

**Organ and Tissue Donation and Transplantation  
Steering Committee Meeting  
January 20, 2010  
Sheraton Gateway Hotel, Toronto**

**Minutes**

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**Attendees:**

Dr. Graham Sher (Chair)  
Commodore Hans Jung  
Dr. Maurice McGregor  
Honourable Anne McLellan  
Dr. Michael Strong  
Dr. Simon Sutcliffe  
Dr. William Wall

**Regrets:**

Dr. Andrew Baker  
Dr. John Hamm  
Dr. Brian Postl  
Dr. Judith Shamian

**Canadian Blood Services Observers:**

Dr. Peter Nickerson, Chair, Organ Expert Committee  
Dr. Locksley McGann, Chair, Tissue Expert Committee  
Ms. Sophie de Villers, Vice-President, Strategy Management  
Dr. Sam Shemie, Medical Consultant, Organ Donation  
Ms. Kimberly Young, Executive Director, Organs and Tissues  
Ms. Sylvia Torrance, Director, Strategic Planning  
Ms. Tracy Brand, Director, Organs and Tissues  
Mr. Mathias Haun, Director, Strategic Planning (Tissues)  
Ms. Sherri Kashuba, Senior Program Advisor, Organs and Tissues  
Ms. Lorna Tessier, Director, Public Relations

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**1. Presentation by Dr. Luc Noel, W.H.O. (Video-conference call)**

Graham welcomed all the Committee members, and then introduced Dr. Luc Noel, Coordinator, Clinical Procedure for human cell, tissue and organ donation and transplantation at the World Health Organization (W.H.O.). Dr. Noel began by presenting the W.H.O. guiding principles for organ transplants. The Declaration of Istanbul was also reviewed as a mechanism to halt organ trafficking and transplant tourism. He noted that member states had responsibilities in implementing these principles and improving self-sufficiency of organs by maximizing donations of deceased donors and live related kidney donors, and by improving disease prevention strategies to reduce demand. He noted that increasing rates of living donation reflects a failure in optimizing deceased donation. Dr. Noel also reviewed W.H.O.'s role in the development of a global coding system to improve traceability and transparency and development of biovigilance and surveillance tools. A discussion period followed, with questions from the group.

**2. Welcome and Follow-Up Action Items**

Graham reviewed the agenda and meeting objectives for the day.

### **3. Review of Activities to Date**

Sophie reviewed the process that is being used to design the national OTDT system. In order to ensure buy-in from the OTDT community, the process has been structured to allow for extensive input from experts, the public and other stakeholders. The process consists of 4 phases: assessment of the current state based on evidence, discussion of issues and problems to determine strategic direction, development of objectives, measures and targets, and finally development of an implementation and governance plan. With the recent expert committee meetings, the second phase has been completed.

Locksley provided an update on the activities of the Tissue Expert Committee. Key recommendations discussed included:

- Implementing a national standardized quality program, with common product coding (ISBT 128) and complete traceability
- Increasing tissue donation by increasing referrals from medical examiners and coroners, using trained requestors, and having a central call centre and mandatory referral legislation in all provinces
- Recovering and processing more corneas, skin, tendons, soft tissue and musculoskeletal tissue
- Training multi-tissue recovery teams
- Centralizing processing, outside the hospital environment

Peter then provided a summary on the outcomes of the Organ Expert Committee. Key recommendations include:

- Implementing a national approach to public awareness
- Developing standardized waitlist referral criteria and a national waitlist
- Implementing national mandatory data reporting
- Making changes to the way funding is provided for ODT services, including patient assessment and testing
- Having a national oversight body to develop policy and standards, with auditing capabilities to ensure compliance

The OEC has also focused extensively on development of allocation principles, to ensure a system that patients, health care professionals and the public can trust.

Sophie then reviewed the feedback that has been received from the public and expert consultations. While the public dialogues had lower attendance than hoped for, the participants rated the sessions very highly. Sophie reviewed some of the comments, indicating that this was just the start of both the public dialogues and the expert consultations, and that a complete analysis would be brought to the committee when more feedback was received.

### **4. International OTDT Models and Performance**

To learn from high performing countries and countries who have recently transformed their systems, the Committee reviewed several international OTDT models. Peter presented the organ transplant systems of Spain, the United States, the United Kingdom, and Australia. Some of the key findings in review of these systems were:

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- A governance body responsible for oversight, policy development, allocation management and compliance is a common national component
- Donation and transplantation services are best delivered by trained specialists (e.g. dedicated physician donation champions in hospitals)
- Profession education and awareness is necessary to achieve optimal system performance
- Public awareness contributes to higher consent rates
- Natural evolution of ODT programs is not sufficient to yield optimal results at a national level. Direct financial investment is needed for transformational change.

Locksley then reviewed the tissue systems in the United States (market based competitive model), the United Kingdom (a government model) and Spain (a mixed model).

Locksley noted some of the key findings:

- Data for tissue donation and transplantation is difficult to obtain
- The U.S., which is a competitive and largely for profit market, is the world leader in both donation and utilization of tissue allografts. It currently has a surplus of tissue product.
- Self-sufficiency varies by tissue type – most countries are at or near self-sufficiency for corneas but importation is critical for advanced tissue types
- In each country, safety regulation is a national role, as is quality (through government regulation or accreditation)
- Based on UK experience, planning capacity for processing facilities should be based on tissue demand

The group discussed several topics related to common success elements of other countries:

- There are various methods of ensuring compliance by organizations involved in donation and transplantation, including financial incentives, organizational structure and legislation. The Committee requested Canadian Blood Services to find out more about the methods of compliance in other systems.
- A society's culture of donation is key to increasing donation rates. The Canadian system needs to be designed so that donation is the norm and that health care systems are actively prepared to make the donation happen.
- The degree of centralization and local variation was discussed. This needs to be clearly defined for the Canadian system. It was suggested that standards and policy could be national, while implementation of the standards could be local/regional. It was agreed that ensuring compliance of organizations and accountability would need to be key components of the system.
- There was a suggestion that tissue traceability could be improved by the distribution of products at the hospital through the hospital blood bank.

### **5. Analysis of Key Government OTDT Reports**

Sophie reviewed nine previous government reports which are publicly available. Many recommendations have been implemented; however, donation rates in Canada have not significantly improved. Sophie noted that recommendations that were less expensive and

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tactical in nature were more likely to be implemented. Some barriers to implementation and potential solutions were discussed:

- National cooperation is necessary for transformational improvements in OTDT but jurisdictional issues continue to impede progress.
- Difference in donation rates provide high performing provinces and programs with less incentive to support national sharing of organs.
- A committed federal champion would be able to assist in selling the plan, as would a famous public champion.
- Because the Federal government has a national mandate for health, they could assist in getting provinces to support the plan.
- The public, health care professionals and patient advocacy groups need to put political pressure on governments, to ensure the plan is adopted.
- The plan should have an economic case, showing cost savings where available and improved efficiencies.
- Current mechanisms should be used to implement change, e.g. the hospital accreditation program

### 6. System Principles

The Committee began their discussion on system principles with a review of comments from the OTDT Expert Committees and the public and expert consultations. Then several of the principles from the last meeting were re-evaluated.

- In light of the presentation by Dr. Luc Noel from W.H.O., the context around self-sufficiency needs to be further defined. Self-sufficiency should be defined as a way to mitigate transplant tourism. Consideration should be given to raising the importance of disease prevention as a strategy or policy as this would decrease the need for organs, and could be initiated by working with disease prevention groups, aligning with their strategies, and working with the federal government.
- Strategies should also target ethnic groups to improve donations, especially groups that have low donor rates but high transplant rates.
- The principle of safety needs to acknowledge that there is inherent risk in OTDT, and that the challenge is to assess and mitigate risk, then take into account the residual risk and cost-benefit of reducing that risk further.
- The Committee agreed that the system needs to be designed based on population/community perspective, as opposed to simply patient needs. This is a system for 34 million Canadians, not just a few thousand transplant patients. As the public is being asked to participate in the system by donating, their support and trust is needed. This is consistent with broader Canadian health system principles.
- Transparency should be considered as a principle.

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- The principle of solidarity should be supported. As voiced in the Romanow report, Canadians support fairness, equity, and solidarity, and want similar access to similar services, regardless of where they live.
- The fact that the OTDT system must work within Canada Health Act and within the larger framework of the Canadian health system should be an assumption, not a separate principle.
- Altruism as a potential principle to discourage transplant tourism was discussed. It was thought that depending on people's altruism was not enough to increase organ donation. Providing incentives may be a solution, however, the line between ethical and unethical behaviour is not always that clear. Simply saying one does not pay for an organ does not address all situations, as we currently reimburse the United States when we receive organs from them and pay for tissue products from other countries. We also import and pay for reproductive tissue from paid donors. If altruism is a principle, it needs to be carefully worded to focus on transplant tourism and commercialization of organ donation.
- While payback (an organ returned for an organ sent) was not generally supported, there needs to be a mechanism to ensure that smaller, high performing regions are not disadvantaged. It will be important to consider consequences of allocation agreements.
- The Committee agree that evidence based decisions should be applied to tissue to determine products purchased and used. Methodologies to promote this are generally accepted and being implemented in hospitals, e.g. health technology assessment (HTA) to look at efficacy for drugs, This may mean that physicians do not have unlimited choice of products and services being paid for by the public health system, but that consideration is given to providing maximum benefit for the maximum number of patients.
- Innovation: Given that the system is being developed for the population as a whole, the Committee felt that the system should not specifically be designed for innovation, but that barriers should not be put in that would discourage innovation. Innovation should not be implemented for its own sake, but should be used to further goals like self-sufficiency.
- It was agreed that for tissue collections should be cost-effective, which may mean not all Canadians will have access to donation.
- The allocation of organs on a local, provincial or national basis was discussed. The consensus was that if the organ has been donated to the public system, then it should be allocated according to transparent and agreed-to allocation criteria. These criteria should be agreed to at a national level, by all participants, and then supported and followed by all parties. Each province should not have different

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criteria. The specifics of where and how organs are distributed can be determined later, taking into account different factors, including medical need, fairness, regional performance.

### **6. Introduction to Organ and Tissue Costing**

Sophie introduced the presentation for costing. This project has been initiated to understand current OTDT costing and funding, as well as to identify critical gaps and assist in the development of costing for the strategic plan. Mhezbin Dharssi then presented the methodology and assumptions of the project, the current available data for OTDT, as well as limitations of the data. It was suggested that the strategic plan be structured to identify absolute costs, what further investments are needed based on current and predicted demand, and outcome of those investments. Costs will also need to be shown at a provincial level. Cost savings, if there are any, should be articulated, as well as non-financial benefits (lives saved, quality of life improvements, shortened wait times). The plan will need to show what the benefits of a national system are for individual provinces. Another suggestion was to estimate patient demand over the next 20 years, and calculate the cost differential between the current system and the new system.

### **7. Wrap Up and Next Steps**

Graham confirmed the dates for the next meetings: the March meeting has been cancelled; the new meeting dates are April 29 and June 16.

Canadian Blood Services will send out the questions from the meeting so any additional feedback can be provided from the Committee members.

Graham thanked the Committee for their input and contribution to the day, and then adjourned the meeting.