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# BMJ Open Exploring key stakeholders' attitudes and opinions on medical assistance in dying and palliative care in Canada: a qualitative study protocol

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#### ABSTRACT

**Introduction** Canadians have had legal access to medical assistance in dying (MAiD) since 2016. However, despite substantial overlap in populations who request MAiD and who require palliative care (PC) services, policies and recommended practices regarding the optimal relationship between MAiD and PC services are not well developed. Multiple models are possible, including autonomous delivery of these services and formal or informal coordination, collaboration or integration. However, it is not clear which of these approaches are most appropriate, feasible or acceptable in different Canadian health settings in the context of the COVID-19 pandemic and in the post-pandemic period. The aim of this qualitative study is to understand the attitudes and opinions of key stakeholders from the government, health system, patient groups and academia in Canada regarding the optimal relationship between MAiD and PC services.

Methods and analysis A qualitative, purposeful sampling approach will elicit stakeholder feedback of 25-30 participants using semistructured interviews. Stakeholders with expertise and engagement in MAiD or PC who hold leadership positions in their respective organisations across Canada will be invited to provide their perspectives on the relationship between MAiD and PC; capacity-building needs; policy development opportunities; and the impact of the COVID-19 pandemic on the relationship between MAiD and PC services. Transcripts will be analysed using content analysis. A framework for integrated health services will be used to assess the impact of integrating services on multiple levels.

Ethics and dissemination This study has received ethical approval from the University Health Network Research Ethics Board (No 19-5518; Toronto, Canada). All participants will be required to provide informed electronic consent before a qualitative interview is scheduled, and to provide verbal consent prior to the start of the qualitative interview. Findings from this study could inform healthcare policy, the delivery of MAiD and PC, and enhance the understanding of the multilevel factors relevant for the delivery of these services. Findings will be disseminated in conferences and peer-reviewed publications.

#### INTRODUCTION

Assisted dying has been legalised in the Netherlands, Belgium, Luxembourg, Switzerland,

### Strengths and limitations of this study

- This study will gather attitudes and opinions of key national stakeholders about evolving medical assistance in dying (MAiD) policy in Canada, the optimal relationship between MAiD and palliative care (PC) services and the impact of the COVID-19 pandemic on MAiD and PC services.
- Qualitative individual semistructured interviews will elicit stakeholder feedback.
- > Stakeholders will include senior healthcare managers, leaders of healthcare provider groups, academic experts and heads of patient representative groups.
- PATH's framework for integrated health services will be applied to analyse the impact of integrating services on the levels of client-centred services, health operations, health system and intersectional initiatives.
- The main foreseeable challenges of this study include the intention to recruit busy key stakeholders during the COVID-19 pandemic, recruitment bias and potential changes to policy or clinical services.

Germany, 10 jurisdictions in the USA, and more recently in Colombia, Canada, Victoria (Australia), Spain and New Zealand. 12 Following a Supreme Court decision in 2016 that decriminalised assisting suicide, the Canadian federal government passed Bill C-14, which legalised medical assistance in dying (MAiD). This includes the direct administration by a physician or nurse of a substance that causes death, or the provision or prescription of a drug that the eligible individual takes themselves, to bring about their own death. From 2016 to 2020, more than 21500 Canadians received MAiD,<sup>3</sup> and MAiD deaths now account for approximately 2.5% of total deaths in Canada.

The eligibility criteria for MAiD continued to be debated after the passage of Bill C-14. In March 2021, the Canadian government passed





Table 1         Medical assistance in dying (MAiD) eligibility criteria in Canada	
2016 MAiD legislation (Bill C-14)	2021 MAiD legislative changes (Bill C-7)
A person may receive MAiD only if they meet all of the following criteria:	
1. They are eligible—or, but for any applicable minimum period, would be eligible—for health services funded by a government in Canada.	As in Bill C-14.
2. They are at least 18 years of age and capable of making decisions with respect to their health.	As in Bill C-14.
3. They 'have a grievous and irremediable medical condition' defined as:	As in Bill C-14.
a. Having a series and incurable illness, disease or disability.	Excludes individuals suffering solely from mental illness until March 2023.
b. Being in an advanced state of irreversible decline in capability.	As in Bill C-14.
c. The illness, disease, or disability or state of decline causes them enduring physical or psychological suffering that is intolerable to them and cannot be relieved under conditions that they consider acceptable.	Where natural death is not reasonably foreseeable, the practitioner must agree that the person has given serious consideration to the reasonable and available means to relieve suffering.
d. Their 'natural death has become reasonably foreseeable', taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining.	'Natural death has become reasonably foreseeable' removed as an eligibility criterion, and positioned as a separate access track with additional procedural safeguards.
4. They have made a voluntary request for MAiD that, in particular, was not made as a result of external pressure.	As in Bill C-14.
<ol><li>They give informed consent to receive MAiD after having been informed of the means that are available to relieve their suffering, including palliative care.</li></ol>	

Not all changes and additions to procedural safeguards in Bill C-7 are shown.<sup>3</sup>

Bill C-7, extending the eligibility for MAiD by eliminating the requirement for a reasonably foreseeable natural death and adding some procedural safeguards (table 1).<sup>3</sup> Unlike most other jurisdictions (such as Luxembourg, USA, Colombia, Australia (Victoria), Spain, and New Zealand), individuals in Canada no longer need to have a fatal or terminal condition to be eligible for MAiD. A 2020 poll by Ipsos found that 86% of Canadians support the Supreme Court of Canada's decision to legalise MAiD and 71% support removing this 'reasonably foreseeable' requirement.<sup>5</sup> Similarly, a 2020 Angus Reid Institute poll found 81% of Canadians support MAiD, with 33% of these being 'enthusiastic supporters' and 48% being 'cautious supporters'.<sup>6</sup>

Requests for MAiD are typically made by patients who are also receiving other health services, including palliative care (PC). Multiple models regarding the relationship between the delivery of MAiD and PC are possible. A systematic scoping review that analysed the relationship of assisted dying with PC in countries where it is lawful found varied relationships including supportive, neutral, coexisting, not mutually exclusive, integrated, synergistic, cooperative, collaborative, opposed, ambivalent and conflict. However, it is not clear which model is most appropriate, feasible or acceptable in different Canadian health settings. The opposition or distancing of PC societies and organisations from the aims or practice

of MAiD highlights challenges that may exist in collaborative planning in the delivery of PC and MAiD. 8-11 In that regard, the European Association for Palliative Care recommended in 2016 that MAiD 'should not be included into the practice of palliative care'. 9 This view is consistent with that of the WHO, which specifies that PC should neither intend to hasten nor to postpone death. 12

Those who support greater coordination of MAiD and PC contend that the aims of these services are similar in that both support patient autonomy, the relief of suffering and the pursuit of a 'good death'. <sup>11</sup> However, a fundamental principle of PC is that it should not shorten life. <sup>12</sup> There is worry by some in the PC community that conflating MAiD and PC in the public perception defeats efforts to reduce stigma about PC by disentangling it from interventions that shorten life. <sup>8</sup>

The majority of physicians and PC professionals in Canada voiced opposition to MAiD in initial surveys (from 2008 to 2015). <sup>8</sup> <sup>14-16</sup> Notably, the Canadian Society of Palliative Care Physicians advocated that MAiD should not be provided by PC services or physicians, and that PC assessments should not include the assessment of MAiD eligibility. <sup>17</sup> <sup>18</sup> It has been argued that the views of such organisations may complicate the coordination and planning of services, and be problematic for those who request MAiD, who also require optimal access to high-quality PC. <sup>13</sup> <sup>19</sup> An alternative view is that the introduction



of MAiD in Canada may present a new opportunity to improve PC for those with advanced disease. In that regard, MAiD legalisation has facilitated the commitment of the Canadian government to improve access to palliative and end-of-life care.<sup>20</sup>

More information is needed about current attitudes of the PC community regarding MAiD. It has been suggested that support for MAiD and for the coordination of MAiD and PC may be increasing in response to MAiD education and training, clearer ethical guidelines and a new generation of healthcare providers entering the field. <sup>21 22</sup> An early indication of this change is evident in surveys of Canadian medical students and residents from 2016 to 2017 in which half believed that MAiD would ultimately be provided by PC physicians, <sup>22</sup> and the majority would be willing to provide a consenting patient with MAiD. <sup>22 23</sup> On the other hand, legislative changes in 2021 that eliminated the requirement for MAiD to only be offered to persons with a reasonably foreseeable natural death would suggest PC involvement in a smaller proportion of MAiD cases.

On 11 March 2020, the WHO declared COVID-19 a pandemic.<sup>24</sup> Health services, such as MAiD and PC, have been adversely affected by the COVID-19 pandemic. 4 25 For example, early in the pandemic there were reported concerns about shortages in the drugs used in MAiD deaths, <sup>26</sup> the difficulty transferring patients to settings where MAiD is delivered and ensuring that MAiD witnessing and assessment for eligibility was available in all Canadian jurisdictions. Some Canadian hospitals temporarily suspended MAiD altogether, so that healthcare staff could focus on pandemic efforts, 27 28 and some community-based MAiD services reportedly reduced home visits to avoid spreading the virus.<sup>4</sup> This has raised questions about whether MAiD should be considered an 'essential service' that is not temporarily delayed or provided with limited access during the pandemic.

The goal of this qualitative study is to inform the complex and evolving discussion on the relationship of MAiD and PC. This includes addressing questions such as whether MAiD should be available to patients with rapidly progressive cases of COVID-19. 26 28 29 We also seek to understand the impact of the COVID-19 pandemic on MAiD and PC services and ways to mitigate perceived challenges by interviewing national key stakeholders who hold leadership positions in Canada relevant to MAiD, PC or both (hereafter key stakeholders). While insights from key stakeholders could improve the relationship and coordinated provision of MAiD and PC services, to the best of our knowledge, no previous study has reported on the attitudes and opinions of key stakeholders across Canada. After 5 years of MAiD implementation in Canada, it is important to understand key stakeholders' experiences of the challenges and opportunities regarding the relationship between MAiD and PC.

#### **Aims and objectives**

The objectives of this qualitative study are to:

- A. Describe the attitudes and opinions of key stakeholders regarding MAiD and PC services and the optimal relationship between them.
- B. Understand stakeholders' attitudes and opinions about the impact of the COVID-19 pandemic on the relationship between the delivery of MAiD and PC, as well as strategies that may help to mitigate challenges in this relationship.
- C. Identify attitudes and opinions of stakeholders that may inform strategies to ensure the timely and appropriate access of patients to MAiD and the availability of PC to such patients in different clinical settings.

Additional aims of this qualitative study may emerge due to changing circumstances and from novel topics emerging from qualitative interviews.

#### **Research questions**

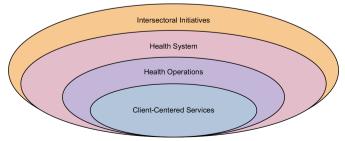
- A. What are stakeholders' attitudes and opinions about the relationship between MAiD and PC?
- B. What strategies would be helpful to mitigate any challenges that the COVID-19 pandemic has presented for the concurrent delivery of MAiD and PC?
- C. What are the attitudes and opinions of stakeholders regarding policies and practices that could facilitate the concurrent delivery of MAiD and PC services in Canada?

# METHODS AND ANALYSIS Study design

This is a qualitative study using semistructured interviews to elicit feedback of 25–30 participants who are key national stakeholders from the government, health system, patient groups and academia regarding their attitudes, opinions and recommendations.

# **Study framework**

We will use PATH's framework for integrated health services (figure 1),<sup>30</sup> which orients researchers to investigate the impact of integrating services on multiple levels. PATH is an international non-profit organisation that aims to create sustainable, culturally relevant solutions. The PATH's framework considers potential integration of health services at four levels including (a) *client-centred services* focusing on the needs of clients, families and the broader community such as considering clinic hours to improve access, more efficient referral systems or access



**Figure 1** PATH's framework for integrated health services. Source: PATH 2011.<sup>30</sup>



to services to enhance care; (b) health operations planning at the organisation focusing on the delivery of services (by ministries of health, non-governmental or local organisations and private sector agencies) and the allocation of resources, time, money or expertise; (c) health system coordination at the national level that includes broader governance and capacity issues, such as joint planning of the policies, processes and infrastructure that make up an overarching health system, and (d) intersectoral initiatives that include intersection with more than one system (such as the health and legal system) (figure 1). Accordingly, key stakeholders from multiple levels across Canada will be interviewed and will be asked about each of these levels.

#### Sample size and recruitment

We aim to sample 25-30 key stakeholders to seek representation from diverse and multilayered (local, provincial/territorial, national) groups across Canada. We will elucidate the attitudes and opinions of individuals who have expertise and engagement with the delivery of MAiD and/or PC services and who are responsible for leadership in their respective organisations. Purposeful sampling emphasises inclusion of participants based on the leadership role of participants. Stakeholder groups will include senior health system leaders such as senior healthcare managers, leaders of healthcare provider groups, academic experts and heads of patient representative groups across Canada. Using a purposive sampling strategy, we will locate and recruit participants who are leaders in hospitals, hospices, pertinent organisations, academia (such as individuals who contributed expert advice to Bill C-14 or Bill C-7, provided guidance for the expert panels on MAiD, or are specialists in PC, bioethics, person-centred care, health administration, or death or dying at Canadian universities), in the government (such as ministers of health) or regional clinical leads.

The criterion of inclusion that will be used to select participants will be the participant's leadership role. We will seek out key stakeholders with expertise in each level of the PATH's framework and ask stakeholders to comment on all levels. Efforts will also be made to enable geographic representativeness where possible to emphasise breadth and variation of stakeholder participants. We will compile a list of key stakeholders and will use expert input to verify the list and prioritise recruitment of key stakeholders. We will subsequently employ snowball sampling techniques to invite and recruit additional participants identified through participants' existing networks. Prospective participants will receive an email from the research team inviting them to take part in the study. Participants will be compensated for their time by receiving a CAD \$20 gift certificate.

# **Data collection**

One-on-one, semistructured qualitative interviews with key stakeholders Canada-wide will be conducted over 6 months in 2021 by the principal investigator (GKS).<sup>6</sup>

All participants will provide their informed consent. Interviews will be conducted using an online videoconferencing platform and will last approximately 60 minutes. All interviews will be conducted in English or French, Canada's two national languages. Sociodemographic characteristics (eg, age, gender, years of experience, sector, region) will be collected at the start of the interviews. The interview guide will include broad open-ended questions about stakeholders' experiences with and attitudes towards MAiD, collaboration in the delivery of MAiD and PC, perspectives on the advantages and disadvantages of the potential coordination of MAiD and PC, capacity-building needs and policy development opportunities, impact of psychosocial and PC on MAiD and impact of COVID-19 pandemic on MAiD and PC services (see online supplemental material). The interview guide (developed by GKS, ET, RN and GR) will be refined and reviewed based on a constant comparative analysis.<sup>31</sup> Emerging themes in earlier interviews may assist in refining later interview questions and probes. The research team will make sampling decisions based on experience and to achieve variation in region and sector. Data collection will cease when no further categories or themes emerge from ongoing analyses. Interviews will be audio recorded, transcribed verbatim, deidentified and verified. Respondent validation (ie, member checking) during the interview, and checking emerging themes with participants who are interviewed later, will be used to ensure the accuracy, validity and generalisability of this study.

Our research team has adopted a neutral position regarding MAiD and the relationship between MAiD and PC with an interest in examining perceived best practices and supporting optimal patient-centred care.

# **Patient and public involvement**

The focus of the present study was understanding the perspectives of senior health system leaders, which include senior healthcare managers, leaders of healthcare provider groups, academic experts and heads of patient representative groups across Canada. Therefore, we did not involve patients, caregivers or the public in this phase of the research, but we agree that they must be involved in the development of plans for policy or clinical practice. We will involve patients, caregivers and the public in the dissemination plan of this research, in policy development and in planning for clinical practice.

### **Analysis**

Data will be managed by NVivo qualitative data analysis software and will be systematically analysed using conventional content analysis techniques, a thematic qualitative methodology.<sup>32</sup> This approach will include initial open coding and categorisation of emerging themes from transcript data by two authors (GKS and ET). We will crossindex themes to allow for the analysis of data items that fit into more than one category. We will use an inductive approach to examine participant experiences, attitudes



and opinions regarding MAiD and PC, alongside a deductive approach to examine the potential impact of integrating services on multiple levels using the PATH's framework for integrated health services. The initial tentative coding scheme will be developed after the first transcripts are analysed, and these codes will be applied to new transcripts and revised accordingly. Further categories may be added to reflect the nuances in the data and to capture issues that emerged from the interviews but were not directly enquired about. Systematic comparative analysis will be used to identify differences and similarities between participant accounts. An iterative analysis will be continued until data saturation is reached and consensus is met among the rest of the research team in ongoing meetings.

# ETHICS AND DISSEMINATION Ethical considerations

All participants will be required to provide informed electronic consent before a qualitative interview is scheduled, and to provide verbal consent prior to the start of the qualitative interview. The consent form that is sent to potential participants will describe the study and outline its objectives, potential benefits and risks, indicate that participants are free to withdraw at any time and outline what safeguards will be taken to maintain confidentiality of data. Participants will be given as much time to review the information and ask questions before being asked to give consent. Participants will provide their consent by email to study staff prior to the start of the interview. All data will be deidentified, linked to a unique participant identification number and stored in a password-protected network. Data that are presented or published will in no way identify the individual participant or disclose their identity. Interview transcripts will be deidentified during the transcription and verification process. This study has received ethical approval from the University Health Network Research Ethics Board (No 19-5518; Toronto, Canada). Any protocol amendments will be submitted to the University Health Network Research Ethics Board for approval.

#### **Declaration of Helsinki**

This study complies with the Declaration of Helsinki, adopted by the 18th World Medical Association (WMA) General Assembly, Helsinki, Finland, June 1964, and last revised by the 64th WMA General Assembly, Fortaleza, Brazil, October (2013).

#### **Output and dissemination**

Study findings will have significant implications for healthcare policy, the delivery of MAiD and PC in Canada and for understanding the multilevel factors relevant for service coordination or collaboration. The findings will be disseminated in conferences and peer-reviewed publications.

#### **DISCUSSION**

This project will be the first national study of the attitudes and opinions of key stakeholders of government, health system leaders, patient groups and academia regarding the delivery and relationship of MAiD and PC services in Canada. The results could have implications for healthcare policy and delivery regarding MAiD and PC in Canada and for understanding the multilevel factors relevant for service coordination, collaboration or integration. These findings have the potential to inform pending changes in MAiD legislature in Canada and other parts of the world. Knowledge translation activities from this project will include publication in high-impact peer-reviewed scientific journals (including open access) and presentations at local, national and international conferences as well as to key stakeholders.

There has been a proliferation of MAiD qualitative research evidence in Canada about perspectives and experiences of patients, 33 family members or caregivers 34 35 and healthcare providers, including allied health professionals, nurses, physicians<sup>36–43</sup> and multidisciplinary palliative and hospice care providers. 44 However, to the best of our knowledge, no previous study has reported on the attitudes and opinions of key stakeholders regarding the optimal relationship between MAiD and PC across Canada. Gerson and colleagues conducted semistructured in-depth qualitative interviews with participants involved in the development of policy, management or the delivery of end-of-life care services in Oregon, Quebec and Flanders. 45 Of the three jurisdictions, the greatest difference of opinion about how the practice of MAiD interacts with the delivery of PC was in Quebec. 45 Nine interviews in Quebec revealed (a) a contested relationship whereby assisted dying was viewed as 'incompatible with' or 'eroding' PC; (b) criticism regarding decisions of independent hospices not to perform MAiD or reversing their decision, leading to confusion and discontent among patients and professionals; and (c) concerns that lack of knowledge about access to PC among the public may lead to avoidable MAiD requests. 43 45 However, there has been no national study of attitudes of national policy leaders regarding the relationship of MAiD and PC. Therefore, there is a pressing need for greater research to understand this relationship across Canada and among multiple key stakeholder groups (ie, not exclusively physician stakeholders).

It may be valuable to understand the perspective of key stakeholders on this question to improve MAiD policy development and clinical practice across Canada and to develop evidence that can inform MAiD policy in other jurisdictions. Another potential strength of this study is the use of the PATH's framework for integrated health services to guide stakeholder interviews, to investigate the impact of integrating services on multiple levels and to inform data analysis.

#### Study challenges

The main foreseeable challenge of this study will be the recruitment of key stakeholders. Particularly during the COVID-19 pandemic, recruitment of health system



leaders and government representatives may be challenging as they will be largely focused on COVID-19 pandemic relief efforts. However, we hope that the importance of the topic, flexibility in scheduling appointments and the protection of stakeholders' anonymity may facilitate their participation.

Despite this being a reasonable sample size for a qualitative study of this kind, 25–30 participants represent a small number of all key national stakeholders. Therefore, we will use this sample size as a recruitment minimum and plan to continue data collection until saturation (ie, when incoming data produce little or no new information). Previous research has indicated that novel information in a qualitative study is usually generated early in data collection with diminishing returns after a small number of interviews.  $^{46\,47}$ 

The purposeful sampling strategy can be limited by variation. Because we used a purposeful sampling technique, we may overlook key stakeholders whose voices would also contribute beneficially. We will seek to enhance variation by encouraging participation from different Canadian regions and leadership in different sectors (eg, healthcare, academia, government, charitable or non-profit organisations), as well as seeking expert input to assist in seeking participation variation. Snowballing techniques will be used in this regard to widen the network of eligible participants while ensuring participants meet the recruitment criterion for the study.

There also may be a potential selection bias whereby stakeholders who support MAiD may be more willing to participate. To minimise bias related to the assumptions and experiences of the study investigators, a critical and independent stance will be maintained in the study design, participant recruitment, interview procedures and interpretation of data. For example, a neutral position was communicated in recruitment materials so not to bias participation of individuals who have positive, negative or neutral views towards MAiD. PC or the relationship between these services. Further, the extent to which there is a selection bias will be revealed by the recruitment rate, which will be reported in the study findings. Potential sources of bias will be considered by the research team and strategies will be adopted to mitigate them. In addition, the data collected will be cross-sectional and provisional in nature as participants' attitudes and opinions on this subject may be mutable.

Lastly, any changes to the landscape MAiD and PC services throughout the study (eg, as a result of the COVID-19 pandemic) will need to be taken into consideration as this may affect attitudes, opinions, practices and policies. 49 50

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Contributors GKS is the main investigator for this project and wrote the protocol. GR is supervising the project and will provide expertise to develop all aspects of the project. GKS, ET and GR will be involved in participant recruitment and interviews and data management and analysis. GKS, ET, RN, CZ, SA, JG, ML and GR will be involved in study design, expert stakeholder assessment and recruitment, and interpretation of results, and will participate in regular team meetings to support this research project.

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