Alberta Health Services

Palliative and End-of-Life Care

Alberta Provincial Framework Addendum 2021

1. Introduction

In 2014 the Palliative and End-of-Life Care Alberta Provincial Framework was published to identify and coordinate activities to fill gaps in Palliative and End-of-Life Care (PEOLC) programs and services in Alberta and to improve the quality of existing PEOLC program and services. The Framework recommended 36 initiatives to help fill gaps and to enhance the quality of PEOLC in Alberta.

Since the development of the Framework, and under the guidance of the Provincial Palliative and End-of-Life Innovations Steering Committee (PPAL/EOL ISC), there have been great strides in improving access to high-quality PEOLC across Alberta. PPAL/EOL ISC has implemented 21 of the 36 initiatives and Alberta is recognized by other provinces and nationally for our innovative and integrated PEOLC programs and services. For example, the EMS Palliative and End-of-Life Care Assess, Treat and Refer (ATR) program has received both the Canadian Foundation for Healthcare Improvement Innovation Award in Palliative and End-of-Life Care and the Health Quality Council of Alberta patient Experience Award in 2017.

In addition to implementing the Framework initiatives, a need was identified by the PPAL/EOL ISC for information on leading practices to support additional improvements in PEOLC in Alberta. A Health Technology Assessment (HTA) report was completed in 2018 through Alberta Health/AHS processes which looked at leading practices in other jurisdictions and made recommendations to support ongoing improvements in Alberta. The report addressed the following policy question:

> *"What is the most appropriate model to enable equitable access to PEOLC in Alberta whereby the model of care includes elements of appropriate population, care, time, place, provider, and cost for PEOLC services across remote, rural, and urban sectors, and any variation between zones is informed by evidence?"*

This HTA report gave a comprehensive overview of what is needed for innovative PEOLC programs and services. Fourteen "quality statements" were identified within this report based on a review of published and peer-reviewed literature that identified essential elements of high-quality palliative care. The quality statements were then adjusted by PPAL/EOL ISC to reflect the Alberta PEOLC perspective.

Alberta Quality Statements related to:

1. Advance Care Planning
2. Public Awareness
3. Early Identification of Patients with life-limiting and life-threatening illnesses
4. Holistic assessments of patients' needs
5. Continuity and coordination of care
6. Person-centred care
7. Support for families and caregivers
8. Preferred location of care and place of death
9. Comprehensive palliative care services
10. Interdisciplinary team-based care
11. Education and training for Health Care Providers
12. Education for families and caregivers
13. Community Support
14. Quality and safety of palliative care services

**See Appendix A for more detailed descriptions of each quality statement*

After adapting the quality statements to the Alberta context, a mapping exercise was completed which:

- reviewed the 36 Framework initiatives to see what has been completed to date and what was still outstanding;
- looked at which Framework initiatives mapped into the quality statements;
- identified outstanding Framework initiatives to fill gaps; and
- identified Framework initiatives that don't map back to the quality statements.

This addendum summarizes how Alberta is currently meeting the majority of the HTA quality statements and describes the plan moving forward to meet the outstanding gaps in the Framework initiatives and HTA quality statements.

This exercise led PPAL/EOL ISC to reframe and prioritize future work. The committee looked at the gaps as identified by the quality statements; compared them to both current and outstanding framework initiatives; and categorized them into 6 themes, which were then prioritized to be addressed if or as resources become available.

*It should be noted that this is a living document and will be reviewed and updated every 3 years or as priorities change

2. Where we were

As part of the development of the Framework, a current state analysis of PEOLC programs and services was completed for all zones in the province.

> "*Calgary and Edmonton [were] the two main urban centres in Alberta that [*were*] considered to have well-integrated and comprehensive PEOLC programs, both of which [*were*] linked to home care programs, secondary level palliative care providers, and tertiary care palliative care units. North, Central, and South Zones [*were*] described as "rural" in nature; their programs and level of integration of services [*differed*] from those in Edmonton and Calgary. The characteristics of integration [*varied*] from each of these rural geographies and also within metro-adjacent areas near the urban zones.*
>
> *An integrated style of nursing practice [*was*] predominant in-home care in rural settings, which [*led*] to fewer opportunities to develop PEOLC expertise. There [*was*] 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 …*
>
> *The Alberta Children's Hospital in Calgary and the Calgary Zone pediatric PEOLC program [*provided*] support to the Central and South Zones. The Stollery Children's Hospital in Edmonton and the Edmonton Zone pediatric PEOLC program [*provided*] support to the North and some of the Central Zones*".
>
> (Framework, p13)

3. Where we are now

Since 2014, there has been considerable progress made by provincial and zone programs regarding access to, and delivery of, high-quality PEOLC. Several initiatives have been implemented to enhance care in the community despite geography, including the EMS PEOLC ATR program for both adults and pediatrics, and the Rural Palliative Care in-Home Funding Program for adult rural palliative patients. The implementation of Connect Care is well underway and a province-wide clinical information system has empowered standardization of provincial policies and best practice guidelines across all the zones. Through the central hub of the provincial PEOLC website, all Zones also have access to PEOLC resources, including the provincially available Bereavement Package, PEOLC services directory, and assessment tools for healthcare providers.

Summary of work

The projects and framework initiatives that have been completed to date, as well as those that are in progress as of 2020, include:

Completed

*Note that some of these completed initiatives also require ongoing maintenance such as Communities of Practice, policy/guideline reviews, and updates, reviewing and updating online content, etc.

- Established the PPAL/EOL ISC
- 24/7 Palliative Care Physician On-Call support to physicians province-wide
- Provincial PEOLC Website for patients and families and health care providers
- Provincial EMS PEOLC ATR program inclusive of pediatrics
- Provincial EMS PEOLC ATR Community of Practice
- Provincially available Bereavement program inclusive of Bereavement Package, Directory and White Rose Program
- Provincially available Volunteer Resource Training and Facilitator PEOLC Manuals
- A Resource Guide for Community Development of PEOLC within Alberta
- Integrated Capacity Planning and Forecasting model
- Patient's Death In the Home Setting Guideline
- Provincial Rural Palliative Care in-Home Funding Program
- Interdisciplinary PEOLC Competencies
- Revised ACP/GCD Policy and Procedure, resources, and website
- ACP/GCD Dashboard
- Provincial ACP/GCD Community of Practice
- Clinical Knowledge Topics (Palliative Sedation; Advance Care Planning/Goals of Care Designation; Care of the Imminently Dying)
- Accreditation Canada Survey 2018
- Provincial PEOLC Policy to meet CCHSS standards
- Participated in discussions with other Provinces and Canadian Partnership Against Cancer (CPAC) regarding Competency work and advocating for National Competencies
- Identified and developed connections to other patient centered initiatives in the province by developing resources such as PEOLC infographics and using agreed upon common language for terms such as palliative end-of-life care
- PPAL/EOL ISC endorsed PEOLC indicators

In Progress

- Hospice minimum dataset
- PEOLC Dashboard
- Connect Care

4. Current State at a Glance

Individual meetings occurred between the provincial PEOLC team and each zone, as well as the Palliative Institute and Pediatrics, to revisit the current state of PEOLC programs and services compared to 2014. The outcome of the meetings was validated by the zones and programs to inform the below table and the following high-level summary.

	North Zone		Edmonton Zone		Central Zone		Calgary Zone		South		Peds North		Peds South	
	2014	2019	2014	2019	2014	2019	2014	2019	2014	2019	2014	2019	2014	2019
Integrated Home Care Teams providing PEOLC	✓	✓	✓ rural	✓ sub urban and rural	✓	✓	✓ rural	✓	✓	✓	✓	✓	✓	✓
Specialized Palliative Home Care Teams			✓	✓	✓ Red Deer	✓ Red Deer & Sylvan Lake	✓	✓						
Secondary Consult support to front line staff	Limited	✓	✓	✓	Limited	✓	✓	✓	Limited	✓	✓	✓	✓	✓
24/7 Palliative Care Physician On-Call adult and pediatrics		✓	✓	✓		✓	✓	✓		✓		✓	✓	✓
EMS PEOLC ATR adult		✓	✓	✓		✓	✓	✓		✓	n/a	n/a	n/a	n/a
EMS PEOLC ATR pediatric		✓		✓		✓		✓		✓	✓	✓		✓
Zone Grief and Bereavement Program		Limited				✓	✓	✓		✓	✓	✓	✓	✓
Interdisciplinary Team Support		✓	✓	✓	Limited	✓	✓	✓	Limited	✓ West; Limited in the East	✓	✓	✓ acute care	✓ acute care
TPCU/IPCU			✓	✓		✓	✓	✓						
Pain and Symptom Clinics		✓ Grande Prairie	✓	✓		✓	✓	✓		✓				✓
Rural Palliative Care in Home Funding Program		✓	✓ Invoicing program serves this population	✓ Invoicing program serves this population		✓		✓ including pediatrics		✓				
PEOLC education for healthcare providers	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	Some	Some	✓	✓
PEOLC Clinical Knowledge Topics available provincially – Palliative Sedation, Care of the Imminently Dying, ACP/GCD		✓		✓		✓		✓		✓		✓		In Progress
Rural Telehealth Consultation				✓ CCI				✓						

4.1 Current State (continued)

AHS continues to deliver 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 and North, Central, and South Zones are described as “rural” in nature.

Calgary and Edmonton zones continue to have well-integrated and comprehensive PEOLC programs and services including adult tertiary palliative care units. These zones have begun partnering with community organizations to better address the needs of the homeless and other marginalized populations such as indigenous communities. Calgary and Edmonton urban areas continue to have specialized palliative home care and integrated home care for suburban/rural areas Edmonton Zone has an integrated quality management staff member who has dedicated time and responsibility for advance care planning and goals of care designation within their role. Calgary Zone has dedicated advance care planning and goals of care designation educators and consultants. Both zones have been able to build on their well-established programs in areas such as data and research.

North, Central, and South zones all have integrated home care programs, except for Red Deer and Sylvan Lake which have specialized palliative home care. Front line staff in Central and South Zones have access to specialized palliative care consult support. North Zone, with funding identified through Enhancing Care in the Community stream one, established a formal palliative care program in 2018. These zones also have more integrated and comprehensive PEOLC programs than they did six years ago as evidenced by an increase in interdisciplinary team members; embedded pain and symptom clinics within cancer centres; and a tertiary palliative care unit in Red Deer Hospital.

4.2 Pediatric Focused Services

The Alberta Children’s Hospital in Calgary and the Calgary Zone pediatric PEOLC program has provided support to the Central and South Zone for the last six years. The Stollery Children’s Hospital in Edmonton and the Edmonton Zone pediatric PEOLC program has provided support to the North and some parts of Central Zone. As of March 16, 2020, there has been a reorganization in AHS and instead of the sector model for pediatrics, there will be a focus on zone operations. Currently, palliative pediatric patients are supported by the home care teams serving the overall pediatric population. The Rotary Flames House in Calgary is the only pediatric standalone hospice in Alberta. It has seven beds and provides symptom management, end-of-life care, and respite care.

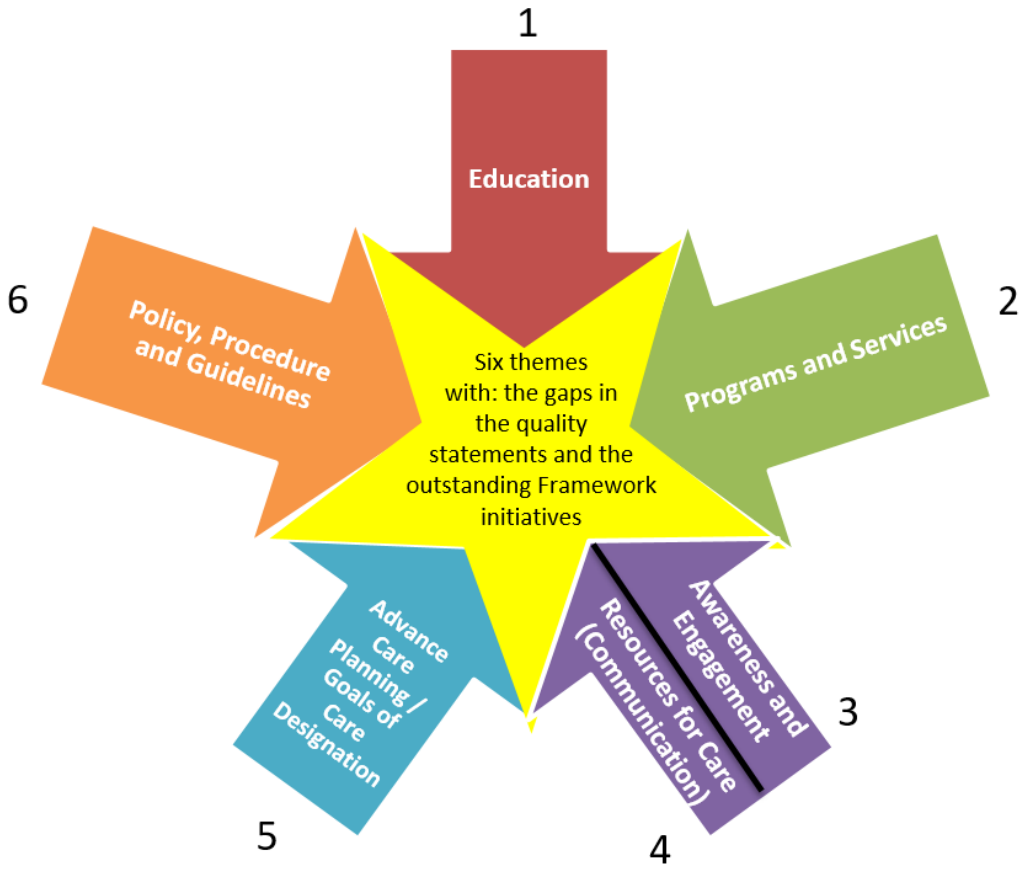
4.3 PEOLC Bed Capacity

	March 31, 2014	January 31, 2021
Community Designated/Supported Palliative Care Beds, including hospice	222	257
Acute Designated Palliative Care Beds, including TPCU/IPCU	133	126
Total	**355**	**383**

*The decrease in acute designated palliative care beds represents a shift to enhancing care in the community by maximizing hospice beds and decreasing acute care utilization of PEOLC beds. For example, Medicine Hat Regional Hospital closed 10 beds and increase their hospice occupancy so there was no loss of beds in that community.

5. Gaps and Challenges

In 2019, PPAL/EOL ISC looked at the gaps identified by incorporation of the quality statements and in the outstanding Framework initiatives and categorized them into six themes, as below, which were then prioritized to be addressed if and as resources become available. See Appendix B for details on each theme.



This was complemented by current state meetings with the provincial PEOLC team, validation by the zones/programs, and ranking of themes according to importance. Specific issues, as identified by Zones/programs within these themes, include:

6. Education and Awareness

*Relates to prioritized themes 1, 3/4 and 5

All Zones and most program areas identified a need for increased PEOLC education and awareness for both healthcare providers and the public. For healthcare providers, this included education related to the PEOLC competency work, the Serious Illness Conversation Program (SICP), ACP/GCD education, and to support Connect Care implementation.

The Covenant Health Palliative Institute, under the auspices of the PPAL/EOL ISC, has developed interdisciplinary PEOLC competencies. Further resources are needed to continue future work which includes a current state analysis of existing education across the province to determine how well current education meets the identified competencies. The development of additional education, where deficiencies are identified, will be needed to support healthcare providers in achieving and maintaining PEOLC interdisciplinary competencies. SICP education needs to be leveraged and spread across the province, utilizing a train the trainer methodology. Calgary Zone is working to develop a pediatric PEOLC specific resident and fellowship program. Healthcare provider education on what PEOLC services and resources are available (e.g., EMS PEOLC ATR, 24/7

palliative care physician on call) is also needed, as well as additional education on methadone prescription for physicians. While there is a methadone course that is recommended by the College of Physicians and Surgeons of Alberta, it is not known how well physicians may be aware of this course.

A public awareness campaign including ACP/GCD, PEOLC, and the differences between Medical Assistance In Dying (MAID) and PEOLC was also prioritized. For example, the public may not understand that PEOLC can occur simultaneously with a patient's eligibility assessment for MAID. Public education to promote publically-funded hospices as well as, the availability of other PEOLC services and resources is desired. Work with various stakeholders will be needed to achieve these education and awareness-raising priorities.

7. Interdisciplinary/Human Resources

*Relates to prioritized themes 2 and 3

For several programs and Zones, and particularly for pediatric PEOLC teams and rural zones, hiring additional PEOLC clinicians was a prioritized need. Of those that wanted to hire additional PEOLC staff, about half wanted to hire physicians, and the other half interdisciplinary team members (including social workers, spiritual care practitioners, and additional resources for 24/7 RN on call). Recruiting palliative care physicians and family physicians with palliative care skills is an issue for several Zones and programs. Additional staff would help meet the increased volume and complexity of clients as well as improve continuity of care.

Beyond hiring staff, Zones, and programs also wanted to develop and enhance comprehensive, holistic interprofessional PEOLC support. This includes collaborating with primary care on physician-specific programming such as the increased capacity for family physicians to provide home visits as well as determining and implementing the best method of PEOLC physician coverage for some sections of the province. Additional program development, where it is needed, such as dedicated Zone and provincial resources for ACP/GCD, increased palliative home care services, and a formalized PEOLC volunteer program was also prioritized. For existing PEOLC teams, there is a desire to clarify the roles and responsibilities of interdisciplinary team members. One Zone specifically wanted to spread an established peer support process to other PEOLC teams within their Zone.

8. Programs/Services

*Relates to prioritized theme 2

Home/community support

PEOLC is impacted by, and contributes to, the AHS focus on shifting care to the community, especially in rural communities. Although Alberta has made great strides in virtual visits and consultations because of the COVID-19 pandemic in 2020, there is still a need to spread existing models including home consultation using Zoom, Skype, and Telehealth to rural areas across the province to efficiently utilize the time and travel of practitioners. Another existing model, the Rural Palliative Care in-Home Palliative Funding Program, has been implemented in all Zones for the adult population, but not yet for the palliative care pediatric population. There is a strong need to establish and improve specialized palliative home care for the pediatric population across the province, inclusive of an enhanced pediatric service package and a hospice to home model. Additional work is needed to strengthen collaborations with PEOLC programs and Primary Care Networks. Also, rural Zones and some suburban/urban Zones have identified that access to community pharmacy needs improvement.

Day program/respite

Three Zones and programs mentioned a need to develop or increase respite and/or day programs. Specific issues included palliative care day programming for the non-cancer population, developing a respite palliative care centre for the pediatric population where needed, and seeking funding for a respite day program in a rural Zone.

Grief and bereavement support

Establishing and enhancing grief and bereavement support programs was identified as a prioritized need by some Zones. The need to implement grief and bereavement support programs for both the adult and pediatric populations and spiritual care to enhance bereavement programs were identified. Ongoing sustainable funding is required because donation dollars are used to fund existing grief and bereavement support programs.

Bed capacity

Capacity planning work was completed in 2013 and 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. The need to increase PEOLC bed capacity to meet the above plan in several care settings, Zones, and programs was also identified. This included hospice as well as designated community PEOLC beds in three Zones, and beds dedicated to PEOLC respite or symptom management for the pediatric population. Hospital overcapacity is a significant issue impacting PEOLC in one rural Zone.

Marginalized/diverse populations

Several Zones and programs expressed a need to better understand and meet the PEOLC needs of diverse and marginalized population groups. This includes population groups such as the homeless and Indigenous populations, including follow through with patients from Indigenous communities after discharge from hospital. There is a desire to focus on palliative care for patients with non-cancer diagnoses, and to better understand and predict the prognosis for this group. A particular group of interest, and where there is a need for understanding and addressing PEOLC needs, are individuals living with dementia. Many Zones and programs are seeing increased mental health complexities among palliative care patients which are impacting their work. The development of patient group-specific resources and educational materials are also needed.

Other programming/service gaps and challenges

There is a need to develop, implement, and evaluate an early palliative care strategy and model across community services. This includes increasing access to early palliative care and improved symptom control for patients with advanced cancer. Additionally, there is a need to develop a more rigorous evaluation process to measure the quality of patient and family experiences during and after their PEOLC journey. This includes examining potential financial barriers associated with dying at home, in comparison to dying in hospice. The financial burdens associated with COVID-19 heighten the importance of reducing the financial barriers to dying at home. There is also a desire to optimize the referrals to pain and symptom clinics embedded within cancer centres. Increasing and optimizing comprehensive interdisciplinary PEOLC support (e.g., social work, Occupational Therapy, child life specialist, overnight respite care, etc.) is needed to improve equity for PEOLC patients in rural areas. Collaborating between AHS and community hospice societies and private hospice sites (funding for beds, referrals, and additional resources) is challenging in some Zones.

Complex Symptom Management

*Relates to prioritized theme 3

All Zones have noted that the complexity of PEOLC symptom management has been increasing over time. Zones and programs prioritized addressing complex symptom management in hospitals, hospices, the pediatric population, and in the context of the opioid crisis.

There is a need for epidural intrathecal pain management to be more available outside of the hospital setting. There are also challenges regarding technological advances such as bi-pap, c-pap, drains, etc. in hospices. Specific to the pediatric population, there is an increased volume of patients with respiratory issues on caseloads, and exploration is being done to determine how to better meet the complex care needs of children in Red Deer to hopefully decrease the need to travel to Calgary and Edmonton for such care.

Policy and procedure

*Relates to prioritized theme 6

Over the last year, there has been a Specialty Design Working Group dedicated to making decisions about PEOLC assessment tools, resources, and information to prepare for the implementation of Connect Care. A sub-working group focused on building necessary ACP/GCD components related to the provincial policy into Connect Care including a way for patients to upload their own personal ACP/GCD related documents. With the implementation of Connect Care, there will be an increased need for standardization of PEOLC practice, policy, tools, etc. across the province.

9. Definitions revisited

Since the development of the Framework in 2014, there have been numerous updates to PEOLC definitions by various provincial, national, and international groups. PPAL/EOL ISC reviewed a variety of definitions and felt that our existing PEOLC definitions align with current approaches to PEOLC across AHS and are also congruent with these updated definitions. The PPAL/EOL ISC opted to broaden the scope of "hospice care" and "palliative approach to care" definitions to better reflect the current use of these terms. The following updated definitions are have been endorsed by the committee:

Hospice care is a specialized service that provides 24/7 facility-based care to those who are approaching end-of-life and whose needs can best be met in this location (based on assessed needs, patient preferences, and available bed capacity). It is provided in designated/supported community spaces, which may include a) stand-alone community hospice beds or b) designated/supported end-of-life care beds in long term care, designated supportive living, or other healthcare facilities located in the community. Hospice care is provided to both the adult and pediatric populations and may include respite. There are specific criteria for referral to hospice and access is determined by specialized palliative care clinicians See Appendix C for general hospice admission guidelines used in AHS and Covenant Health.

*Please note that these designated spaces are funded in a variety of different ways including funding from AHS or Covenant Health, continuing care operators, Alberta Children's Hospital Foundations, private donations, and/or hospice societies.

** The revised definition was adapted from the Cancer Care Alberta definition.

The palliative approach to care focuses on the person and family, and their quality of life throughout the illness trajectory, in advance of and not just at the end-of-life. A palliative approach to care can occur simultaneously with disease-directed treatment.

This includes supporting and managing:

- illness comprehension and coping
- symptoms and functional status
- advance care planning and the patient's preferred method of decision making
- coordination of care
- support for family/caregivers

** The revised definition of the palliative approach is adapted from the Canadian Hospice Palliative Care Association 2009; Pereira 2008; and the Cancer Care Alberta.

10. Annual prioritization of work

The provincial PEOLC strategy team will continue to complete an annual prioritization exercise with PPAL/EOL ISC to plan PEOLC activities that are needed every fiscal year. Appendix D provides an example of the endorsed prioritized plan for the remainder of the 2020/21's fiscal year by the steering committee.

Recommendations for implementation if resources become available

- Include themes, gaps, challenges, and activities identified within this addendum in future annual planning and prioritization work for PPAL/EOL ISC.
    - Prioritize the individual activities within each of the themes and develop action plans.
    - Prioritize the gaps and challenges identified by zones and programs and develop action plans.
- Both PPAL/EOL ISC and Alberta Health have identified Education as the top priority theme to be implemented.
    - Conduct a current state of existing education available in Alberta for the public and health care providers.
    - Leverage the work completed by the Competency Project.
- Focus on the next three top prioritized themes (programs and services, awareness and engagement, resources for care (communication).
- Alberta Health and AHS will need to work collaboratively to develop directional policies to ensure education based on evidence and best practice is successfully delivered across the province.
- Leverage existing work that may meet the gaps and standardize across the province
- Acknowledge the National Framework on Palliative Care in Canada as part of the Federal Government's action plan and its impact and/or alignment within Alberta.

Conclusion

The success of the provincial program can be measured with performance indicators (e.g., decreased unnecessary acute care utilization). This will be accomplished through enhancing care within communities, standardized education, policies, procedures, and assessment tools and implementation of the provincial Connect Care clinical information system.

This addendum will be used by PPAL/EOL ISC to refocus and reframe the work needing to be completed in the years ahead to continue to improve the quality and access to PEOLC care for all Albertans regardless of their geography. Just as with the Framework in 2014, PPAL/EOL ISC will utilize the prioritized themes within the addendum to guide long term action plans to better care for patients, families and support healthcare providers.

Reference: Dowsett L, McCarron T, Farrier C, Lorenzetti D, Brooks K, Holitzki H, Coward S, Han D, Hofmeister M, Memedovich A, MacKean G, Stafinski T, Menon D, Noseworthy T, Clement F. Palliative and End-of-Life Care: A Health Technology Assessment Report. University of Calgary: Cumming School of Medicine, University of Alberta, University of Calgary: O'Brien Institute of Public Health- Health Technology Assessment Unit; 2018.

Appendix A

Detailed Descriptions of the Health Technology Assessment (HTA) Quality Statements

The 2019 HTA report outlined 14 quality statements that, taken together, describe an appropriate model for provision of high quality PEOLC. These broad quality statements were then adjusted by PPAL/EOL ISC to reflect the Alberta PEOLC perspective and context. The HTA report focused on adults, however, the quality statements may be appropriate for pediatrics. The revised statements are as follows:

1. **Advance care planning**

   There is support for all patients to take part in advance care planning discussions with primary, secondary, and tertiary health care providers to ensure everyone involved in their care knows their wishes, preferences, values, and beliefs early in the continuum of care. Discussions are robust and at minimum address goals of care.

2. **Public awareness**

   Information about Palliative Care and End-of-Life Care (PEOLC) is easily accessible and understandable to the public to raise awareness and change the culture around discussions of death and dying.

3. **Early identification of patients with life-limiting and life-threatening illnesses**

   Patients with life-limiting and life-threatening illnesses who have PEOLC needs or could benefit from a PEOLC approach are appropriately identified early in their disease journey.
   Patients may be identified by primary care physicians, palliative care physicians, specialists in other settings (e.g., but not limited to: oncologists in cancer clinics), nurse practitioners and other nursing staff, paramedics, and/or through self-referral.

4. **Holistic assessments of patients' needs**

   The PEOLC needs of patients with life-limiting, and life-threatening illnesses are holistically assessed, re-assessed, and documented to ensure care is responsive to changing needs for comprehensive palliative care services.

5. **Continuity and coordination of care**

   A system is in place to coordinate patient and family care within and across all settings and levels of care, including documentation and communication of patient information (e.g., clinical information; details around all future health-related decisions including goals of care).
   Information is accessible to all healthcare professionals involved in a patient's care within and between settings in a timely and seamless way.
   Ensure services are culturally sensitive and, appropriate (e.g., Indigenous communities) with special consideration given to marginalized populations (e.g., homeless).

6. **Person-centred care**

   Patients and their families receive PEOLC that is individualized to their unique needs including symptom management.
   Patients and families are integral members of the interdisciplinary team, meaning that healthcare teams meaningfully engage with and empower patients and their families, enabling collaboration in decision-making on both clinical and non-clinical aspects of care.

7. **Support for families and caregivers**

   The emotional and practical needs of families and caregivers are proactively assessed, re-assessed, and managed through access to supportive services.

Supportive services (e.g., respite care and bereavement support) are available to family and caregivers after the patient's death regardless of their geographical location.

8. **Preferred location of care and place of death**

   Care in the dying phase is appropriately delivered in the patient's preferred setting, which may be in a private residence, hospice, long-term/ continuing-care facility, or hospital.

9. **Comprehensive palliative care services**

   Patients with life-limiting and life-threatening illnesses have early and appropriate access to an affordable, comprehensive, and integrated PEOLC program, which includes:
   - home palliative care
   - hospice beds
   - a hospital support team
   - a palliative care consult team and/or a specialized palliative care team is available at the request of the treating team, regardless of the setting
   - medication for pain and symptom management
   - specialized equipment and supplies
   - crisis support for patients whose pain and symptoms can no longer be managed at home

10. **Interdisciplinary team-based care**

    An interdisciplinary team of care providers works collaboratively, sharing information and strategies to treat patients with life-limiting and life-threatening illnesses based on their unique needs.
    This team is diverse, including, but not limited to family physicians, palliative care physicians, nurses, allied health professionals, pharmacists, healthcare aides, spiritual care providers, volunteers, and interpreters, depending on the patients' needs.

11. **Education and training for healthcare providers**

    All healthcare professionals and providers involved in the care of patients, with life-limiting and life-threatening illnesses have the knowledge, skills, and attitudes necessary to provide high-quality palliative care.
    This is supported in several ways, including incorporating palliative care into professional programs, providing ongoing training for healthcare providers involved in palliative care, and giving providers access to mentorship from those with palliative care expertise.

12. **Education for families and caregivers**

    The expectations and roles of families and caregivers supporting patients with life-limiting and life-threatening illnesses are clear and they have the education and training required to fulfill their roles for as long as possible.

13. **Community support**

    Existing social capital within communities (e.g., support networks, charities, volunteers, etc.) is recognized and further developed to support PEOLC patients and their families/caregivers.

14. **Quality and safety of palliative care services**

    PEOLC programs and services undergo ongoing quality improvement through data collection and analysis of a standardized set of outcome measures (e.g., clinical; quality-of-life; patient and caregiver satisfaction). Quality improvement and evaluation programs should be palliative care-specific and implemented in addition to general accreditation processes and standards-of-practice for health care providers.

Appendix B

Quality statements and Framework gaps by prioritized themes

1 — Education

Patient Education
Information about Palliative Care and End-of-Life Care (PEOLC) is easily accessible and understandable to the public:

- What does a patient need for PEOLC education? (Q2)
- Public awareness and education for PEOLC (Q2)
- Development of future patient & family education (Q12)

Health Care Provider Education
All healthcare professionals and providers involved in the care of patients, with life-limiting and life-threatening illnesses have the knowledge, skills and attitudes necessary to provide high quality palliative care:

- Role to influence entry level to practice program curricula (Q11)
- Education of current and future practitioners and health care providers (Q11)
- Cost for LEAP Core and LEAP Paramedic training for both participants and facilitators (Q11)
- Inventory core education programs, besides LEAP, that is currently available across Alberta. Determine if it meets the interdisciplinary competencies when they are completed (F6)
- Ongoing funding mechanism needed to further provide PEOLC education across Alberta (F6)

2 — Program and Services

Processes
Act on recommendations from the Action Learning Project (ALP) Study – Embedding a Palliative Approach into Alberta's Primary Health Care System (Q3)
Transition between settings of care (i.e. hospital to home) (Q5)
Standardized process to access PEOLC programs and services across the province (Q9)
Assessment of different models of care across the province for justifiable vs unjustifiable variability (Q9)
Explore and collaborate for opportunities to better support symptom management in the community including after-hours access to medication for pediatric and adult PEOLC patients (Q9)

Program Development
Pediatrics

- Ability to offer 24/7 palliative home care or hospice care for pediatrics (Q9)
- Limited resources for pediatric patients and families with respect to location of care (Q8)

Adults and Pediatrics

- Development of resources continues to be inclusive of a culturally sensitive approach (Q5)
- Funding to spread NavCare across the province (Q13)
- Funding to provide Rural Palliative Care In-Home Funding Program (Q13)
- Inadequate resources across part of the province including but not limited to: (Q7)
  - local bereavement resources
  - Social Work
  - Counselling
  - Transportation
  - Volunteer Support
  - Access to financial supports
  - Respite for pediatric and adults
- Bereavement Package evaluation (on hold) (Q14)

(3 — Resources for Care (Communication)

Patients and families are integral members of the interdisciplinary team.

- Culture around family involvement in care? (Q6)
- For patients who wish to die in a different zone or province, the transfer of care between zones and/or province (Q8)

The PEOLC needs of patients with life-limiting, and life-threatening illnesses are holistically assessed, re-assessed and documented to ensure care is responsive to changing needs for comprehensive palliative care services.

- Ongoing care planning and reassessment (Q4)
- Care planning and reassessment can be site specific. (Q4)
- Tools that accompany comprehensive assessment (Q4)
- Complex Care Plans (Q12)
- Integration of pain and symptom clinics into the palliative care system resources available for primary PEOLC providers across Alberta (Q5)

Information is accessible to all health care professionals involved in a patient's care within and between settings in a timely way.

- Connect Care not available in indigenous communities (Q5)

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

- Unmet hospice Capacity to meet 7.7 hospice beds per 100,000 needs adjusted population across the province for pediatrics and adults (Q9)

4) — Awareness and Engagement

Develop direct links with the Primary Care Networks and Family Care Clinics within local communities and partner with provincial stakeholders building strong relationships with those who can support provision of PEOLC in local communities, such as contracted partners in Long Term Care, Supportive Living and home care as well as community organizations.

- Inconsistent Primary Care / PCN Engagement (Q1) (F1) (F2)
- Does the public know about the initiatives that have been completed to date? (Q2)

5 — Advance Care Planning / Goals of Care Designation

There is support for all patients to take part in advance care planning discussions with primary and secondary health care providers to ensure everyone involved in their care knows their wishes, preferences, values and beliefs early in the continuum of care.

Public

- Educate public on resuscitation through HUTV (Q1)

Health Care Provider

- ACP / GCD conversations needs to be Standard of practice for all interdisciplinary team members (Q1)
- Integrated education program for all providers (Q1)
- Community Information Integration (CII) Implementation initiative that transfers select patient information between community electronic medical records and other members of patient' care team through Netcare. (Q1)
- Transfer of information between primary care and acute care (Q1)
- Documentation of ACP discussions and sharing that documentation to other providers (Q1)
- ACP discussions are needed at the point of hospital admission for chronic disease specialties (Q1)

6 — Policy, Procedure and Guidelines

- Connect Zones to see if there are similar policies and guidelines that are needing to be developed. Facilitate the development of provincial policies and guidelines leveraging existing work completed by the zones. Policies, procedures and guidelines need to be maintained and easily accessible. (F7)
  - Patient's Death in LTC, SL 3, 4, and 4D Guideline (on Hold) (Q5) (F7)
  - Pronouncement of Death (awaiting Corp Policy) (F7)
  - Palliative Sedation Nursing Assessments (CKCM?) (F7)
  - Drains (e.g. PleurX) (not yet assigned) (F7)
  - Exploring opportunities for after-hours access to medication for pediatric and adult PEOLC patients in the community (Q9) (F7)
  - ICD Deactivation (F7)
- No clear way to document the palliative approach early in a patient's disease journey (i.e. inconsistent codes used) (Q3)
- Understanding and interpretation of Alberta Palliative Blue Cross process (Q9)
- Palliative Blue Cross coverage for all EMS transports of PEOLC patients (Q9)

In addition to the gaps listed above, the zones also face gaps and challenges as outlined in the Addendum on pages 7 – 10.

Legend

(Q#) relates to that numbered quality statement

(F#) relates to that numbered framework initiatives

Appendix C

General Guidance for Hospice/End-of-Life Care Admission

An assessment for hospice/EOL care must be completed

- As per the Zone process
- The physician confirms diagnosis & life expectancy
- Meets hospice/EOL criteria – see below

Hospice /EOL care admission criteria

The general guidance for admission, including but not limited to the following criteria:

Note: these criteria are based on hospice criteria that are common across most or all of the five Zones within AHS. Where there were differences between zones (e.g., Palliative Performance Scale (PPS) scores), the more conservative criteria are included, with statements allowing for flexibility in applying criteria. The common criteria are intended to enhance consistency across the Zones while allowing for flexibility and respecting current Zone practices.

Care needs - Patient's care needs can only be met by a PEOLC designated bed whether that bed is located in a hospice, an acute care site, or a continuing care site.

Age – 18 years of age or older

Diagnosis – Diagnosed with a progressive life-limiting disease

Life expectancy – approximately three (3) months or less (guidance), except in respite cases

Goals of Care Designation (GCD) Order – C1, C2 (M2 may be considered), the rationale for M2 would be for specialized for circumstances such as acute leukemic who is receiving a transfer to hospital for blood transfusions for a designated period while awaiting a visit from family member out of the country.

Goals of care – focus on comfort, symptom management, and quality of life; not care with the primary intent to prolong life. However, there may be medications given such as antibiotics to improve quality of life, i.e. antibiotics to treat infections for comfort care.

Palliative Performance Scale (PPS) – 40% or less (guidance), exceptions may be made on a case by case basis.

Valid Alberta Health Care number – exceptions may be made on a case by case basis for out of province and out of country patients and may depend on several factors, including available AHS resources and any other considerations as deemed appropriate by AHS.

Cancer and non-cancer patients – not awaiting consultation for initial assessment, staging, or treatment of disease at cancer centre/hospital/urgent care settings

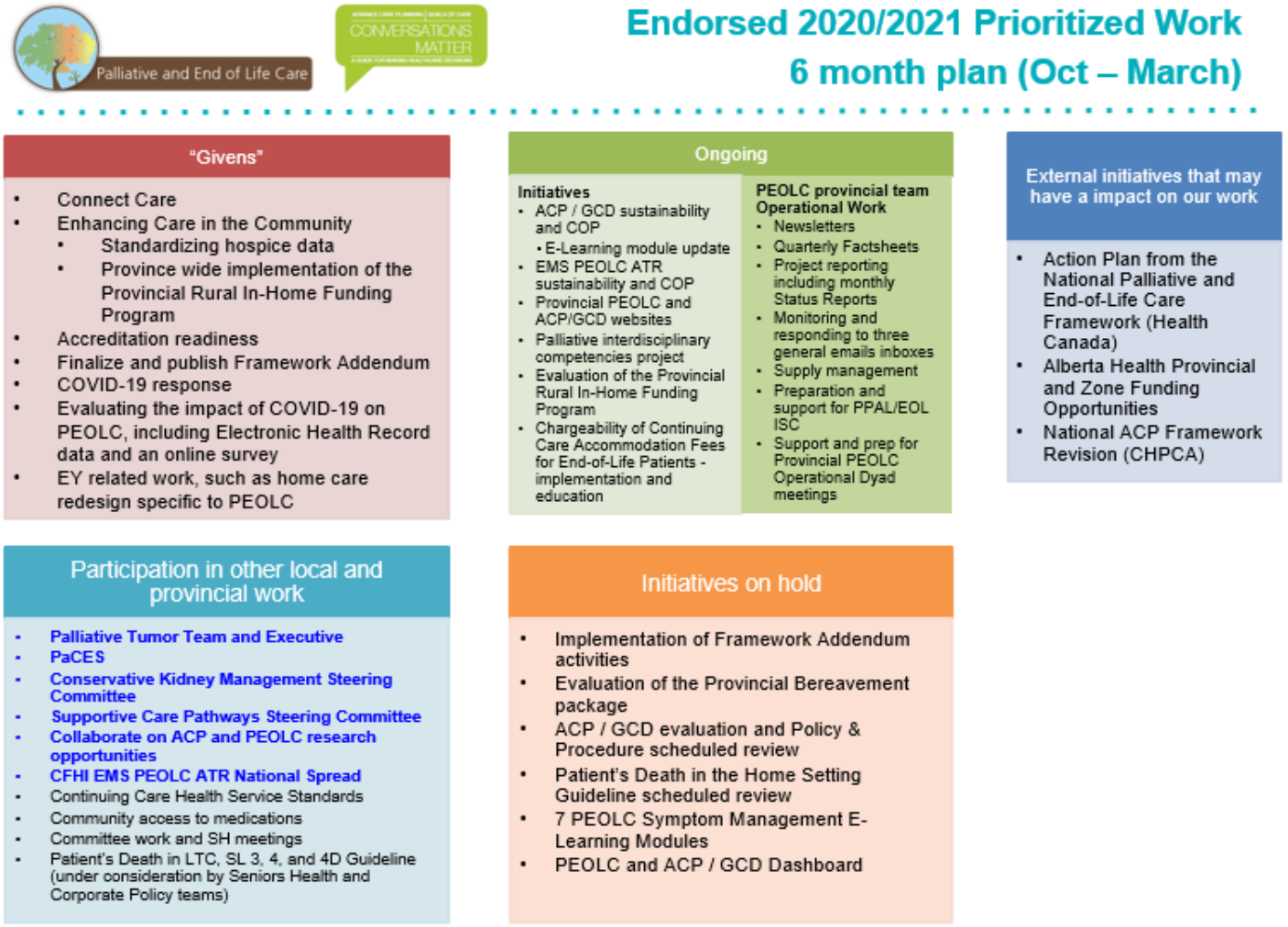
- Can be waiting for or receiving palliative radiation

Discharge from hospice – admission process requires patient and family to be notified of conditions required for continued admission; if the patient is inappropriate for setting then discharge will be arranged.

Appendix D

Prioritized work for the remainder of 2020/21 fiscal year

The PPAL/EOL ISC has prioritized the following work for the 2020/21 fiscal year. This was endorsed at the June 18th, 2020 PPAL/EOL ISC meeting. This work includes the need to respond to the COVID-19 pandemic as well as the results of any Alberta Health funding opportunities.



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- Alberta Health
- Alberta Hospice Palliative Care Association
- Canadian Hospice Palliative Care Association
- Cancer Care Alberta
- Covenant Health Palliative Institute
- Cumming School of Medicine, University of Calgary
- Government of Canada - First Nations Inuit Health Branch
- Health Evidence and Policy Unit, Alberta Health
- Indigenous Communities
- Palliative and Primary Care Physicians
- Patient and Family Advisors
- Primary Care Networks
- Strategic Clinical Networks
- University of Alberta
- University of Calgary

The passion, efforts, and dedication within Alberta and Nationally to improving palliative and end-of-life care services for all citizens provided by the people and organizations included above has been incredibly significant and speaks to the need for further action to accompany the recommendations within this Addendum.

For further information please contact the Provincial Palliative and End-of-Life Care Team
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