1. Purpose

The purpose of this policy is to provide guidelines for how to show appreciation to patient partners using compensation (e.g. honoraria and gifts) as distinct from reimbursement.

2. Scope

This policy covers the relationship between patient research partners and the BC SUPPORT Unit (“the Unit”), including the provincial hub, regional centres, demonstration projects and methods clusters.

3. Definitions

| Compensation   | Something awarded to someone in exchange for a service. This may take the form of an honorarium, in-kind gifts or fixed service income. |
Fixed service income  
Payment through this option is considered employment income by the Canada Revenue Agency (CRA). This means the institution through which funding flows will need to issue a T4A slip and the patient partner will need to declare this compensation on their annual tax form.

Honorarium  
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 (i.e., is another form of reimbursement). While the Canada Revenue Agency (CRA) perspective generally views payments for services made to an individual as either employment income or business income, they do support the notion of small payments that are not subject to the usual tax rules – this is where honoraria fall. The criteria for these payments include:\(^1\):
- They are nominal - $500 or less in a calendar year;
- They are made to an individual for voluntary services for which fees are not legally or traditionally required;
- They are not reflective of the value of the work done;
- They are made on a one-time or non-routine basis to an individual as a “thank-you.”

In-kind gifts  
Compensation in the form of e.g., a gift card, or contribution to helping the patient achieve a life goal (e.g., payment of course fees) Note: The in-kind value of patient compensation may be regarded as taxable income by the Canada Revenue Agency (CRA).

Patient  
An individual with lived experience of the health care system, including informal caregivers such as family and friends.

Patient Partner  
Patients who are involved in a research-related project in any manner other than as a research subject. For the purposes of this policy, patient partners include those who partner with staff of the BC SUPPORT Unit, including: the hub, regional centres, demonstration projects and methods clusters.

Study Participant  
A person who is a research subject

Reimbursement  
Repayment for out-of-pocket expenses related to engagement in an activity; for example, travel costs. Note: It is expected that all out-of-pockets costs will be reimbursed, subject to policies of the Academic Health Science Network.

4. Policy

While showing appreciation for study participants through honoraria and gifts is common practice in health research, this is not routinely done in respect to patient partners, and there are varying opinions on the subject. As a progressive organization and leader in the BC health research landscape, the BC SUPPORT Unit has adopted the stance that it is important to show appreciation beyond reimbursement

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\(^1\) This information is current as of 2017 and will be updated annually.
by providing compensation. The level of compensation is not intended to reflect the market value of a patient’s contributions; it should, however, reflect a meaningful expression of appreciation.

Canada’s Strategy for Patient-Oriented Research (SPOR) encourages researchers and research partners to offer financial compensation to patients who act as partners in research and research-related activities. This recommendation is reflected in the third guiding principle of the SPOR Patient Engagement Framework: 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. ²

- Patient compensation is considered an eligible expense by CIHR.³
- Patient partners will be offered compensation. The level of compensation is not intended to reflect the market value of a patient’s contributions; it should, however, reflect a meaningful expression of appreciation.
- The SUPPORT Unit cannot act as a financial advisor; nor is the SUPPORT Unit responsible for any repercussions experienced by the patient partner as a result of any compensation received.

5. Procedures

The BC SUPPORT Unit values the important contribution of our patient partners and we wish to show appreciation in tangible ways.

- Appreciation will be shown to patient partners of the SUPPORT Unit (including the hub, regional centres, demonstration projects and methods clusters) by offering compensation in accordance with the attached Schedule A, unless an argument can be made for why it is not feasible or advisable.
- Offers of compensation will show flexibility to meet the needs, values and preferences of the patient partners.
- The offer will originate from the staff person who is leading the engagement.
- Before accepting compensation, patient partners have a right to know and understand that accepting compensation, in any of its forms, could affect their personal financial situation if the Canada Revenue Agency (CRA) views this compensation as income. For example, it may increase a person’s tax rate, or may affect their entitlement to disability benefits. Therefore, the BC SUPPORT Unit will advise patient partners about this possibility and provide information about where the patient partner can find information to inform their decision (e.g., links to Canada Revenue Agency at Canada.ca).
- Patient partners have the right to waive compensation.

² CIHR draft compensation guidelines
³ CIHR Staff confirmation (Serenna Dastouri), October 2, 2017
• The individual may be issued a T4A for amounts exceeding $500 accumulated over one calendar year, and when they file their tax return for the year, any taxes owing on the amount paid will be assessed by the Canada Revenue Agency (CRA). Taxes owing are the responsibility of the recipient. (Note: The policy of the organization that pays the compensation (e.g., health authority, university) may affect procedures related to issuing T4As.)

6. Monitoring

The Unit Patient Engagement Lead and the Finance Director, in consultation with the regional centre, methods cluster and demonstration project leads, will review this policy and any accompanying schedules once annually, and provide a report to the Executive Director, including any recommendations for changes.

7. Approvals

Each component of the Unit (Hub, regional centres, methods clusters and demonstration projects) will have a process to approve offers of compensation in accordance with this policy. For example, the Unit Patient Engagement Lead will approve all offers of compensation to patient partners engaged with the Provincial Hub.

8. Documentation

Schedule “A” – Appreciation Guidelines for the BC SUPPORT Unit
Schedule A: Appreciation Guidelines for the BC SUPPORT Unit

The following examples should guide staff in determining the amount and type of compensation to offer. *NB: Practices will be documented over time, and a more detailed schedule with guidelines for additional situations will be created and distributed in the future.

<table>
<thead>
<tr>
<th>Example</th>
<th>Amount and type</th>
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<tbody>
<tr>
<td>1. <strong>BC SUPPORT Unit Patient Council</strong> members – estimated 9 meetings per year of 1.5 to 2 hours in duration by teleconference with some meeting preparation</td>
<td>$500 honorarium paid annually; pro-rated for partial calendar year</td>
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| 2. Patients at the Hub who engage in working groups, ad hoc committees or events outside regular Patient Council meetings. Examples of this include:  
  • ½ day focus group  
  • Speaking at a BC SUPPORT Unit event  
  • Co-presenting a webinar or training  
  • Being a member of a Unit interview or selection committee  
  • Participating in a workshop |  
  Because of the variety of engagement opportunities, the Patient Engagement Lead will work with BC SUPPORT Unit staff (e.g. Director of Finance) to determine an appropriate amount and type of compensation. Options for compensation in these situations include:  
  • Gift card (est.$30-50)  
  • Honorarium (e.g., participate in an all-day event – ranging from $50-150 per day)  
  • Other in-kind gifts such as course or conference fees being paid (est. $200-500) |
| 3. Patients who are members of other advisory and/or working groups associated with regional centres, demonstration projects and methods clusters (e.g. Vancouver Island regional centre’s steering committee; the Interior regional centre’s *Patient Engagement in Research* (PEiR) committee; the *BC Health Research Connections* working group; the *BC Emergency Medicine Network* advisory group; patients who advise the methods clusters) | Staff will determine an appropriate amount and type of compensation. Options for compensation in these situations include:  
  • Gift card (est.$30-50)  
  • Honorarium (e.g., participate in an all-day event – ranging from $50-150 per day)  
  • Other in-kind gifts such as course or conference fees being paid (est. $200-500) |
| 4. **Special Populations** – e.g. Indigenous or homeless people | There is a recognition that it may be necessary to adapt these guidelines to the culture or circumstances of special populations. |