



Executive Summary National Consultation

Organ and Tissue Donation and Transplantation (OTDT)

Ottawa, Ontario
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National Consultation question: “Given the need for national, integrated services in organ donation and transplantation, how do we establish the system that best meets the needs of Canadian patients?”

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Disclaimer: The executive summary is provided as an overview of the consolidated report. For detailed outputs, please refer to the consolidated report.

1. National Model

Mandate

Organs & Tissues

- ▶ OTDT related research should be embedded in the mandate of the new CBS / OTDT.
- ▶ Develop a proactive, risk management system to identify potential / emerging safety issues before they have a major impact.
- ▶ National Agency should establish donation standards and policies in collaboration with other key stakeholders.
- ▶ Provincial agencies and hospitals will work to implement national standards with respect to donation.

Organs

- ▶ 2 mandate statements were proposed and discussed:
 - “We recommend that Canadian Blood Services be given the mandate to oversee, manage, and be accountable for the practice of OTDT in Canada.”
 - “We recommend the mandate of the National Agency be to oversee the practice of organ donation and transplantation and to increase the availability of organs for transplantation in Canada.”
- ▶ We recommend the National Agency use the following key mechanisms in achieving its mandate: national standards, best practices, an expansive set of mandatory data as the key tool for developing national policy; incentives for improving organ donation and organ conversions at the program level, national database of core data, education initiatives with OPOs, innovative research programs, accountability framework, and data collection.

Tissues

- ▶ National integrated governance model – all functions within TDT will either be directly managed by the national body or will have oversight by national body. All standards will be national.
- ▶ There are many important areas of overlap/linkage between organs and tissues (see table in orange).

Governance

Organs

- ▶ We need a governance structure which:
 - Responds to public demand for a safe, transparent, accessible and accountable system.
 - Recognizes that OTDT differs from blood in several key ways:
 - Obtaining resources is more complex (many stakeholders and relationships).
 - The process does not end at the time of tissue or organ transplantation.
 - Health economics and societal impacts of organ failure and OTDT are much, much greater than for blood.

- ▶ A dedicated governance focus should be ensured within Canadian Blood Services for ODT.
 - The Canadian Blood Services Board should change its composition to ensure representation from the OTDT community. The Canadian Blood Services Board should review the Board's committee structure to incorporate accountability for OTDT.
 - Canadian Blood Services should create a separate, National Liaison Committee to advise its Board of Directors on OTDT.

Tissues

- ▶ We all support a national organization, but it's too early yet to determine the full scope of its role.

Funding

Organs and Tissues

- ▶ We see substantial new investment needed (see table in Red Shamrock and Tissue Light blue).
- ▶ We recommend the National Agency link funding to organ and tissues donation and transplantation deliverables (performance).

Organs

- ▶ A key funding role for the National Agency will be to identify specific areas for organ donation and transplantation investment at regional and hospital levels and to gain Provincial agreement that purpose-specific budgets be established outside of global hospital budget envelopes.
- ▶ In addition, the National Agency should have purpose-specific funds that it can use to develop the national infrastructure.
- ▶ Ensure funding of the following core system elements as part of the national infrastructure: ODT information systems; national ODT policies and compliance regimes (to ensure national level accountability); public and HCP education programs; national research agenda; and sustainment of the clinical capacity of the national system.

Tissues

- ▶ Funding allocation should be nationally managed. This would ensure country-wide standards/consistencies and give the national organization "teeth".
- ▶ The national organization would allocate funds based on meeting the needs of Canadian patients, policy, standards, deliverables and performance.

Performance Management

Organs & Tissues

- ▶ Mandatory reporting that drives system performance is the cornerstone of the national system.
- ▶ We recommend that the national OTDT agency take responsibility for measuring and optimizing system performance with respect to organ and tissue donation and transplantation in Canada.
- ▶ We recommend that all OTDT players, including hospitals and OPOs, be required to participate in the national OTDT agency's data collection program.
- ▶ We recommend that the national OTDT agency establish standard data collection procedures AND standard data definitions. This will assist in making valid and rigorous data comparisons by hospital, OPO, and country.

2. System Implementation

Organs & Tissues

- ▶ Involve a cross section of stakeholders from the community in activities leading to system implementation.
 - Organs – Transplant and Donor Advisory Board.
 - Tissues – Transition Steering Committee.
- ▶ Consider what will be required to evolve the culture of Canadian Blood Services.
- ▶ This requires a re-orientation of the mission and may also include a name change.

Tissues

- ▶ Create a Transition Steering Committee to manage the transition to a national, integrated service in OTDT.

3. Public and Professional Awareness & Education

Organs & Tissues

- ▶ Grant the National OTDT Agency the responsibility (in partnership with allied organizations) for funding, designing, creating, supporting and coordinating a long-term national awareness and public education program.
- ▶ Recommended model: National oversight for public and professional awareness programs; National, Provincial and Local Delivery.
- ▶ Create a consistent National message – a call to action – that targets everyone in Canada, developed and delivered in conjunction with all stakeholders and partners.
- ▶ Create an awareness and education program for health professionals.

4. Critical Care & Hospital Donation Practices

Organs & Tissues

- ▶ Donation should become an operational norm of hospital practice.
 - Make donation a standard of care in both Critical Care *and* Hospital Care practices.
 - Establish Mandatory Reporting and Routine Referral for Organ and Tissue Donation – Routine referral should be implemented for all patients “AT OR NEAR TIME OF DEATH”.
 - Consistent, system-wide block funding for dedicated personnel in hospitals.
 - Activity-based funding identified as donation-based and targeted for ICU, ER, OR, EMS departments.
 - Assigning priority services to potential Organ Donors and establishing appropriate cost recovery schemes.
- ▶ Establish a First Person Consent Registry to inform treatment of patients.
- ▶ Establish a National Program for Donor Family Support - may be delivered provincially or locally but with oversight to ensure they are maintaining the national standards.
- ▶ Advocate for Living Donation - expense reimbursement standardization, insurance coverage, public/medical professional awareness and education, hospital commitment, and establishment of achievable targets for Canada.

5. Distribution / Allocation / Utilization

Organs

- ▶ Establish a national, integrated system/Canadian Agency to steward a national listing, allocation and utilization process (from policies to implementation).
 - The system must engage the necessary stakeholders.
- ▶ Establish an Allocation Function – that owns allocation policies and has tools and processes for doing so.
- ▶ Establish a Utilization Function to better understand the utilization side of the equation (seek low hanging fruit for incremental gains).
- ▶ The National Agency should ensure the delivery of specialized transplantation services to patients in provinces whose needs are not being met.
- ▶ The Provinces should work with the national agency to ensure patient care when a province is unable to provide specialized transplant services to specific sub-populations.

Tissues

- ▶ Ensure all Tissue products (imported and domestic) are traceable across all stakeholders (hospitals, clinics, dental offices, etc) in an integrated fashion.
- ▶ National User Advisory Board to recommend a governing/allocation model for scarce tissues at a National level.
- ▶ Develop an integrated national strategy and targets for sufficiency.
- ▶ Focus on developing tissue specific targets and objectives, not macro numbers.

- ▶ Establish a National Virtual (Tissues) Inventory System in support of Traceability.
- ▶ Implement a nationwide information sharing network between current tissue banks to share their existing inventory levels.

6. Information Systems

Organs & Tissues

- ▶ It is critical for the success of the Canadian agency to have a credible, reputable, and transparent national information system for OTDT.
- ▶ We recommend that Canadian Blood Services / OTDT take national responsibility for ensuring relevant data is collected at the local level and integrated into a National Integrated Information System, supporting:
 - Analysis and presentation of data for all stakeholders.
 - Assessment of outcomes.
 - Development of policy.
 - Decision-making on distribution / allocation.
 - Tracking of adverse events (surveillance).
 - Traceability.
 - Improvement of system performance.
 - All other aspects of system management.
- ▶ Ensure mandatory reporting/participation in Canadian Blood Services / OTDT data collection program for all players - including hospitals and OPOs.
- ▶ Canadian Blood Services / OTDT must establish standard data collection procedures AND standard data definitions to allow for rigorous data comparisons by hospital, OPO, and country.
- ▶ The Canadian Agency should engage stakeholders in the development of an appropriate system and assessment of performance.

Tissues

- ▶ Establish a mandatory, standard, harmonized product coding system.
- ▶ Establish an IT system for tissue processing and inventory management to assist with traceability and surveillance.

7. National Infrastructure – Information Technology, Human Resources, Finance, Public Relations

Organs & Tissues

- ▶ Leverage existing capabilities and infrastructure of CBS
 - Purchasing.
 - Transportation.
 - IT, HR, PR, etc.
- ▶ Where appropriate, leverage existing non-CBS capabilities and infrastructure.

8. Accountability

Organs & Tissues

- ▶ There should be clear accountability for the development, monitoring and enforcement of standards.
- ▶ There should be a minimum hospital accreditation process for OTDT in Canada.
- ▶ Utilize Accreditation (in collaboration with Accreditation Canada) and Auditing (an external entity should be responsible for this) to optimize system performance and to ensure standards are being met.
- ▶ Adopt a Membership Model (instead of legislation) to deal with Compliance.
- ▶ The National agency should link funding to organ donation and transplantation deliverables (performance) and integrate it with hospital accreditation standards.

Organs

- ▶ National Agency/Canadian Blood Services to develop an Organ Donation specific accreditation system and support tools.

Tissues

- ▶ Develop a National Accredited Training Program for Eye & Tissue Bank Specialists.

9. Scientific and Social Research

Organs & Tissues

- ▶ A national research and development program requires a perennial, dedicated funding model with specific programs and commitments sustained as an on-going percentage of the total operating budget.
- ▶ The funding should encompass a definition of research that is wide in scope.

10. Strategic Planning

Organs & Tissues

- ▶ Develop the compelling case and business plan – in collaboration with the OTDT community – that will encourage participation by all Provinces.
 - Include in the above business case a cost benefit analysis of Living Donor Programs.
 - Substantial new investment is needed. Donations and Professional Awareness are high priorities.
 - Conduct an analysis of current investment levels across the country as part of developing a proposal for the Provinces and Territories.
- ▶ Explore models of service delivery suitable for Canada (consider international comparisons).

Tissues

- ▶ Conduct an HR Inventory & Develop a Process Map.
- ▶ Carry out a GAP-Analysis and SWOT - to identify strengths and weaknesses of existing systems, look for potential consolidation and gains in efficiency, etc.
- ▶ What is most important (safety, supply, awareness) may not be what is most cost effective.