

# Improving Advance Medical Directives: Lessons from Quebec

Louise Bernier and Catherine Régis

## IN BRIEF

Policy-makers' efforts to increase the uptake of advance medical directives (AMDs), and the legal constraints they impose on health professionals, are bringing greater scrutiny to provincial AMD regimes. In 2015, Quebec introduced a new, legally binding form to be filled out for AMDs, which limits individuals' expression of their wishes to narrow, checklist responses to questions on specific medical interventions. This form-focused regime has other shortcomings: it relies on individuals to self-inform and it does not provide them the opportunity to meaningfully convey their preferences for end-of-life care. A more values-based and collaborative approach provides a better path forward for Quebec and for other provinces.

## EN BREF

Les efforts faits par les gouvernements pour promouvoir les directives médicales anticipées (DMA), mais aussi les contraintes juridiques qu'elles imposent aux professionnels de la santé, ont suscité un examen plus poussé des régimes provinciaux de DMA. En 2015, le Québec a instauré un nouveau formulaire juridiquement contraignant qui limite l'expression des volontés des personnes à une courte liste de questions et réponses sur quelques interventions médicales. Parmi ses lacunes, ce régime basé sur un formulaire fait peser sur les personnes qui souhaitent le remplir la responsabilité de trouver elles-mêmes les informations nécessaires à leur prise de décision et ne prévoit aucune possibilité de discuter en profondeur de leurs préférences en matière de soins de fin de vie. Le Québec et les autres provinces du pays gagneraient à adopter une approche plus collaborative et axée sur les valeurs.

## ABOUT THIS INSIGHT

This paper was published as part of the Faces of Aging research program, under the direction of Colin Busby. The manuscript was copy-edited by Barbara Czarnecki, proofreading was by Zofia Laubitz, editorial coordination was by Francesca Worrall, production was by Chantal Létourneau and art direction was by Anne Tremblay.

## ACKNOWLEDGEMENTS

The authors would like to thank Léa Boutrouille, a JD candidate at Université de Montréal, for her excellent research work, and the reviewers for their insightful comments on this paper.

**Louise Bernier** is a health law professor at the law faculty of Université de Sherbrooke. Her current research interests lie in governance issues in health care and in different approaches to autonomy in the medical setting, and she holds research grants from the CIHR and Québec Bar Association. She is a member of Transplant Québec and CIUSS de l'Estrie CHUS, among other ethics committees.

**Catherine Régis** is a professor at Université de Montréal's Faculty of Law, holds the Canada Research Chair in Collaborative Culture in Health Law and Policy, and is a researcher at the Centre de recherche en droit public. She is also a researcher at the Centre de recherche du Centre hospitalier universitaire de l'Université de Montréal and co-director of the Health Hub – Politic, Organizations and Law (H-POD). Her research focuses on health care governance (at the local, national and international levels), artificial intelligence, conflict prevention and resolution, and the renewal of professionalism in health care.

To cite this document:

Bernier, Louise and Catherine Régis. 2019. *Improving Advance Medical Directives: Lessons from Quebec*. IRPP Insight 26. Montreal: Institute for Research on Public Policy.

---

The opinions expressed in this study are those of the authors and do not necessarily reflect the views of the IRPP or its Board of Directors.

IRPP Insight is an occasional publication consisting of concise policy analyses or critiques on timely topics by experts in the field.

If you have questions about our publications, please contact [irpp@irpp.org](mailto:irpp@irpp.org). If you would like to subscribe to our newsletter, *IRPP News*, please go to our website, at [irpp.org](http://irpp.org).

ISSN 3392-7748 (Online)

**CONTENTS**

Introduction ..... 4

Quebec’s AMD Process ..... 5

Issues with the AMD Regime in Quebec ..... 6

How to Improve Advance Medical Directives ..... 10

Conclusion ..... 14

## INTRODUCTION

Policies related to end-of-life care have been thrust into the spotlight following the adoption in 2015 of the Quebec *Act Respecting End-of-Life Care (AELC)*, the Supreme Court of Canada's *Carter* case in 2015 and the adoption in 2016 of federal Bill C-14 on medical assistance in dying. These legislative initiatives and the court decision have begun to provide clarity on complex aspects of end-of-life care policy frameworks. However, in light of these developments, we should pay further attention to one critical foundation for end-of-life care policies: the process of expressing personal preferences in advance medical directives (AMDs) or other types of advance care planning.<sup>1</sup>

One of the challenges faced by health care policy-makers is how to initiate conversations between patients and health care providers to explore their options and wishes regarding end-of-life care. Not many people fill out AMDs, but policy-makers are trying to encourage greater use of them.<sup>2</sup> A second concern is that, when patients do complete AMD forms, the instructions in them legally constrain the clinical decisions of health care professionals.<sup>3</sup> For these two reasons, the validity and authenticity of the process used to prepare AMDs should be closely examined.

Advance care planning can be undertaken at any stage of life, not just by those already facing serious illness. There are significant benefits to using AMD regimes to register individuals' wishes and values with respect to the health care they want to receive (or not) if they become incapacitated.<sup>4</sup> People often have preferences about types of end-of-life care and about who they would like to have speaking or making decisions on their behalf if they are unable to do so. Yet people who don't articulate these wishes to health care professionals, family, friends and caregivers may receive unwanted procedures, and their loved ones may experience stressful conflict in a time of crisis.

From the policy-makers' perspective, the motivations to improve AMD regimes are many. AMDs can help reduce the stress on health care professionals, decrease the hospitalization of nursing home residents and reduce unnecessary treatments.<sup>5</sup> For some policy-makers, the value of AMDs is to ensure that scarce public resources are not wasted on providing unnecessary or unwanted end of life care.<sup>6</sup> However, the true

<sup>1</sup> For a broader analysis of the advance medical directives regime in Quebec, see L. Bernier and C. Régis, "Regard critique sur le régime québécois des directives médicales anticipées comme véritable consécration de l'autonomie," *Revue générale de droit médical* 62 (2017): 35-64.

<sup>2</sup> Royal Society of Canada Expert Panel, *End-of-Life Decision Making* (Ottawa: RSC, 2011).

<sup>3</sup> T.M. Pope, "Legal Briefing: New Penalties for Disregarding Advance Directives and Do-Not-Resuscitate Orders," *Journal of Clinical Ethics* 28, no. 1 (2017): 74-81. On the legally binding effects of patients' advance directives, see the Georgia Supreme Court decision in *Doctors Hospital of Augusta et al. v. Alicea* (2016), S15G1571, <https://caselaw.findlaw.com/ga-supreme-court/1741593.html>.

<sup>4</sup> W.J. Liu, W.Y. Hu, Y.F. Chiu, T.Y. Chiu, et al., "Factors That Influence Physicians in Providing Palliative Care in Rural Communities in Taiwan," *Supportive Care in Cancer* 13, no.10 (2005): 781-89; J.C. Hofmann, N.S. Wenger, R.B. Davis, J. Teno, et al., "Patient Preferences for Communication with Physicians about End-of-Life Decisions," *Annals of Internal Medicine* 127, no. 1 (1997): 1-12.

<sup>5</sup> See Canadian Medical Association, *CMA Policy: Advance Care Planning* (Ottawa: CMA, 2017), [https://www.cma.ca/Assets/assets-library/document/en/advocacy/cma\\_policy\\_advance\\_care\\_planning\\_pd17-04-e.pdf](https://www.cma.ca/Assets/assets-library/document/en/advocacy/cma_policy_advance_care_planning_pd17-04-e.pdf).

<sup>6</sup> Quebec, National Assembly, Commission de la santé et des services sociaux (Health and Social Services Committee), *Journal de débats* (Debates) 43, no. 35, September 18, 2013, Mme V. Hivon, <http://www.assnat.qc.ca/fr/travaux-parlementaires/commissions/csss-40-1/journal-debats/CSSS-130918.html>.

basis for these regimes should be respect for individual autonomy, which means the right of patients to make decisions regarding their care.

Recent legal challenges like the *Carter* case have raised questions that policy-makers will be pressed to address: for instance, the sensitive issue of whether to allow AMDs for medical assistance in dying.<sup>7</sup> If legislatures are to give serious consideration to this possibility, provincial AMD processes must have robust ethical and legal structures to support highly complex end-of-life decisions.

In this paper, we scrutinize Quebec’s legally binding AMD regime, focusing on the standardized form introduced in 2015. We examine some difficulties with Quebec’s regime, especially in contrast to best practices elsewhere that help individuals carefully and proactively reflect on their most important values and preferences and how these may affect their wishes for end-of-life care. This paper looks particularly at the challenges involved in promoting individual autonomy: supporting individuals to make informed choices about future medical interventions.

We also briefly consider advance care planning regimes in other provinces: Alberta, British Columbia, Ontario and Saskatchewan. Some regimes face challenges similar to Quebec’s, but we also identify examples of progress in the development of policies that lead to clearer, more informed choices. Building on the examples of AMD regimes in Alberta and British Columbia, we recommend that Quebec improve its AMD process for end-of-life care to be more values-based. The objective should be to encourage patients to state their broader desires, their sources of happiness or the value they place on interpersonal relationships and social environments in order to better inform their advance care planning. We also encourage Quebec to explore ways to better integrate the roles and responsibilities of substitute decision-makers in this process; for instance, Quebec could consider combining its form-based AMD with a representative agent agreement, like British Columbia’s.

## QUEBEC’S AMD PROCESS

In 2015, Quebec made significant changes to its AMD regime: it created a process that allows Quebecers aged 18 and over to state on a pre-established form – a downloadable questionnaire – their wishes about accepting or refusing specific medical interventions if they ever become incapable of giving consent.

The scope of AMDs is limited to five types of interventions in specific clinical situations near the end of life or in case of severe, irreversible loss of cognitive functions.<sup>8</sup> This process is not the same as the one by which Quebecers can delegate end-of-life choices to a

<sup>7</sup> In Quebec, as elsewhere in Canada, medical assistance in dying is a separate process requiring different forms and procedures. It cannot, for the time being, be requested in advance.

<sup>8</sup> The five interventions are (1) cardiopulmonary resuscitation; (2) ventilator-assisted respiration; (3) dialysis; (4) force-feeding and hydration; and (5) artificial feeding and hydration. Quebec, “Advance Medical Directives: Requirements,” last updated March 27, 2018, <https://www.quebec.ca/en/health/health-system-and-services/end-of-life-care/advance-medical-directives/requirements/>.

proxy decision-maker through a document called a protection mandate<sup>9</sup> – in fact, in the case of the five treatments specified in the AMDs, the AMDs take precedence over any instructions expressed in a protection mandate (*AELC*, section 62).

The questionnaire begins by addressing a number of frequently asked questions regarding advance directives, then briefly explains the types of procedures to which the directives apply and the legal implications of the completed form.<sup>10</sup> For instance, it states that once health professionals are informed of AMDs, they are obliged to follow them.<sup>11</sup> It then describes a few situations near the end of life that involve severe and irreversible illnesses and loss of cognitive functions; among the examples are being in a comatose state or being deemed in an irreversible or permanent vegetative state. These are followed by checkboxes where a person chooses “I refuse” or “I consent to” for each of the five types of clinical intervention.

The questionnaire thus reduces advance medical care decisions to an apparently simple set of choices. However, in practice, providing consent in advance is complex because medical practice traditionally relies on “informed consent,” that is, patients should be fully informed of the risks and benefits of proposed care before they authorize a medical intervention. With AMDs, not all the information relevant to the decision is at hand at the time when the directives are signed, and this raises a number of important issues.

## ISSUES WITH THE AMD REGIME IN QUEBEC

### Individuals must self-inform

The responsibility to be properly informed in the Quebec AMD regime rests, in practice, on the shoulders of the persons completing them (*AELC*, section 59). They are responsible for getting any additional information they might need to understand the full implications of the options available and make informed medical decisions. There is no requirement that individuals’ decisions be informed or guided by health care professionals, nor does the system always provide the resources people need to understand the options, alternatives and consequences of care choices they are about to make.

These policy choices may have been intended to improve efficiency or to increase the likelihood of individuals completing AMD forms. But we believe that in the

<sup>9</sup> As outlined in section 2166 of the Civil Code of Quebec.

<sup>10</sup> Quebec, Régie de l’assurance maladie (Health Insurance System), “Advance Medical Directives – Download the Form,” accessed December 21, 2018, <http://www.ramq.gouv.qc.ca/fr/citoyens/Pages/directives-medicales-anticipees-telechargement-du-formulaire.aspx>.

<sup>11</sup> “Advance medical directives have the same value as wishes expressed by a person capable of giving consent to care. If an incapacitated person has issued medical directives, the doctor is not required to obtain authorization from the person who can consent to care on the patient’s behalf (their representative). Advance medical directives are binding, which means that health professionals that have access to them are obliged to comply with them.” Quebec, “Advance Medical Directives: Description,” last updated March 27, 2018, <https://www.quebec.ca/en/health/health-system-and-services/end-of-life-care/advance-medical-directives/>.

simplification of the process, the regime has effectively been deprived of elements that are essential to valid consent and the protection and support of patients.<sup>12</sup> Indeed, one of the most important such elements is the conversations between individuals, health care providers and family members or significant others that help ensure all significant issues are covered.

Health care professionals, in particular, can facilitate advance care planning and discussions between patients and their family members by offering and explaining potentially complex information as a way to help individuals articulate their preferences.<sup>13</sup> Communication about, for example, the stages, variants and consequences of a patient's disease could help to ensure that the preferences recorded in the directives are as complete, free and informed as possible. Indeed, it might be difficult for patients to grasp on their own that Alzheimer's, for instance, is a multistage disease that evolves differently from one patient to another and that patients may still enjoy life, to some degree, even at very late stages. Although the documents provided as part of Quebec's AMD regime encourage people to reflect on these issues, this reflection process is not assisted by professionals nor is it required. So it is entirely possible that some patients are making advance care decisions without any communication with anyone but the witnesses to their signatures on the AMD form.<sup>14</sup>

### The constraints of a form-focused AMD process

Although individuals are entitled to modify or revoke their AMDs at any time and periodic updates are recommended, nothing in the system prompts people to review their choices. To modify or revoke their AMDs, individuals must be capable of consent and must file either a new AMD form or a revocation form, unless there is an emergency (AELC, section 54). Once an AMD form is signed, family members have no discretion to introduce new information to help the care team interpret the AMD in order to respect the patient's values and life priorities as much as possible.<sup>15</sup>

The expression of preferences through advance medical directives should be a process that evolves along with a person's condition and the information at their disposal.<sup>16</sup> This is crucial because a patient's perception of a disease can change over time, both with experience of living with a disease and with changes in cognitive functions.<sup>17</sup>

<sup>12</sup> For an enlightening discussion on the importance of reaching a new balance, see D. Groll, "Medical Paternalism – Part 1" and "Medical Paternalism – Part 2," *Philosophy Compass* 9, no. 3 (2014): 186-203. See also A. Wardrode, "Relational Autonomy and the Ethics of Health Promotion," *Public Health Ethics* 8, no. 1 (2015): 50-62; T.L. Beauchamp and J.F. Childress, *Principles of Biomedical Ethics*, 7th ed. (New York: Oxford University Press, 2013); P. Pariseau-Legault and F. Doutrelepon, "L'autonomie dans tous ses états: une analyse socio-juridique du consentement aux soins médicaux," *Recherche en soins infirmiers* 4, no. 123 (2015): 19-35.

<sup>13</sup> Bernier and Régis, "Regard critique."

<sup>14</sup> For a broad analysis of the scope of patients' consent and doctors' duty to inform, see S. Philips-Nootens, R.P. Kouri, and P. Lesage-Jarjoura, *Éléments de responsabilité civile médicale : le droit dans le quotidien de la médecine*, 4th ed. (Cowansville: Éditions Yvon Blais, 2016), paragraphs 107 and 110.

<sup>15</sup> Only a court can invalidate AMDs, if they are contested by a person who has demonstrated having a special interest in the individual in question and reasons to question the validity of the AMDs; AELC, section 61.

<sup>16</sup> Philips-Nootens, Kouri, and Lesage-Jarjoura, *Éléments de responsabilité civile médicale*, paragraphs 107 and 110.

<sup>17</sup> P.T. Menzel and B. Steinbock, "Advance Directives, Dementia and Physician-Assisted Death," *Journal of Law, Medicine & Ethics* 41, no. 2 (2013): 484-500, doi: 10.1111/jlme.12057; J. Gather and J. Vollmann, "Phys-



Recent studies show that ongoing, meaningful communication between patients and physicians is central to ensuring the integrity and validity of the directives, even though such a process can be a challenge to put in place.<sup>18</sup>

Sometimes, when patients are no longer competent to have this discussion, it can be useful to rely on family members or substitute decision-makers to get insights on the patients' values and life history or any changes in their wishes. However, once a patient has a signed and registered AMD form, the Quebec legal regime simply assumes that the care choices on the form remain valid. This leaves very little flexibility for family members who have a different understanding of a patient's wishes, except to contest the validity of the AMD process itself in court (*AELC*, section 61).

Quebec's AMD regime stands in contrast to the often-recommended collaborative model, which calls for physicians, patients and relatives to be involved and considered as partners able to contribute to the process using decision-assistance tools and coaching strategies.<sup>19</sup> Interestingly, a collaborative approach is required for medical assistance in dying (MAiD): the Quebec legislation demands that eligible patients follow a compulsory communication process with their relatives (when possible) and health care teams (*AELC*, section 29, paragraphs 1 and 2) before MAiD can be administered. If MAiD is ever to be incorporated into the AMD regime, a recognition of the need for meaningful dialogue, and the time and mechanisms to carry it out, would have to be embedded in the AMD process.

## Individual and relational autonomy

In the context of AMDs, promoting individual autonomy involves supporting individuals to make informed choices about future medical interventions. It demands that questions be asked: What are each person's views, preferences, dilemmas and hesitations? What are the values and assumptions underlying their choices? How do their familial and social relations factor into their decisions? Quebec's current process,

---

ician-Assisted Suicide of Patients with Dementia: A Medical Ethical Analysis with a Special Focus on Patient Autonomy," *International Journal of Law and Psychiatry* 36, nos. 5-6 (2013): 444-52.

<sup>18</sup> L.A. Siminoff, G.C. Graham, and N.H. Gordon, "Cancer Communication Patterns and the Influence of Patient Characteristics: Disparities in Information-giving and Affective Behaviors," *Patient Education and Counseling* 62, no. 3 (2006): 355-60. In a recent study, Ilan and Carmel present a scale of factors influencing the quality of patient communication in a medical setting: S. Ilan and S. Carmel, "Patient Communication Pattern Scale: Psychometric Characteristics," *Health Expectations* 19, no. 4 (2016): 842-53. A recent empirical study undertaken with 23 Swiss doctors reveals that they use the pre-established form mainly as a conversation starter in their use of AMD: I.N. Otte, B. Elger, C.C. Jung, and K.W. Bally, "The Utility of Standardized Advance Directives: The General Practitioners' Perspective," *Medicine, Health Care and Philosophy* 19 (2016): 2-3.

<sup>19</sup> Ilan and Carmel, "Patient Communication Pattern Scale." See also S. Dawn and F. Légaré, "Engaging Patients Using an Interprofessional Approach to Shared Decision-making," *Canadian Oncology Nursing Journal* 25, no. 4 (2015): 455-69; K.M. Swetz, D.D. Matlock, A.L. Ottenberg, and P.S. Mueller, "Advance Directives, Advance Care Planning, and Shared Decision Making: Promoting Synergy Over Exclusivity in Contemporary Context," *Journal of Pain and Symptom Management* 47, no. 3 (2014): 375-80, doi: 10.1016/j.jpainsymman.2013.10.010; A.M. Stiggelbout, T. Van der Weijden, M.P. De Wit, D. Frosch, et al., "Shared Decision Making: Really Putting Patients at the Centre of Healthcare," *British Medical Journal* 344 (2012): e256, doi: 10.1136/bmj.e256; D. Stacey, F. Legaré, K. Lewis, M.J. Barry, et al. "Decision Aids for People Facing Health Treatment or Screening Decisions," *Cochrane Database of Systematic Reviews* 4 (2017): CD00143, doi: 10.1002/14651858.CD001431.pub5.



which consists of filling in a form with a pre-established checklist of choices for care, is unlikely to fully reflect the complexity of the individual's decision; instead, it reflects the narrow conception of individual autonomy on which this AMD regime appears to be built.

The Quebec government recently updated its AMD webpage to encourage people to think about their values.<sup>20</sup> This is progress, even if no interactive tools are provided to reflect on such values and the form still does not include any space for the expression of those values.

The concept of *relational autonomy* acknowledges that an individual's autonomy and decision-making ability evolve within a broader social context.<sup>21</sup> It requires considering the social, cultural, economic and political elements that constitute a person's background – their thinking about end-of-life care and their capacity to make the necessary choices.<sup>22</sup>

For instance, aging can be experienced and viewed with fear and aversion in societies that value youth, creating a stereotyped perception of elderly people, both in their own eyes and in those of others.<sup>23</sup> People who are dependent on others, to take another example, might not have sufficient decision-making skills or opportunities to make independent and meaningful choices. They may struggle to exercise autonomy in expressing their preferences.

Relational autonomy is also seen in the positive relationships patients have with those close to them – relationships that can be important considerations in guiding their decisions. For instance, many parents would find it important to give their children a chance to see them before they die, because of the impact such a visit would have on their children's psychological and emotional well-being. AMDs that can be personalized would open up an opportunity for dialogue to ensure that a family's important personal considerations can be voiced and taken into account.

Consider the following scenario: a 70-year-old woman, in good mental and physical health, checks off options to refuse care in all the boxes on the AMD form and signs it. Two years later, she suffers a serious accident that places her in a permanent vegetative state, and the physician in charge looks at the AMD form and refrains from

<sup>20</sup> Government of Quebec, "Advance Medical Directives," Health System and Services, <https://www.quebec.ca/en/health/health-system-and-services/end-of-life-care/advance-medical-directives/>.

<sup>21</sup> C. McLeod and S. Sherwin, "Relational Autonomy, Self-Trust, and Health Care for Patients Who Are Oppressed," in *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self*, ed. C. Mackenzie and N. Stoljar (New York: Oxford University Press, 2000); J. Downie and J. Llewellyn, eds., *Being Relational: Reflections on Relational Theory and Health Law* (Vancouver: UBC Press, 2012); C. Mackenzie and N. Stoljar, eds., *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self* (New York: Oxford University Press, 2000); R. Leckey, *Contextual Subjects: Family, State, and Relational Theory* (Toronto: University of Toronto Press, 2008).

<sup>22</sup> McLeod and Sherwin, "Relational Autonomy"; S. Sherwin and M. Winsby, "A Relational Perspective on Autonomy for Older Adults Residing in Nursing Homes," *Health Expectations* 14, no. 2 (2010): 182-90, doi: 10.1111/j.1369-7625.2010.00638.x; Leckey, *Contextual Subjects*.

<sup>23</sup> Sherwin and Winsby, "Relational Perspective," 186.

providing care. But then her son, who lives abroad, phones the doctor and asks him to keep his mother alive for a week so that he can see her before she dies. The son says that this is important for his mourning and that his mother would have wanted it. The doctor is torn: the form does not authorize him to provide the care being asked for, but he understands the importance of the son's request. Moreover, maintaining temporary life support does not involve any physical discomfort for his patient.

This example illustrates how generic AMD forms may fail to capture individuals' life circumstances and values, thus limiting the range of options available to them, their family members and care providers. A regime that allows or even requires broader discussion of the various concerns and constraints that influence individuals' choices can ensure that they get the consideration they deserve. Far from taking away the capacity for self-determination, the involvement of family and others close to an individual helps to ensure fuller expression of their wishes. A system that expands its view of personal choice to embrace this wider relational concept could provide more meaningful autonomy.

## HOW TO IMPROVE ADVANCE MEDICAL DIRECTIVES

Fundamentally, people should have the opportunity to state, in an explicit and meaningful way, their preferences relating to end-of-life care in general. This means allowing people to express the values and interests that give meaning to their life and the circumstances that would justify putting an end to it. For some, physical pain and suffering could be the most important impediment to their well-being; for others, the lack of intellectual capacity or engagement would be decisive. Form-based AMDs that do not record this information, and do not require that individuals speak to health care professionals to better understand what medical interventions entail, may lack the appropriate context and clarity.

Some processes in other provinces highlight how to improve people's ability to express what matters most for them at the end of life.

### Lessons from other provinces

The ways in which provinces design and formalize their advance care planning processes to encourage conversations about potential care needs vary greatly. Some provinces focus only on form-based directives; others allow form-based directives as part of a range of advance care planning options; still others use no forms at all.

Alberta's and British Columbia's regimes (see box 1) stand out in that they strongly support the use of a representative – a proxy selected by an individual – and they encourage health care professionals to engage in meaningful conversations with the person in order to discuss values, wishes and goals. The Alberta regime, in particular, makes dialogue between health care professionals, patients and family members the cornerstone of its advance care planning process and integrates tools

## Box 1: Advance Care Planning in Alberta and British Columbia

### Alberta

Alberta's regime for advance care planning integrates a values-based strategy. The Alberta model proposes a paradigm of advance care planning that hinges on a representative – a proxy – chosen by the patient to act as the final decision-maker in case of incapacity.

Patient engagement and dialogue are key. The tool kit offered to Albertans pinpoints conversation starters that help them to contemplate matters such as suffering, quality of life and duration of life. It includes informative videos and other information on various care interventions and plain-language materials to help people identify preferences. For instance, it prompts people to consider what they enjoy most, what they look forward to and what makes life livable and workable.

### British Columbia

British Columbia's model offers an array of options to patients for their end-of-life wishes. Any capable adult can express his health care decisions, including life support or life-prolonging medical interventions, through an advance medical directive. British Columbia's laws provide the option to combine an AMD with a representation agreement. The representative has decision-making authority on a range of minor and major health care procedures such as major surgery or any treatment involving a general anesthetic. The representative's decision prevails over the advance medical directive unless the representation agreement states otherwise. A representative can "refuse or consent to health care necessary to preserve life."

The advance care planning guide issued by the Ministry of Health aims to enrich patients' conversations with their close family or health care providers. Fictional cases illustrate how various advance care options may suit particular persons or situations. For example, a person without close family or friends could choose the option of an AMD over appointing a representative because she considers only her health care provider trustworthy. On the other hand, a person with good support could appoint a representative without making any advance directives. The guide also offers a series of questions to foster patients' reflection on broad issues such as meaningful aspects of their life.

that allow for a values-based approach.<sup>24</sup> Critically, these discussions are not always limited to specific health care interventions but instead cover more broadly the things in life that people value the most. This dialogue provides family members and health professionals with additional, valuable information when they must make decisions about medical interventions.

British Columbia's system has other features worth mentioning.<sup>25</sup> If people choose not to select an agent, perhaps due to complex issues of family trust, they can bypass this step and register an advance directive, using a signed form, after discussing the issues directly with their health care provider. British Columbia also provides a specific guide for First Nations that invites patients to "provide specific instructions for traditional ceremonies such as smudging, sage burning and spiritual bathing."<sup>26</sup> Since culture strongly influences First Nations people and their decision-making process, this initiative reinforces the idea of relational autonomy.

<sup>24</sup> Alberta Health Services, *Advance Care Planning: Tools and Checklists*, last updated April 2, 2018, <https://myhealth.alberta.ca/Alberta/Pages/advance-care-planning-tools-and-checklist.aspx>.

<sup>25</sup> British Columbia, *Advance Care Planning*, n.d., <https://www2.gov.bc.ca/gov/content/family-social-supports/seniors/health-safety/advance-care-planning>.

<sup>26</sup> British Columbia Aboriginal Health Program, *Advance Care Planning: Respecting Aboriginal Ceremonies and Rites*, 2012, <http://www.health.gov.bc.ca/library/publications/year/2012/aboriginal-health-advance-care-planning-brochure.pdf>.

## Box 2: Advance Care Planning in Ontario and Saskatchewan

### Ontario

The *Substitute Decisions Act* in Ontario does not explicitly refer to “advance care planning” or “advance medical directives.” Instead, it only allows a person to name a power of attorney for personal care, who is responsible for making decisions on health care, nutrition, shelter, clothing, hygiene and safety. As long as the grantor was competent when signing the document, any instructions in it are legally binding on the person designated, unless they are impossible to respect, in which case the incapable person’s best interests should be considered. No specific form is required to incorporate directives into the document.

### Saskatchewan

Under *Saskatchewan’s Health Care Directives and Substitute Health Care Decision Makers Act*, people can adopt a health care directive. It contains specific statements about treatments, but also allows a person to name a proxy as a decision-maker. When health care directives clearly anticipate a specific treatment, proxies must follow patients’ wishes about the treatment. If a proxy is not aware of the patient’s wishes, they must decide according to what they consider the person’s best interests.

The forms for directives provided by the various health regions within the province vary greatly in content and structure. For example, the Saskatoon Health Region offers a form with three scenarios: the patient will likely recover; the patient may require many months or even years to recover; the patient’s death is inevitable. For each scenario, the patient is invited to check “Yes, I would accept” or “No, I would not accept” for various types of care interventions.

Models in Ontario and Saskatchewan (see box 2), by contrast, share the flaws of Quebec’s regime. Ontario’s tool kit and Q&A guide do not encourage patients to reflect on their beliefs, nor do they list or describe any common forms of care interventions.<sup>27</sup> These omissions make the Ontario regime even less informative and detailed than Quebec’s form-based system. The materials repeatedly advise patients to consult a lawyer but never expressly invite them to identify their values. This practice cannot effectively stimulate dialogue between patients and families, since the whole process is seen through only a legal lens. Saskatchewan residents can make health care directives, but the province has no single standard form for them.<sup>28</sup> Where a simplistic “yes or no” checklist is used, it presents the same challenges as Quebec’s regime.

The Alberta and British Columbia approaches could serve as useful models to improve Quebec’s ADM regime (and those of other provinces). Both provinces provide user-friendly tool kits or guides that can help people meaningfully articulate their wishes and have valuable dialogue with their loved ones and health care providers. Despite some recent progress, Quebec’s regime lacks this kind of collaborative and engaging process.

British Columbia’s approach also illustrates how advance medical directives can be combined with a proxy decision-maker agreement. Avenues to leave some role and

<sup>27</sup> Ontario, Ministry of the Attorney General, *Powers of Attorney*, 2012, <https://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/poa.pdf>; Ontario, Office of the Public Guardian and Trustee, *Powers of Attorney: Questions and Answers*, 2007, <https://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/livingwillqa.pdf>.

<sup>28</sup> For example, for the Regina Qu’Appelle Health Region, see Saskatchewan Health Authority, *Advance Care Planning*, 2018, <http://www.rqhealth.ca/department/advance-care-planning/advance-care-planning>. For the Saskatoon Health Region, see Saskatchewan Health Authority, *Advance Care Directive (Living Will)*, last modified July 5, 2017, <https://www.saskatoonhealthregion.ca/patients/Pages/Advance-Care-Directive.aspx>.

influence to substitute decision-makers should be explored in Quebec. As noted earlier, Quebec's regime legally excludes proxy decision-makers from any role in choices about the five treatments specified in an AMD if a patient has filed one. Finding a better balance between the two options could, at least in some circumstances, help everyone involved to better interpret and implement a patient's wishes.

### Concrete measures for better AMD results

People who wish to fill out AMD forms should first discuss the options with a doctor or other medical professional who can provide important information. As part of a comprehensive AMD regime, these discussions could consist of clear, simple, plain-language interactive computer tools that can assess individuals' comprehension and guide them through the process; telephone support provided by physicians; or face-to-face meetings.

An improved AMD process should also leave room for broader, more flexible expression of personal wishes (for instance, the possibility of being kept alive artificially, for a limited period of time, to give family members more time at the patient's bedside). It could also allow a role for a proxy decision-maker for some decisions related to AMDs. Other resources could be added to the documentation, such as a video or audio file in which a person states additional preferences and provides context for their decisions. This recording could be sent to the family and available to medical personnel to help interpret the preferences registered in form-based AMDs.<sup>29</sup>

Many people find the process of reflecting on and stating their wishes for end-of-life care arduous. Policy-makers and health care providers should consider providing assisted communication support, such as bioethics mediation. This form of mediation allows for qualified third-party interveners to use communication techniques that help people highlight and articulate their core values and preferences, then help translate these values into a medical context.<sup>30</sup>

The values critical to end-of-life decisions raise the thorniest questions; they can be difficult to identify, confront and formulate, which is why they often remain unexplored and undeveloped.<sup>31</sup> Assisted communication or bioethics mediation has demonstrated the potential to help people in this regard. It can also make people more aware of the positive and negative relational influences that steer their decision-making process. When useful and appropriate, the mediator can invite those close to a person to participate. Expertise in assisted communication or bioethical mediation could be developed through training of existing health care professionals and could be incorporated into current health care system structures.

<sup>29</sup> D. Shaw, "Personalized Organ Donation Directives: Saving Lives with PODDs," *Critical Care* 18, no. 3 (2014), 141.

<sup>30</sup> For more information on the role and possibilities of bioethics mediation, see N.N. Dubler and C.B. Liebman, *Bioethics Mediation: A Guide to Shaping Shared Solutions*, rev. and expanded ed. (Nashville: Vanderbilt University Press, 2011); E.A. Waldman, "Bioethics Mediation at the End of Life: Opportunities and Limitations," *Cardozo Journal of Conflict Resolution* 15, no. 2 (2014): 449-71.

<sup>31</sup> R.D. Truog, S.D. Brown, D. Browning, E.M. Hundert, et al., "Microethics: The Ethics of Everyday Clinical Practice," *Hastings Center Report* 45, no. 1 (2015): 11-7, doi: 10.1002/hast.413.

## CONCLUSION

Quebec's AMD regime for end-of-life care decisions has some key shortcomings. It relies too much on individuals to do their own research; the process is more or less limited to signing a form; and it does not allow room for people to express what they value most. These issues are of great consequence, and they need to be addressed to maintain public support for these regimes and to prepare patients, families and health professionals for the end-of-life decisions they may have to face.

Quebec should incorporate a broader, more values-based and collaborative approach in its AMD process so that people can more meaningfully express their wishes for end-of-life care. Assisted communication or mediation techniques could provide patients and their families with additional support and help in navigating the complicated aspects of expressing values and preferences in the context of advance care planning.

Although Quebec's regime is the main focus of this paper, the other AMD models we have reviewed here should serve as a reference for provinces looking to improve their own regimes. Examining and improving AMD processes will be a complex but essential task to provide a solid foundation for end-of-life care policies, which are evolving rapidly. This work should precede any consideration of including requests for MAiD in advance medical directives.







*Institute for  
Research on  
Public Policy*

*Institut de  
recherche  
en politiques  
publiques*

Founded in 1972, the Institute for Research on Public Policy is an independent, national, bilingual, not-for-profit organization. The IRPP seeks to improve public policy in Canada by generating research, providing insight and informing debate on current and emerging policy issues facing Canadians and their governments.

The Institute's independence is assured by an endowment fund, to which federal and provincial governments and the private sector contributed in the early 1970s.

Fondé en 1972, l'Institut de recherche en politiques publiques est un organisme canadien indépendant, bilingue et sans but lucratif. Sa mission consiste à améliorer les politiques publiques en produisant des recherches, en proposant de nouvelles idées et en éclairant les débats sur les grands enjeux publics auxquels font face les Canadiens et leurs gouvernements.

L'indépendance de l'Institut est assurée par un fonds de dotation établi au début des années 1970 grâce aux contributions des gouvernements fédéral et provinciaux ainsi que du secteur privé.

---

Copyright belongs to the IRPP.  
To order or request permission to reprint, contact:

IRPP  
1470 Peel Street, Suite 200  
Montreal, Quebec H3A 1T1  
Telephone: 514-985-2461  
Fax: 514-985-2559  
irpp@irpp.org