



Recommendations to enable widespread adoption of this quality standard



Ontario
Palliative Care
Network

About This Document

This document summarizes recommendations at local practice and system-wide levels to support the adoption of the quality standard on palliative care. It was developed in partnership with the Ontario Palliative Care Network (OPCN).

At the local and regional levels, health care providers and organizations in all applicable settings, local health integration networks (LHINs), and other health system partners across the province are encouraged to use the quality standard as a resource for quality improvement. While many organizations and providers may be offering the care described in the quality standard, the statements, related measures, and adoption supports are designed to help organizations determine where there are opportunities to focus their improvement efforts. The <u>Getting Started Guide</u> outlines the process for using this quality standard as a resource to deliver high-quality care.

An important next step will be to put the recommendations included in this document into action. In some situations, this may require a more detailed plan or new resources, or it may require leveraging or expanding existing programs. Many aspects of the quality standard represent care that can and should be made available today.

A monitoring and evaluation strategy is included in the final section, with suggested measures to monitor and track progress. Health Quality Ontario's Quality Standards Committee will review these regularly, including the actions needed to support implementation.

The Palliative Care Quality Standard

This quality standard addresses palliative care for people who are living with a progressive, life-limiting illness, and for their family and caregivers. The goal of palliative care is to relieve pain and suffering, and to improve a person's quality of life. This quality standard focuses on care for people in all settings, including home and community, hospice, hospital, and long-term care.

Click here to access the quality standard.

The Recommendations for Adoption

The purpose of these recommendations is to support the use of the quality standard to promote practice improvement among health care professionals. They are designed to bridge the gaps between current care and the care outlined in the quality statements.

Click <u>here</u> to download the detailed process and methods guide for a description of how the quality standard and recommendations for adoption were developed.

The recommendations for adoption were developed after a review of the available evidence on implementation and a scan of existing programs, as well as extensive consultation with the Palliative Care Quality Standard Working Group, the OPCN, key stakeholders, and organizations that work in this area, interviews with clinicians, and public comment on the quality standard. Several key public reports on the current state of palliative and end-of-life care in Ontario were used to inform this document. These documents include the Auditor General's 2014 Annual Report, the *Palliative and End-of-Life Care Provincial Roundtable Report* (2016), *Advancing High Quality, High Value Palliative Care in Ontario:* A Declaration of Partnership and Commitment to Action (2011), and the Final Report of the First Nations Advisory Committee —Home and Community Care in First Nations Communities in Ontario (2017). (See Appendix A for further details on the development of these recommendations.)

THE RECOMMENDATIONS FOR ADOPTION CONTINUED

These consultations highlighted some common themes, such as the lack of clear differentiation between end-of-life care and palliative care; the lack of available 24/7 palliative care support; the need to enhance care coordination; knowledge gaps in advance care planning, health care consent, and the role of a substitute decision-maker; the need to provide culturally safe and appropriate care; and inadequate access to respite, psychosocial, and spiritual support for caregivers.

A number of equity issues have been identified related to this quality standard topic:

- There is a disparity in the quality and availability of services across the province, putting people living in rural and remote communities at a significant disadvantage
- Patients living in poorer neighborhoods are less likely to receive palliative home care services in their last month of life
- Language differences were a main barrier to accessing culturally appropriate services among some non–English and French speaking populations.

In 2015, the Ministry of Health and Long-Term Care (MOHLTC) conducted roundtable discussions and engagements to identify the needs and challenges of providing quality palliative and end-of-life care across the province. Specific equity issues were identified in the *Palliative and End-of-Life Care Provincial Roundtable Report* (2016),⁴ such as:

- The lack of First Nations, Métis, Inuit, and urban Aboriginal perspectives in service planning and delivery
- Inequitable resource allocation and geographical challenges in rural and northern communities
- Inadequate awareness of and competency for the provision of culturally sensitive (i.e., culturally appropriate and traumainformed) and linguistically appropriate palliative care services
- Challenges in meeting the needs of urban, rural, and remote communities, including various cultural, faith-based, and linguistic groups; vulnerable populations (e.g., people who are homeless or who have mental health or addiction issues); people with disabilities; and Indigenous communities.

THE RECOMMENDATIONS FOR ADOPTION CONTINUED

In addition, services are not always accessible in French. To address this, each LHIN is connected to a French Language Health Services Planning Entity. This group is mandated to support local planning, delivery, evaluation, and improvement of French-language health services.

Specific adoption strategies should not reinforce current states of inequity and inequality. Where possible, they should contribute to improvements or highlight areas of opportunity for equity and equality. More information on equity considerations is available in Appendix B.

- ¹ French SD, Green SE, O'Connor DA, et al. Developing theory-informed behaviour change interventions to implement evidence into practice: a systematic approach using the Theoretical Domains Framework. Implementation Sci. 2012;7:38. Available from: https://implementationscience.biomedcentral.com/track/pdf/10.1186/1748-5908-7-38?site=implementationscience.biomedcentral.com.
- ² Bero LA, Grilli R, Grimshaw JM, Harvey E, Oxman AD, Thomson M. Closing the gap between research and practice: an overview of systematic reviews of interventions to promote the implementation of research findings. BMJ. 1998;315:465-68.
- ³ National Implementation Research Network. Implementation drivers [Internet]. Chapel Hill (NC): FPG Child Development Institute, University of North Carolina [cited 2017 Feb 8]. Available from: http://nirn.fpg.unc.edu/learn-implementation/implementation-drivers.
- ⁴ Fraser J. Palliative and end-of-life care provincial roundtable report. A report from Parliamentary Assistant John Fraser to the Minister of Health and Long-Term Care [Internet]. Toronto (ON): Queen's Printer for Ontario; 2016 [cited 2017 Dec 6]. Available from: http://www.health.gov.on.ca/en/public/programs/palliative/pdf/palliative_report.pdf.

The Ontario Palliative Care Network

The Ontario Palliative Care Network (OPCN) is a partnership funded by the MOHLTC and led by Cancer Care Ontario, the LHINs, Health Quality Ontario, and the Quality Hospice Palliative Care Coalition of Ontario. It is putting patients and families at the centre of every decision and aims to support and strengthen the provision of quality hospice palliative care for all Ontarians, regardless of their age or disease type. The OPCN will help to ensure that hospice palliative care in Ontario is high-quality, sustainable, accessible, continuous, and person-centred.

The OPCN has developed an action plan (2017–2020) that will guide how its partners will work together to improve the availability of and access to equitable, high-quality, sustainable palliative care services for all Ontarians. It presents a way forward for palliative care services in Ontario and promotes collaboration and standardization across the regions. The action plan recognizes the diverse needs of Ontarians. It identifies 38 ambitious but achievable actions in seven areas aligned with the goals of the *Declaration of Partnership and Commitment to Action* and builds on the significant work in hospice palliative care already underway provincially, regionally, and locally within the 14 Regional Palliative Care Networks.

Click here to access the OPCN action plan.

The action plan supports the adoption of Health Quality Ontario's *Palliative Care* quality standard, and several recommendations for adoption are directly aligned with the activities in the action plan. This alignment is indicated where applicable.

The adoption recommendations are organized as follows:

- Integrating the quality standard into practice
 - Quality improvement
 - Access to care
 - Coordination of care
- Education and training
- Policy and system planning

We describe three time frames for adoption: immediate (less than 1 year); medium term (1–3 years); and long term (more than 3 years).

Note that the organizations, programs, and initiatives referenced in this document are examples for consideration. They do not reflect all the organizations, programs, and initiatives doing work in this area.

Appendix C provides a list of these recommendations aligned to specific organizations and groups.

Integrating the Quality Standard into Practice Quality Improvement

*OPCN Action Plan Alignment:

Green: aligns well with 3-year action plan item(s), including language and timeline

Brown: loosely related to items in the 3-year plan

Red: not applicable to the action plan

Gap: There is a lack of practical tools to help providers and organizations integrate the quality standard into daily care practice.

Recommendations	Quality Statements	Action Needed By	*OPCN Action Plan Alignment	Time Frame
Assess the care being provided against the quality standard using Health Quality Ontario's <u>Getting Started Guide</u> , and refer to the <u>action plan template</u> and the <u>measurement guide</u> for this quality standard as tools to support quality improvement.	All	Health care providers Health care organizations	A, D, and F	Immediate
The Regional Palliative Clinical Co-Leads should work with health care organizations to assess the care that is being provided against the quality standard, and use the quality statements, related indicators, and quality improvement science to make improvements to care.	AII	OPCN	B7: The Regional Palliative Care Network will assess the service delivery gaps between existing services and those articulated in the models of care. In their annual work plans, they will identify current and recommended capacity and associated resource requirements to close the gaps over time.	Medium term

Integrating the Quality Standard into Practice Quality Improvement (continued)

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Gap (continued): There is a lack of practical tools to help providers and organizations integrate the quality standard into daily care practice.

Recommendations	Quality Statements	Action Needed By	*OPCN Action Plan Alignment	Time Frame
Develop a provincial strategy to support person-centred decision-making. This includes developing and updating resources for advance care planning, goals of care, and health care consent in alignment with Ontario's legal framework and this quality standard.	AII	OPCN	A2: Each Regional Palliative Care Network will identify existing patient/caregiver resources within their regions in a provincial-scale catalogue. The catalogue will also include advance care planning, goals of care, and health care consent resources developed by Hospice Palliative Care Ontario.	Long term
			A3: Hospice Palliative Care Ontario will continue to develop and update materials for patients and providers to engage them in these conversations.	

Integrating the Quality Standard into Practice Quality Improvement (continued)

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Gap: Provincial and regional measurement efforts need to be aligned, particularly measurement of caregiver experiences, to support quality improvement efforts.

Coordinated efforts to support improvement in the caregiver experience are required.

Recommendations	Quality Statements	Action Needed By	*OPCN Action Plan Alignment	Time Frame
Develop a provincial performance framework to align data collection and measurement across the system and support the province-wide implementation of the CaregiverVoice survey to measure caregiver experiences.	All	OPCN	G1: The Data and Information Advisory Council will develop standardized provincial and regional reports to measure the impact of implementing the action plan.	Long term
			G4: The CaregiverVoice survey will be adopted in all 14 LHINs for patients who receive palliative home care services and hospice services. The survey will also be completed for all patients who receive hospice palliative care in long-term care homes.	
Establish a mechanism to help patients and caregivers understand the services that are available and develop a care pathway to meet their needs.	All	OPCN	A4	Medium term

Integrating the Quality Standard into Practice Quality Improvement (continued)

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Gap (continued): Provincial and regional measurement efforts need to be aligned, particularly measurement of caregiver experiences, to support quality improvement efforts.

Coordinated efforts to support improvement in the caregiver experience are required.

Adoption Considerations:

- The IDEAS Advanced Learning Program will be dedicating a cohort to this quality standard to enhance quality improvement capacity in palliative care.
- Hospice Palliative Care Ontario's Standards and Accreditation Framework shows alignment with the quality statements outlined in this quality standard, and can help support adoption.
- The CaregiverVoice survey has been identified as a tool to support measurement of care experiences in the last months of life.
- The Developing Palliative Care Programs in First Nations Communities: A Workbook can be used in First Nations communities to guide interested organizations through the process of developing local palliative care programs.

Integrating the Quality Standard into Practice Access to Care

*OPCN Action Plan Alignment:

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Gap: Individuals with a progressive, life-limiting illness may not have their palliative care needs met promptly due to the following gaps:

- The misconception that only individuals with a cancer diagnosis could benefit from a palliative approach to care, and the tendency to equate palliative care with end-of-life care.
- Lack of availability of 24/7 palliative care community-based supports and limited access to after-hours pain and symptom management services outside of emergency departments.
- Health care providers are often unaware of what spiritual and psychosocial services, respite, and bereavement supports are available in their regions. This may delay patients' access to non-medical services.
- Access to spiritual care or palliative care providers for early identification is limited in rural and remote areas. Spiritual care
 providers for First Nations, Inuit, and Métis patients are only available in urban hospital settings. For example, Thunder Bay
 Regional Hospital is the only hospital in Ontario with a designated Indigenous Spiritual Care Advisor.
- People living in rural and remote communities have challenges accessing palliative care services due to limited or no availability. First Nations, Inuit, and Métis communities also experience unique challenges caused by jurisdictional funding gaps.

Recommendations	Quality Statements	Action Needed By	*OPCN Action Plan Alignment	Time Frame
Establish a consistent approach to early identification and assessment of needs using evidence-based tools and data sets.	All	OPCN Health care providers Health care organizations	С	Medium term

Integrating the Quality Standard into Practice Access to Care (continued)

*OPCN Action Plan Alignment:

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Gap: continued from page 9

Recommendations	Quality Statements	Action Needed By	*OPCN Action Plan Alignment	Time Frame
Develop flexible care models that address palliative care needs and support where the patient wishes to receive care. This is particularly important for marginalized and vulnerable populations.	All	OPCN	D: Developing models of care for patients residing at home is one component of this work.	Medium term
Develop an appropriate care pathway to improve caregivers' access to respite programs, psychosocial and spiritual care, bereavement services, and supports for caregivers.	All	OPCN	A4	Medium term
Together with health care providers and organizations, conduct capacity planning for community-based palliative	All	OPCN	1. B7 and D: Note that the time frames differ between	Immediate
care supports:		Health care providers	these recommendations and these sections in the action plan 2. E2: Mapping of services	
1. Develop a health human resource plan in each LHIN to support the provision of 24/7 palliative support.		Health care organizations		
2. Map spiritual and psychosocial resources, respite				
services, bereavement supports, and volunteer-led initiatives available in each LHIN, including services offered by regulated and unregulated health care professionals.			3. Standardized referral process not applicable to the action plan	
3. Depending on the availability of services, integrate psychosocial aspects of care into daily care practice and develop a standardized referral process for spiritual and psychosocial services.				

Integrating the Quality Standard into Practice Access to Care (continued)

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Gap: continued from page 9

Recommendations	Quality Statements	Action Needed By	*OPCN Action Plan Alignment	Time Frame
Continue to engage with First Nations, Inuit, and Métis communities, on- and off-reserve, to identify gaps in palliative care; address the identified gaps related to palliative care as stated in the <i>Final Report of the First Nations Advisory Committee</i> (2017).	All	OPCN	В	Immediate
Continue to engage with Francophone communities to identify gaps in palliative care services available in French.	All	OPCN	B4: Each Regional Palliative Care Network will engage with Francophones in an equitable manner to identify gaps.	Immediate

Adoption Considerations:

- The Health Links approach to care can support early identification and assessment of needs for people with progressive, life-limiting illnesses.
- The OPCN is working to review and endorse evidence-based tools to support early identification and assessment of palliative care needs.
- Leverage existing telehomecare and telephone triage services and increase the use of e-Consult to support access to palliative care support. Technology-facilitated access to care is essential for First Nations, Inuit, and Métis communities.
- Safe application and management of "symptom relief kits" adopted by community nurses providing palliative care can support pain and symptom management for people who are approaching end of life in home, community care, and long-term care settings. Leverage existing protocols and processes for appropriate disposal and return of unused medications.

Integrating the Quality Standard into Practice Access to Care (continued)

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Gap: continued from page 9

Adoption Considerations (continued):

- Health care providers and organizations can consider using video remote interpreting services to support medical interpretation required at point of care.
- The Developing Palliative Care Programs in First Nations Communities: A Workbook can support First Nations communities in developing local palliative care programs.
- The Final Report of the First Nations Advisory Committee (2017) mentions the following:
 - First Nations communities should play a role in developing resources to support First Nations patients and caregivers to increase awareness and uptake of available palliative care services, including aftercare, bereavement, and spiritual care.
 - There are a few First Nations communities that have their own service delivery infrastructures, some of which are available on-reserve. These services include nursing, personal support work, case management, palliative care, spiritual health, emotional/mental health, aging at home for seniors, and technology-based health. Medical equipment and supplies to support care are also available. Health care providers should leverage these supports to provide culturally safe palliative care for First Nations patients and caregivers.

Integrating the Quality Standard into Practice Coordination of Care

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Gap: There is no coordinated approach to tracking and documenting patient needs, preferences, and goals of care.

Patients and caregivers receive limited guidance and support during care transitions, as care coordinators are not always fully leveraged.

First Nations patients may experience unique challenges when they transition between First Nations reserves and off-reserve health facilities due to inadequate care coordination support caused by jurisdictional barriers.

Recommendations	Quality Statements	Action Needed By	*OPCN Action Plan Alignment	Time Frame
Improve coordinated care by incorporating evidence-based tools	1: Identification and Assessment of Needs	OPCN	C1 and C7; C1 refers to early identification tools only	Medium term
for early identification, health care consent, advance care planning, goals of care, and individualized care plans into existing digital health information systems.	3: Advance Care Planning – Substitute Decision-Maker			
	4: Goals of Care Discussions and Consent			
	5: Individualized Person- Centre Care Plan			
	11: Setting of Care and Place of Death			
	10: Transitions in Care			

Integrating the Quality Standard into Practice Coordination of Care (continued)

*OPCN Action Plan Alignment:

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Gap (continued): There is no coordinated approach to tracking and documenting patient needs, preferences, and goals of care.

Patients and caregivers receive limited guidance and support during care transitions, as care coordinators are not always fully leveraged.

First Nations patients may experience unique challenges when they transition between First Nations reserves and off-reserve health facilities due to inadequate care coordination support caused by jurisdictional barriers.

Recommendations	Quality Statements	Action Needed By	*OPCN Action Plan Alignment	Time Frame
With the support of Hospice Palliative Care Ontario, ensure organizational policies and forms related to advance care planning, goals of care, and consent reflect the Ontario legal framework.	See previous page	Health care organizations	A3	Immediate
Ensure palliative care needs are included in the broader approach in order to optimize care coordination.	See previous page	LHINs	N/A	Medium term

Adoption Considerations:

- Technology solutions currently in use for Health Links patients with complex conditions can be leveraged to support care coordination. As well,
 the coordinated care plan used across LHINs as part of the common digital solution can support patients who might benefit from palliative care.
- Care coordinators must be trained to provide culturally safe, trauma-informed care to assist in the coordination and provision of the broad range of palliative care services available.
- Patients and caregivers from the First Nations, Inuit, and Métis communities may have unique needs during the decision-making and care-planning process. Providers may have to allow extra time for patients and caregivers to consult with their community of elders.
- Engage local law enforcement and coroners to support communities in providing end-of-life care at home. This is particularly important to support cultural considerations for dying at home processes (Final Report of the First Nations Advisory Committee, 2017).

Education and Training

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Gap: Knowledge gaps in palliative care have been identified in many areas, including:

- · Palliative care philosophy
- · Basic competency for pain and symptom management
- · Appropriate and safe prescribing of pain medications
- · Competency in addressing cultural needs
- Competency in engaging in conversations about palliative care, a person's prognosis, their wishes and goals for care, and end of life
- The distinction and connection between advance care planning, goals of care, and health care consent
- The role of substitute decision-makers and power of attorney for personal care.

Providers, patients, and families/caregivers may not be aware of available resources relating to palliative care.

Recommendations	Quality Statements	Action Needed By	*OPCN Action Plan Alignment	Time Frame
Incorporate the quality standard	1: Identification and Assessment of Needs	OPCN	F4 and F6	Medium term
into the Hospice Palliative Care Ontario competencies, and work with academic institutions and	3: Advance Care Planning – Substitute Decision-Maker			
regulatory bodies to embed	4: Goals of Care Discussion and Consent			
this quality standard into health professional curricula.	6: Management of Pain and Other Symptoms			
	8: Education for Patients, Substitute Decision-Makers, Families, and Caregivers			
	11: Setting of Care and Place of Death			
	13: Education for Health Care Providers and Volunteers			

Education and Training (continued)

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Gap (continued): Knowledge gaps in palliative care have been identified in many areas, including:

- Palliative care philosophy
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- Competency in addressing cultural needs
- Competency in engaging in conversations about palliative care, a person's prognosis, their wishes and goals for care, and end of life
- The distinction and connection between advance care planning, goals of care, and health care consent
- The role of substitute decision-makers and power of attorney for personal care.

Providers, patients, and families/caregivers may not be aware of available resources relating to palliative care.

Recommendations	Quality Statements	Action Needed By	*OPCN Action Plan Alignment	Time Frame
Identify existing patient and caregiver educational resources, and make them available through a province-wide communications platform.	See previous page	OPCN	A1-A3	Medium term
Ensure health care professionals in all care settings have access to team-based learning to address knowledge gaps and cultural sensitivities.	See previous page	OPCN	F	Medium term
Disseminate education opportunities and	See previous page	OPCN	A1-A3; some gaps will be	Immediate
standardized resources to providers, patients, families, and caregivers.		Hospice Palliative Care Ontario	addressed by action items in section F ("Building Provider Competencies in Hospice Palliative Care")	

Education and Training (continued)

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- The distinction and connection between advance care planning, goals of care, and health care consent
- The role of substitute decision-makers and power of attorney for personal care.

Providers, patients, and families/caregivers may not be aware of available resources relating to palliative care.

Adoption Considerations:

- Education materials for patients and caregivers should be offered in different languages.
- Education programs should be competency-based and should include culturally safe and trauma-informed components. The education programs should be developed to support team-based palliative care practice and paired with mentorship opportunities, tools, and resources to support adoption.
- Leverage existing programs, resources, and community-based initiatives to support education and training for health care providers, such as:
 - Hospice Palliative Care Ontario's Health Care Consent and Advance Care Planning Community of Practice
 - Electronic Health Care Consent, Advance Care Planning, and Goals of Care Reference Guide e-learning modules offered by Hospice Palliative Care Ontario
 - The MOHLTC-funded Palliative Pain and Symptom Management Consultation Program (LHIN-wide)
 - Learning Essential Approaches to Palliative Care (LEAP) by Pallium Canada
 - Palliative Care Toolkit for Aboriginal Communities by Cancer Care Ontario
 - Aboriginal Relationship and Cultural Competency courses offered by Cancer Care Ontario
 - The Ontario College of Family Physicians Palliative Care and End-of-Life Care (PEoLC) Network

Education and Training (continued)

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Gap (continued): Knowledge gaps in palliative care have been identified in many areas, including:

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- Competency in engaging in conversations about palliative care, a person's prognosis, their wishes and goals for care, and end of life
- The distinction and connection between advance care planning, goals of care, and health care consent
- The role of substitute decision-makers and power of attorney for personal care.

Providers, patients, and families/caregivers may not be aware of available resources relating to palliative care.

Adoption Considerations (continued):

- The Advance Care Panning toolkit developed under the guidance of the Barrie Area Native Advisory Circle (BANAC)
- Various resources and tools that are available through the Improving End-of-Life Care in First Nations Communities project at Lakehead University.
- Leverage existing programs, resources and community-based initiatives to support education and training for patients, caregivers, families, and volunteers, such as:
 - Advocacy Centre for the Elderly
 - Speak Up Ontario
 - Educational resources found at livingmyculture.ca
 - Hospice Palliative Care Ontario's Hospice Volunteer Training program.
- Caregiver e-learning modules offered by Hospice Palliative Care Ontario.

Policy and System Planning

The recommendations for adoption include those needed at the system level. In accordance with Health Quality Ontario's mandate, set out in the *Excellent Care for All Act*, the board of directors has formally provided the following recommendations about the *Palliative Care* quality standard to the Minister of Health and Long-Term Care.

Re	ecommendations	Time Frame
1.	Expand equitable and timely access to 24/7 home- and community-based supports for patients in accordance with their needs.	Immediate
2.	Collaborate with the Ontario Palliative Care Network to support the multi-year implementation of the action plan.	Immediate
3.	Make palliative and end-of-life care a focus for implementation in the provincial levels-of-care framework currently in development for home and community care.	Medium term
4.	Use recommendations from the Ontario Palliative Care Network's work on models of care to inform resource allocation for team-based service delivery.	Medium term
5.	Collaborate with the federal government to eliminate jurisdictional barriers, including funding gaps in the provision of palliative care, for Indigenous communities.	Medium term

Measurement and Reporting

In conjunction with the OPCN, Health Quality Ontario will develop a monitoring and evaluation plan for these recommendations as part of the broader quality standards evaluation. This plan may require the development of measures and/or a resource plan to support data collection and monitoring. The evaluation will include the following components:

- Identify gaps and prioritize areas for improvement. For this
 quality standard, the following outcome indicators are aligned
 with OPCN's system-level measures and will be monitored
 through available public reporting:
 - Percentage of people who receive the following in their last month of life:
 - Home care services (any home care and palliative-specific home care) (measurable)
 - Health care provider home visits (currently only physician home visits are measurable)
 - Hospice care (in development).
 - Percentage of people who had one or more emergency department visits in their last month of life (measurable).
 - Percentage of deaths that occurred in:
 - Hospitals, including in-patient care, emergency department, complex continuing care, palliative care beds (measurable, with the exception of palliative care beds)

- Long-term care homes (measurable)
- The community, which may include the home, hospice residence, retirement home, or assisted living (measurable).

In addition, the following indicators may be monitored through Quality Improvement Plans (QIPs):

- Percentage of caregivers of people who died of a progressive life-limiting illness who rated the overall care received by the patient in the last 3 months of life as excellent, very good, good, fair, or poor (measurable)
- Percentage of people receiving palliative care services for whom a CaregiverVoice survey was completed (in development).
- 2. Monitor the uptake of the recommendations for adoption.

The Ontario Quality Standards Committee will receive annual updates on the progress of the recommendations and review any additional measurement that may be needed to assess impact.

Appendix A: Process and Methods for Developing the Recommendations for Adoption

The development of the recommendations for adoption involved extensive consultation with stakeholders across the province from a variety of professional roles and perspectives. During the public consultation process, we received 126 responses and considered them in the development of these recommendations.

The following organizations and groups were consulted in the development of these recommendations:

- OPCN Executive Oversight
- OPCN Partnership Advisory Council
- OPCN Implementation Advisory Council
- OPCN Clinical Advisory Council

Note: In November 2017, Health Quality Ontario conducted eight interviews with front-line clinicians, care coordinators, Aboriginal Navigators, and Regional Aboriginal Cancer Leads who serve Indigenous communities across Ontario. This engagement was informed by the Theoretical Domains Framework, which uses 14 domains (knowledge, skills, attitude, etc.) to identify barriers to behavioural change and/or the ability to put the quality standard into practice. We used the results of these interviews to inform the gaps and recommendations outlined in this document.

Appendix B: Further Information on Equity Considerations

Language

Ensure access to palliative care services in a person's preferred language.

Address linguistic needs for advance care planning, goals of care discussions, and informed consent.

Culture

Consider the needs of various cultural, faith-based, and linguistic groups; vulnerable populations; and Indigenous communities at the end of life, and provide culturally sensitive services.

Consider where conversations related to care plans should take place, as some patients and caregivers prefer not to have this conversation in a clinical setting. Other considerations to note:

- Individuals may often leave their communities and receive palliative care far from family supports
- Current access to culturally safe long-term care supports and services is inadequate
- There is a lack of culturally appropriate palliative care and accommodation of traditional practices (e.g., appropriate space for traditional practices)
- There are few resources to build palliative care capacity for caregivers and front-line workers.

Adopt culturally appropriate pain management tools and resources.

APPENDIX B CONTINUED

Socioeconomics

Ensure homeless and vulnerably housed individuals have access to palliative care services.

Other

Acknowledge the following groups may have unique needs when accessing palliative care services:

- People living with dementia, cognitive impairment, or learning disabilities
- Refugees and undocumented communities
- Patients living in prison and correctional facilities
- Members of the LGBTQ community.

Appendix C: Summary Recommendations for Health Sector Organizations and Other Entities

Ontario Palliative Care Network	Time Frame*
The Regional Palliative Clinical Co-Leads should work with health care organizations to assess the care that is being provided against the quality standard, and use the quality statements, related indicators, and quality improvement science to make improvements to care.	Medium term
Develop a provincial strategy to support person-centred decision-making. This includes developing and updating resources for advance care planning, goals of care, and health care consent in alignment with Ontario's legal framework and this quality standard.	Long term
Develop a provincial performance framework to align data collection and measurement across the system and support the province-wide implementation of the CaregiverVoice survey to measure caregiver experiences.	Long term
Establish a mechanism to help patients and caregivers understand the services that are available and develop a care pathway to meet their needs.	Medium term
Establish a consistent approach to early identification and assessment of needs using evidence-based tools and data sets.	Medium term
Develop flexible care models that address palliative care needs and support where the patient wishes to receive care. This is particularly important for marginalized and vulnerable populations.	Medium term
Develop an appropriate care pathway to improve caregivers' access to respite programs, psychosocial and spiritual care, bereavement services, and supports for caregivers.	Medium term

APPENDIX C CONTINUED

 Together with health care providers and organizations, conduct capacity planning for community-based palliative care supports: Develop a health human resource plan in each LHIN to support the provision of 24/7 palliative support. Map spiritual and psychosocial resources, respite services, bereavement supports, and volunteer-led initiatives available in each LHIN, including services offered by regulated and unregulated health care professionals. Depending on the availability of services, integrate psychosocial aspects of care into daily care practice and develop a standardized referral process for spiritual and psychosocial services. 	Immediate
Continue to engage with First Nations, Inuit, and Métis communities, on- and off-reserve, to identify gaps in palliative care; address the identified gaps related to palliative care as stated in the <i>Final Report of the First Nations Advisory Committee</i> (2017).	Immediate
Continue to engage with Francophone communities to identify gaps in palliative care.	Immediate
Improve coordinated care by incorporating evidence-based tools for early identification, health care consent, advance care planning, goals of care, and individualized care plans into existing digital health information systems.	Medium term
Incorporate the quality standard into the Hospice Palliative Care Ontario competencies, and work with academic institutions and regulatory bodies to embed this quality standard into health professional curricula.	Medium term
Identify existing patient and caregiver educational resources, and make them available through a province-wide communications platform.	Medium term
Ensure health care professionals in all care settings have access to team-based learning to address knowledge gaps and cultural sensitivities.	Medium term
Disseminate education opportunities and standardized resources to providers, patients, families, and caregivers with coalition members.	Immediate

APPENDIX C CONTINUED

Hospice Palliative Care Ontario	Time Frame*
Disseminate education opportunities and standardized resources to providers, patients, families, and caregivers with coalition members.	Immediate
Health Care Providers and Organizations	Time Frame*
Assess the care being provided against the quality standard using Health Quality Ontario's <u>Getting Started Guide</u> , and refer to the <u>action plan template</u> and the <u>measurement guide</u> for this quality standard as tools to support quality improvement.	Immediate
Establish a consistent approach to early identification and assessment of needs using evidence-based tools and data sets.	Medium term
Together with OPCN Regional Palliative Care Networks, conduct capacity planning for community-based palliative care supports:	Long term
1. Develop a health human resource plan in each LHIN to support the provision of 24/7	
 palliative support. Map spiritual and psychosocial resources, respite services, bereavement supports, and volunteer-led initiatives available in each LHIN, including services offered by regulated and unregulated health care professionals. 	
3. Based on the availability of services, integrate psychosocial aspects of care into daily care practice and develop a standardized referral process for spiritual and psychosocial services.	
With the support of Hospice Palliative Care Ontario, ensure organizational policies and forms related to advance care planning, goals of care, and consent reflect the Ontario legal framework.	Immediate

APPENDIX C CONTINUED

Local Health Integration Networks	Time Frame*
Ensure palliative care needs are included in the broader approach in order to optimize care coordination.	Medium term
*Three time frames for adoption are referenced: immediate (less than 1 year); medium term (1–3 years); and long term (more than 3 years).	



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LET'S CONTINUE THE CONVERSATION











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