

Tips for Researchers Working with Patient-Partners

Nearly all the tips below are based on the responses of CHILD-BRIGHT members, both researchers and patient-partners, 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



Engage early and be clear about your project

1. Engage patient-partners as early as possible in the research process.
2. Make it clear to patient-partners who join before a project is funded how likely it is that the project will be funded. (Try to be realistic.)
3. Discuss with patient-partners who join after the initial stage what can and cannot be modified, for instance, the selection of outcomes or the determination of inclusion criteria.



Clarify motives & expectations

4. Ask patient-partners about their motives for joining the project and tell them about your motives for leading or participating in the project and for including patient-partners. (Please be candid.)
5. Tell patient-partners, as specifically as possible, what you hope they will contribute and what roles you expect them to play. Then ask them what they hope—and perhaps expect—to contribute and what roles they would like to play. Discussion, even negotiation, should be welcomed. You might consider jointly writing down the role description you and the patient-partner(s) land on.
6. Ask patient-partners how much time they expect to devote to the project. Discuss what help you and others can give them and what help they anticipate needing.
7. Make sure every patient-partner knows whom to contact about scheduling, changes in availability, agenda items, compensation, etc.
8. Make sure to indicate an awareness and an acceptance that circumstances may, at least for a time, reduce the time patient-partners can spend on the project and/or change the ways they can participate.
9. Offer patient-partners choices about how they can participate (e.g., small group meetings, one-on-one meetings, email contact, etc.).
10. Ask patient-partners about their experience with research (either as participants or partners) and tell them about any experience you have with patient-oriented research, what you learned, and what you would still like to learn.
11. Create a timeline for the project that includes expectations of how much and in what ways patient-partners will be involved in different stages of the project and review the timeline periodically (every six months perhaps), noting changes and the reasons for those changes.
12. Make clear to patient-partners that they do not have to describe or make reference to their own or their families' particular diagnoses or healthcare experiences—though they may choose to do so—to participate in and contribute to the project.



Talk about the scientific jargon and vocabulary

13. Avoid acronyms and jargon and tell patient-partners to let you know whenever they don't understand something you have said or written.
14. Make clear that, depending on their roles, patient-partners may have to become familiar with some specialized vocabulary if they are to be full members of the team. Some, for instance, may need to know the difference between statistical and clinical significance or between a primary and a secondary outcome. The key is to provide the resources (e.g., a glossary) and the support (e.g., a go-to person) they need.

MAKING MEETINGS WORK WELL—FOR EVERYONE



Prepare meetings far in advance and involve patient-partners in the organization

15. Send agendas and meeting materials long enough before meetings (at least a couple of days) for patient-partners to be able to review them and prepare questions and suggestions.
16. Schedule meetings as far in advance as possible—perhaps scheduling all of the meetings in a year at once—after checking with the entire team about preferences and availability. Remember that sometimes “untraditional” meeting times (e.g., evening hours) are most convenient or perhaps the only possible times for patient-partners.
17. Make sure the person who is connecting with patient-partners and running the meeting has the time to do this work, is a good facilitator, and makes an effort to include everyone in discussions.
18. Consider asking a patient-partner to chair or co-chair a team meeting, ensuring that the patient-partner is not a nominal chair or co-chair. Be sure to compensate the patient-partners for the extra work required.



Have an interactive meeting

19. Identify the purpose(s) of every meeting at the start.
20. Begin meetings on time and avoid actions that distract or show that you are distracted (e.g., checking your phones/email or having side conversations with colleagues during a meeting).
21. Pause during meetings to allow for questions or comments and allow pauses to be long enough to give those who might be hesitant a chance to speak up.
22. Pay attention during meetings to signs that patient-partners may be confused, anxious, or bored.
23. Check one-on-one with patient-partners after the first meeting they attend and then periodically after (perhaps every six months) about how well the time, duration, or and format of the meeting(s) are working for them.
24. Consider periodic (such as monthly or quarterly) informal “coffee meetings” with the whole team.
25. Make sure patient-partners know whom to contact if they have to miss a meeting, if they have questions about the agenda or items to add to it, or if they want to follow up on something after a meeting.

SUSTAINING AND DEEPENING ENGAGEMENT OVER TIME



Involve patient-partners in your long-term plans

26. Review the project timeline (see tip #11) with patient-partners at least twice a year, noting any changes and the reasons for those changes and discussing with patient-partners the effect of those changes on patient-partners and on the project itself.
27. Allow for flexibility in the active engagement of patient-partners. They may go through periods where their other responsibilities reduce their ability to participate or even render them unable to participate at all. A formal leave of absence may make things easier and clearer for everyone. Don't, however, assume that changed circumstances, even a new serious health problem, will cause a patient-partner to want to suspend his or her participation or his or her communication with the team.
28. When patient-partners do something well, tell them.
29. More specifically, tell patient-partners how their suggestions, questions, insights, or cautions were used and what difference they made to the design or conduct of the project or to the analysis and dissemination of the findings.
30. Consider using the “track changes” function in documents to identify the particular results of the patient-partners' involvement and make sure the patient-partners see the actual changes their involvement effected.
31. When suggestions from patient-partners cannot be adopted, tell them why.
32. Disseminate final project results to all the patient-partners in the project, including those who may have left before it ended.

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

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