



Canadian Blood Services

it's in you to give

Organ and Tissue Donation and Transplantation

Analysis of Key Government Reports

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Introduction

This study provides an analysis of the Organ and Tissue Donation and Transplantation (OTDT) recommendations made in key government (public) reports over the last 10 years. In it, we studied the recommendations which were implemented, partially implemented, or not implemented. This was done by report, by recommendation category, and by other dimensions. From this analysis, we attempted to determine what makes recommendations more likely to be implemented, and what factors may prevent implementation. The results of this analysis will be used to inform future recommendations that could be part of our design of a national system for OTDT, to make them easier to implement and more effective.

Methodology

Nine government reports from the public forum that made OTDT recommendations were chosen for this analysis. The list of reports and recommendations is provided in Appendix B, along with notes regarding implementation.

The recommendations were placed into the categories used in the September 2008 National Consultation on OTDT (see Appendix A). Note that the categorizing of recommendations was subjective, and some broad recommendations could have been considered for more than one category. Also, the comments regarding implementation are based on our expert team's understanding of OTDT activities in Canada. Other interpretations of implementation could be offered for some recommendations. Lastly, our identification of barriers to implementation was also based on our expert team's knowledge and interpretation.

Notwithstanding the above caveats, useful analysis could be done on these reports with the categorization and interpretations provided.

Note that a tenth report, the recently released Ontario Wait Times Panel Report (Levy), was added to Appendix B. A full analysis of this report has not been completed, but its recommendations are discussed below.

Chronology of Reports

The first report studied from the last decade was the 1999 National Volpe report. It was a response to the request which came both from the House of Commons and from the Federal Minister of Health, to propose a plan to improve OTDT performance in Canada. In it, the House of Commons Standing Committee on Health studied and reported on the state of OTDT in Canada. The report recommended high level structure changes to support OTDT in Canada, so mainly provided governance and mandate recommendations. It resulted in the formation of the Canadian Council for Donation and Transplantation (CCDT). In the same year, the National Coordinating Committee (NCC) for OTDT submitted a report to the Federal / Provincial / Territorial Advisory Committee on Health Services. This report was actually begun prior to the Volpe report. It took a more tactical approach, and identified six specific building blocks on which National OTDT strategy should be built. Note that it also linked to some recommendations of the Volpe report, including the formation of a national oversight body.

The next report studied was for the Alberta Advisory Committee on OTD in 2000. It was linked to the NCC report, and provided a similar but much more detailed list of tactical recommendations specifically for Alberta.

Also in 2000, the Ontario Premiers Advisory Board report for OTDT was issued. This report was pivotal to starting many changes in OTDT in Ontario, as it was visibly backed by the Premier and therefore had significant momentum behind it. It laid out a 5 year plan which resulted in the formation of Trillium Gift of Life Network (TGLN). There were two other Ontario reports that followed this. In 2006 TGLN was asked by the Ontario Ministry of Health and Long Term Care (MHLTC) to develop a tissue-specific plan to standardize tissue activities, along some similar lines to their organ activities. Then in 2007, the Citizens panel report was prepared and released at the request of the Ontario Minister of Health. This gathered public views on organ donation, and attempted to impart a sense of urgency on improving OTDT performance in Ontario. It suggested ways to strengthen OTDT performance through actions from TGLN, MHLTC and Ontario hospitals.

In 2006, British Columbia also recommended a feasibility study on the development of a provincial tissue procurement program. Then in 2007, CCDT produced for the Deputy Ministers of Health a 5 year strategic plan. Its recommendations have all been started and are now part of the Canadian Blood Services activities for OTDT.

Most recently in 2009, the National report from the Library of Parliament was released. This report raised concerns that in the ten years since the recommendations made in the two 1999 National Reports, a national strategy to improve donation rates has not been developed, and organ donation rates have not improved. It recommended a central agency such as Canadian Blood Services take action, specifically to develop a central information management system, and to conduct a public awareness campaign on organ donation.

Lastly, although dated from June 2009, the Ontario Wait Times Panel Report was just released at the end of 2009. This report follows the Premiers Report and Citizens Panel Report by making 26 recommendations on a wide variety of aspects of OTDT. It was done at the request of the Ontario Ministry of Health, to advise on a plan to provide Ontarians with equitable access to timely, appropriate and safe organ and tissue transplants.

Findings and Analysis

Among the previous government reports made over the last ten years, more than half of the recommendations made have been implemented. From further analysis of this information, there are a number of findings we can summarize.

Analysis by individual report (details in study Section 1)

The first two reports issued were the Federal government Volpe report, and the National OTDT report developed for the Provinces and Territories. These reports both suggested high level changes in the OTDT system in Canada, and how these changes should be managed. The second report was more tactical in its recommendations, considering how its suggestions could be implemented. Some of the recommendations from both reports were implemented or partially implemented. However, the recommendation that the national oversight body for OTDT activities would also take corrective actions where required, was not implemented. Also, the accountability relationship for managing OTDT activities among the provincial health agencies was not established.

The Alberta OTDT report made similar recommendations to the reports above, but on the provincial level. Its primary recommendation was to establish a governing committee to oversee the OTDT system for the province. This committee was not established, which lessened the effectiveness of those recommendations that were implemented from this report.

Two comprehensive reports for OTDT were made for Ontario (Premiers report and the Citizens panel). These reports received much attention and resulted in a large number of recommendations being implemented. Establishing Trillium Gift of Life and its infrastructure to support OTDT was a key outcome. This also led to actions that provided additional benefits to living donors, resulted in legislated routine referral, improved clarity on hospital donation practices, and increased public and professional awareness and education. However, a number of local health network recommendations were not implemented.

There were two tissue-specific reports, for Ontario and British Columbia. The BC report recommended a pilot study on developing tissue procurement models (which was done). For Ontario, broader recommendations were made. A key recommendation to establish a centralized tissue processing facility was not implemented.

The CCDT 5-year strategic plan was the report drafted for the Provincial Deputy Ministers, which led to the merging of CCDT activities into Canadian Blood Services. Other recommendations in this report centered on leading practices, system performance, public awareness and education, and the development of registries. These are all in the process of being implemented.

The 2009 Federal Library of Parliament report made a few recommendations on national information system and public awareness development. Work was already underway at Canadian Blood Services for these items.

The 2009 Ontario Organ and Tissues Wait Times Report keyed on four component areas: increasing organ and tissue donation, equitable access to organs and tissues, transplant-related care, and accountability for performance. For increasing donation, it tasked TGLN to lead activities to develop active marketing and education plans, to increase both public and health care professional awareness of OTDT. It made many specific recommendations on hospital and funding changes to strengthen the donation culture in hospitals. It also suggested improved support and recognition for donors. For equitable access, the report calls for a review of allocation and distribution processes in Ontario. It also calls for changes specific to tissue recovery, including a central tissue processing and distribution system (a re-iteration of the 2006 recommendations from the Ontario Tissue Report).

For transplant-related care, this report made recommendations for best practices development for health care providers and development of resource manuals for transplant patients. Monitoring patient outcomes was also recommended. For performance, the report recommended development of standard definitions for transplant wait times and target setting for performance indicators. It also suggested that there be accountability for meeting targets, and that the role of oversight for OTDT be determined.

Analysis by categories and scope (details in study Sections 2 and 4)

There were two areas where the largest numbers of recommendations were implemented.

For public and professional awareness and education, although recommendations were implemented, it appears these changes have not been very effective in increasing OTDT (especially donor rate) performance. OTDT activities do not touch a large portion of the population, and awareness in OTDT has not been invested to the same level as other ventures. Also, national marketing programs and culturally focused marketing have not been widely used. Even with successful activities in awareness and education, one could argue that increasing donation rates is much more dependent on hospital changes and donor recognition than on public awareness.

For critical care and hospital donation practices, the biggest implementation has been to have standardized donor recognition practices across the country. Many other small changes have been made to hospital practices, mainly to support living donors and all donors in general.

Note that in the category of funding, the recommendations made were all related to providing sufficient funding for specific OTDT activities. No change in funding structure was recommended.

The government reports described above mainly focused on organ or combined organ and tissue systems. There were much fewer recommendations made only for tissues, and many of these were not supported by provinces.

Over three quarters of the past recommendations studied were made in provincial reports. The implementation of recommendations from provincial reports was also quite high, with over 60% implementation. In comparison, only 38% of recommendations from national reports were implemented.

Analysis of repeat recommendations (details in study Section 3)

There were a number of key recommendations which were repeated in multiple reports. The one most recommended was for a central body to oversee or run some aspect of OTDT, which was mentioned in 7 of 9 reports. This was partially implemented nationally with the formation of CCDT, and implemented in Ontario with Trillium Gift of Life Network in Ontario. Recommendations for a central information system for OTDT data was also often recommended, but has only been partially implemented with the Canadian Blood Services work on national registries, and with the donor intent registry in Ontario. Other repeat recommendations have been implemented to varying degrees.

Note: The latest Ontario Organ and Tissues Wait Times Report has again repeated several key recommendations, in the areas of public/professional awareness, establishing a central body to oversee OTDT, and hospital changes to increase donation.

Conclusion

Through a number of government reports over the past decade, the topic of OTDT has been studied and discussed at both the National and Provincial level. This has involved stakeholders from a variety of disciplines and has considered various options for a Canadian system. Not surprisingly, these studies have resulted in many common recommendations being made. These centered on two theme areas.

One theme area was for tactical changes to be made as follows:

- For increased public and professional awareness and education, to create a greater awareness both with the public and within the health care community of OTDT needs in Canada.
- For changes in critical care and hospital donation practices, to facilitate donor identification, and in the case of living donors, to be sure that donor needs are met.

Many of these tactical changes have been implemented, and have helped develop the OTDT system in Canada. For provinces, such changes had the advantage of being implementable, as they did not require system changes or onerous incremental funding. However, most of these changes have not driven system performance improvements. One exception is for living donor implementations, where recommendations implemented have helped to significantly increase the rate of living donation.

The second theme area was for systemic changes to be made as follows:

- Whether for organs, tissues or both, and whether nationally or provincially, there should be more central oversight and management of OTDT activities.
- Programs and hospitals need to be accountable for increasing donor identification and conversion.
- System performance needs to be measured, and changes to drive improvements must be mandated.
- Information systems need to be put in place to house and to make available central data on performance, registries, and consent.
- In some cases, legislation has been suggested as a means to enforce OTDT change.

These systemic changes hold much greater potential to improve OTDT system performance, but have been more difficult to implement. Note that many systemic changes were proposed in national reports.

Discussion with experts in the Canadian OTDT system has pointed to a few possible implementation barriers. One is the difficulty in resolving National / Provincial / Federal differences to agree on the mandate and authority of any central oversight role. Disagreement on accountabilities and roles and responsibilities among stakeholder groups in the OTDT process has also sometimes prevented implementations. Lack of agreement on required system performance measures, and on how to enforce hospital and program changes to support these measures, has also occurred.

The analysis of repeat recommendations illustrates that there is consistent recognition of areas of potential improvement in the OTDT system. However, the past recommendations (even when partially or fully implemented), have failed to create the desired system improvements, and new versions of similar items keep getting recommended.

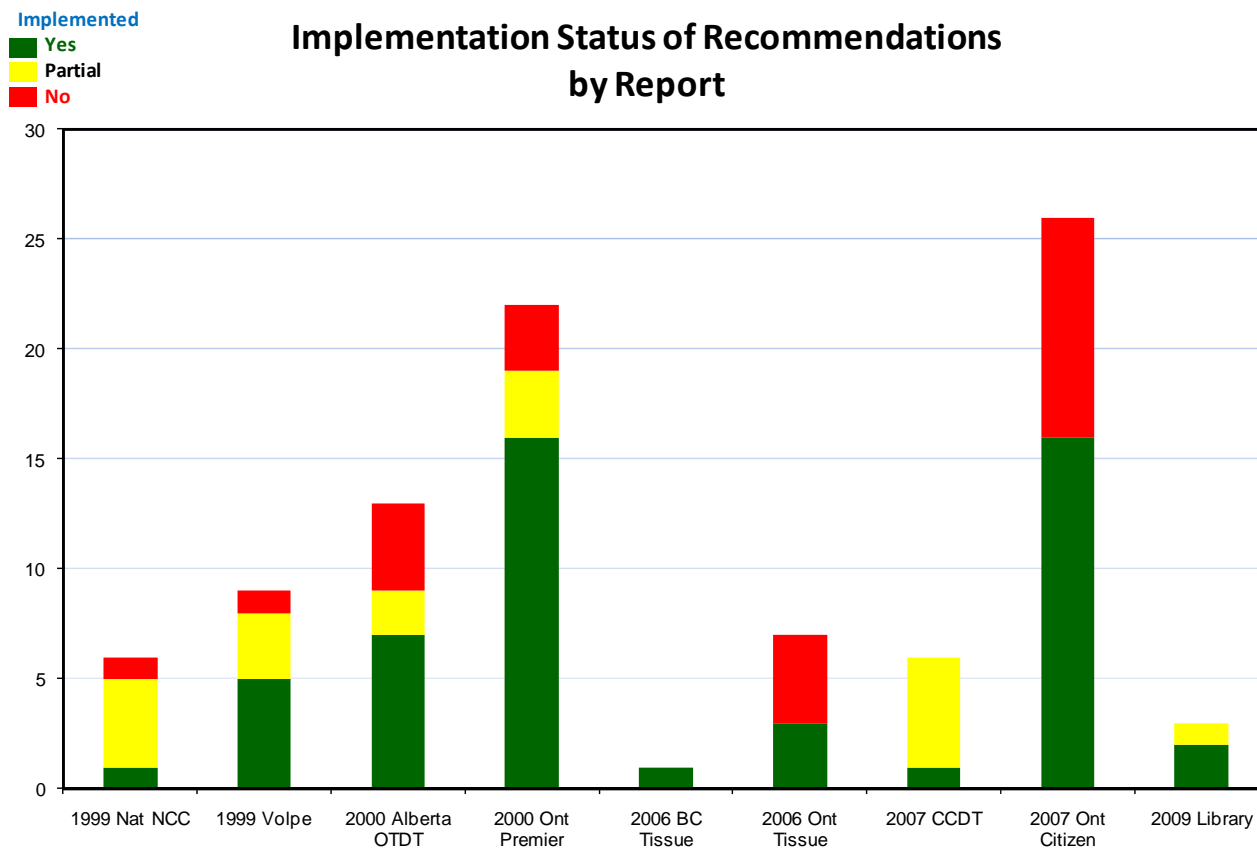
The lessons learned from past government reports can help to shape future recommendations. In particular, these reports illustrate that repeating previously made recommendations in the same manner will not likely result in their implementation. Future recommendations must be designed in a way that makes them easier to implement. In addition, these recommendations must be designed so that they will impact the system in a positive manner, and improve system performance in Canada.

1.0 Implementation Status of Recommendations by Report

Definition

The number of recommendations made and implemented, for each government report. Reports are listed chronologically.

Figure 1.



Observations:

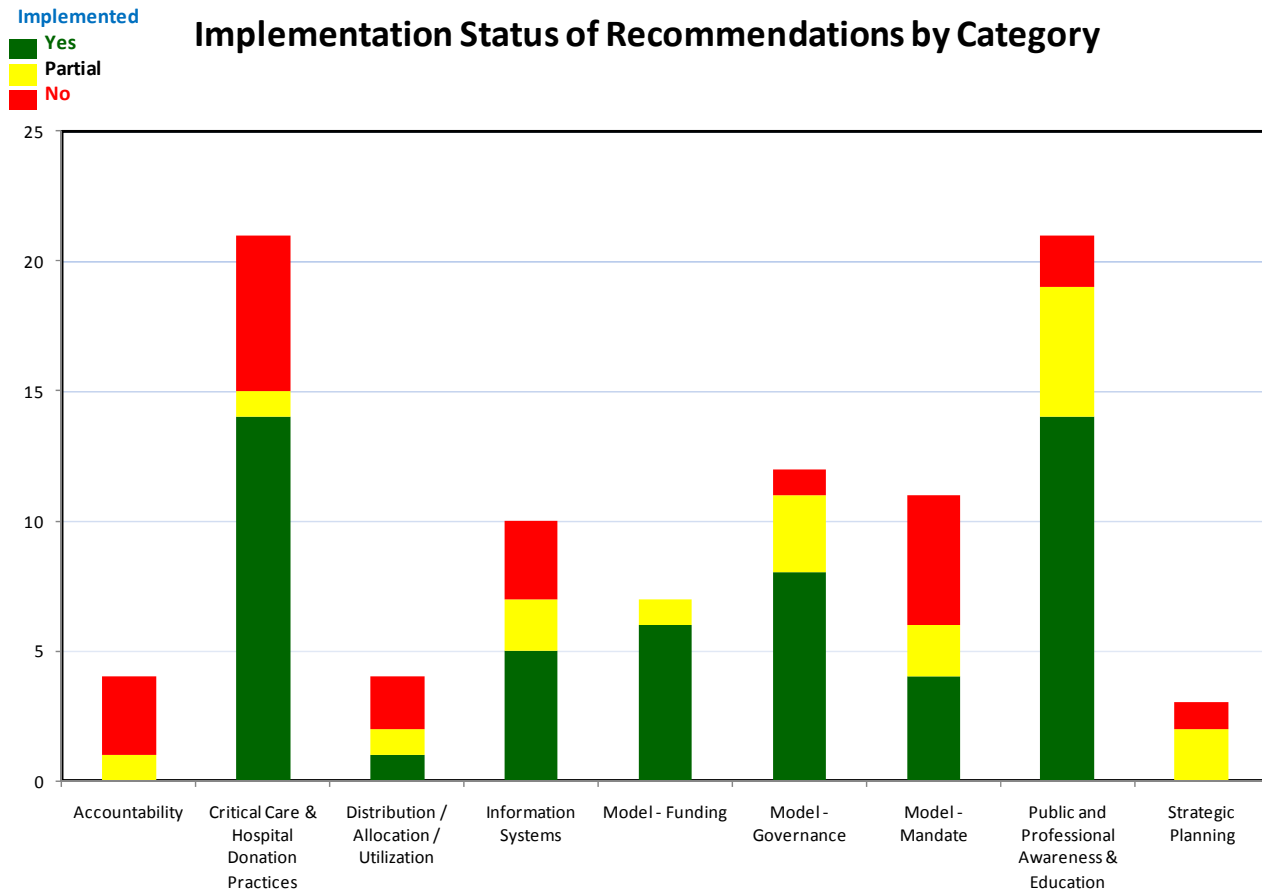
- Recommendations were implemented from every report.
- Reports with the highest number of implementations were the Ontario Premier's report, and the Ontario Citizens Panel report.
- Reports with the lowest implementation rates were the National 1999 OTDT report, the Alberta 2000 OTDT report, the Ontario 2006 Tissue report and the CCDT Strategic Plan.

2.0 Implementation of Recommendations by Category

Definition

The number of recommendations made and implemented, by category of recommendation.

Figure 2.



Observations:

- Recommendations were implemented in every different category.
- The areas of critical care and hospital donation practices, and public and professional awareness and education, both had a large number of implementations.
- The areas with the highest proportion of recommendations not implemented were accountability, distribution/allocation/utilization, strategic planning and model/mandate.

3.0 Repeat Key Recommendations

Definition

A list of repeat key recommendations, which reports made similar recommendations, and which recommendations were implemented.

Figure 3.

Recommendation	1999 Volpe	1999 National NCC	2000 Alberta OTDT	2000 Ontario Premier	2006 BC Tissue	2006 Ontario Tissue	2007 CCDT	2007 Citizen Report	2009 Library	2009 Ont Levy
1. Central body to oversee or to run some aspect of OTDT	✓	✓	✓	✓		✓	✓		✓	✓
2. Central info system for OTDT data		✓	✓			✓	✓	✓	✓	
3. Legislation be passed to support some aspect of OTDT		✓	✓	✓		✓		✓		
4. Public awareness or education activities for organ/tissue donation			✓	✓			✓	✓	✓	✓
5. Hospital changes to increase donors			✓	✓		✓		✓		✓

Observations:

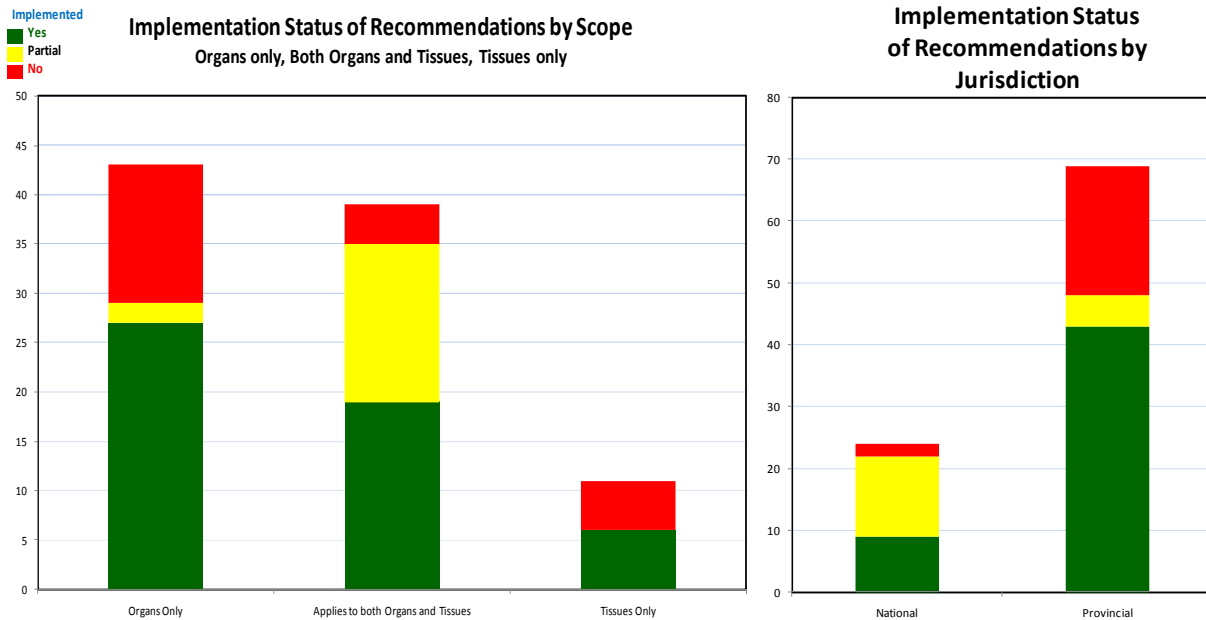
- The formation of a central body is the most common recommendation made across the reports.

4.0 Implementation Status of Recommendations by Scope

Definition

The number of recommendations made and implemented, by scope (organs, tissues, or both, and by national versus provincial)

Figure 4.



Observations:

- In the government reports, organ and combined organ/tissue systems and processes have received much more attention than tissue only.
- 45% of tissue recommendations have not been implemented even partially, versus 22% for organs or combined.
- Many more recommendations have come from provincial reports, and these have also had a much higher implementation rate than national reports (62% for provincial versus 38% for national).

A. National Consultation Categories

1. Model

Mandate - definition of mission of an organization

Governance - framework to respond to public demand for a safe, transparent, accessible and accountable system

Funding – provision for public and private funds directed to OTDT

2. Public and Professional Awareness & Education – increasing public and professional knowledge and appreciation of OTDT

3. Critical Care & Hospital Donation Practices – establishment of OTDT as an operational norm in hospital practice

4. Distribution/Allocation/Utilization – integrated system to steward listing, allocation and utilization process

5. Information Systems – information support required for OTDT processes

6. Accountability - accountability for the development, monitoring and implementation, and enforcement of standards

7. Strategic Planning – integrated planning to implement OTDT vision

B. Organ and Tissue Donation and Transplantation: Listing of Key Government Reports

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

1. Organ and Tissue Donation and Transplantation: A Canadian Approach (Joseph Volpe) (April 1999)

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

Standing Committee on Health report on the state of organ and tissue donation and transplantation in Canada.

Category	Recommendation	Implemented	Comments
Model - Mandate	1. The federal/provincial/territorial ministers of health establish the Canadian Transplant Network to oversee organ and tissue donation and transplantation.	Partial	CCDT was funded to do this, but as an advisory board. They did not receive the mandate to fully oversee OTDT or to take actions where outcomes were not good.
Model - Governance	2. The federal Minister of Health ensure that the establishment of such an organization and accompanying strategy be discussed formally with provincial and territorial counterparts within the next six months	Partial	Not within 6 months
Model - Funding	3. This organization have a permanent secretariat and an appropriate budget	Yes	Implemented through CCDT
Model - Governance	4. This organization provides annual public reports through the F/P/T Conference of Ministers of Health.	Yes	Implemented through CCDT
Model - Governance	5. This organization provides 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.	No	Reports were provided - but not necessarily connected to NODW, and not performance reports

Category	Recommendation	Implemented	Comments
Model - Governance	6. 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.	Partial	CCDT was set up with 3 Advisory committees - Donation, Transplantation and Tissue.
Model - Governance	7. The expert advisory groups be composed of members drawn from existing organizations involved in organ and tissue activities and rotated on a regular basis.	Yes	
Model - Governance	8. The expert advisory groups be responsible for providing direction to the Canadian Transplant Network on the establishment of goals and the measuring of outcomes.	Yes	
Model - Governance	9. These goals and outcomes be included in the annual report produced by the Canadian Transplant Network on each specific program area.	Yes	

2. A Coordinated and Comprehensive Donation and Transplantation Strategy for Canada (A Report from the National Coordinating Committee for Organ Donation, Distribution and Transplantation) (November 1999)

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

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 report describes recommendations for a coordinated and comprehensive organ and tissue donation, distribution and transplant system for Canada.

The coordinated and comprehensive donation and transplant strategy for Canada is built on six building blocks. These six building blocks are considered critical to the over-all strategy and all need to be addressed for the desired targets to be realized. They also define the three levels of accountability and give direction to the provinces / territories to proceed to implement the strategy at both the provincial / territorial and regional / hospital levels.

Category	Recommendation	Implemented	Comments
Strategic Planning	1. Strategic Direction: To keep the strategy focused on the long term objectives, measurable goals, key success factors, performance measures and targets will be defined for the three levels of accountability: regional / hospital, provincial / territorial and nationally. A national target of 25 donors per million population (DPMP) by the year 2005 has been recommended - a target that also exists for the provinces / territories. Performance measures and targets will also be set by each province / territory to measure key outcomes related to donation, tissue banking and transplantation.	Partial	Strategy was followed and target of 25 DPMP was achieved in some areas, but not in aggregate.
Model - Mandate	2. Processes: The core functions and support processes relate to the service delivery component and are a provincial / territorial responsibility. The core functions for organ donation, tissue banking and transplantation describe the critical steps where a direct service is provided. Policies, standards and guidelines must be developed to guide practitioners and provide practice and safety standards for each of these critical steps. This also ensures that performance can be measured, evaluated and reported. Seven support processes are also described. They provide the necessary support services and quality framework for each step in the donation, tissue banking and transplant process.	Partial	Activities were taken towards this goal. However, there was no one with responsibility to deliver them.

Category	Recommendation	Implemented	Comments
Accountability	3. 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.	Partial	CCDT implemented improvements in many areas.
Model - Governance	4. 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 and provinces/territories. Health Canada is in the process of developing safety standards for donation and transplantation. These will be referenced in the Food and Drug Act.	Yes	
Information Systems	5. 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 / 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.	No	
Model - Funding	6. 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.	Partial	Funding received was under \$20M for 5 years.

3. A Framework for Action: A Coordinated and Integrated Organ and Tissue Donation and Transplant System for Alberta (April 2000)

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

Final report of the Alberta Advisory Committee on Organ and Tissue Donation. It formulated ninety-nine recommendations designed to address and improve a 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.

Category	Recommendation	Implemented	Comments
Model - Governance	1. 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.	Partial	Committee was created but never got traction.
Model - Governance	2. 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.	Yes	Alberta's HTGA has been revised and new legislation developed.
Distribution / Allocation / Utilization	3. Designated donation and transplant services will be expanded to five other centres outside of Edmonton and Calgary.	Partial	Expansion did happen into some additional centers
Model - Governance	4. Provincial policies, standards and guidelines will be developed to provide a consistent approach to service delivery, recognizing efficiencies and principles of best practice.	Yes	
Model - Governance	5. The province will participate in the development, implementation, monitoring and enforcement of national safety standards for organ and tissue donation and transplantation.	Yes	
Public and Professional Awareness & Education	6. A province-wide coordinated approach to public and professional education will be developed.	No	Hope north and south each did their own
Critical Care & Hospital Donation Practices	7. 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.	Yes	
Critical Care & Hospital Donation Practices	8. 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.	Yes	

Category	Recommendation	Implemented	Comments
Critical Care & Hospital Donation Practices	9. 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.	Yes	
Model - Mandate	10. 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.	No	
Distribution / Allocation / Utilization	11. 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.	Yes	
Accountability	12. 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.	No	
Information Systems	13. An information system will be implemented to facilitate national access to real time information for patients waiting transplantation and to facilitate the matching of organs with appropriate recipients, with the appropriate safeguards to protect the privacy of individually identifiable health information.	No	

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

<http://hip.assembly.ab.ca/ipac20/ipac.jsp?session=M25B0126523B1.1203248&profile=aep&uindex=BAW&term=Ontario.%20Premier's%20Advisory%20Board%20on%20Organ%20and%20Tissue%20Donation&aspect=subtab13&menu=search&source=-!horizon#focus>

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.

Category	Recommendation	Implemented	Comments
Public and Professional Awareness & Education	1. Legislation be enacted to provide the following: Each hospital in Ontario with organ donation potential shall (i) promote awareness of organ and tissue donation (OTD); (ii) adopt implement and monitor protocol which minimizes the risk that any step in the OTD process does not occur; (iii) ensure that those involved in the OTD process take part in regular professional education related to OTD; (iv) hospitals have trained consent requestors; (v) establish an OTD committee to lead OTD efforts in the hospital.	Partial	TGLN provides all these functions, but not by legislation
Critical Care & Hospital Donation Practices	2. Legislation be enacted to provide the following: Each hospital with a major trauma and/or neurosurgery critical care program shall (i) have an in-hospital organ donation coordinator responsible for OTD activities at the hospital; (ii) have knowledgeable on-call assistance for the coordinator such that the hospital has 24-7 coverage to deal with organ donation opportunities.	Partial	TGLN provides all these functions, but not by legislation
Critical Care & Hospital Donation Practices	3. Legislation be enacted to provide the following: Each hospital will permit inspection of hospital records by Trillium (TGLN) and will ensure that data, information and reports relating to OTD are made available.	Yes	
Critical Care & Hospital Donation Practices	4. Legislation be enacted to provide the following: Routine referral and required request shall be implemented so that (i) each death and imminent death in a hospital is referred to TGLN; (ii) the family of each suitable donor must be informed by a trained requestor of the option to donate organs or tissue.	Yes	Implemented by regulation under the TGLN Act.
Model - Mandate	5. For the trauma and neurosurgery centers, the legislation shall come into force no later than one year after TGLN commences its hospital support operations.	No	

Category	Recommendation	Implemented	Comments
Model - Mandate	6. For other hospitals with organ donation potential, the legislation shall come into force no later than 18 months after TGLN commences its hospital support operations.	No	
Model - Mandate	7. For routine referral and required request, the legislation shall come into force no later than 18 months after TGLN commences its hospital support operations.	No	
Model - Funding	8. The cost of the in-hospital organ donation coordinators shall be paid by the MOHLTC.	Yes	
Model - Funding	9. Hospitals shall be reimbursed by the MOHLTC on a dedicated funds basis for the cost of organ donors at the hospital.	Yes	
Model - Mandate	10. TGLN be created with the power and authority to lead and manage OTD in Ontario, with the mandate, characteristics, structure, accountability, funding and transition described in this Report.	Yes	
Model - Mandate	11. TGLN commission a study of opportunities to expand the number of living donors.	Yes	
Model - Funding	12. The Government of Ontario urge the Government of Canada to make living donors eligible for unemployment insurance and TGLN encourage insurance companies to fund disability insurance for living organ donors, in each case during the period of the transplant operation and convalescence.	Yes	
Model - Funding	13. The MOHLTC review the funding of Ontario's tissue banks to ensure that they have the resources needed to handle increased tissue donations.	Yes	
Model - Mandate	14. The MOHLTC in cooperation with TGLN urge the National Coordinating Committee for OTD to commission a study of the structure of tissue banks in Canada with a view to considering if it would be appropriate to recommend the formation of national tissue banks.	Yes	
Public and Professional Awareness & Education	15. Promotional activities from community events to media relations remain primarily a stakeholder responsibility. TGLN provide materials and staff support to the efforts of stakeholder organizations to increase their promotional efforts.	Yes	
Public and Professional Awareness & Education	16. As budgets allow, TGLN will use advertising as its primary vehicle to supplement the communications efforts of stakeholder organizations.	Yes	

Category	Recommendation	Implemented	Comments
Public and Professional Awareness & Education	17. TGLN include an evaluation component in all of its communications efforts. TGLN provide financial support for approved evaluation projects that test the effectiveness of stakeholder public education campaigns. TGLN facilitate an exchange of knowledge between jurisdictions by disseminating the lessons learned in Ontario to other jurisdictions and to seek similar research in return. TGLN should sponsor events and publications that will ensure the widest possible dissemination of lessons learned.	Yes	
Public and Professional Awareness & Education	18. The Provincial Government proceed with its plan to add OTD as a topic in the Grade 11 curriculum. The Advisory Board stresses that the Ministry of Education must follow through on those changes with adequate support material and training programs. It urges the Ministry to build on materials already developed by several stakeholder groups in conjunction with local school boards.	Yes	
Public and Professional Awareness & Education	19. The Provincial Government implement a recognition program for organ donors and their families using scrolls signed by the Premier and the Minister of Health and Long Term Care. Any such program must have safeguards in place to protect the anonymity of the donors and their families.	Yes	
Public and Professional Awareness & Education	20. TGLN work with stakeholders to develop a standard format for organ donor cards. This format should include a second tear-off card that individuals can give to their next of kin to inform them of their wishes. The Advisory Board also recommends that the government adopt this format in its driver's license program.	Partial	Being done through OHIP cards or Gift of Life consent forms.
Information Systems	21. The Provincial Government wait until evidence has been collected from the British Columbia and Nova Scotia registry systems before investing further resources in the Ontario system.	Yes	
Public and Professional Awareness & Education	22. One of the early priorities of TGLN should be to develop communications material to support the discussion of living organ donation with friends and family of the potential recipient.	Yes	

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

The focus of this report was to determine the feasibility for the development of a provincial tissue procurement program model in British Columbia.

Category	Recommendation	Implemented	Comments
Model - Mandate	1. That British Columbia Transplant Society move forward with the development of program models and a pilot study for pre-hospital tissue procurement in British Columbia.	Yes	

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

Trillium Gift of Life Network was request by the Ministry of Health and Long Term Care to develop a tissue plan that consolidates and standardizes tissue activities in order to meet the province's need for safe and high quality tissue allografts. This strategic plan provides the results of exploring a variety of models for tissue donation.

Category	Recommendation	Implemented	Comments
Critical Care & Hospital Donation Practices	1. Routine Notification and Request (RNR) implementation be limited to Type A and B hospitals, consistent with the current legislation.	Yes	
Critical Care & Hospital Donation Practices	2. Telephone consent and donor screening be obtained by the clinical services team in the Provincial Resource Center (PRC).	Yes	
Critical Care & Hospital Donation Practices	3. Trillium Gift of Life Network develops and manages non-physician based regional recovery teams that are capable of recovering all tissue types. Locally-based enucleation programs should be established in designated hospitals.	Yes	
Critical Care & Hospital Donation Practices	4. Hospital recovery facilities should be identified and provided with funding reimbursement related to the recovery of tissues.	No	
Distribution / Allocation / Utilization	5. A comprehensive non-profit tissue facility that receives, processes and distributes all tissue types be established in Ontario.	No	

Category	Recommendation	Implemented	Comments
Information Systems	6. A cost recovery system be established for all processing centres in Ontario.	No	
Distribution / Allocation / Utilization	7. 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.	No	.

7. Moving Forward to 2012 (CCDT) (March 2007)

The Canadian Council for Donation and Transplantation (CCDT) five year strategic plan to meet new challenges and help bring twenty-first century knowledge about organ and tissue donation and transplantation (OTDT) to those who will benefit.

Category	Recommendation	Implemented	Comments
Public and Professional Awareness & Education	1. Support leading practices through identification, development, knowledge transfer, and standardization	Partial	Started through the National Collaborative
Public and Professional Awareness & Education	2. Support system performance improvement by promoting transparent communication, influencing public policy, and demonstrating the value of OTDT.	Partial	Work in progress
Public and Professional Awareness & Education	3. Facilitate public engagement by enhancing system tools to enable those involved in the OTDT system to engage with the public on key issues.	Partial	Work now on CBS agenda.
Information Systems	4. Improve the foundation for information by being a catalyst for integrating and enhancing the quality of information across the system.	Partial	Work in progress
Strategic Planning	5. Strengthen relationships with and among partners to leverage key priorities.	Partial	Key strategic partnerships were developed during CCDT years
Public and Professional Awareness & Education	6. 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.	Yes	CCDT was transitioned into CBS.

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

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

Report from the Citizen's Panel established by Honourable George Smitherman, to hear the views of Ontarians on organ donation.

Category	Recommendation	Implemented	Comments
Critical Care & Hospital Donation Practices	1. The clause in Trillium Gift of Life Act which allows exemption to consent be amended to require tangible proof of withdrawal.	No	Ministry went with an affirmative donor registry instead.
Public and Professional Awareness & Education	2. Some government forms, such as the OHIP card renewal, require Ontarians to state their organ donation preferences.	Yes	
Information Systems	3. A central database to record these preferences.	Yes	
Critical Care & Hospital Donation Practices	4. This information be sent regularly to the Trillium Gift of Life Network, which will make it available to families and appropriate health care providers at the appropriate time.	Yes	
Public and Professional Awareness & Education	5. A public education campaign be developed assuring the public their wishes will be respected and informing them how this will be done.	Yes	
Public and Professional Awareness & Education	6. The existing school education program, One Life...Many Gifts, be piloted in other Ontario school boards, including Francophone boards.	Yes	
Public and Professional Awareness & Education	7. Consideration be given to creating a youth-oriented website and other programs about organ donation.	Yes	
Public and Professional Awareness & Education	8. The Ontario government bring together a committee or conference of religious leaders to consider engaging religious schools in organ donation and implementing a program which sees religious communities throughout the country observe a National Donor Sabbath in the same week every year.	Yes	
Critical Care & Hospital Donation Practices	9. Every hospital in Ontario that provides donors should institute DCD policies consistent with the National Recommendations.	Yes	
Critical Care & Hospital Donation Practices	10. The Ontario Government enact legislation to ensure living donors are guaranteed job security.	Yes	

Category	Recommendation	Implemented	Comments
Critical Care & Hospital Donation Practices	11. A fund be established to pay for reasonable pre-approved expenses and lost wages.	Yes	
Critical Care & Hospital Donation Practices	12. The Northern Health Travel Grant be extended to living organ donors and potential donors.	Yes	
Information Systems	13. A province-wide database of living donors and unmatched recipients be housed at the Trillium Gift of Life Network.	Yes	Implemented by Canadian Blood Services via the Living Donor Paired Exchange Registry.
Critical Care & Hospital Donation Practices	14. Hospitals consciously select the team which will support families of potential donors in the time of crisis. These teams should themselves be supported with continuing education and case review. Trillium should be engaged to provide consistency and excellence in training.	Yes	
Public and Professional Awareness & Education	15. A conference – or several regional conferences – of volunteer support groups should be held to enhance mutual learning and to examine duplicating models across the province.	Yes	
Critical Care & Hospital Donation Practices	16. The Ministry of Health and Long-Term Care (MHLTC) should provide Trillium with a fund to reimburse reasonable costs to American hospitals for the purchase of U.S. organs.	No	
Critical Care & Hospital Donation Practices	17. Trillium should be allowed to collect reasonable costs from American hospitals for Canadian organs. These costs should mirror American costs.	No	
Strategic Planning	18. 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.	No	
Critical Care & Hospital Donation Practices	19. The Critical Care Strategy group should work with the Trillium Gift of Life Network to develop processes and protocols.	No	The Transplant Wait Times Expert Panel is considering a recommendation to address this.
Critical Care & Hospital Donation Practices	20. A special study of intensivists' compensation for donor management be commissioned and the results be used to advise the MHLTC and the Ontario Medical Association, in future determination of fees.	No	
Accountability	21. The Ministry of Health and Long Term Care include organ donation in its accountability agreements with the Local Health Integration Networks (LHINs), beginning with the 2007-08 fiscal year.	No	

Category	Recommendation	Implemented	Comments
Accountability	22. Each LHIN should strike an accountability agreement with its hospitals which reflect the provincial priorities for organ donation.	No	
Public and Professional Awareness & Education	23. LHINs cooperate with and use TGLN for education and as their common source of knowledge and a common database on transplant matters.	No	
Model - Mandate	24. Trillium be allowed to change its name to something less likely to lead to misunderstanding and in accord with its mandate.	No	
Model - Funding	25. Sufficient resources be allocated to Trillium to carry out its new mandate under the Panel's recommendations.	Yes	
Information Systems	26. Whenever practical and beneficial, Ontario cooperates with other provinces to the fullest extent in developing approaches and systems to support organ donation.	Yes	

9. Organ Donation and Transplantation in Canada (Sonya Norris, Library of Parliament) (June 2009)

An overview of the Canadian experience with respect to the federal role in organ donation and transplantation, particularly in the past 10 years, reveal some of the statistics involved and discuss the options for increasing donor rates. (Document PRB-08-24E)

Category	Recommendation	Implemented	Comments
Information Systems	1. 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.	Partial	National registries being done by CBS will meet some of these requirements.
Information Systems	2. 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.	Yes	
Public and Professional Awareness & Education	3. A public awareness campaign to inform the general population of the importance of organ donation, dispel myths and emphasize the importance of family involvement in the consent process could also be pursued.	Yes	

10. Report of the Organ and Tissue Transplantation Wait Times Expert Panel (Ontario, Dr. Gary Levy, Expert Panel chair) (June 2009)

http://www.health.gov.on.ca/en/public/publications/ministry_reports/wt_transplant/wt_transplant.aspx
http://www.health.gov.on.ca/en/public/publications/ministry_reports/wt_transplant/docs/wt_transplant.pdf

Dated June 2009, the Ontario Wait Times Panel Report was released at the end of 2009. This report follows the Premiers Report and Citizens Panel Report by making 26 recommendations on a wide variety of aspects of OTDT. It was done at the request of the Ontario Ministry of Health, to advise on a plan to provide Ontarians with equitable access to timely, appropriate and safe organ and tissue transplants.

Category	Recommendation	Implemented	Comments
Public and Professional Awareness & Education	1. Trillium Gift of Life Network collaborate with the donation and transplantation communities to develop a strategic marketing and education plan to increase public awareness of donation and transplantation, and build a donation culture where Ontarians believe that organ and tissue donation is part of the cultural fabric of this province. The plan should include a recommended course of action, clear deliverables, timelines and resource requirements.		
Public and Professional Awareness & Education	2. Trillium Gift of Life Network – in consultation with donation and transplantation stakeholders – design and conduct an epidemiological study of donor characteristics that impact on supporting living and deceased donation. The study results should be used to inform efforts to increase organ and tissue donations in Ontario.		
Public and Professional Awareness & Education	3. The Ministry of Health and Long-Term Care support the implementation of online registration to legally record one’s decision to donate organs and tissue in Ontario. Traditional means of registering by mail and through the Service Ontario Health Card Offices (OHIP) should continue.		
Public and Professional Awareness & Education	4. Trillium Gift of Life Network collaborate with the donation and transplantation communities to develop a comprehensive organisation and healthcare provider awareness and education plan to increase awareness about organ and tissue donation. The plan should identify provincial, regional and local solutions to increase education and awareness, and actively engage the participation of organisations, professional associations, health regulatory colleges, and other groups (e.g., Ontario’s Critical Care Secretariat and Neurosurgery Expert Panel). Furthermore, the plan should incorporate innovative ways to promote donation awareness (e.g., develop education programs in		

Category	Recommendation	Implemented	Comments
	partnership with the health regulatory colleges that would recognise the programs as continuing education credits for professional recertification). Trillium should facilitate the implementation of the plan to help raise awareness of donation and transplantation among organisations and healthcare providers, and their clients and patients.		
Critical Care & Hospital Donation Practices	5. Ontario hospitals with Level 3 critical care units identify a donation champion who is responsible for working with others to sustain a strong donation culture in the organisation. The champion should be a well respected physician leader who works closely with the hospital's donation coordinator, if available.		
Critical Care & Hospital Donation Practices	6. Ontario hospitals with Level 3 critical care units be required to establish and operate an Organ and Tissue Donation Committee.		
Critical Care & Hospital Donation Practices	7. Ontario hospitals with Level 3 critical care units be required to notify Trillium Gift of Life Network after the healthcare team and the patient/substitute decision maker have discussed and made the decision to withdraw life sustaining therapies and before the withdrawal of these therapies has begun.		
Critical Care & Hospital Donation Practices	8. Ontario hospitals with Level 3 critical care units adopt standard policies for Donation After Neurological Death, and for Donation After Cardiocirculatory Death that are consistent with those established by the Canadian Council for Donation and Transplantation Consensus Conference and adapted by Trillium Gift of Life Network. The Critical Care Leads for each Local Health Integration Network should ensure that the hospitals within their respective LHINs adopt these policies and use them to guide their clinical practice.		
Critical Care & Hospital Donation Practices	9. Ontario's Critical Care Secretariat, the Neurosurgery Expert Panel, and the Emergency Room/Alternate Level of Care Expert Panel integrate organ and tissue donation as part of end-of-life care in their respective strategic areas. In addition, the Local Health Integration Network (LHIN) Critical Care Leads and Emergency Room Leads should promote and support organ and tissue donation in critical care units and emergency departments, in their respective LHINs, as part of end-of-life care.		
Critical Care & Hospital Donation Practices	10. The Ministry of Health and Long-Term Care continue to fund Trillium Gift of Life Network for the donor coordinator program, assess the adequacy of the current level of support, and make any necessary adjustments.		
Critical Care & Hospital Donation Practices	11. The Ministry of Health and Long-Term Care provide ongoing base funding to Trillium Gift of Life Network to support tissue donor consent and screening.		

Category	Recommendation	Implemented	Comments
Critical Care & Hospital Donation Practices	12. The Critical Care Secretariat of the Ministry of Health and Long-Term Care assess the critical care bed supply in the province to identify facilities that would benefit most from critical care resources to support organ and tissue donation. This should be one criterion used to allocate additional critical care capital and operating resources in the future.		
Critical Care & Hospital Donation Practices	13. The Ministry of Health and Long-Term Care review the payment schedule for organ and tissue donation and transplantation to ensure that hospitals are adequately compensated for the costs of supporting these activities. In addition, the Ministry should review physician compensation within the current Ontario Medical Association funding envelope.		
Critical Care & Hospital Donation Practices	14. The Critical Care Secretariat and the Neurosurgery Expert Panel work with Trillium Gift of Life Network to ensure that the Critical Care Information System, CritiCall, and the Emergency Neurosurgery Image Transfer System be used as tools to provide appropriate alerts to Trillium to enable the agency to evaluate the potential for donation. In particular, neurosurgeons who are viewing the Emergency Neurosurgery Image Transfer System should be required to contact Trillium when potential donation opportunities arise.		
Critical Care & Hospital Donation Practices	15. The Ministry of Health and Long-Term Care – in partnership with Trillium Gift of Life Network and living donors – identify ways to enhance the Program for Reimbursing Expenses of Living Organ Donors (PRELOD) to support potential and actual living donors.		
Critical Care & Hospital Donation Practices	16. Trillium Gift of Life Network collaborate with the donation and transplantation communities to develop a provincial program that recognises all deceased and living organ and tissue donors in Ontario.		
Distribution / Allocation / Utilization	17. Trillium Gift of Life Network and the transplantation community review the allocation and distribution of organs in Ontario and identify improvements to ensure that Ontarians have equitable access to organ transplants based on clinical evidence.		
Model - Mandate	18. The Ministry of Health and Long-Term Care support the development of one coordinated tissue recovery system for Ontario. The recovery system should be managed by Trillium Gift of Life which would be held accountable for setting quality and safety standards, coordinating activities, monitoring best practices and improving performance. Different models should be considered for recovery teams which should be made up of technicians trained to harvest multiple types of tissue (e.g., hire and train recovery technicians to be on call to recover tissue; contract out with recovery teams through a Request for Proposals		

Category	Recommendation	Implemented	Comments
	process, other). The tissue recovery system should be not-for-profit, operate on a cost-recovery basis and be responsible for repaying any start-up costs provided by Government.		
Model - Mandate	19. The Ministry of Health and Long-Term Care support the development of a coordinated, not-for-profit tissue processing and accessing system to meet the needs of Ontarians for tissue. The system should take a provincial consortium approach with several sites operating within a single management structure, and coordinate and integrate the efforts of the current tissue banks in Ontario. This system should build on the investments made by the current tissue banks and by the Ontario government, promote economic development and skilled jobs in Ontario, and enable Ontario's hospitals to purchase Ontario tissue and, thereby, reinvest taxpayer's money in the local economy. The tissue processing and distribution system should be not-for-profit, operate on a cost-recovery basis and be responsible for repaying any start-up costs provided by Government.		
Critical Care & Hospital Donation Practices	20. Ontario's transplantation community compile and/or develop pre- and post-care best practice standards and guidelines by organ, and ensure that healthcare providers use these standards and guidelines to inform their care. The transplantation community should support the use of these standards and guidelines using a number of innovative approaches such as: i) targeting education programs; ii) linking the transplant specialists with care teams in local hospitals, with local primary care providers and community care access centres (this is especially important in northern and rural areas with the support of the Ontario Telemedicine Network); and iii) creating transplant patient and provider portals for information sharing and support.		
Critical Care & Hospital Donation Practices	21. Ontario's transplantation community – in collaboration with Trillium Gift of Life Network, transplant recipients, and other organisations such as the Heart and Stroke Foundation of Ontario, the Kidney Foundation of Canada and the Canadian Liver Foundation – develop a resource manual for people waiting for an organ. The manual should include information on what the hospital and doctor should be doing for the patient and what the patient can do while waiting for a transplant.		
Model – Funding	22. The Ministry of Health and Long-Term Care and the Ontario Medical Association (OMA) address the issue of physician compensation for pre- and post-transplant care within the current OMA funding envelope.		

Category	Recommendation	Implemented	Comments
Critical Care & Hospital Donation Practices	23. Trillium Gift of Life Network and the transplantation community establish a system to monitor the use of best practice standards and guidelines for adult and paediatric organ transplantation, and the outcomes of these procedures. These stakeholders should conduct a regular provincial case review process made up of organ-specific committees and external reviewers who audit cases using agreed-upon criteria. These reviews should discuss appropriateness issues and outcomes, and recommend improvements.		
Information Systems	24. The Ministry of Health and Long-Term Care's Wait Time Information Program – under the direction of eHealth Ontario – work with expert transplant clinicians to develop a consistent standard definition of wait time for an organ, and a provincial priority rating scale with target time frames for organ transplants in Ontario. Using these definitions, the Ministry should extract this wait time information from Trillium Gift of Life's TOTAL information system, and publicly report organ transplant wait times on Ontario's wait time website.		
Accountability	25. The Ministry of Health and Long-Term Care, Trillium Gift of Life Network, and the donation and transplantation community identify performance indicators and set targets for donation and transplantation that are linked to outcomes and accountabilities for performance. These targets should be outlined in appropriate accountability agreements between the Ministry and Trillium, and between the 14 Local Health Integration Networks and transplant and donor hospitals (e.g., Trillium Business Plan; Hospital Service Accountability Agreements, etc.).		
Model - Governance	26. The Ministry of Health and Long-Term Care conduct a role review of Trillium Gift of Life Network and the transplant centres with the goal of determining the best structure to provide effective oversight for the system of donation and transplantation in Ontario.		