

## CIHR Institute of Genetics

### Patient Partner Compensation Guidelines

#### Introduction

CIHR Institute of Genetics (IG) supports research on the human and model genomes and on all aspects of genetics, basic biochemistry and cell biology related to health and disease, including the translation of knowledge into health policy and practice, and the societal implications of genetic discoveries. IG's core approach involves starting from patients and civil society, and working towards meeting research needs to improve health outcomes. This approach means that IG believes in meaningful inclusion and engagement of patient partners. "Patient partner" is an overarching term that includes individuals with lived experience, including patients, caregivers, family, and friends<sup>1</sup>.

This document outlines IG's compensation guidelines for patients and caregivers who contribute their time and expertise to IG's efforts (e.g., committees, working groups) or for patients and caregivers who are invited by IG to attend and participate in specific events (e.g., launch events, workshops, and meetings). These guidelines were developed for individuals who wish to be compensated, recognizing that not all individuals will wish to be. Payment for expenses (e.g., travel) are not considered to be compensation and are reimbursed separately.

These guidelines are meant to help start a conversation between IG and patient partners about compensation. IG values flexibility, equity, and inclusion in its approach to patient partner compensation.

*Please note.* Other institutes and branches of CIHR may use different approaches to compensation for patient partners.

#### Types of contributions

There are many ways for patient partners to engage with IG: providing input on specific projects or initiatives, attending meetings or events, speaking publicly, being part of a committee, doing media interviews, writing newsletter articles, and more. Some patient partners will engage in one-time opportunities, others may work with IG on an ongoing basis. Within the same event, patient partners may do different activities (e.g., attend workshop vs. give a keynote talk at the workshop).

Meetings and events can be held via teleconference, videoconference, and in person. For some meetings or events, materials may require review and preparation in advance. Other opportunities may involve independent work on the patient partner's own time, and reporting back to IG (e.g., writing an article or other document).

The contributions described here are not exhaustive – there may be other ways that patient partners will engage with IG that are not listed here.

## What IG asks of patient and caregivers<sup>2</sup>:

- Declare all actual, potential or perceived conflicts of interest<sup>3</sup>;
- Respect privacy and confidentiality of all meeting proceedings and attendees, as appropriate;
- Arrive for meetings prepared;
- Participate in all activities as arranged and provide IG with reasonable advance notice, whenever possible, if unable to attend the activity;
- Participate in discussions; provide feedback, constructive input and criticism; raise issues; ask questions; and solve problems in an open and collaborative manner;
- Respect all people, even if in disagreement with a point of view;
- Draw upon knowledge, networks, and experience to provide input into discussions and decisions;
- Act as a champion for further patient and caregiver engagement.

## What patient and caregivers can expect of IG:

- Respect for your time, experiences, knowledge, and the recognition of the vulnerability that your participation may bring;
- Meetings scheduled at times and locations that accommodate the majority of participants;
- Attendance and participation in meetings through virtual options will be available;
- Meeting materials provided with enough time in advance for review and reflection;
- Accommodations for disability and/or health requirements as requested by patient partners;
- Openness and willingness to listen to and consider your feedback; ask questions and solve problems in an open and collaborative manner;
- Commitment to work with and learn from you;
- Understanding that sometimes your health and life will not allow you to participate fully;
- 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);
- Upfront payment, where possible, or reimbursement, of expenses to participate in meetings and events (e.g., travel and dependent care; see Government of Canada's policy).

## Considerations

- Compensation for these activities is generally taxable income and it is recommended that this compensation be reported to the Canada Revenue Agency and to Revenu Québec for those living in the province of Quebec; a T4A may be issued.
- Individuals may decline compensation.
- Individuals who are receiving disability payments are advised to investigate how compensation may or may not affect disability payments  
<https://www.canada.ca/en/services/benefits/publicpensions/cpp/cpp-disability-benefit/after-apply.html>

## Terms

- Patient partners can stop taking part in activities or withdraw from committees at any time. Compensation will reflect actual participation.
- We welcome patient partners of all ages. In the case of patient partners who are under the age of majority in their province, we may need permission from parent or guardian to communicate with the patient partner directly or include them in specific activities. Where appropriate, IG will arrange to include parents or guardians in activities, to support the patient partner and/or to travel with them.
- IG will review its budget annually and reserves the right to change compensation rates or levels of patient partner participation that are funded, as needed.
- The guidelines will be applied for all patient partner activities; exact amount and eligibility of compensation for a given activity will be determined in advance with the patient partner in discussion with the Team Lead, Patient Engagement, and approved by the IG Manager, Finance & Administration.

## Process

- Before work begins, the patient partner and Team Lead, Patient Engagement, will discuss the scope of work, expected time commitment, and expected compensation. Communication will be ongoing and adjustments can be made if, for example, more time is required to complete the work.
- The method of payment for a given activity will be determined on a case-by-case basis. Possible methods include cash or gift card payments for small amounts (<\$50; a signed receipt may be required), and cheques or direct deposit for larger amounts or ongoing roles (personal details such as social insurance number [SIN], address, phone number and in some cases direct deposit information may be required).
- The primary point of contact from the IG team (Team Lead, Patient Engagement or other staff member) will advise of the specific process or options in a given activity, and will provide payment directly or follow up with IG's Manager, Finance & Administration to process payment.

<sup>1</sup> Adapted from CIHR's definition - <http://cihr-irsc.gc.ca/e/48413.html>

<sup>2</sup> Adapted with permission from Solutions for Kids in Pain.

<sup>3</sup> Conflict of interest is defined as "a conflict between the private interests and the official responsibilities of a person in a position of trust" [<https://www.merriam-webster.com/dictionary/conflict%20of%20interest>].

## Honorarium rates for time and expertise for patients and caregivers

*Note.* All travel costs and other related expenses (e.g., dependent care) are reimbursed separately.

| Activity  | Level of Engagement  |  | Suggested compensation  | Examples  |
|---|--|--|---|---|
|   | Commitment   | Responsibility and scope   |   |   |
| One-time activity, e.g., media interview, write a blog post or newsletter article   | One-time commitment, plus any preparation required                       | Invited to complete task or take part in a specific activity   | \$40/hour for independent work  | If a media outlet requests an interview with a patient partner, the individual might spend 30 minutes with the reporter and an additional 30 minutes discussing the opportunity with IG to plan what they will say. Total compensation for 1 hour = \$40.                                 |
| Collaborator or working group member for a single, specific project (e.g., develop a tool for patients, co-organize an event) | Availability by email; willing and able to participate in a few meetings | Gives advice and feedback for decision making by team; contributes to a specific tool, product, or project | \$500 to \$800 per year, depending on number of meetings and other requirements | If a working group meets 4 times, for 1 hour each time, and the patient partner works on a draft document for one hour following each meeting and communicates by email ~once every two weeks for 6 months, compensation would be approximately \$500.                                    |
| Attend an event with or on behalf of IG   | One-time commitment, plus any preparation required                       | Invited to attend or participate in a specific event   | \$250 for half-day event<br>\$500 for full-day event                            | If a patient partner attends a workshop (e.g., to discuss opportunities for IG to further its work in patient partnership), the patient partner will have documents to review ahead of time, will participate in the event, and may provide evaluative or other feedback after the event. |

| Activity  | Level of Engagement   |  | Suggested compensation   | Examples   |
|---|---|--|--|--|
|   | Commitment  | Responsibility and scope   |  |  |
| Give a presentation at an event hosted by IG                                    | One-time commitment, plus any preparation required                              | Invited to give a presentation at a specific event   | \$500 for giving a presentation of 1-2 hours, including preparation time.  | <p>If a patient partner gives a presentation at a workshop, they will spend time in advance preparing the presentation, they will give the presentation, and they will participate in discussions.</p> <p>Time spent attending the event will be compensated in addition, according to the amounts for half- and full-day workshops.</p> |
| Member of a committee or working group with broader scope than a single project | Commitment to a committee or group (includes meetings, follow-up actions, etc.) | Participates in decision making by providing recommendations for a subject area or initiative with an institute-wide mandate | \$600 to \$1800 per year, depending on frequency of meetings and volume of independent work outside of meetings. | If committee meets once per month (\$40) and members complete one hour of independent work (\$40) per month, 12 * \$80 = \$960/year  |
| Ongoing advisory role   | Advising IG on an ongoing basis (includes meetings, follow-up actions, etc.)    | Participates in decision making, mobilizing knowledge, liaising between IG and patient communities.                          | \$2000 per year assuming full participation – attending meetings and responding to other communications.         | <p>Expectation of at least quarterly meetings, with additional ad hoc meetings as needed.</p> <p>Correspondence related to agendas, follow-up, and decision-making in between meetings.</p>  |