



SPOR Evidence Alliance
Strategy for Patient-Oriented Research

**Alliance pour des données
probantes de la SRAP** 
Stratégie de recherche axée sur le patient

Strategy for Patient-Oriented Research

SPOR

Putting Patients First 

Patient and Public Partner Appreciation Policy and Protocol

SPOR Evidence Alliance

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To Be Reviewed: August 2022

Prepared By:

The SPOR Evidence Alliance Central Coordinating Office in collaboration with patient partners and members of the governance structure.

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Land Acknowledgement(s)

The SPOR Evidence Alliance located on land now known as Tkaronto (Toronto). Tkaronto is the traditional territory of many groups, including the Mississaugas of the Credit and the Chippewa/ Ojibwe of the Anishnaabe Nations, the Haudenosaunee, and the Wendat. It is now home to many diverse First Nations, Inuit and Métis peoples. We respect the Treaties that were made on these territories; we acknowledge the harms of the past and present; and we dedicate ourselves to work with and listen to First Nations, Inuit and Métis communities in the spirit of reconciliation and partnership.

We are grateful to have this opportunity to work on this land and commit to caring for this land.

Funding Acknowledgement(s)

The Strategy for Patient-Oriented Research Evidence Alliance ([SPOR EA](#)) is supported by the Canadian Institutes of Health Research ([CIHR](#)) under the Strategy for Patient-Oriented Research ([SPOR](#)) initiative.

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Patient and Public Partner Appreciation



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Purpose

The purpose of this document is to provide information on the policies and procedures in place to recognize and appreciate the time and effort of patient and public partners engaged in the Strategy for Patient-Oriented Research (SPOR) Evidence Alliance.

These policies and procedures were developed by the SPOR Evidence Alliance central coordinating office in close consultation with eight patient partners and members of the governance structure.

Scope

This policy and procedure document should be consulted when engaging patient and public partners in any SPOR Evidence Alliance activities. Patient and public partners will also receive a copy of this document when they join the SPOR Evidence Alliance so that they are well informed.

As a Canadian Institutes of Health Research (CIHR) funded initiative, we adhere to CIHR's position that patient and public partners should be offered compensation for their involvement in research activities, and separately reimbursed for eligible expenses. For the purpose of this document, we will be using the term appreciation to describe compensation.

Please note that this is a living document subject to review in collaboration with patient partners on an annual basis to reflect current best practices.

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	An overarching term that 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 and 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 and Public Partner	The SPOR Evidence Alliance uses the term 'patient and public partner' to include both patient and members of the public who join the SPOR Evidence Alliance. Patient partners in research should not be confused with research participants, otherwise known as study subjects.
Appreciation	An acknowledgement and appreciation of time and effort of patient and public partners actively involved in SPOR Evidence Alliance activities. It can be in the form of cash payment, gift cards or in-kind exchanges or incentives.

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

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



	This 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 SPOR Evidence Alliance activities. Eligible expenses include travel, accommodation, per diem meals as per the standard policies of the SPOR Evidence Alliance's administrative ('home') institution: St. Michael's Hospital, Unity Health Toronto.

Appreciation Policy

Principles

The SPOR Evidence Alliance's appreciation policy aims to reflect **choice, fairness, respect, responsiveness, representativeness, and transparency**. It is important to note that patient and public partners represent a diverse population, which may require the protocol to be adapted to different circumstances.

Knowledge base

This document has been developed in consideration of the following resources:

- Strategy for Patient-Oriented Research - Patient Engagement Framework⁴ released by the Canadian Institutes of Health Research (CIHR)
- Recommendation of Patient Engagement Compensation³ prepared by the SPOR Networks in Chronic Diseases and the PIHCI Network
- CIHR document entitled, *Considerations When Paying Patient Partners in Research*⁵
- Compensation and reimbursement policies of SPOR SUPPORT Units

Payment types and structure

Appreciation is primarily offered as an **hourly rate** which can be paid in the form of cash (in Canadian dollars), cash equivalents (e.g., gift cards), or in-kind (e.g., free access to resources).

<i>Payment Rates</i>	
Hourly rate	<p>The hourly rate of the SPOR Evidence Alliance is \$25.00 CAD.</p> <p>This rate aligns with other initiatives within the SPOR enterprise that use a rate structure for patient and public partner appreciation.³</p> <p>It also exceeds the highest living wage in Canada.⁶ The community with the highest living wage in Canada is Yellowknife, Northwest Territories at \$23.95.⁷</p>

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

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

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

⁶ <http://livingwagecanada.ca/>

⁷ <http://livingwagecanada.ca/index.php/living-wage-communities/northwest-territories/>

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<i>Payment Type</i>	
Cash or cash equivalent	<p>Cash payments are offered in the form of a cheque by mail or gift cards (by mail or online).</p> <p>Patient and public partners are encouraged to contact the CRA for information on taxation before accepting any form of cash payment.</p> <p>As a CIHR-funded initiative, we are not able to donate to charities and/or private foundations on your behalf as a form of appreciation, as doing so would not be conducive to the research activities and mandates of the SPOR Evidence Alliance.</p>
In-kind	<p>In lieu of cash or cash equivalent, in-kind support can be arranged based on the patient/public partner preference for alternative goods or services of equal cash value.</p> <p>Examples include providing free access to any fee-based SPOR Evidence Alliance capacity-building opportunities such as, courses, workshops, scientific meetings, etc.</p>

See [Appendix 1: Appreciation Guidelines](#) for appreciation rates and eligible expenses.

Procedural Considerations

At the onset of an engagement

- Patient and public partners should **receive a copy of this document** and have an opportunity to seek clarification as needed.
- Patient and public partners should be asked about their own expectations for appreciation.
- Patient and public partners have the right to **decline appreciation**. All funding of the SPOR Evidence Alliance is used strictly for research and operating cost purposes, including funds declined by patient/public partners.
- Patient and public partners **should fully understand and agree to the payment offered** to them before beginning their work. Recipients are encouraged to disclose funds they receive from the SPOR Evidence Alliance in relevant disclosure obligations (e.g., conflicts of interest disclosure).
- It is important to discuss the **minimum and maximum number of hours expected** of patient and public partners at the time of recruitment. Any changes to the expected hours should be discussed at the earliest opportunity.
- Any **reimbursement of cost to engagement** (e.g., travel, accommodation, etc.) should be discussed prior to the activity commencing (if possible), and is separate from the appreciation payment. In the event of any unexpected expenses (e.g., travel interruptions), the activity/project leader and patient or public partner should communicate at the earliest opportunity.



Payments and financial considerations

- Patient and public 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 (e.g., in-kind instead of cash payment).
Note: We are not able to direct our CIHR funding to charities and/or private foundations on behalf of a patient or public partner.
- Patient and public partners will be responsible for their own finances, and should keep the following in mind:
 - 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 funds⁸. The SPOR Evidence Alliance is not able to answer tax-related questions, please consult your municipal, provincial and federal authorities to learn more.
 - Appreciation payments may alter the benefits status for individuals on disability, pension, or other forms of 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](#)

Tracking and reporting hours

- All payments will be recorded using the internal tracking system. It is the responsibility of patient and public partners to confirm their hours using the [standardized form found on the SPOR Evidence Alliance website](#).
- Patient and public partners can **decide when they would like to receive payments**. For activities/projects with long-term commitments, the SPOR Evidence Alliance will collect hours every 6 months (or at the end of a high volume patient and public partner engagement activity) to make payments in a timely manner.

Complaints Procedure

All complaints should be made to the SPOR Evidence Alliance Central Coordinating Office (SPOREA@smh.ca). The Central Coordinating Office will work with the patient or public partner and researcher (as applicable) to rectify the issue. If a resolution cannot be found, the nominated principal investigator of the SPOR Evidence Alliance, Dr. Andrea C. Tricco, will review the details of the circumstance and provide a final decision.

Authorization

Reviewed by the Partnerships Committee, Steering Committee and the Executive committee and approved by Dr. Andrea C. Tricco in January 2022.

⁸ <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>



Appendix 1: Appreciation Guidelines

ACTIVITY	RECOMMENDED APPRECIATION	ELIGIBLE EXPENSES
<p>1. Meeting, Document Review or Other Advisory Roles</p> <p>Attending meetings, preparing for meetings, providing feedback on documents, and participating in a committee</p>	<p>\$25.00 CAD per hour</p> <p>If any engagement requires less than 0.5 hours, we will round it up to 0.5 hours.</p> <p>A minimum and maximum number of hours required for the engagement will be discussed and agreed upon in advance.</p> <p>*IMPORTANT: It is the responsibility of the patient/public partner to inform the lead if they expect their hours to exceed the maximum.*</p> <p>3 hours of travel time will be covered for patients who spend the day before or after a meeting travelling.⁹</p>	<p>If in-person attendance is required, the following expense(s) will be covered:</p> <p>Travel - This includes economy class airfare, train fare, bus fare or mileage. Taxi fares are covered for short distances.</p> <p>Overnight accommodation - If out-of-town, overnight stay at a nearby hotel will be covered.</p> <p>Meals - All reasonable out of pocket expenses for meals are covered for time spent away from home with original receipts. Alcohol charges are not covered.</p> <p>Dependent care allowance - Eligible to be reimbursed up to \$100 per day (with an invoice) or up to \$50 per day (without an invoice) for dependent care costs (e.g., childcare, elder care, family with differing abilities).</p>
<p>2. Project-based Work</p> <p>Participating in a specific project as a team member</p>	<p>\$25.00 CAD per hour</p> <p>If any engagement requires less than 0.5 hours, we will round it up to 0.5 hours.</p> <p>A minimum and maximum number of hours required for the engagement should be discussed and agreed upon in advance of the activity commencing.</p>	<p>Same as above.</p>

⁹ http://www.bccdc.ca/resource-gallery/Documents/Educational%20Materials/Epid/Other/peer_payment-guide_2018.pdf

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	<p>*IMPORTANT: It is the responsibility of the patient/public partner to inform the lead if they expect their hours to exceed the maximum.*</p>	
<p>3. Presentation</p> <p>Preparing formal presentation and materials (e.g., slides) and delivering presentation</p>	<p>To be determined by the activity leader based on the extent of time and effort required.</p>	<p>Same as above.</p>
<p>4. Panel/Facilitation</p> <p>Participating in a facilitated panel as a member or a facilitator</p>	<p>To be determined by the activity leader based on the extent of time and effort required.</p>	<p>Same as above.</p>
<p>5. External Events</p> <p>Representing the SPOR Evidence Alliance at an external event and reporting back to the SPOR Evidence Alliance central coordinating office (e.g., SPOR Summit)</p>	<p>\$100.00 CAD for half day; 3-4 hours</p> <p>\$200.00 CAD for full day; 7-8 hours</p>	<p>Same as above.</p>
<p>6. Participating in SPOR Evidence Alliance Events</p> <p>Attending optional workshops, webinars or participating in courses</p>	<p>Not eligible for appreciation, unless the patient/public partner is responsible for presenting or co-facilitating the event or the event is mandatory for their specific involvement, in which case please see #1-4.</p>	<p>No costs will be covered unless the patient/public partner is responsible for presenting or co-facilitating the event or the event is mandatory for their specific involvement, in which case please see #1-4.</p>
<p>7. Specific Populations and Communities</p>	<p>It is recognized that these guidelines may need to be adapted to the culture or circumstances of specific populations and communities.</p>	

Patient and Public Partner Appreciation – FORM



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Appendix 2: Patient and Public Partner Appreciation Form

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

We will collect your hours every 3 months at minimum to make payments 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 <i>Example: EC Meeting No. 1</i>	DESCRIPTION <i>(optional)</i>	DATE OF ACTIVITY <i>Example: August 27, 2018</i>	NUMBER OF HOURS
TOTAL HOURS CONTRIBUTED			

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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:

(Please note this data is needed if you anticipate receiving \$500 or more in a given year)

Phone:

Email:

SIGNATURE (*e-signature is acceptable*):

DATE: