The Last Word: Balancing the Family Veto with a Legal Right to (Consent to) Donate Organs

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A thesis submitted in partial fulfillment of the requirements for the
Master's degree in Law

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Abstract

For many Canadians, the decision to register as an organ donor is made at the counter of ServiceOntario (or the provincial equivalent), and is reflected by a small notation on their driver's license. While most potential donors assume this registration carries binding legal effect, substitute decision-makers (SDMs) often invoke a "family veto", whereby this previously expressed intention to donate organs is not honoured. This thesis takes up the following questions: (1) in what ways do current Canadian organ donation and transplantation (ODT) law, policy, and public health messaging (either intentionally or inadvertently) support the continued use of the family veto; (2) to what extent is the family veto contrary to Canadian ODT law; (3) how should Canadian ODT legislation be amended to reduce family veto events; and (4) whether there is a positive legal right to donate organs in Canada, or to consent thereto. Ultimately, this thesis aims to demonstrate how a legal right to donate organs (or, at a minimum, to consent to donation without interference) is supported by accepted legal, medical, and bioethical practice, but that it must be carefully constructed so as not to place healthcare providers in no-win situations when balancing patient autonomy with the desires of the living. Recognition of this right will, in turn, require a reshaping of donation consent frameworks, in law and in policy. For when it comes to donation after death, it is crucial that donors, families, and physicians alike have legal clarity on the question of who gets the last word.

Acknowledgements

I would like to express my sincere gratitude to the Bertram Loeb Organ and Tissue Donation Institute, the Canadian Institutes of Health Research (CIHR), and the Canadian Graduate Scholarship for their financial support.

I am endlessly grateful to my supervisor, Jennifer Chandler, for her generosity, encouragement, and friendship throughout my studies. I would also like to thank Colleen Flood and Vanessa Gruben for their invaluable mentorship during my time at the University of Ottawa.

Finally, I would like to express my deepest gratitude for my wonderful family – my parents, Greg and Shona Lazin, and my sister, Sasha Lazin, who inspire me constantly. I would especially like to thank my husband, Akshay Sathya, whose unwavering support made this all possible.

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Legend

DCD	Donation after circulatory death
FPA	First-person authorization
FV	Family veto
HCCA	*Health Care Consent Act* (Ontario's medical consent legislation)
HCP	Healthcare provider
HOTDA	*Human Organ and Tissue Donation Act* (Nova Scotia's ODT legislation)
MAiD	Medical assistance in dying
NDD	Neurological determination of death
ODT	Organ donation and transplantation
OPO	Organ procurement organization
PMI	Pre-mortem intervention
SDM	Substitute decision-maker
TGLA	*Trillium Gift of Life Network Act* (Ontario's ODT legislation)
UAGA	*Uniform Anatomical Gift Act* (USA's ODT legislation)

Introduction

Healthcare decisions are never made in a vacuum. No matter the prognosis or treatment plan, family members are often keen to weigh in on the decisions facing their loved ones and offer their advice – whether solicited or not. The level of influence held by family members increases exponentially when they adopt a substitute decision-maker (SDM) role after their loved one has died or has lost decision-making capacity of their own. Perhaps unsurprisingly – and despite their best intentions – SDMs may not reflect the wishes or beliefs of the patient when making decisions on their behalf. This is especially true in the context of organ donation.

The "family veto" (also known as the "family override" or "family overrule") occurs when the next-of-kin refuse to authorize donation despite explicit, recorded consent for organ donation given by the deceased prior to their death.[1] While SDMs are expected to act in accordance with the wishes of the patient, the family veto demonstrates how often that does not happen. The stark disparity between those patients who have previously expressed a desire to donate organs, as compared with SDMs who do not honor those desires, has sparked ongoing debate as to whether patient autonomy is diminished by the family veto, and what duties physicians owe – and to whom – when the family veto is enacted. While legal personhood ends at death,[2] at least some degree of patient autonomy is widely regarded to extend to the deceased patient.[3] In addition to legal questions of the patient's autonomy and the physician's fiduciary duty to that patient, the practical implications of this disparity must not be overlooked. It is estimated that 15-20% of families in Ontario "ultimately decline organ donation when a decision to donate has *already been made* by the deceased."[4] In the 2019-2020 year, Ontario alone saw 72 reported family vetoes, "representing a loss of up to 250 potential transplant opportunities."[5] In that same year, 1,135 transplants were performed in Ontario, of which 885 came from deceased donors – both from neurological determination of death (NDD) patients and donation after circulatory death (DCD) patients.[6] At the end of 2020, there were 4,129 Canadians on organ transplant waiting lists – of whom 276 died before receiving a transplant.[7] At the time of writing, there are over 4,300 Canadians presently waiting for a transplant.[8]

Understandably, Weiss et al (amongst others) characterize the family veto as "emotionally charged and ethically ambiguous"[9] and many physicians have experienced moral distress when trying to

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[1] The family veto is distinct from family *refusal*, which occurs when families choose not to consent to organ donation when the intentions of the deceased are unknown.

[2] See Chapter 3 below for a further discussion.

[3] Consider, for example, deference paid to advance directives.

[4] Samantha J. Anthony et al, "Family veto in organ donation: the experiences of Organ and Tissue Donation Coordinators in Ontario" (2021) 68 Can J Anesth 611 at 612 (emphasis added).

[5] *Ibid*. Ontario is the only jurisdiction in Canada that has published rates of family veto events, though it does not do so annually.

[6] "Summary statistics on organ transplants, wait-lists and donors" (15 June 2023), online: *CIHI* <www.cihi.ca/en/summary-statistics-on-organ-transplants-wait-lists-and-donors>.

[7] *Ibid*.

[8] "Organ donation and transplantation collaborative", online: *Government of Canada* <www.canada.ca/en/health-canada/services/healthy-living/blood-organ-tissue-donation/organ-tissue/transplantation-collaborative.html>.

[9] Matthew Weiss et al, "Survey of Canadian intensivists on physician non-referral and family override of deceased organ donation" (2020) 67 Can J Anesth 313. See also Ian M. Ball, Robert Sibbald & Simon Oczkowski, "Family override for organ donation" (2020) 67 Can J Anesth 286 at 286.

balance the wishes of the living with those of the dead,[10] coupled with the ever-growing need for organ donations. This discomfort has been widely documented.[11] To complicate matters further, the contents of provincial consent laws are not reflected in public health messaging regarding organ donation or the policies of individual organ procurement organizations (OPOs). For example, Ontario's *Trillium Gift of Life Network Act* (TGLNA) specifies that previously given consent for organ donation is binding, unless there is reason to believe consent was subsequently withdrawn by the patient between the time of providing consent and their death.[12] However, the province's OPO, the Trillium Gift of Life Network, notes that its clinical practice is "to reaffirm an individual's consent to donate with the family", thus opening the door to the family veto.[13]

While arguments have been made in favour and in opposition to the family veto, the scales are tipped significantly in opposition. Canadian media has condemned the veto as "terribly wrong", "tragic", and "a shame".[14] Medical professionals have described it as "an all too frequent reality that medical authorities would love to see changed."[15] However, in a systematic review of Canadian media's portrayal of the family veto, Anthony et al demonstrate a significant confusion surrounding the state of consent law – "almost two-thirds of the articles stated or implied that family veto is permitted under law, as this is incorrect in every Canadian province and territory." As expressed by Toews and Caulfield, the normalization of this error is represented in hospitals across the country implementing policies that directly contradict consent legislation.[16]

In response, some legal and medical scholars have suggested Canadians have a right to donate their organs[17] – or, more precisely, have a legal right to have their end-of-life decisions respected and their consent honored. However, as will be discussed below, opinions on protecting donation intentions as the "right" of the deceased vary. As expressed by Ball, Oczkowski, and Sibbald, doing so would uphold the ethical obligation to respect patient's wishes to donate, and thus uphold patient autonomy even after death.[18] Per Anthony et al, reducing the family veto would avoid bedside conflicts between healthcare workers and families and reduce the moral distress experienced by healthcare workers during the veto process.[19] It would provide donors with clarity and comfort, knowing their wishes would be respected.[20] And ultimately, a legal right to donate could theoretically reduce family veto rates. In Canada, this could have the effect of increasing deceased donor rates by up to 30%.[21]

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[10] Ian M. Ball, Simon Oczkowski & Robert Sibbald, "Much ado about the family veto" (2021) 68 Can J Anesth 601 at 602.
[11] See Weiss et al, *supra* note 9.
[12] *Trillium Gift of Life Network Act*, RSO 1990, c H20, s 4(3) [TGLNA].
[13] "Frequently Asked Questions", online: *Trillium Gift of Life* <giftoflife.on.ca/en/faq.htm> ["FAQs"].
[14] Samantha J Anthony et al, "Family Veto in Organ Donation in Canada: Framing Within English-Language Newspaper Articles" (2021) 5:4 CMAJ Open E768 at E770 [Anthony et al 2021].
[15] *Ibid* at E771.
[16] Meaghan Toews & Timothy Caulfield, "Evaluating the 'family veto' of consent for organ donation" (2016) 188:17 CMAJ E436 at E436.
[17] For example, see Toews & Caulfield, *ibid*.
[18] Ball, Oczkowski & Sibbald, *supra* note 10 at 601.
[19] Anthony et al, *supra* note 4.
[20] *Ibid*.
[21] Jacob Crawshaw et al, "Exploring the experiences and perspectives of substitute decision-makers involved in decisions about deceased organ donation: a qualitative study protocol" (2019) BMJ Open 1.

Academic arguments against a legal right are less common. One main argument raised is that physicians have a moral obligation to the living. The deceased patient cannot be harmed, but their living family can.[22] This discussion becomes muddied when we consider that legal personhood ends at death – and so do most legal rights – but patient autonomy is widely regarded to extend to the deceased patient and their previously expressed wishes. Further, as expressed by Albertsen, the fact that the dead will not be directly harmed is not sufficient reason to overturn established norms of patient autonomy.[23] Furthermore, he suggests that if we are to focus on the harms caused by allowing or restricting the family veto, we should focus instead on the harm felt by patients waiting for transplants who are exposed to the risk of suffering – or death – while waiting for a donation.[24] A second key argument against a legal right is the fear that any change to the family veto could result in public mistrust of the organ donation system.[25] This mistrust could, in turn, create a risk of reducing donor registration when demand is already very high. However, scholars including Ball, Sibbald, and Oczkowski have argued not only that this fallout is unlikely, but also that we should be prioritizing and legally protecting patient autonomy, even in the face of public backlash.[26] However, global rates of the family veto appear to be increasing. Per Albertsen, there is a notable "reluctance across various procurement systems to act on a wish to donate if the family objects" – this is true of either opt-in or opt-out consent systems.[27]

For now, several questions remain unanswered. What are the legal and ethical consequences of the misalignment between provincial consent laws and individual hospital policies? Why is increasing weight being given to family vetoes while transplant waitlists continue to grow? What impacts does this trend have on patient autonomy and public trust in consent frameworks for posthumous decision-making? And is there a better way to balance the desires of the living with those of the dead?

The goal of this thesis is to address this uncertainty by taking up the following four questions: **(1)** What are the discrepancies in Canadian ODT law, policy, and public health messaging that reinforce the family veto? **(2)** To what extent is the family veto contrary to Canadian ODT legislation? **(3)** Is there a legal right to donate organs in Canada? And **(4)** How would the family veto intersect with this "right"? In doing so, I will demonstrate that the current clash between ODT law and OPO policy and public health messaging is unduly challenging for patients and physicians alike. For example, many Canadians assume their registration to donate will be respected after their death, and are unaware that families may override that wish. Notably, neither opt-in nor opt-out consent systems adequately protect against the family veto when they are implemented in their "soft" forms, and further legal reform is needed to afford sufficient legal protection to donor autonomy and consent.

There is a significant difference between the family veto (based on the personal objections of the SDM to organ donation) and a genuine expression by the SDM that the registered donor had changed their mind and no longer wanted to donate, and simply did not have the opportunity to

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[22] Y. Johnston, "Donation decisions after death: The case for a family veto" (2017) 3 Eth Med Pub Health 486.
[23] Andreas Albertsen, "Against the Family Veto in Organ Procurement: Why the Wishes of the Dead Should Prevail When the Living and the Deceased Disagree on Organ Donation" (2020) 34 Bioethics 272 at 274.
[24] *Ibid*.
[25] Johnston, *supra* note 22.
[26] Ball, Oczkowski & Sibbald, *supra* note 10 at 603.
[27] Albertsen, *supra* note 23 at 273.

revoke their consent before their death. However, where the situation is one of a family vetoing the registered donor's wishes, physicians are caught between wanting to respect the wishes and autonomy of the deceased while facing significant pressure from surviving family members. While many physicians may be hesitant to support an expansive legal "right" to donate given the bioethical and medical dangers associated with using organs that are not suitable for donation (which is prohibited in Canada for this very reason), there is significant frustration within the medical community surrounding the increasing frequency of family veto – especially in the face of a national organ shortage. Taken together, there is no current consensus on whether there *already is* a positive legal right to donate organs in Canada – or whether such a right should exist. Further questions include who would bear this legal right, who would have the reciprocal duties associated with this right (and what those duties would be), and what the reasonable limitations of that right would be.

In this way, this thesis will argue that there should be a legal "right" to (consent to) donate, but that it must be carefully constructed so as not to place healthcare providers (HCPs) in no-win situations. In doing so, the arguments contained within this thesis are two-fold: first, various corners of Canadian jurisprudence – from property law to health law – point in favour of a right to donate (or a right to consent to donate) already existing.[28] In the alternative, the lessons learned from other areas of the law strongly support the creation of such a right. A right to *donate* is (or would be) a positive legal right, whereby consent to donate must be respected whenever medically and logistically possible.[29] A right *to consent to donate* is (or would be) a negative legal right, whereby consent to donate would be protected from undue interference by SDMs.[30] Regardless of which version of the right is contemplated, ODT law and policy must be changed to better protect donation decisions – not only bearing in mind the societal objectives of increasing deceased organ donation rates, but in order to minimize harms experienced by would-be donors, would-be recipients and their families, HCPs, and the grieving families.

Chapter 1 of this thesis begins with a scoping review of the literature addressing the family veto. This review aimed to identify the main themes and conclusions in the literature – whether pertaining to law, medicine, or public health – on families vetoing previously given consent to organ donation. In doing so, the review captured 90 articles from a myriad of countries published over the past 40 years. The clear consensus in the literature is that the family veto is harmful to donors, the would-be donation recipients and their families, and healthcare providers. Families are acting contrary to their legal obligations by pursuing the family veto, but are often allowed to do so by healthcare providers. As such, there is a demonstrable need for OPOs and hospitals to better

[28] See, for example, the deference given to prior wishes discussed below in Chapter 3.
[29] The purpose of this thesis is *not* to argue that right to donate is – or should be – absolute. Reasonable limitations on consent are already contemplated in ODT law (for example, where a donation "cannot for any reason be used for any of the purposes specified in the consent"); here, there is no duty to proceed with procurement if the organs in question are medically unacceptable, there was not a suitable recipient, or if there were no medical staff available to facilitate the donation and transplantation processes. See TGLNA, *supra* note 12, s 8.
[30] Conceiving of the right in this way would leave medical decision-making in the hands of the HCPs (made in accordance with accepted medical practice), but would bar any third party from revoking or amending consent to donation that has already been made by the deceased without extenuating circumstances (for example, a limitation on this right would arise if the SDMs presented evidence that the donor had withdrawn their consent prior to their death. See Nova Scotia's *Human Organ and Tissue Donation Act*, SNS 2019, c 6, s 15(1) [HOTDA].

support physicians in addressing the family veto in clinical settings. There is also a need for donation decisions to be better protected by Canadian law.

Chapter 2 explores the current state of Canadian ODT law, which often stands in direct opposition to much of the country's public health messaging regarding the family veto. The Chapter further examines the elements of consent to donation in each province, and compares the mechanisms that vary between Canadian jurisdictions to record and share consent to donation. In doing so, Chapter 2 illustrates the gaps in Canadian ODT legislation, through which the family veto continues to flourish.

In order to explore the current state of Canadian ODT law and policy, Chapter 3 poses a hypothetical situation, wherein a woman in Ontario registers as an organ donor before passing away many years later. Despite her registration, her parents object to proceeding with organ donation. In using this hypothetical situation as the foundation for our legal analysis, Chapter 3 proceeds to answer three legal questions: (1) whether the family acted according to the law of Ontario; (2) whether the doctors acted according to the law of Ontario; and (3) if one (or both) of the parties acted contrary to provincial law, how might legal claims be brought against them (and to what end). With these questions in mind, Chapter 3 navigates whether it is correct to say there is a legal "right" to donate organs in Ontario, and whether the law should be amended to better protect the autonomous donation decisions of would-be donors.

Chapter 4 walks the road to presumed consent, exploring the national (and indeed, global) progression from opt-in to opt-out consent systems. In this way, Chapter 4 considers the role of SDMs in law and in practice, and discusses the manners in which the family veto is allowed to persist in Canadian ODT law, regardless of which consent system is pursued. This Chapter concludes by considering additional consent mechanisms that could be adopted by those Canadian provinces that remain wary of the shift to presumed consent, while simultaneously improving the autonomy of donors and reducing the rates of the family veto.

The concluding pages of this thesis will turn to ways in which consent processes for organ donation could be restructured in Canada to better promote and protect the autonomy of donors.

Ultimately, this thesis aims to demonstrate the harm caused by the family veto to donors, recipients, families, and healthcare providers. The family veto is an under-studied sociolegal phenomenon which – perhaps inadvertently – leads to hundreds of deaths each year. As law- and policy-makers grapple with whether a shift to an opt-out consent system will bridge the gap between supply and demand of organs, this thesis argues that drastically greater attention must be paid to the family veto. Neither legal reforms nor education campaigns alone are sufficient in addressing this problem, and until public health messaging and policy aligns with ODT legislation, healthcare providers will continue to be placed in emotionally charged, impossible to navigate situations, caught between the final words of the dead and the wishes of the living.

Chapter 1: Scoping Review

1. Introduction

Before delving into the legal and policy ramifications of the family veto, it is first prudent to explain how the family veto is discussed and understood in legal and medical literature. The objective of this Chapter is to understand the prevalence of the family veto in order to determine: the extent to which the family veto poses a medicolegal problem, the manner in which it occurs, and how the family veto can be addressed in law and in policy.

The research stage of this thesis began with a scoping review, with the intention of producing a comprehensive overview of diverse literature from around the world, including ethical and legal commentary, qualitative and quantitative empirical research, and systematic reviews.

2. Materials & Methods

This Chapter follows the method for scoping reviews described by Arksey and O'Malley.[31] In doing so, it follows five steps: **(1)** identify the research questions; **(2)** identify relevant studies; **(3)** select studies for inclusion; **(4)** extract the data from the studies; and **(5)** summarize and present the results.

2.1 Research Question Identification

The objective is to review and map the published peer-reviewed research on the use of the "family veto" or "family override" – the process by which families withdraw consent to organ donation previously given by their deceased family members. This includes texts that explicitly name the phenomenon ("family veto" / "family override" / "family overrule"), as well as those that simply describe the process. The central research question was:

> **What are the main themes and conclusions in the literature on families vetoing or overriding previously given consent to organ donation?**

Importantly, this is distinct from the body of literature on family refusal of organ donation (where families refuse when their loved one's donation intentions were unknown).

2.2 Identifying Relevant Studies

This scoping review began with a search of legal and scientific/medical research databases using a common search string adapted as needed to fit the requirements of the following databases: MEDLINE, Embase, CINAHL, LexisNexis, the Index to Legal Periodicals, and the Law Journal Library (HeinOnline). The search string included terms (and their variants) relating to the following concepts: (1) Organ donation AND (2) Consent AND (3) Family decision-making. A sample search string can be found below in Appendix 1. No restrictions were imposed regarding the date of publication, though included results had to be full sources (rather than stand-alone abstracts) published in English. Results were collected in July 2022.

[31] Hilary Arksey & Lisa O'Malley, "Scoping studies: toward a methodological framework" (2005) 8 Int J Soc Res Methodology 19.

2.3 Selecting Studies for Inclusion

The combined searches yielded 7053 results. After the manual removal of duplicate results, 4569 results were then screened independently by two reviewers according to inclusion and exclusion criteria (described below in Appendix 2). The decision was made to double-screen the results with the assistance of two research assistants (DP and TG) in order to enhance rigor. All other steps of the scoping review were performed only by the thesis author (SJL), except where otherwise indicated.

The inclusion and exclusion criteria were applied by SJL and two research assistants under the supervision of SJL. The criteria were applied to the title and abstract of each reference according to the inclusion and exclusion criteria detailed in Appendix 2.[32] Where abstracts were unavailable and the suitability of a source was unclear from title alone, a full-text search was conducted based on the following terms: family, overrid-, overrul-, veto, wish, intent, intention, decision, and/or desire. Where references lacked an abstract, they were evaluated on their title and – as necessary – their full text. Disagreements were resolved during a conference call with all three team members.[33]

This screening process resulted in a final set of 90 articles, all of which were used in this review.

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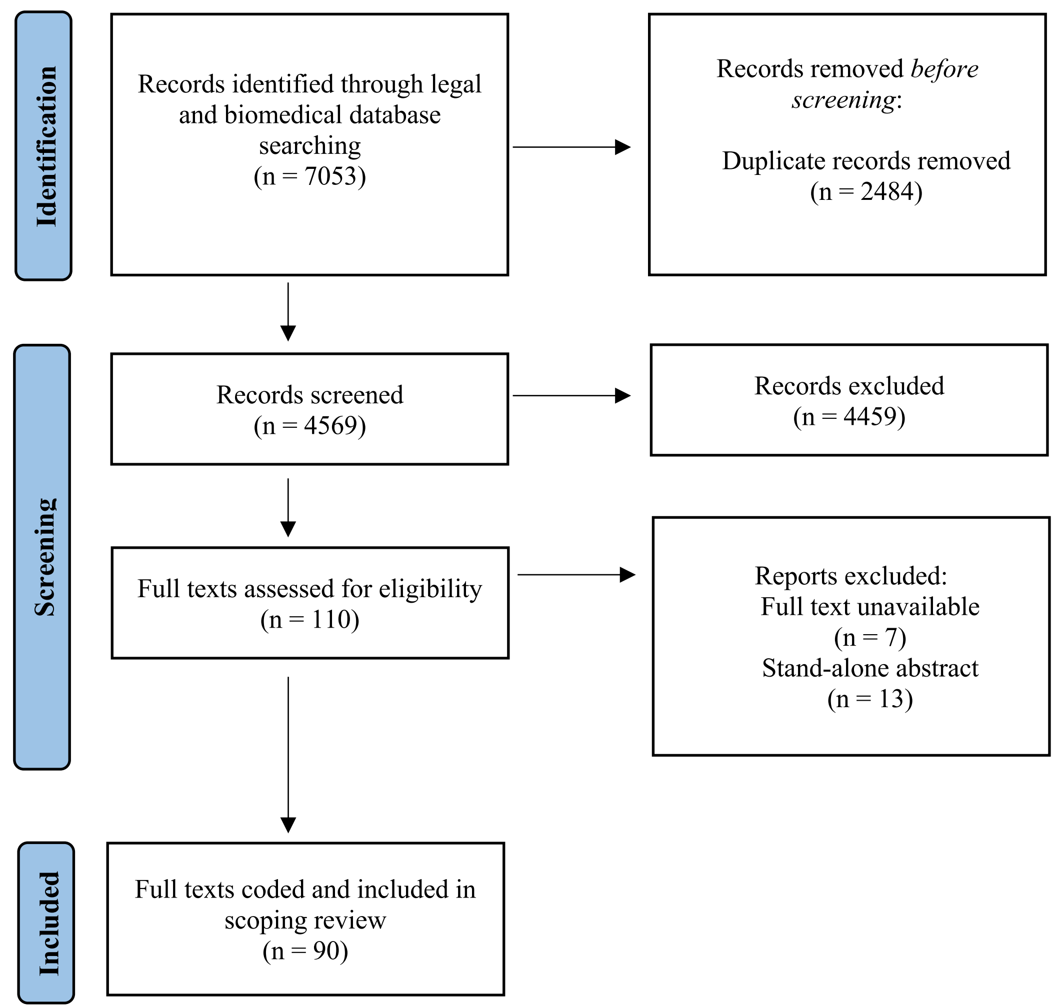
[32] Inclusion and exclusion criteria were applied to every article by SJL, and confirmed by two research assistants, each of whom screened half of the 4569 results.

[33] Disagreements amongst team members was minimal. The most common disagreements were suggestions to include additional results that met exclusion criteria – for example, a number of abstracts seemed promising, but upon further investigation, the full text was available only in a language other than English.

Figure 1: Flowchart of the Screening Process



2.4 Data Extraction & Analysis

The next stage was to review the 90 retained articles after screening to identify discussions – or mentions – of the family veto. This retained set included articles that explicitly mention the "family veto", "family override", or "family overrule" by name, as well as articles that speak to the process of family members withdrawing consent previously given by the deceased to donate their organs. SJL coded the relevant discussions, organizing the points within themes and sub-themes. Nine overarching themes were identified – descriptions of these themes, along with the relevant sub-themes, can be found below.

2.5 Summarizing & Presenting the Results

The themes, topics, and sub-topics emerged during the first two evaluations of the 90 included articles. SJL identified the topics and sub-topics. Rigor was enhanced by having a second reviewer (JAC) confirm the thematic structure, and by resolving divergences through discussion.

3. Results & Discussion

In this section, the results are presented along with discussion of each theme., This review captured 90 articles varying in the depth of coverage of the family veto – some articles only allude to the veto process within broader discussions of organ donation and transplantation.

Table 1: Depth of Coverage of the Family Veto (FV) within the Articles

	Alludes to Process	**Alludes to FV**	**Short Discussion of Process**	**Short Discussion of FV**	**Discussion of Process**	**Discussion of FV**	**Centre of Article (Process)**	**Centre of Article (FV)**
Defined as	A passing mention of a family vetoing previously given consent to donate (without naming the phenomenon)	A passing mention of FV without any in-depth discussion	A maximum of one paragraph discussing the process by which families veto previously given consent to donate	A maximum of one paragraph discussing FV	Substantial discussion of families vetoing previously given consent to donate without that discussion being the central theme of the article in question	Substantial discussion of FV without it being the central theme of the article in question	Families vetoing formerly given consent to donate is the central topic of the article in question	FV is the central topic of the article in question
Number of articles	27	1	10	4	14	10	2	22

Nine main themes emerged from the topics, issues, and evidence contained in these articles:

(1) Family Veto Definition & Context: This theme includes basic definitions for the "family veto", "family override", and "family overrule."

- The total number of articles captured within Theme 1 was **43**.

(2) Rates of the Family Veto: This theme discussed the frequency at which families choose to overturn previously given consent for organ donation.

- The total number of articles captured within Theme 2 was **43**.

(3) Theory vs. Practice: This theme takes up disparities between formal legal/policy rules regarding the family veto, as compared to what is *actually* done at hospitals

- The total number of articles captured within Theme 3 was **58**.

(4) Physician Duty: Questions of what duties are owed by healthcare providers (and to whom – whether the deceased donor, the donor's family, or the recipient)

- The total number of articles captured within Theme 4 was **14**.

(5) Reasons Why the Family Veto is Pursued or Allowed: A plethora of reasons why the family veto is pursued by families and/or allowed to occur by healthcare providers (HCPs). These reasons include, but are not limited to:

  - Family grief, emotional distress, and/or anger
  - Emotional distress of the healthcare team
  - Risk of increasing mistrust in the ODT system
  - The donor changing their mind after giving consent
  - Fear of legal action against HCPs
  - A lack of personhood after death / a lack of ability to give proper consent after death

- The total number of articles captured within Theme 5 was **70**.

(6) Reasons Why the Family Veto Should Not Be Allowed: A plethora of arguments against the family veto, including but not limited to:

  - Ethical issues, including infringement of autonomy and individual rights
  - Moral distress of HCPs
  - Negative public perceptions of or reactions to the family veto
  - Harm to donor families, including those who come to regret their veto
  - Reduction of the donor pool
  - Harm to the transplant recipient, including the death of would-be recipients
- The total number of articles captured within Theme 6 was **61**.

(7) Proposed Solutions to the Family Veto: Strategies proposed in the literature to reduce or eliminate the use of the family veto. These include, but are not limited to:

  - Public education campaigns
  - Creation of a new consent system
  - National registry of protected donation intentions
  - Strengthened donor designation legislation
  - Strict enforcement of donor designation
  - Allowing family veto in some narrow circumstances, such as intense psychological harm
- The total number of articles captured within Theme 7 was **64**.

(8) Opt-In vs. Opt-Out Systems: How different consent systems impact family veto

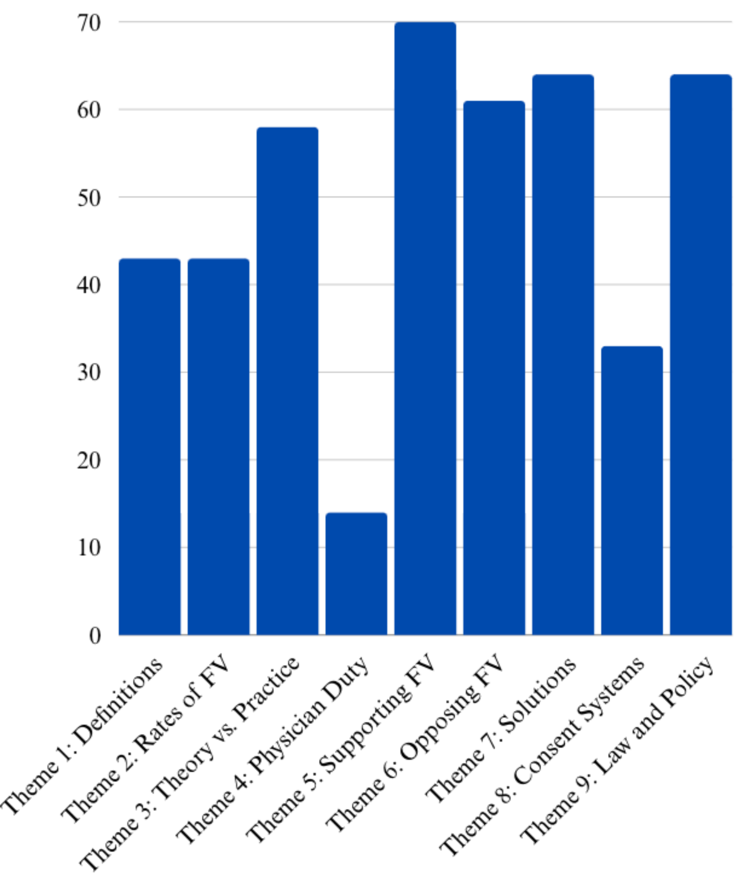
- The total number of articles captured within Theme 8 was **33**.

(9) Legal Framework: The legislative / legal framework surrounding family veto (and the acceptance or prohibition thereof). Sub-themes include:

  - Legal frameworks
  - Policy frameworks, including individual hospital policies
  - Consent legislation
  - Positive or negative legal rights to donate organs
- The total number of articles captured within Theme 9 was **64**.

The results are organized into tables below. Each theme is presented alongside the relevant topics and sub-themes, as well as a brief summary of the literature pertaining to each point.

Figure 2: Prevalence of Themes within the Included Texts



<u>3.1 Theme 1: Definitions & Context (n = 43)</u>

Theme 1 includes articles that either define the family veto (or the "family override" or "family overrule") as a distinct process, or describe the process of a family vetoing formerly given consent to donation without naming the phenomenon.

Throughout the literature, the "family veto" is universally understood as the posthumous overruling of previously given consent to donate organs.[34] While discussions of the family veto often turn on recorded consent (such as through an organ donation registry), consent can also have been communicated with healthcare providers (HCPs) or substitute decision makers (SDMs).[35] The family veto does not arise in situations where the deceased's intentions regarding organ donation are unknown. Much of the literature recognizes the controversial nature of the family

[34] See, among others, Ashley Britton Christmas et al, "A paradigm shift in the approach to families for organ donation: honoring patients' wishes versus request for permission in patients with Department of Motor Vehicles donor designations" (2008) 65:5 J Trauma Injury, Infection, and Critical Care 1507 at 1507. See also Adnan Sharif & Greg Moorlock, "Influencing relatives to respect donor autonomy: Should we nudge families to consent to organ donation?" (2018) 32 Bioethics 155 at 157.

[35] Ball, Oczkowski & Sibbald, *supra* note 10 at 601.

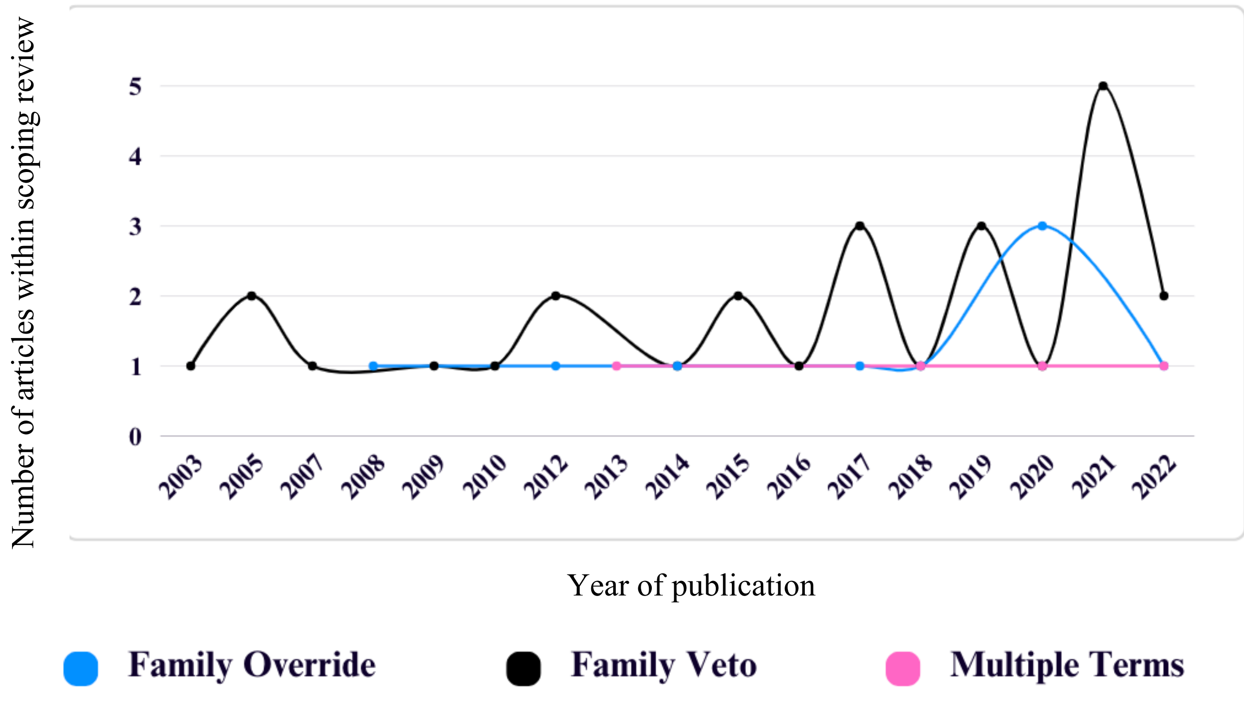
veto,[36] as well as the practical challenges it poses for HCPs and organ procurement organizations (OPOs).[37]

The importance of defining the family veto as a distinct process or phenomenon is three-fold. First, it remains unclear from the literature how the explicit term or concept of the "family veto" emerged. Per Albertsen, the family veto "is often considered a creation of the medical profession",[38] presumably as a means by which medical practitioners could avoid uncomfortable conversations – and perhaps lawsuits – with families who were adamant to refusal organ donation. A good faith argument could also be made that the family veto remains legally permissible in many countries as a failsafe mechanism to ensure the last known wish of a deceased is protected – for example, should the deceased mention their change of donation intention to a family member and then pass away before having the ability to formally change their donor registration status. However, this situation has been described as a "genuine override",[39] dissimilar to a "veto" which gives priority to the wishes and values of the surviving family members over those of the deceased.[40]

Second, it also remains unclear from the literature precisely *when* the mere process of a family vetoing consent to donate organs became known as "The Family Veto" – a medicolegal subject worthy of discussion and study. As can be seen below, discussions of the family veto (as well as "family override" and "family overrule") have increased since 2003. It is also unclear, however, *why* discussions of the family veto continue to increase – are rates of the family veto increasing such that the phenomenon can no longer be ignored? Or has it simply fallen into the public view given other discourse surrounding organ donation (for example, as some jurisdictions switch from opt-in to opt-out consent systems).

[36] T.M. Wilkinson, "Individual and Family Decisions About Organ Donation" (2007) 24:1 J Applied Philosophy 26 at 26; Debbie Cay, "Contemporary issues in law and ethics: exploring the family veto for organ donation" (2019) 29:11 J Perioperative Practice 361 at 361.
[37] Wilkinson, *ibid*.
[38] Albertsen, *supra* note 23 at 272.
[39] *Ibid*.
[40] Anthony et al 2021, *supra* note 14 at E768.

Figure 3: Rates of Discussion of the Family Veto Over Time[41]



Third, it is crucial that the literature clearly distinguishes between the family veto, family refusal, and genuine override in order for the rates of each process to be accurately studied. Several of the articles included in this review appear to conflate family vetoes with family refusal. For example, Johnston writes:

> "It can be stated this way: because a *family veto* lessens the supply of organs available for transplantation and since it is good to supply organs for transplantation and thus save lives, therefore there should not be a *family veto*. Some even go so far as to say a family veto can 'contribute to avoidable harm.' There is research to back up such claims — the British National Health Service estimates that *family refusals* accounted for 1200 missed transplant opportunities between 2010 and 2015."[42]

Here, it is unclear whether the 1,200 instances of families refusing to provide consent to organ donation occurred when the donation intention of the deceased was *unknown* or *known* (and thus

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[41] **NB:** The sudden drop-off of data in 2022 marks the date at which the data for this scoping review was collection. Additional articles have been written on the topic since that time. See for example: David Ernest, "Family Veto in Organ Donation" (2023) 30:4 J Law Med 899; Ruiping Fan, "Organ Donation, Comprehensively Good Incentives, and the Family: A Comment on Hong Kong's Interview Findings and Survey Results" in Ruiping Fan (ed), *Incentives and Disincentives in Organ Donation: Philosophy and Medicine* (Springer: 2023).

[42] Johnston, *supra* note 22 at 487 (emphasis added, citations omitted). Similarly, the language in an article by Zúñiga-Fajuri & Molina-Cayuqueo appears to use the language of "refusal" and "veto" somewhat interchangeably, leading to some confusion as to whether the rates of family refusal in their charts may actually refer to the family veto: see Alejandra Zúñiga-Fajuri & José Molina-Cayuqueo, "Organ donation and family refusal: bioethical reasons for a change"(2018) 38:4 Rev Nefrol Dial Traspl 280 at 282.

overturned by the family). As will be discussed below, although this may seem like a minor point of clarification, conflating or mislabeling the two processes makes it difficult to ascertain the rates of each process (and to suggestion solutions thereto).[43]

Examples of text coded under Theme 1 can be found in Appendix 3.

3.2 Theme 2: Rates of Family Veto (n = 43)

This theme includes articles that describe the frequency of the family veto occurring in a given context. Articles included here discussed rates of the family veto within hospitals/OPOs and within countries.[44]

The literature demonstrates a stark lack of clarity in how often the family veto occurs. The discrepancy in rates reported may be due to factors including the numerous jurisdictions included in the literature, the sizes of the studies, or the ages of the studies.

The discrepancy in rates reported may also stem from a paucity of information collected and/or publicly available. For example, "[a]ccording to a 2012 Victorian parliamentary report, there is *no* data available on how frequently the family veto is exercised in cases where a deceased had explicitly consented-in (on the Australian Organ Donation Register)."[45] Even where precise rates of the family veto are unknown, the literature also provides insight into jurisdictions where the family veto is *allowed* to happen, as enabled by legislation and/or hospital policy.[46]

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[43] For example, Shaw et al write: "[f]amilies frequently refuse and overrule donation in Switzerland; over 40% of donations are stopped by the family, *although there is no data on how many of these are overrules*." See David Shaw et al, "Family over rules? An ethical analysis of allowing families to overrule donation intentions" (2017) Transplantation 101:3 482 at 483 (emphasis added).

[44] Examples of text coded under Theme 2 can be found in Appendix 4.

[45] William Isdale & Julian Savulescu, "Three proposals to increase Australia's organ supply" (2015) 33 Monash Bioethics Rev 91 at 97 (emphasis added).

[46] Shaw et al, *supra* note 43 at 482.

Table 2: Studies and Discussions of Reported Family Vetoes

Rate of Family Veto	Year of Study Conducted	Year of Study Published	Jurisdiction	No. Participants	Commentary
2.4% (6/251)[47]	2009-2011	2012	United States	1,090 families 251 families (23%) of designated donors	1,090 families participated; 839 families did not have donor designation Of those 839 families without designation, 14.4% refused donation (approximately 120 families)
2.5%[48]	2001 – 2004	2008	United States (Florida)	Not specified	"[A]fter Florida had enacted a law against overriding the deceased's wishes to donate … the percentage of family override was only 2.5%"
5-15%[49]	2010-2012	2022	Wales	Not specified	"The rate of family overruling three years before the implementation [of the Human Transplantation (Wales) Act] ranged from 5% to 7.2%; and rose to 15.1%,18 months after implementation."
5-70%[50]	2000-2016	2017	Canada	Not specified	"Among these articles, there was wide variance in the cited occurrence of family veto, ranging from 5% to 70%"
6% (11/175)[51]	Not specified	2017	Netherlands	175 cases	
7.4%[52]	2017	2022	United Kingdom	Not specified	"Indeed, statistics show that when a specialist nurse for organ donation is

[47] Heather M. Traino & Laura A. Siminoff, "Attitudes and acceptance of first person authorization: a national comparison of donor and nondonor families" (2012) 74:1 Trauma Acute Care Surg 294 [Traino & Siminoff 2012].

[48] Margaret Verble & Judy Worth, "Addressing the unintended adverse consequences of first-person consent and donor registries" (2012) 22:1 Nursing & Allied Health Premium 25 at 27-28, citing Richard J. Howard, Danielle L. Cornell & Charles B. Koval, "When the donor says yes and the family says no" (2008) 18:1 Prog Transplant 13.

[49] Allister Lee & Joseph Tham, "Opt-in vs. Opt-out of Organ Donation in Scotland: Bioethical analysis" (2022) New Bioethics 1 at 2, citing Jane Noyes et al, "Short-term impact of introducing a soft opt-out organ donation system in Wales: before and after study" (2019) 9:4 BMJ Open 1.

[50] Anthony et al 2021, *supra* note 14 at E770.

[51] Shaw et al, *supra* note 43 at 483.

[52] Natalia Kyrtata, "Should the Family Be Allowed to Override a Patient's Decision to Become an Organ Donor After Death?" ed by Anna-Henrikje Seidlein & Sabine Salloch, *Ethical Challenges for Healthcare Practices at the End of Life: Interdisciplinary Perspectives* (Springer Nature: 2022), 107 at 115, citing Nuffield

					involved in the decision process **and the patient is known to be on the Organ Donor Register**, the proportion of families who agree to organ donation raises to 92.6%"
10%[53]	Not specified	2012	United Kingdom	Not specified	
10%[54]	Not specified	2020	United Kingdom	Not specified	
10%[55]	2016	2022	United Kingdom	Not specified	"NHS Blood and Transplant published statistics in 2016 indicating that only 47% of families consented to organ donation if they were not aware of their loved one's wish to donate their organs. This proportion increases to nearly 90% when this decision is known to the family."
10.2% (for organ donation)[56]	2008-2010	2012	Australia	Not specified	
10.24% of the 74.27% reversed wishes[57]	1994-1998	2002	United States	171 families (52.5% of families surveyed) knew patient wishes 74.27% of the 171 families said patient wanted to donate	"Of the 13 families who reported they did not donate despite the known desire of the patient to do so, one family chose to remove mechanical supports from the patient with- out understanding this would preclude organ donation."

Council on Bioethics, "Ethics think tank calls for discussion around wishes for organ donation before and after death, and robust evidence before any legal change is considered" (5 September 2017), online: <www.nuffieldbioethics.org/news/ethics-tank-calls-discussion-wishes-organ-donation-death> (emphasis added).

[53] David Shaw, "Don't let families stop organ donation from their relatives" (2012) 345 BMJ 33.

[54] David Shaw et al, "Family overrule of registered refusal to donate organs" (2020) 21:2 J Intensive Care Society 179 at 179 [Shaw et al 2020], citing NHS Blood and Transplant, "Potential Donor Audit Report" (2015-2016), online: *NHS* <www.odt.nhs.uk/statistics-and-reports/potential-donor-audit-report>.

[55] Kyrtata, *supra* note 52 at 116, citing NHS Blood and Transplant, "Families saying no to donation results in missed transplant opportunities for UK patients" (15 January 2016), online: *NHS* <www.organdonation.nhs.uk/get-involved/news/missed-transplant-opportunities-for-uk-patients/>.

[56] Verble & Worth, *supra* note 48 at 28, citing M. Lawlor et al, "Consent for corneal donation: the effect of age of the deceased, registered intent and which family member is asked about donation" (2006) 90:11 Br J Opthalmol 1383.

[57] Laura A. Siminoff & Renee H. Lawrence, "Knowing patients' preferences about organ donation: Does it make a difference?" (2002) 53:4 J Trauma Injury, Infection & Critical Care 754 at 755-756.

11.7% (263/2244)[58]	2012-2015	2018	United Kingdom	2,244 families approached	"Using the average conversion rates for consented deceased donors in the UK over this three-year period, it is estimated that there would have been an extra **59 DBD donations and 95 DCD donations** during this period."
12%[59]	2016	2017	United Kingdom	Approximately 1,000 families	
13%[60] **7.9%** (BD) and **13.2%** (DCD)	2008-2009 2009-2010	Unpublished	United Kingdom	Not specified	
15% (11/71)[61]	2001 – 2004	2008	United States (Florida)	71 cases where deceased had expressed a wish to donate on a driver's license	
15.2% (for cornea donation)[62]	2008-2010	2012	Australia	Not specified	
15-20%[63] 72 vetoes	2018-2020 2019-2020	2021	Canada (Ontario)		"According to the Trillium Gift of Life Network (TGLN), family veto occurred in 15-20% of registered approaches for organ donation in Ontario over the past three years. In 2019/2020, there were 72 family vetoes, representing a loss of up to 250 potential transplant opportunities"
	2006-2007	2008	United States (North & South Carolina)	137 donation approaches made overall	
17%				**Pre-initiative:** 66 approaches made, of	"Only 20 of 24 families of patients with prior DMV designation (83%) chose to

[58] James Morgan et al, "The Rule of Threes: three factors that triple the likelihood of families overriding first person consent for organ donation in the UK" (2018) 19:2 J Intensive Care Soc 101 at 101, 105.
[59] Shaw et al, *supra* note 43 at 482. Also cited by Sharif & Moorlock, *supra* note 34 at 155.
[60] Verble & Worth, *supra* note 48 at 28.
[61] *Ibid*, citing Howard RJ, Cornell DL & Koval CB (*supra* note 48).
[62] *Ibid*, citing Lawlor et al (*supra* note 56).
[63] Anthony et al, *supra* note 4 at 612.

(4/24) [64]				whom 24 patients were registered as donors	donate, and 23 of 42 families of patients with no DMV designation donated (55%).” “Based on our average procurement rate (number of organs per patient), this translated into approximately 17 missed opportunities for potential transplant recipients during the 3-month period”
0% (0/19)				**Post-initiative:** 71 approaches, of whom 19 were DMV-registered donors	“The families of all 19 patients who were DMV-designated donors (45%) consented for donation (100% donation rate).”
20%[65]	Not specified	2014	United States	Not specified	“One study found that 20 percent of families overrode their deceased relatives’ consents to general organ donation.”
21%[66]	2015	2016	Canada (Ontario)	Not specified	“Last year in Ontario, for example, 21% of families of registered donors refused donation.”
25% (5/25)[67]	2006	2008	United States (North & South Carolina)	89 patients total 25 patients listed as organ donors	
31% (12/39)[68]	2001 – 2004	2008	United States (Florida)	39 cases where deceased had signed a donor card or other documentation	
One-third (of registered donors) [69]	2019	2020	United States	148 cases total	47% of patients were registered organ donors

[64] Christmas et al, *supra* note 34 at 1508.

[65] Brendan Parent, “Faces as organ donations: who has the last word?” (2014) 44:6 Hastings Center Report (NP).

[66] Toews & Caulfield, *supra* note 16 at E436, citing Michael Robinson, “Mourning families are increasingly blocking organ donations of loved ones”, *Toronto Star* (16 June 2016), online: <www.thestar.com/news/gta/mourning-families-increasingly-blocking-organ-donations-of-loved-ones/article_7efb6052-80d3-589a-8064-3a95b25939b1.html>.

[67] Ashley Britton Christmas et al, “Organ donation: family members NOT honoring patient wishes” (2008) 65:5 J Trauma Injury, Infection, and Critical Care 1095 at 1096 [Christmas et al 2008].

[68] Verble & Worth, *supra* note 48 at 27-28, citing Howard, Cornell & Koval (*supra* note 48).

[69] Margaret Verble et al, “A Study of Concerns of Families of Potential Donation After Circulatory Death Donors and Recommendations for Raising Donation Rates” (2020) 52 Transplantation Proceedings 2867 at 2870.

			(Colorado, Wyoming, Michigan, South Florida, California)		
36% (5/14) [70]	2003-2012	2014	United States (Minnesota, North & South Dakota, Wisconsin)	15,580 organ donation referrals made to the OPO 14 cases of donor-family conflict	"Temporal distribution of conflict was skewed more toward the period following the 2006 revision to the UAGA (10 cases), with half the total cases in 2008 or 2009. Organ procurement proceeded in the majority (9 of 14) of the cases, with a total of 38 organs donated."
40%[71] *	Not specified	2017	Switzerland	Not specified	* "Families frequently refuse and overrule donation in Switzerland; over 40% of donations are stopped by the family, **although there is no data on how many of these are overrules.**"
40-50%[72]	Not specified	1995	Minnesota	Not specified	
42%[73]	Not specified	2013	United Kingdom	Not specified	
47%[74]	Not specified	2005	United States (California, Colorado, Florida, Mississippi, New York, Pennsylvania, Tennessee, Texas,	26 interviewees (OPOs, surgeons)	

[70] Paul A. Stahler et al, "Honoring patients' organ donation decisions when family conflict is present: Experience from a single organ procurement organization" (2014) 77:4 J Trauma Acute Care Surg 555 at 556.
[71] Shaw et al, *supra* note 43 at 483.
[72] Jennifer L. Mesich-Brant & Lawrence J. Grossback, "Assisting altruism: Evaluating legally binding consent in organ donation policy" (2005) 30:4 J Health Politics, Policy & Law 687 at 691-92, citing Laura A. Siminoff et al, "Public policy governing organ and tissue procurement in the United States. Results from the National Organ and Tissue Procurement Study" (1995) 123 Annals Internal Med 10.
[73] Zosia Kmietowicz, "Doctors should defend the wishes of patients on the organ donor register more 'robustly'" (2013) 346 BMJ 1 at 1.
[74] Mesich-Brant & Grossback, *supra* note 72 at 699.

			Virginia, and West Virginia)		
48.6%[75]	2014	2018	Argentina	Not specified	
30 families[76]	2002-2011	2013	Australia	Not specified	"30 donor registrants overrode their relative's consent and prevented the following donations: 40 corneas, 16 bone donations, 4 heart valves, 4 lungs, 2 kidneys, 2 pancreas and 1 heart."
120 families[77]	2016-2017	2018	United Kingdom	Not specified	"In addition, around 1,200 people miss out on a potentially life-saving transplant each year, due to family members overruling the decision to donate."
125 families[78]	2011-2012	2013	United Kingdom	Not specified	
500 families[79]	2010-2016	2018	United Kingdom	Not specified	
505 families[80]	2012-2017	2018	United Kingdom	Not specified	
A significant number[81]	Not specified	2019	United States	Not specified	"OPOs have employed diverse tactics to implement first-person- authorization statutes—such as communicating to families their desire to honor the

[75] Zúñiga-Fajuri & Molina-Cayuqueo, *supra* note 42 at 281, citing Lee Shepherd, Ronan E. O'Carroll & Eamonn Ferguson, "An international comparison of deceased and living organ donation/transplant rates in opt-in and opt-out systems: a panel study" (2014) 12 BMC Medicine 131. **NB:** This article provides a large number of family *refusal* rates, but only one rate for the family veto.
[76] K. A. Bramstedt, "Family refusals of registered consents: The disruption of organ donation by double-standard surrogate decision-making" (2013) 43 Int Med J 120 at 120.
[77] Cathy Miller & Richard Breakwell, "What factors influence a family's decision to agree to organ donation? A critical literature review" (2018) 10:4 London J Primary Care 103 at 103.
[78] Kmietowicz, *supra* note 73 at 1.
[79] Steve Ford, "Opt-out organ donation register 'unlikely to increase donations'" (16 August 2018) *Nursing Times,* online: <https://www-nursingtimes-net.proxy.bib.uottawa.ca/news/research-and-innovation/opt-out-organ-donation-register-unlikely-to-increase-donations-16-08-2018/>. Also cited by Kyrtata, *supra* note 52 at 110.
[80] Yiling Lin et al, "Underlying Wishes and Nudged Choices" (2018) 24:4 J Experimental Psychology Applied 1 at 4.
[81] Meredith M. Havekost, "The Waiting Game: How States Can Solve the Organ-Donation Crisis" (2019) 72:2 Vanderbilt L Rev 691 at 710 (emphasis added).

					patient's wishes rather than asking for consent—**but a significant number of registered donors' wishes are still not followed**."
A significant proportion[82]	Not specified	2018	United Kingdom	Not specified	"Whilst families are much more likely to support organ donation when a loved one's wishes are known, **a significant proportion continue to override such decisions**."
Most doctors[83] / **Often**[84] / **Typically**[85]	Not specified	2017	United States	Not specified	"Opt-in systems such as those in the United States, England, and New Zealand, are more reliably characterized as "impure" opt-in systems, because in such systems, even if a patient has registered as an organ donor, doctors in practice **often** acquiesce to the wishes of the family regarding donation … Thus, if the donor's family does not want the donor's organs to be removed, doctors **often** honor this request." "However, when a registered donor has viable organs that can be removed for transplantation, **most** doctors will, as a matter of practice, consult the donor's family on their preferences about donation." "If the families have a strong preference against donating their family member's organs, doctors will **typically** act in accordance with the family for various political and practical reasons."

[82] Morgan et al, *supra* note 58 at 101 (emphasis added).
[83] Alexander Zambrano, "Patient Autonomy and the Family Veto Problem in Organ Procurement" (2017) 43:1 Social Theory & Practice 180 at 193 (emphasis added).
[84] *Ibid* at 181 (emphasis added).
[85] *Ibid* at 193 (emphasis added).

No data available[86]	2012	2015	Australia	Not specified	"According to a 2012 Victorian parliamentary report, **there is no data available** on how frequently the family veto is exercised in cases where a deceased had explicitly consented-in."

As we can see, reported rates of the family veto vary between and within jurisdictions. On average, however, it appears that the family veto occurs in approximately 10-30% of organ donation requests (at least within the jurisdictions captured by this scoping review).

[86] Isdale & Savulescu, *supra* note 45 at 97 (emphasis added).

Table 3: Rates of the Family Veto Within the Literature

	10% and Below	11-20%	21-30%	31-40%	41% and Above
Number of Citing Studies / Documents	11	9	2	4	4

Notably, a number of studies have been excluded from Figure 6. One range the frequency of the family veto (5-70%) was too expansive to fit neatly into any of the above listed categories.[87] Similarly, seven studies and/or documents provided number of families who vetoed formerly given consent to donate within a particular jurisdiction, without also providing the total number of families approached (thus negating our ability to provide a percentage).[88] Two articles within this review simply noted that a "significant proportion" or "significant number" of families vetoed the donation intention of a registered donor.[89] Finally, one article specified that there was no data available on the rates of the family veto, thus rendering study of the phenomenon to be limited.[90]

The literature captured within this theme also reflected two other pieces of information that are helpful for understanding the frequency with which the family veto occurs.

First, jurisdictions differ in whether or not they permit next-of-kin to legally veto consent to donate (see Fig. 7). This suggests the likelihood (or at least possibility) of the family veto occurring in jurisdictions not covered in this scoping review. Further research is needed here to update and expand our understanding of where the family veto **could** arise, and where it actually **does** arise.

Table 4: Ability of Next-of-Kin to Veto Consent to Donate[91]

	Next-of-Kin **CAN** Veto Donation	Next-of-Kin **CANNOT** Veto Donation
Presumed Consent Systems	Armenia, Austria, Belarus, Chile, Colombia, Costa Rica, Croatia, Czechia, Ecuador, France, Italy, Luxembourg, Norway, Paraguay, Poland, Russia, Slovakia, Slovenia, Spain, Tunisia, Turkey	Belgium, Finland, Singapore, Sweden
Explicit Consent Systems[92]	Australia, Brazil, Canada, Cuba, Denmark, Estonia, Germany, Iceland, India, Ireland, Israel, Japan, Kuwait, Lithuania, Malaysia, Malta, Mexico, New Zealand, Philippines, Saudi Arabia, South Africa, South Korea, Switzerland, Thailand, Venezuela	Netherlands, Romania, UK, USA

[87] Anthony et al 2021, *supra* note 14 at E770.
[88] Anthony et al, *supra* note 4 at 612; Kyrtata, *supra* note 52 at 110; Kmietowicz, *supra* note 73 at 1; Bramstedt, *supra* note 76 at 120; Miller & Breakwell, *supra* note 77; Ford, *supra* note 79; Lin et al, *supra* note 80 at 4, 6.
[89] Morgan et al, *supra* note 58 at 101; Havekost, *supra* note 81 at 710.
[90] Isdale & Savulescu, *supra* note 45 at 97.
[91] Amanda M. Rosenblum et al, "The authority of next-of-kin in explicit and presumed consent systems for deceased organ donation: an analysis of 54 nations" (2012) 27 Nephrol Dial Transplant 2533 at 2542 (Table 2) and 2543 (Table 3). **NB:** Rosenblum's charts are current to 2012.
[92] Here, the next-of-kin's consent is required *even if* the deceased's wishes are documented: *ibid* at 2543.

Second, several articles approached the rate of the family veto from the perspective of Organ Procurement Organizations (OPOs) and/or HCPs. For example, Woien et al's 2006 study found that "the number of [American] OPOs willing to take organs of a registered donor over the objection of the next of kin had grown from 3 in 2002 to 19 in 2006"[93] (though the total number of OPOs surveyed is unclear). Interestingly, in 2008, Donovan wrote:

> "In a 2001 survey, only 8 percent of Organ Procurement Organizations (OPOs) indicated a willingness to proceed with organ donation in the face of objection by the next-of-kin. While such a concession is *much less likely now*, we must ask if there are ethically valid reasons to support such a concession? Or should the autonomous and legally binding declaration of the donor be honored despite any opposition?"[94]

As demonstrated in Figure 8, the approaches to and attitudes of HCP towards the family veto appear to be ebbing and flowing – indeed, more and more HCP appear to be witnessing family veto events over time, and certainly 2% of HCP proceeding with donation in 2020 in the face of the family veto is not much greater from the 1% who did so in 1998.

Table 5: Attitudes of OPOs and Healthcare Providers Towards the Family Veto Over Time

Year	Attitude	Jurisdiction
1998	35/36 OPOs **will not** proceed with donation in the face of FV (even with a signed donor card)[95]	USA
2001	8% of OPOs willing to proceed with donation in the face of FV[96]	USA
	87% of OPOs adhere to families' wishes "because of concern over the impact that organ procurement may have on the family"[97]	
2002	3 OPOs willing to proceed with donation in the face of FV[98] (compare against 2006)	USA
2005	15/26 responders (executive directors of OPOs, transplant coordinators, surgeons) had experienced FV event Of these, there were 7 instances where procurement did not proceed due to FV (and 3 of these 7 instances "took place in locations where the state and the OPO were enforcing legally binding consent"). 2 respondents stressed the importance of approaching FV on a case-by-case basis "centered on the family's level of resistance."[99]	USA
2006	19 OPOs willing to proceed with donation in the face of FV[100] (compare against 2002)	USA
	UAGA becomes law in USA	

[93] Verble & Worth, *supra* note 48 at 27, citing to Sandra Woien et al, "Organ procurement organizations Internet enrollment for organ donation: Abandoning informed consent" (2006) 7 BMC Medical Ethics 1.
[94] D.W. Donovan, "Defending the donor's decision. An analysis of the ethical issues related to first-person declarations of organ donation" (2008) 89:2 Nursing & Allied Health Premium 61 at 62 (emphasis added).
[95] Thomas May, Mark P. Aulisio & Michael A. DeVita, "Patients, Families, and Organ Donation: Who Should Decide?" (2000) 78:2 Milbank Quarterly 323 at 323-324.
[96] Donovan, *supra* note 94 at 62 (emphasis added).
[97] Christmas et al, *supra* note 34 at 1509.
[98] Verble & Worth, *supra* note 48 at 27, citing to Woien et al (*supra* note 93).
[99] Mesich-Brant & Grossback, *supra* note 72 at 699.
[100] Verble & Worth, *supra* note 48 at 27, citing to Woien et al (*supra* note 93).

	69% of surveyed healthcare providers believed next-of-kin should be respected over the wishes of donor (even with signed donor card or in donor registry)[101]	Canada
2008	OPOs less likely to proceed with donation in the face of FV (at least compared to 2001)[102]	USA
2013	20% of OPOs had not proceeded with procurement in the face of family **objection** 35% of OPOs reported they had not proceeded with organ procurement "from a **registered organ donor** whose family objected to donation." 15% of OPOs had not faced FV, "and may still refuse to procure organs when confronted with family objections."[103]	USA
2014	53% of responding OPOs would follow donor's wishes in **all** cases 45% of responding OPOs would follow donor's wishes in **most** cases[104]	USA
	80% of OPOs report being FPA compliant 20% of OPOs would not proceed with procurement without next-of-kin consent[105]	
2020	55% of survey participants (Canadian intensivists) witnessed family override situations Of that 55%, 91% had seen 1-5 FV events; 3% had seen more than 10 FV events[106] 56% of respondents would not pursue donation in the face of FV (despite previously expressed desire to donate by deceased)[107] 8% of respondents would seek legal guidance in the face of FV; 16% would seek an ethics consultation[108] Of that 16%, 61% would not proceed with donation against SDM wishes, regardless of the outcome of the ethics consultation[109] 2% of respondents would continue with the donation process in the face of FV[110]	Canada

[101] J. Downie, A. Shea & C. Rajotte, "Family Override of Valid Donor Consent to Postmortem Donation: Issues in Law and Practice" (2008) 40 Transplantation Proceedings 1255 at 1259.
[102] Donovan, *supra* note 94 at 62.
[103] Havekost, *supra* note 81 at 710 (emphasis added).
[104] Stahler et al, *supra* note 70 at 556, citing WJ Chon et al, "When the living and the deceased cannot agree on organ donation: a survey of US organ procurement organizations (OPOs)" (2014) 14:1 Am J Transplant 172.
[105] Douglas MacKay & Alexandra Robinson, "The Ethics of Organ Donor Registration Policies: Nudges and Respect for Autonomy" (2016) 16:11 Am J Bioethics 3 at 11, citing Chon et al, *ibid*.
[106] Weiss et al, *supra* note 9 at 313, 317. Also cited by Ball, Sibbald & Oczkowski, *supra* note 9 at 286.
[107] Weiss et al, *ibid*.
[108] *Ibid* at 317.
[109] *Ibid* at 317-318.
[110] *Ibid* at 313.

It should be noted here that while Figure 5 contains sources from the UK, as well as the Netherlands, Switzerland, and Wales, none of the articles from those jurisdictions demonstrated the OPO or HCP perspective (in the same way as the USA, and Canada – to a lesser extent). Again, further research is needed to accurately reflect attitudes towards the family veto within the healthcare sphere.

Taken together, the frequency with which families veto a donor's consent to organ donation does not appear to be readily collected or published – nor do the attitudes towards or approaches to the family veto from the OPO or HCP perspective. Within the Canadian context, only information pertaining to the family veto in Ontario was captured by this scoping review, raising questions about the state of the family veto in every other province and territory. This paucity of information acts as a barrier to fully understanding how common the family veto truly is, the reasons underpinning *why* families might veto consent, and what course of action would be most appropriate in addressing the family veto.

3.3 Theme 3: In Theory vs. In Practice (n = 58)

This theme includes articles that describe the discrepancy between what the law (or hospital policy) says about the family veto, as compared with what is *actually* done in practice.[111] In many cases, the law or policy recommend against – or outright prohibit – the family veto, yet it continues to be allowed to occur in practice.

In theory, a previously expressed intention to donate organs (whether physically recorded or simply shared orally) should be respected by both family members and HCPs. In practice, however, this intention is often overlooked (and overridden) by family members and HCPs alike – even when donor registration is protected by law:

> "Although explicit individual consent is 'binding', HCPs can take a contrary position by respecting the bereaved family's wishes, potentially creating a legal and/or ethical tension. The power of veto is not legally recognized in most countries, although in practice it is used everywhere."[112]

This discrepancy between theory and practice is evident across the literature (and the world), with "most medical professionals in the U.S. (as well as in the U.K. and continental Europe) sid[ing] with the family."[113] As expressed by Johnston, while "laws in most countries do not recognize familial decisions regarding organ donation when the deceased has already consented to donation … [s]till, the practice of asking families for permission, or respecting their adamant refusals, has persisted in many countries where there is no legal precedent for such practice."[114] Furthermore, the tension between theory and policy exists even in those jurisdictions that have ratified explicit

[111] Examples of text coded under Theme 3 can be found in Appendix 5.
[112] Nancy Kentish-Barnes et al, "A narrative review of family members' experience of organ donation request after brain death in the critical care setting" (2019) Intensive Care Med 45 331 at 334-35.
[113] Alida Liberman, "A promise acceptance model of organ donation" (2015) 41:1 Social Theory Practice 131 at 132. See also Shaw et al, *supra* note 43 at 487.
[114] Johnston, *supra* note 22 at 486.

first-person consent laws, which give specific protection to donor consent from being amended or revoked by third parties (such as the UAGA in the United States).[115]

One central explanation for the tension between theory and practice is an asymmetry in perceived risks and benefits. Laws intended to protect donation decisions may not be followed out of respect for the surviving family and/or out of fear of discouraging others from becoming donors.[116] At the same time, there are no real penalties for HCP or families who override patient decisions.[117] Along the same vein, donor registrations in many countries lack protections – whether legal or otherwise – "[w]ithout such protections, the next of kin are truly the 'determined' because they are the party that ultimately permits/denies clinically feasible donation."[118]

Similarly, while donation intentions are protected by law in many jurisdictions, public health messaging is confusing and contradictory. For example:

> "Despite the fact that families have no legal authority to give or refuse consent in the family veto scenario, publicly available policy information from provincial/territorial organ donation organizations and agencies indicate — implicitly, as in Ontario, or explicitly, as in Alberta, Nova Scotia and the Yukon — that family wishes will be followed … In its information to potential donors, the government of New Brunswick misconstrues its legislation by stating that the member of a registered donor's next of kin who is legally entitled to consent will be approached for donation. In fact, no one is 'entitled to consent' when the individual has already consented."[119]

The reasons underpinning *why* HCPs and/or OPOs may choose to side with the family will be discussed further in Theme 5.[120]

The literature focused on two main risks stemming from this tension between policy and practice: the moral distress of HCPs facing a family veto event,[121] and a decrease in the number of organs available for transplant if family vetoes are successful.[122] However, the literature was notably silent

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[115] Christmas et al, *supra* note 34 at 1509; National Conference of Commissioners on Uniform State Laws, *Revised Uniform Anatomical Gift Act, 2006* (July 2006), online (pdf): <https://wcmea.com/wp-content/uploads/2020/01/Uniform-Anatomical-Gift-Act.pdf> [UAGA]. See also Richard Jackson Harris et al, "Consenting to donate organs: whose wishes carry the most weight?" (1991) 21:1 J Applied Social Psychology 3 at 12-13; Stahler et al, *supra* note 70 at 556. If we take Argentina as another example, "although the latest law specifies that donor wishes 'will be honored regardless of manner of consent', the fact is that the next of kin are still called upon to testify to the donor's preference": Zúñiga-Fajuri & Molina-Cayuqueo, *supra* note 42 at 281.
[116] Mesich-Brant & Grossback, *supra* note 72 at 695.
[117] Traino & Siminoff 2012, *supra* note 47 at 296.
[118] Bramstedt, *supra* note 76 at 122.
[119] Toews & Caulfield, *supra* note 16 at E436.
[120] For example, Verble et al cite the "public relations hazards" that could arise when enforcing donation decisions over family objections (*supra* note 69 at 2870). For further discussion, see Chapter 3 below.
[121] Shaw, *supra* note 53; Donovan, *supra* note 94 at 61; Jurgen De Wispelaere & Lindsay Stirton, "Advance commitment: an alternative approach to the family veto problem in organ procurement" (2010) 36 J Med Ethics 180; Aud Orøy, Kjell Erik Strømskag & Eva Gjengedal, "Approaching families on the subject of organ donation: A phenomenological study of the experience of healthcare professionals" (2013) 29 Intensive Crit Care Nursing 202.
[122] Ball, Sibbald & Oczkowski *supra* note 9 at 286.

on the risk of applying laws inconsistently within jurisdictions (and between jurisdictions in the same country).

3.4 Theme 4: Physician Duty (n = 14)

This theme includes articles that discuss the duties owed by healthcare providers, and whether duties are owed to the deceased patient, the living, or the greater public good.[123]

Underlying discussions of the family veto is the inherent tension in the wishes of the deceased and their surviving family members. The literature within this theme raised four potential duties owed by HCPs – that are often at odds with one another – a duty to the patient (the deceased donor), a duty to the patient's surviving family, a duty to the would-be donor recipient, and a duty to public health more broadly.

With regards to the first duty: of the articles that raised questions of duty, all but one argue that HCPs owe a duty to their deceased patient to uphold their decision to donate (whenever medically and logistically feasible).[124] To many authors, the duty of care owed to patients does not entirely end with death, and donation decisions – and indeed, the ability to decide one's own legacy – should be defended by medical teams from external interference.[125] The sole remaining article posed the question of duty rhetorically and without answer.

As such, a thread within this Theme is that of robust duty – not only do HCPs owe a duty to the deceased patient, but they must take active steps to more robustly defending the position of the deceased in the face of familial opposition.[126]

The second major duty contemplated in the literature is the duty owed by HCPs to the bereaved families. The key tension recognized by this duty is between the living and the dead. However, of those authors who consider *duty*, the universal opinion expressed in the literature is that "[while] caring for the family of the donor is an important element of health care … that responsibility is secondary to honoring the declaration of the organ donor."[127]

Though discussed substantially less than the previous two duties, the literature also poses the question as to whether HCPs owe a duty to the would-be organ recipient. Writing in opposition to the use of the family veto, Shaw argues that "[a]lthough we should treat the family compassionately, doctors do not have the same duty to the family as to dying patients or other patients who need organs."[128] He further argues that allowing the veto "may not even be sympathetic medicine because the family are not patients, but the people who will die because of the failure to donate are."[129]

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[123] Examples of text coded under Theme 4 can be found in Appendix 6.
[124] Ball, Sibbald & Oczkowski, *supra* note 9 at 286.
[125] For example: Ball, Sibbald & Oczkowski, *ibid*; Kyrtata, *supra* note 52 at 110; Shaw, *supra* note 53.
[126] Kmietowicz, *supra* note 73 at 1. See also Anthony et al, *supra* note 4 at 617: for example, "one participant described their role as giving a voice to the donor after death: 'Our focus is the patient, definitely…we're the donor's voice'."
[127] Shaw, *supra* note 53; Donovan, *supra* note 94 at 65.
[128] Shaw, *ibid* at 33.
[129] *Ibid*. Shaw also adds that the otherwise preventable injury or death to the would-be recipient caused by the family veto will inevitably cause considerable harm to *their* family. See also Kyrtata, *supra* note 52 at 110, 117.

Finally, a handful of authors also pose the question of whether HCPs owe a broader duty to public health.[130] As expressed by Kyrtata, there are hundreds (if not thousands) of patients on organ transplant waiting lists, arguing it is the clinician's duty "to promote organ donations and ensure that patients receive the best possible care in a timely manner."[131]

While admittedly discussed less often than the other themes, Theme 4 is particularly important for the medicolegal discussion forthcoming in this thesis. Legal duties – as will be discussed at length below – extend beyond a mere moral conception of duty. Instead, they impose tangible (and legally binding) boundaries on what behaviours are expected and tolerated. If it is accepted that HCPs owe a *legal* duty to uphold the registered donation decisions of the deceased (even in the face of the family veto), then it is possible that legal repercussions could be brought against them should they choose to accept the family veto. Similarly, another legal question left to untangle is whether physicians owe duties of care either to the would-be organ recipient and/or public health more broadly – and what this duty could realistically look like in practice.[132]

3.5 Theme 5: Arguments in Favour of the Family Veto (n = 70)

Themes 5 through 7 were the most expansive themes identified within this scoping review, so each has been further divided into multiple sub-themes. This fifth theme includes articles that discuss (1) why families pursue a family veto and/or (2) why OPOs and HCPs allow the family veto to occur. Put another way, these are the arguments **in favour** of the family veto.[133]

The arguments justifying the use of the family veto can be further categorized into the sub-themes below.

3.5.1 Family Grief & Distress

Of those articles that contemplated why FV might be pursued or allowed, the vast majority (74%) considered the distress experienced by grieving families.[134] Such distress (in addition to the loss of a loved one), often stems from a perceived loss of control or respect if HCPs ignore the family's opinion regarding ODT,[135] a mistaken belief held by family members that donation decisions were theirs to make,[136] a lack of understanding amongst family members of brain death,[137] and the fear held by HCPs of adding to the family's trauma by pursuing donation.[138]

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[130] Shaw, *ibid*. See also Ball, Sibbald & Oczkowski, *supra* note 9 at 286.
[131] Kyrtata at 110. Put differently, she argues that doctors have a duty "to promote the wellbeing of patients in need of life-saving transplants" (*ibid* at 117).
[132] Discussions of patienthood, personhood, and legal duty can be found in Chapter 3.
[133] Examples of text coded under Theme 5 can be found in Appendix 7.
[134] See for example: May, Aulisio & DeVita, *supra* note 95 at 235-36.
[135] Diane Dodd-McCue et al, "Family responses to donor designation in donation cases: a longitudinal study" (2006) 16:2 Nursing & Allied Health Premium 150; Stahler et al, *supra* note 70.
[136] Zúñiga-Fajuri & Molina-Cayuqueo, *supra* note 42; David A. Peters, "Protecting autonomy in organ procurement procedures: some overlooked issues" (1986) 64:2 Milbank Quarterly 241.
[137] Alicia Aldridge & Bonnie S. Guy, "Deal breakers in the organ donation request process" (2006) 23:4 Health Marketing Quarterly 17.
[138] May, Aulisio & DeVita, *supra* note 95; De Wispelaere & Stirton, *supra* note 121; Katherine O'Donovan & Roy Gilbar, "The loved ones: families, intimates and patient autonomy" (2003) 23:2 Leg Stud (Soc Leg Scholars) 332.

While these were the reasons most frequently contemplated within this sub-theme, a plethora of other arguments were made pertaining to the potential grief and distress of the surviving family. Within the context of the ICU, these reasons include the family's overall dissatisfaction with patient care,[139] the family's fear that the donor would experience pain, the family's fear of having to bear any costs associated with ODT, and how making this decision in a time-sensitive (if not outright urgent) setting impacted the family's overall decision. In a similar vein, several articles also raise the family's cultural or religious concerns regarding ODT as the reason underlying why they choose to veto previously given consent to donate.[140]

As will be discussed below, the fear of adding to the family's grief or trauma is also used in argument *against* the continued use of the family veto.

3.5.2 Fear of Increasing Mistrust in the ODT System

There is significant fear cited in the literature that barring families from vetoing donation could increase public mistrust in the ODT system. This could – in theory – lead to negative publicity and media attention for specific hospitals (or even specific HCPs),[141] a negative reputation for the medical community more broadly,[142] and even may reduce the rate of future donations (should the public be sufficiently outraged).[143]

3.5.3 Fear of Lawsuits Against Healthcare Providers

Another oft-cited fear is that of potential lawsuits against HCPs who proceed with organ donation in the face of familial opposition (even though the donor themselves had provided consent).[144] However, as will be discussed below in Theme 6, not only is there no evidence of families successfully raising lawsuits against HCPs in this context,[145] it is the act of *not* following the deceased's decision that is contrary to law (and thus raises the likelihood of a successful legal claim against the HCP).[146]

3.5.4 Deceased Changed their Mind

In some circumstances, the deceased may have changed their mind about wanting to donate their organs prior to their death – but may not have formally rescinded their consent to donate. In such cases, families may seek to overturn the formerly given consent to uphold the deceased's true final

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[139] Traino & Siminoff 2012, *supra* note 47; Morgan et al, *supra* note 58 at 102.

[140] Jelena Morris & Janet Holt, "Applying utilitarianism to the presumed consent system for organ donation to consider the moral pros and cons" (2021) 30:19 British J Nursing 1127; Lee & Tham, *supra* note 49 at 2; Aldridge & Guy, *supra* note 137.

[141] Donovan, *supra* note 94; Eike-Henner Kluge, "Decisions about organ donation should rest with potential donors, not next of kin" (1997) 157:2 Can Med Assoc J 160.

[142] Sarah Elizabeth Statz, "Finding the winning combination: how blending organ procurement systems used internationally can reduce the organ shortage" (2006) 39:5 Vanderbilt J Transnational L 1677.

[143] Albertsen, *supra* note 23 at 277; Wilkinson, *supra* note 36; Mark Ammann, "Would presuming consent to organ donation gain us anything but trouble?" (2010) 18(2) Health L Rev 15.

[144] Jeffrey Conyers Kirby, "Organ Donation: Who Should Decide? – A Canadian Perspective" (2009) 6 Bioethical Inquiry 123; Kyrtata, *supra* note 52 at 110; Weiss et al, *supra* note 9 at 320; S. A. Salladay, "Organ donation: family affair" (1994) 8 Nursing 28 at 28.

[145] Albertsen, *supra* note 23 at 277.

[146] Havekost, *supra* note 81 at 712 (at least in those countries where donation consent is explicitly protected by law, as with the UAGA, *supra* note 115).

wishes.[147] This context can be described as "genuine overrule", as the family is only overruling the deceased's recorded consent in order to carry out their final wishes (as opposed to promoting their own opinions or concerns).[148]

3.5.5 Lack of Personhood After Death

An interesting ethico-legal perspective in the family veto literature is the question of when personhood – and legal rights – ends. Those who argue that legal rights and/or personhood are extinguished at death[149] also raise the arguments that the impacts of donation decisions cannot harm the dead, but *can* harm the surviving family;[150] informed consent cannot be given after death;[151] and that autonomy cannot be violated after death.[152] Together, these positions would imply that because the deceased is no longer a "person", the final consent for organ donation instead lies with their SDM. This sub-theme will be discussed at greater length in Chapter 3.

3.5.6 Bodies as Property Belonging to the Family

Several articles contemplate the degree to which surviving family members have a property interest in the body (and indeed, the organs) of the deceased.[153] Arguments raised here include claims of relational autonomy,[154] the family's "investment" in the body,[155] and the common law precedents as to whether families have "ownership" of bodies.[156]

3.5.7 Concerns about Registration and/or Consent

Another line of arguments in defense of the family veto pertains to registration and consent. A handful of authors raise concerns as to whether registration is a legally (or morally) binding promise, or if it is instead a mere intention (which carries different legal weight).[157] Other authors raise concerns regarding the lack of informed consent in the registration process,[158] as well as the lack of ongoing consent in registering (for example, consent is sought numerous times before other medical procedures and is considered to be an ongoing process rather than a stand-alone event).[159] As with the arguments surrounding personhood (or lack thereof), these positions imply that the consent given by the deceased never amounted to a legal consent, thus leaving the door open for

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[147] Toews & Caulfield, *supra* note 16 at E437.
[148] Magda Slabbert & Bonnie Venter, "Autonomy in organ donations v family consent: a South African legislative context" (2019) 52 De Jure L J 458; Alberto Molina-Pérez et al, "Should the family have a role in deceased organ donation decision-making? A systematic review of public knowledge and attitudes towards organ procurement policies in Europe" (2022) 36 Transplantation Rev 100673 1.
[149] Kyrtata, *supra* note 52 at 112.
[150] Downie, Shea & Rajotte, *supra* note 101; T. M. Wilkinson, "Individual and family consent to organ and tissue donation: is the current position coherent?" (2005) 31 J Med Ethics 587 [Wilkinson 2005].
[151] Johnston, *supra* note 22; Kyrtata, *supra* note 52.
[152] O'Donovan & Gilbar, *supra* note 138; Zambrano, *supra* note 83.
[153] Neera Bhatia & James Tibballs, "The Development of Property Rights over Cadaveric Tissues and Organs: Legal Obstructions to the Procurement of Organs in an "Opt-Out" System of Organ Donation in Australia and New Zealand" (2017) 27 New Zealand Universities L Rev 946 at 966.
[154] Johnston, *supra* note 22; Molina-Pérez et al, *supra* note 148.
[155] Johnston, *ibid*.
[156] Bhatia & Tibballs, *supra* note 153.
[157] *Ibid*; Kyrtata, *supra* note 52; Zambrano, *supra* note 83.
[158] Robert D. Truog, "When does a nudge become a shove in seeking consent for organ donation?" (2012) 12:2 Am J Bioethics 42; Johnston, *supra* note 22 at 488.
[159] Shaw et al, *supra* note 43; Kirby, *supra* note 144.

families to consent (or not) to organ donation. This sub-theme will be discussed at greater length in Chapter 3.

3.5.8 Other Sub-Themes

Additional sub-themes discussed in the literature include the emotional distress experienced by HCPs facing a family veto event,[160] hospital policies allowing the family veto to proceed,[161] and a lack of clarity in or understanding of the law by HCPs and donors alike.[162]

3.6 Theme 6: Arguments in Opposition to the Family Veto (n = 61)

This theme includes articles that discuss (1) the risks of allowing the family veto to occur and/or (2) why the family veto should not be allowed to occur. Put another way, these are the arguments **in opposition** to the family veto.[163]

The arguments challenging the family veto can be further categorized into the sub-themes below.

3.6.1 Autonomy

The primary argument raised in opposition to the family veto is that of autonomy – that we alone should be able to decide what happens to our bodies. The autonomy argument goes both ways, that our decision to donate or *not* to donate should be upheld. Curiously, some authors privilege the autonomy argument when an expressed desire *not* to donate is made, while excusing the family veto over decisions *to* donate.[164] This perhaps flows from the significant legal value placed in bodily integrity, and the firm protection against interference with it. A desire to donate entails positive obligations on others to take steps to facilitate that desire, and this is more complicated morally and legally. Other authors go so far as to argue that "respect for personal autonomy is the only moral consideration worth fighting for in the organ shortage debate."[165]

[160] Shaw, *supra* note 53; Orøy, Strømskag & Gjengedal, *supra* note 121; De Wispelaere & Stirton, *supra* note 121.

[161] Peters, *supra* note 136; Ball, Oczkowski & Sibbald, *supra* note 10; Anthony et al 2021, *supra* note 14 at E770.

[162] See Downie, Shea & Rajotte, *supra* note 101 at 1259 and Zúñiga-Fajuri & Molina-Cayuqueo, *supra* note 42, respectively. See also: Peters, *supra* note 136 at 267-268.

[163] Examples of text coded under Theme 6 can be found in Appendix 8.

[164] This perhaps ties into the distinction between positive and negative legal rights. See discussion on legal rights, beginning on page 89.

[165] Slabbert & Venter, *supra* note 148 at 463. There are four central principles of medical ethics: autonomy, beneficence, non-maleficence, and justice: see "The four principles of medical ethics" (8 February 2024), online: *Medical Protection* <www.medicalprotection.org/uk/articles/essential-learning-law-and-ethics >. Slabbert & Venter do not discuss the other principles within their article. However, beneficence (also defined as altruism or the "duty to do good") speaks to both the HCP's "ethical obligation to prioritise their patients' welfare", as well as "the clinician's duty to promote organ donations" on behalf of those patients on the waitlist (Kyrtata, *supra* note 52 at 110). Beneficence also applies insofar as organ donation itself is "a beneficent act and often suggest that overturning such a decision denies the deceased of her or his final opportunity to engage in an act of charity at a low (or even negligible) cost to the deceased" – see Donovan, *supra* note 94 at 63. Arguments regarding non-maleficence (the "duty to do no harm") are raised both in terms of avoiding causing harm to the grieving family, and in avoiding causing further harm to the would-be recipients (see Zambrano, *supra* note 83 at 200). Finally, justice is raised in the literature as pertaining to the family veto infringing on or violating the donor's rights and values by taking away their personal choice about organ donation (see Anthony et al 2021, *supra* note 14 at E771 and Kirby, *supra* note 144 at 125-126).

Literature that discusses autonomy in the family veto context also takes up the ethical principles of beneficence[166] and utilitarianism,[167] as well as legal interests that survive death[168] and the right to self-realization (and one's identity in being an organ donor).[169]

3.6.2 Harm to Recipient

Within this sub-theme, it is argued that allowing the family veto to proceed inherently results in the loss of donation potential.[170] This argument is not difficult to follow – organs are in scarce supply, transplant waitlists continue to grow each year, and every successful instance of the family veto means at least one person cannot receive a desperately needed transplant (though most donors are able to save the lives of multiple recipients).[171] In this way, allowing the family veto to proceed can cause the prolonged illness and/or death of transplant patients who could have received a transplant if not for the vetoing family,[172] as well as harm and distress to their families as a result of watching their loved ones continue to suffer.[173]

3.6.3 Harm to Donor Family

As mentioned above, avoiding harm to the donor's family is raised both in argument for and in opposition to the family veto. In this context, it is argued that removing the ability of families to veto consent removes from them the burden of decision-making,[174] guards against family regret,[175] and promotes family healing.[176] For example, several authors speak to how "family members have been known to subsequently regret a decision to prevent organ [donation]"[177] – in particular, "[o]ne reason families may regret their decision not to donate is the consequence their decision may have had on potential organ recipients."[178] This regret often comes shortly after the decision is made, and can last for decades.[179] On the other hand, it is not clear if disregarding the family veto would have produced a good psychological outcome for objecting families. To understand this, it would be necessary to study the outcomes for families whose veto was disregarded. If they later came to find the donation had assisted them with their grief, and particularly felt they would have regretted their refusal if it had been respected, then this argument would be more clearly established.

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[166] Otherwise known as altruism, or the selfless benefitting of others. In this way, organ donation is seen as an individual's "final opportunity to engage in an act of charity" (Donovan, *ibid* at 63).
[167] Johnston, *supra* note 22. Here, "utilitarianism" regards the "best" or "right" action as that which benefits the largest number of people: see Morris & Holt, *supra* note 140 at 1130.
[168] Zambrano, *supra* note 83.
[169] *Ibid*; Wilkinson, *supra* note 36.
[170] Zambrano, *ibid*; Morgan et al, *supra* note 58; Firàt Bilgel, "The effectiveness of transplant legislation, procedures and management: Cross-country evidence" (2013) 110 Health Policy 229.
[171] Morris & Holt, *supra* note 140 at 1130.
[172] Havekost, *supra* note 81; Kluge, *supra* note 141.
[173] May, Aulisio & DeVita, *supra* note 95; Slabbert & Venter, *supra* note 148; Mesich-Brant & Grossback, *supra* note 72.
[174] May, Aulisio & DeVita, *ibid*; Melissa K. Hyde et al, "Australian perspectives on opt-in and opt-out consent systems for deceased organ donation" (2021) 31:4 Progress in Transplantation 357.
[175] Sharif & Moorlock, *supra* note 34; Shaw et al, *supra* note 43.
[176] Anthony et al, *supra* note 4; Dodd-McCue et al, *supra* note 135.
[177] Zúñiga-Fajuri & Molina-Cayuqueo, *supra* note 42 at 283; Kirby, *supra* note 144 at 126.
[178] Kyrtata, *supra* note 52 at 115.
[179] Shaw, *supra* note 53 at 33.

3.6.4 Negative Public Opinions of the Family Veto

Throughout the literature, public opinion of the family veto is consistently negative. Allowing family vetoes to continue in the face of this negative public opinion risk leading to increased frustration with the ODT system[180] and perhaps even discouraging future donor registration, should it be seen as fruitless.[181]

3.6.5 Infringement on Legal Norms

Numerous articles take up the ways in which allowing the family veto to proceed infringes on legal norms. This includes contravening the intended purpose of ODT statutes,[182] setting a dangerous precedent of overturning legally binding consent,[183] and normalizing violations of the legal rights of the donor.[184] This theme will be discussed at length below in Chapter 3.

3.6.6 Lack of Lawsuits against Healthcare Providers

Despite the fears cited above that preventing the family veto could result in lawsuits against HCPs, the apparent lack of such lawsuits is raised as a reason why the family veto should not be allowed.[185] Not only do the authors captured under this sub-theme raise the arguments that there are practical difficulties in suing HCPs and that such lawsuits would likely fail given the lack of civil liability,[186] the argument is also raised that the potential recipients of the donated organs could make claims against families who veto previously given consent to donate.[187] The merits of these legal arguments will be explored in Chapter 3.

3.6.7 Additional Arguments Against the Family Veto

Additional sub-themes discussed in the literature include ante-mortem harm to the donor,[188] posthumous harm to the donor,[189] moral obligations to donate organs,[190] and the fear of families acting in their own interest (rather than in the interest of the donor).[191]

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[180] Shaw et al, *supra* note 43; Downie, Shea & Rajotte, *supra* note 101.

[181] Ammann, *supra* note 143; Tom Farsides, "Winning hearts and minds: using psychology to promote voluntary organ donation" (2000) 8 Health Care Analysis 101.

[182] Downie, Shea & Rajotte, *supra* note 101.

[183] Bramstedt, *supra* note 76; Kluge, *supra* note 141.

[184] Peters, *supra* note 136.

[185] Downie, Shea & Rajotte, *supra* note 101; Albertsen, *supra* note 23; Brent Arnold, "Legal Solutions to Ontario's Organ Shortage: Redrawing the Boundaries of Consent" (2005) 13 Health L J 139.

[186] See Arnold, *ibid*, and May, Aulisio & DeVita, *supra* note 95, respectively.

[187] Arnold, *ibid*. **NB:** The merits of the legal arguments raised in the scoping review will be evaluated in Chapter 3.

[188] Sharif & Moorlock, *supra* note 34; Zambrano, *supra* note 83.

[189] Michelle J. Irving et al, "Community attitudes to deceased organ donation: a focus group study" (2012) 93(10) Transplantation 1064; Farsides, *supra* note 181.

[190] David Shaw, "Organ donation is the right decision: a delicate truth" (2015) Intensive Care Med 41 1487 [Shaw 2015]; Kyrtata, *supra* note 52.

[191] Shaw et al, *supra* note 43; Ammann, *supra* note 143.

3.7 Theme 7: Solutions to the Current State of the Family Veto (n = 64)

This theme includes articles that discuss how the family veto should be addressed. Most often, these articles argue for ways to reduce the use of the family veto; however, a small number argue for ways to strengthen it.[192]

The proposed solutions to the current state of the family veto can be further categorized into the sub-themes below.[193]

3.7.1 Banning the Family Veto

A small number of authors suggest banning the use of the family veto in all circumstances, regardless of whether the deceased had changed their mind regarding donation prior to their death.[194] However, banning the family veto entirely carries the same risks as imposing a hard opt-out system[195] – namely, public backlash and increased mistrust in the ODT system should the public feel pressured into donating organs.

3.7.2 Allowing the Family Veto in Narrow Circumstances

A more popular solution than banning FV altogether is to allow the family veto only in narrowly defined circumstances, such as intense harm to the surviving family.[196]

3.7.3 Improving Communication with Families

The majority of the articles contained within this theme suggest improving communication with families as a means of reducing the prevalence of the family veto. This includes improving communication by HCPs[197] and ensuring donors adequately communicate their donation intentions to their loved ones.[198] Multiple studies have demonstrated that grieving families are more likely to donate organs if they are confident that is what the deceased wanted.

3.7.4 Education

Public education is a commonly suggested means of addressing the family veto. This includes public education campaigns regarding the ODT system, as well as the importance of sharing donation decisions with family members ahead of one's death to reduce discomfort and tension surrounding ODT decisions.[199]

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[192] Only one article captured in this review raised the argument for codifying the family's rights to make donation decisions on behalf of the deceased in law (regardless of whether they registered to donate or not): see Bhatia & Tibballs, *supra* note 153.

[193] Examples of text coded under Theme 7 can be found in Appendix 9.

[194] Sharif & Moorlock, *supra* note 34; Joan Costa-Font, Caroline Rudisill & Maximilian Salcher-Konrad, "'Relative Consent' or 'Presumed Consent'? Organ donation attitudes and behavior" (2021) 22 European J Health Economics 5.

[195] In opt-out consent systems, consent for organ donation is presumed for all donors who meet legislatively prescribed eligibility criteria, unless they specifically amend or revoke their consent. In "soft" opt-out systems, the next-of-kin are usually still asked to confirm consent for donation prior to procurement. In "hard" systems, SDMs are not permitted to interfere.

[196] Shaw et al 2020, *supra* note 54; Wilkinson, *supra* note 36.

[197] Christmas et al, *supra* note 34; Ball, Sibbald & Oczkowski, *supra* note 9.

[198] Ammann, *supra* note 143; T. Oh, "Organ donation: how to increase the donor pool" (2015) 43:1 Anaesth Intensive Care 12.

[199] Siminoff & Lawrence, *supra* note 57; Lin et al, *supra* note 80.

3.7.5 Legal Solutions

The literature contained a plethora of suggested legal solutions to the family veto. Legislative solutions could include amending ODT legislation to require OPOs to adhere to donor decisions (whenever possible) and to monitor OPOs' compliance with state or provincial health departments.[200] Legal education campaigns could aim to reduce confusion about the state of the law and the language within ODT legislation could be clarified and/or simplified to ensure they are publicly accessible.[201] Donation decisions could be legally protected – either through the strict enforcement of donor designation[202] or by requiring next-of-kin to witness and sign legally binding donor declarations.[203] Finally, several new consent systems were proposed throughout the literature, including mandated choice and Double Veto systems (wherein both the deceased and their families would have the opportunity to veto organ donation).[204] Some of these proposed legal solutions will be discussed in more detail below in Chapter 3.

3.7.6 Policy Solutions

The literature also proposed numerous policy solutions to the family veto. Hospital or OPO policies may include stricter guidelines about when the family veto is permissible[205] and specific donor conflict protocols.[206] Improved donor registration policies could include ongoing communication with registered donors (so donors have the opportunity to formally change their minds).[207] Policy solutions often go hand-in-hand with legal solutions – as demonstrated in the literature, even if there are laws explicitly protecting donor decisions, the family veto often arises at the hospital level, with clinicians allowing the family veto to occur.[208] Thus, legal and policy solutions must work in tandem to ensure the donation decisions are protected in law and in practice.

3.7.7 Healthcare Provider-Centered Solutions

Another stream of solutions is centered on the role of healthcare providers. These include increasing support for HCPs in promoting and protecting donation intentions,[209] increasing support for HCPs in ignoring the family veto,[210] and improving training for HCPs in how to approach the family veto and what the law actually says about consent to donate.[211]

3.7.8 Additional Solutions

Additional solutions proposed within the literature include the need for further research into the family veto (including reliable data on the rate at which families veto consent in different jurisdictions),[212] as well as improving how ODT is approached in pop culture.[213]

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[200] Havekost, *supra* note 81.
[201] Downie, Shea & Rajotte, *supra* note 101.
[202] Dodd-McCue et al, *supra* note 135.
[203] Farsides, *supra* note 181.
[204] Isdale & Savluescu, *supra* note 45.
[205] Shaw et al, *supra* note 43.
[206] Stahler et al, *supra* note 70.
[207] Donovan, *supra* note 94; Farsides, *supra* note 181.
[208] Downie, Shea & Rajotte, *supra* note 101; Weiss et al, *supra* note 9.
[209] Kmietowicz, *supra* note 73; Shaw, *supra* note 53
[210] Ball, Oczkowski & Sibbald, *supra* note 10 at 603; Shaw, *ibid*.
[211] Downie, Shea & Rajotte, *supra* note 101; Ball, Sibbald & Oczkowski, *supra* note 9; Weiss et al, *supra* note 9.
[212] Kentish-Barnes et al, *supra* note 112; Sharif & Moorlock, *supra* note 34; Anthony et al 2021, *supra* note 14.
[213] Anthony et al, *supra* note 4.

3.8 Theme 8: Opt-In vs. Opt-Out Consent Systems (n = 33)

This theme includes articles that discuss **(1)** different consent systems and/or **(2)** how the family veto fits into different consent systems.[214]

ODT consent systems can be loosely categorized into two categories: opt-in and opt-out. Opt-in systems are those where citizens are not presumed to be organ donors, and must register their intention to donate (for example, in a donor registry or on a driver's license), or must share their donation intentions with the next-of-kin. At least in theory, family members within opt-in systems "know the patient's wish. When approached regarding an organ donation decision, their role is to inform of the patient's wish regarding organ donation and to make sure it is respected."[215] However, "families ultimately have the final say as to whether the donation proceeds" and may prioritize their own values and wishes over those of the patient.[216]

Opt-out systems (otherwise known as presumed consent systems) permit organ donation unless the deceased had expressed an unwillingness to donate (again, whether through a donor registry or to their next-of-kin).[217] Opt-out systems are further separated into "soft" or "hard" systems – the former allows (or requires, as the case may be) consent from next-of-kin, while the latter excludes family involvement.[218] In some cases, opt-out systems may be pursued in order to reduce the frequency of family refusal and/or family veto events;[219] however, as with the opt-in system, a soft opt-out system still risks families projecting their own wishes over those of the deceased.[220]

Within the literature, authors are divided as to whether adopting a presumed consent model for organ donation will actually increase the number of donations.[221] Following the adoption of an opt-out system, donation rates were reported to decrease in Chile, France, and Brazil.[222] Furthermore, "[i]f individuals fail to signal their donation preference (eg, register) this may result in uncertainty and increase family veto in default (opt-out) systems."[223] Similarly, the family veto is permitted in countries falling within both camps – occurring, for example, in Canada "([which uses an opt-in system whereby individuals register to be donors), as well as Spain, Norway and Italy (use a presumed consent system along with a registration system whereby individuals can formally document their desire to donate)."[224]

As will be discussed below in Chapter 4, an additional consent system proposed in the literature is a "hard opt-in" system, wherein consent to donate is not presumed (thus potentially avoiding public

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[214] Examples of text coded under Theme 8 can be found in Appendix 10.
[215] Kentish-Barnes et al, *supra* note 112 at 334.
[216] Morris & Holt, *supra* note 140 at 1129.
[217] Orøy, Strømskag & Gjengedal, *supra* note 121 at 203.
[218] *Ibid*; Hyde et al, *supra* note 174 at 357; Ammann, *supra* note 143 para 13.
[219] For example, in Wales, "efforts to limit family influence in situations of genuine conflict have accompanied the introduction of an opt-out procurement system" (see Albertsen, *supra* note 23 at 278).
[220] Morris & Holt, *supra* note 140 at 1129.
[221] According to Ammann, "[s]tudies of European countries comparing different consent systems have, in fact, found that there is very little practical variation between consent systems" (*supra* note 143 para 37).
[222] Nicole Robitaille, "A little nudge goes a long way in increasing organ donor registrations" (2 May 2019) *The Conversation*, online: <https://theconversation.com/a-little-nudge-goes-a-long-way-in-increasing-organ-donor-registrations-115051>.
[223] Hyde et al, *supra* note 174 at 357
[224] Bramstedt, *supra* note 76 at 120.

push-back), but the decision to opt-in is firmly protected from familial interference.[225] Another proposed option is a consent system of mandated choice, offering all adult citizens three options: donate, do not donate, or defer donation decision to a proxy.[226]

While there is no consensus within the literature as to which consent system would best address the family veto, much of the literature cited a desire by the public (or at least those participating in surveys) for "simpler consent system[s] where their family or next of kin could not overrule their wishes for organ donation."[227] It should be noted here that the role of families in medical and legal decision-making inevitably varies between cultures and communities. For example, Luo et al speak to the central role of family members in organ donation decisions in China.[228] However, the dominant position demonstrated by the literature captured in this review is that the ability to choose what happens with your organs – whether you choose to donate or not – is crucial.[229]

3.9 Theme 9: Law & Policy (n = 64)

This final theme includes articles that discuss the legal and/or policy underpinnings of the family veto.[230]

3.9.1 Legislation

More than half of the sources in this review brought up the legislative frameworks of their ODT systems. Legislation contemplated within this sub-theme include consent legislation,[231] ODT legislation,[232] and good faith immunity clauses (to protect HCPs from civil liability).[233]

Most widely discussed in the literature captured by this review is the 2006 Revised Uniform Anatomical Gift Act (UAGA) from the United States. This Act speaks to the family veto, holding that "in the absence of an express, contrary indication by the donor, a person other than the donor is barred from making, amending, or revoking an anatomical gift of a donor's body or part *if the donor [already] made an anatomical gift of the donor's body or part*" under the Act.[234] In this way:

> "Section 8 is designed to state firmly the rule that a donor's autonomous decision regarding the making of an anatomical gift is to be honored and implemented and is not subject to change by others. Section 8 not only continues the policy of making lifetime donations

[225] Hyde et al, *supra* note 174 at 357. While first-person authorization laws could certainly contribute to a hard consent system (either opt-in or opt-out), their effectiveness lies in the adherence thereto – should families still be permitted to veto consent, that jurisdiction would be said to have a "soft" system.
[226] Farsides, *supra* note 181 at 108-09.
[227] Irving et al, *supra* note 189. See also Arnold, *supra* note 185 at para 26. Such a system is evident in Austria, though is much less common than soft opt-out systems (Statz, *supra* note 142 at 1694).
[228] Aijing Luo et al, "A qualitative study in family units on organ donation: attitude, influencing factors and communication patterns" (2022) 35 Transplant International 1.
[229] Hyde et al, *supra* note 174 at 362.
[230] Examples of text coded under Theme 9 can be found in Appendix 11.
[231] Downie, Shea & Rajotte, *supra* note 101; Bilgel, *supra* note 170.
[232] Downie, Shea & Rajotte, *ibid*; C. Bergström et al, "The Swedish transplant coordinators' experience of the new Transplantation Act and the Donor Register 1 year after implementation" (1997) Transplantation Proceedings 29 3232.
[233] Downie, Shea & Rajotte, *ibid.*
[234] UAGA, *supra* note 115, s 8(a).

irrevocable but also is restated to take away from families the power, right, or authority to consent to, amend, or revoke donations made by donors during their lifetimes."[235]

Another widely covered legislative framework is the Human Tissue Act of 2004, pertaining to England and Northern Ireland.[236] This Act gives *priority* to the wishes of the deceased over those of their next-of-kin,[237] but does not outright protect their donation decision.[238]

3.9.2 Comparison to Wills & Advance Directives

> "[T]here is an important precedent for the [Promise-Acceptance] Model that is uncontroversial both in law and common sense morality: namely, legal wills. The state and its representatives are obligated to carry out the terms of a will after an individual's death, and few think that family objections to how the deceased wished to distribute her material goods provide a legitimate veto. If it is unproblematic that the state is obligated to keep legal contracts made to the dead in the case of wills, it should not be especially problematic that it is obligated to keep promissory obligations to the dead in the case of organ donation."[239]

The comparison between wills and recorded intentions to donate organs is evident throughout the literature. However, there is not agreement amongst the authors as to whether this comparison is sound. Some argue that because "it is widely accepted that people's wishes regarding burial/cremation of their body or distribution of their property as requested in their will should be respected where possible, and organ donation seems similar to these in many relevant respect."[240] Others argue that important distinctions must be drawn between wills and donor registries. First and foremost, as organs are not considered property under common law, "the expressed wish of an individual in regard to the disposition of his or her body after death is not legally enforceable or binding on his or her executor or next-of-kin**,** even if expressed in a will."[241] Under Dutch law, for example, "an entry on the donor register does not have the same legal status as a will … a will can only be modified or revoked by the testator, in contrast to the DR, where this rule does not apply."[242]

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[235] *Ibid* at 30. **NB:** It is not clear from the body of the UAGA what the legal ramifications are of SDMs who contravene section 8. Sanctions are discussed in later portions of the UAGA, for example, for liability arising from revoking or amending anatomical gifts *for financial gain*.
[236] Verble & Worth, *supra* note 48 at 27.
[237] *Ibid*. See also De Wispelaere & Stirton, *supra* note 121 at 180.
[238] For example, the Human Tissue Authority provides the following guidance in their Code of Practice: "Where an adult has given valid consent for any particular donation or the removal, storage or use of their body or tissue for scheduled purposes to take place following their death, then that consent is sufficient for the activity to be lawful, subject to any other legislative requirements (for example, written consent or death certification). Where an adult has refused to give consent this cannot be revoked after their death." (see Human Tissue Authority, "Guiding Principles and the Fundamental Principle of Consent: Code of Practice" (20 May 2020) at para 78, online (pdf): *HTA* <https://content.hta.gov.uk/sites/default/files/2020-11/Code%20A.pdf>. As with the UAGA, it is not clear what the legal ramifications are – if any – of SDMs vetoing already given consent.
[239] Liberman, *supra* note 113 at 148.
[240] Sharif & Moorlock, *supra* note 34 at 156. Similarly, Kirby characterizes wills, affidavits, and advance directives as "authority documents", accepted in "most developed countries" (*supra* note 144 at 124).
[241] Downie, Shea & Rajotte, *supra* note 101 at 1257.
[242] Shaw et al, *supra* note 43 at 483.

3.9.3 Positive & Negative Legal Rights

Within this sub-theme, a distinction must be drawn between broadly conceived "rights" and strictly legal "rights" – the former of which represents a moral entitlement, while the latter refers to a legal entitlement and its corresponding responsibilities. For example, a "right" not to be caused distress cannot be legally enforceable in all circumstances.[243] The language of "rights" also appears within the literature as a family's "right" to veto formerly given consent[244] – which, if understood as a legal right – would impose unto HCPs the duty to prioritize their refusal over the consent of the deceased.

Similarly, bodily autonomy dictates that competent, adult individuals have the right to offer their organs for retrieval after their death (and, in doing so, to decide upon their individual legacy).[245] However, this "right" does not include the absolute "right" to have that offer accepted – doing so would require transplant teams to accept all donated organs, even if they posed a threat to the recipient (for example, if the organs were not suitable for transplant).[246]

Some authors suggest that organ donation can be conceived of as a negative right. Johnston, for example, argues that "people have a right to refuse that their organs be donated, but consent to organ donation does not *entitle* an individual to a guarantee of donation."[247] Wilkinson poses the argument that the rights of the deceased *and* of the family could be conceived as negative rights.[248] In this way, the deceased would have the right to *offer* their organs for donation (without having a guarantee of those organs being accepted), and the family would have the negative right to *withhold* donation (but not the positive right to allow donation).[249]

As noted above, these and other legal arguments will be discussed at length below in Chapter 3.

4. Conclusion

This scoping review found that there is a growing body of literature on the next-of-kin vetoing consent to organ donation given by their family members prior to their death. The literature raises a plethora of themes and sub-themes, ranging from explanations as to why families may pursue a veto to policy and legal solutions that would limit families from doing so. While scoping reviews typically refrain from drawing too many evidence-based conclusions (rather, the purpose of a scoping review is to map out existing literature, without assessing the quality of that literature, and it may contain normative discussion that is not clearly amenable to evidence-based conclusions), the literature captured in this review generally reflects a consensus view that the family veto is a problem that should be reduced. In doing so, the literature includes intense medicolegal and ethical debate including whether the duties owed to patients by physicians is extinguished at death,

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[243] Wilkinson, *supra* note 36 at 34. Here, Wilkinson argues that while "[w]e plausibly have a right not to have pain or fear inflicted on us … If the intensivist tells the family members their relative is dead, this might cause distress, but is not an infringement on a right."

[244] Shaw et al, *supra* note 43 at 483.

[245] Cay, *supra* note 36 at 363.

[246] Wilkinson, *supra* note 36 at 32.

[247] Johnston, *supra* note 22 at 491 (emphasis added).

[248] For those unfamiliar, "negative" rights refer to rights against interference, while "positive" rights are rights to assistance (see Wilkinson 2005, *supra* note 150 at 589).

[249] *Ibid*. This is otherwise known as the Double Veto.

whether the dead can consent to organ donation, and whether organ registration can be considered "consent" at all.

In conducting this scoping review, several gaps in the literature became evident. First, it is unclear *why* discussions of FV continue to increase – are rates of FV increasing such that the phenomenon can no longer be ignored? Or has it simply fallen into the public view given other ODT discourse? Second, there is a distinct paucity of data regarding the frequency of family veto events in Canada – this, in turn, obscures which provincial laws and policies are more effective in upholding donation decisions than others, and hinders informed policy-making in the ODT sphere. Finally, further research is needed to examine the nature and severity of the impacts of the family veto on donors, families, and HCPs alike.

The following chapters of this thesis will take up several conclusions and themes contained within this scoping review: **(1)** the degree to which family veto is harmful to registered donors, would-be recipients and their families, and HCPs; **(2)** the degree to which the family veto can also harm the registered donors' families, many of whom will likely later regret their decision; **(3)** whether families may be acting contrary to their legal obligations by pursuing the family veto; **(4)** whether there is a need for OPOs and hospitals to better support HCPs in addressing the family veto in the scope of their practice; and **(5)** whether there is also a need for registered donation decisions to be better protected by Canadian law and policy.

5. Gaps & Limitations

Although the objective of this scoping review was to be as comprehensive as possible, we created exclusion criteria (Appendix 2) to ensure the texts included in this review were sufficiently related to our topic. For example, we excluded literature that only discussed pediatric donation, as consent must be given by an adult family member on behalf of the child.

We included diverse types of literature, ranging from peer-reviewed journal articles to news articles and editorials. However, in order to assess our results with the same degree of thoroughness, conference posters and abstracts (where a full article could not be found) were excluded from consideration. Legislation without commentary was also excluded.

Finally, our results were collected in July 2022 – it is possible that further articles discussing the family veto have since been published.

Chapter 2: Current State of Canadian Law & Policy

6. Introduction

Organ donation and transplantation in Canada is regulated primarily through provincial and territorial legislation, rather than through a federal framework (as in the United States).[250] Ontario became the first Canadian province to create provincial ODT legislation – passing the Human Tissue Act in 1962.[251] Today's ODT legislation in most provinces closely resembles the *Uniform Human Tissue Donation Act*, which was proposed by the Uniform Law Conference of Canada in 1990.[252] There are, however, several exceptions – the *Uniform Human Tissue Donation Act* contemplated opt-in consent systems, whereas Nova Scotia and New Brunswick have (and are transitioning to) opt-out consent systems, respectively.[253] Furthermore, Quebec's ODT legislation is unique by virtue of its incorporation into the province's *Civil Code*, whereas the common law provinces each have separate ODT legislation.[254]

This Chapter provides an overview of the current state of provincial ODT legislation, including an in-depth comparison of each jurisdiction's organ donor registration forms.

7. Common Law Jurisdictions

Irrespective of whether a province uses an opt-in or opt-out consent system, most of the provincial ODT legislative frameworks in Canada look quite similar.[255] Each ODT statute begins with a series of relevant definitions to inform the rest of the text – though the number of definitions provided vary considerably between the provinces. For example, some provinces explicitly exclude certain types of tissue (such as bones or skin) from their legislative definition, while others do not.[256]

Below is a close reading of the pertinent definitions in Canadian ODT legislation, which can be divided into three categories: consent, liability, and additional definitions of interest. A side-by-side comparison of key definitions across provincial ODT legislation can be found in Appendix 12.

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[250] The *Criminal Code* does include a provision pertaining to dead bodies, but not to the use of organs and/or tissues for the purposes of transplantation. See RSC, 1985, c. C-46, s 182(b), wherein it is a criminal offence to "improperly or indecently interfere with or offer any indignity to a dead human body or human remains, whether buried or not." Similarly, the federal *Food and Drug Act* regulates cells, organs, and tissues for transplantation purposes: see SOR/2007-118.

[251] "History of Organ and Tissue Donation Legislation" (1 March 2022), online: *Tissue Exemptions* <www.tissueexemptions.com/history-of-organ-and-tissue-donation-legislation>.

[252] See Manitoba Law Reform Commission, "Presumed Consent Organ and Tissue Donation: Final Report" (February 2022), online at 3 (pdf): <www.manitobalawreform.ca/pubs/pdf/142-full_report.pdf> [Manitoba Report].

[253] *Ibid*. For further discussion of opt-in versus opt-out consent systems in Canada, please see Chapter 4.

[254] *Civil Code of Quebec*, SQ, 1991, c 64, arts. 43-44 [*Civil Code*]; Manitoba Report, *ibid* at 3.

[255] The exception, of course, is in Québec, which uses a civil law system (as will be discussed below).

[256] Compare, for example, British Columbia and Alberta in Appendix 1. While such differences in phrasing may appear insignificant, they are reflected in each province's ODT registration forms – for example, organ donors in Alberta have the option of donating bone, skin, connective tissue, and/or vascular tissue, while donors in British Columbia are offered the umbrella option of "tissue" (the legislative definition of which explicitly excludes bone and skin). It is unclear what the practical implications arise from such disparities and whether those provinces with narrower definitions experience barriers to procuring certain tissues and/or organs for donation.

7.1 Provincial ODT Legislation: Consent

Many of the provincial Acts[257] specifically provide that "consent" refers to consent given under the relevant Act. While never judicially interpreted, it has been argued that defining consent in this way is "intended to be a complete consent regime", distinct from (or perhaps superseding) other forms of provincial consent legislation.[258]

7.1.1 Who can consent to organ donation?

Consent for post-humous organ donation can be given in two circumstances: by the deceased prior to their death, or by the deceased's family following their death. In order for a person to consent to organ donation following their own death, they must meet certain criteria (though these criteria vary slightly between provinces). Each province sets out a minimum age requirement – most often the age of majority – though as young as 16 years of age in some jurisdictions.[259] In Nova Scotia, children 15 years of age and younger are still allowed to register as organ donors, but their registration must be completed by their parents/guardians.[260]

Some provinces, though not all, include additional requirements for potential donors. Alberta and Nova Scotia, for example, require that in order to provide consent for donation, the person must have capacity – defined within their legislation as "the ability to understand information that is relevant to a decision to be made and the ability to understand and appreciate the reasonably foreseeable consequences of a decision or lack of a decision."[261] Similarly, legislation from the Northwest Territories and PEI includes that potential donors must "understand the nature and consequences of transplanting tissue" as a precondition for giving consent to transplant after death.[262]

Consent for organ donation can also be provided by substitute decision-makers (SDMs) if the potential donor has died or is unable to provide consent. Every provincial ODT act specifies that SDMs may provide consent where consent *has not already been provided* by the deceased.[263] The decision-making hierarchy provided by the legislation appears to be consistent amongst the provinces, and is as follows:

- The spouse or adult interdependent partner of that person;
- An adult child of that person;

[257] See for example: British Columbia's *Human Tissue Gift Act*, RSBC 1996, c 211 [BC HTGA]; Alberta's *Human Tissue and Organ Donation Act*, SA 2006, c H-14 [AB HTODA]; Saskatchewan's *The Human Tissue Gift Act,* 2015, SS 2015 c H-15.1 [SK HTGA]; Newfoundland and Labrador's *Human Tissue Act*, RSNL 1999, c H-15 [NL HTA]; and Yukon's *Human Tissue Gift Act*, RSY 2002, c 117 [YK HTGA]. Manitoba does not include consent in its list of preambulatory definitions, but does specify "a consent for the purposes of this Act" in section 12: see *Human Tissue Gift Act,* CCSM c H180 [MB HTGA].

[258] Downie, Shea & Rajotte, *supra* note 101 at 1258.

[259] This is usually the age of majority (either 18 or 19), but is 16 in PEI and the Northwest Territories. In the Yukon, for example, if donors are younger than 19, parents/guardians must also sign the form: see Appendix 29.

[260] "Organ and tissue donation", online: *Government of Nova Scotia* <https://beta.novascotia.ca/organ-and-tissue-donation>. Similarly, people under the age of 14 may register in Québec, provided their parent or guardian co-signs their registration form: see Appendix 24.

[261] See AB HTODA, *supra* note 257, ss 1(b.1), 4(1). The Nova Scotian definition excludes the text underlined above (*supra* note 12, s 2(b)).

[262] *Human Tissue Donation Act*, SNWT 2014, c 30, s 4(1) [NWT HTDA] and *Human Tissue Donation Act*, RSPEI 1988, c H-12.1, s 3(1) [PEI HTDA], respectively.

[263] See for example, AB HTODA, *supra* note 257, s 4(3).

- A parent or guardian of that person;
- An adult sibling of that person;
- Any other adult that is the next-of-kin of that person.[264]

7.1.2 How can consent for organ donation be given?

All Canadian jurisdictions, with the exception of Nunavut, have a unique form for recording written consent to donate organs. Interestingly, some jurisdictions, such as the Northwest Territories, require not only the signature of the donor, but of witnesses.[265] Five provinces define "writing" in their preambulatory definitions for the purposes of written consent to posthumous donation: "includes a will and any other testamentary instrument, whether or not probate has been applied for or granted and whether or not the will or other testamentary instrument is valid."[266] Some provinces, such as BC, also allow for consent to be given orally in the presence of witnesses during the deceased's last illness.[267]

Consent for organ donation can also be given by next-of-kin on behalf of the deceased. Consent can be given by next-of-kin in writing (if signed), orally (provided there are sufficient witnesses), and in some provinces, in recorded messages by the next-of-kin.[268]

A full side-by-side comparison of the substantive and procedural requirements for giving consent to donate organs can be found in Appendix 13.

7.1.3 Is consent to organ donation binding?

Once made, consent given under provincial legislation is legally binding and is full authority for the procurement of organs for transplantation.[269] This is true of both consents given by the deceased and by the SDM. However, each act provides that consent must not be acted upon if there is reason to believe that the consent was subsequently withdrawn.[270] British Columbia offers a notable caveat here, suggesting that withdrawn consent may still be acted upon if that consent is contained in a valid will of the deceased.[271]

7.1.4 When can consent not be given and/or acted upon?

Every act specifies that next-of-kin must not give consent to donate if they have reason to believe that the deceased would have objected to it,[272] nor should consent be acted upon if there is reason to believe either that the deceased would have objected to it, or that someone closer to the deceased in the consent hierarchy objects thereto.[273] Notwithstanding these limitations, however, consent

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[264] See for example, AB HTODA, *supra* note 257, s 4(4) and BC HTGA, *supra* note 257, s 5(1). Interestingly, Alberta specifies spouses/partners who "are not estranged at the time of consenting to donate", but does not so specify for any other party (including parents or guardians).
[265] See Appendix 30.
[266] The wording amongst these five provinces is identical. See BC HTGA, SK HTGA, NL HTA, and YK HTGA (all *supra* note 257); see also TGLNA, *supra* note 12. For a side-by-side comparison of the statutes, see Appendix 13.
[267] See BC HTGA, *ibd*, at s 4(1). SK HTGA, *ibid*, s 7(1) also includes "a manner prescribed in the regulations."
[268] BC HTGA, *ibid*, s 5(1).
[269] Most provinces use the language of "binding" and "full authority". However, some provinces omit "full", which may have the effect of reducing the authority of the consent.
[270] BC HTGA, *supra* note 247, s 4(4).
[271] *Ibid*.
[272] TGLNA, *supra* note 12, s 5(3).
[273] *Ibid*, s 5(4).

for organ donation given by next-of-kin is also considered to be "binding" and the "full authority" for the removal and use of the specified organs for donation and transplantation.[274]

Finally, every act requires that if the organs donated cannot be used for the purposes specified in the consent, then that organ must be dealt with and disposed of as if no consent had been given.[275]

Appendix 14 provides a comparison of how each province legislates consent to organ donation. This chart updates Toews and Caulfield's 2016 appendix for greater clarity.[276]

7.1.5 Additional Consent-Based Definitions

Alberta is the only province whose ODT legislation defines either "consenter" ("a person who gives a consent") or "donation" ("a donation of tissue, an organ or a body under section 4 or 5").[277]

Four provinces define "donor", though there is some disparity amongst these definitions. Interestingly, the Albertan definition of "donor" omits discussion of "consent" (perhaps due to their distinct definition of "consenter").

Table 6: Defining a "Donor"

Province	Definition of "Donor"
Alberta	"[A] person whose tissue, organs or body is being considered for donation or in respect of whom a consent has been given"[278]
Nova Scotia	"[A]n individual who has consented, is deemed to have consented or in respect of whom a consent has been given to donate the individual's organs, tissue or body for transplantation, scientific research or education"[279]
Prince Edward Island	"[A]n individual who has consented to donate his or her tissue or body for transplantation, therapeutic purposes, medical education or scientific research or for whom such a consent has been given in accordance with this Act"[280]
Northwest Territories	"[A] person who consents to the removal of tissue or in respect of whom a consent to such removal has been given in accordance with this Act"[281]

None of the acts use the language of "veto," "override", or "overrule", nor do any of the acts appear to contemplate families withdrawing already-given consent to donate.

[274] *Ibid*, s 4(3).
[275] This also applies to gifts made for research purposes (as opposed to ODT). See BC HTGA, *supra* note 257, s 8; SK HTGA, *supra* note 257, s 14.
[276] Toews & Caulfield, *supra* note 16.
[277] AB HTODA, *supra* note 257, s 1(d).
[278] *Ibid*, s 1(g).
[279] HOTDA, *supra* note 30, s 2(i).
[280] PEI HTDA, *supra* note 262, s 1(b.1).
[281] NWT HTDA, *supra* note 262, s 1.

7.2 Provincial ODT Legislation: Liability

The provincial legislation[282] also identifies two forms of potential liability: a mistaken belief in age or capacity of the consenter, and a general liability clause. However, in identifying these two forms of potential liability, provincial ODT legislation simultaneously protects against liability on these grounds.

With regards to a mistaken belief in the age and/or capacity of the consenter, most provincial acts specify that consent is still valid even if the deceased had not reached the age of majority so long as the person acting on the consent had no reason to believe they were a minor (or lacking capacity).[283] The provinces who are silent on this matter are Alberta, Nova Scotia, and New Brunswick.

Every common law province also provides a good faith immunity clause pertaining to civil liability. At its core, each provincial provision is quite similar: no action (or other proceeding) lies against a person for anything done or omitted to be done in *good faith* and *without negligence* pursuant to the respective ODT statute.[284] However, several nuances arise when comparing the statutes side-by-side. The Saskatchewan provision is considerably longer than those of the other provinces, specifying that "no person has *any* rights or remedies … with respect to any act or omission of that other person done or omitted in compliance with and not in contravention of this Act …".[285] Confusingly, this provision could be read either as severely limiting the legal mechanisms available to address harms caused in the ODT context (as there are no rights or remedies available) *or* it could be read as expanding legal redress depending on how "compliance" and "contravention" are defined. Similarly, several phrases that appear in most (or all) of the statutes, including "good faith" and "without negligence", do not appear to have been judicially interpreted within the ODT context.[286]

With the exception of Manitoba and New Brunswick,[287] every province imposes general offences for those who knowingly contravene the legislation.[288] However, it is unclear precisely who could be found guilty of such offences from the wording of the acts alone (whether HCPs, SDMs, or other parties). The exception here is in Ontario, as the Act specifically shelters HCPs and other staff at designated facilities – it does not extend this same protection to SDMs, for example.[289]

A full provincial comparison can be found in Appendix 15.

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[282] Québec is excluded from this section of the discussion, as their civil law framework operates quite differently from the common law framework adopted in the rest of Canada.
[283] SK HTGA, *supra* note 257, s 7(2); BC HTGA, supra note 257, s 4(2).
[284] For example, BC HTGA, *ibid*, s 9.
[285] SK HTGA, *supra* note 257, s 15(2) (emphasis added).
[286] As discussed on the following page, there appears to be a paucity in Canadian case law pertaining to ODT and donor consent.
[287] These two provinces only contemplate offences for commercial activities. Nunavut is another exception here, as the *Human Tissue Act* is only two pages long, and does not contemplate anything other than direction for the use of a human body (or parts thereof): see RSNWT (Nu) 1988, c H-6 [NU HTA].
[288] These offences range from fines ranging from "not more than $1,000" to "not more than $100,000" and/or imprisonment for a term "of not more than three months" to "of not more than 6 months". See Appendix 15.
[289] TGLNA, *supra* note 12, s 9(1).

7.3 Case Law

There does not appear to be any case law pertaining to the "family veto", "family override", or "family overrule" in any of the Canadian provinces or territories. Similarly, results for "veto", "organ" and "consent" in CanLII are few and far between – none of which discuss ODT or are relevant to this thesis.[290]

8. Presumed Consent Jurisdictions

Nova Scotia and New Brunswick are the only two Canadian provinces with presumed consent legislation – though the new act in New Brunswick has not come into force at the time of writing.

Under Nova Scotia's *Human Organ and Tissue Donation Act*, if an individual has not made a consent or refusal to donate organs and tissue, that person is deemed to consent thereto, and this "deemed consent" provides full authority for transplantation activities, as with consent provided in opt-in jurisdictions.[291] However, there are a number of limitations on deemed consent: there is no deemed consent in circumstances where the individual lacked the capacity to make a donation decision prior to their death, where the individual was not ordinarily a resident of Nova Scotia for at least 12 months prior to their death, or where the individual was under the age of majority at the time of death.[292] Furthermore, consent (whether given or deemed) should not be acted upon if the person has knowledge that the donor subsequently withdrew their consent or objected.[293]

As in other provinces, SDMs in Nova Scotia are also allowed to consent to or refuse organ donation – however, under the Act, they must provide information that would "lead a reasonable person to conclude that an individual would have made a different decision respecting donation after death than the decision recorded in the Registry or deemed under Section 11."[294]

While language such as "family veto" is absent from the Nova Scotian act, there are two notable sections included in the act that are unique to the province: first, is the requirement that "[n]o person shall give false information under this Act."[295] Second, "[n]o person shall give a consent or refusal under this Act if the person has personal knowledge that the individual for whom the consent or refusal is given would have made a different decision."[296] Coupled with the aforementioned requirement that SDMs must provide information to make different decisions than those recorded or deemed, it appears that the Nova Scotian legislation is attempting to limit SDMs imposing their own views of ODT on the decisions of the deceased.

New Brunswick's new act closely resembles that of Nova Scotia – it too allows for presumed consent if an individual has not otherwise made a consent or refusal.[297] As in Nova Scotia, New

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[290] Each province was individually searched in CanLII in November 2023 for the terms mentioned above in quotations. Each result was then reviewed for its applicability.
[291] HOTDA, *supra* note 30, s 11.
[292] *Ibid*, ss 12-14. However, SDMs can still give consent on behalf of the individuals in all of these scenarios.
[293] This is distinct from those provinces that specify "did or *would have* objected" (emphasis added).
[294] HOTDA, *supra* note 30, s 15.
[295] *Ibid*, s 30.
[296] *Ibid*, s 32.
[297] *Human Organ and Tissue Donation Act*, SNB 2023, c 24, s 10 [NB HOTDA]. Section 9 also provides that physicians must check the Registry to determine whether a donation decision has been made prior to undertaking any transplantation activities. **NB**: This act is not yet in force.

Brunswick also holds that consent is not deemed if the individual lacked capacity, was not ordinarily a resident of the province, or had not reached the age of 19.[298]

9. OPOs & Public Health Messaging

As emphasized by Toews & Caulfield, "[d]espite the fact that families have no legal authority to give or refuse consent in the family veto scenario, publicly available policy information from provincial/territorial organ donation organizations and agencies indicate — implicitly, as in Ontario, or explicitly, as in Alberta, Nova Scotia and the Yukon — that family wishes will be followed."[299]

For example, an FAQ page on the BC Transplant website answers the following question:

> **Q:** "Can a family override a person's decision?"
>
> **A:** "Donation happens at a time of tragedy. We ask the family if they are aware of any change in their loved one's decision, and will honour their wishes. In our experience, when a family sees a copy of the signed registration form it provides relief and comfort and helps them support their loved one's wish to be an organ donor. We also encourage each person to talk to their family about their wishes for organ donation, so that they know what their loved one would want."[300]

Similarly, an FAQ page on the Alberta Health website reads:

> **Q.** Will my family be pressured to make a decision to donate?
>
> **A.** No. Organ and tissue donation is a very personal choice. Families are told about the options of what may be possible and then they make a choice about what they want to do.
>
> A family member will be asked to sign a consent form saying they have been informed about, and agree with, the donation process, *even if the person that died has signed the back of his or her Alberta Personal Health Card or registered online*.
>
> The decision to donate is a personal one. Registering your wishes is an important way to communicate your consent to donate your organs or tissues to the medical team. The family helps make decisions about donating and will *most often* agree to carry out their loved one's wishes if they are aware of them.[301]

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[298] See *ibid*, ss 11, 12, and 13, respectively.

[299] Toews & Caulfield, *supra* note 16 at E436.

[300] "Organ Donation FAQs", online: *BC Transplant* <www.transplant.bc.ca/organ-donation/organ-donation-faqs> [BC FAQs]. No results on the BC Transplant page for "veto", "family veto", or "family overrule.".

[301] "Consent to Donate", online: *MyHealthAlberta* <https://myhealth.alberta.ca/Alberta/Pages/organ-and-tissue-donation-consent-to-donate.aspx> (emphasis added).

Other provinces are even more blunt in their messaging. The Yukon, for example, does not shy away from the language of "family overrule":

> "Your family will be asked if they know your wishes about organ donation and for their agreement. While your wishes can be overruled, most families want to carry out the wishes of their loved ones. That's why it's so important to discuss organ donation with your family and let them know your wishes."[302]

However, little is offered by way of explanation as to *why* public health messaging directly contravenes provincial legislation. In 2016, Toews and Caulfield wrote that "BC Transplant and Transplant Quebec explain their positions on following families' wishes on the basis that families may know if their loved one had changed his or her mind."[303] Similarly, some provinces attribute their position to "the practical need for family cooperation to obtain social and medical information about the donor is cited as a reason family agreement is needed."[304] Regardless of the underlying reasons why public health messaging does not align with provincial legislation, the result is widespread confusion by both the public and HCPs – certainly, it can be presumed that an easy-to-navigate public health website is more accessible to most donors and their families than combing through provincial ODT legislation.

A side-by-side comparison of how public health messaging has changed (if at all) since 2016 can be found in Appendix 16.

<u>9.1</u> <u>Registration Forms</u>

As mentioned above, each province and territory in Canada has its own registration form for potential organ donors. These forms vary considerably from one another, both in terms of length and content.

All provinces contemplate the donation of the following: eyes (or corneas), heart, kidneys, liver, lungs, and pancreas.[305] Most provinces[306] include specific types of tissue for potential donation (such as skin and bone), while BC specifies only "tissue" and Saskatchewan specifies "vessels". Every province other than Ontario includes "bowel" on the list of potential organs for donation, and interestingly, only Alberta and the Northwest Territories include "stomach" on the list of

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[302] "Donate Your Organs: Common Questions", online: *Yukon* <https://yukon.ca/en/health-and-wellness/health-concerns-diseases-and-conditions/donate-your-organs#common-questions>. See also: "Donate Your Organs: Talking to Your Family About Organ Donation", online: *Yukon* <https://yukon.ca/en/health-and-wellness/health-concerns-diseases-and-conditions/donate-your-organs#talking-to-your-family-about-organ-donation>: "Even if you've signed a donor card or are registered as a donor, doctors will ask your family before taking organs or tissue. Things can be made a little easier if your family is aware of your wishes. Knowing that your final wishes were carried out and helped save lives can be a great source of comfort for them."

[303] Toews & Caulfield, *supra* note 16 at E437.

[304] *Ibid*.

[305] The exception here are New Brunswick and Newfoundland & Labrador, which do not specify any types of organs or tissues.

[306] See TGLNA, *supra* note 12; HOTDA, *supra* note 30; AB HTODA and YK HTGA (*supra* note 257); PEI HTDA and NWT HTDA (*supra* note 262).

potential organs. However, nearly all provinces also offer the option of donating "all organs and tissues needed for transplant."[307]

A side-by-side comparison of the various registration forms can be found in Appendix 17, and each individual form can be found in Appendices 18-30.

British Columbia
Organ donation registration in British Columbia can be completed online, or by using a mail-in form. Curiously, the paper version of BC's registration form contains a greater level of detail than the online form – where the online form asks simply "I consent to help save lives by becoming an organ and tissue donor after my death" as a Yes/No question, the mail-in form poses three related questions:

1. I wish to be an organ donor: Yes / No
2. I consent to help save lives by donating after my death: ALL organs and tissues needed for transplant / OR; only the checked organs and tissues for transplant (heart, kidneys, eyes, lungs, pancreas tissue, liver, bowel)
3. My donated organs & tissues may also be used for research

Notably, BC's mail-in form provides donors with the opportunity to donate some or all of their organs for transplantation or research, but does not mention medical education. BC's online form is decidedly vague – rather than selecting transplantation, scientific research, and/or medical education, donors simply provide consent "to help save lives". However, the fine print following the consent refers to section 4 of the HTGA (deceased donor organ donation), suggesting that the online form only facilitates donation for the purposes of transplantation.

The fine print at the bottom of the both the online and mail-in registration forms draws an important distinction between "consent" and "wishes" – above the space provided for the Signer's name, the text reads: "[o]nce signed by you, this form constitutes a legally valid decision record regarding '*consent by person for use of body after death'* in accordance with s. 4 of the *Human Tissue Gift Act* (British Columbia)."[308] Below the Signer's name, however, the forms read: "For someone under the age of 19, this record reflects an *expressed wish* about organ donation and is *not a legally binding decision record*, per the *Human Tissue Gift Act*."[309]

The mail-in registration form in BC also offers an innovative mechanism that does not appear to be duplicated in any other province (apart from Manitoba – see below). The form provides a large space for an optional personal message – this message is then presented to the donor's family or loved one(s) at the time of donation. By providing donors the ability to communicate their donation intentions in writing, this form theoretically should help to reduce rates of the family veto by reducing any uncertainty as to the mindset of the donor at the time of signing.[310]

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[307] Exceptions here include Newfoundland and Labrador (which just provides a Yes/No question), and PEI (which requires you to check the boxes of everything you're willing to donate, without giving an all-encompassing option).
[308] See Appendices 18 and 19.
[309] *Ibid*; emphasis added.
[310] However, as discussed throughout this thesis, the exact rates of family veto events across Canada are unknown.

Alberta
Organ donation registration in Alberta encompasses donation for the purposes of transplantation, scientific research, and/or medical education. Donors may choose any or all of these purposes when registering, and may choose from numerous types of organs and tissues to donate. The fine print of the form reads "Alberta Health's receipt of your completed form will provide *evidence of your consent* to be a donor."[311]

Saskatchewan
The registration form in Saskatchewan is unique in two regards. First, it is the only registration form that contemplates both living and deceased organ donation – providing donors with the option of receiving more information about living donation. Second, the form provides a novel mechanism whereby donors can both receive a confirmation email of their own donation decision, and offers the option to share the registration by email with multiple family members. As with the mechanism on the BC form, by providing people the ability to share their donation intentions with their next-of-kin, this form theoretically should help to reduce rates of the family veto by reducing any uncertainty as to the mindset of the donor at the time of signing.

The fine print of the form reads "[t]his form constitutes *a legally valid consent* under the Saskatchewan *Human Tissue Gift Act*. It is valid until it is revoked."[312] The form also includes a long consent declaration, where donors must certify that they have read and understand the consent.

Manitoba
There are a number of interesting features on Manitoba's registration form. The first question asked gives Manitobans the option of "be[ing] placed on the Intent to Donate Registry" or "speak[ing] to [their] family about [their] organ donation wishes." As noted below in Ontario, there is a contrast between "intent" and "wishes" in the language used when documenting donation decisions. The second question asks potential donors if they intend to donate *all* of their organs for transplantation. If "No" is selected, a drop-down menu will appear, whereby donors may select the specific organs they consent to donating for transplantation. Following the list of organs, the drop-down menu also provides a box that reads "or I will speak to my family about donating organs." The same drop-down menu appears if "No" is selected with regards to donating *all* tissues for transplantation. The form extends the choice to donate organs and/or tissues for any combination of transplantation, scientific research, and/or medical education. However, the most notable portion of the registration form is Question #4:

> Please check at least one of the following:
> - I wish to send a message to Friends/Family on my Facebook page that I have registered my intent to be an organ/tissue donor.
> - I wish to send a message to Friends/Family on my Twitter account that I have registered my intent to be an organ/tissue donor.
> - I wish to send an email message to Friends/Family that I have registered my intent to be an organ/tissue donor.

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[311] Appendix 20 (emphasis added).
[312] Appendix 21 (emphasis added).

- I will speak personally to my Friends/Family and let them know that I have registered to be an organ/tissue donor.

If none of these boxes are selected, an error message will appear, prohibiting submission of the form until the potential donor checks at least one of the boxes. Following submission of the form, donors are prompted to create an online account so that they can review their donation decision at any time – those donors who opt not to create an account cannot view previously submitted donation decisions, and can only change their donation decisions by re-registering entirely. Donors are also given the opportunity to generate a printable donor card and share their donation decision through the social media avenue chosen above. However, there is nothing preventing donors from exiting the page at this point without, for example, sharing their decision on Facebook.

In this way, the Manitoban form exceeds the standard set in British Columbia by enabling donors to share their donation intentions in a variety of ways. The form does not describe the quality of consent given (for example, as "binding"), nor does it reference the sharing of consent with family members (as provided by the relevant ODT or privacy legislation). However, if donors elect to generate a printable donor card, the fine print on that document reads:

> "This is a copy of the organ and tissue donation information you have registered on Manitoba's intent to donate registry. This information will be available to medical staff to share with your family in the case where you are able to be a donor. *It is extremely important to discuss your decision with your family to ensure your donation wishes are fulfilled*."[313]

Québec

Consent for organ donation can be provided in Québec by one of three avenues.[314] The primary avenue is to register with the Régie de l'assurance maladie du Québec (RAMQ) organ donor registry: the *Registre des consentements au don d'organes et de tissus*. Registration through the donor registry is collected by a mail-in form, and the information provided to RAMQ is treated confidentially.[315] If/when the time comes, Transplant Québec and Héma-Québec are able "to check quickly, at the request of a physician or other authorized person, whether your consent has been registered."[316] Residents may revoke their consent to donate at any time by using a separate form available from RAMQ.[317]

The form provided by RAMQ is exceedingly simple. All that is required is the signature of the donor and the date, in response to the statement "I hereby authorize organ and tissue removal for transplant or graft, when I die." The form provides a second space for the signature (and attached date) of a parent or guardian for persons under 14 who wish to give their consent.

[313] Appendix 22 (emphasis in original).
[314] "Organ Donor Registries", online: *Transplant Québec* <www.transplantquebec.ca/en/organ-donor-registries>.
[315] *Ibid*.
[316] *Ibid*.
[317] *Ibid*.

Transplant Québec's website states that registering consent in this way will "ensure that your decision is honoured and [will] officialize your consent."[318] While the form primarily uses the language of "consent" (for example, "[p]ersons under age 14 can also give their consent"), it does include the instruction "[o]nce your decision is taken, please inform your loved ones so that your wish is respected," once again indicating potential deference to family members.

A second avenue to register donation consent in Québec is by signing a sticker provided with residents' health insurance card when renewed.[319] The sticker is then affixed to the back of their health insurance card. However, this avenue of "registration" does not appear to actually register residents in the organ donor registry; rather, it simply offers a visual affirmation of donation decisions.

The third avenue to register donation consent is by registering with the organ donor registry managed by the *Chambre des notaires du Québec*. This avenue appears to be completely unique to Québec: residents can discuss organ donation with their notary, who will then note that consent in the resident's Will or Mandate in Case of Incapacity.[320] This consent is also added to a second registry, distinct from the RAMQ registry, established by the *Chambre des notaires du Québec*. As with information provided to the RAMQ registry, "the privacy of consent information is always protected."[321] Transplant Québec notes that this information will be used by authorized personnel to verify the donation consent of potential donors, but stresses that "[r]egardless of how you give your consent, you should always speak to your loved ones about your decision."[322]

Ontario

The Ontario form is distinct in two small ways. First, and as with the form in BC, the language oscillates between "consent" and wish"; however, following the checkboxes where donors consent to donating all or certain organs and tissues, the form reads "[b]y signing below, I am consenting to be an organ and tissue donor after my death." Second, the fine print of the form includes the following: "… for the purpose of facilitating organ and tissue transplants and research as well as sharing this information with your family so that they can honour your wishes at end of life." This is the only registration form that uses the language of "honour your wishes".

Nova Scotia

As one of the two presumed consent systems in Canada, the Nova Scotian form is understandably distinct from the opt-out provinces. The Nova Scotian form offers citizens three options:

- To donate all organs and tissues;
- To donate certain organs and tissues (as selected by the donor); or
- To opt-out from donating organs and tissues.

The fine print of the form includes that a donor's choice to donate some/all organs and tissues "will be confirmed with [their] family at the time of [their] death."

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[318] *Ibid*.
[319] Stickers can also be acquired from numerous healthcare institutions and organizations that promote ODT: *ibid*.
[320] *Ibid*.
[321] *Ibid*.
[322] *Ibid*.

Another curiosity of the Nova Scotian form is that it does not require a donor's signature (whether for reaffirming the presumed consent **or** for opting out). While most documents do not *require* a signature to be legally binding,[323] wills *must* be signed.[324,325]

New Brunswick

The registration form available at the time of writing appears to be consistent with New Brunswick's previous (opt-in) consent regime. Consent to organ donation is given through a larger Medicare Updates and Changes form, though the ODT section is one single question: *do you want to be an organ donor?* Signatures are not collected when giving consent to donate, though they are provided on another page of the form. Only New Brunswick and Newfoundland & Labrador pose the question of organ donation without allowing donors to choose which organs to donate, though the New Brunswick form is certainly the most basic.[326] However, it is likely that following the implementation of their new opt-out consent system, that the New Brunswick form will change to more closely resemble that of Nova Scotia.

Prince Edward Island

Prince Edward Island offers another simple ODT registration form. Potential donors are offered two separate lists of organs and tissues, and may choose any, all, or none of the options that they would be willing to donate. The form indicates that a signature *is* required for donation, and that parents cannot sign on behalf of children (below the age of 16).

Newfoundland & Labrador

As with the current registration form in New Brunswick, ODT registration in Newfoundland & Labrador is encapsulated within their provincial healthcare coverage. The section pertaining to ODT registration is extremely short, and is the only form that refers to registration in the second person: "[i]f anyone on this form wishes to become and organ/tissue donor, please sign in one of the spaces below." Up to four family members can register their intent at once using this form, or each person can register individually using their own online portal.

Yukon

The ODT registration form in the Yukon falls in the middle of the pack – while it does not offer any creative mechanisms for sharing registration with one's family, it offers a wider range of options than Newfoundland or New Brunswick. Here, donors may select to donate any organ or tissue needed for transplant or transplant research, any organ or tissue needed for transplant, or any organs/tissue needed for transplant except for those specified using a checklist. Below the selection is a consent declaration, allowing for donation after their death. The form urges donors

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[323] James R. Brown et al, "Electronic Signatures in the COVID-Age" (9 April 2020), online: *Osler* <www.osler.com/en/resources/regulations/2020/electronic-signatures-in-the-covid-age>.

[324] "What are the requirements for a will to be valid in Canada?", online: *LD Law LLP* <www.ldlaw.ca/wills-and-estate-planning/what-are-the-requirements-for-a-will-to-be-valid-in-canada/> [LD Law Wills].

[325] See the comparison between wills and ODT registration forms below in Chapter 3.

[326] Certainly, questions could be raised as to whether a form of this level of simplicity can (or should) constitute a legal document. While there is no absolute requirement that many legal documents (such as contracts) must be signed, other types of documents (such as wills) *must* be signed. See discussion of wills and legal documents below in Chapter 3.

discussed further below, this is contrary to the law of each province, and creates significant tension between healthcare providers and families in clinical settings.

Finally, there are noteworthy differences between provincial ODT registration forms. British Columbia, Saskatchewan, and Manitoba offer the most creative mechanisms to combat the family veto by helping prospective donors to share their donation decisions with their next-of-kin. While these mechanisms are likely deliberate efforts to both ease the decision-making process for families (and to combat the family veto), it remains unclear how effective these mechanisms are in reducing rates of family veto events in Canada.

Chapter 3: A Legal Right to (Consent to) Donate Organs: Reconciling the Spirit and the Word of Canadian ODT Legislation

11. Introduction

As has been discussed, there is considerable confusion surrounding the legality and ethics of the family veto, and to what degree (if at all) it should be permitted. This Chapter will take up two connected questions: is there a "legal right" to donate your organs after death and/or is the family veto illegal? Under Canadian ODT legislation, consent to donate (most often given through a donor registration form) provides sufficient legal authority to proceed with procurement. The family's approval or disapproval of the donor's decision is not legally relevant. However, the authority provided by the donor's consent is *permissive*, but does not *require* that organ procurement take place. Thus, the questions central to this Chapter are better stated: is the family acting illegally in attempting to persuade doctors to disregard the previously given consent of the donor, and do HCPs act contrary to the law in acceding to family wishes.

12. Case Study

In order to structure the analysis of the legality of the family veto, this Chapter will adopt and analyze the following hypothetical vignette:

An Ontarian woman registers as an organ donor during her early 20s. She is involved in a tragic car accident in her 30s, during which time she becomes severely brain injured. Despite doctors making every effort to save her life, she is declared brain dead. The hospital's transplant team approach her parents and notify them that their daughter is a good candidate for organ donation, asking if they consent to organ donation on her behalf. Despite her donor registration, her parents object to organ donation.

There are numerous reasons why her parents might object to organ donation:

a. They believe their daughter changed her mind;

As discussed in Chapter 1, withdrawing consent to organ donation because the deceased themselves changed their minds about donation prior to their death can be referred to as "genuine override". In this circumstance, the parents' veto aims to ensure that their daughter's true donation decision is followed.[329] Rather than prioritizing their own values or opinions regarding ODT, the family may have the most up-to-date insight into their daughter's wishes and intentions – "insight which might contradict [her] recorded donation decision."[330] However, in a 2018 study, Morgan et al found that only 5% of family vetoes occurred when "the family expressed that their relative had previously stated that they did not wish to be a donor, despite them being on the ODR."[331]

Similarly, the parents may not have clear knowledge that their daughter had changed her mind. Rather, the family may instead have knowledge that donation would be inconsistent with some other known wishes held by their daughter. These contradictions could raise questions about what the true intention of the patient was, rather than situations in which a clear intention to donate was

[329] Johnston, *supra* note 22 at 488-89; Sharif & Moorlock, *supra* note 34 at 156.
[330] Johnston, *ibid*.
[331] Morgan et al, *supra* note 58 at 102.

clearly revoked. For example, Johnston cites situations where the registered donor "was not well informed about donation, or perhaps they expressed a wish to be buried in a specific way."[332]

b. They feel that her medical care was botched and are angry at the medical system; and/or they cannot emotionally face the logistical delays associated with organ donation;

Dissatisfaction with patient care – while perhaps a common reason for pursing a family veto in practice – is rarely cited in the literature as one of the key considerations.[333] A more commonly cited reason for families vetoing donation registration is their feelings towards the length of the ODT process. Concerns about ODT timing can go both ways – some families may feel that they are being rushed into making a decision, while others may feel that the interventions necessary to permit donation prolong their grief and wish to withdraw ventilator support.[334]

c. They do not believe that "brain death" is death, and/or they fear that the removal of her organs will kill their daughter or cause her suffering;

A lack of understanding of brain death is an oft-cited reason as to why families may be hesitant to donate the organs of their deceased loved ones.[335] Given that they may not have experienced circulatory death, confusion about whether brain death is "real death" is often compounded with the fear that their family member will experience additional pain during organ removal.[336] Some families may choose to override the deceased's intention to donate because they want to avoid additional trauma or surgery to the body of the deceased, and/or may feel that the deceased has suffered enough.[337]

d. They have cultural or religious objections to organ donation;

There is an abundance of literature speaking to the relationship between religion and organ donation – while religious concerns are primarily raised in the context of family refusal to donate (where donation intentions by the deceased are otherwise unknown), religious and cultural concerns certainly arise in the family veto context, too.[338] Per Aldridge & Guy, "[i]t is often regarded as the family's final duty towards their loved one to ensure the proper burial or cremation of their body."[339] However, "[a]ll major faith systems in Canada support donation and would welcome help in preparing resources and developing partnerships that would assist them in supporting their members to consider donation, and to talk to their family about their decision."[340]

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[332] See Johnston, *supra* note 22 at 488-89.
[333] Traino & Siminoff 2012, *supra* note 47 at 299 (mentioned in passing); Morgan et al, *supra* note 58 (alluded to).
[334] Shaw et al, *supra* note 43 at 485; Stahler et al, *supra* note 70 at 556-57; Aldridge & Guy, *supra* note 137. For example, in a 2012-2015 study by Morgan et al, 28% of families overrode the wish of a relative to donate their organs "because they felt the length of time for the donation process was too long" (Morgan et al, *supra* note 58 at 102).
[335] See, for example, Aldridge & Guy, *ibid* at 21 and Stahler et al, *ibid* at 557.
[336] Aldridge & Guy, *ibid*; Stahler et al, *ibid* at 556-57.
[337] Morgan et al, *supra* note 58 at 102.
[338] *Ibid*; Luo et al, *supra* note 228; Wendy Sherry, Bernard Tremblay & Andréa Maria Laizner, "An exploration of knowledge, attitudes and beliefs toward organ and tissue donation among the adult Haitian population living in the Greater Montreal Area" (2013) 24:1 Dynamics 12.
[339] Kyrtata, *supra* note 52 at 116.
[340] Canadian Council for Donation and Transplantation, "Faith Perspectives on Organ and Tissue Donation and Transplantation" (2006), online at 13 (pdf): <https://profedu.blood.ca/sites/default/files/Faith-Perspectives.pdf> [Faith Report].

Even in those circumstances where religion does not come into play, there are countless cultural traditions and nuances that may influence how families react to donation registrations that do not match their own beliefs.[341] For example, Luo et al write that family consent for organ donation is considered necessary in China.[342] Similarly, participants in a 2013 study of Haitian communities in Canada "noted that even if an adult child made the decision to donate, older Haitian parents would likely try to override the consent to protect the integrity of the body."[343]

Overall, "the presence of family vetoes depends on individual family cultural characteristics alongside country specific influences such information system characteristics, hospital processes and family support for the deceased."[344] This includes the personal feelings of the next-of-kin on ODT, where their opposition to donation is purely personal, rather than cultural or religious.[345]

e. They have concerns about the quality of consent; or

Within the healthcare (and health law) context, consent must meet certain thresholds to be considered valid. Consent must be **(i)** voluntary, **(ii)** made by someone with the capacity to do so, and **(iii)** that person must have been properly informed.[346] For consent to be voluntary, it must be made without duress or coercion.[347] For an individual to have the capacity to consent, they must be able to understand what they are consenting to, and the consequences of providing or withholding consent.[348]As demonstrated by the provincial ODT legislation, capacity to consent also includes a minimum age requirement, which varies between the provinces.[349] Furthermore, in those situations where the person is incapable of consenting to a particular medical treatment, a substitute decision-maker (SDM) can be appointed to make decisions for that individual, guided by the patient's best interests.[350]

There has been significant debate as to whether organ donation registration meets the standard of "informed consent."[351] Unless donor registration forms are signed following an in-depth consultation with an HCP, it is unlikely that the minimal amount of information provided on Canadian donor forms constitutes "an adequate explanation about the nature of the proposed investigation or treatment and its anticipated outcome as well as the significant risks involved and alternatives available."[352] That said, however, what would be the material benefits of such a

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[341] Lee & Tham, *supra* note 49 at 2.
[342] Luo et al, *supra* note 228 at 2.
[343] Sherry, Tremblay & Laizner, *supra* note 338 at 15.
[344] Costa-Font, Rudisill & Salcher-Konrad, *supra* note 194 at 6.
[345] Aldridge & Guy, *supra* note 137; Slabbert & Venter, *supra* note 148 at 461.
[346] Consent flows from the principle of autonomy and is rooted in the assumption that "every human being of adult years and of sound mind has the right to determine what shall be done with her or her own body": "Consent: A guide for Canadian physicians" (June 2016), online: *CMPA* <www.cmpa-acpm.ca/en/advice-publications/handbooks/consent-a-guide-for-canadian-physicians> [CMPA Handbook].
[347] Duress and coercion include circumstances imposed upon the patient by third parties, including family members or employers; *ibid*.
[348] *Ibid*.
[349] See Appendix 13.
[350] CMPA Handbook, *supra* note 346.
[351] Shaw et al, *supra* note 43 at 484.
[352] *Ibid*. See also CMPA Consent, *supra* note 346. None of the provincial donor registration forms provide any substantial educational material provided in any of the provincial registration forms (see Appendices 18-30).

conversation to the would-be donor, given that there are no significant risks facing the deceased donor,[353] and the only "alternatives" are either donating some, all, or no organs?

Some authors draw attention to the fact that true informed consent is a *process* "that necessarily involves face-to-face interaction between the health care provider 'actor' and the potentially 'acted-upon' person/patient" – rather than simply a signature on a form.[354] For example, "Canadian provincial Colleges of Physicians and Surgeons, and third-party malpractice insurers of physicians … recommend obtaining informed consent through a process of meaningful dialogue."[355] Consenting to an elective surgery, for example, would happen multiple times, thus giving the patient opportunities to ask questions and potentially change their mind. Canadian donor registration forms do not presently include mechanisms for providing donors with regular prompts to reaffirm (or change) their donation intentions. Instead, for most prospective donors, the decision is made once – often while registering for another government program or service – and is often never revisited. Other authors have argued that donor registration cannot equate to informed consent, because the dead cannot consent at all.[356]

However, the argument has been raised that it is precisely *because* there is no risk to the donor's welfare from pursing deceased donation that less information or less formal procedures are required when consenting.[357] Compare, for example, the HCCA with the TGLNA. While the HCCA requires that consent to treatment must be informed,[358] the TGLNA defines consent simply as "consent given under this Act" and requires only that would-be donors reach the age of 16 before registering.[359] Thus, while perhaps registering as an organ donor is not identical to providing informed consent, arguments will be examined below as to why the decision to donate is still legally binding.[360]

f. Other

There are other reasons why families may object to organ donation, even in the face of the deceased having already registered as a donor. These may include a belief held by the next-of-kin that donation decisions belonged solely to them, disagreement amongst family members about whether or not to honour the deceased's donation intentions, or anger over the cause of death when the deceased died by suicide.[361]

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[353] It could be argued that "risks" would include failed procurements or transplantations, but this Chapter proceeds from the assumption that the dead cannot feel pain.

[354] Kirby, *supra* note 144 at 124.

[355] Kirby, *ibid*.

[356] Kyrtata, *supra* note 52 at 112, citing Albert Weale et al, "Human Bodies: Donation for Medicine and Research" (10 October 2011), online (pdf): Nuffield Council on Bioethics <www.nuffieldbioethics.org/publications/human-bodies-donation-for-medicine-and-research >. This view appears to assume that existing consent can never be valid if it cannot be reaffirmed at the time of donation.

[357] Kyrtata, *ibid*.

[358] 1996, SO 1996, c 2, Sch A, ss 11(1) and (2) [HCCA].

[359] As seen in Chapter 2, provincial ODT legislation in other provinces can include further capacity requirements, but none require consent attain the "informed consent" threshold.

[360] See page 76 on discussion of wills.

[361] Stahler et al, *supra* note 70 at 556-57.

13. Legal Questions

Following the family's attempt to veto their daughter's consent to donate, the doctors now face two options:

1. **Proceed with retrieval and donation over the objections of the family; or**
2. **Abandon retrieval and donation because of the objections of the family.**

These options are each accompanied by a plethora of ethical and legal arguments – both in opposition and in favour to the pursuit of that path. While the family is likely only representing their own views on organ donation, the doctors likely represent both the interests of the individual hospital where the conflict is occurring, as well as the broader OPO (in this case, the Trillium Gift of Life Network).[362]

Before turning to the legal implications of each of these two options, attention must first be paid to the reasons *why* the doctors should proceed with organ procurement, as compared to the reasons why they may feel unable to do so.

An overview of reasons why the doctors should proceed with organ procurement

There are numerous arguments made in opposition to the family veto, explaining why HCPs in this position should proceed with organ procurement. Generally speaking, these arguments centre on the autonomy of the deceased. For example, Slabbert & Venter argue that "[i]t is more in line with respect for autonomy to adhere to the wishes of the deceased than to ask relatives at the time of death."[363] In this way, they argue that "[g]iving the relatives decision power with regards to the removal of organs from a deceased body will have to be weighed against possible violations of the respect for the deceased's autonomy to determine a better way forward. According to us, respect for personal autonomy is the only moral consideration worth fighting for in the organ shortage debate."[364] Similarly, Shaw argues that "[c]linicians who heed the veto are complicit in a family denying its loved one's last chance to affect the world."[365]

13.1 Moral arguments opposing the family veto

It should be noted here that the following reasons are rooted in ethics and morality – not the law. While understanding the ethical and moral underpinnings of ODT conflicts, these reasons alone are not legally persuasive (let alone binding).

13.1.1 Moral duties owed by healthcare workers

In the course of their work, physicians owe both legal and ethical duties – but to whom? Arguments in opposition to the family veto raise three distinct physician duties: the duty to public health, the duty to the would-be donation recipient, and – of course – the duty to their patient.

In proposing an ethical duty to broader public health initiatives, some authors argue that in addition to respecting the wishes of the deceased patient, physicians have obligations towards the public:

[362] This Chapter will continue on the assumption that the doctors are acting in accordance with their hospital and / or their OPO's ODT policy.
[363] Slabbert & Venter, *supra* note 148 at 463.
[364] *Ibid*.
[365] Shaw, *supra* note 53; Dodd-McCue et al, *supra* note 135.

"[w]ith hundreds of patients on the organ transplant waiting list, it is the clinician's duty to promote organ donations and ensure that patients receive the best possible care in a timely manner."[366] This duty ties into that owed to would-be donation recipients. As expressed by Shaw:

> "Although we should treat the family compassionately, doctors do not have the same duty to the family as to dying patients or other patients who need organs … In fact, it may not even be sympathetic medicine because the family are not patients, but the people who will die because of the failure to donate are. To respect a family's veto when the patient was on the organ donor register is a failure of moral imagination that leads to a violation of the dead person's wishes and causes the death of several people (and all the sorrow consequent to this), and many family members who stop donation come to regret their decision."[367]

The majority of the literature captured by the scoping review described in Chapter 1 agrees that the primary duty owed by physicians is to the would-be organ donor. Per Kyrtata, clinicians have "an ethical obligation to support their patients' wishes."[368] The importance of showing empathy to a grieving family is widely noted, but it is firmly held that such a responsibility "is secondary to honoring the declaration of the organ donor."[369]

Harm to the would-be donation recipient

The risks posed to would-be donation recipients and their families are perhaps the most tangible impacts of allowing family veto events in clinical settings. Simply put, allowing families to veto consent to donation inherently reduces the number of organs available for transplant. Only 1-2% of people who die are considered for organ donation;[370] by virtue of this hypothetical family being approached for organ donation, their daughter's death offers the potential to directly improve or save dozens of lives.[371]

In this way, each family veto contributes to "avoidable harm."[372] This harm includes the prolonging of suffering, worsening of illness, disability, and even death of would-be recipients now facing longer wait times on the transplant list.[373] Other harm includes prolonged grief and trauma experienced by the next-of-kin of those on the waitlist, as well as an "increased drain on society's health care resources" in caring for terminally ill patients.[374] Thus, even if the rates of family veto events are small, "to patients awaiting transplant, they are significant, and every denied

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[366] Kyrtata, *supra* note 52 at 110. See also Shaw, *supra* note 53 and Ball, Sibbald & Oczkowski, *supra* note 9 at 286.

[367] Shaw, *ibid*. See also Kyrtata, *ibid*.

[368] Kyrtata, *ibid.*

[369] Donovan, *supra* note 94 at 65. See also Ball, Sibbald & Oczkowski, *supra* note 9 at 287; Weiss et al, *supra* note 9 at 320; Shaw, *supra* note 53.

[370] "Organ donation after death", online: *Canadian Blood Services* <www.blood.ca/en/organs-tissues/deceased-donation/organ-donation-after-death> [Donation After Death].

[371] The numbers of potential recipients vary case-by-case. However, as "each donor has the potential to donate up to six organs, as well as multiple types of tissue," up to 8 lives could be saved and/or up to 50 lives could be helped by each donor, marking a significant clinical impact for would-be recipients (and their families): Bramstedt, *supra* note 76 at 120. See also: Morris & Holt, *supra* note 140 at 1130; Slabbert & Venter, *supra* note 148 at 462.

[372] Shaw et al, *supra* note 43 at 498. See also Johnston, *supra* note 22 at 487.

[373] Shaw et al, *ibid*; Bramstedt, *supra* note 76 at 120; Morris & Holt, *supra* note 140 at 1130; Slabbert & Venter, *supra* note 148 at 462.

[374] Shaw et al, *supra* note 43 at 485; May, Aulisio & DeVita, *supra* note 95 at 324-325; Kluge, *supra* note 141 at 161.

donation has ethical and clinical implications."[375] Moreover, "it is unreasonable, highly inefficient and morally objectionable to allow family pain, however great, to result in deaths that could have been prevented."[376]

Harm to the deceased's family

Permitting a family veto to occur is also documented to cause harm to the family of the deceased. The very "option" of overturning the final wishes of their next-of-kin places a significant burden of decision making on grieving families.[377] Per Shaw et al, "it is unfair to expect families to make this decision when they are already so distressed about the loss of a loved one … It is understandable that staff do not want to upset families further, but it is not wise to give families the opportunity to go against the wishes of their deceased relatives when they are already distressed and are likely to make a potentially rash, highly emotional decision."[378]

While "the burden of decision-making during traumatic times, such as when family members have to play the role of surrogates in making end-of-life choices, can be profound," families often find it "liberating to recognize that their role is to help others identify what their loved one would have wanted, rather than having to decide themselves whether or not to "give up" on their loved one."[379] Similarly, many families who allow organ donation to occur "solace in the idea of having helped save a life or lives" – and this comfort is denied by allowing a veto to take place, particularly in highly charged situations.[380]

Furthermore, there is significant evidence that many vetoing families grow dissatisfied – or come to outright regret – their decisions to veto consent to donate once their initial grief has subsided. This regret often appears within two days of the decision, and can last for decades.[381] A 2012 study from Brazil suggests "that the regret often experienced by families who override donation may lead to a change of heart: even in cases where there was no registered intention to donate, over 50% of families who refused to allow donation would subsequently permit it in similar circumstances."[382] Similarly, a 2005 study "found retrospective regret for some non-donor families, whilst no donating families regretted their decision."[383] Thus, preventing families from vetoing consent to donate can be seen to protect their best interests "in the medium to long term, rather than simply granting an attempted overrule."[384]

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[375] Bramstedt, *supra* note 76 at 120.

[376] Zúñiga-Fajuri & Molina-Cayuqueo, *supra* note 42 at 284.

[377] Slabbert & Venter, *supra* note 148 at 464, citing Shaw et al, *supra* note 43; May, Aulisio & DeVita, *supra* note 95 at 331.

[378] Shaw et al, *supra* note 43 at 485: "This could lead to the decision being an impulsive one that fails to reflect their (or the deceased patient's) settled values rather than the emotions that are dominant at this very stressful time."

[379] May, Aulisio & DeVita, *supra* note 95 at 330.

[380] Zúñiga-Fajuri & Molina-Cayuqueo, *supra* note 42 at 283-84; Shaw et al, *supra* note 43 at 485.

[381] Shaw, *supra* note 53 at 33. Per Johnston, this regret can be so life-changing that it often leads to a willingness to donate organs in the future: *supra* note 22 at 487.

[382] Shaw et al, *supra* note 43 at 485, citing M. Morais et al, "Families Who Previously Refused Organ Donation Would Agree to Donate in a New Situation: A Cross-sectional Study" (2012) 44:9 Transplantation Proceedings 2268.

[383] Miller & Breakwell, *supra* note 77 at 105, citing JA Ormrod et al, "Experiences of families when a relative is diagnosed brain stem dead: understanding of death, observation of brain stem death testing and attitudes to organ donation" (2005) 60:10 Anaesthesia 1002.

[384] Shaw et al, *supra* note 43 at 485.

Harm to the healthcare workers
A final kind of harm caused by family veto events is harm to healthcare workers. Morgan et al describe the frustration felt by clinicians in the face of families being unwilling to support the end-of-life decisions of the loved ones,[385] while the participants of the Anthony et al survey describe "moral distress in cases where family vetoes superseded the patient's wishes. This is not surprising vis-a-vis [their] fiduciary responsibility to the patient."[386] As such, it is unsurprising that surveys of healthcare professionals find that respondents oppose the family veto – for example, Slabbert & Venter discuss a survey wherein "98 percent of respondents believed that a conflict between a deceased's wishes to be a donor and family refusal should be resolved by accepting the deceased's directive … It is also a stress reliever for them should there be such a legally valid document indicating the deceased's wish."[387] The stress experienced by healthcare workers is buttressed by the "confusing and problematic situation where following established practice and policy runs counter to the law."[388]

Public opinion

> "As an organ donor, when I first learned that doctors regularly defer to family vetoes in spite of explicit donor status, I felt angry, and even violated."[389]

One final reason as to why the doctors should proceed with procurement is public opinion. Common reactions to learning about the possibility of family members vetoing previously given consent to organ donation range from frustration to feeling "angry and horrified,"[390] especially as vetoes arise in a situation where the deceased is no longer able to insist or protect their own interests.[391]

In a study by Irving et al, "[p]articipants ranked sovereignty over decision as the second highest factor in importance in the decision to register as an organ donor."[392] Ranking sovereignty (or autonomy) in this way "rather it reflects their conviction that their decision, once made, should not be vetoed by family members."[393] Irving et al took up the nuances at play when valuing both autonomy (ranked second) and the input of family members (ranked fourth):

> "There is, however, a distinction – the first is based on perceived infringement of individuals' rights where individuals have lost the control over their ability to undertake the final consent of the donation of their organs; the second is simply a valuing of the opinions of other family members in making this decision and is consistent with individuals' maintaining ultimate rights to determining the fate of their organs. For example, an individual may consult with their family in weighting the decisional factors

[385] Morgan et al, *supra* note 58 at 105.
[386] Ball, Oczkowski & Sibbald, *supra* note 10 at 603, citing Anthony et al, *supra* note 4.
[387] Slabbert & Venter, *supra* note 148 at 465.
[388] Toews & Caulfield, *supra* note 16 at E437.
[389] Liberman, *supra* note 113 at 138.
[390] Liberman, *ibid*, citing Elizabeth Buggins, chair of the U.K. Organ Donation Taskforce; see also May, Aulisio & DeVita, *supra* note 95 at 327-328.
[391] Liberman, *ibid*.
[392] Irving et al, *supra* note 189 at 621.
[393] *Ibid*.

for donation, but, as seen in this study, hold convictions that their decision be upheld should the opportunity arise."[394]

In the Canadian context, surveys conducted by Downie, Shea, and Rajotte "indicate that a very strong majority of Canadians surveyed believe that valid donor consent should be followed: 89% of the public believed that the wishes of the donor should be respected."[395]

Furthermore, permitting family vetoes risks creating public mistrust with the ODT system – "[t]here might be a reluctance to register to donate in the futile setting of having next of kin who knowingly will refuse to honour their donation wishes (even with advance discussions of their values)."[396]

Table 7: Public Reactions to the Family Veto

Percentage of respondents who oppose FV	Excerpt from article
100%	"A recent report by Ontario's Citizens Panel on Increasing Organ Donations concluded after its public consultation process that 'both in discussions and in survey results, the position of Ontarians was unanimous—they want their wishes respected and overridden by no one. This suggests that there would be no negative impact on public perception (indeed, the impact of respecting donor consents would likely be positive)."[397]
98%	"A 1996 survey of health care professionals found that 98 percent of respondents believed that a conflict between a deceased individual's expressed intent to donate and family refusal should be resolved in line with the individual's preference."[398]
89%	"89% of the public believed that the wishes of the donor should be respected."[399]
71%	"71% of respondents felt that disapproval of the next of kin should not override the potential organ donor's wishes as expressed on an donor card … In this case, 16.6% felt that disapproval of the next of kin should override the donor's wishes and 12.4% said they didn't know."[400]
65%	"In a study on prisoners in Poland, 65% "answered that only donors could make a decision regarding donation."[401]
64 to 68%	"[W]hen questions are formulated from the perspective of the donor or in more neutral terms (e.g. *should the families be able to veto their relatives' expressed consent?*), only 8% to 14% of respondents in the UK support the family's right to veto and 64% to 88% oppose it. In Wales, 10% to 22% of respondents support the family's capacity to overrule the deceased's wishes. This result is consistent with qualitative studies in Wales where participants expressed the feeling that organ donation is their decision alone and that their family should not be able to overturn it."[402]
58%	"Most respondents (58%) felt that next of kin should not be able to override a person's desire to donate organs as signified by an organ donor card.

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[394] *Ibid*.
[395] *Supra* note 101 at 1259.
[396] Bramstedt, *supra* note 76 at 121.
[397] Downie, Shea & Rajotte, *supra* note 101 at 1259.
[398] "Sixty-seven percent also *disagreed* with the proposition that when a person has expressed a desire to donate, the family's permission should be required": see May, Aulisio & DeVita, *supra* note 95 at 331.
[399] Downie, Shea & Rajotte, *supra* note 101 at 1259.
[400] Diane L. Manninen & Roger W. Evans, "Public Attitudes and Behavior Regarding Organ Donation" (1985) 253:1 JAMA 3111 at 3111.
[401] Molina-Pérez et al, *supra* note 148 at 7.
[402] *Ibid*.

	The majority of respondents (57.8%) felt that if someone signs an organ donor card, his or her decision should not have to be formally approved by his or her next of kin when he or she dies. Only 34.4% felt that such approval should be necessary, while 7.8% didn't know."[403]
35%	"[Lawlor et al] found that although 35% of respondents thought that family members should definitely not be able to override first-person donation decisions, 22% thought they probably should not be able to do so, and 30% thought they either may or definitely should be able to."[404]
Unspecified ("a large majority of participants")	"Indeed, our study shows that a large majority of participants indicated that the deceased's wishes should be respected no matter what the family thinks."[405]
Unspecified ("most")	"Similarly, a 5-year evaluation of an educational campaign promoting First Person Authorization in Ohio found most respondents stating that donors' wishes should be respected and implemented over family objection."[406]
Unspecified	"Surveys of public opinion reveal some considerable resentment on the part of registered donors that families are allowed to defeat their wishes."[407]
Unspecified	"Work from focus groups had shown that people did not want their family to override their decision to donate organs."[408]

13.2 Legal arguments opposing the family veto

13.2.1 Legal duties owed by healthcare providers

Beyond the moral duties described above, HCPs owe legal duties to their patients – bestowing unto the physician the obligation to act in the patient's best interests, to act with good faith and loyalty, and to avoid allowing personal interests to "conflict with their professional duty."[409] Practically speaking, in the ODT context, "the role of the OPO and HCPs is to ensure that the FMs [family members] understand the situation and the process, and that the patient's wish will be respected."[410]

Who is a "person"? Who is a "patient"?

Among the most contentious of health law definitions is "personhood". Even if the boundaries of personhood are defined as "life" and "death," considerable debate surrounds both of these definitions, too. In Canada, the *Criminal Code* defines where personhood begins,[411] but is silent on where it ends. Similarly, in Ontario (and many other provinces), "[t]here is no legislative definition of death."[412] As will be discussed below, within the ODT context, the boundaries of

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403 Manninen & Evans, *supra* note 400 at 3113.
404 Verble & Worth, *supra* note 48 at 28.
405 Lin et al, *supra* note 80 at 31.
406 Traino & Siminoff 2012, *supra* note 47 at 295.
407 Morgan et al, *supra* note 58 at 105.
408 Kmietowicz, *supra* note 73 at 1.
409 "Duty of Care" (March 2023), online: *CMPA* <www.cmpa-acpm.ca/en/education-events/good-practices/medico-legal-matters/duty-of-care>.
410 Kentish-Barnes et al, *supra* note 112 at 334.
411 See *Criminal Code*, *supra* note 250, s 223(1): A child becomes a human being within the meaning of this Act when it has completely proceeded, in a living state, from the body of its mother, whether or not (a) it has breathed; (b) it has an independent circulation; or (c) the navel string is severed.
412 *McKitty v Hayani*, 2018 ONSC 4015 at para 32. Within the ODT context, only three provinces define "death" within their ODT legislation: Nova Scotia, Prince Edward Island, and the Northwest Territories. Outside of ODT legislation, Manitoba was the first province to statutorily define death through its *Vital Statistics Act*: "[t]he death of a person takes place at the time at which irreversible cessation of all that person's brain function occurs." See *The Vital*

"personhood" may inform which – if any – legal rights transcend the death of the registered donor.[413]

Woven together with the definition of "personhood" is the similarly existential question of whether the deceased is still a patient. Put differently, does the physician's duty of care to a patient end at death, or when the patient "leave[s] the practitioner's workload"?[414]

While arguing in opposition to the family veto, some physicians such as Ball, Sibbald, and Oczkowski acknowledge that "[f]or deceased donation, donors are no longer our 'patients', and thus we are not dealing with a 'treatment' in the legal sense."[415] However, the authors do not believe their fiduciary duty to their patients ends with death:

> "Nevertheless, the clinical team members' duty, even after death, is first and foremost to the patient. It is not logical that our commitments to a patient should change when neurologic death is determined, but this likely occurs because of a motivation to care for families and/or out of fear of the repercussions of defying family wishes."[416]

In this way, even if legal "personhood" is seen to terminate at death, "patienthood" is often seen to extend beyond this boundary; dignity and care are still owed to the deceased after their heart stops beating or they meet the neurological criteria of death.

13.2.2 Patient-Physician Fiduciary Duty: In Life and In Death

One fundamental duty of HCPs that survives the death of a patient is confidentiality. Confidentiality is both a moral and legal duty owed to patients by HCPs – as a general rule, HCPs cannot collect or share personal health information without the express consent of the patient.[417]

There are exceptions to a patient's expectations of privacy – both in life and in death. In Ontario, personal health information is protected under the *Personal Health Information Protection Act* for

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Statistics Act, CCSM c V60 at s 2; see also The Canadian Encyclopedia, "Death" (15 December 2013), online: <www.thecanadianencyclopedia.ca/en/article/death>.

[413] For example, *Hislop* and *Giacomelli* established that section 7 and section 15(1) *Charter* rights do not survive death; however, this rule was adjusted in cases such as *Grant* and *Selkirk*, so as to permit the continuation of *Charter* claims when the alleged *Charter* violation(s) contributed to the death of the claimant: see *Canada (Attorney General) v Hislop*, 2007 SCC 10 [*Hislop*]; *Giacomelli Estate v Canada (Attorney General)*, 2008 ONCA 346 [*Giacomelli*]; *Grant v Winnipeg Regional Health Authority et al*, 2015 MBCA 44 [*Grant*]; *Selkirk et al v Trillium Gift of Life Network et al,* 2021 ONSC 2355 [*Selkirk*].

[414] Morris & Holt, *supra* note 140 at 1129.

[415] Ball, Sibbald & Oczkowski, *supra* note 9 at 286.

[416] Ball, Oczkowski & Sibbald, *supra* note 10 at 601, 603.

[417] "When a family member has questions about privacy and consent", online: *CAMH* <www.camh.ca/en/health-info/guides-and-publications/when-a-family-member-has-questions-about-privacy-and-consent>. This mirrors the duty of confidentiality owed by lawyers and paralegals to their clients. The Law Society of Ontario holds that confidentiality applies to *all information* held by the lawyer, regardless of the relevance of the information to legal proceedings or whether the information was "publicly available or known to others. The scope of the duty of confidentiality is wider than the evidentiary rule of privilege." See "Frequently asked questions about the duty of confidentiality", online: *LSO* <https://lso.ca/lawyers/practice-supports-and-resources/topics/the-lawyer-client-relationship/confidentialite/frequently-asked-questions-about-the-duty-of-confi>. Further, "[t]he duty of confidentiality owed to clients continues indefinitely, even after the client's matter is resolved, the professional relationship with the client has ended (regardless of the reason), or the client dies" (*ibid*).

120 years after the record containing the information was created or 50 years after the death of the individual.[418] However, some information may be disclosed by the health information custodian (here, the HCPs) prior to this deadline in order to identify a deceased individual (if it is reasonably suspected or known to be that person), or to the immediate family of the deceased "if the recipients of the information reasonably require the information to make decisions about their own health care or their children's health care."[419]

If we consider that the duty of confidentiality is widely accepted to continue after the death of a patient, it can be argued that other duties may – or should – survive death, too. HCPs bear "an overriding duty to act in the patient's best interests."[420] This duty does not necessitate HCPs provide any and all treatments requested by a patient – nor do patients have a correlative right to receive any and all treatments they so choose.[421] And while public opinion alone does not create legal duties, the staunch opposition of the Canadian public to the family veto[422] speaks to the expectations that registered donors have within their patient-provider relationship. Thus, barring any new evidence that the registered donor has changed their mind about donation, proceeding with organ donation[423] should be seen as acting within the donor's best interests.

But what level of action by physicians does this duty necessitate? Per Elisabeth Buggins, "doctors needed to be more 'robust' in arguing the case of the people who had signed the organ donor register."[424] In a survey by Anthony et al, "[m]any participants emphasized their responsibility to advocate for the donor's wishes when first introducing organ donation to SDMs … Another participant described their role as giving a voice to the donor after death: 'Our focus is the patient, definitely…we're the donor's voice.''[425]

Canadian ODT statutes do not appear to materially contemplate how consent to donation should be followed in a clinical setting. Ontario's TGLNA for example defines consent to donation as "binding" and "full authority", but does not necessitate acting upon that consent. The exception here is Quebec – per Downie, Shea, and Rajotte, "the [Civil] Code is explicit in establishing a legal duty to follow the donor's expressed wishes."[426] However, they note that "it appears to be open to interpretation under the current law whether family opposition constitutes a compelling reason to not abide by them."[427]

13.3.3 Additional Physician Fiduciary Duties

Despite any moral arguments explored below as to why HCPs may not wish to upset grieving families, it is well established in law that – broadly speaking – there is not a duty of care owed to

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[418] 2004, SO 2004, c 3, Sch A [PHIPA]. Under s 9(1), protection expires at whichever of these dates occurs first.
[419] *Ibid*, s 38(4).
[420] *Rasouli v Sunnybrook Health Sciences Centre*, 2011 ONSC 1500 [*Rasouli* ONSC]. See specifically at para 76, citing Ellen I. Picard & Gerald B. Robertson, *Legal Liability of Doctors and Hospitals in Canada,* 4th ed (Toronto: Thomson Carswell, 2007) at 345 (within the discussion of "Futile or Inappropriate Treatment").
[421] *Ibid*. See also *Rasouli* ONSC at para 58.
[422] See above on pages 64-65.
[423] Assuming the organs are fit for transplantation.
[424] Kmietowicz, *supra* note 73 at 1. Buggins chaired the UK's Organ Donation Taskforce in 2008, tasked advising "the government on boosting transplantations" (*ibid*).
[425] Anthony et al, *supra* note 4 at 617.
[426] Downie, Shea & Rajotte, *supra* note 101 at 1257.
[427] *Ibid*. It does not appear that "compelling reason" has yet been interpreted within the ODT context.

SDMs or family members.[428] The case of *Wawrzyniak* specifically contemplates whether a fiduciary duty and/or a duty of care are owed by HCPs to the family of a patient. In that case, the Court held:

> [370] I accept that recognition of such a duty of care owed by a physician to a family member or substitute decision-maker of an incapable patient would have the potential to put the physician in a conflict of interest because the wishes of the close family member or substitute decision-maker may not align with the physician's medical opinion of what is in the patient's best interests. The imposition of a duty of care owed by a physician to a patient's family members or a substitute decision-maker might influence the physician, in attempting to comply with competing and potentially conflicting duties of care, to act in ways in which he or she would not otherwise act and put the patient at risk of harm …
>
> [376] … If a duty of care was owed to the plaintiff, the applicable standard of care could not be one that would require the defendants to offer and administer CPR to Mr. DeGuerre, a treatment that they had decided was medically inappropriate. This would require them to act in a way that would conflict with their duty to their patient.[429]

Thus, in the ODT context, the duty of care owed by physicians lies only with their patient.[430]

An overview of reasons why the doctors might not proceed with organ procurement

Just as there are numerous arguments made in opposition to the family veto, many arguments can also be made in support – or at least understanding – of the family veto.

13.3 Moral arguments justifying the family veto

13.3.1 Harm to the family

As discussed in Chapter 1, a widely raised argument justifying the family veto is the reluctance of HCPs to contribute to the grief of the family. Even if a formal duty of care is not owed to the surviving family members, HCPs may feel responsible for caring for bereaved family members, who are "going through a unique and distressing experience."[431]

13.3.2 Public opinion

One explanation as to why family vetoes are permitted in clinical practice is that of public opinion. As mentioned above, fear of increasing public mistrust in the ODT system is used as an argument both in favour and in opposition to the family veto.[432]

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[428] *Wawrzyniak v Livingstone,* 2019 ONSC 4900 at para 370 [*Wawrzyniak*]. This position was reaffirmed *Ovari v Brant Community Healthcare System*, 2023 ONSC 6933 at para 40 and *Alafi v Lindenbach*, 2022 ONSC 1435 at para 60.

[429] *Wawrzyniak*, *ibid* at para 2.

[430] It should be noted here that a duty of care could be found in other third party, non-patient relationships if proximity was successfully argued. However, such a relationship has not been found for unharmed family members or SDMs within the context of standard clinical decision making.

[431] Kentish-Barnes et al, *supra* note 112 at 334.

[432] Shaw et al, *supra* note 43 at 484.

Concern is raised by many authors that "disregarding the views of the donors' families, even if morally defensible, would be politically unpalatable and could lead to a significant decrease in organ donors."[433] This fear is echoed by both academics and practitioners – Ball, Sibbald, and Oczkowski describe how a "fear of loss of trust in the donation system" was cited by 81% of survey respondents as a reason to respect family override requests.[434] Albertsen raises three connected possibilities in this regard:

> "Perhaps stories of how family objections are overruled could lead to general mistrust and lower donation rates. Perhaps people will fear that their family cannot protect them against a medical system overly focused on acquiring organs. Perhaps bad experiences will deter the family members from becoming donors themselves."[435]

However, Albertsen reconciles these concerns with current public opinion regarding the family veto. As discussed above, "[t]he few available studies indicate that the majority of people do not believe the family should be allowed to veto the decision to donate."[436]

13.4 Legal arguments justifying the family veto

13.4.1 Fear of lawsuits

Another widely cited reason for doctors permitting family vetoes to occur is their fear of legal retaliation by snubbed families.[437]

In 2008, American OPOs had an estimated "1 in 2500 chance of being sued over whose wishes they followed and virtually no chance of losing the suit."[438] However, section 8 of the Revised *Uniform Anatomical Gift Act* [UAGA] – which at that time "[had] been adopted in some form by all 50 states and the district of Columbia"[439] – explicitly bars anyone from making, amending, or revoking anatomical gifts made by the donor under the Act.[440] Thus, given that "the wishes of patients to donate are legally recognized as superseding family wishes, there is little reason to fear liability for acting on a valid donor card."[441] In 2019, it was found that "[n]o OPO, transplant

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433 Traino & Siminoff 2012, *supra* note 47 at 296; Mesich-Brant & Grossback, *supra* note 72 at 696; Harris et al, *supra* note 115 at 12-13; De Wispelaere & Stirton, *supra* note 121 at 180; Statz, *supra* note 142 at 1689; Ann C. Klassen & David K. Klassen, "Who are the donors in organ donation? The family's perspective in mandated choice" (1996) 125 Ann Intern Med 70 at 71-72.

434 Ball, Sibbald & Oczkowski, *supra* note 9 at 286.

435 Albertsen, *supra* note 23 at 277. See also Kluge, *supra* note 141 at 161.

436 Albertsen, *ibid*. Here, Albertsen cites a Canadian study where 89% of respondents believed that the family should not be allowed to veto a decision to donate, as well as a survey in the UK where 73% of respondents responded "no" to the same question – 16% responded that they did not know, and only 11% responded positively (*ibid*).

437 Anthony et al 2021, *supra* note 4 at E770; Mesich-Brant & Grossback, *supra* note 72 at 696; Liberman, *supra* note 113 at 132-33; Harris et al, *supra* note 115 at 12-13; Dodd-McCue et al, *supra* note 135 at 153; Colleen M. Johnson et al, "Organ donation: a statewide survey of trauma surgeons" (2001) 51 J Trauma Injury, Infection & Critical Care 110 at 115.

438 Christmas et al, *supra* note 34 at 1509.

439 May, Aulisio & DeVita, *supra* note 95 at 333.

440 See UAGA, *supra* note 115, s 8(1): "Except as otherwise provided in subsection (g) and subject to subsection (f), in the absence of an express, contrary indication by the donor, a person other than the donor is barred from making, amending, or revoking an anatomical gift of a donor's body or part if the donor made an anatomical gift of the donor's body or part under Section 5 or an amendment to an anatomical gift of the donor's body or part under Section 6."

441 May, Aulisio & DeVita, *supra* note 95 at 333-34.

center, or doctor has been penalized to date for refusing to honor first-person authorization, which, in turn, creates a perverse incentive for OPOs and others involved in the donation process to keep discarding the express wishes of the decedent in exchange for the grieving family's approval."[442]

In the Canadian context, while HCPs and/or OPOs may be fearful of civil liability arising from organ procurement and donation in the face of a family veto, all Canadian common law provinces include some form of good faith immunity clause within their ODT legislation.[443] Furthermore, "physicians who act on valid donor consent in accordance with the applicable organ and tissue donation legislation are not exposed to civil liability even if the family opposes, as their actions are lawful and the family has no basis for legal action."[444] In 2008, Downie, Shea, and Rajotte "were not able to find any reported decisions of physicians being successfully sued by families for following a valid donor consent" – nor did there appear to be any such reported decisions at the time of writing.[445]

While the viability of hypothetical legal action (in the Ontarian context) will be discussed in further detail below, it does appear – at least from a close reading of Ontario's TGLNA – that HCPs likely need not fear legal ramifications from family members by proceeding with organ procurement and donation in the face of a veto (due both to their specific immunity in the TGLNA and their lack of duty of care owed to the family).

13.4.2 Lack of understanding of / clarity in the law

A final explanation for the continued allowance of the family veto (even in the face of legislation to the contrary) is a lack of understanding of the law. Some healthcare providers may be misinformed as to what the relevant ODT statutes say[446] – and this is perhaps unsurprising given the disparities between the law and public health messaging across Canada.[447] For example, the doctors in this scenario may (incorrectly) "think that the law requires that a person's family "validate" his or her premortem decision to donate before organ removal can take place."[448] Alternatively, they may be aware of the legislation, but believe "that if the law was tested, e.g., if a family challenged organ removal from a relative who was a declared donor absent their consent or over their dissent, that the courts would rule in favor of the family."[449] However, writing in the American context, Peters holds the belief that many organ procurement personnel "appear to be unaware that the standard practice of asking the surviving families of all classes of potential donors (declared and undeclared) for permission to remove organs and tissues from these individuals is inconsistent with the provisions of most state UAGAs."[450]

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[442] Havekost, *supra* note 81 at 711.
[443] See Appendix 15. See also Downie, Shea & Rajotte, *supra* note 101 at 1260.
[444] Downie, Shea & Rajotte, *ibid*. Here, the authors noted that there does exist a possible exception of Québec, given its "compelling reason" exemption.
[445] Downie, Shea & Rajotte, *ibid*. See also Kirby, *supra* note 144 at 127 (published one year later in 2009). In conducting the research for this thesis, I combed through CanLII for each province and territory and could not find a single reported decision on the topic.
[446] Peters, *supra* note 136 at 255.
[447] See Appendix 16. See also Downie, Shea & Rajotte, *supra* note 101 at 1259.
[448] Peters, *supra* note 136 at 255; Downie, Shea & Rajotte, *ibid*.
[449] Peters, *ibid*.
[450] *Ibid* at 267-268.

In the Canadian context, Downie, Shea, and Rajotte argued that "[t]he current law should be taught in relevant health professional degree programs, such as nursing and medicine, and should form part of continuing education programs for health professionals working in this field."[451] Further study is needed to examine precisely how ODT legislation is taught in medical schools across Canada – if at all – and how current professional degree programs equip their students to deal with family veto events in practice.

13.5 Locating the family veto within Canadian legal frameworks

Beyond the ethical and legal reasons why the doctors in our case study may or may not choose to listen to the woman's parents and overturn their daughter's consent to donate, there are numerous legal lenses by which the family veto can be understood. The following section of this thesis will examine both health law and property law (namely, questions of wills and estates). Importantly, ODT law and policy does not fit neatly into either of these frameworks – rather, it lives in a novel corner of health law worthy of further study and attention.

13.5.1 Health Law

The *Trillium Gift of Life Network Act* and the Consent and Capacity Board

Outside of the context of organ donation, the primary statute in Ontario that governs medical consent is the *Health Care Consent Act*.[452] The HCCA and the TGLNA do not intersect, as the HCCA specifically does not come into play where one person is consenting or refusing to donate organs on behalf of another.[453] However, reading these two statutes together provides insight into how courts (and other adjudicating bodies) approach similar end-of-life conflicts where one party is incapable of defending their own healthcare decisions.

There are five key differences between the HCCA and TGLNA that are relevant to the vignette proposed earlier in this Chapter. First, as discussed, the standard for consent for deceased donor organ donation falls below the informed consent threshold that is otherwise required for healthcare interventions. Second, within the hierarchy of parties able to make decisions on behalf of another, the HCCA imposes three additional categories of SDM above those outlined in the TGLNA. The HCCA also gives adult children and parents the same level of decision-making authority, whereas adult children are privileged over parents in the TGLNA.[454] Furthermore, the HCCA speaks to addressing conflict between SDMs of the same level of decision-making authority (while the TGLNA does not).[455] Both statutes aim to prevent SDMs from overstepping into the decision-

[451] Downie, Shea & Rajotte, *supra* note 101 at 1261. By virtue of making this recommendation, the authors appear to suggest that the current law was not widely taught in health professional degree programs (at least not at the time of writing).
[452] HCCA, *supra* note 358.
[453] *Ibid*, s 6.
[454] The order of the SDM hierarchy could have material impacts on how often families veto organ donation. For example, Rodrigue, Cornell & Howard found that parents (65.8%) and adult children (52.5%) are more likely to donate organs than spouses (43.3%) and siblings (42.9%): see JR Rodrigue, DL Cornell, & RJ Howard, "Organ Donation Decision: Comparison of Donor and Nondonor Families" (2008) 6:1 Am J Transplant 190. However, willingness (or unwillingness) to donate is deeply nuanced, and parents may be more or less willing to donate than spouses (and vice versa) depending on the cultural and religious context. See Luo et al, *supra* note 228; Sherry, Tremblay & Laizner, *supra* note 338 at 15.
[455] HCCA, *supra* note 358, s 20(6).

making abilities of a higher ranking SDM.[456] The third key distinction between the statutes can be found in section 20(2) of the HCCA: this statute imposes numerous requirements on SDMs that are not found in the TGLNA, including a willingness "to assume the *responsibility of giving or refusing consent*."[457] Furthermore, the fourth difference of note is the expansive principles of giving or refusing consent (coupled with the definitions of "best interests") provided in the HCCA, but absent from the TGLNA.

Table 8: Comparing the HCCA and TGLNA

Health Care Consent Act	***Trillium Gift of Life Network Act***
There are four mandatory elements that comprise consent: consent must relate to the specific treatment, it must be informed, it must be given voluntarily, and it must not be obtained through misrepresentation or fraud[458] The HCCA further specifies the information required for consent to be "informed"[459]	Consent is defined as "a consent given under this Act"[460]
Wishes **5** (1) A person may, while capable, express wishes with respect to treatment, admission to a care facility or a personal assistance service **Manner of expression** (2) Wishes may be expressed in a power of attorney, in a form prescribed by the regulations, in any other written form, orally or in any other manner **Later wishes prevail** (3) Later wishes expressed while capable prevail over earlier wishes	**Consent [given by the deceased] is full authority, exception** **(3)** Upon the death of a person who has given a consent under this section, the consent is binding and is full authority for the use of the body or the removal and use of the specified part or parts for the purpose specified, except that no person shall act upon a consent given under this section *if the person has reason to believe that it was subsequently withdrawn*[461] **Consent [given by the SDM] is full authority, exceptions** **5**(4) … no person shall act on a consent given under this section if the person has actual knowledge of an objection thereto by the person in respect of whom the consent was given
The HCCA sets out specific requirements for persons giving or refusing consent on behalf of another. These include (among other factors), the capacity and age of the consenter, as well as the requirement that the SDM	

[456] The TGLNA holds that "… no person shall act on a consent given under this section if the person has actual knowledge of an objection … by a person of the same or closer relationship to the person in respect of whom the consent was given than the person who gave the consent" (s 5(4)). The HCCA holds that an SDM "may give or refuse consent only if no person described in an earlier paragraph meets the requirements of subsection (2)" *or* "may give or refuse consent if he or she believes that no other person described in an earlier paragraph or the same paragraph exists, or that although such a person exists, the person is not a person described in paragraph 1, 2 or 3 and would not object to him or her making the decision" (see ss 20(3) and (4), respectively).
[457] HCCA, *supra* note 358, s 20(2) (emphasis added).
[458] *Ibid*, s 11(1).
[459] *Ibid*, ss 11(2) and (3).
[460] TGLNA, *supra* note 12, s 1.
[461] Emphasis added.

<table>
<tr><td>“is willing to assume the responsibility of giving or refusing consent”[462]</td><td></td></tr>
<tr><td>The SDM hierarchy under the HCCA is as follows:
The person’s guardian (provided the guardian has authority to give or refuse consent to the treatment)
The person’s attorney for personal care (if the power of attorney confers authority to give or refuse consent to the treatment)
The person’s representative appointed by the CCB (provided the representative has the authority to do so)
The person’s spouse or partner
The person’s child or parent (or a person who is lawfully entitled to give or refuse consent in the place of a parent)
The person’s sibling
Any other relative of the person[463]</td><td>The SDM hierarchy under the TGLNA is as follows:
The person’s spouse
The person’s (adult) children
The person’s parents
The person’s (adult) siblings
The person’s (adult) next-of-kin
The person lawfully in possession of the body other than, where the person died in hospital, the administrative head of the hospital[464]</td></tr>
<tr><td>Principles for giving or refusing consent
21 (1) A person who gives or refuses consent to a treatment on an incapable person’s behalf shall do so in accordance with the following principles:

1. If the person knows of a wish applicable to the circumstances that the incapable person expressed while capable and after attaining 16 years of age, the person shall give or refuse consent in accordance with the wish.

2. If the person does not know of a wish applicable to the circumstances that the incapable person expressed while capable and after attaining 16 years of age, or if it is impossible to comply with the wish, the person shall act in the incapable person’s best interests.[465]

In determining the person’s “best interests”, SDMs are expected to consider (a) the values and beliefs that the SDM knows the patient held when capable and believes they would still act on if capable; (b) any wishes expressed by the patient with respect to the treatment that are not required to be followed under paragraph 1 of subsection (1); and (c) several medical factors surrounding the treatment and the patient’s condition.[466]</td><td>5 (3) No person shall give a consent under this section if the person has reason to believe that the person who died or whose death is imminent would have objected.</td></tr>
</table>

[462] HCCA, *supra* note 358, s 20(2) (emphasis added).
[463] *Ibid*, s 20(1).
[464] TGLNA, *supra* note 12, s 5(2).
[465] HCCA, *supra* note 358, s 21(1) (emphasis added).
[466] *Ibid*, s 21(2).

A final distinction between the statutes is the clear mechanisms provided in the HCCA for resolving conflicts. If, for example, an SDM refuses to provide consent to withdraw life support but the patient's HCPs believe that continued life support is no longer medically indicated, they can formally challenge the SDM by applying to the Consent and Capacity Board.[467]

In *EI (Re)*, EI's SDM applied to the Consent and Capacity Board (CCB) regarding the removal of mechanical ventilation following EI meeting the neurological criteria for brain death.[468] In this case, the Board described the "legal and medical limbo" experienced by both families and HCPs when navigating the then-newly accepted NDD criteria as "creat[ing] a number of concerns for the health practitioners and broader healthcare team," coupled with the "uncertainty and lack of legal clarity for everyone involved."[469] In briefly mentioning the TGLNA, the Board ultimately deferred to the medical expertise and accepted medical practice of the HCPs, shifting future responsibility to the legislature and/or the Courts (should a legal definition or review of NDD determinations be required).[470]

GL (Re) turned on the applicability of a previously expressed wish by the patient regarding her own treatment.[471] In this case, the Board held that by law, GL's SDMs "were obligated to comply with prior capable wishes applicable to the circumstances."[472] The Board further held that the discretion of the SDMs to act under the Power of Attorney for Personal Care "was circumscribed by their obligations under Section 21 of the HCCA. Discretion does not give SDMs license to do whatever they wanted without regard to the prior capable wishes of GL or her best interests."[473] Based on the evidence at hand, the Board held that the wish contained in her POAPC constituted a prior capable wish under Section 21(1) of the HCCA.[474] Had GL not expressed a prior capable wish, her SDMs would have been required to act in her best interests, as required by section 21(2). For the sake of thoroughness, the Board completed a best interests analysis, holding that SDMs "would be obligated to consider the values and beliefs GL held when capable and would still act upon if capable and the medical factors set out at law."[475] In so doing, the Board found that the medical factors were clear and uncontroverted, and that on a balance of probabilities, GL would *not* have wanted to deviate from her previously expressed wish.[476] Finally, in considering GL's religious and cultural beliefs (as well as the values and beliefs of her family), "there was no

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[467] *Ibid*. Importantly, the majority in *Rasouli* "accepted that the withdrawal of life support was not necessarily a negative outcome in appropriate cases" – instead, the Court in *Rasouli* "was considering whether the withdrawal of life support constituted treatment to which the scheme of the *HCCA* applied": see *JM (Re)*, 2020 CanLII 83845 (ON CCB) at 39.
[468] *EI (Re)*, 2016 CanLII 151974 (ON CCB).
[469] *Ibid*.
[470] *Ibid*. While this case alone is not indicative of how a court is guaranteed to adjudicate end-of-life conflicts, it demonstrates the deference paid to accepted medical practice when navigating complex medicolegal disputes. Notably, in *EI (Re)*, the question of whether EI was a "person" under the HCCA was considered, but ultimately not determined. However, the CCB *did* consider the question of personhood in *UH (Re)*, "and concluded that death terminates the person." As such, the HCCA was not found to apply in that case: see *UH (Re)*, 2016 CanLII 98580 (ON CCB) at 9-10.
[471] 2018 CanLII 132242 (ON CCB).
[472] *Ibid*.
[473] *Ibid*.
[474] *Ibid*.
[475] *Ibid*.
[476] *Ibid*.

evidence about how GL personally interpreted her religion and beliefs as they applied to her present circumstances."[477] Ultimately, the Board found that GL's SDMs "had not complied with the principles of substitute decision-making set out in the Act."[478]

Given that ODT litigation is virtually non-existent in Canada – and thus cannot be relied upon in assessing our vignette – considering the approaches taken by the CCB in similar end-of-life conflicts demonstrates the value placed on prior wishes, as well as the standards to which SDMs are held in other areas of health law.

13.5.2 Wills & Estates

Another way of conceptualizing families vetoing organ donation registration is in comparison to wills and estates law. As expressed by Isdale & Savulescu, "[a]llowing family members to veto explicit donation decisions is inconsistent with the rights we generally think people have over their property and body after they die or lose mental capacity."[479] This sentiment is echoed throughout the literature:

> "The state and its representatives are obligated to carry out the terms of a will after an individual's death, and few think that family objections to how the deceased wished to distribute her material goods provide a legitimate veto. If it is unproblematic that the state is obligated to keep legal contracts made to the dead in the case of wills, it should not be especially problematic that it is obligated to keep promissory obligations to the dead in the case of organ donation."[480]

Isdale & Savulescu further posit:

> "Similarly, a person's wishes as to what happens to their property after their death, as expressed in a will, are legally binding (with some limited possibilities for review by the courts). These are decisions which individuals should be allowed to make for themselves. Why should an explicit decision to donate organs be treated differently?"[481]

Thus, much of the literature takes the position that because society approves of – and ultimately expects – the enforcement of wills (and indeed, places great importance on things such as the last wishes and words of the deceased, as well as personal legacy), then we should automatically accept the enforcement of organ donation where intentions are formally registered. However, while there is a clear legislative framework in Ontario for enforcing the distribution of property in a will, for example, there is no such framework for enforcing the distribution of organs.

Conversely, arguing in favour of the family veto, Johnston acknowledges that "the resources allocated in a will are meant to enrich the family's or community's life in ways the decedent felt appropriate, based on their values, knowledge of their resources and the needs of those around them … Furthermore, a greedy free-for-all may ensue if we let others override their decisions."[482] However, he ultimately argues:

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[477] *Ibid*.
[478] *Ibid*.
[479] Isdale & Savulescu, *supra* note 45 at 96.
[480] Liberman, *supra* note 113 at 148. See also Kyrtata, *supra* note 52 at 112.
[481] Isdale & Savulescu, *supra* note 45 at 96.
[482] Johnston, *supra* note 22 at 488.

> "[W]e respect wills *not because property rights exist beyond death, but because respecting the will of the dead seems good for the living*. While it is straightforward to know how money, or a house, or a car might benefit others, it is not always so clear to a person how their body will be needed beyond death. The process of grief cannot be so easily predicted."[483]

Johnston's view places considerable weight on the grief of the family, ultimately privileging their "need" for the body over that of the hundreds of patients sitting on transplant waitlists.

It is true that bodies are not considered as property under Canadian law. However, the deference paid to wills indicates the law recognizes that some interests survive beyond death. While imperfect, the parallel drawn to wills and estates sheds valuable light on how signed intentions to donate organs should be treated.

To date, it does not appear that organ donation has been judicially considered within a property or wills framework (or considered at all within the family veto context). However, for the sake of argument, if recorded donation intentions are conceptualized within the realm of wills and estates, we can consider the next-of-kin to be the "executors", while the would-be donation recipients (as represented by HCPs) are the "beneficiaries." Executors – in fulfilling their duties as such – "are impressed with obligations as fiduciaries *per se*. Those fiduciary duties are owed to the beneficiaries of the estate and are different from the executors' common law duty to dispose of the deceased person's remains … [T]he common law identifies executors in priority to anyone else because, in part, they are already impressed with a duty to act in good faith."[484] In typical disputes of wills, beneficiaries can complain against the executor(s) of the estate.

A recent case arising in Nova Scotia provides an interesting addition to the wills and estates discourse in the ODT context. In *Curry v Curry*, the family of the recently deceased Anne Curry argued over where the ashes of their mother would reside. In this case, the court had to grapple with two questions:

> **(1)** What factors guide and/or constrain the disposition of cremated remains? Just below the surface of this question lies the question of Anne Curry's own wishes. Are those wishes relevant and, if so, what were they?
>
> **(2)** How does the Court resolve disputes among multiple executors in these circumstances? Does the will of the majority necessarily prevail?[485]

In approaching this case, the Court began by acknowledging the deeply nuanced family dynamics at play in end-of-life decision-making:

> "Overshadowing the legal questions in this case are the complexities of family dynamics, knotted and gnarled by conflicted feelings of loyalty and love; devotion and distrust; sibling respect and sibling resentment. The resulting dissonance is obviously not unique to the Curry family, but it does scrape through the evidence. Each side claims a deep

483 *Ibid* (emphasis added).
484 *Curry v Curry,* 2023 NSSC 402 at para 75 [*Curry*].
485 *Ibid* at para 8.

> understanding of their mother's final wishes; but their respective understandings are incompatible. Each side invokes their mother Anne Curry's life experiences; yet their perspectives are clearly coloured by their own personal (not their mother's) experiences. Each side recalls the deep and loving bond between Anne Curry and all her children; but they have allowed her memory to divide them. Each side is determined to honour and respect their mother; but one is left wondering whether Anne Curry would feel honoured and respected watching her children quarrel in open Court over her remains."[486]

In navigating the first of the two legal questions posed above, the Court provided a rich summary of common law principles and precedents for the disposition of human remains. Despite being rendered over 140 years ago, a fundamental authority regarding the disposition of human remains is *Williams v Williams*.[487] In this case, the deceased Henry Crookenden had written a private letter to his friend, Eliza Williams (who has not named as an executor of his Will), in which he directed his friend to have his body cremated – a choice which was highly controversial in late 19th century England.[488] His Will directed that Eliza Williams deal with his body, and that the executors of his estate were to pay all costs associated with doing so.[489] The executor of the Will did not comply, and Henry Crookenden was buried instead of cremated.[490] Eliza Williams "was determined to fulfill Mr. Crookenden's wishes" – and with perseverance (and deception), she had Mr. Crookenden's body disinterred, transported to Italy, and cremated.[491]

Williams established two key legal principles "that defined the nature of an executor's authority and responsibility regarding the disposition of a deceased's body": [492]

(1) "There is no property in a deceased person's remains" – a principle that "has been repeatedly confirmed in subsequent [Canadian] jurisprudence"[493]

(2) "Executors presumptively retain a right of possession over the deceased person's remains – again, not a right of ownership because there is not property in a body. The right of possession arises solely to ensure that the deceased is 'properly buried … in a manner suitable to the estate he leaves behind him'."[494]

With these questions in mind, the Court in *Curry* posed the following: "the critical questions relate to the executor's obligation to ensure that the deceased is 'properly buried' … What does that mean? What factors inform an executor's decision around a 'proper burial'?"[495] Citing *Deagan*, the Court held that executors are "obliged to dispose of human remains in a manner that is

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486 *Ibid* at para 9.
487 *Williams*, [1882] 20 ChD 659 [*Williams*]. See in particular 664-665, as cited in *Curry*, *ibid*, at para 13.
488 *Curry*, *ibid* at paras 15-20.
489 *Ibid* at para 15.
490 *Ibid* at para 17.
491 *Ibid* at paras 18-24.
492 *Ibid* at para 27.
493 *Ibid* at para 27, citing *Miner v Canadian Pacific Railway*, 1911 CarwswellAlta 23; *Waldman v Melville (City)*, 1990 CarswellSask 131 (Sask. Q.B.); *Mason v Mason*, 2018 NBCA 20 [*Mason*]; and *Krauch v Degan Estate*, 2021 NSSC 108 [*Deagan*].
494 *Curry*, *ibid*, citing *Schara Tzedeck v Royal Trust Co.* [1953] 1 SCR 31 [*Schara Tzedeck*]; *Sopinka (Litigation Guardian of) v Sopinka*, 2001 CanLII 3234 (ONSC) [*Sopinka*].
495 *Curry*, *ibid* at para 29.

'dignified and respectful'."[496] Furthermore, "obviously, executors are equally obliged to comply with any applicable statutes."[497]

Thus, with regard to the first legal question raised in *Curry* (the relevance of Anne Curry's own wishes about her disposition), the Court confirmed that "executors are impressed with the Overriding Obligation to dispose of a deceased person's remains in a manner that is respectful, [and] dignified."[498] In that case, the novel issue at play was the "extent to which the deceased person's own wishes or instructions might be a factor that informs how the executors fulfill their Overriding Obligation."[499] Counsel for the Respondents argued that "[w]hile executors may look to the testator's will for guidance and, indeed, usually do honour the wishes described therein, they do so out of a *moral obligation* as opposed to a *legal obligation*."[500] However, the Court did not agree:

> "To the extent this might be interpreted to mean that the deceased person's wishes or instructions are legally irrelevant and may be ignored by the executors, I respectfully disagree.
>
> The actual wishes of the deceased person are relevant. To suggest otherwise would result in the law appearing inexplicably and rigidly detached from what is an obviously meaningful and instinctive issue, worthy of consideration when deciding how to dispose of a deceased person's remains."[501]

Instead, Canadian case law holds that "if the deceased has left directions as to the disposal of his body, though these are not legally binding on the personal representative, effect should be given to his wishes as far as is possible."[502] That being said, "a deceased's wishes are not determinative. The deceased person may not dictate a particular outcome by leaving written instructions or statements confirming their wishes."[503] Furthermore, in citing Nova Scotia's *Human Organ and Tissue Donation Act* (HOTDA), the Court in *Curry* emphasized that executors must ensure compliance with the applicable statutes – here, "permitting a person to consent in advance to the donation and transplantation (after death) of specified organs or tissues."[504]

Many of the legal questions navigated in *Curry* are applicable to our hypothetical family veto case. Even if we view organ donor registration as not binding (notwithstanding the language used in the TGLNA that states consent *is* binding), effect should be given to her expressed wishes as far as is possible.[505] In this way, and as will be discussed in the following section, the deceased daughter

[496] *Ibid* at para 31, citing *Deagan*, *supra* note 493.
[497] *Curry*, *ibid* para 33.
[498] *Ibid* at para 34.
[499] *Ibid* at para 35.
[500] *Ibid* at para 36 (emphasis added).
[501] *Ibid* at paras 37-38.
[502] *Ibid* at para 39; citing *Schara Tzedeck*, *supra* note 494; *Hunter v Hunter*, [1930] 4 D.L.R. 255; *Abeziz v Harris Estate*, 1992 CarswellOnt 3803 (Ont. Gen Div); *Sopinka*, *supra* note 494; and *Mason*, *supra* note 493.
[503] *Curry*, *ibid* at para 40.
[504] *Ibid* at para 44.
[505] Should a family veto case be litigated through a wills and estates framework in the future, it would be crucial for either the courts or the legislature to narrowly define "as far as is possible" – perhaps to "as far as is medically and logistically possible." If conditional language is left vague, it would mirror the language of Section 43 in Quebec's Civil Code: "... The wishes expressed shall be followed, unless there is a compelling reason not to do so." As noted

in our scenario cannot require HCPs to transplant her organs if, for example, they are not suitable for donation. Furthermore, while our hypothetical scenario does not pertain to burial (as the facts of *Curry* did), it could certainly be argued that the girl's parents (if viewed as executors) are not treating her body in a manner that is "dignified and respectful" by overturning her autonomy, legacy, or final act of selflessness. Finally, it should be noted here that the *Curry* case did not turn on (nor include discussions of) organ donation. The choice of the Court to specifically mention ODT legislation is worthy of particular attention – perhaps the Court intended to reflect the societal value in deceased organ donation and/or the need for donation registration to be respected in the way manner we tend to respect wills. While this is purely speculative, of course, the inclusion of the HOTDA in *Curry* does signal a parallel between organ donor registration and wills and estates law.

In navigating the second of the two legal questions posed in *Curry* (how to resolve disputes regarding the disposition of human remains between executors and non-executors), the Court identified two key principles:

> "1. Non-executors may not insinuate themselves as full participants in this decision-making process when, at law, they play no role; assert no authority; and shoulder no responsibility. Thus, non-executors are not entitled to peel back the layers of the decision-making process and dissect every factor that influenced (or did not influence) the executor's decision. This does not mean that executors are free to act capriciously, or that non-executors are never entitled to raise an objection regardless of the underlying concern. However, in so far as non-executors are concerned, the analysis is outcome oriented. The executors' decision is measured only against the standard of whether the disposition is dignified and respectful – not a more forensic examination of the executors' decision-making process; and
>
> 2. So long as the executors have disposed of the deceased person's remains in a manner which is dignified and respectful, their decisions will be entitled to significant deference. As Richard CJ wrote in *Mason*: "In the case of a dispute over funeral arrangements and the disposal of human remains, a court should defer to the person who is lawfully entitled to make the decision, i.e. the executor, the administrator or the spouse, as the case may be." (at paragraph 32). Indeed, I was neither given nor could find a case in which a Canadian Court rejected an executor's decision regarding the disposition of a deceased person's remains and, instead, imposed the views of a non-executor. The executor's decision has been invariably approved, despite well-intentioned and often highly emotional pleas from a non-executor with close connections to the deceased."[506]

The Court further distinguished cases involving the disposal of human remains from property-based estate conflicts: "As indicated, the law does not recognize any property rights over a human body. The executors' obligation to dispose of human remains is fundamentally different and involve separate, distinct considerations more closely related to the unique nature of the underlying

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above "compelling reason" has not yet been judicially defined. However, particularly when compared to narrower language (such as in Nova Scotia's HOTDA or even the American UAGA), vagueness risks leaving the door open to family veto events.

[506] *Curry*, *supra* note 484 at para 46.

obligations when disposing of a deceased person's body."[507] Furthermore, "where executors are acting under the terms of the valid will, the testator's intentions are a determinative consideration in the management of estate property. By contrast, as indicated, a deceased person's intentions are not determinative when deciding how to dispose of human remains. They are merely one factor to be considered, among others."[508] Here, the Court clarified that similar estates disputes regarding property typically involved "a binary choice between selling/distributing property or continuing to hold the property within the estate."[509] However, these binary choices are not available when disposing of human remains: "[e]xecutors cannot choose whether to dispose of bodily remains, or not. Rather, they are obliged to dispose of the deceased person's remains in a dignified and respectful manner."[510]

Taken together, the application of the second legal question in *Curry* to the ODT context is markedly less clear-cut than the first. In our hypothetical scenario, for example, it is unclear who would be cast as the executors, non-executors, or beneficiaries. Would the family members be considered the executors, while the HCPs are non-executors? Or would the HCPs be considered to be beneficiaries (or, at least, acting on behalf of the beneficiaries, should we consider the would-be donation recipients)? Or further still, could the OPO holding the donor registration be considered the executor while all others are either non-executors or beneficiaries? Perhaps the family members are (or view themselves to be) beneficiaries insofar as they want to prevent the distribution of the deceased's body to others so as to keep it whole for burial?

However, it remains possible that Keith, J. would have been sympathetic to the position of our hypothetical doctors. There are four reasons for believing this to be the case: first, while "dignified and respectful" is not explicitly defined in *Curry*, overturning the final wishes of the deceased (as expressed in an organ donor registration) should not be viewed as "dignified or respectful."[511] Instead, as discussed above, the expressed wishes of the deceased should be followed wherever medically and logistically possible. Second, in requiring compliance with applicable statutes, Keith, J. explicitly cited Nova Scotia's HOTDA. Again, *Curry* was not an organ donation case, yet the Court chose to include the HOTDA as its first example of legislation to be upheld.[512] Third, in *Curry*, the majority of executors "failed to reasonably and respectfully consider information presented by the minority. In other words, the majority was rigidly fixed on their own pre-determined conclusion … and rejected outright any reasonable or respectful consideration of information that might suggest an alternate view."[513] Here, regardless of how the parties in our hypothetical scenario are defined (whether executor, non-executor, or beneficiary), the parents are required to reasonably and respectfully consider information presented by the doctors and/or OPO

[507] *Ibid* at para 55.
[508] *Ibid*.
[509] *Ibid*.
[510] *Ibid*.
[511] This, of course, does not extend to situations where families are able to offer concrete proof that the deceased changed their mind about organ donation, but passed away before formally changing their registration. That exception notwithstanding, per Cay, "[t]here is a fundamental autonomous right to say 'yes' or 'no' and to decide upon individual legacy" (provided the donor is both adult and has the capacity to consent) (*supra* note 36 at 363).
[512] *Curry*, *supra* note 484 at para 74.
[513] *Ibid* at para 80.

– namely, their daughter's intention to donate her organs.[514] Finally, and while not decisive on its own, a document titled "My Last Wish" containing Anne Curry's personal desires for her cremation and burial was viewed to be "clearly important and relevant to the disposition decision which the executors were required to make."[515] However, the court noted that Anne "decided not to permanently finalize her intentions by simply signing the 'My Last Wishes' document.[516] Furthermore, Anne expressed different views about her final resting place in an email dated eight years later. In the facts of our case, the daughter would have signed her Organ and Tissue Donor Registration, lending it the credence and permanence sought by the Court in *Curry*.[517] Her parents have not produced any evidence suggesting their daughter changed her mind in the time since signing her Registration.

It is not the goal of this thesis to argue that the legal frameworks governing wills and estates should be modified to accommodate ODT questions about the family veto, particularly as such questions continue to be purely academic in nature. However, *Curry* provides valuable insight into how a Court *might* approach the issue in our hypothetical scenario, particularly if it is presented within the context of wills and estates.

While writing in the American context, some authors, such as Peters, argue that "overriding a willing donor's documented wishes to donate *should* be grounds for legal action by potential recipients, given the legal status of gifts after death and the rights this bestows on recipients."[518] However, there are two notable concerns to be raised with this assertion. First, it is uncertain how potential recipients and their families would learn about a successful family veto. It is unclear if donation decisions made by SDMs during end-of-life care qualify as personal health information protected by PHIPA – however, donation decisions made by registered donors *are* protected by PHIPA.[519] As an exception to the privacy expectations set out in PHIPA, donor registration is expected to be shared with family members "so they can honour your wishes at end of life."[520] It thus seems unlikely that donation decisions (and in this case, veto decisions) could or would be shared without risking liability under PHIPA. Furthermore, SDMs are approached about consent to donation prior to matching a donor with a potential recipient. While SDMs could conceivably withdraw consent far along into the donation process, a family who is staunchly opposed to donation would probably not be given that opportunity. Instead, they would say "No" when first approached by hospital staff, and in turn, further donation conversations (as well as the medical testing required to match them with recipients) would likely never occur. Thus, there would not be an identifiable would-be recipient who would be aware of the family veto who could raise legal action.

Second, while the family veto can be argued to be contrary to both the word and the spirit of the law, legal action against grieving families should only be pursued as a last resort (if at all). Monetary penalties sought against families would not remedy wasted donation opportunities, and

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[514] However, the same can also be said for ensuring the HCPs are receptive should the parents offer them evidence that their daughter changed her mind about her donation decision.
[515] *Curry*, *supra* note 484 at para 87.
[516] *Ibid* at para 118.
[517] See Appendix 23.
[518] May, Aulisio & DeVita, *supra* note 95 at 333-34; citing Peters, *supra* note 136 (emphasis added).
[519] See the fine print on the Ontario registration form, Appendix 23.
[520] *Ibid*.

would likely lead to significant public backlash against the ODT community. Instead, families should be *informed* of donation decisions, rather than asking them to consent[521] (perhaps shifting their role from an executor to a non-executor role).

However, amendments to ODT law and policy could still be influenced by wills and estates: given the deference paid to wills and advance directives, the use of such documents could be used as a mechanism to reduce – or prohibit – the family veto altogether. As expressed by Tapley & McQuillan, "[f]amilies fail to appreciate the paradox of accepting the person's legal will (and any benefits), but not the person's wishes to donate."[522] Thus, they argue:

> "We could enshrine our wishes in our wills by informing our families that our will contains a wish to donate organs and tissues. Organ donor cards and the organ donor register could acknowledge that our wishes are in our wills, signed and witnessed. The organ donor register could store an electronic copy for verification (such storage agreed within the will itself). Penalty clauses could be included for failure to allow donation."[523]

There are, of course, notable differences between wills and organ donor registration forms. For a will to be valid in Ontario, for example, it must be written in a physical form, rather than in a digital form.[524] Wills must be signed by two witnesses, and wills must be signed.[525] However, five provinces – including Ontario – include "writing" in the preambulatory definitions of their ODT legislation: "includes a will and any other testamentary instrument, whether or not probate has been applied for or granted and whether or not the will or other testamentary instrument is valid."[526] "Testamentary instruments" are defined flexibly, leaving room for a (signed) donor registration to be interpreted as such.[527]

As echoed by Maloof, "the law upholds an organ donation framework that allows the deceased's next of kin to veto donative intent. In the law of wills, such a format would be abhorrent."[528] Ultimately, it is the responsibility of the living to protect the interests of the dead, to treat their final wishes with respect and dignity, and to give effect to intentions to donate as far as is possible.

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[521] May, Aulisio & DeVita, *supra* note 95 at 324.
[522] Patrick L. Tapley & Peter J. McQuillan, "Wills and wishes in organ donation" (2012) 12:344 BMJ e1232 at e1232.
[523] *Ibid*.
[524] LD Law Wills, *supra* note 324. The exception here is British Columbia, where digital wills are valid: "What Are the Requirements for a Will to be Legally Valid in Canada?", online: *Willful* <www.willful.co/learn/what-are-the-requirements-for-a-will-to-be-legally-valid>.
[525] LD Law Wills, *ibid*. As discussed in Chapter 2, the Northwest Territories is the only jurisdiction that requires donor registrations to be signed by witnesses, in addition to the donor. See Appendix 18. Similarly, signatures are not collected on registration forms in Manitoba, Nova Scotia, or New Brunswick.
[526] *Supra* note 266.
[527] A "*testamentary instrument* includes any will, codicil or other testamentary writing or appointment, during the life of the testator whose testamentary disposition it purports to be and after his death, whether it relates to real or personal property or to both (*acte testamentaire*)": *Criminal Code*, *supra* note 250, s 2.
[528] Meredith D. Maloof, *Post-Mortem Organs and Tissue Through at Property Law Lens: How Principles of Property Law Can Guide Lawmakers to a Better Organ Donation Framework* (LLM Thesis, University of Saskatchewan, 2021) [unpublished] at 37.

13.6 Case Study: Applying the Legal Questions

The vignette will now be analyzed in order to determine how Ontario law might apply to the family veto. This section of the Chapter will examine the actions of both the family and the doctors, and the legal implications that result depending on which of the above two paths is pursued. In doing so, this analysis is organized around three central questions:

1. Did the family act according to the law of Ontario?
2. Did the doctors act according to the law of Ontario?
3. Assuming one (or both) parties acted contrary to provincial law, who could bring a claim against them, and what type of claim could they bring? What types of remedies may be available?

13.6.1 Did the family act according to the law of Ontario?

Ontario's *Trillium Gift of Life Network Act* clearly states that consent to organ donation given either in writing (and signed) or orally before at least two witnesses "is binding and is full authority" to proceed with organ donation.[529] The TGLNA does permit family members to give consent to organ donation where consent has not already been given,[530] but does not contemplate families overturning otherwise valid consent to donate.[531] However, the TGLNA's silence on the family veto should not be read in support thereof. Rather, a purposive and contextual approach to statutory interpretation requires the text of an Act be evaluated in relation to factors such as the statute's purpose, societal values, the context in which the statute operates, and related legislative provisions.[532] To provide a brief interpretation of the TGLNA: the statute exists to facilitate living and deceased donor organ donation through the Trillium Gift of Life Network OPO. As mentioned in Chapter 1, there is a growing need across Canada for deceased donor organ donations. There is also significant public support for deceased donor organ donation in Canada, coupled with a notable disapproval of the family veto.[533] When read together, sections 4 and 5 of the TGLNA appear to imply that SDMs should not – and should not be able to – revoke binding consent that is full authority for organ donation.[534]

In this way, while families "can be an invaluable source of information and provide a more personal and updated view of the person's true wishes," they should act as "mere witnesses" to the

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[529] TGLNA, *supra* note 12, ss 4(1) and (3). Such language is permissive, in that it *allows* donation, but does not *require* HCPs proceed with procurement.

[530] *Ibid*, s 5(2).

[531] Downie, Shea & Rajotte define this silence to mean that "[w]ith the exception of Manitoba and possibly Quebec, organ and tissue donation legislation does not permit valid donor consent to be overridden by families" (*supra* note 101 at 1260).

[532] See *Ontario v Canadian Pacific Ltd*., [1995] 2 SCR 1031; "The Modern Approach to Statutory Interpretation" (29 January 2020), online: *Milosevic & Associates* <www.mlflitigation.com/media/the-modern-approach-to-statutory-interpretation/>. See also Marco P. Falco, "'Purposive' Approach to Statutory Interpretation" (7 November 2016), online: *Torkin* <www.torkin.com/insights/publication/the-purposive-approach-to-statutory-interpretation-what-does-it-mean->.

[533] See discussion of public opinion, above at pages 64-65.

[534] For example, why would the TGLNA define consent given by the donor as "binding and full authority" if it was not intended to be used this way? Similarly, why would drafters specify that SDMs can provide consent where consent has not already been given, rather than providing them with unilateral authority to make the final decision about organ donation?

deceased's intention, rather than autonomous decision-makers.[535] As will be discussed below, "the family has no legal grounds for overriding the dead person's wishes if that person clearly wanted to donate—for example, by carrying an organ donor card."[536] Indeed, it is widely argued that "the practice of respecting a family's objection to donation over the deceased's validly executed consent affects the availability of life-saving organs, disrespects donor autonomy and infringes existing Canadian legal norms."[537]

Beyond a close reading of the TGLNA, this Chapter has already discussed several lessons from other corners of health and property law that could be applied to a family veto case. While a family veto case has not yet been heard by a Canadian court, both health law cases raised with the CCB and wills and estates cases place considerable value on the prior expressed wishes of the deceased. While prior expressed wishes cannot guarantee transplantation (insofar as medical or logistical barriers may prevent a successful donation), significant deference should be given to donor registration given the social value of donation and the legal value of autonomy in medical decision-making.

Thus, it can (and should) be argued that the family only acted in accordance with the TGLNA if they genuinely believed that their daughter had changed her mind about organ donation, but had died before withdrawing her registration.[538] Otherwise, they would be revoking consent in a situation where they were not authorized by statute to do so. Had this hypothetical scenario arisen in Nova Scotia instead of Ontario, the family would be required to provide information proving that their daughter would have made a different decision than what was reflected in her registration (or was deemed under their opt-out legislation).[539] However, Ontario law does not presently place this requirement on next-of-kin – inherently creating an "honour system" where the word of the family is often sufficient to overrule the signed intentions of the deceased.

There is one important caveat to note here: in our vignette, the parents were *asked* if they consented to organ donation on behalf of their daughter. In doing so, our hypothetical HCPs would have given the parents the impression that the final donation decision was theirs to make. Coupled with the public health messaging available on Trillium's website,[540] it is understandable why the parents might choose to pursue their own views of organ donation over those of their daughter. While their duty as SDMs is to advance her values and best interests, it is not necessarily reasonable to expect that grieving families are fully versed in the consent rules contained within the TGLNA unless they are properly advised. Of course, ignorance of the law does not negate statutory violations, and it is deeply troubling that some families would veto consent to donation because it does not align with their own values.

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[535] Kyrtata, *supra* note 52 at 112-113; Sharif & Moorlock, *supra* note 34; Molina-Pérez et al, *supra* note 148 at 5.
[536] Shaw, *supra* note 53 at 33.
[537] Toews & Caulfield, *supra* note 16 at E436; see also Ball, Oczkowski & Sibbald, *supra* note 10 at 601; Shaw et al, *supra* note 43 at 485 (UK context).
[538] Under section 5(3) of the Act, consent cannot be given on behalf of an individual if the person has reason to believe that the deceased would have objected to organ donation.
[539] HOTDA, *supra* note 30, s 15(1).
[540] See Appendix 16.

13.6.2 Did the doctors act according to the law of Ontario?

1. **If they proceed with organ procurement despite the parents' refusal**

As discussed above, the daughter's consent to organ donation is legally binding and full authority to proceed with donation under the TGLNA.[541] As such, the doctors are acting within the purview of the Act by pursuing organ procurement, provided they have no reason to believe her consent was subsequently withdrawn,[542] and provided they are only using her organs in such a way that is contemplated by her consent.[543] For example, if she had consented to organ transplant only, her organs and/or tissues may not be used for research. Similarly, if she indicated that there were specific organs and/or tissues that she did not want to donate, those must not be procured.

Additionally, as noted in the caveat above, the HCPs erroneously offered the SDMs the opportunity to consent, where doing so was not required by the TGLNA. As discussed above within the context of the CCB, consent is not required from an SDM where the medical intervention (or withdrawal thereof) falls beyond the definition of "treatment" in the HCCA. In these instances, HCPs can lawfully proceed with withdrawing treatment (for example) despite family protest. Given that the consent of the SDM was not required by the TGLNA, it stands to reason that the HCPs *could* proceed with procurement against the wishes of the parents. However, it is likely that doing so would inflict greater harm on the parents – who will now themselves feel vetoed – than would be inflicted in a similar situation where the parents raised the veto unprompted (and the HCPs continued with procurement anyway).

Furthermore, while continuing with procurement may align with Canadian legal norms, it may be contrary to public health messaging. As discussed in Chapter 2, "[h]ealthcare providers are put in a confusing and problematic situation where following established practice and policy runs counter to the law."[544] For example, an FAQ section on the Trillium Gift of Life Network's website reads:

> **Q.** Can my family overrule my decision to donate?
> **A.** When you register your consent to donate, this information is recorded and stored in a Ministry of Health database. Your decision will only be accessed should there be potential for donation, and your status as a registered donor will be shared with your family. *It is Ontario Health (Trillium Gift of Life Network) practice to reaffirm an individual's consent to donate with the family. In most cases, families honour their loved ones' decision to donate if they have evidence that it's what they wanted.*[545]

This disparity between law and policy likely contributes to the tensions felt between families and healthcare workers. This disparity also exacerbates uncertainty about the degree to which the registration to donate is sufficiently informed. The TGLNA does not require that registration for posthumous donation be "informed" in the way that consent to treatment by a living patient is required. However, there are nagging concerns about whether registration was done with

[541] **NB:** While the above section of this Chapter discussed whether organ registration is akin to informed consent, such a question is moot in the Canadian legal context. Every province (confirm) specifies that "consent" is defined as "consent given under this Act" (for example, see TGLNA, supra note 12, s 1).
[542] *Ibid*, s 4(3).
[543] *Ibid*, s 8.
[544] Toews & Caulfield, *supra* note 16 at E437.
[545] FAQs, supra note 13.

knowledge of the particular procedures and the possible harms and benefits to the family. Divergence between the letter of the law and the public health messaging – which is much more likely to have been consulted by members of the public – make this more of a problem. The divergence opens up the argument that registration may have been made on the assumption that families would have the opportunity to confirm or overrule the donation as they wish. Again, although ignorance of the law is no excuse, this divergence sharpens the concern about whether registration *should* be binding and full authority to proceed with organ procurement.

2. If they do not proceed with organ procurement

As already established, the family veto appears to be contrary to the word and the spirit of the TGLNA. However, nowhere in the text of the TGLNA is the *compulsion* for HCPs to proceed with donation. Even if the donor's consent is "binding", there are practical reasons why absolute compliance with consent cannot (and should not) be statutorily required – namely, HCPs should not be subject to civil liability if, for example, the donor's organs are not suitable for transplantation, medical complications arise during procurement and/or transplantation precluding a successful operation, or if the organs were accidentally damaged during transport. It would also be grossly unfair to hold HCPs to blame for family veto events where they are acting in accordance with the practices and policies of their employers (namely, the individual hospitals and/or OPOs).

13.6.3 Who would bring a claim, and what type of claim would the bring? What kind of remedy would there be?

In addition to the CCB and wills and estates cases discussed above, an additional type of hypothetical legal claim that could be contemplated against the parents and/or the HCPs in this scenario is under civil liability.

Civil Liability Claims

As discussed above, there is significant concern amongst healthcare providers that if they proceed with organ procurement despite an attempted family veto, the family may pursue legal action against the doctors and/or the hospital.

Claims against the doctors

Section 9 of the TGLNA speaks explicitly of immunity from civil liability:

> "No action or other proceeding for damages or otherwise shall be instituted against any of the following individuals for any act done or performed in **good faith** in the performance or intended performance of any duty or function or in the exercise or intended exercise of any power or authority under this Act or for **any neglect, default or omission** in the performance or execution in good faith of any duty, function, power or authority under this Act:
>
> 1. A member of the medical or other staff of a designated facility.
> 2. Any other person employed in a designated facility."[546]

[546] TGLNA, *supra* note 12 (emphasis added).

As demonstrated above, the TGLNA offers personal liability protections to the doctors if they are acting in good faith – that is, "honestly, without malice, ill-will, and negligence, in the execution of their authority to remove organs or tissue, and if they have no reason to think that they are making a mistake."[547] Downie, Shea, and Rajotte argue that the TGLNA is broader than those of other provinces, "in that it does not require physicians to act 'without negligence' for its protections to apply … [and] also protects both acts and omissions."[548]

Not only is it unlikely that a claim against the HCPs would succeed, given both the wording of the TGLNA and the lack of case law citing to the TGLNA, it would be inappropriate to further burden already overworked HCPs with a looming fear of litigation. Litigation of this nature has not succeeded in the United States, nor does it appear to have been pursued in Canada, to date.[549] Furthermore, it would be impractical to expect ODT HCPs (most of whom work in critical care settings, such as ICUs) to determine whether the parents are acting honestly in attempting to overturn their daughter's consent to donate.[550] Instead, it is the legal and moral duty of the next-of-kin, in acting as an SDM, to represent the final wishes of the deceased.

<u>Claims against the parents</u>

In the United States, there has been only one instance wherein "an OPO filed suit to retrieve organs from a registered donor when the family vehemently objected, and the move came with significant backlash."[551] Per Havekost, "[a]lthough the OPO won and procured the registered donor's organs, the local media focused on the family's grief and disbelief that doctors could take its son's organs over its wishes."[552] In this way, Havekost argues that rather than pursuing litigation, "OPOs need stronger incentives to comply with first-person authorization while preserving positive relationships with health-care providers."[553] Similarly, Shaw et al describe how other "attempts to prevent families overruling donation have gone as far as the courts, with court cases resulting in judgments against the families."[554] However, they "would not recommend pursuing such a hard-line approach."[555]

It does not appear that similar suits have been filed in Canada to date. While an absence of existing case law does not preclude lawsuits from being raised against family members in the future for

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547 Downie, Shea & Rajotte, *supra* note 101 at 1258.

548 *Ibid*. Salladay interprets "good faith" in this context to mean carrying out the donor's wishes (*supra* note 144 at 28).

549 See pages 70 and 71.

550 In Nova Scotia, SDMs wishing to overturn consent or refusal to donation must provide evidence proving that the deceased had changed their mind. Witnessed, written documents are considered to be the strongest form of evidence, while uncorroborated, oral statements are considered to be the weakest. See "Human Organ and Tissue Donation Act Information Guide" (June 2020), online at 3 (pdf): *Nova Scotia Department of Health and Wellness* <https://beta.novascotia.ca/sites/default/files/documents/1-2403/human-organ-and-tissue-donation-act-information-guide-en.pdf> [Nova Scotia Consent Guide]. However, there is no requirement for SDMs in Ontario to provide evidence when vetoing consent, nor are there guidelines for HCPs in assessing any information provided by SDMs during family veto events.

551 Havekost, *supra* note 81 at 711-12.

552 *Ibid*.

553 *Ibid*.

554 Per Shaw et al, "[t]he US federal law states that 'a person other than the donor is barred from making, amending, or revoking an anatomical gift of a donor's body or part if the donor made an anatomical gift of the donor's body or part'" (*supra* note 43 at 486).

555 *Ibid*.

preventing organ donation in this way, it is not likely to be the most effective mechanism by which the family veto could be curbed. In reading section 9 of the TGLNA, it is worth noting that unlike other provinces, Ontario's immunity clause is strictly limited to "members of the medical or other staff in a designated facility" (and other employees of designated facilities).[556] Thus, the deceased's woman's parents could hypothetically be liable for violating the TGLNA. Under section 12 of the TGLNA:

> "Every person who knowingly contravenes any provision of this Act is guilty of an offence and on conviction is liable to a fine of not more than $1,000 or to imprisonment for a term of not more than six months, or to both."[557]

However, given that the TLGNA does not currently impose any legal obligations on SDMs, it is unclear precisely where civil liability claims could take root. Even if the "binding and full authority" definition of a donor's consent was judicially interpreted whereby the family veto constituted an offence under the TGLNA, hypothetical remedies sought could include the fine mentioned in section 9 of the TGLNA, or retrieval of the organs. However, neither of these options seem ideal.

The social ramifications of suing a grieving family – even if they had violated a statutorily enshrined obligation – risks painting the ODT system with an ugly brush. Practically speaking, if the length of the litigation closed the window in which organ procurement was viable, suing the vetoing family members for damages will only serve punitive purposes – it will not reopen the window to allow for donation, nor will it alleviate any harm caused to the would-be recipient by preventing donation. While public opinion does appear to sway in an anti-family-veto direction, there is no guarantee how the Canadian public would react to the pursuit of litigation against a grieving family. That said, however, confronting vetoing families with a fine (as considered by the TGLNA) could serve to dissuade to other families attempting to veto consent to organ donation.

14. Legal Analysis

14.1 Is there is a legal "right" to donate organs?

Legal rights are both created and protected by the law itself. They are distinct from moral rights, which may influence the creation of legal rights, but have no direct legal force.

Legal rights can further be split into two categories: negative rights and positive rights. Negative rights refer to *the right to be free from* interference (for example, to be free from cruel and unusual treatment or punishment under section 12 of the *Charter*). Negative rights come hand-in-hand with a reciprocal negative duty for other parties to abstain from interfering with that person in specific ways (for example, the duty not to subject the person to cruel and unusual treatment or punishment). Conversely, positive rights refer to *the right of a person to have* "the positive assistance of others in fulfilling basic constituents of human well-being."[558] Thus, positive rights

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[556] TGLNA, *supra* note 12, s 9. In BC, for example, the civil liability clause reads: "No action or other proceeding for damages lies against a person for an act done in good faith and without negligence in the exercise or intended exercise of any authority conferred by this Act" (BC HTGA, *supra* note 257, s 9).
[557] TGLNA, *ibid*.
[558] Manuel Velasquez et al, "Rights" (8 August 2014), online: *Markkula Center for Applied Ethics* <www.scu.edu/ethics/ethics-resources/ethical-decision-making/rights/>.

impose a positive duty on others to help that person acquire or do something.[559] Legal rights are decidedly narrower than moral or ethical rights – for example, there is no "freestanding constitutional right to health care" in Canada,[560] despite the moral justification of a "right" to adequate healthcare. Instead, in Canada, "where the government puts in place a scheme to *provide* health care, that scheme must comply with the *Charter*."[561] In this way, access to provided health care is a negative right – it must be equitable (or, put differently, it must be free from barriers that would contribute to inequitable access), but health care is not *owed* to all Canadians.[562]

Legal rights can also be viewed within the four Hohfeldian positions: claims, privileges, powers, and immunities.[563] Positive and negative legal rights both fold into "claim" rights – that is, an entitlement to have/do something, or the entitlement to be free from something.[564] Privileges (or "liberties") are similar to claims, but they only infer the privilege to do (or not do) something and do not bear correlative duties unto others.[565] Legal powers, according to Hohfeld, are the "legally recognized [abilities] to change or create legal positions, relations, and norms."[566] Powers include the ability granted through estate law to create wills, or the ability in private law for property owners to gift title to others.[567] Finally, a legal immunity is enjoyed where it prevents another person from altering a certain position.[568] In this way, "[t]he Hohfeldian opposite of an immunity is liability (vulnerability to power)." One such example can be found in Canada's provincial ODT legislation, where immunity is granted for those acting in good faith while performing duties or functions contemplated in the act.[569] Importantly, the Hohfeldian categories of legal rights are not airtight silos – rather, "[l]egal rights are typically composites of more than one Hohfeldian position."[570]

As noted above, legal rights impose reciprocal duties on other people (though duties can also originate elsewhere, such as within contracts and statutes). Within the context of tort law, for example, breaches of duty arise where the person's conduct fall below the accepted standard of care, thus contributing to negligence claims.

Within discussions of the family veto, the concept of "rights" arises frequently. In terms of moral or ethical "rights", the principle of autonomy supports the right of people to exercise control over their own body.[571] The right to autonomy is often – but not unanimously – extended

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[559] *Ibid*.
[560] *Chaoulli v Quebec (Attorney General)*, 2005 SCC 35 at para 104 [*Chaoulli*].
[561] *Ibid* (emphasis added).
[562] See *Canadian Charter of Rights and Freedoms*, s 15, Part I of the *Constitution Act, 1982*, being Schedule B to the *Canada Act 1982* (UK), 1982, c 11 [*Charter*].
[563] Ori Herstein, "Legal Rights" (27 January 2023), online: *Stanford Encyclopedia of Philosophy* <https://plato.stanford.edu/entries/legal-rights/#MoraJustLegaRigh>.
[564] *Ibid*.
[565] *Ibid*.
[566] *Ibid*, citing Wesley Newcomb Hohfeld, "Fundamental Legal Conceptions" in Walter Wheeler Cook, ed, *Fundamental legal conceptions as applied in judicial reasoning, and other legal essays*, (New Haven, CT: Yale University Press, 1919) at 50–57.
[567] Herstein, *ibid*.
[568] *Ibid*.
[569] See, for example, TGLNA, *supra* note 12, s 9(1).
[570] Herstein, *supra* note 563.
[571] Donovan, *supra* note 94 at 62.

posthumously.[572] Just as living donors have the liberty to make autonomous decisions regarding their health, and are permitted to donate blood (or even kidneys though living donor programs), they have the autonomous right to decide upon their individual legacy in their death.[573] Thus, if a donor has the moral or ethical right to choose to donate their organs after their death, their next-of-kin does not have the right to withdraw that consent.[574]

As discussed above, dead bodies cannot be considered "property" in Canada. Yet executors (or next-of-kin) can have a "quasi-property" right over the deceased, insofar as they are able "to sue for damages, including damages for their emotional distress resulting from mutilation of the corpse during an autopsy that they did not authorize."[575] The authors stress, however, that "this right to possession is not absolute and is 'subordinate to the demands of justice or public good'."[576] Furthermore, "the common law is subordinate to legislation … In the case of organ and tissue donation, provincial and territorial legislation has displaced the common law, and these statutes are the primary source of legal authority for postmortem donation in all provinces and territories."[577]

Wilkinson and Johnston each explore the concept of organ donation as a "negative right," wherein people "have a right to refuse that their organs be donated, but consent to organ donation does not entitle an individual to a guarantee of donation."[578] They argue that donation cannot be construed as a positive right, as that would inherently place a reciprocal duty on HCPs and/or OPOs to accept organ donations.[579] Furthermore, if organs were unsuitable for transplantation, or could not be procured in time, the donor would have their right to donate violated.[580] In making this argument, Johnston advocates for a "double veto" system, wherein donors can consent to (or veto) organ donation, just as their SDMs can veto the donor's decision after their death.[581] While Wilkinson contemplates the double veto, he ultimately argues that it is unlikely "that the family has any relevant negative or positive rights … [t]rue though it might be that overriding the family would cause distress … the possibility of distress is not the basis for a right."[582] In this way, scholars from around the world agree that families have no legal rights to veto the valid expression of donation intentions.[583] However, Wilkinson agrees that "it is coherent to say that an individual has a negative right of veto but no positive right to have organs and tissues taken after consenting … there may

[572] Wilkinson, *supra* note 36 at 52.
[573] Cay, *supra* note 36 at 362.
[574] This is particularly true given that SDMs are "meant to act in line with the intentions and values of the patient, rather than their own" (Johnston, *supra* note 22 at 488). See also Wilkinson, *supra* note 36 at 37: "considerations of distress do not justify a right, and conceptions of family autonomy are too underdeveloped."
[575] Downie, Shea & Rajotte, *supra* note 101 at 1257.
[576] *Ibid*.
[577] *Ibid*.
[578] Johnston, *supra* note 22 at 491.
[579] *Ibid*.
[580] *Ibid*.
[581] *Ibid*. This argument is based on the effect of donation on the surviving SDMs – ignoring the effect on the HCPs and would-be recipients.
[582] Wilkinson 2005, *supra* note 150 at 589.
[583] See Downie, Shea & Rajotte, *supra* note 101 (Canada); Harris et al, *supra* note 115 at 12-13 (USA); De Wispelaere & Stirton, *supra* note 121 at 180 (UK); Slabbert & Venter, *supra* note 148 at 466 (South Africa).

be reasons to honour the deceased's offer, such as promoting her autonomy, even if these do not amount to a right."[584]

However, could a (positive) legal right to donate organs not be construed slightly differently? Just as no legal rights in Canada are absolute, the right to donate organs would be limited by the logistical and medical viability of procurement. The reciprocal duty following the "right" to donate could simply be to proceed with procurement (and subsequent transplantation) whenever possible. It is understandable that Johnston and Wilkinson would want to avoid situations wherein OPOs and/or HCPs are held legally responsible if organ procurement cannot occur.[585] However, such a stance seems to be exaggerated. No article captured by the scoping review in Chapter 1 – nor any other literature found while writing this thesis – suggested an absolute right to donate organs. It is well-documented that very few deaths (often below 5%) occur in scenarios where organ donation is viable.[586] Organs would not be forced upon recipients without paying due attention to their compatibility and viability. It is precisely for this reason that all Canadian ODT legislation includes sections pertaining to "intended use" – diverse circumstances wherein procurement and/or donation is not possible have already been considered by legislatures.

In the alternative, instead of viewing this legal right as the "right" to donate organs, we can consider that donors have a legal right to *consent to* donation.[587] In this way, there is not a duty foisted unto HCPs to carry out donation – just as Wilkinson and Johnston contemplated – but rather, donors have a legal right for their consent to be free from intervention from prying SDMs. This right would be maintained under opt-out consent systems (as will be explored in Chapter 4), as donors would still have the ability to make their donation decisions known – whether through consent or refusal.

There are several reasons why a post-humous right to consent to organ donation is valid. Just as with wills, organ donor registration is a decision made in life, with its full ramifications realized after death. While wills are not legally binding, there is a legal expectation that they will be fulfilled wherever possible – with the intention of protecting an individual's interests that survive death. In this way, the "pre-death wishes of the deceased should have the same binding force that an advance directive has when patients are alive but incompetent to make choices."[588] Per Wilkinson, we have already accepted the existence of posthumous rights, as we respect the (posthumous) right to refuse donation: "[t]he question of coherence is how could one have this negative right without also having the right to override one's family?"[589]

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[584] Wilkinson 2005, *supra* note 150 at 589.
[585] Similar risks of an overly broad legal right to donate could include unanticipated liabilities, such as those arising from medical or logistical barriers to donation (for example, damaging the organ during procurement so that it can no longer be transplanted).
[586] According to the Canadian Blood Services, it is often only 1-2% of people who die who can *considered* for organ donation: see Donation After Death, *supra* note 370.
[587] Viewed through a Hohfeldian lens, a right to consent to donation could be understood as both a claim and a privilege – donors would be entitled to register their consent, free from interference, but would only enjoy the privilege of being able to consent without imposing correlative duties unto HCPs or OPOs. Furthermore, a right to consent to donation would provide immunity to registered donors by preventing others (next-of-kin) from altering their position as a registered donor.
[588] Wilkinson 2005, *supra* note 150 at 589.
[589] *Ibid*.

Furthermore, as seen in Nova Scotian and New Brunswicker legislation, two reasonable limits can be placed on the consent for organ donation – where no consent or refusal has been made by the deceased, an SDM may consent or refuse if acting in alignment with the deceased's interests; and pursuing a veto where the SDM has concrete evidence that the deceased changed their mind (thus upholding their genuine final wishes).[590] Additional limits to consenting to organ donation are already in place in every jurisdiction in Canada, such as mandatory minimum age, and the capacity to understand what they are consenting to.

In Canada, "individual consent for donation [already] provides the full legal authority necessary to proceed with organ procurement and is legally binding in most Canadian jurisdictions."[591] As such, respecting a legal right to make one's own decision regarding organ donation – and to have that decision remain free from SDM intervention – is already contained within Canadian ODT legislation. As will be discussed below, the shortcomings of Canadian ODT law are not the lack of *rights*, but the lack of protection for donation decisions that Canadians have the right to make for themselves.

14.2 Should the law be changed?

Canadian ODT law and policy is not sufficiently robust in its current form to adequately protect the registered donation decisions of donors. The family veto is rooted in the vagueness found within ODT legislation; it lingers in the gaps between law and public health messaging, and is inadvertently reinforced by a lack of judicial interpretation or intervention to say otherwise.

As discussed in Chapter 1, there are eight broad categories into which solutions to the family veto problem can be sorted: **(1)** banning the family veto altogether; **(2)** allowing the family veto in narrow circumstances; **(3)** improving communication with families; **(4)** education; **(5)** legal solutions; **(6)** policy solutions; **(7)** healthcare worker-centered solutions; and **(8)** additional solutions. For the purposes of this Chapter, categories 1 and 2 can be folded into categories 4 and 5, as legal and/or policy approaches could take either of these approaches.

The most common recommendations made in the literature include: "1) the need for people who wish to donate their organs to talk to family members and make their wishes known, 2) the need for campaigns to promote organ donation awareness, 3) an "opt-out" or "presumed consent" system, and 4) legislative changes to ensure that potential donors' decisions are respected."[592]

My concern with the first recommendation is three-fold. First, it places the onus on the registered donor to ensure their next-of-kin abide by provincial ODT legislation following their death. Similarly, it is unlikely that discussing donation intentions will materially impact the decisions of families who are diametrically opposed to organ donation. It would also be difficult to prove that such a conversation occurred (particularly following the death of the registered donor)[593] – though

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[590] Toews and Caulfield frame genuine family vetoes slightly differently: "[b]y law, a donor's withdrawal of consent should be respected. However, the need to respect an individual's change of heart does not permit families to veto consent but rather provides a mechanism to better enforce the individual's donation decision." See Toews & Caulfield, *supra* note 16 at E437.

[591] *Ibid* at E436.

[592] Anthony et al 2021, *supra* note 14 at E771.

[593] An exception here is with the intention-sharing mechanisms available in BC, Saskatchewan, and Manitoba – see Chapter 2.

again, why should the responsibility fall on the shoulders of the deceased to ensure their registered intentions are respected?

Public education campaigns are another commonly suggested solution – however, these campaigns focus on educating the public about sharing their intentions with their family members, rather than educating families about their legal obligations to respect registered intentions to donate organs. As demonstrated in Chapter 2, every provincial health website in Canada urges registered donors to "do their part" and talk to their families, placing minimal responsibility on their next-of-kin.

While worthy of discussion in their own right, policy and HCP-centered solutions will not be considered in this thesis. Instead, the remainder of this Chapter will discuss changes that could be made to Ontario's ODT law to limit the use of the family veto.[594]

14.2.1 Amendments to existing legislation

Perhaps the simplest way in which existing ODT legislation could be modified to reduce the family veto is by clarifying the language of provincial ODT legislation to explicitly prohibit the overturning of registered donation decisions.[595] As argued by Downie, Shea, and Rajotte, "[t]he word 'binding' should be explicitly defined in organ and tissue donation legislation (ie, "binding" means the consent must be followed unless clearly articulated statutory exceptions are met)."[596] Similarly, section 5(2) could include specify that "***Only*** [w]here a person who has not given or cannot give a consent under section 4 dies" may an SDM give or refuse consent to donation. Downie, Shea, and Rajotte further argue that "Manitoba should add the word "binding" to its postmortem donor consent provisions."[597] In this way, Alberta, PEI, and the Northwest Territories should amend their legislation to give "full authority" (rather than simply "authority") to consent to donation given under their respective Acts – this would help to ensure uniform interpretation across Canada with respect to the legal weight of registered donation decisions.[598] Finally, they argue that "Quebec should clarify that family opposition is not a compelling reason not to follow the donor's wishes expressed in a valid consent."[599]

Further amendments could be drawn from the HCCA. Among the stated purposes of the HCCA is to "enhance the autonomy" of the patient involved[600] – while the TGLNA does not include any stated "purposes" at the front of the statute. Similarly, the HCCA requires SDMs to give or refuse consent in accordance with previously expressed wishes that are applicable to the circumstances, and where no such wish was expressed, the statute requires SDMs to act in the patient's best interests (and statutorily defines "best interests").[601] Incorporating similar provisions into the TGLNA would strengthen the protections afforded to donor decisions by ensuring SDMs are

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[594] These changes are conceptualized within Ontario's current opt-in consent system. For a discussion of opt-out consent systems, see Chapter 4.
[595] Downie, Shea & Rajotte, *supra* note 101.
[596] *Ibid* at 1260.
[597] *Ibid*.
[598] Alberta's section 8(1) and the NWT's section 12(1) would be changed to "a consent given in accordance with this Act is binding and ***fully*** authorizes" – see AB HTODA and NWT HTDA, *supra* notes 257 and 262, respectively.
[599] Downie, Shea & Rajotte, *supra* note 101 at 1261.
[600] HCCA, *supra* note 358, s 1(c). However, while a stated purpose of protecting donor autonomy would be a welcome addition to the TGLNA, that change alone would not constitute a sufficient response to the family veto.
[601] HCCA, *ibid*, ss 21(1) and (2).

acting in accordance with the priorities and values of the deceased (and not themselves). Finally, as with the HCCA, the TGLNA could specify the appropriate mechanism for approaching disputes between SDMs and HCPs, to ensure greater compliance with the TGLNA.

14.2.2 Provision of proof

Under section 15 of Nova Scotia's *Human Organ and Tissue Donation Act*, SDMs may consent or refuse donation on behalf of the deceased where they provide "information that would lead a reasonable person to conclude that an individual would have made a different decision respecting donation after death than the decision recorded in the Registry or deemed under Section 11."[602] The requirement of providing proof that the donor had changed their mind regarding their recorded donation decision could be added to the ODT legislation of each province across Canada, thus only allowing families to veto recorded consent in those situations where the deceased had changed their mind prior to their death. In theory, this requirement could reduce tensions between families and HCPs in clinical settings, as both the families and HCPs would be bound to respect the recorded donation decisions, provided there was no recorded proof to the contrary. A more radical alteration to Canadian ODT law would also be the inclusion of overturning consent to organ donation without proof of a change of mind in the listed penalties, thus risking fines and/or jail time for vetoing families.[603]

14.2.3 Protecting donor decisions & enhancing consent

Despite the legal status of registered intentions to donate, there persists considerable fear amongst HCPs and academics alike that completing barring the family veto could "cause significant distress, both to relatives and to medical staff," which "may, in turn, negatively affect public perceptions of transplantation."[604] As such, simply amending existing legislation may not be sufficient. Instead, a multi-pronged approach may be better suited to the complexity of the family veto problem.

One avenue to better protecting donation decisions is by appointing a Designated Second Consenter. Under this approach, De Wispelaere and Stirton aim to involve families in the decision-making process in a more positive way, rooted in the consent of the donor. Here, potential "donors would appoint a designated second consenter (DSC), in most cases likely to be a family member, who would as part of the organ donor registration process signal their advance commitment to uphold the donor's decision after the death of the latter."[605] Including family members in this way aims to respect the autonomy of the donor, the needs of the would-be recipients waiting for transplants, and the grief of the family.[606] Appointing a DSC would occur during the registration process, wherein the donor would nominate a DSC, who would then be notified of the donation decision and asked to formally register their agreement to allow the donor's organs to be procured following their death:[607]

[602] HOTDA, *supra* note 30.
[603] Shaw et al, *supra* note 43.
[604] Sharif & Moorlock, *supra* note 34 at 157.
[605] De Wispelaere & Stirton, *supra* note 121 at 180.
[606] *Ibid*.
[607] *Ibid*.

> "When the DSC agrees to undertake this responsibility she receives an explicit request to support the posthumous removal of the donor's organs, under the conditions stipulated by the donor (if any). Importantly, in view of ensuring donor autonomy, the *DSC cannot add or alter any of the stipulations of the donor's consent*."[608]

De Wispelaere and Stirton note that family veto events could still arise under their proposed model, in which case "the local donor coordinator would have to accept that decision and abort the process of organ removal. It is true that this would, in some sense, violate the wishes of the donor as well as ignoring the impact of this decision on the organ recipient."[609]

To improve the efficacy of De Wispelaere and Stirton's proposed model, DSCs could be defined in the relevant ODT legislative framework to be equivalent to the executor of the donor's will and/or SDM. In this way, a legally appointed DSC would have a greater level of decision-making authority over family member SDMs, preventing family members from attempting to veto the donation decision of the deceased.[610] The DSC would also be expected to follow the recorded donation decision of the deceased, just as executors are expected to abide by any directions contained in a will.

Similarly, Downie, Shea, and Rajotte argue that in order "to reduce the potential for uncertainty, valid forms of 'writing' should be clearly identified in the relevant provincial regulations (made under organ and tissue donation legislation), [for example] that 'writing' includes organ donor cards."[611]

A final mechanism to legally strengthen donor decisions is through First-Person Authorization (FPA). As exemplified by the United States' revised *Uniform Anatomical Gift Act*, FPA takes a stronger stance than Canadian opt-in legislation by "dedicating an entire section to the preclusive effects of registering as an organ donor."[612] For example, section 8 of the UAGA imposes a "preclusive effect of anatomical gift, amendment, or revocation."[613] In this way, the statute bars anyone other than the donor themselves from "making, amending, or revoking an anatomical gift of a donor's body or a part", provided the donor made the gift according to the UAGA.[614] However, as is the case with Canadian consent systems, FPA legislation alone is insufficient in protecting donation intentions.[615]

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[608] *Ibid* (emphasis added).
[609] *Ibid* at 181.
[610] "Nine Types of Substitute Decision-Makers (SDM)", online: *Advance Care Planning Ontario* <https://advancecareplanningontario.ca/substitue-decision-makers/who-is-my-sdm/sdm-categories>.
[611] Downie, Shea & Rajotte, *supra* note 101 at 1260. For example, the present definition of "writing" in Ontario's TGLNA is simply: "… includes a will and any other testamentary instrument, whether or not probate has been applied for or granted and whether or not the will or other testamentary instrument is valid" (see TGLNA, *supra* note 12, s 1).
[612] Havekost, *supra* note 81 at 699. See UAGA, *supra* note 115.
[613] UAGA, *ibid*, s 8.
[614] *Ibid*, s 8(a).
[615] Per Havekost, no OPO in the United States has been penalized for refusing to honor FPA, "which, in turn, creates a perverse incentive for OPOs and others involved in the donation process to keep discarding the express wishes of the decedent in exchange for the grieving family's approval" (*supra* note 81 at 711). Here, she argues that "OPOs need stronger incentives to comply with first-person authorization while preserving positive relationships with health-care providers" (*ibid* at 712).

15. Conclusion

Ultimately, while the family veto itself appears to be contrary to Ontarian law, if the doctors allowed the parents to veto their daughter's consent to donate her organs, they would not be in the minority. Per Weiss et al, 55% of surveyed Canadian physicians "stated they had personally witnessed such an occurrence at some point in their career."[616] Of these physicians, "[m]ost (91%, 116/128) had seen one to five events with 3% (4/128) having seen more than ten events."[617] Furthermore, "[a]bout half (56%, 131/234) of respondents stated they would respect the SDM's decision and pursue withdrawal of life sustaining therapy without donation despite a previously expressed intent to donate."[618]

Nearly four decades ago, "[i]n 1987, when the Uniform Law Conference of Canada was considering amendments to its uniform tissue donation statute, it was recommended that "the next-of-kin *should not be able to countermand the wishes of the deceased*."[619] At that time, it was recommended that the issue of the family veto "be *addressed through education rather than through law reform*, as the legislation was sufficient."[620] In 2008, Downie, Shea, and Rajotte argued that "given the obviously limited success of education alone in the past 20 years to rectify the situation, as evidenced by the multitude of government and organ donation program websites that still state that the family can override valid donor consent, law reform should be undertaken in addition to education."[621] In the years since, it appears that little progress has been made. Family veto rates continue to be uncollected, unreported, and unstudied in Canada.[622]

Taken together, there are a variety of approaches Canada could take in strengthening the legal protections offered to donation intentions. However, regardless of which legislative changes are pursued, it is clear that public education and legislative reform must go hand-in-hand.[623] Until then, despite the right of Canadians to choose to donate their organs, families will continue to veto donation decisions, leading to avoidable harm and suffering to those patients on transplant waitlists across the country.

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[616] Weiss et al, *supra* note 9 at 317.
[617] *Ibid*.
[618] *Ibid*.
[619] Downie, Shea & Rajotte, *supra* note 101 at 1260 (emphasis added).
[620] *Ibid* (emphasis added).
[621] *Ibid*.
[622] While some studies have been conducted into the family veto rates in Ontario, numbers are not reliably collected for comparison annually. As discussed in Chapter 1, while this paucity of data makes it difficult to ascertain whether the frequency of family veto events has increased, it is clear that there has been a notable increase in academic discussion of the family veto in the last decade.
[623] For example, per Christmas et al, "[w]e certainly do not wish to discount the importance of education to promote consent for organ donation. However, as we have shown, the definitive solution lies with legislation to enforce and, ultimately, honor the deceased's prior intention for organ donation" (*supra* note 67 at 1097).

Chapter 4: The Road to Presumed Consent

16. Introduction

Chapter 3 explored possible amendments that could be made to existing ODT legislation in Canada (primarily within opt-in consent systems) to address the family veto. This Chapter, however, focuses on the consent system itself, taking up the shift from an opt-in to an opt-out (presumed consent) system. In doing so, this Chapter will explore if either type of consent system is better suited to curbing the use of the family veto (or whether it is better addressed by amending existing statutes and/or through policy initiatives such as public health messaging and education campaigns).

Theoretically, whether within an opt-in or opt-out consent system, the role of SDMs is to protect the expressed intention of the deceased, where this is known. In an opt-in system, the role of the SDM "is to inform of the patient's wish regarding organ donation and to make sure it is respected."[624] In an opt-out system, the role of the SDM "is to confirm that the patient had never expressed a refusal for donation."[625] The underlying principle of both consent systems cannot be overstated: "to respect the patient's decision."[626]

Both opt-in and opt-out consent systems can be further defined as either "soft" or "hard". In soft consent systems, familial approval (or consent) is sought before proceeding with organ procurement and donation, regardless of whether or not the deceased had registered their intention to donate.[627] By giving families the opportunity to veto previously given consent to donate, those countries with soft consent systems maintain what Sharif and Moorlock characterize as "suboptimal" consent rates.[628] Conversely, "hard" systems are characterized by the inability of families to veto the consent of the deceased[629] – in essence, family vetoes are themselves vetoed. However, very few countries have a hard consent system (whether opt-in or opt-out).[630]

Soft opt-out systems are becoming increasingly popular around the world.[631] Many countries are shifting to a presumed consent system, or are strengthening their already-existent presumed consent systems, specifically to limit the intervention of SDMS (particularly in the family veto context).[632] However, soft opt-out systems often see substantial rates of family veto events, given the persisting ability of families to do so.[633]

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[624] Kentish-Barnes et al, *supra* note 112 at 334.
[625] *Ibid*.
[626] *Ibid*.
[627] Sharif & Moorlock, *supra* note 34 at 155.
[628] *Ibid*.
[629] *Ibid*.
[630] *Ibid*.
[631] Bhatia & Tibballs, *supra* note 153 at 956.
[632] These include Argentina, Colombia, France, Uruguay, and Wales. See Molina-Pérez et al, *supra* note 148 at 8; Albertsen, *supra* note 23 at 278.
[633] Lee & Tham, *supra* note 49 at 2. In this way, the increase of registered donors often overshadows the continued family veto rates: see Ford, *supra* note 79.

The merits of presumed consent systems have been widely discussed – largely centering on the ability of presumed consent to increase both donor registration and actual donation rates.[634] For the purpose of this thesis, I will not evaluate the concept of presumed consent; instead, this Chapter will examine the various approaches taken by Canadian jurisdictions in considering presumed consent, as well as investigating the degree to which – if at all – the family veto has come into play in these discussions.

17. Canada's Approach to Presumed Consent

As is often the case in Canadian health law, the country's approach to ODT laws and consent systems varies notably between the provinces. However, despite these differences, the majority of Canadians – from coast to coast – are in favour of implementing presumed consent over their opt-in systems.

Table 9: Provincial Opinions on Shifting From Opt-In to Opt-Out Donation Registration

"Do you think your Canadian province should implement an 'Active Donor Registration' [opt-out] system for organ and tissue donation after death?"[635]								
		Canada	**BC**	**AB**	**SK & MB**	**ON**	**QC**	**Atlantic**
Definitely	2019	36%	36%	39%	38%	29%	39%	39%
	2020	37%	32%	40%	44%	33%	38%	49%
Probably	2019	27%	30%	27%	25%	28%	27%	20%
	2020	33%	33%	34%	29%	35%	35%	24%
Probably not	2019	14%	13%	10%	13%	15%	13%	15%
	2020	9%	11%	8%	8%	11%	8%	4%
Definitely not	2019	11%	9%	10%	5%	14%	10%	15%
	2020	9%	10%	6%	6%	9%	9%	9%
Not sure	2019	13%	12%	15%	19%	14%	12%	11%
	2020	12%	13%	11%	13%	12%	9%	14%

[634] Among others, see: Alberto Abadie & Sebastien Gay, "The impact of presumed consent legislation on cadaveric organ donation: a cross-country study" (2006) 25:4 J Health Econ 599; Karthik K. Tennakore, Scott Klarenback & Aviva Goldberg, "Perspective on opt-out versus opt-in legislation for deceased organ donation: an opinion piece" (2021) 8 Can J Kidney Health Dis 1; Harriet Rosanne Etheredge, "Assessing global organ donation policies: opt-in vs opt-out" (2021) 14 Risk Manag Healthc Policy 1985; Alexandra Glazier & Thomas Mone, "Success of opt-in organ donation policy in the United States" (2019) 322:8 JAMA 719. However, support for presumed consent is certainly not universal. Several studies attribute presumed consent to *lower* donation rates (due in no small part to family intervention): James W. Lytle, "Opt-in vs. Opt-out Organ Donation Schemes: Evidence from the US and UK" (12 January 2021), online: *Petrie Flom Center* <https://blog.petrieflom.law.harvard.edu/2021/01/12/opt-in-out-organ-donation-us-uk/>; and Adam Arshad, Benjamin Anderson & Adnan Sharif, "Comparison of organ donation and transplantation rates between opt-out and opt-in systems" (2019) 85:6 Kidney International 1453.

[635] "Poll Conducted by Research Co. on Organ Donation in Canada" (21 August 2019), online (pdf): <https://researchco.ca/wp-content/uploads/2019/08/Tables_DonationCAN_21Aug2019.pdf> [2019 Poll]; "Poll Conducted by Research Co. on Organ Donation in Canada" (25 August 2020), online (pdf): <https://researchco.ca/wp-content/uploads/2020/08/Tables_Donation_CAN_25Aug2020.pdf> [2020 Poll].

17.1 Nova Scotia & New Brunswick

Nova Scotia and New Brunswick are the two Canadian jurisdictions that have already implemented opt-out consent systems, of which Nova Scotia was the first jurisdiction in North America to do so.

17.1.1 Nova Scotia

Nova Scotia's landmark *Human Organ and Tissue Donation Act* (HOTDA) was passed in April 2019, coming into effect on January 18, 2021.[636] The shift to presumed consent changed not only the province's legislation, but necessitated the establishment of mechanisms within the existing ODT system to support what officials believed "could be as much as a 50 per cent increase in donation rates."[637] The additional resources cost the province about $4 million, including funding given to organ donation, transplantation, and tissue bank services.[638]

By December 2021, only about 5% of Nova Scotia's population had opted-out of organ donation.[639] In the first year of the HOTDA's implementation, the province saw 155 tissue donors, signifying an increase of 40% from 2020.[640] That same year also saw 28 potential donors considered for donation, 23 of whom successfully became donors.[641] Previously, the province typically saw 20 organ donations (or fewer) each year.

However, Nova Scotia's system demonstrates that the shift to presumed consent alone does not impact the ability of families to veto previously given consent to donate organs – despite the provisions in the HOTDA, in practice, "[h]ealth-care teams still have to speak with next of kin before a donation can happen."[642] This sentiment is echoed on the province's website: "[w]hatever you choose, let the people in your life know your decision to ensure it is honoured. Families will continue to be consulted about their loved ones' wishes regarding organ and tissue donation."[643]

During the second reading of the HOTDA (then Bill 133), Nova Scotia's Premier Stephen McNeil described an "important distinction" when HCPs discussion the potential for organ donation with grieving families under presumed consent systems:

> "It allows that conversation to be very different for our health care providers. They are dealing with our families at the most stressful and tragic times – the loss of a loved one – and going to ask for them to be an organ donor is very different than saying that we know all of us are organ donors and we want to know whether you want to fulfill the wishes of

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[636] The HOTDA is described in full detail above in Chapter 2.

[637] Michael Gorman, "Nova Scotia to begin presumed consent for organ donation next January", *CBC News* (30 June 2020), online: <www.cbc.ca/news/canada/nova-scotia/presumed-consent-organ-donation-1.5633185>.

[638] *Ibid*.

[639] Keith Doucette, "N.S. presumes people want to donate organs when they die, but program uptake unclear", *CBC News* (6 December 2021), online: <www.cbc.ca/news/canada/nova-scotia/ns-presumed-consent-organ-donation-uptake-1.6274777>.

[640] Keith Doucette, "Big jump in tissue donations, organ referrals after N.S. presumed consent law", *CBC News* (21 January 2022), online: <www.cbc.ca/news/canada/nova-scotia/ns-presumed-consent-organ-donation-one-year-later-1.6322816>.

[641] *Ibid*.

[642] Gorman, *supra* note 637.

[643] "Changes to organ and tissue donation", online: *Nova Scotia* <https://novascotia.ca/organ-and-tissue-donation-changes/>.

your loved one. That is an important distinction that will allow that conversation to happen across our province."[644]

An additional noteworthy section in the HOTDA is turns on pre-mortem interventions. Pre-mortem interventions (PMIs) are implemented prior to the determination of death of a patient with the intention of preserving and/or enhancing the possibility of organ donation.[645] PMIs "pose varying degrees of risk to the still-living patient and these risks are weighed against the potential benefits of successful donation."[646] Examples of PMIs include installing mechanical ventilation, withdrawing life sustaining therapies, or administering anticoagulants such as Heparin to prevent blood clots that could harm the organs and decrease graft function.[647] The ethics of PMIs are widely debated, in no small part because any risk of harm falls squarely on the shoulders of the donor, while the direct medical benefits would be reaped by the recipients.[648]

Under the HOTDA, consent to organ donation does not imply consent to PMIs.[649] Individuals with the capacity to give *voluntary and informed consent* may consent to PMIs; where the individual has not provided consent and lacks capacity to do so, SDMs may provide or refuse consent.[650] The HOTDA does specify that SDMs "shall follow any instructions in a personal directive made pursuant to the Personal Directives Act, unless there are expressions of a contrary wish made subsequently by the individual while the individual had the capacity to do so."[651] In the absence of instructions, SDMs "shall … act according to what [they] believe the wishes of the individual would be based on what the substitute decision-maker knows of the values and beliefs of the individual and from any other written or oral instructions."[652] However, it is unclear if there are any mechanisms in place to enforce that SDMs act in accordance with the known or believed intentions and values of the deceased.

Furthermore, this section of the HOTDA is particularly interesting when viewing organ donation in the context of wills and estates. Section 22(5) provides that consent to PMIs is full authority for physicians or hospitals to perform the interventions both when consent is made or "where it is contained in a personal directive made pursuant to the *Personal Directives Act* or other lawful advance directive, when the personal directive or advance directive is activated."[653] The deference paid to personal directives here mirrors the deference that many authors expect would also be paid

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[644] Nova Scotia, Legislative Assembly, *Nova Scotia Hansard*, (4 April 2019) at 2889 online: <https://nslegislature.ca/legislative-business/hansard-debates/assembly-63-session-2/house_19apr04> [NS Hansard].
[645] Matthew J. Weiss et al, "Ethical considerations in the use of pre-mortem interventions to support deceased organ donation: A scoping review" (2021) 35:4 Transplantation Rev 1 at 1.
[646] *Ibid* at 2.
[647] *Ibid* at 4.
[648] *Ibid* at 1. The authors note, however, that the fulfilment of the desire to donate was cited as the primary benefit of PMIs by nearly all authors captured within their scoping review: see *ibid* at 5.
[649] HOTDA, *supra* note 30, s 22(1).
[650] *Ibid*, s 22(3).
[651] *Ibid*, s 22(3)(a)(i). The Act provides two further instances where SDMs may depart from the instructions left in a personal directive: "where technological changes or medical advances make the instruction inappropriate in a way that is contrary to the intentions of the individual," or "circumstances exist that would have caused the individual to set out different instructions had the circum-stances been known based on what is known of the values and beliefs of the individual and from any other written or oral instructions." See ss 22(3)(a)(i) and (ii), respectively.
[652] HOTDA, *supra* note 30, s 22(3)(b).
[653] *Ibid*, s 22(5).

to donation decisions captured in wills.[654] Notwithstanding the "No Property" rule – and its limiting effects on treating organs as "property" to be donated upon the donor's death, the respect paid to personal directives (even with complex end-of-life decisions) represents one way in which legal personhood transcends the boundary of death. Here, the text of the HOTDA imposes the expectation that SDMs shall abide by the final wishes of the deceased.

Conversely, this section of the HOTDA – perhaps inadvertently – effectively reopens the door to the family veto. Even if families are not able to veto the *consent* to donate,[655] withholding consent for PMIs could ultimately undermine the ability to donate in the context of DCD, thus nullifying the consent and donation decision of the donor. It is unclear as to whether Nova Scotia has any mechanisms in place to control family refusals to PMIs where consent to donation – either explicit or presumed – has been given. In this way, the HOTDA exemplifies how a shift to an opt-out consent system alone is insufficient in preventing the family veto both by still giving families the last word, and by providing them with additional avenues to prevent donation from taking place.

17.1.2 New Brunswick

While New Brunswick became the second Canadian jurisdiction to implement a presumed consent system, the province's path towards presumed consent was less straightforward than that of its Nova Scotian counterpart. Presumed consent was rejected in New Brunswick as recently as 2017.[656]

In May 2021, Bill 61, *An Act to Amend the Human Tissue Gift Act*, was introduced to the Legislature. In proposing a presumed consent system, the Bill also aimed to – among other purposes – establish a registry for expressing consent or refusal to donation, set out exceptions to the presumption of consent, and require HCPs to check donation status on the registry before proceeding with transplantation activities.[657]

One year later, the Standing Committee on Law Amendments published their deliberations on the Bill. The intent of the Bill was supported by the Department of Health and the Province of Nova Scotia:

> "Based on preliminary data from Nova Scotia, after less than one year under the presumed consent model, the NBOTP expects referrals of potential donors could double if the model is implemented in New Brunswick.
>
> In sharing its experience with the Department, Nova Scotia recommended that sufficient time – perhaps two to three years – be allowed to prepare implementation of a presumed consent model before the legislation is brought into force. This would include educating

[654] See above in Chapter 3.

[655] However, Nova Scotia's public health messaging suggests families are still given the opportunity to do so (see Appendix 16).

[656] Mark Quinn, "Should organ donor consent be assumed? N.L health minister not convinced", *CBC News* (24 March 2017), online: <www.cbc.ca/news/canada/newfoundland-labrador/organ-donation-newfoundland-consent-opt-out-1.4039550>.

[657] New Brunswick, Standing Committee on Law Amendments, *First Report of the Standing Committee on Law Amendments* (May 2022) (Chair: Hugh J. Flemming) at 1 [New Brunswick Report].

> the public and preparing health care providers for bedside engagement with family members."[658]

The Report briefly alluded to the family veto, joining the chorus of public health messaging that emphasizes "how important it is that New Brunswickers discuss their wishes regarding organ and tissue donation with family members. Even under a presumed consent model such as Nova Scotia's, family members of the potential donor may consent or refuse consent even if the potential donor expressly indicated otherwise in a registry or was presumed to consent."[659]

Ultimately, the Committee recommended against Bill 61 proceeding in its then-current form, instead urging the provincial government to redevelop presumed consent legislation in alignment with feedback from the Department of Health.[660]

The amended legislation was adopted in June 2023, receiving unanimous support during its third reading.[661] Known as *Avery's Law*, the *Human Organ and Tissue Donation Act* was named in honour of 16-year-old Avery Astle, who died in 2019. Despite Astle's parents' desire to donate his organs and tissues, "no one from the specialized donation team, which is run by Horizon Health Network, was available to retrieve the organs."[662]

Prior to the passage of Bill 61, 82% of New Brunswickers had already registered their donation decisions, with 46% consenting to organ donation and 36% refusing donation. The remaining 18% of the population who had not registered their intentions, whether positive or negative, were seen as "the additional potential donors who would be added to the pool under a presumed consent model."[663]

17.2 British Columbia

Presumed consent seems to be gaining less traction in British Columbia than other Canadian jurisdictions.

BC Transplant describes queries regarding a potential shift to a presumed consent system as "one of the questions [they] hear most often."[664] To date, the approach by BC Transplant has been focused on education and policy initiatives, rather than legal reform:

> "There is considerable evidence to suggest that strategies such as in-hospital transplant coordinators, education and training for medical professionals, and public education are more effective at increasing donor rates than presumed consent legislation. For example,

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[658] *Ibid*.
[659] *Ibid*.
[660] *Ibid* at 5.
[661] Bobby-Jean MacKinnon, "Avery's Law makes organ, tissue donation automatic in New Brunswick — with some exceptions", *CBC News* (19 June 2023), online: <www.cbc.ca/news/canada/new-brunswick/new-brunswick-organ-donation-presumed-consent-avery-s-law-1.6881139>.
[662] Karissa Donkin, "Parents told no one available to help donate 16-year-old son's organs, tissues", *CBC News* (8 May 2019), online: <www.cbc.ca/news/canada/new-brunswick/astle-organ-donation-1.5125989>.
[663] New Brunswick Report, *supra* note 657 at 1-2.
[664] "Frequently Asked Questions", online at 2 (pdf): *BC Transplant* <www.transplant.bc.ca/Documents/FAQs%20website%20copy2018final.pdf>.

> Spain attributes its world-leading deceased donor rate primarily to its use of transplant coordinators, donation physicians and a robust education program for health care professionals with presumed consent legislation playing a lesser role. For that reason, British Columbia is focused on first investing in these foundational elements to support and increase donation, including donation physicians, education of health care professionals, and implementation of donation after cardiac death. Without these foundational system elements in place, changing the consent legislation alone will not bring about the desired level of increase in donation."[665]

A 2019 poll found that 66% of BC residents think the province should either "definitely" or "probably" adopt an 'Active Donor Registration' (opt-out) consent system.[666] That same year, BC Health Minister Adrian Dix "said his government will be watching the results of [Nova Scotia's opt-out] policy closely, but that there were no plans to implement something similar at home."[667]

One year later, when support for opt-out consent systems increased in every other surveyed jurisdiction, support in BC dipped slightly, with "definitely" answers shifting from 36% to 32%, and "probably" answers increasing from 30% to 33%. At the same time, the "definitely not" and "not sure" responses in the province each increased by 1% as well. While BC demonstrated the lowest levels of support for an opt-out system, over two-thirds of respondents were in favour of switching to presumed consent.[668]

In 2021, a resolution proposing presumed consent was contemplated by the Union of BC Municipalities – however, the resolution was not endorsed, and thus the Union did not request that the province enact presumed consent legislation.[669] In the years since, a number of letters to the editor have been written to BC news outlets[670] and several online petitions have been started, though no meaningful progress has been made to date.[671]

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[665] *Ibid*.

[666] Andrew Weichel, "Majority support opt-out system of organ donation in B.C., poll finds", *CTV News* (22 August 2019), online: <https://bc.ctvnews.ca/majority-support-opt-out-system-of-organ-donation-in-b-c-poll-finds-1.4561023?cache=%3FclipId%3D89926>. See also 2019 Poll, *supra* note 665.

[667] Weichel, *ibid*.

[668] Andrew Weichel, "Increasing number of Canadians support 'opt-out' system of organ donation, poll finds", *CTV News* (25 August 2020), online: <https://bc.ctvnews.ca/increasing-number-of-canadians-support-opt-out-system-of-organ-donation-poll-finds-1.5078632>.

[669] "Resolution: Organ Donation Presumed Consent" (2021), online: *Union of BC Municipalities* <www.ubcm.ca/convention-resolutions/resolutions/resolutions-database/organ-donation-presumed-consent>.

[670] For example: Todd Hauptman, "Letter: Time for B.C. to follow Nova Scotia on organ donation", *Langley Advance Times* (14 January 2022), online: <www.langleyadvancetimes.com/opinion/letter-time-for-b-c-to-follow-nova-scotia-on-organ-donation-2560162>; "Editorial: Opt-out organ donation the way to go", *Vancouver Island Free Daily* (29 January 2021), online: <www.vancouverislandfreedaily.com/opinion/editorial-opt-out-organ-donation-the-way-to-go-7205736>.

[671] Stephen Gammer, "Bringing Presumed Consent Legislation for Organ Donation to BC" (2 December 2019), online: *Change* <www.change.org/p/government-of-british-columbia-bringing-presumed-consent-legislation-for-organ-donation-to-bc>; and United Donors Foundation, "Save Lives Today: An Opt-Out Organ Donation System!" (23 September 2019), online: *Change* <www.change.org/p/british-columbia-government-save-lives-today-an-opt-out-organ-donation>. At the time of writing, these petitions had gained 677 and 203 signatures, respectively.

17.3 Alberta

In 2019, Bill 205, the *Human Tissue and Organ Donation (Presumed Consent) Amendment Act*, passed its first reading and Alberta saw a flurry of media attention on presumed consent.[672] At that time, only 19% of Albertans were registered organ donors.[673] The Bill was referred to a standing committee;[674] shortly thereafter, the Standing Committee on Private Bills and Private Member's Public Bills published their final report on Bill 205.[675] The Report did not contain any discussion of presumed consent or its implementation; rather, it simply recommended that Bill 205 proceed.[676] However, the first session of the 30th Legislature of Alberta was prorogued, killing the Bill.[677]

Bill 205 returned to the Legislature in 2022 with a notable change – rather than promoting presumed consent, the new version focuses on mandatory referral.[678] Under this iteration of Bill 205, HCPs must provide the relevant OPO with the age of the person, the cause (or expected cause) of their death, the time of death (if applicable), and any relevant health information of that person pertinent to ODT.[679] The OPO must then evaluate whether the deceased's tissues and/or organs are suitable for transplantation, and if so, must confirm whether a consent has been given (or must make a request for consent, as applicable).[680] HCPs are not required to refer the patient to the OPO if their organs are unsuitable for transplantation, and/or the HCP has knowledge that the deceased would have refused to consent to donate.[681]

Likely due to the similar names between the two versions of Bill 205, there was considerable confusion amongst media outlets when the Mandatory Referral Act was passed.[682] However, there is no mention of presumed consent in the text. The *Human Tissue and Organ Donation (Mandatory Referral) Amendment Act* gained royal assent on May 31, 2022, and came into force on April 1, 2023.[683]

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672 See for example: "Alberta moves toward 'opt out' organ donation system", *CTV News* (7 November 2019), online: <https://edmonton.ctvnews.ca/alberta-moves-toward-opt-out-organ-donation-system-1.4674115> and Lisa Johnson, "Alberta may adopt presumed consent in organ donation", Edmonton Journal (7 November 2019), online: <https://edmontonjournal.com/news/politics/alberta-may-adopt-presumed-consent-in-organ-donation>.

673 Jordan Omstead, "New law would make Albertans organ donors unless they opt out", *CBC News* (11 November 2019), online: <www.cbc.ca/news/canada/edmonton/alberta-presumed-organ-donation-1.5352489>.

674 Johnson, *supra* note 672.

675 Alberta, Standing Committee on Private Bills and Private Members' Public Bills, *Final Report: Bill 205, Human Tissue and Organ Donation (Presumed Consent) Amendment Act, 2019* (November 2019) (Chair: Mike Ellis) at 4.

676 *Ibid*.

677 Manitoba Report, *supra* note 252 at 18.

678 Bill 205, *Human Tissue and Organ Donation (Mandatory Referral) Amendment Act, 2022*, 3rd Sess, 30th Leg, Alberta, 2022 (assented to 31 May 2022), SA 2022, c 10. Similar legislation was passed 12 years earlier in Nova Scotia: Nova Scotia, News Release, "New Human Organ and Tissue Donation Act Introduced" (30 November 2010), online: <https://news.novascotia.ca/en/2010/11/30/new-human-organ-and-tissue-donation-act-introduced>.

679 *Human Tissue and Organ Donation (Mandatory Referral) Amendment Act*, 2022, SA 2022, c 10, s 7(1) [*Mandatory Referral Act*].

680 *Ibid*, s 7(3).

681 *Ibid*, s 7(2).

682 For example, at least two different outlets confirmed that Alberta had passed deemed consent legislation. See Lauryn Heintz, "Organ donation bill transitions Alberta to aims to increase donations in Alberta", *Rocky Mountain Outlook* (2 June 2022), online: <www.rmoutlook.com/beyond-local/organ-donation-bill-transitions-alberta-to-aims-to-increase-donations-in-alberta-5437776> and Marilynn Larkin, "Deemed Consent for Deceased Organ Donation: Yea or Nay?" (1 November 2022), online: *Medscape* <www.medscape.com/viewarticle/983353>.

683 *Mandatory Referral Act*, *supra* note 679.

The spring of 2022 also saw Alberta introduce its Specialist in End-of-Life Care, Neuroprognostication and Donation (SEND) program, which intended to bring cross-specialty coordination to increase donation rates.[684] Specifically, the role of the 22 HCPs participating in the SEND Program is "to increase awareness, educate and consult with healthcare professionals in emergency departments and ICUs … With improved awareness and training – and coordination of resources – more staff will be able to identify appropriate opportunities for organ and tissue donation and provide support and options to families who have lost a loved one and could consent to donation."[685]

17.4 Saskatchewan

Shifting to a presumed consent system has been contemplated in Saskatchewan for quite some time. In 2016, the Standing Committee on Human Services published an Inquiry into Organ and Tissue Donation. Of the Committee's ten recommendations, four centered on educational programs and campaigns (three for deceased donation and one for living donation).[686] The Committee recommended against a presumed consent system, warning such a system "[had] not been implemented in any jurisdiction in Canada, and that implementation of such a system would likely be challenged in the courts."[687] Instead, it recommended an enhanced opt-in consent system, which would include "the creation of an intent-to-donate registry for both living and deceased organ and tissue donation, with [Saskatchewan Government Insurance] collecting information from those who intend to donate and with health care professionals able to access the registry via e-health."[688] Despite the position of the Committee, then-premier Brad Wall was vocally in favour of the province implementing a presumed consent system.[689]

In 2018, the newly elected government stepped back from the former premier's target of implementing a presumed consent system.[690] Instead, health minister Jim Reiter held that the government's new focus was on "organ-donation awareness, with an education campaign expected to ramp up in the 'near future'."[691] Reiter acknowledged that a presumed consent system had not been ruled out; rather, the province wanted to pursue other initiatives first, such as "mandatory referrals and hiring a 'donor physician' — someone who would educate medical staff in Saskatchewan about encouraging patients to become donors."[692]

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[684] Melissa Gilligan, "Alberta announces new $2M organ donation program", *CTV News* (9 May 2022), online: <https://calgary.ctvnews.ca/alberta-announces-new-2m-organ-donation-program-1.5895010>.
[685] *Ibid*.
[686] Saskatchewan, Standing Committee on Human Services, *Inquiry into Organ and Tissue Donation* (November 2016) (Chair: Dan D'Autremont) at 29-30 [Saskatchewan Inquiry].
[687] *Ibid* at 29. Notably, there does not appear to be any caselaw on Nova Scotia's *Human Organ and Tissue Donation Act* in the five years since it was enacted.
[688] *Ibid*.
[689] Katie Dangerfield, "As N.S. begins 'presumed consent' organ donation, advocates say Canada will be watching", *Global News* (18 January 2021), online: <https://globalnews.ca/news/7582716/nova-scotia-presumed-consent-canada>. See also: Ashley Robinson, "Brad Wall interested in presumed consent to boost organ donations", *Regina Leader-Post* (30 November 2016), online: <https://leaderpost.com/news/saskatchewan/brad-wall-interested-in-presumed-consent-to-boost-organ-donations>.
[690] Stephanie Taylor, "Sask. hits pause on pursuing presumed consent for organ donation", *CBC News* (11 April 2018), online: <www.cbc.ca/news/canada/saskatchewan/saskatchewan-organ-1.4615559>.
[691] *Ibid*.
[692] *Ibid*.

However, following Nova Scotia's enactment of its presumed consent system in 2019, Reiter had somewhat changed his tune – "[t]he intent all along is to move in that direction." However, he emphasized that the province would prioritize other measures first, such as a registry and education campaigns (particularly those led by HCPs).[693] At that time, between 63% and 84% of polled Saskatchewan residents were in favour of implementing presumed consent.[694]

In 2020, the province launched its online organ and tissue donation registry – "open to Saskatchewan residents aged 16 and older who want to make a formal declaration of their wishes to be a donor."[695] However, the registry "does not change the fact that families can go against a person's wishes," just as they could under the previous system.[696] Between 2020 and 2023, nearly 21,000 Saskatchewan residents registered their intentions to donate, and April 2022 to March 2023 saw the highest number of deceased donors ever recorded in the province in a single year.[697]

17.5 Manitoba

Presumed consent was first proposed in Manitoba in a private member's bill in 2017. However, the province's Conservative government voted against the bill, advocating instead for education and promotion of the existing donor registry.[698] Among the reasons offered for the government's vote included "implications for particular religions that want to see their loved ones buried whole," as well as "people [who] may be unaware of how to opt out or [where] English may be a second language."[699]

In 2021, the Manitoba Law Reform Commission published a consultation paper on presumed consent. This paper did not offer recommendations; rather, it sought public input into the scope of presumed consent, the mechanisms for indicating consent and refusal to ODT, the exceptions to presumed consent, and the role of SDMs under a presumed consent system.[700]

In 2022, the Commission published a report on presumed consent.[701] The Report includes 19 recommendations for improving ODT in the province, several of which turn on the transition to a presumed consent system. The recommendations also include the use of a donor registry, and the

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[693] "Saskatchewan reaches out to Nova Scotia to talk automatic organ donation", *CTV News* (3 April 2019), online: <www.ctvnews.ca/health/saskatchewan-reaches-out-to-nova-scotia-to-talk-automatic-organ-donation-1.4364210>.

[694] See chart above and Andrea Hill, "Taking the Pulse: 84 per cent of Sask. residents want presumed-consent organ donation", *Saskatoon Star Phoenix* (3 July 2019), online: <https://thestarphoenix.com/news/local-news/taking-the-pulse-84-per-cent-of-sask-residents-want-presumed-consent-organ-donation>, respectively. **NB:** The chart above combines the opinions of Saskatchewan with Manitoba residents.

[695] "Sask. launches registry for organ and tissue donors", *CBC News* (3 September 2020), online: <www.cbc.ca/news/canada/saskatoon/online-registry-organ-tissue-donors-launched-saskatchewan-1.5711101>.

[696] *Ibid*.

[697] Saskatchewan, News Release, "Saskatchewan Sees Record Organ and Tissue Donation" (5 July 2023), online: <www.saskatchewan.ca/government/news-and-media/2023/july/05/saskatchewan-sees-success-in-organ-and-tissue-donation>.

[698] Dangerfield, *supra* note 689.

[699] *Ibid*. Importantly, while religious views inevitably vary between individuals and families, every major religion in Canada supports ODT: see FAQs, *supra* note 13; Faith Report, *supra* note 340.

[700] Manitoba Law Reform Commission, "Presumed Consent Organ Donation: Consultation Paper" (May 2021), online at 23 (pdf): <www.manitobalawreform.ca/pubs/pdf/presumed_consent_organ_donation.pdf> [Manitoba Consultation Paper].

[701] Manitoba Report, *supra* note 252.

creation of different ways of registering both consent and refusal. Notably, the Report also calls for consultation with Indigenous communities – which is absent from most Canadian ODT literature and discourse.[702]

With regard to the family veto, the Report does not explicitly use the language of "veto", "override," or "overrule" in its 185 pages. Recommendation 15 suggests allowing for certain people to consent to or refuse organ donation on behalf of the deceased in two scenarios: where the SDM provides "information that would lead a reasonable person to conclude that the deceased person would have made a different decision respecting donation after death than the decision recorded in the MB Registry or presumed" or where the deceased has not given a direction regarding donation (and consent cannot be presumed due to reasons such as a lack of capacity or they were underage).[703] Recommendation 15 appears to mirror the equivalent section in Nova Scotia's legislation:

> "For recommendation 15(a), the appropriate person listed in Recommendation 8 should be required to provide the evidence that they believe proves that the deceased person would have made a different decision than what was recorded in the MB Registry or presumed under the presumed consent framework, with the strongest evidence being a witnessed written document, and the weakest evidence being oral and uncorroborated.
>
> In assessing the evidence to determine whether a reasonable person would be satisfied with the evidence presented, the following factors could be considered: (i) whether the evidence is of the deceased person's view as opposed to the family's view; (ii) whether there is corroborating evidence; (iii) how recent the evidence is; and (iv) how well the person providing the evidence knows the deceased person."[704]

Similarly, Recommendation 17 sets out strict guidelines as to who should be empowered to consent to or refuse organ and tissue donation on behalf of another person, including the criterion "is willing to assume the responsibility for making the decision."[705] It is unclear from the Report alone what this "responsibility" entails – whether simply emotional responsibility, or whether there may be civil responsibilities attached to their role as SDM.

Even following the release of this report, Manitoba continued to advocate for the opt-in approach in 2022, "relying on urgent public appeals – and lighting up the legislative building – to encourage people to sign up and become donors."[706] According to MLA Reg Helwer, who previously chaired the province's task force on organ and tissue donation, the province is still considering presumed consent, but cannot provide a definitive estimate on when it might be implemented.[707] Despite the

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[702] *Ibid* at 50 (Recommendation 4). See also Caroline L. Tait, "The rights and interests of First Nations, Métis, and Inuit in debates over deemed consent legislation for deceased organ donation in Canada: calls to action" (2023) 18 Health Policy.
[703] Manitoba Report, *ibid* at 87-88 (Recommendation 15).
[704] *Ibid* at 88. See also Nova Scotia Consent Guide, *supra* note 596.
[705] Manitoba Report, *ibid* at 89 (Recommendation 17).
[706] "Manitoba urges organ tissue donation but moves slow on presumed consent", *CBC News* (25 April 2022), online: < www.cbc.ca/news/canada/manitoba/organ-tissue-donation-manitoba-presumed-consent-1.6430014>.
[707] *Ibid*.

province stating it would be studying the implementation of presumed consent in Nova Scotia, any meaningful progress was slowed by the COVID-19 pandemic.[708]

With regard to the family veto, Health Minister Audrey Gordon expressed at a 2022 press conference that "[s]igning up for donation 'takes the burden of that decision off your family and ensures your intent is known and respected'."[709] However, as demonstrated in Chapter 2, such a statement is weakened by its discordance with Transplant Manitoba's website, which explicitly reads that "[d]onation will not take place without your family's consent."[710]

17.6 Ontario

Nearly two decades ago, Dr. Frank Markel, the president of the Trillium Gift of Life Network held that Trillium "[did not] believe the public of Ontario [was] ready" to pursue presumed consent donor registration.[711] At that time, "neither the Ontario Medical Association nor the Canadian Medical Association [had] spoken in favour of presumed consent."[712] In 2008, presumed consent legislation was proposed in Ontario for the third time with no success.[713]

Fast forward to 2019 – Ontario NDP Health Critic France Gelinas proposed a presumed consent bill. At that time, Trillium continued to advocate for education over legal reform, citing a lack of clear evidence in favour of a presumed consent system.[714] The Bill was never fully considered – despite the bill passing the first reading,[715] "the government decided to prorogue the legislature, ending the first session of the 42nd Parliament, and resulting in all Bills in progress, including Bill 91, dying on the Order Paper."[716]

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[708] *Ibid*.
[709] *Ibid*.
[710] See Appendix 16.
[711] Murray Campbell, "Ontario rejects 'presumed consent' organ donation", *Globe and Mail* (23 September 2005), online: <www.theglobeandmail.com/news/national/ontario-rejects-presumed-consent-organ-donation/article986958/>.
[712] *Ibid*.
[713] "Ontario's NDP calling for law presuming automatic consent for organ donation", *CBC News* (29 July 2008), online: <www.cbc.ca/news/canada/toronto/ontario-s-ndp-calling-for-law-presuming-automatic-consent-for-organ-donation-1.699191>.
[714] Pauline Chan, "Ontario may follow Nova Scotia's lead in adopting 'presumed consent' for organ donation", *CTV News* (17 July 2019), online: <https://toronto.ctvnews.ca/ontario-may-follow-nova-scotia-s-lead-in-adopting-presumed-consent-for-organ-donation-1.4512874>.
[715] Bill 91, *Peter Kormos Memorial Act (Trillium Gift of Life Network Amendment), 2019*, 1st Sess, 42nd Leg, Ontario, 2022 (first reading 28 March 2019).
[716] Manitoba Report, *supra* note 252 at 21.

Further iterations of this Bill were reintroduced in Ontario in 2022[717] and 2023.[718] In total, the 2023 Bill (the *Peter Kormos Memorial Act*) is the seventh presumed consent bill introduced to the provincial legislature.[719] Per Gelinas, this latest version of the Bill "no longer has pushback from labour or religious groups."[720]

Section 5(1) of the Bill allows for objection to tissue procurement by the next-of-kin only where the deceased "die[d] without making an objection in accordance with subsection 4(3)" or where the death of the person is imminent and incapable of making an objection.[721] Similarly, section 5(6) prohibits objecting to procurement and donation on behalf of the deceased "if the person has reason to believe that the person who died … would not have objected to the removal or use."[722] On their face, these sections appear to limit the possibility of the family veto. However, per Gelinas, "people can be assured their next of kin would be asked [for consent] upon their death."[723] This public statement by the Bill's sponsor begs the question of whether – if at all – the family veto will be considered in the legislature's contemplation of the Bill. Bill 84 is currently awaiting a second reading, having passed the first reading on March 23, 2023.[724]

17.7 Québec

Following Nova Scotia's implementation of its presumed consent system in 2019, the medical director of organ transplants at Transplant Québec – Dr. Prosanto Chaudhury – described presumed consent as "something [Quebec] need[s] to explore. We've got our eyes on Nova Scotia … We have to get a sense of what Quebecers want."[725] At that time, Transplant Québec ran "a publicity campaign on organ donation to try to stoke a broader conversation around it,"[726] but the province did not pursue its own presumed consent regime any further – in fact, a presumed consent bill was quashed by the Coalition Avenir Québec (CAQ) political party that year.[727]

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[717] "MPP Gélinas tables bill to increase organ donation" (29 March 2022), online: *Ontario NDP* <www.ontariondp.ca/news/mpp-g-linas-tables-bill-increase-organ-donation>; Bill 107, *Peter Kormos Memorial Act (Saving Organs to Save Lives), 2022*, 2nd Sess, 42nd Leg, Ontario, 2022 (first reading 29 March 2022). The 2022 bill "died on the floor because the legislature dissolved and a provincial election was called" – see Ian Campbell & Dan Bertrand, "NDP again try to change Ontario's organ donation system to an opt-out one", *CTV News* (1 April 2023), online: <https://northernontario.ctvnews.ca/ndp-again-try-to-change-ontario-s-organ-donation-system-to-an-opt-out-one-1.6338903>.

[718] Bill 84, *Peter Kormos Memorial Act (Saving Organs to Save Lives), 2023*, 1st Sess, 43rd Leg, Ontario, 2023 (first reading 23 March 2023) [Bill 84].

[719] Campbell & Bertrand, *supra* note 717.

[720] *Ibid*.

[721] Bill 84, *supra* note 718. This section stands out as a curiosity of the Bill – it is unclear why family members are explicitly given the opportunity to object to donation in circumstances where the deceased did not opt out. The very nature of opt-out consent systems is that if the deceased chose not to opt out, then their willingness to donate is presumed.

[722] Bill 84, *supra* note 718.

[723] Campbell & Bertrand, *supra* note 717.

[724] Bill 84, *supra* note 718.

[725] "Could presumed consent for organ donation work in Quebec?", *CBC News* (5 April 2019), online: <www.cbc.ca/news/canada/montreal/could-presumed-consent-for-organ-donation-work-in-quebec-1.5085747>.

[726] *Ibid*.

[727] Dan Spector, "'Nobody will be against this': Quebec wants to change organ donation rules", *Global News* (26 April 2023), online: <https://globalnews.ca/news/9653278/quebec-changes-organ-donations/>.

However, by 2023, support for a presumed consent system in the province had increased. Bill 194 was tabled (again) at the National Assembly in Quebec in April 2023, with the government describing consideration of a presumed consent system as a "priority".[728] The Bill makes numerous legislative alterations, including to the *Civil Code of Québec*, the *Act respecting the régie de l'assurance maladie du Québec*, and the *Act respecting health services and social services* (among others). The proposed changes to Article 43 of the *Civil Code* read as follows:

> "A person may, for medical or scientific purposes, give his body or authorize the removal of organs or tissues therefrom. However, for a minor under 14 years of age, the consent of the person having parental authority or of his tutor is required.
>
> The authorization or refusal is expressed verbally before two witnesses, or in writing, and may be revoked in the same manner. The authorization or approval expressed shall be followed, unless there is a compelling reason not to do so."[729]

It is curious both that "compelling reason" remains in the proposed text, and no efforts have been taken to clarify what might qualify as a "compelling reason":

> "The provision intends to prevent the deceased's wishes from being set aside by his or her next of kin, however, Transplant Quebec favours decisions that consider the wishes of the family. In such cases, the refusal of family and friends may correspond to the notion of 'compelling reasons', to the detriment of individual autonomy."[730]

Similarly, Article 44 would become:

> "A person of full age is presumed to have authorized the removal of organs or tissues from his body.
>
> A part of the body of a deceased minor may be removed, if the wishes of the deceased are not known, with the consent of the person who was or would have been qualified to give consent to care.
>
> The person who requests the removal must take reasonable measures with the persons close to the deceased to ensure that the deceased had not, by any means, refused consent.

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[728] *Ibid*. Notably, however, even under the proposed opt-out system, "[t]he family can always oppose" and will be given the final word. See Ugo Giguère, "Quebec bill could increase organ donations", *The Gazette* (26. April 2023), online: <https://montrealgazette.com/news/quebec/quebec-bill-could-increase-organ-donations>.

[729] Bill 194, *An Act to establish a presumption of consent to organ or tissue donation after death*, 1st Sess, 43rd Leg, Québec, 2023, at 5.

[730] Jean-Raphaël Champagne, Dara Jospé & Geneviève Shemie, "Organ and Tissue Donation in Quebec: Bill 194 Proposes to Adopt Presumed Consent" (28 August 2023), online: *Fasken* <www.fasken.com/en/knowledge/2023/08/organ-and-tissue-donation-in-quebec-bill-194-proposes-to-adopt-presumed-consent>.

> The measures provided for in the third paragraph are not required where two physicians attest in writing to the urgency of the operation and the serious hope of saving a human life or improving its quality to an appreciable degree."[731]

This final provision in Article 44 is particularly interesting when read next to Article 43. If, for example, two physicians could attest to the urgency of organ procurement and donation, would this not trump any or all "compelling reasons" to deviate from the consent of the deceased? Given the dire need for organ donations at any given time in Canada, what would those "compelling reasons" be? There is a general trend in the literature to permit the family veto where consent ***has*** been provided, yet it appears almost taboo to suggest families should be allowed to veto ***refusal*** to donation.

In October 2023, the Québec government announced a parliamentary committee to study "all of the processes related to organ donation and transplant, including prevention, awareness raising, staff training, collaborative work with Transplant Québec, and, of course, the whole aspect of consent."[732] Transplant Québec also renewed its call for "major social reflection in order to review its laws and put in place effective processes to increase organ donation rates."[733] In its statement, Transplant Québec acknowledged the role of public education, but stressed the need for "coherent reforms," recommending:

> "A comprehensive bill should therefore focus on four main areas: the organization of donation, including structure, processes and powers; training for healthcare professionals; *the role and influence of the deceased's loved ones* and raising awareness among the Québec population; and consent."[734]

It remains to be seen how the committee will report back, and how their findings will be captured in Québec's future ODT legislation. Notably, 26% of refused donations in 2022 were due to family veto events.[735]

Earlier this year, Québec's College of Physicians supported the concept of presumed consent, but advocated that "measures must be put in place to improve the organ and tissue donation process in the province first, like staff training and better organization and public information."[736]

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[731] *Ibid*.
[732] Thomas Laberge & Jean-Philippe Denoncourt, "Quebec will study assumed consent for organ donations", *The Gazette* (18 October 2023), online: <https://montrealgazette.com/news/quebec/quebec-will-study-assumed-consent-for-organ-donations>.
[733] Transplant Québec, Press Release, "Don't put organ donation on the ice: Transplant Québec calls for reform to save more lives" (17 October 2023), online (pdf): <www.transplantquebec.ca/sites/default/files/communique_journee_mondiale_17_octobre_2023_eng.pdf>.
[734] *Ibid* (emphasis added). While family veto is not explicitly addressed, it remains to be seen what the committee will find on the topic.
[735] Erika Morris, "Presumed consent for organ donors must come with systemic changes: Quebec College of Physicians", *CBC News* (30 January 2024), online: <www.cbc.ca/lite/story/1.7099193>.
[736] *Ibid*.

17.8 Prince Edward Island

As of 2021, the ODT community in PEI was watching the impacts of Nova Scotia's opt-out system, but had "not made any decisions about whether to switch to a presumed consent system" itself.[737] However, before presumed consent is actively pursued in the province, further investment must first be made into infrastructure to support ODT. According to medical director of Nova Scotia's Organ and Tissue Donation Program, Dr. Stephen Beed, "[i]nfrastructure to support the identification and support of an organ donor doesn't exist in P.E.I."[738] Per Beed:

> "The starting point for P.E.I. should not be a new law. It should be investment in those sort of basics … If establishing those basics includes a conversation around what the consent model in the province might be then fair enough, you might go there — but without those other things in place a granular conversation around the consent model isn't going to get you anywhere." [739]

This additional infrastructure should include "an accountability structure, administrative support, nursing staff, and a medical director," as well as programs "to support education around [ODT] for healthcare staff."[740] Beed also described the biggest challenge in Nova Scotia as recognizing potential donors "on the front end" – for example, in smaller community emergency departments – and assumed there were the same gaps in identifying potential donors in PEI.[741]

In 2019, 79% of PEI residents supported bringing presumed consent to their province.[742]

17.9 Newfoundland & Labrador

Former Health Minister John Haggie has been adamant that it is unlikely that Newfoundland and Labrador will adopt a presumed consent system. In 2017, Haggie argued that presumed consent "doesn't work … The jury isn't quite in yet. By itself, it hasn't quite made the difference that people wanted … There's no point in doing something just because it sounds right and it's popular. It's got to work."[743] In this way, Haggie cited the presumed consent system in Spain: "[t]heir organ donation rate remained at three of four per cent for 10 years after they changed the law. It was only when they did the education and support piece that their donation rate when up to 12 and 15 percent — which is very good by standards of European countries."[744] Haggie doubled down on the role of education again in 2019, acknowledging the "very poor" donation rates in the province but emphasizing "that education is key in increasing organ donation." [745] In his view, "the answer does not involve joining Nova Scotia in an opt-out program, for the foreseeable future."[746] Notably, in

[737] "PEI watching 'very closely' as Nova Scotia enacts new organ donation system", *CBC News* (8 February 2021), online: <www.cbc.ca/news/canada/prince-edward-island/pei-organ-donations-nova-scotia-presumed-consent-1.5906265>.
[738] Tony Davis, "PEI needs programs to support organ donation, says Nova Scotia doctor", *CBC News* (6 October 2021), online: <www.cbc.ca/news/canada/prince-edward-island/pei-organ-donation-oct-2021-1.6202116>.
[739] *Ibid*.
[740] *Ibid*.
[741] *Ibid*.
[742] "79% of PEI Residents Support Presumed Consent for Organ Donation" (9 July 2019), online: *MQO Research* <www.mqoresearch.com/79-of-pei-residents-support-presumed-consent-for-organ-donation/> [MQO].
[743] Quinn, *supra* note 656.
[744] *Ibid*.
[745] *Ibid*.
[746] *Ibid*.

2019, 83% of Newfoundland and Labrador residents supported the shift to a presumed consent system.[747]

Certainly, it appears that legislative reform falls further down on the list of priorities for Newfoundland and Labrador's ODT community. In 2022, the province's ODT program was suspended due to "mounting problems over the past several months due to staff shortages, pandemic-related burnout and rolling emergency room closures."[748] As per Eastern Health's clinical chief of regional critical care, Dr. Sharon Peters, given the size of the program, "it doesn't take much in terms of staff turnover to put [them] in a precarious position.[749]

Newfoundland and Labrador's average deceased donor rate "is about half the Canadian rate," and as expressed by Dr. Matt Weiss, this low number "is not surprising because the province has many logistical hurdles when it comes to harvesting and transporting organs."[750] As in PEI, Newfoundland and Labrador lack the logistical infrastructure of larger provinces and may struggle further under a presumed consent system, should it raise (attempted) donation rates too greatly.

While Newfoundland and Labrador have previously considered a presumed consent system, the shift from opt-in to opt-out has never materialized.[751]

17.10 The Territories

Perhaps unsurprisingly given the vastly smaller population numbers, there has been significantly less discussion of shifting to an opt-out consent system in the Territories than amongst the provinces.

In 2022, Leader of the Third Party, Ms. White, raised Motion 387 in the Yukon Assembly, urging "the Government of Yukon to introduce legislation to create deemed consent on organ and tissue donation, also called opt-out legislation."[752] While this Motion was again raised in 2023, it does not appear to have made any progress in the Assembly.[753]

Organ donation in the Northwest Territories is completely folded into Alberta's ODT regime; "[n]o organ transplants are done in the NWT as the costs are prohibitive and require specific expertise."[754] When Alberta's private members bill – the Organ and Tissue (Mandatory Referral)

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[747] MQO, *supra* note 742.

[748] Michelle McCann, "No organ donations in N.L. so far this year, with program on hold due to staff shortage", *CBC News* (29 August 2022), online: <www.cbc.ca/news/canada/newfoundland-labrador/organ-donation-program-staff-shortages-1.6562235>.

[749] *Ibid*.

[750] *Ibid*. Transplants are not performed in Newfoundland and Labrador – instead, "staff coordinate with other provinces to procure and send organs and recipients out of province for transplantation" (*ibid*), presumably adding to the logistical labour required by OPO staff.

[751] Elizabeth Whitten, "OPEN is Closed: Why is the province's organ donation program on hold?", *The Independent* (3 August 2022), online: <https://theindependent.ca/news/investigation/open-is-closed-why-is-the-provinces-organ-donation-program-on-hold/>.

[752] Yukon, Legislative Assembly, *Motions Other Than Government Motions*, 35-1 (18 October 2022) at 42.

[753] Yukon, Legislative Assembly, *Motions Other Than Government Motions*, 35-1 (28 March 2023) at 40. There is no mention of the Motion in Volumes 6, 7, or 8 of Hansard (2022-2023).

[754] Eric Bowling, "NWT organ donors unaffected by new Alberta 'opt out' system", *NNSL* (9 April 2023), online: <www.nnsl.com/news/nwt-organ-donors-unaffected-by-new-alberta-opt-out-system-7273600>.

Amendment Act – was granted royal assent in the spring of 2022, a notice appeared on the NWT's provincial website notifying residents that:

> "[T]he sections that set out the 'opt out' or 'presumed consent' clauses will not affect NWT residents who are in or transferred to Alberta due to critical injury … The 'opt out' or 'presumed consent' portion of the bill has several exceptions, including one that requires individuals to reside in Alberta for a 12-month period immediately preceding their death."[755]

There has been minimal discussion of presumed consent in Nunavut; however, Ontario and Nunavut were the sole jurisdictions who agreed to participate in a 2022 federal initiative designed to increase public awareness of ODT.[756] For those provinces and territories that opted in, the CRA modified the income tax and benefit return "by adding a tick box that will let taxpayers indicate if they want to receive information about organ and tissue donation from their provincial or territorial government. This [allowed] the CRA to share a taxpayer's contact information with their province or territory of residence exclusively for this purpose."[757] The initiative added a question to income tax returns "asking filers for permission to share contact information with provinces and territories. When people in those jurisdictions mark a box on the form, provincial governments will send those people information about how they can register for organ and tissue donation."[758] In Nunavut, the information shared with regional governments included names, emails, and mailing addresses.[759] In Ontario, the information shared was limited to the taxpayer's name and email address.[760] While raising awareness of ODT systems and processes is certainly important, the tax program was described as "stand[ing] in contrast to steps taken in Nova Scotia,"[761] which aimed to increase donation rates through legislative reform. That said, however, the first year of the tax form initiative was a resounding success – some 2,450,000 Canadians declared they wanted to become organ donors after they were offered additional information on ODT on their tax forms.[762]

18. Lessons Learned from the International ODT Community

While adopting a presumed consent system may increase organ donation rates, doing so does not guarantee success in eliminating the family veto.[763]

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[755] *Ibid*.
[756] Peter Zimonjic, "Nunavut and Ontario join federal effort to boost number of organ and tissue donors", *CBC News* (21 November 2022), online: <www.cbc.ca/news/politics/organ-tissue-donors-tax-form-1.6656806>.
[757] Canada Revenue Agency, News Release, "Minister of National Revenue announces the participation of Nunavut and Ontario in the organ and tissue donation service offering" (21 November 2022), online: <www.canada.ca/en/revenue-agency/news/2022/11/minister-of-national-revenue-announces-the-participation-of-nunavut-and-ontario-in-the-organ-and-tissue-donation-service-offering.html> [CRA News Release].
[758] Zimonjic, *supra* note 756.
[759] *Ibid*.
[760] CRA News Release, *supra* note 757.
[761] Zimonjic, *supra* note 756.
[762] Marina von Stackelberg, "Nearly 2.5 million Canadians sign up as potential organ donors, thanks to tax form change", *CBC News* (27 November 2023), online: <www.cbc.ca/news/politics/organ-donor-private-members-bill-millions-sign-up-1.7038197>. Of those 2.45 million people, some may have registered as organ donors independently of the tax initiative; further inquiry is needed to determine the precise number of new donors registered because of the initiative; see *ibid*.
[763] Furthermore, presumed consent systems alone do not *guarantee* increased donation rates: see "Opt-Out Systems of Organ Donation" (March 2022), online at 3 (pdf): *Canadian Donation and Transplantation Research Group*

Recent legislative changes in France demonstrate that presumed consent systems alone are insufficient in addressing the family veto, and underline the importance of public education, as well as consultation with the medical community and the public when taking large strides in amending ODT law and policy.[764] France enacted its first ODT legislation in 1976, adopting an opt-out consent system – a system was rooted in the concepts national solidarity and reciprocity.[765] This version of France's ODT law contained no mention of the role of family members.[766] In 1994, the law was completely re-written, and the incoming statute reinforced three central principles for the French ODT system: no financial rewards ("*non monnayable*"), anonymous donation, and presumed consent.[767] The 1994 statute did speak to the role of families, holding there was an "obligation for [the] medical team to specifically search with families for a potential organ donation refusal from the patients (*le médecin doit s'efforcer de recueillir auprès des proches du patient son éventuelle opposition au don d'organes, de son vivant*)."[768] The statute also created a Refusal Registry to record the donation decisions of those wishing to opt-out of organ donation.[769]

Over the next two decades, refusal to organ donation could be shared with HCPs in two ways: through the Refusal Registry, or in meetings between the HCPs and the families. When speaking to HCPs, families could either refuse on behalf of the patient (who had given them an oral refusal prior to their death), or the family itself could object to donation.[770] In 2015, legislation was proposed that would see the Refusal Registry as the only refusal mechanism (essentially bringing France from a soft opt-out to a hard opt-out system). The proposed amendment had three objectives: **(1)** to ensure that the patient's donation is guaranteed; **(2)** to discharge the families from being involved;[771] and **(3)** to increase donation.[772] However, the proposal was widely criticized for the lack of public and expert consultation involved in its drafting.[773] The resulting

<https://cdtrp.ca/wp-content/uploads/2022/11/Opt-Out-Systems-of-Organ-Donation.pdf> [CDTRP]. Rather, deceased donor donation rates are influenced by factors including "legislation, donor availability, organ donation organizations (ODOs), efforts at education and publicity, quality of the information and reporting infrastructure, and national healthcare investment."

[764] Another such example is Brazil. In 1997, Brazil introduced a "hard" opt-out consent system "that was rescinded the following year due to a backlash from both medical professionals and the general public, demonstrating the danger of forcing through radical change without wider engagement (Sharif & Moorlock, *supra* note 34 at 156).

[765] CDTRP, *supra* note 763 at 6. See also: Stanislas Kandelman, "The French Experience with Family Refusal After the 2017 Changes to the French Presumed Consent Law" within "Key Policy Issues in Organ Donation & Transplantation – Panel 4. Opt-Out Systems of Organ Donation" (29 June 2021) at 00h:43m:10s, online (video): *YouTube* <www.youtube.com/watch?v=bVZIWDlbP1Y>.

[766] *Ibid* at 00:43:29.

[767] *Ibid* at 00:43:40; CDTRP, *supra* note 763 at 6.

[768] Kandelman, *ibid* at 00:44:05.

[769] The Refusal Registry came into effect in 1998. See *ibid*; CDTRP, *supra* note 763 at 6.

[770] Kandelman, *ibid* at 00:45:18. Although families objecting on their own behalf was contrary to the spirit of the opt-out system, it was accepted both by HCPs and by law: *ibid* at 00:45:28.

[771] As discussed above in Chapter 3, a central goal of removing the family veto is to reduce the stress experienced by families while already dealing with immense grief and loss by taking the weight of a donation decision off their shoulders.

[772] Kandelman, *supra* note 765 at 00:46:25.

[773] *Ibid* at 00:47:20. See for example: François Béguin, "Des organes bientôt prélevés sans l'avis des familles", *Le Monde* (24 March 2015), online: <www.lemonde.fr/societe/article/2015/03/24/des-organes-bientot-preleves-sans-l-avis-des-familles_4600088_3224.html>; Patrick Verspieren, "Don d'organes. Un amendement deplorable", *La Croix* (31 March 2015), online: <https://ethique-soin.blogs.la-croix.com/don-dorganes-un-amendement-deplorable/2015/03/31/>.

pushback led to discussions with the National Ethics Committee, professional societies, and the French ODT agency; ultimately, the "hard" change was abandoned for a "soft" one.[774]

France's 2017 amended statute (*Relatif aux modalités d'expression du refus de prélèvement d'organes après le décès*)[775] specifies the current three mechanisms for registering refusal in their presumed consent system:

I. Inscription on the Refusal Registry is the main way to refuse organ donation after death (*Une personne peut refuser qu'un prélèvement d'organes soit pratiqué sur elle après son décès, <u>à titre principal</u> en s'inscrivant sur le register national automatise …*)

II. Refusal may be notified to a relative on a signed document (*Une personne peut également <u>exprimer son refus par écrit</u> et confier ce document à un proche. Ce document est date et signé par son auteur dument identifié …*)

III. A relative of a deceased patient may notify the refusal of organ donation that the patient would have expressed orally. In such cases, a document stating this refusal by the patient has to be signed by the relative.
(*Un proche de la personne décédée peut faire valoir le refus de prélèvement d'organes que cette personne a manifesté de son vivant. Ce proche ou l'équipe de coordination hospitalière <u>transcrit par écrit</u> ce refus en mentionnant précisément le contexte et les circonstances de son expression. Ce document est signé par le proche qui fait valoir ce refus et par l'équipe de coordination hospitalière de prélèvement*)[776]

To summarize, there are three mechanisms by which French citizens may opt out of organ donation: through the Refusal Registry,[777] by signing their own written document expressing their refusal (to be presented to HCPs by their family members), or their families may sign an attestation that the deceased would have wanted them to refuse on their behalf.[778] However, this third mechanism leaves the door open to family vetoes – it removes the element of proving donation decisions, as provided for in the second mechanism. Practically speaking, the National Database for Organ Donation no longer includes "refusal from relatives" as a box to tick on donor evaluation forms (as it is technically no longer contemplated by the law). However, the language used procedurally has simply changed to "context has not allowed to pursue an organ procurement procedure"[779] – this all but acknowledges that families are vetoing presumed consent to donation without explicitly saying so.

Following the implementation of the 2017 statute, France saw an almost immediate increase in overall organ donation rates by 2%.[780] At the same time, there was a significant decrease in rates of family refusal (from 21% to 13%).[781] While there was an increase in registrants to the Refusal

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[774] Kandelman, *supra* note 765 at 00:48:12 to 00:48:30.
[775] *Décret no. 2016-1118 du 11 août 2016 (see Art. R. 1232-4-4)*.
[776] Translations provided by Stanislas Kandelman, *supra* note 765 (emphasis in his original translation).
[777] The Registry continues to be the primary way by which French citizens may opt out of donation: *ibid* at 00:48:41.
[778] *Ibid* at 00:50:30.
[779] *Ibid* at 00:50:55.
[780] This increase occurred in the 2017-2018 period, as compared to the 2012-2014 period.
[781] Kandelman, *supra* note 765 at 00:54:50.

Registry in the weeks leading up to the statute coming into effect, the overall numbers of registered refusals remain extremely low.[782] However, there was an increase in "patient" refusals following the implementation of the statute, from 12% to 17%. As noted above, refusals of this nature could be made if the deceased signed a written document that was presented by the family to the HCPs. However, in 91.5% of these "patient" refusal cases, no such document was produced,[783] begging the question of whether the deceased had, in fact, opted out of donation, or if their family was vetoing their presumed consent. It is unclear why these "patient" refusals were accepted, given that they did not meet the legislatively prescribed criteria.

19. Additional Consent Systems & Mechanisms

While organ donation consent systems are primarily viewed in an opt-in versus opt-out dichotomy, there exist a number of intermediary consent mechanisms that could be adopted by those Canadian provinces that remain wary of the shift to presumed consent.

"Active choice" systems, as the name suggests, are those consent systems where potential donors must actively register their intention to donate (as opposed to presumed consent systems). In addition to classic opt-in systems, a second active choice mechanism is "mandatory choice," wherein donor registration is tied to "a regulated program, for which every resident applies. This approach requires that, as part of the application process, individuals declare whether or not they consent to organ donation following death."[784] This system still leaves the choice of whether or not to donate up to the individual, but aims to minimize the number of people for whom a donation decision is unknown. Lin et al argue in favour of mandatory choice (within an opt-in system) over shifting to presumed consent – "ambiguous signals of underlying preference that are attached to default opt-out systems contribute to families' veto decisions compared to active choice systems (opt-in, mandated-choice), which are substantially better at signaling intent than passive ones."[785] Certainly, while opt-out systems increase donation rates, families may be more likely to veto donation "decisions" made under presumed consent.[786]

Mandatory choice is most often viewed as a "nudge" – an attempt to influence decision-making while still protecting the autonomy of the decision-maker. Behavioral nudges run the risk of accidentally nudging people away from organ donation should they feel coerced or do not feel comfortable making a positive decision in favour of organ donation at that particular moment– if the only options offered are "Yes" or "No", it might be easier for some to choose against donation.[787] Where donors are not forced to decide and opt not to make a decision either way, their families could still choose to donate their organs (provided they do not believe the deceased would have objected thereto). However, Thaler and Sunstein, among others, consider mandatory choice "as the most practical nudge to increase consent for organ donation."[788]

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[782] *Ibid* at 00:57:44 to 00:58:30. By June 2021, there were approximately 477,000 people with registered refusals from a population of 55 million people over the age of 13.
[783] *Ibid* at 00:54:50.
[784] Sonya Norris, "Strategies to Optimize Organ and Tissue Donation and Transplantation" (2 February 2022), online at 9 (pdf): *Library of Parliament* <https://lop.parl.ca/staticfiles/PublicWebsite/Home/ResearchPublications/HillStudies/PDF/2020-29-e.pdf>.
[785] Lin et al, *supra* note 80 at 3.
[786] *Ibid* at 31.
[787] Klassen & Klassen, *supra* note 433 at 72.
[788] Sharif & Moorlock, *supra* note 34 at 158.

In theory, mandatory choice guarantees that families will be presented with the deceased's recorded donation intentions – whether positive or negative – thus allowing them to act in the deceased's interest. However, when mandatory choice is presented as part of a soft opt-in system, families are still able to veto the intentions of the deceased. If mandatory choice was implemented as part of a hard opt-in system, at least in theory, the donation intentions of every citizen would be known, and would be binding.

In speaking broadly to nudges intended to increase donation, Sharif and Moorlock argued that "[g]iven the importance of respecting donor wishes, it would be morally legitimate to remove the family veto, thereby rendering the decisions of relatives irrelevant."[789] However, they warned that despite the moral and legal justifications of removing the family veto in entirety, doing so may cause distress to the deceased's next-of-kin, as well as to HCPs.[790] Thus, true "hard" opt-out systems, coupled with mandated choice, may be *too* hard of a consent system to be palatable with the broader Canadian public.

Another mechanism that attempts to increase donation rates is mandatory referral. As discussed above in the context of Alberta, mandatory referral requires HCPs to report all deaths to the relevant OPO where donation is possible under the circumstances, so as to ensure the OPO can pursue consent and donation. By 2018, all provinces with the exception of Saskatchewan and Newfoundland and Labrador "have implemented or are implementing some sort of mandatory referral system in an effort to boost organ and tissue donor rates."[791] At the time of writing, it appears mandatory referral is "under development" in Saskatchewan,[792] and it was included in the recommendations of the Standing Committee on Human Services 2016 Inquiry into Organ and Tissue Donation.[793] However, it is unclear where mandatory referral currently stands in the province, and it appears that the Saskatoon Health Region "is the only health region in Saskatchewan … that has policies to support mandatory referral."[794] Similarly, Newfoundland's *Human Tissue Act* appears to be unchanged since 2006, and it does not seem as though mandatory referral is being meaningfully considered in the province.[795]

Furthermore, as discussed above, first-person authorization (FPA) specifically seeks to "give the wishes of the registered donor priority over those of their relatives."[796] Section 8 of the UAGA, for example, prohibits any person other than the donor "from making, amending, or revoking an anatomical gift of a donor's body or part" when consent is given according to the terms of the UAGA.[797] FPA is akin to a living will or advance directive, making recorded donation decisions legally binding.[798] FPA legislation is shown to "increase the likelihood of familial authorization

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[789] *Ibid* at 160.
[790] *Ibid*.
[791] Norris, *supra* note 784 at 9.
[792] "Organ and Tissue Donation" (2 June 2016), online at 13 (pdf): *Human Services Committee* <https://docs.legassembly.sk.ca/legdocs/Legislative%20Committees/HUS/Tableddocs/HUS%201-28%20Ministry%20of%20Health%20-%20Presentation%20on%20organ%20and%20tissue%20donation%20160602.pdf>.
[793] Saskatchewan Inquiry, *supra* note 686 at vi.
[794] *Ibid* at 12.
[795] NL HTA, *supra* note 257.
[796] Albertsen, *supra* note 23 at 277.
[797] UAGA, *supra* note 115, s 8(a).
[798] Traino & Siminoff 2012, *supra* note 47 at 294.

and satisfaction with the final donation outcome."[799] However, FPA legislation alone cannot guarantee a reduction of the family veto, particularly if there is no penalty for families who override donation decisions.[800]

A final approach to improving Canadian consent systems and reducing the family veto is to ensure consistency across the provinces and territories. As demonstrated in Chapter 2, there is significant variation between provincial organ donor registration forms (in addition to the variation between opt-in and opt-out systems). Even if the provinces maintain different consent systems, consistency in donor registration and in public health messaging could reduce confusion about the role of the family and the importance of upholding registered donation decisions. Furthermore, increasing provincial consistency in ODT law and policy is a necessary precursor to better studying the family veto in Canada. There is a dearth of information available on provincial family veto rates, and it is difficult to ascertain (and address) the underlying causes of the family veto in Canada without having a concrete idea of how often the family veto arises and if it is more prevalent in certain jurisdictions. In this way, provincial discrepancies in law and policy hinder our ability to understand which legal approaches are effective in addressing the family veto. For example, organ donors in British Columbia may select which organs they wish to donate (or not), while organ donors in Québec are not given that opportunity. By posing organ donation as an all-or-nothing selection, this may dissuade potential donors who are uncomfortable with donating certain organs but not all.[801] Families may veto already given consent for donation for this same reason.[802] However, without being able to accurately compare existing ODT law and policy mechanisms, it may be difficult to determine the effectiveness of new mechanisms that aim to reduce the family veto.

20. Moving Forward

In many ways, the shift from opt-in to an opt-out consent systems across Canada seems inevitable. There is growing support across the country for presumed consent, and those jurisdictions with presumed consent already in place have seen stark increases in donation rates. Throughout the literature, presumed consent systems are heralded as one of the most effective means by which to increase organ donation consent rates. However, presumed consent does not *guarantee* increased donor rates. Per von Tigerstrom:

> "In order for organ donation numbers to rise, jurisdictions need to implement a list of measures, including having public education around organ donation, making sure there are transplant specialists in place and having appropriate facilities and systems to make organ donations happen quickly and efficiently when they have to."[803]

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[799] Albertsen, *supra* note 23 at 277.

[800] Traino & Siminoff 2012, *supra* note 47 at 296.

[801] For example, many potential donors are specifically uncomfortable with the concept of donating their eyes, but will consent to donation for their internal organs and tissues. See M. Lawlor et al, "Specific Unwillingness to Donate Eyes: The Impact of Disfigurement, Knowledge and Procurement on Corneal Donation" (2010) 10:3 Am J Transplantation 657.

[802] An Australian study, for example, found that 28.6% of families who consented to multi-organ donation specifically refused to donate the corneas of the deceased. While this study was not limited to families vetoing existing consent, it speaks to the nuanced relationship that families may have with donating certain parts of the body. See Lawlor et al, *supra* note 56.

[803] Hill, *supra* note 694.

It is unclear why many Canadian provinces seem to view legal reform and education campaigns as a one-or-the-other binary. As expressed by former Premier of Nova Scotia, Stephen McNeil, presumed consent "alone will not increase the number of organ transplants in our province. It will be the beginning step of allowing a very different conversation at the bedside for our health care providers, but we also know that in many parts of our province we need to continue to provide training and support teams in and around the issue of organ donation."[804]

For presumed consent to make a material impact on both donor registration *and* donation rates, significant investments must be made into public education, as well as support and training for HCPs. As discussed in Chapter 2, policy makers must also consider whether the provision of consent (or refusal) to organ donation is a one-time occurrence, or if citizens will be reminded of their registered (or presumed) intention and offered the ability to renew or change it. Similarly, policy makers must decide whether or not to implement mechanisms by which donors may share their decisions with their next-of-kin, particularly in those provinces that choose not to better protect donation decisions from the family veto.

There is a myriad of additional considerations to account for when shifting to a presumed consent system. Less populated jurisdictions – such as PEI and the Territories – rely on the OPOs of larger provinces to facilitate organ procurement and donation. In New Brunswick, for example, the province's Organ and Tissue Program (NBOTP) works closely with a Halifax-based team from Nova Scotia's Multi-Organ Transplant Program (MOTP).[805] As there is no New Brunswick-based organ procurement or transplant team, most transplants are performed in Ontario or Québec.[806] As such, the shift to a presumed consent system in New Brunswick has ramifications in Nova Scotia – "[w]hile Nova Scotia is supportive of New Brunswick's implementing a presumed consent model, the MOTP would need time to prepare for the increased referrals expected to result."[807] Presumably, if presumed consent was implemented in the Territories, Alberta would similarly need to prepare for increased referral rates. Conversely, if Alberta was to transition to a presumed consent system, it is unclear if Nunavut and the Northwest Territories would be required to follow suit, given Alberta's coordination of their ODT services.[808]

Similarly, any changes made to Canada's ODT system (whether based in law and/or policy) should include thorough consultation with the public *and* with medical experts, so as to ensure public and medicolegal success.[809] This consultation *must* include meaningful conversations with historically underrepresented and marginalized communities;[810] failure to do so risks further damaging

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[804] NS Hansard, *supra* note 644 at 2889.
[805] New Brunswick Report, *supra* note 657 at 2.
[806] *Ibid*.
[807] *Ibid*.
[808] Mel Woods, "Alberta's Getting Opt-Out Organ Donation. What About Your Province?", *HuffPost* (7 November 2019), online: <www.huffpost.com/archive/ca/entry/alberta-organ-donation-opt-out_ca_5dc48efbe4b02bf5793cf053>.
[809] Consider the backlash to ODT changes in France without sufficient consultation; see Kandelman, *supra* note 765 at 00:47:20.
[810] As expressed by Tait, when considering opt-out legislation, "a predictable and reasonable concern is that legislation could result in increased rates of organ **donation** among Indigenous populations, *but not* to equitable increases in the rates of Indigenous patients **receiving** organs. Missing from discussions about [opt-out legislation] is the inclusion of mechanisms that identify, track and address inequities resulting from the legislation being enacted" (bold emphasis added, italics in original) (*supra* note 702 at 6). Furthermore, insufficient consultation may lead to greater pushback

relationships between underrepresented communities and the ODT system.[811] Further, any changes should be accompanied by accessible, culturally competent education campaigns that specifically address the values, questions, and fears of different communities, in addition to cultural safety training for those involved in the ODT process.[812]

Furthermore, given that the family veto persists in both opt-in and opt-out systems, simply changing to a presumed consent system will not guarantee that family veto rates will fall. The goal of this Chapter was to demonstrate that shifting to an opt-out system without duly considering the family veto is a lost opportunity to meaningfully address family veto rates. Opt-out legislation, as well as refusal mechanisms, must be carefully created so as not to open additional doors for the family veto or create legal loopholes where the veto can be poorly disguised as "patient" refusal.

In this way, it is unclear why little thought is given to the role of the family veto within presumed consent systems. Family veto events are "one of the leading reasons for the gap between supply and demand of organs."[813] Yet across provincial discussions of presumed consent, "it remains unlikely that the implementation of this new regime will change the way doctors take the family's wishes into account."[814] The majority of ODT literature agrees that "every individual should have the right to decide for him or herself what should happen with his or her body after death."[815] In practice, however, Canadian law and policy makers skirt around the issue of the family veto, demonstrating their continued preference for soft consent systems, whether opt-in or opt-out.

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against the legislation by Indigenous groups, which may, in turn, lead to harm to both the Indigenous groups and/or public perceptions of ODT (*ibid* at 6).

[811] CDTRP, *supra* note 763 at 4: "Systemic racism within the healthcare system has led to high levels of mistrust, including the fear of being killed to obtain organs. Participants expressed the need to be able to trust healthcare providers to do everything possible to both save their life and respect the dignity of their bodies post-mortem."

[812] Within her five calls to action, Tait calls for both the investing in resources "to support FNIM [First Nations, Inuit, and Métis] healthcare leaders to develop culturally appropriate public education and consultation strategies aimed at informing FNIM about opt-in and opt-out ODT systems", as well as investing "in cultural safety training for administrators, clinicians, nurses, and patient and family support workers, including education about the intersections between health inequities and barriers preventing FNIM peoples from receiving and donating organs" (Tait, *supra* note 702 at 6-7).

[813] Lin et al, *supra* note 80 at 5-6.

[814] Champagne, Jospé & Shemie, supra note 760.

[815] Slabbert & Venter, *supra* note 148 at 465.

Conclusion

The family veto is harmful to donors, would-be transplant recipients and their families, and healthcare providers. It is also harmful to the surviving families of the donors, who may come to regret their decision to veto the final wishes of the deceased. This remorse, however, cannot turn back the clock does nothing to remedy the loss of a desperately needed donation. Family members appear to be acting beyond the boundaries of their SDM roles by pursuing the family veto, but are encouraged to do so by public health messaging and OPO policies that directly contradict the letter and spirit of Canadian ODT legislation. As a result, donation opportunities are squandered and HCPs are caught in the unenviable position of having to fight the living to uphold the final intentions of the dead.

Thus, there is considerable work to be done in improving the laws and policies buttressing Canada's ODT system. At the local level, OPOs and hospitals need to better support HCPs in addressing the family veto when it arises in clinical practice. Public health messaging should accurately reflect ODT legislation and take the firm stance that registered consent to donate may only be overturned by families with the provision of concrete evidence that doing so properly reflects the final intentions of the deceased.

Given the paucity of data available regarding family veto events in Canada, further study is needed into how frequently the family veto arises, and whether there are differences in frequency between the opt-in and opt-out provinces (particularly given the requirement of providing proof that the deceased changed their mind in Nova Scotia and New Brunswick).

Shifting to a presumed consent system could improve the numbers of registered donors in Canada; however, neither opt-in nor opt-out systems are capable of adequately protecting donor autonomy and consent when they are implemented in their "soft" form. While a hard consent system – wherein consent to donation can *never* be revoked – will likely be unpalatable to Canadian lawmakers (and the public), a hard-*er* system is needed to protect consent to donate from external overrules, save for a small number of explicitly defined circumstances (such as SDMs presenting recent and authoritative proof that the deceased changed their mind regarding donation).[816] Consent to donate organs deserves the same legal protection that is given to other forms of consent in Canada – by respecting a right to (consent to) donate organs, we would both uphold Canadian legal norms and contribute positively to the growing organ shortage. In law, this protection could be provided – for example – by clarifying the language of ODT legislation to firmly define "binding and full authority" to mean that SDMs are not permitted to overturn consent to donate without concrete evidence that the deceased had reversed their own decision to donate prior to their death. In this way, HCPs could proceed with procurement where medically appropriate and practically feasible with reduced conflict with the family. Furthermore, the immunity clauses in ODT legislation could be clarified to explicitly ensure HCPs do not face liability for proceeding organ procurement if they are acting in good faith in accordance with these changes. In policy and practice, this protection could include HCPs *informing* SDMs of donation decisions, rather than asking for their consent where it is not otherwise required. Uniform public health messaging on ODT and donor registration – that plainly explains the role of the family and of HCPs in light of

[816] However, as demonstrated in France, requiring "proof" of donation decisions by law accomplishes very little if they are not also required in practice: see CDTRP, *supra* note 763 and Kandelman, *supra* note 765.

these clarifications – would further reduce the confusion and frustration experienced by both families and HCPs.

In the final days of writing this thesis, a lawsuit emerged in the United States that is similar to the hypothetical fact pattern drawn in Chapter 3. The family of 30-year-old Jaszmine Phillips is attempting to prevent the Gift of Life OPO in Michigan from proceeding with the organ donation process following her death in February 2024. At the time of writing, a temporary protective order was in place to maintain life support and prevent organ procurement.[817] While Jaszmine's license identifies her as an organ donor, her family claims "she had expressed in conversations that she didn't want her organs donated and she planned to update her license when it expired in 2026."[818] When speaking to the media, the language used by Jaszmine's family demonstrates a clear mistrust in the medical system and strong feelings against ODT; while her mother says organ donation is "not what Jaszmine wanted", her unchanged donor registration says otherwise.[819] Due to privacy concerns, neither the hospital in question nor Gift of Life Michigan have yet commented on the situation. However, the OPO reinforced the state's legal stance under the UAGA: "legal next of kin cannot override a first-person authorization without evidence that the donor, even though registered, did not intend to donate or had revoked the registration."[820] If this case goes ahead, it will be one of the first ODT trials of this nature in North America. While Canada and the United States do not necessarily take the same approach on many health-related legal issues, the outcome of this lawsuit could be a troubling influence in Canada, where legal protections offered to donation decisions are already weaker than those under the United States' FPA under the UAGA. Should Canada fail to adequately protect the donation decisions of donors, not only is it likely that donation rates could stagnate – or even decrease – but it could open the door for similar limitations being placed on patient autonomy and consent in other areas of health law.[821]

As organ transplant waitlists continue to grow, attention must finally be paid to the persistence of the family veto in Canada. Hundreds of donation opportunities are lost each year when families overrule previously given consent to donate, even though doing so is argued to contradict ODT legislation in every Canadian jurisdiction. However, transitioning from an opt-in to an opt-out consent system will be insufficient in addressing the family veto if it does not come hand-in-hand

[817] Demetrios Sanders, "Family works to stop organ donation, saying it's against woman's wishes", WoodTV (19 February 2024), online: <www.woodtv.com/news/muskegon-county/family-works-to-stop-organ-donation-saying-its-against-womans-wishes/>.
[818] *Ibid*.
[819] *Ibid*. In particular, Jaszmine's mother describes the ODT process as cutting Jaszmine open, "[sticking her] in a freezer box", and ending up in "[a] room full of strangers tearing [her] apart to get pieces of [her] organs."
[820] *Ibid*.
[821] A second novel case that has arisen this year is an emerging case from Alberta, wherein a father successfully obtained a temporary injunction to prevent his adult daughter from receiving MAiD. While ODT is not contemplated within this context, this promises to be a fascinating case, given the implications of privacy and autonomy. In this case, the daughter, MV, argues that since she has met the medical criteria for MAiD (and was approved for the procedure by two doctors), she has the right to keep her medical records private. Her father, WV, believes his daughter does not have the capacity to consent to MAiD; however, MV's lawyer "stressed the case boils down to an adult's right to medical autonomy"; noting her father "is 'at risk of losing his daughter and while this is sad, it does not give him the right to keep her alive against her wishes … I completely understand [WV] does not want his daughter to die … but that doesn't play into account here'." See Meghan Grant, "Father asks court to stop 27-year-old daughter's MAID death, review doctors' sign-off", *CBC News* (11 March 2024), online: <www.cbc.ca/news/canada/calgary/calgary-maid-father-daughter-court-injunction-judicial-review-1.7140782>.

with specific provisions to strengthen and protect donor decisions – and, by extension, donor autonomy. Thus, the family veto must be adequately addressed in law and policy, so that the rights of donors to (consent to) donate their organs and give the “gift of life” will be upheld.

Appendices

Appendix 1: Search Terms by Database

Database	Search String
CINAHL	**1.** (MH “Organ Procurement+”) OR (MH “Organ Donation”) **2.** TI ((organ? or tissue*) N4 (donor* or donat* or gift* or procur*)) OR AB ((organ? Or tissue*) N4 (donor* or donat* or gift* or procur*)) **3.** S1 OR S2 **4.** (MH “Decision Making+”) **5.** TI ((family or families or kin or kinship or substitute* or surrogate* or relative?) N5 (decision* or decid* or overrid* or over-rid* or veto* or consent* or revok* or withdr* or deny* or denie*)) OR AB ((family or families or kin or kinship or substitute* or surrogate* or relative?) N5 (decision* or decid*or overrid* or over-rid* or veto* or consent* or revok* or withdr* or deny* or denie*)) **6.** S4 OR S5 **7.** (S4 OR S5) AND (S3 AND S6)
Embase	**1.** “Tissue and Organ Procurement”/ **2.** ((organ? or tissue*) adj4 (donor* or donat* or gift* or procur*)).ti,ab,kf. **3.** 1 or 2 **4.** family/ and Decision Making/ **5.** ((family or families or kin or kinship or relative?) adj5 (decision* or decid* or overrid* or over-rid* or veto* or consent* or revok* or withdr* or deny* or denie*)).ti,ab,kf. **6.** 4 or 5 **7.** Decision Making/ **8.** (decision* or decid* or overrid* or over-rid* or veto* or consent* or revok* or withdr* or deny* or denie*).ti,ab,kf. **9.** 7 or 8 **10.** 3 and 6 **11.** 9 and 10
Law Journal Library (HeinOnline)	((organ OR organs OR tissue OR tissues) w/4 (donate OR donation OR donates OR donated)) AND decision* OR decid* OR overrid* OR overrid* OR veto* OR consent* OR revok* OR withdr* OR deny* OR denie* OR "family veto" OR "family override") AND ("decision maker" OR "decision-maker" OR family OR families OR kin OR substitute* OR surrogate* OR relative?)
Index to Legal Periodicals	(family OR families OR kin OR kinship OR substitute* OR surrogate* OR relative?) NEAR/5 (decision* OR decid* OR overrid* OR overrid* OR veto* OR consent* OR revok* OR withdr* OR deny* OR denie*)
LexisNexis	((organ OR organs OR tissue OR tissues) w/4 (donate OR donation OR donates OR donated)) AND decision* OR decid* OR overrid* OR overrid* OR veto* OR consent* OR revok* OR withdr* OR deny* OR denie* OR "family veto" OR "family override") AND ("decision maker" OR "decision-maker" OR family OR families OR kin OR substitute* OR surrogate* OR relative?)
Medline	**1.** “Tissue and Organ Procurement”/ **2.** ((organ? or tissue*) adj4 (donor* or donat* or gift* or procur*)).ti,ab,kf. **3.** 1 or 2 **4.** family/ and Decision Making/

	5. ((family or families or kin or kinship or relative?) adj5 (decision* or decid* or overrid* or over-rid* or veto* or consent* or revok* or withdr* or deny* or denie*)).ti,ab,kf. **6.** 4 or 5 **7.** Decision Making/ **8.** (decision* or decid* or overrid* or over-rid* or veto* or consent* or revok* or withdr* or deny* or denie*).ti,ab,kf. **9.** 7 or 8 **10.** 3 and 6 **11.** 4 and 7 **12.** 3 and (4 or 5)

Appendix 2: Inclusion & Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
• Discussion of family consent to or refusal or organ donation where donor intention had previously been expressed • English language • Peer reviewed journal article, chapter, or book • News article or editorial *Search not limited by article type, but rather the prerequisite that the full text (rather than just the abstract) be available	• Not related to medicine, health, or health law (ex. immigration law) • Not related to ODT (ex. surrogate decision-making in other health contexts) • Barriers to donation by the individual, rather than by their family • Discussions of family refusal where donor intention was unknown (focusing instead on situations where intention was known and overruled) • Donation for the purpose of research • Living donation (where the donor is alive and able to consent) • Pediatric donation (where consent must be given by adult family members) • Language other than English • Pure legislation without commentary • Conference abstracts/posters

Appendix 3: Examples of Theme 1 Coding

Examples of text that outline the process of a family vetoing consent:	Examples of text that define the "family veto":
• "Current practice in the transplant community allows living relatives to 'trump' the previously stated desires of a brain-dead family member to donate"[822] • "[B]ecoming an organ donor is not simply a matter of registering one's intention to donate, and then eventually dying in a way that enables donation; it also requires that one's family does not overrule donation"[823] • "[A]llowing the family to have the final say may give them the right to override the wishes of the deceased"[824] • "There is ongoing debate in Australia and New Zealand, and internationally, about different models of consent, and whether an individual should be able to give binding consent or whether families can and should be able to override the wishes of an individual"[825]	• "Should the family of a registered organ donor hold veto power, allowing them to block the removal of organs for transplantation? While such a family veto is often considered a creation of the medical profession, its ethical permissibility has been questioned"[826] • "[S]ome families refuse to accept the decision to donate and seek to prevent donation going ahead. When this occurs, it is commonly referred to as the 'family overrule', 'family override' or 'family veto'"[827] • "When a family member of a person who has given legal consent to donate decides against donation, this is referred to as family veto. The veto represents a conflict between respect for the deceased person's previously expressed wishes and those of the family"[828]

Appendix 4: Examples of Theme 2 Coding

- "From 1 April 2012 to 31 March 2015, 11.7% of potential donors who had registered their donation wish on the ODR had this wish overruled by their partner, relative(s) or close friend(s)"[829]
- "According to the Trillium Gift of Life Network (TGLN), family veto occurred in 15–20% of registered approaches for organ donation in Ontario over the past three years"[830]
- "In the UK, this lead to approximately 500 families refusing to consent between 2010 and 2016, despite their loved one having registered their wish to be an organ donor"[831]
- "Among these articles, there was wide variance in the cited occurrence of family veto, ranging from 5% to 70%"[832]

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[822] Barbara A. Koenig, "Dead donors and the 'shortage' of human organs: are we missing the point?" (2003) 3:1 Am J Bioethics 26 at 27.
[823] Shaw et al, *supra* note 43 at 482.
[824] Walter Edinger, "Respect for Donor Choice and the Uniform Anatomical Gift Act" (1990) 11:3 J Med Humanities 135 at 137.
[825] Bhatia & Tibballs, *supra* note 153 at 956.
[826] Albertsen, *supra* note 23 at 272.
[827] Shaw et al 2020, *supra* note 54 at 179.
[828] Anthony et al 2021, *supra* note 14 at E768.
[829] Morgan et al, *supra* note 58 at 105.
[830] Anthony et al, *supra* note 4 at 612.
[831] Kyrtata, *supra* note 52 at 110.
[832] Anthony et al 2021, *supra* note 14 at E770.

Appendix 5: Examples of Theme 3 Coding

- "Difficulties can also emerge when there is discordance between the patient's and the family's wishes. Although explicit individual consent is 'binding', HCPs can take a contrary position by respecting the bereaved family's wishes, potentially creating a legal and/or ethical tension. The power of veto is not legally recognized in most countries, although in practice it is used everywhere"[833]
- "In practice, however, such laws are frequently not followed. Most hospitals regularly seek family consent before proceeding with organ transplantation, even when the deceased is on a donor registry. And in cases of conflict, most medical professionals in the U.S. (as well as in the U.K. and continental Europe) side with the family"[834]
- "Although many states adopted these amendments [to the UAGA], procurement organizations still generally defer to family when they disagree with a potential donor's previously expressed consent"[835]
- "Despite federal and state regulations supporting an individual's right to make a donation decision for themselves, OPOS – fearing legal or other negative repercussions from next of kin – have often resisted this right"[836]

Appendix 6: Examples of Theme 4 Coding[837]

Sub-Themes	Examples
Duty owed to the deceased patient	"Nevertheless, the clinical team members' duty, even after death, **is first and foremost to the patient**. It is not logical that our commitments to a patient should change when neurologic death is determined, but this likely occurs because of a motivation to care for families and/or out of fear of the repercussions of defying family wishes."[838]
Duty owed to the living (family of the deceased)	"Based on these common law rules [on] the issue of family overrides it might seem that physicians and hospitals have a **general duty to respect the wishes of the family**, as the expressed wish of the potential donor in regard to the disposition of his or her body is not legally enforceable."[839]
Duty owed to the living (potential organ recipient)	"Although we should treat the family compassionately, doctors do not have the same duty to the family as to **dying patients or other patients who need organs**."[840]
Duty owed to public health / to the greater public good	"[T]ension between duties owed to patients, to their families, and to **the broader public**."[841]
Poses question of duty without explicitly answering	"The question as to whose preferences are paramount could, however, beg the question of when the health professional's duty of care to a patient ends (ie whether it is when the patient dies or when they leave the practitioner's workload)."[842]

[833] Kentish-Barnes et al, *supra* note 112 at 334-35.
[834] Liberman, *supra* note 113 at 132.
[835] Parent, *supra* note 65.
[836] Dodd-McCue et al, *supra* note 135 at 150.
[837] Sub-themes throughout this review are organized by the frequency with which they appear in the literature, with the highest prevalence at the top.
[838] Ball, Oczkowski & Sibbald, *supra* note 10 at 601 (emphasis added).
[839] Downie, Shea & Rajotte, *supra* note 101 at 1257 (emphasis added).
[840] Shaw, *supra* note 53 at 33 (emphasis added).
[841] Ball, Sibbald & Oczkowski, *supra* note 9 at 286 (emphasis added).
[842] Morris & Holt, *supra* note 140 at 1129.

Appendix 7: Examples of Theme 5 Coding

Sub-Themes	Examples
Family grief / distress / impact on family	"Excluding family members from participation in the decision to take organs from the body might well amplify their sense of loss … Health care professionals have described the difficulty of sharing a family's grief and have indicated their reluctance to add another burden to the family's stressful situation."[843]
Fear of increasing mistrust in the ODT system	"Perhaps stories of how family objections are overruled could lead to general mistrust and lower donation rates."[844]
Fear of lawsuits against healthcare providers	"Despite the protection of the UAGA, hospitals and transplant programs fear legal reprisal (even though families haven't prevailed in such lawsuits since the UAGA was enacted about 25 years ago)."[845]
Deceased changed their mind	"BC Transplant and Transplant Quebec explain their positions on following families' wishes on the basis that families may know if their loved one had changed his or her mind."[846]
Lack of personhood after death	"A more radical view is that the dead cannot consent at all: since a person cannot do anything once they have died, they cannot provide consent for organ donation."[847]
Family's cultural and/or religious concerns	"The reasons for family override are 'complex and numerous' [and] include different religious beliefs and younger minorities not adhering to their parents' cultural rules."[848]
Healthcare provider emotional distress	"One must remain mindful, however, of the difficulties of doing so in terms of causing distress to relatives and medical staff."[849]
Bodies as "property" belonging to the family after death	"As noted by the common law, the organs should be recognised as the property of the next of kin."[850]
Concerns about registration and/or consent	"Proponents of the family as decision-maker could, and sometimes informally do, argue that the signing of a donor card or some other consent-to-donate paper document does not constitute informed consent/ choice."[851]
Need for cooperation with families	"Another argument points out that family cooperation is needed in many cases to aid in the donation process … If a family's option to veto ultimately makes them more cooperative in the donation process, then transplants are more likely to be successful."[852]

[843] May, Aulisio & DeVita, *supra* note 95 at 235-36.
[844] Albertsen, *supra* note 23 at 277.
[845] Salladay, *supra* note 144 at 28.
[846] Toews & Caulfield, *supra* note 16 at E437.
[847] Kyrtata, *supra* note 52 at 112.
[848] Lee & Tham, *supra* note 49 at 2.
[849] Sharif & Moorlock, *supra* note 34 at 160.
[850] Bhatia & Tibballs, *supra* note 153 at 966.
[851] Kirby, *supra* note 144 at 124.
[852] Johnston, *supra* note 22 at 488.

Hospital policy/culture to allow family veto	"Other reasons highlighted included 1) "custom" and "culture" of the hospital ("It's custom — not the law, not ethics and not public opinion — to ask the family …"[853]
Lack of clarity in / understanding of the law	"Organ procurement personnel in the United States appear to be unaware that the standard practice of asking the surviving families of all classes of potential donors (declared and undeclared) for permission to remove organs and tissues from these individuals is inconsistent with the provisions of most state UAGAs."[854]
Lack of clarity / contradictions in public health messaging	"Several public statements reflect confusion about the law or, at a minimum, may create confusion for others in regard to the law."[855]

Appendix 8: Examples of Theme 6 Coding

Sub-Themes	Examples from included text
Autonomy	"This statutory position is also ethically sound, as it is supported by the principle of autonomy, the recognition that the donor has interests which survive past death and should be respected, and the substantial benefit of prolonged or improved quality of life experienced by transplant recipients."[856]
Harm to would-be recipient	"Each overridden donation means that several organs are lost from the pool of organs; this in turn means that potential recipients must wait longer for organs, and this wait will often result in avoidable deaths. Even if patients do not die, the wait can be detrimental to their overall health and well-being."[857]
Harm / distress for donor family	"Families often regret the veto within two days, and the regret of having denied a loved one's last wish can last for decades."[858]
Negative public reactions to / opinions of family veto	"Opinion polls show that better than 90 percent of Canadians don't want family views to outweigh their own."[859]
Loss of donation potential	"If the decedent's decision to donate can be refused by the family, then fewer organs will be available for transplantation and fewer lives will be saved."[860]
Infringes on legal norms	"[T]he current practice in most United States hospitals of asking permission of next of kin to remove organs from a brain-dead individual when that individual has properly signed a donation document is contrary to both the spirit and the letter of the Model Act and all state versions of it that retain in unqualified form the specific provisions of the Model Act discussed below."[861]

[853] Anthony et al 2021, *supra* note 14 at E770.
[854] Peters, *supra* note 136 at 267-268.
[855] Downie, Shea & Rajotte, *supra* note 101 at 1259.
[856] *Ibid* at 1260.
[857] Shaw et al, *supra* note 43 at 485.
[858] Shaw, *supra* note 53 at 33.
[859] Anthony et al 2021, *supra* note 14 at E770.
[860] Johnston, *supra* note 22 at 490.
[861] Peters, *supra* note 136 at 247.

Lack of actual lawsuits against HCPs	"While some worry that such practices might lead to lawsuits, these fears seem not to have materialized. Based on the last 10 years, a 2014 study of LifeSource, an OPO that covers Minnesota, South Dakota, and parts of Wisconsin, concluded that 'Fears of legal action and adverse media coverage are unfounded'."[862]
Ante-mortem distress of (harm to) donor	"Opponents of the family veto claim that the family's interference in the donor's decision to donate her organs similarly violates her autonomy, because it violates her right to live her life in accordance with a particular life-plan that includes donating her organs for transplantation purposes."[863]
(Moral) distress of HCPs	"Participants in the Anthony et al. study described moral distress in cases where family vetoes superseded the patient's wishes. This is not surprising vis-a-vis our fiduciary responsibility to the patient."[864]
Posthumous harm	"If one accepts the position articulated by Wilkinson that it is 'a widely shared and basic intuition that my body is mine and I should decide what happens to it', … one must still have an account of how one can be harmed or wronged by things that happen after one's death … Feinberg has argued that autonomy during life can generate interests after death, and that we can be harmed—even after death —by the frustration of these interests."[865]
Moral obligation to donate organs & moral value in donation	"Additionally, the distress experienced by those who desperately need an organ must be considered. From the moral point of view—described by Sidgwick as the ''point of view ... of the universe'' —all harm is relevant … Avoiding some familial distress by letting others die is not justifiable."[866]
Families claiming the donor's mind changed to support family's own agenda	"However, one important criticism of relational autonomy is that it cannot always be guaranteed that the family authentically represents the patient's attitudes."[867]

[862] Albertsen, *supra* note 23 at 277.
[863] Zambrano, *supra* note 83 at 191-92.
[864] Ball, Oczkowski & Sibbald, *supra* note 10 at 603.
[865] Sharif & Moorlock, *supra* note 34 at 156.
[866] Isdale & Savulescu, *supra* note 45 at 97.
[867] Kyrtata, *supra* note 52 at 111.

Appendix 9: Examples of Theme 7 Coding

Sub-Themes	Examples from included text
Banning FV in all circumstances	"Some people have called for the partial or complete abandonment of the 'family veto', which permits relatives to over-rule the recorded wishes of the deceased patient."[868]
Allowing FV only in narrow circumstances	"We suggest that the solution is to continue to permit overrules in very particular circumstances, while working toward modifying the circumstances that may lead to an overrule being considered in the first place."[869]
Improving communication with families	"We suggest that better communication on the part of physicians and more widespread efforts are needed to improve next of kin's understanding of their responsibilities in these difficult situations."[870]
Education	"Legal education and public awareness programs will be crucial to the success of efforts to inform all relevant stakeholders that the current practice of respecting family opposition over valid donor consent is not legally acceptable."[871]
Legal solutions	"In the opt-out systems, law reforms should prevent next of kin to dishonoring the donor's wishes, restricting the confirm[ed] donor status only with the National Donor Registry."[872]
Policy solutions	"We believe, therefore, that the CORE policy of honoring a patient's documented wish to donate, independent of family consent, should become the standard of practice for organ-procurement organizations throughout the country."[873]
HCP-based solutions	"There is evidence that involvement of SNODs [Specialist Nurses for Organ Donation] in the family approach is a powerful predictor of family consent and this study demonstrates that their presence also reduces the likelihood of family overrides in both DBD and DCD donation."[874]

[868] Sharif & Moorlock, *supra* note 34 at 156.
[869] Shaw et al, *supra* note 43 at 486.
[870] Ball, Sibbald & Oczkowski, *supra* note 9 at 287.
[871] Downie, Shea & Rajotte, *supra* note 101 at 1261.
[872] Zúñiga-Fajuri & Molina-Cayuqueo, *supra* note 42 at 284.
[873] May, Aulisio & DeVita, *supra* note 95 at 330.
[874] Morgan et al, *supra* note 58 at 105.

Appendix 10: Examples of Theme 8 Coding

- "From 2015, Wales became the only region in the UK where families are not asked for consent, as the deceased have demonstrated explicit influence in the decision to donate under the 'opt out' scheme."[875]
- "As mentioned in the introduction, Argentina, Colombia, France, and Uruguay recently changed their opt-out policies to prevent the family's intervention in the decision over organ donation."[876]
- "Opt-in systems such as those in the United States, England, and New Zealand, are more reliably characterized as "impure" opt-in systems, because in such systems, even if a patient has registered as an organ donor, doctors in practice often acquiesce to the wishes of the family regarding donation."[877]

Appendix 11: Examples of Theme 9 Coding

Sub-Themes	Examples from included text
Legislation	"The US federal law states that "a person other than the donor is barred from making, amending, or revoking an anatomical gift of a donor's body or part if the donor made an anatomical gift of the donor's body or part."[878]
Comparison to wills / advance directives	"A person's will or testament is legally binding and respected after their death. It involves decisions about an individual's property; so why should a decision about their own body be regarded any differently? … A will cannot be altered, and the family certainly cannot veto the decisions made in the will."[879]
Policy	"[T]he current practice in most United States hospitals of asking permission of next of kin to remove organs from a brain-dead individual when that individual has properly signed a donation document is contrary to both the spirit and the letter of the Model Act and all state versions of it that retain in unqualified form the specific provisions of the Model Act discussed below … Under present policy, then, the interlinked rights of declared donors and donees are ignored completely"[880]
First-Person Consent / Authorization	"First Person Authorization (i.e., donor designation) legislation makes indicating one's intent to be a posthumous organ donor legally binding, much like a living will or advance directive. Such legislation is the most recent in a long history of organ donation policies in the United States and has received little attention in the literature."[881]
Positive and negative legal rights	"[T]his system works if one conceives of organ donation as a negative right … In other words, people have a right to refuse that their organs be donated, but consent to organ donation does not entitle an individual to a guarantee of donation[882] Under the UAGA, the family has no legal right to control the disposition of organs from a dead relative who is a declared donor."[883]

[875] Cay, *supra* note 36 at 362.
[876] Molina-Pérez et al, *supra* note 148 at 8.
[877] Zambrano, *supra* note 83 at 181.
[878] Shaw et al, *supra* note 43 at 486.
[879] Kyrtata, *supra* note 52 at 112.
[880] Peters, *supra* note 136 at 249.
[881] Traino & Siminoff 2012, *supra* note 47 at 294.
[882] Johnston, *supra* note 22 at 491.
[883] Peters, *supra* note 136 at 258.

Property / Gift Law	“Under the common law, as the dead body is not property, the expressed wish of an individual in regard to the disposition of his or her body after death is not legally enforceable or binding on his or her executor or next-of-kin, even if expressed in a will.”[884]

[884] Downie, Shea & Rajotte, *supra* note 101 at 1257.

Appendices: Chapter 2

Appendix 12: Key Definitions within ODT Legislation[885]

	"Consent"	"Organ"	"Tissue"	"Transplant"
British Columbia[886]	"[A] consent given under this Act"		"[I]ncludes an organ, but does not include skin, bone, blood, blood constituent or other tissue"	"[T]he removal of tissue from a human body, whether living or dead, and its implantation in a living human body"
Alberta[887]	"[A] consent given for a donation that meets the requirements of section 9"	"[A] human organ whether whole or in sections, lobes or parts"	"[H]uman tissue excluding organs"	"[T]he operation of transferring tissue or an organ from a human donor to a human recipient"
Saskatchewan[888]	"[A] consent given pursuant to this Act"	"[A] perfusable human organ for use in a transplant, whether whole or in parts, and whose specific function is intended to return after revascularization and reperfusion, and includes any adjunct vessels that are retrieved with the organ for use in the organ transplant;"	"[I]ncludes an organ, but does not include: **(i)** any skin, bone, tendon, blood, blood constituent, or other tissue that is replaceable by natural processes of repair; and **(ii)** spermatozoa, ova, embryos and foetuses"	"**(i)** The removal of tissue from a human body, whether living or dead; or **(ii)** The removal of a part of a human body that is dead; and its implantation to a living human body"
Manitoba[889]			"[A]n organ, a part of a human body and a substance extracted from the human body or from a part of the human body, but does not include **(a)** spermatozoa or ova, or **(b)** an embryo or a fetus or a part of an embryo or a fetus, or **(c)** blood or blood constituent, or **(d)** a placenta"	"[T]he removal of tissue from a human body, whether living or dead, and its implantation in another human body"
Ontario[890]	"[A] consent given under this Act"		"[A] part of a living or dead human body and includes an organ but, unless otherwise prescribed by the Lieutenant Governor in Council, does not include bone marrow, spermatozoa, an ovum,	"[T]he removal of tissue from a human body, whether living or dead, and its implantation in a living human body, and in its other forms it has corresponding meanings"

[885] Limited to common law jurisdictions (as Quebec's *Civil Code* does not offer definitions in the same manner as within common law legislation).
[886] BC HTGA, *supra* note 257, s 1.
[887] AB HTODA, *supra* note 257, s 1.
[888] SK HTGA, *supra* note 257, s 2.
[889] MB HTGA, *supra* note 257, s 1.
[890] TGLNA, *supra* note 12, s 1.

			an embryo, a foetus, blood or blood constituents”	
New Brunswick (2016)[891]			“[I]ncludes an organ, but does not include any skin, bone, blood, blood constituent or other tissue that is replaceable by natural process of repair”	“[T]he removal of tissue from a human body and its implantation in a living human body”
New Brunswick (2023)[892]		“[A]n organ, whether whole or in sections, lobes or parts”	“[A] functional group of human cells, excluding organs”	“[T]he operation of transferring organs or tissues from a donor, whether living or dead, to a living human recipient”
Nova Scotia[893]		“[A]n organ, whether whole or in sections, lobes or parts”	“[A] functional group of human cells, excluding organs”	“[T]he operation of transferring organs or tissues from a donor, whether living or dead, to a living human recipient”
Prince Edward Island[894]			“[A]ny part of a living or dead human body, but does not include **(i)** spermatozoa or ova, **(ii)** an embryo or fetus, or **(iii)** blood or blood constituents”	“[T]he removal of tissue from a human body, whether living or dead, and the implantation of the tissue in a living human body”
Newfoundland & Labrador[895]	“[A] consent given under this Act”		“[I]ncludes an organ, but does not include skin, bone, blood constituent or other tissue that is replaceable by natural processes of repair”	“[T]he removal of tissue from a human body, whether living or dead, and its implantation in a living human body, and in its other forms it has corresponding meanings”
Yukon[896]	“[A] consent given under this Act”		“[A]n organ, but does not include any skin, bone, blood, blood constituent or other tissue that is replaceable by natural processes of repair”	“[T]he removal of tissue from a human body, whether living or dead, and its implantation in a living human body”
NWT[897]			“[A] part of a living or dead human body, including organs, but does not include **(a)** spermatozoa or ova, **(b)** an embryo or fetus, or **(c)** blood or blood constituents”	“[T]he transferral of tissue from a human body, whether living or dead, to another live human body”
Nunavut[898]	No definitions provided			

[891] *Human Tissue Gift Act*, RSNB 2014, c 113, s 1 (outgoing) [NB HTGA].
[892] NB HOTDA, *supra* note 297, s 1 (not yet in force).
[893] HOTDA, *supra* note 30, s 2.
[894] PEI HTDA, *supra* note 262, s 1.
[895] NL HTA, *supra* note 257, s 2.
[896] YK HTGA, *supra* note 257, s 1.
[897] NWT HTDA, *supra* note 262*,* s 1.
[898] NU HTA, *supra* note 287.

Appendix 13: Comparing the Substantive & Procedural Consent Requirements in ODT Legislation

<table>
<tr><th rowspan="2">Jurisdiction[899]</th><th colspan="2">Substantive Consent Requirements</th><th colspan="2">Procedural Requirements</th><th rowspan="2">Statutory Exceptions (to binding nature of valid donor consent)</th></tr>
<tr><th>Age of Donor</th><th>Capacity, Voluntariness, Information</th><th>General</th><th>Consent System</th></tr>
<tr><td>British Columbia</td><td>19</td><td>Consent can be given in writing at any time (s 4(1)(a)) or orally with 2 witnesses at the end of their life (s 4(1)(b))

Capacity, information, etc only discussed in section 3 (living donor)

No explicit requirements for “mentally competent to consent” or “able to make a free and informed decision” in section 4 (but is in section 3)</td><td>Section 4(3): “On the death of a person who has given a consent under this section, the consent is binding and is full authority for the use of the body or the removal and use of the specified parts for the purpose specified.”

Section 5 lays out next-of-kin hierarchy and SDM consent when intention is not known</td><td>Opt-in</td><td>Section 4(4): “[A] person must not act on a consent given under this section if the person has reason to believe that it was subsequently withdrawn, unless the consent was contained in a valid will of the deceased.”</td></tr>
<tr><td>Alberta</td><td>“Adult” (18)</td><td>Section 4(1): An adult with capacity</td><td>Section 8(1): “Subject to section 10, a consent given in accordance with this Act is binding and authorizes
(a) any medical practitioner to make any examination necessary to assure medical acceptability of the donation, and
(b) the use of the body or the removal and use of the specified tissue or organ for the specified purpose.”</td><td>Opt-in</td><td>Section 8(3): “... [A] person must not act on a consent to donate if

(a) the person has personal knowledge that the person to whom the donation relates revoked their consent to donate or otherwise objected to the donation proceeding, or

(b) in the case of a consent to donate made in accordance with section 4(3), the person has personal knowledge that a person in the same priority class or a higher priority class, as described in section 4(4), other than the person who consented to donate, would object to that consent.”

**Amendment from 2023</td></tr>
<tr><td>Saskatchewan</td><td>“Age of majority” (18)</td><td>Section 7(1): “Any adult who has the capacity to consent and who is able to make a free and informed decision may consent, in any of the following manners, to his or her body or the part of his or her body specified in the consent being used after his or her death for the purposes of</td><td>Section 7(2): “... [A] consent given by a person who had not attained the age of majority is valid for the purposes of this Act if the person who acted on the consent had no reason to believe that the person who gave it had not attained the age of majority.”</td><td>Opt-in</td><td>Section 7(4): “No person shall act on a consent given pursuant to this section if he or she has reason to believe that the consent was subsequently withdrawn.”</td></tr>
</table>

[899] The organization of this chart is drawn from Downie, Shea & Rajotte, *supra* note 101.

		transplant, medical education or scientific research: **(a)** in writing signed and dated by him or her at any time; **(b)** orally in the presence of at least two witnesses during his or her last illness; **(c)** in a manner prescribed in the regulations"			
Manitoba	18	"Able to make a free and informed decision" is mentioned for living donation (section 9(1)(b)) but not deceased donation However, effect of direction impacted if not properly understood (section 2(3)(b)) **Section 12:** consent can be given **(a)** in writing; or **(b)** by means of any type of recorded message; or **(c)** orally in the presence of at least two witnesses; or **(d)** by telephone to at least two witnesses	**Section 2(3):** "Upon the death of a person who has given a direction under subsection (1) or (2), the direction is full authority for obtaining possession of the body, and the use of the body or the removal and use of any tissue or specified tissue from the body, as the case may be, for the purposes specified in the direction."	Opt-in	**Section 2(3):** "... [B]ut a person shall not act upon the direction where the person proposing to act has reason to believe **(a)** that the person who gave the direction subsequently withdrew it; or **(b)** that the person who gave the direction was not capable of understanding the nature and effect thereof; or **(c)** that an inquiry or investigation under *The Fatality Inquiries Act* may be required to be held respecting the cause and manner of death, unless a medical examiner or the chief medical examiner appointed under that Act has no objection to the use of the body or the removal and use of the tissue."
Ontario	16	**Section 4(1):** "Any person who has attained the age of sixteen years may consent, **(a)** in a writing signed by the person at any time; or **(b)** orally in the presence of a least two witnesses during the person's last illness, that the person's body or the part or parts thereof specified in the consent be used after the person's death for therapeutic purposes, medical education or scientific research."	**Section 4(3):** "Upon the death of a person who has given a consent under this section, the consent is binding and is full authority for the use of the body or the removal and use of the specified part or parts for the purpose specified …"	Opt-in	**Section 4(3):** "... [E]xcept that no person shall act upon a consent given under this section if the person has reason to believe that it was subsequently withdrawn."
Quebec	14	Nothing in *Civil Code* re: capacity **Section 43:** "These wishes are expressed verbally before two witnesses, or in	**Section 43:** "... The wishes expressed shall be followed, unless there is a compelling reason not to do so."	Opt-in	

		writing, and may be revoked in the same manner." 2010 Act: "Freely given consent"	**2010 Act:** "Consent will be acted upon"		
New Brunswick[900]	19	Language only used in the context of living donation or pre-transplant interventions	**Section 8(1):** "Subject to section 14, a consent under section 7 is full authority for transplantation activities to the extent of the consent."	Opt-out (as of 2023 legislation)	**Section 29:** "No person shall give false information under this Act." **Section 30:** "No person shall act on a consent given or deemed to be given under this Act if the person has knowledge (a) that the donor subsequently withdrew the consent, or (b) of an objection by the donor." **Section 31:** "No person shall give a consent or refusal under this Act if the person has personal knowledge that the individual for whom the consent or refusal is given would have made a different decision."
Nova Scotia	"Age of majority" (19)	**Section 5:** "Only individuals with the capacity to do so may consent or refuse consent"	**Section 9(1):** "Subject to Section 15, a consent under Section 8 is full authority for transplantation activities to the extent of the consent"	Opt-out	**Section 15:** if SDM can prove change of mind **Section 31:** withdrawn consent **Section 32:** different decision

[900] NB HOTDA, *supra* note 297.

Prince Edward Island	16	**Section 3(1):** "... understands the nature and consequences of transplanting tissue from his or her body after death" Nothing about modes of registration / recording consent	**Section 10(1.1):** "A consent given under section 3 or clause 5(1)(a) that complies with this Act is binding and is authority for a medical practitioner or a person directed by a medical practitioner … (b) to remove the tissue referred to in the consent from the body of the donor in accordance with the consent"	Opt-in	**Section 3(2):** "... [P]erson who did not understand the nature and consequences of transplanting tissue…" **Section 10(2):** "Notwithstanding subsection (1), (1.1) or (1.2), no person shall act on a consent if the person has reason be believe that **(a)** in the case of a consent under section 3, 6, 7 or 12, the person who gave the consent subsequently withdrew or would have objected to the consent"
Newfoundland & Labrador	19	"Free and informed decision" language only used for living donors (section 4) **Section 6(1):** Consent may be made (a) in a writing signed by him or her at any time (b) orally in the presence of at least 2 witnesses during his or her last illness	**Section 6(3):** "Upon the death of a person who has given a consent under this section, the consent is binding and is full authority for the use of the body or the removal and use of the specified part for the purpose specified…"	Opt-in	**Section 6(3):** "... [E]xcept that a person shall not act upon a consent given under this section if that person has reason to believe that it was later withdrawn."
Yukon	"Age of majority" (19)	Capacity, information, etc only discussed in section 3 (living donor) **Section 4:** consent can be given: **(a)** in a writing signed by them at any time **(b)** orally in the presence of at least 2 witnesses during the person's last illness	**Section 4(3):** "... [T]he consent is binding and is full authority for the use of the body or the removal and use of the specified part or parts for the purpose specified…"	Opt-in	**Section 4(3):** "... [E]xcept that no person shall act on a consent given under this section if they have reason to believe that it was subsequently withdrawn."
NWT	16	**Section 4(1):** "… [U]nderstands the nature and consequences of transplanting tissue" **Section 11(1):** Consent must be made **(a)** in writing, signed and dated by the person giving the consent, and signed by a witness; or **(b)** orally in the presence of two witnesses	**Section 12(1):** "... [A] consent that complies with this Act is binding and authorizes …"	Opt-in	**Section 12(2):** "A medical practitioner shall not act on a consent if the medical practitioner has reason to believe that **(a)** … the person who gave the consent subsequently withdrew it or would have withdrawn it; or

					(b) … the person on whose behalf the consent was given would have objected to the consent.”
Nunavut	19	Silent re: capacity, information **Section 1(1):** Consent can be made: **(a)** in writing at any time, or **(b)** orally in the presence of at least two witnesses during his or her last illness	**Section 1(1):** “... [D]irection is binding and is full authority …”	Opt-in	**Section 1(2):** “[E]xcept that a person **(a)** shall not act on the direction if that person has reason to believe that the person who gave the direction subsequently withdrew it; and …”

Appendix 14: Comparing the Nature of Consent in ODT Legislation

In order to ascertain the degree to which provincial ODT legislation has changed (if at all) in the last few years, below is a 2023 update of Toews and Caulfield's 2016 chart.[901]

Jurisdiction & Legislation	Is individual consent for organ and tissue donation binding?	Does individual consent for consent provide authority to proceed with procurement?	Is it prohibited to act on an individual's consent if there is reason to believe it was later withdrawn?	Is family consent limited to situations where a potential donor has not already provided valid consent?	If the organs cannot be used, is the body to be treated as if no consent had been given?
British Columbia[902]	**2016:** Yes (s.4)	**2016:** Yes (s.4)	**2016:** Yes, unless contained in a valid will (s.4)	**2016:** Yes (s.5)	**2016:** Yes (s.8)
	2023: Yes [section 4(3)]: "binding and is full authority"	**2023:** Yes [section 4(3)]: "binding and is full authority"	**2023:** Yes [section 4(4)]: "unless the consent was contained in a valid will"	**2023:** Yes [section 5(1)]	**2023:** Yes [section 8]
Alberta[903]	**2016:** Yes (s.8)	**2016:** Yes (s.8)	**2016:** Yes (s.8)	**2016:** Yes (ss. 4,7)	**2016:** Yes (s.8)
	2023: Yes [section 8(1)]: "binding and authorizes…"	**2023:** Yes [section 8(1)]: "binding and authorizes…"	**2023:** Yes [section 8(3)]: *see amending statute*	**2023:** Yes [section 4(3) and 4(5)]: *see amending statute*	**2023:** Yes [section 8(4)]
Saskatchewan (2016)[904]	**2016:** Yes (s.5)	**2016:** Yes (s.5)	**2016:** Yes (s.5)	**2016:** Yes (s.6)	**2016:** Yes (s.9)
Saskatchewan (2023)[905]	**2023:** Yes [section 7(3)]: "binding and is full authority"	**2023:** Yes [section 7(3)]: "binding and is full authority"	**2023:** Yes [section 7(4)]	**2023:** Yes [section 9(1)]	**2023:** Yes [section 14]
Manitoba[906]	**2016:** Not specified	**2016:** Yes (s.2)	**2016:** Yes (s.2)	**2016:** Yes (s.3)	**2016:** Yes (s.5)
	2023: "Binding" is absent from text	**2023:** Yes [section 2(3)]: "the direction is full authority"	**2023:** Yes [section 2(3)(a)] Also if direction wasn't properly understood	**2023:** Yes [section 3(1)(a)] Also if direction made cannot be acted upon [section 3(1)(b)]	**2023:** Yes [section 5(1)]
Ontario[907]	**2016:** Yes (s.4)	**2016:** Yes (s.4)	**2016:** Yes (s.4)	**2016:** Yes (s.5)	**2016:** Yes (s.8)
	2023: Yes [section 4(3)]: "binding and is full authority"	**2023:** Yes [section 4(3)]: "binding and is full authority"	**2023:** Yes [section 4(3)]	**2023:** Yes [section 5(2)]: "has not or cannot"	**2023:** Yes [section 8]
Quebec[908]	**2016:** The Civil Code of Quebec simply provides "The wishes expressed shall be followed, unless there is a compelling reason not to do so" (s. 43)			**2016:** Yes (s.44)	**2016:** Not specified
	2023: Same as above Also, 2010 Act:			**2023:** Yes [section 44]	**2023:** Not specified

[901] *The original source – which supplements Toews & Caulfield, *supra* note 16 – can be found online (pdf): *CMAJ* <www.cmaj.ca/content/cmaj/suppl/2016/11/14/cmaj.160752.DC1/160752-com-1-at.pdf>.

[902] BC HTGA, *supra* note 257.

[903] AB HTODA, *supra* note 257.

[904] *Human Tissue Gift Act,* RSS 1978, c H-15.

[905] SK HTGA, *supra* note 257.

[906] MB HTGA, *supra* note 257.

[907] TGLNA, *supra* note 12.

[908] *Civil Code*, *supra* note 254.

	“(2.0.9): “... that consent will be acted upon for the purposes of a transplant” (open to interpretation)				
New Brunswick (2016)[909]	**2016:** Yes (s.4)	**2016:** Yes (s.4)	**2016:** Yes (s.4)	**2016:** Yes (s.5)	**2016:** Yes (s.9)
New Brunswick (2023)[910]	**2023:** “Binding” is absent from text	**2023:** Yes [section 8(1)]: “full authority”	**2023:** Yes [section 30]	**2023:** N/A	**2023:** Yes [section 31.1]
Prince Edward Island[911]	**2016:** Yes (s.10)	**2016:** Yes (s.10)	**2016:** Yes (s.10)	**2016:** Yes (s.5)	**2016:** Yes (s.10) – limited to tissue already removed
	2023: Yes [section 10(1.1)]: “binding and is authority”	**2023:** Yes [section 10(1.1)]: “binding and is authority”	**2023:** Yes [section 10(2)] Section 3(2): Did not understand the nature and consequences of transplanting tissue	**2023:** Yes [section 5(1)]: Had not given consent, under age of 16, or did not understand nature and consequences	**2023:** Yes [section 10(4)]
Nova Scotia (2016)[912]	**2016:** Yes (s.5)	**2016:** Yes (s.5)	**2016:** Yes (s.5)	**2016:** Yes (s.6)	**2016:** Yes (s.9)
Nova Scotia (2023)[913]	**2023:** “Binding” is absent from text	**2023:** Yes [section 9(1)]: “full authority”* *Subject to s.15	**2023:** Yes [section 31]	**2023:** No* [section 15] *Only if SDM has proof that mind has been changed or would not have agreed with deemed consent	**2023:** Not specified Section 21(2): Deemed consent doesn’t apply to scientific research or educational purposes
Newfoundland & Labrador[914]	**2016:** Yes (s.6)	**2016:** Yes (s.6)	**2016:** Yes (s.6)	**2016:** Yes (s.7)	**2016:** Yes (s.10)
	2023: Yes [section 6(3)]: “binding and is full authority”	**2023:** Yes [section 6(3)]: “binding and is full authority”	**2023:** Yes [section 6(3)]	**2023:** Yes [section 7(1)]	**2023:** Yes [section 10]
Yukon[915]	**2016:** Yes (s.4)	**2016:** Yes (s.4)	**2016:** Yes (s.4)	**2016:** Yes (s.5)	**2016:** Yes (s.8)
	2023: Yes [section 4(3)]: “binding and is full authority”	**2023:** Yes [section 4(3)]: “binding and is full authority”	**2023:** Yes [section 4(3)]	**2023:** Yes [section 5(1)]	**2023:** Yes [section 8]
NWT[916]	**2016:** Yes (s.12)	**2016:** Yes (s.12)	**2016:** Yes (s.12)	**2016:** (Arguably) Yes (s. 12)	**2016:** Yes (s.13)
	2023: Yes [section 12(1)]: “binding and authorizes”	**2023:** Yes [section 12(1)]: “binding and authorizes”	**2023:** Yes [section 12(2)]: “withdrawn or would have been withdrawn”	**2023:** Kind of? [section 5(1)]: ““On the death of a person who does not meet the requirements for giving consent set [above]”	**2023:** Yes [section 13]: limited to tissue already removed
Nunavut[917]	**2016:** Yes (s.1)	**2016:** Yes (s.1)	**2016:** Yes (s.1)	**2016:** Yes (s.2)	**2016:** Not specified

909 NB HTGA, *supra* note 917.
910 NB HOTDA, *supra* note 297.
911 PEI HTDA, *supra* note 262.
912 *Human Tissue Gift Act*, RSNS 1989, c 215.
913 HOTDA, *supra* note 30.
914 NL HTA, *supra* note 257.
915 YK HTGA, *supra* note 257.
916 NWT HTDA, *supra* note 262.
917 NU HTA, *supra* note 287.

	2023: Yes [section 1(2)]: “binding and is full authority”	**2023:** Yes [section 1(2)]: “binding and is full authority”	**2023:** Yes [section 1(2)]	**2023:** Yes [section 2(2)]	**2023:** Not specified

Appendix 15: Potential Sources of Liability in Provincial ODT Legislation

Jurisdiction	Mistaken Belief in Age (or Capacity) of Consenter	Good Faith Immunity Clauses	Offence(s)
British Columbia[918]	**Section 4(2):** "Despite subsection (1), consent given by a person who had not reached age 19 is valid for this Act if the person who acted on it had no reason to believe that the person who gave it had not reached age 19."	**Section 9:** "No action or other proceeding for damages lies against a person for an act done in good faith and without negligence in the exercise or intended exercise of any authority conferred by this Act."	**Section 14:** "A person who knowingly contravenes this Act commits an offence and is liable, on conviction, to a fine of not more than $1,000, or to imprisonment for a term of not more than 6 months, or to both a fine and imprisonment."
Alberta[919]		**Section 11:** "No action lies against any person in respect of anything done or omitted to be done in good faith pursuant to this Act."	**Section 13: (1)** "Subject to subsections (2) and (3), a person who knowingly contravenes this Act is guilty of an offence and liable to a fine of not more than $10,000. **(2)** A person who contravenes section 12(1) is guilty of an offence and liable to a fine of not more than $50,000. **(3)** A person who contravenes section 3(2) is guilty of an offence and liable to a fine of not more than $100,000 or to imprisonment for a term of not more than 6 months or to both."
Saskatchewan[920]	**Section 7(2):** "Notwithstanding subsection (1), a consent given by a person who had not attained the age of majority is valid for the purposes of this Act if the person who acted on the consent had no reason to believe that the person who gave it had not attained the age of majority."	**Section 15: (1)** "No action or other proceeding lies or shall be commenced against any person acting pursuant to the authority of this Act or the regulations for anything in good faith done, caused, permitted or authorized to be done, attempted to be done or omitted to be done pursuant to or in the exercise or supposed exercise of any power conferred by this Act or the regulations or in the carrying out or supposed carrying out of any responsibility imposed by this Act or the regulations." **(2)** "Subject to subsection (1), no person has any rights or remedies and no action or other proceeding lies or shall be commenced against any other person with respect to any act or omission of that other person done or omitted in compliance with and not in contravention of this Act or the regulations or any direction, decision, order, ruling or other	**Section 18: (1)** Every person who contravenes any provision of this Act is guilty of an offence and on summary conviction is liable to a fine of not more than $100,000 or to imprisonment for a term of not more than six months, or to both. **(2)** If a corporation commits an offence pursuant to this Act, any officer or director of the corporation who directed, authorized, assented to, acquiesced in or participated in the commission of the offence is guilty of the offence and liable on summary conviction to the penalties mentioned in this section whether or not the corporation has been prosecuted or convicted."

[918] BC HTGA, *supra* note 257.
[919] AB HTODA, *supra* note 257.
[920] SK HTGA, *supra* note 257.

		requirement made or given pursuant to this Act or the regulations."	
Manitoba[921]	**Section 2(4):** "A direction given **(a)** under subsection (1) by a person who is under 18 years of age; or **(b)** under subsection (2) by a person who is under 16 years of age; that has been acted upon is deemed to be valid for the purposes of this section if the person who acted upon it had no reason to believe that the person who gave the direction was in fact under 18 years of age or under 16 years of age, as the case may be, at the time of giving the direction."	**Section 14:** "No person shall be held liable for damages for anything done or omitted to be done, in good faith and without negligence, in the exercise or intended exercise of any power or authority conferred under this Act."	**Section 15(3):** Pertains only to the sale or dealing in body parts (rather than general offences)
Ontario[922]	**Section 3(2):** "Despite subsection (1), a consent given thereunder by a person who had not attained the age of sixteen years, was not mentally competent to consent, or was not able to make a free and informed decision is valid for the purposes of this Act if the person who acted upon it had no reason to believe that the person who gave it had not attained the age of sixteen years, was not mentally competent to consent, and was not able to make a free and informed decision, as the case may be."	**Section 9(1):** "No action or other proceeding for damages or otherwise shall be instituted against any of the following individuals for any act done or performed in good faith in the performance or intended performance of any duty or function or in the exercise or intended exercise of any power or authority under this Act or for any neglect, default or omission in the performance or execution in good faith of any duty, function, power or authority under this Act: **1.** A member of the medical or other staff of a designated facility. **2.** Any other person employed in a designated facility."	**Section 12:** "Every person who knowingly contravenes any provision of this Act is guilty of an offence and on conviction is liable to a fine of not more than $1,000 or to imprisonment for a term of not more than six months, or to both."
New Brunswick (2016)[923]	**Section 4(2):** "Despite subsection (1), a consent given under this section by a person who had not attained the age of 19 years is still valid if the person who acted on it had no reason to believe that the person who gave it had not attained the age of 19 years."	Section 11: "No action for damages or other proceeding lies against any person for any act done in good faith and without negligence in the exercise or intended exercise of any authority conferred by this Act."	**Section 10:** Pertains only to the sale or dealing in body parts (rather than general offences)
New Brunswick (2023)[924]		**Section 28:** "No action or other proceeding for damages lies against any person in respect of anything done or omitted to be done in good faith and without negligence in the exercise or intended exercise of any authority under this Act."	**32(3):** "Subject to subsections (1) and (2), a person who knowingly violates or fails to comply with a provision of this Act commits an offence punishable under Part 2 of

[921] MB HTGA, *supra* note 257.
[922] TGLNA, *supra* note 12.
[923] NB HTGA, *supra* note 917.
[924] NB HOTDA, *supra* note 297.

			the *Provincial Offences Procedure Act* as a category E offence."[925] Also provides specific offences for proceeding with donation procurement after deceased had refused consent (section 32(1)) and for selling or dealing in body parts (section 32(2)).[926]
Prince Edward Island[927]	**Section 3(2):** "Notwithstanding subsection (1), a consent given by a person who did not understand the nature and consequences of transplanting tissue from his or her body after death is valid for the purposes of this section if the person who acts on it has no reason to believe that the person who gave it did not understand the nature and consequences of transplanting tissue from his or her body after death."	**Section 14:** "No person is liable for anything done or omitted to be done in good faith and without negligence in the exercise or intended exercise of any authority under this Act."	**Section 15(3):** "A person who contravenes this section [selling or dealing in body parts] is guilty of an offence and liable on summary conviction to a fine of not more than $10,000 or to imprisonment for not more than one year, or to both." **Section 16: General Offence** "A person who contravenes a provision of this Act, except section 15, is guilty of an offence and liable on summary conviction to a fine of not more than $1,000 or to imprisonment for not more than three months, or to both."
Nova Scotia[928]		**Section 29:** "No action or other proceeding for damages lies against any person in respect of anything done or omitted to be done in good faith and without negligence in the exercise or intended exercise of any authority under this Act."	**Section 33:** "Every person who knowingly contravenes this Act is guilty of an offence and on summary conviction is liable to a fine of not more than $10,000 or to imprisonment for a term of not more than six months, or to both a fine and imprisonment."
Newfoundland & Labrador[929]	**Section 6(2):** "Notwithstanding subsection (1), a consent given by a person who had not reached the age of 19 years is valid for the purpose of this Act if the person who acted upon it had no reason to believe that the person who gave it had not reached the age of 19 years."	**Section 17:** "An action or other proceeding for damages does not lie against a person for an act done in good faith and without negligence in the exercise or intended exercise of an authority conferred by this Act."	**Section 20:** "A person who knowingly contravenes this Act is guilty of an offence and liable on summary conviction to a fine not exceeding $1,000 or to imprisonment for a term not exceeding 6 months, or to both a fine and imprisonment."

[925] Section 56(5): "Where an Act makes an offence punishable as a category E offence, a judge shall impose a fine of not less than $240 and not more than $5,200." See *Provincial Offences Procedure Act*, SNB 1987, c P-22.1.
[926] As a Category H offence proceeding with procurement following the deceased's refusal warrants a penalty of a fine of not less than $500 and not more than $20,500. As a Category J offence, the selling of or dealing in body parts brings penalty of a fine of not less than $500 and not more than $200,000. See *ibid*, sections 56(8) and 56(10) respectively.
[927] PEI HTDA, *supra* note 262,
[928] HOTDA, *supra* note 30.
[929] NL HTA, *supra* note 257.

Yukon[930]	**Section 4(2):** "Despite subsection (1), a consent given by a person who had not reached the age of majority is valid for the purposes of this Act if the person who acted on it had no reason to believe that the person who gave it had not reached the age of majority."	**Section 9:** "No action or other proceeding for damages lies against any person for any act done in good faith and without negligence in the exercise or intended exercise of any authority conferred by this Act."	**Section 12:** "Every person who knowingly contravenes any provision of this Act commits an offence and on summary conviction is liable to a fine of not more than $1,000 or to imprisonment for a term of not more than six months, or to both."
NWT[931]	**Section 4(2):** "Notwithstanding subsection (1), a consent given by a donor who did not understand the nature and consequences of transplanting tissue from his or her body after death is valid for the purposes of this section if the person who acts on that consent has no reason to believe that the donor lacked the requisite understanding."	**Section 16:** "No action or proceeding may be brought against a person for anything done or omitted to be done in good faith and without negligence by the person in the exercise of a power or performance of a duty under this Act or the regulations."	**Section 19: (1)** "Every person who contravenes this Act, except section 18, is guilty of an offence and liable on summary conviction to a fine of not more the $10,000 or to imprisonment for not more than six months, or to both." **(2)** "Every person who contravenes section 18 [commercial activity is guilty of an offence and liable on summary conviction to a fine of not more than $100,000 or to imprisonment for not more than one year, or to both."
Nunavut[932]	*Not contemplated within the body of the legislation*		

[930] YK HTGA, *supra* note 257.
[931] NWT HTDA, *supra* note 262.
[932] NU HTA, *supra* note 287.

Appendix 16: Comparing OPO Policies & Public Health Messaging on Family Consent for ODT

In order to ascertain the degree to which policy information on family consent has changed (if at all) in the last few years, below is a 2023 update of Toews and Caulfield's 2016 chart.[933]

Source of Policy Information (2016)	Policy on Family Consent (2016)	Source of Policy Information (2023)	Policy on Family Consent (2023)[934]
BC Transplant	"…we ask the family if they are aware of any change in their loved one's decision, and will honor their wishes."	**BC Transplant**[935]	**"Q.** Can a family override a person's decision? **A.** Donation happens at a time of tragedy. *We ask the family if they are aware of any change in their loved one's decision, and will honour their wishes*. In our experience, when a family sees a copy of the signed registration form it provides relief and comfort and helps them support their loved one's wish to be an organ donor. We also encourage each person to talk to their family about their wishes for organ donation, so that they know what their loved one would want."
Government of Alberta	"…the signed, dated and witnessed donation consent form you submit to the Registry is legal consent under Alberta legislation; however, your next of kin will be asked by the donation team to sign a consent form agreeing that your wishes will be followed."	**Government of Alberta**[936]	**"Is registering online providing my legal consent to be a donor?** As of 2020, you are providing your *legal consent to donate* once you have registered your donation wishes online on the Alberta Organ and Tissue Donation Registry. **If I have given consent, will my family still be asked about donation?** "Yes. A family member will be asked to sign a consent form saying they have been informed about, and agree with, the donation process, even if the person that died has signed the back of his or her healthcare card or registered online."
Saskatoon Health Region	"Families who talk about their decision to donate are more likely to honour the wishes of their loved ones should organ and tissue donation be possible after death."	**Saskatchewan Health Authority**[937,938]	"*In Saskatchewan, organs and tissue will not be donated without your family or next-of-kin's consent.* Ensuring that your loved ones know you support organ and tissue donation will help them make this important decision on your behalf after you have died." "Even if you have an orange donor sticker on your health card, the most important thing you can do is talk to your family and let them know your wishes. *Organ and tissue donation is only possible with the consent of your next of kin*."

[933] *The original source – which supplements Toews & Caulfield, *supra* note 16 – can be found online (pdf): *CMAJ* <www.cmaj.ca/content/cmaj/suppl/2016/11/14/cmaj.160752.DC1/160752-com-2-at.pdf>.
[934] **NB:** Any emphasis (italics) has been added.
[935] BC FAQs, *supra* note 300.
[936] "Frequently Asked Questions", online: *MyHealthAlberta* <https://myhealth.alberta.ca/alberta/Pages/organ-and-tissue-donation-faqs.aspx>.
[937] "Talk to Your Family", online: *Saskatchewan Health Authority* <www.saskhealthauthority.ca/your-health/conditions-diseases-services/all-z/tissue-organ-donation/talk-your-family>.
[938] "Quick Facts", online: *Saskatchewan Health Authority* <www.saskhealthauthority.ca/your-health/conditions-diseases-services/all-z/tissue-organ-donation/quick-facts>.

Transplant Manitoba	"If you become a candidate for organ donation, Transplant Manitoba – Gift of Life will ask your next of kin to give their consent to donation on your behalf. Once in hospital, there is usually no chance to discuss donation with the potential donor, which leaves the decision to the family. It is much easier for the family to make the decision if they know the wishes of their loved one before hand."	**Transplant Manitoba**[939]	"**Q:** Can my family overrule my wishes to be a donor? **A:** It is the common practice of Manitoba's human tissue gift agencies to reaffirm an individual's consent to donate with the family. In almost all cases, families honour and respect their loved ones' donation decision if they have evidence that it's what they wanted. Therefore, it's important to register your consent to donate so that your family can be advised of your decision and feel confident about giving consent to donation on your behalf. *Donation will not take place without your family's consent*."
Trillium Gift of Life Network (Ontario)	"If you are a potential organ and tissue donor, your family will be approached by Trillium Gift of Life Network (and health care professionals) to discuss the option of donating your organs and tissue...Therefore, it is important that you share your donation decision with your loved ones, so that they can fulfill your donation decision in the event of your death."	**Trillium Gift of Life Network (Ontario)**[940]	**"Q.** Can my family overrule my decision to donate? **A.** When you register your consent to donate, this information is recorded and stored in a Ministry of Health database. Your decision will only be accessed should there be potential for donation, and your status as a registered donor will be shared with your family. *It is Ontario Health (Trillium Gift of Life Network) practice to reaffirm an individual's consent to donate with the family. In most cases, families honour their loved ones' decision to donate if they have evidence that it's what they wanted*."
Transplant Quebec	"Pursuant to the Civil Code of Quebec, the family must honour the deceased's decision…In practice, doctors take families' wishes into account because the family may be aware of recent changes to their loved one's wishes."	**Government of Quebec**[941,942]	"The Civil Code of Québec states, for instance, that the donation process cannot start before the death of the donor is attested by two doctors who do not participate either in the removal or in the transplantation. In addition, it *obliges the family to follow the deceased person's wishes*. It also prohibits the sale or purchase of human organs or tissues." "Upon your death, your next of kin will be asked if you consented to donating an organ or tissue. This person and the others with whom you have discussed your decision will be able to speak on your behalf and ensure that your wishes are honored."
		Transplant Quebec[943]	"Pursuant to the Civil Code of Quebec, *the family must honour the deceased's decision*. In cases where the deceased had notified loved ones of his or her wishes, it is rare to find instances when they do not honour those wishes. It is usually when the wishes of the deceased are not known that the family will refuse out of fear of having to make a difficult decision on their loved one's behalf. In practice, *doctors take families' wishes into account because the family may be aware of recent changes to their loved one's wishes*. The next of kin may also be able to provide invaluable information on the medical and social background of the deceased. This background is part of the information used to assess a potential donor's eligibility."

[939] "Frequently Asked Questions", online: *Sign Up For Life* <https://signupforlife.ca/faq.html>.
[940] "Frequently Asked Questions: Donation", online: *Trillium Gift of Life Network* <www.giftoflife.on.ca/en/faq.htm#donation>.
[941] "Organ and Tissue Donation: Legal Framework", online: *Québec* <www.quebec.ca/en/health/blood-tissue-and-organ-donation/organ-and-tissue-donation/legal-framework>.
[942] "Sign for Life", online (pdf): *Québec* <https://publications.msss.gouv.qc.ca/msss/fichiers/2019/19-903-03A.pdf>.
[943] "FAQs", online: *Transplant Québec* <www.transplantquebec.ca/en/faqs>.

Legacy of Life Nova Scotia	"Even if you have registered as a donor, health professionals still need to ask your family for consent before recovering organs or tissue. Donation can take place only if your family consents at the time of death."	**Government of Nova Scotia**[944,945]	"Before any transplant activities take place, health professionals check the registry to see if you registered a decision. *Health professionals also meet with your family to review your recorded decision and to see if the family has additional information about your decision*." "*Family's role is not to overrule a person's decision about donation* but they may provide information about the person's wishes if they are different than a recorded decision or deemed consent."
Health PEI	"**Q:** What happens when I die and I have indicated that I want to be an organ donor? **A:** Your family will be offered the option to donate organs."	**Health PEI**[946,947]	"**Q:** What happens when I die and I have indicated that I want to be an organ donor? **A:** Your family will be offered the option to donate organs. If your family supports the option to donate, an organ donor coordinator will talk to them about the donation process, get consent, and ask questions about your social history and medical history." "Occasionally, family members will disagree with the patient's decision to be a donor. *In this case, it is unlikely that the donation will take place*. The organ and tissue donation community does not want to cause undue suffering to families that are already grieving by removing organs and tissues against their wishes. *Without the family's cooperation, the medical social questionnaire cannot be completed and the tissue cannot be retrieved*."
Eastern Health (Newfoundland)	"Although you have indicated your 'Intent to Donate' your organs and or tissues, the final decision rests with your next of kin."	**Eastern Health (Newfoundland)**[948]	"Even though you may indicate your desire to donate, *your next of kin has the final decision*. Timing is critical when it comes to organ and tissue donation. Have the Talk."
Government of New Brunswick	"…the person entitled to consent will be approached by a health professional when death has occurred or is imminent for donation. He or she will be discouraged from overriding your wishes, if known."	**Government of New Brunswick**[949]	**"Can my next of kin withhold permission even if I have registered to be a donor?** Under the Human Tissue Gift Act, the person *entitled to consent* will be approached by a health professional when death has occurred or is imminent for donation. He or she will be *discouraged from overriding your wishe*s, if known."
Yukon Health and Social Services	"Even if you have signed a donor card or are registered as a donor, doctors will still ask your family before retrieving organs or tissue."	**Government of Yukon**[950]	**"Can my family overrule my wishes?** Your family will be asked if they know your wishes about organ donation and for their agreement. *While your wishes can be overruled, most families want to carry out the wishes of their loved ones*. That's why it's so important to discuss organ donation with your family and let them know your wishes."

[944] "Organ and tissue donation", online: *Nova Scotia* <https://beta.novascotia.ca/organ-and-tissue-donation>.
[945] Nova Scotia Consent Guide, *supra* note 596.
[946] "Organ and tissue donation", online: *Health PEI* <http://www.healthpei.ca/organandtissuedonation>.
[947] "Tissue Donation: Resource Manual", online (pdf): *Health PEI* <https://src.healthpei.ca/sites/src.healthpei.ca/files/srcForms/src_tissdon_man.pdf>.
[948] "Organ Donation", online: *Eastern Health* <www.easternhealth.ca/find-health-care/organ-donation/>.
[949] "Organ and Tissue Donation", online (pdf): *New Brunswick* <www2.gnb.ca/content/dam/gnb/Departments/h-s/pdf/en/OrganDonation/organ-and-tissue-donation.pdf>.
[950] "Common Questions", online: *Yukon* <https://yukon.ca/en/health-and-wellness/health-concerns-diseases-and-conditions/donate-your-organs#common-questions>.

Government of NWT	"Until the NWT organ donor registry is fully set up you cannot formally register in the NWT to be an organ or tissue donor. However, you can still tell your family that you wish to be a donor and encourage them to respect your wishes and give permission for organ and tissue donation."	**NWT Health and Social Services**[951]	**"If I have completed my Organ and Tissue Donation Consent Form, will my family still be asked about donation?** Yes. If you are unable to provide your consent immediately before your death due to your illness or injury, a family member will be asked to sign a consent form saying they have been informed about, and agree with, the donation process. The decision to donate is a personal one. Completing the Organ and Tissue Donation Consent Form and adding your name to the Organ and Tissue Donation Registry is an important way to communicate your wishes to your family. *The family helps make decisions about donating and will most often agree to carry out their loved one's wishes if they are aware of them*."
No policy information on family consent was found for Nunavut		Nunavut ODT is still managed through Alberta; see Alberta row above	

[951] "Organ and Tissue Donation Registration Process", online: *Health and Social Services NWT* <www.hss.gov.nt.ca/en/services/organ-and-tissue-donation/organ-and-tissue-donation-registration-process>.

Appendix 17: Comparing Provincial Organ Donation Registration Forms

Jurisdiction	Personal Information Collected	Question(s) Asked	Potential Organs for Donation	The Fine Print	Commentary
British Columbia[952]	Health card number Name Date of birth Address Phone number Email Signature and date	Online form: **I consent to help save lives by becoming an organ and tissue donor after my death** • Yes / No Mail-in form: **I wish to be an organ donor** • Yes / No **I consent to help save lives by donating after my death:** • ALL organs and tissues needed for transplant • Only the checked organs and tissues for transplant (see list in next column) **My donated organs & tissues may also be used for research** • Yes/No	Bowel Eyes Heart Kidneys Liver Lungs Pancreas Tissue	"Once signed by you, this form constitutes a legally valid decision record regarding '*consent by person for use of body after death'* in accordance with s.4 of *the Human Tissue Gift Act* (British Columbia)." "For someone under the age of 19, this record reflects an expressed wish about organ donation and is not a legally binding decision record, per the *Human Tissue Gift Act*."	Form provides space to write an "optional message that will be presented to your family, or loved one(s) at the time of donation." (The online form allows up to 2000 characters for this purpose).
Alberta[953]	Healthcare number Name Date of birth Gender Postal code (first 3 digits) Phone number Signature and date	Mail-in form I choose to donate **all my organs and tissues** for (check all that apply): • Transplantation • Scientific Research • Medical Education **OR**	Bone Bowel ("small bowel") Connective Tissue Eyes Heart Heart Valves Kidneys Liver Lungs Pancreas Stomach Skin	"Alberta Health's receipt of your completed form will provide evidence of your consent to be a donor."	

[952] BC's mail-in form can be found online (pdf): *BC Transplant* <www.transplant.bc.ca/Documents/ODR-Paper-Registration-Form-web.pdf> (see also Appendix 18). BC's online form can be found online: *BC Transplant* <https://register.transplant.bc.ca/> (see also Appendix 19).
[953] Alberta's mail-in form can be found online (pdf): *Canmore Registry* <www.canmoreregistry.com/wp-content/uploads/2020/04/AOTDR-Brochure-revised.pdf> (also see Appendix 20). Alberta does appear to have an online version of their form as well, but it is inaccessible without an Albertan healthcare number.

		I choose to donate **only these organs and/or tissues** (check all that apply) (see list in next column): • Checkbox To be used in (check all that apply): • Transplantation • Scientific Research • Medical Education	Vascular Tissue		
Saskatchewan[954]	Health card number Name Date of birth Phone number Email Signature and date	<u>Online form</u> Please indicate your choices from the following options: • All organs and tissues needed for transplant • Only selected organs and tissues (see list in next column) Living Donation: "A living donor is someone who gives a gift in the form of an organ or part of an organ to another person in need. If you have provided your email address, you can choose to receive more information about living donation. Would you like to receive more information? • Yes / No	Bowel ("small bowels") Eyes Heart Kidneys Liver Lungs Pancreas Vessels	"The Organ and Tissue Donor Registry is an online registry for Saskatchewan residents to register their intentions to donate their organs and/or tissues for transplantation after they die." "Everyone 16 years or older can register their intent to become an organ and/or tissue donor regardless of age, ethnicity, medical condition or sexual orientation." "This form constitutes a legally valid consent under the Saskatchewan *Human Tissue Gift Act*. It is valid until it is revoked."	"If you would like to receive a confirmation email regarding your donation choices, please provide a valid email address." Form offers option to share donation decision and registration with family members (can share with multiple emails): "We encourage you to talk with your family or next of kin about your donation choices. Family are more likely to agree to donation if they are aware of their family member's wishes. If you would like to share your choice to register with your family, please include their email addresses in the field below. Separate multiple addresses with a comma." Form includes a long consent declaration, and donors must certify that they have read and understand the consent
Manitoba[955]	Health card number Name Date of birth	**Question #1:** • I wish to be placed on the Intent to Donate Registry [OR]	<u>Organs</u> Bowel ("small bowel") Heart Kidneys		Option of sharing a message with family and/or friends via social media (Facebook, Twitter, email)

[954] "Saskatchewan Organ and Tissue Donor Registry: Register Your Intent to Donate", online: <organdonor.saskatchewan.ca> (also see Appendix 21).
[955] "Registration", online: *Sign Up for Life* <www.signupforlife.ca/intent/registration> (also see Appendix 22).

	No signature collected (online form)	• I will speak to my family about my organ donation wishes
		
		Question #2:
		• I intend to donate all of my organs for transplantation (Yes / No)
		• My organs can also be used for the following:
		  o Scientific research
		  o Medical education, or
		  o None of the above
		
		Question #3:
		• I intend to donate all of my tissues for transplantation (Yes / No)
		• My tiessues can also be used for the following:
		  o Scientific research
		  o Medical education, or
		  o None of the above
		
		Question #4: Please check at least one of the following:
		• I wish to send a message to Friends/Family on my Facebook page that I have registered my intent to be an organ/tissue donor.
		• I wish to send a message to Friends/Family on my Twitter account that I have registered my intent to be an organ/tissue donor.
		• I wish to send an email message to Friends/Family that I have registered my intent to be an organ/tissue donor.
		• I will speak personally to my Friends/Family and let them know that I have registered to be an organ/tissue donor
			Liver
			Lungs
			Pancreas
			
			Tissues
			Lower extremity bones and soft tissues
			Upper extremity bones and soft tissues
			Ribs and costal cartilages
			Whole eyes
			Skin
			Whole heart (for valves)
			Vessels
			
			*Sorts options between organ and tissue
					informing them of their registered intent to donate

Ontario[956]	Health card number Name Date of birth Phone number	Mail-in form I consent to help save lives by becoming an organ and tissue donor for: • Transplant only, or	Bone Eyes Heart Kidneys	"You must be at least 16 years of age to register as an organ and tissue donor."	"The Trillium Gift of Life Network will collect this information from the Ministry … for the purpose of facilitating

[956] "Organ and Tissue Donor Registration" online: *Ontario* <https://forms.mgcs.gov.on.ca/en/dataset/014-3750-84> (also see Appendix 23).

	Address Signature and date	• Transplant / organ and tissue research I wish to donate: • Any needed orangs and tissues, or • Any needed organs and tissue **except** for those indicated below (see list in next column) By signing below, I am consenting to be an organ and tissue donor after my death.	Liver Lung Pancreas Skin		organ and tissue transplants and research as well as sharing this information with your family so that they can honour your wishes at end of life."
Quebec[957]	Form requires only signature and date While forms are sent by mail with health card renewals, online access to the form requires name, date of birth, SIN, and tax return registry number	Mail-in form: I hereby authorize organ and tissue removal for transplant or graft, when I die.	Not specified	"Persons under age 14 can also give their consent. However, their signature **and** that of the holder of parental authority or guardian are necessary."	
New Brunswick[958]	General information collected on Medicare Updates and Changes form: Medicare # Name Date of birth Gender Language of choice ODT-specific information collected: Name and response (no signature)	Mail-in form (one section in a larger Medicare Updates and Changes form): Do you want to be an organ donor? • Yes / No	Not specified		

[957] "Make my consent to organ and tissue donation official", online: *Québec* <www.ramq.gouv.qc.ca/en/citizens/health-insurance/make-consent-organ-tissue-donation-official> (also see Appendix 24).
[958] "New Brunswick Medicare Updates and Changes Form", online (pdf): *New Brunswick* <www2.gnb.ca/content/dam/gnb/Departments/h-s/pdf/en/Medicare/Medicare-updates-and-changes-form.pdf> (also see Appendix 26).

Nova Scotia[959]	Health card number Name Date of birth No signature required	Mail-in form (or fax-in) Yes, I want to be a donor and donate all organs and tissues (donor 1) Yes, I want to be a donor and ONLY donate the following organs and tissues (donor 2) (see list in next column) No, I don't want to be a donor (opt out)	Organs Bowel ("small bowel") Heart Kidneys Liver Lungs Pancreas Tissues Bone & related structures Eyes Heart valves / pericardium Skin Vein *Sorts options between organ and tissue	"If you are 19 or older and eligible, you will be seen as agreeing to be an organ and tissue donor after your death, unless you register a decision to opt out of a donation. This will be confirmed with your family at the time of your death." "Talk with your family, friends and those closest to you to make sure they know your donation decision."	
Prince Edward Island[960]	Personal health number Name Date of birth Address Signature and date	**I wish to donate:** Organs needed for transplant (see list in next column) • Yes / No Tissues needed for transplant (see list in next column) • Yes / No	Organs Bowel ("small bowel") Heart Kidneys Liver Lungs Pancreas Tissues Bone & related structures Eyes Heart valves / pericardium Skin Vein *Sorts options between organ and tissue	"Your signature is required for organ and/or tissue donation. You must be 16 years or older to sign. Parents cannot sign on behalf of children."	

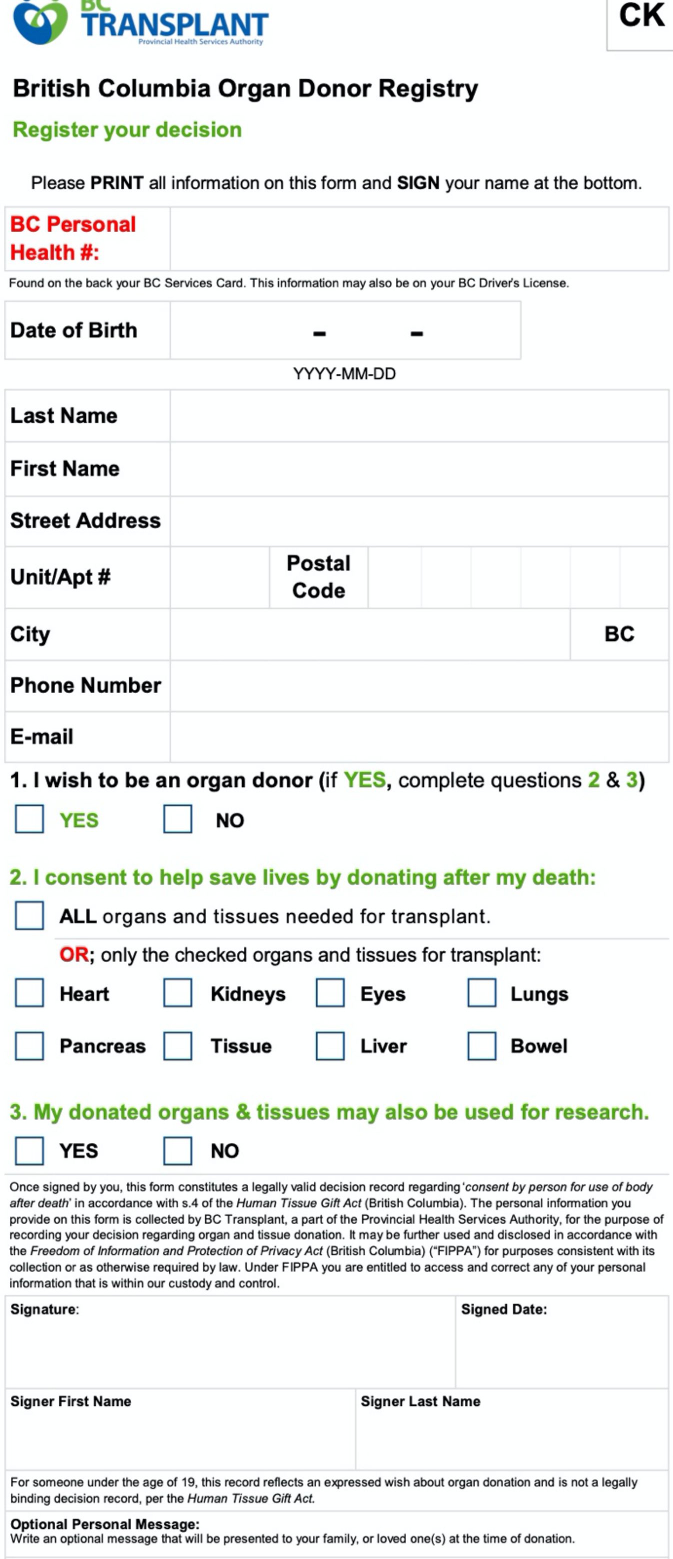
[959] "Your organ and tissue donation decision", online (pdf): *Nova Scotia* <https://novascotia.ca/dhw/msi/docs/MSI-Organ-Tissue-Donation-Form.pdf> (also see Appendix 25).
[960] "Intent to Donate and Language Information", online (pdf): *PEI* <www.princeedwardisland.ca/sites/default/files/forms/intent_to_donate_and_language_information_form.pdf> (see also Appendix 27).

Newfoundland & Labrador[961]	Name Surname at birth Date of birth Gender Address Previous province health insurance no. (if applicable) Signature and date	Mail-in form (one section in a larger application for Health Care Coverage): **Intent for organ / tissue donation** “If anyone named on this form wishes to become an organ/tissue donor, please sign in one of the spaces below. Your intent to donate is supported by the *Human Tissue Act*.” • Electronic or written signature and printed name	Not specified	Can register multiple people (within one family) at a time Form also includes a declaration (signature and date)	
Yukon[962]	Health care insurance card number Name Date of birth Gender Address Signature and date	Online form: Any organ or tissue needed for transplant or transplant research, or • Checkbox Any organs and tissues needed for transplant only, or • Checkbox Any organs/tissues needed for transplant EXCEPT the following (see list in next column) • Checkbox I hereby consent for the purposes of the *Human Tissue Gift Act,* to the above donation after my death (provides space for a signature)	Bone Bowel Cornea Heart Kidneys Liver Lungs Pancreas Skin	“To register for organ donation, you will need to fill out this form. Once you’ve made the decision to become a donor, make it count. Tell a trusted family member about your decision.” “A registry exists to legally record the wishes of organ donors in the Yukon.”	
NWT[963]	Health care number Name Date of birth Phone number Signature and date	Mail-in form: I choose to donate **all my organs and tissues** for transplantation • Checkbox **OR**	Bone Bowel (“small bowel”) Connective tissue Eyes Heart Heart valves	“A friend or co-worker can be your witness. A family member CANNOT be your witness. This includes your spouse, common law partner, parent, child, guardian, or sibling.”	

[961] “Application for Newfoundland and Labrador Health Care Coverage”, online (pdf): Health and Community Services <www.gov.nl.ca/hcs/files/Application-for-Newfoundland-and-Labrador-Health-Care-Coverage.pdf> (see also Appendix 28).
[962] “Organ Donor Registration”, online (pdf): *Yukon* <https://yukon.ca/sites/yukon.ca/files/hss/hss-forms/hss-organ-donor-registration-e_0.pdf> (see also Appendix 29).
[963] “Organ & Tissue Donation for Northwest Territories’ Residents”, online (pdf): *NWT* <www.hss.gov.nt.ca/sites/hss/files/resources/organ-tissue-donation-nwt-residents.pdf> (see also Appendix 30).

	Witness signature and date (2x)	I choose to donate **only these organs and/or tissues** for transplantation: (see list in next column) **OR** I wish to update my donation preferences as indicated above (same checkboxes as previous question) **OR** I wish to be removed from the Organ and Tissue Donation Registry	Kidneys Liver Lungs Pancreas Skin Stomach Vascular tissue	"Here's the most important part: discuss your wishes with your family. They need to know you want to be a donor. Talking with them will help them respect your choices." "*Your information will be shared with **Alberta's Department of Health**, who is maintaining the Organ and Tissue Donation Registry.*"	

Appendix 18: Organ Donation Registration Form – British Columbia (Mail-In)



BC TRANSPLANT
Provincial Health Services Authority

CK

British Columbia Organ Donor Registry

Register your decision

Please **PRINT** all information on this form and **SIGN** your name at the bottom.

BC Personal Health #:	

Found on the back your BC Services Card. This information may also be on your BC Driver's License.

Date of Birth	- -

YYYY-MM-DD

Last Name			
First Name			
Street Address			
Unit/Apt #		**Postal Code**	
City			**BC**
Phone Number			
E-mail			

1. I wish to be an organ donor (if **YES**, complete questions **2** & **3**)

☐ **YES** ☐ **NO**

2. I consent to help save lives by donating after my death:

☐ **ALL** organs and tissues needed for transplant.

OR; only the checked organs and tissues for transplant:

☐ **Heart** ☐ **Kidneys** ☐ **Eyes** ☐ **Lungs**

☐ **Pancreas** ☐ **Tissue** ☐ **Liver** ☐ **Bowel**

3. My donated organs & tissues may also be used for research.

☐ **YES** ☐ **NO**

Once signed by you, this form constitutes a legally valid decision record regarding '*consent by person for use of body after death*' in accordance with s.4 of the *Human Tissue Gift Act* (British Columbia). The personal information you provide on this form is collected by BC Transplant, a part of the Provincial Health Services Authority, for the purpose of recording your decision regarding organ and tissue donation. It may be further used and disclosed in accordance with the *Freedom of Information and Protection of Privacy Act* (British Columbia) ("FIPPA") for purposes consistent with its collection or as otherwise required by law. Under FIPPA you are entitled to access and correct any of your personal information that is within our custody and control.

Signature:	**Signed Date:**
Signer First Name	**Signer Last Name**

For someone under the age of 19, this record reflects an expressed wish about organ donation and is not a legally binding decision record, per the *Human Tissue Gift Act.*

Optional Personal Message:
Write an optional message that will be presented to your family, or loved one(s) at the time of donation.

Appendix 19: Organ Donation Registration Form – British Columbia (Online)

Register your Decision

Register your decision with the British Columbia Organ Donor Registry.

BC's Organ Donor Registry is the official registry of your decision on organ donation. You only need to register one time, unless you would like to update your decision. If you registered before and complete this form again, it will override your previous decision.

You will need

- your BC Personal Health Number.
- your name, birth date and address in British Columbia.

A parent/guardian can sign on behalf of someone who is under the age of 19.

If you are a member of the military and you do not have a BC PHN, please complete this paper form and mail it to BC Transplant.

Personal Information

Id:4ed96930-488d-48f1-811c-a6cc1a1ebcf6

Personal Health Number: 9--- --- ---

Date of Birth: YYYY-MM-DD

If you do not have a Personal Health Number, please complete a paper form and mail it to BC Transplant.

First Name: First Name

Last Name: Last Name

Email: Email

Phone Number: Phone Number

Mailing Address

Street Address: Street Address

Unit / Apt (optional): Unit / Apt (optional)

City: City

Province or Territory: Please Choose...

Postal Code: Postal Code

Country: Canada

Donation Decision

I consent to help save lives by becoming an organ and tissue donor after my death: ◯ Yes ◯ No

Write an optional message that will be presented to your family, or loved one(s) at the time of donation/decision

characters left: 2000

Consent

Once signed by you, this form constitutes a legally valid decision record regarding 'consent by person for use of body after death' in accordance with s.4 of the Human Tissue Gift Act (British Columbia). The personal information you provide on this form is collected by BC Transplant, a part of the Provincial Health Services Authority, for the purpose of recording your decision regarding organ and tissue donation. It may be further used and disclosed in accordance with the Freedom of Information and Protection of Privacy Act (British Columbia) ("FIPPA") for purposes consistent with its collection or as otherwise required by law. Under FIPPA you are entitled to access and correct any of your personal information that is within our custody and control.

Signer's First Name: Signer's First Name

Signer's Last Name: Signer's Last Name

For someone under the age of 19, this record reflects an expressed wish about organ donation and is not a legally binding decision record, per the Human Tissue Gift Act.

Register >

Appendix 20: Organ Donation Registration Form – Alberta

What you need to know:

- The first priority of health care professionals is to save lives. Your choice to be a donor does not affect the quality of life-saving medical care you receive.
- Everyone has the potential to be an organ and/or tissue donor, though you must be at least 18 to register your consent to donate.
- There will be no cost to your family or estate for the donation of your organs or tissue.
- Organ and tissue recovery will only happen after every effort has been made to save your life.
- Organ and tissue donation should not affect preferred funeral arrangements.
- More than 4,400 Canadians, including more than 500 people in Alberta, are on the wait list for an organ transplant.
- It is important to share your organ donation choices with your family and friends.
- Registration to be a donor may be updated or withdrawn through the website, **UltimateGiftAlberta.ca**, or by calling 1-844-815-3315.

Alberta Organ and Tissue Donation Registry

Donation Consent

Your health and personal information is being collected for the purpose of tissue or organ donation for transplantation, scientific research and/or medical education under section 12 of the *Human Tissue and Organ Donation Act*, and other authorized purposes under section 27 of the *Health Information Act* and section 39 of the *Freedom of Information and Protection of Privacy Act*. This information is collected under the authority of section 20 of the *Health Information Act*, section 33 of the *Freedom of Information and Protection of Privacy Act*, and section 12 of the *Human Tissue and Organ Donation Act*. The confidentiality of this information is protected by the provisions of the above-noted legislation. If you have any questions about this collection, please contact the Transfusion and Transplantation Unit, Alberta Health, Phone: 1-844-815-3315 (Edmonton) Monday-Friday 8:15 - 4:30. Closed statutory holidays.

Please select one of the two options below.

1. ○ I choose to donate **all my organs and tissues** for (check all that apply):
   ☐ Transplantation ☐ Scientific Research ☐ Medical Education

OR

2. ○ I choose to donate **only these organs and/or tissues** (check all that apply):
   ☐ Heart ☐ Small Bowel ☐ Eyes ☐ Kidneys ☐ Stomach ☐ Heart Valves ☐ Liver
   ☐ Bone ☐ Skin ☐ Lungs ☐ Pancreas ☐ Vascular Tissue ☐ Connective Tissue
   To be used in (check all that apply):
   ☐ Transplantation ☐ Scientific Research ☐ Medical Education

***If you wish to donate your body, you must also register with your local anatomical gift program:**

Anatomical Gifts Program, University of Alberta, 780-492-2203
Body Donation Program, University of Calgary, 403-220-6950

Alberta Health's receipt of your completed form will provide evidence of your consent to be a donor. **All areas on this form must be completed.** Healthcare Number *(as it appears on your healthcare card)* ____________

Name *(first name)* ____________ *(last name)* ____________ Gender ____________

Date of Birth ____________ Signature Date ____________ Signature **X** ____________

Telephone Number ____________ Postal Code (first 3 digits) ____________

Thank you for registering to be a donor!

Appendix 21: Organ Donation Registration Form – Saskatchewan

Organ and Tissue Donor Registration Form

Instructions: Please fill in this form, print it and sign it. If you require additional assistance, please call eHealth Saskatchewan at 1-844-767-8259. **Return completed form to:** Organ and Tissue Donor Registry, eHealth Saskatchewan, 2130 11th Ave, Regina SK S4P 0J5; OR, Email: donorregistrysupport@ehealthsask.ca

Registry Information:

The Organ and Tissue Donor Registry is an online registry for Saskatchewan residents to register their intentions to donate their organs and/or tissues for transplantation after they die.

Everyone 16 years or older can register their intent to become an organ and/or tissue donor regardless of age, ethnicity, medical condition or sexual orientation. All you need to register is your Saskatchewan Health Services Card number, your full first and last name and your date of birth. For more information, or to register online, please visit www.givelifesask.ca

Donor Information

First Name:		Last Name:	
Saskatchewan Health Card #:		Birthdate (MM-DD-YYYY):	
Email Address:		Contact Number:	

If you would like to receive a confirmation email regarding your donation choices, please provide a valid email address.

Donation Choices

Please indicate your choices from the following options: ☐ All organ and tissues needed for transplant

☐ Only selected organs and tissues:

☐ Eyes ☐ Heart ☐ Kidneys ☐ Liver ☐ Lungs ☐ Pancreas ☐ Small Bowels ☐ Vessels

Living Donation

A living donor is someone who gives a gift in the form of an organ or part of an organ to another person in need. If you have provided your email address, you can choose to receive more information about living donation. Would you like to receive more information? Yes ☐ No ☐

Share Your Consent

We encourage you to talk with your family or next of kin about your donation choices. Family are more likely to agree to donation if they are aware of their family member's wishes. If you would like to share your choice to register with your family, please include their email addresses in the field below. Separate multiple addresses with a comma.

Email Addresses:

Consent Declaration

This form constitutes a legally valid consent under the Saskatchewan *Human Tissue Gift Act*. It is valid until it is revoked. The personal information of personal health information you provide on this form is collected under *The Freedom of Information and Protection of Privacy Act (FOIP)* and *The Health Information Protection Act (HIPA)*. It is collected for the purpose of recording your decision regarding organ and tissue donation.

By submitting your consent, you:

- Understand that your consent may be used and disclosed for other purposes as only permitted under the law (FOIP or HIPA), which may include research.
- You also authorize only the sharing of my personal information or personal health information that is necessary between persons and organizations engaged in donation and/or transplantation for the purposes of facilitation of organ and tissue donation and transplantation across jurisdictions (outside of Saskatchewan).
- Understand that you can change or withdraw your decision at any time in the future without any penalty.

☐ I certify that I have read and understand the above consent.

Signature: ______________________ Date: ____________ (MM-DD-YYYY)

August, 2020

Appendix 22: Organ Donation Registration Form – Manitoba

SIGN UP FOR LIFE.CA

Saturday January 20, 2024

TRANSPLANT MANITOBA | EN FRANÇAIS

SIGN UP | FAQ | LINKS | CONTACT US

Sign Up

Personal Information

First Name:

Last Name:

Health Card Number:

Date of Birth:

Intent to Donate

Question #1:

- (selected) I wish to be placed on the Intent to Donate Registry.
- I will speak to my family about my organ donation wishes.

Question #2:

a) I intend to donate all of my organs for transplantation

Yes   No

My organs can also be used for the following:

- [ ] Scientific Research
- [ ] Medical Education

or

- [ ] None of the above

Question #3:

a) I intend to donate all of my tissues for transplantation

Yes   No

My tissues can also be used for the following:

- [ ] Scientific Research
- [ ] Medical Education

or

- [ ] None of the above

Question #4:

Please check at least one of the following:

- [ ] I wish to send a message to Friends/Family on my Facebook page that I have registered my intent to be an organ/tissue donor.
- [ ] I wish to send a message to Friends/Family on my Twitter account that I have registered my intent to be an organ/tissue donor.
- [ ] I wish to send an email message to Friends/Family that I have registered my intent to be an organ/tissue donor.
- [ ] I will speak personally to my Friends/Family and let them know that I have registered to be an organ/tissue donor.

Submit | Cancel

© 2012 - 2024 Sign Up for Life | Conditions of Use | info@signupforlife.ca

Appendix 23: Organ Donation Registration Form – Ontario

Organ and Tissue Donor Registration

If you needed a transplant, would you have one? If so, help save lives and register today.

One organ donor can save up to 8 lives and enhance as many as 75 others through the gift of tissue.

To register as an organ and tissue donor, complete this form and return it to any ServiceOntario location or mail completed and signed form to: Organ Donor Consent
ServiceOntario
435 James Street South, Unit 113
Thunder Bay ON P7E 6T1

Note: You must be at least 16 years of age to register as an organ and tissue donor.

Step 1. I consent to help save lives by becoming an organ and tissue donor for:

- ☐ 1. Transplant only, or
- ☐ 2. Transplant / organ and tissue research

Step 2. I wish to donate:

- ☐ Any needed organs and tissue, or
- ☐ Any needed organs and tissue **except** for those indicated below.

Check only organs and tissue you **do not** want to donate. If you would like to donate all needed organs and tissue, check the box above.

☐ A. Kidneys	☐ B. Heart	☐ C. Eyes	☐ D. Bone
☐ E. Liver	☐ F. Lung	☐ G. Skin	☐ H. Pancreas

By signing below, I am consenting to be an organ and tissue donor after my death.

Name (as it appears on your health card)

Health Card Number	Date of Birth (yyyy/mm/dd)	Telephone Number

Mailing Address

Unit Number	Street Number	Street Name

City/Town	Province	Postal Code
	ON	

Signature	Date (yyyy/mm/dd)

For information about organ and tissue donation visit BeADonor.ca/about-donation or call 1-888-379-2925. If you have questions about registering, changing or withdrawing your consent, visit us at ServiceOntario.ca/BeADonor or call us at:

Toll free: 1-866-532-3161 or 416-314-5518 (in Toronto)
TTY toll free: 1-800-387-5559 or 416-327-4282 (in Toronto)
or write to: Team Manager, ServiceOntario Contact Centre
PO Box 105, 777 Bay Street, Toronto ON M5G 2C8

Notice: The personal information you provide on this form is collected by the Ministry of Health for the purpose of recording your decision to be an organ and tissue donor. It may be used and disclosed in accordance with the ***Personal Health Information Protection Act, 2004***, as described in the Ministry's "Statement of Information Practices" posted at Ontario.ca/health. The Trillium Gift of Life Network will collect this information from the Ministry in accordance with section 8.19 of the ***Gift of Life Act*** for the purpose of facilitating organ and tissue transplants and research as well as sharing this information with your family so that they can honour your wishes at end of life. If you have questions about the collection, use and/or disclosure of your personal information, please see above for details about how to contact us.

3750–84E (2023/11) © King's Printer for Ontario, 2023 Print Form Disponible en français Clear Form

Appendix 24: Organ Donation Registration Form – Québec

Consent to Organ and Tissue Donation

Before filling out the form, **read the instructions on the reverse.**

Save lives by consenting to organ and tissue donation!

Please note that this consent is not required to obtain your Health Insurance Card.

Persons under age 14 can also give their consent. However, their signature **and** that of the holder of parental authority or guardian are necessary.

Once your decision is taken, please inform your loved ones so that your wish is respected.

I hereby authorize organ and tissue removal for transplant or graft, when I die.

Sign FOR LIFE!

SIGNATURE OF DONOR

X ______________________

DATE OF SIGNATURE Y / M / D

SIGNATURE OF HOLDER OF PARENTAL AUTHORITY OR OF GUARDIAN (in the case of a donor under age 14)

X ______________________

DATE OF SIGNATURE Y / M / D

Return the form without removing or cutting off any part of it.

FOR USE BY THE RÉGIE

☐ C.S. ☐ ☐ ☐ ☐

4120 365 16/04 TT76_V01; Prod; Enr.-1

Appendix 25: Organ Donation Registration Form – Nova Scotia

Hundreds of Nova Scotians are waiting for an organ or tissue transplant.
One donor can save or enhance the lives of more than 80 people.

To indicate a donation decision, please complete the form below.
Each family member must complete a separate form.

Your organ and tissue donation decision

It is your choice. You can indicate a donation decision below or choose not to register one. You can change a previous decision at any time.

If you are 19 or older and eligible, you will be seen as agreeing to be an organ and tissue donor after your death, unless you register a decision to opt out of donation. This will be confirmed with your family at the time of your death.

Learn more about who is eligible at www.novascotia.ca/organtissuedonation or by calling MSI at 1-800-563-8880 or 902-496-7008 in HRM.

Do you want to register a donation decision now?

Completely fill in the circle to mark your choice:

○ Yes, I want to be a donor and donate all organs and tissues (donor 1)

○ Yes, I want to be a donor and ONLY donate the following organs and tissues (donor 2):

Organs: ○ Lungs ○ Heart ○ Liver ○ Kidneys ○ Pancreas ○ Small Bowel

Tissues: ○ Skin ○ Vein ○ Eyes ○ Bone & Related Structures ○ Heart Valves/Pericardium

○ No, I don't want to be a donor (opt out)

Name: ______________ Date of Birth: ______________ Health Card Number: ______________

Talk about it

Talk with your family, friends and those closest to you to make sure they know your donation decision.

Find out more

Learn more about your organ and tissue donation choices, and recent changes to Nova Scotia's organ and tissue donation legislation:

www.novascotia.ca/organtissuedonation

Learn more about organ and tissue donation:

http://www.nshealth.ca/legacy-life
1-877-841-3929 (organ)
1-800-314-6515 (tissue)

Renew your Health Card:
https://novascotia.ca/dhw/msi/
902-496-7008
1-800-563-8880

Please fax your form to MSI Resident Services at 902-481-3160
Or mail your form to:
MSI Resident Services
PO Box 500
Halifax, NS, B3J 2S1

Appendix 26: Organ Donation Registration Form – New Brunswick[964]

New Brunswick Medicare
P.O. Box 5100
Fredericton, NB E3B 5G8
Tel: 1-888-762-8600
Outside North America: (506) 684-7901
Email: Medicare.Eligibility@gnb.ca

New Nouveau Brunswick CANADA

5.4 Adoption

Required Documentation: Copy of Adoption Order - Refer to "*Section 8 - List 3.9*".

Have you recently adopted a child?	☐ YES ☐ NO
If YES:	
Previous Legal First & Last Name of Child:	
Requested Legal First & Last Name of Child:	
Child's Date of Birth:	DD / MM / YYYY

5.5 Organ Donor Change

If you are an organ donor, it is indicated as "D" on the front of your Medicare card.

Please indicate the names of the individuals requesting a change in organ donor status.				
Do you want to be an organ donor?				
First Name:		Last Name:		☐ YES ☐ NO
First Name:		Last Name:		☐ YES ☐ NO
First Name:		Last Name:		☐ YES ☐ NO
First Name:		Last Name:		☐ YES ☐ NO

SECTION 6 - RESIDENT DECLARATION

Please read carefully.

The *Medical Services Payment Act* defines a resident as "a person lawfully entitled to be or to remain in Canada, who makes his home and is ordinarily present in New Brunswick, but does not include a tourist, transient or visitor to the Province".

Maintaining a dwelling, owning property in the province of New Brunswick, or paying New Brunswick property or income tax does not mean you are eligible for insured services under New Brunswick Medicare.

I, the applicant, hereby declare that I have read the definition of a "resident" and that the information given on this form is correct and that the persons listed are permanent residents in accordance with the definition of a "resident".

Signature of Applicant: ____________________ Date: ____________________

SECTION 7 - COMMENTS

For office use only.

[964] **NB:** It is likely that this form will change once the 2023 statute comes into effect.

Appendix 27: Organ Donation Registration Form – Prince Edward Island

Intent to Donate and Language Information

Please print and mail completed form to:

Medicare Office
126 Douses Road
PO BOX 3000
Montague PE C0A 1R0
Canada

Legal Name
Personal Health Number (on health card)
Mailing Address

ORGAN AND TISSUE DONOR DECISION

The information below will be stored in a secure computerized PEI Donor Registry. In the future, your organ and/or tissue donor decision will be displayed on your new Health Card.

I wish to donate:
Organs needed for transplant (lungs, heart, liver, kidneys, pancreas, small bowel)
☐ **YES** ☐ **NO**

Tissues needed for transplant (skin, vein, eyes, bone and related structures, heart valves/pericardium)
☐ **YES** ☐ **NO**

For more information about organ and tissue donation, please call: 902-368-5920

Your signature is required for organ and/or tissue donation. You must be 16 or older to sign. Parents cannot sign on behalf of children.

Signature	Date	Date of Birth

LANGUAGE PROFILE

In order to plan for service delivery, please answer the following questions related to your language profile. In the future, your preferred language of service will be displayed on your new Health Card.

What is your mother tongue? (The language you first learned in childhood and still understand)
☐ **English** ☐ **French** ☐ **Other** (Please specify) ________________________________

If your mother tongue is neither English nor French, in which of Canada's official languages are you most comfortable?
☐ **English** ☐ **French** ☐ **Neither**

What is your preferred language for service delivery?
☐ **English** ☐ **French** ☐ **Other** (Please specify) ________________________________

Consent to organ and/or tissue donation and language profile responses are voluntary and are not required for Health Card eligibility. Personal information on this form is collected under the authority of Section 31(c) of the Freedom of Information and Protection of Privacy Act.

If you provide consent to organ and/or tissue donation in this form, your information will be entered into a record of intent that can be accessed by a health care provider in specific circumstances. Questions on the collection and use of organ and tissue donation information can be directed to the Organ and Tissue Donation and Transplantation Manager at 902-368-5920.

Responses to the language profile questions may be used for planning and service delivery purposes. Questions on the collection and use of language information can be directed to Medicare Services, 126 Douses Road, Montague, PE, C0A 1R0, 1-800-321-5492.

FOR OFFICE USE ONLY- PHN: **HOUSEHOLD NUMBER:**

Appendix 28: Organ Donation Registration Form – Newfoundland & Labrador

Health and Community Services

APPLICATION FOR NEWFOUNDLAND AND LABRADOR HEALTH CARE COVERAGE

mcp

Medical Care Plan

DO NOT ENTER TEXT ON THIS FORM WHEN IT IS OPEN IN A WEB BROWSER
SAVE IT TO YOUR COMPUTER FIRST AND OPEN IT FROM THERE

SECTION 1 — **LIST BELOW YOUR NAME AND THE NAMES OF ANY OF YOUR DEPENDANTS REGISTERING FOR HEALTH CARE COVERAGE (Attach a separate sheet if more space is required)**

Surname	All Given Names (in full) First Name	Middle Name	Surname at Birth	Sex/Gender M / F / X	Birth Date YYYY	MM	DD	Previous Province Health Insurance No. (if applicable)

SECTION 2 — **HOME MAILING ADDRESS**

Home Mailing Address | City / Town | Province **NL** | Postal Code

Phone | Cell Number | E-mail

SECTION 3 — **MARITAL STATUS (If your spouse-legal or common law-is not already registered with MCP they must also register at this time)**

Single ☐ Married ☐ Common Law ☐ Separated ☐ Divorced ☐ Widowed ☐

SECTION 4 — **ANSWER ALL OF THE FOLLOWING QUESTIONS (Please print. See reverse for required documentation.)**

1. Have you or your dependents been registered with MCP before? ☐ Yes ☐ No
   If YES please list on a separate sheet the previous MCP numbers (if available) of all persons to be registered.
2. When did you and/or your dependents move to Newfoundland &Labrador? (YYYY/MM/DD) ____________
3. Are you moving to Newfoundland & Labrador from another part of Canada? ☐ Yes (Province/Territory) ____________ ☐ No
4. Are you moving to Newfoundland & Labrador from outside Canada? ☐ Yes (Country) ____________ ☐ No
5. Reason for moving to Newfoundland & Labrador. ☐ Work ☐ Study ☐ Other
6. How long do you intend to reside in Newfoundland & Labrador? ____________
7. Have all of your dependents moved with you to Newfoundland & Labrador? ☐ Yes ☐ No (explain)
8. Are any of the applicants listed on this form a member of: ☐ Canadian Forces ☐ NATO Forces ☐ Part-time Reserve
   Name(s) of applicants ____________

SECTION 5 — **INTENT FOR ORGAN/TISSUE DONATION (If anyone named on this form wishes to become an organ/tissue donor, please sign in one of the spaces below. Your intent to donate is supported by the *Human Tissue Act*. If signing below, please also print your name)**

Electronic or Written Signature and Printed Name	Electronic or Written Signature and Printed Name
Electronic or Written Signature and Printed Name	Electronic or Written Signature and Printed Name

SECTION 6 — **DECLARATION (This application will not be processed if the section below is not completed. See instructions on reverse side of this form.)**

IT IS AN OFFENCE TO GIVE FALSE INFORMATION FOR THE PURPOSE OF OBTAINING COVERAGE UNDER THE NEWFOUNDLAND & LABRADOR MEDICAL CARE PLAN

I ____________ hereby declare that I am the person named on the form, the information given is correct and the person(s) listed on this form are residents of Newfoundland and Labrador. In lieu of a written signature my typed name on the form shall be considered my electronic signature.

Electronic or Written Signature of Applicant: ____________ Date: ____________

PRIVACY NOTICE: The Newfoundland and Labrador Medical Care Plan (MCP) collects personal health information under the authority of the *Medical Care and Hospital Insurance Act*. Personal health information is collected, used, disclosed and safeguarded in accordance with the *Personal Health Information Act* (PHIA). If you have any questions about the collection or use of this information please contact our office.

MCP 45 Major's Path
PO Box 8700, St. John's, NL A1B 4J6
Telephone: 709-758-1600 Toll Free: 1-866-449-4459 or 1-800-563-1557 Facsimile: 709-758-1694
www.gov.nl.ca/mcp

Appendix 29: Organ Donation Registration Form – Yukon

ORGAN DONOR REGISTRATION

To register for organ donation, you will need to fill out this form. Once you've made the decision to become an organ donor, make it count. Tell a trusted family member about your decision.

REGISTRANT INFORMATION

Print in block letters using ink. No registration confirmation will be sent.

Last name		First name	
Date of birth YYYY/MM/DD	Gender	Yukon health care insurance card number	
Mailing address		City	Postal code

DONATION INFORMATION

☐ Any organ or tissue needed for transplant or transplant research, or
☐ Any organs and tissues needed for transplant only, or
☐ Any organs/tissues needed for transplant EXCEPT the following:

☐ Heart ☐ Kidneys ☐ Cornea ☐ Liver ☐ Bone
☐ Lung ☐ Pancreas ☐ Skin ☐ Bowel

CONSENT

I hereby consent for the purposes of the *Human Tissue Gift Act*, to the above donation after my death.

Signature	Date YYYY/MM/DD

A parent/guardian must sign if donor is under the age of 19.

I am the parent/guardian of the child listed above. I hereby consent for the purposes of the *Human Tissue Gift Act*, to the above donation after death.

Parent/guardian last name	Parent/guardian first name
Signature	Date YYYY/MM/DD

- A registry exists to legally record the wishes of organ donors in the Yukon. Access to these records is restricted to authorized personnel.
- Only those Yukon residents who register with the Yukon Health Care Insurance Plan as an organ donor will be included in the registry.
- Donors will receive a new updated sticker for their health care cards indicating their donor status.
- Donors who have questions or change their mind may rescind their registration at any time by calling 867-667-5209 or 1-800-661-0408, local 5209.

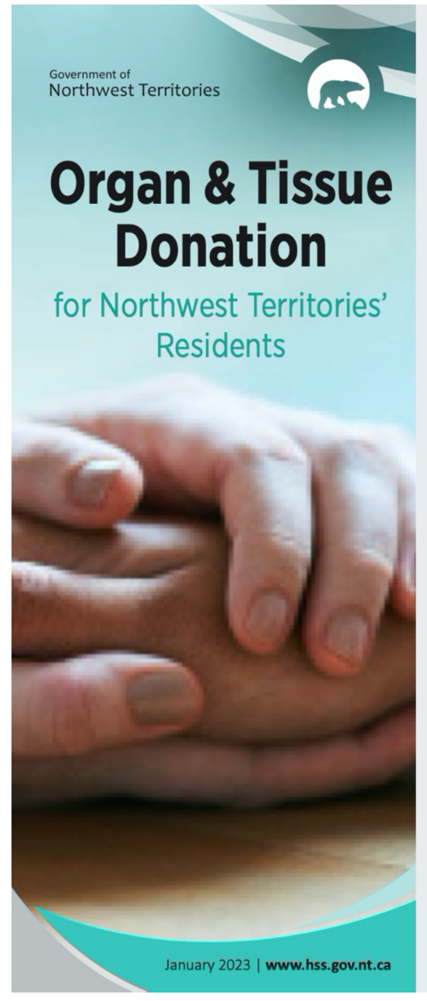
Yukon Health Care Insurance Plan
Box 2703 (H-2), Whitehorse, YT, Y1A 2C6

Information contained in this form is collected, used and disclosed in accordance with Yukon's *Health Information Privacy and Management Act* and other applicable laws. A written statement of Health and Social Services information practices can viewed at www.hss.gov.yk.ca/healthprivacy.php or by contacting the department's Privacy Officer at healthprivacy@gov.yk.ca.

YG(6583EQ)F1 Rev.07/2019

Print Clear

Appendix 30: Organ Donation Registration Form – Northwest Territories



What do I need to know?

- The first priority of health care professionals is to save lives. Your choice to become a donor does not affect the quality of life-saving medical care you receive.
- You must be at least 16 years old to complete the Organ and Tissue Donation Consent Form.
- There will be no cost to your family or estate for the donation of your organs or tissue.
- Organ and tissue recovery will only happen after every effort has been made to save your life.
- By submitting a completed Organ and Tissue Donation Consent Form, your information will be added to an Organ and Tissue Donation Registry.
- If you decide to become an organ and tissue donor, discuss it with your family.
- Registration to be a donor may be updated or withdrawn by resubmitting a completed consent form.

Who can witness my signature?

- A friend or co-worker can be your witness.
- **A family member CANNOT be your witness**. This includes your spouse, common law partner, parent, child, guardian, or sibling.

How do I register?

You can either drop off at your closest health centre, email otdonation@gov.nt.ca, or mail a copy of the completed and signed consent form on the next page to:

Health Services Administration Office
Department of Health and Social Services
Government of the Northwest Territories
Bag #9 | Inuvik, NT | X0E 0T0

Here's the most important part: **discuss your wishes with your family**. They need to know you want to be a donor. Talking with them will help them respect your choices.

For more information, please contact the Office of Client Experience at 1-855-846-9601 or by e-mail at hss_clientexperience@gov.nt.ca. Find out more by visiting www.hss.gov.nt.ca.

Validation Stamp

(to be completed by the HSA Office)

If you would like this information in another official language, contact us at 1-855-846-9601.
Si vous voulez ces renseignements dans une autre langue officielle, communiquez avec nous au 1-855-846-9601.

Organ and Tissue Donation Consent Form

The personal health information on this form is being collected in accordance with the Human Tissue Donation Act (HTDA) *and the* Health Information Act (HIA). *Your information will be shared with* ***Alberta's Department of Health****, who is maintaining the Organ and Tissue Donation Registry. It is protected by the privacy provisions under the HTDA and HIA, and will not be used or disclosed unless allowed or required by the HTDA, HIA, Alberta's Human Tissue and Organ Donation Act, and Alberta's Health Information Act.*

If you have any questions, please contact the Office of Client Experience at 1-855-846-9601 or hss_clientexperience@gov.nt.ca.

◯ I choose to donate **all my organs and tissues** for transplantation.

OR

◯ I choose to donate **only these organs and/or tissues** for transplantation (check all that apply):
☐ Heart ☐ Heart Valves ☐ Small Bowel ☐ Kidneys ☐ Stomach ☐ Eyes ☐ Liver
☐ Bone ☐ Skin ☐ Lungs ☐ Pancreas ☐ Vascular Tissue ☐ Connective Tissue

OR

◯ I wish to update my donation preferences as indicated above.

OR

◯ I wish to be removed from the Organ and Tissue Donation Registry.

Check that you have read and agree:

☐ I understand and agree that the information on this form is being collected by the GNWT, and will be provided to **Alberta's Department of Health**, for use in the Organ & Tissue Registry in keeping with the *Health Information Act*, and s. 11(1) of the *Human Tissue Donation Act*.

☐ I understand that I may withhold consent to the collection, use and disclosure of the personal information set out on this form, and I submit this form voluntarily and without coercion.

☐ I understand that I may withdraw my consent to the collection, use and disclosure of my personal information on this form. In the event that I wish for my personal information to be removed from the Organ & Tissue Donation Registry, I can fill out another form with the "I wish to be removed from the Organ & Tissue Donation Registry" box checked, or otherwise communicate my wishes to the GNWT.

The Health Services Administration Office's receipt of your signed, dated, and witnessed form will provide evidence of your consent to be a donor. **All areas on this form must be completed; please PRINT.**

First Name: ______________________ Last Name: ______________________
Health Care #: ______________ Date of Birth: ______________ Telephone #: ______________
Signature: ______________________________ Date: __________
Witness Name: ______________ Witness Signature: ______________ Date: __________
Note: witness cannot be a family member.

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