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ORGAN EXPERT COMMITTEE:

HOW CAN THE SYSTEM IMPROVE AND INCREASE IDENTIFICATION AND REFERRAL OF POTENTIAL DONORS? (DRAFT SOLUTION DESIGN PAPER)

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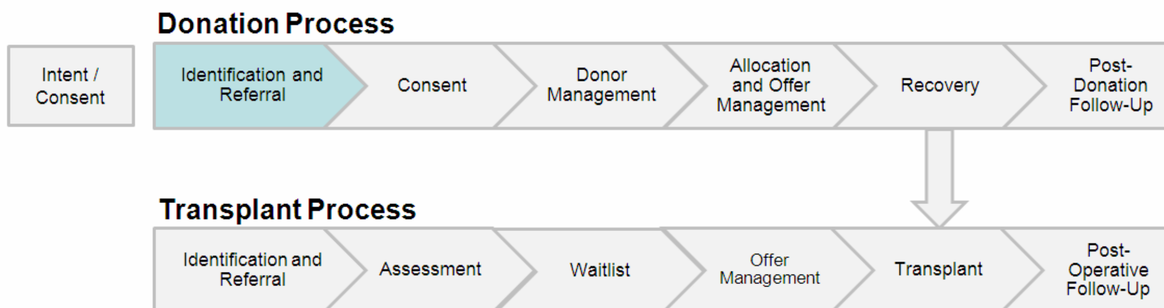
1. Scope

HOW CAN THE SYSTEM IMPROVE AND INCREASE IDENTIFICATION AND REFERRAL OF POTENTIAL DONORS?



There is strong support for organ donation among healthcare professional organizations (i.e.; 99% approve of organ and tissue donation)[1]; however, it is generally agreed that not every potential donor is identified and subsequently referred for donation. This document will explore the current situation and examine solutions to increase potential donor identification and referral in hospital.

The scope of this analysis includes consideration for making identification and referral of potential donors common practice as well as mechanisms for implementing, monitoring and enforcing different identification and referral options. The focus of this question is potential organ donors although it is understood that some findings and recommendations may be relevant for tissue donation. This paper includes consideration for identification and referral of all potential deceased donors, although donation after cardiocirculatory death (DCD) donors may have different processes. Not included in this analysis are donor management, family approach and requesting, and living donors.

[1] Canadian Council for Donation and Transplantation. Health Professional Awareness and Attitudes on Organ and Tissue Donation and Transplantation, including Donation after Cardiocirculatory Death, 2006

2. Current State

This section seeks to provide a brief overview of how the question considered in this paper is being thought about and addressed both within Canada and in foreign systems. The "Current State" sub-section provides a synopsis of the relevant portions of the current Canadian ODT system. The "Current Community Thinking" sub-section summarizes a sampling of domestic and international viewpoints related to the topic. The "Other Models" sub-section highlights a limited selection of organizations or jurisdictions that currently address this paper's central question in ways that may inform a broader view of possible solutions.

A. Current State

Identification of potential organ donors and timely referral to donation programs are critical to increasing the availability of organs for transplant. Potential organ donors are most often identified in emergency departments or intensive care units where the outcome can be largely influenced by the knowledge of donation, commitment, and interest of the health care providers. The process for donor identification and referral varies between hospitals and provinces and is slightly different between brain dead donors and donation after cardiocirculatory death donors.

Although there is variability across the country in the management of catastrophically brain injured patients and the referral for organ donation, there are enough consistencies in the process to identify critical steps to ensure organ donation can happen when appropriate. The recommendations from the Severe Brain Injury to Neurological Determination of Death forum in 2003 provided minimum standards and a code of practice for the care of patients whose injuries result in NDD.[2] Among the recommendations from the forum was the identification of minimum criteria as a Canadian standard for neurological determination of death. These criteria identify clinical testing and the minimum physician qualifications for declaration of NDD. Additionally, the forum included recommendations about the legal timing of death and the reporting of death through a single mechanism, specifically the certificate of death. Finally, the forum provided recommendations for prognostication and management of patients with severe brain injury and a standard for end-of-life care that includes the option of organ and tissue donation for eligible patients.

In Canada neurological death is not a cause of death that is routinely reported and is rarely noted on the death certificate.[3] As a result, it is difficult to estimate with confidence the number of missed potential donors. While this may vary between

[2] Canadian Council for Donation and Transplantation. Severe Brain Injury to Neurological Determination of Death: A Canadian Forum. Report and Recommendations, 2003

[3] Canadian Institute for Health Information. Refining Estimates of Potential Deceased Organ Donors from Patient Hospitalization Discharge Records: Findings of a Pilot Project, 2005

individual centres and regions, it is generally agreed that a large number of potential donors are missed and that referral to critical care for diagnosis and prognostication by an appropriate physician, combined with timely notification of the OPO, would increase the number of organ donors in Canada.

Donation after Cardiocirculatory death (DCD) has been implemented in some hospitals although the number of DCD donors in Canada is still low. The identification and referral of potential DCD donors is different than brain death donors and different attending staff may be involved. Most hospitals that have implemented DCD donation have policies governing the management of these donors which include guidelines for identification and referral.

Many hospitals have criteria to identify potential donors, sometimes called clinical triggers, which guide the treating healthcare staff on when to contact the organ procurement organization (OPO). Knowledge of the criteria may vary, thus potentially reducing the effectiveness of the "clinic triggers". In addition, Accreditation Canada has new standards for hospitals with donation practices. Included in these new standards is the requirement for hospitals to have donation committees.

One strategy common to high performing countries is the existence of in-hospital donor coordinators. Spain has had notable success in increasing organ donation and they credit their network of coordinators as a key element of that success[4]. The United Kingdom has adopted a similar approach and has hired in-hospital coordinators for all their major hospitals. In Canada, some provinces have dedicated in-hospital donor coordinators, others have added donation to the transplant coordinator duties, and in some locations, organ donation is included as part of the job description for nurses in ICUs and EDs. In addition to the clinical responsibilities of organ donor coordinators, they are often also responsible for education and awareness activities to increase awareness among health practitioners and hospital staff.

Legislation exists governing the required referral of donors in British Columbia, Ontario, Alberta and Manitoba. In other provinces, referral is at the discretion of the attending physician.

B. Current Community Thinking

I. Reports and Papers

Organs for Transplants: A report from the Organ Donation Taskforce, 2008[5]

The objective of the UK Taskforce was to identify the obstacles to organ donation and suggest solutions to increase transplantation. The authors suggest that organ donation should be a normal part of end-of-life care (including timely consultation with the NHS Organ Donor Registry) and that each hospital should have an identified clinical donation champion and

[4] Matesanz, Rafael, Beatriz Dominguez-Gil. Strategies to optimize deceased organ donation, 2007
[5] Organ Donation Taskforce (UK). Organs for Transplants: A report from the Organ Donation Taskforce, 2008

committee to help achieve this. Further, this report recommends that minimum notification criteria should be introduced and that donation activity should be monitored and reported.

Deceased Organ Donation in Canada: An Opportunity to Heal a Fractured System, 2008[6]
The authors recommend mandated identification and documentation of brain death by physicians in hospitals in order to improve organ donation in Canada. Further, the authors recommend that demonstration of satisfactory organ donation performance should be required for hospital accreditation.

Parliamentary Information and Research Service. Organ Donation and Transplantation in Canada, 2009[7]
This paper provides an overview of the Canadian experience with respect to the federal role in organ donation and transplantation and discusses options for increasing the donor rate. Included in this paper is a review of required referral and request legislation. The author acknowledges that while the introduction of legislated donor referral would increase the number of donors, it would be a further stressor on the health care profession and would require additional resources.

The Importance of Emergency Medicine in Organ Donation: Successful Donation is More Likely When Potential Donors are Referred from the Emergency Department, 2009[8]
This article reports on a study that was done in the United States with data from 78 hospitals from over a 45 month period. The authors concluded that the referral of potential organ donors directly from the emergency department to the organ procurement service is associated with an increased likelihood of successful organ retrieval compared to referral from other inpatient settings. The authors recommend that further attention and resources should be directed toward the role of emergency medicine in the organ procurement process.

Health Care at the Crossroads: Strategies for Narrowing the Organ Donation Gap and Protecting Patients, 2004[9]
One of the recommendations in this white paper is to create a culture in which organ donation is a priority. Specifically, the Joint Commission recommends encouraging physicians and hospital staff to work in partnership with organ procurement organizations (OPOs) and to place in-hospital coordinators in Level 1 Trauma Centers wherever it is economically and logistically feasible.

[6] Gill, J.S., S. Klarenbach, E. Cole, S. D. Shemie. Deceased Organ Donation in Canada: An Opportunity to Heal a Fractured System, 2008
[7] Norris, Sonya. Parliamentary Information and Research Service. Organ Donation and Transplantation in Canada, 2009
[8] Michael, Glen, E. O'Connor. The Importance of Emergency Medicine in Organ Donation: Successful Donation is More Likely When Potential Donors are Referred from the Emergency Department, 2009
[9] Joint Commission on Accreditation of Healthcare Organizations (US). Health Care at the Crossroads: Strategies for Narrowing the Organ Donation Gap and Protecting Patients, 2004

The authors reference the Organ Donation Breakthrough Collaborative in the Unites States as a tool to identify and spread best practices, ultimately improving organ donation rates in participating locations.

Efficacy of Routine Notification and Request on reducing corneal transplantation wait times in Canada, 2009[10]
The authors studied whether routine notification and referral affected corneal tissue availability and concluded that the legislative changes in routine notification and referral in Manitoba, Ontario, New Brunswick and British Columbia, have been effective in increasing the amount of corneal tissues obtained and utilized. The authors recommend similar legislation for all provinces in Canada and state that education, enforcement, and compliance are critical for the long term success of programs.

II. Forums

Severe Brain Injury to Neurological Determination of Death: A Canadian Forum
(Canadian Council for Donation and Transplantation)
April 9 - 11, 2003
The purpose of the Forum was to initiate the development of a national agreement on the processes of care, commencing with severe brain injury and culminating with neurological determination of death. The overarching recommendation that resulted from the Forum was that "after neurological determination of death, the patient be declared dead". The panel further recommended that for patients who die as a result of severe brain injury, standard post-mortem care include the option for eligible patients of donating organ(s) and/or tissue.

National Consultation: Organ and Tissue Donation and Transplantation
(Canadian Blood Services)
September 22 - 24, 2008, Gatineau, Quebec
Participants in the consultation recommended the establishment of mandatory reporting and routine referral for organ and tissue donation which would be implemented for all patients at or near time of death. They also recommended that donation be made a standard of care in both Critical Care and Hospital Care practices.

C. Other Models

Spanish Model
The Spanish Model includes a network of highly trained donation coordinator physicians, based in hospitals, who are independent of the transplant team. These physicians are directly involved in the process of donation; they develop proactive programs on donor

[10] Rasouli, Mahta, V. Caraiscos, A. Slomovic. Efficacy of Routine Notification and Request on reducing corneal transplantation wait times in Canada, 2009

detection; and they are in charge of donor evaluation and maintenance, family and judicial approach as well as coordination of organ procurement. Spain has applied a continuous audit of brain death in intensive care units to identify areas for improvement. In addition, they have invested effort into training and education of professionals directly or indirectly involved in the process of donation, with special emphasis in the training of new and existing hospital transplant coordinators.[11]

Australia

Australia recently introduced a package of national reforms regarding organ and tissue donation and transplantation. Funding has been provided to employ trained medical specialists dedicated to organ donation in select hospitals. These specialists will coordinate organ and tissue donation activity and outcomes, and support and educate hospital teams in line with the national programs. Australia will be introducing clinical trigger checklists to provide nationally consistent protocol and strict criteria to ensure identification of potential organ donors by clinic staff. In addition, appropriate referral protocols will also be established.[12] As part of the Australian reforms, a new national authority is being established to maintain and audit the implementation of the new protocols and standards.

United Kingdom

The United Kingdom has introduced a number of initiatives aimed at improving organ donation. One of their key activities has been the establishment of dedicated donor coordinators in hospitals who report directly to NHS Blood and Transplant (NHSBT). These coordinators are responsible for supporting organ donation through working with the families and physicians. One key role of the coordinators is to educate healthcare and hospital staff on organ donation. NHSBT has implemented a hospital policy for organ and tissue donation that guides the identification and referral of potential donors and the involvement of the donor coordinator.[13] Chart audits are done to monitor compliance with established protocols. In addition, the UK has identified medical leads in donor hospitals who work with physicians to influence and change practice to improve organ donation.

United States

There is variability in the United States with regard to potential organ donor identification and referral; however, many successful programs have implemented best practices as identified through the Organ Donation Breakthrough Collaborative. The United States government mandates donor referral and many hospitals have in-house organ donor coordinators, widely considered as best practice in the US.

[11] Matesanz, Rafael, Beatriz Dominguez-Gil. Strategies to optimize deceased organ donation, 2007
[12] Government of Australia. A World's Best Practice Approach to Organ and Tissue donation for Australia: Overview. http://www.health.gov.au/ , 8 Sept 2009
[13] UK Transplant. United Kingdom Hospital Policy for Organ and Tissue Donation. 2006

3. Analysis

This section briefly describes the data collected and reviewed, the assumptions made, the analysis conducted, and the findings discovered during the process of identifying a slate of recommendations. For the sake of conciseness, most, if not all, of the background research and analysis details are not included. The findings listed in this section are those that seem most applicable to the evaluation of possible solutions to the central question of this paper.

A. Analysis Approach

A thorough analysis of existing research and legislation has been conducted to provide the basis for this document. In addition, some Organ Expert Committee members have been consulted and their views are reflected within the content of this paper.

Assumptions underlying the analysis include:

- Any additional resources to support implementation will need to be based on a business case that demonstrates opportunities for improved performance.

The analysis included identification of the various stages and potential gaps in organ donor identification and referral. Canadian and international models were compared to identify leading practices, which were further reviewed using a SWOT analysis.

B. Findings

A common model among countries striving to improve organ donation is the establishment of in-hospital donor coordinators. There are various models using in-hospital coordinators with the Spanish Model being an oft-cited best practice. Other countries have modified the Spanish Model and implemented in-hospital coordinators in a structure that responds to their unique environment and needs. Beyond in-hospital coordinators, a number of locations, including Spain and the United Kingdom, have also identified a physician coordinator/champion role that has responsibility for the organ donation program and for effecting change among other physicians.

Another common finding among high performing countries is the attention to professional education and awareness of organ donation. In some countries professional education and awareness is one of the responsibilities of in-hospital coordinators while some locations have given the responsibility to the organ procurement organizations or donor programs. The United States has implemented the Transplant Growth and Management Collaborative as a national professional education and performance improvement model.

4. Options and Considerations

The purpose of this section is to provide options as a starting point for discussing the central question of this paper. The options provided are intended to illustrate a range of plausible solutions; it is likely that the Committee will ultimately recommend solution(s) to this question that incorporate elements of multiple options in addition to any elements or mechanisms that may not be represented in this paper.

In addition to the options, this section suggests "considerations" that may be helpful to reflect on during the discussion of solution options.

A. Options

Options identified during this research and analysis have been presented in response to three broad questions: 'What are the appropriate policy mechanisms to increase referral?'; 'What is the most effective staffing structure to support identification and referral of potential donors?'; and 'What is the most effective funding and implementation structure to support education and awareness among health care professionals of organ donor identification and referral?'.

I. What are the appropriate policy mechanisms to increase referral?

a) Legislated referral of potential donors

Legislated referral would require that health care professionals report all brain deaths and cardiac deaths to the organ procurement organization. A robust accountability framework would be established. Mechanisms to audit and report on performance would be required to ensure accountability and, ultimately, compliance with the legislation.

Strengths	Weaknesses
▪ Would ensure that potential donors are not missed due to a lack of referral ▪ Would build greater access to donation within Canada ▪ Would ensure that potential donors are identified by providing guidance for reporting brain deaths and DCD ▪ Would help to identify opportunities to increase donor identification and referral through audit and reporting	▪ May put a stress on system resources as a result of additional potential donors being identified and referred ▪ Additional resources to audit and report on compliance would require ongoing funding

Barriers
▪ Would require legislative change at the provincial and territorial levels, with the exception of provinces with existing legislation ▪ Brain death is not currently reported on vital statistics forms making it difficult to monitor non-compliance

b) National support of best practices

National support of best practices would involve identification of high performing programs and facilitating the spread and implementation of best practices to other locations. While identification and referral would not be legislated, regular reporting, national recognition of success, and communication of best practices, including clinical triggers, would be part of the feedback loop for this option. This option is similar to the HRSA Transplant Growth and Management Collaborative in the United States.

Strengths	Weaknesses
▪ Would increase donor referral by contributing to a better understanding of potential donor criteria ▪ May increase access to donation across Canada by spreading best practices between hospitals	▪ Would not address the inequalities of the system as there is no requirement for participation or standardization ▪ May put a stress on system resources
Barriers	
▪ Requires a national body to develop and implement the strategy	

c) Status Quo

No changes to the current system.

Strengths	Weaknesses
▪ Would not require additional resources or a change in systems ▪ Provinces could continue to build on their existing process to realize improvement without coordinated involvement	▪ Would not contribute to building greater access to donation across Canada

II. What is the most effective staffing structure to support identification and referral of potential donors?

a) In-hospital donor coordinators

Place donation coordinators in major hospitals with organ donor programs. These coordinators would be responsible for the overall coordination of the organ donation program including the development of protocols, management of donor families, coordination of organ

placement, monitoring of outcomes, and reporting of overall performance.

Strengths	Weaknesses
▪ Would contribute to realizing donor potential and ultimately increasing donation	▪ Existing professional staff shortages may make it difficult to attract and retain sufficient coordinators ▪ Hospital volumes may be too low for dedicated coordinators
Barriers	
▪ Would require funding and infrastructure to support the hiring, training and management of in-hospital coordinators	

Various funding and management structures for the in-hospital donor coordinators could be considered including funding and oversight by the federal or provincial government, funding and oversight by the Organ Procurement Organization, or funding and oversight by a national body.

b) Donor coordinator network

Dedicated donor coordinators who provide support to a network of hospitals but are not located within hospitals. These coordinators would work with a number of hospitals and be responsible for the overall coordination of the organ donation program in their network including the development of protocols, management of donor families, coordination of organ placement, monitoring of outcomes, and reporting of overall performance.

Strengths	Weaknesses
▪ May improve access to organ donation in smaller hospitals by ensuring support of organ donor coordinators	▪ Location of the coordinators may make it difficult to imbed organ donation into the culture of the hospital ▪ Integration of the donor coordinators among hospital staff may be hindered by the structure
Barriers	
▪ Provinces with existing in-hospital coordinators may be experiencing value from the status quo and may not believe a network of coordinators would add additional value ▪ Would require funding and infrastructure to support the hiring and management of coordinators	

Similar to the in-hospital coordinators, various funding and management structures for the donor coordinator network could be considered including funding and oversight by the federal or provincial government, funding and oversight by the Organ Procurement Organization, or funding and oversight by a national body.

c) In-hospital physician donation champions

Identify and fund physician donation champions responsible for the overall direction of the organ donation program. The physician champions would receive remuneration for their involvement and would provide guidance, advice, and support to the organ donation program including working with other physicians to embed organ donation into practice. Depending on the size of the donation program, these physician donation champions may have dedicated time for organ donation or may take on the responsibility in addition to their regular duties/responsibilities.

Strengths	Weaknesses
▪ Would build greater access to organ donation by ensuring a consistent performance standard for organ donation ▪ Would contribute to improved organ donation activities by providing peer support and advice to other physicians ▪ Credibility of physician support could heighten donation success in part through influence on the practices of other physicians	▪ Existing physician shortages and sizeable workloads may make it difficult to attract and retain physician donor champions
Barriers	
▪ Provinces with existing structures that do not include physician champions may not realize additional value from a change in structure ▪ Would require funding and infrastructure to support the identification and support of physician donation champions	

d) Status Quo

No national requirement for organ donor coordinators or physician donation champions and no change to the current system in staffing for organ donation.

Strengths	Weaknesses
▪ Would not require additional resources or a change in systems ▪ Provinces could continue to build on their existing process to realize improvement ▪ Allows the provinces to autonomously determine the most appropriate and beneficial use of their funding and to determine the most effective structure for organ donation within their own jurisdiction	▪ Would not contribute to building consistency in practice with regard to organ donation across Canada

III. What is the most effective funding and implementation structure to support education and awareness among health care professionals of organ donor identification and referral?

a) Nationally funded and implemented education and awareness strategy

A national body would develop and implement a robust education and awareness strategy to improve knowledge among health care professionals about organ donor identification and referral.

Strengths	Weaknesses
▪ Would ensure that all provinces and territories have education / awareness activities regarding organ donor identification and referral improving equity of access to donation across Canada ▪ Would provide a consistent message about organ donation contributing to consistent understanding among those engaged by it ▪ Would allow for economies of scale in the development and production of education / awareness materials	▪ Differences in donor identification and referral processes between provinces and hospitals may make it difficult to develop consistent national messages ▪ Differences in diversity and make-up of regions and differences in local approaches to issues may make it difficult to implement national messages

Barriers
▪ Provinces or OPOs with effective education and awareness activities may not see value in a national program ▪ National responsibility and funding would be required for development and implementation

b) Nationally developed materials to support locally implemented education and awareness strategies

A national body would develop education and awareness materials which would be used locally to improve knowledge among health care professionals of organ donor identification and referral. These materials would build upon current activities and provide consistency in messaging between provinces. The ability to allow local information to be added to the national materials would be determined as part of the development of the materials.

Strengths	Weaknesses
▪ Would provide a consistent message about organ donation, thus contributing to consistent understanding among those engaged by it ▪ Would allow for economies of scale in the development and production of education / awareness materials	▪ Differences in donor identification and referral processes between provinces and hospitals may make it difficult to develop consistent national messages ▪ Existing and emerging resource constraints may impact the ability of programs to implement an awareness program
Barriers	
▪ Provinces or OPOs with effective education and awareness activities may not see value in national materials ▪ National funding would be required for development and production of materials	

c) Status Quo

No national strategy or materials for professional education and awareness regarding organ donor identification and referral. Any awareness activity would remain the responsibility of the local / provincial programs.

Strengths	Weaknesses
▪ Would not require additional resources or a change in current activity ▪ Allows the provinces to determine the most appropriate and effective awareness-building activities within their region	▪ Would not contribute to building consistency in knowledge in regards to organ donor identification and referral across Canada

B. Considerations

During the analysis of data and the identification of options, several considerations to reflect upon were identified during the resolution process. Although these considerations may be more or less applicable depending on the option being discussed, each of them is intended to bring pertinent facts, limitations, ideas, or notes to the attention of the committee before a recommendation or set of recommendations is finalized.

- **Combining Options**
  The options that have been presented can be combined as part of an overall solution to the question. For example, in-hospital donor coordinators could be part of a structure that includes physician champions. In addition, in-hospital coordinators may have professional education and awareness as one of their responsibilities.

- **Size and Capacity**
  Certain options may be more feasible for hospitals of a certain size and capacity for organ donation. A specific option which may seem optimal for one hospital, may not be the best option for another hospital. For this reason, different holistic recommendations for different classifications of hospitals may need to be considered.