THE CANADIAN BAR ASSOCIATION
L'ASSOCIATION DU BARREAU CANADIEN

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Via email: End.of.life.care_Soins.fin.de.vie@hc-sc.gc.ca

Sharon Harper
Policy Director
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Strategic Policy Branch,
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Dear Ms. Harper:

Re: Monitoring of Medical Assistance in Dying Regulations

I am writing on behalf of the Canadian Bar Association's End-of-Life Working Group (CBA Working Group) to comment on proposed text for the *Monitoring of Medical Assistance in Dying Regulations*, published in the Canada Gazette, Part 1, on December 16, 2017 (Vol. 151, No. 50).

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.

The CBA Working Group welcomes elements of the proposed regulations that are responsive to comments made during an earlier consultation process. However, we are concerned that the proposed regulations compel disclosure of potentially self-incriminating information that could eventually be used in a professional regulatory investigation, a civil suit or a criminal prosecution. We believe this will deter practitioners from providing medical assistance in dying (MAID), with adverse consequences for the medical autonomy of patients.

Objectives of the Regulations

Subsections 241.31 (1) and (2) of the C*riminal Code* require medical practitioners and nurse practitioners who receive a written request for MAID, and pharmacists who dispense related substances, to file information required by regulation, unless exempt.[1]

Subsection 241.31 (3) of the *Criminal Code* provides:

> **Regulations**
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> (3) The Minister of Health must make regulations that he or she considers necessary
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> (a) respecting the provision and collection, for the purpose of monitoring medical assistance in dying, of information relating to requests for, and the provision of, medical assistance in dying, including
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> (i) the information to be provided, at various stages, by medical practitioners or nurse practitioners and by pharmacists, or by a class of any of them,
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> (ii) the form, manner and time in which the information must be provided,
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> (iii) the designation of a person as the recipient of the information, and
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> (iv) the collection of information from coroners and medical examiners;
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> (b) respecting the use of that information, including its analysis and interpretation, its protection and its publication and other disclosure;
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> (c) respecting the disposal of that information; and
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> (d) exempting, on any terms that may be specified, a class of persons from the requirement set out in subsection (1) or (2).

The proposed regulations must stay within the scope of authority in section 241.31 of the *Criminal Code*, and be consistent with the objectives of Bill C-14.[2] Further, regulations are scrutinized to ensure they are consistent with the *Charter of Rights and Freedoms* and the *Constitution Act, 1982*.[3]

The Regulatory Impact Analysis Statement (RIAS) identifies the following objectives for the proposed regulations:

- Support public accountability and transparency in relation to medical assistance in dying;
- Support the protection of vulnerable individuals by monitoring the application of the eligibility criteria and safeguards required by the legislation;
- Identify and monitor trends in requests for, and the provision of, medical assistance in dying;
- Help determine whether the legislation is meeting its objectives; and
- Make data available to qualified researchers for the purpose of enabling independent analysis and research.

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1 The proposed regulations would exempt practitioners who provide a second report confirming a patient meets the criteria for MAID.

2 An Act to amend the *Criminal Code and to make related amendments to other Acts (medical assistance in dying)*, SC 2016, ch.3.

3 Cabinet Directive on Regulatory Management (2012), online (http://bit.ly/2E3sJg1).

After closely reviewing the proposed regulations (including the Schedules which set out the precise information to be reported by health professionals) the CBA Working Group concludes that an important objective of the proposed regulations is to monitor compliance by practitioners with the eligibility criteria, procedures and safeguards in Bill C-14. The information to be reported will permit practitioner compliance assessments on an individual and a systemic basis. As a result, the CBA Working Group has significant concerns about the proposed regulations.

Our main concern is summarized as follows. The proposed regulations require personal patient and practitioner information for every written MAID request received by a practitioner. Schedules 4 and 5 require a practitioner to report for each request their assessments, actions and opinions on every element of the eligibility criteria and on every procedural requirement in Bill C-14. This information is compelled on threat of criminal sanction. Under section 14 of the proposed regulations, the information can be shared with provincial and territorial governments and public bodies for "monitoring" purposes. This information is, in effect, evidence that can be used against practitioners by professional regulatory bodies and law enforcement.

Practitioners and pharmacists are used to working in complex regulatory environments. They are subject to oversight by their provincial and territorial regulatory bodies – mature regulatory environments with robust procedural fairness protections. The proposed regulations will compel disclosure of potentially self-incriminating information that could eventually be used in a professional regulatory investigation, a civil suit or a criminal prosecution. There are no notice requirements or procedural safeguards in the proposed regulations.

In *R. v. Fitzpatrick*[4], the Supreme Court decided that the principle against self-incrimination did not apply to information required as part of a regulatory scheme. The Supreme Court relied on the absence of coercion, stating that no one is compelled to participate in regulated activities and so must accept the conditions for their participation. The approach taken in the proposed regulations will create a significant disincentive to practitioner participation in MAID and, most importantly, a subsequent chilling effect on a patient's right to autonomy.

In this context, the Preamble to Bill C-14 was careful to acknowledge the need to balance the autonomy right of persons who request MAID and the protection of vulnerable individuals. This balance is not reflected in the objectives of the Regulations, and should be restored.

Recipient of Reports

The proposed regulations would designate the federal Minister of Health as the recipient for all reports, except in Quebec where reports would be filed with the President of the *Commission sur les soins de fin de vie*. Provinces and territories would have the option of identifying a designated recipient, and we expect that some will be named in the final regulations.

The CBA Working Group generally supports this approach, which is designed to reduce duplication and minimize the burden on reporting officials. Nonetheless, the requirements will add to the workload of practitioners and pharmacists. The absence of compensation strategies in many jurisdictions remains a concern and could be a further disincentive for practitioners and pharmacists to provide MAID services.

Filing Format

The Working Group applauds Health Canada's recognition of the importance of an electronic reporting system and its collaboration with Statistics Canada to develop a secure portal for use by

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4 [1995] 4 SCR 154, 1995 CanLII 44 (SCC)

practitioners and pharmacists when filing reports. In our opinion, this is an essential component of an effective monitoring regime.

Timelines

The CBA Working Group is pleased that Health Canada was responsive to concerns expressed during earlier consultations that proposed timelines were too short, particularly given criminal penalties for failure to report.

Protection and Disclosure of Information

The CBA Working Group is aware that all new federal programs, including MAID monitoring, require a privacy impact assessment. We understand the federal Office of the Privacy Commissioner has also engaged provincial and territorial counterparts on this issue. We support a vigorous and transparent review of the proposed regulations from a privacy perspective.

Subsection 13(4) of the proposed regulations guards against disclosure of personal information in the Minister's public reports on MAID.

Section 15 of the proposed regulations permits personal information other than an individual's name to be disclosed to any individual or organization for research or statistical analysis purposes, with appropriate safeguards. The CBA Working Group acknowledges the importance of evidence-based policy-making and the need for underlying data and research. However, we can find no justification for disclosing personal information such as street addresses, email addresses, or unique identifiers such as health insurance numbers or license or registration numbers. The *Privacy Act* does not authorize disclosure of information that identifies an individual unless there is no other reasonable means to achieve the objectives of the research. We recommend that data be stored in a format that facilitates removal of this information when disclosing records for research or statistical analysis purposes.

Monitoring and Oversight

Technical briefings by Health Canada distinguished between monitoring and oversight. Monitoring was explained as "the collection and analysis of data to provide insight into the implementation of the *Criminal Code* exemptions which permit MAID in Canada." Monitoring activities by the federal Minister of Health were identified as "receiving information, publishing regular reports, and facilitating access to data to inform future policy and enrich the body of scholarly work." Oversight was explained as "the review of individual cases to determine whether applicable laws have been complied with" and was identified as a provincial and territorial responsibility.[5]

As described earlier, the CBA Working Group believes the proposed regulations conflate these functions.

Section 14 of the proposed regulations states:

> Disclosure to provinces and territories
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> 14 The Minister of Health may disclose to a provincial or territorial government, or any of its institutions, or to a public body established under an Act of the legislature of a province or territory personal information that the Minister obtained under these Regulations if the purpose of the disclosure is to support the monitoring of medical assistance in dying in the province or territory.

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5 Health Canada, MAID Monitoring Regulations, Technical Briefings, January 15-16, 2018. These briefings were restricted to health care practitioners and pharmacists. Health Canada gave a copy of the presentation to the CBA Working Group.

"Monitoring" is not defined in the proposed regulations. The CBA Working Group's opinion is that section 14 supports disclosure of personal information for enforcement and compliance purposes, whether prosecution under the *Criminal Code* or disciplinary action by professional regulatory bodies.

Much of the information required under the proposed Schedules is aligned with information required by the Quebec *Commission sur les soins de fin de vie*. However, the express purpose for that information is "to assess compliance with the criteria for the administration of medical aid in dying." By regulation, the Commission is required to act "in a manner that protects the confidentiality of the personal information concerning the person who requested medical aid in dying, the person's close relations and the health and social services professionals involved" and important procedural safeguards are in place before information can be provided to a professional regulatory body.

The RIAS and the proposed regulations are silent on these important issues. The CBA Working Group urges the Minister to address these deficiencies before proceeding with final regulations.

Information to be Reported

The detailed information to be collected is set out in Schedules 1 – 8 of the proposed regulations.

Schedule 1

Schedule 1 requires patient information, including date of birth, sex, and health insurance number or province or territory of usual residence.

The RIAS explains that health insurance numbers are used as unique identifiers for statistical analysis purposes. It is unclear whether this is limited to the production of the Minister's annual statistical reports or for all research purposes authorized under the proposed regulations. These identifiers hold the key to a great deal of information and should not be used unless absolutely necessary. While convenient, health insurance numbers are not required by modern research methods for statistical analysis. The CBA Working Group recommends that health insurance numbers not be provided when releasing personal information for research purposes.

Schedule 1 does not specify what options would be available in the sex field. The CBA Working Group recommends the inclusion of options other than female or male, consistent with current federal initiatives on gender identity.

Schedule 2

Schedule 2 requires information about the patient's referral. The CBA Working Group wonders whether question 2 is designed to capture information about where the practitioner was located when they received the request or where the patient was located when they made the request. In any event, the intent of the question is unclear.

Schedule 3

Schedule 3 requires information about, among others, the patient's marital status and principal occupation during their working life (if applicable). The CBA Working Group previously questioned the purpose of gathering this information. If marital status is intended as a proxy measure for family or social support, it will offer limited information about the rich diversity of individual support systems. If principal occupation is intended as a proxy measure for socio-economic status or education, we recommend a more precise indicator.

Schedule 4

Schedule 4 requires information about eligibility criteria. Generally, these repeat the criteria for MAID, in much the same language as in Bill C-14.

The CBA Working Group is concerned that the Schedule requires a practitioner to report their estimate of the amount of time by which MAID would shorten the patient's life. In *A.B. v. Canada (Attorney General)*, 2017 ONSC 3759, Justice Perell specifically drew attention to paragraph 241.2(2)(d) of the *Criminal Code*:

> (d) their natural death has become reasonably foreseeable, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining.

Justice Perell went on to comment that "the legislation makes it clear that in formulating an opinion, the physician need not opine about the specific length of time that the person requesting medical assistance in dying has remaining in his or her lifetime."

The requirement in Schedule 4 to provide precisely this kind of information is inconsistent with the enabling statute and further complicates a situation that practitioners have identified as troubling and difficult to apply. The language of "shortening the patient's life" is unnecessarily value-laden, given an individual's constitutional right to autonomy in medical decision-making.[6]

In the context of our earlier concerns, we question the purpose of requiring a practitioner to report the *reasons* for their opinion on voluntariness, the *reasons* for their opinion whether the patient had a serious and incurable illness, disease or disability (and a description of same), the *reasons* for their opinion that a person was in an advanced state of irreversible decline in capability (*and a description of the decline*), the *reasons* for their opinion that the patient's decline caused enduring physical or psychological suffering that was intolerable to them and that could not be relieved under conditions that the patient considered acceptable and a *description of the patient's suffering*. In our opinion, the only purpose for which this information could be relevant is oversight. Requiring this level of detail would also add significantly to the regulatory burden.

Schedule 5

Schedule 5, in effect, requires a practitioner to report whether they met every procedural step (safeguard) required by law to provide MAID. The CBA Working Group questions the purpose of this Schedule, and reiterates the concerns above.

Schedule 6

The Ontario Ministry of Health and Long-Term Care (MOHLTC) has advised stakeholders that a practitioner does not have to be present for self-administered MAID. Otherwise, the CBA Working Group would question the purpose of the requirement to report whether a physician was present, reiterating concerns above about oversight.

Schedules 7 and 8

These schedules require information about when and where substances are administered or dispensed, and, for pharmacists, their name and license or registration number. The CBA Working Group believes it would be helpful to ask practitioners if they had access to substances they felt appropriate for their patient. In addition, the CBA Working Group recommends a question about the patient's preferred location for administering MAID and if this preference was accommodated.

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6 See, e.g. *Carter v. Canada (Attorney General)*, [2015] 1 SCR 331, 2015 SCC 5 (CanLII), at para. 67.

Conclusion

The CBA Working Group appreciates the opportunity to comment on these proposed regulations. We believe the regulations conflate monitoring and oversight functions, and could undermine a patient's right to medical autonomy. We recommend the proposed regulations be reconsidered in light of these concerns. We would be pleased to assist in the further development of the regulations.

Yours truly,

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

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