

Learning from a social experiment in consent for deceased organ donation

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The organ donation and transplantation system in Canada is currently transforming from a fragmented system with stagnant performance¹ to a collaborative system with sustained incremental improvement (www.cihi.ca/en/e-statistics-on-organ-transplants-waiting-lists-and-donors). A potential donor intersects with the health care system in a predictable trajectory, from prehospital care to emergency department to intensive care unit to operating room. The transition from attempts to save a life, to acceptance of inevitable death, to organ donation is a complex, fragile and emotionally challenging, albeit predictable, process for both families and health care providers. Optimization of each step is required to improve the system. Provincial organ donation organizations carry the operational workload of managing the donation process and connecting with transplant recipients. In a related research article, Singh and colleagues evaluated factors that influence consent for organ donation in Ontario,² a province that has implemented many of the fundamentals of system improvement to increase deceased organ donation. The authors' findings answer some questions, but raise others in light of recent policy changes in Nova Scotia.

Although much work remains to be done to reduce death and disability among patients on transplant wait lists, collective and coordinated efforts have improved between hospitals, transplant programs, professionals and the societies representing critical care and emergency medicine. The system of deceased donation has changed profoundly, from the early days of provider knowledge gaps, resistance, discomfort and perceptions of conflicts of interest, to a culture of deceased donation into routine end-of-life care. Central to this change has been the development and implementation of national, community-derived best practices that are endorsed by professional societies, and guidelines for each step in the donation process, supported by Health Canada and coordinated by Canadian Blood Services (and its predecessor, the Canadian Council for Donation and Transplantation). Guidance now exists for the neurologic determination of death,³ donor management,^{4,5} donation after circulatory determination of death,⁶ donation after resuscitated cardiac arrest,⁷ donor identification and timely referral (predicated on potential donors audits),⁸ consent conversations at the end of life,⁹ organ donation after medical assistance in dying¹⁰ and donation-focused personnel within critical care.¹¹ The current substantial variations in the performance of provincial organ donation and trans-

Key points

- Improvements in the performance of organ donation systems depend on provincial implementation of national, community-derived leading practices to manage donation opportunities from illness or injury to death to organ donation to transplantation.
- Once foundational practices have been implemented, improving consent rates is the next major challenge.
- Canada lags other countries in collecting performance metric data on organ donations that can usefully inform policy.
- Within opt-in systems, improving consent rates may be achieved by addressing modifiable factors such as use of specially trained personnel, physician participation in consent discussions, consent registration and minimizing family override of the expressed wishes of the decedent.
- The recent legislative change in Nova Scotia to implement presumed consent has created a social experiment that will allow researchers to observe whether the policy can improve organ donation rates without compromising individuals' legitimate right to refuse to donate.

plantation systems may be attributable to differences in the investment in, and implementation of, these fundamental practices.

Once a donation system has optimized foundational practices, the final challenge to improving organ donation and transplant rates is boosting consent. Ontario's performance is similar to that of the United Kingdom, where organ donation and transplant rates have increased substantially with minimal improvements in the consent rate (www.odt.nhs.uk/). Although conscious patients, such as those requesting medical assistance in dying,¹⁰ may provide first-person informed consent, consent must usually be obtained from surrogate decision-makers of comatose, dying patients, presumably informed by registered patient decisions or known preferences.

As the hospital culture in organ donation has evolved, the societal attitudes, as measured by consent rates, has not. An overall consent rate of 60% remains in contrast with the expressed 88% to 95% public support rate for organ donation after death (https://profedu.blood.ca/sites/msi/files/2020_ipsos_public_opinion_polling_-_approval_of_organ_donation_after_death.pdf). Modifiable factors that could affect consent rates

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include in-person approaches by trained personnel, physician participation in consent discussions, consent registration and family override of the expressed wishes of the decedent. The authors of the related research article identified such modifiable factors, but it is not clear that acting on these can affect consent rates. Canada lags other countries in collecting data on donations that can inform performance, including data that would allow calculation of comparative consent rates. Family override of a registered decedent's wishes remains a challenge, and this highlights a disconnect between legislation and practice. Under Canadian law, families have no legal authority to withhold consent if the deceased person provided valid consent,¹² yet family override of legally valid registered consent may be important and modifiable. Staff in intensive care units and organ donation programs understandably do not wish to conflict with families during the delicate phase of end-of-life care, and they may be uncertain about their legal authority to uphold a decedent's wishes rather than those of their family. In the United States, this has been addressed by adopting the legally mandated "authorization to proceed" with organ donation, by which the donor's wishes, not the family's, are honoured.¹³

Addressing the shortage in transplantable organs, and bridging the gap between expressed public support and actual consent rates, has led to frequent calls in the popular press and by politicians for changes in the consent system, from an opt-in to an opt-out or presumed consent approach. Countries with presumed consent systems trend toward higher donation rates and transplant rates. Although presumed consent is intended to improve organ donation and transplant rates, the most relevant metric is such policies' impact on consent rates, yet this outcome is omitted from many published reports. Data from Wales showed statistically significant improvements in donation and consent rates since implementing the assumption of presumed consent.¹⁴ England passed a new presumed consent law in May 2020 (<https://www.organdonation.nhs.uk/uk-laws/organ-donation-law-in-england/>). In January 2021, Nova Scotia became the first jurisdiction in North America to move to presumed consent (<https://novascotia.ca/organ-and-tissue-donation-changes/>).

Presumed consent will not affect organ donation and transplant rates substantially unless health systems also ensure that hospitals are prepared to manage donation with best practices. These include processes to allow for donation after cardiac death, timely and mandatory identification and referral of potential donors, retention of donation-focused personnel, clinical capacity for donation and transplant services, and comprehensive data to inform performance. Nova Scotia has recognized the need for investment in system strengthening, in concert with adopting presumed consent.

Given these requirements, many questions remain about the best ways to optimize consent. For example, should a provincial system address modifiable variables within an opt-in system, as implied by the authors of the related research? Or should the system instead strive ardently to adopt presumed consent, assuming that presumption of consent will also drive an improvement in donor referral rates? Can society see improvements in consent and donation rates without compromising the legitimate right to refuse to donate? What is the best strategy to improve consent rates in a diverse, multiethnic society? Policy-makers, organ donation and

transplant system operators and academics will be closely observing the impact of the social experiment created by Nova Scotia's new policy. Although ethnocultural demographics vary among provinces, contrasting the Nova Scotia opt-out experience with the Ontario opt-in experience will be informative for the whole country.

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