

June 12, 2017

Via email: tara.hutchinson@hc-sc.gc.ca

Tara Hutchinson, Senior Policy Analyst Health Canada End-of-Life Care Unit Health Care Programs and Policy Directorate Strategic Policy Branch Jeanne Mance Building Ottawa, ON K1A 0K9

Dear Ms. Hutchinson:

Re: MAID Monitoring Regime

I am writing on behalf of the Canadian Bar Association's End-of-Life Working Group (CBA Working Group) in response to Health Canada's consultation on regulations for monitoring medical assistance in dying (MAID) as set out in the Stakeholder Reference Document.

The CBA is a national association of 36,000 lawyers, Québec notaries, law teachers and students, with a mandate to promote improvements in the law and the administration of justice. The CBA Working Group comprises a cross-section of members drawn from diverse areas of expertise, including criminal justice, constitutional and human rights law, health law, wills, estates and trusts law, elder law, children's law, corporate counsel, privacy law, dispute resolution and equality issues. The members include lawyers in private practice, the public sector, and in-house counsel.

We offer the following comments on the proposed monitoring regime for MAID.

Who must file

We appreciate that coroners and medical examiners are not required to file information with the federal government. However, the proposals for provider reporting are quite onerous, and we encourage harmonization to minimize the need to report to multiple authorities and to avoid duplicate information. We note the absence of information about fee codes or any other acknowledgement of how practitioners will be compensated for the time spent reporting.

Information to be filed

Referral/transfer of care: We suggest capturing information about requests made but refused (without referral or transfer) for conscientious reasons of the practitioner or institution.

Ineligibility: We suggest including an additional category for those who are initially eligible for MAID but are disqualified prior to the administration of treatment.

Additional information about the patient: We suggest more precise criteria and supporting rationale for specific additional information sought about the patient. It is unclear to us why marital status would be relevant.

Manner and cause of death: Section 3.1 of Bill C-14 (now S.C. 2016, c. 3) permits the Minister to establish guidelines for the information to be included on death certificates, while related amendments deem that persons who receive MAID died as a result of the illness, disease or disability for which they were determined to be eligible to receive that assistance. Information gathered about manner and cause of death should be consistent with this approach or have the objective of being able to determine the consistency of death certificate information with the guidelines and other statutory requirements.

Information about barriers to access: We encourage the collection of information that will uncover barriers to accessing MAID.

Scientific enquiry: We encourage the active engagement of providers and researchers in the consultation process, to ensure the right questions are asked to support an excellent MAID regime. For example, if patients are willing to share, it may be helpful to ask targeted open-ended questions about their reasons for choosing an assisted death.

Time of filing

As advisors to health practitioners, institutions and regulators, CBA Working Group members are aware of the practical context in which their clients work. We have significant concerns about the feasibility of compliance with the proposed 10-day time limit for filing a report. We are aware that the Minister intends to provide a supportive online environment for MAID reporting, but caution that some practitioners will experience challenges in reporting in this timeframe despite the availability of technology.

Generally, the proposed reporting process is cumbersome due to multiple junctures for reporting. The Minister may wish to consider a standardized periodic approach rather than individualized filing.

Protection and disclosure of the information

MAID is not a rare occurrence. Even the incomplete data available in the Minister's interim report identifies just under a thousand MAID deaths in a one-year period. We query the need for identifying information about persons who request MAID.

The proposal contemplates collecting and sharing a great deal of information about patients and providers. The CBA Working Group recommends the Minister commission a privacy impact assessment of the proposed regulations. We also recommend that privacy commissioners in all jurisdictions be given an opportunity to comment.

The CBA Working Group reiterates its support for a comprehensive monitoring regime, with robust and reliable data. Thank you for considering our submission.

Yours sincerely,

(original letter signed by Tina Head for Kimberly J. Jakeman)

Kimberly J. Jakeman Chair, CBA End of Life Working Group