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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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✨ Adapted from the IAP2 Spectrum of Public Participation

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