

**DRAFT Content to Inform the Provincial Palliative Care Frameworks**  
**For Discussion and Feedback only**

**Introduction:**

On December 2, 2020, the Government of Ontario passed the *Compassionate Care Act*, which requires the Minister of Health to develop a provincial framework to support improved access to palliative care. The Ontario Palliative Care Network (OPCN), in its role as a principal advisor to the Ministry of Health (Ministry), is holding consultations with relevant stakeholders to inform OPCN's submission to the Ministry for proposed palliative care frameworks for both adult and pediatric populations.

The draft Pediatric and Adult Palliative Care Frameworks both include:

**Aspirations:** Statements that capture the ideal future state of palliative care

**Building Blocks:** Focus areas that capture the required actions to achieve the aspirations

The content builds on themes previously consulted on, as well as seminal palliative care documents.

**The focus of the consultation session is to obtain feedback on the *draft building block actions*.**

While there is some overlap in the draft content for the Pediatric and Adult frameworks, there are also key differences.

We will discuss feedback for the draft content for the Pediatric and Adult Frameworks separately.

**Action Requested:**

In preparation for the consultation, please review the following DRAFT content for the Pediatric and Adult Frameworks.

It is important to note that because of the length of the document, it will not be possible to walk through each of the actions during the consultation. Instead, we will have an open discussion for each of the building blocks.

**With that in mind, please come prepared to provide your input/suggestions on:**

- 1. Whether we have captured the key actions in each building block**
- 2. If there are any missing actions that need to be added**

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**DRAFT Provincial Palliative Care Framework for Pediatrics**

**Aspirations for Pediatric Palliative Care:**

- All children and families suffering from a serious illness receive holistic, family-centred care in their preferred location, where possible
- Care is timely, coordinated & delivered by an interprofessional team
- Access to pediatric palliative care is equitable
- Providers feel supported and prepared to meet the needs of children and families at any stage of illness

**Building Blocks for Pediatric Palliative Care:**

The following table outlines draft actions under each building block required to achieve the aspirations outlined above.

Name of Building Block	Suggested Actions
<p><b>Child and Family Awareness</b></p>	<ul style="list-style-type: none"> <li>- Establish a centralized web-based clearinghouse with education and resources for the child and family in the preferred language and format that is appropriate to age, cognitive and educational ability of the child and is within a suitable cultural context, and includes:               <ul style="list-style-type: none"> <li>○ Information about benefits of pediatric palliative care, and the value of earlier integration</li> <li>○ Information about available PPC services and supports</li> </ul> </li> </ul>
<p><b>Child and family-centred care</b></p> <p>(Note, this includes addressing social aspects and other unique pediatric palliative care needs e.g. respite, education, play etc.)</p>	<ul style="list-style-type: none"> <li>- Develop processes to ensure that person-centred care planning and decision-making is part of the routine care provided to all children               <ul style="list-style-type: none"> <li>○ Ensure children and family receive age-appropriate resources that provides information about their illness, potential treatments and outcomes, to support decision-making.</li> </ul> </li> <li>- Develop processes and best practices that enable the care team to collaborate with the child and family in developing care plans based on the child’s wishes, values, and beliefs and their identified goals of care.</li> <li>- Standardize elements and documentation of the care plan :               <ul style="list-style-type: none"> <li>○ Includes promoting continued school attendance, access to education and learning opportunities, as well as play and recreational opportunities that are appropriate to both age and cognitive ability of children</li> <li>○ Incorporates other special needs of children (e.g. practical assistance and timely provision of equipment and adaptations)</li> <li>○ Includes consideration for transition planning to adult services to ensure seamless transitions and minimize interruption of services.</li> </ul> </li> <li>- Develop processes to support a triadic model of decision making where parents often make decisions on behalf of incapable children but children’s wishes are considered in such decision making.</li> <li>- Provide funding to enable access and increase availability to non-professional community resources to meet the basic social, emotional and spiritual needs of children &amp; families</li> </ul>

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Name of Building Block	Suggested Actions
	<ul style="list-style-type: none"> <li>- Provide funding to increase availability of psychosocial resources in the community as well as increase visiting hospice resources tailored to the unique developmental needs of seriously ill children and their siblings.</li> <li>- Provide funding to enable equitable access to flexible respite care in the child’s own home and in a home-away-from-home setting, provided by appropriately trained and competent staff.</li> <li>- Develop a process to ensure children and families are connected with grief and bereavement services from the time of the diagnosis to the end of life and beyond</li> </ul>
<b>Integrated care</b>	<ul style="list-style-type: none"> <li>- Develop a coordinated and standardized approach for delivering hospice palliative care services in the province</li> <li>- Develop a hub and spoke model of care to connect community providers with expert teams at the appropriate hubs based in the five Academic Health Sciences Centers</li> <li>- Develop processes to ensure children with complex PPC needs are identified and connected with an expert PPC team</li> <li>- Involve community providers (Adult PC providers, pediatricians, family physicians, Nurse Practitioners, and other allied health providers) in providing PPC to enable care close to home for children and families</li> <li>- Establish mechanism to connect local community providers with an expert PPC for support, consultation and mentorship</li> <li>- Establish a mechanism that enables access to an on-call most responsible community palliative care provider for children and families</li> <li>- Provide funding for the provision of advanced level PPC teams within each of the Pediatric Academic Health Sciences Centres in Ontario (tertiary centres).</li> <li>- Develop a mechanism to share standardized care plans across all settings of care, and among all caregivers and programs/services involved with the child and family.</li> <li>- Establish mechanisms to enable access to electronic medical records across providers and care settings to ensure effective communication across the team</li> <li>- Establish processes for care coordination to support children receiving PPC with transitions between providers and across care settings Develop and expand virtual platforms for PPC and information dissemination to facilitate support available to both children/families and community health care providers (especially for those in remote/rural communities).</li> <li>- Identify and address barriers to accessing PPC for diverse and underserved communities across sectors, settings and professions</li> <li>- Partner with members of diverse and underserved communities to develop and deliver culturally sensitive and informed care.</li> <li>- Address billing code barriers to enable shared care.</li> </ul>

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<b>Name of Building Block</b>	<b>Suggested Actions</b>
<b>Provider education and mentorship</b>	<ul style="list-style-type: none"> <li>- Incorporate basic PPC principles and competencies into foundational training for all healthcare professionals as well as volunteers who provide care to children</li> <li>- Develop a standardized curriculum of PPC based on the 3 levels of PPC (basic, intermediate, advanced).</li> <li>- Make PPC training a mandatory part of adult palliative care fellowships, particularly the 1 year added competency that general practitioners do.</li> <li>- Provide additional training opportunities for pediatric residents and fellows (i.e. Secondary level PPC)</li> <li>- Develop mechanisms that enable community providers to have access to expert support and mentorship based in five academic Health Science Centres</li> <li>- Create formal linkages between specialty PPC hubs and generalists in the community including joint home visits (in person and or virtual) to build capacity.</li> <li>- Build a community of practice through mentorship and collaboration (e.g. Project ECHO which looks at education around real patients that generalists are looking after in the community)</li> <li>- Provide ongoing opportunities for PPC education for professionals, volunteers and informal caregivers.</li> <li>- Develop/adapt common PPC tools and guides to practice (i.e. screening/ assessment tools, patient passport, algorithm/referral template) for implementation across the province.</li> <li>- Establish a centralized web-based clearinghouse that provides access to common tools and guides to practice that includes ongoing updates to the resources</li> </ul>
<b>Evidence and data</b>	<ul style="list-style-type: none"> <li>- Develop mechanism for consistent collection of, and reporting on PPC data to understand gaps and challenges in care and to guide quality improvement initiatives and policy decisions to enhance the quality of life of children and families experiencing serious illnesses.</li> <li>- Develop a centralized database for PPC and establish processes for collecting and feeding data into the database</li> <li>- Develop provincial PPC performance management framework which includes indicators to measure the quality of PPC and evaluate the impact of the implementation of the new Model of Care for PPC delivery.</li> <li>- Ensure PPC programs have a regular performance measurement and quality improvement plan in place.</li> <li>- Support the province-wide implementation of a patient and/or caregiver reported experience measure</li> <li>- Include results from patient/family/caregiver experience measures in planning and decision making</li> </ul>

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<b>Name of Building Block</b>	<b>Suggested Actions</b>
<p><b>Funding and resources (HHR, equipment, more beds etc.</b></p>	<ul style="list-style-type: none"> <li>- Develop a dedicated funding stream for the operationalization of PPC.</li> <li>- Undertake rigorous assessment of funding needs for the staffing and operation of the expert palliative care teams situated in the five Academic Health Sciences Centers, as well as potential outreach professionals</li> <li>- Provide funding for strong, well-resourced PPC hubs available 24/7 to support the spokes as well funding for the members of the team that can bridge the transition from hospital to home (e.g. Community psychosocial services, community outreach nurse practitioner)</li> <li>- Provide funding to support adequate provision of PPC in the community including FNIMul communities, remote/rural communities and other underserved populations.</li> <li>- Provide funding for 24-hour crisis support.</li> <li>- Revise the schedule of benefits (billing codes) to promote a model of shared care.</li> <li>- Provide funding for appropriate training, education and equipment to enable adult hospices to admit pediatric patients in their communities.</li> <li>- Provide funding for essential community services (e.g., social work, hospice services, spiritual care, bereavement etc.)</li> <li>- Providing funding and expand initiatives for caregiver support (e.g. income support).</li> <li>- Develop and implement provincial guidelines for access to provincially funded equipment required for PPC delivery</li> <li>- Develop mechanisms to include PPC in the larger palliative care funding envelope and within the overall agenda of palliative care.</li> </ul>
<p><b>Leadership and Strengthened Accountability</b></p>	<ul style="list-style-type: none"> <li>- Establish strong and visible leadership, across the whole sector, with key people responsible and accountable for effective and efficient service design and delivery.</li> <li>- Expand the role of the Provincial Pediatric Palliative Care Steering to include oversight and accountability for developing a coordinated and standardized approach for delivering PPC in the province and provide dedicated funding to enable these functions.</li> <li>- Develop a comprehensive provincial strategy for PPC</li> <li>- Develop a performance management framework to ensure accountability from all those involved in providing PPC.</li> <li>- Tie funding for PPC to outcomes/indicators through Accountability Agreements to help drive improvements in PPC delivery.</li> <li>- Ensure PPC programs develop, and utilize a systematic approach to improving performance which includes criteria to assess the overall functioning components of the program and the effectiveness of its services.</li> </ul>

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**DRAFT Provincial Palliative Care Framework for Adults**

**Aspirations for Adult Palliative Care:**

- Individuals and their families receive person-centred care, in their preferred location, where possible
- Care is timely, coordinated & delivered by an interdisciplinary team
- Access to palliative care is equitable
- Providers feel supported and prepared to meet the needs of individuals and their families at any stage of illness

**Building Blocks for Adult Palliative Care:**

The following table outlines draft actions under each building block required to achieve the aspirations outlined above.

<b>Building Block: Leadership &amp; Accountability</b>	
Action(s) seen as quick wins	Action(s) needing longer term “investments”
<ul style="list-style-type: none"> <li>• Continue to leverage OPCN and RPCN resources to strengthen provincial and regional accountabilities</li> <li>• Establish data collection and performance measurement processes to assess whether care is being provided in alignment with the Palliative Care Quality Standard</li> <li>• Identify accountability levers</li> <li>• Review and revise contracts with service provider agencies to include appropriate accountabilities to ensure 24/7 access to palliative care support</li> <li>• Consult with Indigenous leaders and researchers to identify Indigenous-specific PC solutions and priorities.</li> <li>• Communicate with leaders and community members to identify how to increase support for BIPOC, 2SLGBTQ+ individuals, persons living with disabilities, homeless</li> <li>• Promote existing provincial palliative care guidance to leverage the expertise and capacities of existing palliative care structures and organizations, and avoid duplication of efforts</li> </ul>	<ul style="list-style-type: none"> <li>• Establish clear accountabilities within Ontario Health &amp; the five regions to drive provincial and regional PC strategies.</li> <li>• Establish clear leadership provincially and regionally with the ability to make and/or influence decisions regarding comprehensive PC delivery</li> <li>• Develop a standard structure for accountability and management of palliative care funds</li> <li>• Leverage emerging health system structures as opportunities to promote palliative care integration</li> <li>• Establish/maintain collaboration between OPCN, OLTC, Advantage ON, MOH and regional partners with specific focus on equitable access to LTC.</li> <li>• Review existing legislation/regulations that govern LTC to address staffing levels, and competencies to support palliative care provision.</li> </ul>

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<b>Building Block: Provider Education and Mentorship</b>	
Action(s) seen as quick wins	Action(s) needing longer term “investments”
<ul style="list-style-type: none"> <li>• Conduct awareness efforts to promote existing palliative care guidance, resources, education programs               <ul style="list-style-type: none"> <li>○ Establish provincial platform for inventory of education programs/ opportunities, reference materials, etc.</li> </ul> </li> <li>• Develop regional education plans focused on strengthening primary level palliative care               <ul style="list-style-type: none"> <li>○ Aligns with the Competency Framework</li> <li>○ Leverages online platforms to increase access</li> </ul> </li> <li>• Explore mechanism(s) to enable easy/timely access to mentorship</li> <li>• Develop mechanism(s) to enable access to supports for providers, including psycho-social supports</li> <li>• Explore best practice models that integrate education and skills training for interdisciplinary teams and others (support staff, volunteers, caregivers, etc.), including communication skills, and advocacy training as core competencies</li> </ul>	<ul style="list-style-type: none"> <li>• Work with academic institutions and regulatory bodies to incorporate the Ontario Palliative Care Competency Framework into education curricula.</li> <li>• Identify and address disparities in funding palliative care education between regions</li> <li>• Ensure all medical schools have a division or department of palliative medicine</li> <li>• Create appropriate residency and mid-career training opportunities for professionals interested in palliative care.</li> <li>• Develop and expand education programs for volunteers</li> <li>• Develop &amp; expand grief &amp; bereavement education</li> <li>• In consultation and collaboration with those who have lived experience, develop education focused on providing palliative care for vulnerable and underserved populations</li> <li>• Provide funding to scale-up existing PC education programs and on-the job training.</li> <li>• Fund research that monitors and evaluates the impact of available palliative care education</li> <li>• Work with Provincial Territorial Organizations and First Nations, Inuit, Métis, and urban Indigenous organizations to plan and deliver competency-based education.</li> </ul>

<b>Building Block: Public Awareness</b>	
Action(s) seen as quick wins	Action(s) needing longer term “investments”
<ul style="list-style-type: none"> <li>• Promote and expand uptake of local Compassionate Communities initiatives</li> <li>• Develop an awareness campaign focused on building an understanding of palliative care, normalizing death and dying, and improving grief and bereavement literacy</li> <li>• Introduce discussions about death and dying in non-medical settings (schools, workplaces, etc.) to increase comfort with the subject and integrate the concept into daily life</li> <li>• Develop local public awareness campaigns to help inform individuals and their family/caregivers of the supports and services available to support them</li> </ul>	<ul style="list-style-type: none"> <li>• Implement the palliative care awareness campaign</li> <li>• Invest in community-based initiatives to scale up and spread innovative models designed to improve access to palliative care services where and when they are needed, particularly for underserved populations</li> <li>• Scale up and spread best practice models designed to increase community capacity in rural and remote areas.</li> <li>• Partner with communities, governments and providers to identify opportunities to advance a Public Health Approach to Palliative Care in Ontario.</li> </ul>



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<b>Building Block: Integrated Care</b>	
<b>Action(s) seen as quick wins</b>	<b>Action(s) needing longer term “investments”</b>
<ul style="list-style-type: none"> <li>• Continue and expand the work of OPCN’s and RPCNs in developing and strengthening collaborative partnerships between organizations and providers to plan for and achieve a consistent approach to coordination that aligns with existing provincial palliative care guidance (i.e. the Quality Standard, Palliative Models of Care)</li> <li>• Leverage the Health Services Delivery Framework for Palliative Care to support OHTs with integrating palliative care into their service delivery planning</li> <li>• Develop regional processes to enable coordination and connection between primary care providers, specialists and across care settings including well defined care pathways and inventories of services</li> <li>• Determine appropriate caseloads for care coordination when planning regional human resources</li> <li>• Identify setting specific barriers that limit access to care and appropriate solutions (e.g., LTC physician not having access to billing code family physician has access to).</li> <li>• Incorporate evidence-based tools to support palliative care delivery into existing digital health information systems</li> <li>• Identify challenges and appropriate solutions to sharing patient information when working between multiple EMR platforms</li> <li>• Standardize elements and documentation of a care plan (i.e. Coordinated Care Plan, which includes a section on Palliative Care)</li> <li>• Identify and expand best practices for community palliative care paramedicine (i.e. the Paramedics and Palliative Care program)</li> </ul>	<ul style="list-style-type: none"> <li>• Establish processes that enable and help maintain coordination and connection between primary care, specialists, other HCPs, and across care settings               <ul style="list-style-type: none"> <li>○ Involve primary care champions in regional planning</li> <li>○ Develop Models of Care for implementation in hospital and in pediatrics that will foster collaboration between health care professionals</li> </ul> </li> <li>• Regional and local planning to include processes and tools that support effective communication between HCPs               <ul style="list-style-type: none"> <li>○ Evaluate and utilize technical solutions as appropriate</li> </ul> </li> <li>• Identify and address barriers to accessing PC for diverse and underserved communities across sectors, settings and professions,</li> <li>• Develop solutions that enable care plans to be shared between multiple providers, and across all care settings               <ul style="list-style-type: none"> <li>○ Include info on available services to meet patient and CG needs</li> </ul> </li> <li>• Widespread adoption of the navigator role (including navigation of informal community resources)</li> <li>• The ministry, and regions to partner with rural, remote, FNIMul communities to determine primary care gaps and seek to fill them</li> <li>• Develop and expand virtual platforms for PC and information dissemination</li> <li>• Establish an on-call service network of palliative care specialists (especially in remote/rural areas).</li> <li>• Conduct an assessment of future palliative care HHR needs</li> </ul>



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<b>Building Block: Person &amp; Family Centred Care</b>	
<b>Action(s) seen as quick wins</b>	<b>Action(s) needing longer term “investments”</b>
<ul style="list-style-type: none"> <li>• Develop a dedicated approach to support uptake and implementation of provincial guidance and identified best-practices</li> <li>• Evaluate patient/family and caregiver experience via PREMs/Caregiver experience measures</li> <li>• Develop, and update regional inventories of existing services to share with providers, individuals and their family/caregivers</li> <li>• Explore effective models of consistent processes that ensure individuals and their family/caregiver(s) members are actively involved in care planning and delivery</li> <li>• Increase the number of providers who are skilled in assisting individuals and their family/caregiver(s) to have culturally sensitive discussions about palliative care, and to engage them in person-centred decision making.</li> <li>• Examine how equitable access to bereavement supports and services can be established</li> <li>• Explore community-based approaches to specific illness or frailty</li> </ul>	<ul style="list-style-type: none"> <li>• Meet the basic social, emotional and spiritual needs of patients &amp; families through non-professional community resources.</li> <li>• Monitor implementation and uptake of existing provincial guidance, support shared learning, and facilitate scale and spread</li> <li>• Develop services related to anticipatory grief and adjustment to losses before death to complement existing bereavement services.</li> <li>• Develop palliative care policies, programs and services applicable across care settings (including the community) that are inclusive and considerate of all ages, sex and gender and cultural diversity</li> <li>• Review existing and emerging policies to ensure access to palliative care services is well defined and assessed through equity lens</li> <li>• Develop provincial guidelines for access to provincially funded equipment required to address palliative care needs</li> <li>• Partner with FNIMul Leaders, provincial and regional leaders to improve access to palliative care in indigenous communities.</li> <li>• Partner with provincial and regional leaders to improve access to palliative care for underserved populations</li> </ul>

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<b>Building Block: Funding</b>	
Action(s) seen as quick wins	Action(s) needing longer term “investments”
<ul style="list-style-type: none"> <li>• Quantify unmet need for palliative care services</li> <li>• Establish a formalized capacity plan to help proactively plan for and meet system capacity needs.</li> <li>• Develop a HHR plan to enable adequate access to palliative care supports, including psychosocial and grief and bereavement supports</li> <li>• ADD OAGO</li> <li>• Develop a new Provincial Palliative Care AFP Construct</li> <li>• Conduct a focused expansion and alignment of current on call programs for palliative care (CPOC and HOCC)</li> <li>• Review and revise palliative care fee codes/definitions/rules in OHIP Schedule of Benefits to align with provincial guidance</li> <li>• Review funding challenges limiting access to palliative care in LTC, and identify opportunities to align with best-practice models of care.</li> <li>• Identify opportunities for palliative care system efficiencies and reinvestment</li> </ul>	<ul style="list-style-type: none"> <li>• Fund research on the impact of all caregiver supports and services</li> <li>• Invest in efforts to improve access and delivery of PC to diverse and underserved populations</li> <li>• Provide community funding envelopes for continued and sustained support for education and on-the-job training.</li> <li>• Produce implementation options for tying provincial palliative care funds to delivery of the standard of care</li> <li>• Develop and implement provincial guidelines for access to provincially funded equipment</li> <li>• Fund essential community services (e.g., social work, hospice services, spiritual care, bereavement etc.)</li> <li>• Fund support services for all providers of palliative care (e.g., workplace wellness, counselling, skill building, bereavement)</li> <li>• Address artificial and health system imposed barriers to accessing palliative care related to billing/coding</li> <li>• Establish deliverables/targets attached to the funding of palliative care               <ul style="list-style-type: none"> <li>○ Integrate approach through funding within programs that provide care and not as a separate add on stream</li> </ul> </li> <li>• Prioritize support and increase the capacity for HCPs who provide home and community care.</li> <li>• Invest in models and structures such as Compassionate communities which partners communities and HCPs together to improve QOL, reduce health inequities, and address social determinants of health, enabling more value for money in PC</li> <li>• Establish funding for resources such as; hospice beds, PC unit beds in hospitals, and more home care resources.</li> <li>• Fund and expand initiatives for caregiver support (i.e. bereavement and income support).</li> </ul>

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<b>Building Block: Evidence and Data</b>	
<b>Action(s) seen as quick wins</b>	<b>Action(s) needing longer term “investments”</b>
<ul style="list-style-type: none"> <li>• Provide ongoing and dedicated resources to support system level measurement</li> <li>• Leverage existing palliative care data that has already been collected and reported on to inform health system planning and decision-making (i.e. OPCN Reporting Products)</li> <li>• Work with OPCN and RPCNs to use existing data</li> <li>• Establish mechanisms to support routine data collection across care settings to monitor palliative care delivery</li> <li>• Design surveys and data collection approaches that include measures of community care, quality of care, outcomes and experiences</li> <li>• Create a multidisciplinary approach to research to help address gaps in all levels of care</li> <li>• Work with data holders/data custodians to develop new processes to improve timeliness of PC data</li> <li>• Evaluate how data is captured in EMR to identify opportunity for improvement in PC reporting.</li> <li>• Plan appropriate model for recruitment, admin, analysis and reporting of PREMs.</li> <li>• Encourage other provinces and federal government to adopt common, nationwide indicators</li> </ul>	<ul style="list-style-type: none"> <li>• Develop an electronic death data registry</li> <li>• Assess palliative care regionally against the quality standard to inform improvements</li> <li>• Develop a provincial performance framework to align data collection and measurement across the system</li> <li>• Support the province-wide implementation of a patient and/or caregiver reported experience measures</li> <li>• Include results from patient/caregiver experience measures in planning and decision making</li> <li>• Promote research to build evidence base for non-medical aspects of PC – including community (non-professional) care delivery models.</li> <li>• Identify and implement methodologies to enable data collection and reporting that reflects the provision of palliative care across the illness trajectory (i.e. not just end-of-life)</li> </ul>