Background Paper for the Organ Expert Committee

How can the organ donation and transplantation system help the public convert its support for donation into action?

Contents

1. Introduction ......................................................................................................................... 2
   A. Background .................................................................................................................... 2

2. Scope ................................................................................................................................. 3

3. Current State ...................................................................................................................... 3
   A. Current State ................................................................................................................ 3
   B. Current Community Thinking ..................................................................................... 4
   C. Other Models ............................................................................................................... 6

4. Analysis ............................................................................................................................. 7
   A. Analysis Approach ...................................................................................................... 7
   B. Findings ....................................................................................................................... 7

5. Options and Considerations ............................................................................................. 7
   A. Options ....................................................................................................................... 7
   B. Consideration .............................................................................................................. 14
1. Introduction

A. Background

Recognizing the need to improve the organ and tissue donation and transplantation (OTDT) system in Canada, the federal, provincial (except Quebec) and territorial governments in April 2008 asked Canadian Blood Services to take on new responsibilities related to OTDT. This included the development of a strategic plan for an integrated OTDT system, in collaboration with the OTDT community. As part of this work, three committees were formed – the Steering Committee, Organ Expert Committee and Tissue expert Committee – to help develop the recommendations through a formal, structured planning process.

This document is one of a series of background documents developed to help the committees in their discussions. These documents focused on the critical issues within the system, describing the current state and examining potential options and solutions. Conclusions from the committee discussions were consolidated and incorporated in the final recommendations of the final report. The full report, Call to Action: A strategic plan to improve organ and tissue donation and transplantation performance for Canadians, can be found at organsandtissues.ca, along with the other background documents in this series.

Limitations of these documents:

- These documents provided an overview of the issue for further discussion by experts in the field of OTDT. The findings and evaluations contained in these documents are not comprehensive—they reflect what was considered to be most applicable to the issue at the time.
- Information in these documents presents knowledge available at the time of the OTDT committee meetings. These documents have been edited for consistency in style and format, but have not been updated to reflect new information or knowledge. References and web links also remain unchanged and may no longer be accurate or available.
- As these are background documents to the Call to Action report which is available in both English and French, they are available in English only. Requests for translation can be made to Canadian Blood Services using the contact information below.

Note: Production of this document has been made possible through a financial contribution from Health Canada. The views expressed herein do not necessarily represent the views of the federal, provincial or territorial governments.

For more information on these documents or the Call to Action report, please contact:

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feedback@blood.ca
How can the organ donation and transplantation system help the public convert its support for donation into action?

2. Scope

This paper explores ways to convert public support for organ donation into action. The scope includes a review of the concept of, and evidence related to, first-person donor intent and consent registration, as well as an analysis of related legislation. The paper also examines public and professional awareness and its contribution to ensuring donors understand the option of donation and the importance of expressing their wishes to families.

Although the primary focus of this paper is organ donor consent, it is understood that tissue donation consent is similar. Although much of the analysis may be relevant for organs and tissues, variations on donor consent options may need to be considered.

This paper does not address either living donors or the identification and referral of potential donors in healthcare settings (the latter is included in another paper).

3. Current State

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 (EDs) or intensive care units (ICUs) where the outcome can be largely influenced by the knowledge of donation, commitment, and interest of the healthcare providers. The process for donor identification and referral varies among hospitals and provinces and is slightly different between brain dead (NDD) donors and donation after cardio-circulatory death (DCD) donors.

Although there is variability across the country in the management of catastrophically brain injured patients and their referral for organ donation, there are enough consistencies in the process to identify the 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 set out minimum standards and a code of practice for the care of patients whose injuries result in NDD.\(^1\)

Among the recommendations was the identification of minimum criteria as a Canadian standard for neurological determination of death—criteria that include clinical testing and the minimum physician qualifications for declaration of NDD. Additionally, the forum included recommendations about the

How can the organ donation and transplantation system help the public convert its support for donation into action?

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 routinely reported cause of death and is, therefore, rarely noted on the death certificate.2 As a result, it is difficult to estimate with confidence the number of missed potential donors. While the number of missed donors likely varies by location, it is generally agreed that the number is large, and that referral to critical care for diagnosis and prognostication by an appropriate physician, combined with timely notification of the organ procurement organization (OPO), would increase the number of organ donors in Canada.

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 NDD donors, and different attending staff may have to be involved. Most hospitals that have implemented DCD donation have policies that govern the management of these donors, and that include guidelines for identification and referral.

Many hospitals identify potential donors according to criteria (sometimes called clinical triggers) that guide treating healthcare staff on when to contact the OPO. Knowledge of the criteria may vary, thus potentially reducing the effectiveness of the clinical triggers. In addition, Accreditation Canada has new standards for hospitals with donation practices. These standards include the requirement for hospitals to have donation committees.

One strategy common to high performing countries is the use of in-hospital donor coordinators. Spain credits its network of coordinators as a key part of its success in increasing organ donation.3 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 transplant coordinator’s duties and, in some locations, organ donation is included as part of the job description for nurses in ICUs and EDs. In addition to their clinical responsibilities, organ donor coordinators are often also responsible for education and awareness activities for health practitioners and hospital staff.

The referral of donors is required by law in British Columbia, Ontario, Alberta and Manitoba. In other provinces, referral is at the discretion of the attending physician.

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

3 Matesanz, Rafael, Beatriz Dominguez-Gil. Strategies to optimize deceased organ donation, 2007

B. Current Community Thinking

This section of the paper presents recent findings and recommendations from national and international reports to inform operating and funding model discussions.

Reports and Papers

Organs for Transplants: A report from the Organ Donation Taskforce, 20084

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 (which should also include timely consultation with the NHS Organ Donor Registry), and that each hospital should identify a clinical donation champion and committee to help achieve this. Further, this report recommends that

4 Organ Donation Taskforce (UK). Organs for Transplants: A report from the Organ Donation Taskforce, 2008
minimum notification criteria should be introduced and that donation activity should be monitored and reported.

The authors recommend that physicians in hospitals be mandated to identify and document brain death 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
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 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 further stress the healthcare profession and 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
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
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 OPOs and to place in-hospital coordinators in level 1 trauma centres wherever it is economically and logistically feasible. The authors reference the Organ Donation Breakthrough Collaborative in the United 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
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.

Forums
Severe Brain Injury to Neurological Determination of Death: A Canadian Forum (Canadian Council for Donation and Transplantation)
April 9 to 11, 2003
How can the organ donation and transplantation system help the public convert its support for donation into action?

The forum initiated 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 to donate organs and tissue.

National Consultation: Organ and Tissue Donation and Transplantation (Canadian Blood Services)

September 22 to 24, 2008 — Gatineau, Quebec

Participants recommended the establishment of mandatory reporting and routine referral for organ and tissue donation. This reporting and referral would be implemented for all patients at or near time of death. Participants also recommended that donation be made a standard in both critical care and hospital care practices.

C. Other Models

Spain

The Spanish system includes a network of highly trained donation coordinator physicians, who are based in hospitals and independent of the transplant team. These physicians are directly involved in the process of donation: they develop proactive donor detection programs, 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, Spanish authorities 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.10

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 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 a nationally consistent protocol and strict criteria to ensure identification of potential organ donors by clinic staff. Appropriate referral protocols will also be established.11 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 key activity 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 by working with physicians and donors’ families. One important 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.12 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

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10 Matesanz, Rafael, Beatriz Domínguez-Gil. Strategies to optimize deceased organ donation, 2007
12 UK Transplant. United Kingdom Hospital Policy for Organ and Tissue Donation. 2006
How can the organ donation and transplantation system help the public convert its support for donation into action?

influence and change organ donation practice to improve outcomes.

United States

There is variability in the United States with regard to identification and referral of potential organ donors; 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 a best practice in the US.

4. Analysis

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.

It is assumed that any additional resources to support implementation will have to be determined 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 approach among countries striving to improve organ donation is the use of in-hospital donor coordinators. There are various models using in-hospital coordinators; however, the Spanish model is an oft-cited best practice. Other countries have modified the Spanish model and implemented in-hospital coordinators in a structure that meets to their individual environment and needs. Beyond in-hospital coordinators, a number of locations, including Spain and the United Kingdom, have also identified a physician coordinator or 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 organ donation professional education and awareness. In some countries, professional education and awareness is one of the responsibilities of in-hospital coordinators; some other locations have given this responsibility to 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.

5. Options and Considerations

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
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What are the appropriate policy mechanisms to increase referral?

**Legislated Referral of Potential Donors**

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

<table>
<thead>
<tr>
<th>Strengths</th>
<th>Weaknesses</th>
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<tbody>
<tr>
<td>• Would ensure that potential donors are not missed due to a lack of referral.</td>
<td>• May put a stress on system resources as a result of additional potential donors being identified and referred.</td>
</tr>
<tr>
<td>• Would build greater access to donation within Canada.</td>
<td>• Ongoing funding would be required to ensure additional resources are available for auditing and reporting on compliance.</td>
</tr>
<tr>
<td>• Would ensure that potential donors are identified by providing guidance for reporting brain deaths and DCD.</td>
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<tr>
<td>• Would help to identify opportunities to increase donor identification and referral through auditing and reporting.</td>
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**Barriers**

• Would require legislative change in some provinces and territories.
• Brain death is not currently reported on vital statistics forms, making it difficult to monitor non-compliance.

**National Support of Best Practices**

National support of best practices would involve identification of high performing programs and facilitating the sharing and implementation of best practices in 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 help ensure effective implementation. (This option is similar to the HRSA Transplant Growth and Management Collaborative in the United States.)
How can the organ donation and transplantation system help the public convert its support for donation into action?

<table>
<thead>
<tr>
<th>Strengths</th>
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</table>
| ● Would increase donor referral by contributing to a better understanding of potential donor criteria.  
● May increase access to donation across Canada by sharing best practices among hospitals. | ● Would not address the inequalities of the system as there is no requirement for participation or standardization.  
● May put stress on system resources. |

**Barriers**

● Requires a national body to develop and implement the strategy.

**Status Quo**

No changes to the current system.

<table>
<thead>
<tr>
<th>Strengths</th>
<th>Weaknesses</th>
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</table>
| ● Would not require additional resources or a change in systems.  
● Provinces could continue to build on their existing processes to realize improvement without coordinated involvement. | ● Would not contribute to building greater access to donation across Canada. |

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

**In-hospital donor coordinators**

Place donation coordinators in major hospital organ donor programs. These coordinators would be responsible for the overall coordination of organ donation program including the development of protocols, management of donor families, coordination of organ placement, monitoring of outcomes, and reporting of overall performance.
How can the organ donation and transplantation system help the public convert its support for donation into action?

<table>
<thead>
<tr>
<th>Strengths</th>
<th>Weaknesses</th>
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</table>
| • Would help realize donor potential and ultimately increase 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 in-hospital donor coordinators could be considered, including funding and oversight by the federal or provincial government, by the OPO, or by a national body.

#### Donor Coordinator Network

In this approach, dedicated donor coordinators 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 a networked organ donation program, including the development of protocols, management of donor families, coordination of organ placement, monitoring of outcomes, and reporting of overall performance.

<table>
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<th>Strengths</th>
<th>Weaknesses</th>
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| • May improve access to organ donation in smaller hospitals that are served by a network. | • Location of the coordinators may make it difficult to imbed organ donation into the culture of each hospital.  
• Integration of the donor coordinators among hospital staff may be hindered by the structure. |

### Barriers

• Provinces with existing in-hospital coordinators may not see additional value in this approach.  
• Would require funding and infrastructure to support the hiring and management of coordinators.
How can the organ donation and transplantation system help the public convert its support for donation into action?

**Donor Coordinator Network (cont.)**

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, by the OPO, or by a national body.

**In-Hospital Physician Donation Champions**

Identify and fund physician donation champions responsible for the overall direction of organ donation programs. These physicians would receive remuneration for their involvement and would provide guidance, and support to organ donation programs partly by working with other physicians to embed organ donation into practice. Depending on the size of the donation program, these physician donation champions may be dedicated to organ donation or may take on the responsibility in addition to their regular responsibilities.

<table>
<thead>
<tr>
<th><strong>Strengths</strong></th>
<th><strong>Weaknesses</strong></th>
</tr>
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<tbody>
<tr>
<td>• Would build greater access to organ donation by ensuring a consistent performance standard for organ donation.</td>
<td>• Existing physician shortages and sizeable workloads may make it difficult to attract and retain physician donor champions.</td>
</tr>
<tr>
<td>• Would contribute to improved organ donation activities by providing peer support and advice to other physicians.</td>
<td></td>
</tr>
<tr>
<td>• Credibility of physician support could heighten donation success in part through influence on the practices of other physicians.</td>
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**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.
How can the organ donation and transplantation system help the public convert its support for donation into action?

### 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.

<table>
<thead>
<tr>
<th>Strengths</th>
<th>Weaknesses</th>
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<tbody>
<tr>
<td>• Would not require additional resources or a change in systems.</td>
<td>• Would not contribute to building consistency in practice with regard to organ donation across Canada.</td>
</tr>
<tr>
<td>• Provinces could continue to build on their existing process to realize improvement.</td>
<td></td>
</tr>
<tr>
<td>• Allows 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 jurisdictions.</td>
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### 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 healthcare professionals about organ donor identification and referral.

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<th>Strengths</th>
<th>Weaknesses</th>
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</thead>
<tbody>
<tr>
<td>• Would ensure that all provinces and territories have education and awareness activities regarding organ donor identification and referral, thereby improving equity of access to donation across Canada.</td>
<td>• Differences in donor identification and referral processes between provinces and hospitals may make it difficult to develop consistent national messages.</td>
</tr>
<tr>
<td>• Would provide a consistent message about organ donation and contribute to a common understanding among those involved in it.</td>
<td>• Differences in regional diversity, make-up and approaches to issues may make it difficult to implement national messages.</td>
</tr>
<tr>
<td>• Would allow for economies of scale in the development and production of education and awareness materials.</td>
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How can the organ donation and transplantation system help the public convert its support for donation into action?

<table>
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<tr>
<th>Barriers</th>
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</table>
| • 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. |

**Nationally developed materials to support locally implemented education and awareness strategies**

A national body would develop education and awareness materials for use locally to improve knowledge among healthcare professionals in organ donor identification and referral. These materials would supplement current education and awareness activities and provide consistency in messaging among provinces. The ability to add local information to the national materials would be determined during development.

<table>
<thead>
<tr>
<th>Strengths</th>
<th>Weaknesses</th>
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</table>
| • Would provide a consistent message about organ donation contribute to a common understanding among those involved in it.  
• Would allow for economies of scale in the development and production of education and awareness materials. | • Differences in provincial and hospital donor identification and referral processes may make it difficult to develop consistent national messages.  
• Existing and emerging resource constraints may impact the ability of programs to implement awareness programs. |

<table>
<thead>
<tr>
<th>Barriers</th>
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</table>
| • 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. |

**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 or provincial programs.
Status Quo (cont.)

<table>
<thead>
<tr>
<th>Strengths</th>
<th>Weaknesses</th>
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<tbody>
<tr>
<td>● Would not require additional resources or a change in current activity.</td>
<td></td>
</tr>
<tr>
<td>● Allows the provinces to determine the most appropriate and effective awareness-building activities within their regions.</td>
<td></td>
</tr>
<tr>
<td>● Would not contribute to building consistency in knowledge in regards to organ donor identification and referral across Canada.</td>
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B. Considerations

Although the considerations listed here may be more or less applicable depending on the option being discussed, each is intended to bring pertinent facts, limitations and ideas to the attention of the committee before recommendations are 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, and in-hospital coordinators could 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 with a certain capacity for organ donation. An option that may seem optimal for one hospital may not be best for another. For this reason, different holistic recommendations for different classifications of hospitals may need to be considered.