

STATE OF KNOWLEDGE ON MEDICAL ASSISTANCE IN DYING FOR MATURE MINORS, ADVANCE REQUESTS, AND WHERE A MENTAL DISORDER IS THE SOLE UNDERLYING MEDICAL CONDITION

Summary of Reports

**STATE OF KNOWLEDGE ON MEDICAL ASSISTANCE IN DYING FOR
MATURE MINORS, ADVANCE REQUESTS, AND WHERE A MENTAL
DISORDER IS THE SOLE UNDERLYING MEDICAL CONDITION**

Summary of Reports

THE COUNCIL OF CANADIAN ACADEMIES

180 Elgin Street, Suite 1401, Ottawa, ON, Canada K2P 2K3

This document is a summary of three reports by the Expert Panel on Medical Assistance in Dying: *The State of Knowledge on Medical Assistance in Dying for Mature Minors*, *The State of Knowledge on Advance Requests for Medical Assistance in Dying*, and *The State of Knowledge on Medical Assistance in Dying Where a Mental Disorder is the Sole Underlying Medical Condition*. This summary of reports was prepared by the CCA at the direction of the four Chairs of the Expert Panel on Medical Assistance in Dying.

The project was undertaken with the approval of the Board of Directors of the Council of Canadian Academies (CCA). Board members are drawn from the Royal Society of Canada (RSC), the Canadian Academy of Engineering (CAE), and the Canadian Academy of Health Sciences (CAHS), as well as from the general public. The members of the expert panel responsible for the reports were selected by the CCA for their special competencies and with regard for appropriate balance.

The three reports were 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.

The full reports are available, free of charge, in French and English on the CCA's website at www.scienceadvice.ca.

© 2018 Council of Canadian Academies

Printed in Ottawa, Canada



Canada This project was made possible with the support of the Government of Canada

The Council of Canadian Academies

The Council of Canadian Academies (CCA) is an independent, not-for-profit organization that supports independent, science-based, authoritative expert assessments to inform public policy development in Canada. Led by a Board of Directors and advised by a Scientific Advisory Committee, the CCA's work encompasses a broad definition of science, incorporating the natural, social, and health sciences as well as engineering and the humanities. CCA assessments are conducted by independent, multidisciplinary panels of experts from across Canada and abroad. Assessments strive to identify emerging issues, gaps in knowledge, Canadian strengths, and international trends and practices. Upon completion, assessments provide government decision-makers, researchers, and stakeholders with high-quality information required to develop informed and innovative public policy.

All CCA assessments undergo a formal report review and are published and made available to the public free of charge. Assessments can be referred to the CCA by foundations, non-governmental organizations, the private sector, or any level of government.

The CCA is also supported by its three founding Academies:

The Royal Society of Canada (RSC)

Founded in 1882, the RSC comprises the Academies of Arts, Humanities and Sciences, as well as Canada's first national system of multidisciplinary recognition for the emerging generation of Canadian intellectual leadership: The College of New Scholars, Artists and Scientists. Its mission is to recognize scholarly, research, and artistic excellence, to advise governments and organizations, and to promote a culture of knowledge and innovation in Canada and with other national academies around the world.

The Canadian Academy of Engineering (CAE)

The CAE is the national institution through which Canada's most distinguished and experienced engineers provide strategic advice on matters of critical importance to Canada. The Academy is an independent, self-governing, and non-profit organization established in 1987. Fellows are nominated and elected by their peers in recognition of their distinguished achievements and career-long service to the engineering profession. Fellows of the Academy, who number approximately 740, are committed to ensuring that Canada's engineering expertise is applied to the benefit of all Canadians.

The Canadian Academy of Health Sciences (CAHS)

CAHS recognizes excellence in the health sciences by appointing Fellows based on their outstanding achievements in the academic health sciences in Canada and on their willingness to serve the Canadian public. The Academy provides timely, informed, and unbiased assessments of issues affecting the health of Canadians and recommends strategic, actionable solutions. Founded in 2004, CAHS now has 670 Fellows and appoints new Fellows on an annual basis. The organization is managed by a voluntary Board of Directors and a Board Executive.

www.scienceadvice.ca

[@scienceadvice](https://twitter.com/scienceadvice)

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.

Hon. Marie Deschamps, C.C., Ad. E. (Chair of the Expert Panel), Former Justice of the Supreme Court of Canada and Adjunct Professor, McGill University (Montréal, QC) and Université de Sherbrooke (Sherbrooke, QC)

The Expert Panel Working Group on MAID for Mature Minors

Dawn Davies (Working Group Chair), Associate Professor, Department of Pediatrics, University of Ottawa; Palliative Care Physician, Roger Neilson House/Children's Hospital of Eastern Ontario (Ottawa, ON)

Gail Beck, O.Ont., Clinical Director, Youth Psychiatry Program, The Royal (Ottawa, ON)

Carrie Bourassa, Chair, Northern and Indigenous Health, Health Science North Research Institute, and Scientific Director, Institute of Indigenous Peoples' Health – Canadian Institute of Health Research (Sudbury, ON)

Franco A. Carnevale, Professor, Ingram School of Nursing, McGill University (Montréal, QC)

Joanna Chung, Psychologist, Medical Psychology and Hematology/Oncology/Bone Marrow Transplant Program, BC Children's Hospital (Vancouver, BC)

Joan Gilmour, Professor, Osgoode Hall Law School, York University (Toronto, ON)

Hon. Stephen Goudge, Q.C., O.Ont., Counsel, Paliare Roland (Toronto, ON)

Mary Ellen Macdonald, Associate Professor, Faculty of Dentistry, McGill University (Montréal, QC)

Jean-Pierre Ménard, Ad. E., Lawyer, Ménard, Martin, Avocats (Montréal, QC)

Cheryl Milne, Executive Director, David Asper Centre for Constitutional Rights, Faculty of Law, University of Toronto (Toronto, ON)

Ubaka Ogbogu, Assistant Professor, Faculties of Law and Pharmacy & Pharmaceutical Sciences, University of Alberta (Edmonton, AB)

Bryan Salte, Associate Registrar and Legal Counsel, College of Physicians and Surgeons of Saskatchewan (Saskatoon, SK)

Kimberley Widger, Assistant Professor, Lawrence S. Bloomberg Faculty of Nursing, University of Toronto; Nursing Research Associate, Paediatric Advanced Care Team, Hospital for Sick Children (Toronto, ON)

Randi Zlotnik Shaul, Director, Department of Bioethics, The Hospital for Sick Children (Toronto, ON)

The Expert Panel Working Group on Advance Requests for MAID

Jennifer L. Gibson (Working Group Chair), Sun Life Financial Chair in Bioethics and Director, University of Toronto Joint Centre for Bioethics (Toronto, ON)

Benjamin L. Berger, Professor, Osgoode Hall Law School, York University (Toronto, ON)

Martha Donnelly, Geriatric Psychiatrist; Associate Professor Emeritus, Department of Psychiatry, University of British Columbia (Vancouver, BC)

Alika Lafontaine, Medical Director North Zone Indigenous Health, Alberta Health Services; Assistant Clinical Professor of Medicine, Anesthesiology and Pain Medicine, University of Alberta; Medical Director, Alignment by Design Labs (Grande Prairie, AB)

Trudo Lemmens, Professor and Scholl Chair in Health Law and Policy, Faculty of Law, University of Toronto (Toronto, ON)

Susan MacDonald, Associate Professor, Medicine & Family Medicine, Memorial University of Newfoundland (St. John's, NL)

Sheila A.M. McLean, Emeritus Professor, Law & Ethics in Medicine, Glasgow University (Glasgow, Scotland)

Dorothy Pringle, O.C., FCAHS, Professor Emeritus, Lawrence S. Bloomberg Faculty of Nursing, University of Toronto (Toronto, ON)

Patricia (Paddy) Rodney, Associate Professor, School of Nursing and Faculty Associate, W. Maurice Young Centre for Applied Ethics, University of British Columbia (Vancouver, BC)

Harvey Schipper, Professor of Medicine and Adjunct Professor of Law, University of Toronto (Toronto, ON)

Samir Sinha, Peter and Shelagh Godsoe Chair in Geriatrics and Director of Geriatrics, Sinai Health System and University Health Network; Associate Professor of Medicine, Family & Community Medicine, and Health Policy, Management and Evaluation, University of Toronto (Toronto, ON)

Tim Stainton, Professor, School of Social Work, University of British Columbia (Vancouver, BC)

Ross Upshur, Professor, Department of Family & Community Medicine and Dalla Lana School of Public Health, University of Toronto; Associate Director, Lunenfeld Tanenbaum Research Institute; Scientific Director, Bridgepoint Collaboratory for Research and Innovation, Sinai Health System (Toronto, ON)

Agnes van der Heide, Professor and Researcher, Erasmus University Medical Center Rotterdam (Rotterdam, the Netherlands)

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

Kwame McKenzie (Working Group Chair), CEO, Wellesley Institute; Professor of Psychiatry, University of Toronto; Medical Director, Health Equity, Centre for Addiction and Mental Health; Commissioner, Ontario Human Rights Commission (Toronto, ON)

Melissa K. Andrew, Associate Professor, Medicine (Geriatrics), Dalhousie University and Nova Scotia Health Authority (Halifax, NS)

Jennifer A. Chandler, Bertram Loeb Research Chair, Full Professor, Centre for Health Law, Policy and Ethics, Faculty of Law, University of Ottawa (Ottawa, ON)

Pierre Deschamps, C.M., Member of Research Group on Health and Law, McGill University (Montréal, QC)

Jocelyn Downie, C.M., FRSC, FCAHS, University Research Professor, Faculties of Law and Medicine, Dalhousie University (Halifax, NS)

Martin Drapeau, Professor, Counselling Psychology and Psychiatry, McGill University (Montréal, QC)

Colleen M. Flood, FRSC, FCAHS, Director, Centre for Health Law Policy and Ethics; Professor and Research Chair in Health Law and Policy, University of Ottawa (Ottawa, ON)

Arthur W. Frank, FRSC, Professor Emeritus, Department of Sociology, University of Calgary (retired) (Calgary, AB); Professor II, VID Specialized University (Oslo, Norway)

K. Sonu Gaiind, Chief of Psychiatry/Medical Director of Mental Health, Humber River Hospital; Associate Professor, University of Toronto; Board Member, World Psychiatric Association (Toronto, ON)

Mona Gupta, Associate Professor and Psychiatrist, Centre hospitalier de l'Université de Montréal (CHUM) (Montréal, QC)

Scott Y.H. Kim, Senior Investigator, Department of Bioethics, National Institutes of Health (Bethesda, MD)

Brian L. Mishara, Director, Centre for Research and Intervention on Suicide, Ethical Issues, and End-of-Life Practices (CRISE), Université du Québec à Montréal (Montréal, QC)

Tanya Park, Assistant Professor, Faculty of Nursing, University of Alberta (Edmonton, AB)

Suzanne Stewart, Director, Waakebiness-Bryce Institute for Indigenous Health, University of Toronto (Toronto, ON)

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.

The three 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,



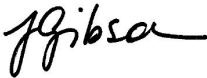
Marie Deschamps, C.C., Ad. E.

Chair, Expert Panel on Medical Assistance in Dying



Dawn Davies

Chair, Expert Panel Working Group on MAID for Mature Minors



Jennifer L. Gibson

Chair, Expert Panel Working Group on Advance Requests for MAID



Kwame McKenzie

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

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.

A handwritten signature in black ink, appearing to read 'Eric M. Meslin', with a stylized flourish at the end.

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.

Special thanks are extended to Elders Dot Beaucage-Kennedy, Jacqui Lavalley, Betty McKenna, Roberta Price, and Ted Quewezance for sharing their knowledge and wisdom with the Panel.

The Panel would also like to recognize the following individuals and organizations: David J. Wright of McGill University for so generously sharing his knowledge; Félix Hébert, Mary Shariff, and Daniel Weinstock for their legal expertise; Metamorfose Vertalingen and Textualis for translation services; and all organizations that provided submissions as part of the Call for Input.

Project Staff of the Council of Canadian Academies

- Assessment Team: Tijs Creutzberg, Director of Assessments
 Janet W. Bax, Project Director
 Jill Watkins, Project Director
 Erin Bassett, Research Associate
 Jennifer Bassett, Research Associate
 Amanda Bennett, Research Associate
 Rebecca Chapman, Research Associate
 Madison Downe, Project Coordinator
 Andrea Hopkins, Lead, Assessment Coordination &
 Planning
 Teresa Iacobelli, Research Associate
 Matthew Ivanowich, Researcher
 Anita Melnyk, Research Associate
- With Assistance from: Jonathan Harris, Research Associate, CCA
 Marc Dufresne, Report Design, CCA
- and: Jody Cooper, Editorial Consultant
 Clare Walker, Editorial Consultant
 François Abraham, Communications Léon Inc.,
 Certified Translator, Translation English-French

Report Review

The three 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 the three reports:

Reviewers of the MAID for Mature Minors Report

Priscilla Alderson, Professor Emerita of Childhood Studies, University College London (London, United Kingdom)

Cécile Bensimon, Director, Ethics and Professional Affairs, Canadian Medical Association (Ottawa, ON)

Marie-Claude Grégoire, FRCPC, Physician, Perioperative Anesthesiology Clinical Trials Group (PACT), IWK Health Centre; Assistant Professor, Dalhousie University (Halifax, NS)

Irma Hein, Child and Adolescent Psychiatrist; Senior Researcher, De Bascule Academic Centre for Child and Adolescent Psychiatry (Amsterdam, the Netherlands)

Stan Kutcher, FCAHS, Professor of Psychiatry, Dalhousie University (Halifax, NS)

Aria Laskin, Lawyer (Vancouver, BC)

Constance MacIntosh, Associate Professor and Viscount Bennett Professor of Law, Schulich School of Law, Dalhousie University (Halifax, NS)

Chantelle Richmond, Professor and Canada Research Chair in Indigenous Health and Environment, Western University (London, ON)

Erica K. Salter, Associate Professor, Health Care Ethics and Pediatrics, Saint Louis University (St. Louis, MO)

Hal Siden, Medical Director, Canuck Place Children's Hospice and BC Children's Hospital (Vancouver, BC)

Sigrid Sterckx, Professor of Ethics and Social & Political Philosophy, Ghent University (Ghent, Belgium)

Reviewers of the Advance Requests for MAID Report

B. Lynn Beattie, Professor Emerita, Department of Medicine, University of British Columbia (Vancouver, BC)

Gina Bravo, Professor, Université de Sherbrooke (Sherbrooke, QC)

Catherine Frazee, O.C., Professor Emerita, Ryerson University (Toronto, ON)

Linda Ganzini, Professor of Psychiatry and Medicine, Oregon Health & Science University (Portland, OR)

Chris Gastmans, Professor, University of Leuven (Leuven, Belgium)

Rosie Harding, Chair in Law and Society, Birmingham Law School, University of Birmingham (Birmingham, United Kingdom)

Philip Hébert, Professor Emeritus, Department of Family & Community Medicine, University of Toronto (Toronto, ON)

Janet Storch, Professor Emeritus, University of Victoria (Victoria, BC)

Tamara Sussman, Associate Professor, McGill University (Montréal, QC)

Nele van den Noortgate, Head, Geriatric Department, Ghent University Hospital (Ghent, Belgium)

Eric Wasylenko, Medical Director, Health System Ethics & Policy, Health Quality Council of Alberta; Clinical Associate Professor, Division of Palliative Medicine, Department of Oncology, Cumming School of Medicine, University of Calgary (Calgary, AB)

Reviewers of the MAID Where a Mental Disorder Is the Sole Underlying Medical Condition Report

Kenneth Chambaere, Assistant Professor, End-of-Life Care Research Group, Vrije Universiteit Brussels and Ghent University (Brussels, Belgium)

Marianne Dees, Senior Researcher, Department of Primary and Community Care, Radboud Institute for Health Sciences, Radboud University Medical Centre (Nijmegen, the Netherlands)

Judy Illes, FRSC, FCAHS, Professor of Neurology and Canada Research Chair in Neuroethics, University of British Columbia (Vancouver, BC)

Rod McCormick, Professor and BCIC Chair in Indigenous Health, Thompson Rivers University (Kamloops, BC)

Bregje Onwuteaka-Philipsen, Professor of End-of-Life Research, Department of Public and Occupational Health, Amsterdam University Medical Centre (Amsterdam, the Netherlands)

Elizabeth Peter, Professor, Lawrence S. Bloomberg Faculty of Nursing and Joint Centre for Bioethics, University of Toronto (Toronto, ON)

Geoffrey Reaume, Associate Professor, Critical Disability Studies Graduate Program, York University (Toronto, ON)

Tom Shakespeare, Professor of Disability Research, University of East Anglia (Norwich, United Kingdom)

Scott Theriault, Deputy Head, Department of Psychiatry, Dalhousie University (Halifax, NS)

Amy Zarzeczny, Associate Professor, University of Regina (Regina, SK)

Special thanks are extended to **David Orentlicher**, Cobeaga Law Firm Professor of Law and Co-Director, University of Nevada – Las Vegas William S. Boyd School of Law (Las Vegas, NV) and **Joris Vandenberghe**, Psychiatrist, University Hospitals UZ Leuven and Professor, University of Leuven – KU Leuven (Leuven, Belgium).

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.

Table of Contents

Introduction and Charge to the Panel 1

**Summary of the State of Knowledge on Medical Assistance
in Dying for Mature Minors 5**

 Issues and Uncertainties Surrounding Healthcare
 Decision-Making for Minors 6

 Canadian Legislation and Court Cases Relevant to Healthcare
 Decision-Making for Mature Minors 9

 Treating Mature Minors Differently Than Capable Adults in
 a MAID Context: Factors for Consideration 9

 MAID for Mature Minors: International Experience 10

 Potential Impacts of Allowing or Prohibiting MAID for
 Mature Minors 11

 Potential Safeguards for MAID for Mature Minors 13

 Final Thoughts from the Working Group on MAID
 for Mature Minors..... 14

**Summary of the State of Knowledge on Advance Requests
for Medical Assistance in Dying 16**

 Differentiating Advance Requests for MAID
 from Advance Directives..... 16

 Why an Advance Request for MAID? 17

 Uncertainties and Issues Surrounding Advance Requests
 for MAID 17

 Evidence from Related Practices 21

 Potential Impacts of Allowing or Prohibiting Advance
 Requests for MAID 22

 Potential Safeguards for Advance Requests for MAID 23

 Final Thoughts from the Working Group on
 Advance Requests for MAID 25

**Summary of the State of Knowledge on Medical Assistance
in Dying Where a Mental Disorder Is the Sole Underlying
Medical Condition 26**

 Mental Disorders in Canada 26

 Issues and Uncertainties Surrounding MAID MD-SUMC 27

 International Evidence 30

 Potential Implications of Prohibiting or
 Expanding MAID-MD SUMC 32

 Unique Considerations for Specific Demographic
 Subpopulations 36

 Knowledge Gaps..... 36

 Potential Safeguards 37

 Final Thoughts from the Working Group on MAID Where a Mental
 Disorder Is the Sole Underlying Medical Condition..... 38

Concluding Remarks from the CCA 39

Introduction and Charge to the Panel

Canada is one of a small number of jurisdictions that allow some form of medical assistance in dying (MAID). The passage of *An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying)* and the practice of MAID in Canada, however, have not settled public debate. Among the topics under discussion are MAID for people under the age of 18 (mature minors), advance requests for MAID, and MAID for people with a mental disorder as their sole underlying medical condition. Parliament has called for one or more independent reviews to study the question of prohibiting or permitting MAID for people in the above groups (Section 9.1 of the Act).

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 a mental disorder as the sole underlying medical condition). 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 reports were organized to answer the Sponsors' question below (also called the *charge*):

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?

The charge also included four general sub-questions and several topic-specific sub-questions:

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.

Topic-Specific Sub-Questions **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.

Responding to the Charge

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. 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. 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. The Panel also recognized 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. To support the Panel's evidence-gathering activity, a Call for Input was carried out, inviting written input from groups and organizations across Canada affected by, or involved in, MAID. In addition, an Elders Circle, facilitated by Indigenous Panel members, was held to provide insight into Indigenous perspectives on MAID, particularly with respect to the three topic areas.

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. As is the practice with every CCA report, the Panel does not make recommendations to the Sponsors. Furthermore, the reports do not evaluate the provisions enacted by Canada's MAID legislation, nor do they revisit the legal arguments and evidence for allowing or prohibiting MAID in general; a formal review of the MAID legislation is required five years after its passage (see Section 10 of the Act).

The Panel understands that MAID is a deeply personal topic; people hold differing views on the relevant evidence, and one's perception about permitting or prohibiting MAID for mature minors, people making advance requests, or people whose 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.

Each report reflects the general view of its Working Group members even if unanimity could not be established on some points. In some situations, even after consideration of available data and Panel discussions, agreement could not be achieved and significant differences of opinion on the interpretation of the evidence remained, reflecting the complex and conflicted nature of the issues under review.

Summary of the State of Knowledge on Medical Assistance in Dying for Mature Minors

In Canada, people under the age of 18 are not eligible for MAID, which raises the following question: Since an adult who suffers intolerably from a grievous and irremediable medical condition, and who is in a state of irreversible, advanced decline, can request and receive MAID, is there a reason to exclude a minor with the same grievous and irremediable medical condition from accessing MAID?

The Working Group was asked to consider MAID for *mature minors*, who are not defined by chronological age, but rather by their capacity for decision-making. While there is no universally accepted definition of a mature minor, Canadian courts, common law, and health law and policy generally view a mature minor as a person under the age of majority with the capacity to make an informed healthcare decision and the ability to act voluntarily with respect to that decision. Quebec does not recognize the concept of a mature minor. Rather, it divides minors into two groups (those under age 14 and those aged 14 to 17) governed by different legal regimes for consent to care. Given the Working Group's charge and the knowledge available, the evidence considered in the report is not restricted to mature minors. In some cases, the age range of participants in a study that is critical to answering the charge may be quite broad, including both children and adolescents. Moreover, the maturity status of study participants is usually unknown.

Figure 1 illustrates the Working Group's use of the terms *children*, *adolescents*, *youth*, *adults*, *minors*, and *mature minors*. Canadian laws relating to age of majority define minors and adults using a strict age cut-off. Depending on the province or territory, minors become adults when they reach the age of 18 or 19. In contrast, there are no agreed-upon age ranges in the literature for children, adolescents, and youth.

A central concern surrounding potential MAID eligibility for mature minors is that this group is in need of heightened protection compared to adults, and is often perceived as vulnerable. The provision of MAID to "vulnerable" groups is a charged issue. Yet, vulnerability includes two aspects that must be considered together: protection from exploitation and protection from exclusion. Thus, in creating laws for minors, a key concern is finding a balance between keeping them safe from harm, while, at the same time, respecting their rights by avoiding unfair and unethical restrictions.

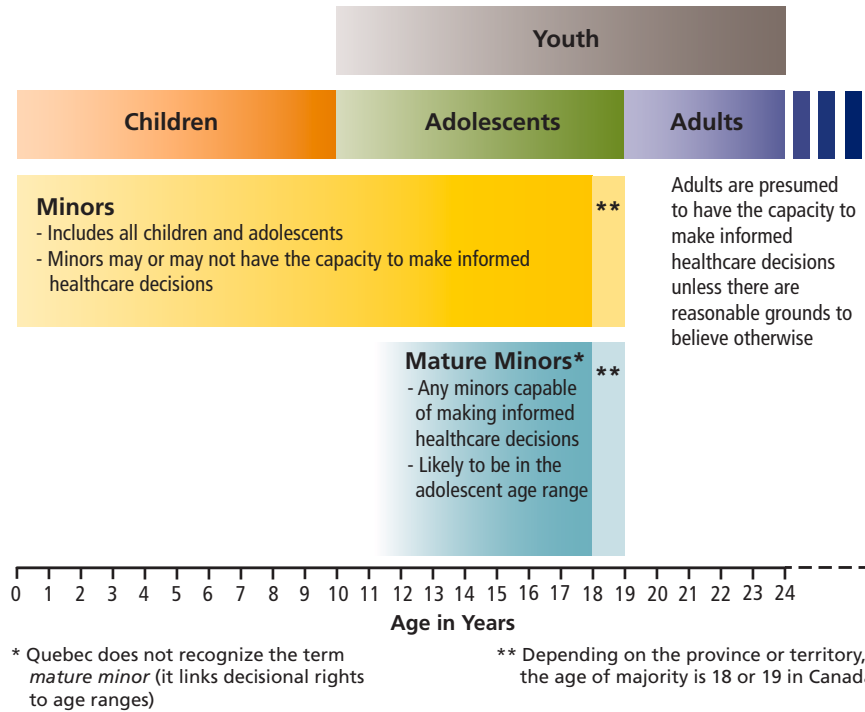


Figure 1
Terms Related to Age and Decision-Making Capacity

Another central issue for mature minors and MAID is how to determine whether a minor is capable of informed consent, which presents a number of ambiguities and challenges. Informed consent includes three key elements: a patient must (i) have the capacity to make a medical decision; (ii) be provided with information in a way that facilitates understanding; and (iii) make a voluntary choice, free from duress or coercion. In part, the hesitation to allow mature minors access to MAID reflects uncertainty about their capacity to provide informed consent.

ISSUES AND UNCERTAINTIES SURROUNDING HEALTHCARE DECISION-MAKING FOR MINORS

Healthcare decisions must be made by a capable, fully informed person exercising free and independent judgment. Decisions with increased risk or complexity incite greater concern over the ability of minors to appreciate the consequences of their choice and to make it voluntarily. Clinical, ethical, and social perspectives on this issue suggest that the ability of minors to make end-of-life decisions cannot be predicated on chronological age alone. In fact,

some argue that viewing decisional capacity as lying solely within a person is detrimental to minors, as it fails to emphasize the way in which capacity is a product of one's social environment. Rather, for critical healthcare choices, the decisional capacity of minors depends on factors linked to intellectual and psychosocial development, social and cultural environment, and the minor's relationships with their family and healthcare team.

Cognitive and Psychosocial Development

Neuroscientific and psychological research examining decision-making abilities over the course of human development can provide important context about the ability of minors to make healthcare decisions. This research has demonstrated that the cognitive foundations for decisional capacity (including language, information processing, and reasoning skills) are typically in place by early adolescence. In contrast, psychosocial maturation (which includes the abilities to control impulses, consider the long-term implications of a decision, and resist peer influence) continues throughout adolescence. Despite the fact that psychosocial maturity lags behind cognitive maturity, some minors below the age of 18 have the capacity to make critical healthcare decisions. Capacity cannot be equated with developmental generalizations, and must be considered on a case-by-case basis. Criteria for informed consent have shifted away from age and towards individual experience and understanding. For example, qualitative research studying minors with chronic or terminal illness has shown that some have remarkable knowledge and decisional capacity in relation to their condition.

Culture

A person's cultural beliefs and values may affect their views on healthcare decision-making and end-of-life care by influencing, for example, how they believe death should be discussed, their attitude toward the medical community, and the importance they place on autonomy. Some cultures may avoid directly addressing death or terminal illness to protect a patient's emotional state. Some may be uncomfortable with entrusting the care of terminally ill minors to hospitals and healthcare workers. Some may view the current Canadian healthcare approach, which places a high premium on respect for autonomy, as isolating to the patient. Although Canadian health law and policy grant many rights to minors with capacity, prioritizing autonomy may, at times, conflict with the personal values of some patients and their families.

Relationships and Support

Whether a minor has sufficient independence and maturity to make certain healthcare decisions autonomously, and therefore satisfy the voluntariness component of informed consent, is a key area of concern in considering whether to allow MAID for this population. The healthcare decisions of minors

are often intimately connected to the emotions and needs of the family unit. Given that minors likely have less experience than adults with complex life choices, some scholars and advocates have questioned whether they truly have the confidence to resist coercive influences when making a serious healthcare decision, and whether they might feel pressure to make end-of-life choices that best protect their families.

However, what constitutes an autonomous healthcare decision does not have a single answer. The fact that minors' healthcare preferences are relationally intertwined with those of their parents does not mean that parents are necessarily coercing their children towards a particular treatment option. A relational conception of autonomy acknowledges that capacity for autonomous decisions originates from, and is shaped by, social interactions. This conception also appreciates that the decisions and preferences of minors can often be understood in relation to the perspectives of parents or guardians and other significant people in their lives, reflecting the way that healthcare decisions are often made. Everyone is relationally embedded to some degree, but this does not usually negate a person's autonomy or ability to provide informed consent.

A relational approach may be valuable when considering the burden of end-of-life choices for both adults and minors. When a request for assisted dying is being weighed, some argue that the needs and values of all participants (patients, families, and healthcare practitioners) should be acknowledged in a framework of shared decision-making. Such a framework may be particularly important for minors. Studies have shown that adolescents facing serious illness can appreciate the complexity of healthcare decision-making and, even if making the final choice independently, may prefer the advice of others as they deliberate. Minors facing terminal illnesses usually make decisions in agreement with their parents and care team. However, if the goals of the patient and family members do not align, a collaborative approach may pose difficulties. For healthcare practitioners, the challenge is to consider the patient both as an individual and as part of a family unit.

An additional consideration for minors is their sensitivity to emotional and social context. For example, if they feel anxious, misunderstood by members of their care team, or are experiencing interpersonal conflict with a family member, their response to these feelings or situations may affect their decision-making abilities. However, conditions that maximize the capacity for well-contemplated decisions can be provided through support from healthcare practitioners, parents, and others who know the minor well. This support includes a trustful relationship between the minor and their healthcare team, and a respectful and empathetic environment.

CANADIAN LEGISLATION AND COURT CASES RELEVANT TO HEALTHCARE DECISION-MAKING FOR MATURE MINORS

Canadian legislation does not provide a definition of a mature minor. Rather, the Supreme Court of Canada recognizes the common law mature minor doctrine, which acknowledges that a minor may have the capacity to make an informed healthcare decision. Patients, parents or guardians, and healthcare practitioners resolve most disputes about mature minors' healthcare. When the courts become involved, the decision about whether to give a minor the right to make their own healthcare choice depends on a complex interplay among numerous factors, including the gravity of the decision (i.e., whether it is life-threatening), the minor's prognosis with and without treatment, and the minor's ability to understand and appreciate their situation. Furthermore, the court's ruling will also depend on whether any provincial or territorial healthcare consent or child welfare legislation applies. Some provinces and territories have enacted healthcare consent legislation that imposes restrictions on the ability of minors to consent to healthcare. In addition, the best interests standard may be applied through provincial or territorial child protection legislation if a minor is refusing to obtain a necessary medical intervention.

Because mature minors cannot currently access MAID in Canada, relevant legal evidence comes from court cases involving minors' refusal of life-sustaining treatment. Prior to 2009, such cases suggested that courts would order treatment with a good chance of success, even if a mature minor were to refuse it. A precedent-setting 2009 Supreme Court of Canada child protection case (*A.C. v. Manitoba*, in which a 14-year-old refused potentially life-saving blood transfusions) gave more weight to a mature minor's decision than previous cases. It recognized that, although the decision-making abilities of a minor must be assessed with the utmost scrutiny when their healthcare decision will have grave consequences, mature minors should be able to decide. The applicability of these cases to MAID depends, in part, on whether one views withholding and withdrawing treatment as ethically distinct from MAID. Despite the conclusion of the trial court in *Carter v. Canada* that MAID is no different from other end-of-life decisions, this remains a highly charged topic.

TREATING MATURE MINORS DIFFERENTLY THAN CAPABLE ADULTS IN A MAID CONTEXT: FACTORS FOR CONSIDERATION

Consideration of whether minors and adults require different ways to relieve suffering and different tools and standards for assessing capacity is directly relevant to MAID for mature minors. There is no evidence to suggest that children and adolescents experience physical pain differently than adults. Furthermore,

many of the psychological symptoms experienced by adults at end of life are also experienced by minors. However, knowledge gaps exist in understanding the spectrum of emotions experienced by minors with life-threatening conditions and their coping mechanisms during the course of their illness.

In general, capacity assessment as a practice focuses on particular attributes of a patient related to decision-making, regardless of age. The majority of research on structured capacity assessment tools has focused on adult populations. However, studies have demonstrated promise for one of the most widely cited and extensively tested tools (the MacArthur Competence Assessment Tool for Treatment) as a means to assess the capacity of adolescents to consent to various healthcare interventions. Thus, it is plausible that guidelines and tools for assessing an adult's capacity to understand the relevant information and appreciate the reasonably foreseeable consequences of a medical decision can apply to minors. At this stage, however, there is a lack of detailed guidelines describing capacity testing for MAID in Canada.

To protect minors from ending their lives prematurely, their capacity to give informed consent is typically more scrutinized than an adult's in life-threatening circumstances. For instance, when a healthcare decision may lead to a minor's death, court cases invoking the mature minor doctrine have considered not only the individual's cognitive ability to understand the pertinent information and appreciate the reasonably foreseeable consequences of the decision, but also their maturity, which includes a broader range of components, cognitive ability being just one of them. This added layer of scrutiny is not typically invoked for adults, as they are assumed to have the maturity and life experience required to make life-or-death healthcare decisions.

MAID FOR MATURE MINORS: INTERNATIONAL EXPERIENCE

The Netherlands and Belgium are currently the only two jurisdictions where assisted deaths are permitted for minors. While Dutch legislation (enacted in 2002) allows euthanasia for capable patients aged 12 or older, patients between the ages of 12 and 16 must have the consent of their parents or guardians. Those aged 16 to 18 must consult with parents or guardians during the decision-making process; however, parents and guardians do not have the right to veto the decision in cases where the patient and their doctors deem euthanasia appropriate. Among 55,872 cases of euthanasia reported in the Netherlands between 2002 and 2017, 11 cases involved minors. As of August 2018, two additional cases were reported, bringing the total to 13, all of whom had a terminal cancer diagnosis. Eleven patients were aged 16 to 18, one was 14, and one was 12. Case reports are publicly available for all 13 patients. None of these

reports mentioned any issues related to assessment of the minor's capacity, and the primary and consulting physicians were in agreement. Furthermore, in all reported cases, parents were involved in the decision leading to euthanasia and supported the request.

Euthanasia was legalized in Belgium in 2002, and in 2014 the law was amended to include all minors with capacity to judge, regardless of chronological age. To be eligible for euthanasia, Belgian minors must be terminally ill, dying in the short term, and experiencing unbearable suffering. This is in contrast to adults whose illness need not be terminal, only serious and incurable. Since 2014, there have been three reported cases of minors receiving euthanasia in Belgium. One patient had glioblastoma (aged 9), one had cystic fibrosis (aged 11), and one had Duchenne muscular dystrophy (aged 17).

POTENTIAL IMPACTS OF ALLOWING OR PROHIBITING MAID FOR MATURE MINORS

To consider the potential implications of permitting or prohibiting MAID for mature minors, the Working Group drew upon a wide body of knowledge. The number of documented cases of euthanasia for mature minors in Belgium and the Netherlands is too small to inform future outcomes in other jurisdictions. Furthermore, the paucity of voices heard from terminally ill minors who may eventually be eligible to access MAID precludes a full understanding of how they may be affected by any change in the legislation.

Allowing mature minors to access MAID would provide them with an increased range of end-of-life choices and a certain degree of control over their death. However, one unintended consequence might be that some terminally ill minors may feel pressure to request MAID as a means of protecting their families from continued financial and/or emotional distress. This pressure might be even more pronounced for minors with added vulnerabilities, including those who are disabled and/or living in the child welfare system. While there is no information directly related to MAID requests by minors in these categories, other evidence shows that they struggle more routinely to have their voices heard in the process of medical decision-making. Another concern is that allowing mature minors to request MAID might normalize suicide among young people, especially those who struggle with mental disorders and may be considered vulnerable. However, rather than focusing on the inabilities of certain groups, it is important to recognize vulnerability as a social construct generated by society's treatment of these groups. Thus, there is a social responsibility to support those who may be perceived as vulnerable by facilitating their ability to make informed, autonomous decisions, rather than diminishing their rights and limiting their options.

No evidence exists on how MAID eligibility for mature minors could affect families. Although this matter has not been sufficiently explored, it is likely that individual outcomes would be dependent on a number of variables, including family relationships, available social supports, and belief systems and culture. Choosing to help a child die may create pain and stress for some parents or guardians, but others might find release in helping their child to end their suffering and fulfill a final wish.

Studies that have assessed the impact of MAID on healthcare practitioners have involved adult patients only, and these results cannot simply be transferred to minors. Healthcare practitioners who treat minors often develop close, long-term relationships with their patients, but it is not known whether they experience a greater emotional burden following patient death than those who treat adults. Compared with healthcare practitioners' views of MAID for adult patients, surveys of those in the pediatric medical field indicate a greater unease about the prospect of providing MAID to mature minors, and a greater unwillingness to participate in the process. However, it is not yet known whether finding healthcare practitioners willing to provide MAID to mature minors would be a challenge.

Denying MAID to mature minors would pose a potential future legal challenge if a case were to be brought forward in which a mature minor argued that their constitutional rights were being denied. Any such challenge, or change in current MAID legislation, might require courts or policy-makers to re-examine prevailing views of minors and their capabilities, and the overlapping considerations of protection from harm and respect for autonomy.

It is unknown what impact MAID eligibility for mature minors might have on pediatric palliative care services in Canada. In Belgium, the Netherlands, and Quebec, passage of assisted dying has included additional legislation to provide increased funding for palliative care services. Therefore, on the one hand, allowing MAID for mature minors might result in increased funding for pediatric palliative care, or at least improved awareness of pediatric palliative care services. On the other hand, MAID might have a negative impact on palliative care services by diverting resources away from palliative care, altering public perception of palliative care, or causing patients to decline pain management because they wish to maintain the capacity to consent to MAID.

POTENTIAL SAFEGUARDS FOR MAID FOR MATURE MINORS

While safeguards for MAID must provide sufficient protection to the group in question, safeguards that are too restrictive might limit the eligibility of people who would otherwise qualify. Safeguards may be put in place by federal legislation, provincial and territorial legislation, or the healthcare sector through its professional and/or regulatory bodies. No evidence has established that a minimum age would be an effective safeguard for protecting those who are incapable of making an informed, voluntary decision about MAID.

Additional safeguards that might be considered include specific medical criteria for the eligibility of mature minors (e.g., only allowing it for terminal illness), and a multidisciplinary medical team to assess capacity in minors. In Canada, healthcare for minors already relies upon an interprofessional approach that includes psychologists and social workers, as well as child/adolescent psychiatrists who may consult with medical teams and families. In the event of a MAID request, these psychosocial professionals, who are already integrated in the healthcare team, might benefit from an existing familiarity with the patient and their particular circumstances when making a determination of maturity or capacity.

Parental consent exists as a safeguard for capable minors requesting euthanasia in Belgium and the Netherlands. This safeguard recognizes the patient and parents or guardians as a decision-making unit in healthcare for minors. While it is intended to protect minors, this safeguard might also pose a risk to minors who have troubled relationships with their parents, or to parents who view the decision to grant permission to MAID for their children as unbearable. Others argue that parental consent is not truly an effective safeguard, as some parents, with the natural inclination to save their child at any cost, might be unable, under any circumstances, to agree to their child's request.

Finally, proponents of increased access to palliative care argue that universal pediatric palliative care, supported by additional resources, can act as a potential safeguard. According to them, before any extension of MAID to mature minors, pediatric palliative care should be available in a timely manner and locally, whether in hospital or at home. While none deny that pediatric palliative care should be an option available to everyone who needs or wants it, critics argue that it will never be a substitute for MAID and that these two options are not mutually exclusive.

FINAL THOUGHTS FROM THE WORKING GROUP ON MAID FOR MATURE MINORS

Many in Canada are grappling with the question about whether to extend MAID to mature minors in a society already exposed to changing ideas about death and dying. Although the Working Group examined a wide range of evidence, it concludes that there are many gaps in knowledge that make it difficult to arrive at definitive answers.

The fact that only two jurisdictions allow MAID for minors, and that cases remain extremely rare within those jurisdictions, means little is known for certain about the practice. There is minimal information about the 16 documented cases, and none about the families in Belgium and Netherlands whose children have gone through the process. Although Canadian courts have addressed cases of minors wishing to withhold or withdraw potentially life-saving or life-prolonging treatment, there have been no cases of minors requesting MAID.

There is little available evidence that documents the perspectives of those who would be most affected by the prohibiting or permitting of MAID for mature minors. These include terminally ill minors, their parents and siblings, bereaved families that have already lost a child to terminal illness, and minors who may be perceived as particularly vulnerable (e.g., those with disabilities, Indigenous youth, and/or those in the child welfare system). There are few clinical studies focusing on the health issues of minors, and even fewer specific to adolescents, the age range most likely to fit the definition of a mature minor. While this report discusses the views of pediatric physicians on MAID, there was no published research reporting the views of other pediatric healthcare practitioners, especially nurses who are often intimately involved in care. Any deliberation on whether to permit MAID for currently excluded groups would benefit from greater engagement with Canadian society, especially those groups most likely to be affected.

This report demonstrates that mature minors are developing autonomy within a relational context, which is extremely important to their decision-making. Thus, safeguards might reflect a relational approach to healthcare decision-making that involves the patient, their family (parents or guardians), and an interprofessional healthcare team. While chronological age can provide some developmental generalizations about decision-making abilities, it is not the most important variable in determining capacity for informed consent. The capacity of a minor to consent to a healthcare intervention must be determined on a case-by-case basis by considering their experiences, maturity, circumstances, and the gravity of the decision at hand.

The view that minors are in need of heightened protection is a widely shared concern. Despite research demonstrating that some minors are capable of making critical healthcare decisions, including end-of-life choices, some argue that minors as a group are too vulnerable to be given the ability to request MAID. However, part of protecting potentially vulnerable patients is to ensure that they are listened to. Thus, it has been argued that, rather than denying healthcare choices to groups frequently labelled as vulnerable, society must provide the accommodations to ensure that everyone is protected not only from exploitation, but also from being ignored and excluded.

Summary of the State of Knowledge on Advance Requests for Medical Assistance in Dying

Legislation in Canada requires medical and nurse practitioners to obtain express consent from a patient immediately prior to providing MAID. This means that people who lack the decisional capacity to consent at the time of MAID provisioning are not eligible to receive MAID; a request for MAID therefore becomes invalid if the person who made it loses the capacity to consent to the procedure. As a result, *advance requests for MAID* (ARs for MAID) — defined as a request for MAID, created in advance of a loss of decision-making capacity, intended to be acted upon under circumstances outlined in the request after the person has lost decisional capacity — are not permitted and currently have no legal or clinical standing in Canada.

DIFFERENTIATING ADVANCE REQUESTS FOR MAID FROM ADVANCE DIRECTIVES

Canadian law recognizes a capable patient's right to choose (or refuse) healthcare treatment. This right can be exercised through the patient's express consent or refusal as they make treatment decisions with their healthcare practitioner or through an advance directive. Advance directives can be used in Canada to designate a substitute decision maker or document wishes, values, and preferences for care in the event of capacity loss. For example, an advance directive may include advance consent to, or refusal of, specific treatments such as administration of blood and blood products, resuscitation in the event of cardiac or respiratory arrest, or artificial nutrition and hydration in the event of a permanent loss of consciousness.

Advance directives and ARs for MAID are similar in that both allow capable individuals to have their treatment preferences and decisions known and followed in the event they lose decision-making capacity. In addition, both require a third party to carry out the instructions when a person cannot confirm or express their preferences. However, while advance directives can involve decisions that will lead to a patient's death (e.g., withholding of treatment), ARs for MAID are a request for only an assisted death.

Allowing ARs for MAID would require an amendment to federal legislation (the *Criminal Code*), whereas provinces and territories regulate advance directives. If ARs for MAID were allowed in Canada, it is unclear how their regulatory framework would differ from that of advance directives. With the exception of Nunavut, all Canadian provinces and territories have their own legislation

that regulates healthcare decision-making for people who lack the capacity to make decisions themselves; the details of these laws vary by jurisdiction. A legal regime for ARs for MAID, established in federal criminal legislation, would form one part of the regulatory picture in Canada, and practical implementation would depend on provincial/territorial legislation as well as professional regulatory schemes.

WHY AN ADVANCE REQUEST FOR MAID?

Societal norms around end-of-life care are changing. It is becoming more common to make treatment decisions and document preferences before a loss of decision-making capacity through advance care planning and advance directives. As Canada's population ages, more people will experience capacity-limiting conditions, which will affect the demand and delivery of healthcare resources. ARs for MAID, should they be allowed, would operate in this evolving clinical and social context.

Key drivers for creating an AR for MAID are the desire to have control over one's end of life and the desire to avoid intolerable suffering. For people who wish to receive MAID, the knowledge that they could lose decision-making capacity and thus become ineligible for MAID is a source of fear. A number of conditions, including neurodegenerative diseases and brain injuries, can bring about loss of decision-making capacity. Following the charge, the Working Group considered three temporal scenarios in which a person might choose to write an AR for MAID: (i) when they have requested and been found eligible for MAID, but fear losing the capacity to provide consent before the procedure;¹ (ii) when they have been diagnosed with a medical condition that is likely to cause capacity loss; or (iii) when they are healthy but wish to document their preference for MAID in the event of a sudden, irreversible loss of capacity.

UNCERTAINTIES AND ISSUES SURROUNDING ADVANCE REQUESTS FOR MAID

All three of these scenarios reveal a number of issues or considerations, many of which are related to the fact that ARs for MAID would require third parties to make a life-or-death decision on behalf of someone else when they can no longer confirm the patient's wishes. This could lead to uncertainty about understanding the patient's physical and/or emotional state, interpreting the AR for MAID and applying it to the patient's circumstances, and determining

1 Canada's MAID legislation requires 10 clear days to pass between the date that a MAID request was signed and witnessed, and the date that MAID is provided. If a patient loses the capacity to consent to MAID during this waiting period, they are no longer eligible to receive it. The waiting period can be shortened if MAID assessors believe that the patient's death, or the loss of their capacity to provide informed consent, is imminent.

the strength and persistence of the patient's wishes. Uncertainty may be greater in cases where the patient's healthcare team and family are not familiar with their values, wishes, and circumstances, and must interpret the AR for MAID without this knowledge. The timing of an AR for MAID in relation to its implementation could also play a role. For example, an AR for MAID prepared when a patient has requested and been approved for MAID, or when a patient has a potentially grievous and irremediable medical condition but is not yet suffering intolerably, would tend to involve less uncertainty than requests prepared several months or years before implementation.

Figure 2 provides an illustration of the uncertainties that could complicate the process of implementing each individual AR for MAID. These uncertainties relate to one of three dimensions: (i) *status of the patient* (level of alignment between their current state, their current desire for MAID, and the conditions described in their AR for MAID); (ii) *clarity of communication* (how well the patient described the circumstances that represent their idea of intolerable suffering in their AR for MAID, how often they discussed their wishes, and how consistent these wishes were); and (iii) *strength of relationships* (whether the patient had strong and open relationships with their healthcare practitioners and loved ones, and whether at least one trusted person was familiar with and supportive of their AR for MAID). Figure 2 assumes that the patient currently lacks the capacity to consent to MAID.

While Figure 2 describes uncertainties that could arise at the level of individual cases, the possibility of permitting ARs for MAID also raises broad questions related to the application of legislative criteria, clinical practice guidelines, and relevant ethical concepts. These include potential issues in the application of the intolerable suffering criterion, the conditions of valid and informed consent, clarification of the role of third-party decision makers, and potential issues arising from conflict between anticipated and present circumstances.

Intolerable Suffering: Under Canada's current legislation, patients can initiate a MAID request if *they* decide that their condition is causing them intolerable suffering. Although healthcare practitioners need to confirm that the intolerable suffering criterion has been met, the legislation does not require an independent judgment of the patient's level of suffering by a third party. It is unclear how an AR for MAID might address this requirement of intolerable suffering and what role the healthcare practitioner would play in assessing it when a patient can no longer communicate their level of suffering at the time that MAID is to be provided. Interpreting suffering in others is difficult since it is a personal, subjective experience. The need to make this interpretation could be substantially

reduced if a patient clearly defined the conditions that represent intolerable suffering to them in their AR for MAID. While a patient’s care team would still need to interpret these conditions and decide whether the patient had met them, less interpretation of the patient’s suffering would be required if their request was clear on this matter. However, when to implement MAID could still be unclear if, having met the circumstances listed in the request, the patient did not otherwise meet all eligibility criteria or did not appear to desire MAID.

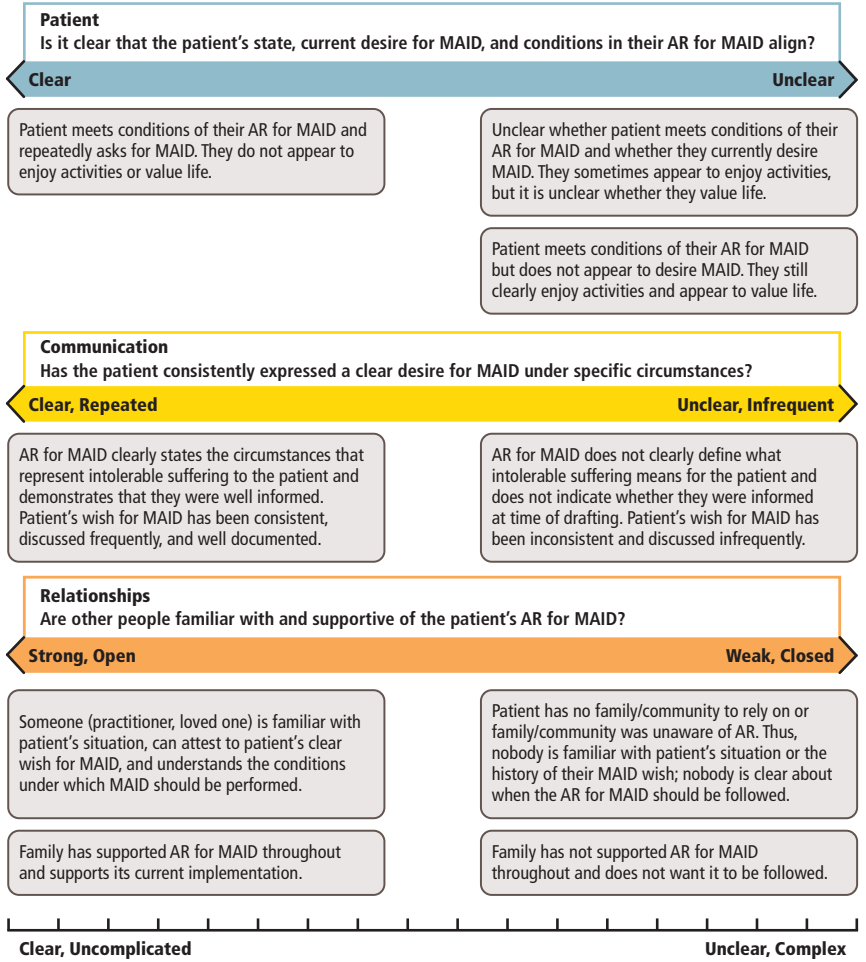


Figure 2
Summary of Uncertainties in Administering Advance Requests for MAID

Informed Consent: Informed consent to healthcare must be voluntary, related to the proposed healthcare, and expressed by a person capable of making a reasonable decision based on truthful and adequate information provided by the healthcare practitioner. Obtaining informed consent is a process through which information is shared and queried. Permitting ARs for MAID would require consideration of the necessary conditions for valid and informed consent to MAID when this consent is given in a written document, which may be prepared well in advance of the MAID procedure. If the document was written in the absence of healthcare practitioners or family members, it may be challenging to assess the adequacy of informed consent from this document alone. Discussions of treatment options, potential outcomes, and motivations are unlikely to have occurred if a person does not yet have a condition that requires treatment. It may be difficult to know the voluntariness of an AR for MAID and to what extent a person was informed of their current situation when they wrote their request, particularly if they wrote it without consulting healthcare practitioners, without witnesses, or before any diagnosis.

The Role of Third-Party Decision Makers: One of the central features of ARs for MAID — the fact that the instructions they contain would not become relevant until a person has lost capacity — would require third-party decision makers to play a major role in their implementation. ARs for MAID could raise questions about the roles of various third-party decision makers in deciding how to best follow a patient's wishes. When substitute decision makers are directing the care of someone who lacks capacity, they are required, based on current Canadian laws, to follow the instructions in a written advance directive (if they are applicable to the circumstances). In the case of ARs for MAID, it could be valuable to consider how the written wishes of a patient, the views of a legally authorized substitute decision maker, the views of family members, and the opinions of healthcare practitioners would be accommodated, particularly if disagreement occurred. Well-defined, legislated limits, along with education, in either the permission or prohibition of ARs for MAID, could provide healthcare practitioners and family members with clarity on end-of-life options.

Potential Conflict Between Anticipated and Present Circumstances: A person who no longer has decision-making capacity may no longer be able to articulate the nature or quality of their condition and experience. Having an AR for MAID, in and of itself, might relieve suffering in anticipation of capacity loss by providing assurance that one's wishes are known and will be followed at some predetermined time. However, the person must rely on others to recognize when the conditions described as intolerable suffering in their AR for MAID

have been met. An AR for MAID would have to specify what criteria the person considers intolerable (e.g., being bedridden, not recognizing family members, difficulty breathing, or experiencing pain), but these are circumstances of anticipated suffering that may not reflect the lived experience of the person when they reach those circumstances. Uncertainty about how to approach an AR for MAID increases if the person who has lost capacity appears indifferent to receiving MAID, expresses a desire to continue living, or physically or verbally resists the MAID procedure.

EVIDENCE FROM RELATED PRACTICES

The use of advance directives for healthcare has been limited, but is increasing in Canada. Research has found occasionally positive, and no negative, effects of advance care planning and advance directives on patient-related outcomes, such as satisfaction with end-of-life care. Cases of conflict over the use of advance directives, and end-of-life decision-making in general, do not often become public record because decision-making at end of life is largely private, confined to the bedside, and not subject to research. From the few cases related to advance directives that have made it to Canadian courts, case law has established the priority of present consent over what is written in an advance directive, the priority of written instruction directives over best interests, and the authority of substitute decision makers to make end-of-life decisions.

Little empirical evidence exists on how well ARs for MAID work in practice. Belgium, Colombia, Luxembourg, and the Netherlands permit some form of AR for MAID (referred to in these countries as *advance euthanasia directives* or AEDs), though their use is rare. Of the four countries that allow AEDs, two (Belgium and Luxembourg) only allow them when a person is irreversibly unconscious, and one (Colombia) allows them only in the context of imminent death. Countries that allow AEDs require that assisted deaths be reported to an oversight body created and regulated through legislation. These oversight bodies, with the exception of Colombia, produce summary documents of reported cases; however, since 2009, only one patient (in 2012) has received euthanasia based on the instructions in an AED in Luxembourg. Thus, Belgium and the Netherlands are the only two countries with any substantial practical experience with AEDs. From 2002 to 2017, there were 322 assisted deaths due to an AED in Belgium, representing between 1 and 4% of all assisted deaths. However, nearly all of the information about implementation of AEDs is from the Netherlands, due to a lack of detailed case information (from either the review commission or academic studies on AEDs) in Belgium.

In the Netherlands, AEDs can only be followed for patients with some level of consciousness, and there are six reported cases of people registered as decisionally incompetent who received euthanasia based on their advance directive. All of these cases involved patients with advanced dementia. The practice of euthanasia for such patients has generated controversy in the Netherlands. In two of the six cases, the Dutch euthanasia oversight body determined that the physician did not act in accordance with the law. By analyzing all reported cases in the Netherlands involving patients with questionable decisional capacity who received euthanasia based on an AED, the Working Group noted that issues are more likely to arise when a person cannot provide express consent immediately prior to receiving MAID. However, the practical application of AEDs, the details of professional judgments in these cases, and the societal impacts of allowing AEDs remain significant knowledge gaps. In addition, the transferability of international evidence to the Canadian context is complicated by differences in legislative approaches to MAID, and may be affected by differences in healthcare systems and professional practices.

POTENTIAL IMPACTS OF ALLOWING OR PROHIBITING ADVANCE REQUESTS FOR MAID

ARs for MAID may give rise to a range of positive and negative impacts, which could be experienced not only by those requesting MAID, but also by those responsible for deciding if and when to follow through with the request and by society as a whole. Allowing ARs for MAID would recognize the values of respecting patient autonomy and self-determination in Canadian society, particularly for those members of society who have lost, or anticipate losing, decision-making capacity. ARs for MAID would give some people who anticipate a loss of decision-making capacity the opportunity to have their previously expressed wish for MAID followed, even if they could not provide consent immediately prior to the procedure. Having some assurance that their request for MAID would be honoured could provide comfort and relieve anxiety and distress at end of life for those who make this choice.

Healthcare practitioners who implement ARs for MAID might feel satisfaction and relief associated with respecting a patient's choice and alleviating suffering. However, they might also feel that deliberately ending the life of someone who cannot consent to this action is an enormous responsibility. A third party would need to decide if and when MAID is an appropriate course of action based on the contents of a patient's AR for MAID, their knowledge of the patient's wishes, and their interpretation of the patient's current state. This may be a difficult decision, particularly if it is unclear whether the patient fulfills the conditions of their AR for MAID or whether they desire MAID.

The Working Group recognizes that some people are concerned that allowing ARs for MAID might have an impact on the way society values people with capacity loss, increasing stigma and signalling that it is acceptable to consider a life with capacity loss as one not worth living. Moreover, some have expressed concern that allowing ARs for MAID would create a society in which MAID was an appropriate alternative to providing quality and accessible care to those with capacity loss, opening the door to cost of care, bed clearing, or other considerations to explicitly or subtly enter the treatment decision-making process. However, little evidence exists as to the likelihood of potential impacts, positive or negative; they are plausible but conjectural.

POTENTIAL SAFEGUARDS FOR ADVANCE REQUESTS FOR MAID

The primary risk involved in ARs for MAID is the risk that a person will receive an assisted death against their wishes. This risk is influenced by systemic and societal pressures, such as accessibility or availability of care, stigma associated with a loss of decision-making capacity, or biased assumptions about quality of life, and may manifest in either the motivations of the person writing the AR for MAID or in a third party's interpretation of the request. Case-specific pressures, including uncertainties about the AR for MAID itself, the patient's condition, and relationships among the patient, substitute decision maker, and healthcare team, also affect this risk. Safeguards can respond to risks by reducing potential impact and/or likelihood, though none can remove a risk entirely. Safeguards represent an effort to mitigate risk to achieve benefits for people in Canada; policy-makers will need to judge whether and/or where safeguards can adequately do so.

A necessary component of any set of safeguards, whether complete prohibition or otherwise, is monitoring — allowing opportunities for analyses and adaptation of policies as needed to address evolving concerns. The report identifies a number of safeguards, including those at the system level and those that are case-specific. Systems-level safeguards involve improving knowledge and delivery of various healthcare components, thereby ensuring that people are aware of, and have access to, the different types of supportive care available; that people are supported in their decision-making; and that patients with a variety of conditions feel valued by society. Case-specific safeguards are directed at reducing uncertainty; they include a range of possible laws and regulations (legal safeguards), clinical practice guidelines (clinical process safeguards), and mechanisms for supporting healthcare practitioners, patients, and families to make the process of following an AR for MAID clearer, safer, and less overwhelming. Table 1 summarizes the specific safeguards discussed in the report.

Table 1

Potential Safeguards Associated with ARs for MAID

	Safeguards
Systems-Level Safeguards	<ul style="list-style-type: none"> • Increased engagement in ACP • Improved palliative care education • A broader approach to palliative care • Effective data collection on MAID cases to enable extraction of useful information • An oversight mechanism with clear avenues for reporting those who are violating the law
Legal Safeguards	<ul style="list-style-type: none"> • Well-defined access criteria (e.g., only allowing ARs for MAID for irreversibly unconscious patients) • Additional review requirements (e.g., consultation with social workers or medical experts such as geriatricians or psychiatrists; prior review of all AR for MAID cases by a multidisciplinary committee) • A registry of ARs for MAID • Time limits on the validity of an AR for MAID (mandatory updating) • Modification of existing safeguards (e.g., informed consent, intolerable suffering) to make them relevant to ARs for MAID • Appointment of an SDM, with clear guidance and limits on the role • Involvement of an independent third party in assessing AR for MAID cases
Clinical Process Safeguards	<ul style="list-style-type: none"> • Counselling for people who wish to draft an AR for MAID • Repeated, documented discussions among patients and their care team
Support for Healthcare Practitioners	<ul style="list-style-type: none"> • Training for healthcare practitioners on legal and clinical aspects of ARs for MAID, ACP, and palliative care • Support services provided by specially-trained healthcare practitioners familiar with ARs for MAID • Emotional support for healthcare practitioners and other staff members
Support for Patients and Families	<ul style="list-style-type: none"> • Facilitation of continued discussion among people and their loved ones about their AR for MAID and the motivations behind their end-of-life wishes • Emotional (e.g., grief and bereavement services) and practical (e.g., legal advice, guidance from peers) support for families before, during, and after MAID

Working Group members differed in their opinions of which potential safeguards are necessary, and whether any set of safeguards would be sufficient to achieve an acceptable level of risk to allow ARs for MAID. For example, some argue that the requirement for consent immediately prior to receiving MAID is necessary to avoid errors and abuse, and to meet the broad goals of Canada's legislation, such as recognizing the inherent value of every person's life. Others focus on the potential benefits of ARs for MAID, such as alleviating suffering and respecting the choices of people who wish to control the circumstances and timing of their death; they can readily conceive of situations in which ARs for MAID could be implemented with an acceptable level of risk, but might not agree on the specific scenarios in which they should be permitted. All Working Group members

recognize the importance of additional research on the experiences of those living with a loss of decision-making capacity, their families and caregivers, and their interactions with the healthcare system.

FINAL THOUGHTS FROM THE WORKING GROUP ON ADVANCE REQUESTS FOR MAID

Allowing ARs for MAID could provide comfort and relieve anxiety and distress at end of life for people who want to receive MAID, but are concerned about losing decision-making capacity prior to the procedure. However, removing a requirement for express consent immediately prior to the MAID procedure raises the possibility that a person might receive MAID against their wishes. Thus, the main issue with ARs for MAID is the uncertainty faced by those responsible for following the request when it comes to gauging when or whether the patient desires an assisted death. The Working Group considered several potential scenarios, distinguished by timing, disease trajectory, and the circumstances of the request, each with different levels of uncertainty. For example, ARs for MAID prepared shortly before an assisted death is provided would tend to involve less uncertainty than those prepared several months or years before implementation. A judgment about whether to continue to prohibit or to permit some form of ARs for MAID would need to consider the inherent tensions among values of respecting autonomy, alleviating suffering, and protecting against vulnerabilities, in light of risks and benefits specific to each scenario.

If some form of ARs for MAID were permitted in Canada, a number of potential safeguards could respond to those risks and vulnerabilities inherent in the pursuit of patient autonomy. Safeguards might operate at different levels, from ensuring a healthcare system is able to support decision-making related to ARs for MAID, to ensuring individual cases represent the voluntary and informed decisions of patients. Consensus on which situations, if any, are suitable for allowing ARs for MAID is unlikely given the differences in how people weigh various factors and interpret evidence; situations with less uncertainty, however, are likely to find greater agreement.

While advance care planning and advance directives in Canada, and AEDs in other countries, can provide insight into some aspects of ARs for MAID, the inferences drawn in this report remain limited by significant knowledge gaps. This highlights the importance of further research on end-of-life practices in Canada and worldwide, including advance care planning, healthcare approaches, healthcare decision-making, and assisted dying.

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

While the legislation mandating this independent review and the charge from the Minister of Health and the Minister of Justice and Attorney General of Canada used the term *mental illness*, the Working Group chose to use the term *mental disorder* in order to be consistent with current clinical and legal practice. 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. 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 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 to cases where a mental disorder is the sole underlying medical condition (hereafter, 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. However, most are unlikely to satisfy all of the current eligibility criteria for MAID. The scope of this report is restricted to those cases that are not permitted under the current law. Furthermore, in this report, the phrase *sole underlying medical condition* 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 the request.

MENTAL DISORDERS IN CANADA

Mental disorders can affect people in all socioeconomic and demographic categories, but the presence of many mental disorders is strongly correlated with certain social, economic, and environmental inequalities, such as poverty, unemployment, homelessness, and violence. Canadian data show that women, youth, and Indigenous people have higher rates of mental health problems than the Canadian average. Additionally, there are variable rates of mental health problems for different immigrant, refugee and racialised (IRER) groups. Many people with a mental disorder do not receive the necessary treatment

for their condition. 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. In addition, people may be reluctant to seek mental healthcare due to stigma, or they may be unable to access mental healthcare for a variety of reasons, including geographical unavailability, long wait times, lack of financial means (or inadequate insurance) for medications and/or outpatient treatment, and lack of social support. Indigenous and IRER populations may have difficulty accessing care they feel is culturally appropriate and there are claims of racism in mental health services.

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, and their freedoms and choices have been unjustly restricted.

ISSUES AND UNCERTAINTIES SURROUNDING MAID MD-SUMC

Many important issues that are unique to mental disorders arise when considering whether to more broadly permit or prohibit MAID MD-SUMC. 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.

Given this wide range of perspectives and the controversial nature of the topic, Working Group members do not agree on some fundamental issues (Box 1). In some areas, the Working Group did not reach consensus on the interpretation and/or significance of the evidence, or about what constitutes relevant evidence.

Capacity and Decision-Making

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. 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 people with mental disorders, and different assessors may disagree about whether or not a person is capable.

Box 1**Working Group Disagreements on Fundamental Issues About 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 disagree 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.

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, even when a person retains decision-making capacity. It may be difficult for a clinician to distinguish between a capable person who is making an autonomous decision for MAID and a person whose pathological desire to die is a symptom of their mental disorder that impairs their decision-making. 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 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.

Are Some Mental Disorders “Grievous and Irremediable” Conditions?

People requesting MAID MD-SUMC may not satisfy several of the four criteria of having a “grievous and irremediable medical condition” (as defined in Bill C-14). Clinicians disagree about when and which mental disorders can be considered incurable (in medicine, there is no single, universally agreed-upon definition of the term *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, natural death has not become reasonably foreseeable (at least not until the person is at an advanced age).

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 when compared to the physical conditions that currently motivate MAID requests. However, predictability can be higher for certain conditions, or for patients who have undergone multiple treatments over a longer period of time. 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.

Suicide

Having a mental disorder is one of the most strongly associated risk factors for suicide. 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). Furthermore, there is some evidence that some people who have sought psychiatric euthanasia and assisted suicide (psychiatric EAS) in jurisdictions that permit it share certain characteristics with people who attempt suicide. Research has found no evidence that the legalization of assisted dying affects suicide rates, including in countries that permit MAID MD-SUMC.

Working Group members have different views about the relationship between MAID MD-SUMC and suicide and whether it is possible to distinguish between them. 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.

Working Group members disagree about whether permitting more MAID MD-SUMC would potentially be incompatible with the current approach to suicide prevention in Canada.

INTERNATIONAL EVIDENCE

There are countries where assisted dying for those with a mental disorder is permitted more broadly than in Canada. Those experiences are reviewed as they may provide insights about potential impacts and possible safeguards. Belgium, the Netherlands, and Luxembourg (collectively termed *Benelux countries*) allow people to seek EAS based on physical or mental suffering alone, with no requirement of terminal illness or foreseeable death. 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 2. The Working Group notes the importance of avoiding either an uncritical extrapolation or a dismissal of Benelux data. Interpreting these data for Canada should take into account differences and commonalities between Canada and the Benelux countries.

Table 2
Stipulations for Psychiatric EAS in the Netherlands, Belgium, and Luxembourg

Stipulation	Country			
	Netherlands Required by Law	Suggested by RTE or NVVP	Belgium Required by Law	Luxembourg 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

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.

In the Netherlands and Belgium, psychiatric EAS, excluding dementia, represent approximately 1 to 2% of all EAS cases. 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). 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.

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 people with depression. Other conditions underlying requests include personality disorders, schizophrenia and other psychotic disorders, post-traumatic stress disorder and other anxiety disorders, eating disorders, autism, and prolonged grief disorder. 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. Psychiatric EAS remains controversial even in jurisdictions that have permitted it for many years, and public debate is ongoing.

POTENTIAL IMPLICATIONS OF PROHIBITING OR EXPANDING MAID-MD SUMC

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. 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 MAID but do not receive it. It is widely agreed that there is a need to avoid both types of cases if MAID MD-SUMC were expanded or prohibited, but the challenges associated with assessing capacity and prognosis in the context of mental disorders suggest that there may be cases where people disagree about whether a particular person would be eligible or not.

Eligibility Criteria

The Working Group identified several important potential implications for MAID MD-SUMC stemming from challenges associated with applying the eligibility criteria from Bill C-14 to people whose mental disorder is their sole underlying medical condition, which may lead to risks of both over-inclusion

and under-inclusion. For example, challenges associated with assessing capacity in people with mental disorders may result in over-inclusion or under-inclusion. In addition, there are many possible interpretations of the term *incurable*, and whether some mental disorders can be considered incurable will depend on the definition chosen. Similarly, many mental disorders can lead to declines in both mental and physical capabilities directly through symptoms, but there is disagreement about whether these declines would be considered as an advanced state of irreversible decline in capability.

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. MAID law in Canada explicitly defines intolerable suffering in *subjective* terms. 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. 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.

Permitting more MAID MD-SUMC may reduce suffering by providing eligible individuals 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 people who were approved for psychiatric EAS withdrew their requests after approval, later indicating that knowing they had the option gave them comfort, although Working Group members disagree about how to interpret this evidence.

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 voluntary stopping of eating and drinking (VSED) in order to hasten the foreseeability of their death. Other Working Group members feel this implication is unsubstantiated based on the evidence available.

This criterion also currently excludes people with a range of physical conditions who would otherwise qualify. 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. For example, a person with severe and difficult to treat 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.

Vulnerability and Autonomy

Some people with mental disorders are considered vulnerable, insofar as having a mental disorder is associated with socioeconomic 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). 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. Concerns related to the vulnerability of the population 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.

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. Other Working Group members think that permitting more MAID MD-SUMC may increase mental health stigma because it might bolster the belief that the lives of people with mental disorders are intolerable, not worth living, and (at least sometimes) hopeless.

Prohibiting or permitting more MAID MD-SUMC may unjustifiably discriminate against people with a mental disorder. 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. 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 (compared to physical disorders), and note that 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.

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. 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, which is itself a complex philosophical and legal concept.

Mental Healthcare

Evidence indicates that MAID MD-SUMC is not acceptable to many mental healthcare practitioners in Canada. Permitting more MAID MD-SUMC might alter mental healthcare in Canada, as it may conflict with their professional views and ethics.

There are challenges associated with access to mental healthcare in Canada. 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. 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. Evidence on the provision of MAID under the current law (which excludes most MAID MD-SUMC) indicates that, in general, those with inadequate healthcare or palliative care are not disproportionately seeking MAID. Despite this, there have been recent concerns raised around access to alternative care to relieve suffering.

There are concerns that permitting more MAID MD-SUMC may have a negative impact on the therapeutic relationship between patients and mental healthcare practitioners. Patients might be reluctant to fully engage with mental healthcare practitioners out of fear that they will be encouraged to seek MAID. On the other hand, it has been suggested that 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.

UNIQUE CONSIDERATIONS FOR SPECIFIC DEMOGRAPHIC SUBPOPULATIONS

The effects of prohibiting or permitting more MAID MD-SUMC will vary among different gender, ethnic, cultural, and socioeconomic populations in Canada — including Indigenous people; immigrant, refugee, ethno-cultural, and racialized groups; women; mature minors; LGBTQ+ people; seniors; Canadian Armed Forces members and Veterans; and incarcerated people — based on differences in the prevalence of mental disorders among demographics, the lived experience of people with mental disorders, suicidality, ability to access mental healthcare and social supports, and interest in MAID.

KNOWLEDGE GAPS

Given that psychiatric EAS is legal in a small number of jurisdictions around the world, direct evidence on the practice is limited. Most 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. 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.

There is little direct 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.

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.

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. 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.

POTENTIAL SAFEGUARDS

There are a range of safeguards that could potentially mitigate some of the risk 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. 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). 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).

The Working Group considered nine safeguards — including those currently implemented in the Benelux countries as well as those that have yet to be implemented in any jurisdiction — and reviewed any evidence relevant to their effectiveness. 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.

Potential safeguards include:

- psychiatric consultation
- multi-disciplinary evaluation
- roundtable, committee, tribunal, or judicial approval
- involvement of family and/or important third parties
- two-track approach during MAID MD-SUMC evaluation
- training of healthcare practitioners consulting on MAID MD-SUMC requests
- longer waiting period between request and administration of MAID MD-SUMC
- agreement on determination of treatment futility
 - minimum number of years with a diagnosed mental disorder
- mandatory reporting and review of cases

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 eligibility criteria or procedural requirements not required of people with physical disorders who qualify for MAID 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).

As some of the safeguards listed above 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 the Benelux countries, 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 (responsible for the *Criminal Code*, which sets out the legal conditions under which MAID is provided) and provincial/territorial governments (responsible for the provision of healthcare and mental health law).

FINAL THOUGHTS FROM THE WORKING GROUP ON MAID WHERE A MENTAL DISORDER IS THE SOLE UNDERLYING MEDICAL CONDITION

Whether to expand, prohibit, or make no changes to the law that governs MAID with respect to the eligibility of those whose sole underlying medical condition is a mental disorder is a contentious subject on which there are differing opinions. 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. The diversity of expertise 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.



Concluding Remarks from the CCA

These reports fulfil a requirement set out in the statute amending *Criminal Code* provisions to allow medical assistance in dying under specific conditions. The purpose of these reports is to inform conversation among Canadians and between Canadians and decision makers about the issues of MAID as it relates to the three topic areas discussed above. To this end, at the request of the Sponsors and in keeping with the CCA's normal practices, these reports do not offer recommendations. Instead, they gather and interpret, with the sensitivity required of the subject, the relevant information and evidence, and they explore the societal, clinical, legal, and practical implications and issues associated with both permitting and prohibiting MAID in the three topic areas.

While each report was authored by its respective Working Group, all three have benefited from the wider expertise of the Expert Panel as a whole, and reflect much of what is known nationally and internationally about the topic areas. Together these reports aim to inform a uniquely Canadian approach and the ongoing international debate and experience.



Council of
Canadian
Academies

Conseil des
académies
canadiennes

180 Elgin Street, Suite 1401
Ottawa, ON K2P 2K3
Tel: 613 567-5000
www.scienceadvice.ca