

Chronic Pain Network: People With Lived Experience (PWLE) Compensation and Appreciation Guidelines

About PWLE Compensation and Appreciation Guidelines: The Compensation and Appreciation Guidelines aim to recognize the valuable contribution of PWLE in research and knowledge mobilization activities, while enacting fundamental principles of Canada's Strategy for Patient-Oriented Research (SPOR) Patient Engagement Framework.

What can PWLEs expect?

- Respect for your time, experiences, knowledge, and the recognition of your participation.
- Meetings scheduled at times and locations that accommodate most participants (a doodle poll or recurring standing meeting dates/times will be conducted before any event/activity).
- Attendance and participation in meetings through virtual options will be available, where possible.
- Co-designed meeting materials and agendas provided with enough time in advance for review and reflection.
- Accommodations for disability and health requirements as requested by participants.
- Openness and willingness to listen to and consider your feedback; ask questions and solve problems openly and collaboratively.
- Commitment to working with and learning from you.
- Training and support where/if required.
- Addressing and responding to your questions and concerns.
- Honorarium for your time, efforts, and expertise (if you wish to accept it).
- Payments or reimbursement of expenses to participate in meetings and events

Expectations from PWLEs

- Declare all actual, potential, or perceived conflicts of interest.
- Read the terms of reference and ask for support if needed.
- Respect the privacy and confidentiality of all meeting proceedings and attendees.
- Arrive for meetings prepared or ask for support.
- Participate in all activities as arranged and provide the committee with reasonable advance notice, whenever possible, if unable to attend the event/meeting.
- Participate in discussions, provide feedback, constructive input, and criticism; raise issues; ask questions; and solve problems collaboratively.
- Draw upon knowledge, networks, and experience to provide input into discussions and decisions.
- Track and claim hours/activities using the standardized online form.
- Act as a champion for future work and engagement.

Rates of Compensation

Rates of compensation can be found below in *Table 1*, a list of eligible activities that PWLE can receive compensation for has also been included. If there are other activities that are not included in the list below, please consult with the Patient Engagement Lead, Chronic Pain Network. Travel and meal cost reimbursement will also be offered as appropriate (see *Table 2: Eligible Expenses*), original receipts will be required for reimbursement.



Table 1. Time and Compensation Rate

Time frame	Rate	Details
Hourly rate for any network activity	\$25	Hourly standard rate
Full day event	\$200	Flat rate

Eligible Network Activities for Compensation

- Time spent on meeting preparation.
- Time spent on attending the network meetings.
- Reviewing the network's documentation (grant applications, guidelines, letters of support, etc.)
- Any training carried out for joining the network or as a network requirement.
- Time spent working on network initiatives or projects.

The compensation guidelines do not apply to patient partners who are engaged in research projects. Researchers who approach the Chronic Pain Network for a suitable patient partner match for their research are advised to discuss the remuneration options with each patient partner to determine the right fit. Different research teams and institutions will offer different rates for engagement in research. This is because there is no set guidance, and some organizations can afford to pay more than others.

Distribution and Frequency of Payments

- Upon onboarding as a patient partner for the Network, you will be asked to submit your address, date of birth, and Social Insurance Number (SIN). This information is used for processing any honoraria.
- Payments will be made every quarter after patient partners submit their hours to the online form found here: https://app.smartsheet.com/b/form/e25233c0f89b432d92eb79addf4b6f75
- All payments for meeting honorarium will be processed_one month after every quarter (i.e. January, April, July, October).
- Travel forms and receipts will be required to reimburse these expenses. They will be
 processed within one month of the event, allowing an additional three weeks for
 processing and delivery. Travel expenses will be processed separately from meeting
 honorarium compensation.
- Cheques will be mailed directly to the patient partner's home address by McMaster University. Note that only cheques can be issued for compensation (ie. gift cards are not permitted). A T4A may be issued by McMaster University annually.

Patient Partners may choose to not receive compensation or only partial compensation for their contribution to the Network due to individual circumstances, such as pension or benefit payments. Income can be deferred for up to 6 months after submission.

Figure 1. Process of reimbursement

Complete the online form

Approval (Lead & Coordinating Centre)

Cheque mailed to home address

For more information contact Patient Engagement Lead, Chronic Pain Network at divyakanwar.bhati@painbc.ca.



Table 2: Eligible expenses for People with Lived Experience (PWLE)

Activity	Description	Amount
Travel	Travel costs for any involvement are covered. This includes economy class airfare, train fare, bus fare or mileage. Taxi fares are covered for short distances.	Reimbursement or covered directly. Mileage is reimbursed at 68¢ per kilometre for the first 5,000 kilometres driven. 62¢ per kilometre driven after that. Parking costs will also be reimbursed.
Overnight accommodation	If participating in a network activity requires their attendance, the PWLE's overnight accommodation (hotel) will be covered. Overnight accommodation in a private residence	Reimbursement or covered directly. \$30/night payable to the PWLE, not the lodging host.
Meals	Reasonable out-of-pocket expenses for meals are covered for time spent away from home with original receipts. Alcohol charges are not covered. Only meal costs incurred while on Network business or during travel for Network business may be claimed. The meal allowance includes gratuities and taxes. The per diem allowance will not apply where meals are included as part of another reimbursable item (for example, conference and transportation). The per diem claim should be reduced accordingly.	A per diem meal allowance may be claimed in lieu of actual costs of \$98.45/day= 21.90/breakfast, \$22.15/lunch \$54.40/dinner) in Canadian dollars for travel in Canada or U.S. dollars for travel outside Canada.
Personal Assistants	Some people with disabilities may have a personal assistant to support them in being actively involved as a PWLE. Approval from the Coordinating Centre is required.	Reimbursement or covered directly
Childcare	 Childcare expenses while a nursing mother or single parent is travelling: The eligible cost for a single parent is limited to overnight childcare costs incurred while the grantee is travelling. The eligible cost for a nursing mother who is travelling with a child is limited to the customary cost of childcare and airfare if applicable. If travelling with a caregiver, travel and accommodation costs can be claimed in lieu of and up to the equivalent of childcare costs. 	Reimbursement or covered directly

Approval of these guidelines

These guidelines were written by the Chronic Pain Network staff with advice from the Patient Engagement Committee members. This document has been viewed and approved by all the network patient partners and the CPN Executive Committee members. The document will be reviewed regularly to reflect any provincial or national changes.

Document version and review:

Version	Author and approval	Date
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	Approved by the Patient Engagement Committee	
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	Committee, and All CPN Patient Partners	
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