

QUALITY STANDARDS

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# Palliative Care

## Care for Adults With a Serious Illness

2024 UPDATE



# Scope of This Quality Standard

This quality standard addresses palliative care for adults with a serious illness, and for their family and care partners. It focuses on palliative care in all health settings, for all health disciplines, and in all health sectors. It includes information about general palliative care that applies to all health conditions. Palliative care can benefit individuals and their care partners as early as at the time of diagnosis of a serious illness through the end of life and bereavement.

A serious illness is a health condition that can lead to death and can affect a person's daily function or quality of life, or that places excessive strains on care partners.<sup>1</sup> The goal of palliative care is to relieve pain and suffering, and to improve a person's quality of life.

Other condition-specific quality standards address palliative care, including those on [heart failure](#)<sup>2</sup> and [chronic obstructive pulmonary disease](#).<sup>3</sup>

Although this quality standard includes information that could apply to infants, children, and youth, a separate palliative care quality standard is being considered for these populations. This document does not address medical assistance in dying, although people who choose medical assistance in dying should receive high-quality palliative care. Health care professionals are expected to manage all requests for medical assistance in dying in accordance with the expectations set out by their regulatory colleges. Health care professionals should refer to their regulatory colleges for more information and guidance on medical assistance in dying.

## What Is a Quality Standard?

Quality standards outline what high-quality care looks like for conditions or processes where there are large variations in how care is delivered, or where there are gaps between the care provided in Ontario and the care patients should receive. They:

- Help patients, families, and care partners know what to ask for in their care
- Help health care professionals know what care they should be offering, based on evidence and expert consensus
- Help health care organizations measure, assess, and improve their performance in caring for patients

Quality standards and their accompanying patient guides are developed by Ontario Health, in collaboration with health care professionals, patients, and care partners across Ontario.

For more information, contact [QualityStandards@OntarioHealth.ca](mailto:QualityStandards@OntarioHealth.ca).

# Quality Statements to Improve Care: Summary

These quality statements describe what high-quality palliative care looks like for adults with a serious illness.

## **Quality Statement 1: Identification and Assessment of Needs**

People with a serious illness have their palliative care needs identified early through a comprehensive and holistic assessment.

## **Quality Statement 2: Timely Access to Palliative Care Support**

People with identified palliative care needs have access to palliative care support 24 hours a day, 7 days a week.

## **Quality Statement 3: Advance Care Planning – Substitute Decision-Maker**

People with a serious 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.

## **Quality Statement 4: Goals-of-Care Discussions and Consent**

People with identified palliative care needs or their substitute decision-makers have discussions with their interprofessional 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 the treatment options so the person or their substitute decision-maker has the information they need to give or refuse consent to treatment.

### **Quality Statement 5: Individualized, Person-Centred Care Plan**

People with identified palliative care needs collaborate with their primary care provider and other health care professionals to develop an individualized, person-centred care plan that is reviewed and updated regularly.

### **Quality Statement 6: Management of Pain and Other Symptoms**

People with identified palliative care needs have their pain and other symptoms managed effectively, in a timely manner.

### **Quality Statement 7: Psychosocial Aspects of Care**

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

### **Quality Statement 8: Education for People With a Serious Illness, Substitute Decision-Makers, Families, and Care Partners**

People with a serious illness, their future substitute decision-maker, their family, and their care partners are offered education about palliative care and information about available resources and supports.

### **Quality Statement 9: Care Partner Support**

Families and care partners 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.

### **Quality Statement 10: Transitions in Care**

People with identified palliative care needs experience seamless transitions in care that are coordinated effectively among settings and health care providers.

### **Quality Statement 11: Setting of Care and Place of Death**

People with identified palliative care needs, their substitute decision-maker, their family, and their care partners have ongoing discussions with their health care professionals about their preferred setting of care and place of death.

### **Quality Statement 12: Interprofessional Team-Based Care**

People with identified palliative care needs receive integrated care from an interprofessional team, which includes volunteers.

### **Quality Statement 13: Education for Health Care Providers and Volunteers**

People receive palliative care from health care providers and volunteers who possess the appropriate knowledge and skills to deliver high-quality palliative care.

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# 2024 Summary of Updates

In 2023/24, we completed a review of the evidence to capture new or updated clinical practice guidelines and health technology assessments published since the original release of this quality standard in 2018. This update aligns with the most recent clinical evidence, and with current practice in the Ontario landscape. Below is a summary of changes to the overall quality standard:

- Updated the links, secondary references, and data sources where applicable
- Updated the formatting to align with current Ontario Health design and branding
- Revised the accompanying resources (e.g., patient guide, placemat, case for improvement slide deck, technical specifications) to reflect changes to the quality standard and align with current Ontario Health design and branding
- Updated the Scope of This Quality Standard section to include information about other condition-specific quality standards that address palliative care, including those on [heart failure](#)<sup>2</sup> and [chronic obstructive pulmonary disease](#)<sup>3</sup>
- Updated the data in the Why This Quality Standard Is Needed section, the case for improvement slide deck, and the data tables, using information from the Ontario Palliative Care Network (part of Ontario Health)
- Updated important terminology:
  - Changed the target population from *people living with a progressive, life-limiting illness* to *people with a serious illness*, based on feedback from the Ontario Palliative Care Network and to align with the [Compassionate Care Act 2020](#)<sup>4</sup> and the [Ontario Provincial Framework for Palliative Care](#)<sup>1</sup>
  - Replaced *interdisciplinary* with *interprofessional* to align with advancement of the literature on interprofessional education and collaborative practice from the World Health Organization<sup>5</sup> and the Registered Nurses' Association of Ontario,<sup>6</sup> and with the need for common terminology in the interprofessional field<sup>7</sup>
  - Replaced *caregiver* with *care partner* to align with Ontario Health preferred terminology

Below is a summary of changes to specific quality statements:

- Quality statement 1: Added a definition of *serious illness*
- Quality statements 4 and 12: Added a definition of *interprofessional health care team* and *interprofessional team* respectively to align with definitions from Interprofessional Research Global<sup>7</sup> and the World Health Organization.<sup>5</sup> In quality statement 4 only, removed definitions for *family* and *caregiver*
- Quality statement 10: Added a mention of the [Transitions Between Hospital and Home](#) quality standard<sup>8</sup>

# Why This Quality Standard Is Needed

Palliative care refers to the relief of suffering and improvement of the quality of living and dying, using a holistic approach.<sup>1,9</sup> Palliative care addresses people's physical, psychological, social, spiritual, and practical needs, as well as their associated expectations, hopes, and fears. It helps people with a serious illness and their family prepare for and manage end-of-life choices, the process of dying, and coping with loss and grief.<sup>9,10</sup> Palliative care does not focus just on end-of-life care; a palliative approach to care can begin upon the diagnosis of a serious illness. People can receive palliative care while actively receiving treatment for their disease.

Despite the clear benefits of palliative care, there are many gaps in its delivery in Ontario, including access to palliative care services. Of the 103,400 community-dwelling people who died in Ontario in 2021/22, approximately 67,700 (65%) received palliative care services on at least 1 occasion in their last 12 months of life, and a third (33.8%) received physician home visits, palliative home care, or both in their last 90 days of life (Regional Profiles Tool and Performance Summary Report, Ontario Palliative Care Network, 2023). Receiving palliative home care has been associated with a 50% reduction in the likelihood of dying in hospital.<sup>10-12</sup> Furthermore, more than half (53.2%) of people who died in Ontario had unplanned visits to the emergency department in their last month of life in 2021/22 (Performance Summary Report, Ontario Palliative Care Network, 2023).

Whether or not people are able to die in the place they choose also reveals gaps in the provision of palliative care across the province. In surveys of patients and care partners, most say they would prefer to die at home.<sup>10,12</sup> And yet, of the approximately 117,400 people who died in 2021/22, 49.2% died in hospital (Performance Summary Report, Ontario Palliative Care Network, 2023). Increased access to palliative-specific home care and home visits from physicians could reduce the number of people who die in hospital.<sup>13</sup>

Equity is also an issue in the delivery of palliative care. In 2022/23, people living in neighbourhoods with the highest levels of material deprivation (a dimension of marginalization) were less likely to receive physician home visits and/or palliative home care in their last 90 days of life (23.1%) than people living in neighbourhoods with the lowest levels of material deprivation (32.3%) (Performance Summary Report, Ontario Palliative Care Network, 2023).

In addition to these equity issues, there is also a need for culturally responsive care to meet the diverse needs of all Ontarians. This includes access to culturally appropriate and safe palliative care across urban, rural, and remote communities, and it includes various cultural, faith, and linguistic groups, as well as vulnerable populations.<sup>14</sup>

The 13 quality statements that make up this quality standard are based on the best available evidence and guided by expert consensus from health care providers and people with lived experience. The statements provide guidance for areas identified by the Ontario Palliative Care Network and the Palliative Care Quality Standard Working Group as having high potential for improvement in the way palliative care is currently provided. Each statement has accompanying indicators to help health care providers and organizations measure the quality of the care they provide and includes details about



how successful delivery can improve palliative care and quality of life for people with a serious illness, their family, their care partners, health care providers, and health services at large.

## Measurement to Support Improvement

Ontario Health has worked with the Ontario Palliative Care Network to ensure that selected measures for this quality standard are aligned with provincial measurement initiatives.

The Palliative Care Quality Standard Working Group identified 4 overarching indicators to monitor the progress being made toward improving care for adults with a serious illness in Ontario.

### Indicators That Can Be Measured Using Provincial Data

- Percentage of people who receive care in their last 12 months, 3 months, and 1 month of life:
  - Home care services (any home care and palliative-specific home care)
  - Health care provider home visits (currently only physician home visits are measurable)
  - Hospice care (currently not measurable provincially; locally measurable)
- Percentage of people who had 1 or more unplanned emergency department visits in their last 12 months, 3 months, and 1 month of life
- Percentage of deaths that occurred in:
  - Hospitals
    - Acute inpatient care
    - Emergency department
    - Complex continuing care
    - Inpatient rehabilitation
    - Palliative care beds (currently not measurable provincially; locally measurable)
  - Long-term care homes
  - The community (may include home, hospice residence, retirement home, or assisted-living home)
- Percentage of people who receive palliative care (or their care partners) who rated the overall care received in their last 12 months, 3 months, and 1 month of life as excellent

# Local Measurement

You may want to assess the quality of palliative care you provide to people. You may also want to monitor your own quality improvement efforts. It may be possible to do this using your own clinical records to measure the indicators above, or you might need to collect additional data.

In addition, each quality statement within this standard is accompanied by 1 or more indicators. These indicators are intended to guide the measurement of quality improvement efforts related to the implementation of the quality statement.

# Quality Statement 1: Identification and Assessment of Needs

**People with a serious illness have their palliative care needs identified early through a comprehensive and holistic assessment.**

Sources: Institute for Clinical Systems Improvement, 2020<sup>15</sup> | National Institute for Health and Care Excellence, 2015<sup>16</sup> | National Institute for Health and Care Excellence, 2019<sup>17</sup> | Registered Nurses' Association of Ontario, 2011<sup>18</sup> | Registered Nurses' Association of Ontario, 2020<sup>6</sup>

## Definitions

**Serious illness:** A serious illness is a health condition that can lead to death and can affect a person's daily function or quality of life, or that places excessive strains on care partners.<sup>1</sup> Examples of illnesses that require a palliative approach to care include cancer; Alzheimer disease and other types of dementia; heart failure; chronic obstructive pulmonary disease; kidney disease; and cirrhosis of the liver.<sup>19</sup> The frail elderly can also benefit from a palliative approach to care.

**Palliative care needs:** Palliative care needs can stem from any part of a person's full range of needs (physical, psychological, social, linguistic, cultural, legal, ethical, or spiritual) at any stage of illness. The goal of palliative care is to help people achieve their best possible quality of life in the face of a serious illness.

**Identified early:** Identifying the need for palliative care can occur as early as the time of diagnosis of a serious illness. Palliative care is not limited to the end-of-life phase, and it is not restricted to specific diseases or conditions.

**Comprehensive and holistic assessment:** This includes a full examination of the domains of care associated with illness and bereavement, including<sup>6,18,20</sup>:

- Disease management
- Physical
- Psychological
- Social
- Cultural
- Legal
- Ethical
- Spiritual
- Practical

- End-of-life
- Loss, 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 sociocultural context, and initial assessments should include inquiry about a person's mother tongue and language of preference.

## Rationale

Palliative care focuses on the person and their family, and on enhancing their quality of life throughout their illness, not just at the end of life.<sup>21,22</sup> The initiation of palliative care should not be delayed for people with a serious illness if they have physical, psychological, social, or spiritual needs during treatment.

General considerations for identifying people who would benefit from palliative care include the following: diagnosis of a serious illness; disease progression; functional decline; presence of pain or other symptoms; or other effects on their full range of needs.<sup>15,19</sup> A comprehensive, holistic assessment allows health care professionals to determine the physical, psychological, social, linguistic, cultural, legal, ethical, and spiritual needs of people with a serious illness and their family or care partners, and the services required to meet those needs. The initiation of palliative care is not determined by prognosis; it can begin as early as the time of diagnosis of a serious illness, and it can be initiated during treatment.<sup>15</sup>

Assessment can be conducted by any knowledgeable and skilled member of the interprofessional health care team (see quality statement 4). After the initial assessment, palliative care needs should be reassessed regularly, because they can change over time.

## What This Quality Statement Means

### For People With a Serious Illness, Families, and Care Partners

Your care team should assess what palliative care or supports you need:

- They should ask questions about your physical and mental health, your support system, and any other needs you feel you have, to understand how best to help you
- They should assess your pain and other health concerns, and manage them quickly and effectively
- They should assess your mental, emotional, social, cultural, and spiritual well-being
- They should ask your family members and care partners about the help they need

### For Clinicians

Assess people with a serious illness to determine whether they would benefit from palliative care. Perform and document a comprehensive, holistic assessment that considers the individual's

diagnosis, disease progression, functional decline, presence of pain or other symptoms, and other effects on their full range of needs. Assessment should be repeated regularly.

### For Organizations and Health Services Planners

Ensure that systems, processes, and resources are in place in all health settings for clinicians to identify and assess people’s palliative care needs. This includes access to screening or assessment tools and timely access to palliative care.

## Quality Indicators: How to Measure Improvement for This Statement

- Percentage of people with identified palliative care needs who have a documented assessment of their palliative care needs, including physical, psychological, social, linguistic, cultural, legal, ethical, spiritual, and other needs
- Number of days between receiving first palliative care service and death
- Evidence of locally adopted tools to:
  - Identify people in need of palliative care
  - Assess their needs

Measurement details for these indicators, as well as overarching indicators to measure improvement for the goals of the entire quality standard, are available in the [technical specifications](#).

# Quality Statement 2: Timely Access to Palliative Care Support

People with identified palliative care needs have access to palliative care support 24 hours a day, 7 days a week.

Source: National Institute for Health and Care Excellence, 2019<sup>17</sup>

## Definition

**Palliative care support:** Palliative care support consists of health advice, resources, treatment, and other assistance provided by the health care team to meet a person's palliative care needs. Support should be culturally relevant, and it can come in many forms, including a telephone call with a registered nurse, a number to call when pain or other symptoms are not well managed, or a home visit from a primary care or palliative care provider.

## Rationale

People with a serious illness may have complex needs that require advice, resources, treatment, or support, and those needs may change over time.<sup>23</sup> The needs of people with a serious illness (and those of their families and care partners) often arise during the evening, overnight, or on the weekend. Palliative care support should be available whenever the person needs it, at any time of day or night. Appropriate palliative care support is determined based on a person's individual needs and does not necessarily mean continuous, around-the-clock care or services.

The availability of coordinated and integrated palliative care support from a knowledgeable and skilled interprofessional care team is important to meet patient, family, and care partner needs.<sup>23</sup> With education to build capacity, palliative care needs can be addressed by primary care providers through primary-level palliative care (a palliative approach to care). Some complex palliative care needs may require consultation and clinician-to-clinician support (shared care) or may require greater involvement or transfer to specialist palliative care teams. All people, regardless of their diagnosis, prognosis, or location, should be able to access palliative care support appropriate to their needs at any time.

## What This Quality Statement Means

### For People With a Serious Illness, Families, and Care Partners

Palliative care support should be available for you whenever you need it, day or night.

### For Clinicians

Ensure that people with identified palliative care needs have access to palliative care support 24 hours a day, 7 days a week, as needed.

### For Organizations and Health Services Planners

Ensure that systems, processes, and resources are in place so that people with identified palliative care needs can receive palliative care support whenever they need it, at any time of day or night.

## Quality Indicators: How to Measure Improvement for This Statement

- Local availability of palliative care support (as defined above) that is accessible 24 hours a day, 7 days a week
- Percentage of people with identified palliative care needs (or their care partners) who state that they are able to receive community palliative care support, including after-hours care, when needed

Measurement details for these indicators, as well as overarching indicators to measure improvement for the goals of the entire quality standard, are available in the [technical specifications](#).

# Quality Statement 3: Advance Care Planning – Substitute Decision-Maker

People with a serious 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.

Sources: Institute for Clinical Systems Improvement, 2020<sup>15</sup> | National Institute for Health and Care Excellence, 2015<sup>16</sup> | National Institute for Health and Care Excellence, 2019<sup>17</sup> | Ontario Health Technology Advisory Committee, 2014<sup>24</sup>

## Definitions

**Advance care planning:** Advance care planning is ongoing and dynamic, because a person’s preferences may change over time as their health changes.<sup>9</sup> It may be initiated at any point, and may involve people who are currently healthy. In advance care planning, a mentally capable person identifies their substitute decision-maker by confirming the automatic substitute decision-maker from [the hierarchy list in the \*Health Care Consent Act\*](#) or by choosing someone else using a “Power of Attorney for Personal Care.”<sup>25</sup> The hierarchy outlined in Ontario’s *Health Care Consent Act* is as follows (note: numbers 1 to 3 occur if people are legally appointed to these roles):

1. Guardian of the person with authority for health decisions
2. Attorney for personal care with authority for health decisions
3. Representative appointed by the Consent and Capacity Board
4. Spouse or partner
5. Child or parent or a children’s aid society (person with right of custody)
6. Parent with right of access
7. Sibling
8. Any other relative
9. Office of the Public Guardian and Trustee

The capable person then shares their wishes, values, and beliefs with the substitute decision-maker and discusses how they would like to be cared for if they become mentally incapable of giving or refusing consent.

**Substitute decision-maker:** A substitute decision-maker is a person who makes care and treatment decisions on another person’s behalf if or when that person becomes mentally incapable of making decisions for themselves.<sup>9</sup> The substitute decision-maker makes decisions based on their



understanding of the person's wishes, or, if these are unknown or not applicable, makes choices that are consistent with the person's known values and beliefs and in their best interests.

**Wishes, values, and beliefs:** A person's wishes, values, and beliefs convey who the person is, how they would make choices for themselves, what they think is important, and what would influence their decision-making.<sup>26,27</sup> Values are the principles on which a person's morality and/or spirituality is based. If a person is mentally incapable of making choices for themselves, the substitute decision-maker (not the health care professional) interprets their wishes.

**Health care consent:** Health care consent refers to an informed and contextualized decision involving a mentally capable person and a health care provider as outlined in the Ontario *Health Care Consent Act*.<sup>25</sup> Health care providers who propose a treatment must obtain informed consent from a mentally capable patient (or their substitute decision-maker, if they do not have the mental capacity). A discussion about consent must address the person's present condition; available treatment options; risks, benefits, side effects, and alternatives to treatment; and what would happen without the proposed treatment.<sup>9</sup>

**Capacity or mental capacity:** Under Ontario's *Health Care Consent Act*, a person is capable with respect to a health care decision if they have the ability to understand the information that is needed to make a decision and have the ability to appreciate the consequences of the decision or lack of decision.<sup>9,25</sup> Capacity is issue- or task-specific.<sup>28</sup> A person's specific capacity to understand information and appreciate the decisions that must be made should be respected so that their mental capacity for a specific health care decision is recognized.<sup>28</sup> A person may be capable with respect to making some health care decisions, but incapable with respect to others.<sup>25</sup> If a person is incapable with respect to making a health care decision, the substitute decision-maker can give or refuse consent on the person's behalf.<sup>25</sup>

## Rationale

Advance care planning includes understanding and confirming a future substitute decision-maker who can communicate a person's wishes, values, and beliefs about future health care, and make decisions when that person is no longer mentally capable of doing this for themselves. The Ontario *Health Care Consent Act* outlines a hierarchical list of people who would automatically be considered a substitute decision-maker when a person is mentally incapable of making decisions about their own care.<sup>25</sup> If a person is not satisfied with their automatic substitute decision-maker, they can formally appoint someone else to be their substitute decision-maker using a "Power of Attorney for Personal Care."<sup>29</sup> A "Power of Attorney for Personal Care" is a legal document in which one person gives another person the authority to make personal care decisions on their behalf if they become incapable.<sup>9</sup> A "Power of Attorney for Personal Care" is for personal care decisions (e.g., health care, nutrition, safety). Financial and property decisions are made through a "Continuing Power of Attorney for Property."

Ongoing communication between the person with a serious illness and their substitute decision-maker is important so that the substitute decision-maker is aware of their role and can participate fully as the decision-maker for the person if or when they are no longer able to communicate. The substitute decision-maker follows the person's wishes where they are known, and acts in the person's

best interests if no wishes are known or applicable to the decision to be made.<sup>15</sup> Advance care planning is relevant for every person and family, and these conversations should take place in health and illness. Advance care planning should be revisited regularly as a person’s condition changes.

## What This Quality Statement Means

### For People With a Serious Illness, Families, and Care Partners

Make sure you know who your future substitute decision-maker will be, by Ontario law, if you become mentally incapable of making health decisions. Ontario’s [Health Care Consent Act](#) automatically assigns a substitute decision-maker based on a ranked list.

If the person automatically assigned to be your substitute decision-maker is not the person you want in this role, prepare a legal document called a “Power of Attorney for Personal Care.” It is not enough to tell your care team that you want a different substitute decision-maker.

Once you have confirmed your substitute decision-maker, talk with them regularly about your wishes, values, and beliefs. This will help them make the right decisions for you, if needed. If your wishes change, keep them informed.

### For Clinicians

Ensure that your patients know who the law considers to be their substitute decision-maker(s) and how they can appoint someone else if they wish. Encourage patients to plan for their care – to think about their values, wishes, and beliefs, and then share those with their family and their substitute decision-maker.

### For Organizations and Health Services Planners

Ensure that information and resources are available for people to learn about Ontario laws related to advance care planning, substitute decision-making, and health care consent.

## Quality Indicators: How to Measure Improvement for This Statement

- Percentage of people with identified palliative care needs who know who their future substitute decision-maker is
- Percentage of people with identified palliative care needs who state that they have shared their wishes, values, and beliefs with their substitute decision-maker regarding the kind of health and personal care they would want to receive in the future

Measurement details for these indicators, as well as overarching indicators to measure improvement for the goals of the entire quality standard, are available in the [technical specifications](#).

# Quality Statement 4: Goals-of-Care Discussions and Consent

People with identified palliative care needs or their substitute decision-makers have discussions with their interprofessional 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 the treatment options so the person or their substitute decision-maker has the information they need to give or refuse consent to treatment.

Sources: Institute for Clinical Systems Improvement, 2020<sup>15</sup> | Ontario Health Technology Advisory Committee, 2014<sup>24</sup>

## Definitions

**Substitute decision-maker:** A substitute decision-maker is a person who makes care and treatment decisions on another person's behalf if or when that person becomes mentally incapable of making decisions for themselves.<sup>9</sup> The substitute decision-maker makes decisions based on their understanding of the person's wishes, or, if these are unknown or not applicable, makes choices that are consistent with the person's known values and beliefs and in their best interests.

**Interprofessional health care team:** An interprofessional health care team includes multiple health care providers with different training and skills, the person with a serious illness, and their care partners, all of whom work together to provide care based on a person's care plan (see quality statement 5).<sup>5,7</sup> The composition of the team varies depending on the services needed and may include physicians, nurse practitioners, registered nurses, registered practical nurses, social workers, psychologists, spiritual care providers, pharmacists, personal support workers, dietitians, and volunteers. Interprofessional care occurs when multiple health care professionals with different areas of expertise provide comprehensive health services by working with patients, their care partners, and communities to deliver the highest quality of care across settings.<sup>5,7</sup>

**Goals of care:** A person's goals of care are their overall priorities and health expectations for care; these are based on their personal values, wishes, beliefs, and perception of quality of life, and what they characterize as meaningful and important.<sup>9</sup> Examples of goals of care could be curing the disease, prolonging life, relieving suffering, optimizing quality of life, maintaining control, achieving a good death, and getting support for family and care partners.<sup>30</sup> Goals of care are not the same as health care decisions or consents to treatment.

**Consent to treatment:** Consent to treatment (health care consent) refers to an informed decision involving a mentally capable person or their substitute decision-maker and a health care provider as outlined in the Ontario *Health Care Consent Act*. Health care providers proposing treatment must

obtain informed consent from either a capable person or their substitute decision-maker if they do not have the mental capacity. This discussion must address the present condition (context), available treatment options, risks, benefits, side effects, alternatives to treatment and what would happen without the proposed treatment.

## Rationale

People with a serious illness (and/or their substitute decision-maker) should have discussions with their interprofessional health care team to address the person's goals of care, obtain health care consent, and inform decision-making when illness is advanced.<sup>9</sup> The purposes of discussions about goals of care are to ensure that the person (or their substitute decision-maker, if the person is incapable) understands the serious nature of their illness, and to help the health care team understand the person's values and goals for their care. These discussions are intended to elicit what the patient wants to achieve as a result of treatment or care that may be provided to them, and to help prepare the patient and the provider to engage in subsequent decision-making and the consent process. Goals-of-care discussions will often lead to the development of a plan of treatment and a care plan (see quality statement 5); however, they do not constitute consent to treatment.

Informed consent must be obtained from the person or substitute decision-maker for any treatment or plan of treatment.<sup>15</sup> A plan of treatment is developed by 1 or more health care professionals. It deals with 1 or more health problems, provides for the administration of various treatments or courses of treatments, and may provide for the withholding and withdrawal of treatment in light of the person's current health condition. When individuals lack the capacity to make decisions, health care professionals must work with substitute decision-makers to determine an appropriate course of action.

## What This Quality Statement Means

### **For People With a Serious Illness, Families, and Care Partners**

Your care team should talk with you about your illness and how it could progress. They should also talk with you about your values and goals and your treatment options. These discussions will help you understand your illness, your goals of care, and your treatment options so you can make decisions about your care and provide health care consent.

### **For Clinicians**

Talk with your patients about their illness, prognosis, goals of care, and treatment options. Ongoing discussions are beneficial for ensuring that patients' values, beliefs, and wishes are aligned with the care provided. Providing information to help the patient or their substitute decision-maker provide informed consent and getting informed consent before providing treatment is your legal and ethical duty.

## For Organizations and Health Services Planners

Ensure that health care professionals are given adequate education and training so that they feel equipped to have meaningful conversations with their patients about their illness, prognosis, goals of care, and treatment options, and to fulfil their duty to obtain informed consent.

# Quality Indicators: How to Measure Improvement for This Statement

- Percentage of people with identified palliative care needs who have documented discussions with a health care professional about their goals of care in their medical record
- Percentage of people with identified palliative care needs (or their care partners) who state that discussions with a health care professional about their goals of care helped them to make treatment decisions
- Percentage of people with identified palliative care needs (or their care partners) who state that discussions about goals of care with a health care professional happened at the right time
- Percentage of people receiving palliative care whose informed consent (obtained directly or from the substitute decision-maker) is documented prior to the initiation of a treatment

Measurement details for these indicators, as well as overarching indicators to measure improvement for the goals of the entire quality standard, are available in the [technical specifications](#).

# Quality Statement 5: Individualized, Person-Centred Care Plan

People with identified palliative care needs collaborate with their primary care provider and other health care professionals to develop an individualized, person-centred care plan that is reviewed and updated regularly.

Sources: National Institute for Health and Care Excellence, 2015<sup>16</sup> | National Institute for Health and Care Excellence, 2019<sup>17</sup>

## Definitions

**Individualized, person-centred care:** Individualized, person-centred care consists of care and treatment that is customized for each person based on their values, wishes, goals, and unique health needs.<sup>31</sup> The person with the serious illness drives the care provided; a person-centred approach involves a partnership between patients and their health care professionals.

**Care plan:** A care plan is a written document that describes a person's health needs and goals and the care that will be provided to meet them.<sup>9,26</sup> A care plan is not the same as having a discussion about goals of care. Nor is it a decision or consent to treatment. A care plan is broader and different from a plan of treatment. A plan of treatment is associated with a health care decision and requires informed consent from the patient or substitute decision-maker.

## Rationale

Creating and documenting an individualized, person-centred care plan improves the quality and efficiency of care.<sup>32</sup> Care plans place the patient at the focal point and guide the care that is provided. The use of care plans promotes communication, continuity of care, and coordination of care.<sup>32</sup> The care plan should include the person's goals and wishes; treatment decisions and consents to treatment or a plan of treatment; preferred care setting; current and anticipated care needs; and the resources required to meet those needs.<sup>16</sup> The care plan is documented in the medical record so that all team members have access to the information.<sup>16</sup> The care plan is shared with the patient or their substitute decision-maker. The person's ability to be involved in making decisions may change as their condition changes, and the care plan should be updated accordingly.<sup>16</sup>

# What This Quality Statement Means

## For People With a Serious Illness, Families, and Care Partners

Your care team should work with you to create a care plan that fits your values, wishes, and goals. Your care team should use this plan to provide palliative care that meets your needs. This care plan should be updated as often as you need.

## For Clinicians

Collaborate with people with identified palliative care needs to create and document a care plan that reflects their individual values, wishes, and goals of care. This plan should be created at the start of their care and then reviewed and updated as needed.

## For Organizations and Health Services Planners

Ensure that all health care settings have the tools, systems, processes, and resources in place for health care professionals and people with identified palliative care needs to create, document, and share individualized, person-centred care plans.

# Quality Indicators: How to Measure Improvement for This Statement

- Percentage of people with identified palliative care needs (or their care partners) who state that they worked together with their health care provider to develop a care plan
- Percentage of people with identified palliative care needs (or their care partners) who state that they have had the opportunity to review and update their care plan when they wanted to do so
- Percentage of people with identified palliative care needs who have a documented care plan in their medical record

Measurement details for these indicators, as well as overarching indicators to measure improvement for the goals of the entire quality standard, are available in the [technical specifications](#).



# Quality Statement 6: Management of Pain and Other Symptoms

People with identified palliative care needs have their pain and other symptoms managed effectively, in a timely manner.

Sources: Institute for Clinical Systems Improvement, 2020<sup>15</sup> | National Institute for Health and Care Excellence, 2015<sup>16</sup> | Registered Nurses' Association of Ontario, 2011<sup>18</sup>

## Definition

**Pain and other symptoms:** Pain and other symptoms are the effects of illness or treatment. Common symptoms associated with serious illness may include but are not limited to the following:

- Agitation<sup>16</sup>
- Anxiety<sup>15,18</sup>
- Changes in respiratory patterns and increased secretions<sup>16</sup>
- Constipation<sup>18</sup>
- Dehydration<sup>16</sup>
- Delirium<sup>16,18</sup>
- Depression<sup>15</sup>
- Diarrhea
- Dyspnea<sup>16,18</sup>
- Fatigue
- Nausea<sup>16,18</sup>
- Pain<sup>15,16,18</sup>
- Poor appetite
- Vomiting<sup>16,18</sup>

Pain and other symptoms can also affect activities of daily living (e.g., bathing, mobility, continence).

## Rationale

Management of pain and other symptoms is an important part of high-quality palliative care and an integral component of the individualized care plan.<sup>15,16</sup> It is important to consider nonpharmacological and pharmacological management throughout a person's illness.



Not all patients who receive palliative care will experience the same pain or other symptoms, so it is important to assess the level and range of severity. Possible causes of symptoms, the person's preferences, management of side effects, and the benefits and harms of intervention should also be assessed. If pain or other symptoms are identified, they should be managed promptly and effectively, and any reversible causes should be treated using evidence-based practice.<sup>16</sup>

An example of pain and symptom management in the community involves the use of "symptom relief kits," which are standardized kits designed to provide the nurse and patient with a supply of commonly used palliative care medications.<sup>33-36</sup> Pain and symptom management require ongoing reassessment to ensure the efficacy of any interventions and monitoring for changes.<sup>16</sup>

## What This Quality Statement Means

### For People With a Serious Illness, Families, and Care Partners

Your health care team should assess your pain and other health concerns and manage them quickly and effectively.

### For Clinicians

Assess patients for pain and other symptoms. Ensure the delivery of high-quality management of pain and other symptoms.

### For Organizations and Health Services Planners

Provide adequately resourced systems and services to ensure that health care professionals can conduct pain and symptom assessments and offer nonpharmacological and pharmacological treatments. Ensure that systems, processes, and resources are in place so that patients have access to timely and effective pain and symptom management.

## Quality Indicators: How to Measure Improvement for This Statement

- Percentage of people who receive palliative care who have documented assessments of their pain and other symptoms in their medical record
- Locally adopted appropriate tools to assess pain and other symptoms for people with identified palliative care needs
- Percentage of people who receive palliative care (or their care partners) who rate the level of support to relieve their pain and other symptoms as excellent

Measurement details for these indicators, as well as overarching indicators to measure improvement for the goals of the entire quality standard, are available in the [technical specifications](#).

# Quality Statement 7: Psychosocial Aspects of Care

**People with identified palliative care needs receive timely psychosocial support to address their mental, emotional, social, cultural, and spiritual needs.**

Sources: Institute for Clinical Systems Improvement, 2020<sup>15</sup> | Registered Nurses' Association of Ontario, 2020<sup>6</sup>

## Definitions

**Psychosocial support:** Psychosocial support involves care related to a person's state of mental, emotional, social, cultural, and spiritual well-being.

**Mental and emotional needs:** Mental and emotional needs relate to a person's psychological and emotional well-being. Issues of concern for a person with a serious illness may include fear, worry, insomnia, panic, anxiety, nervousness, paranoia, or lack of energy.<sup>6</sup>

**Social needs:** Social needs relate to a person's relationships with their family, community, and network (friends, acquaintances, and coworkers).<sup>15</sup> Social needs may relate to family structure and location, family dynamics, communication, social and cultural networks, perceived social support, work and school settings, finances, sexuality, intimacy, living arrangements, care partner availability, medical decision-making, access to transportation, medications, equipment and nutrition, community resources, or legal issues. Associated practical needs include pet care, childcare, transportation, or meals.

**Cultural needs:** Cultural needs relate to the beliefs and preferences that come from one's social and ethnic identity. Cultural needs may include linguistic needs, health beliefs and behaviours, traditions, rituals, or cultural barriers to accessing health care.

**Spiritual needs:** Spiritual needs relate to "the way individuals seek and express meaning and purpose, and the way they experience their connection to the moment, to self, to others, to nature, and to the significant or sacred."<sup>15</sup> Spiritual needs may include religious practices or philosophical reflection.

## Rationale

When people face a serious illness, psychosocial issues may go undetected or untreated, and this can affect their quality of life.<sup>15</sup> Pain and other symptoms may be the initial focus of treatment, but psychosocial well-being should also be assessed regularly. A holistic psychosocial assessment can facilitate the identification of any supports a person needs during their illness.

Psychosocial issues can manifest as physical symptoms (e.g., pain, constipation, nausea). Therefore, it is important that health care professionals be aware of a person's total pain and the physiological symptoms that may be an indication of depression and anxiety.<sup>15</sup> The concept of total pain describes the suffering that expands beyond physical pain by encompassing all of a person's physical, psychological, social, spiritual, and practical struggles.<sup>6</sup>

Illness and the prospect of dying affect and can also be affected by the meaning and purpose of a person's life. A focus on spirituality may include questions about meaning, value, and relationships, and can lead to spiritual concerns, questions, or distress. People may draw on their spirituality as they make health care decisions and as they cope with illness and the experience of dying.<sup>15</sup> No single individual is responsible for addressing all psychosocial needs; rather, it requires expertise from an interprofessional team.

## What This Quality Statement Means

### For People With a Serious Illness, Families, and Care Partners

Your care team should assess your mental, emotional, social, cultural, and spiritual well-being. Your needs should be addressed as part of your care plan and according to your wishes, values, and goals of care.

### For Clinicians

Ensure that the overall psychosocial well-being of people with identified palliative care needs is assessed, and that their needs are incorporated into the care plan.

### For Organizations and Health Services Planners

Ensure that resources are available for health care professionals to assess and meet the psychosocial needs of people with identified palliative care needs.

## Quality Indicators: How to Measure Improvement for This Statement

- Percentage of people who receive palliative care who have assessments of their psychosocial needs documented in their medical record
- Percentage of people who receive palliative care (or their care partners) who state that they received timely psychosocial support to address their identified mental, emotional, social, cultural, and spiritual needs
- Percentage of people who receive palliative care (or their care partners) who rated the level of support in addressing their psychosocial needs (mental, emotional, social, cultural, and spiritual) as excellent

Measurement details for these indicators, as well as overarching indicators to measure improvement for the goals of the entire quality standard, are available in the [technical specifications](#).

# Quality Statement 8: Education for People With a Serious Illness, Substitute Decision-Makers, Families, and Care Partners

**People with a serious illness, their future substitute decision-maker, their family, and their care partners are offered education about palliative care and information about available resources and supports.**

Sources: Ontario Health Technology Advisory Committee, 2014<sup>24</sup> | Registered Nurses' Association of Ontario, 2011<sup>18</sup> | Registered Nurses' Association of Ontario, 2020<sup>6</sup>

## Definition

**Education:** Education topics may include symptom management, grief and loss, coping strategies, available community resources, system navigation, patient rights, health decision-making, medication, practical and physical care, death and dying, vigil practices, and care after death.<sup>18,37,38</sup>

## Rationale

For people with a serious illness, their substitute decision-makers, and their family and care partners, education plays a vital role in increasing their knowledge about their care, providing reasonable expectations about illness progression and palliative care, and preparing them for the decisions they will need to make.<sup>18,37</sup> Education can increase a person's sense of self-control and well-being.<sup>37</sup> Education about symptom management and coping strategies improves symptom control for patients at the end of life and improves quality of life for care partners.<sup>24</sup> It is important that the education provided is sensitive to health literacy and linguistic and cultural preferences. The information can be delivered in a variety of formats, from in-person interaction to using written materials, online self-training, or hands-on skills practice and problem-solving.<sup>37</sup>

## What This Quality Statement Means

### For People With a Serious Illness, Families, and Care Partners

Your care team should give you, your family, your substitute decision-maker, and your care partners information about palliative care. They should also give you information about resources and supports, such as counselling, hospice volunteers, wellness programs, spiritual care, or support groups. This knowledge can help you understand your treatment and service options, how palliative care can improve your quality of life, and how to connect with available supports.

## For Clinicians

Provide education about palliative care to patients, their families, and their care partners, and offer information about available resources and supports.

## For Organizations and Health Services Planners

Ensure that educational resources and tools about palliative care are available for health care professionals, patients, their families, and their care partners.

# Quality Indicators: How to Measure Improvement for This Statement

- Percentage of people with identified palliative care needs (or their care partners) who state that health care professionals helped them understand palliative care and provided information about available resources and supports
- Percentage of people with identified palliative care needs (or their care partners) who state that a health care professional helped them understand what to expect and how to prepare for each stage of the journey toward the end of life
- Local availability of resources and tools for health care professionals to provide education about palliative care to patients, families, and care partners

Measurement details for these indicators, as well as overarching indicators to measure improvement for the goals of the entire quality standard, are available in the [technical specifications](#).

# Quality Statement 9: Care Partner Support

**Families and care partners 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.**

Source: National Institute for Health and Care Excellence, 2019<sup>17</sup>

## Definitions

**Family:** Family consists of those closest to a person in terms of knowledge, care, and affection; this may include biological family or family of origin, family through marriage, or family of choice and friends.<sup>26</sup> The person with the serious illness defines their family and who will be involved in their care.

**Care partner:** A care partner is an unpaid person who provides essential and ongoing care and support, as deemed important to the person with a serious illness. Care partners can be family, chosen family, friends, or anyone else identified by the person with a serious illness. Other terms commonly used to describe this role include caregiver, informal caregiver, family caregiver, carer, or primary caregiver.

**Care partner assessment:** A care partner assessment includes an examination of physical, psychological, social, spiritual, linguistic, cultural, and environmental considerations.<sup>26</sup> The assessment may relate to the care partner's needs and preferences, as well as associated treatment, care, and support. Use of validated tools may help clinicians explore the care partner's values and preferences, well-being, burden, skills and abilities, and resources.<sup>17,18</sup>

## Rationale

Families and care partners of people with a serious illness have needs across multiple domains. Families and care partners benefit from support as they manage medical information, learn how to provide care, and develop coping strategies to deal with medical care, personal care, psychosocial care, loss, grief, and bereavement. General advice and support, along with education to improve coping and communication skills for care partners, are associated with decreased distress.<sup>24</sup>

## What This Quality Statement Means

### For People With a Serious Illness, Families, and Care Partners

Caregiving can be a rewarding experience, but it can also be stressful. If you are a care partner, a member of the care team should assess you to see how you are coping and help you get the supports you need. Supports can include training, support groups, home care, and temporary respite care for

the person you are caring for. Respite care can give you a break from the caregiving routine and give you time to take care of yourself.

### **For Clinicians**

Offer assessment and appropriate support to the family and care partners of people with identified palliative care needs.

### **For Organizations and Health Services Planners**

Ensure that systems are in place to offer assessment and appropriate support to the family and care partners of people with identified palliative care needs.

## **Quality Indicators: How to Measure Improvement for This Statement**

- Percentage of people with identified palliative care needs who have a care partner needs assessment documented in their medical record
- Percentage of care partners of people who receive palliative care who state that they and their family members receive as much help and support as they need
- Percentage of care partners who state that, after the patient's death, they talked to someone from health and supportive services or bereavement services about their feelings regarding the illness and death

Measurement details for these indicators, as well as overarching indicators to measure improvement for the goals of the entire quality standard, are available in the [technical specifications](#).

# Quality Statement 10: Transitions in Care

**People with identified palliative care needs experience seamless transitions in care that are coordinated effectively among settings and health care providers.**

Source: National Institute for Health and Care Excellence, 2019<sup>17</sup>

## Definitions

**Seamless transition:** A seamless transition consists of a set of actions designed to ensure the safe and effective coordination and continuity of care when patients experience a change in health status, health care professional, or location (within, between, or across settings).<sup>39,40</sup>

**Coordinated effectively:** Coordinated care is the deliberate organization of patient care activities between 2 or more participants involved in a patient's care (including the patient) to facilitate the appropriate delivery of health care services. Organizing care involves coordinating people and resources to carry out required patient care activities and is often managed by exchanging information among those responsible for the various aspects of a patient's care.<sup>39,40</sup>

## Rationale

Transitions in care that are based on patient needs involve logistical arrangements to move a person from one care setting to another or from one care provider to another.<sup>39</sup> To ensure continuity of care, transitions in care should be coordinated among knowledgeable and skilled health care professionals who are familiar with the person's clinical status, goals of care, plan of treatment, care plan, and health information needs.<sup>39</sup>

Timely and effective communication is essential to prevent problems that may occur if services and supports are not well integrated (e.g., delayed transfers, readmissions, or poor care).<sup>17,41</sup> Identifying a member of the care team to be accountable for care coordination supports a smooth transition between settings and prevents communication failures.<sup>41</sup> Information-sharing between settings to ensure that all health care providers are aware of the person's current condition is part of effective and coordinated communication. All information-sharing during care transitions must consider legislated privacy and security requirements.<sup>39</sup>

Families and care partners also play a vital role in transitions. Health care professionals should have informed discussions with them about available care settings. Health care professionals should work together – and with the patient, their family, and their care partners – to ensure that transitions in care are timely, appropriate, and safe. For additional information about the transition from hospital to home, see Ontario Health's [Transitions Between Hospital and Home](#) quality standard.<sup>8</sup>



# What This Quality Statement Means

## For People With a Serious Illness, Families, and Care Partners

When you change care settings or care providers (for example, if you return home after being in hospital), your care team should work with you to make sure you and any new team members have the right information (such as information about your medication). They should also make sure you receive the services you need (such as plans for follow-up).

## For Clinicians

Ensure that people moving between care settings or care providers experience coordinated and seamless transitions. This includes facilitating communication between settings and other related processes.

## For Organizations and Health Services Planners

Ensure that systems, processes, and resources are in place to facilitate communication and information-sharing between care providers and care settings during transitions.

# Quality Indicators: How to Measure Improvement for This Statement

- Percentage of people who receive palliative care whose medical record identifies the member of the care team responsible for care coordination
- Percentage of people who receive palliative care (or their care partners) who state that they experienced seamless transitions between care settings

Measurement details for these indicators, as well as overarching indicators to measure improvement for the goals of the entire quality standard, are available in the [technical specifications](#).

# Quality Statement 11: Setting of Care and Place of Death

People with identified palliative care needs, their substitute decision-maker, their family, and their care partners have ongoing discussions with their health care professionals about their preferred setting of care and place of death.

Sources: National Institute for Health and Care Excellence, 2019<sup>17</sup> | Ontario Health Technology Advisory Committee, 2014<sup>24</sup>

## Definitions

**Setting of care:** The setting of care is the place where palliative care is provided.<sup>26</sup> Care settings may include the person's home, a hospice residence or inpatient palliative care unit, a long-term care home, a correctional facility, or for a person who is homeless or vulnerably housed, a shelter or the street.

**Preferred setting of care and place of death:** Discussions with health care professionals about the setting of care and place of death should include the following<sup>24</sup>:

- Interprofessional palliative care in the person's current place of residence
- Time between referral to palliative care services and death
- Type of underlying disease
- Functional status
- Frequency of hospitalizations during the last year of life
- Living arrangements (e.g., living with someone, living alone)
- Presence of a care partner
- Care partner's ability to cope
- Patient or family preference for place of death
- Consideration of previous advance care planning conversations
- Availability of a long-term care home, hospital bed, or hospice residence bed
- Availability of resources to support the patient's physical and psychological needs, where they live, during the end-of-life period

## Rationale

A person's preferences for where to receive palliative care and where to die depend on an interplay of factors associated with the illness, the individual, and the environment. A person's preferred

setting of care and place of death should be part of a care plan (see quality statement 5) that reflects the person's wishes, goals, and needs. Different care settings and places of death are considered, including the person's home (usual place of residence), a long-term care home, a hospice residence, or an inpatient palliative care unit. Safety is a key consideration when discussing the setting of care and place of death. A number of factors increase the feasibility and likelihood of a home death, including the availability of interprofessional home palliative care, early referral to palliative care, patient preferences, having a care partner, and the care partner's ability to cope.<sup>24</sup> Discussions about the setting of care and place of death should be ongoing; a person's choice may change depending on their status.<sup>17</sup>

## What This Quality Statement Means

### For People With a Serious Illness, Families, and Care Partners

Your care team should talk with you about where you would like to be cared for throughout your illness and at end of life (for example, at home, in a home-like environment called a hospice residence, in a hospital, or in a long-term care home). They should give you information about the care available in different locations to help you make the best choices for you, your family, and your care partners. Your wishes may change over time, so you should have regular opportunities to discuss them. You may want to talk about:

- Your preferences
- How your disease affects your ability to perform normal daily activities
- Whether you are living with someone who can help you
- Whether other help you may need is available

### For Clinicians

Provide information about options for the setting of care and place of death to people with identified palliative care needs, their family, and their care partners. This information should include all of the factors outlined in the definitions.

### For Organizations and Health Services Planners

Ensure that resources and tools are available to support discussions between health care professionals and people with identified palliative care needs about their preferred setting of care and place of death.

## Quality Indicators: How to Measure Improvement for This Statement

- Percentage of people with identified palliative care needs who have documentation of their preferred setting of care and place of death in their medical record

- Availability of a survey to capture care partner experience in all care settings (e.g., CaregiverVoice Survey)
- Percentage of people with identified palliative care needs whose medical records indicate that they died in their preferred place of death
- Percentage of care partners of people who died of a serious illness who think that the person they cared for died in the right place

Measurement details for these indicators, as well as overarching indicators to measure improvement for the goals of the entire quality standard, are available in the [technical specifications](#).

# Quality Statement 12: Interprofessional Team-Based Care

**People with identified palliative care needs receive integrated care from an interprofessional team, which includes volunteers.**

Sources: Institute for Clinical Systems Improvement, 2020<sup>15</sup> | Ontario Health Technology Advisory Committee, 2014<sup>24</sup> | National Institute for Health and Care Excellence, 2019<sup>17</sup> | Registered Nurses' Association of Ontario, 2020<sup>6</sup>

## Definitions

**Integrated care:** Health services are managed and delivered so that people receive care that is coordinated across the health system, at all levels and settings, and according to the patient's needs throughout their life course.<sup>42</sup> Integrated care involves the delivery, management, and organization of services for diagnosis, treatment, care, rehabilitation, and health promotion. Integration of care brings about better access, quality, user experience, and efficiency.

**Interprofessional team:** An interprofessional team includes multiple health care providers with different training and skills, the person with a serious illness, and their care partners, all of whom work together to provide care based on a person's care plan (see quality statement 5).<sup>5,7</sup> The composition of the team varies depending on the services needed and may include physicians, nurse practitioners, registered nurses, registered practical nurses, social workers, psychologists, spiritual care providers, pharmacists, personal support workers, dietitians, and volunteers. Interprofessional care occurs when multiple health care professionals with different areas of expertise provide comprehensive health services by working with patients, their care partners, and communities to deliver the highest quality of care across settings.<sup>5,7</sup>

## Rationale

The model of care used to deliver health services can affect the quality of the care received. Team-based, integrated care facilitates continuity for people with a serious illness, their family, and their care partners.<sup>18</sup> The team-based model of care includes the patient, family, and a nurse or physician with the knowledge and skills to deliver palliative care.<sup>24</sup> The team may also include people in other roles, such as social workers, psychologists, spiritual advisors, personal support workers, healers, medicine people, Elders, or volunteers. The services provided by the team include symptom management, psychosocial care, care plan development, advance care planning conversations, goals of care discussions, and care coordination.<sup>24</sup>

# What This Quality Statement Means

## For People With a Serious Illness, Families, and Care Partners

You should have access to care providers who are knowledgeable about palliative care and who will work together to meet your needs and goals of care.

## For Clinicians

Collaborate with other health care providers, volunteers, family, and care partners to meet the needs of people receiving palliative care.

## For Organizations and Health Services Planners

Provide adequately resourced systems and services to ensure that health care professionals, volunteers, and care partners can work in teams to provide integrated palliative care.

# Quality Indicators: How to Measure Improvement for This Statement

- Percentage of people who receive palliative care (or their care partners) who state that they have received care from 2 or more health care providers, such as a physician, nurse, social worker, psychologist, spiritual care provider, volunteer, and others
- Percentage of people who receive palliative care (or their care partners) who state that their health care providers work well together

Measurement details for these indicators, as well as overarching indicators to measure improvement for the goals of the entire quality standard, are available in the [technical specifications](#).

# Quality Statement 13: Education for Health Care Providers and Volunteers

People receive palliative care from health care providers and volunteers who possess the appropriate knowledge and skills to deliver high-quality palliative care.

Sources: National Institute for Health Care Excellence, 2019<sup>17</sup> | Ontario Health Technology Advisory Committee, 2014<sup>24</sup> | Registered Nurses' Association of Ontario, 2020<sup>6</sup>

## Definitions

**Health care providers and volunteers:** These include regulated health care professionals and unregulated care providers.<sup>43,44</sup> In Ontario, regulated health professions (e.g., physicians, nurse practitioners, registered nurses, occupational therapists) are accountable to their regulatory colleges, which ensure that professionals provide health services in a safe, professional, and ethical manner. Unregulated care providers (e.g., palliative care volunteers, personal support workers) may assist with or perform certain aspects of care traditionally provided by regulated health care professionals, based on their role and employment setting, and are accountable to their employers.

**Knowledge and skills:** Education should include communication skills, assessment and care planning, advance care planning, and symptom management.<sup>16</sup> It may also include the following<sup>6</sup>:

- Principles and models of palliative care
- Care of the family and care partner
- Assessment and management of pain and other symptoms (see quality statement 6)
- Assessment and management of psychosocial aspects of care, including spiritual and existential issues (see quality statement 7)
- Effective and compassionate communication
- Mediation and conflict management
- Advocacy and therapeutic relationship-building
- Ethical issues
- Interprofessional practice and competencies (see quality statement 12)
- Knowledge of relevant legislation
- Advance care planning, goals of care, and informed consent as described in the Ontario *Health Care Consent Act* (see quality statements 3 and 4)
- Self-care, including coping strategies, compassion fatigue, and self-exploration of death and dying
- Cultural competency and cultural safety, including care for First Nations, Inuit, Métis, and Urban Indigenous people

- Palliative care issues in vulnerable populations (people with mental health issues, people who are homeless or vulnerably housed, and people who are incarcerated)
- Social and cultural contexts of death and dying
- Dying trajectories and signs of impending death
- Grief, bereavement, and mourning
- Roles of grief and bereavement educators, clergy, spiritual leaders, and funeral directors

## Rationale

People with a serious illness, families, and care partners have complex needs; for this reason, those who provide care should have comprehensive palliative care education. Education that focuses on improving communication skills, knowledge, and attitudes about palliative care has a positive effect on a person's experience of palliative care.<sup>24</sup> Competency-based education materials and programs should be tailored to the health care provider's role and responsibilities.

## What This Quality Statement Means

### For People With a Serious Illness, Families, and Care Partners

You should have access to care providers who have the skills and knowledge to provide palliative care and who will work together to meet your needs and goals of care.

### For Clinicians

Engage in competency-based education, tailored to your role, to obtain the necessary knowledge and skills to effectively provide high-quality care for people with a serious illness.

### For Organizations and Health Services Planners

Ensure that systems, processes, and resources are in place for health care providers and volunteers to receive the education necessary to provide high-quality palliative care.

## Quality Indicators: How to Measure Improvement for This Statement

- Percentage of health care providers and volunteers who provide palliative care who have evidence of receiving palliative care education appropriate to their role
- Percentage of health care providers and volunteers who provide palliative care who state that they have the knowledge and skills to provide palliative care

Measurement details for these indicators, as well as overarching indicators to measure improvement for the goals of the entire quality standard, are available in the [technical specifications](#).



# Appendix 1: About This Quality Standard

## How to Use This Quality Standard

Quality standards inform patients, clinicians, and organizations about what high-quality care looks like for health conditions or processes deemed a priority for quality improvement in Ontario. They are based on the best evidence.

Guidance on how to use quality standards and their associated resources is included below.

### For People With a Serious Illness and Their Families and Care Partners

This quality standard consists of quality statements. These describe what high-quality care looks like for adults with a serious illness, and for their family and care partners.

Within each quality statement, we've included information on what these statements mean for you as a patient, family member, or care partner.

In addition, you may want to download this accompanying [patient guide](#) on palliative care to help you and your family and care partners have informed conversations with your health care providers. Inside, you will find information and questions you may want to ask as you work together to make a plan for your care.

### For Clinicians and Organizations

The quality statements within this quality standard describe what high-quality care looks like for adults with a serious illness. They are based on the best evidence and designed to help you know what to do to reduce gaps and variations in care.

Many clinicians and organizations are already providing high-quality, evidence-based care. However, there may be elements of your care that can be improved. This quality standard can serve as a resource to help you prioritize and measure improvement efforts.

Tools and resources to support you in your quality improvement efforts accompany each quality standard. These resources include indicators and their definitions, available in the [technical specifications](#). Measurement is key to quality improvement. Collecting and using data when implementing a quality standard can help you assess the quality of care you are delivering and identify gaps in care and areas for improvement.

There are also a number of resources online to help you, including:

- Our [patient guide](#) on palliative care, which you can share with patients, families, and care partners to help them have conversations with you and their other health care providers. Please make the patient guide available where you provide care
- Our [measurement resources](#), including the technical specifications for the indicators in this quality standard, the “case for improvement” slide deck to help you to share why this standard was

created and the data behind it, and our measurement guide containing supplementary information to support the data collection and measurement process

- Our [placemat](#), which summarizes the quality standard and includes links to helpful resources and tools
- Our [Getting Started Guide](#), which includes links to templates and tools to help you put quality standards into practice. This guide shows you how to plan for, implement, and sustain changes in your practice
- [Quorum](#), an online community dedicated to improving the quality of care across Ontario. This is a place where health care providers can share information and support each other, and it includes tools and resources to help you implement the quality statements within each standard

## How the Health Care System Can Support Implementation

As you work to implement this quality standard, there may be times when you find it challenging to provide the care outlined due to system-level barriers or gaps. These challenges have been identified and documented as part of the development of the quality standard, which included extensive consultation with health care professionals and lived experience advisors and a careful review of available evidence and existing programs. Many of the levers for system change fall within the purview of Ontario Health, and as such we will continue to work to address these barriers to support the implementation of quality standards. We will also engage and support other provincial partners, including the Ministry of Health or other relevant ministries, on policy-level initiatives to help bridge system-level gaps.

In the meantime, there are many actions you can take on your own, so please read the standard and act where you can.

# Appendix 2: Glossary

Term	Definition
<b>Adults</b>	People aged 18 years and older.
<b>Care partner</b>	An unpaid person who provides essential and ongoing care and support, as deemed important to the person with a serious illness. Care partners can be family, chosen family, friends, or anyone else identified by the person with a serious illness. Other terms commonly used to describe this role include “caregiver,” “informal caregiver,” “family caregiver,” “carer,” and “primary caregiver.”
<b>Children and adolescents</b>	People under 18 years of age.
<b>Family</b>	The people closest to a person in terms of knowledge, care, and affection; this may include biological family or family of origin, family through marriage, or family of choice and friends. The person defines their family and who will be involved in their care.
<b>Health care professionals</b>	Regulated professionals, such as nurses, nurse practitioners, registered practical nurses, pharmacists, physicians, physiotherapists, psychologists, social workers, and dietitians.
<b>Health care providers</b>	Health care professionals, as well as people in unregulated professions, such as administrative staff, behavioural support workers, counsellors, patient transport staff, personal support workers, recreational staff, spiritual care providers, and volunteers.
<b>Home</b>	A person’s usual place of residence. This may include personal residences, retirement residences, assisted-living facilities, long-term care facilities, hospices, and shelters.
<b>Hospice</b>	A community-based organization or program that provides support for people with a serious illness and their care partners, family members, and friends. Support is provided in a variety of settings, including the person’s home. The goal of hospice care is to enhance the person’s quality of life and the well-being of anyone affected by the person’s illness or death. A hospice provides services such as trained volunteers, day programs, psychosocial supports, grief and bereavement support, spiritual care, care partner support, complementary therapies, outreach or shared-care teams, and end-of-life care. <sup>1</sup>

<b>Term</b>	<b>Definition</b>
<b>Long-term care</b>	Care provided in long-term care homes.
<b>Palliative care</b>	Palliative care addresses people’s physical, psychological, social, spiritual, and practical needs, as well as their associated expectations, hopes, and fears with the aim of relieving suffering and improvement of the quality of living and dying. It helps people with a serious illness and their family prepare for and manage end-of-life choices, the process of dying, and coping with loss and grief. <sup>1</sup>
<b>Residential hospice</b>	A health care facility that offers palliative care services provided by an interprofessional team. Care is available 24 hours a day, 7 days a week, in a home-like setting for the person with a serious illness and their family and care partners. <sup>1</sup>
<b>Primary care provider</b>	A family physician (also called a primary care physician) or nurse practitioner.
<b>Serious illness</b>	A health condition that can lead to death and can affect a person’s daily function or quality of life, or that places excessive strains on care partners. <sup>1</sup>

# Appendix 3: Values and Guiding Principles

## Values That Are the Foundation of This Quality Standard

This quality standard was created, and should be implemented, according to the [Patient, Family and Caregiver Declaration of Values for Ontario](#). This declaration “is a vision that articulates a path toward patient partnership across the health care system in Ontario. It describes a set of foundational principles that are considered from the perspective of Ontario patients, and serves as a guidance document for those involved in our health care system.”

These values are:

- Respect and dignity
- Empathy and compassion
- Accountability
- Transparency
- Equity and engagement

A quality health system is one that provides good access, experience, and outcomes for all people in Ontario, no matter where they live, what they have, or who they are.

## Guiding Principles

In addition to the above values, this quality standard is guided by the principles outlined below.

### Acknowledging the Impact of Colonization

Health care providers should acknowledge and work toward addressing the historical and present-day impacts of colonization in the context of the lives of Indigenous Peoples throughout Canada. This work involves being sensitive to the impacts of intergenerational and present-day traumas and the physical, mental, emotional, and social harms experienced by Indigenous people, families, and communities, as well as recognizing their strength and resilience. This quality standard uses existing clinical practice guideline sources that may not include culturally relevant care or acknowledge traditional Indigenous beliefs, practices, and models of care.

### French Language Services

In Ontario, the *French Language Services Act* guarantees an individual’s right to receive services in French from Government of Ontario ministries and agencies in [26 designated areas](#) and at government head offices.<sup>47</sup>

## Social Determinants of Health

Homelessness and poverty are 2 examples of economic and social conditions that influence people's health, known as the social determinants of health. Other social determinants of health include employment status and working conditions, ethnicity, food security and nutrition, gender, housing, immigration status, social exclusion, and residing in a rural or urban area. Social determinants of health can have strong effects on individual and population health; they play an important role in understanding the root causes of poorer health.

## Person-Centred Care

People should receive palliative care services that are respectful of their rights and dignity. Person-centred care – compassionate care that respects people's wishes, beliefs, and values by promoting autonomy, dignity, and inclusion in shared decision-making as appropriate – is fundamental to an ethics-based palliative approach to care.<sup>48</sup>

# Acknowledgements

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# About Us

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We are an agency created by the Government of Ontario to connect, coordinate, and modernize our province's health care system. We work with partners, providers, and patients to make the health system more efficient so everyone in Ontario has an opportunity for better health and well-being.

## Equity, Inclusion, Diversity, and Anti-Racism

Ontario Health is committed to advancing equity, inclusion and diversity and addressing racism in the health care system. As part of this work, Ontario Health has developed an [Equity, Inclusion, Diversity and Anti-Racism Framework](#), which builds on existing legislated commitments and relationships and recognizes the need for an intersectional approach.

Unlike the notion of equality, equity is not about sameness of treatment. It denotes fairness and justice in process and in results. Equitable outcomes often require differential treatment and resource redistribution to achieve a level playing field among all individuals and communities. This requires recognizing and addressing barriers to opportunities for all to thrive in our society.

For more information about Ontario Health, visit [OntarioHealth.ca](https://OntarioHealth.ca).

## About the Ontario Palliative Care Network

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The Ontario Palliative Care Network (OPCN) was established in 2016 to act as the Ministry's principal adviser for high-quality, coordinated palliative care in Ontario. It is a partnership of health service providers, community and social support service organizations, health systems planners, as well as patient and family/caregiver advisors. The Provincial Program that supports the OPCN Secretariat is a part of the Clinical Institutes and Quality Programs portfolio at Ontario Health. The OPCN's work is person centred, focused on supporting quality palliative care for all people in Ontario, no matter what their age or illness.

# Looking for More Information?

Visit [hqontario.ca](https://www.hqontario.ca) or contact us at [QualityStandards@OntarioHealth.ca](mailto:QualityStandards@OntarioHealth.ca) if you have any questions or feedback about this quality standard.

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