



# Consultations on Physician-Assisted Dying Summary of Results and Key Findings

### **FINAL REPORT**



**15 December 2015** 



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ISBN 978-0-660-04244-2

Cat. No. J2-420/2016E-PDF



# External Panel on Options for a Legislative Response to *Carter v. Canada* Comité externe sur les options de réponse législative à *Carter c. Canada*



#### **15 December 2015**

The Honourable Jody Wilson-Raybould Minister of Justice and Attorney General of Canada 284 Wellington Street Ottawa, Ontario K1A 0H8

The Honourable Jane Philpott
Minister of Health
Health Canada
70 Colombine Driveway, Tunney's Pasture
Ottawa, Ontario
K1A 0K9

#### Dear Minister Wilson-Raybould and Minister Philpott:

We are pleased to provide you with a copy of our report summarizing the results and key findings of our consultations in Panel on Options for a Legislative Response to *Carter v. Canada*. We thank you for the confidence fulfillment of the mandate of the External that you placed in us and for the opportunity to serve such an important cause.

With great deference to the Supreme Court of Canada and for the supremacy of Parliament to ultimately decide how Canada will respond to this historic ruling, our goal was to bring the results of our work to the minds of Parliamentarians. We support your efforts to make Canada not only a better country to live in, but a better country to die in. From the outset we set about to enrich the debate around physician-assisted dying. We tried to stay true to our task by listening well and listening from a position of empathic neutrality.

We would like you to know that our meetings across Canada and internationally have been rich in content, respectful in tone, and broad-reaching in consequence. Our hope is simply that the insight we received over the course of our work is reflected in our report.

Following your consideration, it is our expressed desire that this report will be made publicly available in the same spirit of transparency and openness that interveners, stakeholders and indeed Canadians greeted us.

We will gather as a Panel for a final time on December 17, 2015. Our objective for that meeting is twofold. Firstly, we want to assure a smooth and formal transfer of all materials to government and, secondly, to identify the key steps required for ceasing Panel operations.

Any mistakes and oversight in the following pages are our own. We offer our report with hope that it is useful to you and your Parliamentary colleagues as you undertake the next crucial stage of this conversation. We remain grateful for the rich experience and for the honour it has been to serve.

Respectfully,

Dr. Harvey Max Chochinov, O.C., O.M., M.D., Ph.D., FRCPC, FRSC, Chair

Cotherine Frazee

Professor Catherine Frazee, O.C., D.Litt., LL.D., Panel Member

ensit Melleries

Professor Benoît Pelletier, O.Q., FRSC, Ad. E., LL.D., LL.D., LL.D. (hon.), Panel Member

cc: Stephen Mihorean, Executive Director, Secretariat to the External Panel on Options for a Legislative Response to *Carter v. Canada*.

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### **Executive Summary**

The Ministers of Justice and Health formally established the External Panel on Options for a Legislative Response to *Carter v. Canada* (the Panel) on 17 July 2015. The Panel's mandate was to hold discussions with the interveners in *Carter* and with "relevant medical authorities," and to conduct an online consultation "open to all Canadians and other stakeholders." During an ambitious five-month schedule, the Panel held in-depth meetings on physician-assisted dying with stakeholders and experts, both in Canada and abroad. This report presents a summary of the results and key findings of the Panel's direct and online consultation.

The Panel's consultation activities focused on issues that are fundamental to a federal legislative response to the *Carter* ruling, as outlined in the Panel's terms of reference:

- The different forms of physician-assisted dying, namely assisted suicide and voluntary euthanasia
- Eligibility criteria and definition of key terms
- Risks to individuals and society associated with physician-assisted dying
- Safeguards to address risks and procedures for assessing requests for assistance in dying and the protection of physicians' freedom of conscience

The report begins by exploring the legal context surrounding *Carter v. Canada*, the issues raised at trial and the outcome. Along with providing a detailed account of the primary issues, this section examines the relevant areas of law at play in *Carter* and outlines the Supreme Court of Canada's reasoning. The Supreme Court's decision in *Carter* served as the frame for both the consultations and this report. The Panel expresses its unqualified deference to the Supreme Court and its respect for the supremacy of Parliament to ultimately decide how Canada will respond to the *Carter* ruling.

The Panel sought a broad and diverse range of perspectives to ensure that discussions about access to physician-assisted dying and safeguards for vulnerable persons were informed by the insights of patients, family, advocates and all members of multidisciplinary health care teams. Another important aspect of the Panel's investigation came from jurisdictions where various forms of assisted dying are legal. The detailed chronology of Panel activities included in this report helps demonstrate the volume and depth of its investigation.

Over the course of its work, the Panel held meetings with 73 individual experts in Canada, the United States, the Netherlands, Belgium and Switzerland. From 20 October to 6 November 2015, the Panel consulted directly with 92 representatives of interveners, medical authorities and stakeholders from 46 Canadian organizations. In addition, the Panel received and considered 321 written submissions from civil-society organizations, academics and individual citizens.

To solicit opinions online, the Panel posted a questionnaire—the Issue Book—on its website from 20 August to 23 November 2015. In total, 14,949 individuals completed the questionnaire, providing the

Panel with invaluable data detailing the diversity of Canadians' views on the implementation of physician-assisted dying. The total figure included a nationally representative sample of 2,066 Canadians.

The Panel engaged an independent third-party expert to provide an assessment of the conclusions that can reliably be drawn from the extensive data collected and to guide its interpretation. Dr. Richard Jenkins' assessment indicated that the Panel "can and should use the results of the consultation... as a reflection of the views of Canadians on the issue." His full review is provided in Annex B to the Panel's report.

The Report on Issue Book Results (Annex A) provides a rich source of information and insight. For example:

- Participants demonstrated strong levels of support for:
  - A national oversight body for physician-assisted dying (>70%)
  - o A national strategy on palliative and end-of-life care (>76%)
  - A comprehensive national home-care strategy (>78%)
  - o A national strategy on disability supports (>80%)
  - o Palliative care education for all health care providers (>84%)
- Respondents were more likely to agree that physician-assisted death should be allowed when a person faces significant, life-threatening and/or progressive conditions.
- Participants were generally more concerned about risks for persons who are mentally ill, especially those with episodic conditions, and for persons who are isolated or lonely.

The main body of the report is structured to align with the potential process an individual seeking physician-assisted dying may navigate: beginning with discussions of the person's eligibility and request, through processes of assessment, to methods of determination and issues related to the provision of physician-assisted death.

As a preliminary step, the report discusses terminology used to refer to procedures no longer prohibited pursuant to the *Carter* decision. Noting that the Supreme Court of Canada adopts the language of physician-assisted death/dying but does not make findings about terminology, the Panel follows the same approach. The terms physician-assisted death and physician-assisted dying are used interchangeably throughout the report. During its consultations, however, the Panel learned that many healthcare and civil society advocates prefer other expressions, some more explicit—such as assisted suicide and voluntary euthanasia, and some more particular—such as physician-hastened death and physician-administered or physician-prescribed assistance in dying. The connotations, meanings and implications of these different approaches are discussed in the report.

A person seeking physician-assisted death must meet the eligibility criteria set out by the Supreme Court in *Carter*. According to the Court, an eligible individual is:

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.<sup>1</sup>

From this starting point, the report begins to consider the question of who will be eligible to request and receive physician-assisted death. This examination reveals a range of often divergent views on a host of related questions, such as:

- 1) Who is an adult?
- 2) Who is competent, for the purposes of a request for physician-assisted death?
- 3) What does a "grievous and irremediable medical condition" mean?
- 4) What is meant by "enduring suffering that is intolerable to the individual"?
- 5) How is the voluntary nature of the request guaranteed?

The Panel reviewed these and numerous supplementary questions without drawing conclusions, in the interest of representing multiple perspectives and supporting the development of an effective regulatory response to *Carter*.

The report next considers possible parameters for the request itself, reviewing stakeholder submissions that elaborate on the Court's requirement that the request originate from the individual who seeks a physician-assisted death. Stakeholders shared their perspectives on how—and how often—a request must be communicated, whether an independent witness must verify the request, and what roles—if any—family members should play in the process.

Once a request is initiated, an assessment must be conducted to establish eligibility and to determine if the request is truly voluntary. Consistent with good medical care, these processes demand careful consideration of the individual's suffering and some exploration of therapeutic options. A majority of stakeholders in the Panel's consultations indicated that the person's physician should conduct a careful assessment, as is the case in most jurisdictions that permit assisted-dying. The report reviews proposals for possible supplementary or complementary assessments, such as an evaluation by a second physician or a specialist in palliative care or psychiatry. Some stakeholders suggested that assessments involve other professionals, including nurses, pharmacists, spiritual-care providers and Indigenous elders. The Panel also heard calls for the participation of social workers or psychologists to help assess and address the social health determinants that can compromise the autonomy of a person who is vulnerable to abuse, coercion or undue influence.

A section of the report focuses on the legal, ethical and clinical aspects of informed consent—a fundamental safeguard. Another section describes various perspectives on waiting periods, also considered a safeguard. Many stakeholders believe that waiting periods, whether mandatory or discretionary, help ensure that the choice of physician-assisted death is not reflexive, but fully

<sup>&</sup>lt;sup>1</sup> Carter v. Canada (Attorney General), 2015 SCC 5 at para. 127 [Carter].

considered. As in the other sections of the report, well-reasoned and thoughtful submissions canvass the range of possible approaches.

The Panel next focuses its reporting on the contentious question of who will make the final determination in response to a request for a physician-assisted death. The Panel illuminates the various options heard during consultations. Some stakeholders would require a formal authorization from a judge, tribunal or specialty panel; others believe such decisions are best left between individuals and physicians.

In subsequent chapters of the report, the Panel addresses issues of clinical participation and compliance, including the important issue of conscience protection. The *Carter* decision is clear that no physician will be compelled to provide assisted dying if they conscientiously object. Many interveners and stakeholders offered extensive contributions, notably on the matter of referrals—whether a conscientious objector should be required to refer requests to another health care professional or institution. Here again, views diverge widely. The report also explores the notion of a duty to inform a person about where to turn for assistance with physician-assisted death. This section also reflects upon issues of appropriate training and certification for physicians, and addresses the enforcement of regulations and legal protections for those who comply with assisted-dying protocols in good faith.

A vital section of the report identifies a striking outcome of the consultations, namely that the vast majority of participants supported—without debate—the priority of developing an effective system of oversight. Advocacy groups, medical regulators, supporters and opponents all recognized that there should be mechanisms in place to ensure that physician-assisted dying occurs in a transparent, effective and trustworthy manner. The Panel presents its findings on existing oversight mechanisms, and discusses the leadership role that governments might play through the implementation of robust, modern and innovative oversight. While some groups, acknowledging the provincial role in health care, contemplated the use of various provincial and territorial oversight bodies, most were in favour of a pan-Canadian approach that would yield consistent policy throughout the country.

Before concluding its report, the Panel offers its perspective on the larger questions of end-of-life care, bringing particular emphasis, consistent with all that was heard in its consultations, to the urgent need for improved access to excellent palliative care across Canada. The Panel heard on many occasions that a request for physician-assisted death cannot be truly voluntary if the option of proper palliative care is not available to alleviate a person's suffering.

As will be evident from the range and complexity of issues described in this report, responding to the Court's decision in *Carter* requires of our governments and medical regulators a great many deliberations and decisions. Among the competing claims and arguments to be settled in these determinations, none are more fundamental than the issue identified by the Supreme Court as central to its adjudication: namely, the balancing of competing values of great importance. "On the one hand," the Court wrote, "stands the autonomy and dignity of a competent adult who seeks death as a response to a grievous and irremediable medical condition. On the other stands the sanctity of life and the need to protect the vulnerable." The Panel hopes that the contributions of thousands of Canadians, whose perspectives are reflected in its report, will assist the ministers of Justice and Health as they approach the next and final phase of responding to the Court's decision in *Carter*.

## Panel Member Biographies

Dr. Harvey Max Chochinov O.C., O.M., M.D., Ph.D., FRCPC, FRSC, FCAHS Chair



Dr. Harvey Max Chochinov is a Distinguished Professor of Psychiatry at the University of Manitoba and Director of the Manitoba Palliative Care Research Unit, CancerCare Manitoba. He holds the only Canada Research Chair in Palliative Care. His publications addressing psychosocial dimensions of palliative care have helped define core-competencies and standards of end-of-life care. He did his undergraduate medical training and Psychiatric Residency at the University of Manitoba and completed a Fellowship in Psychiatric Oncology at Memorial Sloan-

Kettering Cancer Center, New York, New York. In 1998, he completed a PhD in the Faculty of Community Health Sciences, University of Manitoba. Dr. Chochinov is the Chair of the Canadian Virtual Hospice.

Dr. Chochinov's research has been supported by the Canadian Institutes of Health Research, the Canadian Cancer Society Research Institute and the National Institute of Health. His work has explored various psychiatric dimensions of palliative medicine, such as depression, desire for death, will to live and dignity at the end of life. He has been a guest lecturer in most major academic institutions around the world. He is the only psychiatrist in Canada to be designated as a Soros Faculty Scholar, Project on Death in America. He is a recipient of the Queen's Golden Jubilee Medal, the Order of Manitoba, and in 2014, was appointed an Officer in the Order of Canada. He is the Chair for the Canadian Virtual Hospice, a Fellow of the Royal Society of Canada and a Fellow of the Canadian Academy of Health Sciences. Besides many other national honors, in 2012 the Canadian Medical Association bestowed its highest recognition, the FNG Starr Award.

Dr. Chochinov has served on many prestigious boards, nationally and internationally. He was a member of the Governing Council of the Canadian Institutes of Health Research (CIHR) for seven years, during which time he also chaired the CIHR Standing Committee on Ethics. He is the only Canadian to serve on the Scientific Advisory Board of the National Palliative Care Research Center (NYC, USA); and the only Canadian to serve on the prestigious international scientific expert panel of the Cicely Saunders Foundation (London, UK). In addition to over 200 publications, he is the Co- Editor of the Handbook of Psychiatry in Palliative Medicine, published by Oxford University Press, and the Journal Palliative and Support Care, published by Cambridge University Press. He is a member of editorial boards for most major journals of palliative care. His most recent book, Dignity Therapy: Final Words for Final Days, published by Oxford University Press, was the 2012 winner of the American Publisher's Association Prose Award for Clinical Medicine.

#### Professor Catherine Frazee

O.C., D.Litt., LL.D. Panel Member



Catherine Frazee is a Professor Emerita at Ryerson University where, prior to her retirement in 2010, she served as Professor of Distinction and Co-Director of the RBC Ryerson Institute for Disability Studies Research & Education. Through her scholarship, teaching, art and public service, she has challenged barriers to the full social inclusion of people with disabilities and contributed to reforms in areas ranging from artistic opportunity to legislation.

As the Chief Commissioner of the Ontario Human Rights Commission from 1989 to 1992, Dr. Frazee has worked for decades to advocate for human rights through her involvement with numerous organizations including the Women's Legal Education and Action Fund, the Canadian Association for Community Living, the Council of Canadians with Disabilities, and the Abilities Arts Festival (now Tangled Art + Disability).

She has provided expert testimony before Federal and Provincial Courts and Tribunals on human rights and disability disadvantage and contributed actively in Supreme Court of Canada interventions of strategic concern to disabled Canadians. She has authored a wide array of academic and literary texts and journals and published numerous opinion pieces in Canadian media on human rights, precarious citizenship, and the activist resistance of disabled people.

Dr. Frazee has also been particularly active in the exploration of cultural interpretations of the disability experience. Most notably, she was co-curator of the award-winning exhibition Out From Under: Disability, History and Things to Remember and as collaborator in the 2006 National Film Board film Shameless: The ART of Disability. She has received a number of awards including honorary degrees from Dalhousie University, the University of New Brunswick and McMaster University.

Dr. Frazee was appointed an Officer of the Order of Canada in December 2014 for "her advancement of the rights of persons with disabilities, and as an advocate for social justice".

#### Professor Benoît Pelletier

O.Q., Ad. E., LL.B., LL.M., LL.D., LL.D., FRSC, LL.D. (Hon.) Panel Member



Admitted to the Barreau du Québec in 1982, Benoît Pelletier first practiced law in civil litigation and real estate law with the Department of Justice Canada (1983 to 1989) and with Legal Services of Correctional Service Canada (in 1989 and 1990) in Ottawa. In 1990, he joined the faculty at the University of Ottawa's Faculty of Law, which he still belongs to and where he currently holds the position of full professor. Benoît Pelletier also held the position of assistant dean of that faculty of law from 1996 to 1998.

For 10 years, Benoît Pelletier represented the Chapleau riding in the National Assembly of Québec. He was a minister with the Government of Québec for nearly six years. In that role, he was responsible for such things as Canadian Intergovernmental Affairs, Canadian Francophonie, Aboriginal Affairs and Reform of Democratic Institutions. With a Bachelor of Law from Université Laval, Benoît Pelletier also holds a Master of Law from the University of Ottawa and two Doctors of Law, one from the Université de Paris I (Panthéon-Sorbonne) and the other from the Université Aix Marseille III.

In 1989, Benoît Pelletier received the Medal of the Barreau de Paris, as best student in the graduate studies law programs of the University of Ottawa. In 1998, he was issued the Award of Excellence in Teaching from the University of Ottawa.

Benoît Pelletier is the author of numerous scientific publications, including a major treaty on constitutional amendment in Canada (published in 1996). He has also given numerous speeches in Canada and abroad. He was received as a guest professor by the universities of Nantes, Corse, Paris II, Paris V and Lyon III. He was also received twice, in 2007 and 2009, as Public Policy Scholar by the Woodrow Wilson International Center for Scholars in Washington.

Benoît Pelletier is also the author of a political essay, published in 2010 by the Université Laval presses, entitled Une certaine idée du Québec. Parcours d'un fédéraliste. De la réflexion à l'action.

Since 2006, Mr. Pelletier has received numerous awards and distinctions for his contributions to the promotion and development of the French language and to strengthening and enriching relations between Francophones and Francophiles both in Canada and internationally. In 2010, he was appointed a Commander of the Ordre de la Pléiade, to underscore his outstanding contribution to international francophonie. In 2011, he was made a Commander of the Royal Order of the Crown of Belgium. In 2012, he was made a Knight in the Ordre national du mérite de France. In 2013, he was awarded the Queen Elizabeth II Diamond Jubilee Medal. In 2014, Benoît Pelletier was made an Officer in the Ordre national du Québec. In 2015, he received the gold medal of the Ordre du mérite de la Fédération des commissions scolaires du Québec, for his outstanding contribution to public education.

### **Foreword**

As will be evident from the range and complexity of issues described in this report, responding to the Court's decision in *Carter* requires of our governments and medical regulators a great many deliberations and decisions. Among the competing claims and arguments to be settled in these determinations, none are more fundamental than the single issue identified by the Supreme Court of Canada as central to its adjudication; namely, the balancing of competing values of great importance. "On the one hand," the Court wrote, "stands the autonomy and dignity of a competent adult who seeks death as a response to a grievous and irremediable medical condition. On the other stands the sanctity of life and the need to protect the vulnerable."

As ideological positions, the assertion of personal autonomy and the work of protecting the fragile among us appeared *a priori* irreconcilable in the debates leading up to the *Carter* decision. But closer attention to the values at stake in these debates may help our country to move forward at this time of design and implementation following the Court's ruling. Taking our lead from the Court that neither of these values is paramount, we may discover that in relation to physician-assisted dying, they are in fact complementary and inseparable.

As a cornerstone principle of medical ethics and practice, autonomy is understood as the exercise of control over one's bodily integrity—the right, as Mr. Justice Sopinka wrote in *Rodriguez*, "to choose how one's body will be dealt with." Thus, as *Carter* reminds us, medical treatments can be accepted or refused, or their withdrawal required by any person with capacity to make such decisions. This, at minimum, is what respect for autonomy demands.

The individual at the heart of the *Carter* decision, Gloria Taylor, was described at trial as "a strong and independent person" who lived "a busy life" with the satisfactions of work, a loving and present family, and meaningful community engagement. From the trial records, and from personal accounts heard by the Panel, it is clear that Ms. Taylor was loved, respected, supported and secure—a woman who faced the certainty of her death with clarity and candour. In the circumstances of Ms. Taylor's life, the Court found her request for physician-assisted death to be a fully autonomous and personal choice.

At the same time, among the many perspectives presented to the Panel were those that offered a stark reminder that not all Canadians are so securely positioned within the frameworks we understand today as social determinants of health. The practice of physician-assisted death will be delivered within the context of all that we currently know about the impacts on health and well-being of such conditions as housing, food and income insecurity; discrimination; violence; isolation and lack of needed supports. We know these and other factors to be highly detrimental to health and well-being, and to be the primary contributors to social vulnerability.

Vulnerability, in and of itself, must not preclude the expression and recognition of an autonomous choice to pursue physician-assisted death. Persons far less robustly situated than Ms. Taylor have the same right "to choose how their bodies will be dealt with." Yet vulnerability, as signaled by the Court in

*Carter*, may impede or distort the expression of autonomy, when choices are coerced or induced. This is the point where respect for autonomy intersects with the protection of vulnerable persons.

It is neither the Panel's will nor authority to prescribe the mechanism for attending to this intersection in compliance with the *Carter* decision and with due respect for the rights and protections of the Charter more broadly. It is, however, required by our mandate to convey to the best of our abilities what experts, stakeholders and citizens at large have told us about the delicate calculation of what our moral and social obligations are when an individual who bears intolerable suffering caused by a grievous and irremediable medical condition desires physician-assisted death.

Through the course of our consultations, we have been reminded of the deeply human desire to ease the suffering of others, and of the extent to which our obligations are engaged in circumstances where a person sees death as preferable to continued intolerable living. We have heard that these obligations arise both from the commitment and necessity to respect autonomy, and from the recognition and understanding of vulnerability. Moreover, we know that suffering has many forms, which take hold of a person in ways that are sometimes, but not always, within our human capacity to address.

Respecting autonomy, it seems, commits us to grapple with vulnerability. And grappling with vulnerability, it seems, calls for us to tease apart the tangled roots of suffering in order to discern between an autonomous claim and a cry of unmet need.

An unmet need the Panel heard about repeatedly and consistently was that of palliative care. With the advent of physician-assisted death, it has become critically, even urgently, apparent that Canadian society must address its deficiencies in providing quality palliative care for individuals living with life threatening and life limiting conditions. Our country must rise to this challenge, as no Canadian approaching end of life should face the cruel choice between physician-assisted death and living with intolerable, enduring suffering in the absence of compassionate, comprehensive quality care.

As the Panel concludes its term of service to the government of Canada, we offer the following brief distillations of our major points of learning and reflection on the larger issues at play in the days ahead.

#### A. Jurisdictional Realities

Physician-assisted dying raises questions of jurisdiction in Canada's constitutional system, where legislative responsibilities are distributed between Parliament and the provinces. Physician-assisted death implicates both criminal and health law. The power over criminal law belongs exclusively to Parliament, while health law is an area of concurrent jurisdiction between the federal and provincial legislative assemblies. This division of powers is outlined in greater detail in this report.

Groups and experts appearing before the Panel were generally mindful of the fact that many aspects of the provision of health care—including hospitals, health insurance and the regulation of health care professions—are within provincial jurisdiction. We were also reminded by the Supreme Court in *Carter* that there is no federal regulation of other life and death decision making where individual assessments

of decisional capacity are required, including decisions that are currently governed by advance directives or substitute decision makers. These circumstances are sometimes provincially regulated.

The Supreme Court has indicated in the *Carter* decision that, depending on the focus of legislation, aspects of physician-assisted death could be validly legislated by both levels of government. The Supreme Court invited both Parliament and provincial legislatures to respond by enacting legislation, should they choose to do so. Certain groups appearing before the Panel indicated that a guiding role from the federal government would be useful in order to avoid a patchwork of regimes regulating physician-assisted death. Others have advocated restraint on the part of Parliament and a profound respect for provincial or territorial decisions on this issue.

If the federal government eventually chooses to play a leadership role in the matter of physician-assisted death, it should ideally embrace the principle of cooperative federalism, discussed by the Supreme Court in other decisions. This principle rests on a spirit of collaboration between the federal, provincial and territorial governments. Since physician-assisted death is a topic on which both Parliament and provincial legislatures can legislate, this could constitute a meaningful exercise of intergovernmental cooperation, such as the one our current Canadian government has recently called for. The opportunity for collaboration may be even greater with the province of Québec, where profound reflections on the issue have already been carried out and resulted in the province's legislation providing for medical aid in dying.

#### B. Questions of Definition

The *Carter* decision is clear that physician-assisted death must be available for persons who experience enduring and intolerable suffering as a result of a grievous and irremediable medical condition. Under the terms of our mandate, the Panel invited medical authorities, civil society organizations and Canadians at large to share their understanding of how each of the elements of this declaration should be interpreted and determined.

The various viewpoints and proposals presented throughout our consultations on many questions of definition and determination are summarized in the pages of this report. Of these, perhaps the most wide-ranging discussions have centered upon the issue of what should be considered a "grievous and irremediable" medical condition consistent with the Court's judgment. The Panel heard from many groups and individuals who cautioned against any interpretive overlay upon this central criterion, indicating that individuals and their physicians are best placed to know what it means to have a grievous and irremediable medical condition, and to make the deeply personal decisions that must be made in contemplating physician-assisted death. We are mindful as well, that regimes that have made assisted dying available for several years in the Benelux countries have done so without imposing prognostic or diagnostic limitations on inclusion criteria.

While the Panel is mindful that the Supreme Court itself did not define or restrict these terms in the *Carter* decision and that it would be very difficult to define them precisely in a law, some groups and individuals have argued for the necessity of a more fully descriptive articulation of what is meant by "grievous and irremediable" in the context of physician-assisted death. Various options were suggested

and comparisons made: for example, that Canada consider an Oregon model, which requires a life expectancy of no more than six months; or a Québec model, which requires a serious, incurable illness in an advanced stage of irreversible decline in capability at the end of life. These and other formulations reflect the sentiment held by some that a clear and coherent approach would inspire confidence and build a shared understanding that might be more difficult to achieve if individual patients and physicians variably interpret the "grievous and irremediable" threshold.

#### C. Philosophies of Care

During the time of our assignment to this Panel, both in Canada and beyond our borders, we have been privileged to encounter a great many exceptional individuals, dedicated as learners, scholars and practitioners to the care and service of medicine. It has been our impression that every one of these professionals adheres to the principle of respect for patients as a core value. While there are differences, to be sure, about if and where physician-assisted dying falls along the continuum of care, there is no dispute that the expression of a wish to die does not mitigate the duty to understand the language of suffering and to respond with compassion, integrity and skill.

Those who feel physician-assisted death should be part of the continuum of care see it as an important choice for people facing grievous and irremediable medical conditions that cause enduring and intolerable suffering. From this vantage point, physician-assisted death is a critical option of last resort that people might choose when other measures have failed or are unacceptable to them; for example, when further treatment feels unduly burdensome or conflicts with their personal values. From this perspective, declining or disputing an individual's autonomous request for an assisted death could be construed as abandonment at a critical time of need.

The philosophical counterpoint to this perspective sees physician-assisted death taking medicine down a unique pathway, no longer marked by attempts to help people live longer, live better or live less encumbered by suffering. This outlook characterizes physician-assisted death as a means of ensuring that the person will no longer suffer with the burden of being alive, and that the task of ending life is not part of the continuum of medical care. The field of palliative care is largely dominated by this perspective, given its focus on responding to physical, psychological, existential and spiritual distress for people living with life threatening and life-limiting conditions. Palliative care employs every available measure and intuition to address the many and variable forms of suffering, without hastening or postponing death. The Panel heard that this approach is consistent with a commitment to non-abandonment and the provision of continuous care until the time of physician-assisted or natural death.

#### D. Opportunity for Leadership

All stakeholders—interveners, medical authorities, experts and public alike—who engaged with the Panel recognized the importance of effective oversight. We learned that Canadian society has a real opportunity to establish itself as a world leader by establishing a robust, modern and innovative oversight system that builds upon the lessons of other jurisdictions currently offering physician-assisted death while setting the standard for those to follow.

Each jurisdiction we visited and studied has grappled with the issue of sound data collection, effective system monitoring and reporting practices. Based on what we heard, many stakeholders in various jurisdictions were not entirely satisfied with how their oversight mechanisms operated. While some have established good monitoring structures and have efficient research incentives in place, the limitations of data collection restrict what insights can be gleaned within constituencies practicing physician-assisted dying. Other jurisdictions appear to have strong data collection but the monitoring mechanisms in place are perceived by some as biased, hence undermining stakeholder confidence in their reporting.

Our study missions and consultations have revealed that serious consideration and time should be devoted to determining the information that needs to be collected. We often heard about the importance of being able not only to keep track of the number of physician-assisted deaths and the underlying medical conditions, but also to enable in-depth analysis of the sources of suffering that lead individuals to seek physician-assisted death.

With open data comes the opportunity for Canadians to make a clear statement that we believe in transparency and accountability in relation to physician-assisted death. It also invites us to reiterate our commitment to ensure that steps taken in the name of autonomy do not undermine security for those who are vulnerable, and conversely, that safeguards designed to protect vulnerable persons do not impede the rights of suffering Canadians seeking death-hastening alternatives.

Should an agency or agencies be mandated to produce annual reports on physician-assisted dying activities in Canada? This is not a question that is within our mandate to address, but the suggestions that we received across the spectrum of views on the issue indicated that accessible public reports are key to effective oversight. Through our work we have come to understand that to be credible in the public eye, oversight must be led by trusted individuals, whose work is open, transparent, accountable and rooted in scientific rigor and evidence.

We are mindful of jurisdictional responsibilities as these relate to healthcare services. That is why we want to stress the importance for all governments across Canada to collaborate in establishing strong and efficient oversight, rather than working within silos. Collaboration would help establish datasets that will allow for interprovincial comparisons, stronger analyses and more robust results guiding future policy refinements and direction. Increased collaboration is also likely to lead to a greater degree of consistency in policies across Canada, which is something we often heard would be valued throughout our consultations.

As Canada prepares to go forward with physician-assisted dying, our governments, regulators and civil society have a unique opportunity to learn from each other and to get it right.

#### E. Conclusion

This report represents the culmination of months of labour and reflection, not merely by ourselves and our Secretariat team, but by many thousands of Canadians and international colleagues. For our part, what resonates most powerfully from all that we have heard are the human sounds of need and care.

There have been profoundly intimate moments, painful moments and moments of insight and revelation. Canadians have spoken to us of sorrow and loss, of faith and yearning, of the hunger for justice and the love of humankind. They have shared their vision for what our Supreme Court intended and has rendered possible. They have shared their anguish and their fierce hopes. They have challenged us to earn their trust, and to rise above our own individual histories and inclinations. They have reminded us that the words on the pages of the Court's judgment are so much more than a new law. And they have called upon all of us as Canadians to understand that the promise and the legacy of the *Carter* decision must unfold in accordance with our shared and cherished values of caring, compassion and respect for all.

The implementation of a regime for physician-assisted death is not a simple matter of choosing a template and setting it in motion. The Court spoke of "competing values of great importance," entrusting legislators with "a difficult task," involving "complex issues of social policy and a number of competing societal values."

It is with a profound sense of humility, along with deep and abiding respect for the Supreme Court of Canada and of Parliament, that we submit our report. We sincerely hope that it will help inform our country's decisions and actions in responding to the *Carter* ruling. As we take seriously our responsibilities to those whose suffering is so dire that they wish to die, so we must take seriously the insights, perspectives and considered judgment of all who have come forward in good faith in this consultation to assist the Panel in our task.

To the best of our abilities, this, respectfully, is what we have done.

### Part I – Introduction

#### Chapter 1. The External Panel

When the three members of this Panel first convened on 20 July 2015, it was with a keen sense of the magnitude of the task ahead. Our mandate was clear: "engage Canadians and key stakeholders in consultation on issues that are fundamental to a federal legislative response to the *Carter* ruling." In the five months that followed, we would travel from coast to coast in Canada, visit four international jurisdictions and tap the expertise of hundreds of thousands of Canadians who have thought long and hard about the issue of assisted dying. We would be challenged intellectually, emotionally and physically as we sought to encounter the broadest range of perspectives available to inform a truly open and inclusive consultation on a complex subject of immense importance.

Drawing from the strength and capacity of a small but highly skilled Secretariat, we set in place the ambitious agenda for engagement that is detailed in this chapter. With severe constraints of time, resources and our own individual capacities as volunteers, we are mindful of the constituencies we did not reach, and the questions that we could not fully explore. But as we report now on our encounters and discoveries, we are both humbled and grateful for all that we have heard and learned. It is in this spirit of appreciation for all who have contributed to and supported our process, that we now look back at the particulars of how we approached our task.

Thorough and substantive exchanges with academic experts, medical authorities, Supreme Court of Canada interveners in *Carter* and civil society organizations; reviews of legislation and relevant research; and online processes designed to gather the views of thousands of Canadians: these were the tools and methods of our work. As you will read in the following pages, each of these approaches yielded a wealth of insight and understanding, which, taken together, form the basis for the content of this report. A chronology of the External Panel's key activities can be found in Annex H.

#### A. Mandate

The Panel was tasked with holding discussions with the interveners in *Carter* and "relevant medical authorities." In addition, the mandate called for the Panel to put in place an online consultation "open to all Canadians and other stakeholders." Originally, the Panel was mandated to deliver a report that would include options for a legislative response to the *Carter* decision. On 13 November 2015, shortly following the federal election, the ministers of Justice and Health adjusted the Panel's mandate and removed the requirement to provide legislative options. Instead, the ministers requested a summary of the Panel's consultation activities, including key findings.

The Panel's consultation activities have focused on the following key issues, as identified by the government of Canada and outlined in the Panel's terms of reference:

- The different forms of physician-assisted dying, namely assisted suicide and voluntary euthanasia
- Eligibility criteria and definition of key terms
- Risks to individuals and society associated with physician-assisted dying
- Safeguards to address risks and procedures for assessing requests for assistance in dying and the protection of physicians' freedom of conscience.

This report summarizes the results and key findings of the Panel's consultations. It is expected that this report will inform the government's next stages of work, eventually leading to its response to the Supreme Court of Canada decision in *Carter*.

# B. Consultations with Interveners and Medical Authorities

The Panel's terms of reference required that it meet with the interveners in *Carter*, as well as relevant medical authorities. In total, through direct mandated consultations across Canada, the Panel met with 92 representatives from 46 organizations whose memberships represent several hundred thousand Canadians. The Panel consulted these groups during a series of in-depth, in-person meetings held between 20 October and 6 November 2015 in Ottawa, Montreal, Vancouver, Winnipeg and Toronto. A complete list of individuals and organizations consulted is provided in Annex C. Abstracts of consultation transcripts can be found in Annex E.

#### 1. Consultations with the *Carter* Interveners

Twenty-six organizations intervened at the Supreme Court of Canada in *Carter*. The Panel extended invitations to each of these groups, with the exception of the Attorneys General of Ontario and Québec, whose opinions were to be gathered directly by the federal government through regular federal-provincial-territorial channels. Of the remaining 24 interveners, 19 accepted to participate in the Panel's direct consultations, four declined the invitation, and one no longer existed. The few that declined the invitation noted scheduling issues and/or a lack of time to consult their members. Some also mentioned that their views were represented by other organizations already meeting with the Panel. All groups, including those that could not meet with the Panel, were offered the possibility of presenting their

#### Figure 1

# MEETING THE INTERVENERS

#### Ottawa - October 20 to 22

Canadian Medical Association
Association for Reformed Political
Action Canada

#### Montreal - October 23

Physicians' Alliance against Euthanasia Association québécoise pour le droit de mourir dans la dignité

#### Vancouver – October 26 to 28

Protection of Conscience Project

Euthanasia Prevention Coalition —

British Columbia

#### Winnipeg – October 29

Council of Canadians with Disabilities Catholic Health Alliance of Canada

#### Toronto - November 2 to 6

Euthanasia Prevention Coalition
Canadian Association for Community
Living

Christian Medical and Dental Society of Canada

Christian Legal Fellowship
Canadian HIV/AIDS Legal Network
Evangelical Fellowship of Canada
Dying With Dignity Canada
Canadian Civil Liberties Association
Catholic Civil Rights League
Canadian Unitarian Council
Canadian Federation of Catholic
Physicians' Societies

views and recommendations through a written submission. The participating organizations are listed in Figure 1, along with information on the date and locations of these meetings.

The interveners have significant expertise in the full range of issues related to physician-assisted dying as a result of their extensive involvement in the *Carter* litigation. The Panel is very grateful that these organizations invested time and resources to prepare comprehensive and thoughtful submissions responding to the questions raised in our mandate. The questions the Panel considered were different

from those the Supreme Court addressed in its 6 February 2015 decision; rather than looking at whether or not physician-assisted death should be permitted in Canada, the Panel was tasked with looking at how a framework for physicianassisted dying could be implemented to provide access to eligible individuals while minimizing risks to potentially vulnerable groups. While their fundamental positions on physician-assisted dying generally had not changed, the interveners made their presentations with an understanding that the legal landscape had changed and that concerted efforts must now be made to find common ground that would respect the intent and spirit of the Supreme Court decision. While full consensus on issues related to physicianassisted dying might never be achieved, the Panel observed that there are areas of commonality where divergent opinions can overlap to strike a necessary balance between access and safeguards. The Panel is immensely appreciative of the efforts that all of these groups made to identify areas of commonality. Their contributions not only helped the Panel frame the current report, but will also be of great benefit to governments as they move to implement the Carter decision. Any progress made towards societal consensus will ultimately benefit all Canadians.

#### 2. Meeting with the Carter Claimants

Although its mandate did not require it, the Panel determined that its consultations would be greatly enriched by hearing the perspective of the original claimants in *Carter*. The claimants have had a direct and very personal involvement in this

Figure 2

# RELEVANT MEDICAL AUTHORITIES

#### Ottawa – October 20 to 22

Canadian Nurses Association
Canadian Psychological Association
Canadian Hospice Palliative Care Association
Canadian Nurses Protective Society

#### Vancouver - October 27

Society of Rural Physicians of Canada

#### Toronto - November 2 to 6

Indigenous Physicians Association of Canada Royal College of Physicians and Surgeons of Canada

Canadian Pharmacists Association
College of Family Physicians of Canada
Canadian Psychiatric Association
Canadian Association for Spiritual Care
Canadian Society of Palliative Care Physicians
College of Physicians and Surgeons of British
Columbia

Yukon Medical Council

College of Physicians and Surgeons of Alberta College of Physicians and Surgeons of Manitoba College of Physicians and Surgeons of Saskatchewan

Collège des médecins du Québec College of Physicians and Surgeons of Ontario College of Physicians and Surgeons of New Brunswick

College of Physicians and Surgeons of Newfoundland and Labrador College of Physicians and Surgeons of Nova Scotia College of Physicians and Surgeons of PEI Federation of Medical Regulatory Authorities of Canada issue and brought a perspective that no other Canadians were able to provide. The Panel wishes to gratefully acknowledge the privilege of meeting with Ms. Lee Carter and Mr. Hollis Johnson, as well as representatives from the British Columbia Civil Liberties Association and its guests Elayne and Howard Shapray; the experiences and views that they shared were invaluable.

#### 3. Consultations with Medical Authorities

Because the identification of "relevant medical authorities" was left to the Panel's discretion, the Panel decided early on to adopt a broad and inclusive interpretation of this requirement to gather the widest possible range of perspectives. As a result, the Panel extended invitations to approximately 30 organizations and professional associations representing the fields of medicine, nursing, pharmacy, psychology, psychiatry, social work and pastoral care among others. While not all organizations were able to meet with the Panel due to scheduling challenges or an inability to consult their members in time, the majority accepted the invitation. The Panel is grateful that these organizations took the time to share their points of view, as their members may all be called upon to play significant roles when physician-assisted dying becomes accessible to eligible Canadians. The Panel would also like to take this opportunity to acknowledge the efforts of the Federation of Medical Regulatory Authorities of Canada, which helped facilitate and coordinate a meeting with the colleges of physicians and surgeons, or equivalent medical regulatory bodies, from all provinces and territories across Canada. Figure 2 includes the complete list of medical authorities that took part in the direct consultations.

#### Figure 3

# INDIVIDUAL EXPERTS AND OTHER STAKEHOLDERS

David Baker and Rebeka Lauks – Disability Rights
Lawyers, Bakerlaw

Carrie Bourassa – Professor of Indigenous Health Studies, First Nations University

Sharon Carstairs – Former Senator and Minister with special responsibility for palliative care

Jocelyn Downie – Professor of Law; Associate Dean, Graduate Studies; Schulich School of Law, Faculty of Medicine

Steven Estey – Human Rights Officer, Disabled Peoples International

Yude M. Henteleff – Human rights lawyer; Palliative care advocate

Eike-Henner Kluge – Department of Philosophy, University of Victoria

Michelle Giroux - Health Law advocate

Joshua T. Landry and Dr. Thomas Foreman –
Champlain Centre for Health Care Ethics; Michael
Kekewich – Ethics Consultant, Ottawa Hospital

Anna MacQuarrie – Director of Global Initiatives, Policy and Human Rights, Inclusion International

Isabelle Marcoux – Assistant Professor, Faculty of Health Sciences, University of Ottawa

MedPASS, Medical Student Study Group on Physician-Assisted Suicide

Jean-Pierre Ménard – Ménard, Martin, Avocats Brian L. Mishara – CRISE Director and Psychology Professor, Université du Québec à Montréal

A network of BC Physicians

Dianne Pothier – Professor of Law Emerita, Schulich School of Law, Dalhousie University

David J. Roy – Research Chair, Faculty of Medicine, Université de Montréal

Mary Shariff – Assistant Professor, Faculty of Law, University of Manitoba

Susan Sherwin – Research Professor Emerita,
Department of Philosophy and Department of
Gender and Women's Studies, Dalhousie University

Jocelyne St-Arnaud – Associate Professor, Bioethics,
Department of Social Medicine and Prevention,
University of Montreal School of Public Health

#### C. Expert and Stakeholder Consultations

While direct consultations with interveners and medical authorities promised to be very instructive, there was an early recognition that these consultations might not cover the entire breadth of relevant issues the Panel needed to consider. Because the Panel's terms of reference gave the Chair discretion to reach out to subject-matter experts to familiarize Panel Members with key documents and relevant issues, the Panel extended meeting invitations to individual experts and additional stakeholder organizations involved in areas where knowledge gaps had been identified.

As dictated by its terms of reference, and out of respect for longstanding government practice, the Panel suspended its formal consultations during the federal election period from 2 August to 19 October 2015. Direct consultations were rescheduled beginning on 20 October 2015. During this interval, the Panel took advantage of the opportunity to better prepare for its consultations by meeting a number of experts representing a wide range of disciplines including law, public health, philosophy, ethics, medicine, and women's and Indigenous studies. Expert meetings took the form of informal exchanges between the Panel and the invited experts and allowed the Panel to get a better understanding of the legal framework and implications of physician-assisted dying, as well as many other related issues. These consultations proved to be very helpful for contextualizing the recommendations it heard during direct consultations. Experts consulted are listed in Figure 3 as well as in Annex D.

The purpose of the Panel's stakeholder consultations was the same as that of its expert meetings: filling gaps in the knowledge required to gain a full understanding of the issues relevant to its mandate. Because these consultations involved organizations representing many members—rather than individual experts—they were treated the same way as the Panel's direct consultations and did not take place during the election campaign. As was the case with the Panel's expert consultations, these meetings were very helpful in providing the Panel with a better understanding of the context and issues at play when considering the implementation of physician-assisted dying in Canada. Figure 3 lists the stakeholder organizations and other experts consulted.

#### D. Consulting the Canadian Population

Conducting an online consultation was a specified component of the Panel's mandate. It was clear that governments could not go forward with a decision of such social and legal importance on an issue as sensitive and emotional as physician-assisted dying without seeking input from those who will ultimately be the most affected: Canadian citizens.

While many—if not most—Canadians may have a clearly defined opinion on whether or not they support physician-assisted dying, views are not necessarily as clear when it comes to determining the manner in which the Supreme Court decision should be implemented. Some Canadians who suffer from serious illnesses believe strongly that a physician-assisted death will be the only way to end their life in dignity. The Supreme Court has recognized their right to receive assistance without exposing others to threat of criminal prosecution. At the same time, the Court also recognized that some people may be vulnerable to "being induced to commit suicide at a time of weakness" and that these people need to be protected in a manner that supports their dignity and choice.

Implementing the *Carter* decision also requires us to consider the perspective of health professionals, some of whom may be confronted with patient decisions that go against their personal, clinical or moral convictions. While the Court has indicated that doctors should not be compelled to assist in ending the life of a patient, does this extend to other professionals involved in the care of a patient, or to hospitals or other medical facilities? If their own doctors are unwilling, how will people access physician-assisted death and receive care that does not make them feel they are being abandoned? These are only a few of the complexities we face as a country preparing to provide access to physician-assisted death for those who qualify. Identifying and understanding these complexities promised to be a challenging task.

#### 1. Online Questionnaire: the Issue Book

Because of the complexity of issues associated with physician-assisted dying, and because the focus of the consultation was on designing a physician-assisted dying framework and not simply asking respondents their views in support or against a particular approach, the online consultation could not be limited to a list of questions. The situation called for an educational component to help respondents develop a better understanding of the vocabulary and the scope of topics and circumstances in which assisted dying must be considered before they shared their views. For this reason, the Panel's online consultation went beyond traditional surveys and questionnaires that are typically used in public opinion polls. The name of this online consultation tool, the Issue Book, reflects this process of learning and active engagement in the discussion. Additional resources were also available directly on the Panel's website for those who wished to delve more deeply before sharing their views.

The development of the Issue Book was contracted out to one of Canada's leading strategic communications firms. The contractor handled the design, coding, hosting and operation of the Issue Book and the Panel's website. The Panel allocated a significant portion of its time during its first few weeks of activity to ensure the quality, neutrality and usefulness of the Issue Book and all online material. The intent of the online consultation was not to verify the general opinions about physician-assisted dying that had been collected through regular opinion polls, but to test the borders and limits of a theoretical physician-assisted dying framework. To develop a better understanding of Canadians' views and to assess the finer points of agreement and disagreement, the Panel included questions on issues for which there is no known consensus and where debate can be expected to emerge over time e.g. views on access to physician-assisted dying for mature minors and requests made via advance directives.

Between its launch on 20 August 2015, and its closure on 22 November 2015, a total of 14,949 individuals provided their views through the Issue Book. This includes 12,883 voluntary respondents as well as a group of 2,066 individuals who form a representative sample of the Canadian population. This control group is regularly engaged by the contracted firm and was thus formed prior to, and independently of, any other activities associated with this consultation.

The Panel is grateful to all the individuals who gave their time to share their opinions; their responses have been taken seriously and key observations from the Issue Book have been included in this report. Issue Book results are available in a report provided in Annex A. An independent review of the Issue Book is also appended as Annex B.

The Panel and others closely involved with this project can confirm that personal opinions on physician-assisted dying are not immutable, and positions evolve as understanding deepens and a variety of perspectives are explored. The Panel hopes that those who took the time to complete the Issue Book found the experience to be helpful and thought provoking, and provided them with the opportunity to clarify and express their views. Evaluations completed by respondents of the Issue Book tend to indicate that the main objectives have been achieved:

- 90% of Representative Sample respondents and 74% of Open Public respondents agreed that "The information was clearly presented" (respectively, only 2% and 9% of these groups disagreed);
- 87% of Representative Sample respondents and 65% of Open Public respondents agreed that "The information was well balanced between different views on the issue." (3% and 16% respectively disagreed); and
- 83% of Representative Sample respondents and 61% of Open Public respondents agreed that "This online consultation helped you learn about the key issues and concerns." (3% and 17% disagreed).

#### 2. Online Submissions

Canadians were also given the opportunity to share their views by providing a written submission to the Panel. In this way, individual Canadians and organizations were able to provide more detailed explanations of their thoughts and recommendations regarding forms of assisted dying, eligibility criteria, risks and safeguards. In total, the Panel received 321 such submissions. A summary of all submissions received is provided in Annex F, and the abstracts of these submissions are attached in Annex G. While the online submission tool was primarily intended for those who could not meet with the Panel or who could not offer a complete expression of their views through the Issue Book, some of the groups and

#### Figure 4

# INTERNATIONAL EXPERTS

#### **Netherlands**

#### Ministry of Health, Welfare, and

#### **Sport**

- Marianne Donker, Director of Public Health and Deputy Director General Health
- Jim Terwiel, Policy Coordinator and Deputy Head Ethics department
- Lineke Bloemberg, Policy Officer Euthanasia, Ethics Department

#### Ministry of Security and Justice

 Maartje van der Linden, Senior advisor on medical ethics

### Regional Euthanasia Review Committees

 Nicole Visée, General Secretary to the Regional Euthanasia Review Committees

J.J.M. van Delden, Professor, Utrecht University

#### **Royal Dutch Medical Association**

- Eric van Wijlick, Senior Policy Advisor
- Aart Hendricks, Health Law Professor, Legal Advisor

Paul J. Lieverse, Cancer Institute, Erasmus MC University Medical Center Rotterdam

Johan Legemaate, University of Amsterdam

#### Parliamentary Committee on Health,

#### Welfare and Sport

- Renske Maria Leijten, Socialist
   Party
- Linda Voortman, Green Left Party

#### World Federation for Right to Die

#### Societies

Rob Jonquière, Communications
 Director

individuals participating in the direct consultations also opted to provide written submissions.

The time and effort that individual Canadians and groups spent in preparing quality submissions to share their views, expertise and experiences did not go unnoticed by the Panel. We are deeply grateful for the contributions that the Canadian public has made to this report.

#### E. Learning from other Jurisdictions

There is no roadmap, no simple formula, for the task of creating a legislative framework for physicianassisted death. While the Panel was confident that its direct and expert consultations would be instructive and invaluable, it was clear that few Canadian professionals had the same level of insight as those working in a system where the practice of assisted dying has been a reality for some time.

Although a growing number of nations have or are currently contemplating legislation permitting assisted dying, the total number of permissive jurisdictions remains relatively small. Further, assisted dying is a fairly recent policy development in several of these jurisdictions. Because of this, those with direct experience in implementing, delivering and supervising the practice have valuable expertise to pass along to other jurisdictions. The Panel seized the opportunity during the suspension of its direct consultations in September/October to undertake fact-finding missions in several of these jurisdictions. In total, the Panel travelled to four countries, held 34 meetings and met with 46 experts. Abstracts of the transcripts of these meetings are provided in Annex E.

#### 1. European Countries

From 30 August to 9 September 2015, the Panel travelled to three European countries where assisted dying is practiced. During the tour, the

Figure 4 (continued)

#### INTERNATIONAL EXPERTS (CONTINUED)

#### Belgium

Étienne Montero, Dean, Faculty of Law, Université de Namur

Benoit Mores. Advisor to the Federal Minister of Affairs and Public Health

Joris Vandenberghe, Professor of Psychiatry at KULeuven and a member of the Belgian **Advisory Committee on Bioethics** 

Luc Deliens and Kenneth Chambaere, Endof-Life Care Research Group at the Free University of Brussels (VUB) and Ghent University

Els Van Hoof, Belgian Federal MP for the Flemish Christian-democratic party

Jean-Jacques De Gucht, Member of the Belgian Senate and of the Flemish Parliament (Open VLD - Flemish Liberals)

Jaqueline Herremans, President, Association pour le Droit de Mourir dans la Dignité Belgique (ADMD) (Dying with Dignity Belgium)

Gert Huysmans, Palliative care physician and President, Federation of Palliative Care Flanders Herman Nys, Professor of Health Law, KU Leuven (Katholieke Universiteit Leuven)

#### **Switzerland**

#### **DIGNITAS**

• Silvan Luley, Executive Director

#### Exit

• Bernhard Sutter, Executive Director Georg Bosshard, Head of Clinical Ethics, Zurich University

#### District See/Oberland

• Jürg Vollenweider, Chief Prosecutor

#### Switzerland Federal Office of Justice

• Bernardo Stadelmann, Vice Director and Corine Klöti

#### Canton de Vaud

• Karim Boubaker, Médecin cantonal Steffen Eychmüller, Head of Palliative Care Center, Inselspital

Panel traveled to the Netherlands, where it met with 13 experts over 7 meetings, Belgium, where it met with 10 experts over 9 meetings, and Switzerland, where the Panel met with a further 8 experts over 7 meetings. The selection of countries allowed the Panel to learn about different systems and approaches. While the Netherlands and Belgium both regulate assisted dying through legislation, for example, Switzerland does not regulate the practice through federal laws, but allows assisting suicide for nonselfish motives. These countries have also adopted different eligibility and procedural rules, and different reporting and monitoring mechanisms. Individuals and organizations consulted during the European fact-finding mission included members of parliament, government officials in health and justice, academic experts, advocacy groups, and, in the case of Switzerland, private organizations that facilitate assisted suicide. These individuals and organizations are listed in Figure 4. The Panel is grateful to the Canadian Ambassadors and Embassy staff in each European country visited for taking the time to meet with the Panel, for providing strong contextual briefings, and above all for helping with the coordination and planning of the fact-finding missions at such short notice. Without their assistance, these study missions would never have been possible.

#### 2. Oregon and other U.S. Jurisdictions

An increasing number of American states are contemplating legislation on assisted dying. As of the time of writing, Oregon, Washington, Vermont and California had enacted legislation, and Montana permits assisted dying according to the terms of a decision of its supreme court. The eligibility criteria and processes for assisted dying in these states are significantly different from European models. For this reason, to better understand these differences and to see how an existing assisted-dying

Figure 4 (continued)

# INTERNATIONAL EXPERTS (CONTINUED)

#### Oregon and other U.S. jurisdictions

Kelly Hagan, Member of the neutral task force that worked on producing guidelines for Oregon's Death with Dignity Law

#### Disability Rights Legal Center

Kathryn Tucker

#### **Death with Dignity National Center**

• Eli Stutsman and Peg Sandeen

#### **Oregon Hospice Association**

• Barb Hansen

## Physicians for Compassionate Care Education Fund

 Kenneth R. Stevens Jr. and Charles Bentz

#### **Disability Rights Oregon**

• Bob Joondeph

Barbara Glidewell, Former Ombudsman and Director of Patient Relations, Oregon Health Sciences University Hospital

#### **Compassion and Choices**

• Sue Porter, Kat West and Peter Reagan

Katrina Hedberg, Physician, State Epidemiologist

Linda Ganzini, Psychiatrist/geriatrician

#### **Disability Rights Education &**

#### Defense Fund

 Marilyn Golden, Senior Policy Analyst

framework operates in North America, the Panel undertook a fact-finding mission in Oregon from 1 to 3 October 2015. Because assisted dying has been in place in Oregon since 1997—making its assisted dying regime one of the oldest in the world—experts there had a great deal of insight to offer the Panel. Because of time constraints and the similarity between state models, the Panel travelled only to Oregon, although it did consult with experts from national American disability organizations. Over the course of its Oregon and U.S. study mission, the Panel held 11 meetings with 15 experts, including physicians, members of the task force that produced guidelines for Oregon's *Death with Dignity Act*, as well as

members of groups representing persons with disabilities and organizations that support access to physician-assisted dying. These individuals and organizations are also included in Figure 4.

#### F. Provincial and Territorial Jurisdictions

In *Carter*, the Supreme Court held that the federal government and provincial legislatures could, if they so choose, enact legislation on physician-assisted dying. Given that both levels of government may choose to respond to *Carter*, it is reasonable for parallel processes to be established to inform the creation of mechanisms appropriate for each level. At the time the Panel was appointed, the existence, format and mandate of the Provincial-Territorial Expert Advisory Group were not known. However, consistent with the Panel's mandate to "be mindful of federal and provincial/territorial jurisdictions in health and criminal law," the Panel took advantage of its consultations in Toronto to meet with the cochairs and several members of the Provincial-Territorial Expert Advisory Group. The meeting proved to be an informative, collegial discussion about activities and informal impressions. It became clear that the work of both bodies would be complementary and that governments and Canadians will benefit from these dual deliberations, providing rich and thoughtful sources of information about issues of great importance.

#### G. Reporting

With the culmination of this multi-dimensional process of information gathering and dialogue, the Panel is left with a deep sense of humility and a reminder of the weight of the task with which we have been entrusted. The written briefs and verbal submissions that we received were prepared with integrity and care, expressing respect for the Court's decision and for the mandate with which our Panel was charged. The experts and stakeholder groups with whom we met both within and outside our borders were thoughtful, principled and generous with their time, their research and their expertise. Similarly, Issue Book participants volunteered precious time and attention in an impressive display of civic engagement.

During each of our consultation processes, people have spoken with passion and candour, and although their views may differ widely, each and every one spoke with courage of conviction about the respect and support we owe to those who suffer. There can be no doubt that this is an issue that matters profoundly to Canadians. To honour the contributions of so many individual citizens and organizations in this final report is no small task.

In the pages that follow, the Panel presents a distillation of all that we have heard and learned on the subject of assisted dying over the past five months. The opinions and reflections gathered through the Issue Book, the written submissions, and the direct consultations have made it clear that physician-assisted death is an issue of utmost importance to Canadians. It is in this spirit, and out of respect for all those who invested time and resources in preparing and sharing their views, that this report may include items that, constitutionally, fall outside of the federal responsibilities in health. Ultimately, the Panel concludes that it is important that the federal government, along with provincial and territorial governments, and all Canadians be made aware of the full array of expertise, insights and views that have been shared through this exercise.

## Part II – Relevant Legal Context

Although the Panel's revised mandate no longer requires that it set out legislative options in response to the Supreme Court of Canada's decision in *Carter*, some legal context is important to tell the reader about the principles that informed the Panel's investigation of physician-assisted dying. This part of the report begins with brief summaries of the relevant constitutional principles that guided the Panel's discussions, and ends with a summary of the *Carter* decision.

#### Chapter 2. Division of Federal and Provincial/Territorial Powers

There are few policy areas in which the respective roles of the federal and provincial/territorial governments are as complexly intertwined as in health. Part of this complexity stems from the division of federal and provincial powers as established in the *Constitution Act, 1867*. Sections 91 and 92 outline the areas of legislative authority of Parliament and the provincial legislatures, respectively. Because healthcare as it operates today was not contemplated at the time of Confederation, health is not an enumerated area of legislative authority and instead must be inferred from other sections.

#### A. The Federal Role in Health

The primary areas of federal responsibility under section 91 as they relate to physician-assisted death are the criminal law power, which is set out at section 91(27) and the federal spending power, which, although contested by some, is inferred by others from section 91(1A), which assigns to Parliament legislative authority over "The Public Debt and Property," as well as section 91(3), "The raising of Money by any Mode or System of Taxation."

The criminal law power as it relates to health has been interpreted as regulating or prohibiting practices that could be harmful to the health of Canadians. The Supreme Court has held that

Parliament has power to legislate with respect to federal matters, notably criminal law, that touch on health. For instance, it has historic jurisdiction to prohibit medical treatments that are dangerous, or that it perceives as "socially undesirable" behaviour.<sup>2</sup>

The Supreme Court has also noted the following:

The scope of the federal power to create criminal legislation with respect to health matters is broad, and is circumscribed only by the requirements that the legislation must contain a

<sup>&</sup>lt;sup>2</sup> Canada (Attorney General) v. PHS Community Services Society, 2011 SCC 44 at para. 68 [PHS].

prohibition accompanied by a penal sanction and must be directed at a legitimate public health evil.<sup>3</sup>

One of the most notable examples of the federal spending power as it relates to health is the Canada Health Transfer,<sup>4</sup> addressed in the *Canada Health Act*.<sup>5</sup> The federal government and the province of Québec have in the past referred to "asymmetrical federalism" to express respect for Québec's jurisdiction and a recognition of its "desire to exercise its own responsibilities with respect to planning, organizing and managing health services within its territory" when implementing a ten-year health care plan.<sup>6</sup>

#### B. The Provincial Role in Health

The relevant areas of provincial responsibility as they relate to physician-assisted dying stem from section 92(7), "The Establishment, Maintenance and Management of Hospitals ... in and for the Province;" section 92(13), "Property and Civil Rights in the Province;" and section 92(16), "Generally all Matters of a merely local or private Nature in the Province." These sections are collectively interpreted as assigning to the provinces jurisdiction over health care delivery, health insurance and the regulation of health care professionals, which cover a broad range of issues in the Canadian healthcare system. The Supreme Court has made the following observation about the provinces' power over health: "The provincial health power is broad and extensive. It extends to thousands of activities and to a host of different venues."

#### C. Concurrent Jurisdiction

The Supreme Court in *Carter* made the following finding on federal and provincial jurisdiction as it relates to physician-assisted dying:

Health is an area of concurrent jurisdiction; both Parliament and the provinces may validly legislate on the topic [...] This suggests that aspects of physician-assisted dying may be the subject of valid legislation by both levels of government, depending on the circumstances and focus of the legislation.

In making this finding, the Court was rejecting the arguments of the claimants and the provincial Attorneys General that intervened in *Carter* that there is a "protected core" of provincial responsibility over health. These groups argued that the enumerated areas of legislative authority under sections 91 and 92 of the *Constitution Act, 1867* are "exclusive," and therefore each have a 'minimum and unassailable' core of content that is immune from the application of legislation enacted by the other

<sup>&</sup>lt;sup>3</sup> RJR-MacDonald Inc. v. Canada (Attorney General), [1995] 3 S.C.R. 199, p. 246 [RJR-MacDonald].

<sup>&</sup>lt;sup>4</sup> Department of Finance Canada, <u>Canada Health Transfer</u>.

<sup>&</sup>lt;sup>5</sup> Canada Health Act, R.S.C. 1985, c. C-6.

<sup>&</sup>lt;sup>6</sup> Government of Canada, <u>First Minister's Meeting on the future of health care 2004: A 10-year plan to strengthen health care</u>; Health Canada, <u>Asymmetrical Federalism that respects Quebec's Jurisdiction</u>, September 2004.

<sup>&</sup>lt;sup>7</sup> PHS at para. 68.

level of government." This argument is based on the legal principle of "interjurisdictional immunity," which prevents one level of government from enacting legislation in a "core" area of the other level of government's jurisdiction.

The Supreme Court rejected this argument. As it had in *Canada (Attorney General) v. PHS Community Services Society (PHS)*, another recent decision at the intersection of health and criminal law, the Court set aside interjurisdictional immunity arguments proposing a core provincial power over health, favouring instead the principle of "concurrent" or shared jurisdiction. In *PHS*, the Court noted that rather than relying on interjurisdictional immunity as a guiding principle in the area of health, a more appropriate approach is that of "cooperative federalism:"

In the spirit of cooperative federalism, courts "should avoid blocking the application of measures which are taken to be enacted in furtherance of the public interest."... Where possible, courts should allow both levels of government to jointly regulate areas that fall within their jurisdiction.<sup>9</sup>

The Court noted in *PHS* that the task of "drawing a bright line" distinguishing federal from provincial responsibilities in the area of health would be a "daunting" one.<sup>10</sup> This suggests that significant cooperation between the federal and provincial/territorial governments may be needed to ensure safe and equitable access to physician-assisted dying in Canada.

<sup>&</sup>lt;sup>8</sup> Carter at para. 50.

<sup>&</sup>lt;sup>9</sup> PHS at para. 68.

<sup>&</sup>lt;sup>10</sup> *PHS* at para. 68.

#### Chapter 3. Relevant Sections of the Charter

The Canadian Charter of Rights and Freedoms, <sup>11</sup> part of Canada's Constitution, sets out the rights and freedoms that Canada recognises as fundamental to any interaction between an individual and the state in this country. The most relevant sections of the Charter for the purposes of this report are the following:

- Section 1: The Canadian Charter of Rights and Freedoms guarantees the rights and freedoms set
  out in it subject only to such reasonable limits prescribed by law as can be demonstrably
  justified in a free and democratic society;
- Section 2(a): Everyone has the ... freedom of conscience and religion;
- Section 7: Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice;
- Section 15(1): Every individual is equal before and under the law and has the right to the equal
  protection and equal benefit of the law without discrimination and, in particular, without
  discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or
  physical disability; and
- Section 33: Parliament or the legislature of a province may expressly declare in an Act of Parliament or of the legislature, as the case may be, that the Act or a provision thereof shall operate notwithstanding a provision included in section 2 or sections 7 to 15 of this Charter.

Section 7 was the primary focus of the Supreme Court's decision in *Carter*, and therefore is explored in the greatest depth of all the sections discussed above. Section 1 is discussed in the context of section 7. Although section 15 is not explicitly addressed in the Supreme Court's decision in *Carter*, it informed much of the *Carter* litigation and is therefore briefly explored. Section 33 arose in discussions with and submissions from many groups and individuals, and is therefore also addressed below.

The Supreme Court in *Carter* opted not to delve into the substance of the right encompassed in section 2(a) in the context of its discussion of physicians' right to conscientiously object to physician-assisted death. Furthermore, the Panel did not hear submissions that discussed conscientious objection explicitly within section 2(a). For these reasons, this section of the Charter will not be addressed in detail below.

#### A. Section 7: The Right to Life, Liberty and Security of the Person

Section 7 of the *Canadian Charter of Rights and Freedoms* guarantees "the right to life, liberty and security of the person." This part first explores the content of the rights protected by section 7 of the Charter. It then explains the test to determine whether there is a violation of section 7. Finally, it briefly sets out the justification of a section 7 breach under section 1 of the Charter.

<sup>&</sup>lt;sup>11</sup> Canadian Charter of Rights and Freedoms, Schedule B to the Canada Act 1982 (U.K.), 1982, c. 11 [Charter].

#### 1. Rights Protected under Section 7

Section 7 of the Charter states the following:

Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice.

The rights to life, liberty and security of the person are three distinct interests: a law that negatively impacts any *one* of the three engages section 7. The rights protected under section 7 are generally understood as "negative" rights—that is, while a law cannot limit the right to life, liberty and security of the person, section 7 does not impose a positive duty on government to ensure that all individuals have life, liberty and security of the person.<sup>12</sup>

The right to life is engaged where there is a threat or heightened risk of death, and is generally not concerned with quality of life. Although the application of a law rarely causes death, an increased risk of death that results from a law can be a limit on the right to life. For example, in the case of *Chaoulli v. Québec*, the Supreme Court held that excessive wait times for certain procedures in Québec's public healthcare system affected the right to life since they increased the risk of death for patients.<sup>13</sup>

The right to liberty, and in particular to physical liberty, is often engaged in the sphere of criminal law. A penalty of imprisonment is an obvious example of a restriction on physical liberty. <sup>14</sup> The right to liberty also takes shape in contexts outside of criminal law: a law interferes with liberty if it prevents an individual from making "fundamental personal choices." <sup>15</sup> The right to liberty protected by section 7 is understood to give individuals "a degree of autonomy in making decisions of fundamental personal importance," <sup>16</sup> as well as protecting a "right to an irreducible sphere of personal autonomy wherein individuals may make inherently private choices free from state interference." <sup>17</sup>

The right to security of the person is concerned with health and safety. For instance, in *R. v. Morgentaler*, delays in treatment that increased the health risks for women seeking abortions were found to be a deprivation of security of the person.<sup>18</sup> These delays were caused by the requirement that, before a woman could lawfully obtain an abortion, a "therapeutic abortion committee" had to attest in writing that continuing the pregnancy would endanger her life or health.

Further, in *Rodriguez v. British Columbia*, <sup>19</sup> the physician-assisted dying case that preceded *Carter v. Canada*, the majority of the Supreme Court concluded that security of the person encompasses "personal autonomy, at least with respect to the right to make choices concerning one's own body,

<sup>&</sup>lt;sup>12</sup> Gosselin v. Québec, 2002 SCC 84 [Gosselin].

<sup>&</sup>lt;sup>13</sup> Chaoulli v. Québec, 2005 SCC 35 [Chaoulli].

<sup>&</sup>lt;sup>14</sup> Peter Hogg, *Constitutional Law of Canada*, 5<sup>th</sup> edition (loose-leaf), Carswell, Toronto, 2010, pp. 47-7 to 47-8 [Hogg].

<sup>&</sup>lt;sup>15</sup> Blencoe v. British Columbia, 2000 SCC 44 at paras. 49 and 54 [Blencoe].

<sup>&</sup>lt;sup>16</sup> *R. v. Morgentaler*, [1988] 1 S.C.R. 30 [Morgentaler].

<sup>&</sup>lt;sup>17</sup> Godbout v. Longueuil (City), [1997] 3 S.C.R. 844 at para. 66.

<sup>&</sup>lt;sup>18</sup> Morgentaler.

<sup>&</sup>lt;sup>19</sup> Rodriguez v. British Columbia (Attorney General), [1993] 3 S.C.R. 519 [Rodriguez].

control over one's physical and psychological integrity, and basic human dignity." <sup>20</sup> In this respect, the constitutional right to security of the person is coextensive with the longstanding common law requirement that individuals consent to medical care. <sup>21</sup>

#### 2. Determining whether there is a Violation of Section 7

The wording of section 7 prohibits deprivation of the right to life, liberty or security of the person, except if it is done *in accordance with the principles of fundamental justice*. Therefore, a law will not violate section 7 if the limits it imposes on life, liberty or security of the person are in accordance with the principles of fundamental justice. The result is a two-step inquiry: first, whether the law limits the right to life, liberty or security of the person; and second, whether that limitation respects principles of fundamental justice. If it does, there is no violation of section 7. If it does not, however, the law will be found to violate section 7 of the Charter.

#### a) First Step: Does the Law Impact the Right to Life, Liberty or Security of the Person?

This first step of the test asks whether the law negatively impacts the right to life, liberty or security of the person. In *A.C. v. Manitoba*, the Supreme Court considered the case of a 14-year-old girl whose religious beliefs as a Jehovah's Witness included the refusal of blood transfusions. The law at issue allowed a court to authorize medical treatment for persons under 16, even without the person's consent. At this first step of the test, the Court found that "[t]he inability of an adolescent to determine her own medical treatment ... constitutes a deprivation of liberty and security of the person."<sup>23</sup>

In *Bedford*, the Supreme Court found that prostitution-related offences (keeping a bawdy house, living off the avails of prostitution and communicating in public) limited the right to security of the person because they imposed dangerous conditions for sex workers and limited measures they could undertake to protect themselves.<sup>24</sup>

In *PHS*, the Supreme Court examined the Minister of Health's decision not to exempt Insite, the supervised-injection site in Vancouver's Downtown Eastside, from a law that created an offence with a penalty of imprisonment for possessing prohibited drugs. The Court found that the prohibition on possessing prohibited drugs engaged the liberty rights of the staff working at Insite, which in turn deprived its clients of lifesaving medical care, "thus engaging their rights to life and security of the person." <sup>25</sup>

<sup>&</sup>lt;sup>20</sup> Rodriguez, at p. 588.

<sup>&</sup>lt;sup>21</sup> <u>A.C. v. Manitoba (Director of Child and Family Services)</u>, 2009 SCC 30 at para. 44 [A.C. v. Manitoba], citing Robins J.A. of the Ontario Court of Appeal in *Fleming v. Reid* (1991), 4 O.R. (3d) 74.

<sup>&</sup>lt;sup>22</sup> PHS at para. 84.

<sup>&</sup>lt;sup>23</sup> A.C. v. Manitoba at para. 102 [per Abella J. (LeBel, Deschamps and Charron JJ. concurring)].

<sup>&</sup>lt;sup>24</sup> Canada (Attorney General) v. Bedford, 2013 SCC 72 at para. 60.

<sup>&</sup>lt;sup>25</sup> *PHS* at para. 91.

## b) Second Step: Is the Deprivation of Section 7 Rights in Accordance With Principles of Fundamental Justice?

In the recent case of *Bedford*, the Supreme Court described the principles of fundamental justice in the following manner:

The s. 7 analysis is concerned with capturing inherently bad laws: that is, laws that take away life, liberty, or security of the person in a way that runs afoul of our basic values. The principles of fundamental justice are an attempt to capture those values. Over the years, the jurisprudence has given shape to the content of these basic values.<sup>26</sup>

Three principles of fundamental justice have been central to recent Supreme Court jurisprudence dealing with section 7, including the *Carter* decision: the requirements that a law not be arbitrary, overbroad or have effects that are grossly disproportionate to its object.<sup>27</sup>

All three principles are concerned with the objective of the law, albeit in different ways. The Court described the common feature of these three principles against arbitrariness, overbreadth and gross disproportionality as a "failure of instrumental rationality," meaning that the objective of the law is acceptable, but the means used to achieve it are not.<sup>28</sup> Despite this common feature, the concepts of arbitrariness, overbreadth and gross disproportionality are distinct from one another, and each "can be infringed by the effect of a law on the life, liberty or security of a *single* person."<sup>29</sup>

#### i. Arbitrariness

The principle of arbitrariness examines whether or not the law actually targets its objective, and "whether there is a direct connection between the purpose of the law and the impugned effect on the individual .... There must be a rational connection between the object of the measure that causes the s. 7 deprivation, and the limits it imposes on life, liberty, or security of the person." An arbitrary law affects an individual's section 7 rights for no reason.<sup>31</sup>

For example, in *Morgentaler*, the Supreme Court struck down the restrictions that required abortions to be performed only in accredited hospitals after a therapeutic abortion committee had certified in writing that continuing the pregnancy would endanger the woman's life or health. The effect of the law, which was to create unreasonable delays attributed to requirements of the committee, actually contradicted the objective of the law, which was to enhance women's health.<sup>32</sup>

The case of *PHS* is a recent example of arbitrariness. The Minister's decision not to renew the exemption for the supervised-injection site in Vancouver's Downtown Eastside was found to be arbitrary. The

<sup>&</sup>lt;sup>26</sup> Bedford at para. 96.

<sup>&</sup>lt;sup>27</sup> Carter at para. 72.

<sup>&</sup>lt;sup>28</sup> Hogg, p. 47-58, citing Hamish Stewart, *Fundamental Justice*, Irwin Law, Toronto, 2012, p. 151.

<sup>&</sup>lt;sup>29</sup> Hamish Stewart, "Bedford and the Structure of Section 7," McGill Law Journal, Vol. 60, No. 3, 2015, p. 577. [Stewart].

<sup>&</sup>lt;sup>30</sup> Bedford at para. 111.

<sup>&</sup>lt;sup>31</sup> Stewart, p. 584.

<sup>&</sup>lt;sup>32</sup> Morgentaler.

object of the prohibition on possession of drugs is to protect health and public safety. The evidence showed that the operation of the supervised-injection site actually contributed to the objectives of health and public safety. There was therefore no rational connection between the objective of the law and the decision not to renew the exemption for the supervised-injection site.

#### ii. Overbreadth

An overbroad law is one that reaches too far in the individuals or the conduct it captures. In other words, "the section 7 interests of some (though not all) people it applies to are affected for no reason." <sup>33</sup> It is so broad that it includes some conduct that is not related to its objective. <sup>34</sup>

For example, the prohibition on living off the avails of prostitution in the *Bedford* case was found to be overbroad because it made no distinction between those who exploit sex workers—such as pimps living off sex workers' earnings—and those who could be hired by the sex worker to increase safety, such as drivers, managers or bodyguards. Because the prohibition on living off the avails captured some conduct that was not in line with the law's purpose of criminalizing the pimp, it was overbroad.

It is relevant to note that the legal notion of overbreadth has evolved over the years. Importantly, it has evolved since the Supreme Court decided the previous case on physician-assisted dying in 1993, *Rodriguez v. Canada*. The concept of overbreadth is now explicitly recognized as a principle of fundamental justice, which was not the case in *Rodriguez*, and the question that courts ask when they examine if a law is overbroad has changed. The overbreadth analysis now requires that a court ask "whether the law interferes with some conduct that has no connection to the law's objective." <sup>35</sup>

#### iii. Gross Disproportionality

The principle of gross disproportionality describes laws that, while aiming to respond to a problem, do so in a way that is "so extreme as to be disproportionate to any legitimate government interest" and at too high a cost to the life, liberty and security of individuals. Gross disproportionality is determined by weighing the effect of the limit of the law with any benefit that is derived from it. Where a law has a connection to its objective, but where the resulting deprivation of section 7 rights is so severe that it is out of proportion with the objective the law is trying to achieve, the deprivation of section 7 rights will be deemed grossly disproportionate. 8

For example, the *Bedford*<sup>39</sup> case found two prohibitions to have grossly disproportionate effects: the prohibition on communicating in public, whose objective was to prevent street nuisance, and the prohibition on keeping a bawdy house, whose objective was to prevent neighbourhood disorder. Both these prohibitions increased the risk to sex workers' security by criminalizing attempts to screen

<sup>&</sup>lt;sup>33</sup> Stewart, p. 584.

<sup>&</sup>lt;sup>34</sup> *Bedford* at para. 112.

<sup>&</sup>lt;sup>35</sup> Carter at para. 46, citing Bedford at para. 101.

<sup>&</sup>lt;sup>36</sup> PHS at para. 133, citing *R. v. Malmo-Levine*, 2003 SCC 74 at para. 143.

<sup>&</sup>lt;sup>37</sup> Stewart, p. 585.

<sup>&</sup>lt;sup>38</sup> Bedford.

<sup>&</sup>lt;sup>39</sup> Bedford.

potential clients in public and sex work in a fixed indoor location. The resulting increased risk to sex workers' security was found to be grossly disproportionate to the objectives of the prohibitions.

In sum, interfering with the right to life, liberty and security of the person will be a violation of section 7 if it is done in a way that is arbitrary, grossly disproportionate, or overly broad (or not in accordance with other principles of fundamental justice not discussed here). If a violation of a section 7 right is found, the government that enacted the law could try to justify it under section 1 of the Charter.

#### 3. Justifying Section 7 Violations under Section 1 of the Charter

Section 1 of the Charter provides that rights and freedoms are guaranteed "only to such reasonable limits prescribed by law as can be demonstrably justified in a free and democratic society." As such, rights and freedoms are not absolute, and a government can attempt to justify a violation using section 1.

Violations of the section 7 rights to life, liberty and security of the person may be difficult to justify under section 1 of the Charter. In fact, the Supreme Court has not yet recognized a justified limit on a section 7 right. In the *Bedford* case, the Supreme Court nonetheless commented as follows:

It has been said that a law that violates s. 7 is unlikely to be justified under s. 1 of the Charter. The significance of the fundamental rights protected by s. 7 supports this observation. Nevertheless, the jurisprudence has also recognized that there may be some cases where s. 1 has a role to play ... Depending on the importance of the legislative goal and the nature of the s. 7 infringement in a particular case, the possibility that the government could establish that a s. 7 violation is justified under s. 1 of the Charter cannot be discounted. 40

At this stage of the analysis, the government must show that the infringement of section 7 (or any Charter right) was justified under section 1. To successfully do so, a government must show that the law meets the criteria set out in the *Oakes* test:<sup>41</sup> the law must have a pressing and substantial object, and the means chosen to achieve this object must be proportional. The proportional requirement will be met if "(1) the means adopted are rationally connected to that objective; (2) it is minimally impairing of the right in question; and (3) there is proportionality between the deleterious and salutary effects of the law."<sup>42</sup>

The analysis of whether the limitations are in accordance with principles of fundamental justice under the second step of the section 7 test and the analysis under section 1, call upon similar concepts. However, the Supreme Court has indicated that they are different: while the section 7 analysis is concerned with the narrow question of whether the law infringes individual rights, the section 1 analysis comprises a "justification on the basis of an overarching public goal." <sup>43</sup>

<sup>&</sup>lt;sup>40</sup> Bedford at para. 129 [references omitted].

<sup>&</sup>lt;sup>41</sup> R. v. Oakes, [1986] 1 S.C.R. 103.

<sup>&</sup>lt;sup>42</sup> Carter at para. 94.

<sup>43</sup> Bedford at para. 125.

#### B. Section 15: Equality Rights

Section 15 of the *Canadian Charter of Rights and Freedoms* sets out equality protections for members of Canadian society. Section 15(1) prohibits discrimination on several listed grounds—known as "enumerated" grounds—including physical disability. Other prohibited grounds of discrimination, such as sexual orientation, have been added to this list through Supreme Court of Canada case law. These added grounds are known as "analogous" grounds.

Gloria Taylor, the lead plaintiff in *Carter v. Canada*, argued that sections 241(b) and 14 of the *Criminal Code* violate section 15 of the Charter. She argued that although non-disabled people may choose to commit suicide, people with certain physical disabilities may be unable to do so without assistance, and the *Criminal Code* prohibition on assisting an individual to die therefore has a disparate effect on such people.

Over the 30 years that section 15 has been in force, the Supreme Court has adopted a variety of approaches in its evaluation of section 15 claims. 44 The Court's first section 15 decision in 1989 remains one of its touchstones, however, and the Court often returns to this decision for its basic tenets of equality. In *Andrews v. Law Society of British Columbia*, the Court rejected a "formal equality" understanding of section 15 in favour of one based on a concept that would eventually be named "substantive equality."

Formal equality is a conceptualization of equality based on the idea that people in similar situations should be treated in a similar fashion. Although this may seem fair, the approach can result in serious inequality. The Court in *Andrews* referred to its pre-Charter decision in *Bliss v. Attorney General of Canada* to demonstrate this point. In *Bliss*, a pregnant woman was denied unemployment benefits because of her pregnancy. She argued that the law in place at the time discriminated against her on the basis of sex. Applying the legal test it used at the time, the Court held that because all pregnant people were treated alike, there was no discrimination, ignoring the fact that only women may become pregnant and that the law therefore had a disproportionately negative impact on them.

The Supreme Court in *Andrews* held that formal equality is a "seriously deficient" understanding of equality that could result in "separate but equal" treatment of disadvantaged groups, citing for example racial segregation. A formal equality approach to Gloria Taylor's argument might have resulted in a rejection of her section 15 claim; no one could access assisted dying, so no one was discriminated against.

<sup>&</sup>lt;sup>44</sup> Martha Butler, <u>Section 15 of the Canadian Charter of Rights and Freedoms: The Development of the Supreme Court of Canada's Approach to Equality Rights Under the Charter</u>, Publication no. 2013-83-E, Parliamentary Information and Research Service, Library of Parliament, Ottawa, September, 2013.

<sup>&</sup>lt;sup>45</sup> Andrews v. Law Society of British Columbia, [1989] 1 S.C.R. 143 [Andrews].

<sup>&</sup>lt;sup>46</sup> Bliss v. Attorney General of Canada, [1979] 1 S.C.R. 183.

The Court in *Andrews* adopted a different approach that would come to be known as substantive equality.<sup>47</sup> It held that

the purpose of s. 15 is to ensure equality in the formulation and application of the law. The promotion of a society in which all are secure in the knowledge that they are recognized at law as human beings equally deserving of concern, respect and consideration. It has a large remedial component.

This "large remedial component" is a significant element of substantive equality. A commitment to substantive equality means affirming that certain individuals may need distinct treatment or assistance to achieve true equality.

The Supreme Court in Andrews also defined discrimination. It held that discrimination is

a distinction, whether intentional or not but based on grounds relating to personal characteristics of the individual or group, which has the effect of imposing burdens, obligations, or disadvantages on such individual or group not imposed on others, or which withholds or limits access to opportunities, benefits, and advantages available to other members of society.

Discussing substantive equality, the Supreme Court made the following comments in *Withler v. Canada (Attorney General)*:

Equality is not about sameness and s. 15(1) does not protect a right to identical treatment. Rather, it protects every person's equal right to be free from discrimination. ...

Substantive equality, unlike formal equality, rejects the mere presence or absence of difference as an answer to differential treatment. It insists on going behind the facade of similarities and differences. It asks not only what characteristics the different treatment is predicated upon, but also whether those characteristics are relevant considerations under the circumstances. The focus of the inquiry is on the actual impact of the impugned law, taking full account of social, political, economic and historical factors concerning the group. The result may be to reveal differential treatment as discriminatory because of prejudicial impact or negative stereotyping. Or it may reveal that differential treatment is required in order to ameliorate the actual situation of the claimant group. <sup>48</sup>

The current formulation of the legal test for section 15 claims, which Justice Lynn Smith of the British Columbia Supreme Court applied in *Carter*, is set out below:

- 1) Does the law create a distinction based on an enumerated or analogous ground?
- 2) Does the distinction create a disadvantage by perpetuating prejudice or stereotyping?<sup>49</sup>

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<sup>&</sup>lt;sup>47</sup> The Supreme Court first described its approach in *Andrews* as "substantive, not merely formal equality" eight years later in *Eldridge v. British Columbia (Attorney General)*, [1997] 3 S.C.R. 624 at para. 61.

<sup>48</sup> Withler v. Canada (Attorney General), 2011 SCC 12 at paras. 31 and 39.

<sup>&</sup>lt;sup>49</sup> Withler.

In her application of this test, Justice Smith held that the *Criminal Code* prohibition violated Ms. Carter's equality rights.

The Supreme Court opted not to conduct an analysis of the section 15 claim. This is not inconsistent with many of its recent decisions in which a section 15 claim was advanced along with a claim based on a different section of the Charter. If arguments based on other sections of the Charter are retained, the Court has, of late, generally chosen not to conduct a section 15 analysis. <sup>50</sup>

#### C. Section 33: The Notwithstanding Clause

Section 33 of the *Canadian Charter of Rights and Freedoms*, often referred to as the "notwithstanding clause," provides Parliament and the legislatures with a mechanism to work around the fact that courts may invalidate legislation found to be inconsistent with sections 2 and 7 to 15 of the Charter. It states that Parliament or a legislature may declare that an Act—or a provision in an Act—shall operate notwithstanding any or all of section 2 or sections 7 to 15 of the Charter. Section 33 operates for a maximum period of five years, after which Parliament or legislatures must re-enact the declaration if they wish to continue to use the notwithstanding clause.

Essentially, section 33 may be relied upon in legislation to "override" the rights set out under sections 2 and 7 to 15 of the Charter. This would allow Parliament or a provincial or territorial legislature to enact legislation that could violate Charter rights set out in sections 2 and 7 to 15, but be immune to court challenges for a period of five years. The Charter rights that could be overridden are important; sections 2 and 7 to 15 of the Charter set out the fundamental freedoms, legal rights and equality rights of individuals in Canada.

Constitutional scholar Peter Hogg has made the following observations on the use of section 33:

Only rights set out under sections 2 and 7 to 15 of the Charter may be limited by section 33; other sections of the Charter are immune.

The declaration must be explicit and must specify both to which statute (or provisions) section 33 will apply, and which Charter rights are intended to be overridden.

The declaration must be contained in the statute to which section 33 will apply, although an existing statute could be amended to include such a declaration.

Section 33 may not be applied retroactively.<sup>51</sup>

Section 33 imposes only formal requirements: namely, that Parliament or a legislature enact a declaration, and that it do so every five years. It is not concerned with the substance of, nor the reason for, the override. Political pressure is meant to be the control mechanism for the use of section 33: the

<sup>51</sup> Hogg, pp. 39-1 to 39-12.

<sup>&</sup>lt;sup>50</sup> See for example <u>Ermineskin Indian Band and Nation v. Canada</u>, 2009 SCC 9; A.C. v. Manitoba; <u>Alberta v. Hutterian Brethren of Wilson Colony</u>, 2009 SCC 37; and <u>Ontario (Attorney General) v. Fraser</u>, 2011 SCC 20.

public is generally not agreeable to the negation of fundamental rights and freedoms, and the use of section 33 can come at an "enormous political cost." <sup>52</sup>

The mechanism is to some extent more theoretical than practical because it has been used so infrequently. It has never been used by Parliament. Professor Hogg has argued that the inclusion of section 33 was essential to the provinces' agreement to the entrenchment of the Charter. However, the provinces have also been quite reluctant to use section 33, Québec being the only exception. As indicated by Professor Billingsley, "it appears that use of the notwithstanding clause is largely accepted by the public in Québec, likely because Québec has never ratified the Charter in the first place." 53

Indeed, Québec did not agree to the adoption of the Charter. In 1982, when the Charter came into force, the Québec government passed a law applying the notwithstanding clause to all its current legislation. At the time, the Parti Québécois was in power. The purpose of this omnibus law was to demonstrate the province's disagreement: "this move was political and was not motivated by a substantive legal concern that Québec legislation did not comply or should not comply with the values set out in the Charter." The government continued to insert notwithstanding clauses in almost all of its new legislation until a Liberal government was elected in 1985. The new government used the clause much less frequently, although a high-profile use of the clause was made in response to the Supreme Court decision in *Ford v. Québec (Attorney General)*, where the Court held that provisions requiring unilingual French commercial signs violated the right to freedom of expression guaranteed under section 2(b) of the Charter.

There have been three instances of provinces relying on section 33 outside of Québec:

- Legislation in the Yukon that was never brought into force
- Back-to-work legislation in Saskatchewan
- Legislation opposing same-sex marriage in Alberta.<sup>56</sup>

Many groups opposed to physician-assisted death raised the possibility of using the notwithstanding clause in their submissions to the Panel. Certain groups indicated that using the notwithstanding clause would give Canadian society more time to consider an accessible and safe implementation of a physician-assisted death framework. The mandate of this Panel was to engage in consultations fundamental to a federal legislative response respecting the *Carter* ruling. Accordingly, our attention was not focused on the possible application of section 33 and this report therefore does not feature any extensive discussion of this avenue.

<sup>&</sup>lt;sup>52</sup> Richard Albert, "Advisory Review: The Reincarnation of the Notwithstanding Clause," *Alberta Law Review*, Vol. 45, 2008.

<sup>&</sup>lt;sup>53</sup> Barbara Billingsley, "Section 33: The Charter's Sleeping Giant," Windsor Yearbook of Access to Justice, Vol. 21, 2002.

<sup>&</sup>lt;sup>54</sup> Ibid.

<sup>55</sup> Ford v. Québec (Attorney General), [1988] 2 S.C.R. 712.

<sup>&</sup>lt;sup>56</sup> Hogg, p. 39-4.

## Chapter 4. International Law

The Panel acknowledges the depth of insights that international law could yield. It recognizes that the government of Canada is mindful of its international obligations, by way of the international treaties and covenants of which it is signatory and has ratified. However, as indicated by Yude Henteleff, a lawyer and academic from the University of Manitoba, unless international covenants are incorporated as part of domestic Canadian legislation, they are not binding.

In its submission to the Panel, the Canadian Association for Community Living (CACL) proposed a plan guided by the United Nations *Convention on the Rights of Persons with Disabilities* (the Convention),<sup>57</sup> which was ratified by Canada in 2010. Specifically, the CACL advocated advance independent review of requests for physician-assisted death based on Canada's obligations under the *Convention on the Rights of Persons with Disabilities*. In particular, it based this proposal on Article 10 of the Convention, the "Right to life" and Article 16, the "Freedom from exploitation, violence and abuse."

Some experts with whom the Panel met also discussed the Convention. Anna MacQuarrie, Director of Global Initiatives, Policy and Human Rights at Inclusion International, noted article 12 from the Convention, which stands for equal recognition before the law and states that all measures relating to the exercise of legal capacity must provide proportional safeguards to prevent abuse. She noted that many countries are not in compliance with article 12. Mr. Steven Estey, who was a member of Canada's official government delegation to the UN, indicated to the Panel that Canadians with disabilities were very much involved in the drafting process of the Convention.

The Canadian Association for Community Living also raised the International Covenant on Economics, Social and Cultural Rights (ICESCR),<sup>58</sup> ratified by Canada in 1976, which includes in Article 12 a recognition of the "right of everyone to the enjoyment of the highest attainable standard of physical and mental health." In its submission to the Panel, Human Rights Watch argued that the right to health found in Article 12 of the ICESCR includes a right of access to palliative care, since it is an essential part of health care. According to Human Rights Watch, countries that are parties to the ICESCR should therefore take steps to ensure that palliative care is available.

States that ratify human rights treaties commit themselves to respecting those rights and ensuring that their domestic law is compatible with international legislation. Where domestic law fails to provide a remedy for human rights abuses, parties may be able to resort to international mechanisms for enforcing human rights.

<sup>&</sup>lt;sup>57</sup> United Nations, *Convention on the Rights of Persons with Disabilities*, (entered into force on 3 May 2008).

<sup>&</sup>lt;sup>58</sup> United Nations, <u>International Covenant on Economics, Social and Cultural Rights</u>, (entered into force on 3 January 1976).

## Chapter 5. Carter v. Canada

On 6 February 2015, the Supreme Court of Canada released its decision in *Carter v. Canada (Attorney General)*. This landmark decision will allow certain individuals with serious medical conditions to end their lives with the assistance of a physician. The case involved a claim, brought by Gloria Taylor and others, that the prohibition on assisted dying violates the Charter rights to life, liberty and security of the person and equality rights of certain individuals who seek the assistance of a physician to die. This chapter explores the legal of the claim, along with the issues raised and the outcome of the *Carter* litigation.

#### A. The Context

In 1993, the Supreme Court heard the claim of a woman named Sue Rodriguez. <sup>59</sup> Ms. Rodriguez was living with amyotrophic lateral sclerosis, commonly known as ALS. This disease is fatal. It causes progressive muscle paralysis. At the time of the hearing, Ms. Rodriguez was a relatively young woman; she was 42 years old and had a young son. Her condition was deteriorating rapidly, however, and she knew that she would soon be unable to swallow, speak, walk or move without assistance. Eventually, she would be unable to breathe without a respirator or eat except through a feeding tube inserted into her stomach. She was told that she had between two and 14 months to live.

Ms. Rodriguez did not want to wait until her condition claimed her life. Neither did she want to commit suicide and end her life prematurely while she was still physically able to do so on her own. She therefore sought a court order that would allow her to obtain a physician's assistance to set up some technological means by which she could end her life at the time of her choosing.

Ms. Rodriguez argued that section 241(b) of the *Criminal Code* violated her rights under sections 7 and 15 of the *Canadian Charter of Rights and Freedoms*. <sup>60</sup> Section 241(b) prohibits "aid[ing] or abet[ting] a person to commit suicide, whether suicide ensues or not." Specifically, Ms. Rodriguez asked the court to declare that section 241(b) is invalid to the extent that it "prohibits a terminally ill person from committing 'physician-assisted' suicide." <sup>61</sup>

The Supreme Court's decision in *Rodriguez* was complex and deeply divided. Five of the nine judges held that the law did not violate Ms. Rodriguez's rights under section 7 of the Charter, and that while it could be assumed that the law violated her equality rights under section 15, that this violation was a reasonable limit on her rights justifiable under section 1 of the Charter. Two judges, among them the current Chief Justice of the Supreme Court, Beverley McLachlin, held that the law violated Ms. Rodriguez's right to security of the person, guaranteed under section 7 of the Charter. Another judge

<sup>&</sup>lt;sup>59</sup> Rodriguez.

<sup>&</sup>lt;sup>60</sup> Ms. Rodriguez also argued that section 241(*b*) violated her right "not to be subjected to any cruel and unusual treatment or punishment," which is guaranteed under section 12 of the Charter. As the Court found no violation of this right, however, and because the right was not considered in *Carter*, the section 12 argument is not discussed in this report.

<sup>&</sup>lt;sup>61</sup> Rodriguez.

held that the law violated Ms. Rodriguez's section 15 right to equality. Finally, yet another judge held that the law violated both sections 7 and 15 of the Charter.

The result of the *Rodriguez* decision was that Ms. Rodriguez could not legally seek a physician's assistance to end her life and that physician-assisted dying remained illegal in Canada. Media reports indicated that, despite the prohibition, Ms. Rodriguez died with the assistance of an anonymous physician on 12 February 1994.<sup>62</sup>

Many years after the *Rodriguez* decision, former Supreme Court Justice John Major publicly discussed his experience and that of his Supreme Court colleagues during the hearing and associated deliberations. Justice Major had formed part of the five-judge majority that dismissed the claim. In 2011, he called the case "haunting." <sup>63</sup> In 2013, he stated that "some of [his] former colleagues may have thought one way one day and a different way the next day." <sup>64</sup> He called on Parliament to update assisted dying laws. <sup>65</sup>

Sue Rodriguez's highly publicized efforts to seek the right to obtain a physician's assistance to die thrust the issue of assisted dying into the national consciousness, sparking discussion and debate. In the same month that she died, the House of Commons debated Bill C-215, *An Act to Amend the Criminal Code (Aiding Suicide)*, and a Special Senate Committee was appointed to study assisted dying. <sup>66</sup> Over the next several years, two additional bills were tabled in Parliament dealing with protecting health care workers from criminal responsibility when withdrawing life-sustaining treatment, and several bills were tabled seeking to legalize assisted dying, although none were passed. In 2009, the National Assembly of Québec struck the Select Committee on Dying with Dignity, <sup>67</sup> and in 2011, the Royal Society of Canada published its report entitled *End-of-Life Decision Making*. <sup>68</sup>

It was in this political and legal context that the claimants in Carter brought their claim.

#### B. The Claimants

#### 1. Gloria Taylor

Gloria Taylor was diagnosed with ALS in 2009. Her efforts to secure a physician's assistance to die formed the basis of much of the *Carter* litigation. She, like Sue Rodriguez, faced a terminal diagnosis with increasingly debilitating physical symptoms. As the Supreme Court noted, Ms. Taylor would lose the ability to use her "hands and feet, then the ability to walk, chew, swallow, speak and, eventually,

<sup>&</sup>lt;sup>62</sup> See for example CBC Digital Archives, *Rodriguez chooses suicide*.

<sup>&</sup>lt;sup>63</sup> Kirk Makin, "<u>Haunting right-to-die case weighs on judges' minds, 18 years on</u>," *The Globe and Mail*, 16 December 2011.

<sup>&</sup>lt;sup>64</sup> Duncan McCue, "<u>Assisted suicide laws need updating, says former Supreme Court justice</u>," *CBC News*, 25 October 2013.

<sup>65</sup> Ibid.

<sup>&</sup>lt;sup>66</sup> Martha Butler et al., <u>Euthanasia and Assisted Suicide in Canada</u>, Publication no. 2010-68-E Parliamentary Information and Research Service, Library of Parliament, Ottawa, 2013.

<sup>&</sup>lt;sup>67</sup> National Assembly of Québec, Select Committee on Dying with Dignity.

<sup>&</sup>lt;sup>68</sup> Udo Schuklenk et al., *End-of-Life Decision Making*, the Royal Society of Canada, November 2011.

breathe."<sup>69</sup> Her cognitive functions would remain intact. Ms. Taylor had been told in 2010 that she had a year to live. Her condition progressed more slowly than anticipated, however.

In 2012, Ms. Taylor, along with several other claimants, challenged the *Criminal Code* prohibition on assisted dying. As part of her application to the British Columbia Supreme Court, she said "I want the legal right to die peacefully, at the time of my own choosing, in the embrace of my family and friends... I do not want to die slowly, piece by piece."<sup>70</sup>

#### 2. Lee Carter and Hollis Johnson

Lee Carter and her husband Hollis Johnson were also claimants in the *Carter* litigation. Lee Carter is the daughter of Kay Carter, a woman who had been living with spinal stenosis. Although not fatal, spinal stenosis is a condition that causes progressive compression of the spinal cord, eventually leading to paralysis. Kay Carter reported feeling trapped in her own body.<sup>71</sup>

Kay Carter asked her daughter Lee and her son-in-law Hollis to help her travel to Switzerland to obtain assistance in dying. Switzerland is currently the only country in which it is legal to assist a non-resident to die, as long as this assistance is not provided for "selfish motives." Lee Carter and Hollis Johnson were aware that to assist Kay Carter in this manner posed risks. They could have been charged under section 241(b) of the *Criminal Code* for assisting Kay Carter's death and, if convicted, would have faced up to 14 years in prison. No such charges were ever laid, however. Lee Carter asserts that "her mother died exactly as she wanted and that, as a result, she [Lee Carter] was happy for her and at peace." The could be assisted to obtain a serior to be a serior to

#### 3. The Remaining Claimants

Dr. William Shoichet is a physician practicing family medicine in British Columbia. He claimed that were physician-assisted dying legal, he would be willing to provide this assistance to eligible individuals. He therefore challenged the prohibition against assisted dying on the basis that it is a service that should be provided in appropriate circumstances.

The British Columbia Civil Liberties Association, which has adopted the mandate "to preserve, defend, maintain and extend civil liberties and human rights in Canada," <sup>75</sup> argued that it is "unreasonable to expect grievously and irremediably, and often terminally, ill persons to bring on and carry through to completion a lengthy and involved constitutional challenge." The Association sought and won the right to make arguments before the British Columbia Supreme Court on behalf of such persons, challenging the *Criminal Code* prohibition on assisted dying.<sup>76</sup>

<sup>&</sup>lt;sup>69</sup> *Carter* at para. 11.

<sup>&</sup>lt;sup>70</sup> Carter at para. 12.

<sup>&</sup>lt;sup>71</sup> <u>Carter v. Canada (Attorney General)</u>, 2012 BCSC 886 at para. 60 [Carter BCSC].

<sup>&</sup>lt;sup>72</sup> Code pénal suisse, art. 115 « un mobile égoïste. »

<sup>&</sup>lt;sup>73</sup> *Carter* BCSC at para. 63.

<sup>&</sup>lt;sup>74</sup> Carter BCSC at para. 69.

<sup>&</sup>lt;sup>75</sup> British Columbia Civil Liberties Association, *About*.

<sup>&</sup>lt;sup>76</sup> Carter BCSC at para. 87.

#### C. The Criminal Code

The claimants in *Carter* challenged several sections of the *Criminal Code* on the basis that they prohibit physician-assisted dying for certain individuals with serious medical conditions.<sup>77</sup> These included sections 21 and 22, which deal with being a party to an offence and counselling an offence, and section 222, which deals with homicide.

The Supreme Court held that only section 241(*b*), which prohibits aiding and abetting suicide, and section 14, which prohibits individuals from consenting to having death inflicted upon them, needed to be considered. This, the Court explained, is because the other three sections "are only engaged so long as the provision of assistance in dying is itself an 'unlawful act' or offence."<sup>78</sup>

Operating together, the two remaining sections, 241(*b*) and 14, make it an offence for any individual to assist any other individual to die. The prohibition currently applies to everyone, including physicians. When the Supreme Court's suspension of invalidity expires, however, the *Carter* decision will create an exemption for physicians who provide assistance in dying to certain eligible individuals.

#### D. The Lower Court Decisions

#### 1. The Trial Decision

The claimants in *Carter* applied to the Supreme Court of British Columbia for a declaration that the *Criminal Code* prohibition on physician-assisted dying violates rights set out in the *Canadian Charter of Rights and Freedoms*. Justice Lynn Smith heard the claim. One of the first issues Justice Smith had to address was whether the legal precedent that the Supreme Court of Canada had established in *Rodriguez* 19 years earlier prevented her from making the declaration that the claimants sought.

Outside of Québec, Canada relies entirely on a common law legal system, inherited from England. Within Québec, the common law system applies only to public law, criminal law and other federal law; private matters in Québec fall under the civil law system. The common law system is based on the principle that lower courts must follow legal decisions or precedents established by higher courts. In practice, this means that trial courts are bound by decisions of courts of appeal, all courts are bound by decisions of the Supreme Court of Canada, and generally only the Supreme Court of Canada may depart from its own decisions. The Supreme Court has called the rule of precedent a "foundational principle upon which the common law relies." <sup>79</sup> Justice Smith's interpretation of the leading case on when courts may reconsider set by the Supreme Court of Canada led her to conclude that she could consider the claim despite the *Rodriguez* precedent. <sup>80</sup>

<sup>&</sup>lt;sup>77</sup> Criminal Code, R.S.C. 1985, c. C-46.

<sup>&</sup>lt;sup>78</sup> Carter at para. 20.

<sup>&</sup>lt;sup>79</sup> Bedford at para. 38.

<sup>&</sup>lt;sup>80</sup> Justice Smith had relied on the Ontario Court of Appeal decision in <u>Canada (Attorney General) v. Bedford</u>, 2012 ONCA 186.

Justice Smith considered a vast amount of evidence on palliative care, various end-of-life practices, assisted dying in other jurisdictions, and the ethical implications that these practices might raise. She heard from practitioners and academics from the fields of medicine, nursing, law, ethics, psychology, disability rights, sociology and philosophy. She concluded that the prohibition on assisted dying violates the Charter rights of certain individuals with serious medical conditions. Justice Smith held that the appropriate remedy was a declaration that the relevant provisions of the *Criminal Code* were inoperative, but she suspended her declaration for one year to allow Parliament to amend the legislation.

Ms. Taylor sought an additional remedy. She did not want to have to wait until a new law on assisted dying came into force, so Ms. Taylor sought a constitutional exemption that would allow her to seek a physician's assistance to die while the *Criminal Code* prohibition was still in effect. Justice Smith granted this exemption, with the following conditions:

- (a) Ms. Taylor provides a written request.
- (b) Her attending physician attests that Ms. Taylor is terminally ill and near death, and there is no hope of her recovering.
- (c) Her attending physician attests that Ms. Taylor has been:
  - (i) informed of her medical diagnosis and prognosis;
  - (ii) informed of the feasible alternative treatments, including palliative care options;
  - (iii) informed of the risks associated with physician-assisted dying and the probable result of the medication proposed for use in her physician-assisted death;
  - (iv) referred to a physician with palliative care expertise for a palliative care consultation;
  - (v) advised that she has a continuing right to change her mind about terminating her life
- (d) Her attending physician and a consulting psychiatrist each attest that Ms. Taylor is competent and that her request for physician-assisted death is voluntary and nonambivalent. If a physician or consulting psychiatrist has declined to make that attestation, that fact will be made known to subsequent physicians or consulting psychiatrists and to the court.
- (e) Her attending physician attests to the kind and amount of medication proposed for use in any physician-assisted death that may occur.
- (f) Unless Ms. Taylor has become physically incapable, the mechanism for the physicianassisted death shall be one that involves her own unassisted act and not that of any other person.<sup>81</sup>

Although Ms. Taylor became the first person in Canada to receive a constitutional exemption that would allow her to seek a physician's assistance to die, she never availed herself of that option. She died of an infection on 4 October 2012.<sup>82</sup> Her death rendered the question of the legal merits of her constitutional

<sup>81</sup> Carter BCSC at para. 1414.

<sup>&</sup>lt;sup>82</sup> Wendy Stueck and Rod Mickleburgh, "<u>Assisted-suicide activist Gloria Taylor dies from infection</u>," *Globe and Mail*, 5 October 2012.

exemption moot; neither the British Columbia Court of Appeal nor the Supreme Court explicitly ruled on the exemption.

#### 2. The Court of Appeal Decision

The province of British Columbia and the federal government appealed Justice Smith's decision. The majority of the British Columbia Court of Appeal allowed the appeal, holding that Justice Smith was bound by the *Rodriguez* precedent and therefore could not grant the remedies the claimants sought.<sup>83</sup> The Chief Justice of the Court of Appeal wrote a dissenting opinion in which he upheld Justice Smith's reasoning on all matters except her conclusion with respect to section 15 of the Charter.

The claimants appealed this decision to the Supreme Court of Canada.

#### E. The Supreme Court Decision

By the time that the Supreme Court heard the *Carter* appeal, only one Supreme Court justice remained who had heard the *Rodriguez* claim. This was Chief Justice Beverley McLachlin, who had written one of the three dissenting opinions in *Rodriguez*, and concluded at the time that the prohibition violated section 7 of the Charter.

A notable aspect of the *Carter* decision is its authorship. Typically, one or two judges write decisions of the Supreme Court, and other judges indicate whether they agree with the judgment. If they do not agree, one or more judges might author their own dissenting opinion. In either case, the names of the authors of each decision are usually indicated. In contrast, not only is *Carter* unanimous, but it was authored by "The Court." This is a practice that the Supreme Court generally saves for decisions of significant constitutional value, in which it is important to underscore the unanimity of a decision.

The Supreme Court had to consider several legal issues as part of its decision in *Carter*. Among them are the more procedural questions of whether the trial judge was permitted to depart from the precedent the Supreme Court set in *Rodriguez* and whether physician-assisted dying is a matter that falls under federal or provincial jurisdiction. It also addressed the substantive issue of whether a prohibition against physician-assisted dying violates the Charter rights of certain individuals seeking this assistance.

#### 1. Departing from Rodriguez

In the case of *Canada (Attorney General) v. Bedford*, the Supreme Court held that lower courts may depart from the precedents of higher courts:

(1) where a new legal issue is raised; or (2) where there is a change in the circumstances or evidence that fundamentally shifts the parameters of the debate.<sup>84</sup>

<sup>83</sup> Carter v. Canada (Attorney General), 2013 BCCA 435.

<sup>84</sup> Bedford at para. 42.

Justice Lynn Smith had concluded that there had been substantive developments in the case law on section 7 of the Charter. Further, she considered a sizeable body of evidence supporting the view that safeguards can be established to control the risk of abuse.

The Supreme Court held that both of the conditions in the *Bedford* legal test were met. The change in the analysis that courts must perform when considering claims under section 7 of the Charter met the test for a new legal issue. Given that the first condition was met, it was not necessary to meet the second condition of the *Bedford* test. The Court held, however, that this condition was met as well. At the time that *Rodriguez* was decided, no jurisdiction in the world had legislation in place regulating assisted dying. Between the *Rodriguez* decision and the *Carter* hearing, five jurisdictions enacted legislation. They were Oregon, the Netherlands, Washington, Belgium and Luxemburg. Montana and Colombia had enabled the practice through court decisions, establishing legal requirements in case law rather than through legislation. Justice Smith considered evidence that suggested that there were no significant abuses occurring in these jurisdictions.

The Supreme Court held that this evidence was sufficient to "fundamentally shift the parameters of the debate." Justice Smith was therefore entitled to depart from the *Rodriguez* precedent.

#### 2. Division of Federal and Provincial Powers

With respect to the division of federal and provincial/territorial powers as they relate to assisted dying, the claimants argued that although the criminal prohibition against assisted suicide falls within federal jurisdiction, physician-assisted dying does not, because it "lies at the core of the provincial jurisdiction over health care."

The claimants were making an argument on what is known as an "interjurisdictional immunity." This means they were arguing that within each area of jurisdiction, there are core policy areas so intrinsic to a given level of government's legislative authority that any attempt by the other level of government to legislate in that area would be constitutionally invalid. The Court held, however, that no such protected core has been defined in the area of health, and further suggested that such a core would be very difficult to identify. Citing one of its recent decisions in the area of health law, the Court noted:

Overlapping federal jurisdiction and the sheer size and diversity of provincial health power render daunting the task of drawing a bright line around a protected provincial core of health where federal legislation may not tread.<sup>86</sup>

Rather than identifying with precision which areas within health might fall to the federal government or to the provinces, the Court has, since 1982, held that health is an area of concurrent (or shared) jurisdiction, in which either level of government may enact valid legislation.<sup>87</sup> The Court therefore

<sup>&</sup>lt;sup>85</sup> Carter at para. 49.

<sup>&</sup>lt;sup>86</sup> Carter at para. 51, citing PHS at para. 48.

<sup>&</sup>lt;sup>87</sup> See for example RJR-MacDonald at para. 32; Schneider v. The Queen, [1982] 2 S.C.R. 112, at p. 142.

concluded that "aspects of physician-assisted dying may be the subject of valid legislation by both levels of government, depending on the circumstances and focus of the legislation." 88

#### 3. Section 7 of the Charter

The Supreme Court's consideration of the claimants' Charter arguments, particularly those under section 7, is the primary focus of its decision in *Carter*. As discussed in greater detail elsewhere in this report, section 7 of the *Canadian Charter of Rights and Freedoms* guarantees right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice. This right has been treated as three distinct rights, creating a guarantee that no one may be deprived of the right to life, liberty or security of the person unless such deprivation is in accordance with the principles of fundamental justice.

The Supreme Court considered each of these rights and concluded that, for certain individuals in situations similar to those of Gloria Taylor and Kay Carter, the prohibition against physician-assisted dying violates all three of these rights.

#### a) The Right to Life

The claimants argued at trial that a prohibition on physician-assisted dying might compel certain individuals facing a serious or terminal illness to take their lives prematurely while they are still physically capable of doing so. Gloria Taylor, for example, faced having her condition worsen to a point at which her capacity for voluntary movement would become so limited that she could not end her own life without assistance. She did not want to end her life while she retained this ability, however, because she said she wanted to "get every bit of happiness I can wring from what is left of my life so long as it remains a life of quality." 89

The evidence showing that some individuals might feel compelled to take their life prematurely had convinced the trial judge that the right to life under section 7 was engaged. The government did not challenge this evidence, and so the Supreme Court chose not to interfere with the trial judge's finding. Further, the Court observed that "the case law suggests that the right to life is engaged where the law or state action imposes death or an increased risk of death on a person, either directly or indirectly." <sup>90</sup> Following this reasoning, the prohibition on assisted dying could be seen as indirectly imposing an increased risk of death on certain people facing end-of-life decisions.

The Court noted that while the right to life stems from our understanding that the "sanctity of life is one of our most fundamental societal values," this right should not be seen as a requirement that "all human life be preserved at all costs." <sup>91</sup>

Based on its conclusions with respect to the right to life alone, the Supreme Court was obligated to consider whether the deprivation of a section 7 right was made in accordance with the principles of

<sup>&</sup>lt;sup>88</sup> Carter at para. 53.

<sup>&</sup>lt;sup>89</sup> Carter at para. 12.

<sup>&</sup>lt;sup>90</sup> Carter at para. 62.

<sup>&</sup>lt;sup>91</sup> Carter at para. 63.

fundamental justice. The Supreme Court continued its analysis of section 7, however, by considering whether the rights to liberty and security of the person were engaged as well.

#### b) The Rights to Liberty and Security of the Person

Although the rights to liberty and security of the person are two distinct rights, the Supreme Court dealt with them together in *Carter*, holding that both rights are informed by "a concern for the protection of individual autonomy and dignity." <sup>92</sup> While the right to liberty protects "the right to make fundamental personal choices free from state interference," the right to security of the person protects the right to have "control over one's bodily integrity free from state interference."

As it had with the right to life, the Supreme Court relied heavily on the trial judge's analysis in its reasoning with respect to the rights to liberty and security of the person. Justice Smith had concluded that the prohibition on assisted dying limited Gloria Taylor's rights to both liberty and security of the person because it interfered with her ability to make "fundamentally important and personal" medical decisions, imposed pain and psychological stress, and deprived her of control over her bodily integrity. The Supreme Court agreed. Justice Smith also noted that the prohibition meant that seriously and irremediably ill persons were "denied the opportunity to make a choice that may be very important to their sense of dignity and personal integrity" and that is "consistent with their lifelong values and that reflects their life's experience." Again, the Supreme Court agreed, noting that "an individual's response to a grievous and irremediable medical condition is a matter critical to their dignity and autonomy."

The Court held that the prohibition on assisted dying engages the right to liberty because it can, for certain individuals, interfere with the ability to make decisions about one's bodily integrity and medical care. The Court held that the prohibition engages the right to security of the person because it could leave people like Ms. Taylor to endure intolerable suffering.

Having concluded that all three rights under section 7 were engaged, the framework of the section 7 legal test then required the Supreme Court to consider whether the deprivation of these rights was in accordance with the principles of fundamental justice.

#### c) The Principles of Fundamental Justice

Individuals may not be deprived of the rights to life, liberty and security except in accordance with the principles of fundamental justice. If a court finds that there has been a deprivation of a section 7 right, then, the court must next determine if the deprivation was in accordance with the principles of fundamental justice. The list of principles of fundamental justice that should be considered in the context of section 7 has been developed by the courts over the years. The two principles that the Supreme Court considered in *Carter* were arbitrariness and overbreadth.

<sup>&</sup>lt;sup>92</sup> Carter at para. 64.

<sup>&</sup>lt;sup>93</sup> Carter at para. 64.

<sup>&</sup>lt;sup>94</sup> Carter at para. 65, citing Carter BCSC at para. 1326.

<sup>&</sup>lt;sup>95</sup> Carter at para. 66.

The principle that laws must not be arbitrary requires that there be a "rational connection" between the purpose of a law and limits that it imposes on section 7 rights. <sup>96</sup> The principle that laws must not be overbroad requires that any effects of a law's limitation of individuals' section 7 rights should be confined as much as possible to the individuals or conduct targeted by the law.

To analyze whether a law violates the principles that it should not be arbitrary or overbroad, it is necessary to compare the purpose of the law with the deprivation of section 7 rights. The Supreme Court held that the purpose of the prohibition on assisted dying is to "[prevent] vulnerable persons from being induced to commit suicide at a time of weakness." The Supreme Court held that the prohibition on assisted dying is not arbitrary. It reasoned that given that the purpose of a law is to protect vulnerable persons from committing suicide at a time of weakness, a "total ban on assisted suicide clearly helps achieve this object." The Court held that the prohibition is overbroad, however, because although the law had the purpose of protecting the vulnerable, it also had the effect of prohibiting individuals such as Gloria Taylor, who was "competent, fully informed, and free from coercion or duress" from accessing a physician's assistance to die. 99

#### 4. Section 15 of the Charter

At trial, Justice Lynn Smith had found that the *Criminal Code* prohibition on assisted dying violates the equality rights guaranteed under section 15 of the Charter of persons with physical disabilities. She held that because non-disabled people have the option of committing suicide and some people with physical disabilities do not, a prohibition on assisted suicide imposes a heavier burden on individuals with physical disabilities. She concluded that this distinction amounts to discrimination.

The Supreme Court did not consider section 15 in its analysis of Charter violations. It held that because it had already found that the prohibition on assisted dying violates section 7, it was unnecessary to consider whether it violates section 15 as well.

#### 5. Section 1 of the Charter

Having found that the laws challenged in *Carter* violate a Charter right, the Supreme Court had to consider whether this violation could be justified under section 1 of the Charter. Section 1 states that the rights and freedoms set out in the Charter are "subject only to such reasonable limits prescribed by law as can be demonstrably justified in a free and democratic society." This means that Charter rights are not absolute; they may be subject to reasonable limitations that the government can justify. In *Carter*, the Supreme Court held that the prohibition on assisted dying was not a reasonable limit on the section 7 rights of certain individuals with serious medical conditions.

The Supreme Court began its section 1 analysis by noting that it is difficult to justify an infringement of section 7 rights. The rights to life, liberty and security of the person are fundamental. The Court also considered the degree of deference due to Parliament in this situation. It is the role of Parliament and

<sup>&</sup>lt;sup>96</sup> Carter at para. 85.

<sup>&</sup>lt;sup>97</sup> Carter at para. 78.

<sup>98</sup> Carter at para. 84.

<sup>99</sup> Carter at para. 86.

the provincial legislatures to enact laws, and courts must defer to the expertise of Parliament and the legislatures in this area. Where a high degree of deference is appropriate, courts should not be quick to question choices that Parliament has made in enacting laws. The Supreme Court has held that this is particularly true where Parliament has had to make difficult decisions involving competing social interests. This was the case in *Carter*, as the Supreme Court noted. This level of deference was somewhat tempered by the fact that the prohibition on assisted dying is absolute; if a complex regulatory regime allowing access to assisted dying were in place, it would be due greater deference.

In deciding whether a law's violation of a Charter right may be justified, a court must consider whether the law has a pressing and substantial objective and whether the government has demonstrated that the law is proportionate. In *Carter*, the claimants conceded that the objective of the prohibition on assisted dying—specifically, preventing vulnerable persons from being induced to commit suicide at a time of weakness—is pressing and substantial. The main question for the Supreme Court to consider, then, was whether the prohibition was proportionate. A law is considered to be proportionate if 1) the means used to achieve the law's objective are rationally connected to that objective, 2) the law impairs rights as minimally as possible and 3) there is proportionality between the "deleterious and salutary" (or harmful and helpful) effects of the law. 100

The Supreme Court held that it is "rational to conclude that a law that bars all persons from accessing assistance in suicide will protect the vulnerable from being induced to commit suicide at a time of weakness." The prohibition therefore met the first requirement of the section 1 test. The Court then addressed whether the prohibition impairs rights as little as possible. The Supreme Court noted that this question "lies at the heart of this case." Specifically, the Court asked "whether the absolute prohibition on physician-assisted dying, with its heavy impact on the claimants' rights to life, liberty and security of the person, is the least drastic means of achieving the legislative objective." 102

The Supreme Court agreed with much of the trial judge's reasoning on whether rights were minimally impaired. Justice Smith had held that:

an absolute prohibition would have been necessary if the evidence showed that physicians were unable to reliably assess competence, voluntariness, and non-ambivalence in patients; that physicians fail to understand or apply the informed consent requirement for medical treatment; or if the evidence from permissive jurisdictions showed abuse of patients, carelessness, callousness, or a slippery slope, leading to the casual termination of life. 103

The evidence the trial judge considered convinced her to reject all of these possibilities. She concluded that "a permissive regime with properly designed and administered safeguards was capable of protecting vulnerable people from abuse and error." <sup>104</sup> The Supreme Court agreed, noting that "[w]hile

<sup>&</sup>lt;sup>100</sup> Carter at para. 94.

<sup>&</sup>lt;sup>101</sup> *Carter* at para. 101.

<sup>&</sup>lt;sup>102</sup> Carter at para. 103.

<sup>&</sup>lt;sup>103</sup> Carter at para. 104.

<sup>&</sup>lt;sup>104</sup> Carter at para. 105.

there are risks, to be sure, a carefully designed and managed system is capable of adequately addressing them." <sup>105</sup>

The trial judge had concluded that evidence from other jurisdictions confirmed that regimes can be established that allow eligible individuals to access assisted dying, while protecting vulnerable persons. The Supreme Court therefore held that the prohibition was not minimally impairing, as safeguards could be implemented to allow individuals in situations like Gloria Taylor's to access assisted death while still preventing vulnerable persons from being induced to commit suicide at a time of weakness. The prohibition therefore could not be considered a reasonable and justified limit on the section 7 rights of eligible individuals who seek a physician's assistance to die.

#### 6. The Declaration

Having found a Charter violation that could not be justified under section 1, the Supreme Court was obligated to find an appropriate remedy for the claimants. It opted against considering constitutional exemptions. The two individuals whose lives formed the context of the litigation, Kay Carter and Gloria Taylor, had both died. The claimants Lee Carter, Hollis Johnson, Dr. Shoichet and the British Columbia Civil Liberties Association had no need for a constitutional exemption. The Court therefore considered only the remedy of a declaration of invalidity.

The Court declared that sections 241(b) and 14 of the *Criminal Code* are invalid to the extent that 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." Further, it noted that the term "irremediable" should not be understood as requiring that people must undertake treatments that are not acceptable to them to be considered eligible.

This declaration did not limit access to persons with terminal conditions, or physical conditions. Moreover, the Court did not rule on the possibility of requesting physician-assisted death in an advance directive, or through a substitute decision maker. In fact, the Court took great care to specify that the scope of this declaration was intended to respond to the factual circumstances in this case and made no pronouncement on other situations where physician-assisted dying may be sought.

The declaration was suspended for 12 months to allow time for Parliament and the legislatures "should they so choose, [to respond] by enacting legislation consistent with the constitutional parameters set out in" the decision. 107

#### 7. Conscientious Objection

Several interveners addressed the right of physicians and other health care workers to refuse to provide assistance in dying for reasons of conscience or religion. They included the Catholic Civil Rights League,

<sup>&</sup>lt;sup>105</sup> Carter at para. 105.

<sup>&</sup>lt;sup>106</sup> *Carter* at para. 127.

<sup>&</sup>lt;sup>107</sup> Carter at para. 126.

the Faith and Freedom Alliance, the Protection of Conscience Project, the Catholic Health Alliance of Canada and the Canadian Medical Association.

The Court held that nothing in its declaration could compel physicians to provide assistance in dying. The Court left any additional issues to be resolved by the physicians' colleges, Parliament and the provincial legislatures. It noted, however, that the "Charter rights of patients and physicians will need to be reconciled." <sup>108</sup>

#### F. The Effect of the Decision

The Supreme Court suspended its declaration of invalidity until 6 February 2016. Unless the Court decides otherwise, on that date physicians will be permitted to assist eligible individuals to die. The Court left many considerations to be addressed by Parliament and the provincial legislatures. The federal Ministers of Justice and Health struck this Panel to collect input from Canadians on how to address some of these considerations.

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<sup>&</sup>lt;sup>108</sup> *Carter* at para. 132.

# Part III – A Report on the Panel's Consultations

## Chapter 6. Forms of Assisted Dying and Terminology

"Physician-assisted dying" and "physician-assisted death" are terms the Supreme Court of Canada adopted in *Carter v. Canada* to refer to the act of a physician assisting a person to end their life at that person's request. These are therefore the terms that the Panel has adopted in this report. As part of our mandate, the Panel was tasked with collecting input on two types of physician-assisted death: voluntary euthanasia and assisted suicide. In voluntary euthanasia, the physician takes the final act that will end the individual's life. Often, this act is the intravenous administration of a lethal substance. In assisted suicide, an individual performs the final act to end their life. This often involves ingesting a lethal substance prescribed or provided by the physician. In both types of physician-assisted dying, the act is voluntary and requested by the individual; the only distinction is the actual role the physician plays.

Some jurisdictions expressly allow one or both of these forms of assisted dying. The Netherlands and Luxembourg allow both voluntary euthanasia and assisted suicide, <sup>109</sup> while the American states of Oregon, Washington, Vermont, Montana and California allow only physician-assisted suicide. <sup>110</sup> The province of Québec, in its *Act respecting end-of-life care*, has defined "medical aid in dying" as "care consisting in the administration by a physician of medications or substances to an end-of-life patient, at the patient's request, in order to relieve their suffering by hastening death." <sup>111</sup>

While the Supreme Court's decision in *Carter* did not discuss terminology or distinguish between voluntary euthanasia and assisted suicide, groups appearing before the Panel have raised questions about the use of specific terminology, and have voiced concerns with regard to the practice of each method.

### A. Voluntary Euthanasia and Physician-Assisted Suicide: Terminology

The Panel heard different views on the issue of using the specific terms "voluntary euthanasia" and "assisted suicide," as opposed to the more general terminology of "physician-assisted death" and "physician-assisted dying." Dr. Brian Mishara, a Canadian psychologist and suicide researcher, and the Canadian Federation of Catholic Physicians' Societies noted that the distinction is important and the use

<sup>&</sup>lt;sup>109</sup> While the text of the Belgian legislation technically allows only voluntary euthanasia, physician-assisted suicide has been interpreted as falling under the ambit of voluntary euthanasia, and is therefore also allowed.

<sup>&</sup>lt;sup>110</sup> Oregon Death with Dignity Act, O.R.S. 127 (1994); Patient Choice at End of Life, Sec 1, 18 V.S.A. c. 113 (2013); Washington Death with Dignity Act, R.C.W. c. 70.245 (2008); Baxter v. Montana, Mont. Sup. Ct., 2009 MT 449; and End of Life Option Act (California), Part 1.85, Div. 1, Health and Safety Code (2015).

<sup>&</sup>lt;sup>111</sup> An Act respecting end-of-life care, R.S.Q. c. S-32.0001.

of precise language is essential to facilitate clear thinking about the issue, avoid confusion about which practices are now permitted and ensure that individuals and physicians have a shared understanding of the method contemplated.

Some groups, such as the Physicians' Alliance against Euthanasia and the Protection of Conscience Project, were of the view that using terms other than "euthanasia" and "suicide" would only serve to obfuscate the issue and would impair the ability of those who are unable to participate in this practice for reasons of conscience to fully articulate their reasoning or to specify which procedures they might be able to perform. Dr. Georges L'Espérance, President of the Association québécoise pour le droit de mourir dans la dignité, indicated that even if the term "euthanasia" has a particularly negative connotation because of historical events of the 20<sup>th</sup> century, it is etymologically well defined to mean a good death administered by a physician. Consequently, he argued, the term should be used.

The College of Family Physicians of Canada told the Panel that the terms "medical aid in dying" and "physician-assisted dying" are too general to be used in the clinical setting, potentially leading to confusion and misunderstanding among physicians and individuals. The College argued that voluntary euthanasia and physician-assisted suicide are different, psychologically and ethically, since the former "engages physicians as agents who intentionally end the life of their patients," whereas the latter does not. The College of Family Physicians of Canada therefore encourages the use of the specific terms voluntary euthanasia and assisted suicide.

In a written submission to the Panel, the ARCH Disability Law Centre explored at some length the absence of consensus within disability communities about appropriate terminology. ARCH observed that some of its community partners "appreciated the amount of agency and individual control that the term 'suicide' implies," while others expressed concern about the stigmatizing implications of this highly charged word. Despite these divisions, ARCH noted that most of its partners found "euthanasia" to be a term "particularly abhorrent to individuals with a disability."

The Panel was reminded numerous times throughout the consultation that the phrases "voluntary euthanasia" and "assisted suicide" are emotionally charged and carry considerable stigma. Groups that were of this view advised that it would be preferable to use neutral language when discussing these matters with patients, such as "physician-assisted dying," to avoid the negative connotations associated with the terminology of euthanasia and suicide. The Panel heard from the Canadian Nurses Association that using such language could deter some individuals from initiating meaningful discussions on the topic with their health care providers; they may fear being judged, or believe that they are doing something wrong, thus jeopardizing honest and open conversation.

Since suicide is a source of deep and continuing trauma in many Indigenous communities, using the term "physician-assisted suicide" raised concerns for Melanie MacKinnon, an academic and Indigenous health expert at the University of Manitoba. The Indigenous Physicians Society of Canada indicated that explicitly associating physicians with assisted death could fuel apprehension that individuals must

<sup>&</sup>lt;sup>112</sup> Howard Shapray, appearing with British Columbia Civil Liberties Association and *Carter* claimants, 28 October 2015; Dr. Brian Mishara, 7 October 2015, observing that the language of providing medical aid in dying is more palatable than euthanasia; Canadian Psychiatric Association, 5 November 2015.

eventually engage in this discussion with their physician as a matter of course. Dr. Alika Lafontaine, of the Indigenous Physicians Society of Canada, noted that this may create a further barrier between them and their health care practitioner. Dr. Lafontaine reflected that "changing the language ... may be helpful in having patients willing to have these discussions and not afraid that these discussions will be forced on them."

The Panel heard various suggestions for appropriate terminology. In an online submission, an ethicist from Toronto suggested "legal requested death" to distinguish what he called an "arranged death" from suicide as it is commonly understood. In his view, a request for physician-assisted death is made to curtail the dying process, which is qualitatively different from suicide. He suggested the term "legal" to indicate that not all requests will be granted, since individuals must meet eligibility criteria.

The Canadian Society of Palliative Care Physicians proposed terminology that would make a clear distinction between palliative care and practices that hasten or bring about death, noting that the terms "physician-assisted dying" and "physician-assisted death" are ambiguous and could potentially undermine the practice of palliative medicine. The risk this term could pose to palliative care, the Society argued, is to conflate actively ending an individual's life with supporting an individual through a natural death process, which is the defining feature of palliative care. The Society proposed that the central concept of physician-assisted dying is that of accelerating death. It therefore recommended the use of "hastened death" to replace "assisted dying," combined with a specification of who administers the procedure, such as "patient-administered" or "physician-administered."

Another option the Panel heard is to combine the need for specificity with the benefit of avoiding emotionally charged language by qualifying the term "physician-assisted dying" with reference to the physician's role. Dr. Douglas Grant, President of the Federation of Medical Regulatory Authorities of Canada and Registrar for the College of Physicians and Surgeons of Nova Scotia, used the phrase "physician-administered" and "physician-prescribed" assistance in dying to distinguish between the two methods.

## B. Other Observations on Terminology

#### 1. Death or Dying

Some groups have distinguished between physician-assisted death and physician-assisted dying, noting that health care providers—and particularly palliative care physicians—already assist people with the process of dying by providing care as someone nears the end of life. According to the Canadian Nurses Association, it is worth noting the difference between this support and assisting *death* in scenarios such as the one envisioned in *Carter*; as such, assisted death was their preferred term. In an online submission to the Panel, a physician from Brantford, Ontario, explained that terms like "physician-

<sup>&</sup>lt;sup>113</sup> Canadian Nurses Association, 21 October 2015; Canadian Society of Palliative Care Physicians, 3 November 2015; Edgar-Andre Montigny & Sarah Mackenzie, Written Submissions of ARCH Disability Law Centre Based on ARCH's Community Consults, RE: *Carter v Canada*, Prepared for the External Panel on Options for a Legislative Response to *Carter v. Canada*, p. 23.

assisted death" indicate an event rather than a process, and suggested that this is a helpful distinction where the intended purpose is to bring the dying process to an end.

#### 2. Withholding and Withdrawing Treatment

Some experts, such as Prof. Isabelle Marcoux and Dr. Brian Mishara, also commented on the confusion that exists among the general public and the health care profession between what is already legal and what will become legal once the Supreme Court's decision comes into effect. Specifically, the College of Family Physicians of Canada told the Panel that withholding and withdrawing treatment are different from physician-assisted dying. Indeed, individuals have had a longstanding right to refuse treatment or to withdraw treatment, even if to do so would end their lives.

In a meeting with three bioethicist colleagues, the Panel was presented with slightly different opinions on whether there was a moral difference between withholding treatment, withdrawing current treatment and physician-assisted death. Joshua Landry, of the Champlain Centre for Health Care Ethics at the Ottawa Hospital, opined that there was no difference, while Michael Kekewich, of the same group, thought that reasonable people can disagree on this non-critical issue. The third bioethicist felt that there was a difference between the three concepts, at least from a psychological perspective. Whereas withholding treatment, as Dr. Thomas Foreman, Director of the Champlain Centre for Health Care Ethics at the Ottawa Hospital suggested, is "not intervening to stop [someone from] dying," withdrawing treatment can be seen as "removing the barrier to [allow] the natural process to occur," and physician-assisted dying is actively "intervening to impact the natural process," to "cause an outcome." Withdrawing and withholding treatment are legally distinct from physician-assisted dying and are unchanged by *Carter*.

#### 3. Consent

Some stakeholders, such as Dr. Patrick Vinay of the Physicians' Alliance against Euthanasia, noted that it may be inappropriate or at least inexact to use the term "consent" in the context of physician-assisted dying. Consent in the medical realm denotes agreeing to a procedure or treatment that is proposed to an individual by a physician. Professor Isabelle Marcoux agreed that physician-assisted dying should not be proposed or offered to the individual, but should instead arise directly from the individual. As such, the question should not be one of "consenting" to a treatment that is being offered or recommended, but instead ensuring that the person's request is truly voluntary and well informed.

#### 4. End-of-life Care and Palliative Care

Dying with Dignity Canada commented on the terms "end-of-life care" and "palliative care," indicating that the two should not be treated as synonymous. According to Dying with Dignity Canada, palliative care can be defined as excluding physician-assisted dying if the health care professionals who provide it choose to define it this way, but end-of-life care encompasses both palliative care and physician-assisted dying. This is consistent with Québec's *Act respecting end-of-life care*, which considers medical aid in dying a form of end-of-life care.

Presenting a different perspective, Dr. Susan MacDonald, President of the Canadian Society of Palliative Care Physicians characterized end-of-life care as part of palliative care:

We've looked at the definition of palliative care and that has changed. When I came into the field 20 years ago it was mostly end-of-life care because that's where our skillset was. Over the past 20 years we have tremendous gains in symptom management. We often are involved with patients for years on end. The dying part is a small piece of the process.

Physician-assisted dying is also seen as being different from palliative sedation, which is intended to ensure that people are comfortable until they die from their disease. 114 Palliative sedation is a proportionate response, with dosage adjustments achieving varying effects, depending on the person's circumstances and needs, from calming to full sleep. According to Dr. Ed Dubland, from a network of British Columbia physicians that met with the Panel, palliative sedation consists of suspending the consciousness of people who suffer, allowing natural death to occur without conscious distress. The Panel heard from the Association québécoise pour le droit de mourir dans la dignité that these practices do not conflict with one another.

#### 5. French Terminology for Physician-Assisted Dying

Finally, Professor Marcoux cautioned the Panel on a translation note. The French version of the *Carter* decision uses the term "aide médicale à mourir" as a translation of "physician-assisted dying." Professor Marcoux observed that "aide médicale à mourir" in the Québec legislation has a very technical meaning and is limited only to physicians administering the lethal substance at the request of the individual, and does not contemplate physician-assisted suicide.

#### C. Methods of Physician-Assisted Dying

The Panel also heard different points of view on the relative advantages and disadvantages of the two forms of physician-assisted dying it was asked to consider: voluntary euthanasia and assisted suicide.

Some groups appearing before the Panel commented on the prevalence of physician-assisted deaths depending on method. In Europe, where data are available for both voluntary euthanasia and assisted suicide, 2.8 to 4.6% of all deaths occur as a result of euthanasia, while 0.05% to 0.1% of all deaths are due to assisted suicide. In Oregon, where only assisted suicide is legal, approximately 0.3% of all deaths occur by assisted suicide. There is of course a significant difference in eligibility criteria between Europe and the U.S.; in the U.S., only someone with a terminal illness who is expected to die in less than six months may access assisted dying.

Professor Isabelle Marcoux noted that data from the European countries suggest that individuals who seek assisted dying prefer voluntary euthanasia to assisted suicide when given the choice. Several groups that appeared before the Panel referred to this finding. She added that while people who seek

<sup>&</sup>lt;sup>114</sup> Canadian Virtual Hospice website, <u>Explaining Withholding Treatment</u>, <u>Withdrawing Treatment</u>, <u>and Palliative Sedation</u>.

<sup>&</sup>lt;sup>115</sup> Oregon Public Health Division, *Oregon Annual Report 17: Oregon's Death with Dignity Act—2014*.

physician-assisted dying may prefer voluntary euthanasia, physicians themselves tend to be more comfortable with assisted suicide.

In an exchange with the Panel, Dr. Keith Wilson commented on results from a National Palliative Care Survey which revealed that within a sample of terminally ill people, a third of respondents considered that both methods were equally acceptable, while 25% found that both were equally unacceptable. Over 21% of respondents found voluntary euthanasia to be more acceptable, while 9% found assisted suicide to be the more acceptable method.

Some groups shared their view that there is no ethical difference between voluntary euthanasia and assisted suicide; they are two different ways of operationalizing a person's wishes. The Canadian HIV/AIDS Legal Network noted that in both cases, what is critically important is that consent be free, voluntary and informed. It argued that any distinction drawn between the two methods would be artificial and unhelpful, and would risk creating different regimes for the manner in which people exercise their autonomy at the end of life.

#### 1. Allowing only Physician-Assisted Suicide

The Physicians' Alliance against Euthanasia and the Euthanasia Prevention Coalition were in favour of allowing only assisted suicide. The Panel heard from Dr. Brian Mishara that in the context of assisted suicide, individuals' ambivalence about their request can operate more freely, meaning that they might be more likely to renounce their wish to die. When another person is involved, as voluntary euthanasia requires, Professor Isabelle Marcoux suggested that ambivalence may be constrained. The Panel heard that there is a risk that individuals may feel some degree of social pressure to proceed with voluntary euthanasia if, for example, the procedure is scheduled to happen at a specific date and time, knowing that the administering physician has other scheduled engagements, or even that loved ones are present and are expecting that the procedure will happen. Professor Marcoux noted that allowing only assisted suicide could help ensure that the request to die is truly voluntary, since the final act causing death would belong entirely to the individual seeking death.

Similarly, in a submission to the Panel, Professor Raphael Cohen-Almagor from the University of Hull in the United Kingdom argued that "[i]n ending life, the final control mechanism should be with the patient. Thus physician-assisted suicide is preferred to euthanasia in order to lower the possibility of abuse and of ending the lives of patients without their consent and against their wishes."

The Council of Canadians with Disabilities also recommended restricting the new scheme to assisted suicide. However, when asked to elaborate, the Council's objections pointed to the dangers of unrequested lethal injections, decided by individuals other than the person whose death is contemplated, and done without their knowledge or consent—something which will continue to be a criminal offence, since the Supreme Court in *Carter* emphasised that only an individual who "clearly consents" may access physician-assisted death.

<sup>&</sup>lt;sup>116</sup> Euthanasia Prevention Coalition, 3 November 2015; Dr. Brian Mishara, 7 October 2015.

The Canadian Society of Palliative Care Physicians supported the Oregon model, where only assisted suicide is permitted, over the Québec model, where only medical aid in dying where a physician administers the lethal substance is allowed. The Society noted that some physicians are uncomfortable serving as the immediate agent of death.

Dr. Brian Mishara noted that in Oregon, where only assisted suicide is legal, approximately 37% of individuals who receive a prescription for a lethal dose of medication do not take it. He observed that few individuals who request euthanasia in the countries where it is legal change their mind. He felt that this ambivalence was a key determinant of why death from assisted suicide was less prevalent than death resulting from euthanasia, and advocated for the former over the latter.

#### 2. Risks Associated with Physician-Assisted Suicide

Professor Isabelle Marcoux highlighted that there may be potential medical complications if a person self-administers lethal medication without a physician present. Euthanasia Prevention Coalition raised the risk of coercion by family members if the medication is taken at home, without professional supervision, as well as the risks associated with having a lethal dose of medication in a home setting. The Coalition suggested that a framework for assisted suicide should not allow individuals to take lethal medication home with them, but instead provide the medication only when they are prepared to take it. They suggested that this would eliminate the possibility of lethal medication not being returned to a pharmacy if the individual dies from other causes or chooses not to ingest the medication.

Dr. Georges L'Espérance, President of the Association québécoise pour le droit de mourir dans la dignité told the Panel that permitting only assisted suicide limits access only to those who are physically capable of self-administering medication. This poses a risk of discriminating against those who are physically incapable of certain voluntary movements, including swallowing.

The Collège des médecins du Québec indicated that it was concerned about people being sent home alone to take lethal medication. Under Québec's law, assisted suicide is not permitted. The Collège noted that in rare cases where the medication fails to cause death, there can be serious complications. The Collège saw relying exclusively on medical aid in dying as a way to curb or eliminate this risk by leaving the procedure strictly in the hands of the physician. Mr. Jean-Pierre Ménard, Chair of Québec's committee of legal experts that was tasked with recommending legislative options for implementing medical aid in dying in Québec, indicated that allowing only medical aid in dying was a way to restrict the practice to the medical world.

#### 3. A Regime with both Physician-Assisted Suicide and Voluntary Euthanasia

The College of Physicians and Surgeons of Ontario emphasized the notion of access and patient preference, and indicated that it is preparing guidelines that address both voluntary euthanasia and assisted suicide. The College of Physicians and Surgeons of Nova Scotia considered that the language of the *Carter* decision clearly indicates that both assisted suicide and voluntary euthanasia must be permitted.

The College of Physicians and Surgeons of Saskatchewan suggested that, if the individual requests it, a physician should be present when the medication is taken in cases of assisted suicide to ensure there are no complications. Others indicated that requiring a physician's presence in all cases may be a problem for access due to physicians' busy schedules. Further, Dr. Brian Mishara advised that he would consider it harmful, in the case of assisted suicide, to require that a physician be present at the time of self-administration. According to him, the presence of another person may hinder the expression of ambivalence.

Dr. Douglas Grant, President of the Federation of Medical Regulatory Authorities of Canada and Registrar of the College of Physicians and Surgeons of Nova Scotia, noted that if both voluntary euthanasia and assisted suicide are contemplated, the timing of the evaluation of capacity would be crucial. He observed that the prescribing physician would evaluate capacity at the time the prescription was made out. An individual might then bring the medication home, and it is possible that the individual could, because of a deteriorating condition, no longer have the capacity to consent to medical treatment. Thus, the individual might no longer meet the requirements set out in *Carter*.

A representative of the Protection of Conscience Project noted that a physician willing to provide assisted suicide should also be willing to provide voluntary euthanasia, in the event that complications arise during the assisted suicide and the physician's involvement is necessary to complete the death.

#### D. Conclusion

Where it is necessary to illustrate the differences between assisted suicide and voluntary euthanasia in some instances of the report, or where necessary to capture information provided to the Panel during consultations, the Panel will use such terminology for clarity. The Panel remains mindful of the comments it heard in support of, and in opposition to, these terms.

The Panel also proceeds with the understanding that both methods of physician-assisted death are contemplated by the Supreme Court in *Carter*, and therefore that both may be among the options available to Canadians suffering from grievous and irremediable medical conditions that cause them enduring suffering.

## Chapter 7. Eligibility Criteria

The Supreme Court of Canada held in *Carter* that the *Criminal Code* prohibition on assisted dying violates the rights to life, liberty and security of the person of individuals who meet this profile:

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. 117

For any person to access physician-assisted dying once the Court's declaration of invalidity comes into force, each of the elements in the above profile must be met.

If Parliament and the provincial and territorial legislatures decline to respond in any formal way to *Carter*, the decision itself will stand as the law on physician-assisted dying. Alternatively, legislators may choose to specify in legislation who may access physician-assisted dying and under which conditions, pursuant to the *Carter* decision.

Professor Jocelyn Downie, a heath lawyer and academic, has characterized the *Carter* decision as "a floor and not a ceiling." This means that although the Supreme Court set out the basic requirements to ensure that an exemption to the current prohibition on assisted dying does not violate the Charter rights of eligible individuals seeking assisted death, Parliament and the legislatures would be free to consider issues beyond those addressed in *Carter*. Legislators could choose to expand the scope of physician-assisted dying by permitting access for individuals not contemplated in *Carter*, as one example, incompetent individuals who, while they were competent, requested physician-assisted dying through an advance directive. They could also choose to expand the exemption beyond applying only to physicians to other health care professionals, such as nurse practitioners, as the Canadian Nurses Association had begun to consider.

In seeking to add clarity to our collective understanding of who is included in the profile of a person who may access an assisted death, legislators may choose to define some of the terms and phrases which are central to the Court's declaration. For example, they may wish to address any of the following questions:

- 1. Who is an adult?
- 2. Who is competent for the purposes of a request for assisted death?
- 3. What does "grievous and irremediable" mean, in the context of a request for assisted death?
- 4. What is meant by "enduring suffering" in the context of a request for assisted death?

Any legislation that answers these questions by introducing additional criteria could, of course, be subject to Charter challenges. The Court has held clearly that a regulatory system for assisted dying must

<sup>&</sup>lt;sup>117</sup> Carter at para. 127.

not deprive people of their rights to life, liberty and security of the person, except in accordance with the principles of fundamental justice.

Eligibility criteria necessarily include some and exclude others. The Panel heard from a variety of sources, including Professor Downie and David Baker, a disability rights lawyer in private practice who has drafted model legislation in response to *Carter*, that whatever law is in place, it will likely be subject to Charter challenges by excluded individuals. It will therefore be incumbent on legislators to consider carefully which eligibility criteria are implemented to reduce the uncertainty that could result from repeated litigation.

This chapter considers the eligibility criteria raised in the Panel's meetings with individual experts, its study of other permissive jurisdictions and its direct consultations with stakeholders. Specifically, this chapter addresses age, residency, medical condition, enduring suffering, capacity to consent to medical treatment, and the voluntariness of requests.

#### A. Age

The Supreme Court held that eligible adults must be able to access physician-assisted dying. In Canada, the age of majority is determined provincially, and the provinces have not adopted a uniform age at which an individual is considered an adult for legal purposes. If access to physician-assisted dying is determined according to provincial age-of-majority legislation, some provinces and territories would allow access at 18 years, while others would allow access at 19 years.<sup>118</sup>

Some groups appearing before the Panel, for example the Evangelical Fellowship of Canada, an intervener in *Carter*, suggested that the provincial age of majority should be the age at which individuals may access physician-assisted dying. Many advocated for access starting consistently across the country at the age of 18. It may be worth noting that for the purposes of criminal law, and other federal law, such as federal electoral law, individuals are considered adults at the age of 18.

#### 1. Beyond the Age of Majority

The majority of groups that addressed the age of eligibility with the Panel emphasized that the Supreme Court held that eligible *adults* may access physician-assisted dying and therefore recommended either adopting the age of majority in each province or setting the standard at 18 years. Some submissions the Panel received, however, recommended a higher age threshold for life-ending decisions. For example, a physician in Brantford, Ontario, who made a written submission to the Panel, recommended that "[t]he person requesting death must be an adult, over age 25 years (since brain and impulse control [are] still maturing to that age)." The Canadian Hospice Palliative Care Association recommended an age of eligibility of 21 years, and called for "careful precautions... with those in young adulthood." As will be discussed below, the Panel heard the argument that choosing any specific age for access could be seen

<sup>&</sup>lt;sup>118</sup> In Alberta, Saskatchewan, Manitoba, Ontario, Québec and Prince Edward Island, the age of majority is 18 of age. Elsewhere it is 19 years.

as arbitrary. The Panel knows of no examples in federal or provincial/territorial law in Canada that establish age thresholds beyond the age of 19.

#### 2. Mature Minors

Neither the trial judge in *Carter* nor the Supreme Court addressed the issue of mature minors because the issue was not before them and so no evidence was presented to the courts on this topic. "Mature minor" is a legal term that refers to young people below the age of majority who are deemed competent to make their own medical decisions. The Supreme Court has held that "children are entitled to a degree of decision-making autonomy that is reflective of their evolving intelligence and understanding." <sup>119</sup>

Two legal issues the Panel heard regarding mature minors focused on the status of existing legislation on consent to health care and the equality provisions of section 15 of the *Canadian Charter of Rights and Freedoms*. Specifically, the College of Physicians and Surgeons of British Columbia noted that several provinces have enacted legislation that allows mature minors to make decisions about their medical treatment, and that excluding minors might be inconsistent with these Acts. Further, Professor Jocelyn Downie noted that if access is granted only to adults, a mature minor might have a sound claim under the equality provisions of section 15 of the Charter to challenge the law as discriminatory on the basis of age.

Medical ethicists who appeared before the Panel also addressed the issue of access for minors. Dr. Thomas Foreman, Joshua Landry and Michael Kekewich of the Champlain Centre for Health Care Ethics with the Ottawa Hospital argued that any age-based criterion would be arbitrary. They recommended instead an approach similar to Ontario's *Health Care Consent Act*, <sup>120</sup> which does not include age as a criterion, but instead relies exclusively on decision-making capacity. They noted that the age of majority is currently used as a rough measure of decision-making capacity and argued that instead of relying on an approximate measure of capacity, eligibility should be based on actual capacity.

In a comprehensive submission to the Panel, Professor Wayne Sumner from the University of Toronto outlined the following proposal with regard to physician-assisted dying for persons between the ages of 12 and 18:

The Court did not restrict eligibility for [physician-assisted dying] to competent adults only and there is no justification for doing so. Some provision must also be made for decision-making by 'mature minors' (between the ages of twelve and eighteen). In this case, however, it may be best to reverse the presumption of capacity, so that adolescents will need to demonstrate that they have the maturity to handle a decision of this magnitude. If so, then the decision should be left in their hands, though (especially in the case of younger adolescents) consultation with parents or legal guardians may be mandated; the rule of thumb should be that if a minor is

<sup>&</sup>lt;sup>119</sup> A.C. v. Manitoba at para. 46.

<sup>&</sup>lt;sup>120</sup> Heath Care Consent Act, 1996, S.O. 1996, c. 2, Sched. A.

deemed to be competent to refuse life-sustaining treatment then he or she is also competent to request life-shortening treatment.

In the Netherlands and Belgium, minors have limited access to assisted dying. In the Netherlands, young people between the ages of 16 and 18 who "may be deemed to have a reasonable understanding of [their] interests" and meet the adult criteria may access assisted death as long as their parents have been informed. Individuals between the ages of 12 and 16 who "may be deemed to have a reasonable understanding of [their] interests" and meet the adult criteria may access assisted death with their parents' consent. In Belgium, emancipated minors who meet the adult criteria have been able to access assisted dying since permissive legislation was first enacted in 2002. In 2014, the Belgian law was amended to allow access to assisted death for minors of any age with "the capacity for discernment" who have a condition "that will result in death in the short term," and meet the adult criteria.

Few individuals or groups to appear before the Panel specifically advanced arguments regarding access for mature minors, perhaps understandably, since the issue was not raised in *Carter*. The Panel did not actively seek out expert opinion or perspectives on this issue, nor did it speak with professionals in fields focused on child and adolescent-related issues (e.g. pediatrics or child and adolescent psychology).

Of the few submissions that address this issue, one from a network of British Columbia physicians argued that mature minors might be more subject to coercion than adults. Other groups' choice to explicitly stress access for competent adults in their submissions to the Panel may have been an implicit rejection of the idea of access for children. The Canadian Civil Liberties Association and the HIV/AIDS Legal Network explicitly stated that they did not see any principled reason to deny mature minors assistance in dying should they meet the appropriate criteria and that such a denial could threaten the personal autonomy of minors.

The College of Physicians and Surgeons of British Columbia observed that their province has an *Infants Act*, <sup>124</sup> which allows minors to make medical decisions for themselves. The College saw the Act as being in conflict with the *Carter* age criterion, and suggested that the Act and other provincial health care consent Acts might need to be amended to address inconsistencies.

Of those who responded to the Panel's Issue Book, when presented with a scenario of a request for physician-assisted death by a terminally ill adult, the majority agreed or strongly agreed that physician-assisted death should be available. When the scenario presented a request from a terminally ill 16-year-old, however, there was much less support.

Access for mature minors was perhaps one of the most emotionally charged questions the Panel encountered in its investigations of assisted dying. No one who appeared before the Panel in Canada openly advocated children's access, and although there was more openness to the idea in the

<sup>&</sup>lt;sup>121</sup> Termination of Life on Request and Assisted Suicide (Review Procedures) Act (Netherlands), art. 2 C. pen., art. 2.

<sup>&</sup>lt;sup>122</sup> <u>The Belgian Act on Euthanasia of 2002</u>, English translation provided to the Panel by Mr. Herman Nys. An emancipated minor is one who has been declared by a court to be released from parental authority. Note that emancipation of minors is not recognized in most Canadian jurisdictions.

<sup>123 &</sup>lt;u>Loi relative à l'euthanasie</u> (Belgium). English translation provided to the Panel by Mr. Herman Nys.

<sup>&</sup>lt;sup>124</sup> Infants Act, R.S.B.C. 1996, c. 223.

Netherlands and Belgium, the Panel heard that the practice remains controversial and is extremely rare in those countries.

#### B. Residency

With one exception, every jurisdiction in which assisted dying is practiced has a residency requirement such that only residents of that jurisdiction may access assisted dying. In some jurisdictions, such as Oregon, residency is assessed by the physician. There, physicians may consider documents demonstrating a person's residency, such as their driver's licence, voter registration or state tax return. <sup>125</sup> In Québec, residency is ensured by requiring that only those who are "insured persons" within the meaning of Québec's *Health Insurance Act* may receive medical aid in dying. <sup>126</sup> For most individuals, qualifying as an "insured person" means having lived in Québec for at least three months and having a Québec health insurance card. <sup>127</sup>

There has been considerable media coverage of Canadians and other foreign nationals travelling to Switzerland to obtain an assisted death. Switzerland prohibits assisted suicide only for selfish motives, <sup>128</sup> and six private organizations provide assistance to people who meet the individual organizations' criteria. Three of these six organizations make their services available to non-residents.

The Panel received little input on residency requirements from experts or stakeholders. One exception was the Council of Canadians with Disabilities, which called for a residency requirement of one year in its submission to the Panel. A one-year residency requirement was also suggested in proposed legislation tabled in September 2015 in the United Kingdom. Although a one-year residency requirement is not without precedent in Canadian law, it is not a standard commonly used in health law. A more common standard is three months—the length of time included in the definition of "insured person" in the Canada Health Act. 130

The issue of residency was also raised in discussions with the provincial and territorial physicians' regulatory bodies. These bodies are the independent provincial or territorial associations (most of which are called colleges or colleges of physicians and surgeons) that regulate the practice of medicine in their respective jurisdictions. The Panel met with nearly all of these associations, along with their national association, the Federation of Medical Regulatory Associations of Canada.

The colleges addressed the issue of residency with the Panel, but they presented divergent views. These ranged from concrete plans to develop a residency requirement to an expressed openness to providing

<sup>&</sup>lt;sup>125</sup> Oregon Death with Dignity Act, O.R.S. 127.860, §3.10.

<sup>&</sup>lt;sup>126</sup> An Act respecting end-of-life care, R.S.Q. c. S-32.0001, s. 26.

<sup>&</sup>lt;sup>127</sup> <u>Regulation respecting eligibility and registration of persons in respect of the Régie de l'assurance maladie du Québec</u>, C.Q.L.R. c. A-29, r. 1, s. 4.

<sup>&</sup>lt;sup>128</sup> Code pénal suisse, art. 115.

<sup>&</sup>lt;sup>129</sup> Bill 7, Assisted Dying (No. 2) [HC], 2015—2016 sess, 2015.

<sup>&</sup>lt;sup>130</sup> Canada Health Act, R.S.C. 1985, c. C-6, s. 2.

physician-assisted dying to eligible international visitors. If this issue is to be determined by the regulatory bodies, there may be some variation across the country in terms of access for non-residents.

### C. Grievous and Irremediable Medical Condition

All jurisdictions that regulate assisted dying through legislation have some form of medical eligibility criteria. The definitions of these criteria vary considerably. For example, in the four U.S. states with legislation permitting assisted death, the person making the request must have an incurable disease and be expected to die within six months. In Québec, the person must be at the end of life in an advanced state of irreversible decline in capability. In the Netherlands, the person must have unbearable suffering with no prospect of improvement and no reasonable alternative in light of their situation.

What is declared in the *Carter* decision is that the person must have a grievous and irremediable condition that causes enduring suffering that is intolerable to that person in their circumstances. The Court specified that a grievous and irremediable condition includes illness, disease or disability. The Court's declaration did not indicate that the person must be at the end of life, have a terminal diagnosis or be at an advanced stage of decline.

# 1. Defining (Or Not Defining) "Grievous" and "Irremediable"

Perhaps not surprisingly given the importance of the terms "grievous and irremediable" in determining an individual's eligibility for physician-assisted death, the question of whether or not this phrase requires further legislative definition has given rise to considerable debate.

As some appearing before the Panel noted, the term grievous has a particular connotation in criminal law. "Grievous bodily harm" helps define the amount of force peace officers may use in carrying out their duties. 131 The British Columbia Civil Liberties Association noted that the established definition of "grievous" in the context of criminal law is "serious and non-trivial."

In medical practice the words may be less universally understood. In conversation with Dr. Francine Lemire, Executive Director of the College of Family Physicians of Canada, the Panel explored the likelihood of a diverse group of family physicians coming to agreement on the meaning of the phrase "grievous and irremediable." Dr. Lemire noted that consensus would be difficult to reach, with different physicians strongly expressing different views. It was Dr. Lemire's opinion that the meaning of grievous and irremediable "needed a little sharpening," provided that this was done while still providing sufficient flexibility for clinical judgment.

The Federation of Medical Regulatory Authorities of Canada emphasized the importance of allowing for flexibility in physicians' clinical judgment. Dr. Douglas A. Grant, President of the Federation and Registrar of the College of Physicians and Surgeons of Nova Scotia argued that overly precise, "granular" definition of these terms would take decisions "a long way from the bedside." He noted that the colleges would find the application of precisely defined terms difficult to regulate and further, that

<sup>&</sup>lt;sup>131</sup> Criminal Code, R.S.C. 1985, c. C-46, s. 25.

physicians would find them difficult to administer. The Saskatchewan College voiced their concern somewhat differently:

I'm just worried about the rigidity ... of a number of Members of Parliament trying to define grievous and irremediable in a way that is not too restrictive, that allows for a recognition of advances over time.

The Saskatchewan College identified the importance of allowing for some subjective variation in how "grievous and irremediable" is interpreted, so that a physician who acts in good faith and provides an assisted death to a person the physician considered to have a grievous and irremediable condition would not be vulnerable to criminal prosecution.

While medical regulators were uncomfortable with the imposition of precise criteria for defining "grievous" and "irremediable," there was openness to some degree of guidance or professional standards for the medical community, given the acknowledged difficulty of making these judgments in such weighty circumstances as a request for an assisted death. The College of Physicians and Surgeons of Ontario noted that the terms grievous and irremediable are largely legal terms, and explored the possibility of a panel of experts to define these terms and provide some examples that would help with physicians' interpretation. Other colleges expressed interest in such advice, which could evolve over time to keep pace with contemporary understanding and practice.

Although relatively few submissions examined the meaning of "irremediable" specifically, the Canadian Psychiatric Association noted the following recommendation:

In the context of mental illness, "irremediable" should not be considered to mean "incurable" as this would set the threshold for identifying a condition as irremediable too low (i.e. all chronic mental illness could then be considered irremediable).

On the other hand, the submission noted that "if irremediable is considered untreatable, then very few situations in psychiatry would be considered irremediable."

The term "irremediable" is not often used in the legal context, but the Court offered some definition by specifying that its declaration in *Carter* "does not require the patient to undertake treatments that are not acceptable to the individual." <sup>132</sup> This is an approach similar to the Belgian model where, as Advisor to the Federal Minister of Affairs and Public Health Benoit Mores noted, an individualis required to refuse all possible therapies before the assisted dying option may be pursued.

Several groups, including the Canadian Nurses Protective Society, the British Columbia Civil Liberties Association and the HIV/AIDS Legal Network suggested that the definition of these terms would be best left to physicians. Other groups appearing before the Panel, including the Association for Reformed Political Action Canada and the Physicians' Alliance against Euthanasia, argued that the terms "grievous" and "irremediable" should be explicitly defined in order to provide guidance to the health care professionals who will have to apply these terms. Some of the proposed definitions the Panel heard approximated dictionary definitions. For example, a network of British Columbia physicians who met

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<sup>&</sup>lt;sup>132</sup> *Carter* at para. 127.

with the Panel suggested "severe or end-stage" as a definition for grievous. Dying with Dignity Canada took a different approach, arguing for a subjective interpretation:

A "grievous" medical condition is one that results in unbearable suffering. The decision regarding what constitutes such suffering is for the individual to make. Suffering that for some people is ennobling, for others might be unbearable. To decide otherwise is to infringe on the autonomy of an individual.

Some suggestions tended toward narrowing eligibility criteria so that fewer people would qualify for physician-assisted dying. For example, in his model legislation, David Baker defined "irremediable" as "a terminal disease that is incurable and has been medically confirmed by a physician, and will by evidence-based medicine and using reasonable judgment, produce death within 12 months." He also indicated to the Panel that he favours language adopted in Québec, namely, an "advanced state of irreversible decline in capability." Other submissions, for example one from Citizens with Disabilities Ontario, were unequivocal in urging that access to assisted death "should be restricted to those who are terminally ill and whose death is imminent."

### 2. Objective or Subjective Standards

Another issue that some groups raised was whether objective or subjective standards must be used in defining "grievous" and "irremediable." There was disagreement about whether grievous and irremediable should be defined objectively, meaning according to set criteria or a standard of reasonableness, or whether they should be defined subjectively, meaning relying only on the views of the individual seeking physician-assisted dying or of the physician in consultation with the individual. It may be important to note that "grievous" and "irremediable" appear to be primarily objective tests, while "enduring suffering," addressed below, appears to be subjective.

Given that both "grievous" and "irremediable" are adjectives that modify "medical condition," it may be fair to assume that an objective standard is appropriate. Serious medical conditions likely to qualify as "grievous" are diagnosed largely based on objective medical tests. One's experience of a medical condition is highly personal, but the diagnosis of the condition is made according to established medical standards. There is a subjective element to the "irremediable" test because the Supreme Court held that the test does not require patients to undertake treatments unacceptable to them. Unless the individual deems available treatments unacceptable, objective medical standards will determine whether a condition is irremediable.

# 3. Mental Illness

The Supreme Court in *Carter* did not deal explicitly with mental illness. Gloria Taylor and Kay Carter, the two women whose illnesses framed the *Carter* decision, both lived with conditions that caused physical suffering and deterioration without affecting their competence or mental health. The *Carter* test requires that individuals be competent to be eligible for physician-assisted dying. The Court nonetheless did contemplate psychological suffering in its decision, and did not require that the medical condition leading to the individual's request necessarily have a purely physical origin. This means that legislators will have to consider whether mental illness alone could qualify as a medical condition for the purposes

of the *Carter* test, and whether excluding persons who suffer intolerably from a grievous and irremediable mental illness would deprive those persons of their rights to life, liberty and security of the person.

The Panel heard widely diverging views on where mental illness might fit—or not fit—in a framework for physician-assisted death in Canada. At one end of the spectrum, Professor Eike-Henner Kluge argued that, based on the principles of equality, even if a person's mental illness rendered them legally incompetent, that incompetence should not disentitle individuals who otherwise meet the *Carter* eligibility criteria from accessing physician-assisted dying. On the other hand, groups such as the Catholic Health Alliance of Canada argued that mental illnesses should not be included in the scope of the medical condition eligibility criterion. The Christian Legal Fellowship and the Physicians' Alliance against Euthanasia both advanced similar arguments.

In a written submission, ARCH Disability Law Centre reported on its extensive focus group discussion among people with mental health disabilities. ARCH noted that "[o]ne segment of the population is deeply concerned about the impact PAD [or physician-assisted dying] will have on a vulnerable population." On the other hand, the submission noted a strong sentiment in this community that physician-assisted dying "is about offering choice and self determination to a vulnerable population. Basic equality demands that persons with mental health disabilities should be offered access to PAD on the same basis as other persons; no extra steps or restrictions should be required." The ARCH submission concluded that "at the moment, it is not clear that the potential impact of PAD on the community of persons with mental health disabilities is understood fully enough to allow effective and safe legislation to be crafted."

The Panel heard cogent arguments in favour of ensuring access for eligible persons with mental illness, provided they have the legal capacity to make such decisions. Professor Jocelyn Downie noted that to exclude such individuals could amount to discrimination against an already-marginalized group. A compelling online submission from an individual Canadian urged the Panel to recognize the following:

All suffering isn't physical. People with mental illness suffer too and often suffer intolerably. This is a nuanced and somewhat problematic area but please include in new legislation the right of people with mental illness to access assisted death under certain circumstances.

Dr. Linda Ganzini, a prominent psychiatrist and researcher from Oregon, confirmed that many individuals with serious, chronic mental illness do retain capacity to consent to treatment. However, as the Canadian Psychiatric Association explained, capacity is situation-dependent. One may have capacity to live independently, while lacking capacity to regulate one's financial affairs. Moreover, as ARCH Disability Law Centre pointed out, "it is very possible that a person with a serious episodic mental health disability may, during a period of good health and lucidity, decide that they are not willing to tolerate another period of mental health crisis, and chose instead seek PAD while they are capable to make that decision."

The Canadian Psychiatric Association remains in the process of developing its response to *Carter* and the coming regime of physician-assisted dying. It suggested some additional points to consider in the context of mental health:

- Many individuals with medical illnesses, particularly life-limiting or life-threatening ones, may have comorbid depression
- Depression, which can be difficult to diagnose, may alter an individual's thought processes and influence their wish to die
- Because of the complex course of some mental illnesses, terms related to eligibility such as "irremediable" and "enduring" might have to be interpreted differently when mental illness is involved
- "Treatment-resistant depression" is a clinical term simply meaning depression that has resisted two courses of anti-depressant drug therapy, and would not generally meet the "irremediable" standard.

According to the Canadian Psychiatric Association, when an individual has a mental illness, it can be "difficult, if not impossible, to rule out whether or not [a request for physician-assisted dying] is being influenced by illness-based cognitive distortions." At the time of its meeting with the Panel, the Canadian Psychiatric Association had not yet determined whether it supports the view that grievous and irremediable mental illness alone (in the absence of physical illness) should qualify as a medical condition in the *Carter* test.

# D. Enduring Suffering

The Supreme Court held that to be eligible for physician-assisted dying, individuals must experience "enduring suffering that is intolerable" to them "in the circumstances of [their] condition." A similar criterion appears in Québec's *Act respecting end-of-life care*: "constant and unbearable physical or psychological suffering which cannot be relieved in a manner the patient deems tolerable."

The concept of suffering featured heavily in the *Carter* litigation. Part of Gloria Taylor's argument was that she wanted to be able to end her life at a time when her suffering became unbearable. In fact, the Court held that the lack of availability of physician-assisted dying as an option to individuals with grievous and irremediable medical conditions violated their right to security of the person by compelling them to endure intolerable suffering.

Suffering is a primary consideration for access in the Netherlands and Belgium. In the Netherlands, where legislation includes an eligibility criterion of "lasting and unbearable" suffering, the Panel heard from physicians and researchers including Johan Legemaate and Dr. Johannes JM van Delden that convincing a physician of one's suffering is critical to accessing assisted dying. A problem that Dr. van Delden identified with this model was that it is often easier for socially privileged individuals to access assisted dying. Dr. van Delden speculated that physicians, who are generally among the socially privileged, would be more likely to be "moved" by the suffering of individuals who share their social status and that the socially privileged would be more adept at expressing their suffering. As a result, in his opinion, the "elite" may be more likely to have their requests granted.

In the U.S., there is a very different attitude towards suffering in the assisted-dying context. Suffering is not a criterion in any American assisted-dying legislation. It may be that a suffering criterion was judged unnecessary because of the six-month prognosis criterion. Dr. Brian Mishara, a Canadian psychologist

and suicide researcher, expressed some skepticism about using suffering as a criterion because he noted that people's decision making is compromised when they are in pain. The Physicians' Alliance against Euthanasia made a similar argument. It may therefore be especially important to ensure that suffering is enduring.

From the submissions received by the Panel, there appear to be three main issues to consider with respect to this criterion. The first is how to determine if suffering is "enduring" in accordance with the Court's requirement. A second issue relates to identifying a causal relationship between a person's suffering and their medical condition. Finally, a third issue is how *Carter* requires an individual's suffering to be evaluated: objectively or subjectively.

### 1. Persistence of Suffering

Some existing legislation seeks to assess the enduring nature of a request by requiring multiple requests. In Québec, for example, physicians must verify "the persistence of suffering ... by talking with the patient at reasonably spaced intervals given the progress of the patient's condition." Some groups, such as the HIV/AIDS Legal Network and Dying with Dignity Canada, have indicated that individuals who have, for example, suffered a catastrophic injury may need time to adjust to their new circumstances before a request for physician-assisted dying should be considered. On the other hand, the Panel heard that the concept of "time to adjust" may be inappropriate in the context of end-stage cancer. Some groups have suggested a response that is proportionate to the anticipated course of the individual's illness. This topic is considered in greater depth in the section entitled "Timelines."

### 2. Cause of Suffering

In its declaration, the Supreme Court held that section 241(*b*) violated the Charter rights of eligible individuals with medical conditions that cause "enduring suffering that is intolerable to the individual." Unlike the trial court, which explicitly included physical and psychological suffering but excluded psychosocial suffering, the Supreme Court did not explicitly address which types of suffering a person seeking a physician-assisted death must be experiencing. However, there are indications to suggest that the Supreme Court explicitly considered both psychological and physical suffering. One such indication is that the Court identified a "constant theme" in the affidavits from witnesses in *Carter*: that "they suffer from the knowledge that they lack the ability to bring a peaceful end to their lives at a time and in a manner of their own choosing." Suffering from knowledge would of course be psychological, not physical, suffering. The Canadian Medical Association indicated that it recognizes that both physical and psychological suffering are considered. Some groups appearing before the Panel suggested that other types of suffering may be relevant as well, including existential and spiritual suffering.

Some experts with whom the Panel consulted warned against adopting a restrictive view of suffering. For example, the Death with Dignity National Center in Oregon indicated that suffering "may be pain, but it should not be limited to pain...Somebody with a chronic disease may not have any pain, but [their suffering could] be of a very different nature."

<sup>&</sup>lt;sup>133</sup> *Carter* at para. 14.

In addition, Dr. Eike-Henner Kluge, a professor at the Department of Philosophy of the University of Victoria, indicated that the sources and context of suffering are important as they can inform our understanding of the nature of the suffering. He observed that psychosocial sources of suffering do not call for a medical but a social response. In his view, psychosocial suffering, such as the kind one might expect from a marital breakdown, would fall outside the ambit of a physician-assisted dying framework because it does not call for a medical response.

Additional submissions made points that would support excluding psychosocial suffering, where causes link to the social determinants of health. ARCH Disability Law, for example, referred to "social conditions that could lead to the conditions of life becoming intolerable, such as homelessness, social isolation or lack of treatment options." The Canadian Association for Community Living similarly notes that "when the causes of people's suffering are abuse, discrimination, being devalued by others, lack of support or social isolation, steps can be taken to address them." The Canadian Psychiatric Association noted the following:

We also have to understand the role of psychosocial, cultural and environmental factors because that's the milieu everyone exists in...Things like unstable housing, financial instability, isolation increase the suffering of patients with depression. It would be inappropriate if the societal response was to facilitate these people dying by deeming that person's suffering is enduring and intolerable because of the psychosocial circumstances if we are able to change them. All of these things lead to challenges in identifying when the definition of intolerable and enduring is met.

The Panel heard from some groups that only physical suffering should be considered in assessing individuals' eligibility for physician-assisted dying. For example, the Association for Reformed Political Action, an intervener in *Carter*, argued that to protect the vulnerable, Parliament should enact legislation that explicitly considers only physical suffering.

The Supreme Court declaration requires that individuals must have a grievous and irremediable medical condition and, as a direct result of that condition, experience enduring suffering that is intolerable to them in the circumstances of their condition. Suffering alone or suffering that is not causally linked to a grievous medical condition, whether physical or psychological, would not render an individual eligible.

To be able to understand the root causes of an individual's suffering, it is important to consider suffering in all its forms.

### 3. Evaluation of Suffering

Some groups raised the issue of whether suffering should be evaluated objectively or subjectively. Disability rights lawyer David Baker told the Panel that the evaluation of suffering should include an objective component. He added that in his view, the Supreme Court failed to address that individuals who are refusing treatment are prepared to accept the consequences of their refusal, and therefore it cannot be said that their suffering is "intolerable." Others, including a group of law and medical students from McGill University who formed a collective to discuss and research physician-assisted dying

(MedPASS), argued strenuously that suffering should be considered from a purely subjective perspective.

As the Panel heard from medical ethicists Dr. Thomas Foreman, Joshua Landry and Michael Kekewich of the Champlain Centre for Health Care Ethics at the Ottawa Hospital, each individual's experience of suffering in the context of their illness is unique. What one individual may find unbearable may be tolerable to another. The Evangelical Fellowship of Canada noted that "[p]ain is a physical question which medical professionals are qualified to respond to and treat, but suffering is a more fully human question involving emotional, psychological, spiritual and social dimensions. And it's beyond the expertise of medicine alone to address."

It may therefore be inappropriate to establish an objective standard for an experience as personal as suffering. Further, the language the Supreme Court used to establish the suffering criterion is subjective. Typically, legal tests using an objective standard will rely on the reasonable person, for example asking how much a reasonable person would suffer in a particular situation. Subjective tests, on the other hand, ask what individuals themselves experience. The Supreme Court referred to "suffering that is intolerable" to individuals "in the circumstances of [their] condition." This wording may point to a subjective test.

A submission from Kevin Reel, an ethicist at the Centre for Addiction and Mental Health, underscored for the Panel the profound questions at play in determining whether suffering is evaluated subjectively or objectively:

How does my own hope affect my judgment about your health condition and the sum of its interaction with your social determinants of health? When can that sum be objectively understood to add up to irremediably intolerable suffering? Or should that judgment be a subjective one, made by the client/patient? How will we feel if we find ourselves insisting that people hang in there until we eventually change longstanding resourcing structures so that the socio-environmental context in which they live changes the final calculus of their suffering?

In the final analysis, even if the suffering criterion is evaluated on a purely subjective basis, the test remains suffering that is intolerable to an individual. In addition, this suffering must be causally tied to a grievous and irremediable medical condition, which would be diagnosed based on objective medical criteria.

### E. Capacity to Consent to Medical Treatment

The Supreme Court in *Carter* limited eligibility to competent adults. Competence or capacity—the preferred term varies across jurisdictions in Canada—to consent to medical treatment is addressed in provincial health care legislation. Under Ontario's *Health Care Consent Act*, for example, an individual is "capable with respect to a treatment ... if the person is able to understand the information that is relevant to making a decision about the treatment ... and able to appreciate the reasonably foreseeable

consequences of a decision or lack of decision." <sup>134</sup> It is important to note that individuals are presumed to be competent. Further, competence is not a global assessment; it is recognized to be situation-dependent, meaning that one may have capacity to make certain decisions, but not to make others. The Canadian Psychiatric Association highlighted the specificity of capacity determinations, noting "there have been situations where a patient might not have capacity to make a decision on chemotherapy but they do on surgery for the same illness."

Dr. Linda Ganzini, a psychiatrist and researcher from Oregon, where assisted dying has been available for nearly two decades but limited to persons with terminal conditions in the last six months of life, told the Panel that in the absence of mental illness, capacity assessment for decisions related to assisted dying are relatively straightforward. She suggested that such an assessment should include questions to determine individuals' ability to make a steady choice; to understand the risks, benefits and alternatives of the procedure and to alternative options; and to appreciate the information and apply it to themselves. Dr. Ganzini expressed confidence that most general practitioners could perform capacity assessments for individuals seeking assisted dying.

Conversely, some interveners raised the concern that capacity assessments can be very difficult to perform. For instance, Dr. Catherine Ferrier, President of the Physicians' Alliance against Euthanasia, noted the difficulty in assessing capacity: "I regularly assess decision-making capacity. I teach it. I testify in court for my patients, but if I had to assess a patient's capacity to choose death, there's no way I could be certain that there is no outside influence."

Others who appeared before the Panel were skeptical that decisional capacity in the context of assisted dying could be effectively determined by a person's physician. The Christian Legal Fellowship, for example, argued that:

if lawyers, who are versed in the law and are purported to be experts in a lot of the legal tests related to this issue, [are] not able to detect undue influence in the context of drafting wills, where the stakes are much lower, ... there's a deep concern ... that physicians will not be able to make that assessment for patients.

Dr. Douglas Grant, President of the Federation of Medical Regulatory Authorities of Canada and Registrar of the College of Physicians and Surgeons of Nova Scotia, argued that physicians make determinations every day about whether their patients have the capacity to consent to treatment. Under provincial health care consent legislation, it is illegal to proceed with treatment unless such determinations are made. The Panel heard widely divergent views on whether physician-assisted dying should, because of the finality of the decision, be handled differently from other decision making related to treatment.

<sup>&</sup>lt;sup>134</sup> Health Care Consent Act, 1996, S.O. 1996, c. 2, Sched. A, s. 4.

### 1. Capacity Assessment in the Presence of Mental Illness

Dr. Sonu Gaind, President of the Canadian Psychiatric Association, spoke at some length with the Panel about the relationship between mental illness and capacity:

Mental illnesses can impair and affect cognition, insight and judgment. There are a range of cognitive changes, for example, that people with depression typically have. They will have a cognitive triad of thinking they are bad, the world is bad and the future will be bad.... There is decreased cognitive flexibility meaning the person has a very hard time seeing outside their current experience and imagining it could be different. It also leads to selective ruminations that focus on the negative and can minimize the positive. There are other distortions that can occur in terms of a person's sense of self. They can have feelings of guilt and worthlessness. They can feel a burden to others, loved ones and the world. They also have lower emotional resilience and can be less capable of dealing with life's stressors.

The Canadian Psychiatric Association made two recommendations directly relevant to the issue of assessing decisional capacity in the presence of mental illness. The first was that when mental illness is either the underlying illness leading to a request for physician-assisted dying, or present in addition to a physical illness, "psychiatrists should be involved in assessing whether the patient's mental illness is impairing their capacity to make a decision regarding" physician-assisted death. The second is that, out of "beneficence," individuals whose decision-making processes may be impaired by a mental illness should be deemed ineligible for physician-assisted death.

Dr. Linda Ganzini told the Panel that capacity assessments for decisions related to assisted dying become significantly more difficult when depression is present. Because depression can result in altered cognitive functioning and even suicidal thoughts, it may be difficult for a clinician to determine if a request for assisted dying is genuine if the individual has mild to moderate depression. A concept that she suggested could assist in such situations is the idea of authenticity. If individuals' requests for physician-assisted dying seem consistent with the way they lived their lives, placing strong emphasis on autonomy and independence, it may be less likely that depression is driving the request, in Dr. Ganzini's view. Dr. Ganzini alerted the Panel that her expertise and comments were restricted to her experience in Oregon, which has adopted eligibly criteria that include a criterion of terminal illness with a prognosis of six months.

### 2. The Possible Role of Advance Directives

Consistent with most existing legislation, the Supreme Court in *Carter* required that individuals be competent in order to access physician-assisted dying. In fact, all jurisdictions that have enacted assisted-dying legislation require that the individual be competent at least at the time of their request. Some legislation addresses the possibility of requesting assisted dying through advance directives. As with several other issues, advance directives were not contemplated in *Carter*, but may be considered by legislators.

An advance directive, addressed in several provincial statutes on health care decision making, is a document setting out an individual's wishes for future medical treatment, and often for treatment in the

event of incapacity or unconsciousness. Under Québec's *Act respecting end-of-life care*, people may request many end-of-life treatment options in advance, but they are explicitly prohibited from requesting medical aid in dying via advance directive. This exemption was created during the study of the legislation; the initial draft of Bill 52 would have allowed for requests for medical aid in dying via advance directive.<sup>135</sup>

In the Netherlands, it is possible under certain circumstances to request assisted dying through an advance directive. <sup>136</sup> It could be possible for persons diagnosed with a condition such as early-stage Alzheimer's to draft an advance directive that would request assisted death when their dementia has progressed to a given point, for example. The Panel heard from Professor Johan Legemaate, of the University of Amsterdam, that in practice, this sort of request is very rarely carried out because physicians are generally not willing to follow through with a request to assist an individual with advanced dementia to die. What could happen instead, however, is that individuals may request assisted death upon receiving a diagnosis such as Alzheimer's, and be competent at the time they receive assistance to die, although much of their suffering would be related to the knowledge of their eventual decline, rather than as a direct result of their condition.

As the Panel heard from Herman Nys, a health lawyer and academic, it is possible to request assisted dying via advance directive in Belgium, and to have the request carried out, but only under very specific conditions. If an individual has a valid advance directive requesting assisted dying, the request may only be fulfilled if the individual has an incurable and irreversible disorder, the individual becomes unconscious and the advance directive is no more than five years old.<sup>137</sup>

From the Panel's meeting with the Federation of Medical Regulatory Authorities of Canada, which included most of the country's colleges of physicians and surgeons, it appeared that most medical regulators are not prepared to consider requests made via advance directive. The College of Physicians and Surgeons of Newfoundland and Labrador expressed some concern about the timing of capacity assessments, i.e. whether capacity is determined at the time a request is made or at the time assisted death is administered. Dr. Grant of the Nova Scotia College noted that advance directives are not contemplated in *Carter* and need not be addressed, although he anticipated that litigation may someday raise the question of the validity of an advance directive request for physician-assisted dying. The College of Physicians and Surgeons of Prince Edward Island questioned whether advance directives for assisted dying might be seen to "fly in the face of informed consent" as "nobody can anticipate what they're going to feel or want to do" in a grievous medical situation, while the Saskatchewan College argued that because advance directives are respected in the case of Do Not Resuscitate orders, they should be respected in the case of requests for physician-assisted dying as well.

A number of individual submissions the Panel received raised the issue of advance directives. In one such submission, the author argued strongly for the principle that an advance directive authorizing physician-assisted dying should be respected:

<sup>&</sup>lt;sup>135</sup> Bill 52, An Act respecting end-of-life care, 1st Sess, 40th Leg, Québec, 2013.

<sup>136</sup> Termination of Life on Request and Assisted Suicide (Review Procedures) Act (Netherlands), art. 2 C. pen., s. 2(2).

<sup>137</sup> Loi relative à l'euthanasie (Belgium), s. 4 §1.

Incurable medical conditions, including comas and advanced dementia, should use living wills as a form of consent. Appropriate safeguards are required to protect abuse, but not providing an assisted death when written consent has been given is itself an abuse—not a safeguard.

Since the question of consent by advance directive extends beyond the scope of the Court's declaration in *Carter*, the Panel's attention to the complexities it raises has been relatively superficial. A scenario in the Issue Book raised the issue to test the importance that Canadians place upon this possible dimension of physician-assisted death. The Panel has not undertaken the extensive research and investigation that a question of this importance would warrant. The same is true with regard to substitute and supported decision making, discussed briefly below.

### 3. Substitute and Supported Decision Making

In many provinces, health care consent legislation addresses substitute decision making. A substitute decision maker is a person appointed to make medical decisions on behalf of another person who lacks capacity to make those decisions. In Belgium, the same rules that apply to advance decision making apply to substitute decision making. No other jurisdiction has enacted legislation to allow this form of consent for assisted dying, although Québec explicitly permits substitute decision making for "continuous palliative sedation," but not for medical aid in dying.

In a written submission to the Panel, the Ryerson University School of Disability Studies argued that the notion of consent must be considered very carefully in drafting any future legislation on physician-assisted dying. The School noted that "[o]ften people labeled with cognitive impairments and psychiatric diagnoses are not considered to have the capacity to give informed consent. The request for physician-assisted suicide must not come from a substitute decision maker. It must come from the person themselves."

The Panel heard from Professor Eike-Henner Kluge that there are ethical arguments in favour of expanding access to physician-assisted dying beyond the Supreme Court declaration in *Carter* and permitting access to individuals who request assisted dying via substitute decision maker. Few other groups advanced this argument. In a written submission the Panel received, it heard that for "any cases that are ambiguous, or in which the judgment of the substitute decision maker is in question, a bioethicist should be involved."

Anna MacQuarrie, Director of Global Initiatives, Policy and Human Rights with Inclusion International, a disability rights advocacy group, shared with the Panel information about "supported decision making." She explained that while substitute decision making is a contentious topic in the disability rights community, supported decision making is generally encouraged and promoted. Substitute decision making removes agency from the person deemed incompetent. Supported decision making acknowledges that many people with intellectual disabilities are able to make decisions, provided that they have the required support. This support could take the form of an interpreter, a communications device, plain language information, or the assistance of a trusted individual or individuals.

In its submission to the Panel, the Canadian Association for Community Living (the Canadian member of Inclusion International), argued strongly against authorizing supported decision making in the context of physician-assisted death:

While jurisprudence on decisional capacity and competence points increasingly to the legal obligation to recognize supports in decision making, we propose that a legislative line be clearly drawn. A report for the Law Commission of Ontario recommends that for the purposes of decisions that may fundamentally affect a person's mental or physical integrity, of which physician-assisted suicide and voluntary euthanasia is one, the law require that the person be able to act "legally independently".... That is, a person on his or her own must be able to fully understand and appreciate the nature and consequences of the decision, with supports and accommodations as may be required for this purpose.

## F. Voluntariness

The Supreme Court in *Carter* held that only eligible individuals who "clearly consent" may access physician-assisted dying. Requests must therefore be voluntary. To ensure that a request is in fact voluntary, a person's request for physician-assisted death must be evaluated for possible coercion, undue influence and ambivalence. Coercion and undue influence are external pressures that individuals may experience from family, friends, authority figures—potentially including health care providers—or society at large, while ambivalence reflects the individual's own potentially conflicting thoughts on whether to proceed with physician-assisted dying.

As noted in Chapter 5 of this report, the Supreme Court held that the purpose of the prohibition on assisted dying is to "[prevent] vulnerable persons from being induced to commit suicide at a time of weakness." The many submissions that the Panel received with respect to ensuring the voluntariness of a request for physician-assisted death articulate various approaches to ensure that such inducement does not occur.

Affirming the importance of the principle of voluntariness, and setting out a framework for its determination, Professor Wayne Sumner from the University of Toronto made the following recommendation:

Whatever form the patient's request takes, it must be both voluntary and informed. In order to be voluntary it must be free of undue influence, whether by family, friends, or health care providers. Influence will be 'undue' when it rises to the level of fraud, deceit, duress, or coercion. A patient's decision should be deemed to be voluntary unless there is some reason to think that it is not, in which case the patient should be offered counselling or access to a trusted adviser.

A number of submissions were broadly cautionary, serving to underscore the importance—and at times, the difficulty—of ensuring a standard of "clear consent" in all cases of physician-assisted death. The Evangelical Fellowship of Canada recommended that "federal laws and regulations should clearly address issues of vulnerability, voluntariness and potential coercion." The Fellowship was "concerned

that individuals who feel that they are a burden to their family members or to the healthcare system or to their caregivers may be vulnerable to influence, suggestion or pressure to seek assistance in ending their life."

The trial judge in *Carter* held that physicians are able to assess coercion, undue influence and ambivalence reliably as part of their assessment of individuals' competence and the voluntariness of their requests. Consistent with this finding, the Canadian Medical Association recommended that physicians assess voluntariness in the context of requests for physician-assisted dying by determining whether the decision was "made freely, without coercion or undue influence from family members, health care providers or others;" that there is a "a clear and settled intention to end [one's] own life after due consideration;" and that requests come from individuals themselves "thoughtfully and repeatedly, in a free and informed manner."

The BC Humanist Association supported this position:

Physicians regularly assess patients' competence to make life and death decisions. We rely on their expertise in assessing competence and determining when they need additional information to do so.

On the other hand, the Panel heard that doubt persists among several *Carter* interveners on this point. For example, the Association for Reformed Political Action suggested that while physicians may be able to assess coercion, undue influence and ambivalence, psychiatrists may be best able to do so. The Physicians' Alliance against Euthanasia expressed the view that it is impossible to be entirely sure whether coercion is present. The Canadian Federation of Catholic Physicians' Societies expressed concerns about assessing voluntariness in the presence of mental illness, language and cultural barriers and other social vulnerabilities, Dr. Renata Leong, from the Federation also observed:

As a profession, medicine has not been very good at identifying victims of partner violence and elder abuse. If we cannot identify them, how can we ... be sure that there's no duress and [that decisions are] completely voluntary? Research has consistently shown that we have all kinds of screening tools, but it's not good enough.

The Christian Medical and Dental Society of Canada argued that coercion is difficult to detect because "individual autonomy only works if everyone has the same amount of personal power." Professor Jocelyn Downie expressed a related caution, noting that voluntariness may be particularly difficult to assess in the context of oppression.

Several groups' submissions identified specific responsibilities or procedures to ensure that persons who request physician-assisted dying do so voluntarily, without coercion, undue influence or ambivalence. Some examples are listed below:

 Dying with Dignity Canada proposed that "two physicians must separately assess the individual and must attest that the request is made by the individual without coercion."

- A network of physicians from British Columbia suggested to the Panel that involving multidisciplinary teams in voluntariness assessments could help ensure that no sources of coercion are overlooked.
- The Canadian Association for Community Living recommended that qualified assessors, supplementary to a physician's assessment of decisional capacity, assess "possible undue influence and suspicious circumstances," and explore with the person who has made the request any relevant support alternatives "in the person's family and community social support system."

# Chapter 8. The Request

As Anne Sutherland Boal, Chief Executive Officer of the Canadian Nurses Association aptly expressed, "[physician-]assisted death is not just an act; it's a process. It begins right from the time the patient says that they are considering such a request, and it continues until death." An individual's request for physician-assisted death is a significant step in the process. There are many important considerations and questions related to such a request: how should it be initiated and by whom? What form should the request take? Should the family or other witnesses be involved? This following section will summarize what the Panel heard in relation to these issues.

An observation made by Dr. Renata Leong, a family physician who treats many marginalized patients in a downtown urban hospital, highlighted the importance of a measure of formality in requests when she recounted times when patients have spoken more casually about wanting to die. She reported that her patients:

need to know they can be upset, they can vent, they can just have off-the-cuff remarks, say I want to die because I'm in so much pain. And tomorrow, they might change their mind. And we see that all the time. Once you relieve the pain, or even as simple as arrange Wheel-Trans for my patients who's on crutches who have to travel back and forth, they change their mind.

# A. The Request Must Emanate from the Patient

One point on which the Panel heard differing opinions was on whether requests must always come first from the individual, or whether a physician may (or even should) mention physician-assisted dying as a possible option as part of informed consent. There are several risks associated with a physician raising the issue of physician-assisted dying. The Panel heard from the Physicians for Compassionate Care Education Fund in Oregon that patients who are not contemplating—or are opposed to—assisted dying might feel angered, abandoned or betrayed by a physician who suggests assisted death. The Panel also heard that physicians may have a very strong influence on their patients' choices such that if physicians suggest physician-assisted dying, they could be adding more weight to the option than individuals might on their own. Professor Isabelle Marcoux, Assistant Professor from the Faculty of Health Sciences at the University of Ottawa, noted that requests for physician-assisted death should always emanate from the patient and not from a suggestion of the health care provider.

In a detailed submission articulating guiding principles and a framework of guidelines for physician-assisted death, Professor R. Cohen-Almagor wrote:

[t]he physician should not suggest assisted suicide to the patient. Instead, it is the patient who should have the option to ask for such assistance. Initiation by the physician might undermine the trust between the patient and the physician, conveying to patients that the doctor is giving up on them and values their lives only to the extent of offering assistance to die. Such an offer might undermine the will to live and to explore further avenues for treatment.

The Panel also heard that the option of assisted dying might be an important part of informed consent. The Canadian Hospice Palliative Care Association expressed the challenges its members foresee around the notion of providing this information to patients:

[A]II patients deserve access to information around end of life options and including physician-assisted death. And this hasn't been an easy conversation with our community. And you know, the community realizes that they will need to provide all the options, including physician-assisted death to patients and families, the information around that.

Dr. Marcel Boisvert, with the Association québécoise pour le droit de mourir dans la dignité, observed that requests must come from the patient first, but that after an individual has made a request, "you talk to them about their options, including medical aid in dying. At that point, it's okay to do it." Recalling conversations with his colleagues in the Benelux countries, Dr. Boisvert added that it is "the exception for a physician to talk about medical aid in dying before the patient brings it up." Dr. Georges L'Espérance, from the same Association, argued that the importance of the issue of who raises the question first will soon diminish; public awareness of physician-assisted dying will increase when the service becomes available. He observed that "some people want to make it sound like we are saying ... the patient comes, you give him his diagnosis of serious, severe, irreversible pathology, then you tell him, well, we can do this, we can do palliative care then we can give you medical aid in dying. That's not how it goes in real life."

In Vermont, individuals have the explicit right to "be informed of all available options related to terminal care." <sup>138</sup> In the U.S. jurisdictions where assisted dying is legal, it is available only to individuals with terminal illnesses who have a prognosis of six months or less. Discussions about treatment options in the U.S. would therefore have a more limited scope than in the *Carter* context. The Vermont legislation explicitly states that discussing the option of assisted dying cannot not be construed as "assisting in or contributing to a patient's independent decision" to seek assisted death. <sup>139</sup>

## B. Point of Entry for the Request

The typical scenario foreseen by most groups appearing before the Panel is one where the individual initiates a conversation about physician-assisted death directly with their physician or other health care provider. If the physician does not have a conscientious objection to physician-assisted dying, the process will be initiated and procedural safeguards will flow from that initial interaction. Dr. Rob Jonquière, the Communications Director of the World Federation of the Right to Die Societies, with whom the Panel met in the Netherlands, observed that every single one of these discussions between individuals and their physicians is unique.

In Oregon, the Panel heard from Barbara Glidewell, who was the patient advocate and ombudsperson at the Oregon Health Sciences University (OHSU) in Portland for nearly 30 years. When the *Death with Dignity Act* came into force in Oregon, the OHSU decided to process all requests for assisted dying

<sup>&</sup>lt;sup>138</sup> Patient Choice at End of Life, Sec. 1, 18 V.S.A. c. 113, § 5282.

<sup>&</sup>lt;sup>139</sup> Patient Choice at End of Life, Sec. 1, 18 V.S.A. c. 113, § 5282.

through the patient advocacy office. Ms. Glidewell had direct contact with many individuals seeking assisted death and often met with these individuals along with their families. She noted that discussions often opened up after physicians left the room, allowing her to observe family dynamics. If she detected conflict or coercion, she could raise the matter with the responsible physician as an area to investigate.

Aside from the traditional interaction between individuals and their physicians, other suggestions on how to access physician-assisted dying were brought to the Panel, either as a response to dealing with physicians' conscientious objections or as means of diversifying the possibilities for access.

Dr. Jonquière spoke of the Netherlands' end-of-life clinics, where physicians (other than the patient's primary or family physician) and nurses assess individuals' requests for assisted dying, and provide the service if the legal requirements are met. These clinics are a new initiative set up to address the difficulties that individuals may encounter when physicians are not comfortable providing assisted death, either because of conscientious objection or because they are not sufficiently familiar with the procedure. Individuals can be referred to the clinic following a physician's conscientious objection, or go directly to the clinic themselves.

Dying with Dignity Canada suggested that instead of relying solely on the patient-physician interaction, a system could include multiple points of access. The organization was very concerned about access and highlighted the need to create a government-funded agency to appropriately respond to cases of conscientious objection and to guarantee effective referrals. Dying with Dignity Canada urged that this "one-stop" service should provide multilingual services, and should be accessible to individuals with poor medical literacy and easily reachable on a daily basis either by physician referral or self-referral. According to Dying with Dignity, no such service currently exists in Canada. A service to which patients could self-refer could be beneficial, as it empowers the patient while at the same time removing the onus from health care providers who may conscientiously object.

Some groups have raised general concerns about access, citing for example the barriers to access that Canadians might face if they live in remote regions, or if inconsistent services are provided across provinces and territories. The Canadian Nurses Association suggested a pan-Canadian approach that would ensure equal access for all eligible Canadians by promoting standardization and quality improvement. Other groups have suggested a "mobile" or "itinerant" medical team that could reach Canadians wherever they live. The Canadian Society of Palliative Care Physicians suggested a mobile service as a response to conscientious objections in remote or rural communities. Dr. Alika Lafontaine of the Indigenous Physicians Association of Canada supported the idea of an itinerant team to ensure access in remote communities and specified that it might be necessary to adapt services to meet the needs of Indigenous populations.

## C. Form of the Request

Views concerning the number and type of requests varied among stakeholders and experts. Some were broad in their recommendations. For example, a network of British Columbia physicians with whom the Panel met, as well as the Euthanasia Prevention Coalition, both suggested that requests be "enduring."

The Canadian HIV/AIDS Legal Network also noted that it was important that requests be "repeated clearly" on a number of occasions.

Other groups provided more specific recommendations. The Canadian Medical Association (CMA) recommended that individuals seeking physician-assisted dying submit at least two oral requests, at least 14 days apart, over a period of time that is proportionate to the individual's prognosis. Following the two oral requests, the CMA recommends that individuals would then submit a written request for assisted dying to the attending physician. Such a written document should, in the CMA's view, be in the form of a special declaration to be developed by the government, a ministry of health, a regional health authority or a health care facility.

The Evangelical Fellowship of Canada and the Association for Reformed Political Action Canada recommended that at least three requests be made and that each be video- or audio-recorded. They suggested that such recordings could be useful in preventing abuse and in the event that any criminal wrongdoing is reported.

Several jurisdictions require a written formal request for assisted dying and require that these requests be kept as record. Such records are useful for oversight and data collection, which will be discussed in further detail in Chapter 12. Legislation in Québec<sup>140</sup> and Belgium<sup>141</sup> requires patients to submit written requests to attending physicians. Both jurisdictions also stipulate that accommodation must be made for patients who may be physically incapable of completing written requests. In Oregon,<sup>142</sup> Washington<sup>143</sup> and Vermont<sup>144</sup> patients must, in addition to a written request, make two oral requests to the attending physician. The American statutes do not include accommodation provisions for persons with disabilities. Video recording of requests is not required in any existing legislation.

## D. Witnesses to the Request

The Panel heard and reviewed a number of suggestions about who may act as a witness to a written request for physician-assisted dying, as well as the number of people who must witness such a request.

Professor Jocelyn Downie,<sup>145</sup> a health lawyer and academic, and Mr. David Baker, a disability rights lawyer, proposed that all requests should be signed in the presence of the attending physician and two witnesses. The same requirement appears in S-225, *An Act to amend the Criminal Code (physician-assisted death)*,<sup>146</sup> a Senate public bill introduced in December 2014. Professor Downie offered a second option that would permit an individual to provide a solemn declaration pursuant to section 41 of the

<sup>&</sup>lt;sup>140</sup> An Act respecting end-of-life care, R.S.Q. c. S-32.0001, s. 26.

<sup>&</sup>lt;sup>141</sup> Loi relative à l'euthanasie (Belgium), s. 4.

<sup>&</sup>lt;sup>142</sup> Oregon Death with Dignity Act, O.R.S. 127.840 §3.06.

<sup>&</sup>lt;sup>143</sup> Washington Death with Dignity Act, R.C.W. c. 70.245, § 70.245.090.

<sup>&</sup>lt;sup>144</sup> Patient Choice at End of Life, Sec. 1, 18 V.S.A. c. 113, § 5283.

<sup>&</sup>lt;sup>145</sup> Jocelyn Downie, *Draft Federal Legislation to Amend the Criminal Code to Be Consistent with* Carter v. Canada (Attorney General) *2015 SCC 5* (9 February 2015). Please note that Professor Downie has since updated her model legislation. The Panel's references to her legislation are to the 9 February 2015 version, as this was the version discussed at its meeting with Professor Downie.

<sup>&</sup>lt;sup>146</sup> Bill S-225, An Act to amend the Criminal Code (physician-assisted death), 2nd Sess, 41st Parl, 2014.

Canada Evidence Act, <sup>147</sup> in the event that the two witnesses cannot be physically present at the same time. <sup>148</sup> Mr. Baker adds that the two witnesses must be required to attest that to the best of their knowledge and belief the individual is competent, acting voluntarily and is not being coerced to sign the request.

The requirement that an individual's request for physician-assisted dying be made in the presence of a witness is a safeguard commonly used in jurisdictions in which assisted dying is permitted. Québec's legislation requires that a government form be signed in the presence of, and countersigned by, a health or social services professional. <sup>149</sup> It specifies that if the witnessing professional is not the attending physician, the professional must submit the request to the attending physician. State legislation in Washington<sup>150</sup> and Oregon<sup>151</sup> requires that a request be signed and dated by the patient and witnessed by at least two individuals who, in the presence of the patient, attest that to the best of their knowledge and belief the patient is capable, acting voluntarily and is not being coerced to sign the request. Vermont's legislation differs slightly in that the individual's request must be signed in the presence of two or more witnesses who are required to sign and affirm that the individual appears to understand the nature of the document and to be free from duress or undue influence at the time the request was signed. <sup>152</sup>

In some cases, legislation or model legislation includes certain conditions to ensure that individuals acting as witnesses do not have a potential conflict of interest. The models offered by Professor Downie, Mr. Baker and Bill S-225 include similar requirements. They stipulate that a witness must be at least 18 years old and not be

- a relative by blood, marriage, common-law partnership or adoption
- an owner, operator, employee or resident of the health care facility where the person making the request is receiving treatment
- a physician involved in the care of the patient
- entitled to any portion of the estate upon death under any will or by operation of law at the time of acting as a witness

<sup>&</sup>lt;sup>147</sup> Canada Evidence Act, R.S.C. 1985, c. C-5.

<sup>&</sup>lt;sup>148</sup> Jocelyn Downie, *Draft Federal Legislation to Amend the Criminal Code to Be Consistent with* Carter v. Canada (Attorney General) *2015 SCC 5* (9 February 2015). Please note that Professor Downie has since updated her model legislation. The Panel's references to her legislation are to the 9 February 2015 version, as this was the version discussed at its meeting with Professor Downie.

<sup>&</sup>lt;sup>149</sup> An Act respecting end-of-life care, R.S.Q. c. S-32.0001, s. 26.

<sup>&</sup>lt;sup>150</sup> Washington Death with Dignity Act, R.C.W. c. 70.245, § 70.245.030.

<sup>&</sup>lt;sup>151</sup> Oregon Death with Dignity Act, O.R.S. 127.810, § 2.02.

<sup>&</sup>lt;sup>152</sup> Patient Choice at End of Life, Sec. 1, 18 V.S.A. c. 113, § 5283(4).

<sup>&</sup>lt;sup>153</sup> Please note that Professor Downie has since updated her model legislation. The Panel's references to her legislation are to the 9 February 2015 version, as this was the version discussed at its meeting with Professor Downie.

State legislation in Oregon, <sup>154</sup> Washington <sup>155</sup> and Vermont <sup>156</sup> feature similar witness criteria. Oregon <sup>157</sup> and Washington <sup>158</sup> further require that if the individual is a patient in a long-term care facility at the time the written request is made, one of the witnesses must be an individual designated by the facility and meet the qualifications specified by the appropriate government department.

### E. Role of Family

Some individuals and organizations the Panel heard from felt that the role of the family in the physician-assisted dying process is critical. Others described the process as a deeply personal one, which should remain between the patient and his or her physician. The Panel heard various suggestions on whether or not the family should play a formal role in the physician-assisted dying process.

In Ms. Lee Carter's appearance before the Panel, she discussed her family's role in helping her mother, Kay Carter, to obtain assisted dying in Switzerland. She noted that by the time Ms. Kay Carter decided she wished to pursue assisted death, she could no longer hold a telephone, use a computer or write. Consequently, Lee Carter and her husband, Mr. Hollis Johnston, did all the planning and appropriate paperwork on behalf of Kay Carter. Ms. Lee Carter's experiences demonstrate the supportive role some families may play in this process.

It is important to note however, that many individuals may wish to make this decision privately without the involvement of family or other loved ones. A number of stakeholders and experts emphasized that family involvement could enrich the assisted-dying process for some, but such involvement should never override the principle of individual autonomy. Dr. James Downar of Dying with Dignity Canada noted that health care professionals may encourage individuals to include their family in the process, but any actions beyond encouragement could violate individuals' right to privacy.

Dr. Linda Ganzini highlighted the need to safeguard individuals who may be susceptible to coercion by family members to request assisted dying. She noted that coercion by family members in assisted-dying cases is rare, but that clinical interviews should be held in private (i.e. separate and apart from family) with the individual making the request to rule out the possibility. The Physicians' Alliance against Euthanasia also noted that family involvement could be problematic in scenarios where there may be family conflict over the request for physician-assisted dying or if elder abuse may be occurring. In such sensitive scenarios, medical professionals will play a key role in assessing whether an individual has fully and freely consented to the procedure.

In cases where families are involved, Dr. Katrina Hedberg, State Epidemiologist and State Health Officer at the Oregon Public Health Division, suggested that psychological and social support be provided to the family before, during and after requests for assisted dying are carried out. Ms. Barbara Glidewell, a former patient ombudsperson with a major university hospital in Portland, Oregon, also noted that

<sup>&</sup>lt;sup>154</sup> Oregon Death with Dignity Act, O.R.S. 127.810, § 2.02.

<sup>&</sup>lt;sup>155</sup> Washington Death with Dignity Act, R.C.W. c. 70.245, § 70.245.030.

<sup>&</sup>lt;sup>156</sup> Patient Choice at End of Life, Sec. 1, 18 V.S.A. c. 113, § 5281(a)(6)

<sup>&</sup>lt;sup>157</sup> Oregon Death with Dignity Act, O.R.S. 127.810, § 2.02(4).

<sup>&</sup>lt;sup>158</sup> Washington Death with Dignity Act, R.C.W. c. 70.245, § 70.245.030(4).

involving the family can help ease anxiety for all involved and have a healing effect on relationships with family and loved ones.

Ms. Melanie MacKinnon, an academic and Indigenous health expert at the University of Manitoba, highlighted the important role Indigenous families may play in the dying process. She noted that because palliative and end-of-life care may not be easily accessible or available in many Indigenous communities, families often play an important role in supporting relatives who are at or near end of life. She discussed how entire extended families often aim to reach a "shared decision" concerning the health of an ill family member, but recounted experiences where large family groups have been made to feel unwelcome in hospital settings. Dr. Alika Lafontaine of the Indigenous Physicians Association of Canada echoed Ms. Mackinnon's perspective, and stated:

[I]t's just as important to Indigenous patients to have their family walk along the path of resolving themselves that this is what they want to do and that this is the right decision for them to make, as it is for them to walk along that journey and come to the point where they recognize that this is the direction that they want to go.

Legislation in a number of jurisdictions requires that the attending physician consult (or offer to consult) with the patient's family as part of the process for assessing a request for physician-assisted death. Québec's *Act respecting end-of-life care* requires that if an individual wishes, the attending physician must discuss the request with the individual's close relations. Further, Québec's legislation states that it is the responsibility of the attending physician to make sure that the patient has had the opportunity to discuss the request with the persons they wish to contact. Under state legislation in Oregon and Washington, the attending physician may recommend that the individuals notify next of kin of their request, but individuals who do not follow this recommendation or are unable to notify next of kin cannot have their request denied for this reason. California's legislation requires that individuals explicitly state in their formal request whether they have decided to inform family, or if they have no family to inform.

<sup>&</sup>lt;sup>159</sup> An Act respecting end-of-life care, R.S.Q. c. S-32.0001, s. 28(1)(e).

<sup>&</sup>lt;sup>160</sup> An Act respecting end-of-life care, R.S.Q. c. S-32.0001, s. 28(1)-(2).

<sup>&</sup>lt;sup>161</sup> Oregon Death with Dignity Act, O.R.S. 127.835, § 3.05.

<sup>&</sup>lt;sup>162</sup> Washington Death with Dignity Act, R.C.W. c. 70.245, § 70.245.080.

<sup>&</sup>lt;sup>163</sup> End of Life Option Act (California), Part 1.85, Div. 1, Health and Safety Code, s. 443.11(a).

# Chapter 9. Assessing the Request

In this section of the report, the Panel will provide a brief outline of submissions and recommendations regarding the process of information gathering and assessment that might follow a formal request for physician-assisted dying. Some of these processes—such as an evaluative assessment by a second physician—were widely favoured in many submissions. Others, such as those involving Indigenous elders or traditional healers, were less frequently heard. These various proposals represent a range of options that could form part of the response to requests for physician-assisted death.

### A. Medical Assessments

The Panel heard a variety of views on the need to receive input from various physicians as part of the evaluation of a request. These additional consultations could be provided by specialists in generally relevant fields, such as psychiatry and palliative care, or in the specialty relevant to the patient's medical condition, such as oncology or neurology.

Some were in favour of mandatory additional consultations in all cases. Others, such as Dr. Francine Lemire of the College of Family Physicians of Canada, expressed concern that mandatory consultations with psychiatrists or palliative care specialists could hinder access in communities where it is difficult to obtain such services. She indicated that physicians working in such locations would nonetheless welcome consultations if they were available.

## 1. Confirmation by a Second Physician

Every jurisdiction that has enacted legislation permitting assisted dying requires that a second physician (often called a "consulting physician") confirm the attending physician's approval of a request.

The stakeholders with whom the Panel met widely accepted this requirement as an appropriate safeguard to ensure the careful consideration of physician-assisted dying requests. Stakeholders highlighted numerous benefits: ensuring that decisions are not made hastily, providing increased protection of vulnerable individuals and minimizing the potential for error.

Some groups suggested specific criteria for consulting physicians. The Canadian Medical Association, for example, noted that the consulting physician should be independent of both the individual and the attending physician. A Senate public bill introduced in December 2014, Bill S-225, *An Act to amend the Criminal Code (physician-assisted death)*, <sup>164</sup> includes a requirement that the attending physician have no professional or personal relationship with the consulting physician. Mr. Donato Gugliotta of the Christian Medical and Dental Society of Canada further suggested that an individual's primary care

<sup>&</sup>lt;sup>164</sup> Bill S-225, An Act to amend the Criminal Code (physician-assisted death), 2nd Sess, 41st Parl, 2014.

physician not be permitted to approve such a request and that the two physicians who review the request should be completely independent from the individual.

According to David Baker and Rebecca Lauks, disability rights lawyers in private practice, the second physician involved in the assessment of the request should be a specialist in the underlying condition who can evaluate the source of the suffering. It was further suggested by the Physicians' Alliance against Euthanasia that the consulting physicians have specific expertise pertaining to the individual's medical condition. Dr. Catherine Girouard of the Alliance noted that medicine evolves constantly and it is impossible for a single physician to have expertise in every type of treatment and illness, especially different cancers. She suggested having a physician with relevant expertise review each request to ensure all options have been considered.

Although the Panel heard almost unanimous support for the involvement of a second physician, limiting the eligibility of this second physician could act as a barrier to access in small communities, and in rural and remote areas. As the Society of Rural Physicians of Canada noted, many such areas have a shortage of practising physicians. Finding a consulting physician within a reasonable distance that the attending physician does not know personally or professionally may be difficult.

In response to the question of whether obtaining a second medical opinion might create undue barriers, particularly for those in rural locations, Ms. Barbara Glidewell from Oregon observed that what might be perceived as a hurdle in the process, is instead a clear signal that the person's life is valued and their decision about an assisted death is a weighty one:

I think we need to honour the concept of anticipating one's death by not simplifying it so much that it just is oh, here's a prescription. Go take it if you want to. I think we need to honour the person's dignity by showing them that we've gone through a process that respects their life and respects their decisions [without challenging them] unless we should if they seem off... [They need to understand] how much we respect them as a human being.

From my perspective not to trivialize their life by saying oh, you'd like to do that? Okay, we'll do it. Here it is and we'll find out if you used it.

### 2. Mental Health Consultations

Many groups appearing before the Panel discussed psychological consultations. The Panel learned that psychologists are already called upon to help determine medical decision-making capacity in general, as well as in the context of end-of-life care.

Dr. Keith Wilson advised the Panel to consider whether requiring that individuals who request physicianassisted dying undergo a mental health assessment for depression should be a legal requirement. This assessment could result in an opinion on whether the individual's depression may be treatable. Dr. Wilson warned that some individuals may try to conceal their symptoms, however, if they fear that a diagnosis of depression will impede access to physician-assisted dying. Some groups, including the Association for Reformed Political Action Canada and the Euthanasia Prevention Coalition, have suggested that an independent mental health consultation be mandatory in all requests for physician-assisted dying, to assess capacity, motivations and relational dynamics. Dr. Joris Vandenberghe, a Belgian psychiatrist, offered the same view and noted that the complex factors involved in making the decision to die are key to the practice of psychiatry and psychology. He noted that the expertise of a psychiatrist or psychologist would be particularly important in considering requests from individuals without terminal illnesses. Others proposed that mental health consultations be required only when psychological considerations are relevant or fall outside the attending physician's comfort level. <sup>165</sup>

Eli Stutsman, an expert from the Death with Dignity National Centre in the United States who helped draft Oregon's *Death with Dignity Act*, told the Panel that when the legislation was drafted in 1993, including a mandatory mental health consultation was a contentious issue. Ultimately, health care practitioners convinced legislators that a psychological evaluation could not be made mandatory in all cases, primarily because it was undesirable to characterize all individuals who request physician-assisted dying as having mental health problems. Instead, practitioners would screen for signs of depression and request a mental health consult only if necessary.

The Canadian Psychiatric Association proposed that individuals with a mental illness who are seeking physician-assisted death for another medical condition should be assessed by psychiatrists to determine whether the mental illness impairs their decision-making capacity with regard to physician-assisted death. The Association also called for a psychiatric assessment when an individual requests physician-assisted dying solely because of mental illness. However, the Canadian Psychiatric Association did not advise that a psychiatrist be clinically involved in all requests for physician-assisted death, or in every assessment of capacity.

The Panel met with Dr. Keith Wilson and reviewed a considerable body of research related to the experience of suffering, the prevalence of depression in various populations and the importance of psychological factors in requests for physician-assisted death. On the strength of this research, some of which Dr. Wilson led, he expressed his opinion that:

The provision of medical aid in dying should only occur after thorough assessment of potentially treatable sources of suffering. This would include appropriate medical and palliative care intervention. However, the importance of psychological factors in motivating requests for medical aid in dying should not be underestimated. These factors include diagnosable mental disorders but also broader psychological, social, and existential concerns among those with medical illness. These factors should be considered essential to assessment.

The College of Physicians and Surgeons of Manitoba suggested requiring a psychiatric assessment for individuals without a terminal illness, catastrophic injury, intractable physical pain, who are not in an advanced stage of irreversible and significant impaired function, or who appear to experience a level of

<sup>&</sup>lt;sup>165</sup> Dr. Georges L'Espérance, President, Association québécoise pour le droit de mourir dans la dignité, 23 October 2015; Dr. James Downar, Dying with Dignity Canada, 2 November 2015.

suffering disproportionate to their medical condition. <sup>166</sup> In cases where the grievous and irremediable medical condition relates primarily to mental health, the College of Physicians and Surgeons of Nova Scotia proposed requiring that psychiatrists serve as one of the two physicians assessing requests.

#### 3. Palliative Care Consultations

Some groups expressed the view that palliative care consultations should be mandatory to at least make people aware of care options. According to the Physicians' Alliance against Euthanasia, a consultation with a palliative care specialist is necessary to adequately explain the specific effects of proper palliative care on symptom management; other physicians—such as generalists and specialists in other disciplines—may not be able to describe these options as effectively. The Canadian Society of Palliative Care Physicians indicated that providing this type of expertise to reduce suffering is something its members are very willing to do. Palliative care consultations would only be relevant in life-threatening or life-limiting conditions, bearing in mind that *Carter* extends beyond those diagnostic and prognostic parameters.

Peg Sandeen, Executive Director of the Death with Dignity National Center in the United States, noted that mandatory consultations with hospice or palliative care specialists, or ensuring that one of the two physicians required to review requests be a hospice or palliative care physician, would be a worthy safeguard. She did, however, note the challenges that such a requirement could pose in terms of access in some communities.

### B. Contributions of Allied Health Professionals

Modern medical care increasingly involves teams. Where appropriate, interdisciplinary teams care for patients; they are often comprised of physicians, nurses, psychologists, pharmacists, social workers and other allied health care professionals. Incorporating this team approach into a physician-assisted dying framework could have distinct advantages. The Canadian Nurses Association observed that an interdisciplinary team could offer a comprehensive assessment in cases where physician-assisted dying is requested, and could act as a valuable safeguard. It may be important to consider the insight into family dynamics that allied health care professionals, such as nurses, patient advocates, social workers, spiritual care providers and others may have. Further, these professionals could play an important role in assessments of capacity and voluntariness, and offer insights on the factors that may contribute to suffering and vulnerability.

Dr. Francine Lemire, Executive Director and Chief Executive Officer of the College of Family Physicians, spoke of the importance of benefitting from other providers' expertise when assessing complex requests for physician-assisted dying. Referring back to other kinds of clinical challenges over the course of her career, Dr. Lemire observed:

When I did my training, ... whenever we were wrestling with certain situations that were not easy—and I say this as a trainee—the social worker was the first person we thought about in

<sup>&</sup>lt;sup>166</sup> College of Physicians and Surgeons of Manitoba, *Draft Statement on Physician-Assisted Dying*, 15 October 2015.

Montreal. In Newfoundland, whenever I was in the same situation, the public health nurse was my first person I was thinking about, and who provided some incredible advice, service, you know, you name it, in some of the complex situations.

Explaining the importance of the health care team, Dr. Alika Lafontaine, Vice President of the Indigenous Physicians Association of Canada indicated:

[W]hen I talk about a team ... it's understanding that at end of life, there are multiple people that are involved. Now, as part of the core team ... that provides the care, I'd imagine [you would] probably have a physician who provides the actual physical mechanism of death.

As such, while physician-assisted dying will directly implicate physicians as those who prescribe and/or administer drugs, other health care professionals are also likely to be involved in the process.

#### 1. Nurses

According to the Canadian Nurses Association, registered nurses are Canada's largest group of health care providers. Nurses are omnipresent members of health care teams. They work in many settings: at home, in the community and in hospitals. They are at patients' bedside at all times of day and night, and interact continually with patients, families, support circles and other members of the health care team. For this reason, the Canadian Nurses Association noted that nurses are often an individual's initial point of contact—the first person to whom someone expresses a wish to die or requests assistance in ending their life.

The Canadian Nurses Association noted that physician-assisted dying is a long process. The individual making the request needs information and support not only at the moment of the request and at the moment of death, but also at many moments in between, or "points along the continuum." This support will not always be provided directly by the physician and is likely to be provided by nurses.

The Canadian Nurses Association observed that given nurses' relationships with patients, their role throughout the process of physician-assisted dying could include ascertaining motivation and determining whether coercion or ambivalence are involved. Richard Elliot from the HIV/AIDS Legal Network echoed this perception of the role of nurses as providers "who are going to be closer to the action ... who will be in a better position to sense whether there is something going on. [Such providers] will be the ones who might be able to see if there are any indications of pressure on the decision making by the patient, for example." According to the Canadian Nurses Association, nurses, through their experience and close contact with patients, are particularly well equipped to identify sources of vulnerability and therefore protect vulnerable people. Nurses "bring knowledge ... expertise and experience to those conversations and, with the therapeutic relationship, can be an advocate for those vulnerable patients."

The Panel also heard that nurses may come to be directly involved in physician-assisted dying. The Canadian Nurses Protective Society mentioned the role of the "Most Responsible Professional," or MRP, to denote the main person in charge of an individual's health care. While it was once routine that the MRP be a physician, there has been a shift in the provision of health care, such that, in some provinces,

nurse practitioners can now also be MRPs given their broad scope of practice. According to the Canadian Nurses Association, nurse practitioners have "additional educational preparation and experience" and "competencies to autonomously diagnose, order and interpret diagnostic tests, prescribe pharmaceuticals, and perform specific procedures within their legislated scope of practice." <sup>167</sup>

The Canadian Nurses Association told the Panel that nurse practitioners have their own caseloads and will sometimes be the health care provider with the most contact with patients. Indeed, many nurse practitioners work in areas where they are the sole practitioners. As a means of ensuring access in some communities, the Canadian Nurses Association indicated that it would be worth considering whether nurse practitioners should be authorized to prescribe drugs for physician-assisted dying.

Foreseeing a future role for nurse practitioners with physician-assisted death, the Canadian Nurses Protective Society suggested using the term "practitioner-assisted death," or "medically-assisted death," instead of terminology that implies that the practice would be limited to physicians.

In line with this anticipated role, the Canadian Nurses Protective Society submitted to the Panel that, given the high likelihood of nurses' involvement in this process, there should be explicit protection in the *Criminal Code* "for nursing activities surrounding physician-assisted death." In the Society's view, a legislative response to *Carter* must "specifically address the role of nurses in physician-assisted death." Dr. Douglas Grant, President of the Federation of Medical Regulatory Authorities of Canada and Registrar of the College of Physicians and Surgeons of Nova Scotia, indicated that: "any time there's care delivered in any medical setting, there are other ancillary health professionals involved, and I would hope the amendments to the *Criminal Code* contemplate the roles of other health professionals." The College of Physicians and Surgeons of Ontario echoed this sentiment.

The Canadian Nurses Protective Society saw three specific areas where risks of criminal prosecution exist if nurses are not explicitly protected in the *Criminal Code*. The first involves discussions with patients about physician-assisted death and the offence of counselling a person to commit suicide under section 241(a) of the *Criminal Code*. While the word "counselling" is often used in medical settings to mean providing information or discussing, it has a different meaning in the context of the *Criminal Code*, where it is defined as procuring, soliciting or inciting. <sup>168</sup> The Society noted this distinction, but observed that in a highly emotional context, a health care provider giving information and discussing physician-assisted dying may be perceived as "inciting" an individual to commit suicide. According to the Society, there should be a clear exemption in the *Criminal Code* for discussing physician-assisted death.

The second area where the Canadian Nurses Protective Society saw a risk of criminal prosecution is when a nurse is part of the treatment team providing physician-assisted death. During this process, the nurse may provide various types of care, including discussing treatment options, monitoring indicators of capacity, providing comfort, and preparing or assisting in the administration of the drugs used to induce death. In other words, even in situations where physicians are prescribing or administering the lethal substance, they rarely act in isolation and will likely be assisted by nurses.

<sup>&</sup>lt;sup>167</sup> Canadian Nurses Association, *Position Statement: The Nurse Practitioner*, November 2009.

<sup>&</sup>lt;sup>168</sup> Defined at section 22(3) of the *Criminal Code*, R.S.C. 1985, c. C-46.

The third area of concern relates to nurse practitioners acting as the most responsible professional, and the possibility that they may eventually be called upon to determine if the eligibility criteria have been met and to prescribe the lethal medication. This would be conceivable where nurse practitioners operate within the community or in long-term care facilities, or in remote locations where the nurse practitioner is the only health care provider readily available. According to the Canadian Nurses Protective Society, the protection of nurses should take the form of a clear exemption in the *Criminal Code*.

The Canadian Nurses Protective Society indicated that absent such explicit protections in the *Criminal Code*, there may be a chilling effect within the profession, restricting open and spontaneous communication with patients about their suffering.

In their submission to the Panel, the Canadian Nurses Association also noted that health professionals will have a distinct experience with assisted death:

Assisted death will radically transform the moment of death, changing what health-care providers are used to regarding what a good death looks like. A nurse or physician is generally accustomed to seeing a patient deteriorate over time, eventually becoming less alert, more sleepy, etc. Assisted death will change this. At one moment a patient may look well and be eating breakfast and then, after the administration of the medication, they will stop breathing and changing colour, and their death will be sudden. It is a different way of dying, which health-care providers are not yet familiar with.

The Association called for access—for all health care providers—to ethical and psychological support, to help them cope with and navigate the process of physician-assisted dying, and to resolve any moral distress.

### 2. Pharmacists

The Canadian Pharmacists Association indicated that there is a role for pharmacists to play in physician-assisted dying, and that this role will require some training. Pharmacists work in both hospital and community settings. They will be involved where individuals are prescribed a lethal dose of a given medication. They would fill the prescription and would need to provide counselling on how to take the medication and its effects. Pharmacists would also be involved in situations where a physician administers the medication, since a prescription must also be filled, although the Association indicated that patient counselling may not be necessary in such cases.

According to the Association, pharmacists are largely in favour of legislation that would mandate pharmacist counselling to individuals or their families at the moment of dispensing. It argued that pharmacists should also have access to an individual's diagnosis and care plan when dispensing the lethal medication.

The Association stated that pharmacists could play an important counselling role, given that persons who obtained a prescription for medication in the context of physician-assisted dying may have questions, including how the medication works, what to expect and whether there might be interactions

with other medications. There may also be a role for pharmacists to be present when the lethal medication is taken.

Pharmacists could also play a role in collecting and disposing of unused medication, something that nearly 90% of pharmacies in Canada already do, according to the Canadian Pharmacists Association. This may help to address the concern others raised about prescriptions left unused in home settings when individuals die before taking them.

The Association discussed the need for a more robust prescription system for physician-assisted dying to address its concern that dispensing pharmacists may not know whether the individual seeking the prescription meets eligibility criteria. Representatives of the Association described the triplicate prescription pad currently used for opiates, on which each prescription is reproduced threefold: one for the patient, one for the physician, and one sent to the government for tracking. The Association was not sure about the necessity of this type of system for physician-assisted dying, however, given the emergence of e-health and electronic prescriptions.

The Canadian Nurses Protective Society cited pharmacists as another group of health care providers in need of a clear, explicit exemption under the *Criminal Code* for their involvement in physician-assisted dying.

### 3. Spiritual Care Providers

Mr. Marc Doucet, President of the Canadian Association for Spiritual Care, described spirituality as "whatever connects me to what is beyond myself in an isolated situation... it can be relationship, it can be nature, it can be a supreme being." Spiritual suffering, he explained, is linked fundamentally to identity, and how we understand ourselves in the world. He reflected on the dimensions of spiritual suffering as distinct from, but often connected to, physical pain:

So we can medicate pain, but there can still be suffering. And suffering would be, you know, how do I let go of my life, how do I have a good death, the suffering of not seeing my children raised, not being around for major events, not accomplishing what I wanted. That would be the spiritual suffering.

The Panel heard that spiritual health care workers see themselves as playing an important role in assessing and supporting individuals who express a desire to end their life with the assistance of a physician. The Canadian Association for Spiritual Care argued that a spiritual assessment should be mandatory whenever physician-assisted death is requested and should be conducted by a spiritual care professional. The spiritual care provider would not be part of the decision-making process, but would instead serve to inform that process, to support the person making the request and to explore the depth of self-knowledge expressed in their request. In the Association's view, absent this spiritual assessment, referred spiritual pain risks being experienced as intractable physical pain by some individuals.

### 4. Indigenous Healers and Care Providers

Carrie Bourassa, Professor of Indigenous Health Studies at the First Nations University, informed the Panel that traditional healers have a significant role to play in conversations and assessments related to

physician-assisted dying. Dr. Alika Lafontaine of the Indigenous Physicians Association of Canada proposed an itinerant team, comprised of local health care providers, for Indigenous persons who request physician-assisted dying.

Melanie MacKinnon, Senior Director of the Section of First Nation, Métis and Inuit Health Branch at the University of Manitoba and President of the Aboriginal Nurses of Manitoba, referred to the effect upon Indigenous communities of an increased medicalization of birth and death, and the lack of community-based resources to support these experiences:

Death in our communities, natural death aside from accidents and traumatic death, have been removed from First Nation communities for over the last 50 years... So when we think of who we are from the cycle of life, for having life coming in and being born into our communities and life going out and dying from a physical essence, those two really critical phases of life have been removed from what would be and could be and should be a natural life cycle.

Other experts outlined the need to allow greater flexibility and understanding within medical settings for the presence of Indigenous community and family members, and to accommodate different spiritual practices at end of life. <sup>169</sup>

Melanie MacKinnon also shared with the Panel her view that community health leaders would prefer to be left to do what they know is best for their communities—focus on behavioural and spiritual health—and that funding remunerate elders, thus bringing dying back to the communities.

### 5. Vulnerability Assessment

Mr. Michael Bach, Executive Vice President of the Canadian Association for Community Living, raised the issue of the demographic trends of vulnerability in Canada:

- On the one hand, a rapidly increasing proportion of the population is living now with disability, and confronting a growing gap in access to needed home supports, respite supports and income supports.
- On the other hand, an aging population is poised for the largest inter-generational transfer of
  wealth we have seen, and understood by Law Reform Commissions in Canada to be increasingly
  vulnerable to financial and other abuse.

Mr. Bach told the Panel that vulnerable persons must not be excluded from making autonomous requests for an assisted death. He also suggested that when indications of vulnerability are present, the person be assessed to see whether coercion or inducement contributed to the request. He spoke of what he called the "Carter challenge"—the challenge of providing access to physician-assisted death with due care for persons at risk:

How do we have a nuanced system respecting that people are individually resilient in different ways? [B]ecause one is living in poverty, a caregiver stress situation, [or] lack of support doesn't

<sup>&</sup>lt;sup>169</sup> Carrie Bourassa, professor of Indigenous Health Studies at the First Nations University, 28 October 2015; Indigenous Physicians Association of Canada, 3 November 2015.

necessarily mean that you can't act autonomously and make this decision, but it should give us pause to consider if in your particular situation these factors are working in a way that restricts your liberty.

The detailed framework proposed by the Association called for a vulnerability assessment to be integrated into the process of responding to requests for physician-assisted death. This assessment process would be initiated within 24 hours of a request and would involve a social worker or psychologist. In many cases, the assessment might consist of a single conversation to determine whether any unmet needs have compromised the person's autonomy. In other cases, the assessor would help the person access options and supports to meet their immediate needs.

David Baker provided the Panel with proposed legislation that includes a provision for referral to a "counsellor" in a manner that might lend itself to the vulnerability assessment proposal detailed above. The Panel notes that other organizations, including Citizens with Disabilities Ontario, supported this aspect of the proposed legislation.

### C. Informed Consent

Informed consent is a legal and ethical principle requiring physicians and other health care providers to provide all relevant information so that patients can make a voluntary choice regarding their treatment that is fully informed. At trial in *Carter v. Canada*, Justice Smith specified that:

The doctrine of informed consent protects a patient's right to accept or refuse medical treatment. No medical procedure may be undertaken unless a medical practitioner has obtained the patient's consent after providing her with information sufficient to enable her to evaluate the risks and benefits of the proposed treatment and other available options. Informed consent presupposes the patient's capacity to make a subjective treatment decision based on her understanding of the necessary medical facts provided by the doctor and on her assessment of her own personal circumstances. <sup>170</sup>

Many groups suggested that the medical standards for informed consent should be applied to requests for physician-assisted dying. Many experts and stakeholders told the Panel that informed consent necessarily requires that individuals have the opportunity to consider all reasonable and available alternatives—treatments, approaches and supports that might ease the distress underpinning their request to die. The Canadian Association of Community Living (CACL) further underscored that supporting "real autonomy" in informed consent to physician-assisted death requires facilitating consideration of "alternative courses of action." CACL highlighted that this exploration of alternatives must take into account the social and economic conditions of vulnerability that place some people at risk of being induced to commit suicide in times of weakness.

The Catholic Health Alliance emphasized that informed consent should be understood as an "evolving process," one that must develop over time "and through dialogue between the patient and many

<sup>&</sup>lt;sup>170</sup> Carter BCSC at para. 207.

providers." The submission from the Canadian Federation of Catholic Physicians' Societies echoed this approach, describing informed consent as "more of a process than an event, evolving over time, mirroring maturation of the patient-physician relationship ... where the risks and benefits of a proposed intervention can be shared in a meaningful way."

The Canadian Society of Palliative Care Physicians, among others, raised concerns about who may provide consent for physician-assisted dying. It suggested that a surrogate should never be permitted to consent for such a procedure—that only the individual requesting assisted death can provide the appropriate consent. This is consistent with the conditions specified by the Supreme Court in *Carter*.

To ensure consistent application of informed consent, it may be important to identify the specific information that must be provided to individuals requesting physician-assisted dying. Some jurisdictions set out in legislation the type of information that must be provided. Legislation in Québec, for instance, requires that physicians inform individuals about the prognosis of their illness and about therapeutic options and their likely effects. The common types of information required in Vermont, Washington and Oregon include medical diagnosis, prognosis, life expectancy, the range and likely effects of treatment options (including palliative, hospice and comfort care, pain control, etc.), the specific risks associated with assisted-dying procedures, and the individual's right to revoke a request at any time.

Many of the assessments detailed in previous sections, such as medical opinions and discussions with allied health professionals would form part of a person's informed consent. Not included in other jurisdictions, but raised for consideration during the Panel's consultations, was whether individuals requesting physician-assisted death should be advised about other interventions, such as assistive technology, and income, disability, respite and home supports.

### D. Timelines

The notion of a waiting period is a procedural safeguard that aims to guarantee the enduring nature of a request for a physician-assisted death. It tries to ensure that the request is not impulsive, transient, or made at a particularly difficult moment. Many groups agreed that there should be a waiting period, <sup>172</sup> thus implying a requirement for more than one request. Opinions varied as to whether this waiting period should be prescribed by law or left to physicians' judgment, and whether it should be proportionate to an individual's prognosis.

The concern that most groups expressed with a mandatory waiting period is that a specific, prescribed duration could be arbitrary. A period that is too short might facilitate access for individuals who might have changed their minds given more time. In some cases, however, a mandatory waiting period—even

<sup>&</sup>lt;sup>171</sup> An Act respecting end-of-life care, R.S.Q. c. S-32.0001, s. 29(1)(b).

<sup>&</sup>lt;sup>172</sup> See for example Dr. Douglas A. Grant, President, Federation of Medical Regulatory Authorities of Canada and Registrar, College of Physicians and Surgeons of Nova Scotia and College of Physicians and Surgeons of Ontario, 6 November 2015; Canadian Medical Association, 20 October 2015; Canadian Association for Spiritual Care, 5 November 2015; Evangelical Fellowship of Canada, 5 November 2015; Physicians' Alliance against Euthanasia, 23 October 2015.

if relatively short—could still be too long, deny autonomy and unnecessarily prolong suffering. <sup>173</sup> This could be especially true in cases when suffering is great and death appears imminent.

## 1. Fixed vs. Flexible Waiting Periods

A few groups were in favour of a longer, fixed waiting period. The Canadian Federation of Catholic Physicians' Societies argued that a 15-day waiting period is too short. It noted that life-changing diagnoses can take months to accept. The Canadian Psychiatric Association suggested that when requests come from individuals with a mental illness, a minimum of six weeks should elapse between assessments, and reasonable treatment options should be pursued during this time.

Most groups were of the view that a certain degree of flexibility in the waiting period is necessary. <sup>174</sup> The British Columbia Civil Liberties Association and Mr. Howard Shapray were of the view that no mandatory waiting period should be legislated. Similarly, the Canadian Civil Liberties Association (CCLA) did not see a mandatory waiting period as a meaningful safeguard. If one were legislated, the CCLA argued, exceptions should be available for individuals whose conditions are rapidly deteriorating. The CCLA expressed concerns that waiting periods would impede access.

The Canadian HIV/AIDS Legal Network advised against a fixed waiting period, particularly a long one, as it could unjustifiably extend some individuals' suffering. The Network noted that even a proportionate waiting period, meaning one that would vary according to an individual's prognosis, may not be appropriate. For instance, the Network advised against requiring that someone with a non-terminal illness endure suffering for a year before their request can be considered. While recognizing that it may not be a perfect solution, the Network suggested leaving the determination of the waiting period to the physician, in the context of the therapeutic relationship.

David Baker and Rebecca Lauks, disability rights lawyers in private practice, called for a "short-term infringement of autonomy" for individuals who have recently acquired a disability so that they have time to come to terms with their new circumstances. This, they argued, would help protect potentially vulnerable people from opting for physician-assisted death when their psychological suffering may be transient. Mr. Baker and Ms. Lauks did not suggest how much longer such individuals might have to wait before their requests can be considered.

## 2. Relying on the Physician's Clinical Judgment

The issue of a waiting period also arose in the Panel's discussions with medical regulators and medical authorities. Dr. Douglas Grant, President of the Federation of Medical Regulatory Authorities of Canada and Registrar of the College of Physicians and Surgeons of Nova Scotia, indicated that he does not

<sup>&</sup>lt;sup>173</sup> In an online submission from a person who described their situation as being "severely disabled, in pain, and suffer[ing] miserably," the individual argued that a cooling off period is not necessary, and that a physician can accurately assess their state of mind.

<sup>&</sup>lt;sup>174</sup> A physician indicated in an online submission to the Panel that "[a] waiting period of some two weeks may provide an additional margin of safety but should be waived in cases of extreme suffering."

foresee mandating a specific waiting period. Instead, he suggested intervals "informed by a reasonableness standard in contemplation of the situation of the patient."

The Canadian Medical Association (CMA) argued that a single standard waiting period is not appropriate in all cases, and called for periods proportionate to an individual's prognosis. The CMA generally recommended a 14-day waiting period between requests. The CMA did not suggest this as a hard and fast rule, but rather as a guideline that could be modified according to the physician's clinical judgment.

The Canadian Society of Palliative Care Physicians proposed a waiting period proportionate to a person's life expectancy. The Society noted that most requests for physician-assisted death are not emergencies and that the typical two-week period is arbitrary and may be too short, or too long, in some cases. The Society advocates adopting a degree of clinical judgment because situations will vary; some individuals will have already given the decision much thought before expressing their first request, while others might seek physician-assisted death as a reflexive response to a diagnosis or change in circumstances.

# Chapter 10. Determination of Requests

As earlier sections of this report have demonstrated, there are many specific decision points in the process of physician-assisted dying. Once a person decides initially to make a formal request—a decision that person will be expected to confirm or reconsider at various stages in the process—multiple other decisions and judgments might follow, such as whether the person:

- is an adult
- has a grievous and irremediable medical condition
- has enduring, intolerable suffering caused by the medical condition
- has the capacity to make a request for assisted death
- is fully informed of the diagnosis, prognosis, treatment options and supports, the likely outcome
  of the physician-assisted death procedure or other matters specified in the regulatory
  framework
- clearly consents without coercion, undue influence or inducement

These, of course, are all smaller but significant decisions along the way toward the ultimate determination of whether or not a person's request for an assisted death will be fulfilled. The Panel understands that there may be other decision points not included on this list, depending upon any regulatory structure that may be adopted by provincial, territorial, and federal legislators. For example, a decision about whether a person meets the residency requirements may be added. The above list, however, captures the basic set of incremental decisions required to comply with *Carter*.

Earlier sections of this report discussed each of these decision processes individually, and have identified questions that will be asked and answered as the *Carter* judgment is implemented. How will adult be defined? Can intolerable suffering be understood as a subjective decision to be made only by the individual requesting physician-assisted death? Who will decide whether a condition is grievous and irremediable?

This chapter describes the answers that interveners, stakeholders, medical authorities and individuals provided to questions about how and by whom the final decision will be made to provide physician-assisted death.

In the Panel's meetings with stakeholders and experts, opinions diverged most dramatically on the issue of who may decide whether to grant an individual's request for physician-assisted death. Groups most strongly guided by the principles of individual autonomy and patients' rights felt strongly that the decision should be made jointly and exclusively by the physician and the individual seeking physician-assisted dying. Groups that emphasized the protection of vulnerable persons proposed a variety of more formal decision-making processes, many involving judges, tribunals or external panels to determine whether legal criteria are met.

Many of the *Carter* interveners, as well as some stakeholders who contributed to the Panel's consultations, argued that an important protection for potentially vulnerable people is to have an

objective decision maker or decision-making body review requests for physician-assisted death before a physician may grant it. The most important argument in favour of this position is that physician-assisted dying is irreversible; there is no way to remedy an error after an individual dies. Other supporting arguments included: protecting physicians from prosecution for wrongful determinations; resolving potential conflicts when a physician does not support a request; and relieving physicians of the burden of moral and social responsibility that may accompany physician-assisted dying.

Other interveners and stakeholders strenuously opposed the idea of prior authorization or review by any formal decision-making body as an unreasonable barrier to access. Some of these groups cited previous Supreme Court of Canada jurisprudence in *R. v. Morgentaler*. <sup>175</sup> In *Morgentaler*, the Court held that the abortion provisions in the *Criminal Code* violated women's rights to security of the person under section 7 of the Charter. Central to the decision was the issue of delays inherent in the therapeutic abortion committee process established under the *Criminal Code*. Professor Jocelyn Downie and others have argued that the *Morgentaler* precedent suggests that panels and other external decision makers would create unreasonable barriers to access. In her opinion, the Supreme Court would likely find that administrative delays imposed by a requirement for prior authorization impinge on eligible individuals' right to security of the person.

Outlined below is a brief review of the submissions received by the Panel with regard to the final determination of requests for assisted death in Canada.

#### A. Prior Judicial Authorization

The Association for Reformed Political Action (ARPA) recommended that judges should authorize requests for physician-assisted dying before a physician can proceed. The Association suggested that a superior court judge must screen for misdiagnosis and must determine the severity of the individual's condition, their capacity to consent, the voluntariness of their decision and whether the person requesting physician-assisted death is an adult. ARPA argued that such prior authorization must be granted by a judge and not a tribunal because tribunals may become politicized and therefore biased.

The Euthanasia Prevention Coalition-B.C. also argued that physician-assisted dying should proceed only with a court order, as this would be the best way to promote transparency and to avoid oversight by an "ad hoc pair of physicians ... who report their actions in a potentially self-justifying and self-exculpatory way after the event." The organization dismissed the view that judicial authorization could result in unreasonable delays by saying that the number of individuals who seek physician-assisted dying is expected to be small, although the issue of existing court caseloads was not addressed. The Euthanasia Prevention Coalition [Canada] agreed that there should be judicial oversight, arguing that "[e]uthanasia is a public act... for which condemnation has been deemed appropriate" and that absent judicial authorization, it will be "impossible to, number one, maintain the public nature of the act, and number two, to effectively enforce ... regulation."

<sup>175</sup> Morgentaler.	<del></del>	
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The Christian Legal Fellowship argued in favour of prior judicial authorization as a means of protecting physicians. The Fellowship noted that because physicians could face murder charges, they should have a court's authorization as a form of legal protection. The Evangelical Fellowship of Canada recommended "judicial warrants" analogous to warrants authorizing search and seizure to "safeguard the patient, the physician, and the medical system" and to ensure appropriate scrutiny. The Christian Medical and Dental Society of Canada called for judicial authorization because physicians may show a bias in granting requests, particularly requests from individuals with whom they have had a long relationship. The Society argued that a judge would perform an unbiased evaluation. The Physicians' Alliance against Euthanasia proposed prior judicial authorization as a means of verifying individuals' competence and the voluntariness of their requests.

#### B. Prior Authorization by Administrative Tribunal

Administrative tribunals differ from courts. Although they often perform an adjudicative role, tribunals are arm's length decision-making bodies created through legislation to administer a particular Act or policy. They tend to be less formal than courts and may have more flexible procedures. Some examples include human rights tribunals and municipal boards. Some groups that appeared before the Panel suggested that rather than having a court decide whether an individual may access physician-assisted death, a tribunal could hear such requests. Many tribunals are composed of members with specific expertise.

Some groups that proposed prior authorization by an independent decision maker had not settled on a recommendation for a particular type of adjudicative body, but appeared to favour one over the other. For example, the Council of Canadians with Disabilities in its submission called for a judge or an "administrative law panel" [i.e. a tribunal] to decide on requests for physician-assisted dying, but in its meeting with the Panel, emphasized the tribunal. It called for the establishment through legislation of a body to hear requests on physician-assisted dying. As a model, the CCD pointed to Ontario's Consent and Capacity Board, a tribunal composed of lawyers, psychiatrists and members of the public, which hears matters arising from several of Ontario's healthcare statutes. <sup>176</sup> The Council further suggested that the body should "have the power to subpoena witnesses and request further information as necessary to reach a reasoned and fully informed decision."

David Baker and Rebecca Lauks, disability rights lawyers in private practice who presented draft legislation for physician-assisted dying to the Panel, proposed that determinations be made by Review Boards, established in each jurisdiction in Canada pursuant to section 672.38 of the *Criminal Code*. Mr. Baker reasoned that a system of prior review would respect and encourage the involvement of the physician who knows the person best, would ensure that a person's choice to die is based on accurate and complete information, and would be "rights enhancing" in the sense of assuring that the person's right to available treatment and support has been honoured. In response to the suggestion that a process of this nature might be onerous, Mr. Baker responded that the process could be very informal,

<sup>&</sup>lt;sup>176</sup> Government of Ontario, "About Us," Consent and Capacity Board.

noting that Review Boards in Ontario "go to hospitals, go to where people are, and meet them on their own turf... they are not cloistered away in some remote location which is unapproachable."

While acknowledging Mr. Baker's reasoning that the constitutionality of these Boards has been tested with respect to their current role, and that this role could potentially be adapted, the Panel also recognizes that the role that Mr. Baker and Ms. Lauks envision would represent a significant departure from the Review Boards' existing and highly specialized mandate. At present, these Boards serve to determine the status of individuals found to be "not criminally responsible or unfit to stand trial for criminal offences on account of a mental disorder." <sup>177</sup>

# C. Physician-Assisted Dying Panel

Some groups that proposed prior authorization focused more on the need for a variety of perspectives and checks and balances than the formal procedural requirements that are currently in place at a court or tribunal. The Canadian Association of Community Living (CACL) proposed that all requests for physician-assisted death be decided by an independent review panel. Panels could, the CACL argued, operate flexibly and yet could pull together expertise from a variety of fields. Although the CACL made reference to Ontario's Consent and Capacity Board as an example of a specialized decision-making body, it did not emphasize a need for the formal procedural requirements typically associated with courts and tribunals. The CACL cited international law and Canada's obligations pursuant to the *Convention on the Rights of Persons with Disabilities* in support of its submission that prior review is necessary to protect potentially vulnerable people.

The CACL's submission stressed that the process "should not be onerous where it is not warranted," insisting that the review should be extremely sensitive and adaptive given the need for timely decisions. It noted that there could be provision for an expedited process whenever appropriate.

The Canadian Psychiatric Association recommends that physician-assisted dying panels be established to decide whether a request for assisted dying should be fulfilled. The Association suggested that such panels would help protect the therapeutic alliance between the individual and a clinician by eliminating any obligation on the clinician to decide whether the individual meets eligibility criteria. The Association emphasized that decisions about physician-assisted death "should not be based on a single assessment, but rather on multiple assessments by different experts." Speaking on behalf of the Association, Dr. Sonu Gaind identified two major benefits of such an approach: "It mitigates the risk of there not being the proper expertise pulled into the decision-making process. It also separates the decision making process from the clinical care." In Dr. Gaind's opinion, there would be no reason for concern about lack of access provided that responsibility for delivery was regionally distributed, and did not fall to individual institutions to implement.

Mr. Marc Doucet, President of the Canadian Association for Spiritual Care, also described for the Panel a model involving "a panel of two or three people," perhaps including a physician but not one involved in the direct medical care of the person making the request. He reasoned that "an arm's distance

<sup>&</sup>lt;sup>177</sup> Government of Ontario, "About Us," Consent and Capacity Board.

evaluation" would provide some measure of "consistency across each decision," and guard against situations where a physician's "dual relationships" of responsibility and accountability to a patient or a community might compromise the decision-making role.

# D. A Decision between Individuals and their Physicians

The British Columbia Civil Liberties Association (BCCLA) expressed the view that there should be "no barriers erected to qualifying individuals accessing physician-assisted dying," stressing that such barriers might be deemed unconstitutional. The BCCLA argued that "physician-assisted dying should be considered a private matter between physician and patient, like all other treatment decisions at the end of life or otherwise."

The Disability Advisory Council of Dying with Dignity Canada's position appears to accord with the BCCLA perspective:

It is essential that any measures taken to protect the individuals with disabilities do not create barriers to physician assisted dying for people who are suffering from grievous and irremediable medical conditions, who are rational and who request physician assisted dying. We are most concerned about the various ways in which this soon to be allowable element of medical care may be withheld.

Thomas Foreman, Joshua Landry and Michael Kekewich, ethicists from the Champlain Centre for Health Care Ethics at the Ottawa Hospital, also argued against creating barriers that impede access to physician-assisted dying. They argued that because no prior authorization is required for withholding or withdrawing life-sustaining treatment, no such authorization should be required for physician-assisted dying.

Most of the physicians' professional organizations and regulatory bodies that addressed decision making also argued that decisions should be made by individuals and physicians, not by an external body. For example, Dr. Francine Lemire, Executive Director of the College of Family Physicians of Canada, expressed reservations about an external review process. She told the Panel that she "would favour an approach whereby we can feel more than reasonably comfortable that all the appropriate steps will have been followed by providers in the journey, without needing that tribunal." She reasoned that an external panel might have a depersonalizing effect, tending to "interfere, impact, bring rules and regulation in a journey that is part of a process, a process of life."

During the Panel's meeting with the medical regulators, including almost every provincial and territorial college of physicians and surgeons as well as their national organization, the Federation of Medical Regulatory Associations of Canada (FMRAC), there was little support for the idea of prior authorization. The only college to express support was the Prince Edward Island College, on the basis that a panel could expedite requests for physician-assisted dying by facilitating access to any necessary assessments:

So to have access to a system whereby you can actually get access to a psychiatric consultation instead of waiting six months or to a social worker if you're not sure where there's undue

influence, even to get the information together for an individual physician would not happen. If the system is set up such that the information is gathered, the medical information comes from a physician but there's often more social information that's required that it just would be unavailable to a sole practitioner.

The Saskatchewan College expressed the view that some sort of review body may be beneficial in accessing "the quick consult from the psychiatrist, or to have the social worker able to come and assist" in cases where an individual's capacity is in question. It might also provide a recourse for individuals whose requests for physician-assisted dying were denied. The College emphasised that any review should be conducted after requests are fulfilled; it expressed concern that prior authorization would create a "degradation of the doctor-patient relationship" and a barrier to access.

The New Brunswick College argued that prior authorization "was exactly the kind of thing that was considered unconstitutional in *Morgentaler*, having to go through some committee to decide whether you can have an abortion. I can't see how this is any different." The College of Family Physicians of Canada also likened the idea of prior authorization to the former abortion regime challenged in *Morgentaler*, as did the Association québécoise pour le droit de mourir dans la dignité. The Association argued that any prior authorization process would unreasonably prolong a decision that affects "a single patient at a very particular precise moment in their life." The Ontario College also rejected prior authorization, as did the Manitoba College, noting that any such process would likely be intimidating and cumbersome in comparison with the end-of-life conversations that individuals should have with their physicians.

Dr. Douglas Grant, President of FMRAC and Registrar of the Nova Scotia College of Physicians and Surgeons stated that although his college supports retrospective review, it is not in favour of prospective oversight. He first stated that prior authorization would impede access, then argued that physicians' ability to make decisions about capacity and the appropriateness of treatment formed the "entire backbone of the *Carter* decision." He expressed great concern that the implementation of a prospective process has the potential to undermine confidence in physicians' ability to make these determinations and to "eat at the fabric of what [he thinks] is the essence of medicine."

Some allied health care professionals also weighed in on the issue. The Canadian Pharmacists Association expressed the view that prior authorization by a judge or tribunal would not be necessary to protect its members' interests, arguing instead for clear delineation of pharmacists' liability.

# Chapter 11. Participation and Compliance

Not all physicians will be willing or able to provide assisted death. Those who are may need adequate training. Physicians need clear protections to ensure that they will not suffer professional repercussions from participating or refusing to participate in assisted death. Further, all health care providers who choose to participate in assisted dying in accordance with the *Carter* decision and do so in good faith need assurance that they will not be subject to criminal prosecution. This section outlines these considerations and reviews the main points the Panel heard in the course of its consultations.

#### A. Conscience Protection

#### 1. Physicians' Conscientious Objection

Section 2(a) of the *Canadian Charter of Rights and Freedoms* guarantees the fundamental freedom of conscience and religion. In the *Carter* decision, the Supreme Court confirmed that physicians cannot be forced to provide assistance to an individual who is seeking assistance to die. The Court held:

In our view, nothing in the declaration of invalidity which we propose to issue would compel physicians to provide assistance in dying. The declaration simply renders the criminal prohibition invalid.<sup>178</sup>

The Panel's consultations revealed that the medical profession is divided over the issue of physician-assisted dying. While some physicians consider it an ethical imperative to provide assistance in dying if an individual with a grievous and irremediable medical condition wishes to end their intolerable suffering, others feel that it is fundamentally incompatible with a physician's role in, and commitment to, the practice of medicine. Many stakeholders emphasized that the wide range of clinical, religious, ethical, and personal values held by physicians and other health care professionals (e.g. nurses and pharmacists) will lead some to conscientiously object to directly participating in assisted death. Physicians build relationships of trust with their patients. Consequently, some physicians believe that allowing physicians to facilitate or cause the death of a patient could erode this trust and affect perceptions of physicians' role in, and commitment to, caring for individuals regardless of medical condition.

A related topic is the duty of physicians to refer an individual to another physician or to inform the individual about how to access assisted dying services. Many groups maintained that physicians should provide the individuals who request assisted dying with referrals. Conversely, many others noted that the act of providing a referral or information amounts to complicity, and that physicians should be free from any such obligation. In a written submission to the Panel, Dr. Michael Eleff, a psychiatrist from the University of Manitoba, stated:

<sup>178</sup> Carter at pard	a. 132.

I do not see it as appropriate to compel a physician to refer a patient requesting this procedure to a colleague who is not opposed to participating. ... A mechanism of referral through the provincial Colleges, which might be invited to maintain a voluntary registry, would be less troubling. Essentially, this provides a mechanism for self-referral.

Some groups, such as a network of British Columbia physicians, also proposed that in order to ensure that access to physician-assisted dying is not limited as a result of conscientious objections, physicians should be required only to provide information.

Dr. Linda Ganzini, a psychiatrist and researcher in Oregon, suggested that psychiatrists who oppose physician-assisted dying not be allowed to evaluate individuals making such a request, because their moral beliefs could influence their assessment of an individual's eligibility.

Despite the diversity of approaches, stakeholders were unified in the view that physicians and other health care professionals' conscience rights must be respected and that those who choose not to participate must not face negative repercussions. A number of stakeholders argued that conscience rights are an important safeguard that insulates the medical profession from coercion that could lead to moral distress and burnout. It is important to note that the provincial and territorial colleges of physicians and surgeons establish specific protocols governing conscientious objection.

The Canadian Medical Association (CMA) emphasized that physicians who choose not to participate in assisted dying must not face discrimination. To balance these rights with eligible individuals' need to access physician-assisted dying, the CMA suggested that physicians should be expected to provide individuals with complete information on all options available to them, including physician-assisted dying, and advice on how to access "separate central information, counselling and referral service." Mr. Larry Worthen of the Christian Medical and Dental Society of Canada told the Panel that his organization had made a similar proposal to the CMA and added that many physicians would feel less personally implicated if a self-referral service were available.

The Canadian Pharmacists Association recommended that there be a mechanism allowing an objecting pharmacist to refer to a colleague. The Canadian Nurses Association (CNA) made a similar suggestion and stressed the need to avoid abandoning individuals in the event of a conscientious objection. According to CNA's code of ethics, nurses who conscientiously object must continue to provide care while alternate arrangements are made. The CNA further specified that in the event of an objection, it is essential that the individual receive information about how to pursue physician-assisted dying.

Many groups suggested that robust protection be provided to those who decline to support or participate in physician-assisted dying. Mr. Sean Murphy of the Protection of Conscience Project, for example, suggested procedures to ensure that physicians are not compelled to participate in assisted dying during emergency situations. He also suggested that a physician who agrees to help an individual end their life by prescribing a lethal dose of medication that an individual would self-administer must also be willing to inject the lethal medication should complications arise, to ensure that the obligation would not fall on a colleague who may have a conscientious objection.

The medical regulatory bodies expressed a range of views on the matter. The Collège des médecins du Québec described the process outlined in Québec's provincial legislation, *An Act respecting end-of-life care*. The law requires that an objecting physician ensure the continuity of care to the individual. In addition, a physician who objects must forward the request to the relevant director general, who is then responsible for finding a willing physician.<sup>179</sup>

The College of Physicians and Surgeons of Ontario took the position that physicians who object to physician-assisted dying requests have a positive obligation to make an effective referral. An effective referral, as described by the Ontario College, is a referral made in good faith to a non-objecting available and accessible physician, other health care professional, or agency. The College noted that the medical community has an obligation to ensure access and that conscientious objection should not create barriers. The College of Physicians and Surgeons of Saskatchewan suggested that when an objection to a procedure is made, the physician must provide the individual with the appropriate information regarding an agency that they may contact for advice. The College of Physicians and Surgeons of Manitoba agreed that while physicians who conscientiously object should not be required to provide a referral, they should have an obligation to provide timely access to another person or resource that will provide accurate information about physician-assisted dying.

Dr. Monica Branigan of the Canadian Society of Palliative Care Physicians highlighted how valuable a separate parallel access process could be to palliative care physicians and facilities. She noted that a separate system would not only serve professionals with a conscientious objection, but also reinforce the separation between physician-assisted dying and palliative care. She stressed that links between physician-assisted dying and palliative care should be avoided for the following reasons:

Palliative care providers have spent decades trying to reduce the fear around palliative care. Many equate palliative care with death and harbour concerns that our medications and our care will shorten their live. We must reassure our patients that the pain medications we prescribe won't harm them. Equating hastened death with palliative care will destroy the [hard work we have done] to help patients and families accept our help at the end of life.

The Catholic Civil Rights League (CCRL) noted that some medical professionals consider it objectionable to even make a referral for physician-assisted dying. The CCRL added that requiring physicians and medical students to participate in referral and training regimes for physician-assisted dying could result in the "moral erosion" of the medical profession. On the other hand, Dr. Kevin Imrie of the Royal College of Physicians and Surgeons noted that physicians, regardless of conscience, have a professional responsibility to learn about physician-assisted dying so they may provide individuals with relevant and accurate information.

Dr. John Soles, President of the Society of Rural Physicians of Canada, raised some important considerations regarding rural and remote communities. Due to the limited number of physicians in such areas, he questioned whether it was fair to require individuals to travel great distances to inquire about and receive such services, and whether it was reasonable to require physicians to travel great distances to provide such services. In light of the unique challenges rural communities will face, Dr. Soles

<sup>&</sup>lt;sup>179</sup> An Act respecting end-of-life care, R.S.Q. c. S-32.0001, s. 30.

raised questions that will require consideration when establishing Canada's physician-assisted dying framework. He asked:

if nobody in the community wishes to participate in this process, then what do you do? Do you have somebody come in to have a discussion with the patient? Do you send a patient who's presumably unwell... to some distant place to have that consultation?

The Canadian Unitarian Council echoed concerns about access issues if physicians in remote communities opt out due to conscientious objection. The Council proposed a web platform enabling physicians to see and assess individuals as a way to alleviate access challenges in remote communities.

## 2. Institutional Objection

A number of groups suggested that institutions as a whole should be permitted to conscientiously object to providing physician-assisted dying services. The Euthanasia Prevention Coalition stressed that some health care facilities—for example hospices, long-term care facilities, and faith-based organizations—should be "safe places" and "places of trust" where individuals and their families can be certain that physician-assisted dying will not be raised as an option. Mr. Michael Kekewich, an ethics consultant for the Ottawa Hospital, echoed the sentiment that hospices may not want to engage in physician-assisted dying because it could create confusion about the roles of hospice and palliative care. Mr. Michael Shae of the Catholic Health Alliance of Canada noted that since physician-assisted dying is a direct contradiction of the institutional values and missions of Catholic health organizations, many will not participate in the practice in any form.

The British Columbia Civil Liberties Association argued that public hospitals and clinics are so integral to the health care system that they should not be permitted to conscientiously object. Dying with Dignity Canada made a similar observation: that institutional objections could severely limit access to assisted dying, particularly for individuals who reside in areas with limited health care facilities.

Mr. Jean-Pierre Ménard, Chair of the committee of legal experts Québec tasked with recommending legislative options for implementing medical aid in dying in the province, flagged a challenge that arose as a result of institutional objections. Section 8 of Québec's *Act respecting end-of-life care* requires that "every institution must offer end-of-life care," which includes medical aid in dying. Section 65 of the Act permits palliative care facilities to opt out of this requirement if they offer palliative care exclusively. He noted that as a result of this exception, all palliative care hospices in Québec stated that they would not offer medical aid in dying. He suggested that this is problematic because as public institutions, they should not be allowed to object. In the meantime, a palliative care facility in Québec—Maison Aube-Lumière—has publicly stated it will offer such services. 182

<sup>&</sup>lt;sup>180</sup> An Act respecting end-of-life care, R.S.Q. c. S-32.0001, s. 8.

<sup>&</sup>lt;sup>181</sup> Ibid., s. 65.

<sup>&</sup>lt;sup>182</sup> Kate McKenna, "<u>Doctor-assisted suicide gets green light from Sherbrooke palliative care centre</u>," *CBC News*, 3 November 2015.

Institutional objection is permitted in Oregon<sup>183</sup> and Washington.<sup>184</sup> Laws in both states permit institutions to prohibit a health care provider (a health care professional or a body within the institution, such as a pharmacy or clinic) from providing medication for the purpose of ending an individual's life on the institution's premises. Vermont also permits health care facilities to prohibit a physician from writing a prescription for a person who resides in the facility and intends to use the medication on the facility's premises.<sup>185</sup>

## B. Training and Licensing

The two bodies primarily responsible for establishing standards for physician training in Canada are the College of Family Physicians of Canada and the Royal College of Physicians and Surgeons of Canada. The College of Family Physicians is responsible for family doctors' training standards, and the Royal College is responsible for specialists' standards.

# 1. Training

Following its discussions with the College of Family Physicians of Canada and the Royal College of Physicians and Surgeons of Canada, the Canadian Medical Association (CMA) has agreed to take the lead in establishing training materials for physicians to learn how to perform physician-assisted dying. According to the organization, general practitioners could perform physician-assisted dying because they already possess the required basic skills, although further training may be required. The CMA is not, however, adopting the position that specific accreditation is necessary.

The CMA noted that physicians would have to elect to train for physician-assisted dying and that, as in the Dutch model, ongoing education and follow-up would be provided. The training would cover not only the technical elements of physician-assisted dying, but also matters of consent.

The College of Family Physicians of Canada (CFPC) identified the competencies it plans to ensure are developed. Specifically, it noted that many individuals seeking assisted dying often raise concerns about loss of dignity. The CFPC said it would ensure that family doctors would discuss options for enhancing dignity through appropriate supports. The CFPC said it must remain cognizant of the scope of its responsibility in providing care to a patient. It also committed to ensuring that the:

skills and knowledge training for all aspects of this clinical role—communications, evaluation of the patient making the request, shared decision making where appropriate, prescribing, support for family members, among many others—are delivered and reinforced in residency training and continuing professional development.

<sup>&</sup>lt;sup>183</sup> Oregon Death with Dignity Act, O.R.S. c. 127.885, § 4.01(5)(a).

<sup>&</sup>lt;sup>184</sup> Washington Death with Dignity Act, R.C.W. c. 70.245, § 70.245.190(2)(a).

<sup>&</sup>lt;sup>185</sup> Patient Choice at End of Life, Sec. 1, 18 V.S.A. c. 113, §5286.

The CFPC noted that while it believes that discussions about physician-assisted dying must be part of the core residency curriculum of family physicians, it has yet to determine whether the administration of physician-assisted dying will be part of the core curriculum.

The Royal College of Physicians and Surgeons of Canada told the Panel that it supports the CMA position that some additional training is needed, along with some confirmation that this training has been completed. Further, it noted that such training should be developed in consultation with the CMA and the CFPC to ensure that training for family and specialist physicians is consistent.

#### 2. Licensing

Some of the interveners in *Carter* argued that only physicians with federal licences created under the *Criminal Code* should be permitted to perform physician-assisted dying. The Association for Reformed Political Action (ARPA) was one such group, arguing that:

doctors would need to be licensed in order to make sure that they know the legislative regime, that they know all of the other options out there, like palliative care options, the proper system to ensure consent is found, to make sure that the entire process is properly recorded for verifying consent later on, and so on and so forth.

ARPA did not speculate on how federal licensure for physician-assisted dying might interact with the existing jurisdictional framework, in which the provinces and territories are responsible for licensing professionals, including physicians.

The Physicians' Alliance against Euthanasia also advocated licensure for physician-assisted dying, comparing it with authority to prescribe methadone and medical marihuana. To prescribe methadone, physicians must be exempted under section 56 of the *Controlled Drugs and Substances Act*, and often need the support of their licensing body. <sup>186</sup> The Catholic Health Alliance of Canada and the Evangelical Fellowship of Canada also recommended federal licensure. The Christian Medical and Dental Society of Canada recommended licensure, but did not specify which level of government should take on this responsibility.

#### C. Violations and Penalties

Almost without exception, individuals and groups that appeared before the Panel reiterated the need identified in *Carter* for a system of safeguards to protect vulnerable individuals. As detailed in the earlier sections of this report, many who appeared before the Panel suggested specific safeguards, but few indicated what consequences, if any, should follow if such safeguards are not respected.

Ensuring compliance with procedural safeguards is an important safeguard in and of itself. Safeguards could potentially be meaningless unless compliance is ensured. Most of the compliance obligations will

<sup>&</sup>lt;sup>186</sup> Health Canada, *Methadone Program*.

fall to physicians, and the Panel recognizes that measures must also be taken to protect physicians who comply with the law. These protections are discussed in the following section.

It is also important to distinguish between criminal offences and penalties on the one hand, and professional discipline on the other. The Panel heard in Belgium in particular, as well as in the Netherlands and Oregon, that minor instances of regulatory noncompliance likely do not justify criminal sanctions. Each of Belgium, the Netherlands and Oregon have oversight and monitoring mechanisms in place, but never—until very recently in Belgium—had a case in any of these jurisdictions been referred to a prosecution service. This is not because every assisted death complied with regulations, but rather because minor instances of noncompliance were addressed by professional regulatory bodies. The Christian Medical and Dental Society of Canada proposed that instances of professional misconduct should lead to licence revocation and that physicians should be held criminally responsible if they fail to comply with procedural safeguards.

In Oregon, the Panel heard from Dr. Peter Reagan, a physician and member of the board of Compassion and Choices. He described some examples of minor noncompliance, such as not waiting 14 days to administer assisted dying, and discrepancies between the date of a witness signature and the date of the signature of the individual who obtained assisted death. These examples would not lead to criminal charges, but instead would be referred to Oregon's Board of Medical Examiners. The Panel heard similar reports during a subsequent teleconference with Katrina Hedberg, State Epidemiologist for Oregon.

Media reports suggest that a Belgian case that was referred to prosecution involved more than a minor administrative irregularity. The case involved a physician who assisted in the death of an 85-year-old woman who allegedly had not met the eligibility criteria. The woman was suffering from grief following the death of her daughter three months earlier.

The Panel met with two lawyers who have separately prepared model legislation to respond to *Carter*. Although the two model bills diverge considerably with respect to procedural safeguards, they include similar offences and penalties for failing to comply with safeguards. Professor Jocelyn Downie told the Panel that she published her model bill soon after the *Carter* decision to demonstrate how *Carter* might be implemented easily and efficiently. Her bill would create offences for failing to comply with procedural safeguards. The bill drafted by David Baker adopted many of the same suggestions for related offences.

In her model legislation, Professor Downie created a number of offences, including the following:

- A person commits an offence if he willfully falsifies or forges a [written request for physician-assisted death] ... with the intent or effect of causing the person's death. A person guilty of an offence under this subsection shall be liable, on conviction, to imprisonment for a term not exceeding twenty-five years.
- 2) A witness commits an offence if he willfully puts his name to a statement he knows to be false. A person guilty of an offence under this subsection shall be liable on conviction to imprisonment for a term not exceeding five years.
- 3) A person commits an offence if he willfully conceals or destroys a [written request for physician-assisted death or a revocation of such a request] ... A person guilty of an offence

<sup>&</sup>lt;sup>187</sup> Graeme Hamilton, "Doctor could face charges for role in euthanasia," Saskatoon Star Phoenix, 29 October 2015.

- under this subsection shall be liable on conviction to imprisonment for a term not exceeding five years.
- 4) An assisting or consulting physician involved in the care of a patient commits an offence if he takes any part whatsoever in assisting a patient to die or in giving an opinion in respect of such a patient, or acts as a witness if he has grounds for believing that he will benefit financially or in any other way as the result of the death of the patient. A person guilty of an offence under this subsection shall be liable on conviction to imprisonment for a term not exceeding five years.

Offences 2 through 4 appeared in slightly different versions in Bill S-225, a Senate public bill tabled in 2014. David Baker adopts all of the above offences in his model legislation. It may be important to note that there are elements of knowledge and intentionality in all of these offences. Terms such as "willfully" and "believing" indicate intentional acts rather than errors or omissions. This is consistent with many other criminal offences.

David Baker adds the following offence, which appears in similar form in the Oregon and Washington legislation:

A person commits an offence if he encourages, coerces or unduly influences a Patient to choose Physician-Assisted Suicide. A person guilty of an offence under this subsection shall be liable, on conviction, to imprisonment for a term not exceeding twenty-five years.

This offence, while not directly related to procedural safeguards, could also act as a safeguard that deters coercion. It is similar to the current section 241(a) of the *Criminal Code*, which prohibits counselling suicide, although the penalty of up to 25 years in prison is significantly greater than the 14-year prison term included in section 241(a).

#### D. Good Faith Compliance Protections

In all U.S. jurisdictions that have enacted legislation regulating assisted dying, there are good faith compliance protections for physicians. Oregon has adopted the following provision:

No person shall be subject to civil or criminal liability or professional disciplinary action for participating in good faith compliance with [this Act]. 189

Washington and California adopted similar provisions. Vermont adopted the following provision, limiting protection to physicians:

A physician shall be immune from any civil or criminal liability or professional disciplinary action for actions performed in good faith compliance. <sup>190</sup>

<sup>&</sup>lt;sup>188</sup> Bill S-225, An Act to amend the Criminal Code (physician-assisted death), 2nd Sess, 41st Parl, 2014.

<sup>&</sup>lt;sup>189</sup> Oregon Death with Dignity Act, O.R.S. c. 127.885, § 4.01(1).

<sup>&</sup>lt;sup>190</sup> Patient Choice at End of Life, Sec. 1, 18 V.S.A. c. 113, §5290.

There are opponents to such protections. The Panel heard from Marilyn Golden, a senior policy analyst with the Disability Rights Education and Defence Fund. She called the Oregon provision deplorable, arguing that it unreasonably insulates physicians:

[I]t makes negligence by doctors legal because it says that no practitioner will be subject to any liability—criminal, civil—if they act in good faith, which is something nearly impossible to disprove, making all the other rules about assisted suicide in the Oregon model unenforceable. Even perhaps more serious, for everything else doctors do, they're liable, at least in the U.S., if they're negligent. But with assisted suicide, even if negligent, practitioners cannot be found violating the law as long as they practice in so-called good faith. So that's a big problem.

Anna MacQuarrie, Director of Global Initiatives, Policy and Human Rights with Inclusion International expressed similar concerns.

Such protections are not unprecedented in Canadian law. For example, the following is a *Criminal Code* provision protecting health care providers who must carry out warrants to collect blood:

No qualified medical practitioner by whom or under whose direction a sample of blood is taken from a person ..., and no qualified technician acting under the direction of a qualified medical practitioner, incurs any criminal or civil liability for anything necessarily done with reasonable care and skill when taking the sample.<sup>191</sup>

Because physician-assisted dying is an exemption to the *Criminal Code* prohibition on assisted suicide, a physician who does not comply with the requirements of the exemption could face a charge of assisting suicide and the associated penalty of up to 14 years in prison. The Saskatchewan College of Physicians and Surgeons raised the question of whether there will be protection for physicians in the context of "legitimate differences in perspective as to whether a patient does or doesn't have certain of the criteria that are determined by *Carter*." The College argued that physicians need assurance that if they comply with the requirements and believe in good faith that their patient met the criteria, they will not face criminal charges.

The Ontario College supported the Saskatchewan College's position, as did the Manitoba College, which noted that physicians deserve to feel comfortable in the procedures they perform and that it would be bad for the public if physicians do not feel this comfort. Dr. Douglas Grant, President of the Federation of Medical Regulatory Authorities of Canada and Registrar of the College of Physicians and Surgeons of Nova Scotia called good faith protections for physicians "really necessary."

The Canadian Nurses Protective Society (CNPS) recommended that a clear exemption be created that explicitly acknowledges that physicians and nurses may discuss physician-assisted dying with patients. This concern arose because of the intact section 241(a) of the *Criminal Code*, which prohibits counselling suicide. The CNPS point out that discussions about physician-assisted dying could arise during an individual's care and that it should be appropriate for a health care professional to be engaged in such discussions, regardless of whether an individual meets the eligibility criteria.

<sup>&</sup>lt;sup>191</sup> Criminal Code, R.S.C. 1985, c. C-46, s. 257(2).

If a provision were enacted that protected good faith compliance, it could nonetheless be accompanied by additional provisions that prohibit willful noncompliance and criminal behaviour. For example, while the Oregon Act protects good faith compliance, it also creates offences related to coercion, altering or forging requests for assisted dying, contemplates "civil damages resulting from other negligent conduct or intentional misconduct by any person" and does not "preclude criminal penalties applicable under other law for conduct which is inconsistent with the provisions" of the Act. 192

As with several other topics addressed in this chapter, if protections are created for physicians, it may be important to consider whether to extend such protections to other health care professionals who may be directly or indirectly involved in physician-assisted death.

#### E. Providers' Concerns over Criminal Offences not Addressed in Carter

To adequately protect physicians who are prepared to provide assisted death, and other health care providers who may participate in the procedure, certain sections of the *Criminal Code* not addressed in *Carter* may warrant scrutiny—specifically, the section prohibiting counselling a person to commit suicide, and the one prohibiting the administration of a noxious thing.

#### 1. Prohibition on Counselling a Person to Commit Suicide

Much of the focus of the *Carter* litigation was on section 241(*b*) of the *Criminal Code*, which prohibits aiding or abetting suicide. Receiving significantly less attention was section 241(*a*), which prohibits counselling a person to commit suicide, and calls for the same maximum penalty of a 14-year prison term as does section 241(*b*). In fact, the Supreme Court in *Carter* held that "section 241(*a*) of the *Criminal Code* does not contribute to the prohibition on assisted suicide." <sup>193</sup>

Although section 241(a) is not as directly relevant as 241(b), the Canadian Nurses Protective Society expressed serious concern to the Panel about section 241(a) in the context of physician-assisted dying. Nurses are often the health care providers who have the most direct contact with patients, and may sit with anxious people late into the night discussing treatment options. The Canadian Nurses Protective Society emphasized that if a person wanted to address the option of assisted dying with a nurse during one of these discussions, such a discussion should not lead to criminal charges for the nurse.

The Supreme Court has held in other contexts that "counselling" is a "deliberate encouragement or active inducement." <sup>194</sup> Although this use of the term "counselling" may differ from its use in a therapeutic context, confusion could persist among health care providers. The Catholic Civil Rights League strongly recommended that these provisions be maintained. However, the Canadian Nurses Protective Society explicitly acknowledged that section 241(a) does not capture therapeutic interactions. The Canadian Nurses Protective Society argued that there could be a chilling effect,

<sup>&</sup>lt;sup>192</sup> *Oregon Death with Dignity Act*, O.R.S. c. 127.885, § 4.02.

<sup>&</sup>lt;sup>193</sup> Carter at para. 20.

<sup>&</sup>lt;sup>194</sup> *R. v. Hamilton*, 2005 SCC 47 at para. 29.

whereby nurses and other health care providers might avoid these discussions out of fear of potential criminal implications.

Nurses and other health care providers engage in a great deal of counselling as part of their therapeutic relationships with patients. They must feel confident that they may discuss any legal treatments that a patient chooses to explore. It may therefore be important to consider whether legislative changes are necessary to protect this aspect of care, while at the same time protecting people who may be vulnerable to coercion or undue influence.

#### 2. Administering a Noxious Thing

Individuals and groups also expressed concerns about section 245:

245. Every one who administers or causes to be administered to any person or causes any person to take poison or any other destructive or noxious thing is guilty of an indictable offence and liable

- (a) to imprisonment for a term not exceeding fourteen years, if he intends thereby to endanger the life of or to cause bodily harm to that person; or
- (b) to imprisonment for a term not exceeding two years, if he intends thereby to aggrieve or annoy that person.

This section was not addressed in *Carter*, but the Catholic Civil Rights League raised it as a matter of potential concern. This section has been applied in the medical context. In 1992, a nurse administered a lethal dose of a substance to a 78 year-old man unable to live without life support to alleviate the man's suffering. The nurse was charged with manslaughter, but pled guilty to the lesser offence of administering a noxious thing. <sup>195</sup> In 1993, a physician who performed a similar act on a 70 year-old woman near death was charged with second-degree murder and also pled guilty to administering a noxious thing. <sup>196</sup> It may therefore be important to consider whether legislative changes are necessary to protect physicians administering assisted dying from prosecution under section 245.

<sup>&</sup>lt;sup>195</sup> R. v. Mataya, unreported, but discussed in R. v. Latimer (1995), 134 Sask.R. 1.

<sup>&</sup>lt;sup>196</sup> R. v. de la Rocha, unreported, but discussed in R. v. Latimer (1995), 134 Sask.R. 1.

# Chapter 12. System Oversight

Almost every group and individual to appear before the Panel agreed about the need for adequate oversight. Advocacy groups, medical regulators, supporters and opponents all recognized that mechanisms must be in place to ensure that physician-assisted dying occurs in a transparent, safe and respectful manner. Dying with Dignity Canada argued that "every single case of assisted dying needs to be reported" and each case should be reviewed after death occurs. It also called for systemic review: "this is a matter of public interest. We need to know what's going on."

# A. Oversight Body

Implementing, administering and overseeing physician-assisted dying, which implicates aspects of criminal law and health care delivery, presents a unique challenge in Canada's federal system. The criminal law falls neatly under federal jurisdiction, but health law is, as the Supreme Court noted in *Carter*, an area of concurrent jurisdiction, with the provinces having jurisdiction over health care delivery. Ensuring that a physician-assisted dying framework operates smoothly and is well monitored will require collaboration between the federal government and the provinces and territories.

#### 1. Existing Models

Many jurisdictions that permit assisted dying have formal oversight mechanisms in place. In three jurisdictions, independent bodies monitor assisted dying. The Netherlands has five regional euthanasia review committees; Belgium has the *Commission fédérale de contrôle et d'évaluation de l'application de la loi sur l'euthanasie*; and Québec has the *Commission sur les soins de fin de vie*. American jurisdictions that have legalized assisted dying task their state departments of health with collecting relevant data.

In the Netherlands and Belgium, legislation mandates the composition of the bodies that review data. In the Netherlands, the committees must be composed as follows:

A committee is composed of an uneven number of members, including at any rate one legal specialist, also chairman, one physician and one expert on ethical or philosophical issues. The committee also contains deputy members of each of the categories listed in the first sentence. 197

The review committees in the Netherlands publish a code of practice, which, according to lawyer and academic Johan Legemaate, summarizes "all of the thousands of verdicts [the committees] have given over the past 12, 13 years, summarizing the main focus points of these committees when looking at the legal criteria for assisted dying." There is also a complete review of the operation of the legislation every five years. While the Panel heard assurances that this committee provides fair and impartial oversight,

<sup>&</sup>lt;sup>197</sup> <u>Termination of Life on Request and Assisted Suicide (Review Procedures) Act</u> (Netherlands), art. 2 C. pen., art. 3(2).

others expressed concern about the implications that the committee had not, to date, forwarded one case for prosecution.

In Belgium, the Commission must include among its 16 members eight physicians, four lawyers, and four members familiar with end-of-life care. As indicated by Belgian Senator Jean-Jacques De Gucht, the Commission must table a report in the legislature every two years that presents statistics on assisted dying, the operation of the legislation and any recommended improvements.

During its discussion with Jean-Pierre Ménard, chair of the committee of legal experts Québec tasked with recommending legislative options to implement medical aid in dying in the province, and Michelle Giroux, a health law advocate, the Panel heard about the commission that will establish standards and monitor the practice of medical aid in dying in Québec. Some aspects of the commission's operation are set out in Québec's *Act respecting end-of-life care*.

## 2. Federal or Provincial Oversight?

Although there was a great deal of support for oversight bodies, there were differing views on whether such oversight could or should be performed at the federal level. In its submission to the Panel, the Canadian Bar Association argued for oversight bodies at the provincial level, likely acknowledging the provinces' jurisdiction over health care delivery. Mr. Howard Shapray, a lawyer in private practice and the husband of assisted-dying advocate Elayne Shapray, also called for data to be gathered and analyzed provincially rather than federally. He did, however, note that data could be "dealt with cooperatively between the provincial and federal authorities."

Dr. James Downar, a palliative care physician and executive member of Dying with Dignity Canada's Physicians Advisory Council, argued for separate oversight bodies:

There are two concepts. The individual case review would have to be provincial. It's going to be plugging into local colleges. If you report a case and there's a problem that's got to be referred locally either to the authorities, the police, or referred to the college for professional ramifications. Both of those operate at the provincial level.

Oversight in terms of population-wide reporting and trends in end-of-life care, looking to the effect on palliative care with the legalization of assisted death, that's something it makes more sense to do federally. I could see that happening at two different levels, the individual case oversight and the general research oversight.

Although the Ontario College of Physicians and Surgeons strongly supported the need for monitoring, it did not take a position on whether this function should be performed at the national or provincial level.

Many groups that proposed an oversight body supported the establishment of a national body, noting the need for consistent data collection across the country. The Canadian Nurses Association was one example:

Health care providers need to have the same access to the same information and resources needed for assisted death treatment. We all need to speak the same language ... a national

oversight body to ensure a uniform standard of care and practice, and to ensure consistency of data monitoring and reporting, is required. In this way, trends and adverse events can be tracked and analyzed. Such an approach would allow physician-assisted death to be evaluated properly, and we can make sure it is being provided in a safe, competent, and ethical manner.

The Canadian Federation of Catholic Physicians' Societies called for a national body, not only for consistency, but also for greater transparency and accountability. The Canadian Civil Liberties Association called for a federal body to set best standards for the delivery of physician-assisted dying and to publish data on how the system operates. It noted that an advantage of a federal body could be avoiding complications related to the restrictions on data sharing set out in provincial privacy legislation.

The Saskatchewan College of Physicians and Surgeons argued for a national body over a provincial one:

If it can be done nationally, I think it's going to be a whole lot better than maybe ... an oversight board in Saskatchewan established by Saskatchewan with its own mandate and maybe there won't be one in Manitoba and there will one in Ontario with a different mandate, which I think just creates that patchwork that we're hoping that we can avoid in some way.

Professor Jocelyn Downie, a health lawyer and academic, also suggested that oversight should be at the national level; in model legislation she published soon after the *Carter* decision was released, she proposed the "Commission to Monitor and Report on Physician-Assisted Dying in Canada." <sup>198</sup> The Commission would consist of a chair and ten other commissioners, among them:

- (1) Two members are to be physicians (one of which must be from the palliative care community)
- (2) One member is to be a nurse
- (3) One member is to be a pharmacist
- (4) Two members are to be health lawyers
- (5) Two members are to be health care ethics experts
- (6) Two members are to be lay members of the public

Former Member of Parliament Steven Fletcher proposed a similar body through a private member's bill. 199

#### 3. Alternate Canadian Models

Aside from Québec's newly created Commission, there are existing bodies in Canada that could serve as models for an oversight body. Dr. Downar of Dying with Dignity Canada suggested that a useful model might be an arm's length corporation, such as Canadian Blood Services "funded separately with a specific public mandate." Professor Jocelyn Downie made a similar suggestion. The Saskatchewan

<sup>&</sup>lt;sup>198</sup> Jocelyn Downie, *Draft Federal Legislation to Amend the Criminal Code to Be Consistent with* Carter v. Canada (Attorney General) *2015 SCC 5* (9 February 2015). Please note that Professor Downie has since updated her model legislation. The Panel's references to her legislation are to the 9 February 2015 version, as this was the version discussed at its meeting with Professor Downie.

<sup>&</sup>lt;sup>199</sup> Bill C-582, An Act to establish the Canadian Commission on Physician-Assisted Death, 2nd Sess, 41st Parl, 2014.

College of Physicians and Surgeons proposed oversight bodies similar to the specialty societies in medicine that provide standards and guidance to specialist physicians.

There were also suggestions that existing federal entities could take on the role of an oversight body. Dr. Downar suggested that Health Canada could do so, provided that it had separate, guaranteed funds, and the Canadian Nurses Protective Society suggested that the Canadian Institute for Health Information could take on this role.

Although some very useful suggestions were made, not all of the existing bodies seemed willing to take on the proposed responsibility. For example, the Panel met with a network of physicians in British Columbia that suggested that the colleges of physicians and surgeons could act as oversight bodies. The colleges did not appear receptive to this idea, however. The Panel heard that some physicians may be hesitant to engage with their college, and so might be less likely to comply with reporting requirements if the colleges perform oversight.

Dr. Douglas Grant, President of the Federation of Medical Regulatory Authorities of Canada and Registrar of the College of Physicians and Surgeons of Nova Scotia noted that he had approached the Nova Scotia Medical Examiner Service about its willingness to play an oversight or monitoring role, but he was not sure whether it would agree. Similarly, the Ontario College approached Ontario's Office of the Chief Coroner, and the Office was not willing to be involved.

# 4. The Role of an Oversight Body

The Panel heard many suggestions about potential roles for an oversight body, with data collection, policy leadership and reporting being the most common. The rest of this chapter addresses several of these issues. Professor Jocelyn Downie outlined the following as mandatory roles for the oversight commission she proposed:

- (a) develop a form that the patient must complete and give to the assisting physician for inclusion in the patient's medical record. This form shall solicit non-identifying information including but not limited to information about the patient including demographics (age, sex, marital status, education level, income level), medical condition, and reasons for seeking assistance;
- (b) collect and analyze data from the submitted forms;
- (c) generate and make available to the public an annual statistical report of information collected under this Act;
- (d) oversee the application of the specific requirements relating to assisted dying set out in s. 241.1; and
- (e) carry out any other mandate given to it by the Minister.

Professor Downie further suggested the following tasks the commission could undertake at its discretion:

(a) conduct or commission research it deems necessary in accordance with relevant federal, provincial, and territorial law and policy;

- (b) solicit the opinion of individuals or groups on any assisted dying issue;
- (c) call on outside experts to report on any assisted dying issue; and
- (d) make recommendations to the Attorney General of Canada about potential law and policy reform with respect to assisted dying in Canada.<sup>200</sup>

A national oversight body might also take on a policy leadership role. During the Panel's meeting with the Federation of Medical Regulatory Authorities of Canada, the Saskatchewan College of Physicians and Surgeons recommended that a national oversight body could make "recommendations—if it turns out that there are some issues that aren't being appropriately addressed or complications that weren't really anticipated—[on] improving the system." A national oversight body that reviews trends and draws conclusions might be in an ideal position to inform and shape the future of physician-assisted dying across the country. The Saskatchewan College also suggested that the oversight body provide flexible policy leadership in the future and give guidance on various evolving medical issues.

The Panel met with Linda Voortman and Renske Leijten, members of Parliament in the Netherlands and of the Parliamentary Committee on Health, Welfare and Sport, who explained that their country's regional euthanasia review committees are an appropriate venue to discuss controversial assisted dying cases. In their view, the committee was the right place for this discussion, rather than the Dutch Parliament.

Dr. Thomas Foreman, Director of the Champlain Centre for Health Care Ethics at the Ottawa Hospital, proposed that establishing a robust oversight mechanism could alleviate the concerns of groups speaking on behalf of potentially vulnerable individuals by demonstrating that their concerns are being addressed in a concrete and thoughtful manner:

[We] need to be respectful and considerate of the opinions of communities that feel as though this practice could bleed out and cause vulnerable people to be even more vulnerable. And so I think as a way of giving a nod to the legitimacy of that concern, having a fairly robust system of review post facto will help the system be able to say we've heard what you've said, we've considered what you said and in practice we are controlling for that by having a review. So if we start to see bleed-out, we have an ability to check and stop it.

Dr. Jennifer Tong, from a network of BC physicians who "are deeply concerned regarding the significant risks to vulnerable patients and society at large" as a result of the *Carter* ruling, raised a related point about building trust among those who oppose physician-assisted death:

what we would like to see is that there would be representation of physicians such as ourselves at policy level, so that there could be dedicated time, protected time to ... carefully look into all the details because, as the saying goes, the devil's in the details. And we're concerned to see that ... these details are carefully looked at, not just by physicians who are proponents for physician[-assisted dying], but also those who have concerns.

<sup>&</sup>lt;sup>200</sup> Please note that Professor Downie has since updated her model legislation. The Panel's references to her legislation are to the 9 February 2015 version, as this was the version discussed at its meeting with Professor Downie.

## B. Anonymized Data

Many groups emphasized that data should be collected anonymously, citing the need to protect individuals' privacy and to promote physician compliance in reporting. On the issue of privacy, the College of Physicians and Surgeons of New Brunswick noted that in smaller communities, it could be easy to identify individuals from details in their medical files; "nothing is done without running into your second cousin here."

Marilyn Golden, a senior policy analyst with the Disability Rights Education and Defense Fund in California, argued that data collection is important for researchers, but noted that the data need not include identifying information. The Canadian Nurses Protective Society noted that it was "very convinced [that] anonymized data" would be used and "would be of great interest to researchers of all kinds." The Euthanasia Coalition-B.C. also argued that data could be "decoupled" from personal information.

Dr. Isabelle Marcoux, a psychologist and Assistant Professor with the University of Ottawa, raised the issue of anonymity to ensure physician compliance. She has conducted research in the Netherlands, where physicians' reporting of assisted dying was initially quite poor. She recommended anonymous data to ensure that physicians do not avoid reporting out of fear of reprisals due to noncompliance.

The Panel had two models of data collection presented to it: those of Belgium and Oregon. In both, the assisting physician is responsible for reporting. In Oregon, the consulting physician, pharmacist, and if applicable, psychiatrist or psychologist also have reporting obligations.<sup>201</sup>

In Belgium, the Panel heard from Jacqueline Herremans, a lawyer and member of the Commission de contrôle et d'évaluation de l'euthanasie. She explained that physicians must fill out a two-part form after assisting an individual to die:

One part is confidential, and is sealed. So [members of the Commission] don't open automatically the first part. It's the part with the name of the patient, the name of the doctor, the name of all the people involved, consultants and so on. The second part is not confidential... the part you have to examine, but without names, without the name of the doctor, without the name of the patient.

The identifying portion of the form remains sealed unless the Commission suspects noncompliance with the law. If noncompliance is suspected, the Commission unseals the confidential portion of the form and seeks further information from the assisting physician.

The Panel also heard from Dr. Katrina Hedberg, a physician and State Epidemiologist for Oregon who described data collection in her state. Physicians in Oregon fill out forms to record the individual's medical history, along with some demographic data and the individual's stated reasons for seeking assisted dying. These forms contain identifying information about the individual and the physician. Data

<sup>&</sup>lt;sup>201</sup> Oregon Health Authority, <u>Death with Dignity Forms via PDF</u>.

from these forms are uploaded into a database in an anonymized manner, and analyzed to identify and evaluate trends, but the original forms are destroyed after one year.

## C. Which Data Should be Collected and from whom?

In the course of its meetings, the Panel learned about some of the relevant data collected in other jurisdictions. In Oregon, all data collection occurs through forms available on the Oregon Health Authority's website. <sup>202</sup> The forms seek information from attending and consulting physicians (including mental health professionals, if applicable) and pharmacists. There is a form for an individual's use, called the Patient Request Form, but it asks only whether they have informed their families of their decision. Demographic data and data about motivation are collected from assisting physicians, not from the individuals themselves. Dr. Katrina Hedberg, State Epidemiologist for Oregon, noted that state law requires data collection only up to the point of prescribing lethal medication, with a follow-up form from the pharmacist stating the specific medication dispensed.

Québec lawyer Jean-Pierre Ménard drew the Panel's attention to section 8 of Québec's *Act respecting end-of-life care*, which sets out the data that must be collected under the Act:

[Translation] The report must include the number of end-of-life patients who received palliative care, the number of times continuous palliative sedation was administered, the number of requests for medical aid in dying, the number of times such aid was administered as well as the number of times medical aid in dying was not administered, including the reasons it was not administered.

The report must also state, where applicable, the number of times continuous palliative sedation and medical aid in dying were administered at the patient's home or in the premises of a palliative care hospice by a physician as a physician practising in a centre operated by the institution.

Many groups that met with the Panel argued that the amount of data collected in jurisdictions that monitor assisted dying is insufficient. Marilyn Golden of the Disability Rights Education and Defense Fund critiqued data collection in Oregon as lacking in depth and breadth. She argued that:

Restricting access to information about the indications for assisted suicide, patient data, radiologic documentation, and specific drug therapy limits the opportunity to establish an objective standard of care, provides excessive protection to the physician, and, in the name of confidentiality, leaves patients vulnerable.

Ms. Golden also called for collecting data from sources other than those currently involved in Oregon, including physicians who deny requests for assisted dying; allied health care workers, including nurses and social workers; and family members of the deceased.



A number of other groups and individuals made specific recommendations about data collection:

- Dr. Isabelle Marcoux, psychologist and Assistant Professor with the University of Ottawa, called for data to help researchers determine what motivates people to seek physician-assisted dying. Almost all other groups that called for data collection indicated a need to better understand motivation.
- The Canadian Nurses Protective Society called for data to understand "the profiles of patients who are requesting or receiving" physician-assisted death and "the length of time between request and assistance."
- The Council of Canadians with Disabilities called for data to "track and report on first of all the number of requests, secondly the reasons given, thirdly using aggregate data like medical condition, socio-economic circumstances and demographic factors associated with persons making requests and those whose requests are authorized or denied."
- The Euthanasia Prevention Coalition (Canada) called for interviews with people seeking assisted dying for a more in-depth understanding of motivation.
- Dr. Katrina Hedberg, State Epidemiologist for Oregon, suggested collecting data about support for family members, as did the Canadian Hospice Palliative Care Association.
- Dr. Hedberg suggested collecting data in several other areas, such as "more in-depth information about the patients, both from the time of diagnosis to the decision making and what kind of supports they need all the way up until death;" "understanding that not only what's going into the patient's consideration, but what's going into family members and the healthcare system;" "knowledge, attitude, practices ... What do they think? What are their choices? What kinds of things do they go through?"
- Brian Mishara, Professor of psychology at the Université du Québec à Montréal and Director of a
  research and intervention centre on suicide and euthanasia (Centre de recherche et
  d'intervention sur le suicide et l'euthanasie (CRISE)) suggested that suicide rates be monitored.
  When questioned on a potential association between assisted suicide and suicide rates,
  Professor Mishara responded that there was no such indication from jurisdictions where
  assisted suicide is permitted, and that, as a result, increased efforts in suicide prevention may
  not be required when physician-assisted suicide is implemented. However, several groups raised
  concerns about a potential link between the two concepts and monitoring the situation could
  help provide reassurance.

#### D. Reporting Timelines

To be effective, reporting must be timely. Québec's *Act respecting end-of-life care* mandates reporting to the Commission sur les soins en fin de vie (the Commission) after a physician administers medical aid in dying. The Act requires that a physician give notice to the Commission, in the manner prescribed by regulations, within ten days following the administration of medical aid in dying.<sup>203</sup>

In her draft legislation, Professor Jocelyn Downie proposes a federal oversight body: the Commission to Monitor and Report on Physician-Assisted Dying in Canada. She proposes that an individual who

<sup>&</sup>lt;sup>203</sup> An Act respecting end-of-life care, R.S.Q., c. S-32.0001, s. 46.

requests physician-assisted death must fill out any forms that the Commission requires and that these forms must be submitted to the Commission within 14 days of their being placed in the individual's medical record. Any further information the Commission requires would have to be submitted within 14 days of the individual's death.<sup>204</sup>

#### E. Death Certificates

A crucial role of any oversight body is to collect, analyze and report on data. Many groups, including the Canadian Medical Association, mentioned death certificates as a primary source for data collection. The Panel heard divergent opinions about whether death certificates should list cause of death as physician-assisted dying, or reference the underlying illness, disease or disability.

At the outset, it is important to note that the regulation of death certificates falls under provincial jurisdiction. For this reason, it is difficult to foresee a national oversight body having direct influence on provinces' management of death certificate systems. Nonetheless, the Canadian Medical Association told the Panel that pan-Canadian guidelines are necessary to foster clarity and consistency in these important records.

Medical regulators also addressed the issue of death certificates. Dr. Douglas Grant, President of the Federation of Medical Regulatory Authorities of Canada and Registrar for the College of Physicians and Surgeons of Nova Scotia, indicated that physicians will need clear guidance on filling out death certificates and on the life insurance implications of physician-assisted death.

#### 1. Recording Physician-Assisted Death on Death Certificates

Dr. Isabelle Marcoux and Marilyn Golden recommended that physician-assisted death be listed on death certificates to promote accountability and transparency. The Council of Canadians with Disabilities, the Canadian Federation of Catholic Physicians' Societies and the Catholic Civil Rights League all shared this view.

The Euthanasia Prevention Coalition and a network of British Columbia physicians also recommended this approach, and further suggested that death certificates also record information about the underlying condition, the administering physician and the facility where the procedure took place.

Dying with Dignity Canada supported the idea of recording comprehensive and detailed information on death certificates. The group noted that death certificates are not widely circulated, reducing the likelihood that listing the actual cause of death could compromise individual privacy. Dying with Dignity Canada also suggested that individuals who choose physician-assisted dying should be protected from potential financial losses or loss of insurance benefits by compensation mechanisms.

<sup>&</sup>lt;sup>204</sup> Jocelyn Downie, *Draft Federal Legislation to Amend the Criminal Code to Be Consistent with* Carter v. Canada (Attorney General) *2015 SCC 5* (9 February 2015). Please note that Professor Downie has since updated her model legislation. The Panel's references to her legislation are to the 9 February 2015 version, as this was the version discussed at its meeting with Professor Downie.

Experts in Belgium, including researchers Luc Deliens and health lawyer and academic Herman Nys, told the Panel that physician-assisted death is never listed as the cause of death in that country's death certificates. They advised that death certificates in Canada should list physician-assisted dying as the cause of death for accurate data collection and reporting, and recommended that an oversight body receive all of the information on death certificates in cases of physician-assisted dying.

In Switzerland, Bernhard Sutter, Executive Director of Exit, a society that facilitates assisted dying for Swiss citizens, indicated that death certificates in that country identify assisted suicide as the immediate cause of death, whereas Switzerland's Federal Office of Statistics records the underlying illness.

## 2. Reporting the Underlying Medical Condition on Death Certificates

Several stakeholders indicated that listing assisted death on death certificates is inappropriate because it violates individuals' privacy and could deprive loved ones of benefits from insurance policies and other contracts.

Dr. Katrina Hedberg from Oregon noted that her state's Public Health Division recommends that physicians list the underlying illness as the cause of death on the death certificate, but that the final decision rests with each physician. <sup>205</sup> This recommendation stems from concerns about patient confidentiality, and from the fact that the primary purpose of the death certificate is to act as a legal document allowing others to settle the estate of a deceased. Peg Sandeen, Executive Director of the Death with Dignity National Centre, noted that in the state of Washington, it is mandatory to record the underlying condition on death certificates.

The province of Québec established a mechanism whereby three different notifications arise from the administration of medical aid in dying: an attestation of death (*constat de décès*), a death certificate (*bulletin de décès*), and a notice to the Commission sur les soins de fin de vie. Death certificates list the underlying medical condition as the cause of death and copies are sent to the Institut de la statistique du Québec. Medical aid in dying is not to be listed on the certificates to protect privacy and to avoid prejudice.

The Commission sur les soins de fin de vie, not the Institut de la statistique du Québec, is responsible for keeping a statistical account of medical aid in dying. Consequently, Québec's *Act respecting end-of-life care* requires that after physicians provide medical aid in dying, they must "give notice to the Commission within the next 10 days and send the Commission, in the manner determined by government regulation, the information prescribed by regulation. This information is confidential and may not be disclosed to any other person." <sup>206</sup> The mandatory notices are the Commission's primary source for data on medical aid in dying. This approach, the Panel was told, helps protect confidentiality and maintain accurate statistics.

<sup>&</sup>lt;sup>205</sup> See also Mr. Kelly Hagan, lawyer, 1 October 2015; and Barb Hansen, Oregon Hospice Association, 1 October 2015.

<sup>&</sup>lt;sup>206</sup> An Act respecting end-of-life care, R.S.Q. c. S-32.0001, s. 46.

## F. Open Data and Targeted Funding

The Panel heard that to be useful, data must be accessible and targeted funding must be made available for research and analysis. Johan Legemaate, a lawyer and researcher, indicated that in the Netherlands, data are collected and a systemic review is conducted every five years. The government funds this research; researchers apply for grants and an independent body evaluates their proposals.

Some experts and groups suggested that funding must be set aside to ensure that the practice of physician-assisted dying is properly evaluated in Canada. Dr. Katrina Hedberg noted that Oregon's *Death with Dignity Act* does not set aside funding for data collection and analysis. She indicated that the current level of data collection and analysis is generally considered adequate by all except those opposed to assisted dying. She also indicated that if more extensive data were to be collected and analyzed, earmarked funding would be necessary. Professor Jocelyn Downie advocated earmarked funds, as did Dying with Dignity Canada's Dr. James Downar.

Professor Jocelyne St-Arnaud, a bioethicist at the Université du Québec à Montréal, called for earmarked funding to support independent evaluation of physician-assisted dying. Similarly, Anna MacQuarrie, Director of Global Initiatives, Policy and Human Rights with Inclusion International addressed the importance of making data on physician-assisted dying public so that civil society groups could conduct independent evaluations.

# G. Periodic Review of Legislation

As mentioned above, oversight bodies in the Netherlands and Belgium conduct periodic reviews and produce regular reports about assisted dying. Many groups in Canada recommended periodic review and some would require tabling reports in Parliament. The Council of Canadians with Disabilities, for instance, suggested annual reports to Parliament, while Dying with Dignity Canada advocated regular reviews to help identify abuses of the law and potential barriers to access.

Many federal Acts require reports to Parliament. Under some legislation, such as the *Canada Health Act*, a minister must report annually;<sup>207</sup> other legislation, such as the federal *Access to Information Act* requires a commissioner to report to Parliament.<sup>208</sup> The federal *Privacy Act* mandates a permanent review of the Act by Parliamentary committee.<sup>209</sup> Legislation on physician-assisted dying could also include provisions for regular parliamentary review.

Several groups described review processes to the Panel. The Association for Reformed Political Action, for instance, proposed that a judicial panel evaluate physician-assisted dying legislation every three years:

[I]f a judicial panel finds that the rules are not being followed, or that people are being assisted in their suicide who never gave proper consent, or any sort of slipping or sliding is happening at

<sup>&</sup>lt;sup>207</sup> Canada Health Act, R.S.C. 1985, c. C-6.

<sup>&</sup>lt;sup>208</sup> Access to Information Act, R.S.C. 1985, c. A-1.

<sup>&</sup>lt;sup>209</sup> *Privacy Act*, R.S.C. 1985, c. P-21.

all, that we have the power built into the legislation to stop or at least re-evaluate the legislation. And certainly those who are afraid of a slippery slope would feel much more at ease if there were a proper judicial review every three years.

The Catholic Civil Rights League recommended that either Parliament or a federally appointed panel conduct a review every three to five years. The Evangelical Fellowship of Canada suggested that a federal oversight body be established and that this body should:

collect relevant data, report regularly to Parliament and [this] information needs to be made public so that we can keep ... accurate statistics of what's happening, what kind of requests are being made, what are the circumstances.

# H. Enforcing the Obligation to Report to an Oversight Body

Some groups called for a law making it a criminal offence to improperly report a physician-assisted death. Marilyn Golden with the Disability Rights, Education and Defence Fund in the United States has suggested that reporting requirements can lack "teeth" unless there are penalties for physicians who fail to report properly. The Council of Canadians with Disabilities indicated that voluntary reporting by physicians is insufficient. Similarly, Dr. Isabelle Marcoux noted that voluntary data collection would not ensure proper monitoring because physicians may not report practices that do not conform exactly to legislated requirements, perhaps due to fears of facing prosecution.

To counteract this effect, it may be necessary to create an offence for intentionally failing to report to an oversight body. Professor Jocelyn Downie's model legislation would make it an offence for a physician to wilfully fail to submit required information, such as forms completed by the requesting individual. The offence would be punishable by up to five years in prison.<sup>210</sup> Professor Jocelyne St-Arnaud suggested another way to prevent noncompliance would be to emphasize training rather than punishment.

In cases of delayed reporting, or other minor instances of noncompliance, professional discipline may be more appropriate than criminal sanctions. The Panel heard from Dr. Katrina Hedberg, State Epidemiologist and State Health Officer of Oregon, that Oregon's Public Health Division is responsible for reporting noncompliance to the appropriate licencing board. The licencing board (of physicians, nurses or pharmacists) undertakes its own investigation and imposes any sanctions it deems appropriate.

In Québec, physicians who fail to notify the Commission sur les soins en fin de vie that they have administered medical aid in dying are subject to professional disciplinary measures. A person who is aware of a breach of a reporting requirement must bring it to the attention of the Collège des médecins du Québec.<sup>211</sup>

<sup>&</sup>lt;sup>210</sup> Jocelyn Downie, *Draft Federal Legislation to Amend the Criminal Code to Be Consistent with* Carter v. Canada (Attorney General) *2015 SCC 5* (9 February 2015). Please note that Professor Downie has since updated her model legislation. The Panel's references are to the version discussed at its meeting with Professor Downie.

<sup>&</sup>lt;sup>211</sup> An Act respecting end-of-life care, R.S.Q. c. S-32.0001, s. 46.

# Part IV – End-of-life Care in Canada

There was general agreement that assisted dying frameworks must include mechanisms for careful review, and be accompanied by significant efforts to provide suffering individuals with good-quality health and social services.

Canadians do not want assisted death to become the preferred option simply because other options, such as high-quality palliative care, are not accessible. Physician-assisted dying must not become an indication of the system's failure to provide adequate end-of-life care. There appeared to be overall

"From an autonomy and informed consent perspective, unless there is available, easily accessible, comprehensive, robust end-of-life care, palliative care, to offer the option of assisted death impedes the exercise of self-determination and autonomy because you haven't been given the option, and even if you have, it isn't available to you in a robust way that can be actualized" - Dr. Thomas Foreman, Director, Champlain Centre for Health Care Ethics, Ottawa Hospital

consensus among those who expressed their views to the Panel that a truly informed decision can be made only when the individuals is aware of and understands meaningful alternatives. This section of the Panel's report examines the nature, quality and availability of these alternatives, and explores their relationship with the legalization of physician-assisted dying.

Meaningful alternatives include healthcare services, and social services and supports. The Panel recognizes that these areas are primarily under provincial and territorial jurisdiction, but feels that a full understanding of these alternatives is essential to any thoughtful consideration of physician-assisted dying. The Panel also recognizes that the federal government can encourage the provinces and territories to take action on matters under their jurisdiction. Should it choose to do so, the Panel suggests that such encouragement follow the principle of "cooperative federalism," as affirmed by the Supreme Court of Canada on many occasions.

# Chapter 13. A Critical Issue: Palliative and End-of-Life Care

The Panel believes that there is a broad consensus among Canadians for greater access to quality palliative care. Most interveners, experts and stakeholders—regardless of their position on physician-assisted dying—shared this view. The Panel heard calls for equal access to quality palliative care across Canada from a long list of groups, including the Canadian Society of Palliative Care Physicians, the College of Family Physicians of Canada, the Canadian HIV/AIDS Legal Network, the Canadian Association for Spiritual Care, the Catholic Civil Rights League, the Evangelical Fellowship of Canada, the Christian Legal Fellowship, Dying with Dignity Canada, as well as from experts and representatives of colleges of physicians and surgeons from across Canada. As Wanda Morris, CEO of Dying with Dignity Canada

stated: "[n]obody should have to choose an assisted death because the medical system has failed to give them other options."

# A. Defining Palliative Care

People living with, or dying from, advanced life-limiting illnesses have unique health care needs. Palliative care services are designed to help them live the remainder of their lives in comfort and dignity. The key components of palliative care are pain relief and symptom management, along with social, psychological, emotional and spiritual supports for patients, families, friends and other caregivers. The World Health Organization (WHO) defines palliative care as follows:

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.<sup>212</sup>

The WHO definition makes it clear that the objective of palliative care is to achieve the best possible quality of life for patients. The definition also sheds light on some misconceptions related to palliative care. For one, the definition specifies that the aim of palliative care is neither to accelerate nor to delay death. Also, even though palliative care is more commonly associated with incurable illnesses in near-death situations, it should be mentioned that persons in the earlier stages of illness may also benefit from a palliative approach to improve their quality of life in combination with treatments aimed at curing or resolving aspects of their illness.

Palliative care can be provided not only in hospital, but also in the community, such as at a hospice, long-term care facility, or in the home. Empirical research has found that palliative care is associated

<sup>&</sup>lt;sup>212</sup> World Health Organization, WHO Definition of Palliative Care.

with better outcomes for patients (symptom management, quality of life, overall satisfaction), family caregivers (reduced burden) and the healthcare system (reduced hospital admissions).<sup>213</sup>

Most people approaching the end of their lives are primarily cared for by family members, friends and their family physicians.<sup>214</sup> People with greater personal wealth and resources are often more able to access private services and supports. Where palliative care teams are available, there are specially trained doctors, nurses and other health care providers to provide assistance. Depending on the person's needs, the palliative care team may include nurses with specialized training, a physician who specializes in palliative medicine, a pharmacist, a social worker, a spiritual counsellor, a bereavement support worker, a home care worker, a nutritionist, a physiotherapist and an occupational therapist.<sup>215</sup> Trained volunteers and informal caregivers may also be considered part of the team.

#### B. The State of Palliative Care in Canada

Hospice and palliative care emerged in Canada in the 1970s as greater attention and priority was devoted to managing the pain and other symptoms of cancer patients. <sup>216</sup> With advances in health care, many Canadians live longer lives. At the same time, the incidence of chronic and life-limiting diseases has also increased, <sup>217</sup> with close to 70% of all deaths in Canada due to illnesses such as cancer (30%), circulatory diseases (29%) and respiratory diseases (9%). <sup>218</sup> Many of these people experience pain, discomfort, and generally poor health in the final months and sometimes years of life. <sup>219</sup> When asked, most Canadians say they would prefer to die at home in the presence of loved ones, <sup>220</sup> yet almost 70% of deaths in Canada occur in hospital. <sup>221</sup> Better access to community-based palliative care options could be a way to accommodate Canadians' preference to die peacefully at home.

Unlike countries with explicit priorities, goals and strategies, Canada does not have a national palliative care strategy, nor do most provinces and territories.<sup>222</sup> There is a general sense in the healthcare field

<sup>&</sup>lt;sup>213</sup> See for example S. Hales et al., "<u>The Quality of Dying and Death in Cancer and Its Relationship to Palliative Care and Place of Death,"</u> *Journal of Pain and Symptom Management*, 48(5), 2014 and T.J. Smith et al., "<u>American Society of Clinical Oncology provisional clinical opinion: the integration of palliative care into standard oncology care," *Journal of Clinical Oncology*, 30(8), 2012.</u>

<sup>&</sup>lt;sup>214</sup> L. Del Giudice et al., "Physician care of cancer patients," in L. Jaakkimainen et al. (eds.), *Primary Care in Ontario*. Toronto, ON: Institute for Clinical Evaluative Sciences, 2006 and G.K. Mitchell, "<u>How well do general practitioners</u> deliver palliative care? A systematic review," *Palliative Medicine*, 16(6), 2002.

<sup>&</sup>lt;sup>215</sup> Canadian Hospice Palliative Care Association, <u>FAQs.</u>

<sup>&</sup>lt;sup>216</sup> Mary Brooksbank, "Palliative care: Where have we come and where are we going?" *Pain*, 144, 2009 and G.P. Marchildon, *Health Systems in Transition: Canada*, University of Toronto Press, 2005.

<sup>&</sup>lt;sup>217</sup> Scott A. Murray et al., "Illness trajectories and palliative care," BMJ, 330(7498), 2005.

<sup>&</sup>lt;sup>218</sup> Public Health Agency of Canada, <u>The Chief Public Health Officer's Report on the State of Public Health in Canada</u>, 2012.

<sup>&</sup>lt;sup>219</sup> E. Cochrane et al., "Addressing the needs of patients with advanced non-malignant disease in a hospice day care setting," *International Journal of Palliative Nursing*, 14(8), 2008.

<sup>&</sup>lt;sup>220</sup> Canadian Institute of Health Information, <u>Health Care Use at the End of Life in Western Canada</u>, 2007.

<sup>&</sup>lt;sup>221</sup> Statistics Canada. Table 102-0509, <u>Deaths in hospital and elsewhere, Canada, provinces and territories, annual,</u> CANSIM (database).

<sup>&</sup>lt;sup>222</sup> Canadian Hospice Palliative Care Association, *Palliative Care in the Community: An Environmental Scan of* 

that there is much room for improvement in terms of equity of access and quality as it relates to palliative care in Canada. The Senate of Canada published studies on palliative care in 1995, 2000, 2005 and 2010, and has recommended the development of a pan-Canadian strategy for a comprehensive system of palliative care. What the Panel has heard from interveners, experts and Canadians in general throughout its consultations tends to confirm this observation. Some of the key gaps that have been identified are reported below, followed by avenues that governments can explore to move forward on this issue.

It has been reported that as few as 16-30% of Canadians have access to some level of palliative care. <sup>224</sup> However, empirical evidence about how many Canadians can access and actually receive palliative care at the ends of their lives is limited and the data inexact. <sup>225</sup> Nevertheless, it is generally accepted that there are wide variations in access and quality, with pockets of excellence contrasted with many areas that are woefully underserved. As such, palliative care in Canada is often described as a "patchwork quilt" <sup>226</sup> or as "a work in progress." <sup>227</sup> Unquestionably, too many Canadians and their families do not have access to good quality palliative care and hence, have less than ideal and sometimes even tragic end-of-life experiences. Populations that are particularly vulnerable and often under-served at the end of life include people living outside of urban centres, indigenous people, children and new Canadians.

By international standards, Canada has fewer doctors specializing in palliative care than comparable countries such as the United States and Australia. Out of approximately 77,000 physicians in Canada, 229 a recent survey identified just 51 palliative care specialists, as well as 123 family physicians whose practices focus on palliative care. The survey also identified another 931 family physicians and specialists (e.g., oncologists, pediatricians) who provide some palliative care as part of their practices, but two-thirds of this group reported having no training in palliative medicine.

Frameworks and Indicators, 2013.

<sup>&</sup>lt;sup>223</sup> Senate of Canada, Raising the Bar: A Roadmap for the Future of Palliative Care in Canada, June 2010.

<sup>&</sup>lt;sup>224</sup> Canadian Hospice Palliative Care Association, Fact Sheet: Hospice Palliative Care in Canada, March 2014.

<sup>&</sup>lt;sup>225</sup> See for example: J. Downie and G. Lloyd-Smith, "<u>The Making of a Myth: Unreliable Data on Access to Palliative Care in Canada</u>," *Health Law Review*, 2014; J.D. Henderson, "<u>Canadian Society of Palliative Care Physicians—</u>
Response to 'The Making of a Myth: Unreliable Data on Access to Palliative Care in Canada," *Health Law Review*, 22:3, 2014 and J.D. Shadd et al., "<u>Defining and measuring a palliative approach in primary care</u>," *Canadian Family Physician*, 59, November 2013.

<sup>&</sup>lt;sup>226</sup> Senate of Canada, *Quality End-of-Life Care: The Right of Every Canadian. Final Report, June 2000.* 

<sup>&</sup>lt;sup>227</sup> A.M. Williams et al., "<u>Tracking the evolution of hospice palliative care in Canada: A comparative case study analysis of seven provinces</u>," *BMC Health Services Research*, 10(147), 2010.

<sup>&</sup>lt;sup>228</sup> Dane Wanniarachige, "More palliative care specialists is not enough," Canadian Medical Association Journal, 12 January 2015.

<sup>&</sup>lt;sup>229</sup> Canadian Institute for Health Information, <u>Number of doctors in Canada is rising, but average payments remain steady</u>. <u>Canadian Institute for Health Information</u>.

<sup>&</sup>lt;sup>230</sup> Canadian Society of Palliative Care Physicians Human Resources Committee, <u>Highlights from the National</u> <u>Palliative Medicine Survey: Canadian Society of Palliative Care Physicians</u>, May 2015.

Out of approximately 360,000 registered nurses in Canada,<sup>231</sup> 1,348 have certifications in palliative care,<sup>232</sup> a number that has been relatively constant after almost tripling between 2004 and 2008.<sup>233</sup>

A 2014 survey reported that 23-26% of Canadian general practitioners/family physicians and nurses were very comfortable providing palliative care, 47-55% were somewhat comfortable, and the remainder (22-28%) either not very comfortable or not at all comfortable providing palliative care.<sup>234</sup>

A 2011 survey indicated that only seven of 17 Canadian medical schools had more than ten hours of palliative care in their undergraduate programs.<sup>235</sup>

# C. Other End-of-life Care Options

While most of its conversations about end of life focused on palliative care and assisted death, the Panel heard about other choices and decisions that patients are entitled to make to have their wishes and desires respected.

One such option is for Canadians to state their preferences regarding treatments at the end of life in an advance-care plan or directive. Should a person become unable to make their own health care decisions, the advance-care plan provides guidelines to their loved ones and health care providers about their wishes. <sup>236</sup> In the absence of an advance-care plan (or when the advance-care plan does not address a given situation), an individual acting on the patient's behalf can also make health care decisions for them. These individuals are commonly called proxies or substitute decision makers. <sup>237</sup> Another similar option is for an individual to complete a Do Not Resuscitate order. When such an order has been completed, medical professionals will not attempt to perform cardiopulmonary resuscitation if heart or respiratory failure occurs.

Individuals also have the right to refuse a treatment or to withdraw from a treatment already under way, even though the treatment in question could be needed to save, prolong or sustain their life. Similarly, a person has the right to refuse to take nutrition or hydration by any means (orally or otherwise).

Palliative sedation is a treatment that has been broadly defined and interpreted. According to the Canadian Virtual Hospice, palliative sedation may be an option of last resort when usual treatments cannot relieve severe and unbearable symptoms at the end of life. If this is chosen, and after it has been discussed with a competent individual (or the family or substitute decision maker), a medication is administered to provide comfort that cannot be achieved otherwise. Palliative sedation is a

<sup>&</sup>lt;sup>231</sup> Canadian Institute for Health Information, *Nursing numbers still rising*, 10 January 2013.

<sup>&</sup>lt;sup>232</sup> Canadian Nurses Association, <u>Number of Valid CNA Certifications by Specialty/Area of Nursing Practice and Province or Territory</u>, 2010.

<sup>&</sup>lt;sup>233</sup> Canadian Nurses Association, *Certification Bulletin*, No. 7, Spring/Summer 2009.

<sup>&</sup>lt;sup>234</sup> Ipsos and Canadian Hospice Palliative Care Association, <u>The Way Forward - Moving Towards an Integrative</u> Palliative Approach to Care: Survey of GP/FPs and Nurse in Primary Care, August 2014.

<sup>&</sup>lt;sup>235</sup> Canadian Society of Palliative Care Physicians, <u>Backgrounder: Palliative Care (Medical) Education</u>, January 2015.

<sup>&</sup>lt;sup>236</sup> Canadian Medical Association, <u>End-of-life Care—A National Dialogue</u>, June 2014.

<sup>&</sup>lt;sup>237</sup> Canadian Virtual Hospice, *Advance Care Planning Across Canada*, 15 July 2015.

proportionate response, such that medications and dosages can be adjusted for varying effects (from calming to full sleep) and can also be reversed, allowing the person to be more awake. The goal of palliative sedation is not to cause or accelerate death, but to ensure that people are comfortable until they die from their disease.

Ultimately, Canadians should be able to make a truly informed choice between physician-assisted death, no medical intervention and excellent palliative care.

# Chapter 14. Moving Forward

Disparities in access to palliative care across Canada and the need for a national initiative in this area have long been recognized, as discussed above and evidenced by reports and studies going as far back as 2000. <sup>238</sup> A relevant recent initiative is The Way Forward, a National Framework. <sup>239</sup> Led by the Quality End-of-Life Care Coalition of Canada, <sup>240</sup> managed by the Canadian Hospice Palliative Care Association and funded by the federal government, the initiative aims to guide health care professionals, health systems leaders, program planners and others in implementing an integrated palliative approach to care in their communities and organizations. The initiative could serve as a roadmap for future government funding or at least as a starting point for discussion. The Canadian Medical Association also published a National Call to Action on palliative care in May 2015. <sup>241</sup>

"Given the pressure that the government is under following the Carter decision, this is an extremely important moment for all of us ... to urge the government to actually develop a national palliative care strategy and plan, and to adequately fund it" - Richard Elliott, Executive Director, Canadian HIV/AIDS Legal Network

The Supreme Court decision and the advent of physician-assisted dying in Canada may be the impetus needed to develop and advance a national palliative care initiative. Because responsibility for the delivery of palliative care clearly falls under provincial and territorial jurisdiction, pan-Canadian collaboration would be needed. Many interveners, stakeholders and experts argued that there is a need for uniformity across Canada, which might require

a larger role for the federal government. Some stakeholders, such as the Canadian Society of Palliative Care Physicians, called for the development of quality indicators to help track and measure access to palliative care, as part of the reporting and accountability requirements of a physician-assisted dying framework.

<sup>&</sup>lt;sup>238</sup> For example: Senate of Canada, *Quality End-of-Life Care: The Right of Every Canadian. Final Report,* June 2000 and Commission on the Future of Health Care in Canada, *Building on Values: The Future of Health Care in Canada— Final Report,* November 2002.

<sup>&</sup>lt;sup>239</sup> Canadian Hospice Palliative Care Association, <u>The Way Forward National Framework: A roadmap for an integrated palliative approach to care</u>, March 2015.

<sup>&</sup>lt;sup>240</sup> The Quality End-of-Life Care Coalition of Canada is a network of national organizations representing caregivers, volunteers, health care professionals, patients, families, and others with an interest in quality end-of-life care. For more information, see: Quality End-of-Life Care Coalition, *About Us.* 

<sup>&</sup>lt;sup>241</sup> Canadian Medical Association, <u>Palliative Care - Canadian Medical Association's National Call to Action - Examples of innovative care delivery models, training opportunities and physician leaders in palliative care, May 2015.</u>

# A. Federal Role in Support of Improved Palliative and End-of-life Care

Over the years, the federal government has provided some leadership on issues related to palliative and end-of-life care, in accordance with the federal role in health.<sup>242</sup> Several relevant initiatives are described below.

# 1. Setting and Administering National Principles for the Healthcare System through the *Canada Health Act*

The Panel heard during its consultations that one way to make palliative care more readily and equitably available across the country would be to amend the *Canada Health Act* to specifically include palliative care. Although commonly heard, the proposal appears to reflect a misunderstanding of the *Canada Health Act*. In essence, the *Canada Health Act* establishes the criteria and conditions that provinces and territories must meet to be eligible to receive the funding known as Canada Health Transfer. The Act identifies five main criteria and principles: public administration, comprehensiveness, universality, portability and accessibility. The *Canada Health Act* also establishes that medically necessary hospital and physician services are subject to the Act and that, as such, they must be available under provincial health insurance plans. The Act does not define or specify medically necessary services; this is left up to the provinces and territories. Amending the Act to include palliative care would again leave it to the provinces and territories to determine not only standards of care but also which treatments and services would be publicly funded. Unless all governments are willing to reopen and renegotiate the *Canada Health Act*, other options must be contemplated.

# 2. Assisting in the Financing of Provincial/Territorial Health Care Services through Fiscal Transfers

The federal government commonly funds programs and services delivered by provinces and territories, mainly through four mechanisms: the Canada Health Transfer, the Canada Social Transfer, Equalization, and Territorial Formula Financing. Already the largest major transfer to provinces and territories—worth \$32.1 billion in 2014–15<sup>243</sup>—Canada Health Transfer payments are set to grow by 6% through 2016-17 and will continue to grow by at least 3% per year through 2017-2018. 244 To receive funding under the Canada Health Transfer, provinces and territories must only meet the criteria and conditions outlined in the *Canada Health Act*; there are no other requirements. As a result, it would be difficult for the federal government to require provinces and territories to provide additional services as part of the existing arrangement. If the newly elected government were to reopen discussions with the provinces and territories on healthcare, palliative care would be an obvious item to include on the agenda.

<sup>&</sup>lt;sup>242</sup> Government of Canada, <u>Federal Role in Health</u>.

<sup>&</sup>lt;sup>243</sup> Office of the Parliamentary Budget Officer, <u>2014-2015 Federal Transfers to Provinces and Territories</u>, June 2014.

<sup>&</sup>lt;sup>244</sup> Department of Finance Canada, <u>Canada Health Transfer</u>.

Another way that the federal government can spur the provinces and territories to take action is by exercising its spending power<sup>245</sup> and allocating additional dedicated funding. There are several examples of such funding arrangements in healthcare, although few in recent years.<sup>246</sup> From 2000 to 2006, for example, the federal government's Primary Health Care Transition Fund allocated \$800 million to the provinces and territories, and other health care organizations for improvements in primary health care. A similar mechanism could spur action on palliative care across Canada. It should be noted that some provinces do not recognize the legitimacy or the constitutionality of the exercise of the federal spending power in areas that fall under provincial jurisdiction. Québec, for instance, has in the past used the term asymmetrical federalism to describe federal spending related to healthcare.

#### 3. Delivering Health Care Services to Specific Groups under Federal Jurisdiction

Under the Constitution, the federal government is responsible for providing health care services to members of First Nations and to the Inuit. It also provides health services to serving members of the Canadian Forces, eligible veterans, refugee claimants and persons in federal prisons. Some groups that appeared before the Panel indicated that the federal government could lead by example by providing improved palliative and end-of-life care to these populations.

# 4. Providing other Health-Related Functions, such as Public Health and Health Protection Programs and Health Research

The federal government has a number of healthcare responsibilities beyond funding services delivered by the provinces and territories. Health Canada and the Public Health Agency of Canada handle most of these responsibilities. Health Canada helps protect Canadians from unsafe food, health and consumer products; supports the delivery of health care to members of First Nations and the Inuit; promotes innovation in health care; and provides Canadians with information about health. The Public Health Agency of Canada focuses on preventing chronic diseases and injuries, and responding to public health emergencies and infectious disease outbreaks. A third organization, the Canadian Institutes of Health Research, supports research leading to improved health for Canadians, better health services and products and a stronger healthcare system.

The federal government has also supported a number of independent organizations that promote health system improvements and better decision making through knowledge-based activities. The operation of these organizations does not infringe on provincial-territorial responsibilities, as they do not deliver health care services. The Canadian Partnership Against Cancer, for example, leads and implements the Canadian Strategy for Cancer Control. The federal government could establish a similar process and designate an organization to lead a national palliative care strategy, in the spirit of cooperative federalism.

<sup>&</sup>lt;sup>245</sup> The federal spending power in Canada has been defined as "the power of Parliament to make payments to people or institutions or governments for purposes on which it does not necessarily have the power to legislate." Government of Canada, *Federal-Provincial Grants and the Spending Power of Parliament*, 1969, 4.

<sup>&</sup>lt;sup>246</sup> Department of Finance Canada, *Federal Investments in Health Care*.

In the absence of an organization dedicated to palliative and end-of-life care, other pan-Canadian organizations currently funded by the federal government could—within the scope of their current mandates—consider activities to accelerate the adoption of best practices in palliative care across Canada.

#### 5. Complementary End-of-Life Programs and Services

Although a few groups argued that a good palliative care system needs to be in place before access to physician-assisted dying should be granted, this option appears logistically complex. Dying with Dignity Canada made it clear that it strongly opposes additional delays, because they would punish those who are already suffering. Several submissions indicated that physician-assisted death and palliative care should not be presented and discussed in an antagonistic fashion.

Based on what the Panel heard, both palliative care and physician-assisted dying should be made available to Canadians in a way that meets the population's expectations. Doctor Francine Lemire, the Executive Director and Chief Executive Officer of the College of Family Physicians of Canada, expressed this idea quite clearly during her presentation to the Panel:

While we urgently need better access to high-quality palliative care, better palliative care in and of itself does not address what Canadians are telling us about access to end-of-life options, which include medical aid in dying. Numerous polls indicate that a significant majority of Canadians believe medical aid in dying should be an option. And we have a responsibility as health care providers ... as decision makers and advisors, to listen to the public.

# B. Ensuring Access to Extended Health Care Benefits, including Pharmacare, Home Care and Disability Supports

While palliative care was one obvious topic raised during the consultations, other health and social programs and services were also discussed. Richard Elliott, Executive Director of the Canadian HIV/AIDS Legal Network, highlighted the need for a national pharmacare plan, stating that it "has been a terrible gap in our public health insurance system." Many submissions also described gaps in homecare. The paucity of homecare precludes some individuals from being able to live independently, and limits how and where they can live, work and play. Enhancements to homecare could help alleviate some sources of vulnerability and suffering, potentially reducing some individuals' desire to seek physician-assisted dying.

The Panel also heard that some solutions, such as disability supports and other social programs and services, can come from outside the healthcare system. As stated by David Baker, a disability rights lawyer: "[d]isabled people and terminally ill people need to have access to independent living and the full range of support services. Choices about death should not be made because life has been made unbearable through a lack of choices and control." The expectation is that supports for daily living help ease suffering. Richard Elliott summarized these considerations:

We need to make sure that people actually have adequate basic income and housing. ... [W]e need a national housing strategy, we need a guaranteed annual income, we need proper universal health care, including pharmacare and access to palliative care. ... All of our choices in life are constrained by our circumstances. It doesn't mean we lose all of our autonomy, but we're not all 100 percent autonomous, completely unfettered by the circumstances ... in which we live. To the extent possible, we should be doing what we can ... as a matter of social justice and of human rights, to ensure that people have as much autonomy as possible in making those decisions so that their autonomy is not constrained by poverty, is not constrained by homelessness, is not constrained by the fact that they don't have access to the medicines they need to alleviate pain, prevent suffering, ... treat conditions that can be treated, and that their autonomous decision about ending life, for example, is not being driven by the fact that they don't have access to adequate palliative care. ... So I think it would be really important for this Panel to come back and give to the government some considered views not just about specific parameters for when you might get assistance with dying, but the other things that the government should be doing and should have been doing really from the beginning, which is to adequately fund a health system, including palliative care, including universal pharmacare [and] basic minimum social conditions for life that actually mean that people live with dignity. That's ultimately the underlying structural issue that needs to be addressed here. And the specific parameters about getting assistance in dying [are] really against that larger backdrop. So let's make that backdrop better. The two really need to go hand-in-hand.

## Part V—Conclusion

#### **Closing Reflections**

All members of the Panel feel privileged to have been entrusted with the task assigned to us. Although many called our task daunting, we recognize what a great honour it was to be chosen to engage Canadians on such an important topic. We listened to the concerns and expectations of Canadians, and also sought guidance from experts in jurisdictions that permit various forms of physician-assisted dying.

Physician-assisted death is a complex, challenging and emotionally charged issue. The Panel observed very quickly that individuals' views on the issue are dearly held. Every position the Panel heard—regardless of whether it supported or opposed physician-assisted dying—was informed by compassion, empathy and respect. We have endeavored to reflect, to the best of our ability in the time allotted us, the diversity and richness of these views.

We are convinced that implementing a safe and thoughtful physician-assisted dying framework with equitable access for eligible Canadians will require substantial cooperation between all Canadian jurisdictions. We are aware that the provinces and territories of Canada have worked hard towards establishing a framework. Medical regulators have also been diligent in their preparations.

Implementation will require expertise from many sectors. Our consultations have focused largely on the health care sector, but the Panel also collected valuable insight from the fields of law, ethics and civil society. These fields have a great deal to offer on the topic of physician-assisted death and their contributions should shape future policies. Further explorations within the health care sector will surely prove fruitful, as will additional efforts to engage people in fields such as social work and spiritual care.

An important goal in establishing a physician-assisted death framework in Canada should be moving toward consensus. There are divergent views on many aspects of physician-assisted dying, but there are also areas of growing consensus, including a recognition of the need for carefully considered safeguards, oversight and a strengthened palliative care framework to be developed in parallel with one that provides access to physician-assisted dying in accordance with the *Carter* decision. Whatever system is put in place should be rigorously researched and evaluated periodically to foster improvements, if necessary.

Canadians will soon have choices giving them greater control over how their lives will end. It is incumbent on Canadian society to ensure that those choices are informed, and addressed with consummate skill, compassion and respect.

#### Acknowledgments

First and foremost, we wish to thank and gratefully acknowledge the contributions of all those who gave their time to meet with the Panel and to share their insights and experience through our online consultations. Without exception, the presentations and submissions we have received were authentic, illuminating, and reflective of a genuine commitment to engage constructively on this profoundly important issue. The input we received has both humbled and inspired us. For your generous civic engagement in this shared exercise, we are sincerely and profoundly grateful.

#### Secretariat

Panel members were fortunate to have the assistance of a truly remarkable team of individuals drawn from Justice Canada, Health Canada and the Library of Parliament to support the work of the Panel. We are immensely grateful to Steve Mihorean, Executive Director of the Secretariat, and Scott Hamilton, Director of Operations. With endless skill, fortitude and good humor, both expertly maneuvered the Panel and its activities through many turbulent times, and the occasional calm, to meet its overly ambitious timelines for consulting with Canadians and delivering a professional and thoughtful report to Government. Our heartfelt appreciation also goes out to Rose Homier, Administrative Manager; Martin Ducharme, Senior Policy Analyst; Christine Roush, Senior Communications Strategist; Martha Butler, Lead Writer; Ben Sharpe, Communications Advisor; Michael Lorde, Research Analyst; Caroline Quesnel, Writer; Erin Virgint, Writer; and, Rozie Chaudhry, Administrative Officer.

#### Other Important Acknowledgments

Patricia Seeley made too many contributions to list, and in so many key ways, for which the Panel is indebted.

The Panel also wishes to thank and acknowledge the many other individuals and organizations who contributed to the success of its work. A number of private sector organizations helped with the design and operation of the Panel's website, online consultations, media, editing and translation services, to name a few.

We are also immensely grateful to Michelle Douglas of Justice Canada for allowing us to access her impressive international network, who, together with Canadian mission staff in the Netherlands, Belgium and Switzerland, made our European study mission the success it was.

Finally, we wish to gratefully acknowledge the kind support and assistance of many officials within Justice Canada, Health Canada and the Library of Parliament, for their expert briefings, guidance and support.

All errors and omissions are our own.



External Panel on Options for a Legislative Response to *Carter v. Canada* Comité externe sur les options de réponse législative à *Carter c. Canada* 



**Annex A** 

# Consultations on Physician-Assisted Dying Report on Issue Book Results



On February 6, 2015, the Supreme Court of Canada's decision in *Carter v. Canada* held that sections 241(*b*) and 14 of the *Criminal Code* violate the constitutional rights of certain grievously and irremediably ill adult individuals. These sections of the *Criminal Code* currently make it illegal for anyone, including a doctor, to assist in or cause the death of another person. The Court ordered that the *Criminal Code* provisions remain in force for 12 months to give Parliament time to respond.

On July 17, 2015, the Government of Canada established the External Panel on Options for a Legislative Response to *Carter v. Canada* (the Panel) to consult with Canadians and key stakeholders on important issues relating to physician-assisted dying, such as identifying the risks and considering what rules and safeguards could look like.

This report details the results of the online consultation.

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# **Executive Summary**

#### Consultation Instrument – the "Issue Book"

The Panel used a public consultation methodology called the "Issue Book." A type of workbook, the Issue Book has its roots in the field of public participation and deliberation, rather than a public opinion research survey.

Instead of simply posing questions to measure public views, the Issue Book sought to gather more informed feedback by exposing participants to background information, different perspectives on the issue of assisted dying, and fictional scenarios. The Panel used this instrument to help Canadians consider the various complex issues around assisted dying, and provide their informed input through question sets.

Continued...

#### Consultation Instrument – the "Issue Book" (Continued)

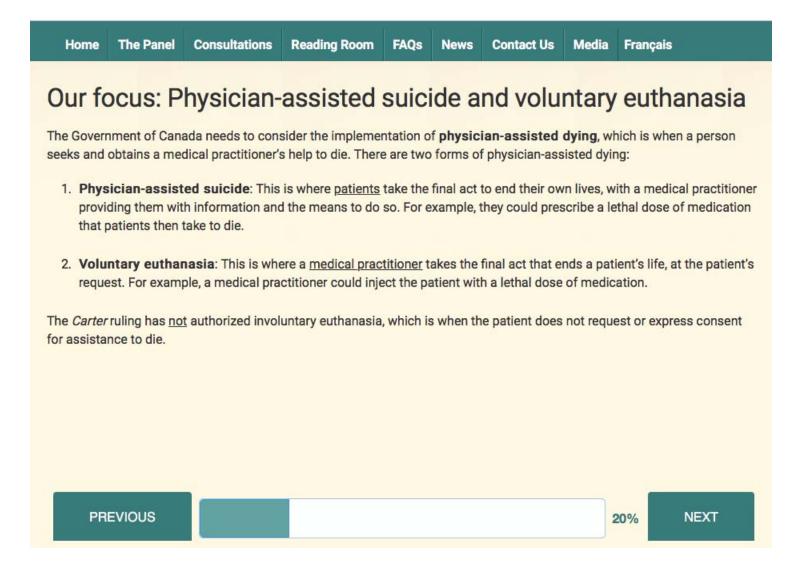
An advantage of the Issue Book methodology is that, by providing information and "food for thought", it ensures participants have a basic understanding of the issue, terminology and different perspectives on the policy issue.

As a result, the Issue Book may not generate the same results as a traditional public opinion survey on the same topic. The information provided to participants is not intended to "persuade" them to respond to questions in a specific, pre-determined way.

Workbooks have been used in many online consultations in the past 15 years.

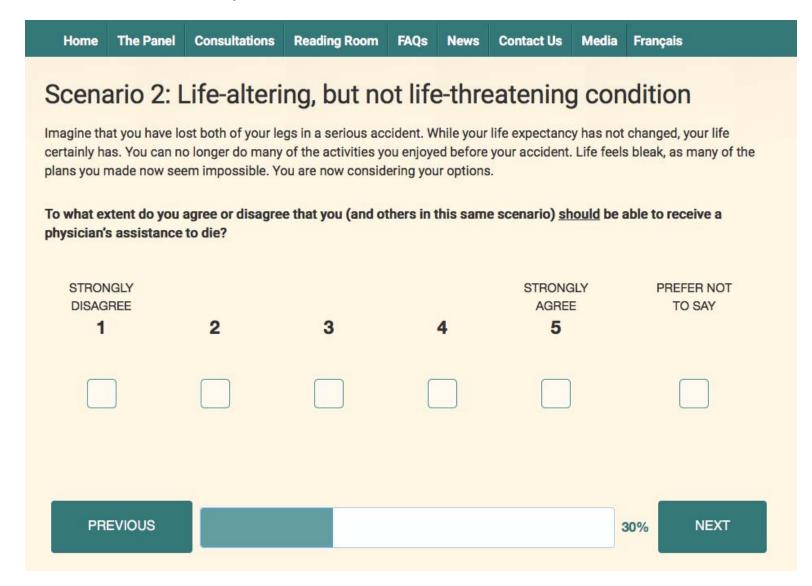
## Sample Issue Book Slide: Background & Context

The Issue Book began by providing participants with factual information about the Panel, its mandate, assisted dying, and related terminology.



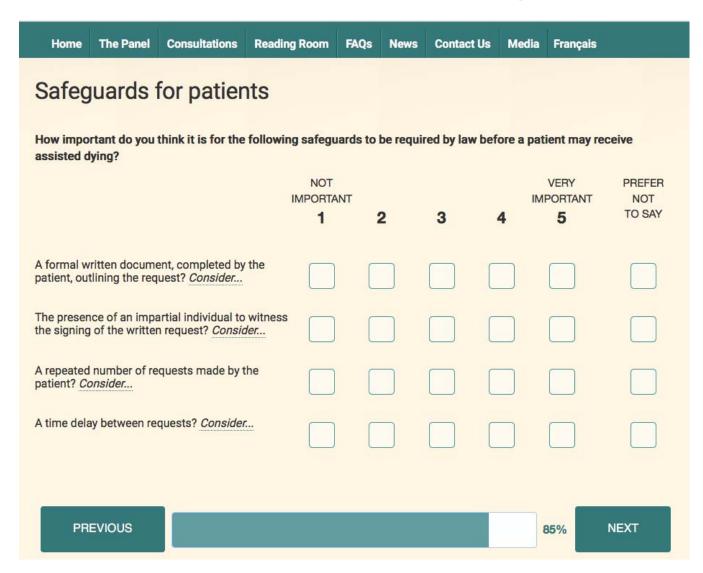
#### Sample Issue Book Slide: Scenarios

The Issue Book provided participants with fictional scenarios to add a "real life" dimension for consideration in responding.



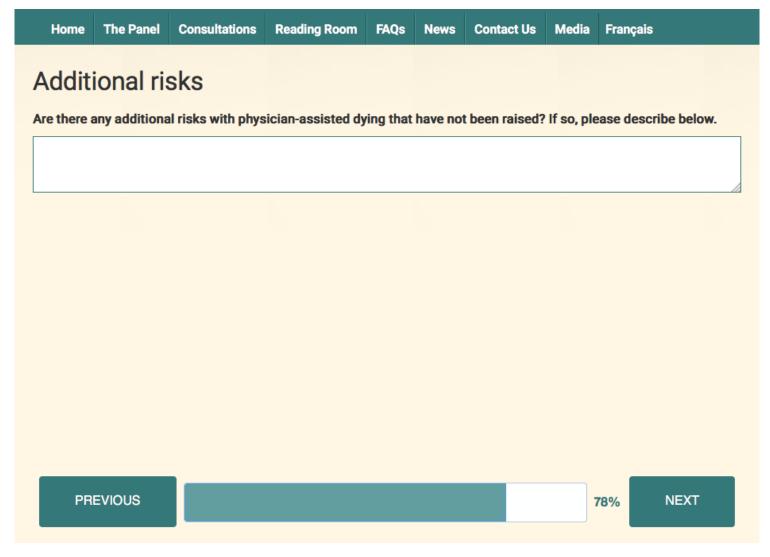
### Sample Issue Book Slide: Safeguards

In another section, the Issue Book asked participants about safeguards while providing additional perspectives to consider by clicking "Consider..."



## Sample Issue Book Slide: Open-Ended Questions

The Issue Book also provided participants with an opportunity to share additional views through a series of open-ended questions at various points through the experience.



#### **Methodology**

- The online Issue Book consultation tool collected feedback on physician-assisted dying from two separate groups of the general Canadian population.
- The first group, the Open Public ("Public"), included responses from any and all individuals interested in contributing to the discourse. Responses from this group were not statistically weighted and results were more polarized on some issues.

#### Methodology

- The second group, the online Representative Sample ("Sample"), included 2,066 responses from a representative sample of the Canadian population, weighted based on the 2011 census according to age, gender and region.
- A sample of this size is considered to be accurate within +/- 2.16% 19 times out of 20. Non-parametric tests were performed for proportions, and all statistical testing was done at a significance level of 0.05.

### Methodology

- The online Representative Sample group was drawn from an actively managed database (the panel) recruited by Leger, the largest Canadian-owned polling, research and strategic marketing firm.
- The Sample group panel comes from several sources: 50% are recruited randomly by Leger's Call Centre; 35% are recruited by invitation and affiliate programs; 5% through social media; 5% by offline recruitment; and, 5% through partner programs and campaigns.
- The Leger panel is an actively managed database, and continuously tests new recruitment methods and processes.

#### <u>Methodology – Use of Fictional Scenarios</u>

At various points in the Issue Book, participants were presented with short fictional scenarios. Each explored a potential situation related to assisted dying. Participants were asked to consider the scenario and respond to a series of follow-up questions.

Scenarios are a normal workbook consultation technique, used to illustrate policy considerations to participants, showing how they might impact people in "real life." Panel members worked carefully to develop fictional scenarios that were realistic, fair, balanced and helped participants consider the broader topic of assisted dying.

Continued...

#### <u>Methodology – Use of Fictional Scenarios (Continued)</u>

A strength of scenarios is that they enable participants to respond to concrete situations – important on a topic like assisted dying, where it may not be appropriate to consider the issue only in abstract terms. The scenarios also make it possible to observe what impact changes in context have on responses to the questions. For example, the proportion of Representative Sample respondents who strongly agree for scenario #2 drops from 13% to 6% when information is added that the event was recent.

The results for each scenario should be interpreted as a whole; by comparing responses to the overarching (first) scenario question with the relative differences in the follow-up scenario questions.

### Analysis Methodology - Qualitative Data

Over <u>1.3 million words</u> of qualitative data (1,368,989) were gathered from participant through the Issue Book's open ended questions (Open Public and Representative Sample datasets). This is equivalent to *over twice* the word count of JRR Tolkien's "The Hobbit" and "The Lord of the Rings" trilogy combined.

This data was reviewed and formally analyzed by a team of trained qualitative researchers, coded using QSR NVivo, a specialized qualitative data analysis instrument. Data was thematically coded and placed into node structures to identify themes in participant responses. Principal themes have been summarized and example quotations identified by our researchers for inclusion in this report.

#### Recruitment and Outreach

The Panel's was prevented from actively promoting its online consultation tool during the 2015 federal election period. However, the Panel did conduct an extensive public outreach campaign to over 200 Canadian organizations (including students, seniors groups, health care practitioners, etc.) to raise awareness of the online consultation. Panel members also participated in a number of media interviews (digital, print, radio and television) and made use of Panel website (ep-ce.ca) and social media tools (Twitter and Facebook) to inform Canadians on the issues and the consultation. These efforts were supplemented by a concentrated digital media advertising campaign which helped boost the number of responses to the Issue Book during the final week of the online consultation.

#### Eligibility

- After reviewing different scenarios, participants were generally more likely to agree physician-assisted dying should be allowed where the individual faces significant, life-threatening and/or progressive conditions. This included scenarios related to advanced dementia, challenging pain control and short-term life expectancy.
- Participants were most likely to disagree it should be allowed in scenarios related to non life-threatening conditions and situations with opportunities for rehabilitation.

#### Risks

- Participants were generally more concerned about risks related to mental health and patients' emotional concerns. These include individuals requesting assistance during an episode that could be temporary, and patient's feeling isolated or lonely.
- They were generally less concerned about implications for medical care or for risks to society, including how this would change their relationship or level of trust with their doctor.

### Safeguards

- The safeguards seen to be the most important by participants included education around palliative care for providers and patients, as well as national strategies on disability supports and home care.
- While still seen as important by a majority of respondents, the safeguards less frequently identified as important largely related to procedural checks, including repeated requests by the patient, evaluation by a group of diverse professionals, consultation with others, and time delays.

#### Evaluation of Issue Book Questionnaire by Respondents

Respondents indicated they were very satisfied with the consultation process, particularly those from the Representative Sample:

- 90% of Representative Sample respondents and 74% of Open Public respondents agreed that "The information was clearly presented." (2% of Representative Sample respondents and 9% of Open Public respondents disagreed)
- 87% of Representative Sample respondents and 65% of Open Public respondents agreed that "The information was well balanced between different views on the issue." (3% of Representative Sample respondents and 16% of Open Public respondents disagreed)
- 83% of Representative Sample respondents and 61% of Open Public respondents agreed that "This online consultation helped you learn about the key issues and concerns." (3% of Representative Sample respondents and 17% of Open Public respondents disagreed)

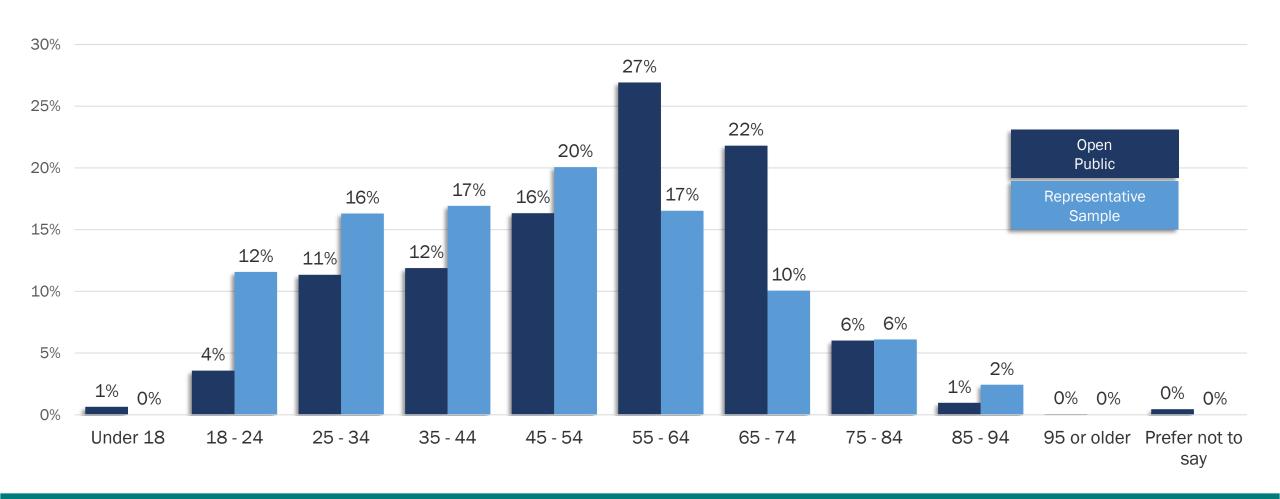
#### Group #1: Open Public ("Public")

Between August 20 and November 23, 2015, the Issue Book questionnaire was completed by 12,883 Canadians. This tool was made available online (and in pdf / paper format, by request) to anyone interested, and represented some of the most active voices in the consultation.

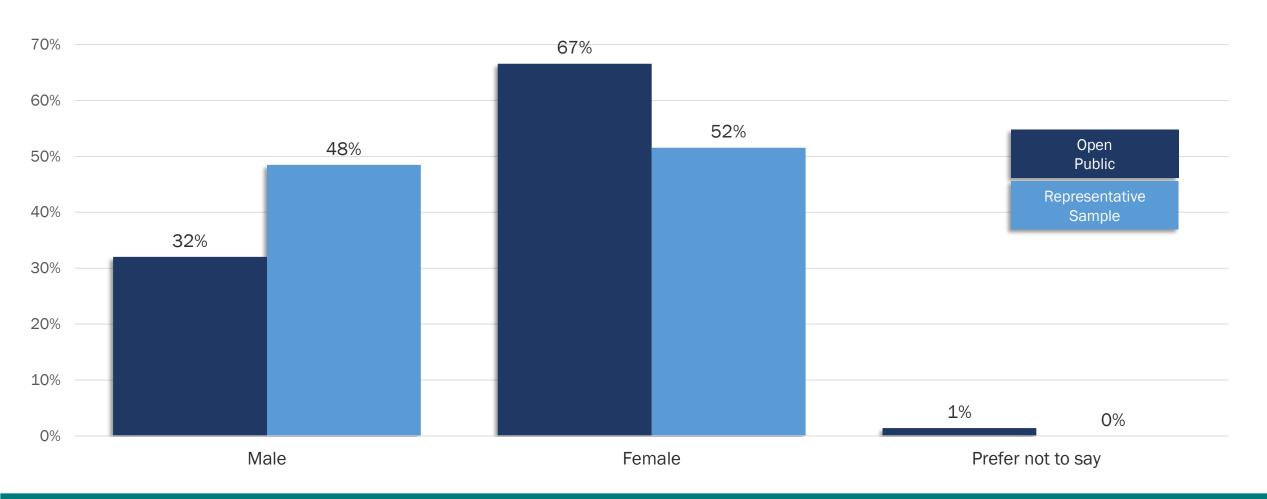
#### Group #2: Representative Sample ("Sample")

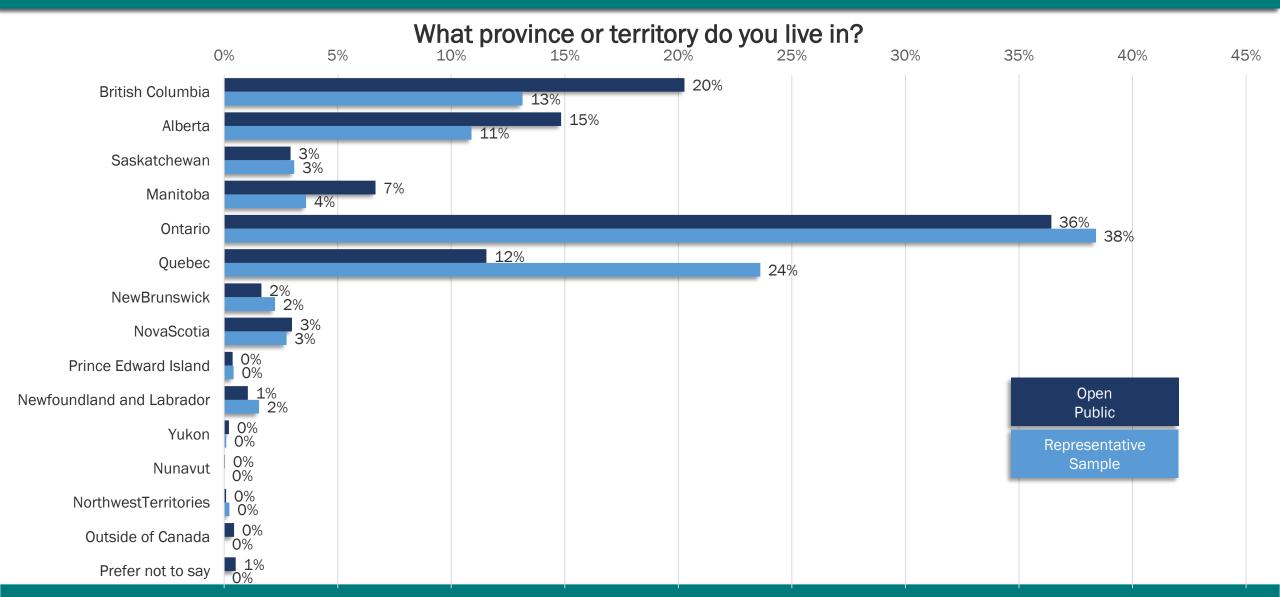
Between October 27 and November 6, 2015, a representative sample of 2,066 Canadians completed the same Issue Book questionnaire online to provide a contextual perspective, using a sample from a panel recruitment supplier.

#### How old are you?

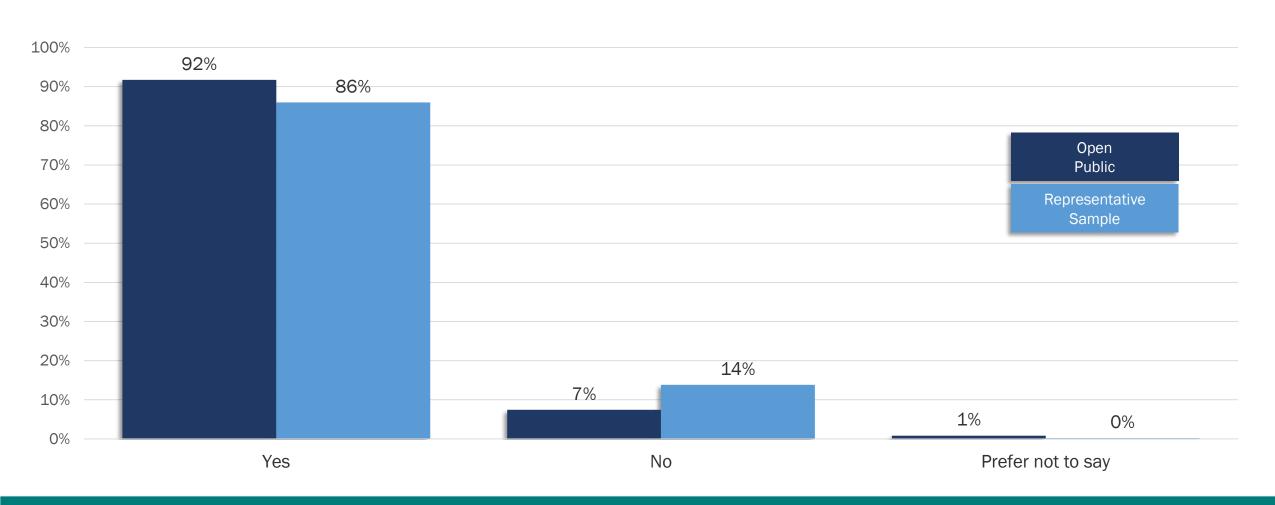


#### What is your gender?

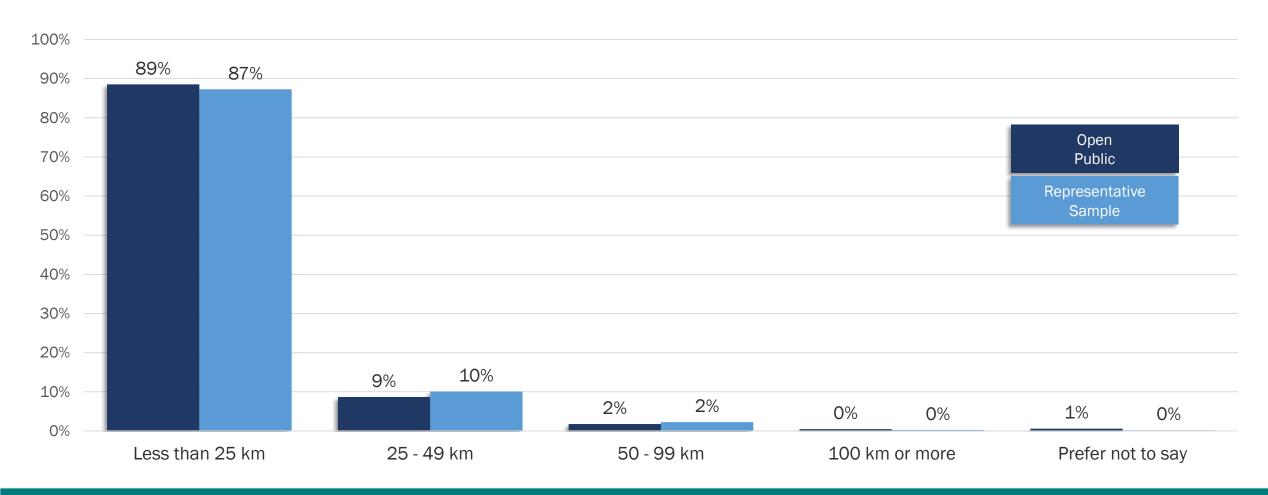




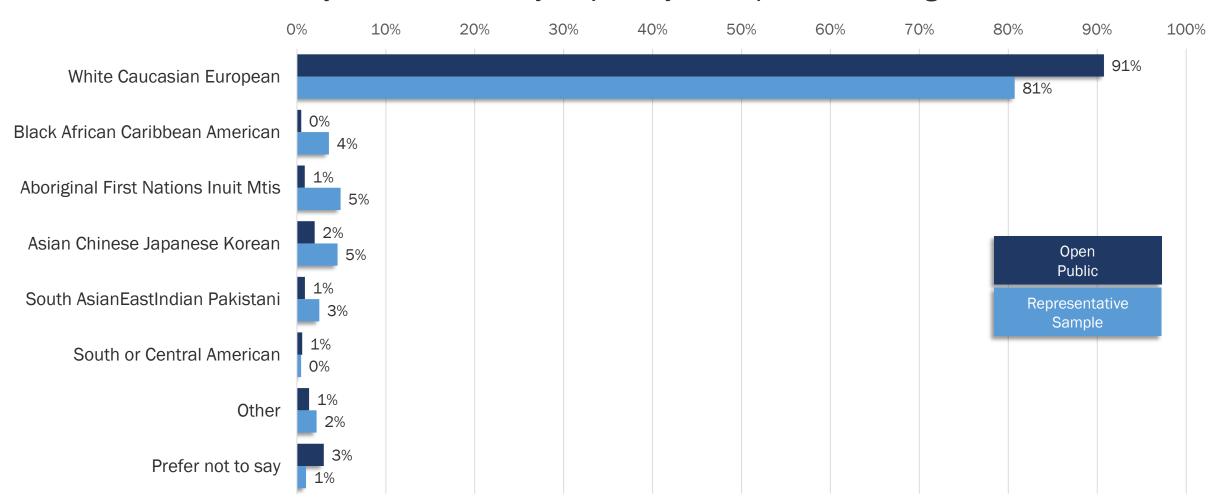
#### Do you have a family doctor?



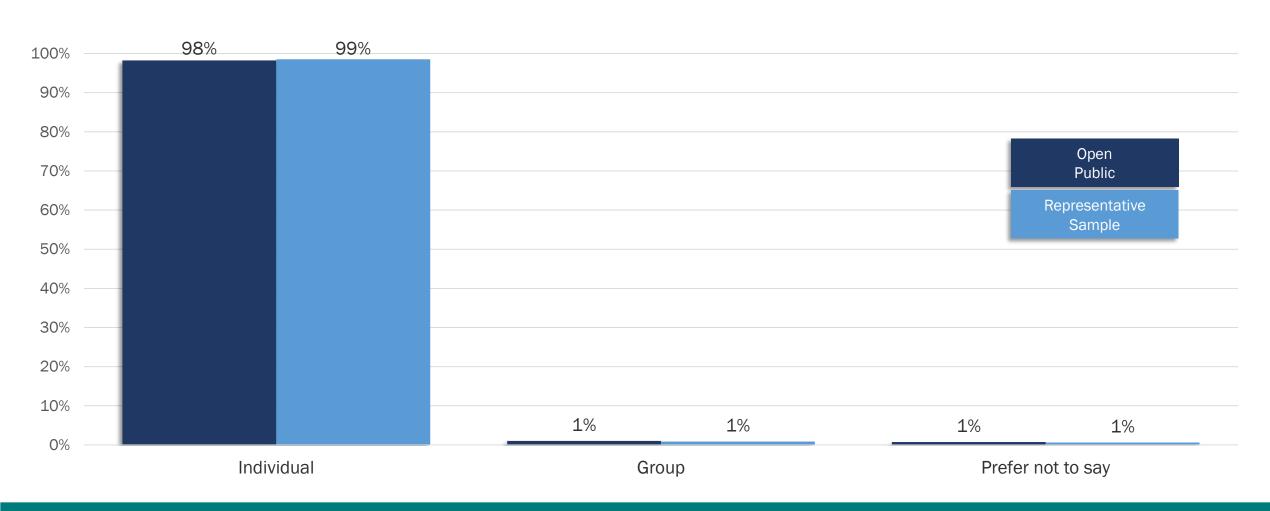
Approximately how far from your home is the nearest hospital to which you could be admitted for care?



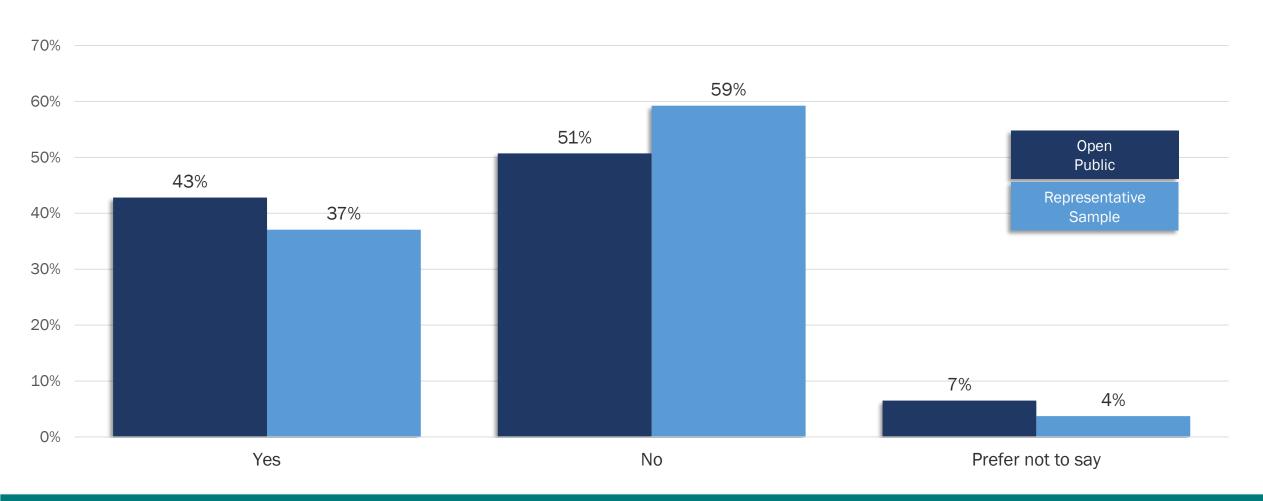
#### What do you consider to be your primary ethnic / cultural background?



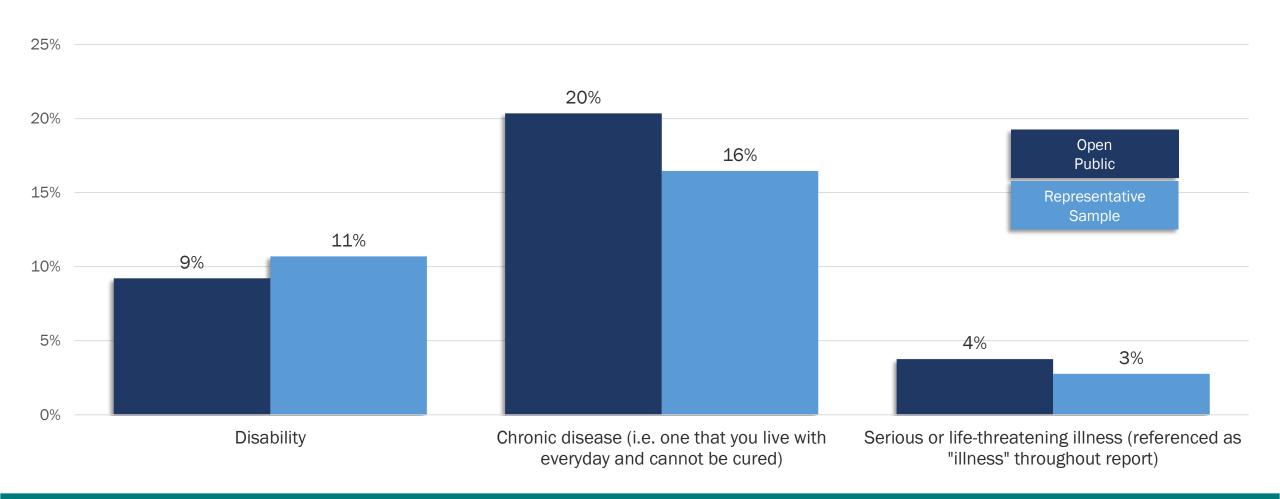
#### Are you responding as an individual, or from a group perspective?



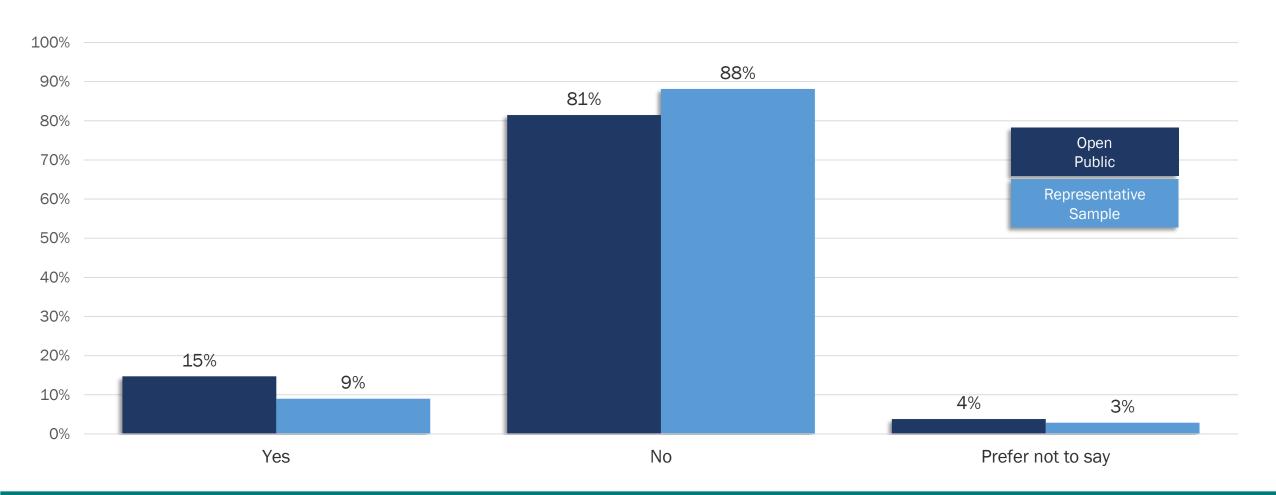
#### Does faith play an important role in how you consider life-and-death issues?



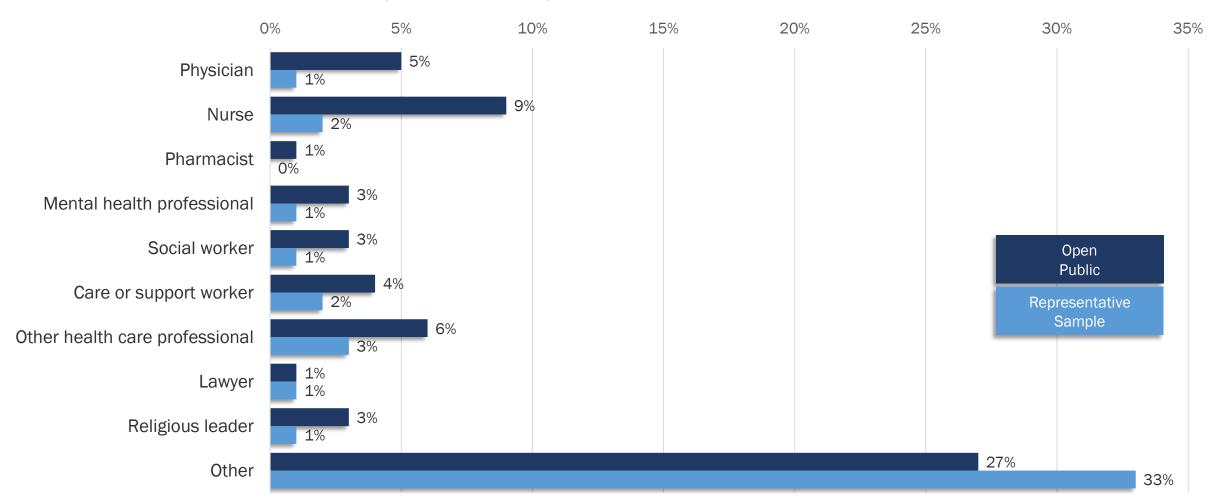
#### Do you have a...



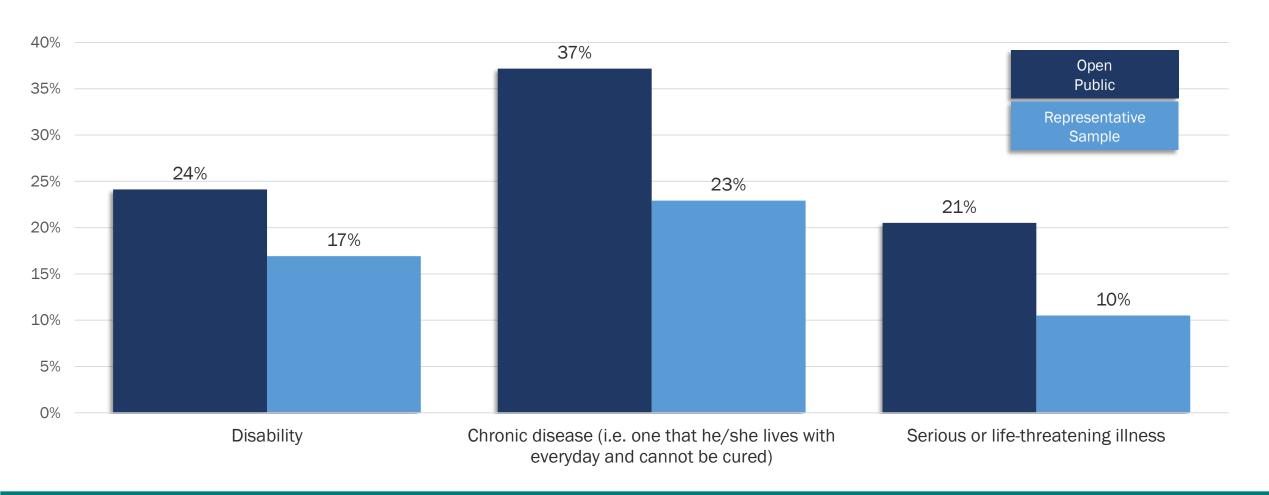
Are you considering / or have you considered asking for assistance to end your life (e.g. from your physician)



#### Do you work in any of these occupations / fields?



#### Do you have a family member or someone close to you with a...



# Detailed Findings

# Eligibility

Participants were asked to imagine how they would feel in different scenarios, to help them think through who might be eligible for assistance in dying.

Specifically, they were asked to imagine how they would feel if they were faced with each of the following diagnoses:

- 1. Significant life-threatening illness
- 2. Life-altering, but not life-threatening illness
- 3. Progressive condition
- 4. Mental health condition

#### **KEY FINDINGS**

- After reviewing different scenarios, participants were generally more likely to agree physician-assisted dying should be allowed where the individual faces significant, life-threatening and/or progressive conditions. This included scenarios related to advanced dementia, challenging pain control and short-term life expectancy.
- Participants were most likely to disagree it should be allowed in scenarios related to non life-threatening conditions and situations with opportunities for rehabilitation.

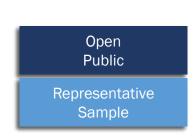
#### **Scenario Presented to Participants:**

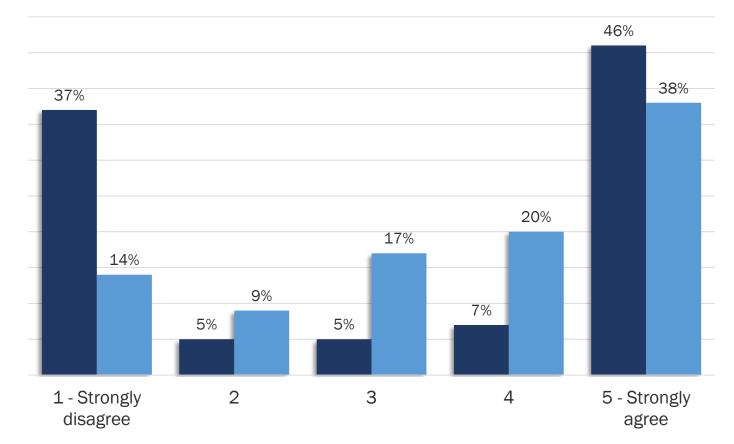
"Imagine that you have a serious life-threatening illness.

Your doctor has told you that the disease has advanced, and that you likely only have months to live.

Despite not having any significant discomfort, you are not interested in going through a long and lingering death. You are considering your end-of-life options."

To what extent do you agree or disagree that you (and others in this same scenario) should be able to receive a physician's assistance to die?

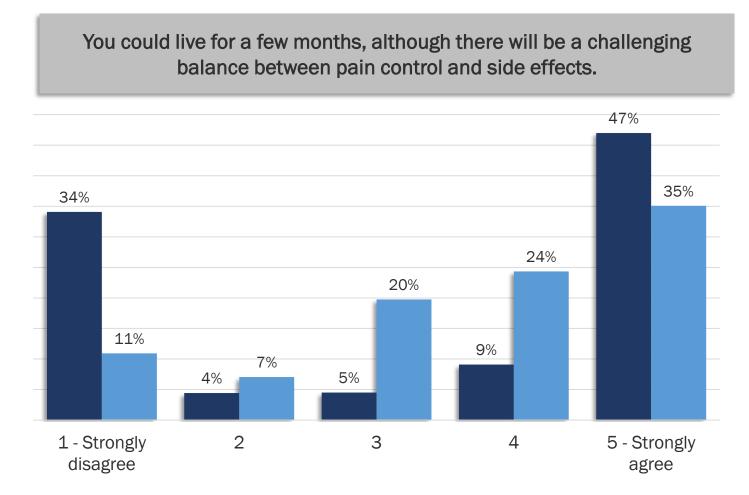




Among the Public, Frenchspeaking participants, Canadians between 55 and 74, and residents of BC, ON, NB and NS were generally the most likely to agree, along with social workers and lawyers.

Among the Sample, residents of SK were less likely to agree.

To what extent do you agree or disagree that you (and others in this same scenario) should be able to receive a physician's assistance to die ... if:



Among the Public, women, Canadians between 55 and 74, and residents of BC, ON, NB and NS were generally the most likely to agree, along with social workers, other healthcare professionals and lawyers.

Among the Sample, men were more likely than women to agree.

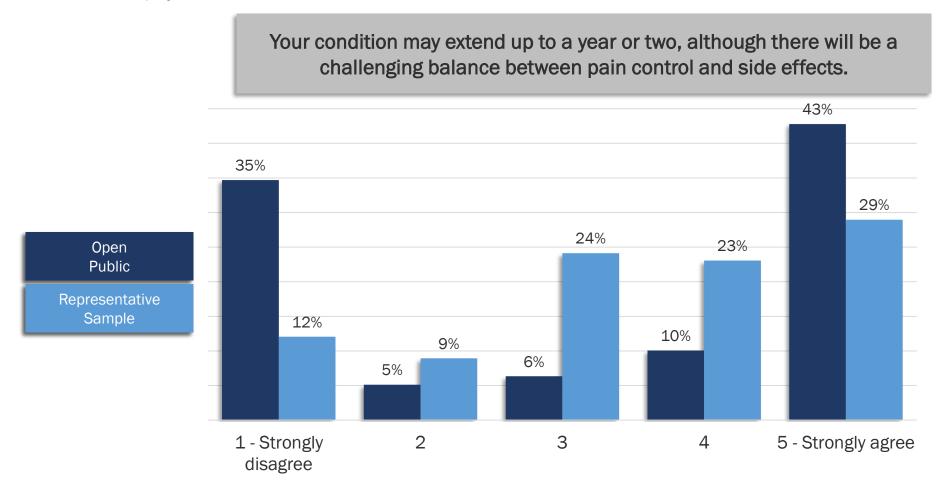
Open

**Public** 

Representative

Sample

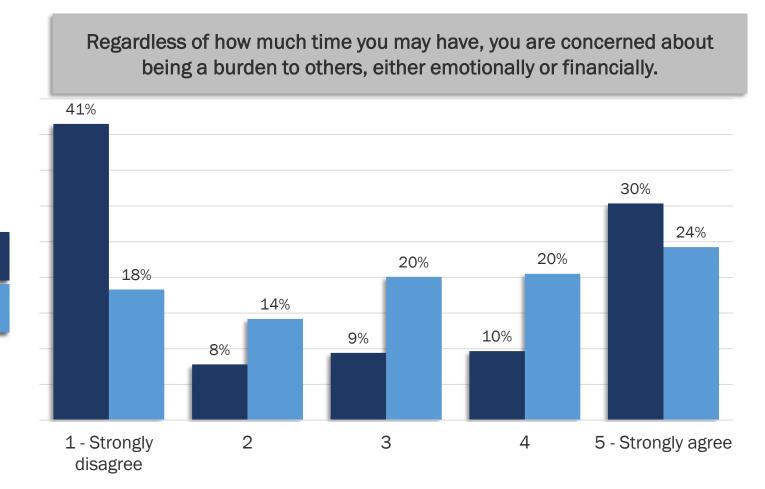
To what extent do you agree or disagree that you (and others in this same scenario) should be able to receive a physician's assistance to die ... if:



Among the Public, Canadians between 55 and 74, and residents of BC, NB and NS were generally the most likely to agree, along with other healthcare professionals and lawyers.

Among the Sample, men were more likely than women to agree.

To what extent do you agree or disagree that you (and others in this same scenario) should be able to receive a physician's assistance to die ... if:



Among the Public, French-speaking participants,
Canadians between 55
and 74, and residents of
BC, NB and NS were
generally the most likely
to agree, along with other
healthcare professionals
and lawyers.

Among the Sample, responses were relatively consistent across demographic groups.

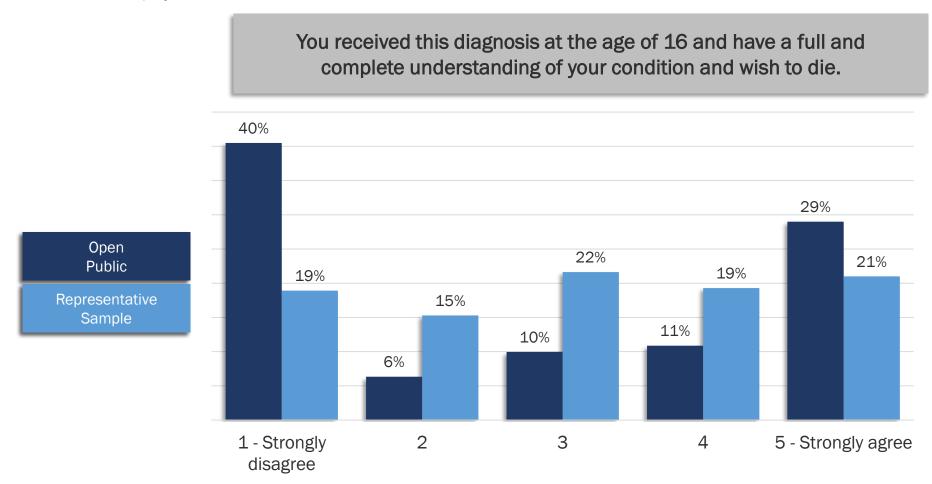
Open

**Public** 

Representative

Sample

To what extent do you agree or disagree that you (and others in this same scenario) should be able to receive a physician's assistance to die ... if:



Among the Public, French-speaking participants, Canadians between 55 and 74, and residents of BC, NB and NS were generally the most likely to agree, along with other healthcare professionals.

Among the Sample, French-speaking participants were more likely than others to agree.

#### **Scenario Presented to Participants:**

"Imagine that you have lost both of your legs in a serious accident.

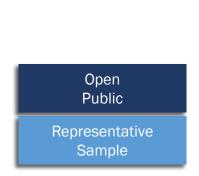
While your life expectancy has not changed, your life certainly has.

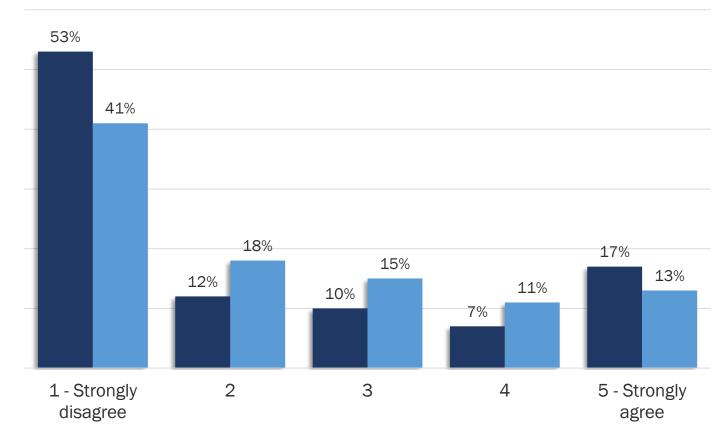
You can no longer do many of the activities you enjoyed before your accident.

Life feels bleak, as many of the plans you made now seem impossible.

You are now considering your options."

To what extent do you agree or disagree that you (and others in this same scenario) should be able to receive a physician's assistance to die?



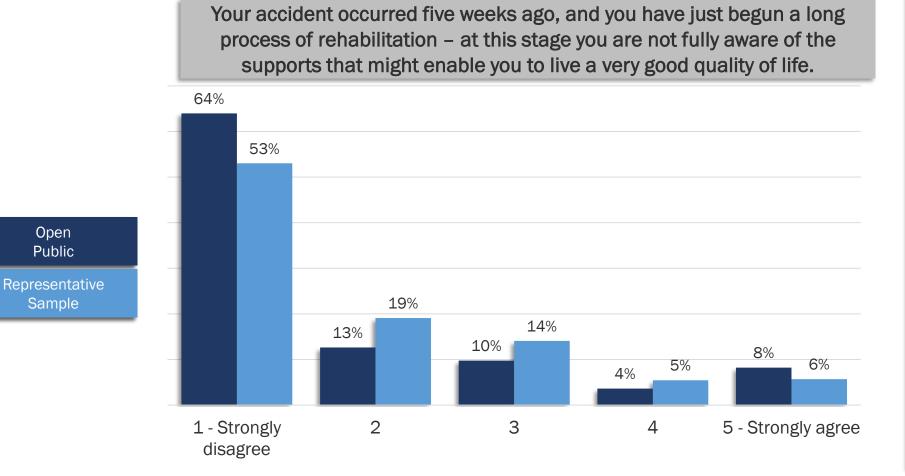


Broadly speaking, all demographics disagreed with this statement.

Among the Public, men, Canadians between 65 and 74, and residents of BC were generally the most likely to agree.

Among the Sample, men were generally more likely to agree in stronger terms than women.

To what extent do you agree or disagree that you (and others in this same scenario) should be able to receive a physician's assistance to die ... if:

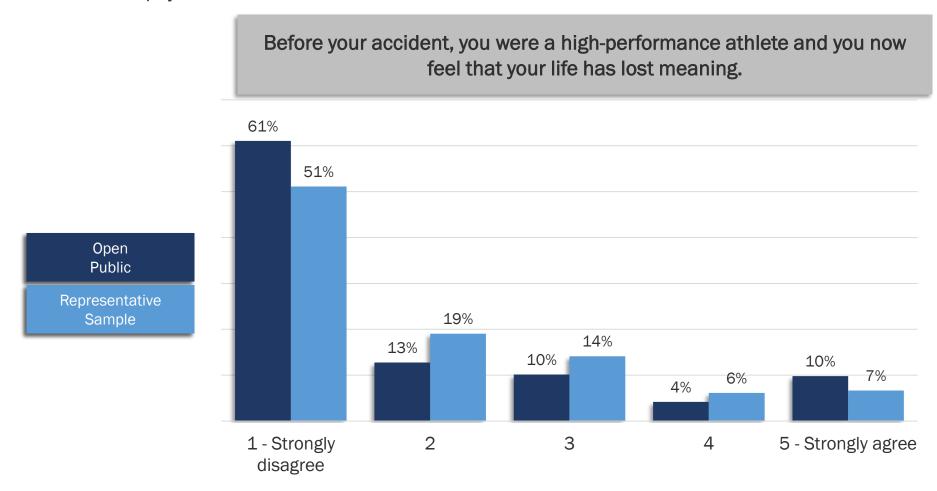


Broadly speaking, all demographics disagreed with this statement.

Among the Public, men, Canadians older than 65, and residents of BC and NB were generally the most likely to agree.

Among the Sample, men and Canadians under 35 were more likely than others to agree.

To what extent do you agree or disagree that you (and others in this same scenario) should be able to receive a physician's assistance to die ... if:

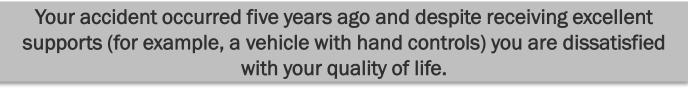


Broadly speaking, all demographics disagreed with this statement.

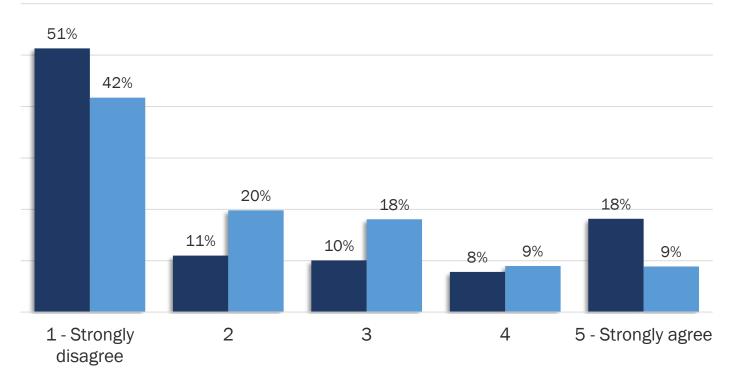
Among the Public, men, Canadians older than 85, residents of BC and lawyers were generally the most likely to agree.

Among the Sample, men were more likely than women to agree, while Canadians between 55 and 64 were more likely to disagree.

To what extent do you agree or disagree that you (and others in this same scenario) should be able to receive a physician's assistance to die ... if:



Open Public Representative Sample

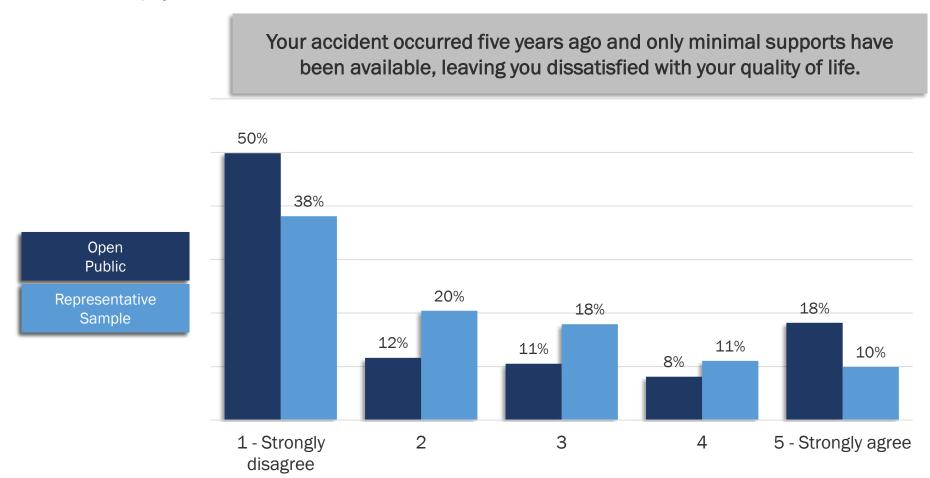


Broadly speaking, all demographics disagreed with this statement.

Among the Public, men, Canadians between 65 and 74, and residents of BC and NS were generally the most likely to agree.

Among the Sample, men were more likely than women to agree.

To what extent do you agree or disagree that you (and others in this same scenario) should be able to receive a physician's assistance to die ... if:



Broadly speaking, all demographics disagreed with this statement.

Among the Public, men, Canadians between 55 and 74, and residents of BC were generally the most likely to agree.

Among the Sample, responses were relatively consistent across demographic groups.

#### **Scenario Presented to Participants:**

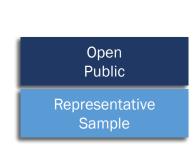
"Imagine that you have just been diagnosed with Alzheimer's.

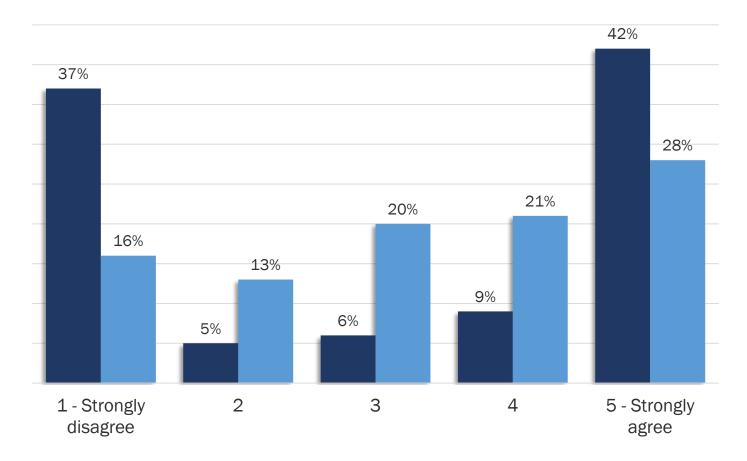
The disease will have a serious impact on your life and will worsen over time.

You have discussed your prognosis extensively with your physician, and you have a clear understanding of what lies ahead for you.

You are considering options available to you."

To what extent do you agree or disagree that you (and others in this same scenario) should be able to receive a physician's assistance to die?

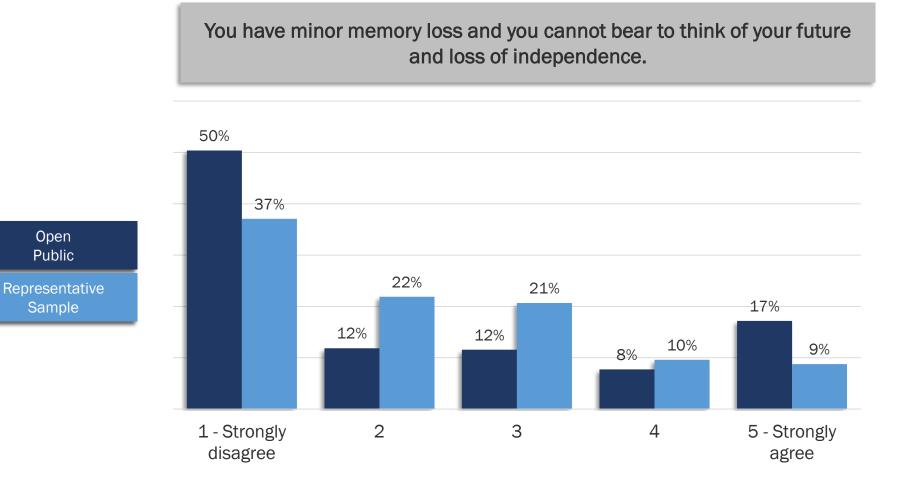




Among the Public, Canadians between 55 and 74, and residents of BC, NB and NS were generally the most likely to agree, along with lawyers.

Among the Sample, responses were relatively consistent across demographic groups.

To what extent do you agree or disagree that you (and others in this same scenario) should be able to receive a physician's assistance to die ... if:

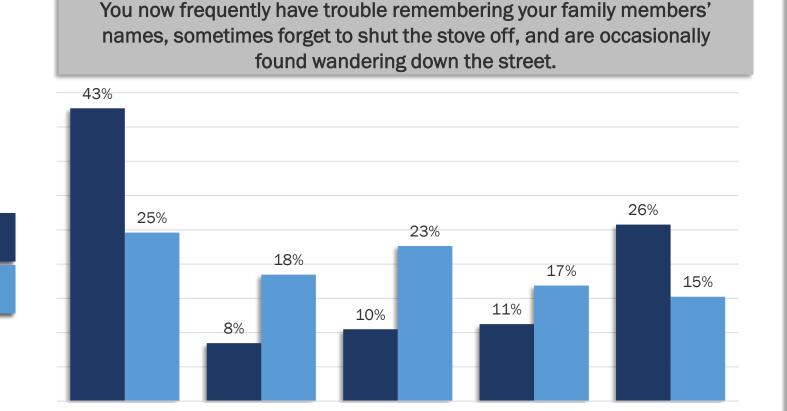


Broadly speaking, all demographics disagreed with this statement.

Among the Public, men and residents of BC and NB were generally the most likely to agree, along with lawyers.

Among the Sample, Canadians between 55 and 74 were more likely than others to disagree.

To what extent do you agree or disagree that you (and others in this same scenario) should be able to receive a physician's assistance to die ... if:



Among the Public, Canadians between 65 and 74 and residents of BC, NB and NS were generally the most likely to agree.

Among the Sample, Canadians between 55 and 64 were the most likely to disagree, while those under 25 were the least likely.

5 - Strongly

agree

4

1 - Strongly

disagree

Open

**Public** 

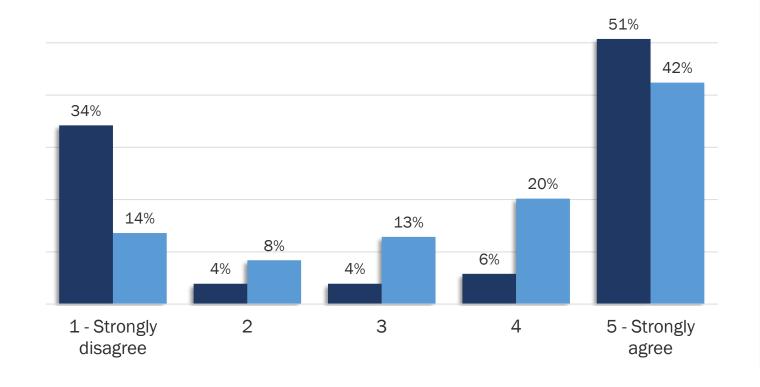
Representative

Sample

To what extent do you agree or disagree that you (and others in this same scenario) should be able to receive a physician's assistance to die ... if:

You now have advanced dementia and cannot make decisions on your own. However, just after your diagnosis you wrote an advance directive indicating that you would want to have a physician's assistance to die at this stage of illness.

Open Public Representative Sample



Among the Public, Frenchspeaking participants, women, Canadians between 55 and 74 and residents of BC, NB and NS were generally the most likely to agree, along with social workers and lawyers.

Among the Sample, French-speaking participants were more likely than others to agree.

#### **Scenario Presented to Participants:**

"Imagine that you have suffered from a mental health condition for much of your life.

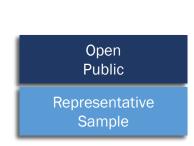
Your condition has interfered with your ability to hold down steady work and has put a strain on your relationships.

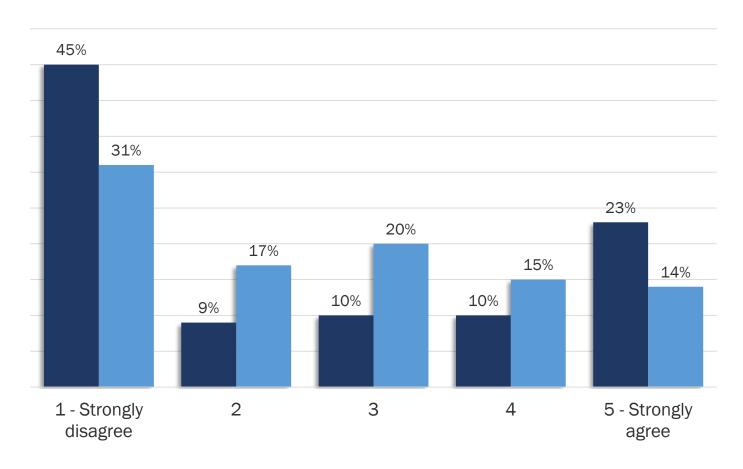
You have tried many treatments, most of which did not help or caused side effects that made you want to quit.

You feel frustrated and hopeless about your future.

Despite excellent care, you are considering ending your life, but you're afraid to try by yourself in case you don't succeed and make things worse."

To what extent do you agree or disagree that you (and others in this same scenario) should be able to receive a physician's assistance to die?



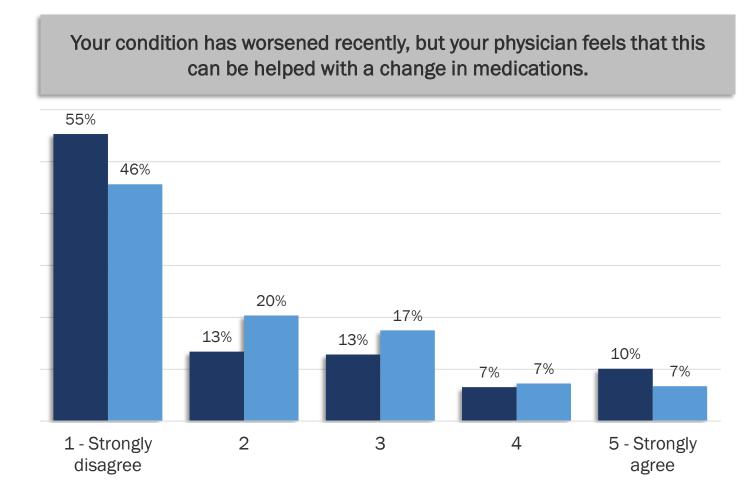


Broadly speaking, all demographics disagreed with this statement.

Among the Public, Canadians between 55 and 74 and residents of BC, NB and NS were generally the most likely to agree.

Among the Sample, responses were relatively consistent across demographic groups.

To what extent do you agree or disagree that you (and others in this same scenario) should be able to receive a physician's assistance to die ... if:



Broadly speaking, all demographics disagreed with this statement.

Among the Public, men, Canadians older than 85 and residents of BC were generally the most likely to agree.

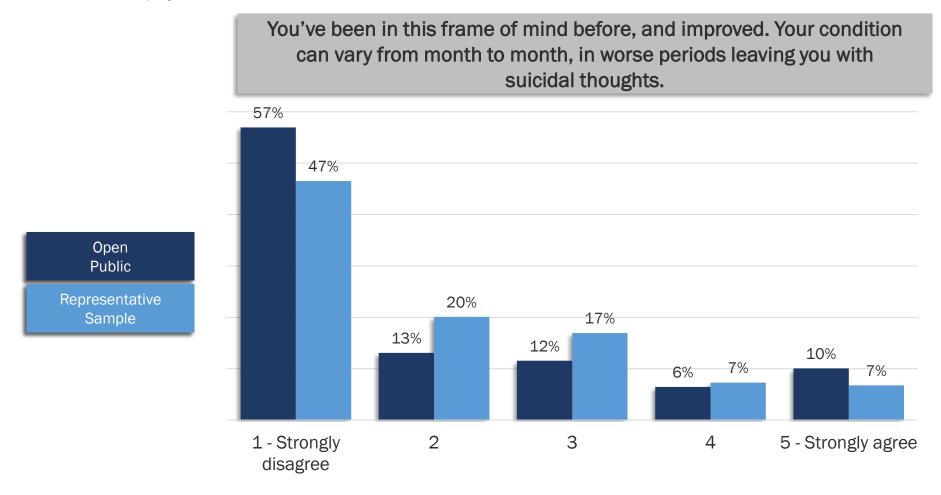
Among the Sample, men were more likely than women to agree.

Open Public

Representative

Sample

To what extent do you agree or disagree that you (and others in this same scenario) should be able to receive a physician's assistance to die ... if:

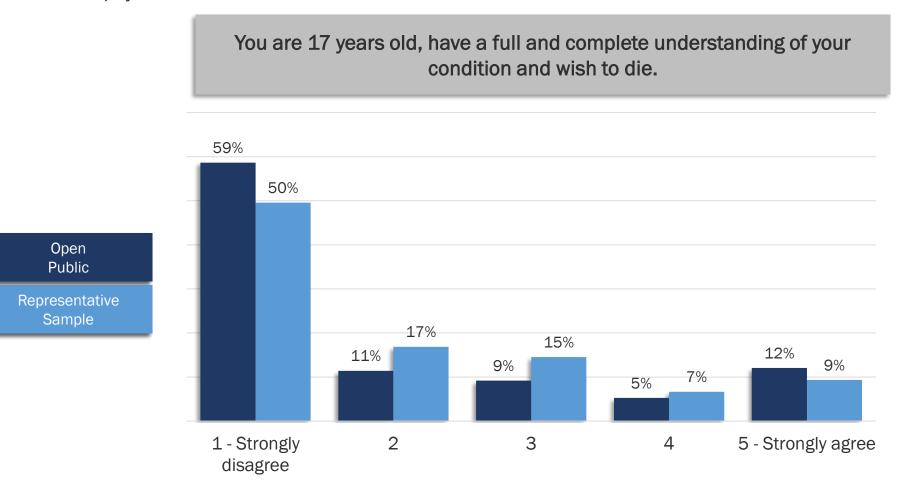


Broadly speaking, all demographics disagreed with this statement.

Among the Public, men, Canadians older than 65 and residents of BC were generally the most likely to agree.

Among the Sample, men were more likely than women to agree.

To what extent do you agree or disagree that you (and others in this same scenario) should be able to receive a physician's assistance to die ... if:



Broadly speaking, all demographics disagreed with this statement.

Among the Public, men, Canadians between 65 and 74 and residents of BC were generally the most likely to agree.

Among the Sample, men were more likely than women to agree.

# Eligibility Scenarios: Strongest participant agreement

Below are the five scenarios in which <u>Public participants</u> agreed most strongly that someone should be able to receive a physician's assistance to die.

You now have advanced dementia and cannot make decisions on your own [but you wrote an] advanced directive that you would want to have a physician's assistance to die

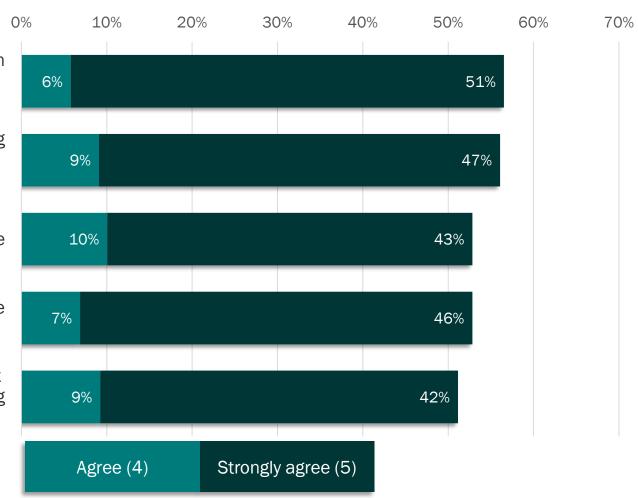
You could live for a few more months with your serious life-threatening condition, although there will be a challenging balance between pain control and side effects

Your serious life-threatening condition may extend up to a year or two, although there will be a challenging balance between pain control and side effects

You have a serious life-threatening illness: Your doctor has told you that the disease has advanced, and that you likely only have months to live.

You are diagnosed with Alzheimer's. The disease will have a serious impact on your life and will worsen over time ... and you have a clear understanding of what lies ahead for you.

<u>Note:</u> The same five scenarios for when someone should be able to receive a physician's assistance to die were most strongly agreed to by both Public and Sample participants (next slide).



# Eligibility Scenarios: Strongest participant agreement

Below are the five scenarios in which <u>Sample participants</u> agreed most strongly that someone should be able to receive a physician's assistance to die.

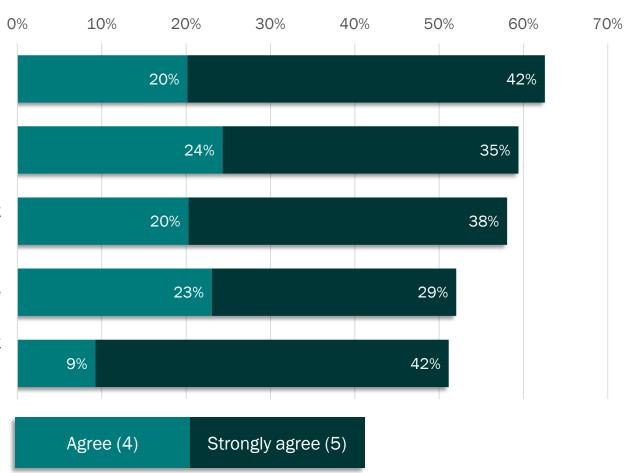
You now have advanced dementia and cannot make decisions on your own [but you wrote an] advanced directive that you would want to have a physician's assistance to die

You could live for a few more months with your serious life-threatening illness, although there will be a challenging balance between pain control and side effects.

You have a serious life-threatening illness: Your doctor has told you that the disease has advanced, and that you likely only have months to live.

Your serious life-threatening condition may extend up to a year or two, although there will be a challenging balance between pain control and side effects.

You are diagnosed with Alzheimer's: The disease will have a serious impact on your life and will worsen over time ... and you have a clear understanding of what lies ahead for you.



#### Eligibility Scenarios: Strongest participant disagreement

Below are the five scenarios in which <u>Public participants</u> disagreed most strongly that someone should be able to receive a physician's assistance to die.

Your life-altering but not life-threatening accident occurred five weeks ago, and you have just begun a long process of rehabilitation – at this stage you are not fully aware of the supports that might enable you to live a...

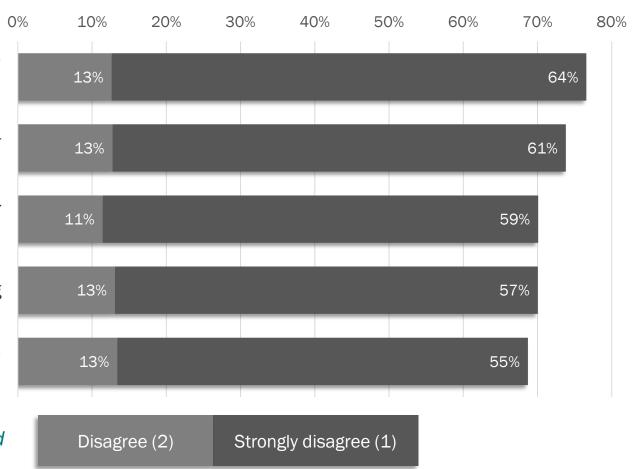
Before your life-altering but not life-threatening accident, you were a high-performance athlete and you now feel that your life has lost meaning.

You are 17 years old, have a full and complete understanding of your mental health condition and wish to die.

You've been in this frame of mind before, and improved. Your mental health condition can vary from month to month, in worse periods leaving you with suicidal thoughts.

Your mental health condition has worsened recently, but your physician feels that this can be helped with a change in medications.

<u>Note:</u> The same five scenarios for when someone should be able to receive a physician's assistance to die were most strongly disagreed with by both Public and Sample participants (next slide).



#### Eligibility Scenarios: Strongest participant disagreement

Below are the five scenarios in which <u>Sample participants</u> disagreed most strongly that someone should be able to receive a physician's assistance to die.

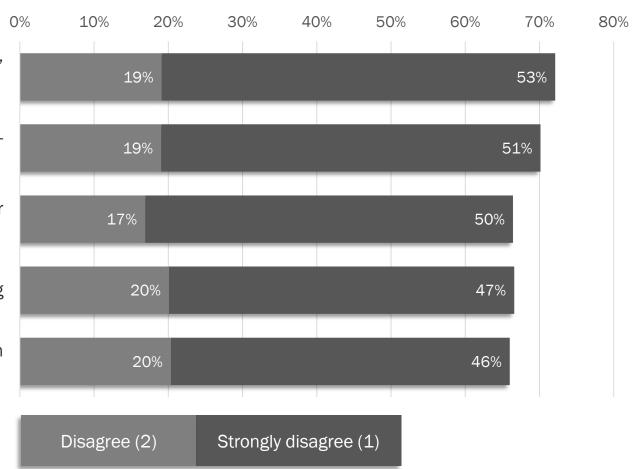
Your life-altering but not life-threatening accident occurred five weeks ago, and you have just begun a long process of rehabilitation – at this stage you are not fully aware of the supports that might enable you to live a...

Before your life-altering but not life-threatening accident, you were a high-performance athlete and you now feel that your life has lost meaning.

You are 17 years old, have a full and complete understanding of your mental health condition and wish to die.

You've been in this frame of mind before, and improved. Your mental health condition can vary from month to month, in worse periods leaving you with suicidal thoughts.

Your mental health condition has worsened recently, but your physician feels that this can be helped with a change in medications.



#### Qualitative Feedback on Additional Eligibility Factors

#### Summary of responses and sampling of quotes grouped by theme for Issue Book question:

Are there any additional factors related to eligibility for physician-assisted dying that you wish to highlight?
 If so, please describe below.

#### Theme 1: Advance health care directives

<u>Summary:</u> Many respondents from the Open Public group mentioned that an advance health care directive to access physician-assisted dying should be honoured. Representative Sample respondents agreed. Respondents were polarized on whether a health care proxy could make such a decision if an advance health care directive was not in place. Some people were also concerned about an advance directive being misused/abused.

#### Quotes:

- "Advance care directives must be considered paramount in decision-making as these are the expressed wishes of an individual while competent." (Representative Sample respondent)
- "A person must be able to make their legal directive for physician assisted dying BEFORE they become incapable of rational decision making." (Open Public respondent)
- "An early diagnosis of Alzheimer's disease should give the patient the right to decide to end their life. There should be a written request signed before two witnesses, and the doctor assigned to the patient must be included in the steps towards aid in dying. An example is if I do not recognize anyone and have no idea of what is happening around me." (Representative Sample respondent, original in French)

Concern about misuse/abuse:

"As a retired health care professional who taught consent legislation to my colleagues, I am aware that Ontario Consent legislation is still
very poorly understood and implemented by health care professionals and ever more poorly understood by the general public. I am deeply
concerned about the abuse of advance directives in such an environment of benign ignorance." (Open Public respondent)

Theme 1: Advance health care directives (continued)

Quotes:

Health care proxy:

- "If a family member with advanced dementia, or other fatal illness, doesn't have a Living Will, there should be a provision for the executor of their will, family members, or whoever holds the enduring power of attorney, to request a doctor investigate the possibility of ending their life." (Open Public respondent)
- "An individual should be able to appoint someone to make a request for assisted death if included in a legal power of attorney for personal care if they become incapacitated and unable to follow through with their own wishes to make such a request." (Open Public respondent)
- "In the scenario of Alzheimer's with an advanced directive, the power over that person's life and timing of death should not be in someone else's hands despite being a health proxy." (Open Public respondent)
- "For progressive illnesses, the requests must be made while the person is still able to understand the ramifications on their families, etc.
   Substitute decision makers should not be making these types of decisions once the person is unable to do so for themselves if they have not previously made such a request." (Representative Sample respondent)

#### Theme 2: Age restrictions

Summary: While age was consistently given as a limiting factor for eligibility for physician-assisted dying, with some expressing that age should not matter, what the age restriction should be varied. In other words, at what age people should become eligible for physician-assisted dying was not clear. The predominant rationale for excluding young people was that they were incapable of truly comprehending their situation or the weight of the decision, and therefore could not properly give informed consent. Similarly many felt that a parent or other health proxy should not be able to give consent for a minor, whereas some thought that a parent or guardian should be able to approve physician-assisted dying.

#### Quotes:

#### Age of eligibility:

- "Anyone under the age of 18 should not have this choice. They have not experienced life enough to make this decision for themselves."
   (Representative Sample respondent)
- "I think the patient should be 19+ and have a full understanding of their condition." (Representative Sample respondent).
- "Children, no matter if they are an infant up until they turn 18, should not be eligible. They have not yet formed the complex thought process involved in making this decision." (Representative Sample respondent)
- "The minimum age should be over 21 years ... and it should only include incurable diseases like Alzheimer's or dementia." (Open Public respondent, original in French)
- "Age of course is an important factor, but consider the minor who has for example a rare disease, is well aware of their prognosis and conditions (most children with rare diseases are very well informed about their disease), and wants to consider options in consultation/collaboration with their primary care giver(s)." (Open Public respondent)

Theme 2: Age restrictions (continued)

Quotes:

Parental consent:

- "This type of decision shouldn't be made by minors, i.e. under age 18. Their parent/guardian shouldn't be able to make it for them. The individual would have to be 18 and capable of making the decision on their own." (Open Public respondent)
- "Age of consent should be considered. Perhaps parent/guardians would need to approve for those under the age of majority." (Open Public respondent)

#### Theme 3: Informed Consent

Summary: Linked to a patient's right to choose physician-assisted dying, respondents in the Open Public and Representative Sample groups emphasized that a person must be *able* to choose physician-assisted dying with a "sound mind" and all of the requisite information to make an informed decision. Some respondents felt that if the person is unable to give informed consent, that a health proxy should be able to make the decision for that person, whereas others felt that only an individual should be able to consent for oneself. Many said that mental health and depression were seen as incapacitations to an informed decision.

#### Quotes:

- "This should be a conversation between the individual and their doctor. All that should be required is informed consent." (Open Public respondent)
- "Anyone contemplating assisted suicide should, by law, have to have an interview or series of interviews with a psychologist or psychiatrist, perhaps one appointed by the courts, to ascertain the person's ability to understand their condition and make an informed decision on the subject." (Open Public respondent)
- "As long as a person 16 years of age or over is able to understand their options and can make their decision with competence and of sound mind, there should be no further debate. However, under no circumstances should anyone be allowed to make the decision on another person's behalf (i.e., family/guardian of a person with an intellectual, mental, physical or other disability). This decision must be made when a person is competent, of sound mind, understands their options and can give informed consent." (Open Public respondent)
- "There should be a thorough discussion with professionals and family before an individual makes the final decision." (Representative Sample Respondent)
- "A person should be terminally ill and be able to make a decision at any point in the illness. Someone who is depressed, mental health issues is not capable of making an informed decision." (Representative Sample Respondent)

#### Theme 4: Patient Choice

<u>Summary:</u> Many respondents in the Open Public and Representative Sample groups mentioned that a patient should be able to choose physician-assisted dying (be the decision-maker) – some stating, without many other limiting factors on eligibility. Others maintained that patients should have the right to choose physician-assisted dying, given that certain eligibility criteria are met.

#### Quotes:

- "It should be the individual's choice (with physician consultation). Adults suffering with physical ailments (cancer, ALS, Alzheimer's etc.) should have few, if any, barriers to accessing physician-assisted dying and voluntary euthanasia. Those under 18 and those struggling with mental health issues that lead them to ask for physician-assisted dying should have different criteria for eligibility. But mentally well adults should be able to make their own decision on this matter with as few hoops to jump through as possible." (Open Public respondent)
- "This should be a personal decision. An individual should have the right to determine whether or not they want to live or die. The patient is the one who has to live with their illness, day to day. No one can determine a rating of "Quality of Life" for anyone else." (Open Public respondent)
- "It's definitely the patient who decides whether to live or die, and this should be done before they no longer have the strength to say it."
   (Open Public respondent, original in French)
- "I believe it should always be the choice of the individual, regardless of their current medical situation, to be able to end their life. It is their right. I do not believe it IS right, just that it is THEIR right." (Representative Sample respondent)
- "If your condition is terminal, you should have the right to die with dignity and stop suffering." (Representative Sample respondent)

#### <u>Theme 5:</u> Significant life-threatening illness

Summary: That a person is both terminally ill and in intolerable pain was the most predominant factor related to eligibility for physician-assisted dying highlighted by respondents in both the Open Public and Representative Sample groups.

Respondents frequently stated that a patient having "no hope" warranted the use of physician-assisted dying as a "last resort." Progressive, degenerative conditions were often listed alongside terminal illness as a justifiable condition for eligibility. However, respondents cautioned against disability and mental health conditions (particularly depression) as reasons for physician-assisted dying.

#### Quotes:

Both terminally ill and in intolerable pain

- "A terminal diagnosis with eminent death or very brief life expectancy, accompanied by extreme pain that cannot be controlled by analgesia." (Open Public respondent)
- "I think the court made it clear: (a) you live in pain and (b) you are about to die anyway. If you have (a) and (b) together, that's the only time the person should be eligible." (Representative Sample respondent)

Progressive condition

- "A person with a life threatening or progressive degenerative condition is already on a path toward death, which can be "hastened." A
  person who is not already at risk of dying due to a medical condition should not be encouraged or supported in choosing death." (Open
  Public respondent)
- "My personal opinion is that only persons with severe, incurable conditions that will not improve, e.g. terminal cancer, Alzheimer's, ALS, etc. should be considered eligible." (Representative Sample respondent)

<u>Theme 5:</u> Significant life-threatening illness (continued)

Quotes:

Disability and mental health condition

- "I feel [physician-assisted dying] should only be available to those who are seriously ill, not just having a disability but actually seriously ill
  and facing intolerable pain with no chance of recovery at all." (Open Public respondent)
- "I believe one should have the option of physician-assisted death in terminal and exceptional impending death but not because the person's mental state does not feel life is worth living because of physical disabilities." (Representative Sample respondent)
- "I think it is important, as shown in your scenarios, that mental health or depression that can be fixed with medication, doesn't get confused with an illness that you are dying from." (Representative Sample respondent)

#### Theme 6: Supports and alternatives

Summary: Another prominent theme that emerged from Open Public responses on factors related to eligibility for physician-assisted dying was that patients have access to palliative care, or alternative treatments (particularly for mental health), to ensure that they have considered all other options before qualifying for physician-assisted dying. Similarly, many participants indicated that it is important that patients have access to social supports and counselling, as well as financial supports so that the lack of these supports is not a factor in their decision-making. Having access to supports and alternatives before considering physician-assisted dying as a "last resort" was also a common theme in the Representative Sample group.

#### Quotes:

Palliative care and alternative treatments

- "All patients should have access to quality palliative care." (Open Public respondent)
- "There needs to be assurance that necessary care is available immediately as needed, be it mechanical, medication, and/or qualified attendant care, in order to maintain quality of life for the greatest length of time prior to termination as this will be a determining factor in maintaining dignity." (Representative Sample respondent)
- "Before suicide should be an option, I think every service for mental help and care assistance should be explored. Afterwards the decision should be up to the affected individual." (Open Public respondent)
- "Many of the people in the scenarios would benefit from better access to mental and physical health care... Along with criteria for assisted suicide, we must ensure that everyone is provided with such access." (Representative Sample respondent)

<u>Theme 6:</u> Supports and alternatives (continued)

Quotes:

Social and financial supports

- "It seems to me that there should be mandatory supports in place for individuals prior to making this decision, for example, social workers, religious supportive community, support groups, counseling, meeting others who face the similar conditions, palliative care professionals, transition counseling, etc." (Open Public respondent)
- "People should not feel a need to die because of their socio-economic situation, for example poverty or feeling like a burden to family." (Representative Sample respondent)

# Risks

In its ruling on *Carter*, the Court recognized that there are risks involved in permitting physician-assisted dying in Canada.

This section focused on the risks for:

- 1. Patients
- 2. Persons with disabilities
- 3. Persons with mental health conditions
- 4. Palliative care
- 5. Canadian society

#### **KEY FINDINGS**

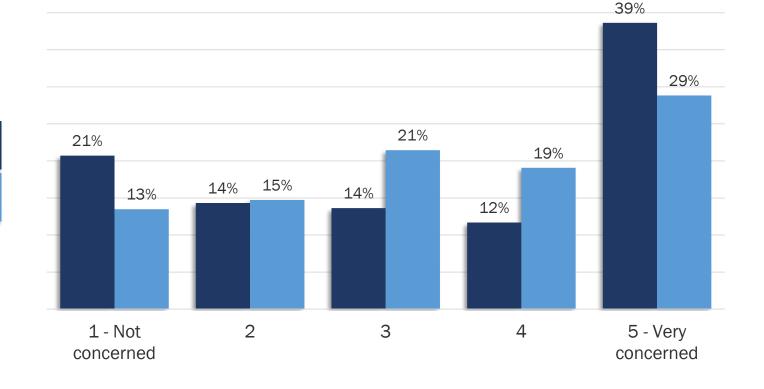
- Participants were generally more concerned about risks related to mental health and patients' emotional concerns. These include individuals requesting assistance during an episode that could be temporary, and patient's feeling isolated or lonely.
- They were generally less concerned about implications for medical care or for risks to society, including how this would change their relationship or level of trust with their doctor.

How concerned are you that physician-assisted dying will pose the following risks?

Patients will be <u>more</u> likely to request assistance from a physician to die because...

They feel pressured or influenced by their family / loved ones.

Open Public Representative Sample



Among the Public, French-speaking participants,
Canadians under 25 and residents of AB, MB and
QC were generally the most concerned, along with religious leaders, physicians and care or support workers.

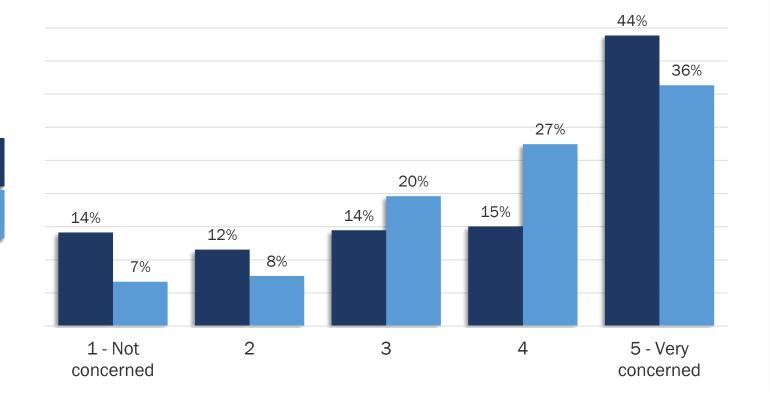
Among the Sample, concern generally increased for older demographics.

How concerned are you that physician-assisted dying will pose the following risks?

Patients will be <u>more</u> likely to request assistance from a physician to die because...

They feel they are an emotional burden to their family / loved ones.

Open Public Representative Sample



Among the Public, French-speaking participants,
Canadians under 35 and residents of AB, MB and
QC were generally the most concerned, along with religious leaders, physicians and care or support workers.

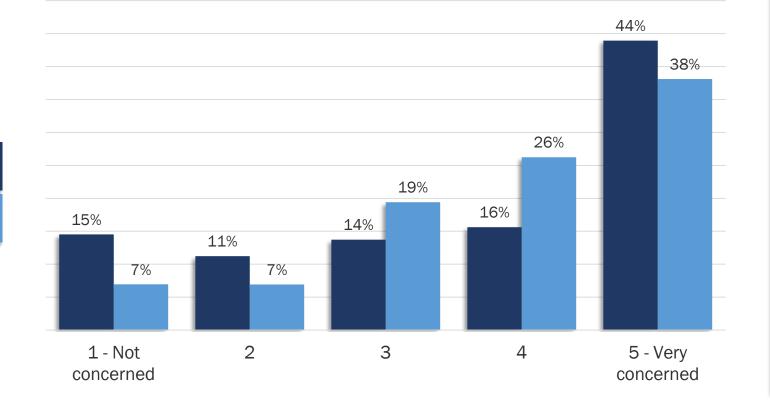
Among the Sample, responses were relatively consistent across demographic groups.

How concerned are you that physician-assisted dying will pose the following risks?

Patients will be <u>more</u> likely to request assistance from a physician to die because...

They feel they are a <u>financial</u> burden to their family / loved ones or to society at large.

Open Public Representative Sample



Among the Public, women, Canadians under 35 and residents of AB, MB and QC were generally the most concerned, along with religious leaders, physicians and care or support workers.

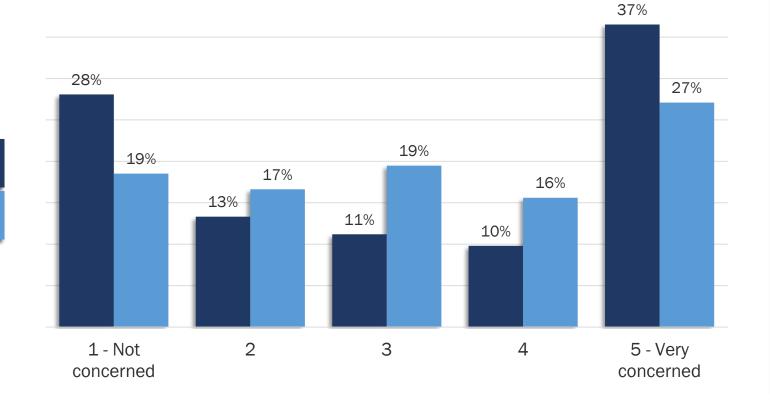
Among the Sample, concern generally increased for older demographics.

How concerned are you that physician-assisted dying will pose the following risks?

Patients will be <u>more</u> likely to request assistance from a physician to die because...

They feel pressured or influenced by a health care provider.

Open Public Representative Sample



Among the Public, Frenchspeaking participants, Canadians under 25 and between 75 and 84, residents of AB, MB and QC were generally the most concerned, along with religious leaders and care or support workers.

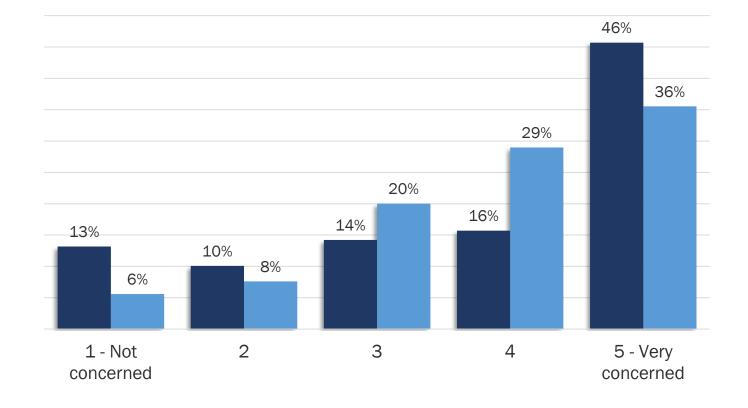
Among the Sample, concern generally increased for older demographics.

How concerned are you that physician-assisted dying will pose the following risks?

Patients will be <u>more</u> likely to request assistance from a physician to die because...

They feel isolated / lonely or lack emotional support.

Open Public Representative Sample



Among the Public, Canadians under 35 and residents of AB, MB and QC were generally the most concerned, along with religious leaders, physicians and care or support workers.

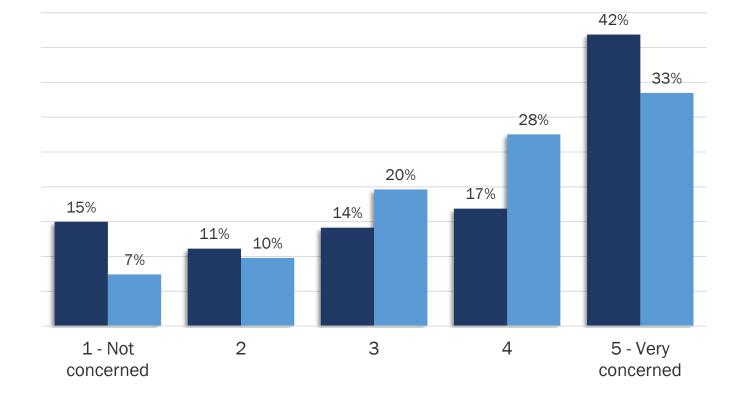
Among the Sample, responses were relatively consistent across demographic groups.

How concerned are you that physician-assisted dying will pose the following risks?

Patients will be <u>more</u> likely to request assistance from a physician to die because...

They are not aware of treatments, technologies or options that might improve their quality of life.

Open Public Representative Sample



Among the Public, women, Canadians between 75 and 84, and residents of AB and MB were generally the most concerned, along with religious leaders, physicians, nurses and care or support workers.

Among the Sample, Canadians between 65 and 74 were generally more concerned than others.

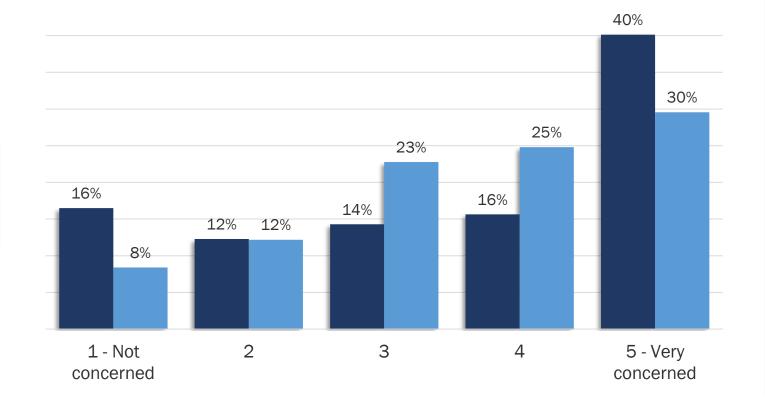
However, French-speaking participants were more likely than others to <u>not</u> be concerned.

How concerned are you that physician-assisted dying will pose the following risks?

Patients will be <u>more</u> likely to request assistance from a physician to die because...

They feel their health care provider doesn't understand or provide them with other options that might address their suffering.

Open Public Representative Sample



Among the Public, French-speaking participants, women, Canadians between 75 and 84, and residents of AB, MB and QC were generally the most concerned, along with religious leaders, physicians and care or support workers.

Among the Sample, Canadians between 65 and 74 were generally more concerned than others.

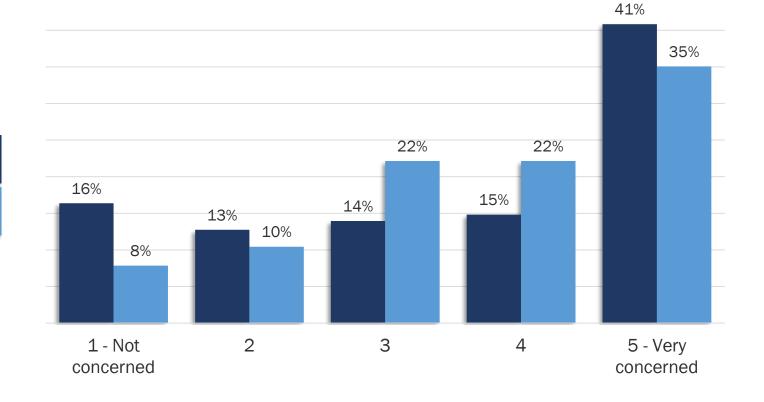
However, French-speaking participants were more likely than others to <u>not</u> be concerned.

How concerned are you that physician-assisted dying will pose the following risks?

Patients will be <u>more</u> likely to request assistance from a physician to die because...

They are basing their decision on an incorrect or inexact diagnosis / prognosis.

Open Public Representative Sample



Among the Public, Canadians between 75 and 84, and residents of AB and MB were generally the most concerned, along with religious leaders, physicians and care or support workers.

Among the Sample, Canadians between 65 and 84 were generally more likely than others to be concerned.

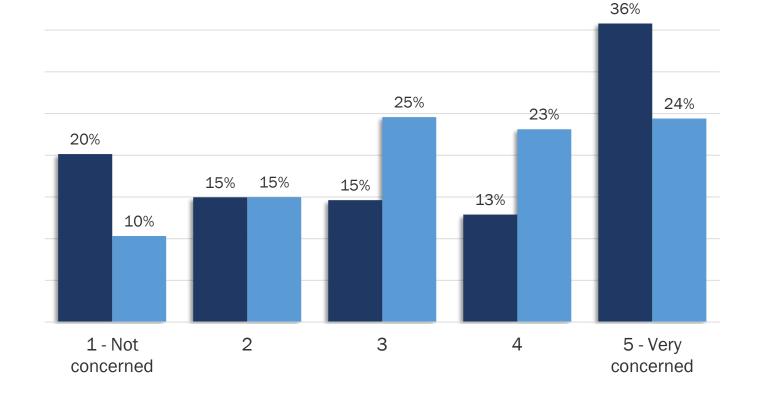
However, French-speaking participants were more likely than others to <u>not</u> be concerned.

How concerned are you that physician-assisted dying will pose the following risks?

Persons with disabilities (and perhaps others) may be more likely to...

Request assistance from a physician to die because of the suffering that arises from the experience of discrimination, deprivation or stigma.

Open Public Representative Sample



Among the Public, Frenchspeaking participants, Canadians under 35, and residents of AB and MB were generally the most concerned, along with religious leaders, physicians and care or support workers.

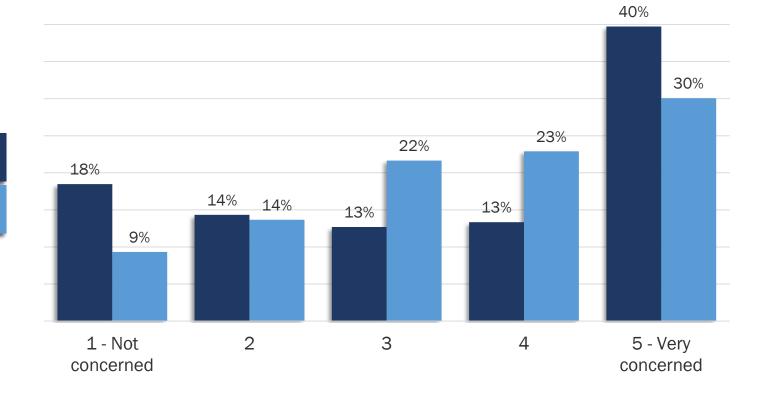
Among the Sample, responses were relatively consistent across demographic groups.

How concerned are you that physician-assisted dying will pose the following risks?

Persons with disabilities (and perhaps others) may be more likely to...

Be influenced to request assistance from a physician to die by a family member or caregiver upon whom they are dependent for support.

Open Public Representative Sample



Among the Public, Frenchspeaking participants, Canadians under 35, and residents of AB and MB were generally the most concerned, along with religious leaders, physicians and care or support workers.

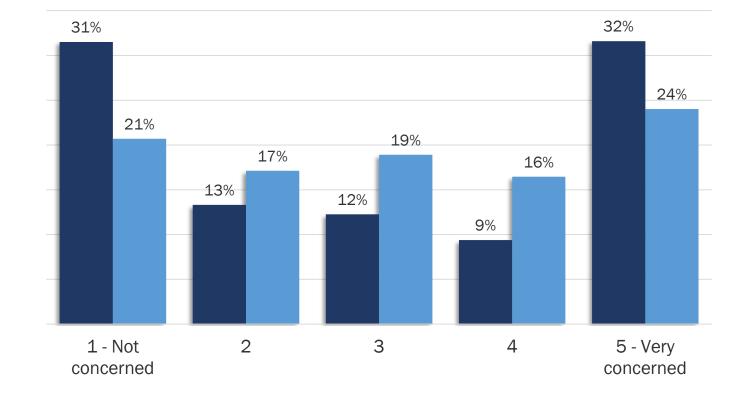
Among the Sample, Canadians between 75 and 84 were more concerned than others.

How concerned are you that physician-assisted dying will pose the following risks?

Persons with disabilities (and perhaps others) may be more likely to...

Request assistance from a physician to die in order to be respected and admired for their sacrifice or bravery, when for much of their lives they have been devalued or ignored.

Open Public Representative Sample



Among the Public,
Canadians between 75
and 84, and residents of
AB and MB were generally
the most concerned,
along with religious
leaders and care or
support workers.

Among the Sample, Canadians between 75 and 84 were more likely than others to be concerned.

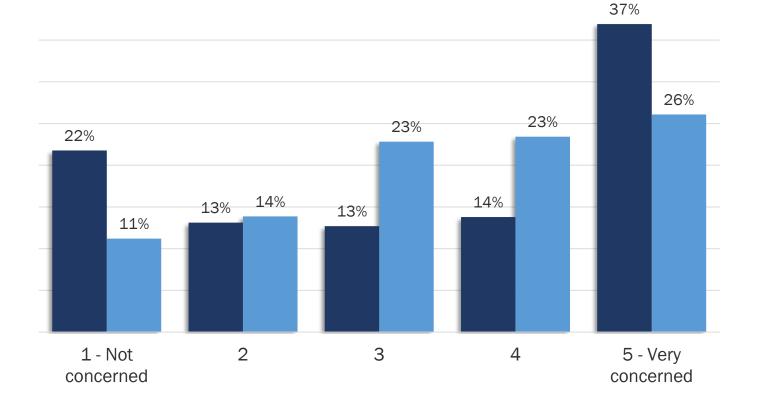
However, French-speaking participants were more likely to <u>not</u> be concerned.

How concerned are you that physician-assisted dying will pose the following risks?

Health care providers...

Being unfamiliar with other ways to address the difficulties or distress a person with disabilities is experiencing.

Open Public Representative Sample



Among the Public, Frenchspeaking participants, Canadians between 75 and 84, and residents of AB and MB were generally the most concerned, along with religious leaders, physicians and care or support workers.

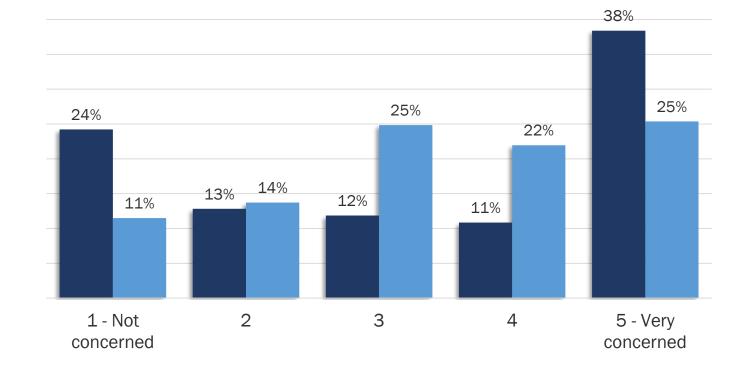
Among the Sample, Canadians between 45 and 54 were more likely to not be concerned.

How concerned are you that physician-assisted dying will pose the following risks?

Health care providers...

Being more inclined to see requests for assistance to die from persons with disabilities as reasonable.

Open Public Representative Sample



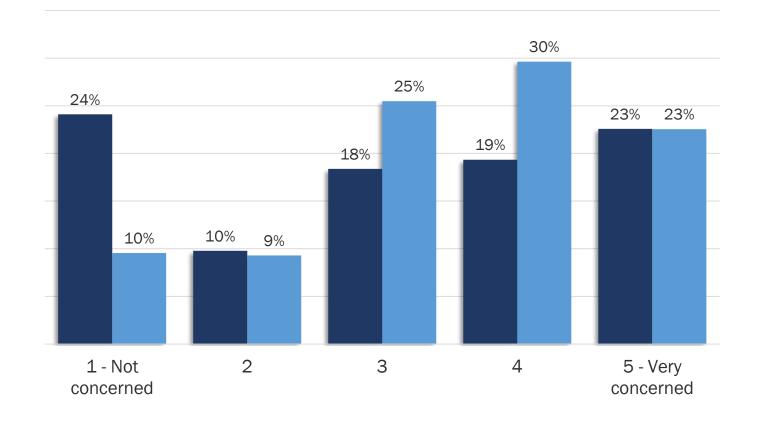
Among the Public, Frenchspeaking participants, Canadians under 35, and residents of AB and MB were generally the most concerned, along with religious leaders, physicians and care or support workers.

Among the Sample, Canadians between 75 and 84 were more likely to be concerned, while those between 45 and 54 were more likely to <u>not</u> be concerned.

How concerned are you that physician-assisted dying will pose the following risks?

A mental health condition could make it more difficult for people to receive a physician's assistance to die.

Open Public Representative Sample



Among the Public, Frenchspeaking participants, Canadians between 65 and 84, and residents of QC were generally the most concerned.

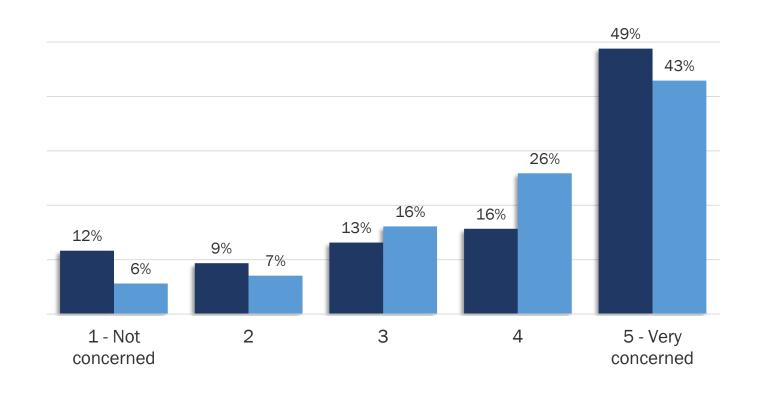
Among the Sample, responses were relatively consistent across demographic groups.

How concerned are you that physician-assisted dying will pose the following risks?

Persons with mental health conditions may...

Request assistance from a physician to die during an episode that could be temporary.

Open Public Representative Sample



Among the Public, Canadians under 35, and residents of AB and MB were generally the most concerned, along with religious leaders, physicians and care or support workers.

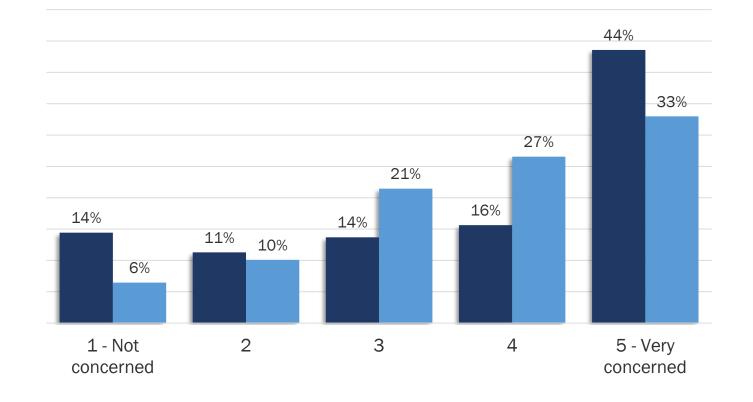
Among the Sample, responses were relatively consistent across demographic groups.

How concerned are you that physician-assisted dying will pose the following risks?

Persons with mental health conditions may...

Request assistance from a physician to die because of suffering / alienation that arises from the experience of discrimination, poverty, violence or stigma.

Open Public Representative Sample



Among the Public, women, Canadians under 35, and residents of AB and MB were generally the most concerned, along with religious leaders, physicians and care or support workers.

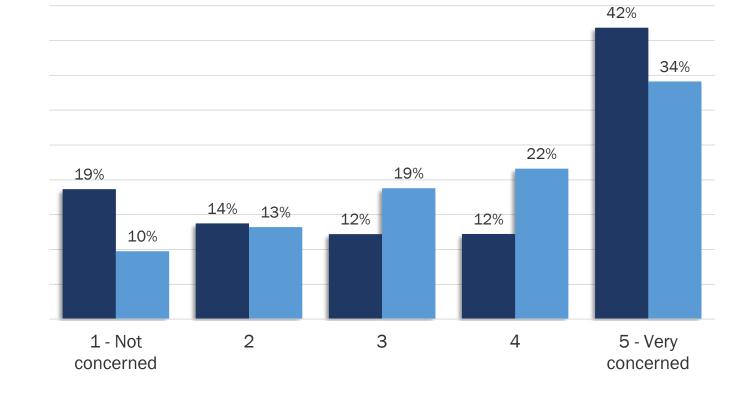
Among the Sample, Canadians between 75 and 84 were more likely than others to be concerned, while those between 45 and 54 were more likely to <u>not</u> be concerned.

How concerned are you that physician-assisted dying will pose the following risks?

Persons with mental health conditions may...

Be influenced by others in positions of authority to request assistance from a physician to die.

Open Public Representative Sample



Among the Public, Frenchspeaking participants, Canadians between 75 and 84, and residents of AB, MB and QC were generally the most concerned, along with religious leaders, physicians and care or support workers.

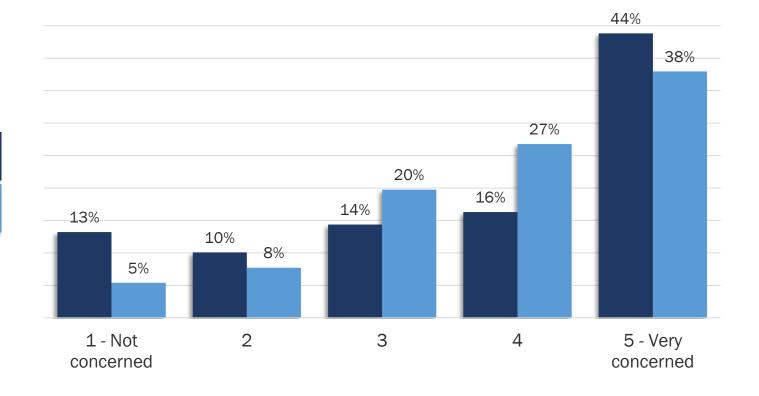
Among the Sample, Canadians between 65 and 84 were more likely to be concerned.

How concerned are you that physician-assisted dying will pose the following risks?

Persons with mental health conditions may...

Have difficulty with the reasoning and judgment required to request a physician's assistance to die.

Open Public Representative Sample



Among the Public, Frenchspeaking participants, and residents of AB, MB and QC were generally the most concerned, along with religious leaders, physicians and care or support workers.

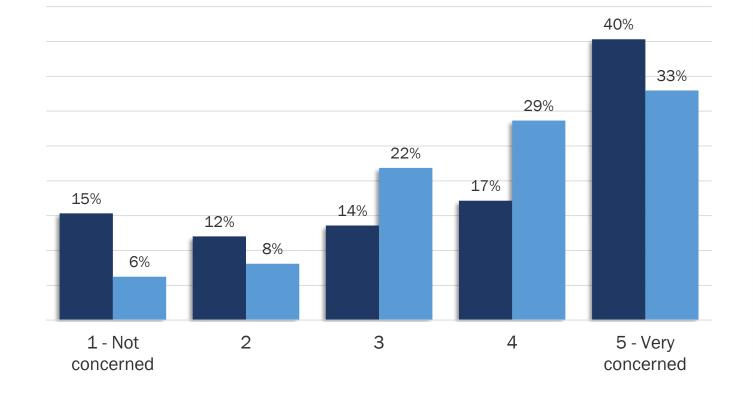
Among the Sample, Canadians between 75 and 84 were more likely to be concerned, while those between 45 and 54 were more likely than others to not be concerned.

How concerned are you that physician-assisted dying will pose the following risks?

Healthcare providers...

May not be able to reliably assess the decision-making capacity of persons with mental health conditions.

Open Public Representative Sample



Among the Public, women, Canadians under 35 and between 75 and 84, and residents of AB, MB and QC were generally the most concerned, along with religious leaders, physicians and care or support workers.

Among the Sample,
Canadians between 75
and 84 were more likely
than others to be
concerned, compared to
those between 45 and 54
who were more likely to
not be concerned.

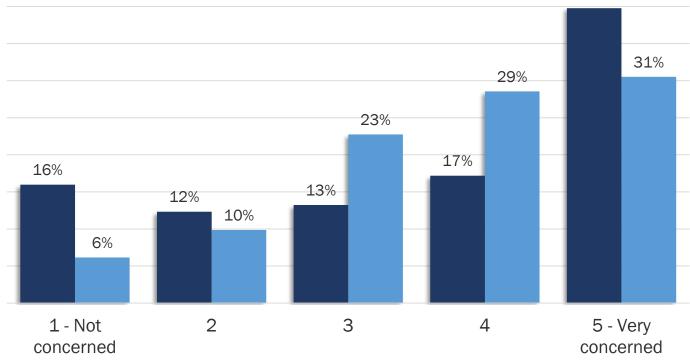
How concerned are you that physician-assisted dying will pose the following risks?

Healthcare providers...

May be unfamiliar with ways to address the difficulties or distress a person with mental health conditions is experiencing.

40%





Among the Public, women, Canadians between 75 and 84, and residents of AB and MB were generally the most concerned, along with religious leaders, physicians and care or support workers.

Among the Sample,
Canadians between 75
and 84 were more likely
than others to be
concerned, compared to
those between 45 and 54
who were more likely to
not be concerned.

How concerned are you that physician-assisted dying will pose the following risks?

Might be less inclined to question requests for assistance to die from persons with mental health Healthcare providers... conditions. 37% 28% 25% 23% 21% Open **Public** 14% 13% Representative 13% 13% Sample 9% 1 - Not 5 - Very concerned concerned Among the Public, French-speaking participants,
Canadians between 75
and 84, and residents of
AB and MB were generally
the most concerned,
along with religious
leaders and care or
support workers.

Among the Sample, Canadians between 75 and 84 were more likely than others to be concerned, compared to those between 45 and 54 who were more likely to not be concerned.

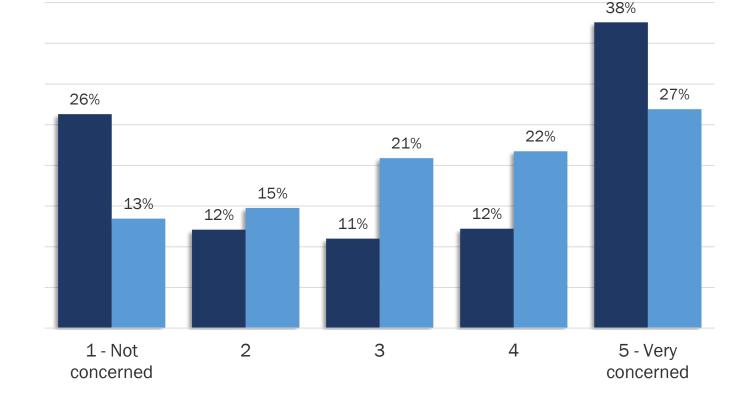
## Palliative care

How concerned are you that physician-assisted dying will pose the following risks?

Patients will be more likely to request assistance from a physician to die because they...

Are not aware of available palliative care services.

Open Public Representative Sample



Among the Public, Canadians between 75 and 84, and residents of AB and MB were generally the most concerned, along with religious leaders, physicians and care or support workers.

Among the Sample, Canadians between 75 and 84 were more likely to be concerned than others, while those between 45 and 54 were more likely to not be concerned.

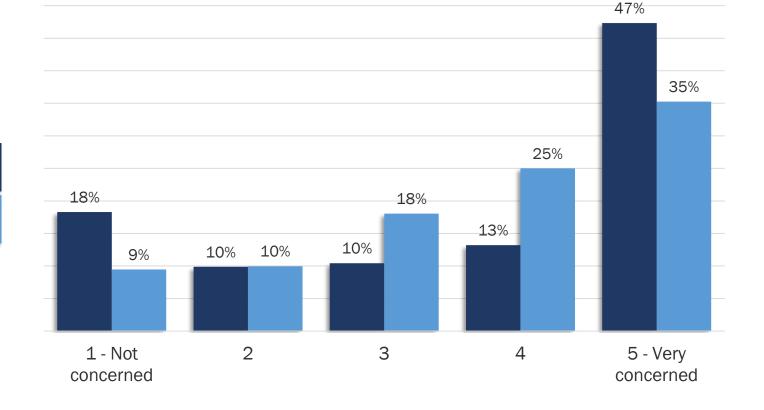
## Palliative care

How concerned are you that physician-assisted dying will pose the following risks?

Patients will be more likely to request assistance from a physician to die because they...

Do not have access to palliative care services and supports.

Open Public Representative Sample



Among the Public, Canadians between 75 and 84, and residents of AB and MB were generally the most concerned, along with religious leaders, physicians and care or support workers.

Among the Sample, Canadians between 75 and 84 were more likely than others to be concerned.

### Palliative care

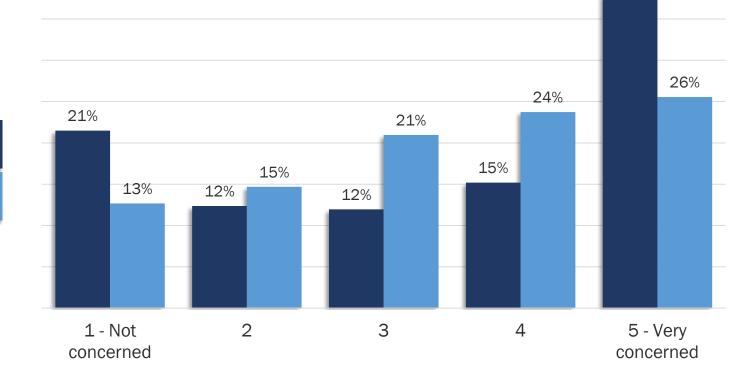
How concerned are you that physician-assisted dying will pose the following risks?

Healthcare providers...

Have not been trained in how to discuss palliative care options with patients.

38%





Among the Public, women, Canadians between 75 and 84, and residents of AB and MB were generally the most concerned, along with religious leaders, physicians and care or support workers.

Among the Sample, Canadians between 75 and 84 were more likely than others to be concerned, while those between 45 and 54 were more likely to <u>not</u> be concerned.

#### Palliative care

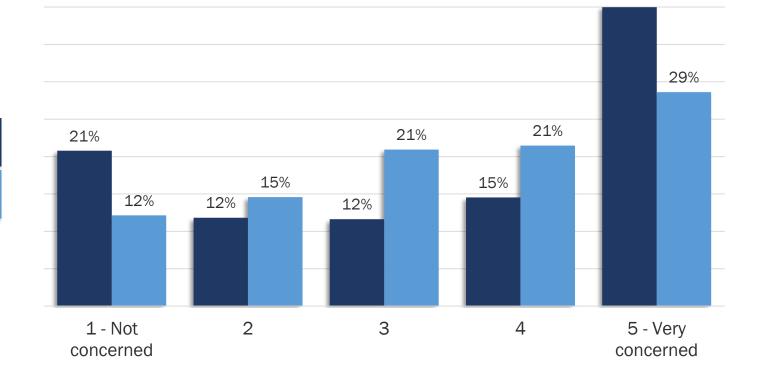
How concerned are you that physician-assisted dying will pose the following risks?

Healthcare providers...

Have not had the education or do not have the skills to provide effective palliative care.

40%



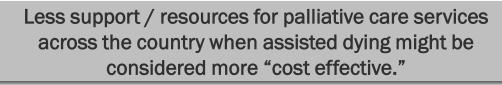


Among the Public, women, Canadians between 75 and 84, and residents of AB and MB were generally the most concerned, along with religious leaders, physicians and care or support workers.

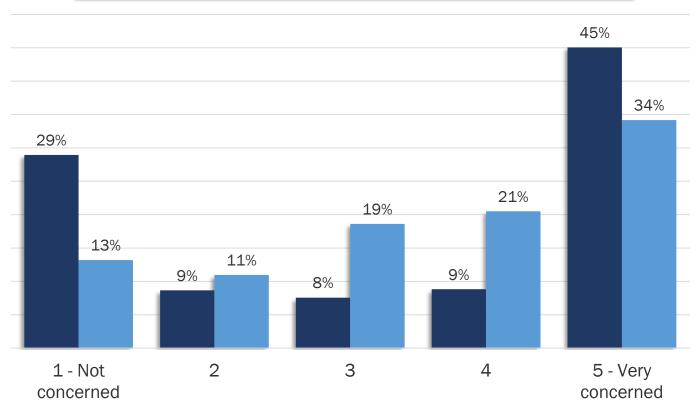
Among the Sample, Canadians between 75 and 84 were more likely than others to be concerned, while those between 45 and 54 were more likely to <u>not</u> be concerned.

#### Palliative care

How concerned are you that physician-assisted dying will pose the following risks?



Open Public Representative Sample



Among the Public, women, Canadians under 35 and between 75 and 84, and residents of AB, MB and QC were generally the most concerned, along with religious leaders, physicians and care or support workers.

Among the Sample, Canadians between 75 and 84 were more likely than others to be concerned, while residents of AB and those between 45 and 54 were more likely to <u>not</u> be concerned.

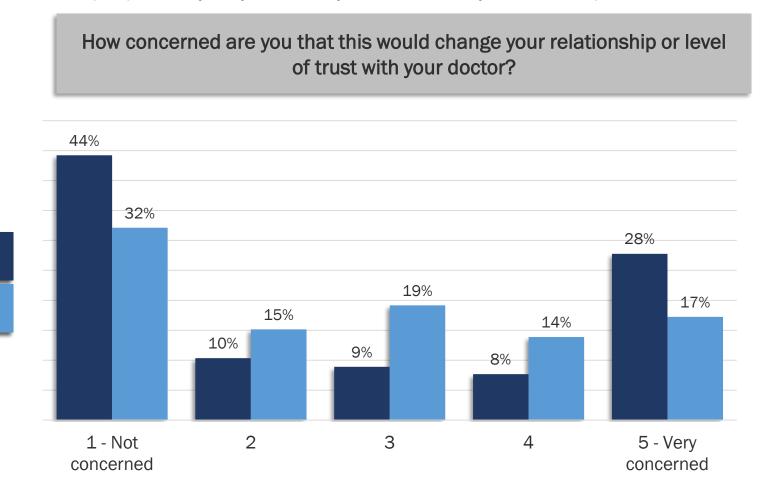
### Implications for medical care

Open Public

Representative

Sample

There are concerns that this could change the way some health care providers define their role and what they do, which some people worry may eventually affect how they serve their patients.

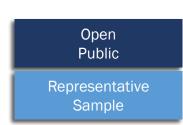


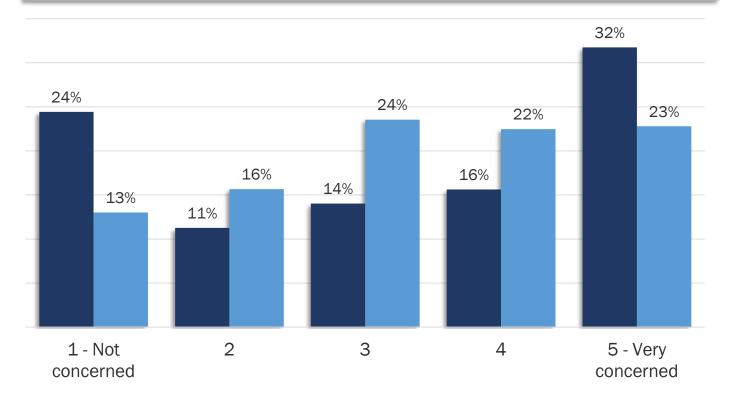
Among the Public, men, Canadians under 25 and between 75 and 84, and residents of AB and MB were generally the most concerned, along with religious leaders and physicians.

### Implications for medical care

There are concerns that this could change the way some health care providers define their role and what they do, which some people worry may eventually affect how they serve their patients.

How concerned are you that physicians may not be aware of or do not have access to the resources needed to support patients who are considering ending their lives?





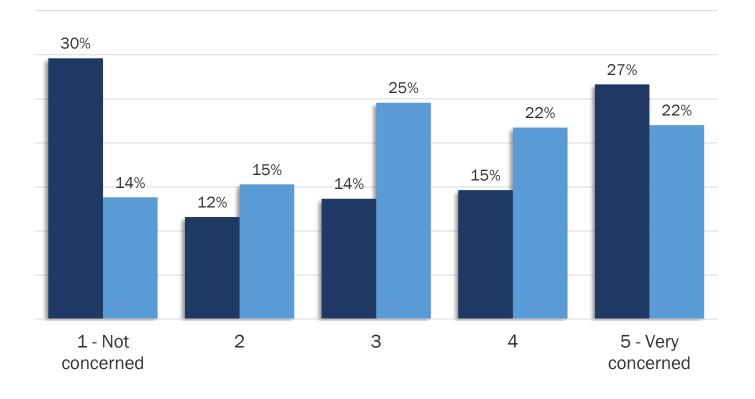
Among the Public, women and residents of AB were generally the most concerned, along with religious leaders and physicians.

### Implications for medical care

There are concerns that this could change the way some health care providers define their role and what they do, which some people worry may eventually affect how they serve their patients.

How concerned are you that physicians may not be aware of or do not have access to the resources needed to facilitate requests to die from eligible patients?

Open Public Representative Sample



Among the Public, women and Canadians between 65 and 84 were generally the most concerned.

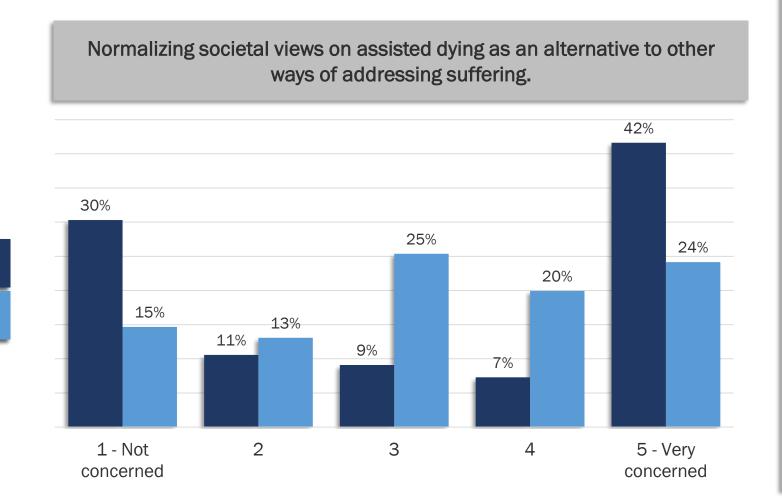
Open

**Public** 

Representative

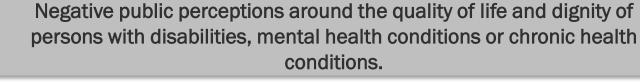
Sample

How concerned are you about the following issues?

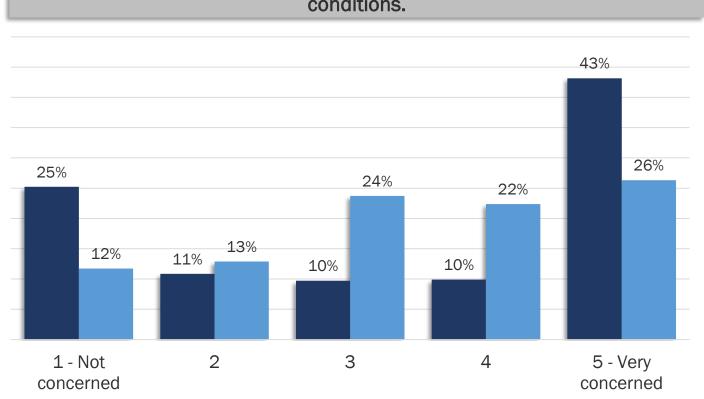


Among the Public, French-speaking participants,
Canadians under 35 and between 75 and 84, and residents of AB and MB were generally the most concerned, along with religious leaders, physicians and care or support workers.

How concerned are you about the following issues?



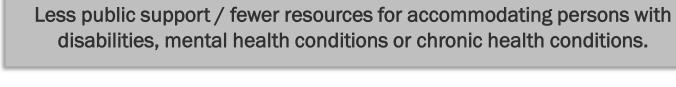
Open Public Representative Sample



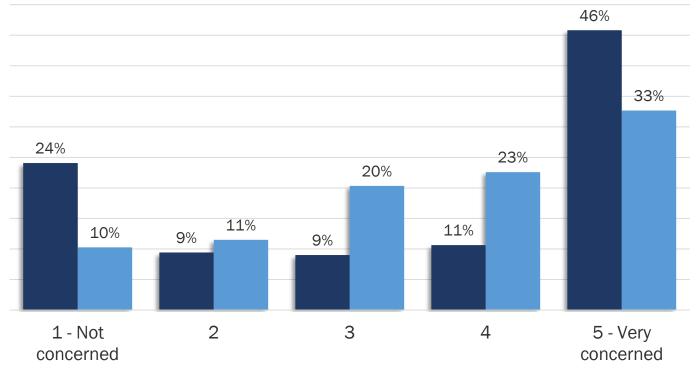
Among the Public, French-speaking participants, women, Canadians under 35 and between 75 and 84, and residents of AB and MB were generally the most concerned, along with religious leaders, physicians and care or support workers.

Among the Sample, men were more likely than women to <u>not</u> be concerned.

How concerned are you about the following issues?



Open Public Representative Sample



Among the Public, Frenchspeaking participants, women, Canadians under 35 and between 75 and 84, and residents of AB and MB were generally the most concerned, along with religious leaders, physicians and care or support workers.

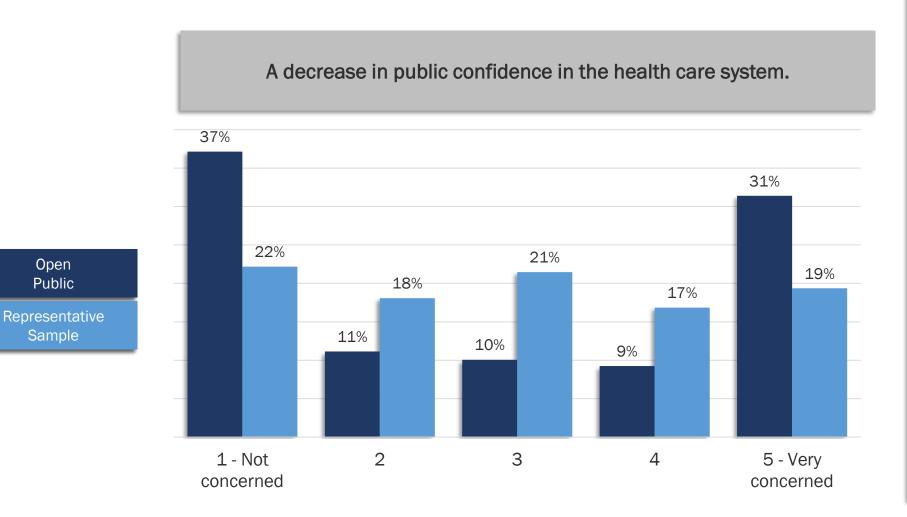
Among the Sample,
Canadians between 75
and 84 were more likely
than others to be
concerned, while
residents from MB were
more likely than others to
not be concerned.

Open

**Public** 

Sample

How concerned are you about the following issues?



Among the Public, Canadians between 75 and 84, and residents of AB and MB were generally the most concerned. along with religious leaders, physicians and care or support workers.

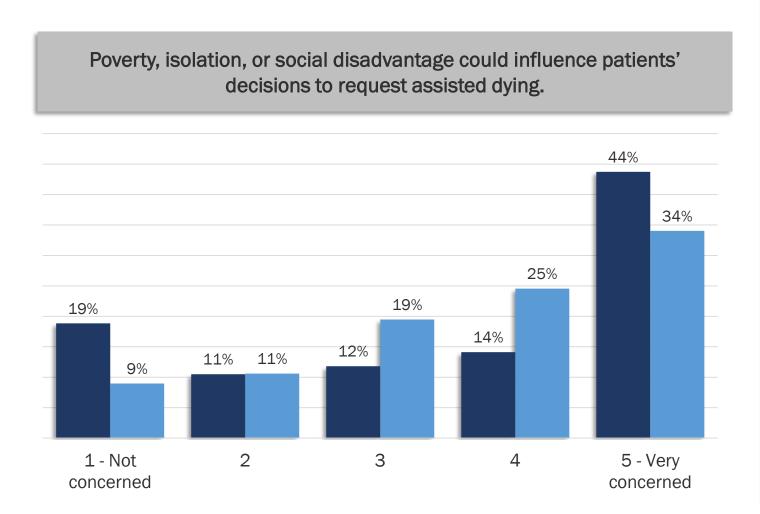
Among the Sample, Canadians between 75 and 84 were more likely than others to be concerned, while men and those between 45 and 54 were more likely than others to not be concerned.

Open

**Public** 

Representative Sample

How concerned are you about the following issues?



Among the Public, Canadians under 35, and residents of AB and MB were generally the most concerned, along with religious leaders, physicians and care or support workers.

Among the Sample, Canadians between 75 and 84 were more likely than others to be concerned, while men were more likely than others to <u>not</u> be concerned.

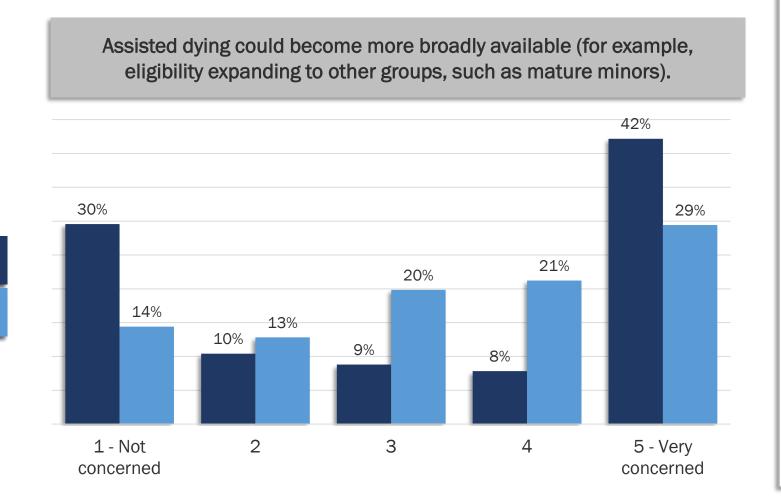
Open

**Public** 

Representative

Sample

How concerned are you about the following issues?



Among the Public, Canadians under 35 and between 75 and 84, and residents of AB, MB and QC were generally the most concerned, along with religious leaders, physicians and care or support workers.

Below are the five risks <u>Public participants</u> were the <u>most</u> concerned about, in relation to physician-assisted dying:

Persons with mental health conditions may request assistance from a physician to die during an episode that could be temporary

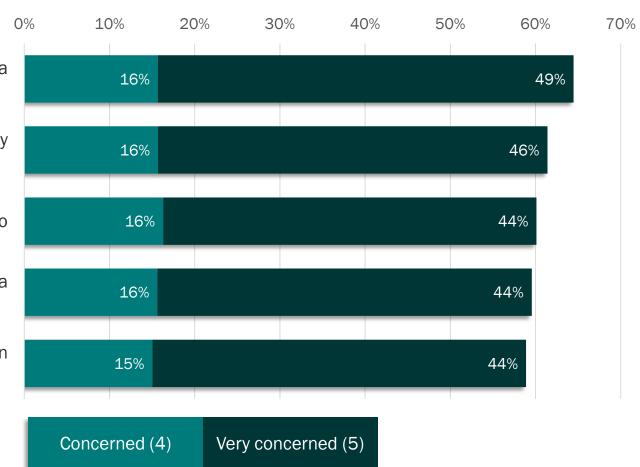
Patients will be more likely to request it because they feel isolated / lonely or lack emotional support

Persons with mental health conditions may have difficulty with the reasoning and judgment required to request a physician's assistance to die

Patients will be more likely to request it because they feel they are a financial burden to their family / loved ones or to society at large

Patients will be more likely to request it because they feel they are an emotional burden to their family / loved ones

<u>Note:</u> The same five risks were identified as being of most concern for both Public and Sample participants (next slide).



Below are the five risks <u>Sample participants</u> were the <u>most</u> concerned about, in relation to physician-assisted dying:

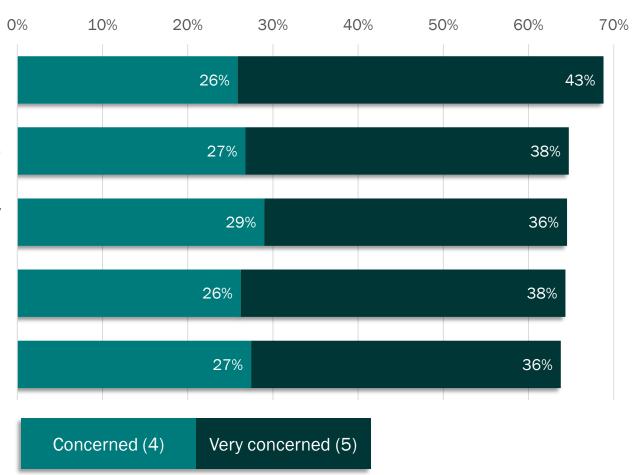
Persons with mental health conditions may request assistance from a physician to die during an episode that could be temporary

Persons with mental health conditions may have difficulty with the reasoning and judgment required to request a physician's assistance to die

Patients will be more likely to request it because they feel isolated / lonely or lack emotional support

Patients will be more likely to request it because they feel they are a financial burden to their family / loved ones or to society at large

Patients will be more likely to request it because they feel they are an emotional burden to their family / loved ones



Below are the five risks <u>Public participants</u> were the <u>least</u> concerned about, in relation to physician-assisted dying:

This would change your relationship or level of trust with your doctor

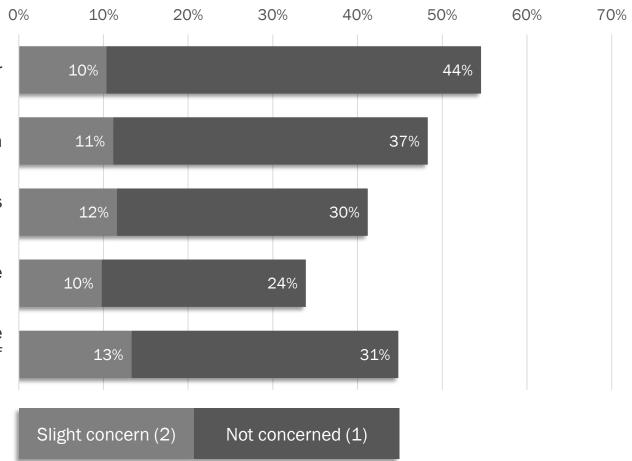
A decrease in public confidence in the health care system

Physicians may not be aware of or do not have access to the resources needed to facilitate requests to die from eligible patients

A mental health condition could make it more difficult for people to receive a physician's assistance to die

Persons with disabilities may be more likely to request it in order to be respected and admired for their sacrifice or bravery, when for much of their lives they have been devalued or ignored

Note: Four of the five risks listed above (1, 2, 3 and 5) were among the five least important risks for Sample participants (next slide) as well.



Below are the five risks <u>Sample participants</u> were the <u>least</u> concerned about, in relation to physician-assisted dying:

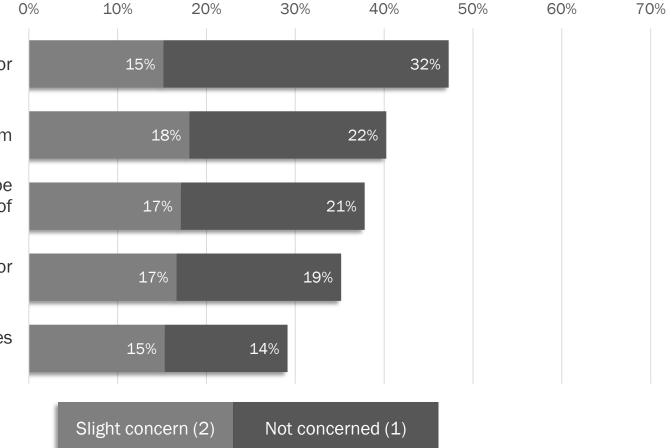


A decrease in public confidence in the health care system

Persons with disabilities may be more likely to request it in order to be respected and admired for their sacrifice or bravery, when for much of their lives they have been devalued or ignored

Patients will be more likely to request it because they feel pressured or influenced by a health care provider

Physicians may not be aware of or do not have access to the resources needed to facilitate requests to die from eligible patients



Summary of responses and sampling of quotes grouped by theme for Issue Book question:

Are there any additional risks with physician-assisted dying that have not been raised? If so, please
describe below.

#### Theme 1: Access to Assisted Dying

#### **Summary:**

Of all the top risks identified, this is the most reflective of respondents' views in support of access to physician-assisted dying. The most significant concern related to access to assisted dying is that patients will not be able to receive assistance to die because there will be many physicians refusing to participate. In this view, many respondents took issue with a physician's personal views impacting their access to the service, as they felt that this is "putting beliefs ahead of patients' needs. Another issue identified by respondents is the level of bureaucracy that will be implemented for physician-assisted dying, which they fear will be too slow, arduous and excessive, leading to the system getting "bogged down" and "making it impossible" to receive assistance to die. If the process is too time-consuming and delayed, it will be especially problematic for patients who are suffering and have "no luxury for multiple options and timelines."

Respondents were also concerned about unequal and inconsistent access to assisted dying, particularly in rural and remote communities that already experience gaps in access to health care services (e.g. palliative care). As a result, access to assisted dying will "depend on where people live", and finding the necessary knowledge and skills – let alone willing physicians – could be particularly challenging for individuals living outside of urban areas. More broadly, some respondents also feared that access to physician-assisted dying could be limited or blocked by religious / advocacy group influence and "intimidation" of both individuals and government / politicians, which they felt is unfair as this impacts end-of-life options for everyone.

Both Open Public and Representative Sample groups highlighted the risks around access to assisted dying, although the Representative Sample respondents focused most on the impact of physicians' beliefs in restricting access (concerns around bureaucracy and geography were not as prominent).

#### Theme 1: Access to Assisted Dying (continued)

#### Quotes:

- "A big risk is a doctor making judgement on his religious feelings and therefore not looking after the patient according to the patient's requirements and needs. The doctors opinion on how we choose to live, die or when, should never be involved." (Open Public respondents)
- "Physicians refusing to assist patients in suicide in accordance with their own moral/religious beliefs, as is sometimes the case with abortion/contraception. This might simply lead to prolonged patient suffering." (Representative Sample respondents)
- "A major risk is that it will turn into a bureaucratic nightmare legal in theory, but inaccessible in practice. I can imagine lengthy forms, lists of documents required, consultations required with multiple health care professionals, each of whom with a long wait list; while the patient suffers and deteriorates and ultimately is not able to access assisted suicide." (Open Public respondents)
- "Changes should be Canada wide. Patients should not have to travel to another province to get the help they want as they now have to travel
  to other countries." (Open Public respondents)
- "Concerned that undue influence from doctors that do not support assisted dying combined with fundamentalist religious groups and conservative politicians' bias, the information and media coverage, preventing a healthy public discourse." (Open Public respondents)
- "We risk that external influences may be more influential than what an individual actually wants for their life." (Open Public respondent, original in French)

Theme 2: Consent and Influence Issues

#### Summary:

Many respondents from both the Open Public and Representative Sample groups expressed concern that more patients will be directed towards physician-assisted dying because of unclear consent parameters and/or influence from other parties, which are closely connected. Many respondents were particularly worried about family influence, as some patients may be encouraged by their family to request this option, or that their family may be more willing to choose it for them if they're unable to communicate themselves. Financial considerations (e.g. inheritance, less of a burden) were the most common rationales suggested by respondents. Some also expressed concerns with physicians, who can exert significant influence over a patient's decision making (both for and against physician-assisted dying, depending on their beliefs).

Respondents also identified risks where a patient may not have given – or be able to provide – clear and explicit consent for a wide variety of reasons, yet may still receive assistance to die (which some suggested is occurring in other jurisdictions). As a result, there were many questions around who can provide consent on behalf of the patient, as well as whose opinion takes precedence. Family / loved ones, physicians, substitute-decision makers, and those with power of attorney were all mentioned. Additionally, some felt that there are risks with consent being provided by patients in moments of temporary distress, who may change their mind over time. It is worth noting that some respondents rejected the premise of anyone but the patient being allowed to provide consent, which they felt effectively reduces the risk of physician-assisted dying.

#### <u>Theme 2:</u> Consent and Influence Issues (continued)

#### Quotes:

- "Family members may request that a patient be "put out of their misery" when in effect, it is for the convenience of the family. This could
  involve wanting to get at the estate of the deceased sooner, rather than waiting until nature took its course." (Open Public respondent)
- "We risk that external influences may be more influential than what an individual actually wants for their life." (Open Public respondent, original in French)
- "Physicians and patients have an unequal relationship. A health professional who has the upper hand might pressure a patient who may not be thinking clearly due to drugs or disease to consent to a procedure that the patient might not fully understand even in the well state. That includes consenting to be euthanized." (Open Public respondent)
- "Questionable competency of the patient requesting assistance to die." (Representative Sample respondent)
- "From my years working in Palliative Care there have been times the patient has said "I wish I could just die" but the following day they have a change of heart & are ready again to take on life whatever it has to offer. Mental health patients will have many ups & downs but are happy when their suicide attempt fails & they finally get the medical attention they require." (Open Public respondent)
- "This is a personal decision and needs to remain within the confines of the choices the individual has made, and only that person can agree to participate in any ongoing discussions, ulterior motives, or harassment from other groups or individuals to influence their decision." (Open Public respondent)
- "I think the only thing that is important is the person's wishes. If they have made the request and they have a terminal illness, it does not matter what society thinks or the doctors think if living in pain and having no quality of life is too much for someone to handle then they should be allowed to end it. The only person that knows what they can handle and what they cannot, is the patient and I don't believe anyone should be allowed to second guess their feelings and wishes." (Representative Sample respondent)

Theme 3: Devaluing Life

#### Summary:

According to many respondents, one of the most concerning risks of physician-assisted dying is that it will contribute to the devaluing of human life, with people's views on the sanctity of life diminishing over time. Some feel that this practice inherently threatens human dignity, as some individuals may be stigmatized and influenced to: view their own life as hopeless / less valuable / "not worth living", feel they are a burden to others, and "need to justify their existence." Participants expressed particular concern for vulnerable groups, such as the elderly, people with disabilities, and people with mental health issues. As a result, many felt that physician-assisted dying will ultimately change how people view each other in Canadian society: with less compassion and perceived duty to help and care for others. Additionally, some respondents discussed the positives (e.g. personal growth, family bonding) that can come from suffering and dealing with difficult situations.

Of all the concerns identified, this contained the most references to religion and spirituality. While both Open Public and Representative Sample groups identified concerns over devaluing life, it was much more prominent among Open Public respondents. Additionally, it is worth noting that these concerns are closely linked to those articulated in another top theme – Relaxing of Eligibility Criteria.

<u>Theme 3:</u> Devaluing Life (continued)

#### Quotes:

- "We are talking about a cultural slide, a degradation of everyone's life when human beings are disposable; this will change the way we treat others in general." (Open Public respondent)
- "Human beings have the right to life simply because they are human -- this is an objectively measurable standard. When the right to life is changed to something subjective, where the right comes from possessing specific abilities or enjoying certain qualities of life that others think are necessary, then the right to life becomes violable. Such a fundamental change makes it logically impossible to draw a fixed line between those who can be killed and those who cannot." (Open Public respondent)
- "PAD emphasizes that we value some lives over others. We are saying that we agree that your life no longer has meaning and importance. Does this not undermine what it means to be Canadian?" (Open Public respondent)
- "Society should be caring, not killing. We should be showing compassion to those suffering, not encouraging them to end their lives. We should be loving and kind to them and help them through their troubles. God has created humans in His image, and by taking our own life we are not showing respect for God's creation." (Open Public respondent)
- "As a society we have been conditioned to believe that suffering and pain are things to be avoided, despite the fact that many people attest to positive outcomes despite pain and suffering." (Open Public respondent)

Theme 4: Violating Health Care Workers' Rights

#### **Summary:**

One of the predominant risks is physicians and other health care workers being pressured or forced to participate in (as well as provide referrals for) assisted dying, even if they are conscientious objectors due to moral, ethical and religious reasons. As a result, there is concern that physicians and others will effectively lose their conscience rights, as their right to refuse the practice may not be heard, respected, or legally protected (there are many questions about how this will work). Respondents felt that this is a significant burden to place on health care workers, especially since they are trained and feel obligated to protect life. Many insisted that these rights must be defended, as physicians and others need the freedom to follow their own conscience and values. There is also the fear that physicians will be discriminated against or punished if they refuse to participate, such as through fines, suspension, dismissal, and loss of their right to practice. As a broader point, some feel that physician-assisted dying will lead to a decline in health care professionals over time, as physicians could start leaving their practices and individuals may be discouraged to enter the field altogether.

Both Open Public and Representative Sample groups highlighted these risks, although it was more prominent (in relation to other identified issues) among Open Public participants. It is also worth noting that some – though far less – Open Public respondents expressed the opposite view: physicians should not be allowed to deny assisted dying due to their personal beliefs.

#### <u>Theme 4:</u> Violating Health Care Workers' Rights (continued)

#### Quotes:

- "I am concerned with the pressures that will be placed on Doctors who have moral objections to this issue and the possibility that they may be legally forced to assist with assisted suicide, if they wish to keep their careers and practices. It should not be a mandatory service they must provide." (Open Public respondent)
- "Ensuring the freedom of conscience on this issue for health care providers." (Open Public respondent, original in French)
- "Health care providers made an oath to 'cause no harm', there will be physicians who will not want to assist in killing their patients, and will not give a referral to a doctor who will. These doctors should have the right to refuse to help their patients kill themselves." (Open Public respondent)
- "An incredible burden to place on physicians whether or not they want to assist in the death of their patient guilt all around."
   (Open Public respondent)
- "Physicians who do not want to participate in assisted-suicide in any form need legal protection. They need to be able to remain in good-standing and suffer no legal / social / financial penalties." (Open Public respondent)
- "Safe-guarding the practice without any discrimination of the physician who is opposed to assisting a patient who has expressed a
  desire to die; and also safe-guarding the practice without any discrimination of the physician who is opposed to referring such
  patient to a doctor who is willing to assist a patient who has expressed a desire to die." (Representative Sample respondent)

<u>Theme 5:</u> Insufficient Training and Professionalism

#### Summary:

Another of the top prevailing risks, respondents emphasized the need to ensure relevant education and training for physicians and other health care professionals in the area of assisted dying. Respondents noted that many physicians are not well informed of the full range of palliative / end-of-life care options more generally, let alone being prepared to effectively handle assisted dying (some indicated that the former is an important foundation / precursor to the latter). Physicians also need training to improve their communications skills in order to effectively assess, inform and discuss assisted dying with their patients. On this note, respondents also expressed concerns with how a physician's personal traits (e.g. lack of empathy) – combined with their personal beliefs and attitudes – may negatively influence how they inform and counsel discussions around assisted dying. Considering these factors, some respondents worried about the overall subjectivity involved: while some doctors will be well equipped to deal with assisted dying, there are many who will not.

More broadly, some respondents also felt that assisted dying degrades the integrity of medical professions and may change perspectives on the patient-provider relationship, as it conflicts with the notion of providing health care, healing, and saving lives. Many respondents suggested that it should not be one physician who decides whether a patient receives assistance to die because it is "too big of a responsibility". Multiple physicians, a team of health care professionals, or specialists in the area should be involved or provide support. While both Open Public and Representative Sample groups identified these concerns as top risks, the latter group was less explicit about the need for education and training.

#### <u>Theme 5:</u> Insufficient Training and Professionalism (continued)

#### Quotes:

- "All health care professionals need additional training to better discuss a full range of options from full aggressive treatment all the way to natural or assisted death. This should be a core skill of all health care providers to ensure patients are well informed." (Open Public respondent)
- "Health care providers do not yet have mandatory training and/or protocols around palliative care. Why would physician-assisted dying
  protocols and training be introduced before physicians have had compulsory training in palliative care, which is aimed at relieving
  suffering?" (Open Public respondent)
- "Different doctors have very different skills sets when it comes to bedside manners. I would hate to think that patients' choice to end their lives could be so dependent on the way in which the "choice" pros and cons are laid out by their doctor. Some doctors could have a higher "death rate" associated with the patients under their care because of the doctor's own personal beliefs and attitudes." (Open Public respondent)
- "Doctor personal bias towards ending lives. Some doctors currently push their own personal bias towards ending life on the elderly and will refuse treatment and downgrade dnr levels on their own." (Representative Sample respondent)
- "A doctor is trained to preserve life wherever that is possible to ask them to participate in assisting suicide is a negation of that training."
   (Open Public respondent)
- "As a nurse I'm concerned that schools of medicine and current physicians are either not adequately trained or comfortable with breaching
  these topics with their patients. In addition I feel this should be approached with the idea of a team approach in mind. One in which, not
  only the physician, but also the patient, clergy, social worker, nurse, family, physio, psychiatrist etc. is involved in approaching the subject
  but also carrying out the wishes of the patient." (Open Public respondent)

Theme 6: Relaxing of Eligibility Criteria

#### Summary:

There are concerns that the introduction of physician-assisted dying in Canada could lead to the eligibility criteria broadening or relaxing over time, resulting in a "slippery slope" (a term used by many respondents) where the practice normalizes and becomes more common. Respondents are worried that more individuals will become eligible to receive assistance to die, and it will become more difficult to determine who qualifies (e.g. how to quantify suffering). Respondents were most concerned about children and the elderly (especially with the aging population in Canada), but also for individuals with mental health issues, illnesses, and disabilities. Many participants warned that eligibility has broadened and assisted dying continues to increase in other jurisdictions where the practice is permitted – particularly the Netherlands. Additionally, some felt that this will also allow for greater abuse and unintended use of the practice overall. For example, there are worries that financial / economic considerations could influence decisions around assisted dying, with people being pressured to make requests because they feel they are a burden to their family / loved ones or society more broadly.

While these risks were identified by both Open Public and Representative Sample groups, it was much more prominent with the former (and is closely tied to another top theme – Devaluation of life). Overall, this was not one of the top risks highlighted by Sample respondents.

Theme 6: Relaxing of Eligibility Criteria (continued)

#### Quotes:

- "I am concerned that as time passes the boundaries will disappear and assisted death would be society's answer to difficult people. As soon as we open these doors others find a way to abuse the rules." (Open Public respondent)
- "How to counter the illusion that assisted dying is a solution that will quickly become the answer, because people in general are terribly afraid of suffering." (Open Public respondent, original in French)
- "There is not a jurisdiction in the world that has been able to successfully respond to the inherent risks with assisted suicide and euthanasia. In fact, peer-reviewed studies show that the number of physician-assisted deaths continue to increase in these other jurisdictions, even in the face of clear evidence that the law is not being properly followed." (Open Public respondent)
- "Being of Dutch background, I know that in a very short period of time, a person can ask to be euthanized for almost any reason he or she gives. Also, those who are a "burden on society" will feel the need to justify being an expense, not only to the medical care, but also to society as a whole i.e., special education programs in schools. But above all, God has created humanity in His image. We have always been taught that it is not right to murder or to kill another human being. If we cross this line, where do we end? What ground will Society stand on? I would think it will be a shifting ground." (Open Public respondent)
- "Rather than society viewing the disabled, elderly and dying with respect and compassion, they will be viewed more in terms of a burden on their family and taxpayers and considered selfish unless they seek to end their life (do the honourable thing)." (Open Public respondent)

#### Theme 7: Trust in Providers and Health care System

#### Summary:

Many respondents felt that the patient-physician relationship will ultimately change as a result of this practice. They suggested that there will be a significant shift in the physician's role (e.g. "from caregiver / healer to death facilitator", "from lifesaving and suffering alleviation to death providing", "and not as a caring human being"), which will erode patient's trust and confidence. Respondents identified various ways in which a physician's approach, motives, and interests could direct patients toward assisted dying in various ways (e.g. feel it is more expedient than long-term care, do not have knowledge of solutions / options, want to be alleviated from being overworked or dealing with a difficult patient). Over time, they feel that more doctors will become desensitized to assisted dying and more likely to suggest it to their patients. It is worth noting that many of these respondents signalled an overall distrust or fear of health care providers and the system, with some citing negative personal experiences. In their view, the introduction of physician-assisted dying amplifies this lack of trust because it gives physicians even more power and authority over patients.

Additionally, some respondents expressed distrust in the health care system more broadly. Given the context of rising costs, significant resource constraints and an aging population, they felt that assisted dying may increasingly be seen as an economic solution for patient care. Both Open Public and Representative Sample groups expressed these concerns but it was more prominent with the Representative Sample.

#### <u>Theme 7:</u> Trust in Providers and Health care System (continued)

#### Quotes:

- "If a doctor brought up the idea of euthanizing me with me, I would never speak to him again. I shouldn't have to die because I have a condition, and no one should ever think that. Worse, he may bring it up with family/loved ones, or they may bring it up with him. I want my doctor to try to save my life and not end it." (Open Public respondent)
- "Thus fundamentally changes the role if healthcare from a professional striving to enhance quality of life to one making decisions regarding prematurely ending life. This paradigm shift reduces the "helping", "caring" aspects of healthcare and will create a generation if health professionals who will have less regard for working with patients to find viable options to work through challenging situations to healthcare providers who gently encourage end of life as a viable option when life us hard." (Open Public respondent)
- "Considering the low qualification of many doctors in this country, and the pressure to reduce costs with health care, my concern is that euthanasia be sold as a solution to keep patient's dignity, or as an act of bravery. There's a lot of brainwashing in this country towards making people believe the most cost effective practices are in fact the best practices for the patients. Euthanasia can be seen as a "normal" solution, and be sold as a right of the patient, and even be extended to other non-life threatening situations (such as people suffering from major depression)." (Representative Sample respondent)
- "In the context of budget cuts, health care professionals can be completely overwhelmed. They can be tempted to "cut corners" and go a little too fast when making these decisions." (Open Public respondent, original in French)
- "The medical system will always lean heavily on the side of Physician-assisted suicide because in the long run it will be much cheaper and cost effective solution to help someone die rather than support them through palliative care." (Open Public respondent)

# Safeguards

The Court recognized that health risks cannot be completely eliminated, because they are "part and parcel of our medical system". However, safeguards can help minimize these risks. This section focused on the safeguards for:

- 1. Patients
- 2. Physicians
- 3. Canadian society, including our public health care system

For certain elements, an optional pop-up box provided additional information for participants to consider when their mouse clicker hovered over a "Why" button. Reading the pop-up box was not required and some participants may have decided against doing so before responding to the question.

#### **KEY FINDINGS**

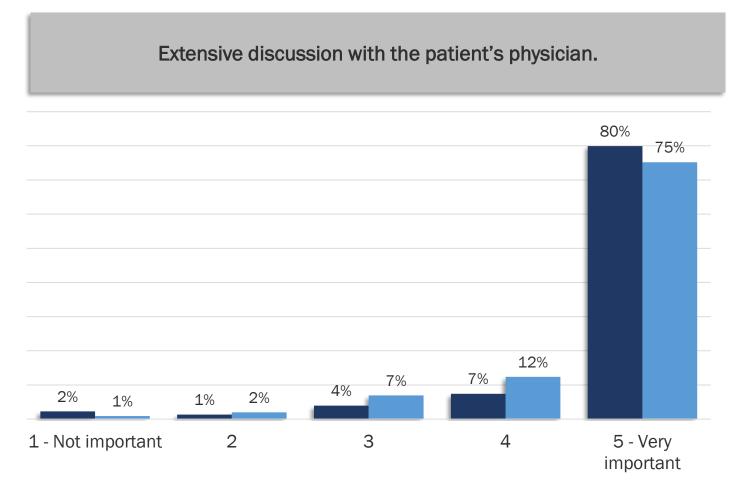
- The safeguards seen to be the most important by participants included education around palliative care for providers and patients, as well as national strategies on disability supports and home care.
- While still seen as important by a majority of respondents, the safeguards less frequently identified as important largely related to procedural checks, including repeated requests by the patient, evaluation by a group of diverse professional, consultation with others, and time delays.

Open Public

Representative

Sample

How important do you think it is for the following safeguards to be required by law before a patient may receive assisted dying?



Among the Public, women, Canadians between 25 and 34, and residents of NL were generally more likely to find this to be very important, along with physicians and nurses.

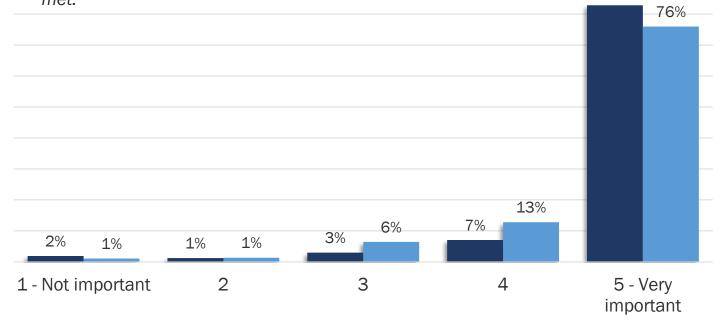
Among the Sample, women and Canadians between 55 and 84 were more likely than others to find this important.

How important do you think it is for the following safeguards to be required by law before a patient may receive assisted dying?

Patients understand and appreciate all palliative and medical care options or supports and services (e.g. psychologist, social worker, pastoral care, medical devices, community support) that might address a patient's suffering.

Pop-up box "Why?": It is possible that sometimes a person's suffering is less directly related to their medical condition and more about not having their support needs met.





Among the Public, English-speaking participants, women, Canadians between 25 and 34, and residents of AB, MB and NL were generally more likely to find this to be very important, along with most professions besides lawyers.

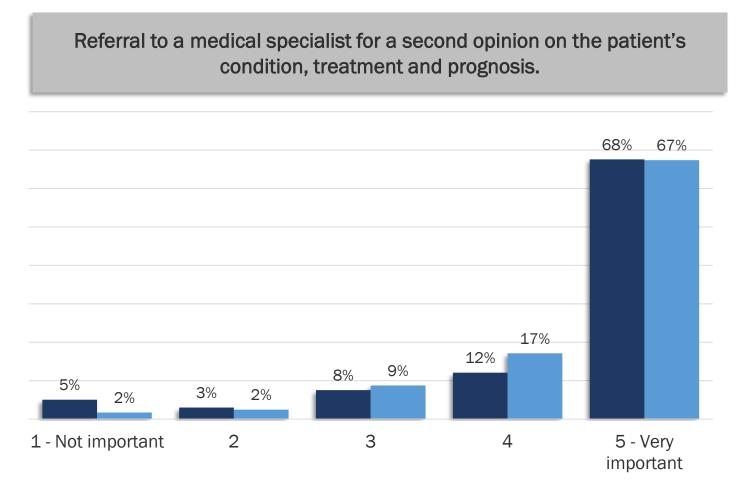
Among the Sample, women and Canadians between 55 and 74 were more likely than others to find this important.

Open Public

Representative

Sample

How important do you think it is for the following safeguards to be required by law before a patient may receive assisted dying?



Among the Public, women, Canadians between 25 and 34, and residents of AB and MB were generally more likely to find this to be very important, along with religious leaders, care or support workers and physicians.

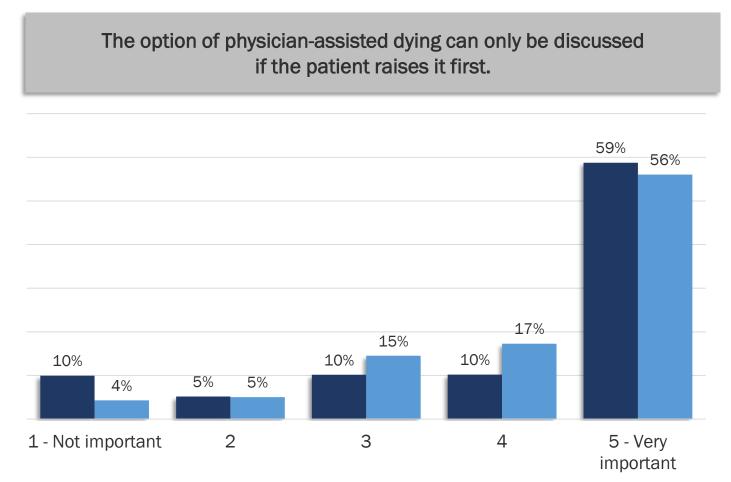
Among the Sample, women and Canadians between 55 and 74 were more likely than others to find this important.

Open Public

Representative

Sample

How important do you think it is for the following safeguards to be required by law before a patient may receive assisted dying?



Among the Public, women and residents of AB, MB and QC were generally more likely to find this to be very important, along with religious leaders and care or support workers.

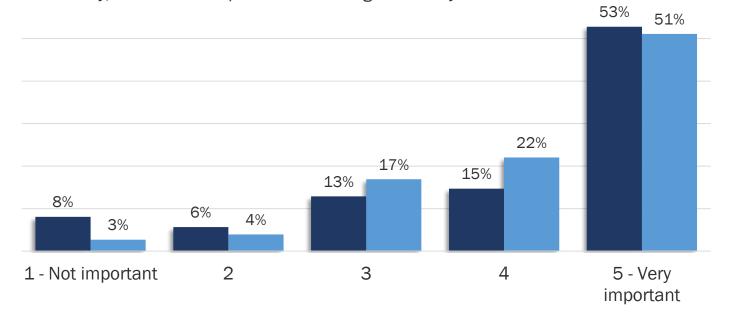
Among the Sample, women were more likely than men to find this important.

How important do you think it is for the following safeguards to be required by law before a patient may receive assisted dying?

A time delay between the diagnosis of condition or injury and when a request can be considered.

Pop-up box "Why?": This could provide patients, who may be vulnerable, time to adjust to a new reality. On the other hand, imposing a delay may seem unfair and arbitrary, since we all experience suffering differently.

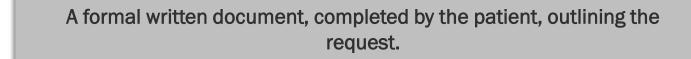
Open Public Representative Sample



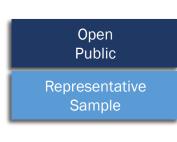
Among the Public, women and residents of AB and MB were generally more likely to find this to be very important, along with religious leaders, care or support workers and physicians.

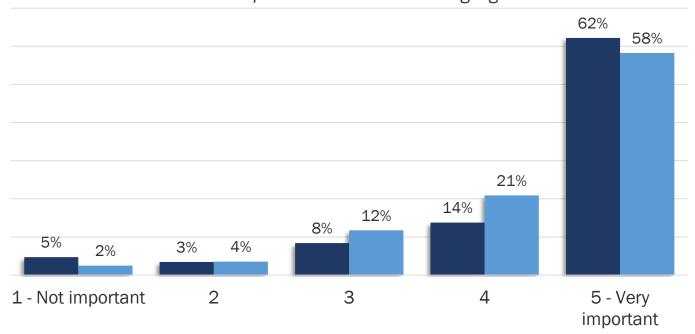
Among the Sample, women and Canadians between 65 and 74 were more likely than others to find this important.

How important do you think it is for the following safeguards to be required by law before a patient may receive assisted dying?



Pop-up box "Why?": This provides a record and evidence of the decision, not only to ensure that it is within the scope of the law but also to highlight how serious it is.





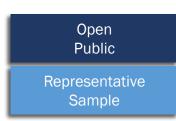
Among the Public, Frenchspeaking participants, women and residents of AB, QC and NL were generally more likely to find this to be very important, along with religious leaders, care or support workers and nurses.

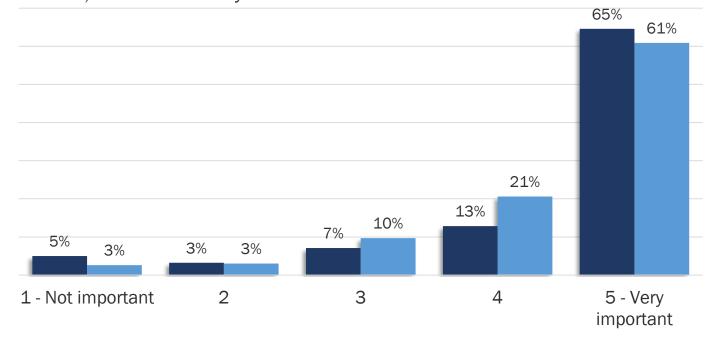
Among the Sample, women and Canadians between 65 and 74 were more likely than others to find this important.

How important do you think it is for the following safeguards to be required by law before a patient may receive assisted dying?

The presence of an impartial individual to witness the signing of the written request.

Pop-up box "Why?": This could help ensure that the request truly reflects the patient's wishes, and not that of anyone else.





Among the Public, women and residents of AB were generally more likely to find this to be very important, along with religious leaders, care or support workers and nurses.

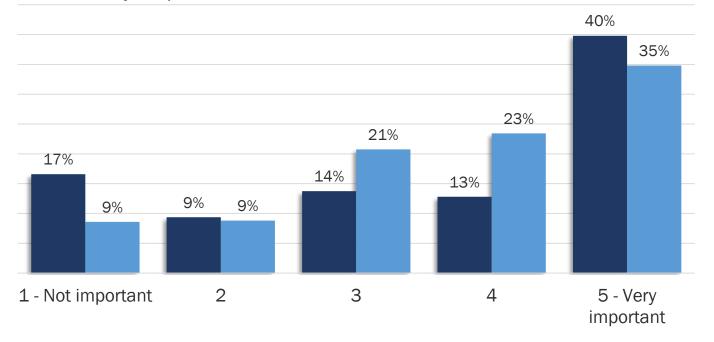
Among the Sample, women and Canadians between 65 and 74 were more likely than others to find this important.

How important do you think it is for the following safeguards to be required by law before a patient may receive assisted dying?

A repeated number of requests made by the patient.

Pop-up box "Why?": This could help ensure the request is both consistent and considered by the patient.

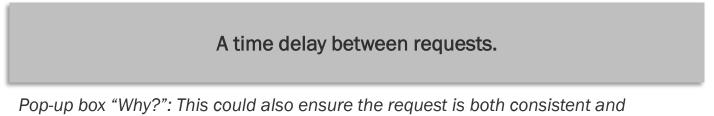
Open Public Representative Sample



Among the Public, women, Canadians under 35 and between 75 and 84, and residents of AB and MB were generally more likely to find this to be very important, along with religious leaders, care or support workers and physicians.

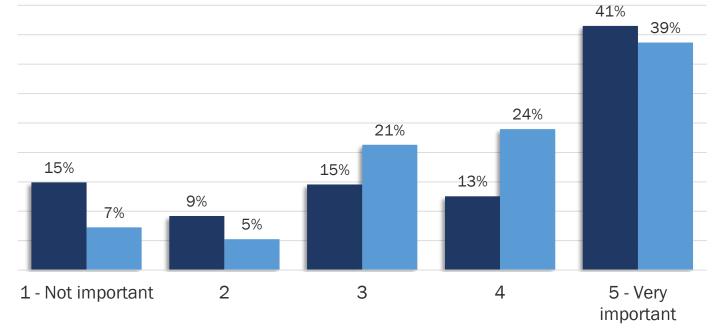
Among the Sample, English-speaking participants, women and Canadians between 65 and 74 were more likely than others to find this important.

How important do you think it is for the following safeguards to be required by law before a patient may receive assisted dying?



Pop-up box "Why?": This could also ensure the request is both consistent and considered by the patient, meeting the Court's requirement of "enduring suffering."

Open Public Representative Sample



Among the Public, women, Canadians under 35 and between 75 and 84, and residents of AB and MB were generally more likely to find this to be very important, along with religious leaders, care or support workers and physicians.

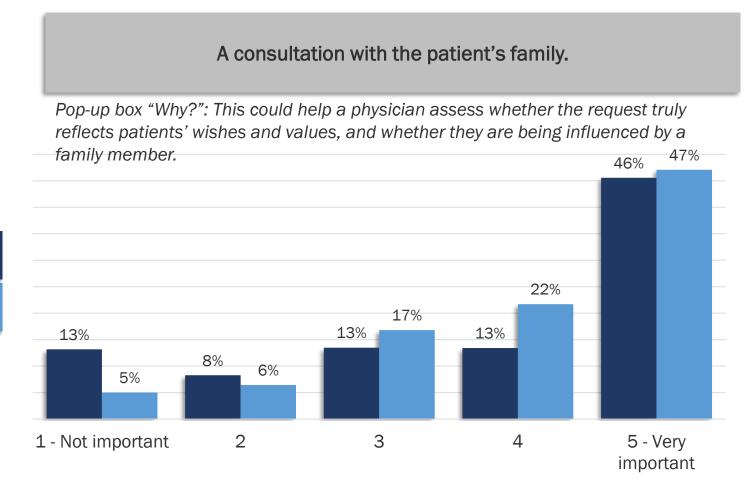
Among the Sample, English-speaking participants and Canadians between 65 and 74 were more likely than others to find this important.

Open Public

Representative

Sample

How important do you think it is for the following safeguards to be required by law before a patient may receive assisted dying?



Among the Public, women, Canadians under 25 and between 75 and 84, and residents of AB and MB were generally more likely to find this to be very important, along with religious leaders and care or support workers.

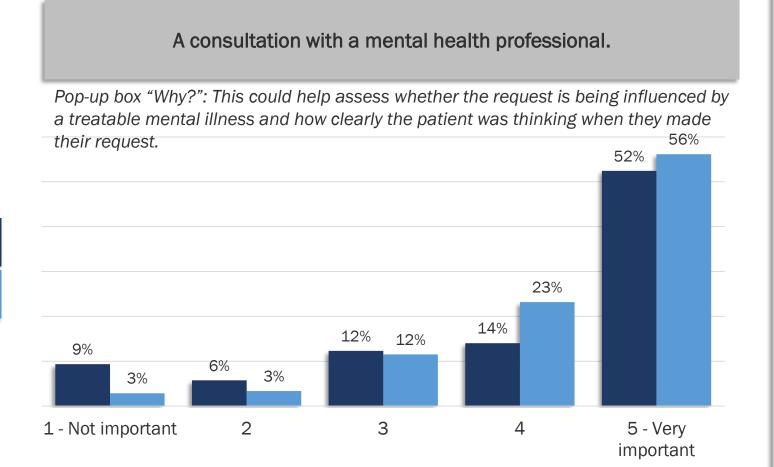
Among the Sample, women and Canadians between 65 and 84 were more likely than others to find this important.

Open Public

Representative

Sample

How important do you think it is for the following safeguards to be required by law before a patient may receive assisted dying?



Among the Public, women, Canadians under 45, and residents of AB and MB were generally more likely to find this to be very important, along with religious leaders, care or support workers and nurses.

Among the Sample, women and English-speaking participants were more likely than others to find this important.

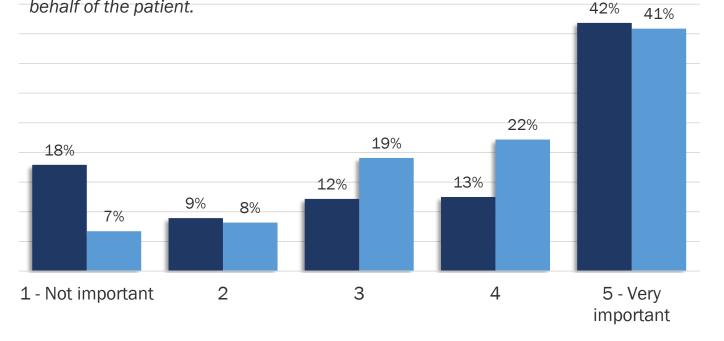
How important do you think it is for the following safeguards to be required by law before a patient may receive assisted dying?

Requests are evaluated by a group of diverse professionals (e.g. doctors, lawyers, social workers).

Pop-up box "Why?": This could help reduce the risk of individual bias in determining consent and capacity, and ensure that diverse perspectives are taken into account on behalf of the patient.

42%
41%

Open Public Representative Sample



Among the Public, women, Canadians under 35, and residents of AB, SK and MB were generally more likely to find this to be very important, along with most professions besides lawyers.

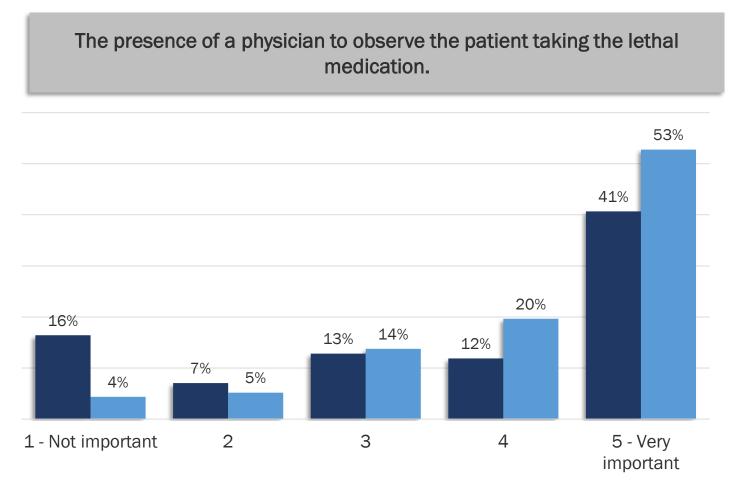
Among the Sample, women and Canadians between 75 and 84 were more likely than others to find this important.

Open Public

Representative

Sample

How important do you think it is for the following safeguards to be required by law before a patient may receive assisted dying?



Among the Public, Frenchspeaking participants, women, Canadians under 35 and over 75, and residents of QC and NL were generally more likely to find this to be very important, along with religious leaders and care or support workers.

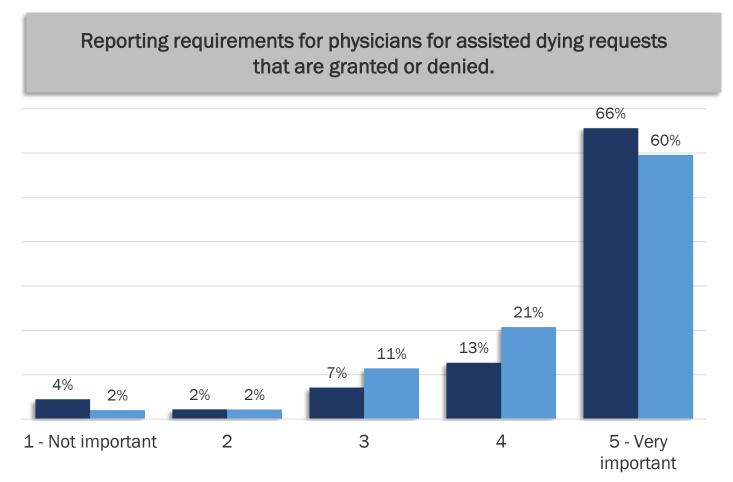
Among the Sample, responses were relatively consistent across demographic groups.

Open Public

Representative

Sample

How important do you think it is for the following safeguards to be required by law before a patient may receive assisted dying?



Among the Public, women and Canadians between 25 and 34 were generally more likely to find this to be very important.

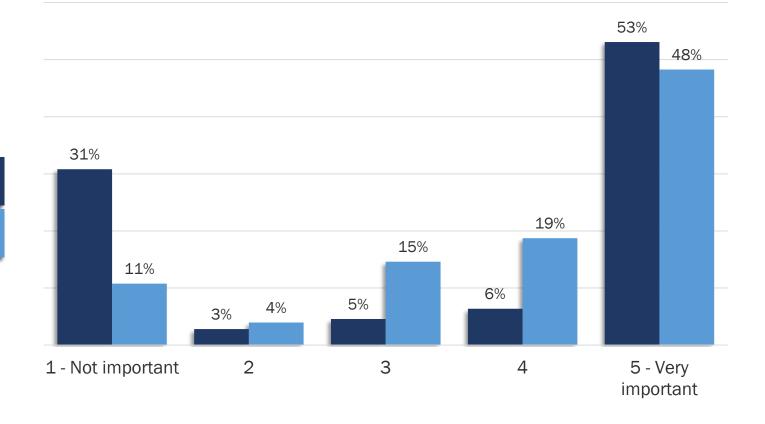
Among the Sample, women and Canadians between 55 and 84 were more likely than others to find this important.

### Safeguards for Physicians

How important do you think it is to create an external mechanism or process to establish that the legal requirements for assisted dying are met before a request is granted?

Pop-up box "Why?": This can help shield physicians from criminal responsibility or civil liability and ensure that professionals with the appropriate expertise are making these decisions.

Open Public Representative Sample

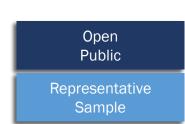


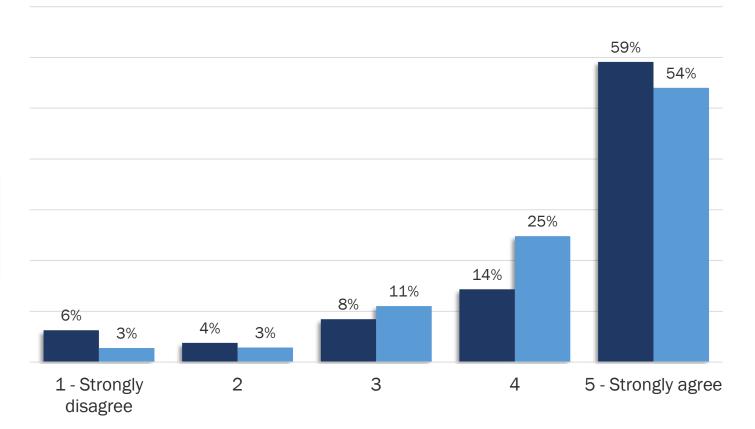
Among the Public, French-speaking participants, women, Canadians between 55 and 74, and residents of BC, NB and NS were generally more likely to find this to be very important, along with social workers.

Among the Sample, French-speaking participants, Canadians between 55 and 74, and residents of QC were more likely to find this important.

### Safeguards for Physicians

Do you agree or disagree that physicians who refuse to provide assisted dying should be required to provide referrals to other physicians who are willing to provide assistance?





Among the Public, women, Canadians under 35, and residents of AB, MB and NL were generally the most likely to agree, along with religious leaders, physicians, nurses and care or support workers.

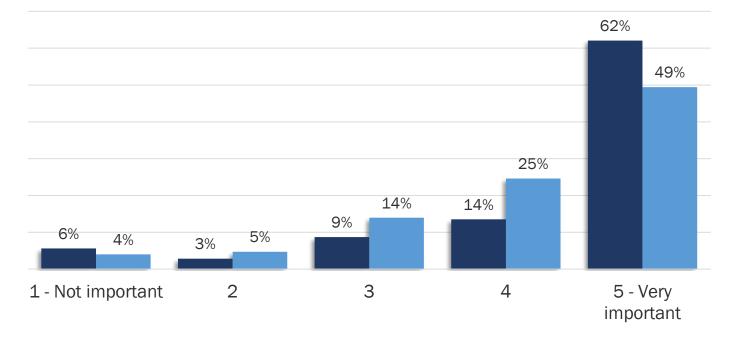
Among the Sample, women and Canadians between 65 and 74 were more likely than others to agree.

How important do you think it is for the following safeguards to be in place?

Public awareness / education campaign on end-of-life options.

Pop-up box "Why?": This could help make people aware of their end-of-life options, as well as the rights and responsibilities of both patients and health care providers.

Open Public Representative Sample



Among the Public, Englishspeaking participants, women, Canadians between 55 and 84, and residents of ON were generally more likely to find this to be very important, along with social workers and nurses.

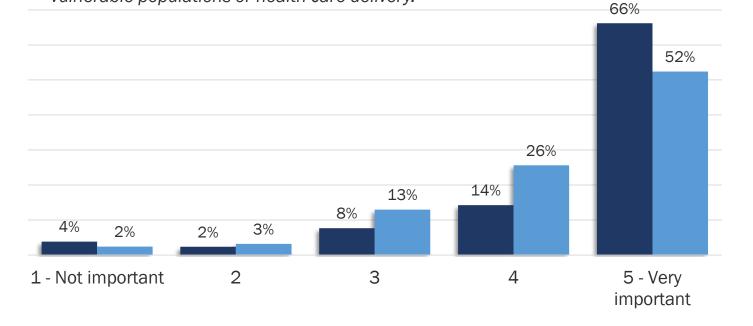
Among the Sample, women and Canadians between 55 and 84 were more likely than others to find this important.

How important do you think it is for the following safeguards to be in place?

Ongoing and mandatory collection, analysis and evaluation of all information pertaining to physician-assisted dying.

Pop-up box "Why?": This could help capture important information, highlight key issues, and enable analysis of social trends or patterns revealing possible impact on vulnerable populations or health care delivery.

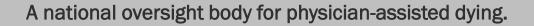
Open Public Representative Sample



Among the Public, English-speaking participants, women and Canadians between 25 and 34 were generally more likely to find this to be very important, along with physicians, nurses, care or support workers and religious leaders.

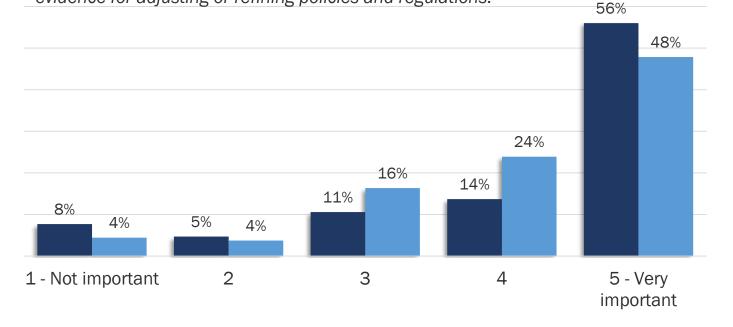
Among the Sample, women, English-speaking participants, and Canadians between 65 and 84 were more likely to find this important.

How important do you think it is for the following safeguards to be in place?



Pop-up box "Why?": This could help determine if policies are being carried out in compliance with regulations, to conduct research for public reporting, and provide evidence for adjusting or refining policies and regulations.

Open Public Representative Sample



Among the Public, English-speaking participants, women, Canadians between 25 and 34, and residents of AB, MB and NL were generally more likely to find this to be very important, along with physicians, nurses, care or support workers and religious leaders.

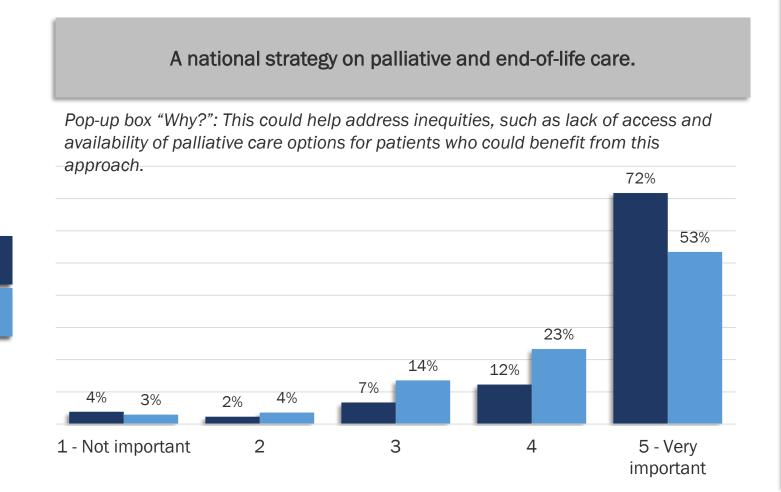
Among the Sample, women, English-speaking participants, and Canadians between 65 and 84 were more likely to find this important.

Open

**Public** 

Representative Sample

How important do you think it is for the following safeguards to be in place?



Among the Public, English-speaking participants, women, Canadians between 25 and 34, and residents of MB and ON were generally more likely to find this to be very important, along with physicians, nurses, social workers, care or support workers and religious leaders.

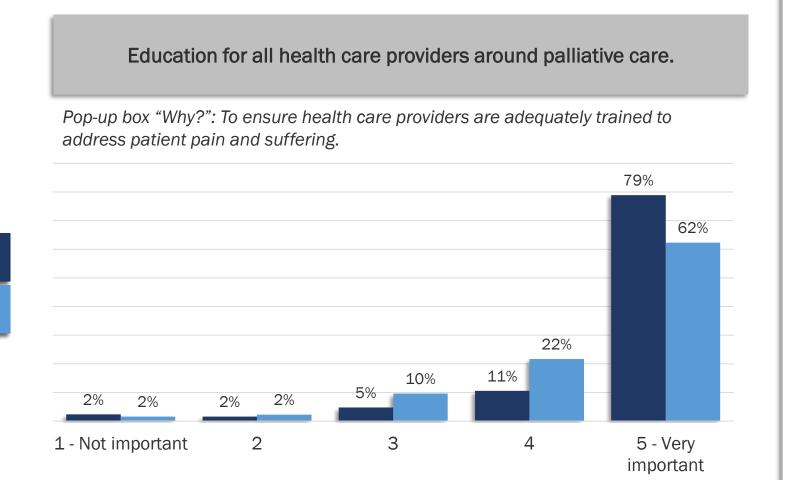
Among the Sample, women and Canadians between 55 and 84 were more likely than others to find this important.

Open Public

Representative

Sample

How important do you think it is for the following safeguards to be in place?



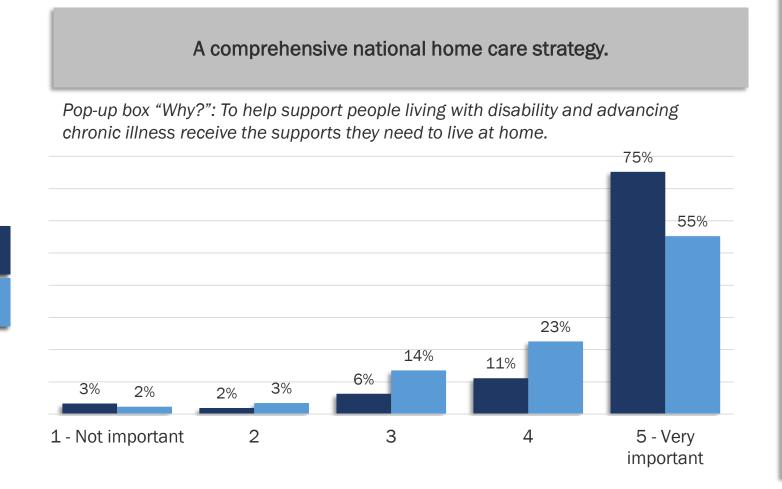
Among the Public, Englishspeaking participants, women, and residents of MB were generally more likely to find this to be very important, along with nurses, social workers, care or support workers and religious leaders.

Among the Sample, women, English-speaking participants and Canadians between 55 and 74 were more likely to find this important.

Open Public

Representative Sample

How important do you think it is for the following safeguards to be in place?



Among the Public, English-speaking participants, women, Canadians between 55 and 74, and residents of MB and ON were generally more likely to find this to be very important, along with nurses, physicians, social workers, care or support workers and religious leaders.

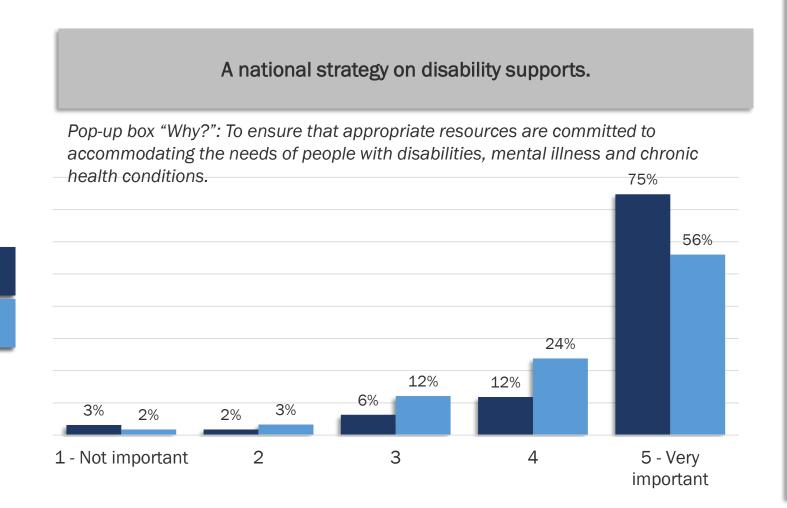
Among the Sample, women, English-speaking participants and Canadians between 55 and 84 were more likely to find this important.

Open Public

Representative

Sample

How important do you think it is for the following safeguards to be in place?



Among the Public, Englishspeaking participants and women were generally more likely to find this to be very important, along with nurses, social workers, care or support workers and religious leaders.

Among the Sample, women, English-speaking participants and Canadians between 55 and 84 were more likely to find this important.

Below are the five safeguards <u>Public participants</u> believed were the most important, on average:

Education for all health care providers around palliative care

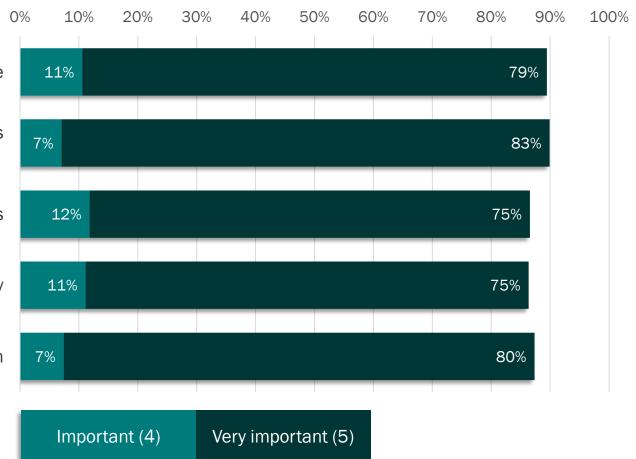
Patients understand and appreciate all palliative and medical care options or supports and services that might address a patient's suffering

A national strategy on disability supports

A comprehensive national home care strategy

Extensive discussion with the patient's physician

<u>Note:</u> Three of the five safeguards listed above (1, 2 and 5) were among the five most important safeguards for Sample participants (next slide) as well.



Below are the five safeguards <u>Sample participants</u> believed were the most important, on average:

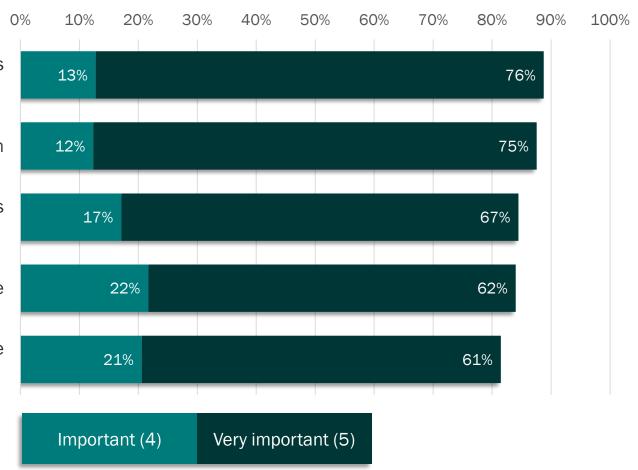
Patients understand and appreciate all palliative and medical care options or supports and services that might address a patient's suffering

Extensive discussion with the patient's physician

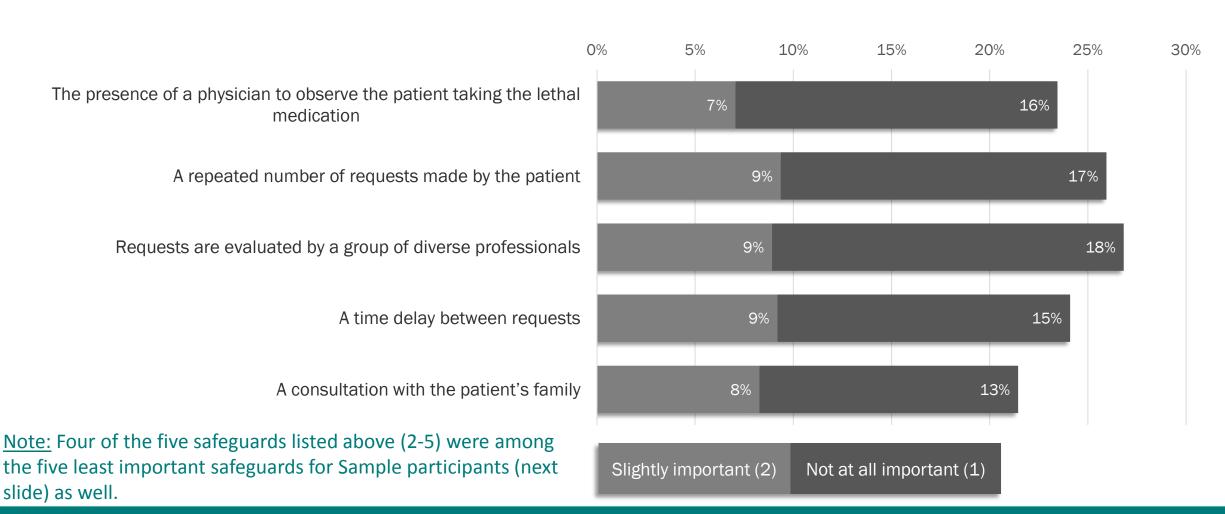
Referral to a medical specialist for a second opinion on the patient's condition, treatment and prognosis

Education for all health care providers around palliative care

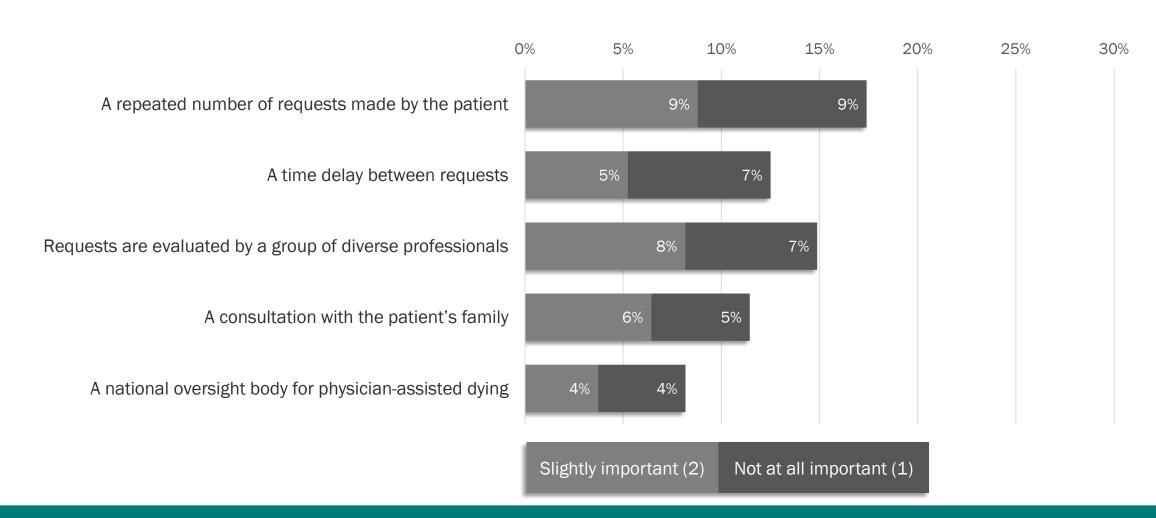
The presence of an impartial individual to witness the signing of the written request



Below are the five safeguards <u>Public participants</u> believed were the least important, on average:



Below are the five safeguards <u>Sample participants</u> believed were the least important, on average:



Summary of responses and sampling of quotes grouped by theme for Issue Book question:

Are there any additional safeguards for physician-assisted dying that have not been raised? If so, please
describe below.

Theme 1: Broad Supports and Alternatives

#### Summary:

Another important theme that emerged was the identification of broad supports and alternatives which might reduce the demand for physician-assisted dying or turn to this as a last option. Both Open Public and Representative Sample respondents highlighted that there is no reason for a person to suffer either physically or mentally because effective alternatives exist to support living or end-of-life care which is dignified, painless and natural. Palliative care was seen by both groups of respondents as a clear alternative to assisted dying with its focus on the primary goal of optimizing quality of life and helping persons with advanced, progressive, life-threatening illnesses to live as well as possible until they die. Investment in broader societal supports e.g. poverty reduction were also seen by respondents as going a long way to reduce the number of requests for assisted dying.

In the view of many, Canada should develop and/or implement national strategies which support the investment in, and assurance of, available/accessible programs, services and health care providers. Areas for investment include: end-of-life care, palliative, hospice or home care; pain control; mental health treatment and recovery; disability benefits; and, long-term and elderly care. These alternatives were noted to offer a "holistic healthcare system approach" which should be invested in together to offer a full range of options and choice. It is important to note that while some respondents saw assisted dying as "one piece" of this range of options or as a "last resort" others expressed that "assisted suicide and euthanasia should not be presented as or perceived as health care acts or medical interventions, so the providers of these actions should not overlap with health care services."

Other coping strategies for stress reduction, pain relief and suffering that were identified by respondents of the Issue Book included: faith-based alternatives which shift "social consciousness toward acceptance of death as inevitable and not something to fear", collaboration with allied health care providers i.e. music therapy, traditional Chinese medicine and Ayurveda.

### Theme 1: Broad Supports and Alternatives (continued)

#### Quotes:

- "We could go a long way toward reducing the number of requests if we as a nation did much better at reducing income inequality, and improving supports for disabled persons and their caretakers, mental health services, end-of-life-care and food security. We have been ignoring many of the things that make life worth living, and I and many I know would be more than happy to pay more in taxes to achieve a civil society in which everyone can live with dignity." (Open Public Respondent)
- "An independent, ongoing review of the availability and funding of programs such as home care, palliative care, counseling [mental health], health care generally, and others I likely haven't thought of, the absence or reduction of which might tend in and of themselves to increase consideration of physician-assisted suicide." (Open Public Respondent)
- "Educate people on the variety of care options and alternatives to physician-assisted dying. Make supports easy to find and access." (Representative Sample Respondent)
- "More free access to specialized services: psychologists, social workers, occupational therapists. Unfortunately, with the austerity and lack of compassion for others, I do not feel that this will open the doors to the well-being of patients." (Open Public Respondent, original in French)
- "Any and all options need to be implemented around giving every individual the help, support, and information that they need so that they do not feel hopeless. Our true goal as a society should be working toward a reality when there would be no one who would want assistance in dying, because they feel fulfilled, wanted, and worthy of the life they are currently living, regardless of disease or condition." (Open Public Respondent)

### Theme 2: Minimal or No Safeguards Needed

#### Summary:

Some Open Public respondents expressed the view that safeguards are either not needed (e.g. Supreme Court has made its ruling and now we need to "move on") or should be minimal because too many safeguards will ultimately prevent access, impede a timely process, or not respect patient wishes. Representative Sample respondents did not express any explicit views in this area.

Some respondents expressed a differing viewpoint concerning the identification of safeguards stating that many of those listed are not actually safeguards but rather should already be in place as necessary parts of the Canadian health care system and independent of regulations that will permit physician-assisted dying e.g. "having good national policies on palliative care and support for people with disabilities is just good health care policy."

#### Quotes:

- "A lot of the items on the previous screens just add incredible delay for people who are suffering incredible physical and mental anguish. A national policy on anything takes decades. Referrals to another physician (GP or Specialist) takes months! Let us start with the basis that people know their physical and mental capacity for pain and suffering. It a person wants to go, let them go." (Open Public Respondent)
- "I believe that strong safeguards must be in place but that they must not be so onerous and time consuming that they serve to delay and put in place so many bureaucratic hurdles that it makes the process too difficult and dissuades the person from pursuing this path or seeking out information. There must be a FAIR balance." (Open Public Respondent)
- "As I understand the Supreme Court's ruling, citizens must have the right to make the choice to die. Presently, individuals and their families have been denied this right by the safeguards put in place by people who wish to protect themselves professionally and legally. It is time to safeguard the right for Canadian citizens to make this choice without interference." (Open Public Respondent)
- "By introducing legal roadblocks the patient's suffering will be increased. The less lawyers are involved with PAD the better. Similarly over sight committees will add a significant additional level of bureaucracy and time delay to a decision that should be the patient's alone, in consultation with a medical professional. The power should remain with the patient." (Open Public Respondent)
- "No, everything is clearly mentioned and ultimately, the patient should have the right to decide on the end of their life if they do not want to suffer physically and psychological and if there is no acceptable quality of life." (Open Public Respondent, original in French)

### Theme 3: Opposition to Assisted Dying

#### Summary:

In response to the identification of additional safeguards, a prominent theme which emerged was opposition to assisted dying. Those who were strongly opposed to assisted dying in the Open Public and Representative Samples felt that no safeguards can be put in place to deem this practice acceptable; thus, it should be criminally prohibited with some going as far as counting it as murder.

Opposition to assisted dying is rooted within the following viewpoints:

- Beliefs and Religion: assisted dying was identified by some respondents as an "immoral practice" which goes against one's basic beliefs of "thou shall not kill" with many emphasizing that only God has the right to end a human life and death is a process which should end naturally.
  - "All the paperwork and legislation in the world will not make physician assisted dying any safer. God is the giver and taker of life. He gives us suffering on this earth to cause us to trust in Jesus for the grace to live each day here. God can also perform miracles and heal people through the power of prayer. The only guidelines that are applicable in this case are in the Bible." (Open Public Respondent)
  - "The best safeguard is for people to be read in the Bible, and recognize that this is only for God to decide." (Representative Sample Respondent)
- Relaxing of Eligibility Criteria: this was based on the belief that over time the practice will become more common leading to unintended changes within our health care system and society at large in how we view care options and value human life "once the line has been crossed, all the safeguards that may be put in place will be subject to constant change and challenge."

Respondents cautioned of a 'slippery slope' some claim has been experienced in other jurisdictions e.g. Netherlands and Belgium. In particular, respondents were concerned of potential abuses occurring in spite of safeguards - unreported euthanasia deaths, euthanasia carried out without consent, new-born infants born with disabilities euthanized, and obtaining euthanasia without any chronic illness.

### <u>Theme 3:</u> Opposition to Assisted Dying (continued)

- Relaxing of Eligibility Criteria (Continued):
  - "Safeguards are only as good as the degree to which they are implemented and enforced. Over time, the acceptance of physician assisted suicide will result in its general acceptance as the norm and the safeguards will slip down the slippery slope." (Open Public Respondent)
  - "Normalizing assisted death as a solution for end-of-life issues will create a societal expectation that this is an option that should be considered. This will inevitably create a pressure on patients to consider this option, especially where they or their family feels that the care required will be a burden." (Open Public Respondent)
  - "Our whole society is going to change with a mindset to end it all if they are depressed, terminal or not pain controlled. Our society will shift from supporting each other at the time of mental illness, terminal disease or pain to solving these dilemmas by getting a doctor to assist in suicide. What a sad way to look at troubles in our life! We need to build community!" (Open Public Respondent)
- Protection of the Vulnerable: tied to concerns of relaxing eligibility criteria was the belief that safeguards are not enough to protect and
  prevent harm to those who are most vulnerable in our society poor, marginalized, disabled and elderly.
  - "Safeguards mean nothing when one group of powerful individuals (i.e. doctors, family members) are empowered by legislation to kill vulnerable patients. Safeguards do not prevent abuse of the vulnerable. They just make us feel better that we did everything we could when the abuse happens. It's better to say no to all abuse than to let some vulnerable patients slip through the cracks and be killed." (Open Public Respondent)
  - "The main goal here is to prevent the most vulnerable people from harm. Prohibiting euthanasia is the best way. If not, make restrictions tight and have a judicial review very regularly to make sure the law is being followed in the assisted deaths." (Open Public Respondent)

### <u>Theme 3:</u> Opposition to Assisted Dying (continued)

- Erosion of Medical Ethics: lastly, arguments against assisted dying were rooted in concerns over asking doctors, nurses or any other health care professionals to engage in activities which would be a violation of fundamental medical ethics and the Hippocratic Oath to cure patients and would therefore "ruin" him or her for the care of others.
  - "Safeguards are only as good as the degree to which they are implemented and enforced. Over time, the acceptance of physician-assisted suicide will result in its general acceptance as the norm and the safeguards will slip down the slippery slope." (Open Public Respondent)
  - "Physicians are not executioners. Their purpose is to promote health and to heal. They should never be put into a position that they have to execute an individual or recommend and executioner to them." (Open Public Respondent)
- Broad Supports and Alternatives: Both groups signaled the importance of practicing comfort and treatments which do not include assistance in ending someone's life.

<u>Theme 4:</u> Participation and Referral - Unforced

### Summary:

According to many Open Public respondents it is important to 'protect freedom of conscience' of all medical and health workers (doctors, nurses, pharmacists). Respondents felt they should not be forced to participate in practices (i.e. assisted dying) which go against their medical ethics but also moral or religious beliefs. This viewpoint was held similarly by a few Representative Sample respondents.

Many noted that physicians should be under no obligation to refer patients to a physician who is willing to conduct this practice rather it was suggested that a self-referral system be implemented to avoid putting the 'burden' on the physician to refer. Through this system it was suggested that patients could conduct their own online search or visit a center that provides the names of doctors providing service in their community. Physicians who feel they cannot participate in assisted suicide, need to be supported in their decision free from any legal ramifications (fines or penalties) or discrimination in particular as it relates to job security.

A suggested alternative to participation and referral includes developing a new professional class with the role of assisting with dying and suicide. This alternative helps to "put doctors who are against assisted suicide out of the picture"; however, the exception is that they need to refer a patient to one of these professionals upon request. This new profession would be trained to ensure proper requirements and techniques are employed, just as current professionals such as engineers, doctors, lawyers do...

<u>Theme 4:</u> Participation and Referral – Unforced (continued)

#### Quotes:

- "All doctors and health care workers should be able to live by their conscience. We need them. They should NOT have to refer
  patients for euthanasia if it is against their conscience or religion." (Open Public Respondent)
- "Explicitly protect the conscience rights of all physicians and health care workers so they have the freedom to refuse to take part in, refer for, or counsel against the killing of any patient. No other jurisdiction that allows euthanasia or assisted suicide imposes a legal duty on physicians who conscientiously object to make referrals for physician assisted death." (Open Public Respondent)
- "Absolute freedom in all provinces and jurisdictions with no reprisals for Doctors who because of conscious objection who will not refer or participate in euthanasia. I see too much in our country of people being forced to live and work outside of their beliefs or conscience." (Open Public Respondent)
- "There is considerable risk to the wellbeing of health care providers involved in the provision of this 'service'. This cannot be a required action in the registration of health care providers or not many of the people you want to attract to this profession will apply. This is not something many health care providers would be comfortable with. It is still a service that is very appropriate within the Canadian health care system, and very much needed to be provided in the correct circumstances." (Representative Sample Respondent)
- "The requirement on the physician is unreasonable because their oath was to preserve life, this changes their profession and it may become an issue to have fewer doctors. We run a risk of changing and losing valuable physicians to a death cultured breed of physician. I personally will lose faith in the professionals." (Open Public Respondent)

Theme 5: Patient Choice / Right to Die

### Summary:

The view that people should have freedom of choice, including the right to control their own body and life, not prolong suffering, and be free from outside influence, was expressed predominantly by Open Public respondents. It was suggested that after considering the information and issues that affect them and their family, patients should have the right to choose physician-assisted dying. Both groups of respondents expressed the belief that with that choice should come the choice as well to change one's mind. Others maintained that a patient's wish to die should be protected, provided they meet the conditions laid down by the Supreme Court.

#### Quotes:

- "I believe that the only person who should be able to make the final decision should be the person whose life is in question. I believe that a doctor can offer life ending options but should never be allowed to make the final decision for the patient, regardless of metal or physical condition." (Open Public Respondent)
- "Although decisions should be carefully weighed and follow a defined process, the 'agreement' of a diverse committee on each end-of-life
  decision threatens to once again remove the autonomy and dignity of the patient. Patients are making a very difficult decision, which should
  be made with the assistance of their physician and mental health professionals, and should be respected. At no point should they be
  requesting 'permission' from an external body." (Open Public Respondent)
- "This should be the right of persons to control and have a say in end of life decisions. That kind of autonomy can only be served by appreciating that most persons would choose life but in situations where it has become unbearable there are ways to be able to end one's life without having to leave your home or Country or suffer by refusing treatment." (Open Public Respondent)
- "Everyone will have a different threshold for what they define as the "tipping point" I believe this must be considered and respected. Physicians must learn to respect and uphold the patients wishes." (Open Public Respondent)

### Theme 5: Patient Choice / Right to Die (continued)

#### Quotes (continued):

- "There must be an easily accessible, always available, none punitive and simple mechanism whereby the patient can change his or her mind regarding any request to terminate his or her life at any point in time right up to the final moment. In other words, a person should have the right and ability to change their mind right up until it is too late to do so." (Representative Sample Respondent)
- "NO pressure from family or caregivers should be experienced when making such a personal decision to end their life. DOCTORS should be
  making referrals for their patient if they REFUSE to participate, its the patients request." (Open Public Respondent)
- "Once the patient has made their decision and it is deemed reasonable and undertaken with full knowledge, the next of kin should not be allowed to interfere. It is my understanding that currently next of kin can override a patient's wish to be an organ donor. This is wrong and it should not be allowed in end-of-life situations." (Open Public Respondent)
- "Safeguards need to be introduced to ensure that access is not denied to any competent adult who is suffering in a manner which is
  unacceptable to THEM. It doesn't have to be unacceptable to a psychologist, a doctor, their family, or any other person. You cannot judge for
  somebody else." (Open Public Respondent)
- "The ability to die should be a choice of the individual, after that individual is informed of their options and still chooses to die. Assisted dying should NEVER be a decision that a committee of professionals needs to approve." (Open Public Respondent)
- "The most significant safeguard that we need to consider is to create a system that safeguards the patient's expressed wish to die, provided they meet the conditions laid down by the Supreme Court. This fundamental right must not be subverted by inaccessible, bureaucratic systems created to appease concerns of the medical profession and religious groups." (Open Public Respondent)

Theme 6: Review and Oversight

### Summary:

In sharing their views on how to mitigate perceived risks and harm of physician-assisted dying for those most vulnerable, respondents identified processes or entities that would provide a review or oversight function before physician-assisted suicide could be provided. It was also suggested that review or oversight should take place afterwards for monitoring and evaluation purposes.

Key processes for review and oversight suggested by respondents of the Issue Book included requiring:

- Counselling: physicians refer patients that may be suffering from psychiatric or psychological disorders or depression for counselling. Death may not be granted until it can be confirmed by the counsellor that the patient is not suffering psychologically or from depression.
- Consent: It was suggested that consent be witnessed by at least two others (one of the witnesses must not be a relative or someone entitled to a portion of their estate), with the entire process video recorded from beginning of request, discussion with doctors, panel hearings, lethal injection and pronouncement of death. These video's must be regularly and independently reviewed by a joint panel of doctors, lawyers and ethicists and must be immediately and full accessibly to any judge, officer of the court or Parliamentarian upon request.

It was also noted that consent must be given both orally and written, no less than 15 days apart, and can be rescinded at any time and in any manner without regard to his or her mental state. While it is important that we have a formal, written process in order to document a request by a patient to end their life, it must not be designed in such a way as to cause an impedance to any individual who seeks to end their life - for example, people with low literacy or language barriers or those who have suffered a severe stroke. As such, all efforts must be made to ensure the process is as inclusive as possible, including providing alternate forms of documentation to those patients who are incapable of physically writing a request (video, sign language). Conversely, many people who are capable of clearly communicating their wish to die may be intimidated by the task of writing a formal request and may not have experience writing formal documents themselves. Therefore, it was suggested that or providing resources to allow these individuals to write a request without relying on the help of friends/family who might influence them.

### Theme 6: Review and Oversight (continued)

#### **Summary (continued):**

• Validation: It was suggested that the onus must be on those who are involved in administering physician-assisted dying to provide evidence from third parties that the request for death is not coerced, in every case. Failure to provide this should result in sanctions and other repercussions potentially including criminal charges.

As a mechanism to support ongoing monitoring, Open Public respondents overwhelmingly identified the need for a judicial review every three years of all assisted suicide deaths. Should it be found that the law is not being followed it was suggested that an immediate moratorium of all assisted deaths be put in place and not lifted until the law can be amended to fully prevent harm.

It was also widely suggested that an agency be created (reporting to the Minister of Justice or be formed through the Canadian Medical Societies/Association) with the mandate of monitoring assisted suicide deaths to ensure the law is being followed. A "Center of Excellence" approach was suggested to provide better control nationally to ensure established protocols are consistently applied and would better enable a reliable statistical data bank for evaluation purposes.

Additional or alternative review and oversight processes or entities suggested by respondents of the Issue Book included:

- Audits and Data Reporting: audits should be conducted with severe penalties for anyone who takes or assists in taking a human life without reporting it; public records should also be maintained on who has received assisted dying services or who has aided in this practice, directly or indirectly.
- Ethics Committees: the role of Ethics is paramount in the formulation of policy related to safeguards.

### Theme 6: Review and Oversight (continued)

Additional or alternative review and oversight processes or entities suggested by respondents of the Issue Book included (continued):

- Review Committees: to oversee and discuss each request submitted by the doctor; this would be a collaborative committee potentially including, physicians, nurses, public, pharmacists, clergy etc. to obtain unbiased evaluation and approval in a timely manner. Such a committee would serve as a support to physicians so that they are not left with the primary decision. The committee should be knowledgeable about the laws as well as medical and moral implications of the decision. There should also be an appeal process for the patient. Patients whose life expectancy is greater than 3-6 months should require a separate and more formal process, including a review board of expertise (legal, medical, ethicists) or hearing.
- Compliance reviews: appointed by an external commission this review would be conducted to ensure that all guidelines are being followed (should be conducted before the death has taken place, rather than afterwards) but this should not impose unreasonable delays i.e., the review shouldn't add more than a few weeks to the process.
- Random Checks: to ensure all policies by patient and physician are being followed.
- **Peer Reviews:** for doctors (not Administrators or HR personnel) to evaluate other doctors, in order to establish and informally certify the health and robustness of the presiding doctors' reasons for engaging in providing assisted-dying services.
- Federal and provincial Ombudsmen: to ensure appropriate and needed legislation and supports are in place.
- Consideration of a cultural and diversity lens in access to physician-assisted dying: issues should also be considered in the process and monitored e.g. Canada already has a disproportionate number of Aboriginal and First Nations people dying by suicide. It would be important to ensure this was not a factor (either way) in access to physician-assisted suicide and therefore any oversight body should include the capacity to monitor with this lens. Consumers/patients/families/citizens should be involved in the design and ongoing monitoring of the process from a purely neutral perspective (i.e. not medical. legal or economic).

# Evaluation of Issue Book Questionnaire by Respondents

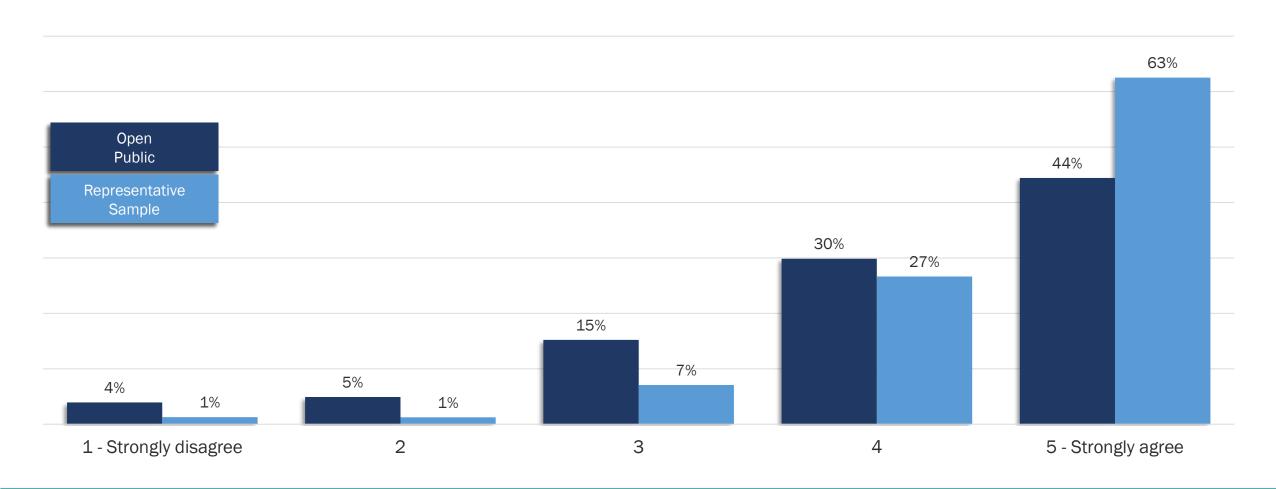
At the end of each Issue Book, participants were asked to evaluate their experience with the consultation and to provide feedback on how information was presented. The following slides present the results of the participant evaluations.

# **KEY FINDINGS**

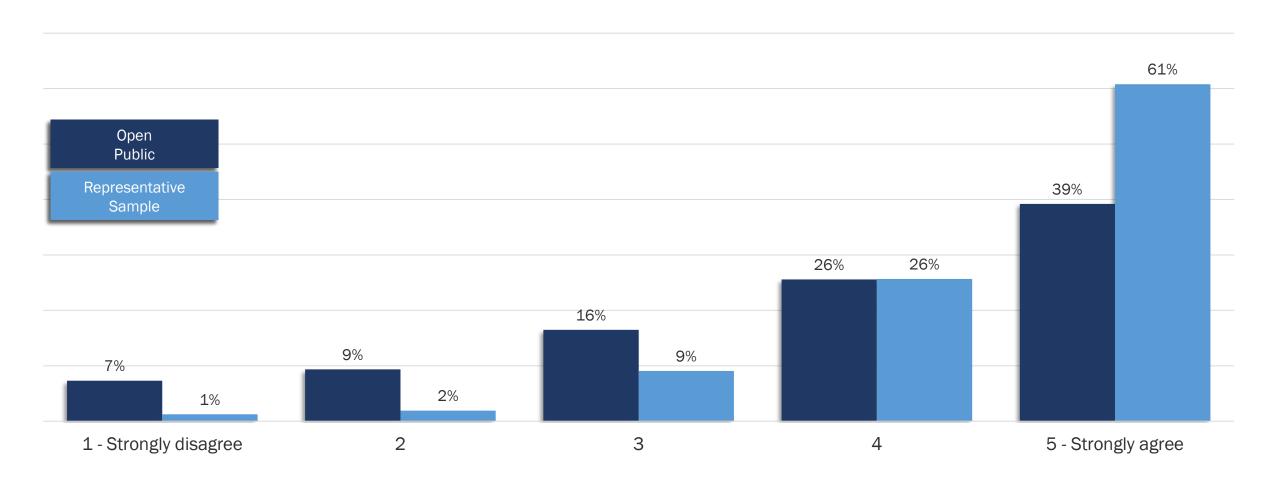
Participants indicated they were very satisfied with the consultation process, particularly those from the Representative Sample:

- 90% of Representative Sample respondents and 74% of Open Public respondents agreed that "The information was clearly presented." (2% of Representative Sample respondents and 9% of Open Public respondents disagreed)
- 87% of Representative Sample respondents and 65% of Open Public respondents agreed that "The information was well balanced between different views on the issue." (3% of Representative Sample respondents and 16% of Open Public respondents disagreed)
- 83% of Representative Sample respondents and 61% of Open Public respondents agreed that "This online consultation helped you learn about the key issues and concerns." (3% of Representative Sample respondents and 17% of Open Public respondents disagreed)

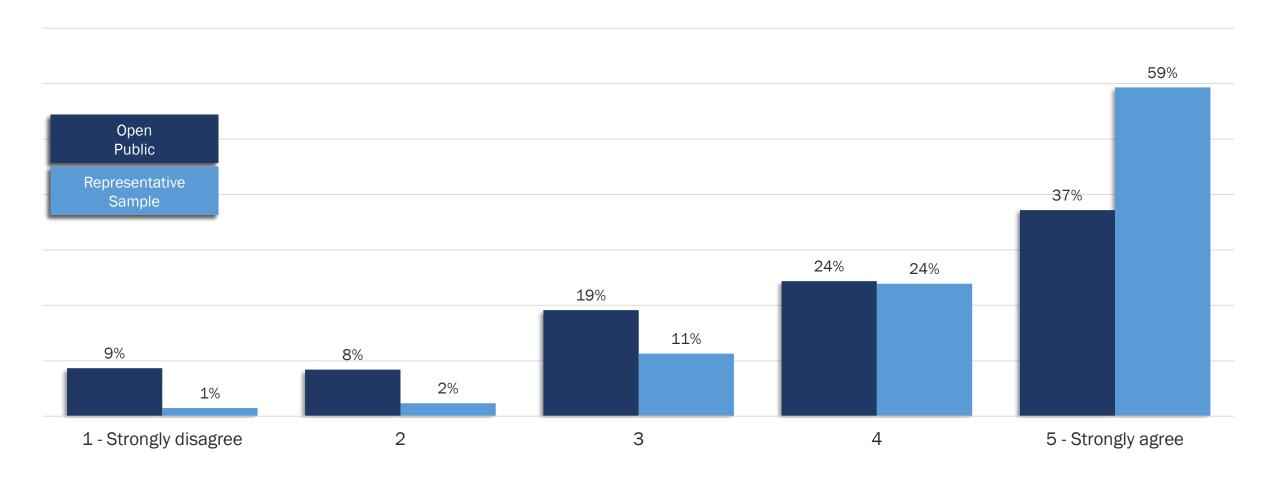
# The information was clearly presented



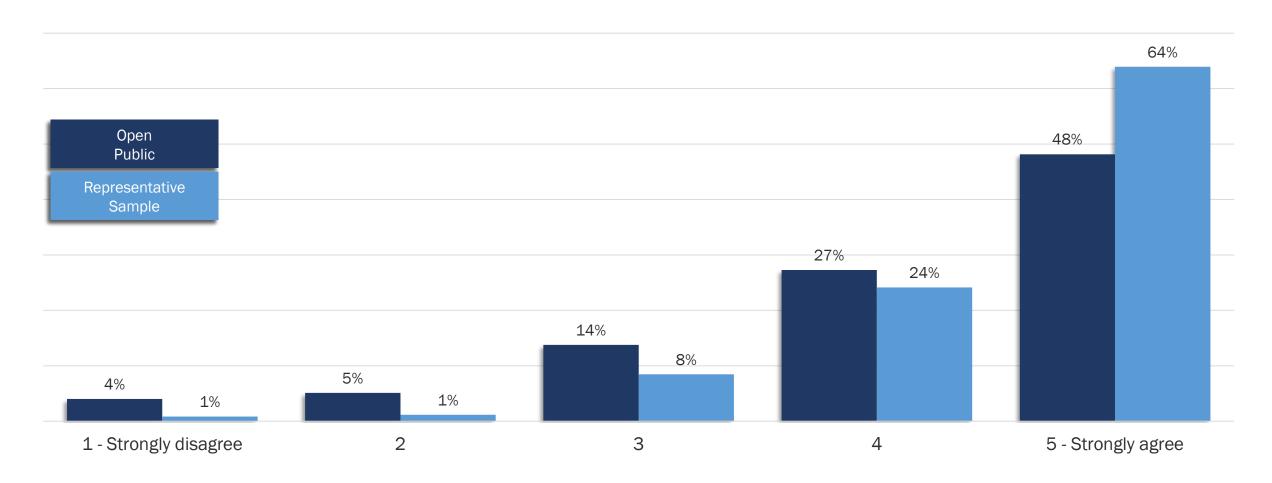
# The information was well balanced between different views on this issue



# This online consultation helped you learn about the key issues and concerns



The online consultation provided you with a good opportunity to express your views on this issue







# Independent Review of the Issue Book Online Consultation for the External Panel on Options for a Legislative Response to *Carter v. Canada*

December 11, 2015

Contract # 4500126656

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# **Executive Summary**

The results of the analysis here support the view that the External Panel on Options for a Legislative Response to Carter v. Canada (the Panel) can and should use the results of the consultation using the Workbook or Issue Book methodology as a reflection of the views of Canadians on the issue. Research by definition involves choices and the result of those choices will influence the nature of the findings and the conclusions drawn from them.

Clearly the Issue Book framed the issue for respondents in a unique way that differs from a traditional survey approach and this must be kept in minding in thinking about the questions and the responses. In addition, the needs and interests of the Panel, as reflected in its mandate, drove the consultation process. The results are not an open investigation into the question of physician-assisted dying.

Like all research there are areas of strength and weakness in the design and analysis provided.

- A strength of the process is clearly tied to its breadth of sample and the fact that while all
  Canadians were welcome to participate (and many did so), the open participation was balanced
  with a closed survey that was designed to mimic as close as possible the demographic character
  of Canada (general public sample). The Panel can situate the expert and stakeholder advice it
  received through the open Issue Book and other submissions within the broader Canadian
  public perspective.
- An obvious strength is the ability to make clear comparisons of how people view the issue across
  a range of scenarios with different informational prompts. While the scenarios could have been
  improved, they clearly function as a way of assessing relative support since the changes to the
  scenario create a comparative context for individuals. The reporting could have more clearly
  explained the purpose of the scenario process and the inferences being drawn for readers.
- A drawback is that a small change in the scenario could make different things salient for the
  individuals and change the distribution of opinion. As a result, responses must always be viewed
  through the lens of the scenarios. This is important since there is no measure of support for
  physician-assisted dying as a policy issue outside of the scenarios to contextualize the scenario
  information.
- The Issue Book contains a considerable amount of information and context for respondents both as part of, and separate from, the scenarios. While this review has not provided an analysis for bias of this content, the Panel should understand that this information (and the absence of other information) provide a critical and possibly controversial context for interpreting the results.

### About the author

Richard Jenkins, Ph.D., has more than 15 years of market research experience, which includes working on more than 15 consultations involving workbook like exercises. He has been directly involved in more than 250 surveys. More about him is available in the appendix.

# **Background and Objectives**

The External Panel on Options for a Legislative Response to Carter v. Canada (the Panel) engaged Richard Jenkins of Jenkins Research Inc. to conduct an independent expert review of the Issue Book Online Consultation that was conducted by the Panel. The consultation was designed to bring public input into the Panel's work process.

The review is to include both the overall methodology and the specific questionnaire/ workbook design used to capture the input of Canadians.

The following specific tasks were conducted:

- Review the questionnaire Issue Book used to capture feedback along with the description of the methodology used overall.
- Review the report based on the public input with particular emphasis on how the information is
  presented including any qualifications on the data validity and interpretation.<sup>1</sup>
- Speak with key stakeholders involved in the construction of the workbook as necessary.<sup>2</sup>
- Review existing external critiques of the methodology.<sup>3</sup>
- Write a report that reviews the online consultation and identifies the following:
  - Advantages and disadvantages of the research tool used and overall approach; and
  - o An opinion on the value and reliability of the data collected and reported.

The approach taken in this expert review takes as its starting point that it is essential to understand three questions when approaching a review of a research program:

- Was the study conducted in a manner consistent with the principles of the research plan? In other words, was the workbook process internally consistent with accepted principles of this form of research?
- Is there any reason to believe that the research was designed to be biased in a particular direction?
- Is the analysis and recommendations supported by the evidence? This includes not only whether the recommendations flow from the actual answers but also whether this type of study can support these recommendations.

It should be noted, that while Richard Jenkins is an expert in survey-based methodologies and consultations, he has only a general knowledge of the issue of physician-assisted dying.

<sup>&</sup>lt;sup>1</sup> The preliminary draft report of the 2015 Issue Book Results Consultations on Assisted Dying was reviewed.

<sup>&</sup>lt;sup>2</sup> In addition to a briefing by the staff of the panel, a conversation with the research firm engaged to conduct the consultation took place after the materials had been fully reviewed and assessed.

<sup>&</sup>lt;sup>3</sup> During the course of this review, a report written by Geordie McRuer, PhD titled, "A Methodological Analysis of the Issues Book Survey on Doctor-Assisted Dying" (November 4, 2015) was reviewed. While this review makes mention of the McRuer report in some places, it is not in any form a response to that report.

# **Analysis of the Methodology**

The Issue Book Online Consultation conducted by the Panel involved the development of an issue book that was designed to develop an understanding of how Canadians think about the issue of physician-assisted dying.

The best starting point for any discussion of the methodology used to capture public input in this case is to understand that the approach differs significantly from a traditional public opinion surveys. While surveys are usually defined in terms of a set of usually neutral questions designed to capture public views on issues, the workbook approach is designed specifically not to be just a measure of what people think but to go beyond that to better capture the role of information and exposure to arguments.

The root of a workbook process has its origin in ideas about deliberative democracy and the idea of deliberative polling in which a representative sample is brought together and provided information and a chance to express views. While the Issue Book process did not involve a coming together of people for deliberation, it did attempt to do more than ask questions. Canada has a history of work book type consultation processes.

Advantages/ Benefits of a Workbook Process:

- On topics that people have not thought much about, the provision of information can ensure
  that those completing the consultation are all working from the same-shared perspective and
  that shared-perspective helps respondents evaluate specific questions more easily than they
  could in the absence of information.
- It ensures that those who are answering are addressing the specific policy choices that are being considered and not just broad value-based answers.

Disadvantages/ Drawbacks of the Workbook Process:

- The results because they are based on a process with information provided to respondents may not be consistent with other surveys of the population.
- By definition, there is considerable influence of information and structure of the workbook on the results. If in the design, key information or policy options are not represented well the results will be biased as a result.

The approach used clearly differs from traditional surveys but is a proven approach for generating deeper more thoughtful insights into public policy.

<sup>&</sup>lt;sup>4</sup> A leading proponent of practical forms of deliberative democracy is James Fishkin (1995) *The Voice of the People*. New Haven: Yale University Press.

# **Analysis of the Sample**

Who participates in the consultation is an important factor in the research but the approach taken for the Panel achieves the best of an open consultation and a controlled public opinion exercise.

Two separate groups or samples of Canadians completed the same instrument and the data is treated separately in analysis. An *open public* group includes anyone who learned about the consultation, through a variety of means and self-selected themselves to complete the workbook. A second, controlled sample of the *general public* was drawn from an online panel and weighted to reflect the population of Canada.

The reason for two separate samples is that the open public is more along the lines of a traditional consultation where anyone interested can speak. This group is more engaged on the topic and will be more vocal in public discourse. The Panel should, as it would with all submissions it receives from interested parties, understand that individuals and groups were motivated to participate.

The general public sample is designed to capture what average Canadians think on the topic. Using an online panel, which in this case was outsourced to Leger Marketing is a reasonable approach. Online panels are a standard market research tool in which participants are recruited, using a combination of methods, to take online surveys as needed by the company. While people self-select themselves into most research panels, they do not do so on the basis of any particular public policy issue (no one knew that they needed to be on the Leger panel in order to be invited to take the Issue Book) so the panel should not have an inherent policy bias. In addition, the data for the general public was weighted so as to ensure that the profile of respondents was a reflection of the Canadian population.

### Observations:

- Drawback: Using an online panel, which is not randomly recruited, does not allow for the use of a margin of error or other probability statistics.<sup>5</sup>
- Strength: Online research is a widely used and generally accepted practice for conducting cost effective market and policy research.

The approach to the two samples is consistent with best practices in the industry and should not be a source of significant risk in terms of interpreting the results. While one might prefer a randomized recruitment method, the Panel should feel comfortable in assessing the data from the two samples.

### The Issue Book

The structure of the Issue Book includes four sections. After capturing demographic and other profile information about the respondent, a set of scenarios are used to develop an understanding of the conditions under which there is support for physician-assisted dying. The Issue Book then separately

<sup>&</sup>lt;sup>5</sup> There are some panels where random recruitment is used.

considers risks and then safeguards. Building the workbook in this manner makes conceptual sense, especially given the mandate of the Panel.<sup>6</sup>

In evaluating the workbook or any questionnaire, one needs to be conscious that the very act of asking questions will shape the answers and data that emerge. Choices about words, scale points, and language clearly have effects. There is no true opinion that just needs to be measured with the right tool. For this reason, the fair approach to take in evaluating the workbook is not to critique questions in terms of the construction, unless it is clearly egregious in producing bias, but rather to understand how the questions and structure limit or constrain the analysis and the confidence one can place in the results.

- <u>Scenarios:</u> There are four overarching scenarios that cover things from a significant life-threatening illness to a mental health condition. The purpose of the scenarios is to focus on "who should have access to physician-assisted dying" (page 8). Within each scenario, there are additional scenarios that qualify the overarching scenario.
  - o It is noteworthy that in the scenarios there is no description of why in the scenario the person should or should not have eligibility. The expectation is that respondents will formulate an explanation based on the information given. For example, in the mental health scenario there is no rationale for why this person might be given the ability to do so or the right not to.
  - o There are two *strengths* of this approach: (1) respondents have a concrete situation to evaluate; (2) it is possible to observe the impact of adding context to the other scenarios on support (for example, the strongly agree for scenario 2 drops from 13% to 6% for the representative sample when information is added that the event was recent).
  - O Drawbacks. A drawback of this approach is that the scenarios can be subject to criticism in terms of their construction and the associated information (for example McRuer 2015). There are grounds for suggesting that the scenarios could have been better constructed and less ambiguous. Each of the scenarios does require a respondent to make assumptions about information not included in the scenario (e.g. when a person is going to have a physician help them die). There are no perfect ways, however, of constructing scenarios.
  - o Choice of scenarios and qualifications. Constructing 4 overarching scenarios, with various other specific scenarios, that are both realistic and which cover off a variety of potential real-life occurrences where physician-assisted dying might be relevant is obviously challenging and opens the process to confusion and criticism. While the scenarios appear to stretch the ideas expressed in the Court decision (based on the information provided to the respondent), there is value in understanding what Canadians are comfortable with and what they are uncomfortable with. A better explanation in the report of why these scenarios were used and the nature of the inferences being made based on how people responded to the overarching and contextual sub-scenarios would improve the report.
- <u>Risks:</u> The section on risks assesses risk in terms of the level of concern with a set of more than 30 different risks for patients, patients with disabilities, persons with mental health conditions, palliative care, and society at large.

<sup>&</sup>lt;sup>6</sup> Inevitably respondents are definitely been exposed to more information and the information was crafted specifically to address the needs and interests of the Panel.

- Strengths: there is a breadth of coverage and the items allow us to have a more nuanced understanding of how Canadians think of the impact of physician-assisted dying. Since the items are all on the same scale, respondents will be evaluating them as a series of concerns.
- Drawbacks:
  - 1. Concern is being used to capture general negative outcomes that could emerge from permitting physician-assisted dying but some of the items are multi-dimensional and we have no way to gauge how big an actual problem the public thinks each of these risks are.
  - 2. There is a framing of these as risks but they may be more appropriately understood as impacts (e.g. "normalizing societal views on assisted dying as an alternative to other ways of addressing suffering" may occur but depending on position on the issue you may see this as a positive not as an area of concern).
- <u>Safeguards:</u> The final substantive section of the Issue Book covers the importance that Canadians
  assign to the presence of 22 safeguards that include such things as waiting periods and public
  awareness campaigns.
  - Strengths: While the number of questions is long, they cover off in a manner that allows respondents to effectively identify important versus unimportant safeguards which are a reflection of both the policies they would want but also the concerns they likely have about physician-assisted suicide.
  - o *Drawbacks*: Many of the questions come with explanatory information that is designed to give respondents extra context for their assessment. It would be reasonable to expect that this content has shaped the answers and this content should be reflected in the report since it is misleading to only include the text of the question. Most of these explanatory statements, in this authors view are designed to explain why the safeguard would be needed so it would be misleading to assume that these are fixed views of Canadians on safeguards. If presented with drawbacks or reasons for not having them, the results might be different.

The questions in the workbook could certainly have been improved to better capture public views on the issues but on balance it is my expert opinion they do not prevent one from drawing reasonable inferences about the state what people care think given the information presented to them. The report, which focuses more on the relative importance of different factors and/ or the impact of information, tends to draw inferences and conclusions at a high level.

It should be noted that there is a risk that other people may interpret the results in a manner that does not recognize the limitations of these question types. As such the report could include a reflection on the best use of the data.

## **Conclusions**

It is worth returning to the three broad questions posed at the beginning of this review.

Was the study conducted in a manner consistent with the principles of the research plan? In other words, was the workbook process internally consistent with accepted principles of this form of research?

Response: Yes. While not everyone agrees that a consultative approach like this would be useful or beneficial, the instrument is available, the samples were created and reported using reasonable standards and the report does not draw inferences that are not supported by the data presented.

Is there any reason to believe that the research was designed to be biased in a particular direction?

Response: There is no clear bias in the overall research plan beyond the bias introduced by appearing to focus on the terms of reference for the Panel. The use of the Supreme Court result to frame the information no doubt contributes to a structure of the Issue Book that might be different if the starting point was some other place. The nature of the safeguard questions with their emphasis on providing information that explained the purpose of the safeguard may, for example, reflect the focus on the terms of reference.

Is the analysis and recommendations supported by the evidence? This includes not only whether the recommendations flow from the actual answers but also whether this type of study can support these recommendations.

Response: Yes. The overall analysis as presented in the report is consistent with the data presented. It would be helpful to have more analysis and more explicit recognition in the report of the limitations and purposes of the questions as asked and posed.

# **Appendix: About Richard Jenkins**

In 2009, Richard Jenkins established Jenkins Research Inc., which specializes in providing market research services to public and private sector organizations. Jenkins Research is able to provide the

capacity of a large firm with the close collaboration of a trusted partner. Throughout his career he has worked on more than 250 surveys.

Before forming his own company, Richard spent over five years as Vice President, TNS Canadian Facts where he was responsible for all public sector (including crown corporations) research and two years at EKOS Research Associates. For two years he was a Postdoctoral Fellow and Assistant Professor at Queen's University.

Richard holds an Honours and Masters degree in Political Studies from Queen's University and a Doctoral Degree in Political Science from the University of British Columbia. His published articles have appeared in a number of respected peer-reviewed journals, including the Canadian Journal of Market Research and the Canadian Journal of Political Science, as well as several edited books.

Richard has considerable experience working on public consultation projects and is familiar with the Workbook process having worked on more than 15 such projects. He has also been called in to assess other research on other occasions for clients.

In the past 7 years, Jenkins Research Inc. has worked on more than 90 projects across a diverse group of clients and business problems.

### Selected Client List

TD Canada Trust

Canadian National Exhibition

Human Resources Professionals Assoc.

MiWay (Mississauga Transit)

Government of Canada

Canada Post

SickKids Foundation

**Hamilton Transit** 

Canadian Centre for Ethics in Sport

**LCBO** 

Primus

ATB

Northern Ontario Tourism

Canadian Tire

CIBC

Bank of Montreal

CIRA

Ontario Lung Association

**Current Position:** President, Jenkins Research Inc.

**Education:** Ph.D. Political Science, University of British Columbia, 1999

M.A. Political Studies, Queen's University, 1994

B.A. (Honours) Political Studies, Queen's University, 1992

## **Previous experience:**

Vice President and Corporate Director of Public Opinion Research, TNS Canadian Facts (2003-2009)

A member of the Senior Management Team for TNS Canadian Facts and on the global sector committee for TNS Global, Dr. Jenkins was responsible for the overall intellectual direction and project management of all public sector (including crown corporations) work. This work included traditional public opinion research, market research for Crown Corporations and program evaluation work.

### Senior Consultant, EKOS Research Associates, 2001-2003

Responsibilities included the project management of three on-going syndicated research products between 2001 and 2003 (*Rethinking Government, Rethinking Citizen Engagement,* and the *Public Security Monitor*), in addition to custom quantitative survey research for clients. Tasks included marketing, client liaison, research design, analysis (including advanced segmentation techniques), reporting and presentation of results to senior managers.

<u>Limited Term Assistant Professor and SSHRCC Post-Doctoral Fellow, 1999-2001, Queen's University</u> (Kingston, Ontario).

Teaching responsibilities included undergraduate and graduate courses in statistics and research methods, elections and public opinion, and Canadian politics. Research and publications focused on the secondary statistical analysis of public opinion data relating to public policy, and Canadian attitude and values.

### **Honours**

Social Science and Humanities Research Council Postdoctoral Fellowship (1999-2001)

Social Science and Humanities Research Council Doctoral Fellowship (1997-1999)

University Graduate Fellowship (1996-1997)

### **Publications**

- Goodman, S., D. Hammond, F. Pillo-Blocka, T. Glanville, and R.W. Jenkins. (2011) "Use of Nutritional Information in Canada: National Trends between 2004 and 2008." Journal of Nutrition Education and Behavior, 43(5), 356-65.
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- Jenkins, R.W. (2001) "The Media, Voters, and Election Campaigns: the Reform Party and the 1993 Election" in Joanna Everitt and Brenda O'Neil eds. *Political Behaviour: Theory and Practice in a Canadian Context* (Toronto: Oxford).
- Johnston, R., Fournier, P. and Jenkins, R.W. (2000) "Party Location and Party Support: Unpacking Competing Models" *Journal of Politics*. 62 (4): 1145-60.
- Jenkins, R.W. (1999) "How Much is Too Much? Media Attention and Popular Support for an Insurgent Party," *Political Communication* 16 (4): 429-445.
- Jenkins, R.W. (1998) "Untangling the Politics of Electoral Boundaries in Canada, 1993-1997," *American Review of Canadian Studies*. 28 (4): 517-38.
- Jenkins, R.W. (1996) "Public Opinion, the Media and the Political Agenda" in James Guy ed., *Expanding Our Political Horizons: A Journal of Readings in Canadian Politics* (Toronto: Harcourt Brace).





# **Annex C**

# **List of Stakeholder Consultations**



15 December 2015



# **List of Stakeholder Consultations**

# **Carter Interveners, Medical Regulatory Authorities, Stakeholders**

Consultations with 92 representatives from 46 organizations representing approximately 749,415 members<sup>1</sup> as well as two claimants.

### Ottawa – 6 organizations; 15 representatives; representing approximately 397,044 members:

- 1. Canadian Hospice Palliative Care Association Represents approximately 3,000 members
  - Sharon Baxter, Executive Director
  - Tamir Virani, Communications Officer
- 2. Canadian Psychological Association Represents approximately 7,000 members
  - Dr. Keith Wilson, Staff Psychologist Rehabilitation Centre of the Ottawa Hospital and Associate Professor of Medicine and Psychology at the University of Ottawa
  - Meagan Hatch, Manager of Public Affairs and Communication
- 3. **Canadian Medical Association** *Represents approximately 80,000 members* 
  - Dr. Cindy Forbes, President
  - Cécile Bensimon, Director
  - Azin Moradhassel, Senior Advisor, Government Relations
  - Louise Sweatman, Legal Counsel
- 4. Canadian Nurses Association Represents approximately 151,404 members
  - Anne Sutherland Boal, Chief Executive Officer
  - Josette Roussel, Senior Nursing Advisor
- 5. **Association for Reformed Political Action Canada** *Represents approximately 30,000 Reformed Christians* 
  - André Schutten, General Legal Counsel
  - John Sikkema, Lawyer
- 6. Canadian Nurses Protective Society Represents approximately 125,000 members
  - Chantal Léonard, Chief Executive Officer
  - Elaine Borg, Legal Counsel
  - Mei St-Cyr, Law Clerk

<sup>&</sup>lt;sup>1</sup> The estimated membership figure reflects the aggregate number of each organization's membership. This figure does not reflect the total number of individuals represented as individuals may carry memberships for multiple organizations. This figure is a minimum number as membership information for several groups was not available.





## Montreal – 3 organizations; 14 representatives; representing approximately 1,225 members:

- 7. **Physicians' Alliance Against Euthanasia** Represents approximately 700 members
  - Dr. Catherine Ferrier, President
  - Aubert Martin, Executive Director of Vivre dans la Dignité (Partner Organization)
  - Michel Racicot, Vice President of Vivre dans la Dignité (Partner Organization)
  - Dr. Caroline Girouard, Oncologist Hôpital Sacré-Coeur; Assistant Professor of Medicine – Université de Montréal
  - Dr. Patrick Vinay, Former Dean University of Montreal Faculty of Medicine;
     Former President Fonds de recherche en santé du Québec; Former Director of Palliative Care Centre hospitalier de l'Université de Montréal
- 8. **MedPASS** Consists of 5 members
  - Félix Couture, M.D., C.M Candidate, Class of 2018, McGill University
  - Koray Demir, M.D., C.M Candidate, Class of 2018, McGill University
  - Michael Lang, B.C.L/L.LB Candidate, Class of 2018, McGill University
  - Zachary Shefman, B.C.L/L.LB Candidate, Class of 2018, McGill University
  - Mark Woo, M.D., C.M Candidate, Class of 2018, McGill University
- 9. **Association québecoise pour le droit de mourir dans la dignité** *Represents approximately 520 members* 
  - Georges L'Espérance, President
  - Hélène Bolduc, Founder and Past President
  - Dr. Nacia Faure, Retired Palliative Care Physician and Endocrinologist
  - Dr. Marcel Boisvert, Retired Palliative Care Physician

# <u>Vancouver – 5 organizations; 14 representatives; representing approximately 4,302 members</u> as well as two claimants:

- 10. **Euthanasia Prevention Coalition British Columbia –** *Represents approximately 225 members and member organizations* 
  - Dr. Williard Johnston, Chair
  - Susan House, Executive Director Catholic Health Association of British
     Columbia and the Denominational Health Association
- 11. **Protection of Conscience Project** Consists of 7 volunteers/staff members
  - Sean Murphy, Administrator
- 12. A Network of BC Physicians Represents approximately 70 members
  - Dr. Ed Dubland, Palliative Care Physician; Medical Coordinator Burnaby Palliative Care Program; Family Physician – Collingwood Medical Clinic
  - Dr. Constant H. Leung, Family Physician Collingwood Medical Clinic
  - Dr. Jennifer Y. Tong, Family Physician Collingwood Medical Clinic





- Dr. Sherry Chan, General Practitioner in Oncology BC Cancer Agency
- Dr. Luke Chen, Hematologist and Residency Program Director Division of Hematology, Vancouver General Hospital and University of British Columbia
- Dr. Margaret Cottle, Palliative care physician Vancouver Coastal Health Authority and Fraser Health Authority Home Hospice Programs
- 13. **BC Civil Liberties Association** Represents approximately 1,000 members
  - Josh Paterson, Executive Director
  - Grace Pastine, Litigation Director
  - Howard Shapray, Partner Shapray Cramer Fitterman Lamer LLP
  - Elayne Shapray, Assisted Dying Activist

### Claimants in Carter v. Canada (Met Panel with BC Civil Liberties Association)

- Lee Carter, Assisted Dying Activist
- Hollis Johnson, Assisted Dying Activist
- 14. Society of Rural Physicians of Canada Represents approximately 3,000 members
  - Dr. John Soles, President

### Winnipeg – 2 organizations; 6 representatives; representing approximately 60,000 members:

- 15. **Catholic Health Alliance of Canada** Consists of 12 organizations that make up 110 Catholic hospitals, community health centres, nursing homes, and long-term care facilities with over 60,000 staff
  - Michael Shea, President and Chief Executive Officer
  - Daniel Lussier, Chair Governing Council of the Catholic Health Alliance of Canada; Chief Executive Officer – Catholic Healthcare Corporation of Manitoba
  - Gordon Self, Vice President Mission, Ethics and Spirituality Covenant Health in Alberta
- 16. Council of Canadian with Disabilities Comprised of 17 member organizations
  - James Hicks, National Coordinator
  - Rhonda Wiebe, Co-chairperson CCD Ending of Life Ethics Committee
  - Jim Derksen, Member CCD Ending of Life Ethics Committee

### Toronto 30 organizations; 43 representatives; representing approximately 287,484 members:

- 17. Indigenous Physicians Association of Canada
  - Dr. Alika Lafontaine, Vice President
- 18. Canadian Association for Community Living Represents approximately 40,000 members
  - Michael Bach, Executive Vice President





- 19. Dying with Dignity Canada
  - Wanda Morris, Chief Executive Officer
  - Shanaaz Gokool, Chief Operating Officer
- 20. **Euthanasia Prevention Coalition** *Represents approximately 15,000 followers* 
  - Alex Schadenberg, Executive Director
  - Hugh Scher, Legal Counsel
- 21. Canadian Pharmacists Association Represents approximately 39,000 members
  - Philip Emberley, Director of Professional Affairs
  - Joelle Walker, Director of Government Relations
- 22. College of Family Physicians of Canada Represents approximately 30,000 members
  - Dr. Francine Lemire, Executive Director and Chief Executive Officer
- 23. Canadian Society of Palliative Care Physicians Represents approximately 350 members
  - Dr. Susan MacDonald, President
- 24. **Christian Legal Fellowship** *Represents approximately 600 members* 
  - Derek Ross, Executive Director
  - John Sikkema, Associate Legal Counsel
  - Ruth Ross, Member
- 25. **Canadian Unitarian Council** *Represents approximately 5,150 members* 
  - Vyda Ng, Executive Director
- 26. **Canadian HIV/AIDS Legal Network** *Represents approximately 120 members and member organizations* 
  - Richard Elliott, Executive Director
- 27. Canadian Federation of Catholic Physicians' Societies Represents approximately 500 members
  - Dr. Thomas Bouchard, President
  - Dr. Renata Leong
- 28. Canadian Association for Spiritual Care Represents approximately 1,100 members
  - Marc Doucet, President
- 29. **Canadian Psychiatric Association** *Represents approximately 4,700 members* 
  - Dr. Sonu Gaind, President
  - Glenn Brimacombe, Chief Executive Officer
- 30. Catholic Civil Rights League Represents approximately 10,000 members
  - Christian Domenic Elia, Executive Director
  - Philip Horgan, President
- 31. Canadian Civil Liberties Association Represents approximately 6,500 members
  - Cara Faith Zwibel, Director Fundamental Freedoms Program





- 32. **Evangelical Fellowship of Canada** Comprised of affiliates including 65 Ministry Organizations, 38 Educational Institutions, 47 Denominations and approximately 7,000 local church congregations totalling approximately 2,000,000 people
  - Bruce Clemenger, President
  - Julia Beazley, Policy Analyst
- 33. **Federation of Medical Regulatory Authorities of Canada** *Comprised of 13*Provincial/Territorial Medical Regulatory Authorities with a combined membership of approximately 89,630
  - Dr. Douglas A. Grant, President
  - Fleur-Ange Lefebvre, Executive Director and Chief Executive Officer
  - Louise Marcus, Director of Professional Affairs
- 34. **College of Physicians and Surgeons of British Columbia** *Represents approximately* 11,361 members
  - Graeme Keirstead, Legal Counsel
- 35. **College of Physicians and Surgeons of Alberta** *Represents approximately 10,345 members* 
  - Sarah Thomas, Senior Advisor
- 36. **College of Physicians and Surgeons of Saskatchewan** *Represents approximately 2,264 members* 
  - Bryan Salte, Associate Registrar and Legal Counsel
- 37. **College of Physicians and Surgeons of Manitoba** *Represents approximately 2,682 members* 
  - Lynne M. Arnason, General Counsel
- 38. College of Physicians and Surgeons of Ontario Represents approximately 33,386 members
  - Dr. Rocco Gerace, Registrar
- 39. Collège des médecins du Québec Represents approximately 22,608 members
  - Dr. Yves Robert, Secretary of the Directorate General
- 40. **College of Physicians and Surgeons of New Brunswick** *Represents approximately* 1,761 members
  - Dr. Ed Schollenberg, Registrar
- 41. College of Physicians and Surgeons of Nova Scotia Represents approximately 2,477 members
  - Dr. Douglas A. Grant, Registrar
- 42. **College of Physicians and Surgeons of Prince Edward Island** *Represents approximately 338 members* 
  - Dr. Cyril Moyse, Registrar
- 43. **College of Physicians and Surgeons of Newfoundland** *Represents approximately* 1,289 members
  - Dr. Linda Inkpen, Registrar





- 44. **Yukon Medical Council, Government of Yukon** *Represents approximately 253 members* 
  - Dr. Michael Noseworthy, Registrar
- 45. **Christian Medical and Dental Society of Canada** *Represents approximately 1,700 members* 
  - Larry Worthen, Executive Director
  - Dr. Diane Haak, President
  - Dr. Donato Gugliotta, Vice President
- 46. **Royal College of Physicians and Surgeons of Canada** *Represents approximately* 44,000 members
  - Dr. Kevin Imrie, President





# **Annex D**

# **List of Expert Consultations**



15 December 2015







# **List of Expert Consultations**

Experts consisted of academics, lawyers, policy advisors, advocates, physicians, government officials and others from various disciplines including human rights, health and disability studies, bioethics and philosophy.

73 experts consulted through 52 meetings in 5 countries.

## Canada - 27 Experts; 18 meetings

- 1. **Prof. Susan Sherwin** Research Professor Emerita, Department of Philosophy and Department of Gender and Women's Studies, Dalhousie University (Halifax, NS)
- 2. **Prof. Jocelyn Downie** Professor of Law; Associate Dean, Graduate Studies; Schulich School of Law, Faculty of Medicine
- 3. **Anna MacQuarrie** Director of Global Initiatives, Policy and Human Rights, Inclusion International
- 4. **Prof. Dianne Pothier** Holds a BA (Hons) (Dalhousie), MA (Pol Sci) (Carleton), LLB (Dalhousie)
- 5. **Steven Estey** Human Rights Officer, Disabled Peoples International
- 6. Me Jean-Pierre Ménard Ménard, Martin, Avocats; Me Michelle Giroux Health Law advocate
- 7. **Prof. Jocelyne St-Arnaud** Associate Professor, Bioethics, Department of Social Medicine and Prevention, University of Montreal School of Public Health
- 8. Brian L. Mishara CRISE Director and Psychology Professor, Université du Québec à Montréal
- 9. Dr. David J. Roy Research Chair, Faculty of Medicine, University of Montreal
- 10. **The Honourable Sharon Carstairs** Former Senator and Minister with Special Responsibility for Palliative Care
- 11. Dr. Isabelle Marcoux Assistant Professor, Faculty of Health Sciences, University of Ottawa
- 12. Professor Eike-Henner Kluge Department of Philosophy, University of Victoria
- 13. **Joshua T. Landry** Champlain Centre for Health Care Ethics; **Dr. Thomas Foreman** Director, Champlain Centre for Health Care Ethics; **Michael Kekewich** Ethics Consultant, Ottawa Hospital
- 14. Dr. Mary Shariff Assistant Professor, Faculty of Law, University of Manitoba
- 15. **Dr. Carrie Bourassa** Professor of Indigenous Health Studies, First Nations University
- 16. Yude M. Henteleff Human rights lawyer; Palliative care advocate
- 17. **David Baker** Disability Rights Lawyer, Bakerlaw; **Rebeka Lauks** Disability Rights Lawyer, Bakerlaw
- 18. Provincial-Territorial Expert Advisory Group Convened on Physician-Assisted Dying
  - Dr. Jennifer Gibson (Co-Chair) Director of the University of Toronto Joint Centre for Bioethics
  - Maureen Taylor (Co-Chair) Physician Assistant in Infectious Diseases and Medical Journalist
  - Dr. Doug Cochrane Patient Safety and Quality Officer for British Columbia and Chair of the BC Patient Safety and Quality Council





- Dr. Jocelyn Downie Professor in the Faculties of Law and Medicine at Dalhousie University
- **Dr. Nuala Kenny** Professor Emeritus of Bioethics at Dalhousie University and Former Ethics and Health Policy Advisor to the Catholic Health Alliance of Canada
- Dr. Trevor Theman Registrar of the College of Physicians and Surgeons of Alberta

# Oregon, USA – 15 experts; 11 meetings

- 1. **Kelly Hagan** Member of the neutral task force that worked on producing guidelines for Oregon's Death with Dignity Law
- 2. Kathryn Tucker Disability Rights Legal Center
- 3. Eli Stutsman and Peg Sandeen Death with Dignity National Center
- 4. Barb Hansen Oregon Hospice Association
- 5. **Dr. Kenneth R. Stevens Jr.** and **Dr. Charles Bentz** Physicians for Compassionate Care Education Fund
- 6. Bob Joondeph Disability Rights Oregon
- 7. **Barbara Glidewell** Former Ombudsman and Director of Patient Relations, Oregon Health Sciences University Hospital
- 8. Sue Porter, Kat West, Peter Reagan Compassion and Choices
- 9. Dr. Katrina Hedberg Physician, State Epidemiologist
- 10. **Dr. Linda Ganzini** Psychiatrist/geriatrician
- 11. Marilyn Golden Disability Rights Education and Defense Fund

### Netherlands – 13 experts; 7 meetings:

- 1. Meeting with Netherlands government officials:
  - Ministry of Health, Welfare, and Sport:
  - **Dr. M.C.H. (Marianne) Donker**, Director of Public Health and Deputy Director General Health
  - R.J. (Jim) Terwiel, LLM, Policy Coordinator and Deputy Head Ethics department
  - E.F. (Lineke) Bloemberg, MSc, Policy Officer Euthanasia, Ethics Department Ministry of Security and Justice:
  - M. (Maartje) van der Linden, LLM, Senior advisor on medical ethics
    - Regional Euthanasia Review Committees:
  - N.E.C. (Nicole) Visée, LLM, General Secretary to the Regional Euthanasia Review Committees
- 2. **Prof. J.J.M. Van Delden** Utrecht University
- 3. Royal Dutch Medical Association
  - **Dr. Eric van Wijlick** Senior Policy Advisor
  - Prof. Dr. Aart Hendricks Health Law Professor, Legal Advisor
- 4. Dr. Paul J. Lieverse Cancer Institute, Erasmus MC University Medical Center Rotterdam





- 5. **Prof. Johan Legemaate** University of Amsterdam
- 6. Parliamentary Committee on Health, Welfare and Sport
  - Renske Maria Leijten Socialist Party
  - Linda Voortman Green Left Party
- 7. **Rob Jonquière** Communications Director, World Federation for Right to Die Societies (WFRtDS), KNMG

## Belgium – 10 experts; 9 meetings:

- 1. **Prof. Étienne Montero** Dean, Faculty of Law, Université de Namur
- 2. Benoit Mores Advisor to the Federal Minister of Affairs and Public Health
- 3. **Prof. Dr. Joris Vandenberghe** Professor of Psychiatry at KULeuven and a member of the Belgian Advisory Committee on Bioethics
- 4. **Prof. Luc Deliens** Chair of the End-of-Life Care Research Group at the Free University of Brussels (VUB) and Ghent University; **Prof. Kenneth Chambaere** Researcher, End-of-life Care Research Group Vrije Universiteit Brussel & Ghent University
- 5. Els Van Hoof Belgian Federal MP for the Flemish Christian-democratic party (CD&V)
- 6. **Senator Jean-Jacques De Gucht** Member of the Belgian Senate and of the Flemish Parliament (Open VLD Flemish Liberals)
- 7. **Jaqueline Herremans** President, Association pour le Droit de Mourir dans la Dignité Belgique (ADMD) (Dying with Dignity Belgium)
- 8. **Dr. Gert Huysmans** Palliative care physician and President, Federation of Palliative Care Flanders
- 9. **Prof. Herman Nys** Professor of Health Law, KU Leuven (Katholieke Universiteit Leuven)

## <u>Switzerland – 8 experts; 7 meetings:</u>

- 1. Silvan Luley Executive Director, Dignitas
- 2. **Bernhard Sutter** Executive Director, Exit
- 3. **Dr. Georg Bosshard** Head of Clinical Ethics, Zurich University
- 4. Mr. Jürg Vollenweider Chief Prosecutor, District See/Oberland
- 5. Switzerland Federal Office of Justice:
  - Mr. Bernardo Stadelmann Vice Director
  - Ms. Corine Klöti
- 6. Dr. Karim Boubaker Médecin cantonal du Canton de Vaud
- 7. **Dr. Steffen Eychmuller** Head of Palliative Care Center, Inselspital





# **Annex E**

# **Abstracts of Individual Transcripts from Stakeholder and Expert Consultations**



15 December 2015





# Annex E – Abstracts of Individual Transcripts from Stakeholder and Expert consultations

# Introduction

The External Panel met with 73 experts from across Canada and from Oregon, the Netherlands, Belgium and Switzerland. They also consulted with 92 representatives of groups including *Carter* interveners, medical regulatory authorities and stakeholder organizations. Discussions focussed mainly on eligibility criteria, defining key terms, the risks of physician-assisted dying to individuals and society, what safeguards can be used to address the risks and finally procedures for assessing requests for assistance in dying.

Issues of primary concern for stakeholders and experts included how to make physician-assisted dying as respectful as possible of the rights of all Canadians; ensuring palliative care is more widely available across the country; protecting the freedom of conscience of physicians, nurses, and other health care workers; referrals from physicians who oppose PAD; and how to strictly enforce and monitor safeguards. Many were also concerned about minimizing the risks to the most vulnerable members of our society, for example, people with mental and physical disabilities.

The following document provides abstracts and additional information for all transcripts prepared in relation to these meetings. Transcripts were prepared for all stakeholder consultations and 42 of 51 expert consultations as transcription services were not able to be coordinated for all European expert consultations.

ID#	Name(s)	Organization(s) / Title	City	Date (M/D/Y)	Transcript Abstract	Language
1	Johan Legemaate	University of Amsterdam	Amsterdam	9/01/15	<ul> <li>Key points from the meeting with Johan Legemaate include:</li> <li>Health and social issues around autonomy and vulnerability;</li> <li>Eligibility criteria surrounding the issues of age, mature minors, a grievous and irremediable medical condition, mental illness, enduring suffering, capacity to consent to medical treatment, advance directives, and voluntariness;</li> <li>Procedural safeguards including consideration of additional consultations (with psychiatric, palliative, and vulnerability assessments), the role of the family, and the need for reporting;</li> <li>System oversight with open data, periodic review and enforcement; and</li> <li>Additional considerations for the involvement of other health care providers, rights in terms of conscientious objection, their duty to refer or inform, whether there should be training or licensing, and a possible good faith compliance that would provide them with additional protection.</li> </ul>	English
2	Paul J. Lieverse	Cancer Institute, Erasmus MC University Medical Center Rotterdam	Rotterdam	9/01/15	<ul> <li>Key points from the meeting with Paul J. Lieverse include:</li> <li>An overview of physician-assisted death and palliative care in Holland;</li> <li>Physician-assisted death is available in hospital and in independent clinics; some patients—especially younger ones—use clinics if they can't access physician-assisted death in hospital;</li> <li>Conflict between physician-assisted death and palliative care when it's delivered in the same place;</li> <li>Issues of uneven access—rich and well-connected people have better access to care; and</li> <li>Supports distancing physician-assisted death from physicians and palliative care.</li> </ul>	English

ID#	Name(s)	Organization(s) / Title	City	Date (M/D/Y)	Transcript Abstract	Language
3	Renske Maria Leijten; Linda Voortman	Parliamentary Committee on Health, Welfare and Sport	The Hague	9/01/15	Key points from the meeting with the Parliamentary Committee on Health, Welfare and Sport include:  • Health and social issues around vulnerability;  • The comparison of euthanasia and assisted suicide;  • Eligibility criteria surrounding the issues of age, mature minors, a grievous and irremediable medical condition, mental illness, capacity to consent to medical treatment, and advance directives;  • Procedural safeguards including consideration for two or more physicians and the need for reporting;  • System oversight with open anonymized data about the patient and periodic review; and  • Additional considerations for the rights of physicians in terms of conscientious objection and their duty to refer or inform.	English
4	Rob Jonquière	World Federation for Right to Die Societies	Amsterdam	9/02/15	Key points from the meeting with Rob Jonquère include:  • Health and social issues around autonomy and the inequality of access to health care;  • The comparison of euthanasia and assisted suicide;  • Eligibility criteria surrounding the issues of age, mature minors, a grievous and irremediable medical condition, mental illness, enduring suffering and ensuring voluntariness from the patient;  • Procedural safeguards including consideration for two or more physicians, informed consent for the patient, the need for a formal request from the patient, having a witness present at the moment of death, consideration for additional psychiatric consultations, the role of the family, proportionate waiting periods and the need for reporting;  • System oversight with periodic review;  • Additional considerations for the involvement of other health care providers, rights in terms of conscientious objection, their duty to refer or inform, whether there should be training or licensing, the discussion of physician-assisted death between patient and physician, and a possible good faith compliance that would provide health care workers with additional protection; and  • Risks around the issues of slippery slope and overly restrictive safeguards.	English

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5	Étienne Montero	Dean, Faculty of Law, Université de Namur	Brussels		<ul> <li>Key points from the meeting with Étienne Montero include:</li> <li>How It's impossible to maintain and enforce strict conditions around physician-assisted death;</li> <li>The Belgian control system does a review after the patient is dead. It's impossible to confirm if consent was given or if the patient had treatment options adequately explained.</li> <li>So in this sense, the legal requirements may be strict but without controls their effectiveness is unclear;</li> <li>The Control Commission increasingly endorses cases of physician-assisted death for patients suffering with depression, dementia or psychiatric disorders; and</li> <li>Sociocultural impact of the law transforms what was an exception in something which is trivial.</li> </ul>	Bilingual
6	Benoit Mores	Advisor to the Federal Minister of Affairs and Public Health	Brussels	9/03/15	<ul> <li>Key points from the meeting with Benoit Mores include:</li> <li>The political evolution of physician-assisted death in Belgium;</li> <li>Mature minors;</li> <li>Problems with advance requests, five year-limit (Alzheimer's example);</li> <li>Consequences for others: family, friends, doctors, health-care workers, society;</li> <li>He doesn't perceive slippery slope;</li> <li>Palliative sedation is not tracked;</li> <li>No rights for a patient to transfer out of non- physician-assisted death facilities; and</li> <li>Advises Canada to avoid making the debate about palliative care vs. physician-assisted death.</li> </ul>	English

ID#	Name(s)	Organization(s) / Title	City	Date (M/D/Y)	Transcript Abstract	Language
7	Joris Vandenberghe	Professor of Psychiatry at KU Leuven and a member of the Belgian Advisory Committee on Bioethics	Brussels	9/03/15	Key points from the meeting with Joris Vandenberghe include:  • The role of psychiatrists in evaluating physician-assisted death requests from patients without a terminal illness;  • Separate processes in Belgium for those with and without terminal illnesses;  • A complex, multifaceted process to determine: a) competency to make decisions, b) whether to approve physician-assisted death;  • The law assumes patients are competent; the onus lies on proving lack of competency. Must also decide whether patient suffering is intolerable with no possible relief;  • Demarcation between normal and pathological is blurry and evolves continually;  • Often hard to distinguish pathology from normal fear;  • The role of the family;  • Three approval stages: physicians, psychiatrist, ethics committee;  • Important criterion of no possible medical alleviation of suffering; and  • Guideline in Holland is that the patient cannot access physician-assisted death unless all alleviation options have been tried.	English

ID#	Name(s)	Organization(s) / Title	City	Date (M/D/Y)	Transcript Abstract	Language
8	Kenneth Chambaere; Luc Deliens	Mr. Deliens: Professor of Public Health and Palliative Care at the Free University of Brussels and Ghent University; and Mr. Chambaere: Sociologist, Researcher, End- of-life Care Research Group at the Free University of Brussels and Ghent University	Brussels	9/03/15	Key points from the meeting with Kenneth Chambaere and Luc Deliens include:  • Health and social issues around autonomy and the need for good palliative care;  • The comparison of euthanasia and assisted suicide;  • Procedural safeguards including consideration for informed consent for the patient, having a witness present at the moment of death, the role of the family, and the need for reporting;  • System oversight with open anonymized data about the patient, data collection from both the patient and physician, specification for death records, and issues surrounding targeted funding; and  • Additional considerations for the rights of physicians in terms of conscientious objection, their duty to refer or inform and whether there should be training or licensing.	English
9	Els Van Hoof	Belgian Federal MP for the Flemish Christian- democratic party	Brussels	9/04/15	<ul> <li>Key points from the meeting with Els Van Hoof include:</li> <li>Health and social issues around the need for good palliative care;</li> <li>Eligibility criteria surrounding the issues of mental illness, a grievous and irremediable medical condition, enduring suffering, the capacity to consent to medical treatment and advance directives;</li> <li>System oversight with open anonymized data about the patient, data collection from both the patient and physician, and periodic review; and</li> <li>Risks around the issues of slippery slope.</li> </ul>	English

ID#	Name(s)	Organization(s) / Title	City	Date (M/D/Y)	Transcript Abstract	Language
10	Gert Huysmans	Palliative care physician and President, Federation of Palliative Care Flanders	Brussels	9/04/15	<ul> <li>Key points from the meeting with Gert Hursmans include:</li> <li>Keeping physician-assisted death and palliative care together;</li> <li>Multidisciplinary consultations are best, also the inclusion of family;</li> <li>Ongoing debate about how far the law should go;</li> <li>Worries that inadequate palliative care drives demand for physician-assisted death;</li> <li>Life End Information Forum: a movement to expand physician-assisted death and to train physicians about providing physician-assisted death advice;</li> <li>The rights of the patient;</li> <li>Divisions within the country; and</li> <li>Flanders wants to liberalize access, older people have different attitudes about aging, doctors, and physician-assisted death.</li> </ul>	English
11	Herman Nys	Professor of Health Law at KU Leuvan	Brussels	9/04/15	Key points from the meeting with Herman Nys include:  • The evolution of physician-assisted death and how it's incorrect to label it as a slippery slope;  • Under Belgian law, physicians are not obligated to provide physician-assisted death;  • In Belgium and Holland there is no right to physician-assisted death; only a right to request physician-assisted death;  • Belgium has a single Control and Evaluation Commission, and there's never been a case referred to the public prosecutor (which is required if two-thirds of Commission members believe there's a problem);  • In Belgium, physician-assisted death is legally considered death by natural causes (affects insurance);  • Aiding a suicide is not a crime in Belgium (not helping a person in grave danger is a crime);  • Interpretations of the SCC decision, and how it's unusual to consider physician-assisted death as a right-to-life issue; disagrees with reasoning that equates withdrawal of treatment with aiding suicide; and  • Don't make physician-assisted death a right. If you do, it removes a safeguard.	English

ID#	Name(s)	Organization(s) / Title	City	Date (M/D/Y)	Transcript Abstract	Language
12	Jacqueline Herremans	Member, Commission fédérale de controle de d'évaluation de l'euthanasie	Brussels	9/04/15	<ul> <li>Key points from the meeting with Jacqueline Herremans include:</li> <li>Health and social issues around autonomy, inequality of access to health care, and the need for good palliative care;</li> <li>Eligibility criteria surrounding the issues of mature minors, a grievous and irremediable medical condition, enduring suffering, advanced directives, substitute decision-making, and ensuring voluntariness from the patient;</li> <li>Procedural safeguards including consideration for two or more physicians, additional consultations (with psychiatric physicians and specialists), ensuring that there is informed consent for the patient, proportionate waiting periods, and the need for reporting;</li> <li>System oversight with periodic review; and</li> <li>Additional considerations for the rights of physicians in terms of conscientious objection and their duty to refer or inform.</li> </ul>	English
13	Senator Jean- Jacques De Gucht	Member of the Belgian Senate and of the Flemish Parliament (Flemish Liberals)	Brussels	9/04/15	Key points from the meeting with Senator Jean-Jacques De Gucht include:  • Health and social issues around autonomy and the need for good palliative care;  • Eligibility criteria surrounding the issues of mature minors, a grievous and irremediable medical condition, mental illness, enduring suffering and advance directives;  • Procedural safeguards including consideration for two or more physicians, the need for a formal request from the patient, having a witness present at the moment of death, consideration for additional psychiatric consultations, the role of the family, and proportionate waiting periods;  • System oversight with periodic review; and  • Additional considerations for the rights of physicians in terms of conscientious objection, their duty to refer or inform, whether there should be training or licensing, and the risk of physician shopping.	English

ID#	Name(s)	Organization(s) / Title	City	Date (M/D/Y)	Transcript Abstract	Language
14	Silvan Luley	Executive Director of Dignitas	Forch	9/07/15	<ul> <li>Key points from the meeting with Silvan Luley include:</li> <li>How the existence of Dignitas reflects the failure of Switzerland's legal and health-care systems to accommodate the wishes of its citizens;</li> <li>Inhibitions, taboos and misunderstanding are the cause of many physician-assisted death-related problems;</li> <li>A comprehensive background of the Swiss system;</li> <li>How most Physician-assisted deaths are performed at home;</li> <li>The role of Dignitas and how foreigners typically stay four-five days and have two physician visits; and</li> <li>All cases are investigated by judicial authorities after the fact.</li> </ul>	English
15	Bernhard Sutter	Executive Director of Exit	Zurich	9/07/15	Key points from the meeting with Bernhard Sutter include:  • The role of Exit and how they counsel 3,000 people a year, assist about 600 suicides, prepare many living wills, and provide legal assistance to help enforce living wills;  • It's impossible to forbid death, you can only make it more humane or make it less humane; and  • How and why Exit works in Switzerland.	English
16	Georg Bosshard	Head of Clinical Ethics, Zurich University	Zurich	9/07/15	Key points from the meeting with Georg Bosshard include:  • Health and social issues around autonomy, inequality of access to health care, and the need for good palliative care;  • Eligibility criteria surrounding the issues of mature minors, a grievous and irremediable medical condition, mental illness, enduring suffering, advanced directives, and ensuring voluntariness from the patient;  • Procedural safeguards including consideration for two or more physicians, additional consultations (with palliative care physicians and specialists), ensuring that there is informed consent for the patient, the role of the family, and proportionate waiting periods;  • System oversight with enforcement and periodic review; and  • Additional considerations for the rights of physicians and institutions in terms of conscientious objection, their duty to refer or inform and whether there should be training or licensing.	English

ID#	Name(s)	Organization(s) / Title	City	Date (M/D/Y)	Transcript Abstract	Language
17	Corine Klöti; Bernardo Stadelmann	Members of the Federal Justice Office of Swizerland	Bern	9/08/15	Key points from the meeting with Corine Klöti and Bernardo Stadelmann include:  • The different categories of euthanasia: direct active (deliberate killing) is illegal, while indirect active (palliative sedation) is generally regarded as permissible, passive euthanasia renunciation or discontinuation of life-prolonging measures is also legal; and  • The lengthy exploration of potential selfish motivation among those who assist with suicides.	English
18	Karim Boubaker	Canton Chief Public Health Officer	Bern	9/08/15	Key points from the meeting with Karim Boubaker include:  • The Historical context of physician-assisted death in Switzerland;  • The evolution of medicine and its effect on society; and  • The difference of opinions between one canton and the next.	English
19	Steffen Eychmüller	Head of Palliative Care Center, Inselpital	Bern	9/08/15	<ul> <li>Key points from the meeting with Steffen Eychmüller include:</li> <li>The polemics in Switzerland around the issue of physician-assisted death;</li> <li>The use of advanced directives;</li> <li>The Health care system's link with economics;</li> <li>How physician-assisted death is disincentivized in Switzerland;</li> <li>Assisted suicide discussions led to a national palliative-care strategy;</li> <li>Cost is a big issue; insurance companies don't want to pay; training in palliative care is expensive; and</li> <li>Swiss commission tried and failed to devise reliable criteria for assisted suicide.</li> </ul>	English

ID#	Name(s)	Organization(s) / Title	City	Date (M/D/Y)	Transcript Abstract	Language
20	Peter Korchnak; Peg Sandeen; Eli Stutsman	Death With Dignity National Center	Oregon	10/01/15	Key points from the meeting with the Death with Dignity Nation Center include:  • Legal discussion involving the division of powers between the federal and provincial governments in Canada, and the implementation of physician-assisted dying within the United States  • Health and social issues around vulnerability;  • Eligibility criteria surrounding the issues of residency, enduring suffering and terminal illness;  • Procedural safeguards including consideration for two or more physicians, additional consultations (with psychiatric and palliative care physicians), informed consent for the patient, having a witness present at the moment of death, and the need for reporting;  • System oversight with open anonymized data about the patient, data collection from both the patient and physician, targeted funding and specification for death records; and  • Additional considerations for the involvement of other health care providers, rights in terms of conscientious objection, and the implementation of an independent institution that can help health care workers with referrals.	English
21	Kathryn Tucker	Disability Rights Legal Center	Oregon	10/01/15	Key points from the meeting with the Disability Rights Legal Center include:  • Legal discussion involving the history of physician-assisted dying within the United States;  • The comparison of the different types of physician-assisted dying;  • Eligibility criteria surrounding the issues of mental illness, terminal illness, having a capacity to consent to medical treatment, and ensuring voluntariness from the patient;  • Procedural safeguards including consideration for additional consultations (with psychiatric physicians and specialists), informed consent for the patient, the need for a formal request from the patient, having a witness present at the moment of death, and proportionate waiting periods;  • System oversight with enforcement; and  • Additional considerations for the rights of physicians in terms of conscientious objection and their duty to refer or inform.	English

ID#	Name(s)	Organization(s) / Title	City	Date (M/D/Y)	Transcript Abstract	Language
22	Kelly Hagan	Oregon Death With Dying Task Force	Oregon	10/01/15	<ul> <li>Key points from the meeting with Kelly Hagan include:</li> <li>Health and social issues around autonomy;</li> <li>The comparison of the different types of physician-assisted dying;</li> <li>Eligibility criteria surrounding the issues of residency and terminal illness;</li> <li>Procedural safeguards including consideration for two or more physicians, additional psychiatric consultations, the need for a formal request from the patient, having a witness present at the moment of death, proportionate waiting periods, and the implementation of a decision-making committee;</li> <li>System oversight with specification for death records; and</li> <li>Additional considerations for the involvement of other health care providers, rights in terms of conscientious objection, their duty to refer or inform, and the implementation of an independent institution that can help health care workers with referrals.</li> </ul>	English
23	Barb Hansen	Oregon Hospice Association	Oregon	10/01/15	Key points from the meeting with Barb Hansen include:  • Health and social issues around autonomy and the need for better home care;  • The comparison of the different types of physician-assisted dying;  • Eligibility criteria surrounding the issues of mental illness, terminal illness and enduring suffering;  • Procedural safeguards including consideration for two or more physicians, additional consultations (with psychiatric and palliative care physicians), informed consent for the patient, the need for a formal request from the patient, having a witness present at the moment of death, the role of the family, and proportionate waiting periods;  • Specification for death records; and  • Additional considerations for the involvement of other health care providers, rights in terms of conscientious objection, their duty to refer or inform, and the implementation of an independent institution that can help health care workers with referrals.	English

ID#	Name(s)	Organization(s) / Title	City	Date (M/D/Y)	Transcript Abstract	Language
24	Charles Bentz; Kenneth Stevens Jr.	Physicians for Compassionate Care Education Foundation	Oregon	10/01/15	Key points from the meeting with the Physicians for Compassionate Care Education Foundation include:  • Health and social issues around autonomy and vulnerability;  • Eligibility criteria surrounding the issues of terminal illness, mental illness, a grievous and irremediable medical condition, enduring suffering, and having a capacity to consent to medical treatment;  • Procedural safeguards including consideration for two or more physicians, additional consultations (with psychiatric and palliative care physicians), and the need for reporting;  • System oversight with open data collected from both the patient and physician, specification for death records, targeted funding, and enforcement; and  • Additional considerations for the involvement of other health care providers, the involvement of the physician, their rights in terms of conscientious objection, their duty to refer or inform, and whether there should be licensing; and  • The abuse of physician-assisted dying in Oregon and risks of a slippery slope.	English
25	Barbara Glidewell	Former Director of Patient Relations at Oregon Health Sciences University Hospital	Oregon	10/02/15	<ul> <li>Key points from the meeting with Barbara Glidewell include:</li> <li>Health and social issues around autonomy and vulnerability;</li> <li>The comparison of the different types of physician-assisted dying;</li> <li>Eligibility criteria surrounding the issues of terminal illness and ensuring voluntariness from the patient;</li> <li>Procedural safeguards including consideration for two or more physicians, additional consultations with specialists, informed consent for the patient, the need for a formal request from the patient, having a witness present at the moment of death, the role of the family, and the need for reporting;</li> <li>System oversight with open data collected from both the patient and physician, and specification for death records, and</li> <li>Additional considerations for the involvement of other health care providers, rights in terms of conscientious objection, their duty to refer or inform, and whether there should be training or licensing.</li> </ul>	English

ID#	Name(s)	Organization(s) / Title	City	Date (M/D/Y)	Transcript Abstract	Language
26	Sue Porter; Peter Reagan; Kat West	Compassion & Choices	Oregon	10/02/15	Key points from the meeting with Compassion & Choices include:  • Health and social issues around autonomy, the inequality of access to health care, and the need for good palliative care;  • Eligibility criteria surrounding the issues of terminal illness, a grievous and irremediable medical condition, and enduring suffering;  • Procedural safeguards including consideration for two or more physicians, additional consultations with specialists, informed consent for the patient, the need for a formal request from the patient, having a witness present at the moment of death, and proportionate waiting periods;  • System oversight with open anonymized data about the patient, and data collection from both the patient and physician; and  • Additional considerations for the rights of physicians in terms of conscientious objection, their duty to refer or inform, the risk of physician shopping, and the implementation of an independent institution that can help provide health care workers with referrals.	English
27	Bob Joondeph	Disability Rights Oregon	Oregon	10/02/15	<ul> <li>Key points from the meeting with Bob Joondeph include:</li> <li>Health and social issues around autonomy, vulnerability and the inequality of access to health care;</li> <li>Eligibility criteria surrounding the issues of terminal illness, mental illness, having a capacity to consent to medical treatment, advance directives, substitute decision-making, and ensuring voluntariness from the patient;</li> <li>Procedural safeguards including consideration for additional consultations with psychiatrists, proportionate waiting periods, and the implementation of a decision-making committee; and</li> <li>The need for system oversight.</li> </ul>	English

ID#	Name(s)	Organization(s) / Title	City	Date (M/D/Y)	Transcript Abstract	Language
28	Linda Ganzini	Director of Geriatric Psychiatry, Portland Health Center System	Oregon	10/03/15	<ul> <li>Key points from the meeting with Linda Ganzini include:</li> <li>Health and social issues around vulnerability, suicide prevention and the inequality of access to health care;</li> <li>Eligibility criteria surrounding the issues of terminal illness, mental illness, having a capacity to consent to medical treatment, and ensuring voluntariness from the patient;</li> <li>Procedural safeguards including consideration for additional consultations with psychiatrists, informed consent for the patient, having a witness present at the moment of death, proportionate waiting periods, and the need for reporting;</li> <li>System oversight with open anonymized data about the patient, data collection from both the patient and physician, and targeted funding; and</li> <li>Additional considerations for the rights of physicians in terms of conscientious objection.</li> </ul>	English
29	Brian L. Mishara	CRISE Director and Psychology Progessor at the University of Québec	Montreal	10/07/15	<ul> <li>Key points from the meeting with Brian Mishara include:</li> <li>Health and social issues around autonomy, suicide prevention and the need for universal palliative care;</li> <li>The comparison of the different types of physician-assisted dying;</li> <li>Eligibility criteria surrounding the issues of advanced directives and ensuring voluntariness from the patient;</li> <li>Procedural safeguards including the need for a formal request from the patient, having a witness present at the moment of death, and proportionate waiting periods; and</li> <li>System oversight.</li> </ul>	English

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30	David J. Roy	Chercheur titulaire, Faculté de médecine, Université de Montréal	Montreal	10/07/15	<ul> <li>Key points from the meeting with David J. Roy include:</li> <li>Health and social issues around autonomy and the need for universal palliative care;</li> <li>The comparison of the different types of physician-assisted dying;</li> <li>Eligibility criteria surrounding the issues of capacity to consent to medical treatment, substitute decision-making and ensuring voluntariness from the patient;</li> <li>Procedural safeguards including the need for reporting;</li> <li>System oversight with specification for death records; and</li> <li>Additional considerations for the involvement of other health care providers, rights in terms of conscientious objection, whether there should be training or licensing, and the implementation of an independent institution that can help health care workers with referrals.</li> </ul>	English
31	Michelle Giroux; Jean-Pierre Ménard	Ménard, Martin, Avocats; et Professeure titulaire a le Faculté de droit, Université d'Ottawa	Montreal	10/07/15	Key points from the meeting with Jean-Pierre Ménard and Michelle Giroux include:  • Legal discussion involving the Carter decision, Quebec's Bill-52, and the division of powers between the federal and provincial governments,  • Health and social issues around autonomy, vulnerability and the need for universal palliative care;  • The comparison of the different types of physician-assisted dying;  • Eligibility criteria surrounding the issues of age, mature minors, residency, a grievous and irremediable medical condition, enduring suffering, capacity to consent to medical treatments, and advanced directives;  • Procedural safeguards including consideration for two or more physicians, informed consent for the patient, the need for a formal request from the patient, having a witness present at the moment of death, consideration for additional consultations (with psychiatric and palliative care physicians), and proportionate waiting periods;  • System oversight with data collected from both the patient and the physician, enforcement and specification for death records; and  • Additional considerations for the rights of physicians in terms of conscientious objection and their duty to refer or inform.	Bilingual

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32	Jocelyne St- Arnaud	Professeure associée aux Programme de bioéthique, Département de médecine sociale et prévention, École de santé Publique de l'Université de Montréal (ESPUM)	Montreal	10/07/15	<ul> <li>Key points from the meeting with Jocelyne St-Arnaud include:</li> <li>Legal discussion involving the Carter decision and relevant international law;</li> <li>Health and social issues around autonomy, vulnerability, the need for better home care, and the need for universal palliative care;</li> <li>The comparison of the different types of physician-assisted dying;</li> <li>Eligibility criteria surrounding the issues of mature minors, enduring suffering, psychological suffering, capacity to consent to medical treatment, and advanced directives;</li> <li>Procedural safeguards involving informed consent for the patient;</li> <li>System oversight with data collected from both the patient and the physician, enforcement and specification for death records; and</li> <li>Additional considerations for the involvement of other health care providers, rights in terms of conscientious objection, their duty to refer or inform, and whether there should be training or licensing.</li> </ul>	Bilingual
33	Sharon Baxter; Tamir Virani	Canadian Hospice Palliative Care Association	Ottawa	10/20/15	Key points from the meeting with the Canadian Hospice Palliative Care Association include:  • More investment in palliative/ home care needed;  • Canadians not well-informed about the difference between palliative care and assisted dying. If they knew more about it, there would be less need for an assisted dying option;  • Comprehensive palliative care could deal with many of the issues, e.g. depression, pain, and symptom managagment;  • Considering those who are mentally handicapped as well; and  • Interventions for those in crisis.	English
34	Cécile Bensimon; Cindy Forbes; Azin Moradhassel	Canadian Medical Association	Ottawa	10/20/15	<ul> <li>Key points from the meeting with the Canadian Medical Association include:</li> <li>Eligibility criteria including competency, capacity, informed decision-making and voluntariness;</li> <li>Safeguards including requirement to inform patient of all available treatment options, consideration of additional consultation needs (i.e., psychiatric, palliative, specialists, etc.), proportional wait times, multiple requests for assisted dying;</li> <li>Conscientious objection for physicians; and</li> <li>Comprehensive national guidelines to ensure consistency across the country.</li> </ul>	English

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35	Meagan Hatch; Keith Wilson	Canadian Psychological Association	Ottawa	10/20/15	<ul> <li>Key points from the meeting with the Canadian Psychological Association include:</li> <li>Issues in assessing patient eligibility, such as cognitive competence and unbearable psychological or physical pain;</li> <li>Assessment of all other potentially treatable sources of suffering before considering assisted dying;</li> <li>Need for patient requests to be voluntary;</li> <li>Requiring two requests over a specified time period to assess patient's conviction; and</li> <li>Mental and physical disorders equal reasons for desiring assisted dying option.</li> </ul>	English
36	Anne Sutherland Boal; Josette Roussel	Canadian Nurses Association	Ottawa	10/21/15	<ul> <li>Key points from the meeting with the Canadian Nurses Association include:</li> <li>Need for nurses on this issue because they are key on health team and their direct relationships with patients give them perspective on policy supports needed;</li> <li>Proper skills training and unencumbered access to information on regulations and resources for developing expertise in pain and symptom management;</li> <li>Psychological support for providers;</li> <li>Need for interdisciplinary team integral to care: social workers, nurses, pharmacists, psychologist, social workers, along with physicians;</li> <li>Rigorous well-understood process and infrastructure that can be evaluated and analyzed;</li> <li>Pan-Canadian approach; and</li> <li>Need to know how and where to get additional support.</li> </ul>	English

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37	Thomas Foreman; Michael Kekewich; Josh Landry	Ottawa Hospital	Ottawa	10/21/15	Key points from the meeting with Thomas Foreman, Michael Kekewich and Josh Landry include:  • Use of terms of positive and negative rights to connect to practices where informed consent (a negative right) is used;  • A lot of weight on individual autonomy in PAD  • How to address referrals and levels of moral culpability;  • How to assess barriers to access for patients; e.g., elderly patients given website and no other information; they won't use that information;  • Challenges in figuring out right to PAD in hospices and palliative care;  • Definition of grievous and irremediable harm needs to be clear and objective, not just subjective;  • Question of advance directives a challenge for ethicists; is the directive always valid when it is needed in PAD?;  • Easily accessed palliative care; if not available, patient's self-determination for PAD impeded because they haven't been given the option;  • Patients need to have and know they have the option of PAD whether they use it or not; and  • Considering existential suffering as well as physical and emotional suffering in the context of a disease.	English
38	Katrina Hedberg	Oregon Public Health Division	Ottawa	10/21/15	<ul> <li>Key points from the meeting with Katrina Hedberg include:</li> <li>Reporting system in place; what to put in the death certificate; it's up to physicians what to write, and that is usually the underlying cause of death;</li> <li>Standard of good faith used, i.e., did physician comply with law; physicians have never been sanctioned in Oregon in PAD situations;</li> <li>Mandatory reporting for pharmacists;</li> <li>No funds for analyzing information as a result of Death with Dignity Act;</li> <li>Making sure people have access to hospice care and palliative care;</li> <li>Collecting data on people who are participating in PAD to cover all end of life issues;</li> <li>Provide more in-depth information for patients: what kind of support they need from time of diagnosis; and</li> <li>Having more options for patients.</li> </ul>	English

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39	Andre Schutten; John Sikkema	Association for Reformed Political Action Canada	Ottawa	10/22/15	<ul> <li>Key points from the meeting with the Association for Reformed Political Action Canada include:</li> <li>Panel should consider putting forward notwithstanding clause to buy time;</li> <li>Importance for Parliament of stating objective of prohibition on assisted suicide;</li> <li>Restrictions to be applied in new law: keeping PAD within Criminal Code; not defining it as medical care; 3 year judicial review; panel of experts;</li> <li>All terms need to be carefully and precisely defined;</li> <li>Risks need to be minimized by carefully designed system imposing stringent limits scrupulously monitored and enforced;</li> <li>Need for psychiatrists, not GPs, to assess patient competence to consent; and</li> <li>Limit assisted suicide to defined terminal illness.</li> </ul>	English
40	Elaine Borg; Chantal Léonard; Mei St-Cyr	Canadian Nurses Protective Society	Ottawa	10/22/15	<ul> <li>Key points from the meeting with the Canadian Nurses Protective Society include:</li> <li>Multifaceted role of nurses in physician-assisted death, not only physicians;</li> <li>The reality of teams: need for patient care team collaboration and coordination;</li> <li>Having nurse practitioners play larger role as MRP (most responsible professional) and be first point of contact for patients;</li> <li>Change in terms with developing role of NP as practitioner-assisted death;</li> <li>Conditions of potential risk for nurses of criminal prosecution; and</li> <li>Need for protection under the Criminal Code for all situations that could arise in interactions with patients.</li> </ul>	English

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41	Isabelle Marcoux	University of Ottawa	Ottawa	10/22/15	Key points from the meeting with Isabelle Marcoux include:  • Health and social issues around autonomy and the inequality of access to health care;  • The comparison of the different types of physician-assisted dying;  • Eligibility criteria surrounding the issues of age, a grievous and irremediable medical condition, enduring suffering, psychological suffering, capacity to consent to medical treatments, advanced directives, and ensuring voluntariness from the patient;  • Procedural safeguards including consideration for additional psychiatric consultations, informed consent for the patient, the need for a formal request from the patient, having a witness present at the moment of death, the role of the family, proportionate waiting periods, the implementation of a decision-making multidisciplinary team, and the need for reporting;  • System oversight with anonymized data collected from both the patient and physician, and specification for death records; and  • Additional considerations for the involvement of other health care providers, rights in terms of conscientious objection, and whether there should be training or licensing.	Bilingual
42	Marcel Boisvert; Hélène Bolduc; Nacia Faure; Georges L'Espérance	Association Québécoise pour le droit de mourir dans la dignité	Montreal	10/23/15	<ul> <li>Key points from the meeting with the Association Québécoise pour le droit de mourir dans la dignité:</li> <li>No conflict between palliative care/sedation and physician-assisted dying;</li> <li>Request must come from patients themselves, never physicians;</li> <li>No such thing as zero risk but major safeguard is that the Criminal Code should apply to any person who is not a physician;</li> <li>A physician's primary duty is no longer to save lives at all costs but to respect the patient's freedom of choice; and</li> <li>Patient's rights don't cease to exist just because they lose their cognitive faculties; advance medical directives important to use.</li> </ul>	Bilingual

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43	Catherine Ferrier; Caroline Girouard; Aubert Martin; Michel Racicot; Patrick Vinay	Physicians' Alliance Against Euthanasia / Collectif des médecins contre l'euthanasie & Living with Dignity	Montreal	10/23/15	<ul> <li>Key points from the meeting with the Collectif des médecins contre l'euthanasie &amp; Vivre dans la dignité include:</li> <li>Best for patients if physician-assisted death remains a criminal offence;</li> <li>Eligibility criteria need to be defined very clearly and strictly;</li> <li>Have doctors opt-in instead of opt-out so only those who freely choose to participate are involved in physician-assisted death;</li> <li>Palliative care consultations should be available to all patients;</li> <li>Only specialist physicians who have specific training and a special licence should be able to perform physician assisted death;</li> <li>We should be finding ways to care for weakest members of our society, not see them as a burden; and</li> <li>Use notwithstanding clause to give more time to think about issue.</li> </ul>	Bilingual
44	Félix Couture; Koray Demir; Michael Lang; Zachary Shefman; Mark Woo	MedPASS	Montreal	10/23/15	<ul> <li>Key points from the meeting with MedPASS include:</li> <li>Definition of what constitutes suffering in Carter is ambiguous, narrowly defined, vague, and could cause chill for doctors;</li> <li>Ethical parameters post-Carter: ethic debate necessary; physicians have important role to play; autonomy is central ethical value; should be patient-centred;</li> <li>No generally accepted definition of suffering in PAD context;</li> <li>Important need for counselling of patient;</li> <li>Pressures on patient that violate informed consent principle;</li> <li>Physicians must play integral role in designing decision-making process;</li> <li>Looked at international comparisons re issue of suffering and to find loopholes and shortcomings in legislation so Canada doesn't make same mistakes;</li> <li>Secure accessible, complete, and universal palliative care; and</li> <li>How to properly judge autonomy and right to consent.</li> </ul>	English

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45	Susan House; Will Johnston	Euthanasia Prevention Coalition - British Columbia	Vancouver	10/26/15	<ul> <li>Key points from the meeting with the Euthanasia Prevention Coalition - BC include:</li> <li>Transparent access and screening—no coerced cooperation of any health care worker or student, nothing done in secret;</li> <li>Necessity of defining right to conscience clearly;</li> <li>Looking for the law to provide a qualified exception to a criminal prohibition, not a right of general access to a newly created service;</li> <li>The law should respect maintaining an extensive safe space in the health care system;</li> <li>Taking a human life goes against the dignity of the human person; and</li> <li>Legislation should focus on a reasonable person's apprehension of what constitutes an extreme medical situation.</li> </ul>	English
46	Marilyn Golden	Disability Rights Education and Defence Fund	Vancouver	10/26/15	Key points from the meeting with Marilyn Golden include:  • Safeguards in US weak and there is huge issue of elder abuse;  • "Doctor shopping" a problem in the US, to get around safeguards;  • Advances in palliative care can relieve symptoms in most patients;  • Pitfalls of Oregon law on assisted suicide;  • How to include safeguards that work: taking financial and emotional pressures into account; don't use good faith standard—can't be disproven;  • A system needs to be set up to investigate abuse—e.g., hotline;  • Psychiatric assessment of patients important to assess competence;  • Consensus among US disability community against physician-assisted death; and  • Oregon system shows no problems or abuse because it's set up not to find it.	English

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47	Sherry Chan; Luke Chen; Margaret Cottle; Ed Dubland; Constant Leung; Jennifer Tong	Network of BC Physicians	Vancouver	10/26/15	<ul> <li>Key points from the meeting with the Network of BC Physicians include:</li> <li>Physician-hastened death poses great risk to vulnerable patients and to society at large; risks should be minimized;</li> <li>Advocate carefully designed system that imposes strict limits, that is scrupulously monitored and enforced;</li> <li>Important that there be legislation that protects physicians' freedom of conscience and professional judgment as a core element of a meaningful system of safeguards;</li> <li>Patients may not access excellent palliative care resources because they'll connect it with physician-assisted death;</li> <li>Keep PAD separate from regular health services; and</li> <li>Access to a central agency for information, counselling, and referral.</li> </ul>	English
48	Sean Murphy	Protection of Conscience Project	Vancouver	10/26/15	Key points from the meeting with the Protection of Conscience Project include:  • Preserving freedom of conscience of health workers is essential;  • Dealing with "obligation to kill" if euthanasia or assisted suicide don't work as expected;  • Eligibility: need to include unspecified conditions beyond illness, disease and disability such as frailty;  • Coerced referral presents unacceptable risks to people's fundamental freedoms;  • Safeguards: a single standard, purely voluntary across the country;  • The problem of referral if physician has conscientious objection—a violation of human dignity to propose a moral duty to do what one believes to be wrong; and  • No one should be punished for refusing to participate in PAD.	English

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49	Eike-Henner Kluge	University of Victoria, Department of Philosophy	Vancouver	10/27/15	<ul> <li>Key points from the meeting with Eike-Henner Kluge include:</li> <li>Focus on patients who have never been competent: include them in legislation;</li> <li>Medically appropriate health care for patients in PAD necessary;</li> <li>Position of substitute decision-makers needs to be clarified;</li> <li>Need for checks and balances: concern that people who lack capacity not be discriminated against in any way or that anyone fall through the cracks;</li> <li>Physicians not required to engage in PAD if it conflicts with their values;</li> <li>Ethical implications of advance directives;</li> <li>Judgment of suffering has to be guided by values of society via judges; and</li> <li>System needs to be accountable with judicial oversight.</li> </ul>	English
50	John Soles	Society of Rural Physicians of Canada	Vancouver	10/27/15	<ul> <li>Key points from the meeting with the Society of Rural Physicians of Canada include:</li> <li>Need for referral mechanism if physician objects to PAD; who to get? how far away to go?;</li> <li>Safeguards include screening patients for depression etc. so clear they are making a rational decision, time to consider their decision, more than one person deciding;</li> <li>Emotional consequences of what to do if physician objects but patient wants their help in PAD situation;</li> <li>Demand for PAD less in rural areas because population older, poorer, less educated, less employed;</li> <li>Professional responsibility to provide info and care regardless of beliefs; and</li> <li>Physicians need proper education and training to deal with PAD.</li> </ul>	English

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51	,	BC Civil Liberties Association	Vancouver	10/28/15	<ul> <li>Key points from the meeting with the BC Civil Liberties Association include:</li> <li>Canadians suffering unbearably at the end of life should have the right to choose a dignified and peaceful death;</li> <li>Kay Carter storyabout less tangible things than pain management;</li> <li>Courts have done government's work for them—leave to provincial health legislative bodies;</li> <li>Vulnerable people not at greater risk of PAD;</li> <li>"Slippery slope" is illusory—no evidence to support it;</li> <li>Decision should be between physician and patient;</li> <li>No physician under any obligation to perform this service (since 1972); and</li> <li>Publicly funded health care system should not be allowed to contract out any services to religious organizations that oppose PAD.</li> </ul>	English
52	Carrie Bourassa	First Nations University	Vancouver	10/28/15	<ul> <li>Key points from the meeting with Carrie Bourassa include:</li> <li>No consensus in indigenous communities on PAD; just as divisive on this issue as it is anywhere else in Canada;</li> <li>Very rare to discuss end of life in indigenous families;</li> <li>PAD not on radar because of other overwhelming issues in communities;</li> <li>Important to communicate the idea of PAD well because people want to die in a good way with as much dignity as possible;</li> <li>Difficulty accessing Canadian health care because of racism so they won't access it unless they have to; and</li> <li>Challenging to figure out how to access the kind of care they want because indigenous health care is fragmented and confusing.</li> </ul>	English

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53	Gordon Self;	Catholic Health Alliance of Canada	Winnipeg	10/29/15	<ul> <li>Key points from the meeting with the Catholic Health Alliance of Canada include:</li> <li>Deliberate taking of life goes against the dignity of the human person and not aligned with principles of Catholic health care;</li> <li>Palliative care does not include physician assisted death;</li> <li>Restrictions needed to minimize harm of PAD; license MDs who provide service;</li> <li>Vulnerable people, health care providers, organizations must never feel coerced or threatened into making/participating in this decision;</li> <li>Won't stop patient from accessing PAD, so set up separate system for self-referral;</li> <li>Give patient more time to reflect on decision and provide support during that time; and</li> <li>Important to restrict meaning of "grievous and irremediable".</li> </ul>	English
54	Jim Derksen; James Hicks; Rhonda Wiebe	Council of Canadians with Disabilities	Winnipeg	10/29/15	<ul> <li>Key points from the meeting with the Council of Canadians with Disabilities include:</li> <li>Preserve autonomy and dignity of persons with disabilities in all circumstances;</li> <li>Legalization should only be about PAD, not euthanasia;</li> <li>Set up independent review panel to determine if patient meets criteria for PAD;</li> <li>Only make PADs available after palliative care plan presented to patient;</li> <li>Interested party who thinks coercion a possibility must be allowed to intervene;</li> <li>Put mandatory system in place to track requests across country; and</li> <li>There are people with disabilities who value their autonomy and right to make these decisions.</li> </ul>	English

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55	Melanie MacKinnon	University of Manitoba	Winnipeg	10/29/15	Key points from the meeting with Melanie McKinnon include:  • Giving indigenous communities more power and autonomy in health care;  • Trying to convince policy-makers to invest in palliative care to bring back dying with dignity to indigenous communities;  • Challenge of expressing free choice challenging because so recently allowed to practise traditional customs and beliefs;  • Paradigm shift needed: govts spend too much money spent on band-aid solutions for indigenous communities; community health leaders want focus on behavioural and spiritual health to reconnect and heal; they need to be given authority to decide what health care they need;  • Language—labels and definitions—key to embracing indigenous community; physician-assisted death, not suicide, since suicide has inflicted deep wounds;  • Few auxiliary policy supports from federal and provincial govts; many services not insured; drugs and palliative care not covered because not core services; this needs to change; and  • Nurses don't provide evening or home support if indigenous patient has terminal illness; rules don't allow patients options; often far away from home in hospital; have to fundraise to allow family member to travel to and from hospital.	English
56	Yude Henteleff	University of Winnipeg	Winnipeg	10/29/15	<ul> <li>Key points from the meeting with Yude Henteleff include:</li> <li>The need for ensuring meaningful access to integrated palliative care for patients with life-limiting illnesses;</li> <li>Conceptual separation of end of life care from health care;</li> <li>Having a uniform system across the country;</li> <li>The need to have reasonable accommodation, otherwise we are diminished as a society;</li> <li>Safeguards have to be reasonable, which depends on the circumstances of each case; doctors have to decide extent of patient suffering;</li> <li>If palliative care not available, how can patient be fully informed and thus have the right to make their choice; and</li> <li>Need to meet person's equality rights may require considering other issues, such as comparing to like groups.</li> </ul>	English

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57	Michael Bach	Canadian Association of Community Living	Toronto	11/02/15	Key points from the meeting with the Canadian Association of Community Living include:  • Proposed framework for vulnerability assessment: how to identify and safeguard vulnerable people in times of weakness with access to PAD, from abuse and error;  • Framework works in stages: patient makes request; assessed by trained physician, social worker, psychologist; stage 2: alternatives, unmet needs etc;  • Current context of vulnerability: more and more people, 3.6 million now, with neurological conditions that are disability related;  • Legislated safeguards would balance the perspective of those at risk against those who seek assistance in dying; and  • Need process for nuanced considerations, like feeling one is a burden.	English
58	James Downar; Shanaz Gokool; Wanda Morris	Dying With Dignity Canada	Toronto	11/02/15	Key points from the meeting with Dying With Dignity Canada include:  • Canadians who are eligible must be able to access assisted dying wherever they live;  • Robust system needed for physicians who are conscientious objectors;  • Effective referrals must give patient access to treatment;  • System must protect the weakest and most vulnerable;  • Be careful about how language of palliative care is used—not synonymous with end of life care;  • Safeguards: higher standard of scrutiny for those not terminally ill;  • How to set up a hotline for patients who need access to information; and  • Find out how many Canadians have access to palliative care.	English
59	Philip Emberley; Joelle Walker	Canadian Pharmacists Association	Toronto	11/03/15	<ul> <li>Key points from the meeting with the Canadian Pharmacists Association include:</li> <li>Eligibility criteria: pharmacists should have access to patient diagnosis and care plan before filling prescription; need to be protected and know extent of their liability if patient doesn't meet criteria;</li> <li>One safeguard to address risks and procedures is by using triplicate forms;</li> <li>Obligation to refer if pharmacist has moral or religious objection;</li> <li>Most pharmacists disagree that they are obligated to participate;</li> <li>See part of role as counselling patient to take medication correctly;</li> <li>Only some medications tracked; no system for all medications; and</li> <li>Interprovincial tracking system for drugs being started by Health Canada.</li> </ul>	English

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60	Monica Branigan; Susan MacDonald	Canadian Society of Palliative Care Physicians	Toronto	11/03/15	Key points from the meeting with the Canadian Society of Palliative Care Physicians include:  • Palliative care is a priority and should be offered to all patients regardless of whether they wish PAD or not;  • Important to reduce risk of premature death, by talking with patient and changing their mind; PCPs have these skills;  • Most members don't think PAD should be provided by PCPs;  • Conscience rights of all physicians need to be protected;  • Distinguish language between practices that hasten death and practices that seek neither to hasten death nor prolong dying; and  • Suggest separate panel process so patients can be referred; models exist for this, e.g. Trillium transplant agency.	English
61	Francine Lemire	College of Family Physicians of Canada	Toronto	11/03/15	<ul> <li>Key points from the meeting with the College of Family Physicians of Canada include:</li> <li>Family physicians responsible for ensuring patients have all the information they need to make informed decisions: potential risks;</li> <li>Oppose actions that would abandon patient without options or direction;</li> <li>Need to find a way not to abandon patients if physician objects to PAD;</li> <li>Need to have a second physician to consult;</li> <li>Possible skills training and assessment for PAD anticipated trying to figure out what additional skills needed to provide PAD: global, comprehensive, compassionate approach as well.</li> </ul>	English

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62	David Baker; Rebecca Lauks	Disability Rights Lawyers	Toronto	11/03/15	<ul> <li>Key points from the meeting with David Baker and Rebecca Lauks include:</li> <li>Provide review board process before PAD decision; will stand up to legal and constitutional scrutiny and provide provincial and federal responsibilities;</li> <li>This provides safeguards against abuse while maximizing rights of person by ensuring supports available;</li> <li>Assistance must then come from physician;</li> <li>Definition of suffering needs to be both subjective and objective to work;</li> <li>Second physician needs to be involved with specialty that address source of patient's suffering as basis for PAD;</li> <li>Appropriate safeguards needed to address vulnerability;</li> <li>PAD should not be seen as medically necessary treatment or therapeutic; and</li> <li>Concern about increasing PAD deaths in Europe because criteria not clear.</li> </ul>	English
63	Alex Schadenberg; Hugh Scher	Euthanasia Prevention Coalition	Toronto	11/03/15	<ul> <li>Key points from the meeting with the Euthanasia Prevention Coalition include:</li> <li>Assisted death should not be permitted;</li> <li>See how law has worked in other jurisdictions to learn from their mistakes, e.g., ensuring physicians get second opinion, that patient makes request, no self-reporting;</li> <li>Effective third-party judicial oversight needed to make sure requirements set out in law are met;</li> <li>Assisted death should not be carried out by doctors, but by someone licensed and certified;</li> <li>There needs to be a safe space so people know PAD won't happen there;</li> <li>Need to have universal access to palliative care; and</li> <li>Proper system of interviewing person to see why they're seeking PAD.</li> </ul>	English

ID#	Name(s)	Organization(s) / Title	City	Date (M/D/Y)	Transcript Abstract	Language
64	Alika Lafontaine	Indigenous Physicians Association of Canada	Toronto	11/03/15	Key points from the meeting with the Indigenous Physicians Association of Canada include:  • Implications of law for indigenous people differ from general population: they have less access to facilities and expertise and distrust govts;  • Law must apply across all jurisdictions: reserves are in different jurisdiction that falls into grey area; neither province or federal govt takes full responsibility for reserve health care;  • Belief that it would be too hard to convince the local physician to get expertise in this or to convince the health authority that they needed access to PAD; and  • Collective autonomy: need to have the family be part of the PAD process if it happens.	English
65	Thomas Bouchard; Renata Leong	Canadian Federation of Catholic Physicians' Societies	Toronto	11/04/15	Key points from the meeting with the Canadian Federation of Catholic Physicians' Societies include:  • Language should be clear: use euthanasia and physician-assisted suicide so everyone is clear about what they are talking about;  • Team evaluation: how to make sure patients' decisions are autonomous;  • Safe spaces needed that are separate from hospitals;  • Practical challenges in assessing capacity and voluntariness;  • Would not withhold information but would not facilitate access;  • Need to uphold conscience protection for doctors;  • More home care availability important for caregivers;  • Safeguards: life insurance policies shouldn't be affected;  • National standard and oversight that is transparent and accountable; and  • Physicians may move to other jurisdictions to avoid dealing with this.	English

ID#	Name(s)	Organization(s) / Title	City	Date (M/D/Y)	Transcript Abstract	Language
66	Richard Elliott	Canadian HIV/AIDS Legal Network	Toronto	11/04/15	<ul> <li>Key points from the meeting with the Canadian HIV/AIDS Legal Network include:</li> <li>Question of patient autonomy important: free voluntary fully informed consent;</li> <li>Law shouldn't reflect any religious teachings;</li> <li>Eligibility: add mature minors if other conditions from Carter satisfied; legislation should set out national standards about eligibility;</li> <li>Risks and safeguards: two separate health care professionals, one of whom experienced in assessing competence; short time period to reflect on request so patient doesn't suffer unnecessarily;</li> <li>Safeguards to make sure patients aren't being pressured;</li> <li>Patients need to have access to good palliative care and universal pharmacare; and</li> <li>Second review to make sure all protocols followed.</li> </ul>	English
67	Vyda Ng	Canadian Unitarian Council	Toronto	11/04/15	<ul> <li>Key points from the meeting with the Cadian Unitarian Council include:</li> <li>Don't delay implementation of legislation;</li> <li>There should be easy access for patients who request PAD;</li> <li>Make sure legislation ensures equal access across country;</li> <li>Safeguards to protect vulnerable people have to be thorough and balanced; two physicians to make assessment in those cases;</li> <li>Final decision up to patient if patient competent to decide; and</li> <li>Canadians have the right to choose time and manner of their death.</li> </ul>	English
68	Derek Ross; John Sikkema	Christian Legal Fellowship	Toronto	11/04/15	<ul> <li>Key points from the meeting with the Christian Legal Fellowship include:</li> <li>More time needed for wider consultation and study after Carter decision;</li> <li>Optimal solution: a complete ban;</li> <li>Safeguards must be scrupulously monitored but do not eliminate all risk;</li> <li>Main risk is that patients may have life taken without their explicit consent;</li> <li>Maintain a culture that discourages suicide as a way to end suffering;</li> <li>Should not be easy to access: good palliative care should have been offered so patient has meaningful choice and choice is voluntary;</li> <li>Don't allow psychiatric illness as reason to access PAD; and</li> <li>Segregate PAD from health care services in separate place.</li> </ul>	English

ID#	Name(s)	Organization(s) / Title	City	Date (M/D/Y)	Transcript Abstract	Language
69	Marc Doucet	Canadian Association for Spiritual Care	Toronto	11/05/15	<ul> <li>Key points from the meeting with the Canadian Association for Spiritual Care include:</li> <li>Establish robust and clear processes and guidelines with strict limits that are scrupulously monitored and enforced;</li> <li>Make sure adequate timing, sequencing, and assessment for vulnerable populations who are legally competent but whose capacity wavers;</li> <li>Ensure independent review process to report and monitor decisions;</li> <li>Encourage development of palliative and hospice care across country so PAD not default; and</li> <li>Independent review of two or three people when patient makes decision.</li> </ul>	English
70	Cara Faith Zwibel	Canadian Civil Liberties Association	Toronto	11/05/15	<ul> <li>Key points from the meeting with the Canadian Civil Liberties Association include:</li> <li>There should be a body that monitors best practices and informs public about how system is working;</li> <li>Equality of access across country;</li> <li>Need for safeguards of allowing more time, but not too much to act as deterrent to access;</li> <li>Need to reconcile patient and physician rights, but physician should have to provide effective referral if no third party available; and</li> <li>If patient in remote community, their right trumps physician's right to object.</li> </ul>	English
71	Glenn Brimacombe; Sonu Gaind	Canadian Psychiatric Association	Toronto	11/05/15	Key points from the meeting with the Canadian Psychiatric Association include:  • Focus on eligibility criteria: if patient accessing PAD has mental illness and medical illness, role of psychiatrist to ensure it is not impairing patient's capacity to make an informed decision;  • Separate biomedical from psychosocial impacts; psychosocial rarely irremediable;  • Risk in determining capacity: if patient undermined by mental illness, may be deemed not capable of making PAD decision; also risk if no clinical certainty in assessing capacity; and  • Safeguards: spread evaluation into physical and mental components; six weeks between assessments, and multiple assessments from different experts.	English

ID#	Name(s)	Organization(s) / Title	City	Date (M/D/Y)	Transcript Abstract	Language
72	Christian Domenic Elia; Philip Horgan	Catholic Civil Rights League	Toronto	11/05/15	<ul> <li>Key points from the meeting with the Catholic Civil Rights League include:</li> <li>Need better and more available palliative care;</li> <li>Understanding conscience rights for all health care workers;</li> <li>Best way of respecting the dignity of the human person is to affirm life;</li> <li>Notwithstanding clause should be given serious consideration;</li> <li>Safeguards illusory in other jurisdictions because of mistakes, inattention, so don't believe they will be effective;</li> <li>No matter what happens it will lead to an innocent death; and</li> <li>Jeopardy for health care providers who refuse to assist in patient suicide.</li> </ul>	English
73	Julia Beazley; Bruce Clemenger	Evangelical Fellowship of Canada	Toronto	11/05/15	<ul> <li>Key points from the meeting with the Evangelical Fellowship of Canada include:</li> <li>Risks of PAD can be identified and minimized with carefully designed systems that impose strict limits and are scrupulously monitored and enforced through system of safeguards;</li> <li>Concerned with threshold of risk set lower in Carter compared to opposition to capital punishment;</li> <li>Prohibition on intentional killing is necessary and should remain;</li> <li>No safeguards can eliminate risk of abuse;</li> <li>Practice of assisted suicide should be federally licensed to minimize risk;</li> <li>Physicians must have right to refuse to participate in PAD if they conscientiously object; and</li> <li>Advocate for national strategy for high quality palliative care.</li> </ul>	English
74	Donato Gugliotta; Diane Haak; Larry Worthen	Christian Medical and Dental Society of Canada	Toronto	11/06/15	Key points from the meeting with the Christian Medical Dental Society of Canada include:  • Concern that vulnerable patients will fall through the cracks and lose their autonomy; the criteria for who is vulnerable should be very broad;  • Physicians must follow all protocols when they are established; revoke licenses or criminal charges if they don't;  • Worry about people's Charter rights to life violated;  • Legislation should clearly articulate the state's interest in protecting the life of every person regardless of circumstances; and  • Patients need safe spaces where not at risk of wrongful death.	English

ID#	Name(s)	Organization(s) / Title	City	Date (M/D/Y)	Transcript Abstract	Language
75	Lynne M. Arnason; Rocco Gerace; Douglas A. (Gus) Grant; Linda Inkpen; Graeme Keirstead; Fleur-Ange Lefebvre; Louise Marcus; Cyril Moyse; Michael Noseworthy; Yves Robert; Dr. Schollenberg; Bryan Salte; Sarah Thomas	Federation of Medical Regulatory Authorities of Canada	Toronto	11/06/15	Key points from the meeting with the Federation of Medical Regulatory Authorities of Canada include:  • Essential to have a national strategy and equal access;  • Focus should be patients' rights, not physicians' rights;  • Meaningful referral resource for patients to access;  • Good faith protection for physicians;  • How to handle conscientious objection without violating code of ethics;  • The problem of effective referral needs to be addressed;  • Discussed the issue of training physicians for PAD but not accrediting them;  • The problem of determining and defining capacity and incapacity;  • Amendments to Criminal Code should address other health care professionals; and  • Need for an oversight body that would monitor and review retrospectively.	English
76	Kevin Imrie	Royal College of Physicians and Surgeons of Canada	Toronto	11/06/15	<ul> <li>Key points from the meeting with the Royal College of Physicians and Surgeions of Canada include:</li> <li>National standard needed to clarify physicians' roles and duties;</li> <li>Need to have partnership among national medical organizations;</li> <li>Need to identify core competencies of physicians in PAD: need to be communicators, collaborators, advocates for patients;</li> <li>Commit to developing PAD educational materials for residents and physicians;</li> <li>Consider PAD in context of more comprehensive strategy for palliative care; and</li> <li>Have developed framework for PAD that encompasses all specialties.</li> </ul>	English





### **Annex F**

### **Summary of Document Submissions Received**



15 December 2015







#### **Executive Summary**

Thousands of Canadians responded to the invitation from the External Panel on Options for a Legislative Response to *Carter v. Canada* (the Panel) to provide input. There were three ways to contribute: by answering the questions in the Panel's online Issue Book; by preparing a formal submission; and by participating in the direct invitation-only consultations. This document summarizes the more than 300 submissions received between August 2 and October 19, 2015.

The submissions varied in virtually every conceivable way: in length, content, tone and style. Some submissions were full-length books and scholarly theses; others were single sentences expressing informal, heartfelt opinions. Many statements described the end-of-life experiences of family members or friends. Others referenced religious texts, philosophers or scholars. On many key points, such as whether Canada should legalize physician-assisted dying, diametrically opposed views were expressed. Many people see the relevant issues in absolutist terms: as a reflection of Canada's moral and ethical principles.

While the opinions expressed seem irreconcilable, the submissions indicate a clear preoccupation with several key themes, issues and questions inspired by the Supreme Court's decision. This report focuses on these in an attempt to summarize the remarkable and valuable outpouring of opinions and thoughts from Canadians.

#### Part 1: Overarching Issues

The largest and most divisive issue raised and considered in the submissions is whether Canada should amend federal law and legalize physician-assisted dying. Most submissions express an absolutist view: that physician-assisted dying must be authorized or must never be authorized. And many submissions back up these views with articulate, sophisticated and well-researched arguments.

Many submissions call for the Government of Canada to override the Supreme Court's ruling by invoking Section 33 of the *Charter*—the so-called "notwithstanding clause." Some of the submissions that recommend this course of action do not take a stand on physician-assisted dying, but instead express concerns that the deadline imposed by the Supreme Court does not allow for sufficient time to identify, develop and implement an effective legislative solution. Many submissions criticize the Supreme Court of Canada for failing to define key terms, such as "competent adult" and "grievous and irremediable medical condition;" some propose definitions of their own, or suggest entirely different terms.

While most submissions call for some type of action from Parliament, ideas about the structure of a regulatory regime for physician-assisted dying vary widely. Many submissions insist that the regime be federal and feature precise standards, eligibility criteria, and reporting and review requirements that would apply across the country. Other submissions call for provincial regimes aligned with regional considerations. There is also significant diversity of opinion about the roles that health-care and legal professionals should play in a physician-assisted dying regime. Some





submissions indicate that physician-assisted dying should require the authorization of a special panel that includes a judge, for instance. Other submissions indicate that physician-assisted dying authorization should require only the consent of two independent physicians.

The third most-divisive issue in the submissions involves the conscience rights of health-care workers and institutions. Many submissions indicate that explicit legal protection is required to ensure that health-care workers who refuse to participate in physician-assisted dying do not suffer any consequences as a result. A key point is whether physicians who reject physician-assisted dying should be legally required to refer patients elsewhere for the service; again, no consensus exists on this point. Similarly, opinions are divided on whether health-care institutions, such as hospitals, should be required to accommodate requests for physician-assisted dying. Some submissions suggest that physician-assisted dying be offered only in facilities separate from traditional health-care institutions.

A final issue commonly raised is the relationship between physician-assisted dying and palliative care. In fact, perhaps the most commonly expressed view is that Canadians must have greater access to high-quality palliative care. Many submissions suggest that limited access to such care is a major contributing factor to demand for physician-assisted dying. Another concern commonly expressed is that physician-assisted dying and palliative care must be separate and distinct; that physician-assisted dying should never take place in a palliative-care facility; and that the professionals involved in palliative care must never be required or coerced into participating in physician-assisted dying.

#### Part 2: Risks

The submissions clearly indicate that the most significant risk is that of wrongful death. The most commonly cited cause of potential wrongful death is one or more mistakes in process: that the process will fail to take into account people who change their mind after previously consenting to physician-assisted dying, for instance, or that someone with power of attorney over someone's medical care will not act in the person's best interest. Several submissions point out the potential for conflict of interest if the person with power of attorney also stands to benefit (e.g. through inheritance) from someone's death.

Many submissions contend that legalizing physician-assisted dying will lead to increased mistreatment of vulnerable groups, such as the aged and persons with mental or physical disabilities. In particular, some see significant risk in the episodic nature of many mental illnesses; someone suffering from an acute but temporary bout of mental illness will request and obtain physician-assisted dying.

Some submissions point to a risk that is difficult to measure: a loss of respect for the elderly, those with disabilities and other vulnerable persons. An idea often expressed is that when death is considered a way to avert potential future suffering and its consequences—for both the individuals and their friends and loved ones—vulnerable groups are at increased risk of harm.





Another risk many submissions identify is that physician-assisted dying could have negative impacts on the health-care system: that it would increase moral distress and burnout among health-care workers who believe in the primacy of life and in the tenet of "first, do no harm." At least one submission identifies potentially increased risks of legal liability for nurses who assist or counsel end-of-life patients.

Many submissions explore the links between physician-assisted dying and palliative care. Some suggest that legalizing physician-assisted dying will have inevitable and harmful effects on the quality and availability of palliative care. A few submissions predict that fear of physician-assisted dying would lead to late referrals and decreased access to palliative care. A common idea expressed is that increasing the quality and availability of palliative care would eliminate (or all but eliminate) demand for physician-assisted dying.

Many of the perceived risks relate directly to physician-assisted dying processes, which have yet to be developed. Inadequate training of those involved in physician-assisted dying could lead to negative consequences, for instance, and more permissive jurisdictions might fail to closely follow legal requirements. Some submissions assume that physician-assisted dying processes will require contemporaneous consent, which will not be possible in some cases due to a deterioration of a person's health.

The concept of the so-called slippery slope—that legalizing physician-assisted dying under very limited circumstances would eventually lead to significantly widened eligibility —is a topic in many submissions. Some claim that the data from jurisdictions with physician-assisted dying regimes (Netherlands, Belgium, Switzerland and Oregon) prove the slippery-slope theory; others claim that these data disprove the theory.

At least one submission suggests that Health Canada's market-authorization procedure does not currently permit the use of pharmaceuticals in the doses needed for physician-assisted dying. If not addressed in legislation, this could expose health-care workers to increased legal liability.

A few submissions point toward risks associated with developing—or not developing—a regulatory regime. Overly strict regulations could jeopardize patient autonomy, for instance, while policies that prioritize patient autonomy could increase harm to patients, their families and society. Finally, some submissions contend that failure to develop legislation would create a legal vacuum and lead to inconsistent practices and policies.

#### Part 3: Safeguards

Including explicit safeguards in the legislation and subsequent regulations was a common topic in the submissions. Many described the importance of clear definitions of key terms, such as terminal illness and patient consent, along with prescribed processes and procedures. Some submissions suggest that the law clarify that physician-assisted dying is not medicine but an exception to laws against homicide.





As noted earlier, perceptions differ on the relationship between jurisdiction over physician-assisted dying and safety. Some believe that it would be safer if physician-assisted dying were a criminal matter under federal jurisdiction, while others believe physician-assisted dying would be safer under provincial jurisdiction.

An idea common to many submissions is the need for an independent agency (or agencies) to provide oversight. Some call for this body to have an precursory role—to screen applications for physician-assisted dying—and others call for it to have a subsequent role—to review past cases of physician-assisted dying, identify trends and issues, and recommend policy and procedural improvements. A few submissions called for a judicial review of physician-assisted dying every three years.

There is similarly no consensus in the submissions on the composition of these agencies; some call for the involvement of at least one federal-court judge, while others would limit membership to physicians. Several submissions point toward Ontario's Consent and Capacity Board as an example of a model review panel.

The most common area identified for safeguards is the physician-assisted dying process: the steps an individual would take to access the service. The variety of safeguards suggested is vast. Many submissions call for two assessments of the patient by independent physicians. Others call for assessments by a multi-disciplinary, inter-professional team comprised of at least one physician, one psychiatrist and one other expert, such as a social worker.

Safeguards related to consent also varied considerably. Some submissions indicate that consent be required both in advance and immediately before death. Other submissions indicate that consent immediately before death (also known as contemporaneous consent) will be impossible in cases when a person's condition has deteriorated past a certain point.

A related concern in many submissions is that of capacity: a person's ability to make a clear choice. Many submissions from mental-health experts point toward the lack of scientific standards to accurately and consistently assess capacity.

A safeguard in many submissions relates to documentation and reporting: that those involved in physician-assisted dying procedures record specific information about requests for physician-assisted dying, along with counselling efforts, consent procedures and other relevant interactions. Many indicate that physicians and health-care workers be required to report all requests for physician-assisted dying.

Some submissions suggest an effective safeguard would be to clarify the roles and responsibilities of everyone involved in physician-assisted dying—from physicians and other health-care professionals to social workers and counsellors. A few submissions suggest that a new licenced position be created—a so-called euthanist or euthanologist—who would have primary responsibility for the procedure. Some even suggest that physicians not be authorized to provide physician-assisted dying.





A key point common to many submissions from the health-care professions is the need to protect the conscience rights of health care workers. Some submissions indicate that health-care workers must be able to recuse themselves completely from physician-assisted dying—without consequences—and not be required to participate or even to refer a patient for physician-assisted dying. Some of these submissions describe a system of self-referral rather than one compelling non-consenting physicians to refer patients to other physicians. Other submissions adopt the opposite view; some contend that conscience rights would have a negative impact on access to physician-assisted dying. A few submissions indicate that health-care workers should not be able to recuse themselves and that publicly funded institutions (e.g. hospitals) be required to provide this service.

A call for greater awareness and education about end-of-life issues is also common to many submissions. Along with raising public awareness, there are calls for targeted training for physicians and health-care professionals.

#### Part 4: Eligibility Criteria

Most submissions explore issues related to eligibility criteria: the qualifications someone would have to meet to access physician-assisted dying. The most common criterion in the submissions is the approval of two independent physicians. Also common are restrictions based on age or on the nature of illness: some indicate that physician-assisted dying should be available only to those suffering from specific, terminal diseases; other submissions use descriptors such as egregious, debilitating and hopeless. Submissions for and against physician-assisted dying cite the absence of empirical measures for suffering or pain to back up their views.

Many of the criteria in the submissions are much more nuanced, such as insisting that physician-assisted dying be available only after a course of palliative care, or only after a patient refuses to agree to a high-quality palliative care plan. There are also many nuances in the submissions related to criteria used to assess competency and mental health. Some submissions indicate that physician-assisted dying be made available to those suffering from mental illness; others indicate the opposite. Some submissions call for assessments by psychiatrists; others call for such assessments only if there is reason to believe the person is suffering from mental illness. At least one submission suggests that the assessment should consider not only physical and mental health, but also the circumstances of close friends and family members.

Another point touched on in many submissions is whether to recognize requests for physician-assisted dying made through advance directives—signed statements directing one's medical treatment once a person's health declines to a specific level. Again, diametrically opposed views are expressed.

In many cases, submissions otherwise critical of legalizing physician-assisted dying backed up these views by describing the difficulty (some claimed impossibility) of developing criteria that would mitigate the potential risks. One submission, for instance, points out that the criteria of a physician-assisted dying regime necessarily define the characteristics of a life worth living, and





that decisions about whether to keep sick people alive will be made by administrators likely to be influenced by other concerns, such as the cost of care.





#### **Annex G**

## **Abstracts of Document Submissions Received**



15 December 2015







#### **Annex G – Abstracts of Document Submissions Received**

#### Introduction

The following document provides abstracts and additional information for all document submissions received throughout the External Panel's consultations.

Submissions received from private individuals have had identifying details such as last names removed to maintain the anonymity of the submitters. Identifying details have been maintained only when specific permission has been received from an individual or the documents are from an individual with whom the Panel met through their in-person consultations. Identifying details have not been removed for submissions made on behalf of organizations.

ID#	Submitted By	Organization	Title	Abstract	Submission Date (D-M-Y)	Language
001	Raphael	Individual Submission	Guidelines for Physician- Assisted Suicide	A philosophical treatise on concepts such as autonomy and respect for others that calls for a PAD process where the patient controls the consumption of the lethal substance. The submission includes a list of 19 proposed safeguards.	07/08/2015	English
002	Esther	Individual Submission	Euthenasia is never the "better" way	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	07/08/2015	English
003	Clarence	Individual Submission	Joe	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	07/08/2015	English
004	John	Individual Submission	impeachment	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	07/08/2015	English
005	Peter	Individual Submission	No to assisted suicide	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	08/08/2015	English
006	Ruth	Individual Submission	ProtectiveMeasures/ Safeguards	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	08/08/2015	English
007	Nancy	Individual Submission	Invoke the Notwithstanding clause	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	08/08/2015	English
008	Anita	Individual Submission	Intolerable pain	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	08/08/2015	English
009	Richard	Individual Submission	The Death of the Right to Life in Canada	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	08/08/2015	English
010		Division of Palliative Medicine, University of Calgary	Perspectives on SCC decision from Division of Palliative Medicine University of Calgary, April 2015	Calls for distinct separation between palliative care and PAD to avoid harmful, unintended consequences for the patient-physician relationship. Also calls for greater access to palliative care.	09/08/2015	English
011	Dean	Individual Submission	We need to love	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	10/08/2015	English
012	Julia	Individual Submission	Submission to Panel Regarding Physician Assisted Dying	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	10/08/2015	English

ID#	Submitted By	Organization	Title	Abstract	Submission Date (D-M-Y)	Language
013	Al	Individual Submission	Assisted death is not health care	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	11/08/2015	English
014	Suzanne	Individual Submission	Respect de vie	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	11/08/2015	Français
015	Derek	Individual Submission	Please be as stringent as possible	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	11/08/2015	English
016	Carlos	Individual Submission	Life is life what a beautiful free gift	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	11/08/2015	English
017	Richard	Individual Submission	Opposé à l'euthanasie	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	12/08/2015	Français
018	Marie- Christine	Individual Submission	Je veux vivre dans un pays civilisé	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	12/08/2015	Français
019	Janina	Individual Submission	No to euthanasia	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	12/08/2015	English
020	Liliane	Individual Submission	favoriser la vie, non pas la mort	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	12/08/2015	Français
021	Meghan Schrader	Autistic Self Advocacy Network/ American Disabled for Attendant Programs Today	Please Remember Systemic Injustice and Invoke the Notwistanding Clause to STOP Euthanasia	Considers PAD from the perspective of persons with disabilities and calls for a ban on PAD.	12/08/2015	English
022	Tim	Individual Submission	Subversive Strategies to Sell Assisted Suicide.	Submission of another author's work discussing lobbying efforts by proassisted dying groups.	13/08/2015	English
023	Caitlin	Individual Submission	Physician assisted euthanasia	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	14/08/2015	English
024	René	Individual Submission	la vie don de Dieu	A bible quote.	14/08/2015	Français

ID#	Submitted By	Organization	Title	Abstract	Submission Date (D-M-Y)	Language
025	Bertrand	Individual Submission	la vie ne nous appartient pas c'est nous qui appartenons à la vie	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	21/08/2015	Français
1026	Allardyce	Canadian Disability Alliance	Canadian Disability Alliance (CDA) comments related to assisted suicide in Canada	Letter presents a resolution supporting the position held by the Council of Canadians with Disabilities, and calling for specific safeguards should a law authorizing PAD be enacted. Includes a thesis on non-consensual euthanasia by Suzanne Share of York University.	24/08/2015	English
027	Faith	Individual Submission	Executioners?	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	25/08/2015	English
028	John	Individual Submission	cocomas and advanced dementia using living wills	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	25/08/2015	English
029	Jill	Individual Submission	Consider the real cost of Assisted Dying	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	25/08/2015	English
030	Sigrid	Individual Submission	My Beliefs on Physician- assisted Dying	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	25/08/2015	English
031	Millicent	Individual Submission	Protect Life Not Death	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	27/08/2015	English
032	Sophie	Individual Submission	Mon point de vue sur l'euthanasie	Personal comment delves into the philosophical questions related to PAD.	27/08/2015	Français
033	Tamas	Individual Submission	A plea from a doctor	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	28/08/2015	English
034	Tim & Louise	Individual Submission	PAS and Euthanasia - Impact on our consciences, our families and our culture	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	28/08/2015	English
035	Michel	Individual Submission	OPTIONS ILLUSOIRES	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	29/08/2015	Français
036	Antoine	Individual Submission	Opinion personnelle.	Personal comment suggests a larger role for the judiciairy in PAD.	30/08/2015	Français
037	Edward	Individual Submission	Letter to Panel	Personal letter from a lawyer who had a personal experience with physician-assisted dying in another country.	01/09/2015	English

ID#	Submitted By	Organization	Title	Abstract	Submission Date (D-M-Y)	Language
038	Sheila	Individual Submission	Letter to Panel	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	01/09/2015	English
039	Wendela	Individual Submission	Letter to Panel	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	01/09/2015	English
040	Donna	Individual Submission	Assisted Dying Should Be Accessible	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	01/09/2015	English
041	Klaus	Individual Submission	Physician-assisted dying	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying. Focuses on Safeguards.	01/09/2015	English
042	Ranhael	Individual Submission	"An Argument for Physician-Assisted Suicide and Against Euthanasia", Ethics, Medicine, and Public Health (2015, forthcoming).	This 35-page thought piece examines key issues such as quality of life, patient autonomy and competence, as well as the conscience rights of caregivers, and provides guidance in the form of safeguards.	01/09/2015	English
043	Dr. Catherine	Physicians' Alliance Against Euthanasia	Considerations for Assisted suicide legislation	Proposes several elements and criteria for consideration in the formulation of a PAD law. Addresses criteria, conditions and application procedures.	01/09/2015	English
044	Shawn	Individual Submission	document	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	01/09/2015	English
045	Rene	Individual Submission	Commentary on PAD	Short preamble followed by a series of other pieces including studies, journal articles and opinion pieces.	01/09/2015	English
046	lWilfred	Individual Submission	Pro-Choice	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	02/09/2015	English
047	David Baker	bakerlaw	Draft legislation	Text of proposed legislation that would amend the Criminal Code to be consistent with the Supreme Court's decision in <i>Carter v. Canada</i> .	02/09/2015	English
048	David Baker	bakerlaw	Backgrounder to Draft Legislation	A supplementary piece to David Baker and Gilbert Sharpe's draft legislation (Submission #047). A series of eligibility criteria and safeguards are outlined.	02/09/2015	English
049	Catherine	Individual Submission	My experience a a Palliative Care nurse	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	02/09/2015	English

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050	Kaitlin	Individual Submission	Mon opinion	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	02/09/2015	Français
051	Flemming	Individual Submission	Danish Ethical Council's considerations on euthanasia	A translated 184-page compilation of three publications: Spiritual care for the Dying, Treating the Dying, and Euthanasia: Legalizing killing on request?	02/09/2015	English
052	Victoria	Socialist Patients Collective/ Patients Front - Multi-focal expansionism Canada	Against the primary (proto- ) medical Modern- EuthaNAZIsm	A statement outlining a series of perceived risks and warning of a slippery slope.	02/09/2015	English
053	Patricia	Individual Submission	Letter to Panel	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	03/09/2015	English
054	David	Individual Submission	We need to care more!	Link to an Association for Reformed Political Action page with an op-ed published in Feb. 2015	03/09/2015	English
055	George	Individual Submission	End Of Life Assisted Dying	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	03/09/2015	English
056	David	Individual Submission	Right to die as a Freedom Issue	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	03/09/2015	English
057	Jeremy	Individual Submission	Time for Ottawa to Act	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying. Suggests a few safeguards and accessibility mechanisms.	03/09/2015	English
058	Harry	Individual Submission	Results Not Intentions	The reprint of an article written by the executive director of a Toronto- based non-profit. The article provides a comprehensive look at the issues involved, identifies risks and provides safeguards.	04/09/2015	English
059	Máire	Individual Submission	The Dangers of Government Assisted Suicide	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	05/09/2015	English
060	Robert	Individual Submission	God's will	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	06/09/2015	English

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061	Jule	Individual Submission	more personal opinions on doctor-"assisted" suicide and mercy killing	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	06/09/2015	English
062	Tom	Individual Submission	Submission, Tom XXXX: Living before dying with dignity	Informed personal comment describes some safeguards and discusses several relevant ethical points.	06/09/2015	English
063	Tom	Individual Submission	XXXX final.pdf	A 99-page presentation to a Quebec Superior Court in a case involving physician-assisted dying.	06/09/2015	English
064	François	Individual Submission	Les dangers de l'euthanasie	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	06/09/2015	Français
065	Francis	Individual Submission		Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	07/09/2015	English
066	Nora	Individual Submission	Right to Die	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	07/09/2015	English
067	Stuart	Individual Submission	Why Canadian Attitudes on Dying Have Changed	An explanation of why Canadians' attitudes on assisted suicide have apparently changed.	07/09/2015	English
068	Jonathan	Individual Submission	Words of Wisdom in Regards to Euthanasia	An excerpt from a letter written by Pope John Paul II	07/09/2015	English
069	Dave	Individual Submission	The Importance of Self- determination	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	07/09/2015	English
070	John	Individual Submission	Addressing Problems with Doctor-Assisted Suicide	Personal comment focuses on two risks (pressuring of vulnerable patients, undermining role of physicians) and offers safeguards	07/09/2015	English
071	Veronica	Individual Submission	Risks of, and Alternative to Physician Assisted Dying (PAD)	Personal comment examines risks and suggests greater support for palliative care.	07/09/2015	English
072	Julie	Individual Submission	Canada; a people of life	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	08/09/2015	English
073	Jesse	Individual Submission	Physician-assisted suicide unforensic and inimical to public good	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	08/09/2015	English

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074	Kenneth	Individual Submission	State Regulated Killing	Brief note encouraging the Panel to consult with specific groups on this issue.	08/09/2015	English
075	Kevin	Individual Submission	The Great Matter of Life and Death - A philosophical perspective	A lengthy (20 pages) philosophical analysis of the Supreme Court's decision and potential responses to it submitted on behalf of the author by a friend with permission.	08/09/2015	English
076	Barbara	Individual Submission	New laws enabling doctor- assisted suicide	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	08/09/2015	English
077	Lynn	Individual Submission	Reasonable safeguards, not unreasonable barriers to access	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	08/09/2015	English
078	Mary	Individual Submission	The Right to Choose	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	09/09/2015	English
079	Lizzy	Individual Submission	Letter to Panel	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	10/09/2015	English
080	Ian Bushfield	British Columbia Humanist Association	Allow assisted dying for all who choose it	Submission provides a humanist perspective on the relevant issues and suggests a few attributes of a potential regime.	10/09/2015	English
081	Christian	Individual Submission	L'euthanasie (aide médicale à mourir) : une forme de corruption sournoise	A book (adaptation of university research into gerontology) warning against perceived inherent risks in legalizing PAD.	10/09/2015	Français
082	Kirsten	Individual Submission	Ron XXXX's Suicide Note	Ostensibly a suicide note from someone who suffered from terminal cancer before taking his own life.	10/09/2015	English
083	Ellinor	Individual Submission	Re: Legislative response to legalization of Physician-Assisted Death	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	10/09/2015	English
084	Daniel	Individual Submission	The Government	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	10/09/2015	English
085	Jule	Individual Submission	Hospital protocols	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	10/09/2015	English

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086	Hilmar	Individual Submission	Comply with the court's decision!	A series of web screens apparently taken from the BC Humanist Association website outline the organization's views on physician-assisted dying, including eligibility criteria and safeguards.	11/09/2015	English
087	Mac	Individual Submission	Considerations from Belgium's experience with assisted dying	Article describes Belgium's physician-assisted dying regime as overly permissive and lacking in safeguards.	12/09/2015	English
088	Francois	Individual Submission		A 10,000-word paper, with detailed footnotes and references, examining the issue from the perspective of geriatric patients and their health-care providers. The paper recommends a series of safeguards and proposes definitions for key terms.	12/09/2015	English
089	Sheila	Individual Submission	Physician-assisted dying	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	12/09/2015	English
090	Adele	Individual Submission	Letter to Panel	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	13/09/2015	English
091	Egbert	Individual Submission	Comments re Putting Down	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	13/09/2015	English
092	Alain	Individual Submission	Justice certaine ou certaine justice?	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	15/09/2015	Français
093	Margaret	Individual Submission	Letter to Panel	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	16/09/2015	English
094	Kathryn Tucker	Disability Rights Legal Center	Declaration of Eric Kress, M.D., In Support of Motion for Preliminary Injunction	Doctor's testimony to a court in Montana hearing a case on assisted dying.	16/09/2015	English
095	Elizabeth	Individual Submission	A huge mistake for all Canadians	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	17/09/2015	English

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096	Markos	Individual Submission	Dying with Dignity: is Euthanasia the Public Policy Answer?	A 14-page paper explores many of the ethical issues raised by the Supreme Court's decision.	17/09/2015	English
097	Mary	Individual Submission	The Greed and Abuse Factor	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	18/09/2015	English
098	Bouchard, Dr Jim Lane	Canadian Federation of Catholic Physicians Societies	Conscience protection in Legislation	A letter from the Canadian Federation of Catholic Physicians Societies outlining their organization's position on physician-assisted dying. The submission also contains materials from other organizations including three letters, a proposal on how to respond to requests for PAD in a way that respects physicians' conscience rights and patient autonomy, and a draft policy from the College of Physicians and Surgeons of Alberta on the same topic.	20/09/2015	English
099	Betty	Individual Submission	Protect and respect life	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	21/09/2015	English
100	Lisa	Individual Submission	I want choice.	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	21/09/2015	English
101	Eva	Individual Submission	Letter to Panel	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	22/09/2015	English
102	Sheila	Individual Submission	Graham XXXXXX Document	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	22/09/2015	English
103	Alain	Individual Submission	LOI ET BIEN COMMUN	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	23/09/2015	Français
104	Alan & Judy	Individual Submission	Assisted Death	A man recounts the daily struggles of his wife who suffers from Multiple Sclerosis.	23/09/2015	English
105	Alain	Individual Submission	Précision constitutionnelle	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	23/09/2015	Français
106	Evelyn	Individual Submission	Letter to Panel	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	24/09/2015	English

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107	Sarah Bastedo	Inter- professional Healthcare Students' Association	Assisted Dying Position Paper	Submission discusses an interdisciplinary approach to assisted dying, by involving many health-care professionals.	24/09/2015	English
108	Elizabeth	Individual Submission	STOP EUTHANASIA	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	24/09/2015	English
109	James Sanders, Chair	Disability Advisory Council of DWDC	Submission to the Federal Panel on PAD from the Disability Community	Submission considers several issues from the perspective of persons with disabilities.	25/09/2015	English
110		Dying With Dignity Canada	Submission to the Federal Panel on PAD from Dying With Dignity Canada	Submission calls for a series of safeguards, defines key terms and discusses perceived weaknesses in the Panel's Issue Book.	25/09/2015	English
111	Vyda Ng	Canadian Unitarian Council	Canadian Provincial/Territorial Expert Advisory Group on Physician-Assisted Dying - Written Submission Stakeholder Form	Submission calls for safeguards such as a detailed assessment of patient needs. Also describes potential barriers to accessing PAD and ways to overcome them.	26/09/2015	English
112	Gerald	Individual Submission	Support for dr assisted end of life with appropriate safeguards	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	26/09/2015	English
113	lMarilvn	Individual Submission	Alternative to physician- assisted suicide and euthansia.	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	26/09/2015	English
114	Carolyn	Individual Submission	Letter to Panel	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	27/09/2015	English
115	PJ	Individual Submission	One physician's perspective on PAD	Submission from a physician expressing a deeply held personal perspective on physician-assisted dying.	28/09/2015	English

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116	Jeanette	Individual Submission	MD Assisted Death	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	28/09/2015	English
117	Jessica	Individual Submission	It's Time to Change the Law	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	28/09/2015	English
118	Richard	Individual Submission	My right to physician assisted dying	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	29/09/2015	English
119	lMargaret	Individual Submission	Consultation on Physician Assisted Dying	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying. Calls for safeguards that do not create unreasonable barriers to access.	29/09/2015	English
120	Aj	Individual Submission	It is time to give people the freedom over their own bodies and lives.	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	29/09/2015	English
121	Marie	Individual Submission	Assisted dying and souls on ice	A bioethicist provides insights into the ethics of PAD.	29/09/2015	English
122	Stella	Individual Submission	Protect vulnerable Canadians!	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	29/09/2015	English
123	Olivia	Individual Submission	This is wrong	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	29/09/2015	English
124	Don	Individual Submission	Voluntary Euthanasia	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	30/09/2015	English
125	Tamara	Individual Submission	Euthanasia should not be legalized	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	30/09/2015	English
126	Taylor	Individual Submission	Freedom of conscience and religion are fundamental freedoms in Canada under Section 2 of the Charter of Rights and Freedoms.	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	30/09/2015	English

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127	Michael Bach	Canadian Association for Community Living	Protecting Choice & Safeguarding Inclusion	Position paper suggests principled eligibility criteria and safeguards to protect vulnerable persons.	01/10/2015	English
128	Kallie	Individual Submission	Letter to Panel	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	01/10/2015	English
129		Individual Submission	The Oregon Experience	A powerpoint presentation examines the 17-year history of legal physician-assisted dying in Oregon.	02/10/2015	English
130	Stern, Executive	The Canadian Medical Protective Association	Options for a Legislative Response to Carter v. Canada	The letter emphasizes physicians conscience rights and calls for legal clarity in light of the Supreme Court's ruling.	02/10/2015	English
131	Brandon	Individual Submission	How to define pain	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	03/10/2015	English
132	Rob Jonquière	World Federation of Right to Die Societies (WFRtDS)	Comment fron a Dutch and World perspective	Former CEO of Dutch Right to Die Society explains the legalities of the Netherlands' law and some relevant statistics from that country.	04/10/2015	English
133	lanet	Individual Submission	In Favour of Physician- Assisted Suicide and Voluntary Euthanasia	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	04/10/2015	English
134	Doris	Individual Submission	Letter to Panel	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	05/10/2015	English
135		Individual Submission	Letter to Panel	Letter from pyschiatrist expresses personal and professional opinion.	05/10/2015	English
136	Philippe	Individual Submission	Principes à respecter dans tout régime d'aide médicale à mourir	This seven-page piece was originally written in 2010 during Parliamentary debate for C-384, rewritten during the review of Quebec's law on PAD and edited again. It is well researched and footnoted, and addresses major ethical and legal issues.	05/10/2015	Français

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137	Justine	Individual Submission	Suggestions to the Panel	Canadian physician apparently based in the U.S. responds to online consultation.	05/10/2015	English
138	Daniela	Individual Submission	Sick Child's Future at Risk	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	05/10/2015	English
139	Elaine	Individual Submission	Letter to authorities from my former husband, Dan Devaney	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	05/10/2015	English
140	Mark	Individual Submission	Opposition to Any Form of Physician Involvement in Suicide	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	05/10/2015	English
141		Individual Submission	Ethical Considerations in the Regulation of Euthanasia and Physician- Assisted Death in Canada	Presents ethical considerations that would be pertinent in the development of policies and regulations in light of the Supreme Court's ruling. Examines regimes in jurisdictions where euthanasia is legal, and explores topics such as patient and provider autonomy from a Canadian perspective.	06/10/2015	English
142	Thomas	Individual Submission	Why the delay?	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	06/10/2015	English
143	Karen	Individual Submission	Legislative Response to Carter v. Canada	Personal comment which describes safeguards.	06/10/2015	English
144	Wayne	Individual Submission	Physician-assisted Dying in Canada: Where do we go from Here?	A thoughtful, lengthy expression of opinions in question-and-answer format that describes safeguards, including review and oversight considerations.	06/10/2015	English
145	Alison	Individual Submission	Euthanasia and Assisted Dying	A community pharmacist outlines suggested procedures for physician- assisted dying and proposes safeguards	06/10/2015	English
146	Tim	Individual Submission	"I desire mercy, not sacrifice."-Jesus	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	06/10/2015	English
147	Ginette	Individual Submission	Palliative Care doesn't kill	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	06/10/2015	English and Français
148	Joan	Individual Submission	Letter to Panel	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	07/10/2015	English

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149	Amy Hasbrouck	Toujours Vivant- Not Dead yet	Goals, Principles and Recommendations: Legislation Governing Assisted Suicide	Expresses concerns that some people with disabilities have regarding potential legislation on physician-assisted dying.	07/10/2015	English
150	Hélène	Individual Submission	Point de vue personnel sur la question	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	07/10/2015	Français
151	Rosa	Individual Submission	Legalizing Assisted Suicide	A petition or declaration that lists several risks.	07/10/2015	English
152	Kevin	Individual Submission	terminology and possible remedies	Column for Hospital News poses a number of questions relating to risks and safeguards.	07/10/2015	English
153	Janet McLean and Judy Lewis	The Catholic Women's League of Canada	The Catholic Women's League of Canada	Expresses concerns about inadequate availability of palliative care and describes some risks.	07/10/2015	English
154	Raphael	Individual Submission	Guidelines for physician- assisted suicide	An article by a professor at the University of Hull, UK delves into philosophical matters and provides guidelines for physician-assisted dying.	07/10/2015	English
155	Greg	Individual Submission	The need for Physician Assisted Death	Submission from an individual highlighting safeguards for physicianassisted dying.	07/10/2015	English
156	Annette	Individual Submission	Respect the right to die with dignity	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	07/10/2015	English
157	Shirley	Individual Submission	The death of Jack XXXX	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	07/10/2015	English
158	Brian		Euthanasia and human rights	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	07/10/2015	English
159	Kit and Pat	Individual Submission	Assisted suicide	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	07/10/2015	English
160	Nicole	Individual Submission	Letter to Panel	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	08/10/2015	Français

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161	André	Individual Submission	· ·	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	08/10/2015	Français
162	Paul	Individual Submission	Feedback for the 2015 Consultation on Legislative Options for Assisted Dying	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying and suggesting safeguards.	08/10/2015	English
163	Vincent	Individual Submission	Ban all forms of assistant killing	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	08/10/2015	English
164	Timothy		Palliative Care for All & Medically-Assisted Rational Suicide (MARS) - towards full Patient autonomy in End of Life Care.	A physician describes the "therapeutic dishonesty" of the status quo and a few safeguards.	08/10/2015	English
165	Pat	Individual Submission	Explore ALL avenues	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	08/10/2015	English
166	Faye Sonier	Canadian Physicians for Life	Canadian Physicians for Life Submission	Submission emphasizes the moral nature of medical practice and proposes mechanisms to ensure that all physicians, regardless of conviction, are treated fairly.	08/10/2015	English
167	Rev. Dr. Darren Roorda	Christian Reformed Church in North America	Submission to the External Panel on Options for a Legislative Response to Carter v. Canada on Physician-Assisted Dying	Letter emphasizes the importance of providing adequate palliative care.	08/10/2015	English
168	Cameron	Individual Submission	More time is necessary	Letter calls for more time to identify and consider options to respond Supreme Court's decision.	08/10/2015	English
169	Michel	Individual Submission	Un pensez-y bien	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	08/10/2015	Français

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170	C. Gwendolyn Landolt	REAL Women of Canada	More Time Required	Letter calls for more time to identify and consider options to respond Supreme Court's decision.	08/10/2015	English
171	Marcia	Individual Submission	Response to Terms of Reference	Letter identifies potential eligibility criteria and procedural safeguards.	08/10/2015	English
172	Cathy	Individual Submission	Risks of Assisted Suicide	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	08/10/2015	English
173	Monique	Individual Submission	Euthanasia	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	09/10/2015	English
174	Tammy	Individual Submission	We need palliative care not end of life	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	09/10/2015	English
175	Jim	Individual Submission	Another vote for doctor assisted death	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	09/10/2015	English
176	lVit∩	Individual Submission	Guidance from God's Biblical Principles	A lengthy submission which makes use of numerous bible quotes to support beliefs regarding human suffering, euthanasia and assisted suicide.	09/10/2015	English
177	Alfred	Individual Submission	Persons and Questions	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	09/10/2015	English
178	Sharon Baxter	Canadian Hospice Palliative Care Association	Consultation submission by the Canadian Hospice Palliative Care Association	Provides context on changes in end-of-life decisions and options, and on increased rates of chronic disease and infirmity. Calls for greater access to hospice and palliative care, and for increased information about end-of-life options and decisions.	09/10/2015	English
179	Hans	Individual Submission	The Carter decision should be overthrown	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	09/10/2015	English
180	John	Individual Submission	The Truth about Euthanasia	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	09/10/2015	English
181	Ginette	Individual Submission	Letter to Panel	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying. Offers guidance on safeguards and principles.	10/10/2015	Français
182	Duncan	Individual Submission	Please, Recommend No	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	10/10/2015	English

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183	Joe	Individual Submission	Time for Action-Leadership is Results not Position	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	10/10/2015	English
184	Michael	Archdiocese of Vancouver	Archbishop Miller - Submission - Consultation on Legislated Options for Assisted Dying	Submission emphasizes risks and mentions a few safeguards.	10/10/2015	English
185	Marie	Individual Submission	Liberté de conscience	Detailed personal comment from a retired physician explores concepts such as conscience, values, medicine and others.	10/10/2015	Français
186	Rev Don Larson	Archdiocese of Vancouver	CONCERN	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	10/10/2015	English
187	Francis	Individual Submission	3.2, abc&d Daughters End of Life	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	10/10/2015	English
188	Linda	Individual Submission	Mandate	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	10/10/2015	English
189	•	Catholic Women's League of Canada	Consultations on Legislation for Assisted Dying	Stresses importance of conscience rights of caregivers and of respect for human life. Cautions against making physician-assisted dying a "right."	11/10/2015	English
190	Liette	Individual Submission	mémoire présenté au comitéexterne sur les options de réponses législatives à Carte c.Canada ( euthanasie)	Submission from a physician expressing a deeply held personal perspective on physician-assisted dying. Focuses on risks, safeguards and vulnerable persons, among other issues.	11/10/2015	Français
191	Associate	Human Rights Watch	Human Rights Watch Submission to External Panel on Options for a Legislative Response to Carter v. Canada	Detailed 12-page position paper with references and footnotes, focusing on the notion of free and informed decision-making, and access and availabiliby of palliative care. Also provides international human-rights based perspective on key issues.	11/10/2015	English

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192	Gordon	Individual Submission	Portant sur la Forme et	An 8,000-word paper considers the various issues in play from a personal and philosophical perspective, and focuses on the potentially negative impacts of a PAD law on persons with disabilities.	11/10/2015	Français
193	Catherine	Individual Submission	Hearing our voice	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	11/10/2015	English
194	Julie	Individual Submission	Minimize Risks to Individuals and Society by Establishing Safeguards through Front Line Workers rds	Describes personal experiences as caregiver during the deaths of two family members in different provinces and vastly different circumstances. Ultimately calls for greater access to standardized palliative care.	11/10/2015	English
195	Jake Sinke	Canada Family Action	Look Closely at the Alternative	Brief letter advocating for greater access to standardized health care. Includes as an attachment a 17-page paper with references and footnotes which examines key issues and calls for greater access to palliative care.	11/10/2015	English
196	Jo	Individual Submission	Life in Canada	Personal comment informed by recent death of loved one.	12/10/2015	English
197	Wendy	Individual Submission	My Choice	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	12/10/2015	English
198	Emily	Individual Submission	Concerns about physician- assisted suicide	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	12/10/2015	English
199	Frances	Individual Submission	Letter to Panel	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	13/10/2015	English
200	André Schutten	Reformed	Protecting Life: How Parliament Can Fully Ban Assisted Suicide Witout Using Section 33	Presents a legal analysis of the Supreme Court decision and offers draft legislation prohibiting assisted suicide by anyone, including physicians and health-care workers.	13/10/2015	English

ID#	Submitted By	Organization	Title	Abstract	Submission Date (D-M-Y)	Language
201	Louis	Individual Submission	Not withstanding Clause	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	13/10/2015	English
202	Elizabeth	Individual Submission	Physician-Assisted Suicide Must Not Come to Canada	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying and proposing various safeguards.	13/10/2015	English
203	Elizabeth Andrzejczak	Kildonan Advocates for Life	Notwithstanding Clause Requested	Expresses concerns about using death to avert potential future suffering and how this logic might have tragic consequences for vulnerable groups in society.	13/10/2015	English
204	IMVrella Rov	Canadian Society of Hospital Pharmacists	Perspectives of the Canadian Society of Hospital Pharmacists on Options for a Legislative Response to Carter v. Canada	Seven-page paper includes a list of risks and corresponding safeguards divided into risks to patients and society (including healthcare professionals).	13/10/2015	English
205	Tonia	Individual Submission	Risks are Substantial	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	14/10/2015	English
206	Cheryl	Individual Submission	Reasons for restrictions	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	14/10/2015	English
207	Michael	Individual Submission	Dealing with dementia	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	14/10/2015	English
208	Chris	Individual Submission	Right to Die	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	14/10/2015	English
209	Flavianne	Individual Submission	Maintain the current law.	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	14/10/2015	English
1210		Not Dead Yet (USA)	Statement of Not Dead Yet (USA)	15-page paper with footnotes and references examines key issues, particularly those related to persons with disabilities, and offers recommendations to mitigate risks.	14/10/2015	English
211	Rosemary	Individual Submission	Stop Euthanasia	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	14/10/2015	English
212	Douglas	Individual Submission	Letter to Panel	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	15/10/2015	English

ID#	Submitted By	Organization	Title	Abstract	Submission Date (D-M-Y)	Language
213	Stephanie	Individual Submission	Protection of the Vulnerable	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	15/10/2015	English
214	Jessica McKeachie	The Salvation Army	Physician-Assisted Dying: The Salvation Army's Perspective	Position paper (bilingual) explains the principles behind the organization's position.	15/10/2015	Bilingual
215	Robert	Individual Submission	The woman who walked into the sea.	Personal comment references the book <i>The woman who walked into</i> the sea: Huntington's and the making of a genetic disease	15/10/2015	English
216	Sujandi	Individual Submission	Submission for Panal and Ministers	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	15/10/2015	English
217	Tina	Individual Submission	Euthanasia and Physician- Assisted Suicide.	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying and proposing varous safeguards.	16/10/2015	English
218	Neil Hilliard	End of Life Care, Fraser Health Authority	Submission to the External Panel on a Legislative Response to Carter v. Canada	Letter from the medical director of the Fraser Health Authority's End of Life Care Program, ostensibly representing the views of the Health Authority's Division of Palliative Medicine, provides a detailed examination of key issues from the perspective of palliative care.	16/10/2015	English
219	Rob Manning	Illness Strategies	Mercy Healing	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	16/10/2015	English
220	Betty-Anne	Individual Submission	Submission for Federal Panel on Physician Assisted Dying (October2015)	Informed personal comments on the issues of eligibility criteria, risks, and safeguards as outlined in the Panel's submission guidelines.	16/10/2015	English
221	Joelle Walker	Canadian Pharmacists Association	Role of pharmacists	Preliminary (prior to federal election and to consultation with Panel) position on key issues.	16/10/2015	English
222	· ·	Catholic Health Association of Saskatchewan	Letter from Catholic Health Association of Sask	Letter states organization's position on an appropriate response to the Supreme Court's decision.	16/10/2015	English
223	Pat	Individual Submission	Mercy	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	16/10/2015	English

ID#	Submitted By	Organization	Title	Abstract	Submission Date (D-M-Y)	Language
224	Adele	Individual Submission	Why has life become disposable?	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	16/10/2015	English
225	Douglas F	Indigene Community www.indigenec ommunity.info	'Indigene (Latin 'self- generating')-'Community' (L. 'com' = 'together' + 'munus' = 'gift-or-service') options for living	Discusses indigenous and colonial perspectives on healthcare and assisted dying.	17/10/2015	English
226	Bob	Individual Submission	why assist	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	17/10/2015	English
227	Carole	Individual Submission	Formal Submission on Assisted Suicide	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	17/10/2015	English
228	Pat Seed	Citizens With Disabilities – Ontario (CWDO)	CWDO Submission to the External Panel on Options for a Legislative Response to Carter v. Canada	Presents perspective of persons with disabilities on key issues, including definitions of terms, and risks and safeguards.	17/10/2015	English
229	Glen	Individual Submission	L'État qui tue	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	17/10/2015	Français
230	Kerry	Individual Submission	Direct Consultation: Physician Assisted-Dying in Canada	Informed personal comment describes safeguards and risks	17/10/2015	English
231	Jennifer Tong	A Network of BC Physicians	Submission to Panel	Calls for a "robust system of safeguardscarefully designed and monitoredto protect individual patient safety and public good." Also emphasizes the need for protection of the conscience rights of physicians	18/10/2015	English
232	Pierre	Individual Submission	lla décriminalisation de	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	18/10/2015	Français
233	Elizabeth	Individual Submission	Physician Assisted Suicide	Personal comment focuses on the issue of consent.	18/10/2015	English

ID#	Submitted By	Organization	Title	Abstract	Submission Date (D-M-Y)	Language
234	Catherine	Individual Submission	Respect, Goodwill and Freedom	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	18/10/2015	English
235	Linda	Individual Submission	When Does an Inch Become a Mile	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	18/10/2015	English
236	Doug Thomas	Secular Connexion Séculière	Key Issues For Non- believers Regarding Physician-assisted Dying in Canada	Proposes safeguards and considers ethical issues from a secular perspective.	18/10/2015	English
237	Susan	Individual Submission	Request To Die	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	18/10/2015	English
238	Richard Elliott	Canadian HIV/AIDS Legal Network	Carter Factum	The joint Factum of the Intervener in the <i>Carter</i> case of Canadian HIV/AIDS Legal Network and HIV/AIDS Legal Clinic Ontario.	19/10/2015	English
239		Canadian HIV/AIDS Legal Network	Submission to Provincial Panel	Emphasizes the importance of respecting patient autonomy in decision-making, of limiting waiting periods and requirements for contemporaneous consent, and for national standards and oversight.	19/10/2015	English
240	Clarice	Individual Submission	Letter to Panel	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	19/10/2015	English
241	Althea	Individual Submission	A Physician's Input to the Expert Panel's Consultation Process	Informed personal comments about physicians' role in palliative care, and describes risks and safeguards.	19/10/2015	English
242	Yaworski	Roman Catholic Diocese of Saskatoon	Submission from Bishop of RC Diocese of Saskatoon	Identifies some of the risks associated with physician-assisted dying.	19/10/2015	English
243	Johnny	Individual Submission	Protection of Physicians' Freedom of Conscience	Personal comment about potential impacts on physicians' conscience rights.	19/10/2015	English
244	Stanley	Individual Submission	Proposal for Criminal Code Reforms in Regard to Voluntary Death	A submission to a Senate Committee that appears to date from 1996.	19/10/2015	English

ID#	Submitted By	Organization	Title	Abstract	Submission Date (D-M-Y)	Language
245	Matthew	Individual Submission	Federal PAD Panel Submission	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	19/10/2015	English
246	Emma	Individual Submission	Better End of Life Care Not Doctor Assisted Suicide	Describes a personal experience with end-of-life care	19/10/2015	English
247	Anastasia Pearse	National Campus Life Network	Legalizing PAS is not in the Best Interest of Canadians	Submission identifies a number of perceived risks presented by PAD.	19/10/2015	English
248	Bruce	Individual Submission	Caution Urged	Describes risks and identifies safeguards.	19/10/2015	English
249	Eric	Individual Submission	Response to External Panel request for input on Assisted Death	Describes risks and identifies safeguards.	19/10/2015	English
250	Randy	Individual Submission	Love	A submission making use of numerous bible quotes to support beliefs regarding human suffering, euthanasia and assisted suicide.	19/10/2015	English
251	Natalie	Individual Submission	Incurrable pain - A Personal Account	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	19/10/2015	English
252	E. P.	Individual Submission	The primacy of individual choice in this matter	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying focuses on safeguards.	19/10/2015	English
253		Registered Nurses' Association of Ontario	RNAO Submission to the Expert Panel for a Legislative Response to Carter v. Canada	Paper outlines RNAO's position and presents a series of recommendations, including a multi-stage collaborative process to develop a regulatory framework.	19/10/2015	English
254	Derek	Individual Submission	•	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	19/10/2015	English

ID#	Submitted By	Organization	Title	Abstract	Submission Date (D-M-Y)	Language
255	and Dr. Rocco Gerace	College of Physicians and Surgeons of Ontario		Presents perceived risks and safeguards, and discusses the conscience rights of physicians and other health-care providers.	19/10/2015	English
256	James	Individual Submission	A personal post-Carter perspective	This comprehensive response includes a discussion of the conscience rights of health-care providers.	19/10/2015	English
257		The Centre for Israel and Jewish Affairs	CIJA Interim Position on Physician Assisted Dying in Canada	Paper discusses eligibility, risks, safeguards and the conscience rights of health-care providers.	20/10/2015	English
258	Andrew Neuner	The Health Quality Council of Alberta	HQCA - Consultation Response	Position is based on considerations of quality and safety, and on the organization's six dimensions of quality: acceptability, accessibility, appropriateness, effectiveness, efficiency and safety.	20/10/2015	English
259	Elizabeth M Davis, RSM	Roman Catholic Religious Leaders of Newfoundland and Labrador	The Dignity Of Each Human Person And The Pursuit Of The Common Good	Paper explores key issues, such as the definitions of "competent adults," "consent," and "grievous and irremediable."	20/10/2015	English
1260	Robert Piasentin	St. Thomas More Catholic Lawyers Guild of British Columbia	IPanel on Assisted Dving	Paper discusses eligibility, risks, safeguards and the conscience rights of health-care providers.	20/10/2015	English
261	Peter	Individual Submission	Should be considered	Submission from an individual indicating support for ARPA Canada's position on this issue and summarizing key points from ARPA's organization position on PAD	20/10/2015	English

ID#	Submitted By	Organization	Title	Abstract	Submission Date (D-M-Y)	Language
262	Anna Farrow	English Speaking Catholic Council	Brief submitted by English Speaking Catholic Council to the External Panel on Options for a Legislative Response to Carter v. Canada	Paper discusses risks, safeguards and the important of protecting conscience rights.	20/10/2015	English
263	Douglas	Individual Submission	A Wide View of Patients' Rights and Support for Conscientious Objection	Analysis of the Court's decision and possible responses to it, including a consideration of invoking the notwithstanding clause.	20/10/2015	English
264	James	Individual Submission	A Federal Legislative Response to Carter	Document was submitted with title only and no substantive content.	20/10/2015	English
265	Matthew	Individual Submission	For Our Young People and Principle	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	20/10/2015	English
266	A.	Individual Submission	Involuntary Assisted Dying in the Acutely III Elderly	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	20/10/2015	English
267	IGranovsky	Canadian Nurses Assocation	Brief for the Government of Canada's External Panel	Identifies importance of making information available to patients and their families, of protecting the liability of health-care providers, and of mitigating potential risks to health-care providers (e.g. increased burnout and moral distress).	20/10/2015	Bilingual
268	Monica Branigan	Canadian Society of Palliative Care Physicians	Submission to External Panel	Emphasizes the importance of adequate palliative care and the role that limited access to palliative care plays in demand for physician-assisted dying. Also calls for better training and increasing public awareness of death-related topics and nature of consent.	20/10/2015	English
269	Georges L'Espérance	Association québécoise pour le droit de mourir dans la dignité	Submission to Panel	Addresses definitions of key words and concepts, such as "medical assistance and euthanasia," and describes some of the risks likely to be incurred by individuals, health-care workers and society.	20/10/2015	Français

ID#	Submitted By	Organization	Title	Abstract	Submission Date (D-M-Y)	Language
270	IMoradhassel I	Canadian Medical Association	CMA Submission to the Federal External Panel on Options for a Legislative Response to Carter vs. Canada (Federal External Panel)	Presents results of consultations and posits 10 foundational principles and a series of recommendations. The submission emphasizes the need for a national legislative and regulatory framework, for protection of conscience rights for health-care workers, and for additional information and support for physicians and the general public facing end-of-life issues.	20/10/2015	Bilingual
271	Judith	Individual Submission	There Is No Mercy In Killing	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	20/10/2015	English
272	Simon	Individual Submission	Do no harm	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	20/10/2015	English
273	The Most Rev. Douglas Crosby, O.M.I.	Canadian Conference of Catholic Bishops	The Position of the Catholic Church and the Stance of the Catholic Bishops of Canada on 'The Giving of Assistance in Dying'	Paper explains the moral and spiritual roots of the Conference's position on relevant issues.	20/10/2015	English
274	John and Michele	Individual Submission	Concerned Citizens	Submission from an individual expressing a deeply held personal perspective on physician-assisted dying.	20/10/2015	English
275	Denise Page	Canadian Cancer Society	The Right to Care	Paper focuses largely on the accessibility of palliative care.	20/10/2015	English
276	Mei St-Cyr	Canadian Nurses Protective Society	Submission to Panel	Emphasizes the need for legislative protection for nurses who, in the normal course of carrying out their duties in accordance with the standard of practice of their profession, provide end-of-life care to patients or engage in discussions with patients about end-of-life options and wishes. Proposes draft legislation.	21/10/2015	English
277	Félix Couture	MedPASS	Defining Suffering	Report on legalities associated with physician-assisted dying examines specific issues, such as notion of "suffering," and considers ethical concerns, such as the right to life, liberty and security of the person. The report also explores the perspectives of patients and physicians, as well as the approaches used in other countries, and makes a series of recommendations about legislative solutions.	22/10/2015	English

ID#	Submitted By	Organization	Title	Abstract	Submission Date (D-M-Y)	Language
278	John Sikkema	Association for Reformed Political Action Canada	Draft Legislation - An Act to amend the Criminal Code in response to the Supreme Court of Canada decision in Carter	Draft legislation invoking the notwithstanding clause to strike down the ruling of the Supreme Court.	22/10/2015	English
279	John Sikkema	Association for Reformed Political Action Canada	Respectfully Submitted: Policy Report for Parliamentarians	Paper examines the ethics of euthanasia and the sanctity of life, and cites statistics from jurisdictions where physician-assisted dying is legal.	22/10/2015	English
1280		Individual Submission	Proposed amendment to the Criminal Code	Draft legislation stipulating that medical practitioners are not required to provide treatment when a patient competently requests non-treatment or cessation of treatment; and that a person can petition a superior court to permit the assistance of a physician to end that person's life.		English
281	André	Reformed	Stemming the Tide: How Parliament Must Mitigate the Harm of Assisted Suicide	Paper explains the legitimacy, in light of both the constitutional division of powers and Section 7 of the <i>Charter</i> as interpreted by the Supreme Court in <i>Carter v. Canada</i> , of comprehensive federal legislation imposing, monitoring and enforcing strict limits on physician-assisted dying.	24/10/2015	English
1282	Catherine Ferrier	Collectif des médecins contre l'euthanasie	Documents from the Collectif des médecins contre l'euthanasie	Presentation notes submitted by representatives of Collectif des médecins contre l'euthanasie from their direct consultation with the Panel in Montreal.	25/10/2015	English/Franç ais
283	Michael Shea	Catholic Health Alliance of Canada	Submission to External Panel	In advance of face-to-face meeting, the paper outlines a few recommendations, such as separating palliative care from physician-assisted dying and respecting the conscience rights of health-care workers.	26/10/2015	English

ID#	Submitted By	Organization	Title	Abstract	Submission Date (D-M-Y)	Language
284	Eike-Henner Kluge	Individual Submission	Euthanasia and Assisted Suicide: Ethical Considerations Touching Possible Amendments to the Criminal Code	Lengthy (39-page) considerations of exceptional cases involving various forms of PAD.	26/10/2015	English
285	Prof. Kathryn Church	Ryerson University School of Disability Studies	Carter vs. Canada External Review Panel Submission	Includes a series of recommendations, including an independent panel to review requests, and greater access to palliative care.	27/10/2015	English
286	Sean Murphy	Protection of Conscience Project	Submission to the (Federal) External Panel on Options for a Legislative Response to Carter v. Canada	Presentation on the relevant issues for physicians and health-care workers with conscientious objections to PAD.	29/10/2015	English
287	Denise	Individual Submission	Speech to the Senate	Speech during debate on Bill S-225 considers various aspects of the issues.	29/10/2015	English
288	David Albert Jones	Individual Submission	A Submission to the External Panel on Options for a Legislative Response to Carter v Canada	Paper considers legal frameworks, risk, consent issues, conscientious objection and PAD systems	30/10/2015	English
289		Individual Submission	Legalisation of assisted suicide: a safeguard to euthanasia?	An academic overview of the Supreme Court's ruling, and of the models and logic of laws that permit euthanasia in other countries.	30/10/2015	English
290	John Sikkema	Christian Legal Fellowship	Christian Legal Fellowship Written Submission to External Panel	Presents a legal analysis of the Supreme Court decision and response options.	30/10/2015	English
291	Ed Montigny	ARCH Disability Law Centre		The submission references consultations and focus groups hosted by ARCH as it responds to the particular questions and issues raised in the Expert Panel's template. Emphasizes the need for additional services (e.g. housing, palliative) particular for vulnerable people.	30/10/2015	English

ID#	Submitted By	Organization	Title	Abstract	Submission Date (D-M-Y)	Language
292	April D'Aubin	Manitoba League of Persons with Disabilities	Submission to Panel on Physician Assisted Death From The Manitoba League Of Persons With Disabilities November 1 2015	Submission calls for the establishment of a panel (modelled on Ontario's Consent and Capacity Panel) to review requests, along with a public reporting system that is monitored continually and informs future amendments.	01/11/2015	English
293	Dr. Louise Coulombe	Community Palliative Care Network	Physician Hastened Death: Complications	Flow chart examines the potential complications involved in completing the current procedures associated with euthanasia.	01/11/2015	English
294	Coulombe	Community Palliative Care Network	The Dying Process	Graphic illustrates and explains the stages leading to death.	01/11/2015	English
1295	II)r Louise	Community Palliative Care Network	Q&A	A series of questions and answers related to death, dying and end-of-life interventions.	01/11/2015	English
296	Karen	Individual Submission	Submission to the Panel on Physician-Assisted Dying	Personal letter from a family physician.	02/11/2015	English
297	Tina Head	Canadian Bar Association	Clarifying Law About End- of-Life Decision-Making	Includes resolutions to encourage provinces and territories to enact harmonized legislation with clear access to physician-assisted dying, safeguards for patients and health-care workers, and a system of oversight. Also calls on health-care regulatory bodies to develop appropriate standards of practice.	02/11/2015	English
298	Alex Schadenberg	Euthanasia Prevention Coalition	Submission to the External Panel	Examines other jurisdictions and calls for adequate legal oversight and objective criteria	02/11/2015	English
299	Eliza Chandler	Canadian Disabilities Studies Association	CDSAACEI Carter vs Canada Submission	"The decision to end one's life with medical assistance is only a real choice if made in a context of adequate home-care services, residential care, income support, palliative care, affordable and universal healthcare, and perhaps most importantly, in a culture that values differently embodied and minded individuals."	02/11/2015	English

ID#	Submitted By	Organization	Title	Abstract	Submission Date (D-M-Y)	Language
300		Canadian Pharmacists' Association	Submission to the External Panel	Presents the results of a survey of 1,000 pharmacists across Canada and examines the impacts on pharmacists in jurisdictions where physician-assisted dying is legal. Also describes relevant practice guidelines for Canadian pharmacists, such as meeting a patient's requirements for pharmaceuticals while respecting a pharmacist's right of conscience.		English
301	,	Canadian Psychiatric Association	Preliminary Remarks on Physician-Assisted Dying	Letter suggests that psychiatrists be involved only in cases where there is evidence of mental illness. Letter also calls for carefully consideration of terms such as "irremediable", and "intolerable and enduring suffering."	03/11/2015	English
302		Canadian Pharmacists' Association	Presentation to the External Panel	Slides to accompany presentation made to Panel. Presents the results of a survey of 1,000 pharmacists across Canada and examines the impacts on pharmacists in jurisdictions where physician-assisted dying is legal. Also describes relevant practice guidelines for Canadian pharmacists, such as meeting a patient's requirements for pharmaceuticals while respecting a pharmacist's right of conscience.	03/11/2015	English
303	Artem Safarov	College of Family Physicians of Canada	CFPC Survey of Members on PAD	Power-point presentation about the results of a members' survey.	04/11/2015	English
304	Artem Safarov	College of Family Physicians of Canada	Study of Family Medicine Curriculum	Study to inform medical curriculum planners measuring the impact of residents' previous exposure to family medicine on their future practice intentions.	04/11/2015	English
305	,	Christian Medical and Dental Society Canada	Response to Questions Posed by the External Panel on Options for a Legislative Response to Carter v. Canada	Expresses concerns about the inadequacy of current resources to support those facing end-of-life decisions (e.g. fee-for-service physicians are disincentivized, limited availability of expert counsellors, dearth of information). Also identifies risk of wrongful deaths, erosion of rights of disabled persons, and encourages the creation of protected spaces (e.g. hospitals, hospices) where euthanasia is not practiced.	04/11/2015	English

ID#	Submitted By	Organization	Title	Abstract	Submission Date (D-M-Y)	Language
306	l eong	Canadian Federation of Catholic Physicians' Societies	Academic Articles to Supplement Consultations with the Panel	Presents copies of studies conducted by outside groups pertaining to PAD in European countries.	04/11/2015	English
307	Bruce Clemenger	The Evangelical Fellowship of Canada	Submission to the External Panel	The submission considers some of the profound social, moral, and philosophical issues raised by PAD and offers optional responses to the Supreme Court's decision. The paper also lists potential safeguards.	05/11/2015	English
308	Christian Domenic Elia	Catholic Civil Rights League	Submission to the External Panel	Letter emphasizes the paramount importance of protecting the sanctity of life. Points out that while the Supreme Court ruling is based on the particular facts of the case presented, the direction to Parliament is for a law of general application.	05/11/2015	English
309	llean Echlin	The deVeber Institute for Bioethics and Social Research	It's Not That Simple: Euthanasia and Assisted Suicide Today	A book of more than 190 pages that explores the Supreme Court's decision, regimes in countries that permit physician-assisted dying and the legal and ethical issues facing the panel and Canada.	06/11/2015	English
310	Douglas A.	Federation of Medical Regulatory Authorities of Canada	Physician-Assisted Dying Guidance Document	Makes clear recommendations and provides foundational principles that should inform a legislative solution. Calls for specific safeguards, including: assessment by a second physician, adequate documentation, involvement of qualified physicians, informed consent of patient.	06/11/2015	English
311	Bryan Saite	College of Physicians and Surgeons of Saskatchewan	Position of the College of Physicians and Surgeons of Saskatchewan in Relation to Physician-Assisted Dying	This position statement calls for a national oversight body, a consistent approach across Canada, a second assessment and additional training for physicians. Calls for legislation to clarify age of consent, liability issues for health-care workers and what constitutes a "grievous and irremediable condition."	06/11/2015	English

ID#	Submitted By	Organization	Title	Abstract	Submission Date (D-M-Y)	Language
312	Meagan Hatch	Canadian Psychological Association	Canadian Psychological Association Submission to the External Panel	Paper references the Canadian Medical Association definitions for euthanasia, medical aid in dying, and physician-assisted dying. Includes frank discussion of the so-called slippery-slope argument—that rigid qualification standards for access to physician-assisted dying would weaken over time.	06/11/2015	English
313		Canadian Association for Spiritual Care	A Submission to the External Panel on Options for a Legislative Response to Carter v Canada	Presents ethical considerations on a few points related to the Supreme Court's decision.	09/11/2015	English
314	Alana Cormier	Canadian Federation of Catholic Physicians' Societies	Submission in Response to Questions Raised during the CFCPS Presentation to the External Panel on Options for a Legislative Response to Carter v. Canada (November 4, 2015)	Letter addresses specific points about incarcerated individuals and physician-assisted dying.	17/11/2015	English
315	Alex Schadenberg	Euthanasia Prevention Coalition	Government Committee Document for Distribution	Paper examines the PAD regimes of other jurisdictions and identifies weaknesses.	18/11/2015	English
316	Cara Faith Zwibel	Canadian Civil Liberties Association	Draft Position Paper: Physician Assisted Dying	Draft position paper discussing guiding principles to inform approaches to PAD, the respective roles of federal and provincial/territorial governments, and the use of appropriate safeguards/eligibility criteria in striking a balance between personal autonomy and the protection of vulnerable individuals.	27/11/2015	English
317	David Baker	BakerLaw	Federal and Provincial Responsibilities to Implement Physician Assisted Suicide	Forthcoming article on a legislative regime for physician-assisted dying shared with the Panel before initial publication.	27/11/2015	English

### **Annex G**

ID#	Submitted By	Organization	Title	Abstract	Submission Date (D-M-Y)	Language
318		The Centre for Israel and Jewish Affairs	CIJA Submission to the External Panel on Options for a Legislative Response to Carter v. Canada	Position paper acknowledges range of opinions and calls for specific safeguards, including those for health-care workers with conscientious objections.	01/12/2015	English
319	Silvan Luley	Dignitas	How Dignitas safeguards the quality of life through comprehesive and openoutcome counselling	Presentation describes Dignitas and its operations, and claims that its existence reflects the failure of judicial and medical systems to meet the needs of citizens. The presentation emphasizes the need to disseminate clear information about end-of-life issues.	07/12/2015	English
320	Silvan Luley	Dignitas	Notes for the Panel by Dignitas	Traces the roots of the organization, describes the procedures it follows, along with systemic safeguards. The paper repeats much of the content from the previous presentation and also refutes several of the specific criticisms of PAD regimes, including the slippery-slope argument.	07/12/2015	English
321	Silvan Luley	Dignitas	How Dignitas Works	Provides a detailed description of Dignitas' processes to assist people with end-of-life issues, including the multiple reviews and other steps involved in accessing PAD. Also explains the organization's ethical and philosophical framework, and its commitment to educating people—both in Switzerland and abroad—about their options and how to access them.	07/12/2015	Bilingual





## **Annex H**

# **Chronology of Key External Panel Activities**



15 December 2015





## **Chronology of Key External Panel Activities**

**December 15, 2015** - the Panel's report is submitted to the Minister of Justice and Attorney General of Canada, the Honourable Jody Wilson-Raybould and the Minister of Health, the Honourable Jane Philpott.

**November 9 – December 14, 2015** – Preparation of final report summarizing results and key findings from Panel consultations.

**October 20 – November 6, 2015** – Direct consultations held with 92 representatives from 46 organizations and groups of interveners in the Carter v. Canada case, medical regulatory authorities and stakeholders.

**October 7, 2015** - News release - Federal Panel Studies U.S. Approach to Physician-Assisted Dying.

**October 1 - 3, 2015** - Federal Panel undertakes study tour to gain insight into assisted dying practices in Oregon, United States.

**September 21, 2015** – News release - Federal Panel gains insight into assisted dying practices in European countries.

**September 4, 2015** - News release - Federal Panel on Physician-Assisted Dying begins a European study tour.

**August 30 - September 9, 2015** – Federal Panel undertakes study tour to gain insight into assisted dying practices in European countries.

**August 28, 2015** - News release announcing launch of online questionnaire - the 'Issue Book' - giving Canadians an opportunity to voice their views and concerns on how physician-assisted dying will be implemented in Canada.

**August 28, 2015** - Panel member Dr. Catherine Frazee meets with Dianne Pothier, Professor Emeritus in the Faculty of Law at Dalhousie, Steven Estey, Human Rights Officer for Disabled Peoples International, and Anna MacQuarrie, Human Rights Officer for Inclusion International.

**August 26-27, 2015** – Second in-person working session in Halifax to plan the Panel's European study tour.

**August 20, 2015** – Panel member Dr. Harvey Max Chochinov meets with Dr. Mary Shariff, Professor in the Faculty of Law at University of Manitoba.



# External Panel on Options for a Legislative Response to *Carter v. Canada* Comité externe sur les options de réponse législative à *Carter c. Canada*



**August 10, 2015 and ongoing** – Submissions and comments received through the website are reviewed and the Panel undertakes ongoing research and meetings with subject-matter experts to further inform their work and prepare for in-person consultations, scheduled to resume following the federal election.

**August 4, 2015** - The Panel's web site (www.ep-ce.ca) continues to receive submissions and comments from interested stakeholders and Canadians. Research and development of the online consultation tool is ongoing.

**August 2nd, 2015** – The federal election is announced and the Panel suspends direct consultations with interveners in the *Carter v. Canada* case and relevant medical authorities, during the election period. Direct consultations are scheduled to resume, as soon as practical, following the election on October 19th, 2015.

**July 31st, 2015** – Invitations are sent to interveners in the *Carter v. Canada* case and relevant medical authorities. The Panel is looking forward to engaging them in consultations.

**July 29th, 2015** –At the invitation of the Chair, the Panel met with two independent experts: Jocelyn Downie, a Professor in the Faculties of Law and Medicine at Dalhousie University and a member of the faculty of the Dalhousie Health Law Institute and Dr. Susan Sherwin, Research Professor Emerita, Department of Philosophy and Department of Gender and Women's Studies, Dalhousie University, Halifax, Nova Scotia.

**July 27th-28th, 2015** – First working session and substantive discussions by panel members in Halifax on how best to deliver on their mandate.

**July 21th, 2015** – Courtesy briefings by officials from the Departments of Justice and Health in Ottawa.

July 20th, 2015 – First introductory meeting of panel members in Ottawa.

**July 17th, 2015** - Government of Canada Establishes External Panel on options for a legislative response to *Carter v. Canada*.





External Panel on Options for a Legislative Response to *Carter v. Canada* Comité externe sur les options de réponse législative à *Carter c. Canada* 



# Media Analysis Sep. 2014 – Nov. 2015



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## **Executive summary**

- There were 8,939 media items that appeared on assisted dying in Canada from September 1, 2014 through November 22, 2015, with a combined circulation of 654,236,718.
- While there were a number of broadcast interviews conducted on the issue, they are not reflected in this report.
- Thirty-five per cent of all articles were published in February 2015, driven by the Supreme Court's ruling on assisted dying. Much of the coverage included reactions from politicians and interest groups.
- A small peak in October 2014 occurred as the Supreme Court was set to hear challenges to the ban on assisted dying, while the formation of the expert panel caused a sustained peak in coverage from August through September 2015.
- While coverage was primarily neutral across the board, opinions were more split around the issue of assisted dying itself.
- Overall, opinions on the panel were 90 per cent neutral, while opinions on assisted dying were 53 per cent neutral.
- Two outlets *National Post* and the *Ottawa Citizen* had both their print and online editions in the list of top ten most prolific outlets.
- Top journalist Sharon Kirkey of Postmedia News had more than four times the articles of the No. 2 journalist, Michael Den Tandt of the Ottawa Citizen.
   Ms. Kirkey wrote widely on the assisted dying issue, with her articles syndicated across Postmedia publications.

# Methodology

### **Objective**

This report offers an examination of media coverage of assisted dying between September 2014 and November 2015, inclusive.

#### Content

Articles pertaining to assisted dying were collected from online and print media sources using MediaMiser's news monitoring modules.

#### Tone

A sample of articles was manually toned for opinions presented on assisted dying, as well as opinions on the external panel and consultation process.

The following rating scale was used:

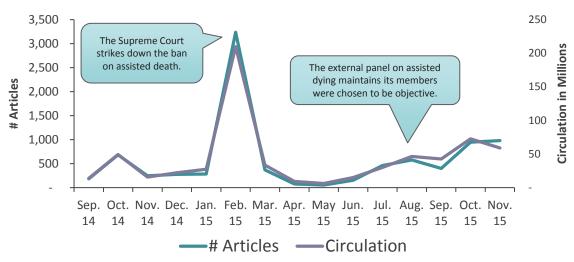
**Added point**: Article is supportive of or in favour of assisted dying, the consultation process, or panel members.

**Loss of Point**: Article is critical of or against assisted dying, the consultation process, or panel members.

**Neutral**: Article is purely factual, with no opinion presented.

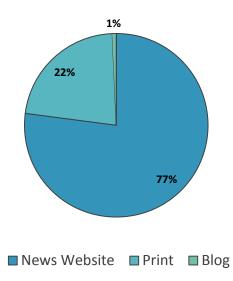
### **Coverage trend**

Articles: 8,939 Circulation: 654,236,718



- Over the nearly-fifteen months, there were 8,939 media items that appeared on assisted dying in Canada with a total circulation of 654,236,718. Of these, 35 per cent were published in the peak period of February 2015. Smaller peaks were also seen in October 2014 and August through November 2015.
- The February 2015 peak was driven by the Supreme Court's ruling on assisted dying, and comprised reactions from politicians and interest groups, including calls for open discussion on the topic ("Nova

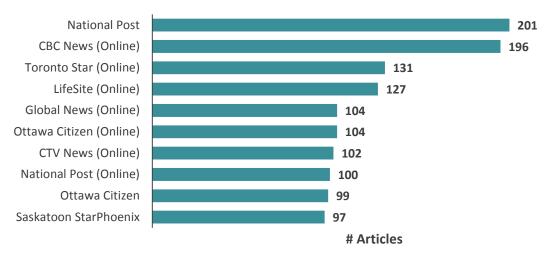
### **Publication types**



Scotia Premier Stephen McNeil wants national discussion on doctor assisted death" in *CTV News (Online)*, Feb. 12, 2015) and denunciation of the decision ("Assisted suicide testifies to a society that has grown cold" in the *Western Catholic Reporter (Online)*, Feb. 17, 2015).

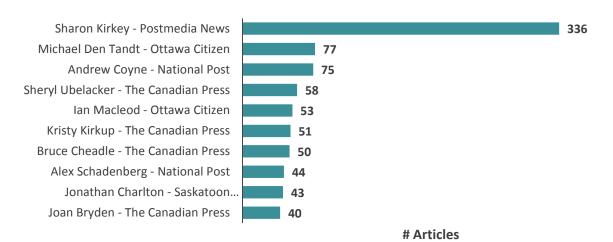
- The small peak in October 2014 came as the Supreme Court was set to hear challenges to the ban on assisted dying ("Suicide assisté - La "patate chaude" entre les mains de la Cour supreme" in Le Devoir, Oct. 1, 2014).
- The continuous peak from August through September 2015 follows the formation of the expert panel, and questions of the panel's independence ("Federal assisted-death panel defends independence as group travels to Europe" in the Penticton Herald (Online), Aug. 31, 2015).

### **Top outlets**

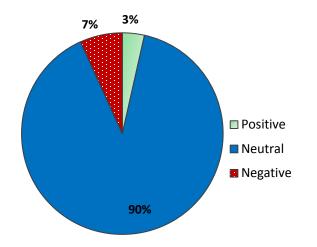


- Two outlets *National Post* and the *Ottawa Citizen* had both their print and online editions in the top ten.
- The No. 4 outlet, LifeSite (Online), was the only online outlet not connected to another news source.
- Top journalist Sharon Kirkey of *Postmedia News* had more than four times the articles of the No. 2 journalist, Michael Den Tandt of the *Ottawa Citizen*. Ms. Kirkey wrote widely on the assisted dying issue, with her articles syndicated across Postmedia publications.

### **Top journalists**



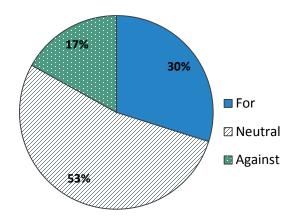
### Chart #1 - Opinions on the panel and consultation process



**Positive:** Supportive of the consultation process or panel members **Negative:** Critical of the consultation process or panel members

- While coverage was primarily neutral across the board, opinions were more split around the issue of assisted dying itself.
- Overall, opinions of the panel were 90 per cent neutral.
- Opinions on assisted dying were 53 per cent neutral, and just under one-third in favor. (Pie-Chart #2)
- Examples of articles both for and against assisted dying are presented below. The following pages will examine by month opinions on both assisted dying and the panel.

### Chart #2 - Opinions on assisted dying



**For:** Supportive or in favour of assisted dying **Against:** Critical of or against assisted dying

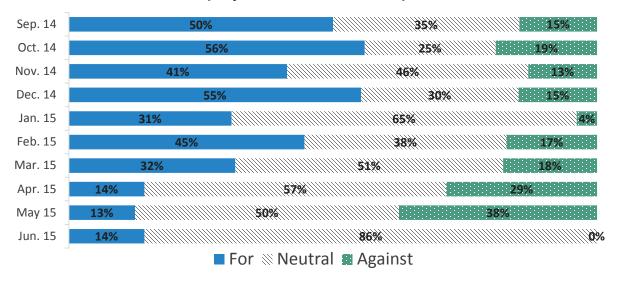
#### **Coverage for:**

- "B.C. woman wants to be first in Canada to receive doctor-assisted death" in the Sudbury Star (Online), February 11, 2015
- "Steven Fletcher: We need physicianassisted death and palliative care" in the Vancouver Province, June 6, 2015

#### **Coverage against:**

- "Margaret Somerville: Rejecting euthanasia and respecting the secular spirit" in the National Post (Online), October 27, 2014
- "Doctor-assisted suicide: Who does the killing?" in the Vancouver Sun (Online), February 10, 2015

# Opinions expressed in media coverage on assisted dying (Sep. 2014 – Jun. 2015)



**Note**: Articles appearing in this section were selected to give examples of the most prominent articles for the month, with attention paid to non-neutral stories. In months with a particularly large percentage for or against, articles were chosen to give examples of coverage that led to this percentage.

#### September 2014

- Sara Fox, the daughter of a B.C. woman who wrote a public letter before taking her own life, spoke in favour of assisted dying in a widely syndicated article. "Certainly, assisted suicide doesn't lead to more deaths. We're all going to die anyway," she said. "It doesn't lead to more deaths but it could lead to less suffering," ("'Ethically, this seems to me the right thing to do': Wrenching suicide of B.C. woman with dementia spurs euthanasia debate ", in the National Post (Online), Sep. 1, 2014).
- In a column in the *Hamilton Spectator*, Daniel Opperwall wrote against assisted dying, writing "Advocates of euthanasia are compassionate people, but they've missed something: there is meaning in suffering. No human life, however agonized, is devoid of significance," ("There is meaning in suffering" in the *Hamilton Spectator (Online)*, Sep. 20, 2014).

#### October 2014

- October had the largest proportion of articles in favour of assisted dying, with advocates speaking up as the Supreme Court heard challenges to the ban.
- At a rally held in Edmonton, Al Hancock, a spokesperson for Dying With Dignity Canada, spoke of his mother's death: "The end of life doesn't have to be terrible, it can be beautiful if you are given that choice. My mother would have been horrified to see the way she died," ("I have to have some options': Advocates march for death with dignity" in the *Calgary Herald (Online)*, Oct. 15, 2014).

Those speaking before the Supreme Court panel were quoted in articles, including lead lawyer for the
appellants Joseph Arvay: "Assisted dying should only be allowed in the most serious cases and not just
because somebody wants to; it's because their condition is not going to get any better," (Supreme
Court confronts right-to-die question" in Metro News (Online), Oct. 15, 2015).

#### November 2014

• November 2014 saw coverage of MP Steven Fletcher's personal stake in the assisted dying debate. Fletcher refuted the idea that right-to-die legislation would devalue the lives of the disabled: "I'm disabled. I'm as disabled as you can get. But I don't think my life is going to be in any way diminished because, in the hospital down the street, there's less suffering," ("Steven Fletcher's Mission; MP's push for legislation on right to die is deeply personal" in the *Montreal Gazette*, Nov. 22, 2014).

#### December 2014

December 2014 coverage was 55 per cent in favour of assisted dying, with coverage of a poll by Angus
Reid Institute that said Canadians support the issue: "Of all the controversial issues you could name, this
is the least controversial," said Arthur Schafer, director of the Centre for Professional and Applied Ethics
at the University of Manitoba, ("Canadians support assisted dying, poll finds" in the Montreal Gazette,
Dec. 17, 2014).

#### January 2015

• Leading up to the Supreme Court ruling, the *National Post*'s series "Exit Strategies" quoted Alain Berard, who has ALS, on assisted dying: "I consider it as an option, like a feeding tube, or a tracheostomy. It's like a treatment for the end of life, when the illness is too difficult to cope with. When you say, you know what? I've had enough. I don't want to do this anymore," ("Exit strategy: 'They want a promise from their doctor, that when they don't want to live, they can stop living" in the *National Post*, Jan. 24, 2015).

#### February 2015

February coverage was filled with reaction to the Supreme Court ruling, and the deadline for legislation:
 "We don't legislate to regulate how doctors withdraw life-saving treatment. Why must we legislate to
 regulate how they administer suicide?" said law professor Amir Attaran in an article debating the issue
 ("No need for suicide legislation: academics" in the National Post, Feb. 27, 2015).

• Lawyer André Schutten came down firmly against assisted dying, writing, "When it comes to the right to life, a substantially minimized risk is an unacceptable risk. Innocent people will die and the state will be complicit in their deaths" ("André Schutten: Thanks to the SCC ruling, the state will be complicit in murder" in the *National Post*, Feb. 10, 2015).

#### **March 2015**

Following the Supreme Court ruling, Dr. Chris Pengilly wrote a column in favour of the decision, writing,
 "The advantages of this legislation are simple but immense. It will give control, and hence peace of
 mind, to patients who are facing progressive illness and helplessness when they know that they are able
 to end it if and when they feel ready," ("With safeguards, assisted suicide works" in the Victoria Times Colonist, Mar. 20, 2015).

#### **April 2015**

A syndicated article looked at some of the issues around training doctors in assisted dying: "There will
be many complexities to this – it's not going to be a simple process – and whatever we teach our
medical students will have to be congruent with the legal parameters," said Dr. Richard Reznick, dean of
the faculty of health sciences at Queen's University ("Canadian medical schools tackle assisted suicide"
in the Calgary Herald, Apr. 2, 2015).

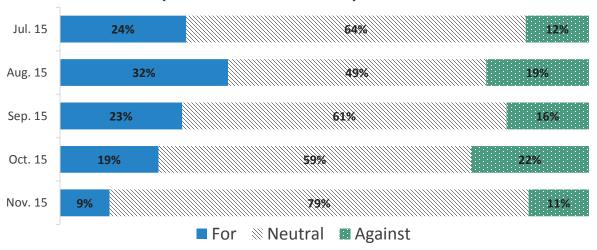
#### May 2015

May had the largest proportion of coverage against assisted dying, but relatively few media items
overall. The largest story was a private members motion allowing MPs to vote freely on matters of
conscience, which brought up the assisted suicide debate. MP Ed Komarnicki introduced the motion,
saying "There are issues of conscience, Supreme Court of Canada decisions, that deal with matters that
are difficult and people have differences of views and differences of opinions on that," ("Upcoming
right-to-die legislation prompts MPs to consider their voting rights" in the Ottawa Citizen (Online), May
28, 2015).

#### June 2015

June saw the federal government put forward the possibility of an extension on the legislative deadline.
 "The legislative time frame to present a bill, to have it go through Parliament, and be seriously debated in Parliament at all its stages, I think would take us well beyond that February date," said Justice Minister Peter MacKay ("Assisted suicide response needs more time" in *Metro News (Online)*, Jun. 16, 2015).

# Opinions expressed in media coverage on assisted dying (Jul. 2015 – Nov. 2015)



#### **July 2015**

July saw the formation of an expert panel to advise the government. Articles about the panel were usually neutral on assisted dying itself, though some affirmed the need to uphold the court's decision: "Whatever advice this panel might provide, it is clear that Parliament must not enact a law that creates barriers for those who wish to access their constitutional right to physician-assisted dying," said Josh Paterson of the B.C. Civil Liberties Association ("Harper government finally launches long-promised consultation on assisted dying" in Canoe Inc., Jul. 18, 2015).

#### August 2015

- The Panel's questionnaire on assisted dying was accused of bias by Wanda Morris, Chief Executive of Dying With Dignity and supporters of the organization: "The federal government has moved from inaction to obstruction," she said. "The questions are clearly designed not to elicit information, but to manufacture fear," ("Rights group decries federal survey on assisted suicide" in *The Globe and Mail*, Aug. 29, 2015).
- The Canadian Medical Association released a summary of online consultation with doctors showing many objections to assisting death, and proposed objecting doctors refer patients to a third party: "A lot of the physicians who oppose this find (referral) absolutely unacceptable," CMA president Dr. Chris Simpson said. But, "we're trying to respect and advocate for everybody's point of view here," ("Assisted death an ethical minefield for doctors" in the *Regina Leader-Post*, Aug. 19, 2015).

#### September 2015

The Assembly of Catholic Bishops in Quebec, opposed to assisted dying, released a document to guide
the faithful: "Pourrait-il y avoir d'autres raisons pour lesquelles on voudrait avoir une loi comme ça au
Québec? Est-ce que la seule raison, c'est vraiment pour soulager les patients?" said Cardinal Cyprien
Lacroix ("Les évêques veulent contrer l'aide médicale à mourir" in La Tribune (Sherbrooke), Sep. 30,
2015).

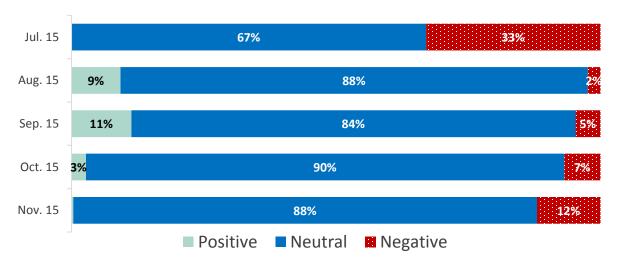
#### October 2015

• After the federal election, religious leaders joined in urging Justin Trudeau to put legislation in place: "On the basis of our respective traditions and beliefs, we insist that any action intended to end human life is morally and ethically wrong," the group said in a joint statement ("Faith group urges palliative care over assisted suicide" in the *Ottawa Citizen*, Oct. 20, 2015).

#### November 2015

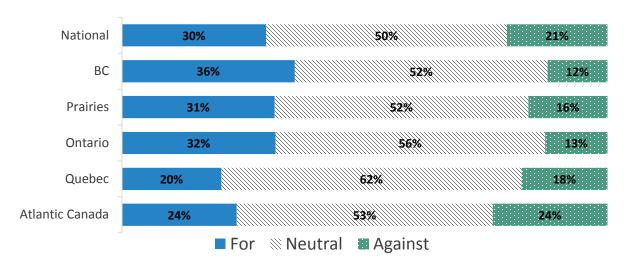
- The Coalition of Physicians for Social Justice in Quebec want to bring further arguments before the Quebec Superior Court to contest the end-of-life care law. Paul Saba says medical aid in dying isn't a health service: "As a doctor, I can't accept something that is non-medical, non-scientific. It even goes against my code of ethics in Quebec. Under the code of ethics, if we have treatments to offer or an operation, we must always use the least dangerous," ("Doctors to contest end-of-life legislation in court" in the *Montreal Gazette*, Nov. 6, 2015).
- In preparation for the upcoming legislation on assisted dying, Saskatchewan's College of Physicians and Surgeons adopted a new policy on the matter: "We all have to make sure we get it right, because as early as Feb. 6, you may have somebody asking you for this service that you really need to know how to handle," said Saskatchewan Medical Association president Mark Brown ("Sask. docs set policy on assisted death" in the Saskatoon StarPhoenix, Nov. 21, 2015).

### Opinions on the panel and consultation process (Jul. 2015 – Nov. 2015)



- Opinions on the expert panel were neutral on average, with only July seeing neutral articles drop to less than 80 per cent.
- September 2015 had the largest proportion of positive articles, with articles about the panel's fact-finding trip to Europe ("Canadian panel looking at assisted dying learns much from European experience" in the *Hamilton Spectator (Online)*, Sep. 21, 2015).
- July 2015 had the largest proportion of negative coverage, after the newly formed panel was met with accusations of bias ("Ottawa stacks assisted-dying panel" in the *Victoria Times-Colonist*, Jul. 13, 2015).
   Justice Minister Peter MacKay also assured Canadians that the panel's findings wouldn't be necessarily binding to the government ("Panel won't dictate response: MacKay" in the *Hamilton Spectator*, Jul. 23, 2015).

### Opinions expressed in media coverage on assisted dying by region



### Assisted dying coverage by region

 A majority of coverage across the provinces was on national issues, with syndicated articles about country-wide events, such as the initial hearing in front of the Supreme Court ("All eyes on Supreme Court this week as it hears assisted suicide appeal" in the Vancouver Province (Online), Oct. 13, 2014).

#### **British Columbia**

• B.C. had the largest proportion of coverage in favour of assisted dying, with local stories about the death of Gillian Bennet ("Dead at Noon: B.C. woman's public plea for assisted suicide spurs debate" in the *Penticton Herald (Online)*, Sep. 1, 2015). This story also ran in publications across the country.

#### **Prairies**

• Publications in the Prairies covered local doctors' expertise on the assisted-dying issue ("Sask. docs set policy on assisted death" in the *Saskatoon StarPhoenix*, Nov. 21, 2015), and local reactions to the repeal of the ban on doctor-assisted dying ("Edmonton reaction mixed to Supreme Court of Canada's decision to strike down the ban on assisted suicide in Canada" in the *Edmonton Sun (Online)*, Feb. 6, 2015).

# General coverage

#### Ontario

- In addition to wide coverage of the issue overall, local Ontario stories included cases of terminally ill patients taking their own lives held up as proof for the need of legislation ("'Devastated' MD sees need for an assisted-suicide law" in the Ottawa Citizen, Dec. 12, 2014).
- A number of Ontario publications also ran articles about the Registered Nurses' Association of Ontario's call for nurses to be consulted in developing laws around assisted dying ("Nurses' group wants say in assisted suicide legislation" in the Kingston Whig-Standard, Feb. 9, 2015).

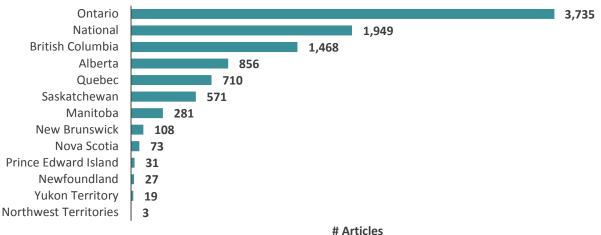
#### Quebec

Quebec had the largest proportion of neutral coverage, with discussions of implementation such as fees ("How much do you charge to help someone die?" in the Montreal Gazette, Oct. 7, 2015). Religious concerns also played a part in Quebec's coverage ("Les évêques veulent contrer l'aide médicale à mourir" in La Presse, Sep. 30, 2015).

#### **Atlantic Canada**

Atlantic Canada's coverage was the most balanced between for and against. Coverage included Nova Scotia's premier calling for mature discussion after the Supreme Court ruling in favour of assisted dying ("McNeil: Public should discuss assisted death" in the Halifax Chronicle-Herald, Feb. 1, 2015).

### **Top regions**



## **About MediaMiser**

#### **About MediaMiser:**

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