Canadian Association of Genetic Counsellors | Association canadienne des conseillers en génétique

CAGC Guideline for Patient Partner Compensation

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Collaboration with people with lived experiences (PWLE) as partners is becoming increasingly common in all facets of healthcare (research, policy development, etc), including genetic counselling. The purpose of this document is to provide guidance about the appropriate compensation for patient/family/community partners who are engaged by the Canadian Association of Genetic Counsellors (CAGC) for any reasons related to CAGC business (including education, research, policy, or other related work).

The CAGC has adopted the guidelines set out by the Canadian Institutes of Health Research - Institute of Genetics (CIHR-IG) for this purpose. These guidelines were last updated on 2022-12-22. **As the rates in this document change, CAGC should also change rates accordingly.** The full guideline document should be reviewed, though a brief summary of key stipulations is provided here:

1. Compensation refers to payment of honoraria only and does not include expenses (e.g. travel) which should be reimbursed separately.
2. Value is placed on flexibility, equity, and inclusion. As such the guidelines should be viewed as a starting point for discussion.
3. Patient Partner contributions can be single encounters or ongoing, held virtually or in person, and can include providing input on specific projects, attending meetings/events, committee participation, research activities, media activities, and more.
4. Compensation is generally taxable income and should be reported to the Canada Revenue Agency and to Revenu Quebec (for those living in Quebec). A T4 may be issued.
5. Scope of work, expectations, exact amounts, and eligibility of compensation for a given activity must be determined in advance and approved by the treasurer of CAGC.
6. Possible methods of payment include cash or gift card payments for small amounts (<$150), and cheque or direct deposit for larger amounts or ongoing roles.
7. Individuals may decline compensation and patient partners can cease activities or withdraw at any time; compensation will reflect actual participation.

To determine an appropriate rate of compensation, please refer to the CIHR-IG compensation guideline table of honorarium rates according to activity & level of engagement.

Appendix: CIHR Compensation Guidelines as of 2022-12-22

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.

	Level of engagement			
Activity	**Commitment**	**Responsibility and scope**	**Suggested compensation**	**Examples**
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 $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.
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.	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. Time spent attending the event will be compensated in addition, according to the amounts for half- and full-day workshops.
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.	Expectation of at least quarterly meetings, with additional ad hoc meetings as needed. Correspondence related to agendas, follow-up, and decision-making in between meetings.