

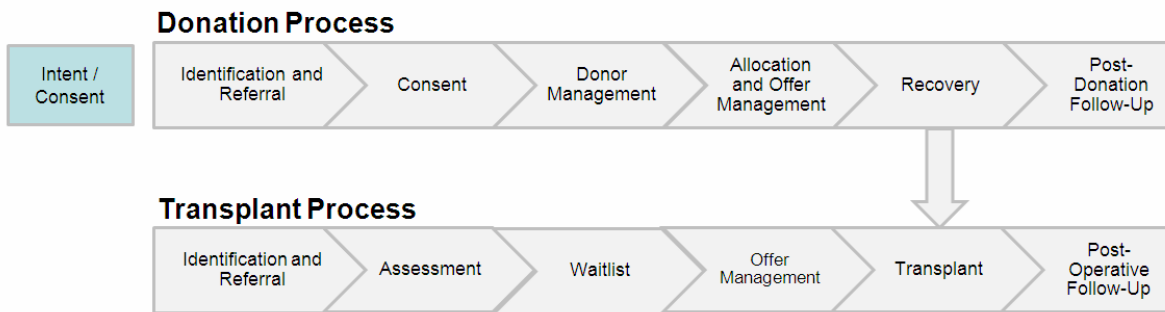
# **ORGAN EXPERT COMMITTEE: HOW CAN THE SYSTEM BETTER ENABLE THE PUBLIC TO TURN SUPPORT FOR ORGAN DONATION INTO ACTION? (DRAFT SOLUTION DESIGN PAPER)**

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# 1. Scope

HOW CAN THE SYSTEM BETTER ENABLE THE PUBLIC TO TURN SUPPORT FOR ORGAN DONATION INTO ACTION?



This document will explore potential solutions to move the public support of organ donation to action.

The scope of this document includes a review of the concept and evidence related to first person donor intent/consent registration including an analysis of related legislation. In addition to a review of first person consent registration, this analysis will include public and professional awareness and its contribution to ensuring donors understand the option of donation and the importance of expressing their wishes to their families. Although the primary focus of this question is organ donor consent, it is understood that tissue donation consent is similar in nature and while much of the analysis will be relevant for both, it is possible that variations on the options will need to be considered. Living donors are not considered in this analysis. Also, not included in this analysis is the identification and referral of potential donors in health care settings as this is included in another solution design question.

## 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

According to a recent survey, awareness of, and support for, the need and opportunity for organ donation in Canada is high, with 96% of Canadians approving of organ donation.<sup>1</sup> Despite this support, only 54% of Canadians have taken the action of indicating their intent by signing a donor card or registering on-line (where available).<sup>2</sup> Of those that have made a decision to donation, 74% indicate that they have discussed their wishes with the person who would act on their behalf in a medical emergency.<sup>3</sup>

All provinces and territories in Canada have processes for first person donor intent/consent that are based on voluntary, opt-in/informed consent practice. In Quebec, a registry is maintained by its notaries.<sup>4</sup> Three provinces, British Columbia, Nova Scotia<sup>5</sup> and Ontario<sup>6</sup>, maintain donor consent, or affirmative, registries. These registries are generally available to health care professionals through contact with the organ procurement organization or, in the case of British Columbia, by direct access to the registry. The remaining provinces and territories have mechanisms in place for interested individuals to indicate their preference regarding organ donation (e.g., motor vehicle licenses, health cards, organ donor cards), however, registration at a central/provincial registry does not occur. In these provinces, it is reportedly rare for hospital staff or organ donation staff to have access to this information as it is not

<sup>1</sup> Canadian Council for Donation and Transplantation. Public Awareness and Attitudes on Organ and Tissue Donation and Transplantation including Donation After Cardiac Death, 2005

<sup>2</sup> *ibid.*

<sup>3</sup> *ibid.*

<sup>4</sup> Norris, Sonya. Organ Donation and Transplantation in Canada. Parliamentary Information and Research Service, 2009

<sup>5</sup> *ibid.*

<sup>6</sup> <http://www.giftoflife.on.ca/>, 19 Aug 2009

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contained in a central location (e.g., registry) nor is the donor card readily available or accessible at bedside. In locations with registries, information on donor consent may not be readily available to hospital staff, but is regularly considered in requesting donation of family members.

Although first person donor consent is legally binding in Canada and there is no legal requirement that the family must also consent, it is common practice to seek consent from next of kin prior to proceeding with donation.<sup>7</sup> In a recent survey, 88% of Canadians surveyed indicated that they are very likely to consent to an organ donation for a deceased loved one who had indicated first person consent to donate and discussed their decision with them.<sup>8</sup>

There is some debate about the value of organ donor registries and whether or not they actually lead to increased donations. Germany does not have an organ donor registry, and in the United States, registries exist only in some areas<sup>9</sup>. Conversely, the United Kingdom and Australia maintain national registries which they actively promote.

Marketing and awareness campaigns have a role in educating the public about the need for organs, how to register or consent to organ donation and the importance of discussing ones wishes with family. A survey that was conducted following a national multi-media advertising campaign in 2002 found that one-third of those who saw the advertising said it made them more likely to consider donation and discuss their wishes with their family.<sup>10</sup> Aside from the national media campaign in 2002, there has been no national, consolidated public awareness campaign in Canada. There exists a range of public education and awareness activities being undertaken across Canada by different organizations. While these organizations are communicating similar key messages, they produce independent materials and there is no established system to share best practices.<sup>11</sup>

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<sup>7</sup> Downie, Jocelyn, Alison Shea, and Chantelle Rajotte. Family Override of Valid Donor Consent to Post-Mortem Donation: Issues in Law and Practice, 2006

<sup>8</sup> Canadian Council for Donation and Transplantation. Public Awareness and Attitudes on Organ and Tissue Donation and Transplantation including Donation After Cardiac Death, 2005

<sup>9</sup> Organ Donation Taskforce (UK), supplement report, 2008

<sup>10</sup> Heath Canada. Organ and Tissue Donation Awareness, Knowledge and Advertising Recall, 2002

<sup>11</sup> Canadian Council for Donation and Transplantation. Environmental Scan of Public Awareness & Donor Recognition Activities and Opportunities for National Collaboration, 2006

## B. Current Community Thinking

### I. Reports and Papers

#### **Family Override of Valid Donor Consent to Post-Mortem Donation: Issues in Law and Practice, 2006<sup>12</sup>**

This paper examines the legal status of family overrides of donor consent, the requirements for valid donor consent, the common practice concerning family overrides of valid consent and recommendations with respect to law reform and action. Donor consent practice in all provinces and territories meet the legislative requirement for written consent (e.g., a signed donor card, a sticker affixed to a health card, designation printed on the health card, or other provincial practice). The authors recommend a law and policy reform to reduce the possibility of family override to valid consent. In addition, the authors recommend policy reform so that protocols accurately reflect the law and that education and public awareness programs are undertaken to inform all relevant stakeholders that current practice of family override is not legally acceptable.

#### **Health Professional Awareness and Attitudes on Organ and Tissue Donation and Transplantation including Donation after Cardiocirculatory Death, 2006<sup>13</sup>**

The survey found that there is strong support from healthcare professionals for organ and tissue donation with the majority of respondents having expressed their intent to donate by either signing a donor card or registering as a donor. While 80% of healthcare professionals surveyed believe that donor's wishes should be respected, more than half identified that family or next-of-kin wishes took precedence in actual practice. Healthcare professionals are divided on the issue of presumed consent with 33% strongly supportive of presumed consent and 22% strongly opposed.

#### **A Systematic Review of Presumed Consent Systems for Deceased Organ Donation, 2009<sup>14</sup>**

This UK review examined the impact of presumed consent legislation on organ donation rates. The authors concluded that presumed consent alone is unlikely

<sup>12</sup> Downie, Jocelyn, Alison Shea, and Chantelle Rajotte. Family Override of Valid Donor Consent to Post-Mortem Donation: Issues in Law and Practice, 2006

<sup>13</sup> Canadian Council for Donation and Transplantation. Health Professional Awareness and Attitudes on Organ and Tissue Donation and Transplantation including Donation after Cardiocirculatory Death. 2006

<sup>14</sup> Rithalia, A., C. McDaid, S. Suekarran, G. Norman, L. Myers and A. Sowden. Health Technology Assessment. NIHR HTA programme (UK). A Systematic Review of Presumed Consent Systems for Deceased Organ Donation 2009

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to explain the variation in organ donation rates among countries and that other factors, for example legislation, availability of donors, system organization, infrastructure, and public attitudes and awareness all play a role in organ donation rates.

### **Parliamentary Information and Research Service. Organ Donation and Transplantation in Canada, 2009<sup>15</sup>**

This paper discusses options for increasing the donor rate including registries, presumed consent, and expanded donor criteria. The author recommends consideration of a national database of intended donors utilizing an opt-in system. The author also makes recommendations for consideration of a federally coordinated public awareness campaign to inform the general population of the importance of organ donation, dispel myths, and emphasize the importance of family involvement in consent.

### **Organ Donor Registries: A Useful but Limited Tool, 2002<sup>16</sup>**

This report concludes that while organ donor registries have contributed to increased effectiveness in OPO activities, the contribution that registries can make to increase organ donation is limited. Many OPOs use data from the registries to monitor the impact of education and marketing programs. The report concludes that caution should be exercised to avoid over-promising on the contributions that donor registries, by themselves, can make to increasing donation.

### **Public Awareness and Attitudes on Organ and Tissue Donation and Transplantation including Donation after Cardiac Death, 2005<sup>17</sup>**

The survey found that there is almost unanimous awareness of organ and tissue donation among Canadians surveyed and almost all approve of organ and tissue donation although only 54% of Canadians surveyed have taken the action of indicating their intent by signing a donor card or registering on-line. The majority believe that the wishes of the deceased either do, or should, take precedence over the wishes of the family when someone has signed a donor card or registered as a donor.

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<sup>15</sup> Norris, Sonya. Organ Donation and Transplantation in Canada. Parliamentary Information and Research Service, 2009

<sup>16</sup> Department of Health and Human Services (US). Office of the Inspector General. Organ Donor Registries. A Useful, but Limited, Tool. 2002

<sup>17</sup> Canadian Council for Donation and Transplantation and Environics Research Group. Public Awareness and Attitudes on Organ and Tissue Donation and Transplantation including Donation after Cardiac Death, 2005

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An earlier survey done by this group in 2001 also examined the issue of presumed consent and found that one half of Canadians surveyed supported changes in legislation for presumed consent while 47% opposed it.<sup>18</sup>

### **Environmental Scan of Public Awareness & Donor Recognition Activities and Opportunities for National Collaboration, 2006<sup>19</sup>**

This report investigated opportunities for national-level collaboration on public awareness and donor recognition. The authors recommended 20 activities for implementation. Included in their recommendations were funding to build capacity, implement a national media campaign, and facilitate networking opportunities and forums so that coordinators across Canada can exchange ideas and best practices. They further recommended raising awareness through national media tools and communications strategies, building a national organ and tissue brand, and recognizing donors, both living and deceased through regional ceremonies.

## **II. Forums**

### **The Citizens Panel on Increasing Organ Donations (Ontario Minister of Health and Long Term Care) November 2006 - February 2007, Various Cities, Ontario**

The Minister of Health and Long Term-Care created the Citizens Panel to hear the views and opinions of Ontarians on organ donation. The Citizens Panel recommended that some government forms, including the Ontario Health Insurance Plan (OHIP) card renewal, require Ontarians to state their organ donation preferences, that a central database record these preferences and that the information be sent regularly to the Trillium Gift of Life Network which will make it available to families and healthcare providers as appropriate.

### **National Consultation: Organ and Tissue Donation and Transplantation (Canadian Blood Services) September 22 - 24, 2008, Gatineau, Quebec**

Participants in the consultation recommended a national awareness and public education campaign with the goal to educate Canadians and allow them to declare their informed intent to donate. The participants also recommended a national first person consent registry.

<sup>18</sup> Health Canada. Organ and Tissue Donations: Canadian Public Awareness, Knowledge and Attitudes, 2001

<sup>19</sup> Canadian Council for Donation and Transplantation. Environmental Scan of Public Awareness & Donor Recognition Activities and Opportunities for National Collaboration, 2006

## C. Other Models

### **Spanish Model**

Spain is considered one of the leading models for organ and tissue donation and transplantation with the highest donation rate per million population in the world. Since the first transplantation law was enacted in Spain, they have operated on a presumed consent or opt-out system. However, if families are available, they are approached for consent and Spain experts report that from a practical point of view, an informed consent or opting in model has always been applied.<sup>20</sup> For this reason, their presumed consent law is not considered one of the elements contributing to Spain's success nor is it a principle of the Spanish Model. Spain considers attention to the media and communicating to the public to be one of the key elements contributing to their success.

### **Trillium Gift of Life (Ontario), BC Transplant, Legacy of Life (Nova Scotia)**

Each of these organizations maintains an organ donation registry for their province, enabling individuals to consent/opt-in as potential organ donors. In British Columbia it is also possible to register to opt-out, or deny consent. In each of these provinces, the registries vary in size, methods for registration and accessibility of the information to hospital and organ donation staff. As in other provinces, it is common practice for physicians to approach family for consent, regardless of the existence of first person consent.

### **Australia & the United Kingdom**

Both Australia and the UK maintain national intent to donate registries. Individuals can register either their consent or their decision not to donate; however, next of kin are always consulted for consent prior to donation. In addition to the registry, the Australian government has developed a national communications strategy to increase awareness of organ donation. In the UK, NHS Blood and Transplant has recently committed £1.0 million to an advertising/public awareness campaign.

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<sup>20</sup> Transplantation Reviews. Strategies to Optimize Deceased Organ Donation. Matesanz, Rafael, B. Dominguez-Gil, 2007

## 3. Analysis

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*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

An analysis of existing research and opinion papers 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 report.

The analysis of this issue was divided into two main sections: intent/consent registries and public awareness activities. Analysis on intent/consent registries included a model comparison of opt-out/presumed consent registries, opt-in/informed consent registries, and models without registries. Donation rates of countries with the different kinds of registries, or no registries, were also compared.

Assumptions underlying the analysis include:

- Any additional resources to support implementation will need to be based on a business case that demonstrates opportunities for increased effectiveness and efficiency.

The analysis on public awareness included a SWOT analysis of current activities and future options for public awareness and education activities. It also included a review of public awareness and education approaches of countries with strong donation statistics.

### B. Findings

A common model for ensuring an individual's wishes for donation are known is the use of donor registries. In these models, individuals register their wish to donate, and sometimes their desire not to donate, in a central database. This information is then available to health care professionals at the time of death and can be referred to when speaking with potential donor families. Although registration on a database is often legally binding, it is extremely rare for health care professionals not to seek the consent

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of the legal next of kin. As such, registries are often used as a marketing technique and a mechanism to monitor public opinion and interest in organ donation as opposed to a legally binding expression of consent. As registries rarely exist without public education activities, it is difficult to determine if registries alone are an effective tool in increasing organ donation.

In areas without registries, other mechanisms usually exist for making ones wishes known regarding organ donation. Examples include declaring consent by completing a donor form and/or card, or indicating a preference for organ donation on another legal form, for example a motor vehicle license or health insurance card.

Registries take three main forms: declared consent using a donor registry, donor card or other mechanism where one registers either their decision to donate or their desire not to; presumed consent, which is often paired with an opt out registry; and affirmative action registries where one registers only if they consent to organ donation.

A common finding among high performing countries is dedicated funding and activities to promote public awareness and education. This is often, though not always done in support of donor registries.

## 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

#### I. What is the most effective mechanism to indicate individual wishes, pre-mortem, with regard to organ donation?

##### a) **National consent/opt-in registry**

Launch a single national registry of people who have consented to organ donation pre-mortem. Individuals would register as having consented to organ donation and this information would be available to specific hospital and/or OPO staff. It is possible to have multiple points of entry to the registry including on-line registration, mail-in forms, registration on provincial health cards, etc. Note that consent registration would be legally binding, as it currently is in all provinces and territories with the exception of Manitoba and Québec where consent can be overridden in certain circumstances.<sup>21</sup>

<sup>21</sup> Downie, Jocelyn, Alison Shea, and Chantelle Rajotte. Family Override of Valid Donor Consent to Post-Mortem Donation: Issues in Law and Practice, 2006

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Strengths	Weaknesses
<ul style="list-style-type: none"> <li>▪ May increase the likelihood of organ donation as health professionals may use this information to inform families at time of death</li> <li>▪ Would contribute to improved access to donation between provinces as information would be available across Canada</li> <li>▪ Significant cost savings as a result of a single technology solution</li> <li>▪ More donors may be realized as family would not be able to legally override an individual's consent</li> </ul>	<ul style="list-style-type: none"> <li>▪ Registration is voluntary and some may consider the lack of registration as indication of a desire not to donate</li> <li>▪ Family consent would likely continue to be commonly sought</li> </ul>
Barriers	
<ul style="list-style-type: none"> <li>▪ Would require a national body to develop, implement and manage</li> </ul>	

**b) National intent to donate registry**

Launch a national registry where individuals can express their intention to donate. This intention would not be legally binding, but would inform healthcare providers and family members of an individual's wishes.

Strengths	Weaknesses
<ul style="list-style-type: none"> <li>▪ May increase the likelihood of organ donation as health professionals may use this information to inform families at time of death</li> <li>▪ Would contribute to access to donation between provinces as information would be available across Canada</li> <li>▪ Significant cost savings as a result of a single technology solution</li> </ul>	<ul style="list-style-type: none"> <li>▪ Not legally binding which could result in family override of individual wishes for organ donation</li> <li>▪ Registration is voluntary and some may consider the lack of registration as indication of a desire not to donate</li> </ul>
Barriers	
<ul style="list-style-type: none"> <li>▪ Would require a national body to develop, implement and manage</li> </ul>	

**c) Provincial registries with national accessibility**

Launch provincial registries where individuals can express their decision to donate. This information would be maintained provincially, but would

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contribute to a national registry to allow access to the information across jurisdictions.

Strengths	Weaknesses
<ul style="list-style-type: none"> <li>▪ May increase the likelihood of organ donation as health professionals may use this information to inform families at time of death</li> <li>▪ Would contribute to improved access to donation between provinces as information would be available across Canada</li> </ul>	<ul style="list-style-type: none"> <li>▪ Registration is voluntary and some may consider the lack of registration as indication of a desire not to donate</li> <li>▪ Family consent would likely continue to be commonly sought</li> <li>▪ Provincial variations in funding and resource availability may result in inequities between provinces</li> </ul>
Barriers	
<ul style="list-style-type: none"> <li>▪ Would require a national body to manage</li> </ul>	

**d) National opt-out registry**

Launch a single national registry of people who do not consent to organ donation. This option assumes that those who do not register support organ donation. Family consent would be required as no record of an individual’s consent to donation would be kept.

Strengths	Weaknesses
<ul style="list-style-type: none"> <li>▪ May make it easier for healthcare providers to approach family since intent is presumed</li> <li>▪ Would contribute to improved access to donation between provinces as information would be available across Canada</li> <li>▪ Significant cost savings as a result of a single technology solution</li> </ul>	<ul style="list-style-type: none"> <li>▪ The concept of an opt-out registry would be new to Canadians and could cause confusion</li> <li>▪ It is unlikely that a public awareness campaign would be launched to promote an opt-out registry so the likelihood of widespread use is limited</li> </ul>
Barriers	
<ul style="list-style-type: none"> <li>▪ Provincial privacy laws may impede the development and accessibility of a national registry</li> </ul>	

**e) No nationally coordinated registry**

Do not launch any new registries in Canada. Current systems would continue with some provinces maintaining registries and others identifying potential donors through current systems (e.g., signing a donor card, indicating intent on health cards)

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Strengths	Weaknesses
<ul style="list-style-type: none"> <li>▪ Would not require any additional systems or resources</li> </ul>	<ul style="list-style-type: none"> <li>▪ Would not contribute to building consistency in practice with regard to organ donation across Canada</li> <li>▪ Provincial variations may result in inequities between provinces</li> </ul>

**II. What would be the most effective approach to increase awareness of organ donation among Canadians?**

**a) Nationally managed and implemented public awareness/marketing strategy**

Develop and launch a national public awareness/marketing strategy to increase knowledge about organ donation among Canadians. Activities would be managed by a national organization, responsible for the development and implementation public awareness/marketing on an ongoing basis.

Strengths	Weaknesses
<ul style="list-style-type: none"> <li>▪ Would ensure that all provinces and territories have education/awareness activities about organ donation contributing to equity across Canada</li> <li>▪ Would allow for economies of scale in the development and production of education/awareness materials</li> </ul>	<ul style="list-style-type: none"> <li>▪ Provincial differences may make it difficult to implement national messages</li> <li>▪ May result in confusion about access to donation in various regions in Canada</li> </ul>
Barriers	
<ul style="list-style-type: none"> <li>▪ Provinces or OPOs with effective education and awareness activities may not see value in a national program</li> <li>▪ National responsibility and funding would be required for development and implementation of strategy</li> </ul>	

**b) Nationally coordinated public awareness/marketing strategy**

Introduce a nationally coordinated public awareness/marketing strategy that would be supported and implemented by local/regional OPOs. Materials would be customizable by province/region, but would contain consistent messages.

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Strengths	Weaknesses
<ul style="list-style-type: none"> <li>▪ Would allow for economies of scale in the development and production of education/awareness materials</li> </ul>	<ul style="list-style-type: none"> <li>▪ Could be differences in provinces' abilities to implement because of availability of resources.</li> <li>▪ May create confusion about who is responsible for OTDT in the province.</li> <li>▪ Could compete with regional/provincial awareness activities.</li> </ul>
Barriers	
<ul style="list-style-type: none"> <li>▪ Provinces or OPOs with effective education and awareness activities may not see value in a national materials</li> <li>▪ National responsibility and funding would be required for development and implementation of strategy</li> </ul>	

**c) Status Quo**

Strengths	Weaknesses
<ul style="list-style-type: none"> <li>▪ Would not require additional resources or a change in current activity</li> <li>▪ Allows the provinces to determine the most appropriate and beneficial use of their funding and to determine the most effective activities within their region</li> </ul>	<ul style="list-style-type: none"> <li>▪ Would not contribute to building consistency in organ donation awareness in Canada</li> </ul>

**B. Considerations**

During the analysis of data and the identification of options, several considerations to reflect on during the resolution process were identified. 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 members before a recommendation or set of recommendations is finalized.

▪ **Registries**

The options do not go into a level of detail to decide what information would be registered. Some informed consent/opt-in systems allow individuals to register both consent or to register their desire not to donate their organs. Some informed consent/opt-in systems only offer consent options. It was decided not to explore these two options as part of this paper as these details would be determined, with consultation, once a decision has been made on whether to launch a

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registry and what format that registry will take (national/regional).

- **Consent / Intent**

There is an important difference between consent and intent. Intent to donate is the expression of one's desire to donate, but is not binding. Registering consent to donate gives full authority for removal of organs for donation and is legally binding in all provinces and territories with the exception of Manitoba and Québec where consent can be overridden in certain circumstances.<sup>22</sup>

- **Public Awareness**

The options do not go into a level of detail with regard to the public awareness strategy. It is assumed that a public awareness strategy would include a call to action to increase organ donation, whether that be to register as a potential donor, sign an organ donor card, discuss one's wishes with their family or other mechanisms to drive action and increase organ donation. Measurement of the effectiveness of public awareness activities will be critical to understanding success and ultimately improving upon it.

- **Combining Options**

The options that have been presented can be combined as part of an overall solution to the overriding question. For example, a national informed consent/opt-in registry could be combined with a national public awareness/marketing campaign.

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<sup>22</sup> Downie, Jocelyn, Alison Shea, and Chantelle Rajotte. Family Override of Valid Donor Consent to Post-Mortem Donation: Issues in Law and Practice, 2006