



## CIHR Institute of Musculoskeletal Health and Arthritis

### Patient Compensation Guideline

#### Introduction

The CIHR-Institute of Musculoskeletal Health and Arthritis (IMHA) is mandated to provide research leadership related to: active living, mobility and the wide range of conditions related to bones, joints, muscles, connective tissue, skin as well as the mouth, teeth and craniofacial region. Musculoskeletal health is critical for mobility, productivity, and general well-being.

The institute has actively encouraged the research community to embrace incorporating patient engagement in the research process since its inception in 2000 and more recently is providing the resources to do it. Patient is an overarching term that includes individuals with lived experience, including patients, caregivers, family, and friends<sup>1</sup>.

These compensation guidelines are for patients who contribute their time and expertise to IMHA's efforts (e.g., members of: the Institute Advisory Board, Patient Engagement Research Ambassadors, committees, working groups, etc. and or for patients who are invited by IMHA to attend and participate in specific events (e.g., launch events, workshops, and meetings). This guideline was developed as a framework to offer compensation to individuals who wish to receive it, recognizing that not all individuals will wish to receive compensation. Payment for expenses (e.g., travel) is not compensation and is reimbursed separately.

IMHA values flexibility, equity, and inclusion in its approach to patient compensation. This guideline should contribute further to the conversation between IMHA and patients about compensation.

#### Types of Patient Contributions

There are many ways for patients to engage with IMHA, such as: providing input on specific projects or initiatives, attending meetings or events, participating in webinars, being a member of the Institute Advisory Board, being a member of the Patient Engagement Research Ambassadors, being part of a committee, writing blog posts, and more. Some patients will engage in one-time opportunities while others may work with IMHA on an ongoing basis. Within the same event, patients may also do different activities (e.g., attend a workshop vs. give a keynote talk at the workshop).

Meetings and events may be held via teleconference, videoconference, and in person. For some engagements, materials may require review and preparation in advance. Other opportunities may involve independent work on the patient's own time and reporting back to IMHA or producing specific deliverables (e.g., writing a blog, article or other document).

The contributions described here are not exhaustive – there may be other ways that patients will engage with IMHA. This document will be updated from time to time if new examples of engagement need to be included.

#### What IMHA Asks of Patients<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 activities prepared;
- Participate in all activities as arranged and provide IMHA with reasonable advance notice if unable to attend the

activity (assuming this is possible);

- Participate in discussions; provide feedback and constructive input; raise issues; ask questions; and solve problems in an open and collaborative manner;
- Respect all people and their opinions, even if one disagrees with a point of view;
- Draw upon knowledge, networks, and experience to provide input into discussions and decisions;
- Act as a champion for patient engagement
- Communication (if possible) about any accommodations are required or that change due to one's health or life.
- Withdraw from an engagement if one's health or life needs to take priority, or if the fit does not feel appropriate.

#### **What Patients Can Expect of IMHA:**

- Respect for their time, experiences, knowledge, and the recognition of the vulnerability that their participation may bring;
- Virtual options for participation;
- For meetings: materials provided in advance to provide time for review and reflection, scheduled at times and locations that accommodate the majority of participants;
- Accommodations for disability and/or health requirements as requested;
- Openness and willingness to: listen, consider feedback, ask questions, and solve problems collaboratively;
- A commitment to work with and learn from patients;
- Understanding that sometimes patients' health and life will not allow them to participate fully and that flexibility to engage will be provided if patients still wish to participate in a capacity that works for them;
- Provide training and support where/if required;
- Address and respond to questions and concerns;
- Compensation for time, efforts, and expertise (if patients wish to accept it);
- Upfront payment where possible—or timely reimbursement of expenses to participate (e.g., travel and dependent care)<sup>4</sup>
- A discussion about fit and ongoing involvement in an opportunity, if there are any concerns

#### **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.
- Compensation would be by Cheque or Electronic Cash Transfer in line with the Host Institution's financial processes.
- Individuals are not obligated to accept compensation.
- Individuals who are receiving disability payments are advised to see if or how compensation may or may not affect disability payments<sup>5</sup>.

#### **Terms**

- Patients may stop participating in activities or withdraw from an engagement at any time without needing to provide a reason. In this case, compensation will reflect their participation to this point.
- Patients of all ages may be invited to participate in IMHA activities. If patients are under the age of majority in their province, IMHA may need permission from a parent or guardian to communicate with the patient directly or include them in activities. Where appropriate, IMHA will arrange to include parents or guardians in activities, for example, to support the patient and/or to travel with them.
- IMHA will review its budget annually and may change the compensation rates or levels of

compensation as needed.

- The guidelines will be applied for all patient activities; the exact amount of and eligibility for compensation for a given activity will be determined in advance with the patient in discussion with the IMHA Patient Engagement in Research Strategy Consultant, and Associate Scientific Director, with approval from the Administrator, Institute Operations.

### **Process**

- Before work begins, the patient partner and IMHA Patient Engagement in Research Strategy Consultant will discuss the scope of work, expected time commitment, and expected compensation, in consultation with the Associate Scientific Director. Decisions will be made on a case-by-case basis. Communication will be ongoing and adjustments can be made if, for example, more time is required to complete the work.
- The process of receiving payment will adhere to CIHR guidelines on the Institute Support Grant and the financial process requirements of the Host Institution, and be supported by the Administrator, Institute Operations (with one-on-one support available as needed). All patient partners must complete a one-time UBC Supplier set up process and for each project/activity, a contract and pro-forma invoice must be signed.

### **References**

1. Adapted from CIHR's definition - <http://cihr-irsc.gc.ca/e/48413.html>
2. Adapted with permission from Solutions for Kids in Pain.
3. 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>].
4. Directive on Travel, Hospitality, Conference and Event Expenditures, Government of Canada [<https://www.tbs-sct.canada.ca/pol/doc-eng.aspx?id=27228>]
5. While on CPP Disability Benefits, Government of Canada [<https://www.canada.ca/en/services/benefits/publicpensions/cpp/cpp-disability-benefit/after-apply.html>]

**Compensation rates for time and expertise for patients**

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

Activity	Level of Engagement		Suggested compensation	Justification and Examples
	Commitment	Responsibility and scope		
One-time activity, e.g., write a blog post or newsletter article, co-present a webinar	One-time	Complete a task or take part in a specific activity	\$40/hour for independent work	<p>If IMHA requests a patient write a blog post, the individual might spend 30 minutes with an IMHA staff member discussing the ideas for the blog post, and 1 hour writing the blog post. Total compensation for 1.5 hours = \$60.</p> <p>If PERA members (see below) co-present at a webinar or a poster/oral presentation for a conference, there would likely be 1-2 hours of preparation (\$40-80) and 1 hour of presentation (\$40) for a total of \$80-120.</p>
Participate in an event hosted by IMHA or attend an event as an IMHA patient representative.	One-time	Attend or participate in a specific event	<p>\$250 for half-day event</p> <p>\$500 for full-day event</p>	If a patient participates in an IMHA workshop, the patient will have documents to review ahead of time, will participate in the event, and may provide evaluative or other feedback after the event. The same would be the case if a patient attends an event as an IMHA patient representative.
Present at an event hosted by IMHA	One-time	Develop and deliver a presentation at a specific event.	\$500 for an approximately 1-hour presentation	<p>If a patient gives an independent 1-hour presentation at an event, they will spend time preparing the presentation, giving the presentation, and participating in discussion/take questions.</p> <p>If a patient spends time attending the full event beyond their presentation day, this will be compensated according to the</p>

Activity	Level of Engagement		Suggested compensation	Justification and Examples
	Commitment	Responsibility and scope		
				amounts for half- and full-day workshops.
Member of a committee or working group with a specific project scope	Term to be defined, might be a few months to a year	Participate in decision making by providing recommendations for a subject area or initiative with an Institute-wide mandate	\$200/meeting	If committee meets once per month (\$200/meeting x 6 months) for 6 months and then hosts an event for 1 day (\$500), the total is \$1,800. This may involve preparation time, some email responses/reading required between meetings plus an event amount (if it leads up to an event).
Member of Patient Engagement Research Ambassadors (PERA)	2-year term (option for an additional year)	Participate in decision-making related to Institute's patient engagement initiatives and direction.	\$200/meeting	If PERA meets monthly and a member attends all monthly meetings, the amount would be \$2,400 (\$200 x 12). This includes a 2-hour meeting plus time to read any materials/prepare in advance. It includes minimal required email activity between meetings. Additional amounts for other activities beyond PERA participation would apply.

Activity	Level of Engagement		Suggested compensation	Justification and Examples
	Commitment	Responsibility and scope		
Ongoing advisory role	3-year term	Participates in decision making and mobilizing; activity has an advisory mandate for the Institute.	\$1,750 per year assuming full participation	For example, meeting virtually 3 times per year for a half day ( $\$250 \times 3 = \$750$ ), and in person once per year for 2 days ( $\$500 \times 2 = \$1000$ ). This includes any preparation in advance of meetings and participation in meetings.