



Diabetes Action Canada

Preventing complications. Transforming lives.

FINANCIAL COMPENSATION POLICY for PATIENT PARTNERS

MAY 02, 2017

Research and other research-related activities funded by Diabetes Action Canada should reflect the time and contributions of all partners. Financial compensation demonstrates recognition of the value and worth of the additional expertise brought by the perspectives of Patient partners. Therefore, covering costs and paying for time should be seen as a tangible way to acknowledge the valued contributions of Patient partners.

By offering compensation, we also seek to (a) reduce power hierarchies caused by the fact that others at the table receive a salary related to their role and (b) ensure that Patient partners who cannot afford to volunteer their time are able to participate in network activities. This helps us achieve our goal that Patient partnership in our network be inclusive.

Who can receive compensation:

All Patient partners* can receive compensation for their contributions to the Network.

*As outlined by the Canadian Institutes of Health Research (CIHR), the term 'patient' under the Strategy for Patient-Oriented Research (SPOR) is understood to include individuals with personal experience of a health issue and informal caregivers, including family and friends.

Types of contributions:

The Network is committed to integrating the patient perspective into every step of the research process including identifying gaps, developing research questions, defining research objectives, recruiting participants, collecting data, evaluating results, and disseminating knowledge. Some patients have the readiness to contribute as full members of research teams, while others bring expertise in a range of other key areas such as ethics or as knowledge brokers. Overall the patients' roles will vary according to the contributions a patient is prepared and willing to offer. Equipping Patient partners to participate in network activities may include offering compensation for time spent in orientation (training, learning activities). 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 and compensation rates for Patient partners of the Network

	ACTIVITY	DESCRIPTION	\$\$\$	half-day (\$)²	full-day (\$)³
ELIGIBLE EXPENSES	Travel	Travel costs for any involvement are covered. This includes economy class airfare, train fare, bus fare or mileage. Taxi fares are reimbursed for short distances. Car rental may also be reimbursed with advance approval.	Reimbursement or covered directly¹	n/a	n/a
		<u>Car travel:</u> \$0.51 per kilometer for the first 20 kilometers, and \$0.42 for additional kilometers.	Reimbursement	n/a	n/a
	Overnight accommodation	The Patient partner may need overnight accommodation (hotel, motel, bed & breakfast, lodge or other) if travelling some distance to take part in an involvement activity such as training or meetings.	Reimbursement or covered directly¹	n/a	n/a
		Overnight accommodation -private residence-	\$25/night	n/a	n/a
	Subsistence	Subsistence costs are for time spent away from home. The maximum per diem amount that can be covered is \$45 per day (breakfast: \$8, lunch: \$14, dinner: \$23).	Reimbursement or covered directly¹	n/a	n/a
	Personal assistants	Some disabled people may have a personal assistant to support them to get actively involved as Patient partners.	Reimbursement or covered directly¹	n/a	n/a
Childcare	Some people may need childcare support to be fully involved as a Patient partner.	Reimbursement or covered directly¹	n/a	n/a	
COMPENSATION	Training and learning	The Patient partner attends a training event (conference, online training course, etc.).	\$25/hr	75	150
	Consultant role	The Patient partner offers his/her opinion, advice or feedback (e.g. Patient Council meetings).	\$25/hr	75	150
	Collaborator role	The Patient partner participates as a member of the research team and takes joint decisions with research projects leads.	\$25/hr	75	150
	Strategic role	The Patient partner plays a strategic role in the Network's governance. (N.B. Compensated only at the request of Patient partners for whom it would be difficult to enact this role without compensation.)	\$25/hr	75	150
	Patient Council members	The Patient partner is a member of a Patient Council.	\$95/meeting (including 0.5 hrs of prep time and 2 hrs for document review) or \$50/meeting for those who cannot attend the meeting but who take time to read the documents and send comments by email		
	Patient partnership consultant	The consultant provides specific expertise, or works to improve a particular component of the Network.	\$50/hr	150	300

¹ The travel costs will be reimbursed or covered directly, for example by booking tickets via a travel agency.

² Half-day compensation at 4 hours.

³ Full-day compensation starts at 7 hours.

Considerations for Patient partners:

- Patient partners should be aware of the items that are covered and the upper limits on expenditures (e.g., per diem amounts), listed in Table 1.
- All expenses are subject to institutional approval. Travel plans and appointing a personal assistant should therefore be discussed with the Patient Engagement Coordinator ahead of time to ensure that all expenses incurred are able to be reimbursed.
- The per diem amounts are daily allowances to cover meals when traveling for the Network. The Patient partners are not required to show receipts for meals, they will receive the per diem amounts listed in Table 1. Group meals beyond this may be covered; these cases should be planned in advance and be part of the budget for the event.
- When participating in a Diabetes Action Canada sponsored event, it is possible for a Patient partner to extend his/her stay after or before the event. However, the price of the plane ticket will have to be equal or cheaper than the price of the ticket with true event dates (with reservations made at least 14 days in advance). If the price of the ticket with extended dates is more expensive, then the Patient partner will have to buy his/her ticket and Diabetes Action Canada will reimburse the price of the ticket with true event dates. In other words, the Patient partner will absorb the difference in price.
- When travelling by car to an event, kilometers are reimbursed according to the rate indicated in Table 1. The distance travelled is calculated using Google Maps from the address of residence to the event location.
- 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 receiving welfare (a.k.a. social assistance or income assistance) should be prepared to report compensation received from the Network.
- Other options for compensation can be explored.
- Patient partners may decline compensation. If compensation is declined, the funds will be used by Diabetes Action Canada for other activities undertaken by the network, including research projects.

Procedures for Patient partners who are members of a research project and Patient partners who are members of Patient Councils:

1) PATIENT PARTNERS WHO ARE MEMBERS OF A RESEARCH PROJECT

The compensation rate is defined in Table 1 of this document. It is important that before each involvement, the number of hours of collaboration expected, the role and responsibilities of the Patient partners be clearly defined.

Patient partners will be asked to submit their hours to research project Coordinator.

If time on a project looks like it may exceed the time estimate, it is up to the Patient partner to let the Project team and Patient Engagement team know. We depend on Patient partners to help keep track of actual time spent in order to ensure that time estimates are reasonable. Due to budget limits, there may not always be additional funds available to compensate Patient partners. At that point, it is up to Patient partners to decide whether to stop or continue collaboration.

Depending on the length of collaboration, Patient partners can choose to receive compensation at intervals as short as two weeks or at the end of the collaboration (not exceeding one year).

Receiving compensation:

Whether attending a training event or consulting with a research team, claims for compensation should be made following the steps below (steps 1 and 2 do not need to be repeated for subsequent compensation claims):

- 1) Fill-out FORM-1: personal information (name, address, phone number, date of birth, social insurance number).**
- 2) Fill-out DIRECT DEPOSIT FORM, else compensation will be sent by check.**
- 3) Send hours to research project Coordinator.**
- 4) Follow approval procedure (via Email).**

2) PATIENT PARTNERS WHO ARE MEMBERS OF A PATIENT COUNCIL

The compensation rate is defined in Table 1 of this document. **To facilitate involvement in the Patient Councils, the number of hours required for meetings and accompanying activities of the Patient Councils has been estimated on a per meeting basis amounting to: \$95 / meeting.**

For example: The Collective Patient Council intends to meet eight (8) times over a period of 12 months; therefore, members of the Collective Patient Council who participate in all meetings will be offered \$760/year in compensation. The Indigenous Patient Advisory Circle and the Francophone and Immigrant Patient Councils intend to meet four (4) times over a period of 12 months; therefore, members of these councils who participate in all meetings will be offered \$380/year. Members who are designated Patient Council liaisons between the Collective Patient Council and one of the other Patient Councils will attend 12 meetings: eight (8) meetings of the Collective Patient Council plus four (4) meetings of one of the other Patient Councils; therefore, Patient Council liaisons who participate in all meetings will be offered \$1140/year in compensation.

Each member will receive compensation after every meeting, in the form of a direct deposit or a check. Compensations amounting to \$95 or less are exempt from tax. You do not need to report these amounts in your income.

Members who cannot attend the scheduled Patient Council meeting for exceptional reasons but who have spent time reviewing documents and preparing for the meeting can claim a \$50 compensation. Cases of absenteeism will be dealt with on a case-by-case basis. In the event of prolonged absenteeism, the Patient Engagement team may suggest that a Patient partner withdraw from a Patient Council temporarily or indefinitely.

Receiving compensation:

When attending a Patient Council meeting, claims for compensation should be made following the steps below (steps 1 and 2 do not need to be repeated for subsequent compensation claims):

- 1) Fill-out FORM-1: personal information (name, address, phone number).**
- 2) Fill-out DIRECT DEPOSIT FORM, else compensation will be sent by check.**
- 3) Follow approval procedure (via Email).**

Obtaining reimbursement for travel expenses (for all Patient partners):

Ideally, expenses (e.g. plane ticket, overnight accommodation, etc.) will be paid directly by the Network on behalf of the Patient partner involved in the activity. The reason for this is to incur the least amount of out-of-pocket expenses to the person involved in the activity. In some cases, it may also be possible to issue advances. However, some expenses may have to be reimbursed after the event.

Original receipts and in some cases boarding passes (please see details in statement 3 below), are required for reimbursement of expenses. Scans of original receipts cannot be accepted. Acceptable receipts show details of the items paid for and the mode of payment.

Please send all original receipts by mail to this address:

**Université Laval
c/o Olivia Drescher
Faculté de médecine
1050, avenue de la Médecine
Pavillon Ferdinand-Vandry, local 2881
Québec (Qc) G1V 0A6**

- 1. Claims for reimbursement should be made within 30 days of return from travel or the date the expense was incurred. If an advance was issued, receipts must be submitted to the university within 30 days.**
- 2. Patient partners should be aware of the three weeks' minimum delay between the moment the claim is received and the reimbursement. Delay may unfortunately sometimes be longer due to university schedules.**
- 3. Claims for reimbursement of travel (plane, train, bus or boat) PURCHASED DIRECTLY by the Patient partner, should include round-trip boarding passes as proof of travel. If the travel expense was paid directly by the Network, Patient partners do not need to save boarding passes.**

Whom to contact:

Please contact Olivia Drescher, Patient Council Coordinator.

Phone: 418 656 2131 ext: 4421

Email: Olivia.drescher@fmed.ulaval.ca

List of consulted resources:

Canadian Institutes of Health Research (CIHR). Strategy for Patient-Oriented Research – Patient Engagement Framework. (2016, September 2nd). From <http://www.cihr-irsc.gc.ca/e/48413.html>

Patient-centered outcomes research institute (PCORI). Financial Compensation of patients, caregivers, and patient/caregiver organizations engaged in PCORI-funded research as engaged research partners. (2016, September 2nd). From <http://www.pcori.org/sites/default/files/PCORI-Compensation-Framework-for-Engaged-Research-Partners.pdf>

Réseau-1 Québec. Lignes directrices pour informer les relations et mandats de partenariat avec des patients. (Version : February 14th, 2016).