



**Palliative Care
Coalition of Canada
Coalition canadienne
pour les soins palliatifs**

Annual Report 2024





Contents

- Background and History of the Palliative Care Coalition of Canada.....3
- Mission and Mandate of the Palliative Care Coalition of Canada.....4
- Palliative Care Coalition of Canada (PCCC)4
- Member Organizations5
- 2024 Activities and Committee Reports.....6
 - 1. Executive Committee Report6
 - 2. Advocacy Committee Report7
 - 3. Education Committee Report9
 - 4. Research and Knowledge Translation (KT) Committee Report.....10

Background and History of the Palliative Care Coalition of Canada

In December of 2000, a group of 23 national stakeholders met to set the groundwork for the development of a Canadian strategy for end-of-life care. The result of this meeting was the creation of the Palliative Care Coalition of Canada (the 'Coalition'), and a working document entitled *Blueprint for Action (2000)*.

Within the Coalition, an Executive Committee and three Working Groups were established. The Coalition has been meeting on an annual basis since 2000. The goal of each annual meeting is to create a work plan for the coming year based on the current iteration of the *Blueprint for Action*. The membership of the Coalition remains strong and is currently made up of 31 member organizations.

Since its establishment in 2000, the Coalition has seen some remarkable successes. These successes include:

- a role in the establishment of the Secretariat on Palliative and End-of-Life Care in 2001.
- the production of *Hospice Palliative Home Care in Canada: A Progress Report and Dying for Care – Status Report*.
- participating in the development of the report *Not to be Forgotten: Care of Vulnerable Canadians*.
- production of the *Blueprint for Action: 2010-2020*, and its 2020-2025 update.
- participation in the development of the *Advanced Care Planning Framework* and the *Speak Up* campaign.
- spearheading *The Way Forward: An integrated palliative approach to care in Canada initiative*.
- strong support for Bill C-277 until its Royal Assent in December 2017.
- and assisting MP Charlie Angus with Motion M-456.

The Coalition members have also attended countless parliamentary events, round table discussions, educational conferences, and research symposia – all in the interest of advancing palliative and end-of-life care in Canada.

In 2009/2010, the Coalition produced the document *Blueprint for Action 2010-2020*. Through this report and other endeavours, the Coalition aims to change the standard of end-of-life care in Canada.

The latest version of the [Blueprint for Action \(2020-2025\)](#) is available on the PCCC website (www.palliativecarecoalition.ca), and outlines the following priorities:

- Increasing public awareness around hospice palliative care's benefits, issues and areas needing improvement, including support for caregivers and those experiencing grief and bereavement.
- Ensuring health care providers, volunteers, communities, caregivers, and others have access to education and training to ensure they possess the required competencies to provide optimal care.
- Contributing to research and systematic, standardized data collection on hospice palliative care with special interests including formal and informal caregivers, and grief and bereavement.
- Advocating for universally accessible and culturally safe access to hospice palliative care for underserved populations and those who provide caregiving and experience grief and bereavement.

Mission and Mandate of the Palliative Care Coalition of Canada

The Coalition believes that all Canadians have the right to quality end-of-life care that allows them to die with dignity, free of pain, surrounded by their loved ones, in the setting of their choice. The Coalition also believes that to achieve quality end-of-life care for all Canadians, there must be a well-funded, sustainable national strategy for an integrated palliative approach to care. It is the mission of the Coalition to work together in partnership with other like-minded national organizations and institutions to achieve their goal.

Palliative Care Coalition of Canada (PCCC)

For more information about the PCCC, please visit www.palliativecarecoalition.ca.

Member Organizations

- 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)
- HealthCareCAN
- Heart and Stroke Foundation of Canada (Heart & Stroke)
- Huntington Society of Canada (HSC)
- Kidney Foundation of Canada (Kidney Foundation)
- Mental Health Commission of Canada (MHCC)
- National Initiative for the Care of the Elderly (NICE)
- Ovarian Cancer Canada (OCC)
- Pallium Canada (Pallium)
- Pan-Canadian Palliative Care Research Collaborative (PCPCRC)
- Realize
- Royal College of Physicians and Surgeons of Canada (RCPSC)
- SE Health
- Speech-Language & Audiology Canada (SAC)

2024 Activities and Committee Reports

1. Executive Committee Report

The Coalition has four active subcommittees:

- Executive Committee
- Advocacy Committee
- Research and Knowledge Translation (KT) Committee
- Education Committee

The chairs of the three main sub-committees, as well as the Coalition Secretariat (Pallium Canada) make up the members of the Executive Committee. The Coalition Secretariat chairs the Executive Committee. Members of the 2024 Executive Committee were:

- Jeffrey Moat (Secretariat / Executive Committee Chair)
- Chris Klinger
- Carolyn McCoy
- Daniel Nowoselski
- Leah Salvage
- Christina Vadeboncoeur
- Julie Wilding

The Executive Committee oversees the work of the Coalition and manages the efficient and effective administration of the Coalition, as well as seeks opportunities and develops partnerships that actively promote access to quality palliative care in Canada.

The Executive Committee members met 10 times between January 1 and December 31, 2024. Over the past year, the Executive Committee's activities included:

- Developed the new Letter of Support Policy and the new Sponsorship Package.
- Onboarded three new member organizations and led two new member orientation sessions.
- Conducted outreach to potential members.
- Adjudicated the Hon. Sharon Carstairs P.C. Award of Excellence in Advocacy.
- Prepared and distributed newsletters to all members on May 16 and October 2, 2024, showcasing key initiatives and achievements across the coalition.
- Preparing a pre-read package for the January 31, 2025, Annual General Meeting of the Palliative Care Coalition of Canada, including securing a keynote speaker and special presentation from Health Canada.
- Provided key messaging for social media to all members to recognize and promote National Hospice Palliative Care Week.
- Sought input and consensus from the Coalition on the Response to Health Canada's Framework on Palliative Care in Canada.

2. Advocacy Committee Report

| Daniel Nowoselski (Co-Chair) | Leah Salvage (Past Co-Chair) |
|-------------------------------------|-------------------------------------|
| Sarah Butson | Sarah Calderwood |
| Bianca Carlone | Laurel Gillespie |
| Monique Lizon | Kim McMillan |
| Carrie Thibodeau | Kimberly Thibodeau |
| Chris Weiss | Laurence Worthen |
| Rochelle Blackwood (former member) | Srishti Datt (former member) |

Objective:

The PCCC provides a forum to develop and amplify a collective voice on issues of importance in hospice palliative care to all or a subset of members at the Federal level, including raising awareness of the importance and urgency of palliative care among the public at large or with specific stakeholders, responding to issues/opportunities in a timely manner, and supporting policy development/refinement. This group can serve to amplify the voices of health care providers, (clinician) researchers, and millions of patients, caregivers, and family members.

2024 Activities:

1. Breakfast on the Hill on April 30:
 - o Attended by several MPs and Senators from multiple parties/caucuses, as well as a broad representation of PCCC members.
 - o Panel discussion focused on helping politicians understand palliative care and why our system needs to address it now.
 - o Event came in well under budget.
 - o Hoping to host a similar event with new MPs post-election to continue this new tradition.
2. Submission to CIHI on Pan-Canadian Health Data Content Framework:
 - o Collaborated with the Research Committee on a submission to better integrate palliative care into framework.
 - o Continue to monitor developments on this issue.
3. PCCC Pre-Budget Submission:
 - o Worked to develop a new Pre-Budget submission for the Finance Committee's pre-budget consultation process.
 - Asked for extending and doubling the funding from Budget 2021 for palliative care.

- Improved our narrative about why palliative care should be a priority for the government.
- Completed outreach to share our asks.

4. Pre-Election Preparation:

- Developed a “menu” of policy options to pitch to parties on what they could do to prioritize palliative care in the next election.
- Developing communication tools to engage the public on this issue and shape the discourse.

Looking Forward:

- Identify what, if any, of our priorities will have time to be addressed by this government before the next election.
- Encourage all parties to prioritize palliative care in their platforms.
- Reach out to the likely high number of new MPs to educate them on palliative care.
- Connect with decision makers in the new government to understand how their priorities will evolve in relation to palliative care.

3. Education Committee Report

| Julie Wilding (Co-Chair) | Carolyn McCoy (Co-Chair) |
|---------------------------------|---------------------------------|
| Cheryl Cameron | Deborah Francis |
| Diana Rasmussen | Bonnie Cooke |
| Hazel Markwell | Holly Finn |
| Jennifer Cameron-Turley | Judy Donovan Whitty |
| Karine Diedrich | Karla Thorpe |
| Kristen DeCaria | Lisa Carroll |
| Salina Fukumoto | Camryn Berry |
| Carly McPhee | Kathy Alarcon |
| Cailey Crawford | Adriana Rengifo |

Objective:

Facilitate awareness of educational/training resources of PCCC members and other organizations; inform and support activities of advocacy and research committees.

2024 Activities:

- Disseminated 2-page resource document on developing discipline-focused competencies (to assist with the development of competencies by different professions/disciplines).
- Developed an updated list of palliative care resources for dissemination to PCCC members.
- Committee members participated in beta-testing of the Learning Journey app.
- Recorded video re: Learning Journey app (edits ongoing).
- Shared information on the national consultation session on National Grief Strategy.
- Members representing OT, PT and SLP collaborated to develop an ECHO session.

Looking Forward:

- Disseminate Learning Journey app video to member organizations.

4. Research and Knowledge Translation (KT) Committee Report

| Chris Klinger (Co-Chair) | Chris Vadeboncoeur (Past Co-Chair) |
|------------------------------|------------------------------------|
| Diana Rasmussen (ex officio) | Nadine Henningsen |
| Jeff Moat | Kate Murzin |

Objective:

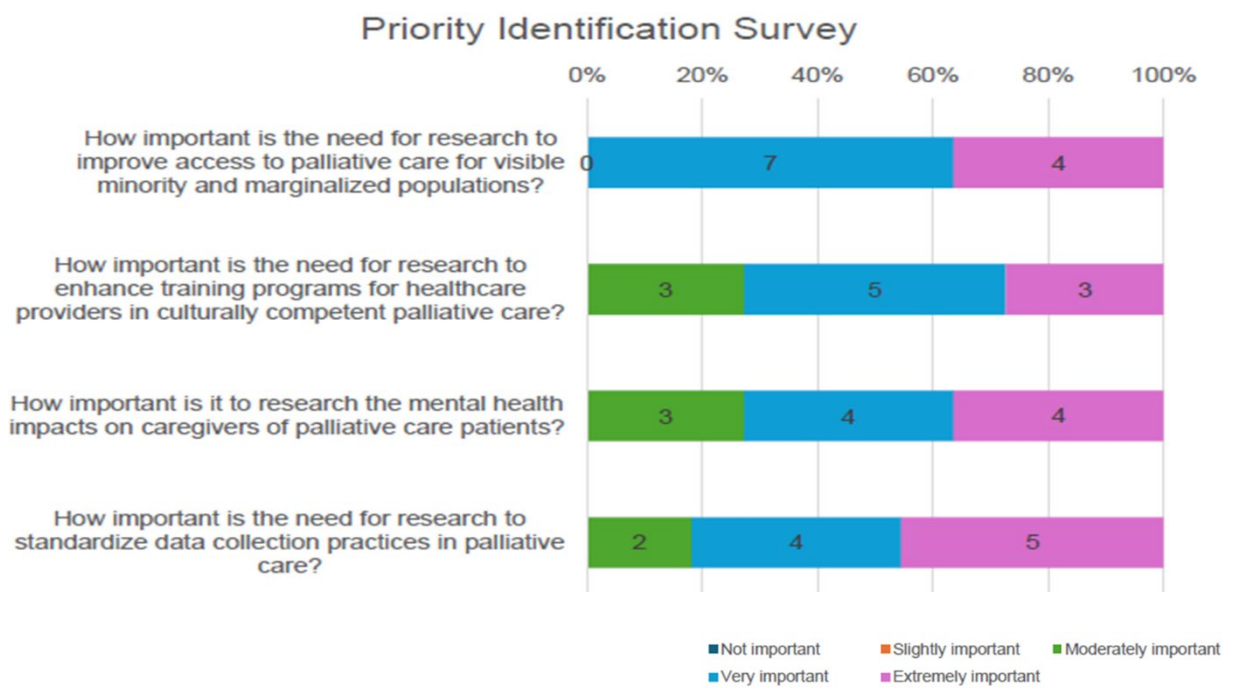
To facilitate research and knowledge translation (KT) toward the PCCC and its member organizations and to engage in broader stakeholder consultations in the area.

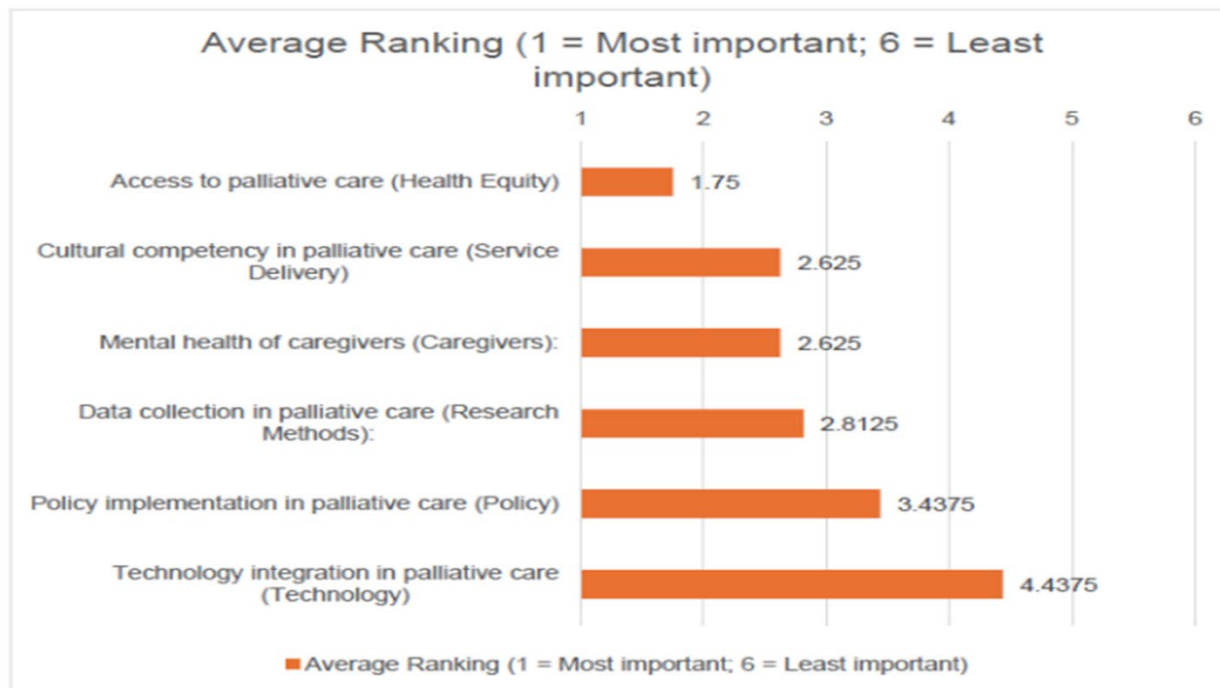
2024 Activities:

There currently are four PCCC member organizations represented. Four Research and Knowledge Translation (KT) Committee meetings have been held since January 2024, facilitating work on all three Work Plan (WP) items and co-ordinating the Committee's contribution to the *Blueprint for Action* update.

Work Plan Item 1: Creating New Knowledge

- The Committee developed an outline toward Palliative Care (PC) Research Priorities based on its scoping review on gaps in hospice and palliative care research (<https://onlinelibrary.wiley.com/doi/pdf/10.1155/2020/3921245>) and conducted a validation and prioritization exercise at the 2024 PCCC 6-Month Meeting:





The results are being integrated into the Coalition's Blueprint for Action update indicating four priority areas:

1. Health Equity,
2. Culturally Competent Care Delivery,
3. Mental Health of Caregivers, and
4. Research Methodology and Data Infrastructure.

Investing in these strategic research priorities will generate the evidence to inform policies, practices, and innovations in palliative care.

Work Plan Item 2: Knowledge Translation and Mobilization

- The Committee contributed to PCCC submissions to the CIHI *Pan-Canadian Health Data Content Framework* consultation and the federal Pre-Budget Consultations, highlighting gaps in hospice and palliative care research, citing the Committee's own scoping review findings. The scoping review itself has meanwhile received 16 citations, including in Health Canada's *Report on the State of Palliative Care in Canada* (<https://www.canada.ca/en/health-canada/services/publications/health-system-services/framework-palliative-care-five-years-later.html>).
- Committee members attended the PCCC's 'Breakfast on the Hill,' and the Spring and Fall meetings of the Pan-Canadian Palliative Care Research Collaborative (PCPCRC) to raise awareness around funding issues related to palliative care/enable further networking.

- A number of PCCC posters are available for display at member organization's conference(s)/summit(s) – please contact the PCCC Secretariat for further details (pccc@pallium.ca).

Work Plan Item 3: Advocacy to Increase Palliative Care Research Funding

- The Committee worked with Health Canada (HC) and the Pan-Canadian Palliative Care Research Collaborative (PCPCRC) on a meeting with the Institute Heads of the Canadian Institutes of Health Research (CIHR)/the joint CIHR - Social Sciences and Humanities Research Council (SSHRC) Committee. The appointment of Dr. Paul Hébert as CIHR President (effective January 2, 2025) hopefully provides a perspective, especially given his prior work on developing the vision for the *Strategy for Patient-Oriented Research (SPOR)*.

A special thank you to Dr. Chris Vadeboncoeur, who has left the PCCC after many years of service as the representative of the Canadian Network of Palliative Care for Children (CNPCC). Her work has been instrumental in getting many of the Committee's scoping reviews to publication and ensuring a voice for pediatric palliative care in the work of the Coalition. Most recently, she was Committee Co-Chair (from July 2023, following Dr. Noush Mirhosseini of the College of Family Physicians of Canada (CFPC)).

Looking Forward:

The Committee is set to work on further alignment with the other PCCC Committees and on knowledge dissemination to member organizations via the News Blast and other means. A focus will be on the Palliative Care Research Priorities and their implementation as part of the Blueprint for Action update.

The Research and Knowledge Translation (KT) Committee is actively inviting participation and is hoping to grow again in size next year.