

# Tips for being a patient partner on research teams

## Setting off on the journey

### For the first meeting

- Ask for the name and contact of the main person you will be interacting with on an ongoing basis
- Request an in-person meeting to meet the team
- Ask to share your story and experience if they forget to ask
- Ask for background information on the project and other details

### Working together

- Work with the team to establish your role, let them know what you can and can not contribute
- Determine if you can commit for the duration of the study and follow through if possible
- Ask questions! Particularly if a concept or step in the study is unclear
- Check your expectations, know there are limitations to the impact the research can have

## It's all part of the adventure

### Be flexible and open

- Be flexible with changes in the research study process
- Research can be subject to change due to: funding issues, adjustments research timelines due to recruitment or other challenges, turnover in staff or team members
- Let them know when your availability or schedule changes too

### Your contributions

- You are not expected to represent all patients
- However, you are representing a patient perspective, if you are aware of other patient perspectives share it with the team
- Note - a research team is not the right forum to do patient advocacy
- Come prepared: review the agenda and read the materials
- Share your feedback

**Spectrum of  
Engagement**

**Inform**  
Provide  
information

**Consult**  
Obtain feedback

**Involve**  
Develop  
alternatives

**Collaborate**  
Partner in  
decision-making

**Empower** ✨  
Decide



# Patient Engagement for Research Teams

## Getting things off the ground

### For the first meeting

- Meet in person
- In advance provide information about the research study, meeting times, agenda and other materials
- Ensure all team members are introduced at the first meeting
- Avoid hierarchical labeling, hint: the title of “Dr” can be intimidating
- Keep the use of acronyms to a minimum, always define acronyms
- Give the patient partner time to share their story with the team

### Establish roles together

- Identify expertise of patient partners such as public speaking and other skills they can contribute
- Identify the level of engagement through the research cycle
- Set realistic expectations for the research study impact
- Discuss what happens at the end of the research study

## Keeping the Project moving

### Be flexible and open

- Change the job/volunteer description as needed
- The patient partner’s schedule, availability, and health status may change
- Check-in with the patient partner for changes in interest, schedule, or other needs

### Demonstrate appreciation

- Communicate at each step of the research process so patient partners know what to expect and feel that they are kept informed.
- Ask for patient partner’s reflections and feedback on the process and the project
- Remember to budget for reimbursement of out-of-pocket expenses
- Be aware that 2 (or so) patient partners are not representative of the whole population

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