Ontario
Palliative Care
Network

Palliative Care Health Services Delivery Framework

Recommendations for a Model of Care to Improve Palliative Care in Ontario

Focus Area 1: Adults Receiving Care in Community Settings

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EXECUTIVE SUMMARY

Palliative care emerged as a new type of healthcare service in Ontario in the late 1970s. Until recently, its delivery has been predominantly driven by grassroots initiatives in response to local palliative care needs. As a result, many communities, mostly urban, have each developed programs and service delivery models based on local resources and cultures.

Despite the benefits of these local programs, the uptake and spread of successful models have been slow. There are still persistent gaps in the availability and delivery of palliative care services within and across Local Health Integration Networks (LHINs). Less than 60% of Ontarians in their last year of life receive palliative care and about half of patients in their last 30 days of life receive home care services. Despite patients' preference to die at home with appropriate support, more than half of the deaths in Ontario occur in hospitals. [1]

One of the actions specified in the Ontario Palliative Care Network (OPCN) Action Plan is the development of a Palliative Care Health Services Delivery Framework (Delivery Framework) to "improve equitable access for patients and caregivers and ensure that they are able to receive the holistic, proactive, timely and continuous care and support they need through the entire spectrum of care." [2]

To achieve this goal, in August 2017 the OPCN established a working group of healthcare providers with expertise in palliative care, administrators, and patient and family advisors from across Ontario to develop the Delivery Framework.

The first area of focus for the Delivery Framework is adults (and their family/caregivers) with a progressive, life-limiting illness who live in the community. This includes people living in homes, retirement residences, assisted living facilities, supportive housing, long-term care homes, First Nations and Indigenous communities, streets and shelters. These patients receive care at home, in outpatient settings, and occasionally in inpatient settings. Future focus areas of the Delivery Framework will address the needs of adult patients receiving palliative care in acute and complex continuing care settings, and pediatric patients.

The Delivery Framework does not include recommendations related to Medical Assistance in Dying (MAID). At this time, the relationship between palliative care, MAID and recommendations for best practice in the delivery of MAID services are evolving. Clinicians should refer to provincial and regional resources (e.g. Provincial Care Coordination Service) for advice on how best to manage patients considering or making requests for MAID.

The Delivery Framework was validated and refined through a broad consultation with stakeholders represented by the OPCN advisory councils, and their partners and stakeholders. Targeted stakeholder engagement was conducted with patient and family advisors, First Nations, Inuit, Métis and urban Indigenous representatives, care providers of vulnerably housed populations, long-term care representatives, and French language health planning entities.

The Delivery Framework recommends a model of care in Ontario that will ensure:

- Palliative care is provided by an interdisciplinary palliative care team so that the right care is provided by the right provider.
- The patient and their family/caregivers are actively engaged as members of the palliative care team and make decisions about their care.
- The patient and their family/caregivers have seamless access to palliative care and support 24/7. To ensure services are integrated, every patient will have a designated care coordinator.
- High-quality, person-centred palliative care is provided to patients wherever they are. Specific attention is paid to priority populations such as First Nations, Inuit, Métis and urban Indigenous people, francophones, homeless and vulnerably housed people, and those living in long-term care homes.

More specifically, the Delivery Framework provides recommendations to guide communities through this transformational change to improve palliative care in Ontario.

Recommendations

1. The patient who would benefit from palliative care will be identified early in their illness.

2. At any point from when the patient's illness is identified through end-of-life and bereavement, there will always be a designated care coordinator.

3. All patients and family/caregivers will have 24/7 access to an interdisciplinary palliative care team.

4. The Core Team will collaborate with the patient (or the Substitute Decision-Maker) and their family/caregivers to regularly assess their needs, and to develop and document a care plan that is based on the patient's wishes, values and beliefs, and their identified goals of care, and to obtain consent for the plan.

5. The patient will have 24/7 access to pain and symptom management from the Core Team or the on-call providers. This may occur in-person or via telemedicine (e.g., telephone support, virtual care, etc.).

6. The patient and their family will have access to emotional, psychological and spiritual care to address their needs in a culturally safe manner.

7. The patient and their family/caregivers will have access to practical and social supports that addresses their needs in a culturally safe manner.

8. Planning for end-of-life care will begin as early as possible and when it is acceptable to the patient and their family/caregivers.

9. The family/caregivers of the patient with a life-limiting illness will be supported throughout the person's illness trajectory, at the end of life, and through death and bereavement.

10. The palliative care needs of the patient living in a long-term care home will be supported by the home in which they reside.

11. The First Nation, Inuit, Métis or urban Indigenous patient and their family/caregivers will receive palliative care that utilizes a grassroots, participatory and collaborative approach and incorporates cultural knowledge into all aspects of care.

12. French language services will be highly visible and easily accessible to the patient and family/caregivers. Healthcare providers must offer these services, guided by the Active Offer Principle, without waiting to be asked.

13. The palliative care needs of the patient who is homeless or vulnerably housed will be identified as early as possible and care will be provided wherever the patient is.

Next Steps

The implementation of the Delivery Framework involves a complex change management process with interdependencies such as improving processes, optimizing roles, and building relationships and capacity. This is an evolutionary process that will build upon existing successful programs and services. Some of the recommendations in the Delivery Framework can happen immediately, but others will need a longer term, phased implementation, investments in planning, and human resources.

While the Delivery Framework provides guidance on the ideal model of community palliative care, it gives the regions flexibility in the nuances of implementation. This approach recognizes that resources and needs for palliative care vary across the province. To succeed, the Delivery Framework must build on existing resources and take into account regional needs and characteristics.

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OVERVIEW

In 2017, the Ontario Palliative Care Network (OPCN) released Action Plan 1: 2017-2020 to improve access to high-quality palliative care for all Ontarians.[2] The Action Plan identifies seven areas of action, one of which is "establishing palliative models of care to increase access and enable adoption of the quality standard." [1 (p.6)] The centerpiece of this action area is the development of the *Palliative Care Health Services Delivery Framework* (Delivery Framework). The implementation of this framework will enable the Health Quality Ontario's (HQO) quality standard, *Palliative Care: Care for Adults with a Progressive, Life-Limiting Illness*,[3] ('*Palliative Care Quality Standard*') and ensure that person-centred, holistic, proactive, timely, and continuous palliative care will be provided to Ontarians throughout the entire continuum of care.

BACKGROUND

Palliative care emerged as a new type of healthcare service in Ontario in the late 1970s. Until recently, its development has been predominantly driven by grassroots initiatives that are in response to local palliative care needs. The result is a group of palliative care programs, mostly in urban communities, that reflect the local needs and resources. Despite the benefits of these programs,[4] the uptake and spread of successful models have been slow. In addition, persistent gaps and variations exist in the availability and delivery of palliative care services within and across Local Health Integration Networks (LHINs) in Ontario.[1,5,6] As indicated in an OPCN report:[1]

- Less than 60% of Ontarians receive palliative care in the last year of life;

- Less than 54% of patients receive home care services in their last 30 days of life; and,

- More than 50% of the deaths in Ontario occur in hospitals, despite the patients' preference to die at home with appropriate support.

GOAL OF THE DELIVERY FRAMEWORK

The goal of the Delivery Framework is to recommend a model of care that delivers high-quality, culturally safe palliative care in Ontario. The Delivery Framework builds on the three strategic goals of the Declaration of Partnership[5]–Quality, Population Health, and Sustainability. Specifically, the Delivery Framework will help us move towards a system that:

a) Provides patients and their families with timely, equitable access to high-quality care as close to home as possible;

b) Supports broader integration and coordination of healthcare resources to deliver seamless palliative care to patients and their families; and,

c) Optimizes the use of health human resources.

APPROACH

The Delivery Framework summarizes the recommendations developed by the OPCN Palliative Care Delivery Framework Working Group ('Working Group'), a multi-disciplinary stakeholder panel from across Ontario (see Appendix A for the Membership List and Appendix B for the Terms of Reference). This work was informed by a review of the scientific and grey literature, current practices in Ontario and other jurisdictions, the Palliative Care Quality Standard,[3] and earlier work done by OPCN's predecessor, the Hospice Palliative Care Provincial Steering Committee.[7,8]

Engagement with patients and their families/caregivers was also instrumental in shaping the Delivery Framework. In addition to having three patient and family advisors on the Working Group, the OPCN held a patient journey mapping exercise, where patients and their families/caregivers identified their palliative care needs and discussed opportunities to improve care.[9] Fourteen patients, family members, and caregivers participated in the exercise. Participants came from different geographic locations and had experience with different life-limiting illnesses. Some common themes for palliative care improvement included better continuity of care, coordination of care, access to key services and providers, and facilitation of planning conversations. Findings from this exercise were used to shape the Delivery Framework.

In addition, targeted stakeholder engagements were conducted with First Nations, Inuit, Métis, and urban Indigenous representatives, physician groups, care providers of vulnerably housed populations, the long-term care and seniors' sectors, and LHIN French language health planning entities. These engagements helped to ensure that unique issues from these priority populations are highlighted and addressed in the Delivery Framework.

Finally, consultation with OPCN advisory councils and regional palliative care networks was conducted to collect feedback, analyze key themes, and refine the Delivery Framework.

GUIDING PRINCIPLES FOR THE DELIVERY FRAMEWORK

In developing the Delivery Framework, the Working Group agreed on a number of guiding principles. Specifically, the Delivery Framework should:

- Centre around the needs and values of the individual patient and their family and take into account their cultural sensitivities and linguistic needs;

- Respect and support the important roles of substitute decision makers (SDMs) and the family;

- Enable access to equitable, high-quality, culturally safe, linguistically appropriate, and coordinated care as close to home as possible for all of the population in need;

- Ensure that interdisciplinary palliative care team members have the necessary competencies (including cultural safety and humility) and are working to their full scope of practice; and,

- Include capacity building to ensure a sustainable system of care for the future.

SCOPE

The Delivery Framework consists of multiple area of focus. This document describes the model of care for adults with a progressive, life-limiting illness along with their families and caregivers living in the community. This includes people living in *homes, retirement residences, assisted living facilities, supportive housing, long-term care homes, First Nations and Indigenous communities (on and off reserve),* **streets and shelters**. It is recognized that throughout the trajectory of illness, this patient population will receive care in multiple settings e.g., at home, in outpatient and inpatient settings.

In-scope for this document are several priority populations: the First Nations, Inuit, Métis, and urban Indigenous and francophone communities and people who are vulnerably housed or homeless. Although many palliative care needs of these populations are addressed throughout the document, the Delivery Framework includes dedicated sections to highlight issues unique to these populations. The Delivery Framework also contains a separate section for care delivery in long-term care homes to address the organizational issues specific to that care setting.

While it is recognized that those who are in the last year of their life will make up the largest portion of this population, the Delivery Framework will be equally applicable to those who would benefit from palliative care earlier in the trajectory of their life-limiting illness.

Future areas of focus for the Delivery Framework will include:

- Adult patients in a hospital setting (e.g., acute and complex continuing care), and

- Pediatric patients receiving palliative care in all settings

Moreover, it is important to note that the Delivery Framework is using 'palliative care' rather than 'palliative care approach' to describe the scope of Delivery Framework following early identification. The rationale for this choice is twofold. First, 'palliative care approach' describes an approach to care whereas the Delivery Framework is focused on specific types of services and providers. Second, 'palliative care approach' is often used to refer to palliative care delivered at a primary or generalist level of competency (e.g., primary care nurse practitioners (NPs) and physicians, disease-specific specialists, etc.) as opposed to palliative care delivered by specialist-level palliative care providers. The Delivery Framework, however, refers to palliative care delivered by providers at <u>all</u> levels of competency participating as members of an interdisciplinary palliative care team.

Out of Scope

Medical Assistance in Dying (MAID).[10] There is a significant intersection between palliative care and MAID. The vast majority of patients who are considering or requesting MAID services have palliative care needs.[11] These patients and their families should receive the full complement of palliative care services that are required to meet those needs throughout their illness trajectory.[11] At this time, the relationship between palliative care and MAID and recommendations for best practice in the delivery of MAID services are evolving. As such, the Delivery Framework will not include recommendations related to MAID services. Clinicians should refer to provincial and regional resources (e.g., Provincial Care Coordination Service) for advice on how best to manage patients considering or making requests for MAID.

Hospice residences. Hospice services are an integral partner within the palliative care continuum. A model of care framework and a set of operating standards for Ontario hospices have previously been established. The Delivery Framework is intended to act as a guiding document for all palliative care providers; however, it does not replace Hospice Palliative Care Ontario's (HPCO) *Hospice Standards*.[12]

HOW TO USE THIS DOCUMENT

The Delivery Framework aims to provide guidance on how to optimize the current palliative care delivery model to ensure that the right care is provided by the right provider at the right time. The primary audience of this document are individuals and organizations who plan or provide care for patients with life-limiting illness. They include system planners (e.g., Ministry of Health and Long-term Care (the ministry), LHINs, and Regional Palliative Care Networks (RPCNs)), providers (e.g., physicians, nurses, allied health) and provider agencies (e.g., contracted nursing agencies, community service agencies, long-term care homes) and hospitals.

The Delivery Framework should be used as a bridge between the Palliative Care Quality Standard[3] and front-line implementation of palliative care services. While the Palliative Care Quality Standard[3] describes what high-quality care should look like, the Delivery Framework provides details on how this care should be organized at the team level. The implementation of the Delivery Framework is expected to be gradual, beginning with a focus on specific areas and priorities and building upon existing high-quality services and programs. However, this document does not offer a prescriptive implementation plan. The Delivery Framework should be interpreted and implemented in alignment with local needs and resources. In communities where successful models exist, the focus should be on enhancing them by incorporating elements described in the Delivery Framework; in communities where new models are being considered, the focus should be to use the Delivery Framework as a roadmap to develop a better way to deliver palliative care. Most importantly, the Delivery Framework should be used to guide leaders from the province, regions, and sub-regions when assessing local resources and the capacity to provide this level of care to the broad population.

Definitions

For the purposes of this work, the Working Group adopted the following definitions of a number of key terms. Additional terms are defined in Appendix C.

- **Patient** is a person with a progressive, life-limiting illness.[13]

- **Family** consists of those closest to a person in terms of knowledge, care, and affection, and may include biological family, family through marriage, or family of choice and friends. The person with the progressive, life-limiting illness defines who constitutes their family and who will be involved in their care.[13] For First Nations, Inuit, Métis, and urban Indigenous, the community has historically been comprised of a larger circle of support, which includes the extended family, larger community, and Elders.

- **Caregiver** is a person who provides care and support in an informal, nonprofessional capacity, such as a family member, a friend, or anyone else identified by the patient.[13]

- **Palliative care** (also known as hospice palliative care) is a philosophy of care that aims to relieve suffering and improve the quality of living and dying.[13] It strives to help individuals and their families to:

- o address physical, psychological, social, spiritual, and practical issues, and their associated expectations, needs, hopes and fears;

- o prepare for and manage end-of-life choices and the dying process;

- o cope with loss and grief;

- o treat all active issues;

- o prevent new issues from occurring; and,

- o promote opportunities for meaningful and valuable experiences, personal and spiritual growth.[13]

- **Hospice** is a community-based organization (or a program offered by a multi-service organization) that provides support to individuals living with a progressive, life-limiting illness and their caregivers, family members, and friends.[12] Support is provided to the service recipient in a variety of settings, including where the individual lives or in a homelike setting. The goal of hospice care is to enhance the quality of life of the individual and the well-being of anyone that is impacted by the person's illness or death. Volunteers play an integral role in achieving that goal. A hospice provides services such as hospice-trained volunteers, day programs, psychosocial supports, grief and bereavement support, spiritual care, caregiver support, wellness programs, complementary therapies, children's programs, outreach/shared care teams, and end-of-life care within a hospice residence.

- **Interdisciplinary Palliative Care Team** is an interdisciplinary team of providers who work together to deliver palliative care to a patient and their family/caregivers based on a person's care plan. This team will consist of a most responsible medical provider (physician or nurse practitioner) and a designated care coordinator and will have an established connection with a palliative care specialist(s) whose role on the team will be to consult with team members and to provide direct patient care as needed. The team will often be expanded to include additional providers, for example, nurses, disease-specific specialists, social workers, psychologists, spiritual care providers, pharmacists, personal support workers, dietitians, Indigenous providers, and volunteers.

RECOMMENDATIONS

The Delivery Framework aims to improve the care that Ontarians with life-limiting illness receive. It is expected that the implementation of the recommendations will lead to the following improvements for the patient and their family/caregivers:

- seamless access to high quality, person-centred palliative care and supports 24/7;

- care from an interdisciplinary palliative care team; and

- active participation in care and decisions about care.

This vision of change is depicted below in Box 1: "One patient, two scenarios." It illustrates one individual's story in two scenarios: one before the implementation of the Delivery Framework and the second one after. The details of this improvement are described in the Delivery Framework, which provides guidance on how palliative care should be organized and delivered to adults living in community settings. Figure 1: Delivery Framework Patient Pathway depicts the high-level journey of the patient and their family/caregivers and summarizes the Delivery Framework. It incorporates the key domains of care outlined by the Canadian Hospice Palliative Care Association.[14]

The Delivery Framework aims to:

1) Provide role clarity for the members of the interdisciplinary palliative care team;

2) Identify how providers and services can be organized and coordinated based on the needs of the patient and their family/caregivers; and,

3) Identify opportunities to create and/or strengthen supports for interdisciplinary palliative care teams to provide high quality, person-centred palliative care in Ontario.

The sections in the Delivery Framework are organized according to how the patient and their family/caregivers would experience the continuum of care, from identification through end-of-life care and bereavement. The Delivery Framework recognizes that this is not a linear pathway and that the patient and family/caregivers receive many of the described services throughout their journey. The Delivery Framework contains elements of best practice such as holistic care provided by an interdisciplinary palliative care team, seamless connection to community services and access to palliative care experts that work synergistically to achieve high-quality, person-centred care.[15]

To demonstrate the alignment between the Delivery Framework and the *Palliative Care Quality Standard*,[3] the relevant HQO quality statement(s) is cited in a textbox next to each section of the Delivery Framework recommendations. Similarly, in the First Nations, Inuit, Métis, and urban Indigenous section, where the Delivery Framework recommendations are aligned with the *Truth and Reconciliation Commission of Canada: Calls to Action*,[16] the relevant Calls to Action are highlighted in a textbox next to it.

Finally, at the end of each Delivery Framework section, there is a set of implementation considerations (in a textbox) describing some of the challenges associated with implementing the recommendations. These considerations are intended to call out areas where provincial, regional, and/or local efforts are required to address these challenges to enable the implementation of the Delivery Framework.

Box 1. One Patient, Two Scenarios….

Selena was diagnosed with heart failure five years ago at the age of 65. Selena and her husband Alex lived in Guelph. Their two daughters lived in Vancouver. So, most of the time, it was just the two of them, taking care of each other.

A year ago Selena started to get sicker. Her appointments with Dr. Baker, her cardiologist, became more and more frequent and she stopped seeing her family doctor altogether.

Six months ago Selena's episodes of shortness of breath became more frequent. She developed pneumonia twice within four months and ended up in hospital three times. Between hospital stays, she continued visiting Dr. Baker. Alex kept a notebook to make sure he was not missing any important information. He was terrified and often felt guilty that he was not taking good care of Selena. He had a feeling that things were spinning out of control.

Selena became more anxious and started thinking about death often. She wanted to be in her own home and spend her final hours with her family but, did not know how to talk about it with Alex, fearing that it would upset him.

Selena was hospitalized again, and over the next two weeks her condition deteriorated. She slipped in and out of consciousness. Alex was by her side. Dr. Baker came in to talk to Alex and told him that there was nothing else they could do. Selena was nearing the end of her life. Alex was devastated. He kept thinking:

"How can that be?! I thought we had more time…"

Selena died in the hospital. The next couple of days were a blur to Alex. It felt like he was sleepwalking.

Alex spent the next week in bed. He did not want to see or talk to anyone. 'What is the point? There is nothing left for me."

_____

Selena was diagnosed with heart failure five years ago at the age of 65. Selena and her husband Alex lived in Guelph. Their two daughters lived in Vancouver. So, most of the time, it was just the two of them, taking care of each other.

A year ago, Selena started to get sicker. Her episodes of shortness of breath were becoming more frequent. She got pneumonia and was hospitalized. The nurse at the hospital connected them with Nicole, a care coordinator from their local Home and Community Care.

The day after the discharge, Nicole called Selena at home. She had already talked to Dr. Ross, Selena's family doctor. Nicole explained that from now on she would coordinate all care and supports for Selena and Alex. A nurse would regularly visit Selena at home. Dr. Ross would continue taking care of her and would consult with Dr. Baker, Selena's cardiologist, whenever that was needed. Nicole gave them two phone numbers: hers and for the on-call nurse in case they needed help in the evenings and on the weekends. Nicole regularly checked with Alex to see how he was doing.

At Selena's scheduled appointment, Dr. Ross said that there was significant damage to Selena's heart. Dr. Ross took the time to explain how her illness would likely progress over the next several months. He worked with Selena and Alex to develop a care plan together. They talked about Alex being the person who would make decisions if Selena was no longer capable. They also talked about where Selena would like to spend her final hours and how their daughters would be informed. Alex felt reassured to know how Selena would be supported and how he could help.

Over the next four months Nicole and the nurse regularly visited Selena. A personal support worker assisted Selena with getting up and dressed in the morning and with taking a bath. Volunteers visited regularly and often spent time with Selena while Alex was taking a nap or going for a walk to clear his head.

As Dr. Ross predicted, Selena was getting sicker. Her shortness of breath was becoming intolerable and medications did not seem to be working. Dr. Ross talked to a palliative care specialist and changed medications to help Selena feel more comfortable. Their daughters came for a visit. As her health deteriorated Selena slipped in and out of consciousness.

Her death was peaceful, at home with Alex and the girls by her side; her favourite song played in the background…
After Selena died, Alex had a profound sense of living in a void. At times, he did not want to get out of the bed, but with his permission, Nicole kept visiting. She connected Alex with a grief counsellor. Alex started to open up and talk about his immense sense of loss and about his cherished memories of Selena.
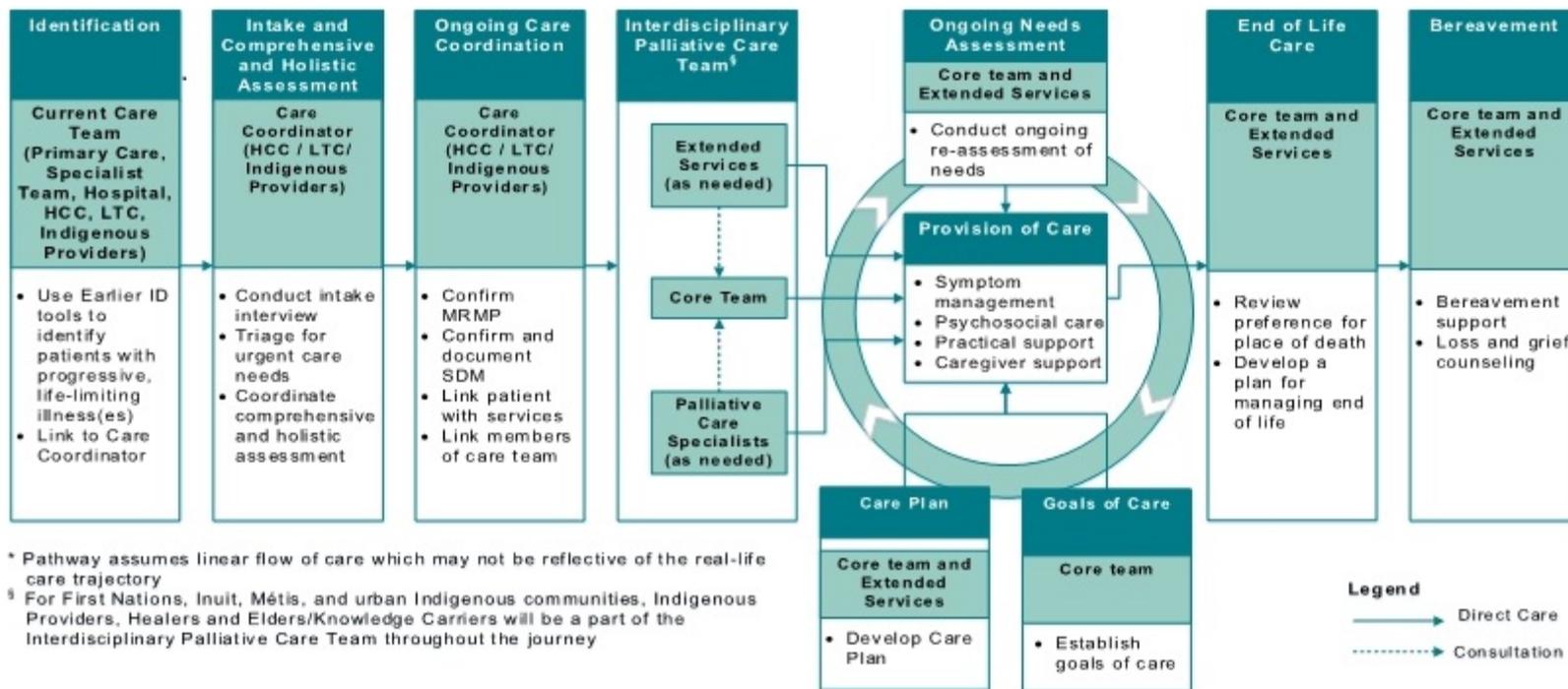
Figure 1. Palliative Care Health Services Delivery Framework: Patient Pathway

This diagram provides a high-level summary of the Health Services Delivery Framework that depicts the key interactions between the patient and their family/caregiver, the responsible provider/team member, and key decision points or responsibilities. The patient's journey starts with early identification, followed by intake, assessment and referral to a Care Coordinator who connects the patient and their family/caregiver with palliative care services. The inter-disciplinary palliative care team is described as a collaborative model of three layers of providers (Core Team, Extended Services, and Palliative Care Specialists). The Pathway also features ongoing assessment of needs, conversations about goals of care, regular updates to the palliative care plan, care at the end of life, and supports for the family/caregiver after patient's death. The pathway includes care throughout the person's illness trajectory, at the end of life, and through death and bereavement, including supports for the family/caregiver.

Identification of Patients

Earlier identification of patients with palliative care needs is essential to the initiation of palliative care.[9,17,18,19] Evidence suggests that when palliative care needs are identified and services are provided earlier, the patient and their family/caregivers tend to experience better quality of life, mood, and greater satisfaction in care. There tends to be greater participation in advance care planning, fewer hospitalizations, and lower medical costs.[20,21,22,23] For some, there is also an indication of longer survival time,[24] as compared to those who received palliative care later. Yet, currently in Ontario, the identification of palliative care needs is often left to the end of life, leaving a significant proportion of Ontarians dying without receiving palliative care.[25] Therefore, the Delivery Framework emphasizes the importance of earlier identification and describes the role of the current care team in identification. OPCN's *Tools to support Earlier Identification for Palliative Care*[26] can be used to support providers and system leaders in earlier identification of patients who would benefit from palliative care. The document provides guidance on preferred identification tools and suggested assessment tools for all healthcare sectors along with implementation considerations.

1. **The patient who would benefit from palliative care will be identified early in their illness.**

> **HQO Quality Statement 1:** People with a progressive life-limiting illness have their palliative care needs identified early through a comprehensive and holistic assessment.

1.1.   Members of the patient's current care team (primary care, specialist team, hospital team, Home and Community Care providers, Health Links coordinators, navigators and coordinators who work with First Nations, Inuit, Métis, and urban Indigenous, etc.) will use the approaches and tools, as recommended by *OPCN's Tools to support Earlier Identification for Palliative Care*, [26] to identify patients who would benefit from palliative care as early as possible.

1.2.   Once the patient is identified as someone who would benefit from palliative care, the current care team will connect the patient and their family/caregivers with a Care Coordinator, who will conduct an intake interview. If the primary care provider was not the one who identified the patient's palliative care needs, they will be informed.

1.3.   The members of the current care team will provide the patient and their family/caregivers with information about the nature and benefits of palliative care and what to expect as a result of the referral to a Care Coordinator. This information will be provided in a format that is appropriate to the linguistic and cultural needs of the patient and their family/caregivers.

Implementation Considerations for Identification of Patients

- Education strategies at a provincial level are needed to promote the importance of earlier identification among healthcare providers.

- *OPCN's Tools to support Earlier Identification for Palliative Care* should be used to help family physicians, hospital staff, specialist teams, and Home and Community Care coordinators gain confidence in identifying patients as early as possible.

- The care teams should be aware of existing coordination services to be able to connect patients and their families/caregivers with Care Coordinators within their regions.

- One of the challenges of understanding the demand of palliative care is the lack of information on who is identified as needing palliative care. A registry can be used to track identified patients, serving as a reference for providers to know which patients may require additional support, and assisting with regional service planning.

- A strategy for public awareness and education around palliative care services is necessary to help the general public better understand that palliative care focuses on improving quality of life regardless of prognosis and extends to care at end of life including bereavement.[27] It should aim to clarify the role of and services/ supports for families/caregivers, highlight the importance of advance care planning, and goals of care and support discussions related to death and dying. This strategy should be developed using a collaborative approach and include all priority populations.

Intake, Comprehensive and Holistic Assessment, and Care Coordination

Once a patient has been identified as benefiting from palliative care, the patient and their family/caregivers will be connected to the appropriate services based on their needs. Well-managed care that includes comprehensive assessment (and regular re-assessments) and care planning, as well as coordinated delivery of services has shown to reduce hospitalization and improve patients' quality of life and satisfaction with care.[28,29] Despite these benefits, coordinating palliative care services has been challenging because services are often siloed in different organizations.[15]

To ensure that patients and their families/caregivers can access services seamlessly, many documents that describe effective palliative care endorse the use of a designated care coordinator.[9,30,31,32,33] The Delivery Framework also envisions having a designated Care Coordinator as a central point of access to care for the patient and their family/caregivers. The roles and responsibilities of the Care Coordinator are based on the description of coordinated care management from Ontario's Health Links Approach.[34] Subsequent sections contain additional details about the role of the Care Coordinator.

2. At any point from when the patient's illness is identified through end-of-life and bereavement, there will always be a designated care coordinator.

> **HQO Quality Statement 1:** People with a progressive, life-limiting illness have their palliative care needs identified early through a comprehensive and holistic assessment.
>
> **HQO Quality Statement 10:** People with identified palliative care needs experience seamless transitions in care that are coordinated effectively among settings and health care providers.

2.1. After being referred by the patient's current care team, each patient and their family/caregivers will be assigned a Care Coordinator. This designated Care Coordinator will be the central point of contact for services and resources and act as the patient and family/caregivers' advocate.

   2.1.1. If the patient already has a Care Coordinator and is currently using community services, the existing Care Coordinator may continue to provide care to the patient and family/caregivers, if appropriate.

2.2. The Care Coordinator will conduct an intake interview to identify any palliative care needs that require urgent interventions (e.g., uncontrolled physical symptoms, urgent needs for personal care services or social work services) and will connect the patient and their family/caregivers with the appropriate services (e.g., primary care provider, ambulatory symptom management clinic, community nursing, personal support worker) to address these urgent issues.

2.3. Following the intake interview and after assessment of urgent issues, the Care Coordinator will ensure that a comprehensive and holistic assessment of the health, social, linguistic, and emotional needs of the patient and their family/caregivers is conducted in collaboration with the members of the patient's current care team along with community providers who may become part of the ongoing interdisciplinary palliative care team. This assessment will be completed in-person.

   2.3.1. The Care Coordinator will assess the patient and their family/caregivers' circumstances and determine the family/caregivers' ability and comfort with participating in patient care.

2.4. The Care Coordinator will discuss the role and responsibilities of an SDM with the patient and their family/caregivers. The Care Coordinator will then ensure that an SDM is identified and documented based on previous advance care planning or relying on the Ontario hierarchy of SDMs as outlined in Ontario's Health Care Consent Act.[35]

2.5. Every effort will be made to connect the patient, their SDM and family with formal interpretation services to ensure that the important and sensitive discussions (e.g., consent to treatment, confirmation of the SDM, and goals of care) take place in the patient's preferred language. The SDM, family members, or caregivers should not be responsible for providing translation or interpretation, unless it is the patient's expressed wish.

2.6. If day-to-day care and practical supports are not required at home at the time of the comprehensive assessment, the Care Coordinator will keep the patient on their caseload for case management purposes only. The Care Coordinator will contact the patient and their family/caregivers at regular intervals to identify any changes to the patient and/or family/caregivers' needs.

2.7. The patient (or the SDM if the patient is incapable[i]) and their family/caregivers reserve the right to refuse care, services, or individual providers, at any time. Therefore, healthcare providers will obtain consent from the patient (or the SDM) and their family/caregivers prior to providing care. If care is declined, the Care Coordinator will keep the patient on their caseload for case management purposes only. The Care Coordinator will contact the patient (or the SDM) and their family/caregivers at regular intervals to identify any changes to the patient and/or family's needs. The patient (or the SDM) and their family/caregivers may also self-refer for access to palliative care services through their current care team at any time.

2.8. The Care Coordinator will maintain consistent communication and collaboration with the patient and family/caregivers and will connect them with appropriate services as needed.

2.9. If the patient is hospitalized, the hospital care team will inform the Care Coordinator. The Care Coordinator will liaise with the discharge team prior to the discharge to ensure a smooth transition back to community.

2.10. A Care Coordinator working with priority and diverse populations will have appropriate expertise and knowledge about the needs of and services for these populations. They will be able to connect them with culturally safe and appropriate healthcare and social services. A Care Coordinator working with the First Nations, Inuit, Métis, and urban Indigenous communities will be prepared to navigate jurisdictional issues to enable access to services and providers both in First Nations communities and outside of these communities.

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[i] When referring to decisions by SDM throughout the Health Services Delivery Framework, it is assumed that these are instances when the patient is incapable at the point of decision making.

Implementation Considerations for Intake, Comprehensive and Holistic Assessment, and Care Coordination

- In Ontario, Care Coordinators may be employed by and located in different organizations. The Delivery Framework expects that the bulk of this workforce will be located in Home and Community Care. However, care coordination may also be provided by long-term care staff, Indigenous Navigators, or case managers who support the homeless and vulnerably housed populations. Early in the trajectory of illness, coordination may also be provided within primary care practices such as Family Health Teams. It is important that collaborative partnerships between organizations and providers be developed to achieve consistent approaches to coordination.

- To ensure high quality and safe care, determination of appropriate caseloads for Care Coordinators should be taken into account when planning human resources in each region.

- Health Links[36] are operating in many regions. There will be a need to ensure effective coordination and integration between Care Coordinators described in the Delivery Framework and Health Links Coordinators to avoid duplication of services.

- At a regional level, processes should be created to enable coordination and connection between primary care and other providers. Care Coordinators should have an up-to-date inventory of services in their region. This inventory should be updated regularly and should include services for priority populations such as First Nations, Inuit, Métis, and urban Indigenous, Francophones, and the homeless and vulnerably housed.

- Regional and local planning need to include processes and tools that support effective communication between care providers. Digital and other technical solutions should be explored to facilitate effective communication.

Interdisciplinary Team-Based Palliative Care

An interdisciplinary palliative care team that is accessible 24 hours a day, seven days per week ('24/7') is a critical component of effective community-based palliative care. [9,15,27,37] Having access to an interdisciplinary palliative care team can improve pain and symptom management and psychosocial outcomes, reduce hospitalizations and emergency department (ED) visits, support patients' choice for place of death, and lower the cost of care.[15,38,39,40,41]

There are a number of interdisciplinary palliative care teams in Ontario that are currently providing care within their communities.[42] Although the composition of these teams varies depending on the local context, they all consist of a core team that provides care and seeks additional expertise when necessary.[43] The Delivery Framework builds on the experience of these existing teams and envisions an interdisciplinary palliative care team model that consists of three layers of providers and services (i.e., Core Team, Extended Services, and Palliative Specialists) with the patient and family/caregivers being at the centre (see Figure 2). The Care Coordinator connects these teams together to provide integrated, person-centred care.

The **Core Team** is responsible for providing direct, day-to-day support to the patient and their family/caregivers, identifying their care needs, and connecting them with appropriate services. This Core Team includes a designated Care Coordinator and a most-responsible medical professional (MRMP) (physician or nurse practitioner). The Core Team has an established relationship with a palliative care specialist team for advice and mentorship or for direct patient care when the patient's needs are more complex. All members of the Core Team will have at least primary-level competencies in palliative care. Depending on the patient's needs, the Core Team may include a nurse (RN or RPN). In Indigenous communities, the Core Team will also include Elders/Knowledge Carriers and Healers.

The **Extended Services** often work very closely with the Core Team. They provide direct care and support to the patient and family/caregivers and may sometimes provide consultation to the Core Team on issues related to care. These providers may include, but are not limited to, pharmacists, personal support workers, trained volunteers, dietitians, rehabilitation therapists (e.g. physiotherapy, occupational therapy, and speech-language pathology), social workers, spiritual care providers, hospice staff, psychosocial service providers, recreation therapists, and Indigenous providers. Extended Services also include specialists with expertise in specific medical fields (e.g., cardiologists, oncologists, and nephrologists). Similar to the Core Team, all providers of Extended Services should have at least primary-level competencies in palliative care.

The **Palliative Care Specialists**, who include but are not limited to, palliative care physicians, nurses, and social workers, provide direct care to patients and their family/caregivers or provide consultation to the Core Team on issues related to patient care and support. All palliative care specialists must have and maintain specialist level competencies[44] in palliative care.

This section focuses on the roles of members of the interdisciplinary palliative care team and their relationships with each other. Additional details on specific roles of providers can be found in subsequent sections.

Figure 2. Interdisciplinary Palliative Care Team Model for Adults in the Community

This figure contains a patient and family/caregiver icon surrounded by three concentric circles, demonstrating person-centered care. The innermost circle is the Core Team with providers including the most responsible physician or nurse practitioner, the designated Care Coordinator, and often a nurse. For First Nations, Inuit, Métis, and urban Indigenous communities, the Core Team also includes Elders/Knowledge Carries and Healers. The patient and family/caregivers are also members of the Core Team. The middle circle is the Extended Services that include: personal support workers, community services providers, pharmacists, hospice services, volunteers, Indigenous providers, disease specialists, spiritual care providers, social workers, rehabilitation therapists, and dietitians. The outermost circle is Palliative Specialists that include palliative care physicians, nurse practitioners, nurses and psychosocial care providers with expertise in palliative care. Lastly, there is a purple bar across the circles labeled 'Coordination'. This bar represents coordination as an essential element of the model connecting providers and the patient and their family/caregivers.

3. The patient and their family/caregivers will have 24/7 access to an interdisciplinary palliative care team.

> **HQO Quality Statement 2:** People with identified palliative care needs have access to palliative care support 24 hours a day, 7 days a week
>
> **HQO Quality Statement 12:** People with identified palliative care needs receive integrated care from an interdisciplinary team, which includes volunteers.

3.1. All patients will have a Core Team of healthcare providers. The Care Coordinator will identify and document the members of the Core Team.

3.2. The patient (or the SDM) and their family/caregivers are active, collaborating members of the Core Team.

3.3. The Care Coordinator will identify the MRMP after having conversations with the patient's primary care provider and the current care team, as well as after considering the patient's needs and preferences. The Care Coordinator will work with the MRMP to establish a relationship with a palliative specialist team for consultation and referral of patients with complex needs as appropriate.

3.4. The MRMP may be an NP or an MD (e.g., primary care provider, disease specific specialist, palliative care specialist). The MRMP will be responsible for ordering tests, making diagnoses, ordering treatments and prescribing medications. The MRMP will receive support from and, in turn, will provide support to the other members of the interdisciplinary palliative care team.

   3.4.1. Primary care providers, family physicians and NPs, will be encouraged and supported to act as MRMP for their patients.

3.5. As the patient and their family/caregivers needs increase and/or change over time, the Core Team will engage Extended Services providers to address these changing needs.

   3.5.1. The patient and their family/caregivers who have been using community services prior to being identified as needing palliative care may continue using those services. Results from the comprehensive assessment will determine if any changes to these services are needed.

3.6. Palliative Pain and Symptom Management Consultants (PPSMC) will provide mentorship and education for the Core Team. PPSMCs create linkages to palliative care resources across the continuum of care. This role has been particularly important in Home and Community Care, long-term care homes, community support services, and primary care.

3.7. As patient and family/caregivers needs increase and/or change over time or become complex, the Core Team may need to engage palliative care

specialists. All interdisciplinary palliative care team members will seek the involvement of palliative care specialists when they recognize one or more of these indicators:

   a) One or more symptoms remain uncontrolled, despite the use of best practices in managing the symptom(s);

   b) Specialized interventions (e.g., interventional symptom management, or palliative care unit/hospital admission for symptom management) are required to manage symptoms;

   c) Clinical syndromes (e.g., agitated delirium) and/or co-morbidities that require specialized expertise;

   d) Complex psychological and spiritual distress remains unresolved, despite best efforts by the Core Team and Extended Service providers;

   e) Complex social conditions (e.g., lack of social supports, precarious housing), which require additional expertise to plan and/or manage;

   f) Difficulties in establishing goals of care and/or obtaining consent for a care plan, despite best efforts to do so or is complicated by legal and/or ethical issues;

   g) Repeated ED visits and/or hospitalizations because of exacerbation of symptoms or distress.

3.8. All interdisciplinary palliative care team members need to achieve appropriate competency in providing culturally safe palliative care to patients and their families/caregivers.

3.9. The Care Coordinator will connect with the members of the interdisciplinary palliative care team on a regular basis, and ensure that all team members are up-to-date on the health status of the patient and their family/caregivers, the current services they are receiving, and any new service requests or change in care plan.

3.10. The patient and family/caregivers will have access to the Core Team or the network of on-call providers for the Core Team 24/7. The Care Coordinator will be the central point of contact during the daytime. If the Core Team has a designated nurse, a nurse will be the first point of contact after hours and on weekends. The nurse will assess the urgency of needs of the patient and the family/caregivers, address the needs and/or will connect the patient and the family/caregivers with the MRMP (or the individual on-call when the MRMP is unavailable). Virtual and other technologies will be used to improve access to care particularly in rural and remote locations.

3.10.1. If the Core Team is comprised only of an MRMP and a Care Coordinator, the MRMP or the individual who is on-call for the MRMP will be responsible for after-hour and weekend coverage.

3.11. Every Core Team will have access to Palliative Care Specialists who will be available 24/7 to provide support and consultation to the MRMP in-person or via telephone or other technologies (e.g., telemedicine, virtual care, secure electronic communication).

3.12. Education and information will be provided to the patient and family/caregivers as early as possible and throughout their experience. While the Core Team will be responsible for ensuring that education and information is provided, all members of the interdisciplinary palliative care team will have a role in supporting the patient and family/caregivers with education and information that is culturally safe and appropriate.

Implementation Considerations for Interdisciplinary Palliative Team-Based Care

- Implementation of the Delivery Framework will be more successful when the patients' primary care providers are engaged in their palliative care. The Regional Palliative Care Networks (RPCNs) have an important role in promoting effective partnerships between primary care and other providers of palliative care. To accomplish this, RPCNs should involve primary care champions as early as possible in the planning process to understand the supports that primary care providers require to be effective members of interdisciplinary palliative care teams.

- When the patient does not have a primary care provider it is important that the patient's current care team (e.g., specialist, hospital staff) work with existing provincial and regional programs and services (e.g., Health Care Connect) and the patient and their family/caregivers to connect the patient with a primary care provider.

- Access to primary care providers is limited in rural, remote, and First Nations, Inuit, Métis, and urban Indigenous communities. The ministry, LHINs, and RPCNs should partner with these communities to determine primary care gaps and seek to fill them.

- Access to palliative care specialists for the Core Team is key to a well-functioning interdisciplinary palliative care team. RPCNs have an important role in promoting a network of local palliative care specialists who will work closely with primary care providers and other members of the interdisciplinary palliative care team. In more remote or rural areas, regional or provincial approaches may be necessary to improve this access.

- An Alternate Funding Plan (AFP) for palliative care specialists is needed to ensure that the palliative care specialists are adequately compensated for both direct care and for building human resources capacity and competency in palliative care (e.g., participating in formal and informal education and mentorship and providing consultations to members of the Core Team).

- The Ontario Health Insurance Plan (OHIP) fee schedule should be reviewed to ensure appropriate compensation for primary care physicians and palliative care physicians. This should include virtual visits with patients and virtual consultations between providers (e.g., eConsults).

- Contracts between LHINs and service provider agencies should include appropriate accountabilities to ensure 24/7 access to nursing support.

- It is recognized that providing the Core Team with 24/7 access to palliative care specialists will be challenging in some regions. To address this issue, the Delivery Framework envisions an on-call service network of palliative care specialists (physicians or NPs), especially in rural and remote areas. This network model should leverage virtual technologies to support consultation needs. A review and revision of on-call funding is required to ensure 24/7 access to palliative care specialists for patients, as well as members of the Core Team. A similar review of on-call funding should occur for primary care providers.

- At a regional level, educational programming for primary-level palliative care competencies should be planned and available for all provider groups in the region. Community funding envelopes should include continued and sustained support for education and on-the-job training. Online education should be considered to increase access to training.

- Technology should be used to enable virtual communication (e.g., eConsults, telemedicine). While these technologies have been adopted by remote and rural communities more readily, urban areas and long-term care homes should also leverage these technologies and increase their use.

- Funding should be available to provide supportive services to all healthcare and community providers who deliver palliative care services. This should include, but not be limited to, workplace wellness policy development, counselling and emotional support and skill building services, formalized debriefing services, anticipatory grief, and bereavement supports.

Goals of Care, Ongoing Assessment of Needs, and Care Plan

Care planning starts immediately after the comprehensive assessment of patient and family/caregivers' needs (see Recommendation 2.3). Patients who have had ongoing conversations about their wishes and preferences for care tend to have better quality of life and fewer depressive symptoms.[21] In addition, those who have engaged in advance care planning are less likely to receive inappropriately aggressive treatments, are more likely to receive care that is consistent with their preferences (including cases when a SDM is involved), use fewer health services and have a lower cost of care.[45,46,47,48,49]

Previous advance care planning where a patient has identified their SDM and reflected on their wishes, values, and beliefs for care can be valuable to inform conversations about the goals of care and care plan. However, it must be understood that these previously expressed wishes and preferences need to be reviewed with the patient or the SDM in context of the patient's present condition and care needs. Identifying the goals of care and deciding on a care plan needs to be preceded by conversations with the patient, SDM, and their family member (assuming the patient or SDM agrees to share that information with the family) about the patient's current health status and the treatment and care options. Once the goals have been established, informed consent must be obtained from the patient (or their SDM) for specific treatments and a plan of care. These conversations should be conducted in a way that is culturally appropriate and safe and should reflect the linguistic needs of the patient. They should also be sensitive to the readiness of patients and families to engage in these conversations.

The Delivery Framework envisions that the Core Team will work with the patient (or the SDM) and their family/caregivers on an ongoing basis to assess their needs, identify their wishes and care preferences, and help them understand their treatment options.[9] The Care Coordinator will ensure that this information is documented in a care plan, kept up-to-date, and shared with other providers.[9]

4. **The Core Team will collaborate with the patient (or the SDM) and their family/caregivers to regularly assess their needs, and to develop and document a care plan that is based on the patient's wishes, values, and beliefs, and their identified goals of care, and to obtain consent for that plan.**

> **HQO Quality Statement 3:** Peoples with a progressive, life-limiting illness know who their future substitute decision-maker is. They engage in ongoing communication with their substitute decision-maker about their wishes, values, and beliefs, so that the substitute decision-maker is empowered to participate in the health care consent process if required.
>
> **HQO Quality Statement 4:** People with identified palliative care needs or their substitute decision-makers have discussions with their interdisciplinary health care team about their goals of care to help inform their health care decisions. These values-based discussions focus on ensuring an accurate understanding of both the illness and treatment options so the person or their substitute decision-maker has the information they need to give or refuse consent to treatment.

4.1. The Core Team along with other members of the interdisciplinary palliative care team will have discussions with the patient (or the SDM) to help them identify the patient's goals of care. The team will review and confirm the individual's goals of care if they have previously been identified.

4.2. The Core Team will review the treatment and care options with the patient (or the SDM), support them in making decisions and obtain consent for the care plan.

4.3.   The Care Coordinator will collaborate with the patient (or the SDM), their family/caregivers, and the interdisciplinary palliative care team to develop and maintain an up-to-date care plan. This plan will be available to the patient, their SDM, and the interdisciplinary palliative care team through a single electronic platform. The Care Coordinator will work with the care providers to ensure that each element of the care plan is implemented by the most appropriate provider.

4.4.   The Care Coordinator will ensure that patient and family/caregivers' needs are reassessed regularly by the most appropriate member(s) of the interdisciplinary palliative care team. Changes to the patient's condition, care preferences and goals of care will be documented in the care plan.

Implementation Considerations for Goals of Care, Ongoing Assessment of Needs, and Care Plan

- The key elements and documentation of a care plan would be a valuable area for regional, if not provincial, standardization.[50,51] The Health Links' Coordinated Care Plan[52] offers a good example of what a standardized care plan can look like.

- A centralized electronic platform for documenting and managing care plans will be an important tool to provide consistent access to same information for all members of the interdisciplinary palliative care team.[53] Provincial- and regional-level planning will be needed to create such a platform, building upon existing resources and initiatives.

- A patient-facing version of the care plan should be available and shared with the patient and their family/caregivers. It can help support the patient and their family/caregivers informed decision-making and will allow them to collaborate effectively with the providers on the care plan.

- Education and communication skills training is needed for providers to ensure they are both comfortable and confident to have difficult discussions with their patients.

Management of Pain and Other Symptoms

Regular assessment and management of pain and other symptoms are essential components of high-quality palliative care.[18] When patients receive proactive symptom management, they experience a reduction in symptom burden and hospitalizations and improvement in quality of life.[4,54,55] In addition, patients can gain confidence in their ability to self-manage their symptoms.[54,56]

This section describes the roles of different providers in pain and symptom management.

5. The patient will have 24/7 access to pain and symptom management from the Core Team or the on-call providers. This may occur in-person or via telemedicine (e.g., telephone support, virtual care, etc.).

> **HQO Quality Statement 2:** People with identified palliative care needs have access to palliative care support 24 hours a day, 7 days a week.
>
> **HQO Quality Statement 6:** People with identified palliative care needs have their pain and other symptoms manages effectively, in a timely manner.

5.1.   The MRMP will assess symptoms, make diagnoses, prescribe medications, and order other treatments. The MRMP may seek consultation from a palliative care specialist, when needed.

5.2.   When there are persistent symptom management issues, an RN should be a part of the Core Team. The RN will assess, manage, and monitor pain and other symptoms. Certain tasks associated with symptom management (e.g., management of tubes and infusion pumps, wound care) may be performed by RPNs in alignment with their scope of practice, knowledge, and skills.

5.3.   With appropriate training and education and with guidance from the RN or RPN, the family may carry out some tasks related to symptom management. The RN or RPN will regularly assess the family's continued ability and willingness to carry out these tasks including, but not limited to, monitoring for signs/symptoms of difficulty with coping, and other indicators of stress or caregiver burden.

5.4.   The Core Team will consult with or engage the appropriate Extended Service providers such as dieticians and speech language pathologists to address specific symptom management needs.

5.5.   The RN or RPN on the Core Team will assess, monitor, and manage the patient's underlying disease(s) and symptoms associated with it and will consult with the MRMP as needed. The MRMP will consult with a disease-specific specialist (e.g., cardiologist, nephrologist) or a provider with expertise in palliative care when the Core Team cannot meet the disease management needs of the patient.

5.6.   Pharmacists, in consultation with the Core Team, will play a significant role in symptom management, medication safety and reconciliation and will support treatment decisions throughout the patient's journey.

5.7.   Standardized symptom management kits and related policies/protocols will be available and safely stored in all community settings (e.g., patient's home, long-term care home) for management of unexpected, emerging, or worsening symptoms.

5.8.   Where appropriate, technology-based healthcare services (e.g., telemedicine virtual care, videoconferencing, e-shift) will be leveraged to bridge current service gaps and improve access to services, particularly for rural and isolated communities.

Implementation Considerations for Management of Pain and Other Symptoms

- There is significant variation in access to medications for palliative care across the province. To support 24/7 access to palliative care, there needs to be reliable and equitable access to pharmacy services and expertise after hours. As well, a full range of palliative care medications and appropriate protocols on doses and dosing formats (oral and parenteral) should to be available to the Core Team.

- Developing provincial standards for symptom management kits that allow for regional/local customization will be an important action. The key elements that need to be standardized include: a) the medications and doses, b) protocols for ordering and dispensing of the kits and monitoring their utilization, c) safety standards, and d) education for community nurses in the use of the kits.

Psychosocial and Spiritual Care

Living with a life-limiting illness can take a toll on the emotional, psychological, social, and spiritual ('psychosocial') well-being of the patient and their family/caregivers.[57,58,59,60] When the patient and their family/caregivers receive psychosocial support, they experience better quality of life and quality of relationships, and their family/caregivers feel more prepared and less distressed during bereavement.[61,62,63] As part of holistic care,[15] it is necessary to ensure that timely and appropriate psychosocial support is available throughout the palliative care experience.

To achieve this, the Delivery Framework envisions that all members of the interdisciplinary palliative care team will provide psychosocial support to the patient and their family/caregivers that is within their scope of practice.[9,59,64] Thus, it is necessary for the interdisciplinary palliative care team to have basic competency in identifying psychosocial needs of the patient and their family/caregivers.

6. The patient and their family will have access to emotional, psychological, and spiritual care to address their needs in a culturally safe manner.

HQO Quality Statement 7: People with identified palliative care needs receive timely psychosocial support to address their mental, emotional, social, cultural, and spiritual needs.

6.1. The Core Team will regularly assess the emotional and psychological needs (e.g., fear, anxiety, and depression) of the patient and their family in a culturally safe manner.

6.2. The Core Team will provide psychosocial care to all patients and their families. These providers will have at least primary-level palliative care competencies.

6.3. The Care Coordinator will refer the patient and their family to Extended Service providers with expertise in psychosocial care (e.g., social workers, trained volunteers, Indigenous providers, grief counsellors, and mental health professionals) and/or palliative care specialists when their needs are more extensive or complex than the Core Team can manage.

6.4. Hospice services will be offered to the patient and their family as needed. These services will be integrated and coordinated as part of the patient's care plan.

6.5. The Core Team will regularly assess the spiritual needs (e.g., existential or faith-based concerns) of the patient and their family. Spiritual/religious care providers who represent the faith/spiritual beliefs of the patient and their family will be available.

6.6. Culturally safe bereavement support, and loss and grief counseling will be provided by the Core Team and/or the Extended Service providers to the family/caregiver throughout their journey. After the death of the patient the team will support the family/caregivers in transitioning their care to appropriate community resources that will include bereavement information and education, one-on-one counseling, peer and/or group sessions and their primary care provider. The unique needs of youth and young children will also be considered.

7. The patient and their family/caregivers will have access to practical and social supports to address their needs in a culturally safe manner.

7.1. The Core Team and Extended Service providers will regularly assess the patient on their activities of daily living (ADL) and instrumental activities of daily living (IADL) and communicate the findings with the Care Coordinator. The Care Coordinator will engage the appropriate Extended Service providers such as personal support worker, physiotherapist, occupational therapist, social worker, and hospice staff to provide practical support as needed.

7.2. The Core Team (or members of the broader interdisciplinary palliative care team) will regularly assess the patient and their family/caregivers' transportation needs to ensure that their access to care is not impeded. This assessment may include the needs of dependents, such as children and others in the household receiving care. The Care Coordinator will connect the patient and their family/caregivers with the appropriate transportation services as necessary. For First Nations, Inuit, Métis, and urban Indigenous, appropriate supports (e.g., Non-Insured Health Benefit Navigator (NIHB)) will be engaged to address transportation needs.

7.3. The Care Coordinator will identify challenges experienced by the patient and their family/caregivers related to the social determinants of health. Specifically, financial insecurity, unstable housing, and food insecurity will be included as a part of the comprehensive and holistic assessment. Extended Services will be engaged to address these needs and advocate for supports, where appropriate. For First Nations, Inuit, Métis, and urban Indigenous, the Care Coordinator will partner with Indigenous Providers to assess the needs of the patient and family/caregivers.

7.4. The approach to providing practical supports to the patient and their family/caregivers will align with the ministry's Levels of Care Framework.[31]

Implementation Considerations for Psychosocial and Spiritual Care

- Significant gaps in access to psychosocial services, particularly in community settings, remains a challenge in Ontario. Adequate provincial funding is needed for community services such as social work, hospice services, nursing, personal support, spiritual care, grief, loss, and bereavement support services for the patient and their family/caregivers.

- Successful implementation of the Delivery Framework will require a focused assessment of the human resource requirements and the associated costs. There should be increased capacity to provide equitable access to in-home services (via in-person and virtual visits), such as hospice volunteers, and personal support. Particular attention should be paid to supporting equitable access to services in remote, rural and First Nations, Inuit, Métis, and urban Indigenous communities. In addition, policies should be reviewed to ensure that access to services is defined and assessed using an equity lens.

- A health human resources plan needs to be developed to ensure adequate access to psychosocial service providers with expertise in palliative care, particularly social workers who can meet the full spectrum of needs (including bereavement and grief) of the patient and their family/caregivers. Special attention should be paid to adequate access to skilled mental health providers to ensure that they are available when needed.

- In addition to professional services, there are various community resources available regionally that can be mobilized to support the patient and their family/caregivers using a compassionate community approach. These opportunities should be leveraged at the regional level.

- There is significant variability in access to equipment (e.g., hospital beds, wheelchairs) across the province due to differences in local or regional policies and criteria for access to equipment. Developing provincial guidelines for access to provincially funded equipment will help improve equity of access.

End-of-Life Care

In the final weeks and days of life, the focus of care moves towards managing the active dying process, which includes identifying that the patient is near death and ensuring that the patient and their family/caregivers understand what they can expect to happen as death approaches.[65,66] Many issues such as holistic comfort measures that address physical, psychological, social, and spiritual needs of the dying patient, cultural and religious practices around death and dying, and practical issues related to care after death, need to be considered and discussed with the patient and their family/caregivers.[59,67,68]

The Delivery Framework envisions that the interdisciplinary palliative care team needs to be particularly vigilant during this time to ensure that the needs of the patient and the family/caregivers are being met.[9]

8. Planning for end-of-life care will begin as early as possible and when it is acceptable to the patient and their family/caregivers.

> **HQO Quality Statement 11:** People with identified palliative care needs, their substitute decision-maker, their family, and their caregivers have ongoing discussions with their health care professionals about their preferred setting of care and place of death.

8.1. The Core Team will work with the patient and their family/caregivers to identify the preferred place of death and will ensure appropriate planning. It is important to recognize that this preference may change as the end of life approaches and that back-up plans may need to be made.

8.2. When death is approaching, the Care Coordinator will ensure that the patient and their family/caregivers' practical, spiritual, and emotional needs are frequently reassessed and monitored. The care plan will be revised to reflect any changes in patient and family/caregivers needs.

8.3. In communities where hospice residences exist, information about the hospice residence will be offered to the patient and family as needed. These services will be integrated and coordinated within the patient's care plan.

8.4. The Care Coordinator will reconfirm with the interdisciplinary palliative care team the communication and linguistic needs of the patient at end of life, as the patient may revert to their first language. Interpretation/ translation services will be available to communicate any information to the patient in their first language.

8.5. The Core Team will develop an emergency management plan with the patient, SDM, and family/caregivers. This plan will include phone contacts for the Core Team and on-call services, and information on when to use or avoid emergency medical services (EMS). A 'Do Not Resuscitate' Confirmation Form (DNR-C) will be completed when there has been

consent from the patient or their SDM for a 'Do Not Resuscitate' order. This order will be documented on the patient's record. The DNR-C will be readily accessible in the home, to ensure that the patient's wishes for a natural death are respected by EMS services.

8.6. The patient (or the SDM) and the appropriate family members/caregivers will have clear information about what to expect as death nears, plans for pronouncement of death, completion of the death certificate, and post-death care. This includes re-confirming the information on who to contact when death has occurred. The provider who will be responsible for pronouncement will also confirm and respect the cultural, religious, and spiritual preferences and practices of the family. The provider responsible for pronouncement will connect with the Care Coordinator and the MRMP (or individual who is on-call) to notify them that death has occurred.

Implementation Considerations for End of Life Care

- Protocols for managing an expected death in the home will be determined at the regional level and will allow flexibility for local customization.

- Protocols and policies will be in place to provide the patient and their family/caregivers with additional support during the last weeks and days of life. This may include increased nursing and personal support work hours, and hospice service. The need for services should be based on the emotional and practical needs of the patient and their family, as well as the symptom management and medical needs.

Family and Caregiver Support

Family and caregivers play a critical role in providing community-based palliative care and are key members of the Core Team. More than 80% of end-of-life care (e.g., emotional support, direct medical care, patient advocacy, and system navigation/coordination) is provided informally by the family.[25,69] Yet, the care demand that is placed upon them can have serious impact on the caregivers' health (e.g., anxiety, depression), quality of life, and finances.[25,61,70] However, when caregivers receive practical and psychosocial support from others, as well as opportunities to learn and master the skills needed to provide care, they feel less burdened by their role, and their quality of life and ability to cope improves.[71,72]

As such, in alignment with other key guidelines and quality standards,[18,25,37,73] the Delivery Framework recognizes the importance of caregiver supports for their health and well-being, and their need for information and education, as well as the need to minimize the financial burden of caregiving.[9]

Some of the details related to caregiver supports such as grief counselling and bereavement support were covered in the above section on Psychosocial and Spiritual Care.

9. The family/caregivers of the patient with a life-limiting illness will be supported throughout the person's illness trajectory, at the end of life, and through death and bereavement.

> **HQO Quality Statement 8:** People with a progressive, life limiting illness, their future substitute decision-maker, their family, and their caregivers are offered education about palliative care and information about available resources and supports
>
> **HQO Quality Statement 9:** Families and caregivers of people with identified palliative care needs are offered ongoing assessment of their needs, and are given access to resources, respite care, and grief and bereavement support, consistent with their preferences.

9.1. The Core Team and Extended Services providers will regularly assess the practical, informational, psychosocial, physical, and emotional needs of the family/caregivers in a culturally safe manner. The Care Coordinator will ensure that relevant providers are engaged as needed.

9.2. Members of the Core Team and/or Extended Services providers will deliver emotional support to the family/caregivers within their scope of practice. Palliative care specialists will be engaged when the needs of the family/caregivers are more complex. When there are young children and teens in the home, age-appropriate assessment of needs will be conducted, and necessary supports will be provided.

9.3. The Core Team and Extended Service providers will ensure that the family/caregivers have access to appropriate and culturally relevant education covering a wide variety of issues (e.g., care provision, what to expect or anticipate, and available services and supports within the community). This education will be offered in multiple languages, including French, and will use a variety of formats (e.g., in-person teaching, written and digital formats).

9.4. The Care Coordinator will frequently check in with the family/caregivers to determine if the services are meeting their needs. When signs appear that patient care needs are exceeding the physical or emotional capacity of the family/caregivers, the Care Coordinator will work with the family/caregiver, the Core Team, and Extended Service providers to determine the levels and types of services necessary to support the family/caregivers. This may include, but is not limited to, respite close to home, volunteer services, personal support, recreational activities, and grief and bereavement counselling.

Implementation Considerations for Caregiver Support

- Availability of resources and services varies across the province. Inventories of existing services (with contact information) for family/caregivers should be shared with providers and family/caregivers. If these inventories do not exist, they should be developed and regularly updated.

- Providers should have knowledge of and easy access to educational and information tools and materials that are available in a variety of formats and languages. They should be shared with the patient and their family/caregivers.

- Currently, many repositories of such materials exist but they are siloed within regions and organizations. A central repository of materials in various formats and languages should be established at the provincial level and updated regularly. Regions should customize the materials to meet their local needs.

Palliative Care in Long-Term Care Homes

Many patients with life-limiting illnesses reside in long-term care homes.[25,74,75] As with individuals living in other community settings, access to timely and appropriate palliative and end-of-life care must be available to them.[3,76] When long-term care residents receive palliative care, they experience better symptom management and quality of care, have fewer hospitalizations and shorter lengths of stay, and are more likely to have advance care planning discussions.[77,78] It is important to note that patients in long-term care homes tend to have more co-morbidities and are more likely to have cognitive issues, where the latter can make symptom assessments more challenging.[79] As such, the care needs of this population must be highlighted and more guidance around provision of palliative care in long-term care settings needs to be provided.[76]

The Delivery Framework acknowledges that because the clinical and administrative environment of long-term care homes is distinct from other community settings, some elements may require modifications to better reflect the organization of this setting. If a specific element of care is not addressed in this section, then the relevant recommendations from the earlier sections should be applied.

10. The palliative care needs of the patient living in a long-term care home will be supported by the home in which they reside.

   10.1. Identification and assessment of its residents who would benefit from palliative care will be managed using internal resources and processes.

   10.2. Staff within the long-term care home will assume the role of the Care Coordinator, as outlined in Recommendation 2.

   10.3. The usual team that provides care for the resident in the long-term care home will act as the Core Team. This team will include an MRMP, a Care Coordinator, a nurse, and any other care providers (e.g., personal support workers, dieticians, recreational therapists, and pharmacists) that are part of the day-to-day care of the resident.

10.4. The Care Coordinator will leverage established relationships with external partners to access outside resources (e.g., psychosocial providers, spiritual counsellors) for additional supports.

10.5. The Core Team within the long-term care home will access providers with expertise in palliative care as needed based on indicators described in Recommendation 3.8. These providers are usually external to the long-term care home and may include palliative care specialists (physician or NPs), PPSMCs, and psychosocial providers.

10.6. Advance care planning and goals of care discussions will take place soon after admission with residents or their SDM as appropriate. Goals of care discussions will be revisited at regular intervals with the resident or SDM and when there have been changes in the resident's health status.

10.7. After the discussions on goals of care, the care plan within the long-term care home will incorporate the necessary elements to address the resident's palliative care needs.

10.8. The resident will receive pain and symptom management both during ongoing care and at end of life that is based on best practices used in other community settings.

10.9. Long-term care homes will provide bereavement care for residents and families who are faced with loss. This will incorporate both internal and external resources.

Implementation Considerations for Palliative Care in Long-Term Care Homes

- Residents in long-term care homes should have the same access to palliative care services as those in other community settings. Availability of services in long-term care homes can vary depending on the home and/or the corporation that operates the home. Some of these variations include access to specialist providers, psychosocial support, medications and equipment. Planning for equitable access to palliative care services in long-term care homes will require collaboration between provincial (e.g., OPCN, Ontario Long Term Care Association (OLTCA), AdvantAge Ontario, and the ministry) and regional partners. This may also require changes to existing legislation and/or regulations that govern long-term care homes.

- Given that palliative care will be provided primarily by existing staff within the long-term care home, these providers will need to have the same level of palliative care competencies as providers working in other community settings. An educational strategy will need to be in place to ensure that existing and new staff are able to achieve the appropriate competencies.

- The ministry and OPCN should collaborate with First Nations, Inuit, Métis, and urban Indigenous communities to identify and fund flexible palliative care rooms and family relief spaces within long-term care homes in those communities.

Palliative Care for First Nation, Inuit, Métis and urban Indigenous Communities

"First Nation communities hold an enormous amount of traditional and community-based knowledge and expertise in negotiating the personal, familial and community experiences of caring for community members who are sick, However, through colonization, health systems have been imposed on First Nations peoples which typically do not support Indigenous approaches to care." [80(p.17)]

Truth and Reconciliation Committee Call to Action #18: We call upon the federal, provincial, territorial, and Aboriginal governments to acknowledge that the current state of Aboriginal health in Canada is a direct result of previous Canadian government policies, including residential schools, and to recognize and implement the health-care rights of Aboriginal people as identified in international law, constitutional law, and under the Treaties.

Truth and Reconciliation Committee Call to Action #20: In order to address the jurisdictional disputes concerning Aboriginal people who do not reside on reserves, we call upon the federal government to recognize, respect, and address the distinct health needs of the Métis, Inuit, and off-reserve Aboriginal peoples (especially Jordan's Principle).

First Nations, Inuit, and Métis peoples are not a cultural group to Canada; they are unique and distinct constitutionally recognized peoples.[81] The Delivery Framework acknowledges that despite these distinctions, all First Nations, Inuit, Métis, and urban Indigenous peoples share collective histories of colonialism involving marginalization, exploitation, and maltreatment. These collective histories have significantly impacted the planning, quality, access, continuity, appropriateness, and delivery of palliative care.[82,83,84,85,86] Moreover, as a result of residential schools, systemic discrimination, and fear of institutionalization, many First Nations, Inuit, Métis, and urban Indigenous patients and their family/caregivers experience unresolved and intergenerational trauma, suppressed Indigenous identity, and disruptions that include language, cultural healing practices, social networks and connection to lands. These traumatic experiences have led to compromised care.[84,87,88,89] Historically, many palliative models of care have highlighted the challenges First Nations, Inuit, Métis, and urban Indigenous patients and their families/caregivers face, drawing attention away from recognizing and building local knowledge and community capacity.[90,91] These challenges include: geographic location; cultural harms introduced by relocating to urban centres for care; unsafe housing and water; food insecurity; jurisdictional governmental disputes over responsibility for funding palliative care; provider staffing shortages; lack of trust in mainstream providers and providers' lack of understanding of Indigenous cultural beliefs, values and practices. [86]

There are many successful local models of care grounded in community strengths that outline how palliative care services can be delivered safely to support and respect Indigenous peoples, languages, history, culture, knowledge and practices.[92,93,94,95,96]

Successful models use a trusting, participatory, and culturally safe approach, involve collaborative interdisciplinary palliative care teams of conventional culturally competent providers, as well as Indigenous providers. They have formalized jurisdictional collaborations across organizations and all level of governments and engage in seamless care coordination and management.[97,98,99,100]

Through these models, First Nations, Inuit, Métis, and urban Indigenous patients have experienced the comfort of dying at home with support from their families, culture, and ancestral land, better medication adherence, improved symptom management and quality of life.[93,96,97,101] Furthermore, they have also reported high satisfaction with emotional, practical, and spiritual support, and greater willingness to engage in advance care planning.[86,92,93,102] There were also provider and system level benefits that include provider satisfaction, reduction in total healthcare costs, hospitalizations, and ED visits.[86,92,93,102]

The Delivery Framework acknowledges Indigenous community resilience and builds on successful local models. The Framework recommends how palliative care service delivery can be planned and developed to respect Indigenous peoples, languages, history, culture, knowledge and practices.[97,103,104,105]

11. **The First Nations, Inuit, Métis, and urban Indigenous patient and their family/caregivers will receive palliative care that uses a grassroots participatory and collaborative approach and incorporates cultural knowledge into all aspects of care.**

> **Truth and Reconciliation Committee Call to Action #22**: We call upon those who can effect change within the Canadian health-care system to recognize the value of Aboriginal healing practices and use them in the treatment of Aboriginal patients in collaboration with Aboriginal healers and Elders where requested by Aboriginal patients.
>
> **Truth and Reconciliation Committee Call to Action #23:** We call upon all levels of government to: Increase the number of Aboriginal professionals working in the health-care field. Ensure the retention of Aboriginal health-care providers in Aboriginal communities. Provide cultural competency training for all healthcare professionals.
>
> **Truth and Reconciliation Committee Call to Action #24:** We call upon medical and nursing schools in Canada to require all students to take a course dealing with Aboriginal health issues, including the history and legacy of residential schools, the United Nations Declaration on the Rights of Indigenous Peoples, Treaties and Aboriginal rights, and Indigenous teachings and practices. This will require skills-based training in intercultural competency, conflict resolution, human rights, and anti-racism.

11.1. The First Nations, Inuit, Métis, and urban Indigenous patient will receive individualized palliative care that uses a trauma-informed approach that is culturally safe, and respects and upholds Indigenous worldviews related to languages, values, culture, land, family, community and end-of-life.

Foundational Indigenous approaches in care will be complemented by conventional Western medicine and approaches.

11.2. The Indigenous Core Team for the First Nations, Inuit, Métis, and urban Indigenous patient will include the MRMP, the Care Coordinator, and an Indigenous Elder/Knowledge Carrier or Healer. These Core Team members will follow the teachings of their ancestors and will know how to put these teachings into practice. They will share their wisdom, culture, history, and the language and will offer healing and/or ceremonies along the entire journey of the patient and their family/caregivers.

11.3. The Care Coordinator supporting the First Nations, Inuit, Métis, and urban Indigenous patient and their family/caregivers will be prepared and able to navigate jurisdictional issues to enable access to services and providers both within and outside of First Nations communities. The Care Coordinator must also be able to navigate disputes between provincial/territorial and federal programs to ensure coverage for appropriate health services for the First Nations, Inuit, Métis, and urban Indigenous patient. This may involve leveraging the expertise of existing First Nations, Inuit, Métis, and urban Indigenous coordination/navigation services, which may include:

- Indigenous Patient Navigators who support discharge planning, liaison between the provincial and federal home, community care, and social services programs, arrangement of language interpretation services, and connections with Indigenous Elders, Healers, or Knowledge Carriers;

- Local First Nations, Inuit, Métis, and urban Indigenous community health worker(s) and health directors;

- Federal Home and Community Care nurses who conduct case management in First Nations communities;

- Non-Insured Health Benefit Navigators;

- Community-based palliative care teams; and,

- First Nations, Inuit, Métis, and urban Indigenous Organizations (e.g., Indigenous Friendship Centres, Métis Nation of Ontario, Inuit Organizations and Aboriginal Health Access Centres).

11.4. The Care Coordinator will stay connected with the First Nations, Inuit, Métis, and urban Indigenous patient and their family/caregivers during any transitions between care settings and work with the discharge teams, along with Indigenous Friendship Centres, Métis Nation of Ontario, Inuit Organizations and Aboriginal Health Access Centres, and First Nations Home Community Care, to ensure supportive and safe transitions.

11.5. The First Nations, Inuit, Métis, and urban Indigenous patient will receive a comprehensive and holistic assessment that takes an Indigenous perspective on wellness, views a whole person as expressed through a sense of balance of spirit, emotion, mind and body, connection to language, land, creation, and ancestry that is supported by a caring family and environment.[106]

11.6. The interdisciplinary palliative care team for the First Nations, Inuit, Métis, and urban Indigenous patient will include Indigenous providers such as Indigenous Community Health/Wellness Workers, Counsellors, Band Council Members and Métis (e.g. Community Support Services, Aging at Home Services) and Inuit stakeholders. These providers will organize and deliver culturally-based services in First Nations, Inuit, Métis, and urban Indigenous communities and support community awareness about the availability of services locally and regionally. Partnerships should be built between all providers and First Nations, Inuit, Métis, and urban Indigenous community organizations around education and awareness activities.

11.7. The interdisciplinary palliative care team will prioritize the cultivation of relationships and partnerships between community members, Indigenous heath organizations and healthcare providers within and outside of these communities to enable greater access to high-quality palliative care. First Nations, Inuit, Métis, and urban Indigenous providers should advocate for cultural assessment and linkages to culturally appropriate supports as needed.

11.8. Outreach teams will be available in all First Nations, Inuit, Métis, and urban Indigenous communities to provide 24/7 access to palliative care in rural locations. These teams will provide direct patient care and consultation to the MRMP. Outreach teams will include palliative care specialist-level providers, Elders/Knowledge Carriers and Healers, and Indigenous providers, as needed. Indigenous outreach teams will have resources (e.g., symptom management kits and sacred items) to support holistic care that addresses cultural, social, and medical needs.

11.9. The Care Coordinator will work with a NIHB Navigator to meet the unique transportation needs and provide seamless travel and supports (including family/caregivers escort accommodation) to the First Nations, Inuit, Métis, and urban Indigenous patient and their family/caregivers living in remote, fly-in, or ice road-only communities.

11.10. The Care Coordinator will support the urban Indigenous patient and their family/caregivers who live far from their communities to relocate back home or to build relationships with urban-based Indigenous networks, palliative care services, and Indigenous providers.

Implementation Considerations for Palliative Care for First Nations, Inuit, Métis, and urban Indigenous

- All levels of government should work together to ensure equitable access to palliative care services. In order to support the First Nations, Inuit, Métis, and urban Indigenous patients who wish to die at home, improvement and funding for access to safe and affordable housing, food, safe water, and electricity are essential.

- In rural, remote, and dispersed First Nations, Inuit, Métis, and urban Indigenous communities, equitable access to primary care providers, specialist physicians (including disease-specific and palliative care), NPs, remotely located Care Coordinators, nursing and other interdisciplinary care providers is needed for 24/7 access to palliative care. Given these needs, federal government should partner with First Nations, Inuit, Métis and provincial/LHIN leaders to make 24/7 care available provincially. While these partnerships are being forged, transitional strategies (e.g., leveraging local hospital ED physicians and nurse practitioners to act as MRMP) should be employed. [107]

- Regions should develop approaches and protocols with Indigenous stakeholders to support safe travel of providers to Indigenous communities.

- Federally and provincially provided health services for First Nations, Inuit, Métis, and urban Indigenous should complement and align with one another. Memorandums of Understanding (MOUs) between First Nations, Inuit, and Métis government, provincial health and social services ministries, and their federal counterparts should be established to improve effective use of resources. [108]

- The roles of Indigenous Navigators currently working within the cancer system should be leveraged, expanded, and funded to provide palliative care more broadly. Federal funding should also be secured to increase the number of NIHB navigators who coordinate access to drugs and medical supplies in First Nations communities.

- Flexible funding through federal or provincial programs should be available for First Nations, Inuit, Métis, and urban Indigenous communities and organizations (e.g., Aboriginal Health Access Centres, Friendship Centres, Métis Nation of Ontario) and for Healers, Elders, and Knowledge Carriers to build capacity in First Nations, Inuit, Métis, and urban Indigenous communities to provide culturally appropriate and safe palliative care. Supports should be in place to create physical space for cultural and spiritual practices/ceremonies. [108]

- Healthcare providers from First Nations, Inuit, Métis, and urban Indigenous communities should have the opportunity to achieve palliative care competency in conventional and cultural approaches through partnerships and education. This competency-based learning should be planned and delivered in partnership with Provincial Territorial Organizations (PTOs) and First Nations, Inuit, Métis, and urban Indigenous organizations.

- Providers outside First Nations, Inuit, Métis, and urban Indigenous communities need to achieve appropriate competency in providing culturally safe and trauma-informed care with First Nations, Inuit, Métis, and urban Indigenous patients and families. Specific education informed by a cultural humility approach, and storytelling from Indigenous patients and families/caregivers about their experiences should be provided. Culturally safe palliative care education should be developed and delivered by local Indigenous experts to all healthcare providers and should be included in university and college curricula for all trainees. Provinces should continue to provide funding to support this education. [108]

- The provincial government and LHINs should enable processes for dying at home in First Nations, Inuit, Métis, and urban Indigenous communities. Such processes should include working with police and coroner services to allow family and care providers to enter the home after death to assist in aftercare and healing. Policies for predictable death in the home should be implemented. [108]

- RPCNs should partner with First Nations, Inuit, Métis, and urban Indigenous organizations and communities to develop and maintain a list of regional/local Indigenous Elders/Knowledge Carriers, Healers, Indigenous interpreters and Indigenous providers that is accessible to the interdisciplinary palliative care team to facilitate better coordination and continuity of care and access to culturally safe care. All printed or electronic, culturally appropriate, patient-facing information should also be centrally maintained and easily available. [108]

- Health information for First Nations, Inuit, Métis, and urban Indigenous patients should be shared among all the members of the interdisciplinary palliative care team using an integrated system for electronic medical records. This system will be accessible to Federal Home Community Care and LHIN Home and Community Care providers.

Palliative Care for Francophones

Around 600,000 people in Ontario speak French at home on a regular basis, according to the 2016 Census.[108] Despite having constitutional rights to access services in French,[109] Ontarians still have limited access.[110,111] Those with language barriers when accessing healthcare services can experience poorer satisfaction with care.[112] Moreover, when people cannot access healthcare services in their preferred language, they can experience poorer awareness of services, have more difficulty in finding a regular care provider, more challenges participating in health promotion and prevention activities and complying with treatment, greater risk of diagnostic and treatment errors and poorer access to pain and symptom management.[112]

While the recommendations in the Delivery Framework generally applies to the francophone population, additional details in this section emphasize specific areas that are aligned with the call for active offer of services from the Office of French Language Services Commissioner,[110] aiming to provide high-quality care for this population.

12. **French language services will be highly visible and easily accessible for the patient and their family/caregivers. Healthcare providers must offer these services, guided by the Active Offer Principle, [110] without waiting to be asked.**

   12.1. The patient's linguistic identity will be captured and documented in their care plan in a standardized way at all stages of service delivery.

   12.2. All efforts should be made to ensure all conversations between interdisciplinary palliative care team members, and between providers and the francophone patient (or the SDM) and their family/caregivers are conducted in French. This is particularly important for discussions about treatment options, obtaining consent, advance care planning, and goals of care.

   12.3. In a Core Team that is bilingual, providers who interact with the patient and their family/caregivers daily (e.g., the Care Coordinator, nurse) will deliver care and information in French.

   12.4. Where bilingual human resources are limited, virtual care innovations (e.g., telemedicine) could be leveraged to improve access to French-language services for francophone patients and their families.

   12.5. Community outreach workers will support dispersed and remote communities where there are severe gaps in French-language services.

   12.6. Formal, third-party interpretation services will be engaged, when palliative care services are not available in French. The SDM or family/caregivers should never be used as translators or interpreters unless the patient expressly requests it.

Implementation Considerations for Palliative Care for Francophones

- Local realities should be taken into consideration when planning for palliative care services for francophones. These include the unique characteristics of francophone communities and the availability of health and social services in French and bilingual human resources.

- Partnerships should be built with local francophone community organizations to share information around education and awareness activities. All printed and electronic information for the patient and family/caregivers should be available in French and should be easily accessible.

- RPCNs, LHINs, and French-language health planning entities should work collaboratively to develop and implement a common approach to collect and document information on francophone language identity to help providers consistently offer francophones services in French.

- RPCNs, LHINs, and French-language health planning entities should work together to determine the regional demand for French-speaking providers to inform human resources capacity planning.

- Translation and interpretation services that are proficient in medical terminology should be funded and readily available. Access to virtual or telephone-based French language services should be an available option for dispersed or remote communities.

- RPCNs should keep an inventory of available French-language services within their region and update it regularly. French-language health planning entities can help connect providers to available French-language healthcare resources. Existing provincial services (e.g., www.thehealthline.ca, Find210, or 310-2222) should be leveraged to improve access to these French-language resources.

Palliative Care for the Homeless and Vulnerably Housed

It is challenging for homeless and vulnerably-housed individuals to access palliative and end-of-life care.[113,114] Personal history, negative feelings and experiences with the healthcare system have made them more reluctant to access formal care.[113,114] In addition, the lack of a regular family physician and medical insurance, as well as reluctance of mainstream healthcare organizations to use specialized approaches (e.g., trauma-informed, anti-oppressive, harm-reduction, etc.) have made it difficult to address the needs of this population.[115,116] However, when palliative care programs offer specialized approaches, homeless and vulnerably housed individuals are more likely to access palliative care, adhere to treatment, and experience greater satisfaction with care.[117,118,119] In addition, these programs cost less than usual care.[118,119]

While the Delivery Framework applies mostly to how this population should receive palliative care, there are some unique challenges that need to be highlighted. Homeless and vulnerably housed individuals often have multiple comorbidities, along with complex social and psychological needs which can significantly shorten their prognoses.[120] Given the complexities they face, the Delivery Framework acknowledges that palliative services for this population often need to be mobile and flexible in order to reach outside of traditional healthcare settings and meet homeless and vulnerably housed individuals where they are, regardless of physical location or stage along their illness trajectory.[113]

13. **The palliative care needs of the patient who is homeless or vulnerably housed will be identified as early as possible and care will be provided wherever the patient is.**

13.1. Earlier identification of the patient who has palliative care needs and is also homeless or vulnerably housed will take into consideration the social and psychological challenges that the patient faces, recognizing that prognosis can be significantly shortened in this population.

13.2. The Care Coordinator for the patient who is homeless or vulnerably housed will likely be from Home and Community Care. Given the challenges of care coordination for this patient, the Care Coordinator will work closely with providers who coordinate care within social service programs.

13.3. The patient will have a consistent MRMP, where possible. However, when the patient is transient or nomadic, the Care Coordinator will connect with the patient's current care team (e.g. shelter physician, hospital physician) to ensure that these providers understand the needs and preferences of the patient when recommending treatment and care and developing plans.

13.4. The Core Team for the patient will be comprised of providers who can best meet the patient's needs at a point in time. Given that this population can be transient and nomadic, the composition of their Core Team may change depending on the patient's current location. The Care Coordinator will monitor and document the changing members of the Core Team and will update this information regularly.

13.5. Outreach/mobile teams will go out to 'meet the patient where they are'. This will be an important resource within regions and communities.

13.6. Prior to discharge from acute care, the hospital team will liaise with the Care Coordinator and, where applicable, the social service agency to ensure smooth transition to community.

13.7. The Care Coordinator (or other members of the interdisciplinary palliative care team) will work with the patient to identify their "chosen" or "street" family. They will ensure that the patient and their family are supported to remain connected through their illness trajectory.

13.8. While the recommendations outlined in this section apply to First Nations, Inuit, Métis, and urban Indigenous individuals who are homeless/vulnerably housed, these patients will also be offered culturally safe assessments and connection to local Indigenous services and resources.

Implementation Considerations for Palliative Care for Homeless and Vulnerably Housed

- Providers working in social service programs (e.g. shelters, mental health programs, and substance abuse programs) and healthcare settings (e.g., hospital in-patient units, outpatient clinics, EDs) will need education and training around identifying palliative care needs in homeless and vulnerably housed individuals.

- The composition of the interdisciplinary palliative care team for this population will need to include providers from the broader community of providers and agencies. This will include not only Home and Community Care providers, but also providers from social service programs (e.g. shelters, mental health programs, and substance abuse programs). The effectiveness of the team will depend on being collaborative and having effective means of communication and information sharing.

- First Nations, Inuit, Métis, and urban Indigenous individuals who are also homeless in urban settings will have additional needs. Palliative care programs and social service agencies will need to establish strong relationships with First Nations, Inuit, Métis, and urban Indigenous community organizations and providers in order to provide appropriate support to these individuals.

- Geographic 'no-go zones' or neighbourhoods/residences where care providers will not enter due to concerns for personal safety, present a specific challenge. Work needs to be done to identify genuine safety issues, establish approaches and policies to mitigate risks, and provide safety support for providers.

- Trauma-informed, harm reduction, and anti-oppressive practices are especially important for this population. Appropriate education on these approaches should be a part of training for providers serving this population.

BROADER AREAS OF SYSTEM IMPROVEMENT

The implementation of the Delivery Framework will require action on some system-wide changes that will apply across many of the recommendations contained in this document. The Working Group has identified a number of system-level considerations and process-improvement opportunities that need to be addressed to facilitate the implementation of the Delivery Framework.

Information Systems

Reliable, effective, and secure access to information is essential to the provision of high-quality care and successful implementation of the Delivery Framework. Having patient records that are accessible across the healthcare system would be ideal. While efforts are made to create mechanisms to safely share health information, patient records currently remain siloed, particularly among community providers (e.g., community nurses and primary care providers).

- To ensure that information about the patient is transferred safely and effectively between providers 24/7 and is available to the patient, a province-wide, centralized, integrated patient information system should be considered. Recognizing that developing this ideal structure may take substantial time, provincial standards should be in place to ensure reliable and secure access to shared patient health information. These standards should be implemented at the regional level.

Achieving Competency

The OPCN's *Ontario Palliative Care Competency Framework*[44] makes recommendations about the palliative care competencies required for providers who are delivering palliative care services. Ensuring that all providers have the appropriate level of competency is an important step in building palliative care human resource capacity in the province.

- Accountability to have appropriate processes in place to ensure the competency of providers within their jurisdiction resides with the LHINs. This would entail including appropriate accountabilities for competency in service agreements and employee contracts.

- Ontario colleges and universities play an important role in implementing the palliative care competencies. Influencing the curriculum at these institutions to reflect the needs of this population will be important at a provincial level.

Human Resources Capacity Building

A critical factor for the successful implementation of the Delivery Framework is having skilled human resources to provide palliative care. To do so, adequate numbers of providers with the appropriate competencies need to be available and integrated into the system of care.

- A provincial-level health human resource plan should be developed and reviewed regularly. This plan should build upon regional data to ensure that an appropriate number of skilled human resources is available across the province.

Evaluation and Continuous Improvement

Evaluation is key in measuring the impact of the Delivery Framework and, most importantly, ensuring continuous improvement throughout implementation.

- At a provincial level an evaluation plan should be developed to assess the impact of the Delivery Framework implementation on patients, providers and the healthcare system. The plan should include short-term process measures as well as long-term outcome measures and indicators[3]. This evaluation may include use of existing administrative databases as well as primary data collection.

NEXT STEPS

It is envisioned that the implementation of Delivery Framework is a multi-year initiative requiring commitment to this important work and mobilization of efforts at local, regional, and provincial levels. This initiative is a complex change management process with many interdependencies (e.g., improving processes, optimizing roles, and building relationships and capacity). It should be viewed as an evolutionary process that builds upon existing successful programs and services. While some of the recommendations in the Delivery Framework can be implemented immediately, others will require a longer term, phased implementation, as well as investments in human resources.

RPCNs, with support from their LHINs, will need to champion the implementation of the Delivery Framework. This will involve catalyzing on existing strengths of local programs, supporting existing relationships and creating new ones. In addition, while interdisciplinary palliative care teams already exist in some Ontario jurisdictions, this document identifies ample opportunities to build relationships, further streamline the processes and maximize scope of practice of providers to enhance patient and caregiver access to high quality palliative care. While the Delivery Framework is providing guidance on the ideal model of community palliative care, it allows the regions flexibility in its implementation to ensure that the improvements in palliative care are in line with regional needs and characteristics.

The Delivery Framework is one of many resources that has been developed by the OPCN[121] (see www.ontariopalliativecarenetwork.ca) with the goal to improve palliative care services in Ontario. All these products should be brought together and used as inputs during the implementation of the Delivery Framework.

Last but not least, the implementation of the Delivery Framework will require continuous stakeholder engagement to ensure that learnings are shared and its progress is monitored. The OPCN should engage key stakeholders, establish opportunities for sharing implementation successes and challenges, and develop solutions to overcome implementation barriers. Additionally, the OPCN should measure the implementation progress and monitor the spread and scale of the Delivery Framework.

APPENDIX A: DELIVERY FRAMEWORK WORKING GROUP MEMBERSHIP

Name	Title
Dr. Robert Sauls (Chair)	Clinical Lead, Health Services Delivery Framework
Beth Archibald	Palliative Liaison Coordinator (Patient Navigator), Haliburton Highlands Health Services, Palliative Care Community Team
Barbara Ballantyne	Clinical Nurse Specialist, Palliative Care OPCN North East LHIN Multidisciplinary Clinical Co-Lead
Robin Cano	Registered Nurse, Certified Hospice Palliative Care Nurse Regional Coordinator, Home and Community Care Program, Ontario Region, First Nations and Inuit Health Branch, Department of Indigenous Services Canada / Government of Canada
Denis Charette	Patient and Family Advisor
Dr. Helen Cluett	Family Physician President and Chair, Prince Edward Family Health Team
Dr. Lisa Del Giudice	Family Physician; Toronto Central LHIN Regional Primary Care Lead; Assistant Professor, Department of Family and Community Medicine University of Toronto
Dr. Bernice Downey	Medical Anthropologist; Assistant Professor, School of Nursing, Dept. of Psychiatry; Indigenous Health Lead, Faculty of Health Science, McMaster University
Janet Elder	Palliative Liaison Nurse Coordinator, The Hospice of Windsor and Essex County OPCN Erie St. Clair LHIN Multi-Disciplinary Clinical Co-Lead
Dr. Laura Harild	Division Head for Palliative Care, Trillium Health Partners OPCN Mississauga Halton LHIN Multidisciplinary Clinical Co-Lead
Susan King	Patient and Family Advisor
Dr. Kathy Kortes-Miller	Assistant Professor, Lakehead University Social Worker
Rachel Lapensee	Nurse Consultant Team Lead, North Simcoe Muskoka Hospice Palliative Care Network
Alice Luk	Palliative Care Nurse Practitioner, Central LHIN
Valerie McDonald	Patient and Family Advisor
Dr. Amy Montour	Palliative Care Physician; OPCN Hamilton Niagara Haldimand Brant Multi-Disciplinary Clinical Co-Lead

Name	Title
Dr. José Pereira	Palliative Care Physician Consultant, William Osler Health Services Brampton Civic Hospital Dr. Gillian Gilchrist Chair in Palliative Care Research Chief Scientific Officer, Pallium Canada Director of Research, The College of Family Physicians of Canada
Pamela Simpson	Pharmacist/Manager, Robinson's Pharmasave, North East LHIN
Dr. Peter Tanuseputro	Associate Scientist, Ottawa Hospital Research Institute Investigator, Bruyère Research Institute Assistant Professor, Department of Medicine, University of Ottawa Adjunct Scientist, Institute for Clinical Evaluative Sciences

APPENDIX B: DELIVERY FRAMEWORK WORKING GROUP - TERMS OF REFERENCE

The service model for palliative care in Ontario varies. As articulated within The Declaration of Partnership ([The Declaration](#)) and the OPCN's capacity planning current state assessment (April 2017), there exists variation in the availability and delivery of services within and across the province. To address this variability, the OPCN seeks to determine what constitutes the optimal palliative models of care to ensure that the right care, is provided in the right place, by the right provider at the right time.

Scope

The Delivery Framework Working Group will seek to determine what constitutes the best service delivery models for patients by focusing on the optimal use of health care personnel, which includes administrative personnel, volunteers, and family/caregivers, and the optimal use of settings.

The following areas of focus (target populations) are within the scope of this project:

1. **Area of Focus:** Adult patients receiving care within the last year of life and residing at home (e.g., patients living in their usual place of residence* and receiving care in their home, at outpatient clinics, or through their primary care provider).

*Usual place of residence can include long-term care homes and retirement homes.

Considerations:
- As the details of the models are determined, differences between pre-last year of life and last year or life will be identified.
- Recommendations to include messaging around the palliative approach to care, earlier identification at the primary care level, and the model using a non-specialist and primary care capacity building approach.

Future Areas of Focus
- Adult patients within the last year of life receiving care in a hospital setting (e.g., acute and complex continuing care).
- Pediatric patients receiving palliative care (e.g., at home and/or in a hospital; all settings).

It is expected that the Terms of Reference will be reviewed prior to the development/design of the future areas of focus.

Deliverables

The purpose of the Working Group is to make recommendations regarding the optimal service delivery model for patients receiving palliative care. Members are expected to:

- Provide feedback on the evidence review and jurisdictional scan (Ontario, Canada, International)
- Advise and achieve consensus on the scope, processes, and approach for models of care recommendations
- Define preferred models of care
- Advise on the outline, structure, and level of detail of the models of care recommendations
- Assist in the development of the models of care recommendations
- Provide input into health human resources planning models related to palliative care, including recommended provider workload measures
- Assist the socialization of final draft recommendations to their local stakeholders.
- Assist in the identification of key stakeholders for the recommendations
- Assist in the identification of implementation considerations

Meetings and Term

The Working Group will meet approximately eight times beginning in August 2017 with some work expected to occur in smaller sub group and over email. The work on the first area of focus is expected to continue until August 2018.

- Members are asked to make every effort to attend meetings.
  - Members unable to attend meetings are encouraged to review meeting notes, materials and connect with other Working Group members or the OPCN Secretariat team to provide input.
- Meetings will be one to two hours in length, to be held in person and with a teleconference provided.

The Terms of Reference and Membership will be reviewed each fiscal year.

Membership (13-15 Members)

Health professionals and administrators currently in engaged in the care of the in-scope patient populations.

Decision Making Process

Decisions will be made by consensus of the members. If there are any issues on which consensus cannot be achieved, the decision-making approach will be decided upon by the Co-Chairs in consultation with the Project Sponsors.

Accountability

The Working Group is accountable through the Co-Chairs to the Clinical Advisory Committee, and ultimately the OPCN Executive Oversight. The Data and Information Advisory Council, Implementation Advisory Council, and Partnership Advisory Council

will also be consulted for their feedback on the recommendations.

Conflict of Interest

Working Group members must ensure that any actual or potential conflict of interest in regards to any matter under discussion by the committee is drawn to the attention of the Co-Chairs. The Co-Chairs will decide what action, if any, is required arising from the conflict of interest and will take appropriate action, including but not limited to requesting the member absent him or herself from participation in discussion of the matter. Members will be required to complete a Conflict of Interest Declaration upon joining the Working Group.

Confidentiality

Unless it is generally available to the public, all data and information acquired or prepared by or for the committee should be treated as confidential. Members should keep these data and information confidential and not directly or indirectly disclose them during or subsequent to their term as a member of the committee. Members will be required to complete a Statement of Confidentiality upon joining the Working Group.

APPENDIX C: GLOSSARY

Active offer: The regular and permanent offer of services to the francophone population. It is the result of a rigorous and innovative process for planning and delivering services in French across the entire health care continuum. It requires partners to exercise appropriate leadership with respect to health services in French and depends on accountability at several levels: system level, organization level, professional level and individual level.[110]

Advance Care Planning (ACP): In Ontario, advance care planning is an iterative process that involves the mentally capable patient in:

IDENTIFYING their future Substitute Decision Maker by either

• Confirming their satisfaction with their default/automatic Substitute Decision Maker in the Substitute Decision Maker hierarchy list in the Health Care Consent Act OR

• Choosing someone else to act as Substitute Decision Maker by preparing a Power of Attorney for Personal Care (a formal written document).

SHARING their wishes, values, and beliefs through conversations with the SDM and others that clarify their wishes, values and beliefs, and more generally, how they would like to be cared for in the event of incapacity to give or refuse consent. Rather than being a single event, advance care planning is ongoing and dynamic, with the potential for personal preferences to change over time as health status changes. It may be initiated at any point in the health care process and may involve individuals who are currently healthy.[13]

Consent (health care consent): An informed and contextualized decision involving a mentally capable person and a healthcare provider as outlined in the Ontario Health Care Consent Act (1996, S.O. 1996, c. 2, Sched. A). Healthcare providers proposing treatment must obtain informed consent from either a capable patient or their Substitute Decision Maker if they do not have the mental capacity. This discussion must address the patient's present condition (context), available treatment options, risks/benefits/side effects, alternatives to treatment and what would happen without the proposed treatment.[13]

Comprehensive and Holistic Assessment: Includes a full examination of the domains of care associated with illness and bereavement, including: disease management, physical, psychological, social, cultural, legal, ethical, cultural, spiritual, practical, end-of-life, loss and grief. Examples of validated tools used for assessment may include the Edmonton Symptom Assessment System, and the Palliative Performance Scale. The comprehensive and holistic assessment considers a person's socio-cultural context and initial assessments should include inquiry about a person's mother tongue and language of preference.[3]

Cultural humility: A process of self-reflection to understand personal and systemic conditioned biases, and to develop and maintain respectful processes and relationships based on mutual trust. Cultural humility involves humbly acknowledging oneself as a life-long learner when it comes to understanding another's experience. Cultural humility enables cultural safety.[122]

Cultural safety: Is predicated on understanding the power differentials inherent in health service delivery and redressing these inequities through educational processes. Addressing inequities, through the lens of cultural safety, enables health professionals to: improve health care access for clients or individuals, aggregates and populations; acknowledge that we are all bearers of culture; expose the social, political and historical contexts of health care; enable practitioners to consider difficult concepts, such as racism, discrimination and prejudice; understand that cultural safety is determined by those to whom health professionals provide care; understand the limitations of "culture" in terms of having people access and safely move through health care systems and encounters with care providers; and challenge unequal power relations.[123]

First Nations, Inuit, Métis and urban Indigenous: Refers to the First Nations, Inuit, Métis and urban Indigenous peoples of Ontario. Here, 'urban Indigenous' refers to First Nations, Inuit, and Métis peoples living in cities and towns in Ontario. More than 85 percent of Ontario's Indigenous people live off-reserve in urban or rural communities; these are self-organized, self-determining Indigenous communities, analogous to a reserve community. This

language shift is part of Canada's commitment to a renewed, nation-to-nation relationship with Indigenous peoples in recognition of rights, respect, and partnership; and reflects culturally safe terminology determined by extensive engagement across Ontario with today's Indigenous peoples.

Goals of Care Discussion: A discussion between a patient (or his/her Substitute Decision Maker if the patient lacks capacity) and healthcare provider(s) that addresses the patient's goals for his or her care in the context of healthcare consent and decision-making in advanced illness. The purpose of these discussions is to outline the patient's values, beliefs, wishes, perception of quality of life and what he or she characterizes as meaningful and important. Other elements include the patient's understanding of current health conditions, prognosis, and likely course of events if his or her goals of care are applied to potential treatment decisions. The goals of care discussion provides the foundation for decision-making and will often include the development of (and obtaining informed consent to) a plan of treatment.[13]

Healer: The Creator and the spirits work through Healers to help people. Healers are guided by spirit, the Creator and spirit helpers, which come in many forms. Each Healer has their own unique way and medicines that they work with; some may work with plants, some may counsel, some may heal with laying of their hands, singing and drumming in prayer. They may also work through ceremonies (e.g., sweat lodge or the shaking tent) to provide healing.[124]

Hospice: Is a community-based organization (or a program offered by a multi-service organization) that provides support to individuals living with a progressive, life-limiting illness and their caregivers, family members, and friends.[12] Support is provided to the service recipient in a variety of settings, including where the individual lives or in a homelike setting. The goal of hospice care is to enhance the quality of life of the individual and the well-being of anyone that is impacted by the person's illness or death. Volunteers play an integral role in achieving that goal. A hospice provides services such as hospice-trained volunteers, day programs, psychosocial supports, grief and bereavement support, spiritual care, caregiver support, wellness programs, complementary therapies, children's programs, outreach/shared care teams, and end-of-life care within a hospice residence.[12]

Indigenous Elder/ Knowledge Carrier: Someone who follows the teachings of their ancestors and knows how to put those into practice. Traditional Elders teach and share the wisdom they have gained of the culture, history and the language. The sharing of their wisdom is healing. An Elder does not have to be a senior but could be someone younger who has many teachings and who has earned the respect of their community by contributing to its spiritual development. These individuals are designated by their community. The role of the Elder and Knowledge Carrier may have varying responsibilities according to their ancestral knowledge and communities.[124]

Indigenous Providers: These providers organize and deliver cultural-based services in First Nations, Inuit, Métis, and urban Indigenous communities to support community knowledge about Indigenous services availability locally and regionally. These providers include but are not limited to: Indigenous Community Health/Wellness Workers, Counsellors, Band Council Members, Métis (e.g. Community Support Services, Aging at Home Services) and Inuit stakeholders.

Interdisciplinary Palliative Care Team: Is an interdisciplinary team of providers who work together to deliver palliative care to a patient and their family/caregivers based on a person's care plan. This team will consist of a most responsible medical provider (physician or nurse practitioner) and a designated care coordinator and will have an established connection with a palliative care specialist(s) whose role on the team will be to consult with team members and to provide direct patient care as needed. The team will often be expanded to include additional providers, for example, nurses, disease-specific specialists, social workers, psychologists, spiritual care providers, pharmacists, personal support workers, dietitians, Indigenous providers, and volunteers.

Linguistic Identity: Refers to the linguistic group to which a person belongs or with which a person identifies. This variable generally remains unchanged over time. There is a distinction between establishing a patient's linguistic identify and her linguistic preference. The patient may express a preference for English for a variety of reasons (timeliness of care, fear of receiving lower level of care, etc.), but as the illness progresses and under stress, linguistic preference should be reassessed.[125]

Jordan's Principle: A Principle named in memory of Jordan River Anderson, a First Nations child born with complex medical needs who spent more than two years unnecessarily in hospital while the Indigenous and Northern Affairs Canada (INAC), the Federal and Provincial Governments disputed coverage for home care costs. Jordan died at the age of five, having spent his entire life in hospital. Jordan's Principle states that when a jurisdictional dispute regarding services to a First Nations child arises the government department of first contact pays for the service and can seek reimbursement from the other government or department after the child has received the service. It is a child-first principle meant to prevent First Nations children from being denied essential public services or experiencing delays in receiving them. Although, Jordan's Principle applies to children, First Nation adults experience jurisdictional disputes, this Principle has come to represent negotiating all disputes so that any Indigenous person receives the care they need.[126]

Most Responsible Medical Professional (MRMP): In the Health Services Delivery Framework, the MRMP is a physician or nurse practitioner. The MRMP will be responsible for ordering tests, making diagnoses, ordering treatments and prescribing medications.

Provincial Territorial Organizations (PTOs): Represented by the Chiefs of Ontario, "is a political forum and secretariat for collective decision-making, action, and advocacy for the 133 First Nations communities located within the boundaries of the province of Ontario. Guided by the Chiefs in Assembly, they uphold self-determination efforts of the Anishinaabek, Mushkegowuk, Onkwehonwe, and Lenape Peoples in protecting and exercising their inherent and Treaty rights. Keeping in mind the wisdom of our Elders, and the future for our youth, we continue to create the path forward in building our Nations as strong, healthy Peoples respectful of ourselves, each other, and all creation."[127]

Palliative Approach: Meeting a person's and his/her family's full range of needs – physical, psychosocial and spiritual – at all stages of a chronic progressive illness. It reinforces the person's autonomy and right to be actively involved in his or her own care – and strives to give individuals and families a greater sense of control. It sees palliative care as less of a discrete service offered to dying persons when treatment is no longer effective and more of an approach to care that can enhance their quality of life *throughout* the course of their illness or the process of aging. The term 'palliative care approach' is also used to refer to palliative care delivered at a generalist level of competency by family physicians, primary care NPs, oncologist, internists, etc. as opposed to specialist level palliative care provided by palliative care specialists.[13]

Substitute Decision Maker: The person or persons who would have the legal authority to make health decisions if the patient is not capable of making their own decisions. This would include treatment and care plan decisions, providing consent for those decisions and decisions about the sharing of the patient's personal health information. The person or persons identified as the SDM will be the highest ranking person(s) in the SDM hierarchy in the Ontario Health Care Consent Act and meets the requirements to be an SDM (Health Care Consent Act, 1996, S.O. 1996, c. 2, Sched. A) [13]

Vulnerably housed: A term that includes low income, socially marginalized individuals living in single room occupancy (SRO) hotels and rooming houses. These individuals often have unstable living arrangements, resulting in frequent transitions between homelessness and vulnerable housing.[128]

APPENDIX D: ACRONYMS

ADL	Activities of Daily Living
AFP	Alternate Funding Plan
DNR	Do not resuscitate
DNR-C	Do Not Resuscitate Confirmation form
ED	Emergency Department
EMR	Electronic Medical Record
EMS	Emergency Medical Services
HQO	Health Quality Ontario
IADL	Instrumental Activities of Daily Living
LHIN	Local Health Integration Networks
MAID	Medical Assistance in Dying
MRMP	Most Responsible Medical Professional
NIHB	Non-Insured Health Benefits
NP	Nurse Practitioner
OHIP	Ontario Health Insurance Plan
OLTCA	Ontario Long Term Care Association
OPCN	Ontario Palliative Care Network
OTN	Ontario Telehealth Network
PPSMC	Palliative Pain and Symptom Management Consultants
RN	Registered Nurse
RPCN	Regional Palliative Care Networks
RPN	Registered Practical Nurse
SDM	Substitute Decision Maker

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