Assessing Vulnerability in a system for physician-assisted death in Canada

Issued By: The Canadian Association for Community Living

April 2016 (Revised)



Canadian Association for Community Living Association canadienne pour l'intégration communautaire

Diversity includes. On se ressemble.

Table of Contents

Introduction	.1
I. Core Concerns	.2
II. Criteria for Assessing Vulnerability among People Requesting Physician- Assisted Death	. 3
A. Suicidality more than a 'Well-Reasoned' Request	. 3
B. Predominance of Psychosocial Dimensions of Suffering	. 6
C. Evidence of Inducement and Coercion	10
1. Disordered insight and self-stigma	10
2. How coercion by others can motivate requests for PAD	12
3. How psychodynamics of the physician-patient relationship can motivate requests	14
D. Degree of Resilience	
E. Potential vs. Actual Vulnerability	
F. Towards a 'Vulnerability Lens' in Requests for PAD	
III. Key Issues in Implementing a Vulnerability Lens	
A. Incomplete and inconsistent statutory obligations for health care consent and to assure absence of coercion, inducement and undue influence	
B. Varying health profession guidelines for informed consent and response to vulnerable persons	23
C. Limitations of relying solely on physicians to assess vulnerability	25
D. Need for valid tools and comprehensive protocol to assess vulnerability	26
Summary	29
IV. Federal legislative requirements to implement a vulnerability lens	30
A. Criminal Code standard for informed consent	31
B. Criminal Code requirement for vulnerability assessment	31
C. Criminal Code requirement for prior review and determination by an independen authority	
Conclusion	35
Appendix A – Growing Vulnerability among Persons with Disabilities in Canada	37

List of Tables

Table 1: Illustration of the Accumulation of Potentiating Risk Factors and Warning	
Signs on Risk of Suicide	. 5
Table 2: Characteristics and End-of-life Care of 752 DWDA [Dying With Dignity Act]	
Patients who Died from Ingesting a Lethal Dose of Medication as of January 17, 2014,	
Oregon, 1998-2013	9
Table 3: Cases of coercion in physician-assisted suicide and euthanasia	13
Table 4: Inducement and Coercion in Dynamics of Patient-Physician Interactions in	
Requests for PAD	16
Table 5: Dynamics of Vulnerability to Inducement to Commit Suicide in Times of	
Weakness	9

Introduction

This report identifies criteria and approaches to assessing vulnerability that could help safeguard vulnerable persons in a system for physician-assisted death. It examines key issues in designing a pan-Canadian and consistent approach to safeguards, and recommends a federal legislative approach to addressing these issues. The report is intended to assist law- and policy-makers in designing safeguards, and to provide civil society organizations a resource to support their participation in the law reform process.

In *Carter v. Canada*¹ the Supreme Court recognized a constitutional right of Canadians to access physician-assisted death, where the person: 1) is an adult; 2) clearly consents to the termination of life; 3) 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; and, 4) is not vulnerable to being induced to commit suicide in a time of weakness.

The Court imposed the fourth criterion, recognizing that Parliament's objective to protect vulnerable persons is a "pressing and substantial" one. In doing so, the Court recognized vulnerable persons' constitutional right to protection of life in a system for physician-assisted death.² It also found that a "stringently limited, carefully monitored system of exceptions" would achieve the objective, but that it was Parliament's responsibility to design the system of safeguards.³ To recommend ways that Parliament can fulfill this responsibility, this report draws on a wide body of research literature and is divided into four main sections.

Section I outlines core concerns that motivate this report.

Section II reviews a large body of research to identify main criteria to assess vulnerability of persons requesting physician-assisted death. These criteria constitute five dimensions of a 'vulnerability lens' to guide review and authorization of requests.

Section III examines issues that would need to be addressed to implement a consistent vulnerability lens for physician-assisted death in the current health care context.

Section IV recommends a federal legislative approach to address these issues, through three main *Criminal Code* provisions.

¹ Carter v. Canada (Attorney General), 2015 SCC 5, [2015] 1 S.C.R. 331.

² A recent legal opinion on the *Carter* decision outlines the constitutional protections for vulnerable persons that the decision recognizes. See Dianne Pothier (2016), "The parameters of a Charter compliant response to *Carter v. Canada (Attorney General)*, 2015 SCC 5 (Social Science Research Network eLibrary, online: http://ssrn.com/abstract=2753167).

³ Carter v. Canada (Attorney General), 2015 SCC 5, [2015] 1 S.C.R. 331 at para. 29.

I. Core Concerns

The main concern prompting this report is that a growing group of vulnerable Canadians will die under the system for physician-assisted death (PAD) in Canada because of a lack of adequate safeguards. People could be vulnerable in two main ways:

1) using the system to commit suicide because they are suffering intolerably from conditions in their lives other than their medical condition, or that significantly compound the suffering their medical condition causes; and,

2) being given an assisted death when in fact their request was neither informed nor voluntary, but instead motivated either by disordered insight or by external inducements, undue influence or coercion sufficient to negate any superficial expression of consent to the termination of their life.

Research on how people become vulnerable in these ways is reviewed in this report. It points to many factors that can motivate suicidality or render people unable to give free and informed consent to terminate their lives, for example: the experience of stigma and social rejection associated with disability; the fear of growing dependence or burden on others; hopelessness caused by a mental health issue or clinical depression; social stigma and isolation; economic insecurity; victimization and domestic abuse; family and caregiver stress; coercion or inducement by a caregiver; and subtle and unconscious inducement that can operate in patient-physician decision-making processes.

In designing a system for physician-assisted death it is important to recognize that these factors are becoming more prevalent in Canadian society. Detailed in Appendix A, they include:

- increasing prevalence and severity of disability and multiple disadvantage;
- increasing prevalence of mental health difficulties and disability;
- lack of access to disability-related supports;
- growing burden of care of family and informal caregivers;
- gaps in palliative care up to 70%;
- high rates of poverty and labour force exclusion among people with disabilities;
- high rates of violence, abuse and insecurity for people with disabilities and seniors;
- barriers to health care access for people with intellectual and other disabilities, differential treatment and poorer outcomes;
- rapid increase in cases of dementia; and
- high rates of depression among seniors in residential care.

Because people may be vulnerable in these ways does not mean that by definition they should be precluded from accessing physician-assisted death. Clear criteria of vulnerability will be required to determine if a person requesting PAD is being induced to commit suicide in a time of weakness and if other measures should be taken to address their suffering.

II. Criteria for Assessing Vulnerability among People Requesting Physician-Assisted Death

Through the research review for this paper five criteria of vulnerability were identified to guide responding to and authorizing requests for PAD. These five criteria of vulnerability are:

- Indications of suicidality rather than a 'well-reasoned' request
- Predominance of psychosocial dimensions of suffering underlying the request
- Evidence of inducements, undue influence or coercion by others
- Low resilience to risk factors
- Evidence that the person is *actually* vulnerable, not only potentially vulnerable.

A. Suicidality more than a 'Well-Reasoned' Request

The trial decision in *Carter* provides a helpful place to begin defining criteria of vulnerability. The decision distinguished between: 1) "sound, rational and well reasoned"⁴ requests to die by patients at the end of life, and, 2) decision making about "suicide related to mental illness, substance use, impulsivity and other psychosocial factors"⁵ and "by persons who are mentally ill, or whose thinking processes are affected by substance abuse, trauma or other such factors."⁶ The Supreme Court adopted this distinction, and found that voluntary requests motivated by a capable reasoning process could be distinguished from requests motivated by suicidality.

While some research findings suggest this distinction may be clearer in theory than in practice⁷, the Supreme Court makes it a legal distinction in *Carter* and in so doing defines a core criterion of vulnerability in a system for PAD. A person is vulnerable where their request to die is motivated more by suicidal ideation than by a well-

⁴ *Carter v. Canada (Attorney General)*, 2012 BCSC 886, at para. 813.

⁵ Carter v. Canada (Attorney General), 2012 BCSC 886, at para. 813.

⁶ Carter v. Canada (Attorney General), 2012 BCSC 886, at para. 814.

⁷ Madelyn Hsiao-Rei Hicks (2006), "Physician-assisted suicide: a review of the literature concerning practical and clinical implications for UK doctors," *BMC Family Practice* (7:39, online: http://www.biomedcentral.com/ content/pdf/1471-2296-7-39.pdf).

reasoned request based on enduring and intolerable suffering caused by the medical condition.

What factors are associated with suicidality, as distinct from 'well-reasoning'? The American Psychiatric Association draws on extensive body of research evidence on risk factors to inform its practice guidelines for suicide prevention and treatment of suicidality.⁸ As well, the U.S. Joint Commission, which accredits almost 21,000 health care facilities and programs in the U.S, identifies risk factors based on event reports from health facilities:

The risk factors common across health care settings include having previously attempted suicide; recent suicide attempt; suicidal thoughts or behaviors; a family history of suicide or psychiatric illness; on antidepressants; physical health problems, including central nervous system disorders such as traumatic brain injury; diagnosis of delirium or dementia; chronic pain or intense acute pain; poor prognosis or prospect of certain death; social stressors such as financial strain, unemployment or loss of financial independence; disability; trauma; divorce or other relationship problems; hopelessness; and substance abuse. Substance abuse may also exacerbate psychological symptoms such as depression, and the disinhibitory effects of alcohol may contribute to impulsive suicidal behavior. Older adults are prone to additional suicide risk factors including declining health, loneliness and recent bereavement.⁹

A number of risk assessment tools have been developed to improve identification and assessment of suicide risk among patients in the health care system.¹⁰ For example, in response to growing concerns about suicide rates and hospitalization for suicidality, the Ontario Hospital Association and the Canadian Patient Safety Institute have developed a comprehensive framework to encourage standardized assessment within health care settings.¹¹ Drawing on an inventory and analysis of fifteen suicide risk assessment tools, the framework distinguishes between 'risk factors' and 'warning signs' to assist health professionals in identifying and responding to suicidal ideation and behaviour in patients (see **Table 1**).

⁸ American Psychiatric Association (2010), *Practice Guideline for the Assessment and Treatment of Patients with Suicidal Behaviours* (online: <u>http://psychiatryonline.org/pb/assets/raw/sitewide/practice_guidelines/guidelines/suicide.pdf</u>); and Michael Gliatto, K Anil and MD Rai (1999), "Evaluation and

Treatment of Patients with Suicidal Ideation," *American Family Physician* (59(6), p. 1500-1506. ⁹ The Joint Commission (2010), "The Joint Commission sentinel event alert: A follow-up report on preventing suicide: Focus on medical/surgical units and the emergency department" (Issue 46, online: http://www.jointcommission.org/assets/1/18/SEA_46.pdf).

¹⁰ R Giordano JF Stichler (2009), "Improving Suicide Risk Assessment in the Emergency Department," *Journal of Emergency Nursing* (35:22-6); For a list and links to resources on suicide prevention and protocols see for example "Practical Tools" published by the British Columbia Ministry of Children and Family Development (online: https://www.mcf.gov.bc.ca/suicide_prevention/practical_tools.htm).

¹¹ Ontario Hospital Association and Canadian Patient Safety Institute, *Suicide Risk Assessment Guide: A Resource for Health Care Organizations* (online:

https://www.oha.com/KnowledgeCentre/Documents/Final%20-%20Suicide%20Risk%20Assessment%20Guidebook.pdf).

Table 1: Risk Factors and Warning Signs on Risk of Suicide¹²

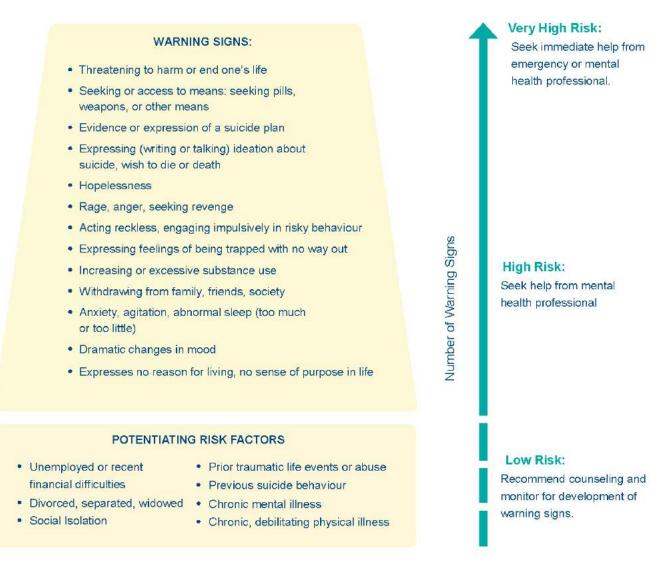


Table 1 Illustration of the Accumulation of Potentiating Risk Factors and Warning Signs on Risk of Suicide

<u>%20Suicide%20Risk%20Assessment%20Guidebook.pdf</u>). The table is adapted in that text from MD Rudd, AL Berman, TE Joiner, MK Nock, MM Silverman, M Mandrusiak, K Orden & T Witte (2006), "Warning signs for suicide: Theory, research, and clinical applications," *Suicide and Life Threatening Behaviour* (36, 255-62).

¹² This table is presented in: Ontario Hospital Association and Canadian Patient Safety Institute, *Suicide Risk Assessment Guide: A Resource for Health Care Organizations* (online: https://www.oha.com/KnowledgeCentre/Documents/Final%20-

Research indicates suicidal ideation and intent is also associated with: onset of physical disability through traumatic injury, long-term health condition or degenerative disease;¹³ intellectual disability when associated with other types of disability in persons with mild intellectual disability (many of whom would be able to consent to PAD); spinal cord injury; and multiple sclerosis.¹⁴

Co-presence of the factors in any particular case – for example, physical disability, plus major psychiatric syndrome, plus domestic violence, plus unmet socio-economic needs – increase the risk of suicidal ideation and intent. Even for patients who come into palliative care with a long history of disability, factors associated with their experience of prejudice, bias, disenfranchisement, and devaluation have been shown to increase their suffering and vulnerability.¹⁵

B. Predominance of Psychosocial Dimensions of Suffering

Research indicates that it is often psychosocial dimensions of suffering that are primary motivators for requesting PAD, in comparison to physical dimensions of suffering. This is another criterion of vulnerability. The trial decision in *Carter* distinguished psychosocial suffering in two ways:

- as a medical condition, in and of itself; and
- as a response to a grievous and irremediable end-of-life condition.¹⁶

Justice Smith concurred with evidence presented at the trial that it was "problematic to conflate decision-making by grievously and irremediably ill persons about the timing of their deaths, with decision-making about suicide by persons who are mentally ill, or whose thinking processes are affected by substance abuse, trauma or other such factors."¹⁷ This led to her conclusion that the term "grievously and irremediably ill persons" should not "incorporate reference to "psychosocial suffering"."¹⁸ The definition was not questioned or altered by the Supreme Court of Canada in its decision in *Carter*.

By definition, then, people whose cause of psychosocial suffering is itself a psychosocial condition, should be identified as being vulnerable to being induced to commit suicide in a time of weakness. Evidence drawn from psychological autopsies of

¹³ D Russell, RJ Turner and TE Joiner (2009), "Physical disability and suicidal ideation: a communitybased study of risk/protective factors for suicidal thoughts," *Suicide and Life-threatening Behaviour* (V. 39 (4), p. 440-451).

¹⁴ MJ Gianni, B Bermark, S Kreshover, E Elias, C Plummer and E O'Keefe (2010), "Understanding suicide and disability through three major disabling conditions: intellectual disability, spinal cord injury and multiple sclerosis," *Journal of Disability and Health* (3(2), p. 74-78).

¹⁵ D Stienstra and HM Chochinov (2006), "Vulnerability, Disability, and Palliative End-of-Life Care," *Journal of Palliative Care* (22, 3, Autumn).

¹⁶ Carter v. Canada (Attorney General), 2012 BCSC 886, at para. 813.

¹⁷ Carter v. Canada (Attorney General), 2012 BCSC 886, at para. 814.

¹⁸ Carter v. Canada (Attorney General), 2012 BCSC 886, at para. 1390.

suicide victims show consistently that almost 100% (varying in some studies between 93 and 98 percent) had psychiatric illness, with high rates of depression, chronic alcoholism or episodes of schizophrenia, acute anxiety or other features known as "axis I" diagnosis in multi-axial assessment of mental disorders.¹⁹

In jurisdictions which provide for psychological conditions as a criterion of eligibility for access to PAD, recent research suggests growing concerns about vulnerability. For example, findings published in February 2016 on voluntary euthanasia provided to 66 patients with psychiatric conditions under the system in the Netherlands²⁰ found that depressive disorders, post-traumatic stress disorder and anxiety disorder were prominent among the cases. Over 50% of those who were euthanized had prior suicide attempts, and 80% had been hospitalized previously for psychiatric conditions. Social isolation and loneliness were significant factors motivating the requests. Research evidence indicates that all these factors are amenable particularly to psychodynamic and psychoanalytic psychotherapies.²¹

The prevalence of these psychosocial factors in motivating requests for PAD, particularly those related to hopelessness, depression, and fears of being a burden and losing independence, are identified throughout the research literature as indicators of vulnerability that can be addressed by other courses of action. Concern about the caregiving burden on others, and fears of losing autonomy and a sense of dignity that one may associate with physical, communicative or cognitive independence are both very real, as the data shows. These fears can become overwhelming as functional capacities decline and caregiving needs increase. However, the suffering may be caused less by the medical condition itself than by lack of: caregiver supports; adaptive capacities that could yet be developed with personal and technological assistance; environmental accommodations to one's changing needs; and, community supports that

¹⁹ See, for example, DG Jacobs, ed. (1999), Harvard Medical School Guide to Suicide Assessment and Intervention (San Francisco: Jossey-Bass, pp 270–286); L Sher, MA Oquendo MA, and JJ Mann (2001), "Risk of suicide in mood disorders", Clinical Neuroscience Research (1:337–344).

 ²⁰ Scott Y.H. Kim, Raymond G. De Vries and John R. Peteert (2016) Éuthanasia and Assisted Suicide of Patients with Psychiatric Disorders in the Netherlands 2011 to 2014", *Journal of American Medical Association – Psychiatry* (Published online February 10, 2016).
 ²¹ See, for example, A Bateman and P Fonagy, (1999), "Effectiveness of partial hospitalization in the

²¹ See, for example, A Bateman and P Fonagy, (1999), "Effectiveness of partial hospitalization in the treatment of borderline personality disorder: a randomized controlled trial", *Am J Psychiatry* 156:1563–1569); A Bateman and P Fonagy (2001), "Treatment of borderline personality disorder with psychoanalytically oriented partial hospitalization: an 18-month follow-up", Am J Psychiatry (158:36–42); J Stevenson and R Meares, (1992) "An outcome study of psychotherapy for patients with borderline personality disorder", *Am J Psychiatry* (149:358–362); ES Paykel, J Scott, and JD Teasdale, AL Johnson, A Garland, R Moore, A Jenaway, PL Cornwall, H Hayhurst, R Abbott and M Pope (1999), "Prevention of relapse in residual depression by cognitive therapy: a controlled trial", *Arch Gen Psychiatry* (56:829–835). For a comprehensive review of the research literature on the impact of psychotherapies in reducing suicidal ideation and behaviour, see American Psychiatric Association (2010), *Practice Guideline for the Assessment and Treatment of Patients with Suicidal Behaviours* (online:

http://psychiatryonline.org/pb/assets/raw/sitewide/practice_guidelines/guidelines/suicide.pdf).

respond to growing dependence on others for certain forms of self-care. As discussed below, these interventions can boost a person's resilience to deal with changing circumstances.

In this regard, the National Cancer Institute of the U.S. National Institutes of Health recommends in-depth examination of four dimensions of suffering in response to requests for PAD: physical, psychological, social and spiritual suffering. It stresses the importance of attending to psychosocial and spiritual dimensions of suffering, particularly the fear of becoming a burden and losing independence:

Physical suffering, including pain, is a less-frequent motivator than many think. In one above-noted study, pain alone was a motivator in 3% of requests; pain was one of several motivators in 46% of requests; and in the remaining 51% of requests pain was not cited as a factor at all. Nonetheless, the contribution of physical suffering is important because it is often treatable... The fear of being a burden and losing independence are the most important correlates of a desire for hastened death, and are more distressing for many patients than physical symptoms. It remains crucial to address physical symptoms in cases of requests for hastened death, but in relative terms, the psychosocial aspect is more important.²²

A 2014 report on data gathered in Oregon system supports this conclusion about the relative importance of psychosocial aspects of suffering motivating requests. **Table 2** presents the findings on reasons for requesting physician-assisted suicide by patients who died from ingesting a lethal dose of medication, as authorized under the Oregon *Dying with Dignity Act.*²³ Over 90% of the748 patients for whom data is available indicate that "losing autonomy" was one of the concerns motivating the request, 50% about losing control of bodily functions, and 40% were concerned about the burden on family, friends/caregivers if they continued to live. This is in comparison to a much smaller proportion (23.7%) for whom inadequate pain control or concern about pain were among the reasons.

²³ See Oregon Public Health Division (2014). Oregon's Death with Dignity Act—2013 (Online: https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Doc uments/year16.pdf.

²² National Cancer Institute, *Education in Palliative and End-Of-Life Care for Oncology: Self-Study Module 14: Physician-Assisted Suicide* (Online: <u>http://www.cancer.gov/resources-</u> for/hp/education/epeco/self-study/module-14/module-14.pdf, p. 5).

Table 2. Characteristics and End-of-life Care of 752 DWDA [Dying With Dignity Act] Patients who Died from Ingesting a Lethal Dose of Medication as of January 17, 2014, Oregon, 1998-2013

Year	2013	1998-2012	Total
END OF LIFE CONCERNS:	(N=71)	(N=677)	(N=748)
Losing autonomy (%)	66 (93.0)	618 (91.3)	684 (91.4)
Less able to engage in activities making life enjoyable (%)	63 (88.7)	602 (88.9)	665 (88.9)
Loss of dignity (%)	52 (73.2)	452 (81.9)	504 (80.9)
Losing control of bodily functions (%)	26 (36.6)	350 (51.7)	376 (50.3)
Burden on family, friends/caregivers (%)	35 (49.3)	264 (39.0)	299 (40.0)
Inadequate pain control or concern about it (%)	20 (28.2)	157 (23.2)	177 (23.7)
Financial implications of treatment (%)	4 (5.6)	18 (2.7)	22 (2.9)

Table 1 Characteristics and End-of-life Care of 752 DWDA [Dying With Dignity Act] Patients who Died from Ingesting a Lethal Dose of Medication as of January 17, 2014, Oregon, 1998-2013

The Oregon data are not unique. Researchers suggest there is "woefully little evidence" supporting the popular notion that physical pain is the primary motivator for PAD, and that data point much more strongly to psychological stress and mental health conditions as primary factors:

It seems that many people imagine the circumstances that might drive them to want to "end it all," and excruciating pain comes to mind. This picture of terminally ill patients writhing in uncontrolled or even uncontrollable pain requesting euthanasia or PAS has dominated all discussions about whether euthanasia or PAS is ethical and should be legalized...

If not pain, then what motivates patient interest in euthanasia or PAS? Accumulating data support what might be called the depression thesis. Most, if not all, studies that have examined this question reveal that psychological distress, including depression and hopelessness, are significantly associated with patients' interest in hastening their own death through euthanasia and/or PAS.²⁴

A wide range of studies over the past fifteen years reach similar conclusions, finding for example that: "For people at the end of life, depression, hopelessness, and psychosocial distress are among the strongest correlates of desire for hastened

²⁴ Ezekiel J. Emanuel (2005), "Depression, Euthanasia, and Improving End-of-Life Care", *Journal of Clinical Oncology* (vol. 23 no. 27, 6456-6458).

death"²⁵, including findings that 80% of patients with cancer who commit suicide have a mood disorder.²⁶

In summary, the evidence suggests that where the reasons motivating the requests are primarily related to psychosocial suffering associated with unmet needs, there is a high risk that a person may be vulnerable to requesting PAD as a result of suicidal ideation and intent rather than a 'well-reasoned' request, which evidence suggests can only be made in the context of end-of-life conditions.

C. Evidence of Inducement and Coercion

In addition to research on factors that can motivate suicidality and on the psychosocial aspects of suffering that underlie requests for PAD, a growing body of findings show how dynamics of inducement and coercion can motivate adult requests. Three distinct but inter-related psychological dynamics of inducement and coercion are found in the research: 1) a patient's disordered insight and judgment caused by depression, hopelessness and/or self-stigma; 2) direct coercion by others; and 3) the psychodynamics of the physician-patient relationship. Each of these dynamics is discussed below.

1. Disordered insight and self-stigma

As evident from research cited in the preceding section, disordered insight resulting from hopelessness, depression or other mental health conditions can motivate requests

²⁵ Linda Ganzini, Elizabeth R Gov and Steven K Dobscha (2008), "Prevalence of depression and anxiety in patients requesting physicians' aid in dying: cross sectional survey" British Medical Journal (v. 337, 1682). For research cited on this finding, see EJ Emanuel (2005), "Depression, euthanasia, and improving end-of-life care" Journal of Clinical Oncology, (23:6456-8); KG Wilson, HM Chochinov CJ McPherson, MG Skirko, P Allard, S Chary, et al. (2007) "Desire for euthanasia or physician-assisted suicide in palliative cancer care", Health Psychology (26:314-23); B Rosenfeld, W Breitbart, C Gibson, M Kramer, A Tomarken, C Nelson, et al (2006) "Desire for hastened death among patients with advanced AIDS", Psychosomatics (47:504-12); JL Werth Jr. (2004) "The relationships among clinical depression, suicide, and other actions that may hasten death" Behavioural Science and the Law (22:627-49); HM Chochinov, KG Wilson, M Enns, N Mowchun, S Lander, M Levitt et al. (1995) "Desire for death in the terminally ill", American Journal of Psyhciatry (152:1185-91); K Blank; J Robison, E Doherty, H Prigerson, J Duffy, HI Schwartz (2001), "Life-sustaining treatment and assisted death choices in depressed older patients" Journal of American Geriatrics Society (49:153-61); W Breitbart, B Rosenfeld, H Pessin, M Kaim, J Funesti-Esch, M Galietta M, et al. (2000), "Depression, hopelessness, and desire for hastened death in terminally ill patients with cancer", Journal of American Medical Association (284:2907-11); EJ Emanuel, DL Fairclough, LL Emanuel (2000), "Attitudes and desires related to euthanasia and physicianassisted suicide among terminally ill patients and their caregivers", Journal of American Medical Association (284:2460-8).

²⁶ MM Henriksson, ET Isometsa, PS Hietanen, HM Aro, JK Lonnqvist (1995), "Mental disorders in cancer suicides", *Journal of Affective Disorders* (36:11-20). Cited in Linda Ganzini, Elizabeth R Goy and Steven K Dobscha (2008), "Prevalence of depression and anxiety in patients requesting physicians' aid in dying: cross sectional survey" *British Medical Journal* (v. 337, 1682).

for physician-assisted death. 'Disordered insight' refers to impairments in reasoning capacity that include inability to connect symptoms to one's illness, to understand the risks and benefits of treatment, or to make a treatment decision based on personal goals and values.²⁷ Insight disorders are associated with brain injury and a many psychiatric conditions. A large body of research also shows how depression tends to significantly impair a patient's medical decision making, with consistent findings across diverse cultural contexts. Research has shown that depression induces feelings of hopelessness, can magnify the experience of physical pain, and impair ability to cope and other functional abilities, all of which can undermine free and voluntary requests for physician-assisted death.²⁸

Hopelessness is another factor that can impair judgment, and it often occurs through the mechanism of self-stigma that can result when a person experiences disability-related discrimination and stigma from others.²⁹ Systematic research review has shown a strong negative relationship between levels of self-stigma and hopefulness, self-esteem and empowerment among people with mental illness.³⁰ The research suggests that stigma is internalized as self-stigma through a "regressive model" that begins with

²⁷ K. William M. Fulford (1998), "Completing Kraepelin's Psychopathology: Insight, Delusion, and the Phenomenology of illness," in Xavier F. Amador and Anthony S. David, eds. *Insight and Psychosis Insight and Psychosis: Awareness of Illness in Schizophrenia and Related Disorders* (Oxford: Oxford University Press).

²⁸ Marsha Garrison cites a number of studies which bear out this conclusion. See citations in Marsha Garrison (2007), "The Empire of Illness: Competence and Coercion in Health-care Decision Making", William and Mary Law Review (Volume 49, Issue 3, 781-843), including: G. Magni et al. (1994), "Prospective Study on the Relationship Between Depressive Symptoms and Chronic Musculoskeletal Pain", Pain (56); C. Dickens and F. Creed (2001), "The Burden of Depression in Patients with Rheumatoid Arthritis", Rheumatology (50, 1327); P.P. Katz and E.H. Yelin (1993), "Prevalence and Correlates of Depressive Symptoms Among Persons with Rheumatoid Arthritis", Journal of Rheumatology (20, 790); Daniel Weintraub et al. (2004), "Effect of Psychiatric and Other Nonmotor Symptoms on Disability in Parkinson's Disease", Journal of American Geriatrics Society (52, 784); N.J. Rubin (1993), "Severe Asthma and Depression," Archives of Family Medicine (2); Mark D. Sullivan (2003), "Hope and Hopelessness at the End of Life", American Journal of Geriatric Psychiatry (11, 393); Harvey Chochinov (2006), "Dying, Dignity, and New Horizons in Palliative, End.of-Life Care", CA: A Cancer Journal for Clinicians (56, 84); Aaron T. Beck et al. (1990), "Relationship Between Hopelessness and Ultimate Suicide: A Replication with Psychiatric Outpatients" American Journal of Psychiatry (147. 190); Aaron T. Beck et al. (1985) "Hopelessness and Eventual Suicide: A 10-Year Prospective Study of Patients Hospitalized with Suicidal Ideation", American Journal of Psychiatry (142, 559).

²⁹ See, for example, L Patterson, K McKenzie and B Lindsay (March 2012), "Stigma, social comparison and self-esteem in adults with an intellectual disability", Journal of Applied Research in Intellectual Disability (25(2):166-76); <u>A Ali, A Hassiotis, A Strydom and M. King (Nov-Dec 2012), "</u>Self stigma in people with intellectual disabilities and courtesy stigma in family carers: a systematic review", *Journal of Intellectual Disability Research* (33(6):2122-40); Elaine Brohan, Rodney Elgie, Norman Sartorius and Graham Thornicroft (2010), "Self-stigma, empowerment and perceived discrimination among people with schizophrenia in 14 European countries: The GAMIAN-Europe study", *Schizophrenia Research*(Volume 122, Issues 1-3:232-238).

³⁰ James D. Livingston, Jennifer E. Boyd (2010), "Correlates and consequences of internalized stigma for people living with mental illness: A systematic review and meta-analysis", *Social Science & Medicine* (Volume 71, Issue 12:2150-2161).

awareness of stigma toward oneself by others, and leads to self-application of the stigma, negative impact on self-esteem and self-efficacy, shame and selfdiscrimination.³¹

Because psychological conditions of disordered insight, depression, hopelessness and self-stigma can motivate requests to die, experts recommend there should be "provision for an exploration of the motivation in patients who make such a request"32 and consideration of other alternatives. In other words, these motivations are signs of vulnerability which should trigger further examination prior to approving a request.

2. How coercion by others can motivate requests for PAD

Research findings also raise concerns about direct coercion motivating requests for PAD. A review of actual cases demonstrates the validity of these concerns, including documentation of coercion in requests for physician-assisted death in both Oregon and Netherlands (see Table 3 for examples).

³¹ Patrick W. Corrigan, Benjamin G. Druss, and Deborah A. Perlick (2014), "The Impact of Mental Illness Stigma on Seeking and Participating in Mental Health Care", Psychological Science in the Public Interest (Vol. 15(2) 37–70). ³² Philip R. Muskin (1998), "The Request to Die; Role for a Psychodynamic Perspective on Physician-

Assisted Suicide" The Journal of the American Medical Association (279(4):323-328).

Table 3 – Cases of coercion in physician-assisted suicide and euthanasia³³

Case 1, Oregon: An 85-year-old cancer patient with worsening dementia requests PAS but her psychiatrist believes that she is being pressured by family. Nevertheless, she is then approved for PAS by a psychologist and receives assisted suicide.

Case 2, Oregon: Louise, who has a degenerative neurological disease, requests PAS. As her disease progresses, those in her network who support her suicide become increasingly anxious that she will become too mentally or physically incapacitated to act on her request. This includes her doctor, her mother, a friend who will be present at her suicide, and the Oregon Compassion in Dying PAS advocate who has arranged for a New York Times reporter to fly in and cover the suicide. Louise says she is almost ready but not quite. She wants a week to relax and be with her mother. On learning indirectly that her doctor thinks she will not be able to act if she waits, she appears startled. Her mother tells her, "It's OK to be afraid." She replies: "I'm not afraid. I just feel as if everyone is ganging up on me, pressuring me. I just want some time".

Case 3, The Netherlands: A wife who no longer wishes to care for her sick, elderly husband gives him a choice between euthanasia and admission to a nursing home. Afraid of being left to the mercy of strangers in an unfamiliar place, he chooses euthanasia. His doctor ends his life despite being aware that the request was coerced.

Case 4, The Netherlands: Cees requests euthanasia one month after being diagnosed with ALS (MND). As required, his request is assessed by the primary doctor who will carry out the euthanasia and by a consultant. During their assessments, both doctors allow Cees' apparently resentful wife to answer all the questions directed to him, even though his speech is still understandable and he can type on a computer. His ambivalence about euthanasia is expressed by repeatedly pushing the date back. It is also expressed by weeping in response to the doctor's pro forma question of whether Cees is sure he wants to go ahead with euthanasia. His wife quickly answers affirmatively for him and then tells the doctor to move away from Cees, saying it is better to let him cry alone. At no point does a doctor ask to talk with Cees alone before his euthanasia.

Table 2 Cases of coercion in physician-assisted suicide and euthanasia

³³ These cases are drawn from Madelyn Hsiao-Rei Hicks (2006), "Physician-assisted suicide: a review of the literature concerning practical and clinical implications for UK doctors," *BMC Family Practice* (7:39, online: <u>http://www.biomedcentral.com/ content/pdf/1471-2296-7-39.pdf</u>).

3. How psychodynamics of the physician-patient relationship can motivate requests

The research also indicates that "[r]equests for PAS and doctors' decisions to assist suicide can be influenced by coercion and by unconscious motivations in doctors, patients and caregivers."³⁴

The psychiatric literature points to ways the psychological dynamics of "transference and countertransference" can operate coercively between patient and physician in the context of requesting, considering and approving a request for PAD:

Transference and countertransference feelings are normal and can occur in any doctorpatient relationship. When these feelings heighten around emotionally intense issues, they can exert coercive pressure on clinical decision-making with an obligatory quality that is difficult to resist. Recognition is complicated by the frequent involvement of unacceptable feelings and urges that both doctor and patient wish to deny.³⁵

The U.S. National Cancer Institute stresses the importance of physicians having insight about how countertransference can operate in this encounter:

To respond effectively to the needs of the patient, the physician must be aware of his or her own biases and the potential for counter-transference. If the idea of suicide is offensive to the physician, the patient may feel his or her disapproval and worry about abandonment. Conversely, if the physician feels it would be best for everyone if the patient were to die soon, the patient may sense this and become more concerned about being an unwelcome burden.³⁶

Documented examples of how transference and countertransference, or unconscious motivations can operate on part of both the physician and the patient in the request process for PAD are presented in **Table 4**. For example, one study reporting on this dynamic states: "The patient's experience of the physician's guilt and the physician's unchallenged acquiescence to the patient's request to die confirm the patient's guilty experience of being bad and unworthy of the physician's healing power."³⁷ The research findings point to the need to be sensitive to the fact that the patient-physician relationship, the patient's psychological condition, and the patient's health care context

³⁴ Madelyn Hsiao-Rei Hicks (2006), "Physician-assisted suicide: a review of the literature concerning practical and clinical implications for UK doctors," *BMC Family Practice* (7:39, online: http://www.biomedcentral.com/ content/pdf/1471-2296-7-39.pdf).

³⁵ Madelyn Hsiao-Rei Hicks (2006), "Physician-assisted suicide: a review of the literature concerning practical and clinical implications for UK doctors," *BMC Family Practice* (7:39, online: http://www.biomedcentral.com/ content/pdf/1471-2296-7-39.pdf).

³⁶ National Cancer Institute, *Education In Palliative And End-Of-Life Care For Oncology: Self-Study Module 14: Physician-Assisted Suicide* (Online: <u>http://www.cancer.gov/resources-</u>for/hp/education/epeco/self-study/module-14/module-14.pdf).

³⁷ Philip R. Muskin (1998), "The Request to Die; Role for a Psychodynamic Perspective on Physician-Assisted Suicide" *The Journal of the American Medical Association* (279(4):323-328).

can influence the request. Moreover these influences can be, as the trial judge in *Carter* found, "subtle and exercised at an unconscious level."³⁸

This body of research raises very serious concerns about how such factors would be identified in a system where physicians undertake both the assessment of eligibility and the authorization of the request. The validity of these concerns is borne out by compelling evidence from the Netherlands. A survey of psychiatrists involved in consulting on requests for PAD in that country found that in their assessment issues of transference and countertransference influenced 25% of the requests in which they had provided psychiatric consultation. And in 19% of cases of PAD, it was authorized by physicians even though the psychiatrist had advised that issues of transference or countertransference appeared to be influencing the decision.³⁹

³⁸ Carter v. Canada (Attorney General), 2012 BCSC 886, at para. 815.

³⁹ JH Groenewoud, A van der Heide, AJ Tholen, WJ Schudel, MW Hengeveld, BD Onwuteaka-Philipsen, PJ van der Maas, and G van der Wal, (2004), " Psychiatric consultation with regard to requests for euthanasia or physician-assisted suicide" *General Hospital Psychiatry* (26:323-330).

Table 4 – Inducement and Coercion in Dynamics of Patient-Physician Interactions in Requests for PAD⁴⁰

Transference is when a patient relates to the doctor in a way that primarily replicates other important, usually parental, relationships. It frequently acts on an unconscious level to covertly affect the patient-doctor interaction. As a general example, patients may relate to the doctor as an omnipotent parental authority figure. Their communications and behaviour may express a wish for approval, a wish for comfort and restoration, fear of abandonment, or rage at perceived abandonment. In any suicidal patient, including the terminally ill, the request to die can be a plea for help or an attempt to be given a reason to live. A request for PAS can be an entreaty for the doctor's true feelings about the patient's value now that he is nearing death. One patient's request for euthanasia was described as *"the patient's way of 'testing' the medical team...to make sure they would not be abandoned. Moreover, as the patient had a difficult relationship with their family – who had asked for euthanasia to be carried out – this request enabled the patient to hear that they still had a certain value in the eyes of the medical team".*

Another example is that of Mr. C., a 72-year-old man with severe obstructive lung disease. This patient asked his doctor, "Can't you do something to just bring it to an end? ...Just put me out of my misery. It would save everyone a lot of trouble." His doctor replied rather awkwardly, "Even though you feel like a burden, I can't do that." Mr. C. asks, "Why not? You'd do it for your dog." His doctor answers, "Because you aren't a dog, Mr. C. You're my patient and I'm your doctor, and I'm trying to help you. And I'll keep trying to help you as long as I have to." Mr. C. took the doctor's hand in both of his and said, "Thank God. I thought everyone had given up on me".

Rene Diekstra, a pioneer of PAS in the Netherlands, described how some doctors coming before a committee that reviewed PAS cases were prematurely ready to provide PAS when feelings of helplessness about the patient's condition influenced them to overestimate the rationality or inevitability of the patient's suicide. Fear of inadequacy and of abandoning patients by denying the PAS request can be observed in... interviews with Oregon doctors. One doctor favorable to PAS said, "...I think I would just feel really uncomfortable if I couldn't help". Whether or not a doctor chooses to provide PAS, the patient's request for PAS can be perceived as a rejection or a condemnation of the doctor's inadequacy. As one doctor said, "It's almost as if your treatments and attempts to make the patient comfortable have been a complete failure if they're going to ask for that". And another: "I feel like there's something with physician assisted suicide, personally, where I see it as a rejection of care...some- how the patient is saying, "Whatever you're doing isn't good enough. It's not meeting my needs."

⁴⁰ The information in this Table is drawn from Madelyn Hsiao-Rei Hicks (2006), "Physician-assisted suicide: a review of the literature concerning practical and clinical implications for UK doctors," *BMC Family Practice* (7:39, online: <u>http://www.biomedcentral.com/ content/pdf/1471-2296-7-39.pdf</u>).

Some doctors feel deep disgust towards disease and can have a profound fear of death and the helplessness that accompanies illness. Dr. Lewis Thomas writes, in an unusually naked portrayal of these feelings, "Death is shocking, dismaying, even terrifying...A dying patient is a kind of freak...an offense against nature itself". Some individuals become doctors as a way of dealing with their death anxiety. Doctors' fears of death and of other issues around PAS can contribute to their avoiding muchneeded discussions with patients about their impending death, both in doctors who support and who reject PAS. An Oregon doctor said about a PAS request, "I kind of dealt with the medical issues and I didn't square up with it...I avoided it". This reaction can lead to doctors giving PAS prescriptions to patients without adequate evaluation...

Table 3 Inducement and Coercion in Dynamics of Patient-Physician Interactions in Requests for PAD

D. Degree of Resilience

Health research suggests that individuals' resilience to suicide risk factors is essential in understanding the dynamics of vulnerability. An extensive review of the literature defines resiliency as:

the process of effectively negotiating, adapting to, or managing significant sources of stress or trauma. Assets and resources within the individual, their life and environment facilitate this capacity for adaptation and 'bouncing back' in the face of adversity.⁴¹

People's resilience in coping with their vulnerabilities varies and depends upon factors such as "the availability or lack of intimate and instrumental support; and neighborhood and community resources that may facilitate or hinder personal coping and interpersonal relationships."⁴² Personal, psychological and social assets have also been shown to be important predictors of vulnerable individuals "bouncing back" from trauma and stress. For this reason, extent of resilience is also identified as a factor in suicide risk assessment and response in the health care context⁴³ and is an important determinant of whether a person's potential vulnerability to being induced to commit suicide makes them *actually* vulnerable and calls for protective or other responses.

https://www.oha.com/KnowledgeCentre/Documents/Final%20-%20Suicide%20Risk%20Assessment%20Guidebook.pdf).

⁴¹ Gill Windle (2011), "What is resilience? A review and concept analysis," *Reviews in Clinical*

Gerontology (21, 2). ⁴² David Mechanic and Jennifer Tanner (2007), "Vulnerable people, groups, and populations: societal view," Health Affairs (V. 26(5): 1220-1230 (Online:

http://www.jenniferltanner.com/docs/HA vulnerablegroupsetc MechanicTanner.pdf). Also see, C Grabovschi, C Loignon and M Fortin (2013), "Mapping the concept of vulnerability related to health care disparities: a scoping review," BMC Health Services Research (V. 13, March, Published online: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3626765/).

⁴³ Ontario Hospital Association and Canadian Patient Safety Institute, Suicide Risk Assessment Guide: A Resource for Health Care Organizations (online:

E. Potential vs. Actual Vulnerability

A number of the risk factors identified above may be present in the circumstances of a person who makes a request for physician-assisted death. However, they may not leave the person at such a high risk of *actual* vulnerability that the person is unable to freely and voluntarily consent. Therefore, assessing vulnerability requires distinguishing between 'potential' and 'actual' vulnerability to being induced to commit suicide.

A recent synthesis of a wide body of research on vulnerability factors presents an understanding of vulnerability as a function of two intersecting dimensions – 'sources' of vulnerability (inherent, situational or pathogenic) and potential (dispositional) or actual (occurrent) 'states' of vulnerability.⁴⁴ Applied to the question of vulnerability to being induced to commit suicide in a time of weakness, the framework would suggest the following:

- Sources of vulnerability would include:
 - Inherent vulnerability (a grievous and irremediable medical condition that causes a person enduring suffering that is intolerable in the circumstances and is motivating a request to die, makes the person at least potentially vulnerable to being induced to commit suicide);
 - Situational vulnerability (factors present in the person's circumstances are associated with suicidal risk – i.e. social isolation – but are not pathogenic per se);
 - Pathogenic vulnerability (the person is in relationships where they are being exploited, neglected, abused, discriminated against or stigmatized).
- Potential and actual states of vulnerability would include:
 - Potentially vulnerable (that the range of inherent, situational and pathogenic factors a person is subject to potentially make them vulnerable to being induced to commit suicide)
 - Actually vulnerable (that these factors *actually* are making the person vulnerable to being induced to commit suicide in times of weakness).

Table 5 provides a typology of these sources and states of vulnerability. Drawing on research findings cited above, the typology suggests indicators of potential states of vulnerability and actually occurring states of vulnerability to being induced to commit suicide through a system of physician-assisted death.

⁴⁴ Catriona Mackenzie, Wendy Rogers and Susan Dodds (2014), "What Is Vulnerability, and Why Does It Matter for Moral Theory?" in Catriona Mackenzie, Wendy Rogers and Susan Dodds, eds., *Vulnerability: New Essays in Ethics and Feminist Philosophy* (Oxford: Oxford University Press).

Table 5 – Distinguishing Potential and Actual Vulnerability

	STATES of Vulnerability			
SOURCES of Vulnerability	POTENTIALLY Vulnerable to being induced to commit suicide in a time of weakness	ACTUALLY Vulnerable to being induced to commit suicide in a time of weakness		
INHERENT sources of vulnerability (to the person)	Patient has a grievous and irremediable medical condition that causes enduring suffering that is intolerable to the person in the circumstances.	If situational and/or pathogenic sources of vulnerability are operating.		
SITUATIONAL sources of vulnerability (in the person's context)	 Patient is in a situation of: unmet needs for medical, financial, psychological, social or caregiving support; or concern or fear about loss of autonomy or dignity, growing dependence, caregiving burden, limited financial or other resources. 	 Patient request for PAD is motivated by: unmet needs resulting from lack of positive interpersonal relationships and social isolation; lack of needed services and supports; lack of insight or understanding about alternative courses of action; and has low resilience to these factors. 		
PATHOGENIC sources of vulnerability (caused by exploitation, neglect, abuse, discrimination or social stigma)	Others are stigmatizing, exploiting, neglecting or abusing the patient (psychologically, physically, sexually, or financially).	 Patient request for PAD is motivated by: stigma, exploitation, neglect or abuse; coercion inflicted or inducements offered by others; discrimination in access to needed health and social supports as a result of physical, financial, cultural, communicational, or attitudinal barriers; or negative psychodynamics in the physician-patient relationship; and, has low resilience to these factors. 		

Table 4 Dimensions of Vulnerability to Inducement and Coercion to Commit Suicide in Times of Weakness

F. Towards a 'Vulnerability Lens' in Requests for PAD

Research reviewed for this report point to five criteria of vulnerability that motivate requests for physician-assisted death: suicidality, predominance of psychosocial causes of suffering, dynamics of inducement or coercion, low resilience, and actually occurring states of vulnerability. Framed as questions, these criteria constitute five dimensions of an evidence-based 'vulnerability lens' to guide review and authorization of requests.

- 1. Is this a well-reasoned request or is the person suicidal because of factors other than the medical condition associated with the request?
- 2. Are there psychosocial factors that are motivating this request, which could be addressed by alternative courses of action?
- 3. Are dynamics of inducement and/or coercion underlying this request whether through disordered insight and self-stigma, direct coercion or inducement by others, or because of the psychodynamics of the patient's relationship to health care or social service professionals and systems?
- 4. Does the person have low resilience to factors that could be motivating this request, other than the medical condition itself, and if so are there alternative interventions that could be used to boost resilience?
- 5. Is the person *potentially* vulnerable to being induced to commit suicide in a time of weakness because of the range of factors that could motivate the request for PAD, or is the person *actually* vulnerable as a result of these factors?

The purpose of this report was not to develop comprehensive indicators and tools for applying this lens. Rather, it was to synthesize findings and evidence on vulnerability in the context of physician-assisted death to determine if a coherent set of criteria emerge from that analysis. The research reviewed identifies a consistent set of evidence-based criteria across diverse sources. Further work is needed by health care professionals and regulatory bodies to translate this set of criteria into assessment tools and protocols for application in the system for PAD. The next section turns to implementation issues that should be anticipated in doing so.

III. Key Issues in Implementing a Vulnerability Lens

To provide consistent application of the vulnerability lens to considering and authorizing requests for PAD, a number of legal, policy, practice and institutional issues would need to be addressed. These issues are outlined below, and include:

 Incomplete and inconsistent statutory obligations for health care consent and to assure absence of coercion, inducement and undue influence;

- Varying health profession guidelines for informed consent and response to vulnerable persons;
- Limitations of relying solely on physicians to assess vulnerability; and,
- Need for valid tools and comprehensive protocol to assess vulnerability.

A. Incomplete and inconsistent statutory obligations for health care consent and to assure absence of coercion, inducement and undue influence

In the *Carter* trial decision, Justice Smith specifies the standards of informed consent that must be met for an authorization of PAD to obtain the constitutional protection of an exception to the ban:

[M]y conclusion is that the unconstitutionality of the legislation arises from its application to competent, fully-informed, non-ambivalent adult persons who personally (not through a substituted decision-maker) request physician-assisted death, are free from coercion and undue influence and are not clinically depressed...⁴⁵

Can the current law, policy and practice framework for informed consent and capacity assessment in Canada ensure that this legal standard – the adult person is non-ambivalent, free from coercion and undue influence and is not clinically depressed – is consistently applied in a system for PAD?

Research findings, including the findings and reports released since the *Carter* trial, suggest substantial reform is required. Only five provincial/territorial jurisdictions in Canada have a statutory framework for health care consent for adults – British Columbia, Ontario, Québec, Prince Edward Island, and the Yukon. New Brunswick has provisions for medical consent for minors.⁴⁶ Other provinces/territories have provisions related to a test for legal capacity to make health, personal care and property decisions.

However, none of the statutory provisions incorporate the standard for undue influence and coercion as specified in the *Carter* decision and international codes. The Québec *Act Respecting End-of-Life Care* does provide for "making sure that the request [for PAD] is being made freely, in particular by ascertaining that it is not being made as a result of external pressure."⁴⁷ However, it does not reference the indirect and

⁴⁵ Carter v. Canada (Attorney General), 2012 BCSC 886, at para. 1390.

⁴⁶ British Columbia, Health Care (Consent) and Care Facility (Admission) Act, RSBC 1996, Chapter 181, ss. 6, 13; Ontario, Health Care Consent Act, S.O. 1996, Chapter 2, Schedule A, s. 11; Québec, An Act Respecting End of Life Care, chapter S-32.0001, s. 29, and An Act Respecting Health Services and Social Services, S-4.2, ss. 8, 9, 10; Prince Edward Island, Consent to Treatment and Health Care Directives Act, R.S.P.E.I. 1988, Cap. C-17.2, s. 6; Yukon Territory, Decision Making, Support and Protection to Adults Acts: Schedule B Care Consent Act, SY 2003, c.21, amended by SY 2008, c.1 and SY 2012, c.17, s. 5; New Brunswick, Medical Consent of Minors Act, SNB 1976, c M-6.1, s. 3.

internalized forms of coercion operating through distorted insight and the psychodynamics of the physician-patient relationship that the research finds are powerful inducing forces.

The existing statutes do make reference to ensuring that health care consent is given "freely" or is "voluntary" and in all the jurisdictions, except Québec, that it is not "obtained by fraud or misrepresentation". In this sense, most current statutory standards in Canada emphasize what has been referred to as "coercive informational influences" (i.e., withholding or misrepresentation of information relevant to a health care decision), but they do not account for the "noninformational forms of coercion and undue influence" which are known to motivate requests for PAD, as the findings cited earlier in this report make clear.

Although the informed consent claim takes account of coercive *informational* influences, it does not address mental, contextual, or emotional factors that might overpower the decision maker's will, like those recognized in the undue-influence and insane-delusion doctrines [in determination of testamentary capacity]... The medical decision induced by grief, shock, or despair is enforceable to the same extent as one induced by a careful appraisal of the patient's long-term goals and values.⁴⁸

In response to this gap in consent and capacity law as it applies to authorizations for PAD, U.S. legal scholar Marsha Garrison has proposed that in order to better protect vulnerable patients, doctrines from the law of wills and testator capacity be incorporated into the legal framework. This would include the doctrines of 'delusion' and 'undue influence' to protect those "suffering from the corrosive emotional influence exerted by depression and hopelessness":

Vulnerable patients need, and deserve, protection from the coercive effects of distorted perception and motivation just as much as vulnerable testators need and deserve protection against scheming gold-diggers. It is time to reform the law of medical decision making to ensure that it provides such protection. Patient health-and life itself-hang in the balance.⁴⁹

In the Canadian context, the legal doctrine applying to testamentary capacity is that of "suspicious circumstances." In *Vout v. Hay,* the Supreme Court of Canada set out three types of suspicious circumstances: "(1) suspicious circumstances raised by events surrounding the preparation of the will; (2) events tending to call into question the capacity of the testator; and (3) coercion or fraud."⁵⁰ These factors are now

⁴⁸ *Ibid.,* 797-798.

 ⁴⁹ Marsha Garrison (2007), "The Empire of Illness: Competence and Coercion in Health-care Decision Making", William and Mary Law Review (Volume 49, Issue 3, 781-843).
 ⁵⁰ See M. Scott Kerwin (2010), *Probate Actions – Estate Litigation Basics* (Vancouver: Continuing Legal

⁵⁰ See M. Scott Kerwin (2010), *Probate Actions – Estate Litigation Basics* (Vancouver: Continuing Legal Education Society of British Columbia, online: <u>https://www.cle.bc.ca/PracticePoints/WILL/11-</u> ProbateActions pdf) Suspicious circumstances doctrine defined in *Vout v. Hay* [1995] 2 S C B 876 at

ProbateActions.pdf). Suspicious circumstances doctrine defined in *Vout v. Hay*, [1995] 2 S.C.R. 876 at para. 25.

incorporated into understanding of testamentary capacity in Canadian law.⁵¹ In the health care context, the concepts have been defined by a Canadian health law expert as follows:

Voluntariness:

refers to the need to ensure that consent is obtained without influences that undermine autonomous choice. Influences can be explicit or implicit, and external or internal. Coercion, undue influence, and fraud or misrepresentation are factors which most commonly affect voluntariness.⁵²

Coercion can be defined to:

characterize an offer that is intentionally made to a person who is extremely vulnerable due to distress, need, or poverty, and who would, under the most basically fair conditions, never accept such an offer. In those circumstances of particular vulnerability, the recipients of the offer may feel that that they have no other option but to accept... Coercion, the intentional use of psychological pressure, physical force, or threat, is more clearly deemed to vitiate consent.⁵³

Undue influence:

Undue influence is commonly used in testamentary law, where several conditions have been identified that relate to the vulnerability of the person, the relation of dependency, and the likelihood that the pressure may have had an effect... Undue influence is seen as impacting more subtly on voluntariness than coercion does... It has been suggested that influence is undue when it makes people 'act against their better judgment'" or "when it leads to distortions of the risks and benefits of participation".⁵⁴

The absence of statutory standards for informed consent that specify the obligation to assure against any forms of coercion or inducement is particularly concerning given the strong evidence that these factors can motivate requests for PAD in complex and not always conscious ways.

B. Varying health profession guidelines for informed consent and response to vulnerable persons

The Canadian Medical Association's (CMA) "Principles-based Recommendations for a Canadian Approach to Assisted Dying", published in January 2016, set a standard for competence and informed consent, much more in line with *Carter*. The principle on "Voluntariness" states:

⁵¹ See, for example, discussion of 'undue influence' and 'suspicious circumstances' in British Columbia Law Institute (2013), *Report on Common-Law Tests of Capacity*. Vancouver: Author.

⁵² Trudo Lemmens (2015), "Informed Consent", In *Routledge Handbook of Medical Law and Ethics,* edited by Yann Joly and Bartha Maria Knoppers (New York: Routledge).

⁵³ Ibid. ⁵⁴Ibid.

The attending physician must be satisfied, on reasonable grounds, that all of the following conditions are fulfilled: – The patient's decision to undergo assisted dying has been made freely, without coercion or undue influence from family members, health care providers or others. – The patient has a clear and settled intention to end his/her own life after due consideration. – The patient has requested assisted dying him/herself, thoughtfully and repeatedly, in a free and informed manner.⁵⁵

Earlier guidelines by the Canadian Medical Protective Association (CMPA) also emphasize the necessity to guard against any form of compulsion in providing informed consent:

Patients must always be free to consent to or refuse treatment, and be free of any suggestion of duress or coercion. Consent obtained under any suggestion of compulsion either by the actions or words of the physician or others may be no consent at all and therefore may be successfully repudiated. In this context physicians must keep clearly in mind there may be circumstances when the initiative to consult a physician was not the patient's, but was rather that of a third party, a friend, an employer, or even a police officer. Under such circumstances the physician may be well aware that the patient is only very reluctantly following the course of action suggested or insisted upon by a third person. Then, physicians should be more than usually careful to assure themselves patients are in full agreement with what has been suggested, that there has been no coercion and that the will of other persons has not been imposed on the patient.⁵⁶

The Federation of Medical Regulatory Authorities of Canada (FMRAC) – a federation of the various provincial/territorial colleges and medical councils of physicians and surgeons – stipulate the standard of voluntariness as follows:

The attending physician must be satisfied, on reasonable grounds, that all of the following conditions are fulfilled: The patient's decision to undergo physician-assisted dying has been made freely, without coercion or undue influence from family members, health care providers or others; The patient has a clear and settled intention to end his or her own life after due consideration; and, The patient has requested physician-assisted dying him/herself, thoughtfully and repeatedly, in a free and informed manner.⁵⁷

It is encouraging to see professional practice guidelines attentive to a higher standard of voluntariness than statutory provisions for informed consent. However, there are important differences among the guidelines presented. The CMA and FMRAC do emphasize that the request must be "without coercion or undue influence" and reflect "a clear and settled intention." The CMPA standard focuses primarily on external third party "compulsions" on the patient. The only national standard to reference vulnerable persons or the wide range of factors known to result in vulnerability and risk of suicidal

⁵⁵ Canadian Medical Association (2016) *Principles-based Recommendations for a Canadian Approach to Assisted Dying* (online: <u>https://www.cma.ca/Assets/assets-library/document/en/advocacy/cma-</u> framework assisted-dying final-jan2016.pdf).

 ⁵⁶ Canadian Medical Protective Association (2006), *Consent: A Guide for Canadian Physicians* [Fourth Edition] (online: www.cmpa-acpm.ca/-/consent-a-guide-for-canadian-physicians#volintary consent).
 ⁵⁷ Federation of Medical Regulatory Authorities of Canada (December 2015), *Physician-Assisted Dying Guidance Document* (online: http://fmrac.ca/wp-content/uploads/2015/12/FMRAC-Guidance-Document-Physician-Assisted-Dying.pdf).

ideation is the CMA statement in a principle that states: "Protection of patients: Laws and regulations, through a carefully designed and monitored system of safeguards, should aim to minimize harm to all patients and should also address issues of vulnerability and potential coercion." Neither the statutory or regulatory framework in Canada currently meets this test.

C. Limitations of relying solely on physicians to assess vulnerability

Justice Smith did find that "coercion and undue influence can be detected as part of a capacity assessment." However, she also found that:

To be accurate and reliable, clinicians who perform such assessments would have to be aware of the risks of coercion and undue influence, of the possibility of subtle influence, and of the risks of unconscious biases regarding the quality of the lives of persons with disabilities or persons of advanced age.⁵⁸

How widespread is this knowledge and expertise base across physicians and other health professions? The Federal External Panel on Options for a Legislative Response to *Carter v. Canada* found widely divergent views by health profession associations and others consulted about whether physicians generally have the training and expertise to discern the sometimes complex dynamics of inducement and coercion⁵⁹; which, as noted above, can include their own participation in such dynamics. This finding is reflected in a U.S. survey of family physicians in relation to detecting for elder abuse and neglect, which concluded: "Despite this expected increased demand for expertise [for detection and assessment], physicians generally lack training, experience, education, and adequate guidelines for the assessment and management of abuse. Less than 2% of reports of elder abuse and neglect... come from physicians."⁶⁰

Health profession regulators in Canada do not appear to be addressing this concern, opting instead it appears, at least for some, a position that declares that by definition physicians are able to undertake this assessment. For example, the College of physicians and surgeons of Manitoba simply relies on the statement by the SCC that "Physicians are capable of reliably assessing patient competence and it is possible to detect vulnerability, coercion, undue influence, and ambivalence as part of the

⁵⁸ Carter v. Canada (Attorney General), 2012 BCSC 886, at para. 814.

⁵⁹ Federal External Panel on Options for a Legislative Response to *Carter v. Canada* (2016), *Consultations of Physician-Assisted Dying: Summary of Results and Key Findings: Final Report* (Ottawa:

Department of Justice Canada, pgs. 64-69, online: <u>http://www.justice.gc.ca/eng/rp-pr/other-autre/pad-amm/pad.pdf</u>,

⁶⁰ Robert M. Hoover and Michol Polson (2014) "Detecting Elder Abuse and Neglect: Assessment and Intervention", *American Family Physician* (Volume 89, Number 6, p. 453).

assessment process for informed consent and medical decision making capacity."⁶¹ In this case, a finding at both the trial and the Supreme Court decisions in *Carter* that "it is possible" for physicians to detect vulnerability, coercion, undue influence and ambivalence, stands in for evidence that this is what all physicians have the skills, training, time and expertise to actually do. The evidence does not bear out this interpretation of the Court's assertion of possibility the declaration.

In response to the concerns about how vulnerability assessment will be conducted, the Canadian Nurses Association recommends ensuring "that requests for PAD are addressed through a comprehensive assessment process by an interprofessional team." This could include, the association recommends, nurses, psychologists, pharmacists and social workers. The CNA stresses that a "reductionist" approach to assessment for vulnerability, relying exclusively on physician assessment of voluntariness and competence is too risky. They recommend an independent assessment by nurses as an important safeguard and one which recognizes the more fulsome relationships that nurses may form with patients, given their greater likelihood of prolonged and intimate observation as patients negotiate illness, relationships and decision-making.⁶²

Thus, even among health professionals in Canada, there is vast disagreement about capacity to undertake adequate assessment of vulnerability in people requesting PAD.

D. Need for valid tools and comprehensive protocol to assess vulnerability

In addition to concerns about lack of expertise and training and an interdisciplinary approach to vulnerability assessment, valid tools for assessing vulnerability in relation to the request for PAD are lacking. In fact, standard capacity or competency assessment tests *are not designed* to capture "coercion and undue influence", "clinical depression" or the negative impact on decision making capacity of the psychological mechanisms and dynamics discussed above. This limitation includes the MacArthur Competence Assessment Tool-Treatment (MacCAT-T), which a Canadian review of competency

http://cpsm.mb.ca/cjj39alckF30a/wp-content/uploads/PAD/PADSchMa.pdf).

⁶² Canadian Nurses Association (October 2016), "Physician-Assisted Death: Brief for the Government of Canada's External Panel on Options for a Legislative Response to Carter v. Canada (2015)" (online: https://www.cna-aiic.ca/~/media/cna/page-content/pdf-en/physician-assisted-death_brief-for-thegovernment-of-canadas-external-panel-on-options-for-a-legislative-response-to-carter-vcanada.pdf?la=en).

⁶¹ College of Physicians and Surgeons of Manitoba (2016), "Physician-Assisted Death: Schedule M attached to and forming part of By-Law No. 11 of the College" (online:

assessment tools refers to as the "gold" standard of competency assessment.⁶³ The difference between this tool and the Scale to Assess Unawareness of Mental Disorder (SUMD), for example, has been noted specifically in relation to requests for PAD because, unlike the MacCAT-T, the SUMD evaluates the various dimensions of insight, including awareness of symptoms, retrospective awareness, and psychosocial consequences.⁶⁴ Thus, a recommended 'gold standard' for competency assessment by health professionals in Canada does not incorporate attention to those dimensions of capable decision making which the evidence indicates are critical in assessing disordered insight.

No comprehensive set of vulnerability assessment tools have been designed or tested for assessing the extent to which any, or some combination, of these factors may be operating to make a person vulnerable to requesting PAD as a way to commit suicide in a time of weakness. Nonetheless, there is growing concern and attention in the health care system to vulnerability of patients, and to risk of suicide in particular. A number of these instruments and protocols could be drawn upon and tested by health researchers and professionals to develop a comprehensive assessment protocol for the purposes of assessing and responding to vulnerability of patients requesting PAD.

For example, and as noted above, the Ontario Hospital Association and the Canadian Patient Safety Institute have developed a comprehensive framework to encourage standardized assessment of suicide risk within health care settings, drawing on an inventory and analysis of fifteen suicide risk assessment tools.⁶⁵ A number of these tools could be considered and adapted for assessing vulnerability in response to requests for physician-assisted death.

As well, more general vulnerability assessment tools have been designed that could also be adapted for the context of physician-assisted death. For example, a "Vulnerability Assessment Tool" has been designed to identify extent of instability in living conditions of homeless persons. It identifies ten domains of vulnerability, and has

https://www.oha.com/KnowledgeCentre/Documents/Final%20-

⁶³ See Deborah O'Connor (2009), *Incapability Assessments: A Review of Assessment and Screening Tools: Final Report*, Prepared for the Public Guardian and Trustee of British Columbia (Online: http://www.trustee.bc.ca/documents/STA/Incapability_Assessments_Review_Assessment_Screening_To ols.pdf).

⁶⁴ Marsha Garrison (2007), "The Empire of Illness: Competence and Coercion in Health-care Decision Making", William and Mary Law Review (Volume 49, Issue 3, 781-843).

⁶⁵ Ontario Hospital Association and Canadian Patient Safety Institute, *Suicide Risk Assessment Guide: A Resource for Health Care Organizations* (online:

^{%20}Suicide%20Risk%20Assessment%20Guidebook.pdf). See also, Registered Nurses Association of Ontario (January 2009), *Nursing Best Practice Guideline Assessment and Care of Adults at Risk for Suicidal Ideation and Behaviour* (online: <u>http://rnao.ca/sites/rnao-</u>

ca/files/Assessment_and_Care_of_Adults_at_Risk_for_Suicidal_Ideation_and_Behaviour_0.pdf).

been both validity- and reliability-tested.⁶⁶ While not designed for assessing vulnerability to being induced to commit suicide in times of weakness, it does assess some of the same factors the research identifies for vulnerability to suicidal ideation and intent. Moreover, it provides helpful scales of the degree of vulnerability in each of the domains it assesses, which could be adapted in designing assessment tools for the purposes outlined here.

In the area of older persons, the "Elder Abuse Suspicion Index" has been validated in health care settings and could be adapted as part of a comprehensive protocol for vulnerability assessment in responding to requests for PAD.⁶⁷

The British Medical Association's "Safeguarding Vulnerable Adults – a Tool Kit for General Practitioners"⁶⁸ is not designed specifically for vulnerability assessment in the context of PAD, but it is informed by concern for the types of vulnerability factors identified above. It could be a helpful template for vulnerability assessment in PAD.

There may also be factors in the adult's experience of health care treatment which are identified as needing more in-depth inquiry. For example, there is increasing use of 'patient reported outcomes' (PROs) to assist health professionals in assessing the impact of health care events, symptom burden, functioning, health status, and health-related quality of life.⁶⁹ Some PRO assessment tools look specifically at the impact of 'events' in the health care system over a period of time, and the "dynamics of care" which may have a cumulative impact on the patient's perception of quality of life, especially those with complex health needs.⁷⁰ A growing body of research is finding that patient perception of care is a predictor of patient quality of life. In this regard, health care researchers in treatment of HIV/AIDS note that patient-oriented outcomes

⁶⁶ Downtown Emergency Service Center, "Vulnerability Assessment Tool for Determining Eligibility and Allocating Services and Housing for Homeless Adults" (Seattle, WA: Author, Online at:

http://www.desc.org/documents/06.30.2015.DESC.Intro_to_Vulnerability_Assessment_Tool.incl%20VAT %20&%201-page%20validity.pdf).

⁶⁷ MJ Yaffe and B Tazkarji (2012), "Understanding elder abuse in family practice", *Canadian Family Physician* (58(12), pgs. 1336-1340).

⁶⁸ British Medical Association (2011), *Safeguarding Vulnerable Adults – A Tool Kit for General Practitioners* (London: Author, Online at:

https://www.google.ca/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&cad=rja&uact=8&ved=0CB0QFjAA ahUKEwjS4v6_-urlAhUGpx4KHdPzAU4&url=http%3A%2F%2Fbma.org.uk%2F-

^{%2}Fmedia%2Ffiles%2Fpdfs%2Fpractical%2520advice%2520at%2520work%2Fethics%2Fsafeguardingvulnerableadults.pdf&usg=AFQjCNEVOS5NTs1XmnkAp7lb0idVbCdEw).

⁶⁹ Neil Aaronson, Thomas Elliott, Joanne Greenhalgh, et al (2015), *User's Guide to Implementing Patient-Reported Outcomes Assessment in Clinical Practice* (International Society for Quality of Life Research, online: http://www.isoqol.org/UserFiles/2015UsersGuide-Version2.pdf).

⁷⁰ See, for example, Bruce Rapkin, Elisa Weiss, Rosy Chhabra, et al (2008), "Beyond satisfaction: Using the Dynamics of Care assessment to better understand patients' experiences in care," *Health and Quality of Life Outcomes* (6:20 March).

assessment "sheds light on concerns that may not make it into care because of patients' sense of futility, embarrassment, or independence."⁷¹

Such assessments also point to a patient's resilience in the face of factors that may make them vulnerable, as discussed above. A number of tools for assessing resiliency are being developed for use in vulnerability assessment in health care contexts.⁷² As such, they provide another source for developing a comprehensive assessment protocol to determine the extent of vulnerability to being induced to commit suicide in a time of weakness.

Particularly applicable in the context of assessing potential vs. actual vulnerability is what has been termed "Focused Risk Assessment." The goal is to "establish an open and therapeutic rapport with the person", and explore in detail the adult's plans, ideation, strengths and supports available that may moderate the risk.⁷³

Summary

In summary, there are a wide range of existing health practice guidelines and tools for both suicide risk assessment and vulnerability assessment more generally. However, no specific set of protocols have been developed for vulnerability assessment in the context of PAD. The research suggests that a range of factors may coerce requests, including psychological factors of depression, hopelessness and self-stigma that can disorder insight, direct coercion by others, and the psychodynamics of patient-physician relationships that evolve in the context of requests for PAD. The "informational" focus of the current legal and practice framework for obtaining consent does not appear to be adequate in surfacing these more complex psychological factors and dynamics.

There is a clear need for investment by health authorities, professional associations and health regulators to develop and validate needed assessment tools and protocols, and to ensure they are part of health care professionals' obligations, with clear practice guidelines for this purpose.

https://www.oha.com/KnowledgeCentre/Documents/Final%20-

⁷¹ Bruce Rapkin, Elisa Weiss, Rosy Chhabra, et al (2008), "Beyond satisfaction: Using the Dynamics of Care assessment to better understand patients' experiences in care," *Health and Quality of Life Outcomes* (6:20 March).

⁷² Gill Windle, Kate M Bennett and Jane Noyes (2011), "A methodological review of resilience measurement scales," *Health Quality Outcome* (9:8).

⁷³ Ontario Hospital Association and Canadian Patient Safety Institute, *Suicide Risk Assessment Guide: A Resource for Health Care Organizations* (online:

<u>%20Suicide%20Risk%20Assessment%20Guidebook.pdf</u>, p. 68). The notion of this 'focused' and more indepth stage of risk assessment is drawn from P. Barker and P. Buchanan-Barker (2005) *The Tidal Model: A Guide for Mental Health Professionals* (New York, NY: Routledge).

It is critically important to recognize, however, that the system for physician-assisted death will be introduced in Canada long before any such comprehensive tools have been designed, clinically tested or systematically evaluated for this purpose. Absence of a clinically proven evaluation protocol to assess vulnerability to being induced to commit suicide in a time of weakness, in the context of requests for PAD, suggests extreme caution should be exercised.

IV. Federal legislative requirements to implement a vulnerability lens

A safeguards system for PAD must be designed to minimize as much as possible the abuse and error that would result if adults received PAD when they were vulnerable to being induced to commit suicide; while at the same time ensuring equitable access for eligible adults. Both objectives must be achieved, with policy architecture and institutional mechanisms that ensure an appropriate balancing is made in assessing and authorizing any request.

This report has drawn on extensive evidence to identify elements of a vulnerability lens to ensure adequate safeguards in decision making in PAD. This lens gives attention to the unmet needs, inducements and coercive forces which make people vulnerable in this context. The analysis has pointed to key limitations in the current legal, regulatory, policy and practice environment in Canada which suggest that the health care system for applying this lens to identify or address vulnerability in a reliable and consistent manner across provincial/territorial jurisdictions.

A national standard for vulnerability assessment in responding to, considering and authorizing requests for PAD is therefore urgently needed. Federal leadership for this purpose is essential. Only with a uniform standard across Canada will provincial/territorial health authorities, health professionals and health care regulators have clarity about the specific legal obligations and needed policies/practices to obtain informed consent in a manner that protects vulnerable persons from being induced to commit suicide in a time of weakness.

Through what means should a national standard be established for this purpose? Because the Supreme Court of Canada mandated that the ban on assisted suicide could be lifted in the exceptional circumstances it defines, a *Criminal Code* amendment seems most appropriate for this purpose. It is the legal framework in which to define the conditions under which assisted suicide, which otherwise remains prohibited under the *Criminal Code*, could be legally authorized. The findings and analysis in this report point to three core elements of a national standard to protect vulnerable persons that could be embedded in the *Code*:

A. Criminal Code standard for informed consent

The statutory standard should require that a person not be vulnerable to being induced to commit suicide in a time of weakness, and that the person make a non-ambivalent, voluntary request, free from coercion, inducement or undue influence. Applying the standard should require:

- a. Two physicians to independently assess the medical condition and suffering and capacity for informed consent, with at least one physician having clinical expertise in diagnosis, prognosis and treatment of the medical condition. This need for at least two independent assessments has been recognized by both the Provincial/Territorial Expert Advisory Group and the Parliamentary Joint Special Committee report on physicianassisted dying.⁷⁴
- b. Independent psychiatric or psychological evaluation where there is any concern that factors external to the condition underlay the suffering and the motivation for the request, including: 1) psychological stressors of distorted insight, depression, hopelessness or self-stigma; 2) coercion by others; and/or 3) the psychodynamics of the patient-physician relationship.
- c. Physician liability for not triggering a more indepth inquiry when there is even minimal concern that a person may be vulnerable to being induced to commit suicide in a time of weakness.

B. Criminal Code requirement for vulnerability assessment

Provisions should require mandatory vulnerability assessment to be undertaken by health and social service professionals and require, in particular:

- a. Vulnerability assessment to be conducted in response to each request, drawing upon designated health professionals within the clinical or health care team whose responsibility, training, and expertise it is to assess vulnerability.
- b. Application of a vulnerability assessment lens that assesses:

⁷⁴ Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying Final Report (November 30, 2015), *Final Report* (Toronto: Ontario Ministry of Health and Long-term Care); Parliament of Canada (42nd Parliament, 1st Session), Special Joint Committee on Physician-Assisted Dying (February 2016), *Medical Assistance in Dying: A Patient-Centred Approach: Report of the Special Joint Committee on Physician-Assisted Dying* (Ottawa: Author).

- i. whether the person may be suicidal because of factors other than the medical condition associated with the request;
- ii. predominance of psychosocial factors motivating this request, which could be addressed by alternative courses of action;
- any dynamics of inducement, undue influence and/or coercion underlying the request – whether through disordered insight and self-stigma, direct coercion or inducement by others, or because of the psychodynamics of the patient's relationship to health care or social service professionals and systems;
- whether the person has low resilience to factors that could be motivating the request, other than the medical condition itself and, if so, if ther are there alternative interventions that could be used to boost resilience;
- v. the extent to which the person is *potentially* vulnerable to being induced to commit suicide in a time of weakness because of the range of factors that could motivate the request for PAD, or is person *actually* vulnerable as a result of these factors.
- c. That, if any member of the health team expresses any concern that the adult may be vulnerable, indepth assessment is conducted and consideration given to the range of factors that may be inducing or coercing the request.
- d. That, if it is determined that the risk is too high that the person is vulnerable to committing suicide in a time of weakness, then alternative courses of action must be taken, with referrals to adult protection services, community supports, or police, as may be required by prevention and response protocols or legal obligations, depending on the particular situation.

C. Criminal Code requirement for prior review and determination by an independent authority

Provision should be established in the *Criminal Code* requiring prior independent review of all requests, either through a provincial/territorial Superior Court judge, a revised mandate of provincial/territorial mental health review boards already established under the *Code*, or through existing or newly established tribunals at the provincial/territorial level.

There are a number of rationales for prior independent review of requests for PAD, as one of the safeguards to protect vulnerable persons:

- Inconsistent or absent statutory standards for informed consent With health regulators using different professional practice standards for assessing voluntariness, coercion and undue influence in medical decision making, in the context of varying or completely absent statutory standards, a mechanism that can consistently apply national standards is required. This would ensure that vulnerable persons have equal access to constitutional protections of the right to life.
- Evidence that health professionals disagree about validity of requests With evidence from other jurisdictions that physicians disagree about validity of requests for PAD, and that unconscious factors may operate in the physicianpatient relationship that can distort insight and the reasoning process, a more independent mechanism is required for authorization of requests.
- No reliable and clinically proven tools for vulnerability assessment Lack of consistent and reliability- and validity-tested tools for vulnerability assessment make it impossible without an independent mechanism that can operate according to consistent guidelines, to meet the legal requirement laid down by the Supreme Court of Canada to protect vulnerable persons.
- Health care system not designed to make the authorizations Physicianassisted death is not a health treatment decision. It is a decision to take a lethal dose of substances intended to terminate life, upon a capable decision to refuse health treatments. Such an intervention may be provided by health professionals, but that is a policy choice about how to deliver the intervention, not a determination of the meaning of the intervention. Moreover, eligibility for PAD may be determined in part through clinical assessments of a person's medical condition and ways to alleviate suffering. These roles fall within the purview of health professionals' competencies and mandates. Authorization of an intervention intended to terminate the life of a person can only be provided as an exception to the *Criminal Code* prohibition. While the intervention may be funded as an 'insured service' under provincial health insurance plans, its authorization as an exception to criminal liability that would otherwise be imposed, is a different matter subject to legal determination.
- **Consistent with Canada's obligations under international law** Prior review is consistent with Canada's obligations under international law to protect the inherent right to life of vulnerable persons. The United Nations Human Rights Committee, which is responsible for monitoring Canada's and other state parties' obligations to protect the "inherent right to life" recognized in Article 6 of the International *Covenant on Civil and Political Rights,* has urged that in approving

requests for PAD independent review be provided for in order to "guarantee that this decision was not the subject of undue influence or misapprehension."⁷⁵ The Committee calls for "independent review by a judge or magistrate" because of the potential for violation of the right to life.

 Provisions already exist in the Criminal Code for prior independent review and for mandating vulnerability assessments – Current provisions in the Criminal provide for provincial/territorial Review Boards to determine who cannot be held criminally responsible due to a mental disorder and to make placement decisions to ensure that such individuals can access needed mental health services. Detailed legislative proposals for adapting existing Boards for the purpose of prior review and authorization for PAD have been developed in light of the Carter decision.⁷⁶

This could include adaptation of existing tribunals like the Ontario 'Consent and Capacity Board' which currently has a mandate to adjudicate on matters of capacity, consent, civil committal, substitute decision making, disclosure of personal health information and mandatory blood testing. In 2014-15 the Board received over 6800 applications and drawing on a roster of part-time lawyers, psychiatrists and public members, convened over 3,500 hearings, with over 500 hearings done by video-conferencing.⁷⁷

Provisions already exist in the *Criminal Code* for receiving and ordering assessments, with respect to placement decisions by mental health review boards currently mandated under the *Criminal Code* (in ss.672.1 to 672.21) and could be adapted for the purpose of ordering additional vulnerability assessments where warranted.

Under such a system, provision could be made for expedited decision making as may be needed where the adult may be close to death or the adult's state of suffering requires urgent decision.

⁷⁵ U.N. Human Rights Committee, Consideration of Reports Submitted by States Parties Under Article 40 of the Covenant, para. 7, U.N. DOC. CCPR/C/NLD/CO/4 (Aug. 25, 2009). See also U.N. Human Rights Committee, Concluding Observations of the Human Rights Committee: Netherlands, para. 5–6, U.N. DOC. CCPR/CO/72/NET (Aug. 27, 2001).

⁷⁶ See David Baker and Gilbert Sharpe (2015), Draft Federal Legislation to Amend the Criminal Code to be Consistent with *Carter v. Canada (Attorney General)* 2015 SCC 5. Toronto: bakerlaw (Online: http://www.cacl.ca/sites/default/files/uploads/Baker-Sharpe%20An%20Act%20to%20Amend%20the% 20Criminal%20Code%20(Physician%20Assisted%20Suicide).pdf).

⁷⁷ Ontario, Consent and Capacity Board (2015), "Consent and Capacity Board: Annual Report 2014-2015" (online: <u>http://www.ccboard.on.ca/english/publications/documents/annualreport20142015.pdf</u>).

Conclusion

The Supreme Court of Canada decision in *Carter* upheld the ban on physician-assisted suicide and voluntary euthanasia for adults who may meet the medical for access, but who are nonetheless 'vulnerable to being induced to commit suicide in times of weakness.' In doing so, the Court recognized constitutional obligations to protect and safeguard vulnerable persons in the strictest manner. However, it left design of a framework for identifying and safeguarding vulnerable persons up to Parliament.

The research findings reviewed for this report point to five main dimensions of a 'vulnerability lens' to identify persons who may be vulnerable in a system for PAD:

- 1. Is this a well-reasoned request or is the person suicidal because of factors other than the medical condition associated with the request?
- 2. Are there psychosocial factors that are motivating this request, which could be addressed by alternative courses of action?
- 3. Are dynamics of inducement, coercion or undue influence underlying this request – whether through disordered insight and self-stigma, direct coercion or inducement by others, or because of the psychodynamics of the patient's relationship to health care or social service professionals and systems?
- 4. Does the person have low resilience to factors that could be motivating this request, other than the medical condition itself, and if so are there alternative interventions that could be used to boost resilience?
- 5. Is the person *potentially* vulnerable to being induced to commit suicide in a time of weakness because of the range of factors that could motivate the request for PAD, or is the person *actually* vulnerable as a result of these factors?

A reliable system of checks and balances to assure consistent application of this lens for vulnerability assessment is essential. Without such attention, there is very real risk that people will die in a manner that violates criminal prohibition. This includes adults who may appear to meet the criteria for PAD but whose suffering is, in fact, substantially related to other factors that induce suicidal ideation and intent and which may underlie an adult's experience of enduring and intolerable suffering. It also includes adults who, because of other factors in their lives or in the dynamics of the relationship with their physician, are actually victims of subtle, unconscious or explicit inducement or coercion in the request for PAD. Such outcomes would not only be an ethical and moral failure of health care and justice systems of immense proportions. Under *Carter*, they would also be a criminal violation.

A number of issues must be addressed in ensuring consistent application of this lens in responding to, considering and authorizing requests for PAD, including:

• Incomplete and inconsistent statutory obligations for health care consent and to assure absence of coercion, inducement and undue influence;

- Varying health profession guidelines for informed consent and response to vulnerable persons;
- Limitations of relying solely on physicians to assess vulnerability; and,
- Need for valid tools and comprehensive protocol to assess vulnerability.

In order to establish a nationally-consistent system for PAD that can address these limitations in the current health care delivery system, this report recommends embedding key safeguard requirements in the *Criminal Code*, including: 1) a legal standard for informed consent that requires a person make a non-ambivalent, voluntary request, free from coercion, inducement and undue influence; 2) mandatory vulnerability assessment; and, 3) prior review and determination by an independent authority.

These recommendations are sensitive to the Supreme Court's imperative that any safeguard system must balance the competing values of protecting the autonomy and dignity of an adult's right to choose, and the need to protect vulnerable persons. To do anything less would be to prioritize the value of autonomy over protecting the vulnerable, and the Supreme Court provided no such avenue in its decision in *Carter*. Given the very real risk to vulnerable persons that could result from a system for physician-assisted suicide and voluntary euthanasia, it is of the utmost urgency and import to develop robust, transparent and consistent safeguards in which all Canadians can trust.

Appendix A – Growing Vulnerability among Persons with Disabilities in Canada

Increasing prevalence in Canadian society of many of the factors associated with vulnerability and suicide risk among people with disabilities in particular, signals the urgent need for a reliable vulnerability assessment process in a system for PAD:⁷⁸

- Severity of disability, and multiple disadvantage Almost 14% of the adult population in Canada has a disability and this prevalence rate is growing year by year. Women are over-represented in almost all age groups.⁷⁹ Among Aboriginal persons, the prevalence of disability is over 30%, with this higher rate due to significant environmental and trauma-related disabilities.⁸⁰ Overall there is an increasing prevalence of people with 'severe' or 'very severe' disabilities, currently estimated at 1.8 million adults in Canada.⁸¹ This is a group particularly vulnerable to abuse, social exclusion, and stigma especially those multiply-disadvantaged by gender or ethno-racial-cultural status.
- Lack of access to disability-related supports A growing gap in needed disability-related supports affects both people with disabilities and families. Statistics Canada reports that unmet need for support increases with severity of disability, with 49% of people with severe disabilities needing help or not receiving enough help. For people with disabilities not living alone, 80% rely on families for needed support. For those living alone, 56% rely on their families.⁸² With the aging of the population this gap will grow substantially because of increased disability prevalence and more limited capacity of aging family caregivers.
- **Gap in palliative care** up to 70% of Canadians are not able to access palliative care.⁸³ This will become a growing issue as annual deaths increase

⁷⁸ The following discussion of vulnerability in Canadian society is drawn from CACL's earlier report, Canadian Association for Community Living (2015), *Protecting Choice and Safeguarding Inclusion: A Proposal to Regulate Physician-Assisted Suicide and Voluntary Euthanasia in Canada* (Online: http://cacl.ca/sites/default/files/uploads/CACL%20-%20Choice%20and%20Inclusion%20-%20%20%28english%29.pdf).

⁷⁹ Statistics Canada, Social and Aboriginal Affairs Division (2013). Disability in Canada: Initial findings from the Canadian Survey on Disability: Fact Sheet. Ottawa: Statistics Canada.

⁸⁰ Douglas Durst (2006). Urban First Nations People with Disabilities Speak Out. *Journal of Aboriginal Health* (September 2006).

 ⁸¹ For a comparison of 2001 and 2006 disability rates in these population groups, see Statistics Canada, *Participation and Activity Limitation Survey: Analytical Report* (Ottawa: Statistics Canada, 2007), online: http://www.statcan.gc.ca/pub/89-628-x/89-628-x2007002-eng.htm (last accessed: 24 September 2014).
 ⁸² Rubab Arim (2015). A profile of persons with disabilities among Canadians aged 15 years or older, 2012. Ottawa: Statistics Canada.

⁸³ The Honourable Sharon Carstairs (2010). *Raising the Bar: A Roadmap for the Future of Palliative Care in Canada*. Ottawa: Senate of Canada, at p. 24.

from the current rate of 260,000 deaths per year to more than 425,000 per year by 2036.⁸⁴ Lack of access contributes to the stress that both patients and family caregivers face at end-of-life, which may contribute to suicidal ideation and intent or coercion, as discussed above.

- Increasing prevalence of mental health difficulties A study for the Mental Health Commission of Canada estimates 20% of Canadians experience mental health difficulties annually, including mood disorders, anxiety disorders, schizophrenia, attention deficit/hyperactive disorders (ADHD), personality disorders, substance use disorders or dementia. It estimates that within a generation more than 8.9 million Canadians will be living with a mental illness.⁸⁵ People with disabilities who experience rates of violent victimization much higher than the general population are also more likely to self-rate poor or fair health status, as well as sleep disorders and use of antidepressants or sedatives, at rates 50% to 90% higher than the general population.⁸⁶
- Mental health disability and other disabilities co-related Statistics Canada estimates there are over 1 million Canadians with mental health disabilities, which are defined for population surveys as a long-term condition that limits daily activities. Of this group, almost 92% also report having at least one other type of disability.⁸⁷
- Poverty and labour force exclusion Working-age adults with disabilities are about twice as likely to live in poverty as the general population (20.5% versus 11%). Almost 40% of Aboriginal persons with disabilities live in poverty. Persons with severe disabilities are multiply disadvantaged, with over 50% living in poverty. Employment rates are far lower for working age adults with disabilities (51.3%) than those without (75.1%). Among working age people with intellectual disabilities, labour force participation is only 30%.⁸⁸ As noted above, in a study of

⁸⁴ Quality End-of-Life Care Coalition of Canada (2010). Blueprint for Action: 2010 to 2020. Ottawa: Author, at p. 1.

⁸⁵ P. Smetanin, D. Stiff, C. Briante, C.E. Adair, S. Ahmad and M. Khan (2011). *The Life and Economic Impact of*

Major Mental Illnesses in Canada: 2011 to 2041. Toronto: RiskAnalytica, on behalf of the Mental Health Commission of Canada.

⁸⁶ See Samuel Perrault (2009). Criminal victimization and health: A profile of victimization among persons with activity limitations and other health problems. Ottawa: Statistics Canada.

⁸⁷ Christine Bizier, Carley Marshall and Gail Fawcett (2014). *Mental health-related disabilities among Canadians aged 15 years and older, 2012.* Ottawa: Statistics Canada.

⁸⁸ Cameron Crawford (2013). Looking Into Poverty: Income Sources of Poor People with Disabilities in Canada. Toronto: IRIS - Institute for Research and Development on Inclusion and Society, 2013. Online: http://www.ccdonline.ca/en/socialpolicy/poverty-citizenship/demographic-profile/income-sources-of-poor-people-with-disabilities; Crawford, C. (2013 version). *Disabling Poverty & Enabling Citizenship:*

Understanding the Poverty and Exclusion of Canadians with Disabilities. Winnipeg: Council of Canadians with Disabilities.

those requesting PAD in Belgium because of psychological suffering, 73% had been found medically unfit to work.⁸⁹

- *Violence, abuse and insecurity*⁹⁰ People with disabilities are twice as likely as non-disabled persons to be victims of violence. People with some form of cognitive or mental disability, including intellectual disability, are four times more likely to be victimized than those without. Women with disabilities are sexually assaulted at a rate at least twice that of the general population of women in Canada. Almost two thirds (65%) of violent crimes against persons with activity limitations were committed by someone who was known to the victim. Persons with disabilities are 2 to 3 times more likely to be victims of the most severe forms of spousal violence, including being sexually assaulted, beaten, struck or threatened with a weapon. It is estimated that 80% of psychiatric inpatients have been abused in their lifetimes.91 Moreover, people with disabilities who are victims of violence are less likely than other victims to be satisfied with the police response and with the ability of courts to deal with the incidents in a timely manner. With the rate of sexual abuse experienced by Aboriginal persons with disabilities at five times the general population,⁹² aboriginal persons with disabilities are particularly vulnerable.
- Barriers to preventive and acute health care People with intellectual disabilities are three to four times more likely to die preventable deaths because of barriers to needed health care and other supports.⁹³

Add to these factors the rapid aging of the Canadian population. This will mean a growing proportion of people with disabilities in the decades ahead and an increasing incidence of financial and other forms of abuse against persons with disabilities including older persons, especially with the large inter-generational transfer of wealth currently underway:

Online: http://www.ccdonline.ca/en/socialpolicy/poverty-citizenship/demographic-profile/understanding-poverty-exclusion.

⁸⁹ Lieve Thienpont, Monica Verhofstadt, Tony Van Loon, Wim Distelmans, Kurt Audenaert and Peter P De Deyn (2015), Euthanasia requests, procedures and outcomes for 100 Belgian patients suffering from psychiatric disorders: a retrospective, descriptive study," *BMJ Open* (5, online: http://bmjopen.bmj.com/content/5/7/ e007454.full).

⁹⁰ For statistics referenced in this section, see Samuel Perrault (2009), *Criminal victimization and health: A profile of victimization among persons with activity limitations and other health problems* (Ottawa: Statistics Canada).

⁹¹ National Clearing House on Family Violence (2004), "Violence Against Women with Disabilities." (Ottawa: Minister of Public Works and Government Services Canada).

⁹² Larry Chartrand and Celeste McKay (2006), A Review of Research on Criminal Victimization and First Nations, Métis and Inuit Peoples 1990-2001 (Ottawa: Department of Justice Canada).

⁹³ See P. Heslop et al (2014), "The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study," *The Lancet*; 383: 9920, 889–895; and Stacey Atkinson, Joanne Lay, Su McAnelly, Malcolm Richardson (eds.) (2015), *Intellectual Disability in Health and Social Care* (New York: Routledge).

- Rapid increase in cases of dementia The almost half a million Canadians with dementia in 2008 will increase 2.3 times by 2038 to over 1,125,000 individuals, at which point there will be 250,000 new cases diagnosed each year.⁹⁴
- High rates of depression among seniors The Canadian Institute for Health Information reports that over 40% of seniors living in residential care in Canada have either been diagnosed with depression or show symptoms of depression.⁹⁵
- *Elder abuse* Estimates of elder abuse prevalence range from 4-10% of the population, with financial abuse being the leading form.⁹⁶

⁹⁴ P. Smetanin, P. Kobak, C. Briante, D. Stiff, G. Sherman, G. and S. Ahmad (2010), *Rising Tide: The Impact of Dementia in Canada 2008 to 2038* (Toronto: Alzheimer Society Canada).

 ⁹⁵ Canadian Institute for Health Information (2010). *Depression among Seniors in Residential Care: An Analysis in Brief*. Ottawa: Author.
 ⁹⁶ See, for example, E. Podnieks (2008), Elder abuse: the Canadian experience. *Journal of Elder Abuse*

⁹⁶ See, for example, E. Podnieks (2008), Elder abuse: the Canadian experience. *Journal of Elder Abuse and Neglect*, (20(2):126-50); Charmaine Spencer (1998), *Diminishing Returns: An Examination of Financial Abuse of Older Adults in British Columbia* (Vancouver: Gerontology Research Centre, Simon Fraser University).