Dying With Dignity Canada
It's your life. It's your choice.

Brief: Stakeholder Consultation on the Proposed Regulations for Monitoring Medical Assistance in Dying

February 13, 2018

Submitted to:

Sharon Harper, Policy Director
Health Care Programs and Policy Directorate,
Strategic Policy Branch
Health Canada
200 Eglantine Driveway, Tunney's Pasture
4th Floor, Room 411A,
Ottawa, ON, K1A 0K9

Submitted by:

Dying With Dignity Canada
Suite 802, 55 Eglinton Avenue East
Toronto, ON, M4P 1G8

Contact:

Shanaaz Gokool, CEO
647-559-4120
shanaaz.gokool@dyingwithdignity.ca

Dying With Dignity Canada
It's your life. It's your choice.

Preface

Dying With Dignity Canada (DWDC) is pleased to have the opportunity to provide feedback on the proposed Monitoring of Medical Assistance in Dying Regulations that were published in the December 16, 2017 edition of *Canada Gazette, Part I.* As the leading organization defending Canadians' right to a peaceful death, we are well-positioned to comment on the proposed regulations, their impacts for individual Canadians and their clinicians, and how they might affect our understanding of how medical assistance in dying (MAID) is being implemented across the country.

In general, DWDC is supportive of how Health Canada has structured its proposal. However, we have concerns about some aspects of the regulatory framework, in terms of their clarity and also the unreasonable burden they risk imposing on clinicians who are involved in this important area of practice. The body of our submission will outline these concerns as well as our recommendations on how they could be rectified. Ultimately, our objective is to support the creation of a MAID monitoring system that helps protect vulnerable Canadians, promotes transparency, and improves our collective understanding of how the MAID rules are being applied, without imposing an undue burden on suffering patients and the clinicians who are responsible for their care. When it comes to all rules and regulations for MAID, the *person* — the vulnerable patient whose rights and interests are most at stake — must come first.

General concerns

Objectives of the federal monitoring system

DWDC strongly supports all five of the main policy objectives that Health Canada has listed in its Regulatory Impact Analysis Statement on the proposed MAID monitoring system. However, this list is currently incomplete because it does not identify upholding and protecting Canadians' right to MAID as a key policy objective. We believe it is incumbent on Health Canada to correct this omission, for reasons we will outline in this section of our submission.

First, supporting the protection of Canadians' right to MAID should be a key goal of the monitoring system because *MAID is a right.* When the Supreme Court issued its 2015 ruling in *Carter v. Canada,* it established MAID as a constitutionally protected legal right. In doing so, the court created a duty for governments in Canada to respect that right. As a result, we believe that identifying threats to that right should be listed as a key objective of any federal regulatory system for the monitoring of MAID.

In addition, this objective must be added because it is a logical extension of another critical policy goal of the monitoring system: supporting the protection of vulnerable Canadians.

Ensuring that vulnerable individuals are shielded from coercion and other forms of abuse is an essential component of any legal framework for MAID. After all, perhaps the most precious right outlined in the *Charter* is the one laid out in Section 7, the right each of us has to "life, liberty and security of the person." Indeed, depriving another person of this right can lead to the most severe punishments our criminal justice system will allow. However, the Supreme Court asserted in *Carter* that the "right to life" does not impose a "duty to live." Conversely, in the high court's view, the old *Criminal Code* prohibitions on MAID violated the right to life, liberty and security of the person "insofar as they prohibit physician-assisted dying for competent adults who seek such assistance as a result of a grievous and irremediable medical condition that causes enduring and intolerable suffering." Without the option of MAID available to them, a person in this position has two options, the court wrote: "She can take her own life prematurely, often by violent or dangerous means, or she can suffer until she dies from natural causes. The choice is cruel."

This passage was obviously written before the legalization of MAID in Canada, but it remains relevant in the present day. It reminds us that, if we, as a country, are seriously committed to creating a framework for MAID that respects Canadians' right to life, liberty and security of the person, then we cannot stop at ensuring that vulnerable individuals are protected from coercion and abuse; we must at the same time ensure that any rules for MAID do not subject Canadians to the same "cruel choice" that the Supreme Court contemplated in *Carter.* These two imperatives — guarding against abuse and ensuring fair access — do not conflict and instead represent different sides of the same coin. Thus, we believe that a monitoring regime that focuses on one side at the expense of the other is ill-equipped to assess the effectiveness, as well as the constitutionality, of our rules for assisted dying.

Recommendations:

- **The following must be added to the list of the main policy objectives of the federal monitoring system: "Support the protection of Canadians' right to medical assistance dying in dying by: 1) monitoring the application of the eligibility criteria and the safeguards required by the legislation; 2) monitoring other factors that could influence whether an individual has fair, equitable access to medical assistance in dying."**

Administrative burden for clinicians

We are seriously concerned that the proposed monitoring system could increase the administrative burden providers of MAID already face. Currently, a single MAID case entails hours of paperwork for the clinicians involved. Providers already have to file reports to the public body in their province or territory that is responsible for recording MAID deaths and, in some cases, a clinician has to file a separate report to the public healthcare institution where a MAID death took place. In general, providers are not

compensated for the time they spend preparing reports for the MAID reporting body in their province or territory.

Wherever possible, Health Canada must take steps to ensure the following: **1) that any monitoring system for MAID does not impose an additional administrative burden on clinicians who are involved in this area of practice; and 2) that clinicians receive fair compensation for the time they spend on satisfying the regulatory requirements for reporting on MAID.** In doing so, Health Canada must accept that filing a detailed report on a MAID death will take much longer than 10 minutes. According to the Canadian Association of MAID Assessors and Providers, answering the questions proposed in the draft regulatory framework would take upwards of 30 to 40 minutes — in addition to the amount of time it would take the clinician to complete documentation required by the provincial-territorial body collecting MAID data in their jurisdiction.

Failing to mitigate the administrative burden involved in providing MAID would, we fear, drive existing providers out of this area of practice and would discourage other physicians and nurse practitioners from getting involved. This would only widen existing gaps in access facing Canadians who wish to exercise their right to a peaceful death, especially for residents of rural and remote communities. In turn, it would undermine the principles of accessibility and universality that are enshrined in the *Canada Health Act* and reflected in the federal laws surrounding MAID.

Recommendations:

- **Health Canada must work with its provincial-territorial partners to eliminate duplication in the collection of MAID data. Providers of MAID should only be required to report the required information a total of one time. The federal government should require each province or territory to establish a single authority to collect all MAID-related data and report it to Health Canada.**
- **If that is not possible, when a MAID death takes place in a jurisdiction where there is no federally designated recipient, it should be up to Health Canada, not the clinician, to share the relevant data with the provincial-territorial body that is collecting MAID-related information.**
  Health Canada must collaborate with its provincial-territorial partners to ensure that clinicians receive fair compensation for time spent satisfying the MAID reporting requirements.

Threat of criminal prosecution for failing to report

Bill C-14 creates criminal offences for "failing to provide the required information and for contravening the regulations" related to MAID. This rule is appropriate insofar as it protects vulnerable Canadians and ensures that clinicians comply with the safeguards laid out in the law. However, we question whether it is reasonable for the threat of criminal

prosecution to apply in cases where the required information is being sought to shape our understanding of trends related to MAID and not primarily for the purpose of upholding public safety. It is difficult to see how criminalizing the failure to properly report *all* MAID data points — including, for example, secondary demographic details or the withdrawal of a MAID request — would meaningfully strengthen the deterrents that already exist to guard against negligence and abuse.

Our main concern about the proposed sanctions is not just that they are overly broad, but rather that they risk creating a "chill" that would discourage clinicians from participating in MAID or even discussing it with a patient. The volume and complexity of the paperwork involved in MAID is already a major disincentive for clinicians to participate. The spectre of being charged for failing to properly file new, potentially more onerous reporting documents, threatens to drive existing providers out of this area of practice. Moreover, threatening criminal prosecution for failing to properly report, while neglecting to ensure that clinicians receive fair compensation for the time they spend filing MAID data, is severe and could be seen as coercive. As an alternative, the job of addressing alleged breaches of the MAID reporting rules could be left to the bodies or mechanisms that already adjudicate in cases of clinician malpractice, such as the professional regulatory colleges or civil litigation. Criminal prosecution may be appropriate in egregious cases and those in which malice is present.

Recommendations:

- **Health Canada must work together with the Department of Justice to define a more narrow set of circumstances under which a breach of the reporting requirements could lead to criminal prosecution.**

Procedural concerns

<u>Reporting outcomes of requests that do not lead to the provision of MAID</u>

Requiring the reporting of outcomes for all MAID requests is highly impractical and would be extremely burdensome for clinicians. And though we recognize the need for rich, high-quality data on MAID, we are concerned that the proposed requirements are so onerous that they would discourage clinicians from answering patients' questions about MAID. As a result, we strongly encourage Health Canada to more clearly and more narrowly define the circumstances in which a report would be required. In addition, Health Canada must encourage and equip their provincial-territorial partners to shoulder as much of the administrative burden as possible, so clinicians can focus on caring for their patients.

Recommendations:

- **Clinicians must not be required to report the patient's withdrawal of their MAID request unless the patient has been formally assessed for MAID by at least one practitioner. The clinician should file the report within 90 days of becoming aware of the withdrawal of the request.**
- **If a clinician determines through a formal assessment that a patient is ineligible for MAID, that outcome should be reported within 90 days, unless the clinician determines during the 90-day period that the patient has subsequently become eligible for MAID. A clinician must not be required to report a determination of ineligibility unless it was arrived at through a formal assessment.**
- **Clinicians must not be required to report the death of a MAID applicant from another cause unless the patient had been found eligible by two assessors. This outcome should be reported within 90 days of the practitioner becoming aware of the patient's death. This provision must not impose a duty for the physician to actively seek out information about whether the patient has died.**
- **In cases where the patient dies after being assessed as ineligible for MAID, the responsibility of reporting this outcome should fall to the provincial-territorial body that tracks vital statistics.**

Reporting the provision of MAID by prescribing or providing administration of a substance

The draft regulations provide timelines for when a clinician should file reports related to the provision of MAID by prescribing or providing a substance for self-administration. However, there is a lack of clarity on what a clinician must do if the MAID applicant dies fewer than 90 days after obtaining the prescription or substance. We urge Health Canada to modify this requirement and take steps to limit the administrative burden it imposes on clinicians.

Recommendations:

- **Clinicians should be required to file a report 120 to 180 days after prescribing or providing a substance for self-administration, unless the practitioner becomes aware within 120 days that the patient has died by self-administration. This outcome should be reported within 30 days of the practitioner learning of the patient's death. This provision must not impose a duty for the physician to actively seek out information about whether the patient has died.**
- **In cases where the patient dies of a cause other than MAID, the responsibility of reporting this outcome should fall to the provincial-territorial body that tracks vital statistics.**

- **In cases where the patient dies by self-administration more than 120 days after being prescribed or given a substance for MAID, the responsibility of reporting this outcome must fall to the provincial-territorial body that tracks vital statistics. (The clinician would still be required to file a report indicating that the patient had been prescribed or provided with a substance for self-administration.)**

Reporting information related to the federal eligibility criteria for MAID

The information requested in Schedule 4 will be crucial to our understanding of the impacts of the legalization of MAID in Canada. However, we have serious concerns about Health Canada's proposal on how this data would be collected. If adopted, the draft monitoring regulations would create duplication in the reporting of data and would require clinicians to file reports that are unnecessary and potentially inappropriate. We urge Health Canada to look for opportunities to reduce the number of instances in which reports involving eligibility criteria are required, streamline the process for clinicians and, wherever possible, require the provincial-territorial bodies that are already involved in monitoring MAID to compile and report the information that Health Canada is seeking.

One of our major concerns about Schedule 4 is that it requires the clinician to describe *why* he or she was of the opinion that the patient satisfies, or does not satisfy, each of a number of the eligibility criteria laid out in Bill C-14. (For example, Schedule 4, paragraph 2(f) asks the clinician to indicate whether, "the patient had a serious and incurable illness, disease or disability and, if the practitioner assessed this criterion and was of the opinion that the patient met it, the reasons why the practitioner was of that opinion, including a description of the illness, disease or disability.") Providing detailed written descriptions for the four eligibility criteria outlined in 2(d), 2(f), 2(g) and 2(h) would be extremely time-consuming and often redundant. In cases where MAID was provided, the clinician would have already provided this information to the provincial-territorial body tasked with collecting MAID-related data, such as the coroner's office.

In addition, the monitoring framework should be revised to reflect the clinical realities of determining a patient ineligible for MAID. A clinician might not provide a full assessment if, for example, it has become clear that the patient no longer has the capacity to consent to MAID. In a case like this, it would make little sense for the clinician to try to ascertain whether the patient satisfies the other eligibility criteria. Therefore, clinicians should not be required to file a full report when a determination of ineligibility is made.

Health Canada must also ensure that the online interface for reporting MAID data is user-friendly and is designed in such a way that it minimizes the amount of time it takes to file the relevant data — and in particular, the information requested in Schedule 4. Wherever applicable, the online portal for reporting MAID data should utilize drop-down menus that

allow the clinician to select from a series of relevant narrative responses. Not only would this cut down on the amount of time it would take to file a report, but it would also reduce inconsistencies in how the information is recorded. However, to account for situations in which the clinician's answer is not reflected in one of the narrative responses listed, the drop-down menus must include response options such as "Other — please explain," "Not sure" and "Not applicable." The drop-down bars for paragraphs 2(d), 2(f), 2(g) and 2(h) under Schedule 4 should each be followed by an **optional** text box where the clinician could explain their answer.

Recommendations:

- **In cases where MAID has been provided, the provincial-territorial body responsible for collecting MAID-related data must be required to, using the information provided in the clinician's assessment record, answer the questions outlined in Schedule 4 of the proposed regulations.**
- **In cases where the clinician is reporting the withdrawal of a request, the clinician must not be required to provide the information requested in Schedule 4, with the exception of the patient's primary underlying medical condition(s).**
- **When reporting a determination of ineligibility, the clinician must only be required to report the criterion or criteria that the patient did not satisfy, along with the patient's primary underlying medical condition(s).**
- **Wherever applicable, the online portal for reporting MAID data should utilize drop-down menus that allow the clinician to select from a series of relevant narrative responses.**

Estimating timeline to natural death

It should not be compulsory for a clinician to report an "estimate as to the amount of time by which medical assistance in dying, if provided, would shorten the patient's life." Such an estimate is specifically not required by the law. According to Bill C-14, two assessing clinicians must determine that the patient's natural death is reasonably foreseeable "without a prognosis necessarily having been made as to the specific length of time that [the patient has] remaining." Ontario Superior Court Justice Paul Perell, in his June 2017 ruling in *AB v. Canada*, confirmed that, when assessing whether a patient's death is reasonably foreseeable, "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." Thus, we believe it is inappropriate for Health Canada to request this information when it is not required as part of the assessment process.

In addition, it is doubtful that requiring such an estimate would yield high-quality data. Some highly specialized clinicians who are involved in the assessment or provision of MAID, such as anesthesiologists, may not be skilled in predicting a patient's survival time.

Even for clinicians who are adept at using the most effective prognostic scoring tools available, the job of estimating the amount of time a patient has left to live remains a notoriously imprecise exercise. In a 2009 study published in the *Journal of Pain and Symptom Management*, University of Victoria health science professor Francis Lau and his co-authors concluded that the "current means of reporting survival estimates in the palliative care settings are variable at best."[1] A more recent study in which Lau was involved — one that examined the accuracy of clinicians' survival predictions in the cases of 1,530 Canadian cancer patients who had received palliative care — found that palliative-care physicians routinely overestimate the amount of time that their end-stage cancer patients have left to live. "[Clinician prediction of survival], even by palliative practitioners, remains overly optimistic with the existence of the horizon effect," the researchers wrote in their 2016 paper, which was published in the *International Journal of Palliative Nursing*.[2] We question the usefulness of requiring clinicians to report survival time estimates, as the resulting data is likely to be inconsistent and, in many cases, inaccurate.

Recommendations:

- **Health Canada must remove the requirement that the clinician must report an "estimate as to the amount of time by which medical assistance in dying, if provided, would shorten the patient's life" from paragraph 2(i) under Schedule 4 of the regulations.**

<u>Reporting of supplementary information about the patient</u>

A number of the questions under Schedule 3 are overly intrusive as well as unnecessary. For example, we believe that it is inappropriate to require the reporting of a patient's marital status and their principal occupation during their working life.

Recommendations:

- **Health Canada must remove Schedule 3 from the proposed regulations; OR make it optional for clinicians to report the information requested under Schedule 3.**

Conclusion

Developing monitoring regulations for MAID is a complex, unenviable task, particularly in the context of Canadian federalism. Health Canada officials deserve considerable credit for

[1] Lau, Francis, et al., "Using the Palliative Performance Scale to Provide Meaningful Survival Estimates." *Journal of Pain and Symptom Management.* Vol. 38, No. 1 (2009).
[2] Thai, Vincent, et al., "Clinical prediction survival of advanced cancer patients by palliative care: a multi-site study." *International Journal of Palliative Nursing*. Vol. 22, No. 8 (2016).

the time, care and effort they have invested in producing their proposed framework. We ask Health Canada to, while considering our feedback and those of the other respondents, keep the individuals whose rights are most at stake at top of mind. In our view, the monitoring framework for MAID can only be successful if it protects the rights of vulnerable Canadians but *doesn't get in the way of their rights* either. We believe that our recommendations, if adopted, will bring us closer to that goal, and we kindly urge Health Canada to incorporate them as it weighs further changes to the proposed regulations.