

## Evaluating the “family veto” of consent for organ donation

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The number of Canadians awaiting transplants continues to exceed the number of organs donated, so the growing concern over “family veto” should come as no surprise.<sup>1-3</sup> 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. Yet many provincial/territorial agencies and organ donation organizations indicate on their websites that families’ wishes take priority over an individual’s legally valid consent. Last year in Ontario, for example, 21% of families of registered donors refused donation.<sup>3</sup> This situation is legally problematic and confusing for the public, patients and health care providers. It also highlights the need for donation and transplantation communities to be aware of, and adhere to, the law governing consent for donation.

The legal authority to procure a deceased person’s organs comes from valid consent for donation. Unlike consent for medical treatment, organ donation legislation does not impose a standard of “informed consent.” A person’s consent is legally valid if it meets the formal legislative requirements: generally, a document that is signed, dated and witnessed. Consent can be given by an individual before death or, in some circumstances, by next of kin<sup>4</sup> (Appendix 1, available at [www.cmaj.ca/lookup/suppl/doi:10.1503/cmaj.160752/-/DC1](http://www.cmaj.ca/lookup/suppl/doi:10.1503/cmaj.160752/-/DC1)). Next of kin have legal authority to consent or withhold consent on the individual’s behalf only in situations where the individual has not already provided valid consent. This is true across Canada, although the

Northwest Territories’ legislation is somewhat unclear on this point. When an individual has already provided valid consent, a refusal by family to also provide consent is legally meaningless.

In most Canadian jurisdictions, individual consent is also “binding,” which generally means it is obligatory<sup>5</sup> or something that “must be followed.”<sup>6</sup> In the event an individual’s organs are not suitable for donation, most jurisdictions provide that consent becomes void and the authority (or obligation) to proceed with donation is extinguished.

If organs are suitable for donation, the deceased had provided valid consent and there is no reason to believe the individual changed his or her mind, full legal authority exists for procurement. In the context of donation after cardiocirculatory death, however, legislation does not address the issue of consent for pre-mortem interventions, such as administering heparin. Consent for these interventions is governed by the law regarding treatment for individuals who lack capacity. Because substitute decision-makers must generally make decisions in accordance with the individual’s known wishes,<sup>7</sup> prior consent to donation would be highly relevant, although perhaps not determinative.

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 (Appendix 2, available at [www.cmaj.ca/lookup/suppl/doi:10.1503/cmaj.160752/-/DC1](http://www.cmaj.ca/lookup/suppl/doi:10.1503/cmaj.160752/-/DC1)). 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 (Appendix 2). In fact, no one is “entitled to consent” when the individual has already consented.

The most striking disconnect exists in Alberta, where legislation explicitly prohibits donation organizations from seeking family consent when an individual has already provided valid consent.<sup>8</sup> Despite this clear directive, Alberta Health states “your next of kin will be asked by the donation team to sign a consent form agreeing that your wishes will be followed” (Appendix 2).

### KEY POINTS

- Under Canadian law, families have no legal authority to give or withhold consent for organ donation if the deceased person provided valid consent.
- Individual consent for donation provides the full legal authority necessary to proceed with organ procurement and is legally binding in most Canadian jurisdictions.
- Publicly available policy information from websites of organ donation organizations and government health authorities indicate that family wishes will be respected regardless of an individual’s prior consent.
- Engagement with and understanding of the concerns of the donation community will be crucial to addressing the disconnect between organ donation legislation and policy in Canada.

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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. By 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.

Blanket policies that prioritize family wishes open the door to objections for reasons much broader than respecting an individual's change of heart. In Alberta, Quebec and Prince Edward Island, the practical need for family cooperation to obtain social and medical information about the donor is cited as a reason family agreement is needed. However, seeking family assistance does not necessitate seeking formal consent or agreement, and this justification fails to acknowledge the possibility of pursuing exceptional distribution should the safety of organs truly be in doubt owing to a family's failure to cooperate.<sup>9,10</sup>

The existing legislation respects an individual's donation decision — whether for or against — by making the decision binding and safeguarding the ability to change one's mind. Despite these legal norms, organizations responsible for facilitating donation have taken a contrary position by respecting family wishes over the individual's. Health care providers are put in a confusing and problematic situation where following established practice and policy runs counter to the law. Although individual providers are certainly entitled under current legislation to uphold individuals' consent, determining best practices for doing so will require a deliberate and coordinated effort by the broader donation and transplantation communities. Specific options for policy change will need to be informed by law, ethics, a clear understanding of the medical community's concerns about what under-

pins family veto, and the experiences of jurisdictions where the manner in which families are approached about organ donation has changed in order to better respect and enforce an individual's consent for donation.<sup>11,12</sup>

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