

Background Paper for the OTDT Committees

Organs and Tissues Donation and Transplantation (OTDT) Listing of Key Government Reports

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1. Introduction

A. Background

Recognizing the need to improve the organ and tissue donation and transplantation (OTDT) system in Canada, the federal, provincial (except Quebec) and territorial governments in April 2008 asked Canadian Blood Services to take on new responsibilities related to OTDT. This included the development of a strategic plan for an integrated OTDT system, in collaboration with the OTDT community. As part of this work, three committees were formed – the Steering Committee, Organ Expert Committee and Tissue expert Committee – to help develop the recommendations through a formal, structured planning process.

This document is one of a series of background documents developed to help the committees in their discussions. These documents focused on the critical issues within the system, describing the current state and examining potential options and solutions. Conclusions from the committee discussions were consolidated and incorporated in the final recommendations of the final report. The full report, ***Call to Action: A strategic plan to improve organ and tissue donation and transplantation performance for Canadians***, can be found at organsandtissues.ca, along with the other background documents in this series.

Limitations of these documents:

- These documents were intended for an audience familiar with the subject matter and contain terms and acronyms that may not be in common usage outside the field.
- In some cases, original documents referenced draft materials which have now been finalized. In these cases, where possible, references have been updated. These situations are clearly marked.

- These documents provided an overview of the issue for further discussion by experts in the field of OTDT. The findings and evaluations contained in these documents are not comprehensive—they reflect what was considered to be most applicable to the issue at the time.
- Information in these documents presents knowledge available at the time of the OTDT committee meetings. These documents have been edited for consistency in style and format, but have not been updated to reflect new information or knowledge. References and web links also remain unchanged and may no longer be accurate or available.
- As these are background documents to the ***Call to Action*** report which is available in both English and French, they are available in English only. Requests for translation can be made to Canadian Blood Services using the contact information below.

Note: Production of this document has been made possible through a financial contribution from Health Canada. The views expressed herein do not necessarily represent the views of the federal, provincial or territorial governments.

For more information on these documents or the ***Call to Action*** report, please contact:

Canadian Blood Services
Organ and Tissues Donation and
Transplantation
1800 Alta Vista Drive
Ottawa ON K1G 4J5

Phone: 613-739-2300
organsandtissues@blood.ca

2. Public Recommendation Reports

A. Standing Committee on Health

The following is a listing of key public recommendation reports from the last 10 years regarding organ and tissue donation and transplantation activities in Canada.

Organ and Tissue Donation and Transplantation: A Canadian Approach (Joseph Volpe) - Standing Committee on Health report on the state of organ and tissue donation and transplantation in Canada (April 1999)

Summary of Recommendations:

- The federal/provincial/territorial ministers of health establish the Canadian Transplant Network to oversee organ and tissue donation and transplantation.
- The federal minister of Health ensure that the establishment of such an organization and its accompanying strategy be discussed formally with provincial and territorial counterparts within the next six months.
- This organization have a permanent secretariat and an appropriate budget.
- This organization provide annual public reports through the F/P/T Conference of Ministers of Health.
- This organization provide annual reports through the federal minister of Health to Parliament on results accrued from federal contributions, and such reports be considered in connection with National Organ Donor Week.
- The Canadian Transplant Network be composed of four permanent program areas using expert advisory groups to address respective areas: individual donor intent; potential and actual donor identification and management; sharing, matching and allocation of donated organs and tissues; and transplantation outcomes.
- The expert advisory groups be composed of members drawn from existing organizations involved in organ and tissue activities and rotated on a regular basis.
- The expert advisory groups be responsible for providing direction to the Canadian Transplant Network on the establishment of goals and the measuring of outcomes.
- These goals and outcomes be included in the annual report produced by the Canadian Transplant Network on each specific program areas.

Link: <http://www2.parl.gc.ca/HousePublications/Publication.aspx?DocId=1031593&Language=E&Mode=1&Parl=36&Ses=1>

B. National Coordinating Committee for Organ and Tissue Donation and Transplantation

A Coordinated and Comprehensive Donation and Transplantation Strategy for Canada—A Report from the National Coordinating Committee for Organ and Tissue Donation and Transplantation (November 1999)

Summary of Recommendations:

The Report from the National Coordinating Committee for Organ and Tissue Donation and Transplantation was submitted to the Federal/Provincial/Territorial Advisory Committee on Health Services. The strategic report sets out recommendations for a coordinated and comprehensive organ and tissue donation, distribution and transplant system for Canada. The report recommended six essential system components that must be addressed for the desired targets to be realized:

- **Strategic Direction:** To keep the strategy focused on long-term objectives, measurable goals, key success factors, performance measures and targets will be defined for three levels of accountability: regional/hospital, provincial/territorial and national. A national target of 25 donors per million population (DPMP) by the year 2005 is recommended—a target that also exists for the provinces and territories. Performance measures and targets will also be set by each province and territory to measure key outcomes related to donation, tissue banking and transplantation.
- **Processes:** The core functions and support processes that relate to the service delivery component are a provincial and territorial responsibility. Policies, standards and guidelines must be developed to guide practitioners and provide practice and safety standards for each the critical steps of these processes. This also ensures that performance can be measured, evaluated and reported.
- **People and Organization:** Accountability relationships, communication flows and responsibilities for all levels of government, hospitals, service providers and the public are described. The Canadian Council for Donation and Transplantation, its secretariat and the three advisory committees will serve as permanent structures to facilitate and support all levels of service delivery through the creation and maintenance of national practice and safety standards, standardizing data sets and facilitating reporting functions. The formal relationship of the council, its advisory committees and secretariat to Health Canada needs to be defined by ACHS.
- **Legislation and Policies:** Policies and guidelines of national concern will be drafted by the council for approval by the ministers of health, based on the recommendations from the advisory committees, provinces and territories. Health Canada is in the process of developing safety standards for donation and transplantation. These will be referenced in the *Food and Drugs Act*.
- **Technology and Information Systems:** An information system built on existing technology will be designed by the council to link service providers and support overall data needs of the strategy. The provinces and territories will be responsible for entering data to support timely matching of organs and tissues with potential transplant recipients, and to evaluate donation and transplant outcomes. The council will assist the provinces and territories to undertake performance monitoring, evaluation surveillance and quality assurance functions.
- **Physical Infrastructure:** It is anticipated that Health Canada will support the operations of the council, three advisory committees and secretariat. The start-up requirements for years one (\$17.33M) and two (\$16.03M) are slightly higher than the anticipated annual operating requirement of \$14.78M.

Link: <http://www.hc-sc.gc.ca/dhp-mps/pubs/biolog/transplantation-eng.php>

C. Alberta Advisory Committee on Organ and Tissue Donation

A Framework for Action: A Coordinated and Integrated Organ and Tissue Donation and Transplant System for Alberta—Final report of the Alberta Advisory Committee on Organ and Tissue Donation (April 2000)

Summary of Recommendations:

The report formulated 99 recommendations to address and improve the provincial system for organ and tissue donation and transplantation, clarify important ethical issues, and offer a legislative framework to facilitate implementation of a coordinated and comprehensive system of service delivery.

- A governing committee, supported by three advisory committees, reporting to the Minister of Health and Wellness, will oversee the implementation and management of a provincial organ and tissue donation and transplant system.
- New comprehensive legislation will be developed to serve as the legal foundation for donation and transplantation in Alberta and to replace the *Human Tissue Gift Act*.
- Designated donation and transplant services will be expanded to five centres besides Edmonton and Calgary.
- Provincial policies, standards and guidelines will be developed to provide a consistent approach to service delivery, recognizing efficiencies and principles of best practice.
- The province will participate in the development, implementation, monitoring and enforcement of national safety standards for organ and tissue donation and transplantation.
- A province-wide coordinated approach to public and professional education will be developed.
- Critical care services in health regions throughout Alberta will be designated to provide support in the identification and care of organ donors. The coordination and management of an organ donor will rest with a critical care specialist.
- Bereavement support services will be available in all facilities designated to manage and support organ donors because the active participation of the public is critical to donation outcomes.
- Living organ and tissue donation will be enhanced to optimize transplant opportunities, while ensuring the donor is provided care independent from the proposed recipient's medical team. Policies will be developed to guard against coercion, to protect the health of the living donor and to ensure the potential donor is able to comprehend the risks and benefits necessary to make an informed decision.
- The Comprehensive Tissue Centre will be renamed the Alberta Comprehensive Tissue Centre (ACTC) and will be reconstituted to support a province wide network of tissue donation, banking and transplantation within Edmonton, Calgary and designated centres. The ACTC will also collaborate with the Lion's Eye Bank in Southern Alberta.
- Transplant centers will participate in the development of national standards for listing recipients for transplant and developing sharing algorithms, based on scientific principles of best clinical practice and ethical principles of fairness and equity.
- The governing committee will develop a comprehensive accountability framework for monitoring, evaluating and reporting donation and transplant outcomes and compliance with the standards and guidelines.
- An information system will be implemented to facilitate national access to real-time information for patients awaiting transplantation and to facilitate the matching of organs with appropriate recipients, with the appropriate safeguards to protect the privacy of individually identifiable health information.

Link: http://www.phen.ab.ca/pcons/docs/Organ_Transplantation.pdf

D. Premier's Advisory Board

Report to the Premier's Advisory Board on Organ & Tissue Donation—Ontario (May 2000)

Summary of Recommendations:

The Premier's Advisory Board on Organ & Tissue Donation was created to advise the Premier on the development and implementation of a provincial strategy and an Organ and Tissue Donor Action Plan for Ontario that will double the organ donation rate by 2005 and improve access to high quality donor transplant services. This report estimated the costs associated with the increase in donor procurement and transplant associated with the hospital care of the donor and the recipient.

- That a detailed organ procurement costing be implemented.
- That an activity-based, prospective analysis be performed to identify the activities that occur in the donor hospital.
- That an analysis of the costs of living donor versus cadaveric donor occurs at transplant centres as well as other donor hospitals.
- That an audit be completed on out-of-province organ quality and costs to

determine the cost-effectiveness of out-of-province organ procurement.

- That the Canadian Institute for Health Information review the coding of live and cadaveric donors, and of transplants.
- That a true assessment of transplantation costs must begin with pre-transplant ambulatory visits, and must end with post-transplant ambulatory and home care. For this reason, the ability to link multiple ambulatory encounters to a single patient is required.
- That an audit of healthcare system utilization be done on an ongoing basis to understand the long term costs and effects of the growing immunosuppressed population.
- That a complete detailed costing of bone marrow transplant occur that reflects the board's recommendations on bone marrow transplant.

Link: <http://www.jppc.org/new/files/acrobat/L-53.pdf>

E. British Columbia Transplant Society - Pre-Hospital Tissue Procurement

Feasibility of a Pre-hospital Tissue Procurement Program in British Columbia (September 2006)

Summary of Recommendations

This report examined the feasibility of the development of a provincial tissue-procurement program model in British Columbia and recommended that the British Columbia Transplant

Society move forward with the development of program models and a pilot study for pre-hospital tissue procurement in British Columbia.

F. Trillium Gift of Life Network

Strategic Plan to Improve Tissue Donation Activities in Ontario (November 2006)

Summary of Recommendations:

Trillium Gift of Life Network was asked by the Ministry of Health and Long-Term Care to develop a tissue plan that consolidates and standardizes tissue activities to meet the province's need for safe and high-quality tissue allografts. This strategic plan examines a variety of models for tissue donation and makes a number of recommendations.

- Routine Notification and Request (RNR) implementation be limited to Type A and B hospitals, consistent with the current legislation.
- Telephone consent and donor screening be obtained by the clinical services team in the Provincial Resource Center (PRC).
- Trillium Gift of Life Network develop and manage non-physician based regional recovery teams that are capable of recovering all tissue types.
- Locally-based enucleation programs should be established in designated hospitals.
- Hospital recovery facilities should be identified and provided with funding reimbursement related to the recovery of tissues.
- A comprehensive non-profit tissue facility that receives, processes and distributes all tissue types be established in Ontario.
- A cost recovery system be established for all processing centres in Ontario.
- A centralized distribution system be developed and managed by the comprehensive tissue centre with direct links to Trillium Gift of Life Network through the TOTAL information system.

G. Canadian Council for Donation and Transplantation

Moving Forward to 2012 (March 2007)

Summary of Recommendations:

The Canadian Council for Donation and Transplantation (CCDT) developed a five-year strategic plan to meet new challenges and help bring current knowledge about organ and tissue donation and transplantation (OTDT) to those who will benefit. Areas of focus included:

- Support leading practices through identification, development, knowledge transfer, and standardization.
- Support system-performance improvement by promoting transparent communication, influencing public policy, and demonstrating the value of OTDT.
- Facilitate public engagement by enhancing system tools to enable those involved in the OTDT system to engage with the public on key issues.
- Improve the foundation for information by being a catalyst for integrating and enhancing the quality of information across the system.
- Strengthen relationships among partners to leverage key priorities.
- Continue to build internal capability and expertise to coordinate and enhance the development of Canada's OTDT community and to ensure that the CCDT remains a productive member.

H. The Citizen's Panel

The Citizens Panel on Increasing Organ Donations Report (March 2007)

Summary of Recommendations:

The Citizen's Panel was established by Honourable George Smitherman to hear the views of Ontarians on organ donation. The report recommended that:

- The clause in *Trillium Gift of Life Act* which allows exemption to consent be amended to require tangible proof of withdrawal.
- A central database be established to record Ontarians' donation preferences, and that this information be sent regularly to the Trillium Gift of Life Network, to be made available to families and appropriate health care providers at the appropriate time.
- A public education campaign be developed assuring the public their wishes will be respected and informing them how this will be done.
- The existing school education program, One Life...Many Gifts, be piloted in other Ontario school boards, including Francophone boards.
- Consideration be given to creating a youth-oriented website and other programs about organ donation.
- The Ontario government bring together a committee or conference of religious leaders to consider engaging religious schools in organ donation and implementing a program that sees religious communities throughout the country observe a national donor sabbath in the same week every year.
- Every hospital in Ontario that provides donors should institute DCD policies consistent with the national recommendations.
- The Ontario government enacts legislation to ensure living donors are guaranteed job security.
- A fund be established to pay for reasonable pre-approved expenses and lost wages.
- The Northern Health Travel Grant be extended to living organ donors and potential donors.
- A province-wide database of living donors and unmatched recipients be housed at the Trillium Gift of Life Network.
- Hospitals consciously select the team that will support families of potential donors in the time of crisis. These teams should be supported with continuing education and case review. Trillium should be engaged to provide consistency and excellence in training.
- A conference, or several regional conferences, of volunteer support groups be held to enhance mutual learning across the province.
- The Ministry of Health and Long-Term Care should provide Trillium with a fund to reimburse reasonable costs to American hospitals for the purchase of organs from the United States.
- Trillium should be allowed to collect reasonable costs from American hospitals for Canadian organs. These costs should mirror American costs.
- The Critical Care Strategy should include organ donation in the planning and consideration of resources needed for an increase of donors to more than 300 per year and widespread use of DCD.
- The Critical Care Strategy group should work with the Trillium Gift of Life Network to develop processes and protocols.
- A special study of intensivists' compensation for donor management be commissioned and the results be used to advise the Ministry of Health and Long-Term Care and the Ontario Medical Association in future determination of fees.
- The Ministry of Health and Long-Term Care include organ donation in its accountability agreements with Local Health Integration Networks (LHINs) beginning with the 2007–2008 fiscal year.

- Each LHIN should strike an accountability agreement with its hospitals to reflect the provincial priorities for organ donation.
- LHINs cooperate with and use the Trillium Gift of Life Network for education and as their common source of knowledge and a common database on transplant matters.
- Trillium be allowed to change its name to something that remains in accord with its mandate, but is less likely to be misunderstood.
- Sufficient resources be allocated to Trillium to carry out its new mandate under the panel's recommendations.
- Whenever practical and beneficial, Ontario cooperate with other provinces to the fullest extent in developing approaches and systems to support organ donation.

Link: http://www.health.gov.on.ca/english/public/pub/ministry_reports/organ_donations_citizens_panel.pdf

I. British Columbia Transplant Society - Strategic Plan

British Columbia Transplant Society & Research Institute Strategic Plan (August 2007)

Summary of Recommendations:

This document expresses the British Columbia Transplant Society's mission, role and strategy for meeting patient care needs in the future:

- Increase organ donor registrations and donor consent through development of strategic community and media marketing plans.
- Improve evaluation of BC organ donation potential through data collection using standard "eligible deaths" criteria.
- Evaluate potential for donation from the pre-hospital setting.
- Implement the recommendations from the Living Donor Kidney Review.
- Evaluate potential for expanded deceased organ donation.
- Expand educational initiatives to allied healthcare providers.
- Develop a recruitment and retention plan for transplant professionals (medical and allied).
- Promote use of new technologies, such as robotics (Da Vinci) and use of digital signature capability for the Organ Donor Registry.
- Develop plan for research network and submit proposal to Michael Smith Foundation for Health Research peer review competition.
- Catalyse peer-reviewed transplant research in partnership with Michael Smith Foundation for Health Research, CF Foundation of Canada, Kidney Foundation of Canada, and Heart & Stroke Foundation.
- Develop Centre of Excellence for Living Donation in BC.
- Complete SOPs from the Health Canada guidance document and CSA standards to ensure compliance. Register with Health Canada.
- Stabilize and improve, if not replace, TADIS information systems to comply with Health Canada requirements (CSA standards) and user needs.

Link: http://www.phsa.ca/NR/rdonlyres/3B51D4FB-5384-4F26-AA50-7B29443DB48B/27280/BCTS_Strategic_Plan_0708_Final.pdf

J. Library of Parliament

Organ Donation and Transplantation in Canada (Sonya Norris, Library of Parliament), PRB 08-24E (June 2009)

Summary of Recommendations:

This document provides an overview of the Canadian experience with respect to the federal role in organ donation and transplantation, particularly in the past 10 years. The document reveals some of the statistics involved and discusses the options for increasing donor rates.

- Establish a central, national information management system, so that cooperation from provincial and territorial jurisdictions could be sought to implement existing policies and legislation aimed at addressing donation rates.
- Canadian Blood Services or another experienced body could study the information

management system used in the United States at the United Network of Organ Sharing (UNOS) to determine whether a similar system would be appropriate for Canada.

- A public awareness campaign could also be pursued to inform the general population of the importance of organ donation, dispel myths and emphasize the importance of family involvement in the consent process.