Access to Palliative Care in Canada

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Executive summary

Canadians are living longer, but they are not always living better. For many people, living longer means a struggle with poor health caused by chronic conditions, degenerative diseases or cancer. Thanks to improved medical treatments, declines in health are now more gradual, but this can also draw out the process of dying. When this happens, palliative care can help to improve quality of life for people of all ages with life-limiting illnesses by relieving symptoms, enabling a peaceful and dignified death, and providing support to family through the dying and bereavement process.

As the population ages and Canadians become increasingly aware that death can be managed better, the need for palliative care is expected to rise. That makes it important to understand whether Canadians in need of palliative care and community supports are receiving these services. When the state of publicly funded palliative care in Canada is understood, health system planners can identify service gaps and develop strategies for improving care. This report is intended to help with that work, although it is limited by gaps in comparable information on access to palliative care in Canada.

This report aims to provide a better understanding of

1. How Canadians access palliative care in the community and other care settings;
2. Whether Canadians have equitable access to palliative care;
3. Whether the care provided is effective and appropriate;
4. Whether clinicians are prepared to provide palliative care; and
5. Whether patients and their families are involved in planning end-of-life care and are receiving the support they need.

The main findings from this report are as follows:

- **Community palliative care allows people to remain at home, whether that's a private residence or a care home.** Surveys of Canadians show that most would prefer to die at home if they could get the support they need. Our research shows that getting palliative care at home or in long-term care in the year before you die increases the chance you will die at home. Canadians who got palliative care at home were 2.5 times more likely to die there than those who received regular home care. Residents who received palliative care in their long-term care home were more likely to die there than residents who did not receive palliative care in the last year of life.
- **Few Canadians receive palliative care at home in their last year of life.** Many Canadian jurisdictions name community palliative care as a priority, but few Canadians receive formal palliative care outside of hospitals. In provinces where this could be measured (Ontario and Alberta), fewer than 1 in 6 people (15%) who died in 2016–2017 received publicly funded palliative home care.

- **Earlier integration of palliative care may provide benefits for both patients and the health system.** Across care settings, most people who had palliative care in 2016 received it only in the last month of life. However, those who received palliative care earlier on were less likely to visit emergency departments frequently or to receive aggressive treatment at the end of life, as measured by stays in intensive care units.
- **There is room to improve both the integration of care and the transition of patients between settings at the end of life.** More than 80% of the time when people in hospital primarily received palliative care, the stay was unplanned or they were admitted through the emergency department. In 10% of those hospitalizations, patients had to wait a median of 9 days to be discharged to a more appropriate setting (while designated as needing an alternate level of care).
- **People who did not die of cancer and older seniors were less likely to receive palliative care in their last year of life.** Although there is unmet need for palliative care across all disease groups, cancer patients were 3 times more likely to receive palliative care than others, both in hospital and at home. Age was also a factor: adults age 45 to 74 were more likely than younger adults and older seniors to receive palliative care across most settings of care.
- **Few providers specialize in providing palliative care.** Although limited, available data suggests that few health care providers in Canada specialize or practise primarily in palliative care. Alberta reports that just 1% of doctors practised primarily in palliative care in 2012–2013, while 2% of licensed practical nurses across Canada in 2016 worked most of the time in this area. Data from an international survey of primary care physicians shows that Canadian doctors, on average, feel less prepared to manage care for palliative patients than do their peers in 10 other countries.
- **Friends and family members play an essential role in palliative home care, although more support may be needed.** Almost all (99%) palliative home care clients had family or friends helping to care for them, making it possible for them to stay at home. About 1 in 3 caregivers reported distress.
- **Variations in provincial and territorial policies, strategies, frameworks and funding models** affect the organization and delivery of palliative care services — and access to them — across the country. There are also variations within jurisdictions, with some health regions or institutions developing their own criteria regarding who qualifies for palliative care.

Limitations in producing this report include the following:

- **Information gaps on access to palliative care,** notably at the community level, where data is lacking on home care, hospice care and residential care: Across all sectors of care, there is a lack of data on the basket of palliative services patients receive, and on what patients and their families experience.
- **The lack of a single shared definition of palliative care in Canada and common standards for delivering it in practice:** Across settings of care, there is no consensus on what receiving palliative care means and what services this should include. This makes comparable measurement a challenge.

About this report

The report uses CIHI’s Health System Performance Measurement Framework as a guide for exploring the different dimensions of access to palliative care, including whether it is patient-centred, is effective, and delivers equitable and appropriate services. For examples of effective palliative care, see “Spotlight on innovation” throughout this report.

The analyses in this report primarily use CIHI data on acute care, complex continuing care, emergency departments, long-term care facilities, home care, physician billings, publicly funded drug programs and human resources.

All deaths in acute care hospitals, long-term care facilities or home care settings were included in the analysis, regardless of the cause of death. Of those who died in acute care, 94% were hospitalized with a non-sudden condition that could potentially have benefited from palliative care. Cancer, renal failure and heart failure were 3 of the most common conditions.

Those 6% who died suddenly in acute care were also included because they might also have had other existing health conditions that could have benefited from palliative care. Many home care clients and long-term care residents included in this report had been living with frailty and/or chronic conditions that might have warranted palliative care.

For the purposes of this report, the following were considered to have received palliative care in their last year of life:

- Those who were identified as palliative home care clients;
- Those who had a long-term care assessment with palliative care recorded;
- Those who had a doctor’s visit billed for palliative care; and
- Those who had a hospitalization primarily for palliative care.

All provinces and territories submit acute care data; however, data is not available for all provinces and territories for care provided outside of hospitals. As a result, some analyses were limited to people who received palliative care and died in the same place.

For certain pieces of this report, analyses are specific to Ontario and Alberta in 2016–2017, because those 2 jurisdictions have more data available from across settings. These analyses include data on home care clients who died at home and those who died in long-term care, and from the emergency department, acute and subacute care settings (including complex continuing care facilities in Ontario). Together, deaths identified in these settings accounted for about 83% of all adult deaths in Ontario and Alberta.

This report is limited to the adult population (age 19 and older) because health conditions affecting children and youth progress differently.

Information on the methods and data sources used for this report are in Appendix A.

Introduction

What is palliative care?

Palliative care addresses the needs of people with life-limiting conditions to improve quality of life for them and their families. Improving quality of life begins with identifying, assessing and alleviating pain and other physical, psychosocial and spiritual issues.[1] Estimates suggest that between 62% and 89% of those who die could benefit from palliative care — including nearly everyone who does not die unexpectedly.[2–6]

Elements of good palliative care

According to the World Health Organization, palliative care

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten or postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patient's illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- Will enhance quality of life and may also positively influence the course of illness; and
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Importance of palliative care

Canadians are dying differently than in the past, when many deaths occurred suddenly, from accidents or heart attacks.[7] In contrast, in 2013, 7 of the top 10 causes of death in Canada were chronic conditions.[8] As the population ages, the prevalence of chronic conditions increases — but at the same time, thanks to improvements in treatments, declines in health are more gradual.[7] This means that people are living longer, but with more life-limiting conditions, such as organ failure, dementia or cancer. Canadians of all ages dealing with these life-limiting chronic conditions can have their quality of life improved by palliative care.

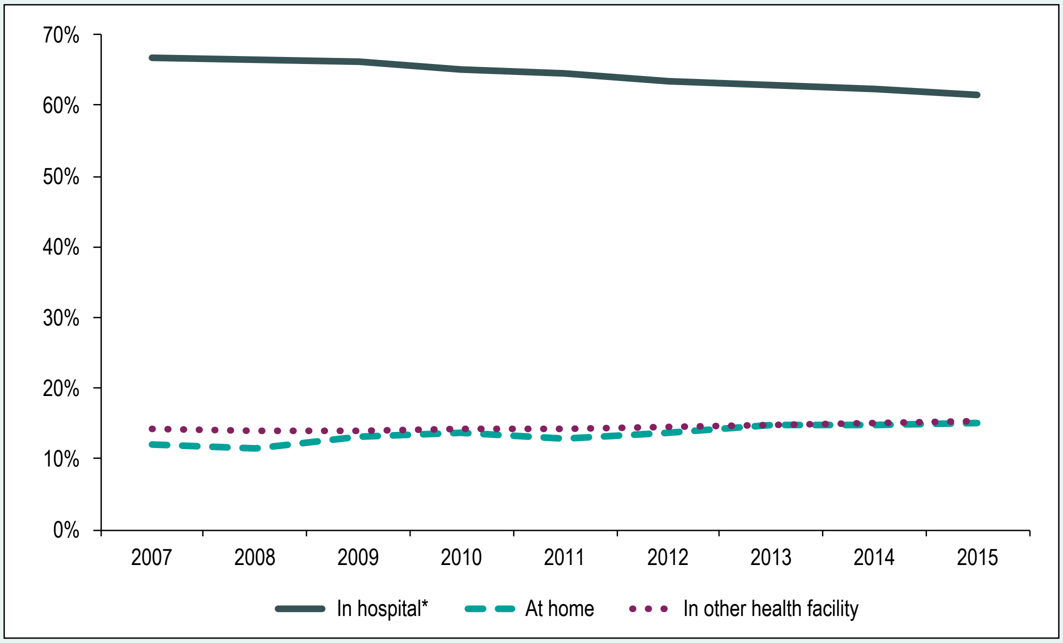
Recent legislative developments have also heightened the need to improve our understanding of access to palliative care in Canada:

- In June 2016, Parliament passed Bill C-14, *An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying).* Similar legislation was enacted in the province of Quebec 6 months earlier. The law allows Canadians age 18 and older who are mentally competent and who have grievous and irremediable medical conditions to receive medical assistance in dying. Debate over the legislation raised questions of whether Canadians are considering assisted death because they lack access to quality palliative care,[9] and the law therefore requires that access to palliative care be measured as part of monitoring medical assistance in dying.[10]
- In August 2017, all provinces and territories agreed to A Common Statement of Principles on Shared Health Priorities. It highlighted the need to improve access to home and community-based services, including palliative home care and residential hospices.[11]
- In December 2017, Parliament gave final assent to *An Act providing for the development of a framework on palliative care in Canada* to support improved access to palliative care.[12] Several provinces and territories have developed their own palliative care frameworks and strategies (see Appendix B).

Location of deaths in Canada

A survey conducted in 2013 found that 75% of Canadians who had a preference would choose to die in their home.[13] It was one of many similar reports over the years. Although some people may change their minds about where they want to die during the course of their illness,[14] statistics suggest that few Canadians are dying where they prefer: in 2015, 61% of Canadians died in hospital while only 15% died at home.

Figure 1 Location of death, 2007 to 2015



Notes

* Statistics Canada's definition of "hospital" includes both acute care and other hospitals not included in CIHI's Discharge Abstract Database and Hospital Morbidity Database, including rehabilitation and geriatric hospitals.

Adapted from Statistics Canada, *Deaths by Locality, 2007 to 2015*. This does not constitute an endorsement of this product by Statistics Canada.

Source

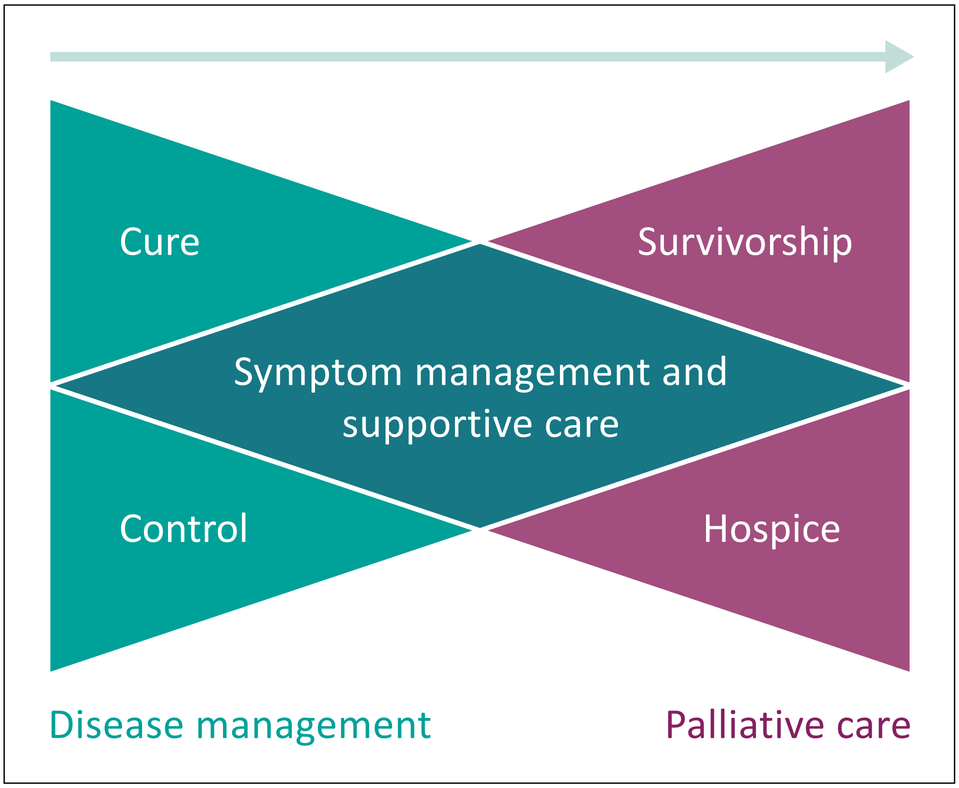
Statistics Canada, *Deaths by Locality, 2007 to 2015*. Reproduced and distributed on an as-is basis with permission from Statistics Canada.

Figure 1 shows that there has been a decrease in the proportion of deaths in hospital (including acute and other types of hospitals) over an 8-year period. The percentage of Canadians dying in other facilities has remained relatively stable since 2007; those facilities include long-term care homes and palliative care residential hospices.

For provincial and territorial details on location of death in 2015, please see Appendix C.

An integrated model of palliative care

Figure 2 Basic model of integrated palliative care



Note
Adapted with permission from Canadian Virtual Hospice.
Source
Canadian Virtual Hospice; Pippa Hawley. The bow tie model of 21st century palliative care. 2015.

This "bow tie" model of palliative care was developed by Pippa Hawley, head of the Division of Palliative Care in the Department of Medicine at the University of British Columbia. Dr. Hawley stated, "Palliative care teams are still often only resorted to when all hope of cure or disease control has been lost. Late referrals limit our ability to achieve maximum potential for the relief of suffering and medical care cost containment."[15]

Ideally, Dr. Hawley said, palliative care should begin alongside curative treatments soon after the diagnosis of a condition that may be life-limiting.[15] It should also incorporate a holistic approach, which addresses physical, psychosocial, religious and spiritual beliefs, and respond to the needs of patients and their families as a person's condition progresses.[15]

Health does not always decline at a steady pace, but in general, treatment and therapy to manage the disease decrease over time and palliative care increases, as the bow tie model shows. The Standards and Norms of Practice model developed by the Canadian Hospice Palliative Care Association also promotes early integration of palliative care alongside active treatment. However, the public's understanding may be more limited. Focus groups conducted as part of CIHI's work on the Shared Health Priorities found that many participants thought of palliative care as limited to comfort care at the end of life, while others had never heard of it.

The lack of a common definition of palliative care, as well as limited resources and funding, also contribute to system-wide limits on access to early and integrated palliative care.[16] For patients, lack of awareness and reluctance (from both patients and health care providers) to discuss palliative care and the dying process can also contribute to delaying access to services.

The importance of early and integrated palliative care is illustrated by the experience of Ing Wong-Ward, who is living with cancer and disability. You can read about her story on CIHI's website.

In Canada, research suggests that the following factors can improve delivery of, and access to, palliative care:

- Frameworks and strategies that define palliative services, and provide coordinated policies, standards and guidelines.[16]
- Eligibility criteria that support early access to a mix of services in the most appropriate place.[17]
- Funding that is stable and predictable, to ensure that integrated and coherent programs are developed across the health system.[18]
- Measurement for monitoring and evaluating progress, quality and outcomes against the frameworks and strategies.[19]

Results from a scan of these factors across the provinces and territories can be found in Appendix B.

Main findings

Access to palliative care in the community

Community-based palliative care is a priority for governments across the country, with an emphasis on services that can help people remain in the community even at the end of life.[20] Community-based palliative care includes visits to doctors' offices, services provided in patients' homes and care provided in long-term care facilities, residential hospices or palliative care homes. Services that are specific to palliative patients can be a part of community-based care more broadly, but they generally entail more comprehensive assessment of each patient's needs and a holistic approach — that is, integrating physical, psychological, social and spiritual care that involves providers from multiple disciplines.

Access to palliative home care

Receiving care and dying where you want are measures of good quality care, and many Canadians prefer to receive their care and die at home.[21] Without palliative home care, dying at home may not be feasible because of how intense and complex end-of-life care can be.[22, 23] Publicly funded palliative home care programs operate across all provinces and territories. The number of palliative home care clients in 2016–2017 ranged from less than 40 in Yukon, where the population is small, to approximately 23,000 each in Ontario and Quebec. More information on palliative home care is available in Appendix D, including eligibility criteria and numbers of home care clients.

Palliative home care usually involves more frequent visits from nurses and other health professionals than regular home care. Like regular home care, it may also include home support services, such as help with preparing meals and bathing.

Few Canadians received palliative care at home in final year of life

Of adults who died in 2016–2017,[i]

- Nearly two-thirds (66%) received some type of home care service in the last year of life; and
- Less than one-sixth (15%) received palliative home care services.

Of home care clients who died at home, 39% received palliative home care services (including data from Ontario, Alberta, British Columbia and Yukon).

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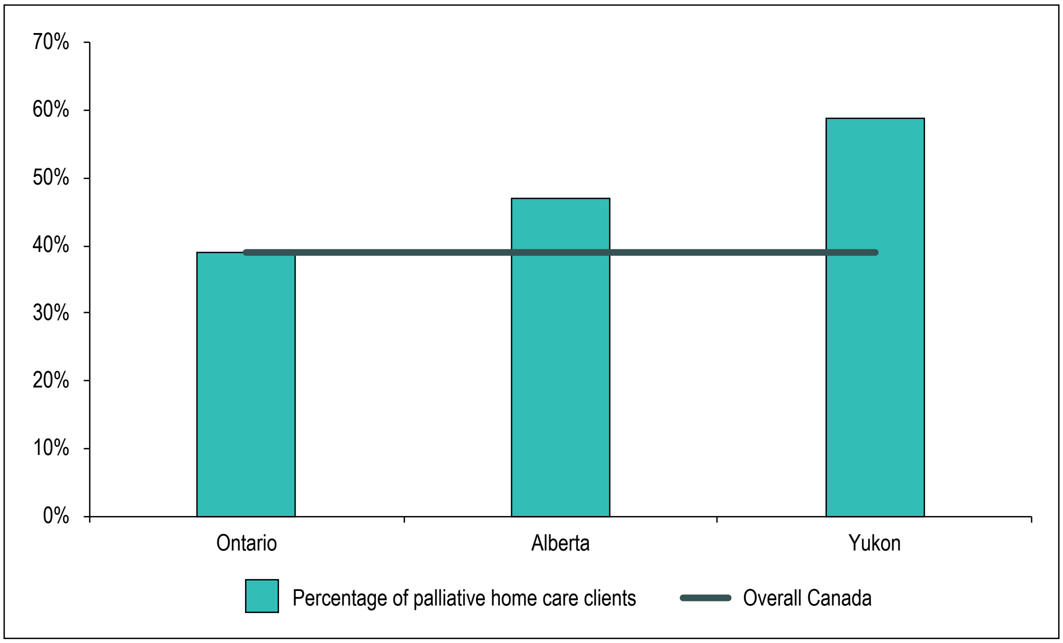
[i] In Ontario and Alberta, where death data is available across sectors of care.

Figure 3 Proportion of home care clients who received palliative home care in the last year of life, selected provinces and territory, 2016–2017



Notes
Due to partial coverage, British Columbia is not displayed individually but is included within the pan-Canadian "Overall Canada" value.
Deaths at home include those who were home care clients in their last year of life and did not have a record of death in long-term care, acute care or complex continuing care, or in an emergency department.
Source
Home Care Reporting System, 2015–2016 to 2016–2017, Canadian Institute for Health Information.

Palliative home care does not necessarily include physician visits to the home. Other studies show that people who died after receiving palliative care from doctors in their homes had fewer stays in hospital and visits to emergency departments[24] and were more likely to die at home, making doctors an important component of palliative home care.[25]

Of those who died in 2012–2013,

- 7% from Alberta and 10% from Ontario were visited by a doctor at home for palliative care in the last year of life.

The difference between Alberta and Ontario may reflect how doctors bill for palliative care in the 2 provinces (see Appendix A). Even when not billed as such, house calls by doctors in the last 3 months of life may be palliative.

- In Alberta, 25% of people who died had a visit at home from a doctor in the last 3 months of life, compared with 17% in Ontario.

Spotlight on innovation

Paramedics Providing Palliative Care at Home Program

In 2014, the Nova Scotia Health Authority and Health PEI launched an inter-provincial paramedic program for palliative care, which is similar to a program in Alberta. The programs supplement regular palliative home care services by training paramedics to deliver care at home for pain and symptoms such as shortness of breath, nausea and agitation, as well as psychosocial support. The main objectives of the programs are to

- Improve access to palliative care support at home;
- Supplement the care provided by the regular care team;
- Reduce emergency department visits;
- Provide care aligned with the patient's wishes and goals for care where they want it; and
- Train paramedics to support palliative care patients and their families.

The Nova Scotia Health Authority and Health PEI are evaluating the impact of the program. Interim analysis in Nova Scotia found that paramedics were able to keep palliative patients at home and prevent avoidable hospital visits 55% of the time.

During the first phase of Alberta's Emergency Medical Services Palliative and End of Life Care Assess, Treat and Refer Program, which ran from April 2015 to April 2016, 89% of patients were treated at home rather than being transported to emergency. In a survey, 94% of family members said the patient was treated in his or her preferred location.[26]

Note: Innovation selected by the Canadian Foundation for Healthcare Improvement.

Access to palliative care in long-term care facilities

Long-term care facilities provide full-time care to people who can no longer live independently due to significant health and/or cognitive impairments.[25] The facilities are funded either partly or fully by provincial and territorial governments. Residents of long-term care facilities can benefit from palliative care, as many have life-limiting conditions, such as dementia, chronic obstructive pulmonary disease (COPD) and heart failure.[27] Those admitted to long-term care stay for an average of 2 years, and most remain there until the end of life,[28] so palliative care can be an important component of long-term care. In jurisdictions where data is available,[ii] almost 30,000 people died in long-term care facilities in 2016–2017, or 17% of all deaths in those jurisdictions.

Most long-term care residents with less than 6 months to live did not have a record of palliative care

Among residents who died in long-term care in 2016–2017,

- 24% were identified as having less than 6 months to live; and
- 6% of all residents — and 22% (or 1 in 5) of those identified as having less than 6 months to live — were recorded as having received palliative care in the last year of life.

Even though few long-term care residents had formal palliative care in the last year of life, it is likely that many got care that was palliative in nature, as most long-term care facilities consider care at the end of life to be a vital part of their practice.[28]

However, some facilities may lack the multidisciplinary skills, knowledge and assessment tools required to provide specialized palliative care services.[28] Other barriers include a lack of time and equipment, inadequate staffing and poor reimbursement.[29] As noted later in this report, residents who received specialized palliative care were more likely to die in their residence and to have their end-of-life wishes respected.

[ii] Includes Newfoundland and Labrador, Ontario, Alberta, British Columbia and Yukon.

Palliative care in residential hospices

Residential hospices provide around-the-clock palliative care services in a home-like setting. They exist in Prince Edward Island, Quebec, Ontario, Manitoba, Saskatchewan, Alberta and British Columbia. In most cases, residential hospices admit only those who are in the very last stages of life, although some may also offer respite services. While this setting plays an important role in the provision of palliative care in Canada, there is no routine collection of pan-Canadian information from residential hospices. In partnership with the Canadian Hospice Palliative Care Association, CIHI conducted a survey of residential hospices in February 2018. In total, 88 hospices were contacted. The following information is based on responses from 30 organizations representing 37 residential hospices in Quebec, Ontario, Manitoba, Alberta and British Columbia:

- All the hospices surveyed received some public funding, but funding levels varied among and within provinces. Residential hospices received between 30% and 100% of their funding from the government, with the remainder coming from private fundraising. These variations in the proportion of public funding can be due to the number of funded beds facilities have, whether services are contracted by regional or provincial health authorities, and the amounts hospices get from fundraising.
- Almost all hospices have eligibility criteria for admission based on how long patients are expected to live, ranging from 4 weeks to 6 months. The majority of hospices require patients to have a life expectancy of 3 months or less to be admitted. Other criteria for hospice stays include referral by a physician (two-thirds require this) and a terminal diagnosis.

Information on residential hospices in each of the provinces and territories can be found in Appendix D.

Palliative care in hospitals

When community support is insufficient, many Canadians must rely on hospitals for palliative care. Even though more people are dying at home than in the past, a substantially larger proportion (42%) of Canadians — or about 116,000 people — died in acute care hospitals in 2016–2017. At least some patients and their families associated hospital deaths with more distress.[30]

Except for Yukon and the Northwest Territories, all jurisdictions have beds or units in hospitals dedicated to providing palliative care services. In some areas, the bulk of palliative care services are located in hospitals.

Our analyses show that 94% of patients who died in a hospital could potentially have benefited from palliative care during their final stay. Of people who died in acute care hospitals across Canadian provinces and territories in 2016–2017,

- 25% received primarily palliative care, which means they were identified as palliative patients for the longest portion of their hospital stay.
- Many patients (44%) who died in hospital were initially admitted for an acute health problem, but they were designated as palliative patients after the problem worsened or for a shorter portion of their hospital stay. It is not clear whether these patients received specific palliative services, or were identified as palliative only because curative treatments were stopped.

For further breakdowns by province and territory, as well as national trends, please see Appendix E.

Spotlight on innovation

Central West Palliative Care Network (Ontario) Early Palliative Identification Project

The Central West Palliative Care Network partnered with its local health integration network (LHIN) to identify patients who need palliative care sooner, in order to improve the experiences of patients and caregivers. The program allowed the Central West LHIN to increase identification of patients with palliative care needs from 5% to 10% of adult home and community care patients. To do that, the partners developed the Early Identification and Prognostic Indicator Guide, which poses questions for care providers to help identify people who could benefit from palliative care. The project resulted in

- A 40% reduction in hospital readmissions/admissions;
- More palliative patients dying at home (54%), compared with patients not identified as palliative (35%); and
- Improved patient and family experience at end of life, including less anxiety because of better planning and earlier conversations with their loved ones.

Note: Innovation selected by the Canadian Foundation for Healthcare Improvement.

Many patients are identified as palliative for the first time in acute care

Most people (88%) who died in hospital had no record of palliative needs when they were first admitted to hospital, despite the fact that people tend to have many interactions with the health care system in their last year of life. Of those who died in hospital in 2016–2017 (including those who were not identified as palliative patients),

- 55% had previously been home care clients;
- 9% were residents of long-term care in their last year of life; and
- 58% had also been hospitalized at least once prior to their final hospitalization.

In Alberta, where data is available, the vast majority (97%) of those who died in hospital also saw a doctor in the community in their last year of life (2012–2013).

Of people in Ontario and Alberta in 2016–2017 who died in home care, long-term care, an emergency department or hospital (acute care, subacute care or complex continuing care), nearly two-thirds (62%) were formally identified as palliative patients only in acute care and usually in their last month of life.

Did patients who chose medically assisted death access palliative care?

Medical assistance in dying is not considered part of palliative care, but it is an end-of-life option for Canadians who meet the legal criteria. Legislation was enacted in Canada in June 2016 permitting medical assistance in dying for mentally competent adults with grievous and irremediable conditions, and as of December 31, 2017, more than 3,700 medically assisted deaths were recorded across the country.[10, 31] Most were performed either at home (about 42%) or in a hospital (about 41%), and the average age of those who died was 73 years.[31] About 64% had a cancer diagnosis.[31]

Although it is important to understand the characteristics of Canadians who received medical assistance in dying, getting more contextual information, including whether they had access to palliative care, has been identified as a priority by provincial and territorial governments.[9] The legislation states that to be eligible for assisted death, people must be informed of ways to relieve suffering, including palliative care.[20]

Between June 17, 2016, and March 31, 2017, 349 records of assisted death in hospital were identified through CIHI's Discharge Abstract Database. Of those patients,

- 70% were identified as palliative at some point during their final hospitalization; 35% were hospitalized primarily for palliative care. The proportion hospitalized primarily for palliative care was higher than for other people who died in hospital (25%).
- 30% of all people who received assistance in dying at a hospital were identified as having palliative needs prior to their hospital admission.
- 70% had cancer and their average age was 73.
- 61% of people who died an assisted death in hospital had an unplanned admission (meaning they were admitted to hospital through the emergency department or by ambulance), compared with 89% of all people who died in acute care.

The median length of stay for people who had an assisted death in hospital was 12 days — a good part of which is likely the 10-day waiting period required between the request and receipt of the service.

More information on medical assistance in dying is available through Health Canada[31] and from CIHI's Medical Assistance in Dying: Information Needs for Health Systems and Public Reporting — Discussion Forum Report.[9]

Access to appropriate care in the community

Access to appropriate palliative care means that it meets the needs of those requiring care at the right time, in the right place and by the right provider.[32] Palliative needs are often highly individual, and measures of whether care is appropriate need to be considered alongside the preferences of patients and families.[33] Little information is being collected on preferences (see Spotlight on innovation below about patient-reported measures). Nevertheless, there are some measures that may indicate poor care at the end of life, such as late introduction of palliative care, frequent visits to the emergency department, stays in the intensive care unit (ICU), admission as an inpatient and death in hospital.[19, 34]

Effective palliative care can help to improve quality of life by preventing care that can be harmful to patients and allowing people to die in their chosen location.[34]

Spotlight on innovation

Patient-reported outcome and experience measures

Patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) are instruments for evaluating care from the patient's point of view.[33] A project funded by the Canadian Partnership Against Cancer, called the Improving Patient Experience and Health Outcomes Collaborative, is developing a common set of indicators for patient-reported outcome and experience measures during cancer treatment, including palliative care. The project's goal is to develop a common measurement system to improve cancer care for patients.

- Outcome measures will include cancer pain, fatigue, anxiety and quality of life.
- Experience measures will assess physical comfort, mental support, access, and communication with and coordination between care providers.

These measures will be integrated into clinical care and later assessed to determine whether they have a positive impact on patient experience and care.[35]

More information on this project is available through the Canadian Partnership Against Cancer.

Potentially preventable hospital care in the last month of life

People need more care as they get closer to death. Some wind up in hospital getting care, which might be avoided with better care in the community. In addition, some types of hospital care may no longer be beneficial, such as admission to an ICU, which may suggest that a patient is getting overly aggressive treatment in the last month of life.[34, 36]

Here are some statistics about hospital care that people received in their last 30 days of life in Alberta or Ontario in 2016–2017. These types of care can be distressing for patients and their families, especially when a person is approaching death:[34]

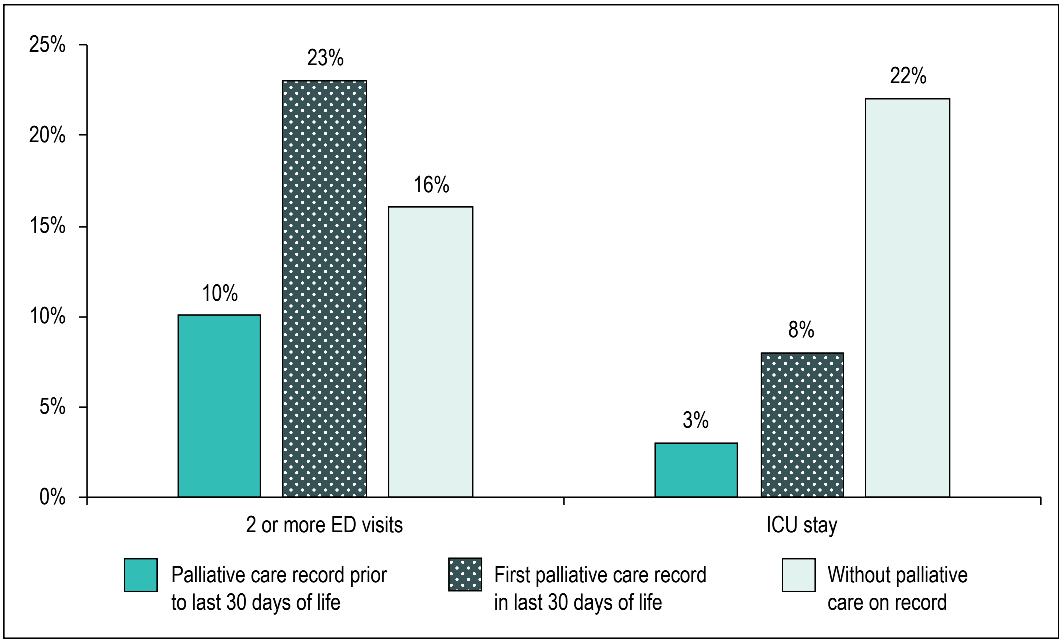
- 58% had an emergency department visit, including 16% who had more than one.
- 53% had an admission to hospital, including 8% who had more than one.
- 16% had an ICU stay.

While these types of care are not always preventable, people who had earlier palliative care appeared to have less frequent hospital care in their last month of life.

Earlier palliative care associated with fewer emergency department visits

As seen in Figure 4, those who received palliative care before their last 30 days of life were the least likely to have 2 or more emergency department visits in their last month. These patients and their caregivers may have been better supported or more prepared to manage symptoms in the community, allowing them to avoid going to the emergency department.[37, 38] The highest proportion of people who had 2 or more emergency department visits in the month before their death were those who had not received palliative care until that time. This suggests that the emergency department is the gateway through which many patients get access to palliative services for the first time, since most people do not receive earlier palliative care in the community.

Figure 4 Proportion of those who died in 2016–2017 with 2+ emergency department visits, or an ICU stay in last 30 days of life, by record of palliative care



Notes

Palliative care record prior to last 30 days includes home care, long-term care, acute care, subacute care, emergency department and complex continuing care.

Includes deaths in Ontario and Alberta only.

A greater proportion of those who have a first record of palliative care in the last 30 days and 2+ emergency department visits in the last 30 days of life may be the result of identification bias, due to the likelihood of being identified as having palliative needs upon going to the emergency department.

Sources

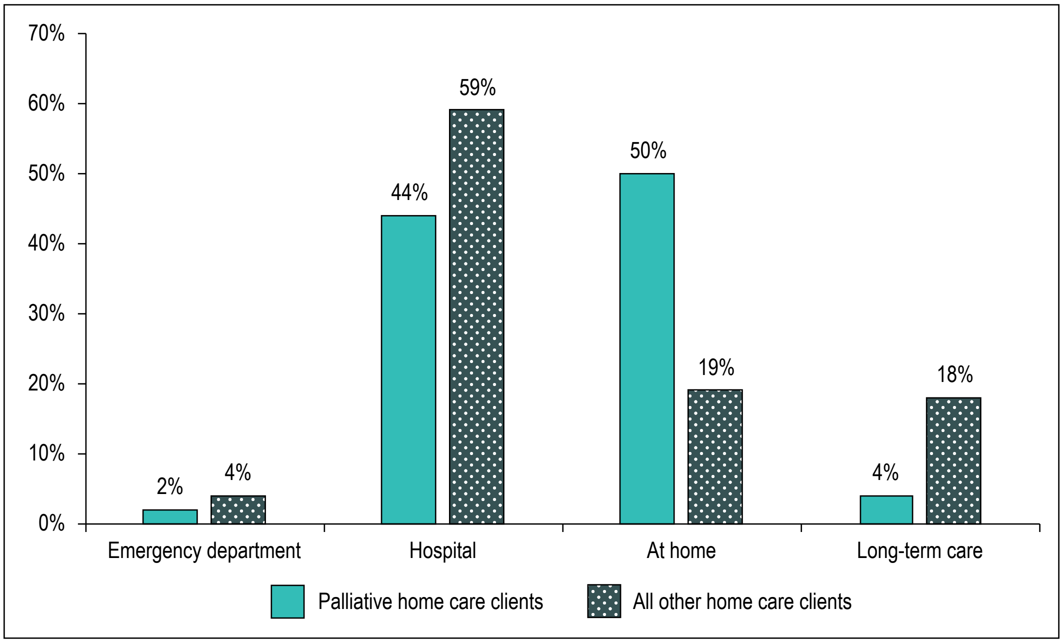
Discharge Abstract Database, National Ambulatory Care Reporting System, Continuing Care Reporting System and Home Care Reporting System, 2015–2016 to 2016–2017, Canadian Institute for Health Information.

Figure 4 also shows use of intensive care units in the last month of life. People with formal palliative care — and earlier palliative care in particular — were less likely to spend time in intensive care, which is primarily for life-sustaining treatment, or for support before or after undergoing complex procedures. ICU stays may reflect overly aggressive treatment for those in the last month of life.[39]

Palliative home care clients are more likely to die at home

People who received palliative home care in their last year of life were 2.5 times more likely to die at home than other home care clients. However, a substantial proportion (44%) died in hospital, which may mean that those who preferred a home death were getting insufficient or inadequate home-based services,[40] or that some patients and their families needed more intensive round-the-clock care.

Figure 5 Location of death in 2016–2017 for people who were home care clients in their last year of life, by client type



Notes
Includes deaths in Ontario and Alberta only.
"Hospital" refers to deaths in acute care, subacute care and complex continuing care.
Sources
Discharge Abstract Database, National Ambulatory Care Reporting System, Continuing Care Reporting System and Home Care Reporting System, 2015–2016 to 2016–2017, Canadian Institute for Health Information.

Palliative care in long-term care helps prevent avoidable hospital transfers

People who received palliative care in their long-term care residence were less likely to die in hospital than other long-term care residents. Of those who died in 2016–2017 who were long-term care residents in their last year of life,

- 97% who received palliative care in long-term care died in their residence while 2% died in hospital; and
- 77% of those without formal palliative care died in their long-term care facility and 18% — or 1 in 5 — died in hospital.

People who receive palliative care are less likely to be transferred to hospital prior to death. Common reasons for hospital transfers from long-term care, such as infections or sudden worsening of chronic conditions, can often be prevented or addressed in long-term care with the right services in place.[40] However, 21% of long-term care residents who died in acute care were hospitalized primarily for palliative care, which suggests a lack of appropriate palliative services or advance care planning in the long-term care sector.

Better patient and family involvement for long-term care residents receiving palliative care

Discussions to plan care can help people at the end of life and their families make difficult decisions and be better prepared for what's coming.[41] Care planning can include preparing advance directives, which let people record their medical care preferences in case a time comes when they are no longer competent to make decisions on end-of-life interventions or treatments.

Among long-term care residents who died in 2016–2017 and who received palliative care,

- 93% had a do-not-resuscitate directive, compared with 84% of those without palliative care; and
- 64% had a do-not-hospitalize directive, compared with 46% of those without palliative care.

A previous CIHI study found that long-term care residents with do-not-resuscitate directives are rarely resuscitated, and those with a do-not-hospitalize directive are half as likely to be hospitalized.[40]

Symptom management, a major focus for those on palliative drug plans

Drug therapy plays an important role controlling symptoms at the end of life. Medications to treat pain, digestive issues and anxiety are often introduced as illnesses progress.[42] In some cases, new medications are introduced as others are reduced.[42] For example, drugs for chronic conditions such as high cholesterol may no longer be useful in the final weeks of life, while drugs that relieve symptoms such as pain improve the quality of life.[42]

Several jurisdictions, including Prince Edward Island, Nova Scotia, Manitoba, Saskatchewan, Alberta, British Columbia and Yukon, specifically fund drugs for palliative care in the community. Others may cover them under general public drug programs.

Table 1 looks at people who made claims to public drug programs in their last year of life. It compares the top 5 drugs claimed on palliative drug programs with those claimed on other public drug plans. People with access to palliative drug plans were more likely to receive drugs to manage symptoms of pain and discomfort at the end of life. People on other public plans most commonly claimed drugs for chronic conditions.

Table 1 Top 5 drug classes claimed in the last year of life in 2016, by drug program claimant type

Top 5 drugs claimed for those on palliative drug plans	Top 5 drugs claimed for those on other public drug plans
Opioids (81%) — primarily used to treat pain	Beta blocking agents (42%) — used to reduce blood pressure
Corticosteroids for systemic use (62%) — used to treat inflammation or pain, or to stimulate appetite	Peptic ulcer and gastric reflux drugs (41%) — used to treat heartburn, ulcers and acid-related digestive problems
Peptic ulcer and gastric reflux drugs (55%) — used to treat heartburn, ulcers and acid-related digestive problems	Lipid-modifying agents (40%) — used to lower cholesterol
Propulsives (43%) — used to treat nausea and diarrhea/constipation	High-ceiling diuretics (38%) — used to reduce blood pressure and swelling due to water retention
Anxiolytics (38%) — primarily used to treat anxiety and/or insomnia, depression, agitation and seizures	Opioids (35%) — primarily used to treat pain

Notes

Includes those who died in acute care in Manitoba, Alberta and British Columbia only, who were 19 or older at death.
“Top 5 drugs claimed for those on palliative drug plans” includes claims to any drug plan in the last year of life among those who submitted to the palliative care drug plans.
Drug classes reported using Anatomical Therapeutic Chemicals Classification System, Level 3.

Sources

Discharge Abstract Database and National Prescription Drug Utilization Information System, 2014–2015 to 2016–2017, Canadian Institute for Health Information.

While the over-prescribing of opioids is a public health concern in Canada, ensuring access to opioids for palliative and end-of-life patients is considered an important part of pain treatment.[43] Opioids are on the World Health Organization's Essential Medicines List for palliative care.[44] Of those who made claims to non-palliative public drug programs in their last year of life in 2016, 35% had a prescription for an opioid. A much higher proportion of people in palliative drug programs (81%) made claims for opioids.

Variations between the 2 groups likely reflect the differences in their health conditions and projected life expectancy. Some diagnoses, such as cancer, have a clearer path allowing physicians and pharmacists to prescribe appropriately for their palliative needs. The majority (83%) of people on palliative drug programs had a cancer diagnosis, while 30% of those making claims on other public drug programs did. People making claims on general drug plans had more chronic conditions, including renal failure, heart failure and COPD.

International Quality of Death Index

In 2015, the Economist Intelligence Unit published the Quality of Death Index that ranked palliative care across the world. The United Kingdom topped the index, followed by Australia. Canada ranked 11th. The index found several common characteristics among countries with a high score for quality of death, including

- Effective implementation of a national palliative care policy framework;
- Large investments of public spending on health care services;
- Focused palliative care training resources for general and specialized medical workers;
- Generous subsidy programs to reduce the financial burden of palliative care on patients and families;
- Wide availability of opioid analgesics and psychological support; and
- Strong public awareness and encouraging conversations about palliative care.

Transitions of care at the end of life

Requiring hospital care at the end of life can be a distressing experience for patients and their families. The vast majority (89%) of those who died in hospital had an unplanned admission on their final hospitalization (meaning they had to be admitted through the emergency department or by ambulance). Even in hospitalizations where patients primarily received palliative care, 84% were unplanned. This may indicate the need for earlier integration of palliative care in the community, so the services that patients need as their illness gets worse can be planned more effectively.

Waits for admission from the emergency department are long

Unplanned admissions can take a particular toll on patients nearing the end of their life and on their families. Data shows that of those admitted through the emergency department who subsequently died in hospital,

- Half waited more than 3.5 hours to be admitted; and
- 1 in 10 patients waited more than 25 hours to be admitted.

Many wait for palliative care in a more appropriate place or location

Hospital patients may also face waits to be discharged to a more appropriate location for palliative care. Alternate level of care (ALC) is the label used for the days a patient remains in a hospital bed while waiting to be discharged to non-acute care, whether that's a continuing care facility, a residential hospice or at home with supports. Among hospitalizations where patients had primarily received palliative care in 2016–2017,[iii]

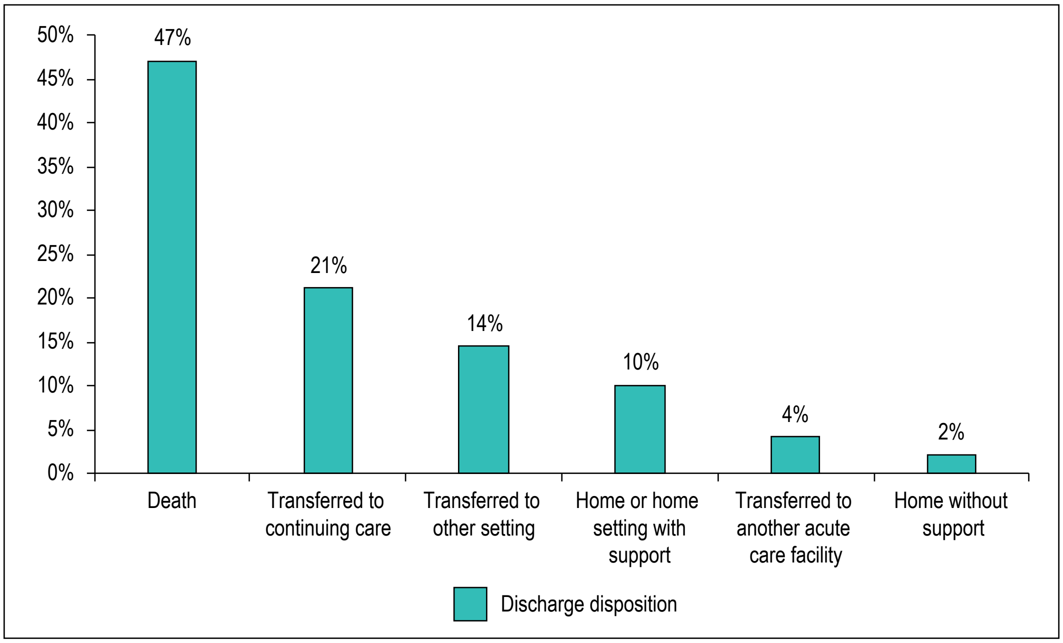
- Nearly 1 in 10 included more than one ALC day, ranging from 3% in New Brunswick to 13% in Prince Edward Island; and
- Waits could be long for an alternate level of care, with a median wait of 9 days. Nearly half (47%) of palliative patients waiting for care in a more appropriate setting died before they could be discharged to one.

Variations in the proportion and number of ALC days may be the result of many factors, including how doctors identify ALC, the availability of palliative care outside the hospital and challenges with coordinating care in the community.

Figure 6 shows where palliative care patients were discharged to after waiting for an alternate level of care. Lengths of stay were similar regardless of where or how patients were discharged.

[iii] Note that Quebec has been excluded from the calculation of ALC metrics.

Figure 6 Discharge disposition for ALC hospitalizations primarily for palliative care, 2016–2017



Notes
Excludes Quebec.
"Transferred to other setting" may include hospice settings.
Source
Discharge Abstract Database, 2015–2016 to 2016–2017, Canadian Institute for Health Information.

Equity in access to palliative care

Ensuring that Canadians have equitable access to the services they need — regardless of their age, income, diagnosis or where they live — is an important dimension of health system performance.

Our analysis found that access to palliative care in Canada was not influenced by a person's sex or income level. However, some groups were more likely than others to receive palliative care at home or in hospital settings, including

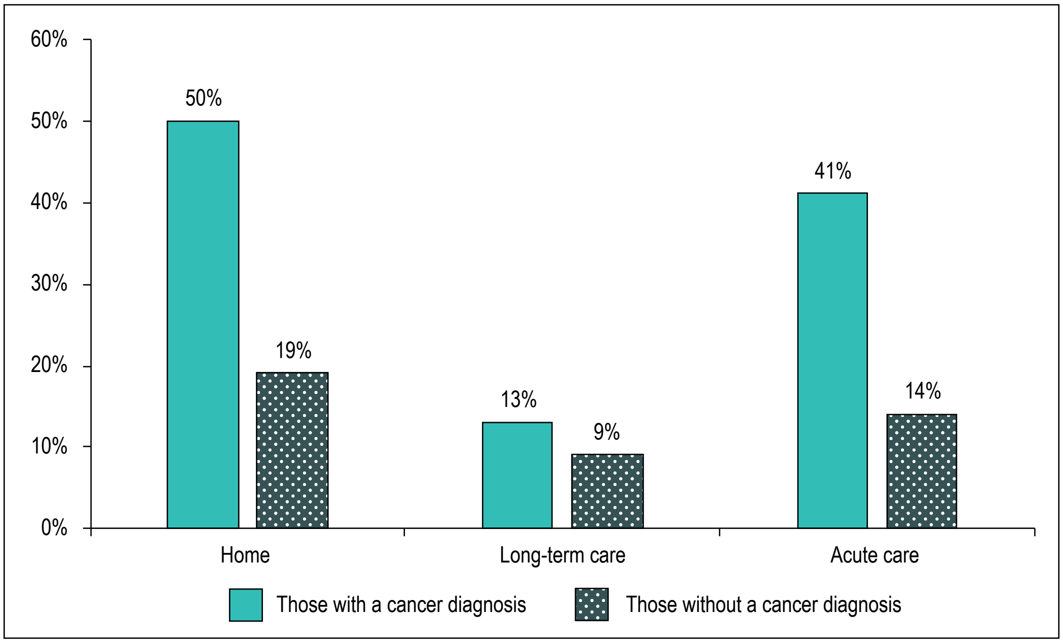
- People with a cancer diagnosis;
- Younger seniors and adults; and
- Those who lived in rural and remote areas.

The receipt of palliative care should depend on patients' needs and personal preferences, rather than on their socio-demographic characteristics or the type of life-limiting disease they have.[45]

More people with cancer receive palliative care

People who had a cancer diagnosis were up to 3 times more likely to have received palliative care in their last year of life.

Figure 7 Proportion of those who died who received palliative care in the last year of life, by cancer diagnosis and place of death, 2016–2017



Notes
Home deaths include Ontario, Alberta, British Columbia and Yukon only.
Home deaths include those who were home care clients in their last year of life and did not have a record of death in long-term care, acute care, complex continuing care or emergency department.
Long-term care deaths include Newfoundland and Labrador, Ontario, Alberta, British Columbia and Yukon.
The proportion of people who died in acute care who received palliative care include only those who were hospitalized primarily for palliative care in their last year of life and excludes those who may have had palliative care in acute care but it did not represent the longest segment of their hospitalization. Quebec acute care deaths are excluded.
Sources
Home Care Reporting System, Continuing Care Reporting System, Discharge Abstract Database, 2015–2016 to 2016–2017, Canadian Institute for Health Information.

The fact that a higher proportion of people with cancer receive palliative care in the last year of life likely reflects its origins as a treatment approach for cancer patients[46] and the greater predictability of the cancer trajectory.[47] It has long been recognized that palliative care is beneficial to people with other conditions as well, including heart failure, lung disease, renal failure, dementia and other neurodegenerative diseases. People with those conditions may benefit as awareness of palliative care grows[47] and the ability to determine their prognoses improves.[48]

However, the data suggests that there is opportunity to improve palliative care even for patients with cancer. Among patients who died in hospital with a cancer diagnosis,

- Less than half (41%) were hospitalized primarily for palliative care; and
- Most (3 in 4) had no indication of palliative needs prior to their final hospitalization.

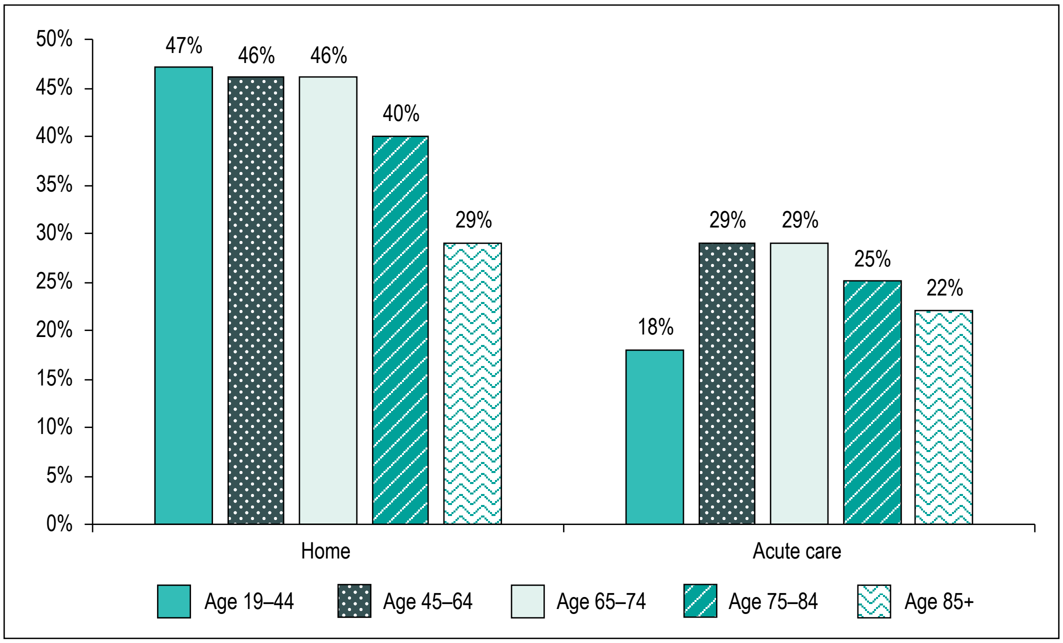
More results showing receipt of palliative care by setting of care and diagnosis appear in Appendix F.

The impact of age on palliative care

While there were no substantial sex- or income-based differences among those who receive palliative care, age was a factor. Seniors, in particular older seniors, appeared to be somewhat less likely to have received palliative care in their last year of life, as seen in Figure 8. Many factors may be contributing to these lower rates. For instance, seniors tend to have a greater number of health conditions that can make planning their care more complex than for younger individuals with life-limiting conditions.[49] The complexity of older age, frailty and a lack of a defined terminal condition may also make it more challenging to predict the end-of-life trajectory for seniors, which makes it harder to identify palliative care needs.[50] Greater awareness of the integrated model of palliative care, which begins earlier for people with life-limiting conditions before they are judged to be near death, may help to reduce age inequities for palliative care.

Among adults who died in acute care, those in the youngest age group were least likely to have received palliative care in their last year of life. This may be because sudden or external causes of death are more common for this age group.[51]

Figure 8 Proportion of those who died who received palliative care in the last year of life, by age group and place of death, 2016–2017



Notes
Home deaths include Ontario, Alberta, British Columbia and Yukon only.
Home deaths include those who were home care clients in their last year of life and did not have a record of death in long-term care, acute care, complex continuing care or emergency department.
The proportion of people who died in acute care who received palliative care include only those who were hospitalized primarily for palliative care in their last year of life and excludes those who may have had palliative care in acute care but it did not represent the longest segment of their hospitalization.
Sources
Home Care Reporting System and Discharge Abstract Database, 2015–2016 to 2016–2017, Canadian Institute for Health Information.

Urban and rural differences for hospital care and home care

Among people who died in hospital, a higher proportion of residents from rural or remote areas were admitted primarily for palliative care in their last year of life (30%), compared with those who lived in an urban area (24%). This finding may be due to fewer locations outside of hospitals, such as hospices, for palliative care in rural and remote areas.[52]

Rural and remote residents who died at home were more likely to have received palliative home care in their last year of life (38% rural versus 29% urban). This finding was unexpected given that access to palliative home care in rural areas is generally thought to be more challenging.[53] In part, it may be due to the higher proportion of people who died with a cancer diagnosis in rural or remote areas (45%) compared with the proportion who died in urban areas (35%).

Workforce preparedness

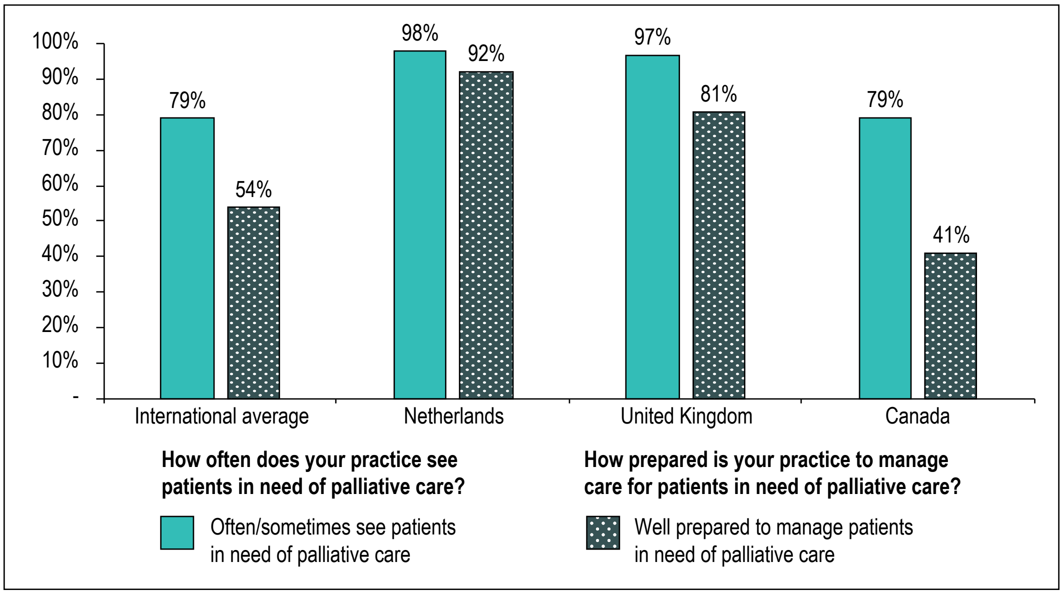
Palliative care is most effective when it is delivered by an interdisciplinary team of health care providers.[54] The professional team comes together with family members, friends and caregivers to form a circle of care. The interdisciplinary team may include, but is not limited to

- Nurses
- Physicians
- Chaplains
- Dietitians
- Pharmacists
- Psychologists
- Social workers
- Speech pathologists
- Integrative therapists
- Occupational therapists
- Physiotherapists
- Recreational therapists
- Volunteers

Studies show that health professionals who provide palliative care need to be properly trained to ensure they are capable of providing the highest standard of care to patients and have appropriate resources, including after-hours schedules.[55] Ideally, primary care providers should be trained to care for palliative patients in the community and have access to consultations with palliative care specialists for more complex cases.[56]

Although little is known about most health care professionals who provide palliative care, information on primary care doctors suggests they may have gaps in their training and feel substantially less prepared than doctors in other countries to manage palliative care. Figure 9 shows how Canada compares with 10 peer countries, including the United Kingdom and the Netherlands, on these 2 points.

Figure 9 A comparison of survey responses from primary care doctors about palliative care, Canada and international peers



Note
“International average” includes New Zealand, Canada, Australia, Switzerland, United Kingdom, United States, Sweden, Norway, France, Netherlands and Germany.

Source
The Commonwealth Fund, The Commonwealth Fund 2015 International Health Policy Survey of Primary Care Physicians, 2015.

Palliative care curriculum in medical schools

To further understand the landscape of palliative care education and preparedness among Canadian health care professionals, the Canadian Partnership Against Cancer and the Palliative and End-of-Life Care National Network surveyed medical schools in Canada. They found the following:

- Although 90% of medical curricula have lectures related to palliative care, there is little mentorship and just 12% of students were required to participate in mandatory clinical rotations in palliative care.
- Few residents are exposed to hands-on palliative care training — 18% in acute care facilities, 16% in palliative care units within an acute care setting, 18% in cancer centres and 11% in a community or outpatient environment.
- There are few faculty positions in Canadian universities to address undergraduate and postgraduate needs for education in palliative care.

On the front lines of care, nurses and doctors play a significant role in providing care to palliative patients both in the community and in hospitals, and some of them are palliative care specialists. Palliative medicine became a physician subspecialty in 2014, and registered nurses can also specialize in palliative care as a nursing practice.

While there is insufficient data to determine how many registered nurses in Canada practise in palliative care,

- Around 2% of licensed practical nurses (LPNs) worked primarily in palliative care in 2016, though many more work with palliative patients at least some of the time.
- Hospitals (40%) and long-term care (27%) were the most common settings where LPNs worked primarily in palliative care.

In Alberta, where physician activity could be further measured,

- 12% of doctors billed for any palliative care service in 2012–2013.
- Of those who did bill for palliative services, few (15%) provided palliative care in patients' homes.
- The proportion of all doctors who practised more extensively in palliative care (with 10% or more of a physician's billings for palliative care in 2012–2013) was small (1%) and similar to the proportion for Ontario (3%).[57] The difference may be the result of different billing practices.

Family involvement in care

In many cases, individuals at the end of life express a preference to remain at home or in the community,[58] which involves relying on care provided by family and friends.[59] These caregivers help to meet the daily physical and emotional needs of patients, participate in making treatment decisions and help to ensure that pharmacological and non-drug therapies are followed.[60] In most cases, Canadians at the end of life would not be able to remain at home without the support of these caregivers.[21]

A profile of Canadian family/friend caregivers

According to results of the General Social Survey, 2012,[62] 13% of Canadians 15 years or older reported providing end-of-life care to a friend or family member at some point in their lives.[61]

Based on data from the survey, caregivers who had provided end-of-life care were primarily female (63%), married (54%), age 45 to 64 (51%) and had a household income of less than $100,000 a year (63%). These characteristics were similar to the profiles of Canadian caregivers more generally.[62]

Almost all palliative home care clients had a family/friend caregiver

For people who were palliative home care clients in their last year of life, 99% had a family/friend caregiver. In some provinces, such as Alberta, you must have a family caregiver to qualify for palliative care at home. Across Canada, these caregivers were primarily the children (44%) or spouses (43%) of the palliative care client. About two-thirds (64%) of palliative clients lived with their family caregiver, compared with 55% of other home care clients. Most family caregivers of palliative home care clients provided

- Emotional support (98%);
- Help with activities related to independent living (92%), such as preparing meals, managing medication, doing housework, managing finances and transportation; and
- Help with basic tasks of daily living (85%), such as feeding, bathing, dressing and grooming, walking and taking the stairs, as well as transferring from bed to chair.

Nearly one-third of family/friend caregivers of palliative home care clients experience distress

Caregivers often experience negative impacts on their emotional and physical health from caregiving, as well as financial strain from time off work or out-of-pocket expenses.[63, 64] The burden of caregiving tends to be greater when caring for a dying family member or friend, due to the intensity of care required while experiencing loss and grief.[64] Here are some figures about caregivers of home care clients in 2016–2017:

- 30% of caregivers for palliative clients reported experiencing distress, which can include feelings of anger or depression, or experiencing conflict as a result of their caregiving activities.
- In comparison, 27% of caregivers for all non-palliative clients reported experiencing distress, though the caregivers of dementia patients had a distress rate of 45%.[65]

Distress experienced by caregivers is likely to be under-reported in home care, as assessments focus on the needs of care recipients.[66] As a result, assessors may not evaluate caregiver distress in depth.

Discussion

Opportunities to improve data

Improvements in the following areas would allow for a more complete picture of access to palliative care in Canada:

- **Comprehensive community data:** While coverage is increasing across the country, home care and long-term care data is still limited to certain jurisdictions, and data from stand-alone hospices and other residential care homes is sparse overall. In addition, little comparable information exists on physician visits in the community for palliative care and on other community support services for patients and caregivers. Lack of data on palliative care from allied health care professionals also contributes to the gap in community data.
- **Common definitions and standards for reporting palliative care services:** In hospitals, where data is complete across the country, it is not possible to determine the specific services palliative patients have received, who provided the services, and whether they were provided in palliative-specific beds or units. This makes it difficult to understand the level and quality of palliative care services provided in hospital settings. Determining which specific palliative services are provided is also a challenge due to data limitations in long-term care and home care.

- **Patient and family-reported data:** The voice of patients and their families is important for understanding whether needs are being met, and if palliative care is making a difference in improving the quality of life for people with life-limiting illnesses and their families. However, few patient-reported experience or outcome measures exist at the pan-Canadian level.

The availability of more comprehensive and comparable palliative care data from across care sectors and jurisdictions is important to evaluate the progress, quality and outcomes of palliative care.

Spotlight on innovation

How data can help

Linked data is being used in Ontario to measure how well the health system provides patients with equitable access to palliative care. The Ontario Palliative Care Network is a partnership funded by the province's Ministry of Health and Long-Term Care. Through the network's Data and Information Advisory Council, linked administrative data is being used to develop indicators related to palliative care in the province. These indicators can help to enhance the quality of services and to increase the consistency of services across the province. Current work includes estimating the provincial and regional numbers of people who could benefit from palliative care. Upcoming work includes developing a method of identifying *in advance* people who would benefit from palliative care. For more information, see the Ontario Palliative Care Network Action Plan 1: 2017–2020.

In Alberta, a dashboard for preliminary results on provincial palliative and end-of-life care indicators has been developed. It contains information on deaths, estimates of people with palliative care needs, health service use in the last year of life and estimates of cost. For some of these indicators, information is available by primary diagnosis, age, and urban or rural area of residence. Results of these indicators are not yet available to the public, as further analysis and validation are still needed.

Conclusion

Estimates suggest that up to 89% of people who die might have benefited from palliative care.[5] However, a substantial proportion of Canadians were neither identified as having palliative needs, nor as having received palliative care in their last year of life. As mentioned in the Canadian Partnership Against Cancer's report *Palliative and End-of-Life Care*, improving the identification of people with palliative needs could help to increase Canadians' access to palliative care. Indeed, our report shows that cancer patients, whose disease trajectories are much better understood, were up to 3 times more likely to have had palliative care than those without cancer.

Even those who receive palliative care could benefit from earlier initiation and integration of palliative care services in the community. Findings in this report show that most Canadians accessed palliative care for the first time in the hospital, usually on an emergency basis and only in the last 30 days of life. Community-based palliative care can help patients and their families ensure that their preferences for remaining in the community and dying at home are met.[22, 36] This report found that Canadians who received palliative care at home were 2.5 times more likely to die at home than regular home care clients. Getting community-based palliative care earlier was also associated with fewer emergency department visits and intensive care unit stays in the last 30 days of life.

Increasing the capacity and preparedness of health care providers to deliver palliative care may help to improve the experience of Canadians in the last year of life.[67] As this report shows, there are few providers practising primarily in palliative care, and primary care doctors in Canada report feeling less prepared to see palliative patients than their peers in other countries. Specialist palliative care providers may have more training in the provision of quality palliative care and be more prepared[67] — but according to available data, only 1% to 3% of physicians or licensed practical nurses worked primarily or more intensively in palliative care. Studies suggest that family and friends who are part of the circle of care also need better training and support.[68, 69]

Looking more broadly at care in the final year of life, it is clear that people often experience many transitions in care, particularly to hospitals. While these transitions are sometimes unavoidable, earlier provision of palliative care may help to prevent the need for inpatient admissions or emergency department visits[38] and reduce the high costs associated with hospital care at the end of life.[70] For long-term care residents, improving the capacity of staff to provide palliative care may also help to prevent avoidable hospital transfers.[29]

Where transitions are unavoidable, there may be opportunities to make them smoother. For example, direct admissions to hospital can help reduce distress and avoid long and potentially uncomfortable wait times in the emergency department.[71] For palliative patients admitted to hospital, waits for discharges to other care settings in the community — such as palliative home care or residential hospices — can also be long; nearly half die while waiting for an alternate level of care. This suggests an opportunity to improve the coordination of services and access to community resources for palliative patients.

Moving forward

There have been many changes to palliative care in Canada since it was introduced more than 40 years ago. Some of these changes include shifts in the provision of palliative care from inpatient hospital settings to patients' homes, growing awareness of palliative care for those with conditions other than cancer, and increasing emphasis on early and integrated care.[72] More recently, medical assistance in dying legislation, the federal, provincial and territorial Common Statement of Principles on Shared Health Priorities, and the enactment of the *Framework on palliative care in Canada* have influenced — and will continue to influence — palliative care. At the jurisdiction level, work by organizations such as the Ontario Palliative Care Network and the British Columbia Centre for Palliative Care will also contribute to the development of palliative care in Canada.

Building on these changes are recommendations made by the Palliative Care Matters and The Way Forward initiatives to address challenges faced by patients and their families when they need palliative care. These recommendations, supported by findings in this report, include establishing consistent definitions and measures of palliative care, improving palliative education for health professionals, ensuring adequate training for caregivers and increasing awareness among patients and their families.[58, 73] More broadly as a society, there is also a recognized need for more frank and open discussions about death and the dying process — to ensure that Canadians have an opportunity to express their wishes and have advance care plans in place to ensure these wishes are respected.

Appendices

Appendix A: Study methods

People age 19 and older at the time of death, and people who received palliative care in the last year of life were identified through all available CIHI data sources. These sources included information on the following: acute care, emergency departments, long-term care facilities, home care, physician billings and claims to palliative care drug programs.

Identifying palliative care

Table A1 Methodology and limitations, by care sector

Care sector (data source)	Methodology	Limitations
Home care (HCRS)	Palliative home care clients are those who • Belonged to the end-of-life client group; or • Had a Resident Assessment Instrument–Home Care assessment conducted in the last year of life which indicated – Palliative goals of care; – That hospice care had been scheduled in the last 7 days; or – That the prognosis was less than 6 months to live.	• Includes data from Ontario, Alberta, British Columbia and Yukon. Data from Northern Health in B.C. was not available. • Palliative home care clients in Alberta may be underestimated due to data submission issues in the Calgary and Edmonton zones. • Clients belonging to the end-of-life client group may be under-reported, as change of client group is not required after admission to home care and is limited to those expected to live for 6 months or less.
Alberta home and community/ outpatient physician care (Alberta PLPB)	**In Alberta**, physician palliative care included the following fee service codes: • 03.05I • 03.05T • 03.05U Services provided at home were identified based on a service event location of "HOME." Services provided in a community/outpatient setting included a facility functional centre code of "CLNC" (clinic), "D/N" (day/night care) or a facility type code (fac_type) of blank or "OFFC" (doctor's office). The blank includes home visits and other community-type settings.	• Fee service codes for palliative care differ across jurisdictions and may not be comparable. • At the time of analysis, Alberta physician billing data was not available beyond 2012–2013.

Care sector (data source)	Methodology	Limitations
Ontario home physician care (Ontario PLPB)	**In Ontario,** patients who were receiving physician home visits for palliative care were identified by the following fee service codes: travel codes B966, B997, B998. Home visits for any reason were identified by the following fee service codes: A901, B960, B961, B962, B963, B964, B966, B990, B992, B993, B994, B996, B997, B998.	• Fee service codes for palliative care differ across jurisdictions and may not be comparable. • Note that code G5111 was not included. It is a billing code for telephone services to patients receiving palliative care at home; it does not denote the home visit specifically.
Long-term care and complex continuing care (CCRS)	Palliative care in long-term care and complex continuing care was identified from an interRAI assessment conducted in the last year of life that indicated that hospice care had been received by the resident in the past 14 days.	• Data for long-term care Includes data from Newfoundland and Labrador, Ontario, Alberta, B.C. and Yukon only. • Variations in reporting suggest that the hospice flag may not be consistently recorded across long-term care facilities. • Results for complex continuing care include Ontario. • Results from Ontario may be different due to differences in the identification of palliative care provided in complex continuing care facilities. • For deaths identified in complex continuing care, approximately 40% of patients die prior to an assessment, which could lead to an under-capture of the receipt of palliative care.

Care sector (data source)	Methodology	Limitations
Acute and subacute care (DAD, HMDB)	Patients admitted to acute or subacute care within the last year of life were *designated* as palliative if they had any of the following on record: • A diagnostic code for palliative care (Z51.5); • A main patient service of palliative care; • A palliative medicine intervention; and/or • A palliative medicine service provider. Patients admitted to acute or subacute care within the last year of life were identified as having been *primarily hospitalized for palliative care* if they had • Z51.5 as the main diagnosis; or • A most responsible diagnosis beginning with C and Z51.5 recorded elsewhere for hospitalizations in Quebec. The diagnostic type code 8 was used to identify those who had previously been identified as having palliative needs prior to their final hospitalization. The proportion of individuals who died in acute care who could have benefited from palliative care was calculated based on the following diagnostic codes for their final hospitalization: palliative care (Z51.5), cancer, heart failure, kidney failure, COPD, dementia, pneumonia and sepsis. It should be noted that some individuals would have benefited from palliative care in combination with curative treatment.	• Palliative designation in acute care could not be calculated for deaths in Quebec due to differences in palliative care coding practices. • Subacute care includes Alberta. • The data did not capture specific services provided or whether services were provided in a palliative care unit or designated palliative care bed.

Care sector (data source)	Methodology	Limitations
Community palliative care drug programs (NPDUIS)	It was inferred that claimants with one or more claims to a palliative drug plan in the last year of life had palliative needs and were community-dwelling at some point in that last year.	• Palliative drug program information for those who died in acute care includes data from Manitoba, Alberta and B.C. only. Palliative drug programs are also available in Nova Scotia, Saskatchewan and Yukon, although this data could not be utilized (N.S.: data was not linkable; Sask.: data was linkable but not distinguishable as palliative program data; Yukon: data was not available). Data was not available from P.E.I.'s pilot palliative drug program. • Drug claims made through palliative drug programs do not include all drugs prescribed for palliative care. Drugs dispensed in hospital are not included within NPDUIS. For drugs in the community, claims can also be made through private insurance or other drug programs (e.g., cancer drug programs, seniors drug plans, private drug plans), or paid out of pocket. • Drug claims data from certain programs in Alberta was not available for this analysis. This includes claims from long-term care residents and claims financed through the following programs: Income Support, Alberta Adult Health Benefit, Assured Income for the Severely Handicapped, and Alberta Child Health Benefit. • There are differences across provinces in drug coverage and access to publicly funded drugs that may limit comparability between provinces.

Notes

HCRS: Home Care Reporting System; PLPB: Patient-Level Physician Billing Repository; CCRS: Continuing Care Reporting System; DAD: Discharge Abstract Database; HMDB: Hospital Morbidity Database; NPDUIS: National Prescription Drug Utilization Information System.

Identifying deaths

Deaths could be identified in some care sectors (acute care, complex continuing care, long-term care and home care). In long-term care and home care data, a record of death (as the reason for discharge) may exist even if the person died in another setting. To ensure that only 1 death was captured for each individual as part of this study, a hierarchy was used so that records of death were prioritized in the following order:

1. Acute care, including subacute care in Alberta
2. Emergency departments
3. Complex continuing care in Ontario
4. Long-term care
5. Home care

Due to greater data availability for Ontario and Alberta, we were able to look across all of these sectors in these 2 provinces.

Records of medical assistance in dying were identified using CIHI's MAID Coding and Abstracting Direction.

Measuring care in the last year of life

Within each care setting, we were able to look retrospectively to determine whether or not patients were provided with palliative services in the 1 year prior to death. Using this information, we were able to look at proxy measures of the appropriateness and outcomes of palliative care.

In some jurisdictions, deaths identified in different care settings were pooled together in order to better understand their health service use in the last year of life, including palliative care. Due to the availability of more data in Ontario and Alberta, we were able to take a more comprehensive look at system-wide interactions in the last year of life for deaths identified across all settings.

Patient characteristic groups

Urban–rural was calculated based on the Statistical Area Classification (SAC) system from Statistics Canada, which relies on postal codes. SAC types 1, 2 and 3 were considered to be urban, and SAC types 4 to 8 were considered to be rural or remote.

Cancer diagnosis was calculated based on codes from the International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Canada (ICD-10-CA) in the Discharge Abstract Database. ICD-10-CA codes beginning with C, D37, D38, D39, D40, D41, D42, D43, D44, D45, D46, D47 and D48 were considered a cancer diagnosis.

Appendix B: Provincial and territorial differences in palliative care policies

The information in Appendix B was identified and validated by provincial and territorial ministries of health.

Table B1 Provincial and territorial palliative care strategies

Province/territory	Palliative care strategy or framework
Newfoundland and Labrador	No provincial strategy or framework
Prince Edward Island	Health PEI Palliative Care Framework and Action Plan 2015–2020*
New Brunswick	Palliative Care in New Brunswick: A Person-Centred Care and Integrated Services Framework
Nova Scotia	Integrated Palliative Care: Planning for Action in Nova Scotia
Quebec	Soins palliatifs et de fin de vie — plan de développement 2015-2020
Ontario	Ontario Palliative Care Network Action Plan 1: 2017–2020
Manitoba	No provincial strategy; regional health authorities provide own respective palliative care programs
Saskatchewan	No provincial strategy or framework; work is in progress to develop an integrated palliative care service document
Alberta	Palliative and End-of-Life Care: An Introduction to Alberta's Framework
British Columbia	The Provincial End-of-Life Care Action Plan for British Columbia
Yukon	Yukon Palliative Care Framework
Northwest Territories	Continuing Care Services Action Plan 2017/18–2021/22
Nunavut	No territorial strategy or framework

Note

* At the time this report was published, the Health PEI document was not publicly available.

Table B2 Provincial and territorial palliative care public funding

Province/territory	Home care	Long-term care	Residential hospice	Clinics/day programs	Inpatient beds/units
Newfoundland and Labrador	Yes	Yes	No	No	Yes
Prince Edward Island	Yes	No	Yes	Yes	Yes
New Brunswick	Yes	No	Yes	Yes	Yes
Nova Scotia	Yes	No	Yes	No	Yes*
Quebec	Yes	Yes	Yes	Yes	Yes
Ontario	Yes	Yes	Yes	Yes	Yes
Manitoba	Yes	Yes	Yes	Yes*	Yes
Saskatchewan	Yes*	Yes	Yes*	Yes*	No
Alberta	Yes	Yes	Yes	Yes	Yes
British Columbia	Yes	Yes	Yes*	Yes*	Yes
Yukon	Yes	Yes	No	No	No
Northwest Territories	Yes	Yes	No	No	Yes

Notes

* Funding is not routine.

Information for Nunavut was unavailable.

Table B3 Provincial and territorial palliative care measures

Province/territory	Collection of measures on palliative care	Collection of measures on palliative home care
Newfoundland and Labrador	No	No
Prince Edward Island	Yes	Yes
New Brunswick	Yes	Yes
Nova Scotia	Yes	Yes
Quebec	Yes	Yes
Ontario	Yes*	Yes*
Manitoba	No	No
Saskatchewan	Yes	No
Alberta	Yes	Yes
British Columbia	Yes	Yes
Yukon	No	No
Northwest Territories	No	No
Nunavut	No	No

Notes

* Measures are in development.

Measures of palliative care and palliative home care include those that are not reported publicly but are collected at the provincial/territorial level.

Appendix C: Locations of death in Canada

Table C1 Location of death by province and territory, 2015

Province/territory	Hospital	Private home	Other health care facility	Other specified locality	Unknown locality	Total number of decedents
Newfoundland and Labrador	62%	14%	20%	4%	0%	5,240
Prince Edward Island	50%	11%	38%	1%	1%	1,265
New Brunswick	61%	15%	22%	3%	0%	7,225
Nova Scotia	57%	19%	21%	2%	0%	9,375
Quebec	79%	9%	0%	12%	0%	64,160
Ontario	56%	19%	19%	6%	0%	97,320
Manitoba	84%*	14%	0%	1%	0%	10,685
Saskatchewan	54%	0%	1%	45%	0%	9,390
Alberta	56%	17%	18%	9%	0%	23,845
British Columbia	46%	17%	34%	3%	0%	35,245
Yukon	58%	19%	12%	9%	2%	215
Northwest Territories	52%	19%	19%	7%	2%	210
Nunavut	38%	34%	16%	9%	3%	160
Canada	61%	15%	15%	8%	0%	264,330

Notes

* In Manitoba, deaths in "Other health care facility" are under-reported due to a data quality issue; deaths in personal care homes were reported within the category of deaths in hospital. It is estimated that approximately one-third of deaths reported in Manitoba as having occurred in hospital actually occurred in a personal care home (other health care facility).

Adapted from Statistics Canada, *Deaths by Locality*, *2015*. This does not constitute an endorsement of this product by Statistics Canada.

Source

Statistics Canada, *Deaths by Locality, 2015*. Reproduced and distributed on an as-is basis with permission from Statistics Canada.

Appendix D: Palliative care in the community

Table D1 Number of palliative home care clients, by province and territory

Province/territory	Number of palliative home care clients in 2016–2017 (unless otherwise stated)
Prince Edward Island	647
New Brunswick	1,572
Nova Scotia	2,767 in 2017–2018
Quebec	22,796
Ontario	Approximately 23,000 in 2014–2015
Saskatchewan	2,194
Alberta	6,912
British Columbia	16,143 in 2015–2016, excluding respite care clients
Yukon	24 to 39

Sources

As reported by provincial and territorial ministries of health.

Table D2 Eligibility criteria for palliative home care

Province/territory	Eligibility criteria for palliative home care*	Maximum duration for eligibility to palliative home care	Maximum number of services available to palliative home care clients
Newfoundland and Labrador	Yes†	Reassessment every 28 days	No
Prince Edward Island	Yes	No	No
New Brunswick	Yes	No	Yes
Nova Scotia	Yes	No	No
Quebec	Yes	No	No
Ontario	Yes	Yes	No
Manitoba	Yes	No	No†
Saskatchewan	Yes	No	No
Alberta	Yes	No	No
British Columbia	Yes	Review required every 12 months	No
Yukon	No	No	No
Northwest Territories	Yes	No	No
Nunavut	No	No	No

Notes

* Generally, diagnosis of a life-limiting illness is a requirement for receiving palliative home care; some jurisdictions and health regions also use prognosis — or how long a patient is expected to live — as criteria for palliative home care eligibility. This ranges across jurisdictions, from “weeks or months” in Saskatchewan, to 3 months in Nova Scotia, to less than 6 months in Alberta.

† Regional health authorities are responsible for developing criteria for their respective programs. Therefore, available services may differ based on geographic area.

Table D3 Number of residential or stand-alone hospices

Province/territory	Number of residential/stand-alone hospices
Newfoundland and Labrador	0
Prince Edward Island	1
New Brunswick	2
Nova Scotia	0; 2 are set to open in the next 2 years
Quebec	30
Ontario	40 organizations, with 72 sites
Manitoba	2
Saskatchewan	2 (one in a residential setting, the other in a supportive care setting)
Alberta	See note
British Columbia	68
Yukon	0
Northwest Territories	0; there are funded beds in each long-term care facility for respite or palliative care
Nunavut	0

Note

Alberta has 243 hospice/designated palliative end-of-life care beds in the community (within designated supportive living or long-term care, or stand-alone hospices) and an additional 135 designated palliative care beds in acute care.

Appendix E: Palliative care in acute care hospitals

Table E1 People who died in acute care in 2016–2017 primarily hospitalized for palliative care and with any designation of palliative care on record in the last year of life

Province/territory	Percentage hospitalized primarily for palliative care	Percentage with any designation of palliative on record	Number of people who died in acute care in 2016–2017
Newfoundland and Labrador	31%	74%	2,509
Prince Edward Island	29%	76%	571
New Brunswick	34%	74%	3918
Nova Scotia	41%	81%	4,678
Quebec	32%	n/a	29,121
Ontario*	20%	66%	40,367
Manitoba	30%	73%	5,135
Saskatchewan	25%	64%	4,311
Alberta†	19%	61%	10,342
British Columbia	21%	68%	14,853
Yukon	38%	79%	84
Northwest Territories	36%	67%	70
Nunavut	n/r	n/r	6

Notes

* When including deaths from complex continuing care facilities in Ontario, 25% were hospitalized primarily for palliative care, 68% had a designation of palliative care, and there were 48,441 deaths in Ontario within acute or complex continuing care.

† When including deaths from subacute care facilities in Alberta, 23% were hospitalized primarily for palliative care, 63% had a designation of palliative care, and there were 10,989 deaths in Alberta within acute or subacute care.

n/a: Not applicable.

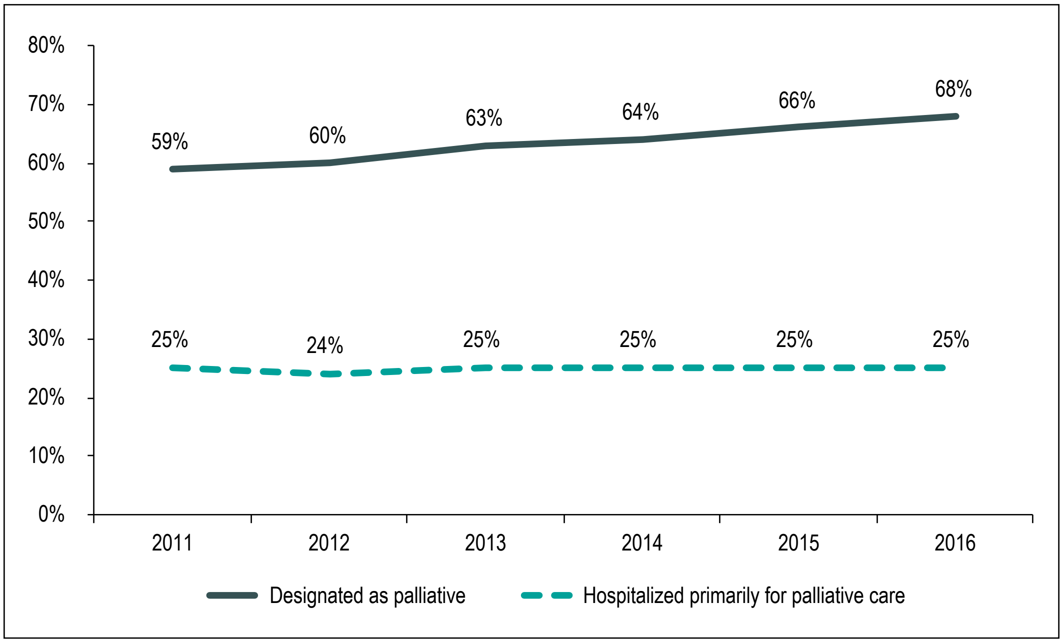
n/r: Not reportable.

Results from Quebec may not be comparable due to differences in coding standards for palliative care.

Sources

Hospital Morbidity Database/Discharge Abstract Database and Continuing Care Reporting System, 2015–2016 to 2016–2017, Canadian Institute for Health Information.

Figure E1 Proportion of Canadians who died in acute care who were designated as palliative or hospitalized primarily for palliative care in the last year of life, 2011–2012 to 2016–2017



Note
The proportion of those designated as palliative includes those hospitalized primarily for palliative care.
Source
Discharge Abstract Database, 2011–2012 to 2016–2017, Canadian Institute for Health Information.

Appendix F: Recipients of palliative care, by diagnosis group

Table F1 Proportion of people who received palliative care in the last year of life, 2016–2017, by cancer diagnosis and care setting

Diagnosis	Home care	Long-term care	Complex continuing care	Acute care
Cancer	50%	13%	79%	41%
Non-cancer (all others combined)	19%	9%	50%	14%

Notes
Excludes Quebec.
The numerator is those who received palliative care in the last year of life in the setting of care where they died.
The denominator is all those with a record of death by stated setting of care (e.g., home care clients with a home death, long-term care residents with a long-term care death).
Sources
Discharge Abstract Database, Continuing Care Reporting System and Home Care Reporting System, 2015–2016 to 2016–2017, Canadian Institute for Health Information.

Table F2 Proportion of people with selected chronic conditions who received palliative care in the last year of life, 2016–2017, by diagnosis and care setting

Diagnosis	Home care	Long-term care	Complex continuing care	Acute care
Heart failure	25%	10%	59%	11%
Dementia	20%	7%	51%	22%
COPD	28%*	10%	63%	20%
Renal failure	26%	12%	64%	14%

Notes
* Includes asthma.
COPD: Chronic obstructive pulmonary disease.
Sources
Discharge Abstract Database, Continuing Care Reporting System and Home Care Reporting System, 2015–2016 to 2016–2017, Canadian Institute for Health Information.

Appendix G: Text alternative for figures

Text alternative for Figure 1: Location of death, 2007 to 2015

This graph shows the trends over time in location of death between 2007 and 2015 in Canada. The percentage of deaths at home rose from 12% in 2007 to 15% in 2015. The percentage of deaths in hospital fell from 67% in 2007 to 61% in 2015. The percentage of deaths in other health facilities remained relatively stable, and went from 14% in 2007 to 15% in 2015.

Notes

* Statistics Canada's definition of "hospital" includes both acute care and other hospitals not included in CIHI's Discharge Abstract Database and Hospital Morbidity Database, including rehabilitation and geriatric hospitals.

Adapted from Statistics Canada, *Deaths by Locality, 2007 to 2015*. This does not constitute an endorsement of this product by Statistics Canada.

Source

Statistics Canada, *Deaths by Locality, 2007 to 2015*. Reproduced and distributed on an as-is basis with permission from Statistics Canada.

Text alternative for Figure 2: Basic model of integrated palliative care

This diagram uses overlapping triangles in the shape of a bow tie positioned below a timeline arrow to represent how disease management can co-occur with palliative care as end of life approaches. As disease management decreases over time, palliative care increases. Symptom management and supportive care are cross-cutting through both disease management and palliative care. The themes of cure and control are aligned with disease management, and the themes of survivorship and hospice are aligned with palliative care.

Note

Adapted with permission from Canadian Virtual Hospice.

Source

Canadian Virtual Hospice; Pippa Hawley. The bow tie model of 21st century palliative care. 2015.

Text alternative for Figure 3: Proportion of home care clients who received palliative home care in the last year of life, by selected provinces and territory, 2016–2017

This graph shows that 39% of home care clients received palliative home care in their last year of life across Ontario, Alberta, British Columbia and Yukon. The specific rates are as follows: Ontario, 39%; Alberta, 47%; and Yukon, 59%. B.C.'s rate is not independently reported due to limited data coverage; rather, it is included in the pan-Canadian "Overall Canada" value, which is 39%.

Note

Deaths at home include those who were home care clients in their last year of life and did not have a record of death in long-term care, acute care or complex continuing care, or in an emergency department.

Source

Home Care Reporting System, 2015–2016 to 2016–2017, Canadian Institute for Health Information.

Text alternative for Figure 4: Proportion of those who died in 2016–2017 with 2+ emergency department visits, ICU stay in last 30 days of life, by record of palliative care

This graph depicts the percentage of people with 2 or more emergency department visits and the percentage of people with an ICU stay in their last 30 days of life. This is among those who died in Ontario and Alberta in 2016–2017. Among those who had their first record of palliative care prior to their last 30 days of life, 10% had 2 or more emergency department visits and 3% had an ICU stay. Among those who had their first record of palliative care during last 30 days of life, 23% had 2 or more emergency department visits and 8% had an ICU stay. Among those who had no record of palliative care, 16% had 2 or more emergency department visits and 22% had an ICU stay.

Notes
Palliative care record prior to last 30 days includes home care, long-term care, acute care, subacute care, emergency department and complex continuing care.
Includes deaths in Ontario and Alberta only.
A greater proportion of those who have a first record of palliative care in the last 30 days and 2+ emergency department visits in the last 30 days of life may be the result of identification bias, due to the likelihood of being identified as having palliative needs upon going to the emergency department.
Sources
Discharge Abstract Database, National Ambulatory Care Reporting System, Continuing Care Reporting System and Home Care Reporting System, 2015–2016 to 2016–2017, Canadian Institute for Health Information.

Text alternative for Figure 5: Location of death in 2016–2017 for people who were home care clients in their last year of life, by home care client type

This graph depicts the setting of death for home care clients in 2016–2017, by type of home care client. For those who were palliative home care clients in their last year of life, 2% died in the emergency department, 44% died in hospital, 50% died at home and 4% died in long-term care. For those who were home care clients in their last year of life, but not for palliative care, 4% died in the emergency department, 59% died in hospital, 19% died at home and 18% died in long-term care.

Notes
Includes deaths in Ontario and Alberta only.
“Hospital” refers to deaths in acute care, subacute care and complex continuing care.
Sources
Discharge Abstract Database, National Ambulatory Care Reporting System, Continuing Care Reporting System and Home Care Reporting System, 2015–2016 to 2016–2017, Canadian Institute for Health Information.

Text alternative for Figure 6: Discharge disposition for ALC hospitalizations primarily for palliative care, 2016–2017

This graph shows the percentage of discharges from hospital by discharge setting for those who were hospitalized primarily for palliative care and had 1 or more ALC days. In 47% of cases, these individuals passed away before they were discharged, 21% were transferred to continuing care, 14% were transferred to other settings such as a hospice, 10% were discharged home with support, 4% were transferred to another acute care facility and 2% were discharged home without support.

Notes
Excludes Quebec.
“Transferred to other setting” may include hospice settings.
Source
Discharge Abstract Database, 2015–2016 to 2016–2017, Canadian Institute for Health Information.

Text alternative for Figure 7: Proportion of those who died who received palliative care in the last year of life, by cancer diagnosis and place of death, 2016–2017

This graph shows the percentage who received palliative care in the last year of life by setting of death and cancer diagnosis. For those who died at home, 50% of those with cancer and 19% of those without received palliative care. For those who died in long-term care, 13% of those with cancer and 9% of those without received palliative care. For those who died in acute care, 41% of those with cancer and 14% of those without received palliative care.

Notes
Home deaths include Ontario, Alberta, British Columbia and Yukon only.
Home deaths include those who were home care clients in their last year of life and did not have a record of death in long-term care, acute care, complex continuing care or emergency department.
Long-term care deaths include Newfoundland and Labrador, Ontario, Alberta, British Columbia and Yukon.
The proportion of people who died in acute care who received palliative care include only those who were hospitalized primarily for palliative care in their last year of life and excludes those who may have had palliative care in acute care but it did not represent the longest segment of their hospitalization. Quebec acute care deaths are excluded.
Sources
Home Care Reporting System, Continuing Care Reporting System, Discharge Abstract Database, 2015–2016 to 2016–2017, Canadian Institute for Health Information.

Text alternative for Figure 8: Proportion of those who died who received palliative care in the last year of life, by age group and place of death, 2016–2017

This graph shows the percentage who received palliative care in the last year of life by setting of death and age group. For those who died at home, these are the percentages of people who received palliative care, by age group: age 19 to 44, 47%; age 45 to 64, 46%; age 65 to 74, 46%; age 75 to 84, 40%; and age 85 and older, 29%. For those who died in acute care, these are the percentages of people who received palliative care by age group: age 19 to 44, 18%; age 45 to 64, 29%; age 65 to 74, 29%; age 75 to 84, 25%; and age 85 and older, 22%.

Notes

Home deaths include Ontario, Alberta, British Columbia and Yukon only.

Home deaths include those who were home care clients in their last year of life and did not have a record of death in long-term care, acute care, complex continuing care or emergency department.

The proportion of people who died in acute care who received palliative care include only those who were hospitalized primarily for palliative care in their last year of life and excludes those who may have had palliative care in acute care but it did not represent the longest segment of their hospitalization.

Sources

Home Care Reporting System and Discharge Abstract Database, 2015–2016 to 2016–2017, Canadian Institute for Health Information.

Text alternative for Figure 9: A comparison of survey responses from primary care doctors about palliative care, Canada and international peers

This graph compares the responses from primary care doctors in Canada on how often they see palliative patients and how prepared they are to manage their palliative care, in relation to responses from the U.K., the Netherlands and an international average of peer countries. 41% of Canadian respondents reported feeling well prepared to manage palliative patients, compared with 81% in the U.K., 92% in the Netherlands and 54% among peer countries. 79% of Canadian respondents reported often or sometimes seeing patients with palliative needs, compared with 97% in the U.K., 98% in the Netherlands and 79% among peer countries.

The survey questions are as follows:

- How often does your practice see patients in need of palliative care?
- How prepared is your practice to manage care for patients in need of palliative care?

Note

International average includes New Zealand, Canada, Australia, Switzerland, United Kingdom, United States, Sweden, Norway, France, Netherlands and Germany.

Source

The Commonwealth Fund, The Commonwealth Fund 2015 International Health Policy Survey of Primary Care Physicians, 2015.

Text alternative for Figure E1: Proportion of those who died in acute care who were designated as palliative or hospitalized primarily for palliative care in the last year of life, 2011–2012 to 2016–2017

This graph shows the trends over time for the percentage designated as palliative and the percentage hospitalized primarily for palliative care among those who died in acute care between 2011–2012 and 2016–2017. The percentage hospitalized primarily for palliative care remained relatively stable (25% in 2011, 24% in 2012, and 25% in 2013, 2014, 2015 and 2016). The percentage designated as palliative rose over time, with 59% in 2011, 60% in 2012, 63% in 2013, 64% in 2014, 66% in 2015 and 68% in 2016. Note that the percentage designated as palliative includes those hospitalized primarily for palliative care.

Source
Discharge Abstract Database, 2011–2012 to 2016–2017, Canadian Institute for Health Information.

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