Best Brains Exchange

Optimizing Policy and Procedures and Enabling Research to Optimize the Care of Patients Requesting Medical Assistance in Dying for Whom Death Is Not Reasonably Foreseeable (‘Track 2’)

May 31–June 1, 2023

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Suggested Citation:
Contents

List of Abbreviations and Terms ........................................................................................................ 4

1.0 Executive Summary ....................................................................................................................... 5
   1.1 Background and Policy Context ................................................................................................. 5
   1.2 Need for Evidence ..................................................................................................................... 5
   1.3 Meeting Purpose & Objectives .................................................................................................. 6
   1.4 Anticipated Outcomes .............................................................................................................. 6
   1.5 Agenda .................................................................................................................................... 7
   1.6 Summary of Key Themes Arising from the Full Deliberations .................................................. 8

Detailed Proceedings ......................................................................................................................... 12

2.0 Opening and Welcome Remarks .................................................................................................. 12
   2.1 Land Acknowledgement .......................................................................................................... 12
   2.2 Foundational Objectives .......................................................................................................... 12
   2.3 Scene-Setting Presentation: Why Are We Here? ..................................................................... 13

3.0 Panel 1: Eligibility for Track 2 .................................................................................................... 15
   3.1 Presentation: Three Principles Based on Two Cases ................................................................. 15
       3.2 Subsequent Discussion ............................................................................................................ 16
   3.3 Presentation: A Study on Irremediable Psychiatric Suffering in the Context of Physician Assisted Death .......................................................................................................................... 17
       3.4 Subsequent Discussion ............................................................................................................ 19
   3.5 Key Takeaways from This Panel: ............................................................................................. 20

4.0 Panel 2: Quality Assurance and Improvement ............................................................................ 21
   4.1 Presentation: MAiD in Belgium: Quality Assurance & Improvement ...................................... 21
   4.2 Presentation: Medical Assistance in Dying .............................................................................. 22
       4.3 Subsequent Discussion ............................................................................................................ 24
   4.4 Key Takeaways from This Panel: ............................................................................................. 24

5.0 Panel 3: Ethical Support for Healthcare Professionals ............................................................. 25
   5.1 Presentation: Ethical Support .................................................................................................... 25
   5.2 Presentation: Optimizing Policy and Procedures and Enabling Research to Optimize the Care of Patients Requesting Medical Assistance in Dying for Whom Death Is Not Reasonably Foreseeable (‘Track 2’) ............................................................................................................................................... 26
       5.3 Subsequent discussion ............................................................................................................ 27
   5.4 Key Takeaways from This Panel: ............................................................................................. 28
6.0 Session 1 Recap and Stage-Setting for Session 2 ................................................................. 28
7.0 Opening Remarks and Session 1 Recap ............................................................................. 29
8.0 Panel 4: Moving Evidence into Policy ............................................................................ 29
  8.1 Presentation: Moving Evidence into Policy (Part 1) ......................................................... 29
  8.2 Subsequent Discussion ..................................................................................................... 31
  8.3 Presentation: Moving Evidence into Policy (Part 2) ......................................................... 32
9.0 Small Group Discussion (1 Hour) ..................................................................................... 33
  9.1 Group 1 .......................................................................................................................... 34
    Key Points: ..................................................................................................................... 34
  9.2  Group 2 ........................................................................................................................ 35
    Key Points: ..................................................................................................................... 36
  9.3 Group 3 .......................................................................................................................... 36
    Key Points: ..................................................................................................................... 37
  9.4  Group 4 ........................................................................................................................ 37
    Key Points: ..................................................................................................................... 38
  9.5 Wrap-Up of Group Discussion ....................................................................................... 39
10.0 Closing Remarks ............................................................................................................. 40
  10.1 Dr. Thorne: .................................................................................................................. 40
  10.2 Razvan Diacu, BC MoH: ............................................................................................. 40
11.0 Additional Links ............................................................................................................. 40
    References ...................................................................................................................... 42
    Further Notes from the Discussion: .................................................................................. 46
    Further Notes from the Discussion: .................................................................................. 47
    Further Notes from the Discussion: .................................................................................. 49
    Further Notes from the Discussion: .................................................................................. 50
List of Abbreviations and Terms

BC – British Columbia
CAMAP – Canadian Association of MAID Providers and Assessors
CPA – Canadian Psychiatric Association
ECE – Expertisecentrum Euthanasie (Netherlands Centre for Expertise on Euthanasia)
FCECE – Federal Commission for Control and Evaluation of Euthanasia (Belgium) - FCEE (Dutch) / CFCEE (French)
FN – First Nations
GP – General Practitioner
HA – Health Authority
HCP – Health Care Professional
MAID – Medical Assistance in Dying
MD-SUMC – Mental Disorder as the Sole Underlying Medical Condition
MoH – Ministry of Health
NP – Nurse Practitioner
QA – Quality Assurance
QI – Quality Improvement
RN – Registered Nurse
RTE – Regional Euthanasia Review Committee (Netherlands)
SDoH – Social Determinants of Health
Track 1 – MAID for serious and irremediable medical conditions for those for whom death is reasonably foreseeable
Track 2 – MAID for serious and irremediable medical conditions for those for whom death is not reasonably foreseeable
1.0 Executive Summary

1.1 Background and Policy Context

In early 2016, to operationalize Federal legislation (Bill C-14) permitting medical assistance in dying (MAID), British Columbia’s Ministry of Health (MoH) convened its MAID Working Group (now the MAID Operational Committee). Ministry staff, representatives from the 7 BC Health Authorities (HAs), and representatives from health professional regulatory colleges collaborate to ensure high-quality MAID care. British Columbia (BC) continues to lead the nation in structure and processes that ensure safe, seamless care, and in access to MAID. In March 2021, revised legislation – Bill C-7 – was passed which allowed MAID for serious and irremediable medical conditions, both for those for whom death is reasonably foreseeable (‘Track 1’) and those for whom death is not reasonably foreseeable (‘Track 2’). C-7 included a clause exempting MAID for patients for whom mental health disorders were the sole or principal cause of suffering. This clause was originally set to lapse on March 17, 2023. On March 9th, 2023, Bill 39 achieved royal assent, delaying the implementation of MAID for persons with mental health disorders to March 17, 2024. In May 2022, Health Canada’s Expert Panel on MAID and Mental Illness released its report, in which the term MAID for Mental Disorder as the Sole Underlying Medical Condition (MD-SUMC) was formalized. Subsequently, in June 2022, the Special Joint Committee on MD-SUMC presented its interim report to Parliament and tabled its final report on February 15th, 2023. In the summer of 2022, British Columbia struck a Subcommittee on MAID and Mental Health including ethicists and representatives from psychiatry and other mental health disciplines across the province, as well as BC Mental Health and Substance Use. The role of the Subcommittee is to develop recommendations to ensure that MAID for MD-SUMC is provided in a safe and appropriate way and to address the practical issues involved in assessing eligibility and providing MAID for this population.

1.2 Need for Evidence

There is an urgent need to develop and implement systems that ensure that the care delivered to Track 2 patients is sustainable, and is as safe, high quality, efficient, appropriate, and ethical as has been the case in Track 1. To date, Track 2 cases have already proven to be more complex than those in Track 1, requiring more time and imposing greater practical and emotional burdens on assessors and providers than with Track 1. This has led to strain on capacity of the MAID system as some of those assessors and providers ‘opt out’. The introduction of MAID for MD-SUMC could further exacerbate this. HAs are already receiving multiple inquiries from patients with MD-SUMC wishing to be considered for MAID, suggesting that requests for MAID Track 2 may increase significantly following March 2024. In addition, public controversy over the appropriateness of MAID in MD-SUMC may further erode public trust in the assessment process and may lead to more assessors and providers choosing not to be involved. An Angus Reid poll released in February 2023 showed that, whereas 61% of respondents supported Canada’s MAID legislation, only 31% supported the concept of MAID for MD-SUMC. For health care professionals involved and the healthcare system, MAID in MD-SUMC brings with it particular challenges, related to potential disagreement on diagnosis and variability and unpredictability in response to treatment and in severity of disorders over time. In addition to practical concerns, the lack of access to specialty mental health care and mental health and primary care community
resources represents particular concerns and raises ethical questions, including but not limited to whether it is ethical to provide MAID to patients who cannot access treatments known to be effective, or to those who may be able to access such treatments in the future but are suffering now and face uncertainty about whether they will benefit from them. Policy and research arising out of lengthy experience with MAID in Belgium and The Netherlands, including MAID for patients with mental health disorders, will help to inform work in Canada; the proposed Exchange seeks to leverage this insight for the evolving Canadian context. For example, research in Belgium showed that a lack of thorough assessment of those requesting MAID for MD-SUMC had a negative impact on them, because of a sense that their problems had been trivialized. However, since MAID was operationalized slowly and had different roots in those countries, this work must be carefully contextualized in British Columbia and across Canada.

1.3 Meeting Purpose & Objectives

The title of the Best Brains Exchange (BBE) was: Optimizing Policy and Procedures and Enabling Research to Optimize the Care of Patients Requesting Medical Assistance in Dying for Whom Death is Not ReasonablyForeseeable (‘Track 2’). It was held virtually over the course of two days, on Wednesday, May 31st and Thursday, June 1st, 2023 9:30am-12:30pm PT / 12:30-3:30pm ET.

The BBE was facilitated by the Canadian Institutes of Health Research in collaboration with representation from British Columbia Ministry of Health Medical Assistance in Dying Operational Committee, British Columbia’s Provincial Health Services Authority, Vancouver Island Health Authority, Vancouver Coastal Health Authority, Fraser Health Authority, Interior Health Authority, Northern Health Authority, and the University of British Columbia.

The BBE examined current evidence and brought together stakeholders from multiple sectors to support the development and implementation of systems that ensure equitable, safe, sustainable, high-quality, efficient, appropriate and ethical care centred on patients requesting medical assistance in dying for whom death is not reasonably foreseeable (Track 2). More specifically, the following objectives guided the process:

1. Identify approaches required to support practitioners in determining eligibility for Track 2 patients including MD-SUMC (Mental Disorder as the Sole Underlying Medical Condition).
2. Establish quality assurance and improvement mechanisms required with MAID for Track 2 patients including MD-SUMC.
3. Determine the needs for ethical support of healthcare professionals caring for patients requesting MAID within Track 2 including MD-SUMC and how they can be incorporated into care.
4. Ascertain how to integrate research into the development of policy as MAID evolves.

1.4 Anticipated Outcomes

1. The establishment of:
a. Evidence-informed policies, procedures, organizational structures, and best practices to support practitioners in determining eligibility for Track 2 patients, including MD-SUMC, such as regional and/or provincial case review panels, ethical supports.

b. Quality assurance and quality improvement mechanisms to monitor the quality, safety and appropriateness of MAID assessment and provision with MAID within Track 2 patients, including MD-SUMC, including the analytic capacity required.

c. Ethical and other supports required by healthcare professionals caring for patients requesting MAID within Track 2, including MD-SUMC.

2. The identification of:

a. Gaps in knowledge needed to inform work on Objectives #1a-c that form opportunities for research.

b. Opportunities for research collaboration.

1.5 Agenda

Over the course of the two-day meeting, Canadian and international experts, psychiatrists, researchers and doctors spoke on the following topics.

<table>
<thead>
<tr>
<th>Agenda Item / Discussion</th>
<th>Speaker(s) / Facilitator(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Day 1</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Opening Remarks</strong></td>
<td>Facilitator: Sally Thorne, Professor, School of Nursing, University of British Columbia</td>
</tr>
<tr>
<td>• Welcome from the BBE Facilitator and hosts</td>
<td></td>
</tr>
<tr>
<td>• Land acknowledgement</td>
<td></td>
</tr>
<tr>
<td>• Format/technical guidance (housekeeping)</td>
<td></td>
</tr>
<tr>
<td>• Roundtable of introductions (in the chat)</td>
<td></td>
</tr>
<tr>
<td><strong>Scene-Setting Presentation: Why Are We Here?</strong></td>
<td>David Robertson, Medical Director, Island Health MAID program, Vancouver Island Health Authority, BC</td>
</tr>
<tr>
<td><strong>PANEL: Eligibility for Track 2</strong></td>
<td>Sisco van Veen, Researcher, Amsterdam University Medical Centre and 113 suicide prevention</td>
</tr>
<tr>
<td>Objective: To identify approaches to support practitioners in determining eligibility for Track 2 patients including MD-SUMC</td>
<td>Mark Lachmann, Vice President, Medical Affairs, Sinai Health</td>
</tr>
<tr>
<td><strong>PANEL: Quality Assurance and Improvement</strong></td>
<td>Kenneth Chambaere, Professor, Public Health, Sociology &amp; Ethics of the End of Life; End-of-Life Care Research Group, Ghent University and Vrije Universiteit Brussel (VUB)</td>
</tr>
<tr>
<td>Objective: To establish quality assurance and improvement mechanisms required with MAID for Track 2 patients including MD-SUMC</td>
<td>Alison Freeland, Vice President, Education and Academic Affairs Associate Dean, Temerty</td>
</tr>
</tbody>
</table>
### PANEL: Ethical Support for Healthcare Professionals
Objective: To determine the needs for ethical support of healthcare professionals caring for patients requesting MAID within Track 2 including MD-SUMC and how they can be incorporated into care

| Isabelle Marcoux, Associate professor, Interdisciplinary School of Health Sciences, University of Ottawa |
| Mona Gupta, Associate Professor and Psychiatrist, Centre hospitalier de l’Université de Montréal (CHUM) |

### Session 1 Recap and Stage-Setting for Session 2
Facilitator: Sally Thorne

### Day 2

#### Opening Remarks and Session 1 Recap
Facilitator: Sally Thorne

#### PANEL: Moving evidence into policy
Objective: To ascertain how to integrate research into the development of policy as MAID evolves

| Barb Pesut, Professor, School of Nursing, University of British Columbia Okanagan |
| Michael McKenzie, Medical Assistance in Dying Medical Director, Provincial Health Services Authority and Radiation Oncologist, BC Cancer-Vancouver |

#### Small Group Discussions

| Vijay Seethapathy, Chief Medical Officer, Provincial Health Services Authority |
| Laurel Plewes, Director of the Assisted Dying Program, Vancouver Coastal Health |
| Julia Gill, Ethicist, Vancouver Coastal Health; Adjunct Lecturer, Clinical Public Health Division, Dalla Lana School of Public Health |
| Tammy Dyson, Regional Lead, Medical Assistance in Dying (MAiD), Fraser Health Authority |

#### Report Back & Discussion: Next Steps
Facilitator: Sally Thorne

| Vijay Seethapathy |
| Laurel Plewes |
| Julia Gill |
| Tammy Dyson |

#### Closing Remarks & Adjournment
Facilitator: Sally Thorne

| Razvan Diacu, Director, Acute Care Access and Policy, Government of British Columbia |

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1.6 Summary of Key Themes Arising from the Full Deliberations

Participants and presenters discussed a wide range of issues associated with Track 2 MAID in the evolving Canadian context, identifying unresolved or contentious issues and also noting aspects in which there was general agreement as to the appropriate course forward. Key themes arising from
the two days of deliberation (including the pre-reading, panel presentations, question and answer periods, digital chat, and small group discussions) included:

- **Support for patients**
  
  - There is an urgent need to ensure patients are supported in their decisions to seek or not seek MAID. For patients requesting MAID, refusing conversations can cause harm. Relational and trauma-informed care in this area involves in-depth conversations with patients, seeking to understand patient perspectives, implementing safeguards, and ensuring care at all stages.
  
  - Health Care Providers (HCPs) must hold space and take time when discussing MAID MD-SUMC with patients, including their families where appropriate. HCPs should work with patients in a relational, trauma-informed style of care that supports patient autonomy.
  
  - Rural and remote areas present unique challenges and require further reflection and strategizing.
  
  - Awareness is needed for the special considerations associated with patients from groups made vulnerable by social context.
  
  - MAID in the context of Indigenous persons and communities has not yet been studied in Canada, and this work will require in-depth community consultation.

- **Mental health supports**
  
  - There is an urgent need to address the adequacy and availability of mental health supports across Canada.
  
  - Providing safe MAID care for MD-SUMC must include addressing a full spectrum of mental health supports, wait times, and aftercare.
  
  - Planning must acknowledge the recognized shortage of assessors and providers (including psychiatrists), and to take action to rectify this.

- **Supports for practitioners**
  
  - Supporting HCPs indirectly supports patients and families. It will be important for Health Authorities (HAs) and leaders to continue developing Communities of Practice and related support systems. HCPs need space to reflect on their personal and professional boundaries, including the conditions under which they may say ‘no.’ Effective systems must be in place to ensure that no one provider bears the burden of work alone, but rather is able to find support through working in teams.
  
  - Appropriate government funding and appropriate billing/remuneration structures must be in place for practitioners engaged in MAID-related work.

- **Team-based care**
  
  - Health Authorities (HAs) must explore future options for navigating team-based care and distributing workload, particularly when it comes to providing supports for patients, utilizing and collaborating with nurse and social worker roles in case management, and connecting patients with allied health professionals and other social supports.
• Team-based care models should be encouraged, particularly for complex assessments.
  o There will be an ongoing need for widespread education about MAID for all healthcare staff working with potentially eligible patients, regardless of involvement with MAID teams.

• Complexity
  o Each Track 2 MD-SUMC case will be unique, with the assessment process not following a standardized algorithm. Each MAID for Track 2 MD-SUMC case will require time, reflection, and in-depth understanding of the patient’s background. (The process cannot be a ‘box-ticking’ exercise).
  o MD-SUMC includes complexity in navigating legal and moral challenges.

• Language
  o Accuracy in prognosis/assessment is highly challenging. Psychiatric suffering reflects a form of suffering in which the psychosocial context is particularly important. Because there will be inevitable uncertainties, policies will need to reflect serious attention to patients’ suffering while also building in safeguards.
  o It may be necessary to standardize language around irreversibility, intolerability, and irremediability, as well as distinguishing ‘mental health’ ‘mental illness’ and ‘mental disorder’. If the idea of ‘terminal psychiatric illness’ is deemed relevant, the concept will require clear definition.

• Building systems and ensuring their functionality
  o Canada can prepare in advance by learning from Belgium and the Netherlands, where researchers and experts have experience-based recommendations on how to proceed in building systems and structures for MAID Track 2 MD-SUMC, including what to expect, and how to mitigate potential challenges. Challenges include but are not limited to long wait times, impact of public media, the advantages and disadvantages of establishing centres of expertise. For example, the Netherlands has learned the value of working with suicide hotlines to ensure that volunteers and workers have access to nuanced and balanced information about MAID.
  o Systems must be in place to ensure that there be no abandonment of patients seeking MD-SUMC or after eligibility is assessed, and aftercare should also be considered.
  o In contrast to other Track 2 cases, for MAID where MD-SUMC, it may be necessary to obtain family involvement as part of eligibility determination.
  o Guidelines should be in place to manage the issues that may arise with patients seeking multiple assessments.

• Quality assurance (QA) and quality improvement (QI)
  o In order to monitor and manage Track 2 MAID, there will be a need for standardization of processes, terminology, and data collection.
- Data sharing will be important for establishing QA and QI, including narrative data and research on and with HCPs, patients, and families.
- Future research will be needed to inform policy in multiple dimensions, including longitudinal research, mechanisms of data collection, research on patient and HCP experience, motivations for seeking MAID Track 2 MD-SUMC, access and barriers to assessment, vulnerable groups, rural & remote settings, and Indigenous perspectives (in collaboration with Indigenous leaders and communities).
Detailed Proceedings

2.0 Opening and Welcome Remarks

*Facilitator: Sally Thorne, Professor, School of Nursing, University of British Columbia*

Dr. Thorne began by welcoming all participants on behalf of CIHR and partners to the BBE. She named the partners and explained that it was being hosted by CIHR, in collaboration with British Columbia Ministry of Health Medical Assistance in Dying Operational Committee, British Columbia’s Provincial Health Services Authority, Vancouver Island Health Authority, Vancouver Coastal Health Authority, Fraser Health Authority, Interior Health Authority, Northern Health Authority, and the University of British Columbia. Dr. Thorne then called on Laurel Plewes to give a land acknowledgement.

2.1 Land Acknowledgement

*Laurel Plewes, Clinical Nurse Specialist and Director of the Assisted Dying Program, Vancouver Coastal Health Authority,* gave a land acknowledgement. She acknowledged being on unceded territories of a wide range of Indigenous peoples, including Musqueam, Squamish, and Tsleil-Waututh Nations, while recognizing that CIHR partners were on ancestral and unceded Algonquin-Anishinaabe territory.

Laurel Plewes provided context to those outside of Canada as to why land acknowledgements are done, a brief history of Europeans coming to the country in the 16th Century, and the colonial structures that have harmed Indigenous peoples. She highlighted the impact of colonial actions which have caused profound generational trauma, including forced sterilizations and residential schools, to name a few. Laurel Plewes also outlined various obligations as a member of settler ancestry community, and the importance for Canadian participants to remember these experiences and perspectives. She concluded that, while a distinct BBE on Indigenous perspectives of MAID in Canada should be held to focus on the distinct complexities for Indigenous populations, for the purposes of the current BBE these insights and acknowledgements would be kept in mind.

2.2 Foundational Objectives

Dr. Thorne welcomed all participants by outlining the aims of the BBE and indicated the two foundational objectives:

1. Enable exchange of research and implementation of knowledge
2. Foster meaningful dialogue between policy and decision makers, implementation experts, health system professionals, and others.

Key principles governing our engagement in this BBE include using a deliberative dialogue approach and following the Chatham House Rules for our discussions with one another, meaning that participants can use the information received, but the identity or affiliation of the speakers who expressed an idea cannot be revealed without that person’s explicit permission. Therefore, the
reporting of presentations in this report is with the permission of those named, and the outcomes of group deliberations are without attribution as to the speaker.

2.3 Scene-Setting Presentation: Why Are We Here?

David Robertson, Medical Director, Island Health MAID program, Vancouver Island Health Authority, BC

Dr. Robertson provided a few minutes of scene-setting, welcoming participants from unceded territories of Coast Salish people on Vancouver Island. He began by briefly describing governance structures of MAID in British Columbia, which is comprised of five regional health authorities and two others – a provincial health authority overseeing a number of provincial programs and a First Nations Health Authority.

Before MAID became legal in 2016, it was decided that it would be led as a provincial service with a centralized reporting structure. MAID oversight committees were established, and it was decided that the Ministry would provide overarching oversight and be responsible for quality assurance, as well as reporting data to Health Canada. Razvan Diacu and Zachary Mokosak were introduced as individuals leading the Ministry’s MAID oversight in BC. Dr. Robertson explained how each regional health authority runs a MAID coordination service to ensure quality in that particular area. He commented that, having watched MAID develop over the years, BC could be considered a model. He then provided context with respect to the uptake of MAID in BC, noting that BC has the highest rate of MAID of any province and that, apart from two small communities in Quebec, Vancouver Island has the highest MAID rates in Canada.

Dr. Robertson then outlined the differing models and organizational structures between BC’s different health authorities. Standard rules exist that all authorities observe, but he noted differences in approaches to MAID across different health authorities. He mentioned that the MAID landscape in BC would be an ideal place for comparative case studies relative to various models of service.

He also provided context as to how, from 2016 to 2021, strong guidelines were developed for the MAID service for people for whom death is reasonably foreseeable. When the law changed in 2021 creating a separate track of care for those whose death is not reasonably foreseeable, it introduced new levels of complexity. He surmised that MAID for mental disorder as sole underlying condition will lead to new challenges. He pointed to the purpose of the presentations and discussions in this BBE as being to develop policies and practices to address these challenges, and to inform research for the increasingly complex persons in challenging clinical and life circumstances who are likely to apply. He referred to this as an opportunity to gather together to develop a research agenda with the goal of informing policy.

Dr. Robertson reiterated the 4 questions outlined earlier by the facilitator:

1. Identify approaches required to support practitioners in determining eligibility for Track 2 patients including MD-SUMC (Mental Disorder as the Sole Underlying Medical Condition).
2. Establish quality assurance and improvement mechanisms required with MAID for Track 2 patients including MD-SUMC.

3. Determine the needs for ethical support of healthcare professionals caring for patients requesting MAID within Track 2 including MD-SUMC and how they can be incorporated into care.

4.Ascertain how to integrate research into the development of policy as MAID evolves.

As of March 2024, we expect that it will become possible to pursue MAID for mental disorder as the sole underlying condition in Canada. Dr. Robertson noted the controversial nature of this change, which has been made evident in the public media even before its arrival. Since March 2021, there has been a wealth of learning about Track 2 MAID. He highlighted many aspects of MD-SUMC, including it still being uncommon, even in jurisdictions in which it is legal, emphasizing that it was inherently complex, that many health care professionals will decline to take this on, and that it will remain contentious in the media.

Dr. Robertson remarked that no one clinician or MAID provider can be an expert in all the issues that will present themselves. He acknowledged that even without these new complexities, supplying MAID services has some gaps and that some changes are required. He sensed the need for support to providers through collaborative case reviews. He spoke to the importance and necessity of standardizing procedures and studying their effectiveness. He also spoke about the importance of providing Track 2 MAID well, ensuring that the eligibility decisions are what they should be, so those who are eligible are indeed eligible, and those who are ineligible are managed appropriately.

Dr. Robertson further suggested the need for heightened Quality Assurance (QA) and Quality Improvement (QI) systems for MD-SUMC cases, and wondered about how we might formalize these processes provincially. He also reflected on how these processes might play out in a system where community physicians and nurse practitioners may not involve facilities or other health personnel in these processes. Dr. Robertson also suggested that we consider an expanded system of post-provision case reviews, noting that, although case reviews have been done since 2016 in his health authority, and have been done separately in the Ministry MAID oversight unit, privacy legislation means case details cannot be shared unless anonymized. He wondered how insights arising from such cases could or should be shared and how research to interpret what can be learned from them could be developed. He reminded the audience that these systems need to be in place for March 2024 so that we can answer questions and face what will be predictable public scrutiny.

Finally, Dr. Robertson introduced a number of hypothetical and practical questions pertaining to ethics. He noted that reflecting on ethics involved with Track 2 MAID is inherently challenging due to its complexity. Some ethical questions he posed included:

- What to do when reasonable treatments are unavailable or unaffordable?
- How to understand and integrate the social determinants of health?
- How to handle any MAID applicant who refuses to have family involvement?
- What structures should be offered to someone who has issues such as these?
- How can research on Track 2 MAID be done well and ethically?
3.0 Panel 1: Eligibility for Track 2

Objective: To identify approaches to support practitioners in determining eligibility for Track 2 patients including MD-SUMC

3.1 Presentation: Three Principles Based on Two Cases

Mark Lachmann, Vice President, Medical Affairs, Sinai Health, Geriatric Psychiatrist

Dr. Lachmann presented his reflections from a relational perspective, and emphasized that learning through cases and stories was important. His presentation offered an appreciation for the depth of seriousness for this topic and the need to address it thoughtfully.

Dr. Lachmann’s presentation used a narrative form, based on the telling of two stories, and concluding with three principles that he identified as key in any work going forward. Dr. Lachmann contextualized his position as a geriatric psychiatric physician in an administrative role in Toronto at Sinai Health, also having worked as a coroner in Toronto for 15 years. Dr. Lachmann shared two particularly difficult and complicated cases, including a patient who died by suicide, who had been treated for depression and was feeling completely abandoned by the psychiatric profession. Drawing upon his experience as a coroner, Dr. Lachmann noted how psychiatrists do not have experience on scene when people die by suicide and so may not understand the far-reaching repercussions. The second case Dr. Lachmann shared was about a patient with chronic pain and a profound and serious history of trauma. Dr. Lachmann described lengthy and open conversation with that patient when the patient was found eligible due to a lack of capacity to make an informed decision, and how the patient subsequently arranged a trip overseas to have euthanasia in a country where it was legal.

From these two stories, Dr. Lachmann extracted three principles that relate to working through challenging Track 2 cases.

1. Non-abandonment of patients:
   - Dr. Lachmann emphasized being explicit in all procedures about non-abandonment of patients. This includes situations when a patient approaches a psychiatric team, wanting to explore MAID. If members of the team don’t wish to engage in that conversation, the referral should still be done with explanation of how the referral is just for evaluation, and does not mean the person is being discharged from other forms of ongoing care.

2. Relational, trauma-informed, reflective practice:
   - As HCPs work with patients, whether in the process of requesting MAID or supporting someone going through assessment, practitioners need to be relational, trauma-informed, and reflective in all interactions recognizing that assessments can have a profound impact on patient experience.
3. Building a community of practice:

- Working with people requesting MAID means recognizing that the HCP is inevitably working with trauma. Dr. Lachmann emphasized a rule in psychiatry about not working with trauma alone. There is a necessity to build a community of practice of assessors and providers and their colleagues, which is not about case-based discussions and meeting qualifying criteria or procedures; rather, it is important to build a mutually respectful team (community of practice), which becomes a safe space for people to reflect on their experience of working with MAID assessment or provision, especially since the circumstances of Track 2 will pull HCPs in different ways. As this population is very different from working with individuals with terminal cancer requesting MAID, the conversations are very different, and as such, having access to a community of practice support is key.

3.2 Subsequent Discussion

Participants strongly supported the idea of a community of practice. One participant asked a question about whether there is a role for assessing peer support, social networks, social isolation. Dr. Lachmann responded with reference to the dialectical behavioral therapy model, a psychotherapy modality in which there is an expectation that the therapists meet to support each other as they work with a group that has high relational needs. Some parts of that model, including a 24-hour phone line, group, individual therapy, may be worth considering as we move into increasingly complex Track 2 MAID. He also noted there are other examples from psychotherapy that can be leveraged and built into practices. In this context, he discussed boundaries, noting the importance of saying “no”, observing personal and professional boundaries, and emphasizing that is it acceptable to do so, referring again to a community of practice to support one another.

Dr. Thorne probed further about the nature of these boundaries – when talking about something that is morally complex, the question of who should be involved in such discussions is sometimes challenging. Dr. Lachmann noted the procedural and legal standards, as well as written policies that form a complex web. He emphasized that how decisions that will be made will not be made by algorithm – rather, describing it as a series of interconnecting relationships. These relationships would not just be between assessor and family but, he emphasized, they would be between the expert and medical community doing this work as well. Dr. Lachmann noted an existing evidence base from communitarian and feminist ethics about working through difficult problems and reaching consensus in a group-like setting, again reaffirming the importance of having a community. He noted that how the discussions are documented remains an open question, although these will be a valid way to manage consultation with informed individuals through complexity. Dr. Lachmann emphasized that from his perspective, best practices would include meeting regularly to work through questions and allowing a space to talk through challenges, and that HCPs working in this space should have access to the opportunity for such discussions.

A participant posed a question relating to being reflective as it relates to trauma. Knowing that the experience of trauma is systemic, personal and historic, how can HCPs best support people when trauma is generational and embedded in our history? Specifically,
• how HCPs can best support people, knowing the larger context beyond a paper MAID assessment
• how HCPs can best support people before determining eligibility to MAID
• how HCPs can best support people wanting MAID because of their background.

A related question reinforced that the element of control and choice is important in MAID.

In response, Dr. Lachmann shared a case example of a patient experiencing multiple vulnerabilities, bringing up both patient autonomy and the value of a group approach to have colleagues with whom to discuss complex cases, especially as there are so many unknowns that clinicians will face in these evolving times. Although much remains to be understood about best practices, he concluded 1) that validating and verbalizing the patients’ suffering experience was important and 2) that MAID in this context is not an emergency, and time must be taken to answer the questions around it. He made reference to a book that might be helpful for considering this issue (*The Abuse of Casuistry* by A.R. Jonsen, see additional links). He and a number of participants agreed that the number one way to reduce moral distress was by talking to colleagues.

A participant asked about “terminal psychiatric illness,” when an individual may have a psychiatric illness that is incurable, specifically wondering whether discussion in a group about a psychiatric illness might help with agreement or consensus that a patient’s psychiatric illness was incurable, adding questions such as: what the benchmarks would be, how comprehensive this would be, and what conversations would need to occur? Other participants highlighted the need to reconcile that prior attempts to treat psychiatric illness may not have helped, that individuals may know themselves best, and that patient perceptions may not align with HCPs understanding of illness trajectory and stage. Dr. Lachmann responded to this by stating that providers need to know what it means to walk along with someone, especially one who is suffering, particularly when there is no sense that anything can be done and there is no simple solution to alleviate the suffering. He further emphasized that challenges that arise from walking along with someone in this situation are not the patient’s problem, but rather the provider’s problem. Thus, it may be worth considering an established best practice in psychiatry of HCPs using therapy to help them preserve boundaries when engage with these particularly challenging situations in their work. Again, he emphasized that communities of support can allow for clear thinking and clear relationships as HCPs help people through intensely challenging situations.

3.3 Presentation: A Study on Irremediable Psychiatric Suffering in the Context of Physician Assisted Death

_Sisco van Veen, Researcher & Psychiatrist, Amsterdam University Medical Centre and 113 suicide prevention_

Dr. van Veen gave a brief overview of the context and history of MAID in the Netherlands, noting that it was available since the 1960s. He discussed 1980s jurisprudence from the Supreme Court of the Netherlands, leading to the 1994 Chabot Case. Dr. van Veen noted that non-medically assisted suicide is still illegal, punishable by 3 years imprisonment for helping someone to die, and 10 years for euthanizing someone without adhering to the rules. He noted how the Netherlands’
MAID law is an exemption to the criminal code, that only doctors can provide MAID in the Netherlands, and that it has become a highly medicalized procedure.

Dr. van Veen’s presentation highlighted details about the roles of physicians in the Netherlands when it comes to MAID. These include that the physician must:

- be satisfied that the patient’s request is voluntary and well-considered;
- be satisfied that the patient’s suffering is unbearable and irremediable;
- inform the patient of his or her situation and further prognosis;
- discuss the situation with the patient and come to the joint conclusion that there is no other reasonable solution;
- consult at least one other physician with no connection to the case, who must then see the patient and state in writing that the attending physician has satisfied the due care criteria listed in the four points above;
- exercise due medical care and attention in terminating the patient’s life or assisting in his/her suicide.

Dr. van Veen then focused on the importance of the term “irremediability,” explaining that “unbearableness” is highly individual and subjective; what is unbearable for one person is maybe not for another person. He noted how, in the Netherlands, unbearableness must be understandable by the physician, but irremediability is seen more as something that must be decided via dialogue.

Dr. van Veen described the guidelines for MAID in the Netherlands, considering that patients first make a MAID request in the context of a patient-doctor or psychiatrist relationship. Secondly, the psychiatrist makes their own decision and every physician decides whether they will take part in MAID or not. In this first phase of the MAID request, physicians conduct a suicide assessment; because suicide can look like a MAID request and vice versa, physicians must ensure they are not dealing with a suicide request.

Dr. van Veen explained the importance of mentioning family to the patient, and ensuring their family is aware. If the patient doesn’t want family involvement, assessors and physicians need to have a conversation about the reasons for not wanting this. He highlighted the importance of assessors and physicians being transparent and open about their own role and the road ahead. He cautioned about the potential to cause emotional damage in situations where physicians or psychiatrists who are unsure about whether they want to participate begin the process of assessing but then withdraw from this.

Dr. van Veen also explained the system of assessment in the Netherlands requiring a second opinion of a specialized psychiatrist who is asked to look specifically at whether there are any treatment options left and ensure the diagnosis is correct. He emphasized the importance of this process and the necessity that at least two psychiatrists participate. He also explained that, in the Netherlands, every case is ultimately assessed by coroners, then reviewed by a board with an ethicist and a lawyer.

Dr. van Veen then shared a graph showing that, although Netherlands has experienced an increase in MAID for psychiatric suffering, the overall number is still quite low, constituting approximately
3% of all MAID deaths in the country. The numbers began to increase with the establishment of the Expertise Centre for Euthanasia (ECE) in 2013, which has been proactive in this more specialized work, relieving other psychiatrists who are less comfortable with it from being fully responsible for determinations.

Dr. van Veen concluded with two explicit recommendations: 1) MAID should not be a right of the patient or a duty of the physician, and 2) that other countries or contexts try to avoid a situation where a small group of progressive providers performs all of the complicated MAID cases.

3.4 Subsequent Discussion

A participant posed a question about the wording and the differences between the Netherlands and the Canadian legal system. Dr. van Veen responded by discussing the complications associated with understanding another country’s legal system. He spoke to the more nuanced rules that are not found in the text of the law as written, but contained in the details of practice guidelines. He also noted that the text of Dutch law differs from that of Canada, highlighting that the patient and physician need to make the decision together in the Netherlands.

Another question concerned whether a mental health condition could be deemed exhaustively treated, particularly in complex situations such as prison environments. Dr. van Veen responded that he had not yet done sufficient work on prison populations to be able to answer that. Regarding the conditions that are exhaustively treated, he pointed to his own doctoral work, which raised questions around when psychological suffering can be considered irremediable. He stated that irremediable psychiatric disorders do indeed exist; those working in psychiatry have seen patients where they’ve tried everything and patients who suffer irremediability. He emphasized that the most important question is whether these patients can be recognized, and whether an accurate prognosis of unresolvable psychiatric suffering can be made. He reiterated that this is challenging and that it can be difficult to estimate whether a patient will still be suffering after a set amount of time. He went on to explain that psychiatric suffering is different from other disorders; psychiatric suffering should not only be viewed from a medical lens, as the psycho-social context is important. He emphasized the need to be open to and embrace uncertainties, while building in more due diligence, such as second opinions, while always taking the patient’s suffering seriously.

Participants asked for clarification as to whether a psychiatrist must confirm suffering, and raised the problem of doctor-shopping, expressing concerns about the lack of a panel, recording, or narrative data, wondering whether Canada has weaker safeguards than other countries, and asking for further insight into ideological positions within the Expert Centre for Euthanasia. Dr. van Veen stated that he believed the Expert Centre for Euthanasia does good work, and contextualized how it grew naturally out of the right to die movement, but is legally separate from the right to die group. He noted how expertise centres can pool people who share an ideology, given that their purpose or mission is to converse with people who want to discuss MAID for psychiatric suffering. He expressed discomfort with labeling it as ‘shopping,’ but noted that, because there are practitioners who, based on religious or other reasons, don’t want to have these conversations, the Expert Centre for Euthanasia allowed for such conversations about MAID, and that this is why this filled a gap.
Dr. van Veen also gave context as to psychiatrists’ overwork, and how the Expert Centre for Euthanasia worked well for several years when its work could alleviate some workload from other psychiatrists. However, he explained that the Expert Centre for Euthanasia began to receive more societal attention and has ultimately collapsed under its own success – noting the challenges of managing the many patients and a current wait time of 3 years, which may lead to potentially stopping services as well as fueling conflict towards other psychiatrists who have not been involved in MAID. He spoke to how many psychiatrists have been pushed beyond their comfort zones in such cases, and cautioned Canada about societal push and pull if things move too fast and a broad base of support cannot be found from medical professionals prepared to provide MAID in these complex contexts.

3.5 Key Takeaways from This Panel:

• Three key principles based on two complex MD-SUMC cases: 1) non-abandonment of patients, 2) relational, trauma-informed, reflective practice, and 3) building a community of practice.
• It is important to create and maintain communities of practice, where HCPs have a safe space for people to reflect on their experience of assessing or providing MAID and have access to the important support that comes from discussing challenging cases with colleagues.
• There will be a need to attend to boundaries as this practice evolves, including the right of individual HCPs to be able to say “no”.
• Case examples can help illustrate the complexity of Track 2 cases and elicit reflection on approaches to unique patient situations.
• Non-abandonment of patients is particularly important when patients are exploring MAID or a MAID request is denied. When team members do not wish to engage with this issue, it is essential to ensure that appropriate referrals are made, and such referrals pertain to MAID assessment and not discharge from the mental health service.
• All of our approaches must prioritize validating patients who have experienced suffering.
• We can learn lessons from the Netherlands, particularly when examining the advantages and disadvantages of creating MAID centres of expertise. Dr. van Veen cautions us against a system where a small group of providers perform all complicated MAID cases.
• Family involvement is important when in the case of irremediable psychiatric suffering.
• MAID should not be considered a right of the patient or a duty of the physician/provider.
• Having accurate prognoses for patients is important and challenging, as psychiatric suffering it is difficult to assess, but ensuring that HCPs consider all factors and take the patient’s suffering seriously is fundamental to process integrity.
4.0 Panel 2: Quality Assurance and Improvement

Objective: To establish quality assurance and improvement mechanisms required with MAID for Track 2 patients including MD-SUMC

4.1 Presentation: MAiD in Belgium: Quality Assurance & Improvement

Kenneth Chambaere, Professor, Public Health, Sociology & Ethics of the End of Life; End-of-Life Care Research Group, Ghent University and Vrije Universiteit Brussel (VUB)

In a pre-recorded presentation (as he was unable to join in person until Day 2), Dr. Chambaere provided a critical analysis of current Belgian statistics and guidelines, acknowledging that there was still much to learn. He provided a short overview of Belgian euthanasia law, highlighting the general requirements and the additional requirements if death is not reasonably foreseeable, which included a second consultation with a psychiatrist and a one-month waiting period. He reported that deaths for patients for whom death is not expected in the foreseeable future comprised 17.3% of euthanasia cases and 0.44% of all deaths in 2022, and cautioned that this could increase with time.

In regards to legislation, Dr. Chambaere outlined the interpretive nature of laws and noted that Belgian law stays silent on a number of issues such as the role of family. He remarked that this silence was understandable as laws cannot cover every detail, which is why deferring to specialists is helpful. He explained that Belgium was not prepared for the number of non-terminal cases that had come forward, and spoke about a rush or ‘scramble’ to get processes put into place. He reported that there had been public concerns, fueled by anecdotes and stories, of overly permissive cases, and also of physicians being unwilling to provide the services.

Dr. Chambaere’s presentation noted four main areas of debate which focused on:

- Adequate access for patients
- Patient safety
- Feasibility for system
- Support and protection for engaging physicians

Dr. Chambaere distinguished between various kinds of policies, explaining how professional guidelines, as well as committee advice documents can also play a minor or major role in euthanasia practices. He illustrated the Belgian governing sources for euthanasia, and gave a critical overview of all the guidelines. As an example, the deontological guidelines for 2022 were very limited, but the Flemish Association of Psychiatry (VVP) advisory text provides detailed guidance, including clarity on how to assess specific to MD-SUMC, the component of needing two psychiatrists, and a vision for keeping a life track open while a death track is also explored.

He commented that openness to discussing death may open up new avenues to try new approaches to life, especially as both the life track and the death track are managed by the treating physician. He also outlined a number of other intra-organization protocols such as mental health institutes, umbrella organizations for nursing homes, and Ghent University Hospital that provide further training and guidelines.
Dr. Chambaere noted that there is still very little training devoted to euthanasia, and that what exists is ad hoc, fragmented and diverse. He identified Quality Assurance (QA) as a main gap, specifically regarding the training of health care professionals. He stressed the importance of policy that allows for uniformity and consistency, emphasizing that a level of consensus is important and will go a long way to increase willingness of physicians to engage. It will also prevent ‘shopping’ of patients who then end up with the same small group of physicians.

A trend he noted is that the “colloque singulier” – which he referred to as the almost sacred bond between patient and physician – is being eroded as decision-making requires advice from multiple independent physicians, all of whom must have a positive response or the case will not proceed. Because of this, team involvement is important in decision-making and has now become the standard of care.

Dr. Chambaere then described the Expertise Centres in Belgium, explaining how they had sprung up to fill existing gaps. He reported that centres such as those in Ulteam, Brussels and Vonkel, Ghent, which saw complex patients, had become quickly over-loaded, and were seen as an ‘easy out’ for other physicians to offload their complex patients. Similar to the situation in the Netherlands, these Belgian centres see long wait times and, with few physicians willing to take on this form of work; further, there is a view that these centres are being run by the most permissive physicians. Dr. Chambaere advised that we need to look to the centres of expertise model with considerable caution, as it can offload the work to a few ‘champions’ and can also raise public concern about permissiveness.

Dr. Chambaere concluded by presenting other QA proposals, such as requiring palliative care as a means to alleviate suffering for all populations requesting euthanasia. As most of the time these patients won’t have been introduced to palliative care, the requirement to inform them can improve their quality of life. He also weighed the pros and cons of a mandatory pre-reporting committee, considering whether this would be redundant and potentially prolong suffering of patients. He also noted that further clarification is needed of the family role when death is not reasonably foreseeable, as many physicians will not go through with euthanasia unless the family agrees. He felt that a formal policy on post-assessment would be helpful, and recommended that physicians follow up with all patients, including exploration of socio-economic contexts. Although incentivizing training and collaboration is important, a first obstacle is to avoid stigmatizing physicians, and QA in this context should be no different from QA with respect to their normal practice.

4.2 Presentation: Medical Assistance in Dying

Alison Freeland, Vice President, Education and Academic Affairs Associate Dean, Temerty Faculty of Medicine, University of Toronto Mississauga

Dr. Freeland presented from the perspective of the Canadian Psychiatric Association (CPA), a national organization with about 2500 members. She spoke about Quality Assurance in MAID as it relates to MD-SUMC, emphasizing evaluation and research on MAID and the importance of
engaging and involving psychiatrist colleagues about their role in participating in the MAID process.

Dr. Freeland noted that the CPA has found this to be a challenging and complex process over the last few years, as MAID for MD-SUMC has been hotly debated and contentious. She emphasized the need for standardizing language about irreversibility, intolerability, and irremediability, and noted the importance of culturally appropriate conversations, of timely services being available to all Canadians, and of suicide prevention strategies being maintained and strengthened, along with appropriate government funding.

Dr. Freeland outlined ways in which the CPA has been actively involved and engaged to try and understand its members’ perspectives. It established a MAID Working Group in 2020 for the purpose of developing a discussion paper, providing education, and soliciting member input via a survey. On the basis of this survey (23% response rate), they learned:

- 79% agreed MAID should be available for eligible individuals
- 63% agreed that it’s possible for a mental disorder to be grievous and irremediable.
- 41% agreed MD-SUMC should be eligible
- 87% indicated they needed more training.

She also presented the CPA position statement formed by that Working Group, updated in 2021, including the following points:

- Psychiatrists need to have a working knowledge of MAID legislation.
- If all Canadians have access, a group of Canadians cannot be excluded; if eligibility is met, they should have the same options.
- Psychiatrists must be impartial. Conscientious objection is permitted but referral is expected, and rigor in conducting capacity assessments is expected.

Dr. Freeland also shared a CPA discussion paper, which was used to solicit feedback from members and over 50 stakeholder organizations, focused on the issue of safeguards and Quality Assurance. Some elements of that paper included implementing and evaluating safeguards, as comprehensive assessment of mental disorder, the idea that assessors should be independent practitioners, not the treating physician, and that it was important to have access to expertise, separate from consultation. It also raised the following questions:

- How to engage a broad number of psychiatrists regardless of their work to provide expert assessment?
- In the context of capacity assessments, what is the threshold for capacity?
- Do practitioners have to hold people with MD-SUMC to a higher standard?

Dr. Freeland recommended expertise in assessment of vulnerability, including socioeconomic issues, minority, gender, disability etc. and how this can play into an assessment of psychiatric illness. She reiterated that robust assessment and documentation was important, as was carefully evaluating suicidal ideation. She also noted the issue of ‘durability,’ explaining that a MAID request should be considered and sustained, not the result of a transient and impulsive wish. The episodic nature of mental disorder require that these cases allow for sufficient time for reflection
(reflected in the 90 day wait period), as well as accounting for the length of time a patient has considered MAID. Freeland also highlighted the challenge of “voluntariness of the request,” as persons with mental disorders may be particularly susceptible to the influence of others. She concluded by noting that rigorous oversight processes of related mechanisms are required, both prospectively and retrospectively, and Canadian psychiatrists will play various roles in MAID considerations beyond those of assessing or providing.

4.3 Subsequent Discussion

Questions were raised about potential challenges from using independent psychiatric providers versus those who have spent years getting to know a patient, and the challenge of objectivity. Dr. Freeland commented on the tension between theory and implementation, and the ability to assess someone ‘objectively’. She also reflected on the lack of available psychiatrists willing to participate, concern about having a small group of providers, and physician burden when cases are shifted to expertise centres in other countries. Discussants considered the additional efforts needed to ensure access, including team assessment and the role of primary care providers, not just psychiatrists, in mental health care provision.

Some participants predicted an initial rush once the law passes and the potential for systems to be overwhelmed. Hearing the experience from other countries helps allay fears, guiding us on how to provide education and tackle this challenge in a systematic manner. Participants recognize that access to culturally appropriate and safe MAID care will require ongoing advocacy.

A participant posed a hypothetical situational highlighting patients without GPs and who have never seen a psychiatrist or had access to a multidisciplinary team. This led to discussion on the complexity of boundaries, and whether irremediability could be equated to lack of access. In this context, Dr. Freeland offered insight into the importance of standardized processes for determining eligibility, concluding with the importance of procedures, skill and expertise, and ensuring clear steps for a screening, proper diagnoses, and checks and balances on decisions.

4.4 Key Takeaways from This Panel:

- Policies arise from laws, but also from a variety of other documents such as guidelines and association recommendations.
- A critical analysis of Belgium’s system can inform Canada as to what is working and where some gaps exist.
- Palliative care may be useful for all persons requesting euthanasia.
- Uniform and consistent policy can facilitate a level of consensus that increases physicians’ willingness to participate and potentially reduce ‘doctor-shopping’.
- Insights from the impact of centralizing structures such as expert centres in both Netherlands and Belgium may help us consider advantages and disadvantages of that model.
- Follow-up mechanisms are an essential part of QI processes.
- Training and team collaboration for physicians can help avoid the very real problems associated with stigmatization.
• Robust eligibility assessment will require expertise not just in mental disorder but in the specific disorder the individual has in order to have confidence that options that might actually help have been offered.
• Assessment must take vulnerabilities into consideration. Processes must be designed to prevent abandonment.
• Voluntariness is a key consideration with mental disorders.

5.0 Panel 3: Ethical Support for Healthcare Professionals

Objective: To determine the needs for ethical support of healthcare professionals caring for patients requesting MAID within Track 2 including MD-SUMC and how they can be incorporated into care

5.1 Presentation: Ethical Support

Isabelle Marcoux, Associate Professor, Interdisciplinary School of Health Sciences, University of Ottawa

Dr. Marcoux’s presentation spoke broadly about support for healthcare professionals, drawing from her studies, primarily in Quebec. Beginning by noting that MAID clinical challenges can occur at any of the four main stages of the MAID process, she presented data on HCP’s knowledge and training to clarify the extent to which they were aware of MAID eligibility and treatment alternatives. A study conducted with physicians and nurses in 2015 (after the bill was tabled in QC but before law came into effect) showed that 44% of respondents knew that withdrawal of life-prolonging treatment was legal, and that 27% indicated that the clinical procedure would soon be authorized. A study conducted with Canadian physicians in 2017 (after the law came into effect at the federal level) revealed that almost 80% of respondents felt they had insufficient training to deal with MAID.

Dr. Marcoux observed the different challenges to be faced in assessing eligibility criteria for MD-SUMC – incurability, irreversibility, capacity, suicidality, and the inherent subjectivity and multidimensionality of suffering. She noted the less-discussed, systemic dimension of suffering, which mostly involve difficulties in accessing MAID like: discussing MAID with doctors or nurses, finding an HCP willing to provide MAID, but also the negative effects of attempting recommended treatment alternatives, and the lack of confidence in the health care system. These ‘systemic suffering’ factors will also be complicated by social determinants of health, therefore emphasizing the importance of working in a multiprofessional team.

Dr. Marcoux also referred to a study in Quebec with suicide prevention workers, showing that 76% of respondents had experiences with people suffering grievous illness. 61% found MAID acceptable for an end-of-life condition while only 6% found MD-SUMC acceptable. Those who found MD-SUMC acceptable were more likely thinking that suffering can rarely or never be relieved. This illustrated the wide range of perspectives from different groups that will be closely involved with the MAID MD-SUMC population. An analysis of briefs submitted to the special commission in Quebec showed HCPs as well as patients or relatives who submit a brief were more
likely to find MD-SUMC unacceptable, while organizations that represent HCPs were more favorable. Despite this difference, HCPs and their organizations tend to believe that the difficulty of assessing MD-SUMC is a concern, and that concerns around assessing could lead to problems around access.

Dr. Marcoux then commented on the difficulty of being assessed as being eligible for MAID when death is not reasonably foreseeable, as well as the difficulty for physicians to do this practice in this context. She drew on some Dutch studies that have highlighted lack of communication between physicians and patients after the refusal of their MAID request, and noted the difficulties this could pose for physicians, especially if there were threats of suicide, as some people may die by suicide after rejection of a MAID request. She also spoke about grief when death is not reasonably foreseeable and referenced a qualitative study conducted with adult children after one parent died by MAID in Quebec. She finished her presentation by asking what we are doing for those who remain: patients whose request are refused, those in grief when death is not reasonably foreseeable, HCPs uncomfortable with the provision of MAID or HCPs who must compensate for those who refuse to provide MAID? Recommendations include the importance of guidelines for sound clinical and ethical decision-making for MD-SUMC, to address training needs and interdisciplinary work in the context of MD-SUMC, and concrete support measures (self-care days, mentoring, support group, etc.).

5.2 Presentation: Optimizing Policy and Procedures and Enabling Research to Optimize the Care of Patients Requesting Medical Assistance in Dying for Whom Death Is Not Reasonably Foreseeable (‘Track 2’)

*Mona Gupta, Psychiatrist, Centre Hospitalier de l’Université de Montréal (CHUM) Associate Clinical Professor, Département de Psychiatrie et d’Addictologie, l’Université de Montréal*

Dr. Gupta began by addressing the recurring issue of the resource dilemma. She explained that some frame the problem in the following manner: for individuals negatively affected by social determinants of health, modifying those social determinants of health may be hard or impossible, as racism and ableism are structural problems. Where an individual who fulfills eligibility criteria makes a request for MAID, the impacts of social determinants of health may have contributed to or worsened the person’s suffering and incurability, creating moral issues for those involved. If the social determinants of health could have been modified, but the individual never could have accessed supports to modify them for structural reasons, then MAID is morally wrong. And MAID assessments must be done in a way that disallows this possibility. She noted that this is not unique to Track 2, although we tend to focus on it in that context.

In discussing potential approaches to this moral challenge (framed in this manner) she described two possible directions that are often raised:

1. Excluding these individuals, because the constrained choices associated with their structural vulnerability mean they cannot be considered to be making a voluntary choice. They are ‘victims’.
2. Making MAID assessors and providers responsible for addressing problems of someone’s structural vulnerability before finding them eligible.
Dr. Gupta noted that neither of these solutions is appropriate. First, people in positions of structural vulnerability make choices in their medical path all the time. Dr. Gupta discussed how individuals with medical problems and co-existing psychiatric problems already make high-stakes decisions while experiencing vulnerability, and noted that nowhere else in the medical care context are these decisions considered non-voluntary. Second, the expectation that individual MAID practitioners could solve structural issues is unrealistic – if these are structural, then by definition they cannot be solved or undone by individual clinicians.

She pointed out that neither solution works because of how the problem is framed and understood. Instead of framing structural vulnerability as unique to the MAID context, we should think about the issue as we do in other areas of care and draw upon the usual mechanisms to address this issue. For example, HCPs always try to mitigate unmet needs by mobilizing existing resources. A robust MAID coordination service that supports MAID requestors and assessors and providers would be a concrete way to facilitate this work. She referred to this as a key form of ethical support, as it relieves some of the predictable moral tensions. Similarly, as in other areas of practice, slowing down in the assessment process and taking the time necessary to get to know an individual patient and circumstances. This, also allows for greater time for ethical reflection regarding the specific case.

Dr. Gupta noted that practitioners should keep in mind that they are never required to provide MAID if they find it morally wrong to do so. This was addressed directly in the Model Practice Standard and Advice to the Profession documents drafted by the by the Health Canada Task Group on MAID Practice Standards.

5.3 Subsequent discussion

Discussion topics included the 90-day reflection period, and accessing different types of knowledge, particularly accessing knowledge relationally – beyond simply accessing charts. There was discussion on how to mobilize such relational knowledge and to distinguish it from bias. Such Building a Community of Practice would be one means by which to mobilize this knowledge.

A participant asked about how one might mitigate the situation for patients with chronic pain who can’t access specialized services, or patients who choose MAID and refuse to accept the year-long wait for the consultation. This led to a discussion on MAID being an option because of a lack of access to care, to which Dr. Marcoux made observations about the ease of accessing MAID in comparison to accessing palliative care at home.

Dr. Gupta spoke about the importance of developing pathways for care to help MAID requesters gain access to services they need. The MAID system can draw upon the same capacities that allowed for the creation of care pathways for Track 1 requesters.

Dr. van Veen remarked on how the media coverage in Canada was very different from that of the Netherlands. He reiterated the importance of taking time, and noted that 4-6 months of waiting time had worked well in the Netherlands as it allowed for impulsive death requests to be filtered out, but cautioned that a 3 year wait time was too long. He shared examples from patient’s
perspectives that being denied MAID was harmful and insulting, noting that this perspective appeared to be missing in the Canadian media landscape.

There was also discussion about individuals who would be helped by a service for which there is a long waitlist, which would then mean that MAID was not ‘yet’ an option for them.

The discussion concluded with the importance of having conversations earlier, finding a way to bridge conversations to validate an ongoing deliberation process when individuals ultimately make a formal MAID request, and minimizing the possibility of MAID requests arising out of persistent feelings of being unheard or frustrated with systems.

5.4 Key Takeaways from This Panel:

- It is importance to provide training and sensitization of HCPs to what MAID is and what it means for people who are not in Track 1.
- Interdisciplinarity is important, due to the complexity of suffering.
- More concrete support measures for HCPs were recommended, for example self-care days after doing MAID due to emotional difficulty.
- Mentoring and supports are important for HCPs engaged in this work.
- Longstanding problems with social determinants of health cannot become the responsibility of individual MAID assessors and providers.
- People in positions of structural vulnerability make choices about their healthcare all the time – MAID should not be an exception.
- Practitioners should not provide MAID if they feel it is morally wrong to do so.
- Robust supports are required for clinicians making these complex decisions; decisions that should not be rushed

6.0 Session 1 Recap and Stage-Setting for Session 2

The first day’s session was wrapped up by Dr. Thorne, who captured the following themes:

- Complexity, reflecting on different jurisdictions in Canada and also internationally.
- Legal and moral challenges.
- Supporting a workforce of people so they can do robust assessments in a context where trauma and suffering is present.
- Learning from encouraging models and suggestions on how to mitigate challenges.
- How to build systems and formalize these practices to ensure safeguards are fully in place.
- The role of media, as well as trial by social media.
- MD-SUMC being similar but also different to other tracks, and the nuances of nature and degree.

Dr. Thorne concluded that there is much more work to be done and expressed gratitude to the BC Ministry of Health support, and noted that Ministries across Canada will have to be involved to figure out collective roles. She reiterated how Canada poses a unique challenge with its large geography and rural and remote population, which would need to be factored in when learning from other contexts. She noted that the following day’s presentations would touch on continuing discussions for policy and research, and exploring MD-SUMC in a safe, social, ethical, and relational way.
June 1st

7.0 Opening Remarks and Session 1 Recap

Dr. Thorne opened the session and welcomed participants to day 2 of the BBE, recapping the 3.5 intensive hours the previous day filled with presentations, discussion and reflection. Dr. Thorne reminded participants of the acknowledgement of the land that Laurel Plewes had given on Day 1, bringing listeners into reflection on our relationship to the land and our responsibilities to the land. She invited all participants to take a moment to reflect on our individual relationship to the land.

She introduced the first two presenters to provide a summary of themes that arose, and provide an idea of where we are and where we are going.

8.0 Panel 4: Moving Evidence into Policy

Objective: To ascertain how to integrate research into the development of policy as MAID evolves

8.1 Presentation: Moving Evidence into Policy (Part 1)

Barbara Pesut, Professor, School of Nursing, University of British Columbia Okanagan

Dr. Pesut reviewed evidence from the literature, identifying the policy issues from the previous day’s presentations as well as those that had not yet arisen. She explained that this context would be important in articulating the main priorities for developing research.

Dr. Pesut presented results from a rapid review conducted in March 2023, focusing on MAID where death was not reasonably foreseeable. Although the review was limited (theoretical articles not included), it yielded insight about seven aspects.

1. Protocols, Guidelines and Processes (2 Studies)

Dr. Pesut highlighted 3 important criteria in the Ghent University hospital protocol: 1) Ethics committee review, 2) two positive assessments from psychiatrists, and 3) involvement of the treating physician, which was mentioned in Dr. Chambaere’s presentation on the previous day. An analysis of 5 Belgian guidelines was reminiscent of Dr. van Veen’s presentation, and highlighted additional safeguards. This material also aligned with themes from the previous day about non-abandonment of patients, as well as involvement of many people, including family, which would be a significant deviation from current experiences in BC.

2. Capacity Evaluation (2 Studies):
One study from the Netherlands was a retrospective review about capacity, while another from Belgium consisted of interviews with physicians, finding differences across physicians in how they prioritized communication, understanding, appreciation and reasoning.

3. Characteristics of Clients (7 Studies):

These studies reflected characteristics gleaned from retrospective chart reviews. Of concern were that the majority of requests had been from women, although the percentage of requests granted were low (around 2-5%, usually because of not meeting due care criteria). The articles reviewed found that the entire procedure typically took 14 months, similar to what the presenters from the previous day had mentioned. Significantly, many clients had comorbid conditions.

4. Irremediable Suffering (2 Studies):

Dr. Pesut highlighted a Delphi study of Dutch and Belgian experts which focused on the need for clear attempts at treatment, suffering that had been present for several years, and evidence of efforts to improve the social situation. A challenge was comorbidity, which impacted evidence-based treatment guidelines. Dr. Pesut noted that, in the Canadian context, suffering will be self-defined by the patient, but must also be identifiable to the clinician.

5. Client Perspectives (5 Studies):

These studies documented patient autonomy, the desire to end suffering, a wish for a dignified end of life, recognition of experience, treatment burden (iatrogenic suffering) and social suffering as featuring in patient decisions to seek MAID. Studies showed how taking the request seriously and subsequent discussion can open up new possibilities for their situation, leading to hope and meaning. One intriguing finding was the degree of ambivalence from requestors.

6. Family Perspectives (3 Studies):

These studies were about family experiences, highlighting key topics around ambivalence, isolation, misunderstanding, awareness and involvement desire, and how grief with MAID may be less than suicide. Dr. Pesut noted that this topic had not been addressed at any length in the first day of our discussions.

7. HCP Perspectives (3 Studies):

One study of psychiatric nurses in Belgium highlighted a perceived lack of information and skills, and a great need for more information. A Canadian survey of psychiatrists published in 2017 showed 29.4% supportive of MD-SUMC, and Dutch psychiatrists indicated a range of divergence of opinion in the studies examined.

Dr. Pesut discussed important future research questions, noting that little is known about MAID in relation to Indigenous peoples. She also noted the role of Registered Nurses
(RNs), highlighting how nurses will become increasingly important in Track 2 as they act as pre-screeners, coordinators, and navigators. She concluded with a broad question, inviting participants to discuss how it can be ensured that nurses are included as full team members, what are unique ways to expand that role, what more needs to know about that role, and what priorities in the BC context are.

8.2 Subsequent Discussion

Participants noted a range of potential topics for future research, including:

- Why a high number of psychiatrists presented in one study were not in support of MD-SUMC,
- Concerns in the literature about the concept of consent, particularly in the Netherlands,
- Special context of individuals with autism spectrum disorder,
- Barriers to access to MAID for people on Track 2,
- Data on institutions that don’t allow MAID to be provided on premises.

Participants also discussed challenges associated with MAID Track 2. These included:

- Lengthy assessment processes,
- Shortages of providers and assessors,
- Threats of harassment that providers or assessors can face,
- The difficulty of quantifying or measuring suffering.

We need critical analysis of survey results, as the positioning of questions can sometimes be biased, which needs to be taken into consideration. Therefore, it will be important to focus attention on accurately formulating surveys that could yield statistically accurate and meaningful information.

The importance of formally tracking access to care was noted. Other data that would be helpful include retrospective data around Track 2 to date, and interviewing individuals or families waiting for MAID.

A number of issues also arose involving health care team roles:

- The unique position of psychiatrists was noted, as they often deal with individuals who want to die, which is not the case for other specialties. There is a need for research that probes into where anxiety and challenges are present for psychiatrists who are not supportive of MD-SUMC, with caution not to homogenize the entire psychiatrist population, as wide variations exist, and these variations make quantification problematic. There was also discussion on whether thresholds used in other country contexts such as Belgium would be directly applicable or usable in the Canadian context. Unique challenges will be associated with rural and remote vs. metropolitan sites in the Canadian context. Psychiatrists feel very concerned about lack of definitions around irremediability and the lack of evidence for evidence-based practice in this regard. Assessment of suicidality is also a concern. Survey results show overwhelming support for learning more about MD-
SUMC, indicating openness about wanting to learn more, including about the role of psychiatry.

- The role of nurses acting as pre-screeners was discussed, recognizing that nurses in BC, as outlined in guidelines, cannot serve as assessors. While social workers, nurses and care coordinators do play a role in easing the burden on assessors, they cannot make a determination of eligibility. If there was a way for nurses to have a screening tool where they can help or assist but not actually do an assessment, that could be helpful, but their role should not be to bar someone from proceeding with an assessment. Other ideas were discussed for facilitating triage or team-based pre-assessment. For example, if someone who doesn’t meet the age criteria inquiries about MAID, nurses could determine ineligibility.

8.3 Presentation: Moving Evidence into Policy (Part 2)

*Michael McKenzie, Medical Assistance in Dying Medical Director, Provincial Health Services Authority and Radiation Oncologist, BC Cancer-Vancouver*

Dr. McKenzie highlighted how Track 2 work necessitates a different approach from Track 1. His presentation considered various policy issues we are facing as we move forward with Track 2.

**Policy Issue 1:** What is needed to support front line providers caring for patients requesting MAID Track 2?

- a. How do we make MAID a shared responsibility so that complexity is not borne by one clinician?
- b. What concrete support measures should we put in place to support MAID clinicians?
- c. How should we address educational needs of all healthcare professionals, including those involved in MAID care?
- d. How might we develop communities of practice?

Dr. McKenzie explained that the above issues could be addressed in Health Authorities across Canadian provinces. He further highlighted the importance of the process of assessment being safe, referring to the assessments themselves as being dynamic, lengthy, and requiring dialogue and reflection with family and other providers. Dr. McKenzie echoed previous presenters who noted that MD-SUMC will not be as straightforward a process as Track 1 MAID. He emphasized reflection being important, and the need to take time to enable reflection. Dr. McKenzie linked this back to the importance of teams, which was another strong theme from the previous presentations.

**Policy Issue 2:** What processes are needed to ensure the safety of assessment of patients requesting MAID Track 2 Mental Disorder as the Sole Underlying Medical Condition (MD-SUMC)?

- a. How do we establish that a patient has ‘terminal psychiatric illness’?
- b. How do we facilitate addressing vulnerabilities such as unstable housing and poverty?
- c. What is needed to ensure equity of MAID care of those from underserved communities?
- d. How do we approach ‘doctor shopping’?
e. How might we incorporate an additional mental health assessment of patients requesting MAID?

Policy Issue 3: What structures are needed to optimize the quality of care of patients requesting MAID Track 2?

a. How do we develop and implement a team-based approach?

b. What do we need to develop and implement to ensure equity of MAID care of patients living in rural and remote communities?

c. What use might we make of an ‘Expert Centre in MAID’ model and how would we mitigate the impact this might have on the attitudes of health care providers elsewhere?

d. What do we need to put in place to monitor post-provision the appropriateness and quality of MAID care?

A discussion point was raised about the importance of careful post-provision review, with consideration of who to involve in that review. Policy Issues 2 and 3 also created discussion among participants about expert centres that exist in other countries such as the Netherlands, with questions around whether this is something that should be considered in Canada, and what the unintended consequences of this strategy might be. Participants raised further questions about MAID for patients or families coming from rural and remote locations, or for individuals who are housing unstable and other vulnerable groups.

Policy Issue 4: What is needed to support patients requesting MAID Track 2 and their families?

a. What use might we make of peer support models for patients and families?

b. What do we need to put in place to support patients deemed ineligible?

c. What is needed to ensure that previous trauma is identified and that appropriate support for it is provided?

d. What is needed to incorporate consideration of family dynamics into MAID care?

Both presenters emphasized systematizing across Health Authorities, and considering various forms of trauma, including those relating to family, colonialism, and the health care system as directions for ongoing consideration. To conclude, the presenters noted that this discussion would continue in the small group session oriented around two main questions: What policies, structures, and systems are needed to be put in place to ensure safety? And what research is required to inform and support ongoing policy direction?

9.0 Small Group Discussion (1 Hour)

Dr. Thorne explained the breakout group process. She introduced the moderators for each of the four breakout groups as well as the assigned notetakers. She explained that moderators had each been assigned one of four main questions to discuss in small groups, and how they would share highlights of what each group discussed when the group returned to the main plenary session. While this ensured a focus on each of the main questions, each group was welcome to also include discussion of the other questions, time and interest permitting.
Small Group Moderators:

- Vijay Seethapathy, Chief Medical Officer, Provincial Health Services Authority
- Laurel Plewes, Director of the Assisted Dying Program, Vancouver Coastal Health
- Julia Gill, Ethicist, Vancouver Coastal Health; Adjunct Lecturer, Clinical Public Health Division, Dalla Lana School of Public Health
- Tammy Dyson, Regional Lead, Medical Assistance in Dying (MAiD), Fraser Health Authority

Discussion Questions:

1. What is needed to support frontline providers caring for patients requesting MAID Track 2?
2. What processes do we need to implement to ensure safety of assessment of patients requesting MAID Track 2 MD-SUMC?
3. What structures are needed to ensure the quality of care of patients requesting MAID Track 2 MD-SUMC?
4. What is needed to support patients requesting MAID Track 2 and their families?

Each of the four questions had the same two sub-questions to probe further in discussion groups:

- What policies/structures/systems are needed?
- What research is required to inform/support ongoing policy direction?

Key points are reported here. More detailed discussion comments are located in Appendix 1.

9.1 Group 1

1. What is needed to support frontline providers caring for patients requesting MAID Track 2?
   • What policies/structures/systems are needed?
   • What research is required to inform/support ongoing policy direction?

Vijay Seethapathy reported back to the plenary. The group discussed the importance of interdisciplinary teams and the different models for operationalizing and making them more achievable. Interdisciplinary teams were discussed as one of the tools providers will need to engage in these cases, keeping in mind the variability of availability from one Health Authority to the next. Certain Health Authorities don’t have formal structures, and so recommendations for looking to model those structures after other health authorities were made. Group discussion also highlighted the issues of billing and lack of assessor interest, and the importance of addressing these issues.

Key Points:
Multidisciplinary teams are important, as is involving the patient’s care team, particularly in cases involving Track 2 patients. Different members of the team, such as social workers, can assist in accessing supports for patients. Robust training would be a key part of team-based care.

Discussion of models from Belgium highlighted differences between regions, the importance of uniformity in training and guidelines, and some caution about expertise centres in relation to potential long wait times.

Billing is a major issue, as well as the pay gap between physicians and Nurse Practitioners doing the same work. Support from the Ministry of Health on billing would be important to address with regards to providing justifications for going over caps, as the current pay structure is a major deterrent to anyone considering taking on these cases. Billing schemes for psychiatrists were also mentioned.

Standardization is important, and practitioners require knowledge and training in the gold standard of assessment.

Grief needs to be considered. If families are not looped in, it can be a traumatic sudden death for them. Grief for the patient between the finding of eligibility and the actual provision was also discussed as a consideration.

Peer support for clients and their families, support for clinicians in the form of CoP, and appropriate remuneration in recognition of the amount of time required for Track 2 are key to addressing challenges such as the complexity of Track 2 assessments, and the lack of interest from assessors.

9.2 Group 2

2. What processes do we need to implement to ensure safety of assessment of patients requesting MAID Track 2 MD-SUMC?

- What policies/structures/systems are needed?
- What research is required to inform/support ongoing policy direction?

Laurel Plewes reported back in the plenary. The group discussed first and foremost that all work needed to be grounded in humility and culturally safe care, not just for MD-SUMC but MAID in general. A question was brought up about whether there was a definition of terminal psychiatric illness, with request for clarification if this is to be considered an understandable concept. Structural vulnerabilities in these cases were also mentioned.

Suggestions included a more specific psychosocial evaluation to help understand what a person is going through, potentially provide peer support, and navigators to help individuals identifying as Indigenous. The group discussed a range of topics, including capacity assessment and ensuring their consistency. There were also suggestions about a review process or panel, where a support system and network can assist an individual through any process, to help understand what the person has been experiencing. This was discussed as something that would be external to the MAID team and which would reduce moral distress for family and patients. A central tracking system was also discussed to avoid MAID assessment ‘shopping’, in order to see if requests for MAID have occurred prior.
In terms of the research required to inform ongoing policy, the group discussed a centralized resource to ensure provision of informed care. Research, quality, and innovation were discussed, as well as looking to the Netherlands’ 5-year research cycle, current Track 2 patients and what barriers they experienced, general patient experiences, and services they can access, and further research for those not found eligible.

**Key Points:**

- There is a need to provide MAID-specific education within MAID team, potentially shifting roles and responsibilities to people extern to MAID teams.
- There is a need to provide education and support to medical staff outside of MAID teams.
- A definition of terminal psychiatric illness is required if the idea is to be relevant.
- If external panels are created, these should not become additional barriers. Clarification would be required for any questions around where shared decision-making would be situated within our legal framework.
- Processes need to be trauma-informed, and ensure peer involvement in this process.
- An Indigenous navigator model may be necessary to ensure Indigenous patients are appropriately supported.
- There is need for clarity when patients initially enter the MAID process, and it is important to create guidelines for patients seeking multiple assessments.
- Approval by a review panel may be important; however, such a panel should not be approving or dismissing cases, but rather seen as ‘circle of support’.
- A centralized resource is needed, and it should be funded to ensure research, quality, and equity, looking to the Netherlands as an example.

**9.3 Group 3**

3. What structures are needed to ensure the quality of care of patients requesting MAID Track 2 MD-SUMC?

- What policies/structures/systems are needed?
- What research is required to inform/support ongoing policy direction?

Julia Gill reported back in the plenary. She highlighted key takeaways of this group, that included assuring quality of care of mental health services in general. Underfunding and lack of resources for mental health programs creates ethical tensions and questions, particularly in the context of rural and remote care. At a structural level, the sharing of resources across Health Authorities, academia, and internationally was discussed, along with probes about data privacy.

The group also discussed the importance of specific language and precise wording, as ‘mental illness’ or ‘mental disorder’ may not accurately capture diverse diagnoses, and the tendency to refer to ‘mental health’ can confuse the issue. Better guidance and benchmarks for irremediability were discussed.

In terms of the research topics required to inform policy, the group discussed whether certain provinces such as British Columbia would be in a position to have a CIHR grant to do MAID
research for Track 2 immediately, and whether a large umbrella grant might ask a range of important questions for the purpose of ensuring quality of care for patients.

The group raised as high priorities for research questions around equity, why individuals are accessing MAID, the experience of waiting for MAID, barriers to accessing mental health resources, and other aspects leading up to accessing MAID. Other research areas would include what gaps exist in care, especially mental health resources that need to be put in place to ensure a support.

A specific question around IV versus prescription also came up in the group discussion as a possible research topic.

Comprehensive holistic care is necessary for all Track 2 patients. The fee-for-service structure could disincentivize such care as it pushes for quick services rather than those that are drawn out over a longer time.

Key Points:

- Sharing of resources (data privacy, experts, etc.) was discussed, emphasizing that if a patient declines access to information, it cannot be shared.
- MAID should not be given precedence over other medical services, and providers need to be unafraid to say “no”. Other medical services have wait times. Furthermore, there was emphasis on ensuring that lack of access to services does not become a reason to access MAID.
- There is a need for a clear diagnosis, a course of treatment that leads to a diagnosis, understanding how this leads to a definition of irremediability, and ultimately better descriptions of this for professionals.
- There is also a need to better understand the team that could be implemented to fully serve these patients to come to a reliable conclusion.
- Better, more precise wording (e.g., major psychiatric illness) is required so that refining care and benchmarks, guidance, and definition of irremediability can occur.
- Rural areas were highlighted as a challenge, along with psychiatrists not being enthusiastic about involvement.
- Appropriate funding is required for effectively resourcing a team to do quality work, which will require careful consideration given the under-resourcing of mental health supports. This also includes examining the fee-for-service structure.
- Benchmarks and basic standards of care are needed. A minimum standard of care for the province was noted as something important to have before developing more sophisticated quality standards.
- The importance of involving families in the care was mentioned, as well as concern around a broken mental health system Canada-wide.
- Research is required to develop high standards and quality goals, and also to understand factors influencing individuals to seek end of life.

9.4 Group 4
4. What is needed to support patients requesting MAID Track 2 and their families?

- What policies/structures/systems are needed?
- What research is required to inform/support ongoing policy direction?

Tammy Dyson reported back in the plenary. She spoke about the group discussion on a continuum of support for practitioners, families and patients. There was discussion on patients being supported in their suffering, engaging in conversations on safety and how it’s connected to suicide. She reported how the group also discussed insights from the Netherlands on how to support patients and families.

Aftercare was discussed as key, including after determining eligibility as well as after death. Supporting patients also meant examining the role and rate of suicide of individuals who die by suicide during and after the assessment process, with patient engagement as they live through the assessment process considered essential. Further topics included providing education to patients about what the process looks like, including family in the assessment, and a case management model to improve access. Information and support for suicide hotlines for consistency in information about suicide were also discussed.

In terms of research, topics were proposed around suicide, transparent reporting, and what happens when a patient refuses treatment and what that means for different assessors. A case management model could extend capacity for a primary care provider because case management can occur over time. Other topics around studying and analyzing anonymized reports and gaining clarity on how to ‘measure’ conversations with patients were discussed, as well as measuring variability of assessments.

Key Points:

- Support for practitioners as well as families in a continuum of support meant that supporting practitioners also meant supporting patients and families.
- Support for practitioners:
  - Given the small number of assessors and providers, GPs can easily opt out. A stronger policy about the primary care provider would be helpful.
  - Case management – it is important to ensure that the bulk of work is not left to one person alone.
  - An example was given of a system where, every 2 weeks, clinicians can meet and share psychological and emotional support around all aspects of this work, potentially including a psychiatrist in that meeting.
  - Assessors may benefit from working in collaboration with RNs or social workers who take on case management roles in various settings, so that individuals experiencing social issues are always connected with support. Although the administrative work associated with that may necessitated additional support staff in such settings, if assessors do not have this support, this may contribute to unwillingness to take on these Track 2 cases. When other HCPs engage in the process, work and burden can be distributed more evenly.
Structures and challenges can be anticipated in Canada from looking at examples from the Netherlands and Belgium.

- One example of preparation could be to create scripts and contact suicide prevention hotlines so that the volunteers receive training and information to provide nuanced and balanced information about MAID.
- Harm can take place when there is no aftercare, so this is an important component post-assessment.
- The family should not be forgotten in the process. Support groups and networks for families connected to psychiatric MAID will be important.
- Reports can be studied, but require transparent reporting. Having access to anonymized reports may be a rich source for researchers to expand our knowledge.
- Research may also be needed to understand the variability of raters or assessors.

9.5 Wrap-Up of Group Discussion

Groups were given 40 minutes to report back and for further discussion. Some of the topics raised in this wrap-up session included the following:

The term ‘terminal psychiatric suffering’, along with the term ‘irremediability’ as possibly a more neutral term.

Suggestions of ethnographic, longitudinal research, including following-up with patients, families, and HCPs for the entire process was proposed.

Discussion also highlighted the need for research to create policy and structure, including research into variability of ideas among assessors, quality and performance, and what leads to end-of-life decisions. Research on social determinants, trauma, gaps in care and expectations around wait times is needed, as well as reasons why people do or do not choose to provide MAID.

The educational needs of HCPs were emphasized, as was the idea of creating a safe system for all concerned. The discussion raised the importance of HCPs not doing the work alone, and reiterating the importance of a circle of support not just to discuss eligibility criteria, but as a community of practice.

Participants considered a number of concerns around data collection and the need for more standardized data, noting the complexities around privacy rules and making data accessible. The idea of making BC into a centre of excellence for MAID research attracted some enthusiasm.

Capitalizing on the role of nurses, given their roles as coordinators and on the front line of practice in settings that serve Track 2 patients was supported. The lack of visibility of these roles within current MAID practice standards was noted, given the particular expertise they could bring to the complex assessment processes we face when MAID is requested. Participants brainstormed ways of using pre-existing nursing roles and expanded roles to maximize case management. For innovation and optimization of the MAID assessment and provision processes across Track 2, involvement of teams that extend beyond current assessors and providers will be important.
10.0 Closing Remarks

10.1 Dr. Thorne:

Dr. Thorne thanked the presenters for synthesizing so much complexity, and thanked participants for their observations and insights, as well as for the profound and difficult questions raised in the sessions. She noted that this was a remarkable opportunity for BC at this very critical time in this evolution of MAID practice. She closed by thanking the BC planning team for placing their trust in the CIHR Best Brains Exchange to support policy development as we collectively tackle this challenge.

10.2 Razvan Diacu, BC MoH:

Razvan Diacu, Director of Acute Care Policy, Programs and MAiD, made closing remarks. He thanked the planning team and moderators for ensuring the smooth running of the BBE, and thanked colleagues at CIHR for support, as well as all speakers and participants for making this fulsome dialogue possible. He spoke to the eye-opening nature of delving into these issues and hearing from experts in BC, Canada, and the world who are on front lines of this high-stakes and entirely new area of practice. Razvan Diacu observed that many topics and details came out of the presentations that will clearly be important as Canada prepares for the upcoming expansion.

Razvan Diacu noted that the wide range of expertise in the BBE process had allowed for all participants to gain new insights and perspectives from the discussions. He spoke about how many different members of the health care system are now preparing for the expansion of the legislation, and considering what new safeguards are needed for MD-SUMC. He noted that other governmental groups are also looking at operational issues relating to oversight, care coordination centres, responsibilities for service delivery and supporting patients and practitioners. The BC MoH has responsibility to set the framework for MAID at the provincial level and for providing oversight. Work is currently underway, and the takeaway insights from this BBE will be informing work in developing safeguards, oversights, QA, and resources to ensure that MD-SUMC is provided in a safe, appropriate, consistent manner. The evolving dialogue will inform our future research agenda so we can continue to learn and improve our processes over time.

11.0 Additional Links

The following additional links were shared in the chat:

1. Model Practice Standard for Medical Assistance in Dying (MAID) – Canada.ca


   https://www.canada.ca/content/dam/hc-sc/documents/services/medical-assistance-dying/advice-profession/advice-profession.pdf
2. The Abuse of Casuistry suggested by Dr. Lachmann


3. “Practical help guides” discussed by Dr. van Veen

https://dejongepsychiater.nl/thema-s/recht/eerste-hulp-bij-psychiatrische-euthanasieverzoeken/#:~:text=Bel%200800%2D0113%20of%20chat,7%20open%2C%20anoniem%20en%20vertrouwelijk

4. Dr. van Veen’s Ph.D. thesis on irremediable suffering. The art of letting go: A study on irremediable psychiatric suffering in the context of physician assisted death.

https://books.gildeprint.nl/thesis/575842-vanveen/
References

Angus Reid Institute. Mental health and MAiD: Canadians question looming changes to Canada’s assisted-death law [Internet]. 2023 Feb 13 [cited 2023 Jul 11]. Available from: https://angusreid.org/assisted-dying-maid-mental-health/


Lengvenyte A, Strumila R, Courtet P, Kim SYH, Olié E. “Nothing hurts less than being dead”: psychological pain in case descriptions of psychiatric euthanasia and assisted suicide from the Netherlands: « rien ne fait moins mal qu’être mort »: la douleur psychologique dans les descriptions de cas d’euthanasie et de suicide assisté psychiatrique aux Pays-Bas.


Appendix 1: Additional Comments from Group Discussions

Group 1. What is needed to support frontline providers caring for patients requesting MAID Track 2?

- What policies/structures/systems are needed?
- What research is required to inform/support ongoing policy direction?

Further Notes from the Discussion:

- The importance of multi- and interdisciplinary teams was emphasized given the relevance of social determinants of health for Track 2 patients. An example from Quebec was given about the usage of interdisciplinary group support to healthcare professionals (mainly physicians) with assessment of a given case, including ethicists, family physicians, nurses, specialists, social workers. Each of these groups can provide important advice or insight depending on the unique situation and the specialty that would be involved.
- Lessons that could be learned from areas outside of MAID were also discussed. For example, pre-gathering, screening, and summarizing information before collaborating with a psychiatrist could be a more efficient usage of psychiatrist time.
- The amount of time required of health care professionals for Track 2 was discussed, particularly in relation to the struggle with billing. While Track 1 cases may be discernable from one interview, Track 2 cases can take much more time, and the amount of time required is not appropriately considered in billing.
- Applying legal criteria was discussed, as was the concern that many patients do not have a GP or care team that they are connected with, which can lead to more time delays. Education and encouraging practitioners in their learning processes was also noted as important, given the mental health co-morbidity common for Track 2 MAID requestors, and the importance of connecting them to psychiatric care.
- A lack of regulatory support was mentioned, as was the need for uniformity of training and guidelines as well as regional variability.
- Noting the context of Canada, whether implementing multidisciplinary expertise centres in major cities would be feasible was considered, given examples from Belgium where such centres created a lack of confidence in psychiatrists and physicians knowing what would and would not be perceived as good practice by their peers.
- Training modules before someone can provide MAID were discussed.
- Impartiality and trust can be fostered through interdisciplinary cooperation which provides a range of expertise.
- Different members of the team, such as social workers, can assist in accessing some types of social supports beyond medical supports. Currently, if teams are involved, it is important to make sure their perspectives are valued and their opinions taken into account. Health Canada’s Task Group has developed practice standards.
- The question of how to support front-line providers was brought up, and standardization was discussed. An example from Manitoba was given, where a team assists individuals who have not been found eligible.
- In order to mitigate provider burnout, the psycho-social-spiritual dimension of care was also mentioned in the capacity of grief supports for families to deal with trauma.
• A community of practice model or network can also be an important support. Support was discussed not only in terms of for providers, but also supporting the families and caregivers.

• The role of interdisciplinary teams was discussed, as well as onboarding, training, discussion, grief modules as part of dissemination. Interdisciplinary care teams’ remuneration was also discussed, as well as the role of existing community groups and how they might be remunerated.

• A CoP or network model was discussed as a possible BC provincial approach.

• Some cautionary discussion about the role of expertise centres, as well as the potential of longer wait times.

• The importance of providing access, although no one is obliged to provide MAID

• Housing, poverty, and inequality remain complex challenges potentially contributing to a MAID request for Track 2 cases in particular.

Group 2. What processes do we need to implement to ensure safety of assessment of patients requesting MAID Track 2 MD-SUMC?

• What policies/structures/systems are needed?

• What research is required to inform/support ongoing policy direction?

Further Notes from the Discussion:

• Expert case review panels were discussed. These wouldn’t have responsibility, but play a shared role in assessment. Expert case review panels could help build resilience and moral distress for prescribers, for them to feel confident that the case does not hinge on just their opinion but a group that is there to provide their opinion. This could also provide more nuance and detail.

• Language matters. We need to reflect on whether or not to use terminology such as ‘terminal psychiatric illness’ as these choices have different meanings and political connotations for various groups.

• There was suggestion of a panel overseeing aspects, such as limiting the number of psychiatrists that can be seen, as a safeguard. This could lead to potential legal challenges. Given the hierarchy of law (federal, provincial/territorial (including colleges)), the panel could potentially operate at a provincial level, with Colleges helping with clarification on trickier ground, recognizing that all would be subject to constitutional challenges.

• Additional supports for Indigenous communities could include:
  o HAs doing an engagement process with Indigenous communities and organizations across the country. Extensive feedback to CAMAP curriculum, trauma-informed approaches, considering vulnerabilities and precarious social situations when doing assessments, acknowledging and understanding racism as a reason to not engage in the HC system.
  o MAID is new concept for Indigenous communities, engaging with FN navigators in HAs would help. The need to engage psychiatry and psychiatric nurses to understand upcoming changes was also discussed.
Vancouver Coastal Health is partnering with Indigenous Health to create a position that creates an engagement strategy to engage with the 14 Nations, as well as urban Indigenous youth, and Metis communities.

- The group discussed potential shared decision-making processes in a review panel, and if the role recommends but doesn’t require, providers will not go ahead without the recommendation from committee.
- Questions arose about potential entanglement with Charter rights issues, access to supports for clinicians seeking consultation and formal consults, and issues arising from creating barriers.
- It is important to not stigmatize mental disorders, with a need to distinguish between terminal and whether mental disorder is incurable or not. The idea of trying to manage patients seeking multiple assessments could be paternalistic. Without evidence that clinicians are saying yes to those who are not eligible, ‘rationing’ healthcare would need to be done ethically. The MAID system can say that a certain number of assessments can be done within time period, but this would have to be due to lack of resources, not a paternalistic rationale.
- The stigma experienced by people with mental illness cannot be underestimated. There are differences in the episodic nature of those illness, and concerns from cases that have arisen in other countries with individuals with intellectual disabilities who were turned down by multiple assessors and continued seeking approval until an assessor granted it. There are differences of perspective as to whether those with mental health diagnoses experience more barriers than other Track 2 cases.
- Thinking outside the box in terms of resourcing in relation to the wider context of social determinants of health was also discussed. Psychosocial aspects could provide more security, but there are serious limitations for a health authority in providing supports such as housing. A review panel would be helpful, given the exceptionally thin amount of data, information, narrative data, and lack of oversight system currently in place.
- Regarding rural and remote cases and concerns about virtual assessments not being ideal for complex cases, the common feeling among Track 2 assessments being more effective when done in-person was discussed. This was highlighted as an important area of recognition and for the Ministry to understand this. The idea of a centralized MAID program was challenged given the potential for hubs that would be inaccessible to rural areas in the context of Canada’s geographic distribution.
- The group noted that Track 2 cases have not been sudden decisions, but rather individuals experiencing suffering and decline over a long period of time. It is important to understand their experiences. A potential research component could be doing detailed interviews prior to provision, comparing these patients with those not accepted, to see differences between complex requestors.
- Other related topics included:
  - Lack of post-provision case review done outside of the ministry at provincial level.
  - Learning from the Netherlands to set up a more robust system for post-case review processes that could inform policy changes in the future.
  - For individuals not accepted for MAID, particularly with mental illness, it would be important to track what was done to improve their situation and/or whether they request again after a certain period of time. Commonalities among requestors could be studied.
Looking at Belgium and the Netherlands in terms of research funding, the 5-year review funded by government was mentioned as a positive example.

- Capacity concerns around ensuring expertise for assessment.
- Other intersectional issues for Track 2 research include other potentially more vulnerable groups, such as transgender individuals.
- Research having a broad reach was discussed, with the importance of capturing a variety of voices on the complex issues surrounding MAID.

- One suggestion was creating and funding a formally convened group acting as a centralized resource for the province, with the purpose of improving processes, ensuring quality and research. Questions arose concerning who would fund this. Gathering information to inform policy was also highlighted to help inform decision-makers and influence the system.

### Group 3. What structures are needed to ensure the quality of care of patients requesting MAID Track 2 MD-SUMC?

- What policies/structures/systems are needed?
- What research is required to inform/support ongoing policy direction?

### Further Notes from the Discussion:

- The group discussed (1) The challenge with mental disorder (MD) is the biopsychosocial nature of it. Several needs were outlined, including the need for: a clear diagnosis, a course of treatment that leads to a diagnosis, understanding how this leads to a definition of irremediability, and ultimately better descriptions of this for professionals. (2) The need to better understand the team that could be implemented to fully serve these patients and to come to a reliable conclusion as to eligibility.
- In a team-based setting, there is going to be a significant responsibility with ensuring that the care and the information is coordinated and collated.
- Appropriate funding is required for effectively resourcing a team to do a quality work, which will require careful consideration given the under-resourcing of mental health supports.
- Basic mental health care being difficult to access was discussed. Boundaries for HCPs were also discussed in the context of this service not having to be an emergency, HCPs being able to say ‘no’, and uncertainties about data sharing.
- Monitoring pre-MAID was mentioned as important.
- Several contextual concerns were brought up, particularly the lack of human resources post-pandemic to provide health care services, with concern that lack of preparedness can potentially cause harm.
- At CAMAP, the Physicians and Surgeons College registrar made a presentation that they were hoping that common requirements could be seen across the country. In BC, we potentially have a system where a provider can present to a panel before MAID is provided to help them make decisions. This would not be yes or no, but a support.
- In Canada, some of our mental health legislation and decisions are rudimentary and do not provide much of a starting point. E.g., Starson v Swayze decision.
- The MAID process is an open and safe-space for individuals to discuss their situation and their preferences for dying. Not all of these patients will go on to receive MAID. The MAID process is about providing options and coming to conclusions. However, approaching this as a holistic assessment, rather than a purely medical assessment is important.
  - In terms of supports and guidance, serial and sequential assessments.
  - Some providers are worried about autonomy or coercion.
  - BC is well-organized and should have this research as CIHR-funded research, so that it begins as soon as MAID for MD-SUMC is allowable, so that these standards and quality goals can be fully realized and improved over time.
- Research is needed into quality and performance, as well as research on what leads to end of life decisions, including research on social determinants, trauma, and other issues. Research on gaps in care, expectations around wait times, reasons why people choose to provide MAID or not, and longitudinal research would also be useful.

**Group 4. What is needed to support patients requesting MAID Track 2 and their families?**

- What policies/structures/systems are needed?
- What research is required to inform/support ongoing policy direction?

**Further Notes from the Discussion:**

- It would be helpful if primary care providers were responsible for starting that conversation and exploring the reasons for a patient’s request, and ensuring appropriate medical consultations are included even before a maid assessment goes forward. GPs do that assessment, but in BC there is a small number of assessors and providers, and GPs can easily opt out. Given the GP shortage as well, a stronger policy about the primary care provider being integral to that would be helpful.
- Case management is really important, as BBE speakers have mentioned the burdens on psychiatrists in the Netherlands and Belgium, given the lengthy process to alleviate suffering and complex SDoH. HCPs require support in order to provide care and ensure patients and families are supported. Potential of using nurses’ roles discussed. Anticipating and mitigating problems before they happen is important, as is recognizing this is not a simple process of determining eligibility or ineligibility. This is a complex process engaging in all parts of the health care system, and the case management component is key.
- Not everyone will be eligible and this can increase risk of suicide. Alleviating suffering might be a role in and of itself. Alleviating suffering and putting effort and focus into this discussion can mitigate potential problems, given the shortage of physicians and backlogs of mental health services.
- Knowing there is additional support, like a panel where HCPs can discuss, makes it less daunting so that HCPs know they alone do not have to hold one person’s suffering.
- Leveraging existing teams will be essential to support HCPs so they do not have to work alone.
- Track 2 screening will require a large amount of work, and the impact on clinical and support staff will be strong. The impact is felt by GPs and assessors, as the system is interconnected.
• Policy to support individuals and their families is connected to supporting clinicians to build a community, provide space for clinicians to discuss emotional and practical questions. Support for individuals going through a request and being found ineligible will also require policy, and this may be enhanced through insights that come from informal or formal case reviews.

• In terms of directly supporting patients, there was discussion on how with psychiatric patients, suicidality and MAID requests are often interlinked. An example from the Netherlands was discussed about the ECE waiting lists getting longer, and at the same time more suicides occurring for patients wanting MAID. When individuals make a MAID request, it was mentioned that this is a moment to try and direct them to suicide prevention therapy where it paradoxically might mean that they are being supported to survive the assessment period, so that they may die humanely via MAID. Families are generally open to this, and so the paradox of suicide prevention therapy in MAID requests must become a topic for ongoing discussion.

• Being on a MAID waitlist after the process of asking for MAID can be stressful and can increase suicidality, and long wait lists can increase risk of suicidality, which all relates to the process being difficult for patients. Another group at high risk of suicide are those who have been refused MAID. The ECE in Netherlands does the majority of MAID assessments in country, but because they’re so busy they have no aftercare for the patients that are refused, and patients have to go back to their own care providers. This is where a lot of harm can take place. If designing a system anew, it is important to be mindful of that aftercare component.

• Another example from supporting patients in the Netherlands provided insight into the confusion and lack of information patients receive, where MAID for MD-SUMC is expected to be quickly and readily accessible.

• Regarding support for family, there was discussion on how family often wants to be involved, and that often family supports patients, with it being rare that the family rejects it. The family should not be forgotten in the process. In psychiatric MAID, family members of a loved one who has received MAID can find support groups and networks. Another anticipation for MD-SUMC is age of patients being lower, so parents losing their children to MAID may occur. As a result, peer support networks have been a positive development in the Netherlands as they are empowering and a voice in public debate. If there are ways to start or support these peer support groups and networks, this can be helpful in Canada.

• The distinction between MAID and suicide was discussed, with the connection between impulsivity of suicide vs. MAID being made.

• Patient reactions including anger were discussed, attributed to the lengthy waiting and the difficulty of the process, as the due diligence can feel insulting to patients, although clinicians support these so-called ‘hoops’.

• A question was asked about how to mitigate high-profile media cases when family has disagreed with the patient, or the patient has not informed family. There was consensus that it is not always preventable, as people can be very angry about family members. Assessments in psychiatry around irremediability requires family, and some psychiatrists won’t proceed without an assessment with family. The uniqueness of each case was highlighted, however, depending on family trauma. Mitigating media cases can be done if one insists on involving the family more.
• Reflecting on our relationships, and dignity therapy was also mentioned. Dying is a part of life, there is learning to do and work to do – the work is about relationships and forgiveness, about gratitude/saying thank you for the relationship we’ve had, saying goodbye. When contextualized this way, people may pause and reflect. MAID is not an emergency service; it is a process that occurs as part of a person’s development. Discussion about re-directing and re-framing to peoples’ responsibilities can be helpful.

• The different contexts between Canada and the Netherlands were discussed, as acceptance of euthanasia is very high in the Netherlands. There can be stark contrasts in different cases and also across countries and their different contexts.

• Further discussion about establishing irremediability occurred. While a community of practice can help ensure uniformity, there is still great variability. Research designs where assessors could be given case vignettes and asked to assess cases as irremediable or not, could capture any variance. Codifying irremediability is personal – conceptualizing the idea of how perfect assessor reliability may not be achievable, but guidelines can be discussed.