

FINANCIAL COMPENSATION POLICY for PATIENT PARTNERS

Updated March 2, 2023

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.

All negotiations on Patient Partner compensation will occur between Diabetes Action Canada and the research teams prior to recruitment of Patient Partners. It is our goal to ensure patient engagement in research is a collaborative and equitable experience. It is the responsibility of the research team to inform Diabetes Action Canada of the time Patient Partners spent on projects and/or activities and to complete all requested forms.

<u>Table 1: Eligible expenses and compensation rates for Patient Partners of the Network</u>

| | ACTIVITY | DESCRIPTION | | | \$\$\$ | half-day (\$) ² | full-day (\$) ³ |
|----------------------|-------------------------|--|--|--|--|----------------------------|----------------------------|
| | Travel | covered. This incl | • | related meetings and/or events are s airfare, train fare, bus fare or for short distances. | Reimbursement or covered directly ¹ | n/a | n/a |
| | | Car rental: Rental advance approval | | | | | |
| | | Original receipts r | | | | | |
| | | Car travel: \$0.55 | per kilometre | | Reimbursement | n/a | n/a |
| | Overnight accommodation | & breakfast, lodge | • | ght accommodation (hotel, motel, bed ing some distance to take part in an or meetings. | Reimbursement or covered directly ¹ | n/a | n/a |
| | | Overnight accomm | modation -private r | esidence- | \$25/night | n/a | n/a |
| ELIGIBLE EXPENSES | Subsistence | Subsistence costs are for time spent away from home. Meal expenses will be reimbursed for out-of-town DAC-related meetings and/or events. The maximum amount of reimbursement per day is \$70.00, as detailed in the table below. Detailed, itemized receipts of the meal must be submitted for meal reimbursement. | | | Reimbursement or covered directly ¹ | n/a | n/a |
| | | Table 1: Maximum meal reimbursement rates Meal Breakfast Lunch Dinner Total | Within Canada (Max. reimbursement /day) \$ 15 CAD \$ 20 CAD \$ 35 CAD \$ 70 CAD | International, including USA (Max. reimbursement /day) \$ 20 CAD \$ 30 CAD \$ 45 CAD \$ 95 CAD | | | |
| | | As cash advances are not a permitted practice, Patient Partners may request a pre-paid Visa/Mastercard gift card to cover the cost of meals for out-of-town DAC-related meetings and/or events, where required. | | | | | |

| | Personal assistants | Some disabled people may have a personal assistant to support them to get actively involved as Patient Partners. | Reimbursement or covered directly ¹ | n/a | n/a |
|------------------|--------------------------------|--|--|-----|-----|
| | Childcare | Some people may need childcare support to be fully involved as a Patient Partner. | Reimbursement or covered directly ¹ | n/a | n/a |
| COMPENS ATION | 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 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.
- 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, kilometres 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.

Procedure for recruiting Patient Partners to research activities

- 1) Research teams must always engage with Diabetes Action Canada patient engagement personnel prior to requesting Patient Partner time and expertise, even if previous relationships have been established with Patient Partners for other activities.
- 2) Diabetes Action Canada will request the following information to draft an open call to either all or a subgroup of Patient Partners depending on eligibility:
 - a. Research Team
 - b. Title
 - c. Project summary (in lay terms appropriate for non-academic audiences)
 - d. Request for participation
 - e. Time Commitment
 - f. Compensation
- 3) The paymaster for Patient Partner compensation will be decided prior to sending the open call. Diabetes Action Canada will support Patient Partner compensation for research planning and consultative purposes, but expects research teams to budget for continued Patient Partner compensation once the proposal is funded.

- 4) Diabetes Action Canada will manage recruitment for Patient Partners and provide research teams with support throughout the engagement process.
- 5) It is the responsibility of the research teams to follow the process below for Patient Partner compensation for their time and expertise.

Procedure for Patient Partners who are members of a research project

 The compensation rate is defined by the <u>Diabetes Action Canada Patient Partner</u> <u>compensation policy</u>. It is important that before each involvement, the number of hours of collaboration expected and the roles and responsibilities of the Patient Partners be clearly defined.

If the time needed exceeds the time estimate, Patient Partners must inform the Project team and Patient Engagement team. 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.

- Research teams must complete the form, DAC Patient Partner Participation
 Form_Other and provide additional information as requested (i.e. call for Patient Partners, agenda, etc.) and send to Mildred Lim at Mildred.Lim@uhnresearch.ca
- 3) Payment will be processed via Direct Deposit by the University Health Network. Please note the turnaround time is 2 to 4 weeks from time of payment requisition. If cheque is the preferred method of payment, this can be accommodated, but processing time will be between 6-8 weeks. Depending on the length of the collaboration, Patient Partners may wish to receive compensation at intervals rather than at one time. Patient Partner compensation requests MUST be received within one week of collaboration.

Procedure of Patient Partners who are members of Advisory Committee

1) The compensation rate is defined by the <u>Diabetes Action Canada Patient Partner</u> compensation policy. It is important that meeting frequency, prep time for meetings and meeting duration are clearly defined for Patient Partners.

If the time needed exceeds the time estimate, Patient Partners must inform the Project team and Patient Engagement team. 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 participating on Advisory Committees.

- Research teams must complete the form, DAC Patient Partner Participation
 Form_Meeting and provide additional information as requested (i.e. call for Patient Partners, agenda, etc.) and send to Mildred Lim at Mildred.Lim@uhnresearch.ca
- 3) Payment will be processed via Direct Deposit by the University Health Network. Please note the turn around time is 2 to 4 weeks from time of payment requisition. If cheque is the preferred method of payment, this can be accommodated, but processing time will

be between 6 to 8 weeks. Patient Partner compensation requests MUST be received within one week of the meeting.

Procedure of Patient Partners who are members of a Patient Council

- The compensation rate is defined by the <u>Diabetes Action Canada Patient Partner compensation policy</u>. 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. 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.
- 2) DAC PE Personnel will complete the form, DAC Patient Partner Participation Form_Meeting and provide additional information as requested (i.e. call for Patient Partners, agenda, etc.) and send to Mildred Lim at Mildred.Lim@uhnresearch.ca
- 3) Payment will be processed via Direct Deposit by the University Health Network. Please note the turn around time is 2 to 4 weeks from time of payment requisition.

Please note that Patient Partner engagement at meetings and as a member of research projects is considered consulting by UHN Finance and amounts over \$500 per annum will be taxable. Patient Partners will receive a T4A from University Health Network for this remuneration.

Obtaining reimbursement for travel expenses (for all Patient Partners)

Ideally, travel expenses (e.g. plane ticket, overnight accommodation, etc.) will be paid directly by Diabetes Action Canada on behalf of the Patient Partner involved in the activity. This is to minimize the amount of out-of-pocket expenses for the person involved in the activity. Where required, Diabetes Action Canada may issue pre-paid VISA/Mastercard gift cards. 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 the following address:

University Health Network c/o Mildred Lim 200 Elizabeth Street, 12EN-242 Toronto, ON M5G 2C4

Please note:

1) Claims for reimbursement should be made within 30 days of return from travel or the date the expense was incurred.

- 2) Patient Partners should be aware of the four weeks' minimum delay between the date of the claim and the reimbursement. Delay may unfortunately sometimes be longer due to university schedules.
- 3) Claims for reimbursement of travel (plane, train, taxi, bus or ferry/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 are asked to save their boarding passes and submit to Mildred Lim (contact below).

Whom to contact:

Please contact Mildred Lim, Business Officer.

Email: Mildred.Lim@uhnresearch.ca

Phone: 416-340-4800 x 2522