



Patient Partner Appreciation – NL SUPPORT Guidelines

Introduction

Patient-Oriented research (POR)¹ is a collaborative approach to research that engages patients² as partners³ in the research process. When patients become partners in research and research-related activities, they dedicate their time and expertise to the betterment of the overall project just as the other members of the research team, albeit with a different lens.

Canada's Strategy for Patient-Oriented Research (SPOR) encourages researchers and research partners to offer financial compensation to their patient partners.

Effective from fiscal year 2017 – 2018 the following guidelines will govern the compensation of patient partners ("patients") in the field of Patient-Oriented Research working with NL SUPPORT at Memorial University ("the University").

These guidelines apply to patients who are engaged in NL SUPPORT related activities.

These guidelines do not apply to patients engaged in research projects. Researchers are strongly advised to discuss appreciation options with each patient partner to determine which option is a best fit. Researchers may use these guidelines when discussing forms of appreciation with patient partners. Researchers who are not employees with the University should confirm patient pay rates and guidelines with their employer and/or funder.

These guidelines were written by NL SUPPORT staff with advice from our Patient Advisory Council and Human Resources department at Memorial University.

Terms are explained in the brief Jargon Buster.

Forms of appreciation

There are different forms of appreciation. Some ways can include: thank you cards, acknowledgments, letting patients know how they made a difference, payments etc.

This document outlines the NL SUPPORT guidelines on payments to patients contributing to the work of NL SUPPORT. All payments offered by NL SUPPORT are honorarium payments as a form of recognition for the contribution that patients make to our work.

The honorarium offered will depend on the level of time and complexity of the engagement opportunity as well as the effort and skill level of the patient.

- Time spent on meeting preparation and travel time is included in the honorarium and will not be compensated separately.
- The honorarium will be in addition to any reimbursement of expenses incurred by patients when attending meetings (such as costs of traveling, accommodation).

The honoraria are described below. For more information, or if you have any questions please contact NL SUPPORT.

Rates

The honoraria below have been agreed with the Human Resources department at Memorial University. The categories are as follows:

Honorarium	Description	Criteria
\$ 200 per annum	This is the standard one-time honorarium offered for preparation, attendance at and follow up activities from the Patient Advisory Council meetings.	This honorarium will be offered to patient partners who are: <ul style="list-style-type: none">• Recruited based on NL residency and experiences with our health care system, requiring a general interest in improving healthcare through Patient-Oriented Research• Attending 75% of the meetings per year (3 out of 4 patient advisory council meetings per year).
\$ 300 per annum	This is the standard one-time honorarium offered for patient partners involved in reviewing funding applications, being part of a working group, scientific advisory committee,	This fee will be offered to patient partners who are: <ul style="list-style-type: none">• Recruited for specific tasks as described in this table, in addition to NL residency and

	and/or steering committee (not project-specific).	<p>experiences with our health care system.</p> <ul style="list-style-type: none"> • Patient partners may be involved in multiple activities. It's up to the patient how much time the patient would like to give. Patients will be offered a single honorarium of \$300 per annum regardless of the number of meetings attended/ activities undertaken in this category.
Other forms	For more involved engagement with NL SUPPORT related activities, the lead and the patient partner should discuss the most appropriate form of appreciation. This could include a flat rate per day or even contractual arrangements.	This applies to patient partners who are recruited for a skill set or a specific task not described in one of the above categories (such as a patient co-facilitator).

How will patients be paid?

- Patients will be offered an honorarium based on their involvement with NL SUPPORT.
- To claim the honorarium that has been offered, patients and an authorized representative of NL SUPPORT should sign a direct pay claim form at the end of each fiscal year based on their involvement in that year (April 1 – March 31). NL SUPPORT will provide this form at the end of the fiscal year.
- Memorial University will pay by cheque. In order to do so, the University will need the date-of-birth and SIN number of the patient partner.
- The University will provide a T4 for income tax purposes.

Other things that are important

- Patients may decline the offer; declining will not affect engagement in projects nor any reimbursement for costs incurred.
- Patients must be aware that any income received from their involvement with NL SUPPORT must be claimed on their annual Canadian Revenue Agency income tax

return. Before confirming that they wish to accept the offer patients should consider the impact of the payment on their benefits, pensions etc.

- Patients should know that while NL SUPPORT encourages researchers to offer patient appreciations, it is **not mandatory**. The nature of the research project and the level of funding awarded may limit the type of appreciation offered to patients.
- Different research teams and institutions will offer different rates for engagement in research. This is because there is **no set guidance** on this and some organizations can afford to pay more than others.

Approval of these guidelines

This document has been viewed and approved by NL SUPPORT and the Human Resources department of Memorial University. The document will be reviewed regularly in order to ensure that it remains current and reflects any local or national changes.



Catherine Street

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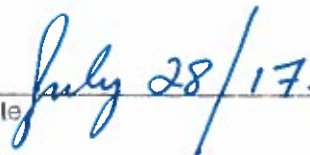
Date



Kim Blanchard

Manager Client and Advisory Services,
Human Resources Department
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Date

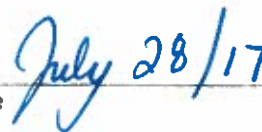




for Glen Roberts

Manager Pensions and
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Date



Brief Jargon Buster

¹Patient-oriented research refers to "research that engages patients as partners, focusses 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." (<http://www.cihr-irsc.gc.ca/e/41204.html>)

²The SPOR Patient Engagement Framework defines the term 'patient' broadly as: "An overarching term inclusive of individuals with personal experience of a health issue and informal caregivers, including family and friends." (<http://www.cihr-irsc.gc.ca/e/45851.html>)

³We define the term 'partner' as a person who is engaged in research including priority-setting, participation in governance committees, consultation on research design and knowledge translation activities to name a few.