

**Canadian Council for Donation and  
Transplantation (CCDT)  
Summative Evaluation  
Final Report**

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Canadian Council for Donation and Transplantation (CCDT) Summative Evaluation: Final Report– December 31, 2006

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## Glossary of Terms

ACHS	Federal/ Provincial/ Territorial Advisory Committee on Health Services
AD	Australians Donate
CBS	Canadian Blood Services
CCDT	Canadian Council for Donation and Transplantation
CCRB	Coordinating Committee on Reciprocal Billing
CCOHTA	Canadian Coordinator Office for Health Technology Assessment
CDM	Federal/ Provincial/ Territorial Conference of Deputy Ministers of Health
CIHI	Canadian Institute for Health Information
CIHR	Canadian Institutes for Health Research
CMAJ	Canadian Medical Association Journal
CORR	Canadian Organ Replacement Register
DCD	Donation after Cardiocirculatory Death
DCM	Data Collection Matrix
FPT	Federal/ provincial/ territorial
HPB	Health Protection Branch
MEMODOP	Medical Management to Optimize Donor Organ Potential
NCC	National Coordinating Committee for Organ and Tissue Donation
NGO	Non-governmental organization
OTDT	Organ and Tissue Donation and Transplantation
RBAF	Risk-based Audit Framework
RMAF	Results-based Management and Accountability Framework
SCH	Standing Committee on Health
SBINND	Severe Brain Injury to Neurological Determination of Death



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# Executive Summary

## Context

The Canadian Council for Donation and Transplantation (CCDT) arose from concerns about the shortage of organs and tissues for transplantation in Canada where donation rates were among the lowest in developed countries. The CCDT was established in October of 2001 as an advisory body to the Federal/Provincial/Territorial (FPT) Conference of Deputy Ministers of Health (CDM) in its efforts to coordinate activities related to organ and tissue donation and transplantation. It works to develop organ and tissue donation and transplantation (OTDT) advice in a wide range of areas. It is currently a federally incorporated non-profit organization funded through a contribution agreement with Health Canada.

## Evaluation Design

The purpose of this evaluation was to explore the development and implementation processes of the CCDT during its first mandate and to evaluate the outcomes resulting from these processes. Evaluation topics addressed in this report include program process—foundational supports/inputs, implementation process/key activities, and products/outputs; relevance; design—formative evaluation follow-up; outcomes and successes; and cost effectiveness. 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 and Accountability Framework (RMAF) for the CCDT was used extensively in the design of this summative evaluation along with a program theory developed specifically for this 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 Non-governmental organizations (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 an Evaluation Steering Committee that was comprised of representatives from Health Canada, provincial governments, senior hospital administration, and CCDT Council and staff.

## Evaluation Findings

Overall, the results from this evaluation show that the CCDT has largely been successful in addressing its objectives. It must be noted that the CCDT's long-term outcomes were not evaluated in this 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 mandate at the time of the evaluation and it was considered premature for long-term outcomes to be affected. Another important contextual factor that affected achievement of outcomes was the significant organizational change that occurred in response to a formative evaluation conducted in 2003. Keeping in mind these constraints, study findings lead to the following evaluation conclusions:

**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. The evaluation only explored the federal government's continued involvement as they were the sole funder of the CCDT during its first mandate. Several unique and critical roles were identified for the federal government, 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.

In the view of the OTDT community, CCDT activities have been very relevant in addressing the deficiencies identified in the pre-CCDT period. The view was also generally held 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 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.

**Design—Formative Evaluation Follow-up:** The issues regarding the governance, staffing, project management, communication and evaluation, as highlighted in the 2003 BearingPoint formative evaluation, have been adopted or addressed by 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.

**Outcomes and Successes:** 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 RMAF:

- 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;
- 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 of OTDT Best Practices developed by CCDT by stakeholders, including provinces and territories.



**Cost Effectiveness:** The CCDT has been successful in managing its resources and has made significant progress in all areas of the OTDT system compared to the pre-CCDT period. Compared to a similar but smaller organization with a narrower scope, *Australians Donate* (AD), 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.

## Conclusions

Areas of particular success include:

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

Areas where more moderate success has been achieved to date include:

1. Having a more consistent focus on activities that will lead to the achievement of the long-term outcome of improved donation and transplantation rates;
2. Supporting the adoption of best practices through greater diffusion to health care providers and middle managers;
3. Working more closely with OTDT non-governmental organizations and health profession organizations;
4. Exploring program systems, linkages and interoperability related to information management systems;
5. Disseminating more fully the knowledge and advice that is produced; and
6. 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.

## Recommendations

Based on the findings of this evaluation, the following recommendations are advanced for consideration:

### **Recommendation 1. 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.

### **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 profession organizations and health care practitioners more directly into the collaborative approach to system change.

### **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.

### **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.



## **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 and 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.

## **Recommendation 6. Performance Measurement and Evaluation**

*In order to obtain evidence that the work of the CCDT has had an impact on its identified goal 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 refining and implementing on-going performance measurement and evaluation strategies to continually measure CCDT outcomes.





# 1.0 Introduction

The Canadian Council for Donation and Transplantation (CCDT) arose from concerns about the shortage of organs and tissues for transplantation in Canada where donation rates were among the lowest in developed countries. The CCDT was established in October of 2001 as an advisory body to the Federal/ Provincial/ Territorial (FPT) Conference of Deputy Ministers of Health (CDM) in its efforts to coordinate activities related to organ and tissue donation and transplantation. It works to develop organ and tissue donation and transplantation advice in a wide range of areas. It is currently a federally incorporated non-profit organization funded through a contribution agreement with Health Canada.

## 1.1 Evaluation Purpose, Scope and Stakeholder Needs

A summative evaluation of the CCDT at the end of its first mandate is required by the CDM, by Health Canada and by the CCDT itself. The requirements are outlined in the CCDT's Results-based Management and Accountability Framework (RMAF) that was developed collaboratively by Health Canada and the CCDT and that forms part of its Contribution Agreement with Health Canada.

Program evaluation is defined as the use of social research procedures to systematically investigate the effectiveness of social intervention programs (Rossi et al, 1999) and to determine their merit, worth and value (Scriven, 1991). Because of issues of both criticality and efficiency, a rigorous approach can provide *information of sufficient credibility under scientific standards to provide a confident basis for action and to withstand criticism aimed at discrediting it* (Rossi et al, 1999). As a result, a strong and comprehensive evaluation design was prepared and data was obtained through a rigorous yet collaborative process. Barrington Research Group, Inc. (BRG) was commissioned to conduct this summative evaluation.

The purpose of this evaluation was to understand and describe the development and implementation processes of the CCDT during its first mandate and to evaluate the outcomes that have resulted from these processes. Evaluation topics addressed in this report include program process (foundational supports/inputs, implementation process/key activities and products/outputs); relevance; design—formative evaluation follow-up; outcomes/successes; and cost effectiveness.

The scope of the evaluation addressed three stages of organizational development at the CCDT. These included 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 external context and factors that facilitated and inhibited each of these stages have been considered as well. The results of this summative evaluation will be used to define the process for developing a new mandate for the CCDT.

The evaluation was designed to recognize the evaluation needs of a number of primary stakeholders. These included the CDM, the FPT body that both initiated and continues to oversee the CCDT's mandate and is the recipient of CCDT policy advice on organ and tissue donation and transplantation issues; Health Canada, the funder of the CCDT and an organization committed to continuous quality improvement; and other stakeholders in the broader organ and tissue donation and transplantation (OTDT) community who are partners, participants and recipients of CCDT reports and recommendations.

To ensure that the needs of all primary stakeholders were met, an Evaluation Steering Committee comprised of representatives from Health Canada, provincial governments, senior hospital administration, the Council itself, and CCDT staff, guided the evaluation. A strong, comprehensive evaluation design was prepared and data was obtained through a rigorous and collaborative process. Barrington Research Group, Inc. (BRG) was commissioned by the CCDT to conduct this summative evaluation.



## 1.2 Organization of this Report

The report is organized into a number of sections that provide evaluation findings and answer the evaluation questions for key topics presented in the Data Collection Matrix found in Appendix 2. These include:

### Evaluation Design

This section describes the design of this evaluation, its conceptual frameworks, data collection methods, and strengths and limitations.

### Findings- Process

This section provides information on foundational supports and inputs, such as the background and development of the CCDT; the division of powers in Canada for health, the CCDT's mandate, terms of reference, organizational structure, staffing, and committees. It also explores the implementation process and key activities and the term *providing advice*. Key activities during the first mandate are described according to three distinct periods: the formative years (2001-2002 to 2003-2004), the developmental year (2004-2005) and the transition year (2005-2006). Some stakeholder perceptions about the CCDT's organizational structure and current activities are also presented. Finally, it describes the knowledge products that have resulted from the activities including briefings, reports, reviews, scans, surveys, tools and other publications, as well as consensus recommendations produced to date.

### Findings- Relevance of the CCDT

This section summarizes study findings related to the continued need for the CCDT and whether or not the CCDT is the most appropriate organization to provide advice to the CDM. It focuses on key questions to do with the continued need for the CCDT in Canada.

### Findings- Design- Formative Evaluation Follow-up

This section presents a brief review of the formative evaluation of the CCDT that was conducted in 2003 and describes the subsequent activities undertaken to address identified issues.

### Findings- Outcomes and Successes

This part of the report presents evaluation findings related to outcomes and to the overall success of the CCDT in achieving its goals to date. Immediate, intermediate and long-term outcomes are explored in terms of study findings and the overall success of the CCDT is considered.

### Findings- Cost-effectiveness

This section addresses the topic of cost effectiveness. It compares the CCDT activities and objectives during the evaluation period with those of Health Canada prior to the establishment of the CCDT; reviews topics of *relevance, performance, effectiveness, economy, and efficiency*; looks at the costs associated with the CCDT; and offers a broad comparison with an alternative organization, *Australians Donate*.

### Discussion, Conclusions and Recommendations

The final part of the report provides a brief discussion about evaluation findings offers some conclusions and advances recommendations for consideration.



## 2.0 Evaluation Design

This section describes the design of this evaluation, including the conceptual frameworks that provided the foundation for evaluation activities, the data collection methods, and the limitations and strengths of this particular design.

### 2.1 Conceptual Frameworks

This evaluation used a structured approach to data collection that was based on two interlacing conceptual frameworks—the Results-based Management and Accountability Framework (RMAF), as defined by Treasury Board, and a program theory and logic model that were developed for this study and were elaborated in a data collection framework.

#### 2.1.1 Treasury Board Results-based Management and Accountability Framework

The Results-Based Management Accountability Framework (RMAF) is defined by Treasury Board as a blueprint to help managers focus on measuring and reporting outcomes throughout the lifecycle of a policy, program or initiative.<sup>1</sup>

It establishes a commitment to outcome measurement and leads to formative and summative evaluation activities. It provides clear roles and responsibilities for the main partners involved in delivering the program; outlines a results-based logic model and a related performance measurement strategy; identifies the evaluation work to be performed over the lifecycle of the program; and sets the stage for the adequate reporting of outcomes. It is based on the guiding principles of utility, shared ownership, transparency, credibility, flexibility and a decision and/ or action orientation.

The CCDT's RMAF was developed during the first mandate by the Health Products and Food Branch (HPFB) Program Evaluation and Audit Coordination Office of Health Canada in collaboration with CCDT staff and was finalized in April 2006. Copies of the RMAF logic model and the related Evaluation Strategy Table are provided in Appendix 1. The RMAF was used extensively in the development of evaluation questions for this study and provided a critical component for the overall architecture of this summative evaluation. In some cases, questions from the RMAF Evaluation Strategy Table were encompassed within larger evaluation questions or were addressed through several evaluation questions. The related RMAF questions and their related sections are outlined below. In addition, footnotes are provided to this effect where relevant.

<b>RMAF Question</b>	<b>Related Evaluation Questions</b>	<b>Section</b>
Is the advice received from CCDT appropriate and of high quality?	<i>How does the CCDT develop knowledge and provide the CDM with quality advice?</i>	3.2.1
	<i>Is CCDT the most appropriate organization to provide recommendations to the CDM regarding OTDT or could this function be transferred to another organization?</i>	4.2
Has CCDT been successful in identifying areas of emergent interest related to organ and tissue donation and transplantation in Canada?	<i>What briefings have been prepared related to emergent issues identified by CCDT?</i>	3.3.1
Have reports and recommendations been developed and disseminated to improve organ and tissue	<i>What recommendations has CCDT made in relation to OTDT in Canada?</i>	3.3.1
	<i>What reviews of literature and policy and legal/ ethical</i>	

<sup>1</sup> Treasury Board of Canada Secretariat. Guide for the Development of Results-based Management and Accountability Frameworks. August 2001. p. 1.



donation and transplantation in Canada?	<i>issues, environmental scans, surveys, datasets, tools or educational resources, articles in peer-reviewed journals, and other research reports has CCDT written and disseminated related to OTDT in Canada?</i>	3.3.2
	<i>What non-regulatory standards, clinical practice guidelines and best practice guidelines has CCDT created related to OTDT in Canada?</i>	3.3.3
Is there an alternative way to deliver this type of program?	<i>Is there an alternative way of delivering the objectives of CCDT in a more cost-effective manner?</i>	7.0

## 2.1.2 Program Theory and Evaluation Framework

To ensure that the summative evaluation could not only report on the achievement of outcomes, but also on the CCDT's response to the findings of the 2003 formative evaluation within the context of resulting organizational change, a broad scope was required. A program theory and its associated logic model were developed to guide the evaluation. They were based on an analysis of the assumptions<sup>2</sup> underpinning the CCDT. The theory was organized into two main components:

### 1. Program Process: including

- **Foundational supports and inputs**, or how resources were gained, configured and deployed and how program activities were organized so that the intended program activities could be developed and maintained;
- **Implementation process and key activities**, or how the intended target populations received the intended interventions through the program's key activities; and
- **Products and outputs**, or the products and services delivered to program participants and other such activities viewed as part of the program's contribution to society.

### 2. Program Outcomes, or the results of process activities showing how the intended interventions brought about the desired social benefits, including:

- **Immediate outcomes**;
- **Intermediate outcomes**; and
- **Long-term outcomes**.

This theory was presented visually as a logic model for the evaluation and is presented in Appendix 2 along with the framework developed for the summative evaluation known as the Data Collection Matrix (DCM). The DCM links the evaluation topics with the evaluation questions, performance indicators, research methods, and data sources. (See Appendix 2 for more details.) The evaluation questions from the DCM are highlighted throughout this report as appropriate.

## 2.2 Data Collection Methods

A brief description of the evaluation methods and tools used in this study follows.

### 2.2.1 Document & File Review

An extensive review of documents and files was conducted for this evaluation. This included administrative documents, business/work plans, communications and media documents, background and historical documents, evaluation documents and plans, minutes and other governance documents. In addition, the documents produced by the CCDT, including reviews, environmental scans, survey tools and resources, publications and reports, and recommendations with CDM briefing notes were also reviewed. In all, 251 documents were

<sup>2</sup> Rossi, Peter H, Howard E. Freeman & Mark W. Lipsey. *Evaluation: A Systematic Approach*. 6<sup>th</sup> edition. Thousand Oaks: Sage. (1999).



reviewed. A Document/File Review Template organized according to topics on the DCM was used for the review. A complete list of the documents reviewed is provided in Appendix 3.

## 2.2.2 Stakeholder Internet Survey

There were many different groups of stakeholders involved in the CCDT evaluation. In consultation with CCDT staff and the Evaluation Steering Committee, a representative cross-section of 227 stakeholders was identified for the study. An email invitation on CCDT letterhead was sent to the stakeholders that contained a link to the secure survey site. Survey Monkey software was used. The survey was provided in both official languages and was available from May 25, 2006 to June 13, 2006. A copy of the survey is provided in Appendix 4.

Survey responses were closely tracked. Two follow-up reminder emails were sent and a random sample of respondents was also contacted by telephone to encourage participation. It should be noted that, in some cases, stakeholders forwarded the survey to other individuals (e.g., members of a professional organization) and, in others, several individuals met and prepared a single response. As a result, response rates are only an estimate. Of the 227 stakeholders who were sent the survey, seven email addresses were incorrect, resulting in a survey population of 220 individuals. A total of 138 individuals responded for a response rate of 62.7%. Table 1 provides a summary of the stakeholder groups who were invited, those who participated in the survey, and the overall proportion of respondents by sub-group.

**Table 1. Internet survey response rates by sub-group**

Stakeholder Group	Invited N	Participated	% of sub-group responding	% of total survey respondents
<b>1. Council's Stakeholders:</b>				
• Council Members	36	25	69.4%	18.1%
• FPT/Ex Officio				
<b>2. ODTD Stakeholders:</b>				
• Organ Procurement Organizations	68	43	63.2%	31.2%
• Organ Transplant Organizations				
• Eye & Tissue Centres				
<b>3. Experts:</b>				
• Initiative Committee Members	63	33	52.4%	23.9%
• Standing Committee Members				
<b>4. Health Professions &amp; NGOs:</b>				
• Health Professional Organizations	27	26	96.3%	18.8%
• Non-governmental Organizations				
<b>5. Care Providers:</b>				
• Hospitals and Critical care	33	11	33.3%	8.0%
Sub-total	227	138	60.8%	-
(less incorrect email addresses)	(7)	-	-	-
<b>Total</b>	<b>220</b>	<b>138</b>	<b>62.7%</b>	<b>100.0%</b>



As individuals could identify with more than one sub-group, many indicated membership in several. As a result, the sub-groups were organized in the sequence presented in the above table, with those closest to the CCDT in the first category (i.e., Council Members and FPT/Ex Officios) and those furthest removed from direct involvement (i.e., Care Providers) in the fifth category. Survey respondents who checked membership in more than one category were placed in the sub-group most closely connected to the CCDT. Thus, an individual who was both a Council Member and a Care Provider was categorized as a Council Member. The result is that the Care Provider group seems under-represented but their perspective may have been captured in other sub-groups. On the other hand, it is also possible that this group was less aware of CCDT activities than other groups and therefore was less likely to complete the survey. The four other sub-groups were well represented. These five groupings were used throughout this report to present the findings.

### **2.2.3 Analysis of Internet Survey Data**

The quantitative data obtained from the Internet Survey was analyzed using the Statistical Package for the Social Sciences (SPSS). Prior to analysis, the data were examined for accuracy. If the error-rate was greater than 2%, further error checks were made. In addition, the minimum and maximum values, means and standard deviations of each variable were inspected for plausibility. Analysis techniques involved descriptive techniques and the information was compiled into summary tables. Open-ended comments were analyzed using traditional content analysis techniques (Krippendorff, 1980). The results of the Internet Survey were circulated to the Evaluation Steering Committee in the Interim Report for preliminary discussion and interpretation.

### **2.2.4 Key Informant Interviews**

Two groups of Key Informants were selected for the interviews conducted in the second stage of the evaluation. The first set of interviewees included individuals whose participation was deemed essential to provide depth to the study and so they could not be selected through a random selection process. They included representatives of the CDM, key OTDT stakeholders, and a few representatives of the Expert and Health Profession and non-governmental organization (NGO) categories. While some of these individuals may have completed the Internet Survey, this was not a requirement for participation in the interviews.

The second group of interviewees was selected to provide breadth to study findings by probing the views of the survey respondents who had provided either high or low ratings on the survey. The method used for their selection was the Success Case Method (Brinkerhoff, 2003) as it is often used to explore differing views. Participation in the Internet Survey was a pre-requisite. The survey results were analyzed to determine which sub-groups had the highest or lowest ratings to survey items overall and, while there were no significant differences between the groups (using a one-way Anova test), the Experts responded more positively and the Health Professional Organizations/NGOs responded less positively than other groups. A random sample was selected from these two sub-groups for the interviews.

The interview questions built on the findings of the Internet Survey and explored particular topics in greater depth, focusing on the participants' areas of specialized knowledge. The interview protocols are provided in Appendix 4. Table 2 provides a summary of the Key Informants who were invited to participate and those who participated in the interviews.



**Table 2. Key Informants by sub-group**

<b>Groups:</b>	<b>Invited</b>	<b>Participated</b>
1. Council Members and FPT/ Ex Officio	9	8
2. OTDT Stakeholders	6	5
3. Experts/ Committee Members	12	10
4. Health Professions & NGOs	7	7
5. Care Providers	1	0
Total	35	30

Overall, 30 of the 35 Key Informants were interviewed, for an 85.7% response rate. Considering the fact that these interviews were conducted in July 2006, the response rate was considered to be excellent.

### **2.2.5 Analysis of Interview Data**

The interview data was analyzed using a qualitative analysis program, NVivo (QSR NUD\*IST Vivo) and traditional content analysis techniques were used. Comments were grouped by the main themes identified in the DCM, data summaries were produced, and themes were mapped using Mind Manager technology. The researchers reviewed the results for a validity check. Comments were sorted and summarized in tables and anonymous representative quotes were selected for this report to clarify or expand key perspectives.

### **2.2.6 Cost Effectiveness Review**

In order to best answer the cost effectiveness questions identified in the Health Canada RMAF, a cost effectiveness review was conducted. The review used four methods including the following:

1. A pre/post- comparison of outcomes based on the pre-CCDT period and the CCDT's subsequent accomplishments;
2. A review of the relevance and performance of the CCDT including effectiveness, economy and efficiency;
3. A cost review; and
4. A comparison with an alternative organization, *Australians Donate (AD)*.

## **2.3 Evaluation Strengths and Limitations**

There were several strengths demonstrated in the conduct of this evaluation, as well as a number of challenges and limitations. These are described below.

### **2.3.1 Evaluation Strengths**

There were some particular strengths associated with the conduct of this evaluation including:

- Extensive involvement of the Evaluation Steering Committee, who provided input into study design, instrument design, and report preparation to ensure appropriateness, relevance and clarity;
- Adherence to the Code of Conduct of the Canadian Evaluation Society and to the Guiding Principles of the American Evaluation Association by the evaluators and research team;
- Use of accepted research and evaluation methods for all data collection and analysis;
- Adherence to privacy and confidentiality requirements and maintenance of data security; and
- Extensive evaluator experience in studies of a similar scope and nature.



### 2.3.2 Evaluation Limitations

Several challenges or limitations were experienced in conducting this evaluation that may limit the robustness of the findings. As a result, this report should be read with the following in mind:

- The long-term horizon required to demonstrate change means that outcome data in terms of changes to organ and tissue donation and transplant rates is unlikely to be available for at least five more years; as a result, no long term outcomes were evaluated;
- The availability of outcome data was likely limited by the organizational changes undergone by the CCDT during this five-year period;
- There is little or no benchmark data available for comparison purposes. With the exception of AD, no other organization was identified whose main function is to provide advice to a council of national, provincial and territorial representatives;
- Very little cost information was available regarding national activities/coordination of OTDT in the pre-CCDT period at Health Canada;
- The study occurred during the summer of 2006 and some potential respondents may not have been available; and
- Due to privacy concerns, potential survey respondents and interview participants were invited to participate by the CCDT.

## 2.4 Summary—Evaluation Design

This section provided an overview of the evaluation design used in the summative evaluation of the CCDT. It described the conceptual frameworks that provide the structure of the evaluation, including the Health Canada RMAF and the program theory developed for this evaluation. The Data Collection Matrix that guided research activities was described along with data collection methods including the document and file review, the Stakeholder Internet Survey and the Key Informant interviews. Quantitative and qualitative analysis methods were outlined and evaluation limitations and strengths were briefly described. The remainder of this report presents the findings of the evaluation.

## 3.0 Findings- Process

### 3.1 Foundational Supports and Inputs

This section addresses the three Process components of the program theory and DCM. It describes the background to the development of the CCDT, the division of powers with regard to health matters in Canada, and the CCDT's mandate, terms of reference and organizational structure. It also provides some information on other administrative supports required for its operation. Key evaluation questions from the DCM are provided as appropriate. The information presented in this section was largely obtained from the extensive document review conducted for this study but several pertinent items from the Internet Survey and Key Informant interviews are also included. The section closes with a brief summary.

#### 3.1.1 Background to the Establishment of the CCDT

##### *Why was CCDT established?*

In the late 1990's, the long-standing issue of organ and tissue shortages in Canada became prominent. A series of committees was established to review the issue and to develop recommendations and three key documents were produced that provided important background information about the context in which the CCDT was developed. They were in fact the precursors to the establishment of the CCDT and are briefly summarized below.

##### **a) Federal/Provincial/Territorial Advisory Committee on Health Services (ACHS)**

The long-standing issue of organ and tissue shortage was raised on several occasions at meetings of the Federal/Provincial/Territorial Conference of Deputy Ministers of Health (CDM) and, as a result, an inter-provincial working group was established to identify and assess the issues associated with organ donation and distribution in Canada, and to recommend strategies



for improvement. This group, known as the Federal/ Provincial/ Territorial Advisory Committee on Health Services (ACHS), prepared a report in September 1996 entitled *Organ and Tissue Donation and Distribution in Canada: A Discussion Document*. It identified a number of underlying reasons for low donation rates in Canada, including:

- Professional attitudes and lack of knowledge;
- Systemic and financial barriers to hospital/ physician/ health professional involvement;
- Lack of public awareness;
- Cultural barriers;
- Ethical issues; and
- Non-utilization of transplantable organs and tissues.

Specific issues regarding distribution were also identified, including:

- Lack of or insufficient standards;
- Regional variations and geographical distance;
- Insufficient information systems;
- Lack of financial incentives for sharing;
- Lack of public voice; and
- Lack of accountability.

The report recommended a 13-point national strategy that encompassed 35 different initiatives and recommended a multi-faceted approach that involved government, societies and foundations. ACHS also prepared an implementation plan with a description of each of the 13 areas, a timeframe, a cost, and the identification of specific lead organizations for each area. The CDM received the ACHS report and established the National Coordinating Committee for Organ and Tissue Donation, Distribution and Transplantation (NCC).

#### **b) Role of the National Coordinating Committee for Organ and Tissue Donation (NCC)**

The NCC was established to examine the implementation of the 13-point strategy proposed by the ACHS report. It was composed of five governmental members (western region, Quebec, Ontario, eastern region and Health Canada) and five non-governmental members (Canadian Transplant Society, Canadian Association of Transplantation, Canadian College of Health Services Accreditation, Kidney Foundation and the Canadian Institute for Health Information). It was allocated \$500,000 for a three-year period to maintain a secretariat (\$150,000) and support specific contracts to analyze options for implementation (\$350,000). It reported semi-annually to the ACHS.

Several other key partners at the time included:

- Coordinating Committee on Reciprocal Billing (CCRB);
- Canadian Coordinator Office for Health Technology Assessment (CCOHTA);
- Canadian Institute for Health Information (CIHI); and
- Canadian Blood Services (CBS).

#### **c) Standing Committee on Health (SCH)**

In December 1998, the Honourable Allan Rock, Minister of Health, announced the Standing Committee on Health (SCH) would undertake a study of the donation crisis in Canada. The NCC was then asked to put its development of an implementation strategy on hold while it supported the SCH to conduct extensive national-level consultations with a wide variety of stakeholders. The findings of this inquiry were summarized in the document, *Organ and Tissue Donation and Transplantation: A Canadian Approach* (April 1999). An appropriate role for the federal government was considered in relation to the development of national safety, outcome and process standards for organ and tissue donation and the promotion of public and professional awareness and knowledge. The SCH also looked at related legislative and regulatory regimes in other countries.



The report concluded with 48 recommendations divided into 18 areas to develop a coordinated, comprehensive donation and transplantation system for Canada. In particular, it recommended that the CDM establish the Canadian Transplant Network to oversee organ and tissue donation and transplantation, to report annually through the CDM to the federal Minister of Health and Parliament and to be supported by a permanent secretariat and budget.

#### **d) The NCC Framework**

In June 1999, the CDM directed the NCC to bring forward an interim report to include the following:

- A framework for action at the local, provincial/ territorial and national levels that would result in a sustained systematic approach to increasing the rates of organ and tissue donation and transplantation in Canada;
- A statement of principles to guide officials in preparing an organizational and financial plan for collaborative action to support donation and transplantation activities;
- A timeline for the submission of a detailed plan for approval; and
- A goal expressed in organ donations per million population annually in Canada by the year 2005.

As part of the development, NCC held an invitational workshop of experts in Aylmer, Quebec to develop recommendations and processes to address the 13 strategy elements. The NCC proceedings included recommendations to the ACHS for a set of principles to direct a sustained effort to increase the level of organ and tissue donation and transplantation in Canada. The need for a coordinated and comprehensive strategy was clearly identified.

In September 1999, the CDM approved the NCC's framework for action. In November 1999, the NCC presented its final report to ACHS. It was entitled, *A Coordinated and Comprehensive Donation and Transplantation Strategy for Canada* (referred to here as the Framework Report). It included a vision for Canada's health system; a strategy for designing a donation and transplant system; a strategic direction; core functions for organ donation, transplantation and tissue banking; and support processes.

In designing a strategy for a coordinated network of services, the goals agreed to by the CDM were addressed, including (1999, p.4):

- To preserve, protect and improve the health of Canadians;
- To ensure reasonable access to an appropriate range of health benefits anywhere in Canada based on need and not the ability to pay; and
- To ensure long-term sustainability of the health system.

#### **Key findings:**

- The three seminal documents described in this section, *Organ and Tissue Donation and Distribution in Canada: A Discussion Document*. (1996), *Organ and Tissue Donation and Transplantation: A Canadian Approach* (1999), and *A Coordinated and Comprehensive Donation and Transplantation Strategy for Canada* (1999) (known as the Framework Report) provided the rationale for the establishment of the CCDT.
- They raised the long-standing issue of organ and tissue shortages in Canada, assessed these issues, and recommended strategies for improvement.
- They provided the rationale, impetus, purpose and original organizational structure for the CCDT.

The CCDT was established in response to identified organ and tissue shortages in Canada. A series of three seminal reports produced at the national level provided the rationale, impetus and structure for the CCDT.



### 3.1.2 Division of Powers with regard to Health Matters

*How has the federal/ provincial/ territorial and regional division of powers influenced the way CCDT provides advice?*

An important topic clarified in the Framework Report (1999) was the division of powers (also known as levels of accountability) and the roles of key stakeholders that feature so prominently in the Canadian health system. They are worth reviewing here because the division of powers between the federal and provincial/territorial governments is key to the way in which the CCDT was able to provide advice and to effect change with regard to the development of a national OTDT strategy.

The CCDT's mandate is to provide advice to the CDM, a body made up of both federal and provincial/territorial representatives. It was then up to the provincial/territorial levels (because health care is delivered at that level) to implement or not implement the recommendations. As the Framework Report stated, the federal government's key roles in the health of Canadians includes the protection of their health, promotion of strategies to improve their health and support of the healthcare system. Of relevance here is the federal government's role with regard to:

- Supporting the healthcare system through the Canadian Health and Social Transfer;
- Monitoring and administering the *Canada Health Act* and its five principles (accessibility, portability, comprehensiveness, public administration and universality);
- Protecting the health of Canadians, directly and in cooperation with other federal agencies and provincial governments through legislation such as the *Food and Drugs Act* and specific regulations; and
- Working in partnership with provincial and territorial governments to foster national approaches to health programs and services.

Health Canada has a primary responsibility for safety standards through the *Food and Drugs Act* and its regulations. The Health Protection Branch (HPB) administered programs to ensure safety in relation to food, drugs, medical devices, preventable diseases, environmental pollutants and hazardous products, and undertakes work on blood, semen and other tissues, organs and xenotransplantation. The Therapeutic Products Programme of HPB provided direction and inspection on regulations adherence regarding organs and tissues. Finally, the Laboratory Centre for Disease Control of HPB contributed to research and surveillance in the area.

Constitutionally, the provincial and territorial governments have wide powers to regulate local health matters, particularly the delivery of healthcare services. They have the authority to make laws concerning the establishment, maintenance and management of hospitals, asylums and charitable institutions, giving provinces and territories the primary role in healthcare activities and legal concerns related to organ and tissue donation and transplantation. Provincial and territorial governments are accountable for the delivery of core functions related to donation and transplantation. They are responsible for the development and maintenance of policies, standards and guidelines to direct service provision and to ensure quality, safety, acceptability, equity and cost effectiveness. In addition, they have overall responsibility for the delivery of donation and transplantation programs and for ensuring compliance with policies, standards and guidelines.

A third level of accountability outlined in the report was the regional/ hospital level. The mandate at this level is the delivery of designated services to the population as a whole and to those at risk of specific health problems. This level is responsible for facilitating donation, transplantation and tissue banking in designated facilities, ensuring that those facilities are accredited, and providing the policies and support structures required to manage and coordinate these processes.

A final level of accountability was the service provider level. Service providers play a key role in the provision of health care to individual consumers. They manage their own profession's continuing education; comply with national standards, policies and guidelines in terms of donation and transplantation practices; coordinate the donation, transplantation and tissue banking processes; and deliver health care to potential donors, families and transplant recipients.



### Key findings:

- The division of powers with regard to health matters in Canada has had a major influence on the way in which the CCDT provided advice and effected change.
- The CCDT was established to provide advice to the CDM and it was hoped that system change would result.
- Linkages could be improved among the various levels of stakeholders responsible for influencing OTDT system change as a result of CCDT advice and recommendations:
  - Between the CDM and FPT governments,
  - Between the federal government and the provincial and territorial governments,
  - Among the FPT governments, health regions, and OTDT organizations, and
  - Among health regions and hospitals, professional organizations, and service providers.
- No accountability loops or feedback requirements were built into this structure to either track change or to monitor impact.

The division of powers has had a significant influence on the way the CCDT provides advice and affects change. There is room for improved feedback on the adoption and implementation of advice provided by the CCDT and for improved linkages and collaboration among the stakeholders responsible for influencing OTDT system change.

### 3.1.3 Mandate and Terms of Reference

#### *To what extent has the work of the CCDT addressed its terms of reference?*

In response to the compelling case advanced by the above-mentioned reports, the CCDT was established in October 2001 as an advisory body to the Federal/ Provincial/ Territorial Conference of Deputy Ministers of Health. It was structured as a Secretariat within Health Canada, the sole funder of the Council. Its original mandate was described as follows:

*The mandate of the Council is to provide advice to the FPT Conference of Deputy Ministers of Health in support of their efforts to coordinate FPT activities relating to organ and tissue donation and transplantation. The authority to make decisions with respect to organ and tissue donation and transplantation matters shall remain with the FPT governments.*

In order to carry out this mandate, the CCDT Terms of Reference (June 7, 2001) identified the following nine tasks:

1. Provide advice on a coordinated FPT strategy on organ and tissue donation and transplantation as well as advice on the development of high quality provincial/ territorial strategies;
2. Provide advice on, and a forum for, members to discuss opportunities for the enhancement of standards, clinical practice guidelines and best practices;
3. Provide a forum for members to discuss issues including: information sharing; provincial/ territorial initiatives related to donation and transplantation; and ethical issues related to donation and transplantation;
4. Consult with relevant health care organizations as required for the purposes of formulating advice only;
5. Recommend practice guidelines based on an assessment of best practices;



6. Provide advice on program and system linkages and interoperability with respect to: information management systems; and educational resources for interdisciplinary professionals involved in donation and transplant processes;
7. Provide advice on social marketing strategies and their implementation;
8. Monitor, for the purposes of providing advice in accordance with its mandate only, the implementation of a FPT strategy and identify areas of emergent interests; and
9. Monitor, for the purposes of providing advice in accordance with its mandate only, donation and transplant outcomes, both quantitative and qualitative, measured against international and the Canadian experience; and on the outcomes of the FPT strategy, measured against target goals established by the provinces/ territories.

#### **Key findings:**

- The CDM planned to review the Terms of Reference at the end of the five-year mandate.
- The CCDT RMAF addresses the Terms of Reference in its logic model and Evaluation Strategy and hence are addressed throughout this summative evaluation.

The achievement of the CCDT's Terms of Reference has been addressed in this summative evaluation by answering the evaluation questions outlined in the RMAF.

### **3.1.4 Organization Structure and Committees**

#### *What is the organizational structure of CCDT?*

The CCDT Council was comprised of 15 members plus a Chair, including representatives of key donation and transplantation organizations, non-governmental organizations, the ethics community, spiritual and pastoral community, transplantation recipients and donor families. The Council included Ex-Officio members and regional representatives who served as liaison between the CCDT and the government, region or organization that they represented. The Council Executive oversaw and advised on governance, communications and overarching initiatives and issues. Three Standing Committees in the areas of Donation, Transplantation, and Tissue were established to provide expert guidance on CCDT initiatives.

Following the 2003 formative evaluation report, the CCDT moved from being a Secretariat that was internal to Health Canada to an independent, federally incorporated non-profit organization fully funded by Health Canada in 2005. Staffing was expanded to include a Chief Executive Officer, a Managing Director of Initiatives, Directors of Initiatives, Corporate Services, and Finance; a Communications Manager, an Information Systems Manager, a Research Coordinator, and a Financial Administrator. The staff supports all CCDT activities including initiative project management, financial and contract administration, coordination of meeting logistics, communications, policy research evaluation. The CEO reports on a quarterly basis to the Executive Committee and Council regarding finances, operations and initiative progress and the CCDT provides an annual report to the CDM in December of each year.

#### **Key findings:**

- In 2005 the CCDT changed its organizational structure from a Secretariat within Health Canada to that of a federally incorporated non-profit organization fully funded by Health Canada.
- Governance and administrative structures and functions were clearly defined at that time
- The basic reporting structure to the CDM has remained unchanged.

The current organizational structure of the CCDT is that of a federally incorporated non-profit organization fully funded by Health Canada.



*What role do the various CCDT committees play?*

Three initiative-focused Standing Committees were established, including:

- Organ and Tissue Donation;
- Organ Transplantation; and
- Tissue Banking and Transplantation.

The role of the Committees was to scope out and provide expert guidance on initiatives, in order to bring forward standards, policies and best practices for review and ratification by the Council as the basis of advice to the CDM. Over the years, working groups have been added. One example is the Ethics Working Group, established in October of 2002. Another is the Ethno-cultural Working Group, established as a sub-group of the Donation Committee in early 2003. These have included non-Council experts to augment expertise relative to particular areas of focus.

**Key findings:**

- The role of CCDT committees is to scope out and provide expert guidance on initiatives in order to bring forward standards, policies and best practices for review and ratification by the CCDT.
- The knowledge products developed by the committees provide the basis for the advice that is then forwarded to the CDM.

The CCDT committees play an essential role in the development of the knowledge products that provide the basis for advice forwarded to the CDM.

*Is the current design of CCDT an effective way to formulate its advice about OTDT to CDM?*

In the Internet Survey, respondents were asked to rate the effectiveness of various components of the CCDT's organizational structure (both past and present) in support of mandate achievement. These results are presented in Table 3. (Also see Appendix 5 for an analysis of responses by the five subgroups.)

**Table 3. Overall ratings of the effectiveness of CCDT's organizational structure**  
(n=138)

Please rate the effectiveness of the following components of the CCDT's organizational structure in supporting its ability to achieve its mandate, namely providing the CDM with advice on issues related to organ donation and transplantation (A five-point scale has been provided where 1 = Very ineffective and 5 = Very effective):		
	n	Mean
a) Operating as a Secretariat within Health Canada.	87	3.23
b) Operating independently as a non-profit organization funded by Health Canada	103	3.81
c) Reporting to Health Canada and the CDM on work plan initiatives and recommendations	95	3.69
d) Having a central administrative office to coordinate activities and conduct policy research (e.g., reviews, environmental scans, publications, research reports, best practice guidelines, briefing notes)	112	3.85



Stakeholders rated the current organization structure of the CCDT as quite effective. The current reporting structure was also rated quite highly; while the former structure was seen to be less effective. The sub-groups had some differing views. Council Members and FPT/ Ex-Officio Members rated the former structure “*Operating as a Secretariat within Health Canada*” as significantly less effective (mean rating of 2.71)<sup>3</sup> than any of the other stakeholder groups (mean rating of 3.39)<sup>4</sup> and rated the new structure, “*Operating independently as a non-profit organization funded by Health Canada*” as more effective (mean of 3.86), suggesting a definite preference for the current structure. The Experts rated the new structure as significantly more effective (mean of 4.20) than any of the other groups (combined mean of 3.68). Council Members and FPT/ Ex-Officio Members also rated “*Having a central administrative office to coordinate activities and conduct policy research (e.g. reviews, environmental scans, publications, research reports, best practice guidelines, briefing notes)*” as significantly more effective (mean of 4.32) than the other groups (combined mean of 3.73).

The Key Informants commented that the current organizational structure was an improvement over the previous one and they praised the current leadership of the Chair and the CEO. They saw the increased staffing complement as a positive move and several hoped this staffing increase would result in increased responsiveness to OTDT issues.

#### Key findings:

- Stakeholders rated the current organization structure, as a non-profit organization funded by Health Canada with a central administrative office as very effective.
- The current reporting structure to Health Canada was rated as effective.
- The former structure as a Secretariat within Health Canada was seen less effective, particularly by Council Members and FPT/ Ex-Officio Members.

The current organization structure, as a non-profit organization funded by Health Canada with a central administrative office, is seen to be effective.

### 3.1.5 Contribution Agreement

*What impact does CCDT's contribution agreement have on its ability to achieve its objectives?*

Originally, the CCDT was a secretariat located within Health Canada, and operated on a budget of approximately \$3.8 million per year, beginning in the 2001-2002 fiscal year. Council minutes from March 7-8, 2005 noted that:

*Since its inception, it has been the intention that the CCDT would assume operations under a contribution agreement as an independent and 'arm's length' organization. A contribution agreement is a legally binding document that transfers funds from the federal government, in this case Health Canada, to local, provincial, and national organizations for the purpose of funding operations and initiatives.*

In that year, the CCDT became a federally-incorporated non-profit organization, funded by Health Canada under a contribution agreement. There has not yet been sufficient time to evaluate the impact of the CCDT's contribution agreement on its ability to achieve its objectives, particularly as the CCDT RMAF was only completed in April 2006.

<sup>3</sup> All mean scores have been calculated for results of 5-point Likert type scales where 1=Not at all and 5=A great deal.

<sup>4</sup> The difference between the means was statistically significant (P<.05) based on an independent samples t-test



#### **Key finding:**

- The contribution agreement between CCDT and Health Canada for its new organizational structure came into effect in 2005.

It is too soon to evaluate the impact of the CCDT's contribution agreement as it has only been in effect for one year.

### **3.1.6 Strategic Plans and Work Plans**

#### *How have the CCDT's strategic plans and work plans been implemented?*

A number of planning documents and work plans were reviewed as part of this evaluation. Beginning with its first meeting in October of 2001, the Council and its Standing Committees devoted significant time to development of its work plan which went through several iterations. Some components of it (for example, the Public Awareness/Social Marketing component and the Neurological Determination of Death component) were approved by the CDM at its December 2002 meeting, and the CCDT was mandated to pursue these initiatives. However, a complete work plan was not approved by the CDM until June of 2004.

On a process level, the work plans were developed collaboratively between the Standing Committees, which scoped out, scanned and defined OTDT issues, and the Council as a whole, for approval by the CDM. Over time, reporting on progress made on specific initiatives became much more systematic. An Initiative Report tool was developed by October 2004 that provided historical activity, including spending, on each initiative. This tool was updated for each Council meeting providing not only background for any new Council and/or Ex-Officio members but also a historical documentation of activities for each specific initiative.

A review of three work plans (2002-2005, 2004-2006 and 2005-2007) was conducted. It revealed that of the activities identified in the 2002-2005 work plan, only 57% were addressed to some extent; however, of the activities planned in the 2005-2007 work plan, 84% were addressed by June 2006. This suggests that the new organizational structure has facilitated the completion of planned initiatives.

#### **Key findings:**

- The CCDT prepared a number of planning documents and work plans for the period 2002-2007.
- Work plans became increasingly effective after the formative evaluation in 2003.
- By 2005-2007, the CCDT was able to address most work plan activities suggesting that its new organizational structure has facilitated initiative completion.

Over time, the CCDT has been able to address its work plans more effectively, particularly since 2005, suggesting that its new organizational structure is better able to support the completion of planned activities.

### **3.1.7 Communications**

#### *What forms of internal/external communications does CCDT use?*

At its first meeting in October 2001, Council members approved the establishment of an Intranet site, to be used as a central repository of Council documents and as an interactive tool to facilitate discussion between meetings. In the early years this web site was not used extensively, especially for internal discussion. In October 2003, the Council contracted a consultant to develop a Comprehensive



Communication Strategy for the CCDT for both internal and external communications and the final report was presented at the Council's June 2004 meeting in Toronto but it was not until after the transfer in April 2005 that the CCDT could proceed with the development of communications tools and a corporate "brand". The document review showed that extensive work has since been done in this area.

Currently, the CCDT has a bilingual web site with an extensive listing of reports including background documents that the Council has completed.

**Key findings:**

- The CCDT has developed and implemented a comprehensive strategy for both internal and external communications.
- Extensive work has been done to develop communication tools and create a corporate brand.

The CCDT has a comprehensive strategy for both internal and external communications.

### **3.1.8 Volunteers, Collaborations and Partnerships**

#### *How do volunteers support CCDT?*

The CCDT has been a stakeholder and volunteer-driven organization since it began in 2001. Even though Council members are paid honoraria, it is certain that this acknowledgement does not begin to compensate the effort that goes into this work, especially given that many Council members are medical doctors and senior administrators. Volunteers, including partners and stakeholders, have played a major role in the work that has been carried out.

The CCDT mandate included building consensus on what needed to be done in terms of OTDT policies, practices and guidelines in Canada, as a method of formulating advice to the CDM. It has done this through the organization of consensus forums, where national and international experts have been brought together for a day or more. Each forum has resulted in a report and recommendations, with a briefing note and advice to the CDM. Participants are listed in each of these reports, a practice that lends credibility to the findings and provides an important acknowledgement to the contribution of volunteers.

**Key findings:**

- Volunteers play a critical role in sitting on expert and advisory committees to address specific issues.
- Volunteers are the lifeblood of the CCDT and the multi-faceted products and activities that have been completed to date could not have been done without them.

Volunteers are essential to the work of the CCDT and the multi-faceted products and activities completed to date could not have been done without them.

#### *What types of partnerships and collaborations have been established by CCDT?*

CCDT partners and stakeholders have been involved in CCDT activities in many ways, including as representatives on initiative steering committees; through attendance at consensus forums; through other forms of stakeholder consultation; and through dissemination of information through their own organizations. A recent list of partners and stakeholders that is provided on the CCDT website shows the breadth of current collaboration with over 35 organizations represented.



In the Internet Survey, respondents were asked to rate the effectiveness of the CCDT's work with volunteer committees and multi-level stakeholders to support the achievement of its mandate. These results are presented in Table 4. (See Appendix 5 for a sub-group analysis).

**Table 4. Overall ratings of the effectiveness of the CCDT's work with volunteers and stakeholders**  
(n=138)

Please rate the effectiveness of the following components of the CCDT's organizational structure in supporting its ability to achieve its mandate, namely providing the CDM with advice on issues related to organ donation and transplantation (A five-point scale has been provided where 1 = Very ineffective and 5 = Very effective):	n	Mean
Making extensive use of volunteer committees to address specific issues	105	3.98
Working collaboratively with multi-level stakeholders	122	4.00

Overall, the stakeholders viewed the ability of the CCDT to work collaboratively with multi-level stakeholders as very effective; their view was similar regarding the use of volunteer committees to address specific issues.

**Key findings:**

- A very broad range of OTDT partners and collaborators have become involved in CCDT activities.
- Stakeholders indicated that the CCDT's collaboration with multi-level stakeholders and its extensive use of volunteer committees were effective ways of working to achieve its mandate.

A broad range of partners, collaborators and multi-level stakeholders have been involved in CCDT activities. This is seen as an effective way of achieving the CCDT's mandate.

**3.1.9 Summary—Foundational Supports and Inputs**

This section has reviewed the evaluation findings related to the administrative supports and other inputs required to develop the CCDT and support its key activities. The three background reports that influenced the establishment of the Council were reviewed and the division of powers with regard to health matters in Canada was summarized in order to clarify the context in which the CCDT operates. The CCDT's mandate and terms of reference were presented and the organizational and committee structures explained. Stakeholder effectiveness ratings of various aspects of the CCDT's organizational structure were presented. The CCDT's Contribution Agreement with Health Canada was discussed briefly. The CCDT's planning documents were also discussed and a review of work plans over time revealed increasing success on the part of the CCDT in terms of accomplishing its plans, suggesting that its new organizational structure is more effective. Information was presented regarding communication strategies employed by the CCDT. Finally, an overview was provided about the role of volunteers in the CCDT and the types of collaborations and partnerships that have been established. Examples of partners and other stakeholders were provided and stakeholder effectiveness ratings were presented regarding the CCDT's extensive use of volunteers and its collaboration with multi-level stakeholders.



## 3.2 The Implementation Process and Key Activities

This section addresses the second Process component of the evaluation program theory and DCM. It explores what it means to *provide advice*, the main function of the CCDT. An overview of key activities during the first mandate of the CCDT is provided, organized around the three developmental periods. Highlights of the work of each of the three Standing Committees are also summarized for these periods. Key evaluation questions from the DCM are provided as appropriate. The information presented in this section was largely obtained from the extensive document review that was conducted for this study.

### 3.2.1 The Advice Cycle

*How does the CCDT develop knowledge and provide the CDM with quality advice?*<sup>5</sup>

In order to understand the unique role of the CCDT, it is important to explore what it means to *provide advice* to the CDM. A model was developed to depict the steps that are involved in developing and providing advice and includes a number of stages and it is presented below. CCDT staff indicated that it takes between 18 and 24 months to complete the cycle for any one issue or topic. The steps include to:

- **Scope, scan and define issues**—During this initial phase, a specific OTDT issue is identified, usually by conducting preliminary environmental scanning and by accessing expert opinion and stakeholder input. A steering committee is established to determine the best approach to tackling the issue and terms of reference are developed for the project. These outline expert leadership, goals and objectives, processes and deliverables.
- **Conduct health policy research**—In this second phase, health policy research is conducted to clarify the issue. This may include such things as literature reviews, national and international program or practice scans, legal and ethical reviews, and surveys of the general public, health professionals and programs. A typical initiative can have between two and ten pieces of health policy research completed depending on the complexity of the issue.
- **Build consensus**—Generally, a broad spectrum of stakeholders is then invited to participate in a collaborative process that can take the form of a task group or forum. The health policy research developed in the previous phase, along with the experience and opinion of national and international experts, provides an informed basis for consensus building in order to develop recommendations on the OTDT issue in question.
- **Synthesize information**—All of the information obtained to this point is synthesized to develop final recommendations and advice.
- **Provide advice to the CDM**—The advice is reviewed and approved by Council and then forwarded to the CDM for acceptance. It is then distributed to FPT governments for consideration and implementation at the policy level.
- **Disseminate information**—Subsequently, the health policy research reports and consensus recommendations are disseminated broadly. OTDT stakeholders receive either hard or electronic copies of reports, information and reports are posted on the CCDT website, and information is compiled for presentations or journal publications.

A final step, **Monitor the implementation of advice**, was added to the CCDT's mandate in late 2004 following a request by the CDM. Currently, the required tracking and monitoring systems are under development.

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<sup>5</sup> This question is a compilation of a number of questions in the DCM. The section tries to address the topic of how knowledge and advice are produced. Details about the results of these activities are presented in the section entitled, Outputs. This question also partially responds to the following RMAF question- "*Is the advice received from the CCDT appropriate and of high quality?*" as it outlines the process to ensure development of quality advice.



### Key findings:

- The CCDT Advice Cycle was designed as a model to describe the process by which the CCDT develops knowledge and provides the CDM with quality advice.
- At the time of the evaluation, there were six key components that contributed to the development of advice. *Monitoring the implementation of advice* was added at the request of the CDM.
- It generally takes between 18 and 24 months to complete the Advice Cycle for one issue or topic.

The CCDT engages in a six-step cycle of developmental activities for each topic that is addressed. It generally takes between 18 and 24 months to complete one full cycle.

### 3.2.2 Key Activities

#### *What were the key activities of the CCDT during its first mandate?*<sup>6</sup>

There were several distinct stages to the development of the CCDT and a number of key activities were associated with each stage. These included the formative years (2001-2002 to 2003-2004); the developmental year (2004-2005); and the transition year when the CCDT transferred from Health Canada (2005-2006). The information in this section is based on an extensive document review that was conducted as part of this summative evaluation and briefly describes the CCDT's development and key activities at each stage.

#### **a) The Formative Years (2001-2002 to 2003-2004)**

Much of the Council's time during the formative years was focused on scoping issues and developing an initial Work Plan which was first presented to the CDM in May 2002. It was revised several times before being accepted in June 2004. The Council's mandate and role was frequently discussed at Council meetings; in particular, public awareness and social marketing initiatives were discussed at some length. While the Council initiated a fair amount of work on this issue, questions arose regarding whether it was within the CCDT's mandate to carry out a social marketing campaign, or whether, because of its advisory role, the funds should be allocated to Health Canada for implementation.

A number of specific issues were pursued by the three Standing Committees but because of the complexity of the topics, initiatives were often multi-phased, multi-year and, in many instances, involved multiple stakeholders. As a result, few products were completed during this period.

In early 2003, a formative evaluation of the CCDT was initiated. The final report was completed in October 2003, making 33 recommendations related to issues of governance, staffing, project management, communications and evaluation. By the end of the formative period, the Council's Work Plan had not yet been approved by the CDM and as a result, the CDM selected certain priorities from the Plan for the CCDT to address. All of them related to the topic of donation, essentially putting the work of the other committees on hold. At its December 2003 meeting, the CDM discussed the final report of the formative evaluation and requested that, the CCDT produce a two-year work plan, budget (2004-2005 to 2005-2006) and a response to the formative evaluation by April 30, 2004. (NB More information about the formative evaluation is provided in the section entitled Design—Formative Evaluation Follow-up.)

<sup>6</sup> Again, this process question summarizes a number of questions in the DCM related to implementation. The results of these activities are described in the section entitled, Outputs.



## **b) The Developmental Year (2004-2005)**

In January 2004, the CCDT Chair resigned and an Interim Chair was appointed. Much of the Council's time during 2004 was devoted to responding to the formative evaluation and developing the 2004-2005 to 2005-2006 Work Plan. It was accepted by the CDM in June 2004. Steps were taken to transfer the CCDT from Health Canada. A Transition Committee was established to determine the cost of Secretariat operations and services. It developed a detailed Transition Action Plan; solicited legal advice; and met and negotiated with Health Canada to ensure a smooth transition. Initially, the CCDT entered into an administrative cost-sharing arrangement with the Canadian Blood Service in Edmonton to share office space and various services.

## **c) The Transition Year (2005-2006)**

During this year, the CCDT became an arms-length, federally incorporated non-profit organization funded through a Contribution Agreement with Health Canada. Much of the CCDT's time was devoted to developing a new governance model including relevant by-laws, policies and nominating processes, and a new organizational structure. This major administrative change took significant time and energy in terms of hiring staff, locating office space and arranging for services previously provided in-house by Health Canada such as IT support, communications, financial management, and human resource services. The first Annual General Meeting of the CCDT was held in Halifax on September 26-27, 2005, followed by a meeting of Council Directors and Ex-Officio members/ Regional Representatives.

At the same time, in addition to continuing with the initiative work, significant effort was devoted to the dissemination of a large and growing body of knowledge and information regarding the development and enhancement of standards, clinical practice guidelines and best practices. The objective of this knowledge transfer was to promote changes in health care knowledge, practice and policy. In particular the three national consensus forums organized by the Donation Committee between April 2003 and February 2005 (Severe Brain Injury to Neurological Determination of Death (SBINDD), Medical Management to Optimize Donor Organ Potential (MEMODOP), Donation after Cardiocirculatory Death (DCD) had produced a number of important documents and during this transition year, a focus was placed on disseminating the results to both Canadian and international health practitioners.

### **Key findings:**

- During its first mandate the CCDT went through three developmental stages: the formative years (2001-2002 to 2003-2004); the developmental year (2004-2005); and the transition year (2005-2006).
- The three Standing Committees identified and pursued a number of specific issues during each of these periods by conducting activities related to these issues and developing knowledge products and advice.
- Over the five-year period, the CCDT took on a growing number of activities and challenges, and increasingly was able to produce important outputs.

Throughout the three stages of the CCDT's development in its first mandate, and increasingly over time, the three Standing Committees (as well as other initiative-based committees) conducted activities and produced knowledge products and advice for the CDM.



### 3.2.3 Summary—The Implementation Process and Key Activities

This section has provided an important overview and description of how the CCDT actually operates and what it was able to accomplish during its first mandate. The concept of *providing advice* was unpacked to reveal a cycle of activities that occur for each key topic addressed by the Council and a graphical representation of this process was presented. These activities include scoping, scanning and defining issues, conducting health policy research; building consensus through forums and other collaborative activities; synthesizing the information obtained through these preliminary activities; providing the resulting information and advice to the CDM; disseminating the information obtained in this manner to interested stakeholders in the form of reports and other publications; and (added most recently) monitoring the implementation of that advice. The key activities during the first mandate of the CCDT were summarized, providing highlights for each of the three developmental periods. Over time, the CCDT took on a growing number of tasks and challenges, and increasingly was able to produce important outputs. These outputs will be described in more detail in the following section entitled: Products and Outputs.

## 3.3 Products and Outputs

This section addresses the third Process component of the evaluation program theory and DCM. It looks at the CCDT's products and outputs, including advice to the CDM, knowledge products, and consensus recommendations. Key evaluation questions from the DCM are provided as appropriate. The information presented in this section was largely obtained from the extensive document review conducted for this study. A description of each of the key types of information produced is provided, including advice to the CDM, knowledge products, and consensus recommendations. The section concludes with a summary of outputs produced.

### 3.3.1 Advice to the CDM

#### *What recommendations has CCDT made in relation to OTDT in Canada?*<sup>7</sup>

The document review identified eight Briefing Notes that were prepared during the five-year mandate of the CCDT. Each contained advice to the CDM. Each Briefing Note resulted from a consensus forum or a consultation, both of which brought together national and international experts. More detail is provided below in Section 4.3, Consensus Forums.

The Briefing Notes included the following:

1. *Severe Brain Injury to Neurological Determination of Death (SBINDD)* (2003)
2. *Medical Management to Optimize Donor Organ Potential (MEMODOP)* (2004)
3. *Promoting Organ and Tissue Donation in Canada: A Framework and Guide for Public Awareness and Education* (2005)
4. *Assessment and Management of Immunologic Risk in Transplantation* (2005)
5. *Donation after Cardiocirculatory Death (DCD)* (2005)
6. *Diverse Communities: Perspectives on Organ and Tissue Donation and Transplantation* (2006)
7. *Canadian Highly Sensitized Patient and Living Donor Exchange Registries* (pending 2006)
8. *Enhancing Live Donation* (pending 2006).

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<sup>7</sup> This outputs question summarizes a number of questions in the DCM related to specific outputs as well as the following RMAF question- "Have reports and recommendations been developed and disseminated to improve organ and tissue donation and transplantation in Canada?"



**Key findings:**

- The CCDT produced eight Briefing Notes during the first five-year mandate of the CCDT and these constituted advice to the CDM.
- Each Briefing Note resulted from a consensus forum or a consultation, both of which brought together national and international experts.
- Each Briefing Note resulted in a number of knowledge products that were disseminated to stakeholders in the OTDT community.

Eight Briefing Notes were produced for the CDM; each resulted from a consensus forum; each produced a number of knowledge products that were disseminated to the OTDT community.

*What briefings have been prepared related to emergent issues identified by CCDT?<sup>8</sup>*

The CCDT also identified and discussed several emergent issues, often in response to a direct request for information. One such issue identified in the document review was the West Nile virus. Another emergent issue that was identified resulted in the following recommendation to the CDM:

- Recommendations to the FPT Advisory Committee on Health, to ensure that all tissues implanted in Canadian recipients meet the Canadian Safety Standards. October 6, 2002. Accepted by the CDM in December 2002 and forwarded to Health Canada.

**Key findings:**

- The CCDT responded to emerging issues as needed.
- One formal set of recommendations was prepared for an FPT Advisory Committee on tissue implants.

The CCDT responded to emerging issues as needed. One set of recommendations was prepared in response to a specific request.

### 3.3.2 Knowledge Products

*What reviews of literature and policy and legal/ ethical issues, environmental scans, surveys, datasets, tools or educational resources, articles in peer-reviewed journals, and other research reports has CCDT written and disseminated related to OTDT in Canada?<sup>9</sup>*

During its first mandate, the CCDT authored or created and published approximately 122 documents. As many of the documents served multiple functions, some knowledge products may be accounted for more than once. To facilitate an examination of the knowledge product development and dissemination process, the evaluation identified a list of representative knowledge products that were disseminated to a broad audience and were judged by CCDT staff to have had sufficient time in the field to engender a response from stakeholders. The list of these nine key reports is presented in Table 5 along with a brief description of the contents and dissemination strategy for each.

<sup>8</sup> This question is a variation of the RMAF question, "Has the CCDT been successful in identifying areas of emergent interest related to organ and tissue donation and transplantation in Canada?"

<sup>9</sup> This outputs question summarizes a number of questions in the DCM related to specific outputs as well as the following RMAF question- "Have reports and recommendations been developed and disseminated to improve organ and tissue donation and transplantation in Canada?"



**Table 5. Sample CCDT Knowledge Products**

Report Title	Contents	Dissemination Strategy
1. Planning and Budgeting Public Awareness and Education Initiatives to Promote Organ and Tissue Donation: A CCDT Planning Guide (2005)	32-page planning resource to promote organ and tissue donation keeping in mind that most Canadian donation stakeholders have limited financial resources dedicated to public awareness.	Approximately 150 hard copies distributed to Organ Procurement Organizations, Transplant Programs, Non-government Organizations and posted on CCDT website.
2. Diverse Communities' Perspectives on Organ and Tissue Donation and Transplantation: Summary Report (2005)	21-page summary report of the findings from consultations with various communities regarding their values, attitudes and beliefs about OTDT.	Approximately 100 hard copies distributed to Organ Procurement Organizations, Non-government Organizations and posted on CCDT website.
3. Severe Brain Injury to Neurological Determination of Death Forum Report and Recommendations (SBINND) (2003)	43-page report & recommendations based on background research and a consensus forum. Outlines minimum standards and a code of practice for the care of patients whose injuries result in neurological determination of death (SBINDD).	Approximately 1400 hard copies distributed (with a CD Rom included) to Forum Participants, Organ Procurement Organizations, Transplant Program, Health Professional Associations, Non-government Organizations, Critical Care Units across Canada and posted on CCDT website.
4. Medical Management to Optimize Organ Donor Potential Forum Report and Recommendations (MEMODOP) (2004)	105-page report & recommendations based on background research and a consensus forum. Outlined guidelines and recommendations for the maximization of donor organ potential from neurological determination of death and consent to donation and surgical procurement.	Approximately 1400 hard copies distributed (with a CD Rom included) to Forum Participants, Organ Procurement Organizations, Transplant Program, Health Professional Associations, Non-governmental Organizations, Critical Care Units across Canada and posted on CCDT website.
5) Donation After Cardiocirculatory Determination of Death Forum Report and Recommendations (DCD) (2005)	86-page report & recommendations based on background research and a consensus forum. Outlined proposed principles, procedures & protocols for the implementation of donation after cardiocirculatory death (DCD) within a medical, ethical and legal framework.	Approximately 700 hard copies distributed to Forum Participants, Organ Procurement Organizations, Transplant Program, Health Professional Associations, Non-governmental Organizations, Critical Care Units across Canada and posted on CCDT website.
6. Assessment and Management of Immunologic Risk in Transplantation (2005)	101-page report & recommendations based on background research and a task force of healthcare professionals. Outlines recommendations for practitioners and health care providers related to the assessment and management of immunologic risk.	Approximately 145 hard copies distributed to Forum Participants, Organ Procurement Organizations, Transplant Programs, Non-governmental Organizations and posted on CCDT website.
7. Demand for Human Allograft Tissue in Canada (2003)	97-page report based on environmental scan & interviews regarding current and predicted demand for human allograft tissue in Canada.	Distribution to survey participants, eye and tissue banks and posted on CCDT website.
8. Demand for Human Allograft Tissue in Canada: Integrating Dental Industry (2003)	77-page report based on environmental scan & interviews of dental industry user groups regarding current and predicted demand for human allograft tissue in Canada.	Distribution to survey participants, eye and tissue banks and posted on CCDT website.
9. Supply of Human Allograft Tissue in Canada- Final Report (2003)	72-page report based on key informant interviews regarding supply of human allograft tissue from Canadian tissue banks.	Distributed to interview participants, eye and tissue banks and posted on CCDT website.



#### Key findings:

- The knowledge products developed by the CCDT during its first five-year mandate included:
  - 44 research reports;
  - 42 environmental scans;
  - 33 surveys;
  - 31 reviews;
  - 10 publications; and
  - 3 tools/ resources.

A total of 122 documents, including advice to the CDM, knowledge products, and consensus recommendations have been produced by the CCDT since its inception.

### 3.3.3 Consensus Recommendations

*What non-regulatory standards, clinical practice guidelines and best practice guidelines has CCDT created related to OTDT in Canada?<sup>10</sup>*

The CCDT held a number of key consensus forums, beginning in 2003 that resulted in recommended standards, practice guidelines and best practice guidelines. Among the most notable consensus recommendations are the following:

1. *Severe Brain Injury to Neurological Determination of Death (SBINDD) Report and Recommendations (2003).*
2. *Medical Management to Optimize Donor Organ Potential (MEMODOP) Report and Recommendations (2004)*
3. *Human Leukocyte Antigen (HLA) Consensus Forum Report, Recommendations and Clinical Practice Guidelines (2005)*
4. *Donation after Cardiocirculatory Death (DCD) Report and Recommendations. Can be used as a Best Practice Guide. (2005)*
5. *Highly Sensitized Patient and Living Donor Paired Exchange Registries Task Force Report and Best Practice Guidelines (2005).*
6. *Live Donation Consensus Forum Report, Recommendations and Best Practice Guide (2006).*

The CCDT also held consultations on a number of issues, as follows:

1. *Diverse Communities: Perspectives on Organ and Tissue Donation and Transplantation, Report, Recommendations and Best Practice Guide (2005).*
2. *Faith Perspectives on Organ and Tissue Donation and Transplantation (2006)*
3. *Public Awareness/Social Marketing which resulted in a number of documents to guide best practice:*
  - *Promoting Organ and tissue Donation in Canada: Model and Options for Awareness and Education Initiatives: Report and Recommendations. August 2005.*
  - *Planning Public Awareness and Education to Promote Organ and Tissue Donation: A CCDT Planning Guide. August 2005.*
  - *Public Framework to Promote Organ and Tissue Donation in Canada. December 2005.*
  - *Briefing Note to CDM: Promoting Organ and Tissue Donation in Canada: A Framework and Guide for Public Awareness and Education.*

<sup>10</sup> This outputs question summarizes a number of questions in the DCM related to specific outputs as well as the following RMAF question- "Have reports and recommendations been developed and disseminated to improve organ and tissue donation and transplantation in Canada?"



#### Key findings:

- The non-regulatory standards, practice guidelines and best practice guidelines developed by the CCDT during its first five-year mandate included:
  - 6 Best Practice Guidelines;
  - 4 Non-regulatory Standards; and
  - 4 Clinical Practice Guidelines.
- These products were the result of a number of consensus forums and consultations that have been held since 2003.
- The information produced has been disseminated to both the CDM and to the broader OTDT community for possible adoption.

The CCDT produced a number of best practice/clinical guidelines and standards during its first mandate.

### 3.3.4 Summary—Products and Outputs

This section highlighted the CCDT's products and outputs that have resulted from the wide variety of activities associated with providing advice to the CDM. As a by-product to the development of briefs for the CDM, the various information-gathering activities conducted by the CCDT during its first mandate have resulted in many knowledge products including reviews, environmental scans, surveys, tools and resources, publications in peer-reviewed journals, and research reports. These products have been disseminated to the broader OTDT community as well as to the CDM. This section summarized the Briefing Notes produced to date, provided a list of representative CCDT knowledge products along with a description of their nature and the dissemination strategy for each, and presented a number of consensus forums and collaborative activities that resulted in a number of non-regulatory standards, clinical practice guidelines and best practice guidelines.

## 4.0 Findings- Relevance of the CCDT

This section addresses the topic of Relevance, a key component of the Health Canada RMAF. It provides feedback obtained from the Key Informants regarding two important questions. They were asked if there is still a continued need for the federal government to be involved in a coordinated approach to OTDT in Canada. As outlined in the RMAF, the summative evaluation only explored the federal government's continued involvement as they were the sole funder of the CCDT during its first mandate. Secondly, they were asked if the CCDT is the most appropriate organization to provide advice to the CDM. A final question about relevance is addressed in the section entitled, Cost Effectiveness Findings. A summary concludes the section.

### 4.1 Continuing need for federal government involvement

*Is there a continued need for the federal government's involvement in the development of a coordinated FPT strategy to improve organ and tissue donation and transplantation in Canada? (RMAF)*

The Key Informants provided a clear answer to this question and it was unequivocally, Yes, *there is a continued need for the federal government's involvement in the development of a coordinated FPT strategy to improve organ and tissue donation and transplantation in Canada.* They indicated a number of continuing roles for the federal government as follows:

- **To provide national leadership**—The Key Informants valued highly the utility of the forums that have been spearheaded by the CCDT and they have used the resulting knowledge products extensively. The common ground provided by the CCDT for this interaction allows the FPT players to come together to discuss issues of common concern on a level playing field. The presence of



the federal government provides a pan-Canadian authority that adds more legitimacy to these discussions. In their view, a national OTDT strategy requires continued federal involvement.

- **To address a national responsibility**—They saw the continued involvement of the federal government in the development of a coordinated FPT strategy for OTDT as critical, given the division of powers in Canada. This role cannot be transferred to the provinces because it transcends geographic and political boundaries. Given the variation of fiscal and health care resources, as well as population size, only a federal presence helps to ensure equitable access to consensus building activities, knowledge product development, and policy and practice recommendations.
- **To provide national funding**—They indicated unanimously that federal funding should continue to support a coordinated FPT strategy for OTDT in Canada. They saw continued federal funding as essential because individual provinces would not take on what was seen as a federal responsibility, especially due to the provinces' current high levels of commitment to ensuring standards of care. Federal involvement is an appropriate and necessary role because only the federal government was seen to be able to provide the needed resources.
- **To provide national coordination**—They indicated that coordination of OTDT has to occur at what they described as a *high level*. The federal support to the coordination of OTDT not only confers funding and legitimacy but also supports cross-jurisdictional and cross-organizational collaboration among provincial/territorial governments, OTDT and other health care organizations, professional bodies and community stakeholders. No other stakeholder would be able to ensure collaboration and reduce the possibility of redundancy or duplication of effort.
- **To provide regulatory oversight**—They shared the view that federal involvement in OTDT was essential to ensure a consistent minimum level of OTDT practice, resulting in consistent practice to maximize patient safety.

Representative comments provided by the Key Informants include:

*The Federal Government needs to continue to provide the leadership and forum for provinces/jurisdictions to come together and discuss issues of common interest to Canadians. Any province will not be in a position to provide some kind of national leadership, respecting each other's independence in health policy development, and also in terms of the logistical requirements that are currently provided by CCDT. (Council Members and FPT/ Ex Officios)*

*Only a national organization that has resources, money, leadership, and national regulatory oversight can ensure a minimum level of consistent practice of OTDT programs. (OTDT Stakeholders)*

*The difficulty, as we all know, is the provincial healthcare delivery model in Canada and the institutional variances within this model, so coordination is not an easy undertaking. Seeking out areas of common interest that transcend these boundaries is where the opportunity for coordination exists, and that is what, to my knowledge, the CCDT has been exceptionally good at. (Health Professionals/ NGOs)*

#### Key findings:

- **Federal involvement is necessary to address several unique and critical roles**—The Key Informants strongly supported the continued involvement of the federal government in



the development of a coordinated FPT strategy for OTDT:

- To provide **national leadership** and a pan-Canadian authority to the issue;
- To address a **national responsibility** that cannot be addressed by individual provinces or organizations as a result of the division of powers related to health care in Canada;
- To provide **national funding** because no individual province or organization would be able to contribute these resources;
- To provide **national coordination** at a high level in support of cross-jurisdictional and cross-organizational collaboration and reduce duplication of effort;
- To provide **regulatory oversight** to ensure a consistent minimum level of OTDT practice in order to maximize patient safety in Canada.

The Key Informants strongly supported the continued involvement of the federal government in the development of a coordinated FPT strategy to improve OTDT in Canada. In their view, no other government body or non-governmental group can fulfill this function or address this national responsibility by providing national leadership, funding, coordination and regulatory oversight.

## 4.2 Providing Advice to the CDM

*Is CCDT the most appropriate organization to provide recommendations to the CDM regarding OTDT or could this function be transferred to another organization? (RMAF)<sup>11</sup>*

Most of the Key Informants indicated that the CCDT is the most appropriate organization to provide recommendations to the CDM regarding OTDT. They gave a number of reasons for this view:

- **The CCDT has a proven track record**—Many Key Informants indicated that the CCDT has established itself as a recognized national leader on OTDT matters and has already provided the CDM with appropriate information on which to base health care decisions.
- **The CCDT is the only option to lead the development of a Canadian consensus on OTDT**—Many Key Informants indicated that the CCDT is well placed and well informed on issues, is both objective and inclusive, has a national perspective, and has developed rapport with many stakeholders. A few individuals suggested that if the CCDT were not fulfilling this function, another organization would have to be established to do the same thing. However, the view of the CCDT as the only option was not universal and some individuals commented that organizations, such as the Canadian Society of Transplantation and the Canadian Society of Nephrology, could be helpful in working with the CCDT towards shared goals.

Representative comments included:

*The organization of CCDT (i.e. involving experts, members of the public and government reps) was deliberately set up so that CCDT would have credibility with the CDM. An organization with only government representatives or with no government representatives would either a) not meet the needs of the transplant providers and community; and/ or b) not have credibility with the CDM. (Council Members and FPT/ Ex Officios)*

*The CCDT has broad expertise and is not organ-specific. There is input from ethicists, health experts, donor families, etc. (Experts)*

<sup>11</sup> This question partially responds to the following RMAF question- "Is the advice received from the CCDT appropriate and of high quality?"



#### Key findings:

- **The Key Informants indicated that the CCDT is the most appropriate organization to provide advice to the CDM.** They indicated that the CCDT is already doing a good job providing high quality advice to the CDM and a number of initiatives have already been put into practice. They wondered what benefit could result from another organization taking on this function when it is already being well handled.
- **Most Key Informants saw the CCDT as the only option for providing advice to the CDM;** however this view was not universal and several Key Informants suggested that other health professional organizations or non-governmental organizations could be providing more input as well.

The Key Informants indicated that the CCDT is the most appropriate organization to provide advice to the CDM and in fact most of them saw the CCDT as the only organization that can fulfill this role.

### 4.3 Summary—Relevance

In terms of the continued Relevance of the CCDT, Key Informants strongly endorsed the continued involvement of the federal government in the development of a coordinated FPT strategy for OTDT because of its unique position in Canada. They saw the continued need for it to provide national leadership and a pan-Canadian authority for OTDT; to address a national responsibility that cannot be addressed by individual provinces or organizations because of the division of powers in Canada; to provide national funding because no jurisdiction or organization would be able to do so; to provide national coordination at a high level to support collaboration and reduce duplication of effort; and to provide regulatory oversight to ensure a consistent minimum level of OTDT practice so that patient safety is maximized.

Further, most Key Informants saw the CCDT as the most appropriate organization to provide recommendations to the CDM because of its proven track record in providing advice that has already been adopted. Several individuals wondered what advantage there would be to starting over with another organization in this role, considering the headway that the CCDT has already made and the generally positive view currently held by a broad range of stakeholders. A few individuals suggested that other health professional organizations or non-governmental organizations could be providing more input to the advice prepared by the CCDT that is going forward to the CDM.

## 5.0 Findings- Design—Formative Evaluation Follow-up

This section addresses the topic of Design, a key component of the Health Canada RMAF that relates in particular to the follow-up of the formative evaluation conducted in 2003 by BearingPoint. A brief description of the evaluation approach and methodology used in the formative evaluation is provided along with a summary of key findings, recommendations and the subsequent action taken by the CCDT. The information provided in this section is based on the extensive document review conducted for this summative evaluation, as well as on CCDT staff verification of the organization's response to the formative evaluation's recommendations. A summary of findings concludes the section.



## 5.1 Formative Evaluation Overview

*To what extent have the issues regarding the governance, staffing, project management, communication and evaluation, as highlighted in the 2003 BearingPoint formative evaluation, been addressed by CCDT in their entirety? (RMAF)*

From the time that the CCDT was established, issues arose regarding its role and operations as an advisory body to the CDM. As a result of an inability to resolve these issues, the CDM requested that a formative evaluation be undertaken earlier than initially planned, “to provide timely, strategically focused, objective and evidence-based information on this unique FPT model to enhance organ and tissue donation rates and transplantation outcomes in Canada.” (BearingPoint LP, 2003)

The formative evaluation addressed four areas of concern to the CDM:

- **Adequacy of the CCDT design**—Strengths of the design and barriers working against its success;
- **Adequacy of the CCDT delivery**—Extent to which the CCDT undertaking has been implemented as planned;
- **Likelihood of the CCDT meeting its objectives**—evidence of progress towards the achievement of the outcomes; and
- **Performance measurement and reporting**—Tracking, monitoring and reporting mechanisms that have been put in place and the extent to which achievements on outcomes and results are being reported.

The evaluation consisted of a review of background materials and documents regarding the implementation and operation of the CCDT, as well as in-depth interviews and/ or surveys. All members of the Council, its Standing Committees, other Working Committees and the CCDT Secretariat were given an opportunity to provide feedback: 28 participated in in-depth and targeted interviews; another nine completed the in-depth survey for a total of 37 respondents out of a possible 47 participants, or a 78.7% response rate.

## 5.2 Key Findings

Findings about the **governance structure and functioning** of the CCDT included:

- CCDT mandate and relationship to the CDM were unclear and broad in scope;
- Council behaviours and actions suggested a lack of understanding of roles and responsibilities;
- Council lacked representation in some key areas;
- A disconnect in leadership style, skill set and knowledge requirements was suggested;
- Ex-Officio observer roles, participation and seniority varied widely; and
- Standing Committees actions and interaction with Council suggested a “silo” approach and lack of clarity in roles and responsibilities.

Findings about the **Secretariat structure and functioning** included:

- Divergent views were held about the Secretariat role and responsibilities;
- A disconnect in knowledge and skill sets in executing on core business processes essential to the mandate of the CCDT were suggested by Secretariat behaviours and actions;
- Multiple reporting arrangements with Health Canada added some complexities; and
- CCDT corporate presence and image was under-developed.

Findings about **other key issues** included:

- Delays were experienced in terms of the development of the FPT Accord and contribution agreement within the context of timing and appropriateness;
- An honoraria issue hindered Council proceedings; and
- A lack of formal Council orientation and ongoing development processes hindered Council start-up.



### 5.3 Recommendations and Subsequent Action

The formative evaluation resulted in 33 recommendations regarding issues of governance, staffing, project management, communications and evaluation. In summary, Recommendations 1-17 were addressed by the change in structure to a non-profit incorporated body operating at arm's length from Health Canada. Recommendations 18-33 related to changes to core business practices and policies and procedures and many systems and processes were developed to address these concerns. A detailed description of the 33 recommendations in the formative evaluation report along with the subsequent actions that CCDT took is provided in Appendix 6. In the end, there were only four recommendations that the CCDT and/or the CDM did not accept and/or address. These included:

- **Recommendation 1:** to maintain a focus on donation and tissue banking only (i.e. not transplantation). This was not implemented and it was decided that for the remainder of its first mandate the CCDT would continue to focus on addressing donation and transplantation issues related to perfusable organs (heart, kidneys, lungs, liver, whole pancreas, stomach, small intestine and bowel) and tissues (cardiovascular, skin, Islets, musculoskeletal, amnion and ocular tissues);
- **Recommendation 3:** to be structured as an unincorporated body with Terms of Reference replaced by a Memorandum of Understanding and Letter of Agreement. Health Canada did not support this approach. Instead, the CCDT became an incorporated non-profit organization and signed a Contribution Agreement with Health Canada in June 2005. Recommendations 4 and 5 also addressed these issues;
- **Recommendation 12:** to replace the Ex-Officio observers with a Government and Stakeholder Liaison Group. The CDM decided to retain the Ex-Officio group but committed to reviewing its membership in light of the CCDT request to develop advice on implementation strategies. Additional Ex-Officio members were added as an interim measure to ensure appropriate and full representation of jurisdictions and stakeholders. The idea of a Stakeholder Liaison Group was to be re-visited in the second mandate; and
- **Recommendation 16:** to replace the current Standing Committee structure with a flexible working group structure organized around initiatives. The CCDT has maintained the current committee structure but will explore this recommendation as part of its next mandate.

#### Key findings:

- **The formative evaluation provided the impetus for organizational change.**
- **The issues identified in the 2003 BearingPoint formative evaluation have all been addressed.** These include the CCDT mandate and relationship to the CDM and Health Canada, CCDT governance structure and functions, CCDT administrative structure and functions, CCDT standing committees and other committees and working groups, and other recommendations for improving the effectiveness and efficiency of the CCDT core business processes.
- **A significant body of documentation was prepared** in response to these recommendations and it has provided the foundation for good organizational practices going forward.
- **The CCDT has moved on and made significant progress since the 2003 BearingPoint formative evaluation.** The formative evaluation has fulfilled its purpose and, at this point in the development of the CCDT, should be laid to rest. The turnaround that has been achieved in a fairly short period of time is noteworthy.

The issues identified in the 2003 BearingPoint formative evaluation have been addressed and all the report's recommendations have been adopted or addressed. The CCDT has moved on and made substantial and noteworthy progress since then.



## 5.4 Summary—Design

A formative evaluation was conducted in 2003 at the request of the CDM because there were concerns about the role and operations of the CCDT. The key findings of the evaluation related to issues associated with governance structure and functioning, Secretariat structure and functioning, and other key issues. A list of 33 recommendations was produced and all but four of them were addressed in the following year. The formative evaluation provided the impetus for the changes that were subsequently made to the CCDT's organizational structure and the impact of many of them already become apparent. They are described throughout this summative evaluation report.

## 6.0 Findings- Outcomes and Successes

### 6.1 Immediate Outcomes

This section looks at immediate outcomes in three main areas: knowledge transfer, health-care practice related to OTDT, and OTDT policies and procedures (organizational level). Key evaluation questions from the DCM are highlighted as appropriate. The information presented in this section was largely obtained from the Internet Survey and from Key Informant interviews. As each topic is addressed, overall ratings from the Internet Survey are presented first followed by related open-ended comments from the survey and then by information obtained from the Key Informant interviews as appropriate. A summary of findings concludes the section.

#### 6.1.1 Knowledge Transfer

*Has CCDT been successful in generating and sharing a national body of knowledge related to OTDT in Canada? (RMAF)*

In the Internet Survey, respondents rated the achievement of the CCDT in terms of developing and sharing a national body of knowledge related to OTDT in Canada. A summary of their responses is provided in Table 6. A more detailed analysis of findings by the five sub-groups of stakeholders is provided in Appendix 5. *(Note that when survey data is reported below, the overall number of possible respondents is provided under the table title, while the actual number of respondents to any particular survey item is provided within the table along with the mean response based on the five-point rating scale.)*

**Table 6. Overall ratings regarding knowledge transfer**  
(n=138)

Please provide your opinion by rating the extent to which CCDT has achieved its designated outcomes (A five-point scale has been provided where 1 = Not at all and 5 = A great deal).		
	N	Mean
<b>Immediate Outcomes:</b>		
Has CCDT been successful in generating and sharing a national body of knowledge related to OTDT in Canada?	122	3.85

The overall mean for this item was quite high at 3.85; responses by sub-group varied from 3.92 for Experts (n=33) to 3.29 for Care Providers (n=7).

The Key Informants held very favourable views on this topic. They indicated that a body of knowledge had indeed been generated although some issues were identified regarding the lack of dissemination of the information produced. Some sample comments follow:



*I'd give a strong yes to that, I definitely see that. CCDT came about in fall of 2001, I started in March 2002, in the early days, everything seemed kind of confusing. But it really became clear—the volume of work they were doing. Every consensus forum, you could really see the building of knowledge.... There wasn't any formal meeting that brought organizations together before the CCDT.... There was no national coordination being done of groups involved in OTDT. I know that's not CCDT's job, but they have really taken on that role, in my view. Especially for the smaller provinces that don't have as many resources, we could never do the kind of background work that they've done for the consensus forums. (Council Members and FPT/Ex-Officios)*

*Extremely successful. From my understanding, the ability to finally have a national body to bring these important issues to the forefront, to get consensus across the country was sorely needed. I was not involved in OTDT before coming to [name of organization] four and a half years ago. I can appreciate what we were working through without having those national guidelines. In a business where we're constantly sharing, working with partners across the country, it makes it much more critical to have a national body that produces these types of reports. (Experts)*

*In terms of spreading it, there have been a couple articles from the CCDT that have reached out, but disseminating knowledge has been challenging. Some of their plans for the future might certainly address this. (Experts)*

#### **Key findings:**

- **A body of knowledge related to OTDT in Canada has been generated and shared.** Stakeholders rated the CCDT as being successful in generating and sharing a body of knowledge related to OTDT in Canada (mean of 3.85).
- **The CCDT is filling a gap.** Key Informants indicated that the CCDT was filling a gap that had been experienced prior to its inception in terms of both identifying issues and developing consensus on them.
- **More dissemination of the knowledge produced needs to occur.** Key Informants suggested that there was a need to disseminate the knowledge produced from these efforts more widely. Since the transfer to a non-profit status, dissemination strategies have been more actively pursued.

The CCDT has been very successful in generating and sharing a body of knowledge related to OTDT in Canada. More dissemination of knowledge products needs to occur.

*To what extent has the advice from CCDT been received/ responded to and/ or adopted by stakeholders? (RMAF)*

Survey respondents were asked if they had read any reports on a list of nine reports provided in the survey. If a respondent indicated having read a particular report, a subsequent question was asked regarding its utility. Table 7 provides a summary of their responses. (Note that in each case, the “n” represents the number of respondents who had read the report and the mean score reflects their rating of the report’s utility.)



**Table 7. CCDT Knowledge Products**  
(n=138)

Please review the following list of key reports prepared by the CCDT. If you have read a particular report, please rate its utility. (A five-point scale has been provided where 1 = Not useful at all and 5 = Very useful).		
	n	Mean
a) <i>Planning and Budgeting Public Awareness and Education Initiatives to Promote Organ and Tissue Donation: A CCDT Planning Guide (2005)</i>	66	3.45
b) <i>Diverse Communities' Perspectives on Organ and Tissue Donation and Transplantation: Summary Report (2005)</i>	61	3.62
c) <i>Severe Brain Injury to Neurological Determination of Death Forum Report and Recommendations (SBINND) (2003)</i>	91	4.47
d) <i>Medical Management to Optimize Organ Donor Potential Forum Report and Recommendations (MEMODOP) (2004)</i>	88	4.32
e) <i>Donation After Cardiocirculatory Determination of Death Forum Report and Recommendations (DCD) (2005)</i>	85	4.00
f) <i>Assessment and Management of Immunologic Risk in Transplantation (2005)</i>	64	3.92
g) <i>Demand for Human Allograft Tissue in Canada (2003)</i>	44	3.77
h) <i>Demand for Human Allograft Tissue in Canada: Integrating Dental Industry (2003)</i>	28	3.46
i) <i>Supply of Human Allograft Tissue in Canada- Final Report (2003)</i>	39	3.77

Survey results indicated that three reports prepared by the CCDT had been read by over 60% of the survey respondents and were highly rated. These are:

- *Severe Brain Injury to Neurological Determination of Death Forum Report and Recommendations (SBINND) (2003)*. Usefulness rated at 4.47; read by 65% of respondents.
- *Medical Management to Optimize Organ Donor Potential Forum Report and Recommendations (MEMODOP) (2004)*. Usefulness rated at 4.32; read by 63% of respondents.
- *Donation After Cardiocirculatory Determination of Death Forum Report and Recommendations (DCD) (2005)*. Usefulness rated at 4.00; read by 61% of respondents. The Experts rated this report significantly higher (mean of 4.50) than the combined responses of the other groups (combined mean of 3.68)<sup>12</sup>

The other six reports identified in the survey were also rated as quite useful to very useful (mean rating between 3.46 and 3.92), but were read by fewer respondents (20-47% of respondents). Two of these reports elicited significantly different responses from particular sub-groups, as follows:

- *Diverse Communities' Perspectives on Organ and Tissue Donation and Transplantation: Summary Report (2005)*. Council Members and FPT/Ex-Officios rated this report as significantly higher (mean of 4.00) than the other groups (combined mean of 3.47).
- *Demand for Human Allograft Tissue in Canada (2003)*. Council Members and FPT/ Ex-Officios rated this report as significantly higher (mean of 4.21) than the other groups (combined mean of 3.57).

After the survey respondents had rated the utility of each report read, they were asked to comment further on how that specific report had affected policy or practice for themselves and/or their organization. Over 130 comments were received and sample comments about the impact of each report follow<sup>13</sup>. Because of

<sup>12</sup> The difference between the means was statistically significant (P<.05) based on an independent samples t-test

<sup>13</sup> Note that limited feedback was received regarding reports "h" and "i" and so no comments are provided.

the differing nature of the various stakeholder groups that responded to the survey, a number of representative comments were selected to demonstrate the breadth of the perspectives obtained.

**a) Planning and Budgeting Public Awareness and Education Initiatives to Promote Organ and Tissue Donation: A CCDT Planning Guide (2005)**

*One of the most useful aspects of this guide was having the benefit of extensive market research and segmentation analysis to inform the decisions we make in our public awareness and education activities. It's also a practical hands-on resource that anyone can use, irrespective of his or her experience in communications. The comments I have heard from the field are very positive, though it is difficult to know to what extent it is being used as a template for planning and budgeting OTD awareness activities, since its use is ultimately contingent on available resources. (Health Professions & NGOs)*

**b) Diverse Communities' Perspectives on Organ and Tissue Donation and Transplantation: Summary Report (2005)**

*...this document is a good example of the challenges with dissemination and the importance of targeting all levels of the organization in dissemination. A gap we have identified through this evaluation process is the middle operational leaders. Often the organizational leaders are aware and the clinical practitioners are engaged in the various CCDT initiatives - but the middle manager who can facilitate change in practice has not been engaged. This is a challenge for both our organization as well as CCDT to address. (Health Professions & NGOs)*

**c) Severe Brain Injury to Neurological Determination of Death Forum Report and Recommendations (SBINND) (2003)**

*We provided education sessions including this information for frontline nursing staff and the information is included in our teaching for ICU medical residents. Performance of the neurological determination of death is more consistent and better understood among medical professionals. We have also changed our hospital policy according to the new guidelines. (OTDT Stakeholders)*

**d) Medical Management to Optimize Organ Donor Potential Forum Report and Recommendations (MEMODOP) (2004)**

*This forum and follow up report has resulted in less confusion and much harmony within the OPO and transplant communities. This has worked very well in our region and has resulted in optimizing the quality of the organs as well as less animosity between OPO's and transplant programs. (OTDT Stakeholders)*

**e) Donation After Cardiocirculatory Determination of Death Forum Report and Recommendations (DCD) (2005)**

*The most potentially valuable report to the field of organ donation yet produced by CCDT. Other reports have been well done, however, do not have the potential to markedly increase the number of donor organs for transplantation. Ostensibly CCDT was created to improve rates of organ donation. This report contributes directly to this agenda (as does Living Donor). (Council Members and FPT/ Ex-Officios)*



*This forum did not address nor did the report reflect the views and rights of the neurologically injured patient. This is an essential component and without it and further knowledge on the triggers for withdrawal in these patients. DCD cannot move forward. (Health Professions and NGOs)*

#### **f) Assessment and Management of Immunologic Risk in Transplantation (2005)**

*An outstanding document. This could represent a national consensus which is badly needed to deal with the highly sensitized patient. Represents a scientific framework to move toward national sharing for certain indications. (Health Professions and NGOs)*

*Very important work but revealed error in process; i.e., work that has provincial fiscal implications needs advance planning or strategies. (Council Members and FPT/ Ex-Officios)*

#### **g) Demand for Human Allograft Tissue in Canada (2003)**

*Ground breaking work. There has been no literature in the world published on the national demand for tissue. This is the first of its kind data and worthy of publication internationally. (Council Members and FPT/ Ex-Officios)*

#### **Key findings:**

- The findings are based on nine CCDT reports used as exemplars of potential knowledge transfer.
- **Stakeholders rated the utility of nine sample CCDT reports very highly:**
  - Three reports were read by over 60% of respondents and were rated as Very useful (mean ratings of 4.0-4.47);
  - Six reports were read by fewer respondents (20-47%) but were also rated as Useful to Very useful (mean rating of 3.46—3.92);
- **CCDT recommendations and guidelines have been adopted or endorsed**—Anecdotal evidence suggests that recommendations or guidelines in the nine selected reports have been adopted, endorsed, or used in a number of organizations, *DCD* (2005) was mentioned the most frequently.
- **CCDT reports have provided useful background information**—Many comments suggested that these reports provided useful background information; *SBINND* (2003) was mentioned the most frequently.
- **CCDT reports have influenced health care practice**—Two reports have had an influence on health care practice: *SBINND* (2003) and *MEMODOP* (2004) were each mentioned 10 times or more.
- **Dissemination of information produced by CCDT needs to be expanded**—A number of respondents were unaware of some of the reports.

A number of government-level policies were identified that have been developed based on information, reports and recommendations emerging from the CCDT. At the organizational level, the CCDT has contributed to improvements in OTDT policies and procedures. Future policy change is also being planned. As it takes 18 to 24 months to develop a topic to the point of dissemination, as adoption generally takes place after that, and as the CCDT has only been in operation since late 2001, early evidence of adoption is promising.



## 6.1.2 Improvements in health care practices related to OTDT

*Has the work of CCDT contributed to improvements in health care practices related to OTDT in Canada? (RMAF)*

In the Internet Survey, respondents were asked to rate the achievement of the CCDT in terms of contributing to improvements in OTDT health care practices in Canada. A summary of their responses is provided in Table 8.

**Table 8. Overall ratings regarding improved OTDT health care practice**  
(n=138)

Please provide your opinion by rating the extent to which CCDT has achieved its designated outcomes (A five-point scale has been provided where 1 = Not at all and 5 = A great deal).	n	Mean
<b>Immediate Outcomes:</b>		
Has the work of CCDT contributed to improvements in health care practices related to OTDT in Canada?	109	3.70

The overall mean for this survey item was positive at 3.70 (n=109). The sub-group responses varied from 3.90 for Experts (n=29) to 3.17 for Care Providers (n=6). Because the respondents tended to be leaders or key decision makers, limited information was obtained regarding individual practice change. Instead, more information was obtained about change at the broader organizational or governmental levels.

Key Informants were also asked to comment on this topic. As the following comment suggests, practice change is indeed occurring, and in some cases, quite rapidly:

*...These recommendations touch directly our practice in terms of organ donation. ...[We] jumped on them when they were produced ...So it does influence what we do. We didn't wait for the recommendations to come from Health Canada. We adopted them directly through the forum reports, also through medical publications, for example, in the Canadian Medical Association Journal. (OTDT Stakeholder)*

### Key findings:

- **The CCDT has made a positive contribution to OTDT practice in Canada**— Respondents rated the CCDT's contribution quite highly (mean response of 3.70);
- **Practice change is occurring**—Two reports have had an influence on health care practice (*SBINND* and *MEMODOP*). (See Key Findings in Section 6.1.1.)
- **The informal diffusion of information is affecting practice**—Anecdotal evidence suggests that information produced by the CCDT is being adopted through informal channels, sometimes quite rapidly.

The CCDT has made a positive contribution to health care practice related to OTDT in Canada. The most influential reports to date are *SBINDD* (2003) and *MEMODOP* (2004). Anecdotal evidence suggests that Individual health professionals are able to adopt recommendations quickly through informal channels.



### 6.1.3 Improvements in OTDT policies and procedures (organizational level)

*Has the work of CCDT contributed to improvements in OTDT policies and procedures within organizations in Canada? (RMAF)*

In the Internet Survey, respondents were asked to rate the achievement of the CCDT in terms of contributing to improvements in OTDT policies and procedures in Canadian organizations. A summary of their responses is provided in Table 9.

**Table 9. Overall ratings regarding improved organizational policies and procedures for OTDT**  
(n=138)

Please provide your opinion by rating the extent to which CCDT has achieved its designated outcomes (A five-point scale has been provided where 1 = Not at all and 5 = A great deal).		
	n	Mean
<b>Immediate Outcomes:</b>		
Has the work of CCDT contributed to improvements in OTDT policies and procedures within organizations in Canada?	106	3.68

The overall mean for this item on the Internet Survey was 3.68 (n=106). Responses by sub-group varied from 3.81 for Experts (n=27) to 3.17 for Care Providers (n=6). While knowledge diffusion and influence is difficult to quantify, a significant amount of anecdotal evidence was obtained in this evaluation regarding the CCDT's impact on OTDT organizations to date. This information was obtained from both the open-ended comments on the Internet Survey and from the Key Informant interviews. It is in no way comprehensive and simply reflects the experience of study participants. Sample findings by region follow:

**In Nova Scotia** (the only province where transplants are done in the Maritimes):

- Documents on tissue supply, demand and donation potential were used extensively in operational plans and long term strategic planning;
- Research on legal issues associated with tissue banking were used in organization's business planning model;
- NND recommendations were adopted at a major hospital; and
- As a result of the DCD forum, four working groups have been set up around the province to look at public awareness, education, standards and data collection/monitoring.

**In Quebec:**

- NND guidelines and a checklist have been developed and a checklist for NDD infants under one year of age is currently in process;
- A protocol based on the DCD guidelines has been developed; and
- MEMODOP recommendations will likely be adopted in the next few months.

**In Ontario:**

- SBINND recommendations have influenced operating procedures profoundly;
- MEMODOP was adopted as a standard for organ recovery and donor management;
- A number of CCDT recommendations have provided a foundation for policies and procedures in a major NGO;
- DCD recommendations have been very useful in guiding response to a recent newsworthy case;
- Standardized practices for NDD and donor management have been adopted in a major health centre and have optimized organ donations as a result; and
- Draft recommendations from the Living Donor forum have already influenced communication processes.

**In Saskatchewan:**

- CCDT documents have been foundational to the development of an Human Leukocyte Antigen lab.



#### In **Alberta**:

- Edmonton and Calgary had different guidelines for NDD; after the forum on this topic, a consistent protocol between both health regions was developed;
- MEMODOP recommendations have been used by these two regions to manage organs more consistently; and
- In Calgary, NDD and NND guidelines have been adopted and are in practice system-wide.

#### In **British Columbia**:

- NND guidelines were implemented by a major OPO; and
- An individual has been hired to work with diverse ethno-cultural communities as a result of CCDT recommendations.

Many respondents also indicated that the CCDT website is helpful in providing information as needed and has been used by individual organizations to craft public position statements and develop advocacy strategies.

#### **Key findings:**

- **The work of CCDT has contributed to improvements in OTDT policies and procedures within organizations in Canada**—Survey respondents rated the CCDT's contribution quite highly (mean of 3.68);
- **Evidence of improvements in policies and procedures in Canadian health organizations resulting from the work of the CCDT was provided**—In particular, anecdotal evidence suggests:
  - **OTDT policy change has occurred**—Specific OTDT policies and procedures at the organizational level are being developed or changed as a result of the reports and recommendations provided by the CCDT.
  - **Future OTDT policy change is planned**—CCDT reports and recommendation are being accessed as an information resource for policy changes that organizations are planning for the near future.

The work of the CCDT has contributed to OTDT policies and procedures in Canadian health organizations. Study respondents provided anecdotal evidence that OTDT policy change has occurred. Plans also exist for future policy change.

#### **6.1.4 Summary—Immediate Outcomes**

There is growing evidence to indicate that the work of the CCDT is resulting in positive changes to OTDT policies and practices in Canada. A national body of knowledge related to OTDT is being developed and this information is influencing the development of practice guidelines, health care policy and health care practice. The most influential reports to date have been the SBINDD, MEMODOP and DCD reports but others are being considered for adoption as well. Knowledge diffusion is occurring through informal channels. Key Informants suggested that more attention should be paid to dissemination strategies.

## **6.2 Intermediate Outcomes**

This section looks at intermediate outcomes including the CCDT's contribution to OTDT policies and procedures in the FPT government levels, to OTDT best practices, to policy research related to OTDT, and to coordinated and integrated activities related to OTDT at the FPT levels. Key evaluation questions from the DCM are highlighted as appropriate. A summary of findings concludes the section.



## 6.2.1 Improvements in OTDT policies and procedures (government level)

*Has the work of CCDT contributed to improvements in OTDT policies and procedures in the Federal/Provincial/Territorial government levels? (RMAF)*

In the Internet Survey, respondents were asked to rate the achievement of the CCDT in terms of the intermediate outcome of contributing to improvements in OTDT policies and procedures at various government levels. A summary of their responses is provided in Table 10.

**Table 10. Overall ratings regarding improved government policies and procedures for OTDT**  
(n=138)

Please provide your opinion by rating the extent to which CCDT has achieved its designated outcomes (A five-point scale has been provided where 1 = Not at all and 5 = A great deal).	n	Mean
Has the work of CCDT contributed to improvements in OTDT policies and procedures in the Federal/ Provincial /Territorial (F P T) government levels?	82	3.18

The overall mean for this item on the Internet Survey, while positive, was rated relatively low at 3.18 (n=82). It received the lowest rating of the four intermediate outcomes presented in the survey. Responses by sub-group varied from 3.30 for Council Members and FPT/Ex-Officios (n=20) to 2.00 for Care Providers (n=3).

CCDT knowledge products have had an impact at the government level. While knowledge diffusion and influence is difficult to quantify, some anecdotal evidence was obtained regarding the CCDT's impact in this area. The information was obtained from both the open-ended comments on the Internet Survey and from the Key Informant interviews and is in no way comprehensive. It simply reflects the experience of study participants.

At the **national level**, government staff indicated that they have used CCDT research on tissue banking to provide baseline information for the development of regulations and have used other information produced by the CCDT to identify other OTDT gaps and issues.

At the regional and provincial levels, the following impacts were recorded:

### In Atlantic Canada:

- *SBINDD* and *MEMODOP* recommendations have been adopted by the only two hospitals in the region that do transplants, and they are starting to look at implementing the *DCD* guidelines as well;
- In Nova Scotia, tissue donor numbers have tripled as a result of the work of the CCDT; a provincial audit is currently under way to assess tissue donation potential compared to actual donations in each of the health districts; and
- OTDT topics related to ethics and legal issues that have been addressed by the CCDT have influenced the development of policies and procedures.

### In Ontario:

- When the *SBINDD* report with recommendations was released, the Ministry stopped former NDD protocols and implemented these recommendations instead. Coordinators now use these guidelines when they go into hospitals;
- *DCD* recommendations have been implemented across the province;
- *MEMODOP* recommendations have been adopted across the province;
- Current Ministry initiatives are looking at HLA testing and the cost implications of implementing recommendations from *Assessment and Management of Immunologic Risk in Transplantation*; and
- CCDT materials are used routinely to prepare Ministry briefs.



**In British Columbia:**

- DCD recommendations have been implemented in ICU's.

Overall, respondents indicated that these initiatives would not have happened in a consistent and concerted way without the work of the CCDT. As one Key Informant commented:

*... a key element of [the CCDT's] success [was] the sequence of the different forums. It was judicious in its choice of topics...also the fact they were able to re-group a lot of people in the whole country, they've had a lot of recognition by the different medical associations, medical societies. This was a huge task to bring people together, to get everyone at the table, and they were able to do that...if they keep this way of working, there is nothing standing in their way to explore more topics. (OTDT Stakeholders)*

**Key findings:**

- **Survey respondents were somewhat positive about the contributions of the CCDT to OTDT policies and procedures at the FPT levels.** They did rate the achievement of this intermediate outcome lower than other intermediate outcomes although their views were still positive.
- **Anecdotal evidence of OTDT policy change at the FPT levels was provided.** A number of government-level policies were identified that have been developed based on information, reports and recommendations emerging from the CCDT:
  - **CCDT recommendations contributed to the development of tissue banking regulations at the federal level.**
  - **CCDT reports and recommendations have influenced changes to policies and procedures at the regional/provincial level.** Specific OTDT policies and procedures at the provincial or regional level (i.e., Atlantic Canada) are being developed or changed as a result of the reports and recommendations provided by the CCDT.
  - **Future OTDT policy change is planned.** CCDT reports and recommendation are being accessed as an information resource for policy changes that various provincial governments are planning in the near future.
- **Increased tissue donor rates have resulted in Nova Scotia because of policy changes that were made based on CCDT recommendations.** Anecdotal evidence indicated that tissue donor rates have increased in Nova Scotia as a result of the work of the CCDT.

While survey respondents rated this outcome as the lowest of the intermediate outcomes, their response was still somewhat positive. Anecdotal evidence of OTDT policy change at the FPT levels was provided. A number of government-level policies were identified that have been developed based on information, reports and recommendations emerging from the CCDT. In addition, future policy change was planned.

### **6.2.2 Adoption of best practices**

*To what extent have OTDT best practices developed by CCDT been adopted by stakeholders, including provinces and territories? (RMAF)*

In the Internet Survey, respondents were asked to rate the achievement of the CCDT in terms of the adoption of OTDT best practices by stakeholders (including governments). A summary of their responses is provided in Table 11.



**Table 11. Overall ratings regarding adoption of best practices**  
(n=138)

Please provide your opinion by rating the extent to which CCDT has achieved its designated outcomes (A five-point scale has been provided where 1 = Not at all and 5 = A great deal).		
	n	Mean
Have OTDT best practices developed by CCDT been adopted by stakeholders, including provinces and territories?	93	3.30

The overall mean for this item was 3.30 (n=93). Responses by sub-group varied from 3.42 for Council Members and FPT/ Ex-Officios (n=19) to 3.00 for Care Providers (n=5).

In terms of the adoption of best practices, limited information was obtained on the survey. However, in their interviews, Key Informants did provide some examples of regional influence, as the following comments suggest:

*We have adopted guidelines from the SBINDD and the MEMODOP forums. At [name of hospital], they look after all transplants in the **Maritimes** (including New Brunswick and Prince Edward Island). If there is an identified donor, they would be brought to us, they're managed in our ICU. We're kind of a unique situation. We have a Multi-Organ Transplant Team (MOTT). Newfoundland has their own team, but uses the services of our MOTT. Newfoundland is using the same guidelines. So, in effect, we can say that the guidelines from the first two forums have been adopted in Atlantic Canada (i.e., at the hospital level, not provincially—but it's the same thing since there are only two hospitals, one in each of Nova Scotia and Newfoundland that do transplants). (Health Professions and NGOs)*

*...in **Alberta** the regions are really responsible for organ and tissue donation. As an example, Capital Health (in Edmonton) was using different guidelines and procedures than the Calgary health region regarding NDD. After the forum, there was a lot of discussion, and now there is a consistent protocol used in both health regions. (Council Members and FPT/ Ex-Officios)*

*The two documents that are most referred to are the SBINDD and MEMODOP....they've had a profound impact on everything we've done. The timing was good with [name of NGO] being a relatively new organization. We were able to incorporate all the guidelines into our operating procedures so we're totally in sync and consistent with the documents that the CCDT produced. (Experts)*

**Key findings:**

- **Survey respondents were fairly positive about the adoption of best practices developed by the CCDT**—However, limited anecdotal information was provided in the survey.
- **Key informants provided examples of the regional adoption of best practices developed by the CCDT**—They indicated that the work of CCDT is indeed contributing to the adoption of best practice guidelines at both the organizational and government levels.
- **The most influential reports prepared to date by the CCDT are SBINDD, MEMODOP and DCD**—These reports have resulted in the adoption of best practices in several



regions.

- **Health professionals are choosing to adopt best practices regionally**—As best practice information is being produced by the CCDT, health professionals are getting together at the regional level and choosing to adopt the recommended approach.

OTDT Best Practices have been adopted by stakeholders to some extent. Recommendations from specific reports, including *SBINDD*, *MEMODOP* and *DCD*, have been adopted in several regions. Again, the length of time to adoption must be considered. Anecdotal evidence suggests that health care professionals are getting together to discuss and adopt best practices as they are released by the CCDT.

### 6.2.3 Increased policy research related to OTDT

*Has CCDT been successful in contributing to increased policy research related to OTDT in Canada? (RMAF)*

In the Internet Survey, respondents were asked to rate the achievement of the CCDT in terms of the intermediate outcome of contributing to increased policy research related to OTDT. A summary of their responses is provided in Table 12.

**Table 12. Overall ratings regarding increased policy research**  
(n=138)

Please provide your opinion by rating the extent to which CCDT has achieved its designated outcomes (A five-point scale has been provided where 1 = Not at all and 5 = A great deal).		
	n	Mean
c) Has CCDT been successful in contributing to increased policy research related to OTDT in Canada? (e.g., document reviews, environmental scans)	95	3.46

The overall mean for this item on the Internet Survey was fairly high at 3.46 (n=95). Responses by sub-group varied from 3.73 for Council Members and FPT/ Ex-Officios (n=22) to 3.08 for Health Professions and NGOs (n=13).

While this item was rated the highest of the topics about intermediate outcomes on the survey; Key Informants' responses were fairly diverse. A number held the view that the CCDT's knowledge products were based on sound evidence and they mentioned again specific reports produced by the CCDT that they thought were important. They cited policy development that had resulted from the CCDT's work. On the other hand, a number of respondents, particularly the OTDT stakeholders, mentioned the limitations that are placed on the CCDT regarding the conduct of policy research because of its advisory mandate. Sample comments include the following:

*What is more difficult is that organ donation doesn't have a lot of high level of evidence, medically-speaking. This limits them to some extent...we have to live with expert opinion.... this is one of principle limitations (i.e., the lack of medical research). That's one of the problems that critics of the CCDT have, that most of what's been produced is expert panel recommendations—there is not a lot of science or high level of evidence behind those recommendations. But the fact that we were able to agree at the same table on some guidelines of practice, this is great. It's good work but the level of evidence is low. Now we can start doing that policy research. (OTDT Stakeholders)*



*I think they should influence the research but not DO it themselves. CCDT is not a research body, these are people who are practitioners or bureaucrats or managers, not researchers. I would discourage them from trying to be a research body. What's more relevant is the idea that they would stimulate research or fund it or encourage it. (OTDT Stakeholders)*

*It's maybe more a summarization of the available literature than generation of new knowledge, but it's a synthesis of existing knowledge into some kind of coherent document that participants at the forums can take, can use to make sense of an issue, and can discuss and come up with the right approach to an issue (i.e., guidelines, best practices). That is what has been happening. Until then, it was all disparate pieces of information in the literature, not presented in an integrated way that could be used to develop guidelines, best practices. So whether that is considered "policy research," I don't know but it's important work that the CCDT needs to do. (OTDT Stakeholders)*

**Key findings:**

- **Survey respondents were positive in general terms about the CCDT's success in contributing to increased OTDT policy research;**
- **Knowledge products and recommendations have been influential**—All of the influential reports cited by study participants were based on a significant amount of policy research. These products are well regarded.
- **The CCDT's role in conducting research needs clarification**—Participants' views were mixed about the role of the CCDT in conducting policy research and it was felt that the term "policy research" was not well understood by some who suggested that this role should be clarified. However, it must be noted that the participants valued highly the policy research completed by the CCDT to date. (For example, see Table 7, page 33.)

Stakeholders recognize that the CCDT has produced a number of knowledge products that are based on policy research. They value this work highly. A number of Key Informants suggested that the research role of the CCDT needs further clarification.

**6.2.4 Coordinated activities related to OTDT at the FPT levels**

*Has CCDT been successful in contributing to the development of coordinated and integrated activities related to OTDT at the FPT levels? (RMAF)*

In the Internet Survey, respondents were asked to rate the achievement of the CCDT in terms of contributing to the development of coordinated and integrated activities related to OTDT at various government levels. A summary of their responses is provided in Table 13.

**Table 13. Overall ratings regarding coordinated OTDT activities at FPT levels**  
(n=138)

Please provide your opinion by rating the extent to which CCDT has achieved its designated outcomes (A five-point scale has been provided where 1 = Not at all and 5 = A great deal).	n	Mean
Has CCDT been successful in contributing to the development of coordinated activities related to OTDT at the FPT levels?	102	3.27



The overall mean for this item on the Internet Survey was somewhat positive at 3.27 (n=102). Responses by sub-group varied from 3.56 for Experts (n=27) to 3.12 for OTDT Stakeholders (n=33). However, a more detailed survey question also asked respondents to rate the success of the CCDT in terms of coordinating and integrating specific OTDT activities. Their rating of these more specific activities was much higher. A summary of their responses is provided in Table 14.

**Table 14. Overall ratings of coordination and integration activities**  
(n=138)

<b>How successful has the CCDT been in coordinating and integrating activities related to OTDT in Canada in the following areas (A five-point scale has been provided where 1 = Very unsuccessful and 5 = Very successful):</b>	<b>n</b>	<b>Mean</b>
a) Developing work plans reflective of emerging needs and interests in OTDT	117	3.80
b) Contributing to increased policy research related to OTDT (e.g., reviews, environmental scans, publications, research reports, best practice guidelines, briefing notes)	113	3.85
c) Conducting consultations and forums related to OTDT	117	4.12
d) Supporting partnerships and networks related to OTDT	108	3.59
e) Building consensus and linkages related to OTDT	112	3.86
f) Synthesizing information and preparing reports, resources and recommendations related to OTDT (e.g., reviews, environmental scans, publications, research reports, best practice guidelines, briefing notes)	116	4.10

Generally, stakeholders were very positive about the CCDT's success in coordinating and integrating OTDT activities in Canada. In particular, the forums and consultations, as well as the reports and recommendations that resulted from them, were rated highly with means of 4.12 and 4.10 respectively. While the support provided by the CCDT in terms of OTDT partnerships and linkages received the lowest rating, at 3.59 it was still considered satisfactory.

The sub-group analysis of these items revealed some interesting differences among the stakeholder groups. Council Members and FPT/ Ex-Officio Members tended to have more positive views than the other groups. Three of the items received significantly higher ratings from them compared to the other groups: *Developing work plans reflective of emerging needs and interests in OTDT* (mean of 4.26 compared to a combined mean of 3.69); *Contributing to increased policy research related to OTDT* (mean of 4.26 compared to a combined mean of 3.74); and *Conducting consultations and forums related to OTDT* (mean of 4.26 compared to a combined mean of 3.74).

On the other hand, the OTDT Stakeholders held less positive views although they were still generally positive overall. They rated three items at significantly lower ratings than other groups: *Developing work plans reflective of emerging needs and interests in OTDT* (mean of 3.54 compared to combined mean of 3.93); *Conducting consultations and forums related to OTDT* (mean of 3.81 compared to a combined mean of 4.26); and *Supporting partnerships and networks related to OTDT* (mean of 3.26 compared to a combined mean of 3.75).

All respondents were positive in their view that the CCDT should continue to play the following roles:

- Providing the CDM with advice;
- Identifying and responding to overarching issues related to OTDT in Canada;
- Conducting consensus forums on key OTDT topics;
- Communicating with stakeholders from government to grass roots levels; and



- Producing credible knowledge products.

They 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 over and over, particularly as it relates to organ donation issues, national standards, national registry systems and public awareness. The advisory mandate that CCDT currently holds was seen to provide some limitation to pan-Canadian solutions at the FPT level. 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.

Sample comments by key informants that reflect these perspectives include:

*...it should continue doing what it's been doing. It's had a significant impact on OTDT. I don't know how Canada and Ontario could actually proceed in an expeditious manner in some of these initiatives had there not been the forums...the CCDT needs to continue facilitating such forums. ... In terms of function, the mandate that they put forward to the CDM is an appropriate mandate. (Council Members and FPT/ Ex-Officios)*

*Basically, the CCDT needs to determine what their mandate truly is...it needs to be more clear-cut... Should it be strictly advisory? No, they've proven themselves to be very successful in that role. They've been surprisingly able to mobilize all experts across country. They now have credibility and experience and an ability to become more proactive...to operationalize some of the recommendations. I'm speaking as someone from a smaller province that doesn't have much in the way of resources. (Professions and NGOs)*

*Their mandate is a problem. They give advice to people who do not provide organs. They don't have any teeth. If they are not to alter behaviour, to create organized practice in Canada, then don't be surprised if you don't achieve it. It may be the best they can do but in terms of barriers that is one of them. (Health Professions and NGOs)*

*All those groups are working from their own little perspective...their own branding etc. Unless we have a national body with some operational directives, many great ideas will be halted. (Experts)*

#### Key findings:

- **Overall, respondents were fairly positive about the success of the CCDT in developing coordinated and integrated OTDT activities at the FPT levels;**
- **Specific CCDT activities were rated much higher**—*Conducting consultations and forums related to OTDT and Synthesizing information and Preparing reports, resources and recommendations related to OTDT* received very high success ratings.
- **The Council Members and FPT/ Ex-Officios tended to have the most positive views about the CCDT's success**—OTDT Stakeholders were less positive than other sub-groups.
- **All stakeholders believe that the CCDT should continue its coordination and integration function**—In particular it should continue to provide advice to the CDM, identify and respond to overarching OTDT issues, conduct consensus forums on key OTDT topics, communicate with stakeholders from government to grass roots levels and produce credible knowledge products.
- **All stakeholders stressed the continued and critical need for a coordinated national**



**OTDT strategy in Canada**—In particular, organ donation issues, national standards, national registry systems and public awareness needs should be addressed.

- **The work of the CCDT is producing positive results**—However, stakeholders stressed the need for much more work to be done in order to coordinate and integrate OTDT activities at the FPT levels.
- **The CCDT mandate of *providing advice* was seen as a limitation by many Key Informants.**

Stakeholders view the CCDT as very successful in coordinating OTDT activities in Canada. They believe that the CCDT should continue its coordination and integration function, should continue to provide advice to the CDM, identify and respond to overarching OTDT issues, conduct consensus forums on key OTDT topics, communicate with stakeholders from government to grass roots levels, and produce credible knowledge products.

### 6.2.5 Summary—Intermediate Outcomes

In terms of intermediate outcomes, Stakeholders indicated that OTDT policy change has occurred as a result of the CCDT. Specific examples were provided at the FPT government levels. Anecdotal evidence indicated that donor rates increased in Nova Scotia as a result of policy changes emerging from the work of the CCDT. Other policy changes were being planned based on information provided by the CCDT. Best practices are being adopted based on recommendations in a number of CCDT reports, particularly *SBINND*, *MEMODOP* and *DCD*. In some regions, health professionals are choosing to adopt some of the CCDT recommendations across organizations in what amounts to regional implementation. The CCDT's knowledge products and recommendations were based on a significant amount of policy research but some stakeholders suggested that the CCDT's research role needs clarification. Finally, stakeholders were very positive in their views that the CCDT should continue its coordination and integration function at the FPT levels should continue to provide advice to the CDM, identify and respond to overarching OTDT issues, conduct consensus forums on key OTDT topics, communicate with stakeholders from government to grass roots levels and produce credible knowledge products. However, while the CCDT's work is producing positive results, they stressed the continued need for a coordinated national OTDT strategy in Canada.

## 6.3 Long-term Outcomes

This section looks at long-term outcomes. Four evaluation questions in the DCM and the RMAF addressed the long-term outcomes. These included the following:

*To what extent has the CCDT influenced the increase of intended donors, donations, and organs since the inception of the program?*

*To what extent has CCDT contributed to the optimization of transplant outcomes, including access to wait lists, allocation, matching, transplant and transplant follow-up?*

*What is the evidence that the work generated by CCDT in terms of organ and tissue transplantation has contributed to improving the health of Canadians and to saving lives in Canada?*

*To what extent has the credibility and effectiveness of the OTDT system been enhanced?*



### 6.3.1 Reasons why Long-term Outcomes Were Not Measured

There were several reasons for delaying the measurement of these long-term outcomes:

- The length of time required to demonstrate change at the level of national health statistics is fairly long;
- During the first three years, the CCDT dealt with the governance, administrative, and core business issues that arose and subsequently led to the formative evaluation and the need to respond to its recommendations. This limited the CCDT's ability to address less immediate issues.
- The Advice Cycle presented in this evaluation suggests that it takes 18 to 24 months to define an issue, conduct research, build consensus, synthesize information, produce knowledge products, prepare advice for the CDM and disseminate the resulting information. As a result, many initiatives that have been begun in this mandate will actually produce results in the coming years.

Now that the CCDT has established a satisfactory infrastructure and developed processes for building consensus and developing knowledge, the next five years should focus more directly on the achievement of long-term outcomes. At that time it will be important to determine if there has been an impact on donation and transplantation rates, the health of Canadians and the credibility and effectiveness of the OTDT system.

#### Key findings:

##### **The evaluation did not explore long-term outcomes for the following reasons:**

- The time required to demonstrate change at the level of national health statistics is lengthy;
- Governance, administrative, and core business issues that were addressed following the formative evaluation limited the Council's ability to address longer-term issues;
- The advice cycle takes 18 to 24 months to produce influential knowledge products. Few initiatives have been fully completed and disseminated for adoption and many others will only affect change in the coming years.

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.

## 6.4 Overall Success

*How successful has the CCDT been in achieving its mandate during the first five-year period?*

The RMAF prepared by Health Canada posed 15 questions about program success. This summative evaluation obtained information on 11 of them (see Section 3.3, 6.1 and 6.2). It was determined to be too soon to address the remaining four questions related to long-term outcomes (see Section 6.3 above). Of the 11 questions about program success, evaluation findings were very positive for eight of the questions and, while still positive, less strong for the remaining three.

### 6.4.1 Evidence of Success

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, on-going and emergent in nature, the CCDT has contributed significantly and produced positive change with regard to the following outcomes, as identified in the above sections of this report:



- Identifying areas of emergent interest in relation to OTDT in Canada
- 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
- Contributing to increased policy research related to OTDT in Canada
- Contributing to the development of coordinated activities related to OTDT

#### 6.4.2 Evidence of Moderate Positive Change

While the extent of the impact was more limited, the CCDT also produced positive change with regard to the following outcomes, as identified in the above sections of this report:

- The receipt/response and/or adoption of CCDT advice and recommendations by provinces and territories, and by organizations and stakeholders);
- The contribution to improved OTDT policies and procedures at government levels; and
- The adoption of CCDT-developed OTDT Best Practices by stakeholders, including provinces and territories.

#### Key findings:

The CCDT has been very successful in achieving most of the outcomes stated in its mandate (excluding long-term outcomes). It has effected significant positive change in the OTDT community in Canada.

The CCDT needs to continue working with stakeholders, including provinces and territories, to enhance the adoption of best practices and the implementation of improved OTDT policies and procedures.

## 7.0 Findings- Cost Effectiveness

This section addresses the Cost Effectiveness questions of the Health Canada RMAF. It provides an analysis conducted by external health economists who reviewed the findings of this summative evaluation report, interviewed key Health Canada staff, reviewed financial documents such as the CCDT annual reports and obtained information from other sources as needed.

As with the overall summative evaluation, the cost effectiveness review was conducted within the CCDT's larger organizational context. First of all, it took into consideration the minimal length of time in which to measure the CCDT's success and effectiveness since its inception in 2001. In the realm of health system and health outcome change, five years is a relatively short period of time and the attainment of long-term outcomes is not reasonable. This is particularly important given the advisory role of the CCDT, whereby proposed system change is dependent on implementation by jurisdictions and OTDT stakeholders beyond the direct control of the Council. Secondly, the analysis recognized the unique model of the CCDT as a national advisory body to the CDM. There are very few comparable organizations in terms of mandate, roles and resources. Thirdly, it took into account not only OTDT activities prior to the CCDT's formation, but also the CCDT's evolution from a Health Canada Secretariat (October 2001-March 2005) to a federally incorporated non-profit organization (April 2005- present).



In light of these considerations, a full cost effectiveness analysis, in terms of changes in societal costs and changes in final health outcomes, would be premature. Rather, the cost-effectiveness review examined CCDT costs compared with activities/outcomes to determine its performance efficiency in the formulation of OTDT advice for the CDM.

In conducting the review, a number of definitions were required. A specific *perspective* was used to assess the cost-effectiveness of CCDT *activity* in attaining the CCDT *objective* during the prescribed *timelines*. This *perspective* was based on the fact that Health Canada is the sole funder of the CCDT. The *activity* was interpreted as the operations of the CCDT. The *objective* was determined to be an improvement in the OTDT system. Finally, the *timelines* were defined as being from 2001 when the CCDT was established to mid-2006 (present).

The review model employed four methods of comparison, as follows:

1. The CCDT activities and objectives during the evaluation period were compared with Health Canada activity prior to the establishment of the CCDT (five years prior or starting in 1996).
2. CCDT activities and objectives during the evaluation period were examined in terms of *relevance* and *performance* based on the Health Canada RMAF. Performance was further broken down into *effectiveness*, *economy*, and *efficiency*.
3. CCDT activities and objectives during the evaluation period were compared with the costs associated with the CCDT.
4. CCDT activities, objectives, outcomes and costs during the evaluation period were broadly compared against those of an alternative organization, *Australians Donate*.

A number of methods were utilized in conducting the review. These included: a review of CCDT documents, telephone interviews with Health Canada representatives, interviews with CCDT staff members, a review of *Australians Donate* documents, and personal contacts with other healthcare professionals. It is important to note, that very little information was available related to national OTDT activities prior to the establishment of the CCDT. This is not surprising given that such a lack of activity was one of the primary reasons for the establishment of the CCDT in 2001. However the three foundational documents summarized in Section 2.1 were utilized to gain an understanding of the context at that time.

Two key RMAF questions relate to the topic of cost effectiveness. The first question is as follows and is addressed in Sections 7.1 and 7.2:

*Is the current design of the CCDT an efficient way to formulate its advice about organ and tissue donation and transplantation (OTDT) for the FPT Conference of Deputy Ministers of Health (CDM)?*

The second RMAF question is as follows and is addressed in Section 7.3:

*Is there an alternative way of delivering the objectives of CCDT in a more cost-effective manner?<sup>14</sup>*

## 7.1 Pre-CCDT Comparison

The status of the organ and tissue donation and transplantation system before 2001 has been described in *Organ and Tissue Donation and Distribution in Canada: A Discussion Document* (1996), in *Organ and Tissue Donation and Transplantation: A Canadian Approach* (1999), and in *A Coordinated and Comprehensive Donation and Transplantation Strategy for Canada* (1999). These reports identified key areas within the OTDT system that required reform. The topics addressed by these reports can be summarized into ten themes (Review of Foundational Documents: Unresolved Issues: 2006), as follows:

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<sup>14</sup> The RMAF also included the question, “*Is there an alternative way to deliver this type of program?*” . given the difficulty in locating an alternative organization, the concept of alternative delivery was only explored as it relates to cost-effectiveness.



1. Safety;
2. Donation process;
3. Transplant process;
4. Information management;
5. Access;
6. Public awareness;
7. Education;
8. Research;
9. Pan-Canadian organization; and
10. Pediatric patients.

The reports provided very little information on how OTDT activities were organized, undertaken or financed in that pre-CCDT period. As a result, this component of the review focused solely on the CCDT's progress in addressing the identified OTDT themes by developing relevant advice and by collaborating with OTDT stakeholders in Canada. This analysis categorized outputs by theme and is summarized in Table 15.

**Table 15. Pre-CCDT OTDT Issues and CCDT Activities**

Pre-CCDT OTDT Issues (1996-1999)	CCDT Activities (2002-2006)
1. Safety issues: develop, monitor and evaluate safety standard for OTDT	1 set of recommendations on tissue implantations to the CDM in October 2002 and accepted December 2002 (NB. OTDT Safety is the responsibility of Health Canada. The CCDT contributes to work in this area primarily as a collaborator.)
2. Donation process: develop and incorporate outcome standards and to develop clear protocols for the identification and management of donors.	Reports, recommendations & advice to the CDM: <ul style="list-style-type: none"> <li>• SBINDD, (2003)</li> <li>• MEMODOP, (2004)</li> <li>• DCD, (2005)</li> </ul> Reports on Allograft Tissue (3) (2003) Reports on Estimates of Organ & Tissue Donor Potential (3) (2004-2006)
3. Transplantation process: develop standard for transplantation and develop guidelines for tissue banks and laboratories.	Reports, recommendations & advice to the CDM: <ul style="list-style-type: none"> <li>• Living Organ Donation (2006)</li> <li>• Human Leukocyte Antigen (HLA) (2005)</li> <li>• Assessment and Management of Immunologic Risk (2005)</li> </ul> Economic Analysis of Human Tissue Banking (2) (2003) Consensus Guidelines: <ul style="list-style-type: none"> <li>• Eligibility for Kidney Transplantation (2005)</li> </ul> Reports on: <ul style="list-style-type: none"> <li>• Surgical Bone Banking (2005)</li> <li>• Tissue Recovery (2) (2005-2006)</li> <li>• Demineralized Bone Matrix (2) (2006)</li> <li>• Tissue Banking Practices (2006)</li> </ul>



Pre-CCDT OTDT Issues (1996-1999)	CCDT Activities (2002-2006)
<p>4. Information management: establish a national database for potential donor and transplant recipients, organ placement and to track transplant outcomes.</p>	<p>Reports, recommendations &amp; advice to the CDM:</p> <ul style="list-style-type: none"> <li>• Highly Sensitized Patient and Living Donor Exchange Registries (2006)</li> </ul> <p>Reports on:</p> <ul style="list-style-type: none"> <li>• Minimal Data Set for A National Living Donor Registry (2004)</li> <li>• OTDT Information Needs (2006)</li> <li>• Donation and Transplantation Information Management Inventory (2006)</li> <li>• Feasibility study for Highly Sensitized Patient and Living Donor Exchange Registries (2006)</li> </ul> <p>Consultation Report:</p> <ul style="list-style-type: none"> <li>• National Reporting Standards on Potential Organ Donors in Canada (2005)</li> </ul>
<p>5. Access: investigate the discrepancies in access to OTDT services and cost associated with distribution across provinces and territories.</p>	<p>Reports, recommendations &amp; advice to the CDM:</p> <ul style="list-style-type: none"> <li>• Access to Organ Transplantation in Canada: Phase 1 Kidney allocation (in progress 2006)</li> </ul> <p>Reports:</p> <ul style="list-style-type: none"> <li>• Kidney Allocation in Canada (2005)</li> <li>• Barriers and Modeling Options for Human Tissue Recovery (2005)</li> </ul>
<p>6. Public Awareness: increase public awareness on OTDT</p>	<p>OTDT Public Awareness, Knowledge &amp; Attitudes activities (2003-2006):</p> <ul style="list-style-type: none"> <li>• Reports (8)</li> <li>• Surveys (1)</li> <li>• Social Marketing Frameworks &amp; Planning Guides (3)</li> <li>• Best Practice Documents (2)</li> </ul> <p>Attitudes, Beliefs and Values about OTDT:</p> <ul style="list-style-type: none"> <li>• Reports (5)</li> <li>• Diverse Communities Consultations (4)</li> </ul>
<p>7. Education: Coordinate the development of education for the professionals and public on OTDT issues.</p>	<p>Distribution of reports, presentations, and professional journal publications (ongoing) Knowledge Transfer Pilot Project (2006)</p>
<p>8. Research: research studies on transplantation, health and social issues, prevention and practice outcome.</p>	<p>All of the work of the CCDT requires the completion of extensive background research. (Ongoing)</p>
<p>9. Pan-Canadian Organization: to provide national leadership on the enhancement of OTDT.</p>	<p>Acts as national leader in organizing discussion forums for the professionals and the public, developing standards and protocols, conducting research studies and providing advices to the CDM on various OTDT issues. (Ongoing)</p> <p>Legal and ethical issues explored in most CCDT initiatives.</p> <p>Reports:</p> <ul style="list-style-type: none"> <li>• Jurisdictional Accountability Review (2003)</li> <li>• Privacy Legislation (2003)</li> <li>• Summary of OTDT in Canada (1998-2004)</li> </ul>
<p>10. Pediatric patients: to oversee the requirements of the pediatric transplant recipients.</p>	<p>Explored as part of each of the forums related to leading practices (e.g., SBINND, MEMODOP, DCD)</p>



It can be seen that the greatest number of CCDT products and activities occurred in the area of public awareness (23 products/activities) followed by access issues for OTDT services (21 products/activities). Both the transplantation process (10 products/ activities) and the donation process (9 products/activities) received a great deal of attention. It should be noted that tissue transplantation was not identified as an issue in the pre-CCDT period; however, the CCDT has completed 7 products/activities on this topic. Information management issues have also been addressed with 6 products/activities conducted in this area. With the exception of OTDT safety (which is the responsibility of Health Canada), and pediatric patients (addressed within the major forums), the other issues have become simply the way CCDT conducts its work, including education/knowledge transfer and research.

Based on the above pre-/post-analysis, it can be concluded that the CCDT has made significant progress in all areas of the organ and tissue donation and transplantation system identified by the foundational reports.

## 7.2 Analysis of Relevance and Performance

This section addresses the topics of *relevance* and *performance*. Performance is further broken down into *effectiveness*, *economy*, and *efficiency*.

### 7.2.1 Relevance

The *relevance* of CCDT's activities can be inferred from the responses to the Internet Survey that have been reported extensively in this document (see Section 4.0). As mentioned above, the three pre-CCDT reports identified a series of themes that need to be addressed in OTDT activities in Canada and the CCDT began addressing many of these in its activities and reports. According to the Internet Survey results, respondents were satisfied that many of these issues were being addressed in a relevant manner. Other issues have just begun to be addressed in CCDT research reports.

Based on the findings of this evaluation, in the view of the OTDT community, CCDT activities have been very relevant in addressing deficiencies that were identified in the pre CCDT period.

### 7.2.2 Performance

As outlined in Table 15 above, the CCDT has conducted significant activities during the period of the review. These activities are revisited in Table 16 by year. (Note that many activities have overlapping descriptors but an attempt has been made here to select only one category for each activity.)

**Table 16. Summary of CCDT Activities by Year of Operation**

Year of Operation	Advice to CDM/ Forum/ Recommendation	Report	Analysis/ Review/ Estimate	Survey	Public Awareness / Marketing Support	Data Set	Other	Total
2001-2002 (Formative year)	-	1	-	-	1	-	-	2
2002-2003 (Formative year)	1	2	-	1	-	-	-	4
2003-2004 (Formative year)	1	7	4	-	1	1	2	16
2004-2005 (Developmental year)	2	6	1	2	-	-	1	12
2005-2006 (Transition year)	4	7	6	-	1	-	1	19
<b>Total</b>	<b>8</b>	<b>23</b>	<b>11</b>	<b>3</b>	<b>3</b>	<b>1</b>	<b>4</b>	<b>53</b>

It is interesting to note the increasing number of activities/products completed by the CCDT during its first mandate, particularly in light of the organization's stage of development. It is not surprising that the number of activities/products decreased slightly in 2004-2005, the developmental year during which the CCDT was responding to the findings of the formative evaluation conducted in 2003 and producing an extensive number of internal documents.

In addition to the activities/products summarized in Table 15, it should be noted that all of the work completed by the CCDT is based on extensive background research reports and, in fact, the CCDT has produced upwards of 75 reports in the areas of transplantation, health and social issues and prevention and practice outcomes to inform various activities. As background documents, these are included in many of the other activities/products reported above. Much of the CCDT's work has had elements of knowledge transfer to health professionals and this has occurred through the distribution of reports, presentations, and professional journal publications. Legal and ethical issues have also been explored as part of most CCDT initiatives.

Further, the Internet Survey presented earlier in this document included an assessment of the usefulness of the knowledge products developed and the advice that has been provided to the CDM. On a scale of 1 (Not useful at all) to 5 (Very useful), three key reports received mean ratings of 4.0-4.47 and were read by over 60% of survey respondents; six other reports received mean ratings of 3.46-3.92 but were read by fewer respondents.

Based on the above analysis, it can be concluded that, overall, the CCDT's activity level has risen dramatically during the five years represented here. It has made significant progress in terms of its ability to address issues with an increasing level of activity on an annual basis. Further, survey respondents rated the utility of its products as Useful or Very useful. As such, the general performance of the CCDT has been very positive.

### **7.2.3 Effectiveness**

Program *effectiveness* is related to the impact that CCDT activities have on program objectives. The effectiveness of CCDT as perceived by a wide range of OTDT stakeholders was presented previously in this report (see Section 6.0). Accordingly, the CCDT has been very successful in its overall task of generating and sharing knowledge, leading to improvements made by health providers (mean of 3.75). The CCDT has been somewhat successful in changing government policies (mean of 3.18) and in coordinating provincial and federal initiatives (mean of 3.27). Stakeholders were also asked to rate the CCDT's effectiveness as a Secretariat within Health Canada (mean of 3.23) versus operating as an independent non-profit organization (mean of 3.81).

Based on these evaluation findings, it can be concluded that the CCDT has been quite effective in bringing about changes at the practitioner level but less so at effecting change at the government level. However, the time lag required for policy change must also be taken into account.

### **7.2.4 Economy**

Program *economy* is related to the increase in the program budget over the pre-CCDT period. There was no information available on how much was being spent on advisory activities by the federal government before 2001-2002. As such, while the costs of the CCDT are discussed, no comparison can be drawn to pre-CCDT costs. The annual breakdown of allocated funds and expenditures for the fiscal years from 2001-2002 to 2005-2006 is presented in Table 17.



**Table 17. CCDT Budget and Expenditure by Fiscal Year**

Budget/Year	2001/02	2002/03	2003/04	2004/05	2005/06
<b>Budget</b>	3,818,000	3,818,000	3,818,000	3,818,000	3,800,000
<b>Distribution of Funds:</b>					
• Secretariat	488,319	507,120	508,603	731,830	898,567
• Council	-	595,835	369,256	488,748	344,916
• Public Awareness	2,469,000	-	-	-	-
• Initiatives	-	503,550	897,298	1,512,206	2,556,491
• Business Planning	-	82,264	-	-	-
<b>Total Expenditure</b>	<b>2,957,319</b>	<b>1,688,770</b>	<b>1,775,157</b>	<b>2,732,784</b>	<b>3,799,974</b>
<b>Surplus</b>	860,681	2,129,230	2,042,843	1,085,216	26

Expenditures for the first four years of CCDT operation (2001-2002 through 2004-2005) were \$2.9 million, \$1.7 million, \$1.8 million, and \$2.7 million, and for the final year (2005-2006) after CCDT became an independent non-profit organization \$3.8 million.

By far the single largest cost in any given year has gone towards a public awareness campaign that was conducted in 2001-2002. Since this was the first year of CCDT operations, and only a partial one since they started in October 2001, CCDT and Health Canada as the funder, agreed to utilize the majority of the financial resources toward a national campaign which was coordinated by Health Canada.

Over this five-year period, the greatest increases in expenditures have been for initiatives and Secretariat costs to fulfill the CCDT work plans and mandate. The annual increases have corresponded consistently with increases in CCDT activities and products/activities as shown in Table 16. The decrease in Council costs over the years was the result of several factors. The number of in-person Council meetings has fluctuated over the years of operation. Particularly in 2002-2003 there were an increased number of in-person meetings to conduct strategic planning and to establish organizational processes. As well, costing practices related to Council activities were reassigned. From 2002-2003 to 2004-2005, the activities/costs of the Donation, Transplantation and Tissue Committees were assigned to Council. In 2005-2006 these same costs were assigned to Initiatives to more accurately reflect the primary work of these Committees. Initiative costs also increased significantly in 2005-2006 in conjunction with the CCDT transfer from Health Canada. As an independent organization with increased staffing capacity, the CCDT was able to effectively complete its workplan initiatives and deliverables in all areas including donation, transplantation, tissue banking and overarching. As well, there were significant increases to Secretariat operating costs associated with the CCDT's transfer related to services that were previously provided in-kind within the government i.e., office space, information technology support, accounting and payroll services, human resources.

While it is possible, in light of the deficiencies and issues identified in the three foundational reports discussed above, that advisory activities might have increased even if the function had remained in Health Canada, these figures can be considered as the upper end of program *net* costs. An analysis of program economy should tell us whether CCDT was operating with only those resources necessary to do the required tasks. The main indication that this has indeed been the case is the fact that the majority of expenses have been devoted to program activities, rather than to administrative functions. However, as the CCDT was mandated to coordinate activities, a core staff is required to conduct the tasks of management and coordination. Generally, the size of the staff would have to grow as initiatives grew and this was the case with the CCDT.

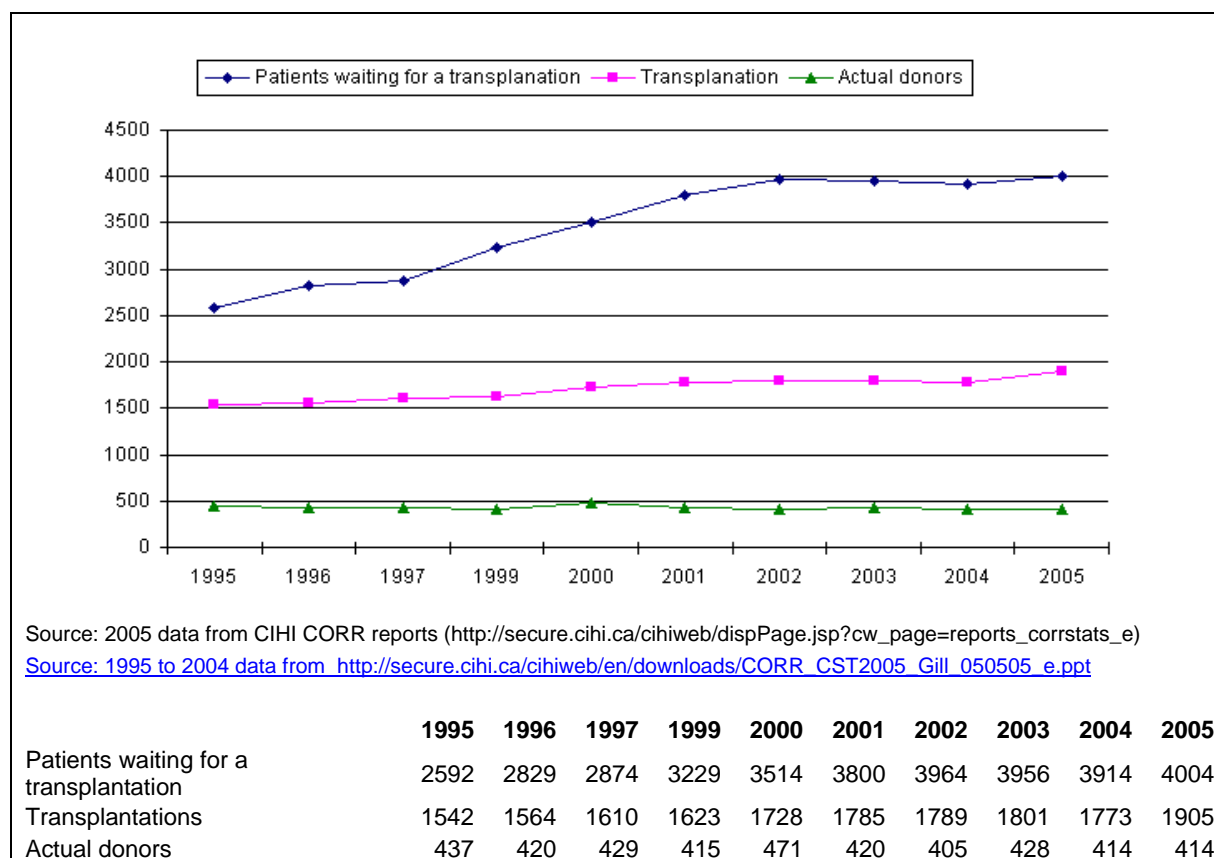
Based on this analysis and because no pre-CCDT benchmark costs were available, it can only be concluded that CCDT has been operating with moderately increasing administrative overhead while it has simultaneously generated increasing activities and products.

### 7.2.5 Efficiency

Program *efficiency* refers to value for money. As mentioned above, outcomes can be expressed in terms of improvements in process or in health outcomes. Improvements in *process* have been discussed above and throughout this evaluation report. It is the perception of OTDT stakeholders that, as a result of CCDT activities and products, considerable improvements have been achieved, especially at the level of the health care providers. All of the deficiencies that were identified in the pre-CCDT period, particularly related to the OTDT process, have been addressed to some extent or are currently being addressed. The OTDT stakeholders also recognized improvements in the policy area, but to a lesser degree.

To date, the CCDT's effect on the OTDT system in Canada has been related to immediate and intermediate outcomes. While it was not the intent of this review to assess the CCDT's effectiveness in terms of long-term outcomes, as this was deemed premature, the indicators are discussed here for information. In the long term, improvements in the OTDT system are expected to result in increases in the number of donors, the number of individuals on waiting lists, and the number of transplants. Current numbers are shown graphically in Figure 1.

**Figure 1 Trend of organ donation and transplant, Canada 1995-2005**



The number of actual donors nationwide has not increased between the pre- and post-CCDT periods. The number of transplants has increased from 1,542 in 1995 to 1,905 in 2005, but most of this increase was affected by 2002. Although the number of transplants has increased during this time; some portion of this increase was due to increases in live kidney donations.



While, for the purposes of this evaluation, the short operational time of the CCDT (five years) did not allow for the measurement of improvements in long-term outcomes, it is important to stress that these indicators should be monitored to track progress in the system in future years.

With regard to the first RMAF question on cost effectiveness as addressed in Sections 7.1 and 7.2, key findings are provided below.

*Is the current design of the CCDT an efficient way to formulate its advice about organ and tissue donation and transplantation (OTDT) for the FPT Conference of Deputy Ministers of Health (CDM)?*

**Key findings:**

- Little information was available from the pre-CCDT period about how OTDT activities were organized, undertaken or financed. Based on the number of CCDT products/activities that were completed during its first mandate in the areas of public awareness, access issues for OTDT services, the transplantation process, and the donation process, as well as in a number of other important issues related to OTDT, it can be concluded that the CCDT has made significant progress in all areas of the OTDT system as they were identified by the foundational reports (see Table 15).
- In the view of the OTDT community, CCDT activities have been very relevant in addressing deficiencies that were identified in the pre-CCDT period.
- The CCDT's activity level has risen dramatically during its five-year mandate despite the internal changes that occurred during that period.
- The CCDT has been quite effective in bringing about changes at the practitioner level, but less so at effecting change at the government level. However, the time lag required for policy change must also be taken into account.
- Related to the increase in the program budget over the pre-CCDT period, the CCDT has been operating with moderately increasing administrative overhead while it has simultaneously generated increasing activities and products.
- Referring to cost-effectiveness or value for money, the number of donations and transplants has not increased and the number of patients on the waitlists has not decreased since 2001; however, this change was not anticipated in the short term.

It can be concluded that the CCDT has been successful in managing its resources and has made significant progress in all areas of the OTDT system compared to the pre-CCDT period. 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.

## **7.3 Comparison with Australians Donate**

### **7.3.1 Comparison of Service Delivery**

An international organization, *Australians Donate*, was used as a comparison for the CCDT. *Australians Donate* (AD) is a non-profit incorporated association, overseen by a management board, appointed by the Australian Health Ministers' Advisory Council (AHMAC), and is administered by a small secretariat. They are currently funded through a three-year contractual agreement, which will be up for renewal in June 2007. The Federal Commonwealth's Department of Health and Ageing manages the contract and provides half of the funds. The other half comes from the state and territory governments and is determined on a per capita basis.

This delivery structure is very similar to that of the CCDT because AD reports to a high level of government (Australian Health Ministers' Advisory Council), is administered through a Secretariat, working in partnership and collaboration, and is funded by the federal government. However, unlike the



CCDT, AD also receives a portion of its funding from the state and territory governments. AD works toward increasing awareness and understanding about organ and tissue donation, increasing confidence in the donation system, and maximizing the rate of organ and tissue donation in Australia by doing the following:

- Working with communities and also with clinicians to improve the identification of potential donors, and developing a nationally consistent approach in these efforts;
- Improving clinical practice, primarily by providing education, training and information to health care professionals, through training programs, symposiums, and collaborative models, etc.;
- Conducting surveys with the public and with health professionals to assess attitudes and beliefs toward organ donation;
- Recommending policy changes to the Commonwealth to improve clinical practice and increase donation rates;
- Maintaining several partnership programs to raise awareness about organ donation in schools and workplaces; and
- Raising public awareness regarding organ and tissue donation by participating in Australian Organ Donor Awareness Week and the associated website.

The scope of core services of both organizations is outlined in Table 18.

**Table 18. Core Service Comparison: CCDT and Australians Donate**

Core Service	CCDT	Australians Donate
Manages transplantation waiting lists and organ allocation	Does not manage the waitlist, but works collaboratively with stakeholders in the transplant community to explore issues of allocation etc.	No
Tracks donation and transplantation outcomes	Does not track donation and transplantation outcomes, but works collaboratively with stakeholders in the OTDT community to explore issues related to data sets, performance measures, etc.	No
Develops or improves clinical protocols	Yes, related to OTDT.	Yes, related to organ and tissue donation <u>only</u>
Provides ongoing education to healthcare professionals	Yes	Yes
Provides recommendations for policy changes	Yes, related to OTDT	Yes, related to organ and tissue donation <u>only</u>
Raises public awareness and education	Yes	Yes

Based on this comparison, it can be concluded that AD has a narrower scope of core services, particularly with regard to one important component. The focus of AD is strictly on organ and tissue donation, whereas the CCDT focuses on all aspects of the organ and tissue donation *and transplantation* system.

### 7.3.2 Comparison of Budgets and Expenditures

Another point of comparison is the allocation of resources and the resulting expenditures in each organization. A brief comparison, along with the ratio of expenditures to total budget for the 2004-2007 period, is provided in Table 19. Note that AD only began operation in 2004.



**Table 19. Comparison of CCDT and Australians Donate Budget and Expenditure Ratios**

Budget Category/Year	CCDT		AD	
	Expenditure	% of Budget	Expenditure	% of Budget
<b>Core Operations/ Council:</b>				
• 2004-2005	1,220,578	45%	780,000	65%
• 2005-2006	1,243,483	33%	805,000	40%
• 2006-2007	1,054,365	28%	838,000	30%
<b>Initiatives:</b>				
• 2004-2005	1,512,206	55%	420,000	35%
• 2005-2006	2,556,491	67%	1,206,000	60%
• 2006-2007	2,745,635	72%	1,976,000	70%
<b>Total Budget:</b>				
• 2004-2005	2,732,784	100%	1,200,000	100%
• 2005-2006	3,799,974	100%	2,011,000	100%
• 2006-2007	3,800,000	100%	2,814,000	100%

Based on this analysis, it can be concluded that both organizations have consistently reduced the proportion of expenditures to total budget for core operations and Council costs while at the same time, the proportion of expenditures to total budget has increased to support initiatives. Thus in both cases, administrative costs have decreased proportionately while activity costs have increased, suggesting that as the organizations mature, they are using their resources more effectively.

With regard to the second RMAF question on cost effectiveness as addressed in Section 7.3, key findings are provided below.

*Is there an alternative way of delivering the objectives of CCDT in a more cost-effective manner?*

**Key findings:**

- When compared *Australians Donate*, a similar organization with a smaller scope and budget, resource use appeared to be comparable.
- A fuller comparison of effectiveness could not be made because AD has not yet been evaluated.

It can be concluded that compared to a similar but smaller organization with a narrower scope, *Australians Donate* (AD), 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 more cost-effective delivery model was identified.



## 7.4 Summary—Cost Effectiveness

Since its establishment, the CCDT has undergone significant transitions in terms of its legal status, operational structure and relationship to government, in particular to Health Canada as sole funder. Throughout these stages, it managed to achieve its outlined objectives. Its activities were targeted to address the issues within the OTDT system as identified in the pre-CCDT foundational documents. Specifically, it has proven itself successful in achieving goals related to knowledge transfer, OTDT health-care practice improvement, OTDT policy and procedure improvement at the organization and government level, adoption of best practice, increased OTDT policy research and enhancement of the coordination and integration of FPT OTDT activities.

The CCDT has also demonstrated that its design is an efficient way to formulate advice about OTDT for the CDM. The CCDT is cost effective in delivering on its objectives within the budget allocated from Health Canada. Any increases in expenses can be directly linked to increased activities related to OTDT system issues. Further, the impact of these activities was reported broadly in this report. Although the number of donations and transplants has not increased nor has the number of patients on the waitlists decreased since 2001, these long-term outcomes should be achieved in the longer term, if the CCDT continues to be successful in achieving its immediate and intermediate outcomes.

An attempt was made to find another similar type of organization and *Australians Donate* was used for comparison purposes. It is a newer organization than the CCDT and less information was available about it; further, no evaluation of its effectiveness has yet taken place while the CCDT has experienced two evaluations (formative and summative). The comparison did suggest, however that as these organizations mature, they become more effective at managing their administrative costs so that proportionately more resources can go to the support of mandate-related activities.

## 8.0 Discussion, Conclusions and Recommendations

### 8.1 Discussion

Overall, the results of this evaluation show that the objectives of the CCDT in its first mandate have been achieved. It was not an easy road for the new organization and the first three years were particularly difficult as internal issues and structures were being addressed. The new arm's length relationship with Health Canada and the CCDT's coming of age as an independent non-profit federally incorporated agency have been well received by the OTDT community. The results of this transition are beginning to be demonstrated as more and more projects, activities and products reach its drawing board. The CCDT has made a secure national role for itself within OTDT as a leader as well as an advisor, facilitator, and collaborator.

The evaluation findings clearly indicate that the CCDT has made a difference in the OTDT community. It has increased credibility for OTDT because of its pan-Canadian perspective, stable federal funding and cross-sectoral representation. It has fostered productive discussion and debate among the various stakeholders, not only among medical researchers and practitioners but also ethicists, legal experts, cultural representatives and donor families. It has produced a high quality body of knowledge that is credible and evidence-based.

The national issues that were identified in the foundational documents from the 1990's including unclear leadership and roles, duplication of effort, and limited availability of information regarding OTDT, highlighted the critical need for a coordinated Canadian strategy and approach to address the critical need for more organs and tissues. As our population ages, this need can only intensify. The CCDT has addressed many of these issues by providing leadership, coordination, evidence-based information and a collaborative forum for the many stakeholders to come together. It is now positioned to be effective in meeting the longer-term outcomes related to positive change in donation and transplantation rates in Canada. The Council has much to look forward to as it addresses the many challenges that remain in this



field and it can move ahead with confidence because its stakeholder community has clearly indicated the value that is placed in its work.

## 8.2 Conclusions

A detailed evidence table has been prepared which links the evaluation questions with the evidence obtained during this evaluation, the conclusions drawn and the recommendations advanced for consideration. It is presented in Appendix 7 and summarized in Table 20 below.

While the activities given to the CCDT are enormous in scope and on-going and emergent in nature, it has contributed significantly to, and produced positive change in a number of areas. Areas of particular success include:

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

In other areas, while some moderate success has been achieved to date, further development is required:

1. Having a more consistent focus on activities that will lead to the achievement of the long-term outcome of improved donation and transplantation rates;
2. Supporting the adoption of best practices through greater diffusion to health care providers and middle managers;
3. Working more closely with OTDT non-governmental organizations and health profession organizations;
4. Exploring program systems, linkages and interoperability related to information management systems;
5. Disseminating more fully the knowledge and advice that is produced; and
6. 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.**

Table 20 below provides a summary of conclusions related to the CCDT's relevance, formative evaluation, outcomes, overall success and cost effectiveness.



**Table 20. Evaluation Questions and Conclusions**

Evaluation Questions	Evaluation Conclusions
<b>Relevance of the CCDT</b>	
Is there a continued need for the federal government's involvement in the development of a coordinated FPT strategy to improve organ and tissue donation and transplantation in Canada? (RMAF)	The Key Informants strongly supported the continued involvement of the federal government in the development of a coordinated FPT strategy to improve OTDT in Canada. In their view, no other government body or non-governmental group can fulfill this function or address this national responsibility by providing national leadership, funding, coordination and regulatory oversight.
Is CCDT the most appropriate organization to provide recommendations to the CDM regarding OTDT or could this function be transferred to another organization? (RMAF)	The Key Informants indicated that the CCDT is the most appropriate organization to provide advice to the CDM and in fact most of them saw the CCDT as the only organization that can fulfill this role.
<b>Design Formative Evaluation Results</b>	
To what extent have the issues regarding the governance, staffing, project management, communication and evaluation, as highlighted in the 2003 BearingPoint formative evaluation, been addressed by CCDT in their entirety? (RMAF)	The issues identified in the 2003 BearingPoint formative evaluation have been addressed and all the report's recommendations have been adopted or addressed. The CCDT has moved on and made substantial and noteworthy progress since then.
<b>OUTCOMES: Immediate Outcomes</b>	
Has CCDT been successful in generating and sharing a national body of knowledge related to OTDT in Canada? (RMAF)	The CCDT has been very successful in generating and sharing a body of knowledge related to OTDT in Canada. More dissemination of knowledge products needs to occur.
To what extent has the advice from CCDT been received/ responded to and/ or adopted by stakeholders? (RMAF)	A number of government-level policies were identified that have been developed based on information, reports and recommendations emerging from the CCDT. At the organizational level, the CCDT has contributed to improvements in OTDT policies and procedures. Future policy change is also being planned. As it takes 18 to 24 months to develop a topic to the point of dissemination, as adoption generally takes place after that, and as the CCDT has only been in operation since late 2001, early evidence of adoption is promising.
Has the work of CCDT contributed to improvements in health care practices related to OTDT in Canada? (RMAF)	The CCDT has made a positive contribution to health care practice related to OTDT in Canada. The most influential reports to date are SBINDD (2003) and MEMODOP (2004). Anecdotal evidence suggests that Individual health professionals are able to adopt recommendations quickly through informal channels.



Evaluation Questions	Evaluation Conclusions
Has the work of the CCDT contributed to improved organ and tissue donation and transplantation policies and procedures within organizations and jurisdictions in Canada? (RMAF)	The work of the CCDT has contributed to OTDT policies and procedures in Canadian health organizations. Study respondents provided anecdotal evidence that OTDT policy change has occurred. Plans also exist for future policy change.
<b>OUTCOMES: Intermediate Outcomes</b>	
Has the work of CCDT contributed to improvements in OTDT policies and procedures in the Federal/ Provincial/ Territorial government levels? (RMAF)	While survey respondents rated this outcome as the lowest of the intermediate outcomes, their response was still somewhat positive. Anecdotal evidence of OTDT policy change at the FPT levels was provided. A number of government-level policies were identified that have been developed based on information, reports and recommendations emerging from the CCDT. In addition, future policy change is planned.
To what extent have OTDT best practices developed by CCDT been adopted by stakeholders, including provinces and territories? (RMAF)	OTDT Best Practices have been adopted by stakeholders to some extent. Recommendations from specific reports, including <i>SBINDD</i> , <i>MEMODOP</i> and <i>DCD</i> , have been adopted in several regions. Again, the length of time to adoption must be considered. Anecdotal evidence suggests that health care professionals are getting together to discuss and adopt best practices as they are released by the CCDT.
Has CCDT been successful in contributing to increased policy research related to OTDT in Canada?	Stakeholders recognize that the CCDT has produced a number of briefs, knowledge products and consensus recommendations that are based on policy research and they value this work highly. A few Key Informants suggested that the research role of the CCDT needs further clarification and it was felt that the term "policy research" was not well understood by them.
Has CCDT been successful in contributing to the development of coordinated and integrated activities related to OTDT at the FPT levels? (RMAF)	Stakeholders view the CCDT as very successful in coordinating OTDT activities in Canada. They believe that the CCDT should continue its coordination and integration function, should continue to provide advice to the CDM, identify and respond to overarching OTDT issues, conduct consensus forums on key OTDT topics, communicate with stakeholders from government to grass roots levels, and produce credible knowledge products.
<b>OUTCOMES: Long-term Outcomes</b>	
To what extent has the CCDT influenced the increase of intended donors, donations, and organs since the inception of the program?	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.
To what extent has CCDT contributed to the optimization of transplant outcomes, including access to wait lists, allocation, matching, transplant and transplant follow-up?	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.
What is the evidence that the work generated by CCDT in terms of organ and tissue transplantation has contributed to improving the health of Canadians and to saving lives in Canada?	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.



Evaluation Questions	Evaluation Conclusions
To what extent has the credibility and effectiveness of the OTDT system been enhanced?	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.
<b>Overall Success</b>	
How successful has the CCDT been in achieving its mandate during the first five-year period?	<p>Evaluation findings were very positive with regard to 8 of the 15 evaluation questions as follows:</p> <ul style="list-style-type: none"> <li>• Identifying areas of emergent interest in OTDT</li> <li>• Developing and disseminating reports and recommendations to improve OTDT in Canada</li> <li>• Providing appropriate and high quality advice for stakeholders</li> <li>• Generating and sharing a national body of knowledge related to OTDT in Canada</li> <li>• Contributing to improved health care practices related to OTDT in Canada</li> <li>• Contributing to improved OTDT policies and procedures in organizations and jurisdictions in Canada</li> <li>• Contributing to increased policy research related to OTDT in Canada</li> <li>• Contributing to the development of coordinated activities related to OTDT</li> </ul> <p>With regard to 3 other questions, the CCDT produced positive change; however the extent of the impact was more limited:</p> <ul style="list-style-type: none"> <li>• The advice from CCDT has been received/ responded to and/or adopted (e.g., by provinces and territories, organizations and stakeholders)</li> <li>• The work of the CCDT has contributed to improved OTDT policies and procedures at government levels</li> <li>• The OTDT Best Practices developed by CCDT have been adopted by stakeholders, including provinces and territories.</li> </ul> <p>The remaining 4 questions related to long-term outcomes and it was determined to be too soon after the initial five-year period to anticipate positive change in OTDT rates on a national scale.</p> <p>The CCDT has been very successful in achieving most of the outcomes stated in its mandate (excluding long-term outcomes). It has effected significant positive change in the OTDT community in Canada.</p> <p>The CCDT needs to continue working with stakeholders, including provinces and territories, to enhance the adoption of best practices and the implementation of improved OTDT policies and procedures.</p>
<b>Cost Effectiveness</b>	
Is the current design of the CCDT an efficient and effective way to formulate its advice about OTDT to CDM?	<ul style="list-style-type: none"> <li>• 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. 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.</li> </ul>



Evaluation Questions	Evaluation Conclusions
<p>Is there an alternative way of delivering the objectives of CCDT in a more cost-effective manner?</p>	<ul style="list-style-type: none"> <li>• Compared to a similar but smaller organization with a narrower scope, <i>Australians Donate (AD)</i>, 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 more cost-effective delivery model was identified.</li> </ul>



### 8.3 Recommendations

Based on the findings of this evaluation, the following recommendations are advanced for consideration:

#### **Recommendation 1. 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.

#### **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 profession organizations and health care practitioners more directly into the collaborative approach to system change.

#### **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.



#### **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.

#### **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 and 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.

#### **Recommendation 6. Performance Measurement and Evaluation**

*In order to obtain evidence that the work of the CCDT has had an impact on its identified goal 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 refining and implementing on-going performance measurement and evaluation strategies to continually measure CCDT outcomes.



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