

# Engaging People with Lived Experience (PWLE) Appreciation Policy

## Our approach to recognition and compensation

The Ted Rogers Centre for Heart Research (TRCHR) recognizes the invaluable contribution that all people with lived experience (PWLE), such as patients and caregivers, provide to TRCHR research, programs, and initiatives. We also recognize the importance of compensating Indigenous Elders and Knowledge Keepers for their contributions, and the need to show appreciation in accordance with appropriate culturally sensitive practices. 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 heart health.

Compensation demonstrates recognition of the value and worth of the expertise brought by the perspectives of our PWLE. By offering compensation, TRCHR not only acknowledges these valued contributions but seeks 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.

We also recognize the contributions of Elders and Knowledge Keepers. For more details about please read our Indigenous Elders and Knowledge Keepers Appreciation Policy [COMING SOON].

## Who can receive compensation?

All PWLE can receive compensation for their contributions. Our definition of PWLE is meant to align with the definition of “Patient” outlined by the Canadian Institutes of Health Research (CIHR) Strategy for Patient Oriented Research (SPOR)<sup>1</sup> which includes individuals with personal experience of a health issue and/or informal caregivers, including family and friends. This policy builds on and adapts SPOR’s Patient Partner Appreciation Policy and Procedure<sup>2</sup>, with specifics for TRCHR’s context.

## Who provides compensation?

PWLE should always be offered compensation for contributions. This contribution can be made throughout the research life cycle and takes many forms, from defining the research question to advocating for implementation of the research results as part of knowledge translation. It is preferable and more aligned to the intent of patient engagement in research for patients to be engaged from the beginning of projects and research, having an ongoing voice and place on the research team. It is the responsibility of the team(s) recruiting PWLE to budget for and provide compensation.

---

<sup>1</sup> Canadian Institutes of Health Research (2016). Strategy for Patient-Oriented Research – Patient Engagement Framework. Retrieved from <http://www.cihr-irsc.gc.ca/e/48413.html>

<sup>2</sup> SPOR Evidence Alliance (2022). Patient Partner Appreciation Policy and Protocol. Toronto, ON: SPOR Evidence Alliance. Retrieved from: <https://sporevidencealliance.ca/about/policies-procedures/>

# Engaging People with Lived Experience (PWLE) Appreciation Policy

## Option to decline and right to choose

All PWLE deserve the right to accept or decline compensation at any time. PWLE also will have the option to choose the format of their compensation (i.e., cash payment vs gift card) to manage tax or other implications of participation, such as for the Ontario Disability Support Program. Some formats may be limited by institutional policies for reimbursement (e.g., limits to value of gift cards).

Whenever possible, compensation should be provided in ways that do not require identification (such as a SIN number) to reduce barriers and burdens of participation. This will assist with maintaining good relationships with PWLE and encourage future participation.

## Considerations for implementing compensation

Compensation should always be discussed with PWLE prior to the initiation of any research or programmatic activities requiring engagement. To support ease of implementation, compensation may be tracked using the [TRCHR Appreciation and Compensation Tracker](#)<sup>3</sup>.

## Compensation versus expenses

Compensation should not be confused with covering expenses incurred when participating in TRCHR initiatives. Compensation for PWLE refers to paying an individual for their time, skills and expertise when partaking in a research or programmatic activity. PWLE should be offered compensation for their time and expertise brought to a research project or related activity **in addition** to covering any expenses related to their participation in those activities.

TRCHR investigators will cover PWLE expenses (such as travel costs, meal and accommodation reimbursement, event fees), which are not covered by this Policy. TRCHR investigators/staff should refer to institutional expense reimbursement policies in addition to any policies that govern grant funds received from external organizations. TRCHR investigators/staff should clarify what expenses PWLE will incur and confirm what will be reimbursable in advance and what documentation is required to satisfy institutional policies.

## Types of PWLE contribution and Rates of Compensation

Activities for which PWLE will be compensated may vary by research and programmatic initiatives. The following table describes compensation types and outlines considerations and compensation rates/amounts.

---

<sup>3</sup> Adapted from the SPOR Evidence Alliance. (2019) Patient Partner Appreciation Policy and Protocol. Toronto, ON: SPOR Evidence Alliance. Retrieved from [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)

# Engaging People with Lived Experience (PWLE) Appreciation Policy

Compensation table<sup>4,5,6</sup>

Type	Description	Compensation	Considerations
Advisory role as PWLE committee members	PWLE is a member of an advisory or project team council/committee	\$100/meeting (including 0.5 hrs of prep time and 2 hrs for document review) or \$40/meeting for those who cannot attend the meeting but who take time to read the documents and send comments by email	Share committee Terms of Reference with PWLE so they understand time commitment and role  If role is ongoing, TRCHR may establish a set “renumeration” with the PWLE.
Consultation	PWLE offers their opinion, advice, or feedback	\$33.15 per hour	Clearly define scope or work and timelines
Collaboration	PWLE participates as a member of the team (i.e., conducts work that would otherwise be completed by staff member or researcher)	\$40 per hour	Clearly define scope or work and timelines Depending on length/scope, consider if a short-term contract is more appropriate
Strategic or leadership role	PWLE plays a strategic role in TRCHR governance or leads execution of a program/project	\$40 per hour	Depending on the nature of the program/project and time requirements, TRCHR may establish a set “renumeration” with the PWLE.
Training/Learning	PWLE attends a training event (conference, online training course) to engage with TRCHR	\$33.15 per hour	This training/learning would be a requirement to the engagement.
Indigenous Elders/ Knowledge Keepers	Any Indigenous Elder or Knowledge Keeper assisting TRCHR	\$150 flat rate for opening and closing ceremonies  \$250 flat rate for a half-day event.  \$500 flat rate for a full day event.  Appropriate gift	See Indigenous Appreciation Policy (COMING SOON)

<sup>4</sup> Adapted from Diabetes Action Canada. (2017) Financial Compensation Policy for Patient Partners. Retrieved from [https://diabetesaction.ca/wp-content/uploads/2018/02/2017-05-02-FINANCIAL-COMPENSATION-POLICY\\_ENG.pdf](https://diabetesaction.ca/wp-content/uploads/2018/02/2017-05-02-FINANCIAL-COMPENSATION-POLICY_ENG.pdf)

<sup>5</sup> Adapted from University Health Network’s Pride in Patient Engagement in Research (PiPER) Compensation Policy (coming soon).

<sup>6</sup> Adapted from Dalla Lana School of Public Health (2021). Guideline for DLSPH Honorariums.

# Engaging People with Lived Experience (PWLE) Appreciation Policy

## Compensation Limits

For all PWLE, there is a compensation limit of \$2,500 in a fiscal year for participation. For ongoing work beyond the types above and this compensation limit, a short-term contract should be established.

## Types of Compensation

There are a variety of types of compensation for PWLE. The most commonly used are fixed service income, honoraria, cash-equivalent, and gifts/tokens of appreciation. It should be noted that gifts and cash-equivalent compensation also applies to the \$500 per year CRA threshold for T4/T4A creation that invoiced remuneration does as outlined below.

## Payment Type and Frequency

Payments may be made cash, a near-cash equivalent, direct deposit, cheque, or gift. It should be noted that any of these forms of compensation contribute to the \$500 limit at which point a T4/T4A slip must be created by the relevant finance department.

## Additional Considerations

For additional considerations for appreciation and compensation, please refer to SPOR's Considerations when paying patient partners in research<sup>7</sup>.

All interactions involving the recognition and compensation of PWLE should honor and respect the participant, and not pose more harm or trauma.

## Definitions

1. **Cash:** Cash includes currency or its equivalent such as cheques that can be taken into any store or bank and deposited or spent. This action is processed by the appropriate payroll department.
2. **Compensation/Remuneration:** Paying a PWLE for their time engaging in projects or research. The contractual relationship can be employment or non-employment in nature and will be determined by tasks given and hours spent by individual as determined by the appropriate HR department.
3. **Honoraria:** Paying a PWLE for their one-time/one-off engagement in projects or research. This is seen as compensation/remuneration, but the underlying relationship is not an employee contract. This action is processed by the appropriate payroll department.
4. **Gifts or Tokens of Appreciation:** Gifts are for a special occasion such as a religious holiday, a birthday, a wedding, or the birth of a child. Gifts can be provided in gift cards including gift certificates, chips, and electronic gift cards.

---

<sup>7</sup> Canadian Institutes of Health Research. (2016) Strategy for Patient-Oriented Research - Considerations when paying patient partners in research. Retrieved from <https://cihr-irsc.gc.ca/e/51466.html>

# Engaging People with Lived Experience (PWLE) Appreciation Policy

5. **Gift Cards:** Prepaid cards that you can use to pay for purchases. These cards can be used at a single merchant or a group of merchants (e.g., shopping mall). They must be physical or electronic and come with money on them already. Gift cards do not have an expiry date, associated fees, and cannot be redeemed for cash. When purchasing a gift card, businesses cannot charge harmonized sales tax (HST).

Gift cards can be considered a non-cash gift if all of the following criteria apply:

- The gift card comes with money already on it and can only be used to purchase goods/services from a single/group of merchants(s) identified on the card.
- The terms and conditions of the gift card clearly state the amount loaded and cannot be converted to cash.
- A log is kept recording the gift card information: Name of recipient; Date gift card was given to the recipient; reason for providing the gift card; type of gift card; name of the retailers.

6. **Non-Cash gift:** Unlimited number of non-cash gifts or awards within the \$500 limit including tax. Non-cash gifts or awards can be small items of little monetary value such as tea, coffee, t-shirts, mugs, plaques, trophies, AND long service awards. Some exclusions apply:

- Gifts or awards provided by non-arm's length employees (relative, shareholder or person related to them).
- Gifts or awards provided by manufacturers and other payers to your employees (under \$500, if more these providers must report it).
- Gifts or awards provided through prize draws.
- Loyalty and other points programs such as social events and hospitality functions.

A donation to a charitable organization can be considered non-taxable if it meets the following criteria:

- The individual had the option of receiving a non-cash gift/award/long service award.
- The individual chose to have the employer direct the amount to a charity in lieu of the non-cash gift or award.

The gift or award, if it had been received would have met the policy conditions.

7. **Near-Cash Equivalent:** Easily converted to cash such as bonds, securities, or precious metals/jewels. Includes gift cards that do not meet all conditions for non-cash; a prepaid card issued by a financial institution to certain payment card networks which can be used to pay for purchases; digital currency like electronic money.

## Policy Alignment

[Pride in Patient Engagement in Research \(PiPER\)](#) is a strategic research initiative at University Health Network that officially launched in February 2022, whose mission is make engaging patients, families, and care partners in research a new culture that can enhance health research, outcomes, and care experiences for all. PiPER has developed and is preparing to launch an UHN-wide compensation policy for patients and caregivers involved in research. Members of TRCHR have been involved with this development and have aligned the TRCHR policy with the proposed compensation for UHN.