

The Chronic Pain Network (CPN) is a national collaboration of patients, researchers, healthcare professionals, educators, industry and government policy advisors with a goal to direct new research and train researchers and clinicians, ultimately translating research finding into knowledge and policy. The goals of the network are to increase access to care for people living with pain and speed translation of research into care.

As one of CIHR's Strategy for Patient Oriented Research (SPOR) networks, the CPN aligns with their vision that the involvement of patients in health research will lead to improved health outcomes and an enhanced health care system.

Patient Oriented Research is a continuum of research that includes patients as partners. It focuses on patient-identified priorities in order to improve patient outcomes. It is conducted by multi-disciplinary teams in partnership with relevant stakeholders and aims to apply the knowledge generated to improve healthcare systems and practices.

Patient Engagement in Patient Oriented Research is meaningful and active collaboration with patient partners in governance, priority setting, designing and conducting research and knowledge translation. It is research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them (from CIHR's Foundations in Patient Oriented Research Module 1, INVOLVE).

Patient partners as defined by CIHR are understood to include individuals with personal experience of a health issue and informal caregivers including family and friends. All patient partners can receive compensation for their contribution to the Chronic Pain Network.

Guiding Principles for Patient Engagement in Research:

- **Inclusiveness** – "patients are bringing their lives into this"
- **Support** – safety, cultural competence, training, education
- **Mutual Respect** – acknowledge each other's' experience and experiential knowledge as evidence
- **Co-build** – working together as partners from the beginning

Ref: CIHR's Foundations in Patient-Oriented Research Module 1, SPOR Patient Engagement Framework 2014

Types of Contributions:

At the time of writing, the CPN has 12 committees, each with at least 2 patient partners. Committee meetings vary in their scheduling from bi-yearly to monthly. Meeting length is usually 1-2 hours. We anticipate there will be one in-person meeting each year of the network for an annual general meeting. Overall, the patient roles will vary according to the contributions the patient is able to offer.

What the Network Asks of Patient Partners:

- Declare all actual, potential or perceived conflicts of interest;
- Demonstrate preparedness for meetings;
- Take part of all meetings and teleconferences (as health & life permit)
- Openly and constructively participate in discussions, provide feedback, raise issues and solve problems collaboratively;
- Foster and contribute to an open, collaborative climate, independent of personal vested interests;
- Work for the benefit of the Network;
- Actively provide constructive criticism;
- Draw upon knowledge, personal and professional networks, and experience to provide informed input into discussions and decisions;
- Act as a catalyst for further patient engagement.

Ref: Adapted from Terms of Reference for Patient Advisory Committees, Université de Montreal Centre of Excellence for Partnership with Patients and the Public.

What Patient Partners Can Expect from the Network:

- Respect for your experiences, knowledge, and the vulnerability that your engagement may bring;
- Meetings to be scheduled at times that work for you;
- Openness and willingness to listen to and consider your feedback;
- Collaborative spirit;
- Commitment to work with and learn from you;
- Understanding that sometimes your health and life will not allow you to participate fully;
- Honorarium for your time and efforts
- Payment of expenses required for Network business and meetings.

The following table breaks down the different compensation rates for the various roles of patient partners, as well as the different eligible expenses.

Table 1: Eligible expenses for Patient Partners of the Network

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
Overnight Accommodation	If taking part in a network activity requiring their attendance, the patient partner's overnight accommodation (hotel) will be covered. Overnight accommodation in private residence	Reimbursement or covered directly \$25/night
Meals	Reasonable out of pocket expenses for meals are covered for time spent away from home with original receipts. Alcohol charges are not covered.	Reimbursement or covered directly

Personal Assistants	Some people with disabilities may have a personal assistant to support them to get actively involved as a patient partner.	Reimbursement or covered directly
Childcare	<p>Child care expenses while a nursing mother or single parent is travelling:</p> <ul style="list-style-type: none"> The eligible cost for a single parent is limited to overnight child care 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 child care and airfare if applicable. If travelling with a caregiver, travel and accommodation cost can be claimed in lieu of and up to the equivalent of child care costs. 	Reimbursement or covered directly

Table 2: Compensation rates for Patient Partners of the Network

Activity	Description	Amount	Half Day	Full Day
Training and learning	Training and learning sessions required and/or hosted by the Network (online or in person)	\$50/ session	\$125	\$250
Annual Meeting	In person attendance at the CPN Annual meeting	Flat Rate	\$125	\$250
Committee Meetings	In Person committee meetings outside of the annual meeting	Flat Rate	\$125	\$250
Committee Member Role/ Consultant Role	The patient partner provides his/her opinion, advice or feedback as a member on a Network Committee	\$50/ meeting		
Project Consultant Role	The patient partner provides his/her opinion, advice or feedback on a Network Project	\$50/ meeting		
Strategic Role	The patient partner is a member in the Network Steering Committee or Executive Committee	\$50/ meeting		

- Half day compensation is at 4 hours
- Full day compensation is at 7 hours

Considerations for Patient Partners

- Patient partners should be aware of the items that are covered and the upper limits on the expenditures listed
- Original receipts are required for reimbursement
- Reimbursement for expenses is generally not subject to tax as it is not counted as income but if a Patient partner is self-employed they may need to declare expenses
- Patient partners should be prepared to report compensation received from the Network
- Patient Partners may decline compensation
- Patient partner compensation may not be donated to another organization from the Network

Process

Patient partner meeting attendance will be recorded by the CPN Coordination Centre. Patient partners are asked to review the meeting minutes to check that their attendance was noted properly.

Twice yearly, in March and September the compensation for meeting attendance will be processed by the finance department and a cheque will be mailed to the address provided.

Travel forms and receipts will be required for reimbursement of expenses to attend the annual meeting and they will be processed within one month of the event allowing an additional 3 weeks for processing and delivery. Travel expenses will be processed separately from meeting honorarium compensation.

A T4A may be issued yearly for the compensation from the Network to patient participants.

Related Documents/Resources

Terms of Reference for Patient Advisory Committees, Université de Montreal Centre of Excellence for Partnership with Patients and the Public

Contacts

Please direct general questions regarding this policy to the CPN Coordination Office. If you have specific questions please contact Kimberly Begley at begleyk@mcmaster.ca

Authorization

Reviewed and approved by the CPN Patient Engagement Committee, Steering Committee and Executive Committee in February 2017.