

## Patient Partner Appreciation Guidelines: Compensation in Research

### Purpose

The purpose of these guidelines is to show how to recognize and acknowledge the time and effort of patient partners engaged in health research beyond the role of a participant distinct from expense reimbursement. We aim to provide a roadmap to help reduce financial barriers to inclusion and increase access to opportunities for patient partners to advise and inform, collaborate on and/or lead research studies. These guidelines were co-developed by the Alberta Strategy for Patient-Oriented Research (SPOR) SUPPORT Unit (AbSPORU) and the Patient Engagement Platform Compensation Working Group.

### Scope

This is a living document subject to review in collaboration with patient advisors on an annual basis to reflect trends and changes of content and context of health research in Alberta. At this time, the guidelines apply only to AbSPORU’s procedures and practices, and do not reflect the current environment in Alberta, where compensation is not routinely and consistently offered to patient partners.

**Table 1. Glossary of Terms**

Term	Definition
Patient	A person with lived experience of a health condition, experience with the health system, or both. A person may self-identify in many ways besides as a patient, including as a caregiver, caretaker, carer, family member, member of the public and citizen. The term “patient” can create healthy discourse <sup>1</sup> .
Patient Partner	Patients who inform and engage meaningfully in the health research process as more than subjects or participants of research.
Patient Participant (formerly Subject)	Individuals who participate in a research study as ‘testers’ to help researchers learn if their treatment or intervention works as intended.
Compensation	Payment for the time, skills, lived experience and expertise patient partners bring to a research project or related activity.
Reimbursement	Covering of the direct costs and expenses associated with participating in research and research-related activities including travel, parking and child care.

<sup>1</sup> Canadian Institutes of Health Research. (2019). *Strategy for Patient-Oriented Research: Patient Engagement Framework*. Retrieved from <http://www.cihr-irsc.gc.ca/e/48413.html>

Depending on their interest, skills and available time, patient partners can be engaged at any, or several, stages of the health research cycle. This includes identifying and prioritizing research topics or questions, study design, planning and preparation, development of grant proposals, data collection, analysis and interpretation, knowledge translation and dissemination, and evaluation of patient engagement and the outcomes and impacts of the research project or activity. Patients who choose to engage at different levels (see Appendix A) play a vital role as partners in research.

## Principles

Patient appreciation in health research is a common practice either through honoraria or gifts when they participate in research studies. In this document, we suggest how patient partners who contribute their time, effort and expertise in different capacities on a research project can be compensated (see Appendix A). The Patient Engagement Platform Compensation Working Group's approach and recommendation to compensation encompasses principles of respect, value, fairness, equity, inclusivity, responsiveness and choice. These principles are aligned with CIHR, who suggest that offering to pay patients who engage in research makes the participation more equitable and diverse, as it can help to remove barriers<sup>2</sup>.

## Important Considerations

Compensation should reflect the time, effort and expertise the patient partner brings to the research project, but may not always be possible due to budget constraints. One size does not fit all and each patient partner is a unique individual with personal preferences and circumstances. Types, amounts and methods of payments should be nimble, responsive and flexible. Compensation payment may not always be possible on all projects due to budget constraints.

- Compensation offered to patient partners may have tax implications. Under the *Income Tax Act*, honoraria, gifts or near-cash gifts (see Table 2) are considered taxable income for which a T4A will be issued. Patient partners are encouraged to contact their financial advisor, accountant, or Canadian Revenue Agency. Discussions about tax implications arising from compensation are out of scope for AbSPORU Platforms and Alberta Innovates.
- Patient partners have the right to waive compensation.
- These guidelines may have to be adapted to cover expenses for unique populations and communities including Indigenous Elders and Knowledge Keepers, e.g. flat fee rates or gifts. Consult with communities and institutions to determine appropriate and respectful approaches to recognition for populations with unique considerations.
- Organizational and financial structure of Platforms, policies and procedures of Leads' home institutions will supercede recommendations in these guidelines. Alberta Innovates can

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<sup>2</sup> Canadian Institutes of Health Research. (2019). *Considerations for Paying Patient Partners in Research*. Retrieved from <http://www.cihr-irsc.gc.ca/e/51466.html>

support compensation of patient partners if Leads' home institutional procedures for compensation have not been set up.

- Some institutions have maximum amounts for compensation. Patient partners paid more than this amount would be on contract or salaried, which is beyond the scope of these guidelines. Researchers are encouraged to check the policy and procedures of their organizations.

**Table 2. Types of Payment**

<b>Method of Payment</b>	<b>Description</b>
Fixed service	Related to a specific service (patient partners who invoice for services provided on a fixed rate)
In-kind compensation	Alternate forms of recognition: conference attendance, co-authorship, invitation to special events, etc.
Gift	May include <u>non-cash gifts</u> : e.g. flowers, fruit baskets, etc; <u>near-cash gifts</u> : e.g. gift cards/gift certificates; <u>minor gifts</u> /small gestures of appreciation with monetary value under \$25.
Cash	Currency with appropriate paperwork that meets financial reporting procedures.
Honorarium	A one-time payment to cover costs for volunteers or guest speakers, for which fees are not traditionally required.

## **Conflicts of Interest**

Another relevant process is identifying, disclosing, and managing real, potential, or perceived conflicts of interest. Conflict of interest policies are described in the relevant policies of all universities and Alberta Innovates. Conflicts of interest may arise in research when activities or situations place an individual in a real, potential, or perceived conflict between the duties or responsibilities related to the research, and personal, institutional, or other interests.

## **Acknowledgements**

We acknowledge and thank each of the Patient Engagement Compensation Working Group members (Yazid N. Al Hamarneh, Janet Bauer, D'Arcy Duquette, Susan Entz, Jessica Havens, Jeannette Jackson, Ken Landry, Jennifer Rees, Gerry Robinson, Melanie Rosario, Allan Stordy, and Sharon Unger) for their dedication, passion, time, and robust discussion to co-author these guidelines. Members provided perspectives as patients or family members or researchers and/or based on their affiliations with the following organizations: AbSPORU Career Development and Consultation and Research Services Platforms, Alberta Health Services, Athabasca University Research Office, Health Quality Council of Alberta, University of Lethbridge Office of Research Ethics (ORE), Patient Engagement Platform Advisory Council (PEPAC), Researchers, and the SPOR National Steering Committee.

The content of these guidelines were also informed by conversations with members from the BC SUPPORT Unit and NL SUPPORT Unit and their respective guidelines as below:

British Columbia Academic Health Science Network. (June 3, 2019) *Patient Partner Appreciation Policy* (Version 2.0). Vancouver, British Columbia.

Newfoundland and Labrador Support for People and Patient-Oriented Research and Trials. (May, 2019). *Patient Partner Appreciation – NL Support Guidelines*. St. John’s, Newfoundland.

### Appendix A: Suggested Rates for Compensation

Examples of Engagement Activities		Compensation Rate
1.	A one-time request to contribute (Consult-Level)	Hourly @ \$25 Half-day (+/- 4hrs) @ \$100 Full-day (+/- 8hrs) @ \$200
2.	Committee members on a standing working group (Involve-Level)	< 4 times/yr between \$100-\$200 > 4 times/yr between \$200-\$400 Includes prep time and post-meeting work. Paid at the end of the commitment period of one year.
3.	Partners on research projects (Collaborate-Level)	Refer to rates in #2 for ongoing collaborations; refer to rates in #1 for one-time consultations

### Practical Approaches

- Become familiar with the policies, guidelines and monetary rates of your institution. Consult AbSPORU for assistance to plan and budget for patient partner compensation.
- At the start of your research project, discuss compensation with patient partners. Review these guidelines to determine if patient partners want to be compensated, and the amount and payment methods for compensation.
- Budget adequately for patient partner compensation in your grant application. Include compensation costs associated with dissemination including co-authorship and co-presentation of research findings at conferences, workshops, or forums.
- Reimbursement of expenses associated with participating in a research project or activity is necessary and should be a separate conversation from compensation.