

**Organ and Tissue Donation and Transplantation
Organ Expert Committee Meeting
June 22, 2009
Sheraton Gateway Hotel, Toronto
Minutes**

Attendees:

Dr. Peter Nickerson (Chair)	Dr. Debra Isaac	Ms. Raylene Matlock
Dr. Stephen Beed	Dr. Anthony Jevnikar	Dr. Joe Pagliarello
Dr. Michel Carrier	Dr. Shaf Keshavjee	Ms. Deanna Paulson
Dr. Noel Gibney	Dr. Norman Kneteman	Dr. Sam Shemie
Dr. David Grant	Dr. Greg Knoll	Dr. John Tallon
Dr. Greg Grant	Dr. Adeera Levin	Ms. Kimberly Young
Dr. Tom Blydt-Hansen	Dr. Robert Levy	

Regrets:

Dr. Ian Alwayn
Dr. Frank Markel
Mr. Scott McIntaggart

Canadian Blood Services Representatives:

Dr. Graham Sher, Chair, Steering Committee
Ms. Sophie de Villers, Vice-President, Strategy Management
Ms. Sylvia Torrance, Director, Business Initiatives
Ms. Lorna Tessier, Director, Public Relations

1. Welcome and Administrative Items

- Peter Nickerson welcomed all Members and thanked them for attending the first face-to-face meeting of the Organ Expert Committee (OEC).
- Minutes from the Committee's conference call on May 20, 2009 were approved.
- The Committee Key Messages Sheet was reviewed. Peter Nickerson indicated that this would be updated and sent to Members.
- Ground rules for the Committee were discussed. The following decisions were noted:
 - Canadian Blood Services will look into the availability of web/video conferencing for use by the Committee, which could be considered for occasional Committee meetings.
 - Members who are unable to attend a meeting will contact the Chair prior to the meeting to discuss any issues they may wish to have discussed at the meeting.
 - Members who are unable to attend a meeting will be able to vote on issues.

- Documents for the Committee are to be sent out to Members by e-mail.
 - Committee membership will be published.
 - E-mails of Committee Members will be shared with all other Committee Members, including the OTDT Steering Committee and Tissue Expert Committee.
 - Canadian Blood Services will let Members know in advance of any press releases being made about the OTDT Committees. Members who are contacted by the media will refer any questions about Canadian Blood Services to Lorna Tessier. Members can also contact this person for assistance or support with any media inquiries.
 - Meeting discussions and materials will generally not be confidential. Exceptions may be identified, e.g. draft Committee recommendations that have not yet been approved by the Committee.
 - Key messages and future meeting dates will be developed at the end of each meeting.
- A question was raised regarding the relationship of OEC Members with the other OTDT Committees. It was noted that the OEC does not report to the Steering Committee, nor does the Steering Committee approve the OEC's recommendations. Rather the Steering Committee provides expertise in health care system design, governance and funding.
 - It was noted by Peter Nickerson that Members, with the exception of Greg Knoll from the Canadian Society of Transplantation and Joe Pagliarello from the Canadian Critical Care Society, have been selected as subject matter experts and do not formally represent their organizations.
 - The Terms of Reference was approved with minor changes:
 - Purpose: The OEC will ~~support~~ **work with** the OTDT Steering Committee This was changed to reflect the actual relationship between the Committees
 - Membership: Members shall be appointed by the ~~CEO, Canadian Blood Services~~ **Chair**. This was changed to ensure consistency within the document and indicate the proper authority.

2. 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.

3. Introduction to Canadian Blood Services

Sophie de Villers 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 Methodology to Design National System

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.

5. Draft Case for Change

Sophie de Villers provided an overview to the draft Case for Change, including its purpose and how the document was structured. The problem statements as described in the draft Case for Change document were discussed through breakout sessions and a plenary. (Notes for each problem are attached as appendices.) There was also general discussion that touched on all problems:

- There is a need to ensure the proper tone for the problem statements. If it is too mundane and soft, it will not motivate government to support OTDT over other health care initiatives looking for funding. If it is too crisis provoking, public trust will diminish, donation rates will drop and the good work done by programs will be minimized. One suggestion was to state that the system had reached its capacity and is now unable to cope with current and future demands. Solutions are available, but are blocked by the current system.
- The number of affected Canadians needs to include those that have end stage organ failure, not only those that make it to the wait list.
- The language should be changed to be more accessible to the general public.

Peter Nickerson stated that Canadian Blood Services would update the problem definitions based on the comments from the Committee and provide notes from the discussions. He also indicated that some of the Committee Members may be contacted for further data to support the Case for Change.

6. Discuss Solution Design Topics

After an introduction to the session by Ms. Sophie de Villers, the group discussed OTDT issues that needed further discussion at future meeting, under four topic areas: donation, transplantation, allocation and governance. It was determined that two sub-groups of the Committee would be formed: one to discuss questions related to donation, and another to discuss question on transplantation. These groups would bring back options to the full Committee. For allocation, a process with broader participation from the ODT community will be developed. For governance, Canadian Blood Services will prepare a proposal for approach and present to the full Committee for review.

Peter Nickerson will put together the two sub-groups for donation and transplantation and asked Members to e-mail him if they had specific preferences. He will inform the Committee of the Membership of these sub-groups.

7. Meeting Adjournment

Peter Nickerson thanked the Committee Members for their participation in this process. The next meeting will be held on October 19, 2009.

Breakout Session 1: Donation Problem Statement

Participants: Peter Nickerson, Steve Beed, Noel Gibney, Greg Grant, Norman Kneteman, Raylene Matlock, Joe Pagliarello, Deanna Paulson, Sam Shemie, John Tallon,
Facilitator: Andrew Pateman

Comments on Problem 1: Canada is failing to realize its potential for organ donation

- **Strong public support for ODT does not ultimately translate into commensurate rates of registered intent/consent and family approval**
- **Registered intent/consent of potential donors is not regarded as binding despite its legally-binding nature**

Remove this bullet. The focus in moving forward should be evaluation of the effectiveness of a national registry for intent/consent and public awareness and education, not trying to improve through a legal solution. There has not yet been much discussion on registries and their effectiveness. This should be a topic of discussion for this Committee. Education needs to be available to healthcare professionals as well.

- **Donor identification and referral remain a professional option, rather than an obligation; best practices in identification, referral, and consent are adopted inconsistently**

Resources in donation are small compared to transplantation. There is a lack of dedicated system funding - donor coordinators are financed locally and are subject to hospital budget cut-backs. These positions should be separately funded and supported nationally to protect them. Education is a necessary component, both at medical schools and for EMS professionals. There is a need for a mandatory notification system for OPOs that involves them at the appropriate time. Donation activities must be centrally managed, well structured, well funded, and based on best practices. Donor evaluation and management requires best practices and audit. Concentrate on developing a process for notification that is appropriately resourced.

- **Donation by Living Donors and Donation after Cardiac Death, practices with potential for increasing organ donation, are under-utilized**

Add 'optimize NDD'. Need to be sensitive to geography, as the system must function in smaller places.

- **Financial disincentives to accommodate organ donation impair donation performance**

This needs to be reworded to eliminate the double negative. Incentives are disparate across the system. List what the disincentives are, e.g. accessing ICU services. Incentives must be created to identify, refer, and assess donors.

Priorities:

- Education (government, EMS, other health care professionals, the public)
- Best Practices
- Focus on areas where there is a qualitative impact: consent, DCD, identification of donation opportunities
- Roles, responsibilities, and accountability must be clarified

Data Required:

- Donor potential from all jurisdictions to evaluate capacity for improvement
- Data on disincentives for organ donation (national and international)
- Data on conversion rates (national and international)
- Funding and OTDT incentives across jurisdictions

General Comments:

- There is a need for grass roots organizations and for regarding donors and families as 'high value'. End of life care must be treated as a priority.
- Need to distinguish between living donation and deceased donation in the problem statements and description.
- Need to solve the lack of dedicated funding across the system.

Breakout Session 2: Transplantation Problem Statement

Participants: Michel Carrier, David Grant, Tom Blydt-Hansen, Debra Isaac, Tony Jevnikar, Shaf Keshavjee, Greg Knoll, Adeera Levin, Robert Levy, Kimberly Young

Facilitator: Sophie de Villers

Problem 2: Patients with end-stage organ failure are an under-served population

Reword: "Canadians with end-stage organ failure do not have adequate access to transplantation and will die without a transplant"

- **Patient assessment and waitlist referral practices vary by province and practitioner, leaving some patients with a lower likelihood of transplant**

Potential wording: "Patient referral, assessment, and wait list practices are disorganized, inconsistent, poorly integrated and opaque." While objective criteria for transplantation referral exist for different organ types, there is a lack of awareness in health care professionals about these criteria, i.e. referring physicians are not aware that their patients that could benefit from transplantation. When they are referred and assessed, they may not be put on the wait list, even if they could be eligible.

- **Referral and allocation practices are not transparent and patients do not have visibility into their waitlist status**

Add at the end "...which erodes trust in the system." Remove reference to wait list status. Patients and health care professionals do not understand the system. Referral, allocation, access are not transparent, and are difficult to understand, and vary widely. Where a patient is on the wait list can change day to day, and doesn't mean much in isolation from other information. There is a need to make the system understandable to patients, public and health care professionals, including the ICU docs who may be referring donors.

- **Likelihood of receiving a transplant varies widely based on a patient's province of residence**

"Likelihood of receiving a transplant varies widely." Delete "based on a patient's province of residence", as there a number of factors that affect this, including referral bias.

- **Highly-sensitized patients receive a disproportionately small share of the available organs**

Several vulnerable populations, such as Aboriginals, have tended to have poorer transplant outcomes than the rest of Canadians.

Priorities:

- Referral and assessment

Data Required:

- Life time risk of getting end-stage organ failure
- Number of Canadians with end-stage organ failure, e.g. In Canada, there are (??) patients on dialysis, (50%?) are eligible for transplantation but only (3,000?) are on the wait list
- Death on the wait list is still an important indicator, though it does not include those who died after being taken off the wait list, or those who died without being put on a wait list.
- Wait time once listed by province
- International and provincial data to show that even our best programs are underperforming

General Comments:

- When making the business case, there is a need to look at the financial aspect, including cost avoidance. It is cheaper for the health care system for patients to receive a kidney transplant, than to stay on dialysis. Likewise, for other organs it is cheaper to get a transplant than suffer chronic illness and die in an expensive ICU/ER bed.
- Having national standards for referral, assessment, and allocation will ensure that when difficult decisions need to be made, that they are made in a uniform way across the country.

Breakout Session 3: Infrastructure and Technology Problem Statement

Participants: Peter Nickerson, Steve Beed, Michel Carrier, Noel Gibney, David Grant, Greg Grant, Shaf Keshavjee, Norman Kneteman, Raylene Matlock, Robert Levy, Joe Pagliarello, Deanna Paulson, Kimberly Young
Facilitator: Andrew Pateman

Problem 3: The quality and efficiency of allocation, utilization, and transplantation of donated organs are constrained by resource and technology limitations

- **There is limited capacity in hospitals to optimally maintain potential donors**

Reword: "There is limited capacity in hospitals to accept and optimally maintain donors, and conduct surgeries." ODT is in competition for critical care resources: ICU beds, OR rooms, OR nurses. This may be an occasional event for most hospitals; therefore, having an extra ICU bed exclusively for ODT is not practical. Instead, "surge capacity" should be looked at as a potential solution.

- **Constraints on recovery facilities, transportation and on recovery and transplantation team availability negatively impact donation quantity and organ quality**

The limitations are availability of transportation resources (i.e. jets) for recovery teams and shipping organs, as well as availability of teams to recover organs.

- **Limited automation in matching and offer management is inefficient and can result in sub-optimal matching or lost transplantation opportunities**

Other suggested wording was, "Technology does not support optimal allocation of organs." Manual matching systems are ineffective, unsafe, expensive and lead to missed opportunities. Current technology is not leveraged, which results in donors that are declined who could have been used and retrieved organs do not always get allocated appropriately to the person at the top of the list.

- **(New Bullet) There is a lack of standardization in testing, utilization practices and post-transplant monitoring, and quality to ensure patient safety.**

Lack of standardization in testing for Hep C (NAT), HIV, EMV, BKV, EBV – need to have reference standards. This applies to other diagnostic services as well.

Priorities:

- Focus on increasing system capacity; first people, then beds.

Data Required:

- None identified

Breakout Session 4: Measurement and Accountability Problem Statement

Participants: Tom Blydt-Hansen, Debra Isaac, Tony Jevnikar, Greg Knoll, Adeera Levin, Sam Shemie, Graham Sher, John Tallon

Facilitator: Sophie de Villers

Problem 4: The current ODT system lacks the measurement and accountability mechanisms to drive consistent, system-wide performance improvement

- **Inconsistent data capture and quality and the lack of centralized reporting and analysis diminish the system's ability to make evidence-based improvements in practice or policy**

Include mandatory: "... lack of mandatory centralized reporting..." Lack of mandatory reporting at a national level is a severe limitation in improving the system. It also leads to underestimating the size of the problem. Numerators are captured, e.g. the number of transplants performed, but the denominators are not captured, e.g. the number of patients with end stage organ failure. Because of the voluntary nature, there is not much faith in the data. One of the main problems is lack of resources at the program level to collect and enter the data. This would be easier if data collection were embedded in the process, to improve both accuracy and efficiency. There is no national data on identification, referral, consent stats.

- **Uncoordinated policy development and implementation limit the system's ability to respond to emerging issues and safety incidents**

Add "Patient safety is being compromised by uncoordinated and fragmented policy development and implementation and limited ability to respond to" This bullet should focus on safety. There is no data to assess safety and the welfare of patients. Coordinated policy is needed to ensure patient safety standards and inform and promote quality improvement in the OTDT system, as well as ensure prudent spending.

- **Best practices and national guidelines and policy are not adopted quickly and consistently**

The current fragmented system does not facilitate adoption of best practices. It is difficult to implement best practices and guidelines over 10 different systems, with different implementation and communication mechanisms. There are no consequences for not following these practices, e.g. cardiac allocation guidelines.

- **Unclear and uncoordinated audit and accountability diminishes both incentives and mechanisms for effecting improvement**

The general public doesn't know if programs are performing well or poorly, because the data is not there to determine performance. We should be able to benchmark organizations against each other and against standards. If you can't measure, you can't demonstrate to the public that the money is being spent wisely. While organizations are

accountable to their Boards or Administration, they are not accountable to the system. There is no linking of resources invested and performance results.

Priorities:

- Mandatory reporting for all components of the system (and resources for data collection at program level)

Data:

- Donation costing (for both living and deceased donors): cost/donor for work-up, cost/donor/province over time
- Kidney allocation algorithm changed because of data received from CORR/CIHI, but this was driven by CST Kidney group, not CORR

General Comments:

- Each new program, when implemented, needs baseline data required to be collected. Data capture must be a mandatory and integral part of the process.
- Informative for Ministers to know what questions we are not able to answer because we have no data.
- National transplantation measures are further ahead than donation measures