

# SUMMATIVE EVALUATION

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EXECUTIVE SUMMARY AND MANAGEMENT RESPONSE  
March 31, 2007



CANADIAN COUNCIL FOR  
DONATION AND TRANSPLANTATION

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## INTRODUCTION

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The Canadian Council for Donation and Transplantation (CCDT) advises the Conference of Deputy Ministers of Health (CDM) on coordinating and improving Canada's organ and tissue donation and transplantation (OTDT) system. Established in October 2001, the CCDT works closely with federal, provincial, and territorial (FTP) governments and with the OTDT community.<sup>1</sup>

In 2006 an external summative evaluation was conducted. The purpose of the evaluation, conducted by Barrington Research Group Inc., was to determine the impact and outcomes of the CCDT during its initial mandate.

The CCDT has achieved results (generating a national body of knowledge, improved health care practices; increasing policy research) that would not have been accomplished without the CCDT.

The CCDT has had positive impacts on OTDT in Canada and there is strong support for them to continue.

The CCDT has the strategies in place to continue and evolve its work.

The evaluation resulted in six major recommendations. This document highlights the evaluation findings and presents the actions that the CCDT will implement to address these recommendations. The full *Summative Evaluation Report* can be found at [www.ccdt.ca](http://www.ccdt.ca).

<sup>1</sup> Canada's OTDT community has many members. They include: organ procurement organizations, transplant programs, health professional associations, eye and tissue centres, the informed and general public, ethno-cultural and faith communities, universities and research organizations, non-government organizations, and patient care delivery organizations. While we have not explicitly named all groups, we recognize their importance to the field and their collaborative and coordinated approach to organ and tissue donation and transplantation in Canada.

Overall, the results from the evaluation show that the CCDT has been largely successful in addressing its objectives.

### RELEVANCE

Study respondents strongly supported the continued involvement of the federal government in the development of a coordinated FPT strategy to improve OTDT in Canada. Several unique and critical roles were identified for the federal government,<sup>2</sup> including:

- > Providing national leadership and a pan-Canadian authority to the issue of OTDT;
- > Addressing a national responsibility that resides only with the federal government as a result of the division of powers related to health care in Canada;
- > Providing national funding because no individual province or organization would be able to contribute these resources;
- > Providing national coordination at a high level in support of cross-jurisdictional and cross-organizational collaboration and reduce duplication of effort; and
- > Providing regulatory oversight to ensure a consistent minimum level of OTDT practice in order to maximize patient safety in Canada.

The perspective from the OTDT community clearly recognized CCDT activities as having been very relevant in addressing the deficiencies identified in the pre-CCDT period. Consistently, it was stated that the CCDT was the most appropriate organization to provide recommendations to the CDM regarding OTDT, that it was already doing a good job providing advice to the CDM and that a number of the CCDT initiatives had already been put into practice.

The stakeholders indicated that the CCDT is on the right track, but there is still much work to be done in this complex, changing and important field. The critical need for a coordinated national OTDT strategy in Canada was stressed repeatedly, particularly as it relates to organ donation issues, national standards, national registry systems and public awareness. The stakeholders indicated that the advisory mandate held by the CCDT needed strengthening to support the implementation of widespread Canadian solutions. Even so, the changes that have resulted to date due to the CCDT's efforts suggest that national interests are being addressed – practitioner by practitioner, organization by organization and province by province.

### OUTCOMES

Evaluation findings were strong and unequivocal regarding the CCDT's success in addressing most of its short- and intermediate-term outcomes. Although it must be acknowledged that these activities are enormous in scope, and on-going and emergent in nature, the CCDT has contributed significantly and has produced positive change with regard to the following outcomes specified in the Results Based Management and Accountability Framework submitted to Health Canada:

- > Identifying areas of emergent interest in OTDT;
- > Developing and disseminating reports and recommendations to improve OTDT in Canada;
- > Providing appropriate and high quality advice for stakeholders;
- > Generating and sharing a national body of knowledge related to OTDT in Canada;
- > Contributing to improved health care practices related to OTDT in Canada;
- > Contributing to improved OTDT policies and procedures in organizations and jurisdictions in Canada;

<sup>2</sup> The summative evaluation only explored the federal government's continued involvement as they were the sole funder of the CCDT during its first mandate.

- > Contributing to increased policy research related to OTDT in Canada; and
- > Contributing to the development of coordinated activities related to OTDT.

While the extent of the impact was more limited, the CCDT has also produced positive change with regard to the following outcomes;

- > The receipt/ response and/or adoption of CCDT advice and recommendations by provinces and territories, as well as by other organizations and stakeholders;
- > The contribution to improved OTDT policies and procedures at government levels; and
- > The adoption by stakeholders, including provinces and territories, of OTDT best practices developed by the CCDT.

## **COST EFFECTIVENESS**

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The CCDT has been successful in managing its resources efficiently and has made significant progress in all areas of the OTDT system compared to the pre-CCDT period. Compared to *Australians Donate (AD)*, a similar but smaller organization with a narrower scope, the CCDT has used resources in a similar way, decreasing administrative costs proportionately while increasing activity costs, suggesting that as the organizations mature, they are using their resources more efficiently. A further comparison between the two organizations was not possible because AD has not completed an evaluation at this time. No other cost-effective delivery model was identified.

The CCDT's activity level has risen dramatically over the five-year period and it has been quite effective in bringing about change at the practitioner level, but less able to effect change at the government level. Because of the short operational time frame of the CCDT, improvements in long-term outcomes were not expected but these should be monitored in future years in order to track overall progress in the system.

## **SUCCESSSES**

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### **Areas of particular success included:**

- > Preparing briefs on important OTDT topics for the CDM and identifying areas of emergent interest;
- > Developing and disseminating reports and recommendations to improve OTDT in Canada;
- > Providing a non-threatening forum for OTDT stakeholders to come together;
- > Providing appropriate and high quality advice for stakeholders;
- > Creating, and sharing a body of knowledge related to OTDT in Canada;
- > Contributing to increased policy research related to OTDT in Canada;
- > Providing recommendations for OTDT best practices and contributing to improved health care practices related to OTDT in Canada;
- > Having a positive influence on OTDT policies and procedures in Canadian health organizations and jurisdictions; and
- > Contributing to the development of coordinated and integrated OTDT activities in Canada.

### **Areas where more moderate success has been achieved to date included:**

- > Having a more consistent focus on activities that will lead to the achievement of the long-term outcome of improved donation and transplantation rates;
- > Supporting the adoption of best practices through greater diffusion to health care providers and middle managers;
- > Working more closely with OTDT non-governmental organizations and health profession organizations;
- > Exploring program systems, linkages and interoperability related to information management systems;
- > Disseminating more fully the knowledge and advice that is produced; and
- > Supporting and monitoring the adoption of CCDT advice (including recommendations, policies and procedures and best practices) by governments, organizations and other stakeholders.

Overall it was concluded that the CCDT has been very successful in achieving its goals during its first mandate and has effected significant positive change in the OTDT community.

## CONCLUSION

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**The Council of the CCDT found the summative evaluation process to be an invaluable exercise. The findings from the evaluation identified the strengths as well as the gaps within the CCDT framework and will assist in guiding the future work of the organization.**

The evaluation identified a number of strengths and successes that the CCDT has been able to achieve while operating in a venue of uncertainty and instability. It is obvious from the report that the stakeholders within the OTDT community value the work of the CCDT, its inclusive method of operating and believe there is a stronger role for the CCDT to undertake in the future. Of course, such a role is dependent on the stability of resources and support from the funding agencies of the CCDT, as well as the CDM to which it reports.

The volunteers and staff of the CCDT are proud of the work that has been achieved to date and look forward to addressing the many challenges faced by the OTDT system in Canada. The volunteer Council of the CCDT believes it can assist to improve the OTDT system for donors, patients, families, governments, stakeholders and others involved in the OTDT community through a collaborative, supportive and compassionate process of resolve.

The evaluation supports the successful collaborative effort of the CCDT with the OTDT community. The extensive contribution of the entire OTDT community to the work of the CCDT is one of the primary reasons that changes and improvements within the OTDT system are now being realized.

It is the intention of the CCDT to build on these relationships for stronger collaborative partnerships that will successfully achieve the needs identified in the six major recommendations of the *Summative Evaluation*.

## RECOMMENDATIONS and MANAGEMENT RESPONSE

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### **RECOMMENDATION I: DONATION AND TRANSPLANTATION RATES**

*Study participants strongly endorsed the continued involvement of the federal government in the development of a coordinated FPT strategy to improve OTDT in Canada. They indicated that the CCDT is the most appropriate organization to provide advice to the CDM regarding OTDT in Canada because it is objective and operates at arm's length from both governments and other stakeholders, is trusted by stakeholder groups, speaks to all government levels, is inclusive in its approach, has a proven track record and is the only organization that offers a national perspective. It is able to identify, coordinate and respond to overarching OTDT issues, to conduct consensus forums, to communicate with stakeholders from government to grass roots levels, and to produce credible knowledge products.*

*While the CCDT has made significant progress in many areas of the OTDT system, the number of donations and transplants has not increased nor has the number of patients on the waitlists decreased since 2001. This change was not anticipated in the short term but it is anticipated that these indicators will be positively impacted in the next five years with continued collaborative effort among OTDT stakeholders. Therefore:*

**The CCDT should continue to work with all stakeholders in the OTDT system to ensure that donation and transplantation rates are positively impacted in the next five-year period by:**

- > Engaging the CDM and a wide variety of OTDT stakeholders in responding to the changing and complex needs of OTDT; and
- > Providing leadership, coordination and a pan-Canadian perspective for OTDT.

**RESPONSE**

As identified in the *Summative Evaluation* report, the CCDT has been largely successful in addressing its objectives. The CCDT will continue to foster relationships that provide collaborative solutions with the aim of improving the OTDT system. Additionally, the CCDT will initiate an emerging-issues framework and develop stronger intergovernmental processes and relationships in order to identify common issues with a view to coordinating a national response.

Contributing to improved donation and transplantation rates is a priority for the CCDT and headway is being made. According to the Canadian Organ Replacement Register,<sup>3</sup> the numbers of both deceased (414 in 2005 to 468 in 2006) and living organ donors (504 in 2005 to 555 in 2006) increased in 2006. This 13% increase was the first increase in five years. This is a positive reflection of the collective effort of the OTDT community, including the work of the CCDT.<sup>4</sup>

A broader view of OTDT performance measures is needed given the system's complexity. The CCDT is exploring new measures such as optimizing potential donors. This issue is discussed further in this report relative to Recommendation 5.

The CCDT is well positioned to collaborate to improve system outcomes with governments, organ procurement organizations (OPOs), organ transplant organizations, eye and tissue centres, health professional associations, non-government organizations (NGOs), university research centres, and patient-care delivery organizations. In addition to strengthening these relationships, the CCDT has identified four key areas of effort:

- > Development and knowledge transfer of leading practices (Recommendations 2 and 3);
- > Public engagement (Recommendation 4);
- > Improvement of data and improved patient access (Recommendation 5); and
- > System performance improvement (Recommendation 5).

**RECOMMENDATION 2: OTDT SYSTEMS, PRACTICES AND POLICIES**

*Study participants identified a number of governmental and organizational policies and procedures that have been based on the information, reports and recommendations emerging from the CCDT. Future policy changes are also planned. CCDT knowledge products have influenced health care practice and several best practices developed by the CCDT have already been adopted in several regions by a number of stakeholders. Therefore:*

**The CCDT should continue to facilitate OTDT systems, practices and policy change by:**

- > Working with stakeholders towards the goal of advancing OTDT policies, practices and protocols in Canada; and
- > Supporting current linkages among stakeholders as well as by building additional connections to bring OPOs, NGOs, health professional organizations and health care practitioners more directly into the collaborative approach to system change.

**RESPONSE**

To realize the success of other countries, jurisdictions and programs working in isolation will not be able to maximize the OTDT opportunities. The CCDT plays a role in facilitating agreements between diverse OTDT stakeholders on complex OTDT issues. As identified in the *Summative Evaluation* report, one of the greatest strengths of the CCDT is the realization by these diverse groups that the CCDT is able to provide an objective perspective to discussions since the CCDT is an arm's length NGO. Consequently, the CCDT is able to provide a forum for governments, OPOs, and other members of the OTDT community to discuss, work together and often agree on complex OTDT issues. This consensus process has resulted in changes to health care practices and policies at the organization and government levels; patients and families benefit from this work through improved access to care.

<sup>3</sup> Table 1A: Transplants by Organ and Donor Type, Province of Treatment, Canada (Number); and Table 4: Deceased Organ Donors by Province/Region/Identifying Donor, Canada (Number).

<sup>4</sup> Since the first five-year time frame was too short for an impact to occur, the *Summative Evaluation* did not examine the CCDT's impact on these rates.

As in the past, the CCDT will continue to work to develop consensus-built leading practices, including organ-sharing allocation agreements for liver, heart, and lung. The CCDT will contribute to developing a tissue banking traceability and surveillance system and will continue to work with the national and international OTDT community to address mutual issues such as OTDT legal issues and OTDT registries.

As part of its work plan, the CCDT intends to continue to maximize collaborative opportunities by seeking feedback from stakeholders on CCDT initiatives, developing stronger external relations and partnerships with Canada-wide organizations, and strengthening links with centers of research excellence.

### **RECOMMENDATION 3. DIFFUSION OF INFORMATION**

*The CCDT has already begun to create a body of knowledge related to OTDT in Canada and has shared it to some extent, although not all study participants were aware of key knowledge products. While diffusion through informal channels can be rapid, more formal dissemination takes longer and key audiences need to be identified and accessed. Therefore:*

#### **The CCDT should continue to foster the diffusion of information about OTDT by:**

- > Increasing and broadening dissemination strategies to ensure that information is shared in a more timely way, using a wider variety of media and targeting health care providers as well as policy makers;
- > Disseminating recommendations, knowledge products and practice guidelines throughout the OTDT community; and
- > Raising the profile of the knowledge gained through the activities of the CCDT and its stakeholders in the international community.

#### **RESPONSE**

The CCDT has identified the transferrance of knowledge as one of its key priority areas. These plans include:

- > Developing and implementing a knowledge transfer framework;
- > Expanding CCDT communications capacity (e.g., website, community technology sites, discussion forums, and newsletters); and
- > Implementing peer-to-peer learning activities in the form of virtual forums, web-based communities, and the “Collaborative Method”.<sup>5</sup>

### **RECOMMENDATION 4: PUBLIC AWARENESS**

*Now that the CCDT has established a satisfactory infrastructure and effective policy research development processes, the next five years should focus more directly on the achievement of long-term outcomes. In order to influence the increase of intended donors, donations, and organs, public awareness about OTDT needs to be increased in Canada. Therefore:*

#### **The CCDT should expand public awareness regarding OTDT by:**

- > Continuing to work with a broad range of OTDT stakeholders to develop and implement OTDT public awareness strategies; and
- > Increasing its profile in the OTDT community and with the public by developing additional corporate identity and by expanding communications through the CCDT website and other online strategies.

#### **RESPONSE**

The CCDT identifies strongly with this recommendation. While the organization has provided advice on public awareness in the past, as the CCDT moves forward it will work collaboratively with OTDT organizations to apply what has been learned about public awareness opportunities.

Through a public engagement strategy, the CCDT will ensure that public feedback is incorporated into its plans and OTDT policy discussions. This includes Canada’s ethno-cultural and faith communities. As part of this strategy, the CCDT will develop a web-based clearinghouse for improved access to OTDT resources including public awareness messages and templates that local jurisdictions can use for networking.

<sup>5</sup> The collaborative method is a learning series with ongoing support that educates and supports hospital teams as they implement best practices.



## RECOMMENDATION 5: OTDT SYSTEM DEVELOPMENT

All stakeholders stressed the continued and critical need for a coordinated national OTDT strategy in Canada. In particular, national standards, national registry systems, national information systems, and databases were identified as needing development. Therefore:

### The CCDT should facilitate OTDT system development by:

- > Contributing to the development and implementation of national OTDT information systems and databases; and
- > Addressing issues associated with creating a national system for OTDT performance and outcomes.

### RESPONSE

Going forward, the CCDT will build on its preliminary work to improve the quality and timeliness of information. In continued collaboration with governments, members of the OTDT community, and, in particular, information management partners such as the Canadian Institute for Health Information and Canadian Organ Replacement Registry, the CCDT will play a key role in the planning and coordinating of the national interface with existing jurisdictional systems. Planned activities include:

- > Developing a coordinated OTDT information strategy for Canada;
- > Reaching agreement on standard use and accountability for inter-provincial algorithms for organ sharing;
- > Developing real-time waitlist management capacity. This capacity will supplement existing provincial registries to improve high status organ sharing and develop a new and linked registry for highly sensitized individuals;
- > Developing a registry for living donor-paired exchanges; and
- > Supporting the new systems for organ and tissue surveillance and adverse event reporting.

The OTDT community agrees that the current donation-rate/million is not the best measure of improvement. The CCDT will strive to build consensus on credible and meaningful indicators, measures, and reporting mechanisms for donation and transplantation. In this way, the CCDT in collaboration with the entire OTDT community can help develop consistent OTDT system performance measurement across Canada.

## RECOMMENDATION 6: PERFORMANCE MEASUREMENT AND EVALUATION

In order to obtain evidence that the work of the CCDT has had an impact on its identified goals and objectives, including the long-term outcomes identified in this evaluation, on-going performance measurement and evaluation systems must be developed and implemented in conjunction with planning activities. Therefore:

### The CCDT should continuously focus on its own performance and outcomes by:

- > Developing a system to further support and track the adoption of CCDT recommendations by stakeholders; and
- > Building on its current evaluation activities by developing and implementing on-going performance measurement and evaluation strategies to continually measure CCDT outcomes.

### RESPONSE

The CCDT has made many strides in measuring our performance and outcomes. Operating in an arena of facilitation and advocacy, one of the unique challenges faced by the organization is the measurement of outcomes not directly controlled by the organization itself. However, the CCDT recognizes the need for continued development and is committed to:

- > Supporting and tracking the adoption of CCDT recommendations in local jurisdictions;
- > Updating our evaluation framework;
- > Implementing ongoing performance measurement in areas of governance, operations and initiatives; and
- > Reporting results to our funders and stakeholders.

### EVALUATION DESIGN

The purpose of the evaluation was to explore the development and implementation processes of the CCDT during its first term and to evaluate the outcomes resulting from these processes. Evaluation topics addressed included: program process (foundational supports/inputs, implementation process/key activities, and products/outputs); relevance; design (formative evaluation follow-up); outcomes; cost effectiveness; and successes.

The evaluation reviewed three stages of organizational development at the CCDT, including: the formative years (2001-2002 to 2003-2004); the developmental year (2004-2005); and the transition year (2005-2006), during which the CCDT transferred out of Health Canada. The Health Canada Results Based Management for Accountability Framework for the CCDT was used extensively in the design of the summative evaluation, along with a program theory developed specifically for the study.

Data collection methods included: an extensive document review of over 250 documents; a Stakeholder Internet Survey to which 138 individuals from five different stakeholder groups replied (a 62.7% response rate); and 30 Key Informant Interviews from individuals in the five identified sub-groups (an 85.7% response rate). These groups included Council Members and FPT Ex-Officios, OTDT Stakeholders, Experts/Committee Members, Health Professions and NGOs, and Care Providers.

An iterative analysis process was used so that the results of the Internet Survey informed the interview questions for the key informants. A cost effectiveness analysis was also conducted. The study was overseen by the Summative Evaluation Steering Committee which was comprised of representatives from Health Canada, provincial governments, senior hospital administration, and CCDT Council and staff.

It must be noted that the CCDT's long-term outcomes were not evaluated in the study because of the lengthy time horizon required to demonstrate change to organ and tissue donation and transplant rates in Canada. The CCDT was just completing its first five-year term at the time of the evaluation and it was considered premature for long-term outcomes to be affected.

### DESIGN—FORMATIVE EVALUATION FOLLOW-UP

The recommendations regarding governance, staffing, project management, communication and evaluation, as highlighted in the 2003 BearingPoint formative evaluation, have been adopted or addressed by the CCDT. A significant body of documentation was prepared in response to that report, providing a foundation for good organizational practices going forward. The formative evaluation fulfilled its purpose and closure was achieved.

Another important contextual factor that affected achievement of outcomes was the significant organizational change (transition from federal government to non-government organization) that occurred in response to a formative evaluation conducted in 2003.