

## ORGAN AND TISSUE DONATION AND TRANSPLANTATION (OTDT)

### Public and Expert Interim Report – Key Messages

Between October 2009 and June 2010, a series of public and expert dialogues are being held across Canada. Canadian Blood Services is facilitating these sessions in order to obtain both public and health care professional (clinical and administrative) response to and feedback on the OTDT national system design.

As of March 31, 2010, seven public dialogues have been conducted. To ensure diverse representation at these dialogues, Canadian Blood Services recruited participants through a wide range of groups, which were attended by more than 230 Canadians. Stakeholder partnerships have been key in publicizing the dialogue sessions, and in securing additional feedback and input from the public. Partnerships have been built with groups like the Kidney Foundation, Canadian Liver Foundation, Canadian Diabetes Association, The Crohn's and Colitis Foundation, The David Foster Foundation, MedicAlert, Cystic Fibrosis, the Canadian National Institute for the Blind, and the Canadian Transplant Association. In total, those groups represent almost 14 million Canadians.

In addition, there have been 12 multi-disciplinary expert group meetings held in 8 provinces through March 31, 2010, with over 390 attendees. There have also been a number of smaller meetings with other expert and stakeholder groups across the provinces. Public input has also been received on the [www.blood.ca/speakup](http://www.blood.ca/speakup) website, which has received more than 1500 unique visitors since it was launched in November. Detailed feedback was collected from four of the public dialogues, the website, from expert sessions and from smaller meetings, totalling over 400 comments. This combined feedback was used as the basis for this report.

The following report captures the expert and public key messages (those points most often raised). These comments are summarized for tissues and for organs. The key messages have also been grouped into categories pertaining to different elements of the evolving design for the Canadian OTDT system.

Further details on the comments and feedback gathered are available on the committee website by following this link: <http://www.ccdt.ca/committee/index.htm>. The username is **committee** and the password is **OTDT**.

There are a number of public and expert sessions still to be held. An analysis of the complete feedback will be done once these sessions are complete.

## Key Messages—Tissues

### Principles

- Need one consistent national system. (Public)
- Need a safe, trustworthy and transparent system, to build public confidence and trust. (Public)
- There is a need for an ethical component in assessment of system design. (Expert, Public)

### Public and Professional Awareness and Intent to Donate

- Need for increased public awareness around tissue donation. (Expert)
- Need for increased professional awareness around tissue donation, and an understanding of its benefits to recipients and to donor families. (Expert)
- Need to improve public understanding of consent, and educate different demographic and cultural groups about this (i.e., social marketing). (Expert)
- Intent to donate registries should be used. (Expert)
- Need to increase public awareness on tissue transplantation and its frequency of occurrence. (Expert)
- National school curriculum on donation. (Public)

### Donation

- Need to increase donation for tissues. (Expert, Public)
- Need to recognize the biggest tissue donor potential is outside of the ICU, in emergency departments or outside of the hospital. (Expert)
- Need to support and leverage the medical examiners and coroners to help identify potential donors. (Expert)
- Mandatory referral of tissue donors should be considered. (Expert)
- Should implement a call centre for tissue referrals. (Expert)
- Need to make donor identification part of end-of-life care. (Expert)
- Need to work with hospitals to increase identification and referral of potential tissue donors. (Expert)
- Obtaining family consent is sometimes a challenge. (Expert)
- Consent should be obtained by trained professionals. (Expert)
- Need to support outlying hospitals to identify and refer potential donors. (Expert)
- Train all health professionals to recognize donation opportunities. (Public)
- Change system to ensure donors' wishes are respected. (Public)

### Processing and Distribution

- Centralize, enhance and streamline the capabilities of tissue processing and distribution. (Public)
- Centralizing of processing should be considered to take advantage of economies of scale. (Expert)
- Assess costs of local versus imported tissues. (Public)
- Canada needs to increase its recovery and processing of tissue allografts. (Expert)
- Processing of some tissues in the U.S. is likely to be an on-going requirement; Look at Canadian Blood Services experience with U.S. volume purchasing of plasma products as a model for tissue. (Expert)
- Need to determine the right balance of domestic and imported tissue. (Expert)
- Need to create a training plan, and a professional identity to help recruit and retain tissue bank staff. (Expert)
- Recovery should maximize the donor's gift. (Public)
- To make inventory management more efficient, consolidate processing and distribution. (Public)

### **Allocation and offer management (Corneas)**

- Allocation practices should be fair and reasonably equitable. (Expert)
- System must be fair and equitable no matter where you live. (Public)
- Consider a national allocation and offer management centre. (Expert)

### **Transplantation**

- Need data on allograft utilization. (Expert)
- Need to ensure that recipients are informed of and consent to receiving tissue before transplantation occurs. (Expert)

### **Safety and quality**

- Create a national program for traceability. (Public)
- Need for traceability and surveillance. (Expert)
- Centralization to support quality; leverage quality expertise from Canadian Blood Services. (Expert)
- Improve standardization to improve safety and quality. (Expert)
- National safety and quality standards are required. (Expert)
- Need a central organization to help develop standards consistently across the country. (Expert)
- Develop a national quality system which supports standardization, training and accreditation. (Public)

### **Policy development**

- Important to involve physicians in the development of system design. (Expert)
- Need national policy leadership to increase donation. (Expert)
- Need to describe the governance structure for a national system and ensure that all provinces/territories have representation. (Expert)

### **Information management, measurement and reporting**

- Create electronic information systems for performance data to allow comparisons, to stimulate donation rate improvements and to support accountability. (Expert)
- Need to drive measurement to support decision making and system-wide improvement. (Expert)
- Need real-time data repository that is available nationally. (Expert)
- Need tracking and traceability, and ability to report and share data between jurisdictions. (Expert)
- Need an integrated data management system linked to registries, outcomes of donors and recipients wait listing. (Expert)

### **Audit and accountability**

- Need accountability mechanisms in the TDT system. (Expert)
- Use accreditation to ensure compliance with standards and metrics. (Expert)
- Ensure monitoring and compliance to standards. (Expert)
- Need open, transparent and accountable system and process which discloses all information. (Public)

### **Funding**

- Given that funds are scarce, funding is best addressed through the development of a strong business case for TDT, including costs. (Expert)
- Adequate funding will be a key success factor to implement national TDT improvements. (Expert)
- Need to understand the true cost of supporting TDT and fund accordingly. (Expert)

## Key Messages—Organs

### Principles

- Need one consistent national system. (Public)
- Need a safe, trustworthy and transparent system, to build public confidence and trust. (Public)
- Base system on ethical concerns. (Public)
- There is a need for an ethical component in assessment of system design. (Expert)

### Public and Professional Awareness and Intent to Donate

- Emphasis on educating the general public through diverse channels on the importance of donation and issues relating to consent. (Public)
- Support for donor registries. (Public, Expert)
- Standardize processes for donor consent and make it easier for donors to express consent. (Public)
- Presumed consent (opt-out model) should be considered. (Public, Expert)
- Address public awareness regarding ODT to increase donation. (Expert)
- Need professional education to increase understanding and recognition of potential donors and to make donation a routine part of end-of-life care. (Expert)
- Need to improve public understanding of consent, and educate different demographic and cultural groups about this (i.e., social marketing). (Expert)

### Donation

- Streamline system for identification and referral of potential donors. (Expert)
- Need to make donor identification a routine part of end-of-life care. (Expert)
- System design needs to address ICU capacity. (Expert)
- Opportunity to increase donors through greater identification of potential DCD donors and extended criteria donors. (Expert)
- Need to support outlying hospitals to identify and refer potential donors. (Expert)
- Obtaining family consent is sometimes a challenge. (Expert)

### Allocation

- Promote fair allocation standards at the national level. (Public)
- There should be equal access to transplantation. (Expert)
- Consistent national application of agreed upon allocation principles with accountability for practices, so net exporters of organs are not disadvantaged. (Expert)
- Need to determine whether organs are a local, regional or national resource. (Expert)
- Allocation practices should be fair and reasonably equitable. (Expert, Public)
- Consider a national allocation and offer management centre. (Expert)
- Exporting organs out of province could have a negative effect on donation in that province. (Expert)
- Need a real-time central donor database to facilitate organ allocation. (Expert)
- Concern about sharing organs with poor-performing programs. (Expert)
- Establish a national, integrated IT registry system to coordinate organ distribution. (Public)
- Transparency and reasonable rationale in allocation decisions is important, and information needs to be shared.. (Expert)
- Need a “payback” system for exporters of organs to other provinces. (Expert)

### **Transplantation**

- Advocate for a national wait list. (Expert)
- Standardized criteria for transplantation eligibility across the country. (Public)
- Need support group for transplant patients. (Public)

### **Safety and Quality**

- National safety and quality standards are required. (Expert)
- Need a central organization to help develop standards consistently across the country. (Expert)

### **Policy development**

- Important to involve physicians in the development of system design. (Expert)
- Need national policy leadership to increase donation. (Expert)
- Need to understand what a national system can deliver to a high performing province. (Expert)
- Need to describe the governance structure for a national system and ensure that all provinces/territories have representation. (Expert)

### **Information management, measurement and reporting**

- Create electronic information systems for performance data to allow comparisons, to stimulate donation rate improvements and to support accountability. (Expert)
- Need national metrics with respect to donation, freely shared among jurisdictions. (Expert)
- Need to drive measurement to support decision making and system-wide improvement. (Expert)
- Need real-time data repository that is available nationally. (Expert)
- Need resources to support accurate data collection, input, analysis and reporting. (Expert)
- Need tracking and traceability, and ability to report and share data between jurisdictions. (Expert)
- Need an integrated data management system linked to registries, outcomes of donors and recipients wait listing. (Expert)

### **Audit and accountability**

- Auditing process to identify what is currently done well and where improvement is needed. (Expert)
- National oversight of organ procurement organizations. (Expert)
- Need accountability mechanisms in the ODT system. (Expert)
- Use accreditation to ensure compliance with standards and metrics. (Expert)
- Ensure monitoring and compliance to standards. (Expert)
- Need open, transparent and accountable system and process which discloses all information. (Public)

### **Funding**

- Include funding for living donor reimbursement and living donor assessments. (Expert)
- Need for financial support for patients who incur personal costs for transplantation (especially relocation). (Expert)
- Adequate funding for hospitals, ORs and ICUs is required to implement ODT system improvements and to support increased donation. (Expert)
- Need to understand the true cost of supporting ODT and a strong business case to support its funding. (Expert)
- Need funding to follow the patient, but need to ensure that funding for donation avoids the perception of “paying for donors”. (Expert)