



WE-SPARK Health Institute L.E.A.R.N. Program Compensation Policy

WE-SPARK's Approach to Compensation

WE-SPARK Health Institute and its L.E.A.R.N. Program recognize the invaluable contribution that people with lived experience (PWLE) provide to research, programs, and initiatives. We acknowledge that without the perspectives, ideas, and time granted to us by PWLE, it would be difficult to meet our objectives and make meaningful contributions to health research.

Compensation can take many forms and should be discussed early with PWLE. Compensation demonstrates the value and worth of the expertise brought by the perspectives of our PWLE. By offering compensation, we not only acknowledge these valued contributions but seek to further create an open dialogue, reduce power hierarchies caused by the fact that others at the table receive a salary related to their role, and help to ensure that PWLE who may not have the resources to volunteer are able to participate. Moreover, we strive to demonstrate respect for community protocols and practices.

Canada's SPOR Compensation Guidelines

Introduction

The Canadian Institutes of Health Research (CIHR) Strategy for Patient-Oriented Research (SPOR) encourages researchers and research partners to offer payment to patients, or people with lived experience (PWLE), who act as partners in research and research-related activities (i.e., L.E.A.R.N. Program members). The SPOR Patient Engagement Framework identifies a number of areas for engagement including involvement in priority-setting, participation in governance committees, and consultation on research design and knowledge translation activities, to name a few. When PWLE 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 a different lens. Offering payment to PWLE who undertake this important work helps make participation in research more equitable and diverse by helping to remove barriers to participation in research.

SPOR promotes the view that, whenever possible, PWLE should be offered appropriate payment for their added value to the research activity to which they are contributing. Engagement of PWLE is an ever-evolving field. As such, we recognize that this is a 'living' document. Ongoing feedback from the community will be used to update and improve it.

To whom do these considerations apply?

There are two main target audiences for these considerations: (1) PWLE, or 'patients' (as defined in the SPOR Patient Engagement Framework); and (2) researchers, research administrators and their administering organizations.

What is the difference between PWLE as research 'partners' and research 'participants'?

Traditionally, PWLE engagement in research and research-related activities has been restricted to engaging as research participants. Research participants are volunteers who elect to participate in a research study as a recipient of a variable being tested. For example, in clinical trials, research participants (who may or may not be PWLE) receive the treatment being investigated or a placebo or alternate treatment. The voluntary contribution by research participants to be the 'testers' of scientific discoveries is essential in order to help researchers determine whether their treatment or intervention works as intended. There are clear rules and ethical guidelines on payment for those who participate in research as research participants.

The SPOR Patient Engagement Framework recognizes that in addition to the very important role of research participants, there needs to be a role for PWLE that allows them to contribute to research and research related activities as a partner in the research process.

This document provides considerations for offering payment to lived experience partners, *NOT* to research participants.

What is the difference between covering expenses and paying PWLE?

For the purposes of this document, 'compensation' will be referred to as 'payment'. Payment is defined as "the act of awarding something to someone in exchange for a service. While this is often monetary compensation in the form of salary or stipends, it can also be in the form of services, honoraria, gifts or in-kind exchanges or incentives."

Payment should *NOT* be confused with 'covering expenses.' When an organization offers to cover expenses for participation in an activity such as an event, conference or workshop, this refers to paying for, or reimbursing, costs associated with a person's participation in the activity (e.g., travel to the event, fees to participate in the event, hotel accommodations or covering meal costs). While covering expenses is one way to remove barriers to PWLE participation in research, it does not fit the definition of payment in the sense this document seeks to highlight. For any questions related to

covering expenses and expense reimbursement, researchers are encouraged to consult their institutional policies in addition to any policies that govern the grant funds they received from external organizations.

Paying PWLE refers to paying an individual for their time, skills and expertise when partaking in an activity. In the context of WE-SPARK Health Institute, L.E.A.R.N. Program members should be offered payment for their time and expertise brought to a research project or related activity in addition to covering any expenses related to them participating in those activities. It is important for researchers to recognize that PWLE may have expenses that fall outside the typical expenses that faculty, staff, or students might have. Researchers should work with their institutions to ensure that their policies encourage fair and reasonable expense reimbursement for PWLE who incur costs when participating in research.

Considerations for Research Teams and Advisory Boards

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

The following are general guiding principles that can be used when offering payment to PWLE engaged in research and research-related activities.

1. **Who is a Lived Experience Partner?** If PWLE are involved in a research project in any manner other than as a research participant, they are considered 'lived experience partners'. Some examples of the lived experience partner role may 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 analyzing data and knowledge translation.
2. **Flexibility:** SPOR encourages flexibility with the kinds of payment they offer to their lived experience partners. There may be situations when offering payment to PWLE may not be possible due to budget constraints (e.g., was not planned in the budget) or the type of payment may need to be negotiated or discussed with the lived experience partner.
3. **Informed Consent:** While offering payment to lived experience partners is highly recommended, it should be offered in a manner whereby PWLE are allowed to make an informed choice about accepting it or not. PWLE should be able to refuse payment without it impacting their ability to participate in the research project. Similarly, PWLE should feel comfortable asking about what kinds of payment are available to them. Therefore, when possible, researchers should identify in recruitment material whether payment will be made available, and should familiarize themselves with the types of payment allowed for by their institutions. Finally, researchers and lived experience partners are encouraged to

decide on the best form of payment together and remain mindful that this occurs on a case-by-case basis – what might be right for one PWLE, may not work for another.

4. **Fair and Equitable Payment Rates:** When considering monetary compensation rates, researchers should consider the lived experience partner's 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 lived experience partner. The rate of pay should be comparable to the rates of pay to other professionals in similar roles, such as is recommended by international organizations such as the United States' Patient-Centred Outcomes Research Institute (PCORI) and the United Kingdom's INVOLVE. Finally, it is highly recommended that within each institution compensation rates for lived experience partners remain consistent.

What forms of payment are there?

Regardless of whether PWLE receive payment, sincerely thanking and acknowledging them for their time, effort and contributions should occur whether additional forms of payment are offered or not. This creates an atmosphere that reinforces a sense of belonging to the research process. Similarly, lived experience partners should be acknowledged appropriately for their contribution in any scientific publications. There are many forms of payment available; below are four options for consideration. It should be noted that SPOR and WE-SPARK do not endorse any one option over the other; the decision on which form of payment to use will depend on a combination of factors including institutional policies, research budgets, stipulations of external funding sources, and PWLE preferences.

1. **Fixed Service Income:** With this option, the lived experience partner receives a fixed rate (e.g., per hour, per day, etc.) 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 lived experience partners and is subject to relevant institutional and provincial/territorial policies governing those institutions. Researchers are encouraged to speak with their institutions to determine an acceptable range and to help them determine the tax implications of payment through this option so PWLE can take this into consideration when considering payment options.
 - Payment through this option may be considered employment income by the Canada Revenue Agency (CRA) and may be subject to taxation. Please contact CRA for more information.
 - Researchers should inform PWLE that they may need to collect Social Insurance Numbers in order to provide any applicable tax forms related to

the payment to lived experience partners. A process for collecting and confidentially sorting this information will be needed.

2. **Salary/Stipend:** Similar to the above option, the lived experience partner may be offered a salary or stipend for their participation on a research project. Again, there is no nationally determined or prescribed salary or stipend rate that SPOR recommends.
 - Payment through this option may be considered employment income by the CRA and may be subject to taxation. Please contact CRA for more information.
 - It is important to note that while salaried lived experience partners do exist, this is rare. PWLE would have to adhere to the regular employment practices of the administering institution.
3. **Honoraria:** With this option, the lived experience partner will receive a one-time payment as a thank-you for their contribution to the research project or activity. This type of payment may be more appropriate for instances where one-off consultations with PWLE occur (e.g., workshops) or if their contribution is short in length.
 - According to the 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 cover costs for volunteers or guest speakers. Please contact CRA for more information on issuing and receiving honoraria.
4. **In-Kind Payment or Gifts:** Another option is to offer PWLE in-kind payment or gifts. For example, some may wish to take a course or training at the institution where the research project activity is taking place. Gift cards, donations to a specific group, attending a conference, or helping the lived experience partner achieve personal goals (e.g., taking a course at the institution) are other options that could be explored.
 - It should be noted that CRA has rules and regulations around non-cash gifts for employees. Since many lived experience partners will not be employees of the research institution through which the gift is offered, the in-kind value of their gift may be regarded as taxable income by CRA. Please contact CRA for more information.
 - It is encouraged that researchers cover the costs of PWLE 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 PWLE conference attendance in the grant application.
5. **Payment offered to Indigenous Elders/Knowledge Keepers:** Indigenous Elders/Knowledge Keepers require a different protocol when it comes to payment as a lived experience partner. In addition to covering expenses related

to their participation in a project or activity (i.e., transportation, meals, and accommodation if necessary), they receive a flat rate for the day regardless of the amount of time spent on the activity. Finally, an appropriate gift should be offered (e.g., tea, blanket, scarf, etc.).

- When seeking the participation of an Elder/Knowledge Keeper on a research project, researchers are encouraged to check with their institution to see if there is already a protocol or policy on working with Elders/Knowledge Keepers in addition to speaking with the community and the Elder themselves on what is considered appropriate payment for their time.

6. **PWLE May Choose to Decline all Forms of Payment:** In recent years, many PWLE 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 payment. Some PWLE may feel that acknowledgement for their participation is appropriate payment.

What should lived experience partners consider before accepting an offer?

1. Lived experience partners should know that the time and expertise they bring to each health research project and related activities is highly valued and that SPOR and WE-SPARK support the principle that lived experience partners should be offered payment for their role in advancing health research.
2. PWLE should fully understand and agree to the payment offered to them before beginning work on a research project.
3. PWLE should know that they have a right to express if they feel the payment 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 payment policies and procedures, it is nevertheless important information that helps the institution understand what is considered fair and appropriate. Since lived experience partner payment is new to many institutions, it is expected that policies on this will emerge and evolve over time. Similarly, lived experience partners should know that they have a right to decline any form of payment offered to them for participating in research and research-related activities without it impacting their ability to partake in the activity.
4. PWLE should know that while SPOR strongly encourages researchers to offer payment to lived experience partners, 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 and amount of payment for lived experience partners. Further, it is important to keep in mind that SPOR aims to grow the practice of PWLE research across Canada, and therefore this approach may be new to many researchers. Some researchers

may have already applied for their grants when they learn about incorporating lived experience partners into their research projects and may not have the budget available to offer payment. SPOR is trying to address this by informing researchers that it is important to budget for PWLE partnership from the beginning of the research project.

5. PWLE should be advised that many forms of payment received through their participation in a research project or related activity are subject to relevant tax laws and regulations issued by the CRA and the lived experience partner's home province. While researchers should inform PWLE when a payment option has the potential to impact their financial situation, it is ultimately the responsibility of the lived experience partner to determine whether that option is the right fit for them.

What should researchers or research managers consider before offering payment to lived experience partners?

1. **Budget for PWLE engagement:** While paying lived experience partners is a new practice and many researchers may be considering engaging PWLE after they have received their grant funding, researchers are encouraged to budget for PWLE engagement in future applications.
2. **Determine if PWLE payment is an eligible expense under the terms of your grant:** Researchers can receive research funding through a number of avenues. Researchers should know that if they receive research funding through CIHR, a key partner in SPOR, this document was drafted in accordance with the Use of Grant Funds section outlined in the Tri-Agency Financial Administration Guide. Therefore, payment to lived experience partners with CIHR funds is considered an eligible expense if the work performed by the lived experience partner contributes towards the direct costs of the research/activities. If a researcher is working with funds received through a different funding source, they should consult their funding body to determine whether PWLE payment is an eligible expense.
3. **Know the local policies or guidelines that affect payments in your jurisdiction:** Researchers are strongly encouraged to seek guidance from their administering institution's financial department to determine:
 - What forms of payments can be issued from the list above (e.g., fixed-service, honoraria, in-kind exchanges, etc.).
 - How to advise lived experience partners when payment could become taxable income in order to allow the lived experience partner to reflect on how accepting payment may impact their financial situation. Furthermore, in order to allow lived experience partners from lower income families to participate, it is recommended that researchers ask their finance department if they may be available to provide specific

advice (or resources) to PWLE who do not have a financial advisor so that they can make informed choices about accepting payment.

- **What the process is for issuing payment in your institution:** 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 payment options with your lived experience partner. While it is important to understand what kinds of payment options you are able to provide before engaging PWLE, it is also important not to decide on the payment you will provide for your lived experience partner. Give them options and discuss what is feasible together. Also, if your lived experience partner proposed a different option, explore the feasibility of providing that option. Finally, the principle of equity should be adhered to when offering payment to lived experience partners to encourage diversity; different payment styles and amounts may be more appropriate for members of minority groups who are less represented in research (e.g., First Nations, Inuit and Metis peoples, immigrants and refugees).

How can researchers' institutions/organizations facilitate payment to lived experience partners?

1. Research institutions should consider crafting their own policies or guidelines on PWLE payment for their researchers. It is highly encouraged that these guidelines enable flexibility on the type of payment that can be issued to lived experience partners.
2. Ensure the monetary payment rates are consistent within your institution. Furthermore, it is recommended that you collect information on the types of PWLE payment options being offered by your research teams; paying for lived experience partnership is new and this information can be used to improve research institutions' policies over time.
3. Consider having a member of your financial department specialize in PWLE-partner payment and making them available to speak to lived experience partners who may need assistance in determining the impact of accepting payment on their income status.
4. Determine whether the storage of lived experience partner Social Insurance Numbers (SIN) requires added security measures in your computer systems.

***** Please note, references to potential taxable income throughout this document should NOT be considered tax advice *****