



Medical Assistance in Dying

Key Priorities and Opportunities — Proceedings Report



Canadian Institute
for Health Information

Institut canadien
d'information sur la santé

Production of this document is made possible by financial contributions from Health Canada and provincial and territorial governments. The views expressed herein do not necessarily represent the views of Health Canada or any provincial or territorial government.

All rights reserved.

The contents of this publication may be reproduced unaltered, in whole or in part and by any means, solely for non-commercial purposes, provided that the Canadian Institute for Health Information is properly and fully acknowledged as the copyright owner. Any reproduction or use of this publication or its contents for any commercial purpose requires the prior written authorization of the Canadian Institute for Health Information. Reproduction or use that suggests endorsement by, or affiliation with, the Canadian Institute for Health Information is prohibited.

For permission or information, please contact CIHI:

Canadian Institute for Health Information
495 Richmond Road, Suite 600
Ottawa, Ontario K2A 4H6

Phone: 613-241-7860

Fax: 613-241-8120

www.cihi.ca

copyright@cihi.ca

ISBN 978-1-77109-665-2 (PDF)

© 2017 Canadian Institute for Health Information

How to cite this document:

Canadian Institute for Health Information. *Medical Assistance in Dying: Key Priorities and Opportunities — Proceedings Report*. Ottawa, ON: CIHI; 2017.

Cette publication est aussi disponible en français sous le titre *Aide médicale à mourir : priorités et possibilités — compte rendu*.

ISBN 978-1-77109-666-9 (PDF)

Table of contents

Executive summary	4
Introduction	6
MAID data collection: In development or under way	7
MAID data collection: Priorities and opportunities	9
Conclusion	11
Appendix A: Framework for mapping MAID information needs	12
Appendix B: Participant list	16
Appendix C: MAID annual federal monitoring report — draft outline	18
Appendix D: Additional resources recommended by consultation participants	19
Appendix E: Detailed information needs by topic	20
References	23

Executive summary

Since the fall of 2016, the Canadian Institute for Health Information (CIHI) has worked closely with leaders in medical assistance in dying (MAID) from across Canada to better understand their MAID-related information priorities. These activities culminated in a pan-Canadian working meeting in June 2017, where leaders in MAID information explored their priority information needs, assessed the access to and availability of information to address those priorities, and identified opportunities to leverage information currently being collected to support health system decision-making.

This meeting advanced lessons from the [first pan-Canadian dialogue in 2016](#) and feedback provided by MAID leaders in one-on-one consultations in the first half of 2017.

MAID information needs are diverse

MAID leaders have diverse information needs related to

- System participants, including MAID patients and MAID providers and assessors;
- System access, including patient pathways and timeliness;
- System process, including quality and safety;
- Experience of MAID patients and their families; and
- Experience of MAID assessors, providers and care teams.

These needs reflect the breadth of topics and priorities for MAID providers and professional associations, national and provincial organizations dedicated to quality and patient care, and provincial and territorial governments monitoring MAID activities within their own jurisdictions.

CIHI developed a provisional framework to map these needs. This framework builds on the feedback collected throughout CIHI's MAID activities, including pan-Canadian meetings hosted in 2016 and 2017 and in-person consultations with organizations and jurisdictional and academic experts from across the country.

While the framework maps a breadth of information, it is critical to acknowledge the burden already associated with the provision of MAID services. Data collection and reporting should be driven by specific objectives and the intended use of the data. For information about the organizing framework, including background, definitions and methods, check [CIHI's web page on MAID](#) and [Appendix A](#) of this document.

Collection and reporting of MAID information is already under way

Jurisdictions across Canada have been collecting and reporting data on MAID since 2016. The federal legislation that permits MAID in Canada requires the federal minister of health to make regulations for the purpose of monitoring its implementation. Until this permanent monitoring system is in place, the federal government is working with provincial and territorial governments to provide interim updates that provide a picture of MAID across the country. Beyond the federal monitoring regime, jurisdictions can determine what other information should be collected and by what means. Some examples of the types of information being collected by multiple provinces includes patient-related demographics, diagnosis prompting the MAID request, date of first request for MAID and type of facility where MAID was provided.

Health Canada has committed to monitoring and reporting on medical assistance in dying and will be producing annual reports on MAID in Canada. Reports will include the number of written requests for MAID and their outcomes; how the service is being carried out; characteristics of those requesting and receiving MAID; and insight into the application of the eligibility criteria and the safeguards.

CIHI has developed [interim standards and coding direction](#) for the collection of pan-Canadian MAID information in acute and ambulatory care settings. This direction is currently available on [CIHI's MAID web page](#), with further guidance in development for 2018–2019.

Canadian researchers have tackled important questions related to MAID, including topics such as costs¹ and program implementation,² and have developed tools for measuring the prevalence of medical end-of-life practices and the underlying decision-making processes in Canada.³ The Canadian research community can be a partner in addressing the information priorities identified by MAID leaders. Collaboration can help ensure that data collection, analysis and reporting is not duplicated.

CIHI's commitment

- Map MAID information priorities to proposed federal monitoring and communicate information gaps consistent with the mandate of the monitoring system to the federal/provincial/territorial MAID working group.
- Develop standards for reporting MAID events occurring in acute and ambulatory care.
- Leverage CIHI's expertise in linkage, privacy, confidentiality and appropriate use of information to support comparable pan-Canadian reporting on MAID.
- Encourage communication among MAID information leaders to avoid duplication of effort, align methodologies and support the conversation on pan-Canadian health system information.

Introduction

In June 2016, following the decision of the Supreme Court of Canada to decriminalize medical assistance in dying (MAID), the Canadian government enacted Bill C-14, which legalizes MAID under certain conditions and authorizes the federal minister of health to make regulations in support of a MAID-monitoring regime.

As the leader in health information in Canada, the Canadian Institute for Health Information (CIHI) is committed to working with provincial and territorial governments, Health Canada, Statistics Canada and other data partners to support comparable reporting on MAID. Comparable, high-quality information is critical to improve the quality, safety and experience of MAID for providers and care teams, patients and their families, and to support high-quality end-of-life research.

In June 2017, CIHI hosted a meeting of MAID leaders from across Canada. This working meeting followed on the findings and commitments from CIHI's [pan-Canadian discussion forum](#) in November 2016 and feedback from stakeholders in the first half of 2017.

The objectives of the meeting were

1. To review potential data sources for health system priorities related to MAID;
2. To refine a provisional framework for exploring and mapping MAID information; and
3. To identify practical next steps for the collection of comparable, high-quality MAID information.

June 2017 meeting of MAID leaders: Event summary

The working meeting was held June 20, 2017. It was attended by 31 MAID leaders from across the country, representing federal, provincial and territorial (FPT) ministries of health, many of whom sit on the FPT MAID working group. Attendees also included MAID providers and coordinators; representatives from coroner's offices, care provider associations and national statistical bodies; researchers; and data users. See [Appendix B](#) for a list of participants.

MAID data collection: In development or under way

The pre-meeting consultation and work on the day highlighted a common desire to capture data efficiently and minimize provider burden. While there is currently no single system to capture all information needs, several data collection and reporting mechanisms are currently in development or in place to support public transparency, accountability and health system decision-making.

CIHI invited speakers with 3 distinct collection and reporting objectives to

- Present their work to date;
- Help participants better understand how their information needs might be met; and
- Uncover potential opportunities for enhancements or improvements to mitigate data collection burden and leverage the data already being collected.ⁱ

Health Canada presentation: Update on the federal monitoring regime for MAID

The assistant deputy minister of the Strategic Policy Branch at Health Canada provided an update on the MAID monitoring regime. The presentation highlighted the objectives of the monitoring regime, which include

- Public accountability and transparency;
- Reporting on the application of the eligibility criteria and safeguards; and
- Improving public understanding of trends and issues related to MAID.

It also described the secondary objective of making this data available to qualified researchers when appropriate mechanisms for the protection of privacy and confidentiality of patients and providers are in place. The presentation mentioned the need to mitigate potential overlap of FPT data collection processes; the desire to minimize administrative burden on providers; and the need to ensure that the collection burden reflects only the minimum required to achieve the objectives of the system.

i. Full presentations are available on request.

It is anticipated that public reports from the monitoring system will be released annually and will include the number of written requests and their outcomes; how the service is being carried out (e.g., trajectories and timelines of requests), characteristics of those requesting and receiving MAID, and insight into the application of the eligibility criteria and the safeguards, including whether or not a patient had access to palliative care. Data will be presented on a national level, broken down by jurisdiction or region (where numbers permit). See [Appendix C](#) for the draft outline of the annual federal monitoring report.

Pending the implementation of the monitoring regime, governments are collaborating to provide interim updates on MAID. The [first interim report](#) of the monitoring system was released in April 2017, the [second](#) in October 2017. Further releases are expected at 6-month intervals.

CIHI presentation: CIHI's acute and ambulatory care data is a source for MAID information

CIHI staff presented updates on the development of data standards for the collection of comparable, pan-Canadian information on MAID interventions occurring in Canadian hospitals and clinics. CIHI released [interim coding direction](#) for MAID interventions for 2 databases, with further guidance in development for 2018–2019. Future guidance will address consultations for MAID, intervention and discharge dates, pharmacological agents used, adverse effects and whether MAID was elected prior to or after admission.

Current CIHI data holdings related to pharmaceuticals, case costing, and home and continuing care have the potential to help provide a more fulsome picture of the MAID experience.

As MAID information evolves and additional data possibly becomes available to CIHI, CIHI remains open to the potential for linkage opportunities and further analyses in these areas. CIHI has also developed business processes, practices and guidelines to ensure that CIHI information products containing MAID-related information are consistent with jurisdictional legislative requirements and CIHI's updated privacy [policies and procedures](#).

With respect to broader questions about palliative care, CIHI is producing a pan-Canadian baseline report on access to palliative care that will leverage existing data sources and highlight information gaps. This work is scheduled to be released in 2018.

Research presentation: Beyond monitoring and compliance — Data for quality, access and equity

James Downar and Jennifer Gibson, both academic researchers, presented on the value of exploring concepts of equity, access and quality for MAID patients and their families. They highlighted their interest in exploring what we can learn about MAID experiences based on the first year of available data. Here are some of their key questions:

- Who is accessing MAID?
- Who is providing MAID and where is it being provided?
- Why are patients requesting and how are we assessing their eligibility?
- How do we know whether the system is working well?

The presentation described their experiences exploring access to and availability of MAID data through provincial/territorial data custodians to help address these questions. In their early research, they encountered the challenges of establishing who the data custodian would be in each jurisdiction, and of understanding the varying approaches that jurisdictions had taken to collecting data.

Their presentation also highlighted the importance of collaboration to ensure that data collection, analysis and reporting is not duplicated among bodies involved in MAID data and research. It also conveyed the important role of researchers as partners in a pan-Canadian MAID data collection effort. For examples of other relevant research and tools produced by MAID leaders involved in CIHI's consultations, see [Appendix D](#).

MAID data collection: Priorities and opportunities

Leaders in MAID and MAID information acknowledge the role of data collection and reporting at the FPT levels to achieve monitoring and compliance objectives. They recognize the important role of organizations like Health Canada, Statistics Canada and CIHI in helping to address a breadth of information needs.

These information needs reflect priorities that range from short term (e.g., understanding demand for and system capacity to address MAID requests) to longer term (e.g., exploring the MAID experience for patients and their families; developing quality measures that ensure ongoing quality assurance). Participants clearly articulated the value in building systems that leverage opportunities for data linkage where appropriate, and the importance of avoiding unnecessary reporting for already resource-limited MAID providers.

What follows is a synopsis of pre- and post-meeting consultation results and participant reflections from the June 2017 meeting. See [Appendix E](#) for the full list of questions related to participants' priority information needs.

MAID assessors and providers: In the short term and going forward, there is a need to understand the number of MAID assessors and providers in specific settings and to determine whether there is sufficient supply, distribution and training available to support the demand for this service.

MAID patients: The most cited priorities were understanding patient access to and use of other services (including palliative care) at the end of life. A better understanding of patient vulnerability at the end of life was also flagged as an important component of understanding MAID patient profiles.

System access: Another short-term priority identified by participants was understanding the temporal components of patient access to MAID pathways and services. They identified a need to understand the time between various stages of the process. Referrals, transfers and travel time were underlying themes in questions about access.

System process: Participants noted the importance of understanding how MAID systems are functioning now in order to support quality assurance over time. They noted the importance of qualitative information related to safety and efficiency to complement baseline statistics about the number of requests for MAID, details of the decisions (e.g., proportion agreed/refused), setting, etc., to tell a more fulsome story.

Patient and family experience: Participants were interested in understanding why patients decide to request MAID, and in understanding the relationship between patient experience and their socio-demographic characteristics. Some suggested the potential of leveraging coroner's or medical examiner's data to garner more information about the patient experience. Others highlighted the need to better understand how families and supporters of MAID patients are involved in patients' end-of-life decision-making and how they are supported.

Provider experience: Canadian media, professional associations and academic researchers have highlighted the need to better understand and improve the training, supports and (in some jurisdictions) compensation available to MAID assessors and providers and the broader care team. Participants reiterated the importance of exploring provider experience (including their training needs and resiliency supports) and to support the spread and scale of best practices, programs and training that are known to be available.

Conclusion

In June 2017, CIHI convened MAID information leaders from Health Canada, Statistics Canada, and national, provincial and territorial governments and organizations to identify and consider priority MAID data gaps from a health system perspective. This meeting was the culmination of more than 12 months of exploration and consultation with leaders from across the country.

At the meeting, participants shared a breadth of information priorities, reflecting the varied perspectives of MAID leaders from across the health system. They reiterated the value of the data to be collected by the federal MAID monitoring system and acknowledged other information needs that are outside of the scope of that system. They emphasized the need to ensure that data is available to inform health system questions (e.g., access, quality, safety) and that collection and reporting of information respect provider burden and leverage opportunities for collaboration to reduce duplication in an already constrained MAID system.

Since then, CIHI has undertaken a number of activities in support of our stakeholders' priorities:

- In collaboration with MAID leaders from across Canada, developed a MAID [information needs framework](#) that can help map stakeholders' priorities to available data and identify gaps;
- Is developing standards for reporting MAID events occurring in acute and ambulatory care and is currently collecting data for MAID in these settings;
- Updated our policies and procedures such that CIHI cannot release information that identifies a facility or that could be used to identify a facility that has consulted about, transferred a patient for or provided MAID; and
- Continues to support, encourage and facilitate information exchange among CIHI, Health Canada, Statistics Canada and provincial/territorial leaders in MAID information.

Mapping MAID information priorities to what is known about current and anticipated data collection provides opportunities to address key questions in both the short and longer terms. The regulations for the federal MAID monitoring system are expected to be published in 2018 and will help to further clarify which data may be available to answer these questions and where opportunities exist for further work.

Appendix A: Framework for mapping MAID information needs

The original objective of the MAID Information Needs Framework was to serve as a tool for consultation meetings hosted by CIHI with MAID information leaders in June 2017. It was used at a pan-Canadian meeting to explore what we know and don't know about the availability of information to address MAID-related health system priorities. Participants described a number of other ways in which the framework could be used to support their work, including

- As a reference for understanding various interests and intersections when developing a comprehensive model for MAID implementation;
- As a tool to help interested organizations focus on key questions related to MAID-provider experience; and
- For organizations with specific stakeholder interests, providing a fulsome picture of the priorities of a diversity of actors outside of their own.

Finally, some consultation participants noted the value of the framework for the research community in identifying the priority information needs for MAID leaders from across the country.

We are pleased to make this framework publicly available to fulfill those and any other needs. What follows is an overview of the development of the framework and considerations for its adaptation and use.

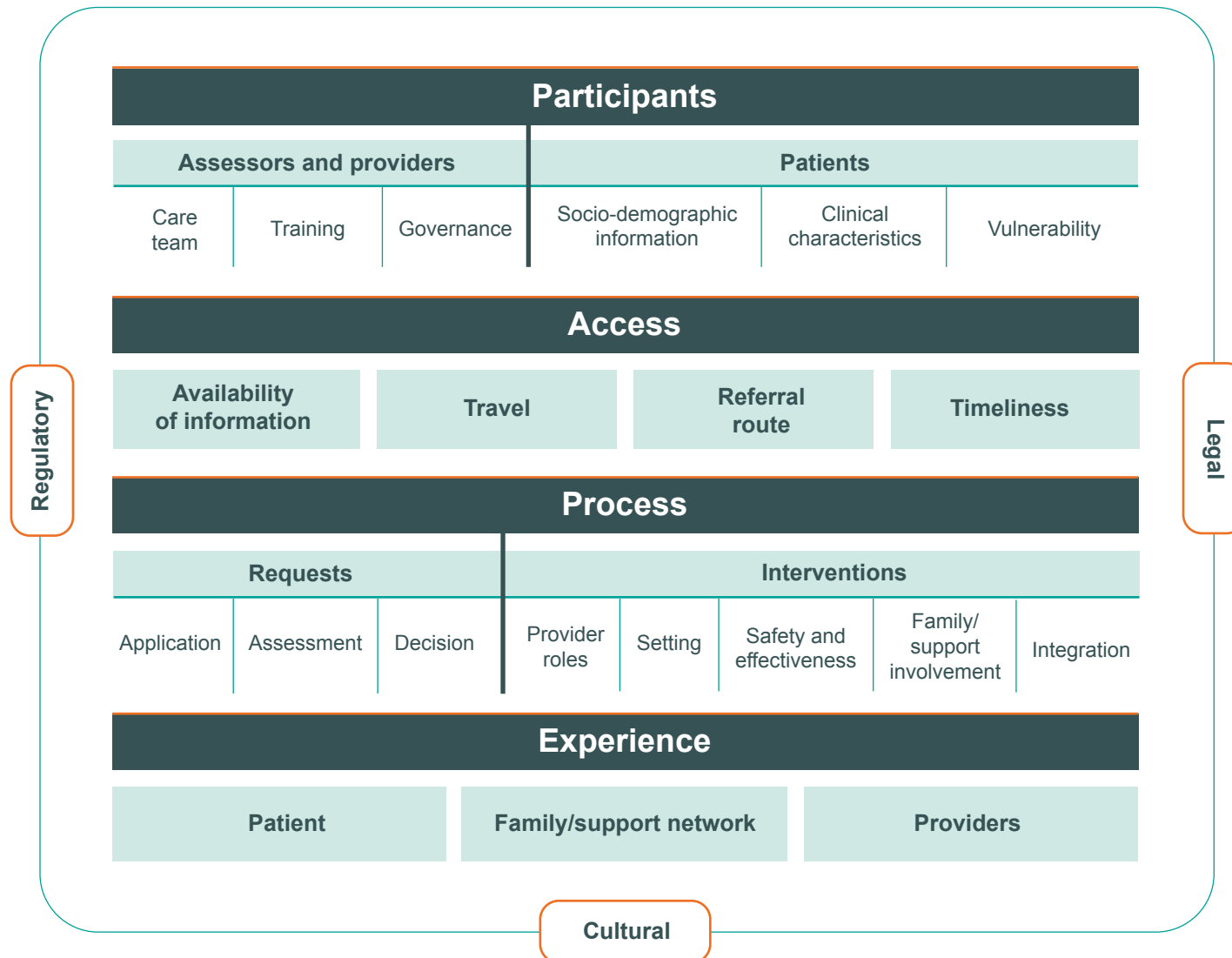
The framework is composed of 4 information categories:

- MAID system participants, including patients and MAID providers;
- MAID system access, including patient pathways and timeliness;
- MAID process, including quality and safety; and
- Experience of MAID patients, their families, MAID providers and care teams.

The information categories (participants, access, process and experience) reflect information needs that may appear throughout the MAID journey, and may interact or overlap. Each category is composed of subtopics (second level) and areas of focus (third level). The contextual environment (legal, regulatory and cultural) will vary in each jurisdiction and will influence the relationships among the dimensions of the framework in different ways. As provincial and territorial approaches to administering MAID evolve, so too will the ways in which the contextual environments change and influence the information categories set out in this framework.

Figure Organizing framework for MAID information needs

Provisional Framework for MAID System Information Needs



Key concepts and definitions

The following definitions have been developed in consultation with experts in MAID information. They reflect potential data elements that could be included for each information category. Illustrative examples gathered from consultations during the development process are also included. These definitions and examples may be adapted to ensure that the framework meets the needs of the organization, jurisdiction or researcher employing it.

MAID system participants

Assessors and providers — Information about the number, distribution and allocation, and tenure of assessors and providers, and the training they and other members of the care and coordination teams receive (including existing standards for training and training tailored to specific roles and settings). This information category may also capture the governance and coordinating mechanisms for MAID, including quality assurance and the specific practices of provinces, territories or health regions.

Patients — The socio-demographic and clinical characteristics of patients seeking information about and/or formally requesting MAID. This includes information about patient vulnerability and factors contributing to a patient's decision to request MAID.

MAID system access

MAID system access — Information about MAID and the pathways to MAID, such as referral route (including previous medical care), transfers, travel and (non-legislated) wait times for consultations, assessments and procedure. This may include standards for timelines (e.g., time from request to procedure, time between steps).

MAID process

MAID requests — Requests for information about or for the delivery of MAID, eligibility assessments, approvals and denials for MAID, and number of patients receiving MAID.

MAID interventions — Information about the setting of MAID interventions; the safety and effectiveness of the intervention (including drug protocols); the integration of the intervention with other services at the end of life (e.g., spiritual, organ transplant); roles and responsibilities of other members of MAID providers and the formal care team; and engagement of family/support network.

Experience

Patient experience — Includes the patient trajectory leading to the person's request for MAID, as well as their perceptions of the quality of their end-of-life experience, including respect for their wishes, privacy, dignity, and appropriate, timely and effective care. It could also include access to other end-of-life services and options.

Family and support network experience — Includes the quality of their experience with their loved one at the end of life, including the availability of information about the MAID procedure and expectations pre- and post-MAID; their ability to be engaged in the process (consistent with patient wishes); their experience with bereavement and other supports; and their understanding of other available end-of-life treatment options.

Provider experience — Includes perceptions of MAID providers' and MAID care teams' readiness to participate in MAID processes and procedures (including supports for conducting assessments and enhancing resiliency); understanding provider interaction with patients and their families or supports; perceptions of appropriateness of training for procedures and documentation; and perceptions of support after delivering MAID services.

Visit [CIHI's MAID web page](#) to learn more about the MAID Information Needs Framework and other MAID-related work.

Appendix B: Participant list

Name	Organization
Aaron McKim	Eastern Health, Newfoundland and Labrador
Abby Hoffman*	Health Canada
Brent Diverty	Canadian Institute for Health Information
Brooke Ballance	Manitoba Health, Seniors and Active Living
Caroline Beck	Saskatchewan Ministry of Health
Caroline Heick	Canadian Institute for Health Information
Cheryl Gula	Canadian Institute for Health Information
Cindy Mosher	Canadian Institute for Health Information
Derek Rains	British Columbia Ministry of Health
Dirk Huyer	Office of the Chief Coroner, Ontario
Francois Nault	Statistics Canada
Isabelle Marcoux	University of Ottawa
Jacque Lemaire	Health Canada
James Ayles	New Brunswick Department of Health
James Downar*	Faculty of Medicine, University of Toronto
Jeff Blackmer	Canadian Medical Association
Jennifer Fournier	Canadian Nurses Association
Jennifer Gibson*	Joint Centre for Bioethics, University of Toronto
Jim Silvius	Alberta Health Services
Kathleen Morris	Canadian Institute for Health Information
Kelly Hogan	Canadian Institute for Health Information
Kyra Wager*	Canadian Institute for Health Information
Kim Dolhan	Yukon Health and Social Services
Kim Wiebe	Winnipeg Regional Health Authority
Kimberley Widger	Faculty of Nursing, University of Toronto
Kimberly Riles	Department of Health and Social Services, Northwest Territories
Lauren Kelly	Health PEI
Lori Moen	Coroners Service of British Columbia
Matthew Murphy	Nova Scotia Health Authority
Melanie MacInnis*	Canadian Institute for Health Information
Melissa Prokopy	Ontario Hospital Association
Nancy Cooper	Ontario Long Term Care Association
Pam Jones	Nova Scotia Health and Wellness
Raquel Shaw Moxam	Canadian Partnership Against Cancer

Name	Organization
RJ Edralin	University Health Network
Robert Weiler	Saskatoon Health Region
Sean Court	Ontario Ministry of Health and Long-Term Care
Susan Brien	Health Quality Ontario
Valérie Gaston	Statistics Canada

* Speaker.

Appendix C: MAID annual federal monitoring report — draft outline*

Core statistics

- Number of written requests for MAID and breakdown of their outcomes, for example
 - Numbers found eligible/not eligible
 - Of those found eligible, how many resulted in MAID?
 - Of MAID deaths, how many were self-administered or provider-administered?
- System-level information on doctors/nurse practitioners (MDs/NPs) and pharmacists, for example
 - Number involved in MAID requests and breakdown by MD/NP, and by specialty for MDs
 - Number of cases per provider (range, average)

Dynamics of requests for and provision of MAID, including

- Trajectories (e.g., received directly, received through referrals/care coordination services)
- Role of consultations with other professionals
- Timelines and settings

Medical circumstances of those assessed for MAID, including

- Data relating to the “grievous and irremediable medical condition” criteria (e.g., illnesses, diseases or disabilities giving rise to requests for MAID)

Nature of suffering for persons receiving MAID

- As described by the patient

Socio-demographic characteristics of those receiving MAID, including

- Age, gender, marital status, principal occupation during working life

Relevant findings respecting eligibility criteria and safeguards, including

- Eligibility criteria that were not met in cases where requests were not granted

Trends

- As annual data becomes available from year to year

* Data aggregated nationally, with other breakdowns as numbers permit.

Appendix D: Additional resources recommended by consultation participants

British Columbia Coroners Service. [*BC Coroners Service Death Review Panel: A Review of Medically Assisted Deaths for the period of January 1–December 31, 2016*](#). October 3, 2017.

Canadian Medical Association. [*CMA Policy: Medical Assistance in Dying*](#). 2017.

Joule, A CMA Company. [*Medical assistance in dying*](#). Accessed October 18, 2017.

Canadian Mental Health Association. [*Canada Mental Health Association's Position Paper on Medical Assistance in Dying \(MAiD\)*](#). August 2017.

Canadian Nurses Association. [*National Nursing Framework on Medical Assistance in Dying in Canada*](#). 2017.

Canadian Pharmacists Association. [*Toward a Framework for Assisted Dying in Canada*](#).

Trachtenberg A, Manns B. [*Cost analysis of medical assistance in dying in Canada*](#). *CMAJ*. January 2017.

Li et al. [*Medical assistance in dying — Implementing a hospital-based program in Canada*](#). *The New England Journal of Medicine*. May 2017.

Downar J, Francescutti LH. [*Medical assistance in dying: Time for physicians to step up to protect themselves and patients*](#). *CMAJ*. June 2017.

Marcoux et al. [*Medical end-of-life practices among Canadian physicians: A pilot study*](#). *CMAJ Open*. 2016.

[*Vulnerable Persons Standard*](#). March 9, 2016.

[*Vulnerable Persons Standard FAQs*](#). March 18, 2016.

Appendix E: Detailed information needs by topic

Assessors and providers

Are there enough assessors and providers?

What is the actual distribution of assessors and providers between the hospital and community setting?

How is the number of assessors and providers offering MAID changing over time?

How many assessors and providers are trained to participate in MAID?

Is there an adequate number of willing and trained assessors and providers within the system to support timely delivery of MAID services for patients in our province?

What is the best way to train clinicians to do assessments and MAID procedures?

What resources are being allocated on a provincial level to establish high-quality MAID programs?

What are other provinces doing re: governance and coordination and what is government's role?

Patients

What is driving patients to make this decision?

What were the patients' symptoms prior to requesting MAID?

What are the socio-demographic and clinical characteristics of people seeking MAID by system? Does that differ by sector?

Are patients choosing MAID because other end-of-life options are limited or unavailable?

What do we know about health care service utilization of patients requesting MAID?

Are mature minors seeking information about MAID? If so, is the socio-demographic and/or clinical profile of mature minors seeking information about MAID different from that of older adults?

System access

Are patients who are seeking MAID receiving the information and services they need in a timely and appropriate manner?

What do we know about the (non-legislated) waiting periods between phases of a MAID request?

What is a reasonable time to wait to receive MAID?

Are patients waiting too long?

Why do patients receive MAID in the hospital setting?

What factors impact access (time to care) in delivery of MAID in non-hospital settings?

Are current care pathways creating timely access to the service for those patients who qualify? Where are the delays?

How can we best facilitate access to information and resources to make the MAID process understandable and accessible for those wishing to avail of this service?

How do we ensure that patients/families/supporters are able to access MAID within the context of a system that includes objecting providers and facilities?

Provider experience

Are there any negative long-term or lasting effects on MAID assessors and providers?

Do assessors and providers in the community feel that they have been provided adequate training and education?

How many providers have declined to participate in MAID processes only because they lack adequate training (i.e., they might otherwise have been willing to participate)?

What are the training needs for all members of the interdisciplinary team?

What supports are provided to providers who are directly or indirectly involved in MAID?
When are those supports provided (e.g., prior to the procedure, after the procedure)?

What information is necessary to ensure quality, safety, oversight, monitoring, etc., without creating an administrative burden such that providers may choose not to be involved?

How can we assist the assessors and providers with resiliency and supports that will allow them to have a long-term and sustainable role in the MAID program?

How do we educate all providers so that they feel comfortable answering questions about MAID?

Patient and family experience

What are the expectations of families/supporters and patients, and how do we know whether they are receiving timely, appropriate and effective care?

Are specialized palliative care teams involved in assessing patients, addressing symptoms and/or concerns prior to or as part of MAID process?

Is there any association between earlier palliative care involvement and prevalence of MAID requests?

How often do families agree/disagree with the patients' requests for MAID?

What supports are provided and how can these inform the creation of a minimum core “basket” of supports to be provided to all families/networks around the person seeking MAID?

Are patients and their families and support persons having an overall positive experience with the process of accessing MAID?

Do patients and families feel that their personal wishes and choices are being respected and supported through this difficult time?

How do we support families who don't always agree and have to cope and come to terms with a family member's decision?

Did the family have an understanding of end-of-life care options?

Did the family understand that palliative care includes managing pain and suffering?

What was the family's experience with bereavement supports?

References

1. Trachtenberg A, Manns B. [Cost analysis of medical assistance in dying in Canada](#). *CMAJ*. January 2017.
2. Li et al. [Medical assistance in dying — Implementing a hospital-based program in Canada](#). *The New England Journal of Medicine*. May 2017.
3. Marcoux et al. [Medical end-of-life practices among Canadian physicians: A pilot study](#). *CMAJ Open*. 2016.



CIHI Ottawa

495 Richmond Road
Suite 600
Ottawa, Ont.
K2A 4H6
613-241-7860

CIHI Toronto

4110 Yonge Street
Suite 300
Toronto, Ont.
M2P 2B7
416-481-2002

CIHI Victoria

880 Douglas Street
Suite 600
Victoria, B.C.
V8W 2B7
250-220-4100

CIHI Montréal

1010 Sherbrooke Street West
Suite 602
Montréal, Que.
H3A 2R7
514-842-2226

cihi.ca

16367-1017

