RECOMMENDATIONS ON PATIENT ENGAGEMENT COMPENSATION

Prepared by the SPOR Networks in Chronic Diseases and the PICHI Network

Abstract

The SPOR Networks in Chronic Disease and their Patient Partners make recommendations on harmonizing an approach to Patient Partner Compensation across all SPOR Networks and SPOR SUPPORT Units

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Acronyms used in this document

ACCESS: Youth and Adolescents Mental Health – ACCESS Open Minds (SPOR Network)

Can-SOLVE CKD: (**CAN**adians Seeking **SOL**utions and innOVations to overcome **C**hronic **K**idney **D**isease)

CHILD-BRIGHT: Child **H**ealth **I**nitiatives **L**imiting **D**isability-**B**rain **R**esearch **I**mproving **G**rowth and **H**ealth **T**rajectories.

CIHR: Canadian Institutes of Health Research

IMAGINE: Inflammation, **M**icrobiome and **A**limentation: **G**astro-**I**ntestinal and **N**europsychiatric **E**ffects (SPOR Network)

INVOLVE: A charitable organization in the UK founded in 2003 that supports people and institutions to collaborate to achieve social change

NPA: Nominated Principal Applicant of a SPOR Network

PCORI: Patient-**C**entered **O**utcomes **R**esearch **I**nstitute (USA)

PIHCI: Primary and Integrated Health Care Innovations (SPOR Network)

SPOR: Strategy for Patient-Oriented Research

SPOR SUPPORT Unit: SPOR Support for People and Patient Oriented Research and Trials Unit

Definitions

Administration:
The academic or research hospital non-academic institution that creates and deploys policies and procedures related to the SPOR patient-oriented research activities.

Governance:
The highest decision-making and policy-enforcing oversight body within a SPOR Network or SUPPORT Unit. Both the Scientific and management leads within the SPOR Network or SUPPORT Unit are advised by and report both to this oversight body and to their institutional administration.

Management:
The non-academic professionals within the SPOR Network or SUPPORT Unit who assist in day to day duties necessary for all activities related to the organization including, but not limited to, finance, human resources, communication, agreement and contract development and execution, and interaction with the NPI, researchers, Patient Partners, administrative staff and governance bodies.

Patient:
An overarching term inclusive of individuals with personal experience of a health issue and informal caregivers, including family and friends. http://www.cihr-irsc.gc.ca/e/48413.html

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. http://www.cihr-irsc.gc.ca/e/48413.html

Patient-Oriented Research:
Patient-oriented research refers to a continuum of research that engages patients as partners, focuses 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.http://www.cihr-irsc.gc.ca/e/48413.html

Patient Partner:
A Patient who is a SPOR Partner engaged in a CIHR SPOR Patient-Oriented Research activity.
http://www.cihr-irsc.gc.ca/e/48413.html

Patient Partner Compensation:
Fair recognition to a Patient Partner for their engagement in a SPOR activity that is commensurate with and reflective of the value of their time and effort. Compensation may be cash, cash-equivalent or some other form valued by and agreed to by the Patient Partner.

Patient Partner Reimbursement:
Expenses incurred by Patient Partners related to their engagement in SPOR activities are separate from compensation. Eligible expenses, e.g., travel, accommodation, per diem meals, are dictated by the administrative policies of the SPOR Network or SUPPORT Unit home institution responsible for auditable CIHR expenses.

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. http://www.cihr-irsc.gc.ca/e/48413.html

1. Overview

The SPOR Networks are fully engaged with Patient Partners as advisors and collaborators in a wide spectrum of activities including, but not limited to patient-oriented research teaching and learning, knowledge translation, research and governance. Patient engagement is mandated in the terms and conditions of the CIHR SPOR Network agreements and in their annual performance reporting. To remove barriers to participation for Patient Partners compensation is advised by the SPOR program. While much experience exists in compensating patients for their roles as participants in research, there is little experience in compensating patients for roles as partners in the research enterprise, as directed by the SPOR Program. In the summer of 2017, the CIHR SPOR Program issued a draft document entitled *"Compensation Guidelines for Engaging Patients as Partners in Research"*, later revised to be called a "considerations, not guidelines document" as further changes to Tri-Council Policy are in currently underway. However, on review of this document, the SPOR Chronic Disease Networks, ACCESS and PIHCI SPOR Network Directors agreed that it does not address some of the key challenges arising in the real-world experience of offering compensation to Patient Partners. Furthermore, information on how to incorporate the *Truth and Reconciliation Commission of Canada: Calls to Action* is not clear. Many SPOR Networks developed their own policies and procedures for patient compensation to address their patient engagement activities in advance of the preparation of the draft CIHR SPOR considerations document.

Many SPOR Networks have experienced challenges with respect to the administration of patient compensation. In response to concerns raised by the SPOR Network Directors about these challenges, the CIHR SPOR Program advised that solutions should be addressed directly by the SPOR Networks. Therefore, the SPOR Network Directors launched a Task Force with clear terms of reference (**Appendix A**) and the intent of reporting their findings to the SPOR Networks and CIHR SPOR Program as soon as possible. To accomplish the necessary background information gathering and analytics, the Task Force launched three working groups.

Working Group #1: This group conducted an environmental scan of the existing policies, guidelines and procedures published by other organizations that compensate patients for their involvement as partners in research. These organizations included the following: CIHR and the requirement to report to the Federal Government (i.e., Treasury Board), Canadian Universities, Academic Hospitals, Non-Profit Organizations, Patient-Centered Outcomes Research Institute (PCORI), and International Patient Engagement organizations (i.e., James Lind Alliance). In addition, this environmental scan investigated Canada Revenue Agency requirements for compensation and how these might affect patients who are receiving remuneration from the government (e.g., pension, disability pension).

Working Group #2: This Group reviewed the documents required for implementing a Patient Compensation strategy and created a list of guiding principles to consider when engaging Patient Partners to participate in research and related activities.

Working Group #3: This group gathered all Patient Engagement Compensation policies and procedures among the SPOR Networks and SPOR SUPPORT Units and compared similarities and differences.

In this report, the results from each Working Group will be discussed and areas for harmonization in Patient Partner Compensation across both the Networks and SPOR SUPPORT Units will be identified. Furthermore, the challenges in implementing a harmonized national approach will be discussed and recommendations on how to manage these scenarios with administering institutions (i.e., Universities) will be presented.

Prior to finalizing this report, the Task Force submitted the document and recommendations in draft first to the SPOR Network NPAs and Directors to seek feedback from their governance bodies. Then, the draft will be submitted to the CIHR SPOR Program for advice on the content and recommendations. After these review steps, the report and recommendations will be finalized and submitted to the SPOR Networks and CIHR SPOR Program leads.

1.1 Recommendations

Given the challenge of harmonizing compensation and reimbursement for eligible expenses across institutions, CIHR's endorsement of the recommendations in this report will support the efforts of all people involved as we seek to realize the potential of Patient-Oriented Research in Canada. Our five recommendations are:

1. **A harmonized, standard approach to Patient Partner compensation be established, based on the guiding principles outlined in this Task Force Report, among the SPOR Networks and SPOR SUPPORT Units for all SPOR-related activities**.

2. **Organizations and institutions responsible for Patient Partner reimbursement of expenses recognize eligible expenses in the context of SPOR program activities and aim to harmonize reimbursement policies to the greatest extent possible**.

3. **SPOR Networks and SUPPORT Units consider adopting Model A or B (see pages 16 and 17), or a blend of both, and the minimum of quarterly compensation payments to Patient Partners.**

4. **Reimbursement for expenses should adhere to the following:**
    - **Travel expenses should be covered directly by the Network, e.g. airfare, hotels, meals (as much as is possible)**
    - **A per diem should be offered for meals that are not included in Network events, without the requirement of receipts. The per diem rate, although based on the grant holding institution's policy, should be harmonized as much as possible across the**

Networks and include flexibility for geographic location. Ideally, the per diem reimbursement should be paid in advance to the Patient Partner.

- **Reimbursement may include costs that may be required for people living with health conditions to fully partner in research activities but are nonstandard at the research institutions administering funds. CIHR should support SPOR researchers in implementing new policies at their institutions so that patient partnership is not impeded by institutional policies developed prior to CIHR's initiation of SPOR.**
- **Because some institutions may reimburse expenses more slowly than expected or desired, out of pocket expenses for Patient Partners should be strictly minimized. When these do occur, if reimbursement will not be possible within less than 30 days (or one credit card cycle), Patient Partners should be notified ahead of time so that they may make an informed decision about whether or not to participate in the activity.**

5. **SPOR Networks and others adopt the process for Indigenous Elder compensation established by the Can-SOLVE CKD SPOR Network**

2. Task Force Members

The membership of this Task Force on Patient Engagement Compensation consists of Patient Partners and representatives (Directors and/or Patient Engagement Leads) for each of the SPOR Networks in chronic disease and the national Primary and Integrated Health Care Innovations (PIHCI) Network. The full Task Force membership can be seen in Table 1.

Table 1: Membership of the Task Force on Patient Engagement Compensation

Network	Staff and Academic Representatives	Partner Representatives
Chronic Pain:	Kimberly Begley Dawn Richards	Linda Wilhelm
Can-SOLVE CKD:	Heather Harris (Co-Chair)	Mary Beaucage (Co-Chair) Hans Vorster
CHILD-BRIGHT:	To Nhu Nguyen	Kate Robson
Diabetes Action Canada:	Holly Witteman (Co-Chair) Catharine Whiteside Tracy McQuire	Howard English (Co-Chair)

Network	Staff and Academic Representatives	Partner Representatives
IMAGINE:	Aida Fernandes, Deborah Marshall	Sara Blake
PICHI	Ivy Wong Bob Walsh	Roger Stoddard

As indicated in Table 1, the Network Co-Chairs for this Task Force were as follows:

- Holly Witteman: Diabetes Action Canada Patient Engagement Co-Lead, Steering Committee Member, and person living with type 1 diabetes
- Heather Harris: Can-SOLVE-CKD, Network Director
- Howard English: Diabetes Action Canada Patient Partner, Collective Patient Circle Member and person living with type 2 diabetes
- Mary Beaucage: Can-SOLVE-CKD Patient Partner and Patient Council co-Chair.

The Co-Chairs along with Catharine Whiteside (Executive Director) and Tracy McQuire (Manager, Research Operations) from Diabetes Action Canada prepared the following report that was approved by the Task Force members.

3. Guiding Principles

From the outset of the Task Force deliberations, the members believed that a principled approach must guide the analysis and recommendations related to Patient Partner compensation. Therefore, the following principles were articulated based on best practices revealed by the external scan and from the experience to date of the SPOR Networks. All of the following principles are considered equally important for the development and implementation of policies, guidelines and procedures for Patient Partner compensation. Some of these principles are also relevant for the policies and procedures for reimbursement.

3.1 Overarching principles

The following principles are relevant for all members of the SPOR Network and SUPPORT Unit teams of researchers and managers, as well as for the administration of the home research institutions.

Value

Patient Partners bring time, effort, expertise, experiences, networks, and more to the table. Compensation policies and practices should reflect that these contributions are valued.

Respect
Compensation policies should reflect meaningful respect for Patient Partners, including cultural competence.

Fairness
Patient compensation should be fair and equitable. This means different things in different contexts, but in general, we should avoid large gaps between compensation offered to different people doing the same work.

Transparency
Everyone should have the opportunity to review the policies, to understand them, and to track how they are being enacted (e.g., to know who around the table is being compensated, when and how compensation will be provided).

Clarity of expectations
Expectations regarding goals, deliverables and timeframes should be clear for all members in advance.

Representativeness
Patient Partners represent the patient population, and compensation policies should recognize this diversity. This may require adaptation to different circumstances reflective of this diversity. (See also: Minimal barriers.)

Responsiveness
Compensation should be responsive to Patient Partners' needs to enable participation. Such needs may include caregiving needs, reimbursement for expenses that are uncommon in research including preparation/orientation for meetings, etc. Needs may differ from one person to the next.

Flexibility
Compensation policies should have flexibility to address unexpected circumstances. Such flexibility should include respect for people's individual situations and their availability to engage at some times and not at others. Compensation policies should reflect explicit entry and exit points (start and end dates) that can accommodate the availability of Patient Partners and the opportunities, as they arise, for them to engage in SPOR activities.

Choice
Patient Partners may choose to decline compensation under some or all circumstances, and may propose alternative methods for others to recognize the value they bring to activities.

3.2 Principles for Research Administration and Management

The following principles focus on the development of policy and procedures by institutions and their implementation by the managers of the SPOR Networks and SUPPORT Units.

Minimal barriers
To the greatest extent possible, compensation and reimbursement policies should minimize barriers to Patient Partners' participation and enable inclusion. Policies should aim to cover costs that people might incur in order to participate fully. Time and effort may need to be devoted to recruitment and retention, and to ways of addressing barriers that may prevent people from participating (e.g., lack of internet access).

Dignity and privacy
Compensation policies should preserve the dignity of all people involved by respecting personal privacy and avoiding requirements of proof of a particular need if possible.

Distinction from paid and volunteer work
Patient compensation policies should reflect the concept of Patient Partnership and avoid overlap with paid and volunteer work. It should not invite application of laws that apply to paid employment, nor should it impact negatively on traditions of volunteering. It is important to honour and respect the work that volunteers do, and to recognize that compensated activities are different.

Distinction between compensation and reimbursement
Compensation for time and expertise brought to SPOR activities should be distinguished from reimbursement for expenses incurred during participation. Both compensation and reimbursement are important, and both should be included in policies.

Timeliness
Patient Partners should not to have to wait too long for compensation or expense reimbursement. Advance payment or payment in cash may be required to avoid a temporary financial burden experienced by a Patient Partner.

Mutual accountability
Compensation should include an accountability framework to clarify who is accountable to whom, in what cases are advance approvals required, and other details required to assure timely and appropriate compensation.

Reliability
Patient Partners and research groups are responsible for providing accurate information. Policies should ensure that systems are reliable by including checks and balances, internal controls, and other methods of verifying the accuracy of information.

4. External Scan – Compensation Guidelines from Patient-Oriented Research Organizations within Canada and Other Countries

An external scan of the patient compensation policies and procedures developed and implemented by patient-oriented research groups similar to the SPOR Program was conducted to learn from established organizations who have experience engaging Patient Partners in research activities. With advice from our Patient Partners we have focused on key issues that are particularly relevant to the circumstances experienced to date by the SPOR Networks. We gathered a number of documents from Canadian and international organizations with many years' experience in this process describing recommendations on how to approach Patient Partner compensation. We placed a SPOR lens on these findings to focus on approaches that appeared to be of value to our Task Force.

4.1 Establishing Volunteer Patient Partner Compensation Policy and Procedure

The Working Group reviewed documentation from the following sources:

- PCORI (USA) https://www.pcori.org/sites/default/files/PCORI-Compensation-Framework-for-Engaged-Research-Partners.pdf
- INVOLVE (UK) http://www.invo.org.uk/wp-content/uploads/2012/11/INVOLVEPayment-Guiderev2012.pdf
- BC – Centre for Disease Control – Peer Payment Standards (Canada) http://www.bccdc.ca/resource-gallery/Documents/Educational%20Materials/Epid/Other/peer_payment-guide_2018.pdf
- The Change Foundation (Canada) http://www.bccdc.ca/resource-gallery/Documents/Educational%20Materials/Epid/Other/peer_payment-guide_2018.pdf
- Canada Revenue Agency https://www.canada.ca/en/services/taxes/income-tax/personal-income-tax.html
- CIHR Project Grant; Spring 2018 Application Instructions http://www.cihr-irsc.gc.ca/e/49560.html

- CIHR Guide to Researcher and Knowledge-User Collaboration in Health Research http://www.cihr-irsc.gc.ca/e/44954.html

- CIHR Compensation Considerations (formerly Guidelines) for Engaging Patients as Partners in Research (2017) – personal communication, not published

The following summarizes key issues recognized by all of the above external organizations related to Patient Partner Compensation. All these organizations recognized the fundamental principle that if Patient Partners elect to receive compensation that these individuals should not have to pay to participate in research activities. They should receive full reimbursement for expenses and be offered fair compensation that is distributed in an equitable manner among participants for their engagement.

1. Reimbursement for expenses must be separated from compensation (cash, honorarium, gifts) for time spent in engagement by Patient Partners. It is noted that reimbursement for expenses paid through institutions such as universities must follow institutional policies and procedures that may not fully cover all the contingencies required for individuals engaged in SPOR Network activities. Any restrictions on either expense reimbursement or compensation set out by the CIHR or universities must be fully understood (or negotiated to change to these policies and procedures) at the outset of the patient-oriented research activities, e.g., child-care support or personal healthcare devices such as supplemental oxygen for a plane trip, may not be recognized as a legitimate expense by an institution, but may be necessary to enable an individual to volunteer their time as a Patient Partner.

2. Sufficient information must be provided and explained to Patient Partners about the policies, procedures and potential personal financial consequences with respect to receiving compensation. The following are examples of important issues for Patient Partners in Canada:

    - compensation above $500 per year is considered taxable income and the institution providing compensation will be issuing a T4A for the cash, cheque or funding equivalent (e.g., gift card) for these funds; https://www.canada.ca/en/revenue-agency/services/tax/businesses/topics/payroll/completing-filing-information-returns/t4-information-employers/t4-slip/what-report-what-report-on-t4-slips.html
    - Canada Pension Disability requires disclosure of compensation above a specific amount that varies from year to year (recently $5,500); https://www.canada.ca/en/employment-social-development/services/pension/reports/cppd-insert-2017.html
    - Compensation may alter the benefits status for individuals on disability or pension disability income;
    - Eligibility for non-taxable Indigenous ceremonial gifts; and, other considerations; and,
    - Preference for a mixed approach to compensation, e.g., cash compensation up to a specific limit, mixed with an in-kind or non-monetary benefit (conference registration, materials), to avoid any negative consequences relevant to personal financial circumstances.

3. Patient Partners must decide whether they are willing to receive compensation (or not) for the specific activities in which they may engage on behalf of the research organization. Consideration must also be given to options for non-monetary compensation (attendance at conferences, education, etc.). This communication should occur in advance of engagement in research activities and be revisited at appropriate intervals (at least yearly) during the course of the research program.

4. The organization of remuneration administration for Patient Partners must occur within budgeted expenditures that cannot exceed or fall short of designated revenues and must be compliant with the CIHR and university institutional policies and procedures. This includes the management of confidential information related to the Patient Partners, e.g., Social Insurance Numbers.

5. Different levels of engagement in patient-oriented research activity may be compensated at different levels (and at different stages of the research process). *Example:* The Change Foundation's compensation calculation tool based on an engagement and impact point system. *"Should Money Come Into It? A tool for deciding whether to pay patient-engagement participants. "*

6. The BC Centre for Disease Control document entitled *"Peer Payment Standards: for short-term engagements created in collaboration with peers and providers"* provides a comprehensive and relevant set of payment principles and recommendations about Patient Partner engagement in research-related activities. This document logically describes approaches to address many of the challenges faced by the SPOR Networks such as inclusion of individuals from diverse socio-economic backgrounds.

7. PCORI provides a model for addressing fair compensation for engaged research partners in which compensation aligns with engagement activity levels ranging from simply providing information to full participation in independent research initiatives. *"Financial Compensation of Patients, Caregivers, and Patient/Caregiver Organizations Engaged in PCORI-Funded Research as Engaged Research Partners."*

8. From the current CIHR Guide to Researchers and Knowledge-Collaboration in Health Research (Section 3: Taking Stock of Barriers and Facilitators) the following is stated under "Compensation". Barrier: Many integrated knowledge users may have to work above and beyond their normal job requirements both intellectually and physically (e.g., if meetings are held during evenings or weekend). Researchers should not expect partners to volunteer their time without paid compensation or expenses. Possible Solution: Many grants may permit budgeting for 'salary release time' for partners. This money is paid to partner institutions in order to free up paid time of employees to participate in research projects for loss of

productivity or work time or to hire replacement staff. If salary compensation is not possible, then out-of-pocket expenses (e.g., parking, gas stipends, babysitters, etc.) should be provided.

9. From the CIHR Project Grant: Spring 2018 Application Instructions under Task 5 (budget information) the following is stated about compensation for engagement of Indigenous peoples/communities: "*Eligible costs include: costs to community mobilization and engagement, including relevant promotional items such as tobacco, cloth, and cash reimbursements (in a method acceptable to the individual or community being reimbursed) to compensate for community participation; and, contracts and/or consultant fees for knowledge translation and communication activities for Elders, community members, and other Knowledge Holders involved in activities related to the Indigenous community*."

5. Current Status of SPOR SUPPORT UNIT and SPOR Network Patient Partner Compensation Policies and Procedures

An environmental scan was completed to compare the policies and procedures on Patient Engagement Compensation already established in the chronic disease SPOR Networks, PICHI Networks, and provincial SUPPORT Units. Since compensation usually accompanies expense reimbursement, expense reimbursement practices were also examined.

The SPOR Chronic Disease Networks were funded in early 2016 and were approaching the third year of operation at the time of this report. Over this time, the Networks have amassed experience in compensating Patient Partners for participation in research activities. With the expectation that the Networks must engage Patient Partners in all aspects of their research activities and compensate Patient Partners for doing so, it was found that each Network had developed Patient Engagement Compensation policies, procedures or guidelines. All the policies, guidelines and procedures on Patient Engagement Compensation and expense reimbursement created by the SPOR Networks and SUPPORT Units are summarized in **Appendix B.**

Structural and functional differences between the SUPPORT Units and the Networks have resulted in differences in how various entities respond to the need to compensate Patient Partners for their participation in research activities. The SUPPORT Units commenced activities at different time points over the last five years and even though their business plans and budgets were approved by CIHR, we found that the majority of the SUPPORT Units were still in the early stages of developing their policies and procedures for patient compensation. In speaking with the Patient Engagement leads of the SPOR SUPPORT Units from different provinces it appears that the needs for engagement of Patient Partners in research activities within the SUPPORT Units are not as defined or robust as within the Networks. This means that Patient Partner engagement in specific research projects, from planning to implementation,

is largely undertaken by the Networks and not the SUPPORT Units. Furthermore, the Networks are functioning at a pan-Canadian level and may require more complex levels of interaction with their Patient Partners than provincially-run SPOR SUPPORT Units. Therefore, some SUPPORT Units were unable to share completed policies and procedures at the time of writing this report. The Information that was gathered on SPOR SUPPORT Units Patient Engagement Compensation practices can be found in **Appendix B**.

Once the policies, procedures and guidelines from each of the SPOR entities were collated we were able to compare existing practices and to identify best practices and potential issues for remuneration of Patient Partners by the Networks. Below are some of the findings from this review.

- Provincial SPOR SUPPORT Units align with Provincial Governments on compensating patients and this may limit their ability to adopt a standard harmonized approach to Patient Engagement Compensation (i.e. The province of Saskatchewan has a provincial policy on issuing honoraria for such activities that the SPOR SUPPORT Unit has adopted).
- Cost of living in areas across Canada affects the rate of compensation and the maximum daily expenses allowed by SPOR Network host institutions (i.e. universities).
- Annual compensation in excess of $500 may impact government assistance remuneration (i.e. disability, social welfare, etc.) *See previous reference in Section 4.1.*
- The SPOR Networks in chronic disease are split in their compensation model between honoraria and hourly rates for patient engagement activities.
- Many of the Networks offer a per diem for meals and most cover travel expenses directly; however it is preferred by Patient Partners to have expenses paid in advance.

Furthermore, upon review of the information collected, the following opportunities for further clarifying and harmonizing compensation policies and procedures have surfaced.

- There is a need for accepted, standard definitions of the roles for which compensation is offered.
- To ensure equity and enable participation in SPOR activities of Patient Partners representing all relevant Canadian populations, rates of compensation should be harmonized among all the SPOR Networks and SUPPORT Units.
- Expense reimbursement guidelines should be standardized and broadened to ensure acceptable expense categories are provided to enable participation of all Patient Partners.
- A national protocol on Indigenous Elder Compensation using the Can-SOLVE CKD approach as a template could be adopted as a standard practice (see **Appendix C**).

Of note, we have encountered variability in expense reimbursement policies of academic institutions, where the Networks are hosted. For instance, some institutions are able to provide cash upfront to Patient Partners for participating in research activities, whereas other institutions require that attendance be documented with an agenda and that Patient Partners by compensated after their participation in research activities. Furthermore, some institutions require receipts for reimbursing

meals whereas others will offer a per diem without requiring receipts. To fully understand the differences in remuneration and expense reimbursement practices for Patient Partner across various host institutions, further consultation is required. With that said, we hope that this report will guide host institutions to adopt a harmonized approach to Patient Engagement Compensation and provide more flexibility in remuneration and expense reimbursement practices to enable Patient Partner participation in research activities. An important consideration for CIHR is to determine whether clearer guidance on the utilization of grant funds for Patient Partner Engagement Compensation and expense reimbursement practices would assist in harmonizing policies and procedures across CIHR-eligible institutions. A national strategy requires a national approach to implementation.

6. SPOR Network Harmonized Patient Compensation Policy and Procedure

6.1 Harmonization of Patient Partner Compensation for National SPOR Networks

CIHR's considerations document (draft summer 2017) differentiates between the concepts of compensation for participation of Patient Partners in patient-oriented research programs and compensation for individuals who consent to be research participants. CIHR endorses the premise that Patient Partners should be compensated for their roles in SPOR activities and separately reimbursed for eligible expenses. The CIHR considerations document remains silent on suggested rates of compensation for SPOR-related Patient Partner activities. As national Networks, we believe guidance in this area is paramount. Without a harmonized approach to Patient Partner compensation and expense reimbursement, we risk establishing a non-standardized and potentially inequitable framework for remuneration of our Patient Partners. We believe that compensation should be harmonized for similar activities undertaken by Partner Partners among the SPOR Networks and SUPPORT Units. Expense reimbursement must remain subject to differing institutional policies and procedures although these should be revised to include all eligible expenses incurred by Patient Partners.

In addition, it is noted that the CIHR considerations document is targeted mainly at researchers providing compensation to Patient Partners they have engaged as research team members. It is important to understand that the SPOR Networks in Chronic Disease are engaging Patient Partners in all aspects of the research enterprise, including governance activities, i.e. Steering Committees and Patient Councils, working groups and committees and as conference attendees and presenters. These roles add tremendous value to the Networks and are a significant component in enabling the culture change that is SPOR.

Recommendation 1

A harmonized, standard approach to Patient Partner compensation be established, based on the guiding principles outlined in this Task Force Report, among the SPOR Networks and SPOR SUPPORT Units for all SPOR-related activities.

Recommendation 2

Organizations and institutions responsible for Patient Partner reimbursement of expenses recognize eligible expenses in the context of SPOR program activities and aim to harmonize reimbursement policies to the greatest extent possible.

6.2 Compensation Rates

As referenced in the CIHR considerations document, compensation can be provided in various forms to Patient Partners, e.g., cash or equivalent, or alternative funding such as covering the costs of conference attendance.

6.2.1 Proposed Rates of compensation

Compensation policies, procedures and guidelines as well as rate structures for the national SPOR Networks and the provincial SPOR SUPPORT Units were reviewed and compared. There are two primary models used by the different networks: compensation by unit of time and compensation by level of engagement. Comparisons suggest that these two models award similar total amounts of compensation, but different groups may prefer one model to the other.

Based on our review of current compensation structures across the SPOR Programs, we propose that SPOR entities adopt either a rate structure option as outlined in Table 2 or a level of engagement model as outlined in Table 3, or in some instances a blend. We suggest the Networks adopt whichever model fits best for their current Patient Partner remuneration practices. Different groups may provide this compensation via cash, cheque, gift card, or other cash equivalent, depending on Patient Partner preferences and institutional policies. Some levels or forms of Patient Partner involvement (e.g., Patient Partners leading research) may require different models, and these two could be combined if deemed appropriate to accommodate the evolving roles of Patient Partners in research activities.

Table 2: Model A: Compensation by unit of time

Timeframe	Rate	Details
Hourly rate	$25.00	For activities less than 4 hours.
Half day rate	$100.00	+/- 4 hour commitments
Full day rate	$200.00	+/- 8 hour commitments

An hourly rate of $25 was deemed to be a fair rate of compensation by the Task Force as it is currently commonly in use across a number of SPOR entities and it is substantially above minimum wage.

Patient Partners may also have relevant professional experience or qualifications in research projects in addition to their experiential expertise. It is important to distinguish between Patient Partner roles and professional roles. While a Patient Partner may have professional expertise that enables them to offer suggestions from that perspective, when someone is serving primarily in a professional capacity in research activities, this falls under paid employment. Paid employment is outside the scope of this report.

NOTE: an annual cap on compensation per Patient Partner may be necessary to adhere to budget limitations and potential impact on government assistance. Such caps will be determined by each SPOR entity based on their Patient Engagement budget and other considerations. When relevant for Patient Partners, SPOR entities should take care not to exceed maximum earnings allowed before impacting Canadian Pension Plan Disability benefits (currently $5,500)

Table 3: Model B: Compensation by level of engagement

Level of Engagement			Example of activity	Suggested compensation
Commitment	**Responsibility**	**Scope**		
Availability by email; willing and able to participate in a few meetings by phone or in person	Contributes advice and feedback for decision making by research team	Assigned to a specific research project	Patient Partner for a single, specific research project	$500 to $800 per year, depending on number of meetings and other requirements

Level of Engagement			Example of activity	Suggested compensation
Commitment	**Responsibility**	**Scope**		
Commitment to a committee or group (includes meetings, follow-up actions, etc.)	Participates in decision making by providing options and recommendations	Activity has a network-wide mandate	Member of a committee, council, or workgroup with more meetings than a single research project	$1000 to $1200 per year, depending on frequency and numbers of meetings and other factors deemed important by the team
Contributing member in a governing committee (includes meetings, follow-up actions, etc.)	Has joint responsibility for decision making and mobilizing; Initiates and leads activities	Activity has a governing mandate for a network	Member of steering committee and/or executive committee	$1500 per year

As discussed in the CIHR considerations document, compensation may take different forms, from cash to cash equivalents to alternative methods. Most of these are considered to be taxable income and Patient Partners must be advised accordingly and receive appropriate documentation about their compensation.

NOTE: Dependent on the number of levels of engagement of a Patient Partner, the annual compensation package would be additive, meaning participation in more than one category is possible. The compensation rate at each level of engagement is a suggested range based on usual commitment in a category. Therefore, compensation can increase for people who assume greater responsibility or who do more work than is described for a given category.

6.2.2 Frequency of payment

For monetary compensation, the frequency of payment is recommended to be quarterly at a minimum or immediately following participation in a specific event (i.e. Annual Workshop, Conference, etc.) and the frequency of payment should be stipulated in an agreement with the Patient Partner. Some Networks may elect to provide compensation on a more frequent basis.

Recommendation 3

SPOR Networks and SUPPORT Units consider adopting Model A or B, or blend of both, and the minimum of quarterly compensation payment to Patient Partners.

6.3 Expense Reimbursement

6.3.1 Reimbursement for all Patient Partners

As mentioned in our guiding principles, respectful Patient Partner engagement should include minimizing financial hardship experienced by Patient Partners if out-of-pocket payments are required for participation in SPOR activities. Typically, Patient Partner expense reimbursement is subject to the same policies and procedures as institutional employees, taking weeks or even months for payment through local institutions. While we understand the requirement for good accounting practices by our host institutions, there is a need for some flexibility in terms of the length of time taken to reimburse and/or compensate our Patient Partners. Furthermore, the categories of expenses that are deemed eligible for SPOR activities should be considered separately from employee expense allowances at large academic institutions. If the process of payment for expenses is a barrier to Patient Partner participation, then patient-engagement SPOR activities will be biased toward those who can afford to participate.

Furthermore, Institutions should be made aware that some patient partners may not have credit cards that can be used to participate in Network activities (i.e. book flights or check in at hotels for conferences/workshops). Patient Partners are responsible for incidental costs incurred during their hotel stay but should not be burdened with a cash or debit deposit upon check-in if they do not have a credit card. To accommodate this, flights and hotels may be booked using a corporate card or through a travel agency that invoices the institution ***including a statement that the Patient Partners are not to be asked for a credit card for incidentals at check-in.*** **This is particularly important to respect principles of Representativeness, Minimal Barriers, and Dignity and Privacy.**

Of interest, in our Task Force meetings, it was noted that the reimbursement of expenses and respect for personal financial circumstances were more important than compensation for most Patient Partners.

Following review of the available policies, our recommendations are listed as follows:

Recommendation 4

Reimbursement for expenses should adhere to the following:

- **Travel expenses should be covered directly by the Network, e.g. airfare, hotels, meals (as much as is possible)**

- **A per diem should be offered for meals that are not included in Network events, without the requirement of receipts. The per diem rate, although based on the grant holding institution's policy, should be harmonized as much as possible across the Networks and include flexibility for geographic location. Ideally, the per diem reimbursement should be paid in advance to the Patient Partner.**
- **Reimbursement may include costs that may be required for people living with health conditions to fully partner in research activities but are nonstandard at the research institutions administering funds. CIHR should support SPOR researchers in implementing new policies at their institutions so that patient partnership is not impeded by institutional policies developed prior to CIHR's initiation of SPOR.**
- **Because some institutions may reimburse expenses more slowly than expected or desired, out of pocket expenses for Patient Partners should be strictly minimized. When these do occur, if reimbursement will not be possible within less than 30 days (or one credit card cycle), Patient Partners should be notified ahead of time so that they may make an informed decision about whether or not to participate in the activity.**

The Patient Partner relationship with the SPOR Networks differs from that of an employee – employer relationship in terms of expectations and potential eligible expenses. Our Patient Partners give us their time, in the form of lunch breaks, vacation time, evenings and weekends. It is not their "job" to participate in SPOR activities. Therefore, the expectation for timely reimbursement should differ for those of employees, as should the list of eligible expenses.

For Patient Partners, eligible expenses are those that reduce the barriers to their participation in network activities, including, but not limited to the following:

- Caregiver support to travel with the Patient Partner;
- Child care, elder care, respite care;
- Mileage, parking, public transit;
- Airline seat selection, luggage fees;
- In some cases, items such as phone and internet service may be considered eligible expenses; and,
- Tobacco and related expenses for gifting to Indigenous Elders.

We recognize that the grant holding host institutions across the Networks have differing expense reimbursement policies. The CIHR considerations document refers the reader to the "researcher's institution" or to the local SPOR SUPPORT Unit. As each of these options is regional or provincial, these are difficult to apply in a pan-Canadian context, thereby necessitating a pan-Canadian policy for CIHR pan-Canadian Networks. Without a harmonized policy, we risk, and are currently experiencing, inequities in expense reimbursement for similar activities. This could affect Patient Partner engagement as their compensation and expense reimbursement agreements may be perceived unequal or unfair. For example, the per diem rate for meals ranges from $45 to $60 across the host institutions.

As a starting point, as stated in Recommendation 4, all SPOR entities should offer Patient Partners a per diem for meals and that this per diem be paid in advance of the activities. Harmonizing eligible expenses for SPOR-related activities across all Canadian CIHR-eligible institutions is beyond the short-term scope of this Task Force, but this report can be a launching point for discussions with institutional policy-makers, especially when such a practice is endorsed by CIHR.

6.4 Working with Indigenous Elders

Recommendation 5

SPOR Networks and others adopt the process for Indigenous Elder compensation established by the Can-SOLVE CKD SPOR Network (see below).

Several of the SPOR Networks work with Indigenous Elders in Network research and other activities (i.e. land recognition, opening and closing ceremonies and to gather their feedback as prominent members of their community). To engage Elders in a culturally respectful manner special guidance is provided below for compensation and expense reimbursement. The content for recommendation 5 was adopted by the Can-SOLVE CKD Elder Protocol (**Appendix C**).

6.4.1 Honoraria and Expenses for Indigenous Elders

An honorarium should be offered to an Elder for his/her role in Network activities, such as providing opening ceremonies for meetings or participating in sessions. Honoraria should not be viewed as a payment for service, but rather as a gift exchange for knowledge, ceremonies, or blessings[1]. It is particularly important that the honorarium is available at the time of the event and presented prior to the activity in which the Elder has been invited to conduct or participate. Suggested compensation rates are outlined in Table 4.

Additional costs incurred by the Elder, such as parking, mileage, meals and accommodations, must be reimbursed. Elders are never "paid" for their "work" as it would be culturally inappropriate to appear as though they are "selling" Indigenous knowledge. Traditional Indigenous and cultural knowledge is not, and cannot be owned by an individual or institution. Elders must never be asked to sign a "receipt" as acknowledgement of their gift even if it is financial nor should they be asked for their Social Insurance Number (SIN), or their birthdates.

Table 4: Sample Requests for Reimbursement and Compensation

[1] Adapted from: Cultural Protocol Guidelines: Recommended Practices for First Nations, Metis and Inuit Cultural Engagement, University of Calgary, 2011

Request	Daily Compensation	Travel	Travel & Accommodations
Welcome to Territory	$150 – $200	Taxi/mileage/parking	Hotel/Accommodation/meals
Welcome to Territory/Opening & Closing Prayer	$300 - $500	Taxi/mileage/parking	Hotel/Accommodation/meals
Welcome to Territory/Opening & Closing Prayer/ Ceremony	$600 - $800	Taxi/mileage/parking	Hotel/Accommodation/meals
Welcome to Territory/Opening & Closing Prayer/ Ceremony/ Elder remains throughout event	$800 - $1200	Taxi/mileage/parking	Hotel/Accommodation/meals

*Ceremony could include: Smudging, facilitating a Sharing/Talking/Healing Circle

7. Recommendations for Next Steps by the SPOR Networks and CIHR SPOR Program

While this Task Force report was advised by a Committee with equal membership of Patient Partners and Network administrative leadership, we recognize that other stakeholders would need to be consulted before a final document is presented. Below we have outlines a series of tasks that must be completed prior to finalizing this report.

1. Review of the draft Harmonized Patient Compensation Policy and Procedures by the SPOR Network Directors, Nominated Principal Investigators, Governing Committees followed by necessary (final) revision

2. Review of the Report of the Task Force including the Harmonized Patient Compensation Policy and Procedures by the CIHR SPOR Program Director (Nancy Mason-MacLellan) followed by any necessary revision
3. Submission of the Final Report of the Task Force to the SPOR Program Lead (Anne Martin-Matthews) and the SPOR Network Governance Committees recommending adoption
4. Evaluate the outcomes and impact of adopting the Harmonized Policy and Procedures after 1 and 2 years by the SPOR Networks

APPENDIX A: Terms of Reference for Task Force on Patient Compensation

Strategy for Patient-Oriented Research (SPOR) Network Task Force on Patient Compensation

Acronyms used in this document

ACCESS: Youth and Adolescents Mental Health – ACCESS Open Minds (SPOR Network)
Can-SOLVE CKD: [**CAN**adians Seeking **SOL**utions to o**VE**rcome **C**hronic **K**idney **D**isease]
CIHR: Canadian Institutes of Health Research
NPA: Nominated Principal Applicant
PIHCIN – Primary and Integrated Health Care Innovations Network (SPOR)
SPOR: Strategy for Patient-Oriented Research

Terms of Reference

Preamble
The SPOR Networks are fully engaged with patient partners as advisors and collaborators in the wide spectrum of activities including, but not limited to patient-oriented teaching and learning, knowledge translation, research and governance. Patient engagement is mandated in the terms and conditions of the CIHR SPOR Network agreements and in their annual performance reporting. In the summer of 2017, the CIHR SPOR Program issued a draft document entitled *"Compensation Guidelines for Engaging Patients as Partners in Research"*. However, on review of this document, the SPOR Chronic Disease Networks, ACCESS and PIHCIN SPOR Network Directors agreed that it does not address some of the key challenges arising in the real-world experience of offering compensation to patients. Furthermore, information on how to incorporate the *Truth and Reconciliation Commissions of Canada: Calls to Action* are not clear in the provided guidelines. Many SPOR Networks have already developed their own policies and procedures for patient compensation to address their patient engagement activities in advance of these draft CIHR Guidelines.

Many SPOR Networks have experienced challenges with respect to the administration of patient compensation. In response to concerns raised by the SPOR Network Directors about these challenges, the CIHR SPOR Program advised that solutions should be addressed directly by the SPOR Networks. As a result, the SPOR Network Directors are launching this Task Force with the following terms and with the intent of reporting their findings to the CIHR no later than the end of March 2018.

Task Force Members
Co-Chairs:
Holly Witteman (Diabetes Action Canada)

Heather Harris (CANSOLVE CKD)
Mary Beaucage (CANSOLVE-CKD)
Patient Partner 2 to be identified (network)

Co-chairs share the leadership of the Task Force and are responsible for the successful delivery of the Task Force's expected outcome. The dual post of Network and Patient Advisor co-chair is to represent a fuller range of skills, experiences and perspective. Together the Co-chairs are responsible for the following:

- Preparing agenda's for the Task Force meetings
- Lead meeting discussion on agenda items
- Coordinate the activities of the Task Force working groups.

Members:

- Director/ Scientific Lead and/or Patient Engagement Lead from each of the 5 Chronic Disease SPOR Networks, ACCESS and PIHCIN Networks – 7 total
- One Patient Partner from each of the SPOR Networks, including members from the Indigenous Patient population

Administrative Support:

Diabetes Action Canada: Tracy McQuire, Catharine Whiteside, Jessica Antwi

Key Questions for the Task Force

1. What compensation guidelines have been established in similar jurisdictions engaged in patient-oriented research activities. (For example, United Kingdom, Australia, United States)?

2. What are the fiscal and human resources policies at the institutional (university or affiliated hospital) and federal (Treasury Board, Canada Revenue Agency) levels that must be considered when establishing policies and procedures for patient compensation by SPOR Networks?

3. What are the guiding principles for patient compensation for enabling patient participation in SPOR Network Activities based on a conceptual framework on the types of and intent for appropriate compensation?

4. What expenses should be included as part of Patient Compensation (i.e. not covered by host institution reimbursement policies)?

5. Can the SPOR Network Patient Compensation Policies and Procedures be harmonized so that patient partners/advisors and collaborators receive similar compensation for the same activities undertaken at different Networks?

6. Should SPOR Network compensation policies be specialized for Indigenous peoples and Elders and if so how?

7. Should SPOR Network compensation policies be specialized for vulnerable, marginalized and/or underrepresented populations and if so how?

8. What recommendation(s) can be made to policy and decision-makers to simplify/standardize patient compensation?

Expected Outcomes

1. This Task Force will produce a document based on the work undertaken to address the above key questions
2. Outline of the guiding principles for compensation of patients engaged in the CIHR SPOR Networks
3. Draft a harmonized policy and procedure template (that can be further customized by each Network) for patient compensation that may be used by all the CIHR SPOR Networks and that aligns with institutional and federal requirements

Process (4-6 months) – Workplan and Results

An inaugural meeting of the Task Force members will be held to ratify their terms of reference will be held in November 2017. Following this meeting a work plan will be developed to accomplish the following tasks:

1. Conduct an external scan of best practices in similar jurisdictions
2. Carry out key informant interviews and information gathering
3. Review and understand institutional and federal requirements for compensation (with assistance from CIHR)
4. Create a draft of guiding principles. This will be circulated to SPOR Network Directors and Networks' NPAs for feedback
5. Draft terms of a harmonized patient compensation policy and procedures that will be circulated to the SPOR Network Directors and NPAs for feedback
6. Draft a Report of the Task Force that includes the guiding principles and harmonized policy and procedures and circulate to the SPOR Network Directors and NPAs for final input and approval
7. Submit the report to the CIHR. This report will be submitted to the SPOR Program Lead (Anne Martin-Matthews) and governance committee of each SPOR Network
8. Publish the work of the Task Force (Month 6 and onward)
9. Evaluate the outcomes and impact of adopting a harmonized policy after a 1 and 2-year period.

APPENDIX B: Summary of SPOR SUPPORT UNIT and SPOR Network Patient Engagement Compensation and Expense Reimbursement

Figure 1: SPOR SUPPORT Unit summary of Patient Engagement compensation policies

SPOR SUPPORT Unit	SCPOR (Saskatchewan)	BC	Ontario	Manitoba	Quebec	Maritimes	Newfound land	Alberta	North West Territories	Yukon
Type of Compensation	Honorarium	Honorarium, in-kind, gift cards	In progress	In Progress	In progress	Honorarium	Honorarium	In Progress	No Policy	No policy
Types of roles							(1)Patient Advisory Committee (2)Patient participation in working four, scientific advisory committee (3) Expert			
Amount	$100/day (prorated if < 5 hours)	$500 / year (prorated if less) for patient council $30 to $50 gift card $50 to $150 honorarium in-kind gifts like conferences $200-$500				$50/day	(1)$200/year (2)$300/year (3) Variable		$25/day minimum depending on role	

SPOR SUPPORT Unit	SCPOR (Saskatchewan)	BC	Ontario	Manitoba	Quebec	Maritimes	Newfound land	Alberta	North West Territories	Yukon
Considerations	Ministry of Health Policy Public Service Employees, U of Saskatchewan, Health Quality Council, U of Regina are not eligible for honorarium.	BC Academic Health Science Network Partner organizations can develop their own processes (Has not yet started to compensate) Outdated information – policy release in late Feb							Large Indigenous population and patients are considered 'consultants'. Remuneration is consistent for what government pays for knowledge	
Expenses	Case by case basis, child care, elder care, respite, parking, transit	Travel expenses reimbursed according to BCAHSN policy.				Taxi between patients home and location of event $20/trip ($40 total) Child care ($15/hr for 3hr max)				

Figure 2: SPOR Network summary of Patient Engagement compensation policies

NETWORK	Can-SOLVE CKD (UBC)	Can-SOLVE CKD (UBC) – Elder	Diabetes Action (Laval)	CHILD-BRIGHT	Chronic Pain Network	IMAGINE (McMaster)	PICHI
Types of Compensation	Honorarium – event based	Honorarium – event based	Hourly rates, half day and full day and per meeting rate	Annual honorarium, depending on role	Per meeting rate, half day and full day rates for participation.	Consulting / collaboration hourly rates, half and full day rates.	Honorarium
Types of roles	Patient Council Members	(1)Welcome to Territory &/or (2)Opening & Closing Prayer &/or (3)Ceremony &/or (4)Elder remains throughout event	Training and Learning, Consultant, Collaborator, strategic role, Patient circle member	See below	Training and Learning, Annual Meeting participant, Committee Member/Consultant, Project Consultant, Strategic role,	Training and Learning, Consultant, Collaborator	Variable
Amount	$150 full day $75 half day	(1) $150 - $200 (2) $300-$500 (3) $600-$800 (4) $800-$1200	Hourly rate $25 Half day $75 Full Day $150 Patient Circle Members - $95/meeting Consulting Hourly rate $50/hr Half day $150/hr Full day $300/hr	$500 (e.g. research project team) $1000 (e.g. committee member, Citizen Engagement Council) $1500 (Steering Committee or Executive Council)	$50 per meeting or session $125 for half day $250 for full day	$20 per hour $75 per half day $150 per full day	NL: $200 honorarium to attend 75% of meetings and additional $300 for consulting work (Total $500) BC: $150 per day ($100 per half day- regular meetings and the preparation for

NETWORK	Can-SOLVE CKD (UBC)	Can-SOLVE CKD (UBC) – Elder	Diabetes Action (Laval)	CHILD-BRIGHT	Chronic Pain Network	IMAGINE (McMaster)	PICHI
							council meetings counted a half day of work)
Considerations	Requests to donate honorarium back to Kidney Foundation of Canada or Network (Via UBC) can be honoured as a charitable donation.	Tobacco is exchanged at time of request	Patient partners are asked to keep track of time commitments.	Patient partners could have multiple roles.	Coordinator keeps track of attendance. Meeting attendance compensation processed twice yearly	Compensation can be declined and if so is reallocated to network activities. Patient partners submit expected hours in advance for approval	BC: Uses BC SPOR SUPPORT Unit guidelines PEI: Dependent on event and leadership for event
Expenses	Travel expenses are covered directly. A per diem for non-covered meals is offered to avoid collection of receipts.	Travel expenses are covered directly	Travel costs are covered directly. Per diem rate of $45 for non-covered meals. Child care and personal assistants also covered	Expenses for meals and mileage aligned with policies of host institutions RI-MUHC, SickKids, UBC).	Travel expenses covered directly, receipts required for meals non-covered meals. Personal assistants and child care covered	Travel expenses covered directly. Per diem of $51 for non-covered meals.	Travel expenses and meals

APPENDIX C: Elder Protocols and Guidelines

Elder Protocols and Guidelines

Elder Protocols and Guidelines
For
Can-SOVLE CKD Network
July 31, 2017
Working Draft

The purpose of this document is to provide guiding principles for the Can-SOLVE CKD Network as it strives to respect and honor the protocols of our host Indigenous communities across Canada.

We begin by noting that the Indigenous Peoples of Canada have distinct histories and diverse cultural and social practices. We do not intend this to be a general guide, and recommend that presenters and organizers always be as specific as possible in their approach to protocol.

These guidelines outline observances to be followed by community members who wish to respectfully engage Indigenous Knowledge Keepers, appropriate cultural representatives, Indigenous Leaders and Elders in the sharing of Indigenous protocol, knowledge and experiences. [2]

As with all complex issues rooted in distinct histories, discussions and dialogue on this important matter are ongoing.

The Can-SOLVE CKD Network recognizes that we are on Indigenous land. It is recognition of their presence both in the past and the present. It is a part of the Can-SOLVE CKD Network's broader strategy to establish healthy and reciprocal relationships with Indigenous communities. These relationships are key to reconciliation, a process to which the Network is committed.

Cultural protocols are crucial in the diverse Indigenous communities throughout Canada. Respect is a universal Indigenous value and how relationships are initiated and maintained is crucial to engaging Indigenous peoples and groups.[3]

Terms

There are various terms associated with First Nations, Métis and Inuit peoples such as Indigenous and Aboriginal, as well as various names associated with the diverse cultures, languages, and peoples across the provinces and the nation. It is important to note this diversity and our commitment to inclusion. This respect to the local communities and the traditional territory of the local

[2] Adapted from: Ryerson University, 2017Protocol, Guidelines, and Recommended Practices of Host Indigenous Communities in Toronto,
Retrieved from
https://www.congress2017.ca/sites/default/files/sites/default/uploads/Documents/congress-2017-indigenous-protocol-and-guidelines-en.pdf

[3] Adapted from Indigenous Wisdom: Protocols Guide, Step Up BC
Retrieved from https://www.stepupbc.ca/sites/default/files/downloadable-material/02%20Aboriginal%20Innovation%20Group-Protocols%20Guide.pdf

people is in keeping with Indigenous protocol across the nation and around the world.[4]

The significance of Acknowledging Traditional Territory

Cultural Differences

A connection to the land is inextricably linked to Indigenous identity. Historically, the cultural protocol of acknowledging traditional territory symbolizes the importance of place and identity for Indigenous peoples. Within many Indigenous communities, protocol requires that individuals situate themselves, and their relationships to the people and the land. For many Indigenous peoples in Canada, and increasingly in broader Canadian society, traditional territory acknowledgements are an important cultural protocol practiced at meetings and events to acknowledge and honor Indigenous peoples' connections to their ancestral lands (McGill University, 2017)

What is its purpose?

The purpose of acknowledging traditional lands and territory is to recognize that for settlers, and those who are not from a First Nation or Indigenous group, are guests on their land.

Acknowledgements have become increasingly common in non-Indigenous spaces and in support of the Truth and Reconciliation (TRC) 94 Calls to Action. Many organizations are thinking about what is needed in response to the TRC. It is about acknowledging what happened in the past and what changes can be made going forward. [5]

A lot of people are unaware of Canada's actual history and this gets people talking about it.

Acknowledging the traditional territory ensures:

- The Can-SOLVE CKD Network is respectful to, and honors, Indigenous histories, cultures, and identities;
- Recognition is given to the land's history to strengthen and cultivate relationships with the local Indigenous communities;
- A welcoming space for Indigenous Elders, Leaders, patient partners, staff, and other Indigenous participants.
- An activation of Indigenous culture, and;

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[4] Adapted from: University of Lethbridge, Blackfoot and First Nations, Metis and Inuit Protocol Handbook, 2013
Retrieved from: http://www.uleth.ca/policy/blackfoot-and-first-nations-metis-and-inuit-protocol-handbook
http://www.uleth.ca/governance/sites/governance/files/Protocol%20Document%20%28Blackfoot%20and%20FNMI%29%20GFC%20Approved%20Oct%207%202013_0.pdf

[5] Adapted from: CBC/Radio-Canada, 2017
Retrieved from: http://www.cbc.ca/news/canada/toronto/territorial-acknowledgements-indigenous-1.4175136

- An essential step toward reconciliation.

Guidelines – Ceremonies and Events

Acknowledging the territorial land at ceremonies and events.

The only people who would provide a 'Welcome' are the Indigenous people of the territory, anyone else, including other Indigenous people, would simply acknowledge the territory.[6]

The host or Emcee is the only person who needs to acknowledge the traditional territory. For larger events, it is respectful to have a member of the local Indigenous Nation, preferably an Elder, provide a welcome.

How to acknowledge the host Indigenous territory

1. The preferred way of honoring and showing respect to the Indigenous territory or land is either to acknowledge the territory at the beginning of the event or, when appropriate, to invite a local Elder or Indigenous Leader to extend a welcome.
2. For official events, the Can-SOLVE CKD Indigenous Liaison Manager is responsible for contacting the appropriate Nation for a representative.

How to request an Indigenous Elder or Leader to attend or speak at your event

In First Nations, Métis and Inuit cultures, Elders and traditional teachers play a prominent, vital and respected role. Elders and traditional teachers are held in high regard as they are the knowledge keepers. They are leaders, teachers, role models, and mentors in their respective communities who sometimes provide the same functions as advisors, professors and doctors.[7]

Scope

This protocol will apply to all investigators, management, staff and contractors who engage the experiences and knowledge of Traditional Indigenous Elders, in carrying out their duties as part of the Patient Oriented Research activities.[8]

These guidelines are for members of the Can-SOLVE CKD Network, who will be working with Elders. Members of the Network are encouraged to use the following guidelines to request and secure the services of an Elder.

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[6] Adapted from: GUIDELINES - ACKNOWLEDGING THE MUSQUEAM FIRST NATION AT CEREMONIES AND EVENTS, UBC Ceremonies Office in conjunction with the Musqueam Protocol Office and the First Nations House of Learning, 2016
Retrieved from: http://ceremonies.sites.olt.ubc.ca/files/2010/10/Guidelines-Musqueam-Jan-2016.pdf

[7] Adapted from: Guidelines for Working with First Nations, Inuit and Métis Elders, Carlton University, 2017
Retrieved from: https://carleton.ca/indigenous/resources/guidelines-for-working-with-elders/

[8] Adapted from the work of Traditional Peoples Advisory Committee (TRAC) at the University of Manitoba
Retrieved from: http://umanitoba.ca/student/indigenous/tpac/1440.html

Guidelines

Decide on the intended purpose of the Elder's role. The Can-SOLVE CKD Indigenous Liaison Manager can help guide the process of approaching an Elder if needed. If this is your first time seeking service of an Elder, the Indigenous Liaison Manager can assist in making initial contact with the Elder.

Extending Invitations (how to make a request)

A request should be sent well in advance when extending an invitation to an Elder. Here are some guidelines on how to extend an invitation to an Elder in person.

Offer tobacco and/or gift

For First Nations or Métis Elders one must offer tobacco. Tobacco is one of the four sacred medicines, and it is offered when making a request. The offering can be in the form of a tobacco pouch or tobacco tie (loose tobacco wrapped in small cloth). The tobacco pouch or tie should be prepared by the person making the request. As the pouch or tie is being made it is good to think about what you are asking for, and put good thoughts and prayers into the offering. When making a request, offer the tobacco by holding it in your left hand (in front of you), state your request (be specific), and if the Elder accepts your request place the tobacco in their left hand. Inuit Elders do not expect tobacco offerings, because traditionally it is not part of their custom. a small gift may be offered in the same token as one would make a request to a First Nations or Metis Elder. Place the gift in front of you and state your request, the Elder indicates acceptance of your request by taking the gift in their hands.

The exchange of tobacco/gift is like a contract between two parties where the Elder is agreeing to do what is asked, and the one offering is making a commitment to respect the process. Ask the Elder if there is anything they need for the event (Carlton University, 2017).

If the Elder cannot fulfill your request, contact the Indigenous Liaison Manager to be recommended to another Elder.

Invitation by telephone

Preferably, requests are made to Elders in person. However, many Elders also accept requests by telephone or by email. If you are making

a request to an Elder by telephone, let the Elder know that you have tobacco or a gift to offer when you see them, then make your request.

Follow-up

If the Elder agrees to accept the request, you must follow-up with a telephone call a few days before the event to ensure they are still available for the occasion. Be prepared for the possibility they may change their mind, if an unforeseen circumstance arises making it impossible for them to be in attendance. In this case, you can contact the Indigenous Liaison Manager to determine whether another Elder may be available.

Respectful Care

Ensure to coordinate a host/escort for the Elder. The host/escort is responsible for:

- Ensuring appropriate transportation to and from the event;
- Greeting and meeting the Elder upon arrival;
- Taking care of the Elder until their departure (i.e. offer and assist with getting drinks, food, etc.).

Elders Helper

In some cases, Elders may be accompanied by an "Elders Helper". This person will have an established relationship with the Elder and will be available to assist the Elder with whatever they may need. Nevertheless, a host/escort should be arranged since the Elder and Helper likely will not know their way around the location of the meeting/event.

Photographs, audio, and/or video recordings are often not acceptable when an Elder is conducting a spiritual ceremony. Explicit consent must be received from the Elder before any recordings are taken. Often Elders will carry sacred items, such as pipes, qulliq[9], eagle feathers, medicine pouches., do not touch these items unless they give you permission.
In respect of the Elder, always ask permission and seek clarification if there is something you do not understand, (Carlton University, 2017).

[9] Retrieved from: Inuit Cultural Resources Online, Canadian Heritage, http://icor.ottawainuitchildrens.com/node/28

Role of Audience

During an Elder-led ceremony, everyone stands and hats are removed. Do not sit until the Elder has finished speaking. Do not talk, text or take telephone calls during the ceremony. Be in the moment and ask the group or audience to also be in the moment. Be gentle and understanding of those with challenges.

Elder Acknowledgement

If Elders are present at a presentation, meeting or event, it is a sign of respect to acknowledge their presence. Although you may be on a first name basis with an Elder you should use caution as people may not know that you are on a first name basis and may be offended with your use of their name. At a formal event or meeting use both the first and last name. name is stated ahead of title. **Please confirm how the Elder would like to be introduced.** [10]

Honoraria

Honoraria should not be viewed as a payment for service, but rather as a gift exchange for knowledge, ceremonies, or blessings.[11]

Ensure that the honorarium is available at the time of the event. Additional costs incurred by the Elder, such as parking, mileage, meals and accommodations, must be reimbursed.

Elders are never "paid" for their "work" as it would be culturally inappropriate to appear as though they are "selling" Indigenous knowledge. Traditional Indigenous and cultural knowledge is not, and cannot be owned by an individual or institution. Elders must never be asked to sign a "receipt" as acknowledgement of their gift even if it is financial. Nor should they be asked for their Social Insurance Number (SIN), or their birthdates (University of Manitoba).

If you have questions about the honorarium, contact the Indigenous Liaison Manager.

[10] Adapted from: Elder Protocols and Guidelines, SD 58, Aboriginal Advisory Council, 2017
Retrieved from:
https://nortonsafe.search.ask.com/web?q=Elders%20Protocols%20and%20Guidelines%20for%20School%20District%2058&o=APN11910&chn=1004490&guid=0877F5DA-0051-4CA1-9A4E-6443588CBA06&doi=2017-01-03&ver=22.8.1.14&prt=NSBU&geo=US&locale=en_US&ctype=&tpr=121

[11] Adapted from: Cultural Protocol Guidelines: Recommended Practices for First Nations, Metis and Inuit Cultural Engagement, University of Calgary, 2011
Retrieved from

When making your request, please provide the following information to the Can-SOLVE CKD Indigenous Liaison Manager:

- Event name;
- Purpose of event, background information, attendees and outline of program;
- Date & Time (with suggested time of arrival);
- Location, Directions, Parking;
- Dress Code: (whether business/casual/regalia)

Sample Requests and Compensation

Request	Daily Compensation	Travel	Travel & Accommodations
Welcome to Territory	$150 – $200	Taxi/mileage/parking	Hotel/Accommodation/meals
Welcome to Territory/Opening & Closing Prayer	$300 - $500	Taxi/mileage/parking	Hotel/Accommodation/meals
Welcome to Territory/Opening & Closing Prayer/ Ceremony	$600 - $800	Taxi/mileage/parking	Hotel/Accommodation/meals
Welcome to Territory/Opening & Closing Prayer/ Ceremony/ Elder remains throughout event	$800 - $1200	Taxi/mileage/parking	Hotel/Accommodation/meals
Ceremony could include: Smudging, facilitating a Sharing/Talking/ Healing Circle			

On-site contact at event:

Once contact is made, a formal invitation or letter of invitation may be requested to be sent to a representative of the local Indigenous Nation. The Indigenous Liaison Manager will confirm if a representative is available to attend your event. If a representative is confirmed, please ensure that you have the correct name, pronunciation, and title of the representative before introductions are made, or event materials are printed.

Order of Speakers

Following the Emcees' opening remarks; the Indigenous representative is typically the first speaker.

Introduction of representative at event

The following are a couple of suggested phrases that can be used by an Emcee or host prior to introducing the Indigenous elder or Leader to acknowledge the relationship with the local Indigenous Nation and the Can-SOLVE CKD presence on the said traditional territory.

"I would like to acknowledge the traditional, ancestral, unceded territory of the **** First Nation, Métis, and/or Inuit peoples upon which we gather today and I will now ask **** to bring a welcome on behalf of the ****."

"I would like to acknowledge that we are on the traditional, ancestral, unceded territory of the **** First Nations, Métis and/or Inuit peoples, and I will now ask **** to bring a welcome on behalf of ****."

If there is no representative attending your event but you still wish to acknowledge the local Indigenous nations, you may use but are not restricted to one of the following:

"I would like to acknowledge the traditional, ancestral, unceded territory of the First Nation, Métis and/or Inuit lands upon which we are gathered today.

"I would like to acknowledge that we are on the traditional, ancestral, unceded territory of the **** First Nation, Métis and/or Inuit peoples" (Musqueam Protocol Office).

Elders

Elders may be invited to participate in various Can-SOLVE CKD Network events, especially if the content involves Indigenous Peoples. In this case it is expected that a relationship already exists between Elders and members of the Network.

If they do not, we have provided some guidance below with a caution: If those relationships with the Indigenous community do not exist, care must be taken to avoid tokenizing Indigenous knowledges and reducing Indigenous content to performance. Critically reflect on why you are inviting an Elder.

To establish and maintain positive relationships with the community, it is imperative that the Can-SOLVE CKD Network representatives honor, respect, and learn the cultural protocols of communities from the point of contact, throughout the engagement, and beyond.

The definition of "Elder" is not a simple task; "Elder" is a complex concept that is integrally tied to important issues relation to leadership, knowledge, intergenerational societal teaching, change, and recent history. It is emotionally charged because "Elder" represents many things to people – families, the past, strength, experiences, survival, language, communities, and Indigenous societies. "Elder" is also a politically volatile concept that has come to include both implicit and explicit ideas about authority, power, authenticity, and political correctness, and is a highly contested construct that bristles with

questions about who is an Elder, what the qualifications of an Elder are, the different kinds of Elders and Elder roles.

An Indigenous Elder is a male or female adult that has earned a reputation for being traditional wisdom and spiritual knowledge keepers. Elders seldom announce their status or position; however, they are well known in their communities. Indigenous Elder figures are recognized prominently in their urban and rural communities. Many Indigenous peoples value their Elders and address them with the utmost respect. Although age is not a factor in distinction as an "Elder" they can be of any age but, typically seen as the older members of their communities.[12]

Each Indigenous society can have its own definition of what it means to be an Elder.

In conducting research for this document, several protocol documents were used, ensuring that the diversity of Indigenous Nations across Canada were represented.

To further assist with identifying traditional territories please see the Canadian Association of University Teachers, CAUT, Guide to Acknowledging Traditional Territory, website at: https://www.caut.ca/docs/default-source/professional-advice/list---territorial-acknowledgement-by-province.pdf?sfvrsn=12

Native-Land.ca is an online resource to help North Americans learn more about their local history.
https://native-land.ca/

[12] Adapted from: Regina Catholic Schools, First Nations & Metis Elders HANDBOOK
Retrieved from: www.rcsd.ca