

Compensation Guidelines for Engaging Patients as Partners in Research

Introduction

Canada's Strategy for Patient-Oriented Research (SPOR) encourages researchers and research partners to offer financial compensation to patients who act as partners in research and research-related activities. This recommendation is reflected in the third guiding principle of the SPOR Patient Engagement Framework:

Adequate support and flexibility are provided to patient participants to ensure that they can contribute fully to discussions and decisions. This implies creating safe environments that promote honest interactions, cultural competence, training and education. Support also implies financial compensation for their involvement.

The SPOR Patient Engagement Framework identifies a number of areas for engagement including priority-setting, participation in governance committees, consultation on research design and knowledge translation activities to name a few. When patients¹ act as partners in research and research-related activities, they are dedicating their time and expertise to the betterment of the overall project in a similar fashion to other members of the research team, albeit, with different lens. Furthermore, compensation helps make participation in research more equitable and encourages diversity of participants by helping to remove barriers to participant in research for some groups. As such, SPOR promotes a view that, whenever possible, patients should be offered appropriate compensation for their added value to the research activity they are contributing to. These guidelines are considered a first iteration and their application will be monitored moving forward to learn about and improve compensation practices across Canada.

To Whom Do These Guidelines Apply?

There are two main target audiences for these guidelines: (1) patients (as defined by the SPOR Patient Engagement Framework above); and (2) researchers, research administrators and their host organizations. These guidelines discuss what kinds of compensation models currently exist as well as important considerations that need to be taken into account when discussing compensation with patient-partners.

Background

What is the Difference Between Research Partners and Research Participants?

Traditionally, patient engagement in research and research-related activities has been restricted to engagement as *research participants*. Research participants are volunteers who elect to participate in a research study as a recipient of the variable being tested. For example, in clinical trials, research participants, who may or may not be patients, receive the treatment being investigated or receive a placebo or alternate treatment. The voluntary contribution by research participants to be the 'testers' of scientific discoveries is

¹ As a reminder, the 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."

necessary in order to help the researcher determine whether their treatment or intervention works in the way it is intended to. Depending on the size, scale, budget and nature of the research project, some researchers are able to provide financial compensation to attract research participants to their research studies. There are clear [rules and ethical guidelines](#) on compensation for patients who participate in research **as research participants**.

As noted above, the SPOR Patient Engagement Framework recognizes that there needs to be a role for patients outside that of the research participant, one which allows them to contribute to research and research-related activities as a partner in the research process. Therefore 'patient partners' – are individuals who take part in research or research-related activities as *collaborators* rather than research participants.

The remainder of this document provides guidelines and considerations on how to offer compensation to patient partners for their role in research and research-related activities. It should be noted that these guidelines apply specifically to patients as partners and **not** to patients as research participants.

What is the Difference Between Covering Expenses and Compensation?

For the purposes of this document, the guidelines provided below strictly relate to compensation as defined below:

Compensation refers to the act of awarding something to someone in exchange for a service. While this is often monetary, it can also be in the form of honoraria, gifts or in-kind exchanges.

Compensation **should not** be confused with 'covering expenses'. When organizations offer to cover expenses for participation in some sort of activity like an event, conference or workshop, they are referring to paying for, or reimbursing, all costs associated with a person's participation in the activity. This can include paying for travel to the event, fees to participate in the event, hotel accommodations or covering meal costs. While paying expenses is one way to remove barriers to patient participation in research, it is not compensation.

Compensation refers to paying an individual for their time, skills and expertise when partaking in an activity. Like covering expenses, it also helps remove barriers to participation in research by members of the public. In the context of patient-oriented research, patient partners should be offered compensation for time and expertise brought to a research project or related activity *in addition to* covering any expenses related to them participating in those activities. For any questions related to covering expenses and expense reimbursement, researchers are encouraged to consult their host organization's internal policies in addition any policies that govern the grant funds they received from external organizations. The remainder of this document will be referring strictly to patient compensation for their role in research related activities, not covering expenses.

Guidelines:

What do you need to know about offering or accepting compensation?

The following are general guiding principles on compensation for engaging patient partners in research and research related activities.

1. **Who is a Patient Partner** - If patients are involved in a research project in any manner other than as a research participant they are considered 'patient partners'. This means that patient partners may come in many forms depending on the project in question. Some examples of the patient partner role include: participation on governing boards or committees, being consulted on survey design for a study, co-developing the research methodology with a researcher, taking part in priority-setting activities to determine new areas of research, and collecting and/or analysing data and knowledge translation.
2. **Flexibility** - SPOR encourages researchers and research managers to be flexible with the kinds of compensation that they offer to their patient partners. The notion of compensating patient partners for the part they play in the research and research-related activities is relatively new in the health research context. As such, there may be situations where compensating patients for their efforts may not be possible due to budget (i.e., if a researcher is mid-way through a grant cycle) or the type of compensation may need to be negotiated or discussed with the patient. Similarly, researchers need to be sensitive to the realities and desires of their patient partners when deciding on appropriate types of compensation. For example, if a patient partner's livelihood is impacted by their decision to participate in a research project (e.g., they lose benefits or an income source, they cannot work an extra shift, or need to leave work early to make a meeting) these factors should be reflected in discussions around compensation.
3. **Informed Consent** - While offering compensation to patient's partners is highly recommended, it should be offered in a manner where the patient is allowed to make an informed choice about accepting it. Patients should be able to refuse compensation without it impacting their ability to participate in the research project. Similarly, patients should feel confident about asking what kinds of compensation are available to them. Therefore, where possible, researchers should identify in recruitment material whether compensation can be made available as well as be familiar with the types of compensation allowed for by their institutions. Finally, researchers and patient partners are encouraged to decide on the best form of compensation together and that this occurs on a case-by-case basis – what might be right for one patient, may not work for another.
4. **Fair and Equitable Compensation Rates** - When considering *monetary compensation rates* researchers should consider the patients' contributions to the research project. Monetary compensation should reflect the level of time, effort, lived experience and skill level brought to the project by the patient partner in addition to providing comparable rates of pay to other professionals in similar roles. It is worth noting that some international organizations including the United States' Patient-Centred Outcomes Research Institute ([PCORI](#)) and the United Kingdom's [INVOLVE](#) recommend that these rates be similar to other members of the research team. Finally, while there may be differences in rates of compensation between different institutions and even provinces, it is

highly recommended that within each institution compensation rates for patient partners remain consistent.

What forms of compensation are there?

Regardless of whether a patient receives compensation, sincerely thanking and acknowledging the patient for their time, effort and contributions should occur whether additional forms of compensation are offered or not and creates an atmosphere that reinforces a patients sense of belonging to the research process. Similarly, patient partners should be acknowledged appropriately for their contribution in any scientific publications.

That said, there are many forms of patient compensation available. Below are four options for consideration. It should be noted that SPOR is not endorsing any one option over the other - the decision on which form of compensation to use will depend on a combination of factors including institutional policies, research budgets and patient preferences:

1. Fixed service income

With this option the patient receives a fixed rate either per day or by hour for their contribution to the research project. There is no nationally determined or prescribed rate that SPOR recommends. The amount will be determined by the research team in consultation with their patient partner and is subject to relevant institutional and provincial policies governing those institutions. Researchers are encouraged to speak with their institutions and their local SUPPORT Unit to determine what an acceptable range would be and to help them determine the tax implications of payment through this option so the patient can take this into consideration when considering compensation options.

Important Considerations:

- Payment through this option is considered employment income by the Canada Revenue Agency (CRA). This means the institution through which funding flows will need to issue a T4A slip and the patient partner will need to declare this compensation on their annual tax form.
- It is important that research staff **clearly communicate** that receiving compensation in this form can potentially impact the patients' tax status. This is important as individuals on medical pension or disability leave, or who receive social assistance, child benefits or GST/HST credits may see a reduced amount as a result of accepting this form of compensation depending on the amount. As each case will be different and will depend on the province in which the patient resides, it is **strongly recommended** that researchers discuss this with their patient partner, and if necessary direct them to any services that would help them determine whether their financial situation may be impacted by accepting payment. For example, such services exist in [city] at [place]. Researchers should refer to this list of services in case their patient partners do not already have access to such services ...
- Researchers should inform patients that their institution will need to collect Social Insurance Numbers in order to provide T4A's to patient partners. A process for collecting and confidentially sorting this information will be needed.

2. Honoraria

With this option the patient will receive a one-time payment as a thank-you for their contribution to the research project or activity. This type of compensation may be more appropriate for instances where one-off consultations with patients occur (e.g., workshops) or if the patient partner's contribution is short in length. As with the fixed service income option, there can be tax implications for those who choose to receive honoraria.

Important Considerations:

- According to the Canada Revenue Agency (CRA), an honorarium is a voluntary payment made to a person for services for which fees are not legally or traditionally required. An honorarium is typically used to help compensate volunteers or guest speakers. While the CRA perspective generally views payments for services made to an individual as either employment income or business income, they do support the notion of small payments that are not subject to the usual tax rules – this is where honoraria fall. The criteria for these payments include:
 - They are nominal - \$500 or less in a calendar year;
 - They are made to an individual for voluntary services for which fees are not legally or traditionally required;
 - They are not reflective of the value of the work done;
 - They are made on a one-time or non-routine basis to an individual as a “thank-you”.
- An honorarium paid to a resident of Canada who **is not** an employee of a research institution through which they are receiving the payment is not subject to tax deductions; however, this does not mean that the recipient does not have to pay taxes on the amount received. The individual will be issued a T4A for the payment, and when they file their tax return for the year, any taxes owing on the amount paid will be assessed by the CRA. For this reason, it is also recommended that researchers clearly communicate this to their patient partners and direct them to any services that would help them determine whether their financial situation may be impacted by accepting an honorarium.

3. In-Kind Compensation or Gifts

Another option is to offer patients in-kind compensation or gifts. For example, some may wish to take a course or training option at the research institution where the research project activity is taking place. Gift cards, donations to a specific group, attending a conference or helping the patient achieve life goals (e.g., taking a course at the institution) are other options that could be explored.

Important Considerations:

- It should be noted that CRA has rules and regulations around non-cash gifts for employees. Since many patient partners will not be employees of the research institution through which the gift is offered, the in-kind value of their compensation may be regarded as taxable income by CRA. As with the previous options it is highly recommended that the researcher clearly communicate the implications of offering in kind contributions or gifts to their patient-partner and direct them to any services that would help them determine whether their financial situation may be impacted by accepting payment.
- It is encouraged that researchers cover the costs of patients attending a conference *that presents their research*; it is acknowledged that this can sometimes amount to a considerable expense. For

this reason it is important to budget for patient conference attendance into the grant application.

4. Patient May Opt to Decline all Compensation

In recent years many patients have been consulted about whether they wish to be compensated for the role they play in a research project or related activity. For many individuals, a sincere thank you from their research team is enough and they do not feel the need to accept compensation. Some patients may feel that acknowledgement for their participation is appropriate compensation.

What should Patient Partners Consider Before Accepting an Offer?

1. Patient partners should know that the time and expertise they bring to each health research project and related activities is highly valued and that SPOR supports the principle that patient partners should be offered compensation for their role in advancing health research.
2. Patient partners should fully understand and agree to the compensation offered to them before beginning work on a research project.
3. Patient partners should know that they have a right to express if they feel the compensation offered for their participation is not sufficient and discuss their options with the research team. While their feedback may or may not result in a change to institutional compensation policies, it is nevertheless important information that helps the institution understand what is considered fair and appropriate. Since patient partner compensation is new to many institutions, it is expected that policies on this will evolve over time. Similarly, patient partners should know that they have a right to decline any form of compensation offered to them for participating in research and research-related activities without it impacting their ability to partake in the activity.
4. Patient partners should know that while SPOR strongly encourages researchers to offer patient-partner compensation, it is not mandatory. The nature of the research project, the level of funding the researcher is awarded and the institution for which the researcher works may determine the type/amount of compensation offered to patient partners. Furthermore, since patient-oriented research is a relatively new concept, some researchers may have already applied for their grants when they learn about incorporating patient partners into their research projects and not have the budget available to offer compensation. SPOR is trying to address this by informing researchers that it is important to budget for patient partnership from the beginning of the research project.
5. Patient partners should be advised that many forms of compensation received through their participation in a research project or related activity is subject to relevant tax laws and regulations issued by the Canada Revenue Agency and the patient partner's home province. While researchers should inform patients when a compensation option has the potential to impact a patient's financial situation, it is ultimately the responsibility of the patient partner to determine whether that option is the right fit for them.

What Should Researchers or Research Managers Consider Before Offering Compensation to Patient Partners?

1. Budget for Patient Engagement! While patient compensation is a new practice and many researchers may be considering engaging patients after they have received their grant funding, researchers are encouraged to budget for Patient Engagement in future applications.
2. Determine if patient compensation is an eligible expense – Researchers can receive research funding through a number of avenues. Researchers should know if they receive research funding through the Canadian Institutes of Health Research (CIHR), a key partner in SPOR, patient compensation is considered an eligible expense. If researchers are working with funds received through a different funding source, they should consult them to determine whether patient compensation is an eligible expense.
3. Know the local policies or guidelines that affect compensation - Researchers are strongly encouraged to seek guidance from their respective institution's financial department and local SUPPORT Unit to determine :
 - a. What forms of compensations can be issued from the list above (i.e., monetary, honoraria, in-kind exchanges).
 - b. How to advise patient partners when compensation can become a taxable income in order to allow them to reflect on how accepting compensation may impact their financial situation. Furthermore, in order to allow patient partners to participate from lower income families, it is recommended asking your finance department if they may be available to provide specific advice (or resources) to patients who do not have a financial advisor so that they can make informed choices about receiving compensation.
 - c. What the process is for issuing compensation. For example, what documentation is needed and how will information be confidentially shared? What will the turn-around time be from participation to payment?
4. Discuss compensation options with your patient partner – while it is important to understand what kinds of compensation options you are able to provide before engaging patient partners, it is also important **not to decide** on the compensation you will provide **for** your patient partner. Give them options and discuss what is feasible together. Also, if your patient partner proposed a different option, explore the feasibility of providing that option. Finally, the principal of equity should be adhered to when offering compensation to patient partners to encourage diversity.

How Can Researchers Institutions/Organizations Facilitate Compensation to Patient Partners?

1. Research institutions should consider crafting their own policies or guidelines on patient compensation for their researchers. It is highly encouraged that these guidelines enable flexibility on the type of payment that can be issued to patient partners. Research institutions are also encouraged to share these policies with their local SPOR SUPPORT Unit who will be collecting data on patient compensation practices to help improve practices across Canada.

2. Ensure the monetary compensation rates are consistent within your institution. Furthermore, it is recommended to collect information on the types of patient compensation being offered by your research teams; compensation for patient partnership is new and this information can be used to improve the research institutions policies around compensation over time.
3. Consider having a member of your financial department specialize in patient compensation and be available to speak to patient partners who may need assistance determining the impact of accepting compensation on their income status.
4. Determine whether the storage of patient partner Social Insurance Numbers (SIN) requires added security measures in your computer systems.

For More Information on Existing Patient Compensation Practices Please See the Following:

- [PCORI \(United States\)](#)
- [INVOLVE \(United Kingdom\)](#)
- [A Guide for Paying Peer Research Assistants \(British Columbia\)](#)
- [The Change Foundation – Should Money Come into It \(Patients Canada\)](#)
- [Pacific AIDS Network – Compensating Peer Researchers](#)

For More Information on Tax implications please see the following CRA guidelines:

- Employment Income (includes honoraria): <http://www.cra-arc.gc.ca/tx/ndvdl/tpcs/ncm-tx/rtrn/cmpltng/rprtng-ncm/lns101-170/101/menu-eng.html>
- Receiving Gifts: <http://www.cra-arc.gc.ca/chrts-gvng/chrts/prtng/gfts/menu-eng.html>
- Gifts and Income Tax: <http://www.cra-arc.gc.ca/E/pub/tg/p113/README.html>
- Community Volunteer Income Tax Program: <http://www.cra-arc.gc.ca/volunteer/>

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