

**Organ and Tissue Donation and Transplantation
Steering Committee Meeting
June 29, 2009
Sheraton Gateway Hotel, Toronto**

Minutes

Attendees:

Dr. Graham Sher (Chair)	Honourable Anne McLellan
Dr. Andrew Baker	Dr. Brian Postl
Dr. John Hamm	Dr. Judith Shamian
Commodore Hans Jung	Dr. Michael Strong
Mr. Craig Knight	Dr. Simon Sutcliffe
Dr. Maurice McGregor	Dr. William Wall

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, Business Initiatives
Ms. Lorna Tessier, Director, Public Relations
Ms. Tracy Brand, Director, Organs and Tissues

1. Welcome and Administrative Items

- The Chair welcomed all Members and thanked them for attending the first face-to-face meeting of the Steering Committee.
- Minutes from the Committee's conference call on May 11, 2009 were approved.
- Ground rules for the Committee were discussed:
 - It was agreed that common key messages for meetings would be developed.
 - Meeting discussions and materials will generally not be confidential. Exceptions to this rule will be identified by the Committee as they arise.
 - In responding to media inquiries, Graham Sher will be the main spokesperson for the Committee. If media wish to speak with other members of the Steering Committee, responses will be coordinated through the Canadian Blood Services Public Affairs division. Canadian Blood Services will provide media support to Members for both French and English media, as required.
- The Terms of Reference were approved with the following change:
 - Duties of the Members: Champion the project throughout the health care community.

2. Current State Briefing

Graham Sher, along with Peter Nickerson and Locksley McGann, presented information and answered questions on the current state of organ and tissue donation and transplantation (OTDT) in Canada.

- It was noted that stem cells and cord blood were outside the scope of this group, as there already exists a national system for stem cells, and one for cord blood has recently been approved by the Deputy Ministers of Health.

Action Item: A description of stem cell programs and their supply chains will be provided by Canadian Blood Services.

- The involvement of Quebec was discussed. It was noted that the Government of Quebec did not sign the Letter of Intent between the Provinces/Territories and Canadian Blood Services. However, some physicians within Quebec's transplant community are actively involved in the current inter-provincial sharing system, and have indicated interest in the new Living Donor Paired Exchange. Since Quebec has already done work in consolidating their tissue system, there may be occasion to learn from their work. There may be opportunities for the Steering Committee to engage Quebec representatives in further discussions.
- Public opinion polling should be considered by Canadian Blood Services to obtain more information on the public's attitude to donation and family consent.
- The strategic plan needs to take into account the full supply chain, as well as the ethical issues associated with OTDT.

3. Introduction to Canadian Blood Services

Dr. Graham Sher provided information on Canadian Blood Services, including its history and success in transforming its operations using the Balanced Scorecard strategic planning methodology.

4. Review of OTDT System Design Methodology

Sophie de Villers provided a review on the methodology that will be used to develop the strategic plan, including the process steps that will be followed. She indicated that the Case for Change was a key deliverable for the first phase. The timelines were also reviewed. The work of the Committees is expected to be completed by March 2010. During discussions, Members indicated a need to develop principles of the system, metrics to evaluate the plan, a process to evaluate implementation of the plan, and strategies in dealing with barriers and sources of resistance.

5. Review of 2008 National Consultation Results

Kimberly Young gave a presentation on the OTDT Stakeholder Consultation hosted by Canadian Blood Services in September 2008. She briefly went through the objectives of the meeting, the Syntegration process that was used for the consultation, the topics discussed, and the key learnings from the meeting. A discussion followed on the issue of barriers to change.

6. Draft Case for Change

The Committee discussed the draft Case for Change document. Key questions put to the group were: Were these compelling enough to warrant F/P/T support and funding? What was missing? What additional data/inputs must be acquired? What happens if we do nothing? What has prevented/delayed these efforts in the past? The following key points were noted:

- Costing analysis (cost benefits as well as cost avoidance) and benefits to patients will need to be important components of the plan. Finance Ministers should also be consulted as they play an important role in the approval of health initiatives, likely via Health Ministers.
- Deputy Ministers should be provided a number of scalable options in the plan.
- More data is needed to support the case, including international comparisons (e.g. are more people dying on wait lists in Canada than in other developed countries?), system potential (especially donor potential), and how the system is performing currently in relation to that potential.

Action Item: Canadian Blood Services will provide data regarding death on wait lists as compared to other countries.

- The strategic plan must consider the impact on and integration with the entire health care system, including transportation, education, and staff resources. For example, if donations increase by 20%, are staff and operating rooms available to handle the transplantations without displacing other surgeries? Do we know the capacity of the system to respond?
- Performance targets were discussed: improve access to transplantation, increase number of transplantations, shorten wait times, decrease or eliminate deaths on wait lists. No consensus was reached on what success would look like, though some cautioned that high goals may be unattainable and create unrealistic expectations. It may be more realistic to set target based on international averages and standards.
- As there is the potential to meet Canadian demand for tissue with Canadian donors, there is a business case that is sellable around safety and self-sufficiency. A national, centralized solution for tissue is feasible, as demonstrated by the fact that Quebec has already made the business case to proceed with centralized tissue services within its province.

Some Members expressed concerns regarding the potential safety risks associated with tissue banking. Questions were raised about the responsibility of the Steering Committee in raising these safety risks with Deputy Ministers, ahead of the presentation of the final recommendations.

Action Item: Canadian Blood Services will develop recommendations on whether this is necessary for the Committee.

7. Discuss Solution Design Topics

The Committee then discussed the types of issues that they felt they could address and provide guidance, for the development of the strategic plan. Four topics were discussed: principles, solution feasibility, national OTDT governance, and health care integration.

- Members felt that in order to guide development of the plan/system, overarching policies needed to be developed, expressed in a Canadian context. These could include equitability, based on need; transparency to the public and the patient; self-sufficiency, taking into account safety of supply, economics, traceability; and standardization across the country, in terms of wait list and allocation principles.
- In order to present a feasible plan, funding options will need to be cost conscious and reasonable. The Committees need to look at creative ways to use current money more effectively, look at cost savings, and consider reallocation of money.
- The solution must also take into account impacts that go beyond health care and ensure integration with other types of systems.
- Distinction between the organ and tissue system is key for discussions.

8. Discuss the Key Elements of the Strategic Plan

Graham Sher stated that several plans to improve OTDT in Canada had previously been presented to governments. The Committee discussed reasons that these plans had limited success. Some of these barriers and sources of resistance were identified and discussed:

- Canada has 13 different health care systems that are not integrated and do not provide seamless services for patients. There are many institutional and system barriers that prevent inter-provincial cooperation.
- The current system is designed to meet the needs of the individual, not the population.
- Organ transplantation is a specialized, "niche" part of the public health system and doesn't affect large numbers of patients. It is in these small yet critical areas where provincial systems do not serve patients well, and where the scale related to national size becomes important.
- Political barriers were mentioned as a major challenge.
- Some provinces and organizations do not believe there is value for them in a national system. As a result, the plan will need to define benefits for them and identify areas where it is difficult for one province to succeed alone (e.g. living donor paired exchange). The solution will need to be one that others will want to join.
- Privacy issues will be very challenging in developing inter-provincial patient registries. Balance will need to be achieved between protection of individual information and proper information transfer to ensure a safe and effective system.
- Changing the OTDT service provider and consumer cultures will be difficult.

9. Wrap Up and Next Steps

Graham Sher thanked the Committee Members for their participation at the meeting. He requested Members to contact him if they felt additional Members were needed to augment the expertise of the Steering Committee. He indicated that the next meeting would be held on October 14, 2009 in Toronto.