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The Standing Committee on Justice and Human Rights,

House of Commons, 131 Queen Street, 6-07

Ottawa, ON, K1A 0A6

Dear Committee Members,

As a transfusion medicine specialist and clinical hematologist engaged professionally in hemovigilance, I perceive serious gaps in C-14 and propose **more specific monitoring mandates** in physician-assisted suicide or voluntary euthanasia, henceforth referred to as *medical assistance in dying* (MAID). I am mindful of the fact that nearly 20 years after the recommendations of the Krever Commission, the re-construction of a federal blood system with provincial implementation through hospital transfusion services was neither a rapid (nor as yet fulfilled) response. **MAID**, by virtue of its **consequence** and **novelty within a system which at the outset is strained in its preparedness**, calls for substantial diligence in its proper and transparent characterization.

Section 241.31 speaks to requirements for filing information, with 241.31(3) giving the Minister of Health the discretion to make regulations “respecting the use of that information, including its analysis and interpretation, its protection and its publication and other disclosure.” The proposed amendment would be “respecting the use of that information, FOR VIGILANCE PRACTICE AND REPORTING,...”, in each of the following ways (and for each of the associated reasons):

1. **Explicit benchmarks are required to ensure that MAID rates do not reach unacceptable levels.** If MAID comes to account for >4-5% deaths as it does in the BeNeLux experience, this would be tantamount to a leading cause of death in Canada, given that all 8 causes after the top two (ie-cancer at 30%, heart disease at 20%) exhibit 1-5%-range-accountabilities. Although the sentiments of Canadians towards MAID may be more agreeable (than not), whether a rate of 4-5% represents a signal which ought not to be exceeded is unclear. Citizens and public health leaders have not yet provided input on whether MAID should be temporarily halted for jurisdictional assessment if exceeding a pre-established (or precedent-guided) frequency limit. If MAID rates vary from jurisdiction to jurisdiction, thresholds of significant variance should be defined, with considerations for different limits in vulnerable areas or populations such as those with high pre-existing suicide rates. The assessment of global and regional statistical frequencies at pre-defined intervals and within stated limits is advised, especially from the federal vantagepoint bearing a power for wide views.
2. **MAID rates must be contextualized by other “intentional killing” rates.** To the extent that *homicide* and *suicide* rates are reported, *MAID* rates must be reported likewise, with interval assessments for directly or inversely correlated trends in all three phenomena, so as to detect evidence of life-terminating behaviour changes within jurisdictions (ie- all rates increasing in parallel), and/or the possibility of concealed cross-over (ie- homicide and suicide rates decreasing by virtue of their absorption within fraudulent MAID activities), with particular attention to socioeconomic demographics. Pre-defined signals of concern should be set, with stopping rules for MAID if rate-boundaries cross.

3. **Oversight structures must be built from the bottom up, for institutional to provincial/territorial to federal data**

review: High risk activities and/or increasing (or leading) causes of death are of public health interest; MAID qualifies in both regards. MAID calls for the standardized formation of facility-based oversight committees to interrogate and regularly report on the quality and quantity of these activities. Institutional reviews must occur at a regular frequency (minimum on a quarterly basis, and not wider than one year intervals).

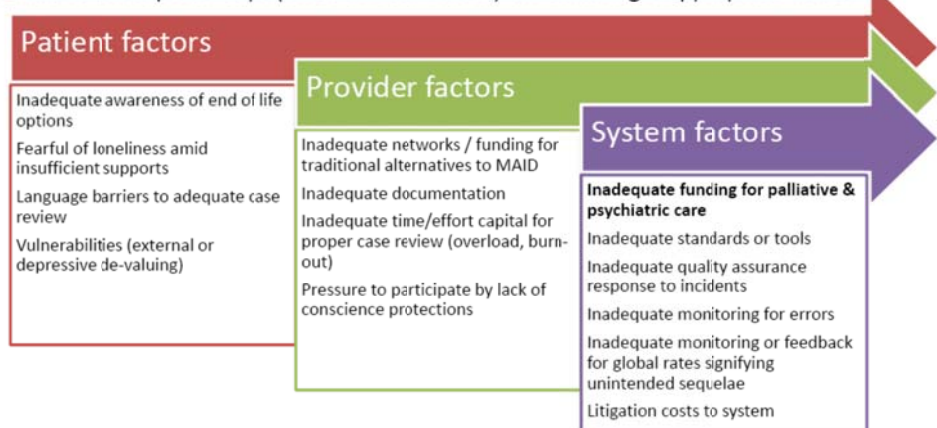
- a. **Essential documentation** itself is subject to flaws (with incomplete and/or incorrect information), be this in death certificates and/or in the antecedent consent forms and clinical assessments of vulnerability and mental health. As with transfusion medicine standards, *accredited hospitals must be engaged in serial audits* to examine the quality and adequacy of the narrative chain of discoverable information in each case of MAID.
- b. The frequency of MAID must be quantified against case referral volumes, with sufficient documentation to analyze **temporal management and outcome profiles**, as these may reveal signals of potentially inappropriate speeds or access-inconsistencies in a zone of assessment:
 - i. time from referral to assessment for MAID (and whether or not the choice of physician-assisted suicide or voluntary euthanasia is made, and whether or not this choice is maintained or switched from one to the other)
 - ii. post-referral outcomes, eg:
 1. time to completion of requested mode of MAID from assessment time, vs
 2. time to natural death if the MAID request still pending, vs
 3. time from assessment to the decision to withdraw the MAID request, with the ensuing outcome:
 - a. time to natural death, or
 - b. survival at the analysis point (reporting time)
- c. Because the time required to engage in each phase of referral, assessment, qualification, and action remains unknown in Canada, particularly with respect to **best-practices-expectations for all choices** (eg. *time to referral for mental health assessment, time to referral for palliative care assessment*, and time from MAID referral to termination of life [as per 3.b.]), these intervals represent the most basic units by which to set standards, ascertain regional variations, and prioritize resource allocations for services that may be lacking, especially if MAID becomes a high-speed default.
- d. **Medical errors** and preventable adverse events are a leading cause of death, and interventions applied to misidentified patients are also a frequent occurrence. For an act whose end is lethal, with virtually no capacity for course-correction in an unintended recipient, high attention to a spectrum of errors is merited, with failure modes effect analysis (FMEA), in keeping with the standard of all critical incident reviews in healthcare. Error surveillance provides a surrogate measure for the quality of the activity's general performance, and its sensitivity is maximized when incorporating near-miss events as well. As with transfusion error surveillance systems, MAID cases should be tracked for:
 - i. **prescribing incidents** (incorrect dose, incorrect timing);
 - ii. **evidence of unsatisfactory positive patient identification (PPID) activity**, abiding by the minimum blood administration/human tissue & transplantation standard (of a two-person check and/or machine-readable identification technologies), with reporting and management of any PPID failure, irrespective of outcome, as a critical event;
 - iii. **retraction contingencies**: MAID may be a multi-stage process, and if a recipient wishes to abdicate termination of life, the best possible resuscitation/reversal care protocols must be established and enacted, with FMEA and reporting of such events and their outcomes to the oversight committee.

- e. **Prescription accountability.** As with blood system traceability standards (and increasing rigors in controlled-substance [eg. narcotic] accounting), the disposition of all drugs prescribed in MAID must be reconciled, and unused materials repatriated expeditiously, particularly for dispensed oral drugs for physician assisted suicide in homes and hospices. Failure to achieve evidence of post-release-return is grounds for the suspension of an institution’s privilege to offer MAID. The obvious concern is deliberate consumption and/or illegal trade of lethal drugs by proximal agents (kin and/or healthcare workers), the incidence of which should also be a reportable event of interest.
 - f. **Litigation.** The burden of legal cases (by kin or “support persons” against healthcare practitioners and/or institutions involved in allegedly inappropriate MAID) is another metric of significance for system impact analysis, as is the evolution of settlements in Canada’s litigation economy. Pre-emptive judicial review might better mitigate this outcome, and assure more thorough case assessment.
 - g. **Practitioner competency/safety/volume.** MAID is not provided without formally defined requirements for its practitioners, including criminal record re-screening to validate licensing records at a minimum, and evidence of sufficient practice networks with mental health and palliative care services.
4. **The capture of such data, and its availability for analysis, calls for the construction of a national registry.**
 To the extent that a registry or database may be developed, and in emulation of Canadian hemovigilance (in the Transfusion Transmitted Injuries Surveillance System [TTISS]), an electronic platform is best suited to capture anonymized data from 1-3, by data officers in MAID teams based at institutions, enabling the pooling of data at the P/T and federal level for timely analysis. Data moves upwards after submission deadlines (eg. one quarter after the previously completed year), enabling trend review and a national response to any signals of concern, as per the aforementioned metrics and benchmark thresholds.
5. **Disaster Preparedness and Access to MAID.** Hurricane Katrina challenged New Orleans and provoked acts of euthanasia of dubious voluntariness. Hospitals are required to develop disaster plans, which may include reverse triage (ie- restricting limited healthcare resources/services to those most likely to survive, rather than to the sickest who are already nearest to death). The role of MAID in reverse triage must be specified, be this a complete and temporary ban on the activity (due to limitations in capacity to meet assessment goals), and/or statements on whether or not antecedent obligations can be waived. The standards for access to MAID should not be relaxed if the retrospective review of appropriateness is technically impossible. Euthanasia may otherwise be repurposed as a tool of eugenics in challenging environments.

Case- and system-based gaps may permit inappropriate acts of MAID, as summarized in this fishbone figure:

Thank you for the opportunity to express concerns and to offer **specific federal vigilance suggestions** so that this system is conscientiously executed with **strong accountability and warning power**. HIV was in our blood supply for a good decade before an approved interdiction test became broadly available. We do not want another national tragedy to unfold, for lack of foresight and monitoring.

Fishbone Concept for Gaps (Swiss Cheese Model) in Permitting Inappropriate MAID



Sincerely,