

# MANDATORY REFERRAL

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## INTRODUCTION

### MANDATORY REFERRAL IS AN EVIDENCE-BASED BEST PRACTICE

In 2021, The International Donation and Transplantation Legislative and Policy Forum, hosted by Transplant Québec and co-hosted by the Canadian Donation and Transplantation Research Program (CDTRP), assembled international experts in the fields of donation and transplantation to provide expert guidance on the structure of an ideal organ and tissue donation and transplantation system.

The Forum concluded that mandatory referral is a key evidence-based best practice among global deceased organ and tissue donation and transplantation leaders.

### WHAT IS MANDATORY REFERRAL?

Mandatory referral is a legal requirement that healthcare professionals report all patients who may become potential donors to their organ donation organization (ODO) [1]. This requirement is an essential building block of a high-functioning organ and tissue donation and transplantation (OTDT) system because it supports the timely identification, referral, and assessment of potential donors [2,3,4,5]. Notifying the ODO reduces the effect of clinical bias or lack of knowledge regarding donation, which has been identified as a leading cause of non-referral [6,7]. Mandatory referral is independent of the consent model and does not affect how families are approached to discuss consent to donate.



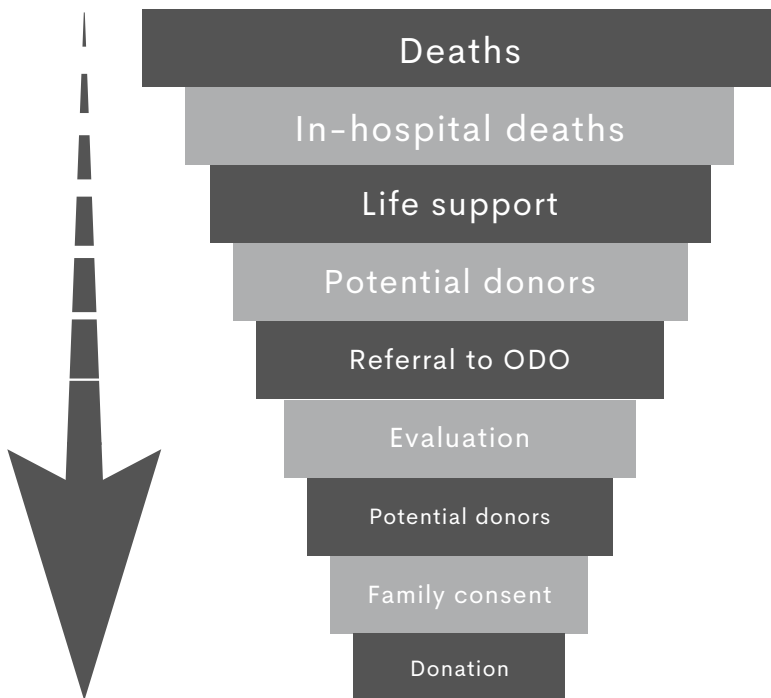
# WHY IS MANDATORY REFERRAL IMPORTANT?



Registering as an organ donor or sharing your wishes with your family does not mean you will become an organ donor. The pathway to becoming a deceased organ donor is complex because individuals need to die in circumstances where donation is even possible. Contrary to common assumptions, those circumstances are rare. As a proportion of total deaths in Canada, approximately 1.2% have the potential to become donors [8]. Each patient who is potential donor is rare and identification and referral of those patients is the only way they will become an actual donor.

However, failure to identify possible donors is the largest factor explaining differences in deceased donation rates nationally [9] and internationally [4]. Missed donor opportunities occur when potential donors are not identified and ODOs are not notified [1] or referrals are received too late [10]. Missed donor opportunities also occur when potential donors are identified by the treating medical team, but they choose not to notify the ODO [1]. In cases of late or non-referral, life-sustaining therapy is withdrawn in a way that excludes the possibility of donation, [11,12,13,14] preventing the wishes of the patient and their families towards donation to even be considered [2,15].

## Pathway to deceased donation



Mandatory referral should be coupled with requirements for public reporting and investigation of missed donor opportunities to ensure compliance. This is done through auditing death records (i.e., retrospective auditing of the records of all patients who could have been donors) allowing OTDT systems to learn from missed donor opportunities and implement system improvements [2,16]. Public reporting also helps maintain trust in an OTDT system.

# BENEFITS OF MANDATORY REFERRAL

- Mandatory referral ensures that every family and individual is given the opportunity to include donation in their end-of-life care if they so desire.
- The patient's medical suitability for donation is assessed earlier by clinicians who are experts in donation and transplantation. This may reduce delays for the hospital and ensure the availability of supporting infrastructure (i.e., operating room).
- Assessment of donation suitability can occur in all instances with the timely identification of potential organ donors, helping avoid missed donation opportunities.
- It ensures that a potential donor is maintained on life support, which is essential to the usability of organs.
- Family discussions can be planned when suitability for donation has been determined, which gives families the right information at the right time. This reduces uncertainty and disappointment on occasions when families are approached too soon, and then later told their loved one is not actually eligible to be a donor.



## MANDATORY REFERRAL IN CANADA

A 2014 report on deceased organ donor potential in Canada reviewed the medical records of deceased patients who were clinically eligible to donate. Only 1 in 6 potential donors in Canada are converted to donors [17].

British Columbia, Manitoba, Ontario, Quebec, and Nova Scotia have aspects of legislated mandatory referral. Alberta's legislation currently includes mandatory consideration, which states, "when a person dies, the medical practitioner who makes the determination of death must consider and document in the patient's record the medical suitability of the deceased person's tissue or organ for transplantation" [18]. A criticism of this system is that the medical practitioner may or may not be informed of the details that will determine if person is suitable to become an actual donor. No other provinces and territories has similar provisions in their legislation.

In addition to the recent Forum, mandatory referral is supported by Canadian Blood Services and patient organizations (i.e., The Kidney Foundation of Canada, Canadian Liver Foundation, the Lung Association) [19]. A 2018 report to the federal government's Standing Committee of Health identified mandatory referral as a priority recommendation and has been identified as a priority policy choice by experts in donation policy [20,4,21,22,9].

## MANDATORY REFERRAL VS PRESUMED CONSENT (OPT-OUT)

Mandatory referral is not presumed consent and does not presume all individuals have consented to donation. Mandatory referral requires clinicians or administrators to notify the ODO about a potential donor for evaluation, and the families of eligible potential donors are then approached for consent if they are deemed medically eligible. A presumed consent model presumes all individuals have consented to donation unless measures were taken before death to opt-out (e.g., via an online registry, sharing decision with next of kin). In Canada, only Nova Scotia has legislated the presumed consent model. Their legislation also includes mandatory referral. With all donor identification practices and ethical consent models, families/next-of-kin are involved in the decision to donate.



## EVIDENCE THAT MANDATORY REFERRAL IMPACTS DECREASED DONATION RATES

It is difficult to measure the impact of a single system change, such as mandatory referral, on deceased donation rates. In Canada, the provinces with mandatory referral have also implemented additional strategies to optimize deceased donation rates. This includes the adoption of donation after circulatory death, the establishment of agencies responsible for the implementation and monitoring of donation strategies, (e.g., BC Transplant, Trillium Gift of Life Network, Transplant Québec), establishment of donation specialist teams responsible for the management of potential donors, and investment in public awareness campaigns and professional education.

When Nova Scotia became the first Canadian province to implement a presumed consent model, and included mandatory referral in its legislation, Health Canada funded the Legislative Evaluation – Assessment of Deceased Donation Reform Program (The LEADDR Program). The LEADDR Program will evaluate how Nova Scotia's legislation impacts deceased donation rates, and will quantify the impact of mandatory referral through the review of potential donor audits [23].

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