Onboarding Guide for New Patient-Oriented Research Teams

SCPOR

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.

Onboarding guide for Patient Partners new to a Patient-Oriented Research Team

SCPOR

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 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.