

Public Deliberation for Ethically Complex Policies: The Case of Medical Assistance in Dying in Canada

Délibération publique pour des politiques complexes sur le plan éthique : l'aide médicale à mourir au Canada



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Abstract

Almost 50,000 people in Canada have had a medically assisted death since federal legislation was passed in 2016. Still, the debate about the permissibility of medical assistance in dying (MAiD) continues to rage. The central role of shared values and ethics in public policy making emphasizes the importance of engaging the public, particularly around heavily value-laden issues such as MAiD. Public deliberation, a mode of engagement that fosters sustained and reasoned discussion between participants, is well-suited to addressing such ethically contentious policy issues. In this paper, we review recent efforts to engage the public on assisted dying within and outside Canada and explain how public deliberation could contribute substantively to MAiD policy making.

Résumé

Près de 50 000 personnes au Canada ont eu une mort par assistance médicale depuis l'adoption de la loi fédérale en 2016. Néanmoins, le débat sur la permissibilité de l'aide médicale à mourir (AMM) est toujours en cours. Le rôle central des valeurs et de l'éthique dans la formulation des politiques publiques souligne l'importance de la participation du public, particulièrement en ce qui concerne les questions fortement liées aux valeurs comme l'AMM. La délibération publique, un mode de participation qui favorise une discussion soutenue et raisonnée entre les participants, est bien adaptée pour aborder ce type de politiques controversées sur le plan éthique. Dans ce document, nous examinons les efforts récents pour mobiliser le public sur l'aide à mourir au Canada et à l'étranger et nous expliquons comment la délibération publique pourrait contribuer de façon substantielle à l'élaboration des politiques de l'AMM.

Background

Medical Assistance in Dying (MAiD) legislation has seen swift and significant change since the landmark *Carter v. Canada* decision (2015), which struck down the Criminal Code prohibitions on assisted dying (Downie 2022). The unanimous Supreme Court decision led to the passing of federal Bill C-14 in 2016, which allowed MAiD for those with a grievous and irremediable medical condition and a reasonably foreseeable natural death. Since then, we have seen amendments to remove the “reasonably foreseeable natural death” requirement for MAiD eligibility (i.e., in 2021 through Bill C-7), with expectations for those with mental illness as their sole underlying condition to become eligible for MAiD in 2027 (Department of Justice 2021; Health Canada 2024). Despite these notable policy evolutions, the general public has had little opportunity to deliberate about the state of MAiD in Canada, the profound social implications that changes in MAiD policies have on Canadians and the shared values that underlie these contentious issues.

Values such as compassion, autonomy, equity, fairness and protection of vulnerable persons are at the centre of the MAiD debate and need to be brought to the surface and directly questioned in conversations around assisted dying (Buchman 2019; Fontalis et al. 2018; Herx et al. 2019; Schüklenk et al. 2011). The ethical acceptability of MAiD policies should be judged by how well they reflect commitments to these underlying values in their design and execution. Engagement with the public is needed to determine the full range of these values, how they may be appropriately balanced against one another and how they can inform MAiD policy making. MAiD is a unique health policy issue; rather than focusing on standardized indicators for health policy success like improved health outcomes, assisted dying policies require values-based reasoning to determine whether a policy truly reduces suffering, improves autonomy or reflects compassion. Discussion of the values that underpin MAiD, potential trade-offs between them and how they are operationalized into policies have been

relegated to the courtroom and Parliament to date but would be better served by directly engaging the individuals who will be impacted by MAiD policies.

There are numerous aspects of MAiD policy making that could benefit from public deliberation. Most pressing is the eligibility of individuals with mental illness as the sole underlying condition. While the sunset clause to include this eligibility criteria was to come into effect in March 2024, the federal government has been granted an extension until 2027 (Health Canada 2024). This extension period is an opportunity for federal and provincial governments to seriously engage with the public about whether eligibility for persons with mental illnesses still aligns with Canadian values. This could include questions such as these: Should people with mental illnesses as their sole underlying condition be eligible for MAiD? Would all mental illnesses qualify for eligibility and if not, how would we fairly decide which ones would be eligible? Would additional safeguards be needed for those who fall under this eligibility criterion? Other issues include how healthcare providers should discuss MAiD with their patients (i.e., whether this conversation should be initiated by the patient or the provider) (Bryden 2020), the ethical acceptability for organ donation after MAiD (Middleton 2019; Mulder 2019) and how to handle access issues emerging due to a lack of willing providers, especially for cases where death is not reasonably foreseeable (Frolic and Oliphant 2022).

We argue in this paper that public deliberation is a particularly fruitful approach to engaging Canadians about MAiD. We start by outlining the recent history of public engagement on assisted dying policies in Canada, then address the question “Why deliberation?” before describing Canadian and international experiences with deliberation on assisted dying. We argue that such engagement is imperative due to the value-laden nature of assisted dying policies, as well as the constantly evolving nature of Canada’s MAiD regime. We discuss potential pitfalls of using deliberation for ethically contentious health policies like MAiD and how they can be avoided. While we do not take a stance on the ethical permissibility of MAiD in this paper, we do believe that approaches to public engagement thus far have been insufficient and that public deliberation can improve the ethical acceptability, transparency and trustworthiness of MAiD policy decisions.

Government-Initiated Public Engagement for MAiD in Canada

The evolution of MAiD in Canada has been marked by government-initiated expert panels, parliamentary committees and public consultations. The earliest example is the 2010 public consultation headed by the National Assembly of Québec’s Select Committee on Dying with Dignity (2012). Following the release of a consultation paper, individuals and organizations could submit briefs, attend public hearings or answer an online questionnaire. More than 6,500 responses to the online questionnaire were received and 239 individuals and organizations contributed to the public hearings. The consultation covered all end-of-life policies, not only assisted dying, and the culminating report paved the way for the *Act Respecting End-of-Life Care* in Quebec (Downie 2022).

The federal government first engaged with Canadians about MAiD in 2015 after the Supreme Court decision that removed Criminal Code prohibitions on assisted dying (Downie 2022). The federal government responded by establishing an external panel mandated to consult Canadians and key stakeholders to inform its legislative response (External Panel on Options for a Legislative Response to *Carter v. Canada* 2015). Over a three-month period, almost 15,000 responses were received on their online consultation tool, *The Issue Book*, which sought to educate respondents on issues around assisted dying while also eliciting their perspectives on key issues such as eligibility and safeguards (External Panel on Options for a Legislative Response to *Carter v. Canada* 2015). The panel's final report noted that particularly complex issues such as advance directives for MAiD or eligibility for mature minors are issues for which "there is no known consensus and where debate can be expected to emerge over time" (External Panel on Options for a Legislative Response to *Carter v. Canada* 2015: 12).

Also in 2015, the provincial and territorial governments appointed an expert advisory group to advise the ministers of health and justice who would be responsible for implementing the federal legislation (Provincial–Territorial Expert Advisory Group on Physician-Assisted Dying 2015). This group engaged in consultations with stakeholder groups, including patient advocacy groups, but not with the public or individual patients. In the same year, the House of Commons and Senate created a special joint committee to "consult with Canadians, experts and stakeholders, and make recommendations on the framework of a federal response on physician-assisted dying that respects the Constitution" (Special Joint Committee on Physician-Assisted Dying 2016: 2). The committee received briefs from a number of organizations and individuals and met with witnesses across their meetings.

Despite these initial opportunities, Canada's most extensive public consultation on MAiD did not occur until 2020, after a Quebec Superior Court ruling struck down the "reasonably foreseeable natural death" requirement for MAiD (Department of Justice 2021; Government of Canada 2020). The two-week public consultation consisting of a short questionnaire received more than 300,000 responses, and elicited Canadians' perspectives on establishing additional procedural safeguards for non-terminally ill patients seeking MAiD. In 2021, Bill C-7 was passed that removed the eligibility criterion of a "reasonably foreseeable natural death" and enacted a sunset clause wherein people with mental illness as their sole underlying condition would automatically become eligible for MAiD in March 2023 (now extended to 2027) (Department of Justice 2021; Health Canada 2024). This new controversial issue led to the creation of the Expert Panel on MAiD and Mental Illness (2022), which did not engage in public consultations.

Critiques of Current Public Engagement Efforts for MAiD Policy Making

The federal and provincial governments have clearly initiated efforts to engage the public on MAiD policy, most commonly through public consultations. These engagements have used

short surveys, comment periods, or public hearings to elicit the views of the already-interested public. However, these engagement methods fall short when trying to ascertain public views on such ethically complex issues. One-time surveys can only garner the immediate views of the public, which may not reflect well-informed or reasoned perspectives (Solomon and Abelson 2012). Further, survey questions may be phrased to reflect the policy priorities and vision of policy makers, and closed-ended response categories (e.g., Likert scales, multiple choice) limit opportunities for respondents to share nuanced perspectives. This is in tension with the inherent complexity of the MAiD debates, which necessitate deeper engagement.

Feedback-style activities like surveys and submitted briefs require members of the public to initiate engagement. This skews participation to those individuals who are already interested in a policy issue and have the personal resources to be engaged (e.g., time, internet access) (Dhamanaskar et al. 2024). It may also lead to the overrepresentation of organized interests, such as nonprofits and professional organizations that have the resources to mobilize their membership and/or engage on their behalf. Importantly, self-selection into engagement can inadvertently lead to the exclusion of certain groups, often vulnerable groups, from participation. This becomes problematic as MAiD uniquely impacts certain vulnerable populations, like disabled persons and individuals who lack access to social support (e.g., housing).

Finally, surveys, comment periods and public hearings often resemble a one-way dialogue between decision makers and the public, giving little room for members of the public to actively engage in the policy making process (Dhamanaskar et al. 2024). Such engagements do not give the public the opportunity to imagine what a policy may look like in practice and to deal with the consequences and trade-offs that emerge when implementing policy in the real world. While hundreds of Canadians have been engaged through consultation methods so far, it is unclear how public views have been factored into MAiD policy decisions, potentially indicating a lack of transparency and accountability mechanisms to report on the impact of engagement.

The Role of Public Deliberation in MAiD Policy Making

An extensive literature supports the use of public engagement to foster public trust and approval of political institutions and design policies attentive to public needs (Bherer et al. 2016). Deliberative forms of public engagement offer an alternative and possibly more meaningful approach to public engagement on MAiD. While feedback-style engagement elicits the public's immediate and pre-conceived ideas, deliberation gives participants the opportunity to be informed about a policy issue, consider and share differing perspectives and possibly even transform their own thinking (Blacksher et al. 2012). This encourages participants to not only consider the values at stake in various MAiD policies, but to also imagine what those values look like when actualized into policy. Deliberative activities tend to avoid recruitment through self-selection, instead opting to invite individuals directly and possibly reaching individuals who may not have chosen or known how to engage otherwise (Longstaff and Burgess

2010). Interestingly, the external panel, expert panel and special joint committee on MAiD all call their committee meetings (among committee members) “deliberations,” suggesting that they see the value in reasoned discussion to form policy recommendations.

Policy making for MAiD has four features that make it well-suited for deliberative public engagement: (1) it reflects conflicting values about the public good, (2) it is an inherently controversial and divisive topic, (3) it combines technical and real-world knowledge and (4) it is a policy area where trust can be easily eroded (Solomon and Abelson 2012). First, MAiD policy making obviously deals with conflicting public values, including compassion, autonomy, protecting vulnerable persons and justice. Many disability activists argue that Canada’s increasingly permissive MAiD system reveals a lack of respect and value for disabled lives, which are made inherently vulnerable due to ableist systems (Coelho et al. 2022; Herx et al. 2019). Conversely, MAiD supporters argue that people with disabilities should have the autonomy to choose a dignified death and MAiD should be seen as a compassionate response to intolerable suffering (Adams et al. 2017; Buchman 2019). Ultimately, the appropriate balance between these values to form a MAiD regime that is ethically acceptable to Canadians is of profound public concern. Deliberation is particularly useful as it allows participants to consider how policy decisions impact not only themselves but large communities, understand the underlying values that produce divergent opinions and meaningfully engage with opposing viewpoints (Solomon and Abelson 2012).

Policy making for MAiD also combines technical expert knowledge and real-world experience. While consultation with experts, such as healthcare professionals, lawmakers, policy makers and bioethicists, is obviously important and has been the mandate of many government panels and committees, the lived experiences of patients, disabled persons and other individuals cannot be undermined. Many disability activists argue that general support for MAiD may reflect a misunderstanding about the difficulties of living with a disability, which many attribute not to the disability itself but to the lack of social supports to live *with* the disability (Lemmens and Krakowitz-Broker 2020). Public deliberation can help bridge the gaps between these important and sometimes contrasting views of experts and persons with lived experience, giving the public access to a broad range of experiences and evidence to inform perspectives on MAiD.

Finally, MAiD policy making, by virtue of its inherently value-laden and controversial nature, can erode public trust in the MAiD regime and even the healthcare system more broadly. There has been rising concern about unethical practices within Canada’s MAiD administration. These include individuals seeking and becoming eligible for MAiD due to a lack of social supports like housing and medical care (Mulligan and Bond 2022). Individuals with disabilities also report being offered MAiD by their healthcare providers, noting this as a harmful sign of ableism in the healthcare system (CTV News 2018). Public deliberation can be an important avenue for policy makers to hear and consider public concerns, while also increasing transparency and accountability for complex policy decisions.

As MAiD policy making continues to evolve in Canada, the need for public deliberation is apparent. The eligibility of mental illness as the sole underlying condition has now been delayed three times, suggesting that federal and provincial governments do not feel ready to move forward with this eligibility criterion (Osman 2024). Public deliberation can help policy makers engage members of the public in deeper conversations about MAiD and mental illness and test out different policy outcomes on a smaller scale. This can help increase confidence in policy decisions that have been deliberated by the public. Lack of public awareness about MAiD and end-of-life care in Canada also calls into question the value of consultations that may be eliciting the misinformed or underinformed views of the public (Ipsos 2016). The information-giving aspect of deliberation can ensure that public perspectives are shaped by trustworthy information about what death and dying look like in Canada. Without good-faith discussions between individuals who share different viewpoints, MAiD debates risk becoming even more polarized over time. Recognizing that values like equity and compassion are shared, regardless of support for MAiD, can help the public and policy makers see the merit in opposing perspectives.

Promising Examples and Potential Pitfalls: Lessons from Canada and Beyond

While federal and provincial governments have yet to engage Canadians in deliberations about MAiD, the use of deliberation is not new to Canada nor to the issue of MAiD. Public deliberation has been used in Canada to address ethically complex policy issues like biobanking and childhood vaccination (Burgess et al. 2008; O'Doherty et al. 2021). Researchers from Quebec have used deliberative methods to engage the public and healthcare professionals about informational needs about MAiD (Boivin et al. 2019). Leveraging a strong history of leadership in the public deliberation field, Canadian policy makers have existing structures and rich experiences to draw on when designing deliberative activities to engage the public on MAiD (Bentley et al. 2018; MAP Centre for Urban Health Solutions 2024).

International experiences also provide key teachings for Canada. In 2018, the Minister for Health and Social Services in Jersey established a citizens' jury on assisted dying (Jersey Assisted Dying Citizens' Jury 2021). The jury, consisting of 23 demographically representative residents, were asked to answer the question, "Should assisted dying be permitted in Jersey and, if so, under what circumstances?" They heard from a wide variety of experts and persons with lived experience on both sides of the issue across 10 deliberative sessions. Some important reflections by jury members were that the issue was "a lot more complicated than [they] first thought," that they were "now in a better position to take an informed position [on assisted dying]" and that they "[became] more accepting of opposing views" (Jersey Assisted Dying Citizens' Jury 2021, pp. 30–31).

However, participants in the Jersey citizens' jury felt that the voting process at the end of the deliberation (which sided with permitting assisted dying) may have alienated participants on the opposing side. A key lesson for policy makers here is that perceptions about the fairness and success of deliberative activities depends on how they are designed. While

policy makers might prefer the conclusiveness of voting-based deliberations, especially in cases where deliberations directly shape policy making, the voting process may interfere with good-faith discussions by arranging participants as winners and losers. Building consensus, through voting or other methods, is not always the outcome of deliberations. This was the case for a researcher-initiated citizens' jury in New Zealand on the ethical permissibility of assisted dying, which saw the deliberative group become more polarized in their views after deliberation (Walker et al. 2020).

Lack of consensus or even increased polarization after deliberations may be a sign of the inherent complexity of MAiD debates rather than cause for concern. The New Zealand citizen's jury was useful in uncovering disagreement, improving understanding between conflicting views, and clarifying rationales for differing viewpoints. Many participants changed their views during the process, demonstrating the power of deliberation's information-giving and discussion-based features to shift and potentially shape more informed positions. While policy makers may feel wary of initiating deliberations that do not produce clear findings, individual disagreement can still lead to viable policy solutions through greater acceptance of divergent viewpoints and discussions about the broader public good (Solomon and Abelson 2012).

Increasing polarization during or after deliberations can also hint at design flaws in deliberative processes that require attention. For example, the information-giving portions of deliberations about MAiD policies may be a source of mistrust if the expert viewpoints or lived experiences shared are perceived as biased or skewed toward one perspective. Initial malleability to new arguments and information may shift to more rigid positioning as a result of this mistrust. Allocating enough time and attention to selecting experts and persons with lived experience on both sides of the issue, with neutral perspectives if possible, will be particularly important for MAiD deliberations.

Designing inclusive activities is also an important consideration that can challenge current norms in deliberative practice. Deliberative activities tend to invite individuals to engage using a stratified random sample to reproduce the demographic diversity of a particular region (Longstaff and Burgess 2010). However, demographic representation can lead to the domination of majority interests, which may not sufficiently consider how MAiD disproportionately affects groups such as disabled persons and individuals lacking access to social supports (Ott and Knopf 2019). In such cases, deliberations may warrant the "overrepresentation" of certain perspectives; for example, deliberations about mental illness may want to prioritize engagement with individuals with mental illness.

Finally, the capacity for deliberation to increase trust in MAiD policy decisions depends on whether participants feel their contributions made a difference; engagement that is perceived to be tokenistic or just for show can undermine public trust in the process (Solomon and Abelson 2012). For highly contentious policy issues like MAiD, policy makers may be reluctant to clearly state whether public viewpoints will influence policy decisions, increasing the risk of tokenistic engagement. Accountability and transparency are key tenets of

meaningful engagement, where individuals are informed about the potential impact of their engagement on the policy making process (Li et al. 2015). When assurances of policy impact are not possible, transparency is essential to clarify goals and set the terms of engagement.

Conclusion

As assisted dying policies continue to evolve in Canada, governments have a responsibility to meaningfully engage Canadians on the design and implementation of our MAiD regime. While public consultations have been interspersed with key legal and policy developments, opportunities for deep and sustained reflection are notably lacking. Deliberation offers an alternative and essential route for Canadians to critically reflect on the values and tensions underlying MAiD and for policy makers to seek the informed perspectives of the public. Policy makers who plan to conduct and learn from such deliberations would benefit from collaborations with researchers in Canada who have expertise with such methods and trusted community organizations that represent key target populations for engagement. Truly transformative engagement on MAiD requires policy makers to create opportunities for deliberation that are responsive to issues of polarization and mistrust that can arise in these ethically complex discussions and attentive to the communities commonly excluded from them that may be uniquely affected by changes in MAiD policies.

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