

# Palliative and End of Life Care

Alberta Provincial Framework  
2014

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# 1. Executive Summary

## **Audience:**

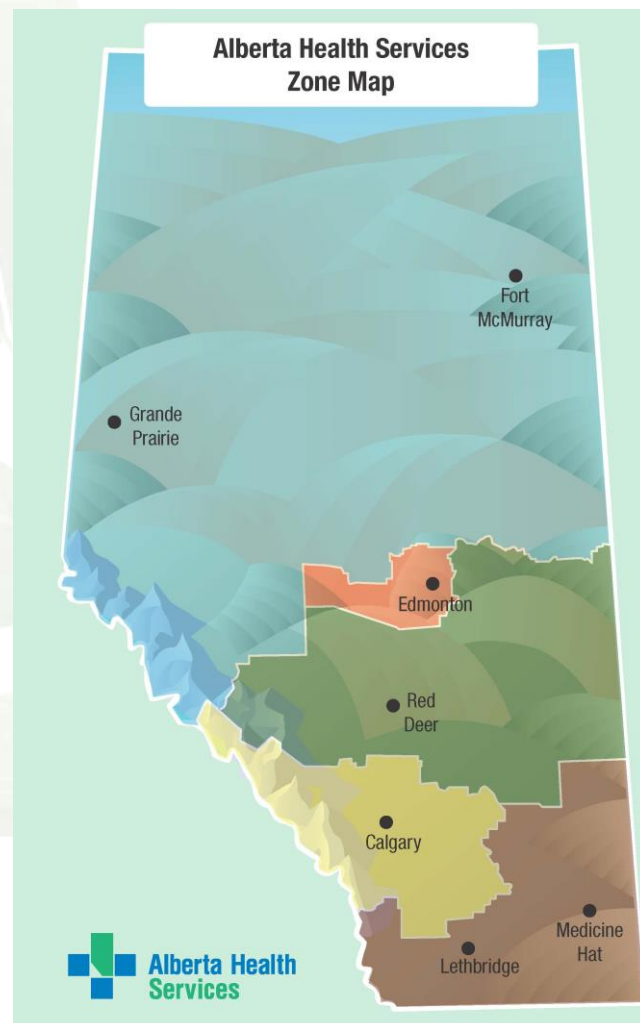
*This Palliative and End-of-Life Care (PEOLC) Provincial Framework has been written by experts in PEOLC across Alberta. The primary audience for this document is PEOLC interdisciplinary team providers, policy makers and service administrators. Additionally, the framework is a resource for clinicians who are not familiar with PEOLC and want to offer high quality PEOLC services. Albertans are encouraged to be aware of and review the document, but it is not intended as an informational guide for patients and families going through the PEOLC journey. There will be a companion document developed for patients and families with this focus.*

*The framework and the action items outlined in the initiatives are relevant to many other health and community services such as senior executives within Alberta Health Services (AHS), the Government of Alberta, Primary Care Providers and Networks, and Family Care Clinics.*

Across Alberta, PEOLC is provided for patients and families in many different settings, with a variety of programs and services from an array of standards. While there are some exceptional service delivery models and programs, they are not available within all geographies, creating inequity of services for Albertans. Many of these programs are internationally recognized for having led the way in the development of integrated PEOLC services. These integrated programs have made a substantial difference for patients, families and providers over 20 or more years. After this length of time, the program models need to take into account the changing needs and expectations of the population, as well as an evolving system organization. Local operational programs also need to incorporate provincial models, provincial planning and oversight. This framework provides a standardized approach and will direct the development of integrated and accessible care for the dying in our province.

Historically, PEOLC program development has driven local programs and services. The standardization and provincialization of the programs and services represented in this framework will help address inequities in the availability of services and programs for Albertans living with limited care options. Because of limited choices for where care can be provided, many people at the end of their lives will be admitted to the hospital when they could be cared for in a community setting. Alberta's PEOLC framework will outline provincial standards that will enable exceptional services and introduce innovative program solutions with the goal of reaching a level of equity that provides choice, dignity, and care supports for patients and their families, clinicians, and care providers, under a patient-centred model.

We know that in other jurisdictions, PEOLC is provided successfully at the primary health-care level if clinicians, care providers, patients and families are supported well when complexities and emergencies arise. The ideal model for Alberta is one that continues to integrate programs and services, and focus on diverse populations such as those with chronic diseases. Supporting practitioners at the primary health-care level and ensuring that Primary Care Networks, Family Care Clinics and independent physicians are aware of available resources and supports will lead to increased confidence for those managing individuals with life-limiting



illnesses within the community and result in decreased acute care usage. We need to identify patient movement through data and information analysis. We also need better integration between and within primary, secondary and tertiary levels of care.

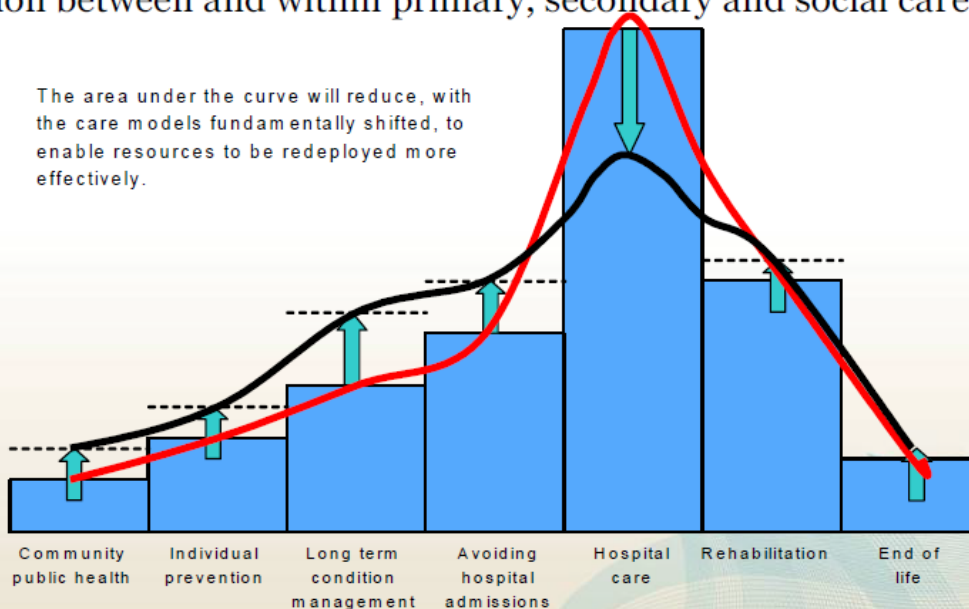
*The diagram below demonstrates that increased emphasis on building resources within community-based care for the PEOLC population can re-shape and reduce the need for care delivery within the acute care settings. The intent is to move resources from the red to the black line (3).*



### 3 – Investing in better models of care

New models of care = more care provided in communities and better integration between and within primary, secondary and social care

The area under the curve will reduce, with the care models fundamentally shifted, to enable resources to be redeployed more effectively.



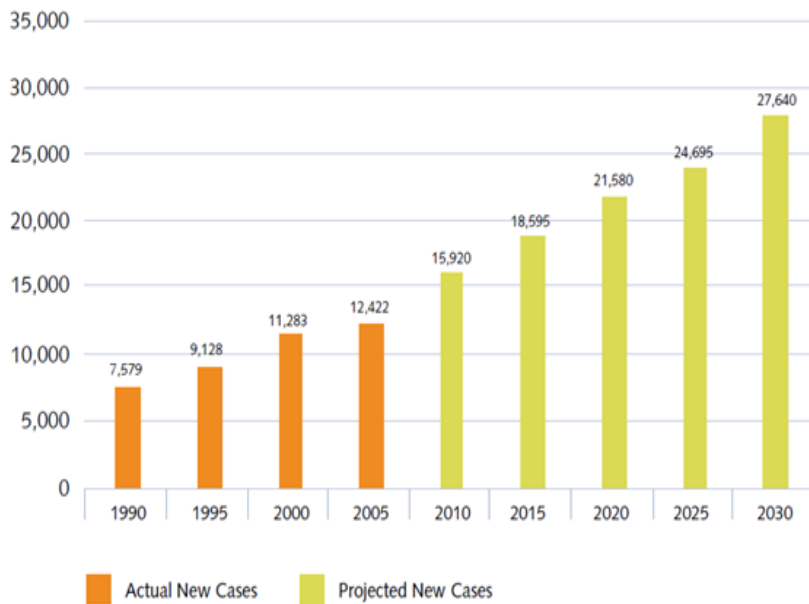
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#### Canada and Alberta Population

In Canada, seniors make up Canada's fastest growing age group. It is estimated that seniors 65 years of age and up will account for up to 25% of the total population by 2036. Only 16% to 30% of Canadians currently have access to or receive PEOLC services. In Alberta, the need for PEOLC spaces will only continue to grow.

As demonstrated by the accompanying diagram, we see increased rates of cancers, and trends show increasing rates of chronic illness. This suggests that we need to plan for increased services and providers for PEOLC over time.

**Figure 11: Actual and Projected Number of New Cases of Invasive Cancer, Alberta, 1990–2030**



*The number of new cancer cases in Alberta is expected to increase steadily to about 27,640 in 2030; this is mainly due to the increases in the age and size of Alberta’s population. In 2011, 16,200 Albertans were diagnosed with cancer. Approximately 1 in 2 Albertans will develop cancer in their lifetime, and 1 in 4 will die from cancer. Neoplasms, or cancer-related deaths, account for approximately 85% of palliative care service currently (4).*

### The Goal

The Alberta PEOLC framework has been developed with the goal of improving access to and strengthening PEOLC programs and care for Albertans by:

- encouraging and supporting Advance Care Planning/Goals of Care Designations (ACP/GCD)
- introducing a standardized provincial model for PEOLC services
- spreading and integrating existing successful services
- introducing innovative service delivery methods
- developing provincial guidelines and standards, including enhancing education and resources for patients, families and clinicians
- standardizing communication and strengthening information integration
- conducting research, evaluation and measuring performance and outcomes

Tied to this framework is a list of initiatives that have been identified as areas that require development to ensure that equitable services are made available for all Albertans regardless of age or geography. Clinicians need to be well supported, research and innovation need to be incorporated, and outcomes for patients and families need to be measured to ensure improvement is constant.

The framework clearly articulates the current status of PEOLC across Alberta and the identified areas that require strengthening and development through initiatives. The initiatives listed within the framework are foundational to all the stakeholders who: deliver PEOLC; educate others with a palliative approach; conduct research; and evaluate the effectiveness of program improvements. Alberta Health and Alberta Health Services (AHS) require supportive directional policies and funding to ensure success.

## 2. Introduction

This document represents a re-examination and cross-collaborative effort toward the development of a provincial PEOLC framework. Regional, comprehensive, integrated and co-ordinated PEOLC programs were pioneered in Alberta in the mid-1990s. However, more options for care and improved integration and co-ordination of care are needed for all Albertans regardless of type of illness or geographical setting. In addition, the need for, and timing of, a sharpened focus on a PEOLC provincial framework is reinforced and supported through the following recent business strategies and developments in Alberta:

- Alberta's Cancer Plan to 2030
- Organizational changes in AHS leading to the launch of Strategic Clinical Networks
- Creation of the Palliative Institute through Covenant Health
- Foundational, preliminary work completed by Alberta Health
- Development of a joint strategy to meet the needs for palliative oncology care (Cancer Care Action Plan, 2012)

The development of a Provincial End-of-life Strategy represents a joint collaboration between the Cancer Strategic Clinical Network (SCN), Seniors SCN and the division of Seniors Health, and Primary and Community Care. The work was vetted through a provincial PEOLC Steering Committee consisting of experts in PEOLC across the province. Additionally, patient and family representatives were consulted and provided feedback for this document through specific focus groups and advisory committee engagements, which clearly identified the need for a more public-facing companion document.

PEOLC is a “specialized” interprofessional approach to care for children and adults with serious life-limiting illnesses, including cancer, chronic diseases and frailty. It requires targeted training, programs, resources and the tools necessary to provide quality care. For this reason, a comprehensive strategy that encompasses all of the contributing elements that make PEOLC a distinct practice is needed to ensure that evidence-informed best practices and services are performed and available for all Albertans.

We believe that independent evolution of palliative programs across the province, a lack of provincial co-ordinated policies, standards and knowledge-informed guidelines and the absence of performance measurements represents a gap and opportunity to continually improve care and outcomes for patients and families. As a result, this document describes a strategic and co-ordinated plan toward the development of a common population-based provincial program for policy formation, financing and delivery of palliative care services to dying Albertans and their caregivers.

This cross-collaborative effort and consensus building exercise takes into account best practices that have been developed across English speaking and developed countries. A jurisdictional systematic review and synthesis of policy and operational documents across the globe was accomplished at the National, Provincial or Territorial, and regional levels of health governance. Both the organization and content of this framework have been informed through a review and synthesis of best practices in Alberta, Canada, United Kingdom, Ireland, United States, New Zealand and Australia. This review facilitated the assembly of this document with the aims of comprehensiveness and timeliness. A total of 86 documents were identified (see Appendix E and Bibliography for details).

### 3. Vision

This Alberta PEOLC Provincial Framework defines the strategic direction and overarching principles to set the foundation for provincial program development. The provincial program will be informed by best available evidence and research, be patient and family-centred (5-9), culturally sensitive and created with a sustainable focus (5-9). Appropriate providers will promote, co-ordinate and deliver integrated services that are designed to meet patient needs and their caregivers and/or families (10-12).

The overall goal for the development of a provincial PEOLC program is for all Albertans to have equitable and timely access to high quality interdisciplinary PEOLC services regardless of life-limiting illness or geography (13-16). While identical PEOLC services will not be provided in all settings of care, access to a PEOLC team, care guidelines and services will be available to meet the PEOLC needs of all Albertans.



"You matter because you are you. You matter to the last moment of your life, and we will do all we can, not only to help you die peacefully, but also to live until you die."

- Dame Cicely Saunders

## 4. Values, Norms, Culture and Belief

### 4.1. Values

PEOLC is an approach to care that not only addresses the physical experience of illness and treatment, but also focuses on psychological, spiritual and social domains (17-19). As such, it is imperative that not only principles are articulated, but also the values we hold as a community are outlined. **Values** are fundamental beliefs on which practice is based (8;20).

The following comprises the values expressed within the Canadian Hospice Palliative Care Association (CHPCA) national *Norms of Practice* (6;7;12;20):

1. **Autonomy:** Each person is an autonomous and unique individual. Care is guided by quality of life as defined by the individual. Care is only provided when the person and family are prepared to accept it.
2. **Self-Actualization:** Dying is part of living, and both living and dying provide opportunities for personal growth and self-actualization.
3. **Dignity:** Caregivers enter into a therapeutic relationship with patients and families based on dignity and integrity.
4. **Community:** A unified response to suffering strengthens communities.

### 4.2. Norms, Culture and Beliefs

“How much more empowering to believe the system was walking with you, attending to how you defined quality of life given your age and stage of life, and responding with a care plan that realistically reflected quality of life. Quality of life is not just about the number of breaths we take, but of the quality and meaning of ALL these moments” (2).

A **norm** is a statement of common or average practice and is thought to be less rigid than a standard (8;20). Patients have the right to expect caregiver services that are respectful of what provides meaning to people’s lives, their values, culture, beliefs and religious practices (7;12;19;21). Numerous studies devoted to how understanding culture is relevant to death and dying found that communication was the greatest barrier between the health-care provider and the patient and family during end-of-life care (22-24).

A provider needs to learn about, consider and respect the patient and family’s perspective on the following (25):

- death and dying
- health and suffering
- hospice and palliative care services
- western health-care practices
- awareness of practices and norms from other cultures
- complementary and alternative modalities/practices
- the role of spiritual and religious beliefs and practice
- the role of the family, including who is considered part of the family
- effective communication (such as the need for translation services or only using certain words that are acceptable when discussing illness and dying)
- their role in problem-solving and decision-making



## 5. Principles

A **principle** can be defined as a fundamental truth (8;20). The PEOLC Provincial Steering Committee compiled and developed the following principles for patients and families as a foundational process in providing PEOLC in Alberta:

1. **Patient and Family-Centred:** It is important that patients and families are placed at the centre of their care to foster participation and collaboration. They will be empowered to make informed choices, and their needs, culture, values, religion, language and preferences are respected and honoured. The patient and family's capacity to cope will be recognized, which will allow a flexible approach to care (6;7;12;13;20;26-31).

2. **Equitable and Accessible:** All Albertans should have equitable and timely access to quality interdisciplinary PEOLC services despite illness or geography (13-16). It is not the intention that the same services will necessarily be provided in all settings, but that the access to expertise will be equitable across Alberta. Timely access to PEOLC services and programs will be facilitated by system processes for patients and providers at all levels of health care. (6;12;13;20;29-32).

3. **Collaborative and Integrated Team Service Delivery:** In order to meet the individual needs of patients and families, comprehensive interdisciplinary teams with varying skills and knowledge are required to safely and effectively care for Albertans who are palliative or are at the end of life. The systems of care, including patients and families, providers, policy makers, educators and organizations that can influence programming need to share information about experiences and practices that promote the best possible outcomes for patients and families (6;7;12;13;20;26-31).

4. **Communication and Information Sharing:** There is a need for improved structured options, including information technology for knowledge transfer at all levels (patient and family, service delivery and system) and the use of common tools, language and utilization of the most appropriate documentation to support seamless transitions of patients, to convey appropriate information, and to safely manage patient and family issues (8;11;13;20;33-35).

5. **Safe, Ethical and Quality Care:** Comprehensive assessments by adequately skilled professionals and providers are at the heart of quality and ethical care delivery. The provision of care that is appropriate to all domains, including physical, psychological, social and spiritual requires knowledge and tools related to assessment in these areas. Practice that promotes consistency, co-ordinated activities and collaborative approaches with minimal duplication will foster best outcomes (6;7;12;13;20;29-31).

6. **Sustainable and Accountable:** Adequate and appropriate resources will be available for PEOLC programs and services for both cancer and non-cancer patients, their families and their health-care providers with the goal of providing the right care at the right place at the right time. A mixture of structure, process and outcome indicators established for PEOLC services are needed to measure symptom improvement, accessibility of services and equitable distribution of services across Alberta (6;7;12;13;20;26;28;30;32).

7. **Governance and Administration:** Clearly defined governance and administration models are required to influence accountability and to support the development of PEOLC programs. Exploring palliative care from a public health, health promotion perspective and aligning palliative care with a population needs approach is important for future planning. Broad-based governance includes community representatives, caregivers, service providers, patients and families (32).

8. **Research, Education and Advocacy:** High quality PEOLC that is supported by the best available evidence positively impacts quality of life. Continued learning and education should work toward information, research and advocacy for the development and maintenance of public policy, palliative care standards and resources to improve the delivery of palliative care. Clearly defined programs and activities will help support providers and improve patient outcomes (6-9;12;14;17;20;26;33;35;36).

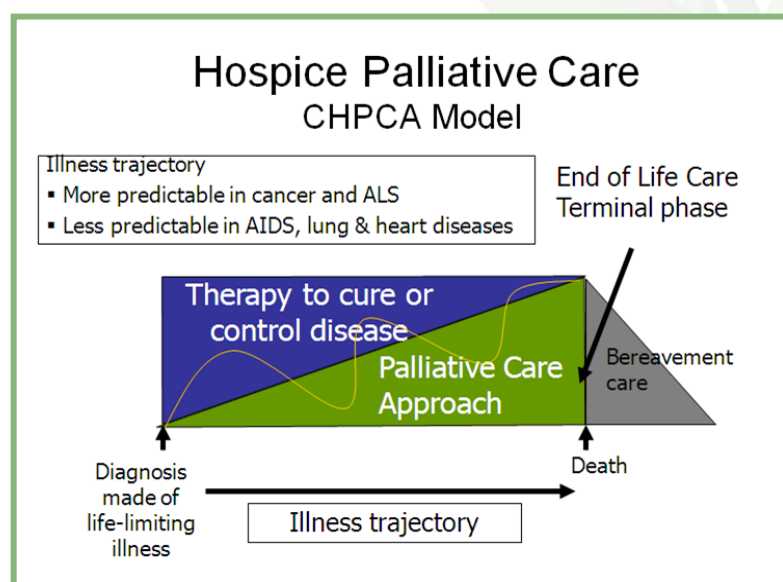
## 6. Definitions

### 6.1. Palliative and End-of-life Care Services: Philosophical Definition

The following philosophical definition was guided and endorsed by the PEOLC Provincial Steering Committee to describe both adult and pediatric PEOLC within Alberta.

**PEOLC** is both a philosophy and an approach to care that enables all individuals with a life-limiting and/or life-threatening illness to receive integrated and co-ordinated care across the continuum. This care incorporates patient and family values, preferences and goals of care, and spans the disease process from early diagnosis to end of life, including bereavement (5-7;37;38).

Palliative care aims to improve the quality of life for patients and families facing the problems associated with a life-limiting illness through the prevention and relief of suffering by means of early identification, comprehensive interdisciplinary assessments and appropriate interventions (6;12;14;16;20;36;39-43).



Throughout the continuum of PEOLC, health-care teams utilize an interdisciplinary approach to meet the individualized needs of patients, their families and/or caregivers. The interdisciplinary team addresses physical, emotional, spiritual, practical and social concerns that arise with advanced illness for individuals at all ages and developmental stages of life (5;7;9;36;37;39;44).

End-of-life-care is care provided to patients and their families when they are approaching a period of time closer to death, which may be exemplified by an intensification of

inter-disciplinary services and assessments such as anticipatory grief support, and pain and symptom management (13;18;37;39;40).

The above diagram describes PEOLC as a continuum of care from the time of diagnosis of a life-limiting illness through to the time of death and into bereavement. It demonstrates that a palliative approach to care can occur simultaneously with a curative approach or during treatment (9;45).

There is acknowledgement of the difficulty in dealing with life-limiting non-oncological diseases with poorly defined disease trajectories. There is a need to have education for providers who care for these patients and have better information for patients and families in the later stages of these diseases. There is also increasing recognition for the need to embed palliative and end-of-life philosophy and principles in the management of all life-limiting diseases, including, but not limited to chronic disease, frailty and cancer illness trajectories, including vulnerable populations. The benefits for these individuals are numerous, including earlier attachment to services and expertise that can aid in planning for PEOLC and improve troubling symptoms.

## 6.2. Palliative and End-of-Life-Care Services Administrative Definition (16)

Administratively, PEOLC can be accessed via three levels of care for patients and families: primary, secondary and tertiary. Primary level care is foundational and needs to be developed and supported to improve PEOLC in Alberta. Access to a secondary level of palliative-trained providers who support primary care providers may be done either through a face-to-face meeting or via telephone or email.

### Primary Level

PEOLC is provided in partnership with patients and families by primary care interdisciplinary teams who have fundamental knowledge, skills and competencies in palliative care (5;36;37;39;43;46) and:

- is available in every care setting, including palliative designated care areas and involves primary care providers who are able to identify, refer and provide care based on the core competencies of palliative care as described by the CHPCA;
- includes interdisciplinary health-care teams that provide direct and ongoing PEOLC for individuals and their family by addressing their physical, emotional, social, practical, cultural and spiritual needs, and respecting their personal autonomy with dignity and compassion;
- provides clinical management and care co-ordination, including assessments, interventions, referrals and triage using a palliative approach for patients within the level of expertise of the primary care team;
- utilizes and accesses specialized palliative services (both secondary and/or tertiary level providers) through a consultation process to support palliative care patients, their families and/or caregivers.

### Secondary Level

PEOLC consultation and advice is provided by an interdisciplinary palliative care team member(s) to primary care providers (5;37;39;40) and:

- is accessible in home and all other settings of care, including hospice 24 hours a day, 7 days a week (virtual and/or in-person);
- is care that is delivered by interdisciplinary health-care providers with advanced training and expertise in managing pain and other symptoms, including psychosocial and spiritual support (these providers can be consulted for advice and information, and provide mentorship for primary care providers);
- provides a flexible array of consultants (virtual and/or in-person) and shared palliative care support for patients and families whose needs exceed the capability of primary care providers;
- ensures that adequate assessment and management of symptoms, psychological distress, practical and financial issues, and spiritual needs are incorporated into comprehensive care for the patient and family.

### Tertiary Level

PEOLC is provided for patients and families in a tertiary health-care setting by an interdisciplinary palliative care team (8;37;40;43) and:

- provides a level of service for patients who require specialized, frequent and skilled assessments and interventions. In addition, patients may require diagnostic tests and/or invasive procedures, and/or have significant issues leading to a degree of complexity best managed in this tertiary setting;
- provides an acute care setting with appropriate tertiary resources;
- includes experts in PEOLC care that provide direct care for patients with complex PEOLC issues;
- provides formal and informal expert palliative care consultation and support (educate and train) to secondary experts and primary care providers;
- includes experts that conduct research and develop advocacy strategies that advances approaches to PEOLC.

Comprehensive integrated palliative care programs in Alberta will provide secondary and tertiary level care to support primary level health-care providers.

## 7. Alberta's Palliative and End-of-Life Care Overview

### 7.1. Historical Development

Numerous key developments have occurred in Alberta since the early 1980s, resulting in internationally recognized and respected service delivery models for PEOLC today (47). For many years, providers and planners within Alberta have actively sought direction and collaboration to improve access for people who could benefit from PEOLC care services and to improve the quality of the care delivered. Their efforts have been intentional and creative by utilizing resources that were within reach. A lack of co-ordinated funding and overarching provincial governance has led to a variation in program design, delivery methods, data systems and resources as they evolved in isolation from each other.

There have been a multitude of external and internal influences that have informed us of standardized processes and guidelines that are needed to ensure quality care. Past policy shifts have contributed to the idea that expanding care beyond acute care into communities was necessary to provide a continuum of care. Some more recent policy influences and key developments focused on co-ordinated access with home care services to produce mechanisms that align needed services and maintain people in their communities as long as possible. Increasingly, we recognized that acute care was not an appropriate place for many palliative and end-of-life care patients to die. However, we recognize that there will be individuals who should and do die in acute care settings, and will continue to do so. Therefore, it is important that good quality and appropriate care for the needs of the individual is provided in these settings. Collaboration between health-care sectors was considered essential to improve services and care in all settings where patients may die.

Between 1988 and 1998 Albertans saw improvements with respect to accessing adult PEOLC services and other supports through home care with the amendment of the Co-ordinated Home Care Program Regulation. This was supported by the Provincial Policy Framework, which was introduced in 1993. These changes led to improved access to and co-ordination of PEOLC services. As a result, acute care beds were utilized less by terminally ill cancer patients in Calgary and Edmonton. In 1995 and 1996, Edmonton and Calgary organized multiple locations for integrated adult palliative care programs, which gave many Albertans improved options for care and gave health-care providers more support. Hospice and palliative care units were recognized as essential components of this comprehensive integrated palliative care program model, but existed in varied locations and numbers across Alberta.

The next decade (from 1999-2009) focused on new issues that arose such as the aging population, increased immigration and the need for integration of chronic diseases so that all people who could benefit from and access PEOLC services. Palliative drug program policy changes and long-term care accommodation exemptions provided needed resources for patients receiving palliative support in the continuum of care. Rural programs were developed and these regions became the focus of planners, resulting in innovative practice models that eventually served to inform other jurisdictions such as British Columbia, Ontario and Saskatchewan.

Small, specialized pediatric palliative care teams were developed at Alberta Children's Hospital and Stollery Children's Hospital. These teams have provided a consultation service for clinicians caring for children across Alberta for many years. As palliative care is a relatively new field in pediatrics, many clinicians and families were not aware of the services unique to pediatric palliative care, which could be offered. Targeted education and advocacy efforts have substantially increased the number of children referred to the programs, but there has not been a commensurate increase in the resources for the two programs. Services that can be provided for children who would benefit from palliative care are limited. But, more importantly, education for providers at the primary and secondary levels of care, which would increase overall capacity has been reduced because of the demands of the clinical work. In 2010, Alberta's only hospice for children was opened in Calgary to provide respite and end-of-life care for children with life-limiting illness.

Adult PEOLC is a shared responsibility between primary, secondary and tertiary levels of health care. But the quality of care remains dependent on the strong linkages with clinicians providing primary level care. Primary Care Networks were identified as requiring more alignment with palliative care, and evidence-based practices and care.

Alberta has consistently shown an increase in PEOLC service utilization over time, but the funding and resources have not always matched the needs of PEOLC patients and families. Alberta has shown examples of innovation and perseverance; however, for almost two decades evidence-based standards and practices continued to have variations, limited knowledge transfer and knowledge translation, and impeded our quality of service delivery.

## 7.2. Current State Analysis

A current state analysis was conducted to provide a summary of PEOLC services in Alberta and to identify the existing gaps and barriers. The analysis was conducted using three methodologies.

1. A systematic review and synthesis of strategic planning and policy initiatives focused on local, national and international PEOLC programs, services and practices.
2. Qualitative analysis using questionnaires and surveys to gather information on existing programs and services.
3. Quantitative data gathering and analysis to identify trends, gaps and variations in PEOLC across the province.

AHS delivers care across Alberta in five geographically defined administrative zones: North, Edmonton, Central, Calgary and South. Calgary and Edmonton are the two main urban centres in Alberta that are considered to have well-integrated and comprehensive PEOLC programs, both of which are linked to home care programs, secondary level palliative care providers, and tertiary care palliative care units. North, Central and South Zones are described as “rural” in nature; their programs and level of integration of services differ from those in Edmonton and Calgary. The characteristics of integration vary from each of these rural geographies and also within metro-adjacent areas near the urban zones.

An integrated style of nursing practice is predominant in home care in rural settings, which can lead to fewer opportunities to develop PEOLC expertise. There is less overall availability of other disciplines such as occupational therapy, respiratory therapy, social work, and other health disciplines in many rural regions, resulting in decreased ability to provide comprehensive assessment and challenges to the “timeliness” of needed assessment.

Other issues for many rural communities include physicians need to be generalists and carry a full and varied practice that leaves little time to focus on specialized palliative care knowledge and skills. In addition, there is reduced on-call coverage by home care related to lack of availability of staff. Case manager to patient ratios vary within specific zones with some zones having a higher ratio of patients than others. Inequity exists across the zones (and rural to urban) in regards to hospice beds per capita, in addition to services and programming. Most urban centres reported affiliations with universities, colleges and research programs; however, Central Zones reported that they take students within and outside their zone for practicum and preceptorships (nursing and medical); they also participate in individual research projects.

### Pediatric Focused Services

The Alberta Children’s Hospital in Calgary and the Calgary Zone pediatric PEOLC program provides support to the Central and South Zones. The Stollery Children’s Hospital in Edmonton and the Edmonton Zone pediatric PEOLC program provides support to the North and some of the Central Zones (48).

“Children living with life-threatening conditions have always been part of the health care system; however, only now is an integrated vision toward their care emerging” (49). Medical and

technological advances have reduced infant and child mortality rates, and improved survival rates for children with severe and long-standing conditions (50;51), leading to a greater number of children for whom palliative care would be beneficial. As a specialty, pediatric palliative care is new and developing. There are, however, internationally recognized principles of pediatric palliative care. Guidelines have been developed, refined and adapted for local health systems and diverse communities. There are also some epidemiological and scientific data beginning to emerge.

The key principles and values espoused for palliative care in this framework are also the foundation of palliative care for children. Indeed, pediatric palliative care developed out of the specialty of pediatrics, which has always advocated for integrated, comprehensive, interdisciplinary and family-centred care. Compared to palliative care for adults, there are some unique aspects to the provision of pediatric palliative care, which must be considered in the development of effective service provision models.

- Pediatric palliative care is more predominately about integrated care for children living with a life-threatening or life-limiting condition and their families, rather than dying children. The prevalence of children living with life-limiting conditions is estimated to be at least 10-15:10,000 children (900-1400 children in Alberta). The family is the recognized “unit of care”.
- Care is provided to children with a wide range of ages and developmental needs. More than half of childhood deaths (0-18 years) occur in the first year of life (52). Pediatric palliative care may begin antenatally if a fetus is diagnosed with a life-limiting condition. The skill set needed to support this family will be quite different from what is needed to provide palliative care to an emancipated 17 -year -old. Thus, a wide range of knowledge and specialized skill sets are required for the provision of medical, psychosocial and spiritual care for children of all ages and their families.
- Life-limiting conditions in children are rare and medical care towards cure or control of the condition is by sub-specialists at tertiary centres. In most pediatric palliative care programs, 70% or more of the children on the program have chronic neurological or genetic (often multi-system) conditions and a much smaller percentage have cancer. The trajectory of the illnesses is mainly that of chronic disease with decreasing function and increasing needs over time and great uncertainty about when death might occur. This means that, for many years, palliative care will be provided along with aggressive care for cure or control of the condition emphasizing the importance of integrating the palliative approach to care.
- There are some ethical and legal issues unique to parents as substitute decision-makers, including the rights of children to be involved in decisions based on developmental capacity.

Parents as caregivers carry a heavy burden for providing complex medical care in the home, as well as co-ordination of services for their child. A child may be followed by multiple specialists, care clinicians in the community, allied health providers, home care, agencies, respite providers, and social and educational services. Grief support for parents includes support for the losses they experience all along the trajectory when a child is diagnosed with a life-limiting condition. A large percentage of children with life-limiting conditions also have intellectual and physical disabilities.

## Where are we now?

We know that:

- there is a mixture of service delivery models across Alberta;
- the access to services and programs varies between zones, regions and settings of care; it is not always co-ordinated, equitable or available;
- the level of knowledge and skill varies among providers across sectors, and within the same sector, depending on the location and despite role or discipline;
- there is inconsistent use of appropriate assessment tools, standardized techniques, policy and evaluation;
- there is inconsistent data collection and no sharing or merging of data with sectors;

- there are inconsistent practices/programming around PEOLC between Primary Care Networks and they are not consistently aware of policy changes and integration efforts with their primary and secondary care partners and community-based supports;
- there is inconsistent communication across the zones between levels of health care and between settings leading to fragmentation/duplication of services;
- the lack of co-ordinated resources, training, workforce, standards of practice, programs in rural regions, as well as service options within Calgary and Edmonton Zones further challenges pediatric palliative care;
- the lack of a provincial standardized PEOLC framework allows for incongruence in decision-making around support for both pediatric and adult PEOLC programs and services.

## 7.2.1. Identified Gaps/Barriers

### Co-ordination

All the programs within the zones report that communication between acute care facilities, home care and other primary care providers, such as family physicians, lack processes and tools to ensure ease of information transfer. Palliative care consultations are not consistently available or on Netcare. At times, this has led to a delay in appropriate therapies and/or investigations, and duplication of assessments.

### Data Collection/Performance Evaluation

Data is not collected in a consistent and standardized process across Alberta. The Edmonton and Calgary Zone programs have data collection practices, but follow individual zone practices. Additionally, primary care providers, including individual physician offices and Primary Care Networks do not collect specific PEOLC data such as patient satisfaction, desired location of care/death and ACP/GCD. Home care programs across AHS are becoming more standardized and collect various assessments within the Electronic Health Record (EHR), but practices across the different programs across the province vary. Currently, comprehensive performance measures with matched indicators are not developed for evaluating PEOLC services and programs.

### Human Resources

Although there are educational programs available across Alberta, there is no set standard of PEOLC training available for the primary level care provider. Training for specific secondary teams also varies, as there is no predetermined minimum level of adult and/or pediatric PEOLC training. There is no AHS provincial hub for PEOLC education or resources, including practice procedures, policies, online tools and general care instructions for caregivers, clinicians, patients and families. Interdisciplinary educational sessions are held across AHS, but they are specific for each zone.

Additionally, inadequate primary level staffing and staff with general PEOLC skills for patients with symptom issues at end-of-life in Long-Term Care (LTC), Supportive Living (SL), Rural Home Care and Acute Care has been identified as a factor that leads to unwanted and avoidable emergency department visits and hospitalizations.

Many providers at the primary care level participate in a variety of PEOLC educational opportunities, but by virtue of their rural generalist caseloads, the nature of their service delivery and the raw numbers in rural and community home care offices, it is usually only the palliative consultants, specialized palliative home care nurses and hospice nurses that have the advanced training and expertise in palliative and end-of-life care. Residents within assisted care settings are primarily cared for and managed by health-care aides who, at times, can receive consultative services by visiting home care nurses, although this is not formalized in all settings. Many health-care disciplines are required to provide adequate PEOLC for Albertans, but are not available across all geographic settings. For example, respiratory therapy technicians are not available within certain geographic areas for patients requiring extraordinary support, advanced airway care and complex oxygen

requirements. Also, there is specialized PEOLC resource inequity in terms of educators available within each zone to support clinicians at the primary care level.

### Access to Services and Programs

Both pediatric and adult PEOLC resources such as 24/7 access to palliative physicians, nurse practitioners, consult service and palliative home care is not available in all zones. There has been a lot accomplished with standardizing home care, but more is needed to be completed and implemented. A single centralized point of access for each zone is not consistently available. Additionally, provincial access points such as a phone number and website for information is not available for palliative and end-of-life care resources and services.

Bereavement services vary across the province both within hospices and in community settings, but they are not congruent with evidence-informed best practice in all settings. Additionally, spiritual care, social work and pharmacy service availability is inconsistent across the province.

There is a large gap in hospice space availability for Albertans. Based on the capacity planning work completed in 2013, a ratio of 7.7 beds per 100,000 people [population] (adjusted for disease and age) has been accepted as the standard for hospice beds in Alberta. Only the Calgary Zone is currently at a sufficient baseline for hospice beds per population. Access and wait times vary between zones for many services, including hospice admissions.

The process for accessing palliative care providers varies between zones, as do the models of the palliative care programs in both structure and design. There is no evidence of how this affects outcomes for palliative care patients. It is difficult to co-ordinate care across the province and plan for future service models. There is inequity across the province for access to direct care for palliative emergencies and specialized care needs. There is a lack of awareness and a non-uniform service model to access respite services across the zones. Cost incurred by patients (i.e. medications/equipment) also varies from site to site within hospice and respite settings. Clinical interventions and the intensity of services vary between hospice sites.

Palliative care team consultation can be provided in all settings of care within continuing care (including SL and LTC) and acute care facilities in Edmonton and Calgary. Other zones have varying access to palliative care team consultation with one zone having very limited access.

### Assessment/Communication Process

Utilization of assessment tools varies from site to site, although most are evidence-based. Not all sites have the actual tools; others have the tools, but the appropriate health-care practitioner might not be using them or trained to use them for a comprehensive assessment. No standardized patient/family satisfaction tool is utilized within Alberta. There is a general misunderstanding of terms used to describe “palliative” and/or “end-of-life” patients within the health-care system.

There is a lack of a standardized communication process such as transfer of information and access to policies and procedures across the province, which inhibits information transfer and effective communication. IT systems are not integrated and not all contract providers have access to patient information through Netcare.

### Pediatric Gaps

There is a need for more information about designated pediatric PEOLC services and resources in most settings across the province. The lack of comprehensive PEOLC pediatric services, especially in the rural settings, training and resources to provide pediatric palliative services and dedicated home care pediatric palliative services is a significant gap in supportive and co-ordinated services for primary care providers, pediatric patients and families.



## 7.3. Introduction of Need for Improvement

The Alberta PEOLC Provincial Framework has been developed through an academic process that examined the current state in Alberta. It is supported by the defined principles and is in line with our Vision statement. Strategic initiatives align with the chosen principles to realize an improved provincial approach to guide service provision and program development. There is recognition that in areas within the province, highly integrated (i.e., access to secondary and tertiary level of care) PEOLC services already exist, but there is a need to optimize and create opportunities that support equitable access to care across all five AHS Zones.

Our prospective strategic initiatives incorporate elements that are necessary to improve PEOLC services in all three levels of health care (primary, secondary and tertiary) with the main priority being a standardized integration of care at all three levels across Alberta. A provincial approach with a common oversight is necessary to plan and deliver such a standardized and integrated approach. A provincial approach would also facilitate communication and knowledge sharing. Implementing new programs, while building on those that exist will require prioritization, innovation and careful evaluation so that improvement is cost-efficient.

**From here...**fragmentation, inequity across regions, and undetermined accountability; **to there...**integrated, functionally planned, innovative rural contingency planning, common messaging & transparent accountability structures.

Program strategic investments such as creating and expanding inter-professional teams will help build community capacity. Initiatives at the primary care level include improving the integration of family physicians/nurse practitioners with secondary level partners to share care that benefits the palliative population. Primary health care requires an awareness of community-based supports for practitioners to provide practical support for patients/families and a common resource site or repository to guide their practice. Both urban and rural access to palliative care providers, co-ordination efforts, navigation and standardized care are just some of the drivers of comprehensive assessment and alignment of needed services to adequately manage palliative care individuals and their families. Achieving an optimal level of continuity that enables effortless transitions of care relies on co-ordinated service delivery and system/sector level integration. Integration alone is not enough to provide quality care, which must also be met with evidence-based standards and skill sets that are foundational to quality care.

**From here...**navigation challenges, palliative care provider access variance, lack of standards;...**to there...**similar services in all settings of care, provincially standardized co-ordinated access, timely access to palliative care providers both palliative and chronic diseases, primary care practitioners integrated with their community partners & quality care.

Successful home-based assessment, case management and patient-centred care planning can better support Albertans to receive care in place, reduce utilization of acute care resources and encourage connections between families and communities. Our provincial work needs to encompass multiple system, process, service and patient level strategies that, when combined, will foster improvements in the partnerships that exist now and look to innovations that can move us beyond. This can include investments in: technology, data collection systems, health human resources, education and research, which collectively will affect and facilitate service delivery to improve the experience of those diagnosed with a life-limiting illness. Care settings and services need to be sufficient for Albertans now and in the future, which requires us to plan diligently and recognize that capacity planning will be affected by our population characteristics.

**From here...**lack of skilled practitioners across the continuum, lack of communication between sectors, lack of caregiver support and bereavement for families, hospital based deaths when home or hospice is preferred, poor symptom management;...**to there...**the right mix of providers, a mix of community based supports and formal health care supports including education for care providers, policy direction regarding support for caregivers, choices of settings of care, adequate psychosocial and spiritual support & pain and symptom management, culturally sensitive & contextualized care. Care that focuses on the individualized needs of the patient and their families.

## 8. Care Service Delivery and Organizational Evolution

### 8.1. Introducing Innovative Service Delivery Concepts

Within Alberta there are many PEOLC and other innovations that have helped shape other programs across the nation and internationally. The formation of integrated systems within urban centres has proven to be successful. Additionally, the adoption of Advance Care Planning and Goals of Care Designation policies have allowed for Albertans and care providers to plan and discuss end-of-life goals before life-limiting illness presents (37;47).

It has been well-documented around the globe that delivery of PEOLC needs to revolve around an integrated system that provides care at the primary level with secondary and tertiary supports. Calgary's at-home death rate is substantially different from the rest of the country as a result of leading home-based care. This integrated approach to providing PEOLC is the innovative model of delivery that will expand across all geographical areas within Alberta (6;11;16;26;37;42;44).

Innovation: Develop a consistent system of incentives (monetary and non-monetary) for those providing PEOLC that supports community physicians, nurse practitioners, clinicians and caregivers as the primary providers of care throughout Alberta with secondary and tertiary services available for all those who require them.

Many successful international programs have found efficiencies and success for patients by creating a single point of access and care management. The advantages of a standardized, co-ordinated approach to directing service availability and access co-ordinated provincially through a single point, including case management include: efficient use of resources, less duplication, availability to keep all partners informed and involved, and more timely care for patients and families (5;6;10;12;37;40;42).

Innovation: Create a consistent, standardized approach to information for assessment and/or PEOLC services for Albertans that will build on existing points of access in a zone/sector and is readily transferrable across zones/sectors.

Innovation: Create one harmonized system for Albertans that will focus on standardizing information and tools/resources in a single point/centre across Alberta.

PEOLC needs to be provided to Albertans 24/7 within their care settings and by the local community support care teams. In order to keep Albertans in the community setting, avoid unnecessary use of the acute care system, support families and caregivers when needed, and reduce the burden on community practitioners and support those who wish to die within their community setting. A 24/7 community service needs to be established across the province that is equitable, efficient, and provides the right care at the right time (5;12;14;37;53).

Innovation: Establishing access to a 24/7 on-call PEOLC consult service for adults and pediatrics either locally or remotely that are available to primary care practitioners and other providers to support care within their community.

Albertans have told us that they want to receive care within their communities. In many parts of the province, hospitals are a part of the community. In other areas, Albertans who may wish to and can be supported to die in a different setting of choice, still die within hospitals. There are many challenges to shifting PEOLC to the community. These include:

- A requirement for stronger roles and supports for family physicians;
- Dedicated and consistent senior leadership support;
- A focus on changing organizational culture and attitudes about PEOLC;
- A commitment to patient and family-centred care and providing choices for Albertans, including how and where they would prefer to receive PEOLC prior to and at death (10;12;37;40;53).

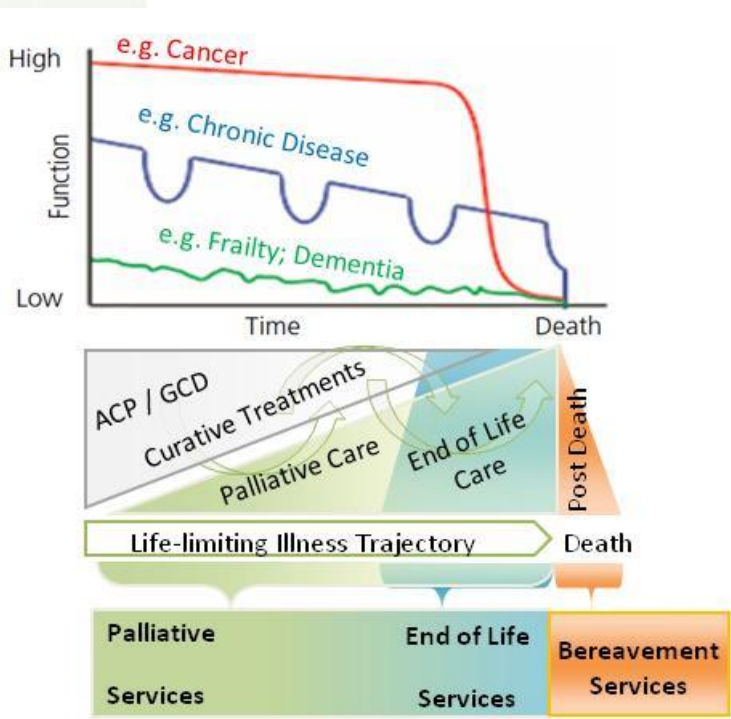
**Innovation:** Establish a Provincial Palliative and End-of-Life Care Innovations Steering Committee (PPAL/EOLC ISC) that is focused on identifying, trialing and implementing innovative ways to deliver care within community settings across all areas within Alberta; create alliance with Alberta Health through the PPAL/EOLC ISC to maintain alignment with public messaging around PEOLC.

## 8.2. Palliative and End-of-Life Care Programs and Services

### 8.2.1. Matrix Model

The fundamental PEOLC services that patients and their families receive from initial diagnosis of a life-limiting illness to post-death bereavement care is to be equitable regardless of the type of life-limiting illness patients have or where they live; these fundamental services within Alberta are categorized into Service Menus.

The PEOLC Service Menus will be developed to ensure that patients and families have the appropriate services available to meet their individual needs. PEOLC programs and services can be aligned with the illness trajectory regardless of the type of illness. The Alberta Patient and Family PEOLC Service Menu Model should be utilized as a tool to guide Albertans and all health-care teams to increase their awareness of the potential care needs and related services required for patients and their families during their PEOLC journey.



Common end-of-life trajectory models. Adapted from (1)

### 8.2.2. Alberta Patient and Family Palliative & End-of-Life Care Services

## Service Menus

Equitable access to fundamental services for all individuals diagnosed with a life-limiting illness and their families will be available across Alberta despite geographical location. There are two main Service Menus (16): the PEOLC Service Menu and the Bereavement Service Menu. While some services are typically required near the end of life, others span the continuum of PEOLC services. Each of the Service Menus is designed to meet the individual needs of patients and their families as they move from one stage to the next, recognizing that individuals with life-limiting conditions can have a wide range of different needs at different times (53). These services and providers will

address physical, emotional, spiritual, practical and social concerns of all individuals with a life-limiting illness. The approach to service provision will follow the same concepts irrespective of the diagnosis. For recognized, specialized, high needs or complex populations, more intense services and/or integration of palliative and end-of-life care programs may need to be built into the service models that are developed by specialized programs providing the bulk of their care and supports.

The Alberta Patient and Family PEOLC Service Menu will introduce a standard approach to managing an individual's need for services and programs that are patient and family-centred. They will be utilized to guide Albertans and all health-care teams to better understand and be aware of the potential care needs and related services required for patients and their families during their PEOLC journey. The PEOLC Service Menu is available from the initial diagnosis of a life-limiting illness through to the end stage of their illness trajectory (16;40;54). The Bereavement Service Menu is structured to provide supports to family members, caregivers and patients in anticipation of and/or after an individual's death. Not all services within a Service Menu need to be utilized by all patients and families, but as those with a life-limiting illness progress through their illness trajectory they may require varying degrees of services from those offered at the primary level to palliative care provider services within acute care settings (11;54). Similar to the Australian Population-Based Palliative Approach Model (5), the Alberta PEOLC Model focuses care efforts at the primary level, with secondary and tertiary level care available, if required.

As part of the development of provincial services and supports, consideration will be given to the evaluation of new and existing services and supports, demonstration of quality, value and outcomes, and to the research potential. The services and supports will be developed in collaboration with patients, families and care providers. Information obtained will also be used to support quality and service improvement, as required.

## Palliative and End-of-Life Care Services

This menu of services directly aligns with Alberta's PEOLC philosophical definition, which states that: "Palliative care aims to improve the quality of life of patients and families facing the problems associated with a life-limiting illness through the prevention and relief of suffering by means of early identification, comprehensive interdisciplinary assessments and appropriate interventions." Alberta's PEOLC philosophical definition also states that: "End-of-Life Care is care provided to an individual and their family when they are approaching a period of time closer to death, which may be exemplified by an intensification of services and assessments."

The components of the PEOLC services menu are provided to the patient and family from early diagnosis of a life-limiting illness until the end of life. Components of this menu include the following (this list is not intended to address how these services will be implemented, but rather the services that need to be available):

### **Public and Provider Services**

- Access to a Provincial PEOLC Program that encompasses a palliative approach to care inclusive of system co-ordination, navigation and case management.
- Access to a 24-hour telephone clinical support by palliative care providers (21).
- Access to an available program package of palliative interdisciplinary resources and information, including Advanced Care Planning/Goals of Care Designations (ACP/GCD), and other available programs and services.
- Access to the following additional educational resource material (availability dependent on audience, illness type and trajectory):
  - Final Days: designed for use in the terminal phase of care, although not all people nearing the end of their life will have a distinct and notable final days phase

- Stabilization: used as a short-term strategy in response to a rapid escalation of symptoms or shift in the burden of disease or in response to a family psychosocial crisis
- Caregiver Respite: for short periods of both planned and unplanned caregiver respite
- Preparation and support of the patient and family for continuing care in the “actively dying” phase of end-of-life at home or for those who would otherwise require overnight admission in a hospice or a hospital
- Vulnerable groups, specific to location or circumstance (43)
- To meet the diversity of cultural needs
- Access to information related to complementary resources
- Partnerships with external providers, including disease-specific societies, community support groups and employers

### **Physical Services**

- Access to 24/7 palliative and end-of-life primary care inclusive of an individualized care plan:
  - standardized comprehensive interdisciplinary palliative assessments for individuals with life-limiting illnesses and their families/caregivers;
  - palliative interdisciplinary consultation teams that provide specialized clinical and educational support (face-to-face or virtual) for primary care providers and to staff in all locations of care and, in some cases, limited direct services to individuals (55);
  - expert palliative interdisciplinary consultant services and supports for primary care providers and patients (virtual, Telehealth, face-to-face, palliative pain and symptom management) (54);
  - palliative home care for needs across the illness trajectory;
  - urgent access to services in communities for palliative emergencies;
  - medications and prescriptions/pharmaceutical services, including consultation in a timely fashion;
  - standardized PEOLC best practices, policies and procedures;
  - information, including guidelines and associated tools based on best practice and inclusive of consistent language/terminology.
- Access to appropriate end-of-life settings in communities and hospitals, if needed (e.g., designated palliative care beds, acute palliative care beds, hospice, tertiary beds)
- Timely access to palliative respite beds and services throughout the illness trajectory

### **Volunteer Resource Services**

- Volunteer Hospice Programs (54)
- Volunteer resources for activities such as companion sitting, coffee break and transportation(19)

## **Practical, Psychosocial and Spiritual Services**

- Comprehensive, accessible information initially focused on Hospice Palliative Care (HPC) related services for individuals, family members and professionals to assist with system navigation (10)
- Electronic health record/Telehealth and other technologies to support care delivery and education (39)
- Crisis Response (13)
- Spiritual care support to facilitate religious rites, sacraments and give pastoral care to help with existential suffering
- Anticipatory grief and emotional support for patients, their families and caregivers of all ages
- Bereavement Risk Assessment Tool (BRAT) (56) from Victoria Hospice to assess risk from complicated grief, multiple grief experiences and need for follow-up
- Preparing for death information package (booklet on what to expect during the last days of life)
- Funeral planning guidance
- Organ/ocular donation counseling
- Patient advocacy
- Financial assistance guidance for low income individuals
- Compassionate leave and funding for caregivers
- Equipment and medical supplies inclusive of palliative drug program (e.g., insurance coverage) (19)
- Guidance on access and funding for AADL's and caregiving support, and Respiratory and Oxygen services
- Information for children and adults needing to access a children's support program

Other considerations include addressing/re-addressing ACP/GCD at the diagnosis of a life-limiting illness and at any transitions, including change in status and/or care setting. Other support services need to be utilized as demonstrated through literature (and/or based on evidence) to have a significantly positive impact on quality of life or patient/ family outcomes.

## **Bereavement Services**

The Bereavement Services Menu is structured to support those who are bereaved, inclusive of family caregivers, health-care providers and others who are in need of supportive service interventions. The following list is not intended to address how these services will be implemented, but rather the services that need to be available.

- Evidence-informed provincial standardized Bereavement Program for all ages, inclusive of one-on-one counselling after the loss of a family member or patient
- Age-appropriate, evidence-informed standardized Hospice Bereavement Program(s) (e.g., remembrance service, grief resources and information packages, newsletters, sympathy cards from volunteers, telephone support from counsellors and volunteers)
- Spiritual care visits to facilitate religious rites and spiritual needs and/or to help with existential suffering
- Bereavement Risk Assessment Tool (BRAT) follow-up and bereavement counselling services (8;38;56)
- Information and education about grieving, and grief and bereavement support groups
- Grief and bereavement services and support groups
- Standardized evidence-informed children's Grief Support Programs
- Funeral planning guidance
- Specialized bereavement workshops at different points in time following the death of a family member/ significant other
- Partnership with external providers, including Primary Care Networks, Family Care Clinics, religious organizations, community support groups and employers

## 9. Strategic Future Pillar Initiatives

Future initiatives are built on the foundation provided by preceding sections of this document. The initiatives within this Alberta PEOLC Provincial Framework, when implemented, will provide a comprehensive system of services and supports to meet the individualized needs of PEOLC patients and their families at any age. It will be integrated across sectors and accessible to all those who require it. The framework will also incorporate technologies to enable, facilitate and support service needs and transitions. It will be grounded in evidence and best practice, subject to ongoing evaluation and quality improvement, and both supportive of and supported by research that leads to positive outcomes for individuals with life-limiting illnesses and their families.

The Initiatives are categorized into five main colour-coded pillars: Program Development, Partnerships and Innovations, Practice and Standards, Education and Awareness, and Communication. These pillars are foundational to the development of a PEOLC provincial program. A complete list of the initiatives is in appendix C.

Program Development

Partnerships and Innovation

Practice and Standards

Education and Awareness

Communication

### 9.1. Program Development

As Alberta works to transform PEOLC services under a standardized provincially focused model, there is a need to integrate and spread the recognized exemplary service models that currently exist in various zones across the province.

Specifically, within pediatric PEOLC services, the ability to provide comprehensive assessments and complex symptom management without the support of secondary services for children with life-limiting illnesses and their families requires a depth of expertise that cannot be provided by generalist practitioners in primary care, acute care or in home care. Even in the urban areas, specialized palliative home care does not exist. Although generalist pediatric home care is available in Edmonton and Calgary, it is not provided 24/7, which makes it challenging to support the death of a child in his/her home. In most rural areas, services for children may be provided by an integrated home Care team. These services involve physicians in primary care that are supported by the specialized pediatric palliative care team.

The ability to provide adequate home care coverage varies widely in rural areas based on staffing levels, the size of the base office and the comfort of the staff that provides palliative care to children. In both centres, the consult team members are heavily involved in program development, as well as advocacy. They also provide education to all disciplines across undergraduate and post-graduate education and continuing professional development for acute care and home care clinicians to build awareness of the integrated model of pediatric palliative care. Educational initiatives are aimed at increasing awareness of the services provided by the pediatric palliative care teams to encourage early referrals and to build capacity at the primary and secondary levels of care.

**Initiative:** Integrate zone PEOLC strategy and operations across all zones as part of a provincial program for both pediatrics and adults. Within the pediatric programs, assess current resources and requirements for existing specialized palliative care programs, including providing access to high-quality palliative services for all infants, children and youth.

**Initiative:** Working from the success of the programs within zones that offer 24/7 services, standardize access points and spread 24/7, on-call PEOLC consult services for adults and pediatrics for primary care practitioners, care givers, patients and families to support care

within the community, including strategies that support rural/remote practitioners such as regular rounds by Telehealth. This will allow interdisciplinary access in areas where it is limited and build capacity when knowledge and skills are transferred to local practitioners.

### Specialty Palliative Clinics

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There are many specialty palliative clinics in Alberta. The Pain and Symptom Control Clinics at the Cancer Centres in Edmonton and Calgary are accessible by many Albertans and are an important support for patients with cancer-related symptoms. For the North and Central Zones, the Pain and Symptom Control Telehealth Clinic from the Cross Cancer Institute (CCI) has been established. These clinics provide comprehensive assessments and recommendations to primary level care providers (including oncologists and family physicians) to address symptoms in the context of managing the underlying disease. Services are available to patients receiving active treatment for cancer. Once the patient is diagnosed as needing palliative care, they are seen by the community consult team. Patients seen by these clinics benefit from interdisciplinary teams who have palliative expertise.

**Initiative:** Formally integrate the Pain and Symptom Clinics into the palliative system resources available for primary PEOLC providers across Alberta.

### Community Cancer Clinics/Nurse Navigators

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Community Cancer Clinics are an important setting for the initiation of palliative services. Staff is in an excellent position to identify patients who may benefit from a palliative consult for symptom management, or when their care transitions from being curative to becoming palliative. Nurse navigators have an important role in connecting patients to other resources such as home care, palliative consultation services and community resources.

**Initiative:** Build connections between cancer nurse navigators and 24/7 Palliative Care Consult Teams, including nurse practitioners, to enhance integration of services for PEOLC patients and their families.

Nurse navigator roles have been shown to be effective in early stages, transitions and various settings such as cancer care, chronic disease and other complex patient populations. Palliative care nurse co-ordinators have also gained popularity in the rural settings. It is especially key for pediatrics that every child and their family have an identified key worker or care co-ordinator. This is considered to be a primary feature of excellent models of care for children with chronic complex conditions and for pediatric palliative care teams. Parents of medically complex children and/or children with life-limiting conditions have identified supportive case co-ordinated care including respite provision as paramount. The role of palliative care nurse co-ordinators would be to help advocate for families, contact services, call physicians, book appointments and liaise with providers of all settings.

**Initiative:** Identify the need for a key worker/co-ordinator or a nurse navigator and raise awareness of existing roles to improve patient and family ability to navigate the health care system along the trajectory of care.

### Emergency Medical Services (EMS) Management of Palliative Emergencies

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Calgary has an EMS program where EMS staff has access to a palliative physician who can assist with the management of palliative emergencies that reduce the need for emergency department visits. This program is expanding from urban Calgary into the rural area of the zone and is being explored for feasibility within the Lethbridge geographical area. The Edmonton Zone also has a collaborative partnership between Continuing Care and EMS, which is called Palliative Care and Treat in Place. Urgent care is provided by EMS paramedics and home care or supportive living staff. They support patient/family choices in the home to prevent visits to the emergency. However, we do acknowledge that there will always be a percentage of the PEOLC population that will access services through the emergency room, and this may be appropriate. It is the place where serious life-threatening illness is often found and where goals of care are identified for the first time. Training in



symptom control and increasing awareness of PEOLC care programs and services by emergency physicians will improve integration of care.

**Initiative:** Formalize and expand the EMS and palliative care collaboration in Alberta.

## Community Hospice & Designated Palliative Care Spaces

All zones have designated hospice care spaces available, but not in every urban centre. Additionally, only the Calgary Zone has an adequate number of spaces to serve the needs of its current population and Calgary has the only dedicated pediatric hospice. Hospice spaces can exist in either free-standing hospices or units within other care facilities. There are no provincial standards regarding hospice care teams and inequity exists regarding coverage for medications.

In some rural communities where numbers do not support the sustainability of dedicated units, there has been the identification of a small number of palliative beds in an existing facility, either in acute care or in long-term care. The identification of one or two beds in these settings allows individuals to die “in their community” even though this may be in an acute care setting.

In addition, attention needs to be paid to the need for palliative care respite spaces to be made available in communities throughout the PEOLC trajectory. Local capacity needs to be identified to allow individuals with life-limiting illnesses and their families to be supported at points where a respite would be required. Respite would support care and allow the patient to then return to the community.

**Initiative:** Develop a detailed hospice capacity plan until 2034 that encompasses strategies for rural geographies where hospice centres are not viable, but local hospice spaces within other settings (community or acute) are utilized and supported directly by local 24/7 Palliative Care Consult Teams.

## Complex and/or High Needs Patients

Patients with chronic disease, frailty, cancer, or from a recognized vulnerable population will often have significant and unique needs. Many would benefit from a palliative approach, and should be eligible for PEOLC programs. Various jurisdictions have also developed programs for high needs, high cost patients. Typically, these patients have multiple co-morbidities, limited support, frequent re-admissions to acute care, and limited primary or family support. These programs could be aligned with PEOLC programs or PEOLC programs could be aligned with the complex, high needs programs, supporting both the integration of PEOLC and keeping high needs patients in the most appropriate care setting (5;12;37;44;54;57).

**Initiative:** Develop delivery concepts for complex, high needs patients (infants, children, youth and adults) and integrate home care, primary care, EMS and acute services, PEOLC services, and other community based services such as volunteers and non-government offices that help to meet some of the high needs of PEOLC patients and their families.

## ***Practical Supports***

At the frontline, the ability to deliver care in the patient/family setting of choice is often hindered by the lack of, or difficulty obtaining specific equipment, supplies or other resources. Having either an easily accessible single point of co-ordination or a location to retrieve information on where and how to obtain equipment, oxygen, IV tubing and solutions, financial support and caregiver education would allow health-care providers to overcome some of the barriers that may result in patients being admitted to acute care, or providing care without adequate supports (10;12;13;38;39;55;58).

**Initiative:** Develop a one-stop information portal that includes information on equipment and medication access with links to other programs and information sources such as Virtual Hospice, Caregiver College, and online grief and bereavement resources for both PEOLC pediatrics and adults.

**Initiative:** Review whether or not adequate funding is in place for short term and specialized equipment and supply needs. If gaps are identified, develop a strategy to resolve them.

As the structure of continuing care changes over time, it will be important that people are supported to die within their residences, if they wish to do so. At this time, many residents of long-term care will die within their facilities. Currently, a provincial PEOLC educational support program for providers in long-term care and other supportive living settings is not uniformly available. There is a need for all staff within these facilities to be engaged, knowledgeable and supported to provide skilled PEOLC. In particular, health-care aides, who provide a great deal of direct care, benefit from targeted intervention and strategies.

**Initiative:** Identify and implement PEOLC care models specific to supporting those within long-term care and supportive living.

### ***Patient and Family Satisfaction***

While patient satisfaction may be more challenging to measure in a palliative care population, there are strategies that could be applied to some aspects, especially if a “palliative approach” is used more consistently. Accreditation Canada Hospice Palliative End-of-life Standards (59) include an expectation to incorporate an accepted scale as a source of information and feedback to teams. Previous work in the Helping Operationalize Palliative Expertise (HOPE) project (60) included the development of brief evaluation tools for both patients and families (16;39;44;59).

**Initiative:** Develop infrastructure, including funding and data analysis to support the use of a patient/family reported outcomes model such as the Famcare scale or a standardized tool and mechanism for results to be used locally and rolled up provincially based on best practice.

### **Grief and Bereavement Services**

Grief and bereavement support are only available sporadically across Alberta, and there is a lack of clarity around what constitutes best practice. In Edmonton and Calgary, where services are more formalized, gaps in services are still reported. In the rural zones, volunteer groups provide some grief follow-up and counselling. The Central Zone also notes that the Palliative Consult Team is able to provide some anticipatory grief counselling. Additionally, current literature indicates that morbidity and mortality is higher in individuals who are grieving, which has a larger impact on the system.

**Initiative:** Identify a provincial model, and develop provincial and local grief and bereavement programs within each zone/geographic area that capitalizes on local resources and builds on programs and strategies that have been successful in other jurisdictions (10;12;21;33;39;41;58).

### **Volunteer Services**

PEOLC volunteer availability and training varies widely across Alberta. PEOLC volunteers provide grief counselling and also support patients with social and/or practical needs such as travel to appointments, fundraising for equipment and companionship/family support, depending on the area. There are a number of smaller communities that are developing outreach and volunteer programs for home-based hospice care addressing gaps in service delivery. There is a need to encourage and support these volunteers. Although provincial guidelines exist for training volunteers, there are not enough resources to provide support for volunteers, and co-ordinate and teach volunteers about palliative care.

**Initiative:** Explore developing a provincial PEOLC volunteer network that co-ordinates and expands existing volunteer programs.

## 9.2. Partnerships and Innovation

Building an innovative service delivery PEOLC program in Alberta that is patient-centred, relies on primary care providers, requires specific PEOLC expertise, and has unique, diverse care options requires a dynamic and stable provincial foundation that combines current service models with innovative methods. The following initiatives need to be sustainable and accountable; they need to help drive innovation within PEOLC in Alberta, and strengthen the care models.

### Patient and Family-Centred Care

Patient-centred care language is emerging in various programs, strategies, and directional documents in Alberta, as well as other jurisdictions. Examples include the Case Management Framework in Seniors Health, and the patient-centred program in AHS Cancer Care (61), and various patient-centred approaches led by contracted providers. Edmonton Zone EOL Care Pathway guides the health team based on patients' end-of-life wishes and ensures evidence-based pain and symptom management (6;10;16;26;37;39;44;47).

**Initiative:** Identify and develop connections to other patient-centred initiatives in the province, and continue to maintain alignment with patient-centred concepts across the health care spectrum.

### Community Capacity

The capacity to provide palliative care in the community can take various forms, depending on the community, geography and local assets. Identifying the strengths and challenges that communities face is an important part of building capacity. Looking beyond the formal health-care system to be inclusive of partners such as community agencies and disease specific societies is also part of building community capacity(6;10;11;13;39;43;44;54).

**Initiative:** As part of a provincial PEOLC program, develop direct links with the Primary Care Networks and Family Care Clinics within local communities and partner with provincial stakeholders to build strong relationships with those who can support the provision of PEOLC in local communities such as contracted partners in long-term care, supportive living and home care, as well as community organizations.

### Health Promotion

Considering PEOLC services in Alberta through a health promotion lens can help shift the momentum towards earlier use of a palliative approach, pain and symptom management (harm reduction), engagement in advance care planning discussions, education about dying and death, greater community engagement and participation, and grief and bereavement support. Discussion is growing in Canada and internationally about how to use a health promotion approach to move PEOLC from a specialist model to an integrated and community-focused model. This would also align PEOLC more closely with chronic disease programming, emphasizing a close tie to early integration of a palliative approach (15;42;44;53;55;62-64).

**Initiative:** Identify and connect with a health promotion framework (e.g., the Ottawa Charter, framework for integrated care [CHPCA, QEOLCC Quality End of Life Coalition of Canada]), and palliative service development and programs.

### Supportive Infrastructure and System Integration

Many different organizations support PEOLC patients and families by health and social supports. These organizations bring immense value, but if they are not aware of the provincial transformation to an integrated primary level approach to PEOLC, duplication of efforts and divisions in alignment structures will occur.

**Initiative:** Establish a Provincial Palliative and End-of-Life Care Innovations Steering Committee (PPAL/EOL ISC) that is focused on identifying, trialing and implementing

innovative ways to deliver care within the community settings across all areas within Alberta. Create an alliance with Alberta Health through the PPAL/EOL ISC to maintain alignment with public messaging around PEOLC.

**Initiative:** Supported by the PPAL/EOL ISC and with the establishment of the provincial PEOLC program, work collaboratively with other national networks and take full advantage of local and national initiatives that will strengthen PEOLC within Alberta.

**Initiative:** Review the current structure and develop a consistent system of incentives (monetary and non-monetary) to support physicians to collaborate with primary care health teams in providing a palliative approach to care (44).

**Initiative:** Create synergies amongst existing organizations/services within Alberta (e.g. Community services, Covenant Health, Family Care Centres (FCC's), Home Care, Primary Care Networks (PCN's), primary care services, Strategic Clinical Networks (SCN's), Towards Optimized Practice (TOP), and secondary levels of care). These partnerships need to be supported with education and practice guidelines that are evidence-based, standardized and easily accessible.

### 9.3. Practice and Standards

Provincially standardized clinical procedures, guidelines and care standards applicable to PEOLC currently do not exist to support clinicians and/or patients and families. Within each individual zone, there are local standard assessment tools, educational resources, care pathways, eligibility criteria for access to PEOLC secondary and tertiary services, and other guidelines to support PEOLC services within specific geographical settings. However, due to varied local tools in place, service inequity for Albertans exists in areas that do not benefit from the availability of updated evidence-informed guidelines and standards of care.

#### Provincial Standardization

PEOLC within Alberta is mainly provided by community practitioners at the primary care level. Evidence-informed, best practice standards help guide palliative care practitioners on how to manage care. Service guidelines that are developed by palliative care experts who have pooled their knowledge and experience help ensure quality standards and equity improvement for Albertans (19). Some guidelines available within the zones may have been developed prior to the establishment of AHS's Governance Document Framework.

**Initiative:** Identify current local best practices, design a provincial standard, and implement practice standards, guidelines and protocols to assess and manage PEOLC symptoms (including dementia) for primary and secondary level care providers (5;6;10;44).

Across the zones, many proven assessment and screening tools are utilized, but due to both the variation in tools used and the difficulties with information exchange, patients transitioning between sectors, care settings, care teams, and/or geographical settings may be subject to repetitive reassessments to gather information already collected, but not easily shared. There is a need to standardize assessment tools and guidelines to provincially streamline practices, which leads to a better experience for patients and families, and increases system efficiencies through collaboration and alignment to avoid duplication.

**Initiative:** Identify and agree on a set of provincially standardized common screening, assessment tools and guides to practice. Some examples of these tools are ESAS-r, Palliative Performance Scale, Collaborative Care Plans and Symptom Management Guides to Practice (6;10;12;16;44).

Albertans who are receiving PEOLC services require a clear understanding of which programs and services are available to them. These PEOLC services are divided into Service Menus, but there is a

lack of clarity as to which services are accessible and available across Alberta. There is a need to define and standardize the terms and criteria for receiving PEOLC services within each menu.

**Initiative:** Eligibility criteria definitions and service standards (home care supports, pharmacy services, hospice settings.) are to be provincially standardized across all care settings to ensure equitable access to PEOLC programs and services (10;19;44).

### Policy Development

There is a need across the province to develop PEOLC policies and procedures, as well as guidelines/pathways that are provincially applicable across AHS. This might include, for example, a provincial guideline for palliative sedation and other clinical topics (Calgary's guideline is 2009; Edmonton's is 2005.) There is also a need to develop and/or update current zone/local PEOLC policies and procedures to ensure evidence-informed resources are available for all PEOLC providers.

**Initiative:** Create a provincial policy development expert panel under the guidance of the PPAL / EOL ISC that works with the AHS clinical policy team and addresses the clinical supports that are needed, which are applicable to primary and secondary providers such as a provincial palliative sedation clinical guideline (12;15;44).

### Data: Collection, Analytics, Evaluation, and Reporting

Within the Edmonton and Calgary Zones data resources are allocated for the collection of specific PEOLC data, including consultations, hospice utilization and patient demographics. Additionally, within the Edmonton Zone, annual statistics, including a performance report is publically published. This annual publication has been celebrated internationally as a transparent model that is in place to improve PEOLC across the globe.

**Initiative:** Develop provincial standards for the collection of specific PEOLC data for adult and pediatric patients. Begin to collect data for all patients who receive secondary or tertiary PEOLC within all the zones, develop a provincial analytics dashboard and publish provincial performance reports annually.

## 9.4. Education and Awareness

There are a variety of educational resources around the province, some ongoing and broadly related to PEOLC, and others tailored to requests from specific areas/units/programs that relate to an identified need for their staff. These vary from short just-in-time sessions, to full day or multiple day workshops and conferences available in Alberta. Methods of advertising open education sessions vary. Some are accessible online via provincial web-supported programs; others are posted or advertised in local or zone newsletters or websites. A central and accessible means of advertising does not exist, but would provide a conduit for all staff and partners within the province to learn what is available to them for training opportunities.

### Enhancing Education

Specially developed PEOLC education exists locally in all zones. For example, the Central Zone delivers a workshop on "Death, Dying and Dementia" to address the increasing numbers of individuals dying either directly from dementia or in conjunction with other diseases. The workshop's focus is on dementia-specific issues such as the assessment of symptoms in non-communicative patients, as well as on decision-making and the importance of a team approach to planning care for the individual. In the Edmonton Zone, a one-day workshop on "Pain and Symptom Management" is offered throughout the year for front-line nurses caring for palliative patients. In the Calgary Zone, "Navigating the Journey toward Death" education days are advertised within local newsletters. Additionally, many good resources have been developed and are available for patients, families and informal caregivers. One such example, A Caregiver's Guide, was developed in Alberta. Both Edmonton and Calgary PEOLC programs have incorporated family resident palliative care

experience as a required rotation for physicians. All zones provide Learning Essential Approaches to Palliative Care (LEAP) training several times per year. This is a nationally recognized program developed by the Pallium Project. Many online resources are also available such as CHPCA, Alberta Hospice Palliative Care Association (AHPCA), Virtual Hospice, and a variety of resources from AHS, zone-specific websites, and community and hospice groups throughout our province. Also, all zones have created resources such as pamphlets and information packages for local use.

**Initiative:** Build on the established education programs, procedures, and access to tools within each zone and leverage the existing infrastructure by identifying all forms of PEOLC educational resources available across Alberta, standardize the methods under a provincial focus, and create tools and programs for making the resources easily accessible for care providers across all geographies to decrease the duplication of similar resources developed in isolation.

**Initiative:** A central repository that is maintained/updated regularly for sharing family resources or allowing central access online for patients and families is to be developed to provide readily accessible resources. There is also a need to expand and evaluate virtual education (5;10;40).

The LEAP modules are currently in the process of being updated and revised by Pallium to ensure that they are reflective of current evidence and the changing populations that health-care professionals serve. This work is being done through an extensive literature and peer review process with the engagement of palliative medicine experts throughout Canada, and will be ongoing for quality assurance purposes (65).

The Helping Operationalize Palliative Expertise project (HOPE) (60), which was operational from 2007 to 2011, with participation from all areas of the province, facilitated delivery of many educational programs, including training LEAP facilitators, developing a LEAP Facilitator Guidebook, and organizing LEAP delivery in all areas of the province during the project. Telementoring programs to support rural nurses, facilitating educational rounds and evaluating different methods of delivering Health Care Aide PEOLC education were also outcomes of this project that saw varying degrees of success. Gaps that existed at the end of this project, related to their expected outcomes, were sustainability efforts for education and for resource capture, and accessibility for the whole province. These gaps continue to exist today as there is no one list of education resources available to all AHS and partner-provider staff, nor is there a provincial plan or fund that ensures sustainability of quality PEOLC education throughout the province. It is noted that Covenant Health's Palliative Institute focuses its activities in five core areas, one of which is education. It is described as: Advancing the education of health-care providers in PEOLC by providing tools and training opportunities, and by promoting integration of PEOLC material into curricula.

The Palliative Institute will partner to add support to this area of accountability, in support of evidence-based curricula for preparing palliative care givers, and those currently in practice.

**Initiative:** Inventory existing resources that have already been developed. Partner with national organizations offering educational resources, as well as educational institutions such as universities within Alberta, to develop an innovative and collaborative plan to establish and support minimum standards of education and ongoing education for those working directly in PEOLC; therefore, improving quality of care for patients locally (10;16;38;44).

**Initiative:** Work with academic institutions to identify and introduce standards that support palliative care providers with relevant qualifications (CNA Canadian Nurses Association Hospice Palliative Care certification, PEOLC certification) or strategies and supports to train staff to these standards.

## Resourcing Education

There are several options to apply for funding assistance such as internal and external bursaries and grants, or funding opportunities available through various professional organizations. However, these provide limited funding to a finite and small group of people. Staff will be required to attend and pay

for education up front before knowing if any assistance will be approved. As well, many staff report that it is challenging to get time away from work approved to attend educational courses due to workload and staffing issues.

**Initiative:** Develop a provincial funding mechanism that allows clinicians/providers across Alberta to apply for exceptional PEOLC educational resources, including advanced education and seminars such as anticipatory grief and bereavement sessions.

There is a need for resources that are dedicated to support education. The facilitation of education becomes the responsibility of clinicians or consultants working in PEOLC, whose primary role is clinical care. While many of these health-care workers are trained physicians and nurses, they may not be adequately supported by the principles of adult education, nor have the resources to address educational requests. This also means few established qualifications/competencies of a standardized nature exist throughout the province. Additionally, within rural and remote communities there is a need for quality education to be provided by the best possible facilitators; this gap needs to be addressed through an innovative approach. Some of this has been addressed by using current technology such as sharing Grand Rounds or facilitating courses online and via Telehealth. But it cannot be supported by the bandwidth available in certain geographic areas of our province.

**Initiative:** Identify specific educational and resource gaps in educational availability within rural and remote communities, pilot solutions and roll out. Establish proven methods to spread resources across all geographies (26).

## 9.5. Communication

### Public and Provider Resources

Patients and families are seeking easily accessible PEOLC information and supports, as well as information on complementary resources that may be beneficial in self-management. Albertans need access to information about the benefits of PEOLC programs and services. Currently, information for Albertans is difficult to find, fragmented and not current. Additionally, access points for patients and families are not clearly articulated and many providers at the primary level are also unaware of how to access PEOLC resources, education and services across Alberta. Currently, information regarding PEOLC services is not routinely posted for each zone and, where information is available, it is often not clear that the information is zone-specific.

**Initiative:** Create interactive, standardized PEOLC web pages for clinicians, patients and families that are user-friendly, maintained and updated regularly, including zone-specific information and details (12;19;40;44).

A structure for communicating information on educational opportunities for clinicians across Alberta is not centralized. This leads to localized and geographic-specific events such as palliative rounds, online seminars and interactive forums attended by a limited number of clinicians.

**Initiative:** Develop provincial educational avenues for clinicians, health-care aides and volunteers such as rounds/seminars and forums (12;15;19;44).

### Information Exchange at Transitions

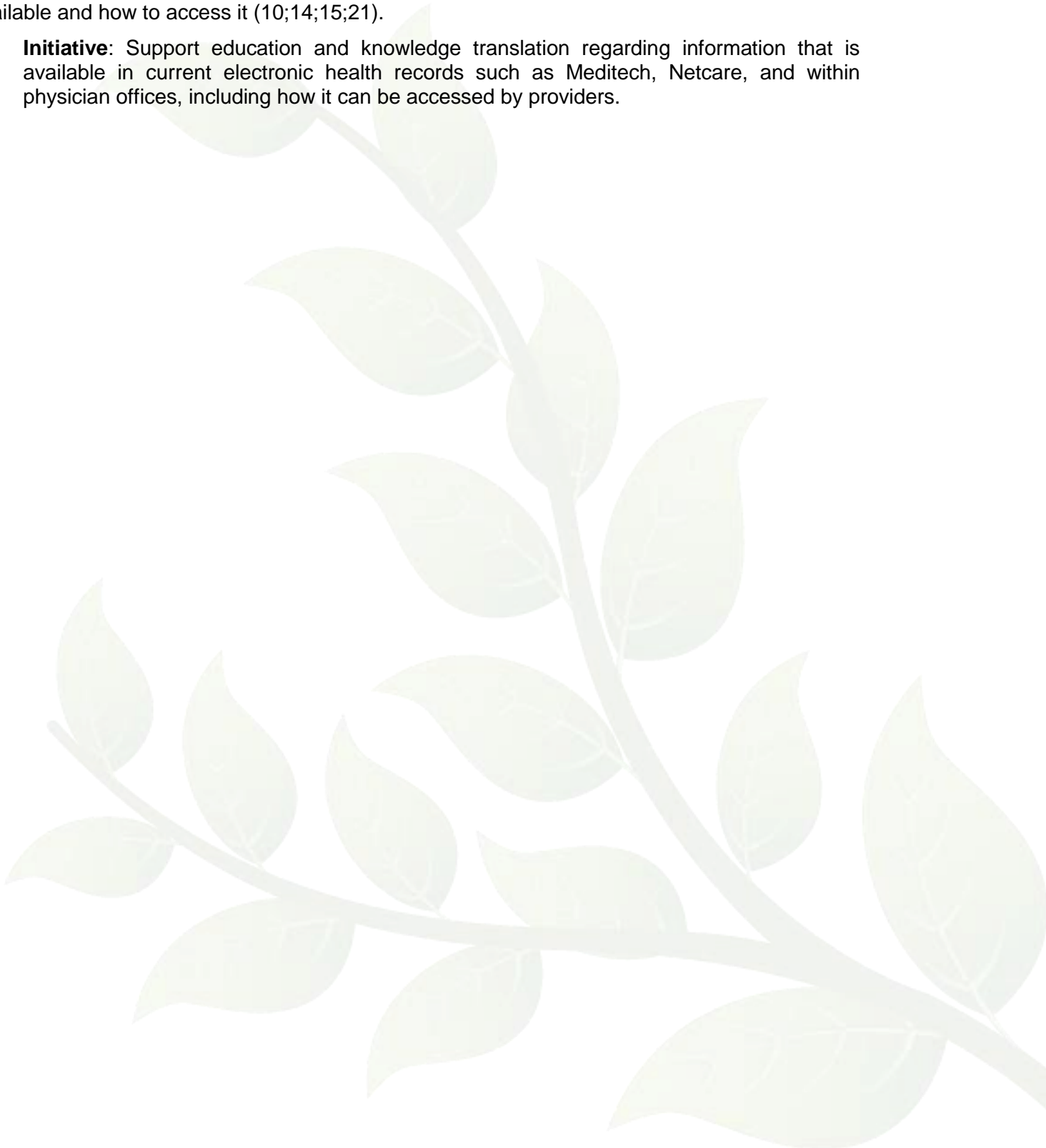
Regardless of geography or zone, effective communication of patient information is not ideal and no provincial communication standards or tools are in place that supports clinicians who provide PEOLC with all settings of care, including at the primary care level. It has been noted that standard communication to support seamless care transitions is required. The current lack of processes results in services and programs not being able to “talk” with each other, which affects the continuity of care. Enhanced communication and “bridges” between emergency clinicians and palliative care would be beneficial for patients and providers.

**Initiative:** Enhance and provincially standardize both the referral and the transition communication processes, ensuring concordance with requirements from Accreditation

Canada (59). Identify possibilities within electronic health records or paper-based processes that follow the patient as they move through the system, including exploring the option, feasibility and potential benefits of a provincial registry (12;15;19;26;33;44).

Multiple platforms for documentation exist throughout Alberta with limited connectivity between them. This limits the ability to share information easily and puts added burden on patients and families who must repeat their stories and risk the loss of critical information at transition points. While work continues to integrate these systems, it is important for users to be aware of what information is available and how to access it (10;14;15;21).

**Initiative:** Support education and knowledge translation regarding information that is available in current electronic health records such as Meditech, Netcare, and within physician offices, including how it can be accessed by providers.





## 10. Research, Evaluation and Quality Improvement

Ensuring that all Albertans have access to comprehensive, co-ordinated, and integrated palliative care and high quality care at the end of life requires a commitment to conduct research, and evaluate and employ quality improvement initiatives (5;13;37;58). Capacity to conduct these activities requires investment, predominantly into research education and data warehousing initiatives (53). Human capacity can be enhanced through enticing both new and existing researchers and educators into the field of palliative and end-of-life care (36).

The provincial program developed through the provincial PEOLC framework will partner with the SCNs, academic centres across Alberta, the Palliative Institute at Covenant Health, and other external partners to support the generation of research in PEOLC topics and the translation of research findings into policy and practice. Strong linkages between support teams (research, innovation and analytics) and clinic teams will diminish theory-practice gaps. Consensus across organizations and disciplines on research priorities will enable experts, both academic and those in direct practice, to plan and manage research initiatives based on changes in the PEOLC environment, including the outcomes of Advance Care Planning and Goals of Care Designation research and initiatives.

A focus on patient-centred care through research and engagement with specific patient engagement is important. With a large proportion of the population over age 80, it will be important to learn from them their end-of-life expectations and needs that may be quite different from those at mid-life.

Although the approach to palliative care has been around for many years as a “discipline,” palliative care is relatively new and a comprehensive evidence-base does not exist for most topics. The nature of the research is difficult. Many patients die before the research can be concluded because research about treating PEOLC symptoms is complicated by patient morbidity. Symptoms themselves constitute a major focus for research and evaluation; for example, pain, shortness of breath, fatigue, appetite, anxiety and depression (42). Quality of life encompasses all of these symptoms and is a research topic on its own. Caregiving constitutes substantial societal resources that are provided to dying patients. Both the intensity and duration of caregiving results in adverse consequences for caregivers and is responsible for research (66). Bereavement signals a time for care after death. Health services research and health-care delivery evaluations are needed to improve the conceptual, operational and policy domains for co-ordinated and integrated services across diverse health-care settings (5). Finally, addressing psychosocial, spiritual and existential concerns is a major topic for research and evaluation.

## 11. Policy and Funding

Albertans need a full continuum of palliative care services in place to improve care supported and endowed by a comprehensive provincial policy. Organizing this integrated system of care requires a dedicated governance structure and affiliated network to align service compatibilities and address challenges in a broad, yet intentional fashion (10;13;37;44).

Building relationships with all sectors and settings where people with life-limiting conditions receive care requires policy and practice changes. Equitable access to PEOLC services for individuals with non-malignant conditions requires further development of governance and monitoring systems enabled by policy implementation (e.g., Advanced Care Planning and Goals of Care Designation).

Clear policy and funding parameters are absent in our current system for PEOLC apart from government mandates, related legislation and regulations. Some examples of this are the following acts:

- The Public Health Act requires AHS to provide palliative care;
- Under the Nursing Homes Act palliative care patients are exempt from accommodation charges;
- The Alberta Blue Cross Palliative Care Drug coverage program;
- The Continuing Care Health Service Standards require AHS to have operational policies and processes for PEOLC; and
- The Compassionate Care Leave Bill which may impact our need to ensure that caregiver resources are in place.

These impart funding obligations for health care for essential PEOLC services/resources, but do not provide comprehensive coverage under any specific policy direction. Funding models with guidelines and policy direction will support an integrated system that operates seamlessly, which supports efficient and effective care delivery. Various regions (e.g., zones/sectors) require well-defined provincially-based guidelines of practice and standards that can be appropriately adjusted for regional resources and service needs. Other jurisdictions note that PEOLC strategies will not be sustainable without an integrated, system-wide policy. Our priority setting at the provincial level will drive common practices and knowledge in a purposeful, uniform direction. Identifying where to allocate resources and provide funding opportunities for research topics is a priority and is essential for early phases of further developing PEOLC in Alberta (10;37;44;54).

Consistent and adequate funding for professionals, programming (designated palliative care spaces, including residential hospices, palliative care consultation teams/services) and supplies are some of the key considerations related to funding and guideline considerations. Policy can further shape organizational culture and promote the adoption of a palliative approach to care by setting parameters for reporting and evaluating care (37;44). Collaborative work between Alberta Health and AHS will enhance operational policy and ensure alignment between Primary Health Care initiatives and ongoing operational strategies. We need to develop robust primary care services for PEOLC and ensure that primary health-care strategies are linked with the evolution of PCNs and FCCs, and make sure that family physicians and nurse practitioners are engaged in this process. Monitoring the efficacy of community-based palliative care programs and services will be demonstrated by reducing unwanted/avoidable service utilization and improving patient and family satisfaction.

With an enhanced system-level framework, the potential for safer, more effective patient care, increased satisfaction of providers and reduced costs across the system as a whole can be realized. It will guide future decisions on policy changes and will help us work towards an integrated system of care with sustainable funding mechanisms. Palliative care as a distinct program with dedicated funding will improve care in all settings by targeting the needs of patients, families, providers, programs and regions that are relative to the communities that encompass these elements of care. Funding for programs and professionals should also incorporate education and research needs not only for practitioners, but also for trainees (undergraduate, post-graduate). Ultimately, a system-wide provincial program will bring us together for consensus building and sharing of knowledge about key priorities for improving PEOLC for all Albertans, as well as for our Pan-Canadian partners (10;13;37;54).

## 12. Performance, Accountability and Outcomes Measurement

Albertans have stated that they want to be cared for within their homes and communities, which can include their last days of life. In Canada, 60% to 70% of Canadians still die in the hospital (44). In Alberta, depending on geography, up to 85% of adult Albertans are dying in hospitals either by choice or because resources may not be in place to support individuals in their community. The ultimate goal is that patients, whether or not they are pediatric or adult, should die in their place of choice with quality palliative and end of life care. The development of the PEOLC provincial program, as outlined in the Palliative and End-of-Life Care Provincial Framework, is to ultimately introduce and support innovative PEOLC solutions and augment existing PEOLC services across the province. The current state of PEOLC services and the success of the shift in how PEOLC is expanded needs to be measured across the province by utilizing standardized tools.

The success of the provincial program can be measured with performance indicators. Outcomes for Albertans can be measured accurately and within set standards across all zones and contracted partners. Examples of performance indicators include symptom control, patient and family satisfaction, location of care prior to and at death, and judicious use of acute care services such as emergency departments.

Within Alberta, many performance measures are published quarterly by AHS. Currently, measures do not include specific indicators that describe or portray PEOLC services performance; therefore, Alberta Health, AHS, and other contracted partners have no formal accountability of responsibility to provide funding, resources and services for PEOLC patients and families. This lack of accountability contributes to the inequitable PEOLC services that exist across Alberta.

To ensure that the provincial program implements positive changes for Albertans, areas of performance measures need to be developed and reported against the current state of services available today. Six are identified and described below.

*These are preliminary suggested indicators and will require further discussion and development.*

Indicator	Goal (from baseline)
<b>1. System Outcomes (12;16;20;38;39;44;58)</b>	
1.1. Emergency department utilization 30, 60 and 90 days prior to patient death	Decrease
1.2. Length of stay within acute care settings during the last 90 days prior to death	Decrease
1.3. Patients within care settings with GCD orders	Increase
1.4. Use of irrelevant/inappropriate treatments or interventions	Decrease
1.5. Number of patients dying within acute care settings	Decrease
1.6. Number of family caregivers who receive psychosocial and spiritual support through the course of the disease and through bereavement care	Increase
1.7. Number of Albertans who are aware of ACP	Increase
1.8. Use of PEOLC resources by those with non-malignant life-limiting illnesses (frailty and organ failure)	Increase
1.9. Number of volunteer resources within all zones	Increase
1.10. Numbers of interprofessional palliative experts	Increase
1.11. Access to palliative approach early in trajectory	Increase
1.12. Received care in location of choice	Increase
1.13. Death in location of choice	Increase
1.14. EOL Care Pathway implementation	Increase
<b>2. Access (12;16;20;38;39;44;58)</b>	
2.1. Number of PEOLC designated non-acute care spaces per capita (goal = 7.7/100K)	Increase
2.2. Wait-times for Albertans for hospice	Decrease
2.3. Number of Albertans dying on wait lists for hospice care	Decrease
2.4. Number of PEOLC secondary level consults	Increase
2.5. Availability of 24/7 PEOLC secondary consultation adults	Increase
2.6. Number of avoided emergency department visits through EMS on site interventions	Increase
2.7. Availability and utilization of tertiary/intensive palliative care units	Increase
<b>3. Patient Outcomes (12;16;20;26;38;39;44;58)</b>	
3.1. Successful management of pain and symptoms	Increase
3.2. Patient and family satisfaction regarding PEOLC received	Increase
3.3. Death in the setting of choice	Increase
3.4. Deaths at home with Notices of Anticipated Death	Increase
3.5. Number of adverse events reported regarding annual PEOLC services	TBD
3.6. Number of patient and family complaints regarding PEOLC services received	TBD
<b>4. Policy, Procedures, Guidelines and Assessment Tools (39;58)</b>	
4.1. Standardized and evidence-informed symptom management procedures across Alberta	Increase
4.2. Standardized evidence-informed assessment tools across Alberta	Increase
<b>5. Provincial Education, Supports and Resources (20;39;40;58)</b>	
5.1. Development of standardized resources for patients and families	Increase
5.2. Availability of standardized resources for patients and families	Increase
5.3. Development and maintenance of a comprehensive online resource for Albertans	Increase
5.4. Number of formal PEOLC education sessions provided	Increase
5.4.1. Number of participants	Increase
<b>6. Fiscal Outcomes (39;44;58)</b>	
6.1. Costs of care for those who died within the last 90 days of life	Decrease
6.2. Funds raised through events and donations to support PEOLC	Increase
6.3. Costs to the health-care system per patient within the last year of life	Decrease
6.4. Costs avoided	Increase

### A brief history of palliative and end-of-life care in Alberta

- In 1980, Mr. Syd Kahanoff donated \$1.8 million to start palliative care programs in Calgary and the Hospice Calgary Committee (eventually established as Hospice Calgary Society) was formed.
- In 1984, the Hospice Calgary Committee gave \$500,000 as seed money to start the first palliative care teams in each of the eight hospitals.
- In 1988, Albert discussed issues in PEOLC through the auspices of the Alberta Palliative Care Network, which sought to develop recommendations for palliative care in Alberta.
- In 1989, service guidelines and principles of palliative care were described by Health and Welfare Canada. These Federal and Provincial Advisory members, aided by experts, documented reasoning for the philosophy and principles of palliative care to apply to populations other than the dying. The authors acknowledged that admission to acute care was only one aspect of total care requiring us to think of other linkages along the continuum (67). They describe recommended principles that still resonate with providers today.
- The Palliative Care Association of Alberta was incorporated in 1990, influenced by CHPCA.
- In 1992, the first-free standing hospice opened in Calgary: The Salvation Army Agapé Hospice.
- In 1993, Alberta Health released the Palliative Care Policy Framework, acknowledging the need for a co-ordinated continuum of care and support services for palliative care patients and their families. Regionalization began in 1994 where each regional health authority was mandated to determine the needs for “hospice palliative care” in their own region.
- Consistent with the provincial policy framework, the Co-ordinated Home Care Program Regulation was amended in 1991, which exempted palliative care patients from the maximum dollar limit for home care services. Priority was given to improve the co-ordination of programs and services.
- In 1995 and 1996, integrated comprehensive palliative care programs were established in Edmonton and Calgary. In 1998, the Alberta Cancer Board (ACB) implemented the Palliative Care Network (PCN); this was renamed Hospice Palliative Care Network in 2003.
- 1999: Implementation of the Alberta Palliative Care drug program.... The Palliative Care Drug Coverage Program offers financial support for palliative care patients with a designated prognosis.
- In 2000, the Alberta Cancer Board established the Palliative Care Research Initiative (PCRI) funded by the Alberta Cancer Foundation.
- In August of 2003, the Nursing Homes Operation Regulation was amended to reflect new LTC accommodation changes / no charge to residents receiving palliative care or sub-acute (AH&W Alberta Health & Wellness 2004)
- 2003: Feb Alberta Cancer Board – Hospice Palliative Care Network vision of heading toward a strategic alliance / 3 levels of care provision
- In 2003, Co-ordinated Home Care Program Regulation; “Palliative care client” was defined and the regulation instructed the regional health authority to ensure that PEOLC services are made available to all palliative care patients admitted to the program. This was amended in 2007 and 2012.
- In March of 2004, AH&W funded a stakeholder meeting from across the province that sought to address critical issues in rural hospice palliative care, which led to the development of an ad hoc group from the (Alberta strategic alliance for Palliative Care)
- In 2004, The First Minister’s Accord released a 10-year plan to strengthen palliative/EOL care in Canada. One hundred million dollars were given to Alberta to implement palliative care, with a

specific focus on home care. AH&W directed the bulk of the funding to primary care to strengthen palliative/EOL care in the province. The decision was to send second disbursement to regions to strengthen palliative care; however, no official provincial strategy was developed.

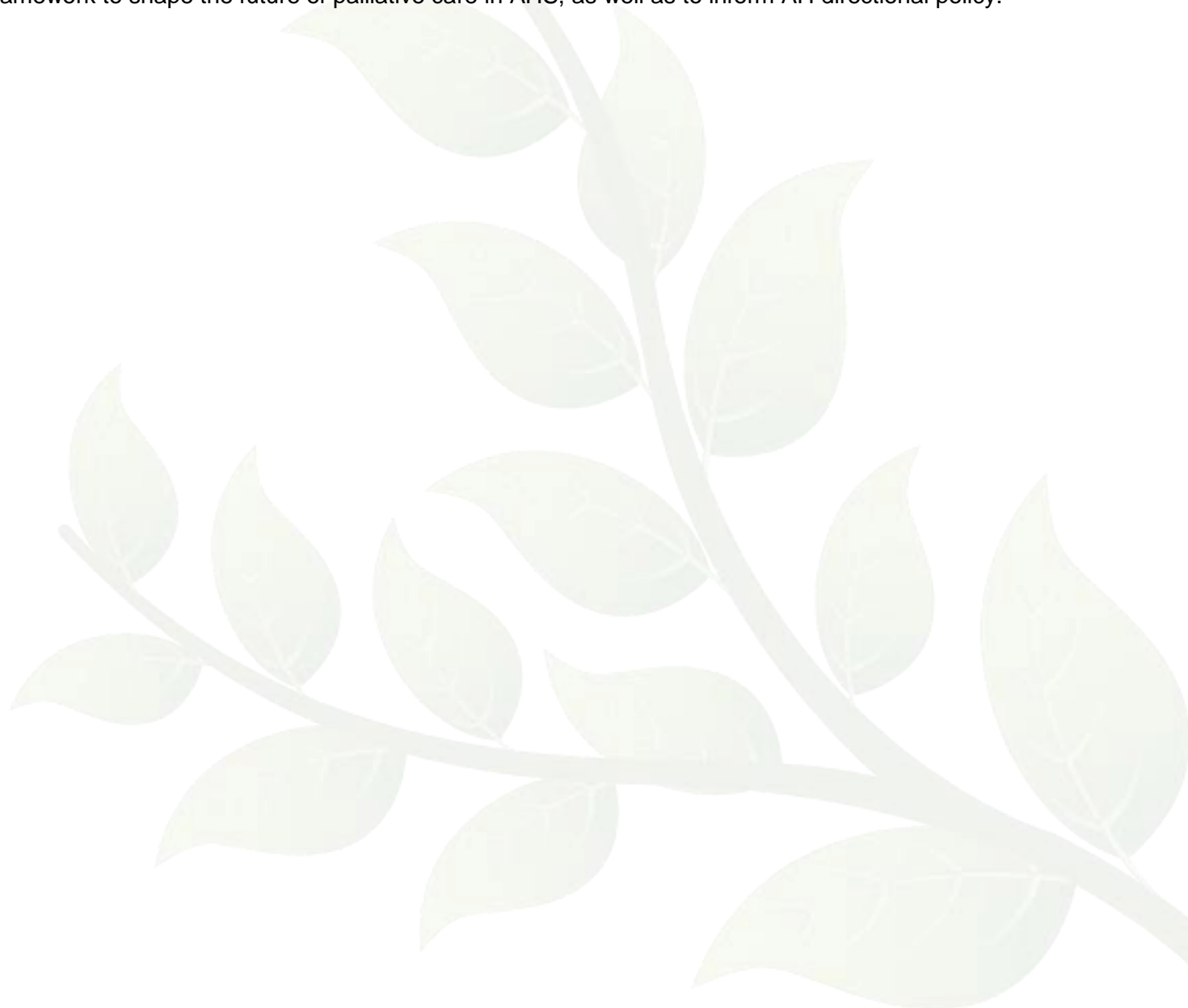
- In 2004, the former David Thompson Health Region and East Central Health Region developed programs to provide PEOLC services.
- In October of 2005, the AH&W Hospice PC Provincial Policy Guide recommended core services for homes, Continuing Care Standards developed in Alberta (68).
- In May of 2006, the Provision of the Continuing Care Health Service Standards required AHS to have operational policies and processes for palliative and end-of-life care. These standards only apply to services provided through the continuing care stream (LTC, SL and home care) and not to acute care, cancer care and other programs outside of the continuing care stream.
- In 2006, the Gold Standards Framework, which guides the standards of care for home-based patients (The Canadian Hospice Palliative Care Association in partnership with the Canadian Home Care Association has defined the “gold standard” for each of the four home care services to be funded by government: case management, nursing, palliative-specific pharmaceuticals and personal care at the end of life).
- In 2008, health-care delivery in Alberta underwent a significant change. There was an amalgamation of the province’s nine regional health authorities, the Alberta Mental Health Board, the Alberta Alcohol and Drug Abuse Commission and the Alberta Cancer Board into a single health authority. This restructuring of the health regions and the integration of the multiple health services has created a system that is better positioned to meet the needs of all Albertans now and in the future (ASAP from Concept to structure Final paper January 18 2005).
- In February of 2009, The AHS PEOLC Services paper, “History of successes and opportunity for further integration and innovation” (48) formed the basis for the AH and AHS joint committee on PEOLC in 2010 and 2011, which informed the initial draft of the AH policy guide document.
- In 2011, the AH and AHS Policy Guide developed through a joint steering committee representation.
- In February of 2012, the Review of the Quality of Care and Safety of Patients Requiring Access to Emergency Department Care and Cancer Surgery and the Role and Process of Physician: HQCA RECOMMENDATION #6: AHS continues with innovative solutions to support palliative care patients in their community setting and prevent, wherever feasible, the transfer of these patients to emergency departments.
- The 2011 HOPE project work was very successful at bringing together representatives from zones and other stakeholder groups, and achieved and exceeded many of the set outcomes (60).
- The Pallium project was very influential in Alberta in its early years and provided considerable support for clinicians in the province and beyond.
- The 2012 Accreditation Canada Standards for Hospice Palliative End-of-Life were introduced as part of the Accreditation Canada survey for the first time (59).
- In 2013, there has been a significant increase of hospice care in Alberta since 1992. Calgary now has seven hospices, an Intensive Palliative Care Unit (IPCU), as well as The Rotary Flames House (seven beds), which is a hospice for children. Edmonton has four hospice units and a Tertiary Palliative Care Unit (TPCU).

### Alberta Health funded initiatives

1. **PEOLC Care Priorities:** This project focused on developing gap analysis and identifying priorities for palliative care services from stakeholder consultation. Stakeholders were identified from AH, AHS Zone's Senior Health Executive Directors responsible for palliative care, clinical care professionals and managers of individual teams and program/service areas representing the care continuum. A large stakeholder consultation meeting was held in June 2011 to obtain feedback and opinions for direction. Multiple priorities were identified. Amongst these, ACP and GCD were ranked as a high priority within the zones that do not have this policy in place. Grant funds were used to initiate the development of an implementation plan with Calgary Zone experts. A separate grant request has been submitted to AH for additional funding to support the implementation of the plan in the community settings.
2. **PCN Demonstration Project:** The purpose of this initiative was to test feasibility of enhanced palliative care services at the Primary Care Network level. This project enhanced palliative care through education for home care staff, volunteer services, and supplying medical equipment and supplies to patients in their homes. In total, 23 palliative care patients were served in their homes, 15 volunteers were trained and a variety of comfort care equipment was provided. This project demonstrates the feasibility of providing palliative care at the community and primary care network level. Findings also identified the need for a 24/7 palliative care consultative service with physician and nurse consultants across the care continuum.
3. **Residential Hospice Review:** The purpose of this project was to review residential hospice facilities across the province to generate the strategic recommendation to enhance quality, access and sustainability. A sample of eight hospice facilities was reviewed in terms of care models, zone contract agreements and leadership challenges. Thirteen recommendations were formulated to operationalize the CHPCA hospice palliative care model in both stand alone and congregate hospice settings. The Central Zone received grant funding to implement dedicated case management at the Red Deer Hospice.
4. **Web-Based PEOLC Care Education:** This initiative developed education modules on core topic areas for palliative and EOL care for health professionals. The module topics include Introduction to Palliative Care, Introduction to Pain, Pain Assessment, Pain Management, Communication, Constipation, Nausea and Vomiting, Dyspnea, Delirium, Palliative Sedation, Last Days and Hours, Loss, and Grief and Bereavement. Content experts led by a dedicated project lead developed the educational content and modules.
5. **SL Demonstration Project:** This project demonstrated the feasibility of providing palliative care in SL facilities. This project utilized two Community Support Beds in a SL facility operated by the Good Samaritans Society (GSS) in the rural community of Cardston. This initiative provided palliative care education for 100+ staff in the SL facility, created local integration of services and received tremendous support from local physicians. This project is being recommended as a provincial model for implementation in targeted communities where a hospice palliative-end-of-life care strategy for remote, rural and small communities is required.
6. **Virtual Pain and Symptom Control Clinic:** In this initiative, specialist multi-disciplinary Pain and Symptom Control consultation was extended to cancer patients and providers in rural communities. Videoconferencing was used to connect them with the team at the Cross Cancer Institute, and rural nurses received training to participate in patient assessment. Evaluation of the pilot project revealed that the model is feasible, may improve symptoms, results in cost savings to patients and families, and is satisfactory to users. Based on the pilot experience, AHS Cancer Control has assumed responsibility for funding ongoing operations of the clinic.
7. **Family Caregiver Support:** This initiative compiled a list of caregiver support tools by literature review and validated a caregiver support toolkit called the "Changes Tool" in collaboration with the U of A and led by Dr. Wendy Duggleby. The toolkit was deemed valid by an empirical study. The

tool was launched online and 1,000 paper copies were printed for distribution to palliative care service teams as part of the grant deliverable.

8. **Added Care Funding in Home-Based Settings:** As a part of this initiative, added care dollars were not required for the SL demonstration project. With the enhancement of home care funding to each of the zones in the past fiscal year, zone operations were able to cover the costs of added care in the SL project.
9. **Standardized Assessments:** This initiative developed the standardized Non-RAI Meditech assessment for palliative home care patients. The tool has been implemented in the Edmonton Zone and North Zone. The user education of this tool has been a challenge due to the time restriction of the grant. Lessons learned from this initiative indicated a need to build a sustainable strategy for the delivery of palliative education.
10. **The EOL grant has been utilized to fund the above initiatives that are targeted to an integrated, coordinated, standardized and comprehensive approach to palliative and EOL care in the province of Alberta.** Supporting documents related to each of the initiatives funded by this grant are available on request and are accessible through the Seniors Health Provincial Team. Knowledge gathered and lessons learned from these initiatives are used to formulate the concept of a strategic framework to shape the future of palliative care in AHS, as well as to inform AH directional policy.





### Initiatives

Identify current local best practices, design a provincial standard, and implement practice standards, guidelines and protocols to assess and manage PEOLC symptoms (including dementia) for primary and secondary level care providers.

As part of a provincial PEOLC program, develop direct links with the Primary Care Networks and Family Care Clinics within local communities and partner with provincial stakeholders to build strong relationships with those who can support the provision of PEOLC in local communities such as contracted partners in long-term care, supportive living and home care, as well as community organizations.

Develop a one-stop information portal that includes information on equipment, medication access with links to other programs and information sources such as Virtual Hospice, Caregiver College, and on-line grief and bereavement resources for both PEOLC pediatrics and adults.

Working from the success of the programs within zones that offer 24/7 services, standardize access points and spread 24/7, on-call PEOLC consult services for adults and pediatrics for primary care practitioners, care givers, patients and families to support care within the community, including strategies that support rural/remote practitioners such as regular rounds by Telehealth. This will allow interdisciplinary access in areas where it is limited and build capacity when knowledge and skills are transferred to local practitioners.

Eligibility criteria definitions and service standards (home care supports, pharmacy services, hospice settings) are to be provincially standardized across all care settings to ensure equitable access to PEOLC programs and services.

Create synergies amongst existing organizations/services within Alberta (e.g. Community services, Covenant Health, Family Care Centres (FCC's), Home Care, Primary Care Networks (PCN's), primary care services, Strategic Clinical Networks (SCN's), Towards Optimized Practice (TOP), and secondary levels of care). These partnerships need to be supported with education and practice guidelines that are evidence-based, standardized and easily accessible.

Build on the established educational programs, procedures, and access to tools within each zone and leverage existing infrastructure by identifying all forms of PEOLC educational resources available across Alberta, standardize the methods under a provincial focus, and create tools and programs for making the resources easily accessible for care providers across all geographies to decrease duplication of similar resources developed in isolation.

A central repository that is maintained/updated regularly for sharing family resources or allowing central access online for patients and families is to be developed to provide readily accessible resources. There is also a need to expand and evaluate virtual education.

Identify and agree on a set of provincially standardized common screening, assessment tools, and guides to practice. Some examples of these tools are ESAS-r, Palliative Performance Scale, Collaborative Care Plans, and Symptom Management Guides to Practice.

Identify and develop connections to other patient-centred initiatives in the province, and continue to maintain alignment with patient-centred concepts across the health care spectrum.

Enhance and provincially standardize both the referral and the transition communication processes, ensuring concordance with requirements from Accreditation Canada. Identify possibilities within electronic health records or paper-based processes that follow the patient as they move through the system, including exploring the option, feasibility and potential benefits of a provincial registry.

Formalize and expand the EMS and palliative care collaboration in Alberta.

Inventory existing resources that have already been developed. Partner with national organizations offering educational resources, as well as educational institutions such as universities within Alberta, to develop an innovative and collaborative plan to establish and support minimum standards of education and ongoing education for those working directly in PEOLC; therefore, improving quality of care for patients locally.

Establish a Provincial Palliative and End-of-Life Innovations Steering Committee (PPAL/EOL ISC) that is focused on identifying, trialing, and implementing innovative ways to deliver care within the community settings across all areas within Alberta. Create an alliance with Alberta Health through the PPAL /EOL ISC to maintain alignment with public messaging around PEOLC.

Identify specific educational and resource gaps in educational availability within rural and remote communities, pilot solutions and roll out. Establish proven methods to spread resources across all geographies.

Create a provincial policy development expert panel under the guidance of the PPAL/ EOL ISC that works with the AHS clinical policy team and addresses the clinical supports that are needed, which are applicable to primary and secondary providers such as a provincial palliative sedation clinical guideline.

Develop a detailed hospice capacity plan until 2034 that encompasses strategies for rural geographies where hospice centres are not viable, but local hospice spaces within other settings (community or acute) are utilized and supported directly by local 24/7 Palliative Care Consult Teams.

Develop provincial standards for the collection of specific PEOLC data for adult and pediatric patients. Begin to collect data for all patients who receive secondary or tertiary PEOLC within all the zones; develop a provincial analytics dashboard; and publish provincial performance reports annually.

Identify and implement PEOLC care models specific to supporting those within long-term care and supportive living.

Review the current structure and develop a consistent system of incentives (monetary and non-monetary) to support physicians to collaborate with primary care health teams in providing a palliative approach to care.

Work with academic institutions to identify and introduce standards that support palliative care providers with relevant qualifications (CNA Canadian Nurses Association Hospice Palliative Care certification, PEOLC certification) or strategies and supports to train staff to these standards.

Build connections between cancer nurse navigators and 24/7 Palliative Care Consult Teams, including nurse practitioners, to enhance integration of services for PEOLC patients and their families.

Support education and knowledge translation regarding information that is available in current electronic health records such as Meditech, Netcare, and within physician offices, including how it can be accessed by providers.

Identify the need for a key worker/co-ordinator or a nurse navigator and raise awareness of existing roles to improve patient and family ability to navigate the health care system along the trajectory of care.

Identify and connect with a health promotion framework (e.g., the Ottawa Charter, framework for integrated care [CHPCA, QEOLCC Quality End of Life Coalition of Canada]), and palliative service development and programs.

Integrate Zone PEOLC strategy and operations across all Zones as part of a provincial program for both pediatrics and adults. Additionally, within the pediatric programs, assess current resources and requirements for existing specialized palliative care programs, including the ability to provide access to high quality palliative services for all infants, children and youth.

Create interactive, standardized PEOLC web pages for clinicians, patients and families that are user-friendly, maintained and updated regularly, including zone-specific information and details.

Develop provincial educational avenues for clinicians, health-care aides and volunteers such as rounds/seminars and forums

Develop delivery concepts for complex, high needs patients (infants, children, youth and adults) and integrate home care, primary care, EMS and acute services, PEOLC services, and other community based services such as volunteers and non-government offices that help to meet some of the high needs of PEOLC patients and their families.

Supported by the PPAL /EOL ISC and with the establishment of the provincial PEOLC program, work collaboratively with other national networks and take full advantage of local and national initiatives that will strengthen PEOLC within Alberta.

Review whether or not adequate funding is in place for short term and specialized equipment and supply needs. If gaps are identified, develop a strategy to resolve them.

Identify a provincial model, and develop provincial and local grief and bereavement programs within each zone/geographic area that capitalizes on local resources and builds on programs and strategies that have been successful in other jurisdictions.

Develop a provincial funding mechanism that allows clinicians/providers across Alberta to apply for exceptional PEOLC educational resources, including advanced education and seminars such as anticipatory grief and bereavement sessions.

Develop infrastructure, including funding and data analysis to support the use of a patient/family reported outcomes model such as the Famcare scale or a standardized tool and mechanism for results to be used locally, and rolled up provincially based on best practice.

Explore developing a provincial PEOLC volunteer network that co-ordinates and expands existing volunteer programs.

Formally integrate the Pain and Symptom Clinics into the palliative system resources available for primary PEOLC providers across Alberta.

### PEOLC Glossary

**24/7 community service:** Individuals can access services through home care, and palliative care specialist support for primary care providers shall be available 24 hours per day and seven days a week.

**Active dying:** (Actively Dying or Imminently Dying) A prognosis of death is expected to occur within hours to days (69).

**Centralized point of access/single point of access:** (Directional) Individuals can access continuing care health services through self-referral or referrals made by family, friends, health-care providers, or other community agencies acting on their behalf. (Operational) A single co-ordinated call centre supported with an integrated electronic information system is created to manage and direct inquiries for continuing care health services (70).

**Community-based supports:** Supports that are delivered and available within communities to support people to die well in their community. **Comprehensive interdisciplinary teams:** Palliative care focuses on helping individuals with life-limiting illnesses to manage their pain and other symptoms, and to enhance the quality of their lives by providing them with psychological and spiritual support through to the end of their lives. An interdisciplinary team can include doctors and nurses, social workers, rehabilitation staff, chaplains or other spiritual workers, dietitians, and others to provide support to PEOLC patients. Adequate and timely communication among those practitioners who are involved with an individual and their family/ caregivers is essential for optimum outcomes.

**Equity:** Equity means that all Albertans will have fair opportunities to access supports and services that will provide similar health outcomes irrespective of the method of delivery. Equity does not equal equality. In Alberta, geographic and human resource considerations mean that identical services and programs cannot be delivered in the same fashion to all Albertans.

**Expected home death:** In PEOLC, notification of expected death is formalized so that patients avoid transfer at end-of-life. The notification provides practitioners and EMS with necessary documentation that reduces liability when responding to a crisis with palliative care patients. This document is not a replacement for ACP. Expected death means where it is reasonable to anticipate death and where there is no available treatment to restore health due to the irreversibility and/or irreparability of a patient's condition or illness, and which does not occur under the circumstances identified in the Fatality Inquiries Act (71).

**Hospice:** A designated non-tertiary space, specifically providing end-of-life care.

**Illness trajectory:** Three typical illness trajectories have been described for patients with progressive chronic illness: cancer, organ failure, and the frail elderly or dementia trajectory. Physical, social, psychological, and spiritual needs of patients and their care givers are likely to vary according to the trajectory they are following. Being aware of these trajectories may help clinicians plan care to meet their patients' multidimensional needs better, and help patients and care givers cope with their situation. Different models of care may be necessary that reflect and tackle patients' different experiences and needs (72).

**Integration (Integrated nursing practice/well-integrated programs and services):** Linkages between palliative care programs and services for all settings of care in all sectors where patients may die. Non-cancer and cancer-related deaths require integration between palliative care and chronic disease groups, as well as major cancer centres and their satellite programs. These sectors and services are linked by common practice, processes, structures and education with adequate numbers of trained professionals. An overarching program ensures the accessibility, efficiency, effectiveness and sustainability of these programs (73).

**Interprofessional (74):** Interprofessional collaboration occurs when health professionals from different disciplines work together to identify needs, solve problems, make joint decisions on how best to proceed and evaluate outcomes collectively. Interprofessional collaboration supports patient-centred care and takes place through teamwork. Team interactions, wider organizational issues and environmental structures such as safety, quality, efficiency and effectiveness issues influence this model of care. These broader contextual influences affect practice where there are tensions between the ideals of interprofessional collaboration and the realities of practice. This is evident when the patient and family position in interprofessional collaboration is considered.

**Alberta Netcare:** a secure and confidential electronic system of Alberta patients' health information.

**Nurse navigator role:** Although their role may vary by setting, nurse navigators promote and facilitate continuity of care across care settings and between care providers by sharing information on the client's current situation, plan of care and goals. The registered nurse assists the client in navigating the health-care system through understanding its structure, system and process, and provides them with strategies to work within that system. Nurse navigators offer support, education, information and resources. Their role is to help clients with complex health needs navigate the health system and access the right services at the right time. A core component of navigation is case management. In Alberta, registered nurses are practising as nurse navigators in cancer care settings, in Primary Care Networks, and in emergency and cardiology departments (75).

**Palliative approach:** Access to a palliative approach in primary care requires that, in every primary care setting, (outpatient offices, home care organizations, LTC facilities), providers of every discipline (family physicians, nurses, nurse practitioners, pharmacists, personal support workers, paramedics, social workers) possess and implement the basic palliative care knowledge, skills, and attitudes pertinent to their discipline. This requires not just education, but also an infrastructure, a policy environment and a culture of care delivery that facilitates a palliative approach in primary care. A palliative approach in primary care also requires appropriate support from palliative care providers for patients with complex needs. High-quality palliative care, like high-quality maternity care or mental health care depends on co-operation and co-ordination between primary care and consultant palliative care teams (76).

**Palliative Care Consultant(s):** In Alberta, palliative care consultants are primarily nurses and physicians who have specific training and experience in PEOLC. Training for nurse consultants varies across the province and from rural to urban locations, and is dependent on their scope of practice. Consultants provide guidance and suggestions for care for palliative individuals after assessment.

**Provider:** A formal caregiver who is a member of an organization and accountable to norms of conduct and standards of practice. They may be professionals, support workers or volunteers (77).

## Appendix E

Level I – international or federal (national) level; Level II – province (Canada), territory (Canada, Australia, and New Zealand), state (USA, Australia), and country (UK: England, Wales, Scotland, and Ireland); Level III – lower administrative level; NR – not reported

Document title	Level I	Level II	Level III	Year	Document type		
Cancer Control Knowledge in Action. WHO Guide for Effective Programmes. Palliative Care (78)	International			NR	guide		
Standards for Providing Quality Palliative Care for all Australians (79)	Australia	New South Wales		2005	standards		
National Palliative Care Strategy A National Framework for Palliative Care Service Development (80)				2000	strategy		
Palliative Care Service Provision in Australia: A Planning Guide (36)				2003	planning guide		
A Guide to Palliative Care Service Development: A population based approach (5)				2005	guide		
Health System Reform and Care at the End of Life: a Guidance Document (81)				2010	guidance		
Supporting Australians to live well at the end of life (82)				2010	strategy		
An ethical framework for integrating palliative care principles into the management of advanced chronic or terminal conditions (18)				2011	ethical framework		
Guideline - Palliative Care Role Delineation Framework (83)		Hunter New England	Central Sydney	2007	guideline		
Policy Directives. Palliative Care Strategic Framework 2010-2013 (84)				2010	strategic framework		
Palliative Care Development Planning Framework 2011-2014 (85)				2011	framework		
Guideline - Paediatric Palliative Care Planning Framework 2011-2014 (86)				2011	guideline/planning framework		
The NSW Government plan to increase access to palliative care 2012-2016 (87)				2012	plan		
Framework for the Statewide Model for Palliative and End of Life Care Service Provision (11)				2013	framework		
HNE Health Palliative Care Services Plan 2009-2013 (88)						2009	service plan
Palliative care service plan 2002-2005 (89)						2002	service plan
Palliative Care Strategy 2005-2009 (90)				Northern Territory		2005	strategy
Palliative Care Services Plan (43)				South Australia		2009	service plan
Tasmanian Palliative Care Plan (91)		Tasmania		NR	plan		
Strengthening palliative care: Policy and strategic directions 2011–2015 (92)		Victoria		2011	policy and strategic direction		
Rural Palliative Care Model in Western Australia (93)		Western Australia		2008	framework		
Applying A Model to Guide Hospice Palliative Care (17)	Canada			2005	toolkit		
Pediatric Hospice Palliative Care Guiding Principles and Norms of Practice (8)				2006	guiding principles and norm of practice		
A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice Revised and Condensed Edition: 2013 (7)				2013	guide		
Framework for a National Strategy on Palliative and End-of-Life Care (66)				2005	framework		
The Pan-Canadian gold standard for palliative care (33)				2006	standards		

Canadian Hospice Palliative Care Nursing Standards of Practice (9)		2009	standards			
Raising the bar (15)		2010	roadmap			
The Way Forward National Framework: a Roadmap for the Integrated Palliative Approach to Care (44)		2013	roadmap			
A Provincial Framework for End-of-Life Care (13)	British Columbia	Northern region	2006	framework		
The provincial end of life care action plan for BC (53)			2013	action plan		
Northern Health Hospice Palliative Care Framework (Program) Manual (94)		Fraser	2011	framework (program) manual		
Fraser Health Hospice Residences Creating a healing & caring environment at the end of life (55)			2007	standards and guidelines		
Norms of Practice Hospice Palliative Care Provincial Palliative Care Network Manitoba (20)	Manitoba		2005	framework		
Provincial Framework for Palliative Care in New Brunswick Draft 5 (6)	New Brunswick		2010	framework		
Provincial Hospice Palliative Care Project (12)	Nova Scotia		2005	report and recommendations		
Dying with Dignity (42)	Quebec		2012	public consultation		
Quebec End-of Life Palliative Care Policy (19)			2010	policy		
Improving the quality of palliative care services for cancer patients in Ontario (14)	Ontario		2006	framework		
Regional Models of Care for Palliative Cancer Care (16)				2009	recommendations	
A Provincial System Design Framework (54)				2010	framework	
Champlain Regional Hospice Palliative Care Program Plan 2010 (10)			Champlain	2010	program plan	
System Design Framework. Developing a Regional System of Hospice Palliative Care in Erie St. Clair (95)			Eire St. Claire	2009	framework	
A regional framework for palliative care services in Halton-Peel (41)			Halton-Peel	2004	framework	
Integration Plan Kawartha Lakes Hospice Services (34)			Kawartha Lakes	2010	integration plan	
Hospice Palliative Care Northwest (35)			Northwest	2001	report	
Toronto Central Palliative Care Network 2009-10 to 2011-12 Strategic Plan: Setting a new course (96)		Toronto	2009	strategic plan		
The New Zealand Palliative Care Strategy (97)	New Zealand		2001	strategy		
Resource and Capability Framework for Integrated Adult Palliative Care Services in New Zealand (98)				2012	capability framework	
Hospice New Zealand Standards for palliative care (58)				2012	standards	
Northland Palliative Care Strategic Action Plan (99)			Northland		2007	strategic action plan
Palliative Care Strategy Plan 2005-2010 (100)			Waikato		2005	strategy plan
Wairarapa Palliative Care Plan (101)			Wellington	Wairarapa	2007	plan
In-hospital Adult Palliative Care Strategy and Service Development Plan 2006-2010 (102)			Auckland	Waitemata	2007	strategy and service development plan
Palliative Care for All. Integrating Palliative Care into Disease Management Frameworks (37)			Republic of Ireland		2008	report
Quality standards for end-of-life care in hospitals (103)	2011	quality standards				
The Irish hospice Foundation Strategic plan 2012-2015 (104)	2012	strategic plan				
Palliative Care Services - Five Year/Medium Term Development Framework (105)	2009	framework				
Palliative and end of life framework 2012-2014 (106)	UK		2012	framework		

End of Life Care Strategy Quality Markers and measures for end of life care (39)		England	2009	quality markers		
End of Life Care Strategy. Promoting high quality care for all adults at the end of life (107)			2008	strategy		
Better Care: Better Lives (108)			2008	framework		
Avon palliative care strategy group. Strategy for children and young people's palliative care (109)			Avon	2013	strategy	
Dying Matters in Devon. Strategy for Living Well Until the End of Life (110)			Devon	NR	strategy	
Strategy for Adult Palliative and End of Life Care Services (111)			Durham	NR	strategy	
End of Life Care Strategy (Adults) 2012/13 – 2015/16 (112)			Heywood, Middleton and Rochdale	2012	strategy	
End of Life Care Strategy 2010-2013 (113)			London (Richmond)	2010	strategy	
End of Life Care Strategy 2010-2015 (114)			Mid Essex	NR	strategy	
Milton Keynes Adult End of Life Care Strategy 2012-15 (115)			Milton Keynes	2012	strategy	
End of Life Care Strategy 2011-2016 Pennine Lancashire Integrated Health and Social Care Economy (116)			Pannie Lancashire	NR	strategy	
Sheffield's End of Life Care Strategy (117)			Sheffield	2008	strategy	
Palliative and End of Life Care Strategy (118)			Shropshire	2009	strategy	
Wiltshire End of Life Care Strategy 2009 – 2014 (119)			Wiltshire	NR	strategy	
Palliative care for children with lifelimiting conditions in Ireland - A National Policy (120)			Northern Ireland	2009	policy	
Living Matters Dying Matters A Palliative and End of Life Care Strategy for Adults in Northern Ireland (40)				2010	strategy	
Vision for Palliative Care. Northern Health and Social Care Trust (121)			The Northern Health and Social Care Trust	2009	mission statement	
Living and Dying Well. A national action plan for palliative and end of life care in Scotland (122)			Scotland	2008	action plan	
A Framework for the Delivery of Palliative Care for Children and Young People in Scotland (123)				2012	framework	
Palliative Care Strategy. Improving Palliative Care and End of Life Services in Lanarkshire (124)				Lanarkshire	2013	strategy
Living & Dying Well in Lothian (125)				Lothian	2010	framework
A Strategic Direction for Palliative Care Services in Wales (126)	Wales	2003	strategic directions			
National Standards for Specialist Palliative Care Cancer Services 2005 (127)		2005	standards			
Together for Health – Delivering End of Life Care A Delivery Plan up to 2016 for NHS Wales and its Partners (128)		2013	delivery plan			
A National Framework and Preferred Practices for Palliative and Hospice Care Quality (129)	USA	2005	consensus report			
Providing Hospice and Palliative Care in Rural and Frontier Areas (130)		2005	framework			
National Centre for Care at the End of Life, 2013-2015 Strategic Plan (131)		2013	strategic plan			



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For further information please contact Alberta Health Services.