Stakeholder Engagement in the CHILD-BRIGHT Network, 2018 to 2020

Summary of Preliminary Findings

How did it all start?

In 2018, we launched our first engagement evaluation. We were interested in how different Network members experienced involvement. We invited researchers, patient-partners (including parents and youth), trainees, and committee members to complete an online survey, the **Community-Based Participatory Research (CBPR)** questionnaire. We sent the CBPR to stakeholders in 2018, 2019, and 2020.

What were our main CBPR findings?

2018 167 respondents*	86%	91%
	Researchers felt they engaged with patient-partners in their CHILD- BRIGHT research to a moderate or great extent.	 Patient-partners felt comfortable sharing their opinions with CHILD-BRIGHT. 83% felt it was a true partnership. 84% were satisfied with their level of involvement. 88% felt there were high levels of trust.
2019 92 respondents*	100% All researchers felt that they had engaged to a great degree with patient-partners.	 100% All patient-partners reported agreeing to feeling comfortable sharing their opinions. 81% agreed that their engagement represented a true partnership. 89% noted that they were satisfied with their level of involvement.
2020 62 respondents*	100% All researchers felt that they had engaged to a great degree with patient-partners.	100% All patient-partners had high levels of trust and were satisfied with their level of involvement. Patient-partners had the highest level of involvement in creating research instruments or guidelines and in disseminating or sharing findings.

Responses were consistently very positive. The pattern showed growing patient engagement and a deepening of the quality of the partnerships.

How has patient engagement measurement unfolded since then?

In 2020, we aimed to further enrich our understanding of patient engagement and proceeded to conduct projectspecific engagement evaluations using a different online survey, the Public and Patient Engagement Evaluation Tool (PPEET).²

What did we find using the PPEET survey?



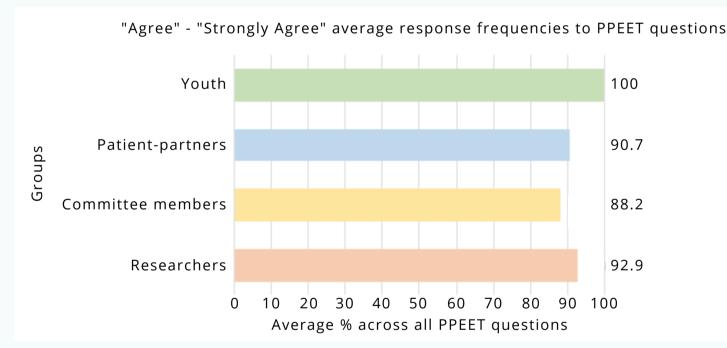
105 Network members completed the PPEET surveys.*

Patient engagement and its impacts were consistently highly rated across the different CHILD-BRIGHT Network stakeholder groups, especially within research project teams.



Researchers, committee members, and patient-partners reported high levels of satisfaction with patient engagement in the Network.

Figure 1. Agreement to PPEET questions



Example of a PPEET question: Patient-partners have the supports they need to participate (e.g. meetings time and methods, travel, accommodations, etc.).

What is the take-home message?

Our findings to date suggest we are effectively implementing strategies for authentic and impactful patient-oriented research. Overall, patient-partners are satisfied with their level of engagement in the Network's research and governance. The quality of patient engagement is highly rated across the different stakeholder groups of the Network.

What are our next steps?

Our evaluations have shown us **areas for improvement**, including:









Helping stakeholders adjust their availability to the requests made.

Communicating more effectively to clarify project goals and to allow stakeholders to stay actively involved. Increasing the diversity of our group members.

We will analyze the open-ended responses to the CBPR and PPEET surveys in more detail. The Network has also conducted semi-structured interviews with different stakeholders to complement those findings, which are currently being analyzed.

*The full breakdown of the stakeholders who completed the CBPR and the PPEET is available in the report (below).

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://childbright.ca/s/ENG_Stakeholder-Engagement-Evaluation-Report_Oct-2021_Final.pdf

References

- 1. The University of New Mexico, Health Sciences Center, Center for Participatory Research. CBPR Project: Research for Improved Health 2009 - 2013 [Internet]. Available from: https://cpr.unm.edu/research-projects/cbpr-project/researchfor-improved-health.html
- 2. McMaster University Faculty of Health Sciences. PPEET Public and Patient Engagement Evaluation Tool [Internet]. Available from: https://ppe.mcmaster.ca/our-products/public-patient-engagement-evaluation-tool

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