



Summary

In its report on the progress made on the goals and priorities outlined in the Framework on Palliative Care in Canada, Health Canada provides an update on the progress achieved in the last 5 years through the collective efforts in governments, civil society, and in health care. Positive strides are noted in many areas including the availability of palliative care education and training for health care professionals, awareness and uptake of advance care planning, and improvements in leave benefits for caregivers. While there has been progress across all four goals the Framework describes, the report underscores the need for continued collective action to ensure that the Framework's long-term goals can be achieved in the next 5 years.

Among the dozens of sector-wide actions needed to achieve the Framework goals identified in the report, Health Canada committed to:

- Continuing its multi-year palliative care awareness campaign.
- Continuing to support health care provider and caregiver education, adding new disciplines to the Interdisciplinary Competency Framework, and including it in more education programs and employment standards, and supporting education to strengthen provider communication skills.
- Continue collaborating with governments and partners, especially on growing the Compassionate Communities movement and on improved community and home-based palliative care.
- Expanding research networks to build research capacity, moving toward data standardization across jurisdictions including common indicators and better data on palliative care provision and outcomes.
- Developing policy frameworks to reflect the distinct end-of-life care needs of Indigenous Peoples, creating resources that address the specific needs of underserved populations, and scaling models of care for persons living with homelessness.

The report also identifies a number of areas where Health Canada will “work with governments and stakeholders to accomplish.” From the perspective of PCCC, we are prepared to support many of these areas, and should use these priorities to inform our work going forward and advocate for Health Canada to follow through on the remaining medium- and long-term goals they need to accomplish.



Key messages

- The Palliative Care Coalition of Canada welcomes findings about the progress made so far on the Framework and Action Plan, and the gaps that remain to be addressed.
- We support the collective actions that Health Canada has identified in their report in the next steps, and we are fully prepared to do our part to ensure everyone in Canada has equitable access to palliative care.
- We look forward to working with Health Canada to identify the specific actions it will be taking moving forward to increase equitable access to palliative care across Canada.

Background

The Government of Canada passed a Private Members' Bill introduced by MP Marilyn Gladu (CPC, Sarnia-Lambton) on December 12, 2017 (Parliament of Canada, 2017) providing for the Minister of Health to create a framework on palliative care. The Act states that the Minister must:

- develop a framework that supports improved access to palliative care across Canada within a year, which it did on December 4, 2018.
- consult provinces, territories, and palliative care providers to make the framework.
- report on the state of palliative care in Canada after 5 years, by December 4, 2023.

According to the Government of Canada, the Framework was developed through broad consultation as a consensus, strategic policy document. It offers a guideline for all palliative care stakeholders to work toward the shared vision of "all Canadians with serious illness living well until the end of life." After this report after 5 years, there are no additional requirements to report back to Parliament on the Government of Canada's progress to implement the Framework on Palliative Care in Canada. PCCC in its many iterations advocated for and participated in the development of the Framework and Action Plan on palliative care. Ensuring its implementation is part of the core of the mission of PCCC.

Goals of the Framework on Palliative Care in Canada

1. Palliative care training and education for health care providers and other caregivers

- a. Short-Term Goal (1–2 years): Training and education needs are identified for health care providers as well as other caregivers.
- b. Medium-Term Goal (3–5 years): Palliative care providers have access to training, education, and tools to meet the goals of individuals and their caregivers.
- c. Long-Term Goal (5–10 years): All providers have increased capacity to deliver quality care, and caregivers have appropriate supports to perform their roles.



Actions Health Canada has taken to accomplish this goal:

- Invested just under \$18.5 million in training, resources, and supports for providers and caregivers.
- Provinces and territories reported having some degree of focus on workforce education.
- Half of survey respondents in 2021 said they felt the availability of health care professionals trained in palliative care had improved.
- Health Canada funded the Palliative Care ECHO Project, led by Pallium Canada and partners.
- Health Canada and CPAC developed the Canadian Interdisciplinary Palliative Care Competency Framework (and a First Nations, Inuit, and Métis-specific competency framework).
- The report outlines work being done by the Canadian Home Care Association, Pallium Canada, the Canadian Society of Palliative Care Physicians, the British Columbia Centre for Palliative Care, and in the Yukon to improve education for palliative care.

Actions Health Canada will be taking, according to the report:

- Continue ongoing work to support health care provider and caregiver training and add new disciplines to the Competency Framework.
- Increase palliative care education, experiences, and mentorship for health care provider students.
- Include the Canadian competency framework in more education programs and employment standards.
- Continue to support education focused on improved communication skills.

Additional actions we hope Health Canada will take to achieve its long-term goals:

- Establish new national standardized / accredited education for **all** health disciplines.
- Support the development of mandatory palliative care courses as part of undergraduate health provider curricula.
 - o In addition to this existing priority as outlined in the Framework, we believe that mandatory grief education for all health provider curricula, especially among mental health care providers, should be supported.
- Explore best practice models that integrate palliative care training and education for interdisciplinary teams and others (support staff, volunteers, caregivers, etc.), including communication skills, and advocacy training as core competencies.
 - o While progress on health and allied health care provider education is clear in the report, we recommend the government dedicate additional focus on caregiver education as integral members of care teams.
 - o Pesut et al. 2022: “Respondents perceived that family caregiver education had either not changed (43%) or improved (39%). In the open-ended responses, respondents described how providing education for family caregivers has largely been delegated to hospice societies and other non-profit community organizations.”



Feedback:

PCCC strongly encourages the federal government to continue to invest in training and education as well as health human resources recruitment and retention as it relates to palliative care and the delivery of a palliative approach to care in all settings. We know it is not just palliative care facing these challenges – but we encourage Health Canada to view palliative care as a priority and part of the solution when looking to address these challenges. PCCC sees opportunities with the creation of Healthcare Workforce Canada and the development of a Safe Long-Term Care Act for Health Canada to take further steps to achieve its long-term goals.

2. Measures to support palliative care providers and caregivers.

- a. Short-Term Goal (1–2 years): Supports required for palliative care providers and caregivers are identified, considering the range of wishes and needs of people with life-limiting illnesses.
- b. Medium-Term Goal (3–5 years): Caregivers and providers are aware of and can access supports to meet the goals of the individual and their caregivers; there is an increased awareness of palliative care, and uptake of advance care planning and advance directives.
- c. Long-Term Goal (5–10 years): Canadians and caregivers understand and plan for palliative care and develop advance care plans.

Actions Health Canada has taken to accomplish this goal:

- Since 2018–19, Health Canada has invested \$8.3 million to raise awareness of palliative care.
- Health Canada and partners (but they only mention CCS) have launched a public education campaign on palliative care in 2022–23.
 - o When surveyed in 2022, 58% were somewhat to very familiar with palliative care, and 45% agreed or strongly agreed that they would know where, when, and how to seek help with grief. Health Canada will follow up at the end of their campaign in 2026–27 to track their progress.
- According to the report, more Canadians are engaging in Advance Care Planning, and Health Canada is working with the Canadian Hospice Palliative Care Association to continue expanding the availability of these resources to people with disabilities and highlights some provincial examples to promote Advance Care Planning.
- The report highlights several initiatives regarding compassionate community initiatives and supports for caregivers such as the work happening in the British Columbia Centre for Palliative Care and Covenant Health’s Palliative Institute, and that Statistics Canada has partnered with Health Canada and the Canadian Institute for Health Information has added questions about Compassionate Communities to the Canadian Social Survey (results will be available in spring 2024).

- The report also highlights Canadian Virtual Hospice’s resources on grief and bereavement and the Action Plan Health Canada is funding to advance grief literacy.

Actions Health Canada will be taking, according to the report:

- Continue ongoing collaboration with governments and partners, especially on how to grow the Compassionate Communities movement in Canada.
- Continue ongoing 6-year palliative care awareness campaign to help more people understand palliative care and how to access it.
 - o Will commission a follow-up survey to the one conducted in 2022 to assess changes in people’s understanding of palliative care and grief following the six-year awareness campaign.
- Continue to promote improved care in the community, including home-based palliative care.

Additional actions we hope Health Canada will take to achieve its long-term goals:

- Strengthen and include caregiver assessment to understand the unique needs and capacity of each caregiver.
 - o Pesut et al. 2022: “Despite improvements in education, technology and advance care planning, survey participants perceived that many aspects of the support received by family caregivers had worsened. This included respite, in-home supports, and access to bereavement services.”
- Build greater care capacity in communities (e.g., by fostering the Compassionate Communities movement) to alleviate pressure on health care systems and caregivers.
 - o Pesut et al. 2022: “Volunteer hospice societies make vital contributions to palliative care in Canada and yet experience numerous barriers to doing their work well. The valuable work of these volunteers was severely limited during the COVID-19 pandemic. There is an urgent need to take practical steps, such as enhanced funding, to better support those organizations that contribute to building community capacity.”
- Promote the use of technology to enhance communication between specialized palliative care providers and community-based care providers, including caregivers.
- Support the development of **local** public awareness campaigns in order to inform caregivers of the supports and services available to them.

Feedback:

PCCC welcomes the efforts to support increasing uptake of advance care planning, awareness of palliative care and grief supports and literacy, and expanded compassionate care benefits. We were also proud to support expanded bereavement leave for federally regulated employees. We encourage the federal government to keep taking steps to improve support for the challenges caregivers and care providers face and ensure integration of advance care planning and grief support across all settings of care in ways that are culturally safer for communities to access. While progress has been made, there is still a long way to accomplish the long-term goal Health Canada has set.



3. Measures to support palliative care providers and caregivers.

- a. Short-Term Goal (1–2 years): Existing research and data collection gaps are identified.
- b. Medium-Term Goal (3–5 years): Research is undertaken, applied, and promoted. Data collection activities are planned and reported to align with policy goals.
- c. Long-Term Goal (5–10 years): Research, data collection, and best practices are implemented to inform and support policy decisions and government directions about palliative care.

Actions Health Canada has taken to accomplish this goal:

- Health Canada has invested \$3.7 million since 2021 to improve palliative care research and data collection.
- The Canadian Institutes of Health Research have invested more than \$30 million in palliative care research since 2019, mostly through the Institutes of Aging, Cancer Research, and Health Services and Policy Research.
- The report highlights investments through the Pan-Canadian Palliative Care Research Collaborative, Lakehead University, and a joint project between McMaster and Dalhousie Universities.

Actions Health Canada will be taking, according to the report:

- Statistics Canada will be launching a new initiative called Health Care Access, Experiences, and Related Outcomes, to improve data on supportive care, primary care, and medications across all health care settings. There will be a survey on palliative care to launch at some point, with results available in spring 2025.
- Include more diverse populations, illnesses, and care providers in research and measure equitable access to care.
- Build research capacity through expanded research networks.
- Move toward data standardization across jurisdictions, including common indicators and better data about palliative care delivery and patients' and families' outcomes and experiences.

Additional actions we hope Health Canada will take to achieve its long-term goals:

- Develop economic models and methodologies for further integrating palliative care into home and long-term care (LTC)
 - o Despite significant increases in the rates of access and documented provision of palliative care among LTC residents, notably for those with a prognosis of less than 6 months, rates of access to palliative care remain significantly lower in LTC than the average across all settings.





- Continue developing capacity in all aspects of palliative care research through a multidisciplinary approach that generates new knowledge, addresses gaps, and improves care practices.
- Improve data collection on the uptake and consistency of advance care plans, focusing on where, how and by whom they are most used.

Feedback:

PCCC has advocated for several years for the need for national standards, indicators, and an atlas to map out where palliative care services are located. Significant funding has been dedicated to improving health data in Canada through the bilateral agreements with provincial and territorial governments. We hope that Health Canada will dedicate the funding we have asked for (\$7.5 million over three years) to achieve their short-, medium-, and long-term goal of implementing better data collection.

PCCC has also advocated for dedicated funding for palliative care research and a dedicated home for that work, especially without barriers to access this funding such as requirements for matching dollars. We think this would go a long way to help Health Canada achieve its medium-term and long-term goals in this area as well as the capacity for future research in palliative care in Canada.

4. Measures to facilitate equitable access to palliative care across Canada.

- a. Short-Term Goal (1–2 years): Best practices and barriers to consistent access to palliative care are identified.
- b. Medium-Term Goal (3–5 years): Mechanisms to facilitate consistent access are advanced and barriers are addressed; and action aligned with the Framework is taken at multiple levels to improve palliative care and achieve the goals of individuals with life-limiting illness.
- c. Long-Term Goal (5–10 years): All individuals with life-limiting illness and their caregivers benefit from a palliative approach to care with all players cooperating to help achieve the goals of individuals throughout the continuum of care.

Actions Health Canada has taken to accomplish this goal:

- Provinces and territories are developing a range of strategies for improving access to palliative care for diverse populations, including rural and remote communities, people with illnesses other than cancer and particular linguistic communities.
- Health Canada has invested \$4.9 million to date to facilitate equitable access to palliative care, including investments for Indigenous communities.
- Health Canada is supporting the Equity in Approaches to Palliative Care collaborative through the University of Victoria, which will be informing a federally funded improvement partnership led by Healthcare Excellence Canada working with the Canadian Partnership Against Cancer,



that will support up to 20 communities over four years to improve palliative care for people experiencing homelessness.

- Healthcare Excellence Canada and the Canadian Partnership Against Cancer launched a five-year initiative to integrate paramedics into the delivery of palliative care.

Actions Health Canada will be taking to accomplish this goal, according to the report:

- Health Canada is developing policy frameworks to reflect the distinct end-of-life care needs of First Nations, Inuit and Métis peoples, which will require continued engagement with First Nations, Inuit and Métis communities.
- Spread and scale models of care that improve access for underserved populations.
- Spread and scale models of care that address the needs of persons living with homelessness or who are vulnerably housed.
- Create and share resources and supports that address the specific needs of underserved populations.

Additional actions we hope Health Canada will take to achieve its long-term goals:

- Ensure that, while funding for home and community care through the bilateral agreements with provincial and territorial governments comes through the new Aging with Dignity Stream, underserved populations such as children and youth are still supported through the funding to improve their access to palliative care.
- Recognize and ensure the continued inclusion of lay and spiritual counsellor positions in inter-professional health care teams to increase access to non-medical aspects of palliative care.
 - o Pesut et al. 2022: "... respondents wrote that although there are efforts to expand palliative care knowledge into other healthcare professions, it was still very focused on nurses' and physicians' roles. These respondents suggested that more could be done to learn from other healthcare providers like spiritual care providers and social workers."
- Define palliative care integration strategies within health care systems and regional health authorities, to implement across care settings and in the community, always through a culturally sensitive, age-appropriate lens.

Feedback:

PCCC welcomes the initiatives to date to improve equitable access to palliative care. We would note, though, that the needs of pediatric palliative care patients, as well as their families and the health care workers who care for them, are only mentioned in the context of the gaps in research and data in this area, and no specific initiatives at the federal level are highlighted. Additionally, as the next four years of funding for home and community care which includes palliative care will be integrated into the new Aging with Dignity bilateral agreements, we hope to see the palliative care needs of children and families specifically addressed and included in those agreements. There is substantially more work to do to address the needs of underserved communities, but it will require additional data to accurately capture those needs and assess whether those gaps are being fixed.



Looking forward – Health Canada’s next steps

The report lays out additional steps that governments and partners could take but only commits Health Canada to continue to strategically invest the funding provided by Budget 2021 in support of the Action Plan on Palliative Care.

Next steps

So that Canadians and caregivers understand and plan for palliative care and develop advance care plans, all governments and partners could:

- continue to destigmatize palliative care so people can benefit sooner in their illness journey.
- ensure more equitable access to grief and bereavement support.
- sustain efforts to raise awareness and encourage advance care plans.
- support compassionate communities.
- tailor and disseminate patient and caregiver tools and resources to better support individual needs.

To ensure all providers have increased capacity to deliver quality care, and caregivers have appropriate supports to perform their roles, all governments and partners could:

- continue to advance leading practices in education and training, including mentorship and experiences for health provider students, improving cultural competencies and improving communication skills.
- continue to expand processes and mechanisms to support navigation of available care and resources.
- continue to increase the use of the Canadian Competency Framework as the national standard for education and employment for all health care providers.
- work with Indigenous peoples to develop and disseminate cultural competency guidelines.
- collaborate with organizations to develop and share competency training so that the needs of underserved populations are met.
- implement best practice models that integrate palliative care education for interdisciplinary teams.

In order that research, data collection, and best practices are implemented to inform and support policy decisions and the provision of palliative care, all governments and partners could:

- build on current expertise to continue developing capacity in all aspects of palliative care research.
- build data capacity, including implementing standardized person- and family-reported outcomes measures.
- develop and adopt precise palliative care indicators.
- further our understanding of approaches to palliative care in home and long-term care.





So that the care goals of all people with serious illness and their caregivers are supported, and they benefit from a palliative approach to care, all governments and partners could:

- use a lens of cultural sensitivity and age-appropriateness, and to continue to look for ways to integrate palliative care across care settings.
- focus on inclusive palliative care policies, programs, and services to reduce barriers to access.
- continue to engage with First Nations, Inuit, and Métis people and to support community-led initiatives to address the needs they identify.
- invest in scaling and spreading innovative models of care, particularly for Indigenous Peoples and other underserved populations (for example, seriously ill children and their families and for those experiencing illnesses other than cancer).
- develop palliative care policies, programs, and services that are inclusive and considerate of all ages, sex and gender, and cultural diversity.

Opportunities for the PCCC and the palliative care community

This report lays out where the Government of Canada hopes to see palliative care continue to improve. The lack of specific commitments from Health Canada in this report in terms of next steps is disappointing. However, the report lays out specific areas of action the government would like to see, which create opportunities for PCCC and members of the broader palliative care community to identify initiatives and projects which align with these areas. Moving forward, PCCC should look to the next steps outlined to inform its work in advocacy, education, and research and knowledge translation.

Tweets / social media posts

Twitter / X thread:

The Palliative Care Coalition of Canada welcomes the Health Canada Report on the State of Palliative Care in Canada findings on the progress so far on the #PalliativeCare Framework and Action Plan, and the remaining gaps to be addressed. palliativecarecoalition.ca

The Coalition supports the collective next steps that Health Canada identified in their report and are eager to continue collaborating to ensure everyone in Canada has equitable access to palliative care.

We look forward to working with @GovCanHealth to identify the specific actions it will be taking moving forward to increase equitable access to palliative care across Canada.

