

# End-of-Life Decision Making: Policy and Statutory Progress (2011-2020)

*October 2020*



*An RSC Policy Briefing*

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### **Cover Art**

Liz Ingram, FRSC, *Ultimate Synthesis: Finite Source V* (2008)

Inkjet, etching, drypoint and chine-collé

The human body and the elemental in nature are recurring sources for Liz Ingram's art practice which investigates transitional states between material presence and the ephemeral, and issues relating to the fragility of life and the environment. In an attempt to reawaken an experiential understanding of our fundamental connections with nature, she often uses images of glistening water and the human body sourced from a lake and stream in the boreal forest of Alberta. With the aid of the printed image, paper and ink, Liz wishes to give the viewer an experience that will celebrate the cycle of life and the wonder of water, this endangered substance that is so essential to existence. Her work represents an attempt to highlight the elemental aspect of water to all life forms, while emphasizing our fundamental connections and oneness with the natural world.

### **Land Acknowledgement**

The headquarters of the Royal Society of Canada is located in Ottawa, the traditional and unceded territory of the Algonquin Nation.

***The opinions expressed in this report are those of the authors and do not necessarily represent those of the Royal Society of Canada.***

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## Background on the Policy Briefing Report Process

In 2009, the *Royal Society of Canada (RSC)* identified a series of urgent scientific and public policy questions and established a series of Expert Panels to study the issues and provide recommendations for next steps. The series began with the Expert Panel on *Health and Environmental Impacts of Canada's Oil Sands* (2010). This was followed by *End-of-Life Decision Making* (2011); *Sustaining Canada's Marine Biodiversity* (2012); *Early Childhood Development* (a partnership with the *Canadian Academy of Health Sciences*) (2012); and *Canada's Libraries, Archives and Public Memory* (2014).

What has been the impact of these reports? Have their recommendations been implemented? What are the next steps in terms of policy options? These questions are all at the heart of the current Strategic Plan of the *RSC*. In keeping with the *RSC's* Strategic Priority to implement a sharpened focus for contributing advice on specific themes, it is now timely to revisit the findings of recent *RSC* Expert Panels.

To do so, the *RSC* is establishing a Policy Briefing Committee (PBC) for each of the original Expert Panel reports. Each PBC will include new voices, such as members of the *RSC College of New Scholars, Artists and Scientists* and others, such as public policy practitioners and NGO (Non-governmental Organization) leaders, with a view to enhancing the focus on policy developments.

The mandate of each PBC is to: (a) describe the context, findings and recommendations of the *RSC* Expert Panel report; (b) track the public policy developments since publication in the context of the panel's findings and recommendations; and (c) identify the policy issues (and leading options) that lie ahead.

An important distinction from the work of each original Expert Panel is that the PBCs will not undertake reviews of the scientific literature since publication of the Expert Panel reports, but instead focus on matters with respect to findings and recommendations issued by the reports and public policy developments since then.

## Overview of the 2020 Policy Briefing Committee Report on End-of-Life Decision Making

This PBC report comprises four parts.

Part I provides a brief review of the 2011 Expert Panel Report, describing its motivation, mandate, objectives, and findings.

Part II examines the impact of the Expert Panel Report through its influence on subsequent legal decisions and public policy deliberations.

Part III—the main body of the report—tracks public policy developments since 2011 in the context of the Expert Panel's findings and recommendations. The PBC report follows up on the six modes of end-of-life care which the Panel investigated and for which it made recommendations: withholding and withdrawal of potentially life-sustaining treatment; advance directives; palliative care; potentially life-shortening symptom relief; terminal sedation; and assisted suicide and voluntary euthanasia

Part IV identifies ongoing policy challenges in these six areas and the further steps that would be needed to implement the Panel's recommendations.

The PBC acknowledges with thanks the research assistance provided by Simon Giasson.

## Executive Summary

### Overarching Findings of the 2011 Expert Panel

- Clarification is needed of the legal, ethical, and clinical status of withholding and withdrawing potentially life-sustaining treatment, especially where mature minors are concerned, and where treatment is withheld or withdrawn unilaterally by physicians.
- Research, education, and governmental resources are needed to facilitate advance care planning (including advance directives) by members of the public.
- Initiatives are needed to ensure better access to palliative care and to expand palliative care beyond cancer care to other areas of need.
- Legal guidelines and educational programs are needed regarding the administration of potentially life-shortening symptom relief.
- Legal clarification, clinical guidelines, and public education are needed regarding the practice of terminal sedation.
- Canada should have a permissive yet carefully regulated and monitored system with respect to the provision of assisted suicide and voluntary euthanasia.

### Impact of the 2011 Expert Panel Report

- The Report has been cited numerous times in the scholarly end-of-life literature, in policy documents, and in the media.
- The Report was cited by the trial judge in *Carter v Canada (Attorney General)*, the case that led to the legalization of Medical Assistance in Dying (MAiD) in Canada.
- There have been many subsequent developments in end-of-life policy and law in Canada that align with the Report's recommendations.

### Policy and Statutory Developments since the 2011 Expert Panel Report

#### *Good progress:*

- Research on advance care planning
- Resources to facilitate advance care planning
- Legalization of MAiD through Bill 52 (Quebec) and Bill C-14 (federal Parliament)

#### *Moderate progress:*

- Efforts to expand access to palliative care

#### *Limited progress:*

- Some attempts to clarify the legal status of withholding and withdrawal of potentially life-sustaining treatment, the mature minor rule for end-of-life decision-making, and unilateral withholding and withdrawal of potentially life-sustaining treatment
- No attempts by governments, prosecutors, or regulators to clarify the legal status of terminal sedation, except in Quebec

*No progress:*

- No guidelines or educational initiatives regarding potentially life-shortening symptom relief

## **Tracking Policy and Statutory Progress Since 2011**

### ***Expert panel recommendations on withholding and withdrawal of potentially life-sustaining treatment***

*Limited progress:*

There has been no clarification of the legal status of withholding and withdrawal of potentially life-sustaining treatment by statutory amendment or by prosecutorial guidelines. However, the need for such clarification is now arguably less pressing due to statements made by the courts and by the federal Justice Department counsel. Legislators and government departments did not address the need for clarification with respect to the mature minor rule for end-of-life decision making. However, other organizations have offered clarifications for their members, clients, or communities. There remains a need to resolve the differential treatment of MAiD for mature minors and other health care decision making (including decisions with the consequence of ending life) for mature minors. The Expert Panel's concerns about the confusion, conflict, and controversy surrounding unilateral withholding and withdrawal of potentially life-sustaining treatment remain valid and inadequately addressed.

### ***Expert Panel Recommendations on Advance Directives***

*Good progress:*

More research has been conducted into advance care planning and efforts have been made by both governmental and non-governmental actors to develop resources to foster such planning.

### ***Expert Panel Recommendations on Palliative Care***

*Moderate progress:*

Progress has been made by governments, health care institutions, and health care providers toward ensuring that high quality palliative care is accessible to individuals that need and want it, including expanding palliative care beyond cancer.

### ***Expert Panel Recommendations on Potentially Life-Shortening Symptom Relief***

*No progress:*

The concerns that motivated the Expert Panel's recommendations regarding potentially life-shortening symptom relief remain valid and have not yet been addressed.

## **Expert Panel Recommendations on Terminal Sedation**

### *Limited progress:*

The concerns identified in the Expert Panel Report remain valid and have not yet been addressed anywhere other than in Quebec (and, even in Quebec, only for a subset of the types of sedation identified in the Report).

## **Expert Panel Recommendations on Assisted Suicide and Voluntary Euthanasia**

### *Good progress:*

MAiD has been legalized in Canada, under carefully circumscribed circumstances, first by statute in Quebec (Bill 52) and then by amendments to the *Criminal Code* (Bill C-14). However, many of the concerns identified by the Expert Panel remain valid:

- Exclusion of persons not at the “end of life” (Quebec) or whose natural death is not “reasonably foreseeable” (*Criminal Code*);
- No provision for advance requests;
- Exclusion of mature minors;
- 10-day waiting period.

The federal government took further steps toward bringing the law closer to the Expert Panel recommendations in Bill C-7. If passed as introduced, it would allow for advance requests for MAiD by persons who have been assessed and found eligible where their natural death has become reasonably foreseeable and would eliminate the waiting period for such persons. However, other significant inconsistencies with the Expert Panel recommendations would still remain, especially the exclusion of mature minors. There is also an explicit exclusion of persons with mental illness from the eligibility criterion of serious and incurable illness. Furthermore, Bill C-7 stipulates a 90-day waiting period for those whose natural death has not become reasonably foreseeable. There also remains a need for a national oversight commission to monitor and report annually and publicly on MAiD in Canada. The federal government has undertaken to study the issues of advance requests and mature minors further in its five-year review of the legislation.

## **Ongoing Policy and Statutory Challenges**

### ***Withholding and withdrawal of potentially life-sustaining treatment***

Meeting the Expert Panel recommendations would require the following steps:

- provision of a statutory clarification by all provincial/territorial governments that do not currently provide clarity with respect to consent and mature minors;
- the federal government making a choice between permitting MAiD for mature minors (through amendments to the *Criminal Code*) and justifying treating decision making about MAiD differently than other health care decision making (including decisions with the consequence of ending life) for mature minors;
- provincial/territorial governments clarifying when, if ever, health care professionals have the legal authority to unilaterally withhold or withdraw potentially life-sustaining treatment;

- health care professional regulators (other than Manitoba, Ontario, and Quebec) amending their policies to make it clear when, if ever, health care professionals have the legal authority to unilaterally withhold or withdraw potentially life-sustaining treatment;
- health care regulators providing clinicians with more guidance in this area;
- health care professional educational institutions providing education to trainees and practitioners in this area.

### **Palliative care**

Efforts are still needed to ensure that high quality palliative care is accessible to individuals who need and want it and that palliative care continues to be expanded beyond cancer.

### **Potentially life-shortening symptom relief**

Efforts are still needed to clarify the legal and clinical status of the use of potentially life-shortening symptom relief for individuals who are experiencing enduring, intolerable, and irremediable suffering but are not eligible for MAiD.

### **Terminal sedation**

To meet the Expert Panel recommendations the federal government would need to revise the *Criminal Code* to make it clear that palliative sedation in circumstances where it *will* hasten death is MAiD for the purposes of the *Criminal Code*, and is subject to the same procedural conditions and requirements as other forms of MAiD, and that palliative sedation in circumstances where it only *may* hasten death is not MAiD for the purposes of the *Criminal Code*.

The ongoing areas of concern—which include differences in clinical and legal definitions of palliative sedation, lack of data concerning its incidence and prevalence, as well as the ambiguities concerning what does and does not hasten death—indicate the need for collaboration between government, legal bodies, health care professional regulators, and clinicians in establishing legal and clinical standards that are clear to patients, clinicians, and the courts.

### **Assisted suicide and voluntary euthanasia (now known as MAiD)**

Meeting the Expert Panel recommendations would require the following steps:

- the federal Parliament amending the *Criminal Code* and the Quebec National Assembly amending their *Act respecting end of life care* to permit respecting requests for MAiD made while capable but in advance of loss of capacity;
- the federal Parliament and Quebec National Assembly each amending their legislation to allow mature minors to access MAiD;
- the federal Parliament *not* amending the MAiD legislation to exclude all persons with mental illness as their serious and incurable illness, disease, or disability;
- the federal Parliament amending the MAiD legislation to remove the 10-day waiting period for all and *not*, as proposed, adding a 90-day waiting period for patients whose natural death is not reasonably foreseeable;
- the Colleges of Physicians and Surgeons and Colleges of Nurses that have not already done so including a duty of effective referral or transfer of care in their professional standards;



- the federal Parliament establishing a national oversight commission to monitor MAiD requests, work collaboratively with the Quebec's End of Life Care Commission and report annually and publicly on MAiD in Canada.

# Part I: The 2011 Expert Panel Report on End-of-Life Decision Making: A Brief Review

## 1.1 Setting the Stage

The appointment of the RSC Expert Panel was motivated primarily by continuing public interest in the question whether to legalize (what has subsequently come to be known as) medical assistance in dying (MAiD). At the time both forms of MAiD—provider- and self-administered (then known as voluntary euthanasia and physician-assisted suicide respectively)—remained prohibited activities under the *Criminal Code of Canada*, while one or the other, or both, had become legal in Belgium, Colombia, Luxembourg, the Netherlands, Switzerland, and three U.S. states.

Public support for legalizing MAiD had been high for a number of years and was continuing to increase. However, the issue remained very contentious and opinion on it highly polarized. Legalization had not been addressed by the courts since the 1993 Supreme Court decision in *Rodriguez*,<sup>1</sup> and not by any governmental body at the federal level since a 1995 report by the Special Senate Committee on Euthanasia and Assisted Suicide.<sup>2</sup>

Several sporadic attempts to amend the law had been made in Parliament in the intervening years, none of them successful. However, in October 2009 the Collège des médecins du Québec published a discussion paper on “Physicians, Appropriate Care and the Debate on Euthanasia”<sup>3</sup>, based on the analysis of its working group on clinical ethics. The group argued that assistance in dying could be understood as appropriate end-of-life care when no other therapeutic means existed to relieve a person’s suffering. This work, in part, prompted the Quebec National Assembly to establish a Select Committee on Dying With Dignity two months later.

Clearly, the issue had once again become timely.

The Expert Panel decided not to examine the legalization of MAiD as a stand-alone question. Instead, it saw MAiD as but one form of end-of-life care, construed broadly as patient care either when death is imminent or when the patient has decided that their medical condition has made their continued life not worth living. Important ethical, social, and legal issues also arise for other forms of such care: withholding and withdrawal of potentially life-sustaining treatment, advance directives, palliative care, potentially life-shortening symptom relief, and terminal sedation. The Expert Panel Report therefore comprised end-of-life care as a whole.<sup>4</sup>

## 1.2 Panel Mandate

The Expert Panel was asked to undertake four tasks:

1. Examine and summarize the extensive medical and social-science evidence concerning all of these issues.
2. Present evidence about experience in the various jurisdictions that have legalized some form of MAiD.
3. Provide a careful, balanced review of the pros and cons of legalizing MAiD in Canada.
4. Formulate policy recommendations on all of these issues for public consideration.

To carry out this mandate, the Panel was composed of Canadian and international experts in bioethics, clinical medicine, health law and policy, and philosophy. The members were selected for their expertise, not for any professional role held or position on the issues.

### **1.3 Report Objectives**

The Expert Panel aimed to stimulate a new conversation about end-of-life law, policy, and practice in Canada. The Panel acknowledged that passions run deep in discussions about end-of-life matters but noted that even in the face of profound disagreements it is possible, and necessary, for those involved in the conversation to listen carefully to all positions presented and to work together to find a policy position consistent with the core features of Canada's parliamentary democracy and the *Charter of Rights and Freedoms*. Finally, the Panel hoped that, through this conversation, all stakeholders would be able to find common ground to better respond to the wishes and needs of Canadians at and for the end of their lives.

### **1.4 What Did the Expert Panel Find?**

The Expert Panel Report began with an extensive review of the existing evidence concerning social attitudes and practices with respect to the various forms of end-of-life care in Canada, then transitioned to an overview of the legal status of those practices that carry the potential to hasten death. On the ethical issue, the Panel argued that the core values central to Canada's constitutional order, especially the value of autonomy, provide a strong argument for a moral right to choose MAiD, and that arguments supporting the limitation of this right are flawed. The Panel therefore contended that Canada should have a permissive yet carefully regulated and monitored system with respect to the provision of MAiD.

The Panel concluded with some thirty recommendations for reform with respect to the full range of end-of-life care, among them detailed proposals for an appropriate system for the provision of MAiD. The recommendations, of necessity, were directed at a range of agents, since in Canada the jurisdiction over these activities is dispersed among different levels of government and sectors. Many called for legal reforms, while others identified the need for better education of both health care providers and members of the public concerning options at and for the end of life.

## Part II: The 2011 Expert Panel Report on End-of-Life Decision Making: Assessing Impact

The timing of the Expert Panel Report turned out to be fortuitous. It arrived in November 2011, just as arguments were being heard in *Carter v Canada (Attorney General)* in the British Columbia Supreme Court. The plaintiffs in that action were challenging the constitutionality of the two sections of the *Criminal Code* prohibiting euthanasia and physician-assisted suicide. Despite a challenge from the Attorney General of Canada, Madam Justice Lynn Smith admitted the Report into evidence “in the main for the fact that the Expert Panel made the recommendations that it did”.<sup>5</sup> In her subsequent review of the expert evidence, Justice Smith referenced the Report, noting in particular that it had “identified a number of core elements of a permissive regime”.<sup>6</sup> She later reviewed these elements in detail in the course of assessing safeguards for managing the risks of legalizing MAiD.<sup>7</sup> That assessment concluded that “the risks inherent in permitting physician-assisted death can be identified and very substantially minimized through a carefully-designed system imposing stringent limits that are scrupulously monitored and enforced”.<sup>8</sup> That conclusion, completely consistent with the contentions of the Expert Panel Report, was central to Justice Smith’s June 2012 decision that the two *Criminal Code* sections were in violation of the *Charter of Rights and Freedoms*, and therefore of no force and effect.

Both Justice Smith’s conclusion concerning the risks of legalization and her overall decision were affirmed in February 2015 by the Supreme Court of Canada, which offered Parliament a period of twelve months (later extended to sixteen months) to pass appropriate amendments to the *Criminal Code* before its decision striking down the prohibitions would take effect.<sup>9</sup> During this period two influential public bodies produced reports with recommendations on the shape of the legislation that would establish the parameters for legal access to MAiD. The Final Report of the Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying appeared in November 2015, while the Report of the Special Joint Committee of the House and Senate on Physician-Assisted Dying was released in February 2016.<sup>10</sup> Both reports featured detailed recommendations on eligibility criteria and procedural safeguards for MAiD that were very much in alignment with those made by the Expert Panel.

At the provincial level, the Committee on Dying with Dignity of the Quebec National Assembly released its report in March 2012. It too concluded that it was possible to permit MAiD in a carefully regulated regime and it explicitly referenced, and was in large measure aligned with, the findings and recommendations made by the Expert Panel. In June 2014 the Quebec National Assembly passed legislation covering most of the end-of-life issues addressed by the Expert Panel.<sup>11</sup> The legislation was again largely consistent with the Panel’s recommendations. Most recently, the 2019 report by a Quebec Expert Group on MAiD for incapable persons cited the Expert Panel Report favourably on a number of end-of-life topics.<sup>12</sup>

When Bill C-14, the federal MAiD legislation, was finally passed by Parliament in June 2016,<sup>13</sup> some of its key provisions departed from the Expert Panel’s recommendations (and from the recommendations of both the Provincial-Territorial Expert Advisory Group and the Special Joint Committee). These departures will be discussed in detail in Parts III and IV of this report.

Along with the Collège des médecins du Québec, the 2011 Expert Panel was one of the first public bodies in Canada to make a detailed and carefully reasoned case for the legalization of MAiD.

Since its release, the Expert Panel Report has been cited numerous times in the scholarly end-of-life literature, in policy documents, and in the media. It has clearly played a role in shaping public opinion and, more specifically, in the subsequent course of events culminating in the current legal regime for MAiD in Canada.

## Part III: Tracking Policy and Statutory Progress

### 3.1 Withholding and Withdrawal of Potentially Life-sustaining Treatment

**Recommendation 1:** *The federal government should revise the Criminal Code to make it clear that the withholding and withdrawal of potentially life-sustaining treatment for which there has been a legally valid refusal does not constitute criminal negligence and will not attract criminal liability.*

The *Criminal Code* has not been amended to clarify the legal status of the withholding and withdrawal of potentially life-sustaining treatment.

However, Quebec explicitly addressed this issue in its *Act respecting end-of-life care*:

5. Except as otherwise provided by law, a person of full age who is capable of giving consent to care may, at any time, refuse to receive life-sustaining care or withdraw consent to such care.

To the extent provided by the Civil Code, a minor of 14 years of age or over, and in the case of a minor or a person of full age who is incapable of giving consent, the person who may give consent to care on their behalf may also make such a decision.

The refusal of care or withdrawal of consent to care may be expressed by any means.

The physician must make sure that such a decision is made freely and provide the person with all information needed to make an informed decision, in particular information about other therapeutic possibilities, including palliative care.

6. A person may not be denied end-of-life care for previously having refused to receive certain care or having withdrawn consent to certain care.

**Recommendation 2:** *Unless or until the Criminal Code is revised as described above, prosecution guidelines should be drafted to make it clear that the withholding or withdrawal of potentially life-sustaining treatment consistent with the law will not be subject to criminal prosecution.*

No prosecutorial charging guidelines have been drafted to provide guidance on when charges will or will not, should or should not, be laid in relation to the withholding and withdrawal of potentially life-sustaining treatment.

**Recommendation 3:** *Health care professional educational institutions and regulators should ensure that their trainees and members understand their legal obligation to respect refusals of potentially life-sustaining treatment so that unwanted health services are not provided (i.e., legally valid refusals of treatment are not respected) out of misplaced fear of liability.*

#### **Educational institutions**

Respect for refusals of medical treatment—by a person with decision-making capacity, a capable substitute decision maker (SDM) for that person, and by a person without decision-making capacity in the absence of a court order (Québec only)—is a fundamental legal and ethical obligation of health care providers. Indeed, Canadian courts have repeatedly reaffirmed a patient’s right to refuse treatment, even if it is necessary to preserve life.<sup>14</sup> These legal and ethical obligations are widely taught in health care professional educational institutions.

Health care professional education is dispersed through a variety of institutions. Health care professional students learn within their universities and colleges. Some learning also takes place in clinical settings, but the individual educational institutions are responsible for ensuring that learning standards are met. For example, medical students learn in university faculties of medicine who are accountable to the accreditation standards set by the Association of Faculties of Medicine of Canada.<sup>15</sup> They are also responsible for ensuring that their students are sufficiently trained to pass the national licensing examination which is set by yet another organization, the Medical Council of Canada.

Postgraduate trainees (such as medical residents) also learn within university faculties of medicine/health science. Training standards are established and enforced by the Royal College of Physicians and Surgeons of Canada (for specialists) and the Canadian College of Family Physicians (for family physicians). For trained practitioners, several organizations, ranging from provincial and territorial medical associations, to the Canadian Medical Association, to the national and provincial specialty societies, are all involved in continuing education. These organizations operate independently from each other.

Because of the breadth of the Expert Panel's recommendation, it has not been possible for the PBC to trace subsequent educational developments on this issue across all health care professions.

## **Regulators**

Medical professional colleges throughout Canada have published standards of practice related to refusal of consent for medical treatment. As examples, the College of Physicians and Surgeons of Alberta, in their guideline on informed consent, specifically states that "patients must be free of compulsion, duress, or coercion when consenting to or refusing treatment,"<sup>16</sup> while the College of Physicians and Surgeons of Newfoundland and Labrador notes that "patients have the legal right to refuse or withdraw consent. Physicians... should ensure that the patient understands the consequences of not undertaking the treatment and any available or alternative treatment."<sup>17</sup> In the same vein, the College of Physicians and Surgeons of Nova Scotia includes the following in its *Professional Standard and Guidelines Regarding Informed Patient Consent to Treatment*:

### ***Professional Standard***

- 1) Physicians must ensure that consent is obtained from patients before performing an examination or treatment, except where specifically permitted by law.

### ***Guideline***

- 4) A physician must respect the right of a patient to withdraw consent at any time.<sup>18</sup>

However, regulators in only three provinces provide guidelines specifically regarding withholding or withdrawing life-sustaining treatment: Manitoba, Ontario and Quebec.

In its *Standards of Practice of Medicine* the College of Physicians and Surgeons of Manitoba (CPSM) provides clinical guidance for assessment, communication, implementation, and documentation in situations where life-sustaining therapy is being withheld or withdrawn.<sup>19</sup> The CPSM explains that when faced with a refusal of such treatment, the doctor should ensure that the patient is capable and that the refusal is valid (free and informed), and then treat the refusal of life-sustaining treatment in the same way as any other refusal of treatment.

The policy document *Planning for and Providing Quality End-of-Life Care* issued by the College of Physicians and Surgeons of Ontario (CPSO) specifically emphasizes the imperative of obtaining consent prior to life-saving and life-sustaining treatment, to ensure that unwanted treatments are not provided.<sup>20</sup> The CPSO explains consent at large, and mentions that in the case where patients or SDMs wish to continue or start a non-medically indicated treatment (including life-sustaining ones), the physician is bound to consult the Consent and Capacity Board (CCB). The CPSO does not mention specifically what is to be done when a patient refuses a life-sustaining treatment that is medically indicated, perhaps because such refusals are understood to be no different from refusals for ordinary treatment.

The Collège des médecins du Québec (CMQ) explains clearly in publications intended for its members what is to be done in the event of patient refusal of life-sustaining treatment, stating that from a legal point of view such cases should be dealt with in the same manner as all other refusals of treatment.<sup>21</sup> The physician must explain the indications of the suggested treatment, verify that the capable patient's refusal is free and informed, and, if the refusal is deemed valid, discuss the alternative options, (re)open the discussion about the goals of care, and ultimately respect the patient's decision.

No other regulator in Canada specifically mentions what to do in the event of a refusal of potentially life-sustaining treatment, even though most have general guidelines on patient consent. Many regulators, despite not having specific guidance on refusal/withdrawal of life-sustaining treatment, refer to guidelines issued by the The Canadian Medical Protective Association (CMPA). In its handbook *Consent: A Guide for Canadian Physicians*, the CMPA makes it clear that physicians are obligated to honour refusals of life-saving treatment, although they emphasize the importance of thorough explanations of the consequences of any refusal "without creating a perception of coercion in seeking consent".<sup>22</sup> In its guide *Providing Quality End-of-Life Care* the CMPA states that in the event of refusal of such treatment, the consent and capacity assessment should be considered no different than in cases of ordinary treatment, and respected by the physician when the capable patient's refusal is deemed free and informed.<sup>23</sup> In cases where the patient is not capable, or the SDM's decision is deemed inappropriate, the physician is then directed to refer to local judicial or administrative authorities for more guidance.

While not target actors in the Expert Panel Report recommendations, professional societies have also commented on the right to refuse treatment. The Royal College of Physicians and Surgeons of Canada, in its bioethics curriculum, reminds learners of a patient's right to refuse any treatment, even if the withdrawal from, or refusal of, treatment may result in death.<sup>24</sup> The Canadian Hospice Palliative Care Association (CHPCA) in its guidance document on ethics at the end of life, affirms the respect of patient autonomy in withholding and withdrawing treatment if it is not within a patient's goals of care, reminding clinicians that interventions should be only be initiated if they are aligned with a patient's desires in their current state of illness.<sup>25</sup> The Canadian Paediatric Society, in their position paper on medical decision-making in pediatrics, addresses withholding and withdrawing treatment, and outlines province-by-province policies around consent and refusal of treatment.<sup>26</sup> The Canadian Critical Care Society's position paper on withholding and withdrawing treatment emphasizes respect for the autonomy of patients to accept or refuse treatment.<sup>27</sup>

**Recommendation 4:** *The federal government in collaboration with provincial/territorial governments should educate the public regarding the legal status of the withholding and*



*withdrawal of potentially life-sustaining treatment so that they can better advocate for themselves and their loved ones.*

In following subsequent progress on this recommendation, the PBC has focused on identifying those resources produced by governments, and intended for the general public, that are specific to the legal status of withholding and withdrawing potentially life-sustaining treatment.<sup>28</sup>

The government of British Columbia has produced an online advance care planning guide entitled *My Voice* which outlines different methods for consenting to or refusing life-sustaining treatment (temporary substitute decision-makers, representation agreements, and advance directives).<sup>29</sup> *The BC Elders' Guide*,<sup>30</sup> a collaborative publication with the First Nations Health Authority, provides similar information with the reminder that the physician has a duty to apply advance directives including in situations of life-sustaining treatment.

In a document produced for public education, the government of Quebec explains clearly that a person can refuse or withdraw consent for any form of treatment (including hydration and feeding).<sup>31</sup> It has also produced a public-facing website that explains the advance directive mechanism for consent to, or refusal of, certain interventions as created by the *Act respecting end-of-life care*.<sup>32</sup>

The government of Alberta has not produced resources specifically for the public; however, information intended for health care professionals that discusses valid refusal of treatment is freely available online.<sup>33</sup>

**Recommendation 5:** *The Panel notes the importance of clarity with respect to the mature minor rule for end-of-life decision making and recommends that this issue be taken up by provincial/territorial Departments of Health and Community Services (or equivalent governmental departments) as it can best be dealt with in a proactive way through their consent and child protection legislation and through the relevant departments clarifying the consent law for mature minors in their jurisdiction (in whatever direction is deemed appropriate following a public consultation and legal and ethical analysis). The law on mature minors, as drafted in the various jurisdictions, should then apply to all aspects of end-of-life decision making.*

### **Amendments to consent or child protection legislation**

With one exception, no amendments have been made to clarify the provincial/territorial law with respect to mature minors and end-of-life decision-making.<sup>34</sup> The exception is Quebec which included in its *Act respecting end-of-life care* the following provision:

Except as otherwise provided by law, a person of full age who is capable of giving consent to care may, at any time, refuse to receive life-sustaining care or withdraw consent to such care.

To the extent provided by the Civil Code, **a minor of 14 years of age or over**, and in the case of a minor or a person of full age who is incapable of giving consent, the person who may give consent to care on their behalf may also make such a decision.<sup>35</sup>

### **Non-statutory clarifications**

No health or community service departments have taken steps to clarify for clinicians and the public what the consent law is for mature minors in their jurisdiction.

## **Non-legislative clarifications**

In the absence of legislative reform or government departmental clarification following the Expert Panel's recommendations, professional associations and protective associations have issued statements. For example, the Canadian Paediatric Society issued *Medical Decision-making in Paediatrics: Infancy to Adolescence* in 2018,<sup>36</sup> the Canadian Family Practice Nurses Association issued a *Mature Minor Assessment Tool* in 2017,<sup>37</sup> the CMPA published an article "Can a child provide consent?" in 2014, revised in 2016,<sup>38</sup> and the Canadian Nurses Protective Society issued *Ask a lawyer: Mature minor*.<sup>39</sup>

In addition, the Council of Canadian Academies Expert Panel Working Group on MAiD for Mature Minors included a review of the legal status of mature minors' health care decision making in their 2018 report on *The State of Knowledge on Medical Assistance in Dying for Mature Minors*.<sup>40</sup>

Mature minors have the authority to refuse potentially life-sustaining treatment in many circumstances in all provinces and territories.<sup>41</sup> However, mature minors are not eligible for MAiD in Canada; under the *Criminal Code* one must be eighteen years of age in order to access MAiD.<sup>42</sup> Therefore, contrary to the 2011 Expert Panel's recommendation, the law on mature minors is inconsistent as between MAiD and other forms of end-of-life decision-making.

**Recommendation 6:** *Provincial/territorial governments should ensure that their consent legislation and health care professional regulators should ensure that their policies make it clear when, if ever, health care professionals have the legal authority to unilaterally withhold or withdraw potentially life-sustaining treatment.*

**Recommendation 7:** *Health care professional educational institutions and regulators should ensure that their trainees and members understand their legal obligations with respect to unilateral withholding or withdrawal of potentially life-sustaining treatment.*

**Recommendation 8:** *The provincial/territorial governments should educate the public regarding the legal status of unilateral withholding and withdrawal of potentially life-sustaining treatment so that they can better advocate for themselves and their loved ones and better communicate with health care providers.*

## **Provincial/territorial governments**

No provincial or territorial government has amended its consent legislation specifically to address the unilateral withholding or withdrawal of life-sustaining treatment. The PBC also found no government documents on this issue specifically intended for the public. However, the documents cited below are all publicly accessible.

## **Educational institutions**

A review of the curricula of all health care professional educational institutions in Canada was outside the scope of the PBC. We have therefore focussed instead on medical regulators, with additional contributions from medical professional societies, as most clinical guidance in this area is created by, and for, physicians, and because only physicians have both the responsibility and the authority to write orders for the withholding or withdrawal of life-sustaining treatment.

## Regulators

Since the Expert Panel Report, discourse concerning unilateral withholding and withdrawing of treatment has continued. To some extent, this has been in reaction to *Rasouli*,<sup>43</sup> which dealt with the question whether the physicians of a severely brain-injured man could unilaterally discontinue mechanical ventilation that they thought was futile, despite the objections of his SDM. The Supreme Court affirmed that withdrawal of life support, under the Ontario Health Care Consent Act, constituted “treatment” which requires consent and that physicians therefore cannot unilaterally withdraw life-sustaining treatment without consent. Rather, in Ontario, cases in which physicians want to withhold or withdraw treatment that the patient or SDM wants should be taken to the CCB.

The CPSO has taken steps since 2011 to address the issue of unilateral withholding or withdrawal of potentially life-sustaining treatment in *Planning for and Providing Quality End-of-Life Care*:

Physicians **must not** unilaterally make a decision to withdraw life-sustaining treatment and **must** obtain consent in order to withdraw life-sustaining treatment.

- a. As part of the consent process physicians **must** explain why they are proposing to withdraw life-sustaining treatment and provide details regarding any treatment(s) they propose to provide (e.g., palliative care).
- b. When consent is not provided, physicians **must** engage in the conflict resolution process as outlined in this policy, which may include an application to the Consent and Capacity Board.

It is likely that Ontario has moved on this issue because it has an active CCB which has had unilateral withholding and withdrawal cases brought before it, and has had challenges subsequently taken to court (both *Rasouli* and *Wawrzyniak*<sup>44</sup>).

Withholding of cardiopulmonary resuscitation (CPR) may be the most common form of withholding and withdrawing of potentially life-sustaining treatment. In its policy document the CPSO also instituted policy changes with regards to no-CPR orders:

Physicians **must not** unilaterally make a decision regarding a no-CPR order.

- c. Before writing a no-CPR order in the patient’s record, physicians **must** inform the patient and/or substitute decision-maker that the order will be written and the reasons why.
- d. If the patient or substitute decision-maker disagrees and insists that CPR be provided, physicians **must** engage in the conflict resolution process as outlined in this policy and **must not** write the no-CPR order while conflict resolution is underway.
- e. If the patient experiences cardiac or respiratory arrest while conflict resolution is underway regarding the writing of a no-CPR order, physicians **must** provide all resuscitative efforts required by the standard of care, which may include CPR.<sup>45</sup>

This policy, it should be noted, has generated considerable controversy.<sup>46</sup>

The CPSM has likewise described clinical processes for withholding and withdrawing treatment, including procedures for obtaining consensus when a physician feels life-sustaining treatment should be withheld and the patient or SDM disagrees.<sup>47</sup> The College’s guidelines set out the clinical circumstances in which unilateral withholding and withdrawing of treatment can occur.

These include situations in which a physician believes that the minimal goal of life-sustaining treatment<sup>48</sup> is not realistically achievable, when it may be achievable but the physician believes that life-sustaining treatment should still be withdrawn or withheld, and in emergency situations. The guidelines go on to describe the procedures to follow in such circumstances.

In 2018 the CMQ published a guide which covers unilateral withholding of treatment in a variety of ways.<sup>49</sup> First, it instructs physicians to ensure that a patient's care is medically necessary. In cases of disagreement with SDMs, particularly concerning do-not-resuscitate orders, physicians must not act unilaterally but instead avail themselves of conflict resolution processes. However, physicians are instructed not to provide care they believe to be harmful to the patient. It is at the physician's discretion not to provide care they believe not to be beneficial, even if it is not harmful.

Several provinces and territories do not provide their own guidance but refer instead to the CMPA's *Medical-legal Handbook for Physicians in Canada*.<sup>50</sup>

In response to *Rasouli*, the CMPA released a guidance document specifically advising physicians of the need to obtain consent before life support is withdrawn.<sup>51</sup> This document emphasized that *Rasouli* was specific to legislation in Ontario and other jurisdictions that have similar legislation, and in these jurisdictions the CMPA advised physicians to continue to rely on existing dispute resolution mechanisms to reach appropriate consensus. The guideline also outlined the process physicians should follow when disagreements arise in this clinical context.

Finally, the Canadian Critical Care Society has also published guidelines for withholding and withdrawal of life-sustaining treatment, emphasizing the importance of communication, collaboration, and transparency in difficult clinical situations.<sup>52</sup>

The legal, ethical, and clinical landscapes concerning unilateral withholding and withdrawing potentially life-sustaining treatment remain hotly contested. In particular, much remains legally unsettled with respect to the authority of a physician to make a unilateral decision to withhold or withdraw treatment.<sup>53</sup> While the law in Ontario is relatively clear, it is much less so in the rest of the country. This legal confusion will continue to make it challenging for regulators and health professions educational institutions to provide their members and trainees with sound advice regarding their legal obligations.

### 3.2 Advance Directives

**Recommendation 9:** *More research should be funded and conducted into how best to facilitate the completion of valid and useful advance directives and to engage in advance care planning.*

As this recommendation was not specific, and as research financing and activity involve many institutions and many individuals, the PBC found it difficult to know how to determine whether the recommendation has been taken up or not. In the end we limited ourselves to a Pubmed search using the search terms 'directives' and/or 'advance care planning'. Use of both terms was necessary due to the varying terminology between provinces. The term 'directive' always appears but is preceded by different adjectives or noun clusters. 'Advance care planning', however, was consistently used.

The use of Canada [affiliation] allowed us to identify articles in which at least one author was Canadian. This does not guarantee Canadian financing nor that the study was conducted only in Canada. This could only be confirmed by a manual search.

We compared the number of publications in the same time frame (eight years) prior to the Expert Panel Report and since its publication. Of course, no causal link can be drawn between the publication of the Report and the publication of the articles. We found 73 published results for the period 2003-11 as compared to 238 publications for 2011-19.

**Recommendation 10:** *Better education of health care providers and the public should be provided on how to complete advance directives and the benefits of doing so.*

**Recommendation 11:** *More resources should be directed to encouraging and facilitating discussions of advance directives and advance care planning.*

These recommendations are based on the assumption that increased completion of advance directives will lead to benefits without specifying the kinds of benefits to be expected. Therefore, in order to track this recommendation, we attempted to determine whether educational strategies had been developed and on what date.

The table below enumerates resources produced by ministries of health, regional health authorities, medical regulators, and non-governmental organizations. These resources include websites, guides/booklets, promotional items (posters, cards, brochures), videos, and miscellaneous items, including FAQ lists, personal narratives, and webinars. Approximately 25% of resources identified were undated; therefore, they are not counted in this table. It is also not possible to determine whether older resources have been withdrawn, leading to an underestimation of what was available prior to 2011. Many NGO resources were developed in the context of the SpeakUp campaign, part of the Advance Care Planning in Canada initiative developed by the CHPCA. While many resources were developed after 2011, it is important to note that the ACP initiative began in 2008, before the publication of the Expert Panel Report.

Total ACP educational/promotion resources created by year	
2004	1
2005	4
2006	2
2009	1
2010	5
2011	7
2012	13
2013	13
2014	11
2015	13
2016	43
2017	27
2018	55
2019	40

**Recommendation 12:** *More effective administrative mechanisms should be developed to ensure that the results of discussions of advance directives and advance care planning are made evident in a variety of contexts of care.*

It is difficult to follow up on this recommendation due to the lack of information readily available on the local administrative mechanisms to ensure the continuity of advance care planning information between different care settings.

Registries have been created in Quebec and Alberta for advance medical directives and personal directives respectively. No other provinces/territories or regional health authorities seem to have such measures in place.

In British Columbia, a private company allows people to file their advance directives.<sup>54</sup> The primary purpose of this registry is to enable SDMs to readily access the directives. However, users can authorize health care providers to access them when necessary.

### 3.3 Palliative Care

**Recommendation 13:** *Governments, health care institutions, and health care providers should work together to ensure that resources that could be better used for wanted palliative care are not diverted to unwanted acute care.*

This recommendation speaks to the need for intentional, coordinated, and systems-oriented action to increase palliative care infrastructure and capacity, thus avoiding unwanted acute care. Unfortunately, evidence has shown that palliative care in Canada remains hospital-centric.<sup>55</sup> In Ontario, for example, much of palliative care is still delivered in hospitals, with disparate access to home-based care across geographic regions.<sup>56</sup> This may in part be due to the lack of a coordinated and integrated system of palliative care delivery in that province.<sup>57</sup> Since 2011, several strategies and frameworks have been developed, both provincially/territorially and nationally, that have suggested how such systems might be achieved.

In March 2015, the Quality End-of-Life Care Coalition of Canada, managed by the CHPCA, released *The Way Forward National Framework: A roadmap for an integrated palliative approach to care*.<sup>58</sup> This was the culmination of a three-year consultation process which engaged stakeholders on multiple levels. *The Way Forward* provided recommendations for federal, provincial, and territorial governments, as well as regional program planners and front-line care providers, to integrate a palliative approach to care into all clinical settings.

This was followed, in November 2016, by a report by the Canadian Society of Palliative Care Physicians (CSPCP) entitled *How to improve palliative care in Canada: a call to action for federal, provincial, territorial, regional, and local decision-makers*.<sup>59</sup> It built on the foundations in *The Way Forward*, offering specific recommendations on key areas for investment, creation of national standards for palliative care in Canada, and promotion of technological innovation. This report also recommended the re-establishment of the Canadian Palliative Care Secretariat, which had existed between 2002 and 2007 and whose aim had been to support a government-appointed minister tasked with implementing the 2001 *Strategy on Palliative and End-of-Life Care*.

The federal government responded to the identified gaps in palliative care by passing the 2017 *Act providing for the development of a framework on palliative care in Canada* with unanimous support in Parliament. After extensive consultation with provincial and territorial governments,

individuals with advanced illnesses, caregivers, and other national stakeholders, Health Canada released the 2018 *Framework on Palliative Care in Canada*.<sup>60</sup> This framework was meant to provide a “structure and an impetus for collective action to address gaps in access and quality of palliative care in Canada”. The *Framework* also provided for the creation of the Office of Palliative Care, which was tasked with supporting the implementation of the *Framework*. Much like the defunct Canadian Palliative Care Secretariat, mentioned above, it would act as a “single focal point...to help connect and facilitate activities at various levels seeking to improve access to palliative care in Canada”. While it is too soon to assess the impact of this framework, it provides a useful, broad-strokes blueprint for the development of the sort of palliative care infrastructure that the Expert Panel had envisioned and endorsed.

The last five years have also seen the creation of provincial and territorial frameworks for integrated palliative care service delivery, including in British Columbia,<sup>61</sup> Yukon,<sup>62</sup> Northwest Territories,<sup>63</sup> Alberta,<sup>64</sup> Ontario,<sup>65</sup> Quebec,<sup>66</sup> New Brunswick,<sup>67</sup> and Nova Scotia.<sup>68</sup> Monitoring and evaluation of these frameworks are ongoing.

***Recommendation 14:*** *Palliative care specialists should continue to expand their scope beyond cancer and specialists in areas other than cancer care should continue to expand their understanding and use of palliative care.*

As noted in the Expert Panel Report, palliative care has historically been centred on the needs of those with end-stage cancer. However, in the context of an aging population, the Report highlighted the unmet palliative care needs of those with end-stage chronic diseases, specifically dementia, kidney disease, heart disease, and chronic obstructive pulmonary disease. The report recommended that health care providers continue to expand their scope of practice to integrate palliative care principles into the care of those with non-cancer diagnoses.

Since the Report’s release in 2011, the discourse concerning the importance of, and mechanisms for, the integration of palliative care principles into chronic disease paradigms has continued.<sup>69</sup> The 2018 *Framework* included several guiding principles, one of which emphasized the integration of palliative with other forms of care, such as chronic illness management. The Royal College of Physicians and Surgeons, which accredited a subspecialty in Adult Palliative Medicine in 2017, included several non-cancer rotations in its curriculum requirements. Nevertheless, challenges persist: in Ontario, for example, those dying of terminal illnesses such as cancer are much more likely to receive palliative care, compared to those with organ failure or frailty.<sup>70</sup>

Herein, we summarize recent Canadian evidence addressing the Expert Panel’s recommendation for expansion and integration of scopes of practice for palliative care and non-cancer health care providers.

## **Dementia**

The need for palliative care services in advanced dementia continues to be emphasized in the Canadian literature. Particular emphasis has been placed on the need for clarification of advance directives, goals of care, and family education,<sup>71</sup> as well as the management of symptoms of dementia, which may be analogous to those of terminal malignant illnesses.<sup>72</sup> It appears that much work continues to be done: one study of clinical practice guidelines for dementia found that many of them lacked content related to end-of-life care.<sup>73</sup> There have, however, been documented examples of the kind of broadening of scope that the Expert Panel Report encouraged.<sup>74</sup>

## **Chronic Obstructive Pulmonary Disease**

Involvement of palliative care in the management of advanced COPD continues to be encouraged. A 2018 editorial in *The Lancet* emphasized the importance of recognizing the limitations of curative treatment in COPD, despite the difficulties on the part of clinicians and families in accepting palliative care.<sup>75</sup> A Canadian review of palliative care in COPD noted that intensive symptom management is needed regardless of diagnosis, especially given that cancer and COPD may carry similar symptom burdens,<sup>76</sup> including loss of dignity.<sup>77</sup> Primary care physicians, however, may have significant discomfort with symptom management approaches in COPD, in particular the use of opioids—a common medication for the palliative management of dyspnea.<sup>78</sup>

Despite a high symptom burden, referrals to palliative care for COPD continue to occur later and less frequently than for cancer,<sup>79</sup> and rates of home death, both in Canada and internationally, continue to be low for those with COPD compared to those with lung cancer.<sup>80</sup> One study of Ontarians with advanced COPD did show that the use of formal palliative services increased by 1% per year between 2004 and 2014,<sup>81</sup> and there have been several Canadian examples of integrated palliative approaches to COPD, which had varying degrees of success.<sup>82</sup>

## **End-stage renal disease**

Palliative care remains under-utilized for patients with end stage renal disease.<sup>83</sup> While there are low rates of understanding of palliative care among those with advanced kidney disease, once palliative care is described, patients may see these services as valuable.<sup>84</sup> Nephrologists have begun to respond to the need for integration of conservative care, which includes an emphasis on shared decision-making, active symptom management, advance care planning, psychological and social support, cultural and spiritual domains of care, and intervention to delay progression of disease, not including dialysis.<sup>85</sup> While there remains little evidence as to optimal models of care, one Canadian urban nephrology centre described a cohort of renal patients who adopted a conservative approach to care, and found high rates of advance care planning and death in the location of choice.<sup>86</sup>

## **Congestive heart failure**

Despite improvements in care, heart failure continues to have a high mortality rate.<sup>87</sup> The mechanism of death, however, has evolved from sudden cardiac death to a more prolonged pump failure, which reinforces the importance of palliative care for cardiac patients.<sup>88</sup> Integration of palliative care competencies into provision of cardiac care has been recommended by all major cardiovascular societies.<sup>89</sup> Indeed, the *2017 Comprehensive Update of the Canadian Cardiovascular Society Guidelines for the Management of Heart Failure*<sup>90</sup> noted that access to palliative care was a feature of successful health system integration and that integration of palliative care services for patients with advanced heart failure can improve symptoms while also decreasing health system utilization. This guideline also recommended provision of palliative care based on symptom burden, rather than prognosis. Approaches to assessing symptom burden using standardized instruments have been proposed.<sup>91</sup>

Despite these recommendations, unmet palliative care needs remain. For example, home care patients with heart failure have similar palliative needs to those with cancer; however, they are less frequently recognized as having a terminal prognosis.<sup>92</sup> This lack of awareness may contribute to the poor access to palliative care services documented by Nazim et al. in their retrospective study



of terminal hospital admission of those with advanced heart failure, which found that palliative care referrals were often absent, or limited to the final days of life.<sup>93</sup>

For health care providers integrating palliative and cardiac care, several Canadian studies have focused on the importance of communication competency. Even when patients possess detailed knowledge of heart failure, this may not translate into understanding the consequences of their illness.<sup>94</sup> The expert relational skills in goals of care and end-of-life communication are especially critical.<sup>95</sup>

Integration of palliative care into cardiac care is needed to meet the complex care needs of patients with heart failure, and not just for those who are at the very end of life.<sup>96</sup> A recent Canadian review noted several challenges to integration, however, including prognostic uncertainty, difficulty communicating this uncertainty, and fear of taking away hope, among others.<sup>97</sup> Nevertheless, promising models of multidisciplinary integrated care are emerging.<sup>98</sup>

### 3.4 Potentially Life-shortening Symptom Relief

**Recommendation 15:** *Health care providers, regulators, and prosecutors should collaborate on the development of guidelines with respect to what they consider to constitute the Criminal Code standards of “reasonable knowledge, skill and care” and “wanton or reckless disregard” in the context of the provision of potentially life-shortening symptom relief.*

No guidelines have been produced by health care providers, regulators, or prosecutors with respect to what they consider to constitute the *Criminal Code* standards identified in the Expert Panel Report.

**Recommendation 16:** *Health care providers, institutions, and regulators and prosecution services should collaborate on the development and delivery of programs to educate the public and health care providers, regarding the fact that health care providers must provide symptom relief that accords with the guidelines and that they are protected from liability if they do.*

To our knowledge, no such educational programs have been developed.

### 3.5 Terminal Sedation

The Expert Panel Report defined ‘terminal sedation’ as “potentially life-shortening deep and continuous sedation, intentionally combined with the cessation of nutrition and hydration”. The Expert Panel considered ‘terminal sedation’ to be a contested subtype of ‘palliative sedation’ as it may hasten death, while otherwise palliative sedation will not hasten death. The Report provided a clinical example of ‘terminal sedation’: a 55-year-old woman with pancreatic cancer with a prognosis of approximately three months, with severe pain despite intensive analgesia, whose SDMs are requesting sedation without artificial hydration and nutrition.

Downie and Liu, however, have since offered a finer-grained classification of palliative sedation without artificial nutrition and hydration (ANH): Type 1, in which a patient is expected to die within 24-48 hours and sedation without ANH *will not* hasten death; Type 2, in which a patient is expected die within 10-14 days and sedation without ANH *might, but is not certain to*, hasten death; and Type 3, in which a patient is expected to live for more than 14 days and sedation without ANH *is certain to* hasten death. While Type 1 is clearly lawful, the legal status of Types 2

and 3 (which correspond to the Expert Panel's definition of terminal sedation) is unclear. They note that there are still considerable legal ambiguities that clinicians may not appreciate.<sup>99</sup>

**Recommendation 17:** *The federal government should revise the Criminal Code to make it clear that terminal sedation in circumstances where it is not required to alleviate physical suffering should be considered euthanasia and be subject to the same procedural conditions and requirements as other forms of euthanasia.*

The federal government has not addressed terminal sedation in the *Criminal Code*.

**Recommendation 18:** *Health care providers, regulators, and prosecutors should collaborate on the development of guidelines with respect to what they consider to constitute the Criminal Code standards of "reasonable knowledge, skill and care" and "wanton or reckless disregard" in the context of the provision of terminal sedation.*

### **Regulators**

Only the Quebec College has addressed this issue. In 2016 the CMQ published a comprehensive set of practice guidelines on *Palliative Sedation at the End of Life*.<sup>100</sup>

### **Prosecutors**

No Directors of Public Prosecution have developed guidelines for the exercise of prosecutorial discretion with respect to terminal sedation.

### **Provincial/territorial governments**

While not identified as a target actor in the Expert Panel Report recommendations, the Quebec government addressed continuous palliative sedation in its *Act respecting end-of-life care*. It defined the term as follows:

"continuous palliative sedation" means care that is offered as part of palliative care [defined as care that does not hasten death] and consists in administering medications or substances to an end-of-life patient to relieve their suffering by rendering them unconscious without interruption until death ensues;

The Act imposed reporting requirements about the number of times continuous palliative sedation is provided upon the executive directors of institutions.<sup>101</sup> It also established the following rules with respect to palliative sedation:

24. Before giving consent to continuous palliative sedation, an end-of-life patient or, where applicable, the person who may give consent to care on behalf of the patient must among other things be informed of the prognosis for the illness, the irreversible nature of the sedation and the anticipated duration of the sedation.

In addition, the physician must make sure that the request is being made freely, in particular by ascertaining that it is not being made as a result of external pressure.

Consent to continuous palliative sedation must be given in writing on the form prescribed by the Minister and be filed in the patient's record.

## **Health care providers**

The disconnect between clinical and legal understandings of palliative sedation is evident in the palliative sedation guidelines that have proliferated since 2011, which generally include Type 1 and Type 2 within the bounds of reasonable clinical practice (i.e., for patients whose underlying illness is likely to result in death within two weeks) while appearing to exclude Type 3. These include guidelines from regional health authorities such as Fraser Health and the Champlain Hospice and Palliative Care Program, a review article in *Canadian Family Physician*, and, most prominently, guidelines from the CSPCP and the CMQ.<sup>102</sup> Type 2 sedation may, however, be more problematic than clinicians realize, given that it “might, but is not certain to” hasten death.

Many clinicians may not see a meaningful clinical distinction between Types 1 and 2 sedation, insofar as the medical literature has not demonstrated a sufficiently significant likelihood of hastening death in these contexts. There is also an ongoing reliance on the doctrine of double effect, which may be—at least legally and ethically—misplaced. Clinicians may understand only Type 3 sedation to be a problematic—and exceptionally rare—sedation practice, which was clear in a discourse that unfolded in the *Canadian Medical Association Journal* in 2014. A news item in the CMAJ describing Quebec’s Bill 52, *An act respecting end-of-life care*, stated: “As it stands, hospitals in Quebec and the rest of Canada often offer palliative sedation to ease suffering. In extreme cases, doctors use ‘terminal sedation’, in which patients are medicated and deprived of artificial nutrition to expedite imminent death.”<sup>103</sup> This generated responses from palliative care physicians who argued that ‘terminal sedation’ was not a prevalent or accepted practice, that it did not represent clinical reality, and that guidelines did in fact exist which provided a framework for reasonable sedation practices at the end of life.<sup>104</sup> However, these clinical practice guidelines may not be as definitive or comprehensive as clinicians assume and, as Downie and Liu note, may in fact be ignorant of the legal implications of some sedation practices. Furthermore, sedation practices that expedite death may go unseen or unreported for fear of legal liability, obscuring their incidence and prevalence and preventing the medical community from addressing what many would consider to be problematic practices.

**Recommendation 19:** *The federal government in collaboration with the provincial/territorial governments should develop and deliver programs to educate the public and health care providers regarding the fact that health care providers must provide terminal sedation that accords with the guidelines and that they are protected from liability if they do.*

The federal government has not developed any programs with respect to terminal sedation.

## **3.6 Assisted Suicide and Voluntary Euthanasia**

**Recommendation 20:** *The prohibitions on assisted suicide and voluntary euthanasia in the Criminal Code should be modified such that, in carefully circumscribed and monitored circumstances, they are legally permissible.*

The prohibitions on MAiD have been modified.

In *Carter v. Canada (Attorney General)*, the Supreme Court of Canada declared that:

- s. 241 (b) and s. 14 of the *Criminal Code* are void insofar as they prohibit physician-assisted death for a competent adult person who (1) clearly consents to the termination of life; and (2) has a grievous and irremediable medical condition (including an illness, disease or disability)

that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition. “Irremediable”, it should be added, does not require the patient to undertake treatments that are not acceptable to the individual.<sup>105</sup>

The SCC suspended the effect of its declaration for twelve months to give the government time to put in place a legislative framework for MAiD if it wanted to do so. This suspension was subsequently extended by four months to take account of delays caused by a federal election.<sup>106</sup>

In June 2016, the federal Parliament passed Bill C-14, establishing the eligibility criteria and procedural safeguards for MAiD in Canada.<sup>107</sup>

Events in Quebec are also relevant here (albeit unanticipated in the Expert Panel Report). While it lay outside the jurisdiction of the province of Quebec to amend the *Criminal Code*, the National Assembly acted under its jurisdiction over health. In June 2014, the National Assembly passed *An Act respecting end-of-life care* (including but not limited to MAiD) establishing a legal framework for permissible MAiD.<sup>108</sup>

See below for details re: circumscription and monitoring under both the *Criminal Code* and the Quebec legislation.

**Recommendation 21:** *Unless or until the Criminal Code is reformed as recommended above, those with authority over prosecutorial policies in all provinces and territories should introduce such policies to provide guidance with respect to the exercise of prosecutorial discretion and to make clear the circumstances within which a prosecution for assisted suicide or voluntary euthanasia would not be in order.*

Except for a brief period in Quebec,<sup>109</sup> no prosecutorial charging guidelines were introduced as the *Criminal Code* was amended.

**Recommendation 22:** *Unless or until the Criminal Code is reformed or prosecutorial charging guidelines are implemented as recommended above, provinces and territories should consider implementing a restorative justice process for assisted suicide and voluntary euthanasia cases.*

No restorative justice process was implemented as the *Criminal Code* was amended.

**Recommendation 23:** *The person making the request for assisted suicide or euthanasia must be competent or, while competent, must have expressed the wish for voluntary euthanasia through a valid advance directive. Great care must be taken to ensure that, at the time of the decision, the person is able to understand and appreciate the nature and consequences of the decision. However, this level of care is not unique to assisted suicide and euthanasia. Many health care decisions bring with them the possibility or even certainty of death (e.g., risky surgery and cessation of treatment) and many require the ability to understand more complex information than is required to decide whether to commit suicide. For the same reason, there is also no justification for requiring unique skills in competency assessment of the health care providers in the context of assisted suicide or euthanasia. Of course, as with any assessment of competence for the purposes of health care decision-making, if an individual physician is uncertain about the competence of the person making a request, she must take all necessary steps to resolve this uncertainty (e.g., consulting with a colleague with greater experience or expertise).*

### **An Act respecting end-of-life care (Quebec)**

Under the Quebec legislation the person accessing MAiD must be capable.<sup>110</sup> However, requests made in advance of loss of capacity are not permitted.<sup>111</sup> The Quebec government subsequently commissioned an expert panel on this issue and this panel recommended amending the law to allow MAiD through advance requests.<sup>112</sup> The Quebec government is also engaging in a public consultation on the issue.<sup>113</sup> No unique skills in competency assessment are required under the legislation.

### **Criminal Code of Canada**

Under the federal legislation the person accessing MAiD must be competent.<sup>114</sup> Contrary to the Expert Panel's recommendation, and recommendations made subsequently by the Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying and the Special Joint Committee of the House and Senate on Physician-Assisted Dying,<sup>115</sup> however, requests made in advance of loss of capacity are not permitted.<sup>116</sup>

Under the terms of C-14, the federal government commissioned the Council of Canadian Academies to conduct an independent, evidence-based review of "the state of knowledge on advance requests for MAiD". That review, carried out by the CCA Expert Panel Working Group on Advance Requests for MAiD, appeared in December 2018.<sup>117</sup> The Working Group was tasked solely with assessing relevant available evidence, including experience with advance requests for MAiD in other jurisdictions. It was not asked to make any recommendations for or against changes in the law. Since then, the federal government has conducted a public consultation on advance requests by people who are already considered eligible for MAiD.<sup>118</sup> It has also committed to review (as part of the five-year review required by the legislation<sup>119</sup>) the issue of advance requests made by people before they are considered eligible for MAiD.

Bill C-7 *An Act to amend the Criminal Code (medical assistance in dying)* was introduced on February 24, 2020.<sup>120</sup> If passed as introduced, it will permit respect for requests made in advance of loss of capacity for individuals who meet the eligibility criteria for MAiD, for whom natural death has become reasonably foreseeable, and who meet the procedural safeguards for what is called "final consent waiver". [section (3.2) and (3.3)] It will also permit respect for requests made in advance of loss of capacity for individuals who self-administer MAiD but do not die within the period specified in the arrangement between the person and the medical or nurse practitioner present when they self-administer. This is called "Advance consent – self-administration."

No unique skills in competency assessment are required under the federal legislation. Rather, the *Criminal Code* MAiD provisions establish that, "[m]edical assistance in dying must be provided with reasonable knowledge, care and skill and in accordance with any applicable provincial laws, rules or standards."<sup>121</sup>

**Recommendation 24:** *Any age restrictions for access to assisted suicide or voluntary euthanasia should flow from the mature minor law in the particular jurisdiction.*

### **An Act respecting end-of-life care (Quebec)**

The Quebec legislation restricts access to MAiD to patients "of full age".<sup>122</sup>

## **Criminal Code of Canada**

Contrary to the Expert Panel's recommendation, and recommendations made by the Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying and the Special Joint Committee of the House and Senate on Physician-Assisted Dying,<sup>123</sup> the *Criminal Code* restricts access to MAiD to "adults".<sup>124</sup>

The federal government also commissioned a review by the Council of Canadian Academies on "the state of knowledge on MAiD for mature minors".<sup>125</sup> As with advance requests, the Expert Panel Working Group presented extensive evidence on the issue, including experience in other jurisdictions, but made no recommendations concerning the *Criminal Code* exclusion of mature minors.

The federal government did not change the age criterion for access to MAiD in Bill C-7 but has committed to exploring the issue of mature minors and MAiD in the five year review intended to have commenced in June 2020 but delayed due to the COVID-19 pandemic.

**Recommendation 25:** *The decision must be voluntary and informed.*

Both the Quebec legislation and the *Criminal Code* require that the decision be voluntary and informed.<sup>126</sup>

**Recommendation 26:** *"Terminal illness" should not be used as a prerequisite for requesting assistance.*

## **An Act respecting end-of-life care (Quebec)**

'Terminal illness' is not a prerequisite for requesting MAiD in the Quebec Act.

However, under the legislation as originally passed, MAiD is limited as follows:

26. Only a patient who meets all of the following criteria may obtain medical aid in dying:
- (1) be an insured person within the meaning of the Health Insurance Act (chapter A-29);
  - (2) be of full age and capable of giving consent to care;
  - (3) be at the end of life;
  - (4) suffer from a serious and incurable illness;
  - (5) be in an advanced state of irreversible decline in capability; and
  - (6) experience constant and unbearable physical or psychological suffering which cannot be relieved in a manner the patient deems tolerable.

In *Truchon and Gladu v. Attorney General (Canada) and Attorney General (Quebec)*,<sup>127</sup> the eligibility criterion "at the end of life" was found by a Quebec Superior Court judge to violate the *Canadian Charter of Rights and Freedoms*. She declared the provision to be invalid. The declaration of invalidity was suspended for six months to give the Quebec National Assembly time to respond if it wanted to. The Quebec Attorney General chose not to appeal this decision. The "end of life" provision therefore ceased to have any effect as of March 2020. At the time of this writing, Québec has signalled no intention to introduce changes to its own law. However, it has indicated its intention to address the issue of eligibility for MAiD where mental disorder is the sole underlying medical condition.

## **Criminal Code of Canada**

'Terminal illness' is not a prerequisite for requesting MAiD in the *Criminal Code*. However, as originally passed, the legislation limited access to MAiD to those with a "grievous and irremediable medical condition" which is defined as:

- having a serious and incurable illness, disease or disability;
- being in an advanced state of irreversible decline in capability;
- that illness, disease or disability or that state of decline causing them enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that you consider acceptable; and
- their natural death having become reasonably foreseeable, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining.

In *Truchon and Gladu*, the eligibility criterion "natural death having become reasonably foreseeable" was also found by a Quebec Superior Court judge to violate the *Canadian Charter of Rights and Freedoms* and was declared invalid. The federal government also chose not to appeal this decision. The "reasonably foreseeable" provision will therefore cease to have any effect in Quebec as of December 2020 (there is some dispute over the effect of the decision in the rest of Canada as the Attorney General argued that its effect was limited to Quebec but the judge expressed doubt about that claim given that the Attorney General had chosen not to appeal the decision).

In Bill C-7, the Government removed the eligibility criterion of "reasonably foreseeable natural death". However, it retained the distinction between natural deaths that are reasonably foreseeable and those that are not; the latter must meet additional procedural safeguards en route to MAiD (e.g., a 90-day waiting period between the request and provision). [section 1(3)]

Part of what the federal Parliament must wrestle with is one effect of the removal of the "reasonably foreseeable" criterion, i.e., the expansion of those who could be eligible for MAiD. In particular, more persons with mental disorders as their sole underlying medical condition may become eligible. As required by their own MAiD legislation, the federal government commissioned an independent review on "the state of knowledge on MAiD for persons with mental disorders as their sole underlying medical condition". As with advance requests and mature minors, the Council of Canadian Academies Expert Panel Working Group on mental disorders presented extensive evidence on the issue, including experience in other jurisdictions, but made no recommendations concerning the appropriate legislative responses to MAiD for persons with mental disorders as their sole underlying medical condition.<sup>128</sup>

In Bill C-7, the Government included a provision that excludes all persons with mental illness as their sole underlying medical condition (by stipulating that a mental illness is not considered a "serious and incurable illness, disease or disability"), indicating that it intends to explore this issue through the five-year review.

**Recommendation 27:** *There should be a short (for example, twenty-four hours) pause before assistance is provided to allow confidence that all of the conditions and procedural requirements have been met. Beyond that, the Panel does not recommend any delay requirements.*

The Quebec legislation does not require a waiting period. The *Criminal Code* requires 10 days between the request for MAiD and its provision (unless loss of capacity or natural death are imminent).<sup>129</sup> Under Bill C-7, there would no longer be a waiting period (where natural death has become reasonably foreseeable) but there would be a 90-day waiting period (where natural death has not become reasonably foreseeable).

**Recommendation 28:** *Health care professionals should be permitted to provide assistance with suicide or voluntary euthanasia.*

The *Criminal Code* permits both physicians and nurse practitioners to assess and provide MAiD.<sup>130</sup>

The Quebec legislation only contemplates physicians providing MAiD.<sup>131</sup>

**Recommendation 29:** *Health care professionals should not be required to provide assistance. However, should they decide not to provide assistance, they are obligated to pass the person requesting assistance on to a professional who will provide such assistance.*

The Quebec legislation explicitly addresses conscientious objection:

31. A physician practising in a centre operated by an institution who refuses a request for medical aid in dying for a reason not based on section 29 must, as soon as possible, notify the executive director of the institution or any other person designated by the executive director and forward the request form given to the physician, if that is the case, to the executive director or designated person. The executive director of the institution or designated person must then take the necessary steps to find, as soon as possible, another physician willing to deal with the request in accordance with section 29.

If the physician who receives the request practises in a private health facility and does not provide medical aid in dying, the physician must, as soon as possible, notify the executive director of the local authority referred to in section 99.4 of the Act respecting health services and social services (chapter S-4.2) that serves the territory in which the patient making the request resides, or notify the person designated by the executive director. The physician forwards the request form received, if that is the case, to the executive director or designated person and the steps mentioned in the first paragraph must be taken.

If no local authority serves the territory in which the patient resides, the notice referred to in the second paragraph is forwarded to the executive director of the institution operating a local community service centre in the territory or the person designated by the executive director.

32. All information and documents in connection with a request for medical aid in dying, regardless of whether the physician administers it or not, including the form used to request such aid, the reasons for the physician's decision and, where applicable, the opinion of the physician consulted, must be recorded or filed in the patient's record.

A decision to withdraw a request for medical aid in dying or to put off the administration of such aid must also be recorded in the patient's record.<sup>132</sup>

The legislation that amended the *Criminal Code* also explicitly addresses conscientious objection as follows in its preamble:

Whereas nothing in this Act affects the guarantee of freedom of conscience and religion;



And in the body of the legislation:

(9) For greater certainty, nothing in this section compels an individual to provide or assist in providing medical assistance in dying.<sup>133</sup>

Instructions and/or guidelines concerning the obligations of health care professionals who conscientiously object to providing or assisting in MAiD fall to provincial/territorial regulatory bodies. In Ontario the CPSO requires objecting physicians to provide their patients with an “effective referral...to a non-objecting, available, and accessible physician or agency”.<sup>134</sup> This policy was challenged by the Christian Medical and Dental Association of Canada on the ground that it violated physicians’ freedom of conscience and religion. In its decision the Ontario Superior Court of Justice rejected this argument and upheld the effective referral requirement.<sup>135</sup> This decision was upheld on appeal.<sup>136</sup>

**Recommendation 30:** *A national oversight commission should be established to monitor and report annually and publicly on assisted suicide and voluntary euthanasia in Canada. The Panel sees two roles for this oversight body. The first role is maintenance of public trust in the system. The second is the prevention of mistaken or intentional violations of the new law. The means of realizing the first objective is the collection of data and the reporting of the data in aggregated form. The means of realizing the second is expert assessment of specific cases with appropriate follow-up, which could be engagement with specific individual providers or more general education programmes for health care providers or the general public. Obviously, the coroners, police and prosecution services will continue to have the authority and responsibility to investigate and prosecute potential violations of the law.*

A national oversight commission has not been established. However, the first objective identified in the Expert Panel Report for the commission is being met by Health Canada. MAiD providers must report directly<sup>137</sup> or indirectly (through their province/territory<sup>138</sup>) to Health Canada<sup>139</sup> and Health Canada reports aggregated data at least annually.<sup>140</sup>

The second objective described in the Expert Panel Report has not been assigned to anybody at the federal level. To date, there is no national process for reviewing MAiD deaths. Individual provinces and territories provide oversight of these deaths, and they are generally reported to and investigated by Offices of the Chief Coroner, Chief Medical Examiners, designated MAiD investigation units, or Ministries of Health. These bodies generally escalate any potentially problematic practices to medical regulatory colleges.

Provincial/territorial coroners, medical examiners, police, and prosecution services continue to have the authority and responsibility to investigate and prosecute potential violations of the law. Their involvement in cases of MAiD is inconsistent across the country (e.g., MAiD deaths must be reported to the Coroner or Medical Examiner in Ontario but not in Nova Scotia).

As a non-legislative step announced at the same time as the introduction of Bill C-7, the government made the following commitment: “Minister of Health to work with provinces and territories, health system partners and health practice regulatory bodies to develop, implement, monitor and report on MAiD practice guidelines, training and retrospective review processes and results.”

As required by Bill C-14, the federal government issued non-binding guidelines for reporting cases of MAiD (i.e., what information to include on death certificates).<sup>141</sup> These are non-binding because death reporting and investigation falls within provincial/territorial jurisdiction. Despite

the publication of the federal guidelines, reporting of MAiD on medical certificates of death is inconsistent across Canada.<sup>142</sup>

Quebec is unique in Canada as, under its MAiD legislation, it established a Commission on End of Life Care.<sup>143</sup> The Commission performs both functions recommended by the Expert Panel: gathering and reporting on aggregate data and assessment of specific cases to assess and ensure compliance with the legislation.

**Recommendation 31:** *Requirements for assessments, declarations of request, statements of reasons for requests, and document filing should be set out in statute and be designed to minimize the intrusion on the person seeking assistance but also be sufficient to make possible effective oversight.*

The federal government passed regulations that require most but not all of the information the Expert Panel recommended gathering.<sup>144</sup> Notably, however, the regulations do not require reporting on the reasons for requests for MAiD and the regulations are not sufficient to make the recommended oversight possible as specific cases are not assessed.

In Bill C-7, the government has amended the reporting requirements to expand data collection (e.g., expanding reporting requirements to pharmacy technicians and to practitioners who assess MAiD eligibility—whether formal or preliminary assessments—even before a written request).

Similarly, the Quebec *Act respecting end-of-life care* requires most but not all of the information. Again, statements of reasons for requests are not required. However, unlike the federal regulations, the Quebec approach is sufficient to make the recommended oversight possible.

Oversight in the other provinces/territories varies in terms of such details as who receives the reports on requests (whether it is all requests or only those that are fulfilled), what information is gathered, and what kind of scrutiny specific cases receive. MAiD data are published by some provincial and territorial bodies, and Health Canada has published several interim reports containing this data.<sup>145</sup> Health Canada began formally collecting MAiD-related data from all provinces and territories in late 2018 in an effort to increase transparency of national MAiD practices. Annual public reporting of this data began in Spring 2020.

## Part IV: Ongoing Policy and Statutory Challenges

### 4.1 Withholding and Withdrawal of Potentially Life-sustaining Treatment (Recommendations 1-8)

#### *Withholding and withdrawal of potentially life-sustaining treatment*

Arguably, there are no longer strong reasons to press the Expert Panel's recommendations concerning the legal status of these practices, given the statements made by the courts in recent MAiD cases and by the federal Justice Department counsel during hearings on Bill C-14.

For example, Justice Smith in *Carter* summarized the law as follows:

[220] Since *Rodriguez*, the common law principles relating to competent adult patients have been clear. Individual autonomy gives competent, informed patients the right to consent to treatment, including the right to withdraw consent to life-sustaining treatment.<sup>146</sup> [position affirmed by Supreme Court of Canada<sup>147</sup>]

Consistent with this, Joanne Klineberg, Senior Counsel, Criminal Law Policy Section, Department of Justice, testified before the Special Joint Committee of the House and Senate on Physician-Assisted Dying:

As a preliminary matter, there sometimes appears to be some uncertainty, at least among some Canadians, about what physician-assisted dying is and what it is not. Physician-assisted dying is not the act of withdrawing medical treatment that a patient does not want, nor does it refer to a patient's right to refuse treatment or medicine in the first place. In these circumstances, if death does result from the withdrawal or the refusal of the medication, this is not a crime because the cause of death is the underlying medical condition. No mentally competent person can be compelled to receive treatment they do not want, as this would amount to an assault in criminal law and also a civil wrong. Physician-assisted dying refers to conduct that involves someone, a physician, actively participating in bringing about the death of another person.<sup>148</sup>

#### **Mature minors**

Legislators and government departments have not addressed the need for clarification with respect to the mature minor rule for end-of-life decision-making identified in the Expert Panel Report. However, as noted in section 3.1 (above), other organizations have offered clarifications for their members, clients, or communities. The need for legislative action has therefore now diminished. That said, statutory clarification would still be useful if for no other reason than to reduce the need for costly and corrosive litigation in specific cases in which the legal status of mature minors' decisions is contested.

**Meeting the Expert Panel's recommendation would require the provision of a statutory clarification by all provincial/territorial governments that do not currently provide clarity with respect to consent and mature minors.**

On the reasoning of the Expert Panel, there would now be a need to resolve the differential treatment of MAiD for mature minors and other health care decision making (including decisions with the consequence of ending life) for mature minors because: MAiD is now legal for adults in Canada; mature minors have the legal authority to refuse potentially life-sustaining treatment; and

in *Carter v Canada* the British Columbia Supreme Court found the distinction between MAiD on the one hand and withholding or withdrawal of potentially life-sustaining treatment on the other to be arbitrary and unsustainable.

**Meeting the Expert Panel’s recommendation would further require the federal government to make a choice between permitting MAiD for mature minors (through an amendment to the Criminal Code) and justifying treating decision-making for MAiD differently than other health care decision making (including decisions with the consequence of ending life) for mature minors.**

See Section 4.6, below, for recommendation of the first of these two options.

### ***Unilateral withholding and withdrawal of potentially life-sustaining treatment***

The Expert Panel’s concerns about confusion, conflict, and controversy surrounding this issue remain valid and inadequately addressed.<sup>149</sup>

**Meeting the Expert Panel’s recommendations would require provincial/territorial governments to make it clear when, if ever, health care professionals have the legal authority to unilaterally withhold or withdraw potentially life-sustaining treatment.**

It would further require health care professional regulators (other than Manitoba, Ontario, and Quebec) to amend their policies to make it clear when, if ever, health care professionals have the legal authority to unilaterally withhold or withdraw potentially life-sustaining treatment.

In addition, health care professional educational institutions should continue to ensure that clinicians are educated on this issue.

## **4.2 Advance Directives (Recommendations 9-12)**

Since 2011 there has been a noticeable increase in research into advance care planning. Both before and after the publication of the Expert Panel Report, considerable efforts were already underway nationwide by both governmental and non-governmental actors to increase awareness and develop resources to foster advance care planning. **Now that excellent resources exist, the next phase should turn to implementation, focusing on both patients and providers.** It remains to be seen whether an administrative mechanism such as a registry (whether provincial or local) is used by the public or proves useful in clinical care.

## **4.3 Palliative Care (Recommendations 13-14)**

Since 2011, considerable efforts have been made by governments, health care institutions, and health care providers in addressing the concerns identified by the Expert Panel Report. These concerns, however, remain significant.

**Efforts are still needed to ensure that high quality palliative care is accessible to individuals that need and want it, including expanding palliative care beyond cancer.**

At the federal level the statutorily-mandated five-year review of the MAiD legislation must include “the state of palliative care in Canada”. This review will provide an opportunity to identify where the gaps are so that further initiatives can be taken to target those gaps.

#### 4.4 Potentially Life-shortening Symptom Relief (Recommendations 15-16)

The Expert Panel Report identified a number of risks for clinicians resulting from a lack of clarity concerning potentially life-shortening symptom relief, including fear of liability, insufficient symptom relief, and use of potentially life-shortening symptom relief instead of MAiD.

**While some of these risks have been reduced by the legalization of MAiD, the need for clarification remains for cases in which individuals are experiencing enduring, intolerable, and irremediable suffering but are not eligible for MAiD.**

#### 4.5 Terminal Sedation (Recommendations 17-19)

The concerns identified in the Expert Panel Report remain valid and have not yet been addressed anywhere other than in Quebec (and, even in Quebec, only for continuous palliative sedation that will not hasten death).<sup>150</sup>

**Meeting the Expert Panel’s recommendations would require the federal government to revise the *Criminal Code* to make it clear that palliative sedation in circumstances where it *will* hasten death is MAiD for the purposes of the *Criminal Code*, and is subject to the same procedural conditions and requirements as other forms of MAiD, and that palliative sedation in circumstances where it only *may* hasten death is not MAiD for the purposes of the *Criminal Code*.**

The ongoing areas of concern—which include differences in clinical and legal definitions of palliative sedation, lack of data concerning its incidence and prevalence, as well as the ambiguities concerning what does and does not hasten death—indicate the need for collaboration between government, legal bodies, health care professional regulators, and clinicians in establishing legal and clinical standards that are clear to patients, clinicians, and the courts.

#### 4.6 Assisted Suicide and Voluntary Euthanasia (Recommendations 20-31)

Many of the Expert Panel’s recommendations on this topic are now moot since the legalization of MAiD. However, on some issues the Expert Panel’s concerns remain valid and inadequately resolved.

##### **Advance requests**

**Meeting the Expert Panel’s recommendation would require the federal government to amend the *Criminal Code*, and the Quebec government to amend their *Act respecting end of life care*, to permit respecting requests for MAiD made while capable but in advance of loss of capacity.**

The federal government took a first step toward meeting this recommendation in Bill C-7, which effectively allows for waiver of the final consent requirement for persons who have been assessed and found eligible for MAiD where their natural death has become reasonably foreseeable and procedural safeguards have been met. It also allows for advance consent to provider administration of assistance in dying in cases in which a person has lost capacity after supervised self-administration of a lethal substance that fails to take effect within a specified period of time. The question whether to allow advance requests for MAiD before the person has been assessed as meeting

the eligibility criteria, and before procedural safeguards have been met, will be considered in the five-year review of the 2016 legislation. The Quebec National Assembly has already initiated a reflection and consultation process with an expert panel report on the topic.

### ***Mature minors***

**Meeting the Expert Panel's recommendation would require the federal Parliament and Quebec National Assembly each to amend their legislation to allow mature minors to access MAiD.**

This issue will also be explored in the course of the five-year review of the federal legislation.

### ***Mental illness***

The federal government's Bill C-7 explicitly excludes persons with mental illness as their sole underlying medical condition from eligibility for MAiD.

**Meeting the Expert Panel's recommendation would require the federal Parliament *not* to amend the MAiD legislation to exclude mental illness as an illness, disease, or disability.**

This issue will also be explored in the course of the five-year review of the federal legislation.

### ***Waiting period***

The concerns about anything more than a short (for example 24-hour) waiting period identified by the Expert Panel remain active and the arguments with respect to delays remain valid.

Through Bill C-7, the government intends to remove the 10-day waiting period entirely for individuals whose natural death has become reasonably foreseeable. For those whose natural death has not become reasonably foreseeable, there will be a 90-day waiting period.

**Meeting the Expert Panel's recommendation would require the federal Parliament to amend the MAiD legislation to remove the 10-day waiting period for all and not, as proposed, add a 90-day waiting period for those whose natural death is not reasonably foreseeable.**

### ***Conscientious objection***

**Meeting the Expert Panel's recommendation would require the Colleges of Physicians and Surgeons and Colleges of Nurses that have not already done so to include a duty of effective referral or transfer of care in their professional standards.**

### ***Oversight and reporting***

The Quebec National Assembly has created a provincial oversight body to perform the functions identified by the Expert Panel. The federal parliament has not. What follows is directed at the federal parliament.

The inconsistencies in approach to oversight of MAiD across the country will make comparative analysis difficult. The lack of a central repository of reports and inconsistency concerning medical certificates of death will make research difficult. Therefore, the goal of maintenance of the public trust identified by the Expert Panel is less likely to be achieved than if the Panel's recommendations had been followed.

There also remains a need to gather information about the incidence of findings of ineligibility, and the reasons for these findings, in order to be able to evaluate possible lack of access to MAiD (which is the inverse of the risk of overinclusion identified by the Expert Panel). This issue has been at least partially addressed through the expansion of reporting requirements to include clinicians who have conducted an actual or preliminary assessment of eligibility for MAiD even before a written request.

While introducing Bill C-7, the government also committed to non-legislative measures in respect of reporting: “Minister of Health to work with provinces and territories, health system partners and health practice regulatory bodies to develop, implement, monitor and report on MAiD practice guidelines, training and retrospective review processes and results.”<sup>151</sup>

The positive benefits of a national oversight commission and the concerns about not having one remain active (indeed are manifest through the patchwork system that has developed) and the arguments with respect creating such a commission remain valid.

**Meeting the Expert Panel’s recommendation would require the federal Parliament to establish a national oversight commission to monitor and report annually and publicly on MAiD in Canada. This commission would have to work collaboratively with the Québec End of Life Care Commission to ensure comparability in the data collected and reported. The commission would have two roles: maintenance of public trust in the system; and the prevention of mistaken or intentional violations of the MAiD law.**

# Appendix I: From the Expert Panel to C-14 (and Beyond): The Evolution of MAiD Legislation in Canada

Legend	
Yes	
No	

	RSC Expert Panel <sup>152</sup>	Quebec Bill 52 <sup>153</sup>	Carter decision <sup>154</sup>	Prov/Terr Expert Advisory Group <sup>155</sup>	Special Joint Committee <sup>156</sup>	Canada Bill C-14 <sup>157</sup>	Truchon/Gladu decision <sup>158</sup>	Quebec post 11/03/20	Canada Bill C-7 <sup>159</sup>
	2011	2014	2015	2015	2016	2016	2019	2020	2020
Competent	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Special skills for eligibility assessments	No	No	No	No	No	No	No	No	If not NDRF
Advance request before diagnosis	Yes	No	N/A	Study further	No	No	N/A	No	Study further
Advance request after diagnosis before eligibility	Yes	No	N/A	Yes	Yes	No	N/A	No	Study further
Advance request after assessed and approved	Yes	No	N/A	Yes	Yes	No	N/A	No	If NDRF
Mature minors	Depends on P/T	No	N/A	Yes	Yes	No	N/A	No	Study further
Voluntary and informed	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Incurable/irremediable condition	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Irreversible decline	No	Yes	No	No	No	Yes	Yes	Yes	Yes
Irremediable suffering	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Terminal	No	No	No	No	No	No	No	No	No
Natural death reasonably foreseeable (NDRF)	No	No	No	No	No	Yes	No	No	No
End of life	No	Yes	No	No	No	No	No	No	No
Mental illness excluded	No	No	No	No	No	No	No	No	Study further
Waiting period	"Short" (24hr)	0	N/A	flexible	flexible	10 days	N/A	0	0 or 90 days (NDRF)
Provider- and self-administered	Yes	No	Yes	Yes	Yes	Yes	Yes	No	Yes
Duty to provide	No	No	"reconcile"	No	No	No	silent	No	silent
Duty to refer/transfer care	Yes	Yes	"reconcile"	Yes	Yes	silent	silent	Yes	silent
Reporting requirements	Yes	Yes	N/A	Yes	Yes	Yes	N/A	Yes	Yes
Oversight commission	Yes	Yes	N/A	Yes	No	No	N/A	Yes	No



## References

- 1 Rodriguez v. British Columbia (Attorney General), (1993) 3 S.C.R. 519. There was one later case: Wakeford v Canada (2001), 81 CRR (2d) 342, upheld in Wakeford v Canada 91 CRR (2d) 213, leave to appeal denied SCC 2002. The case failed to progress because the Supreme Court ruled that the matter had already been determined in Rodriguez.
- 2 Canada, Special Senate Committee on Euthanasia and Assisted Suicide, Of Life and Death—Final Report (Ottawa: Special Senate Committee on Euthanasia and Assisted Suicide, 1995).
- 3 <http://www.cmq.org/publications-pdf/p-1-2009-10-01-en-medecin-soins-appropries-debat-euthanasie.pdf>
- 4 [https://rsc-src.ca/sites/default/files/RSCEndofLifeReport2011\\_EN\\_Formatted\\_FINAL.pdf](https://rsc-src.ca/sites/default/files/RSCEndofLifeReport2011_EN_Formatted_FINAL.pdf)
- 5 Carter v Canada (Attorney General), (2012) BCSC 886, at para 129.
- 6 Ibid., at para 296.
- 7 Ibid., at para 866.
- 8 Ibid., at para 883.
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- 18 <https://cpsns.ns.ca/guideline/informed-patient-consent-to-treatment/>
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- 21 Guide: pratique médicale en soins de longue durée - <http://www.cmq.org/publications-pdf/p-1-2015-04-01-fr-pratique-medicale-en-soins-de-longue-duree.pdf> ; Guide: le médecin et le consentement aux soins - <http://www.cmq.org/publications-pdf/p-1-2018-09-11-fr-medecin-consentement-aux-soins.pdf>
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- 24 Bioethics, Section V- End of Life Care. <http://www.royalcollege.ca/rcsite/bioethics/bioethics-cases-e>
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- 27 Bandrauk N, Downar J, Paunovic B. Withholding and withdrawing life-sustaining treatment: The Canadian Critical Care Society position paper. *Can J Anaesth.* 2018;65(1):105-122.
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- 29 <https://www.health.gov.bc.ca/library/publications/year/2013/MyVoice-AdvanceCarePlanningGuide.pdf>
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- 32 <https://www.quebec.ca/en/health/health-system-and-services/end-of-life-care/advance-medical-directives/requirements/>
- 33 <https://extranet.ahsnet.ca/teams/policydocuments/1/clp-consent-to-treatment-prr-01-02-procedure.pdf>
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- 35 Emphasis added.
- 36 <https://www.cps.ca/en/documents/position/medical-decision-making-in-paediatrics-infancy-to-adolescence>
- 37 <https://www.cfpna.ca/single-post/2017/04/03/Mature-Minor-Assessment-Tool>
- 38 <https://www.cmpa-acpm.ca/en/advice-publications/browse-articles/2014/can-a-child-provide-consent>

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- 41 *Ibid.*, Section 3.5.
- 42 An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying), SC 2016, c 3, s 241.2(1)(b).
- 43 *Cuthbertson v. Rasouli*, 2013 SCC 53, [2013] 3 S.C.R.
- 44 *Wawrzyniak v. Livingstone*, 2019 ONSC 4900.
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- 47 Standards of Practice of Medicine. <http://www.cpsm.mb.ca/laws-and-policies/standards-of-practice-of-medicine>. The CPSM had a policy on this issue that predated the Expert Panel Report: Downie, J, McEwen, K. The Manitoba College of Physicians and Surgeons position statement on withholding and withdrawal of life-sustaining treatment (2008): Three problems and a solution. *Health Law J* 2009;17:115-37.
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