

## Background

### Description of Palliative Care

Palliative care focuses on the relief of pain and other symptoms for patients with advanced illnesses, and on maximizing the quality of their remaining life. It may also involve emotional and spiritual support as well as caregiver and bereavement support, and provides comfort-based care as opposed to curative treatment. Typical illnesses for which palliative care is provided include cancer, heart disease, respiratory disorders, HIV/AIDS, muscular dystrophy, multiple sclerosis, and kidney or liver failure. For patients who are terminally ill and within their last few weeks or months of life, palliative care is often referred to as end-of-life care.

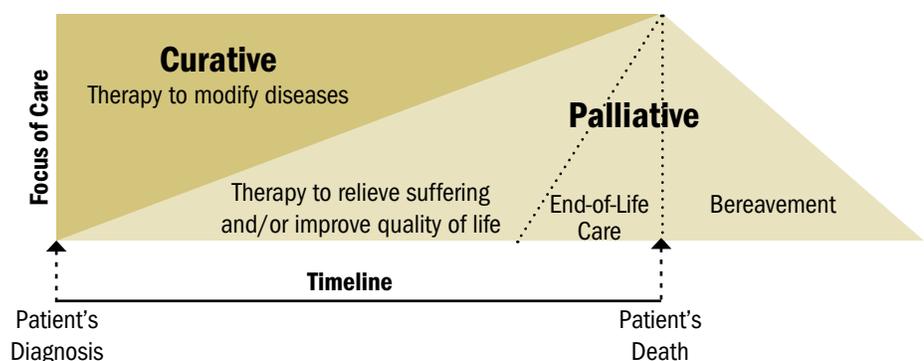
### The Palliative-care Continuum

Key stages in palliative care, as shown in **Figure 1**, are as follows:

1. **Patient is diagnosed with a chronic or life-threatening illness.** The patient might seek measures to fight the disease, such as undergoing curative treatments to stop or alter the disease progression. The patient might also receive some treatment to manage pain and symptoms, but this is not traditionally considered to be palliative care because the main focus of the care is curative.
2. **Disease progresses.** If the patient's response to curative treatment is not positive, or the patient and family decide to no longer seek this treatment, the focus of care gradually shifts from curative therapies to palliative care.

**Figure 1: Palliative-care Continuum**

Adapted by the Office of the Auditor General of Ontario from information from the Canadian Hospice Palliative Care Association



3. **Patient approaches death.** The primary focus is on palliative end-of-life care to manage pain and symptoms, including breathlessness and nausea, as well as to address any spiritual or psychological needs of the patient or family to make the patient's remaining life as comfortable as possible.
4. **Patient dies.** The individual's family and loved ones can receive bereavement support, also considered a component of palliative care, to help them cope with, among other things, grief, anger, depression and guilt.

Patients most often receive palliative care in:

- their home (through the local Community Care Access Centre);
- hospitals;
- hospices, which are home-like facilities that focus on palliative care; and
- long-term-care homes.

## Responsibility and Funding for Palliative Care

Many parties play a role in providing palliative care in Ontario, as shown in **Appendix 1**. In particular, the Ministry of Health and Long-Term Care (Ministry) has overall responsibility for health care in Ontario, including palliative care. It funds 14 Local Health Integration Networks (LHINs), which are responsible for planning, co-ordinating, funding and monitoring palliative-care services in their respective regions. The LHINs in turn fund 155 hospitals that may provide inpatient palliative-care services; 14 Community Care Access Centres (CCACs), one in each LHIN, that provide palliative-care services in patients' homes; and about 630 long-term-care homes that may provide palliative-care services to their residents. There are also 36 hospices (32 of which receive Ministry funding, mostly through the CCACs) that provide inpatient beds in a home-like setting and care for patients in their last few weeks to months of life. As well, there are a number of other organizations, over 60 of which receive funding from the Ministry, that

provide additional support such as companionship visits and group counselling sessions for persons with an advanced illness.

In addition, the Ministry funds Cancer Care Ontario, a provincial government agency whose responsibilities include ensuring access to palliative care for patients with cancer and chronic kidney disease. The Ministry also funds hospitals, through Cancer Care Ontario, for providing certain palliative-care cancer programs, among other things. As well, the Ministry directly funds physicians for the hospital-, community- and home-based palliative care that they provide, and funds drug costs for eligible people through the Ontario Drug Benefit Program.

The total amount of Ministry funding used to provide palliative-care services is not known. Funding to hospitals (\$16.3 billion in the 2013/14 fiscal year) and long-term-care homes (\$3.4 billion in 2013/14) is not tracked specifically enough to isolate the amounts spent on palliative care. Similarly, the total cost of drugs for palliative-care patients is not tracked. While CCACs spent \$112 million in 2013/14 (\$108 million in 2012/13) on end-of-life home-care services during the last six months of patients' lives, information was not tracked on how much was spent in total on palliative-care services that commenced prior to the patient's last six months of life. As well, while CCACs funded hospices a total of \$21 million in the 2013/14 fiscal year (\$19 million in 2012/13), the Ministry had no information on funding that LHINs paid directly to hospices. Ministry information indicated that it paid physicians \$62 million for providing palliative-care services to patients in 2012/13, the most recent period for which figures are available. Overall, palliative-care funding, based on costs that are known, was about \$190 million in the 2012/13 fiscal year. This total is likely considerably lower than actual costs since it does not include, among other things, hospital-based costs and publicly funded drug costs.

## Future Need for Palliative Care

The need for palliative care is growing due to the aging population. People aged 85 and over constituted the fastest-growing segment of Ontario's population between 2006 and 2011, with their number increasing by 29% over that period. The number of people aged 65 and over is expected to more than double from 2 million in 2012, when baby boomers began to turn 65, to over 4 million by 2036, when seniors will constitute 24% of Ontario's population. Because a larger percentage of Ontario's population will be nearing their end of life, and may also be living longer with advanced illnesses, this will create greater need for the provision of palliative care.

### Summary

Many initiatives relating to palliative-care services are under way across Canada at both the national and provincial levels. They cover a wide variety of issues, including the need for better physician communication with patients about prognosis and the aim of treatment, the importance of patients developing an advance care plan outlining their end-of-life wishes, and improved integration of patient services so that people get the cost-effective care they need when they need it. Given Ontario's aging population and the expectation that people will live longer with advanced illnesses, both of which will likely increase the demand for palliative care, we thought it was important to audit this evolving area.

Palliative-care services in Ontario developed in a patchwork fashion, often being initiated by individuals who had a passion for this area of care, wherever they were located in the province. As a result, although efforts have been made to create an integrated, co-ordinated system to deliver palliative care in Ontario, no such system yet exists.

Currently, the Ministry lacks information on the palliative-care services available, their costs, the patient need for these services, or what mix of services would best meet patient needs in a cost-effective manner. Overall, despite its many initiatives, the Ministry does not yet have effective processes in place to ensure that there is sufficient public information on palliative-care services, or that patients nearing their end of life have timely and equitable access to cost-effective palliative services that meet their needs. The Ministry also lacks performance measures to help determine its progress in meeting its goal of providing the "right care at the right time in the right place," as stated in its 2012 Action Plan for Health Care in Ontario.

Some of the more significant areas we noted for improvement are as follows:

- **Strategic policy framework not in place for palliative-care delivery system:** In Ontario, one key initiative is the 2011 Declaration of Partnership, which established a common vision for the delivery of palliative-care services in this province and included over 90 commitments by various stakeholders to improve these services. However, three years after its creation, significant work still needs to be done to meet most of the commitments made in the Declaration of Partnership and measure the results achieved. Further, while the Declaration of Partnership is a good initiative, it should form part of a strategic policy framework for palliative care, which needs to be developed. Such a framework can provide direction to support the implementation of the commitments on a timely basis. It can also better support the many individuals we spoke with during our audit, whether at hospices or hospitals, who shared a passion for providing care to patients to maximize the quality of their remaining life.
- **Ministry needs better information for decision-making and planning:** There is little province-wide or LHIN-level information on the supply of or demand for palliative and

end-of-life care. For example, the Ministry does not have accurate information on the number of palliative-care beds in hospitals across the province, nor is the number of patients served tracked consistently. Consistent and comparable information is needed to make good decisions regarding current and future palliative-care services, and to ensure that patients get the services they need in the most cost-effective manner. This will be even more important in coming years because demand for palliative care is expected to increase as baby boomers approach the end of their lives.

- **Mix of services should be reviewed to ensure patients' needs are met cost-effectively:** While most people would prefer to die at home, most actually die in hospital. This is likely because people who need health care will go to a hospital when community services are not available. But over 60% of deaths are caused by cancer and chronic illnesses, which should allow planning that would let many of these patients die comfortably at home or in a hospice. Caring for terminally ill patients in an acute-care hospital is estimated to cost over 40% more than providing care in a hospital-based palliative-care unit, more than double the cost of providing care in a hospice bed, and over 10 times more than providing at-home care. In particular, the cost of providing palliative care in the last month of a patient's life averages about:
  - \$1,100 per day in an acute-care hospital bed;
  - \$630 to \$770 per day in a bed in a palliative-care unit (at the two hospitals visited that tracked this information in a comparable way);
  - \$460 per day in a hospice bed; and
  - under \$100 per day where at-home care is provided.

By reviewing and adjusting the mix of services available, patient needs could be met more cost-effectively.

- **Access to palliative-care services is not equitable:** Because eligibility for and the supply of palliative-care services varies, patients who qualify for services in one area of the province may not have access to similar services in another area. For example, although best practices in various jurisdictions suggest there should be at least seven hospice beds per 100,000 people, Ontario has fewer than two, and some LHINs have no hospice beds at all. Therefore, patients who would benefit from these services may not be able to access them.
- **Hospice beds could serve more patients:** Overall, most hospices have an average daily occupancy rate of about 80%, which means beds are vacant up to 20% of the time, or the equivalent of over two months a year. The Ministry continues to fund hospices while the beds are vacant. The occupancy rate means Ontario hospices have the potential to serve more patients. Edmonton, for example, has a 92% occupancy benchmark.
- **Patient care could be improved and health-care costs reduced:** Physicians might not be comfortable talking about dying with patients. As a result, patients might not understand their prognosis, might not have an end-of-life care plan in place setting out their wishes, and might not be referred for palliative care until they are close to death, if at all. This can lead to increased costs in the health-care system—for example, due to prolonging expensive treatments such as chemotherapy that might neither extend nor improve life. Patients might suffer unnecessarily and have to visit their local emergency department, which also increases health-system costs, when they could more comfortably receive care at home.
- **Education standards needed for physicians and nurses to help ensure proper patient care:** There are no minimum education requirements for physicians or nurses providing palliative care, and differences in credentials were noted at the hospitals visited. In

addition, any physician can refer to himself or herself as a palliative-care physician, regardless of the extent of education or training received. The lack of standards in education and training could have an impact on patient care and comfort.

- **Most publicly funded services used by cancer patients:** Most of Ontario's publicly funded palliative-care services are used by cancer patients, even though as many people die each year from advanced chronic illness, including heart disease, stroke and chronic obstructive pulmonary disease. Without access to palliative-care services, patients with advanced chronic diseases other than cancer might not receive the best care, including better symptom control, in a cost-effective manner.
- **More public awareness and education needed:** Many people are not aware of palliative-care services or how to access them, which could result in unnecessary patient suffering and increased health-care costs. Patients might end up at an acute-care hospital instead of receiving more cost-effective care at home that better meets their needs.

## OVERALL MINISTRY RESPONSE

The Ministry appreciates the comprehensive audit conducted by the Auditor General of palliative-care services and commits to fully responding to the recommendations.

This report and its recommendations represent an important complement to Ontario's blueprint for improving end-of-life and palliative care, *Advancing High Quality, High Value Palliative Care in Ontario: A Declaration of Partnership and Commitment to Action* (Declaration of Partnership). The Declaration of Partnership was established in 2011 by the Ministry with over 80 stakeholders and partners, and laid out a vision for improved end-of-life care for Ontarians. The Declaration of Partnership commits to establishing a system that serves all citizens

with life-limiting illness and their families by working with key partners to support timely palliative care in all care settings.

As part of delivering on the commitments in the Declaration of Partnership, the Ministry and its partners have been working toward clearer descriptions of how much palliative care is provided to Ontarians and where this is provided. There are two key challenges: the sensitivities of delivering end-of-life care to patients and their families who may not be willing to accept this diagnosis, and the fact that not all life-limiting diseases follow a predictable trajectory. These challenges mean that not all patients nearing the end of their life have been assessed as palliative, and their care is not always categorized as palliative. However, the Ministry and its partners are committed to a model that integrates palliative care into chronic disease management. This model spans all phases of illness, recognizing that palliative care can be given at the same time as disease treatment and with the intensity of the supports increasing toward the end of life.

Ontarians benefit from a wide network of dedicated health-care professionals, volunteers, caregivers and family members, who collectively provide palliative care to patients nearing the end of their life. In addition, Ontario's Local Health Integration Networks (LHINs), responsible for planning, funding and integrating local health services, are establishing regional palliative networks composed of local health-service providers. These networks use the Declaration of Partnership to support the integration of services based on local circumstances and need, while collaborating at a provincial level to support best practices, consistency and standardization across the system.

The responsibility for establishing education standards for palliative-care health-service providers rests with our partners, including the Committee on the Accreditation of Canadian Medical Schools, the Royal College of Physicians

and Surgeons of Canada, the College of Family Physicians of Canada, the College of Physicians and Surgeons of Ontario and the College of Nurses of Ontario. The Ministry will continue to work with these partners to ensure that Ontario's health-care system has the health human resources it needs.

## Audit Objective and Scope

The objective of our audit was to assess whether the Ministry of Health and Long-Term Care (Ministry), in conjunction with the Local Health Integration Networks (LHINs), has effective processes in place to ensure that there is sufficient public information readily available on palliative-care services and that patients nearing their end of life have timely and equitable access to cost-effective palliative services that meet their needs. In addition, we assessed whether the services also meet the Ministry's goal of providing the "right care at the right time in the right place," as stated in its 2012 Action Plan for Health Care in Ontario.

We also assessed information available on the status of the commitments the Ministry made in the 2011 Declaration of Partnership and Commitment to Action titled *Advancing High Value, High Quality Palliative Care in Ontario*. Our audit work focused on palliative-care services for adults.

We conducted our audit work at the Ministry's offices and at the following facilities:

- three LHINs of varying sizes serving different regions of the province (Central West in Brampton, South West in London, and Toronto Central in Toronto);
- three Community Care Access Centres (CCACs) associated with the LHINs visited;
- three hospitals, one in each LHIN visited:
  - William Osler Health System, with a 25-bed palliative-care unit in Brampton (reduced to 14 beds in September 2014)

and a 12-bed palliative care unit in Toronto (Central West);

- St. Joseph's Health Care in London, with a 14-bed palliative-care unit (South West); and
- Sunnybrook Health Sciences Centre, with a 32-bed palliative-care unit (Toronto Central).
- three hospices, one in each LHIN audited, in communities from urban to rural:
  - Bethell Hospice in Inglewood, with 10 beds (Central West);
  - Sakura House in Woodstock, with 10 beds (South West); and
  - Kensington Hospice in Toronto, with 10 beds (Toronto Central).

Senior ministry management and management at the LHINs, CCACs, hospitals and hospices we visited reviewed and accepted our objective and associated audit criteria. We conducted our field-work from February through May 2014.

The scope of our audit included the review and analysis of relevant files and administrative policies and procedures, as well as the results of patient and caregiver satisfaction surveys. In addition, we conducted interviews with staff. We also reviewed relevant research, including best practices for palliative-care services in other jurisdictions. (See **Appendix 4** for a list of selected reference sources.) As well, we obtained the perspective of the Ontario Hospital Association, which represents Ontario hospitals; Hospice Palliative Care Ontario, an organization that promotes awareness, education and best practices for hospice palliative care in Ontario; the Ontario Association of Community Care Access Centres, which represents the 14 CCACs across the province; and representatives from Cancer Care Ontario. We also obtained the perspective of the College of Nurses of Ontario and the Ontario Medical Association. We met with several expert palliative-care physicians from a variety of different organizations and engaged the services of an independent expert in palliative care to advise us.

## Detailed Audit Observations

The following sections provide our audit observations on the palliative-care delivery system in Ontario, co-ordination of palliative-care services, access to end-of-life care services, education on end-of-life care services and planning, monitoring performance of the palliative-care delivery system, and implementation of the commitments in the 2011 *Advancing High Quality, High Value Palliative Care in Ontario: A Declaration of Partnership and Commitment to Action* (Declaration of Partnership).

### Strategic Policy Framework Not in Place for Palliative-care Delivery System

#### Limited Information on System Demand and Capacity

The Ministry has not considered the demand for palliative care or determined the service levels needed to meet the demand. It relies on the 14 LHINs to determine the local level of need because they are responsible for planning and integrating local health services, including palliative care. However, none of the LHINs we visited had determined the local need for palliative-care services. The LHINs we visited told us that they usually relied on service providers—that is, individual hospitals, CCACs and hospices—or the local Palliative Care Network to identify and address any gaps in their services. All three of the LHINs we visited intended to play a more significant role in planning for palliative care in their regions in the future.

In December 2013, the Ontario Association of Community Care Access Centres released a series of four reports titled *Health Comes Home: A Conversation about the Future of Care*, which discussed the aging population and anticipated the increase in demand for palliative care. The reports pointed out certain changes that will be needed to meet demand, such as establishing a system that sup-

ports people who wish to die in their own home. The use of technology will also be important—for example, to support remote clinical interactions that enable patients who want to stay at home or in hospices to receive care.

Despite this recognition of the growing need for palliative-care services, no good information is available on the province's current capacity for providing these services, or how it will meet future demand. An April 2014 report by the Ontario Medical Association also noted that it is very difficult to determine service capacity because data is not kept on the number of palliative-care beds in the province or in each region. Furthermore, there is no data on the number of palliative-care service providers or the number of palliative-care services provided in hospitals or in the community.

Without reliable information on current service levels and demand for services, it is hard to make good decisions about where resources should be allocated to best meet the demand. As previously mentioned in the Background section, having this information will become even more important as the population ages.

#### Number and Type of Palliative-care Beds Needs Review

Many reports, including a 2007 report by the Canadian Institute for Health Information, indicate that most people would prefer to die at home if support were available. However, about 60% of deaths in Ontario occur in hospital. Many of these deaths are not sudden and could have been planned to occur elsewhere, such as at home or in a hospice. For example, over 30% of deaths are due to chronic illnesses and another 30% are due to cancer. Many people with these conditions could choose to die at home or in a hospice if they had adequate support.

Providing palliative care at home is less expensive (averaging less than \$100 per patient per day, excluding drug costs, in the last month of life) than providing acute care in a hospital (over \$1,100 per patient per day). A 2010 study called

*Ideas and Opportunities for Bending the Health Care Cost Curve* estimated savings of about \$9 million for every 10% of patients who are shifted from receiving palliative care in an acute-care hospital to receiving care at home. In addition, when properly resourced, home-based palliative-care services result in higher patient and caregiver satisfaction with end-of-life care.

Hospice care is also less expensive than hospital care. According to Hospice Palliative Care Ontario, the total average cost of a palliative-care hospice bed is \$460 a day (excluding drug costs). This is much less than the \$1,100 provincial average daily cost of providing palliative care to a patient in an acute-care hospital bed.

Even within hospitals, the cost of palliative care in a unit designated for such purposes is less expensive than providing palliative care in an acute-care bed. (Hospitals can choose to treat palliative-care patients in regular acute-care beds located throughout the hospital, or they can designate a unit of the hospital for palliative care.) For example, at the two hospitals visited that tracked comparable information, the cost of a bed in a palliative-care unit ranged from \$630 to \$770 per day, compared to the provincial average of over \$1,100 per day for a regular acute-care hospital bed.

Since acute-care hospital beds are the most expensive option for palliative-care services, they should be used only for patients with complex conditions requiring that level of care. Therefore, it is important to have the right mix of hospital and hospice beds to meet the needs of patients who cannot be cared for at home or prefer not to have a planned home death. Practices in various other jurisdictions indicate that in order to meet patients' needs, seven to 10 palliative-care beds (combined total in hospitals and hospices) should be available for every 100,000 people. A couple of jurisdictions have further broken down the suggested mix of hospice and hospital beds. For example, the Edmonton Zone of Alberta Health Services and British Columbia's Fraser Health Authority both propose that about 80% of beds should be in hospices and 20% in hospitals.

By these standards, Ontario should have about 945 to 1,350 palliative-care beds province-wide, with about 755 to 1,080 beds in hospices and 190 to 270 in hospitals. However, we noted that Ontario's total of 271 hospice beds (of which 260 are funded by the Ministry) is significantly less than the estimated 755 to 1,080 hospice beds required to meet the needs of palliative-care patients cost-effectively. Given that hospital-based beds cost significantly more than hospice beds, there may be a need to rebalance the proportion of palliative-care beds in hospices to those in hospitals.

The Ministry lacks reliable information on the total number of palliative-care beds province-wide or even the total number of hospitals providing palliative-care services in Ontario. Furthermore, the Ministry was not aware of 10 hospices with a total of 59 beds, even though six of the hospices received Ministry funding through other programs. Without accurate information, the Ministry is unable to determine whether an appropriate number of palliative-care beds are available province-wide, and is unable to plan properly for future needs.

We found that the Ministry has not analyzed the costs of palliative-care services provided by hospitals, hospices and CCACs to determine any differences. Although the Ministry identified, in December 2013, the types of patients it expected to be served by each type of service provider, it had not provided any guidance or recommendation on the type of patients who would be best served by each type of provider. As a result, the Ministry has not determined the optimal mix of hospital beds, hospice beds and home-care services to best meet patients' needs cost-effectively.

### Access to Palliative-care Beds Differs across the Province

Palliative-care services in Ontario have developed in a piecemeal fashion over the years. For example, hospitals can decide the extent of palliative-care services they will provide and whether any of their beds will be dedicated to palliative care. Hospices

were often initiated by people with an interest or passion in the provision of end-of-life care. This has resulted in varied services and levels of service available across the province. The Ministry has not done an overall assessment of how palliative-care beds should be distributed geographically or how many are needed in each region to meet demand, to ensure that patients meet the Ministry and other stakeholders' core value, as stated in the 2011 Declaration of Partnership, of having equitable access to care regardless of where they live.

With respect to hospices, the 260 Ministry-funded hospice beds are not distributed equitably across the province, as shown in **Figure 2**. In particular, one LHIN has six hospices with 57 beds, while two other LHINs have no hospice beds at all. This disparity has existed since the Ministry started funding hospice beds in 2005. Funding was not based on an analysis of patient numbers or needs or any other factors. Instead, the Ministry funded all hospices with palliative-care beds that were operating at that time, and agreed to fund future hospice beds run by organizations that shared their

plans with the Ministry at that time. As a result, easier access to hospice services depends on where a person lives.

We also noted that of the 34 hospices originally approved in 2005 for future funding by the Ministry, nine years later only 26 had opened.

While the Ministry did not have information on the total number of dedicated palliative-care beds (both in hospitals and hospices) in each LHIN, large discrepancies existed in the number of palliative-care beds in the LHINs we visited. One LHIN had only 5.9 palliative beds per 100,000 residents (dropping to 4.2 beds per 100,000 as of September 2014), while another had over triple this number at 18.5 palliative beds per 100,000 residents. However, while the LHIN with the higher number of beds also had more people over age 75, which may increase demand for palliative care beds as they are closer to the end of their lives, it was not triple the number. As a result, availability of palliative-care services varies greatly among regions. Provincial-level planning would better ensure that palliative beds are distributed based on patient need.

**Figure 2: Publicly-funded Hospices with Palliative-care Beds, by Local Health Integration Network, September 2014**

Source of data: Ministry of Health and Long-Term Care and Hospice Palliative Care Ontario

LHIN	# of Hospices	# of Beds	Total Hospice Beds per 100,000 Population
Central East	0	0	0.0
North West	0	0	0.0
Central	1	3	0.2
South East	1	3	0.6
Central West	1	10	1.2
Toronto Central	2	16	1.4
Mississauga Halton	3	18	1.5
Waterloo Wellington	2	16	2.1
South West	3	26	2.7
Erie St. Clair	2	18	2.8
North East	2	20	3.6
Hamilton Niagara Haldimand Brant	6	52	3.6
Champlain	6	57	4.5
North Simcoe Muskoka	3	21	4.5
<b>Total</b>	<b>32</b>	<b>260</b>	

## Education Varies among Physicians and Nurses Providing Palliative Care

There are no province-wide mandatory education standards or programs for health-care providers who primarily provide palliative-care services. While all medical students must have at least some education on end-of-life care, any physician in Ontario can refer to himself or herself as a palliative-care physician. For example, at one hospital visited, experience among the physicians in the specialized palliative-care consultation team ranged from having no additional palliative-care education, to having taken some courses toward a palliative-care medicine program, to having completed a palliative-care program. The Royal College of Physicians and Surgeons of Canada announced in October 2013 that it is developing a two-year subspecialty program in palliative care. Once this program is introduced, it is expected that physicians will need to meet its requirements to call themselves palliative care specialists.

We also noted that the education requirements of nurses working in palliative care varied at the three hospitals visited. For example, one hospital did not require nurses to be certified in palliative care, but encouraged it. Another hospital, with two palliative-care programs, required newly hired nurses at one program to complete some courses on palliative care within 12 months, while existing staff were not required to do so. At its other program, nurses were encouraged to take additional courses but it was not required. The third hospital required all nurses to take a palliative-care fundamentals course within the first year of hire, and complete a more detailed course within 24 months. As a result, the level of nursing expertise on palliative-care units across the province can vary significantly, which may affect patient care and comfort.

## Hospices Economically Dependent on Fundraising, Donations and Volunteers

The Ministry fully funds the cost of palliative-care services provided in hospitals. However, for hospices, it pays only a per-bed amount to cover the costs of nursing and personal support services. Hospice Palliative Care Ontario estimates that this amount covers just over 50% of the cost of providing hospice services. At the two hospices we visited that tracked costs in a comparable manner, ministry funding covered 64% and 75% of costs, respectively, which is still much less than total costs.

Hospices are expected to generate their own revenues for the remainder of their costs through fundraising or donations. Hospices also rely heavily on volunteers in order to operate. The hospices we visited had upward of 200 volunteers providing services such as reception, food preparation, grounds maintenance, companionship for patients and fundraising. As a result, there is a risk that hospices might not have the resources to operate if volunteering and fundraising priorities change in their community. In fact, one Ministry-funded hospice closed in part because it was unable to raise sufficient funds to continue operations.

### RECOMMENDATION 1

The Ministry of Health and Long-Term Care, in conjunction with the Local Health Integration Networks, should create an overall policy framework on the provision of palliative-care services in Ontario. This framework should include:

- the determination of available palliative-care resources and the total cost of currently providing palliative care services;
- an analysis of the cost of providing palliative care through different service providers (for example, hospital versus hospice versus home care);
- a projection of the best mix of services (for example, hospital versus hospice versus home care) to meet current and future patient needs;

- an assessment of current and potential future funding structures; and
- a position on educational requirements for health-care providers who provide palliative care.

In addition, a plan should be developed to implement the policy framework and ensure the ongoing provision of palliative-care services in accordance with the framework.

## MINISTRY RESPONSE

The Ministry supports this recommendation and will work with the LHINs and other partners to develop and implement a policy framework that builds on the strong consensus achieved through the development of the Declaration of Partnership and Commitment to Action, by setting out Ontario's vision, goals and key performance metrics for a high-quality, high-value palliative-care system.

### Lack of a Co-ordinated System

The Ministry has had two key palliative-care initiatives—the End-of-Life Care funding initiative (2005) and the Declaration of Partnership (2011). However, Ontario does not yet have a co-ordinated system for the delivery of palliative care that enables patients to move easily among health-care providers to receive needed services on a timely basis. Therefore, patients might not be connected with the services that best meet their needs and patient information might not be accessible to service providers on a timely basis for decision-making. As a result, patients might not receive the right care at the right time in the right place, in accordance with the Ministry's goal.

Furthermore, each LHIN can decide its own level of involvement with local palliative-care co-ordination. Not having a co-ordinated system has resulted in overlap and the duplication of efforts both within the LHINs and across the province. For example:

- Each of the CCACs produced unique brochures about its services to provide to patients and the public.
- Many of the hospices visited offered bereavement programs for families and caregivers, and each developed its own program.
- Each of the 14 LHINs is setting up a regional palliative-care process within its boundaries. Although some flexibility is needed to allow for local circumstances, there should be some standardized components to the process that could be adopted by each LHIN. Instead, each LHIN has created its own processes.

As well, there is no province-wide electronic patient records system that can be accessed by all care providers 24 hours a day, seven days a week. As a result, there is no consistent way of ensuring that patient information required for timely decision-making is readily available to all service providers of palliative care. For example, one hospital visited shared some clinical records electronically with other hospitals in its region; the second hospital visited shared some clinical records with hospitals in the region and in a neighbouring region; and the third hospital visited shared many records electronically with some other hospitals in its region. However, hospitals could not access CCAC records for a patient. Only one of the CCACs visited would forward patient referral information electronically to some of the hospitals in its region, although this and another CCAC visited were able to receive hospital referrals electronically. In addition, two of the three CCACs visited had an electronic process in place to refer patients to one hospice in their region. The other service providers we visited all relied on fax, phone or mail to transfer patient information.

The Province has ongoing initiatives by eHealth Ontario to enable the sharing of patient-related information among health-care providers caring for the patient, including the protection of the patient's privacy. Until these initiatives are implemented (well into the future), the cost-benefit of more widely adopting the electronic systems used for sharing patient information at the locations

we visited should be reviewed. For example, such sharing can provide information to improve patient care and reduce unnecessary or duplicate tests when a patient arrives at the emergency department of a hospital.

The challenge of co-ordinating the delivery of palliative care services is not unique to Ontario. There is also no national strategy for palliative care. In June 2014, the Canadian Medical Association published *End-of-life Care: A National Dialogue*, which summarized the results of town hall meetings held across the country on palliative care, advance care directives for end-of-life care, and euthanasia. Among other things, it recommended developing a national strategy to support and improve access to palliative and end-of-life care.

## RECOMMENDATION 2

To reduce the overlap and duplication of efforts both within the Local Health Integration Networks and across the province, the Ministry should implement a co-ordinated system for the delivery of palliative care that enables patients to move easily among health-care providers and receive needed palliative-care services on a timely basis. This should include consideration of the cost-benefit of shorter-term information technology solutions (such as those currently used by some health-care providers to inform patient-care decisions and reduce unnecessary or duplicate tests) to increase the sharing of patient related information, while longer-term initiatives are being pursued by eHealth Ontario.

## MINISTRY RESPONSE

The Ministry will work with the Local Health Integration Networks (LHINs) and other partners to improve the co-ordination and delivery of palliative care, including facilitating the transition for patients who move between care settings and health-service providers.

The Ministry, LHINs and eHealth Ontario have been working to develop an approach

that enables providers to transfer standardized patient information and make referrals between health-service provider organizations. The Ministry, through the provincial Resource Matching and Referral initiative, is supporting LHINs in implementing standardized referral tools, processes and data for referring patients from acute care to other care settings. Pilot projects are also underway to explore a range of technologies aimed at improving patient care.

## Difficulties Accessing End-of-life Care Services

### Barriers to Identifying and Informing Patients

The 2011 Declaration of Partnership indicates that a key priority is giving patients more timely access to palliative-care services. Early identification of people who would benefit from such services can help improve the comfort and quality of a patient's remaining life. However, the Ontario Medical Association, as well as other research, indicates that palliative-care patients are not being identified early for a number of reasons. The Clinical Council of the Hospice Palliative Care Provincial Steering Committee was established to drive clinical change for palliative care.

One reason is that there are no province-wide standardized tools or processes to identify patients who could benefit from palliative care. A simple method to assist service providers in identifying patients nearing their end of life is widely used in the United Kingdom, and is being adopted in many other jurisdictions. Under this method, physicians and other service providers ask themselves: "Would you be surprised if this patient died within one year?" If the answer is no, then discussions should be held with the patient about their prognosis and care options. At one hospital we visited, physicians asked this question about their cancer outpatients. This hospital told us it is planning to expand this practice for all of its inpatients by spring 2015.

Cancer Care Ontario commenced a pilot of this initiative in January 2014 at three regional cancer centres, and expected to determine if this initiative should be more widely adopted after the project's completion in 2017. Currently, Ontario physicians do not use any standard approach to identify candidates for palliative care.

According to a 2013 McMaster Health Forum evidence brief titled *Improving End-of-life Communication, Decision-making and Care in Ontario*, another reason that patients are identified late is that family physicians lack training about the palliative approach to care. Physicians may also find it difficult to discuss bad news with patients. Conversations we had with palliative-care physicians indicated that many family physicians, and sometimes specialists, are uncomfortable discussing dying with their patients. The June 2014 report by the Canadian Medical Association, *End-of-life Care: A National Dialogue* indicated that medical students and practising physicians require more education about palliative-care approaches, as well as how to initiate discussions about advance planning for end-of-life care.

Although there is a lack of province-wide tools or processes for the early identification of people requiring palliative care, the CCACs were undertaking an initiative that included meeting with family physicians in their area to inform them about CCAC services, including palliative care. As part of these discussions, the CCACs encourage physicians to identify patients who would benefit from palliative care. The three CCACs visited were at different stages of implementing this initiative and had connected with 12%, 36% and 91% of family physicians respectively. In addition, nurses from the palliative-care unit at one of the hospitals we visited held daily meetings with other nurses at the hospital to, among other things, help identify patients who would benefit from palliative care.

Palliative-care decisions are ultimately up to the patients and their caregivers. However, without complete information from their physician on their prognosis and options, patients and caregivers

might believe that opting for palliative care is “giving up” and therefore continue to try all possible curative treatments, even when their condition means the harshness of the treatments could reduce their quality of life or hasten their death. As a result, people might not be referred for palliative-care services until they are very close to death, if they are referred at all. This can lead to increased costs in the health-care system—for example, due to prolonging costly treatments that might neither extend nor improve life. Furthermore, people might suffer unnecessarily or go to their local emergency department, which also increases health-system costs, when they could more comfortably receive care at home. A 2010 study published in *The New England Journal of Medicine* found that cancer patients receiving early palliative care experienced significant improvements in both quality of life and mood, received less aggressive (and therefore less expensive) care at the end of life, and lived 2.5 months longer than patients who continued with aggressive treatments. As also reflected in a 2013 McMaster Health Forum evidence brief, the current system does not support patients and families to make knowledgeable choices.

Although patients with terminal diagnoses of all conditions are eligible for services at the palliative-care providers we visited, we noted that most palliative-care services were provided to patients with cancer, due in part to its more predictable disease trajectory. Although cancer patients represent only 30% of Canadian deaths annually, they make up 80% of end-of-life clients for the CCACs and occupy approximately 85% of hospice beds. As a result, patients with other diseases who would benefit from palliative care might not have equal access to it when needed.

### RECOMMENDATION 3

To better ensure that patients have complete information about their prognosis and care options, including palliative care (which can increase quality of remaining life and reduce health-care costs), the Ministry, in conjunction

with stakeholders such as the Clinical Council of the Hospice Palliative Care Provincial Steering Committee, should:

- promote the adoption of a common process that enables physicians to more easily identify patients who might benefit from palliative care, such as by asking themselves: “Would you be surprised if this patient died within one year?”; and
- put processes in place, such as through education, to ensure that physicians are sufficiently knowledgeable about the palliative approach to care and are comfortable having end-of-life conversations with their patients, including discussing a terminal diagnosis and care options with patients who are dying.

## MINISTRY RESPONSE

The Ministry accepts this recommendation and will work with the Clinical Council of the Hospice Palliative Care Provincial Steering Committee to develop an implementation plan.

At a patient level, it is important for providers within primary care, community, long-term-care homes (LTC homes), geriatric services as well as disease specialists like oncologists to be able to identify the patients within their programs and practices who are likely to die in the next year—to plan with them the care they want to receive over the last stages of their journey and to begin connecting them to the full range of supports and services they will need. Accordingly, the Ministry will continue exploring the use of appropriate assessment and identification tools, including standardized frailty measures in primary, community, LTC homes and specialty care to help providers ensure that more of their patients are appropriately identified. For example, the Ministry will continue to support the INTEGRATE project, which is developing an early identification tool-kit with check-lists and prompts based on the UK Gold Standards Framework and will evaluate its use

in selected Ontario Family Health Teams and regional cancer centres.

The Ministry will work with its partners to continue to build upon educational standards and policies such as the “Decision-making for the End of Life Policy” developed by the College of Physicians and Surgeons of Ontario, to promote timely end-of-life conversations between physicians and patients.

## Eligibility Requirements Vary among Service Providers

Various sources can refer patients for palliative care. For example, referrals to CCACs and hospices can be from family doctors or hospital discharge planners, or made by caregivers or patients themselves. For hospitals, referrals come from a physician or other health-care provider, such as a nurse.

Once a patient is referred, CCACs, hospices and hospitals assess the patient’s eligibility for their services. While there are no province-wide standardized criteria for palliative-care services, all the hospices and hospitals visited based their determination, at least in part, on the Palliative Performance Scale, and one CCAC used it as a guideline. The scale helps determine a person’s condition in several areas, such as evidence of disease, ability to perform self-care, intake of food and fluids, and level of consciousness. Based on research in this area, the score on this scale equates to an estimated time left to live for most patients, with a score of 100% indicating no evidence of disease and a score of 0% being death. (Dementia patients, who live longer than the prognosis attached to their score, are an exception.) Each of the hospices and hospitals we visited had developed its own eligibility criteria for the services provided based on the scale and other factors. Although the eligibility criteria at the hospices visited were not substantially different, each hospital visited required patients to have a different Palliative Performance Scale score, and therefore a different life expectancy, to be eligible. The required

scores ranged from a low of 30% (totally bed-bound), with an estimated life expectancy of about 20 days at one hospital, to 40% (mainly in bed), with a life expectancy of about 39 days at another, to a high of 50% (mainly sit or lie down), with a life expectancy of about 76 days at the third.

In addition, one hospital program accepted patients referred by certain community physicians but had no process in place to confirm whether these patients otherwise met the criteria.

The CCACs also used different criteria and tools to assess patient eligibility for palliative home-care services. For example, one CCAC used the Palliative Performance Scale as a general guideline to help determine admission while the other two did not use this scale, and used alternative tools.

As a result, because eligibility for palliative-care services can vary, patients eligible for services in one area of the province might not be eligible for similar services in another.

Most of the service providers we visited also required patients who need end-of-life palliative care, and who are otherwise eligible for services, to agree to certain care approaches. For example:

- Two of the CCACs visited required patients to agree to a palliative approach, which includes pain and symptom management, and all three hospices visited required patients to cease any curative treatment, unless it was being administered to reduce pain, which is consistent with a palliative approach.
- All of the hospitals and hospices visited required inpatients to agree to a do-not-resuscitate confirmation in the event they stopped breathing or their heart stopped beating.

Patients who did not agree to these conditions could not access these services.

## RECOMMENDATION 4

To better ensure that patients requiring palliative care, including end-of-life care, have similar access to similar services across the

province, the Ministry, in conjunction with stakeholders including the Hospice Palliative Care Provincial Steering Committee, should ensure that standardized patient eligibility practices for similar palliative-care services are developed and implemented.

## MINISTRY RESPONSE

The Ministry will work with the Clinical Council of the Hospice Palliative Care Provincial Steering Committee to explore the development of guidelines to support clinical decision-making regarding access to palliative care, including promoting consistent eligibility practices for similar palliative-care services.

### Community Services Could Reduce Unnecessary and Expensive Hospital-based Care

For people receiving palliative care at home, access to care around the clock is critically important to their comfort and ability to remain at home. If adequate palliative-care services, such as access to physicians and nurses, are not available when needed, patients will likely go to the emergency department to get the required care. This is more difficult for patients because they must travel to hospital, sometimes by ambulance, and is also more expensive than providing patients with the care they need at home.

### Better Access to Physicians Needed

In April 2014, the Ontario Medical Association estimated that the province has 150 to 250 palliative-care specialist physicians, and an additional 200 family physicians who provide mostly palliative care. However, the Ministry had not analyzed their distribution across the province relative to population or where they might be needed most.

Physicians determine whether they wish to provide home-based palliative care to patients. If they decide to do so, they may visit patients at home or

be on call to provide telephone advice during evenings or weekends, for example. All three CCACs we visited had on-call physicians for evenings and weekends, although their availability varied. One of the CCACs visited had palliative-care physicians who made home visits only under exceptional circumstances, while another CCAC indicated that physicians have varying ability to do home visits.

In some instances, physicians might be reluctant to refer a patient to another physician for palliative care, because only one physician is permitted to bill the \$63 fee each week for the patient's palliative-care case management. This fee is in addition to other fees the physician can bill for when providing care for the patient. Despite physicians' values stipulating that patients needs are paramount and must be considered before all else, the billing structure may inhibit good patient care. For example, specialists such as oncologists might be reluctant to refer patients to palliative-care physicians. As a result, some patients might not be referred to palliative-care specialists even though the referral might result in more suitable care. We were informed that the Ontario Medical Association has plans to clarify which physician should bill for a patient's palliative-care case management.

At the time of our audit, 15 expert palliative-care teams, operating in various parts of Ontario, were publicly funded through several Ministry programs. The teams include a physician and others specializing in palliative care, who supported family physicians involved in delivering palliative home care. A 2013 study commissioned jointly by the Ministry and Canadian Institutes of Health Research looked at 11 of these teams and found that their patients had a 30% lower likelihood of visiting an emergency department in their last two weeks of life and a 50% lower likelihood of dying in hospital. The study concluded that the expert palliative-care teams were effective at helping end-of-life patients avoid expensive late-life acute-care hospitalization. Health Quality Ontario, a provincial government agency that, among other things, reports to the public on the quality of the health care system,

supports quality improvement activities and makes evidence-based recommendations on health-care funding, also noted in its summer 2014 report (released for public comment) that implementing palliative-care teams to provide in-home care could result in cost savings of at least \$191 million a year. Increasing the number of such teams has the potential to reduce the need for patients nearing the end of their lives to visit emergency departments. The 2011 Declaration of Partnership proposed a new model under which family physicians could provide basic palliative care to patients instead of referring them to palliative-care physicians. This would free up the palliative-care physicians' time to focus on more complex patients, and to provide support to family physicians and other palliative-care providers when needed for less complex patients. However, according to an April 2014 report by the Ontario Medical Association, family physicians might have the misperception that they will be insufficiently compensated for providing palliative care, even though the report indicates that billing correctly for these services brings generous compensation. To mitigate this issue, the Ontario Medical Association is planning to arrange seminars on billing for palliative care.

## RECOMMENDATION 5

In order to provide patients with the care they need in the community, and help prevent unnecessary and more expensive hospital-based care, the Ministry, in conjunction with the LHINs, should consider options for promoting the provision of palliative care by family physicians, such as the creation of additional palliative-care teams to support family physicians who deliver home-based palliative care. As well, the Ministry should assess physician payments for palliative care, within a palliative-care policy framework, to ensure that patients' needs are best met cost-effectively.

## MINISTRY RESPONSE

The Ministry agrees with the recommendation that primary-care providers play a key role in the provision of palliative care. In conjunction with our partners, the Ministry will consider options for promoting the provision of palliative care by family physicians, within a palliative-care policy framework, to ensure that patients' needs are best met cost-effectively.

### Better Access to Nurse Practitioners and Nurses Needed

The Ministry's September 2011 initiative for new nurse practitioners provided funding for 70 nurse practitioners for palliative care across the province. However, the allocation of funding, which was expected to amount to \$8.1 million per year when all nurse practitioners were fully hired, was not based on factors such as the size of the LHIN, its existing resources, population needs or anticipated demand for palliative services. Instead, the funding was distributed evenly across the province, with each of the 14 LHINs receiving the same level of funding for five new nurse practitioners.

One of the Ministry's key objectives was to let patients have 24/7 access to palliative care at home. However, three years after its announcement, this initiative is not yet achieving its objective. Specifically:

- As of March 2014, the LHINs still had 14 of the 70 nurse practitioners left to hire, or 20%. By summer 2014, only eight of the 14 LHINs had filled all five positions; the rest were still in the process of hiring. The LHINs and CCACs visited indicated that they had difficulty filling these positions due to a lack of available nurse practitioners with palliative-care experience.
- At two of the CCACs visited, the nurse practitioners worked regular weekday hours, when other health-care services were also readily available. They normally did not work evenings or weekends. At the third CCAC, nurse

practitioners worked from 8 a.m. until 8 p.m. seven days a week. This CCAC found that adding the nurse practitioners had a positive impact on hospital admissions: the admission rate for palliative patients without a nurse practitioner was 14% in the 2013/14 fiscal year, while for those with a nurse practitioner, it was only 2%. None of the CCACs visited had a formal on-call schedule for after-hours coverage by the nurse practitioners.

In the 2010/11 fiscal year, one CCAC we visited started an innovative program that involved one nurse working from home, providing advice to four personal support workers who work in patients' homes at night. The personal support workers received additional training to act on the nurse's behalf, and the contact nurse could dispatch a nurse from a CCAC home-care service provider to go to the patient's home if required. While this program did not lower costs, it increased the number of people available to provide care to patients at night. According to the CCAC's analysis, the percentage of patients with a hospital admission in the last 30 days of life decreased significantly under this program when compared to patients receiving regular home-care services.

## RECOMMENDATION 6

The Ministry, in conjunction with the Local Health Integration Networks, should review the distribution of nurse practitioners to ensure that it reflects patient needs and provides patients with access to palliative care at home 24 hours a day, seven days a week. The Ministry should also work with other service providers to develop innovative alternatives for providing nursing care to patients at home.

## MINISTRY RESPONSE

The Ministry will work with the LHINs to review the distribution of nurse practitioners and support palliative patients with access to care at home 24 hours a day, seven days a week. The

Ministry will also work with partners to identify and promote innovative alternatives that support access to care from a range of providers for patients at home.

### Patients Waiting in Hospital for Other Palliative-care Services

People who no longer require hospital care but who remain in hospital while waiting for care elsewhere, are called alternate-level-of-care (ALC) patients. For example, palliative-care patients may wait in an acute-care hospital bed for home-care services, a hospice bed or transfer to a bed in a hospital palliative-care unit. Waiting in an acute-care bed is more expensive than receiving care elsewhere, and can be detrimental to the patient's health for various reasons, including the potential for a hospital-acquired infection. It also prevents other patients who could benefit from an acute-care hospital bed, such as those waiting in hospital emergency departments, from accessing a bed in a timely manner.

According to a report prepared by Cancer Care Ontario for the Ontario Hospital Association, as of April 2014, 137 of the province's 3,808 total ALC patients were waiting in a hospital bed for palliative services elsewhere. Further, according to Ministry data, 10% of all ALC days in Ontario in the 2013/14 fiscal year were due to patients waiting in hospital for palliative care elsewhere. This ranged from about 7% in the Waterloo Wellington and Central West LHINs to 15% in the North East LHIN.

We also noted that not all ALC days were tracked, although the Ministry requires hospitals to do so. Two of the three hospitals we visited did not reclassify patients as ALC if their discharges were delayed due to home-care services, including required equipment, not being ready. One of these hospitals told us that its CCAC does not meet with patients until their discharge date, and therefore, when larger equipment is needed (for example, a hospital-style bed), a patient's discharge is usually delayed a day or two until it can be put in place.

## RECOMMENDATION 7

The Ministry, in conjunction with the Local Health Integration Networks, should ensure that hospitals across the province consistently track and report the extent of time patients no longer requiring acute care must wait in this more expensive setting for care at home or in a hospice, and take action where necessary.

## MINISTRY RESPONSE

The Ministry agrees with the recommendation and presently requires hospitals to track the length of stay of patients designated alternate level of care (ALC). This information is regularly, on a monthly basis, reported by the Local Health Integration Networks (LHINs) and hospitals. However, the Ministry will review the current reporting requirements and will work with the LHINs to ensure that hospitals are consistently tracking and reporting this information for patients requiring palliative care.

### Hospice Beds Not Used Optimally

For a number of reasons, hospices can have vacant beds but not accept patients. Some of the reasons are understandable: for example, hospices need some time after a patient's death to prepare the room for the next patient. However, other reasons are less understandable. For example, one of the hospices we visited limited patient admissions to one per day because of physician availability. As well, this hospice did not admit patients on week-nights or weekends because the pharmacy it used was closed. Another hospice accepted only crisis admissions on evenings and weekends, but this occurred only rarely. At the third hospice, admissions could occur at any time, with most made on weekdays. There is a risk that hospices do not serve as many patients as they could, and some patients not served may seek more expensive hospital care.

The Ministry requires hospices to have a minimum occupancy rate of 80% to fully fund them. In other words, their beds are to be occupied at least 80% of the time on average, and beds can be vacant up to 20% of the time, or over two months a year.

The occupancy rate at two of the hospices we visited was about 80% for the 2013/14 fiscal year—similar to the average occupancy rate province-wide. One of these hospices had a wait list. The third hospice had a lower occupancy rate of only 65% for the 2013/14 fiscal year, but even so, it received full funding from the Ministry. We noted that the Edmonton Zone of Alberta Health Services has a benchmark of 92% occupancy for the hospice sites it fully funds. Given this, and given that the average occupancy rate in Ontario hospices is only 80%, the potential is there for hospices to serve more patients.

### RECOMMENDATION 8

To better ensure that hospice beds are available to patients when needed, the Ministry should explore, such as by reviewing best practices in other jurisdictions, the feasibility of increasing the occupancy rate of hospice beds from the current minimum of 80%.

### MINISTRY RESPONSE

The Ministry agrees with the recommendation and will work in conjunction with the LHINs to review occupancy rates in residential hospices and consider the feasibility of increasing the occupancy rate of hospice beds.

## Public Education on End-of-life Care Services and Planning Needs Improvement

### Easier Public Access Needed to Information on Palliative-care Services

To help patients who could benefit from palliative care, more people need to learn what palliative care

entails, what services exist in the community, and how to access these services. Otherwise, there is a risk that patients will suffer unnecessarily by not receiving timely palliative care, or that the health system will incur unnecessary costs when patients go to a hospital emergency department.

Information on palliative care is available from CCACs, hospitals, family physicians and other service providers. This information may be provided through websites, verbal discussion, brochures and/or newsletters to patients and their families, but not everyone knows to ask for the information or where to look for it. To address a broader spectrum of the population, the province-wide CCAC-sponsored website ([thehealthline.ca](http://thehealthline.ca)) provides thousands of listings of health-care facilities, support groups and other services, including end-of-life care. However, this website does not provide eligibility criteria for services or any associated costs, so people cannot readily determine if a program might be appropriate for them or a loved one. The 2011 Declaration of Partnership also highlighted the issue that patients and their families do not know how to access the palliative-care services available to them.

At the time of our audit, the Communication and Awareness Working Group of the Ministry's Hospice Palliative Care Provincial Steering Committee was reviewing the public information available about palliative-care services. The working group planned to create a list of educational resources for the public and health-service providers by March 2015.

### Need for Advance Care Planning for End-of-life Care

Advance care planning lets individuals communicate their values and wishes regarding health care in the event they become incapable of making such decisions. This planning involves discussions with family, friends and health-care providers, as well as appointing a substitute decision-maker who can speak for the person if the patient is unable to do so. For patients with a terminal illness, advance

care planning helps ensure that they receive health care consistent with their preferences. For example, the plan might instruct a substitute decision-maker to withhold consent for aggressive treatment that could reduce the quality and in some cases the length of a person's remaining life. Advance care plans can be updated as needed, such as when a patient's condition or wishes change.

Health-care providers have recognized the importance of advance care planning, and initiatives to increase public awareness have taken place. Nationally, the Speak Up campaign, sponsored in part by Health Canada, began in 2011 and encouraged people to have conversations with loved ones about their plans. The Ministry endorses the associated Speak Up Ontario campaign, which informs Ontarians about advance care planning.

In April 2014, the Ontario Medical Association also indicated the importance of advance care planning in its End-of-Life Care funding initiative and highlighted the importance of making conversations about death and dying a more normal part of health-care discussions. The initiative cited 2011 research that 42% of dying patients require someone to make decisions for them, but noted that only one-quarter of people over the age of 30 had made an advance care plan for end-of-life care. The initiative also noted that advance care planning can lower health-care costs by decreasing the use of intensive-care units in hospitals and reducing the use of unbeneficial chemotherapy.

While only two of the hospices and one of the CCACs visited had a formal policy on discussing advance care planning with their patients, the other organizations visited all indicated that they would discuss advance care planning with their patients. However, we noted that once a patient creates an advance care plan, it is not readily available to all of the patient's health-care providers. For example, the CCACs we visited kept a copy of patients' advance care plans in their electronic information systems, which outside health-care providers, such as hospital staff and physicians, could not access. Having this information available to all of the

patient's health-care providers would better ensure that providers can readily obtain consent from the patient or their substitute decision-maker to provide care in accordance with the patient's wishes.

Two hospitals we visited shared some patient clinical records electronically with hospitals in the region or in a neighbouring region, but not the advance care plans. However, another hospital we visited shared clinical records electronically, including advance care plans, with six other hospitals in the region. This hospital indicated that there is currently no province-wide standardized policy on where advance care plans should be documented in a patient chart, and so they are often documented as part of clinical notes. Therefore, although advance care plans are shared, other health-care providers have to go through lengthy records to find them. On this hospital's standard discharge summary, which is automatically shared with the patient's other service providers such as the family physician, one section indicates whether a patient opted to not receive cardiopulmonary resuscitation; however, a patient's full advance care plan is not included.

## RECOMMENDATION 9

To better ensure that patients receive health care consistent with their preferences and reduce unnecessary health-care costs, the Ministry, in conjunction with stakeholders, should ensure that:

- public information is readily available on palliative-care services and how to access them, as well as on the importance of advance care planning for end-of-life care to communicate health-care preferences; and
- processes are in place to allow health-care providers timely access to patients' advance care plans to inform their discussions with patients or their substitute decision-makers.

## MINISTRY RESPONSE

The Ministry will work with its partners to implement this recommendation by continuing

to broaden the availability of public information on palliative care and the importance of advance care planning. The Ministry will also continue to support the work which is underway through the Communications and Public Awareness Working Group, which has been established by the Palliative Care Steering Committee.

## Lack of Measures to Monitor Performance

Collecting and reviewing performance indicators is vital to assess whether a program is effective and helps identify areas that need improvement. Without a good monitoring system, resources can be misallocated. In this regard, we found that standardized measures were not in place to track palliative-care services. For example, although all CCACs recorded information on certain aspects of palliative care, such as number of patients served and number of home visits to patients, it was not being tracked in a consistent and comparable manner.

Although all the LHINs have service accountability agreements with both their CCACs and every hospital, only one hospital we visited had an agreement containing specific palliative-care indicators. This agreement was between one LHIN and one hospital and included two indicators: the proportion of admissions to palliative-care units through the emergency department, and the rate of hospital readmission for patients requiring palliative care. Overall, the LHINs had little information on the delivery of palliative-care services at hospitals and CCACs, and could not evaluate the efficiency or effectiveness of these services.

With respect to hospices, the Ministry has not analyzed whether the \$108 million provided in total through the CCACs to hospices between the fiscal years 2005/06 (when the Ministry first started funding hospices) and 2013/14 has reduced the number of alternate-level-of-care patients (that is, patients who are waiting in an acute-care hospital bed for care elsewhere) or reduced emer-

gency department visits. Furthermore, while most hospices voluntarily submitted information to the Hospice Palliative Care Association on indicators such as the locations from which patients were admitted, age of patients served and the number of deaths, this data was not tracked in a consistent manner and was therefore not comparable.

To help address the lack of standardized performance measures for palliative care, a working group of the Hospice Palliative Care Provincial Steering Committee is attempting to identify five key provincial palliative-care indicators. The group expects to complete this work by fall 2014. It will be collaborating with a working group of Health Quality Ontario, which is in the early stages of developing best-practice and evidence-based quality indicators for palliative care.

Consistent and comparable information is needed to make good decisions about current and future palliative-care services. A provincial set of performance indicators would allow benchmarks to be established and comparisons to be made across similar programs province-wide; this could facilitate the sharing of palliative-care best practices. These indicators could also be used for LHINs to hold health-care service providers accountable for achieving a certain level of performance and in turn for the Ministry to better hold LHINs accountable.

### RECOMMENDATION 10

To better monitor the delivery of palliative-care services in Ontario, the Ministry, in conjunction with the Hospice Palliative Care Provincial Steering Committee, should adopt standard palliative-care performance indicators and associated targeted performance levels for all key service providers to allow the comparison of their programs' efficiency and effectiveness, and to identify areas requiring improvement.

## MINISTRY RESPONSE

The Ministry supports this recommendation and will work with its partners to address implementation.

Work is underway through a Data and Performance Working Group, which is co-chaired by the LHINs and Cancer Care Ontario, to develop and implement a data and performance measurement strategy for the delivery of palliative care in Ontario.

### 2011 Vision for Palliative Care Lacks Linkage to Government Policy Framework

Since 2005, the Ministry has supported a number of initiatives intended to improve palliative-care service delivery. As shown in **Appendix 2**, these initiatives focus on a number of areas, including improving patient access to palliative care (for example, through better co-ordination and integration of palliative-care services and service providers); providing educational support for service providers; building public awareness of palliative services and the importance of advance care planning for end of life; and developing provincial indicators for monitoring palliative care.

In 2005, the Ministry established a three-year provincial End-of-Life Care funding initiative to:

- shift care of the dying from acute-care settings (mainly hospitals) to appropriate alternative settings such as at home and hospices;
- enhance and develop multidisciplinary service capacity in the community; and
- improve access to, co-ordination of and consistency of services and supports across the province.

A Ministry-funded analysis completed in 2008 found that an increased number of patients were receiving care in the community. It also found improved communication among providers of palliative-care services and improved care co-ordination

for patients. However, it noted that inequities and barriers to accessing end-of-life care still existed across regions and service sectors in Ontario.

Subsequently, in 2011, *Advancing High Quality, High Value Palliative Care in Ontario: A Declaration of Partnership and Commitment to Action* (Declaration of Partnership) was issued jointly by the Ministry, LHINs and the Quality Hospice Palliative Care Coalition of Ontario. The document reflected a collaboration by more than 80 stakeholders from across Ontario to develop a vision for the delivery of palliative care in the province. These stakeholders included the Ministry, LHINs, CCACs, hospitals, Hospice Palliative Care Ontario, the College of Nurses of Ontario and the Ontario College of Family Physicians. The Declaration of Partnership's main goal is greater system integration that puts patients and their families at the core of decisions being made to improve end-of-life care. Other key goals are to improve client/family, caregiver and provider experience by delivering high-quality, seamless care and support; improve, maintain and support the quality of life and health of people with progressive life-limiting illnesses; and deliver better care more cost-effectively and create a continuously self-improving system.

The Declaration of Partnership includes over 90 commitments by stakeholders to improve the delivery of palliative care in Ontario. Responsibility for most of the commitments rests with the following three parties:

- the Ministry (responsible for about 35% of the commitments, many in partnership with the LHINs and other stakeholders)—for creating policy and providing stewardship;
- the LHINs (responsible for about 45% of the commitments)—for implementing a regional structure to deliver palliative care; and
- the Quality Hospice Palliative Care Coalition of Ontario (responsible for about 20% of the commitments)—for strengthening caregiver supports, improving service capacity and developing public education and awareness opportunities.

In December 2012, a Hospice Palliative Care Provincial Steering Committee was established to oversee the implementation of the Declaration of Partnership. The committee oversees three working groups and a clinical council:

- Residential Hospice Working Group—to develop, among other things, options for the implementation of best practices for hospices;
- Data and Performance/Quality Working Group—to develop a set of provincial indicators for palliative care;
- Communication and Awareness Working Group—to review websites regarding palliative care, with a goal of creating a central hub of information; and
- Clinical Council—to drive clinical change and ensure physicians are engaged and supportive of the work being undertaken on the Declaration of Partnership.

The Hospice Palliative Care Provincial Steering Committee is expected to report in fall 2014 on the status, as of March 2014, of the Declaration of Partnership commitments.

Although the Declaration of Partnership is comprehensive with regard to palliative care, we noted that it included almost no timelines for implementation or other accountability components. Instead, the stakeholders committed to take action “as soon as practical.” The Ministry did establish a March 2015 deadline for the LHINs to accomplish seven core deliverables, including the creation of a regional palliative-care structure and outreach processes, implementation of a care co-ordination role, establishment of performance-related measures and an update of accountability agreements with service providers to improve accountability. We found that all the LHINs visited had made some progress in implementing a care co-ordination role and were working toward accomplishing the other core deliverables. However, at the time of our audit, it was unlikely that the three LHINs visited would meet all of the core deliverables by the March 2015 deadline.

Overall, significantly more work needs to be done by the Ministry, LHINs and the Quality Hos-

pice Palliative Care Coalition of Ontario to complete the key commitments in the Declaration of Partnership. For example, the LHINs visited still need to complete a gap analysis of the palliative-care services that exist within their areas and update their accountability agreements with hospitals and CCACs to include palliative-care performance. The Ministry still needs to develop policy statements to promote interprofessional teams to deliver palliative care. As well, the Quality Hospice Palliative Care Coalition of Ontario still needs to co-ordinate common information guides that would be available provincially and adopted by all sectors. The commitments in the Declaration of Partnership should be linked to a policy framework for approval by the government. This framework could outline the necessary direction and funding to support the implementation of the commitments.

### RECOMMENDATION 11

To better ensure that the key goals and commitments made in the 2011 document *Advancing High Quality, High Value Palliative Care in Ontario: A Declaration of Partnership and Commitment to Action* (Declaration of Partnership) are being addressed on a timely basis, the Ministry, in conjunction with the Hospice Palliative Care Provincial Steering Committee, should link the Declaration of Partnership to a policy framework for approval by the government. Such action would provide the necessary direction and funding if needed to ensure that timelines for implementing the commitments are established, along with effective oversight to regularly monitor the implementation’s progress and take action where necessary.

### MINISTRY RESPONSE

This Ministry appreciates the Auditor General’s positive feedback regarding the strategic value of the Declaration of Partnership and will take appropriate steps to develop and seek approval for a policy framework that addresses this recommendation.

## Appendix 1—Roles and Responsibilities of Selected Organizations

Prepared by the Office of the Auditor General of Ontario

Organization*	Key Responsibilities
Ministry of Health and Long-Term Care (Ministry)	<p>The Ministry of Health and Long-Term Care has overall responsibility for Ontario's health-care system, including palliative-care services. This involves establishing overall strategic direction; monitoring and reporting on the performance of the health system; planning for and establishing palliative-care funding models; and ensuring that strategic directions and expectations are fulfilled.</p> <p>The Ministry funds various palliative services through the Local Health Integration Networks, including hospitals, Community Care Access Centres, hospices and long-term-care homes. The Ministry also funds Cancer Care Ontario to fund certain hospital services, including palliative care for cancer and chronic kidney disease patients.</p>
Local Health Integration Networks (LHINs)	Ontario has 14 Local Health Integration Networks. LHINs are responsible for planning, co-ordinating, funding and monitoring palliative-care services in their regions. LHINs also lead the development of palliative-care models, which set out how palliative-care services are delivered within their area. As well, LHINs flow Ministry funding to palliative service providers either directly (such as to hospitals and some hospices) or through the Community Care Access Centres.
Community Care Access Centres (CCACs)	There are 14 Community Care Access Centres across the province, one in each LHIN. The CCACs accept referrals and determine eligibility for patients requiring home-care services, such as in-home nursing and personal support, or a hospice. The CCACs arrange for these services, which they provide directly or through external service providers. As well, the CCACs provide referrals to other community-based support services, such as those offering transportation.
Hospitals	Ontario hospitals may provide palliative-care services to patients in a regular acute-care bed, in beds used for palliative care that may be in a separate hospital ward, or through outpatient services.
Hospices	Ontario has 36 hospices with 271 beds (including four hospices with 11 beds that are not funded by the Ministry) that provide a home-like environment where people with life-threatening illnesses receive end-of-life care. These services include pain and symptom management, and compassionate care during the last stages of a patient's life. Hospices may offer day programs and other programs such as anticipatory grief and bereavement counselling for family and caregivers.
Long-term-care (LTC) Homes	Ontario has over 630 long-term-care homes with 76,000 beds. LTC homes may provide palliative-care services to residents as needed.
Palliative Care Networks	Twelve of the 14 LHINs have a Palliative Care Network. Members of the networks are palliative-care service providers, including the associated CCAC, hospitals and physicians within the LHIN. The networks' goal is to improve palliative-care services within the LHIN by bringing service providers together to discuss, plan and co-ordinate palliative care.
Cancer Care Ontario and Regional Cancer Programs	Cancer Care Ontario is the provincial government agency primarily responsible for, among other things, improving Ontario's cancer and chronic kidney disease health systems, including access to palliative care for these patients. Its palliative-care services program is provided through 13 Regional Cancer Programs.

\* In addition to the organizations listed, there are a number of other community-based organizations, over 60 of which receive funding from the Ministry, that provide support services, such as companionship visits, caregiver support and group counselling sessions, for persons with advanced illness in their homes or in the community.

## Appendix 2—Key Ministry Initiatives to Improve Palliative Care in Ontario

Prepared by the Office of the Auditor General of Ontario

**Provincial End-of-Life Care Funding Initiative, October 2005**—The objectives of this three-year funding initiative were to:

- shift care of the dying from acute-care settings (mainly hospitals) to appropriate alternative settings, such as at home and hospices;
- enhance and develop multidisciplinary service capacity in the community; and
- improve access, co-ordination and consistency of services and supports across the province.

**Integrated Client Care Project, March 2011**—This is a multi-year initiative that focuses on integrating services across certain health-care areas: primary care, home care, hospitals and community support services. The project's second phase, which was launched in September 2011, involves palliative care and is ongoing. It includes developing a process for patients to navigate the palliative-care system, and using care teams to assess patients' needs and co-ordinate care with the appropriate health service providers (e.g., home-care providers or other community support service organizations).

**Palliative Care and Collaborative Practice Mentorship Program, December 2011**—This program, run through Cancer Care Ontario, aimed to build supportive relationships between inter-professional primary health-care teams (including physicians and nurses) and palliative-care experts, increase palliative-care knowledge and skills, and enhance collaborative practice. This program is in the last of four phases, and is expected to benefit cancer patients as well as palliative-care patients with other diagnoses.

**Community-based Nurse Practitioners Initiative (9,000 Nurses Initiative), September 2011**—This initiative included Ministry funding for the addition of 70 nurse practitioners (five new nurse practitioners per Community Care Access Centre) to provide community-based palliative care across the province. The program's goals included providing 24/7 coverage for patients requiring palliative care at home.

**Advancing High Value, High Quality Palliative Care in Ontario—A Declaration of Partnership and Commitment to Action, December 2011**—This document outlines a shared vision of the Ministry and about 80 other stakeholders, and goals for Ontario's palliative-care system. It includes over 90 commitments by stakeholders to improve the delivery of palliative care.

**Hospice Palliative Care Provincial Steering Committee, December 2012**—This committee was created to guide collaborative efforts to achieve the commitments in the Declaration of Partnership. Membership consists of stakeholders including representatives from the Ministry, LHINs, CCACs, Quality Hospice Palliative Care Coalition, Cancer Care Ontario, Ontario Hospital Association, Hospice Palliative Care Ontario, Provincial End of Life Care Network, Ontario Long-Term Care Association, Ontario Association of Non-Profit Homes and Services for Seniors, Community Support Service providers and the Ontario College of Nurses. The committee reports to the Ministry/LHIN CEO Management Committee, which meets to discuss major system transition issues, strategies and policy changes.

The steering committee has three working groups and a council:

- Residential Hospice Working Group—to develop, among other things, options for the future implementation of best practices for hospices;
- Data and Performance/Quality Working Group—to develop a set of provincial indicators for palliative care;
- Communication and Awareness Working Group—to review websites regarding palliative care, with a goal of creating a central hub of information; and
- Clinical Council—to drive clinical change and ensure that physicians are engaged and supportive of the work being undertaken on the Declaration of Partnership.

**Health Links, December 2012**—Established to encourage greater collaboration among health-care providers, including family physicians, specialists, hospitals and home-care service providers, for their high-needs patients. These may include patients requiring palliative care. As of July 2014, 47 Health Links groups have been established and more are planned.

## Appendix 3—Glossary of Terms

Prepared by the Office of the Auditor General of Ontario

**Acute-care hospital**—A hospital that offers short-term, intensive inpatient treatment and care to patients with serious health problems. An acute-care hospital can provide palliative care to patients in a designated palliative-care unit or in regular beds throughout the hospital.

**Advance care planning**—A process to communicate an individual's values and wishes to others regarding future health-care preferences in the event that the patient becomes incapable of making health-care decisions.

**Alternate level of care (ALC)**—A designation that is applied when an individual is ready to be discharged from hospital, but is waiting in a hospital bed for post-discharge care to be arranged, such as home-based palliative care or placement in a hospice or long-term-care facility.

**Canadian Hospice Palliative Care Association (CHPCA)**—A national association that advocates for good-quality palliative care, including end-of-life care. This includes promoting public policy, education and awareness of palliative care.

**Canadian Institute for Health Information (CIHI)**—A not-for-profit organization created by the federal, provincial and territorial governments that collects and analyzes information on health-related matters in Canada, including palliative care. CIHI's data and reports may be used to inform health policies, support the effective delivery of health services and raise awareness among Canadians of the factors that contribute to good health.

**Canadian Institutes of Health Research**—The government of Canada's health research investment agency, which works to create new scientific knowledge and to enable its translation into improved health, more effective health services and products, and a strengthened Canadian health-care system. It is composed of 13 institutes and provides leadership and support to health researchers and trainees across the country.

**Canadian Medical Association**—A voluntary professional association that, among other things, advocates for physicians and patients in Canada.

**Cancer Care Ontario**—A provincial government agency responsible for, among other things, improving cancer and chronic kidney disease services, including palliative care, in Ontario.

**Community Care Access Centres (CCACs)**—CCACs co-ordinate home and community services for seniors, people with disabilities and people who need health-care services to help them live independently. CCAC services include providing palliative home-based care, and co-ordinating long-term-care home placements and most hospice placements. There are 14 CCACs across the province, one for each Local Health Integration Network.

**Cardiopulmonary resuscitation (CPR)**—A series of lifesaving procedures that include chest compressions to assist with blood circulation to the heart and brain, improving the chance of survival for patients who experience cardiac arrest.

**Declaration of Partnership**—The short name for the 2011 vision for palliative care in Ontario: *Advancing High Quality, High Value Palliative Care in Ontario: A Declaration of Partnership and Commitment to Action*. This document was developed by the Ministry of Health and Long-Term Care and about 80 stakeholders. The Declaration of Partnership outlined goals for a palliative-care system, and included over 90 commitments by stakeholders to improve the delivery of palliative care in Ontario.

**Do-not-resuscitate (DNR) confirmation**—A document signed by a medical professional indicating that a patient does not want lifesaving measures such as cardiopulmonary resuscitation (CPR) if his or her heart or breathing stops. DNR confirmations are mostly used by patients who would not benefit from CPR, for example, because they have a terminal illness and are nearing their end of life.

**Health Quality Ontario (HQP)**—A provincial agency that evaluates the effectiveness of new health-care technologies and services, reports to the public on the quality of the health-care system, supports quality improvement activities, and makes evidence-based recommendations on health-care funding.

**Hospice**—A home-like facility that provides palliative care to terminally ill people and their families. Residential hospices provide accommodation for people who do not require hospital-based care, but either cannot be cared for at home or do not wish to remain at home, in the last weeks or months of life.

**Hospice Palliative Care Ontario (HPCO)**—An organization that, among other things, promotes awareness, education and best practices in the provision of palliative care in Ontario. Its member organizations deliver palliative-care services in Ontario.

**Hospice Palliative Care Provincial Steering Committee**—A committee of numerous stakeholders established in December 2012 to guide collaborative efforts to achieve the commitments in the Declaration of Partnership. Members include the Ministry of Health and Long-Term Care, LHINs, CCACs, Hospice Palliative Care Ontario, Quality Hospice Palliative Care Coalition, Cancer Care Ontario, Ontario Hospital Association, Provincial End of Life Care Network, Ontario Long-Term Care Association, Ontario Association of Non-Profit Homes and Services for Seniors, Community Support Service providers, Cancer Care Ontario palliative-care physician group, and the Ontario College of Nurses. The committee reports to the Ministry/LHIN CEO Management Committee, which meets regularly to discuss major system transition issues, strategies and policy changes.

**Local Health Integration Network (LHIN)**—LHINs are responsible for prioritizing and planning health services in Ontario and for funding certain health-service providers, including hospitals and CCACs. There are 14 LHINs, representing 14 geographic areas of Ontario; each LHIN is accountable to the Ministry of Health and Long-Term Care. Each hospital and CCAC is directly accountable to its LHIN, rather than to the Ministry, for most matters.

**Long-term-care home (LTC home)**—These provide care, services and accommodations to people who require the availability of 24-hour nursing care, supervision in a secure setting, or frequent assistance with activities of daily living such as dressing and bathing. LTC homes can provide palliative care to their residents. LTC homes are sometimes called nursing homes or homes for the aged. LTC homes are legislated by and receive funding from the Ministry of Health and Long-Term Care.

**Nurse practitioner (NP)**—A registered nurse with additional education and experience, and therefore able to order and interpret diagnostic tests, communicate diagnoses and prescribe drugs to patients.

**Oncologist**—A physician who specializes in treating people with cancer.

**Ontario Association of Community Care Access Centres (OACCAC)**—A not-for-profit organization that represents and supports the common interests of the 14 Community Care Access Centres.

**Ontario Medical Association**—A professional association that represents the interests of Ontario's medical profession, including negotiating compensation for Ontario's physicians with the Ministry of Health and Long-Term Care.

**Palliative care**—Palliative care is aimed at relieving pain and suffering and improving the quality of life for people who are living with, or dying from, an advanced illness or are bereaved. Palliative care aims to meet not only physical needs, but also the psychological, social, cultural, emotional and spiritual needs of each patient and his or her family.

**Palliative Care Network**—Brings together local stakeholders (such as hospitals, CCACs, community support services, physicians and educators) to improve the quality of palliative care. Membership usually includes individuals or organizations with an interest in palliative care. The networks coincide with LHIN geographic boundaries; currently, 12 of the 14 LHINs have a network.

**Palliative-care physician**—A physician with competence in the provision of palliative care including the ability to assess and manage pain, and to address psychological, social, and spiritual issues that might arise when treating patients with a terminal illness.

**Palliative-care unit**—An inpatient hospital unit that focuses on providing care and comfort, including pain control and symptom management, for people who are nearing the end of life, as well as helping patients and their families manage distress and other emotions faced at the end stages of life.

**Palliative Performance Scale**—An assessment tool that measures a patient's functional status and assigns a score. The lower the score, the less time the patient is estimated to have remaining to live. The scale provides a way to measure progressive decline over the course of a patient's illness.

**Personal support worker**—Provides non-medical care to patients, which may include assistance with tasks of daily living such as personal hygiene and eating, as well as homemaking, such as changing bed linens and meal preparation.

**Quality Hospice Palliative Care Coalition of Ontario**—Formed in 2010 to bring together Ontario organizations with an interest in palliative care, including Hospice Palliative Care Ontario, the Ontario Association of CCACs, the Ontario Medical Association and universities. The coalition's goal is to ensure good-quality palliative care for all Ontarians. It participated in developing the Declaration of Partnership report.

**Royal College of Physicians and Surgeons of Canada**—The national professional association that oversees, among other things, the medical education of specialists in Canada, including accrediting university programs that train resident physicians for specialty practices.

**Speak Up**—A national campaign developed by organizations including the Canadian Hospice Palliative Care Association and the Canadian Researchers of the End of Life Network to raise awareness of the importance of advance care planning.

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