

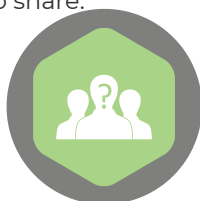


General Information for Researchers

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

Who is who?

- Use first names so that everyone feels welcome.
- Describe everyone's role on the team.
- Think about creating team bios to share.
- Create a contact list for the team.
- Identify who the Patient Partners go to when there is a problem.
- Who will provide IT support?
- Who will answer honoraria and expense questions?



Getting to know everyone

- Use ice-breaker questions and activities to build relationships.
- Consider informal check-ins with **every** meeting. E.g., How is everyone doing?
- Learn why this project matters to **everyone** on the team?
- How can you build trust?
- Ask your team what you can do to make them feel safe and supported.
- How can you encourage **everyone** on the team to share and ask questions?



Understanding each other

- Don't use acronyms during meetings.
- Create a glossary of terms specific for your project.
- Check in often to make sure everyone understands what is being said.
- Make sure your language is accessible - check the reading level of your documents.
- Create a description of your project **together**, using easy to understand language.



Hearing from everyone

- If you can, have more than one Patient Partner on the team so they aren't alone.
- Make space in meetings to hear everyone's perspective.
- Send out questions for consideration beforehand so everyone has time to think about them.
- Ask people how they want to connect (e.g., phone, email, newsletter, Facebook groups) and create a way to connect between meetings.
- Build your meeting agenda with your team.



Project information

- Be transparent & share details about the project, including the timeline and funding details.
- Look at how the budget affects honoraria **together**.
- Ensure the Patient Partners know when honoraria payments will go into their accounts.
- Share resources with Patient Partners who want to learn more.
- Explain the research cycle for everyone that is new.
- Share the history of the project.



Project goals & outcomes

- Can everyone on your team identify why they are there and why this project matters to them?
- Is your project addressing research questions that were identified by Patient Partners?
- What does everyone want to get out of their experience on your team?
- How will you track what impact the Patient Partners are having on your project?
- Is the scope of what you are trying to achieve clear?



Team charter

- Consider building a team charter **together**.
- It will help to:
 - Clarify the roles of your members.
 - Highlight what commitment to the team looks like.
 - Identify your team values.
 - Identify barriers to engagement & plan ways to overcome them.



Terms of reference

- Build your terms of reference **together**.
- It will help everyone know:
 - When you will meet.
 - Who will send out the agenda.
 - Who is taking minutes/notes.
- Make sure to include a communication plan for keeping everyone informed and connected.
- Consider flexible meeting times so everyone can attend.

