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RE: Monitoring of Medical Assistance in Dying Regulations, Canada Gazette, Vol. 151, No. 50 — December 16, 2017

Dear Ms. Harper:

The purpose of this letter is to offer feedback on the proposed regulations for monitoring Canada’s medical assistance in dying program. In keeping with our mission to clearly identify the purpose of life-ending policies, we will use the more accurate term, assisted suicide and euthanasia (AS/E).

Toujours Vivant-Not Dead Yet was established in 2013 by the Council of Canadians with Disabilities to focus on assisted suicide, euthanasia, and other ending-of-life practices that have a disproportionate impact on people with disabilities. Though not all disabled persons have a terminal illness, all people with terminal illness have a disability, and many non-terminal disabled people are deemed eligible for euthanasia. Our goal is to inform, unify and give voice to the disability-rights opposition to medical homicide.

In a letter to former Health Minister Jane Philpott (dated March 22, 2017) we described what data we felt would need to be collected in order to:

1. Understand who is using the program, and why.
2. Ensure that “vulnerable persons” are not being induced to commit suicide in a time of weakness.
3. Ensure that all safeguards and eligibility requirements are complied with.
4. Track the impact of AS/E on Canadian society.
5. Assess the impact of suicide prevention strategies on the numbers of AS/E.
6. Evaluate the impact of AS/E on the medical profession, practitioners and the doctor/patient relationship.
7. Examine the role of advocates for assisted suicide and euthanasia in the operations of the program.
8. Evaluate the role of economic considerations in end-of-life decision making.
9. Identify gaps in services (such as mental health care, personal assistance and suicide prevention services, and palliative care) which lead people to request AS/E.
10. Ensure transparency, accountability and effective enforcement of the MAID program.

We are gratified to see that much of what we suggested has been included in the proposed regulations. However, we do not believe that the draft regulations are sufficient to meet either their stated goals, nor the objectives outlined above.

**General Comments:**

1. Besides “providing transparency and fostering public trust,” the “purpose” of the regulations should also include:

* oversight of the program;
* enforcement of the law’s safeguards and penalties; and
* protecting vulnerable persons.

We do not believe that these objectives have received enough emphasis in the regulations. Further, based on evidence from Québec and other jurisdictions, we are convinced that weak oversight, enforcement and protections are likely to result in deaths due to abuse, coercion, error, and lack of needed services.

1. Health Canada engaged in a “pre-regulatory” process for developing these regulations, wherein unnamed individuals and organizations collaborated on a “first draft.” This process was not open to the public, and we have no way of knowing whether organizations representing the interests of people with disabilities were included. This secret “pre-regulatory” process flies in the face of the Minister’s stated goal of transparency and raises numerous questions, including:

* Where are the records of these meetings?
* Where is the list of the groups who were consulted?

Those of us who weren’t at the table to state our case for a wider scope of data to be collected – and for stricter safeguards – have little confidence that the Health Minister did an adequate job representing those interests.

1. The socio-demographic information to be collected (schedule 3) is insufficient to meet the regulations’ stated goals, as described in the Consultation section, issue 2(c). There is insufficient information to determine if people making the request are subject to external pressure or if they’re vulnerable to inducement to commit suicide in a time of weakness.
2. The regulations do not provide any mechanism to verify that medical practitioners actually file their reports. This will lead to non-reporting of AS/E, as happens in the BeNeLux countries. Even in Québec, where there is a system to cross-check the number of reports filed by doctors against statistics reported by institutions, this has not prevented doctors from filing late, or not at all. In the two years since Québec’s program has been in operation, the discrepancy between the number of reports filed by doctors and institutions has not been investigated, and doctors have not been sanctioned for failing to report performing euthanasia.
3. The regulations, as drafted, are inadequate for enforcing the law, i.e. ensuring that those who are killed meet all eligibility criteria and that safeguards are fully complied with. We have already seen, in Québec and other jurisdictions, the result of inadequate enforcement; people who do not have a “grievous and irremediable medical condition” or who are not at the “end of life” have been euthanized, without consequence. The proposed regulations lay the responsibility for enforcement of this federal law onto local law enforcement officials, without ensuring that they are directly informed of violations. For example, without a mechanism for verifying that doctors file reports of AS/E, there is no way violators can be identified and referred to local authorities for indictment, as provided for in § 241.31(5). Nor do the regulations guarantee that local authorities will have means or incentive to bring prosecutions for violations. Given society’s bias in favour of AS/E and the prevalence of the “better dead than disabled” mentality, the criminal justice system will treat deaths which violate the MAiD law in the same way as the murders of disabled people – lackadaisically and with indifference.

As well, the regulations make no provision for tracking the outcome when drugs are dispensed for “assisted suicide.” There is nothing to prevent a third party from stepping in to administer the lethal dose to the person against their will; without a practitioner or other witness, who would know? This fact has led to a great gap in documentation of the problem in the states of Washington and Oregon, but anecdotal evidence (e.g. the case of Thomas Middleton) shows that such fraud and abuse does happen. There is also the possibility that dangerous substances will be left around the house, subject to theft and resale or accidental ingestion by children. In addition, complications associated with assisted suicide, such as choking, vomiting or awakening from a coma, are likely not to be managed effectively or documented.

1. The regulations also leave Canada open to unreported medical homicide by failing to provide for checking doctors’ reports of AS/E against all deaths, so as to verify that all “medically-induced” deaths are counted. This technique has been the only effective method for detecting such problems in other jurisdictions. Studying and drawing conclusions only from doctors’ reports of AS/E guarantees that such research will be based on incomplete and false data. Health Canada must ensure its annual reports show the actual number of medical homicides.
2. The regulations don’t describe a process whereby recipients of reports (either the Minister of Health or provincial authorities) are to get additional information or clarifications when reports filed by doctors are incomplete. This is a very common occurrence in Québec, and based on the reports from the *Commission sur les soins de fin de vie*, the back-and-forth between the commission and the reporting doctor can be time-consuming and accompanied by conflict.
3. These regulations will not be effective in monitoring the program should AS/E be expanded to include mature minors, eligibility based on psychological suffering, or advance directives for people with dementia. The Minister of Health should at least include a note recognizing that the regulations will have to be amended should the law be changed to add any of these categories of eligibility.
4. There are several terms or phrases used in the regulations that are not defined or explained, or which create a standard that is less than optimal. These include:

* “…an indication of whether…” is not defined. Sometimes it applies to an “either/or” choice, sometimes it applies to a multiple-choice proposition. Reducing some of these evaluations to a yes-or-no checkbox does not give a clear idea of the nature of the procedure that was followed.
* “…to the best of the practitioner’s knowledge or belief.” This phrase is often used with regard to the practitioner’s responsibility to gather demographic data (schedule 3), but it also refers to eligibility-related items, such as the practitioner’s obligation to ensure palliative care is available to the person making the request. It sets a very low standard, of responsibility on the practitioner to obtain and transmit important information.
* “…if known…” Similarly, adding this caveat at the end of requirements related to prescribing drugs for assisted suicide (and other tasks) relieves the practitioner of any responsibility to follow up on the prescription and learn the outcome. While this may seem unimportant (due to the small number of people requesting assisted suicide at the moment), it’s better to put an effective system into place than to come up short should trends and preferences change.

1. There remains no effective safeguard in the law or regulations to prevent a third party from making a request on behalf of a person who has a communication disability or who is under the influence of the third party. This is a loophole in the law itself, which could have been closed by the regulations. For example:

* Practitioners could be obliged to meet one-on-one with the person making the request (without any family or others in attendance) to verify that there is no coercion;
* The requirement for communication accommodations could be made more specific and applied earlier in the eligibility determination process, to ensure effective and impartial communication (see comment on schedule 5 § (1)(J) below);
* A requirement for a “protective services” evaluation could be added to detect potential abuse.

1. There is no mechanism to track the participation of assisted suicide advocates in the process of formulating the request and making the eligibility determination. This practice should be discouraged for several reasons. First is the potential for the advocacy group to persuade the person that AS/E is the best choice, even if the person is ambivalent.  Second, the advocacy group may be making money for their services through "donations" or "legacies" made by the person.  Finally, advocacy organizations’ participation could have an effect on the process; advocates may be asked to act as witnesses to the signing of the application, and practitioners may begin to off-load certain tasks (of informing or documentation) onto them.  For these reasons, their participation should be tracked.
2. Demographic information collected is insufficient to determine the role of economic factors in a decision to request AS/E. Schedule 3, under “place of residence,” does not include a choice for long-term hospitalization or for people who are homeless. Household composition and income, home-ownership (or lack thereof), date of onset of disability, and illness- and disability-related expenses are all factors that affect the person’s economic situation. (A more detailed description of items to be added to schedule 3 appears below).
3. Proponents of assisted suicide and euthanasia are attempting to re-define the word “suicide” to exclude those who ask for AS/E. They justify their view by saying that “medical aid in dying” (or “dying with dignity”) is not the same as committing suicide, because the goal is to “end suffering.” However, experts in suicidology remain staunch in their belief that the issues presented and behaviours manifest by people seeking AS/E are the same as for people who attempt and commit suicide.

AS/E promoters’ doublespeak campaign has been successful; suicide prevention organizations, legislatures, and the media are now parroting their propaganda when making a (false) distinction between AS/E and “medical aid in dying.”

One result of this redefinition has been to exclude any reference to “suicide prevention” from the law and regulations allowing AS/E. In the preamble of Bill C-14, suicide is described as “a significant public health issue that can have lasting and harmful effects on individuals, families and communities.” The preamble also mentions the statutory goal of protecting vulnerable persons “from being induced, in moments of weakness, to end their lives.”

The federal framework on suicide prevention (from a report published in 2016 pursuant to Bill C-30 adopted in 2012) defines suicide as: "’death caused by self-directed injurious behaviour with *any intent to die* as a result of the behaviour.’ Many factors and circumstances can contribute to someone considering, attempting or dying by suicide (e.g., loss, addictions, childhood trauma or other forms of trauma, depression, serious physical illness, mental illness and major life changes).” (emphasis added). The framework recognizes the impact of physical illness and disability as a risk factor for suicidality, and calls for more research on suicide among people with disabilities.

Yet the suicide prevention framework is not reflected in the regulations governing the assisted suicide / euthanasia law. There is no requirement to document efforts at suicide prevention. Aside from informing the person making the request of the availability of palliative care, there is no obligation to identify and refer for needed services such as home modifications, personal assistance services or mental health treatment. The Minister of Health must remedy these omissions.

1. The section on “administrative burden” estimates 5,709 deaths per year from AS/E. When will this total be reached and exceeded?
2. The “administrative burden” is calculated only as filling out an (as yet to be developed, multiple-choice) online form. Yet compliance with the law requires much more than simply filling out a data sheet. The Minister of Health should account for the clinical time for evaluation, referrals, follow-up, administration or dispensing of the substance, paperwork, record-keeping and other tasks.
3. The Minister of Health proposes an online form including multiple choice answers and yes-or-no checkboxes. While drop-down menus and similar functions may save time in filling out forms, such devices risk pigeon-holing people and may give an inaccurate picture of those making the AS/E request. There must also be provision for narrative answers, to enable practitioners to describe the unique situation of each person.
4. A strict application of the “one-for-one” rule would put pressure on practitioners and the system as a whole to curtail supportive services that are supposed to accompany the eligibility determination process. Cutting corners on capacity determinations and referrals for psychiatric evaluations, palliative care, personal assistance services, peer counseling, or other suicide prevention services will increase the numbers of people dying by AS/E.
5. It appears that, during the closed pre-regulatory process, Health Canada conceded to pressure to push back deadlines for doctors’ reports. In addition, they have also broadcast their intention not to enforce the timelines; by stating that “events [don’t] occur within particular time frames.” The regulations seem to allow that, if the request does not result in euthanasia, the obligation to report it will disappear after 90 days. In order to understand the full scope of the AS/E application process, including situations where requests are withdrawn or candidates are deemed ineligible, it is important that all requests be documented, regardless of outcome.
6. The proposal to allow for multiple systems for collecting data (federal or provincial “recipients”) could create confusion and a lack of uniformity. Also, where provinces provide an agglomeration of data, it may be impossible to identify anomalies/violations in individual cases. For enforcement purposes, it is particularly important that details of individual cases be available where the law and regulations have been violated.
7. There is no provision in the regulations for documenting the process of death by euthanasia, e.g. time between injections, onset of coma, time between administration and death, documenting complications, and what measures are taken to resolve them. This is an area that needs to be more fully documented and studied. Nor is such information required in the case of assisted suicide.

The failure to include this information is a reflection of, and contributor to, the reluctance of legislators and officials to confront the physical realities of illness and disability. This societal squeamishness plays a large part in the widespread belief that losing control of bodily functions makes one “undignified;” and that “dignity” can only be regained through death.

1. The regulations do not say how long the data will be kept. In the states of Washington and Oregon, the data on which the annual reports are based are destroyed once the state reports are published. This has contributed to the impression that the process is not transparent; and indeed, destroying the data limits the possibility of both in-depth and long-term analysis.

As well, the draft regulations do not clarify the issue raised in the pre-regulatory consultation process about whether “day” means “working day” or “calendar day.”

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You will find more specific comments on the attached item-by-item survey of the proposed regulations.

Please feel free to contact me with any questions you may have.

**Proposed regulations for monitoring**

**Medical Assistance in Dying**

Item by item review

**Text of regulations:**

**Background** – The primary purpose of monitoring is to provide transparency and foster public trust\* regarding the implementation of the new law. The proposed monitoring regime would use data to build a picture of how the legislation is working — for example core statistics regarding the number of requests and their outcomes, the circumstances of patients requesting and receiving medical assistance in dying — and how the eligibility criteria are being applied. Contraventions of the legislation are currently, and would remain, under the purview of local law enforcement. \*\*

**Comments:**

* Where do the goals of oversight, enforcement, and protecting vulnerable persons come in?
* \*If transparency is among the purposes of the regulations, why was there a secret, pre-regulatory process?
* \*\*How are violations to be identified and referred to local law enforcement?
* What incentives do local law enforcement officials have to prosecute?

**Text of regulations:**

**Objectives**

the federal monitoring regime, … would

* 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.

**Comments:**

What about:

* Examining the role of advocates for assisted suicide and euthanasia in the operations of the program?
* Evaluating the role of economics in end-of-life decision making?
* Discovering gaps in services (such as mental health services, suicide prevention and palliative care) which need to be filled?

**Text of regulations:**

**Practitioners**

Practitioners, meaning a nurse practitioner or a medical practitioner, would be required to file reports concerning written requests for medical assistance in dying. Reporting requirements vary based on the outcome of the request, i.e. whether the practitioner refers the request to another practitioner, the patient withdraws the request, the practitioner determines the patient is, or has become, ineligible, the patient has died from a cause other than medical assistance in dying, or medical assistance in dying is provided.

The reporting requirements discussed above would cease 90 days after the practitioner received the request, except in cases where medical assistance in dying is provided.

A second practitioner who provides a written report confirming that the patient meets all of the criteria, as required as one of the safeguards under the Act, would not be required to file the reports described above.

**Comments:**

* What happens when information is missing, insufficient or isn’t provided in the report, or the report is not filed by the deadline?
* Essentially, if the request does not result in euthanasia, the reporting requirement disappears after 90 days.

**Text of regulations:**

**Recipient of reports:**

The proposed Regulations would designate the federal Minister of Health as the recipient for all reports, except those filed in Quebec. Reports filed in Quebec would be filed with the President of the *Commission sur les soins de fin de vie*.

**Comments:**

Has the health minister verified that the information collected by Québec’s commission on end of life care satisfies the regulatory requirements?

**Text of regulations:**

Other provinces and territories have the opportunity to nominate a recipient to receive reports from practitioners and pharmacists in their respective jurisdictions. Those individuals would be identified as designated recipients in the final Regulations. There may be two designated recipients for practitioners and pharmacists in a province or territory, depending on their individual circumstances. For example, in provinces where medically assisted deaths are reported to the Chief Coroner, he or she may be identified as the designated recipient in cases where medical assistance in dying was provided, and another recipient may be designated for information regarding requests which did not result in death.

**Comments:**

* How does the federal government propose to ensure that provincial reporting mechanisms gather the same information required by federal regulations?
* How does the Health Minister propose that provinces transmit information to the federal government?
* If an agglomeration of information is transmitted from the provinces to the Minister of Health, will it be possible to track details (anomalies, violations) in individual cases?
* Will practitioners be obliged to submit reports both to provincial recipients and on the electronic form created by the Minister of Health?

**Text of regulations:**

Where provincial or territorial recipients are designated, these recipients would be required to provide all information that must be reported by practitioners and pharmacists under the proposed Regulations to the federal Minister of Health on a quarterly basis, except information required only for administrative purposes by designated recipients.

In cases where a province or territory has not nominated a recipient, the federal Minister of Health would remain the designated recipient for all reports.

**Comments:**

* What happens when information is missing, insufficient or isn’t provided within the deadline (either by the medical providers, or by the provincial recipient)?
* What happens when physicians refuse to provide requested information?

**Text of regulations:**

***Publication of Information***

At least once a year, a report would be published on the Government of Canada website presenting aggregate data on information obtained under the proposed Regulations. This report would include data elements such as:

* the number of requests made,
* the results of those requests,
* characteristics of patients requesting and receiving medical assistance in dying,
* criteria that were not met in cases of ineligibility, and
* time periods relating to the handling of requests.

The report would not contain any personal information.

**Comments:**

What about:

* Reasons requests were withdrawn?
* Disagreements between physicians as to eligibility?
* Services provided (or not) to people who asked for AS/E?

There isn’t enough information about people asking for AS/E to determine if they are subject to external pressure or vulnerable to inducement to commit suicide in a time of weakness.

**Text of regulations:**

**The “one for one” rule / Administrative burden**

The valuation of the administrative burden was undertaken using the assumption that 2.05% of Canadian deaths would occur as a result of medical assistance in dying, for approximately 5,709 deaths each year.

It was assumed that approximately 10 minutes are required to electronically file each report submitted by a practitioner, except in cases where a 90-day waiting period applies. In those cases, an additional 10 minutes was estimated to accommodate administrative burden associated with a waiting period.

**Comments:**

The “10 minute” estimate assumes that most of the form will be multiple-choice or check-boxes, with very little narrative content. Such a process will not capture the unique circumstances of each person making the request.

Counting only the time necessary to electronically fill out the form doesn’t capture the additional time commitment required to determine eligibility and administer euthanasia. This does not include additional clinical time involved with conducting physical examinations, administering tests and analyzing results, communicating with the person, making referrals for additional services (e.g. palliative care, psychiatric services), and many other tasks.

Application of the “one-for-one” rule would tend to curtail the support services that are supposed to accompany the eligibility determination process. Cutting corners on referrals for psychiatric evaluations, palliative care, personal assistance services, peer counseling, or other suicide prevention services is a bad idea.

**Text of regulations:**

**Consultation**

Health Canada conducted pre-regulatory consultations with key stakeholders between April and June 2017.

**Comments:**

If “transparency” is one of the goals of the regulations, where are the records of these meetings? Where is the list of the groups who were consulted?

**Text of regulations:**

Issues identified in the pre-regulatory process: Protecting the privacy of patients, practitioners, and pharmacists.

“…Some questioned why certain data elements were being collected at all — in particular socio-demographic characteristics and information allowing identification of patients, practitioners and pharmacists.”

**Comments:**

In this secret pre-regulatory process, those of us who weren’t at the table to state our case for a wider scope of data to be collected – and for stricter safeguards – have to trust that the Health Minister did an adequate job.

**Text of regulations:**

“**Consultation, issue 2(c)** – *Socio-demographic information*: As medical assistance in dying involves permitting individuals to be actively involved in terminating the lives of others who request their help*,*the objectives of the monitoring system include seeking to understand the characteristics of individuals who request medical assistance in dying, the circumstances in which requests arise, and whether individuals are seeking assisted dying due to certain socio-demographic conditions, as opposed to suffering emanating from their medical condition and the dying process. To this end, the monitoring regime includes a number of socio-demographic elements.”

**Comments:**

The socio-economic information to be collected is described in schedule 3 and is inadequate to meet the program’s goals. (See the note, below under Schedule 3)

**Text of regulations:**

**Consultation, Issue 3: Clarity on Reporting Requirements**

the data requirements have been significantly reduced and revised, and guidance documents will be developed to provide clarity on who is required to file information, and in what circumstances. Health Canada is developing an electronic reporting system in collaboration with Statistics Canada that would guide the practitioner or pharmacist through an electronic questionnaire to identify their reporting obligations when Health Canada is the designated recipient. This would include “help” and “information” features to provide definitions, outline frequently asked questions, and direct practitioners or pharmacists to where they can access additional support if required. The electronic portal will maximize the use of features such as drop-down menus to reduce the time required for completion, while ensuring consistency and ease of roll-up of data.

**Comments:**

* Will the development of “guidance documents” occur as part of another secret and private regulatory scheme like the “pre-regulatory process”?
* While drop-down menus and similar functions may save time in filling out forms, pigeon-holing people into restrictive categories may give an inaccurate picture of those making the AS/E request.
* The pre-regulations process raised the issue of whether “days” are “working days” or “calendar days” but the question is not answered in the draft regulations.

**Text of regulations:**

**Consultation Issue 4: Timelines.**

timelines were lengthened to 30 days or longer in most cases. Guidance documents for practitioners and pharmacists would explain that the Regulations do not presuppose that events occur within particular time frames.

**Comments:**

* Not only has Health Canada bowed to pressure to lengthen the timelines, they have also broadcast their intention not to enforce the timelines; by stating that “events [don’t] occur within particular time frames.
* What happens when medical practitioners or provincial authorities don’t comply with timelines?

**Text of regulations:**

**Rationale**:

Medical assistance in dying in Canada is permitted through exceptions to criminal laws that prohibit terminating and participating in the end of human life. A robust monitoring regime reflects the significance and gravity of permitting practitioners to help end life.

... It is critical that the outcomes of the Canadian regime are sufficiently monitored.

**Comments:**

* While this is a positive statement, without compliance and enforcement, monitoring is meaningless.
* There are several areas in which information to be gathered is insufficient to meet the goals of the monitoring regime.

**Text of regulations:**

**Benefits:** Collecting, analyzing and publicly reporting on data for monitoring purposes is critical to foster public trust and provide transparency and accountability in relation to the legislation. The proposed regime would provide Canadians with a clear picture of how the legislation is working

**Comments:**

The scope of the proposed data is insufficient to meet this goal.

**Text of regulations:**

**Costs:**  …Introducing any kind of administrative burden may prove to be a deterrent to some practitioners and pharmacists in providing medical assistance in dying.

Provincial and territorial governments may incur costs if practitioners and pharmacists are remunerated for the time required to file reports.

The federal government, as well as provinces and territories designated in the final Regulations, would incur costs to establish and administer reporting systems (or, in the case of provincial or territorial designated recipients, modify existing systems). These costs are expected to decrease as reporting systems are operationalized.

**Comments:**

* Higher costs and administrative burdens may also incite practitioners not to file reports, or to do the minimum possible. There must be consequences and enforcement to prevent non-reporting.
* Cost minimization by provincial and territorial governments may result in poor quality reporting systems that don’t capture the unique circumstances of each person who asks for AS/E.

**Text of regulations:**

***Implementation:***

The Regulations would come into force a minimum of one month after they are registered. Health Canada is working with Statistics Canada to develop an electronic portal for the receipt of data for monitoring purposes, and they will collaborate on the production of reports.

**Comments:**

Health Canada appears to be encouraging health practitioners to submit their reports directly to the federal government via the electronic forms. As noted elsewhere in the regulations, this creates several potential problems related to conflicting/overlapping information, or follow-up when information is missing or insufficient, etc.

**Text of regulations:**

***Enforcement:***

The Act creates an offence for practitioners or pharmacists who knowingly fail to provide information for monitoring purposes, and for others who knowingly breach the Regulations. The designated recipient for information in a province or territory — whether federal, provincial, or territorial — could bring allegations regarding such offences to the attention of local law enforcement authorities, who would ultimately make the decision about whether to lay charges.

**Comments:**

* How would doctors’ failure to file reports be detected?
* This does not oblige the designated recipient to refer violations to local law enforcement. What incentive does the designated recipient have to bring such allegations?
* What incentive does local law enforcement have to lay charges?

**Text of regulations:**

***Service standards***

Service standards for the federal government are not proposed, because the proposed Regulations would stipulate timelines for the federal Minister of Health to publish reports

**Comments:**

* Wouldn’t the electronic data entry and access portal also be considered part of the “service” prescribed by these regulations?
* What about the “service” of making the data available to researchers?

**Text of regulations:**

**TABLE 1: INFORMATION REQUIREMENTS FOR FEDERAL MONITORING OF MEDICAL ASSISTANCE IN DYING**

Provision of medical assistance in dying by administering a substance:

**Comments:**

There is no requirement to describe either the administration of the lethal substance, nor any complications which may have occurred during administration and the dying process.

**Text of regulations:**

Provision of medical assistance in dying by prescribing or providing a substance for self-administration.

**Comments:**

* There is no required follow-up to determine:
  + If and when the person died;
  + No indication as to whether the person took the drugs;
  + No proof that the person took the drug themselves or if they were administered by another person,
  + No proof that the person took the drug willingly,
  + No information as to whether there were complications

**Text of regulations:**

Determination of ineligibility

**Comments:**

* Why is schedule 3 (demographic) information excluded for this group?
* Reasons for determination of INeligibility are NOT required by schedule 4 information. Reasons for eligibility determination are required.
* Why is schedule 5 (application of safeguards) information excluded for this group? (Especially where the person is initially deemed eligible but later becomes ineligible).
* Some of the safeguards should be applied before a determination of eligibility is made, to wit:
  + Ensure the request was made in writing and was duly signed, dated and witnessed;
  + Person was informed they had a grievous and irremediable medical condition;
  + Inform the person they may withdraw the request at any time;
  + Take all necessary measures to ensure effective communication.

**Text of regulations:**

Withdrawal of request.

**Comments:**

* ALL information should be gathered up to the point where request is withdrawn, and included in the final report.
* Includes reason for withdrawal of the request.

**Text of regulations:**

Referral of patient to another practitioner, or care coordination service

Death of patient from another cause

**Comments:**

* ALL information obtained prior to the person’s death should be included.
* Includes date and cause of death.

**Text of regulations:**

**Definitions …**

* ***medical certificate of death*** includes, in the Province of Quebec, an attestation of death. (*certificat médical de décès*)
* ***refer***does not include referring a patient to a practitioner in order to obtain that practitioner’s written opinion, for the purposes of paragraph 241.2(3)(e) of the Code, regarding whether the patient meets all of the eligibility criteria. (*aiguiller*)

**Comments:**

“Medical certificate of death:” This is not a definition, it is a specification.

“Refer:” This also is not a definition. It says what “refer” does not mean, not what it *does* mean.

**Text of regulations:**

**PRACTITIONERS: Withdrawal of request**

**5**A practitioner must provide the following information to the recipient designated under section 2 within 30 days after the day on which the practitioner became aware of the withdrawal of a patient’s written request for medical assistance in dying that they received:

**(a)**the information referred to in Schedule 1;

**(b)**in the case where the practitioner has determined that the patient met all of the eligibility criteria:

**(i)**the information referred to in Schedule 3, to the best of the practitioner’s knowledge or belief,

**(ii)**the information referred to in Schedule 4;

**(c)**the patient’s reasons for withdrawing the request, if known;

**(d)**an indication of whether the patient withdrew their request after having been given an opportunity to do so under paragraph 241.2(3)(h) of the *Code*.

**Comments:**

* Why is there a limitation on the requirement to provide demographic information?
* Why are practitioners not obliged to provide the information on schedule 5 (application of safeguards)?

**Text of regulations:**

**Ineligibility:**

**6 (1)**A practitioner who has received a patient’s written request for medical assistance in dying and determines that the patient does not meet one or more of the eligibility criteria must provide the recipient designated under section 2 with the information referred to in Schedules 1 and 4 within 30 days after the day on which the practitioner made that determination.

**Comments:**

* Why doesn’t the practitioner have to provide demographic information from schedule 3?
* Since some of the safeguards are applied before eligibility is determined, shouldn’t the practitioner be obliged to submit evidence that those safeguards were complied with? (This would certainly apply where the person was deemed eligible, then became ineligible. See § 6 (2)).

**Text of regulations:**

**Prescribing or providing a substance**

**7 (1)**A practitioner who has received a patient’s written request for medical assistance in dying and provides medical assistance in dying by prescribing or providing a substance to the patient must provide the recipient designated under section 2 with the following information no earlier than 90 days after the day on which the practitioner prescribed or provided the substance and no later than 120 days after that day:

**(a)**the information referred to in Schedules 1 and 4 to 6;

**(b)**the information referred to in Schedule 3, to the best of the practitioner’s knowledge or belief.

**Comments:**

* Why is the practitioner not obliged to verify the information on schedule 3?
* See comments above re: lack of follow-up on prescribing substances for assisted suicide

**Text of regulations:**

**Administering a substance**

**8**A practitioner who has received a patient’s written request for medical assistance in dying and provides medical assistance in dying by administering a substance to a patient must provide the recipient designated under section 2 with the following information within 10 days after the day on which the patient died:

**(a)**the information referred to in Schedules 1, 4, 5 and 7;

**(b)**the information referred to in Schedule 3, to the best of the practitioner’s knowledge or belief.

**Comments:**

* Why is the practitioner not obliged to verify the information on schedule 3?
* Why is there no information collected about complications or the dying process?

**Text of regulations:**

**Death — other cause**

**9 (1)**A practitioner who has received a patient’s written request for medical assistance in dying and becomes aware that the patient died from a cause other than medical assistance in dying must provide the recipient designated under section 2 with the following information within 30 days after the day on which the practitioner became aware that the patient died:

**(a)**the information referred to in Schedule 1;

**(b)**in the case where the practitioner has determined that the patient met all of the eligibility criteria:

**(i)**the information referred to in Schedule 3, to the best of the practitioner’s knowledge or belief,

**(ii)**the information referred to in Schedule 4;

**(c)**the date of the patient’s death, if known, and, if the patient’s medical certificate of death was completed by the practitioner, the immediate and underlying causes of death as indicated on the certificate.

**Comments:**

* Again, demographic information should be complete and obligatory.
* Why not the information in schedule 5 (application of safeguards)?

**Text of regulations:**

**Cessation of certain requirements**

**10**A practitioner who has received a patient’s written request for medical assistance in dying is not required to provide the recipient designated under section 2 with information under a provision of these Regulations — other than sections 7 and 8 — with regard to any circumstances relating to the request that the practitioner becomes aware of after the 90th day after the day on which the practitioner received the request.

**Comments:**

In other words, if the outcome is something other than assisted suicide or euthanasia, the doctor doesn’t have to report anything? This will not give a complete picture of the practice.

**Text of regulations:**

**Collection of Information**

**Coroners and medical examiners**

(2) Without restricting the generality of subsection (1), the Minister of Health may, for the purposes of monitoring medical assistance in dying, request that the Chief Coroner or Chief Medical Examiner of a province or territory provide him or her, on a voluntary basis, with personal information relating to the death of patients who died as a result of having received medical assistance in dying in the province or territory including:

(a) the number of patients who died;

(b) copies of medical certificates of death of those patients;

(c) the finding of any investigations undertaken by the Chief Coroner or Chief Medical Examiner in respect of the deaths of those patients.

**Comments:**

The Minister of Health should be *obliged* to collect information from coroners and medical examiners on the *total number* of people who died, then undertake studies to trace the *cause of death* to its origin, to determine if medical homicide is being practiced outside the scope of the law.

**Text of regulations:**

**Report**

13 (1) The Minister of Health must cause to be published, at least once a year, on the website of the Government of Canada a report that is based on information that the Minister obtained under these Regulations.

**Content — period covered by report**

**(2)**The report must contain information relating to written requests for medical assistance in dying received by practitioners and the provision of medical assistance in dying during the period covered by the report, including:

**(a)**the number of requests that were made and the results of those requests;

**(b)**the characteristics, including medical characteristics, of patients;

**(c)**the nature of the intolerable physical or psychological suffering of patients who received medical assistance in dying;

**(d)**the reasons for which patients did not receive medical assistance in dying, including which of the eligibility criteria were not met by patients;

**(e)**the locations in which medical assistance in dying was provided;

**(f)**time periods relating to the handling of requests and the provision of medical assistance in dying;

**(g)**the nature of consultations by practitioners with other health care professionals or social workers regarding requests;

**(h)**the nature of involvement of practitioners in requests and the provision of medical assistance in dying, including

**(i)**the respective involvement of medical practitioners and nurse practitioners, and

**(ii)**the existence of therapeutic relationships between patients and practitioners before requests were made.

**Comments:**

Additional information that would be important to provide in the report:

* Document the involvement of assisted suicide advocates in requests for assisted suicide
* Document “Therapeutic relationships prior to the request being made” to detect:
  + Doctor shopping;
  + Whether people have primary care physicians.
* Additional services needed (e.g. palliative care, personal assistance services, home modifications, peer counseling, mental health services, etc.), and whether such services were provided.
* Suicide prevention services provided.
* Efforts made to detect and stop abuse.
* Whether the person was given an opportunity to speak with others living successfully with similar disabilities
* Demographic information about person making the request
* Information about how many AS/E have been done by each practitioner.
* The reasons people are requesting assisted suicide and euthanasia (nature of the suffering);
  + Loss of autonomy,
  + Loss of ability to do favorite activities,
  + Loss of control over bodily functions,
  + Feeling tired of life
  + Perceived loss of dignity,
  + Feeling like a burden,
  + Pain,
  + Other physical distress,
  + Fear of pain or physical distress
* Any discrepancies between the number of euthanasia reported by medical practitioners and those reported by institutions and coroners
* The geographic distribution of requests for and approval of MAID
* Statistical classification by age, race, gender, language, household income, date of onset of illness/disability, nature of illness/disability.
* Information on methods of administering euthanasia, the frequency and nature of complications, what measures are taken to resolve complications

**Text of regulations:**

SCHEDULES OF INFORMATION

**Schedule 1 Basic Information — Request for Medical Assistance in Dying**

1 The following information in respect of the patient:

(a) date of birth;

(b) sex;

(c) health insurance number and the province or territory that issued it or, in the case where they do not have a health insurance number, the province or territory of their usual place of residence.

2 The following information in respect of the practitioner:

(a) name;

(b) an indication of whether they are a medical practitioner or nurse practitioner;

(c) if they are a family physician, an indication to that effect;

(d) if they are a medical practitioner other than a family physician, their area of specialty;

(e) the province or territory in which they practice and, if they practice in more than one province or territory, the province or territory in which they received the request;

(f) the license or registration number assigned to the practitioner in the province or territory in which they received the request;

(g) work address and, if applicable, work email address;

(h) an indication of whether, before receiving the request, they had a therapeutic relationship with the patient.

3 The following information in respect of the request:

(a) the date on which the practitioner received the request;

(b) an indication of whether the practitioner received the request from the patient directly, another practitioner, a care coordination service or another third party.

**Comments:**

* Information about how many AS/E have been done by any given practitioner should be included in the reports, as well as information about previous applications for AS/E made by the person.
* How is the medical practitioner supposed to ensure that the request is not a result of external pressure if a (completed, signed, witnessed) request is handed over by a third party?
* If the “third party” is an assisted suicide advocacy organization, this should be specified.

**Text of regulations:**

**Schedule 2** – **Referral of Patient**

**1**The date on which the patient was referred.

**2**If the practitioner received the request in a hospital, a residential care facility or a palliative care facility, an indication of whether the decision to refer the patient was the result of the application of the policies on medical assistance in dying of the hospital or facility.

**3**An indication of whether the practitioner had determined that the patient met or did not meet all of the eligibility criteria before they referred the patient.

**Comments:**

If the referring party is an assisted suicide advocacy organization, this should be specified.

**Text of regulations:**

**Schedule 3** – **Supplementary Information About Patient**

**1**An indication of which of the following locations describes the patient’s usual place of residence or, if their usual place of residence is elsewhere, a description of that location:

**(a)**residential care facility;

**(b)**private residence.

**2**The postal code of the patient’s usual place of residence.

**3**The patient’s marital status.

**4**The patient’s principal occupation during their working life, if applicable.

**Comments:**

Other demographic information that should be included:

* Race
* Religion
* Ethnic background
* Household composition
* Income range
* Usual residence:
  + Residential care facility
  + Private residence
  + Hospitalized
  + Homeless
* Is the person a home-owner?
* Is the residence accessible and adapted to the person’s needs?
* If the person needs personal assistance services
* How many hours of personal care are required per day?
* Are the person’s personal assistance needs being met, and by whom?
* If the person receives mental health counseling
* Language spoken (whether person is receiving services in their first language)
* Whether the “serious and incurable medical condition” is:
  + Lifelong / onset in childhood
  + Adult onset
  + Recent (within one year) onset
* Who is the primary health care provider?
* Does the person report problems in their living situation?
* Are there indications of abuse?
* Is there supplemental health insurance?
* How much are disability-related expenses?

Using the entire postal code to identify the person's location could violate their privacy rights. The three-digit "postal zone" should be sufficient to identify the general area and character of the person’s neighbourhood.

**Text of regulations:**

**Schedule 4** – **Eligibility Criteria and Related Information**

**1**An indication of whether the practitioner consulted with other health care professionals or social workers in order to determine whether the patient met the eligibility criteria and, if so, the professions of those persons.

**2**An indication of which of the following eligibility criteria were assessed by the practitioner and whether the practitioner was of the opinion that the patient met or did not meet each of those criteria:

**(a)**the patient was eligible — or, but for any applicable minimum period of residence or waiting period, would have been eligible — for health services funded by a government in Canada;

**(b)**the patient was at least 18 years of age;

**(c)**the patient was capable of making decisions with respect to their health;

**(d)**the patient made a voluntary request for medical assistance in dying that, in particular, was not made as a result of external pressure 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;

**(e)**the patient gave informed consent to receive medical assistance in dying after having been informed of the means that are available to relieve their suffering, including palliative care;

**(f)**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;

**(g)**the patient was in an advanced state of irreversible decline in capability 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 decline;

**(h)**the illness, disease or disability or state of decline caused the patient enduring physical or psychological suffering that was intolerable to them and that could not be relieved under conditions that they considered acceptable 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 the patient’s description of the suffering;

**(i)**the patient’s natural death had become reasonably foreseeable, taking into account all of their medical circumstances 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 the practitioner’s estimate as to the amount of time by which medical assistance in dying, if provided, would shorten the patient’s life and the practitioner’s anticipation of the likely cause of natural death of the patient.

**3**An indication of whether the patient received palliative care, if known, and, if they did not receive palliative care, an indication of whether, to the best of the practitioner’s knowledge or belief, palliative care was accessible to the patient.

**4**In the case where the practitioner, after having determined that the patient met all of the eligibility criteria, determines that the patient no longer meets one or more of those criteria, an indication of whether the patient lost the capacity to make decisions with respect to their health. \*

**Comments:**

* Copies of documents from the medical file should be required to indicate that eligibility criteria have been evaluated and met, and that safeguards have been applied.
* Paragraph 2 seems to allow for the possibility that an eligibility criterion might not be assessed by the practitioner.
* Information should be added about the *means* by which the person’s capability to make decisions was assessed and the *criteria used*.
* \*What about people who became ineligible for reasons other than loss of capacity?
* Additional information that should be provided:
  + The date of diagnosis and date of onset of the “serious and incurable illness;”
  + Method of diagnosis; the nature and results of tests that confirmed the diagnosis of the “serious and incurable illness;”
  + The reason given by the applicant for seeking AS/E;
  + Any history of suicidal or self-harming behavior, mental illness, alcoholism or substance abuse;
  + Whether the “serious and incurable illness” or any treatments for such illness, are likely to cause disruptions in mood, judgment, or capacity to make health care decisions;
  + Information about services the person was offered but refused, and why.
* What happens if the practitioner did not assess all of the eligibility criteria?
* What happens if there is disagreement between the two doctors? Will there be any indication as to whether the primary doctor consulted multiple doctors to get a favourable “second opinion?”
* Shouldn’t the regulations clarify the definition of “reasonably foreseeable”?

**Text of regulations:**

**Schedule 5** **Procedural Requirements — Providing Medical Assistance in Dying**

**1**An indication of whether

**(a)**the practitioner was of the opinion that the patient met all of the eligibility criteria;

**(b)**the practitioner ensured that the patient’s request was made in writing and was signed and dated by the patient or by another person who met the requirements set out in subsection 241.2(4) of the *Code*;

**(c)**the practitioner ensured that the request was signed and dated after the patient was informed by a practitioner that the patient had a grievous and irremediable medical condition;

**(d)**the practitioner was satisfied that the request was signed and dated by the patient — or by another person who met the requirements set out in subsection 241.2(4) of the *Code* — before two independent witnesses who met the requirements set out in subsection 241.2(5) of the *Code* and who then also signed and dated the request;

**(e)**the practitioner ensured that the patient was informed that they may, at any time and in any manner, withdraw their request;

**(f)**the practitioner ensured that another practitioner provided a written opinion confirming that the patient met all of the eligibility criteria and, if so, an indication of whether the other practitioner is a medical practitioner or nurse practitioner and the date on which the other practitioner signed that opinion;

**(g)**the practitioner was satisfied that they and the practitioner referred to in paragraph (f) were independent within the meaning of subsection 241.2(6) of the *Code*;

**(h)**the practitioner ensured that at least 10 clear days elapsed between the day on which the request was signed by or on behalf of the patient and the day on which the medical assistance in dying was provided or, in the case where the practitioner considered a shorter period appropriate in the circumstances, an indication of which of the following was the basis for that determination:

**(i)**the patient’s death was imminent,

**(ii)**the loss of the patient’s capacity to provide informed consent was imminent;

**(i)**the practitioner, immediately before providing the medical assistance in dying, gave the patient an opportunity to withdraw their request and ensured that the patient gave express consent to receive medical assistance in dying;

**(j)**in the case where the patient had difficulty communicating, the practitioner took all necessary measures to provide a reliable means by which the patient may have understood the information that was provided to them and communicated their decision;

**(k)**the practitioner informed a pharmacist, before the pharmacist dispensed the substance that the practitioner prescribed or obtained for the patient, that the substance was intended for the purpose of providing medical assistance in dying.

**2**The date on which the request was signed by the patient or by another person who met the requirements set out in subsection 241.2(4) of the *Code*.

**Comments:**

* Copies of documents from the medical file should be required to indicate that eligibility criteria have been evaluated and met, and that safeguards have been applied.
* In Table 1, Schedule 5 is referred to as “Application of safeguards” which is different from “procedural requirements – Providing medical assistance in dying.” This creates confusion.
* (1)(a) (“Met all the eligibility criteria”) calls for a single response to a multi-part question. Practitioners need to be accountable for each and every eligibility criterion, including, e.g. (2)(e) the informed consent requirement wherein the person must be told of the option of palliative care.
* In regard to item (1)(J)
  + This requirement should be applied at the beginning of the process to ensure effective communication throughout the eligibility determination and safeguard application procedures.
  + The word “reliable” is insufficient to describe a method that enables effective expressive and receptive communication for someone with such a limitation. “Reliable” means something usually works as it’s supposed to, but if the tool is not well-adapted to the user or the task, it will not be useful or effective. “Usable, impartial and effective” (in combination) would be a better way to describe the required communication method.

**Text of regulations:**

**Schedule 6** -- **Prescribing or Providing a Substance**

**1**The date on which the practitioner prescribed or provided the substance to the patient.

**2**An indication of which of the following locations describes where the practitioner prescribed or provided the substance to the patient or, if they prescribed or provided the substance elsewhere, a description of that location:

**(a)**medical office;

**(b)**hospital;

**(c)**palliative care facility;

**(d)**residential care facility;

**(e)**private residence.

**3**The following information:

**(a)**an indication of whether the patient self-administered the substance, if known;

**(b)**in the case where the patient self-administered the substance,

**(i)**an indication of whether the practitioner was present when the patient self-administered the substance,

**(ii)**the date on which the patient self-administered the substance, if known,

**(iii)**an indication of which of the following locations describes where the patient self-administered the substance or, if they self-administered the substance elsewhere, a description of that location, if known:

**(A)**hospital,

**(B)**palliative care facility,

**(C)**residential care facility,

**(D)**private residence;

**(c)**in the case where the patient did not self-administer the substance,

**(i)**an indication of whether the patient has died, if known,

**(ii)**in the case where the patient has died, the date of death, if known.

**Comments:**

* Item (3)(b)(i) should be moved up. The presence (or not) of the medical practitioner is a very important datum, and is not contingent on whether or how the drug was administered (item (3)(b)). If the medical practitioner is present, they can
* Be an impartial witness to the proceedings
* Ensure that the person has a final opportunity to change their mind
* Monitor any complications and intervene as necessary
* Record the amount of time between administration and death
* Information about the method of administration (pills dissolved in liquid or food, pills taken orally, etc.) should be gathered.
* Item (3)(a) is subject to more than two possible outcomes. Therefore, the information to be gathered must be more comprehensive:
  + The person elects to not take the drug
  + The person self-administers the drug
  + The drug is administered by another person
  + The drug is self-administered with the help of the practitioner or a third party
  + Following complications or a failed administration (by self- or third-party), the practitioner or third party intervenes to “complete” the assisted suicide
* Similarly, item (3)(c) assumes that the only alternative to self-administration is that the drug was not taken. The regulations must anticipate and compensate for potential problems. Failing to gather detailed information on assisted suicides leaves the process, and people making the request, open to abuse.

**Text of regulations:**

**Schedule 7 -- Administering a Substance**

1 The date on which the practitioner administered the substance to the patient.

2 An indication of which of the following locations describes where the practitioner administered the substance to the patient or, if they administered the substance elsewhere, a description of that location:

(a) hospital;

(b) palliative care facility;

(c) residential care facility;

(d) private residence.

**Comments:**

Additional information should be collected:

* Time between injections
* Onset of coma
* Time between administration and death
* Any complications which occurred and measures taken to deal with them
* Information about the effectiveness of the dosage given, allergic reactions, pain or discomfort experienced by the person before death occurs.

**Text of regulations:**

**Schedule 8 -- Dispensing a Substance**

1 The following information in respect of the patient for whom the substance was dispensed:

(a) date of birth;

(b) health insurance number and the province or territory that issued it or, in the case where they do not have a health insurance number or the pharmacist does not know the patient’s health insurance number, the province or territory of their usual place of residence.

2 The following information in respect of the pharmacist:

(a) name;

(b) the province or territory **in which they practice and, if they practice in more than one province or territory, the province or territory** in which they dispensed the substance;

(c) the license or registration number assigned to the pharmacist in the province or territory in which they dispensed the substance;

(d) work address and, if applicable, work email address.

3 The following information in respect of the practitioner who prescribed the substance or obtained the substance from the pharmacist:

(a) name;

(b) the license or registration number assigned to the practitioner in the province or territory in which they received the request.

4 The following information in respect of the dispensing of the substance:

(a) the date on which the substance was dispensed;

(b) an indication of which of the following locations describes where the pharmacist dispensed the substance or, if they dispensed the substance elsewhere, a description of that location:

(i) hospital pharmacy,

(ii) community pharmacy.

**Comments:**

Sufficient data need to be gathered to link the dispensed drugs to the person who made the request for medical assistance in dying. If the person does not have a health insurance number, some other identifying datum (such as a passport number) must be substituted.

In section (2)(b), the highlighted text can be removed.