MEDICAL ASSISTANCE IN DYING: CANADIAN REGISTRY RECOMMENDATIONS

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Medical assistance in dying (MAID) is a relatively new phenomenon in Canada, and is therefore a growing area of interest in the legal and medical communities. Research is hampered, however, by the lack of a standardized approach to collecting data on MAID cases. The authors first discuss the importance of having comprehensive data to improving preventative and end-of-life care across Canada. The authors then canvas the existing framework for reporting MAID cases in Canada before noting its deficiencies, most importantly, a lack of comprehensive, nation-wide data collection. The authors then propose a model for national data collection based on the existing Canadian cancer registry system.

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I. INTRODUCTION

Medical assistance in dying (MAID) became the law of the land in Canada on 17 June 2016.[1] The term "MAID" encapsulates this newly legal medical practice: first, MAID encompasses two distinct types of acts, including where a medical professional directly administers a substance that causes the death of a patient (traditionally known as voluntary euthanasia) and where a medical professional prescribes to a person a substance they can self-administer to cause death (traditionally known as physician-assisted suicide); second, MAID is legal in a medical context only; third, physicians and nurse practitioners are able to provide MAID; and fourth, the words "in dying" suggest that eligibility is limited to patients who are dying, that is, nearing a natural death.[2]

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1 Bill C-14, *An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)*, 1st Sess, 42nd Parl, 2016 (assented to 17 June 2016), SC 2016, c 3 [Bill C-14].

2 Government of Canada, "Questions and Answers: Medical Assistance in Dying," online: <justice.gc.ca/eng/cj-jp/ad-am/faq.html>; Rose M Carter & Brandyn Rodgerson, "Medical Assistance in Dying: Journey to Medical Self-Determination" (2018) 55:3 Alta L Rev 777 at 779.

Over one year following implementation of legislation legalizing MAID, it remains difficult to obtain comprehensive data — in terms of number of variables and frequency of reporting — on how many Canadians have applied for MAID, how many were denied, reasons for rejection, and other relevant variables. This is due to an absent streamlined collection mechanism, inconsistency amongst provinces and territories in collecting data, and expressed confidentiality concerns by provinces and territories with a low rate of MAID cases.

Comprehensive data collection is critical as Parliament analyzes and attempts to improve the Canadian approach to this medical procedure. Maintaining data through a streamlined collection system has the promise of coalescing a wide range of medical and legal functions, such as clinical support, preventative health management, and ensuring that statutory requirements across the provinces and territories are being adhered to.

The objective of this article is to highlight the need to establish a national Canadian standard for data collection, without which researchers, the federal government, and others are prevented from conducting comprehensive research and analyzing trends in basic and reliable information that could otherwise improve preventative initiatives, societal understanding, and end-of-life care across the country. The first section will discuss the value that comprehensive data collection brings to understanding MAID in Canada. The second section will provide an overview of the legal framework in which MAID operates in Canada, as well as a brief discussion on where data collection is currently failing, as evidenced by the first three interim government reports on MAID.[3] Finally, this article will propose that the federal government should set up a national MAID registry for MAID cases successfully or unsuccessfully carried through, based on the current structure of the Canadian cancer registry system. Setting up a system that assembles valid, consistent, reliable, and uniform data on all known MAID patients in defined populations whose demographic characters are known will ensure that future policies are based on accurate and reliable evidence.

II. MONITORING MAID IN CANADA

With MAID having been initiated in Canada in 2016, the provinces and territories have been tasked with tracking cases that have occurred.[4] This is due to the practical implication of the division of powers in Canada, whereby the federal government may develop appropriate eligibility criteria and safeguards while provinces and territories are responsible

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3 Government of Canada, "Interim Update on Medical Assistance in Dying in Canada June 17 to December 31, 2016" (Ottawa: Government of Canada, 2017), online: <https://www.canada.ca/en/health-canada/services/publications/health-system-services/medical-assistance-dying-interim-report-dec-2016.html> [First Interim Report]; Government of Canada, "2nd Interim Report on Medical Assistance in Dying in Canada" (Ottawa: Government of Canada, 2017), online: <https://www.canada.ca/en/health-canada/services/publications/health-system-services/medical-assistance-dying-interim-report-sep-2017.html> [Second Interim Report]; Government of Canada, "Third Interim Report on Medical Assistance in Dying in Canada" (Ottawa: Government of Canada, 2018), online: <https://www.canada.ca/en/health-canada/services/publications/health-system-services/medical-assistance-dying-interim-report-june-2018.html> [Third Interim Report].

4 *Carter v Canada (Attorney General)*, 2015 SCC 5 at para 117 [*Carter*]; House of Commons, Special Joint Committee on Physician-Assisted Dying, *Medical Assistance in Dying: A Patient-Centred Approach*, 42nd Parl, 1st Sess (February 2016); Government of Canada, "Legislative Background: Medical Assistance in Dying (Bill C-14)," online: <www.justice.gc.ca/eng/rp-pr/other-autre/ad-am/p2.html> [Government of Canada, "Legislative Background"].

for specific policies pertaining to administration of health services.[5] Due to this division of powers, policies relating to implementation and reporting on MAID vary considerably across jurisdictions,[6] so it is vital to develop a coordinated mechanism for tracking cases. This is necessary to ensure consistency in data reporting, to monitor patterns and trends, and to provide transparent and reliable information to the Canadian public.[7] Unfortunately, formal structures have not yet been standardized. While recent reports issued by the federal government are an important step towards creating a comprehensive data collection scheme, there are noticeable gaps and inconsistencies in data collection variables across provinces and territories.

The essentiality of data collection is well recognized. The Canadian government has explicitly acknowledged this by indicating that: (1) Health Canada must lead a cooperative process with provinces and territories to create and analyze national reports on MAID cases, and these reports are to be tabled annually in Parliament; and (2) a mandatory statutory review of applicable federal legislation must be conducted every four years after the coming into force of applicable legislation.[8] Accordingly, within Bill C-14 was the power for the Federal Minister of Health to make regulations establishing a monitoring system. These regulations could allow for collection of data and information relating to MAID, including information provided by medical or nurse practitioners; form, manner, and circumstances in which information was provided; details about how data would be analyzed and reported to the public; and rules for protection and disbursement of such information.[9]

The federal government recently released draft regulations to establish a federal monitoring system,[10] which will come into force on 1 November 2018.[11] The proposed regulations "require medical practitioners, nurse practitioners, and pharmacists to file reports containing certain information related to requests for, and the provision of, medical assistance in dying … within prescribed deadlines."[12] These are then sent to Health Canada, with reports published once a year.[13] Health Canada is currently "developing an online portal jointly with Statistics Canada that will help make it easy to submit the required information and ensure that ... all personal information is protected."[14]

Interim reports released by the federal government are the public's first glimpse at what this system may look like in Canada. While these reports act as a temporary reporting system until the permanent process is fully developed,[15] the *manner* of reporting adopted will likely

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5 First Interim Report, *supra* note 3.
6 Second Interim Report, *supra* note 3.
7 Carter & Rodgerson, *supra* note 2 at 802.
8 Special Joint Committee on Physician-Assisted Dying, *supra* note 4.
9 Bill C-14, *supra* note 1, cl 241.31(3).
10 Monitoring of Medical Assistance in Dying Regulations, (2017) C Gaz I:151:50, 4917, online: <www.gazette.gc.ca/rp-pr/p1/2017/2017-12-16/html/reg6-eng.html> [Proposed Regulations].
11 Government of Canada, "Backgrounder: Regulations for Monitoring Medical Assistance in Dying" (August 2018), online: <https://www.canada.ca/en/health-canada/news/2018/08/backgrounder-regulations-for-monitoring-medical-assistance-in-dying.html> [Government of Canada, "Backgrounder"].
12 Proposed Regulations, *supra* note 10 at 4918. According to the proposed regulations, reporting requirements would vary based on the type of request (that is, if the request was withdrawn, the patient died of other natural causes, and so on).
13 *Ibid*.
14 Government of Canada, "Backgrounder," *supra* note 11.
15 Government of Canada, "Medical Assistance in Dying," online: <https://www.canada.ca/en/health-canada/services/medical-assistance-dying.html>.

be similar given that other international jurisdictions with legalized assisted death have implemented similar processes.[16] The Oregon Public Health Division is required to collect compliance information from reporting forms and death certificates and issue an annual report to the public.[17] Regional euthanasia review committees in the Netherlands gather reports from attending physicians and municipal pathologists to ensure compliance with the legislation, make a record of all reported cases, and submit a joint annual report to the Ministers of Justice and Health.[18]

The few jurisdictions permitting assisted death — including Canada, as evidenced by the proposed regulations — have yet to move away from this reporting structure to a comprehensive patient registry system that collects and allows for analysis of massive quantities of data essential to improving health care[19] even though patient registries can serve as powerful tools. Such registries assist with observing the course or history of a disease, understanding variations in treatment and outcomes, assessing effectiveness and disparities in care delivery, monitoring safety and harm, and improving quality of care.[20] Registries have great potential to ensure high standards and quality, and better data will create better policy.[21]

The authors argue that the potential for a MAID-focused registry is extensive. Registry data analytics could be used to turn large amounts of data into actionable information across a wide range of scenarios, including (but not limited to): identifying those who would benefit from preventative care by analyzing trends within collected patient profiles; identifying and minimizing potentially coercive or negligent behaviour by medical or health professionals; identifying regions where end-of-life care options are limited and investing in necessary improvements could increase access and quality of care; and greatly expanding research and development related to MAID.[22]

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16 The scope of information in the Canadian interim report is limited compared to other data summaries of international jurisdictions, discussed more in depth in Part IV, below.

17 See Public Health Division, Center for Health Statistics, "Oregon Death with Dignity Act: Data Summary 2016" (10 February 2017), online: <www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year19.pdf>. Similarly, the Washington State Department of Health releases an annual summary from data collected from required documents submitted by attending physicians and pharmacies to the Department: Washington State Department of Health, "2015 Death with Dignity Act Report: Executive Summary," online: <https://www.doh.wa.gov/portals/1/Documents/Pubs/422-109-DeathWithDignityAct2015.pdf>.

18 See Regional Euthanasia Review Committees, *Annual Report 2015* (The Hague: RTE, 2016), online: <https://www.euthanasiecommissie.nl/binaries/euthanasiecommissie/documenten/jaarverslagen/2015/april/26/jaarverslag-2015/Jaarverslag2015ENG.pdf>.

19 See Wullianallur Raghupathi & Viju Raghupathi, "Big Data Analytics in Healthcare: Promise and Potential" (2014) 2:3 Health & Information Science & Systems 1.

20 See Richard E Gliklich, Nancy A Dreyer & Michelle B Leavy, eds, *Registries for Evaluating Patient Outcomes: A User's Guide*, 3rd ed (Rockville, Md: Agency for Healthcare Research and Quality, 2014), online: <https://www.ncbi.nlm.nih.gov/books/NBK208616/>. See also Statistics Canada, "Canadian Cancer Registry (CCR)," online: <www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&SDDS=3207#a1>.

21 Information collected in the national cancer registry system is used to assist and support health planners and decision-makers at all levels of government to identify risk factors; plan, monitor and evaluate cancer-related initiatives; and research. See Statistics Canada, "Canadian Cancer Registry (CCR)," *ibid*.

22 See Raghupathi & Raghupathi, *supra* note 19 at 2–3.

Some criticisms have emerged in relation to patient registries,[23] the most relevant to a potential MAID registry being that meta-analysis across registries may be challenging, especially where competing registries are collecting different data from the same patients over a different period, as well as lack of resources and privacy concerns.[24] However, the usual problems with patient registry meta-analysis can be minimized in a MAID registry if the core data being collated in each location can be standardized while allowing for a location to collect optimal information as they see fit. While these concerns are discussed further below, it is vital to stress that despite the expressed concerns over registries, such systems yield significant research,[25] greatly improve clinical effectiveness and treatment options, and aid in monitoring patient safety.[26]

III. LEGAL FRAMEWORK

In February 2015, the Supreme Court of Canada in *Carter*[27] unanimously declared that certain provisions of the *Criminal Code*[28] prohibiting MAID were unconstitutional. The Supreme Court held that the provisions infringed section 7 of the *Canadian Charter of Rights and Freedoms*[29] and were thus void

> insofar as they prohibit physician-assisted death for a competent adult person who (1) clearly consents to the termination of life; and (2) has a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition.[30]

The Supreme Court suspended this declaration of invalidity for one year[31] during which Parliament could craft an appropriate legislative response to MAID in Canada. Consequently, the federal government held the burden of establishing clear rules as to who is eligible to obtain MAID, what safeguards must be in place to protect vulnerable individuals, and to

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23 Many criticisms are not applicable to a potential MAID registry. For instance, patient-generated registries have been criticized because only well-educated and able-bodied patients have meaningful participation. Furthermore, concerns relating to tissue samples submitted to biobanks have proven to be controversial. See Thomas A Workman, "Engaging Patients in Information Sharing and Data Collection: The Role of Patient-Powered Registries and Research Networks" (Rockville, Md: Agency for Healthcare Research and Quality, 2013) at 4, online: <https://www.ncbi.nlm.nih.gov/books/NBK164513/pdf/Bookshelf_NBK164513.pdf>.

24 *Ibid*.

25 *Ibid*. There are also ethical concerns surrounding using health information for research purposes. Applicable regulatory requirements can allay these concerns. See European Union Rare Diseases Task Force, "Patient Registries in the Field of Rare Diseases: Overview of the Issues Surrounding the Establishment, Management, Governance and Financing of Academic Registries" (2011) at 15, online: <www.eucerd.eu/?post_type=document&p=1218>. See also Nimi Bassi et al, "Big Data and Data Analytics" (2016) Canadian Health Information Management Association, Professional Practice Brief 0041.16 at 6–7, online: <https://www.echima.ca/uploaded/pdf/emails/0041.16_Big%20Data%20and %20Data %20Analytics.pdf>.

26 European Union Rare Diseases Task Force, *ibid* at 5–7. Furthermore, the national cancer registry system has internal processes to eliminate duplicate or conflicting information: see Statistics Canada, "Canadian Cancer Registry (CCR)," *supra* note 20.

27 *Supra* note 4. See Carter & Rodgerson, *supra* note 2 for an in-depth discussion on the history of assisted dying in Canada and legal developments moving forward.

28 RSC 1985, c C-46.

29 Part I of the *Constitution Act, 1982*, being Schedule B to the *Canada Act 1982 (UK)*, 1982, c 11 [*Charter*].

30 *Carter*, *supra* note 4 at para 127.

31 *Ibid* at para 128.

create a monitoring regime to ensure consistency across Canada to obtain accountability, transparency, and public trust.[32]

On 17 June 2016, Bill C-14,[33] received royal assent, thus drastically altering the Canadian approach to end-of-life care.[34] While this new legislative scheme amended the criminal law to permit professionals to provide MAID,[35] it did so under restrictive legislative eligibility requirements, in that individuals requesting MAID must:

- be eligible for health services funded by a government in Canada;
- be at least 18 years old and capable of making decisions with respect to their health;
- have a grievous and irremediable medical condition, meaning they have a serious and incurable illness, are in an advanced state of irreversible decline in capability or physical/psychological suffering intolerable to them and cannot be relieved under conditions considered acceptable, and their death has become reasonably foreseeable;
- have made a voluntary request for MAID that was not made as a result of external pressure; and
- give informed consent to receive MAID after having been informed of the means available to relieve their suffering, including palliative care.[36]

In addition to these eligibility requirements, the government set out an extensive list of safeguards in the new legislation, including ensuring that individuals understand they may withdraw their request at any point, that two independent medical professionals have written opinions confirming the patient meets all requirements, and there is at least a ten-day period between the day on which the request was originally signed and the day on which a second medical professional conducts an independent second review.[37] Any medical professional that does not comply with these new safeguards is guilty of an offence and liable to not more than five years imprisonment on conviction on indictment, or eighteen months imprisonment on summary conviction.[38]

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32 *Ibid*.

33 *Supra* note 1.

34 Government of Canada, "Legislative Background," *supra* note 4.

35 The government chose to add an exemption to protect medical practitioners and nurse practitioners from being persecuted under section 241(b) of the *Criminal Code* (*supra* note 28, ss 241(2)–(7)). That is, the government left section 241(b) in place to prevent against anyone other than a medical professional from carrying out any act of euthanasia or assisted suicide.

36 *Criminal Code*, *ibid*, s 241.2(1)–(2). Any person who has not reached the age of majority or has limited mental capacity due to a disability or otherwise is not eligible under the new legislative scheme. As per clause 9.1(1) of Bill C-14 (*supra* note 1), the Ministers of Justice and Health must, no later than 180 days after the day on which the *Act* receives royal assent, initiate one or more independent reviews of issues relating to requests by mature minors for MAID, to advance requests and to requests where mental illness is the sole underlying medical condition. In December 2016, the federal government announced these reviews will be conducted by the Council of Canadian Academies (CCA), an independent organization that undertakes evidence-based, expert assessments to support and inform public policy development in Canada: Government of Canada, "Medical Assistance in Dying," *supra* note 15.

37 An abridgment of the ten days is permitted if there is a concern the patient may lose capacity: *Criminal Code*, *ibid*, s 241.2(3)(g). For a complete list of safeguards, see *ibid*, s 241.2(3).

38 *Ibid*, s 241.3.

IV. CURRENT GAPS AND INCONSISTENCIES IN REPORTING

Since the new legislation received royal assent, the federal government has been working with the provinces and territories to support its implementation.[39] As part of this collaboration, the federal government and provinces and territories have agreed to provide interim updates while regulations for the federal monitoring system are under development, the third of which was recently released.[40] The first report covers the first six months during which MAID was available in Canada (17 June to 31 December 2016).[41] The second report covers 1 January 2017 to 20 June 2017.[42] The third report covers 1 July 2017 to 31 December 2017.[43]

As revealed in the reports, Health Canada is collecting data on the following from most provinces and territories:

- aggregate number of medically assisted deaths;
- basic information on persons receiving MAID including age and gender;
- most common underlying health conditions of persons receiving MAID;
- circumstances surrounding MAID procedures, including number of clinician-administered deaths (i.e. voluntary euthanasia) and number of self-administered death (i.e. assisted suicide); and
- setting in which MAID occurred.[44]

Aside from data suppression concerns,[45] divergent reporting standards between locations and possibly within a single jurisdiction, have led to troubling gaps in reporting. For instance, the underlying health condition was not reported in 8 percent of all reported cases.[46] Not all jurisdictions have reported on the number of inquiries, requests, and refusals in requests for MAID.[47] Furthermore, the total number of reported medically assisted deaths may not equal the number of requests made less number of requests denied, as withdrawn requests or patients who die from natural causes are not consistently recorded.[48] The Ontario Ministry of Health and Long-Term Care has directed Ontario physicians that for MAID cases, the illness or disease leading to the request for MAID is to be recorded as the underlying cause

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39 First Interim Report, *supra* note 3.
40 *Ibid*; Third Interim Report, *supra* note 3.
41 First Interim Report, *ibid*.
42 Second Interim Report, *supra* note 3.
43 Third Interim Report, *supra* note 3.
44 First Interim Report, *supra* note 3; Second Interim Report, *supra* note 3; Third Interim Report, *ibid*.
45 Data suppression issues in numerous provinces and territories exist due to various restrictions on privacy. That is, providing information of significant levels of detail risks revealing information that may inadvertently reveal personal health information. Consequently, the First Interim Report does not include data from Nunavut or the Yukon; the second report does not include data from Nunavut, the Yukon, or the Northwest Territories. The report has included these numbers in the national roll-up, where possible. See First Interim Report, *ibid*; Second Interim Report, *ibid*; Third Interim Report, *ibid*.
46 First Interim Report, *ibid* at n 6; Second Interim Report, *ibid* at 6, n €. See also Third Interim Report, *ibid* at 11, n ‡.
47 Second Interim Report, *ibid* at 7, 13; Third Interim Report, *ibid* at 10–11.
48 Second Interim Report, *ibid* at 7; Third Interim Report, *ibid* at 7, 9.

of death and will be selected for vital statistics. "No reference to MAID or the drugs administered for the purpose of MAID" are to be included on death certificates in that jurisdiction.[49] For data that is available, variables collected by individual provinces and territories vary.[50] For instance, the Alberta government lists institutional versus home-based medically assisted deaths while other jurisdictions specify hospital, nursing home, hospice, or other settings.[51]

The fact that these interim reports are inadequate is unsurprising since the federal government is currently developing a new monitoring system.[52] These gaps in reporting, and inconsistency in available data, nonetheless underpin the importance of a standardized reporting system. Consider the overarching goal of the new MAID legislation: to balance individual autonomy and dignity at the end of life with the protection of vulnerable persons.[53] By utilizing comprehensive analytics enabled through a registry system model, the federal government can best examine this balancing act. Data compiled on both a personal and population-level basis can be used to: (1) improve end-of-life care to informed, consenting individuals living with unbearable suffering; and (2) ensure safeguards are protecting vulnerable individuals.

V. RECOMMENDATIONS

In accordance with one of the six core functions of public health — namely, health surveillance[54] — a model for a registry system already exists in the national cancer registry system, a collaborative and dynamic patient-based system that provides a database of information to produce standardized statistics on cancer in Canada.[55] It is proposed that rather than reinvent a new registry model, each province or territory should establish a comparable reporting system for MAID cases based on the Canadian Cancer Registry's (CCR) and provincial and territorial cancer registries' accepted models of high standards and quality.

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49 Letter from Government of Ontario, Ministry of Health and Long-Term Care to all Ontario physicians (June 2017), online: <www.cpso.on.ca/CPSO/media/documents/Policies/Policy-Items/MAID-Bill-84-passage-letter-to-physicians-Jun2017.pdf>.

50 Given variations in reporting requirements under its provincial legislation, findings in the First Interim Report do not include the province of Quebec. See First Interim Report, *supra* note 3 at n 1. Data in the Second Interim Report was compiled from publicly available reports posted on the websites of Quebec's health and social services institutions but does not represent official provincial data. See Second Interim Report, *supra* note 3 at 4. See also Third Interim Report, *supra* note 3 at 4–5.

51 First Interim Report, *ibid*.

52 See Second Interim Report, *supra* note 3 at 3; Proposed Regulations, *supra* note 10; Third Interim Report, *supra* note 3 at 12.

53 Government of Canada, "Medical Assistance in Dying: Overview of Federal Government Response" at 4, online: <justice.gc.ca/eng/cj-jp/ad-am/docs/overview.pdf>. These objectives are reflected in the Preamble of Bill C-14, *supra* note 1.

54 Government of Canada, *The Chief Public Health Officer's Report on the State of Public Health in Canada 2008: Addressing Health Inequalities* (Ottawa: Minister of Health, 2008), online: <www.phac-aspc.gc.ca/cphorsphc-respcacsp/ 2008/fr-rc/pdf/CPHO-Report-e.pdf>.

55 Data from provincial and territorial cancer registries is submitted and collated nationally in the Canadian Cancer Registry (CCR). In 1992, the CCR emerged from the National Cancer Incidence Reporting System established in 1969. The data is maintained through collaboration with the 13 provincial and territorial registries and the Health Statistics Division of Statistics Canada. See Alberta Health Services, "Surveillance & Reporting Activities," online: <www.albertahealthservices.ca/cancer/ Page2171.aspx>. See also Statistics Canada, "Canadian Cancer Registry (CCR)," *supra* note 20.

Every jurisdiction in Canada has a public cancer registry, operated by a cancer agency or subsumed by some government department. These population-based cancer registries compile identifying features of Canadians living with cancer along with their medical characteristics. This information is essential for surveillance of cancer over time and by geographic area, for collaboration with multiple stakeholders to improve research and clinical outcomes, and to respond to community inquiries and facilitate community awareness.[56]

A comparable MAID registry could be created by having each province and territory send representatives to a national gathering augmented by appropriate staff from Statistics Canada. This registry should assemble identifying features of persons who have requested MAID — whether or not it was carried out — as well as MAID applicants' underlying medical characteristics. Setting up a MAID registry that assembles data on all MAID applicants in a defined population whose demographics are known — in other words, setting up a population-based MAID registry — would assist in ensuring that future policy discussions are based on accurate and reliable evidence.[57] This is vital moving forward since findings from any reported data are only as good as the original facts upon which they rest.

The CCR and provincial and territorial cancer registry model is appropriate for two main reasons: (1) there is significant overlap between MAID patients and cancer patients; and (2) the high standards and quality of data produced by Canadian cancer registries. First, cancer is the most frequently cited medical condition associated with MAID deaths (65 percent).[58] With high rates of cancer in Canada — 19,685 Albertans are expected to be diagnosed with cancer in 2017 alone[59] — and considering the high rate of cancer-related assisted deaths in foreign jurisdictions,[60] the overlap between MAID and cancer patients will undoubtedly continue. Given this overlap, a small subset of reported cancer cases in the national cancer registry system would parallel a major core of the MAID registry system: individuals specified as having cancer and contained in the MAID registry would also be found in the provincial or territorial cancer registry. Both registry systems could be linked together through numerous common denominators such as age, gender, and disease entity.[61] Both registry systems could then provide population-based data to augment information being provided to Vital Statistics and subsequently Statistics Canada.

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56 Pierre R Band et al, *The Making of the Canadian Cancer Registry: Cancer Incidence in Canada and its Regions, 1969 to 1988* (Ottawa: Statistics Canada, 1993) at 1. See also Alberta Health Services, "Surveillance & Reporting Activities," *ibid*.

57 One province (Alberta) has already recognized the potential of a central registry office, based on recent consultations with patients, health care professionals, academia, the legal profession, and other stakeholder groups: Government of Alberta, *Alberta Health: What We Heard: Medical Assistance in Dying* (Edmonton: Government of Alberta, 2016) at 12 [Government of Alberta, *What We Heard*].

58 Third Interim Report, *supra* note 3 at 9.

59 "Alberta Health Services 2017 Report on Cancer: By-the-Numbers" *Leap Magazine* (Fall 2017) 9.

60 Cancer represents the most common underlying medical condition among those receiving assistance in dying: First Interim Report, *supra* note 3; Second Interim Report, *supra* note 3 at 6; Third Interim Report, *supra* note 3 at 9.

61 National linkage between the CCR, Canadian Vital Statistics Death Database, and the potential MAID registry would be important to reduce duplicate records, identify missing cases, and enhance the accuracy of vital statistics information: Statistics Canada, "Canadian Cancer Registry (CCR)," *supra* note 20.

Second, the CCR and individual provincial and territorial cancer registries are known for their compilation of essential information and have been the foundation for countless research programs and papers, helping to improve the quality of care in Canada while saving health care costs.[62] In 2015, the North American Association of Central Cancer Registries awarded ten Canadian provinces and territories a Gold Standard for complete, accurate, and timely data.[63] Consequently, the national cancer registry system, aided by cancer being a reportable disease, provides an appropriate model for ensuring acceptable standards of validity, consistency, reliability, and uniformity; validity in terms of its applicability to the problem at hand and ensuring what is recorded is that which is intended to be recorded and reflective of the true situation; consistency in terms of labeling and definitions used — what is meant by "home," "hospital," or "hospice?"; reliability as the degree of variability in a measuring instrument, ensuring a given measure can generate the same results under similar circumstances; and, when coding or abstracting, uniformity in terms of consistent translation of information from one form to another to ensure that variation does not occur. Similar to the cancer registry with cancer being a reportable disease, a MAID registry would have an advantage of each MAID qualifier being reported. By following this well-established national cancer registry model, a national MAID registry has great potential to ensure that accurate and comprehensive data is collected and recorded.

Major distinctions between these two registries will exist. Due to the high incidence of cancer in Canada,[64] a major distinction between the national cancer registry system and a MAID registry system would be the sheer number of reported cases. The extent of data obtained would also be drastically different since a cancer case typically involves a greater number of involved physicians, more variables, and a longer period of time over which those variables are recorded as continuing updates for a given cancer patient are collected. In contrast, the number of variables being collected for a potential MAID registry would be relatively limited and the registry would essentially take a "snapshot" of a patient's death at a specific point in time without further updates. This smaller database — in numbers of registrants, fewer parameters for each registrant, and a more finite data collection period — will minimize the common problems experienced by *large-scale* patient registries as mentioned above in Part II, particularly the resources required to establish and maintain such a structure.

By exploring and implementing a similar system to the national cancer registry system, provinces and territories can best explore the following questions: how will the MAID registry be structured? How should cooperation with the medical profession be approached?

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62 Barbara von Tigerstrom & Nola M Ries, "Cancer Surveillance in Canada: Analysis of Legal and Policy Frameworks and Tools for Reform" (2009) 17 Health LJ 1.

63 These included British Columbia, Alberta, Saskatchewan, Manitoba, New Brunswick, Newfoundland, Nova Scotia, Prince Edward Island, Northwest Territories, and the Yukon. See North American Association of Central Cancer Registries, "Dynamic Certified Registries," online: <https://www.naaccr.org/dynamic-certified-registry-old/#1480681725248-4a4d1363-cba2>.

64 An estimated 206,200 new cases of cancer and 80,800 deaths from cancer would occur in Canada in 2017: Canadian Cancer Society, *Canadian Cancer Statistics 2017* (Toronto: Canadian Cancer Society, 2017) at 6, online: <www.cancer.ca/~/media/cancer.ca/CW/cancer%20information/cancer%20101/Canadian%20cancer%20statistics/Canadian-Cancer-Statistics-2017-EN.pdf?la=en>. This is compared to 1,982 MAID-related deaths between 17 June 2016 and 30 June 2017: Second Interim Report, *supra* note 3 at 5.

What data will be requested? How will concerns of confidentiality be dealt with appropriately?

A. STRUCTURE

To begin, the administrative structure of a proposed MAID registry could be closely based on the current structure of the CCR system, with constitutional law providing the ultimate framework. Local health care delivery, including maintaining cancer registries and regulation of personal information used within the health sector, is a provincial and territorial responsibility.[65] Further, the provinces and territories have ultimate authority and responsibility for completeness and quality of data[66] and the federal government has constitutional jurisdiction over census and statistics.[67] This does not preclude establishing such a registry system, however, because the federal government operates Statistics Canada — a national data agency operating under authority of federal legislation — which is still able to collect information on cancer data via agreements and collaboration with provinces and territories for the exchange of data.[68]

This provincial and territorial autonomy arising from the constitutional division of powers has resulted in a "patchwork"[69] legislative framework for setting up registries, with provincial and territorial cancer registries' structures varying across the country. The legislative frameworks for collecting information involve various statues and regulations specific to each province and territory. While some jurisdictions have implemented statutes or regulations specific to cancer,[70] others have implemented cancer-specific provisions in their public health statutes or regulations.[71] Others still have no cancer-specific legislative provisions, though they have relevant provisions that generally address health and surveillance.[72] Consequently, the legislative framework for collection, use, and disclosure of MAID-related health information can and will vary across provinces and territories. Some jurisdictions have already taken steps to address their ideal legislative framework in which MAID reporting should operate.[73]

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65 These powers derive from provincial constitutional authority in relation to "the Establishment, Maintenance, and Management of Hospitals," "Property and Civil Rights in the Province," and "Generally all Matters of a merely local or private Nature in the Province" (*Constitution Act, 1867* (UK), 30 & 31 Vict, c 3, reprinted in RSC 1985, Appendix II, No 5, ss 92(7), 92(13), 92(16) [*Constitution Act*]). See also D Forman et al, eds, *Cancer Incidence in Five Continents*, vol x (Lyon, France: International Agency for Research on Cancer, 2014) at 192.

66 Statistics Canada, "Canadian Cancer Registry (CCR)," *supra* note 20.

67 *Constitution Act*, *supra* note 65, s 91(6).

68 von Tigerstrom & Ries, *supra* note 62 at 5, 13.

69 *Ibid* at 31.

70 This includes British Columbia, Alberta, Saskatchewan, Manitoba, and Ontario (*ibid* at 9).

71 This includes British Columbia, Manitoba, Nova Scotia, Prince Edward Island, Northwest Territories, and Nunavut (*ibid*).

72 *Ibid*.

73 Ontario and Quebec remain the only provinces with provincial legislation pertaining to the monitoring and reporting of MAID. See Bill 84, *An Act to amend various Acts with respect to medical assistance in dying*, 2nd Sess, 41st Leg, Ontario, 2017 (assented to 10 May 2017), SO 2017, c 7. The legislation ensures that insurance benefits that would otherwise be paid out to individuals are not denied because of a MAID death, provides protections to practitioners from civil liability when lawfully providing MAID, and requires health providers to notify the Chief Coroner of all MAID deaths. See Government of Ontario, "Backgrounder: The Medical Assistance in Dying Statute Law Amendment Act" (7 December 2016), online: <https://news.ontario.ca/mohltc/en/2016/12/the-medical-assistance-in-dying-statute-law-amendment-act.html>. Quebec's *Act Respecting End-of-Life Care*, RSQ 2014, c S-32.0001, s 8 mandates that the "executive director" of all institutions must adopt a policy with respect to end-of-life care and report annually to their board of directors on number of requests for MAID and the number

It is undoubtedly tempting to use federal regulations to outline minimum data collection requirements.[74] However, the Canadian experience with the cancer registry system suggests that provinces and territories should maintain their own autonomy, be able to opt in or out of each proposed variable, keep data on their *own* databases, and maintain ultimate authority and responsibility for the degree of coverage and quality of data submitted to Statistics Canada, as was the case with establishing the CCR.[75] Collaboration between provinces and territories and a national body, such as the Canadian Council of Cancer Registries, can successfully establish effective national definitions and standards.[76]

In practice, this complicates matters slightly. To begin, the current approach to information sharing primarily relies on "ad hoc" informal collaboration between provinces and territories.[77] This creates somewhat of an inconsistent approach to data sharing and raises questions as to whether these agreements have proper legal authority.[78] Issues of ethics with surveillance and data sharing also arise;[79] the inherent tension between the risk of violating Canadians' privacy and anticipated health benefits resulting from comprehensive health activities raises a number of ethical questions that should enhance and broaden any governments' decision-making.[80]

Despite the divergence in legislative frameworks, the provincial and territorial cancer registries are similar in intent on basic issues. Typically, the provinces and territories employ registry staff involved in coding and abstracting, quality assurance activities, passive follow up activities with Vital Statistics, case ascertainment, and research projects.[81] Provincial and territorial vital statistics legislation mandates registration of all reportable cancers from diagnostic facilities and medical practitioners within the province.[82] Statistics Canada, Canada's national statistical agency, operates under authority of the federal *Statistics Act*,[83] which authorizes it to collect, analyze, and publish statistics on health. After provinces and territories collect and store population-based cancer incidence data in their respective cancer registry, Statistics Canada then collects that data through agreements and collaboration with provincial governments for the exchange of data.[84] The CCR, operated by Statistics Canada,

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of times MAID was administered or not administered (and reasons for or against). Alberta currently collects MAID data pursuant to the *Health Information Act*, RSA 2000, c H-5.

74 As evidenced by the Proposed Regulations, *supra* note 10.

75 See Statistics Canada, "Cancer Incidence in Canada: About the Canadian Cancer Registry," online: <www.statcan.gc.ca/pub/82-231-x/2010001/part-partie1-eng.htm>.

76 *Ibid*.

77 Pan-Canadian Public Health Network, "Blueprint for a Federated System for Public Health Surveillance in Canada: Vision and Action Plan" (2016) at 15, online: <www.phn-rsp.ca/pubs/bfsph-psfsp-2016/pdf/bfsph-psfsp-2016-eng.pdf>.

78 *Ibid*.

79 See e.g. Comité d'Éthique de Santé Publique, Government of Quebec, "Summary of Ethical Concerns Raised in the Surveillance Plans Reviewed by the Comité d'Ethique de Santé Publique Between 2003 and 2012" (Quebec City: Government of Quebec, 2016).

80 For instance, governments should consider practical applications of ethics in health surveillance to ensure that data is only acquired that is reasonably necessary to achieve a specific purpose, that the data is used only for that legitimate purpose, that the data is subject to strict privacy and confidentially standards, and that the data is appropriately stored: see Pan-Canadian Public Health Network, *supra* note 77 at 13–14; *ibid*.

81 Statistics Canada, "Canadian Cancer Registry (CCR)," *supra* note 20.

82 For the Alberta legislative regime, see *Regional Health Authorities Act*, RSA 2000, c R-10; *Cancer Registry Regulation*, Alta Reg 71/2009; *Vital Statistics Act*, SA 2007, c V-4.1; *Vital Statistics Information Regulation*, Alta Reg 3/2012; *Vital Statistics Ministerial Regulation*, Alta Reg 12/2012.

83 RSC 1985, c S-19.

84 See von Tigerstrom & Ries, *supra* note 62 at 13.

compiles this data and publishes an annual report containing pan-Canadian incidence and survival information for cancer control.[85]

B. COOPERATION WITH THE MEDICAL COMMUNITY

Provincial and territorial governments must then weigh their options to encourage optimal and consistent participation in the proposed MAID registries. While a consistent national approach to establishing a MAID registry system is desirable, the Canadian experience with cancer registries has demonstrated that a pan-Canadian registry system can be developed from regional systems which differ in approaches and methods as outlined in their respective provincial and territorial health acts. Surveillance may be passive or active; mandated by law or voluntary. Differing greatly between the provinces and territories, participation with a registry system may be encouraged by financial incentive,[86] reportable by law,[87] or enabled by policy[88] or protective or endorsing legislation.[89] Each province or territory's experience with their respective cancer registry will likely dictate how the province or territory would approach the establishment of a MAID registry.

C. VARIABLES

Provincial and territorial governments must also choose what variables they request. It is imperative to keep in mind that, generally, the more complete the population base, the more reliable the inferences drawn. With fewer assessments and number of physicians assisting MAID patients as compared to cancer documentation, the amount of information should be easier to manage. The success of any registry is in jeopardy if cases are excluded because of the demand for excessive details.[90] The authors recognize the need for clarification between this statement and the overall goals of establishing a comprehensive monitoring system, as discussed above. Certainly, broad participation and multiple variables are desirable to achieve these goals. Experience dictates, however, that while this is a commendable goal, it may be difficult (if not impossible) to get agreements between the federal and provincial and territorial governments on such a wide scope. The authors therefore believe that it is preferable to start with something manageable, and expand its scope over time.

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85 Forman et al, *supra* note 65 at 192.

86 In Saskatchewan, for example, physicians are required to report all new cancer diagnoses to the registry to be eligible for cancer payments under their universal plan (*ibid* at 214).

87 For example, Manitoba (*ibid* at 198).

88 For example, British Columbia (*ibid* at 196).

89 For example, Ontario and Alberta (*ibid* at 208, 194). The Alberta Cancer Registry uses a passive case finding approach as reports such as pathology, cytology, scans, and others, are sent to the registry (*ibid* at 194).

90 See J Knowelden, T Mork & AJ Phillips, eds, *The Registry in Cancer Control* (Geneva: International Union Against Cancer, 1970) at 18.

Evidence from other jurisdictions' experiences with assisted dying indicates that most legally binding safeguards are adhered to in reported cases.[91] One of the greatest challenges at the outset, though, is ensuring that cases are being reported: in the Netherlands the reporting rate is 80 percent, while it is 53 percent in Belgium.[92] The primary reasons for non-reporting appear to be differences in labelling and awareness of reporting obligations,[93] which underscores the need for provinces and territories to agree on identical variables and definitions to ensure adequate and consistent minimum reporting to the national Canadian registry.

Looking to various jurisdictions can guide the governments' decision as to what variables are relevant and the best forum to collect information relating to those variables. Based on publicly available information, Alberta Health Services (AHS) appears to have the most comprehensive model in place (compared to other Canadian jurisdictions) in terms of variables collected and frequency of reporting. AHS collects data through standardized forms[94] and breaks down MAID data into two sections. Section 1 includes cumulative provincial data on zone, setting, and number of approved MAID cases.[95] Section 2 includes the average age of patients, number of people who did not meet federal mandatory eligibility requirements and common reasons why, the most cited underlying health conditions, and number of patients transferred from faith-based or non-participating institutions to participating institutions. This data is updated on a monthly basis.[96] The Alberta MAID Regulatory Review Committee collects information from standardized forms "for the purpose of confirming that the requirements of standards and legislation applicable to [MAID] are met."[97]

Information on individuals that initiated the process but did not complete it for whatever reason should also be collected and categorized accordingly. These cases may include individuals that do not meet legal requirements, those that initiated the process but died from natural causes before MAID was carried out, and those who withdrew their request for MAID prior to it being carried out.

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91 There is no evidence in Oregon, Belgium, or the Netherlands that individuals who have not been diagnosed with a terminal illness are receiving assistance in dying; there is no evidence that incompetent individuals are receiving assistance in dying in Switzerland, the Netherlands, or Oregon; recent reported cases in the Netherlands and Belgium have all met voluntariness criterion when examined by reviewing bodies; restrictions on age appear to be well observed in all jurisdictions; having two independent physicians assess the patient appears to be effective in screening out any voluntariness concerns; and in the Netherlands, Belgium and Oregon, the consultation requirements are met in virtually all reported cases. See Penney Lewis & Isra Black, "The Effectiveness of Legal Safeguards in Jurisdictions that Allow Assisted Dying," *Commission on Assisted Dying* (London, UK: Demos, 2012) at 64.

92 *Ibid* at 69.

93 *Ibid* at 70.

94 See Alberta Health Services, "Medical Assistance in Dying: Patients and Families," online: <https://www.albertahealthservices.ca/info/Page14380.aspx>; Alberta Health Services, "Medical Assistance in Dying: Health Professionals and Volunteers," online: <https://www.albertahealthservices.ca/info/Page14381.aspx>.

95 Alberta Health Services, "Medical Assistance in Dying: Data and Stats," online: <https://www.albertahealthservices.ca/info/Page14930.aspx>.

96 *Ibid*.

97 This information is collected pursuant to the *Health Information Act*, *supra* note 73, ss 20(b), 21, 22(1), 27(1)(g), 27(2)(a)–(b), 27(d). See Alberta Government, "Record of Request Form for Medical Assistance in Dying," online: <www.health.alberta.ca/health-info/medical-assistance-dying.html>.

Currently, only some provinces provide information about the number of inquiries for MAID and whether these requests were declined, withdrawn, or unfulfilled.[98] Yet, there is valuable information to gain from data on cases in which MAID was not carried out. For instance, common reasons for denying MAID can inform policymakers as to whether there are current barriers to accessing MAID: is the requirement that the applicant's death be reasonably foreseeable too restrictive? Are large numbers of applicants being denied solely because they suffer from mental illness or are mature minors? Are delays in the assessment process preventing applicants from actually receiving MAID? Collecting information related to such questions is crucial to ensure all Canadians have meaningful access to MAID. These variables, considered together with variables collected in other foreign jurisdictions,[99] bear directly on the overarching legislative goals of the new MAID legislation, as discussed above in Part IV.

At a minimum, provincial and territorial governments should collect information on variables relating to statutory eligibility requirements to ensure minimum requirements are met and are adequately protecting vulnerable Canadians. Recent case law has already revealed points of contention on certain requirements and safeguards that may be subject to variability or non-compliance. Variability in opinions over whether a person's condition must be "terminal,"[100] what constitutes a reasonably foreseeable natural death,[101] and whether mental illness may constitute a grievous and irremediable condition,[102] should all be observed closely.

Access to MAID has also been problematic in a variety of ways. Geographical access has been limited since practitioners and entire health-care facilities cannot be legally compelled to participate in MAID.[103] Variables such as setting, zone, and number of patients transferred from faith-based institutions or non-participating institutions to participating institutions should thus be utilized to determine where access is limited. Meaningful access may also be limited due to delays in the assessment process; up to 24 percent of persons requesting MAID (in the second reporting period) in reporting jurisdictions died prior to completion of

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98 Second Interim Report, *supra* note 3 at 7; Third Interim Report, *supra* note 3 at 9.

99 For instance, Oregon collects information on the following variables: sex, age, race, marital status, education, residence, end-of-life care, underlying illness, setting, end-of-life concerns of the patient, and complications with the MAID procedure: Public Health Division, Center for Health Statistics, *supra* note 17 at 9–11.

100 This was recently rejected by the Ontario Superior Court in *AB v Canada (Attorney General*), 2017 ONSC 3759 [*AB*]. See *Canada (Attorney General) v F(E)*, 2016 ABCA 155 at para 41 [*EF*] (severe conversion disorder) where the Alberta Court of Appeal stated that nowhere in *Carter* is the right to assisted death expressly limited only to those who are terminally ill or near the end of life. See also *IJ v Canada (Attorney General)*, 2016 ONSC 3380 at para 19 (not terminal, suffered from spinal stenosis; discogenic disease; neurogenic claudication; lumbosacral facet osetoarthropathy; spondylolisthesis; rotoscoloiosis; major kyphosis; and sacroiliac joint complex pain disorder). These cases were decided before the federal legislation was released, but they may provide insight into how Canadian courts may interpret the "floor" as set out in *Carter*.

101 See *AB*, *ibid* ("what is a reasonably foreseeable death is a person-specific medical question" at para 79).

102 See *EF*, *supra* note 100 at para 59. Considerable disagreement in other jurisdictions also exist over the influence that mental illness may have on capacity to request assisted dying, "exacerbated by the fact that competence itself is a complex concept … and decision-making capacity in dying patients is not clearly understood" (Lewis & Black, *supra* note 91 at 64).

103 See *Criminal Code*, *supra* note 28, s 241.2(9). See also Nicole Ireland, "One Year After Canada's Medically Assisted Dying Law, Patients Face Uneven Access" *CBC News* (18 June 2017), online: <www.cbc.ca/news/health/medically-assisted-dying-access-one-year-later-1.4165936>. There has been a marked increase in the number of deaths taking place at home: Second Interim Report, *supra* note 3 at 6. While it is too early to confirm, there is speculation that this may be in part due to geographical barriers in smaller communities. See Second Interim Report, *ibid* at 8.

the assessment process.[104] Data on timing of assessments can be helpful to ensure all Canadians have meaningful access to MAID.

Beyond that, provinces and territories would maintain their independence to collect any patient-profile related variables believed to be of practical use, such as underlying medical conditions, age, gender, zone (urban versus rural), ethnicity, religion, level of income, and education. Such variables would be useful for research purposes and potentially improving health outcomes by proactively diverting resources to identify those that would benefit from preventative initiatives or better end-of-life options (hospice).

Aside from basic descriptive statistics, the CCR is structured to allow for detailed analyses. Comparative statistics that can be generated by the CCR would be useful for the proposed MAID registry which would, for example, allow for comparisons between genders, age groups, locations, and other variables. As well, correlative and trend analysis would allow the public to have more understanding and confidence in MAID, and assist policy makers moving forward.

D. CONFIDENTIALITY AND PRIVACY

As to confidentiality and privacy, Canadians will likely raise concerns about potential privacy concerns and may wonder why certain variables — such as socio-demographic characteristics that could identify participants — are being collected.

Privacy concerns are certainly a core consideration relating to health surveillance. Yet, as noted by the Comité d'Éthique de Santé Publique, this concern is typically "resolved through the idea of an implicit social contract … in which the population accepts that the information concerning it be collected and used so that health care services and public policies can be implemented to better serve it."[105] As Canada wades into new territory, certain variables — including socio-demographic variables — are necessary for the regime to function properly, achieve the legislative objectives, and better serve the entire Canadian population.[106]

Flowing from this implicit social contract, there is an understanding, from an ethical standpoint, that the recipient of the data will uphold values of human dignity, individual freedom, and autonomy.[107] Beyond that, though, the law is well equipped to deal with these concerns, as a number of laws aimed specifically at protecting private information have been enacted in Canada. Currently, the law prohibits release of information collected that could identify any person, business, or organization unless consent has been given or legislation allows release.[108] Various confidentiality rules apply to all data prior to their release.[109] As

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104 Second Interim Report, *ibid* at 9. This number fell to 14 percent during the third reporting period: Third Interim Report, *supra* note 3 at 9.

105 Comité d'Éthique de Santé Publique, *supra* note 79 at 5.

106 See Proposed Regulations, *supra* note 10.

107 *Ibid* at 14.

108 Statistics Canada, "Canadian Cancer Registry (CCR)," *supra* note 20.

109 Confidentiality rules apply in a number of contexts: the federal government has established personal information protection law, such as the *Personal Information Protection and Electronic Documents Act*, SC 2000, c 5 which applies in some provinces and territories to regulate how organizations like physicians' offices handle personal information. The sharing of personal information must respect privacy interests under the *Charter*, *supra* note 29, especially those rights protected by section 7, the right to personal security, and section 8, the right to be free from unreasonable search and seizure by

recommended in the proposed regulations, applicable government authorities should go a step further and undertake a privacy impact assessment to ensure that all privacy implications are identified and resolved.[110] Proactive consultations with the provincial or territorial privacy commissioner or ombudsperson on handling and protection of personal information would also be helpful to ensure compliance with privacy laws in Canada.[111] These safeguards all assist in ameliorating privacy concerns.

Nonetheless, it is also settled law that patients' personal health information can be disclosed to third parties with their consent, or "as provided for by law" as per applicable provincial or territorial legislation.[112] Consequently, as indicated by the Office of the Information and Privacy Commissioner of Alberta, there must be clear authority for collection, use, and disclosure of personal information and health information required to provide MAID, as discussed above.[113] Such an approach ensures confidentiality rules are respected while building a pan-Canadian MAID registry system.

VI. CONCLUSION

Following the Supreme Court of Canada's decision in *Carter* and subsequent initiation of MAID practices in Canada, thousands of cases have been approved.[114] Yet, it is still early days in attaining standards of tracking MAID accurately, as seen in the federal government interim reports. There is little doubt that further data and more formal ways of presenting it will develop over time, but at this point there are troubling inconsistencies and gaps in

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governmental authorities (see *Cheskes v Ontario (Attorney General)* (2007), 288 DLR (4th) 449 at para 62 (Sup Ct); *R v Plant*, [1993] 3 SCR 281 at 293). The Supreme Court has described the physician-patient relationship as fiduciary which entails that a physician must "hold information received from or about a patient in confidence" (*McInerney v MacDonald*, [1992] 2 SCR 138 at 149) and the Canadian Medical Association has a Code of Ethics and a Health Information Privacy Code which set out ethical principles to guide the medical practice (Canadian Medical Association, "Code of Ethics" (2004), online: <https://www.cma.ca/En/Pages/code-of-ethics.aspx>).

110 Proposed Regulations, *supra* note 10.

111 von Tigerstrom & Ries, *supra* note 62 at 11–12:

> Most Canadian information and privacy legislation establishes the office of an Information and Privacy Commissioner (IPC) to perform functions such as: receive complaints about alleged breaches of personal information protection laws; conduct investigations, hearings and/or audits to ensure compliance with personal information protection laws; make recommendations and/or orders; issue public statements or reports about privacy issues; and determine applications for secondary use of personal information for research, statistical or other purposes.

112 For example, collection is allowed under Alberta's *Health Information Act*, *supra* note 73, if authorized by another enactment, thus the *Cancer Registry Regulation*, *supra* note 73, provides explicit authority for collection, use, and disclosure of relevant data. Other provinces and territories have similar legislative provisions in place. See e.g. British Columbia, *Freedom of Information and Protection of Privacy Act*, RSBC 1996, c 165 and *Laboratory Services Act*, SBC 2014, c 8; Saskatchewan, *The Health Information Protection Act*, SS 1999, c H-0.021 and *The Cancer Agency Act*, SS 2006, c C-1.1; Manitoba, *The Personal Health Information Act*, SM 1997, c 51 and *The Protecting Children (Information Sharing) Act*, SM 2016, c 17; Ontario, *Personal Health Information Protection Act, 2004,* SO 2004, c 3, Schedule A and *eHealth Ontario*, O Reg 43/02; Quebec, *Act Respecting the Sharing of Certain Health Information*, SQ 2012, c 23; New Brunswick, *Personal Health Information Privacy and Access Act*, SNB 2009, c P-7.05 and *Prescription and Catastrophic Drug Insurance Act*, RSNB 2014, c 4; Nova Scotia, *Personal Health Information Act*, SNS 2010, c 41 and *Midwifery Act*, SNS 2006, c 18; Newfoundland and Labrador, *Personal Health Information Act*, SNL 2008, c P-7.01 and *Centre for Health Information Act*, RSNL 2018, c C-5.2; Prince Edward Island, *Freedom of Information and Protection of Privacy Act*, RSPEI 1988, c F-15.01; Nunavut, *Access to Information and Protection of Privacy* Act, SNWT (Nu) 1994, c 20; Yukon, *Health Information Privacy and Management Act*, SY 2013, c 16 and *Child and Family Services Act*, SY 2008, c 1; Northwest Territories, *Health Information Act*, SNWT 2014, c 2 and *Public Health Act*, SNWT 2007, c 17.

113 See Government of Alberta, *What We Heard*, *supra* note 57 at 12.

114 See Third Interim Report, *supra* note 3.

reporting. National Canadian standards must be established prior to individual provinces and territories moving in their own directions and establishing inconsistent reporting regimes. The federal government must gain the public's trust and ensure that the legislative scheme for MAID is being followed. Establishing a national registry for MAID cases can assist the government in accomplishing these goals. As demonstrated by the cancer registry system in Canada, such a reporting system for MAID would encourage comprehensive data reporting, facilitate assessments in the effectiveness and disparities in MAID practices across the country, enable accessibility, ensure safeguards are effective, and improve quality of care.