

# Sepsis Canada: Patient Partner Compensation Guidelines



## **PURPOSE:**

This document outlines the principles that should be followed by Sepsis Canada members when compensating patient partners in research. Within this document, we also present the models by which Sepsis Canada leadership will compensate patient partners, to provide network members with an example of how patient partner compensation can be executed. Sepsis Canada funded teams must present these guidelines (or an adaptation of these guidelines) to patient partners, prior to engaging them in research activities related to the network. These guidelines may be adapted by Sepsis Canada funded teams as needed to reflect the diversity of our patient partner and researcher population, and the institutions that they will work within.

## **DEFINITIONS:**

Canadian Institutes of Health Research (CIHR): Canada's federal funding agency for health research. Composed of 13 institutes, CIHR collaborates with partners and researchers to support the discoveries and innovation that improve health and strengthen the health care system.

Patient Engagement: Meaningful and active collaboration in governance, priority setting, conducting research and knowledge translation. Depending on the context patient-oriented research may also engage people who bring the collective voice of specific, affected communities <sup>1</sup>.

Patient Partner: An overarching term that includes individuals with personal experience of a health issue as well as informal caregivers, including family and friends <sup>1</sup>.

Sepsis Canada Leadership: Committee, councils or working groups within the Sepsis Canada Network who govern and lead the network. Examples include the Sepsis Canada Executive Committee, Steering Committee and Patient Council.

Sepsis Canada Network (also referred to as Sepsis Canada throughout this document): A federally funded research network of researchers, clinicians and patient partners working towards reducing the burden of sepsis in Canada.

Researcher: Within this document, researcher refers to a member of Sepsis Canada who holds an academic appointment and studies a topic to discover new information or better understand the topic.

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## 1.0 IMPORTANCE OF PATIENT PARTNER COMPENSATION:

Sepsis Canada is a Canadian Institutes of Health Research (CIHR) funded network. Our network will follow the CIHR [“Considerations when paying patient partners in research”](#)<sup>2</sup>.

Patient partners who participate in research provide their time and lived experience to help advance research projects and programs. By compensating patient partners, we demonstrate our appreciation of their time and expertise, promote equity amongst team members, remove barriers for their engagement in research and demonstrate respect for them<sup>3</sup>.

These guidelines are meant to help guide conversations between patient partners and researchers about compensation. All research teams funded by Sepsis Canada are encouraged to engage patient partners in research, and budget for patient partner compensation.

## 2.0 LEVELS OF ENGAGEMENT IN HEALTH RESEARCH:

Patient partner engagement in research may vary depending on the goals, knowledge, time commitment, resources and experiences of the patients and researchers<sup>4</sup>. In the “Levels of Patient and Researcher Engagement in Health Research” spectrum, impacts on decision making for both patient partners and researchers increases from the left to the right (Figure 1). Accordingly, the time commitment and level of knowledge also increases for both patient partners and researchers<sup>4</sup>. Within our network, this schematic will be used as a starting point for dialogue between the patient partners and the researcher to understand what level of engagement is appropriate for a given activity. The patient partner will be compensated commiserate to the level of knowledge and experience needed to participate in the activity.

**Levels of Patient and Researcher Engagement in Health Research**

← - TIME AND KNOWLEDGE NEEDED + →

	LEARN/INFORM	PARTICIPATE	CONSULT	INVOLVE	COLLABORATE	LEAD/SUPPORT
Patient's Goal	To ask questions and learn about how to get more involved	To act as a subject or participant in a research study	To provide feedback and advice on specific research activities	To work directly with a research team throughout the project	To partner on equal footing with researchers in all aspects of research	To make final decisions and lead research activities
Researcher's Goal	To provide information, listen, and answer questions honestly	To act ethically and respectfully in the conduct of research	To seek your input on an ad hoc basis	To include you as standing members in an advisory capacity	To partner equally with you as team members	To follow your lead and support your decisions
How This Can Be Done	In an open atmosphere for sharing through orientation and information sessions, and media campaigns	Through quantitative, qualitative, or mixed methods research	Through scientific cafes, focus groups, priority-setting activities, and as members of ad hoc working groups or expert panels	As members of standing working groups and advisory committees or panels	Patients as co-investigators and research partners, and as members of research steering committees	Through patient or community steering committees and patients as principle investigators



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Figure 1: Levels of patient and researcher engagement in health research. Figure taken from “Patient and Researcher Engagement in Health Research: A Parent’s Perspective”. Amirav I, Vandall-Walker V, Rasiah J, Saunders L. *Pediatrics*. 2017 Sept; 140(3) e20164127; DOI: <https://doi.org/10.1542/peds.2016-4127>

### **3.0 INITIATING PATIENT PARTNER ENGAGEMENT:**

For any teams funded by Sepsis Canada, patient partners working with those teams will receive a copy of this document prior to engaging in research and will be given the opportunity to ask the research team questions. Patient partners will be given the option to choose how and if they would like to receive compensation. Patient Partners may decline compensation for their engagement in research or they may choose to receive compensation in the form of money or in-kind compensation equivalent to a set monetary value (such as gift cards, conference registration, courses etc.). If there is another preference for receiving appreciation (eg. authorship, acknowledgements), Sepsis Canada members are encouraged to work to accommodate these preferences, as appropriate. The agreed upon form of compensation should be outlined and signed by both parties using section 8.0 “Compensation Agreement with Patient Partners”.

If the patient partner chooses to receive monetary compensation, Sepsis Canada members may choose to compensate patient partner’s using one of the models outlined below.

### **4.0 MODELS OF PATIENT PARTNER COMPENSATION:**

#### **4.1 HOURLY COMPENSATION:**

Patient partners that are consistently engaged in ongoing work within the network that requires a high level of skill or knowledge, and an unpredictable number of hours, should be compensated on an hourly basis. The standard rate for hourly compensation of patient partners is \$25 / hour.

Sepsis Canada teams are encouraged to work with the human resource teams at their Universities to compensate patient partners on an hourly basis and determine what salary scale patient partners fall into at their institutions, for patient partners that are consistently engaged in ongoing work within their teams that requires a high level of skill or knowledge, and an unpredictable number of hours.

#### **4.2 MEETING COMPENSATION:**

Patient partner’s that engage in research via meetings, may be compensated via the meeting compensation model. Below we outline the meeting compensation model that Sepsis Canada leadership will follow, which we have adapted from the SPOR Evidence Alliance “Patient Partner Appreciation Policy and Protocol”<sup>4</sup>. Sepsis Canada funded teams are encouraged to follow similar models of compensation when they engage patient partners in research via meetings.



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Meeting	Description	Compensation
Committee / Working Group / Advisory Group Member	A patient partner that participates in a set number of meetings (committee's, working group's or advisory group's) per year and gives their input or advice to the group.	\$50 per meeting (includes compensation for the time spent in the meeting and pre- and post- meeting work).
Half-Day Meeting	A patient partner that participates in a half-day meeting (4 hours or less).	\$100 per meeting (includes compensation for the time spent in the meeting and pre- and post-meeting work).
Full-Day Meeting	A patient partner that participates in a full-day meeting (greater than 4 hours but less than 8 hours).	\$200 per meeting (includes compensation for the time spent in the meeting and pre- and post-meeting work).

### 4.3 SET COMPENSATION

Patient partner's that are doing defined work within the network, for a pre-determined number of hours, with a start date and end date may be compensated via the set compensation model.

To start, the researcher and the patient partner must have a discussion where they agree on expectations in terms of the level of engagement from both parties, the time commitment, and compensation (as well as payment frequency).

Below we give examples of how the set compensation model may look. The set compensation model gives researchers the ability to more accurately budget and predict patient partner compensation. However, agreed upon engagement and time commitment may vary once the project begins and throughout the life of the project. For this reason, patient partners and researchers are encouraged to revisit expectations and compensation at least 3 months into the engagement and annually thereafter when using this model.

Type of Engagement	Time Commitment	Compensation
A patient partner will conduct 10 interviews with participants and perform qualitative analysis for the interviews.	The researcher and the patient partner agree that this should take approximately 60 hours to complete, beginning in	The researcher and the patient partner agree that the patient partner will be compensated a total of \$1500 for this engagement. \$750 will be paid halfway

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	January of 2021 and ending by June 2021.	through the engagement (March 2021) and the remaining \$750 will be paid when the analysis has been completed.
A patient partner will co-designs the study material and recruit participants for a pilot study.	The researcher and the patient partner agree that the design of study materials will take approximately 20 hours. Starting in October, the patient partner will recruit for 10 hours / week. This commitment begins in April 2021 and ends in March 2022.	The researcher and the patient partner agree that the patient partner will be compensated a total of \$7000 for this engagement. \$500 will be paid once the study material is designed. And the patient partner will be compensated on a monthly basis from October onward for recruitment of study participants.

### 5.0 TRAVEL, HOTEL AND REGISTRATION FEE REIMBURSEMENT:

**Travel Expenses:** If patient partners are asked to travel or attend an event by Sepsis Canada leadership, expenses for that event will be covered. These expenses may include airfare, travel (such as taxi fare or transit fare), hotels, conference registration and a per diem rate for food. Sepsis Canada leadership will book and pay for the travel expenses on behalf of the patient partner, where possible. Expenses incurred by the patient partner will be reimbursed. Patient partners must keep original copies of all proof of payment (eg. receipts, invoices) and travel tickets (eg. airline tickets, bus tickets). Prior to travel, the patient partner will be given guidance around limits for expenses that may be incurred. Teams funded by Sepsis Canada must cover or reimburse expenses for events that their patient partners are asked to attend.

### 6.0 METHOD OF PAYMENT AND FREQUENCY OF PAYMENT

Patient partners engaged in activities with Sepsis Canada leadership who are compensated on an hourly basis, must submit their hours via the McMaster [Mosaic portal](#) each week. They will be paid on the same schedule as staff at McMaster University (Friday every two weeks - [https://hr.mcmaster.ca/app/uploads/2020/10/4\\_Alumni-Donor-Wallpaper-Calendar-2020-2021\\_WIDE\\_150\\_2-1-scaled-1.jpg](https://hr.mcmaster.ca/app/uploads/2020/10/4_Alumni-Donor-Wallpaper-Calendar-2020-2021_WIDE_150_2-1-scaled-1.jpg))

Patient partners compensated via the meeting model will be compensated within 4 weeks after participation in each meeting.

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Patient partners compensated via the set compensation model will be compensated according to the frequency agreed upon by the researcher and the patient partner.

### 7.0 IMPORTANT CONSIDERATIONS FOR PATIENT PARTNERS:

- Compensation above \$500 per year is considered taxable income;  
<https://www.canada.ca/en/revenue-agency/services/tax/businesses/topics/payroll/completing-filing-information-returns/t4-information-employers/t4-slip/what-report-what-report-on-t4-slips.html>
- Canadian Pension Disability requires disclosure of compensation above a specific amount that varies from year to year (recently \$6,600);  
<https://www.canada.ca/en/services/benefits/publicpensions/cpp/cpp-disability-benefit/after-apply.html>
- Compensation may alter the benefits status for individuals on disability or pension disability income.

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**8.0 COMPENSATION AGREEMENT WITH PATIENT PARTNERS**

The Researcher [INSERT RESEARCHER NAME] and the Patient Partner [INSERT PARTNER NAME] agree to the following:

- 1. The Researcher will compensate the Patient Partner using the following model of compensation [INSERT MODEL OF COMPENSATION].
- 2. The Researcher and the Patient Partner’s collaboration will start on [DATE] and end on [DATE]. The Researcher and the Patient Partner will revisit this agreement on an [Enter Frequency such as Monthly or Yearly] basis.
- 3. During which time, the Patient Partner will engage in the following research activities (Example #1 conduct 10 study interviews and perform qualitative analysis for those interviews. Example #2 attend and give their input at 4 steering committee meetings):

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- 4. The Patient Partner will receive compensation as follows for their engagement in the activities listed above (Example #1 the patient partner will be compensated a total of \$1500 for this engagement. \$750 will be paid halfway through the engagement and the remaining \$750 will be paid when the analysis has been completed. Example #2 \$50 per meeting):

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*This agreement does not oblige the Patient Partner to complete the activities listed above, nor does it oblige the Researcher to pay the Patient Partner for the activities listed above if they are not completed. The above outlines the Model of Compensation that will be used if the Patient Partner engages and completes the activities listed above.*

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Researcher

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Patient Partner

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Date

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Date

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These guidelines were created using information from the following documents:

1. “Strategy for Patient-Oriented Research – Patient Engagement Framework” Prepared by the Canadian Institutes of Health Research: <https://cihr-irsc.gc.ca/e/48413.html#a11>
2. “Considerations when paying patient partners in research” Prepared by the Canadian Institutes of Health Research: <https://cihr-irsc.gc.ca/e/51466.html>
3. “Patients as Partners in Research: How to Talk About Compensation With Patient Partners”. Richards DP, Jordan I, Strain K, PressZ. J Orthop Sports Phys Ther. 2020 Aug; 50(8): 413-414. DOI: 10.2519/jospt.2020.0106.
4. “Patient and Researcher Engagement in Health Research: A Parent’s Perspective”. Amirav I, Vandall-Walker V, Rasiah J, Saunders L. Pediatrics. 2017 Sept; 140(3) e20164127; DOI: <https://doi.org/10.1542/peds.2016-4127>
5. “Patient Partner Appreciation Policy and Protocol” Prepared by the SPOR Evidence Alliance: [https://sporevidencealliance.ca/wp-content/uploads/2019/08/SPOR-EA\\_Patient-Partner-Appreciation-Policy-and-Procedure.pdf](https://sporevidencealliance.ca/wp-content/uploads/2019/08/SPOR-EA_Patient-Partner-Appreciation-Policy-and-Procedure.pdf)
6. “Recommendation on Patient Engagement Compensation” Prepared by the SPOR Network in Chronic Diseases and the PICHI Network: [https://diabetesaction.ca/wp-content/uploads/2018/07/TASK-FORCE-IN-PATIENT-ENGAGEMENT-COMPENSATION-REPORT\\_FINAL-1.pdf](https://diabetesaction.ca/wp-content/uploads/2018/07/TASK-FORCE-IN-PATIENT-ENGAGEMENT-COMPENSATION-REPORT_FINAL-1.pdf)
7. “Peer Payment Standards: for short-term engagements created in collaboration with peers and providers” Prepared by the BC Centre for Disease control: [http://www.bccdc.ca/resource-gallery/Documents/Educational%20Materials/Epid/Other/peer\\_payment\\_guide\\_2018.pdf](http://www.bccdc.ca/resource-gallery/Documents/Educational%20Materials/Epid/Other/peer_payment_guide_2018.pdf)

