

Access to Palliative Care in Canada

Key findings from CIHI's Baseline Report

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Access to Palliative Care in Canada

Project objectives

- To provide baseline measurement of access to palliative care in Canada, using available data
- Highlight data and care gaps
- Spotlight innovations in palliative care

Key themes

Report

- Access to palliative care in the community
- Access to appropriate and effective care
- Equity in access
- Workforce preparedness
- Family involvement in care
- Opportunities to improve data

Web home page

- Patient and family perspective



Data and methods

Looked at palliative care in the last year of life across different sectors:

- Inpatient hospital care: **DAD/HMDB**
- Emergency department: **NACRS**
- Long-term care and complex continuing care: **CCRS**
- Home care: **HCRS**
- Physician services in the community: **PLPB**



Supplementary and contextual information:

- Prescription medications: **NPDUIS**
- Physician preparedness: **Commonwealth Fund Survey**
- Caregiver information: **HCRS, GSS**
- Location of deaths: **Statistics Canada**
- *Survey of provincial and territorial palliative care policies and programs*
- *Survey of residential hospices (w/CHPCA)*

Data coverage for palliative care analysis

Data holding	NL	PE	NS	NB	QC	ON	MB	SK	AB	BC	YT	NT	NU
Inpatient acute care	X	X	X	X	X	X	X	X	X	X	X	X	X
Emergency Department		*	*			X	*	*	X	*	X		
Long term care	X		*	*		X	*	*	X	X	X		
Complex Cont. Care						X	*						
Home Care			*			X	*		X	X	X		
Palliative Drug Program			*				X	*	X	X	*		
Physician billing						X	*	*	X				

X : CIHI data utilized in report

* : Data available but limitations in coverage or quality⁵

Few Canadians receive palliative home care in the last year of life



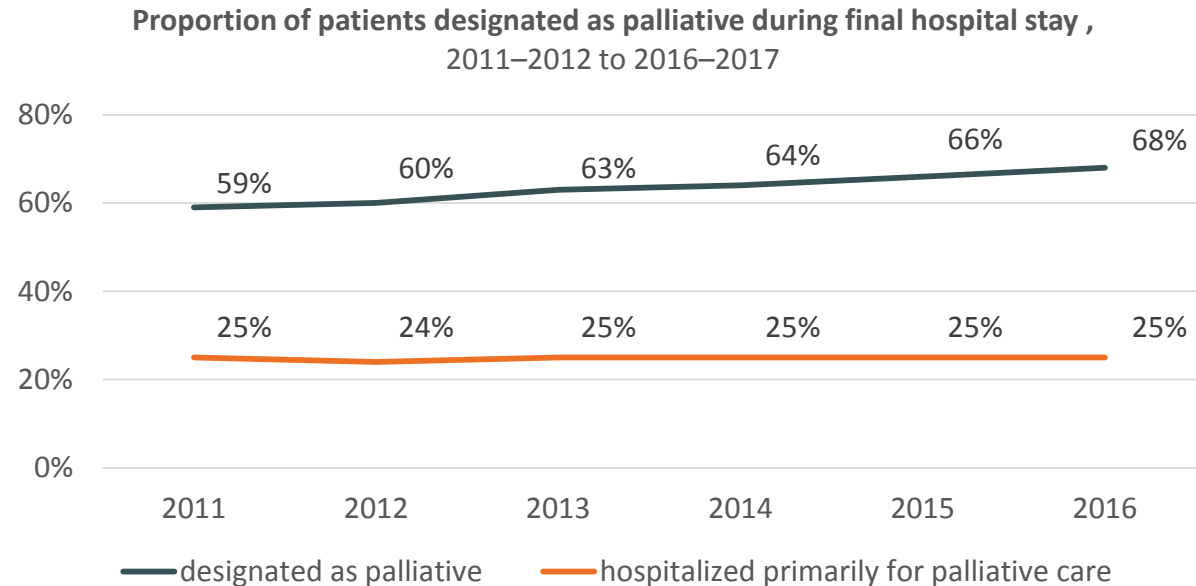
15% of people who died in Ontario and Alberta in 2016–2017 received publicly funded palliative home care

Most (**62%**) Canadians identified as having palliative needs:

- only in the last month of life
- only in a hospital setting

Many only identified as “palliative” for the first time in hospital

- About 116,000 Canadians died in acute care in 2016-2017
- Few (19%) had record of palliative treatment plan prior to final admission

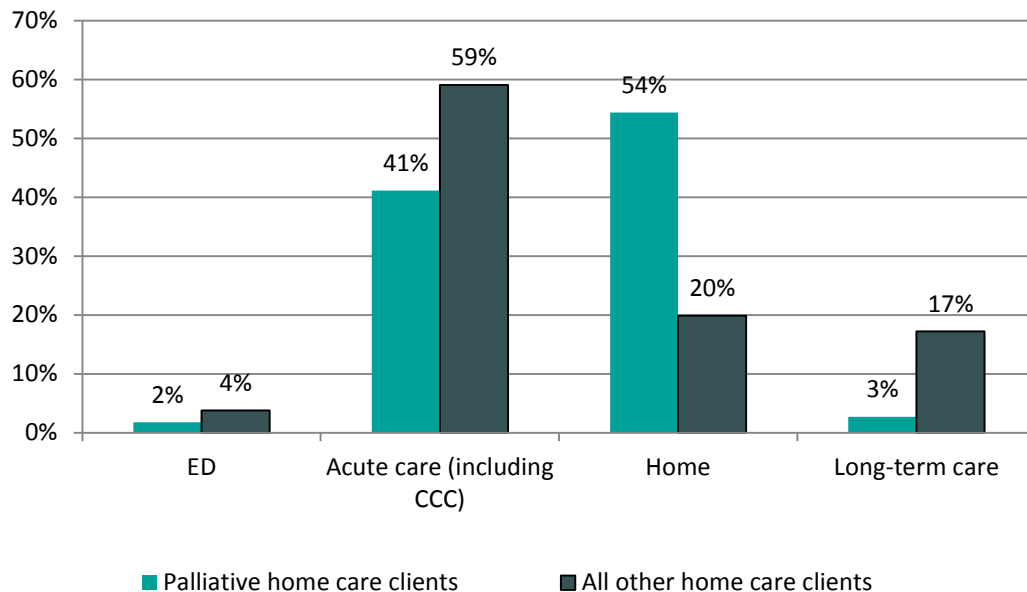


*The proportion of those designated as palliative includes those hospitalized primarily for palliative care.
(Source: DAD, HMDB)*

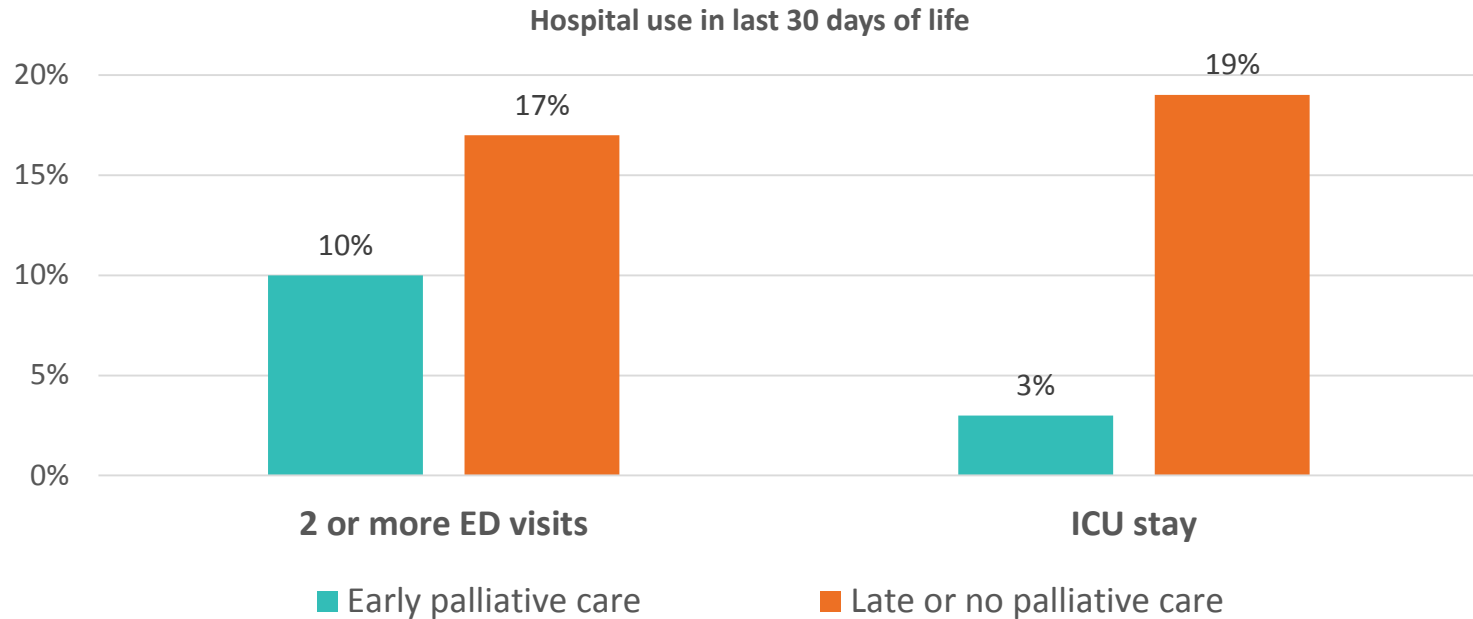
Palliative home care clients more likely to die at home

- Palliative home care clients were **2.5 times** more likely to **die at home** than other home care clients in the last year of life

Location of death for home care clients in last year of life, by client type (2016-2017)



Early palliative care effective in reducing emergency visits, ICU stays in last month of life



Early palliative care = *prior to the last 30 days of life*

Opportunities for earlier integration, better transitions of care for palliative patients



1 in 5 long term care residents with no record of palliative care in long term care died in acute care hospital

(compared to 2% of those with PC in LTC)



84% of hospitalizations for palliative care were unplanned

- 10% of those admitted through ED waited more than 25 hours
- Median waited more than 3.5 hours



10% of those hospitalized primarily for palliative care waited for discharge to a more appropriate setting (> 1 ALC days)

- Median wait: 9 days
- Nearly half of these waits ended in death

Likelihood of receiving palliative care differs by disease and age groups



In 2016–2017, people with cancer in Canada were 3 times more likely to receive palliative care than people with other illnesses

- **No sex or income differences** (based on neighborhood income)
- **Canadians 45-74 more likely to receive palliative care than older seniors or younger adults**
- **Largest differences in cancer vs. non-cancer patients, though unmet needs across disease groups**

Opportunities to improve training for health professionals

3/5



A majority of Canadian primary care doctors say they don't feel well prepared to help people in need of palliative care

Source: 2015 Commonwealth Fund Survey

- Canadian family doctors report feeling less prepared than average of their peers in 11 countries to manage care for palliative patients
- Survey found few mentorship opportunities and only 12% of medical residents have clinical rotations in palliative care (CPAC/PEOLC National Network survey of medical schools)

Friend and family caregivers essential partners in palliative care



99%

of palliative home care clients
had a caregiver



Caregivers for palliative home care clients provided emotional support (97%), help with IADLs (92%) and help with ADLs (85%)



30% of

palliative caregivers
experienced distress;
(average for all caregivers is
27%)

Do MAID patients have access to palliative care?

- Preliminary CIHI analysis of acute care data
- Small sample: 349 recorded cases of medical assistance in dying
- June 2016 and March 2017



Do MAID patients have access to palliative care?

- Based on hospital records of MAID patients:
 - 69% were designated as palliative at some point during their final hospital stay,
 - **35%** hospitalized primarily for palliative care – **higher than for other hospitalizations ending in death** (25%)
 - However, only **30%** had palliative care as part of their treatment plan **prior to their final hospitalization**

Variation in P/T policies and programs

Dimension	Results
Palliative Care Frameworks	Most provinces and territories had an existing framework or strategy in place
Palliative Home Care	<ul style="list-style-type: none">• Consistently publicly funded across jurisdictions• Eligibility criteria varied across the country• Estimated prognosis (e.g. 3 months or less in NS, 6 months or less in NB and AB)
Other Community Services	<ul style="list-style-type: none">• Residential hospices are operating in 7 out of 12 jurisdictions but funding levels vary greatly (30%- 100%)• Funding also varies for palliative care clinics/day programs
Measurement	<ul style="list-style-type: none">• 5 provinces in total collect and report on measures related to palliative care• Ontario and Alberta developing indicators

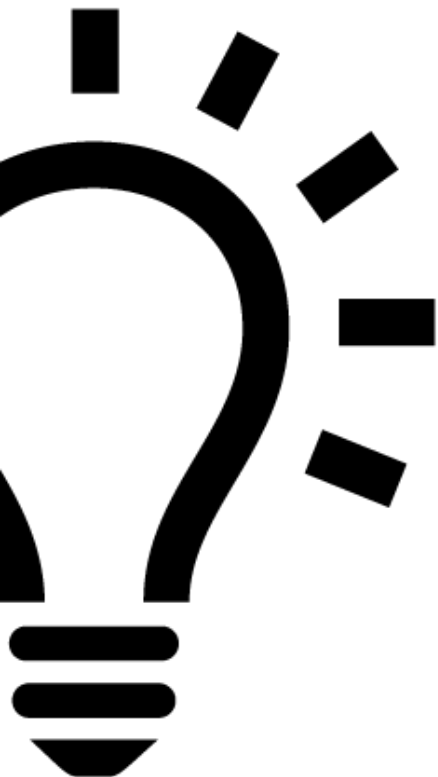
Data challenges

- **Limitations:**

- Limited data coverage outside of acute care
- No common standards on when to initiate palliative services or what basket of services to provide
- Patient and family-reported data on experience/outcomes is an important information gap



Opportunities for better data and measurement



- **In progress**
 - **CIHI:** improved coding standards for
 - ambulatory care (NACRS, 2018)
 - home care statistical information (MIS, 2019)
 - **CPAC:** Improving Patient Experience and Health Outcomes Collaborative
 - **Statistics Canada:** Data linkage and analysis
 - **Jurisdictions:** Provincial indicator development and data collection initiatives
- **On the horizon**
 - *CIHI Data Advancement Strategy:* community palliative care (i.e. home care, primary care) identified as a priority
 - Indicator development as part of F/P/T Shared Health Priorities
 - Federal Palliative Care Framework



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Annex

About Shared Health Priorities

- (Aug. 2017) Federal, Provincial and Territorial (FPT) Health Ministers' commit to:
 - Improve access to **mental health and addictions services**
 - Improve access to **home and community care**, including for palliative care
 - Work collectively and with CIHI to develop a focused set of common indicators to measure progress
 - Share relevant data to permit CIHI to produce annual public reports
- **Health Ministers' Meeting (June 2018)**
 - Health Ministers endorsed 12 indicators proposed by CIHI-FPT working groups
 - ~100 indicators per sector evaluated for relevance, impact, actionability, interpretability and readiness – after extensive consultation
 - 1 PEOLC indicator survived: *Death at home, not in hospital* * (to be defined)

Endorsed SHP indicators

Mental Health and Addictions

Hospitalization rates for problematic substance use

Rates of repeat ED or urgent care centre visits

Rates of self-injury, incl. suicide

Wait times for community mental health services

*Early identification for early intervention in youth (10-25) **

*Awareness/successful navigation of services **

Home and Community Care

Alternate level of care length of stay for inpatients requiring home care

Caregiver distress

(In)appropriate move to long term care

Wait times for home care services

Home care services helped recipient stay home

*Death at home, not in hospital **

Methodology



- **Identification of palliative care**
 - **Acute care**: palliative care limited to hospitalizations for palliative care (palliative care as the main diagnosis) – **REVISED!**
 - **Home care**: use of EOL client group to identify palliative home care clients – **REVISED!**
 - **Long-term care and CCC**: use of hospice flag in resident assessments
 - **Physician services**: use of billing codes for palliative care services
 - **Pharmaceuticals**: persons with claims to palliative drug programs
- **Identification of deaths**
 - Death discharges from acute care, LTC, CCC, HC and ED records
- **Contextual information**
 - Data from HHR databases, survey data, Vital Stats

Priority Indicators: Palliative care

Access dimension: person-centred, appropriate and effective

Indicator	Relevance	Impact on Health	Actionability	Interpretability	Availability & Readiness	Overall Priority
55. Wait times for palliative home care services	8	8	8	8	6	7.5 (*)
63. Deaths at home for palliative clients	8	7	7	6	7	7
60. ED visits by home care clients within last 30 days of life	7	7	7	7	7	7 (*)
59. Emergency department (ED) visits by palliative home care clients	8	7	7	7	6	7
56. Home care at end of life	7	7	7	7	7	7
58. Home support for palliative hospital patients	7	7	7	6	7	7 (*)

(*): agreed on and rated high overall priority by FPT