



## Patient Partner Compensation Policy and Procedures

**Effective Date:** February 1, 2022

**Date to be Reviewed:** January 31, 2023

### Purpose

The purpose of this document is to provide information on the policies and procedures in place to show recognition and appreciation of patient partner contributions via compensation at Canadian Cancer Society (CCS).

### Scope

CCS staff should use this document when engaging patient partners in CCS activities. Patient partners will also receive a copy of this document when they contribute to CCS activities as patient experts so that they are aware of the compensation and reimbursement policy and procedure.

Patients bring the perspective as "experts" from their unique experience and knowledge gained through living with a condition or illness, as well as their experiences with treatments and the health care system. Patient engagement is the provision of this patient expertise to a project. This is different from volunteering, where the provision of patient experience may be valuable but may not be the primary contribution or focus of the role. CCS considers the following as core areas for patient engagement:

- Partnering on governance and decision-making
- Capacity development

There are different levels of engagement that can occur, such as informing, consulting, co-creating and leading initiatives. Patient engagement activities where compensation is encouraged will most often be forms of engagement such as patients co-creating and leading projects. While less involved levels of engagement such as informing or consulting patients may also occur, those will more commonly be viewed as volunteer activities. For any patient engagement activity with compensation, this will be described at the beginning of the activity, for instance in a terms of reference document.

This policy does not apply to compensation for Indigenous-specific involvement (Elder/Knowledge-language-culture holders) due to the distinct nature of engagement. Indigenous-specific engagement practices are being co-developed with Indigenous partners.

<b>Definitions</b>	
Patient	An overarching term inclusive of individuals with personal experience of cancer and includes informal caregivers including family and friends.
Patient Partner	CCS uses patient partner to include both patients and public who partner with teams at CCS. Patient partners should not be confused with research participants, otherwise known as study subjects. Patient partners are equal team members on a project.
Patient Engagement	Meaningful and active involvement in all activities including governance, priority setting, decision-making, planning, conducting research and knowledge translation.
Compensation	Fair recognition and appreciation to a patient partner for their engagement in a CCS activity that is appropriate and reflective of the value of their time and effort. It can be in the form of cash payment, gift cards or in-kind exchanges or incentives. Compensation is separate from reimbursement of out-of-pocket expenses incurred to participate in an activity.
Reimbursement	Repayment of out-of-pocket expenses incurred by patient partners related to their engagement in CCS activities. Eligible expenses include travel, accommodation, per diem meals as per the standard policies of CCS and caregiver expenses (such as costs incurred by a caregiver when taking time away from caregiving to participate).

## Policy

### 1.1 Guiding Principles

The rate of compensation is to reflect **choice, respect, responsiveness, representativeness, and transparency**. It is important to note that patient partners represent a diverse population, and compensation procedures should recognize this diversity, which may require the procedure to be adapted to different circumstances. For more on Guiding Principles, see the Patient Engagement in Research Strategy (Section 4.0).

### 1.2 Payment Rates and Types Available

Depending on the type of activity, compensation is offered as either a fixed service income (hourly rate) or an honorarium (one-time payment); both of which can be paid in the form of cash/cash equivalent payment (e.g., cheque, gift cards) or in-kind payment (e.g. conference attendance).

Payment Rates	
<b>Fixed Service Income</b>	An hourly or daily rate is paid to recognize patient contribution. The hourly rate of CCS in 2021/2022 is \$25 as per best practices and the recommendations by SPOR.
<b>Honoraria</b>	A one-time lump sum payment is made for attending an event or for participating in a short-term activity.
Payment Type	
<b>Cash or Cash Equivalent</b>	Cash payments are offered in the form of a cheque/electronic fund transfer (EFT) or gift cards (if preferred).
<b>In-Kind Payment or Gifts</b>	In-kind support can also be arranged, such as access to CCS webinars, events or training for free, support to cover conference registration fees, etc.

*\*See Section 2.3 Payment Amounts for details on specific rates. Patients are encouraged to contact the CRA for information on taxation before accepting an offer of payment.*

## Procedures

### 2.1 Before Engagement

- Patients should receive a copy of this policy and procedures document and have a chance to ask questions.
- Patients should discuss, fully understand and agree to the payment being offered before beginning work.
- Estimated minimum and maximum hours and responsibilities should be discussed. If any changes occur, another conversation should be held, and if necessary, payment should be adjusted.
- Re-imbursement should be discussed with each individual and provided separate from compensation.
- Patient partners should feel comfortable raising any concerns, suggesting their preferred forms of compensation, and refusing compensation if they so choose. Any concerns should be reviewed by their CCS staff liaison and a member of Finance and documented in our confidential Patient Partner Database.
- Patient partners should know that the payment received for their engagement can be subject to relevant tax laws and regulations issued by the Canada Revenue Agency (CRA), as well as the province in which they reside and can potentially impact their finances.
- All patient partners will have the option to waive the compensation offered. If patients waive compensation, they are still considered patient partners.

### 2.2 Tracking Contribution and Processing Payments

- Patient partners are responsible for tracking and claiming their own hours.
- Patient partners will be consulted to set the frequency of payment, but patients are asked to submit their hours every 3 months to their staff liaison.
- CCS endeavours to provide compensation in a timely manner – for instance, by asking for any hours logged to be submitted within two weeks of an engagement activity ending, and by processing payment in 5-10 business days once hours are received or once an activity has ended (if tracking of hours was not required).
- Patient partners will have the option to customize the type of payment they wish to receive in order to avoid any negative consequences to personal financial circumstances.
- Patient partners will be responsible for their own finances, and should keep the following in mind to inform their decisions regarding all offers of compensation:
  - Any form of cash payment totaling \$500 or more in a given year is considered taxable income and CCS will automatically issue a T4A for these funds, which may be considered income by the CRA. In this case, patient partners will have to disclose their Social Insurance Number (SIN). This information will be kept confidential.
  - Canada Pension Disability requires disclosure of compensation above a specific amount which varies from year to year (recently \$5,500).
  - Compensation may alter the benefits status for individuals on disability or pension income.

- To learn more about tax implications, visit the CRA website:
  - [Employment income \(includes honoraria\)](#)
  - [Expenses incurred by volunteers](#)
  - [Community volunteer income tax program](#)
  - [Contact the CRA](#)

### 2.3 Payment Amounts

Type of Work	Recommended	Other Costs to Cover
<b>Meeting, Document Review or Other General Input</b> Attending meetings, preparing for meetings, providing feedback on documents or other content	\$25 per hour. If any engagement under this category requires less than one hour in duration the full hour will be compensated. A minimum and maximum number of hours required for the engagement will be discussed and agreed upon in advance	Transportation costs. Accommodation (if out-of-town). Meals per diem (if out-of-town). 3 hours of travel time will be covered for patients who spend the day before or after a meeting travelling. Any other expenses incurred related to the engagement (e.g. long distance charges, expenses incurred by caregivers taking time away from caregiving, expenses for a support person for a patient to participate).
<b>Project-based Work</b> Participating in a specific project as a team member	Same as above.	Same as above.
<b>Patient Reviewer</b> Participating in grant review as a panel member	Same as above.	Same as above.
<b>Committee Member, Advisor, Or Facilitator</b> Participating in a committee as a member, advisor or a facilitator	Same as above	Same as above.
<b>Presentation</b> Preparing a formal presentation and materials (e.g., slides) and delivering the presentation	\$100 per presentation.	Same as above.
<b>External Events</b> Representing CCS at an external event and reporting back to CCS (i.e. CCRC conference)	\$100 for half day. \$200 for full day.	Same as above. Registration fees.

### 2.4 Patient Compensation Tracking Form

See form below.

## Canadian Cancer Society

### Patient Partner Activity Log

As a valued patient partner of the Canadian Cancer Society (“CCS”), your contributions and time are important to us. To ensure your hours are accurately logged, we kindly ask that you use this tracking sheet to keep a record of all your activities conducted for CCS. Please review the Patient Partner Compensation Policy and Procedures for more details on the rate, as well as the payment options available to you. Please submit this form to your CCS staff liaison every 3 months or at the agreed upon times so that we can provide you with your preferred payment in a timely manner. All cheques will be mailed to the address provided with your submission. Please be advised that it typically takes 5-10 days to process your payment, plus additional courier time. Thank you for your support and contribution to CCS. We value your partnership!

First and Last Name:

Period of Engagement (e.g. January – April 2022):

Engagement Record:

<b>Activity Name</b> (e.g. Patient engagement strategy development member)	<b>Description</b> (e.g. committee meeting, mileage)	<b>Date of Activity</b> (e.g. January 10, 2022)	<b>Compensation Rate</b>	<b>Number of Hours</b>
			\$25 / hour	
			<b>Total Hours</b>	
			<b>Total Payment</b>	<b>\$</b>

Preferred Form of Payment:

- I wish to accept payment in the form of cash (cheque) for my total contribution
- I wish to accept payment in the form of cash (Electronic Funds Transfer (EFT)) for my total contribution – *see form for banking information*
- I wish to accept payment in the form of a gift card for my total contribution (please list desired gift card(s): \_\_\_\_\_)
- I wish to accept payment in the form of cash (cheque/EFT) and in-kind payment (please describe): \_\_\_\_\_
- I wish to accept payment in the form of a gift card and in-kind payment (please describe): \_\_\_\_\_
- I do not wish to receive any form of payment

Other (please describe): \_\_\_\_\_

Special Requests:

Please describe any special requests you may have in receiving payment for your contribution.

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Preferred Frequency of Payment:

- Please process my payment upon receipt of this submission
- Please keep my hours logged for now; I will inform you when I wish to receive payment  
(Hours can be stored until the end of the calendar year)
- I do not wish to receive any form of payment

*By signing below, you are acknowledging that you completed the work above and agree to receiving recognition in the preferred form of the payment selected above.*

**Privacy & Confidentiality**

I understand that my personal information provided below is being collected by CCS and will be strictly used for payment purposes and stored securely in the CCS network. It will be accessible only to the CCS staff member and finance member working with me. This information will only be used and shared for the purposes identified above, or as required by law. This information will be destroyed after 3 years of inactivity (3 years after I have stopped engaging with CCS). For more information about our privacy practices, visit-<https://cancer.ca/en/privacy-policy>.

First Name and Last Name: \_\_\_\_\_

Mailing Address: \_\_\_\_\_

Social Insurance Number: \_\_\_\_\_

Email: \_\_\_\_\_

Phone: \_\_\_\_\_

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date