

# Executive summary

On November 24, 2016, the Canadian Institute for Health Information (CIHI) hosted the Medical Assistance in Dying (MAID) Discussion Forum: Information Needs for Health Systems and Public Reporting. MAID implementation leaders from across the country reflected on information needs to support a better understanding of health systems' response to MAID.

## Comparable pan-Canadian MAID information

The enactment of medical assistance in dying legislation by the Government of Canada in 2016 authorizes the minister of health to make regulations to establish a MAID-monitoring regime. The legislation requires physicians, nurse practitioners and pharmacists involved in cases of MAID to report to a federally mandated body.

Several provinces have made great strides in their collection and reporting of MAID data. At the forum, participants expressed a desire for comparable, pan-Canadian MAID information, leveraging systems and standards that are already in place. Collection of this information must respect the already great clinical and administrative burden on MAID-providing clinicians and balance the need for patient and provider privacy with transparency and public accountability.

## Shared information needs

Comparable pan-Canadian MAID information is a priority. Topics of common interest include the following:

- MAID activity reporting and basic patient demographics
- MAID in the context of end-of-life care
- Patient and family experience with MAID
- Provider experience with MAID

## CIHI's commitment

In response to key priorities identified by participants, CIHI will undertake the following:

### **Support the conversation on pan-Canadian measurement**

- Convene leaders from the broader health information community to discuss a minimum data set and data collection standards for MAID information; and consider whether and how CIHI can continue to play a convenor role as MAID information needs evolve
- Engage our partners at Health Canada and the MAID federal/provincial/territorial table to ensure that CIHI's MAID-related activities align with and complement their work

### **Establish standards and data quality and improve data collection**

- Consult with CIHI's national coding advisory committee to establish standards for reporting MAID data for the acute and ambulatory sectors
- Map MAID information needs to CIHI's data holdings to identify potential adjustments or enhancements to improve collection and reporting
- Over time, close data gaps in priority areas to broaden our understanding of trajectories of care at end of life

### **Promote comparable reporting and actionable analysis**

- Provide baseline information on services available at the end of life in Canada
- Consider, with our partners, the development of access-focused palliative care performance indicators
- Explore national and international perspectives on end-of-life care, including medical assistance in dying, through existing resources (e.g., Statistics Canada, The Commonwealth Fund)

# Introduction

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

As the leader in health information in Canada, CIHI is committed to working with the federal, provincial and territorial governments to support comparable reporting on MAID. Comparable, high-quality information is critical to improve the quality, safety and experience of MAID for providers, patients and their families, and to support high-quality end-of-life research.

On November 24, 2016, CIHI hosted the MAID Discussion Forum: Information Needs for Health Systems and Public Reporting. It was the first opportunity for leaders in MAID implementation to reflect on information needs for supporting a better understanding of health systems' response to MAID. The objectives of the forum were

1. To showcase and reflect on provincial and international examples of data collection and reporting about MAID;
2. To establish a common understanding of health system and public reporting information needs for MAID;
3. To prioritize MAID information needs that are shared across Canadian jurisdictions; and
4. To inform future activities to support the development of comparable MAID information.

**Event details:** The forum was held November 24, 2016. It was attended by 42 MAID leaders from across the country, representing federal, provincial and territorial ministries of health, regional health authorities, health care facilities, coroner's offices, departments of vital statistics, care provider associations, researchers, quality councils, data users, law and policy experts and health media. See Appendix A for a list of participants.

## Forum highlights and shared priorities

The following section includes highlights from presentations and small group discussions, and feedback from participants unable to attend the forum (submitted via email). Full presentations are available upon request. Selected discussion group outputs are provided verbatim in Appendix B.

### **Forum Objective 1: Consider federal, provincial and international examples of data collection and reporting about MAID**

#### **What we learned**

##### **The federal and provincial/territorial governments are working closely to develop monitoring and compliance regimes for MAID**

Abby Hoffman, assistant deputy minister of the Strategic Policy Branch at Health Canada and lead for the MAID portfolio, provided an overview of the development of the regulations for MAID monitoring. The presentation included the legislative parameters that will guide federal monitoring and the regulatory development process. She included the proposed plan for interim data collection and reporting (prior to the enactment of the monitoring regime), which will include the number of MAID deaths, basic demographic characteristics of those receiving MAID, and the most common medical circumstances giving rise to MAID requests.

##### **Monitoring and reporting on MAID looks different across the country and internationally**

Current and proposed monitoring and compliance systems support public trust, transparency, legislative compliance and protection of vulnerable patients. There is variability across the country and internationally, however, in how data is collected and where data is submitted.

##### **There is a need for robust information about patient, family and provider experiences with MAID**

Information beyond what is submitted for the purposes of monitoring and compliance should be collected from patients, their families and clinicians. This includes both qualitative and quantitative data to help decision-makers better understand the reasons patients seek MAID; the frequency and range of interventions accessed by patients at the end of life; patient and family experiences with the provision of the service; and the implications for clinicians involved in the provision of MAID (e.g., additional administrative work, mental and physical health).

## Forum objectives 2 and 3: Establish and prioritize shared MAID information needs

### What we learned

#### Comparable pan-Canadian MAID information

Participants expressed concerns about inconsistent reporting of MAID both within and across jurisdictions. Their remarks highlighted the importance of a common framework, standards and minimum data set, and the need to leverage data collection mechanisms already in place to avoid duplication of effort and provider fatigue.

#### Activity reporting and basic patient demographics

Comparable reporting on service statistics — including completed MAID requests and information about patient requests that did not meet eligibility criteria (and the reasons why) — is a priority for participants. As well, underlying medical conditions and previous interactions with the health care system were flagged as priority information needs. Information about the safety and effectiveness of drug protocols, reporting of adverse events and the security of drugs dispensed for interventions performed at home were also highlighted.

#### MAID in the context of end-of-life care

Participants need a better understanding of patient access pathways for MAID and the integration of MAID with other health care services. They want to understand geographic variation in patient access to MAID and other end-of-life services, and barriers faced by patients. This includes understanding challenges related to

- Finding physicians willing to perform MAID;
- The travel required to locations where MAID services are provided;
- Timely access to required medications;
- Access to palliative care; and
- Engagement with palliative care physicians.

There is a need to understand which patients had been diagnosed as palliative prior to requesting MAID, patients' exploration of other end-of-life care options, and how a patient's anxiety about death influenced the decision to pursue MAID.

*“At the forum it was apparent that MAID is but a piece of an individual's journey. The larger picture is end-of-life care overall.”* (Participant feedback, December 2016)

### **Patient and family experience with MAID**

There is a desire to understand patients' suffering and vulnerability prior to their request for MAID. Other information needs include a broader understanding of the assessment process, ranging from understanding the relationship between patients and eligibility assessors, to the time lapse between first and second assessments, the need for transfers to receive assessments and families' perspectives of the assessment experience.

Patients' and families' wishes for, as well as their perceptions of, the quality of death and the dying experience were also identified. This includes support for bereaved patients and families after the patient has been found to meet, or not meet, MAID eligibility criteria.

### **Provider experience with MAID**

Participants identified information needs related to the experiences of MAID-providing clinicians and interdisciplinary care teams — particularly related to the burden of service provision. This includes information about the additional emotional demands on clinicians and teams involved in the provision of MAID and the supports available to them.

Other experience-related information needs include a better understanding of the roles and responsibilities of the care team (e.g., supporting patients and families, liaising with coroners, administrative responsibilities) and the education and training available to clinicians and care teams to support the clinical and emotional components of this work.

They noted a need for guidance on assessing eligibility criteria for MAID requests, and some suggested the need for more information about what is required to fulfill reporting obligations (e.g., appropriate levels of completeness and timeliness for data submissions).

## **Forum Objective 4: Inform future activities to support the development of comparable MAID information**

Following the forum, CIHI conducted a short evaluation and survey to determine participants' recommended next steps for CIHI to continue to support their work. Consistent with what was reported in the small group discussion, the majority of respondents recommended that CIHI convene a group of experts to help develop standards and a minimum data set for the collection of MAID information. The second most frequently cited option was to convene a group to discuss MAID reporting on death certificates.<sup>i</sup>

*“One of the key and clear messages from the discussions was the serious need for a national minimum data set ASAP — I would propose that any future endeavours should drive directly to this goal.”* (Participant feedback, December 2016)

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i. Note that federal MAID legislation requires the federal minister of health to establish guidelines on the information to be included on death certificates in cases where MAID has been provided. This guidance is expected to be released in 2017.

# Conclusion and CIHI's commitment

The enactment of medical assistance in dying legislation by the Government of Canada in 2016 authorizes the minister of health to make regulations to establish a MAID-monitoring regime. This includes public reporting of the statistical profile of MAID in Canada and the application of eligibility criteria and safeguards.

CIHI is committed to engaging with clients and stakeholders to enable better use of health data and information. We recognize that pan-Canadian, provincial and territorial health information organizations from across the country are leading important MAID-related activities, and we will continue to support them in their work.

More specifically, CIHI will . . .

## **Support the conversation on pan-Canadian measurement**

- Convene leaders from the broader health information community to discuss a minimum data set and data collection standards for MAID information; and consider whether and how CIHI can continue to play a convenor role as MAID information needs evolve
- Engage our partners at Health Canada and the MAID federal/provincial/territorial table to ensure that CIHI's MAID-related activities are aligned with and complement their work

## **Establish standards and data quality and improve data collection**

- Consult with CIHI's national coding advisory committee to establish standards for reporting MAID data for the acute and ambulatory sectors
- Map MAID information needs to CIHI's data holdings to identify potential adjustments or enhancements to improve collection and reporting
- Over time, close data gaps in priority areas to broaden our understanding of trajectories of care at the end of life

## **Promote comparable reporting and actionable analysis**

- Provide baseline information on services available at the end of life in Canada
- Consider, with our partners, the development of access-focused palliative care performance indicators
- Explore national and international perspectives on end-of-life care, including medical assistance in dying, through existing resources (e.g., Statistics Canada, The Commonwealth Fund)

# Appendix A: Participant list

<b>Name</b>	<b>Organization</b>
<b>Abby Hoffman*</b>	Strategic Policy Branch, Health Canada
<b>André Picard*</b>	The Globe and Mail
<b>Andrea Dutchak</b>	eHealth Saskatchewan
<b>Catherine Gaulton</b>	Nova Scotia Health Authority
<b>Christine Gibbons</b>	Nova Scotia Department of Health and Wellness
<b>Christine Raves</b>	Northwest Territories Department of Health and Social Services
<b>Daniel Fontaine</b>	B.C. Care Providers Association
<b>Derek Rains</b>	British Columbia Ministry of Health
<b>Elizabeth Chiu</b>	University Health Network
<b>Esther Green</b>	Canadian Partnership Against Cancer
<b>Gina Bravo*</b>	University of Sherbrooke
<b>James Ayles</b>	New Brunswick Department of Health
<b>James Silvius*</b>	Alberta Health Services
<b>Jean Cox</b>	Manitoba Health, Seniors and Active Living
<b>Jeff Blackmer</b>	Canadian Medical Association
<b>Jennifer Kitts</b>	HealthCareCAN
<b>Jocelyn Downie*</b>	Dalhousie University
<b>John Hirdes</b>	University of Waterloo
<b>Jonathan Harris</b>	Saskatchewan Ministry of Health
<b>Judy Davidson</b>	Newfoundland and Labrador Department of Health and Community Services
<b>Julie Bernier</b>	Statistics Canada
<b>Katy Short</b>	Nunavut Department of Health
<b>Kim Wiebe</b>	Manitoba Health, Seniors and Active Living
<b>Lauren Kelly</b>	Prince Edward Island Department of Health and Wellness
<b>Leeca Sonnema</b>	Alberta Health Services
<b>Madelaine Li</b>	University Health Network



<b>Name</b>	<b>Organization</b>
<b>Melissa Prokopy</b>	Ontario Hospital Association
<b>Michael Harvey</b>	Newfoundland and Labrador Department of Health and Community Services
<b>Mike Chandler</b>	British Columbia Ministry of Health
<b>Mila Ray-Daniels</b>	Hamilton Niagara Haldimand Brant Community Care Access Centre
<b>Naira Yeritsyan</b>	Health Quality Ontario
<b>Nathalie Quann</b>	Justice Canada
<b>Reuven Jhirad</b>	Ontario Deputy Chief Coroner
<b>Robert Weiler</b>	Saskatoon Health Region
<b>Sandra Tomkins</b>	Health Canada
<b>Sean Court*</b>	Ontario Ministry of Health and Long-Term Care
<b>Stéphanie Goulet*</b>	Commission sur les soins de fin de vie (Québec)
<b>Susan MacDonald</b>	Canadian Society of Palliative Care Physicians
<b>Tara Chorney</b>	Alberta Health
<b>Valérie Gaston</b>	Statistics Canada

**Note**

\* Speaker.

# Appendix B: Discussion group highlights

Participants were asked to consider the following questions:

**3 years from now, if we have MAID information that meets all health system stakeholder needs, which health system questions would you want to be able to answer? Consider the following areas:**

**Health system responsiveness (e.g., access, effectiveness, safety, comprehensiveness, integration of services)**

- Number of requests that were completed versus requested
- Time from request to service
- Is there comprehensive access across Canada? How do we address a lack of access?
- Can we capture both written/oral requests?
- Are oral requests appropriately actioned? Are they minimized/ignored?
- Are there consequences for the providers/institutions if they ignore a request (verbal)?
- Can it be provided in the location that the patient requests/home/hospital?
- What do we need: how do we get to an appropriate system for assisted suicide?
- Real-time advice on administering the service (for providers)
  - Timeliness issue, response time for advice
- Provider's participation and non-participation
  - Number completed per provider
- Where are patients getting the service?
- Travel requirements
- Are palliative care providers engaging in MAID?
- Defined access pathways in rural and remote areas
- Nurse practitioners' participation to the extent of their scope
- Protocols for self-administration in place?
  - Deal with drug safety and effectiveness
- Services accessed prior to MAID
- Qualitative info about the time leading to event
  - Suffering, vulnerability (patient experience)
- Access variation by geography/province, rural/urban

- Variation by underlying condition
- Demographic, socio-economic status, other equity
- Is service delivered in a timely manner?
- Do travel requirements influence uptake?
- Family involvement an important issue for some Indigenous families that require travel
- Does requestor have a regular MD?
- Did patients access appropriate wraparound services?
- How is MAID integrated into other services?
- Where are gaps?
- What are harm incidents (by setting, provider, etc.)?
- How do we ensure access to MAID providers and assessors — urban/rural/remote?
- What is comprehensive?
- What are patterns by
  - Socio-economic status
  - Rurality
  - Disease
  - Family support
  - Respite availability
- Are those who want access to the services able to do so in a timely fashion?
  - Eligibility assumed
  - Identify barriers to access
    - Geography
    - Provincial resources
    - Consultants
    - Inter-professional integration
- Occurrence of mishaps, broadly defined
- Roles and responsibilities in absence of organizational accountability
- What is the safety re: unused oral drugs?
- What is the optimal administration model (not drugs)?
- Seamless care of patient-integration of services; consider patient transfers
- Barriers to access — perceived/real (individual providers and institutions)

- Variations in the limitations on access resulting from variation in eligibility criteria
- Average wait time from patient request to assessment; request to procedure
- Barriers to access presented by 10-day wait period and requirement for reconfirmation
- Cost of end-of-life services for those who received MAID and those who did not
- Is privacy/security upheld?
- Was travel required (patient or provider)?
- Who provided MAID?
  - GP, nurse practitioner, specialist?
  - Was it the eligibility assessor or a different provider?
- Supply of MAID providers and variation by location
- Location of procedure
  - Home/community
  - Hospital
  - Other
- Linkage between MAID and palliative care provider

### **Patient journey, experience and quality of care**

- Impact of MAID (pre-procedure) on quality of death and dying — patient and caregiver perspectives
- Death anxiety
- Existential distress
- Predictors of those who make request and fulfill request (demographics, disease, personality traits)
- Impact on bereavement and family (pre-procedure)
- Access to palliative care
- How do they access MAID? Satisfaction with access process?
- Did the patient have to self-starve to qualify? Withhold pain medication to qualify?
- Ever feel abandoned in the process?
- Families feel supported through process?
- Did you apply earlier than you'd wanted to?
- Did you choose MAID because other options not available?
- What gaps in the health care system did they experience?

- Was it challenging to access?
- Did they feel there were no other choices available?
- How did physicians explore all other avenues first? And does it even make sense to do that?
- (How long) Does the patient have to use other services before MAID?
- How was the patient's experience throughout the patient journey (granted and denied)?
- What was the patient's family's experience during the journey and after?
- Where did the patient initially obtain information about MAID?
- Where was the request made versus where did it occur?
- Where would the patient like to have had the procedure done?
- Reason for change in plans?
  - Granted but changed mind?
  - Granted but died naturally?
- Wait times/delays/logistics (especially for remote communities)
- Adverse events/effects
- How long between request and provision of MAID?
  - For example, transfers, referrals (e.g., written), information seeking
  - Could look to family experience to get reflections pre- and post-procedure
- Do requests expire?
- Eligibility criteria — intolerable suffering
- Can we determine symptom burden?
  - Determine suffering
  - Clinical- and patient-reported measures
- How many patients are palliative?
- Where are they on the scale of reasonably foreseeable?
- What is the experience of ineligible?
  - When did they die?
  - Do they make a second request?
- Is the drug regime effective?
  - Errors?
- What supports do patients and families need and have (survey please)?
- Are we providing the right service and quality of care to ensure that a patient makes the decision for the right reasons, not because there's a lack of . . . ?

- Why is the patient requesting the service?
- Do providers have the right training and skills to manage this?
- What would a patient identify as a need for a good quality death?
- How are we helping patients from a spiritual perspective?
  - May not get support from family or community
- What creates the best clinical course for the patient's care through the process?
- Access, number of patient transfers for assessment for MAID
- Were there other choices (palliative care, hospice, home care)?
  - Was the patient aware of those options?
  - Did choices influence decisions?
- What is the start time for thinking about MAID?
- What happens to the treatment (medication) if the patient at home changes their mind?
- What is the patient and family experience?
  - What wraparound services are available?
  - By sector/across sectors?
- What are roadblocks in the process?
  - Can't find MD?
  - Wait for a second opinion?
- How many die between request and planned end of process?
- Did lack of care lead to an end-of-life situation?
- How long is the decision-making process? What influences those who decide not to proceed?
- Is MAID provided by a familiar provider or someone new to patient?

#### **Needs of clinicians and support teams who are providing MAID services**

- The experience providing MAID (comfort, willingness, skill confidence, stress)
- Would it be the same groups always performing MAID? A specialty group? If yes, what is their mental health? What support do they need?
- How many practitioners refuse to sign/authorize?
- How will cross-jurisdictional service work?
- What would practitioners do differently?
- Geographic distribution — if MAID was not provided, and why?

- What is the time commitment to provide MAID?
- Gaps/strengths in training and resources
- Does the provider feel safe?
- What [data] do I need to collect to meet my obligations?
- Correlation between level of care provided (high quality/high access versus low quality/low access) and likelihood of requesting MAID
  - What has proven effective to reduce the request rate?
- Do patients have enough access to palliative care?
- What is at the root cause of an individual decision?
- How do we define success?
- Are we exploring options for system improvement as part of the conversation?
- Is there a maximum exposure to MAID a physician should experience (e.g., mentally healthy exposure)?
- Did provider get procedural/technical support, oversight/guidance (peer support/network or facility support), financial support for time and effort?
- Self-care: work could be distressing
- Did they receive stigma? Some providers want to be anonymous?
- Are there educational changes in schools?
- Burnout rates in those offering service?
- Support for full team
- Unexpected impacts to other care
- What was the impact to clinicians and their families?
- What was the impact to the team you work with?
- Did the practice normalize among teams?
- Integration with organ donation?
- Are there gaps in teams?
- Who is in the circle of care?
- Is information accessible and shared with the care team?
- Does this lead to a coordinated approach to care?
- Is there appropriate access to resources — drugs, policies, HR support?
- Comparative information on practice patterns; clinical characteristics
- What are the best ways/processes; protocol of care?

- Adverse events/success rate
- Provider's experience in their professional community
- Clinical prognosis of the requestor
- What are the needs of caregivers/families during and after the process?
- Is there access to training/education resources?
- What is the client–patient experience?
- Are clinicians appropriately educated about MAID?
- Are there sufficient emotional resources to support providers in this respect?
- Helping providers consider MAID in the context of quality palliative care
- Needs of clinicians and support teams providing services
- What education and support tools are available?
- How are providers made aware of protocols to follow?
- Provider support for how they individually feel about MAID
- Access to system-level and own data about MAID services
- Referral resources available and accessible for new and conscientious objectors
- Expert advice for eligibility assessment
- Experience providing MAID
- How would cross-jurisdictional service work?
- How may practitioners refuse to sign an assessment?
- Gaps in training resources?
- Does provider feel safe?

**Health system resources (e.g., human, financial, infrastructure, pharmaceuticals)**

- Core structure across jurisdictions
- How did patient access system?
  - Request/referral?
- What drugs are being used?
  - Who pays?
  - Distribution system
  - Availability and access
  - Pricing changes over time?
- Who were providers, what was their role?



- Are publicly funded institutions permitted to refuse MAID?
- What are the performance and quality indicators?
- Structure, process, quality, outcomes
- Utilization rates:
  - MAID drugs
  - Palliative drugs
- What is the efficacy of specific drug regimes?
- Will drug cost change over time?
- Will drugs continue to be funded?
- What are the staffing support needs and costs in acute care versus community settings?
- Who is providing MAID, by geography?
  - Team-based or single clinician?
- How many providers per population?
- Where is MAID happening?
- Do patients have to be transferred to receive MAID?
- Will there be standardized training?
  - Is there a gold standard?
- Investment required for reporting infrastructure
- What are additional staffing/administrative costs (coroners, collection/reporting of vital stats, etc.)?
- Do we pay MDs for data?
  - Is it part of the existing fee code structure?
  - Training to ensure data quality?
  - Who pays?
- Who pays/what percentage?
- Is the distribution of work across clinicians reasonable (do we have enough social workers, ethicists resourced)?
  - Provider inventory and distribution
  - How many conscientious objectors?
- Is there sufficient supply to provide the service in the community?
  - Do patients have to be admitted to hospital?
  - What needs to happen to make home setting safe and appropriate?

- What is the cost/benefit of self-administration?
- College regulations/policy
- What rights exist for institutions to opt out?
- What are the associated costs and accountabilities and how are they being managed?
- What are the key success factors for a successful patient experience?
- Have we advantaged assisted death over other end-of-life options (palliative care)?
- Time spent (consulting and reporting)
- Completeness and timeliness of data collection
  - Cross-jurisdictional
  - Data source agreements, including definitions
  - Some reporting structures
- If certain facilities perform more MAID procedures, will there be issues recruiting/retaining staff?
- Do professionals have correct/enough access to information, support, tools?
- Safety for institutions and pharmacies
- Does every institution have the ability to handle MAID or are the agreements across a variety of institutions?
- Travel logistics cost and coordination
- Policies governing institutional requirements for delivery of MAID
- Who is the central group with oversight?
- How are providers reimbursed? Will home visits be funded?
- Are there incentives to perform (or not perform) MAID?

**This is a shared journey in a complex environment, with multiple stakeholders:  
What health system and public reporting needs are best tackled together?**

- Those that need comparable data
- Transparent data to provide trust to public
- Manner and cause on death certificate
- Common repository for patient, families, providers to access information
- Common data collection tools
- Coding/hospitalization data
- Education and training for providers around how to provide the service
- Developing mental health supports for providers

- Aggregate reporting
- Need a minimum data set developed by all provinces/territories — existing sources, linkages
- Ensuring patients have access to MAID no matter where they live
- Data quality and standards
- High-level dashboard of indicators
- No consensus on all
- Indicator fatigue is real. Health providers expect data collection not to duplicate
- Access: tap into existing data sources, quality, experience, safety, compliance indicators
  - Prioritize points in each category
- May be a role for local qualitative case analysis
- Develop online tool, pre-populate provider info, send to different recipients automatic
- Minimum data set, standard reporting, template
- Common data standards and strategies for obtaining data
- Definitions of data
- Minimum data set: terminology — not just legal requirements
- Common methods to run reports
- Reporting system specs
- Neutrality — no bias
- Rules about accessing and sharing data
  - Which data is public/private?
- Benefit from cross-pollination of diverse practices
- Compliance = provincial/territorial reporting
- System performance = pan-Canadian; clinical reasons for not seeking, safety, etc.
- Why wouldn't we tackle all together?
- Equity for all Canadians — need common reporting
- International comparison = Canada vs. other countries
- Small number of patients — benefit of pooled data

**This is a shared journey in a complex environment, with multiple stakeholders:  
In what areas should we have comparable information across the country?**

- Patient and family experience
- Quality and safety measures
- Clinical protocols
- Clinical reporting: vital/mortality stats
- Jurisdiction scan awareness of variation between provincial/territorial policies
- Variation in process
  - Non-compliance
- Review lessons learned
- Access and communication issues
  - Eligibility criteria
- Compliance data
- Education and training
- Demographics
- Outcomes of requests
- Location of procedure
- Underlying conditions
- Cost
  - Provincial programs/billings
  - Average cost
- Reasons requests could not be fulfilled
- Demographics
- Reason for request
- Number granted
- Number declined and why
- Other services offered
- Underlying conditions, manner of death
- Costs, resources, how providers are paid
- How drugs are funded
- Providers and patient/families experience

- Follow-up support services
- Consent process
- Location and why
- Who is present
- Complications
- Adverse events
- Compliance with Bill C-14 (MAID Act)
- Common prognosis
- Those requesting and those who died by MAID
- Wait times
- Access to other services, quality of life programming, palliative care, psychosocial, allied health
- Clinical characteristics of those who did and did not request/receive MAID
- Who is the eligible population (what is the denominator?)
- Number of clinicians providing
- Data sources
- Timeliness of data/reporting deadlines
- Information on death certificate
- Costs
- Number requests: accepted/rejected
  - Basic patient characteristics, diagnosis/age/sex/location/socio-economic status
- Trajectory of care
- Health system performance — quality and safety
- Access (all parts of the system)
- Data on full range of end-of-life options/care
- Patient experience, family caregiver experience, provider experience
- Focus on ensuring comparability of new data elements