

**Organ and Tissue Donation and Transplantation  
Organ Expert Committee Meeting  
June 7, 2010  
Sheraton Gateway Hotel, Toronto  
Minutes**

---

**Attendees:**

Dr. Peter Nickerson (Chair)	Dr. Anthony Jevnikar	Mr. Scott McIntaggart
Dr. Ian Alwayn	Dr. Shaf Keshavjee	Dr. Joe Pagliarello
Dr. Stephen Beed	Dr. Norman Kneteman	Ms. Deanna Paulson
Dr. Michel Carrier	Dr. Frank Markel	Dr. Sam Shemie
Dr. Tom Blydt-Hansen	Ms. Raylene Matlock	Ms. Kimberly Young
Dr. Debra Isaac		

**Regrets:**

Dr. David Grant  
Dr. Noel Gibney  
Dr. Greg Grant  
Dr. Greg Knoll  
Dr. Adeera Levin  
Dr. Robert Levy  
Dr. John Tallon

**Canadian Blood Services Representatives:**

Dr. Graham Sher, Chair, Steering Committee  
Dr. Locksley McGann, Chair, Tissue Expert Committee  
Ms. Sophie de Villers, Vice-President, Strategy Management  
Ms. Sylvia Torrance, Director, Strategic Planning  
Ms. Lorna Tessier, Director, Public Relations  
Ms. PJ Vankoughnett-Olsen, Senior Project Manager, Organs and Tissues

---

**1. Welcome and Follow-Up of Action Items:**

Peter welcomed the Committee members to the meeting and outlined the agenda for the day. The follow-up action items were then reviewed:

- The OEC meeting minutes from April 27, 2010 were approved by the Committee.
- Peter informed the group that the Case for Change had been updated based on the Committees' comments. The Case for Change was being presented to Deputy Ministers on June 7, 2010. The document will then be finalized and sent to Committee members.
- OEC members previously noted a research and development gap in the strategic map. In order to address this, Canadian Blood Services is planning a research and innovation roundtable for the fall. More details will be provided later, and the output from this meeting will be provided to Committee members when available.

**2. Activity to Date**

The strategic planning process was reviewed with the Committee, including the steps of the process that would be addressed at this meeting: measures, targets, roles and responsibilities, and implementation priorities. Sophie noted that these items would not be finalized at this meeting and that work would continue over the summer. Committee members will have the opportunity to provide further feedback. As well, a final meeting with all of the OTDT Committees is being planned

for October 4, 2010. At this meeting, final recommendations will be reviewed. Confirmation of the date of this meeting will be sent out by e-mail shortly.

An update was also provided on recent public, expert and government engagement activities. Public dialogues have now been completed, with the last two sessions being held in Moncton and Toronto. Though all transplant programs, OPOs and tissue programs have been contacted through the expert engagements, work will continue to keep them informed. As well, efforts will be made to reach out to additional professional associations and organizations. Partnership work with patient advocacy groups continues, as does work with government representatives and officials.

### **3. Public Opinion on ODT**

An Ipsos Reid public opinion poll on ODT was commissioned by Canadian Blood Services. The report was provided to Committee members and key findings were presented to the group. The Committee then discussed how these findings impacted ODT strategy and system design:

- Given the continued gap between public awareness and action, there was debate whether increasing efforts in building public awareness would result in increased donations. The strategy should instead focus on ensuring the system is in place to support families and provide opportunity for donation when there is a potential donor.
- The poll results show that the public is divided on whether family approach should be mandatory or at the discretion of the physician in charge. This finding underlines the importance of educating physicians, including those outside of tertiary hospitals, to ensure that they are committed to organ donation and can provide the appropriate information and support to families in a donation situation.
- Improving access to organ transplants was rated as a high priority for those responding to the poll. This message should be conveyed to Deputy Ministers of Health.
- A request was made to include in the executive summary of the report a statement that the findings are based on nationally aggregated data and may not reflect individual difference between provinces.

The report will be finalized and sent to Committee members. The report will also be made available to other groups and individuals beyond the Committees.

### **4. Changes to System Strategy Map**

Changes to the ODT strategy map, based on previous comments from the OEC and the Steering Committee were reviewed. The group had suggestions to improve the destination statement: “A trusted system to increase and improve organ transplants for Canadian patients.” The group felt that the destination statement lacked impact. It was not sufficient to make small increases in the number of transplants. It was suggested that the statement include a qualifier that declared the extent of the increases being targeted, e.g. answer demand, top in class, amongst international leaders, top 10 countries, double transplants.

### **5. System Measures and Targets**

Sophie provided information on the purpose of measures and targets in the context of strategic planning. Criteria to consider when evaluating measures were also reviewed. The Committee members divided into groups to discuss the draft measures for the donation and transplantation themes.

**Donation Theme:**

**P8: Support for and active commitment to donation**

- Public commitment to donate (registration where available; survey of action taken where not available)

The group felt that intent /consent registry rates and results of surveys were good measures of public commitment to donate. They suggested that survey measures should not only be directed to the public, but to professional health care providers and medical/nursing students as well.

**P9: Maximize identification, referral and consent by ensuring the system offers every opportunity to donate**

- Donors PMP
- Consent Rate
- Referral Rate
- Identification Rate

“Identification rate” was considered an effective measure of potential donors (DCD, NDD) and the need to determine how to collect this data (e.g. chart review) should be considered a priority. “Referral rate” and “consent rate” were good measures. It was recognized that “donors PMP” was an imperfect measure, but since it was commonly used internationally it was suggested that it should continue to be included.

**P10: Optimize and use every possible organ**

- Organs Transplanted Per Donor (SCD, ECD, DCD)
- % of Organs Not Utilized (by Organ, by Category)

It was recommended that “% of organs not utilized” should also be tracked by the reason the organ was not used. “Organs transplanted per donor” was considered a good measure.

**Transplantation Theme:**

**P11: Ensure consistency in identification, referral and listing for patients**

- Variation in % of Patients with End Stage Organ Failure Added to Wait List
- Standards Compliance (e.g. via chart audits)

Another measure could be “% of indications/referral criteria written and published by organ type”. Standards compliance should look at whether patients on the wait list match the criteria and whether patients who were not listed should have been. This would need to be done through chart audits. With respect to the measure “variation in % of patients with end stage organ failure added to the wait list”, it was felt that the denominator for this measure would be difficult to determine for non-renal patients.

**P12: Allocate according to established allocation principles**

- % of Organ Allocation Rules and Sharing Agreements Completed and Documented
- Principles Compliance (e.g. via post-transplant on-site allocation audits)

It was felt that the “principles compliance” measure should be calculated at a national (sharing) level and at a local/provincial level, as there could be many different allocation algorithms.

**P13: Improve outcome tracking and drive patient outcome improvements**

- % Compliance Submitting Post-Transplant Data

The group suggested that the target for this should be 100%.

**Outcome Measures:**

**S2: Ensure the system gives patients the best opportunity possible to receive a transplant, with optimal outcomes**

- Transplant PMP (Living and Deceased Donation)
- Median Wait Time (Case Adjusted, by Organ)
- Graft Survival Rate (by Organ)
- Patient Survival Rate (by Organ)

Other potential measures to add could include: removal from wait list and quality of life measures. Graft and patient survival rates should not only be stratified by organ, but should also be risk adjusted and should look at longer term survival (5 or 10 years, not 1 year survival). It was recommended that the rate of removal from waitlist (by reason: death, disability, improvement, etc) should also be tracked.

**S3: Ensure fair access to transplants for patients with end-stage organ failure**

- % Variation in Wait Time (by organ, by category, e.g. province, ethnicity, age, sensitization)
- Referral-to-List Variation (by organ)

Measures could also include the rates of transplant by patient category relative to rates of patients on wait lists (e.g. 5% of transplants go to HSP who make up 30% of the wait list). Referral to list variation could also be categorized by province.

After the plenary session, the group quickly reviewed the measures for the themes of accountability, collaboration and infrastructure/capabilities. It was noted that work would continue over the summer to further develop measures from all themes.

**6. Targets**

The Committee reviewed international and Canadian data provided on the outcome measures, and then discussed potential targets. It was decided that more work was needed in establishing current baseline values for most of the measures. This would include developing and performing a public survey with a series of questions on trust, and obtaining better data for other measures. The Committee did agree that an overall target could be established for total transplants per million population. If the ODT system targeted 75 transplants pmp for deceased donation and 20 transplants pmp for living donation, this would bring the target for total transplants pmp to 95. This is comparable to the current rates for world leaders (US and Spain ~92 transplants pmp), recognizing that these countries also continue to strive to improve their rates.

**7. Roles and Responsibilities**

Sophie presented the overview of the emerging organ system design that was developed from the discussions and recommendations from the previous meeting. The Committee members then proceeded to discuss roles and responsibilities, through break-out groups and in a plenary.

**Public and Professional Awareness and Education**

➤ **Patient Advocacy and Support**

Responsibilities:

- Advocate for patient at a local and national level
- Raise public awareness
- Provide information to patients
- Raise money for recipient, living donors, and donor family expenses

Raise money for research

It was recommended that patient advocacy groups, NGOs (e.g. Kidney Foundation) should continue to advocate for and support patients. It was noted that living donor reimbursement programs are administered by both NGOs and OPOs, depending on the province.

➤ **Social Marketing and Public Awareness**

Responsibilities:

National

- Conduct social marketing research
- Design national public awareness strategy
- Develop and manage national public awareness campaigns and materials, in coordination with local efforts

Local

- Design and manage local public awareness efforts, in alignment with national messaging and in coordination with national efforts

Many groups currently perform some social marketing and public awareness campaigns for ODT: OPOs, patient advocacy/support groups, CST. Though these groups have the subject matter expertise and established relationships with local communities and patients, it was suggested that Canadian Blood Services should lead the development of national messaging and campaigns because of its expertise with social marketing on a national scale, its work with minority groups (OneMatch) and its established presence across the country. Canadian Blood Services should work with the ODT stakeholders to develop the strategy and campaigns. This would then be coordinated with and leveraged by local groups to deliver a uniform message.

➤ **Medical Education Programs**

Responsibilities:

- Work with medical and nursing colleges to develop and integrate ODT education into training curriculum

It was recommended that professional societies are in the best position to work with their respective colleges to improve ODT training curriculum because of their strong connections to their community groups and their subject matter expertise. This would include:

- Canadian Society of Transplantation
- Canadian Critical Care Society
- Canadian Association of Emergency Physicians
- Canadian Association of Critical Care Nurses
- Canadian Nursing Association
- Royal College of Physician and Surgeons of Canada

Canadian Blood Services would support the professional societies in their work to integrate ODT into college training curriculum.

➤ **In-Hospital ODT Training**

Responsibilities:

- Develop training programs / materials for health professionals associated with ODT
- Deliver training

There was discussion on whether a national training program with standardized training material and delivery would bring significant improvement. It was felt that many programs

already had adequate training programs and a national training program should not be a high priority for the strategic plan. OPOs/donor coordinators, hospitals, transplant programs should continue to develop and deliver training for their health care professionals.

### **Donor Identification and Management**

#### ➤ **Donor Identification and Referral**

Responsibilities:

- Identify potential donors (NDD and DCD)
- Refer potential donors to OPO
- Support families

It was identified that the groups currently performing these functions would continue to do so: ICU/ED staff, tertiary care physicians. This would also be part of the role of Donation Physician Specialists.

#### ➤ **Donor Management**

Responsibilities:

- Clinically manage donors

Donor management will remain with ICU/ED staff, supported by OPOs in providing expert advice.

### **Donation Consent and Coordination**

#### ➤ **Donation Approval**

Responsibilities:

- Authorization of donation

The current groups performing this role would not change: families, physicians, and the medical examiner/coroner (where applicable).

#### ➤ **Donation Coordination**

Responsibilities:

- Screen potential donors
- Obtain consent
- Ensure donor testing
- Support families
- Provide logistics coordination

It was recommended that OPOs/Donor Coordinators and physicians within emergency departments and critical care continue to perform these functions. Registries would also be used to determine whether the potential donor had indicated intent or consent to donate.

### **Organ Recovery and Transplant**

#### ➤ **Organ Recovery and Transplant**

Responsibilities:

- Assess and care for potential recipients and recipients
- Conduct work-ups and assessments of living donors

- Recover donor organs
- Transplant donor organ
- Provide logistical support (OR)

Transplant Programs will continue to look after potential recipients, recipients and living donors, and perform the actual organ recovery and transplant. OPO staff/donor coordinators would continue to assist in recovery, perfusion, labeling, and packaging, where they currently do it today.

### **Registries and Allocation**

#### ➤ **Donor Intent / Consent Registry System**

Responsibilities:

- Lead the development of a single donor intent/consent registry system:
- Lead alignment of existing provincial systems
- Link provincial systems to national registry, as required
- Preserve and link multiple input points, as required (e.g. health card and motor vehicle license registration and renewal)

The pros and cons of the current intent to donate registry operators were discussed. Government agencies that register intent at time of card renewal (driver's license, health card) had effective contact with the public, but their databases could not always be accessed. As well, they do not have a national scope. Several OPOs also have systems that are functioning, though with different formats and standards. Medic Alert has a national scope and deals with patient databases. Canadian Blood Services also works with donor registries through its OneMatch stem cell and blood donor programs. The group felt that Canadian Blood Services should work with the different registries stakeholders and develop a system that would result in a consistent approach with national access to data.

#### ➤ **Allocation and Offer Management**

Responsibilities:

- Develop, implement, and maintain a single waitlist for each organ type
- Develop, implement, and maintain a central IT system supporting national and local allocation
- Develop, implement, and maintain an interface for donor information
- Allocate and offer organs nationally, as per allocation rules and algorithms

Several potential operators of a national IT system were discussed including OPOs, transplant programs, London Health Science Centre, Canadian Blood Services and UNOS. Though some have existing systems in place, it was felt that an OPO or a transplant program would not have the IT expertise or the national scope required to develop, implement and operate such a system. London HSC was not interested in continue this role. Though UNOS in the United States has expertise in this area and would be capable of this role, it was felt that their focus would be on the American system and that Canadian requests or changes may not be prioritized. It was suggested that Canadian Blood Services would be the best organization for this, as it already was developing the LDPE, the urgent status, and the highly sensitized patient registries and had proven success with the LDPE. This would allow for an integrated system and national support, and would leverage existing infrastructure.

It was also recommended that:

- Organ sharing agreements and allocation rules would be developed in consensus process with broad group of experts and stakeholders and participation from all provinces.
- Provincial allocation rules were to follow national principles and policies, however, flexibility and local variation should be allowed based on evolving practice, regional requirements, and to allow R&D of new ideas to improve policies.

## **National Policies, Standards and Leading Practices**

### ➤ **Coordination of Standards Development**

Responsibilities:

- Lead process for the development and maintenance of national standards for CTOs

Organizations that currently have mandates for standards development are Accreditations Canada (standards for hospital accreditation) and Canadian Standards Association (standards for Cells, Tissues and Organs for safety and effectiveness). It was felt that these groups should continue to develop standards, in collaboration with a broad group of experts and stakeholders (such as OPOs, CST and CCCS) who have subject matter expertise.

### ➤ **Coordination of Policies Development**

Responsibilities:

- Lead process for the development and maintenance of national policies for ODT (National allocation criteria, national organ-specific standards for patient referral, listing for transplant and waitlist management, etc)

While it was felt that many groups could lead the process for the development of national policies, the best organization was thought to be Canadian Blood Services. In spite of the lack of subject matter expertise that others like the CST and CCCS could provide, Canadian Blood Services has experience in developing national policies (former CCDT work), can coordinate policy for all aspects of ODT, and is viewed as a neutral third party.

### ➤ **Policies and Standards Development**

Responsibilities:

- Participate in the development of national policies and standards

Regardless of the organization leading the development of national policies, these will need to be developed in a consensus process with broad group of experts and stakeholders, with participation from all provinces, including OPOs, transplant programs, intensivists, professional societies (e.g. CST), ethicists, and the public.

### ➤ **Leading Practices Development and Monitoring**

Responsibilities:

- Develop leading practices for donation and transplantation
- Promote and monitor adoption of leading practices

It was suggested that ODT service delivery organizations (e.g. OPOs) would be in the best position to develop, test and refine leading practices. Canadian Blood Services could support these groups by ensuring that leading practices were disseminated to other groups and monitoring their effectiveness and uptake.

➤ **Policies, Standards, Leading Practices Implementation**

Responsibilities:

- Implement national policies, standards, and leading practices

All service delivery organizations would be required to implement national policies, standards and leading practices.

**Performance Management**

➤ **Data Collection**

Responsibilities:

National:

- Develop data requirements and data definitions in collaboration with OPOs, transplant programs, others in the OTDT community and international groups
- Consolidate and manage data
- Develop IT links to collect local data from provincial systems, where applicable
- Support data requirements for scientific and clinical efforts

Local:

- Collect donation, allocation, and transplantation data (including patient outcome data)
- Provide data for national consolidation

There are many ODT organizations that collect data and will continue to do so. For the purposes of monitoring and analyzing performance data, it was suggested that Canadian Blood Services would be in the best position to do this. Through its work on the registries, Canadian Blood Services will have much of the data needed for performance. Canadian Blood Services also has experience through its Collaborative work on the definition of donation and transplantation metrics and the infrastructure to support this work. Service delivery organizations will participate in the development and definition of measures and will be required to provide data for national consolidation. It was recognized that resources may be needed for local collection of data.

➤ **Data Analysis and Modelling**

Responsibilities:

- Provide data analysis and modeling to help inform policy and system improvements

Many organizations are capable of performing this function: Accreditation Canada, Canadian Blood Services, CIHI/CORR, CST, SRTR in the United States, universities, etc. The group decided that further analysis is required to determine the best organization, based on economics, expertise and service delivery requirements.

➤ **Strategy Management**

Responsibilities:

- Maintain and refresh ODT strategy and performance measures and targets
- Monitor and report on performance of the system in relation to the strategy
- Guide the community in system change decisions

It was felt that Canadian Blood Services should be responsible for strategy management, given its experience in this area, and its neutrality. It was also recommended that periodically there should be review of Canadian Blood Services performance in this role by an independent third party.

### **Legislation and Regulation**

No changes were identified as to current roles in the development, implementation and enforcement of legislation and regulation.

- **Safety Regulations: Health Canada**
  - Establish and maintain regulations for organ donation and transplantation
  - Audit service delivery organizations against the regulations
  - Monitor critical incidence
  
- **Surveillance and Public Health: Public Health Agency of Canada (PHAC)**
  - Surveillance of adverse events (CTOSS)
  
- **Legislation: Provincial Governments**
  - Establish and maintain legislation for human tissue (includes legal requirements for identification and referral of donors)

### **8. Implementation Priorities**

Sophie presented a map which plotted the ODT initiatives based on their relative impact (on system outcomes) and their relative effort required to implement. Several initiatives were moved on the map:

- ODT professional college curriculum development was thought to require medium, not high effort.
- Development of an optimal funding model was thought to be the initiative that would require the highest effort, but would also provide the most impact on performance.

The Committee also quickly reviewed ODT initiatives that could be started now, without additional funding or new mandates: Changes to the list included:

- Required referral legislation implementation was moved into “could do now” category
- Living donor optimization/re-imburement required new money for living donor work-up
- Optimal funding model development should include donation and transplantation, as well as both living and deceased donations

### **9. Wrap-Up and Next Steps**

Peter thanked the Committee members for their excellent work over the past year. He reminded them that work would continue over the summer and that final recommendations would be reviewed at the October meeting.