



How to improve palliative care in Canada

A call to action for federal, provincial, territorial, regional
and local decision-makers

From the Canadian Society of Palliative Care Physicians

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1. Purpose

This document highlights Canadian Society of Palliative Care Physicians (CSPCP) recommendations to the federal, provincial and territorial (FPT) governments on how to improve, monitor and evaluate the quality of and access to palliative care across Canada.

Healthcare costs are escalating as a consequence of failure to adapt to changing demographics of Canadians and advances in chronic disease management, including cancer. Change is now long overdue. Continued failure to invest in palliative care will be a lost opportunity to achieve better efficiencies, improve outcomes and reallocate budget to other priorities. The status quo neither meets Canadians' needs nor is financially sustainable.

The CSPCP has special expertise and can provide leadership in modifying the healthcare system to achieve the most cost-efficient and effective improvements necessary to care for an increasingly elderly and chronically unwell population.

Areas of strategic investment that will have immediate and long-term, cost-effective benefits have already been identified and need to be addressed on an urgent basis.

The current discussion about a new FPT health accord presents an immediate opportunity for change that should be seized.

Palliative care is an area of medicine that has been identified as a priority because of the aging of our population.

The federal government has committed funds for home care and palliative care without an implementation plan or commitment to universal access. Canadians now have the right to access medical assistance in dying. We need a similar right to access to palliative care.

A coordinated public health approach throughout multiple parts of our healthcare system and other public services requires a pan-Canadian approach, most effectively achievable through support of Bill C-277 and reinstatement of the Canadian Palliative Care Secretariat.

The Canadian Society of Palliative Care Physicians is collaborating with a number of other institutions providing similar guidance to governments. This document focuses on aspects of the issue specifically related to physicians, as this is our expertise. This is not meant to diminish the importance of the roles of other members of the multidisciplinary team, but to allow the report to be sufficiently focused to maximize its usefulness, considering the Society's unique role within the multidisciplinary care environment.

2. Recommendations from the Canadian Society of Palliative Care Physicians

Steps to ensure that all Canadians have access to high-quality palliative care

1. Implement a palliative approach to care, as outlined in the national framework document [The Way Forward](#). This approach is a high-quality, cost-effective service delivery model that will help Canadians with life-threatening illnesses live as fully as possible.
2. Make new investments to transition to the palliative approach to care, building on past investments wherever possible. Specifically:
 - a. Identify targeted funding to address the immediate shortfall in physician resources, in order to provide an acceptable standard of care for those who are nearing end of life.
 - b. Provide targeted funding to universities to ensure core competencies in palliative care are achieved by every medical school graduate.
 - c. Provide targeted funding to universities to at minimum double the number of residency training positions for palliative care across Canada for at least the next 5 years. Further requirements can then be assessed by the reinstated Secretariat.
 - d. Make a stable long-term funding commitment to Pallium Canada to enable them to continue to develop high-quality educational programs for all medical disciplines and primary palliative care providers.
 - e. Make a stable long-term funding commitment to Canadian Virtual Hospice to enable ongoing provision of high-quality online support for patients, families and professionals.
 - f. Consider strategic targeted funding for the appropriate human resources and infrastructure to meet the palliative needs of vulnerable and marginalized populations (e.g. First Nations, Inuit, Metis, rural and remote populations, and the homeless, disabled or incarcerated).
3. Set, monitor and enforce national standards for palliative care in Canada. Make accreditation of healthcare services (hospitals, long-term care homes, home care services, etc.) contingent on palliative care service provision to nationally accepted standards.
4. Promote recruitment and retention of palliative care providers, including expectations of wage equity as compared with similar work.
5. Standardize provincial drug plans and health supplies coverage to include all patients who require palliative care and the medicines and supplies needed to adequately care for them.
6. Promote technological innovation such as telemedicine and minimally invasive palliative procedures, which enable delivery of effective care to remote populations and those with the most extreme suffering.

Mechanisms for implementation

1. Establish a new national health accord that includes dedicated funding for palliative care, makes funding contingent on governments meeting national standards for palliative care and measures progress through strict reporting requirements.
2. Reinstate a Canadian Palliative Care Secretariat to provide standards to guide the provinces and territories in service development.
3. Support Private Member's [Bill C-277](#): providing for the development of a framework on palliative care in Canada, sponsored by MP Marilyn Gladu.

3. Introduction

There have been many reports in the past addressing this issue. These reports are listed in the Appendices, with links to the source documents. These have all contained sensible recommendations, many or most of which have not been followed, with negative consequences for Canadians. Healthcare costs are escalating as a consequence of failure to adapt to the changing demographics of Canadians and advances in chronic disease management, e.g. for cancer. Change is now long overdue. Ongoing failure to invest in palliative care will be a lost opportunity to save substantial amounts of money. The status quo neither meets Canadians' needs nor is financially sustainable.

A number of Canadian institutions are currently pursuing initiatives designed to inform the planning process in more detail at the federal and provincial levels in years to come. For example, the Canadian Reference Working Group, representing the Canadian public and major stakeholders, was convened by Covenant Health Palliative Institute on June 15, 2016, and is continuing work on determining the recommendations that have the greatest likelihood of improving the quality of palliative care for all Canadians. This project is called "Palliative Care Matters: Building National Consensus" and will analyze data collected from a recent Ipsos-Reid Pan-Canadian survey of the public. These recommendations will be available by early 2017.

There is, however, already sufficient evidence to be able to make firm recommendations on the **immediate** measures that need to be taken to improve the availability, effectiveness and efficiency of palliative care for all Canadians.

Background

First it is important to understand what palliative care actually is. Palliative care is the health discipline focused on improving the quality of life of people living with life-threatening illness. It includes, but is not limited to, end-of-life care. The World Health Organization (WHO) defines it as follows:

The WHO Definition of Palliative Care for Adults

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient's illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Children have distinct additional needs, which the WHO has also defined.

The WHO Definition of Palliative Care for Children

Palliative care for children represents a special, albeit closely related field to adult palliative care. The WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other pediatric chronic disorders (WHO; 1998a):

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's homes.

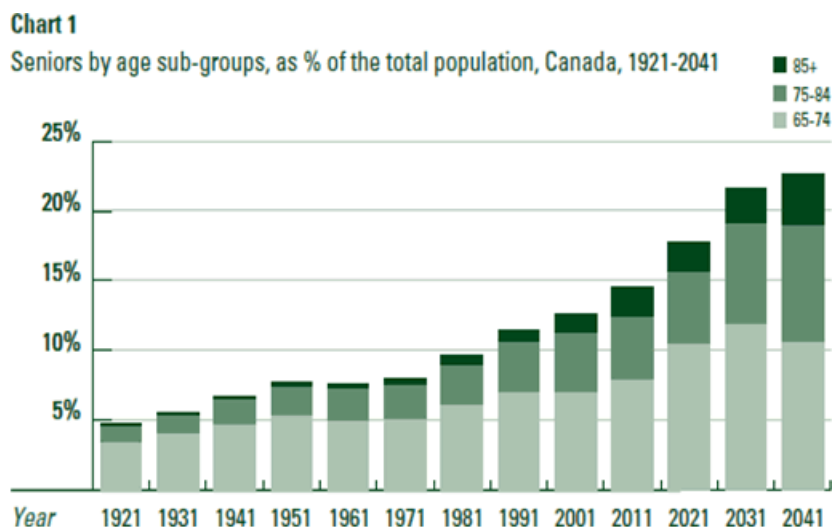
It is particularly important to distinguish the palliative approach to care from specialist palliative care services.

The Palliative Approach to Care describes the application of core palliative care competencies to the care of people with chronic life-limiting conditions, and embedding these competencies into the delivery of care across different healthcare sectors and professions. A palliative approach specifically acknowledges the capability of healthcare professionals who do not specialize in palliative care to attend to the needs of people who have advancing serious illnesses, regardless of the sector of care (home care, residential, hospital, etc.) and the stage the patient is at in the disease trajectory. There are different models for achieving this interaction.^{1,2}

Specialist Palliative Care Services provide expert advice to generalists and care to patients whose needs are so complex they cannot be met by their primary care team. This expert care can be provided in an outpatient clinic setting, by a hospital consultation service for inpatients, on home visits in home hospice programs (including long-term care homes), and for the most complex patients, in palliative care units or hospices. It should be noted that specialist palliative care is not consistently available in all of these settings throughout Canada and in many communities is not yet available at all.

Why Now?

The renegotiation of the health accord between the federal and provincial governments is coming at a time of crisis within the Canadian healthcare system. Changes have to be made in order for our healthcare system to be sustainable and to meet the changing needs of Canadians, not least driven by demographic changes, with seniors having a much higher need for palliative care than younger people.



The key points that inform the urgent need for change are:

- The demographics of Canadians show a marked increase in the number of seniors, many living with life-threatening chronic illnesses for prolonged periods.
- The legalization of Medical Assistance in Dying (MAiD) has reinforced the imperative for all Canadians to have access to palliative care, which is currently not the case.
- Only 30% of Canadians have access to specialized palliative care, and with current funding and workforce shortages, specialist palliative care services in all jurisdictions are facing pressures from changing needs and expectations.
- Current specialist palliative care services are already desperately under-resourced, especially in rural areas.
- In the past, hospice palliative care was provided only in the last few weeks or months of life. With advances in treatment, time of death is less predictable and people with a wide range of chronic life-limiting illnesses now need hospice palliative care services over a longer period of time.
- In Canada most patients receive palliative care too late in their illness to achieve those savings and there is heavy dependence on hospital-based care with corresponding costs.
- Healthcare systems need to reduce inappropriate and costly hospital and emergency admissions by providing more cost-effective care in the community. To impact care trajectories, palliative care needs to be made available early in the course of illness in order to achieve cost savings.
- The current specialized palliative care workforce is not large enough to meet the growing demand and changing needs. More people are retiring than entering the specialist palliative care workforce.
- There is growing pressure for other providers to care for people who do not have complex medical needs, so that specialized providers can concentrate on those who need their skills. The delivery of the palliative approach to care cannot happen without education, and those with the necessary teaching skills to do this are currently overwhelmed with providing clinical care to patients.

It is crucial that federal, provincial, territorial, regional and local decision-makers address these issues through funding, policies and opportunities such as the health accord and Bill C-277.

4. Models of Care

To meet the needs of those living with serious illness, especially those who are approaching the end of life, requires a population health or public health approach to care. All who die from expected or natural death should have access to healthcare services that meet their needs in a timely fashion in order to minimize expensive and preventable use of the emergency room and futile medical interventions. All bereaved families should also have access to appropriate bereavement support, whatever the cause of their loved one's death.

Levels of Care

The levels of care that need to be provided are illustrated in the diagram below. There are a number of more sophisticated models illustrating the complex relationship between the different parts of the system, but this simple schematic is useful in describing the components of the healthcare system that need to be provided and the patients who move through each part of the system.

It should be noted that only a small percentage (11%) of adult Canadians who die each year would be expected to have no preceding symptoms or other sources of distress – for example, those who die from sudden catastrophic stroke or fatal cardiac arrhythmia. These people are considered not eligible for palliative care services for the purpose of this discussion. Though these people will not need palliative care services to be provided to them in time of illness, this does not however mean that they would not benefit from advance care planning as part of general medical care, nor that their loved ones would not benefit from grief and bereavement support.

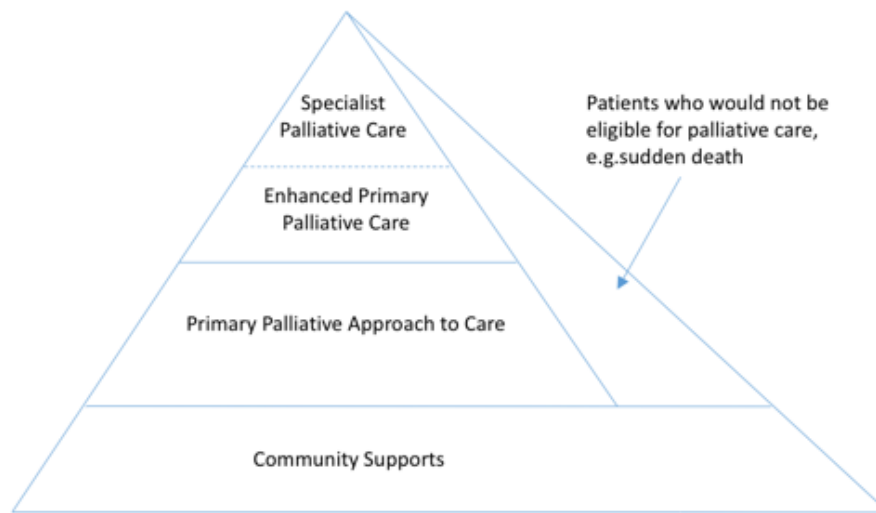
The main disease groups now identified as needing (eligible for) palliative care are:

- advanced cancers
- end-stage organ failures (heart, lung, liver, kidney, etc.)
- neurodegenerative diseases such as Amyotrophic Lateral Sclerosis (ALS), Multiple Sclerosis (MS), Huntington's disease and Alzheimer's disease.

Early attempts at quantifying the need for palliative care were based primarily on cancer patients and estimated at approximately 70% of deaths, but more recent inclusion of non-cancer diagnoses and more sophisticated data analyses have led to higher and more accurate estimates³⁻⁶. A 2011 funding review estimate from the UK identified that between 69% and 82% of adult deaths would be expected to have palliative care needs, and this was confirmed in 2014 by another British group in an extensive analysis based on linked mortality and hospital episode data. A New Zealand report using methods developed in Australia suggested up to 93.6%. Canadian national data on cause of death (<http://www.statcan.gc.ca/>) suggests around 89% of deaths are due to chronic illnesses which are likely to generate palliative care needs.

The model below shows this group alongside the 11% of adults who die who would not be expected to benefit from palliative care for their actual cause of death. It should be noted that the 11% are included in the base layer of the needs model, under community supports, as they would benefit from advance care planning and their families would benefit from bereavement support.

Figure 1. The Palliative Healthcare System According to Need



Community Supports

The community components are represented in the base of the triangle and include many of the social aspects of care that are not provided by the healthcare system but by other government ministries and social entities, e.g. financial support through various compassionate leave, sick leave and disability benefit programs, and companionship and bereavement support provided by volunteer groups and societies. These are central to the well-being of people with advanced illness and their family/friend caregivers, and need support within an integrated public health-based model of service delivery.

Some patients living with chronic life-threatening illnesses will be cared for in their communities by their families and are represented by this bottom layer of the model, with little interaction with the healthcare system. As indicated in the model, community supports need to be available for the families of those who would not be eligible for palliative care themselves due to sudden death.

Primary Palliative Approach to Care

The second layer of the triangle represents those people (patients) who will require care that is within the scope of primary care. This can be provided by internal medicine, surgeons and other non-palliative care specialists, as well as family doctors, nurses and other primary healthcare providers who have been appropriately trained and are appropriately supported in a palliative approach to care.

Specialist Palliative Care

The top layer of the triangle represents those people who will have needs that are not able to be met by their primary healthcare providers and non-palliative care specialists, and for whom more specialized palliative care will be required. The care provided to patients in the top layer of

the model needs to be provided by physicians and other healthcare professionals who have made palliative care their career focus, seeking formal training such as full-time fellowships and practicing exclusively in palliative care. These physicians provide not just clinical support for the most complex patients, but also teaching, research, leadership and administrative supports that are vital in building much-needed capacity in the healthcare system.

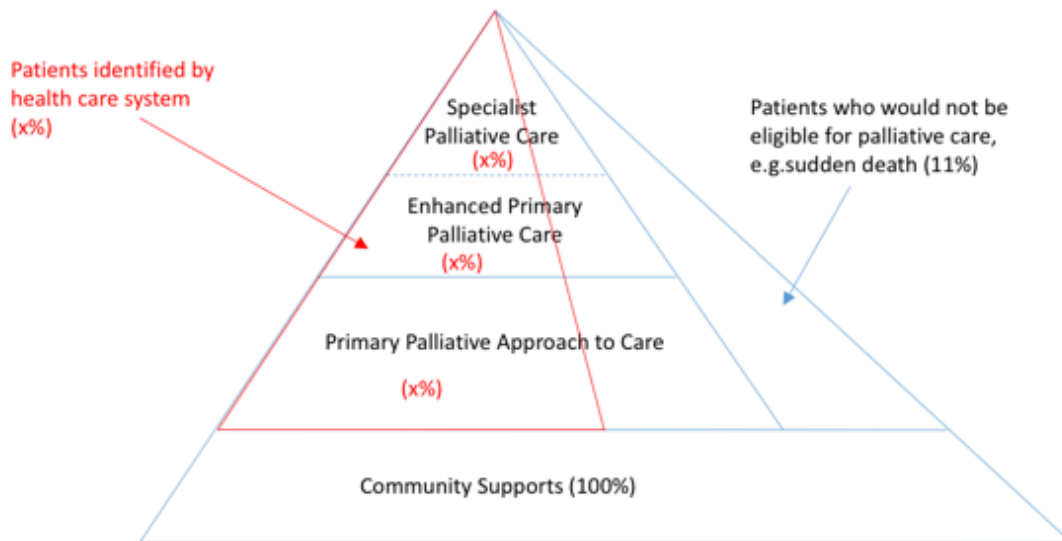
Care is often provided by healthcare professionals whose primary occupation is not as a palliative care specialist, but who have a degree of extra training or have acquired extra experience as a result of self-identifying as a resource for their colleagues, and focusing on this area of practice, experience conferring them with enhanced skills. It is important to recognize that the scarcity of palliative care specialists necessitates the recognition that a large part of palliative care services is delivered through these secondary-level providers, and that this allows for the most cost-effective use of the available resources. Palliative care specialists need to be allowed time and resources to be able to train and support their colleagues in other disciplines in order to develop this capacity.

5. Current Reach of Services

We know that the vast majority of Canadians who could benefit from palliative care do not receive these services. According to the [National Palliative Medicine Survey report](#), access to palliative care in Canada is highly variable. It depends on where you live, how old you are, and what you are dying from. It also depends on how you count it. In trying to improve access to palliative care is important to find a way to report it that can be used to monitor progress. As shown in Figure 2 below, it would be possible to estimate on a population level the number of patients who would be expected to have palliative care needs, and to determine how many of them were reached by existing health service delivery data in provincial Ministry of Health databases. This data could then be used to monitor progress in ensuring equitable access across the country.

It has been estimated that in Canada only 15% of those patients with expected palliative care needs receive specialist palliative care services, and care providers indicate that this care is often received for **only short periods prior to death**. It is not known whether that care is not provided because of lack of availability, or because of lack of need. Population-based needs assessments need further exploration with a national perspective, incorporating the projected Canadian demographic changes.

Figure 2. Suggested Reporting Method for Palliative Care Services Accessed



6. A Public Health Approach

There are a variety of ways in which components of palliative care can be made available at the different levels, depending on geographic, social and cultural factors. The key principle is that **each part of the system needs to be integrated with the others** for the most appropriate care to be provided in the most efficient and cost-effective manner possible. From an advocacy to government perspective, it is important to present a **public health approach** to designing a healthcare system to meet the needs of a population.

There are 3 basic models of implementing change in healthcare:

1. a top-down/whole systems model
2. a bottom-up/health promoting model
3. a mixed combination of the 2 models

The **mixed model appears to be the most effective for delivering cost-effective palliative care**. However, it is important to understand each of the models in some detail. The 3 models are briefly described below.

1. **A top-down/whole systems model** aims to extend health services to community settings through the system's efforts. The model focuses on establishing necessary system infrastructure and resources, such as policies, strategy, data system, quality assurance, capacity development, evaluation and research. A good example of one of these models, with particular relevance to Canada, is the Catalonia WHO Public Health Palliative Care Project^{8,9}. This was a very large demonstration project to investigate the effect of

implementing a systematic and comprehensive approach to establishing or integrating palliative care services into a health system. Similar benefits have also been seen in other public health-based projects in the United Kingdom, Australia, Japan, India, Germany, Italy, France, Norway and Hawaii. But the Catalonia project has been particularly well described and, having started in 1990, there has been sufficient time for the long-term effects of the project to be properly studied.

The Catalonia Project

Catalonia is one of Spain's richest and most highly industrialized regions. The demographics of the population and its healthcare system are very similar to Canada's. About 17% of the 7.3 million residents is older than 65 years (2009 data). The life expectancy is 79 years for men and 85 years for women (2010 data). There were around 59,500 deaths per year in 2009 – chronic conditions accounted for more than two-thirds of all deaths, and 28% of all deaths were due to cancer. Healthcare in Catalonia is financed publicly, and services are provided by a mixture of public and non-profit organizations. Healthcare resources include hospitals, an extended primary care system, and socio-health centres that care for geriatric, terminally and chronically ill patients by offering rehabilitation, day care and long-term care.

The Catalonia Project provided clear evidence for the effectiveness and efficiency of a whole system model of the public health approach to palliative care that is readily available in all care settings and provided by competent multi-professional teams. Catalonia's experience indicated that, for treating advanced disease inpatients in a publicly funded and freely accessible health system, shifting the use of acute resources to palliative care beds improves the quality of care at end of life, lessens patients suffering and generates substantial cost savings. Table 1 below illustrates the cost savings achieved by the project when last published. The full potential for cost avoidance has yet to be realized, as the project continues to expand to cover more of the non-cancer conditions than at the outset.

Table 1 Catalonia WHO Project – achieved outcomes 2001–2010

	1989	2001	2005	2010
Needs and coverage				
Patients needed palliative care (n)			(~ 20,000–31,000)	
Patients received care (n)		9,000	21,400	23,100
Service coverage – geographic area (%)		95%	>95%	100%
Service coverage – cancer (%)		67%	79%	73%
Service coverage – non-cancer (%)		N/A	25–57%	31–58%
Resource utilization				
Hospital admissions	63%	16%		
Emergency department use	52%	16%		
Mean length of stay in hospital (days)	12.0	8.0		
Costs and savings				
Total cost of palliative services (millions)			€40.3	€52.6
Total savings (millions)			€48.0	€69.3
Net savings (millions)		€3.0	€8.0	€16.7
Net savings per patient received palliative care				€690.0

2. **A bottom-up/health promoting model** recognizes the social character of frailty, illness and dying, emphasizes education and information-sharing, and enhances collaboration and participatory relationships between the health system and the community. An example of an initiative using this model is one from Kerala in India [<http://palliumindia.org/cms/wp-content/uploads/2014/01/palliative-care-policy-Kerala-109-2008-HFWD-dated-15.4.08.pdf>]. This project involved community-led engagement and development strategies. The project resulted in the creation of compassionate communities in which the responsibility of care for experiences of death, dying and loss is shared among province-wide networks of community members and groups. In Kerala, the model successfully expanded the range of palliative care beyond health services and professional care, significantly increased palliative care coverage and enhanced quality at the end of life.

A top-down approach leaves out some vulnerable groups, such as the non-cancer patients in Catalonia, and the bottom-up approach such as that used in Kerala may be unable to provide the high-level services needed by those few patients with the most complex conditions and severe suffering. **The mixed approach is therefore most likely to provide the best of both** models.

3. **The mixed model** recognizes health promotion and awareness as integral parts of a whole system approach to palliative care. This model has been extensively applied in the UK, Australia and Japan, and includes national engagement programs and awareness

campaigns, which are often funded and led by the government. Communities are involved in planning their own palliative and end-of-life support programs. They also prompt and direct society's efforts toward common national objectives.

A public health approach to service delivery necessitates identification of the unique needs of vulnerable and marginalized groups, for example:

- homeless and vulnerably housed
- Indigenous Canadians
- refugees, immigrants and undocumented
- prison population
- people with disabilities

Special projects targeting these groups include the following Canadian examples.

- The Palliative Education and Care for the Homeless (PEACH) program in Toronto demonstrates that these individuals can be helped and that the impact on patients and to the healthcare system can be dramatically beneficial. [TED talk about this at <https://www.youtube.com/watch?v=jcdm5fEqJmk>].
- The Cool Aid project for marginalized youth in Victoria is similar in aims and success. A research program guided by a conceptual framework of community capacity development created by Dr. Mary Lou Kelly has increased access to quality palliative care for people in rural, remote and Aboriginal communities and in long-term care homes in Northwestern Ontario and has relevance for many similar communities in other provinces¹⁰.
- The Canadian Virtual Hospice is Canada's leading web-based resource, providing information and support to over 1.2 million people each year. Forty percent of visitors to Virtual Hospice identify themselves as healthcare providers, and thus this resource is an important support for professionals caring for dying patients and their families. With funding from the Canadian Partnership Against Cancer, Virtual Hospice recently launched <http://livingmyculture.ca/culture/>. This unique initiative is comprised of over 650 videos, capturing 64 storytellers, representing 11 prominent Canadian cultural groups, describing their community's perspectives on death, dying and bereavement.

Within the healthcare system, the 3 levels of service provision have some core and some unique features. These are detailed in The Way Forward, by the Quality End of Life Care Coalition of Canada and the Canadian Hospice Palliative Care Association¹¹. This comprehensive document presents the rationale for choosing models of care most appropriate to the geographic and cultural context. Though there are core requirements for all populations, the service delivery model will look different in different communities.

7. Strategic Investment

There is strong evidence that a public health approach to palliative care presents sustainable solutions to the problems of access, equity and quality of palliative care and is the optimal route to achieving maximal cost benefit.

With regard to its impact on patient and system outcomes, all public health approaches to providing palliative care have showed:

- improved patient and provider experience
- enhanced quality of life
- greater opportunity for people to die in dignity in home-like settings
- creation of compassionate caring communities
- overall cost savings

To illustrate just one way in which quality of care can be achieved without an overall increase in spending, 16% of Canadian hospital beds — at a cost of more than \$800 per day — are occupied by seniors waiting for a more appropriate place to go. This \$2.3 billion per year price tag could be better spent if seniors got the care they needed in long-term care or through home and community care. The Canadian Medical Association (CMA) has proposed a Home Care Innovation Fund, which would include benchmarks agreed to by all signatories, so the funds assigned would be used to achieve the best results. Though not strictly a palliative care initiative, this proposal's goals would be very consistent with the palliative care advocates' drive to invest in the community support base layer of the service delivery pyramid model of integrated palliative care — one of the parts of the system that need improvement.

Another example is a study of hospitalized cancer patients at Johns Hopkins Hospital in Baltimore, Maryland, presented at the Palliative Care in Oncology Symposium in San Francisco on September 9, 2016, (Abstract 173) by Dr. T. Smith. It showed that in addition to improving quality of care and patient satisfaction, the combined inpatient and consultation palliative care programs contributed to substantially lower costs. Receipt of a palliative care consultation within 2 days of admission was associated with 22% lower costs for patients with moderate comorbidities and with 32% lower costs for those with high comorbidities. The estimated saving from their 11-bed palliative care unit was calculated at \$1,336,000 per year, or \$6.7 million over 5 years. For their palliative care consultation service, the total estimated savings in direct costs were \$2,530,000 per year, or \$12,650,000 over 5 years. See <http://www.medscape.com/viewarticle/868672> for more details.

The financial benefits of palliative care have been best reviewed and described in The Way Forward Integration Initiative report [<http://hpcintegration.ca/media/24434/TWF-Economics-report-Final.pdf>]. This review made clear that for the most cost savings from palliative care to be realized, services have to be provided in sufficient quality and early enough in the course of illness to have time to work. It is not possible at this time to put a dollar figure on the financial benefit of investment in palliative care, as so little data is collected in Canada. High-quality randomized controlled trials in this context are impossible, and comparisons

between cohorts in different regions or systems are difficult to draw firm conclusions from. There is, however, ample data from other countries, (as well as some data from Canada), which is entirely consistent with the international experience that would lead us to expect substantial savings from a system-wide investment in quality palliative care services from the level of community supports, through primary care, to the specialist and sub-specialist levels. The enormous cost of care for Canadians living with life-threatening chronic illnesses makes delay or failure to act an irresponsible waste of taxpayers' money.

Primary Palliative Approach to Care

The palliative approach to care requires that all healthcare providers have at least basic training in the principles of palliative care, and this can only be achieved through investment in education. This includes the undergraduate curricula of all the health disciplines.

For physicians, the new and revised postgraduate curricula from the Royal College and the College of Family Physicians are using the CanMEDS framework. This framework is also being introduced at the undergraduate level. Since its approval in 1996, CanMEDS has become the most widely accepted physician competency framework in the world. Updated in 2015, the 7 CanMEDS roles focus on the physician as a professional, a communicator, a scholar, a collaborator, a health advocate and a leader to achieve being a medical expert. The roles interplay and form the basis for developing a palliative care curriculum. At present, the core palliative care curriculum is still in its infancy, and training and exposure for medical learners are very inconsistently available. A CSPCP survey of Canadian medical schools has shown that only a small proportion of requests for undergraduate palliative care electives are able to be accommodated because of limited clinical teaching venues. Residency program rotations are also severely restricted in most medical schools, and many expressed needs for electives are not able to be met. This is an area that needs to be developed across the country so that all medical students and residents have access to at least a basic rotation in palliative care.

Although this document is focused on physicians, we recognize that other disciplines that make up the interdisciplinary team also offer some forms of basic training in palliative care. Physicians are required to deliver key parts of that education, in addition to training physicians.

Enhanced Primary Palliative Care (Secondary Level Care)

Opportunities need to be provided for primary care providers to enhance their skills beyond basic levels by accessing courses and other educational initiatives. Along with a number of provincial and regional organizations, Pallium Canada offers a variety of nationally standardized interprofessional courses and course facilitator training, and (at a higher level) Victoria Hospice in BC offers week-long courses attended by physicians, nurses and pharmacists from across Canada. Though not providing training to the level of a specialist, these opportunities significantly enhance capacity in primary care and can raise standards of care in areas with no local access to specialists.

Specialist Palliative Care

Where available, specialist palliative care professionals provide most of the care in palliative care

units, hospices, outpatient consultation services and in-home hospice programs. However, the shortage of specialists requires some secondary level personnel to step up into these roles, so there is not yet a clear distinction between these levels. For physicians, this is expected to change as the Royal College and the College of Family Practitioners develop their certification programs in the subspecialty Palliative Medicine (FRCPC-PM) and Added Competence in Palliative Care (CCFP-CAC). The CFPC has, however, not yet determined the process for a practice-eligible route to CAC, and the Royal College will not have a practice-eligible route to certification until 2020 at the earliest. While physicians negotiate the certification processes, those providing specialty level service over the next 5 years or so need to be recognized. Fee codes and sessional/service contract rates need to recognize those who are providing consultant-level expertise to be able to incorporate these services into their practice without loss of income, which is currently not the case. Most palliative care physicians take extra training only to earn less than their peers.

For example, in BC a palliative care consultation is reimbursed at \$100–\$150 by the Medical Service Plan depending on the age of the patient, whereas a geriatric consultation of similar complexity earns \$300. Palliative care physicians staffing specialist palliative care units and performing specialist consultations in hospitals are paid a sessional rate of \$125 per hour, whereas hospitalists with no specialist training providing primary care are paid \$135–\$165 per hour. In Ontario, a special palliative care consultation in office, home or hospital, which usually takes over an hour, reimburses \$144.75. A general consultation in geriatrics can reimburse \$185.00. A comprehensive geriatric consultation (equivalent to a complex palliative care assessment), which the physician spends at least 75 minutes to complete, reimburses \$300.70. If the geriatric consultation extends beyond 90 minutes, the physician is reimbursed \$395.65.

Specialists provide the leadership and mentoring required to develop capacity in primary care and provide quality care to the more complex patients. Without sufficient support from specialists, primary palliative care will not be able to deliver the changes necessary to impact quality or costs of care. A service cannot be rapidly made to exist without the human capital required to develop, lead and operate it.

Though not provided by palliative care physicians, there are some specialist palliative care interventions that are required for those patients who experience the very worst suffering. These include procedures such as cement injection into fractured bones in the spine and pelvis, and spinal infusions of pain-relieving medicines when traditional routes of medication administration prove to be inadequate. These interventions require close collaboration between specialist palliative care services and subspecialists, such as interventional radiologists and anesthesiologists. These techniques need to be supported in a small number of centres in order to maintain competency and provide training opportunities, and need to be supported by telemedicine for consultations to patients who do not reside in the regional centres.

Though relatively few in number, these patients' experiences have an immense impact on the families and healthcare professionals caring for them and lead to fear of suffering in those diagnosed with similar conditions. This fear of suffering is a common reason for requests for

MAiD. Canadians have now been granted a right to access MAiD, yet their right to access advanced pain management services that can relieve the most severe suffering is severely constrained in almost all regions of the country, and access to necessary palliative care medications is at the same time becoming more constrained, not less. Substance Use Disorder (including diversion) consumes vast resources, not just in the health care system, but also in law enforcement, the justice system and loss of productivity. Raising the level of competence of physicians will reduce the impact of poor prescribing, which is currently very much in the news.

Core Palliative Care Program Requirements

In looking at the innovative models of care described in the most recent national report, *The Way Forward*, there is an emphasis on the different tiers of service that need to be integrated. Collectively they form programs that have defined core requirements. These are:

- 24/7 access
- inclusion of patients with all serious illnesses, not just cancer
- inclusion of children
- a multidisciplinary team approach
- integration with other healthcare providers
- inpatient's preferred location of care – i.e. must be available at home, in outpatient clinics, in hospitals and in residential care homes (including hospices)
- respect for patients' choices and cultural preferences (including support for advance care planning)
- high quality

These requirements are all strongly supported by the public as demonstrated by the recent Palliative Care Matters national public survey.

8. Core Program Requirements

24/7 access

A single point of contact for specialist palliative care services is the most efficient way of ensuring 24/7 access to appropriate services. Telephone support from an appropriate professional should be provided for both patients and families and for healthcare providers working outside of business hours.

Inclusion of people with all serious illnesses, not just cancer

Currently cancer patients make up 65%–80% of patients who receive specialist palliative care, despite non-cancer patients experiencing similar levels of symptom severity as cancer patients and having the same or more complex medical needs. They have the same need for advance care planning, and their families have the same needs for support. In children, the rates are reversed, with approximately 80% of children who receive specialist palliative care across Canada having a non-cancer primary diagnosis.

Inclusion of children

Across Canada, 3,247 children ≤ 19 years of age died from all causes in 2012. After excluding 930 who died as a result of external causes (e.g., homicide, accidents, Sudden Infant Death Syndrome, complications of medical and surgical care), there were 2,317 children where pre-death palliative care may have been appropriate, based on the expected symptoms and needs. Of these, only 431 (18.6%) received specialized pediatric palliative care (PPC) – an increase from 2002 when only 5% of deceased children who might have benefited received specialized PPC. In 2002 we used estimates that 5 out of every 10,000 living children might benefit from PPC at a population level. However, more recent and validated estimates of the prevalence of life-threatening conditions for children in Canada suggest that 9.8 out of every 10,000 children might benefit from PPC services. Based on a population of 7,826,123 children ≤ 19 years of age, the proportion who received specialized PPC was 18.3% in 2012 and 4.2% in 2002¹².

Between 2002 and 2012, the number of children receiving specialized PPC more than quadrupled, but the vast majority of children who might benefit still do not receive these services. As well, core staffing in these programs only increased by a factor of 2.8 over the same period. Feasibility and sustainability of smaller programs continues to be a concern, with some programs providing care to 50 children a year with only one full-time person or less. As noted in other research, team composition and availability has little association with program utilization and the number of program staff may naturally grow as increasing referrals indicates the need for services. A recent survey of children's hospitals in the United States estimated that 50% had a PPC program. As there are only 16 children's hospitals in Canada, a high proportion (81%) had a PPC program in 2012. In a recent survey of pediatricians in Canada, only 18% of responders indicated that they did not have access to PPC. Despite this high prevalence and availability of programs and the increase in the proportion of children who received care since 2002, our data indicates that less than 20% of children living with or who died from a life-threatening condition actually receive specialized PPC. As well, no significant change in timing of referrals was noted over a 10-year span – nearly 25% receive specialized PPC for only the last 30 days of life. Clearly, barriers remain that prevent full and timely use of these services by the children who need them.

A multidisciplinary team approach

Physicians, nurses of different types and psychosocial support professionals would be the minimum to constitute a multidisciplinary team. Additional professional resources may be included in the team (but not necessarily palliative care specialist roles): pharmacy, spiritual care, psychiatry, physiotherapy, occupational therapy, music and art therapy, and other disciplines as appropriate under the circumstances.

Integrated with other healthcare providers

Currently in Canada, access to palliative care support is unequal. Most Canadians have access to a primary care provider (family doctor or nurse practitioner), but because integration of palliative care principles into the educational curriculum is only recent (and not universal), many of these providers have had no training in how to provide quality palliative care. The current specialized palliative care providers need both to train more specialized new colleagues and to educate all primary care providers in a palliative approach to care. Care at all levels needs to be

interdisciplinary, and we know from Public Health Approach initiatives that shared care models allow care to be provided to a larger number of individuals, with the individual patient receiving the level of care required at the right time, in the right place for them.

Inpatients' preferred location of care

Palliative care should be able to be delivered at home and in hospices, outpatient clinics and hospitals, and residential care homes (including long-term care). Special populations – children, the mentally ill, the disabled, those in prisons, the homeless, those with addictions, refugees and cultural minorities – need special services.

Respecting patients' choices and cultural preferences

Patients should be able to access care that is respectful of their culture. Examples of this include being able to hold smudging ceremonies for First Nations people in facilities by having smoke alarm systems that can be selectively deactivated for short periods. Care of bodies after death should be according to the family's preference, without a need to get the next patient in the bed immediately.

Advance Care Planning

Patient preferences can be clearly communicated by advance care planning (ACP). ACP is a process of reflection that allows people to think about their values and wishes in regard to the kind of health and personal care they would want in the future if they are not able to speak for themselves. This is done through discussions with family and friends, especially the substitute decision-maker (SDM) – the person who will speak for the patient if they cannot speak for themselves. Advance care planning is important to palliative care as often times a lot of futile treatments, or treatments a patient would not want, can be avoided by having these conversations before a person is extremely ill and is in a time of crisis. ACP should be done by everyone, not just people with a life-limiting illness. It is not something that is set in stone, but rather, it should be reviewed whenever a person's medical condition changes.

Advance Care Planning needs to be supported by the community, from a legal and administrative perspective. Public education about ACP should also be supported to ensure patients are aware of the importance of preparing for their care.

Of high quality

Programs should incorporate systematic assessment and documentation into their care plans and use evidence-based guidelines where appropriate, ensuring consistency in standards of care. The CHPCA already has standards that should be implemented across the country.

Research is essential to validate best practices, and ongoing evaluation of service delivery at the individual, community and regional levels allows care to be tailored to the needs of patients. Research and teaching should be included in the mandates of all programs and be funded accordingly.

Specialist training should be made available to all relevant healthcare disciplines, and recognition of training reflected in compensation.

In looking at delivery models in the CMA's National Call to Action, for patient- and family-centred care to be the focus, the ideal model would support patients and families in all locations of care.

- In a suburban or more rural setting, this could involve the same team providing care, with individual team members providing the care in different locations.
- In large urban settings, care could be provided in all locations in the urban area, but some of the patients will be referred in from distant communities. Integration of information between the urban and home location is essential so that the care remains centred on the patient's wishes and individual care needs.

Examples:

- Asha is a 6-year-old girl from rural New Brunswick. She is diagnosed with cancer and referred to Halifax for diagnosis and treatment. Part of her treatment involves a bone marrow transplant, which occurs in Toronto. Unfortunately, her cancer recurs and her parents decline the experimental treatment that is offered to her.

The standard we strive for would be that all Asha's medical information from New Brunswick will have been shared with the medical team in Halifax, then with the hospital in Toronto. Once Asha's parents return with her to New Brunswick, all medical information from Halifax and Toronto should have been shared, ideally including a palliative care assessment done in Toronto to determine known current and predicted future needs in her home community. The palliative care assessment should include the resources available in Asha's home community and referral to that team who will then take over her care. The quality of care provided should not depend on whether Asha is from rural New Brunswick, Nunavut, Toronto or Vancouver.

- Beth is a 67-year-old woman with a slow heart rate and moderate heart failure secondary to coronary artery disease who lives in Comox, BC. She has a cardiac pacemaker-defibrillator implanted in Vancouver after discussion about her goals of care, and is managed with medication through her family doctor, with periodic trips to the cardiology clinic. Some years later she has another heart attack and develops severe heart failure. No one at the local hospital realizes how important it is to have the defibrillator deactivated when it becomes clear she is dying.

Beth's family doctor and local hospital should have been instructed as to when and how to deactivate the defibrillator at the time it was inserted, along with regularly reviewing her goals of care. Deactivation prevents pain and fear of being shocked repeatedly as her body is naturally shutting down during the dying process.

- Stephen is a 63-year-old man from Swift Current, SK, who is diagnosed with advanced metastatic bowel cancer. He is referred to the cancer referral center in Regina and has treatment initiated there, but his metastatic disease progresses and he declines further therapy. He returns to Swift Current and to his family physician, who has never had any training or experience in palliative care.

Stephen's family doctor in Swift Current would ideally be kept informed by the care team in Regina and have specialist palliative care supports available for guidance. The care provided in rural Saskatchewan should be supported if care needs arise that are beyond the experience of the providers in Stephen's home community.

- Eric is a 51-year-old man with interstitial lung disease, who is on an oxygen machine at home. He is now breathless at rest and no longer able to travel to see his respirologist in Thunder Bay. He is not a transplant candidate because he has a number of other chronic illnesses. Eric is now followed by a family physician with a Certificate of Added Competence in Palliative Care in his own small town in Northern Ontario.

Few patients will have Eric's good fortune, but even in small communities, one or two physicians should have access to "Enhanced Skills" training in palliative care, so that they can provide support to the more complex patients in the area, support their colleagues in caring for their own patients, and provide a point person for communication with a specialist providing support from a larger community.

9. Role of the Palliative Care Secretariat

Canada needs to set standards for optimal staffing of palliative care services across different settings, including community- and hospital-based support teams and palliative care units. Guidelines are needed for the appropriate number and ratio of professionals using population-based indicators. A properly resourced Palliative Care Secretariat would be an optimal entity to providing those standards. Alternatives such as a Centre of Excellence may also be considered, but for maximal efficiency and effectiveness, whatever institution is chosen needs to be national in scope.

There are some hospitals across the country that have no palliative care team at all and others that have minimal palliative care services despite being very large hospitals with many patients who have palliative care needs. Some community teams across Canada have no physicians, while others have only 1 or 2 to cover large geographic areas and impossibly large numbers of patients. In those hospitals fortunate enough to even have a service, there are widely varying staffing ratios for palliative care units and consultation services. Some palliative care units have no psychologist or psychology coverage, no physiotherapy or occupational therapy support and minimal or no social worker or chaplain coverage – all key components of an effective palliative care team. The secretariat should establish guidelines for the provinces on what the optimal palliative care staffing and staffing ratios should be, based on demographics, death rates, number of beds and type of care provided in each care setting. To be effective, these standards need to be mandated to the provinces, such as through accreditation.

The secretariat should also study optimal funding models for physicians who can meet patient needs while supporting the rest of the system and building capacity through activities such as teaching, quality improvement and system leadership and design. An example of a recent policy

mistake is the current move in Ontario toward paying palliative care specialists in a fee for service model. This has been found to undermine the primary care sector's involvement in providing basic palliative care, which is conversely expected to increase healthcare costs and lower quality of care. These kinds of mistakes will continue to be made without national oversight and input from multiple stakeholders.

10. Workforce Planning

Current workforce

The difficulty in enumerating palliative care physicians is complicated by the challenges of differentiating specialists from physicians with enhanced skills. It is also difficult to count the many part-time physicians who spend a variable proportion of their time doing palliative care work.

The first-ever **National Palliative Medicine Survey** was conducted by the Canadian Society of Palliative Care Physicians (CSPCP), the Canadian Medical Association (CMA), Royal College of Physicians and Surgeons of Canada (Royal College), the College of Family Physicians of Canada (CFPC) and the Technology Evaluation in the Elderly Network (TVN). The survey, released in May 2015, gathered responses from 1,114 physicians from across Canada who answered Yes to the question of whether or not they provided at least one of the following services:

- Palliative care consultations and direct follow-up visits
- Acting as a palliative care resource to other care providers
- Indirect care as part of a local or regional palliative care service

This study has provided critical direction for improving access to palliative care services for all Canadians. There is no database or list of palliative care physicians in Canada, so the survey was broadly distributed electronically (in November 2014) to all members of the CFPC and Royal College (over 60,000 email contacts). Additional physicians were reached through the widespread promotion of the survey. This survey was not designed to count the number of palliative care physicians, but to determine the types of physicians who deliver palliative care, how they do it, their training and how each physician prepared in order to reach their practice level. The findings are summarized as follows:

- For the vast majority (84%) of physicians who provide palliative medicine services, it is not their primary field of practice.
- Family physicians with a focused practice in palliative medicine and palliative medicine specialists (16% of all respondents) reported working an average of 36 hours per week in palliative care. Physicians who provide palliative care as part of their other clinical duties (84% of respondents) reported working an average of 7 hours providing palliative care services.
- The majority (78%) of palliative care physicians reported that they do not see children, and only 50% of respondents reported having access to specialized pediatric palliative

care services.

- Just 35% of palliative medicine physicians in rural and remote areas reported having specialized palliative care teams to provide care in their area, compared to 79% of physicians in urban areas.
- Formal home healthcare for patients wishing to die at home was reported to be available by 49% of urban palliative medicine physicians versus 30% of rural physicians.
- Palliative medicine as a distinct discipline must be further developed to better meet the complex needs of patients. There must be an emphasis on growing the discipline of palliative medicine, which needs to be valued by universities and medical schools with protected time and other requirements to foster academic growth and to improve how we take care of patients living with and dying from advanced and incurable conditions.
- Canada must ensure that minimum palliative medicine standards are met. National standards for practice, including guidance for interdisciplinary care, hours of coverage etc., need to be developed. Different strategies are needed for rural and urban settings to meet the needs of the population in a realistic yet appropriate way. It is important that the palliative care workforce, including physicians and the other healthcare professionals who play a role in palliative care, be considered in workforce planning in all jurisdictions.

Primary care has been the focus of palliative care programs in the hope that many family physicians will provide the basic day-to-day symptom management required. This group needs to be adequately supported, with both resources and compensation, so that it can continue to grow to meet patients' healthcare needs.

The report concluded that Canada needs an adequate palliative medicine workforce. Physicians providing palliative care services must be properly trained and assessed to ensure they are capable of providing the highest standard of care. They must have resources to do the work, including the support of allied health professionals in interdisciplinary teams, access to in-hospital beds and services, after-hours schedules and supports, and community supports and services.

Impact of Medical Assistance in Dying

The advent of Medical Assistance in Dying (MAiD) has focused attention on the urgent need for an influx of funding to address suffering in Canada. If we assume that these people currently considering requesting MAiD are not currently accessing specialist palliative care we need to consider the extra workload needing to be accommodated to be able to provide service to those patients. Statistics Canada anticipates 260,000 deaths in 2017, and if Canadians request MAiD with the same frequency as those in Belgium which has the most similar law to the one now in place in Canada, 4% of these will result from MAiD. We know that only about 1 in 6 requests actually lead to the procedure, 5 out of 6 not being pursued after palliative care is provided. These 10,400 assisted deaths will therefore be a subset of approximately 62,400 people who request it, each of whose suffering will require palliative care expertise. Based on current experience, each of these evaluations will require approximately 5 hours of time to complete. This would total 312,000 hours. If full-time employment consists of 40 hours/week x 46 weeks, this would total 1,840 hours per year/full-time palliative care physician. $312,000/1,840 = 170$ full-

time equivalent physicians. This is about double the current number of known practicing palliative care specialists in Canada, already working to (and often beyond) sustainable capacity. Though this represents a substantial short-term investment, it will be more than offset by subsequent savings in costs of care, as shown by multiple studies in multiple health care systems.

Population-based workforce needs assessment

One way of estimating clinical physician workforce needs is to determine the optimal services required for a population, and then determine the physician staffing levels for these services. The desired numbers of physician full-time equivalents (FTEs) can thus be calculated based on known demographics. Note that the additional needs expected from universal access to MAiD are not included in these calculations, and there are other unknowns, which will become clearer over time as we adjust to the reality of MAiD legalization.

Independent assessments from British Columbia, Alberta, Ontario, Quebec and Nova Scotia suggest that there should be 8–10 residential hospice beds supported by at least 2 palliative care unit (PCU) beds per 100,000 residents, assuming an average distribution of ages.

Additional palliative care specialists are also needed to provide in-home (or in residential care homes) consultation for those who wish to die at home and to provide consultative support to oncologists in cancer centres. There is no estimated number of people who wish to die at home, are ambulatory and do not have cancer, but are living with organ failure or neurodegenerative diseases such as ALS and MS. Finally, the estimates of workforce required for conventional medical settings may not apply to special populations such as the homeless or incarcerated. For those, a higher ratio of specialists is likely to be required.

These estimates would need to be adjusted for local demographics. An adjustment factor determined by the Statistics Canada–derived death rate as a proportion of the total population could be considered, or calculations could be based simply on regional death rates as a marker of need in adults only. This would not be a useful marker for children as only ~10% of pediatric palliative care patients die each year. Adjustments will also be necessary when planning for services in remote or rural communities, where time will need to be spent travelling or using telehealth equipment.

It is also important to note the changing demographics of Canadians. As the baby boomers (born between 1946 and 1965) age, the senior population is expected to reach 6.7 million in 2021 and 9.2 million in 2041 (nearly 1 in 4 Canadians). In fact, as stated by Health Canada, the growth of the senior population will account for close to half of the growth of the overall Canadian population in the next 4 decades. These seniors will have greater need for palliative care than younger cohorts.

It is not possible at this time to recommend specific staffing recommendations for the various palliative care settings requiring specialists, due to lack of current data on the different service delivery models currently in existence in Canada, and the need to consider each model as a complex system. For example, having good support from a sufficient number of highly

competent nurses or nurse practitioners may reduce the number of specialist physicians required in a system. Inadequate numbers of available hospice beds would lead to patients “backing up” into acute care beds, requiring more in-hospital consultation services and resource-intensive complex care in the community. Attempts to quantify staffing requirements by other countries have been made but are either now out of date or not readily transferable to the Canadian context¹³. A National Palliative Care Secretariat would be ideally placed to review all the available evidence and produce detailed Canadian workforce planning estimates. We do know that there are many unfilled palliative care physician positions throughout Canada, and the demographics of the current workforce indicate that over the next 10 years a large proportion of those who founded the discipline and are currently providing service will retire. Current Canadian training programs are barely producing sufficient specialists to replace the retirements, let alone meeting the current and growing needs of the population.

Non-Clinical Work

One important factor to bear in mind when planning for physician resources is the need to budget and plan for adequate time to do the necessary non-clinical work, which is particularly critical now, as we create capacity within the healthcare system. Looking at similar groups can help inform the estimate of desired clinical to non-clinical time. A 2011 job profile of 109 pediatric hemato-oncologists showed the median time spent on different kinds of activities was 60% clinical, 15% education, 15% research and 10% administration¹⁴. Other studies have suggested a wide range of between 20% and 50% of working time should be set aside for non-clinical work.

The special and current need to educate the primary- and secondary-level care providers in palliative care suggests that the non-clinical proportion of time should be higher than in more established disciplines. Dr. David Weissman, a leading palliative care educator from the University of Wisconsin, has recommended that palliative care physicians should be spending 50% of their time in clinical practice and 50% in non-clinical activities¹⁵. As palliative care is integrated into the undergraduate and postgraduate medical training curricula, it is anticipated that this current educational deficit will lessen as new trainees with established core competency in palliative care enter practice.

Although the National Palliative Medicine Survey identified 1,104 physicians providing palliative care consultation services in Canada, the vast majority (84%) were working part-time in palliative care (average of 7 hours per week) and had no formal training. Many were expecting to retire in the next 5–10 years. To put this number in context, currently there are approximately 1,870 mostly full-time specialist obstetricians in Canada, another service where shortages have become critical and where family doctors provide services supported by the specialists in a similar way to palliative care services. A reasonable preliminary estimate is that the number of specialty palliative care trainee positions (including those training under both colleges) should immediately be at minimum doubled (from the current 25–30 trainees per year) for at least the next 10 years and be spread more evenly across the country than they are currently. Once the generalist workforce has been educated in core principles of palliative care and has the skills to incorporate the palliative approach to care in their everyday practice, it is likely that the number

of new trainees required annually would be able to be reduced. This time frame will coincide with the demise of the last of the baby boomer generation, following which death rates are expected to lessen.

11. Outcome Indicators

Economic indicators need to be selected in order to ensure the most cost-effective delivery of services. These should include those for people living with all chronic life-threatening conditions, not just cancer. The most relevant economic outcome indicators are not yet well established for Canada outside of the cancer context and should be selected and systematically tracked to ensure the best use of resources.

Documentation of relevant patient and family-reported outcomes (PROs), such as symptom severity, level of distress and satisfaction with care, is key to ensuring that services achieve their goals. PROs are not routinely collected, and some work is still required to select the most important outcomes to track.

The Canadian Partnership Against Cancer (CPAC) has made preliminary recommendations for some quality outcome indicators, which include measures of effectiveness and impact on known high-cost interventions of palliative care services:

1. % of deaths in hospital
2. Length of Stay (LOS) in acute care in last 6 months of life
3. Emergency Department (ED) visits in last 2 weeks of life
4. Home care in last 6 months of life
5. Intensive Care Unit (ICU) in last 2 weeks of life
6. Chemotherapy in last 2 weeks of life
7. % of patients with symptom severity scores ≥ 4 and 7 out of 10 for pain, anxiety and depression in those jurisdictions where this indicator is measured and recorded.

Work is already under way to track these measures. The Palliative Care Matters consensus project and multiple partners plan to refine these measures further.

12. Recommendations (repeated from front of this document)

Steps to ensure that all Canadians have access to high-quality palliative care

1. Implement a palliative approach to care, as outlined in the national framework document [The Way Forward](#). This approach is a high-quality, cost-effective service delivery model that will help Canadians with life-threatening illnesses live as fully as possible.
2. Make new investments to transition to the palliative approach to care, building on past investments wherever possible. Specifically:
 - a. Identify targeted funding to address the immediate shortfall in physician resources, in order to provide an acceptable standard of care for those who are nearing end of life.
 - b. Provide targeted funding to universities to ensure core competencies in palliative care are achieved by every medical school graduate.
 - c. Provide targeted funding to universities to at minimum double the number of residency training positions for palliative care across Canada for at least the next 5 years. Further requirements can then be assessed by the reinstated Secretariat.
 - d. Make a stable long-term funding commitment to Pallium Canada to enable them to continue to develop high-quality educational programs for all medical disciplines and primary palliative care providers.
 - e. Make a stable long-term funding commitment to Canadian Virtual Hospice to enable ongoing provision of high-quality online support for patients, families and professionals.
 - f. Consider strategic targeted funding for the appropriate human resources and infrastructure to meet the palliative needs of vulnerable and marginalized populations (e.g. First Nations, Inuit, Metis, rural and remote populations, and the homeless, disabled or incarcerated).
3. Set, monitor and enforce national standards for palliative care in Canada. Make accreditation of healthcare services, (hospitals, long-term care homes, home care services, etc.) contingent on palliative care service provision to nationally accepted standards.
4. Promote recruitment and retention of palliative care providers, including expectations of wage equity as compared with similar work.
5. Standardize provincial drug plans and health supplies coverage to include all patients who require palliative care and the medicines and supplies needed to adequately care for them.
6. Promote technological innovation such as telemedicine and minimally invasive palliative procedures, which enable delivery of effective care to remote populations and those with the most extreme suffering.

Mechanisms for implementation

1. Establish a new national health accord that includes dedicated funding for palliative care, makes funding contingent on governments meeting national standards for palliative care and measures progress through strict reporting requirements.
2. Reinstate a Canadian Palliative Care Secretariat to provide standards to guide the provinces and territories in service development.
3. Support Private Member's [Bill C-277](#): providing for the development of a framework on palliative care in Canada, sponsored by MP Marilyn Gladu.

13. Appendix A: List of National Reports on Palliative Care, compiled by the "Palliative Care Matters" initiative, with online links accessed Sept 26, 2016.

1. June 1995. Of Life and Death. Final report of the special senate committee on euthanasia and Assisted suicide. senate of Canada. the hon. senator Joan Neiman, chair.
<http://www.parl.gc.ca/content/sen/committee/351/euth/rep/lad-e.htm>
2. June 2000. Quality End-of-Life Care: The Right of Every Canadian Final report of the subcommittee to update of life and death of the standing senate committee on Social Affairs, science and technology. Senate of Canada. the hon. senator Sharon Carstairs, Chair. <http://www.parl.gc.ca/Content/SEN/Committee/362/upda/rep/repfinjun00-e.htm>
3. March 2002. Discussion Paper on End of Life. Palliative Care for Aboriginal Peoples. National Aboriginal Health Organization.
http://www.naho.ca/documents/naho/english/pdf/re_briefs2.pdf
4. October 2002. The Health of Canadians – The Federal Role volume six: recommendations for reform. Final report of the standing senate committee on social Affairs, science and technology. senate of Canada. the hon senator Michael J.I. Kirby, chair.
<http://www.parl.gc.ca/Content/SEN/Committee/372/soci/rep/repoct02vol6-e.htm>
5. November 2002. Building on Values: The Future of Health Care in Canada Final report of the royal commission on the Future of health care in Canada. Government of Canada. Roy J. Romanow, qc, commissioner.
http://www.cbc.ca/healthcare/final_report.pdf
- June 2004. Dying for Care, Quality End-of-Life Care Coalition of Canada.
6. June 2005. Still Not There. Quality End-of-Life Care: A Progress Report senate of Canada. the hon. Sharon Carstairs, P.C. Author.
[http://www.chpca.net/media/7883/Still Not There June 2005.pdf](http://www.chpca.net/media/7883/Still_Not_There_June_2005.pdf)
7. December 2006. The Pan-Canadian Gold Standard for Palliative Home Care: Toward Equitable Access to High Quality Hospice Palliative and End-of-life Care at Home, The Canadian Hospice Palliative Care Association and the Canadian Home Care Association.
[http://www.chpca.net/media/7652/Gold Standards Palliative Home Care.pdf](http://www.chpca.net/media/7652/Gold_Standards_Palliative_Home_Care.pdf)
8. March 2007. Moving Forward by Building on Strengths, A Discussion Document on Aboriginal Hospice Palliative Care in Canada. CHPCA.
<http://nshpca.ca/wp-content/uploads/2014/03/Moving-Forward.pdf>

9. August 2007. A Pan Canadian Partnership for Palliative and End-of-Life Care, Quality End-of-Life Care Coalition of Canada.
http://www.qelccc.ca/media/3839/qelccc_pan_cdn_partnership_2007.pdf
10. May 2008. Hospice Palliative Home Care in Canada: A Progress Report, Quality End-of-Life Care Coalition of Canada.
https://www.nbhpcaspcnb.ca/links_liens/national_reports_rapports_nationaux/Hospice_Palliative_Home_Care_Progress_Report.pdf
11. April 2009. Canada's Aging Population: Seizing the Opportunity- Final report of the special senate committee on Aging. senate of Canada. the hon. Sharon Carstairs, P.C. Chair.
<http://www.parl.gc.ca/content/sen/committee/402/agei/rep/agingfinalreport-e.pdf>
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14. Appendix B: Provenance of this document

This document is respectfully submitted by the Board of the Canadian Society of Palliative Physicians on behalf of its 500 members. The document was developed by a working group comprised of leading palliative care physicians from across Canada and finalized by the Board.

Working Group Members

- Pippa Hawley FRCPC (Chair) – Vancouver, BC
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CSPCP Board Members

- David Henderson, President – Truro, NS
- Susan MacDonald, Past President – St. John's, NL
- Leonie Herx, Treasurer – Calgary, AB
- Stephanie Connidis, Secretary – Kingston, ON
- Anne Boyle – Hamilton, ON
- Monica Branigan – Toronto, ON
- Bruno Gagnon – Quebec, QC
- Pippa Hawley – North Vancouver, BC
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