

CHILD-BRIGHT's Compensation and Recognition Guidelines for Partners with Lived and Living Experience (PWLE)

These guidelines support the contribution of partners with lived and living experience, or PWLEs (formerly known as patient-partners), in research, governance and other activities as CHILD-BRIGHT members. The term “PWLE” refers to children, youth, and adults with lived or living experience of a brain-based developmental disability who are involved in patient-oriented research (POR) projects, committees, and other CHILD-BRIGHT activities. It may also include research partners who are parents, caregivers, or family members of children, youth and adults with lived or living experience of a brain-based developmental disability. In this document, PWLE is the acronym used to describe these research partners engaged in patient-oriented research in our network.

The PWLEs involved in CHILD-BRIGHT's network activities are offered compensation in recognition of their contributions.

For each fiscal year, compensation is paid twice yearly, in November and in May. A PWLE may choose not to be compensated. For example, for fiscal year 2024 (running April 1, 2023 to March 31, 2024) requests should be submitted by **May 10, 2024**.

Guidelines for research project coordinators, program coordinators, and committee chairpersons:

- A PWLE should be able to make an informed choice about whether to participate in a research project. Research project coordinators, program coordinators, and committee chairpersons should provide the best estimate of time and effort required specific to the project or committee.
- Expectations of attendance, contribution, financial considerations and designated compensation should also be communicated before the PWLE's activity with the project or committee starts.
- Send any requests, questions or concerns to the CHILD-BRIGHT Network's Engagement Program and Projects Manager at engagement@child-bright.ca

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Research project coordinators, program coordinators, and committee chairpersons must submit:

- 1) A complete/updated list of the PWLEs on their project, program, or committee.
- 2) Annual compensation expectations for PWLEs on their project, program, or committee. This includes participation in network-level activities, such as responding to network surveys on training and engagement, or participating in an interview.
- 3) Should a PWLE (or activity for which PWLEs will be compensated) be added to a project or committee plan after May 10, please advise CHILD-BRIGHT immediately at engagement@child-bright.ca

Suggested compensation amounts are described in the table below. The amounts reflect the estimated [level of engagement](#) required for these different activities.

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Role	Commitment	Responsibility	Scope	Suggested Compensation
Member of the research project team as a PWLE	Availability by email; willing and able to participate in 3 to 5 meetings by phone or in person per year, attending training may be required	Contributes advice and feedback for decision making by research team	Partnering on a specific research project	\$600.00 per year (15-20 hours of work per year)
Additional duties on a research project/committee	Running breakout Zoom rooms Moderating group chats Interviewing participants Other work	Varies	Depends on the work and project	\$30 per hour, up to an additional maximum of \$600 per year
Network activities	Completing 2 yearly surveys, reading newsletters & sharing network information, talking with the Parent Liaison, Knowledge Mobilization, or Communications team (for blog posts, etc.) Attending optional training	Depends on chosen task	Complete 2 surveys (e.g., engagement surveys, training surveys) and do at least one of the other activities each year	\$100 per year (3-4 hours of work per year)

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Role	Commitment	Responsibility	Scope	Suggested Compensation
<p>Member of one or more CHILD-BRIGHT committee(s):</p> <ul style="list-style-type: none"> -Training & Capacity Building -Knowledge Mobilization -Engagement Council - <p>Partners with lived and living experience (PWLE)</p> <ul style="list-style-type: none"> -National Youth Advocacy Council (NYAC) - Implementation Science Research - Equity, Diversity, Inclusion – Decolonization and Indigenization (EDI-DI) 	<p>Commitment to a committee (includes meetings, follow-up actions, etc.)</p>	<p>Participates in decision making by providing options and recommendations</p>	<p>Activity has a network-wide mandate</p>	<p>\$1,000.00 per year (30-35 hours of work per year) per committee membership</p>
<p>Indigenous Advisory Council (IAC) Member</p>	<p>Email availability. Willing and able to participate in 3 to 5 virtual meetings per year and commitment to a committee (includes meetings, follow-up actions, etc.)</p>	<p>Varies between feedback for decision making within the network and/or towards the research projects. Compensation should be based on knowledge, lived experiences, and time contributed rather than solely based on the identity of First Nations, Métis and Inuit Peoples</p>	<p>Activity has a network-wide mandate</p>	<p>\$33.19 (Urban) - \$39.35 (Rural/Remote) per hour. Maximum of \$800 per year (15-20 hours of work per year) *</p>

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Member of a working group	Commitment to a group stemming from a program (e.g., Annual General Meeting planning committee, Engagement Working Group on Measurement, EDI, POR Toolkit etc.)	Collaborates with group members towards program/network-related goals or outputs (varies)	Activity has a network-wide mandate	\$30 per hour up to a maximum of \$600 per year per working group
Member of a committee as a chairperson or co-chairperson	Chairperson or co-chairperson	Previewing agendas, planning meeting content, leading meetings	Activity has a network-wide mandate	\$100 preparation in addition to the committee honorarium (3-4 hours of work per year)
Member of the CHILD-BRIGHT Network Steering Committee	Contributing member of a governing committee (includes meetings, follow-up actions, etc.)	Has joint responsibility for decision making and mobilizing Initiates and leads activities	Activity has a governing mandate for the network	\$1,000.00 per year (30-35 hours per year)
Member of the CHILD-BRIGHT Executive Committee	Contributing member of the executive committee (includes meetings, follow-up actions, etc.)	Has joint responsibility for all network-level activities and budgets	Activity has a governing mandate for the network	1,500.00 per year (48-53 hours per year)

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Role	Commitment	Responsibility	Scope	Suggested Compensation
Presenter	Preparing presentation and materials (e.g., slides) and delivering a presentation	Preparation and delivery of a formal presentation, either in person or via a webinar, after working with organizers to ensure alignment with objectives	Making a formal presentation at the CHILD-BRIGHT Annual Meeting or a training/KM session	\$100 - \$200** Depends on length of presentation and preparation required
Panelist or small group facilitator	Preparing for and performing the role as a PWLE representative	Participation in an informal panel or facilitation of a small group	Being part of an informal panel or facilitating a small group at the CHILD-BRIGHT Annual Meeting or training session	\$30 per hour** Pay for preparation, meetings prior, and event itself.
Attendee – conference as CHILD-BRIGHT representative	Representing CHILD-BRIGHT at a SPOR Summit or other event	Attending an event and reporting on it to the appropriate network's Executive member	Active participation at an external event as a PWLE	\$100 per ½ day** \$200 per full day
Attendee – mandatory training	Time of training session and any preparation	Check if the training falls outside the scope and hours paid by projects or committees	Attending and participating in the training	\$30 per hour** Maximum of \$200 per full day
Engaging children under 10 years of age	For example, reviewing an assent form or interview questions for young children	Should be kept short and reasonable for the age of the individual	Project level	\$20 per task (minimum \$15 per hour) in gift cards***

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In cases where a PWLE in a project contributes substantially more over the course of a year than is described under “Commitment” and “Responsibility” in the first row, compensation should be calculated at approximately \$30 per hour for the additional work, up to a maximum of \$600 additionally per year. If the project and the PWLE agree that the PWLE’s role and contribution should be compensated at an amount greater than \$1,200 per year, the amount over \$1,200 should be paid from the project’s budget.

***For the IAC:** Individuals providing substantial aid or assuming leadership roles within the IAC & its initiatives shall be subject to these compensation criteria. Conversely, participation in initiatives as a council or committee member, encompassing diverse or general mandates, may not fall under these guidelines. Please refer to our [website](#) for guidance on engaging First Nations, Métis, and Inuit advisors. Alternatively, you may consult with the CHILD-BRIGHT EDI-DI co-leads and/or coordinator.

**The PWLE and/or the researcher must obtain approval for these activities from the CHILD-BRIGHT Executive Committee prior to the event, or the payment may not be made.

***When engaging children under 10 years of age, consider how the parents will be supporting their child to engage. You may need to consider payment to parents for travel and/or for their role as a support person during meetings depending on the circumstances.

CHILD-BRIGHT suggests a rate of \$30 per hour as a guideline for compensation for roles outside of those listed above. Please contact and discuss compensation with your PWLE before the work begins to ensure the expectations are clear on both sides. Any amounts paid by the CHILD-BRIGHT Network not in budget forecasts should be cleared by the Director of Engagement before offers are made.

Travel expenses

Travel expenses (e.g., airfare, ground transportation, hotel, food) that are reasonable and necessary for participation in network-wide activities, such as the annual meeting or face-to-face committee meetings, will be covered in line with the reimbursement policies of the host institution for the project or program administering the PWLE’s activities. Included in these expenses are those incurred by parents to provide care for their children while they engage in project and network activities.

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Childcare and support person expenses

CHILD-BRIGHT will reimburse PWLE \$15-20 per hour for childcare or support person costs, up to a maximum of \$500 per event. Please consult with the Engagement Program at engagement@child-bright.ca if your childcare support person costs exceed this amount. PWLE must submit a request for reimbursement for travel and childcare/support person costs in advance of the event and for receipts (or other appropriate documentation) after the event. If pre-approved, compensation for these activities will be covered by the CHILD-BRIGHT Network Central Office budget.

Tax information

Note: The PWLE should be advised that compensation (including money and/or gift cards) received as compensation or recognition of their participation in network activities are subject to relevant tax laws and must be reported on both federal and provincial tax forms. Research leaders or committee chairs should inform PWLE that compensation has the potential to impact PWLE's financial situation and inform them that it is the PWLE's responsibility to determine whether payment is the right fit for them.

Other information

Note: PWLE cannot request payment from CHILD-BRIGHT if they work for an organization that also pays them for those same hours worked.

Considerations in PWLE recognition

In addition to compensation, research leaders and committee chairs should also carefully consider what recognition would be appropriate for their PWLE (e.g., named on grant applications, websites, presentations, and research articles).

It is also important that research leaders and committee chairs clearly inform PWLE when anonymity is not possible when being part of a research team, unlike when they are a participant in a research project. As many grants, competitions, and even scientific journals require engagement with PWLE, being a member of a research team may mean the PWLE's name will be included in grant applications and on project materials.

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Ethical considerations

Note: PWLEs should consider public recognition carefully, as it may involve ethical implications for their family, such as the publication of personal health information about their child or family. Research leaders and committee chairs should keep track of where PWLEs agree to have their names released and should collect consent prior to publishing or disclosing any details shared by PWLEs about their family or personal journey.

Other considerations (e.g., co-authorship)

When discussing certain recognition activities, research leaders and committee chairs should ensure that PWLEs understand what additional work may be required and understand if that work will be compensated.

Final remarks

As with most work with PWLEs, preferences may vary widely between partners, so research leaders and committee chairs must ensure they collect consent and keep channels of communication open.

These guidelines are reviewed and updated by the CHILD-BRIGHT Engagement Council – Partners with Lived and Living Experience (PWLE), the National Youth Advocacy Council (NYAC), and the Network Steering Committee yearly, at a minimum.

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