

Engaging People with Lived Experience (PWLE) Appreciation Policy

Our approach to recognition and compensation

The Ted Rogers Centre for Heart Research 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 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 Appreciation Policy [COMING SOON].

Who can receive compensation?

All PWLE can receive compensation for their contributions. In this case, 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)¹ which is understood to include 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 Procedure², with specifics for TRCHR’s context.

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.

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.

¹ 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>

² SPOR Evidence Alliance (2019). Patient Partner Appreciation Policy and Protocol. Toronto, ON: SPOR Evidence Alliance. Retrieved from: <https://sporevidencealliance.ca/about/policies-procedures/>

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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](#)³.

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 them participating in those activities.

TRCHR may cover PWLE expenses (such as travel costs, meal and accommodation reimbursement, event fees), which are not covered by this Policy. TRCHR staff should refer to institutional expense reimbursement policies in addition to any policies that govern grant funds received from external organizations. Before initiating the covering of expenses TRCHR is responsible for asking what expenses our PWLE will require to be reimbursed.

Types of PWLE contribution

Activities for which PWLE will be compensated may vary by research and programmatic initiatives. Please refer to the following table for compensation types and amounts.

Compensation table⁴

Type	Description	Hourly Compensation	Half-Day Compensation	Full Day Compensation	Considerations
Training/Learning	PWLE attends a training event (conference, online training course) in order to engage with TRCHR	\$25	\$75	\$150	This training/learning would be a requirement to the engagement.
Consultation	PWLE offers their opinion, advice, or feedback	\$25	\$75	\$150	N/A
Collaboration	PWLE participates as a member of the team (i.e., conducts work that would otherwise be completed by staff member or researcher)	\$25	\$75	\$150	N/A
Strategic or leadership role	PWLE plays a strategic role in TRCHR governance or leads execution of a program/project	\$25*	\$125*	\$250*	*Depending on the nature of the program/project and time requirements, TRCHR may establish a set "renumeration" with the PWLE.

³ 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

⁴ 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

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PWLE Council 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 \$50/meeting for those who cannot attend the meeting but who take time to read the documents and send comments by email	N/A
Indigenous Elders/Knowledge Keepers	Any Indigenous Elder or Knowledge Keeper assisting TRCHR	\$200 flat rate per day regardless of amount of time spent Appropriate gift	See Indigenous Appreciation Policy (COMING SOON)

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.

Additional Considerations

For additional considerations for appreciation and compensation, please refer to SPOR's Considerations when paying patient partners in research⁵.

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

⁵ 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>