough time to determine what you want to share.
- Has the team created a way to connect between meetings?(e.g., phone calls, newsletters, email, Facebook group)
What method do you prefer?



Project information

- Can you describe the project in your own words?
- Find out about the timeline and funding for your project.
- Understand how the budget affects honoraria.
- Will this limit the amount you want to be engaged? Talk to your team.
- What would you like to learn more about? Do you want to learn about the research cycle? Is there other training that would be helpful? Let your team know.



Project goals

- What is the goal of this research project?
- Why is this project important to you?
- What would you like to get out of your time working with this research project?
- How will you know if you have had an impact?
- Is your project addressing research questions that are meaningful to yourself and other Patient Partners?
- Do you know the scope of the project and what you are trying to achieve?



Team charter

- What are the team's values?
- Do you know what your role will be? Help co-develop what you will do with your research team.
- Are there things that prevent you from being fully engaged? Let your team know what might help.
- Can you fully commit to the meetings? If you can't be there, let someone know and make a plan for catching up.
- Listen to a recording, read the minutes or meet with the researcher to go over what happened.



Terms of reference

- Does your team have a terms of reference agreement that you built together?
- Terms of Reference should tell you:
 - When you will meet.
(Are the meeting times flexible?)
 - Who will send out the agenda.
 - Who is taking minutes/notes.

