

THE STATE OF KNOWLEDGE ON MEDICAL ASSISTANCE IN DYING WHERE A MENTAL DISORDER IS THE SOLE UNDERLYING MEDICAL CONDITION

The Expert Panel Working Group on MAID
Where a Mental Disorder Is the Sole
Underlying Medical Condition

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Is the Sole Underlying Medical Condition**

THE COUNCIL OF CANADIAN ACADEMIES

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This report was prepared for the Government of Canada in response to a request from the Minister of Health and the Minister of Justice and Attorney General of Canada. Any opinions, findings, or conclusions expressed in this publication are those of the authors, the Expert Panel Working Group on MAID Where a Mental Disorder Is the Sole Underlying Medical Condition, and do not necessarily represent the views of their organizations of affiliation or employment, or of the sponsoring organizations, Health Canada and the Department of Justice Canada.

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The Expert Panel on Medical Assistance in Dying

Under the guidance of its Scientific Advisory Committee, Board of Directors, and the Academies, the CCA assembled the Expert Panel on Medical Assistance in Dying to undertake this project. Each expert was selected for their expertise, experience, and demonstrated leadership in fields relevant to this project.

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The CCA also recognizes the important contributions of **Yves Beauchamp**, Vice-Principal, Administration and Finance, McGill University (Montréal, QC).

Message from the Chairs

Medical assistance in dying (MAID) has been a topic of public debate in Canada for over 50 years. In 2015, the Supreme Court of Canada opened a new chapter in the debate with its *Carter* ruling, which was followed 18 months later by the passage of Bill C-14, *An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying)*. This unprecedented change in the legal landscape — welcomed by some and repudiated by others — reflects an evolving conversation about death and dying that is uniquely Canadian. This conversation continues through the work of the Expert Panel on Medical Assistance in Dying, convened by the Council of Canadian Academies (CCA).

It has been a privilege to serve over the past 18 months as Chairs. More than 40 experts from Canada and abroad, with diverse disciplinary and professional backgrounds, were convened as the Expert Panel while an additional 35 national and international experts served as independent Report Reviewers. The Panel undertook an evidence-based assessment of the state of knowledge surrounding three topics specified in the Act for independent review: MAID for mature minors, advance requests for MAID, and MAID where a mental disorder is the sole underlying medical condition. The three reports reflect a broad range of knowledge, experience, and perspective among relevant healthcare professions, diverse academic disciplines, advocacy groups, Indigenous Elders, and from regions where MAID is permitted.

The Expert Panel's work could not have been accomplished without the time and dedication of so many. First, we would like to thank the Panel members themselves, whose exceptional commitment and expert contributions ensured a fair assessment of the evidence. We would also like to express our gratitude to the Report Reviewers, whose detailed and constructive comments improved the depth and quality of each report. Special thanks go to the 59 groups and organizations across Canada affected by or involved in MAID, which responded to our Call for Input and submitted evidence, insight, and stories to enrich the Panel's work. Finally, on behalf of all Panel members, we would like to thank the CCA staff, who worked tirelessly to bring their tremendous research expertise, professionalism, dedication, and good humour to this project, under the guidance of Dr. Eric Meslin, CCA President and CEO.

These reports reflect a particular moment in Canada's history, in the breadth and availability of evidence, and in the evolution of thinking and practice related to MAID. We invite the Canadian public as well as Parliamentarians to engage in a wider discussion about MAID in the weeks and months following release of these reports. It is our hope that the Panel's reports will foster this Canadian conversation.

With our thanks for this opportunity to serve,



Marie Deschamps, C.C., Ad. E.

Chair, Expert Panel on Medical Assistance in Dying



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Message from the President and CEO

Every CCA assessment focuses on a topic of importance to the Sponsor who requested it and to those who await the Expert Panel's findings. Each is unique in its own way. But when the Minister of Health and Minister of Justice referred MAID-related questions to the CCA, we knew we were undertaking one of our most challenging assignments. For obvious reasons, policy topics about how people live and die are especially difficult because they speak to fundamental concepts of human dignity, autonomy, liberty, and suffering; they remind us of long-standing conversations and debates about the rights of patients and the duties of clinicians; and they reflect diverse social norms and cultural perspectives. With respect to MAID for mature minors, advance requests for MAID, and MAID where a mental disorder is the sole underlying medical condition, the task is especially daunting given that domestic and international experience is limited and the existing published literature cannot provide a complete picture of MAID as experienced by patients, families, communities, and healthcare practitioners.

This assessment required care, sensitivity, and wisdom to identify what is known and what gaps in knowledge remain to be filled. While no assessment can include every possible perspective, the CCA was mindful of the need to gather abundant expertise for this project: we invited specialists with clinical, legal, and regulatory expertise to the table; we sought authoritative scholars and practitioners from the fields of law, medicine, nursing, mental health, bioethics, anthropology, and sociology; and we included input from Indigenous elders. Drawing on experts from across Canada and other countries, the CCA established a panel of 43 individuals who together reflected the breadth of knowledge and experience required to answer the Sponsors' questions.

Leadership for this Expert Panel was provided by the Honourable Marie Deschamps, our overall Panel Chair, and by three Working Group Chairs: Dr. Dawn Davies, Prof. Jennifer Gibson, and Dr. Kwame McKenzie. I am grateful to all four Chairs for their dedication and commitment to ensuring these reports reflect the considered views and deliberations of Panel members. I am particularly appreciative of the commitment of every Panel member, each of whom volunteered their time in the service of this important task.

I also wish to express sincere thanks to the three Academies — the Royal Society of Canada, the Canadian Academy of Engineering, and the Canadian Academy of Health Sciences — for their support and expert assistance; to the CCA's Board of Directors and Scientific Advisory Committee for their advice and input; and to our dedicated staff for their hard work in support of the Expert Panel.

Finally, I would like to thank the Minister of Health and Minister of Justice for entrusting the CCA with the responsibility to undertake an assessment of such importance to Canada and Canadians. The products of the Expert Panel's work are now in the hands of the Government of Canada, as requested, and will be widely disseminated. It is our hope that this assessment will inform policy discussion and public discussion in Canada and abroad.



Eric M. Meslin, PhD, FCAHS
President and CEO, Council of Canadian Academies

Acknowledgements

Over the course of its deliberations, the Panel reached out to many individuals and organizations that provided valuable evidence, information, and assistance in the development of the reports. The Panel wishes to thank the following people for their participation in an early planning meeting: Jeff Blackmer, Canadian Medical Association; Jennifer A. Chandler, University of Ottawa; Dawn Davies, University of Alberta; Jocelyn Downie, C.M., FRSC, FCAHS, Dalhousie University; Catherine Frazee, O.C., Ryerson University; Jennifer L. Gibson, University of Toronto; Jean Gray, C.M., FCAHS, Dalhousie University; Douglas Ruth, FCAE, University of Manitoba; Janet Storch, University of Victoria; and Randi Zlotnik Shaul, The Hospital for Sick Children.

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These reports were reviewed in draft form by reviewers selected by the CCA for their diverse perspectives and areas of expertise.

The Report Reviewers assessed the objectivity and quality of the reports. Their submissions — which will remain confidential — were considered in full by the Panel, and many of their suggestions were incorporated into the reports. They were not asked to endorse the conclusions, nor did they see final report drafts before release. Responsibility for the final content of these reports rests entirely with the authoring Expert Panel Working Group and the CCA.

The CCA wishes to thank the following individuals for their review of these reports:

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Report Review Monitors

The report review procedure was monitored on behalf of the CCA's Board of Directors by three members of the CCA's Scientific Advisory Committee. The MAID Where a Mental Disorder Is the Sole Underlying Medical Condition report review was monitored by **David Castle**, Vice-President Research, University of Victoria; the Advance Requests for MAID report by **Malcolm King, FCAHS**, Professor, University of Saskatchewan; and the MAID for Mature Minors report by **Stuart MacLeod, FCAHS**, Professor Emeritus (Pediatrics), University of British Columbia.

The role of the report review monitor is to ensure that the Panel gives full and fair consideration to the submissions of the reviewers. The CCA Board authorizes public release of an expert panel report only after the report review monitors confirm that the CCA's report review requirements have been satisfied. The CCA thanks Drs. Castle, King, and MacLeod for their diligent contributions as report review monitors.

List of Acronyms and Abbreviations Used in the Reports

ACP	Advance Care Planning
AED	Advance Euthanasia Directive
CAMAP	Canadian Association of MAID Assessors and Providers
CAMH	Centre for Addiction and Mental Health
CAYAC	Child and Youth Advisory Council at the Alberta Children's Hospital
CCB	Consent and Capacity Review Board of Ontario
CFCEE	Commission fédérale de Contrôle et d'Évaluation de l'Euthanasie (Belgium)
CNCE	Commission Nationale de Contrôle et d'Évaluation (Luxembourg)
CPS	Canadian Paediatric Society
CPST	Continuous Palliative Sedation Therapy
CSPCP	Canadian Society of Palliative Care Physicians
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, 5 th Edition
EAS	Euthanasia and Assisted Suicide
IRER	Immigrant, Refugee, Ethnocultural, and Racialized
MAID MD-SUMC	Medical Assistance in Dying Where a Mental Disorder is the Sole Underlying Medical Condition
NVVP	Nederlandse Vereniging voor Psychiatrie (Dutch Psychiatric Association)
PAD	Physician Aid in Dying
PAS	Physician-Assisted Suicide
PPC	Pediatric Palliative Care
RTE	Regionale Toetsingscommissies Euthanasie (Regional Euthanasia Review Committees), the Netherlands
SCEN	Steun en Consultatie bij Euthanasie in Nederland (Support and Consultation on Euthanasia in the Netherlands)
SDM	Substitute Decision Maker
SLK	Levenseindekliniek (End-of-Life Clinic), the Netherlands
VPS	Vulnerable Persons Standard
VSED	Voluntary Stopping of Eating and Drinking
VVP	Vlaamse Vereniging voor Psychiatrie (Flemish Psychiatric Association)

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1

Introduction

- The Charge
- Scope
- The Expert Panel
- Terminology
- Evidence Considered
- How to Read this Report

1 Introduction

Canada has become one of a small number of jurisdictions to allow some form of medical assistance in dying (MAID). The Supreme Court of Canada's *Carter v. Canada* decision in 2015 held that an absolute prohibition against physician-assisted death was unjustifiable (SCC, 2015). The landmark ruling was followed by the passage of Bill C-14, *An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying)*. The Act amended the *Criminal Code* to allow for the provision of MAID under specific circumstances (GC, 2016b).

The passage of the Act and the practice of MAID in Canada, however, have not settled public debate. Among the issues under discussion are eligibility criteria and procedural safeguards in the legislation, including the criteria that people under the age of 18 are not eligible for MAID; that it is not possible for a person to consent to MAID through an advance request; and that very few people with a mental disorder as their sole underlying medical condition will meet eligibility criteria for MAID (e.g., that natural death must be reasonably foreseeable). Parliament has called for one or more independent reviews to study the question of prohibiting or permitting MAID to people in the above groups (Section 9.1 of the Act).

To meet their obligation, the Ministers of Health and Justice, on behalf of Health Canada and the Department of Justice Canada (the Sponsors), asked the Council of Canadian Academies (CCA) to conduct independent, evidence-informed reviews of the state of knowledge on MAID as it relates to these three topic areas (mature minors, advance requests, and where a mental disorder is the sole underlying medical condition). The reviews were initiated with a public announcement in December 2016.

1.1 THE CHARGE

The objective of the reviews, herein referred to as the *reports*, was to gather and assess information and evidence relevant to the three topic areas in order to inform a national dialogue among the Canadian public, and between the public and decision-makers. The Sponsors therefore asked the CCA to answer the following general questions:

Main Question

What is the available evidence on, and how does it inform our understanding of, medical assistance in dying (MAID) in the case of mature minors, advance requests, and where mental illness is the sole underlying medical condition, given the clinical, legal, cultural, ethical, and historical context in Canada?

General Sub-Questions

What are the potential implications for individuals and other affected persons, including their families, care providers, and health professionals, related to MAID for the three topic areas?

*What are the potential impacts on society of permitting or prohibiting requests for MAID for the three topic areas?**

What are the potential risks and safeguards that might be considered related to MAID for the three topic areas?

What are the relevant gaps in domestic and international knowledge and research related to MAID for the three topic areas?

*E.g., Suicide prevention strategies and medical responses; availability and efficacy of palliative care; dementia-related and mental health services and supports; risks to vulnerable populations; discrimination and stigma related to chronological age, dementia and related illnesses, and mental illness; and risks of inducements.

The charge also included sub-questions specific to the three topic areas:

Requests for MAID by Mature Minors

What is the impact of chronological age on the legal capacity to request and consent to MAID?

What are the unique considerations related to mature minors requesting MAID (e.g., mature minors vs. adults and MAID vs. other healthcare decisions)?

Advance Requests for MAID

How is an advance request for MAID similar to or different from advance directives for healthcare under existing provincial/territorial regimes?

*What are the unique considerations to be taken into account depending on when an advance request is made?***

** That is: 1) before diagnosis; 2) after diagnosis but before onset of suffering; 3) after all of the eligibility criteria and procedural safeguards have been met, except for the 10 day waiting period and the reconfirmation immediately prior to provision of MAID.

Requests for MAID Where Mental Illness Is the Sole Underlying Medical Condition***

What is the impact of mental illness in its different forms on an individual's legal capacity to request and consent to MAID?

*What are the unique considerations related to individuals living with mental illness (including mature minors) requesting MAID where the mental illness is the sole underlying medical condition?*****

*** For certainty, the study is concerned with requests where mental illness is the sole underlying medical condition and does not include circumstances where a person with a mental illness is eligible under the existing law.

**** Both in communities or institutions.

1.2 SCOPE

The reports address the questions set out in the charge. They focus on what is known and not known about MAID as it relates to mature minors, advance requests, and a mental disorder as the sole underlying medical condition. The reports do not provide recommendations to governments. It is also important to note that the reports do not evaluate the provisions enacted by Canada's MAID legislation; a formal review of MAID is required at year five (see Section 10 of the Act). Nor do they revisit the legal arguments and evidence for allowing or prohibiting MAID in general.

1.3 THE EXPERT PANEL

To address its charge, the CCA assembled a multidisciplinary panel of 43 experts from Canada and abroad (the Panel), divided into three Working Groups. Each Working Group focused on one of the three topic areas. The Panel's expertise covered academic, clinical, legal, and regulatory fields from the disciplines of medicine, nursing, law, bioethics, psychology, philosophy, epidemiology, anthropology, and sociology. Each member served on the Panel on a *pro bono* basis as an informed individual, rather than as a representative of a particular community, discipline, organization, or region. The Panel met in person six times from May 2017 through to July 2018 at various locations across Canada. Panel members convened both in plenary and within their respective Working Groups to deliberate over the evidence.

The Panel also organized three parallel sessions to discuss aspects of the charge that intersected with more than one topic area. These sessions examined the social determinants of health relevant to all three topic areas, the relationship between advance requests and mental disorders, and the intersection between mental disorders and mature minors. The result of these sessions informed each of the reports. The Working Groups and various subgroups also held discussions via teleconference as required to advance the reports between in-person meetings.

1.4 TERMINOLOGY

Medical Assistance in Dying

For the purposes of the reports, and consistent with the federal legislation, the Panel uses the term *medical assistance in dying (MAID)*, which, as defined in the legislation, means:

- (a) the administering by a medical practitioner or nurse practitioner of a substance to a person, at their request, that causes their death; or
- (b) the prescribing or providing by a medical practitioner or nurse practitioner of a substance to a person, at their request, so that they may self-administer the substance and in doing so cause their own death.

(GC, 2016b)

The gathered evidence often used alternative words and phrases, including *euthanasia*, *assisted suicide*, *physician-assisted suicide*, *physician-assisted death*, or *medical aid in dying*. When referring to evidence from other jurisdictions, the reports use the terminology common to the relevant jurisdiction. A table of legal terminology with notes on common usage in other regions is available in Appendix A.

Mature Minor

A *minor* is a person under the age of majority (18 or 19 depending on the province or territory). A *mature minor* is a minor who has the capacity to understand and appreciate the nature and consequences of a decision. The Panel's use of further terminology and nuances related to minors, such as *children*, *adolescents*, *youth*, and *adults*, are explained in *The State of Knowledge on Medical Assistance in Dying for Mature Minors*.

Advance Requests for MAID and Advance Directives

The Panel defines an *advance request for MAID* (AR for MAID) as a request for MAID, created in advance of a loss of decision-making capacity, intended to be acted upon under the circumstances outlined in the request after the person has lost decisional capacity.

ARs for MAID should be distinguished from provincially and territorially regulated *advance directives*, which are documents that “allow a decisionally-capable individual either to designate someone to make decisions about health care on his or her behalf, or to specify types of treatment to be accepted or rejected, should the need arise, or both,” in the event that the individual loses decision-making capacity (Gilmour, 2017). *The State of Knowledge on Advance Requests for Medical Assistance in Dying* explores in detail the possible relationship between ARs for MAID and advance directives.

Mental Disorder and Mental Illness

MAID legislation and the charge use the term *mental illness*. However, the Working Group chose to use the term *mental disorder* to be consistent with current clinical and legal practice. *Mental disorder* is the term used in the two primary classification systems in psychiatry: the World Health Organization's *International Statistical Classification of Diseases and Related Health Problems (ICD-10)* (WHO, 2016) and the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)* (APA, 2013).

1.5 EVIDENCE CONSIDERED

The CCA has a long-established approach for convening experts and assessing evidence. Throughout the assessment process, the Panel was asked to identify the range of knowledge and evidence relevant to the charge, examine this body of evidence, and interpret it in the form of findings. The Panel recognizes that the breadth of experience is limited, as a small number of jurisdictions permit some form of MAID and fewer still permit MAID in the three topic areas.

Given the complex, interdisciplinary nature of the topics, the Panel recognized the importance of interpreting evidence broadly and included empirical evidence such as peer-reviewed research and grey literature, normative evidence such as bioethical argumentation, and other forms of evidence such as lived experiences. To this end, the Panel identified and assessed evidence that was found in, but was not limited to, peer-reviewed publications from health disciplines, ethics, social sciences, humanities, and law; professional standards and guidelines; regulatory, legislative, and compliance materials; policy documents; and media reports.

Panel members identified evidence in multiple ways. For example, they drew on their respective disciplinary expertise to identify important evidence in their fields, conducted literature searches, and reviewed responses from the CCA's Call for Input (Section 1.5.1). Evidence gathering also included conversation with Indigenous Elders (Section 1.5.2). Literature searches were carried out using search terms that reflected the diversity of terminology that describes MAID domestically and internationally (Appendix A), as well as related concepts and practices. Literature searches were iterative, informed by Panel deliberations, and included examining literature cited by relevant articles and reports.

The Panel acknowledges a number of challenges and limitations associated with assessing evidence from such diverse sources. In addition to varying quality and availability of research, disciplines may also differ in the evidentiary standards

they apply and in the methods of establishing those standards. It was important, therefore, for the Panel to consider the value and quality of the evidence from the standards of their respective disciplines.

The Panel also recognizes that different types of evidence are not necessarily commensurable, and cannot be ordered within a single hierarchy of credibility. Ethical argumentation, empirical medical research, traditional knowledge, and lived experiences, for example, each give understanding, perspective, and nuance to MAID-related issues that no one type of evidence can provide on its own. Moreover, the Panel recognizes that not all questions that matter can be addressed by empirical research; in some cases, an anecdote conveying meaning through lived experience or an argument based on logic may be more relevant to the question.

To the extent that the evidence allowed, the Panel also considered how MAID legislation regarding the three topic areas might impact diverse groups of people. Panel deliberations therefore considered gender, race, ethnicity, ability, socio-economic status, and other factors affecting the determinants of health, including healthcare access and delivery of services.

The reports are a synthesis of knowledge available to the Panel through the academic and policy literature, the CCA's Call for Input, and its diverse interdisciplinary and professional expertise. The Panel's findings provide a lens into what is currently known about MAID with respect to the three topics at issue. They also shed light on relevant values for MAID policy in Canada, including how differences in values may lead to differences in the interpretation of evidence. The final text is the product of a collective effort to engage with these evidentiary and evaluative inputs to address the charge questions. Each report reflects the general view of its Working Group members even if on some points unanimity could not be established. In some situations, even after consideration of available data and Panel discussions, agreement could not be achieved and significant differences of opinion remained, reflecting the complex and conflicted nature of the issues being reviewed; in those instances, such disagreement is reflected in the reports.

1.5.1 Call for Input

As part of the Panel's evidence-gathering activity, a Call for Input was carried out by the Panel over a three-month period beginning in July 2017. In addition to inviting written input from 500 groups and organizations across Canada affected by, or involved in, MAID, the Call for Input was made available online to any interested organizations. Specifically, the Panel asked organizations to:

- (i) describe their main issues concerning requests for MAID in the three topic

areas under study; and (ii) submit, or provide links to, any knowledge they would like the Panel to consider. The CCA received 59 submissions from a wide variety of organizations in the areas of advocacy, medicine, nursing, pharmacy, social work, law, and religion (Box 1.1).

Call for Input submissions were shared with Panel members and reviewed to identify issues related to the three topic areas. Call for Input submissions also identified a range of evidence, including professional guidelines and codes of ethics, additional peer-reviewed articles, surveys of membership of professional bodies, and lived experience testimony, not previously available to, or identified by, the Panel. Where relevant, these sources were included in the body of evidence assessed by the Panel.

1.5.2 Indigenous Elders Circle

An Elders Circle, facilitated by Indigenous Panel members, was held in February 2018 to provide insight into Indigenous perspectives on MAID, particularly with respect to the three topic areas. Six Elders from Métis and First Nations in British Columbia, Saskatchewan, Manitoba, and Ontario offered their knowledge of end-of-life attitudes, practices, issues, and concerns. Notably, the Elders felt that Indigenous Peoples had not been consulted on the issue of MAID. The Panel recognizes that the Elders Circle was limited in scope and representation, and does not constitute consultation with Indigenous Peoples on the topic of MAID. This remains a significant knowledge gap.

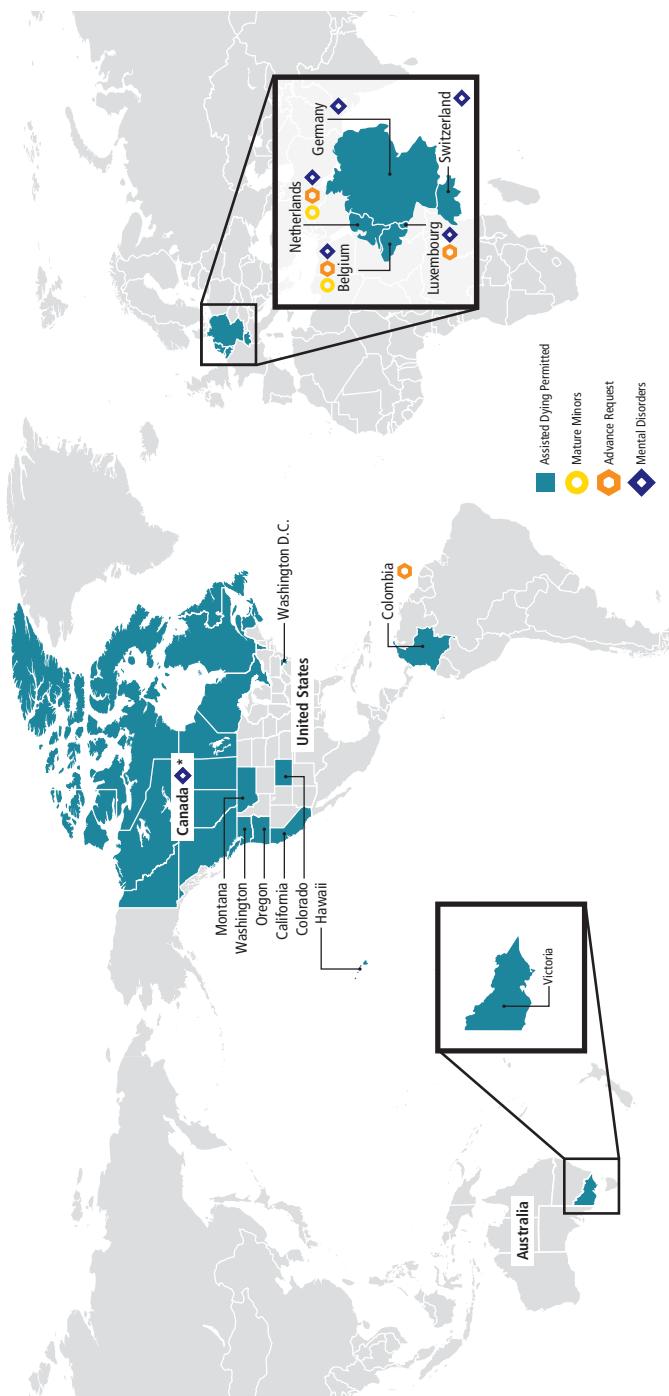
1.5.3 International Experience

The Panel considered the experiences and evidence from other countries that allow some form of assisted dying. In cases where access to relevant documents from other countries was impeded by language, professional translators were engaged.

Assisted dying is legal or partially decriminalized in a small number of jurisdictions (Figure 1.1); areas that allow assisted deaths do so with specific access criteria and safeguards. The Panel considered and assessed critically the international evidence in light of the Canadian healthcare environment, its unique geography and history, and the contemporary political and social policy context within which the MAID conversation is occurring.

Box 1.1**Organizations That Made a Formal Submission to the CCA's Call for Input**

- Addictions and Mental Health Ontario
- Alberta College of Social Workers
- Alzheimer Society of British Columbia
- Alzheimer Society of Nova Scotia
- Association for Reformed Political Action
- Association médicale du Québec
- Association of Registered Nurses of British Columbia
- Autism Canada
- British Columbia College of Social Workers
- British Columbia Humanist Association
- Canadian Association for Community Living
- Canadian Association of MAID Assessors and Providers
- Canadian Bar Association
- Canadian Coalition for the Rights of Children
- Canadian Federation of Catholic Physicians' Societies
- Canadian Medical Association
- Canadian Medical Protective Association
- Canadian Mental Health Association
- Canadian Physicians for Life
- Canadian Psychiatric Association
- Canadian Society of Palliative Care Physicians
- CARP
- Catholic Civil Rights League
- Catholic Health Alliance of Canada
- Centre for Addiction and Mental Health
- Christian Legal Fellowship
- Christian Medical and Dental Society of Canada
- Collège des médecins du Québec
- College of Licensed Practical Nurses of Manitoba
- College of Physicians and Surgeons of Ontario
- College of Registered Nurses of Manitoba
- College of Registered Psychiatric Nurses of Manitoba
- Community Health Nurses of Canada
- Covenant Health
- Dying with Dignity Canada
- Empowerment Council
- Evangelical Fellowship of Canada
- Federation of Medical Regulatory Authorities of Canada
- Institut de planification des soins
- Manitoba Provincial MAID Clinical Team
- National Association of Pharmacy Regulatory Authorities
- Nova Scotia College of Pharmacists
- Nurse Practitioner Association of Canada
- Nurse Practitioner Association of Manitoba
- Ontario College of Social Workers and Social Service Workers
- Ontario Psychiatric Association
- Ontario Shores Centre for Mental Health Sciences
- Ottawa Catholic Physicians' Guild
- Physicians' Alliance Against Euthanasia
- REAL Women of Canada
- Right to Die Society of Canada
- Salvation Army
- St. Joseph's Health Care London
- The Hospital for Sick Children
- Toronto Catholic Doctors' Guild
- Toujours Vivant-Not Dead Yet
- University Health Network
- University of Toronto Joint Centre for Bioethics MAID Implementation Task Force, MAID Advance Request Working Group
- West Coast Assisted Dying



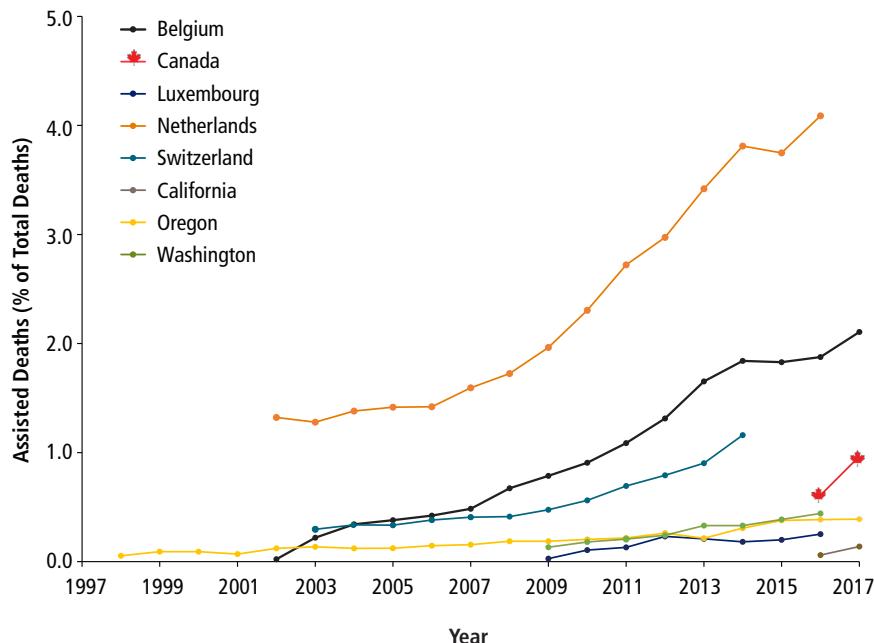
Data Source: Bruns, 2016; GC, 2016b; Gov. of Belgium, 2002; Gov. of CA, 2015; Gov. of CO, 2016; Gov. of Colombia, 2015; Gov. of DC, 2016; Gov. of Germany, 1998; Gov. of HI, 2018; Gov. of Luxembourg, 2009; Gov. of the Netherlands, 2002; Gov. of OR, 1997; Gov. of Switzerland, 1942; Gov. of Victoria, 2017; Gov. of WA, 2009; Supreme Court of the State of Montana, 2009

Figure 1.1 Map of the World Showing Places Where Some Form of Assisted Dying is Allowed

This figure represents the understanding of the Expert Panel regarding the status of assisted dying worldwide, given the available knowledge at the time this report was written. Jurisdictions vary in terms of the legal mechanism by which assisted dying is allowed (e.g., through legislation or a court decision), the form of assisted dying that is permitted (e.g., self-administration or physician administration of a lethal substance), and the specific eligibility criteria (e.g., requirement of a terminal illness or a minimum age). For additional information, see Appendix A. The symbols on the map indicate the countries in which assisted dying can be accessed by mature minors, through advance requests, or by people with a mental disorder as their sole underlying medical condition.

*To access assisted dying in Canada, including for a mental disorder, death must be reasonably foreseeable, but this is not a requirement in Belgium, Luxembourg, or the Netherlands.

Rates of uptake vary considerably among, and even within, regions; in U.S. states, which only allow self-administration by patients with a diagnosis of terminal illness, the proportion of deaths attributed to physician-assisted suicide remains under 1% (Figure 1.2). The Panel notes that data collection and reporting procedures vary substantially both within and among jurisdictions. Relevant details and discussion of evidence from foreign jurisdictions are included in the body of the reports.



Data Source: Belgium (CFCCE, 2004, 2006, 2008, 2010, 2012, 2014, 2016, 2018; SB, 2018); Canada (GC, 2017b, 2017c, 2018b; StatCan, 2018c); Luxembourg (CNCE, 2017; Gov. of Luxembourg, 2018); Netherlands (RTE, 2003, 2004, 2005, 2006, 2007, 2008, 2009, 2010, 2011, 2012b, 2013, 2014a, 2015d, 2016c, 2017d; CBS, 2018; RTE, 2018b); Switzerland (Gov. of Switzerland, 2018b, 2018a); California (Gov. of CA, 2017, 2018); Oregon (Gov. of OR, 2018a, 2018b); Washington: (Gov. of WA, 2018b, 2018c)

Figure 1.2

Reported Assisted Deaths as a Percentage of Total Deaths per Year by Location

Not all locations where some form of assisted dying is permitted publicly report the number of such deaths each year; data presented in the figure are the best available at this time. Note that assisted dying practices vary among U.S. states; data from individual states are presented where available.

1.5.4 Knowledge Gaps

Direct evidence on the practice of assisted dying in the three topic areas is limited to publicly available documentation from the few countries that allow assisted dying for mature minors, through advance requests, or where a mental disorder is the sole underlying medical condition. However, many of the questions and issues related to the three topic areas identified by the Panel do have an evidence base, often spanning multiple disciplines including law, ethics, medicine, nursing, psychology, psychiatry, and sociology. This evidence forms the core of what the Panel assessed. There are nonetheless knowledge gaps for these issues; where they exist, the Panel identified and factored them into its findings.

1.6 HOW TO READ THIS REPORT

This report is one of three related reports that collectively examine the evidence related to medical assistance in dying: MAID for Mature Minors, Advance Requests for MAID, and MAID Where a Mental Disorder Is the Sole Underlying Medical Condition. Though each report is authored by a different Working Group of the Expert Panel, the three reports have been developed in parallel and benefitted from common discussions across the Working Groups.

These reports can therefore be read independently or as a single body of work. To support this structure the three topic area reports share the same first two chapters: Chapter 1: *Introduction* and Chapter 2: *MAID in Canada: Historical and Current Considerations*. These two chapters provide common information and context relevant to all three reports. The chapters that follow comprise the core of the topic area assessment. Chapters 3 through 5 present context, issues, and evidence specific to the respective topic area. Chapter 6 is a discussion of potential impacts, implications, and safeguards. Each report concludes with its own Chapter 7, which provides summary answers to the charge.

2

MAID in Canada: Historical and Current Considerations

- **How Did We Get Here?**
- **Implementation of MAID in Canada**
- **Provision of Healthcare in Canada**
- **Healthcare Decision-Making**
- **Chapter Summary**

2 MAID in Canada: Historical and Current Considerations

The partial decriminalization of MAID in Canada followed a succession of legal challenges, societal and technological changes, advocacy and scholarly work, and public and professional discussions, some of which began more than 50 years ago. The Panel understands that MAID is a deeply personal topic about which there are differing views on the relevant evidence, and that one's perception about the need for the practice to include mature minors, advance requests, or where a mental disorder is the sole underlying medical condition is informed by life experiences, values, and beliefs. Moreover, Panel members, regardless of their own disciplinary expertise, recognize that clinical, ethical, legal, and societal considerations may be in tension with one another. This chapter provides a context for current discussions of MAID in Canada with the understanding that these discussions will continue to evolve.

The chapter begins with an overview of some pivotal points in this history, along with certain contemporary realities of delivering healthcare services in a culturally diverse and geographically expansive country. The three topic areas also touch on several common considerations — informed consent, decision-making capacity, and decision-making authority — each of which is discussed in the context of MAID in Canada. Given the breadth and complexity of issues, the chapter seeks to provide the reader with a common starting point for thinking about MAID in the three topic areas. It does not purport to be a definitive or comprehensive examination of the historical, social, and political context of MAID in Canada.

2.1 HOW DID WE GET HERE?

The public conversation in Canada about end-of-life decision-making dates back more than half a century. The development of new life-prolonging technology and medical interventions prompted conversations about their use and/or withdrawal among patients, families, clinicians, and institutions. Arnup (2018), citing Smith and Nickel (2003), points out that healthcare in Canada in the post-war years featured new technologies and focused on saving lives, and that “little thought was given to dignity, pain relief or quality of care” of the dying. By the late 1960s, however, the palliative care and hospice movements began to take hold, based on the idea that patients at the end of life required equal clinical attention — albeit of a different kind — even when cure was no longer possible (Mount, 1976; Saunders, 2001; Arnup, 2018). High-profile cases, such as that of Karen Ann Quinlan in the United States, brought public attention to end-of-life discussions about cessation of treatment and quality of life (Martin, 2016).

In 1982, the Law Reform Commission of Canada published a working paper, followed in 1983 by a full report, entitled *Euthanasia, Aiding Suicide and Cessation of Treatment* (LRCC, 1982, 1983). The Commission recommended against decriminalization or legalization of euthanasia or assisted suicide, but did make recommendations to clarify the legal right of a patient to refuse treatment and of a physician to cease treatment that has become therapeutically useless and is not in the best interests of the patient (LRCC, 1983). Nine years later, the decision in the case of Nancy B. in Quebec City affirmed a capable patient's right to refuse life-sustaining treatment even if such a decision led to death (QCCS, 1992).

2.1.1 Sue Rodriguez Challenges the Assisted Suicide Prohibition in Canada

In the early 1990s, Sue Rodriguez, a woman with amyotrophic lateral sclerosis (ALS), applied to the Supreme Court of British Columbia to have the *Criminal Code* prohibition on assisted suicide declared unconstitutional. After the British Columbia Supreme Court dismissed her application, Ms. Rodriguez appealed to the British Columbia Court of Appeal and, after being unsuccessful there, to the Supreme Court of Canada (SCC, 1993).

The key constitutional rights implicated by the prohibition on assisted suicide were Sections 7 and 15(1) of the Canadian *Charter of Rights and Freedoms* (GC, 1982). Section 7 states that everyone has "the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice." Section 15(1) states that every person has the right to "equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability." While actions taken by governments are subject to these provisions, Section 1 of the Charter states they may limit rights insofar as such limits are "reasonable," "prescribed by law," and "demonstrably justified in a free and democratic society." Ms. Rodriguez argued that she would be unable to take her own life without assistance when she no longer had the capacity to enjoy life because of her disease. Ms. Rodriguez stated that, since suicide is legal under the *Criminal Code*, prohibiting assisted suicide discriminates against people with a physical disability that makes them incapable of taking their own life (SCC, 1993).

On September 30, 1993, the Supreme Court of Canada ruled, by a five-to-four majority, that the prohibition against assisted suicide was in accordance with the principles of fundamental justice and as such did not violate Section 7 of the Charter. The Supreme Court also concluded that a violation of Section 15(1) of the Charter would be "demonstrably justified in a free and democratic society" and ruled that the prohibition was constitutional (SCC, 1993).

2.1.2 Public Conversation, Consideration, and Study

Discussions of choice at end of life did not stop after the *Rodriguez* decision. Following a series of papers published by the Canadian Medical Association on assisted suicide and euthanasia in 1993, the Senate of Canada appointed a Special Committee in 1994 to “examine and report on the legal, social and ethical issues relating to euthanasia and assisted suicide” (SSCEAS, 1995). The Committee heard testimony and reviewed letters and briefs from across Canada for 14 months, before publishing a final report in 1995, with a majority recommending against changing the legal status of euthanasia and assisted suicide in Canada (SSCEAS, 1995).

Criminal cases reported in the media across Canada in the 1990s, such as those of Robert Latimer in Saskatchewan and Dr. Maurice Généreux in Ontario, inspired further public and private debate (see Deschamps, 2017a for a review of cases). Moreover, Canadians were not insulated from highly publicized international cases, such as those of Dr. Jack Kevorkian in the United States (Martin, 2016). Advocacy groups, such as Dying with Dignity Canada and its Quebec counterpart, Association québécoise pour le droit de mourir dans la dignité, campaigned for choice at end of life in Canada. Within clinical practice, discussions of appropriate end-of-life care practices and policy development were ongoing (e.g., CFPC, 2012; CMA, 2014).

Academic study of the issues of euthanasia and assisted suicide by scholars in Canada from a range of disciplines, including law, bioethics, philosophy, and history, informed perspectives about the practice (e.g., Somerville, 2001; Downie, 2004; Dowbiggin, 2005; Sumner, 2011). In 2011, the Royal Society of Canada published a multidisciplinary review of end-of-life decision-making that included research on assisted death (RSC, 2011).

In recent decades, legislative attempts to amend the *Criminal Code* to permit euthanasia and/or assisted suicide in limited circumstances were unsuccessful. These attempts came from diverse political parties: Svend Robinson (New Democratic Party, 1992, 1994), Francine Lalonde (Bloc Québécois, 2005, 2008, 2009), Stephen Fletcher (Conservative Party, 2014), and Nancy Ruth (Conservative Party, 2014) (Butler *et al.*, 2013; Deschamps, 2017a).

2.1.3 Quebec Enacts End-of-Life Legislation that Includes Medical Aid in Dying

In 2006, Quebec’s medical regulator, Collège des médecins du Québec (CMQ), embarked on a three-year process to study appropriate care at the end of life (CMQ, 2009). In November 2009, a working group report concluded that, despite advances in palliative care, there were exceptional cases in which clinical

interventions were ineffective and, in those situations, a patient would have no option but to suffer until death (CMQ, 2009); this position was subsequently adopted by the CMQ (Robert, 2010). In December 2009, the National Assembly of Quebec unanimously adopted a motion to create a select committee of members to study the issue of dying with dignity (Gov. of QC, 2012).

Reporting to the National Assembly in March 2012, the committee noted that opinion had shifted in public polls in support of euthanasia and assisted suicide, and among healthcare practitioners in surveys conducted by professional associations (Gov. of QC, 2012). In June 2014, the Quebec government passed *An Act Respecting End-of-Life Care* (Gov. of QC, 2014), which took effect in December 2015. This Act addresses patients' entitlement to receive the full spectrum of care at the end of life, and includes medical aid in dying. The Quebec eligibility criteria and safeguards are similar, but not identical, to those of the federal statute (Gov. of QC, 2014).

2.1.4 *Carter v. Canada* Overturns the Blanket Prohibition on Assisted Suicide

In 2011, two family members of Kay Carter (a woman with spinal stenosis who had travelled to Switzerland for an assisted suicide), William Shochet (a medical doctor willing to participate in physician-assisted deaths), and Gloria Taylor (a woman with ALS) joined with the British Columbia Civil Liberties Association to challenge federal prohibition on physician-assisted dying. In 2015, the Supreme Court of Canada concluded that the challenged provisions of the *Criminal Code* were void insofar as:

[T]hey 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.

(SCC, 2015)

In contrast to the five-to-four decision in *Rodriguez v. Canada* (1993), the *Carter* decision was unanimous (9-0); the decision stated that a blanket prohibition on assisted suicide deprives adults of the right to life, liberty, and security of the person. For the purposes of the reports, it is important to note that *Carter* considered the case of adults with decision-making capacity, and that it made "no pronouncement on other situations where physician-assisted dying may be sought" (SCC, 2015). The Supreme Court confirmed at the same time the role of the criminal law, suspending the declaration of invalidity of the criminal prohibition for one year to allow time for a legislative and regulatory response to the judgment (SCC, 2015).

2.1.5 Bill C-14 and the Partial Decriminalization of MAID

In response to the *Carter* ruling, after study and consultation (e.g., PTEAG, 2015; SJCPAD, 2016), the federal government introduced Bill C-14, *An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying)*. The Act received Royal Assent on June 17, 2016, creating the federal statutory framework for MAID (GC, 2016b).

The preamble to the federal MAID legislation takes into consideration the autonomy and intolerable suffering of persons with grievous and irremediable medical conditions who wish to seek MAID; the need for “robust safeguards ... to protect against errors and abuse;” affirmation of the “inherent and equal value of every person’s life” and the avoidance of “negative perceptions of the quality of life of persons who are elderly, ill, or disabled;” the protection of vulnerable persons from “being induced, in moments of weakness, to end their lives;” and the recognition that “suicide is a significant public health issue that can have lasting and harmful effects on individuals, families and communities” (GC, 2016b). The preamble concludes:

permitting access to medical assistance in dying for competent adults whose deaths are reasonably foreseeable strikes the most appropriate balance between the autonomy of persons who seek medical assistance in dying, on one hand, and the interests of vulnerable persons in need of protection and those of society, on the other.

A specific concern of the legislators, as evidenced in the preamble to the Act, was a possible impact of MAID on suicide rates and suicide prevention. Suicide is not a criminal offence in Canada, but assisting a person to end their life is illegal unless the conditions of the MAID legislation are met (GC, 2016b). In addition to being a public health issue, suicide prevention is also foundational to the practice of mental health services. Suicide, suicide prevention, and the possible impacts of MAID laws are discussed in detail in Sections 3.2 and 4.2.

The legislation provides eligibility criteria and procedural safeguards to establish the parameters of legally permissible MAID in Canada (Box 2.1).

Box 2.1**Eligibility Criteria for Accessing MAID in Canada**

241.2 (1) A person may receive medical assistance in dying only if they meet all of the following criteria:

- (a) they are eligible — or, but for any applicable minimum period of residence or waiting period, would be eligible — for health services funded by a government in Canada;
- (b) they are at least 18 years of age and capable of making decisions with respect to their health;
- (c) they have a grievous and irremediable medical condition;
- (d) they have made a voluntary request for medical assistance in dying that, in particular, was not made as a result of external pressure; and
- (e) they give informed consent to receive medical assistance in dying after having been informed of the means that are available to relieve their suffering, including palliative care.

241.2 (2) A person has a grievous and irremediable medical condition only if they meet all of the following criteria:

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

Two independent medical or nurse practitioners must be of the opinion that the person requesting MAID meets all of the eligibility criteria. Furthermore, there must be 10 clear days between the formal request and the provision of MAID, unless the person's death or loss of capacity is imminent. Immediately prior to the provision of MAID, the person must be given an opportunity to withdraw their request and must give express consent to the procedure (GC, 2016b).

Thus, mature minors under the age of 18 are not eligible for MAID; competent persons cannot provide valid consent by means of an advance request for MAID; and competent persons with a mental disorder as their sole underlying medical condition will rarely meet all of the eligibility criteria.

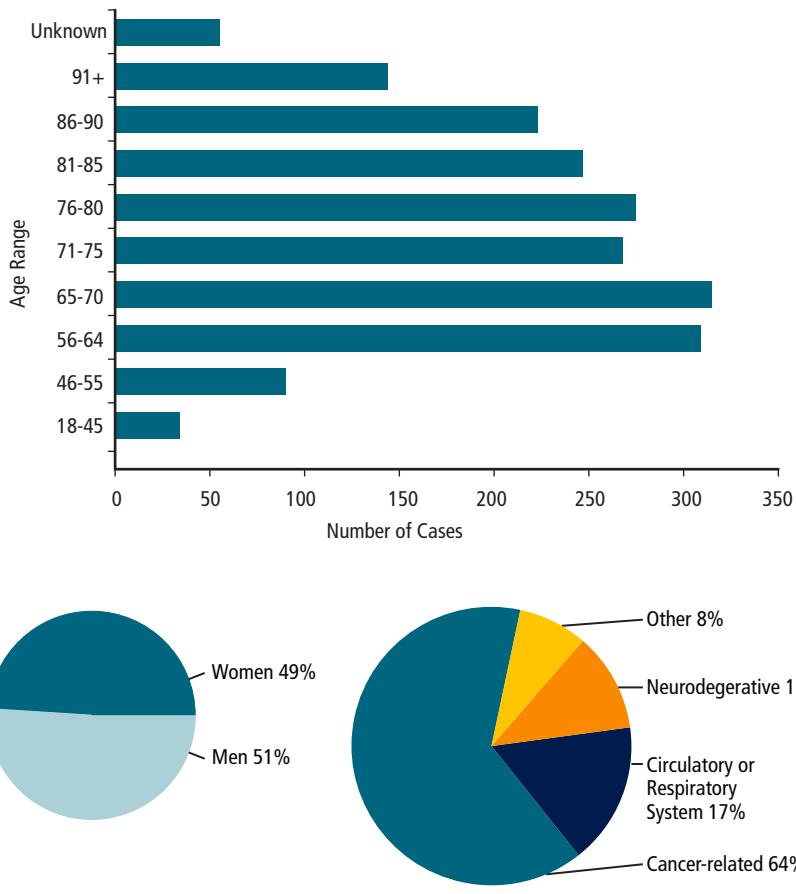
2.2 IMPLEMENTATION OF MAID IN CANADA

The best available data indicate that 3,714 people in Canada accessed MAID between December 10, 2015 and December 31, 2017 (GC, 2018b). This number includes data from Quebec (but only until June 9, 2017), and excludes data from Yukon, Northwest Territories, and Nunavut. In 2017, MAID deaths represented approximately 1% of all deaths in Canada (GC, 2018b).

The most common underlying conditions among those who received MAID in 2017 ($n=1,961$)¹ were cancer (64%), followed by diseases of the circulatory/respiratory system (17%), and neurodegenerative conditions (11%); 51% of recipients were men and 49% women. People ranged in age from 18–45 to over 90 years old, with the largest demographic being 65–70 years of age (Figure 2.1).

New federal monitoring regulations, introduced July 25, 2018, specify reporting requirements and designate a recipient to receive reports from medical and nurse practitioners and pharmacists in each province and territory (GC, 2018a). Prior to the introduction of federal monitoring regulations, Health Canada produced three interim reports based on available data from the provinces and territories (GC, 2017b, 2017c, 2018b).

¹ Excludes data from Yukon, Northwest Territories, Nunavut, and Quebec.



Data Source: GC, 2018b

Figure 2.1

Characteristics of Reported MAID Deaths in Canada in 2017

MAID deaths in Canada, as reported to Health Canada in 2017, by age, gender, and underlying medical condition. The figure excludes data from Yukon, Northwest Territories, Nunavut, and Quebec.

In Quebec, *An Act Respecting End-of-Life Care* legislated the creation of a commission that submits an annual activity report, no later than September 30, to the Minister of Health and Social Services (Gov. of QC, 2014). Since its inception, the Commission has published two reports, the first in October 2016 (Gov. of QC, 2016) and the second in October 2017 (Gov. of QC, 2017a). Additionally, executive directors of health and social services institutions, as well as the CMQ (which collects reports directly from individual private practice physicians), are required to publicly report on numbers of MAID requests and outcomes (GC, 2018b).

2.2.1 Pending Legal Challenges to MAID Legislation

The British Columbia Civil Liberties Association and Julia Lamb, a 25-year-old woman with spinal muscular atrophy (a progressive degenerative condition), filed a constitutional challenge to the federal Act on June 27, 2016 (BCCLA, 2016). The lawsuit challenges eligibility criteria (reasonably foreseeable death, incurable illness or condition, advanced state of irreversible decline), arguing that the federal legislation unjustifiably limits Sections 7 and 15 of the Charter and is not saved by Section 1 (BCCLA, 2016).

In Quebec, in June 2017, Jean Truchon, a 49-year-old man with cerebral palsy, and Nicole Gladu, a 71-year-old woman with post-polio syndrome, filed a legal challenge against the assisted dying laws in Canada and Quebec (QCCS, 2017a). They argue that the eligibility criteria in the legislation (“natural death has become reasonably foreseeable” and “end of life”) are too restrictive, violate Sections 7 and 15 of the Charter, and cannot be saved under Section 1.

Also in Quebec, Paul Saba, a physician, has variously challenged the validity of the Quebec statute on assistance in dying and the federal MAID law on several bases, including that the current deficiencies in healthcare services prevent patients from giving informed consent. He also claims that the regime is unconstitutional and goes against Quebec’s *Code of Ethics of Physicians* and the *Canada Health Act* (QCCS, 2017b).

In a statement of claim filed with the Ontario Superior Court of Justice, Roger Foley, who has a serious neurological disability, claims that the defendants (his local hospital, local health integration network, and others) have violated his Charter rights by failing to provide adequate and appropriate home care services to relieve his suffering. Additionally, he claims the defendants have offered to provide assisted suicide instead of an assisted life. He also seeks, in part, a declaration that the MAID provisions in the *Criminal Code* are unconstitutional and therefore invalid (ONSC, 2018).

2.2.2 Legal Interpretations of MAID Legislation

In 2017, the Ontario Superior Court of Justice made an *interpretive declaration* regarding the eligibility criterion of a reasonably foreseeable death in the discussion of a case involving a patient seeking MAID (*AB v. Canada (Attorney General)*). Referring to the language used in Canada's MAID legislation, the Court stated:

This language reveals that natural death need not be imminent and that what is a reasonably foreseeable death is a person-specific medical question to be made without necessarily making, but not necessarily precluding, a prognosis of the remaining lifespan.

(ONSC, 2017)

The College of Physicians and Surgeons of Nova Scotia has similarly provided a broad interpretation of reasonable foreseeability in its *Professional Standard Regarding Medical Assistance in Dying*, referencing the *AB v. Canada (Attorney General)* case (CPSNS, 2018). Furthermore, an Inquiry Committee for the College of Physicians and Surgeons of British Columbia found a woman had met MAID eligibility criteria “despite the fact that her refusal of medical treatment, food, and water undoubtedly hastened her death and contributed to its ‘reasonable foreseeability’” (CPSBC, 2018).

The College of Physicians and Surgeons of Ontario has two policies requiring physicians who conscientiously object to MAID to make an effective referral for patients who request MAID (CPSO, 2015, 2016). Several groups and individual physicians challenged these policies, stating they violate one's right to freedom of religion, freedom of conscience, and right to equality. The Ontario Superior Court of Justice (Divisional Court) decided on January 31, 2018 that any infringement on physicians' freedom of religion was justified given its objective of ensuring equitable access to healthcare (ONSCDC, 2018). An application for leave to appeal was filed in the Ontario Court of Appeal on February 20, 2018 (Golding & Rosenbaum, 2018).

2.2.3 MAID Delivery and Regulation

MAID is an exemption in the *Criminal Code* to criminal offenses of homicide and assisted suicide, as long as specific eligibility criteria are met and certain safeguards are followed (Box 2.1). Debates about eligibility criteria for MAID include debates about the scope of criminal law, the prohibitions on causing death that the criminal law contains, and the social norms represented therein. However, MAID is also a medical act, regulated and delivered through the healthcare system, as, by law, only medical and nurse practitioners can provide MAID in Canada. Thus, a brief overview of MAID delivery and regulation in the healthcare system follows.

Provinces and territories are primarily responsible for delivering healthcare services to their residents; however, the federal government has responsibility in providing primary healthcare to certain groups (GC, 2012a). Provincial and territorial healthcare legislation defines the obligations of health authorities, healthcare institutions, and individual practitioners with respect to the delivery of healthcare services. These obligations are set out in legislation regulating, for example, hospitals (e.g., Gov. of NS, 1989) and healthcare consent (e.g., Gov. of ON, 1996). In the case of Quebec, provincial legislation regulates end-of-life care, including MAID (Gov. of QC, 2014). Subsequent to the passage of the federal MAID legislation, Manitoba and Ontario introduced or amended statutes to address implementation (e.g., Gov. of MB, 2017; Gov. of ON, 2017).

Provincial and territorial legislation establishes regulatory colleges that enforce standards of practice and regulate the conduct of professional healthcare providers, such as nurses, physicians, and pharmacists. Colleges enforce standards through the licensing and disciplining of professional members; their purpose is to serve and protect the public, ensuring competency and quality of practice within their professions (e.g., Gov. of BC, 1996a). Quebec has legislation defining codes of ethics for specific professions, such as physicians (Gov. of QC, 2017b). Many regulatory colleges have developed professional standards and policies for the assessment and provision of MAID by their members (e.g., CPSO, 2016; CPSNS, 2018; CRNBC, 2018).

Hospitals also regulate the practices provided by their institutions and within their facilities, including the provisioning of MAID. There may be public and independent health facilities regulated by different pieces of legislation within a province or territory (e.g., Gov. of ON, 1990a, 1990b, 1990c). Physicians, in law, are generally treated as independent contractors; however, hospitals exert control over the professional conduct of physicians, for instance, by granting or revoking privileges to provide care in their facility. Hospitals hold the authority to hire and regulate the conduct of other healthcare professionals, such as nurses and pharmacists. Many hospitals have developed policies to regulate the provision of MAID (e.g., TOH, 2016).

Professional associations and societies, such as the Canadian Association of MAID Assessors and Providers (CAMAP), the Canadian Society of Palliative Care Physicians (CSPCP), and the Canadian Nurses Association, are organizations of healthcare practitioners and scholars. These organizations seek to provide support, information, and guidance to healthcare practitioners, but do not license members and do not have regulatory authority.

2.2.4 End-of-Life Practices Other than MAID

Though MAID is a novel practice in Canada, subject to eligibility and safeguards prescribed by the *Criminal Code*, it is implemented in a healthcare context where long-standing end-of-life practices exist, such as withdrawing or withholding treatment, continuous palliative sedation therapy, and abstaining from nutrition and hydration. This section briefly reviews their legal status in Canada.

Withdrawing or Withholding Life-Sustaining Treatment

Under Canadian law, people with decision-making capacity clearly have the right to refuse treatment even where that refusal will result in their death (QCCS, 1992). There is no formal requirement in law that refusals be well considered or settled. Mature minors and individuals with a mental disorder who have decision-making capacity may choose to withdraw or withhold life-sustaining treatment, as may their substitute decision makers (SDMs), should they later lose decisional capacity.

Refusals of treatment can be expressed through an advance directive, which may be in the form of written instructions or a chosen SDM. An SDM appointed by operation of a statute (e.g., family member) may decide, on behalf of a patient who lacks decision-making capacity, to withdraw or withhold life-sustaining treatment if they believe it is in accordance with the patient's wishes (where known), or the best interests of the patient (where the patient's prior capable wishes are not known) (see Section 3.3.2 in *The State of Knowledge on Advance Requests for Medical Assistance in Dying*.

Continuous Palliative Sedation Therapy (CPST)

The Canadian Medical Association defines CPST as “complete sedation, with the intent of rendering the patient unable to experience the environment, sensation or thoughts, until the patient dies naturally from the underlying illness” (CMA, 2017). CPST is clearly legal when it does not cause death — that is, when delivered in combination with cessation of artificial hydration and nutrition where death is anticipated within approximately 48 hours (Downie, 2017). Where death is anticipated within two weeks, CPST with the provision of artificial hydration and nutrition is clearly legal (again, it does not cause death) (Downie, 2017). In practice, CPST is generally done without artificial hydration and nutrition. Where death is anticipated within 14 days, the legal status of CPST in combination with cessation of artificial hydration and nutrition is less clear (Downie, 2017); however, it is arguably legal (Downie, 2018). Where death is not anticipated for some time, the legal status of CPST in combination with cessation of artificial hydration and nutrition is unclear.

Voluntary Stopping of Eating and Drinking (VSED)

Some patients choose to stop eating and drinking, knowing they will die as a result. Competent patients can refuse oral hydration and nutrition (e.g., holding a glass to a person's lips, spoon-feeding) and artificial hydration and nutrition (e.g., intravenous fluids, feeding tube), and advance directives (where applicable in Canada) may also include refusal of artificial hydration and nutrition (Downie, 2017). In some provinces (e.g., Nova Scotia), oral hydration and nutrition can also be refused through advance directives; however, this is less clear in some other provinces (e.g., BCCA, 2015).

VSED has been used in Canada as a pathway to eligibility for MAID. If one stops eating and drinking, their natural death becomes reasonably foreseeable (or, in Quebec, the person reaches their "end of life"). For example, a Quebec man refused food for 53 days and water for 8 days in order to become eligible for MAID (McKenna, 2016). Similarly, a woman in British Columbia refused food and water for 14 days in order to become eligible to receive MAID (CPSBC, 2018).

2.3 PROVISION OF HEALTHCARE IN CANADA

As a first point of contact, primary healthcare services offer immediate care for health problems, routine care, or health information. Family physicians, nurse practitioners, pharmacists, and telephone advice lines can provide these kinds of services. Primary healthcare also provides coordination of specialized services, such as specialist consultation and care (e.g., cardiologists, allergists, psychiatrists) or care provided in hospitals (GC, 2012b).

In 2013, about 29% of people in Canada aged 15 or older reported difficulty in accessing healthcare services, most commonly due to wait times or difficulty securing appointments (Clarke, 2016). In 2016, 15.8% of those aged 12 or older reported that they did not have a regular healthcare provider² (StatCan, 2017b). Men aged 18 to 34 were the most likely group to report not having a regular healthcare provider (approximately 33%), whereas men and women over the age of 65 were the least likely group (6.5% of men and 5.3% of women). Self-identified Indigenous people were more likely to report not having a primary healthcare provider (19.2%) compared to the rest of the population (15.8%) (StatCan, 2017b). Large geographic distances among communities and low population densities make healthcare more costly in remote areas, resulting in reduced access to services and professionals; this is most pronounced in northern parts of Canada, where visiting professionals or locums provide many

² Estimates exclude the territories, because the survey did not cover all communities in 2016.

key health services periodically on a short-term basis (NCCAH, 2010). To receive specialized care, patients are often required to leave their home communities by flying to more densely populated centres (NCCAH, 2010; MacIntosh, 2017).

With respect to end of life, access to palliative care also varies across Canada. Access to palliative care and coverage of services such as pharmaceuticals, home care, psychologists, and residential long-term care exist piecemeal across provinces and territories, and are funded through a mix of public programs, private insurance, and out-of-pocket payments by individuals (Carstairs, 2010; Chappell & Hollander, 2011; Verma *et al.*, 2014). Gaps in existing data present challenges in understanding the full extent of this issue (Canadian Cancer Society, 2016). An oft-cited statistic notes that only 16 to 30% of people in Canada have access to palliative care (Carstairs, 2010), though it is based on a study of in-hospital palliative care in Western Canada only (Downie & Lloyd-Smith, 2014). Barriers to access include issues of training and education among healthcare professionals, such as the lack of adequate training in palliative care in Canada (Stonebridge, 2017). In a letter to the Quebec Health Minister dated May 29, 2018, the CMQ raised concerns that, because palliative care and social services are increasingly diverted to those who make a request for MAID, patients may seek to access these services by requesting MAID (CMQ, 2018).

2.3.1 Health and Health Equity in Canada

There are significant disparities in health in Canada. For example, life expectancy is consistently lower than average in regions with high unemployment rates, lower educational achievement, and greater material and social deprivation (PHAC, 2018). Low socio-economic status is also related to higher incidences of chronic disease, such as arthritis, asthma, and diabetes (PHAC, 2018). Studies have demonstrated that immigrant, racialized, and ethnocultural groups face barriers in accessing physical and mental healthcare (McKenzie *et al.*, 2016). Disparities in preventive care such as reduced access to breast cancer screening or mental healthcare, as well as outcomes of care such as lower cancer survival rates, have been reported (Booth *et al.*, 2010; Kumachev *et al.*, 2016; McKenzie *et al.*, 2016).

Such systemic factors (or social determinants of health) are estimated to influence up to 60% of a population's health status (CMA, n.d.). Healthcare access can explain up to 25% of a population's health status, while biology and genetics account for 15% (CMA, n.d.). Social determinants of health include community, housing, food security, physical environment, gender, ability, race, and Indigenous status, among others (PHAC, 2018).

Social determinants can affect the risk of developing an illness, the course and severity of the illness, and the availability of treatment. Stigma and discrimination influence health outcomes, affecting some groups and individuals differently. People with disabilities and their families have reported, for many years, that the healthcare system makes negative assumptions about the quality of their lives (e.g., Stanton & Besser, 1998; Gill, 2000; Drainoni *et al.*, 2006); some health professionals believe life with extensive disabilities is not worth living (Gill, 2000). The need for improved health equity is a fundamental issue in Canada, increasingly enshrined in provincial and territorial legislation. Improving health equity allows people to achieve their full health potential by removing preventable and avoidable systemic conditions that constrain life choices, including choices at the end of life (e.g., Batavia, 2001).

2.3.2 Barriers to Healthcare for Indigenous People

Reconciliation with Indigenous people calls for the provision of services consistent with their cultures and needs. Yet, formal healthcare for Indigenous people in Canada has historically been highly segregated and of low quality (FNHA, 2017; Geddes, 2017). The sharing of responsibilities among federal, provincial, and territorial governments has created a patchwork healthcare system. Payment disputes between federal and provincial/territorial governments can result in delayed access to necessary health services (NCCAH, 2010).

Healthcare inequities experienced by Indigenous people have been well documented (e.g., Loppie *et al.*, 2014; Allan & Smylie, 2015; Hart & Lavallee, 2015; TRC, 2015a). Racism continues to create and reinforce disparities (Loppie *et al.*, 2014; Allan & Smylie, 2015), and, as noted in Section 2.3.1, inequitable access to healthcare leads to poor health outcomes (Reading & Wien, 2009). A lack of appropriate and safe healthcare can prevent Indigenous people from seeking treatment (NCCAH, 2010); deficiencies in cultural safety and competence, as well as historical and current abuses, have resulted in some Indigenous people losing trust in the healthcare system (Geddes, 2017). Indeed, the Truth and Reconciliation Commission called for the Canadian healthcare system to recognize the value of Indigenous healing practices and use them when treating Indigenous patients (TRC, 2015a).

Indigenous Peoples hold a variety of spiritual views that may inform conceptions of health, death, and dying that are both different from and similar to Western conceptions. Traditional teachings stress the interconnectedness of all of creation, and that humankind is to live in harmony with the natural world (NFB, 2015). In contrast to the positivist (i.e., empirical data-focused) attitudes that dominate modern Western medicine, Indigenous conceptions of health are more holistic in nature (Stewart & Marshall, 2017). For many Indigenous people, connections to family, friends, community, nature, and culture are an

important part of the healing process, suggesting that they may be more receptive to healthcare services based on a theme of interconnectedness (McCormick, 1997). The medicine wheel, for instance, underscores the importance of balance and emphasizes four interrelated forms of health: physical, emotional, spiritual, and mental/intellectual (Dyck, 1996). Some conceptualizations of the medicine wheel also represent the four stages of life in the physical world: birth, youth, adulthood, and death (NLM, n.d.). Many Indigenous people believe in an afterlife and some view the dying process as preparation for the afterlife journey (Kelly & Minty, 2007).

The Indigenous Elders who shared their knowledge and experiences at the Elders Circle (Section 1.5.2) stated that life is sacred and, therefore, death should not be the subject of casual discussion, which risks diminishing life's value. Ideally, individuals make end-of-life decisions as part of a community, embedded in supportive relationships. The Elders felt that allowing MAID for people with mental disorders could be damaging in communities experiencing youth suicide crises. Elders also shared experiences of systemic barriers that prevented them or their loved ones from accurate diagnoses and appropriate treatment. Without basic access to appropriate healthcare and social services in the community, the Elders expressed concern that MAID is a highly inappropriate care option. Consideration of MAID in the three topic areas is a low priority for most Indigenous communities that are also dealing with a lack of clean water, food security, healthcare, and other basic needs. The Elders, while appreciative of the CCA's effort in facilitating the Elders Circle, noted that they do not speak for all Indigenous perspectives. The Panel recognizes that too little input from Indigenous people creates a significant gap in the evidence considered for these reports. It is important to consider the potential needs and concerns of Indigenous Peoples with respect to MAID in the three topic areas.

2.3.3 Culture and End-of-Life Care

Family, ethnicity, religion, workplace, education, as well as other factors contribute to one's cultural experience. Culture can be profoundly influential in how people, both patients and healthcare practitioners, view end-of-life medical care, and death and dying in general (Chakraborty *et al.*, 2017). As a result, one's choice in medical treatment is likely affected by one's personal views on death. While discussions on medical options to prolong life may be appropriate and desirable for some, others may view them as an interference in the natural passage of life (Coolen, 2012). In some cultural traditions, suffering is an essential and spiritually meaningful part of life, and something to be experienced and endured rather than avoided (Searight & Gafford, 2005). Lived experience of racism and historical trauma in the healthcare system also play a role in attitudes towards end-of-life care (e.g., Welch *et al.*, 2005).

Religion and spirituality can be especially important when making end-of-life medical decisions (Chakraborty *et al.*, 2017). Religion may play an essential role in providing meaning and insights into issues of health, medicine, death, dying, and philosophies about an afterlife (O'Connell, 1995). There are diverse perspectives among and even within the faith traditions, which are not homogenous (e.g., orthodox or conservative versus reform or liberal perspectives). This diversity of perspective shapes the opinions that religious people may have about MAID.

The diversity of cultural experiences in Canada influences any examination of the impacts and implications of MAID in the three topic areas. A thorough consideration of these perspectives was beyond the scope of the reports and remains a significant knowledge gap.

2.4 HEALTHCARE DECISION-MAKING

In Canadian law, respect for a person's autonomy and the protection of their bodily integrity are the core values underlying the principle that decisions made by capable individuals must be respected, and the more specific rule that consent must be obtained prior to treatment (Gilmour, 2017). There are exceptions to this general rule: for example, in some provinces and territories, refusals made by capable minors (Day, 2007) or by capable adults who are involuntarily committed to hospital because of mental disorders may not be followed (Wildeman, 2016). Discussions of healthcare decision-making occur more specifically in each topic area report, but three decision-making concepts are important to clarify for consistency: informed consent, decision-making capacity (as a clinical and legal concept), and decision-making authority.

2.4.1 Informed Consent

Provincial and territorial legislation specifies that informed consent must be:

- related to the proposed healthcare;
- given voluntarily;
- not obtained by fraud or misrepresentation;
- given by a person capable of making the healthcare decision;
- given by a person who has had the opportunity to ask questions about the proposed care and alternatives, and receive answers; and
- given by a person adequately informed to understand the proposed care, including information on the nature of the proposed care, its risks and benefits, and on reasonable alternatives to the proposed care, including non-treatment.

(Gov. of BC, 1996c; Gov. of ON, 1996;
Gov. of PE, 1988; Gov. of YK, 2003a)

Nova Scotia requires hospitals to obtain informed consent to care for patients; however, this statute does not extend to facilities other than hospitals (Gov. of NS, 1989). Quebec requires physicians to obtain informed consent from patients as stated in the *Code of Ethics of Physicians* (Gov. of QC, 2017b) and established in the *Civil Code of Quebec* (Gov. of QC, 1991). Outside Quebec, common law determines informed consent requirements for provinces and territories that do not have explicit legislation and for practices that are outside the scope of legislation on healthcare consent (Wahl *et al.*, 2014).

2.4.2 Decision-Making Capacity

All adults are presumed to have decision-making capacity unless there are reasonable grounds to believe otherwise or unless legislation removes that presumption (Gilmour, 2017). A patient has capacity when they have the ability to understand and appreciate the nature and consequences of their decisions. Capacity refers to the cognitive abilities necessary for sound decision-making — specifically, being able to understand information relevant to making a decision and the ability to appreciate the reasonably foreseeable consequences of a decision (or lack of decision). When questioned, capacity becomes decision- and time-specific; it is assessed in relation to the decision to be made and at the time of its implementation. It is not a global determination of the presence or absence of a person's overall decision-making ability (Gilmour, 2017).

Guidelines, policies, and guidance related to capacity and consent are provided by health regulatory colleges, and in some cases by employers (e.g., hospitals, health authorities), experts, scholars, and organizations such as the Canadian Medical Protective Association (CMPA) (LCO, 2017; CMPA, n.d.). There is no universally accepted clinical approach to capacity assessment (Seyfried *et al.*, 2013) and little data on the assessment of capacity in the specific circumstances of MAID (i.e., in the presence of intolerable suffering) (Cartagena *et al.*, 2016). In determining capacity for clinical decisions, healthcare practitioners typically use either a directed clinical interview or a formal capacity assessment tool such as the MacArthur Competence Assessment Tool (MacCAT) (Grisso *et al.*, 1997) or Aid to Capacity Evaluation (ACE) (Etchells *et al.*, 1999).³ Formal capacity assessment tools remind clinicians what dimensions of understanding and appreciation to question; it is then up to the clinician to judge whether a person's abilities fulfil (or not) the criteria laid out in law or policy.

Clinicians determine when a capacity assessment is appropriate (Leo, 1999; Ganzini *et al.*, 2004; Dastidar & Odden, 2011), unless a court has already determined a person is legally incompetent or the person is deemed to lack capacity by the operation of a statute. The purpose of a clinical capacity

³ For a comprehensive list of clinical capacity assessment tools, see Kim (2010).

assessment is to provide a yes/no judgment about whether a specific person can consent to a specific medical treatment (at a specific time, in a specific context) (Charland, 2015).

2.4.3 Decision-Making Authority

Adults with decision-making capacity have legal authority over their healthcare decisions. However, the decision-making authority of minors and involuntarily committed patients, regardless of capacity, is constrained in some provinces and territories (more details can be found in this report and the report *The State of Knowledge on Medical Assistance in Dying for Mature Minors*). If an adult is found to lack decision-making capacity, the healthcare practitioner must notify and explain this finding to the individual. The next step is to determine whether there is a valid instruction directive, applicable to the medical decision at hand. The healthcare practitioner must identify (or determine) who the SDM is. That may be someone identified by the patient in a written document prior to losing capacity (i.e., a proxy directive) (Dalhousie Health Law Institute, 2017). The SDM may also be a guardian or person appointed by a statute or court. Some provinces and territories have recognized alternative models to substitute decision-making in limited circumstances, such as supported decision-making (e.g., Gov. of BC, 1996b; Gov. of YK, 2003b; Gov. of AB, 2008; Gov. of MB, 1993) and co-decision-making (Gov. of SK, 2000).

If there is no recognized, appointed SDM, most provincial and territorial legislation defines a nearest relative who can act on behalf of the person for the specific treatment decision at hand (e.g., Gov. of BC, 1996c; Gov. of SK, 2015). SDMs act in accordance with the person's prior capable wishes; if unknown, the SDM makes a decision in the person's best interests. For more information on advance directives, see Section 3.3.2 of *The State of Knowledge on Advance Requests for Medical Assistance in Dying*.

2.5 CHAPTER SUMMARY

Recent changes in Canadian law have led to the partial decriminalization of MAID. Informed discussions of MAID must consider the complex legislative and regulatory Canadian contexts outlined above, as well as the broader historical context that informs a diversity of perspectives on how best to approach MAID with respect to the three topic areas. The relative significance of healthcare and specialized services regulation, delivery, and access, however, varies across the three topic areas, and considerations of informed consent, decision-making capacity, and decision-making authority will particularly diverge. Indeed, as presented in these reports, MAID as it relates to mature minors, advance requests, and where a mental disorder is the sole underlying medical condition gives rise to distinct issues that interface differently with the various aspects of Canada's healthcare and legal systems.

3

Mental Disorders in Canada

- The Concept of Mental Disorder
- Suicide
- Prevalence and Socio-Economic/Demographic Correlates of Mental Disorders, and Access to Care in Canada
- Indigenous People and Mental Health
- Other Specific Populations and Mental Health
- Legal Landscape for Mental Health and MAID
- Knowledge Gaps

3 Mental Disorders in Canada

Key Findings

In Canada, all adults — including those with mental disorders — are presumed to have the legal capacity to make medical decisions. The presumption of capacity can be overridden in cases where a formal capacity assessment by a healthcare practitioner indicates that a person lacks decision-making capacity (Section 3.6.2).

There is a long history of stigma, discrimination, and paternalism against people with mental disorders in Canada and elsewhere. The lives of those with mental disorders have been valued less than the lives of those without mental disorders. Freedoms and choices have been unjustly restricted (Section 3.3.3).

Most mental disorders lack the prognostic predictability of the physical conditions that currently motivate MAID requests in Canada. There is less certainty about how a person's mental disorder will evolve over time and whether treatments and/or social interventions will be effective in relieving their suffering and improving their quality of life. However, predictability can be higher for certain conditions, or for patients who have undergone multiple treatments over a longer period of time (Section 3.1.2).

Having a mental disorder is one of the strongest risk factors for suicide (Section 3.2.1).

A range of policies and laws in Canada demonstrate society's commitment to suicide prevention. Research demonstrates that most people who attempt suicide are ambivalent about wanting to die (Section 3.2.1).

Although mental disorders can affect anyone, having a mental disorder is strongly correlated with certain social, economic, and environmental inequalities, such as poverty, unemployment, homelessness, social isolation, stigma, and discrimination. Further, people with mental disorders face impediments to accessing appropriate mental healthcare in Canada (Section 3.3.2).

Provinces and territories have enacted mental health laws and policies acknowledging that differential treatment of those with mental disorders is acceptable in certain specific situations due to characteristics of the mental disorder (Section 3.6.3).

The evidence examined in this report has been gathered to help inform policy-makers about the potential implications of permitting or prohibiting medical assistance in dying in cases where a mental disorder is the sole underlying medical condition (such cases are hereafter referred to in this report as *MAID MD-SUMC*). The phrase “sole underlying medical condition” originated in Bill C-14 and is provided in the charge (Section 1.1); it serves to differentiate between cases in which a person with a mental disorder already meets MAID eligibility criteria due to a physical condition from those cases in which a mental disorder is the only illness, disease, or disability that motivates a MAID request. As noted in the charge, this report does not examine cases in which a person with a mental disorder as their sole underlying medical condition qualifies for MAID under the existing eligibility criteria.

The report uses the language of *prohibiting* and *permitting more* (or *expanding*) MAID MD-SUMC. The term *prohibiting* refers to the status quo in Canadian law and to restricting MAID MD-SUMC further. The phrase *permitting more* acknowledges that the current law allows MAID MD-SUMC, provided a person meets all of the eligibility criteria.

Under current Canadian federal law and Quebec law, people whose mental disorder is their sole underlying medical condition are not excluded from MAID eligibility. The Expert Panel Working Group (hereafter Working Group) identified one report of a person in Canada (“E.F.”) who received MAID when a mental disorder seemed to be their sole underlying medical condition (E.F. had conversion disorder, properly known as *functional neurological symptom disorder*) (ABC, 2016). The request was made and carried out in early 2016, after the *Carter* ruling but before Bill C-14 came into force, and was granted by the Alberta Court of Appeal under the Supreme Court of Canada’s decision on constitutional exemptions to the ban on MAID. However, it is usually difficult for someone with a mental disorder as their sole underlying medical condition to meet the eligibility criteria set out in Bill C-14 due to the nature of those disorders (see Section 4.1 for a detailed discussion of issues relating to mental disorders and current MAID eligibility criteria).

The Working Group that produced this report was composed of experts from a range of different disciplines, from different backgrounds, and with different experiences. Each of these experts brought unique views and perspectives to bear on the issue of prohibiting or permitting more MAID MD-SUMC. All of these perspectives have informed and influenced the final report, which is unlike the report that any single Working Group member would have produced on their own. Nevertheless, it is the view of the Working Group that this report can ultimately serve to help inform policy-makers about the issues and evidence related to prohibiting or permitting more MAID MD-SUMC in Canada.

Given this wide range of perspectives and the controversial nature of the topic, Working Group members do not agree on some fundamental issues. These issues include the weighing of different outcomes resulting from prohibiting or permitting more MAID MD-SUMC, the ethical and practical significance of the reasonable foreseeability of a person's death in the context of MAID, the distinction (or lack thereof) between suicide and MAID MD-SUMC, the impact of permitting more MAID MD-SUMC on current suicide prevention strategies, and the distinction (or lack thereof) between MAID and other highly consequential decisions that may result in a person's death (e.g., refusing life-sustaining treatment). In many areas, the Working Group did not reach consensus on the interpretation and/or significance of the evidence, or about what constituted relevant evidence. These disagreements are indicated in the text, and are summarized in Box 7.1.

3.1 THE CONCEPT OF MENTAL DISORDER

The field of psychiatry has found it challenging to determine which conditions ought to be considered *mental disorders* (Murphy, 2017; Perring, 2018). Because of this, the Working Group chose to rely on the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5), a standard psychiatric diagnostic classification scheme used in Canada.⁴ The DSM-5, published by the American Psychiatric Association, serves various purposes beyond providing clinicians with diagnostic criteria for mental disorders. It is also used for statistical, judicial, and reimbursement purposes. In other words, it provides an exhaustive inventory of conditions that may be of importance in diverse, non-clinical settings. As a result, this expansive compendium may include conditions that psychiatrists do not routinely treat, and which those affected do not consider to be mental disorders, such as intellectual disabilities. Nevertheless, in this report, the term *mental disorders* includes this full range of conditions. Although narrowing the term's definition to correspond to medical practice patterns and/or patients' self-identification may be possible, the Working Group considered this task to be beyond the scope of its charge.

⁴ Although the World Health Organization's *International Statistical Classification of Diseases and Related Health Problems* (ICD-10) is Canada's official classification system, the DSM system is widely used by many Canadian mental healthcare practitioners. The DSM is the most widely used classification scheme in North America, while the ICD-10 is the most widely used system in most of the rest of the world (Goldner *et al.*, 2016).

3.1.1 Defining Mental Disorders

Mental disorders can be defined as health problems that disturb or impair a person's thoughts, experiences, emotions, behaviour, and/or ability to relate to others (GC, 2002; APA, 2015; PHAC, 2015b). This broad definition includes hundreds of conditions with diverse clinical profiles. While the focus of this report is on *mental disorders* as a single category, it is important to note that generalizations cannot be made about this category just as they cannot be made about *physical disorders* as one group. Mental disorders may be characterized by a relapsing and remitting course (as is often the case in bipolar disorder), a stable course (as is usually the case for intellectual disabilities), a course of progressive decline (e.g., most dementias),⁵ or an unpredictable course (e.g., addictions) (APA, 2013). Certain conditions (e.g., schizophrenia) may impact a person's ability to function personally or professionally, while many people with other conditions (e.g., anxiety disorders) function well, to the extent that their mental disorder does not significantly impact their life.

The threshold at which an experience or behaviour becomes pathological is often determined not only by biological and psychological factors, but also by social factors and cultural norms. In short, the identification, classification, and diagnosis of mental disorders are not exclusively scientific, objective, and value-neutral; rather, some normative, subjective, or value-laden sociocultural conception of what counts as normal often frames society's and clinicians' perceptions of mental health and mental disorders (Perring, 2018).

The debate about the removal of the so-called “bereavement exclusion” from the DSM-5 (Zachar, 2015; Zachar *et al.*, 2017) illustrates this point. Until the fifth edition of the DSM (2013), a person could not be diagnosed with major depressive disorder within two months of the death of a loved one, even if their experience of bereavement was indistinguishable from the symptoms of major depression.⁶ This was not the case for other troubling life events such as divorce or the onset of serious disease, which could lead to a diagnosis of major depressive disorder in those who fulfilled depressive criteria following these events. The bereavement exclusion was therefore removed from the DSM-5, on the grounds that many difficult life events can trigger depressive episodes and sometimes lead to recurrent depression, and that all such episodes are equally pathological with respect to long-term outcomes. Those who opposed

5 Dementia is treated in greater detail in *The State of Knowledge on Advance Requests for Medical Assistance in Dying*

6 Except in certain clinical circumstances, such as when the patient's symptoms are “characterized by marked functional impairment, morbid preoccupation with worthlessness, suicidal ideation, psychotic symptoms, or psychomotor retardation” (APA, 1994).

the removal of the bereavement exclusion argued that intense grief following the death of a loved one is a normal and appropriate human experience, which should not be pathologized (Wakefield, 2011; Wakefield & First, 2012). Supporters of the removal argued that, in cases where a person's bereavement fulfilled the DSM criteria for major depression, diagnosis and prognosis were similar to cases brought on by other negative life events (Lamb *et al.*, 2010; Zisook *et al.*, 2012). Importantly in this debate, both points of view consider the *same set of clinical circumstances*, yet arrive at different judgments about whether a certain experience is pathological or not.

Complicating matters further is the fact that, like many other mental disorders, grief is (at least in part) culturally defined, which makes it difficult to apply strict diagnostic criteria across multiple cultural settings. For example, according to the DSM-5, complicated grief disorder can be diagnosed if a person is grieving for more than six months (APA, 2015). However, different cultural groups have different customs around grieving that do not correspond to the DSM-5's criteria. For example, some Indigenous Peoples have a traditional grieving period of one year (HC *et al.*, 2000).

3.1.2 Diagnosis, Prognosis, and Treatment Effectiveness

While there has been extensive research into the underlying biological basis of mental disorders (including genetic, neurophysiological, and neuroanatomic lines of inquiry), their underlying causes remain largely unknown (Cooper, 2016; Perring, 2018), with the exception of some dementias and some intellectual disabilities. As a result, most mental disorders are referred to as *syndromes* (i.e., clusters of associated symptoms and signs) (Nasrallah, 2009; APA, 2013; Murphy, 2017). To be diagnosed with a mental disorder, a person's symptoms and presentation must satisfy a certain number of that disorder's diagnostic criteria. Since people in the same diagnostic category can satisfy different criteria, these categories contain considerable heterogeneity (APA, 2013; Murphy, 2017). That is, two people can share the same diagnosis but have different symptom profiles.

Furthermore, diagnoses of most mental disorders do not refer to specific pathology within the body, and they often lack the stability of diagnoses of most physical disorders. As a result, it can be difficult for clinicians to know when they have reached a reasonable degree of certainty that a given diagnosis will persist over time, the way they can with many of the physical conditions that currently underlie most MAID requests in Canada (e.g., cancers and diseases of the circulatory/respiratory system). If a person has lived with a mental disorder for a long time, diagnostic change may be less likely. However, diagnostic stability

does not guarantee accurate prognostication (i.e., the prediction of the course of the illness over time). For example, clinicians historically believed that borderline personality disorder was a lifelong condition. However, longitudinal research demonstrates that, for many people, a significant proportion of symptoms remit over time (Gunderson *et al.*, 2011), to the extent that the diagnosis ceases to apply. Similarly, some people with substance-use disorders spontaneously remit (even in severe cases), ceasing to use a substance after many years and with no assistance of any kind, while others continue to use for years despite their desire to stop and despite extensive medical and mental health support (Klingemann & Sobell, 2007). Furthermore, with many mental disorders it is difficult to predict which patients will remit and relapse, or be chronically affected.

While there exists a body of clinical research on the treatment of certain mental disorders (e.g., major depressive disorder, schizophrenia, and bipolar disorder), there is uncertainty surrounding the effectiveness of many standard treatments (Cooper, 2007; Hautamäki, 2018). The syndromal nature of mental disorders means that patient groups in clinical trials are often more heterogeneous than those in clinical trials for physical diseases, which are selected with careful attention to diagnostic homogeneity (Cooper, 2007). On the other hand, attempts to more rigorously select for homogenous patient groups can restrict the degree to which the results of a clinical trial can be generalized (Tcheremissine *et al.*, 2014). Furthermore, what counts as therapeutic efficacy in clinical research is usually measured over relatively short periods of time (weeks or months), whereas mental disorders can persist over much longer periods of time. As a result, it can be difficult to predict the long-term effectiveness of many psychiatric treatments (Cooper, 2007).

Even when clinical trial data suggest treatment efficacy, applying these data to an individual patient's context is not straightforward. The heterogeneous nature of the diagnostic categories for mental disorders makes it difficult to know which specific patient will benefit from which of the available treatments. Systematic trial and error of available treatments is the primary method for identifying effective treatment in a given patient. Some people benefit from the first treatment they try, others pass through a series of individual and combination treatments, while others are resistant to treatment.

While prognosis is therefore difficult to determine for many patients with a mental disorder, it is possible to classify a patient's mental disorder as being *treatment-resistant* after a sustained period of treatment trial and error. In its broadest sense, the term *treatment-resistant* refers to situations in which symptoms of a person's mental disorder have not been meaningfully reduced following a

certain number or type of treatments under appropriate conditions.⁷ However, the term is also problematic, as there is no agreed-upon definition of what constitutes treatment resistance (Berlim & Turecki, 2007; Conway *et al.*, 2017; Anderson, 2018). For instance, there is no consensus about what constitutes meaningful or sufficient symptom reduction, about the proper number and type of interventions that must be tried, or about the proper conditions under which treatment attempts should occur. The term also tends to exclusively refer to psychopharmacological treatments (i.e., medication) and excludes psychological treatments such as therapy. Furthermore, there is little empirical evidence that any of the various definitions of treatment resistance can help predict a person's future outcomes (Anderson, 2018). Indeed, treatment resistance is a *retrospective* concept, and does not indicate that a person has no hope of improvement (Blikshavn *et al.*, 2017). It is also important to note that treatment resistance refers to the reduction of the *symptoms* of a person's mental disorder, and not necessarily to the relief of suffering or a desire to die. That is, there will be situations in which a person has a treatment-resistant mental disorder but their suffering can be relieved or their desire to die can be successfully treated.

Treatment response is further complicated by questions of treatment objective. While traditional clinical research focuses on symptom reduction as the goal of treatment, numerous commentators argue for other outcomes, including quality of life, recovery, and acceptance (Anthony, 1993; Jacobson & Greenley, 2001; Davidson & O'Connell, 2005). For a given person, these outcomes may or may not include symptom reduction. See Section 4.4.1 for a discussion of the recovery movement in mental health, which focuses on what outcomes are important to people with mental disorders.

The preceding discussion highlights the fact that there is usually less stability in diagnosis, and poorer predictability in prognosis and treatment effectiveness, for mental disorders compared to the physical conditions that typically motivate MAID requests. Particularly when an apparent mental disorder is in its early stages, it can be difficult to determine whether a problem is in fact a mental disorder (diagnosis), and how that problem will evolve over time (prognosis). It may also be difficult to know to what extent attempts to treat the condition will relieve the person's suffering (treatment effectiveness). However, there will also be clinical circumstances in which there is a relatively higher degree of certainty about these features, particularly when a person has suffered

⁷ The term *treatment-refractory* is sometimes used interchangeably with *treatment-resistant*, and is sometimes taken to suggest a greater degree of resistance. However, it has been argued that this distinction is somewhat arbitrary, and that the terms are in fact essentially synonymous (Berlim & Turecki, 2007; Trevino, 2014).

over a long period of time despite repeated clinical attempts to alleviate that suffering, or in the case of mental disorders that are associated with conditions such as Huntington's or Alzheimer's disease, where the underlying pathology is better understood.

3.2 SUICIDE

In its preamble, Bill C-14 acknowledges that suicide and MAID are related and notes that “suicide is a significant public health issue that can have lasting and harmful effects on individuals, families and communities” (GC, 2016b). This section examines the prevalence of suicide in Canada, risk factors for suicide, and the relationship between suicide and mental disorders. The relationship between suicide and MAID MD-SUMC is discussed in Section 4.2.

At the beginning of the 19th century, it was a criminal offence to attempt suicide in many countries, and survivors of suicide attempts could be prosecuted (Mishara & Weisstub, 2016). The justification for criminalizing suicide was originally a religious one (i.e., it was a sin or immoral act), and later a utilitarian one based on the belief that the threat of punishment might reduce suicides. However, data did not support the deterrence theory — rates do not increase when suicide is decriminalized (Mishara & Weisstub, 2016). Furthermore, over the last century the understanding of suicide has changed. It is now generally considered to be associated with mental disorders and difficulty coping with social hardships, rather than as an offence against moral or religious interdictions. Attempted suicide was decriminalized in Canada in 1972 (Spiwak *et al.*, 2012).

3.2.1 Suicide Rates and Risk Factors

Intentional self-harm was the cause of 1.5% of all deaths in Canada in 2016 (StatCan, 2018b), compared to 1.4% worldwide in 2012 (WHO, 2014a). The age-specific mortality rate from suicide in Canada is more than triple for men as compared to women (StatCan, 2018b). It is not possible to say what proportion of suicides are completed by people facing intolerable suffering at the end of life. In Canada, older people have a much lower suicide rate than younger people; in 2016, intentional self-harm was the cause of death in 0.7% of those aged 65 to 74, 0.3% in those aged 75 to 84, and 0.1% in those 85 and older (StatCan, 2018b).

Although chronic pain and illness are listed as risk factors for suicide (WHO, 2014a), they are only two among a number of life circumstances that contribute to increased suicide risk when there are insufficient protective factors (Mishara & Tousignant, 2004; WHO, 2014a). Research indicates that physical conditions are among the less frequently mentioned reasons for wanting to die in those who

attempt suicide (Wang *et al.*, 2015; Burón *et al.*, 2016). More common reasons include macro-level variables such as unemployment; individual demographic characteristics such as gender, age, and marital status; a wide range of social variables (e.g., social support); and the psychological characteristics of the person (e.g., personality traits, coping strategies) (Mishara & Chagnon, 2016). Certain environmental variables, particularly access to means of suicide, are also associated with an increased risk of a suicide attempt (WHO, 2014a). The most widely held view among suicide researchers is that suicide is a multi-determined outcome that occurs when individual and contextual risk factors outweigh protective factors (WHO, 2014a; Mishara & Carindal, 2015). These factors have been identified through a substantial body of empirical research (Mishara & Tousignant, 2004).

There are multiple factors associated with suicide risk apart from having a mental disorder (Mishara & Tousignant, 2004; WHO, 2014a). Having a mental disorder is, however, one of the most strongly associated risk factors for suicide (WHO, 2014a; Mishara & Carindal, 2015). Systematic reviews and meta-analyses have found that up to 90% of those who die by suicide may have had a diagnosable psychiatric disorder (as determined by a retrospective psychological autopsy) (Cavanaugh *et al.*, 2003; Arsenault-Lapierre *et al.*, 2004). Studies show that the most common diagnoses are affective disorders (particularly depression), substance use disorders, personality disorders, and schizophrenia. The lifetime risk of completed suicide is estimated to be 2% for people with affective disorders (Bostwick & Pankratz, 2000), 5% in people with schizophrenia (Palmer *et al.*, 2005), 8% in people with alcohol dependence (Schneider, 2009), and 8% in people with bipolar disorder (Nordentoft *et al.*, 2011). Although most mental disorders are associated with an increased suicide risk, there are a few exceptions. For example, people with a diagnosis of dementia generally do not have a higher risk of dying by suicide, except in cases of Huntington's disease, and during the period directly following diagnosis (Haw *et al.*, 2009).

Research shows that the majority (approximately 85%) of people who seriously consider suicide will never attempt it (Nock, 2008), and fewer than 5% of those who attempt suicide will die (WHO, 2014a). Most people who attempt suicide are ambivalent about wanting to die — unclear, uncertain, and/or unstable wishes are common in this population (WHO, 2014a). Ambivalence about dying is considered to be a primary characteristic of the desire to kill oneself (Kastenbaum, 2003), and it fluctuates with a person's experiences, including the experience of initiating a suicide attempt (Bergmans *et al.*, 2017). Kevin Hines provides a dramatic example. He was diagnosed with bipolar disorder, attempted suicide by jumping off the Golden Gate Bridge in San Francisco in 2000, and later reported that he had no doubts about his plan until he

was falling from the bridge (Hines, 2013). This example illustrates how a person's decision to die by suicide is not a binary choice, and may be at odds with the usual characterization of healthcare decision-making as a process of gathering information and choosing among options (Appelbaum & Grisso, 1988). To complicate matters further, although rare, some people impulsively kill themselves with little advance warning (WHO, 2014a).

The lay understanding of the relationship between mental disorders and suicide is that suicide is a direct consequence of a mental disorder (Mishara & Chagnon, 2016). According to this model, the symptoms of a mental disorder are a determining factor in the desire to die and engaging in suicidal behaviours. For example, depressive symptoms may alter a person's perceptions of reality, such as perceiving their situation as hopeless when their prognosis may actually be positive (Berghmans *et al.*, 2013; Hindmarch *et al.*, 2013; Blikshavn *et al.*, 2017). Other explanations of the relationship between mental disorders and suicide suggest that psychosocial factors resulting from living with a mental disorder (e.g., social isolation, stigma, unemployment, poor social supports) increase suicide risk (Mishara & Chagnon, 2016). However, no reasons for suicidal thinking are associated with more or less determination to die or the persistence of these desires. And in both models, interventions exist (medical, psychological, social) that reduce risk (Mishara & Chagnon, 2016).

3.3 PREVALENCE AND SOCIO-ECONOMIC/DEMOGRAPHIC CORRELATES OF MENTAL DISORDERS, AND ACCESS TO MENTAL HEALTHCARE IN CANADA

This section provides an overview of the prevalence of mental disorders in Canada (Section 3.3.1), the socio-economic and demographic correlates of mental disorders (Section 3.3.2), the history of care for people with mental disorders in Canada (Section 3.3.3), and access to mental healthcare services and supports in Canada (Section 3.3.4).

3.3.1 Prevalence of Mental Disorders

Table 3.1 summarizes the prevalence of certain mental disorders in Canada (i.e., estimates of the number of cases at a given point in time), but the data sources are not robust. These data are partially drawn from the 2012 *Canadian Community Health Survey* (CCHS), which provides an estimate of the prevalence of mental health problems at the sub-provincial and territorial level in Canada. However, because these data are based on self-reported symptoms rather than clinical diagnoses (MHCC, 2014a; StatCan, 2016), they may under-represent less common mental disorders and psychoses. The CCHS data in Table 3.1 are complemented by data drawn from clinical research, as well as data from administrative sources that include inpatient treatment settings.

Table 3.1

Prevalence of Various Mental Disorders in Canada

Mental Disorder*	Status in Canada
Mood Disorders (e.g., major depressive disorder, bipolar disorder)	In 2012, 12.6% of people in Canada aged 15 years and older (about 3.5 million) met the criteria for a mood disorder (including a major depressive episode or bipolar disorder) in their lifetime (Pearson <i>et al.</i> , 2013). Mood disorders were most prevalent in youths aged 15–24 with 8.2% having experienced a mood disorder over the past year. Rates of mood disorder over the previous 12 months were lowest in those aged 65 and older (1.7%). Women (5.8%) had higher 12-month rates of mood disorder than men (3.6%) in all age groups except for 65+ (Pearson <i>et al.</i> , 2013).
Post-Traumatic Stress Disorder	In 2008, lifetime prevalence of post-traumatic stress disorder (PTSD) in Canada was estimated to be 9.2% (about 3 million people) (Ameringen <i>et al.</i> , 2008).
Generalized Anxiety Disorder	In 2012, 8.7% of people in Canada aged 15 years and older (about 2.4 million) met the criteria for generalized anxiety disorder (Pearson <i>et al.</i> , 2013).
Major Neurocognitive Disorders (e.g., Alzheimer's dementia)	About 7.1% of people in Canada 65 years and older (about 402,000) live with dementia, two-thirds of whom are women. Both the prevalence of dementia and the risk of developing dementia increase with age, "as does the differential in prevalence and incidence estimates between men and women" (PHAC, 2017).
Personality Disorders	No Canada-specific data could be found about the prevalence of personality disorders. However, they are estimated to affect between 6–15% of the adult population (APA, 2013; Gawda & Czubak, 2017).
Somatic Symptom Disorders (e.g., conversion disorder)	Data about the prevalence of somatic symptom disorders are inconsistent, and no Canada-specific prevalence data could be found (except in pediatric settings). However, the DSM-5 estimates the prevalence of somatic symptom disorders to be approximately 5–7% in the general adult population, and more prevalent in women than in men (APA, 2013).
Schizophrenia or Psychosis	In 2012, 1.3% of people in Canada (about 360,000) had received a diagnosis of schizophrenia or psychosis in their lifetime (StatCan, 2013).
Eating Disorders (e.g., anorexia nervosa, bulimia nervosa)	In 2012, 0.4% of people in Canada (about 113,000), had a diagnosis of an eating disorder (StatCan, 2013). The hospitalization rate for eating disorders among women and girls in 2012–2013 was 15 times that of men and boys (CIHI, 2014).

* Individuals may have more than one mental disorder.

3.3.2 Socio-Economic and Demographic Correlates of Mental Disorders

Mental disorders can affect people in all socio-economic and demographic categories (GC, 2002), but the presence of many mental disorders is strongly correlated with certain social, economic, and environmental inequalities

(WHO, 2014b), such as poverty, unemployment, homelessness, and violence (Kirby & Keon, 2006; CIHI, 2007; WHO, 2010; CMHA Ontario, 2011; MHCC, 2014b). Canadian data show that women, youth, and Indigenous people have higher rates of mental health problems than the Canadian average (GC, 2006; StatCan, 2013, 2015b). Depression, anxiety disorders, and eating disorders are more common in women, and are strongly associated with women's greater exposure to poverty, discrimination, socio-economic disadvantage, and gender-based violence. On the other hand, there is no noticeable gender difference with respect to bipolar disorder or schizophrenia (WHO, 2001).

The relationship between social factors and mental disorders is complex and bi-directional: social factors can increase a person's risk of developing a mental disorder, and having a mental disorder can increase a person's exposure and vulnerability to social factors that are detrimental to their mental health (WHO, 2014b; Mental Health Foundation, 2016; Carod-Artal, 2017). As Chandler (2016) writes, "while social marginalization can raise the risk of experiencing a mental health disability, those disabilities also often lead to social marginalization, with higher rates of homelessness and incarceration than the rest of the population."

People living with mental disorders often lack equity in access to educational and employment opportunities, and may lack family or social relationships that could help support recovery (GC, 2002; WHO, 2010; MHCC, 2015). The care requirements and stigma surrounding mental disorders can strain families, often leading to further social isolation (GC, 2002). People with mental disorders are heavily overrepresented in the homeless population, and family relationships have been found to be a significant variable in exiting homelessness (Bonin *et al.*, 2017). For example, while schizophrenia has a worldwide prevalence of approximately 1%, people with schizophrenia account for 11% of the homeless population worldwide (Bonin *et al.*, 2017). People with mental disorders have an increased risk of being the victim of crime, physical or emotional abuse, and sexual assault (Teplin *et al.*, 2005; McFarlane *et al.*, 2006; WHO, 2010; StatCan, 2015a). Worldwide, they face restrictions on their civil rights, and may be denied the opportunity to make decisions for themselves and manage their lives (WHO, 2010).

People with mental disorders also face additional challenges with respect to their physical health and are at higher risk of developing chronic physical disorders (including but not limited to diabetes, heart disease, stroke, and respiratory disease) (Price *et al.*, 2007; CMHA, 2008). They are less likely than those living without mental disorders to receive needed treatments for such physical disorders (Kisely, 2007; CMHA, 2008). They may also engage in behaviours that increase the risk of developing complications or other disorders, such as smoking and substance use (CMHA, 2008).

3.3.3 A Brief Historical Overview of the Care of People with Mental Disorders

The history of treatment of those with mental disorders in Canada is important context for examining MAID MD-SUMC. Before the establishment of a formal system of care in Canada, including publicly funded mental health institutions, people with mental disorders were often placed in prisons or almshouses, or were left in the care of their families or to fend for themselves (Sussman, 1998; Dowbiggin, 2011). As colonialism expanded across Canada, a network of what were then called “lunatic asylums” was established prior to Confederation and continued to be developed throughout the 19th century (Moran, 2001; Dowbiggin, 2011). By the early 20th century, the formal diagnosis of mental disorders was rising and more people were being committed to institutions, which created crowding and funding challenges for government operators (Dowbiggin, 2011; Niles, 2013). Most of the people living in institutions were under medical supervision and received varying degrees of psychiatric treatment.

In the latter half of the 19th century, the eugenics movement was used to explain the growing numbers of registered “insane,” blaming defective heredity and “mentally unsound” immigrants arriving on Canadian soil (McLaren, 1997; Chadha, 2008; Strange & Stephen, 2010). In 1921, the Canadian National Committee for Mental Hygiene recommended sexual sterilization of people with mental disorders (Amy & Rowlands, 2018). British Columbia and Alberta passed sterilization legislation to ensure that “mentally defective” individuals would be prevented from reproducing (Dyck, 2013). In Alberta, the *Sexual Sterilization Act*, in force from 1929 to 1972, created the Alberta Eugenics Board, which allowed for the sterilization of people living in mental health institutions as a condition for their release into the community. Evidence suggests that women and Indigenous people were disproportionately sterilized as part of this program, and that in many cases sterilization was undertaken without the person’s consent (Grekul *et al.*, 2004; Boyer & Bartlett, 2017).

In the first half of the 20th century, both the medical community and the public generally supported sterilization programs (Dowbiggin, 1997; McLaren, 1997). In the view of the Working Group, supporters of sterilization justified such practices on the basis of a widely held belief that the lives of people with mental disorders were less valuable than the lives of those without. Although the eugenics movement was discredited following World War II, the mistreatment of people with mental disorders in the healthcare system continued; paternalistic practices restricted civil liberties and denied people choices, freedoms, and autonomy.

One well-reported example of such practices occurred in the 1950s and 1960s. The Allan Memorial Institute in Quebec experimented on psychiatric inpatients without their knowledge or consent as part of the CIA's MK-ULTRA mind control program. These experiments were partially funded by the Canadian government, and included intensive electroconvulsive therapy (ECT), sleep and sensory deprivation, administering LSD to patients, and putting people in drug-induced comas (CBC, 2017a). In Ontario, the Oak Ridge Psychiatric Unit, a maximum-security mental health facility, used similar techniques on its patients between 1966 and 1983 (Power, 2017). In 2017, the Ontario Superior Court of Justice found that, although such techniques were part of generally accepted medical practices of the time and may even have been undertaken in good faith, the methods employed at Oak Ridge "were torture and a degradation of human dignity" (ONSC, 2017).

The deinstitutionalization of people with mental disorders began in the 1950s and accelerated in the 1960s and 1970s in Canada. This movement reflected the growing knowledge of mental health rehabilitation practices; a growing emphasis on the civil liberties of patients with mental disorders; the impact of new psychopharmacological therapies; acknowledgement of the harms and abuses in the institutional care system; as well as the desire of provinces to reduce costs (Morrow *et al.*, 2008; Flood & Thomas, 2016). As part of the deinstitutionalization movement, a number of large mental health institutions were either downsized or phased out entirely, with patients discharged into community care settings. However, community mental health options in the 1980s and 1990s were not provided with sufficient resources to respond to the growing need for care in the community (Epp, 1988; Commission on the Future of Health Care in Canada, 2002; Romanow & Marchildon, 2003; Flood & Thomas, 2016; Dyck & Deighton, 2017). This contributed to high readmission rates of people with mental disorders to psychiatric units, the growing problem of homelessness among people with mental disorders, and the overrepresentation of people with mental disorders in the criminal justice system. While many instances of injustice towards people with mental disorders in Canada and abroad occurred in the past, there continues to be mistreatment today.

In the view of the Working Group, the history of mistreatment of many people with mental disorders in the delivery of healthcare — the early asylums, the eugenics movement, the institutional abuses of the mid-20th century, and the failure to provide sufficient resources following deinstitutionalization — demonstrates how such people could be vulnerable to further mistreatment in the context

of MAID MD-SUMC. On the one hand, prohibiting MAID MD-SUMC may be seen as perpetuating paternalistic practices that restrict the civil liberties of people with mental disorders, and deny them freedom, choice, and autonomy. On the other hand, permitting MAID MD-SUMC more broadly may be seen as perpetuating an ideology that devalues people with mental disorders by suggesting that their lives may not be worth living and by promoting civil liberties without providing necessary resources.

3.3.4 Access to Mental Healthcare Services

Many people with mental disorders do not receive the necessary treatment for their condition (WHO World Mental Health Survey Consortium, 2004; MHCC, 2016b). This is because they may be reluctant to seek mental healthcare due to stigma (CMHA, 2008; Knaak *et al.*, 2017), or they may be unable to access mental healthcare for a variety of reasons (discussed further below). In 2012, 10.9% of people in Canada reported accessing a professional mental healthcare service (StatCan, 2013). At the same time, in 2012, 26.3% of people in Canada aged 12 and older with a mental disorder reported that they perceived a need for mental healthcare in the past year but did not receive it (MHCC, 2016a). In 2014 and 2015, more than 222,000 Canadian hospital stays were a result of mental health or addiction issues (CIHI, 2016). Factors that may impede access to mental healthcare services are presented in Box 3.1.

Box 3.1

Some Impediments to Accessing Mental Healthcare

Some impediments to accessing mental healthcare include:

- lack of access to primary care providers (Ross *et al.*, 2015);
- primary care providers who are insufficiently trained in the delivery of mental healthcare (Ross *et al.*, 2015; Flood & Thomas, 2016);
- long wait times for psychiatrists (Flood & Thomas, 2016);
- lack of access to psychiatrists, especially in rural and remote areas (Slaunwhite, 2015; McKenzie *et al.*, 2016);
- inadequate or absent insurance coverage for medications, psychological services, rehabilitative measures, and other types of outpatient treatment (Flood & Thomas, 2016);
- lack of social supports (e.g., subsidized housing and/or transportation) (Ross *et al.*, 2015; Slaunwhite, 2015); and
- stigma towards people with mental disorders (Ross *et al.*, 2015; Slaunwhite, 2015; Knaak *et al.*, 2017).

Given that living with mental disorders is often correlated with poor socio-economic status, that mental health-promoting services can be difficult to access, and that improving mental health often requires access to a broad array of resources beyond medical care (such as income stability, secure housing, and social support), there is the possibility that people who seek MAID MD-SUMC may be individuals who are socially and economically marginalized. In support of this, a qualitative study of patients who requested euthanasia or physician-assisted suicide for psychiatric disorders (psychiatric EAS) in the Netherlands found that, in some cases, a lack of socio-economic resources contributed to their suffering (Verhofstadt *et al.*, 2017). On the other hand, a 2007 study of requests for assisted dying in Oregon and the Netherlands suggests that people who enjoy comparatively *higher* social, economic, and educational privilege are more likely to access MAID than those who are marginalized (Battin *et al.*, 2007). However, Oregon does not allow assisted dying in cases where a mental disorder is the sole underlying medical condition, and the study does not disaggregate requests for *psychiatric* EAS in the Netherlands from all requests for EAS in that country. Indeed, data on socio-economic and demographic variables related to requests for assisted dying specifically for mental disorders in jurisdictions that allow it are almost nonexistent,⁸ so the Working Group could not extrapolate the demographic and socio-economic status of MAID MD-SUMC requesters from all assisted dying requesters. The socio-economic and demographic characteristics of people with a mental disorder who request MAID MD-SUMC may be different from those who request MAID for a physical condition.

3.4 INDIGENOUS PEOPLE AND MENTAL HEALTH

According to the 2016 Census, there were 1,673,785 Indigenous people in Canada in 2016, accounting for approximately 4.9% of the total population (StatCan, 2017a). Although there is great heterogeneity among individuals, Indigenous people overall experience mental health issues at a higher rate than the non-Indigenous population (StatCan, 2015b). Nearly 39% of Indigenous people in Canada live in rural areas (StatCan, 2018a), and may have limited access to formal mental health supports. While 30% of Indigenous people in Canada live in large population centres and consequently should have better access to mental healthcare, some individuals experience racism as they navigate the mental healthcare system and/or cannot access culturally appropriate and safe mental healthcare (Allan & Smylie, 2015; Boksa *et al.*, 2015), in addition to facing the impediments to care listed in Box 3.1. Direct and intergenerational traumas or past discrimination within the healthcare system may deter some Indigenous people from seeking needed mental healthcare (Boksa *et al.*, 2015).

⁸ The two exceptions to the lack of demographic data on people who request psychiatric EAS are gender and age (see Sections 3.5, 5.5, and 6.3).

In addition, there is a general lack of attention paid to Indigenous knowledge and understanding of mental health in the Canadian healthcare system (Boksa *et al.*, 2015; Stewart & Marshall, 2017), which may differ significantly in important ways from Western conceptions of mental health (Oulanova & Moodley, 2017).

Rates of suicide among Indigenous people are disproportionately high. Among First Nations, the suicide rate is roughly double that of the total Canadian population (Kirmayer *et al.*, 2007). This disparity is even more pronounced among Indigenous youth. The suicide rate for First Nations youth living on reserve is five to seven times higher than for non-Indigenous youth. In Inuit youth, the suicide rate is 11 times higher (GC, 2016a). There have been clusters of Indigenous youth suicides in communities such as Attawapiskat First Nation in Ontario (Spurr, 2016), Pimicikamak Cree Nation in Manitoba (Puxley, 2016), and across northern Saskatchewan (Cowan, 2016). The Truth and Reconciliation Commission's (TRC) report connects the disparity in suicide rates and other health outcomes in Indigenous communities directly to Canada's colonial legacy, including residential schools and a reserve system that "separated Aboriginal people from their traditional lands and livelihoods, confining them to cramped and inadequate housing on reserves that lacked the basic sanitary services" (TRC, 2015b). In the view of the Working Group, the potential impact of MAID MD-SUMC, if any, on suicide prevention efforts is an issue that will need to be explored more deeply with Indigenous people. Further, Indigenous knowledge and practices related to death and dying generally may be unknown or unexplored by healthcare practitioners when discussing end-of-life issues with Indigenous patients (Kelly & Minty, 2007).

3.5 OTHER SPECIFIC POPULATIONS AND MENTAL HEALTH

In Canada, different gender, ethnic, cultural, socio-economic, and demographic groups experience differences in the prevalence of and risk factors for mental disorders, suicidality, and access to mental healthcare and social supports. In addition, certain unique issues related to capacity, voluntariness, vulnerability, discrimination, or other factors may apply to specific populations such as children, seniors, and institutionalized individuals. This section examines issues related to mental health and mental disorders for specific sub-populations in Canada. See Section 6.3 for a discussion of the potential implications for these groups should MAID MD-SUMC be prohibited or permitted more broadly.

Gender

There is evidence that women in Canada experience certain mental disorders at a higher rate than men (Pearson *et al.*, 2013). In addition, women in Canada are three to four times more likely to attempt suicide than men, although men

are more likely to die by suicide (StatCan, 2017c). Mental disorders such as depression, anxiety, eating disorders, body image problems, and PTSD following sexual abuse and other gender-based violence cannot be attributed only to biology, or divorced from cultural, gender-related factors and the unequal power structures that women face (WHO, 2001).

Gender (along with age) is one of the two exceptions to the paucity of data on demographic factors associated with psychiatric EAS in international jurisdictions. Evidence from Belgium and the Netherlands show that more women than men have requested and accessed psychiatric EAS (Groenewoud *et al.*, 1997; Thienpont *et al.*, 2015; Kim *et al.*, 2016). It is unclear whether the greater number of women seeking psychiatric EAS in Belgium and the Netherlands is proportionate to their incidence of mental disorders. The ratio of women to men requesting psychiatric EAS in the Netherlands (2.3 to 1) is nearly identical to the ratio of women to men attempting suicide in the Netherlands (Kim *et al.*, 2016).

Sociocultural and Racialized Groups

Mental disorders do not affect all populations in Canada equally. Immigrant, refugee, ethnocultural, and racialized (IRER)⁹ populations are found to have lower rates of mental disorders compared to the general population when investigated as a single group (McKenzie *et al.*, 2016). However, this approach obscures the diversity within IRER groups, and the specific mental health challenges faced by individuals in these groups (McKenzie *et al.*, 2016). IRER individuals and groups are more likely to experience racial discrimination and other social inequalities that increase the risk of mental disorders and decrease the rate of recovery from mental health problems. For example, people in IRER groups often experience workforce discrimination, leading to difficulty earning a decent income or obtaining adequate housing, factors that are key social determinants of mental health. They are also less likely to have equitable access to culturally appropriate and effective mental healthcare and social supports that take their specific needs into account (MHCC, 2012).

⁹ *Racialized* is a term used in lieu of sometimes-inaccurate terms such as *minority* or *person of colour*. Using the term *racialized* acknowledges the social construction of race (McKenzie *et al.*, 2016). *Sociocultural groups* are those that share “common ancestry and cultural characteristics” (McKenzie *et al.*, 2016). The grouping of immigrant, refugee, ethnocultural, and racialized populations, and the acronym IRER, are adapted from a 2016 Mental Health Commission of Canada report on improving mental healthcare services in these populations (McKenzie *et al.*, 2016). The Working Group decided to group IRER populations together due to a paucity of available population-specific evidence and data.

However, there is significant variability in the rate of certain mental disorders within different generations of the same ethnic group, among different country-of-origin groups, and among immigrant and refugee groups. For example, recent immigrants are less likely to report depression than immigrants who have been in Canada for a longer period of time (the “healthy immigrant” effect) (Stafford *et al.*, 2010). Rates of depression in longer-term immigrants to Canada are more similar to the general Canadian population (Stafford *et al.*, 2010). With each year of residence in Canada, the healthy immigrant effect diminishes (Ng, 2011; Patterson *et al.*, 2012).

People in IRER groups can face a number of challenges in accessing mental healthcare services. These barriers include service accessibility, difficulties in patient-provider interaction, circumstantial challenges (e.g., transportation, ability to pay, isolation), language barriers, stigma, and fear (McKenzie *et al.*, 2016). The experience of racism in and of itself can negatively affect mental health (Nestel, 2012), and systemic racism against IRER groups exists in the Canadian healthcare system (SHS, 2017). Culture also plays a role in how barriers to mental healthcare are experienced by people in IRER groups. Some, particularly recent immigrants, may have difficulty navigating the Canadian healthcare system and in finding care that is culturally appropriate (Koehn, 2009). In all cultural groups, stigma about mental disorders may delay an individual from reaching out for help (McKenzie *et al.*, 2016). Having a first language other than English or French may also affect a person’s ability to obtain help and follow professional advice (McKenzie *et al.*, 2016).

LGBTQ+ People

While the LGBTQ+ community is diverse, those who identify as such are overall at greater risk of experiencing certain mental disorders compared to the rest of the population, including anxiety disorders, mood disorders, and substance use disorders (Diamant & Wold, 2003; Cochran & Mays, 2007; McCabe *et al.*, 2010; MHCC, 2016a; Pakula *et al.*, 2016). Lesbian, gay, and bisexual people have double the risk for PTSD as compared to heterosexual people (Roberts *et al.*, 2010). Studies have further demonstrated that lesbian, gay, bisexual, and transgender people are more at risk of suicide (Bauer *et al.*, 2010; Benibgui, 2010; Bauer & Scheim, 2015). Lesbian, gay, and bisexual people in Canada are also more likely to both consult a mental healthcare practitioner and state they have unmet mental healthcare needs as compared to heterosexual people (Tjepkema, 2008). The reasons for these mental health challenges are complex, but seem to include the stigma, discrimination, and family rejection faced by some people in the LGBTQ+ community, as well as their greater risk of being the target of assault and harassment (Meyer, 2003; Pascoe & Smart Richman,

2009; Benibgui, 2010). The stress associated with modifying behaviour or concealing sexual orientation may also have negative impacts on mental and physical health (Selvidge *et al.*, 2008; Pascoe & Smart Richman, 2009).

Seniors

Dementia is more common among older people as compared to other demographic groups. Other mental disorders also have an impact on older adults, who have a higher risk of developing depression, especially beyond 75 to 80 years of age (McCrone *et al.*, 2008).

In high-income countries, mental health inequalities among older people are correlated with socio-economic status, among other factors (Allen, 2008; McCrone *et al.*, 2008). Seniors in Canada are more likely to be considered low-income than other adults. People living on low incomes may have greater challenges in accessing mental healthcare services. Older people also have a higher risk of social isolation because of the greater chance of compromised health status, living alone, death of family or friends, changing family structures, and retirement (The National Seniors Council, 2014).

Youth (Mature Minors)

Prognosis of mental disorders is particularly difficult in young people because they are in the process of rapid and significant change during adolescence, and because they have a shorter treatment history and/or less experience coping with symptoms. Current evidence indicates that brain development is not complete until approximately 25 years of age (Giedd, 2015); it is therefore even more difficult for a clinician to confidently determine whether a minor's mental disorder is irremediable as compared to adults over the age of 25.

Suicide is the second-leading cause of death for people in Canada aged 15 to 24, and the leading cause of death for those aged 10 to 14 (StatCan, 2017c). As mentioned in Section 3.4, the suicide rate for First Nations youth living on reserve is five to seven times higher than for non-Indigenous youth. In Inuit youth, the suicide rate is 11 times higher (GC, 2016a).

Canadian Armed Forces Members and Veterans

Active Canadian Armed Forces members have significantly higher rates of major depression, generalized anxiety disorder, and suicidal ideation compared to the general population (Rusu *et al.*, 2016), and there is evidence these higher rates extend to veterans (Mahar *et al.*, 2017). Studies have found that Canadian Armed Forces members, particularly those with suicidal ideation, may have better access to mental healthcare services that meet their needs as compared

to the general population (Fikretoglu *et al.*, 2016; Sareen *et al.*, 2017). However, a 2014 report by the Auditor General of Canada found that, despite putting in place important mental health supports for veterans, “Veterans Affairs Canada is not adequately facilitating timely access to mental health services,” and that the agency’s “mental health outreach strategy is not comprehensive enough” (AGC, 2014).

Incarcerated People

Mental disorders are prevalent and rates are increasing among incarcerated people. Their rates exceed that of the general population (Service, 2010). Further, the suicide rate of those incarcerated in federal facilities is more than seven times the Canadian average (Service, 2010), and Canada faces “significant shortfalls” in meeting the mental healthcare needs of people in the criminal justice system (MHCC, 2012).

Incarceration may also complicate the assessment of capacity, since little is known about how life in prison affects decisional capacity for people with mental disorders; there may also be unique issues of undue influence (e.g., by correctional officials, other inmates, or gangs). Suicidality is treated as a risk in correctional settings, and attempts or indications of attempts may lead to solitary confinement. Incarcerated people may therefore resist expressing a considered desire to die if they fear being put on suicide watch or having their freedoms curtailed (ICEL2 Satellite Workshop on Medical Assistance in Dying for Canadian Prisoners, 2017).

3.6 LEGAL LANDSCAPE FOR MENTAL HEALTH AND MAID

In Canada, much of the legal authority for mental healthcare and treatment is based on the common law and, where statutory, falls within provincial/territorial jurisdiction — this includes laws relating to voluntary and involuntary hospitalization, capacity determination, requirements for informed consent, and human rights legislation. The *Canadian Charter of Rights and Freedoms* also provides guidance on these issues, as do decisions by the Supreme Court of Canada. The federal government is responsible for Canada’s *Criminal Code*, which sets out the legal conditions under which MAID can be provided.

3.6.1 The Law on Informed Consent

The common law and Quebec’s Civil Code underscore the requirement that a patient must provide consent before medical treatment, and that such consent be “voluntary, informed and capable” (Wildeman, 2016). A number of provinces and territories have further codified these requirements. Section 7 of the

Canadian Charter of Rights and Freedoms has also been interpreted to include a right to informed consent. For example, in the unanimous judgment in *Carter v. Canada*, the Supreme Court of Canada noted:

The law has long protected patient autonomy in medical decision-making [...] “[C]ompetent individuals are — and should be — free to make decisions about their bodily integrity” [...] This right to “decide one’s own fate” [...] underlies the concept of ‘informed consent’ and is protected by s.7’s guarantee of liberty and security of the person [...] [T]he right of medical self-determination is not vitiated by the fact that serious risks or consequences, including death, may flow from the patient’s decision.

(SCC, 2015)

Informed consent in Canada must be voluntary, but mental disorders complicate this requirement. For example, in some provinces and territories, a person may be chemically or physically restrained unless medication is taken if they pose a danger to themselves or others due to their mental disorder (Wildeman, 2016). Further, for informed consent to be valid, a person must have the capacity to provide such consent (this issue is examined in more detail in Section 4.1.1). There is disagreement over whether people with mental disorders should have the right to refuse treatment when they have been involuntarily hospitalized, even if they are deemed to have legal capacity. This debate has been characterized as a contest between the *need for treatment* view and the *civil libertarian* view:

From the treatment-oriented perspective, autonomy and dignity are eroded by untreated mental illness, and can be restored by treatment. This “need for treatment” approach tends to favour a lower threshold for involuntary intervention in order to promote the medical “best interests” of people with mental health problems. From the civil libertarian perspective, however, forcing an intervention on an unwilling person harms liberty and dignity. A strict civil libertarian approach would intervene only where a person poses an unreasonable threat to others.

(Chandler, 2017)

The civil libertarian stance, which focuses on fundamental individual rights, is in part a response to the belief that psychiatric treatment in the past too often included the non-consensual use of interventions that, in retrospect, had dubious scientific validity (SSO, 2013). This stance arose in the context of the general movement towards patient autonomy, the rise of the civil rights movement, a

growing cultural backlash against invasive treatments such as lobotomy and non-consensual ECT, and the desire of some patients and their supporters to protect bodily integrity against treatments perceived — as Wildeman (2016) describes — as “profound identity-annihilating violence.” In contrast, the need for treatment view argues that treatment may be in a person’s best interests (even if it goes against their wishes) and, in some cases, respect for a patient’s autonomy requires considering the impact of non-treatment on the patient, their family, and others (Section 4.3.2). The latter stance also notes the harm caused by deinstitutionalization, which was driven by civil libertarian values, and which failed to adequately support people with mental disorders in the community (Section 3.3.3).

3.6.2 Capacity to Make a Decision with Respect to One’s Health

Capacity is a legal concept that is applied in clinical practice when healthcare decisions must be made.

In Canada, all adults are presumed to have the legal capacity to make medical decisions, and “the onus lies on the one challenging capacity to rebut this presumption” (Wildeman, 2016). Capacity is always assessed relative to a particular decision, and a person might have capacity to make some decisions but not others (Gilmour, 2017). Provincial and territorial legislation typically places responsibility for determining capacity on healthcare practitioners. During a capacity assessment, a healthcare practitioner must determine whether a person’s abilities are sufficient to meet the relevant legal test for capacity.

While there is no single, uniform test or definition of capacity in Canadian law (Bach & Kerzner, 2010), a two-criteria test that focuses on two particular abilities — (i) the ability to understand information relevant to making a decision, and (ii) the ability to appreciate the reasonably foreseeable consequences of a decision — can be found in several pieces of provincial and territorial legislation, including Ontario’s *Substitute Decisions Act* and *Health Care Consent Act*, Saskatchewan’s *Adult Guardianship and Co-decision-making Act*, and Manitoba’s *Vulnerable Persons Living with a Mental Disability Act* (MLRC, 2004; Bach & Kerzner, 2010; OHA, 2016; CPSS, 2017). The criteria of the understand/appreciate test were also affirmed by the Supreme Court of Canada in *Starson v. Swayze* (SCC, 2003).

The “understanding” criterion requires that the patient be able to comprehend information such as the medical condition(s) that the treatment is intended to address, the nature of that treatment, the potential risks and benefits of the treatment, and any alternatives to the proposed treatment, including electing to forego the treatment (CPSS, 2017; Deschamps, 2017b). The “appreciation”

criterion often proves more complex; to meet this test, a person generally must admit they have symptoms, even if they disagree with the diagnostic label given to the condition (SCC, 2003; Dull, 2009). The person must also be able to apply the information presented to them to their own situation and assess how the proposed treatment (or lack of treatment) may affect their quality of life (CPSS, 2017).

Box 3.2**Incapacity due to Failing to Satisfy the “Appreciation” Criterion: Two Examples**

A patient diagnosed with schizophrenia is able to understand the information about the illness, and that it can affect some people, but does not believe that they have that illness, in spite of a two-year history of symptoms consistent with schizophrenia, hospitalization, and treatment.

A patient diagnosed with anorexia nervosa is able to understand and intelligently discuss the nature and consequences of the illness and readily acknowledges that people have to eat or may die. In spite of this, the patient is not able to eat and maintains that they will be fine.

Excerpted from OHA (2016)

The Supreme Court of Canada has recognized that people with mental disorders risk being unduly assumed to lack capacity. In *Starson v. Swayze*, Justice Major, writing for the majority, cited a 1990 report by Ontario’s Committee on the Enquiry on Mental Competency (Weisstub, 1990), stating:

The tendency to conflate mental illness with lack of capacity, which occurs to an even greater extent when involuntary commitment is involved, has deep historical roots, and even though changes have occurred in the law over the past twenty years, attitudes and beliefs have been slow to change. For this reason it is particularly important that autonomy and self-determination be given priority when assessing individuals in this group.

(SCC, 2003)

In some provinces and territories, a patient can challenge a determination of incapacity (for example, in Ontario a person can appeal a finding of incapacity to the Consent and Capacity Board). If it is determined that a person lacks the

capacity to make a healthcare decision, then treatment decisions are normally made by a substitute decision-maker (SDM). The SDM is usually a family member, and if there are none, the Public Guardian (Wildeman, 2016). SDMs must follow one of three legislated approaches (which vary by province and territory) when making a decision on behalf of those they represent: (i) respect a patient's prior wishes, if known and made when capable; (ii) determine what is in the patient's best interest; or (iii) use a hybrid model that requires compliance with prior known wishes unless this would endanger the physical or mental health of the patient or a third party (Wildeman, 2016).

3.6.3 Involuntary Admission and the Right to Refuse Treatment

Provincial and territorial mental health legislation sets out the criteria for involuntary admission to a psychiatric facility and involuntary treatment (see Appendix B for a list of mental health legislation in individual jurisdictions). Generally, mental health laws set limits on a person's civil rights (specifically the right to liberty, by confinement in a mental health facility) where there is a significant risk of harm to the person or to the public due to the person's mental disorder (Nunnelly, 2016; Bhugra *et al.*, 2017).

Canadian courts have ruled that people with decision-making capacity have the right to refuse medical treatment, including the right to refuse life-sustaining treatment. In *Starson v. Swayze*, which examined the right to refuse medical treatment in an individual with a mental disorder, the Supreme Court of Canada ruled that the "right to refuse unwanted medical treatment is fundamental to a person's dignity and autonomy. This right is equally important in the context of treatment for a mental illness" (SCC, 2003). Thus, patients with mental disorders who are judged to have capacity have the right to refuse treatment even where the consequence of the refusal may be death or indefinite confinement in a psychiatric institution.

Notwithstanding *Starson v. Swayze*, there is variability in provincial and territorial approaches to whether an involuntarily hospitalized person can refuse treatment for their mental disorder (Nunnelly, 2016; Wildeman, 2016; Chandler, 2017). Treatment for purposes unrelated to the person's mental disorder is subject to the generally applicable laws regarding consent to treatment (Gilmour, 2017). In Ontario, a person with a mental disorder always has the right to refuse treatment when they have decision-making capacity (Chandler, 2017). However, such people can still be involuntarily hospitalized, and can continue to be detained as long as they continue to meet criteria for detention. In contrast, in British Columbia, people with a mental disorder who have been involuntarily

hospitalized have no right to refuse treatment. Instead, such patients are deemed to consent to any treatment authorized by the director of the psychiatric care facility.¹⁰ In Nova Scotia, Newfoundland, and Saskatchewan, incapacity is a precondition for involuntary hospitalization; therefore, the issue of treatment refusal by people with capacity who have been involuntarily hospitalized does not arise. In Alberta and New Brunswick, a person with a mental disorder who has decision-making capacity has the right to refuse treatment following involuntary admission to a psychiatric facility, but this refusal can be overridden in certain circumstances — for example, when it is judged to be in the person's best interests (Chandler, 2017; Gilmour, 2017). Finally, in Quebec, a person who represents a danger to themselves or to others and who has been hospitalized in a psychiatric facility cannot be treated against their will if they categorically refuse treatment. However, if the person is incapable of giving consent and categorically refuses to be treated even with the consent of an SDM, forced treatment can be imposed with a court order (Deschamps, 2017b).

3.6.4 Conflicts in Laws and Jurisdiction

In the context of MAID MD-SUMC, potential tensions exist between federal and provincial and territorial laws, and there may be issues of constitutional jurisdiction and paramountcy in the context of enacting safeguards on the practice of MAID MD-SUMC, were it more broadly permitted. Whereas the federal government is responsible for Canada's *Criminal Code*, which sets out the legal conditions under which MAID can be provided, areas of mental health law such as informed consent and capacity are normally considered matters of provincial and territorial jurisdiction. These issues are relevant to some of the safeguards discussed in Chapter 6.

3.7 KNOWLEDGE GAPS

Data on mental disorders and mental healthcare in Canada are incomplete. There are limited data on mental healthcare services delivered in the community (MHCC, 2014a), despite the importance of community mental health treatment in the management of mental disorders.

Given the existing inequalities in access to mental healthcare and social services in Canada, it is unknown whether people who might request MAID MD-SUMC have adequate access to mental healthcare and social services that could potentially alleviate their suffering. Concerns have been raised by the Collège des médecins du Québec about the possibility that patients might request MAID in response to insufficient access to other end-of-life care (CMQ, 2018).

¹⁰ As of October 2018, there was a challenge to this law before the Supreme Court of British Columbia (Woo, 2016).

There are almost no data on the demographic and socio-economic characteristics of people requesting psychiatric EAS in other jurisdictions (beyond age and gender). Therefore, it is difficult to hypothesize about the demographic and socio-economic characteristics of people who may request MAID MD-SUMC in Canada.

More research is required to clarify the relationship among the gender ratio of mental disorders, the gender ratio of psychiatric EAS requests in Belgium and the Netherlands, and the gender ratio in attempted suicide rates, in order to determine whether women are disproportionately likely to seek assisted dying for mental disorders, and if so, whether that is due to social inequalities.

4

Mental Disorders and MAID — Key Issues

- **Issues Regarding Current Eligibility Criteria**
- **Suicide and MAID MD-SUMC**
- **Vulnerability and Autonomy**
- **Mental Healthcare and Treatment**
- **Knowledge Gaps**

4 Mental Disorders and MAID — Key Issues

Key Findings

Most people with a mental disorder as their sole underlying medical condition cannot satisfy the current eligibility criteria for MAID, including several of the criteria for a “grievous and irremediable medical condition” such as “natural death has become reasonably foreseeable” (Section 4.1.2).

What it means to respect the autonomy of an individual with a mental disorder is complex. Some believe that respect for autonomy requires non-interference in a capable person’s decisions and self-determination. Others argue that respect for autonomy requires consideration of a person’s social relationships and other resources necessary for autonomous decision-making (Section 4.3.2).

Most people with mental disorders have the capacity to make treatment decisions, but evidence shows that some mental disorders can impair decision-making and increase the risk of incapacity. Capacity evaluations can vary in reliability and validity depending on the population evaluated, the decisions involved, and the method of evaluation (Section 4.1.1).

Suicide is a major public health concern. There is some evidence that some people who have sought psychiatric euthanasia and assisted suicide in jurisdictions that permit it share certain characteristics with people who attempt suicide. Working Group members have different views about the relationship between MAID MD-SUMC and suicide and whether it is possible to distinguish between them (Section 4.2).

The symptoms of some mental disorders can affect decision-making in significant ways, including leading to a desire to die, hopelessness, and a negative view of the future, even when a person retains decision-making capacity (Section 4.3.3).

As demonstrated in the previous chapter, the mental disorders landscape in Canada is legally and medically complex, and its problematic history has had especially negative impacts on marginalized people. Prohibiting or more broadly permitting MAID MD-SUMC is a question that must be considered alongside key issues such as eligibility criteria, including capacity to provide consent; vulnerability and autonomy; the state of mental healthcare and treatment in Canada; and the realities of suicide. This chapter addresses those issues in relation to MAID MD-SUMC.

4.1 ISSUES REGARDING CURRENT ELIGIBILITY CRITERIA

People with a mental disorder as their sole underlying medical condition are not explicitly excluded from access to MAID, but very few are likely to qualify under the current eligibility criteria.

Bill C-14 — *An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying)* — establishes that a person may receive MAID only if they meet all of the following eligibility criteria (GC, 2016b):

- “they are eligible [...] for health services funded by a government in Canada;
- they are at least 18 years of age and capable of making decisions with respect to their health;
- they have a grievous and irremediable medical condition;
- they have made a voluntary request for medical assistance in dying that, in particular, was not made as a result of external pressure; and
- they give informed consent to receive medical assistance in dying after having been informed of the means that are available to relieve their suffering, including palliative care.”

The law defines a person as having a *grievous and irremediable medical condition* by four factors, all of which need to be present (GC, 2016b):

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

Because mental disorders are diverse and heterogeneous, and because they affect individuals in different ways, the implications of each eligibility criterion will vary for different people. This variability is also linked to people’s individual support networks. The course of a mental disorder and its impact on a person is a complex interaction among the disorder, the individual, and their social environment.

In its review of the evidence, the Working Group identified three main issues associated with the current eligibility criteria that have particular implications for MAID MD-SUMC in Canada:

1. Mental disorders may impair a person's capacity to make decisions with respect to their health and their ability to give informed consent to MAID.
2. Mental disorders may not satisfy all four criteria of a grievous and irremediable medical condition as defined by Bill C-14.
3. A MAID MD-SUMC request may be less likely to be voluntary and more likely to be the result of external pressure.

4.1.1 Capacity

To be eligible for MAID under Canadian law, a person must be able to provide informed consent and be “capable of making decisions with respect to their health” (GC, 2016b). The Department of Justice (2016) glossary for MAID (now archived) further defines being “mentally competent or capable;”

A person is mentally competent or capable when they have the capacity to understand the nature and consequences of their actions and choices, including decisions related to medical care and treatments.

This is similar to the understand/appreciate test for capacity described in Section 3.6.2. In Canada, people are presumed to have the capacity to make decisions about their health unless there is sufficient evidence to the contrary (Gov. of ON, 1996; Wildeman, 2016). The vast majority of people with mental disorders are deemed to have capacity to make treatment decisions, but it is accepted that mental disorders can affect a person's decision-making.

The Impact of Mental Disorders on Decision-Making Capacity

Mental disorders can affect decision-making capacity in many ways. In some instances (e.g., certain neurocognitive disorders like dementia, neurodevelopmental disorders and intellectual disabilities, and some cases of schizophrenia), there is a clear decline in the cognitive abilities needed to understand and appreciate information. In other instances (e.g., depressive, bipolar, and anxiety disorders), a person's capacity for making decisions can be impaired by the disorder's impact on their mood and emotions. For example, depression can impair one's ability to deliberate about the future (Meynen, 2011; Halpern, 2012; Owen *et al.*, 2013) or to maintain a minimal concern for self (Elliot, 1997). Furthermore, some disorders, such as bipolar disorder, may be characterized by manic, depressive, or mixed states, in which the impact of emotion on capacity will vary.

Clinical symptoms and diagnoses may indicate impaired decision-making capacity. However, by themselves, neither symptoms of a mental disorder nor diagnoses on their own justify a designation of incapacity; a clinical assessment of a patient's decision-making abilities is always necessary (Kim, 2010; Candia & Barba, 2011). Nevertheless, a systematic review of studies examining the impact of mental disorders on decision-making capacity found that capacity is more often impaired in people with psychotic disorders than in those with non-psychotic disorders, and most (but not all) of the studies examined found that the severity of psychopathology is associated with a loss of capacity (Okai *et al.*, 2007).

Specific symptoms have been linked with impairment of decision-making capacity in certain disorders. For example, a 2009 study found hallucinations and poor cognitive performance were more strongly associated with incapacity in non-psychotic disorders (such as depression and personality disorder) compared to psychotic disorders (such as schizophrenia) and bipolar disorder (Owen *et al.*, 2009a). In contrast, conceptual disorganization was associated with lack of capacity in psychotic disorders and bipolar disorder, but not in non-psychotic disorders (Owen *et al.*, 2009a). Depressed mood was found to be strongly associated with incapacity in patients with non-psychotic disorders. However, in patients with psychotic disorders, depressed mood was more closely associated with intact decision-making capacity (Owen *et al.*, 2009a).

Owen *et al.* (2009a) and Cairns *et al.* (2005a) found that *insight* — measured by the degree to which a person is aware of their mental disorder — was the psychopathological variable most strongly associated with capacity. This association was found to hold across all mental disorders examined in the studies, although it was strongest in psychotic disorders and bipolar-affective disorder, and weaker in non-psychotic disorders (in which severity of depressed mood was more strongly associated with capacity status when compared to other types of disorders) (Owen *et al.*, 2009a). Although insight is not explicitly featured as a criterion of capacity, it arguably can be considered to be subsumed under the “appreciation” criterion of capacity tests (Spencer *et al.*, 2017) used under Canadian law and in clinical practice (Section 3.6.2). In addition, both Owen *et al.* (2009a) and Cairns *et al.* (2005a) found that the presence of delusions was associated with findings of incapacity. Elated mood was strongly associated with lack of capacity in bipolar disorder (Owen *et al.*, 2009a), as were mania and hypomania for those with bipolar disorder and psychosis (Cairns *et al.*, 2005b).

A systematic review of studies examining the impact of mental disorders on decision-making capacity found that rates of incapacity in psychiatric inpatients varied widely among studies; one study found that up to 50% of people admitted

voluntarily to an inpatient unit had significant impairment in capacity, while another found 10 to 95% of people who were already inpatients lacked capacity (Okai *et al.*, 2007). A study by Cairns *et al.* (2005b) found that about 44% of psychiatric inpatients lacked capacity to make treatment decisions, while Owen *et al.* (2009a) reported that 58% of inpatients in their study lacked capacity.

However, these findings should be treated with caution, for a number of reasons. First, they are based on studies conducted on psychiatric inpatients, who have often either (i) been involuntarily hospitalized for their mental disorder, or (ii) are undergoing voluntary hospitalization because they are in a state of crisis, thereby likely skewing the findings towards a greater prevalence of incapacity.¹¹ International evidence suggests that, if MAID MD-SUMC were more broadly permitted in Canada, the majority of those requesting MAID MD-SUMC would not be inpatients; a 2016 review of 66 case summaries of patients who received psychiatric EAS in the Netherlands found that 24% of patients (16 of 66) were institutionalized, and that 76% (50 of 66) were not institutionalized (Kim *et al.*, 2016). Second, these studies involved different contexts, treatment decisions, and patient populations. Since capacity is always assessed relative to a particular person, for a particular decision, and in a particular context, it is difficult to extrapolate generalized conclusions from these data about the prevalence of decisional capacity among people with mental disorders. Finally, none of the above studies specifically examined decision-making capacity in the context of a MAID MD-SUMC request. Most of them focused on an inpatient's decision to accept or refuse psychiatric treatment (e.g., taking medication), or their decision about admission to the unit. As a matter of life and death, a MAID MD-SUMC request involves a different set of considerations and therefore requires a high threshold of capacity (this issue is discussed further in the following section).

Reliability and Accuracy of Capacity Assessments

The capacity of people with mental disorders to make decisions about their health is assessed with or without the use of formal tools such as the MacArthur Competence Assessment Tool (MacCAT) (Grisso *et al.*, 1997) or Aid to Capacity Evaluation (ACE) (Etchells *et al.*, 1999).¹² The evaluation of capacity is not straightforward, even when formal tools are used, because these tools provide data on a scale of a person's abilities (such as the ability to understand and appreciate information, to think and reason rationally, and to communicate a stable choice), whereas the task of the evaluator is to generate a categorical yes or no judgment about the patient's capacity to make a particular decision (Grisso *et al.*, 1997; Kim, 2006; Appelbaum, 2007).

¹¹ A systematic review found that patients who had been involuntarily hospitalized were more likely to be found to lack capacity (Okai *et al.*, 2007).

¹² For a comprehensive list of different clinical capacity assessment tools, see Kim (2010).

There is conflicting evidence on the reliability of capacity assessments, as measured by the degree of agreement among independent assessors. Part of the reason for this conflict is because of differences in study design; different studies assess the reliability of decision-making capacity in different contexts, using different tools and methods, with different patient groups, and about different decisions.

A 2007 systematic review of studies that examined the reliability of capacity assessment found high rates of agreement among independent clinicians who assessed capacity in psychiatric patients (Okai *et al.*, 2007). Furthermore, some studies reported that the MacCAT can be a useful instrument for helping to reliably produce agreement among capacity assessors for psychiatric inpatients (Cairns *et al.*, 2005b), people with Alzheimer's disease (Kim *et al.*, 2001), and people with schizophrenia (Kim *et al.*, 2007).

Other studies found significant rates of disagreement among capacity assessors (Marson *et al.*, 1997; Kim, 2006). A 1997 study found that physicians with experience assessing the decision-making capacity of dementia patients agreed 56% of the time on capacity assessments of people with mild Alzheimer's disease (Marson *et al.*, 1997). Kim (2006) also found that rates of disagreement among experienced capacity assessors changed based on the level of risk involved with the proposed treatment: the higher the risk of the treatment, the higher the rate of disagreement among assessors, and the more likely patients would be assessed as lacking capacity.

It is not surprising that capacity assessments of the same person may vary depending on the perceived risk of the intervention. Evaluation of capacity is always made in relation to a specific decision, and different thresholds for capacity are appropriate for different decisions and in different contexts, taking into account the patient's individual circumstances, such as diagnosis, risks, benefits, and potential outcomes. As noted in Section 3.6, a person might have the capacity to make some decisions but not others. As Kim (2010) puts it, "it is widely accepted that the level of abilities required — the threshold for competence — increases as the risk-to-benefit ratio increases." In short, the riskier the outcome, the higher the bar for capacity. This view is supported by the Canadian Psychiatric Association (CPA, 2014).

Even if current capacity assessment procedures and instruments are reliable, it does not mean they are valid. *Reliability* is the degree to which an assessment test or tool produces stable and consistent results. But while a tool may be stable and consistent, it may not be accurate. The *validity* of the capacity assessments — how well they actually measure the capacity to make decisions — cannot be measured

by rates of agreement among capacity assessors. In other words, the fact that a certain capacity assessment tool can produce high rates of agreement among capacity assessors does not mean that tool is itself a valid way to measure capacity. Reliability does not guarantee validity, although reliability is a necessary condition for validity. For instance, a capacity assessment tool may reliably assess some of the factors important for capacity, such as cognitive abilities, but not sufficiently capture other factors, such as a person's emotions or values with respect to a particular decision (Charland *et al.*, 2016). In addition, the validity of the tool may vary depending on the type of decision being made — a particular tool may be valid in some contexts or for some decisions, but inappropriate and invalid in other contexts or for other decisions.

Finally, capacity is a complex concept that relies on both empirical and normative considerations. Grisso (2003) concluded that a capacity evaluation must take into account the causal component (the disorder causing impairment), the functional component (such as understanding and appreciation), the interactive component (a person's abilities in relation to the demands of the context), and a judgmental (or normative) component (which "invariably constitutes a legal, moral, or social judgment"). There is no objectively correct answer to the question of whether or not an individual really has capacity. Rather, capacity is a *socionormative construct* — an evaluative standard that combines objective information about the effects of mental disorders with societal values about the kinds of abilities that a person ought to have in order to be allowed to make certain kinds of decisions (Beauchamp & Childress, 2013). This, in turn, determines how people may permissibly be treated.

Challenges in Assessing Decision-Making Capacity in MAID MD-SUMC Cases

There is a unique challenge in assessing decision-making capacity for MAID MD-SUMC in people with mental disorders: their desire to die could be a symptom of their condition (Appelbaum, 2016). Although most people with mental disorders do not want to die, suicidal ideation is a common symptom of some mental disorders (e.g., major depressive disorder). Of course, a desire to die may also reflect a person's autonomous and well-considered decision to end their life, even if they have a mental disorder. A desire to die in a person with a mental disorder is not necessarily pathological or non-autonomous. However, it may be difficult even for experienced clinicians to distinguish between (i) an autonomous, well-considered decision to die in a person with a mental disorder, and (ii) a pathological desire to die that is a symptom of that person's mental disorder. This challenge may also arise in cases where a person with a mental disorder refuses or requests the removal of life-sustaining

medical treatment, which will result in their death (Downie & Dembo, 2016). See Section 4.1.4 for further discussion of the similarities and differences between MAID MD-SUMC and other highly consequential decisions.

Some experts have suggested that, in order to determine whether a patient's decision to die is a symptom of their mental disorder, assessments of capacity must take into account not only the cognitive abilities but also the emotions, values, and valuing abilities of the patient (Tan *et al.*, 2006; Charland *et al.*, 2016; Kim, 2016). Some have argued that formal capacity assessment tools such as the MacCAT focus only on cognitive abilities and do not sufficiently capture a person's emotions or values with respect to a particular decision, making them inappropriate for assessing capacity in the context of MAID MD-SUMC (Charland *et al.*, 2016).

Clinicians may also assess the long-term stability of a person's desire to die in order to determine whether it is pathological. A desire to die that decreases as the episode of the mental disorder responds to treatment is more likely to be pathological, and less likely to be an autonomous, well-considered decision. The trajectory of the desire to die is not included as a criterion of the understand/appreciate test for decision-making capacity found in Canadian law; however, stability of choice is part of the most widely used clinical model of capacity (Appelbaum & Grisso, 1988). In the Netherlands, assessing the trajectory of the desire to die is required when evaluating a request for EAS (Chapters 5 and 6).

4.1.2 Are some Mental Disorders “Grievous and Irremediable” Conditions?

People requesting MAID MD-SUMC may not satisfy several of the four criteria (listed in Section 4.1) of having a “grievous and irremediable medical condition” (GC, 2016b). Clinicians disagree about when and which mental disorders can be considered incurable. People with mental disorders can experience an advanced state of decline in capabilities (especially in neurocognitive disorders such as some dementias), but for some conditions it is not clear how often such declines are irreversible. However, it is generally accepted that some mental disorders can produce enduring and intolerable suffering. In the vast majority of cases where a mental disorder is the sole underlying medical condition, a person's natural death has not become reasonably foreseeable (at least until the person is at an advanced age). Each of these issues is discussed in detail below.

Incurability

In order to be eligible for MAID in Canada, a person must have a “serious and incurable” condition (GC, 2016b). In medicine, there is no single, universally agreed-upon definition of the term *incurable*. Stedman's Medical Dictionary

defines *cure* as “[t]o heal; to make well” and “[a] restoration to health” (Stedman, 2006), but does not define the term *incurable*. Other major medical dictionaries such as Webster’s New World Medical Dictionary do not define either term (Shiel *et al.*, 2009). The Oxford English Dictionary defines *incurable* as “cannot be cured; incapable of being healed by medicine or medical skill” (OED, 1989).

Understood in strictly biological, reductionist terms, the term *cured* may sometimes refer to a state in which an underlying pathophysiological process has been eradicated (Moncrief, 2008). Since most mental disorders are usually not defined in terms of underlying pathophysiology (Section 3.1.2), they typically cannot be characterized as either curable or incurable going by this understanding of the term.

Although in clinical practice the term *incurable* is not typically used to describe most mental disorders, a variety of other possible definitions of incurability can be found (e.g., in common or lay usage, or in the Canadian legal context), and a mental disorder may be considered to be incurable based on one or more of these other definitions. For example, mental disorders that persist are considered to be chronic conditions (Ratnasingham *et al.*, 2012; PHAC, 2015a; Perring, 2018), and it is generally accepted that chronic conditions are usually not curable. The focus of treatment for chronic mental disorders tends to be management of symptoms, restoration of function, and decreasing the risk of complications (such as suicide) and relapse of symptoms (Miller *et al.*, 2006). The risk of relapse is linked to the type of mental disorder and individual vulnerability, but also often to the social context in which the person lives, available supports, and possible treatments (Rickwood, 2006).

Another potential way to interpret incurability in the context of mental disorders is in terms of *treatment resistance* — i.e., the absence of meaningful symptom reduction following a certain number or type of interventions under appropriate conditions. This term arises from a biological psychiatry perspective that focuses on the success of pharmaceutical trials, and typically excludes psychological interventions such as therapy (Anderson, 2018). However, treatment resistance is also a problematic concept (see Section 3.1.2), and cannot be taken to indicate that a person has no hope of future improvement. A person’s symptoms can change over time, as can the impact of interventions. Moreover, treatment-resistance specifically refers to a lack of reduction in the *symptoms* of a person’s mental disorder, and not necessarily to the relief of their suffering or reduction of their desire to die.

Even when a person's mental disorder has been deemed treatment-resistant, it does not necessarily mean there has been no improvement in the patient's condition. Symptom reduction is only one way of measuring clinical improvement — a person's functioning and their quality of life may only be partially linked to symptom reduction. For people with mental disorders, quality of life can also be linked to social determinants of health including stigma, employment, education, housing, and social relationships (MHCC, 2012).

From this perspective, a person's mental disorder might be considered to be incurable *when the goal of treatment cannot be achieved*, which may or may not include symptom reduction. For example, Hearing Voices Network does not see the eradication of auditory hallucinations as the goal of treatment, but rather learning to live well with the phenomenon (HVN, 2018). Similarly, the *recovery* movement in mental health (Section 4.4) emphasizes living “a satisfying, hopeful, and contributing life, even when there are ongoing limitations caused by mental health problems and illnesses” (MHCC, 2012). However, proponents of recovery-oriented practice also argue that the concept of recovery is not synonymous with *cure*, and does not necessarily imply remission of symptoms or a return to normal functioning (Anthony, 1993; Jacobson & Greenley, 2001; Davidson & O'Connell, 2005; Davidson & Roe, 2007; MHCC, 2012). In this view, regardless of whether the symptoms are alleviated, a person might be unable to recover from their mental disorder due to ongoing social hardships such as stigma, unstable housing, or financial precariousness.

Incurability in the context of mental disorders may also relate to the *acceptability* of treatment. Some argue that, if a person's symptoms cannot be reduced or eradicated by a treatment that is acceptable to them, their condition should be considered incurable, even if an effective treatment is available (Downie & Chandler, 2018). According to this view, if a person has an infection that could be treated with an antibiotic, but refuses the medication on the grounds that it is not acceptable to them, their condition could be considered incurable. Similarly, a person's mental disorder might be considered incurable on this view if the available treatments are unacceptable to them.

In the context of mental disorders, treatment success (or failure) is often evaluated in terms of functional improvement, symptom reduction, or improvement in quality of life, rather than in terms of curability. For many people with mental disorders, effective treatment can profoundly improve quality of life (Ratnasingham *et al.*, 2012). A variety of terms are used to categorize

treatment outcomes of mental disorders (Box 4.1). In the view of some Working Group members, the most relevant issue with respect to incurability and MAID MD-SUMC is not whether treatment can cure a person's mental disorder, but whether it can alleviate suffering and reduce the symptoms that are motivating their request for MAID. See Section 4.4 for more information on treatment of mental disorders.

Box 4.1**Selected Mental Disorder Treatment Outcome Definitions***Episode*

"the period during which an individual meets full symptomatic criteria for the disorder"

Remission

"the interim period (e.g., 2 weeks to 6 months) during which the individual's symptoms have decreased sufficiently that he or she has only minimal symptoms and no longer meets full diagnostic criteria"

Partial Remission

"a period of decline from the episode to full remission"

Response (to treatment)

"the point at which partial remission begins"

*Recovery (from the episode, not necessarily the illness)**

"when an individual remains minimally symptomatic beyond the defined period of remission (e.g., more than 6 months)"

Relapse

"when symptoms meeting full diagnostic criteria reappear during the period of remission (but before recovery)"

Recurrence

"the reappearance of a new episode once recovered"

(Bruce & Raue, 2013)

*This meaning of the term *recovery* should not be conflated with its meaning in the phrase *recovery-oriented practice*.

Despite the debate about incurability described above, there is some consensus in the literature that some mental disorders are currently incurable, such as neurocognitive disorders like dementia associated with Alzheimer's disease (Jennekens, 2014). In addition, some argue that certain psychiatric conditions such as depression can be considered potentially incurable since some people with the condition do not respond to multiple treatments (Downie & Dembo, 2016). Others argue that "it is essentially impossible to describe any psychiatric illness as incurable, with the exception of advanced brain damage as occurs in progressive neurodegenerative disorders such as Alzheimer's disease and Huntington's disease" (Kelly & McLoughlin, 2002), given the continuing evolution of mental health research and the challenges associated with predicting changes as a result of treatment or whether a patient's condition will undergo remission (Walker-Renshaw *et al.*, 2015).

In summary, a variety of interpretations of incurability exist with respect to mental disorders. Under some interpretations, a person's mental disorder may be considered to be incurable; using other interpretations, the mental disorder may be considered curable (or cured); and using still other interpretations, the concept of (in)curability simply does not apply to most mental disorders in the first place.

Regardless of which definition of incurability is adopted, there may be further questions about whether clinicians can reliably determine if a particular person with a mental disorder meets that definition, thus adding a further layer of complexity to the use of the term *incurable* in the context of mental disorders. As discussed in Section 3.1.2, it can be difficult to determine with any degree of certainty how a person's mental disorder will evolve over time (prognosis), and to what extent attempts to treat the condition will relieve the person's suffering and/or desire to end their lives, or improve their quality of life (treatment effectiveness).

Advanced State of Irreversible Decline in Capability

In order to be eligible for MAID in Canada, a person must be "in an advanced state of irreversible decline in capability" (GC, 2016b).¹³ There is some uncertainty about the precise meaning of this criterion. First, it is not clear whether an "irreversible" decline means that the condition (i) "cannot be reversed *by any means*," or that it (ii) "cannot be reversed *by means available and acceptable to the patient*," as with the requirement for intolerable suffering (Downie & Dembo,

¹³ Despite their terminological similarity, the term *capability* should not be conflated with *capacity*. Whereas *capacity* specifically refers to a patient's ability to understand and appreciate information for the purposes of providing consent to treatment (Sections 3.6 and 4.1), *capability* refers to general abilities and functioning.

2016, emphasis added). Second, it is not clear whether a decline in capability must occur over a period of time, or whether a sudden decline would also qualify (Downie & Chandler, 2018). Finally, it is unclear what this eligibility criterion includes — as Downie and Dembo (2016) put it, “capability to do what?” A person may irreversibly lose the capability to see due to progressive macular degeneration, or lose the capability to regulate their blood sugar due to adult-onset diabetes (Downie & Dembo, 2016). However, it is not clear whether such conditions would meet this criterion.

People with mental disorders can experience declines in capability, both mental and physical. People with a severe mental disorder score lower on measures of physical functioning than the general population. For example, in one study, people with mental disorders in residential care in their 40s had levels of physical functioning that were comparable to “the elderly” (Chafetz *et al.*, 2006). Declines in capability may result directly from the symptoms of the mental disorder itself, or may result from indirect factors related to the mental disorder, such as co-morbid physical disorder(s), socio-economic hardship, social isolation, homelessness, and addiction. MAID law in Canada does not state that the decline must result from the condition itself.

A mental disorder may directly lead to physical and mental decline. For example, eating disorders such as anorexia nervosa can result in severe malnutrition, leading to organ failure, premature osteoporosis, and cognitive declines that may be irreversible in some cases (APA, 2013). In some cases of schizophrenia there is a clear decline in cognitive abilities (APA, 2013). Neurocognitive mental disorders such as dementia due to Alzheimer’s disease can lead to an advanced state of irreversible decline in capability, even before such conditions result in the loss of a patient’s decision-making capacity.

In addition, some Working Group members believe that a mental disorder may indirectly lead to a state of decline due to the effects of the disorder on a person’s social situation, including isolation, inability to engage in social relationships, homelessness, inability to access educational and employment opportunities, and lack of self-care (Downie & Dembo, 2016). In the view of these Working Groups members, these social factors can exacerbate a person’s mental disorder, contribute to a decline in capability, and may be considered irreversible. For some people with mental disorders, social supports and interventions may be ineffective at mitigating their social problems, or may not be acceptable to the person. For example, a 2015 study of housing interventions for people with mental disorders in five Canadian cities found that 27% of participants were no

longer in stable housing within one year of the intervention, which included rent supplements, assistance to find housing, and assertive community treatment (Aubry *et al.*, 2015). However, other Working Group members disagree that a state of decline caused or exacerbated by the social hardships associated with mental disorders should satisfy the “advanced state of irreversible decline in capability” criterion, and disagree that such declines should be considered irreversible.

Finally, some Working Group members believe that a mental disorder may lead to an irreversible state of decline because the person may not seek help for other undetected co-morbid physical disorders. As explained by Downie and Dembo (2016): “Individuals with severe persistent mental illness (SPMI) may cease to seek medical attention” and they may not participate in preventative health care, leading to a higher risk that serious illnesses will not be detected (Stern *et al.*, 2016 as referenced in Downie & Dembo, 2016). Again however, other Working Group members disagree that such declines should satisfy the “advanced state of irreversible decline in capability” criterion.

Suffering

To be eligible for MAID in Canada, a person must have an “illness, disease or disability or [...] state of decline [that] causes them enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable” (GC, 2016b). Mental disorders can cause severe, enduring, and intolerable suffering. However, the concept of suffering can be difficult to understand in the context of mental disorders.

Several definitions of suffering in the literature share common elements: suffering is distinct from pain or physical distress, is not a symptom itself (unlike fear or pain), and results from the meaning that a person gives their lived experience (Cassell, 1982, 1991; Dees *et al.*, 2009; Svenaeus, 2014; Gupta *et al.*, 2017). As Gupta *et al.* (2017) note, “suffering is an interpretation of experience, not a sum of symptoms.” An influential definition of suffering comes from Cassell (1982), who defined suffering as “the state of severe distress associated with events that threaten the intactness of the person.” In this way, suffering is closely related to *personhood*, and occurs when different aspects of a person are threatened, damaged, or lost. Through an integrative literature review, Dees *et al.* (2009) found that suffering in the context of requests for assisted dying is related to “factors undermining the quality of life and by the perceived loss of meaning and purpose in life.”

Under Canadian law, both physical and psychological suffering can qualify a person for MAID (GC, 2016b). Belgium and Luxembourg also identify both physical and psychological suffering as qualifying a person for EAS (Gov. of Belgium, 2002; Gov. of Luxembourg, 2009). However, it has been argued that categorizing suffering in this way may be inappropriate, unnecessary, and/or impractical (Svenaeus, 2014; Gupta *et al.*, 2017). A physical symptom can become psychologically unbearable if a patient believes it will not lessen through time, or if they are afraid it will worsen; suffering is both physical (pain) and psychological (beliefs, fears) (Gupta *et al.*, 2017). Moreover, mental disorders can cause physical pain and suffering, as in the case of conversion disorder. The Netherlands does not distinguish physical and psychological suffering in their assisted dying law (Gov. of the Netherlands, 2002).

Intolerable Suffering

In order to be eligible for MAID in Canada, a person must experience suffering that is “intolerable” to them (GC, 2016b). Similarly, in Belgium, the Netherlands, and Luxembourg (the Benelux countries), people must experience “unbearable” suffering to qualify for EAS.

A qualitative study of 26 requests for psychiatric EAS in Belgium by Verhofstadt *et al.* (2017) analyzed patients’ descriptions of their unbearable suffering. The study found that the unbearable suffering experienced by these people included a wide variety of factors beyond the symptoms of their mental disorders alone, and identified five broad categories of suffering — medical, intrapersonal, interpersonal, societal, and existential — all of which contributed to the unbearability of their suffering. In the medical domain, the study found that, in addition to their psychological symptoms, patients also suffered due to physical and psychosomatic symptoms, although mental suffering was experienced as more disruptive than physical suffering. The study also found that patients experienced suffering from issues related to treatment of their disorder, and that the act of applying for EAS could also contribute to a patient’s suffering. In the intrapersonal domain, a history of traumatic experiences and self-destructive thoughts was found to contribute to patients’ suffering; in the interpersonal domain, a lack of social support and understanding contributed to their suffering, as did conflicts with important people in their lives and bereavement. In the societal domain, social hardships, social isolation, and a lack of socio-economic resources were found to contribute to suffering. Finally, the study found that patients’ suffering became existential when they perceived their situation as futile, with no prospect of improvement (Verhofstadt *et al.*, 2017).

The Verhofstadt *et al.* (2017) study confirmed an earlier finding by Dees *et al.* (2011) that psychiatric patients may suffer continuously. A literature review of descriptions of suffering associated with requests for assisted dying found that psychological symptoms, most notably hopelessness, were important factors contributing to the intolerability of suffering (Dees *et al.*, 2009). Furthermore, the study found that, although medical and social factors both caused and contributed to suffering, it was primarily the presence of psychological, emotional, and existential problems that caused suffering to become intolerable (Dees *et al.*, 2009). In a follow-up qualitative study of 31 patients who requested EAS, Dees *et al.* (2011) identified physical suffering as less important, and found that those who emphasized *continuous* feelings of intolerable suffering had depression (2 patients). However, it is important to note that the majority of the studies reviewed by Dees *et al.* (2009) included only cancer patients, not patients with a mental disorder as their sole underlying medical condition, although four of the patients in Dees *et al.* (2011) identified a diagnosed psychiatric disorder as motivating their requests for EAS.

Importantly, the tolerability of suffering is also highly individual. Dees *et al.* (2009) found that the tolerability of suffering was the result of a complex interaction of the person's life history, symptoms, personality, social situation, and "existential motivations," and emphasized that "unbearable suffering [...] in the context of a request for EAS must do justice to the uniqueness of the individual who makes the request" (Dees *et al.*, 2009). Likewise, as the Netherlands' Regional Euthanasia Review Committees (RTE) Code of Practice points out:

What is bearable for one patient may be unbearable for another. This depends on the individual patient's perception of his situation, his life history and medical history, personality, values and physical and mental stamina. It is therefore important to consider the patient's 'biography' when assessing his suffering.

(RTE, 2015b)

The type, severity, and pervasiveness of psychiatric symptoms can vary widely from person to person, as can the effect of these symptoms on someone's distress and ability to function. One individual may experience many symptoms of a mental disorder but still function well in their personal and social relationships, despite suffering because of their disorder. A different individual with the same disorder might function poorly in their personal and social relationships, yet not suffer due to their disorder. And yet a third individual with the same

disorder may experience minimal symptoms but find these to be severely debilitating, thus impairing their ability to function (Bruce & Raue, 2013). In order to assess a patient's suffering, healthcare practitioners must understand the person as a whole, taking into account personality characteristics such as values, roles, relationships (Gupta *et al.*, 2017), biographical attributes, and the "patient's perspectives of the past, the present, and expectations of the future" (Dees *et al.*, 2011).

Evaluating a Patient's Suffering

As with evaluations of capacity (Section 4.1.1), assessments of a patient's suffering may differ among evaluators, since healthcare practitioners do not necessarily share the same values and experiences, and may therefore have different interpretations of a patient's experiences (and suffering) (Gupta *et al.*, 2017). It has been proposed that good clinical practice may direct a practitioner to *explore* (rather than *evaluate*) a patient's suffering, considering a patient's own account first, the observations of the people around them (family, friends, other healthcare practitioners), and the current clinical snapshot (e.g., treatment history, prognosis, treatment options going forward) (Gupta *et al.*, 2017).

Typically, a clinical assessment of a patient's suffering is undertaken in order to know whether (and how) it can be relieved through treatment. However, in a MAID context, where "intolerable suffering" is an eligibility criterion, assessments of suffering are more complex. MAID law in Canada explicitly defines intolerable suffering in *subjective* terms — i.e., "suffering that is intolerable *to them* and that cannot be relieved under conditions *that they consider acceptable*" (GC, 2016b, *emphasis added*). While a healthcare practitioner must "be of the opinion that" these conditions are met, if a patient truly believes their suffering is intolerable, and believes that existing means to relieve their suffering are not acceptable to them, they thereby meet the criteria for intolerable suffering set out in the legislation. However, the healthcare practitioner's role remains important even with respect to this subjective element of Bill C-14, as they must determine whether there is any way of relieving a patient's suffering that is acceptable to that patient.

Some Working Group members believe that defining the relievability of suffering solely in terms of subjective acceptability to the patient (as Canadian MAID law currently does) would allow a person with capacity, whose decision is nonetheless coloured by symptoms of their mental disorder, to reject a reasonable and effective treatment, even if the treatment itself does not cause them additional suffering. Distorted perceptions of intolerance and irreducibility (i.e., the belief that nothing can ever make a person feel any better) are common symptoms in some psychiatric patients (such as those with personality disorders or major

depression, or those whose coping capacity is under stress) (MacLeod *et al.*, 2004; Halpern, 2012); these perceptions could change. Indeed, modern cognitive behavioural therapies are designed to address just such distorted perceptions, based on the idea that important therapeutic effects can result from helping a person to become aware of the ways in which automatic thoughts shape and distort their emotions and perceptions, and reframing those thoughts to reduce their suffering (Wenzel *et al.*, 2009; Beck & Beck, 2011). It may therefore be difficult for a clinician to determine the permanence of a patient's suffering given the possibility of remission and/or a change in the patient's distorted perceptions. This points to a special vulnerability of people with mental disorders in the context of MAID MD-SUMC: there will be situations in which a patient's perception of their intolerable suffering could be addressed clinically despite their view that it is irremediable. Compared to Canada, assisted dying laws in Belgium and the Netherlands contain a more objective definition of treatment futility, wherein the patient and physician must together determine whether or not there is no alternative to EAS — i.e., whether there are acceptable means by which the patient's suffering can be relieved (Gov. of Belgium, 2002; Gov. of the Netherlands, 2002). See Section 5.6 for further discussion.

Reasonable Foreseeability of a Natural Death

In order for a person to be eligible for MAID in Canada, their “natural death [must have become] reasonably foreseeable, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining” (GC, 2016b). This requirement would likely disqualify most people from eligibility in cases where a mental disorder is their sole underlying medical condition.

There are some mental disorders for which the natural death of a person with that disorder may be reasonably foreseeable, including certain neurodegenerative conditions (such as dementia caused by Alzheimer's disease) and some other psychiatric conditions (such as anorexia). In addition, once a person is sufficiently old, they may satisfy the “reasonably foreseeable” criterion due to age. Downie and Chandler (2018) have suggested that Kay Carter would have qualified on this basis (she was 89 years old and did not have a terminal condition; see Section 2.1.4), and in 2017 the Ontario Superior Court of Justice ruled that a 77-year-old woman met the “reasonably foreseeable” criterion on the basis of her age and health, despite not having a terminal condition (ONSC, 2017). In addition, the Attorney General of Canada has stated that age is a factor to consider when determining the reasonable foreseeability of a person's death in the context of MAID (Standing Committee on Justice and Human Rights, 2016a).

Although having a mental disorder is among the most important risk factors for suicide, the increased risk of suicide in people with mental disorders is not relevant to the “reasonably foreseeable” criterion because the current legislation specifically requires that the person’s *natural* death has become reasonably foreseeable, and suicide is not considered to be a natural death. Suicide in the context of MAID MD-SUMC is discussed further in Section 4.2.

4.1.3 Voluntariness

Canadian MAID law requires that a person make “a voluntary request for medical assistance in dying that, in particular, was not made as a result of external pressure” (GC, 2016b). Given the history of stigma and discrimination against people with mental disorders (Chapter 3), there may be concerns that (i) someone’s decision to seek MAID might be due to stigma or the perception that people with mental disorders are burdens on families, and/or that (ii) families may pressure a person with a mental disorder to seek MAID. According to the *Derde evaluatie Wet toetsing levensbeëindiging op verzoek en hulp* (Third Review of the Dutch Act), in which psychiatrists evaluating patients for EAS in the Netherlands were asked detailed questions about the last time they had refused a request, respondents felt that “the patient was making the request under the pressure of those close to him or her” in 5 of 66 (8%) cases (Onwuteaka-Philipsen *et al.*, 2017).¹⁴ Notably, psychiatrists also felt that they were pressured “by those close to the patient to refuse the request” in 5 of 66 (8%) cases.¹⁵

4.1.4 Assessing Capacity and Prognosis: Comparing MAID MD-SUMC to Other Highly Consequential Decisions

It can often be challenging to assess capacity and prognosis in some people with a mental disorder. This can be a particular concern in the context of highly consequential decisions that will lead to a patient’s death, such as MAID. This section examines the similarities and differences between assessing a patient’s capacity and prognosis (i) in the context of MAID MD-SUMC, versus (ii) in the context of other highly consequential decisions that will lead to a patient’s death, such as refusing life-sustaining medical treatment or MAID MD-SUMC where a person is already eligible under the current law. Working Group members do not agree about whether (and how) these situations differed, about whether MAID MD-SUMC is novel and/or unique with respect to assessments of capacity and prognosis, nor about whether existing practices in such situations could inform the practice of MAID MD-SUMC in Canada, were it permitted more broadly.

¹⁴ Unofficial translation.

¹⁵ Unofficial translation.

Some of these disagreements are related to the ethical and practical distinction (or lack thereof) between acts and omissions (i.e., between killing and letting die), as well as the ethical and practical significance (or lack thereof) of the reasonable foreseeability of a person's death. Some Working Group members believe that there is a crucial ethical distinction between: (i) a healthcare practitioner respecting the boundaries of a patient's body and respecting a competent patient's treatment refusal, leading to the patient's death due to an underlying disease process, and (ii) a healthcare practitioner injecting a lethal medication to end the life of a patient who is not dying. Other Working Group members, however, reject the argument that there is a morally significant distinction between acts and omissions that justifies a different approach to MAID MD-SUMC, and point out that with Bill C-14, Canadian law has accepted that active assistance in ending a person's life is acceptable in at least some circumstances. They also note that capable people with stable but serious conditions (e.g., kidney failure) are permitted to refuse life-sustaining treatment, despite their potential for a long life, even in circumstances where they have a mental disorder.

Capacity

Some Working Group members point out that capacity assessments for people with mental disorders must already be undertaken for certain highly consequential decisions that could result in death, such as refusing life-sustaining treatment (e.g., dialysis) or in MAID MD-SUMC cases where a person is eligible under the current law (e.g., cases involving older people). In the view of these Working Group members, it is not clear whether the complexity or challenges of assessing capacity in these contexts is any greater than in other MAID MD-SUMC contexts. Other Working Group members believe that such situations are extremely rare and, as such, there are no existing capacity evaluation practices that could be transferred over to MAID MD-SUMC, were it more broadly permitted.

If MAID MD-SUMC were more broadly permitted, the potential number of cases in which capacity assessments must be made for highly consequential decisions would increase, along with the frequency of potential errors both ways (i.e., assessing capable patients as lacking capacity, and assessing incapable patients as having capacity). That said, some Working Group members note that Dutch assessors who evaluated the decision-making capacity of people who requested psychiatric EAS agreed with one another in most cases; disagreements about whether the patient had the capacity to consent to EAS occurred in 12% (8 of 66) of cases (Doernberg *et al.*, 2016) (see Section 5.6 for further discussion). Other Working Group members believe that this finding must be contextualized within Dutch practice and note that the same study also found that these

disagreements occur despite the fact that, in the view of Doernberg *et al.* (2016) and these Working Group members, the thresholds used for capacity in the Dutch practice of psychiatric EAS are not high.

Prognosis

For some patients with a mental disorder, it can be challenging to predict the natural course of the disease and the effectiveness of treatment. For example, a patient with depression may refuse life-saving medical treatment (e.g., kidney dialysis), and there may be good information and high certainty about the prognosis relating to the underlying physical condition (e.g., kidney failure), but less information and lower certainty in relation to the prognosis relating to their mental disorder.

In such cases, a patient may refuse medically necessary treatment in order to escape the symptoms of the mental disorder and end their suffering. Some Working Group members believe that, even in such cases, prognostic uncertainty about the patient's mental disorder (i.e., not knowing whether their depression will improve or not) is not a valid reason for overriding a capable patient's refusal of treatment (although incapacity would be a valid reason to do so).

Other Working Group members believe that, although refusal of life-sustaining dialysis does sometimes occur in patients with mental disorders, the above example is not analogous to a MAID MD-SUMC situation. They believe that in order for the analogy to apply to MAID MD-SUMC, the person with a mental disorder should have a physical disorder that is fatal but trivial to treat, rather than one that requires a burdensome treatment such as dialysis — for example, a person with depression who has an infection that can be easily treated by simply taking an antibiotic and which would be fatal without treatment. In the view of these Working Group members, it is not clear that there is an established practice regarding such situations from which inferences can be drawn. They believe that, given that the patient refusing the antibiotic is known to be depressed, current practice would likely be an assessment of suicidality. Moreover, they believe that, even if a capacity evaluation became relevant, such a case would most likely need to be adjudicated, and that no general inferences can therefore be drawn regarding MAID MD-SUMC. In contrast, other Working Group members believe that, if found to have capacity, such a person would be entitled to refuse treatment, even if it resulted in their death.

Incurability and Relief of Suffering

In Canada, current eligibility criteria for MAID require that a patient's condition be incurable and that their suffering cannot be relieved under conditions that they deem acceptable (GC, 2016b). Since those with a mental disorder as their sole underlying medical condition are not excluded from MAID eligibility, some

Working Group members point out that clinicians are already required to assess incurability and non-relievable suffering in patients who are seeking MAID MD-SUMC and whose natural death has become reasonably foreseeable — for example, in the case of an older patient with major depression. In 2017, the Ontario Superior Court of Justice ruled that a 77-year-old woman (without a mental disorder) met the “reasonably foreseeable” criterion on the basis of her age and health, despite not having a terminal condition (ONSC, 2017). In addition, the Attorney General of Canada has stated that age is a factor to consider when determining the reasonable foreseeability of a person’s death in the context of MAID (Standing Committee on Justice and Human Rights, 2016a) (Section 4.1.2).

However, other Working Group members believe that even if such assessments might be currently required *in principle*, they are not currently undertaken *in practice*. According to these Working Group members, the example of the older depressed patient is too speculative to be helpful, given that, to date, there have been no such reported cases (in the Ontario case described above, the patient did not have a mental disorder). Further, they believe that the supposition that older patients could meet the “reasonably foreseeable death” criterion on the basis of their advanced age is an evolving legal matter that has not been addressed by the Supreme Court of Canada or in federal, or provincial or territorial legislation, and as such, is not settled law. Thus, they believe there are no currently existing practices or inferences that could be applied to MAID MD-SUMC, and that, at most, the Ontario example demonstrates that situations requiring eligibility decisions based on uncertain prognoses may already be occurring.

If MAID MD-SUMC were made more broadly available, there would be an increase in the potential number of cases in which these challenging prognostic decisions must be made, along with the frequency of potential errors. However, some Working Group members point out that — as discussed further in Section 5.6 — the available evidence suggests that Dutch assessors agreed about treatment futility (i.e., incurability and non-relievable suffering) in the majority of psychiatric EAS cases; disagreements occurred in 20% (13 of 66) of cases (Kim *et al.*, 2016). Other Working Group members believe that differences between the Dutch and Canadian assisted dying laws must be taken into account when discussing this finding. Specifically, the Dutch law requires that both the patient and the physician must together agree there are no reasonable treatment options before EAS can be accessed, which arguably provides an objective criterion for treatment futility. In contrast, Canadian MAID law is based on a patient’s subjective views of what constitutes “acceptable treatment,” and does not require that the patient attempt any available treatments for the purposes of MAID eligibility.

4.2 SUICIDE AND MAID MD-SUMC

The preamble to Bill C-14 includes several statements that are relevant to an analysis of the relationship between suicide and MAID MD-SUMC:

- Whereas the Parliament of Canada recognizes the *autonomy* of persons who have a grievous and irremediable medical condition that causes them enduring and intolerable *suffering* and who wish to seek medical assistance in dying; [...]
- Whereas it is important to affirm the inherent and equal value of every person's life and to *avoid encouraging negative perceptions* of the quality of life of persons who are elderly, ill or disabled;
- Whereas *vulnerable persons must be protected from being induced, in moments of weakness, to end their lives*;
- Whereas *suicide is a significant public health issue that can have lasting and harmful effects on individuals, families and communities*;
- Whereas, in light of the above considerations, permitting access to medical assistance in dying for competent adults whose deaths are reasonably foreseeable strikes the most appropriate *balance* between the *autonomy* of persons who seek medical assistance in dying, on one hand, and the interests of *vulnerable persons in need of protection and those of society*, on the other.

(GC, 2016b, emphasis added)

MAID currently allows a person to end their suffering by accelerating the timing and manner of their reasonably foreseeable death. Under the current law, self-administered MAID is considered to be a form of suicide — aiding self-administered MAID is an exception to the Criminal Code's prohibition on assisting suicide (GC, 2016b). In most cases of MAID MD-SUMC, death would generally occur when the person's natural death has not yet become reasonably foreseeable, as is the case for most people who die by suicide. Expanding MAID MD-SUMC means determining whether it is ethical to assist people with mental disorders whose natural death is not reasonably foreseeable to end their lives, considering the association between suicide and mental disorders (Section 3.2). And even if such acts are ethical, there remains the question of whether it is possible to reliably identify those suicides that society wishes to assist and those it wishes to prevent. This section explores the Working Group's divergent views on why society tries to prevent suicide, and whether suicide can be differentiated from MAID MD-SUMC. Chapter 6 includes a discussion of the implications of prohibiting or more broadly permitting MAID MD-SUMC related to suicide, as well as an examination of related safeguards.

4.2.1 Why Does Society Seek to Prevent Suicide?

Suicide is identified as a significant public health issue in the preamble to Bill C-14 (see above). Additionally, *An Act Respecting a Federal Framework for Suicide Prevention* became law in December 2012, and the resulting framework's stated vision is "a Canada where suicide is prevented and everyone lives with hope and resilience" (GC, 2016c). Both the framework and Bill C-14 emphasize that suicide can have lasting and harmful effects.

Working Group members had different perspectives on what suicide prevention information should be presented in this report. This is not surprising given the range of disciplinary and experience-informed perspectives among Working Group members. Two perspectives are presented here.

One Perspective

In the view of some Working Group members, society's justifications for seeking to prevent suicide can include: (1) beliefs about the value of life (whether these are religiously-based or secular); (2) religious views that God, not humans must decide the timing of death; (3) arguments that suicide causes harm to people apart from the one who dies (e.g., family members), society or both; and/or (4) concerns that suicide is non-autonomous (Cholbi, 2017). These Working Group members acknowledge that some scholars argue the primary justifications to prevent suicide are: (i) based on the observation that the majority of people whose suicides are prevented are grateful for having been stopped (or saved) from completing suicide; and (ii) in some instances of suicide, harm is done to the individual (see *Another Perspective* below). These Working Group members believe that (i) maps onto justification (4) (autonomy) and (ii) maps on to justification (1) (value of life), respectively.

An Act Respecting the Federal Framework for Suicide Prevention notes that "[p]eople experiencing thoughts of suicide or suicide-related behaviour may feel hopeless or overwhelmed and see no other option" (GC, 2016c). Embedded within this statement is the idea that suicide is not a true reflection of what such people want, and that their appraisal of their situation may be mistaken or distorted. If offered appropriate help, they could potentially find solutions for the problems that led them to feel hopeless or overwhelmed. Thus, in the view of these Working Group members, such thoughts of suicide or suicide-related behaviour are in some sense non-autonomous (Section 4.3.2), and this lack of autonomy could be further understood in at least two different ways:

- **Incapacity:** As discussed in Section 4.1.1, while the majority of people with mental disorders have decision-making capacity, in some cases the symptoms of mental disorders can compromise decision-making. A person may make a decision to attempt suicide when they lack the capacity to understand and appreciate the consequences of that decision. For example, a person with a psychotic disorder might hold a delusional belief that if they were to die by suicide, they would save the world.
- **Authenticity:** As discussed in Sections 4.1.1 and 4.3.2, the desire to die in people with mental disorders may be a symptom of their disorder rather than a choice based on their values and beliefs. That is, even if such people fulfil the legal criteria for decision-making capacity, their expressed desire to die is inconsistent with their non-disorder-related values, goals, and/or life history. In short, the concern is that the person does not really want to die. For example, prior to the onset of a major depressive episode, a person may have always been goal-oriented and resilient. Now, as a result of the impact of depression on their thinking, they believe that they can never accomplish their goals, feel hopeless, and see no purpose in living. There are philosophical and legal disagreements about the existence and/or relevance of authenticity to decision-making.

Additionally, as stated above, the preamble to Bill C-14 expresses concern for those who might end their lives “in moments of weakness” (GC, 2016b). In the view of these Working Group members, two characteristics of suicidality that might be relevant to such moments of weakness are *ambivalence* (Section 3.2) and *impulsivity*:

- **Ambivalence:** The same Working Group members believe there are at least two ways in which ambivalence can be understood in the context of suicide prevention: (i) when a person fully changes their mind (i.e., is confident they want to attempt suicide at one time and is confident they do not want to at another time); (ii) when a person is of two minds at once (i.e., both wants to attempt suicide and does not want to at the same time or, put differently, simultaneously wants to live and wants to die). For example, a person might attempt suicide while experiencing a desire to die, but, had they waited or received some form of suicide prevention intervention (or had their circumstances otherwise changed in material ways), they would have changed their mind and no longer desired to die. Another possibility is that, on balance, the person wanted to die, but, had they waited or received treatment (or had their circumstances otherwise changed in material ways), the balance between their competing desires would have shifted and, on balance, they would have wanted to live. As discussed in Section 3.2, ambivalence about dying is considered to be a characteristic of the desire to kill oneself.

- **Impulsivity:** The importance of impulsivity in the context of MAID is illustrated in the preamble to Bill C-14 (“Whereas vulnerable persons must be protected from being induced, in moments of weakness, to end their lives” (GC, 2016b)). The concern expressed here is that a person might attempt suicide suddenly and without careful thought and, had they waited or thought more carefully, they would no longer have desired to end their lives. The extent to which impulsivity is involved in suicide is a matter of debate. For example, Anestis *et al.* (2014) concluded that the role of impulsivity in suicide is likely to be small, whereas the World Health Organization states that “many suicides happen impulsively in moments of crisis with a breakdown in the ability to deal with life stresses, such as financial problems, relationship break-up or chronic pain and illness” (WHO, 2018).

Another Perspective

Other Working Group members hold that suicide prevention activities — ranging from interventions with suicidal people, to national policies such as restricting access to lethal means — can be justified by ethical beliefs and practical experiences. However, in the view of these Working Group members, the main justification for suicide prevention in Canada is the concern expressed in the preamble to Bill C-14, in *The Federal Framework for Suicide Prevention*, in various provincial and territorial mental health laws, and within suicide prevention communities and organizations: society engages in suicide prevention because of the belief that there is value in saving the lives of people who, although feeling hopeless, have the potential to enjoy fulfilling lives when provided with adequate treatment, help, and support.

Canada has suicide prevention measures, policies, and practices — including laws on involuntary commitment — that do not refer to religious considerations or authenticity. From a suicide prevention perspective, there is no distinction made between suicides that are to be prevented and those that are not to be prevented.

People involved in suicide prevention may adhere to a wide range of ethical perspectives concerning suicide, of which the four justifications provided in the previous section (*One Perspective*) are a limited sample. Mishara and Weisstub (2010) explain that the ethical views and empirical presuppositions of a person involved in suicide prevention will have implications for the nature of interventions that they use when a suicide is imminent, but none of these contravene work to prevent deaths by suicide in any group. In addition to the four justifications provided in the previous section (*One Perspective*), Mishara and Weisstub (2010) emphasize that consequentialist ethical arguments pervade the suicide prevention community. People who work in suicide prevention are

encouraged to continue their work because people whose deaths by suicide were prevented are generally thankful, do not attempt suicide again, and therefore have the opportunity to go on to live fulfilling lives (Mishara & Weisstub, 2010). Some suicide centres report that people who are rescued — against their wishes — from dying by suicide often call back to thank the centre for saving their lives (Mishara & Weisstub, 2010).

As noted above, the ethical philosophies of suicide prevention workers may determine their view on the acceptability of potentially intrusive interventions (e.g., tracing a telephone call and sending an ambulance, or hospitalizing a person who is considered to be at risk of suicide). However, these philosophies are not relevant to the decision to provide help to suicidal people to prevent an avoidable death. Two large suicide prevention organizations, the Samaritans (in the United Kingdom) and Befrienders Worldwide, are non-political, non-sectoral, and believe that the right of people to make their own decisions — including whether to live or die — must always be respected (Bale, 2003). Despite this, the Samaritans still attempt to convince callers not to end their lives, regardless of the circumstances. If their efforts fail and the caller still proceeds with a suicide attempt, the Samaritans will not trace calls in order to send an ambulance, but will stay on the line and try to convince the person to accept medical help (Samaritans, 2018). This differs from the approach of the American Association of Suicidology (AAS), an organization that accredits suicide prevention centres in the United States. The AAS requires more extraordinary actions be taken to prevent death, including tracing a call to send emergency services (AAS, 2012). Mishara and Weisstub (2010) explain that the Samaritans are successful in preventing suicide, stating “it is the experience of Samaritan organizations that most people, once they begin to talk about their distress and despair, become less suicidal, and that those who are still at high risk or have initiated an attempt generally ask for help.”

The views of these other Working Group members on ambivalence, impulsivity, incapacity, and authenticity, and how these are (or are not) relevant for suicide prevention are as follows:

- **Ambivalence:** These Working Group members note the dominant perspective in suicide prevention literature is that ambivalence in persons who are suicidal involves the co-existing desire to live with the desire to die (Shneidman, 1972, 1996; WHO, 2000). These Working Group members believe that this tension between the will to live and a desire to kill oneself is present in almost all suicidal people. Interventions with suicidal people work by shifting the balance between the will to live and die, and while suicidal thoughts may persist, they can be outweighed by a stronger desire to continue living. In the view of these

Working Groups members, the legal test for capacity in Canadian law and the usual methods of assessing it do not necessarily take into consideration this ambivalence about wanting to die, although stability of choice is part of the most widely used clinical model of capacity (Appelbaum & Grisso, 1988).

The view that ambivalence about whether to live or die is a characteristic of suicidal individuals can be considered a complementary justification for suicide prevention (WHO, 2000). Research shows that the vast majority of people who seriously consider suicide will never attempt suicide, and only approximately 5% of people who attempt suicide will die from their attempt (WHO, 2014a). Most people who initiate a suicide attempt do not die (WHO, 2014a). The reason that so few die is not that humans are generally incapable of ending their own lives. Rather, the majority of those who attempt suicide, if they are physically able, stop the attempt or call for help and thus avoid a lethal outcome (Mishara & Tousignant, 2004).

It has been shown that ambivalence about whether to live or die can fluctuate with one's experiences (Bergmans *et al.*, 2017). Although having attempted suicide is a significant risk factor for attempting again, with roughly 10% of attempts making a second suicide attempt in the following year, the majority do not attempt again (Chung *et al.*, 2012; Murphy *et al.*, 2012; Kwok *et al.*, 2014; Martiniuk *et al.*, 2015; Owens *et al.*, 2018). In addition, suicide prevention centres report that almost all people who survive a suicide attempt against their will thank the responders once they are out of danger (Mishara & Tousignant, 2004).

Furthermore, in the view of these Working Group members, no suicides can be considered entirely rational. The entry on *Rational Suicide* in the *Encyclopedia of Death and Dying* argues that when people talk about rational suicide they usually mean that the reasons given for the suicide can be understood by someone else (Mishara, 2003). There are strong emotional components to suicidal decision-making (as with all human decisions), regardless of peoples' rational abilities to come up with justifications.

- **Impulsivity:** The extent to which impulsivity is involved in suicide is a matter of debate, and its relevance to MAID (where there is a delay between request and procedure) is uncertain. Research shows that, in impulsive suicide attempts, the delay between the decision to kill oneself and the suicide attempt is, on average, a matter of minutes or a few hours at most. For example, in reported impulsive suicide attempts, less than five minutes elapse between a person's decision to attempt suicide and their suicide attempt (Simon *et al.*, 2001). Impulsive suicides typically occur in acute crisis situations (e.g.,

learning that a spouse is leaving, losing a job, or when being surrounded by police after committing a crime), and usually when some means to attempt suicide is easily accessible (WHO, 2014a).

The World Health Organization (WHO) affirms that, when suicide is considered on a worldwide scale, many suicides occur in crisis moments related to life stresses (e.g., financial problems, relationship break-ups) (WHO, 2018). However, the WHO findings about suicide around the world must be understood in the context of regional differences. Impulsivity in suicide attempts is common in Asia (Anestis *et al.*, 2014). For example, Wei *et al.* (2013) found that 45% of suicide attempts were impulsive, with less than two hours between the time someone first decides to attempt suicide and their attempt, often when the person has consumed large quantities of alcohol. But in Western countries such as Canada, impulsive suicides constitute a small percentage of all suicide deaths, and they often occur when the person has consumed alcohol or taken illicit drugs. The aforementioned meta-analysis by Anestis *et al.* (2014) found that there is a very small, non-significant relationship between impulsivity and suicide in Western countries.

Thus, these Working Group members believe, because people cannot use MAID to complete an impulsive suicide (since MAID is not permitted within hours of making a request), discussion of impulsive suicides is not relevant to MAID MD-SUMC.

- **Incapacity and Authenticity:** In the view of some Working Group members, the issues of incapacity and authenticity are not relevant to the practice of suicide prevention. For example, suicide prevention hotlines do not assess capacity or authenticity — they simply do their best to intervene to stop suicide. In the experience of these Working Group members, people who engage in suicide prevention do so regardless of issues of capacity and incapacity, and authenticity is never considered in contemporary suicide prevention practices. As illustrated by the practice of the Samaritans, people who are viewed as fully capable of autonomous decision-making still receive intensive suicide prevention interventions, regardless of their life circumstances and the source of their suffering and despair.

Suicide Prevention and Bill C-14

Some Working Group members believe that with the passing of Bill C-14, society no longer seeks to prevent all suicides. They believe that while alternatives to suicide must first be offered to all patients, society now allows medical and nurse practitioners to aid suicide where the conditions for self-administered MAID are met. In the view of these Working Group members, while suicide

prevention professionals may disagree, society no longer sees all suicides as a harm. That said, most suicides are clearly still seen as harms and most are clearly still to be prevented. Thus, in their view, Bill C-14 requires society to ask the question of how to distinguish between suicide that society seeks to prevent and MAID when it meets the criteria of Bill C-14.

This contrasts with the view of other Working Group members, who believe the legalization of assisted suicide under Bill C-14 was not intended to change society's commitment to preventing all suicides, nor was MAID (under the current law) intended to be legalized as an alternative to suicide. These Working Group members believe that, because of the "natural death has become reasonably foreseeable" criterion (GC, 2016b), people eligible for MAID under Bill C-14 are effectively advancing the timing of their death and changing the manner in which they will die. Suicidal people are rarely in a situation where their natural death is reasonably foreseeable. In a study of reasons for suicide given by 4,673 people who attempted suicide in nine European countries, only 4.3% said that physical disorder was the main reason for their suicide attempt (Burón *et al.*, 2016). In a different study of suicide attempts among gay men in Switzerland, only 2.6% (3 out of 127) said that their attempt was associated with physical disorder (Wang *et al.*, 2015). People who attempt suicide often have one or more mental disorders (Section 3.2.1).

4.2.2 Can Suicide Be Reliably and Validly Differentiated from MAID MD-SUMC?

Working Group members also diverged on the answer to the question of whether suicide can be differentiated from MAID MD-SUMC. In this section, these two divergent viewpoints are described.

One Perspective

Some Working Group members note that *suicide* can be defined as a situation in which a person intentionally ends their life to terminate suffering they perceive as being intolerable, interminable, and inevitable (Mishara & Tousignant, 2004). In contrast, *MAID* is defined as: "(a) the administering by a medical practitioner or nurse practitioner of a substance to a person, at their request, that causes their death; or (b) the prescribing or providing by a medical practitioner or nurse practitioner of a substance to a person, at their request, so that they may self-administer the substance and in doing so cause their own death" (GC, 2016b).

Some Working Group members believe that a recent statement from the American Association of Suicidology (AAS, 2017), which claims that physician aid in dying (PAD) can be distinguished from suicide that should be prevented, is not evidence-based. The AAS statement maintains that suicide is not the same as PAD as it is currently practiced in jurisdictions that permit it, and notes 15 differences between PAD and “suicide in the ordinary, traditional sense” (AAS, 2017). However, while the AAS statement is intended to cover all existing assisted dying practices, including assisted dying for people with a mental disorder as their sole underlying medical condition, most of the differences between suicide and PAD identified by the AAS are differences between suicide and PAD for a terminal illness, or between suicide and cases where a person’s natural death is otherwise reasonably foreseeable (Kim *et al.*, 2018). As such, in the view of these Working Group members, the AAS statement does not explain how to distinguish between traditional suicides (which they seek to prevent) and MAID MD-SUMC (AAS, 2017; Kim *et al.*, 2018).

Despite advances in the understanding of the risk factors for suicide (Section 3.2), there remains an important limitation when it comes to predictability. While the risk factors for suicide are well known, they cannot be applied in a straightforward manner to people in order to reliably predict who will and will not die by suicide. This means that, despite the fact that *suicide*, *assisted suicide*, and *euthanasia* have different definitions, some Working Group members believe it is not possible to distinguish empirically between people who are suicidal from those who have made an autonomous request for MAID MD-SUMC. There is evidence that some patients who have sought psychiatric EAS in jurisdictions that permit it share key features with those who make suicide attempts (these features are discussed in Chapter 3; international data are discussed in Chapter 5). These shared features include: having psychiatric disorders that are risk factors for suicide; ambivalence (as demonstrated by people withdrawing their psychiatric EAS requests either before or after approval¹⁶ (Thienpont *et al.*, 2015)); a demoralized belief that life is unbearable and that no solutions are possible; and being socially isolated or lonely (Kim *et al.*, 2016). These are all features of suicide that ought to be prevented, as defined by AAS (AAS, 2017).

WHO considers suicides preventable (WHO, 2014a) and its public health perspective informed the development of Canada’s *An Act Respecting a Federal Framework for Suicide Prevention* (GC, 2016c). Many countries engage in a range of suicide prevention activities, from interventions with suicidal people to

¹⁶ Out of a total of 100 applications for psychiatric EAS in Belgium, 11 postponed or cancelled the procedure after approval (for 8 patients “simply having this option gave them enough peace of mind to continue living,” 2 withdrew requests due to strong family resistance, and 1 person could not have EAS because they were incarcerated), while 38 withdrew their requests before a decision was reached (Thienpont *et al.*, 2015).

national policies such as restricting access to lethal means. Some Working Group members believe expanding MAID MD-SUMC could significantly affect suicide prevention strategies in Canada, as healthcare practitioners would no longer strive to prevent the suicide of everyone with a mental disorder who wants to end their life (See Chapter 6 for a discussion of the implications of prohibiting or more broadly permitting MAID MD-SUMC on suicide prevention).

Unlike many physical disorders, the effectiveness of treating some mental disorders is generally determined by a trial and error approach; if certain treatments do not adequately alleviate symptoms, alternative treatments are tried (Section 3.1.2). As noted in Section 4.1.2, Canadian MAID law does not require a patient to try potential treatments that a healthcare practitioner may believe could alleviate the suffering that motivates the patient's request for MAID (GC, 2016b). Rather, a patient can refuse any potential treatment that they do not consider to be acceptable. As such, Canadian MAID legislation differs from EAS law in the Netherlands, which requires that both the healthcare practitioner and the patient agree together that there are no available, untried treatments that might alleviate the patient's suffering before they can access EAS (Chapter 5). These Working Group members believe that, because of the ethical distinction between hastening a foreseeable death and providing MAID to someone who is not terminally ill, and because interventions for mental disorders require trial and error to determine their effectiveness in treating the symptoms that cause suffering, a potential safeguard to consider is requiring physician agreement on the futility of untried treatment options as a prerequisite to granting a request for MAID MD-SUMC, should it be expanded (Section 6.4.8). These Working Group members believe that this is an ethical imperative supported by existing mental health legislation throughout Canada that recognize people with mental disorders as a vulnerable population that needs specific protections.

In the view of these Working Group members, if MAID MD-SUMC were more broadly permitted in Canada under the current situation wherein the capable patient alone determines whether any potential treatment is acceptable, it could have important implications for suicide prevention and further problematize how some people with mental disorders (and society) view their prognosis (Chapter 6). Many suicide prevention efforts focus on building hope regardless of the person's state of despair (WHO, 2014a). At the present time, it is difficult to accurately determine whose symptoms can be alleviated and whose cannot, unless a range of treatments are tried (Section 3.1.2). In addition, these Working Group members believe that there is also no method to conclusively determine whether an individual's desire to die is pathological and should be treated aggressively, or whether a MAID MD-SUMC request should be facilitated. They believe that if treatment futility is left up to the patient alone to determine, as

is the case in current Canadian MAID legislation, suicidal people who currently benefit from treatment for their symptoms and feelings of hopelessness may have their deaths facilitated if they request MAID MD-SUMC.

These Working Group members do not believe that Bill C-14 has shifted the way suicide prevention is viewed in Canada. For example, mental health legislation in most provinces and territories allows for involuntary hospitalization in specific circumstances when a person lacks capacity and is in danger of attempting suicide due to a mental disorder (Section 3.6.3). Furthermore, people who work in suicide prevention are not neutral, as they intervene in any potential suicide (including non-mental disorder suicides) and with people who would otherwise meet the eligibility criteria for MAID. In the view of these Working Group members, the only circumstance where suicide prevention interventions are not offered is when MAID is provided to someone who meets all requirements under C-14 (including that their death is reasonably foreseeable). Further, these Working Group members believe that people who qualify for MAID under Bill C-14 rarely come into contact with suicide prevention workers but, if they did, their desire for death by MAID and potential ambivalence would be explored and help would be offered (without interfering with their MAID request).

Another Perspective

Other Working Group members note that some suicide prevention organizations have argued that suicide can be differentiated from MAID. For example, the Centre for Suicide Prevention, a branch of the Canadian Mental Health Association, has developed a graphic to explain the differences between suicide and MAID (in reference to people accessing MAID who would be eligible under the current law) (Centre for Suicide Prevention, 2016).¹⁷

Nevertheless, these other Working Group members believe that the concepts of suicide and MAID are themselves overlapping, for the following reasons:

- Suicide and MAID fall within a broad category of self-directed death.
- Unassisted suicide and self-administered MAID are forms of suicide.
- Legally speaking, self-administered MAID is a sub-category of assisted suicide (i.e., it is medically-assisted suicide).

These Working Group members believe that, through Bill C-14, society has determined that some self-directed deaths are to be facilitated, some are to be prevented, and some are to be neither facilitated nor prevented. The current

¹⁷ As noted above, the American Association of Suicidology has also taken the position that suicide can be differentiated from physician aid in dying (AAS, 2017).

eligibility criteria offer a normative threshold for determining who should receive MAID by providing ethical and legal standards in deciding whose deaths should be facilitated. Whether these criteria offer an adequate normative threshold for MAID MD-SUMC, and if so, with what accompanying safeguards, are ethical questions. If MAID MD-SUMC were expanded, the challenge would be to determine criteria for access that both facilitate suicide prevention (and, in some cases, restrict liberty or prohibit a third party's conduct to do so) for those suicides that society has determined should be prevented, while providing MAID to those whom society has determined should be eligible.

Some Working Group members believe that society has already made certain judgments about how to respond to various requests for or attempts at self-directed death. For example, society may:

- limit a person's liberty to prevent harm to themselves or others due to a mental disorder (through the procedures allowed by mental health legislation in some jurisdictions);
- prohibit aiding, abetting, and counselling in regards to suicide (that does not meet the eligibility criteria for MAID);
- not interfere in or facilitate a person's suicide in cases where they are not a danger to self due to a mental disorder and do not meet the eligibility criteria for MAID;
- allow access to MAID where a person meets all the eligibility criteria in the federal legislation.

In the view of these Working Group members, society may shift its judgments related to self-directed death in the future. For example, society may decide to limit involuntary hospitalization of those who pose a danger to themselves due to a mental disorder to only those who lack decision-making capacity, or it may decide to require a finding of non-ambivalence for all refusals of life-sustaining treatment, or it may decide to change or remove one or more criteria for MAID eligibility.

4.2.3 Impact of Legalized MAID on Suicide Rates

There are some data on the impact of legalizing assisted dying on suicide rates, but none of this research focuses specifically on assisted dying for people with a mental disorder as their sole underlying medical condition. A 2015 regression analysis found "no evidence that PAS [physician-assisted suicide] is associated with reductions in the non-assisted suicide rate or with increases in the mean age of death for non-assisted suicide" (Jones & Paton, 2015). Furthermore, commenting on Jones and Paton (2015), Lowe and Downie (2017) note the evidence also shows "that non-assisted suicide rates were already changing in states with PAS before it was legalized, and that legalization had no effect"

on suicide rates in these jurisdictions. However, Jones and Paton (2015) only examined suicide rates in U.S. states that have legalized assisted dying, and none of these jurisdictions permit assisted dying for mental disorders.

In jurisdictions where psychiatric EAS is permitted, OECD data show that, on average, the non-assisted suicide rate decreased in the Benelux countries between 1990 and 2016 (OECD, 2018). More recently, the suicide rate has increased in the Netherlands since 2007, while remaining relatively stable in Belgium. Generally, suicide rates are decreasing worldwide (WHO, 2014a). There is no evidence of any association between the legal status of assisted dying in a country and its suicide rate: some jurisdictions where assisted dying is legal have higher suicide rates than jurisdictions where the practice is illegal, and vice-versa (OECD, 2018). Suicide rates in any given country are related to a multitude of factors.

4.3 VULNERABILITY AND AUTONOMY

As the Bill C-14 preamble states, protecting vulnerable people from ending their lives in a moment of weakness is an objective of the legislation (GC, 2016b). Another objective is to “[recognize] the autonomy of persons who have a grievous and irremediable medical condition that causes them enduring and intolerable suffering” (GC, 2016b). There is often a tension between respecting autonomy and protecting the vulnerable: permitting MAID MD-SUMC more broadly may recognize and respect the autonomy of people with mental disorders, but it may also increase the risk of harm to this potentially vulnerable population (see Chapter 6 for further discussion). Indeed, Canada has a history of denying autonomy to people with mental disorders and failing to respect their choices for their own protection. In the view of the Working Group, respecting the autonomy of people with mental disorders may be viewed through the lens of protecting vulnerable people overall.

4.3.1 Vulnerability

People with mental disorders are sometimes considered to be vulnerable, insofar as some have an increased risk of experiencing inequalities such as socio-economic hardship (e.g., poverty, housing instability), lack of social support, discrimination and stigma, violence and abuse, and disability (i.e., a reduced ability to defend or promote their own interests). Furthermore, the vulnerability of people with mental disorders is legally recognized in Canada, both in provincial and territorial Human Rights Codes and in the *Canadian Charter of Rights and Freedoms*, which explicitly prohibits discrimination on the basis of mental disability. Historically, broad practices introduced to protect vulnerable groups have been used to justify the exclusion of people with

decision-making capacity from participating in activities, such as biomedical research, which those same people may consider to be of personal or group benefit (Rhodes, 2005).

In Canada, the *Vulnerable Persons Standard* (VPS) was developed “by a body of advisors with expertise in medicine, ethics, law, public policy and needs of vulnerable persons” in response to the *Carter* decision, to “ensure that Canadians requesting assistance from physicians to end their life can do so without jeopardizing the lives of vulnerable persons who may be subject to coercion or abuse” (VPS, 2017). The VPS notes that extraneous factors, unrelated to their medical condition, may influence a vulnerable person’s decision-making.

Rooney *et al.* (2017) propose that the key vulnerability factor for psychiatric patients that is specifically relevant to MAID is the difficulty in determining whether such patients have the decision-making capacity to make the request. These authors argue that other factors that influence vulnerability, such as abuse, fraud, poverty, and violence, are equally applicable to patients with terminal illnesses as they are to psychiatric patients. While all people are initially presumed to have decision-making capacity in Canada, healthcare practitioners are required to conduct capacity assessments before a patient can qualify for MAID if they suspect that a person’s capacity might be impaired.

4.3.2 Autonomy

The concept of autonomy is fundamental to MAID MD-SUMC. Autonomy provides the basis for informed consent, and arguments for both permitting and prohibiting MAID MD-SUMC are based on the value of respecting the autonomy of people with mental disorders. However, the concept of autonomy is complex and can be defined in different ways. Traditionally, people are thought to be autonomous when they have the capacity for self-determination and the ability to make decisions according to their own values and beliefs, free from coercion and outside interference (Christman, 2018). A person who lacks autonomy is in some sense “controlled by others or incapable of deliberating or acting on the basis of his or her desires or plans” (Beauchamp & Childress, 2013).

In the *individualistic* view of autonomy, individuals are seen as independent decision-makers, and respecting their autonomy requires both non-interference in their decision-making and ensuring they have the necessary information to make an informed decision. Once relevant and desired information is available, individuals have the right to make a decision that accords with their own personal values, preferences, beliefs, and desires, without controlling interference or limitations that prevent meaningful individual choices (Beauchamp & Childress, 2013).

The individualist notion of autonomy has been challenged by critics who advocate a *relational* view of autonomy (Mackenzie & Stoljar, 1999; Sherwin, 2012). This view emphasizes that individuals are embedded in a network of social, political, and economic relationships with others, and that autonomy depends on such relationships (Hall, 2012). In this view, it is not the mere *ability* to make a decision that is important; rather “[a]utonomy becomes possible in social interactions through relationships” (Leckey, 2008).

[R]elational autonomy embraces (rather than ignores) the fact that persons are inherently socially, politically, and economically-situated beings. A relational approach to autonomy directs us to attend to the many and varied ways in which competing policy options affect the opportunities available to members of different social groups [...] and to make visible the ways in which the autonomy of some may come at the expense of others. Relational autonomy encourages us to see that there are many ways in which autonomy can be compromised. It allows us to see that sometimes autonomy is best promoted through social change rather than simply protecting individuals’ freedom to act within existing structures.

(Kenny *et al.*, 2010)

In some relational views, appropriate inclusion of family and healthcare practitioners during medical decisions is a way to foster — and not detract from — autonomy. Indeed, it has been argued that MAID, as an act that inevitably involves both patient and healthcare practitioners, and will implicate family and others, is an inherently relational act and, as such, should be conceptualized within the framework of relational, rather than individual, autonomy (Deschamps, 2016).

Further, relational views of autonomy emphasize not just the importance of interpersonal relationships in the provision of healthcare, but also the socio-political contexts in which healthcare is delivered. As noted in Chapter 3, there are long-standing inequities in access to resources for health and appropriate healthcare, particularly in the realm of mental healthcare. Conceptualizing autonomy as relational underscores the need to “better understand and deal with the complex socio-political climates in which health care is delivered and in which resources for health are embedded” (Rodney *et al.*, 2013). Furthermore, relational views of autonomy provide a framework for understanding how various social determinants of mental health (e.g., unstable housing, financial hardship, stigma and discrimination, as noted in Chapter 3) can affect the autonomy of people with mental disorders.

Some Working Group members expressed concerns about the impact of constrained choices on autonomous decision-making. They consider that, whereas the individualistic conception of autonomy emphasizes lack of outside interference, other conceptions of autonomy emphasize that no one can be truly autonomous if they are not supported socially, culturally, and economically (e.g., McLeod & Sherwin, 2000; Beaudry, 2018). These Working Group members state that this broader conception of autonomy demonstrates how a strictly subjective definition of irremediability of suffering (such as the one found in Bill C-14) could be discriminatory and disrespectful of someone's autonomy. Specifically, they believe that if an individual receives MAID because they cannot obtain resources (e.g., mental healthcare, social support) that society can provide, then that person is not being respected as autonomous. Rather, they are forced into a choice they do not truly wish to make, and as such the choice is not autonomous. For example, the plaintiff in the ongoing Foley case in Ontario (ONSC, 2018) claims he was offered MAID but was not provided with the option of self-directed management of homecare (Section 6.1.3). Moreover, these Working Group members believe that if the lack of resources is based on historical abuses or inequalities linked (for example) to gender, ethnicity, or disability, the lack of freedom of choice is especially discriminatory and damaging to the person's autonomy.

Other Working Group members believe that all decisions are made under conditions of constrained choice, and under variable social, cultural, and economic conditions. They expressed concern that characterizing the decisions of socially, culturally, or economically marginalized people as non-autonomous puts those people at risk of having their decisions disregarded or not invited in the first place. Further, these Working Group members believe that if the type of social, cultural, and/or economic supports required to satisfy others that a person's decisions meet some threshold of autonomy are unlikely to be provided, then characterizing that person's decisions as non-autonomous amounts to paternalism, compounding their marginalization and lack of freedom. In the view of these Working Group members, such treatment would be discriminatory and disrespectful of capable people's right to self-determination as they make do as best they can in an imperfect world. Further, these Working Group members believe that even if such choices are being withheld from people with a mental disorder in order to bring about positive social change (e.g., reducing social inequality, or increasing resources for mental healthcare), these people are nevertheless potentially being used to serve others' objectives. In the view of these Working Group members, a preferable approach would be one that seeks to maintain maximal freedom for the self-determination of capable people within constrained circumstances, while also seeking to remedy unjustified inequalities (Downie & Sherwin, 1996).

Autonomy and Mental Disorders

Whereas autonomy is often characterized by an absence of *external* interference, mental disorders can be understood as a kind of *internal* interference (Widdershoven & Abma, 2012). That is, pathological states of mind (e.g., depression, anxiety, delusion) can interfere with or distort a person's normal pattern of thoughts, feelings, and behaviour, potentially impairing their decision-making capacity or leaving them unable to reason rationally, perceive their situation clearly, or pursue their desires, preferences, and goals in accordance with their values. As Bolton and Banner (2012) put it, "a person's mental states and behavior, when mentally ill, may not be considered a true expression of themselves, but rather as expressions of the illness, and therefore as lacking autonomy in this sense." In short, a person whose decisions are controlled by their mental disorder is not autonomous.

For these reasons, it is difficult to know when a person's mental disorder may be interfering with their decision-making, or whether the decisions that they make reflect their beliefs, desires, values, and preferences. In some instances, protecting a person's autonomy might even require involuntary hospitalization and/or forced treatment to determine if they pose a danger to themselves or others. Such measures are predicated on the belief that the person is not currently behaving autonomously due to an ongoing episode of their mental disorder, which will abate with time and/or treatment. This amounts to protecting the autonomy of a person's future self from the non-autonomous decisions of their current self.

Similarly, in situations where involuntary hospitalization is not warranted (because the person does not pose a threat to themselves or others), respecting the autonomy of people with mental disorders might require more than simply doing whatever the patient desires. In a relational view of autonomy, the goal of good clinical practice is to help the patient develop their capability for autonomous decision-making. This is accomplished by engaging with the patient in a reciprocal dialogue, exploring the desires, values, and preferences of the patient, as well as helping them to examine, evaluate, and deliberate about those values and preferences in order to make an autonomous decision (Kim, 2010; Widdershoven & Abma, 2012).

4.3.3 Impact of Mental Disorders on Decision-Making

Fully assessing the impact of a mental disorder on a person's decision-making may demand a more thorough evaluation than that required to meet the legal standard for capacity. While the autonomous choices of a person whose decision-making capacity is intact must be respected, some have suggested

that “respecting and promoting patient self-determination requires more than simply doing whatever the patient wants, and to ensure that what the patient wants is what he truly desires” (Kim, 2010).

This suggestion is driven by the perceived professional responsibility of clinicians to consider the ways in which a mental disorder might be affecting a patient’s decision-making, even when that person has legal capacity. A clinician might consider a patient’s past decisions leading up to the request for MAID, such as the decision of whether or not to engage in treatment; the decision to isolate themselves socially; ambivalence, indecision and regret after suicide attempts; and so on. This is because mental disorders can significantly affect a person’s decision-making, even in cases where they have capacity. However, a capable person’s wishes cannot legally be overruled, even if a clinician believes they are not autonomous because a mental disorder has influenced their decision-making.

In addition to requiring that the patient have capacity, the law in the Benelux countries requires that a patient’s decision for EAS must be voluntary and well-considered (Gov. of Belgium, 2002; Gov. of the Netherlands, 2002; Gov. of Luxembourg, 2009). The Dutch RTE Code of Practice explains that the “well-considered” criterion requires that “the patient has given that matter careful consideration on the basis of adequate information and a clear understanding of his illness,” that the patient has not made the request on impulse, and that the patient’s request is consistent, “taking account of all the patient’s circumstances and utterances” (RTE, 2015b). In the case of patients with mental disorders, the RTE Code of Practice goes further, stating that the “well-considered” criterion also requires that “it must be ruled out that the patient’s psychiatric disorder has impaired his ability to form judgments” (RTE, 2015b).

In the Canadian context, there is no distinction made between having the capacity for a decision and the degree to which a decision is well-considered. It is possible that a patient with a mental disorder might be found to have the legal capacity to consent to MAID, and yet their decision would not be well-considered by the standards of the Benelux countries, due to the influence of that person’s mental disorder on their decision-making. How these criteria are implemented in the Benelux countries is discussed in Chapter 5, and their potential implications for the practice of MAID MD-SUMC in Canada is discussed in Chapter 6.

4.4 MENTAL HEALTHCARE AND TREATMENT

For many people with mental disorders, effective treatment can profoundly improve their quality of life (Ratnasingham *et al.*, 2012). However, there is also evidence that some conditions are difficult to treat. For example, a review of the literature of treatment-resistant depression found that despite trying multiple medications and other “more aggressive” treatment regimes, 15% of patients diagnosed with major depressive disorder continue to experience symptoms of depression, and about 20% of patients with depression experienced symptoms up to two years following a major depressive episode (Trevino, 2014).

Nevertheless, it is rare that a patient does not make any improvement with treatment. Symptom combinations tend to be complex, and some symptoms may improve while others may not. However, in the Working Group members’ clinical expertise, the most likely outcome is improvement in general. The question remains, however, whether this improvement relieves the patient’s suffering to the point where they no longer experience it as intolerable. For example, a patient may have improvement in their mood without improvement in their sleep, and still suffer due to their mental disorder.

A single mental disorder may have a number of symptoms and impacts. For instance, depression may affect sleep, energy, appetite, mood, one’s ability to think clearly, and one’s perception of the past and future (APA, 2013). This may have impacts on a person’s job performance, relationships, and ability to carry out parenting roles. Treatment of depression may include increasing the patient’s knowledge about the disorder (and the knowledge of their friends and family), evaluating and reducing the stressors in their life, psychotherapy, exercise, diet, medication, and/or couple or family therapy (APA, 2010). In some cases, deep brain stimulation or ECT may be recommended. Different treatments can have different impacts on the complex set of psychological, social, and biological factors that are linked to the persistence of depression. Treatment impact varies from person to person.

When left untreated, the course of a mental disorder varies for different mental disorders and for different people. Some mental disorders are characterized by a single episode followed by a complete remission of symptoms (APA, 2013), but courses vary even in disorders that can be chronic and persistent. For example, about 25% of people with schizophrenia experience a single episode that fully subsides, while the majority will have a lifelong condition with episodic relapses and remissions (Rosen & Garety, 2005). Variable outcomes are also found in severe depression and bipolar disorder (APA, 2013). In addition, some

conditions that have historically been considered to be lifelong problems, such as personality disorders, are now understood to improve over time in some people, or show significant fluctuations (Gunderson *et al.*, 2011).

4.4.1 Recovery-Oriented Practice

In 2012, the Mental Health Commission of Canada developed the *Mental Health Strategy for Canada*, which takes a *recovery-oriented* approach to the treatment of mental disorders. In this context, the term *recovery* refers to one's ability to live "a satisfying, hopeful, and contributing life, even when there are ongoing limitations caused by mental health problems and illnesses" (MHCC, 2012). The goal of recovery-oriented practice is to improve the quality of life for people with mental disorders and allow them to "engage in a life of meaning and purpose" (MHCC, 2012). The concept of recovery is not synonymous with cure, nor does it necessarily imply remission of symptoms or return to normal functioning (Jacobson & Greenley, 2001; Davidson & O'Connell, 2005; Davidson & Roe, 2007; MHCC, 2012).

One of the most influential recovery models is Europe's CHIME model (Leamy *et al.*, 2011). Built on a systematic review and narrative synthesis of personal recovery, CHIME stands for: Connectedness; Hope and optimism about the future; Identity; Meaning in life; and Empowerment. A 2011 systematic review and narrative synthesis of information obtained from minority ethnic groups in Europe identified similar themes of recovery, but placed additional emphasis on two particular aspects of recovery: spirituality and stigma. Moreover, this analysis identified two additional themes in recovery for minority ethnic groups, namely, "culture-specific factors and collectivist notions of recovery" (Leamy *et al.*, 2011).

Rather than focusing on symptom reduction or improved functioning with respect to treatment outcomes, clinicians in Canada increasingly include concepts of recovery such as CHIME when developing indicators. Advocates of recovery-oriented practice argue that recovery principles offer a valuable basis for how mental healthcare services should be developed and delivered. The recovery model is now "recognized as key to achieving better mental health outcomes and improving mental health systems" (MHCC, 2015, 2018), and most provinces and territories have begun to incorporate the model into their mental health policies, strategies, and planning documents (MHCC, 2015).

4.4.2 End-of-Life Treatment Preferences in People with Mental Disorders

Potentially useful insights about MAID MD-SUMC may be gained by considering end-of-life decision-making and treatment preferences in people with mental disorders. Research on this topic typically focuses on end-of-life decision-making in people with mental disorders who also have a co-morbid life-limiting physical illness. Thus, although this evidence does not examine people for whom a mental disorder is their sole underlying medical condition, it may nevertheless offer insight into a field that has considered the impacts of mental disorders on end-of-life preferences and clinical practice.

The American Psychiatric Association has developed a set of core principles for end-of-life care in psychiatry (APA, 2001). These principles have been described as recognizing “the rights of autonomy for people with palliative care needs who also suffer with mental health issues” (Webber, 2012). Nevertheless, researchers report that people with mental disorders may be marginalized from end-of-life decision-making for a number of reasons, including a presumption of incapacity, a concern that discussion of end-of-life issues could potentially be emotionally and/or cognitively destabilizing, a lack of knowledge or training about end-of-life care on the part of mental healthcare practitioners, and a lack of training or knowledge about mental disorders on the part of end-of-life healthcare practitioners (Foti, 2003; Foti *et al.*, 2005a; Woods *et al.*, 2008; Webber, 2012; Sweers *et al.*, 2013; Shaylev *et al.*, 2016). However, research demonstrates that people with mental disorders are emotionally and cognitively capable of discussing issues related to end-of-life decision-making without experiencing ongoing negative effects (Foti *et al.*, 2005b; Woods *et al.*, 2008; Sweers *et al.*, 2013; Elie *et al.*, 2017).

Two studies have compared the end-of-life treatment preferences in people with mental disorders to other populations. A 2005 study reported that people with a mental disorder were less likely to state they would discontinue certain intensive end-of-life treatments (e.g., artificial life support) as compared to the general population in other studies, although the results were similar to those expressed by certain racialized groups who experience healthcare disparities (Foti *et al.*, 2005a). Sweers *et al.* (2013) reported that end-of-life perspectives and expectations in people with schizophrenia were similar to those of the general population.

Three studies have found commonalities in end-of-life concerns between terminally ill people with and without a mental disorder, including the feeling that one is a financial or emotional burden on loved ones; desire to control

symptoms, pain and suffering; control over degree of treatment in order to avoid prolonging the dying process; and maintaining meaningful relationships with those close to them (Foti *et al.*, 2005b; Woods *et al.*, 2008; Webber, 2012).

MAID as an End-of-Life Preference in People with Mental Disorders

There is conflicting evidence about whether people with mental disorders are more or less likely to consider MAID in end-of-life situations. A 2005 study found that only 34% of patients with a mental disorder would want a physician to agree to a request to provide them with “enough medication to die by overdose” in a hypothetical scenario involving terminal cancer with terrible pain (Foti *et al.*, 2005a); however, some may not consider this to be equivalent to MAID MD-SUMC given that the mental disorder was not the sole underlying medical condition motivating the request. Similarly, Elie *et al.* (2017) found that when presented with a hypothetical scenario involving intractable pain or suffering, people with severe and persistent mental illness (SPMI) were 52% less likely to consider MAID than people with a chronic physical disorder. A majority (55%) of SPMI patients in the study rejected MAID as an end-of-life treatment option, and having an SPMI was found to be independently associated with decreased support for MAID (Elie *et al.*, 2017).

A 2001 study of depressed and non-depressed hospitalized older adults found that, compared to non-depressed peers, depressed patients were 13 times more likely to accept physician-assisted dying when considering their current situation (and twice as likely in hypothetical scenarios of terminal illness or coma) (Blank *et al.*, 2001). A 2011 systematic review that examined the association between depressive symptoms and requests for assisted dying found conflicting evidence among the studies examined, although it concluded that the strongest data “do not convincingly show that depression is more common in patients making a request for euthanasia/PAS than in the surrounding population of terminally or seriously ill patients” (Levene & Parker, 2011). However, nearly all of the studies reviewed concerned depressive symptoms in patients who requested EAS for a non-psychiatric terminal illness, not patients who requested EAS for a mental disorder that was their sole underlying medical condition. A more recent study by Elie *et al.* (2017) found no association between specific psychiatric symptoms and a preference for MAID.

The implications of these studies for people who might request MAID MD-SUMC and who are not currently eligible under the current law are not clear. These studies typically examine the preference for assisted dying in situations where a person with a mental disorder is suffering due to a physical condition or terminal illness that would likely qualify them as eligible under the current law, rather than situations where a person is requesting MAID MD-SUMC and would not be currently eligible.

4.4.3 Stability of Treatment Preferences in People with a Mental Disorder

The impact of a mental disorder on a person's decision-making can vary over time. This section examines the stability of treatment preferences in people with a mental disorder. The stability of a treatment preference, however, may not be a reliable indicator of the stability of a preference for MAID or a desire to die. Moreover, people with mental disorders may change their treatment wishes.

Patients who are treated for their mental disorder against their will usually agree that treatment was the best option once their symptoms improve (Owen *et al.*, 2009b; Tan *et al.*, 2010). There is relatively little research on the impact that mental disorders have on the stability of preferences for life-sustaining treatment. Most existing studies have examined the impact of psychiatric symptoms such as depression or anxiety on the stability of treatment preferences in people with a serious physical condition or in older patients, with varying results.

A systematic review by Auriemma *et al.* (2014) identified eight studies that examined the relationship between depression and stability of treatment preferences. Four of the studies found no association. Two studies found that an improvement in depressive symptoms was associated with an increased preference for life-sustaining treatment in at least some senior psychiatric patients with depression (Ganzini *et al.*, 1994; Eggar *et al.*, 2002). The two remaining studies both examined the impact of worsening depressive symptoms on treatment preferences, and had opposite findings. The first found that worsening symptoms of depression were associated with a decreased preference for life-sustaining treatment in patients with advanced, life-limiting physical disorders (Janssen *et al.*, 2012). The second found that worsening symptoms of depression were associated with an increased preference for life-sustaining treatment in senior primary care outpatients (Danis *et al.*, 1994).

Studies have examined the stability of a person's decision for psychiatric EAS in jurisdictions that permit it (Groenewoud *et al.*, 1997; Thienpont *et al.*, 2015). As discussed in more detail in Chapter 5, a 2015 analysis of 100 consecutive patients in Belgium who made a request for psychiatric EAS found that 49 withdrew their request before the procedure could be carried out (Thienpont *et al.*, 2015). Of those 49 people, 11 withdrew their request after it had been approved, whereas the other 38 withdrew their request while it was still pending — i.e., before it had been either approved or denied. Among these 38 patients, the reasons for withdrawing their request are not known. However, among the 11 patients who withdrew their request after it had been approved, 8 explained that knowing they had the option of assisted death “gave them sufficient peace of mind to

continue their lives,” 2 withdrew their request due to strong family resistance, and 1 was forced to withdraw because they were imprisoned (Thienpont *et al.*, 2015). See Chapters 5 and 6 for further discussion.

4.5 KNOWLEDGE GAPS

There is a need for better evidence on the validity of capacity assessment for people with mental disorders, particularly but not exclusively for people who request MAID MD-SUMC.

There is a lack of adequate evidence about the relationship among the severity of symptoms of a person’s mental disorder, their quality of life, and their desire for MAID.

It is unknown whether physicians who assess requests for psychiatric EAS in jurisdictions that permit it have difficulty distinguishing between autonomous, well-considered requests and pathological suicidal requests that are symptomatic of a mental disorder.

There is inadequate evidence on any links among voluntariness, external pressure, and MAID MD-SUMC requests. There is also a need for better evidence on any links among voluntariness, paternalism, and denials of eligibility with respect to MAID MD-SUMC.

5

Assisted Dying for People with Mental Disorders Worldwide

- Why Look to International Evidence on MAID MD-SUMC?
- The International Legal Landscape
- Sources and Quality of Evidence Relating to Psychiatric EAS
- Psychiatric EAS: Frequency and Trends in the Netherlands and Belgium
- Characteristics of Individuals Who Request/Receive Psychiatric EAS
- Evaluation of Patients Requesting Psychiatric EAS
- How Psychiatric EAS is Monitored in the Netherlands and Belgium
- Implications of the International Data

5 Assisted Dying for People with Mental Disorders Worldwide

Key Findings

About two decades of Dutch and Belgian experience offers evidence on MAID MD-SUMC. Interpreting these data for Canada should take into account differences in cultures, geographies, demographics, healthcare, and legal and regulatory structures, but also commonalities in relative wealth, medical/scientific concepts and literature, democratic ideals, and views on human rights (Section 5.1).

In the Netherlands and Belgium, psychiatric euthanasia and assisted suicide (psychiatric EAS), excluding dementia, represent approximately 1 to 2% of all EAS cases (40 of 2,309 Belgian EAS cases and 83 of 6,585 Dutch EAS cases in 2017). The number of psychiatric EAS cases have been increasing in recent years in the Netherlands (Section 5.4).

There is a wide diversity of psychiatric conditions found among those who request psychiatric EAS in the Netherlands and Belgium, but the highest number of requests come from individuals with depression. Other conditions underlying requests include personality disorders, schizophrenia and other psychotic disorders, post-traumatic stress disorder and anxiety disorders, eating disorders, autism, and prolonged grief disorder (Section 5.5).

In the Netherlands and Belgium, more than twice as many women than men seek and receive psychiatric EAS, in contrast to all EAS cases, where the proportion of men and women is roughly equal (Section 5.5). The reasons for the difference are unclear but may be due to women having a higher prevalence of those psychiatric conditions that more frequently lead to psychiatric EAS requests, which in turn may be due to their greater exposure to social and economic inequalities.

Psychiatric EAS remains controversial even in jurisdictions that have permitted it for many years, and public debate is ongoing (Section 5.2).

Social isolation and loneliness occur in about half of the people who request psychiatric EAS in the Netherlands (Section 5.5).

The research on psychiatric EAS in the Netherlands and Belgium shows: that physicians disagreed about patients' eligibility for psychiatric EAS in 24% of Dutch cases; and, 38% of Belgians requesting psychiatric EAS withdrew their requests before a decision

continued on next page

was reached, 11% postponed or cancelled the procedure after their request was accepted, and 57% of those who initially requested psychiatric EAS were alive one to four years later (Section 5.6).

There has been an increase in the number of psychiatric EAS cases performed by a clinic that specializes in providing EAS to individuals whose physicians have declined their request in the Netherlands. Cases from this clinic are overrepresented among those deemed by review committees as not having met legal due care criteria (Section 5.4).

Note on terminology: most references and reporting statistics from the Benelux countries (Belgium, the Netherlands, and Luxembourg) use their legal terms *euthanasia* and *physician-assisted suicide*; therefore, the acronym *EAS* is used in this chapter, as is the term *psychiatric EAS* to refer to MAID where psychiatric illness (the term used in place of mental disorder in these jurisdictions) is the cause of suffering.

5.1 WHY LOOK TO INTERNATIONAL EVIDENCE ON MAID MD-SUMC?

Since MAID MD-SUMC is not common in Canada, direct Canadian evidence on its impact has not been published. As there are countries where it is permitted, those experiences may provide insights about potential impacts and possible safeguards. The Benelux countries allow people to seek EAS based on physical or mental suffering alone, with no requirement of terminal illness or foreseeable death. Switzerland and Germany also forego a “terminal illness” or “foreseeable death” criterion, and requests can be based on physical or mental suffering, but only assisted suicide is permitted in these jurisdictions. Thus, the legal measures and clinical experiences in Belgium and the Netherlands — where most permitted euthanasia and assisted suicide deaths for psychiatric conditions (i.e., psychiatric EAS) have occurred — may provide important insights about potential impacts and possible safeguards. These observations may also help inform policy-makers about whether to leave unchanged, prohibit, or permit more MAID MD-SUMC in Canada.

Aside from some sparse statistics indicating that psychiatric EAS is rare, relatively little evidence is available from Switzerland; no cases of psychiatric EAS have been reported in Luxembourg. There is one report from Germany describing patients who received EAS from a German right-to-die organization; some of those were psychiatric EAS (Bruns *et al.*, 2016). However, the law in Germany prohibits commercial organizations from assisting in suicides (Gov. of Germany, 2015).

Although the Working Group also reviewed information from jurisdictions that have restricted assisted dying to those at end of life (including Quebec, some U.S. states, and Victoria, Australia) and from those currently debating assisted dying (e.g., United Kingdom), no evidence related to the practice of MAID MD-SUMC exists in those jurisdictions.

5.1.1 Uses and Limits of International Data on Psychiatric EAS

The best available evidence for MAID MD-SUMC comes from Belgium and the Netherlands. Nevertheless, the differences and similarities between the Benelux countries and Canada must be taken into account in assessing the implications of this evidence.

Canada is less densely populated than Belgium or the Netherlands, with different governance structures and legal traditions. It has a more multicultural population, a greater diversity of religions, multiple orders of government involved in the governance and delivery of healthcare, and Indigenous Peoples whose views must be considered and whom must be consulted during the development of legislation. On the other hand, Canada, Belgium, and the Netherlands are all wealthy countries, with similar GDP per capita, and they share a common medical vocabulary based on the same scientific framework, evidence base, diagnostic schemes, and treatment modalities.

While the Working Group was not tasked with reviewing the mental health or legal systems in Belgium and the Netherlands, or these systems' relationship to the practice of psychiatric EAS, Working Group members do note that striking differences exist among jurisdictions. They also note the importance of avoiding either an uncritical extrapolation or a dismissal of Benelux data, but rather to consider each potential impact and safeguard in light of specific differences and commonalities among jurisdictions, including differences in social background and cultural context. For example, most people in Belgium, compared to Canada, are in closer reach of mental healthcare given the country's higher population density. Thus, requiring expert psychiatric treatment and evaluation prior to psychiatric EAS may be less of a barrier in Belgium than it might be in Canada. In Canada, which is less densely populated and has greater disparities in healthcare access, that same safeguard may be more necessary to avoid errors should MAID MD-SUMC become more widely available.

5.2 THE INTERNATIONAL LEGAL LANDSCAPE

5.2.1 Legal Background

The Netherlands

Although the *Termination of Life on Request and Assisted Suicide (Review Procedures) Act* was introduced in 2002 (Gov. of the Netherlands, 2002), in practice EAS had been accepted in the Netherlands for decades prior to the 2002 Act (Rietjens *et al.*, 2009). As explained by Rietjens *et al.* (2009), the law “officially legalized euthanasia, but in effect it mainly legalized an existing practice” that was already legally protected through prior court decisions. There was also broad public support for legal EAS (general EAS, not psychiatric EAS specifically) by the time the Act was passed (Cohen *et al.*, 2006). Therefore, there was minimal debate about the legalization of EAS compared to some other countries at the time of legislation because there was existing case law (e.g., Griffiths, 1995). In 1994, case law established that EAS for mental suffering is permissible (Griffiths, 1995).

The Act legally protects the practice of EAS when a physician has complied with the Act’s due care criteria. The due care criteria encompass both eligibility criteria and procedural safeguards. Section 2(1) of the Act outlines the due care criteria, and, as translated in the RTE Code of Practice, states that “the physician must:

- (a) [b]e satisfied that the patient’s request is voluntary and well-considered;
- (b) be satisfied that the patient’s suffering is unbearable, with no prospect of improvement;
- (c) have informed the patient about his/her situation and prognosis;
- (d) have come to the conclusion, together with the patient, that there is no reasonable alternative in the patient’s situation;
- (e) have consulted at least one other, independent physician, who must see the patient and give a written opinion on whether the due care criteria set out in (a) to (d) have been fulfilled;
- (f) have exercised due medical care and attention in terminating the patient’s life or assisting in his suicide.”

(RTE, 2015b)

There are also reporting requirements in the Netherlands, whereby the physician must inform the RTEs after the fact about an EAS (Gov. of the Netherlands, 2002). The RTEs release an annual summary report of EAS cases. The RTEs are unique among jurisdictions in publishing reports of EAS cases they consider particularly instructive or controversial.

Belgium

While Belgium does not have the same history of EAS as the Netherlands, “prosecutions were unusual and, generally speaking, the practice of euthanasia was tolerated” by 2002 (Cohen-Almagor, 2009). Public acceptance of EAS, as measured by a survey of the Belgian public ranking their acceptance of EAS from 1 to 10 (1 meaning EAS was “never justified,” and 10 meaning it was “always justified”), was fairly high prior to the passing of their law, having increased by 69% between 1981 (when the mean surveyed acceptance rate of EAS was 3.5) and 1999 (when the mean surveyed acceptance rate of EAS was 6.0), as calculated by the percentage difference in mean survey acceptance rates on a scale of 1 to 10 (Cohen *et al.*, 2006).

The Belgian Act on Euthanasia (2002) contains eligibility criteria and procedural safeguards that must be followed when EAS is to be performed, and, similar to the Dutch Act, has always included suffering of either a physical or mental nature as grounds for an EAS request (Gov. of Belgium, 2002). With respect to eligibility requirements, the Belgian law states that physicians who carry out EAS are not committing a crime, provided they ensure that:

- “the patient has attained the age of majority or is an emancipated minor, and is legally competent and conscious at the moment of making the request;
- the request is voluntary, well-considered and repeated, and is not the result of any external pressure;
- the patient is in a medically futile condition of constant and unbearable physical or mental suffering that can not be alleviated, resulting from a serious and incurable disorder caused by illness or accident”¹⁸ with no reasonable treatment alternatives or therapeutic perspectives.

(Gov. of Belgium, 2002).

Procedural safeguards include the consultation of a physician, independent from the physician initially evaluating the request, about the serious and incurable nature of the condition (Gov. of Belgium, 2002). In cases where death is not foreseeable:

- a third physician (second consultant), who is an expert in the disorder in question, is required to consult; and,
- a one-month waiting period between the written request and the act of EAS is required.

(Gov. of Belgium, 2002)

As in the Netherlands, the physician reports the EAS after the fact, to a retrospective review committee (Gov. of Belgium, 2002).

¹⁸ Unofficial translation.

Luxembourg

Luxembourg modelled its EAS Act largely on the Belgian Act (Nys, 2017). The eligibility requirements for EAS are the same in Belgium and Luxembourg. However, the procedural safeguards in the Belgian Act that apply when a patient's death is not foreseeable were not adopted in the Luxembourg Act (i.e., a third expert consultation and one-month waiting period between request and EAS) (Gov. of Luxembourg, 2009).

Luxembourg also has reporting requirements. Every time a physician performs EAS, an official declaration document must be obtained from the Commission Nationale de Contrôle et d'Evaluation (CNCE), completed by the physician, and sent back to the CNCE for review (Gov. of Luxembourg, 2009). The CNCE is legislated to publish a statistical report on the information collected from the declarations every two years.

Switzerland

In Switzerland, the law allows for assisted suicide (not euthanasia) if the person assisting does so for unselfish reasons (Gov. of Switzerland, 1942).

The 2006 Swiss *Haas* case involved a person who suffered from bipolar affective disorder for about 20 years and who had twice previously attempted suicide (European Court of Human Rights, 2011). Haas petitioned the Swiss government to allow assisted suicide on the basis of his mental disorder (European Court of Human Rights, 2011). The Swiss Federal Supreme Court held that it was not against the law to provide a lethal prescription to people with mental disorders, provided certain eligibility criteria were met. These additional eligibility criteria included a thorough psychiatric evaluation with a specialist to establish whether the decision is "autonomous and all-encompassing," such that:

- the patient has capacity;
- the request does not stem from a treatable condition; and
- the request is made without undue influence.

(Black, 2012, 2014)

Germany

Similar to Switzerland, as of 2015, German law allows for assisted suicide (not euthanasia) if the person assisting does not do so with a commercial intent (Gov. of Germany, 2015). Close relatives or other people close to the person seeking an assisted death are exempt from criminal liability (Gov. of Germany, 2015).

5.2.2 Laws and Guidelines for Psychiatric EAS in Benelux Countries and Switzerland

Benelux Countries

The eligibility criteria, procedural safeguards, and reporting requirements that must be met by a physician in the Benelux countries for psychiatric EAS are summarized in Table 5.1.

The Dutch Act contains few details on the actual procedures that patients and physicians should follow when dealing with an EAS request; the Dutch RTEs have therefore published a Code of Practice to help patients and physicians request and carry out EAS in a manner that complies with the Act (RTE, 2015b). The Code of Practice is a “summary of the considerations that the committees have published in their annual reports and findings in recent years” (RTE, 2015b). The Dutch Psychiatric Association (Nederlandse Vereniging voor Psychiatrie, or NVVP) has published and revised guidelines on the role of psychiatrists who receive EAS requests from patients with psychiatric disorders (Berghmans *et al.*, 2009). The Flemish Association for Psychiatry (Vlaamse Vereniging voor Psychiatrie, or VVP) also recently published guidelines (VVP, 2017); however, these are not included in Table 5.1 as it is unclear how these Belgian guidelines will influence clinical practice going forward. Before the release of these guidelines, Belgian psychiatrists looked to the NVVP guidelines. Although the guidelines suggested by the RTE Code of Practice and the NVVP are not official laws, they are included in Table 5.1 as a separate column, as they can inform RTE deliberations (Onwuteaka-Philipsen *et al.*, 2017).

While consultation with an additional physician (or physicians) is a safeguard in Benelux countries, confirmation or agreement with the requesting physician is not. The consultation procedural safeguard involves the consulting physician seeing the patient and giving a written statement of judgment on whether the person making the request meets eligibility requirements (RTE, 2015b). The Dutch consultant’s written report is provided to the RTE (RTE, 2015b); the Belgian consultant’s opinion is conveyed through the report of the physician performing the EAS (Gov. of Belgium, 2002). As explained below, while the Dutch RTEs publish instructive or controversial cases (e.g., they published all psychiatric EAS cases reported in 2013) (RTE, 2014), the Belgian Commission fédérale de Contrôle et d’Évaluation de l’Euthanasie (CFCEE) does not make any of their cases public, even in anonymized form.

Table 5.1**Stipulations for Psychiatric EAS in the Netherlands, Belgium, and Luxembourg**

Stipulation	Country			
	Netherlands	Suggested by RTE or NVVP	Belgium	Luxembourg
Required by Law	Required by Law	Required by Law	Required by Law	Required by Law
Request must be voluntary and well considered	X	(X)	X	X
Physician must be satisfied that patient's suffering is unbearable, with no prospect for improvement	X	(X)	X	X
Physician must inform patient about situation, prognosis	X	(X)	X	X
Physician must have come to the conclusion, along with the patient, that there is no reasonable alternative	X	(X)	X	
Unless the patient objects, the physician must discuss the request with the patient's representative and/or family members			X	X
Patient's case must be assessed by independent consulting physician	X	X*	X*	X
Consultant must be an expert in the disorder or disease causing suffering		X	X	
One-month waiting period between request and EAS when death is not imminent			X	
EAS deaths must be reported to an oversight committee	X	(X)	X	X
Statistical data and information on implementation are regularly reviewed and reported publicly (annually or biannually)	X	(X)	X	X

Source: Gov. of the Netherlands, 2002; Gov. of Belgium, 2002; Berghmans *et al.*, 2009; Gov. of Luxembourg, 2009; RTE, 2015b, 2016

Bolded stipulations relate directly to cases where the patient's death is not foreseeable (for countries that rely on this criterion). Brackets indicate that these criteria are already part of the Dutch law. Acronyms in table: euthanasia and assisted suicide (EAS), Nederlandse Vereniging voor Psychiatrie (NVVP), and Regional Euthanasia Review Committees (RTE).

* If death is not foreseeable in Belgium, two additional independent physicians who are experts in the disorder must be consulted. Only one consulting physician is required in the Netherlands and Luxembourg by law, although the Dutch RTE Code of Practice recommends consulting a regular, independent physician, as well as an independent psychiatrist for psychiatric EAS requests.

To help consulting physicians, both the Netherlands and Belgium have established specialized support services (Van Wesemael *et al.*, 2009a). The Royal Dutch Medical Association (KNMG) trains a cohort of physician-consultants through the Support and Consultation on Euthanasia in the Netherlands (SCEN) program (Brinkman-Stoppelenburg *et al.*, 2014). In Belgium, the Life End Information Forum (LEIF) was established in 2003 to help physicians deal with EAS requests (Van Wesemael *et al.*, 2009a; Van Wesemael *et al.*, 2009b). Unlike the Dutch SCEN, which was founded by the KNMG, LEIF was founded by “individual professionals with experience in palliative care and the association Right to Die with Dignity” (Van Wesemael *et al.*, 2009a).

While differing in organizational structure, regulation, and origins, as well as in mandate (LEIF has a broader consultation role by providing information on all end-of-life care), both SCEN and LEIF require the same number of training hours for physicians (approximately 23 hours) (Van Wesemael *et al.*, 2009a).

Switzerland

In Switzerland, two main groups serve people who request assisted suicide: EXIT and DIGNITAS (other right-to-die groups include Lifecircle/Eternal Spirit). These groups have additional requirements above those set out in legislation. For example, EXIT requires that those requesting assisted suicide whose sole underlying medical condition is a mental disorder have a hopeless prognosis, or have unbearable symptoms, or have unacceptable disabilities (EXIT, 2016); the individual requesting an assisted suicide judges what is unacceptable, along with two independent expert opinions and the verdict of the Society’s Ethics Commission (EXIT, 2016). DIGNITAS, which accepts both Swiss and non-Swiss cases, requires that, as a prerequisite for the preparation of an assisted suicide, the person “must have a disease that will lead to death, and/or [have] an unendurable incapacitating disability, and/or [be] in unbearable and uncontrollable pain” (DIGNITAS, 2017).

5.2.3 Practitioner and Public Opinions on Psychiatric EAS in the Netherlands

A 2010 Dutch survey revealed wide support for the eligibility criteria and procedural safeguards for EAS in general among physicians (n=793), nurses (n=1,243), and the public (n=1,960) (Kouwenhoven *et al.*, 2012). Specifically, 88% of physicians, 77% of nurses, and 64% of the public agreed with the requirement of a patient request, and 71% of physicians, 64% of nurses, and 48% of the public agreed with the absence of a requirement about life expectancy. There was less support for psychiatric EAS (which in the survey included early dementia cases) — 35 to 36% of healthcare practitioners and 28% of the public found EAS for chronic depression acceptable. In the case of severe dementia, 33% of physicians, 58% of nurses, and 77% of the public approved

of performing EAS based on an advance directive (for further discussion, see *The State of Knowledge on Advance Requests for Medical Assistance in Dying*) (Kouwenhoven *et al.*, 2012). Another survey of Dutch physicians (n=1,456) found that 34% could conceive of granting psychiatric EAS in general, 40% for patients with early-stage dementia, and 29 to 33% for patients with advanced dementia (Bolt *et al.*, 2015).

The Third Review of the Dutch Act (*Derde evaluatie — Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding*) surveyed 500 psychiatrists about their experiences with, and views on, psychiatric EAS requests, and 207 responded (Onwuteaka-Philipsen *et al.*, 2017). Thirty-two percent (66 of 207 respondents) had previously granted and/or refused a request for psychiatric EAS. These 66 respondents were asked additional questions about the last request they had granted or refused. The percentage of psychiatrists who had not performed EAS but would conceivably do so decreased from 47% in 1995 to 37% in 2016. Of those who had never performed EAS in 2016, 63% thought it inconceivable that they would ever perform EAS, and, out of this 63%, 3% would not refer a request to another doctor. Of the psychiatrists who thought it was inconceivable they would perform EAS, 4% were in favour of a general prohibition of EAS, and 7% were in favour of prohibiting psychiatric EAS. When surveyed about their reason not to perform EAS in the last request they evaluated (n=66), 75% stated the primary reason was that due care requirements were not met (Onwuteaka-Philipsen *et al.*, 2017).

These data are similar to a recent Canadian survey of psychiatrists (n=528), which found that 72% supported MAID, at least for some situations, while 29% supported MAID MD-SUMC (Rousseau *et al.*, 2017).

Dutch psychiatrists were also asked about arguments that support permitting or prohibiting psychiatric EAS (Onwuteaka-Philipsen *et al.*, 2017). Arguments psychiatrists mentioned that support psychiatric EAS included: it is unfair to exclude this group when it is possible they fulfil the due care criteria; psychiatric suffering might be worse than somatic suffering; the right to self-determination; offering a dignified end of life to patients who otherwise might die by suicide; and the conviction that seriously considering a request for EAS is part of the responsibility of a physician. Arguments psychiatrists mentioned that support prohibiting psychiatric EAS included: the risk of countertransference (a therapist transferring emotions to a patient in therapy); conflicts between treatment goals and termination of life; interpretation of due care requirements in people with psychiatric disorders, including doubts about the extent to which the request of a psychiatric patient can be voluntary and well-considered; and the question of whether one should consider granting an EAS request when the quality of mental healthcare is not sufficient (Onwuteaka-Philipsen *et al.*, 2017).

The Third Review of the Dutch Act also discussed EAS for people with dementia. In a survey of Dutch citizens, 60% agreed that people with dementia should qualify for EAS, 24% were neutral, and 16% disagreed (Onwuteaka-Philipsen *et al.*, 2017). Physicians were also surveyed about the conceivability that they would perform EAS for early dementia (i.e., where the patient has capacity); in 2016, 52% of general practitioners (n=607), 25% of medical specialists (n=331), and 53% of geriatricians (n=209) could conceive of providing EAS for early dementia.

5.2.4 Practitioner and Public Opinion on Psychiatric EAS in Belgium

A Belgian survey of psychiatric nurses (n=627) showed that 84% support EAS for people with psychiatric disorders (including dementia) who experience unbearable mental suffering (De Hert *et al.*, 2015). There are, however, no Belgian survey data relating to the views of physicians and the public. The VVP states that it is currently impossible to obtain a consensus from their member psychiatrists as to whether psychiatric EAS should be permissible, as members were strongly divided (VVP, 2017).

5.3 SOURCES AND QUALITY OF EVIDENCE RELATING TO PSYCHIATRIC EAS

In Belgium and the Netherlands, psychiatric EAS cases comprise a small proportion (0.5 to 3%, depending on the year) of the total number of EAS cases, but are becoming more frequent (Dierickx *et al.*, 2017; RTE, 2017b). With respect to EAS deaths overall in Belgium and the Netherlands, there are two primary sources of statistics. First, the CFCEE in Belgium and the RTEs in the Netherlands (both review bodies) publish reports; the RTEs also publish summaries of selected cases. Second, estimates of the total cases are published in periodic studies (approximately every five to six years), conducted by independent researchers commissioned by the government in the Netherlands and supported by a federal research funding agency in Flanders (the Dutch-speaking region of Belgium; no similar studies are done in the French-speaking region). These studies also contain excerpts that are published in major international journals (e.g., Champaere *et al.*, 2015; van der Heide *et al.*, 2017). Flanders and the Netherlands have shown an increase in the overall rate of EAS since 2002, accounting for 1 in about 25 deaths (4.5% in the Netherlands in 2015, and 4.6% in Flanders in 2013) (Champaere *et al.*, 2015; van der Heide *et al.*, 2017).

In Luxembourg, 34 EAS cases were declared between 2009 and 2014, of which none were psychiatric EAS, but 6 cases involved people with neurodegenerative disorders (CNCE, 2015). In Switzerland, psychiatric EAS does occur but only limited data are available, since only cases with depression as the sole underlying

medical condition are reported. Given that data are not available for the entirety of psychiatric EAS practices in these jurisdictions, this chapter will focus on Belgium and the Netherlands.

5.3.1 Sources of Evidence Specific to Psychiatric EAS

Most of the data on psychiatric EAS in Belgium come from three sources. The first is a study of 100 consecutive requests for psychiatric EAS reported by a research group (Thienpont *et al.*, 2015). The 35 cases of psychiatric EAS that were carried out (from a total of 100 requests) mentioned in Thienpont *et al.* (2015) likely represent a substantial proportion of the cases of psychiatric EAS between 2007 and 2011 in Belgium, although the CFCEE does not provide specific data on psychiatric EAS during this period (but the classification of *neuropsychiatric disorders* which include psychiatric EAS cases, and those stemming from neurodegenerative disorders, did not exceed 100 cases for the same time period) (Claes *et al.*, 2015). The group also published a qualitative analysis of testimonials written by 26 of these patients (Verhofstadt *et al.*, 2017). The second source, Dierickx *et al.* (2017), published a summary of psychiatric and dementia cases from 2002 to 2013; they used official data from the CFCEE database. The third source is made up of Flemish studies that also provide some disorder-specific information (e.g., Dierickx *et al.*, 2015).

In the Netherlands, in addition to the every-five-year national studies — two of which survey Dutch psychiatrists (Groenewoud *et al.*, 1997; Onwuteaka-Philipsen *et al.*, 2017) — and resulting papers, the RTEs make public the case summaries of those they deem educational or controversial. Much of what we now know about psychiatric EAS at the patient level comes from these reports.

Summaries of many Dutch psychiatric EAS cases have been published. As a result, Kim *et al.* (2016) were able to analyze 78% (66 of 85 cases) of all known cases from 2011 to early 2014.¹⁹ These case summaries may contain much more information than the physicians' written reports because, in controversial practices such as psychiatric EAS, the RTEs may conduct follow-up interviews with the involved physicians (thus, some reports can be 12 to 13 single-spaced pages, though many are approximately 2 to 3 pages) (RTE, 2017b). These case summaries are based on reports written around the time of the EAS, compared to surveys of psychiatrists in national studies, which require recollection of events that sometimes occurred years before. According to the RTEs, "the joint

19 In early 2014, for the years 2011 to 2014, there were 85 reported cases of psychiatric EAS mentioned on the RTE website (<https://www.euthanasiecommissie.nl/oordelen/>): 13 cases in 2011, 14 in 2012, 42 in 2013, and 16 in 2014 (the final number for that year was not available at the time). Sixty-six of those cases were published online.

annual reports of the [RTEs] and the findings published on their website give an impression of how the committees apply and interpret the statutory due care criteria for euthanasia” (RTE, 2015b).

The Working Group notes that there are limitations associated with conclusions from the RTE case studies. Case summaries are comprised of reports submitted by the physician associated with the EAS, request as well as RTEs’ follow-up communications with them (written feedback as well as face-to-face interviews in some cases), and therefore may not include all details of how the physician evaluated the due care criteria.

5.3.2 Jurisdictions Not Discussed in Detail Due to Limited Data

In addition to Belgium and the Netherlands, psychiatric EAS has occurred in Germany and Switzerland. In Germany, a recent case series of 117 assisted deaths from 2010 to 2013 performed by Sterbehilfe Deutschland (Euthanasia Germany) showed that 17 people (15%) “had a predominant psychiatric diagnosis,” and 9 people (8%) had no mental disorder or medical condition; 83 cases (71%) involved women (Bruns *et al.*, 2016).

In Switzerland, among 43 cases of assisted suicide performed by EXIT in the Basel region, 6 people had a psychiatric diagnosis (mainly depression) (Frei *et al.*, 1999; Frei *et al.*, 2001). Among 331 EXIT cases in the Canton of Zurich, 9 people (2.7%) had depression or schizophrenia between 1990 and 2000 (Bosshard *et al.*, 2003). Gauthier *et al.* (2015) found 14 cases (1.5%) of non-Swiss residents with a mental disorder receiving assisted suicide in the Canton of Zurich from 2008 to 2012. More recent data indicate that depression was reported as the underlying disease in 3% of assisted suicide cases among Swiss residents from 2010 to 2014 (0.8% of cases reported dementia), with no other psychiatric conditions being identified in the report (FSO, 2014).

5.4 PSYCHIATRIC EAS: FREQUENCY AND TRENDS IN THE NETHERLANDS AND BELGIUM

In the annual Dutch RTE reports and the Belgium CFCEE reports, EAS cases are described by the nature of the disease that causes suffering; the categories *psychiatric disorders* and *dementia* are both used. As the Working Group chose to use the DSM-5 definition of *mental disorders* in this report, the categories *psychiatric disorders* and *dementia* are both considered in this section. However, the focus of much of the international evidence presented in the remainder of this chapter is on psychiatric EAS cases involving people diagnosed with psychiatric disorders excluding dementia (hereafter the use of *psychiatric EAS* refers to requests and cases not stemming from dementia, unless otherwise noted).

The reason for this is two-fold. Most of the published academic studies that have analyzed these data have focused principally on the cases classified under *psychiatric disorders* (e.g., Thienpont *et al.*, 2015; Kim *et al.*, 2016). Additionally, some of the international dementia cases would not be classified as MAID MD-SUMC, since those requesting EAS did not have capacity (these types of cases are discussed in *The State of Knowledge on Advance Requests for Medical Assistance in Dying*).

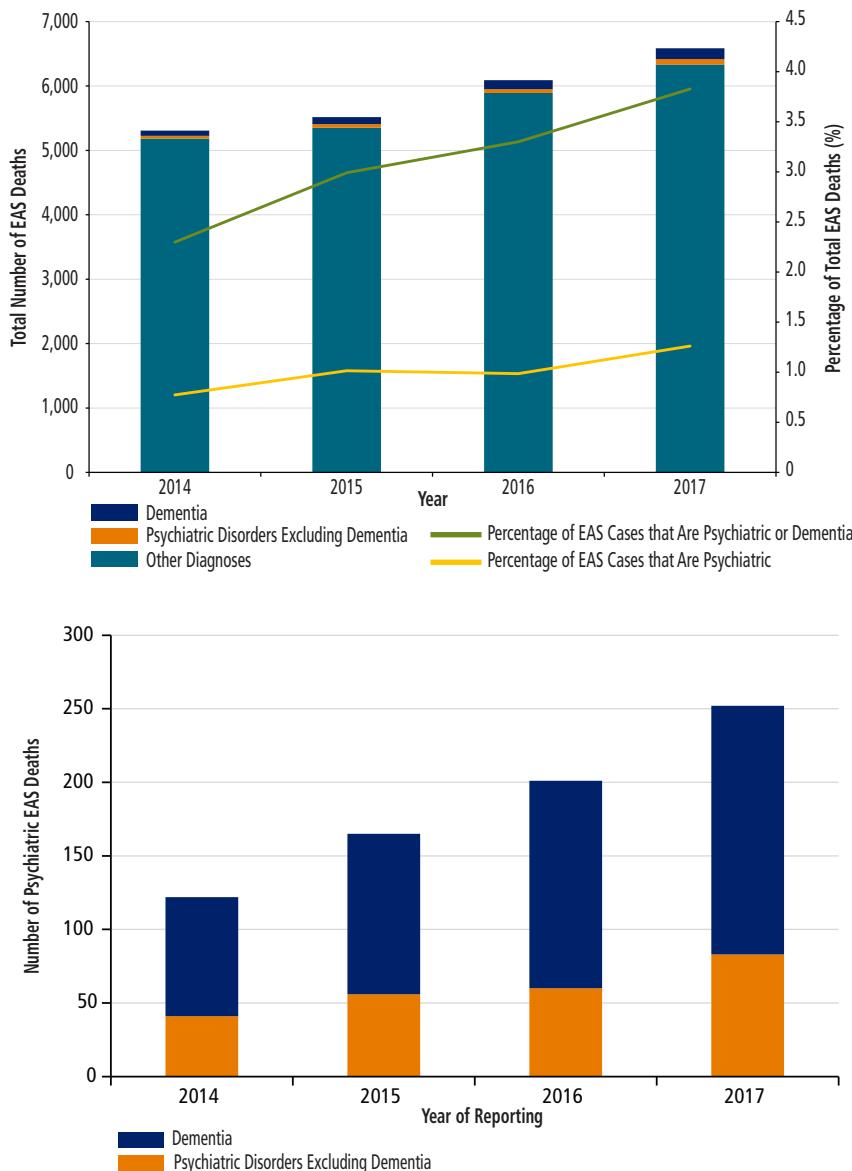
In the Netherlands, some of the cases categorized as *psychiatric disorders* or *dementia* also involved an underlying physical disorder. In these cases, however, the suffering was judged to be mainly due to psychiatric disorder(s) or dementia (RTE, 2017b).

5.4.1 The Netherlands

In the 1990s, psychiatric EAS was rare. It was estimated to occur 2 to 5 times per year in 1995, accounting for 0.1 to 0.3% of all EAS cases; the total number of reported EAS cases in 1995 was 1,463 (Groenewoud *et al.*, 1997; Rurup *et al.*, 2008). This continued until about 2011, after which the rate began to rise so that, by 2017, psychiatric disorders accounted for about 1% of the total number of EAS deaths (RTE, 2018a). In terms of number of requests, Dutch physicians received an estimated 320 psychiatric EAS requests in 1995, with 2 to 5 cases performed that year (approximately 0.6 to 1.5% acceptance rate); in 2008 there were approximately 500 requests and 30 cases of psychiatric EAS performed (approximately 6% acceptance rate); and in 2016 there were approximately 1,100 requests and 60 cases of psychiatric EAS performed (approximately 5% acceptance rate) (Onwuteaka-Philipsen *et al.*, 2017).

The number of psychiatric EAS cases (n=83) increased to 1.2% of all EAS cases in 2017, from 0.77% in 2014 (n=41) (RTE, 2018a) (Figure 5.1). When dementia cases are also included (n=169),²⁰ together the two categories comprise 3.8% of all EAS cases, increasing from 2.3% in 2014 (n=122) (RTE, 2018a) (Figure 5.1).

²⁰ In 2017, the Dutch RTEs began including two dementia reporting categories: *dementia in the initial phase*, and *farther advanced dementia*. For comparison with past years, these data were grouped and termed *dementia* for this report.



Data Source: RTE, 2015a, 2016, 2017b, 2018a

Figure 5.1

Reported EAS Cases in the Netherlands, 2014 to 2017

Each year EAS cases are reported to RTEs in the Netherlands, and published in annual reports. In 2017, RTEs began including two dementia reporting categories; *dementia in the initial phase*, and *farther advanced dementia*. For comparison with past years, these data were grouped and termed *dementia* for this report.

5.4.2 Belgium

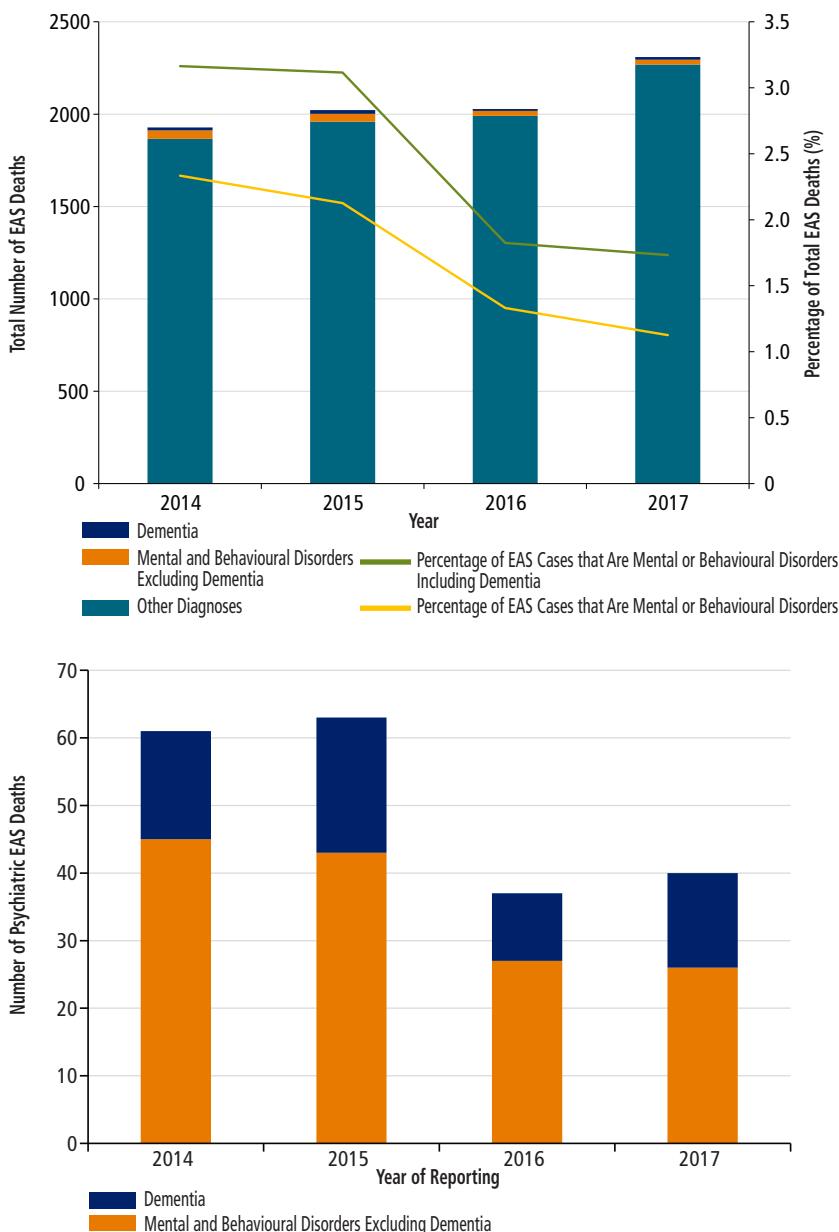
There were 6 reported cases that identified neuropsychiatric conditions (“affection neuropsychiatrique”) as the underlying medical condition in Belgium in 2004 (2.0% of all EAS cases), increasing to 40 cases identifying mental and behavioural disorders as the underlying medical condition (of which 14 of these cases were dementia) in 2017 (1.7% of all EAS cases) (CFCEE, 2006, 2018a). Between 2014 and 2017, both the total number and percentage of all EAS cases that were psychiatric, including dementia, decreased (Figure 5.2). The number of mental and behavioural disorder EAS cases, excluding dementia ($n=26$), decreased to 1.1% of all EAS cases in 2017, from 2.3% in 2014 ($n=45$) (CFCEE, 2018a) (Figure 5.2). When dementia cases are also included ($n=40$), together the two categories comprise 1.7% of all EAS cases in 2017, decreasing from 3.2% in 2014 ($n=61$) (CFCEE, 2018a) (Figure 5.2).

In a chronological study of reported Belgian psychiatric EAS cases from 2002 to 2013 by Dierickx *et al.* (2017), one or more psychiatric disorders were the cause of suffering in 117 requests. Over the 11-year range, this number rises to 179 requests if dementia cases are included. Of these 179, diagnoses included mood disorders ($n=83$), dementia ($n=62$), as well as mood disorders accompanied by another psychiatric disorder ($n=12$); 77% of the 117 psychiatric disorder cases ($n=88$), and 58% ($n=36$) of the dementia cases involved women (Dierickx *et al.*, 2017).

5.4.3 Increase in Psychiatric EAS Cases in the Netherlands and Belgium

In the Netherlands, there has been an increase through time in both the number of psychiatric EAS cases (excluding dementia), as well as the percentage of total EAS deaths comprising psychiatric cases (excluding dementia) (Figure 5.1) (Chabot, 2017; RTE, 2018a). In Belgium, while the total yearly number of psychiatric EAS cases (excluding dementia) has increased since 2004, in recent years (2014 to 2017) both the number and percentage of total EAS deaths comprising psychiatric cases (excluding dementia) has decreased (Figure 5.2) (CFCEE, 2018a; Dierickx *et al.*, 2017).

**The State of Knowledge on Medical Assistance in Dying
Where a Mental Disorder Is the Sole Underlying Medical Condition**



Data Source: CFCEE, 2018a

Figure 5.2

Reported EAS Cases in Belgium, 2014 to 2017

Each year EAS cases are reported to the CFCEE in Belgium, and published in reports every two years.

The overall increase in the total number of psychiatric EAS cases (excluding dementia) since 2002 has stimulated discussion (Claes *et al.*, 2015; Dierickx *et al.*, 2015, 2016; Chabot, 2017; Dierickx *et al.*, 2017). This increase may reflect a normal process of change, by which certain groups (both patients and their physicians) explore and adapt to new legal options. For example, a gradual increase was observed for other types of EAS cases after the introduction of the *Belgian Act on Euthanasia*: patients with a diagnosis of cardiovascular disease, those with a college or university education (Dierickx *et al.*, 2015), non-terminally ill patients (Dierickx *et al.*, 2016), and older patients (Dierickx *et al.*, 2015, 2016) all increasingly sought EAS. Some have argued that part of the increase may be due to the media reporting of noteworthy cases of psychiatric EAS (including individuals with dementia), such as the death of Hugo Claus, who had early-stage Alzheimer's (Van Brussel & Carpentier, 2012). In Belgium, reported cases of people who were not expected to die in the near future increased, from 8.1% (n=19) of all EAS cases in 2003 to 14.7% (n=266) in 2013 (Dierickx *et al.*, 2016). In the Netherlands, however, this explanation does not account for the increase in psychiatric EAS occurring later than the increases in other types of EAS. All types of EAS had been legally permitted since 2002, although in practice EAS had been accepted for decades prior, and psychiatric EAS accepted since the 1994 Chabot case.

5.4.4 The Increasing Role of the End-of-Life Clinic

In the Netherlands, there has been an increase in psychiatric EAS cases performed by the End-of-Life Clinic (Levenseindekliniek), an organization that does not treat patients for illnesses but whose mission is to evaluate and provide EAS to those whose doctors have declined to perform the procedure (Box 5.1). The number of EAS cases the End-of-Life Clinic performs is published in the annual RTE reports and by the Clinic itself. In 2015, 60% of Dutch psychiatric EAS cases were performed by this clinic, and in 2016, 75% (46 out of 60 cases) (Chabot, 2017). In contrast, the Clinic performs approximately 5 to 8% of the total number of EAS cases in the country (RTE, 2015a, 2016, 2017b).

Box 5.1
End-of-Life Clinic

In the Netherlands, the End-of-Life Clinic (Levenseindekliniek) was established in 2012 by the country's leading euthanasia advocacy organization to assess, and if the case qualified, provide EAS to people whose request was initially denied by their own physician (Levenseindekliniek, n.d.-b). As a result, physicians offering EAS through the Clinic are always new to the patient.

The Clinic is subject to the same legal criteria as all other Dutch EAS providers, and as such all requests are evaluated to see whether they meet due care criteria. The evaluation, as described by Snijdewind *et al.* (2015), proceeds as follows: "When authorized by the patient, the clinic obtains the medical files from the treating physician or physicians. On the basis of the application form and medical files, a nurse makes a first classification. Some applications are rejected. A mobile team, consisting of a nurse and physician working for the clinic, further assesses the others [...] If a case is further assessed, the mobile team contacts the treating physician to discuss their reasons for rejecting the request and visits the patient (most often multiple times). In this stage, a case can be rejected if it seems unable to meet the due care criteria. If the mobile team decides that the due care criteria can be met, a physician from [SCEN] specifically trained to give independent consultations about requests for [EAS] is consulted, as is required by Dutch law. A meeting then follows with the mobile team, another physician working for the clinic, and a lawyer. If all those participating in the meeting agree that the due care criteria can be met, a request for [EAS] is granted. During the entire process, the patient can withdraw his or her request at any time."

One-third of all applicants to the Clinic are psychiatric patients (Levenseindekliniek, n.d.-a). In its first year of operation, 5% of EAS requests (6 of 121) from individuals with a psychiatric condition were granted (Snijdewind *et al.*, 2015).

5.5 CHARACTERISTICS OF INDIVIDUALS WHO REQUEST/RECEIVE PSYCHIATRIC EAS

5.5.1 The Netherlands

More than Twice as many Women than Men Receive Psychiatric EAS

A review of 66 Dutch psychiatric EAS case summaries from 2011 to early 2014, representing 78% of all psychiatric EAS cases reported during that period,²¹ found that people receiving EAS for psychiatric disorders were mostly women (70%, n=46), of diverse ages, and with complex as well as chronic psychiatric and medical histories (Kim *et al.*, 2016). The gender disparity in psychiatric EAS cases contrasts with the ratio of 43% women to 57% men among all EAS recipients in the Netherlands (Onwuteaka-Philipsen *et al.*, 2012). This finding of a preponderance of women in psychiatric EAS cases is consistent with previous studies from the Netherlands (Groenewoud *et al.*, 1997; Groenewoud *et al.*, 2004).

A Wide Diversity of Conditions Qualify for Psychiatric EAS

The wide diversity of psychiatric disorders cited in these psychiatric EAS cases is notable. Some people had a chronic psychotic disorder (with active hallucinations and delusions) while others had a more recently diagnosed condition: one patient received EAS 12 months after her husband’s death, for prolonged grief disorder. A consultant reported that this woman felt her life had no meaning after her husband’s death and yet “did not feel depressed at all. She ate, drank, and slept well. She followed the news and undertook activities” (Kim *et al.*, 2016).

Depressive disorders were the primary psychiatric condition presenting in 36 of 66 cases (55%) (Kim *et al.*, 2016). Psychotic disorders were not unusual, with 17 of 66 (26%) people having some form of psychotic condition (schizophrenia, schizoaffective disorder, psychotic depression, and other psychotic disorders). PTSD-related and other anxiety disorders were prominent (28 of 66 people, or 42%). Four people (3%) had cognitive impairment — one of whom had a legal guardian at the time of their EAS (but was judged “competent” by two independent consultants, including one psychiatrist). Four women (3%) had chronic eating disorders with borderline personality disorders. Two people had autism spectrum diagnoses and two had prolonged grief. Fifty-two percent had personality-related problems (34 of 66). Fifty-two percent had attempted suicide in the past (34 of 66), and 80% had been hospitalized at some point during their life (53 of 66). Social isolation or loneliness were mentioned in 56% of cases (37 of 66) (Kim *et al.*, 2016).

²¹ From 2011 to early 2014, there were 85 reported cases of psychiatric EAS mentioned on the RTE website (<https://www.euthanasiecommissie.nl/oordelen/>): 13 cases in 2011, 14 in 2012, 42 in 2013, and 16 in early 2014 (the final number for that year was not available at that time). Sixty-six of those cases were published online.

In a study of the first year of the End-of-Life Clinic's operation that compared granted (n=162) and rejected requests (n=300), individuals who had their requests rejected were more often single (58%) than married or living together (20%), or widowed (21%) (Snijdewind *et al.*, 2015). Individuals who had their requests rejected were also more often childless (50%), than those who had one child (13%) or more than one child (37%). Note that this study included all requests received, not just those for psychiatric EAS (Snijdewind *et al.*, 2015).

Based on data from the 1996 national Dutch study, Groenewoud *et al.* (1997) found that mood disorders were common diagnoses associated with psychiatric EAS requests; 64% of the sampled requests received by psychiatrists had diagnoses of a personality disorder (130 of 202 people), and approximately 2 to 5 psychiatric EAS cases were granted per year out of approximately 320 requests per year from psychiatric practice. More recently, data from a 2016 survey of Dutch psychiatrists showed they received approximately 1,100 requests for EAS from psychiatric patients, of which an estimated 60 were granted (Onwuteaka-Philipsen *et al.*, 2017). In 2016, psychiatrists reported they received on average roughly one EAS request per year each. Among refused psychiatric EAS requests (n=66), 59% had a personality disorder diagnosis, 50% had an affective disorder, 17% had a psychotic disorder, and 9% were diagnosed with autism spectrum disorder (patients could have more than one diagnosis) (Onwuteaka-Philipsen *et al.*, 2017).

Age

In 2017, within the dementia and psychiatric disorders categories (reported together in the latest data release), the highest number of psychiatric EAS cases, including dementia, reported to the RTEs involved people 80 to 90 years old (n=63) and 50 to 60 years old (n=16) (RTE, 2018a).

5.5.2 Belgium

Belgian Findings Are Similar to the Netherlands

In the most recent CFCEE report covering EAS cases from 2014 to 2017, 36% of psychiatric EAS cases (73 of 201) involved individuals identified as having mood disorders (e.g., depression, bipolar disorder), 30% (60 of 201) involved individuals with dementia, and 3.8% (23 of 201) involved individuals with personality disorders (CFCEE, 2018a). In a Belgian case series of 100 consecutive requests for psychiatric EAS, 58 individuals (58%) presented with “treatment-resistant depression” (48 with major depressive disorder and 10 with bipolar disorder), 14 with schizophrenia or other psychotic disorders, 13 with PTSD, 11 with anxiety disorders, 10 with eating disorders, 10 with substance use disorders, 9 with somatoform disorders, 7 with Asperger syndrome (with potentially 12 additional cases after follow-up psychiatric evaluations),

1 with attention deficit hyperactivity disorder, 7 with obsessive compulsive disorders, 7 with dissociative disorders, and 6 with complicated grief, among others (some had more than one disorder) (Thienpont *et al.*, 2015). Fifty percent of those making a request had personality disorders (Thienpont *et al.*, 2015). A similar diversity of conditions was seen in the Netherlands (Kim *et al.*, 2016).

Across 100 consecutive Belgian requests for psychiatric EAS, the majority (77%) came from women (Thienpont *et al.*, 2015), which is consistent with the Dierickx *et al.* (2017) study of cases reported in the CFCEE database from 2002 to 2013. However, with respect to dementia cases in Belgium, the gender of those requesting was more balanced; 58% of cases involved women (Dierickx *et al.*, 2017). The most recent CFCEE report did not provide gendered data relating to psychiatric EAS requests, but, in 2017, the ratio of women to men requesting all EAS was roughly equal: 51% of requests were from men (n=1,175) and 49% of requests were from women (n=1,134) (CFCEE, 2018a).

Of the 100 people included in the Thienpont *et al.* (2015) study, 26 provided written testimonies to their doctors, which were qualitatively analyzed (Verhofstadt *et al.*, 2017). Themes related to a patient's suffering were identified and included lack of hope of getting better given previous treatment failures, feeling like "there's nothing left to work on" in therapy, and no quality of life (Verhofstadt *et al.*, 2017). Some patients explained why, after receiving approval for EAS, they changed their minds: "[T]he people around you cannot believe that you want to die, because you're looking so good [...] So when I finally got the permission to die, that was a huge relief [...] I have to admit that since [the approval], I'm experiencing better moments and I'm also in doubt now" (Verhofstadt *et al.*, 2017).

Other themes included lack or loss of social supports or understanding from important others; mourning over the death of important others; solitude or loneliness because of a lack of social support from society in general; socio-economic problems including lack of financial resources; and low income (Verhofstadt *et al.*, 2017), raising questions about whether socio-economic supports might alleviate suffering in some cases.

In 2017, within the psychiatric disorders (excluding dementia) category, the highest number of psychiatric EAS cases reported to the CFCEE involved people 60 to 69 years old (n=6), 40 to 49 years old (n=5), and 50 to 59 years old (n=5) (CFCEE, 2018a). From 2014 to 2017, the highest number of psychiatric EAS cases (excluding dementia) reported to the CFCEE involved people 50 to 59 years old (n=36), out of a total of 141 reported cases during that period (CFCEE, 2018a).

In 2017, the highest number of psychiatric EAS cases for dementia reported to the CFCEE involved people aged 80 to 89 years old (n=8) (CFCEE, 2018a). From 2014 to 2017, the largest number of psychiatric EAS cases reported to the CFCEE for dementia involved people aged 80 to 89 years old (n=29), out of a total of 60 reported cases during that period (CFCEE, 2018a).

5.6 EVALUATION OF PATIENTS REQUESTING PSYCHIATRIC EAS

5.6.1 The Netherlands

In 2017, there were 83 psychiatric EAS cases (excluding dementia) in the Netherlands (RTE, 2018a). The physician granting EAS was a psychiatrist in 43% of these cases (n=36), a general practitioner in 27% (n=22), a geriatric specialist in 7.2% (n=6), and another type of doctor (e.g., a doctor training to be a psychiatrist) in 23% (n=19). The breakdown of reporting physicians was not provided for dementia EAS cases (RTE, 2018a).

Unbearable Suffering

This criterion is recognized in the Dutch literature as being difficult to define and apply (Dees *et al.*, 2009; Pasman *et al.*, 2009; van Tol *et al.*, 2010) and is “the most debated requirement for due care” (Onwuteaka-Philipsen *et al.*, 2007 as cited in Pasman *et al.*, 2009). Consistent with the priority placed on a patient’s subjective interpretation of what constitutes unbearable suffering, as noted above, there is a wide range of descriptions of suffering. Some patients had chronic, severe, difficult-to-treat depression and had undergone repeated ECT treatments; two patients had received deep brain stimulation (a surgical intervention) (Kim *et al.*, 2016). Two-thirds of patients had psychiatric histories of more than 10 years (Kim *et al.*, 2016). Others, such as the woman with prolonged grief disorder (Section 5.5.1), received EAS for a disorder lasting 12 months (see below).

A recent study of nine EAS cases from 2012 to 2016 involving people with intellectual disabilities or autism spectrum disorder points to the challenges in applying the Dutch suffering criterion using a medical model of disability. “Difficulties arise when the suffering, or the fact that the suffering cannot be relieved, is related to the nature of autism spectrum disorder or intellectual disability itself — as was the case for those who were highly dependent, had difficulties with social functioning, difficulties in coping with social circumstances, or a tendency not to cooperate with treatments” (Tuffrey-Wijne *et al.*, 2018).

In a 2016 survey of Dutch psychiatrists, respondents considered the lack of hopelessness or unbearable suffering an important reason to refuse the request in 25% of the 66 refused psychiatric EAS requests (Onwuteaka-Philipsen *et al.*, 2017). Of all Dutch psychiatrists surveyed (n=207), 70% disagreed (18% were neutral, 12% agreed) with the statement “it is impossible to assess whether a psychiatric patient’s suffering is unbearable and hopeless”²² (Onwuteaka-Philipsen *et al.*, 2017).

No Prospect of Improvement and No Reasonable Alternative

The Dutch EAS law requires that the patient’s unbearable suffering must also have no prospect of improvement and that there is no reasonable alternative to EAS, as determined by the patient and the doctor together (Gov. of the Netherlands, 2002). In cases of psychiatric EAS, Kim *et al.* (2016) reported that most patients had extensive treatment histories with long-standing disorders, and 56% (37 of 66) had refused at least some treatment. The most common reasons were lack of motivation (n=18), concern about harmful side effects (n=12), and doubt about efficacy (n=10). Twenty percent (n=13) of patients did not have a history of inpatient treatment. Depressive disorders were the primary condition in 55% of cases (36 of 66), 39% (26 of 66) had received ECT (the primary treatment for severe, refractory depression), and 11% (7 of 66) had tried an MAO inhibitor (an established drug for treatment-resistant depression, as mentioned in the NVP guidelines) (Kim *et al.*, 2016). Based on data from the 1996 national Dutch study, Groenewoud *et al.* (1997) found that, among those making a request for psychiatric EAS, 64% (129 of 202) had refused remaining treatment options (medication, psychotherapy, electroconvulsive therapy, and inpatient or day-treatment).

There is one example in the Netherlands of someone accessing psychiatric EAS for prolonged grief (RTE, 2012). A woman between 70 and 80 years old received psychiatric EAS for prolonged grief 12 months after the death of her husband (RTE, 2012). Some Working Group members feel that having a request for EAS accepted on the basis of this disorder after 12 months of symptoms was surprising because the disorder itself is not well understood. Other Working Group members disagree that it was surprising. The DSM-5 lists Persistent Complex Bereavement-Related Disorder under “Conditions for Further Study;” it requires 12 months of symptoms for the diagnosis in adults (APA, 2015), and may not be well understood (Prigerson & Maciejewski, 2017;

²² Unofficial translation.

Reynolds *et al.*, 2017). The RTE deemed this case to meet the “no reasonable alternative” criterion, after consultation with a SCEN doctor and another independent psychiatrist:

The patient was experiencing serious psychological suffering in reaction to what was an irremediable and disastrous situation for her, accompanied by symptoms of reactive depression that stemmed from a complex prolonged grieving process. It is the opinion of the committee that her suffering is of a medical nature. The patient had tried both medication and intensive counselling as part of the bereavement process. Neither type of treatment had any effect at all. Given this fact, the reporting doctor and the independent doctors consulted concluded that there was just a small chance that the life situation of the patient would improve enough for her to find life bearable. As such, the committee is of the view that the unbearable suffering of the patient without any prospect of improvement is supported by sufficient reasoning.²³

(RTE, 2012)

The RTE’s judgment accepted the following interpretation of futility used by one of the consultants: “[I]t is never possible to be certain if pathological grief will disappear when time passes, but due to the intensity of the grief a year after the loved one died, the limited social network, and the persisting wish of the patient to no longer live without her husband, recovery seemed less likely” (RTE, 2012).²⁴ Some Working Group members believe that such an interpretation of futility sets a low bar on what qualifies as futile to treat, while other Working Group members disagree.

The study by Kim *et al.* (2016) also found that physicians disagreed about the results of evaluating patients for various eligibility criteria in 24% of cases (16 of 66); 81% of disagreements (13 of 16) were about judgments of the futility of treatment. In the 1996 national study, 11% (7 of 62) of psychiatric EAS cases involved people whose psychiatric consultants had determined they had a treatable psychiatric disorder (Groenewoud *et al.*, 1997). The 1996 study also found that, among 202 psychiatric EAS requests, psychiatrists reported that 63% of people (128 of 202) were still living; 35% (70 of 202) no longer wished to die, 18% (37 of 202) still persistently asked for EAS, and 10% (21 of 202) still asked for EAS but less persistently. In 2% of the requests (4 of 202), EAS was performed by the responding psychiatrist, another physician performed EAS in 3% of cases (6 of 202), 5% (10 of 202) died from natural causes, and 16% (32 of 202) died by suicide (Groenewoud *et al.*, 1997).

²³ Unofficial translation.

²⁴ Unofficial translation.

In the 2016 survey of Dutch psychiatrists, respondents indicated that the availability of alternative treatment(s) was an important reason to refuse the request in 53% of the 66 refused psychiatric EAS requests (Onwuteaka-Philipsen *et al.*, 2017). Of all Dutch psychiatrists surveyed (n=207), 56% agreed (22% were neutral, 22% disagreed) with the statement “that a psychiatrist, when deciding whether or not to grant a request, need not take account of the solely theoretical possibility that an effective therapeutic treatment might become available in future” (Onwuteaka-Philipsen *et al.*, 2017).²⁵

Capacity Assessment

The NVVP states that:

[I]n principle, each [due care] requirement must be met. However, the committee sees scope for allowing a small margin in specific cases. This will require the interrelationship of each of the requirements to be examined. This applies primarily to the criterion of the unbearable nature of the suffering, the most subjective criterion and the one that is most difficult to establish objectively. A situation is possible where one of the requirements will not have been met in full, but the patient's suffering is so evidently unbearable that the healthcare practitioner is nevertheless able to rely on duress in the sense that he or she was acting out of necessity.

For instance, a psychiatrist may feel that the situation he or she is dealing with is one of particularly urgent necessity if the patient is in an unbearable, inhumane situation with no prospect of improvement (for example, in the case of very lengthy use of segregation or forced feeding) and clearly and repeatedly requests assistance with suicide. If the request is convincing, understandable and palpable, a departure from the guidelines could be regarded as unjustified on the basis of a strict standard of decisional competence, for example, because the patient may also be harbouring psychotic motives. In the committee's view, there should be scope for assisted suicide in such cases.²⁶

(Berghmans *et al.*, 2009)

Therefore, according to the NVVP, there may be situations where people do not meet a high standard of decisional competence, yet still should be permitted to received EAS (Berghmans *et al.*, 2009). Doernberg *et al.* (2016) argue that the normative stance, the lack of a high level of scrutiny, and

25 Unofficial translation.

26 Unofficial translation.

the relatively low threshold used by physicians are areas of concern for the practice of psychiatric EAS in the Netherlands. This could be particularly problematic, as some psychiatric disorders associated with psychiatric EAS requests — including schizophrenia, cognitive impairment, eating disorders, and severe depression — raise the risk of incapacity (Section 4.1.1).

According to the RTEs' definition, "decisional competence means that the patient is able to understand relevant information about his situation and prognosis, consider any alternatives and assess the implications of his decision" (RTE, 2015b). This definition, which refers to the patient's ability to understand and appreciate relevant information, is quite similar in content to Canadian criteria for capacity discussed in Section 4.1.1. In Belgium, the person must be competent and conscious at the time of making the request (Gov. of Belgium, 2002).

Doernberg *et al.* (2016) argue that their study of 66 Dutch psychiatric EAS case report summaries from 2011 to 2014 shows that, even in complex psychiatric cases, the physicians involved (and the RTE reviewing them) did not seem to use a high level of scrutiny nor require a high threshold for capacity. In 55% (36 of 66) of cases, the reports contained assertions about judgments relating to global capacity (e.g., "the patient was mentally competent"), without any reference to specific capacity criteria (such as the ability to understand, appreciate, or reason), even in, for example, patients with schizophrenia who may have prominent psychotic symptoms, or patients with psychotic depression. In such complicated cases of people at risk for incapacity, the authors note, "more explicit discussion of how such patients were able to meet the various capacity-specific criteria, despite their symptoms, would be expected" (Doernberg *et al.*, 2016). In 32% (21 of 66) of cases, the physicians provided further evidence regarding capacity-specific abilities, such as "perfectly able to indicate what were the pros and cons to her of the alternatives offered, thus it was assessed that she was able to weigh information" (Doernberg *et al.*, 2016). In the view of Doernberg *et al.* (2016), some of these explanations indicate a low threshold was used. For example, a physician said "in general" the patient was competent despite noting their ability to "use information in a rational way was doubtful" (Doernberg *et al.*, 2016). Overall, considerable weight was placed on a patient's ability to communicate a stable choice, which was present in all 66 cases. In 12% (8 of 66) of cases, the primary physician and consulting physician disagreed about a patient's capacity to consent to EAS, and the RTE generally accepted without comment the judgment of the primary EAS performing physician, even in cases where the physicians chose to follow generalists' opinions over specialists' opinions (Doernberg *et al.*, 2016).

It should be noted that this study was based on RTEs' summaries of the reports submitted by the physician, as well as on the RTEs' follow-up communications with physicians (written feedback or face-to-face interviews in some cases). There is a question whether high-threshold evaluations were generally performed, but details were not included in the RTE case reports. Doernberg *et al.* (2016) argues that this is unlikely, given that, in a third of the cases (often where people did not have major risk factors for incapacity), the reports include physicians' criteria-based reasoning; further, it is assumed that the RTE would not omit supporting evidence in more complex cases as the reports can be quite detailed. There were also cases in which physicians explicitly said that a person's ability (e.g., to use information in a rational way) was lacking but still found the person competent — with the RTE accepting this reasoning (Doernberg *et al.*, 2016).

In contrast, Rooney *et al.* (2017) state that “[RTE case reports] are summary documents meant to encourage discussion, not grounds for accurate generalizations about medical practice,” and note that they are plain-language reports that might not contain technical details.

A recent detailed analysis of nine cases of EAS from 2012 to 2016 involving people with intellectual disabilities or autism spectrum disorder echoed the findings of Doernberg *et al.* (2016): “In the reported case summaries, it appears that the bar [for capacity] is not set high” (Tuffrey-Wijne *et al.*, 2018).

In a 2016 survey of Dutch psychiatrists, respondents who had previously granted and/or refused psychiatric EAS requests (66 of 207 respondents) answered detailed questions about the last time they had refused a request for psychiatric EAS (Onwuteaka-Philipsen *et al.*, 2017). Eight respondents (12%) indicated that the main reason they declined the request for EAS was that it was not voluntary and well-considered. All of the psychiatrists who were sent the survey were asked about the NVVP guidelines concerning requests for psychiatric EAS from people with reduced “decisional competence” (Berghmans *et al.*, 2009) (see above quote at the start of this section). Of the 207 psychiatrists who completed the survey, 82% disagreed with the statement: “[i]n the case of chronic psychiatric patients less demanding requirements need to be set for the decisional competence requirement,”²⁷ and 18% agreed a lower threshold may be acceptable in some cases (Onwuteaka-Philipsen *et al.*, 2017). Some Working Group members observe that the majority of Dutch psychiatrists (63%) would not perform psychiatric EAS (Onwuteaka-Philipsen *et al.*, 2017) and hypothesize that these psychiatrists may be unlikely to support the use of

27 Unofficial translation.

a low degree of scrutiny or a low threshold for capacity assessments in the EAS context. In addition, these Working Group members believe that psychiatrists who do not agree with the need for high scrutiny or a high threshold for capacity may be more likely to be involved in psychiatric EAS. Other Working Group members believe that, while this survey sheds light on the attitudes of Dutch psychiatrists, it does not provide any evidence that a high level of scrutiny or high threshold for capacity are not used in practice.

Consultations

Dutch law does not require unanimity among consultants prior to providing EAS (approval does not require more than one consultant), and in general, the decision on whether to proceed lies with the responsible physician (i.e., the physician performing EAS). While consultation with other physicians was widespread, one in nine cases had no independent psychiatric input (7 of 66), contrary to NVVP guidelines or the general recommendation of the RTE. In 18 cases (27%), the physician performing EAS was new to the patient, and in 14 of these 18 cases, physicians were from the End-of-Life Clinic (Box 5.1). Disagreement among physicians about patient eligibility occurred in 24% (16 of 66) of cases (Kim *et al.*, 2016). Cases of psychiatric EAS in which psychiatric consultants “explicitly had advised against” EAS were reported as early as the 1996 national study (Groenewoud *et al.*, 2004). That study also noted that 19% (13 cases) of psychiatric EAS were carried out “despite the consultant’s judgment that transference (i.e., patient’s redirected emotions from a past figure onto the physician) and countertransference (i.e., the physician’s emotional reaction to the patient) had influenced the decision-making.” In a paper focused on nine EAS cases involving people with intellectual disabilities and/or autism spectrum disorder, Tuffrey-Wijne *et al.* (2018) note that the involvement of specialists (i.e., with expertise in intellectual disabilities) in the evaluation of such cases is rare (it occurred in one of nine cases).

Rate of Psychiatric EAS Approval in the Netherlands

A 1996 survey of psychiatrists (as part of an early national study) showed that about 10% (20 cases) of psychiatric EAS requests were approved (Groenewoud *et al.*, 2004), 35% of people (70 cases) no longer wished to end their lives, 16% of people (32 cases) ended their lives without assistance from a physician, and 5% of people (10 cases) died of natural causes. The remainder still requested EAS, but the exact effective approval rate was not clear (Groenewoud *et al.*, 1997). The every-five-year Dutch national study used data collected through physician surveys on refused requests. Therefore, data is available about the number of physicians refusing requests, and why (i.e., whether they felt the cases met the due care criteria); however, the total number of refused requests is not known (Onwuteaka-Philipsen *et al.*, 2017).

Snijdewind *et al.* (2015) reviewed the End-of-Life Clinic's first year of operation and found that, based on registration materials (provided by patients and their families), 121 requests were received from those with psychiatric conditions. Of those 121 psychiatric EAS requests, 5.0% were granted (6 of 121), 74% were rejected (89 of 122), the patient died before a decision was reached in 7.4% cases (9 of 121), and the request was withdrawn in 14% of cases (17 of 122).

The most recent national study, The Third Review of the Dutch Act, asked 207 psychiatrists about their experiences with psychiatric EAS (Onwuteaka-Philipsen *et al.*, 2017). Dutch psychiatrists received approximately 1,100 requests for EAS from psychiatric patients in 2016, of which an estimated 60 (5%) were granted (Onwuteaka-Philipsen *et al.*, 2017). In the same survey, 10 psychiatrists answered questions about the last time they granted an express request for EAS from a patient with a psychiatric disorder. The patients who had their requests refused were more often female, were younger on average (59.5 years), were more likely to have a personality disorder, and were less likely to have a secondary physical disorder. When psychiatrists were asked to compare the differences between the express requests they had accepted and past requests they had refused, they found that fewer of the refused patients were assessed as having decisional competence, and that a lower percentage of those with refused requests were regarded as being capable of making a voluntary and well-considered request. Treatment options were also deemed available in the case of refused requests, whereas this was not so for granted requests (Onwuteaka-Philipsen *et al.*, 2017).

5.6.2 Belgium

Unbearable Suffering

Thienpont *et al.* (2015) state that “the concept of ‘unbearable suffering’ has not yet been defined adequately, and that views on this concept are in a state of flux.” Nevertheless, they describe the 100 consecutive people requesting psychiatric EAS as follows: “in all patients, the suffering was chronic, constant and unbearable, without prospect of improvement, due to treatment resistance” (Thienpont *et al.*, 2015). A related study qualitatively analyzed the testimonies of 26 of these patients and described their suffering (Verhofstadt *et al.*, 2017); some of the findings are discussed in Sections 4.1.2 and 5.5.2.

No Prospect of Improvement and Futility

As noted above, all 100 patients in the Thienpont *et al.* (2015) were deemed to be suffering “without prospect of improvement, due to treatment resistance.” Further testing and/or treatment to confirm diagnoses or to ensure that conditions were not remediable was required for 38 patients (Thienpont *et al.*, 2015).

Of the 100 psychiatric EAS requests reported by Thienpont *et al.* (2015), 48 were accepted for EAS, and EAS was performed for 35 individuals; 11 cancelled or postponed the procedure (the authors explain that for 8 of these 11 patients “simply having this option gave them enough peace of mind to continue living,” 2 withdrew requests because of strong family resistance, and 1 person could not have EAS because they were incarcerated); and 2 died by suicide prior to the procedure. Of the patients whose requests were not accepted ($n=52$), 38 withdrew their requests before receiving a decision, 8 “continued to pursue” their requests, 4 died by suicide, and 2 died from other causes. Thus, 43 people died, 8 were still pursuing a request for psychiatric EAS, and of the remaining 49, 38 withdrew requests before a decision was reached and 11 cancelled or postponed the procedure after their request was accepted (Thienpont *et al.*, 2015).

Between one and four years after their initial evaluation, 43 patients had died, either by EAS ($n=35$, as noted above), suicide ($n=6$), palliative sedation ($n=1$), or anorexia nervosa ($n=1$) (Thienpont *et al.*, 2015). Of the 57 people who were alive one to four years later, 9 requests “were still in process and no decision had been reached,” and 48 requests were on hold because the patients were “managing with regular, occasional or no therapy” (Thienpont *et al.*, 2015).

Capacity

In the (Thienpont *et al.*, 2015) study, all 100 people in the consecutively requested psychiatric EAS were deemed competent. A number of diagnoses were associated with an increased risk of incapacity, but no information is given as to how their status was determined.

Consultations

Consulting a specialist (psychiatrist in cases of psychiatric disorders) is a legal requirement only in Belgium for cases where death is not foreseeable (Gov. of Belgium, 2002; RTE, 2016). However, this consultation does not always occur. Dierickx *et al.* (2017) found that, in cases where the patient did not have a foreseeable death, the third physician involved was a psychiatrist in all cases of mood disorder accompanied by an additional psychiatric disorder, in all cases of “other psychiatric disorders,” and in 87% of mood disorder cases (i.e., with no additional psychiatric disorder diagnoses). For comparison, the second physician involved was usually a general practitioner in cases of mood disorders (69%) and other psychiatric disorders (59%) (Dierickx *et al.*, 2017).

In 2017 in Belgium, there were 26 psychiatric EAS cases (excluding dementia), and in 96% of these cases ($n=25$), the second doctor consulted was a psychiatrist (CFCEE, 2018a). In 17% of these cases ($n=4$), the psychiatrist had also received

additional training related to end-of-life decision-making. There were also 14 psychiatric EAS cases involving people with diagnoses of dementia, and in 43% of these cases (n=6) the second doctor consulted was a psychiatrist (CFCEE, 2018a).

Rate of Psychiatric EAS Approval in Belgium

While the psychiatric EAS acceptance rate is not known, the rate of granted requests for all EAS in Belgium increased from 55% in 2007 to 77% in 2013, with 100% of EAS requests granted for some groups of patients, such as those with nervous system disorders (Dierickx *et al.*, 2015). An estimate of the psychiatric EAS acceptance rate in Belgium from 2007 to 2011 is provided by Thienpont *et al.* (2015). Excluding those who changed their minds (and those who died) prior to completion of their evaluation, the acceptance rate is 48 of 56, or 86%. However, if those who changed their minds and withdrew requests, and those who died, are included in the acceptance rate calculation, approximately half of those seeking psychiatric EAS were not approved (a 48% acceptance rate) (Thienpont *et al.*, 2015). It is difficult to statistically evaluate what predicts the approval of a psychiatric EAS request, because the Flemish studies do not use a category specific to psychiatric EAS requests. Instead, such requests fall within the “other diseases” category, making direct estimates of granted psychiatric EAS requests difficult to enumerate.

5.7 HOW PSYCHIATRIC EAS IS MONITORED IN THE NETHERLANDS AND BELGIUM

Both the Netherlands and Belgium monitor EAS through a retrospective review of physician self-reports, in order to determine whether physicians are following the legal due care criteria (i.e., eligibility criteria and procedural safeguards) (CFCEE, 2016b; RTE, 2016; Rooney *et al.*, 2017). It is estimated that 20% of all EAS cases are not reported to the RTEs in the Netherlands (Rietjens *et al.*, 2009; Onwuteaka-Philipsen *et al.*, 2017), and in Flanders, Belgium an estimated 47% of EAS cases were not reported to the CFCEE in 2007 (Smets *et al.*, 2010). Non-reported cases often involved patients 80 years or older, with a primary diagnosis of cancer (i.e., not psychiatric), and physicians noted that the degree of life shortening was limited to a week or less (Onwuteaka-Philipsen *et al.*, 2017). Others have noted that these physicians did not consider the deaths to be EAS (Rietjens *et al.*, 2009). The primary feature of these unreported cases is that doctors tended to use morphine rather than drugs designated for EAS. In all of these cases, physicians reported that they intentionally hastened deaths at the request of the patients (Onwuteaka-Philipsen *et al.*, 2017).

Of over 62,000 combined cases of EAS between 2002 and 2016, due care was judged to have not been met in 89 cases in the Netherlands and 1 case in Belgium (Mason & Weitenberg, 2015; Miller & Kim, 2017). A recent study examined the 32 of the 33 cases in the Netherlands where the RTEs judged “due care not met” (DCNM) between 2012 and 2016 (Miller & Kim, 2017). Most DCNM cases were due to violations of procedural criteria (e.g., use of incorrect medications, lack of independence of consultants), mostly in the context of terminal cancer. In ten cases, the RTEs found violations in the application of the eligibility criteria. Eight of these ten cases involved either neurological or psychiatric disorders or both. In seven of the ten cases, the violation involved the “no reasonable alternative” criterion. Five of the ten cases were performed by physicians from the End-of-Life Clinic (during which time the Clinic was involved in 5% of all Dutch EAS cases). In addition, some physicians performed EAS when they “realised that it was a very difficult case and that the limits of the law would be sought here” (Miller & Kim, 2017).

The role of consultants specially trained in EAS law (SCEN doctors) in DCNM cases has been reviewed in the literature. The RTEs have found that, in the DCNM cases described above, these consultants often either agreed with the primary physician or they played an active role in facilitating EAS. This more active role can include: taking over key aspects of the case; advising referral to the End-of-Life Clinic where the clinic physician then engaged this consultant as an “independent consultant” for the case; and advising a consulting physician not to seek further specialist consultation (where not seeking consultation was the focus of the RTE’s DCNM judgment) (Miller & Kim, 2017).

5.7.1 Monitoring of Psychiatric EAS

As of 2016, there were a combined few hundred cases of psychiatric EAS in the Netherlands and Belgium. Each country has had one DCNM psychiatric EAS case. In the Dutch case, a woman in her 80s with chronic depression wanted assistance from the End-of-Life Clinic (Case 2014-01) (RTE, 2015a). The clinic physician, who was not a psychiatrist, met the patient for the first time just over three weeks before her death, and did not conduct any one-on-one interviews with the patient (the patient’s children were present during both interviews). He did not consult any psychiatrists, was not familiar with the NVVP guidelines, and stated he “was in no doubt” about the patient’s prognosis. The RTE found that the notifying physician should have taken more time to talk with the patient, and an additional expert should have been consulted (RTE, 2015a).

The single DCNM case in Belgium involved a physically healthy 85-year-old woman who requested EAS for reactive depression after her daughter died. No detailed official account has been released; the case was documented by an Australian journalist on video (Mason & Weitenberg, 2015).

The extremely low rate of DCNM cases (0.2% in the Netherlands and 0.008% in Belgium) may reflect that, for the RTEs, the EAS law's primary function is:

1. to create legal certainty for doctors caught in conflicting obligations;
2. to provide transparency in the practice of EAS and public scrutiny; and
3. to safeguard, monitor and promote the care with which medical decisions about termination of life on request are taken and the quality of such decisions by bringing matters into the open and applying uniform criteria in assessing every case in which a doctor terminates life.

(RTE, n.d.)

One psychiatric EAS case further illustrates the RTEs' interpretation of the EAS law as it relates to creating legal certainty (case 2013-27). This patient had attempted suicide by jumping off a building, which led to a broken thigh and hospitalization. The patient refused all medical treatments and requested EAS. In the words of the RTE, the physician "complied with the patient's wish almost at once" (as quoted in Kim *et al.*, 2016). The RTE was "puzzled" by this haste; it criticized the physician for prematurely opting for the EAS evaluation, even going so far as to state that the RTE could "not exclude the possibility that the patient might yet have accepted treatment..." (as quoted in Kim *et al.*, 2016). The RTE deemed that due care was met for this EAS, reasoning that, despite their skepticism about the doctor, the case met the due care criteria at the moment EAS was implemented (Kim *et al.*, 2016).

It should be noted that the role of the RTEs, through annual reports and the Code of Practice, is not to ensure that physicians follow EAS law, but rather to determine whether physicians conducted EAS in a thorough, professional manner (Miller & Kim, 2017).

5.8 IMPLICATIONS OF THE INTERNATIONAL DATA

5.8.1 New Safeguard Developments in Belgium and the Netherlands

Recently, several documents related to psychiatric EAS have been published by prominent organizations in Belgium that argue for supplemental or further safeguards beyond what is required by the law.

First, in November of 2017, the VVP in Flanders approved an advisory document (VVP, 2017) that is heavily based on the 2009 Dutch NVVP guidelines (Berghmans *et al.*, 2009). The document follows the NVVP's guidelines in assessment of suffering, capacity and informed consent, transference/countertransference, and futility. For example, a patient can be deemed untreatable only after all indicated standard biological, psychotherapeutic, and social interventions have been tried and tested. The VVP document also states “[e]very patient is entitled to refuse a treatment offering a reasonable prospect of success, but this will make it impossible to show that the ‘medically hopeless condition,’ ‘untreatable,’ and ‘impossibility of alleviating the suffering’ criteria have been met, and will thus preclude euthanasia” (VVP, 2017).²⁸

But the 2017 VVP advisory document also emphasizes the following points (note this list is not exhaustive):

- It advocates a “twin track policy” in which, during the EAS evaluation process, the person making the request is also required to pursue recovery-oriented engagement with a different physician, i.e., not just to focus on the wish to die but also on life.
- At least two psychiatrists must be involved in each case. All three doctors must ensure that all of the due care criteria are evaluated.
- “There must be two positive recommendations and any negative recommendations must also be taken into account.”
- The evaluation process must be one where “sufficient time is taken and there are multiple conversations with the patient” and that this period must be “far longer” than the statutory minimum of one month.
- Consultation with current and previous key practitioners providing care to the patient is essential; if the patient refuses to allow the assessing physician access to the previous practitioner’s views, then the physician “may decide that he or she will be unable to” perform or evaluate EAS.
- There should be a strong emphasis on the involvement of family and significant third parties. “The patient’s refusal to have third parties involved may, however, result in the doctors being unable to perform or evaluate EAS.”
- The final evaluative process and decision-making should involve more than the patient and the three doctors (the doctor performing EAS and two consultants), forming a “round table” representing all doctors and healthcare providers to the patient so they can “discuss it openly and jointly weight up all the considerations.”

(VVP, 2017)²⁹

28 Unofficial translation.

29 Unofficial translation.

Second, an organization representing hospitals and institutions in Belgium, Zorgnet-Icuro, recently published its ethical opinion on EAS for non-terminal patients with serious psychiatric disorders (Zorgnet-Icuro, 2018). In it, they call for legislative changes to the Belgian EAS law, including the following:

- At least one year's time between the patient's writing of the EAS request and, if accepted, their death, rather than one month.
- That the patient discuss their EAS request with designated loved ones (this is currently optional).
- That an interdisciplinary team of experts examine the EAS request and the patient's situation for a longer period of time.
- That the treating physician consult two psychiatrists with expertise in the patient's condition. These experts must be independent in relation to each other, to the patient, and the treatment team. They should examine the patient's decision-making ability and the medical hopelessness of their condition.
- For any EAS request to be granted, the unanimous agreement of both consulting psychiatrists is required (in the current law, consulting one psychiatrist is sufficient, and the advice of this psychiatrist is not binding).
- That at least one psychiatrist be part of the CFCEE (nothing is said in the current law, and there is currently no psychiatrist on the CFCEE).

(Zorgnet-Icuro, 2018)

5.9 KNOWLEDGE GAPS

One major gap in the evidence is that, beyond gender, age, and physical comorbidities, there are no associated data on race, ethnicity, socio-economic status, family involvement, or the social effects of psychiatric EAS. A lack of patient voices in the discourse surrounding EAS in Belgium and the Netherlands has also been identified as a knowledge gap (Van Brussel *et al.*, 2014).

There is also no evidence on the effects of psychiatric EAS on families, friends, physicians, and other healthcare practitioners. Most of the data on effects of EAS on families and friends are based on terminal patients, and tend to show there is less grief among the loved ones of patients who chose EAS versus patients who died through natural causes (Swarte *et al.*, 2003; Kimsma, 2010).

Although there have been cases of psychiatric EAS in the Switzerland and Germany, little is known about them.

6

Potential Implications of Prohibiting or Permitting More MAID MD-SUMC

- Potential Implications
- Speculative Implications
- Unique Considerations for Specific Populations
- Potential Safeguards
- Conclusion

6 Potential Implications of Prohibiting or Permitting More MAID MD-SUMC

Key Findings

Whether to alter the existing law to expand or restrict MAID MD-SUMC eligibility is a challenging question upon which people disagree. Empirical data and legal arguments inform specific aspects of the question but whether or not to further permit or prohibit MAID MD-SUMC also requires ethical judgments by policy-makers.

Evidence can be drawn from Belgium and the Netherlands to inform the discussion on prohibiting or permitting more MAID MD-SUMC in Canada, while recognizing the differences that exist among jurisdictions. Despite this evidence, there still exist important knowledge gaps about potential implications of prohibiting or permitting more MAID MD-SUMC in Canada, and the effectiveness of possible safeguards.

No other country permits MAID MD-SUMC where one of the eligibility criteria is based on an individual's personal assessment of what conditions for relief of their intolerable suffering they consider acceptable. If Canada were to expand MAID MD-SUMC using this criterion, it could become the most permissive jurisdiction in the world with respect to how relief of suffering is evaluated.

If MAID MD-SUMC were expanded, potential safeguards could be adopted to attempt to ensure that eligibility criteria are observed and evaluation processes are valid and reliable in distinguishing between those who should and those who should not be eligible. Ultimately, there is a trade-off inherent in safeguards between taking steps to prevent MAID MD-SUMC in cases where someone should be ineligible (over-inclusion), and creating unnecessary delays or impediments where someone should be eligible (under-inclusion).

If different criteria or evaluation processes are used to assess MAID requests from people with mental disorders and people with physical disorders, these will need to be justified based on the unique characteristics of MAID MD-SUMC versus MAID.

Policy-makers in Canada may be faced with the question of restricting or permitting more MAID MD-SUMC for those not already eligible for MAID. Various groups have made assertions about the potential impacts of permitting or prohibiting this practice, from ethical, legal, social, and clinical points of view. The Working Group studied these claims, and, based on the evidence

(including the CCA’s Call for Input submissions) and their collective expertise, have identified important potential implications for policy-makers to consider while engaged in future public debate and decision-making on this issue.

The Working Group brought different perspectives and lenses to bear on the probability and significance of particular implications, and on how to balance and respect competing concerns. Since it is the role of policy-makers rather than the Working Group to make these judgments, this chapter does not offer recommendations. Rather, it provides, as comprehensively as possible, a summary of the potential implications of prohibiting or permitting more MAID MD-SUMC, as well as the evidence underlying these potential implications.

Drawing upon the evidence presented in Chapters 3 to 5, the purpose of Chapter 6 is to address three key elements of the charge:

- The potential implications for individuals and other affected people, including their families, care providers, and health practitioners, with respect to prohibiting or permitting more MAID MD-SUMC.
- The potential impacts on society with respect to prohibiting or permitting more MAID MD-SUMC.
- The potential safeguards that might be considered should MAID MD-SUMC be prohibited or expanded in Canada.

6.1 POTENTIAL IMPLICATIONS

The Working Group found a range of potential implications that could arise from changes to the current Canadian MAID law (making it more or less restrictive), although members disagree on the probability of different implications occurring, as well as on the significance of different implications. This section considers the potential implications that could occur were the current legal status of MAID altered to expand or further restrict MAID MD-SUMC, or if its status were to remain unchanged. For simplicity, the Working Group uses the terms *prohibiting* and *permitting more* (or *permitting more broadly*) MAID MD-SUMC. The term *prohibiting* generally refers to both the status quo and restricting MAID MD-SUMC further. The term *permitting more* refers to expanding MAID MD-SUMC so that more people whose sole underlying medical condition is a mental disorder could be eligible for MAID.

Many of the implications discussed relate to concerns about the potential over-inclusion or under-inclusion of people receiving MAID MD-SUMC. *Over-inclusion* refers to people receiving MAID in cases where it should not occur (due to ineligibility or undue influence), while *under-inclusion* refers to capable, eligible people who request the procedure not receiving MAID.

While the Working Group uses the terminology of *over-* and *under-inclusion*, they make no assumption that the law will be changed. It is widely agreed that there is a need to avoid cases of over-inclusion and under-inclusion if MAID MD-SUMC were expanded or prohibited, but the conceptual difficulties with diagnosis and prognosis in the context of mental disorders (Section 3.1) and the challenges associated with capacity assessment (Section 4.1) suggest that there may be cases where people disagree about whether a particular person would be eligible or not. Were MAID MD-SUMC permitted more broadly, the line determining who would be eligible and who would not be eligible would be based on ethical and policy choices made by policy-makers, and enacted by changes to the current MAID legislation. Alternatively, policy-makers may decide that no changes are needed if the current normative criteria create their desired division between eligibility and ineligibility. Some Working Group members note that there is a need for clear, unambiguous criteria in the legislation, particularly as it applies to people with mental disorders, as was highlighted by the Canadian Bar Association and the Federation of Medical Regulatory Authorities of Canada in the CCA's Call for Input (CBA, 2017; FMRAC, 2017). Other Working Group members believe that commenting on the current legislation was not within the scope of this report.

Along with the potential implications, the Working Group identified several speculative implications for which there was very little or no evidence specifically related to MAID MD-SUMC. These speculative implications are discussed in Section 6.2. There is no clear evidentiary line separating potential implications from those that are speculative, and Working Group members disagree about how to balance the evidence supporting each implication. The Working Group notes that there is speculative evidence for all potential implications, as they all make reference to a hypothetical future.

6.1.1 Current Eligibility Criteria

Current MAID law in Canada does not specifically exclude people whose sole underlying medical condition is a mental disorder, provided they meet all of the law's eligibility criteria. However, in most cases, people will not meet one or more of the current eligibility criteria; these ineligible cases are the focus of the following discussion.

As it is beyond the scope of this assessment to evaluate the current legislation, and as there are many different mechanisms by which MAID MD-SUMC could be permitted, the Working Group for the most part avoided discussing scenarios in which one or more of the eligibility criteria were changed in order to further permit or restrict MAID MD-SUMC. Some Working Group members also felt that discussions of MAID MD-SUMC in reference to the current law were out of scope of the assessment.

The current eligibility criteria that are most relevant in the context of MAID MD-SUMC are:

- Decision-making capacity (s.241.2(1)(b)); and
- A grievous and irremediable medical condition (s.241.2(2)):
 - “incurable illness, disease or disability” (s.241.2(2)(a))
 - “advanced state of irreversible decline in capability” (s.241.2(2)(b))
 - “enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable” (s.241.2(2)(c))
 - “natural death has become reasonably foreseeable” (s.241.2(2)(d))

(GC, 2016b)

The Working Group identified several important potential implications for MAID MD-SUMC stemming from challenges associated with applying these eligibility criteria to people with a mental disorder as their sole underlying medical condition, which may lead to risks of both over-inclusion and under-inclusion. For example, in regard to prognosis, some people requesting MAID MD-SUMC may be assessed as eligible even if their condition would have improved in the future (potential over-inclusion), and others may be assessed as ineligible whose condition would never improve (potential under-inclusion). The impact of these risks is different: in the case of over-inclusion, the risk is that a potentially full lifespan ends prematurely. Unlike errors of under-inclusion that may be detected after the fact, it will never be possible to know whether the person who received MAID might have improved. Thus, over-inclusion cannot be corrected and, in general, it may be difficult to measure how successful safeguards are in mitigating this type of risk. In contrast, it may be possible to detect cases of under-inclusion for specific people (e.g., by noting over time that the anticipated improvement has not occurred), and to re-assess eligibility as experience accrues and if prognosis becomes clearer over time. However, if further treatment or supports prove ineffective or unacceptable, not allowing an individual to receive MAID MD-SUMC will have caused the prolongation of intolerable suffering.

Mental disorders are a large and heterogeneous group of conditions, and include those that can be characterized as having a stable, relapsing and remitting, progressive, or unpredictable course (Section 3.1). Additionally, most mental disorders are syndromes (defined by clusters of symptoms and signs), and different people with the same diagnosis may experience different symptoms. Prognostication is often difficult, but this is not always the case. For example, the course of dementia due to Alzheimer’s disease is much clearer than that of depression (Section 3.1). The Working Group recognizes that such heterogeneity means the implications of prohibiting or permitting more MAID MD-SUMC

in relation to the eligibility criteria will vary among different types of mental disorder. Therefore, while the implications discussed below are relevant for many mental disorders, they are not relevant for all mental disorders.

Capacity

Potential Implication: Were more MAID MD-SUMC permitted, challenges associated with assessing capacity in people with mental disorders may result in over-inclusion or under-inclusion.

Under Canadian law, a person with a mental disorder is, by default, presumed to have capacity to make profound healthcare decisions, including the decision for MAID (e.g., Gov. of ON, 1996) (Sections 3.6 and 4.1.4). As stated by the Canadian Psychological Association, “a mental disorder does not *ipso facto* indicate that an individual is not competent to make a MAiD decision” (Mikail *et al.*, 2018). However, as discussed in Section 4.1, the symptoms of mental disorders can affect decision-making capacity in various ways. A mental disorder may affect a person’s cognitive faculties, perhaps to the degree where they lack insight into the presence of the mental disorder and its possible impact on their thinking. Where a person’s cognitive faculties are sufficiently affected, they should be regarded as lacking capacity and therefore ineligible should they request MAID MD-SUMC. This is similarly true for other end-of-life decisions, including refusing life-sustaining treatment and/or artificial nutrition and hydration, and consenting to palliative sedation. Mental disorders can also affect a person’s emotions. Where emotional or affective symptoms are sufficiently severe, incapacity may arise due to an inability to understand and/or appreciate the nature and consequences of treatment decisions. As these symptoms relate to emotions and thinking, it can be clinically challenging to establish with confidence the point at which people with certain mental disorders lose capacity.

The challenge of assessing capacity for MAID in people with a mental disorder as their sole underlying medical condition was noted by most stakeholder organizations in their responses to the CCA’s Call for Input on MAID MD-SUMC, including medical and legal professional organizations, advocacy groups, and healthcare facilities. This challenge has been identified by organizations outside Canada as well. For example, in their statement on physician assisted suicide, the Royal Australian and New Zealand College of Psychiatrists (RANZCP) states “ensuring that a person with mental illness has capacity in the [physician assisted suicide] context may pose significant challenges” (RANZCP, 2016). These difficulties raise the possibility that, were MAID MD-SUMC more broadly permitted, some patients might be found capable when they are incapable (over-inclusion) and some might be found incapable when they are capable (under-inclusion). As discussed in Section 4.1.1, the reliability of capacity assessments is unclear, with some studies showing high agreement among

independent psychiatrists assessing decision-making capacity in people with mental disorders (Kim *et al.*, 2001; Cairns *et al.*, 2005b; Kim *et al.*, 2007; Okai *et al.*, 2007), and others finding significant rates of disagreement (Marson *et al.*, 1997; Kim, 2006). Typically, the rate of disagreement is higher for novel or controversial decisions (Kim, 2006), and MAID MD-SUMC would likely be seen as a controversial decision. As discussed in Section 5.6.1, a study of 66 case reports for psychiatric euthanasia or physician-assisted suicide (psychiatric EAS) in the Netherlands found that the two assessors disagreed on capacity in 12% (n=8) of cases and agreed in 88% (n=58) of cases (Doernberg *et al.*, 2016). While the rate of disagreement was relatively low, in most of these cases psychiatric EAS was carried out without resolving the disagreement (Doernberg *et al.*, 2016). Under Canada's current MAID law, two independent assessors must both agree that a person is eligible for MAID (GC, 2016b).

There are also questions about the appropriate threshold for capacity with respect to a MAID request, and how it is evaluated. Some Working Group members think there is a need for a high degree of scrutiny of a patient's decision-making abilities, and a high threshold for capacity in cases of MAID MD-SUMC. As discussed in Section 5.6, some authors argue that, based on their study of psychiatric EAS eligibility assessments in the Netherlands, clinicians do not always apply the degree of scrutiny or threshold for capacity that is appropriate when evaluating requests for psychiatric EAS (Doernberg *et al.*, 2016). On the other hand, using too high a threshold for capacity could result in under-inclusion whereby capable people are denied MAID. As discussed in detail in Section 4.1.4, Working Group members disagree about whether using different thresholds for capacity for MAID MD-SUMC than for other highly consequential decisions would be justified on the basis of the characteristics of MAID MD-SUMC.

Grievous and Irremediable

In order to qualify for MAID in Canada, a person must have a grievous and irremediable medical condition, as defined by the criteria listed at the start of this section. The Working Group has identified potential implications related to each of these criteria. A common theme of these implications (which are related to all of the criteria except suffering) revolves around *certainty*. To be clear, the issue is not whether there are people who have mental disorders that are irremediable, but rather whether clinicians can confidently determine whether a particular case is irremediable. According to the Canadian Psychiatric Association (CPA) “[t]here is no established standard of care in Canada, or as far as CPA is aware of in the world, for defining the threshold when typical psychiatric conditions should be considered irremediable” (Standing Senate Committee on Legal and Constitutional Affairs, 2016). Likewise, the Centre for

Addiction and Mental Health (CAMH) has stated that “[t]here is not enough evidence available in the mental health field at this time for clinicians to ascertain whether a particular individual has an irremediable mental illness” (CAMH, 2017). A number of other organizations that responded to the CCA’s Call for Input shared this view, including the Canadian Mental Health Association, the Canadian Association for Community Living, and the Ontario Shores Centre for Mental Health Sciences, among others (CACL, 2017; CMHA, 2017; OSCMHS, 2017). Others have argued that mental disorders can sometimes be considered irremediable based on studies that demonstrate there are at least some people who do not respond to treatment (von Fuchs, 2017; Dembo *et al.*, 2018).

Incurable

Potential Implication: Were more MAID MD-SUMC permitted, there could be confusion around eligibility as it is not clear whether many mental disorders could meet the criterion of “incurable.”

There are many possible interpretations of the term incurable and whether some mental disorders can be considered incurable will depend on the definition chosen (Section 4.1).

Many mental disorders are considered to be chronic conditions, where the focus is not on a cure, but on the management of symptoms, restoration of function, and decreasing the risk of complications and relapse (Sections 3.1 and 4.1). Treatment can often effectively alleviate symptoms, improve quality of life, and restore a person’s desire to live. With some mental disorders, however, a person would not be considered cured even if they were displaying no symptoms.

Some people have mental disorders that clinicians deem treatment-resistant, meaning that a person’s symptoms have not been sufficiently reduced after having attempted multiple treatments under appropriate conditions. However, even in these cases, under some definitions, a mental disorder may not be clinically labelled as *incurable*. This is not the case for all mental disorders or for all definitions of incurability, however. CAMH has noted that using a definition of incurable that defines such a medical condition as *not fully abating* would mean that many mental disorders could be considered incurable (CAMH, 2017). As explained below, CAMH does not support expanding MAID MD-SUMC. In addition, one may infer from the development of the field of palliative psychiatry (Berk *et al.*, 2012; Trachsel *et al.*, 2016) that at least some psychiatrists believe that some mental disorders are incurable (Downie & Dembo, 2016). While there are exceptions (e.g., dementia as a result of Alzheimer’s disease), the term *incurable* is not used by clinicians in the context of most mental disorders.

There are circumstances in which prognosis is more reliable for certain mental disorders than for certain physical disorders. For example, determining a prognosis for some neurocognitive disorders is relatively easy, while the future course of remitting-relapsing forms of multiple sclerosis can be challenging to predict. On the whole, however, this is not the norm for most mental disorders.

Irreversible Decline

Potential Implication: Were more MAID MD-SUMC permitted, there could be uncertainty around eligibility, as it is not clear whether most people whose mental disorder is their sole underlying medical condition could meet the criterion of “advanced state of irreversible decline in capability.”

Many mental disorders can lead to declines in both mental and physical capabilities directly through symptoms. Some Working Group members also believe that indirect factors such as socio-economic hardship, social isolation, homelessness, addiction, or co-morbid physical conditions can also exacerbate the symptoms of a person’s mental disorder and thereby contribute to declines in capabilities (Section 3.3). It is unclear whether these declines would be considered as an advanced state of irreversible decline in capability, as there is a lack of clarity about the precise meaning of the irreversible decline criterion, as well as disagreement about its interpretation in practice. As the Canadian Medical Protective Association (CMPA) notes:

The CMPA is also aware of the ongoing debate concerning whether the eligibility criteria in the Criminal Code that the patient be in an “advance state of irreversible decline in capability” requires an irreversible decline in physical capability, or whether it should be interpreted broadly so as to include those suffering only from a decline in mental capability. While the CMPA interprets the provision based on the information currently available as requiring an advance state of irreversible decline in physical capability, clarity is required on this issue.

(CMPA, 2017)

Others have offered a different interpretation:

“Advanced state of irreversible decline in capability” includes declines in cognitive as well as physical functions; sudden as well as gradual losses of capability; and ongoing as well as stabilized declines in capability. It is assessed by the medical or nurse practitioner, and it is assessed relative to the patient’s prior capability.

(Downie & Chandler, 2018)

This issue is particularly relevant for MAID MD-SUMC, as there may be cases where people requesting MAID are not experiencing physical declines in capability. Additionally, the course of many mental disorders is fluctuating, making it challenging for clinicians to identify whether a decline in capability is irreversible or temporary (Section 3.1.2). Some organizations, such as the Canadian Mental Health Association, are of the opinion that the “irreversible decline” criterion “likely exclude[s] mental illnesses, as they often fluctuate in symptoms and are remediable with appropriate treatment” (CMHA, 2017).

As discussed broadly for the “grievous and irremediable” criterion, in many cases the issue is not whether people can be in an advanced state of irreversible decline because of certain mental disorders, but rather whether clinicians can confidently determine that the decline is irreversible. These issues will not be relevant for all MAID MD-SUMC requests as, in some instances, a decline in capability is predictable, especially when it is the result of certain mental disorders (e.g., dementia due to Alzheimer’s disease).

International evidence shows that those assessing eligibility for psychiatric EAS in Belgium and the Netherlands sometimes disagree about whether a psychiatric illness has no prospect for improvement. As noted in Section 5.6.1, a study of 66 cases of psychiatric EAS in the Netherlands found that assessors agreed there was no prospect of improvement in 80% of cases (n=53), and disagreed in 20% (n=13) of cases (Kim *et al.*, 2016). In most cases of disagreement, EAS was administered without resolving the disagreement (Kim *et al.*, 2016). In Canada, under the current MAID law, two assessors must both agree that the person is eligible for MAID (GC, 2016b).

Intolerable Suffering

Canada has a subjective standard for intolerable suffering (“suffering that is intolerable to [the person] and that cannot be relieved under conditions that they consider acceptable”) (GC, 2016b), which leaves the determination of intolerable suffering to the patient. This differs from the laws in the Benelux countries, wherein the clinician and patient together determine whether there are no means by which suffering can be relieved (see Section 5.6 for the full list of requirements).

Potential Implication: Were more MAID MD-SUMC permitted, it may be difficult to distinguish between (i) a person’s rational perception of intolerability and irremediability of suffering, versus (ii) a distorted perception that is driven by feelings of hopelessness.

Mental disorders can and do cause enduring and intolerable psychological and physical suffering. However, certain mental disorders can impair a person’s ability to rationally reflect on the intolerability and irremediability of their own suffering, and these disorders are common in people who request psychiatric EAS in international jurisdictions. For example, in psychiatric EAS studies, many requestors had a personality disorder (50 out of 100 requesters in a Belgian study, and 34 out of 66 requesters in a Dutch study)³⁰ (Thienpont *et al.*, 2015; Kim *et al.*, 2016). Personality disorders, and other psychiatric disorders such as severe depression, involve maladaptive “ways of perceiving and interpreting self, other people, and events” (APA, 2013). Not all cases of MAID MD-SUMC would involve personality disorders, and not all personality disorders impair a person’s ability to rationally reflect on their suffering. However, it may be difficult to determine clinically whether a person who requests MAID MD-SUMC has a distorted perception of their suffering (as intolerable with no potential for improvement) resulting from a symptom of their disorder. In some cases, it may be that the patient’s symptoms and/or suffering could be reduced through treatment or other changes in their lives (e.g., feeling supported, making new friends), despite their feelings of hopelessness at the time of their MAID MD-SUMC request. Some Working Group members believe that, in some cases, it may be possible to determine that a person has a rational perception of the intolerability and irremediability of their suffering.

Potential Implication: Permitting more MAID MD-SUMC may reduce suffering by providing eligible people with that option, if needed.

Having the option for MAID may offer a therapeutic benefit to some people, including those with mental disorders. International evidence suggests that some (8 of 48) people who were approved for psychiatric EAS in Belgium withdrew their requests after approval, later indicating that knowing they had the option “gave them sufficient peace of mind to continue their lives” (Thienpont *et al.*, 2015). Working Group members disagree about how to interpret this evidence. Some members believe it indicates that these patients’ suffering was not in fact intolerable and irremediable due solely to their mental disorders. Others believe it indicates that being approved for MAID either reduced these patients’ suffering or altered the tolerability of their suffering.

³⁰ “Fifty-two percent (34 of 66) of patients had personality related problems, sometimes without a formal diagnosis but indicating significant effect on the EAS evaluation” (Kim *et al.*, 2016).

Evidence from Oregon shows that about one-third of those given a lethal prescription to administer themselves (physician aid in dying, or PAD) never take the drug, and some suggest this is because they derive comfort from having it (OHA, 2007; Lindsay, 2009). This is consistent with two interactions described by Li and Kain (2018) in which two patients experienced relief after being found eligible for MAID. However, neither of these studies examined requests for assisted dying where a mental disorder was the sole underlying medical condition, and thus the relevancy of this evidence is unclear. While research related to MAID in general may be relevant for MAID MD-SUMC, some evidence suggests caution. In Belgium and the Netherlands, data demonstrate that the characteristics of patients accessing EAS are different from those accessing psychiatric EAS. For example, while men accessed 51% of all EAS in the Netherlands in 2017 (RTE, 2018a), women accessed 70% of psychiatric EAS between 2011 and early 2014 (Kim & Lemmens, 2016).

Natural Death Has Become Reasonably Foreseeable

The majority of people with a mental disorder as their sole underlying medical condition will not qualify for MAID because they do not meet the “natural death has become reasonably foreseeable” criterion. As discussed in Section 4.1.2, there is disagreement over what is meant by the term “reasonably foreseeable,” and different MAID assessors and providers across Canada use different interpretations.

Potential Implication: Permitting more MAID MD-SUMC through the removal of the “reasonably foreseeable” criterion may expand the MAID eligibility to include many chronic conditions.

While MAID MD-SUMC is permitted in Canada, the majority of people with mental disorders are excluded because their natural deaths are not considered “reasonably foreseeable.” This criterion also excludes people with a range of physical conditions who would otherwise qualify. For example, a person with severe pain from arthritis could meet the criteria of being capable, having an incurable illness, being in a state of irreversible decline, and having intolerable suffering that cannot be alleviated by treatments they find acceptable, but may be in a position where their death is not considered reasonably foreseeable. Therefore, were MAID MD-SUMC permitted more broadly through the elimination of the “reasonably foreseeable” criterion, a range of conditions in addition to mental disorders could become eligible for MAID. As discussed in Chapter 5, evidence from the Netherlands and Belgium demonstrates that people have accessed psychiatric EAS for a range of conditions where death is

not reasonably foreseeable. These conditions include depression, personality disorders, and anxiety disorders, but also autism (CFCEE, 2016; Kim *et al.*, 2016), which may fall outside of what some would consider to be a mental disorder.

Potential Implication: Prohibiting MAID MD-SUMC may potentially cause people with mental disorders to engage in voluntary stopping of eating and drinking (VSED) in order to become eligible for MAID or as an alternative way to die.

As most people with a mental disorder as their sole underlying medical condition will not meet the “reasonably foreseeable” criterion for MAID, some Working Group members think it is important to consider that this lack of access to MAID may potentially lead some people to engage in VSED in order to hasten the foreseeability of their death. At present, there is limited evidence related to VSED and MAID MD-SUMC specifically. Other Working Group members feel the following discussion of this implication is unsubstantiated based on the evidence available.

At least two people in Canada have used VSED to qualify for MAID where they met all but one of the eligibility criteria (Section 2.2.4). One of these, a 56-year-old woman, had multiple sclerosis and initially failed to meet the criterion of “natural death has become reasonably foreseeable” (GC, 2016b; CPSBC, 2018). The other (a 61-year-old man in Quebec) experienced a series of debilitating strokes that resulted in an inability to walk, losing his ability to speak, and experiencing a large amount of pain. He initially failed to meet the criterion of “at the end of life” (a requirement for assisted dying in Quebec) (Gov. of QC, 2014; McKenna, 2016; Standing Committee on Justice and Human Rights, 2016b; CPSBC, 2018). However, neither of these people had a mental disorder as their sole underlying medical condition, and thus the relevancy of this evidence to MAID MD-SUMC is unclear. Prior to the legalization of MAID in Canada, a woman with a mental disorder (Huntington’s disease) chose to publicly end her life through VSED in order to control her death while she had the capability to do so (Martin, 2014).

In the Benelux countries, people with psychiatric disorders are not excluded from accessing psychiatric EAS by a “reasonably foreseeable death” criterion. However, there is evidence that VSED has been used as an alternative way to die when EAS requests have been refused. In one study from the Netherlands, 7 out of 6,861 deaths resulted from VSED after requests for EAS were refused (Onwuteaka-Philipsen *et al.*, 2012). It is not known whether any of these people had a mental disorder.

6.1.2 Vulnerability and Autonomy

Vulnerable groups and individuals are susceptible to harm. As noted in Chapter 3 and Section 4.3, some people with mental disorders are considered vulnerable, insofar as having a mental disorder is associated with socio-economic hardship, discrimination, and disability. As a result, some people with mental disorders may be less independent and have a reduced ability to defend or promote their own interests (whether those interests are to avoid or to access MAID). The difficulty of addressing vulnerability is that restricting some people's choices in order to protect them may simultaneously deny their (and others') autonomy. Concerns related to the vulnerability of those who would request MAID MD-SUMC centre on voluntariness and ensuring that MAID requests are autonomous and not a result of pressure from other people or society, and that MAID requests are not denied as a result of paternalistic attitudes about people with mental disorders.

Vulnerability

Potential Implication: Prohibiting or permitting more MAID MD-SUMC may have an impact on mental health stigma and the vulnerability of people with mental disorders.

Some Working Group members believe that permitting more MAID MD-SUMC may reduce mental health stigma by demonstrating that people with mental disorders have capacity, that their suffering is serious, that mental disorders are not due to character flaws or circumstances within their control, and that their right to self-determination should be respected.

Walker-Renshaw and Finley (2016) ask, "Would prohibiting the availability of physician-assisted death for capable persons suffering intolerably from severe, treatment refractory mental illness be just another form of stigmatizing mentally ill persons?" In the past, there has been significant stigmatization of people with mental disorders in Canada (Chapter 3). This stigma continues today, and may contribute to people's suffering and vulnerability. There is some empirical evidence, based on an Australian survey, that suggests that lower public support for MAID MD-SUMC, as compared to MAID for physical disorders, is due to perceptions that people with mental disorders have less autonomy — and at the same time are more in control of their own condition — than people with physical disorders (Levin *et al.*, 2018).

Other Working Group members think that permitting more MAID MD-SUMC may increase mental health stigma because it might bolster the beliefs that the lives of people with mental disorders are intolerable, not worth living, and (at least sometimes) hopeless. In Canada, both provincial/territorial Human Rights Codes and the *Canadian Charter of Rights and Freedoms* explicitly prohibit

discrimination on the basis of mental disability, including mental disorders (GC, 1982). There is, however, a history of discrimination against people with mental disorders, including forced institutionalization and sterilization in the name of eugenics (Section 3.3.3). Some organizations, such as the Council of Canadians with Disabilities, have argued that permitting MAID MD-SUMC would “increase the vulnerability of Canadians with psycho-social impairments” (CCD, 2017). For example, there is the possibility that permitting more MAID MD-SUMC may result in people with mental disorders seeking it disproportionately as a way out of chronically difficult circumstances (e.g., poverty, homelessness, unemployment) that are more likely to affect them compared to the general population (Section 3.3.2), or due to coercion. In a study of Dutch practice, social isolation or loneliness was cited as contributing to the suffering of people who accessed psychiatric EAS in 37 of 66 cases (Kim *et al.*, 2016). In addition, 5 of 66 psychiatrists surveyed about the last time they had refused a request for psychiatric EAS in the Third Review of the Dutch Act stated that “I had the impression that the patient was making the request under the pressure of those close to him or her” (Onwuteaka-Philipsen *et al.*, 2017). Notably, the same number (5 of 66) stated “I felt pressurised by those close to the patient to refuse the request” (Onwuteaka-Philipsen *et al.*, 2017).³¹

Potential Implication: Prohibiting or permitting more MAID MD-SUMC may unjustifiably discriminate against people with mental disorders.

People with mental disorders have a history of experiencing discrimination in Canada (Chapter 3). Under the current law, people whose mental disorder is their sole underlying medical condition are not prohibited from receiving MAID; however, the majority will not meet all of the existing eligibility criteria.

People with mental disorders have the right to make end-of-life decisions, such as requesting palliative sedation, refusing artificial nutrition and hydration, and refusing or requesting the removal of life-sustaining treatment. As discussed in detail in Section 4.1.4, Working Group members disagree about whether differential treatment between MAID MD-SUMC and other highly consequential decisions would be justified because of the characteristics of MAID MD-SUMC.

Some Working Group members believe that prohibiting MAID for people with mental disorders when it is permitted for people with other conditions can be seen as discriminatory. These Working Group members note that historically, broad practices put in place to protect vulnerable groups have been used to justify the exclusion of people with decision-making capacity from participating in activities (e.g., biomedical research) when those same people

31 Unofficial translation.

considered the activity to be of personal or group benefit (Rhodes, 2005). Other Working Group members believe that differential treatment of people with mental disorders in relation to MAID is warranted based on the unique characteristics of mental disorders (such as their impact on people's capacity, decision-making, and perceptions of the future); the history of promoting liberties without providing supporting resources and safeguards leading to adverse outcomes; and the fact that there are already laws that permit special protections of people with mental disorders.

Autonomy

Potential Implication: Prohibiting or permitting more MAID MD-SUMC may or may not respect the autonomy of people with a mental disorder as their sole underlying medical condition.

Respect for autonomy underlies the legal presumption that adults have decision-making capacity, and that all capable adults have the right to give or refuse consent to medical treatment. However, it is also recognized that mental disorders can impair a person's ability for autonomous decision-making (Section 4.3). Furthermore, the concept of autonomy is complex and can be defined in different ways (Section 4.3). Thus, whether prohibiting or permitting more MAID MD-SUMC respects or limits the autonomy of people with mental disorders depends on one's view of autonomy.

From the individualistic perspective of autonomy, permitting more MAID MD-SUMC may respect the autonomy of individuals with a mental disorder by allowing them to independently determine whether (and when and how) their lives will end. Using this lens, when a person has decision-making capacity, they have the right to make decisions with respect to their health without external interference or limitations. Thus, prohibiting MAID MD-SUMC might fail to respect the autonomy of people with mental disorders who make an informed and autonomous decision for MAID.

However, permitting more MAID MD-SUMC might also fail to respect the autonomy of people with mental disorders if there are not sufficient safeguards to ensure that a patient's decision for MAID is in fact an autonomous one. A person may be found to have the legal capacity to make a decision for MAID, but that decision may not be autonomous if the symptoms of their mental disorder or a lack of resources is affecting their choice (Chapter 4). For example, a mental disorder might affect a person's emotions, distorting their view of their situation or their ability to reason about the future. Additionally, the severity or nature of the symptoms of a mental disorder may be affected by a lack of resources or by other social inequities (e.g., those based on gender or race).

From a perspective of relational autonomy, respecting a patient's autonomy requires that the clinician (and possibly others, such as family members) be involved in the decision-making process, supporting the patient to make a decision that accords with their preferences and values (Section 4.3.2).

Some Working Group members believe that insofar as mental disorders may interfere with a patient's autonomy, and in some cases may specifically predispose a patient towards wanting to die, prohibiting MAID MD-SUMC might be seen as respecting and supporting the autonomy of people with mental disorders by preventing them from making a choice that is not an expression of their desires, beliefs, values, and preferences. Other Working Group members believe that if it is acknowledged that all decisions are made under conditions of constrained choice, labelling the decisions of people who may be classified as marginalized (socially, culturally or economically) as non-autonomous puts them at risk of having their decisions disregarded or never invited in the first place. These other Working Group members argue that if the support required to satisfy others that a marginalized person's decisions meet some threshold of freedom is unlikely to be forthcoming, this paternalism compounds their lack of freedom (Section 4.3.2).

6.1.3 Mental Healthcare

It is important to consider the implications that prohibiting or permitting more MAID MD-SUMC may have for mental healthcare in Canada, given the impact of mental healthcare on the outcomes of those living with mental disorders, and given that MAID is a service provided by the healthcare system.

Potential Implication: Permitting more MAID MD-SUMC might alter mental healthcare in Canada, as it may conflict with the professional views and ethics of many mental healthcare practitioners.

Evidence obtained through CCA's Call for Input, and the Working Group's own expertise, indicate that MAID MD-SUMC is not acceptable to many mental healthcare practitioners in Canada. CAMH states, “[f]or many mental health care providers, empowering their patients to access MAID would push that risk taking beyond the limits of their duty of care and compromise their other responsibilities to promote life and (to the extent possible) prevent suicide” (CAMH, 2017). A 2017 survey of 528 psychiatrists in Canada found that 29% “supported MAID on the basis of mental illness” while 61% opposed it and 10% did not know (Rousseau *et al.*, 2017). A lack of support is also expressed by psychiatric associations outside Canada. For example, the American Psychiatric Association (APA) argues that “a psychiatrist should not prescribe or administer any intervention to a non-terminally ill person for the purpose of causing

death” (APA, 2016). Similarly, the RANZCP states they “[do] not believe that psychiatric illness should ever be the basis for [physician assisted suicide]” (RANZCP, 2016).

The limited support for MAID MD-SUMC may stem from healthcare practitioners’ use of recovery-oriented approaches to mental healthcare, as advised by the Mental Health Strategy for Canada (Section 4.4.1) (MHCC, 2012). In the recovery-oriented approach to mental healthcare, *recovery* refers to the ability to live “a satisfying, hopeful, and contributing life, even when there are ongoing limitations caused by mental health problems and illnesses” (MHCC, 2012); some consider this approach as being in direct conflict with permitting MAID MD-SUMC (Chochinov, 2016). In the view of some Working Group members, permitting more MAID MD-SUMC may fundamentally alter the practice of psychiatry in Canada. Some clinicians disagree, however. The Ontario Shores Centre for Mental Health Sciences has noted that while “the majority of mental health professionals believe that the recovery philosophy of care in mental health is not compatible with the provision of MAID services,” they argue that “MAID and recovery are not mutually exclusive,” and that “[d]enying access to the entire mental health population does not align with recovery principles” (OSCMHS, 2017).

Some Working Group members believe that if the professional views of mental healthcare practitioners in Canada are in conflict with MAID MD-SUMC, providing MAID MD-SUMC could be problematic. In Canada, healthcare practitioners have the right to refuse to participate in MAID or the assessment of MAID eligibility. If MAID MD-SUMC were more broadly permitted, access may be limited if health practitioners refuse to participate in assessments of eligibility or in the delivery of MAID, most notably in regions of the country where there are already insufficient mental healthcare resources. This may be particularly relevant if consultation with one or more psychiatrists becomes mandatory for accessing MAID MD-SUMC, as is the case in Belgium and the Netherlands for psychiatric EAS (Section 5.2). Other Working Group members believe that offering MAID MD-SUMC in a setting where mental healthcare is not available raises important ethical concerns because, if a person is at risk of seeking MAID MD-SUMC due to insufficient mental health resources, they will also be at risk of receiving an inadequate MAID eligibility evaluation due to the same lack of resources.

Potential Implication: Permitting more MAID MD-SUMC may affect the therapeutic relationship between patients and healthcare practitioners.

Permitting more MAID MD-SUMC may have a negative impact on the therapeutic relationship between patients and mental healthcare practitioners by making it easier for healthcare practitioners to give up on challenging patients. This may in turn encourage some patients to believe there is no hope and that continuing to live may not be worth the struggle. They might also be more reluctant to fully engage with mental healthcare practitioners out of fear that they will be encouraged to seek MAID. One example of this view was provided by the Ottawa Catholic Physicians' Guild:

Tampering with the trust needed in the doctor-patient relationship by inserting the possibility of [MAID MD-SUMC] as an outcome, may undermine psychiatric treatment; ambivalent patients, knowing that [MAID MD-SUMC] could be placed on the table as a treatment option, but not really wanting death, may avoid disclosing their suicidal ideations to their physician for fear of having MAID foisted upon them.

(OCPG, 2017)

On the other hand, permitting more MAID MD-SUMC may have a positive impact on therapeutic relationships by encouraging healthcare practitioners to ensure they propose all possible non-MAID options to relieve suffering. Permitting more MAID MD-SUMC may also improve the therapeutic relationship because the patient feels respected, and does not fear being abandoned by their psychiatrist if they ask about or ultimately choose MAID.

Potential Implication: Were more MAID MD-SUMC permitted, an individual may request MAID if they are not accessing (or cannot access) psychological interventions, mental healthcare, or social supports that could relieve their suffering.

There are challenges associated with access to mental healthcare in Canada, especially for certain sub-populations (Chapter 3 and Section 6.3). Globally, mental healthcare services are poorly funded compared with other health sectors, and it is more common for patients to feel unsupported or to be unable to access such care on a timely and frequent basis (Lancet Global Mental Health Group, 2007). This is especially true outside Canada's urban centres; many rural and remote communities lack equitable access to mental health treatment (Slaunwhite, 2015; McKenzie *et al.*, 2016).

As a result, there are concerns that, were MAID MD-SUMC permitted, some people may request it because they cannot access or afford other mental health treatments that may reduce their suffering. This is a form of reduced voluntariness (i.e., lack of choice constrains voluntariness of choice). These concerns have been raised by a number of organizations in the CCA's Call for Input — including CAMH, Community Health Nurses of Canada, Covenant Health, the Ottawa Catholic Physicians' Guild, and Toujours Vivant – Not Dead Yet, among others (CAMH, 2017; CH, 2017; CHNC, 2017; OCPG, 2017; TV – NDY, 2017). Some believe that MAID MD-SUMC could replace treatment for some people's mental disorders, especially given the challenge of accessing appropriate and adequate mental healthcare in Canada. For example, the sense of isolation brought about by suffering could potentially be mitigated by a skilled therapist who can provide the patient with a sense of being understood (Clayton, 2016), but only if such treatment is available.

It is unknown, however, whether those who might seek MAID MD-SUMC are more or less likely to have access to adequate mental healthcare and social support. In Belgium and the Netherlands, patients are prevented from accessing psychiatric EAS if their physician identifies a reasonable alternative treatment for reducing their suffering (Section 5.2). In the Netherlands, those accessing psychiatric EAS generally had extensive treatment histories (Kim *et al.*, 2016). This evidence does not indicate the quality of the mental healthcare received, although there is no indication that it was anything other than what it normally is for those not seeking or receiving EAS. Research from Belgium indicates that some people requesting psychiatric EAS cite socio-economic problems such as low incomes and financial problems, and environmental factors such as social isolation, as contributing to their suffering (Verhofstadt *et al.*, 2017).

Evidence on the provision of MAID under the current law (which excludes most MAID MD-SUMC) indicates that, in general, those with inadequate healthcare (including palliative care) are not disproportionately seeking MAID. Despite this, there have been recent concerns raised around access to alternative care to relieve suffering. In May 2018, the Quebec College of Physicians (CMQ) sent a letter to Quebec's Minister of Health and Social Services stating that they have raised concerns about the availability of palliative care in the province and that there may have been cases where patients have requested MAID to die with dignity because alternative care was not available³² (CMQ, 2018). The

³² "Le Collège a lui-même constaté à diverses reprises des difficultés quant à l'accessibilité de plusieurs patients en fin de vie à des soins palliatifs [...] Dans certains cas bien identifiés, des patients, à défaut de bénéficier de ces soins, pourraient n'avoir eu d'autre choix que de demander une aide médicale à mourir pour finir leurs jours « dans la dignité », ce qui nous préoccupe."

CMQ further explains they have received reports that patients who request MAID receive priority for resources over others with similar needs³³ (CMQ, 2018). In Ontario, a man with a serious neurological disability, Roger Foley, has launched a lawsuit that includes a challenge of the MAID provisions in the Criminal Code in response to his being denied self-directed management of home care (ONSC, 2018). The statement of claim states that the defendants in the case (his local hospital, health integration network, and others) are “attempting to force discharge on the plaintiff [from hospital], to work with contracted [home-care] agencies that have failed him, at the same time offering to refer him for assisted suicide” (ONSC, 2018). Mr. Foley is claiming that in lieu of *assisted life* (adequate home–care services to relieve his suffering) he has been offered *assisted death*.

6.2 SPECULATIVE IMPLICATIONS

The Working Group identified several potential implications for which there was no evidence or no evidence specifically related to MAID MD-SUMC. As noted, the Working Group cautions that evidence related to MAID in general may not be applicable to MAID MD-SUMC because of the likelihood of differences in characteristics among those seeking MAID more generally and those who would seek MAID MD-SUMC. Despite this lack of evidence, the Working Group believes these speculative implications are important to include in order to demonstrate that these issues were considered, and to identify important knowledge gaps.

Speculative Implication: Impacts on family and friends of people with mental disorders who receive MAID.

Bereavement may be less acute for the family and friends of those whose receive MAID, as a result of going through anticipatory grief. Studies have found that anticipatory grief has resulted in less acute bereavement after cancer patients accessed EAS in the Netherlands (Swarte *et al.*, 2003). In addition, a study of family members of patients who received PAD in Oregon found that it “does not appear to have a negative effect on surviving family members and, in fact, may help some family members prepare for death” (Ganzini *et al.*, 2009). However, there are no specific data related to MAID MD-SUMC as there is no international evidence about the impacts of psychiatric EAS on friends and family.

³³ “Il a été signalé au Collège que les patients qui demandaient une aide médicale à mourir devenaient prioritaires quant aux ressources disponibles (en matière d'évaluation médicale, psychosociale, d'accompagnement spirituel, etc.) pour les accompagner jusqu'à leurs derniers moments, au détriment des autres patients en fin de vie ayant des besoins similaires.”

Some Working Group members feel that, compared to suicide, MAID MD-SUMC may reduce psychological harm to family and friends, who can avoid the shock of finding the body or of unanticipated death, the guilt over failure to prevent the death or not having been present to help, and the sorrow over having been absent.

In contrast, other Working Group members feel that permitting more MAID MD-SUMC may create psychological harm for family and friends, such as stress over how to respond to an individual's desire for MAID, and concern over whether that request will or should be granted. It may provoke feelings of anger and/or distrust toward the medical system, which can complicate grief. Furthermore, because some mental disorders have genetic components and may be common among relatives of those who seek MAID MD-SUMC, some Working Group members worry such relatives may be quicker to give up on life rather than seek (or continue) treatments for their own conditions.

Speculative Implication: MAID MD-SUMC and the overall suicide rate in society.

It is unclear whether permitting more MAID MD-SUMC would increase or decrease suicide rates, or leave them unchanged. Research has found no evidence that the legalization of assisted dying affects suicide rates, including in countries that permit MAID MD-SUMC (Section 4.2.3).

Speculative Implication: Compatibility of MAID MD-SUMC with the current approach to suicide prevention in Canada.

Some organizations that responded to the CCA's Call for Input (such as Canadian Physicians for Life, the Canadian Federation of Catholic Physicians' Societies, the Christian Medical and Dental Society of Canada, Physicians' Alliance Against Euthanasia, and the Ottawa Catholic Physicians Guild) have argued that MAID MD-SUMC is incompatible with suicide prevention efforts (CPL *et al.*, 2017; OCPG, 2017; PAAE, 2017). Some Working Group members agree. One of the key messages of WHO's 2014 report *Preventing Suicide* is "health-care services need to incorporate suicide prevention as a core component" (WHO, 2014a). If MAID MD-SUMC were more broadly permitted, it would be treated as a healthcare service. Therefore, the healthcare system may find itself trying to prevent suicide for some people with mental disorders, and at the same time providing MAID MD-SUMC to others.

Other Working Group members believe that there is no clear evidence that permitting more MAID MD-SUMC would be incompatible with suicide prevention initiatives.

Speculative Implication: Distinguishing suicidal people from those desiring MAID MD-SUMC autonomously.

Having a mental disorder is an important risk factor for suicide; a review of suicide studies found that up to 90% of all people who die by suicide may have had a diagnosable psychiatric disorder, as determined by retrospective psychological autopsy (Cavanaugh *et al.*, 2003; Arsenault-Lapierre *et al.*, 2004). The symptoms of some mental disorders may result in distorted thinking that influences a person's desire to end their life. For example, personality disorders involve maladaptive changes to cognition, such that one's perception of self is altered (APA, 2013). It may therefore be difficult for a clinician to determine whether someone with a personality disorder who requests MAID MD-SUMC has a rational or distorted view of the hopelessness of their condition.

Some Working Group members argue there is little evidence on how suicidal people can be reliably and validly distinguished from those who have an autonomous desire for MAID MD-SUMC and whose sole underlying medical condition is a mental disorder, regardless of the criteria in place. Other Working Group members believe that it is possible to distinguish between these two groups once eligibility criteria are established, but whether such criteria would offer an adequate threshold for MAID MD-SUMC is an ethical question.

Speculative Implication: Relationship between MAID MD-SUMC, individuals, and suicide.

Among people with enduring, intolerable, and irremediable suffering due to a mental disorder who would otherwise die by suicide, it is not clear how many would be eligible for MAID MD-SUMC, or how many would pursue that option were it more broadly available. Wait times may have an impact on whether suicides are prevented. Boer (2017) argues that permitting more MAID MD-SUMC is not likely to prevent suicide, especially not impulsive suicide, as the wait time to receive psychiatric EAS in the Netherlands can be quite long (7 out of 10 people included in the study had to wait at least one year to receive EAS after their first request). Thienpont (2015) found that 2 out of 35 people whose psychiatric EAS request was approved died by suicide before the procedure could be provided.

If MAID MD-SUMC continues to be prohibited for most people with mental disorders, some Working Group members believe it is possible that some people with a mental disorder who want to end their lives will resort to attempting suicide instead. The College of Registered Psychiatric Nurses of Manitoba has argued that “[i]f individuals with a primary diagnosis of a mental illness are not provided with the same freedom and liberties to be eligible for Medical Assistance

in Dying, [...] some may see suicide as their only option" (CRPNM, 2017). As discussed in Section 5.6, evidence from Belgium shows that approximately 8% (4 of 52) of those whose requests for psychiatric EAS were not accepted died by suicide (Thienpont *et al.*, 2015). In Canada, the death of Adam Maier Clayton garnered significant media attention (e.g., Martin, 2017; Picard, 2017). According to media reports, Mr. Clayton was deemed ineligible for MAID because his death was not reasonably foreseeable. Mr. Clayton had several mental disorders including depression, anxiety, obsessive-compulsive disorder, and somatic symptom disorder. Mr. Clayton was a vocal advocate for extending MAID eligibility to people with a mental disorder as their sole underlying medical condition. In April 2017, he died by suicide (Martin, 2017; Picard, 2017). Another death reported in the media was that of 90-year-old Donna Mae Hill, who attempted suicide three times in the last five years of her life, including once after being told it would be unlikely she would qualify for MAID in Ontario (Hill, 2018). While Ms. Hill — who died by an assisted suicide in Switzerland in May 2018 — had bipolar disorder and lived with "low grade depression," she had not had a psychiatric collapse since 1981 according to her son, and the symptoms of her mental disorder were not the motivating factor for her desire to access MAID (Hill, 2018).

Other Working Group members believe that if MAID MD-SUMC were more broadly permitted, there may be cases in which someone may die by MAID MD-SUMC but who might have otherwise been glad it was not available to them. Mark Henick, who has depression, an anxiety disorder, and a history of trauma, has explained that he is happy to be alive despite previously having felt that death was the only option to relieve his intolerable suffering (CTV News, 2016; Henick, 2016). Mr. Henick is now a mental health advocate who believes MAID should not be available to those who request it because of the suffering associated with a mental disorder.

Speculative Implication: Impacts of MAID MD-SUMC on the public's perception and trust of healthcare practitioners.

Permitting more MAID MD-SUMC may affect public trust and confidence in mental healthcare practitioners. It may lead to greater trust and confidence if healthcare practitioners are seen to respect patient autonomy and to observe the principle of non-abandonment. Alternatively, people with mental disorders may become more apprehensive about seeking mental healthcare services, concerned that they will be encouraged to seek MAID. It may also lead to the public losing some trust in healthcare practitioners who would now be seen as facilitating or providing death.

Speculative Implication: MAID MD-SUMC and access to mental healthcare and social supports.

Permitting more MAID MD-SUMC may affect public support for, and governmental decisions related to, funding for mental healthcare and social support services for people with mental disorders. It may increase resources directed to mental healthcare and social support services, as was the case with palliative care in Oregon, Belgium, Quebec, and the rest of Canada following legalization of assisted dying (BCSC, 2012; Bernheim *et al.*, 2014; Plante, 2015; CBC, 2017b). Alternatively, since chronically ill patients who receive MAID will no longer need services and therefore reduce costs, some Working Group members believe there may potentially be a counter-productive incentive to decrease services even further.

Speculative Implication: MAID MD-SUMC and physical risk and trauma for bystanders and first responders.

If permitting more MAID MD-SUMC reduces suicide (either by offering an alternative way to die, or because in seeking MAID a person enters treatment), danger and trauma to third parties may be reduced. Conversely, if permitting more MAID MD-SUMC changes social norms in a way that increases suicide, danger and trauma to third parties may be increased. However, there is no evidence that the legalization of MAID in any jurisdiction has altered rates of suicide (Section 4.2.3).

6.3 UNIQUE CONSIDERATIONS FOR SPECIFIC POPULATIONS

The effects of prohibiting or permitting more MAID MD-SUMC will vary among different gender, ethnic, cultural, and socio-economic populations in Canada. These variations are the result of differences in the prevalence of mental disorders among different demographic groups, the lived experience of people with mental disorders, suicidality, ability to access mental healthcare and social supports, and interest in MAID (Section 3.5). Issues related to capacity, voluntariness of request, vulnerability, discrimination, and/or other factors may arise uniquely for specific populations such as children, seniors, and institutionalized people. While there are few data on the potential impacts for most specific sub-populations, the Working Group has identified several unique considerations, as well as important knowledge gaps related to MAID MD-SUMC and these populations.

Gender

Women in Canada experience certain mental disorders at a higher rate than men (Pearson *et al.*, 2013) and are three to four times more likely to attempt suicide (although men are more likely to die by suicide) (StatCan, 2017c). The high prevalence of certain mental disorders in women are strongly associated with women's greater exposure to several social and economic inequalities, including poverty, discrimination, and gender-based violence (WHO, 2001) (Section 3.5).

International experience suggests that permitting more MAID MD-SUMC in Canada may lead to a greater proportion of women than men requesting it. Evidence from Belgium and the Netherlands indicates that women access psychiatric EAS more than twice as often as men in those countries (Thienpont *et al.*, 2015; Kim *et al.*, 2016). This differs from the gender proportions among MAID cases in Canada, where men and women have received the procedure roughly equally (GC, 2017b). It is probable that the greater proportion of women accessing psychiatric EAS in these jurisdictions is related to their greater incidence of some of the mental disorders that frequently motivate psychiatric EAS requests (e.g., depression). Some Working Group members expressed concern that permitting more MAID MD-SUMC in Canada would perpetuate the social and economic injustices that lead to greater instances of mental disorders in women by offering them MAID while these injustices remain. Other Working Group members believe that, although permitting more MAID MD-SUMC would not fix those injustices, autonomy should not be violated to further social change, and Canada can both respect autonomy and promote social and economic justice. Also, if it is acknowledged that all decisions are made under conditions of constrained choice (whether due to social and economic injustices or not), then overruling the decisions of women who face constrained choice risks having their decisions ignored or never invited. Further, if the support necessary to make a person's decisions meet some threshold of autonomy is unlikely to be provided, then overruling that person's decisions amounts to paternalism that compounds that person's marginalization and lack of freedom (Section 4.3.2).

Indigenous Peoples

There are disproportionately higher rates of suicide in some Indigenous communities and Indigenous people are known to face a range of challenges related to mental healthcare in Canada. Access to adequate and culturally appropriate mental healthcare and social support is often limited (Section 3.4). There are also access issues related to geographical location: while 30% of Indigenous people in Canada live in large population centres and consequently should have better access to mental healthcare, nearly 39% live in rural areas

(StatCan, 2018a), and may have limited access to formal mental health supports. In addition, racism within the healthcare system may increase risks of unequal access for all Indigenous people. Issues related to access may extend to MAID MD-SUMC; Indigenous people who want MAID may not request it because of their mistrust of the healthcare system, because healthcare practitioners are not available where they live, or because healthcare practitioners may not be willing to provide MAID. On the other hand, poorer access to mental healthcare on the part of Indigenous people may lead to increased suffering that may result in them seeking MAID MD-SUMC.

On the whole, it is difficult to assess how MAID MD-SUMC might affect Indigenous people, since little is known about how diverse Indigenous communities and individuals view MAID generally. MAID may not be culturally appropriate within the context of Indigenous views on end of life and end-of-life care (Elders Circle — Section 1.5.2), or in the context of Indigenous views on mental health (Section 3.4). The Working Group identified direct Indigenous consultation, and the incorporation of traditional knowledge, as important areas of evidence that require further attention and inclusion in the literature, including ongoing MAID research and assessments.

Sociocultural and Racialized Groups

Immigrant, refugee, ethno-cultural and racialized (IRER) people have lower rates of mental disorders compared to the general population when investigated as a single group, but this ignores the diversity within IRER populations (McKenzie *et al.*, 2016). People in IRER groups face a number of challenges in accessing mental healthcare services, including cultural barriers and discrimination (McKenzie *et al.*, 2016; SHS, 2017) (Section 3.5). These barriers may apply to MAID and would likely apply if MAID MD-SUMC were permitted. For instance, a study found that patients receiving MAID in the University Health Network in Toronto tend to be Caucasian (Li *et al.*, 2017).

LGBTQ+ People

The LGBTQ+ population is diverse, but overall at a greater risk of mental disorders and suicide (Bauer *et al.*, 2010; Benibgui, 2010; Mustanski *et al.*, 2010) (Section 3.5). No implications for MAID MD-SUMC and this population group are currently known.

Seniors

Compared to other demographic groups, older adults who request MAID MD-SUMC may uniquely be eligible for the procedure. While there is an evolving definition of “natural death has become reasonably foreseeable,” older people are more likely to satisfy this criterion for two reasons. First, they are more likely

to have frailty, and frailty (and age) have been identified by the Attorney General of Canada and the Canadian Association of MAID Assessors and Providers (CAMAP) as factors to consider when determining whether a person's natural death has become reasonably foreseeable (Standing Committee on Justice and Human Rights, 2016a; CAMAP, 2017b). Second, case law suggests that, once people reach a sufficiently advanced age, their natural death can be considered reasonably foreseeable even if they do not have a terminal illness (Section 4.1.2). It is unclear, however, at exactly what age a person can be considered to meet this criterion. Some Working Group members raised concerns around ageism and the devaluing of the lives of older people if age alone makes them uniquely eligible for MAID with respect to the "reasonably foreseeable death" criterion, and that expanding eligibility for MAID MD-SUMC could further contribute to this ageism and increase vulnerability in older adults with mental disorders.

In a study of 66 cases of psychiatric EAS in the Netherlands, the proportion of requests from people aged 70 or above (32%) (Kim *et al.*, 2016) was greater than the proportion of that age group in the general population (11%) (CBS, 2011). Compared to other demographics, older people are at a greater risk of social isolation (The National Seniors Council, 2014), and there is some evidence from the Netherlands that social isolation contributes to individuals with mental disorders seeking psychiatric EAS (Kim *et al.*, 2016). Additionally, some Working Group members and others have expressed concerns about potential over-inclusion of older people in psychiatric EAS in Belgium and the Netherlands *beyond* those with a diagnosed mental disorder, as a result of the acceptance of "tired of life" as sufficient psychiatric suffering (Lerner & Caplan, 2015). Other Working Group members note that under the laws of Belgium and the Netherlands, accessing EAS solely due to being "tired of life" is not permitted; a serious and incurable condition is required in order to access EAS in Belgium, while suffering has to be from a medical condition in the Netherlands (Gov. of Belgium, 2002; Cohen-Almagor, 2017; RTE, 2018b).

MAID MD-SUMC requests from older people may occur most often in the context of dementia, which is more common in older adults as compared to other demographic groups. Importantly, those who have dementia may retain their capacity to provide informed consent during the early stages of the disease (Kim, 2010). Dementia is well accepted as satisfying the eligibility requirements for EAS in the Netherlands, and the majority of these cases occur while patients retain the capacity to consent at the time of the procedure (de Beaufort & van de Vathorst, 2016; RTE, 2016). RANZCP has identified misconceptions

about older adults, PAS and suicide, and the rights of older adults in general as important issues to consider when considering physician-assisted suicide (RANZCP, 2016). Further, this organization has expressed concerns about the impacts of “debates about euthanasia on older persons” as it relates to risks of suicide (RANZCP, 2016).

Youth (Mature Minors)

While currently prohibited in Canada, the possibility of MAID being accessed by mature minors warrants discussion. Suicide is the second-leading cause of death for those in Canada aged 15 to 24, and the leading cause of death among those aged 10 to 14 (StatCan, 2017c). Because of the significant changes taking place during adolescence, prognosis of mental disorders is particularly difficult in young people. Additionally, brain development is not complete until approximately 25 years of age (Giedd, 2015). Therefore, it is even more difficult for a clinician to confidently determine whether a minor’s mental disorder is irremediable as compared to an adult over 25. Finally, the Working Group on MAID for Mature Minors found that when one considers the natural history of mental disorders that begin in childhood, it is highly unlikely that a mental disorder would be deemed irremediable before a capable minor reaches the age of majority (age 18 or 19 in Canadian jurisdictions).

Submissions obtained through the CCA’s Call for Input expressed concerns that permitting more MAID MD-SUMC would put psychologically unstable young people at risk (OCPG, 2017). Some organizations (e.g., Community Health Nurses of Canada) have suggested that there should be a minimum age for MAID MD-SUMC that would exclude mature minors (CHNC, 2017). Additional discussion on MAID and mature minors can be found in *The State of Knowledge on Medical Assistance in Dying for Mature Minors*.

Canadian Armed Forces Members and Veterans

Active Canadian Armed Forces members and veterans have higher rates of certain mental disorders, and may have better access to mental healthcare services compared to the general population (Fikretoglu *et al.*, 2016; Rusu *et al.*, 2016; Mahar *et al.*, 2017; Sareen *et al.*, 2017). However, in 2014 the Auditor General of Canada found that the mental health outreach strategy of Veterans Affairs Canada was “not comprehensive enough” and the department was not “adequately facilitating timely access to mental health services” (AGC, 2014). No implications for MAID MD-SUMC and this population group are currently known.

Incarcerated People

Mental disorders are prevalent and growing among incarcerated people, and the suicide rate of those incarcerated in federal facilities is more than seven times the Canadian average (Service, 2010). The view of suicidality in prisons may become more complicated should MAID MD-SUMC be expanded. Suicidality is treated as a risk in correctional settings, and attempts or indications of attempts may lead to solitary confinement. Incarcerated people may therefore resist expressing a considered desire to die if they fear being put on suicide watch and having freedoms curtailed (ICEL2 Satellite Workshop on Medical Assistance in Dying for Canadian Prisoners, 2017). In addition, as there is an overrepresentation of Indigenous people in prisons, expanding MAID MD-SUMC may create a greater risk for Indigenous people in these facilities, especially Indigenous men.

Canada faces “significant shortfalls” in meeting the mental healthcare needs of people in the criminal justice system (MHCC, 2012). Therefore, MAID MD-SUMC may be desired by some incarcerated people with mental disorders, even if their symptoms could be lessened had they better access to care. These issues have been highlighted by the Toronto Catholic Doctor’s Guild:

Our current correctional system does not have adequate capacity to appropriately manage inmates with mental health illness (evidenced by inhumane solitary confinement duration and substandard or inappropriate responses to cries for help à la Ashley Smith). If psychiatric illness is allowed as the sole criteria for MAID, inmates will be disproportionately affected.

(TCDG, 2017)

Existing Correctional Services guidelines provide operational direction related to the provision of MAID to people incarcerated in Canadian correctional institutions (CSC, 2017).

6.4 POTENTIAL SAFEGUARDS

In current Canadian law, several MAID safeguards, including both eligibility criteria and procedural requirements, seek to protect vulnerable populations. These safeguards prevent eligibility for most people with a mental disorder as their sole underlying medical condition, despite the procedure not being specifically prohibited under the current law. Were MAID MD-SUMC more broadly permitted, however, the modification or addition of safeguards may help to protect vulnerable people.

Given that experience with psychiatric EAS has now accrued in Belgium and the Netherlands, the Working Group believes it is useful to consider the safeguards used in these jurisdictions as well as their effectiveness. Further, some potential safeguards that have not been implemented anywhere may be effective in Canada. In some cases, implementing potential safeguards would require a change in the current eligibility criteria. These additional safeguards may be worth consideration by policy-makers in their deliberations. Of note, if safeguards were added that apply *only* to MAID MD-SUMC, people with mental disorders seeking MAID MD-SUMC may be required to satisfy more eligibility criteria or procedural requirements than people with physical disorders who qualify under the current law. In order for such additional steps to be justified, it would need to be demonstrated that the safeguards unique to those seeking MAID MD-SUMC were guarding against risks that are not faced by those seeking MAID for physical disorders. Differential treatment of those with mental disorders may be warranted due to unique characteristics of such disorders (e.g., their impact on capacity, altered decision-making, and perceptions of the future).

Safeguards are aimed at preventing over-inclusion — that is cases where MAID MD-SUMC should not occur due to ineligibility (e.g., as a result of coercion or lack of capacity). On the other hand, safeguards might mean capable and eligible people are unable to obtain MAID MD-SUMC (under-inclusion) or are forced to navigate unnecessarily complicated or long processes while experiencing intolerable suffering. In most safeguards, there is an inherent trade-off between steps to protect vulnerable people and creating unnecessary delays or impediments (which can also contribute to vulnerability).

In the following section, the Working Group considers nine safeguards for MAID MD-SUMC and any evidence about their effectiveness while keeping this trade-off in mind. The discussion of safeguards is meant to inform policy-makers; the Working Group makes no assumption that the law will be changed, nor do they endorse or dismiss any particular safeguard. Additionally, the safeguards listed are not presented in ranked order and the Working Group does not intend to suggest limits on what policy-makers may or may not do or consider.

Some Working Group members believe that, even with safeguards in place, some of the previously identified risks of over-inclusion would still not be mitigated should MAID MD-SUMC be expanded. These Working Group members note that the safeguards are discussed conditionally in reference to answering the charge (i.e., *if* MAID MD-SUMC were to be permitted), and should not be taken to imply an endorsement of permitting more MAID MD-SUMC. Other Working Group members believe that, with proper safeguards, that risks of both over- and under-inclusion could be sufficiently balanced were MAID MD-SUMC expanded.

6.4.1 Psychiatric Consultation

Clinical assessment of a candidate's eligibility forms the basis for the primary safeguard for MAID in Canada. If MAID MD-SUMC were more broadly permitted, a potential safeguard might include increasing the requirements that form these assessments. As described in Chapter 5, Belgium and the Netherlands require additional independent assessment(s) of eligibility for those seeking EAS when death is not imminent, as is the case for most psychiatric EAS requests. In Switzerland, there is an informal version of this safeguard in place despite not being part of the legislation; the Swiss EAS organization EXIT requires that two independent experts agree that a person is eligible for an assisted death on the basis of a psychiatric disorder. The repetition and independence of eligibility assessments offers an opportunity to prevent over- or under-inclusion.

Belgium and the Netherlands also require that assessors have relevant medical expertise to ensure they are qualified to evaluate the eligibility of those seeking psychiatric EAS. More specifically, in Belgium, if death is not foreseeable, two additional independent assessors — at least one of whom has expertise in the particular disorder (generally a psychiatrist for psychiatric EAS cases) —must be consulted. In the Netherlands, while only one additional independent assessor is legally required, the RTE Code of Practice recommends that an independent psychiatrist be consulted in cases of psychiatric EAS, in addition to another independent physician.

It is important to note that the role of the physician or nurse practitioner in determining eligibility for MAID under the current system in Canada is different in some respects from their role in Belgium and the Netherlands. For example, under Canadian law, healthcare practitioners evaluate the eligibility criterion related to suffering in reference to the patient's subjective perceptions of their suffering and what conditions for relief the patient considers acceptable. In Belgium and the Netherlands, a physician must agree that a patient's suffering has no prospect of improvement.

Given the challenges of assessing capacity and prognosis in people with mental disorders who request MAID MD-SUMC, the inclusion of psychiatrists in the evaluation of psychiatric EAS requests in Belgium and the Netherlands is not surprising, even if not always followed in practice (Kim *et al.*, 2016; Dierickx *et al.*, 2017). Although the mandatory inclusion of psychiatrists (or other experts in the disorder) in the evaluation process may improve the reliability of capacity assessments, difficulties in prognostication for most mental disorders means disagreement about incurability and advanced state of irreversible decline will likely remain among such experts, were this safeguard to be implemented in Canada. For example, there was disagreement among consulting physicians

in 16 of 66 (24%) psychiatric EAS cases examined in the Netherlands (Kim *et al.*, 2016). Agreement is not required among consultants in the Netherlands, and EAS was provided in all of the studied cases where there was disagreement among consultants. If adopted in Canada, this safeguard could potentially be strengthened by requiring that all consultants agree a patient is eligible for MAID MD-SUMC before allowing them to receive the procedure. However, some Working Group members believe this could potentially lead to unnecessary delays or impediments for those seeking MAID. Under Canada's current MAID law, two independent assessors must agree that a person is eligible for MAID (GC, 2016b).

As discussed in Chapter 5, recent advisory documents and statements have been issued in Belgium examining ways to strengthen safeguards related to evaluation. An advisory document from the Flemish Association of Psychiatry (VVP) and an organization representing hospitals and institutions in Belgium (Zorgnet-Icuro) endorses the requirement that at least two psychiatrists be involved in every case of psychiatric EAS, and that there be two positive recommendations (VVP, 2017; Zorgnet-Icuro, 2018). The VVP further states that any negative recommendation also be considered in order to address the issue of doctor shopping, and that consultation with current and previous key healthcare practitioners providing care to the patient is essential (VVP, 2017).

Some Working Group members believe that placing additional requirements on eligibility assessments for MAID MD-SUMC would result in unwarranted steps not imposed on people with physical disorders who meet the current eligibility criteria for MAID. Other Working Group members believe that such additional requirements may be warranted because of the unique characteristics of mental disorders (such as their impact on capacity, decision-making, and perceptions of the future). Additionally, as discussed in Section 4.1.4, Working Group members disagree on whether differential treatment of those seeking MAID MD-SUMC compared to those making other highly consequential decisions would be justified by the characteristics of MAID MD-SUMC.

The psychiatric consultation safeguard was considered and rejected by Parliament in the context of passing federal legislation (Bill C-14) that ultimately applied mainly to non-psychiatric conditions (SJCPAD, 2016). However, given that permitting most cases of MAID MD-SUMC would require a change in the existing law, policy-makers may wish to re-examine the psychiatric consultation safeguard. Additionally, while the requirement for additional expert consultation in this context would usually require a psychiatrist, it may also demand consultation with different specializations or different professions in some cases. Some Working Group members believe such a safeguard may lead to problems

of unequal access to MAID MD-SUMC if it were more broadly permitted, as specialists may only be available for assessments in large urban centres. Other Working Group members note that offering MAID MD-SUMC in a setting where there are limited or no mental healthcare services raises important ethical concerns. Specifically, if a person is at risk of seeking MAID MD-SUMC due to insufficient mental health resources they will also be at risk of receiving an inadequate MAID eligibility evaluation because of the same lack of resources.

6.4.2 Multi-Disciplinary Evaluation

Explicitly requiring that the examination of a person's suffering go beyond medical factors has been proposed as a possible safeguard to ensure a more thorough evaluation for MAID MD-SUMC. This would entail evaluation of suffering beyond what is included in the current Canadian law, wherein suffering is assessed based on the patient's subjective perceptions of intolerability and acceptability of treatment. Such a safeguard could include the explicit requirement that there be a process that considers psychosocial or non-medical factors that contribute to suffering, such as grief, loneliness, stigma, shame, or lack of support for the patient or their caregivers. To the extent that some physicians and nurse practitioners may not have the experience and ability to effectively evaluate matters such as psychological and cognitive functioning or social conditions, other experts could be included in the evaluation process. According to the Canadian Psychological Association (2016), "the assessment of a person's capacity to give informed consent, particularly when that person has a concomitant psychological or cognitive disorder, must be left to those regulated health providers with the training and expertise to undertake these kinds of complex assessments," adding that "when a person presents with a grievous and irremediable medical condition concomitant with a cognitive and/or psychological one, the person's capacity to give consent (should) be assessed by a regulated health provider whose scope of practice includes the assessment of cognitive and/or psychological conditions." As people seeking MAID MD-SUMC would have a psychological or cognitive disorder, this recommendation could extend to many MAID MD-SUMC requests. Other members of evaluation teams have also been proposed; for example, Zorgnet-Icuro in Belgium recommended including social workers in the assessment of MAID MD-SUMC requests (Zorgnet-Icuro, 2018).

Some Working Group members believe that placing additional requirements on assessments of suffering for those requesting MAID MD-SUMC would create unwarranted steps not imposed on those with physical disorders who meet the current eligibility criteria for MAID. Other Working Group members believe

that additional safeguards for MAID MD-SUMC may be warranted precisely because of the unique characteristics of mental disorders (such as their impact on capacity, decision-making, and perceptions of the future).

6.4.3 Roundtable, Committee, Tribunal, or Judicial Approval

Several organizations have suggested the use of an additional step in the approval process, be it through a roundtable, committee, tribunal, or judicial approval. This type of safeguard seeks to provide another means to ensure all aspects are examined when assessing factors such as capacity, prognosis, and undue influence on decision-making in those requesting MAID MD-SUMC. Provided it is well-resourced, an additional approval step could serve this function by including a broader range of views and perspectives in the assessment process, and by providing an opportunity to include all information pertinent to the decision.

Committee approval exists informally in Switzerland, despite not being prescribed by law, as EXIT requires that any assisted suicide for those with a mental disorder as their sole underlying medical condition be approved by their Ethics Commission (EXIT, 2016). The Working Group did not identify any data related to the approval or rejection of cases by this Commission. In Belgium, the recent advisory document from the VVP recommends that, while the patient and three physicians (the one providing EAS and two consultants) make the final decision about psychiatric EAS, all of the patient's doctors and healthcare practitioners should be involved. The VVP suggests that this be done in a roundtable format to enable the group to discuss the request openly and jointly, and to weigh all considerations (VVP, 2017). In Canada, the Vulnerable Persons Standard (VPS) suggests that “expedited prior review and authorization by a judge or independent body with expertise in the fields of healthcare, ethics, and law” be required prior to approval for all cases of MAID (VPS, 2017). The VPS safeguard was considered and rejected by Parliament in the context of passing federal legislation (Bill C-14) that ultimately applied mainly to physical conditions (those where death has become reasonably foreseeable) (SJCPAD, 2016). However, policy-makers may choose to consider this safeguard if MAID MD-SUMC is permitted more broadly.

Some Working Group members believe a disadvantage of requiring additional approval steps is that the procedure may become burdensome for people who are suffering intolerably. The risk of unnecessary suffering would increase if any additional steps were not completed in a timely manner due to an overly complex process or insufficient resourcing. The issue of burdensome delay may

be different for many potential cases of MAID MD-SUMC compared to other conditions. Delays in cases where natural death or loss of capacity is imminent may foreclose eligibility for MAID. In contrast, delays in cases where natural death has not become reasonably foreseeable (as with most cases of mental disorders) will not necessarily foreclose eligibility for MAID, although it will extend the length of time during which a person suffers intolerably. Undergoing the evaluation process, however, does not preclude continued treatment and efforts to relieve the person's suffering. A second potential disadvantage of prior judicial review in particular is that it may create a barrier to access for those living on low incomes if access to the courts is not free.

Some Working Group members note that introducing additional approval steps for people with a mental disorder as their sole underlying medical condition may mean they would face unwarranted processes not faced by those with physical disorders who meet the current eligibility criteria for MAID. Other Working Group members believe that additional approval steps for MAID MD-SUMC may be warranted because of the unique characteristics of mental disorders (such as their impact on capacity, decision-making, and perceptions of the future), the history of promoting liberties without supporting resources and safeguards leading to adverse outcomes, and the fact that some laws which already permit special protections of people with mental disorders.

Currently, people with mental disorders have the right to make end-of-life decisions, such as requesting palliative sedation, refusing artificial nutrition and hydration, and refusing or requesting the removal of life-sustaining treatment without additional approval steps. As discussed in detail in Section 4.1.4, Working Group members disagree on whether differential treatment between MAID MD-SUMC and other highly consequential decisions would be justified by characteristics of MAID MD-SUMC.

6.4.4 Involvement of Family and/or Important Third Parties

The inclusion of family or important third parties in the decision-making process for MAID MD-SUMC is a potential safeguard against the possibility that a MAID request might not reflect the autonomous wishes of the person making the request. By discussing the request with the person's family, assessors may have greater confidence that the patient's decision is not the result of undue influence, either from the symptoms of their disorder or from external psychosocial factors.

As noted in Chapter 5, the laws in Belgium and Luxembourg provide that physicians should discuss the EAS request with the patient's representative and/or family members unless the patient objects or there are well-founded reasons for not doing so. Recent recommendations from the VVP and Zorgnet-Icuro in Belgium strongly suggest that family and significant others be involved in decisions regarding psychiatric EAS, and that physicians would be unable to perform their tasks adequately if patients refused to have them included (VVP, 2017; Zorgnet-Icuro, 2018). It is not recommended by these organizations that family members approve EAS, but rather that their thoughts and feelings be included in the discussions about the procedure (VVP, 2017).

Some Working Group members note that this safeguard may be viewed as creating a risk for vulnerable people who do not want their families involved in the process. There are a variety of reasons why this may be the case, including familial abuse. Furthermore, requiring patients to allow involvement of family (or other third parties) if they wish to be evaluated for MAID may violate well-established legal norms in Canada regarding patient autonomy and privacy; this safeguard would make MAID MD-SUMC the only medical decision legally requiring capable people to involve family members. Other Working Group members emphasize that the safeguard would not necessarily have to be a requirement, but rather an option for MAID evaluators.

6.4.5 Two-Track Approach During MAID MD-SUMC Evaluation

A process that explicitly includes an examination of other treatment options has been proposed as a potential safeguard to ensure patients are aware of these options. Such a safeguard could determine whether a patient's suffering might be relieved by other kinds of psychological interventions. Specifically, the recent advisory document from the VVP recommends that during the process of evaluating eligibility for psychiatric EAS, physicians should maintain a "two track" process involving two different psychiatrists: one conducts a thorough and extended evaluation for MAID eligibility, while the other explores treatment options with the person requesting MAID from a recovery-oriented perspective (VVP, 2017). Some Working Group members note that, under current Canadian law, a patient is not required to accept treatment for the purposes of MAID eligibility; it is only required that they be informed of the means available to alleviate their suffering in order to give informed consent for MAID. Other Working Group members believe that, since expanding eligibility for MAID MD-SUMC would involve changes to the existing MAID law, it will be up to policy-makers to consider what (if any) changes in the current law they consider to be warranted.

6.4.6 Training of Healthcare Practitioners Consulting on MAID MD-SUMC Requests

Specialized training for healthcare practitioners involved in MAID MD-SUMC could be used as a safeguard to address the difficulties of assessing factors such as capacity, prognosis, and undue influence on decision-making in people with mental disorders who request the procedure. Training and expertise could be shared through CAMAP, a voluntary organization that already offers tools and an information library, as well as an online forum for MAID providers (CAMAP, 2017a). The Canadian Medical Association could also provide such training, as they already do for MAID across the country, with the exception of Quebec. The need for better and targeted capacity assessment tools, as well as education for healthcare practitioners in order to improve their ability to assess capacity in people with mental disorders, was highlighted by several organizations in the CCA's Call for Input. These organizations include the Canadian Bar Association, the College of Registered Psychiatric Nurses of Manitoba, and the Nurse Practitioners Association of Canada (CBA, 2017; CRPNM, 2017; NPAC, 2017). It is not clear what training specific to MAID MD-SUMC should contain, nor how effective it would be as a safeguard given the need for specialty (and sometimes subspecialty expertise) in evaluating mental disorders.

6.4.7 Waiting Period Between Request and Administration of MAID

The presence of a waiting period between the request and provision of MAID MD-SUMC is a safeguard intended to ensure that a person's desire for MAID is stable rather than impulsive. Such a waiting period could be longer than the 10-day period required in the current Canadian MAID law (GC, 2016b). As discussed in Chapter 5, laws in Belgium specify that, in cases where a person's death is not reasonably foreseeable, there must be a one-month waiting period between the request and the administration of EAS (Gov. of Belgium, 2002). In a Belgian study that examined psychiatric EAS, 11 of 48 patients approved for the procedure postponed or cancelled the procedure after approval (Thienpont *et al.*, 2015). Eight people explained that knowing they had the option of psychiatric EAS "gave them sufficient peace of mind to continue their lives," two changed their mind "due to strong family resistance," and in one case, EAS could not be implemented because the patient was in prison (Thienpont *et al.*, 2015). A further 38 withdrew their request before a decision was reached (Thienpont *et al.*, 2015). An even longer waiting period has been suggested for MAID MD-SUMC cases given the episodic nature of many mental disorders. For example, recent recommendations from the VVP and Zorgnet-Icuro suggest a waiting period longer than the current required month, to ensure sufficient time is taken in evaluating the patient and to ensure the request is persistent (VVP, 2017; Zorgnet-Icuro, 2018). In one case, the recommendation is for a waiting period of at least one year (Zorgnet-Icuro, 2018). Some Working

Group members noted such a safeguard would mean that people with mental disorders would face barriers to accessing MAID not imposed on those with physical disorders who meet the current eligibility criteria. Other Working Group members believe that such a safeguard may be needed to accommodate the unique features of MAID MD-SUMC, if it were expanded.

Some Working Group members believe that adding a waiting period would delay the provision of MAID MD-SUMC for those who do qualify, thereby prolonging their suffering. Indeed, in the Thienpont *et al.* (2015) study, 4% of those approved for psychiatric EAS (2 out of 48 approved requests) died by suicide during the waiting period after approval, before the procedure could be carried out. In at least one case, this was due to the fact that the person “found the waiting time after the approval unbearably long” (Thienpont *et al.*, 2015). However, other Working Group members believe that, without sufficient waiting periods, some people who would change their minds, given enough time, may receive MAID MD-SUMC. As noted above, in Thienpont *et al.* (2015), 11 of 48 people (23%) whose requests for psychiatric EAS were accepted postponed or cancelled the procedure before it was carried out. In addition, out of 100 total applicants, 38 people withdrew their requests for psychiatric EAS before a decision was reached regarding their eligibility (Thienpont *et al.*, 2015). Thus, approximately half of the requests were withdrawn either before or after a decision was reached.

6.4.8 Agreement on Determination of Treatment Futility

A potential safeguard aimed at avoiding over-inclusion in MAID MD-SUMC would be to require that both a physician and patient agree on the futility of treatment. The current MAID law reflects the importance placed upon informed consent and self-determination with respect to medical decision-making in Canadian constitutional and common law. Canadian MAID law specifies that the alleviation of a patient’s suffering is not determined by the availability of effective treatment, but by whether the patient regards the treatment as acceptable. Therefore, the patient’s own views about whether a treatment is acceptable and whether their suffering is intolerable are determinative. This is in contrast with the approaches in Belgium and the Netherlands where the law requires that a physician and patient together agree that suffering has no prospect for improvement based on best current scientific evidence (Chapter 5). The advisory document from the VVP, citing the 2009 Dutch psychiatric guidelines, suggests that, while a patient is “entitled to refuse a treatment offering a reasonable prospect of success,” this refusal should preclude EAS, as it makes it impossible to then determine that the condition is medically hopeless and untreatable, and that suffering cannot be alleviated (VVP, 2017). The document argues

that a patient should be deemed untreatable only after all standard biological, psychotherapeutic, and social interventions indicated for that patient have been attempted (VVP, 2017).

Whether the Belgian and Dutch approach is a useful safeguard depends on how one understands the definition of *irremediable* (Chapter 4), and how one views the risks of over-inclusion or under-inclusion. Some Working Group members emphasize that rigorous evaluations of futility may help prevent the over-inclusion of people whose suffering may be remediable; other Working Group members note that this may cause under-inclusion by creating unwarranted barriers for those who are suffering and who view the harms of potentially effective treatment as unacceptable to them. Canada already permits MAID MD-SUMC based on a person's subjective assessment of the intolerability of their suffering, although few people with a mental disorder as their sole underlying medical condition will meet all of the other eligibility criteria, such as a reasonably foreseeable natural death. Some Working Group members argue that if Canada were to permit more MAID MD-SUMC based only on a person's subjective assessment of intolerable suffering and of what conditions for relief they consider acceptable, it could become the most permissive jurisdiction in the world in terms of how suffering is evaluated.

In the Canadian context, consent laws are normally considered a matter of provincial or territorial jurisdiction. It would be up to policy-makers to assess how to implement a safeguard that requires a physician to concur with the patient regarding the lack of acceptable treatment options, given the division between federal, provincial, and territorial jurisdictions over health law.

Years Affected

Uncertainty surrounding the prognosis of many mental disorders has potential implications for MAID MD-SUMC. However, as noted in Section 3.1.2, the longer a person has a mental disorder and the better the course of that disorder is known, the greater confidence a physician may have in the prognosis. Thus, a possible safeguard could be to limit eligibility for MAID MD-SUMC to people who have lived with a mental disorder for a certain period of time. This safeguard would, by its definition, likely exclude minors from obtaining MAID MD-SUMC even if the minimum age requirement were eliminated. Some Working Group members note that such a safeguard could extend years of suffering prior to an individual becoming eligible for MAID MD-SUMC.

6.4.9 Mandatory Reporting and Review of Cases

A mandatory reporting system and review process could together contribute to a potential safeguard to detect over- and under-inclusion and allow for an understanding of who is requesting and receiving MAID MD-SUMC. The regulations around monitoring MAID were released in the summer of 2018 (GC, 2018a). The regulations came into force on November 1, 2018 (GC, 2017a). The purpose of these regulations is to collect and analyze “data about medical assistance in dying from a societal perspective” and is not intended to “assess individual medical or nurse practitioners’ compliance with the *Criminal Code* exemptions” (GC, 2018a). These regulations require the reporting of a range of information including certain demographic factors (age, sex, postal code) as well as data related to the eligibility criteria. The regulations also require reporting on findings of ineligibility and withdrawal of MAID requests; this information would permit the reporting system to detect cases of over- and under-inclusion. Canada does not currently have an oversight review process for MAID cases, and the MAID regulations note that issues of non-compliance with the *Criminal Code* “falls outside the scope of the federal monitoring regime, and is under the purview of local law enforcement” (GC, 2018a).

The Benelux countries require that physicians report all cases of EAS to an oversight committee so that compliance with both eligibility criteria and procedural elements of the law can be verified (Section 5.7). This oversight system has detected a very small number of cases where requirements were not met: 89 cases in the Netherlands and 1 case in Belgium, out of approximately 62,000 combined cases of EAS, from 2002 to 2016 (Mason & Weitenberg, 2015; Miller & Kim, 2017). These numbers refer to all cases of EAS, not only psychiatric EAS. The actual number of cases where eligibility criteria were not met may be higher, however, as there is some evidence that the review committees may not always make a finding of non-compliance with due care criteria where the rules were not followed (Kim *et al.*, 2016; Dierickx *et al.*, 2017). In addition, some have argued that the small number of such cases might not be because the system is successful at preventing over-inclusion, but rather “because the system is not designed to, or cannot, provide such strict oversight” (Miller & Kim, 2017).³⁴

Quebec also has a mandatory reporting system, operated through Commission sur les soins de fin de vie (Gov. of QC, 2014). The Commission’s mandate is to “examine any matter relating to end-of-life care,” including MAID. Physicians

³⁴ This study examines all “due care not met” EAS cases in the Netherlands, not just those that relate to psychiatric EAS.

who provide MAID in Quebec must submit a report to the Commission within 10 days. These reports are reviewed to ensure compliance with Quebec's end-of-life legislation (Gov. of QC, 2014).

A reporting system in Canada could contain requirements beyond those in the Benelux countries. It has been suggested that more detailed and accurate records should be collected in MAID MD-SUMC cases, including data related to standardized methods for diagnosis and capacity assessment (Lopez-Castroman, 2017). The inclusion of psychiatric expertise on review committees may support the detection of over-inclusion or under-inclusion related to assessing capacity, prognosis, suffering, and undue influence on decision-making in people with mental disorders. Currently there are no psychiatric experts on the Belgian review committee (Zorgnet-Icuro, 2018), while the inclusion of such expertise on the Dutch RTE is relatively recent (Onwuteaka-Philipsen *et al.*, 2017).

6.5 CONCLUSION

The Working Group brought of range of perspectives on prohibiting or permitting more MAID MD-SUMC, and through their deliberations and review of the evidence, identified several potential implications and unique consideration for specific populations. These implications fell into three categories: (i) those related to the current eligibility criteria, (ii) vulnerability and autonomy, and (iii) mental healthcare. Working Group members do not agree on the probability of each implication occurring, nor on how to balance the evidence supporting each implication. The above discussion of implications does not present the consensus view of the Working Group; rather, it is intended to provide policy-makers with a comprehensive summary of the potential implications (and unique considerations) related to prohibiting or permitting more MAID MD-SUMC, as well as a review of the evidence underlying these potential implications.

Several potential safeguards were also identified by the Working Group through a review of the evidence, including evidence from jurisdictions that currently allow psychiatric EAS. While the Working Group makes no assumption that Canadian MAID law will be changed, this examination of safeguards addresses part of the charge by considering how they may (or may not) help protect vulnerable people were eligibility for MAID MD-SUMC expanded. As with the potential implications, the discussion of safeguards is meant to inform policy-makers, and the Working Group does not endorse or reject any safeguards.

As summarized at the end of Chapters 3 to 5, there are many important knowledge gaps concerning mental disorders, key issues related to mental disorders and MAID, and psychiatric EAS worldwide. These knowledge gaps limited the degree of certainty and level of analysis with which the Working Group could examine potential implications and safeguards. Moving forward, continued research and examination of the issues outlined in this report will help to address some uncertainties and reduce or remove these knowledge gaps. Ultimately, however, the issue of whether to alter the existing law to further permit or restrict MAID MD-SUMC is a challenging question upon which people disagree. While empirical data, legal arguments, and clinical practice can inform specific aspects of the question, whether or not to further permit or restrict MAID MD-SUMC ultimately requires ethical judgment by policy-makers.

7

Conclusion

- Answering the Charge
- Final Thoughts

7 Conclusion

This report answers the charge posed to the CCA by the Ministers of Health and Justice, on behalf of the Sponsors, Health Canada and the Department of Justice Canada, as it relates to medical assistance in dying for those with a mental disorder as their sole underlying medical condition (MAID MD-SUMC). As noted in Chapter 1, which presents the charge and the evidence considered, the legislation mandating this independent review and the Sponsor’s charge used the term *mental illness*. However, the Expert Panel Working Group chose to use the term *mental disorder* in order to be consistent with current clinical and legal practice, and relied on the American Psychiatric Association’s *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) to determine the scope of conditions considered within this report. The Working Group notes that the term *mental disorder* covers a diverse and heterogeneous range of conditions, with distinct clinical profiles and underlying causes. There is wide variability in symptoms and clinical presentation even within individual diagnostic categories, and the impact of a mental disorder on a person’s thoughts, emotions, behaviour, functioning, and quality of life is highly individual. As such, it is difficult to make any generalizations about this broad category, especially when discussing potential implications of prohibiting or further expanding MAID MD-SUMC.

Under the current law, people with a mental disorder as their sole underlying medical condition are not excluded from MAID provided they meet all of the eligibility criteria. The scope of this report, however, is restricted to those cases that are not permitted under the current law, as will be the case for most people whose mental disorder is their sole underlying medical condition.

As requested by the main question of the charge, this report brings together the available evidence to inform the understanding of MAID MD-SUMC, considering the clinical, legal, cultural, ethical, and historical contexts in Canada. The charge also includes a number of sub-questions, the answers to which are summarized in this chapter. Brief summaries of the questions that were directly answered in Chapter 6 — which covered potential implications of prohibiting or permitting more MAID MD-SUMC as well as possible safeguards — are presented first, followed by answers to the remaining questions, appearing in the order that they are addressed in Chapters 3 to 5. These three chapters present an overview of mental disorders in Canada, key issues for mental disorders and MAID, and assisted dying for people with mental disorders worldwide.

7.1 ANSWERING THE CHARGE

What are the potential implications for individuals and other affected persons, including their families, care providers, and health professionals, related to MAID where [a mental disorder]³⁵ is the sole underlying medical condition?

What are the potential impacts on society of permitting or prohibiting requests for MAID where [a mental disorder] is the sole underlying medical condition?

Based on their deliberations and review of the evidence, the Working Group identified potential implications and impacts related to prohibiting or permitting more MAID MD-SUMC. Those who could be impacted include people with mental disorders, healthcare practitioners, people with chronic conditions, and the family and friends of those with mental disorders. Impacts on society include those on the mental healthcare system, suicide prevention, and discrimination and stigma against people with mental disorders.

There is a wide range of potential impacts and implications, and these may vary depending on the individual as well as on the mental disorder in question. Furthermore, the Working Group does not agree on the probability of each implication occurring, nor do they agree on how to weigh the evidence about each implication. All potential implications and impacts, and the evidence underlying them, are discussed in Chapter 6.

What are the unique considerations related to individuals living with [a mental disorder] (including mature minors) requesting MAID where [a mental disorder] is the sole underlying medical condition, both in communities and institutions?

The impacts of prohibiting or permitting more MAID MD-SUMC will vary among different populations based on variations in the prevalence of mental disorders, the lived experience of people with mental disorders, suicidality, the ability of people to access mental healthcare and social supports, and their views on MAID. Many of the knowledge gaps concern what is not known about MAID MD-SUMC for several population groups.

The Working Group identified Indigenous consultation and the incorporation of traditional knowledge as important areas of evidence that require further attention and inclusion by policy-makers and researchers. What evidence exists

³⁵ Original language in the charge was *mental illness*.

with respect to unique considerations for other specific populations — including immigrant, refugee, ethno-cultural and racialized groups; women; mature minors; LGBTQ+ people; seniors; Canadian Armed Forces members and Veterans; and incarcerated people — are briefly summarized in Chapter 6. The unique considerations for mature minors are summarized in Chapter 6 and were considered by the Mature Minors Expert Panel Working Group.

What are the potential risks and safeguards that might be considered related to requests for MAID where [a mental disorder] is the sole underlying medical condition?

The main risks of prohibiting or further expanding MAID MD-SUMC relate to over-inclusion or under-inclusion. *Over-inclusion* refers to people receiving MAID in cases where it should not occur (due to ineligibility or undue influence), while *under-inclusion* refers to capable, eligible people not being able to receive MAID. Existing safeguards in Canada's MAID law prevent eligibility for most people with a mental disorder as their sole underlying medical condition (as they do for some people with chronic physical conditions), though there is not a specific blanket prohibition for people with such conditions. There are a range of safeguards that could potentially mitigate some of the risks of over-inclusion were MAID MD-SUMC permitted more broadly, although there is disagreement among Working Group members about whether safeguards could mitigate certain risks (Chapter 6). In addition, what is a safeguard to some people might be a barrier to others, and some safeguards may create a risk that capable and eligible people are unable to obtain MAID MD-SUMC (under-inclusion). In Chapter 6, the Working Group considers nine safeguards — including those currently implemented in Belgium and the Netherlands countries as well as those that have yet to be implemented in any jurisdiction — and reviews any evidence relevant to their effectiveness.

What is the impact of mental [disorders] in [their] different forms on an individual's legal capacity to request and consent to MAID?

In order to provide informed consent for MAID, a person must have the legal capacity to make that decision. In Canada, all adults, including those with mental disorders, are presumed to have the legal capacity to make consequential medical decisions. This presumption can only be overturned after a formal capacity assessment undertaken by a healthcare practitioner indicates that a person's decision-making capacity is impaired. Moreover, as capacity is always evaluated relative to a particular decision, a person might have the legal capacity to make some decisions but not others (Chapter 3).

Most people with mental disorders have the capacity to make highly consequential decisions about medical treatment. However, evidence shows that some mental disorders can impair a person's decision-making and increase their risk of incapacity. There may also be challenges associated with assessing decision-making capacity in some individuals with mental disorders, and different assessors may disagree about whether or not a person is capable. A particular challenge for some people who request MAID MD-SUMC is that their desire to die could be a symptom of their mental disorder. Suicidal ideation is a common symptom of some mental disorders, and some mental disorders can distort a person's thoughts and emotions, leading to a desire to die, hopelessness, and a negative view of the future. It may be difficult for a clinician to distinguish between a capable person who is making an autonomous decision for MAID MD-SUMC and a person whose pathological desire to die is a symptom of their mental disorder that impairs their decision-making.

People with mental disorders undergo capacity assessments with respect to other highly consequential decisions that are likely to result in the person's death (e.g., refusing life-sustaining treatment). However, Working Group members disagree about whether such decisions are comparable to MAID, partly for reasons related to the ethical and practical distinction (or lack thereof) between acts and omissions, or killing versus letting someone die (Box 7.1).

As discussed in Chapter 4, decision-making may be affected by the symptoms of a person's mental disorder even when they meet the legal test for capacity. For a more detailed discussion of the impact of some mental disorders on the capacity to provide informed consent for MAID and decision-making, see Chapter 4.

What are the relevant gaps in domestic and international knowledge and research related to requests for MAID where [a mental disorder] is the sole underlying medical condition?

Given that assisted dying for those with mental disorders is legal in a small number of jurisdictions around the world, direct evidence on the practice is limited. Little is known about assisted suicide for mental disorders in Switzerland and Germany, despite the fact that it does occur in those countries. Thus, most direct evidence regarding MAID MD-SUMC comes from Belgium and the Netherlands. Despite decades of research on the practice of psychiatric EAS in those countries, knowledge gaps exist. For example, there are few data on the sociodemographic characteristics of people who request and/or receive psychiatric EAS in Belgium and the Netherlands, beyond gender and age. Therefore, if more MAID MD-SUMC were permitted in Canada, it is difficult to predict who might request it. There is also a need for the integration of patients' voices in discussions around psychiatric EAS in Belgium and the

Netherlands. Finally, the impact of psychiatric EAS on Dutch and Belgian physicians and healthcare practitioners, as well as on the family and friends of those who request this procedure, is not known.

Thus, there is little evidence on the potential impacts of prohibiting or permitting more MAID MD-SUMC in Canada on affected individuals, or on Canadian society. Similarly, the potential impact of prohibiting or permitting more MAID MD-SUMC on the societal perceptions and stigmatization of people with mental disorders is unknown. As with Belgium and the Netherlands, the inclusion of patient voices and the views of those with disabilities in discussions of MAID MD-SUMC in Canada could be an important step in addressing some of these knowledge gaps. It is also not known how permitting more MAID MD-SUMC might affect funding for mental healthcare and social support services, nor its potential impacts on how suicide prevention is practised in Canada.

Finally, there are knowledge gaps related to both the effectiveness and the legality of certain potential safeguards for MAID MD-SUMC. As some of the safeguards examined in Chapter 6 have not been implemented anywhere in the world, there is no evidence on their effectiveness; other safeguards have been implemented in the practice of psychiatric EAS in Belgium and the Netherlands, but evidence of their effectiveness is sometimes either lacking or open to interpretation. Additionally, even if a safeguard has been implemented elsewhere, its relevance and effectiveness in the Canadian context are unknown. Important contextual factors include: cultures; geographies; demographics; healthcare systems; and legal systems such as different laws, differing judicial approaches, and differences in jurisdictional divisions between the federal government (which is responsible for the *Criminal Code*, which sets out the legal conditions under which MAID is provided) and provincial and territorial governments (which are responsible for the provision of healthcare and mental health law).

7.2 FINAL THOUGHTS

Whether to expand, prohibit, or make no changes to the law that governs MAID with respect to the eligibility of those with a mental disorder as their sole underlying medical condition is a contentious subject on which there are differing opinions. The Working Group's expertise came from a range of disciplines and experiences that gave each member a unique perspective on MAID MD-SUMC. Each Working Group member brought their own expertise to the deliberations, and the assessment process enabled a robust exchange of viewpoints, which often diverged. Working Group members feel that the opportunity to participate in a constructive exchange of ideas resulted in a report that shows the breadth of viewpoints and perspectives on the evidence.

Box 7.1**Working Group Disagreements on Fundamental Issues on MAID MD-SUMC****Weighing of outcomes**

The Working Group disagrees about how to balance two risks: ending the life of a person with a mental disorder whose condition would have improved and who would have regained the desire to live, and denying MAID MD-SUMC to a person whose condition would not have improved and who would continue to live with intolerable suffering.

How and when to die vs. whether to die

Some Working Group members believe that there is a fundamental difference between MAID in circumstances where death is reasonably foreseeable, and most MAID MD-SUMC (where death is not reasonably foreseeable). They see the first instance as being about changing the *timing* and *manner* of death, and the second instance as being about *whether* death will occur for those who may have many years still to live. Other Working Group members believe that it is not clear that this distinction is a fundamental ethical difference that justifies a different approach to MAID MD-SUMC.

Distinguishing between suicide and MAID MD-SUMC

The Working Group disagrees about whether it is possible to have a valid and reliable method of distinguishing between individuals who have made an autonomous, well-considered decision for MAID MD-SUMC and individuals whose desire to end their lives due to suffering is pathological, and due to a symptom of their mental disorder.

Potential implications of MAID MD-SUMC

The Working Group disagrees about how to interpret and assess the evidence as it relates to the potential implications of prohibiting or permitting more MAID MD-SUMC. Differences in how Working Group members view issues such as autonomy, discrimination, and human rights influenced their interpretation of the evidence. In particular, the Working Group disagrees about how permitting more MAID MD-SUMC would affect suicide prevention strategies.

Differences between MAID and other highly consequential decisions

The Working Group disagrees about whether decisions about MAID are different from other highly consequential decisions (e.g., refusing life-sustaining treatment). Many of these disagreements relate in part to whether there are ethical and practical distinctions between a medical professional actively assisting someone's death, versus letting the person die through non-intervention.

This divergence and diversity of interpretations and views are important for policy-makers. At the conclusion of the assessment process, however, there are fundamental issues on which Working Group members continue to disagree. These issues are outlined in Box 7.1.

The Working Group agrees on the need for research to understand better, and to a greater depth, the implications for individuals with mental disorders, healthcare practitioners, and society of permitting more or continuing to limit MAID MD-SUMC. This research would be beneficial regardless of whether more MAID MD-SUMC is permitted or not. Better research can be accomplished through investments, but also by removing barriers to investigation — for example, by standardizing reporting requirements across provinces and territories. The Working Group's findings also indicate that there are limitations of the current notions of what counts as evidence in this field of study.

The diversity of expertise and perspectives among Working Group members has informed and influenced all aspects of this report, and while the final text is not what any single Working Group member would have produced on their own, it reflects their collective effort. Although this is not a consensus-based report, it presents the available evidence related to MAID MD-SUMC, describes various interpretations of that evidence, and raises different viewpoints on several important issues. The Working Group hopes that this report will help inform those policy-makers who will ultimately make decisions relating to MAID MD-SUMC in Canada.

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APPENDIX A: ASSISTED DYING TERMINOLOGY IN JURISDICTION WORLDWIDE

Jurisdiction	Year Allowed	Terminology	Definition	Notes
Victoria, AUS	2019	Voluntary Assisted Dying	The administration of a voluntary assisted dying substance and includes steps reasonably related to such administration.	The Voluntary Assisted Dying Bill was passed in 2017, and will come into power June 19, 2019 at the latest.
Hawaii, USA	2019	Medical Aid in Dying	Not explicitly defined; a qualified patient may request and obtain a prescription for medication that they may self-administer to end their life in a humane and dignified manner.	The Our Care, Our Choice Act was signed into law on April 5, 2018, to take effect on January 1, 2019. Physician Assisted Death (PAD) or Physician Assisted Suicide (PAS) are commonly used in the American media.
District of Columbia, USA	2016	Death with Dignity	The request and dispensation of covered medications to qualified patients seeking to die in a humane and peaceful manner.	Physician Assisted Death (PAD) or Physician Assisted Suicide (PAS) are commonly used in the American media.
California, USA	2016	End of Life Option: Aid-in-Dying Drug	A drug determined and prescribed by a physician for a qualified individual, which the qualified individual may choose to self-administer to bring about his or her death due to a terminal disease.	Physician Assisted Death (PAD) or Physician Assisted Suicide (PAS) are commonly used in the American media.
Canada	2016	Medical Assistance in Dying	The administering by a medical practitioner or nurse practitioner of a substance to a person, at their request, that causes their death, or the prescribing or providing by a medical practitioner or nurse practitioner of a substance to a person, at their request, so that they may self-administer the substance and in doing so cause their own death.	
Colorado, USA	2016	Medical Aid-in-Dying	The medical practice of a physician prescribing medical aid-in-dying medication to a qualified individual that the individual may choose to self-administer to bring about a peaceful death.	Physician Assisted Death (PAD) or Physician Assisted Suicide (PAS) are commonly used in the American media.

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Jurisdiction	Year Allowed	Terminology	Definition	Notes
Colombia	2015 (1997)	The Fundamental Right to Die with Dignity	The procedure to address the request to exercise the fundamental right to die with dignity is not explicitly defined.	The Ministry of Health and Social Protection issued a regulation on the fundamental right to die with dignity in 2015. The legal judgment that first recognized such a right in Colombia occurred in 1997.
Quebec, CAN	2014	Medical Aid in Dying	Care consisting in the administration by a physician of medications or substances to an end-of-life patient, at the patient's request, in order to relieve their suffering by hastening death.	Physician Assisted Death (PAD) or Physician Assisted Suicide (PAS) are commonly used in the American media.
Vermont, USA	2013	Patient Choice at the End of Life	Not explicitly defined; physicians are allowed to prescribe medication to a patient with a terminal condition for the purpose of hastening the patient's death if they meet certain criteria, but may not be involved in the administration of the medication.	The provision of physician aid in dying is permitted through the Supreme Court of the State of Montana ruling that found a terminally ill patient's consent to physician aid in dying constitutes a statutory defense to a charge of homicide against the aiding physician when no other consent exceptions apply (Supreme Court of the State of Montana, 2009). Physician Assisted Death (PAD) or Physician Assisted Suicide (PAS) are commonly used in the American media.
Montana, USA	2009	Physician Aid in Dying	Not explicitly defined; in physician aid in dying, the patient — not the physician — commits the final death-causing act by self-administering a lethal dose of medicine.	

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Jurisdiction	Year Allowed	Terminology	Definition	Notes
Luxembourg	2009	Euthanasia and Assisted Suicide	Euthanasia: The act performed by a physician, which intentionally ends the life of a person at the express and voluntary request of that person. Assisted Suicide: a doctor intentionally helps another person to commit suicide or to provide another person with the means to that end, at the express and voluntary request of the latter.	Physician Assisted Death (PAD) or Physician Assisted Suicide (PAS) are commonly used in the American media.
Washington, USA	2008	Death with Dignity	Not explicitly defined; an adult who qualifies may make a written request for medication that the patient may self-administer to end his or her life in a humane and dignified manner.	Termination of Life on Request is commonly referred to as euthanasia and assisted suicide (EAS).
The Netherlands	2002	Termination of Life on Request and Assisted Suicide	Termination of Life on Request: Not explicitly defined. Assisted Suicide: Intentionally assisting in a suicide of another person or procuring for that person the means [thereto].	Termination of Life on Request is commonly referred to as euthanasia and assisted suicide (EAS). The Federal Control and Evaluation Commission on Euthanasia has stated that it considers assisted suicide to fall within the definition of euthanasia, and has approved cases of assisted suicide in Belgium as meeting legal requirements (NvS, 2017).
Belgium	2002	Euthanasia	Intentionally terminating life by someone other than the person concerned, at the latter's request.	The Belgian Act only refers to euthanasia; however, assisted suicide is not expressly prohibited in criminal law. Both are practised and are commonly referred to as euthanasia and assisted suicide (EAS). The Federal Control and Evaluation Commission on Euthanasia has stated that it considers assisted suicide to fall within the definition of euthanasia, and has approved cases of assisted suicide in Belgium as meeting legal requirements (NvS, 2017).
Oregon, USA	1997	Death with Dignity	Not explicitly defined; an adult who qualifies may make a written request for medication that the patient may self-administer to end his or her life in a humane and dignified manner in accordance with the law.	Physician Assisted Death (PAD) or Physician Assisted Suicide (PAS) are commonly used in the American media.

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Jurisdiction	Year Allowed	Terminology	Definition	Notes
Germany	–	Assisted Suicide	Not explicitly defined; suicide is exempt from criminal punishment, as is aiding suicide. However, killing a person at the express and earnest request of the victim (“mercy killing”) is a criminal offence.	A 2015 law makes it illegal to assist in suicide for commercial intent. Relatives or other persons closely related to the patient who are only involved as non-business participants are exempt.
Switzerland	–	Assisting Suicide	Not explicitly defined.	Art. 115 of the Swiss Criminal Code (1942) states: Any person who for selfish motives incites or assists another to commit or attempt to commit suicide is, if that other person thereafter commits or attempts to commit suicide, liable to a custodial sentence not exceeding five years or to a monetary penalty.

Sources: Constitutional Court of Colombia, 2014; GC, 2016a; Gov. of Belgium, 2002; Gov. of CA, 2015; Gov. of CO, 2016; Gov. of DC, 2016; Gov. of Germany, 2015; Gov. of Luxembourg, 2009; Gov. of the Netherlands, 2002; Gov. of OR, 1997; Gov. of QC, 2014; Gov. of Switzerland, 1942; Gov. of Victoria, 2017; Gov. of VT, 2013; Gov. of WA, 2009; Nys., 2017; Supreme Court of the State of Montana, 2009

Table of terminology and legal definitions used in euthanasia and assisted suicide law around the world, including notes about commonly used terms in local media and academic literature when different from the official legal terminology.

APPENDIX B: SUMMARIES OF PROVINCIAL AND TERRITORIAL MENTAL HEALTH AND HEALTHCARE CONSENT LEGISLATION

The following tables contain a list of provincial and territorial legislation that address mental health and healthcare consent. This list is not exhaustive, and the distinction between legislation that deals with mental health and legislation that deals with healthcare consent is not well-defined.

Table B.1

Provincial and Territorial Mental Health Legislation

Jurisdiction	Act
British Columbia	Mental Health Act, RSBC 1996, c. 288
Alberta	Mental Health Act, RSA 2000, c. M-13
Saskatchewan	Mental Health Services Act, SS 1984-85-86, c. M-13.1
Manitoba	The Mental Health Act, CCSM c. M110
Ontario	Mental Health Act, RSO 1990, c. M.7
Quebec	Civil Code of Quebec, CCQ-1991, c. 64 Act respecting the protection of persons whose mental state presents a danger to themselves or to others, c. P-38.001
New Brunswick	Mental Health Act, RSNB 1973, c. M-10 Mental Health Services Act, RSNB 2011, c. 190
Nova Scotia	Involuntary Psychiatric Treatment Act, SNS 2005, c. 42
Prince Edward Island	Mental Health Act, RSPEI 1988, c. M-6.1
Newfoundland and Labrador	Mental Health Care and Treatment Act, SNL 2006, c. M-9.1
Yukon	Mental Health Act, RSY 2002, c. 150
Northwest Territories	Mental Health Act, RSNWT 1988, c. M-10
Nunavut	Mental Health Act (Nunavut), RSNWT 1988, c. M-10

Table B.2
Provincial and Territorial Healthcare Consent Legislation

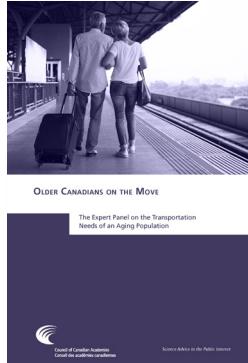
Jurisdiction	Act
British Columbia	Health Care (Consent) and Care Facility (Admission) Act, RSBC 1996, c. 181 Representation Agreement Act, RSBC 1996, c. 405
Alberta	Adult Guardianship and Trusteeship Act SA 2008, c. A-4.2 Personal Directives Act, RSA 2000, c. P-6
Saskatchewan	The Health Care Directives and Substitute Health Care Decision Makers Act, 2015, c. H-0.002
Manitoba	The Health Care Directives Act, CCSM c. H27 The Vulnerable Persons Living With a Mental Disability Act CCSM, c. V90
Ontario	Health Care Consent Act, SO 1996, c. 2 Sched. A Substitute Decisions Act, 1992, SO 1992, c. 30
Quebec	Civil Code of Quebec, CCQ-1991, c. 64
New Brunswick	Infirmité Persons Act, RSNB 1973, c. I-8
Nova Scotia	Personal Directives Act, SNS 2008, c. 8 Adult Capacity and Decision-making Act, SNS 2017, c. 4 Hospitals Act, SNS. 1989 c. 208
Prince Edward Island	Consent to Treatment and Health Care Directives Act, RSPEI 1988, c. C-17.2
Newfoundland and Labrador	Advanced Health Care Directives Act, SNL 1995, c. A-4.1
Yukon	Care Consent Act, SY 2003, c. 21, Sched. B
Northwest Territories	Personal Directives Act, SNWT 2005, c. 16

Council of Canadian Academies' Reports of Interest

The assessment reports listed below are accessible through the CCA's website (www.scienceadvice.ca):



Building on Canada's Strengths in Regenerative Medicine
(2017)



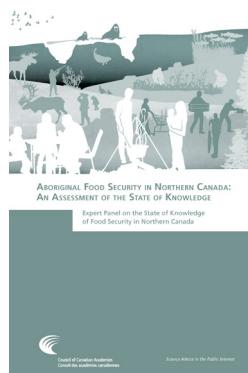
Older Canadians on the Move
(2017)



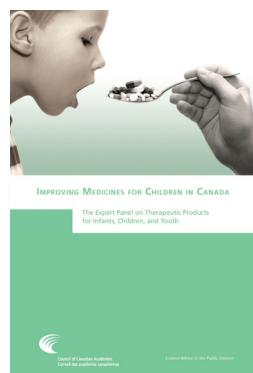
Accessing Health and Health-Related Data in Canada
(2015)



Health Product Risk Communication: Is the Message Getting Through?
(2015)



Aboriginal Food Security in Northern Canada: An Assessment of the State of Knowledge
(2014)



Improving Medicines for Children in Canada
(2014)

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