

## **INTERIM UPDATE ON MEDICAL ASSISTANCE IN DYING IN CANADA**

### **June 17-December 31, 2016**

#### **Introduction**

On June 17, 2016, An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying), which permits the lawful provision of medical assistance in dying to eligible Canadians, received Royal Assent. Since then, the federal government has been working closely with provinces and territories to support its implementation.

In countries that permit some form of assisted dying, public reporting is generally considered to be a critical component in fostering transparency and public trust, and to reflect the seriousness of medical assistance in dying as an exception to the criminal laws that prohibit the termination of a human life. To this end, the legislation that permits medical assistance in dying in Canada authorizes the federal Minister of Health to make regulations to collect and publicly report on information relating to requests for, and the provision of, medical assistance in dying in Canada. Health Canada is currently developing regulations to establish the federal monitoring system, which are expected to come into force in 2018.

Federal, provincial and territorial governments recognize the importance of the timely release of accurate information on this issue, and have agreed to collaborate to provide interim updates while the regulations for the federal monitoring system are under development. This update covers the first six months during which medical assistance in dying has been available in Canada (June 17 – December 31, 2016)<sup>1</sup>.

#### **Implementation of Medical Assistance in Dying**

While federal legislation establishes the eligibility criteria and safeguards related to medical assistance in dying that are in force throughout Canada, it is the provinces and territories that are responsible for the delivery of health care services and the administration of justice. The practical implication of this division of powers is that, while the federal legislation ensures a consistent approach across Canada, the specific policies and processes related to the implementation and monitoring of medical assistance in dying varies across jurisdictions. These differences often reflect the unique geographic, regulatory and cultural contexts of individual jurisdictions.

More information on end-of-life care, including medical assistance in dying, across Canada may be found on [Health Canada's website](#).

#### **Methodology and Findings**

Most provincial and territorial governments were able to provide Health Canada with the aggregate number of medically assisted deaths in their jurisdictions since the legislation came into force on June 17, 2016. In addition, the province of Quebec has its own legislation on end-of-life care, which came into effect on December 10, 2015, and includes its own reporting

requirements. Under Quebec's [Loi concernant les soins de fin de vie](#), physicians and institutions are required to report the number of requests for medical assistance in dying received, declined, or provided<sup>2</sup>. Table 1, Total Number of Publicly-Reported Medically Assisted Deaths in Canada, December 10, 2015 – December 31, 2016, presents the total number of publicly-reported medically assisted deaths in Canada when all of these sources are considered.

<b>Table 1. Total Number of Publicly-Reported Medically Assisted Deaths in Canada, December 10, 2015 – December 31, 2016<sup>i</sup></b>	
Number of medically assisted deaths under <b>Quebec legislation</b> between December 10, 2015 and June 9 or 10 2016 (as per the parameters of the Commission's report)	167
Number of medically assisted deaths in Canada under <b>Quebec and federal legislation</b> between June 17 and December 31, 2016 <sup>ii</sup>	803
<b>Total number of medically assisted deaths</b> in Canada under Quebec and federal legislation between December 10, 2015 and December 31, 2016	970

<sup>i</sup> Due to privacy concerns arising from small numbers, data from the Yukon and Nunavut are not available. Also, on January 15, 2016, the Supreme Court of Canada granted the Government of Canada an extension of four months, or until June 6, 2016, to respond to the Supreme Court of Canada's ruling in *Carter v. Canada*. The Court also granted an exemption to those who wished to exercise their rights to assisted dying by allowing them to apply to the superior court of their jurisdiction for approval, in accordance with the criteria set out in the Carter decision. Prior to the enactment of the legislation on June 17, 2016, a number of individuals sought assistance in dying through this process. These numbers have not been publicly reported.

<sup>ii</sup> Data for Quebec is for the period June 10 – December 9, 2016. This data was compiled from publicly available reports posted on the websites of Quebec's health and social services institutions and the *Collège des médecins du Québec*, but does not represent an official report from the Government of Quebec.

Although the implementation of the new legislation is in its early stages, and the scope of data currently available on medically assisted deaths in Canada is relatively limited, most jurisdictions were able to provide Health Canada with data on:

- the aggregate number of medically assisted deaths;
- basic demographic information on persons receiving assisted dying;
- the most common circumstances, illnesses, diseases or disabilities of persons receiving assisted dying; and,
- the setting in which medical assistance in dying occurred.

Table 2, Profile of Medically Assisted Deaths in Participating Jurisdictions Between June 17 and December 31, 2016, presents nationally-aggregated data on these elements. Additional information on individual provinces and territories, where available, is provided in the Annex. In instances where there are fewer than six cases reported in a province or territory on any one data element, the data has been suppressed to protect the privacy of both patients and providers. However, these numbers have been included in the national roll-up, wherever possible.

<b>Table 2. Profile of Medically Assisted Deaths Between June 17 and December 31, 2016 in Participating Jurisdictions (Excludes QC, NU, YT)<sup>i</sup></b>	
Total number of medically assisted deaths	507
Number of clinician-administered deaths (voluntary euthanasia)	504
Number of self-administered deaths (assisted suicide)	3
Settings in which assistance in dying occurred <sup>‡</sup> :	
In-hospital <sup>ii</sup>	249 (50%)
Home	182 (37%)
LTC facility or Nursing home	30 (6%)
Other <sup>iii</sup>	37 (7%)
Average age <sup>iv</sup> of persons receiving assisted death	72.27 years of age
Proportion of men/women receiving assisted death <sup>‡</sup>	49% men 51% women
Proportion of individuals receiving assisted death in large urban centres vs. smaller population centres <sup>v‡</sup>	65.8% large urban centres 34.2 % smaller population centres
Most common underlying medical circumstances of patients who obtain assistance in dying <sup>vi‡</sup>	56.8% Cancer-related 23.2% Neuro-degenerative 10.5% Circulatory/respiratory system 9.5% other causes

<sup>i</sup> Given variations in reporting requirements under its provincial legislation, findings do not include the province of Quebec. Due to privacy concerns arising from small numbers, data from the Yukon and Nunavut are not available.

<sup>ii</sup> The province of Alberta did not provide specific location, but rather the number of assisted deaths provided in institutional vs. home-based settings. For the purposes of this summary, the 45 cases of assisted death that took place in health care facilities in Alberta have been included within the category of “in-hospital”

<sup>iii</sup> Other includes: palliative care hospice; clinician office; facility; undisclosed.

<sup>iv</sup> This figure is a mean of provincial and territorial averages, and not a calculation based on individual data; as such, it is not weighted to reflect an actual national average.

<sup>v</sup> A large urban centre consists of a population of 100,000 or more (Statistics Canada).

<sup>vi</sup> Cases where the underlying medical condition was not reported, approximately 8% of all cases, have not been included in this calculation.

<sup>‡</sup> Due to privacy concerns, data for the province of New Brunswick were suppressed, and are not included in the calculations for this indicator. Totals may not equal 100% due to rounding or suppression of data.

## Summary of Findings

Medically assisted deaths accounted for less than 0.6% of all deaths in Canada from June – December 2016<sup>3</sup>. By comparison, the proportion of medically assisted deaths in international jurisdictions in 2015 was 3.75% in the Netherlands and 1.83% in Belgium<sup>4</sup>, and 0.37% in Oregon in 2016<sup>5</sup>.

The most common underlying medical circumstances among those receiving assistance in dying were related to cancer (neoplasm), neurological illness (e.g., multiple sclerosis, amyotrophic lateral sclerosis), and cardiovascular/respiratory disease. Cancer was the most frequently cited underlying medical condition associated with an assisted death, representing approximately 57% of all assisted dying cases among reporting jurisdictions<sup>6</sup>. This is consistent with international findings. Approximately 30% of all deaths in Canada are attributed to cancer every year<sup>7</sup>. The incidence of cancer-related deaths in countries which permit assisted dying ranges between 22% and 31%<sup>8</sup>, and cancer represents the most common underlying medical condition among those receiving assistance in dying (72% Oregon<sup>9</sup>, 69% in Belgium<sup>10</sup>, and 71% in the Netherlands<sup>11</sup>).

The average age of individuals for whom medical assistance in dying was provided was approximately 72 (range 69 to 74<sup>12</sup>). There is very little comparable international data for this measure.<sup>13</sup> The relative proportion of men (49%) and women (51%) who received a medically assisted death is consistent with the general population at the same age (in 2016, approximately 48% of Canadians aged 70-74 were men, and approximately 52% were women<sup>14</sup>). Internationally, men generally account for a slight majority of assisted deaths (52% in Belgium, 53% in Washington, and 54% in Oregon).<sup>15</sup>

The frequency with which medical assistance in dying is provided in different settings varies considerably across jurisdictions. In British Columbia and Manitoba, most assisted deaths occurred in the home, in contrast to Ontario where the majority occurred in hospitals. Factors which may contribute to this finding include, for example, patient preference, institutional barriers to providing medical assistance in dying in hospitals in some jurisdictions, lack of infrastructure for providing this service in the community in others, and provider preference.

In 2014, 69.9% of all Canadians lived in a large urban population centre (100,000 or greater)<sup>16</sup>; and during the reporting period in 2016, 67% of all medically assisted deaths occurred in these centres. In the absence of more detailed information on whether the setting in which medical assistance in dying was administered was near a person's usual place of residence, however, conclusions about access to assisted dying according to community size are limited.

In Canada, a very small number of medically assisted deaths during the reporting period have been self-administered (0.4% of medically assisted deaths). Factors contributing to this finding may include patient and provider preference, and lack of ready availability of drugs for self-administration<sup>17</sup>. Other countries with regimes allowing both practices report higher proportions of self-administered cases of assisted dying, but they are still very low relative to

provider-administered assisted dying. For example, 3.8% of all assisted deaths in the Netherlands were self-administered in 2015<sup>18</sup>.

Although the numbers of nurse practitioners (NPs) have not been presented here due to privacy considerations, among jurisdictions with available data, very few NPs have been reported to have been involved with cases of medical assistance in dying. While this finding reflects the relatively low number of NPs in Canada (about 4,000 in 2015, or approximately 1% of all registered nurses<sup>19</sup>), there are also known barriers to NP involvement in medical assistance in dying including the lack of authorization to prescribe controlled substances in some jurisdictions (e.g. Ontario), or to sign death certificates in others (e.g. Manitoba).

### **Ongoing reporting**

While the permanent federal monitoring regime will continue to report on the data elements identified in this interim report, it will also differ from it in significant ways. It will:

- Include a broader set of data, which will enable: a statistical profile of all requests for medical assistance in dying and their outcomes (i.e. not limited to cases in which the service was provided); further information on the medical circumstances and other characteristics of those requesting and receiving an assisted death; findings regarding the application of eligibility criteria and safeguards; and, trends over time;
- Be based on data and information provided directly by physicians, nurse practitioners, and pharmacists involved in cases of medical assistance in dying, as required by legislation; and,
- May be supplemented by information from coroners and medical examiners.

Later this year, the draft regulations will be available for comment by the public and stakeholders in the [Canada Gazette I](#).

The federal government, in collaboration with participating provincial and territorial governments, will continue to provide additional updates until such time as regular reporting under the permanent monitoring and reporting system commences.

## ANNEX

Table 3. Profile of Medical Assistance in Dying by Jurisdiction/Region						
	British Columbia	Alberta	Saskatchewan	Manitoba	Ontario	Atlantic (NB, NS, NL, PEI)
Number of contacts or inquiries about medical assistance in dying	N/A	299 <sup>i</sup>	46	96	N/A	N/A*
Total number of requests for medical assistance in dying	N/A	124	39	68	N/A	60
Number of requests for medical assistance in dying that have been declined	N/A	36	N/A*	20	N/A	N/A*
Total number of medically assisted deaths <sup>ii</sup>	188	61	11	21	189	37
Setting in which medically assisted deaths occurred	Home - 82 (43.6%) Hospital - 57 (30.3%) Hospice - 17 (9%) Other - 32 (17%)	Home - 17 (25%) Facility – 44 (73%)	Hospital – 8 (73%) Other – 3 (27%)±	Home – 13 (62%) Hospital – 7 (33%) Other – 1 (5%)	Hospital – 110 (58.2%) Home – 65 (34.3%) Other – 14 (7.5%)	Hospital – 23 (82%)‡ Home – 5 (18%)
Number of physicians that have provided a second assessment to confirm eligibility for medical assistance in dying	129	61 <sup>iii</sup>	9	N/A	N/A	N/A*
Average age of persons receiving medical assistance in dying	74	69.3	77	70	73.3	72
Proportion of men/women receiving medical assistance in dying	49% male 51% female	41% male 59% female	55% male 45% female	48% male 52% female	48% male 52% female	68% male‡ 32% female

	British Columbia	Alberta	Saskatchewan	Manitoba	Ontario	Atlantic (NB, NS, NL, PEI)
Proportion of individuals receiving an assisted death in large urban centres vs. smaller population centres	54% urban centres <sup>iv</sup> 46% smaller centres	69% urban centres 31% smaller centres	85% urban centres 15% smaller centres	72% urban centres 28% smaller centres	75% urban centres 25% smaller centres	40% urban centres‡ 60% smaller centres
Most common underlying medical condition of patients who obtain a medically assisted death, in order of frequency	Cancer-related Nero-degenerative Circulatory/Respiratory	Cancer-related Nero-degenerative Other	Cancer-related Nero-degenerative Other	Cancer-related Nero-degenerative Other	Cancer-related Nero-degenerative Circulatory/Respiratory	Cancer-related Nero-degenerative

<sup>i</sup> The total number of medically assisted deaths may not equal to the number of requests less the number of requests declined. For example, individuals submitting a request for medical assistance in dying may have later withdrawn the request, or died of natural causes.

<sup>ii</sup> There is no legal requirement to report requests for medical assistance in dying to the Care Coordination Service at Alberta Health Services. Therefore there may have been more individuals who contacted or made inquiries to a practitioner, or requested medical assistance in dying from a practitioner, who are not captured in these figures.

<sup>iii</sup> The figure reflects the 61 second assessments to confirm eligibility performed in Alberta, as required by law. It does not represent the individual number of physicians that have performed a second assessment.

<sup>iv</sup> The figure for large urban centres excludes municipalities with a population of less than 100,000 but which are part of the larger urban Vancouver/Lower Mainland area - New Westminster, West Vancouver, Maple Ridge and Port Moody

\*Number suppressed due to privacy concerns

±Categories have been collapsed to protect privacy

‡New Brunswick did not provide data to protect the privacy of patients; the calculations presented here do not include New Brunswick cases.

## **Referral Services Available for Clinicians and Patients**

To facilitate care coordination, a number of provinces and territories have introduced mechanisms to support access and referrals for medical assistance in dying and end-of-life care. This includes helping to connect patients with a physician or nurse practitioner willing to provide medical assistance in dying, while protecting the privacy of all parties. With support from provincial and territorial health officials, a [federal webpage](#) was launched in June 2016 to support access and care coordination. Information is also available via 1-800-O-Canada. This content is being maintained and updated regularly. A brief description of these referral systems, as available, is provided below.

### **British Columbia**

Each health authority in British Columbia has implemented a care coordination service to ensure reasonable, safe access to medical assistance in dying. The care coordination service provides an additional point of contact for patients who require assistance in navigating access to medical assistance in dying. The service also serves to support health care providers and organizations to identify appropriate patient pathways, facilitate transfers, and connect patients with willing providers.

### **Alberta**

Alberta Health Services has developed a [Medical Assistance in Dying Care Coordination Service](#) (CCS) which provides information to patients, families and practitioners on assisted dying. The CCS will help individuals find a practitioner to assess them and provide the service as well as arrange transfers if needed.

### **Saskatchewan**

Each regional health authority has a delegate who has agreed to be the primary contact point for information requests on medical assistance in dying. Practitioners and patients can directly contact the regional delegate for assistance with all aspects of requests for assisted dying. The Ministry of Health has access to contact information for these delegates and can contact or refer individuals to them if required.

### **Manitoba**

Manitoba has introduced an [inter-disciplinary MAID team](#) which serves as the central consultative and practical resource for health professionals, patients and families in Manitoba. The team is housed out of the Winnipeg Regional Health Authority.

### **Ontario**

Ontario has a referral service available for clinicians. A toll-free telephone number and email address for [the referral service is posted on the Ministry of Health and Long Term Care website](#). Ontario will also be developing a Care Coordination Service (CCS) to assist patients and caregivers in accessing additional information and services for medical assistance in dying and



other end-of-life options. Once in place, the CCS will also perform the function of the current clinician referral service. Further details about the CCS will be made publicly available in spring 2017.

### **Northwest Territories**

The Northwest Territories has established a [Central Coordinating Service](#) (toll-free phone number) that facilitates access to willing practitioners (to provide more information, assess, or provide a secondary assessment).

### **Newfoundland and Labrador**

A referral service is under development.

### **Prince Edward Island**

PEI has established a process to help facilitate coordination for the provision of medical assistance in dying services. Physicians and nurse practitioners may contact their Health PEI Medical Director and Health PEI's Medical Affairs office to help facilitate the assessment process, and the provision of medical assistance in dying for eligible cases. For those patients without a primary care provider, patients are encouraged to call 811 for more information.

### **Nova Scotia**

A central intake process is coordinated through the Nova Scotia Health Authority's Vice President of Medicine's office.

### **New Brunswick**

Patients can be connected to family physicians or nurse practitioners to obtain information about medical assistance in dying in the following ways: the websites of the two Regional Health Authorities ([Vitalité Health Network](#) and [Horizon Health Network](#)); using the 811 Provincial Tele-care line; by contacting [Patient Representatives Services](#) or the Regional Ethics Office (as applicable); or through speaking with one's family physician or nurse practitioner directly. New Brunswick has also produced an [information brochure](#) on medical assistance in dying for patients.

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<sup>1</sup> Yukon and Nunavut have not provided data due to privacy concerns where small numbers are involved. Findings from the province of Quebec have been drawn from publicly available documents. More information on data sources and limitations is provided in the section on Methodology and Findings.

<sup>2</sup> Further information on medical assistance in dying in Quebec, including a statistical profile and reasons for the non-provision of assisted dying between December 10, 2015, and June 9 or 10, 2016 (as per the parameters of the Commission's report), may be found in the first annual report of the *Commission des soins de fin de vie* ([http://www.ledevoir.com/documents/pdf/rapport\\_csfv2016.pdf](http://www.ledevoir.com/documents/pdf/rapport_csfv2016.pdf)).

<sup>3</sup> This calculation is based on an estimate of 131,816 deaths in Canada from July 1 – December 31, 2016, which is 49% of Statistics Canada's preliminary data for deaths in Canada in 2015/2016 (n=269,012) See:

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<http://www.statcan.gc.ca/tables-tableaux/sum-som/l01/cst01/demo07a-eng.htm>. The 49% figure is the proportion of deaths which occurred in the latter half of the year in 2013 (the last year for which monthly data is available. See: <http://www5.statcan.gc.ca/cansim/a26?lang=eng&id=1020502>)

<sup>4</sup> Source: <http://www.dyingforchoice.com/docs/AssistedDyingPracticeInBeneluxWhitepaper1b2016.pdf>

<sup>5</sup> Source :

<http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year19.pdf>

<sup>6</sup> This figure is not definitive as cases where the underlying medical condition was not reported, approximately 8% of all cases, have not been included in this calculation.

<sup>7</sup> Source : <http://www.cancer.ca/en/cancer-information/cancer-101/cancer-statistics-at-a-glance/?region=on>

<sup>8</sup> Sources : [http://ec.europa.eu/eurostat/statistics-explained/index.php/File:Causes\\_of\\_death\\_%E2%80%94\\_malignant\\_neoplasms,\\_residents,\\_2013.png](http://ec.europa.eu/eurostat/statistics-explained/index.php/File:Causes_of_death_%E2%80%94_malignant_neoplasms,_residents,_2013.png), <http://www.medicalnewstoday.com/articles/282929.php>

<sup>9</sup> Source :

<https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year18.pdf>

<sup>10</sup> Source : <http://www.cmaj.ca/content/early/2016/09/12/cmaj.160202.full.pdf>

<sup>11</sup> Source : <http://www.dyingforchoice.com/resources/fact-files/netherlands-2015-euthanasia-report-card>

<sup>12</sup> This number should be interpreted with caution as it is not weighted to reflect variations in the number of cases in each jurisdiction/PT size. Participating provinces provided the mean age for their jurisdiction, from which an average was calculated at a national level.

<sup>13</sup> In Oregon, the median age of recipients of assisted suicide was 73 in 2016 (Source:

<http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year19.pdf>)

<sup>14</sup> Source: Statistics Canada, Population Estimates and Projections by Sex and Age Group.

<http://www.statcan.gc.ca/tables-tableaux/sum-som/l01/cst01/demo10a-eng.htm>

<sup>15</sup> Data for Belgium for 2015 (Source:

[http://organesdeconcertation.sante.belgique.be/sites/default/files/documents/7\\_rapport-euthanasie\\_2014-2015-fr.pdf](http://organesdeconcertation.sante.belgique.be/sites/default/files/documents/7_rapport-euthanasie_2014-2015-fr.pdf)); Washington for 2015 (Source: <http://www.doh.wa.gov/portals/1/Documents/Pubs/422-109-DeathWithDignityAct2015.pdf>), and Oregon for 2016 (Source:

<http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year19.pdf>).

<sup>16</sup> Source: <http://www12.statcan.gc.ca/census-recensement/2011/ref/dict/table-tableau/table-tableau-7-eng.cfm>

<sup>17</sup> Also, provider-administered assisted dying is the only form of assisted dying available in Quebec.

<sup>18</sup> Source : <http://www.dyingforchoice.com/resources/fact-files/netherlands-2015-euthanasia-report-card>

<sup>19</sup> Taken from the Canadian Institute for Health Information's Health Workforce Database. In the same year, there were approximately 82,000 physicians in Canada (Canadian Institute for Health Information, *Physicians in Canada 2015*).