

Solutions for Kids in Pain (SKIP) Patient Partner Compensation Guidelines

Introduction

SKIP is a national knowledge mobilization network whose mission is to improve children's pain management by mobilizing evidence-based solutions through coordination and collaboration. SKIP is a "Patients Included" organization. This means that SKIP believes in meaningful inclusion and engagement of patient partners. "Patient partner" is an overarching term that includes individuals with lived experience with pain, including patients, caregivers, family, and friends¹.

This document outlines SKIP's compensation policy for patients and caregivers who contribute their time and expertise to SKIP's efforts (e.g. members of the Board, committees, working groups, etc.) or for patients and caregivers who are invited by SKIP to attend and participate in specific events (e.g. launch events, workshops and meetings). This policy was developed for individuals who wish to be compensated for their efforts, recognizing that not all individuals will wish to for their own reasons.

Types of Contributions

There are many ways for patient partners to engage with SKIP, e.g., providing input on specific projects or initiatives, attending meetings or events, public speaking, being part of a committee, doing media interviews, writing (e.g., newsletters, blog posts, articles).

Some patient partners will engage in one-time opportunities, others may work with SKIP on an ongoing basis. Meetings and events will be held via teleconference, videoconference, and in person. For some meetings or events there may be materials that require review and preparation in advance. Other opportunities may involve independent work on the patient partner's own time, and reporting back to SKIP, e.g. writing an article or other document.

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

What SKIP Asks of Patient and Caregivers²:

- Declare all actual, potential or perceived conflicts of interest³;
- Respect privacy and confidentiality of all meeting proceedings and attendees, as appropriate;
- Arrive for meetings prepared;

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

² Adapted with permission from Terms of Reference for Patient Advisory Committees, Université de Montreal Centre of Excellence for Partnership with Patients and the Public.

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>].

- Participate in all activities as arranged (in person or via teleconference as required) and provide SKIP 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 opinions, even if in disagreement with a point of view;
- Promote and contribute to an environment that is free of personal interests;
- 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 SKIP⁴

- 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;
- 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;
- Your questions and concerns to be addressed and responded to;
- Honorarium for your time, efforts, and expertise (should you wish to accept it);
- Upfront payment, where possible, or reimbursement, of expenses to participate in meetings and events (e.g., travel and childcare; see SKIP's Expense Policy).

⁴ Adapted from the Chronic Pain Network Patient Honorarium Policy (Draft), used by permission from Kim Begley, Managing Director.

Honorarium rates for time and expertise for patients and caregivers

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, speak at a conference or workshop	One-time commitment, plus any preparation required	Invited to complete task or take part in a specific activity.	\$30/hour for independent work	If a media outlet requests an interview with a patient or parent, the individual might only spend 30 minutes with the reporter, but might take an additional 30 minutes to discuss the opportunity with SKIP and plan what they are going to say. Total compensation for 1 hour = \$30.
Attend an event with or on behalf of SKIP	One-time commitment, plus any preparation required	Invited to attend, participate in, or speak at a specific event.	\$200 for half-day event \$400 for full-day event Preparation time compensated at \$30/hour Travel costs reimbursed separately	If a patient partner is going to sit on a panel at a full-day workshop, they might spend 1 hour discussing the opportunity with SKIP staff or other panelists, and one hour preparing their speaking points. Total compensation would be \$400 + \$60 = \$460.
Patient collaborator or working group member for a single, specific project, e.g., develop a tool for	Availability by email; willing and able to participate in a few meetings by	Contributes advice and feedback for decision making by team;	\$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, over the course of 6 months, and the

Activity	Level of Engagement		Suggested compensation	Examples
	Commitment	Responsibility and scope		
parents, co-organize an event	phone or in person	contributes to a specific tool, product or project		patient partner works on a draft document for one hour following each meeting, and communicates by email ~once every two weeks, compensation would be approximately \$500.
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 options and recommendations for a subject area or initiative with a network-wide mandate	\$600 to \$1800 per year, depending on frequency and numbers of meetings as well as volume of independent work outside of meetings. Assume \$50 for a 1-hour meeting (to cover travel time as well), \$30/hour for independent work outside of meetings	If committee meets once per month (\$50) and members complete one hour of independent work (\$30) per month, 12 * \$80 = \$960/year
SKIP Board member	Contributing member of SKIP board (includes meetings, follow-up actions, etc.)	Has joint responsibility for decision making and mobilizing; activity has a governing mandate for a network	\$1500 per year assuming full participation – all meetings and responsive on other communications. Travel costs reimbursed separately.	Board meets by phone twice per year for 90 minutes, and in person once per year for 2 days. Correspondence related to agendas, follow-up, and decision-making in between meetings. Travel costs reimbursed separately.

Considerations

- Compensation for these activities is generally taxable income and must be reported to the Canada Revenue Agency; a T4A may be issued;
- Individuals may decline compensation;
- Individuals who are receiving disability payments are advised to look into how compensation may or may not affect disability payments. For example, if receiving CPP Disability benefits: “You can earn up to a certain amount without telling us and without losing your benefits. For 2018, this amount is \$5,500 (before taxes). This amount may increase in future years. If you earn more than the amount allowed, you must contact Canada Pension Plan. From: <https://www.canada.ca/en/services/benefits/publicpensions/cpp/cpp-disability-benefit/while-receiving.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 Partner directly or include them in specific activities. Where appropriate, SKIP will make arrangements to include parents or guardians in activities, to support the Patient Partner and/or to travel with them.
- SKIP 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 above 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 and approved by the SKIP Managing Director.

Process:

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 SIN, address, phone number and in some cases direct deposit information may be required). The primary point of contact from the SKIP team (Knowledge Broker 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 SKIP’s Administrative Centre to process payment.