

Tips for Patient-Partners Engaged in Patient-Oriented Research

Many of the tips below are based on the responses of CHILD-BRIGHT members, both researchers and patient-partners (mainly parents and caregivers), to the open-ended questions in the Public and Patient Engagement Evaluation Tool (PPEET) survey (you can read more about the study [here](#) (blog). We have done some minor rewording of some of the responses to put them in the form of tips. To these, members of CHILD-BRIGHT's Citizen Engagement Council added tips of their own.

GETTING STARTED



Assess your motives & expectations

1. Identify (even if only to yourself) your motive(s) for becoming a patient-partner. Be willing to probe.
2. Ask researchers about their motives for working on/leading this project and for including patient-partners.
3. Assess and consider discussing whether your motives and those of the researchers align, conflict, or neither closely align nor conflict.
4. Discuss with team members what contribution you expect to make and what contribution you are expected to make. Let them know what role(s) you would both like to play and feel comfortable playing. You should review your role(s) periodically while engaged in the project.
5. Ask whether, as a patient-partner, you will be expected to describe parts of your own individual experience or your own family's experience. Many have found it helps to decide ahead of time what aspects or details of your and your family's experience you do not want to share or refer to. You can and likely will draw upon that experience while contributing to the project whether or not you choose to disclose certain details.



Ask others

6. Ask others, especially the leaders of your team or committee, whether you were recruited to be or are regarded as a representative of a particular group or community. And ask yourself if—in this role—you regard yourself as such a representative. (While having patient-partners from a diversity of backgrounds is certainly desirable or even necessary, some think it unfair and not useful to expect patient-partners to be representatives.)



Identify your particular skills, experiences, and knowledge

7. Identify particular skills, experiences, and kinds of knowledge not related to your lived experience as a patient or caregiver (perhaps related to your education, your work, or a particular interest) you might be able to draw upon in contributing to the project. Inform the appropriate person on the research team about them.

COMPENSATION FOR YOUR TIME AND YOUR WORK



Ask about compensation

8. If the project has yet to receive grant funding, ask how likely it is that it will be funded and whether you will be compensated for your contribution to the development of the grant planning (whether or not the project is funded).
9. Discuss how much, how often, and in what form you will be compensated. (Some patient-partners turn down compensation; most do not.)
10. Check whether the compensation will affect your eligibility for certain government income supports or the amount of support you receive.
11. If the amount or nature of your work changes and you think your compensation should be adjusted accordingly, let your contact person know.

DETAILS ABOUT WHAT YOU WILL DO



Obtain more information about the project

12. If you joined the project after the grant application has been completed—and perhaps after the project has begun—ask which parts of the plan (for instance, the choice or order of outcomes or the tool used to measure quality of life) can be changed and which cannot.
13. Ask about how much time you are expected to devote to the project every week or month, when there are likely to be busy times or times when you will have little or nothing to do, and how you will be notified of changes to the project timeline.
14. Don't hesitate to ask about the meaning of unfamiliar terms or acronyms when they are used in meetings and ask about a glossary that can help you understand commonly used terms in research. You might also create and add to your own glossary. (Learning some “research language” can be helpful, but the process is a gradual one and should not be rushed.)

COMMUNICATION STRATEGIES AND MEETINGS



Communicate your preferences with your contact person

15. Make sure you have a contact person on the team who you can ask about materials you need, changes in the time you are able to spend on the project, questions related to reimbursement of expenses, etc.
16. Let others know how you prefer to communicate, whether it be by phone, email, text, and so on.
17. Let team members know if you prefer to meet in small groups or have one-to-one conversations instead of larger group meetings.
18. If “untraditional” meeting days and times (for instance, weekends or evenings) are best for you, or the only times you are free, let your contact person or the rest of the team know.



Get clarity

19. If after a meeting you feel uncertain about why you were asked to attend, what value there was in your attending, or what the point of the meeting was, tell your contact person. Discuss with that person (or someone else on the team) how the problem can be addressed.



Identify your role during meetings

20. Consider whether it would be helpful for you or another patient-partner to play a particular role in meetings (perhaps chairing or co-chairing it). If you think it would, make the suggestion.
21. Like all other participants in a meeting, avoid actions that distract or show others that you are not paying attention (for instance, checking your phone or email, having side conversations, etc.)



Suggest meeting accommodation and processes

22. Make sure others know how far ahead of a meeting you need to receive the minutes of the previous meeting, the agenda for the upcoming meeting, and any other relevant documents to be able to review all in time to prepare.
23. If you require an accommodation to prepare for or participate in a meeting, be sure to let the appropriate person know in advance.
24. If you think another venue (such as a less formal or institutional one) or format (such as interactive breakout segments or a check of action items from the last meeting) would improve the meeting, make a suggestion.

CHALLENGES WITH ENGAGEMENT



Reach out!

25. If your ability to participate changes (for instance, due to a change in your or a family member's health or to a change in job status or school schedule) or if your interest in participating has diminished, let your contact person know. If you need to take a leave of absence, request one.
26. If you are hearing less than expected or promised about the project, let your contact person know and ask for an update.
27. If you are hearing more than expected or desired about the project or the research network the project is part of, let your contact person know and discuss which communications are needed and which are not.
28. If you can't see any effect or impact of your contribution on the work of the project over time, ask whether others see an impact and what it is.

BENEFITS OF ENGAGEMENT



Recognize your contribution & share

29. Make a list of your contributions and of all that you've learned.
30. Be sure to let others know the particular ways they've helped you and thank them.

The Report: The CHILD-BRIGHT Network Measuring Patient Engagement Working Group. Stakeholder Engagement in the CHILD-BRIGHT Network, 2018 to 2020, Preliminary Findings [Internet]. October 2021. Available from: https://child-bright.ca/s/ENG_Stakeholder-Engagement-Evaluation-Report_Oct-2021_Final.pdf

The CHILD-BRIGHT Network Measuring Patient Engagement Working Group
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