

**Organ and Tissue Donation and Transplantation
Steering Committee Meeting
November 15, 2010
Hilton Garden Inn, Ottawa Airport
Minutes**

Attendees:

Dr. Graham Sher (Chair)
Dr. Andrew Baker
Dr. John Hamm
Commodore Hans Jung

Dr. Maurice McGregor
Honourable Anne McLellan
Dr. Michael Strong
Dr. William Wall

Regrets:

Dr. Brian Postl
Dr. Judith Shamian
Dr. Simon B. Sutcliffe

Canadian Blood Services Observers:

Ms. Sophie de Villers, Vice-President, Strategy Management
Ms. Kimberly Young, Executive Director, (Organs and Tissues)
Ms. Tamara Mazerall, Project Manager, Strategy Integration (Organs and Tissues)

1. Welcome and Opening Remarks

Graham welcomed the members of all three OTDT committees to today's joint committee meeting. He thanked the participants for their efforts, and noted that he would be presenting the preliminary recommendations to the federal/provincial/territorial Deputy Ministers of Health at their December 9, 2010 meeting. Graham also indicated that while this was the last formal meeting of the committees, Canadian Blood Services would continue working with many of them.

2. Context and Objectives for the Meeting

Graham then presented the agenda for the day. He noted that the meeting would focus on reviewing and endorsing the system strategy and design, and discussing remaining challenges and implementation options. He also provided an update on the activities since the June meetings. In addition to advancing the work on system strategy and system design, there were several meetings with expert stakeholders, patient partner groups, and government officials, to inform and seek input. He indicated that there would be continued consultation throughout the winter with the OTDT community to help finalize the recommendations. These would then be submitted to the Deputy Ministers in the spring of 2011, followed up with another meeting in June 2011 to receive the decision of the Deputy Ministers. The participants then adjourned to their individual committee sessions.

3. Objectives for the Steering Committee Breakout

Graham welcomed the Steering Committee members to their meeting. Graham walked through a short agenda that focused on key emerging issues. The session began with a review of the current position of each province, in relation to OTDT. After this, it was agreed that Sophie would review the tissue strategic plan; that Kim would walk through the organ strategic plan; and that there would be discussion about several gaps—governments and accountability (Organs), system funding, and impacts to Canadian Blood Services.

4. Update on Government Activities

Graham introduced the discussion with a review of the current position of each province, in relation to OTDT; an explanation of the PT Blood Liaison Committee, and its role in relation to Canadian Blood Services and the OTDT mandate; and the existence of OTDT leads located elsewhere in the provincial ministries. Graham informed the committee that Quebec had signed on to the Living Donor Paired Exchange (LDPE). It was understood that Quebec would consider additional opportunities for participation as they arose and the committee agreed that ongoing collaboration with Quebec was needed for an integrated system.

The main issues that were raised in this discussion were: the issue of regional implementation in the west; competing healthcare priorities, particularly in Alberta (wait-times); support from the Saskatchewan Deputy Minister of Health who sees a number of similarities between the blood system and an integrated tissue system; extensive investment in OTDT in Manitoba in the form of funding physician specialists to advocate organ donation and the intent to invest in an intent-to-donate registry; the challenges of ensuring alignment with efforts in Ontario when it has been difficult to get a clear picture of what those provincial efforts are; the tremendous support from Nova Scotia whose Deputy Minister is an avid champion of an integrated solution; and finally with challenges regarding the wording of the Case for Change for Tissues, with Health Canada.

5. Tissue Strategic Plan

Graham spoke briefly about the presentation to the Deputy Ministers on December 9. Graham explained that the key messages were finalized but that the materials were still being assembled. He assured the group that they would receive the material ahead of the DM Meeting. The committee suggested that the presentation parallel how the proposed plan differs from what occurs now.

Sophie then walked the Committee through the Tissue Strategic Plan. She reviewed the planning process, how it was consultative, systematic, and focused; that the efforts have focused on the most urgent priorities identified by the experts and how this approach is different from other approaches that have come before.

Sophie then walked the Committee through the strategy map. She spoke to the importance of a funding model that would encourage the right kind of behaviour. It was noted that the cost of the system have not been looked at before so there is no sense of where efficiencies could be made—the cost of tissue banks are usually part of the operational budget of the hospitals.

At the conclusion of the strategy map review, the committee made several observations/suggestions for consideration:

- There are sensitivities regarding consolidation of tissue banks given the fact that some domestic banks are looking at revenue generation to fund other initiatives.
- The Tissue Expert Committee's focus on Quality and Safety should be messaged in a positive light—that suggested changes do not run counter to Health Canada efforts but rather compliment them.
- “Direct funding to optimally resource delivery of services” (wording on tissue strategy map) might be misleading in that it suggests open-ended funding. Sophie provided clarification—that it is about clarity and visibility into funding whereas today it is buried in hospital funding.

The conversation then moved to draft measures and targets. Questions were raised about baselines. It was explained that this data came from surveys done by Canadian Blood Services with tissue banks. The committee discussed the situation in the U.S. and the fact that the targets outlined in this strategy were low in comparison. The discussion also included a review of adverse reporting and auditing in the U.S. where it was explained that many blood banks (having experience with traceability), manage tissues in the state. Graham concluded that in Canada, although regulations improve the integrity of the system, full traceability to the patient is still incomplete. Unlike blood that follows a single path, tissues follow many. The committee discussed the matter of security of supply and making a strong financial case for improving Canada's system. Graham noted the challenges of finding related data. Sophie then reviewed the system design elements.

The committee discussion returned to the presentation to the Deputy Ministers, where they made several suggestions with regards to key messages:

- The presentation needed to focus on what is wrong with the system; how it can be fixed; and what are the consequences of not fixing it.
- Canada should be embarrassed about the current state of organs and tissues.
- Although people are dying in healthcare all the time, people who die because of a shortage of organs die unnecessarily. It's about a shortage of resources, not a shortage of solutions.

This portion of the session closed with Graham explaining that the tissue community asserts that what is needed is an integrated system—a huge shift in what exists today.

6. Organ Strategic Plan

Kim led the discussion on the organ strategic plan beginning with the strategy map. Graham noted that the major emphasis for organs is the need to create behaviour changes amongst system participants. There is an over-riding need for greater accountability and collaboration between all players in the system. Kim walked the Committee through the strategy destination statement—the initial one and the modified one that had been shared with the Organ Expert Committee that morning. The new statement reflected “transformational” change—having the system perform in the top 5 international systems.

The committee raised the issue of “quality” (survivability) in comparison to this strategy's focus on quantity.

A discussion about living donation occurred with the issue of increased living donation rates being a sign of failure of deceased donation program being the focus. Graham explained that living donation can be part of a healthy program (i.e., kidneys). Graham clarified that in terms of metric, living donation metrics were not the leading ones.

Graham asked the Steering Committee if the reference to international systems (strategy destination statement) was problematic. The advice given by the committee was to benchmark against other countries but focus on an objective that serves Canadians.

Kim moved the discussion forward with a discussion on measures and targets. Kim revealed that the Organ Expert Committee moved to align measure definitions with the World Health Organization, earlier that morning. These changes pertain to the critical pathway for donation and the defined stages of that pathway. In this way, changes are made to those stages where donors are lost from the system. Kim also noted that wait-times metrics were changed. The Organ Expert Committee felt these

should be organ-specific and that further discussion with organ-specific groups is necessary.

Graham continued the discussion and talked about the importance of measuring trust as a key outcome objective and how it relates to increased donation. He also discussed professionalization of donation services—in particular, the establishment of donation physician specialists in hospitals. Graham mentioned that in February he will meet with the Canadian Critical Care Society on the topic.

Discussion then broadened to include mandatory referral, intent-to-donate and the public's confusion on how to indicate consent. Kim continued walking through the map explaining improved access, collaboration and infrastructure and capacity. This led to a discussion about the value of improved OTDT with regards to healthcare more broadly.

This section of the meeting closed with the suggestion that the value-add being proposed by this strategy is transformational change rather than incremental change.

7. Accountability

Graham suggested that based on feedback, he would remove system funding from the discussion in order to concentrate on a key challenge for organs –accountability.

Graham walked through the existing accountabilities in today's system stressing that there is no accountability for inter-provincial collaboration. As he explained, the issue is how to create multi and dual party accountability. The committee agreed that greater accountability was dependent upon accreditation, auditing and reporting mechanisms. The discussion returned to the matter of the Deputy Minister meeting in December. The committee suggested an additional message for this audience:

- Canada is the only country without an official oversight body for OTDT; that because of our history and provincial healthcare model the country can't improve performance in OTDT but that those on the frontlines have come together to formalize how to fix it.

The group then rejoined the rest of the committees for the closing plenary session.

8. Synthesis and Next Steps (Plenary)

Graham welcomed members back to the plenary. Peter Nickerson and Locksley McGann presented the organ and tissue system strategy respectively, summarizing the system strategy and design, and identified the gaps that still needed to be worked on.

Graham then provided a summary of the steering committee discussions. They focused on governance, discussing challenges and potential solutions in dealing with the provincial governments, and the best way to position the plan for the F/P/T governments. He noted that there was agreement with OEC in emphasizing mandatory data reporting, transparency and reporting of non-compliance as effective accountability mechanisms.

Graham reviewed next steps. The meeting on the December 9 with the Deputy Ministers of Health was to present the preliminary recommendations. The Deputy Minister would then receive final recommendations with costing and implementation options in the spring of 2011. He told the group that Canadian Blood Services would send committee members the material going to the DM meeting before the meeting. Graham closed the meeting by once again thanking them for their contribution and giving a commitment to keep them informed of the progress with the DMs and the final documents.