FEDERAL MONITORING OF MEDICAL ASSISTANCE IN DYING REGULATIONS

Submission to Health Canada

February 13, 2018
The Canadian Medical Association (CMA) is the national voice of Canadian physicians. Founded in 1867, the CMA’s mission is empowering and caring for patients.

On behalf of its more than 85,000 members and the Canadian public, the CMA performs a wide variety of functions. Key functions include advocating for health promotion and disease/injury prevention policies and strategies, advocating for access to quality health care, facilitating change within the medical profession, and providing leadership and guidance to physicians to help them influence, manage and adapt to changes in health care delivery.

The CMA is a voluntary professional organization representing the majority of Canada’s physicians and comprising 12 provincial and territorial divisions and over 60 national medical organizations.
The Canadian Medical Association (CMA) is pleased to provide input on the proposed regulations of the federal monitoring of Medical Assistance in Dying in Canada.

The CMA fully supports the proposed intent of the regulations, in particular, public accountability and transparency and safeguards for vulnerable patient populations. Tracking trends and carrying out research is very important to monitor the implementation and implications of medical assistance in dying.

The CMA further supports the intent to provide electronic reporting and guidance documents, and to leverage any synergies between the federal and provincial/territorial governments, especially to prevent duplication and to promote consistency in reporting across the country.

The CMA would like to raise the following critical areas for your consideration:

1. **Definitions/parameters of terms**
   There continues to be a need to more clearly define several terms to ensure consistency of reporting. For example:
   
   a. Who constitutes a “practitioner”? One can argue that there is a broad scope of who is “a medical practitioner or nurse practitioner”. Is it the practitioner who provides MAiD? Or he practitioner who first reads a patient’s request for MAiD? Or is the first practitioner? Or second practitioner who assesses the patient?
   
   b. What constitutes a therapeutic relationship (as one of the eight proposed items to be collected about the practitioner)? A therapeutic relationship is not required to access MAiD. This criterion should be removed and if not, given the differences in opinion in the health professions as to what constitutes a therapeutic relationship includes, it should be clearly defined.
   
   c. What constitutes a request, a written request, the receipt of a request? If reporting obligations are “triggered” by a patient’s “written request”, at what point is that request actually triggered? The very first practitioner who receives the patient’s written request? Or the practitioner who conducts the eligibility assessment upon receipt of the written request? Or the practitioner who provides the prescription or carries out the procedure?
   
   d. On a related point, without clear definitions, any future comparative analysis of research or trends will be difficult as there will be no common starting point.
   
   e. There continues to be confusion on how to count or when to start counting the required 10 clear days. There are many reasons why this requires more clarity.

2. **Collection and protection of data**
   We applaud Health Canada for further reducing and revising data requirements. We submit, however, that further reductions are required for several reasons, including adherence to privacy best practices that require the collection of the least amount of data necessary to achieve reasonable purposes. In particular:
   
   a. In view of the quantity and highly personal and sensitive data that will be collected about patients and practitioners, data sharing agreements should be required; for example, agreements between the federal government and provincial/territorial governments or between researchers and others requesting use of the data to facilitate the appropriate sharing of data.
   
   b. Collection of personal information should be limited to what is relevant to the purpose of monitoring medical assistance in dying. Personal information, such as the patient’s full postal code, marital status, or principal occupation is beyond the scope of the eligibility criteria outlined in the legislation and thus beyond the scope of the purpose of monitoring the impact of the legislation.
   
   c. Any “characteristics” of the patient should refer only to the eligibility criteria. If other data will be collected beyond that scope, the justification for doing so, and the characteristics themselves, should be clearly outlined.
d. The scope of the information collected about the practitioner could be narrowed. As is, it is very broad—a list of eight items—while the Quebec regulations, as a comparator, have only three-four items that must be collected in relation to the physician who administers MAiD.

3. Additional requirements
Schedule 4 [section 2(i)] of the proposed regulations requires that the practitioner opine as to whether the patient met, or did not meet, all of the eligibility criteria outlined in the legislation—with two significantly expanded requirements; the requirements that the practitioner: 1) provide an estimate as to the amount of time MAiD shortened the patient’s life; and 2) indicate the anticipated likely cause of natural death of the patient.

These additional requirements are beyond the letter and spirit of the legislation and, in many ways, are in direct contradiction to the legislation. The Legislature was not unaware when it drafted the Act that it did not follow other jurisdictions’ criteria requiring either a terminal illness or a prognosis of time within which the practitioner believed the patient would die, e.g., “within the next 6 months”.

It is specifically the lack of a timeframe that makes the legislation unique and provides flexibility for both patients and practitioners. By adding these two additional criteria for reporting, in effect, they become additional criteria for eligibility which is, as stated above, beyond the scope, and in contradiction to, the legislation.

4. Lack of clarity of reasons for ineligibility
There is a potential for misunderstanding as to whether reasons are required when the patient does not meet the criteria under Schedule 4, section 2(a) – (h). The introduction to section 2 speaks to the practitioner giving an indication as to (a) whether the patient met or (b) did not meet the criteria. However, in the itemized criteria [2(a)-(h)] it only speaks to the practitioner having to provide reasons when the patient meets the criteria (and not when the patient has not met the criteria). It would be helpful to specify that reasons should be required when the patient does and does not meet the criteria. This is also crucial for the publication of the Minister of Health’s annual report requiring that the reasons, and which eligibility criteria were not met, be addressed.

Conclusion
The CMA recognizes the importance of regulations to capture the provision, collection, use, and disposal of information for the purpose of monitoring MAiD. The CMA cautions against introducing reporting requirements that are beyond the scope of the legislation.

As noted in the legislation, practitioners who fail to provide information under the regulations may be found guilty under the Criminal Code and subject to possible imprisonment. It is thus imperative that the federal government drafts clear regulations that respect the legislation, privacy, research ethics, and a de minimus approach.