

# Health Quality Ontario

The provincial advisor on the quality of health care in Ontario

**June 28, 2016**

**Indicator Technical Specifications for the Palliative Care at  
the End of Life Report**

**Technical Appendix**



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## 1. Introduction

The technical appendix provides general information on the data sources, analytical methods, limitations, as well as detailed information for each indicator presented in the *Palliative Care at the End of Life* report.

## 2. Data Sources

The health care utilization indicator results presented in this report are provided by Institute for Clinical Evaluative Sciences (ICES) based on analysis of administrative databases. The findings related to patient and caregiver experience are based on select questions from the 2014 and 2015 Commonwealth Fund International Health Policy Surveys and the CaregiverVoice survey conducted in selected residential hospices from November 2014 to October 2015

The data source(s) for each indicator are listed within the individual templates. More details on the specific data sources that HQO used to produce the indicators are noted section 5, [Indicator Templates](#).

### CaregiverVoice (CV) Survey

The CaregiverVoice (CV) Survey was developed to measure patients' and families' experiences with end-of life care from the self-reported perspectives of the patient's primary informal caregiver after the patient has died. The intention of the survey is to provide user-derived information to guide local quality improvement activities and provide an indication of palliative care quality at community and provincial levels. The CV Survey is a care experience questionnaire as opposed to an outcome measure. The 62-item CV Survey measures the care experience across multiple care settings and at different time points in the care trajectory, including in the last three months of life, the last week of life, and at the time of death. Domains of care assessed are pain management, symptom management, emotional support, spiritual support, and practical support (in the home), as well as care in urgent situations, primary care involvement, decision making, continuity between care settings, advance care planning, and bereavement support. The data presented in the report is based on the CV survey conducted in selected residential hospices for 534 caregivers of people who died in these hospices.

### Commonwealth Fund's (CMWF) International Health Policy (IHP) Survey

As part of its mandate, the Commonwealth Fund (CMWF) has been conducting the International Health Policy Survey in 11 countries (Australia, Canada, France, Germany, Netherlands, New Zealand, Norway, Sweden, Switzerland, United Kingdom and United States) for more than a decade. In a triennial cycle, the IHP survey targets different populations, including physicians, older adults, and the general adult population. Data for this report are taken from the 2014 and 2015 years of the survey. The 2014 CMWF survey reflects the perceptions of a random sample of adults aged 55 or older who were surveyed via telephone between March and May 2014. The data were weighted to represent the Canadian and Ontario population aged 55 and older. Parameters used for weighting were age-by-gender, education and knowledge of either English or

French, all based on information from the 2011 census by Statistics Canada. The 2015 CMWF survey reflects the perceptions of a random sample of primary care physicians who were surveyed online, by mail, and telephone between March and November 2015. The data were weighted to account for the over-representation of primary care doctors in some provinces, the availability of the email addresses, and the differential non-response along known geographic and demographic parameters. The weighting adjustment was conducted in 2 stages: design weight and stratification weight. Data were weighted by age and gender within Ontario, Quebec and the rest of Canada. Additionally, it was subsequently weighted to reflect Canada's distribution of primary care doctors by province. All benchmarks were derived from the January 2015 Canadian Medical Association Masterfile. In this report, we compare Ontario data to the international survey results where possible.

### Continuing Care Reporting System (CCRS) – Canadian Institute for Health Information (CIHI)

CIHI developed the CCRS to enhance the collection of standardized facility-based long-term care and complex continuing care information for national comparative reporting. The CCRS contains demographic, administrative, clinical and resource utilization information on individuals receiving continuing care services in hospitals or in long-term care homes in Canada. Participating organizations also provide information on facility characteristics to support comparative reporting. The clinical data are collected using an internationally accepted standard, the Resident Assessment Instrument-Minimum Data Set Version 2.0 (RAI-MDS 2.0). Each resident in a long-term care home is assessed at admission and every three months or whenever they experience a significant change in health status. The RAI-MDS 2.0 assessment includes patient-level measures of function, mental and physical health, social support and service use. It was modified by CIHI with permission for Canadian use. All long-term care homes in Ontario have submitted data to CIHI on a quarterly basis since 2009.

### Discharge Abstract Database (DAD) – Canadian Institute for Health Information (CIHI)

The DAD is a database of information abstracted from hospital records that captures administrative, clinical and patient demographic information on all hospital inpatient separations, including discharges, deaths, sign-outs and transfers. CIHI receives Ontario data directly from participating facilities or from their respective regional health authorities or the Ministry of Health and Long-Term Care. The DAD includes patient-level data for all acute- and chronic-care hospitals, and rehabilitation hospitals in Ontario. Data are collected, maintained and validated by CIHI. The main data elements of the DAD are patient identifier (e.g. name, health care number), administrative information, clinical information (e.g. diagnoses and procedures) and patient demographics (e.g. age, sex, geographic location).

### Home Care Database (HCD) – Ministry of Health and Long-Term Care (MOHLTC)

The HCD is a clinical, patient-centred database that captures all home care services provided or coordinated by Ontario's Community Care Access Centres (CCACs), including government-funded Health Quality Ontario | Measuring Up 2015 | Technical Appendix 12 home and community services. The HCD is managed by the Ontario

Association of Community Care Access Centres (OACCAC). It includes patient, intake, assessment, and admission/discharge information. This information is used to determine the eligibility of patients and the intensity of care coordination, care planning, and services that align with their care needs. Clinical data are collected using standardized interRAI tools, including the Resident Assessment Instrument for Home Care (RAI-HC).

#### National Ambulatory Care Reporting System (NACRS) – Canadian Institute for Health Information (CIHI)

NACRS contains data for all hospital-based and community-based emergency and ambulatory care, including day surgeries, outpatient clinics and emergency departments. Data are collected, maintained and validated by CIHI. CIHI receives Ontario data directly from participating facilities or from their respective regional health authorities or the Ministry of Health and Long-Term Care. Data are collected, maintained and validated by CIHI. Data elements of the NACRS include patient identifier (e.g. name, health care number), patient demographics (e.g. age, sex, geographic location), clinical information (e.g. diagnoses and procedures), and administrative information.

#### National Rehabilitation Reporting System (NRS) – Canadian Institute for Health Information (CIHI)

The National Rehabilitation Reporting System (NRS) was developed by CIHI in 2001 to support data collection by hospitals for inpatient rehabilitation clients who are mainly age 18 and older. The rehabilitation services are usually provided in specialized rehabilitation hospitals and in general hospitals within rehabilitation units, programs or groups of rehabilitation beds. The NRS database captures clients with a range of health conditions, including strokes, orthopedic conditions and amputations.

#### Ontario Health Insurance Plan (OHIP) – Ministry of Health and Long-Term Care (MOHLTC)

The OHIP claims database covers all reimbursement claims to the MOHLTC made by fee-for-service physicians, community-based laboratories and radiology facilities. The OHIP database at ICES contains encrypted patient and physician identifiers, codes for services provided, date of service, the associated diagnosis and fee paid. Services which are missing from the OHIP data include: some lab services; services received in provincial psychiatric hospitals; services provided by health service organizations and other alternate providers; diagnostic procedures performed on an inpatient basis and lab services performed at hospitals (both inpatient and same day). Also excluded is remuneration to physicians through alternate funding plans (AFPs), which could distort analyses because of their concentration in certain specialties or geographic areas.

#### Registered Persons Data Base (RPDB) – Ministry of Health and Long-Term Care (MOHLTC)

The RPDB provides basic demographic information about anyone who has ever received an Ontario health card number. The RPDB is a historical listing of the unique health numbers issued to each person eligible for Ontario health services. This listing

includes corresponding demographic information such as date of birth, sex, address, date of death (where applicable) and changes in eligibility status. Data from the RPDB are enhanced with available information through other administrative data sources at the Institute for Clinical Evaluative Sciences (ICES); however, even the enhanced dataset overestimates the number of people living in Ontario for several reasons, including the source of death information and record linkage issues. Although improvements have been made in recent years, the RPDB still contains a substantial number of individuals who are deceased or no longer living in Ontario. As such, the RPDB will underestimate mortality. To ensure that rates and estimates are correct, a methodology has been developed to adjust the RPDB so that regional population counts by age and sex match estimates from Statistics Canada.

### 3. Analysis

The analysis plan was developed based on a review of relevant published and unpublished literature, particularly drawing from work conducted in Ontario (i.e. HSPRN paper “Understanding the Provision of End-of-Life and Palliative Care Services in Ontario” and the Ontario Ministry of Health and Long-Term Care Quarterly Report, April 2015) [1,2,3] and in consultation with the Ontario Palliative Care Network and subject matter experts (Dr. Peter Tanuseputro and Dr. Hsien Seow).

#### Significance Testing

##### *Administrative data*

Statistical significance was determined by comparing the 95% confidence intervals for each value. Confidence intervals were used to compare results at the regional, neighbourhood income and urban/rural levels. A value is said to be significantly different from another if the confidence intervals for the two values do not overlap. The report states higher/lower result only when results are statistically significant based on this method of testing.

##### *Commonwealth Fund survey data*

Social Sciences Research Solutions conducted statistical analyses to compare responses across countries and provinces within Canada. For provincial comparisons, statistical tests were conducted to compare each province’s response to every other province and to Canada as a whole. Ontario’s results were also compared to other countries. Significance was assessed based on a P-value of less than 0.05, meaning

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<sup>1</sup> Tanuseputro P, Budhwani S, Bai YQ, Wodchis WP. How much palliative care is delivered at the end-of-life? A population-level observational study in Ontario. Presented at Canadian Association for Health Services and Policy Research Conference; Toronto (ON). 2015 May.

<sup>2</sup> Tanuseputro P, Budhwani S, Bai YQ, Wodchis WP. Understanding the Provision of End-of-Life and Palliative Care Services in Ontario. Health System Performance Research Network. 2013 Jun.

<sup>3</sup> Health Analytics Branch, Health System Information Management and Investment Division, Ontario Ministry of Health and Long-term Care. The Quarterly. Health Care System Quarterly Reporting for Ministry Senior Management Health Analytics Branch, Health System Information Management and Investment Division. Toronto (ON). 2015 Apr; 13: 1-18.

that there was less than a 5% probability that the difference was due to chance rather than real differences in respondents' experiences.

### Limitations

- The results should be interpreted with caution as regional variation in the observed rates of services could potentially be affected by availability of resources for providing palliative care (i.e. palliative designation in home care, SRC-95).
- In some sectors, administrative databases do not capture care provided by non-physicians such as nurses and nurse practitioners who may be providing a substantial portion of palliative care (i.e. OHIP).
- Administrative data has a limited capacity to capture clinical details, quality of care received or appropriateness of health service utilization.
- The presented results do not capture the number and frequency of palliative care services received by each palliative care patient. Also, there is no evidence on what constitutes the appropriate number of palliative care services and whether receiving one service is sufficient. For this reason, it is not possible in this report to comment on the quality or appropriateness of care.

For details on additional indicator-specific details and limitations, please see the individual indicator templates in section 5, [Indicator Templates](#).

## 4. Palliative Care Patient Population

PALLIATIVE CARE PATIENT POPULATION	
<b>Description</b>	<p>The palliative care patient population for this report was defined as:</p> <ul style="list-style-type: none"> <li>• People who died in 2014/15 in Ontario, who received any palliative care services or were designated as end of life in their medical records in the last 12 months of life. Deaths in 2014/15 in Ontario were identified from RPDB</li> <li>• Using the ICES Key Number (IKN), death records identified from RPDB were linked to the CCRS, DAD, HCD, NACRS, and OHIP to select records that had at least one palliative care service code or EoL designation in the last 12 months of life.</li> </ul> <p><b>Note:</b> This population serves as the DENOMINATOR for the indicators.</p>
<b>Calculation</b>	<p>In developing the palliative care patient population, palliative care patients were counted only once if there were multiple records of palliative care services identified. Diagnoses and service codes that were used for selecting the palliative care services and end of life designation grouped by care settings:</p>

	<p><b>1. Outpatient / Community</b></p> <p>OHIP (Individuals with physician visit(s) for palliative care)</p> <ul style="list-style-type: none"> <li>• A945: Special palliative care consultation in clinic, office, home; minimum 50 minutes</li> <li>• K023*: Palliative care support in half hour increments; may be used to add time for longer consultations where Location = 'O' or 'H' or 'P'</li> <li>• G512: Weekly care case management from palliative primary care management (Mon-Sun) – This code should be considered as outpatient (however, sometimes, it may be billed in hospital).</li> <li>• G511: Telephone services to patient receiving PC at home (max 2/week)</li> <li>• B966: Travel premium for palliative care (billed with B998/B996)</li> <li>• B998: Home visit for palliative care between 07:00 and 24:00</li> <li>• B997: Home visit for palliative care between 24:00 and</li> <li>• K700: Palliative care out-patient case conference</li> </ul> <p>Home based physician visits</p> <ul style="list-style-type: none"> <li>• Travel codes B966, B997, B998 and telephone consult code G511</li> </ul> <p><b>2. Acute care (Hospital admissions)</b></p> <p>CIHI-DAD</p> <ul style="list-style-type: none"> <li>• ICD-10 Code: Z51.5 and ICD-9 Code: V66.7: Any diagnosis of “palliative”</li> <li>• PATSERV = 58: main patient service of “palliative care” was responsible for care</li> <li>• PRVSERV[1-8] or INSERV[1-20] = 00121: “palliative medicine” was a provider who provided service, or an intervention service code of palliative medicine was provided.</li> </ul> <p>OHIP billings</p> <ul style="list-style-type: none"> <li>• A945: Special palliative care consultation (afterhours billing) where location = 'I'</li> <li>• K023*: Palliative care support in half hour increments, if patient was in hospital during date of claim. Location = 'I'</li> <li>• C945: Special palliative care consult (minimum 50 minutes); K023 may be used to</li> </ul>
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	<p>add time for longer consultations following a code for C945, or may be billed alone;</p> <ul style="list-style-type: none"> <li>• C882: Family medicine palliative care, non-emergency (routine) hospital inpatient service</li> <li>• C982: Specialist palliative care, non-emergency (routine) hospital inpatient service;</li> </ul> <p>NACRS (ER room visits)</p> <ul style="list-style-type: none"> <li>• PRVSERV [1-10] = 00121: Provider service code of palliative medicine</li> <li>• CONSULTSERV1 to CONSULTSERV3 = 00121: Consult service of palliative medicine was called</li> </ul> <p><b>3. Home Care</b></p> <p>HCD</p> <ul style="list-style-type: none"> <li>• SRC_admission = 95: Service recipient code (i.e., classification) of end of life on admission</li> <li>• Service_RPC = 95: Service care goal of end of life; patient provided service under end of life designation</li> <li>• Residence_type = 2000: Staying in hospice or palliative care unit while receiving service</li> <li>• SRC_discharge = 95: Service recipient code of end of life on discharge (Note: Select all records with SRC-95 in any assessment record.)</li> </ul> <p>RAI-HC</p> <ul style="list-style-type: none"> <li>• P2S = 1 or 2: Hospice care was provided with complete or partial adherence</li> <li>• CC3f goals of care = palliative care (cc3f = 1)</li> </ul> <p>RAI-CA</p> <ul style="list-style-type: none"> <li>• B2c = 1: Referral to initiate/continue palliative care FROM RAI-CA</li> <li>• B4 = 12: Expected place of stay during service of Hospice facility or Palliative Care Unit</li> <li>• Questions on RAI-CA (E7=2 end of life), RAI-HC (K8e: Prognosis of less than 6 months to live – e.g. physician has told client or client's family that the client has end-stage disease)</li> </ul> <p><b>4. Long-term care (LTC) facilities</b></p> <p>OHIP billing codes:</p> <ul style="list-style-type: none"> <li>• A945: Special palliative care consultation (afterhours billing) where location = 'L'</li> <li>• K023*: Palliative care support in half hour increments if delivered in LTC. Location = 'L'</li> <li>• W872: Family physician palliative care subsequent visit</li> </ul>
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	<ul style="list-style-type: none"> <li>W972: Specialist physician palliative care subsequent visit</li> </ul> <p>Continuing Care Reporting System (CCRS-LTC):</p> <ul style="list-style-type: none"> <li>P1AO = 1: Received hospice care in last 14 days (from RAI-MDS assessment)</li> </ul> <p><b>5. Complex Continuing care (CCC)</b></p> <p>OHIP billing codes:</p> <ul style="list-style-type: none"> <li>W882: Family physician palliative care subsequent visit</li> <li>W982: Specialist physician palliative care subsequent visit</li> </ul> <p>Continuing Care Reporting System (CCRS):</p> <ul style="list-style-type: none"> <li>P1AO = 1: Received hospice care in last 14 days (from RAI-MDS assessment)</li> </ul> <p><b>Exclusions:</b></p> <ul style="list-style-type: none"> <li>Invalid IKN</li> <li>Age &gt;115</li> <li>Non- resident in Ontario</li> <li>Missing/invalid sex or birthdate</li> <li>Patients with OHIP records &gt; 30 days after death date</li> <li>Patients who died of significant trauma or injury (MCC = '19' and dischdisp = '07')</li> </ul> <p><b>Notes:</b></p> <ul style="list-style-type: none"> <li>*Determining location of K023 OHIP records: The location of K023 defaults to office even if physician visit did not occur in an office. In order to try to determine a more accurate location of K023 all OHIP billings for that patient from the same physician on the same servdate were compared. If the location of the other billings were different from the K023 billing (i.e. Inpatient, ED, Home, Phone, or LTC) then the other location was assigned. If no other billings from the same physician on the same day exist, the location of K023 was assigned as (office).</li> <li>For each palliative care patient, the first month when palliative care was observed over the 12 month period was identified.</li> <li>Multiple service codes billed on the same day from one source (OHIP) was counted as one claim.</li> </ul>
<b>Data source / data elements</b>	Continuing Care Reporting System (CCRS), Discharge Abstract Database (DAD), Home Care Database (HCD), National Ambulatory Care Reporting System (NACRS), Ontario Health Insurance Plan (OHIP), Registered Persons

	<p>Data Base (RPDB), provided by the Institute for Clinical Evaluative Sciences (ICES)</p> <p><b>Note:</b></p> <ul style="list-style-type: none"> <li>- This applies to the entire palliative care patient population (which serves as the denominator for the indicators); for data sources specific to each indicator, please see data sources section of the indicator of interest</li> </ul>
<b>Limitations / Caveats</b>	<ul style="list-style-type: none"> <li>• The number of palliative care patients in the selected population may be underestimated due to limitations in coding practices, i.e. in some cases, palliative care may be delivered but not coded as such. This is more pronounced for the long-term care sector where a significant proportion of long-term care residents likely receive palliative care, however it may not be coded as palliative.</li> <li>• The services that qualified palliative care patients for inclusion in the selected population were subsequently used to measure the indicators (e.g., ED visits, hospital admissions, etc.) which may bias the results.</li> <li>• Some palliative care patients included in the selected population may not have been eligible for any other palliative services in the community as they may have received their first palliative care service in that 12 month period during the hospitalization at their last month of life, and died during that admission. While patients who died of significant trauma or injury were excluded from the analysis, it was difficult (and not feasible with our data) to identify other deaths that can be classified as sudden and would have also been excluded.</li> </ul>

## 5. Indicator Templates

HOME CARE SERVICES IN THE LAST 30 DAYS OF LIFE	
<b>Description</b>	<p>This indicator measures the percentage of (community-dwelling) palliative care patients who received at least one home care service within their last 30 days of life, reported as:</p> <ol style="list-style-type: none"> <li>1. Any home care</li> <li>2. Palliative home care</li> </ol> <p>A higher percentage is better.</p>
<b>Relevance/Rationale</b>	<p>Frequent admissions to hospital at the end of life may indicate that primary care or community-based services are not meeting all of patients' end-of-life care needs, and may contribute to challenges with continuity of care.[1] Receiving palliative home care was associated with a 50% reduction in the risk of dying in an institution.[2] According to a study of terminally-ill patients, those who received in-home palliative care from an interdisciplinary team were more satisfied with care, more likely to die at home, less likely to visit emergency department, and less likely to be admitted to hospital.[3] A Canadian report estimated that shifting 10% of palliative care patients from acute care to home care would save \$9 million in health care costs.[4]</p>
<b>HQO reporting tool</b>	Palliative Care at the End of Life Theme Report
<b>Reporting tools external to HQO</b>	None
<b>Unit of analysis</b>	Percentage
<b>Calculation</b>	<p><b>Numerator</b></p> <p>Number of (community-dwelling) palliative care patients who received at least one home care service within their last 30 days of life, reported as:</p> <p><b>1. Any home care</b></p> <p>Home Care Database (HCD): services variable  SERVICE = [1-13, 16-18]  SERVICE = Type of service provided (home care service)</p> <ul style="list-style-type: none"> <li>- 1 = Nursing - Visit</li> <li>- 2 = Nursing - Shift (Hour)</li> <li>- 3 = Respiratory Services</li> <li>- 4 = Nutrition/Dietetic</li> <li>- 5 = Physiotherapy</li> <li>- 6 = Occupational Therapy</li> </ul>

	<ul style="list-style-type: none"> <li>- 7 = Speech Language Therapy</li> <li>- 8 = Social Work</li> <li>- 9 = Psychology</li> <li>- 10 = Case Management</li> <li>- 11 = Personal Services (Hour)</li> <li>- 12 = Homemaking Services (Hour)</li> <li>- 13 = Combined Ps And Hm Services (Hour)</li> <li>- 14 = Placement Services</li> <li>- 15 = Respite</li> <li>- 16 = Mental Health and Addiction Nursing Visit</li> <li>- 17 = Nurse Practitioner Palliative Visit</li> <li>- 18 = Rapid Response Nursing Visit</li> <li>- 99 = Other</li> </ul> <p><b>2. Palliative home care</b></p> <p>Home Care Database (HCD):</p> <ul style="list-style-type: none"> <li>- SRC_admission = 95: Service recipient code (i.e., classification) of end of life on admission</li> <li>- Service_RPC = 95: Service care goal of end of life; patient provided service under end of life designation</li> <li>- Residence_type = 2000: Staying in hospice or palliative care unit while receiving service</li> <li>- SRC_discharge = 95: Service recipient code of end of life on discharge</li> </ul> <p><b>Denominator</b></p> <p>The number of palliative care patients**</p> <p><b>Exclusions:</b></p> <ul style="list-style-type: none"> <li>- Palliative care patients who spent their last month in the hospital, LTC/CCC or NRS.</li> </ul> <p><b>Note:</b></p> <ul style="list-style-type: none"> <li>- **See the denominator methodology details in the palliative care patient population technical template</li> </ul> <p><b>Methods</b></p> <p>Numerator/Denominator*100</p> <p><b>Adjustment</b> (<i>risk, including age/sex standardization</i>)</p> <p>N/A</p>
<p><b>Data source / data elements</b></p>	<p>Home Care Database (HCD) and Registered Persons Data Base (RPDB) provided by the Institute for Clinical Evaluative Sciences</p> <p><b>Note:</b></p>

	<ul style="list-style-type: none"> <li>- This applies to the numerator; see data sources for constructing the palliative care patient population (denominator) in the palliative care patient population technical template</li> </ul>
<b>Levels of comparability/stratification descriptions</b>	Provincial, LHIN, age groups, sex, urban/rural setting, neighbourhood income quintiles
<b>Limitations / Caveats</b>	<ul style="list-style-type: none"> <li>- The data don't show information on the details and quality of the home care, health care needs, preferences and appropriateness of the care</li> <li>- The data shows the number of palliative care patients that had at least one home care service. which may not be sufficient There is no evidence of what is the appropriate amount or mix of home care services for palliative care patients to which this could be compared.</li> <li>- The data do not show if palliative care patients had any other support or a caregiver.</li> </ul>

1. Dudevich A, Chen A, Gula C, Fagbemi J. End-of-life hospital care for cancer patients: an update. Healthc Q. Toronto (ON). 2013 Dec;17(3):8-10.
2. Tanuseputro P, Beach S, Chalifoux M, Wodchis W, Hsu A, Seow H, et al. Effect of physician home visits for the dying on place of death. [Under publication].
3. Brumley R, Enguidanos S, Jamison P, Seitz R, Morgenstern N, Saito S, McIlwane J, Hillary K, Gonzalez J. Increased satisfaction with care and lower costs: results of a randomized trial of in-home palliative care. J Am Geriatr Soc. 2007 Jul 1;55(7):993-1000.
4. Hodgson C. Cost-effectiveness of palliative care: A review of the literature. Prepared for Canadian Hospice Palliative Care Association. Ottawa (ON). [Date unknown]. Available from: <http://hpcintegration.ca/media/24434/TWF-Economics-report-Final.pdf>

<b>HOME VISITS BY A DOCTOR IN THE LAST 30 DAYS OF LIFE</b>	
<b>Description</b>	<p>This indicator measures percentage of (community-dwelling) palliative care patients who received a home visit by a doctor within their last 30 days of life, reported as:</p> <ol style="list-style-type: none"> <li>1. Any home visit by a doctor</li> <li>2. Palliative care home visit by a doctor</li> </ol> <p>A higher percentage is better.</p>
<b>Relevance/Rationale</b>	<p>There are several factors that may affect the place of death and one of the key factors is getting physician house calls.[1] Previous studies conducted in Ontario showed that the proportion of patients receiving a house call in the last six months was 33%. The same study showed that patients receiving home care or house calls are much less likely to die in hospital.[2] After adjustment for multiple factors (including patient illness, home care services, and days of being at</p>

	<p>home), receiving at least one physician home visit in the last year of life from a non-palliative care physician was associated with a 47% decrease of dying in hospital. When a palliative care physician specialist was involved, the overall risk declined by 59%.[3] Based on a College of Physicians and Surgeons of Ontario policy statement on “Planning for and Providing Quality End-of-Life Care,” physicians are key to planning for end-of-life and can ensure that the care provided to patients aligns with their wishes, values and beliefs.[4] A physician visit at the end-of-life may provide symptom relief and psychological support that may prevent a visit to the emergency room and a subsequent admission into hospital. An involved physician may also facilitate access to additional services, including those provided through home care, which involves allied health care practitioners and, at times, the care of a specialist palliative care team.[3]</p>
<b>HQO reporting tool</b>	Palliative Care at the End of Life Theme Report
<b>Reporting tools external to HQO</b>	None
<b>Unit of analysis</b>	Percentage
<b>Calculation</b>	<p><b>Numerator</b></p> <p>Number of (community-dwelling) palliative care patients who received a home visit by a doctor in their last 30 days of life, reported as:</p> <p><b>1. Any home visit by a doctor</b></p> <ul style="list-style-type: none"> <li>- G511: Telephone services to patient receiving PC at home (max 2/week)</li> <li>- B966: Travel premium for palliative care (billed with B998/B996)</li> <li>- B998: Home visit for palliative care between 07:00 and 24:00 (Sat, Sun, and holidays) or</li> <li>- B997: Home visit for palliative care between 24:00 and 07:00</li> <li>- A901 (GP/FP house call)</li> <li>- B990 Special visit to patient’s home (weekday/daytime)</li> <li>- B992 Special visit to patient’s home (weekday/daytime), with sacrifice to office hours</li> <li>- B994 (special visit to patient’s home, non-elective, evenings)</li> <li>- B996 (special visit to patient’s home, night time, first patient of the night)</li> </ul>

	<b>2. Palliative care home visit by a doctor</b> <ul style="list-style-type: none"> <li>- G511: Telephone services to patient receiving PC at home (max 2/week)</li> <li>- B966: Travel premium for palliative care (billed with B998/B996)</li> <li>- B998: Home visit for palliative care between 07:00 and 24:00</li> <li>- B997: Home visit for palliative care between 24:00 and 07:00</li> </ul>
	<b>Denominator</b> The number of palliative care patients**
	<b>Exclusions:</b> <ul style="list-style-type: none"> <li>- Palliative care patients who spent their last month in the hospital, LTC/CCC or NRS.</li> </ul>
	<b>Note:</b> <ul style="list-style-type: none"> <li>- ** See the denominator methodology details in the palliative care patient population technical template</li> </ul>
	<b>Methods</b> Numerator/Denominator*100
	<b>Adjustment</b> ( <i>risk, including age/sex standardization</i> ) N/A
<b>Data source / data elements</b>	Ontario Health Insurance Plan (OHIP) and Registered Persons Data Base (RPDB) provided by the Institute for Clinical Evaluative Sciences
	<b>Note:</b> <ul style="list-style-type: none"> <li>- This applies to the numerator; see data sources for constructing the palliative care patient population (denominator) in the palliative care patient population technical template</li> </ul>
<b>Levels of comparability/stratification descriptions</b>	Provincial, LHIN, age groups, sex, urban/rural setting, neighbourhood income quintiles
<b>Limitations / Caveats</b>	<ul style="list-style-type: none"> <li>- The data doesn't include information on the quality of the care, clinical details, health care needs, preferences and appropriateness of the house call.</li> <li>- The data shows the number of palliative care patients that had at least one house call. There is no evidence of what is the appropriate number of house calls to which this could be compared</li> </ul>

1. Costa V. The Determinants of Place of Death: An Evidence-Based Analysis. Ont Health Technol Assess Ser [Internet].. 2014 Dec;14(16):1-78. Available from:

<http://www.hqontario.ca/evidence/publications-and-ohtacrecommendations/ontario-health-technology-assessment-series/eol-determinants-place-of-death>

2. Barbera L, Sussman J, Viola R, Husain A, Howell D, Librach SL, et al. Factors associated with end-of-life health service use in patients dying of cancer. *Healthc Policy*. 2010 Feb;5(3):e125-143.
3. Tanuseputro P, Beach S, Chalifoux M, Wodchis W, Hsu A, Seow H, et al. Effect of physician home visits for the dying on place of death. [Under publication].
4. College of Physicians and Surgeons of Ontario. Planning for and Providing Quality End-of-Life Care. CPSP Policy statement #4-15. Toronto (ON). 2016 May. Available from: <http://www.cpsso.on.ca/CPSO/media/documents/Policies/Policy-Items/End-of-Life.pdf?ext=.pdf>

<b>UNPLANNED EMERGENCY DEPARTMENT (ED) VISITS IN THE LAST 30 DAYS OF LIFE</b>	
<b>Description</b>	This indicator measures the percentage of palliative care patients who had at least one unplanned emergency department (ED) visit in their last 30 days of life.
<b>Relevance/Rationale</b>	The ED may not be the best treatment place for patients with a terminal illness. A palliative care patient who needs to visit the ED may be considered as a failure of the health care system.[1] Another study suggests that visits to the ED at the end of life are considered as an indicator of poor-quality care for patients with cancer as the visit can be disruptive, distressing and exhausting. [2] It also represents a transition in a patient's care and creates challenges for the continuity of care, and increases the risk of either miscommunication or lack of documentation of care among changing care providers. While not every ED visit is unwanted and a proportion of these visits may be needed, a study suggested that nearly one-fourth of ED visits by patients with advanced cancer receiving palliative care can be potentially avoidable.[3]
<b>HQO reporting tool</b>	Palliative Care at the End of Life Theme Report
<b>Reporting tools external to HQO</b>	Similar indicators: <ul style="list-style-type: none"> <li>- OPCN has "Percentage of Ontario palliative care patients who visited the ER in the last 2 weeks of life" for LHIN reporting.</li> <li>- Cancer Care Ontario in CSQI is reporting "Percentage of cancer patients who visited the emergency department in the last two weeks of life"</li> </ul>
<b>Unit of analysis</b>	Percentage
<b>Calculation</b>	<b>Numerator</b>

	<p>The number of palliative care patients who had at least one unplanned emergency department visit within their last 30 days of life.</p> <p>People who had unplanned ED visit in NACRS          Unscheduled/unplanned ED visits are identified by:          NACRS variables VISITTYPE = [1,2,4] OR          SCHEDEDVISIT = N</p> <p><b>Exclusions:</b></p> <ul style="list-style-type: none"> <li>- Planned ED visits</li> </ul>
	<p><b>Denominator</b></p> <p>The number of palliative care patients**.</p> <p><b>Exclusions:</b></p> <ul style="list-style-type: none"> <li>- Palliative care patients who were in hospital for the entire period of their last 30 days of life as people who are in hospital during this time cannot be having an unplanned ED visit</li> </ul> <p><b>Note:</b></p> <ul style="list-style-type: none"> <li>- ** See the denominator methodology details in the palliative care patient population technical template</li> </ul>
	<p><b>Methods</b></p> <p>Numerator/Denominator*100</p>
	<p><b>Adjustment</b> (<i>risk, including age/sex standardization</i>)</p> <p>N/A</p>
<b>Data source / data elements</b>	<p>National Ambulatory Care Reporting (NACRS) and Registered Persons Data Base (RPDB) provided by the Institute for Clinical Evaluative Sciences</p> <p><b>Note:</b></p> <ul style="list-style-type: none"> <li>- This applies to the numerator; see data sources for constructing the palliative care patient population (denominator) in the palliative care patient population technical template</li> </ul>
<b>Levels of comparability/stratification descriptions</b>	<p>Provincial, LHIN, age groups, sex, urban/rural setting, neighbourhood income quintiles</p>
<b>Limitations / Caveats</b>	<ul style="list-style-type: none"> <li>• Missing the information on clinical details, health care needs, preferences and appropriateness of the hospital visits.</li> </ul>

	<ul style="list-style-type: none"> <li>Hard to interpret as there are no benchmarks or targets on the acceptable rate of ED visits in this patient population.</li> </ul>
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1. Lawrenson R, Waetford J, Gibbons V, Kirk P, Haggart S, Reddy R. Palliative care patients' use of emergency departments. N Z Med J. 2013 Apr 5;126(1372): 80-88.
2. Barbera L, Paszat L, Chartier C. Indicators of poor quality end-of-life cancer care in Ontario. J Palliat Care. 2006 Apr 1;22(1):12-17.
3. Delgado-Guay MO, Kim YJ, Shin SH, Chisholm G, Williams J, Allo J, Bruera E. Avoidable and unavoidable visits to the emergency department among patients with advanced cancer receiving outpatient palliative care. J Pain Symptom Manage. 2015 Mar 31;49(3):497-504.

BEING ADMITTED TO HOSPITAL IN THE LAST 30 DAYS OF LIFE	
<b>Description</b>	This indicator measures the percentage of palliative care patients who had at least one hospital admission in their last 30 days of life
<b>Relevance/Rationale</b>	While studies show that most people prefer to die in their usual place of residence [1], hospitals remain the provider of end-of-life care for a majority of Canadians.[2] With patient-focused concerns of delivery of healthcare, there is a need to examine current end-of-life practices and try to better match the healthcare desires of patients to deliver this care. Hospital admissions or intensive care admissions at the end of life are considered an indicator of poor quality of care at the end of life. High rates of hospital use may indicate lack of appropriate palliative care at the end of life and also show challenges with access to primary health care or other community-based services. However, the realities of dying are much more complex and unpredictable.
<b>HQO reporting tool</b>	Palliative Care at the End of Life Theme Report
<b>Reporting tools external to HQO</b>	None
<b>Unit of analysis</b>	Percentage
<b>Calculation</b>	<p><b>Numerator</b></p> <p>The number of people in the denominator who had at least one hospital admission in their last 30 days of life.</p> <p><b>Note:</b></p> <ul style="list-style-type: none"> <li>- Analysis includes palliative care patients who had at least one hospital admission, therefore, data do</li> </ul>

	<p>not show if palliative care patients had multiple admissions.</p> <ul style="list-style-type: none"> <li>- if the patient was admitted more than once in the month then it is only counted once in the numerator</li> </ul>
	<p><b>Denominator</b></p> <p>The number of palliative care patients**</p> <p><b>Exclusions:</b></p> <ul style="list-style-type: none"> <li>- Patients that were in the hospital for the full duration of their last 30 days of life.</li> </ul> <p><b>Note:</b></p> <ul style="list-style-type: none"> <li>- ** See the denominator methodology details in the palliative care patient population technical template</li> <li>- Palliative care patients who spent their entire last 30 days of life in hospital but were transferred to a new hospital at some point in the last 30 days of life were also excluded from the analysis as the transfer that occurred was not counted as an additional hospital admission.</li> </ul>
	<p><b>Methods</b></p> <p>Numerator/Denominator*100</p>
	<p><b>Adjustment</b> (<i>risk, including age/sex standardization</i>)</p> <p>N/A</p>
	<p><b>Data source / data elements</b></p> <p>Discharge Abstract Database (DAD) and Registered Persons Data Base (RPDB) provided by the Institute for Clinical Evaluative Sciences</p> <p><b>Note:</b></p> <ul style="list-style-type: none"> <li>- This applies to the numerator; see data sources for constructing the palliative care patient population (denominator) in the palliative care patient population technical template</li> </ul>
<b>Levels of comparability/stratification descriptions</b>	<p>Provincial, LHIN, age groups, sex, urban/rural setting, neighbourhood income quintiles</p>
<b>Limitations / Caveats</b>	<ul style="list-style-type: none"> <li>- No benchmark/target, not all hospital admissions near end-of-life are avoidable</li> <li>- Missing the information on clinical details, health care needs, preferences and appropriateness of the hospital admission</li> <li>- A minority of palliative care patients may need hospitalization for symptom relief, and may need support from a Palliative Care Unit (PCU). As there</li> </ul>

	are very few PCU beds in Ontario, few people can be admitted into one of these beds for the necessary palliative care.
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1. Brazil K, Howell D, Bedard M, Krueger P, Heidebrecht C. Preferences for place of care and place of death among informal caregivers of the terminally ill. Palliat Medicine. 2005 Sep 1;19(6):492-499.
2. Fowler R, Hammer M. End-of-life care in Canada. Clin Invest Med. 2013 Jun 1;36(3):127-132.

TIME SPENT IN HOSPITAL IN THE LAST 30 DAYS OF LIFE	
<b>Description</b>	<p>This indicator measures the length of stay in hospital among palliative care patients in the last 30 days of life, reported as:</p> <ol style="list-style-type: none"> <li>1. Median number of days spent in the hospital</li> <li>2. Number of palliative care patients who spent time in hospital: 0 days, 1-4 days, 5-14 days, and more than 15 days</li> </ol>
<b>Relevance/Rationale</b>	<p>Hospital length of stay (LOS) is used in assessment of quality of care, costs and efficiency. According to an Ontario study, almost three-quarters (72%) of end-of-life health care costs were for acute care services excluding ICU stays.[1] Therefore, for this population, hospital LOS also shows the duration and provision of palliative care in a hospital setting.</p>
<b>HQO reporting tool</b>	Palliative Care at the End of Life Theme Report
<b>Reporting tools external to HQO</b>	None
<b>Unit of analysis</b>	<ol style="list-style-type: none"> <li>1. Days</li> <li>2. People</li> </ol>
<b>Calculation</b>	<p><b>Numerator</b></p> <p>For the last 30 days of life:</p> <ol style="list-style-type: none"> <li>1. Median number of days spent in the hospital per palliative care patient</li> <li>2. The number of palliative care patients who spent time in hospital categorized as: 0 days, 1-4 days, 5-14 days, and more than 15 days</li> </ol>
	<p><b>Denominator</b></p> <p>The number palliative care patients**</p> <p><b>Note:</b></p> <ul style="list-style-type: none"> <li>- ** See the denominator methodology details in the palliative care patient population technical template</li> </ul>
	<p><b>Methods</b></p> <ol style="list-style-type: none"> <li>1. Calculate median</li> <li>2. Calculate the number of palliative care patients in each category</li> </ol>
	<b>Adjustment</b> ( <i>risk, including age/sex standardization</i> )

	N/A
<b>Data source / data elements</b>	<p>Discharge Abstract Database (DAD) provided by the Institute for Clinical Evaluative Sciences</p> <p><b>Note:</b></p> <ul style="list-style-type: none"> <li>- This applies to the numerator; see data sources for constructing the palliative care patient population (denominator) in the palliative care patient population technical template</li> </ul>
<b>Levels of comparability/stratification descriptions</b>	Provincial, LHIN, age groups, sex, urban/rural setting, neighbourhood income quintiles
<b>Limitations / Caveats</b>	<ul style="list-style-type: none"> <li>- There are no benchmarks or targets on the acceptable rate (extent of palliative care need in the hospital) for this patient population.</li> <li>- Missing the information on clinical details, health care needs and appropriateness of the hospital stay.</li> </ul>

1. Hodgson C. Cost-effectiveness of palliative care: A review of the literature. Prepared for Canadian Hospice Palliative Care Association. Ottawa (ON). [Date unknown]. Available from: <http://hpcintegration.ca/media/24434/TWF-Economics-report-Final.pdf>

LOCATION OF DEATH	
<b>Description</b>	<p>This indicator measures the palliative care patients deaths:</p> <ul style="list-style-type: none"> <li>- Hospital (inpatient, ED, CCC and rehab)</li> <li>- Long-term care</li> <li>- Community (home, residential hospices, retirement homes and assisted living homes)</li> </ul>
<b>Relevance/Rationale</b>	<p>Most caregivers reported that they and the care recipient had a preferred place of death (77% and 68%, respectively) with over 63% reporting home as the preferred place of death.[1] However, most deaths happen in the hospital.[2] Based on the Health Quality Ontario's Evidence-Based Analysis, the appropriate place of death may depend on the needs of each patient. There are several factors that may affect the place of death such as: multidisciplinary end-of-life care in the home or nursing home, type of underlying disease, functional status, and hospitalizations during the end-of-life period, living arrangements and the presence of an informal caregiver, caregiver coping, patient and family preference for place of death as well as existence of advance directives, nursing home bed availability, and the availability of an inpatient medical unit in the nursing home.[3]</p>

<b>HQO reporting tool</b>	Palliative Care at the End of Life Theme Report
<b>Reporting tools external to HQO</b>	Statistics Canada reports hospital deaths (CANSIM table 102-0509) in the total population
<b>Unit of analysis</b>	Percentage
<b>Calculation</b>	<p><b>Numerator</b></p> <p>The number of people who died in each of the following settings:</p> <ul style="list-style-type: none"> <li>- Hospital (inpatient, ED, CCC and rehab)</li> <li>- Long-term care</li> <li>- Community (home, residential hospices, retirement homes and assisted living homes)</li> </ul> <p><b>Inclusions:</b></p> <p>Hospital deaths are identified by the following codes:</p> <ul style="list-style-type: none"> <li>- Inpatient: DAD – SDS dischdisp = 07</li> <li>- ED: NACRS – Visit disposition = 10 or 11</li> <li>- CCC: CCRS discharge_to_facility_type = 11</li> <li>- Rehab: NRS dreason=8</li> </ul> <p>LTC</p> <ul style="list-style-type: none"> <li>- CCRS-LTC discharge_to_facility_type = 11</li> </ul> <p>Community</p> <ul style="list-style-type: none"> <li>- All other deaths not included in one of the above categories</li> </ul> <p><b>Note:</b></p> <ul style="list-style-type: none"> <li>- If there are multiple death records with different death date in each of the above administrative database, the last (i.e. most recent) death record for each unique health card number was selected.</li> <li>- If one health card number appears in multiple care settings, the following hierarchy based on the care intensity were used to assign death setting: acute care, Emergency, CCC, Rehabilitation facilities, LTC homes. There should only be one record per health card number.</li> <li>- If there are multiple death records with different death date in each of the database, the last death record for each unique health card number was selected.</li> </ul> <p><b>Denominator</b></p> <p>The number of palliative care patients**</p>

	<b>Note:</b> <ul style="list-style-type: none"> <li>- ** See the denominator methodology details in the palliative care patient population technical template</li> </ul>
	<b>Methods</b> Numerator/Denominator*100
	<b>Adjustment</b> ( <i>risk, including age/sex standardization</i> ) N/A
<b>Data source / data elements</b>	Discharge Abstract Database (DAD), Home Care Database (HCD), Ontario Health Insurance Plan Claims Database (OHIP), National Ambulatory Care Reporting System (NACRS), National Rehabilitation Reporting System (NRS), and Registered Persons Database (RPDB) provided by the Institute for Clinical Evaluative Sciences  <b>Note:</b> <ul style="list-style-type: none"> <li>- This applies to the numerator; see data sources for constructing the palliative care patient population (denominator) in the palliative care patient population technical template</li> </ul>
<b>Levels of comparability/stratification descriptions</b>	Provincial, LHIN, age groups, sex, urban/rural setting, neighbourhood income quintiles
<b>Limitations / Caveats</b>	<ul style="list-style-type: none"> <li>- The data show the location of the death, but not the location where care was received before death (i.e. the death may have occurred in the ED but in general the care may have been provided in LTC).</li> <li>- No information of the preferred place of death is provided.</li> </ul>

1. Brazil K, Howell D, Bedard M, Krueger P, Heidebrecht C. Preferences for place of care and place of death among informal caregivers of the terminally ill. *Palliat Medicine*. 2005 Sep 1;19(6):492-499.
2. Jayaraman J, Joseph KS. Determinants of place of death: a population-based retrospective cohort study. *BMC Palliat Care*. 2013 May 1;12(1):1.
3. Health Quality Ontario. Team-based models for end-of-life care: an evidence-based analysis. *Ont Health Technol Assess Ser* [Internet]. 2014 December;14(20):1–49. Available from: <http://www.hqontario.ca/evidence/publicationsand-ohtac-recommendations/ontario-health-technology-assessment-series/eol-team-based-models>

PERCENTAGE OF OLDER ADULTS WHO REPORT HAVING A DISCUSSION WITH FAMILY, A CLOSE FRIEND, OR WITH A HEALTH CARE PROFESSIONAL ABOUT WHAT HEALTH CARE TREATMENT THEY WANT, OR DO NOT WANT IN THE EVENT THEY BECOME VERY ILL OR INJURED AND CANNOT SPEAK FOR THEMSELVES	
<b>Description</b>	This indicator measures the percentage older adults who reported having a discussion with family, a close friend, or with a health care professional about what health care treatment they want, or do not want in the

	<p>event they become very ill or injured and cannot speak for themselves.</p> <p>A higher percentage is better.</p>
<b>Relevance/Rationale</b>	Having difficult conversations about end of life should be happening earlier, while people are still in good health and able to express their wishes to their loved ones or their health care providers. Having these decisions documented in a will or in a patient health record is also important. By encouraging and normalizing these conversations, it can be ensured that the patients' wishes could be respected and that they can receive the care that they want when the end of life stage approaches.
<b>HQO reporting tool</b>	Palliative Care at the End of Life Theme Report
<b>Reporting tools external to HQO</b>	Canadian Institute for Health Information Chartbook. <i>How Canada Compares: Results From The Commonwealth Fund 2014 International Health Policy Survey of Older Adults.</i>
<b>Unit of analysis</b>	Percentage
<b>Calculation</b>	<p><b>Numerator</b> Number of respondents who reported having a discussion with family, a close friend, or with a health care professional about what health care treatment they want, or do not want in the event they become very ill or injured and cannot speak for themselves</p> <p><b>Survey question</b> In the event you become very ill or injured and you cannot make decisions for yourself, have you had a discussion with family, a close friend, or with a health care professional about what healthcare treatment you WANT, or DO NOT WANT?  - <b>Yes</b>  - No</p>
	<p><b>Denominator</b> All respondents</p> <p><b>Exclusions:</b>  ○ Those that skipped the question</p>
	<p><b>Methods</b>  <math>\text{Numerator/Denominator} \times 100</math></p>
	<p><b>Adjustment</b> (<i>risk, including age/sex standardization</i>)  None</p>

<b>Data source / data elements</b>	Commonwealth Fund International Survey of Older Adults 2014
<b>Levels of comparability/stratification descriptions</b>	International and provincial
<b>Limitations / Caveats</b>	<ul style="list-style-type: none"> <li>- Data are available once every three years</li> <li>- Does not capture the content and quality of the conversation</li> <li>- This is not specifically for population approaching end of life, but older adults (55 and older) in general</li> <li>- This discussion may not be consistently documented and some patients may not be ready to have these kinds of discussions.</li> </ul>

<b>PERCENTAGE OF PRIMARY CARE DOCTORS THAT ROUTINELY OR OCCASIONALLY HAVE CONVERSATIONS WITH OLDER OR SICKER PATIENTS ABOUT THE HEALTH CARE TREATMENT THEY WANT OR DO NOT WANT IN THE EVENT THEY BECOME VERY ILL, INJURED, OR CANNOT MAKE DECISIONS FOR THEMSELVES</b>	
<b>Description</b>	<p>This indicator measures the percentage of primary care doctors that routinely or occasionally have conversations with older or sicker patients about the health care treatment they want or do not want in the event they become very ill, injured, or cannot make decisions for themselves</p> <p>A higher percentage is better.</p>
<b>Relevance/Rationale</b>	Having difficult conversations about end of life should be happening earlier, while people are still in good health and able to express their wishes to their loved ones or their health care providers. Having these decisions documented in a will or in a patient health record is also important. By encouraging and normalizing these conversations, it can be ensured that the patients' wishes could be respected and that they can receive the care that they want when the end of life stage approaches.
<b>HQO reporting tool</b>	Palliative Care at the End of Life Theme Report
<b>Reporting tools external to HQO</b>	None
<b>Unit of analysis</b>	Percentage
<b>Calculation</b>	<b>Numerator</b>

	<p>The number of primary care doctors who reported routinely or occasionally having conversations with older or sicker patients about the health care treatment they want or do not want in the event they become very ill, injured, or cannot make decisions for themselves</p> <p><b>Survey question</b>  Do you have conversations with older or sicker patients about the health care treatment they want or do not want in the event they become very ill, injured, or cannot make decisions for themselves? Would you say routinely, occasionally or no?</p> <ul style="list-style-type: none"> <li>- <b>Yes, routinely</b></li> <li>- <b>Yes, occasionally</b></li> <li>- No</li> </ul>
	<p><b>Denominator</b>  All respondents</p> <p><b>Exclusions:</b></p> <ul style="list-style-type: none"> <li>- Those that skipped the question</li> </ul>
	<p><b>Methods</b>  Numerator/Denominator*100</p>
	<p><b>Adjustment</b> (<i>risk, including age/sex standardization</i>)  None</p>
<b>Data source / data elements</b>	Commonwealth Fund International Survey of Primary Care Doctors 2015
<b>Levels of comparability/stratification descriptions</b>	International and provincial
<b>Limitations / Caveats</b>	<ul style="list-style-type: none"> <li>- Data are available once every three years</li> <li>- Does not capture the content and quality of the conversation</li> <li>- This is not specifically for population approaching end of life</li> <li>- Definition of an older or sicker patient may vary across primary care doctors</li> <li>- This discussion may not be happening as patients may not be ready to have these kinds of discussions</li> </ul>

<b>PERCENTAGE OF PRIMARY CARE DOCTORS WHO ROUTINELY OR OCCASIONALLY DOCUMENT THEIR PATIENTS' PREFERENCES IN THEIR MEDICAL RECORDS AFTER HAVING CONVERSATIONS (ROUTINELY OR OCCASIONALLY) WITH THEIR OLDER OR SICKER PATIENTS ABOUT THE HEALTH CARE TREATMENT THEY WANT OR DO NOT WANT IN THE EVENT THEY BECOME VERY ILL, INJURED, OR CANNOT MAKE DECISIONS FOR THEMSELVES</b>	
<b>Description</b>	<p>This indicator measures the percentage of primary care doctors who routinely or occasionally document their patients' preferences in their medical records after having conversations (routinely or occasionally) with their older or sicker patients about the health care treatment they want or do not want in the event they become very ill, injured, or cannot make decisions for themselves</p> <p>A higher percentage is better.</p>
<b>Relevance/Rationale</b>	<p>Having difficult conversations about end of life should be happening earlier, while people are still in good health and able to express their wishes to their loved ones or their health care providers. Having these decisions documented in a will or in a patient health record is also important. By encouraging and normalizing these conversations, it can be ensured that the patients' wishes could be respected and that they can receive the care that they want when the end of life stage approaches.</p>
<b>HQO reporting tool</b>	Palliative Care at the End of Life Theme Report
<b>Reporting tools external to HQO</b>	None
<b>Unit of analysis</b>	Percentage
<b>Calculation</b>	<p><b>Numerator</b></p> <p>The number of primary care doctors who reported routinely or occasionally documenting their patients' preferences in their medical records</p> <p><b>Survey question</b></p> <p>You mentioned that you routinely/occasionally have conversations with older or sicker patients about their health care treatment in the event they become very ill, injured or cannot make decisions for themselves. Are your patients' preferences then recorded in their medical record? Would you say routinely, occasionally or no?</p>

	<ul style="list-style-type: none"> <li>- <b>Yes, routinely</b></li> <li>- <b>Yes, occasionally</b></li> <li>- No</li> </ul>
	<b>Denominator</b> All respondents who reported routinely or occasionally having conversations with older or sicker patients about the health care treatment they want or do not want in the event they become very ill, injured, or cannot make decisions for themselves.
	<b>Survey question</b> (Do you have conversations with older or sicker patients about the health care treatment they want or do not want in the event they become very ill, injured, or cannot make decisions for themselves? Would you say routinely, occasionally or no?" <ul style="list-style-type: none"> <li>- <b>Yes, routinely</b></li> <li>- <b>Yes, occasionally</b></li> <li>- No</li> </ul>
	<b>Methods</b> Numerator/Denominator*100
	<b>Adjustment</b> ( <i>risk, including age/sex standardization</i> ) None
<b>Data source / data elements</b>	Commonwealth Fund International Survey of Primary Care Doctors 2015
<b>Levels of comparability/stratification descriptions</b>	International and provincial
<b>Limitations / Caveats</b>	<ul style="list-style-type: none"> <li>- Data are available once every three years</li> <li>- Does not capture the content and quality of the conversation</li> <li>- This is not specifically for population approaching end of life</li> <li>- Definition of an older or sicker patient may vary across primary care doctors (the survey question does not specify it in the instrument)</li> <li>- This discussion may not be happening as patients may not be ready to have these kinds of discussions</li> </ul>

## 6. CaregiverVoice Survey Questions

CaregiverVoice in the Report	Questions from the CaregiverVoice Survey	Base Population
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Percentage of caregivers who stated that, in the last 3 months of life, services the patient received at home worked well together	<p>When he/she was at home in the last 3 months of life, did all these services work well together?</p> <ul style="list-style-type: none"> <li>- <b>Yes, definitely</b></li> <li>- <b>Yes, to some extent</b></li> <li>- He/she did not receive any care</li> <li>- No, they did not work well together</li> <li>- Don't know</li> </ul>	All survey respondents who spent time at home during the last 3 months of life
Percentage of caregivers who thought they and their family got as much help and support from health and supportive services as they wanted when the patient was at home in the last 3 months of his or her life	<p>Overall, do you feel that you and your family got as much help and support from health and supportive services as you needed when caring for him/her?</p> <ul style="list-style-type: none"> <li>- <b>Yes, we got as much support as we wanted</b></li> <li>- Yes, we got some support but not as much as we wanted</li> <li>- No, but we did not ask for more help</li> <li>- No, although we tried to get more help</li> <li>- We did not need help</li> </ul>	All survey respondents who spent time at home during the last 3 months of life
Percentage of caregivers who stated the patient they cared for experienced smooth transitions between settings of care in their last 3 months of life	<p>Did you feel that he/she experienced smooth transitions between settings of care during the last 3 months of life?</p> <ul style="list-style-type: none"> <li>- <b>Yes, definitely</b></li> <li>- Yes, to some extent</li> <li>- No, not at all</li> <li>- Don't know</li> </ul>	All survey respondents
Percentage of caregivers who rated overall care of the patient they cared for in their last 3 months of life as outstanding or excellent	<p>Overall, and taking all services into account, how would you rate his/her care in the last 3 months of life?</p> <ul style="list-style-type: none"> <li>- <b>Outstanding</b></li> <li>- <b>Excellent</b></li> <li>- Good</li> <li>- Fair</li> <li>- Poor</li> <li>- Don't know</li> </ul>	All survey respondents
Percentage of caregivers who rated pain management for the patient they cared for in	<p>During the last week of life, what is your assessment of the overall level of support given in the following areas for him/her?</p> <p>Relief of physical pain.</p>	All survey respondents

their last week of life as excellent	<ul style="list-style-type: none"> <li>- <b>Excellent</b></li> <li>- Good</li> <li>- Fair</li> <li>- Poor</li> <li>- Does not apply</li> <li>- Don't know</li> </ul>	
Percentage of caregivers who rated emotional support in their last week of life as excellent	<p>During the last week of life, what is your assessment of the overall level of support given in the following areas for him/her?</p> <p>Emotional support.</p> <ul style="list-style-type: none"> <li>- <b>Excellent</b></li> <li>- Good</li> <li>- Fair</li> <li>- Poor</li> <li>- Does not apply</li> <li>- Don't know</li> </ul>	All survey respondents
Percentage of caregivers who knew where the patient wanted to die	<p>Did he/she ever say where he/she would like to die?</p> <ul style="list-style-type: none"> <li>- <b>Yes</b></li> <li>- No</li> <li>- Not sure</li> </ul>	All survey respondents
Percentage of caregivers who knew where the patient wanted to die that reported having this information recorded by a health care provider	<p>Did the health care providers have a record of this?</p> <ul style="list-style-type: none"> <li>- <b>Yes</b></li> <li>- No</li> <li>- Not sure</li> </ul>	All survey respondents who knew where the patient wanted to die
Percentage of caregivers who thought the healthcare providers helped him/her understand what to expect and how to prepare for the patient's death	<p>Did your healthcare providers help you, the caregiver, understand what to expect/how to prepare for his/her death?</p> <ul style="list-style-type: none"> <li>- <b>Yes, definitely</b></li> <li>- Yes, to some extent</li> <li>- No</li> <li>- Don't know</li> </ul>	All survey respondents
Percentage of caregivers who thought the discussion between the patient they cared for and the healthcare providers regarding advance care planning came at the right time	<p>Did this discussion come:</p> <ul style="list-style-type: none"> <li>- Too early</li> <li>- Too late</li> <li>- <b>At the right time</b></li> <li>- Don't know</li> </ul>	All survey respondents that indicated that their family member/friend was given the opportunity to discuss advance care planning with his/her

		health care providers
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