

Submission to:
Pan-Canadian Discussion Forum on Medical Assistance in Dying (MAiD):
Information Needs for Health Systems and Public Reporting
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Submission from:
Vulnerable Persons Standard Secretariat
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1. Why is a conversation about MAiD information needs for health systems and public reporting a priority for you?

The Vulnerable Persons Standard (VPS) Community includes: i) over 50 VPS Advisor experts in law, clinical practice, medical ethics and disability studies; and ii) over 50 VPS Supporting Partner organizations, which include local-to-national membership organizations representing the voices of people with disabilities, other marginalized groups, health professionals, and faith-based organizations. Our shared purpose is to ensure robust safeguards to protect persons who may be vulnerable to being induced or coerced to request and consent to MAiD and to guard against the perpetuation of prejudice, stigma and harmful stereotypes in our social and cultural ethos. More information about the Vulnerable Persons Standard, Founding Advisors, supporting organizations and information resources can be found online at www.vps-npv.ca.

Fundamentally, the VPS community conceptualizes the collection and reporting of MAiD as a weighty responsibility that extends well beyond the strict domain of conventional population health data. We take seriously the affirmations contained within the preamble of Canada's new law, in particular that "... robust safeguards, reflecting the irrevocable nature of ending a life, are essential to prevent errors and abuse in the provision of medical assistance in dying". The conversation which CIHI is convening must be understood within the larger context of Canadian and international human rights norms. It is not a mere technical exercise, but a venture in human rights monitoring that must be open, transparent and highly participatory¹, and must build public confidence in a system that neither produces nor reproduces disadvantage, social violence or structural inequality.

VPS members have an over-riding interest to ensure availability of extensive, publicly accessible information on which to reliably monitor the impacts of MAiD on Canadian society and the capacity of the MAiD system to differentiate between fully capable and autonomous requests, on the one hand, and requests influenced by vulnerability, inducement

¹ See for example, Marcia H. Rioux, Paula C. Pinto, Gillian Parekh (2015), *Disability, Rights Monitoring, and Social Change: Building Power out of Evidence*, Canadian Scholars Press

or coercion by external forces on the other hand. This interest is formulated in light of the Supreme Court of Canada's decision in *Carter v. Canada*, recognizing: 1) that Parliament's objective to protect vulnerable persons from being induced to commit suicide in a time of weakness was of "high importance";² 2) that Parliament "must weigh and balance the perspective of those who might be at risk in a permissive regime against that of those who seek assistance in dying";³ and, 3) that "the risks associated with physician-assisted death can be limited through a carefully designed and monitored system of safeguards."⁴

Moreover, we emphasize the need for such information in light of the fact that there is no systematic, universal approach to assessing for vulnerability to inducement or coercion, although the federal legislation requires that the person must meet the criterion that the request "was not made as a result of external pressure".⁵ This is a new standard for informed consent in Canadian health law and, accordingly, imposes a higher standard of assessment of possible 'external pressures' than is currently required. In fact, only five provincial/territorial jurisdictions in Canada have a statutory framework for health care consent for adults (British Columbia, Ontario, Québec, Prince Edward Island, and the Yukon). Québec's *Act Respecting End-of-Life Care* is the only jurisdiction which requires the higher standard for informed consent in the context of MAiD, and states that responsible health professionals must make sure the request for MAiD "is being made freely, in particular by ascertaining that it is not being made as a result of external pressure."^{6 7}

As well, there is a preambular commitment in the federal legislation authorizing MAiD to ensure "the most appropriate balance between the autonomy of persons who seek medical assistance in dying, on one hand, and the interests of vulnerable persons in need of protection and those of society, on the other..."⁸

2. Organizations and jurisdictions from across Canada are at various stages in their work to address MAiD.

- **What kind of work is taking place in your organization/jurisdiction?**
- **What do you hope to learn at this event to inform your approach?**

See response to Question 3 below. We are not directly involved in the event and are not presently resourced to undertake the research, education, policy and advocacy work mandated by VPS membership consensus.

² *Carter v Canada (Attorney General)*, [2015] 1 SCR 331 at para 90.

³ *Ibid* at para 98.

⁴ *Ibid* at para 117.

⁵ *Ibid* s 241.2 (1)(d).

⁶ Québec, *An Act Respecting End of Life Care*, chapter S-32.0001, s. 29(1)(a).

⁷ For a discussion of research evidence on forms of coercion, inducement and external pressure in systems for physician-assisted death, see Canadian Association for Community Living (2016), "Assessing Vulnerability in a system for physician-assisted suicide and voluntary euthanasia in Canada" (online: <http://www.cacl.ca/sites/default/files/uploads/CACL%20Vulnerability%20Assessment%20Apr%208%202016%20-%20Final.compressed.pdf>).

⁸ *An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)* SC 2016, c 3.

3. When it comes to MAID-related information needs, which stakeholders do you serve (e.g. physicians, nurses, pharmacists, patients, their families, the public, facility governance or oversight, ministry of health)? What are their information needs? What are your information needs?

In order to ensure publicly-available information to address the concerns about persons who may be vulnerable to being induced or coerced into requesting and giving consent to the intervention, the following kinds of information are required:

- Detailed socio-demographic information about all persons requesting this procedure, including but not limited to age, gender, marital status, living arrangements, ethnicity, immigrant status, Indigenous status, social network⁹, education, income, main activity (going to school, working, looking for work) and identification of any recent changes in status related to these elements;
- Particulars of the medical condition for which such assistance was sought including but not limited to date of diagnosis of the “grievous and irremediable” medical condition, other medical conditions, nature and extent of disability (DSQ);
- Detailed reasons why the physician or nurse practitioner concluded that the person’s natural death was reasonably foreseeable;
- A fulsome report of the nature of the person’s suffering, explicitly addressing not only physical and psychological suffering, but also social, spiritual and existential forms of suffering;
- A report of all measures offered, accepted or declined to alleviate the person’s suffering;
- An inventory and assessment of all disability-related supports (personal, social, cultural and technological) made available to the person;
- An assessment of any communication barriers and accommodations required and provided at all stages of the process;
- A comprehensive assessment of the person’s potential vulnerabilities to inducement to suicide;
- An explicit articulation of the person’s reasons for making this request;
- The results of an appropriate palliative care consultation;
- A report on whether the person was found capable to provide informed consent to medical assistance in dying;
- A record of measures taken to determine that the patient was not subject to coercion or external pressure, including any attempts made to obtain collateral information;
- A record of the patient’s current medication at the time of giving consent, including any medications which have sedative properties that might affect the consent process;
- A record of the outcome of the process, i.e., whether the person chose to proceed with an assisted death; if **Yes**, the form of assistance provided and if **No**, description of any changes of circumstance, treatment, support or other intervention understood to have played a significant factor in the person’s choice not to proceed;
- Identification of the physicians and/or nurse practitioners involved in the assessment and administration process.

⁹ The importance of understanding the extent to which a person has or does not have a robust social network is underscored by a recent study of euthanasia among persons with psychiatric diagnoses in the Netherlands, indicating that most of these people were socially isolated or lonely. See Scott Y. H. Kim et al. (2016) Euthanasia and Assisted Suicide of Patients with Psychiatric Disorders in the Netherlands 2011 to 2014. JAMA Psychiatry, 2016;73(4):362-368, online: <http://jamanetwork.com/journals/jamapsychiatry/article-abstract/2491354>

All of this data, both quantitative and qualitative, must be anonymized and made publicly available in a timely manner and in formats that are accessible to laypersons and useful for researchers. For statistical purposes, it is recognized that much of the rich information obtained through patient interviews and clinical notes will be summarized. However, **the VPS community should play an integral role in the development of appropriate coding structures and evaluation of those structures.**

We would emphasize in this regard that the information needs of Canadians, and of the VPS community in particular, are not purely statistical. Richly textured data, such as that obtained through qualitative methods of inquiry (patient interviews, clinical notes, etc.) are an essential basis for understanding the individual and social impacts of medical assistance in dying. The development of a system that provides access to these detailed data by members of the VPS community is essential.

Entirely new methods of data collection and analysis may indeed be called for, in order to ensure that the complexity and nuance of MAiD-related data do not trigger exclusion or eliding of “outlier” data¹⁰. As Sally Engle Merry has written: “insiders with skills and experience have a greater say in developing measurement systems than those without—a pattern that excludes the inexperienced and powerless.”¹¹ The VPS community urges CIHI and its collaborators to approach this process in such a way as to guard against such exclusion.

4. Assuming data to support legal monitoring requirements for MAiD (e.g basic counts, eligibility criteria and safeguards) are already available, what other MAiD-related health system questions should we be able to answer in three to five years?

Consider the following areas:

- Patient journey**
 - Care trajectory, care experience and quality of care**

See response below re health system responsiveness

- Clinicians and support teams experience**
 - Training and preparation, support, mental and physical experience**

The phrase “training and preparation” would suggest a MAiD-specific orientation, which is appropriate and important and worthy of research. In this regard, we would emphasize the critical importance that clinicians demonstrate ability to determine vulnerability to coercion and external pressure across diverse socio-economic and disability-related demographics.

We would argue as well for careful attention to the broader questions of ethics and values in healthcare education, meaningful exposure and interaction with marginalized groups and robust attention to the humanities in medical education¹². Each of these areas are equally worthy of attention and research.

¹⁰ See Jutta Treviranus (2014) “The Value of the Statistically Insignificant”, Educause Review, online: <http://er.educause.edu/articles/2014/1/the-value-of-the-statistically-insignificant>

¹¹ Merry Engle, S. (2016) *The Seductions of Quantification: Measuring Human Rights, Gender Violence, and Sex Trafficking*. Chicago: Univ. of Chicago Press.

¹² See Ben Utter and Lesley Curtis (2016), “What Your Literature Professor Knows That Your Doctor Might Not: A Review of Paul Kalanithi’s *When Breath Becomes Air*”, *Vital*, online: <https://the-vital.com/2016/09/06/literature-professor-knows-doctor-might-not/>

□ **Health system responsiveness**

- **access, effectiveness, safety, comprehensiveness, integration of services**

Availability of high quality palliative care, psychological and spiritual counselling, qualified translation and interpretation, appropriate communication supports, disability and home care supports, assistive technologies, peer support, animal companionship and other interventions that build resilience, alleviate suffering, and enable persons to continue to flourish until their time of natural death.

□ **Health system resources**

- **human, financial, infrastructure, pharmaceuticals**

5. From a pan-Canadian perspective, what MAID-related health system questions require comparable information?

Health systems should be able to provide comparable information on the following questions to ensure that vulnerability is being systematically identified, assessed and responded to:

1. Were persons motivated by factors other than the medical condition and associated suffering?¹³
2. Were there psychosocial factors motivating requests, which could be addressed by alternative courses of action?
3. Were there any dynamics of inducement, coercion or undue influence underlying requests – whether through disordered insight and self-stigma, direct coercion or inducement by others, or because of the psychodynamics of the patient’s relationship to health care or social service professionals and systems?
4. Did those requesting MAiD have low resilience to factors that could be motivating the request, other than the medical condition itself¹⁴?
5. Were persons requesting and approved *potentially* vulnerable to being induced to commit suicide in a time of weakness because of the range of factors that could motivate the request for PAD, or were persons *actually* vulnerable as a result of these factors?

These questions constitute a ‘vulnerability lens’, and are based on work conducted by the Canadian Association of Community Living, a VPS supporting organization, reviewing international research on vulnerability and factors associated with external pressures to request and consent to physician-assisted death.¹⁵ Checks and balances are required to ensure consistent application of this lens for vulnerability assessment and pan-Canadian comparable information sets are essential for this purpose.

¹³ This distinction was identified in the original trial in *Carter. Carter v. Canada (Attorney General)*, 2012 BCSC 886 at paras 813-814. It is further discussed in Canadian Association for Community Living (2016), “Assessing Vulnerability in a system for physician-assisted suicide and voluntary euthanasia in Canada” (online: <http://www.cacl.ca/sites/default/files/uploads/CACL%20Vulnerability%20Assessment%20Apr%2008%202016%20-%20Final.compressed.pdf>).

¹⁴ *Supra*, note 9.

¹⁵ *Ibid.*

Without such data, there is very real risk that factors will not be identified that lead people to request and consent to MAiD in a manner that violates the *Criminal Code* prohibition to assisted suicide where the eligibility criteria go unmet. This includes adults who may appear to meet the criteria for PAD but whose suffering is, in fact, substantially related to other factors that induce suicidal ideation and intent and which may underlie an adult's experience of enduring and intolerable suffering. It also includes adults who, because of other factors in their lives or in the dynamics of the relationship with their physician, are actually victims of subtle, unconscious or explicit inducement or coercion in the request for MAiD.

6. What is your biggest challenge related to health system information and public reporting related to MAiD?

We believe the biggest challenges are:

- consistency in data collected across provinces/territories;
- consistency in the methods used to analyse and code the qualitative information
- participation of informed civil society players and VPS community experts in the development of coding structures for qualitative data;
- availability of the "raw" data to researchers from the VPS community and other civil society players with expertise in social vulnerability and disadvantage;
- ongoing unbiased data from the population at large to measure attitudes towards MAiD using survey instruments such as the General Social Survey, the Canadian Community Health Survey, the supplementary capacity of the monthly Labour Force Survey and the Canadian Survey on Disability;
- integration of data related to social determinants of health with clinical data gathered through health systems.

7. What, if any are the most pressing challenges we should tackle together?

It will be essential to create standardized questions and tools for identifying and assessing vulnerability as outlined in our responses above, and to be innovative and inclusive with regards to methodologies and approaches. Working with a wide range of health institutions and across provincial-territorial governments will certainly pose challenges. Clear leadership from the federal government in regulations to the federal *Act* that are in keeping with the preamble to that Act, would help establish the context and framework for needed collaboration. Time is of the essence, since the present patchwork of regulatory approaches and the complete absence of meaningful data puts many Canadians at risk and threatens to undermine the public confidence upon which any system of medical assistance in dying must be founded.