

Strategy for Patient-Oriented Research

**S** **P** **O** **R**

Putting Patients First

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# Patient Engagement Framework

## Acknowledgements

The Canadian Institutes of Health Research greatly acknowledges the contributions of the patient representatives and patient engagement experts who participated in the SPOR Patient Engagement Consultation Workshop (on January 9, 2014) for the creation of this Framework. Their ongoing support and advice throughout the process is truly appreciated.

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## Introduction

An important goal of Canada's Strategy for Patient-Oriented Research (SPOR) is for patients, researchers, health care providers and decision-makers to actively collaborate to build a sustainable, accessible and equitable health care system and bring positive changes in the health of people living in Canada. Since patients are at the heart of SPOR, they must be involved as much and as meaningfully as possible in order for health research to be more responsive to the needs of Canadians.

If patient-oriented research is intended to focus on priorities that are important to patients and produce information that is truly taken up and used to improve health care practice, therapies and policies, a strong foundation for ensuring successful collaboration must be laid. SPOR's National Steering Committee has requested that a Patient Engagement (PE) Framework be developed that will outline key opportunities for action, setting the stage for worthwhile collaborations in the identification of health research priorities as well as in the design and conduct of research projects.

*[Patients] must be involved as much and as meaningfully as possible in order for health research to be more responsive to the needs of Canadians*

A consultative process was undertaken to develop this PE Framework. A workshop held in Ottawa on January 9th brought together a cross-representation of Canadian patients and patient engagement experts, serving as a pivotal step in the process to identify patients' aspirations for engagement in SPOR. Since that time, CIHR has presented the draft to SUPPORT Unit leads, the SPOR Working Group, and the SPOR National Steering Committee for validation and further input. It will be shared with SPOR stakeholders so that there is a common understanding and alignment of goals for patient engagement.

It is important to note that this Framework will be a living document and it will be re-evaluated as the various components of SPOR are implemented.

## Vision

Patients are active partners in health research that will lead to improved health outcomes and an enhanced health care system.

## Objective

The SPOR Patient Engagement Framework is designed to establish key concepts, principles and areas for patient engagement to be adopted by all SPOR partners.

## Definitions

It is crucial that key concepts and terms are defined to develop a common understanding across SPOR. We recognize there may be no catch-all term that fits everyone; the word ‘patient’, for example, is meant as inclusive but may initially evoke a range of meanings or limitations depending on the audience. Even so, the following definitions serve to clarify and establish terminology used throughout this document and SPOR.

### Patient:

An overarching term inclusive of individuals with personal experience of a health issue and informal caregivers, including family and friends.

### Patient Engagement:

Meaningful and active collaboration in governance, priority setting, conducting research and knowledge translation. Depending on the context patient-oriented research may also engage people who bring the collective voice of specific, affected communities.

### Patient-Oriented Research:

Patient-oriented research refers to a continuum of research that engages patients as partners, focusses on patient-identified priorities and improves patient outcomes. This research, conducted by multidisciplinary teams in partnership with relevant stakeholders, aims to apply the knowledge generated to improve healthcare systems and practices.

### SPOR Partner:

Are key stakeholders collaborating in patient-oriented research, such as the SUPPORT Unit jurisdictional leads for each province and territory, patients, researchers, policy makers, decision-makers, health organizations, provincial/territorial health authorities, academic institutions, charities and the pharmaceutical sector.

*Patient-oriented research is ultimately aimed at achieving benefits that matter to patients:*

- *Improved health*
- *Improved access to the health care system*
- *The right treatment at the right time*
- *Being an active and informed partner in health care*
- *Quality of life that is tied to patient-oriented outcomes*
- *Make a contribution to improving the cost effectiveness of the health care system*

## What can patients contribute and why it is needed?

Patients bring the perspective as ‘experts’ from their unique experience and knowledge gained through living with a condition or illness, as well as their experiences with treatments and the health care system. Involvement of patients in research increases its quality and, as health care providers utilize research evidence in their practice, increases the quality of care. *‘Engaging patients in health care research makes (investments in) research more accountable and transparent, provides new insights that could lead to innovative discoveries, and ensures that research is relevant to patients concerns. The international experience with engaging citizens and patients in research has shown that involving them early in the design of studies, ideally as early as at the planning stage, leads to better results.’*<sup>1</sup> By encouraging a diversity of patients to tell their stories, new themes may emerge to guide research. Patients gain many benefits through their involvement including increased confidence and master new skills, access to information they can understand and use, and a feeling of accomplishment from contributing to research relevant to their needs.

## Patient Engagement in SPOR

Patient engagement means fostering a climate in which researchers, health care providers, decision-makers and policy-makers understand the value of patient involvement and patients see the value of these interactions.

Engaging patients is an integral component in the development and implementation of all elements of SPOR such as, but not limited to, SUPPORT Units and Networks. As such, stakeholder (patients, researchers, health care providers and decision-makers) uptake on orientation and engagement tools is imperative to the success of the model.

Patients’ roles vary according to the contributions a patient is prepared to offer; however, the bar needs to be raised to allow jurisdictions to push the boundaries on the potential to build their capacity to engage patients in truly innovative roles and models of patient engagement. The patient perspective is integrated into every step of the research process including developing research questions, defining research objectives, collecting data and evaluating results. Some patients have the readiness to contribute as full members of research teams while others may bring a range of expertise such as in ethics or as knowledge brokers. Other patients bring the collective voice of specific, affected communities. Their knowledge and expertise offers insights about people who are unable to communicate on their own behalf.

The meaningful involvement of patients can include the following roles:

- As research committee members, planning, designing and guiding the project as it progresses. This involvement in decision-making processes and in bringing forward priority issues for research is integral to patient-oriented research.

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<sup>1</sup> *Methods for Involving Patients in Topic Generation for Patient-Centered Comparative Effectiveness Research, An International Perspective (2012), p.8*

- As competent patient engagement researchers. *“They have mastered the specific research skills and know how to engage other patients, capture and articulate their ideas, support these ideas with valid research, and bring them to the table.”*<sup>2</sup>
- As contributors to identifying the right research question, study design, recruitment, data collection, and analysis of findings. Patients can also have a role in reviewing stories to identify common threads/relevant themes. This ensures that the outcomes important to patients are supported and measured.
- As supporters of participant-friendly research studies, improving access to patients via peer networks and accessing difficult-to-reach patients and groups.

## Guiding Principles

Patient engagement in research will improve the relevance of the research and improve its translation into policy and practice, contribute to more effective health services and products, and ultimately, improve the quality of life of Canadians and result in a strengthened Canadian health care system. Underpinning this Framework are guiding principles to which SPOR partners will adhere in pursuing the goal of integrating patient engagement into research:

***Inclusiveness:*** Patient engagement in research integrates a diversity of patient perspectives and research is reflective of their contribution – i.e., patients are bringing their lives into this.

***Support:*** Adequate support and flexibility are provided to patient participants 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 (see Appendix 3 for more detail).

***Mutual Respect:*** Researchers, practitioners and patients acknowledge and value each other’s expertise and experiential knowledge.

***Co-Build:*** Patients, researchers and practitioners work together from the beginning to identify problems and gaps, set priorities for research and work together to produce and implement solutions.

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<sup>2</sup> <http://webapps2.ucalgary.ca/~crds/greymattersinaction/docs/AHS%20Patients%20Matter%20Progress%20Report%20April%2015%202013.pdf>

## Core Areas for Engagement

### 1. Patient Engagement in Governance and Decision-Making

To achieve the vision of patients as active partners in health research, it is imperative that patients are involved in key governance structures and decision-making processes in all of SPOR's present and future core elements. There needs to be a commitment to engage patients in decision-making, in peer review and in priority setting committees. A principle-based approach for patient representation on boards/committees is needed to clarify roles and expectations and to ensure that those who are impacted by the direction of research have a say (i.e., nothing about us without us). The following are non-exclusive examples crucial to integrating patient engagement into SPOR's foundational structures: i. SPOR National Steering Committee: Patients need to be adequately represented on this committee; ii. SUPPORT Units: Each SUPPORT Unit will develop and implement a patient engagement plan which includes patient participation in governance and decision-making processes. SUPPORT Units will track and report on results of patient engagement activities in their jurisdiction; iii. SPOR Research Networks: Networks will create a process for patients, citizens and community stakeholders to be actively involved in research governance and as active participants in the research itself.

### 2. Capacity Building for Patient Engagement

To achieve an active collaboration between patients and researchers, health care providers and decision-makers for patient-oriented research, a change in culture must happen. Capacity development in SPOR focuses on approaches to overcoming the obstacles that inhibit these stakeholders from realizing PE objectives. It also focuses on enhancing their abilities so that measurable and sustainable results are achieved. What actions can support researchers, health care providers and decision-makers to engage patients and to see the benefits of PE? What needs to be in place so that patients are willing to participate in producing and using health research?

A variety of areas have been identified in which mechanisms are needed to address different audiences:

- Identify research funding mechanisms which will support SPOR to meaningfully engage patients in patient-oriented research;
- Integrate patient engagement into training strategies, including with research/trainees/interns and opportunities for patients;
- Adopt a partnership approach to build capacity for patient engagement by leveraging the existing work and expertise of other organizations/networks, including training and evaluation models in the health care context;
- Support patients to share in the responsibility of engaging/reaching out to under-represented groups as well as mentor other patients; and



- Implement tangible incentives to encourage participation of patients such as patient important outcome measures that can improve their quality of life.

### 3. Tools and Resources

The creation of tools and access to resources is encouraged in order to implement research collaborations among researchers, patients, practitioners and decision-makers:

- Create a pool of patient participants: a cross-section of participation with representatives from diverse populations in different geographic, socioeconomic and cultural contexts who also reflect gender and age representation;
- Provide education, orientation, and training for patients, researchers, health care providers and decision-makers so that they can work and communicate meaningfully and efficiently;
- Share best practices on a range of engagement approaches and role definitions in order to meet the needs of a variety of patients, population and age groups
- Support researchers to identify and engage under-represented patient groups; and
- Support patients in their efforts to engage/reach out to under-represented groups.

### Evaluation of Patient Engagement in SPOR

*The consultation workshop sought input from patients and patient engagement experts on their desired outcomes for patient engagement.*

- Inclusive mechanisms and processes are created;
- Capacity for respectful collaboration is established amongst patients, researchers and health care providers;
- The experiential knowledge of patients is valued as evidence as part of the research process;
- Research is informed and co-directed by patients; and
- Everyone shares the goal of timely implementation of quality research.

**Appendix 2** expands on these outcome statements which were described as ‘conditions for success’ by the patient representatives who participated at the Patient Engagement Workshop on January 9, 2014.

The above outcomes will be used in the development of patient engagement performance indicators and integrated within the overall SPOR Performance Measurement Strategy. These indicators are currently in development as CIHR is consulting with other organizations with experience in evaluation of patient

engagement programs. Both the scan and consultation processes will inform the development of patient engagement performance indicators.

## Appendix 1: PE Framework Dashboard



### VISION

*Patients are active partners in health research that will lead to improved health outcomes and an enhanced health care system*

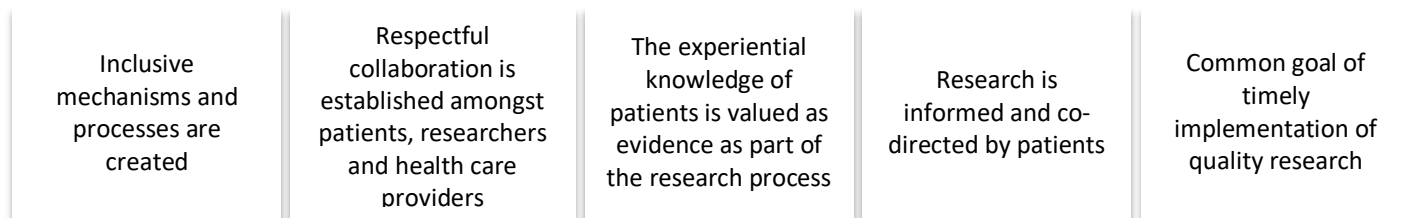
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### OBJECTIVE

The SPOR Patient Engagement Framework is designed to establish key concepts, principles and areas for patient engagement to be adopted by all SPOR partners.

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### DESIRED OUTCOMES OF PATIENT ENGAGEMENT



### GUIDING PRINCIPLES

Underpinning this Framework are guiding principles to which SPOR partners will adhere in pursuing the goal of integrating patient engagement into research.



## Appendix 2: What does Success Look Like?

These conditions for success are derived from the SPOR Patient Engagement consultation workshop that took place on January 9, 2014.

Successful patient engagement includes the following:

- i. **Inclusive Mechanisms and Processes:** Patient involvement at all levels is a desired aspiration that also means shared leadership and decision-making processes in which patients are co-building with researchers, practitioners and other decision-makers in collaborative research teams. There is also opportunity for peer to peer recruitment and engagement. (Patient-led research is supported).
- ii. **Multi-Way Capacity Building:** This ensures that the capacities of patients, researchers, and health care providers are being developed in order to work effectively together. There is support for creating safe environments that promote honest interactions, cultural competence, training and education.
- iii. **Multi-Way Communication and Collaboration:** A safe environment of mutual respect is fostered and is characterized by honest conversations that inform and involve people.
- iv. **Experiential Knowledge Valued as Evidence:** Experiential knowledge of patients, families and caregivers is mobilized and translated.
- v. **Patient-Informed and Directed Research:** Research approaches engage patients in collaborative methods and the research is inclusive of a range of patients. Recognition is given to a diversity of patients' needs and expectations through a range of roles.
- vi. **A Shared Sense of Purpose:** All participants work together towards the goal of timely improvements to the quality of research driven by patient-oriented outcomes. Mechanisms are in place for a continuous feedback loop in which the results of patient-oriented research are communicated back to patients.

## Appendix 3: Considerations when Paying Patient Partners in Research

**\*\*\*Please note, references to potential taxable income throughout this document should not \*\*\*  
be considered tax advice.**

### *Introduction*

Canada's Strategy for Patient-Oriented Research (SPOR) encourages researchers and research partners to offer payment to patients who act as partners in research and research-related activities. The SPOR Patient Engagement Framework identifies a number of areas for engagement including involvement in priority-setting, participation in governance committees, and consultation on research design and knowledge translation activities, to name a few. When patients act as partners in research and research-related activities, they are dedicating their time and expertise to the betterment of the overall project in a similar fashion to other members of the research team, albeit, with a different lens. Offering payment to patients who undertake this important work helps make participation in research more equitable and diverse by helping to remove barriers to participation in research.

SPOR promotes the view that, whenever possible, patients should be offered appropriate payment for their added value to the research activity to which they are contributing. This is reflected in the third guiding principle of the SPOR Patient Engagement Framework:

*Adequate support and flexibility are provided to patient participants 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.*

Patient engagement is an ever-evolving field. As such, we recognize that this is a 'living' document. Ongoing feedback from the community will be used to update and improve it.

### *To whom do these considerations apply?*

There are two main target audiences for these considerations: (1) patients (as defined in the [SPOR Patient Engagement Framework](#)); and (2) researchers, research administrators and their administering organizations.

### *What is the difference between patients as research 'partners' and research 'participants'?*

Traditionally, patient engagement in research and research-related activities has been restricted to engaging as research *participants* (formerly referred to as 'subjects'). Research participants are volunteers who elect to participate in a research study as a recipient of a variable being tested. For example, in clinical trials, research participants (who may or may not be patients) receive the treatment being investigated or a placebo or alternate treatment. The voluntary contribution by research participants to be the 'testers' of scientific discoveries is essential in order to help researchers determine whether their treatment or intervention works as intended. There are clear [rules and ethical guidelines](#) on payment for those who participate in research as **research participants**.

The [SPOR Patient Engagement Framework](#) recognizes that in addition to the very important role of research

participants, there needs to be a role for patients that allows them to contribute to research and research-related activities *as a partner* in the research process.

N.B.: This document provides considerations for offering payment to **patient partners**, **not** to research participants.

### *What is the difference between covering expenses and paying patients?*

**For the purposes of this document, ‘compensation’ will be referred to as ‘payment’.** Payment is defined as:

*The act of awarding something to someone in exchange for a service. While this is often monetary compensation in the form of salary or stipends, it can also be in the form of services, honoraria, gifts or in-kind exchanges or incentives.*

Payment **should not** be confused with ‘covering expenses’. When an organization offers to cover expenses for participation in an activity such as an event, conference or workshop, this refers to paying for, or reimbursing, costs associated with a person’s participation in the activity (e.g., travel to the event, fees to participate in the event, hotel accommodations or covering meal costs). While covering expenses is one way to remove barriers to patient participation in research, it does not fit the definition of payment in the sense this document seeks to highlight. For any questions related to covering expenses and expense reimbursement, researchers are encouraged to consult their institutional policies in addition to any policies that govern the grant funds they received from external organizations.

**Paying patient partners refers to paying an individual for their time, skills and expertise when partaking in an activity.** In the context of patient-oriented research, patient partners should be offered payment 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. It is important for researchers to recognize that patient partners may have expenses that fall outside the typical expenses that faculty, staff, or students might have. Researchers should work with their institutions to ensure that their policies encourage fair and reasonable expense reimbursement for patient partners who incur costs when participating in research.

## Considerations

### *What do you need to know about offering or accepting payment?*

The following are general guiding principles that can be used when offering payment to patient partners engaged in research and research-related activities.

1. **Who is a Patient Partner?** - If patients are involved in a research project in any manner other than as a research participant, they are considered ‘patient partners’. Some examples of the patient partner role may include: participation on governing boards or committees, being consulted on survey design for a study, co-developing the research methodology with a researcher, taking part in priority-setting activities to determine new areas of research, and collecting and/or analyzing data and knowledge translation.

2. **Flexibility** - SPOR encourages flexibility with the kinds of payment they offer to their patient partners. There may be situations when offering payment to patients may not be possible due to budget constraints (e.g., was not planned in the budget) or the type of payment may need to be negotiated or discussed with the patient.
3. **Informed Consent** - While offering payment to patient partners is highly recommended, it should be offered in a manner whereby the patient is allowed to make an informed choice about accepting it or not. Patients should be able to refuse payment without it impacting their ability to participate in the research project. Similarly, patients should feel comfortable asking about what kinds of payment are available to them. Therefore, when possible, researchers should identify in recruitment material whether payment *will be made* available, and should familiarize themselves with the types of payment allowed for by their institutions. Finally, researchers and patient partners are encouraged to decide on the best form of payment together and remain mindful that this occurs on a case-by-case basis – what might be right for one patient, may not work for another.
4. **Fair and Equitable Payment Rates** - - When considering *monetary compensation rates*, researchers should consider the patient’s contributions to the research project. Monetary compensation should reflect the level of time, effort, lived experience, and skill level brought to the project by the patient partner. The rate of pay should be comparable to the rates of pay to other professionals in similar roles, such as is recommended by international organizations such as the United States’ Patient-Centred Outcomes Research Institute ([PCORI](#)) and the United Kingdom’s [INVOLVE](#). Finally, it is highly recommended that within each institution compensation rates for patient partners remain consistent.

### *What forms of payment are there?*

**Regardless of whether a patient receives payment, sincerely thanking and acknowledging the patient for their time, effort and contributions should occur whether additional forms of payment are offered or not.**

This creates an atmosphere that reinforces a sense of belonging to the research process. Similarly, patient partners should be acknowledged appropriately for their contribution in any scientific publications.

There are many forms of patient payment available; below are four options for consideration. It should be noted that SPOR is not endorsing any one option over the other; the decision on which form of payment to use will depend on a combination of factors including institutional policies, research budgets, stipulations of external funding sources, and patient preferences.

1. Fixed Service Income

With this option, the patient receives a fixed rate (e.g., per hour, per day, etc.) for their contribution to the research project. There is no nationally determined or prescribed rate that SPOR recommends. The amount will be determined by the research team in consultation with their patient partners and is subject to relevant institutional and provincial/territorial policies governing those institutions. Researchers are encouraged to speak with their institutions and their local SUPPORT Unit to determine an acceptable range and to help them determine the tax implications of payment through this option so the patient can take this into consideration when considering payment options.

**Important Considerations:**

- Payment through this option may be considered employment income by the [Canada Revenue Agency \(CRA\)](#) and may be subject to taxation. Please [contact CRA](#) for more information.
- Researchers should inform patients that they may need to collect Social Insurance Numbers in order to provide any applicable tax forms related to the payment to patient partners. A process for collecting and confidentially sorting this information will be needed.

## 2. Salary/Stipend

Similar to the above option, the patient partner may be offered a salary or stipend for their participation on a research project. Again, there is no nationally determined or prescribed salary or stipend rate that SPOR recommends.

### **Important Considerations:**

- Payment through this option may be considered employment income by the [Canada Revenue Agency \(CRA\)](#) and may be subject to taxation. Please [contact CRA](#) for more information.
- It is important to note that while salaried patient partners do exist, this is rare. Patients would have to adhere to the regular employment practices of the administering institution.

## 3. Honoraria

With this option, the patient will receive a one-time payment as a thank-you for their contribution to the research project or activity. This type of payment may be more appropriate for instances where one-off consultations with patients occur (e.g., workshops) or if the patient partner's contribution is short in length.

### **Important Considerations:**

- According to the [Canada Revenue Agency \(CRA\)](#), an honorarium is 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. Please [contact CRA](#) for more information on issuing and receiving honoraria.

## 4. In-Kind Payment or Gifts

Another option is to offer patients in-kind payment or gifts. For example, some may wish to take a course or training at the institution where the research project activity is taking place. Gift cards, donations to a specific group, attending a conference or helping the patient achieve personal goals (e.g., taking a course at the institution) are other options that could be explored.

### **Important Considerations:**

- It should be noted that CRA has rules and regulations around non-cash gifts for employees. Since many patient partners will not be employees of the research institution through which the gift is offered, the in-kind value of their gift may be regarded as taxable income by CRA. Please [contact CRA](#) for more information.

- It is encouraged that researchers cover the costs of patients attending a conference *that presents their research*; it is acknowledged that this can sometimes amount to a considerable expense. For this reason it is important to budget for patient conference attendance in the grant application.
5. Payment offered to Indigenous Elders/Knowledge Keepers

Indigenous Elders/Knowledge Keepers require a different protocol when it comes to payment as a patient partner. In addition to covering expenses related to their participation in a project or activity (i.e., transportation, meals, and accommodation if necessary), they receive a flat rate for the day regardless of the amount of time spent on the activity. Finally, an appropriate gift should be offered (e.g., tea, blanket, scarf, etc.).

**Important Considerations:**

- When seeking the participation of an Elder/Knowledge Keeper on a research project, researchers are encouraged to check with their institution to see if there is already a protocol or policy on working with Elders/Knowledge Keepers in addition to speaking with the community and the Elder themselves on what is considered appropriate payment for their time.
6. Patient May Opt to Decline all Forms of Payment

In recent years, many patients have been consulted about whether they wish to be compensated for the role they play in a research project or related activity. For many individuals, a sincere thank you from their research team is enough and they do not feel the need to accept payment. Some patients may feel that acknowledgement for their participation is appropriate payment.

*What should patient partners consider before accepting an offer?*

1. Patient partners should know that the time and expertise they bring to each health research project and related activities is highly valued and that SPOR supports the principle that patient partners should be offered payment for their role in advancing health research.
2. Patient partners should fully understand and agree to the payment offered to them **before** beginning work on a research project.
3. Patient partners should know that they have a right to express if they feel the payment offered for their participation is not sufficient and discuss their options with the research team. While their feedback may or may not result in a change to institutional payment policies and procedures, it is nevertheless important information that helps the institution understand what is considered fair and appropriate. Since patient partner payment is new to many institutions, it is expected that policies on this will emerge and evolve over time. Similarly, patient partners should know that they have a right to decline any form of payment offered to them for participating in research and research-related activities without it impacting their ability to partake in the activity.
4. Patient partners should know that while SPOR strongly encourages researchers to offer payment to patient partners, it is not mandatory. The nature of the research project, the level of funding the researcher is awarded and the institution for which the researcher works may determine the type and amount of payment for patient partners. Further, it is important to keep in mind that SPOR aims to grow the practice of patient-oriented research across Canada, and therefore this approach may be



new to many researchers. Some researchers may have already applied for their grants when they learn about incorporating patient partners into their research projects and may not have the budget available to offer payment. SPOR is trying to address this by informing researchers that it is important to budget for patient partnership from the beginning of the research project.

5. Patient partners should be advised that many forms of payment received through their participation in a research project or related activity are subject to relevant tax laws and regulations issued by the Canada Revenue Agency and the patient partner's home province. While researchers should inform patients when a payment option has the potential to impact a patient's financial situation, it is ultimately the responsibility of the patient partner to determine whether that option is the right fit for them.

### *What should researchers or research managers consider before offering payment to patient partners?*

1. Budget for patient engagement: While paying patient partners is a new practice and many researchers may be considering engaging patients after they have received their grant funding, researchers are encouraged to budget for patient engagement in future applications.
2. Determine if patient payment is an eligible expense under the terms of your grant – researchers can receive research funding through a number of avenues. Researchers should know that if they receive research funding through the Canadian Institutes of Health Research (CIHR), a key partner in SPOR, this document was drafted in accordance with the Use of Grant Funds section outlined in the *Tri-Agency Financial Administration Guide*. Therefore payment to patient partners with CIHR funds **is considered an eligible expense** if the work performed by the patient partner contributes towards the **direct costs of the research/activities**. If a researcher is working with funds received through a different funding source, they should consult their funding body to determine whether patient payment is an eligible expense.
3. Know the local policies or guidelines that affect payments in your jurisdiction. Researchers are strongly encouraged to seek guidance from their administering institution's financial department and local SUPPORT Unit to determine:
  - a. What forms of payments can be issued from the list above (e.g., fixed-service, honoraria, in-kind exchanges, etc.).
  - b. How to advise patient partners when payment could become taxable income in order to allow the patient partner to reflect on how accepting payment may impact their financial situation. Furthermore, in order to allow patient partners from lower income families to participate, it is recommended that researchers ask their finance department if they may be available to provide specific advice (or resources) to patients who do not have a financial advisor so that they can make informed choices about accepting payment.
  - c. What the process is for issuing payment in your institution. For example, what documentation is needed and how will information be confidentially shared? What will the turn-around time be from participation to payment?

4. Discuss payment options with your patient partner. While it is important to understand what kinds of payment options you are able to provide before engaging patient partners, it is also important **not to decide** on the payment you will provide **for** your patient partner. Give them options and discuss what is feasible together. Also, if your patient partner proposed a different option, explore the feasibility of providing that option. Finally, the principle of equity should be adhered to when offering payment to patient partners to encourage diversity; different payment styles and amounts may be more appropriate for members of minority groups who are less represented in research (e.g., First Nations, Inuit and Metis peoples, immigrants and refugees).

### *How can researchers' institutions/organizations facilitate payment to patient partners?*

1. Research institutions should consider crafting their own policies or guidelines on patient payment for their researchers. It is highly encouraged that these guidelines enable flexibility on the type of payment that can be issued to patient partners. Research institutions are also encouraged to share these policies with their local SPOR SUPPORT Unit who will be collecting data on patient payment practices to help improve practices across Canada.
2. Ensure the monetary payment rates are consistent within your institution. Furthermore, it is recommended that you collect information on the types of patient payment options being offered by your research teams; paying for patient partnership is new and this information can be used to improve research institutions' policies over time.
3. Consider having a member of your financial department specialize in patient-partner payment and making them available to speak to patient partners who may need assistance in determining the impact of accepting payment on their income status.
4. Determine whether the storage of patient partner Social Insurance Numbers (SIN) requires added security measures in your computer systems.

For more information on existing patient payment practices, please see the following resources:

- [PCORI \(United States\)](#)
- [INVOLVE \(United Kingdom\)](#)
- [A Guide for Paying Peer Research Assistants \(British Columbia\)](#)
- [The Change Foundation – Should Money Come into It \(Patients Canada\)](#)
- [Pacific AIDS Network – Compensating Peer Researchers](#)

For more information on tax implications, please consider the following CRA guidelines:

- Employment Income (includes honoraria): <http://www.cra-arc.gc.ca/tx/ndvdl/tpcs/ncm-tx/rtrn/cmpltng/rprtng-ncm/Ins101-170/101/menu-eng.html>
- Receiving Gifts: <http://www.cra-arc.gc.ca/chrts-gvng/chrts/prtng/gfts/menu-eng.html>
- Gifts and Income Tax: <http://www.cra-arc.gc.ca/E/pub/tg/p113/README.html>
- Expenses incurred by volunteers: <http://www.cra-arc.gc.ca/chrts-gvng/chrts/plcy/cpc/cpc-025-eng.html> Community Volunteer Income Tax Program: <http://www.cra-arc.gc.ca/volunteer/>

**\*\*\*Please note, references to potential taxable income throughout this document should not \*\*\*  
be considered tax advice.**

## Acknowledgements

SPOR greatly acknowledges the contributions of all the patient partners, SPOR SUPPORT Units, SPOR Networks, Patient Engagement Ethics Working Group and CIHR's Institute for Indigenous Peoples Health members whose important feedback is captured in this document.