

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

Attendees:

Dr. Peter Nickerson (Chair)	Dr. Debra Isaac	Ms. Raylene Matlock
Dr. Ian Alwayn	Dr. Anthony Jevnikar	Mr. Scott McIntaggart
Dr. Stephen Beed	Dr. Robert Levy	Dr. Joe Pagliarello
Dr. Michel Carrier	Dr. Shaf Keshavjee	Ms. Deanna Paulson
Dr. Tom Blydt-Hansen	Dr. Norman Kneteman	Dr. John Tallon
Dr. David Grant	Dr. Frank Markel	Ms. Kimberly Young
Dr. Greg Grant		

Regrets:

Dr. Noel Gibney
Dr. Greg Knoll
Dr. Adeera Levin
Dr. Sam Shemie

Canadian Blood Services Representatives:

Ms. Sophie de Villers, Vice-President, Strategy Management
Ms. Sylvia Torrance, Director, Strategic Planning
Ms. PJ Vankoughnett-Olson, Senior Program Manager, 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 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. System Strategy – Strategy Map

Peter welcomed the OEC to the meeting and reviewed the strategic planning process. Kim then reviewed the revised destination statement for the Organ Strategy Map, which was changed from “A trusted and self-sufficient system for Canadian patients by 2016” to “By 2017, our integrated and trusted system will be performing enough transplants to secure us a place as one of the leading international systems.” The changes were made to reflect the time that funding was likely to be received, as well as explicitly indicating the performance levels expected from the system.

The committee made several comments on the destination statement: it was too wordy; it needed to focus on the patient; it needed to be more declarative. Some felt that quality should be included in the statement, though the majority felt it was part of being an international leader. The group also reaffirmed the overall performance target for the system, i.e. increase transplants to 95 transplants per million population. The destination statement will be edited to reflect comments from the group.

4. System Strategy - Measures

Kim presented the draft key measures for the system and noted that these were based on work going on in the country and internationally, including the Collaborative, the W.H.O. and Accreditation Canada. The committee members broke up into groups and discussed the definitions of the measures, whether they were the right key measures, what was missing, and how to set targets or obtain data for baselines. The following is the outcome of those discussions:

- The group agreed to adopt the W.H.O. definitions for organ donation and transplantation measures and definitions, as Canada would be compared internationally, and there would have to be justification in deviating from measures that had been agreed to at an international level. The group noted that the following W.H.O. donor measures would be useful to track in Canada:
 - **Possible Deceased Organ Donor:** A patient with a devastating brain injury of lesion OR a patient with circulatory failure AND apparently medically suitable for organ donation
 - **Potential DBD (Donation after Brain Death) Donor:** A person whose clinical condition is suspected to fulfill brain death criteria
 - **Eligible DBD Donor:** A medically suitable person who has been declared dead based on neurological criteria as stipulated by the law of the relevant jurisdiction
 - **Potential DCD (Donation after Circulatory Death) Donor:** A person whose circulatory and respiratory functions have ceased and resuscitative measures are not to be attempted or continued OR a person in whom the cessation of circulatory and respiratory functions is anticipated to occur within a time frame that will enable organ recovery
 - **Eligible DCD Donor:** A medically suitable person who has been declared dead based on the irreversible absence of circulatory and respiratory functions as stipulated by the law of the relevant jurisdiction, within a time frame that enables organ recovery
 - **Actual Donor:** A consented eligible donor in whom an operative incision was made with the intent of organ recovery for the purpose of transplantation an/or from whom at least one organ was recovered for the purpose or transplantation
 - **Utilized Donor:** An actual donor from whom at least one organ was transplanted

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- The following were other measures and suggested targets that the committee felt would be useful. They also noted that organ-specific advisory groups will need to be consulted to determine and/or validate measures, definitions, baselines and targets.

Measure / Definition	Baseline	Target
Transplants PMP: Patients transplanted per million population	49 PMP (from deceased) 15 PMP (from living donor) 64 PMP (total)	44 PMP (from SCD) 21 PMP (from ECD) 10 PMP (from DCD) 20 PMP (from living donor) 95 PMP (total)
Referral Rates (NDD and DCD donors): Potential donors referred to OPOs/ Potential donors (%)	Not available	100%
Approach Rates(NDD and DCD donors): Families approached/ Referred donors (%)	Not available	100%
Consent Rates (NDD and DCD donors): Consents received/ Families approached (%)	Not available	75%
Conversion Rates (NDD and DCD donors): Utilized Donors/ Potential Donors (%)		60%
Donors PMP: Actual donors per million population	Not available	Based on 50% SCD, 30% ECD and 20% DCD donors of total: 11 PMP (SCD) 7 PMP (ECD) 4 PMP (DCD) 22 PMP (total)
Organs Transplanted Per Deceased Donor (SCD, ECD, DCD): Organs transplanted/ Actual donor	Not available	Based on 50% SCD, 30% ECD and 20% DCD donors of total: 4.0 PMP (SCD) 3.0 PMP (ECD) 2.75 PMP (DCD) 3.45 PMP (total)
Attempted DCDs: Consented Donors who die within the timeframe for DCD/ Consented DCD donors	Not available	75%
Patient Survival <ul style="list-style-type: none"> By organ type At 30 day, 1, 5, 10 year Stratified by risk/acuity/status 	Not available	Increase or maintain in face of increasing number of transplants
Graft Survival <ul style="list-style-type: none"> By organ type At 30 day, 1, 5, 10 year Stratified by risk/acuity/status 	Not available	Increase or maintain in face of increasing number of transplants
Death/Removal from Wait Lists: Number of deaths and disqualifications on wait list per year	Deaths = 249 (2009) Removal = 313 (2009)	TBD
Median Wait Time (kidney): Median time from start of dialysis to transplantation	Not available	TBD – potentially related to less variation across the country

Measure / Definition	Baseline	Target
Work-Up Time (By Organ Type): <ul style="list-style-type: none"> From referral to eligibility decision From eligibility decision to listing 	Not available	TBD
ESOF Patients referred to wait lists, by organ type: TBD - for renal this could potentially be the percentage of dialysis patients on transplant wait lists		
Patient net benefit measure: TBD – this could potentially be based on LYFT, life years prolonged, and/or quality of life		
Public Trust Index		
Health Care Professional Index		
Intent to Donate Registration, by jurisdiction: Percentage of population that has registered on Intent to Donate Registry	Not available	50%

- Other standard definitions need to be developed to implement these measures in some cases, e.g. categories for disqualification from wait lists.
- The need for rates of diseases leading to end-stage organ failure for the Canadian population was identified as a pre-requisite in determining measures and targets for number of patients who should be referred for donation. It was identified that this data would be difficult to obtain.

5. System Design – Recap and Checkpoint

Kim reviewed the proposed system design. This includes the critical system design elements that support the system strategy and preliminary recommendations. Kim also reviewed system roles and responsibilities for clinical service delivery and for supporting functions such as registries and inter-provincial coordination activities. It was noted that there was still work to be done in determining roles and responsibilities for integrated data management and analytics. The recommendations as presented were endorsed by the committee members.

6. System Design – Accountability and Governance

Sophie began the governance discussion by outlining the gaps in the accountability framework and some of the requirements for a successful structure. Discussion also focused on the potential issues of dual accountability of service providers, i.e., reporting to Ministries of Health as well as working towards national performance targets and standards. The committee members then broke out into groups to discuss a proposed governance structure and various accountability mechanisms. While the committee agreed that more work needed to be done, their suggestions for improvements included the following:

Governance

- There needs to be a component for research in the model, which includes CIHR
- There is a need for a infectious diseases sub-committee
- The model needs to show the relationship and accountability between programs and the Canadian Standards Association and Accreditation Canada, as well as Health Canada
- Clinical sub-committees should have a role in the development of standards

- Future activities need to be reconciled with the current mandates of the Canadian Society of Transplantation, and CORR/CIHI
- OPO representation is needed beyond the Donation sub-committee
- Public representation needs to be included in the structure to receive input and ensure transparency

Accountability Mechanisms

- Accountability for safety regulations remains with Health Canada
- It was felt that it will be difficult to develop accountability for patient referral to transplant programs. However, organ specific groups should still set eligibility and referral criteria.
- Transparency of mandatory performance data, and auditing of compliance to standards and reporting requirements were believed to be effective accountability mechanisms
- Some felt that having a membership standing could also be effective. Members would be required to meet agreed-to standards to participate in inter-provincial programs.
- Auditing should include baseline/entrance auditing, routine auditing, and triggered audits
- Organ specific committees, as well as the advisory committee, through Canadian Blood Services would report to provincial governments on system performance. Provincial governments would then have information to act on poor performance. Hospital leadership would also be alerted to performance issues.
- Some felt that performance should be reviewed and reported to provincial governments by an independent group, separate from Canadian Blood Services.
- It was suggested that some money could be channelled through Canadian Blood Services to provide financial incentives for performance or compliance with reporting requirements.
- Government support would be required to ensure that provincial organizations understood and accepted their responsibilities for performance and reporting.

7. System Implementation

The group reviewed the list of implementation priorities and briefly discussed the different activities. There was generally agreement with the time frames presented. However, many indicated agreement that performance reporting should start sooner, and that development of a new funding model needed to start right away. It was also clarified that this was the development and implementation of a new funding model to better support ODT activities, and was distinct from incremental funding to support increased activities. While the model is being developed, it is still critical to increase the investment immediately at the front-line for the additional donations and transplantations that are being targeted.

8. Organ Expert Committee Wrap-Up

Peter then reviewed the activities that would take place over the next six months. These included continued consultation with ODT experts, programs and associations. The purpose is both to inform and receive input on the recommendations, so that they can be finalized. Peter also requested that the members talk to their peers to inform them about the strategic plan and proposed recommendations. The group then rejoined the rest of the committees for the closing plenary session.

9. Synthesis and Next Steps (Plenary)

Graham welcomed members back to the plenary. Peter and Locksley 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.