

**Organ and Tissue Donation and Transplantation
Steering Committee Meeting
June 16, 2010
Sheraton Gateway Hotel, Toronto
Minutes**

Attendees:

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

Regrets: Dr. Andrew Baker Dr. Brian Postl

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
Mr. Mathias Haun, Director, Strategic Planning (Tissues)
Ms. Sherri Kashuba, Director, Organs and Tissues
Ms. PJ Vankoughnett-Olson, Senior Program Manager, Organs and Tissues

1. Welcome and Follow-Up of Action Items:

Graham welcomed the committee members to the last formal meeting of the Steering Committee. The agenda and meeting minutes from April 29, 2010 were reviewed. The minutes were approved, with the following change:

- On page one, related to amendments to the Case for Change, the number of patients with kidney failure and diabetes requires correction.

2. Activities to Date and Next Steps

Sophie reviewed the strategic planning process noting that activity since the April meeting has focused on development of system measures and targets and starting to look at implementation approaches. Engagement activity since the last meeting was reviewed along with participation and upcoming events:

- 300+ individuals were engaged in public dialogues.
- 450+ OTDT and health system experts were engaged in expert engagement consultations.
- Presence at the Transplant Games and participation in the Canadian Society of Transplantation and XXIII International Congress of The Transplant Society, both in August.

Graham and Sophie commented on recent government engagements, which have included one-on-one meetings with all but two F/P/T Deputy Ministers (DMs) and the June 7 meeting with the Conference of DMs. Highlights of discussions included:

- Conference of DMs remains supportive of work to develop the national plan and asked that the Case for Change not be released without recommendations to address the challenges it identifies.
- Individual meetings with DMs have been positive; follow-up meetings will occur through the summer and fall.

- Health Canada concern about aspects of the Tissue Case for Change related to the recognition of the CTO regulations in advancing quality and safety of tissue.

The Committee discussed the outcomes of the meetings and asked whether there were any areas identified as unsupportable. Graham noted that it was apparent that national recommendations need to recognize and align with provincial structures and programs.

Sophie noted that while much has been accomplished, there is work to be completed over the summer.

3. Public Opinion on OTDT

Kimberly reviewed the results of a public opinion poll conducted by Ipsos-Reid on behalf of Canadian Blood Services in March 2010. Key findings included:

- Little or no change in views of Canadians in the past 10 year.
- Rating of the principle of fairness the highest, followed by safety and efficiency.
- Identification of public education, sharing organs and tissues between provinces to balance wait times, education of health professional and increasing donation as highest priority actions.
- Strong support for sharing organs across provinces with those with the greatest need.

The Committee discussed the findings and the merits of public opinion polls. Clarification was requested about the impact of removing Quebec on the results. One committee member noted the key message is that nothing has changed in 10 years, which signals that opportunities exist for improvement.

4. System Strategy and Design Updates - Organs

Peter reviewed the status of system design and updates to the strategy map requested by the Organ Expert Committee:

- Strengthening of language related to development, sharing and adopting leading practices
- Adding research and development
- Revising language related to increased organ donation to be more action oriented.
- Replacing “respecting the gift of donation” with “offering every opportunity to donate”.
- Adding optimal outcomes to the goal of maximizing the number of transplants.
- Replacing the concept of self-sufficiency with the concept of achieving world class standing within the destination statement.

The committee supported the addition of research and asked for clarification of the intent. Peter noted that a roundtable of research experts (e.g., CIHR, Heart and Stroke, Kidney Foundation, etc) is being convened in September to obtain input to that component of the plan. Some discussion also occurred about the limitations of setting a target to achieve “world class” status.

5. Measures and Targets - Organs

Peter reviewed the measures and targets developed for as part of the system design. He noted that for transplant volumes, the OEC recommends setting a stretch goal of 95 transplants per million population (pmp) by 2016. Achieving this overall target would place Canada among the world leaders for this measure and reflects what the OEC wanted to see in the destination statement.

The Steering Committee commented positively on what was proposed and advised against using targets and messaging that reference achieving “world class performance”. They recommended using more focused metrics that can be personalized and can demonstrate improved local or provincial performance. Discussion occurred about the absence of metrics on preventing end stage organ failure and the need to acknowledge this larger context even though it is beyond the CBS mandate. Graham agreed that the ODT plan needs to reference the context of both supply and demand and the continuum of care (health promotion/disease prevention through to acute and home care).

The Steering Committee commented on the compelling nature of measures of donation performance and number of deaths on the waiting list. Additional advice to enhance messaging included:

- Providing province-specific information on the amount of investment required to implement the strategy with the associated business case
- Focusing on the value of life gained through transplantation, e.g., productive return to work.

6. System Design - Organs

Peter reviewed the common themes, the emerging system design, roles and responsibilities and implementation options, noting the following:

- Transplant programs, OPOs and the critical care associated with organ donation would continue to be operated in within current provincial structures.
- New roles and responsibilities include integrated data collection, a single waitlist and allocation / offer system, and standards for operating in ODT programs.
- Some organizations would continue to have the same roles with modified responsibilities.

The Committee generally supported Canadian Blood Services taking on new national roles related to integrated data collection; national consent registry, national social marketing plans, and central patient registries, in collaboration with relevant organizations. The potential role of Canadian Blood Services in national policy/standards development and compliance, leading practice development and dissemination, performance measurement and strategy management was discussed. Graham noted that current thinking would have CBS focus on monitoring and reporting and that P/T Ministries of Health would continue their compliance related to roles and responsibilities.

In response to a question about whether the P/Ts have expressed any preference for a new OTDT organization to assume new, national roles rather than Canadian Blood Services, Graham referenced the past decision to expand the CBS mandate rather than establish a new organization for OTDT.

Committee members provided the following comments and advice on roles and responsibilities:

- Recognize the roles of primary health care providers in the emerging design.
- Build on the proven record of Canadian Blood Services in operating the blood system.
- Focus on building trust and confidence within the OTDT community.
- Consider the role of the federal government and Health Canada within a new national OTDT system and the potential funding that will need to flow to support it.

7. Implementation – Organ

Sophie introduced the implementation approach by reviewing potential initiatives to achieve the desired outcomes and discussed initiatives that could be advanced now within CBS' current mandate and those that require a new mandate and/or funding.

The Committee generally supported the implementation approach and the strategy of advancing work now, wherever possible to demonstrate commitment and maintain momentum. Discussion occurred about how this might be achieved. Thoughts included CBS acting like it has a national mandate now and CBS leverage social marketing expertise and infrastructure to begin implementation now. Another view expressed was the requirement for both a clear mandate and separate funding to demonstrate F/P/T endorsement of the recommendations and enable implementation.

8. System Strategy – Tissue

Locksley prefaced the update by noting that the TEC is meeting on June 18, consequently elements of the strategy are presented in draft. He reviewed the strategy map and associated updates noting minor changes to:

- Emphasize safety and recognize the importance of innovation.
- Delete “honouring the gift of donation” to avoid implying a right to donation, which is not financially viable.

9. Measures and Targets – Tissue

Locksley reviewed the measures related to safety, quality, security of supply and efficiency that are proposed to evaluate progress toward achieving the strategic destination. He noted that the lack of TDT data as a major challenge in setting measures and targets and understanding baseline performance.

The Committee acknowledged the need for baseline data and discussed the draft performance measures. Comments noted the value proposition to the provinces in being able to quantify money spent on TDT. Committee members agreed that variability of cornea transplant wait times is a significant issue which warrants a recommendation to advance inter-provincial sharing. Mike noted that another compelling story / value proposition could be made related to tendons which are also in short supply.

Additional discussion related to measures included a recommendation to add a measure related to the number of transplants, the need to link transplant records to allografts to achieve quality targets and a suggestion that the quality / safety and traceability targets should be 100%.

10. System Design – Tissue

Locksley noted emerging directions in system design: emphasis on quality and standardization and centralization of processes and infrastructure. The World Health Organization’s emphasis on standardized labelling and CBS’ recent experience in implementing this labelling for the blood system were identified by the Committee as opportunities to be leveraged for the tissue system.

Locksley provided an overview of the proposed roles and responsibilities to be presented to the TEC noting new responsibilities related to quality and safety and supply chain. He also reviewed the potential organizations (i.e., CBS, existing tissue banks, new national agency) to assume these new roles and responsibilities.

Graham asked for the committee’s views on the notion of a system that fully integrates the full supply chain with one organization providing the product. Committee members discussed the model, the resistance experienced by Héma Québec with this approach and concerns about creating a monopoly provider. Economies of scale that may be through integration were noted as one of the prime benefits of full integration.

11. Implementation – Tissue

Mathias reviewed the major initiatives that are part of the design and implementation of a national tissue system, the potential sequencing for implementing options and the initiatives that could be started prior to new mandates or funding. Committee members’ discussion of implementation noted:

- The value of implementation sequencing that addresses recipient needs starting with corneas.
- The importance of addressing quality and safety.
- The potential of a province by province approach to result in significant time passing before those provinces scheduled for later implementation to realize any benefit, though it may be simpler to implement a new program or a change on a province by province basis.
- The possibility to focus on donation as the first priority.

12. Wrap Up and Next Steps

Graham adjourned the meeting by thanking the Steering Committee for their wisdom, insights and commitment over the past year. He noted that although this is the last official meeting, CBS will be contacting them over the summer to get feedback on final reports and recommendations and for review before publication occurs.

A joint meeting of the Steering Committee and Expert Committees to review the outputs of the work is being planned for early October before taking the plan to the Conference of DM in November.