



## Palliative Care Coalition of Canada Terms of Reference

### ***“Advocating for better palliative care for all residents of Canada”***

#### **Background:**

The Palliative Care Coalition of Canada (PCCC) is a group of national organizations dedicated to improving palliative care for those living in Canada. The Coalition believes that all those living in Canada who are aging or living with a serious illness have the right to a palliative approach to care. To achieve this, there must be a well-funded, sustainable national strategy for palliative care. It is the mission of the PCCC to work together in partnership to achieve this goal.

#### **Purpose:**

The PCCC is an informed network of national organizations who are united and aligned around key issues in palliative care and work collaboratively to identify and to suggest specific issues to the federal government/the Council of the Federation that impact millions of people living in Canada, and to influence policy and funding decisions in alignment with the *Framework on Palliative Care in Canada*. The core priorities and values of the PCCC are set out in a strategic plan known as the [Blueprint for Action](#), and the PCCC adheres to the descriptions of a palliative approach to care contained therein.

The PCCC is also a valued forum for generating and exchanging knowledge on numerous topics pertaining to palliative care (e.g., caregiver support, grief and bereavement, training and professional development) and a catalyst for bi-lateral or multi-lateral collaboration among members.

Its activities include:

- 1) **Advocacy** – The PCCC provides a forum to develop and amplify a collective voice on issues of importance in palliative care to all or a subset of members at the Federal/Council of the Federation level(s), including raising awareness of the importance and urgency of palliative care among the public at large or with specific external parties, responding to issues/opportunities in a timely manner, and supporting policy development/refinement. The PCCC can serve to amplify the voices of health care providers; (clinician) researchers; and patients, caregivers, and family members.
- 2) **Collaboration** – The PCCC provides a forum for members to identify and initiate opportunities for collaboration based on areas of shared interest. This collaboration could be bi-lateral (i.e., organization to organization) or multi-lateral (i.e., among several interested organizations).



- 3) **Knowledge Creation** – The PCCC will generate, collect, organize, analyze, and share the collective knowledge and wisdom of its members to improve palliative care in Canada. This may include analyses, research and evaluation projects, etc. from individual members, a subset of members, or all PCCC members alongside knowledge synthesis to inform advocacy initiatives/the *Blueprint for Action* priorities.
- 4) **Knowledge Exchange** – The PCCC provides a national forum for members to share information, spark discussion, and receive feedback and advice related to current and future activities in palliative care in which their organizations are interested and/or involved.

### **Governance:**

The work of the Coalition is structured and championed with the support of an elected Executive Committee, and project team leads:

- Elected positions on the Executive Committee will include a Chair or two Co-Chairs, Membership Director, and Secretary.
- Elected positions will be voted on with each member organization having one vote.
  - When multiple individuals are interested in serving for one of the Executive Committee roles, an election will be convened.
  - Calls for nominations will occur in the fall, with the election occurring at the Annual General Meeting.
- One or two leads from each project team will be identified at the Annual General Meeting (AGM).

### Executive Committee Terms

- Elected members of the Executive Committee will normally serve two-year terms, renewable once.
- Term lengths for project team leadership roles will be the duration of the project.

### Executive Committee Responsibilities

The Executive Committee responsibilities are to:

- Coordinate PCCC meetings, soliciting suggestions for agenda items and vetting documentation (including annual financial statement).
- Review and approve agendas and meeting materials.
- Prepare and review meeting minutes for the Annual General Meeting and coalition-wide meetings for approval.
- Draft and distribute any necessary communications required between meetings including drafts of the Coalition's Annual Report.
- Complete an annual review of membership list, considering the larger palliative care community in order to identify possible new member organizations.
- Maintain membership list and encourage member participation at meetings/in projects.
- Convey information and decisions that affect the Coalition.
- Provide oversight to project teams.



- Facilitate synergy between and ensuring project teams have what they need to succeed.
- Oversee the Coalition's membership including:
  - Review any requests for membership.
  - Identify gaps in representation (including soliciting and reflecting on member feedback).
  - Orient new members.
  - Engage in dialogue with non-participatory members.
- Solicit, receive and address member feedback to help enhance the Coalition's functioning.
- Facilitate the PCCC Hon. Sharon Carstairs, P.C. Award of Excellence.
- Facilitate the Coalition's business between full Coalition meetings.
- Complete an annual review of the PCCC Terms of Reference prior to the AGM
  - Significant changes (i.e., those beyond updates to the Membership List) will be reviewed and approved at the following Annual General Meeting of the Coalition.

### Project Teams

A large portion of the Coalition's work occurs within project teams, each focused on a distinct priority area in line with the *Blueprint for Action* and determined by discussion and voting (as necessary) among Coalition members. Members are encouraged to identify and actively contribute to at least one project annually that best aligns with their personal interests and expertise and/or organizational priorities.

Project proposals will be solicited in advance of coalition-wide meetings, reviewed by the Executive, and considered at full coalition-wide meetings. The Executive can also initiate the creation of a Project Team in between full coalition-wide meetings in response to emerging issues.

Each project team is led/co-led by up to two Coalition members, to be determined at the time the project is selected.

Project team meeting frequency is determined within each team, and each group commits to meeting as required in order to carry out its work and to facilitate updates to the Executive Committee/the full Coalition. Each team is responsible for establishing their own project plan which will be reviewed by the Executive Committee for consistency and feasibility. Project teams can solicit financial support from their organizations, however requests to external organizations (on behalf of PCCC) must be approved by the Executive Committee.

Project Team Lead/Co-Leads responsibilities are to:

- Participate in the Executive Committee.
- Facilitate the development of project plans.
- Develop project team meeting agendas.
- Chair project team meetings.
- Maintain membership list of project team.
- Correspond with project team members.



- Schedule project team meetings.
- Disseminate project team meeting materials.
- Report back to the Executive Committee and/or the full Coalition.

Project team member responsibilities are to:

- Participate in project team meetings.
- Share administrative responsibilities of the team, such as recording meeting minutes or action items.
- Provide timely feedback within the timeframe determined by the Project Team Leads/Co-Leads, or within the timeframe determined by the Executive Committee .
- Exchange knowledge and resources.
- Actively contribute to the activities in the project plan.

Each project team will exist until its goal(s) have been achieved or the Coalition agrees by consensus to reprioritize its focus at an Annual General Meeting.

### **PCCC Meeting Frequency and Structure:**

The Coalition will convene virtually at least twice a year. One meeting will be designated as the Annual General Meeting (AGM).

All members are welcome to propose agenda items for discussion. At a minimum, each meeting will consist of updates from the Executive Committee as well as an opportunity to discuss and exchange feedback on activities taking place within each project team or any other matter relevant to the Coalition and its mandate.

Coalition meetings will be open to member organizations only, with an exception for guest speakers who will only remain for the duration of their presentation and related question and answer/discussion period, if applicable. This is to ensure free and open discussion among the Coalition. It is the responsibility of the Chair/Co-Chairs to ensure compliance with this requirement.

Expert advisors may be invited to participate in the work of the PCCC where it is agreed upon by the Executive Committee.

### **Language:**

While the bulk of the Coalition's discussions and correspondence occur in English, reasonable efforts will be made to remove barriers for Francophone members to actively engage in the Coalition's work.

### **Equity, Diversity, Inclusion and Accessibility:**



The Coalition and its members are committed to creating a respectful, diverse, inclusive, and healthy environment as they work to advance the Coalition's mandate and objectives.

The Coalition aims to promote an equitable, inclusive, and accessible environment for all. Given that the Coalition is volunteer-based and does not have a dedicated budget, the Coalition's ability to do so is limited. Where financially and otherwise possible, the Coalition will make reasonable efforts to accommodate requests related to equity, inclusivity, and accessibility.

### **Decision-making:**

PCCC is a Coalition that strives to make decisions by consensus and where necessary, through majority decision-making.

While members decide the PCCC's direction and priorities, a member organization may decide to opt out of specific projects or activities if these do not match their organization's strategic priorities. For written submissions and communications, the option to opt out of specific projects or activities will be provided when it is proposed that individual organization names or logos be included in the written submission or communication.

Feedback, review of documentation, and/or sign-on/off is to be provided within the timeframe requested by the project team (Co-)Chair(s) and/or Executive Committee members, as applicable.

### **Feedback:**

To enhance the Coalition's functioning, all members are encouraged to share open, constructive feedback via an Executive Committee member and/or during the annual member survey/the Coalition meetings.



## Appendix A: Membership

Member participation in the Coalition is guided by the following core values:

- Members represent the views of their organizations and are encouraged to be agents of positive change, building on known strengths, assets, and resources. Members in turn are responsible for sharing information stemming from the Coalition within their organizations/networks/communities, according to its own policies.
- Exchange of and respect for all forms of knowledge (e.g., Indigenous, quantitative, practical, qualitative, lived experience) related to palliative care is encouraged to increase the capacity to generate, synthesize, and use knowledge, and to advance action through participatory community-driven approaches.
- Diverse backgrounds, experiences (e.g., cultural and lived experience), and opinions of members are valued equally and enhance discussion and potential collaboration.
- Members generate an environment in which there is a willingness to provide (and receive) respectful and timely feedback from all members, when appropriate.

Potential new members will be reviewed by the Executive Committee, and brought to the membership for a vote at the next AGM.

Each member organization is expected to identify one person to serve as their point of contact. This person should be able to actively participate in the AGM and semi-annual meeting to reflect their organization's views, however, the organization may send an alternate representative as required (in which case it is the responsibility of the initial representative to provide their alternate with the context and information they may need to actively participate). Recognizing that representation from member organizations may change over time, member organizations agree to notify the Executive Committee in a timely manner of any changes to their primary representative and/or alternate.

Member organizations will be asked to reaffirm their desire to sit on the PCCC every five years. Should an organization need to withdraw at any point, it is requested that they notify the Executive Committee.

In addition to participating in the Coalition meetings, members are also expected to actively contribute to at least one project that aligns with their personal interests and expertise and/or organizational priorities.

Member organizations may request more than one representative attend PCCC meetings and engage in the work of the project teams. In such cases, each organization will only have one vote when required to make decisions impacting the Coalition.

### Membership Criteria

To be considered for membership in the Coalition, an organization must:



- Be currently involved in activities related to palliative care at a national level, or conduct work that can influence the national agenda.
- Acknowledge the Coalition's Priorities and Core Values as outlined in these Terms of Reference.
- Commit to actively participating in the semi-annual Coalition meetings and actively contributing to the work of at least one project to support the mandate of the Coalition.
- Agree to disseminate information shared through the Coalition to their organization/networks, when appropriate.



## Appendix B: Membership List

- ALS Society of Canada (ALS Canada)
- Alzheimer Society of Canada (Alzheimer Society)
- Canadian AIDS Society (CAS)
- Canadian Association for Spiritual Care (CASC)
- Canadian Association of Occupational Therapists (CAOT)
- Canadian Association of Psychosocial Oncology (CAPO)
- Canadian Association of Social Workers (CASW)
- Canadian Breast Cancer Network (CBCN)
- Canadian Cancer Society (CCS)
- Canadian Home Care Association (CHCA)
- Canadian Hospice Palliative Care Association (CHPCA)
- Canadian Lung Association (CLA)
- Canadian Network of Palliative Care for Children (CNPCC)
- Canadian Nurses Association (CNA)
- Canadian Palliative Care Nursing Association (CPCNA)
- Canadian Partnership Against Cancer (CPAC)
- Canadian Physiotherapy Association (CPA)
- Canadian Society of Palliative Medicine (CSPM)
- Canadian Society of Respiratory Therapists (CSRT)
- Canadian Virtual Hospice (CVH)
- Catholic Health Alliance of Canada (CHAC)
- Christian Medical and Dental Association (CMDA)
- College of Family Physicians of Canada (CFPC)
- Covenant Health Palliative Institute
- HealthCareCAN
- Heart and Stroke Foundation of Canada
- Huntington Society of Canada (HSC)
- Kidney Foundation of Canada
- Mental Health Commission of Canada (MHCC)
- National Initiative for the Care of the Elderly (NICE)
- Ovarian Cancer Canada (OCC)
- Pallium Canada
- Pan-Canadian Palliative Care Research Collaborative (PCPCRC)
- Realize
- Royal College of Physicians and Surgeons of Canada (RCPSC)
- SE Health
- Speech-Language & Audiology Canada (SAC)