

FAST FACTS

CONTENT: MARCH 2022

OPT-OUT SYSTEMS OF ORGAN DONATION

INTRODUCTION

Canadian provinces and territories, apart from Nova Scotia, administer organ donation on an opt-in basis. Under opt-in systems, people register their willingness to donate their organs after death. Those who have not registered may still be donors if their next of kin consent. In contrast, opt-out systems – also known as presumed or deemed consent systems – automatically consider everyone to be a potential organ donor, unless the individual explicitly opts out of donation.



On January 18, 2021, Nova Scotia's new Human Organ and Tissue Donation Act [1] went into effect to transition to an opt-out model. [2] The new legislation aims to increase organ and tissue donation in the province. [3] All Nova Scotians 19-years of age and older will be considered potential donors unless they meet the narrow categories for exemption (e.g., adults who lack mental capacity to consent) or opt-out via the Registry or family refusal. [4] Partial consent for the donation of only certain organs is possible. [5] While Nova Scotia is the first jurisdiction in North America to adopt an opt-out system, other nations such as Spain, Wales, France, and Chile already use such a system with varying degrees of success in increasing donation rates. [6]

The Views of Historically Underrepresented Communities in Nova Scotia

The Role of Solidarity in Opt-Out Systems

The French Experience with Opt-Out Laws

THE VIEWS OF HISTORICALLY UNDERREPRESENTED COMMUNITIES IN NOVA SCOTIA

The views of underrepresented and equity-seeking communities need to inform the roll-out of Nova Scotia's new opt-out system legislation. A recent interview-based study with leaders from faith-based communities, the African Nova Scotian community, the 2SLGBTQIA+community, and newcomers to Canada revealed four main themes: [7]

1. SUPPORT FOR ODT

All participants supported organ donation and transplantation (ODT) programs as they aligned with their personal values. Organ donation conformed with the religious beliefs of various faith-based communities. Deemed consent for tissue donation posed a more complex issue for participants, specifically those from the Jewish and Islamic communities due to potential conflicts with religious customs.

2. TRUST AND RELATIONSHIPS

Participants discussed how broken relationships need to be addressed in order to move forward. 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. Men who have sex with men (MSM) noted that their damaged relationship with the blood donation system had impacted their perceptions of the ODT system.

3. CULTURAL COMPETENCE

All participants discussed how cultural competence and safety are essential at all levels of the ODT system, from legislative drafting to clinical implementation. Governments and health leaders need to recognize the historical and modern harms experienced by communities and respond to their needs.

4. EDUCATION & COMMUNICATION

Participants expressed a strong desire for increased communication and education about the new opt-out system and ODT as a whole. This communication must be accessible to communities (e.g., the availability of information in several languages) and culturally competent.

Overall, participants possessed a genuine desire to participate in Nova Scotia's new opt-out ODT system, so long as the system was culturally competent and safe.

THE ROLE OF SOLIDARITY IN OPT-OUT SYSTEMS

In the fields of bioethics and healthcare ethics, solidarity refers to the feeling of unity, mutual support, and reliance within a community. Solidarity has been identified as one of the central values that should guide the design and operations of ODT systems in Canada, as these systems fundamentally depend upon the willingness to donate to help others in need.

Calls for solidarity need to be attentive to the social, historical, and cultural contexts in which the term is used. [8] Solidarity is challenging to define, but there are three critical aspects to consider more in depth:

- Relationships: who are we in solidarity with and what defines that relationship?
- Intentional commitments: what is the aim of our solidarity and where do these commitments stem from?
- Actions: what am I willing to do and give up in order to ensure the well-being of others? [9]

The Canadian publicly funded healthcare system reflects a concept of civic solidarity. [10] It is based on an acknowledgement of universal vulnerability and a willingness to offer mutual support, via the indirect pathway of taxation. ODT asks for more direct and personal expressions of solidarity through the donation of organs for the benefit of those in need. An important aspect of policies based on solidarity is attention to whether everyone actually is "all in this together."

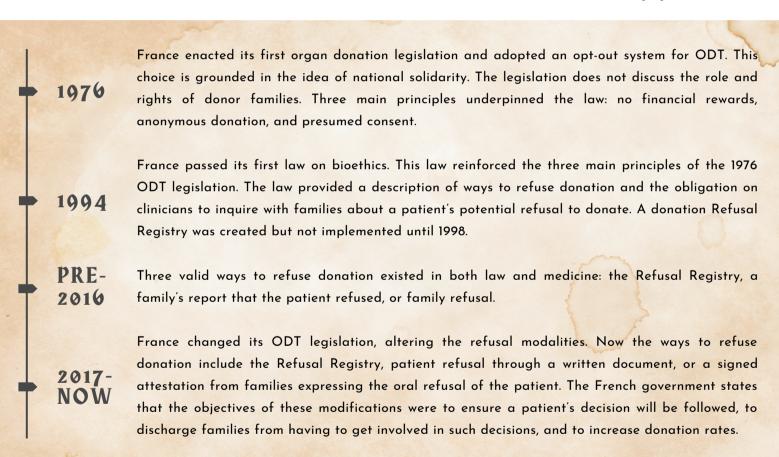


THE FRENCH EXPERIENCE WITH OPT-OUT LAWS





THE HISTORY OF ORGAN DONATION LEGISLATION IN FRANCE [11]



Global refusal (including cases of family or patient refusal) remained stable with no major change after the implementation of the new legislation. France did however experience a slight increase in donation rates. Data for 2017 and 2018 shows that family refusal decreased from 21% to 13% and patient refusal increased from 12% to 17%. [12] The Refusal Registry's new inscription rates increased at the time of the legislative change and again right before the application of the law, but overall, rates continue to remain low.

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- [2] Nova Scotia Department of Health and Wellness. (2020, June). Human Organ and Tissue Donation Act Information Guide. Province of Nova Scotia, page 1.

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- [3] See above.
- [4] See above at 1-3.
- [5] See above at 1.
- [6] See note 1 at 258. See also: Krmpotic, K., Isenor, C. & Beed, S. (2020). Deceased Organ Donation in Nova Scotia: Presumed Consent and System Transformation. Healthcare Management Forum, 33(5). 210–213 at 211–12; Domínguez, J. & Rojas, J.L. (2013). Presumed Consent Legislation Failed to Improve Organ Donation in Chile. Transplantation Proceedings, 45(4), 1316–17.
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www.oise.utoronto.ca/oise/News/2020/What_is_solidarity_during_coronavirus.html [10] See above.

[11] Kandelman, S. [University of Ottawa Centre for Health Law, Policy and Ethics]. (2021, June 29). The French Experience with Family Refusal After the 2017 Changes to the French Presumed Consent Law at 00h:41m:36s. [Video]. YouTube. www.youtube.com/watch?v=bVZIWDIbP1Y [12] Data extracted from French nationwide database on organ donation (Cristal Database), for the period 2017-01-01 to 2018-12-31, for the CANEVAS study (to be published), funded by Agence de la biomédecine and Société française d'anesthésie reanimation.