

Patient Partner Appreciation Guidelines: Compensation in Research

Prepared by the AbSPORU Patient Engagement Team

Purpose

Patients hold a vital role in patient-oriented research teams. Depending on their interest, skills, and available time, patient research partners can be essential collaborators to research priority setting, grant funding applications, study design, data collection, data analysis, knowledge translation, sharing of results, and evaluation (<https://cihr-irsc.gc.ca/e/51910.html>). In this document, we suggest how patient partners can be recognized financially for the essential lived experience and other expertise they bring to POR projects.

Our approach to patient partner compensation encompasses principles of respect, value, fairness, equity, inclusivity, responsiveness, and choice. These principles are aligned with Canadian Institutes of Health Research (CIHR) Supporting Patient-Oriented Research (SPOR). "Adequate support and flexibility are provided to patient partners 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" (<https://cihr-irsc.gc.ca/e/48413.html>).

Patient partners contribute their essential lived experience expertise as active and equal members of research teams. Therefore, **patient partner compensation differs from 'tokens of appreciation' often given to participants** who contribute data to research projects (https://ethics.gc.ca/eng/policy-politique_tcps2-eptc2_2018.html) **and from reimbursement of direct expenses of engaging in a project or activity**. Patient partner compensation requires unique considerations and planning.

Scope

This is a living document subject to review in collaboration with patient partners on a regular basis to reflect trends and changes in health research contexts in Alberta. Because of the unique geographical and health care ecologies of the individual SPOR jurisdictions, each SPOR Support unit has co-developed their own patient partner compensation guidelines. We encourage you to reach out to the units through their respective websites. Links to respective SPOR SUPPORT Unit websites can be found here: <https://cihr-irsc.gc.ca/e/45859.html>.

Table 1. Glossary of Terms

Patient	An overarching term inclusive of individuals with personal experience of a health issue, and informal caregivers, including family and friends. See https://cihr-irsc.gc.ca/e/48413.html “Who is a patient?” (60-second video) https://www.youtube.com/channel/UCrLgpRV0t4CeOp69XyzPffQ
Patient-Oriented Research (POR)	A continuum of research that engages patients as partners, focuses on patient-identified priorities, and seeks to improve patient outcomes. This research, conducted by multidisciplinary teams in partnership with relevant stakeholders, aims to provide patient-centred evidence to improve healthcare systems and practices (https://cihr-irsc.gc.ca/e/48413.html). Depending on the context, patient-oriented research can also bring the collective voice of specific affected communities. See https://cihr-irsc.gc.ca/e/51910.html .
Patient Engagement	In Patient-Oriented Research, patient engagement describes patients engaged as active and equal research team members, beyond the role of participant. Patient partners collaborate early, often and in meaningful ways at any or all stages of the research process including priority setting, project design, grant applications, data collection, data analysis, knowledge translation, and evaluation. See https://cihr-irsc.gc.ca/e/48413.html
Patient Partner	Patients who collaborate as active and equal members of Patient-Oriented Research teams, in any or all the roles identified in the CIHR SPOR Health Research Cycle - see Part II in this document here: https://cihr-irsc.gc.ca/e/51910.html As members of health research teams, advising, providing feedback, and working together on research projects and activities through a lived-experience lens, this role does not require Research Ethics Board (REB) approval.
Patient Participant	A patient involved in a research study whose data, or responses to interventions, stimuli, or questions by a researcher, are relevant to answering the research question (https://cihr-irsc.gc.ca/e/51910.html) See also Glossary, Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans, 2 nd Edition (TCPS 2) https://ethics.gc.ca/eng/policy-politique_tcps2-eptc2_2018.html
Compensation (Patient Partner)	Payment for the time, skills, lived experience and expertise patient partners bring to a research project or research related activity. Compensation is offered as recognition of the essential contribution patient partners bring to the research activity. There is no obligation to accept compensation. Compensation should not be understood as the market value of patient partner collaboration.

Appreciation (Patient Participant)	A token of appreciation, usually in the form of a pre-paid gift card or honorarium, given to a patient participant in a study or trial.
Reimbursement	Covering of the direct costs and expenses associated with engaging in research and research-related activities either as a patient partner or a patient participant. These include travel, parking, meals, care giving, digital access and other expenses and should be covered up front whenever possible.

Compensation Considerations

Compensation may not always be possible due to budget constraints. This can also be the case on grant applications and when funding has not been secured.

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 where possible.

Compensation is offered. There is no obligation to accept. It is essential to have a conversation about compensation at the beginning of working together in patient-oriented research. More about this compensation conversation can be found in the References section below.

Compensation offered to patient partners may have tax implications. Under the *Income Tax Act*, honoraria, gifts, or near-cash gifts 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 the scope of AbSPORU and Alberta Innovates.

These guidelines may have to be adapted to cover expenses for unique populations and communities including Indigenous Elders and Knowledge Keepers, i.e., flat fee rates or gifts. Consult with communities and institutions to determine appropriate and respectful approaches to recognition for populations with unique considerations.

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.

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. Please reach out for our University of Calgary and University of Alberta Patient Partner Compensation guidance documents.

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. It is important to identify, disclose, and manage real, potential, or perceived conflicts of interest. Conflict of interest policies are described in the relevant policies of all universities and Alberta Innovates.

Reimbursement Considerations

Patient partner compensation should not be confused with reimbursement of the direct expenses of contributing to a research project. Reimbursement of expenses associated with engaging in a research project or activity is necessary and should be a separate conversation from compensation. Direct expenses can include travel, parking, caregiving, digital access, training, and other similar costs.

These costs should be paid upfront by the research team as much as possible, rather than burdening the patient partner with the outlay of funds or added work of submitting an expense claim.

Each institution will have its own processes for pre-paying and reimbursing expenses. Be sure to check prior to engaging and having your patient partners incur expenses they can't be reimbursed for in a timely manner.

Table 2. Methods of Payment

Payment	CIHR defines payment as “the act of awarding something to someone in exchange for a service”. Methods of payment can include salary, stipends, honoraria, in-kind exchanges and gift cards or gifts. See our companion document for guidance on UCalgary payment processes
Fixed service	Related to a specific service (patient partners who invoice for services provided on a fixed rate)
In-kind compensation	Alternative forms of recognition including conference fees, co-authorship, training, invitation to special events, etc.
Honorarium	A one-time payment for cover costs for volunteer or guest speakers for which fees are not traditionally required
Pre-paid gift cards	Prepaid gift cards may still be considered income
For more information about payment methods and processes please see our University of Calgary and University of Alberta patient partner payment process guides here: https://absporu.ca/	

Table 3. Rates of Payment

Example of Engagement Activity		Suggested Compensation Rate
1	A one-time request to collaborate*	Hourly @ \$25/hour Half-day (+/- 4 hours) = \$100 Full-day (+/- 8 hours) = \$200
2	Member of working group, advisory council, or committee*	<4 times per year between \$100-\$200/year >4 times per year between \$200-\$400/year
3	Partner on research project or activity See Part II of this document https://cihr-irsc.gc.ca/e/51910.html	Refer to #2 for standing collaborations Refer to #1 for one-time or active collaboration
*It is essential that compensation is offered for pre-meeting activities such as reviewing agendas, documents and for time providing feedback through email communication.		

Please check <https://absporu.ca/> for additional resources to support your patient partner compensation budgeting and processes.

Please reach out if you have questions or if you would like to learn more about our other supporting documents, resources and supports: peplatformab@gmail.com

References

Alberta SPOR SUPPORT Unit (AbSPORU) Website: <https://absporu.ca/>

Canadian Institutes of Health Research (CIHR), Considerations when paying patient partners in research <https://cihr-irsc.gc.ca/e/51466.html>

Canadian Institutes of Health Research (CIHR), Ethics Guidance for developing partnerships with patients and researchers <https://cihr-irsc.gc.ca/e/51910.html>

Canadian Institutes of Health Research (CIHR), Strategy for Patient-Oriented Research <https://cihr-irsc.gc.ca/e/41204.html>

Canadian Institutes of Health Research (CIHR), Strategy for Patient-Oriented Research – Patient Engagement Framework <https://cihr-irsc.gc.ca/e/48413.html>

Richards et al. (2022) [Identifying potential barriers and solutions to patient partner \(payment\) in research](#)

Richards et al. (2020) [Patients as Partners in Research: How to talk about compensation with Patient Partners](#)

Richards et al. (2018) [Patient partner compensation in research and health care: the patient perspective on why and how](#)

Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans - TCPS2 (2018)
https://ethics.gc.ca/eng/policy-politique_tcps2-eptc2_2018.html