



Medical Assistance in Dying

A Framework for Mapping Information Needs



Canadian Institute
for Health Information

Institut canadien
d'information sur la santé

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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

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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 commits the federal government to develop a MAID monitoring system. The federal monitoring system will be established in 2018, and interim data collection and public reporting is currently under way. Leaders in MAID information recognize the important role of this system in achieving monitoring and compliance objectives. At the same time, they have broader information needs driven by the diverse priorities of their organizations, jurisdictions and stakeholders.

Since the fall of 2016, the Canadian Institute for Health Information (CIHI) has convened and consulted leaders in MAID information from across Canada to better understand and respond to their information needs. In the spring of 2017, CIHI developed a provisional framework to map these diverse needs.

How to use this framework

The original objective of this framework was to use it 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 the following:

- 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, to provide a fulsome picture of the priorities of diverse actors outside of their own.

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

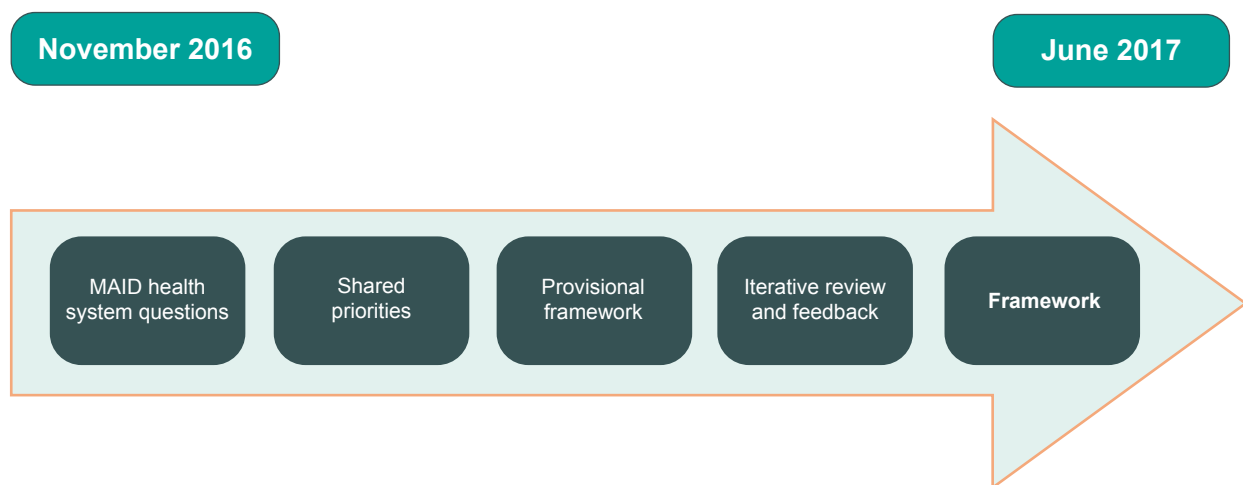
We are pleased to make this framework publicly available to fulfill those and any other needs. What follows is an overview of the development of the framework and considerations for its adaptation and use.

MAID is a distinct option for people who meet specific criteria and who may or may not also be accessing other end-of-life care options. This framework focuses on health system information needs for MAID only. Information needs for other end-of-life care treatment pathways are important and may be addressed elsewhere.

Framework development

The MAID Information Framework builds on CIHI's [Health System Performance Measurement Framework](#), which explores health system performance through the lens of inputs, outputs and outcomes in the context of particular political, economic and demographic context. Using that framework as a foundation, CIHI undertook the following process to develop its MAID Information Framework:

1. Convened a [pan-Canadian meeting with MAID stakeholders in 2016](#) to understand MAID-related health system questions and identified participants' shared priorities.
2. Refined and categorized shared priorities and developed a provisional information framework.
3. Consulted with experts from academia, health care and MAID delivery and implementation on the potential use of the provisional framework.
4. Convened a second pan-Canadian meeting and piloted the framework as a tool to help identify information needs for addressing priorities.
5. Collected recommendations from meeting participants on how to improve the framework.



Organizing framework for MAID information

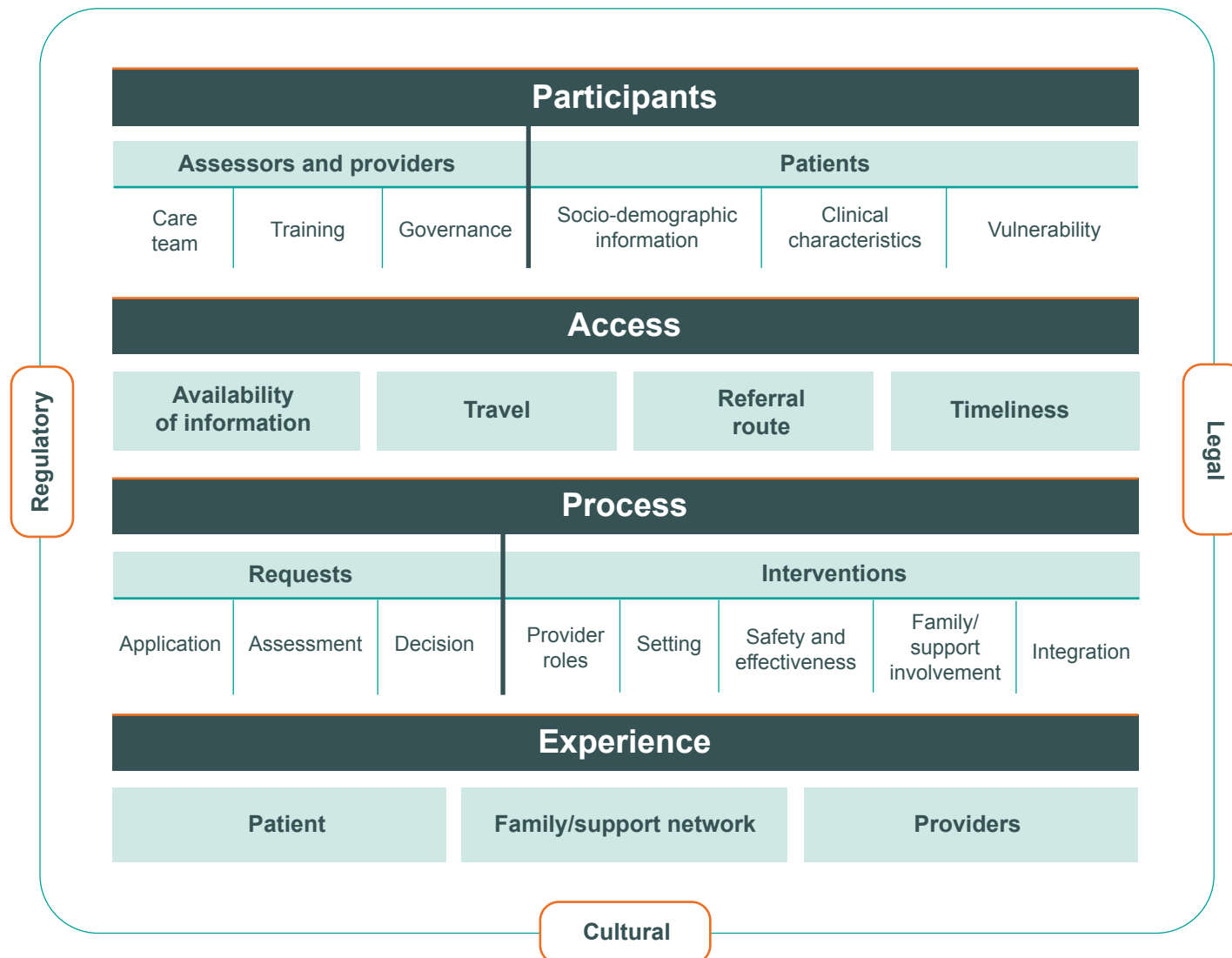
The framework has 4 information categories:

- **Participants** — MAID system participants, including patients and MAID providers
- **Access** — MAID system access
- **Process** — MAID process
- **Experience** — Experience of MAID patients, their families, MAID providers and care teams

The information categories reflect information needs that may appear throughout the MAID journey; as such, they 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.

Conclusion

CIHI developed this framework to facilitate the exploration of MAID-related health system information needs. This framework should be adapted as required by users. It should serve as a foundation for understanding information needs in a variety of health care environments, and can be used to map what is known about available information to address priority health system questions. CIHI encourages those interested to use this framework and welcomes comments on its ongoing utility, adaptability and relevance in Canada's changing health landscape.



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

16412-1117

