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Patient Partner Appreciation Policy and Protocol

SPOR Evidence Alliance

Date Effective: July 2020

To Be Reviewed: July 2021

Prepared By:

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Suggested citation: SPOR Evidence Alliance (2019). Patient Partner Appreciation Policy and Protocol. Toronto, ON: SPOR Evidence Alliance.



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 in the Alliance.

Scope

All Alliance researchers and activity leaders should use this document when engaging patient partners in Alliance activities. Patient partners will also receive a copy of this document when they join the Alliance so that they are aware of the appreciation (i.e., compensation) policy and procedure.

Definitions

Patient	An overarching term inclusive of individuals with personal experience of a health issue and includes informal caregivers, including family and friends. ¹
Public	Encompasses interested representatives of the general public, consumers of health services, patients, caregivers, advocates and representatives from affected community and voluntary health organizations. ²
Patient & Public Engagement	Meaningful and active involvement in all activities including governance, priority setting, planning, conducting research and knowledge translation. ¹
Patient-Oriented Research	Patient-oriented research refers to a continuum of research that engages patients (and public) as partners, focuses on patient-identified priorities and improves patient outcomes. This research, conducted by multidisciplinary teams in partnership with relevant stakeholders, aims to apply the knowledge generated to improve healthcare systems and practices. ¹
Patient Partner	The Alliance uses patient partner to include both patients and public who partner with research teams and activity leaders within the Alliance. Patient partners in research should not be confused with research participants, otherwise known as study subjects.
Compensation	Fair recognition and appreciation to a patient partner for their engagement in an Alliance 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. ³
Reimbursement	Repayment of out-of-pocket expenses incurred by patient partners related to their engagement in Alliance activities. Eligible expenses include travel, accommodation, per diem meals as per the standard policies of the Alliance's administrative ('home') institution: St. Michael's Hospital, Unity Health Toronto. ³

¹ <http://www.cihr-irsc.gc.ca/e/48413.html>

² <http://www.cihr-irsc.gc.ca/e/34190.html>

³ https://diabetesaction.ca/wp-content/uploads/2018/07/TASK-FORCE-IN-PATIENT-ENGAGEMENT-COMPENSATION-REPORT_FINAL-1.pdf



Policy

4.1 Guiding Principles

This document has been developed in accordance with the following SPOR-related sources:

- Strategy for Patient-Oriented Research - Patient Engagement Framework⁴ released by the Canadian Institutes of Health Research,
- Recommendation of Patient Engagement Compensation³ document prepared by the SPOR Working Group, and the
- CIHR document entitled, *Considerations When Paying Patient Partners in Research*.⁵

The rate of compensation is to reflect **choice, fairness, respect, responsiveness, representativeness, and transparency**. It is important to note that patient partners represent a diverse population, and compensation protocols should recognize this diversity, which may require the protocol to be adapted to different circumstances.

4.2 What rates and types of payment options are available through the Alliance?

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. free access to a resource).

Payment Rates*	
Fixed Service Income	An hourly or daily rate is paid to recognize patient contribution. The hourly rate of the Alliance is \$25 as per the recommendations by the SPOR Working Group.
Honoraria	A one-time lump sum payment is made for attending an event or for participating in a short-term activity.
Payment Type	
Cash or cash equivalent	Cash payments are offered in the form of a cheque or gift cards (if preferred).
In-Kind Payment or Gifts	In-kind support can also be arranged, such as access to Alliance capacity-building courses for free, support to cover conference registration fees, etc.

*See [section 5 Payment Amounts](#) for details on specific rates. Patients are encouraged to [contact the CRA](#) for information on taxation before accepting an offer of payment.

5. Protocol

5.1 Prior to Engagement

- Patient partners will **receive a copy of this document** and have an opportunity to ask questions.
- Patient partners **should fully understand and agree to the payment offered** to them before beginning their work.

⁴ <http://www.cihr-irsc.gc.ca/e/48413.html#a4>

⁵ <http://www.cihr-irsc.gc.ca/e/51466.html>



- The **minimum and maximum number of hours expected** from their engagement in the work should be discussed. Should the number of hours change, a conversation should be held between the activity/project leader and patient partner immediately.
- Any **reimbursement of cost to engagement** (e.g., transportation, accommodation, etc.) will be discussed prior to the activity, and is separate from compensation.
- Patient partners should be asked of their **own expectations for compensation**.
- Patient partners have the **right to express any concerns** about the payment being offered. Each concern will be reviewed and resolved by the Nominated Principal Investigator and the Executive Committee with appropriate documentation and rationale for the final decision.
- 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**, 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 offered compensation**.

5.2 Tracking Contribution and Processing Payments

- Patient partners are responsible for tracking and claiming their own hours of contribution using the [standardized form found on the website](#).
- Patient partners will be consulted to set the **frequency of payment** according to their preferences, but patients are asked to submit their hours every 3 months for recordkeeping.
- 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.
 - **Note:** Since we are a publicly-funded initiative, we are unable to make donations to charities.
- Patient partners will be responsible for their own finances, and should keep the following in mind to inform their decisions regarding all offers of appreciation:
 - Any form of cash payment totaling \$500 or more in a given year is considered taxable income and the host institution (i.e., the institution of the team you are directly working with) will automatically issue a T4A for these funds,⁶ which may be considered income by Canada Revenue Agency (CRA).
 - Canada Pension Disability requires disclosure of compensation above a specific amount which varies from year to year (recently \$5,500)⁷.
 - Compensation may alter the benefits status for individuals on disability or pension income.

To learn more about tax implications, please consider the following CRA guidelines:

- [Employment Income \(includes honoraria\)](#)
- [Receiving Gifts](#)
- [Gifts and Income Tax](#)
- [Expenses incurred by volunteers](#)
- [Community Volunteer Income Tax Program](#)

⁶ <https://www.canada.ca/en/revenue-agency/services/tax/businesses/topics/payroll/completing-filing-information-returns/t4a-information-payers/t4a-slip/what-report-exceptions.html>

⁷ <https://www.canada.ca/en/services/benefits/publicpensions/cpp/cpp-disability-benefit/while-receiving.html>



Payment Amounts

TYPE OF WORK	RECOMMENDED	OTHER COSTS TO COVER
<p>Meeting, Document Review or Other Advisory Role Attending meetings, preparing for meetings, providing feedback on documents, and participating in a committee</p>	<p>\$25 per hour.</p> <p>If any engagement under this category requires less than one hour in duration, the full hour will be compensated.</p> <p>A minimum and maximum number of hours required for the engagement will be discussed and agreed upon in advance.</p>	<p>Transportation costs.</p> <p>Accommodation (if out-of-town).</p> <p>Meals per diem (if out-of-town).</p> <p>3 hours of travel time will be covered for patients who spend the day before or after a meeting travelling.⁸</p> <p>Any other expenses incurred related to the engagement (e.g. long distance charges).</p>
<p>Project-based Work Participating in a specific project as a team member</p>	<p>\$25 per hour.</p> <p>If any engagements under this category require less than one hour in duration, the full hour will be compensated.</p> <p>A minimum and maximum number of hours required for the engagement will be discussed and agreed upon in advance.</p>	<p>Same as above.</p>
<p>Presentation Preparing formal presentation and materials (e.g., slides) and delivering presentation</p>	<p>\$100 per event.</p>	<p>Same as above.</p>
<p>Panel/Facilitation Participating in a facilitated panel as a member or a facilitator</p>	<p>\$100 per event.</p>	<p>Same as above.</p>
<p>External Events Representing the Alliance at an external event and reporting back to the Alliance central coordinating office (e.g., SPOR Summit)</p>	<p>\$100 for half day.</p> <p>\$200 for full day.</p>	<p>Same as above.</p>

⁸ http://www.bccdc.ca/resource-gallery/Documents/Educational%20Materials/Epid/Other/peer_payment-guide_2018.pdf

Patient Partner Appreciation – FORM



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Patient Partner Appreciation Form

(Download fillable form [here](#).)

As a valued patient partner of the Alliance, 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 the Alliance. Please review the Patient Partner Appreciation Policy for more details on the rate, as well as the payment options available to you.

Please submit this form to the Central Coordinating Office (SPOREA@smh.ca) every 3 months 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 45 days to process your payment, plus additional courier time.

Thank you for your support and contribution to the SPOR Evidence Alliance. We are truly grateful to have your partnership!

Patient Partner Activity Log:

First and Last Name	
Period of Engagement <i>(E.g. January 2019-April 2019)</i>	

Engagement Record:

ACTIVITY NAME	DESCRIPTION (optional)	DATE OF ACTIVITY	NUMBER OF HOURS
<i>E.g. EC Meeting No. 1</i>	<i>E.g. Recurring meeting to discuss business</i>	<i>E.g. August 27, 2018</i>	
TOTAL HOURS CONTRIBUTED			

Patient Partner Appreciation – FORM



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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 (cheque) and in-kind payment (*please describe in the text box provided*)
- I do not wish to receive any form of payment
- Other (*please describe in the text box provided*)

Special requests

Please use the text box below to describe any special requests you may have in receiving payment for your contribution.

Click or tap here to enter text.

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
- 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

Information provided will be strictly used for payment purposes and will be stored securely in the St. Michael's Hospital network drive. They will be accessible only to the nominated principal investigator, study team and office of research administration at St. Michael's Hospital. Should there be any breach of privacy, you will be informed right away, but the chance that this information will be accidentally released is judged to be very small.

First and Last Name:	
Mailing Address:	
Social Insurance Number: <i>(Please note this data is needed if you anticipate receiving \$500 or more in a given year)</i>	
Phone:	Email:
SIGNATURE:	DATE: