

# **ORGAN EXPERT COMMITTEE:**

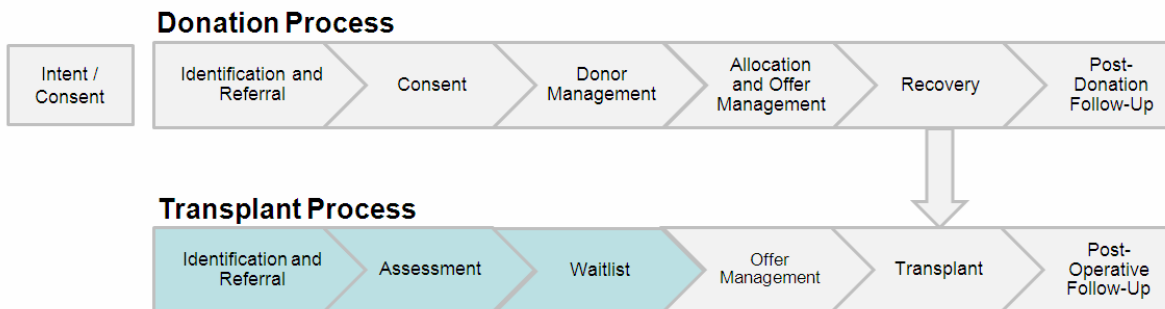
**TO WHAT EXTENT SHOULD PRACTICES  
IN PATIENT REFERRAL AND WAITLIST  
MANAGEMENT BE CONSISTENT?  
WHAT ARE THE BEST MECHANISMS  
FOR ACHIEVING THIS?  
(DRAFT SOLUTION DESIGN PAPER)**

## **CONTENTS**

<b>1. Scope</b> .....	<b>3</b>
<b>2. Current State</b> .....	<b>5</b>
A. Current State.....	5
B. Current Community Thinking .....	7
C. Other Models.....	10
<b>3. Analysis</b> .....	<b>13</b>
A. Analysis Approach .....	13
B. Findings.....	14
<b>4. Options and Considerations</b> .....	<b>15</b>
A. Options.....	15
B. Considerations .....	20
<b>Appendix A</b> .....	<b>21</b>

# 1. Scope

TO WHAT EXTENT SHOULD PRACTICES IN PATIENT REFERRAL AND WAITLIST MANAGEMENT BE CONSISTENT? WHAT ARE THE BEST MECHANISMS FOR ACHIEVING THIS?



The identification and referral process leading to the placement of an individual on an organ transplant waitlist may begin in the community or acute care setting and involves a number of steps in advance of the assessment to determine the individual's eligibility for placement on an organ transplant waitlist. Waitlist is defined as the list of transplant-ready candidates who are waiting to be matched with specific donor organs in hopes of receiving transplants<sup>1</sup>. The goals of waitlist management are to ensure that those accepted to the waitlist are appropriately listed; and to have any recipient on the list ready to be called in for a transplant at any time<sup>2</sup>.

This question seeks to contribute to discussion on how best to provide access to solid organ transplantation for Canadians with end stage organ failures, who are potential candidates for transplant. This paper highlights what is known about the identification and referral of end stage organ failure patients through assessment to activation on an organ transplant waiting list (excluding the Living Donor Paired Exchange Waitlist). It explores options and mechanisms regarding the level of consistency in how patients are referred, placed on waitlists, and how eligibility is maintained on waitlists so that they are ready to receive a transplant when an organ becomes available. For the purposes of options discussed in this paper, patient referral begins with the referral of a patient to a

<sup>1</sup> Adapted from United Network for Organ Sharing. Policy Management. Policies. [http://www.unos.org/PoliciesandBylaws2/policies/pdfs/policy\\_4.pdf](http://www.unos.org/PoliciesandBylaws2/policies/pdfs/policy_4.pdf), 13 Aug 2009

<sup>2</sup> Adapted from OneLegacy. Health Professionals. Wait List Management – Anne Sanford. [http://www.onelegacy.org/prod/components/docs/COP07\\_TxCenters\\_WaitlistManagement\\_Sanford\\_060607.ppt](http://www.onelegacy.org/prod/components/docs/COP07_TxCenters_WaitlistManagement_Sanford_060607.ppt), 13 Aug 2009

**ORGAN EXPERT COMMITTEE:  
TO WHAT EXTENT SHOULD PRACTICES IN PATIENT  
REFERRAL AND WAITLIST MANAGEMENT BE  
CONSISTENT? WHAT ARE THE BEST MECHANISMS FOR  
ACHIEVING THIS?**

---

transplant program for assessment. Assessment of the validity of patient referral and waitlist criteria is outside the scope of this discussion.

## 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

To obtain access to an organ transplant, patients diagnosed with end stage organ failure must be identified by a physician as a potential transplant candidate. These patients are referred to a transplant program where they undergo rigorous testing and assessment to determine suitability. A physician, in consultation with a multi-disciplinary team, determines whether a patient is placed on a waitlist and regularly reviews the list to assess patients’ readiness for transplant and to remove, or put on hold, candidates who are no longer eligible due to illness, death, or improvement in status.

Eligibility criteria are used to determine which patients will be placed on a waitlist and with what status. Efforts have been made to develop consensus approaches for referral, with formally published national kidney assessment guidelines<sup>3</sup>, the waitlisting algorithm (CanWAIT) for liver<sup>4</sup>, and standard guidelines on cardiac transplantation<sup>5</sup>; and draft eligibility criteria for lung transplantation. A consensus process has also been used to develop recommendations to improve immunologic risk assessment and management in transplantation<sup>6</sup>, as well as listing criteria for patients to be included on a Canadian

---

<sup>3</sup> Knoll, G, S Cockfield, T Blydt-Hansen, et al. “Canadian Society of Transplantation consensus guidelines on eligibility for kidney transplantation”. CMAJ. 173. 10. S1-S25 (2005)

<sup>4</sup> Bazarah, S M, K Peltekian, VC McAlister, et al. “Utility of MELD and child-Turcotte-Pugh scores and the Canadian waitlisting algorithm in predicting short-term survival after liver transplant.” Clin Invest Med, 27. 4. 162-167 (2004)

<sup>5</sup> Haddad, H, D Isaac, JF Legare, et al. “Canadian Cardiovascular Society Consensus Conference on cardiac transplantation 2008: Executive Summary”. Can J Cardiol. 25.4.197-205 (2009)

<sup>6</sup> Canadian Council for Donation and Transplantation. “Assessment and management of immunological risk in transplantation: A CCDT Consensus Forum”. Canadian Council for Donation and Transplantation, 2005

**ORGAN EXPERT COMMITTEE:  
TO WHAT EXTENT SHOULD PRACTICES IN PATIENT  
REFERRAL AND WAITLIST MANAGEMENT BE  
CONSISTENT? WHAT ARE THE BEST MECHANISMS FOR  
ACHIEVING THIS?**

Highly Sensitized Patient Registry<sup>7</sup>. Organ-specific sub-groups of the Canadian Society of Transplantation (CST) review organ transplantation activities annually, including review and updates of listing criteria.

Kidney and non-kidney waitlists are maintained by each province as indicated in Appendix A. The only national waitlists are the Canadian Blood Services' Living Donor Paired Exchange registry and the national urgent status waitlist for hearts, lungs, and livers. The latter is currently a manual paper/fax process operated by London Health Sciences Centre, in which all non-renal transplant programs in Canada participate to list urgent status potential candidates.

Waitlist criteria are not generally made public and there is no systematic visibility for patients who want to understand their status. In Canada, highly-sensitized patients are not currently assigned a higher waitlist status<sup>8</sup> and there is currently no data available on patients who are never referred for transplantation or who are withdrawn from the waiting list, with the exception of deaths on waitlist<sup>9</sup>.

There is little published information on patient referral, assessment, and waitlist status management processes. Among provinces and practitioners, there is inconsistency in how patients are assessed, the composition of the multi-disciplinary teams conducting the assessment, and how the criteria are applied to make waitlist placements<sup>10</sup>. For example, there is variability among provinces in how patients are placed on the waiting list for a kidney transplant from a deceased donor<sup>11</sup>. It has been noted that, despite consensus guidelines on eligibility, clinical judgment plays a role in this decision-making; therefore, there will still be variability in clinical practice across the country<sup>12</sup>.

Patient referral and waitlist management practices operate within a legislative framework. The federal government monitors and administers the *Canada Health Act* which requires reasonable access to medically necessary services for all Canadians. Section 7 of the *Canadian Charter of Rights and Freedoms* guarantees Canadians the right to life, liberty, and security of the person. Governments in Canada have been

<sup>7</sup> Canadian Council for Donation and Transplantation. "Canadian highly sensitized patient and living donor paired exchange registries: Task Force Discussion Document". Canadian Council for Donation and Transplantation, 2005

<sup>8</sup> Canadian Blood Services. "Organ Donation and Transplantation - Case for Change (Draft)". Canadian Blood Services, 2009

<sup>9</sup> Zaltzman, JS. "Kidney transplantation in Canada: unequal access". CMAJ. 175. 5. 489-490 (2006)

<sup>10</sup> Canadian Blood Services. Organ Donation and Transplantation - Case for Change (Draft). Canadian Blood Services, 2009

<sup>11</sup> Zaltzman JS. (2006)

<sup>12</sup> Knoll, G, S Cockfield, T Blydt-Hansen, et al. "Canadian Society of Transplantation consensus guidelines on eligibility for kidney transplantation". CMAJ. 173. 10. S1-S25 (2005)

challenged by patients waiting to access necessary health care on the basis of violating this section<sup>13</sup>.

## B. Current Community Thinking

### I. Reports and Papers

#### **Organs for Transplant - A report from the Organ Donation Taskforce, 2008<sup>14</sup>**

In this 2008 report, the UK Organ Donation Taskforce identifies barriers and proposes solutions to increase transplants; it estimates that current waitlists do not reflect the true extent of need, as many clinicians are reluctant to list more patients than are realistically likely to receive organs.

#### **Kidney transplantation in Canada: unequal access, 2009<sup>15</sup>**

Dr. Jeffrey Zaltzman notes that statistics are not available for those patients who are never referred for transplantation and those withdrawn from the waiting list. There is also a lack of information on patients referred for pre-transplant evaluation, as well as how many are deemed eligible and ultimately placed on the waitlist. He also states that it is well known that placement on transplant waiting lists can be quite variable.

#### **Referral for lung transplantation, 2009<sup>16</sup>**

Minai and Budev, in this 2005 commentary, while lauding efforts to better define lung transplant candidacy guidelines; note that much less attention has been given to the timing of referral of patients for initial lung transplant evaluation. They call for more studies to develop accurate, disease-specific predictors of progression and increased dialogue in the lung transplant community to better define guidelines for referring physicians.

#### **Canadian Society of Transplantation consensus guidelines on eligibility for kidney transplantation, 2005<sup>17</sup>**

<sup>13</sup> Lawson Lundell LLP. Chaoulli v. Quebec (Attorney General): The Supreme Court of Canada Sets the Stage for Fundamental Health Care Reform. [http://www.hg.org/articles/article\\_698.html](http://www.hg.org/articles/article_698.html) Reasons for Judgment of McLachlin CJ and Major and Bastarache JJ., 24 Aug 2009

<sup>14</sup> Organ Donation Taskforce. "Organs for Transplant- A report from the Organ Donation Taskforce". Department of Health: NHS, 2008

<sup>15</sup> Zaltzman JS. "Kidney transplantation in Canada: unequal access". CMAJ. 175. 5: 489-490 (2006)

<sup>16</sup> Minai, OA, MM Budev. "Referral for Lung Transplantation". CHEST. 127. 705-707 (2005). [www.chestjournal.org](http://www.chestjournal.org). 18 Aug 2009

<sup>17</sup> Knoll, G, S Cockfield, T Blydt-Hansen, et al. "Canadian Society of Transplantation consensus guidelines on eligibility for kidney transplantation". CMAJ. 173. 10. S1-S25 (2005)

**ORGAN EXPERT COMMITTEE:  
TO WHAT EXTENT SHOULD PRACTICES IN PATIENT  
REFERRAL AND WAITLIST MANAGEMENT BE  
CONSISTENT? WHAT ARE THE BEST MECHANISMS FOR  
ACHIEVING THIS?**

Knoll, Cockfield, Blydt-Hansen, et al., document the expert consensus on eligibility for kidney transplantation in the hope of contributing to consistency in determining which patients are eligible and accepted for kidney transplantation. The authors suggest that in the absence of a uniform national policy, each program should evaluate its practices regarding the timing of referral and listing to minimize waiting time on dialysis.

**Adult liver transplant survey: policies towards eligibility criteria in Canada and the United States, 2007<sup>18</sup>**

In this 2007 paper to assess the current practice patterns of liver transplant centres in Canada and the USA regarding transplant eligibility, Kroeker, Bain, et al., note that policies and practices of transplant programs when considering patients for transplantation may be controversial and there may be little available transplant evidence or “weak” evidence by clinical epidemiology standards. Important decisions regarding transplant eligibility still have to be made empirically in the absence of scientific literature about various social issues.

**Managing the kidney waiting list, 2006<sup>19</sup>**

In a 2006 US survey to determine current practices in managing kidney waiting lists, A. Zarifian and M. O'Rourke of the Tulane Abdominal Transplant Institute report a change in the demographics of potential recipients on waitlists over the past 15 years, including increasingly more persons older than 50 years of age, and increased number of co-morbid conditions. As such it is important that transplant centres update their systems to ensure all active candidates are prepared to accept an organ at any time. Since their study, the institute has developed a formal list maintenance protocol, which includes annual telephone review and appointments scheduled for any changes in health status.

**Heart transplantation: the transplant evaluation, 2009<sup>20</sup>**

D. Dressler, in this discussion on suitability of a candidate for transplantation, highlights that patients may require re-evaluation and periodic reassessment while on the waiting list, and stresses that the education of the patient and family is extremely important so they understand if there are concerns regarding their candidacy.

<sup>18</sup> Kroeker, KI, VG Bain, T Shaw-Stiffel, T Ling. “Adult liver transplant survey: policies towards eligibility criteria in Canada and the United States 2007”. *Liver International* (2008). [http://www.medscape.com/viewarticle/583223\\_print](http://www.medscape.com/viewarticle/583223_print), 13 Aug 2009.

<sup>19</sup> Zarifian, A, M O'Rourke. “Managing the kidney waiting list”. *Progress in Transplantation*. 16: 242-246 (2006)

<sup>20</sup> Dressler, Diane K, “Heart Transplantation: The Transplant Evaluation”, in *Organ Transplantation: Concepts, Issues, Practice and Outcomes*, (2002), [http://www.medscape.com/viewarticle/436544\\_4](http://www.medscape.com/viewarticle/436544_4), 18 Aug 2009

**Waiting time for transplantation, 2006<sup>21</sup>**

Dr. John Gill, St. Paul's Hospital, Vancouver, in this 2006 paper, highlights significant regional variation in median waiting times across Canada and the impact of waiting time on pre- and post-transplant morbidity and mortality. He notes also that the assumption that all waitlisted patients are equally eligible for transplant becomes more uncertain as waiting time increases. Optimizing the medical surveillance of waitlisted patients will become increasingly important as the number and age of waitlisted patients continues to increase.

Over the years, discussions in the organ donation and transplantation community have highlighted the need for common standards to assess patient eligibility and list patients to ensure equity and transparency, along with the need to track clinical status of transplant candidates so that urgent patients receive expedient care. The Report of the Standing Committee on Health in 1999 highlighted the need for national standards and real-time national waiting lists for solid organs<sup>22</sup>.

## II. Forums

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

**September 22-24, 2008, Gatineau, Quebec**

Participants in this consultation recommended, as a top priority for an OTDT system in Canada, the establishment of standards for referral and listing criteria for each organ, standards for highly-sensitized patients and other testing, and ensuring an audit and compliance function<sup>23</sup>.

**Canadian Blood Services Consultation with the Canadian Lung, Liver and  
Heart Working Groups on Organ Allocation Systems  
(Canadian Society of Transplantation)**

**March, 2009, Banff, Alberta**

This consultation at the Canadian Society of Transplantation annual meeting in 2009 identified general support for an oversight committee to approve policies governing the listing and allocation of organs to patients in a national system,

<sup>21</sup> Gill, JS. "Waiting Time for Transplantation". Canadian Council for Donation and Transplantation, 2006

<sup>22</sup> Volpe, Joseph. "Organ and Tissue Donation and Transplantation: A Canadian Approach". A Report of the Standing Committee on Health. 1999

<sup>23</sup> Canadian Blood Services. "Organ Donation and Transplantation Syntegration Consolidated Output". Canadian Blood Services, 2009

mandated data reporting as an integral part of a national system, and policy compliance monitoring by a national agency<sup>24</sup>.

## C. Other Models

Details related specifically to the patient referral, assessment for transplant eligibility, and waitlist status management processes are generally not well documented in descriptions about organ donation and transplantation models. However, high-level descriptions of models used in other countries provide insights into general approaches that could be considered if a high degree of consistency in this process is desired. Models from other sectors and programs in the health system may also provide lessons and insights for potential mechanisms for consistent patient referral and waitlist status management across Canada.

Australia's national reform package includes the establishment of the **Australian Organ and Tissue Donation and Transplantation Authority** (Authority), an independent statutory agency within the government of Australia Health and Ageing portfolio. Objectives for the Authority, specified in legislation, include coordinating a national network of clinicians and other hospital staff dedicated to organ and tissue donation (OTD) in hospitals across Australia; overseeing a new national network of state and territory OTD agencies; and formulating national policies (with the Department of Health and Ageing) and protocols relating to OTD, and transplantation matters, including working closely with clinical and professional organizations to develop consistent clinical practice protocols and standards. The Authority, in collaboration with relevant professional societies, will be responsible for maintaining and auditing the implementation of approved national transplantation protocols and standards to "ensure that the management of transplant waiting lists and the allocation of organs and tissues are effective, equitable and transparent, regardless of where the donor and recipient reside"<sup>25</sup>.

The **Eurotransplant International Foundation** (ET) is an international collaborative responsible for the mediation and allocation of organ donations in seven European countries. The data of all potential recipients, such as blood group, cause of the disease, clinical urgency, etc, are passed on to Eurotransplant. This information is stored in a central computer database. Subsequently, the patient is put on the (inter)national waiting list. Eurotransplant has well defined quality standards and practices and an audit

<sup>24</sup> Canadian Blood Services. "Consultation with the Canadian Lung, Liver and Heart working Groups on Organ Allocation Systems". Summary Report Draft. Canadian Blood Services, 2009

<sup>25</sup> Government of Australia. Australian Organ and Tissue Donation and Transplantation Authority Agency - Resources and Planned Performance. [http://www.health.gov.au/internet/budget/publishing.nsf/Content/2009-2010\\_Health\\_PBS](http://www.health.gov.au/internet/budget/publishing.nsf/Content/2009-2010_Health_PBS), p. 438, 23 Sep 2009

**ORGAN EXPERT COMMITTEE:  
TO WHAT EXTENT SHOULD PRACTICES IN PATIENT  
REFERRAL AND WAITLIST MANAGEMENT BE  
CONSISTENT? WHAT ARE THE BEST MECHANISMS FOR  
ACHIEVING THIS?**

system for evaluating the High Urgent status of patients on the waiting list. ET is supported by nine advisory committees, who provide clinical and ethical advice to the governing Board; and has established relationships with organ procurement organizations in each member country. Health ministers from member countries sign a declaration of intent subscribing to ET protocols, and clear rules are established to align ET policies to different jurisdictions' laws<sup>26</sup>.

The **United Network for Organ Sharing** (UNOS) is a non-profit, scientific and educational organization that administers the Organ Procurement and Transplantation Network (OPTN), established by the U.S. Congress in 1984. The OPTN strives to increase the effectiveness and efficiency of organ sharing and equity in the national system of organ allocation. It maintains the only national patient waiting list and collects and manages data about every transplant event occurring in the US. UNOS has developed a collaborative policy development, monitoring, and enforcement process for the OPTN. By agreeing to become UNOS members, transplant hospitals and organ procurement organizations are required to comply with UNOS policies and bylaws. UNOS monitors member compliance with policies to ensure the greatest possible equitable treatment of all patients<sup>27</sup>. The OPTN Evaluation Plan explains to OPTN Members how UNOS, as the OPTN contractor, assesses compliance with OPTN Policies and By-laws, including the UNOS Patient Waiting List Policies. The Plan includes details of compliance expectations and how policies are monitored<sup>28</sup>. For example, specific to waiting lists, UNOS has a peer review system to determine whether a listing is appropriate. A Regional Review Board determines the appropriateness of urgent status listings, exceptional points, estimated values or specific diagnosis for liver, lung, and heart candidates<sup>29</sup>.

**National Health Services Blood and Transplant** (NHSBT) is a special health authority of the English National Health Service (NHS). Its responsibilities include managing the National Transplant Database; contributing to the development of performance indicators, standards and protocols; auditing and analyzing results of organ transplantation; and serving as a central point of information and support to transplant units in the UK and Ireland<sup>30</sup>. The National Transplant Database includes details of all donors and patients who are waiting for, or who have received, a transplant. Patients are placed on the transplant waiting list by their local consultant physician or surgeon and in accordance with nationally agreed criteria. Their names are then notified to UK

<sup>26</sup> Eurotransplant International Foundation. <http://www.eurotransplant.nl>, 14 Aug 2009

<sup>27</sup> United Network for Organ Sharing. <http://www.unos.org/>, 14 Aug 2009

<sup>28</sup> Organ Procurement and Transplant Network. OPTN Evaluation Plan June 30 2009, [http://optn.transplant.hrsa.gov/SharedContentDocuments/090630\\_Evaluation\\_Plan\\_-\\_Complete\\_Document\\_bookmarked\\_tsr\\_finalversion.pdf](http://optn.transplant.hrsa.gov/SharedContentDocuments/090630_Evaluation_Plan_-_Complete_Document_bookmarked_tsr_finalversion.pdf), 18 Aug 2009

<sup>29</sup> *ibid.*

<sup>30</sup> National Health Service. NHS Blood and Transplant. [http://www.organdonation.nhs.uk/ukt/about\\_us/about\\_us.jsp](http://www.organdonation.nhs.uk/ukt/about_us/about_us.jsp), 18 Aug 2009

**ORGAN EXPERT COMMITTEE:  
TO WHAT EXTENT SHOULD PRACTICES IN PATIENT  
REFERRAL AND WAITLIST MANAGEMENT BE  
CONSISTENT? WHAT ARE THE BEST MECHANISMS FOR  
ACHIEVING THIS?**

Transplant for inclusion on the national transplant database<sup>31</sup>. Rules are drawn up by the appropriate advisory committee, to ensure that each patient, as far as possible, is provided with equal access to available organs. The procedures for organ donation, allocation, retrieval and transplantation are set and monitored by advisory groups which focus almost exclusively on issues to do with specific organs. These groups enable an exchange of views and information on practical and strategic issues and recommend changes, as necessary, to the nationally agreed protocols<sup>32</sup>.

<sup>31</sup> National Health Service. Organ Donation.  
[http://www.uktransplant.org.uk/ukt/newsroom/statements\\_and\\_stances/statements/equality\\_of\\_access\\_to\\_donor\\_organ.jsp](http://www.uktransplant.org.uk/ukt/newsroom/statements_and_stances/statements/equality_of_access_to_donor_organ.jsp), 18 Aug 2009

<sup>32</sup> National Health Service. Organ Donation.  
[http://www.uktransplant.org.uk/ukt/about\\_us/advisory\\_groups/advisory\\_groups.jsp](http://www.uktransplant.org.uk/ukt/about_us/advisory_groups/advisory_groups.jsp), 18 Aug 2009

## 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

The analysis was conducted with the understanding that practices in patient referral and waitlist status management for organ transplantation occur within the broader health system, recognizing the complex interplay between supply and demand, health system processes and other factors that contribute to patient outcomes. The analysis and development of options was undertaken with the assumptions that:

- patient referral and waitlist management practices should:
  - benefit patients,
  - be transparent, and
  - improve equity of access to transplantation;
- by definition, the purpose of organ waitlists is to match transplant-ready candidates with specific donor organs;
- there are variations in health delivery systems between provinces, including availability of human resources, access to diagnostic services, etc., and differences in provincial directions and priorities; and
- clinical judgment will always play a role in patient referral and waitlist decision-making.

An assessment of the strengths, weaknesses, opportunities and threats of the current state was conducted. A literature review identified common themes and mechanisms for comprehensive, effective approaches to patient referral and waitlist status management in organ transplantation as well as in cancer care, cardiac care and surgical services. These mechanisms were assessed against the assumptions of patient benefit, transparency and equity of access to determine if they are in alignment. The mechanisms were then used as the basis for comparing models from other jurisdictions, in the organ transplantation field and other sectors of the health system. Options were then identified and analyzed in terms of how they would address weaknesses and threats identified in the assessment of the current state.

## B. Findings

A common feature of many of the models reviewed was a focus on consistency of practices for patient referral and waitlist status management<sup>33,34,35,36,37,38,39</sup>. Mechanisms to achieve consistency that are common in the models reviewed include:

- Standardized policy
- Centralized electronic databases/registries
- Communication
- Education
- Measurement and audit.

It should be noted that an approach that integrates these mechanisms is important for achieving consistency. For example, it would be difficult to achieve consistent practice by simply developing a policy without communicating the policy, providing education to support implementation of the policy, gathering data, monitoring the data, and auditing practices to determine whether the policy has been consistently implemented and whether it has achieved the intended objective. Based on models reviewed, jurisdictions may implement the above mechanisms in various ways including consensus approaches such as expert panels for development of policies; centralized processes such as national databases; education approaches to translate evidence to practice, such as the IHI's Collaborative Model for achieving breakthrough improvement; centralized structures such as a national coordinating body or monitoring body; and other coordination mechanisms such as networks<sup>40,41,42,43</sup>.

- <sup>33</sup> National Clinical Taskforce on Organ and Tissue Donation (2008) "National Clinical Taskforce on Organ and Tissue donation Final Report: Think Nationally Act Locally". Commonwealth of Australia.
- <sup>34</sup> Danovitch, GM, S Hariharan, JD Pirsch, et al. "Management of the Waiting List for Cadaveric Kidney Transplants: report of a survey and recommendations by the Clinical Practice Guidelines Committee of the American Society of Transplantation". J Am Soc Nephrol. 13:528-535 (2002)
- <sup>35</sup> Government of Australia. Practice Approach to Organ and Tissue donation for Australia: Overview. [http://www.health.gov.au/internet/main/publishing.nsf/content/B5AC5303C8932F30CA25747A000BF6A4/\\$File/ORGAN%20FACT%20SHEET.pdf](http://www.health.gov.au/internet/main/publishing.nsf/content/B5AC5303C8932F30CA25747A000BF6A4/$File/ORGAN%20FACT%20SHEET.pdf), 17 Aug 2009
- <sup>36</sup> Glynn, P, Taylor, M, Hudson, A, "Surgical Wait List Management: A Strategy for Saskatchewan – a report to SK Health" (2002); <http://www.health.gov.sk.ca/surgical-wait-list-management>, 18 Aug 2009
- <sup>37</sup> Ontario Department of Health and Long-term Care. Ontario Wait Time Strategy Overview. Government of Ontario, [http://www.health.gov.on.ca/transformation/wait\\_times/providers/strategy/wt\\_strat\\_overview.pdf](http://www.health.gov.on.ca/transformation/wait_times/providers/strategy/wt_strat_overview.pdf), 24 Aug 2009
- <sup>38</sup> Monaghan, B, Morgan, C, Shragge, B, Higginson, L, Vimr, M, Trypuc, J. "Through the Looking Glass: The Cardiac Care Network of Ontario 10 years Later". Hospital Quarterly Spring 2001: 30-38.
- <sup>39</sup> Ministry of Health. "A Summary of the Improving Patient Pathways – Diagnostic Pilots". Elective Services Project. New Zealand Ministry of Health, 2009
- <sup>40</sup> A World's Best Practice Approach to Organ and Tissue donation for Australia: Overview. <http://www.health.gov.au/>, 13 Aug 2009
- <sup>41</sup> Eurotransplant International. <http://www.transplant.org>, 18 Aug 2009
- <sup>42</sup> United Network for Organ Sharing. <http://www.unos.org/>, 18 Aug 2009
- <sup>43</sup> Cardiac Care Network, <http://www.ccn.on.ca/>, 24 Aug 2009

## 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

For each option presented it is given that:

- organ specific considerations would need to be addressed in its implementation;
- national eligibility criteria exist for kidney, liver, heart (published), and lung (draft under discussion amongst experts);
- there is an existing national urgent status waitlist for non-kidney organs and work is underway on a registry for highly-sensitized patients; and
- some provinces work together in a regional approach and some territories work with nearby provinces to facilitate patient access to services; and
- patient data for waitlists must include all the information necessary to make allocation decisions.

Each of the options presented would require implementation of mechanisms through which consistency could be achieved. These mechanisms are briefly described at the end of the section, as they could be applied in each model.

#### I. To what extent should practices in patient referral and waitlist management be consistent?

##### a) Provincial

- Provincial waitlist(s)
- Nationally consistent waitlist eligibility criteria
- Consistent provincial referral and waitlist management practices
- Provincial mechanisms to promote consistency of referral and waitlist management practices and application of national eligibility criteria

**ORGAN EXPERT COMMITTEE:  
TO WHAT EXTENT SHOULD PRACTICES IN PATIENT  
REFERRAL AND WAITLIST MANAGEMENT BE  
CONSISTENT? WHAT ARE THE BEST MECHANISMS FOR  
ACHIEVING THIS?**

Strengths	Weaknesses
<ul style="list-style-type: none"> <li>▪ In provinces that currently have more than one waitlist, this option would enable provincial allocation</li> <li>▪ There would be less duplication of effort within provinces that are currently operating more than one waitlist, which could produce fiscal savings</li> <li>▪ Provincial waitlist(s) already exist in most provinces</li> </ul>	<ul style="list-style-type: none"> <li>▪ There could still be inconsistency in practices between provinces which could contribute to inequitable access and potentially benefit patients unequally across the country</li> <li>▪ This option would require the integration of data or listings from multiple systems to obtain national data</li> <li>▪ Mobility of patients may compromise their position on a waitlist. In moving between provinces they could lose their place on one waitlist and perhaps be placed lower on another province's waitlist</li> <li>▪ This fails to address inconsistencies across provinces that impact upon national outcomes</li> </ul>
Barriers	
<ul style="list-style-type: none"> <li>▪ This option would require financial and technology resources to consolidate multiple waitlists for provinces that do not already have provincial waitlist(s)</li> <li>▪ This option would require each province to bring people together to agree on referral and waitlist management practices and on how consistency would be achieved</li> <li>▪ It would also require the funding and infrastructure to re-assess patients and refer additional patients</li> </ul>	

**b) Provincial with national coordination**

- Centralized national waitlist(s)
- Nationally consistent waitlist eligibility criteria
- Consistent provincial referral and waitlist management practices
- Provincial mechanisms to promote consistency of referral and waitlist management practices and application of national eligibility criteria
- National coordination approach that could include:
  - developing policy consensus across jurisdictions;
  - providing advice on complex issues that provinces have in common;

**ORGAN EXPERT COMMITTEE:  
TO WHAT EXTENT SHOULD PRACTICES IN PATIENT  
REFERRAL AND WAITLIST MANAGEMENT BE  
CONSISTENT? WHAT ARE THE BEST MECHANISMS FOR  
ACHIEVING THIS?**

- facilitating resolution of issues or disputes that may voluntarily be brought forward;
- managing the database;
- reporting to various stakeholders; and
- monitoring national waitlist(s) to inform policy review and development.

Strengths	Weaknesses
<ul style="list-style-type: none"> <li>▪ This option would enable provincial allocation</li> <li>▪ A patient's position on the waitlist would not be compromised by moving to another province</li> <li>▪ Centralized national waitlist(s) and the monitoring thereof could clarify accountability</li> <li>▪ Centralized national waitlist(s) would improve the ease of Canada's ability to report internationally</li> </ul>	<ul style="list-style-type: none"> <li>▪ National policies would need to be accommodated in provincial practices</li> <li>▪ Provincial latitude in application of national policies could result in continued inconsistency of practices between provinces which would contribute to inequitable access and potentially benefit patients unequally across the country</li> <li>▪ A national coordination approach would be limited to influencing rather than directing improvements for consistency of practices across provinces</li> </ul>
Barriers	
<ul style="list-style-type: none"> <li>▪ This option would require each province to bring people together to agree on referral and waitlist management practices, given national policies, and to agree on how consistency in the province would be achieved</li> <li>▪ This option would require significant human and fiscal resources for the development of the database and the information technology and infrastructure to support a centralized national waitlist</li> <li>▪ This option would require agreement on a national coordination approach, recognizing that provinces have legislated responsibility and authority for delivery of health services in their respective jurisdictions</li> <li>▪ It would also require the funding and infrastructure to re-assess patients and refer additional patients</li> </ul>	

**c) National**

- Centralized national waitlist(s)
- National consistent eligibility criteria
- Nationally consistent referral and waitlist management practices
- National authority for coordination and monitoring (structured with appropriate committees) that could include responsibility for:
  - developing policy consensus across jurisdictions;

**ORGAN EXPERT COMMITTEE:  
TO WHAT EXTENT SHOULD PRACTICES IN PATIENT  
REFERRAL AND WAITLIST MANAGEMENT BE  
CONSISTENT? WHAT ARE THE BEST MECHANISMS FOR  
ACHIEVING THIS?**

- providing advice and support on complex issues;
- facilitating resolution of issues or disputes;
- managing the database;
- developing performance measures;
- reporting to various stakeholders; and
- auditing for consistency of referral and waitlist management practices and application of national eligibility criteria; and
- monitoring of national waitlist(s) and performance measures to inform policy review and development.

Strengths	Weaknesses
<ul style="list-style-type: none"> <li>▪ This option would enable national allocation</li> <li>▪ Centralized national waitlist(s) along with national performance measures and monitoring mechanisms would contribute to improved transparency of practices and outcomes</li> <li>▪ Centralized national waitlist(s) would improve the ease of Canada's ability to report internationally</li> <li>▪ Centralized national waitlist(s) and the monitoring thereof could clarify accountability</li> <li>▪ There would be less provincial latitude in application of national policies</li> </ul>	<ul style="list-style-type: none"> <li>▪ Nationally consistent practices may not take into account the needs of certain practitioners</li> </ul>
Barriers	
<ul style="list-style-type: none"> <li>▪ This option would require significant human and fiscal resources for the development of the database and the information technology and infrastructure to support a centralized national waitlist</li> <li>▪ A national authority for coordination and monitoring would require a mandate agreed to by all provinces and territories along with adequate resources to fulfill its responsibilities</li> <li>▪ It would also require funding and infrastructure to re-assess patients and refer additional patients</li> </ul>	

**II. What are the best mechanisms for achieving consistency?**

There are a number of mechanisms that are common to models that aim for coordinated, consistent approaches to practice. While this solution design question is specific to patient referral and waitlist management practices, the

**ORGAN EXPERT COMMITTEE:  
TO WHAT EXTENT SHOULD PRACTICES IN PATIENT  
REFERRAL AND WAITLIST MANAGEMENT BE  
CONSISTENT? WHAT ARE THE BEST MECHANISMS FOR  
ACHIEVING THIS?**

mechanisms can be applied at any level to develop coordinated approaches to health system issues.

- **Standardized policy:** policy instruments could include standardized referral processes, guidelines and wait time targets; assessment and re-assessment protocols; waitlist/registry eligibility criteria; waitlist maintenance criteria and protocols; legal criteria and legislation. Policy development processes also include review and renewal of policies based on results of measurement and audits.
- **Centralized electronic databases/registries:** this refers to central information/data collection systems that house data on patients waiting for organ transplants, and that help improve identification of compatible organ recipients, track wait times and outcomes.
- **Communication:** clear lines of communication and continuous communication are seen as critical to transparent, effective practices. This may include methods to make information accessible to health professionals and patients/families. Many programs/jurisdictions include a coordinator role which may include facilitating physician-physician communication, maintenance of candidates on waiting list, keeping the waitlisted patient/family informed, and coordination of activities<sup>44,45,46,47,48,49</sup>.
- **Education** (patient and professional): Patient education is a common feature of many transplant and other health care programs. Education of physicians and other health care providers is also integral to the transplantation process<sup>50</sup>. International models such as ONT in Spain, Eurotransplant, and the Australian Organ Donation and Transplantation Authority all have responsibility for ongoing education to health professionals.
- **Measurement and audit:** These are critical mechanisms contributing to transparency and accountability for consistent practices and outcomes. International and national models reviewed all featured

<sup>44</sup> Glynn, P, M Taylor, A Hudson, Surgical Wait List Management: A Strategy for Saskatchewan – a report to SK Health (2002); <http://www.health.gov.sk.ca/surgical-wait-list-management>, 18 Aug 2009

<sup>45</sup> Cardiac Care Network, <http://www.ccn.on.ca/>, 24 Aug 2009

<sup>46</sup> National Health Service. <http://www.nhs.uk/Livewell/Donation/Pages/Transplantcoordinator.aspx>, 24 Aug 2009

<sup>47</sup> Zarifian, A, M O'Rourke. "Managing the kidney waiting list". Progress in Transplantation. 16: 242-246 (2006)

<sup>48</sup> United Network for Organ Sharing. <http://www.unos.org/>, 18 Aug 2009

<sup>49</sup> Dressler, D. Heart Transplantation: The Transplant Evaluation. [http://www.medscape.com/viewarticle/436544\\_4](http://www.medscape.com/viewarticle/436544_4), accessed 2009 Aug 18

<sup>50</sup> Minai, Omar A, Marie M Budev. Referral for Lung Transplantation: Chest 2005 127; 705-707 COI 10.1378/chest.127.3.705. <http://www.chestjournal.org/content/127/3/705/full/html>, 18 Aug 2009

monitoring or auditing and evaluation functions. Measurement and audit inform ongoing policy review, renewal and development.

## B. Considerations

The analysis of data and the development of options raised considerations that may be germane to the discussion of options.

- **System Capacity**

“Work load and expense generated by the broadly accepted necessity to constantly update the medical and demographic relevance of the waiting list in the manner reported by most transplant programs that responded to our survey are enormous and will inevitably increase as waiting times are prolonged.”<sup>51</sup>

- **Alignment With Allocation Principles**

Options related to the level of consistency of patient referral and waitlist management practices must be underpinned by the same principles governing the broader organ and tissue donation and transplantation system, and must be particularly well aligned with the principles that should guide an improved approach to allocation.

---

<sup>51</sup> Danovitch, GM, S Hariharan, JD Pirsch, et al. “Management of the Waiting List for Cadaveric Kidney Transplants: report of a survey and recommendations by the Clinical Practice Guidelines Committee of the American Society of Transplantation”. J Am Soc Nephrol. 13:528-535 (2002)

# Appendix A

## Provincial Variation in Waitlists<sup>52</sup>

Province	Kidney Waitlist	Non-kidney Waitlist
BC	BC Transplant	BC Transplant (liver, heart lung, pancreas islet)
AB	HOPE South HOPE North	Organ-specific transplant programs
SK	Saskatchewan Transplant Program	Patients placed on transplant program waitlist in other provinces
MB	Transplant Manitoba	Organ-specific transplant programs
ON	Trillium <ul style="list-style-type: none"> <li>• London</li> <li>• Hamilton</li> <li>• Toronto</li> <li>• Ottawa</li> <li>• Kingston</li> </ul>	Trillium
QC	Québec Transplant	Québec Transplant
NB, NS, PEI, NL	Capital Health Multi-Organ Transplant Program	Capital Health Multi-Organ Transplant Program
National	LPDE operated by Canadian Blood Services	National urgent status waitlist operated by London Health Sciences Centre

<sup>52</sup> Canadian Blood Services. Organ Donation and Transplantation Process Flows. Canadian Blood Services, May 2009