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# Treatment of End-Stage Organ Failure in Canada 1997 to 2006

2008 Annual Report

Canadian Organ Replacement Register



Canadian Institute  
for Health Information

Institut canadien  
d'information sur la santé

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**2008 Annual Report—  
Treatment of End-Stage Organ Failure in Canada, 1997 to 2006**

**Table of Contents**

Acknowledgements .....	iii
Executive Summary .....	v
1 Introduction .....	1
1.1 Data Sources .....	1
1.2 Data Quality.....	2
1.3 Organization of the Report .....	3
2 Renal Replacement Therapy for End-Stage Renal Disease .....	5
2.1 Incident ESRD RRT Patients .....	5
2.1.1 Activity .....	5
2.1.2 Patient and Treatment Characteristics.....	6
2.2 Prevalent ESRD RRT Patients.....	9
2.2.1 Activity .....	9
2.2.2 Patient and Treatment Characteristics.....	10
2.3 Outcomes of Dialysis Treatment in Canada .....	16
2.4 Kidney Transplantation: Adult Recipients .....	16
2.4.1 Activity .....	17
2.4.2 Recipient Characteristics.....	19
2.5 Kidney Transplantation: Pediatric Recipients .....	21
3 Liver Transplantation.....	25
4 Heart Transplantation .....	29
5 Lung Transplantation.....	33
6 Pancreas Transplantation .....	37
7 Intestinal Transplantation.....	39
There's More on the Web! .....	41

## **Appendices**

Appendix A—Canadian Organ Replacement Register (CORR) Board of Directors and Members of the Advisory Committee.....	43
Appendix B—Canadian Transplant Hospitals, Canadian Hospitals and Independent Health Facilities Providing Dialysis to Chronic Renal Failure Patients as Reported to CORR.....	45
Appendix C—Canadian Organ Procurement Organizations .....	51
Appendix D—CORR Data Quality Documentation: 1997 to 2006 .....	53
Appendix E—Glossary and Commonly Used Acronyms .....	67
Appendix F—Analytical Methods .....	71
Appendix G—Treatment of End-Stage Organ Failure in Canada, 1997 to 2006: Outcomes, Clinical Indicators and International Comparisons .....	77

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*Treatment of End-Stage Organ Failure in Canada, 1997 to 2006* was developed at CIHI by the following:

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## Executive Summary

*Treatment of End-Stage Organ Failure in Canada, 1997 to 2006* draws on data from CIHI's Canadian Organ Replacement Register (CORR) for the years 1997 through 2006. The report examines dialysis, transplantation and organ-donation characteristics and trends in Canada during that period.

The information presented is of relevance to a wide array of stakeholders. Individuals interested in the policy, clinical and service-management components of the health care system as they pertain to end-stage organ failure will find the report to be of interest, as will individuals and groups generally interested in end-stage organ failure in Canada.

Overall, there were 2,087 transplants of solid organs performed in Canada in 2006. This includes kidney, liver, lung, heart, and pancreas transplants.

There were an estimated 33,832 people with end-stage renal disease (ESRD) in Canada at the end of 2006, an increase of 69.7% since 1997. Of these, 20,465 were on dialysis and 13,367 were living with a functioning kidney transplant. There were 5,321 ESRD patients who initiated renal replacement treatment (RRT) in 2006, representing an increase of 1.0% over the previous year. Of these, 165 received pre-emptive transplant,<sup>i</sup> which is becoming an increasingly important treatment option in Canada, although the proportion of new patients receiving this treatment remains low. Diabetes continues to be the predominant cause of ESRD in Canada, identified in 34.4% of new cases in 2006, followed by renal vascular disease (19.5%). However, while diabetes is the most frequent cause of ESRD, it remains the least common in kidney transplant. The aging of the Canadian population is reflected in the demographic profile of new ESRD patients, with 53.3% of those who initiated RRT age 65 or older. The demographic changes in ESRD patients will necessitate the development of tailored strategies for support of aging patients receiving treatment.

Liver transplantation has undergone tremendous innovation in technique as well as pre- and post-surgical care that have vaulted it to the forefront as the treatment of choice for end-stage liver disease in Canada. With these innovations there was a 16.7% increase in the number of pediatric transplants performed between 1997 and 2006, and a 35.0% increase in the number of adult transplants. There were 466 liver transplants performed in Canada in 2006. With liver transplant as the gold-standard treatment and in parallel with the increasing numbers of procedures, there are increasing numbers of patients waiting to receive a liver transplant, with a 214% increase in the number waiting over the 10 years (from 42 in 1997 to 129 in 2006).

The number of heart transplants performed in Canada continued to grow, with a 9% increase over the years between 1997 and 2006. Overall, 1,575 Canadians received a first heart transplant in this time frame, and 58 were retransplanted. On average, there were 163 heart transplants performed each year in Canada between 1997 and 2006. In 2006, there were 87 Canadians waiting for a heart transplant, with 13 deaths on the waiting list that year.

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i. Renal transplant performed immediately at diagnosis of end-stage renal failure, with no time on dialysis.

End-stage lung disease treated by lung transplant in Canada increased by 84% for adult Canadians between 1997 and 2006. Increasingly, bilateral lung transplants are being utilized and accounted for 75% of the lung transplants performed in Canada in 2006, a number that more than doubled since 1997. When bilateral procedures are performed, they are most likely to be in recipients with cystic fibrosis as the cause of disease (31.4%). When a single lung transplant is undertaken in Canada, the most frequent diagnosis of the recipient is emphysema (50%). In 2006, there were 251 Canadians waiting to receive a lung transplant, up from 119 in 1997 (111% increase).

Transplantation for pancreatic disease was first performed in 1996 in the United States and has evolved since then to become a well-recognized treatment for pancreatic disease. There were 603 pancreatic transplants performed in Canada between 1997 and 2006, two-thirds of which were simultaneous pancreas–kidney transplants. The number of Canadians waiting for a simultaneous pancreas–kidney transplant peaked in 2001 (172) and dipped to 113 in 2006. Over the decade, the number of individuals waiting for a single pancreas transplant went from 8 to 63 per year, reflecting the emergence of pancreatic transplant as a viable procedure.

Small intestine transplantation is an emerging and evolving field with the potential to improve the outcomes of children and adults with intestinal failure in Canada. Between 1988 and 2006, there were 45 such procedures performed in Canada, with 53% of recipients younger than 18 years of age.

End-stage organ failure presents complex issues and challenges for Canadian clinicians, the health care system and patients. Treatment options continue to evolve and organ-donation practices and processes are being examined to optimize outcomes. It is only through the ongoing and systematic collection of data that sound information can be produced. It is the intent of this report to provide such information in an effort to improve the health of Canadians with end-stage organ failure.



# 1 Introduction

The Canadian Organ Replacement Register (CORR) is a pan-Canadian information system for renal and extra-renal organ failure and transplantation in Canada, with a mandate to record and analyze the level of activity and outcomes of solid organ transplantation and renal dialysis activities. In various forms, there has been a Canadian register of renal failure statistics since the early 1970s.

The first renal failure registry in Canada was started in 1972 under the leadership of Dr. Arthur Shimizu. In 1973, the registry was transferred to Statistics Canada, with the collaboration of The Kidney Foundation of Canada. Its first report was produced in 1974. In the mid-1970s, the Canadian Renal Failure Register, as it was then called, developed more detailed annual reports of dialysis and kidney transplantation activity. The operation of the project faltered briefly in the late 1970s, but was revived in 1980 under a new partnership formed among The Kidney Foundation of Canada, Health Canada and Statistics Canada, with guidance from the Canadian Society of Nephrology.

In 1987, with the support of the Federal/Provincial Advisory Committee on Institutional and Medical Services (ACIMS), the register was expanded to include data on extra-renal organ transplants. The expanded register was originally maintained by the Hospital Medical Records Institute (HMRI). In 1995, responsibility for CORR transferred to the Canadian Institute for Health Information (CIHI), which maintains numerous health-system-related pan-Canadian data holdings.

The current mission of CORR is to provide pan-Canadian information on vital organ replacement therapy in Canada, with the goal of enhancing treatment, research and patient care. The CORR board of directors is responsible for providing strategic advice to the Register. (For a membership list of the board of directors as of May 1, 2008, please see Appendix A.)

## 1.1 Data Sources

CORR collects data from hospital dialysis programs, regional transplant programs, organ-procurement organizations (OPOs) and kidney dialysis services offered at independent health facilities. (For a list of the hospitals and facilities with transplant and dialysis activity reporting to CORR, please refer to Appendix B.) CORR receives data on standardized paper forms or spreadsheets. Currently, all data are entered at CIHI by specially trained staff. Data within the database are collected and reported on a calendar-year basis (January 1 to December 31), as is the practice in other international registries reporting on end-stage organ failure, therefore allowing international comparative reporting.

Patients are tracked from their first treatment for end-stage organ failure (dialysis or transplantation) to their death, unless they become lost to follow-up. Only treatments provided in Canada are included in this report. For the purposes of recording continuity of care, however, CORR does capture out-of-country transfers when informed by reporting facilities. Information on organ donors is linked to recipient information. At the present time, CORR does not collect patient-level information on those who have been listed for transplant but do not receive a transplant.

## 1.2 Data Quality

Data quality is ongoing within CORR, including the annual completion of the CIHI Data Quality Framework and the subsequent production of a data quality report that can be found in Appendix D.

There are no known coverage errors within CORR. The program is aware of all hospitals that should report. Hospitals not included in the frame do not report to CORR. While completeness of key data elements has improved over time, the proportions of unknown values reported for primary diagnosis, cause of death and cause of graft failure continue to exceed 10% in many cases. Users should consider this when interpreting trends.

At present, CORR does not receive individual patient data on those wait-listed for transplant. Aggregate counts of patients waiting for solid organ transplants are provided on a quarterly basis by 8 of 10 reporting OPOs. The OPOs that contribute wait-list counts are the British Columbia Transplant Society, H.O.P.E. Calgary, H.O.P.E. Edmonton, the Saskatchewan Transplant Program (Saskatoon and Regina), the Transplant Manitoba Program—Gift of Life Program, the Trillium Gift of Life Network (Ontario), Québec-Transplant and the Nova Scotia Multi-Organ Transplant Program (for the Atlantic region). A complete list of OPOs is provided in Appendix C.

In Canada, deceased organ donors are defined as donors from whom at least one organ was recovered and transplanted. This definition is more conservative than that used by the United Network of Organ Sharing (UNOS), which includes donors whose organs were recovered, but not transplanted. This is an important distinction to consider when making comparisons of deceased donor rates between countries.

It is important to note that all data presented in this report are subject to change based on future data submissions or corrections. Analytical conventions used in this report may vary from previously published reports. Discrepancies from previously published reports may reflect database updates and/or differences in analytical approaches.

Please see Appendix D—CORR Data Quality Documentation: 1997 to 2006, for further detail regarding the completeness and coverage of reporting in CORR.

## 1.3 Organization of the Report

This report summarizes information on end-stage organ failure treatments in Canada. Chapters 2 to 7 report on the following:

- Renal replacement therapy for ESRD patients (dialysis and renal transplant);
- Liver transplantation;
- Heart transplantation;
- Lung transplantation;
- Pancreas transplantation; and
- Intestinal transplantation.

Appendix A provides a list of the CORR board of directors.

Appendix B provides information on the Canadian transplant programs, including what solid organ transplants they perform, and the listing of Canadian hospitals and independent health care facilities that provide dialysis treatment in Canada.

The organ-procurement organizations (OPOs) that provide organ donation statistics to CORR are listed in Appendix C.

The CORR data quality documentation for the years 1996 to 2007 is outlined in Appendix D.

A glossary of the terms used in this report is provided in Appendix E.

Analytical methods used in this report, as well as population figures used for Canada and other countries, are provided in Appendix F.

In addition to this annual summary report, more information and data tables are available online at [www.cihi.ca/corr](http://www.cihi.ca/corr), in the form of special reports (analyses in brief) and semi-annual reports from the OPOs called *E-Statistics on Organ Transplants, Waiting Lists and Donors*. A list of tables and figures available on the website is found in Appendix G. The website also features PowerPoint presentations with summary data.

If you have questions about this report or would like further information, please email CORR at [corr@cihi.ca](mailto:corr@cihi.ca).



## 2 Renal Replacement Therapy for End-Stage Renal Disease

This section presents information, including trends about newly diagnosed (incident) end-stage renal disease (ESRD) patients, and the total number of patients being treated for ESRD in Canada at a given point in time. Renal replacement therapy (RRT) encompasses those being treated for kidney failure with dialysis or with functioning transplants. The section also presents ESRD patient characteristics, including age at initiation of treatment and at certain points in time, most responsible diagnoses for renal failure and causes of death. The intent of the information is to support the various programs providing care to ESRD patients in Canada and to help inform decision-making at clinical, facility and policy levels.

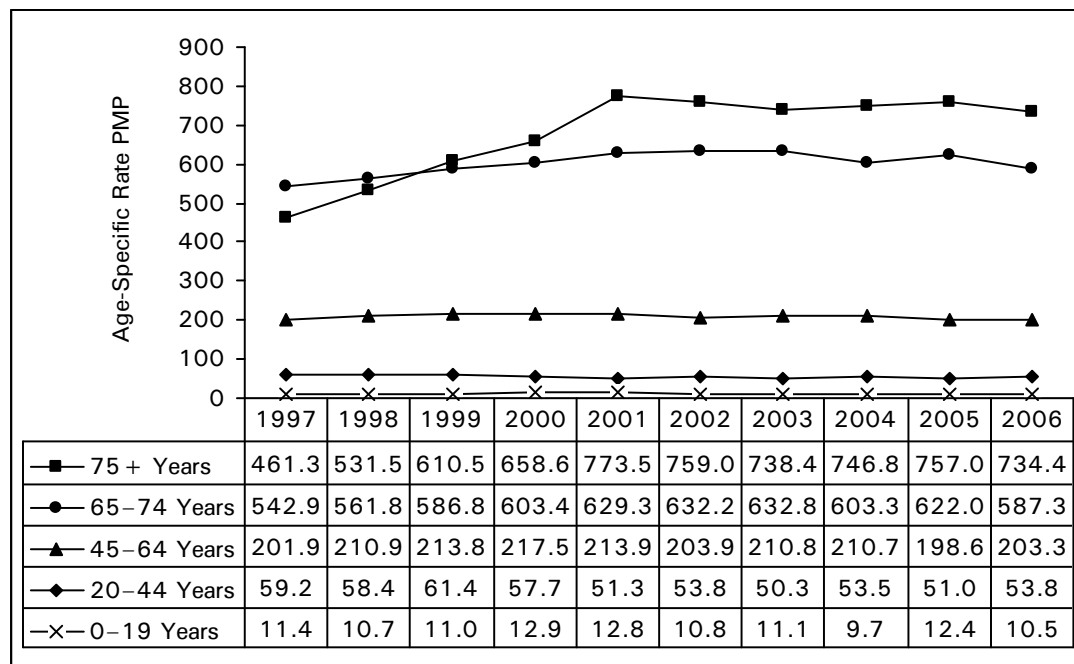
### 2.1 Incident ESRD RRT Patients

An *incident patient* refers to a new case within the population with a defined disease that requires some treatment; in this case, ESRD. Incidence is usually presented as rate per million population (RPMP) so that there is an understanding of the relative proportion of people in the population who are newly diagnosed. The trends in ESRD incident patients in Canada are presented by age groups over time in the following figures and tables.

#### 2.1.1 Activity

There were 5,321 newly diagnosed patients with ESRD in 2006, an increase of 34% in the number of cases since 1997 (3,958). The highest RPMP of newly diagnosed ESRD is in those age 75 and older, beginning in 1999 and continuing through 2006 (Figure 1). This age group also had the biggest rate increase over time. Those aged 44 years and younger saw a slight decline in the rate of new diagnoses of ESRD over the ten years.

**Figure 1 Incident ESRD Patients, Age-Specific RPMP, Canada, 1997 to 2006**



## 2.1.2 Patient and Treatment Characteristics

The patient and treatment characteristics of newly diagnosed patients with ESRD in Canada have changed over time. At the end of 2006, the largest proportion of all new patients initiated treatment on hemodialysis<sup>ii</sup> (HD) (82.1%), up from 74% in 1997. Over time, the number of pre-emptive kidney transplants performed for newly diagnosed patients increased by 92%, from 86 in 1997 to 165 in 2006.

While Figure 1 shows that those age 75 and older had the highest rate of ESRD diagnosis, the largest number of new patients was seen in the group of patients age 45 to 64 (Table 1). As Table 2 shows, HD was consistently utilized as the primary modality of treatment throughout the decade, while the number of new patients receiving peritoneal dialysis<sup>iii</sup> (PD) as an initial treatment remained fairly consistent through the time period. The use of pre-emptive transplants increased consistently over time, nearly doubling. When dialysis was used to treat incident patients in 2006, all provinces used HD the majority of time, with New Brunswick having the highest proportion of HD (90.9%) followed by Newfoundland (89.6%). The highest proportion of PD use was seen in British Columbia (17.0%) (Table 3).

Diabetes continued to be the most frequently reported primary cause of ESRD in Canada (Figure 2).

**Table 1** Distribution of Incident ESRD RRT Patients by Age Group, Canada, 1997 to 2006 (Number, Percent)

Age Group		Year									
		1997	1998	1999	2000	2001	2002	2003	2004	2005	2006
0–19 Years	N	91	86	88	103	102	86	88	76	97	82
	%	2.3	2	1.9	2.2	2	1.7	1.7	1.5	1.8	1.5
20–44 Years	N	695	684	718	674	601	632	591	629	601	634
	%	17.6	16.2	15.8	14.2	12	12.5	11.5	12.1	11.4	11.9
45–64 Years	N	1,314	1,415	1,482	1,559	1,585	1,565	1,673	1,726	1,678	1,771
	%	33.2	33.5	32.6	32.8	31.6	31.1	32.7	33.2	31.9	33.3
65–74 Years	N	1,145	1,195	1,253	1,295	1,360	1,375	1,386	1,335	1,391	1,335
	%	28.9	28.3	27.5	27.2	27.1	27.3	27.1	25.6	26.4	25.1
75+ Years	N	713	849	1,008	1,124	1,363	1,380	1,385	1,440	1,500	1,499
	%	18	20.1	22.2	23.6	27.2	27.4	27	27.7	28.5	28.2
<b>Total</b>	<b>N</b>	<b>3,958</b>	<b>4,229</b>	<b>4,549</b>	<b>4,755</b>	<b>5,011</b>	<b>5,038</b>	<b>5,123</b>	<b>5,206</b>	<b>5,267</b>	<b>5,321</b>

- ii. Hemodialysis works by circulating the blood through special filters outside the body. The blood flows across a filter, along with solutions that help remove toxins. This form of dialysis must be performed in a health care facility.
- iii. Peritoneal dialysis filters waste using the peritoneal membrane inside the abdomen. The abdomen is filled with special solutions that help remove toxins. The solutions remain in the abdomen for a time and are then drained out. This form of dialysis can be performed at home.

**Table 2 Incident ESRD RRT Patients by Year, Age Group and Initial Treatment Modality, Canada, 1997 to 2006 (Number)**

Age Group	Initial Modality*	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006
		N = 3,958	N = 4,229	N = 4,549	N = 4,755	N = 5,011	N = 5,038	N = 5,123	N = 5,206	N = 5,267	N = 5,321
0–19 Years	HD	52	40	37	46	45	36	40	34	44	56
	PD	28	33	36	34	40	24	29	28	31	14
	Pre-empt	11	13	15	23	17	26	19	14	22	12
20–44 Years	HD	487	462	472	444	401	440	425	419	425	440
	PD	163	176	180	171	133	147	123	155	134	143
	Pre-empt	45	46	66	59	67	45	43	55	42	51
45–64 Years	HD	948	1,058	1,119	1,153	1,180	1,198	1,274	1,285	1,219	1,318
	PD	325	322	321	356	359	326	343	391	367	367
	Pre-empt	41	35	42	50	46	41	56	50	92	86
65–74 Years	HD	919	935	995	1,052	1,118	1,140	1,151	1,112	1,133	1,095
	PD	221	257	253	240	232	232	229	211	249	226
	Pre-empt	5	3	5	3	10	3	6	12	9	14
75+ Years	HD	585	719	828	966	1,162	1,205	1,227	1,243	1,305	1,324
	PD	128	130	180	158	201	175	158	196	195	173
	Pre-empt	0	0	0	0	0	0	0	1	0	2
Total	HD	2,991	3,214	3,451	3,661	3,906	4,019	4,117	4,093	4,126	4,233
	PD	948	918	970	959	965	904	882	981	976	923
	Pre-empt	86	97	128	135	140	115	124	132	165	165

**Note**

\* HD = hemodialysis; PD = peritoneal dialysis; Pre-empt = pre-emptive kidney transplant.

**Table 3 Incident Patients on Dialysis, by Type of Treatment and Province of Treatment, Canada, 2006 (Number, Percent)**

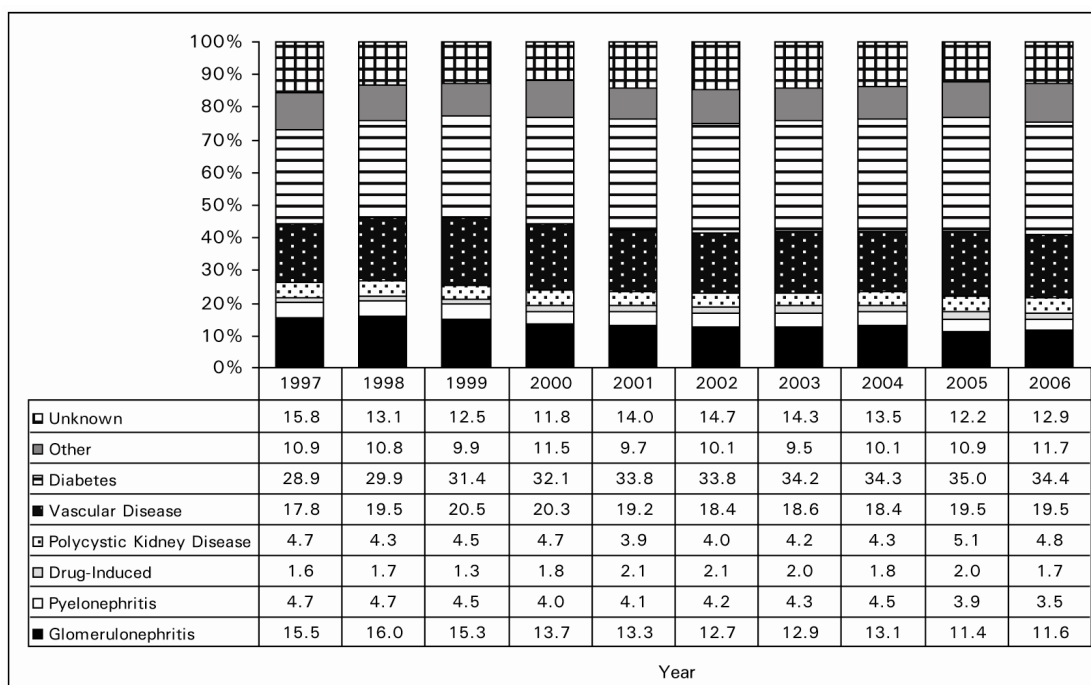
Type of Treatment		Province of Treatment									Canada
		B.C.	Alta.	Sask.	Man.	Ont.	Que.	N.B.	N.S.	N.L.	
HD	N	512	383	155	244	1,776	858	120	116	69	4,233
	%	77.1	81.8	85.6	85.0	79.5	88.0	90.9	83.5	89.6	82.1
CAPD <sup>*</sup>	N	113	68	24	26	275	109	12	21	8	656
	%	17.0	14.5	13.3	9.1	12.3	11.2	9.1	15.1	10.4	12.7
APD <sup>†</sup>	N	39	17	2	17	182	8	0	2	0	267
	%	5.9	3.6	1.1	5.9	8.2	0.8	0.0	1.4	0.0	5.2
<b>Total</b>	<b>N</b>	<b>664</b>	<b>468</b>	<b>181</b>	<b>287</b>	<b>2,233</b>	<b>975</b>	<b>132</b>	<b>139</b>	<b>77</b>	<b>5,156</b>

**Notes**

\* CAPD = continuous ambulatory peritoneal dialysis

† APD = automated peritoneal dialysis

**Figure 2 Distribution of Incident ESRD RRT Patients by Primary Diagnosis Category, Canada, 1997 to 2006 (Percentage)**





## 2.2 Prevalent ESRD RRT Patients

*Prevalence*, by definition, is the number of people or proportion of people in the entire population who are found with a defined disease at a specified point in time; in this case, ESRD. Prevalence is usually presented as RPMP so that there is an understanding of the relative proportion of people in the population living with the cited disease. In CORR, prevalence is measured as of December 31 each year. As treatments and outcomes improve for patients, it is anticipated that the prevalent number and rate will increase.

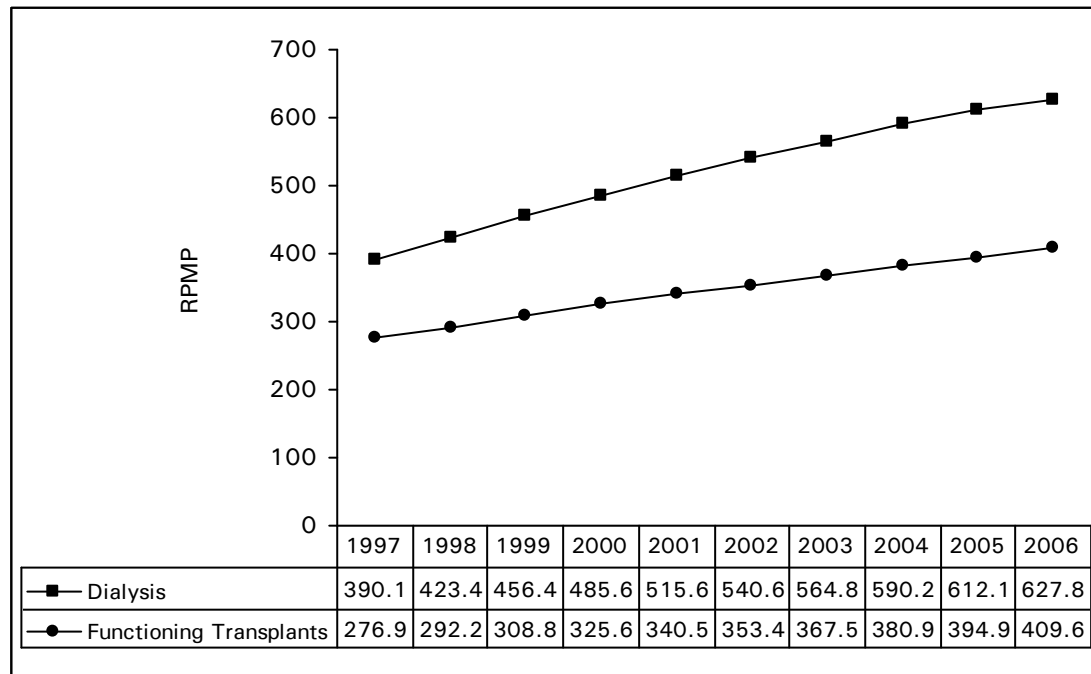
In this section the trends in ESRD prevalent patients in Canada are presented over time in the following figures and tables.

### 2.2.1 Activity

As of December 31, 2006, there were 33,832 people in Canada being treated for ESRD, with almost half (49.0%,  $n = 16,704$ ) receiving HD, followed by 40.0% (13,367) living with a functioning kidney transplant and 3,761 (11%) being treated with PD.

The prevalent RPMP for people being treated both by dialysis and through a transplanted organ increased steadily over time. There was a 60.9% increase in the prevalent rate for dialysis, and a corresponding 47.9% increase in the rate of people living with a transplant, between 1997 and 2006 (Figure 3).

**Figure 3** Prevalent Rate for Patients on Dialysis or With Functioning Transplant in Canada, 1997 to 2006 (RPMP)



### **2.2.2 Patient and Treatment Characteristics**

The profile of prevalent ESRD patients in Canada has changed over time. At the end of 2006, the largest proportion of all patients were receiving HD (49.4%), but this was followed closely by the number of ESRD patients living with a functioning kidney transplant (39.5%) (Table 4). The highest prevalence of any treatment, at 2,509.3 RPMP, was seen for those age 75 and older being treated with HD (Table 5).

HD that is provided in an institutional setting is the most common form of RRT across the country (47.7%), followed by transplant (39.5%). However, in Nova Scotia/Prince Edward Island, Alberta/the Northwest Territories and B.C., transplant is the leading treatment seen in prevalent patients with ESRD (55.4%, 49.2% and 43.4%, respectively) (Table 6).

Each dialysis treatment is provided at a dialysis “station”, which treats one individual patient at a time. The number of HD stations available for treatment is a relatively crude indicator of the system’s capacity to treat those with ESRD in a facility, region or province (Table 7). Ontario has the highest number of patients treated per station, with 5.1 patients per station, while New Brunswick has the lowest, at 3.2 per station. (Table 7).

PD includes total care as well as limited self care treatments. Some patients received a combined HD and PD regimen of treatment. There were 3,627 patients being treated with PD in 2006, with the majority (58.2%) being treated with Home APD, followed by Home CAPD (38.4%) (Table 8).

**Table 4** Prevalent ESRD Patients by Treatment, Age Group, Sex and Primary Diagnosis, Canada, at December 31, 2006 (Number, Percent)

		Number, Percent			Total
		HD	PD	TX	
Total	N	16,704	3,761	13,367	33,832
	%	49.4	11.1	39.5	
<b>Age Group</b>					
0–19 Years	N	75	48	424	547
	%	0.4	1.3	3.2	1.6
20–44 Years	N	1,961	564	3,804	6,329
	%	11.7	15	28.5	18.7
45–64 Years	N	5,495	1,450	6,766	13,711
	%	32.9	38.6	50.6	40.5
65–74 Years	N	4,051	947	1,872	6,870
	%	24.3	25.2	14	20.3
75+ Years	N	5,122	752	501	6,375
	%	30.7	20	3.7	18.8
<b>Sex</b>					
Female	N	7,018	1,645	5,084	13,747
	%	42	43.7	38	40.6
Male	N	9,684	2,116	8,283	20,083
	%	58	56.3	62	59.4
Other	N	2	0	0	2
	%	0	0	0	0
<b>Diagnosis</b>					
Glomerulonephritis	N	2,462	702	4,132	7,296
	%	14.7	18.7	30.9	21.6
Diabetes	N	5,527	1,151	1,941	8,619
	%	33.1	30.6	14.5	25.5
Renal Vascular Disease	N	2,952	667	791	4,410
	%	17.7	17.7	5.9	13
Polycystic Kidney Disease	N	777	222	1,455	2,454
	%	4.7	5.9	10.9	7.3
Drug-Induced	N	288	51	158	497
	%	1.7	1.4	1.2	1.5
Pyelonephritis	N	837	174	1,118	2,129
	%	5	4.6	8.4	6.3
Other	N	1,607	366	1,819	3,792
	%	9.6	9.7	13.6	11.2
Unknown	N	2,254	428	1,953	4,635
	%	13.5	11.4	14.6	13.7

**Table 5** Prevalent Patients by Treatment, Age Groups, Sex and Primary Diagnosis, Canada, December 31, 2006 (RPMP, Percent Change)

	RPMP			Annual Percent Change 2002 to 2006		
	HD	PD	TX	HD	PD	TX
<b>Age Group</b>						
0–19 Years	9.6	6.1	54.3	-1.6	-6.5	0.6
20–44 Years	166.4	47.9	322.9	1.7	-2.9	0.1
45–64 Years	630.7	166.4	776.5	5.6	3.5	6.7
65–74 Years	1,782.2	416.6	823.6	4.0	3.9	11.2
75+ Years	2,509.3	368.4	245.4	9.7	7.5	25.3
<b>Sex</b>						
Male	599.4	131.0	486.5	5.6	4.8	3.4
Female	426.2	99.9	308.7	6.0	0.8	5.6
<b>Diagnosis</b>						
Diabetes	169.4	35.3	59.5	8.6	4.8	7.2
Glomerulonephritis	75.5	21.5	126.7	3.5	-0.9	4.9
Vascular Disease	90.5	20.4	24.2	5.0	5.2	7.6
Pyelonephritis	25.7	5.3	34.3	3.7	-2.9	2.6
Polycystic Kidney Disease	23.8	6.8	44.6	5.1	13.3	6.2
Drug-Induced	8.8	1.6	4.8	3.7	9.5	8.5
Other	49.3	11.2	55.8	6.5	1.5	5.1
Unknown	69.1	13.1	59.9	3.8	2.0	3.6

**Table 6** Prevalent ESRD Patients, by Type of Treatment, Province of Treatment, Canada, 2006 (Number, Percent)

Treatment Type		Province of Treatment									Canada
		B.C.	Alta./ N.W.T.*	Sask.	Man.	Ont.	Que.	N.B.	N.L.	N.S./ P.E.I.†	
HD Home	N	119	61	0	6	298	64	5	10	0	<b>563</b>
	%	2.7	1.8	0	0.4	2.2	0.9	0.6	1.5	0	<b>1.7</b>
HD Institutional	N	1,737	1,362	520	834	7,031	3,482	432	308	435	<b>16,141</b>
	%	39.7	40.2	49.6	55.0	51.2	49.2	51.2	47.7	35.4	<b>47.7</b>
CAPD	N	208	111	75	58	621	351	70	25	67	<b>1,586</b>
	%	4.8	3.3	7.2	3.8	4.5	5	8.3	3.9	5.5	<b>4.7</b>
APD	N	413	196	53	127	1,035	233	50	22	46	<b>2,175</b>
	%	9.4	5.8	5.1	8.4	7.5	3.3	5.9	3.4	3.7	<b>6.4</b>
Transplant	N	1,896	1,655	400	490	4,738	2,941	286	281	680	<b>13,367</b>
	%	43.4	49.2	38.2	32.3	34.5	41.6	33.9	43.5	55.4	<b>39.5</b>
<b>Total</b>	<b>N</b>	<b>4,373</b>	<b>3,385</b>	<b>1,048</b>	<b>1,515</b>	<b>13,723</b>	<b>7,071</b>	<b>843</b>	<b>646</b>	<b>1,228</b>	<b>33,832</b>

**Notes**

\* Alberta includes the populations of the Northwest Territories, the Yukon and Nunavut.

† Nova Scotia includes the population of Prince Edward Island.

**Table 7 Point Prevalent Hospital, Independent Health Facility and Community Centre HD Patients\* by Stations† and Province of Treatment, Canada, 2006 (Number)**

Province of Treatment	Stations (N) <sup>†</sup>	Patients (N) <sup>‡</sup>	Patients per Station	Population <sup>§</sup>	Stations per Million Population
British Columbia	371	1,699	4.6	4,341,681	85.5
Alberta	347	1,428	4.1	3,448,406	100.6
Saskatchewan	111	538	4.8	985,386	112.6
Manitoba	175	852	4.9	1,177,765	148.6
Ontario	1,420	7,310	5.1	12,686,952	111.9
Quebec	817	3,477	4.3	7,651,531	106.8
New Brunswick	136	430	3.2	749,168	181.5
Nova Scotia	142	552	3.9	1,072,924	132.3
Newfoundland and Labrador	91	325	3.6	509,677	178.5
<b>Total</b>	<b>3,610</b>	<b>16,611</b>	<b>4.6</b>	<b>32,623,490</b>	<b>110.7</b>

**Notes**

- \* Data are incomplete for 2006 for one centre in Alberta, three centres in British Columbia, two centres in Ontario and five centres in Quebec. Data were imputed based on data of previous year.
- † It is estimated that for stations, the number imputed is 242 for HD and 188 for satellite stations. This table includes information about stations located in and patients being treated at full-care hospitals, independent health facilities and community centres. Satellite stations refer to a facility where nephrology inpatient services are not onsite. This includes mobile dialysis services and dialysis provided at independent health facilities.
- ‡ It is estimated that the number of imputed patients is 2,272 for HD and 545 for PD (17% of patient total).
- § Alberta includes the populations of the Northwest Territories and Nunavut. British Columbia includes the population of the Yukon. Nova Scotia includes the population of Prince Edward Island.

**Table 8 Point Prevalent Peritoneal Dialysis Patients, by Type of Treatment and Province of Treatment, Canada, 2006 (Number, Percent)**

Province of Treatment		Home CAPD	Home APD	Chronic Care CAPD*	Chronic Care APD	Hospital CAPD†	Hospital APD*	Combined PD and HD	Total
British Columbia	N	179	387	1	10	7	2	12	<b>598</b>
	%	29.9	64.7	0.2	1.7	1.2	0.3	2.0	<b>100</b>
Alberta	N	62	92	2	1	0	0	0	<b>157</b>
	%	39.5	58.6	1.3	0.6	0.0	0.0	0.0	<b>100</b>
Saskatchewan	N	71	54	0	1	0	0	3	<b>129</b>
	%	55.0	41.9	0.0	0.8	0.0	0.0	2.3	<b>100</b>
Manitoba	N	47	126	0	0	0	0	0	<b>173</b>
	%	27.2	72.8	0.0	0.0	0.0	0.0	0.0	<b>100</b>
Ontario	N	577	1,036	17	17	0	4	11	<b>1,662</b>
	%	34.7	62.3	1.0	1.0	0.0	0.2	0.7	<b>100</b>
Quebec	N	285	303	5	1	7	2	2	<b>605</b>
	%	47.1	50.1	0.8	0.2	1.2	0.3	0.3	<b>100</b>
New Brunswick	N	64	54	1	0	1	0	12	<b>132</b>
	%	48.5	40.9	0.8	0.0	0.8	0.0	9.1	<b>100</b>
Nova Scotia	N	82	40	0	1	1	0	1	<b>125</b>
	%	65.6	32.0	0.0	0.8	0.8	0.0	0.8	<b>100</b>
Newfoundland and Labrador	N	25	20	0	0	0	0	1	<b>46</b>
	%	54.3	43.5	0.0	0.0	0.0	0.0	2.2	<b>100</b>
<b>Total</b>	<b>N</b>	<b>1,392</b>	<b>2,112</b>	<b>26</b>	<b>31</b>	<b>16</b>	<b>8</b>	<b>42</b>	<b>3,627</b>
	<b>%</b>	<b>38.4</b>	<b>58.2</b>	<b>0.7</b>	<b>0.9</b>	<b>0.4</b>	<b>0.2</b>	<b>1.2</b>	<b>100</b>

**Notes**

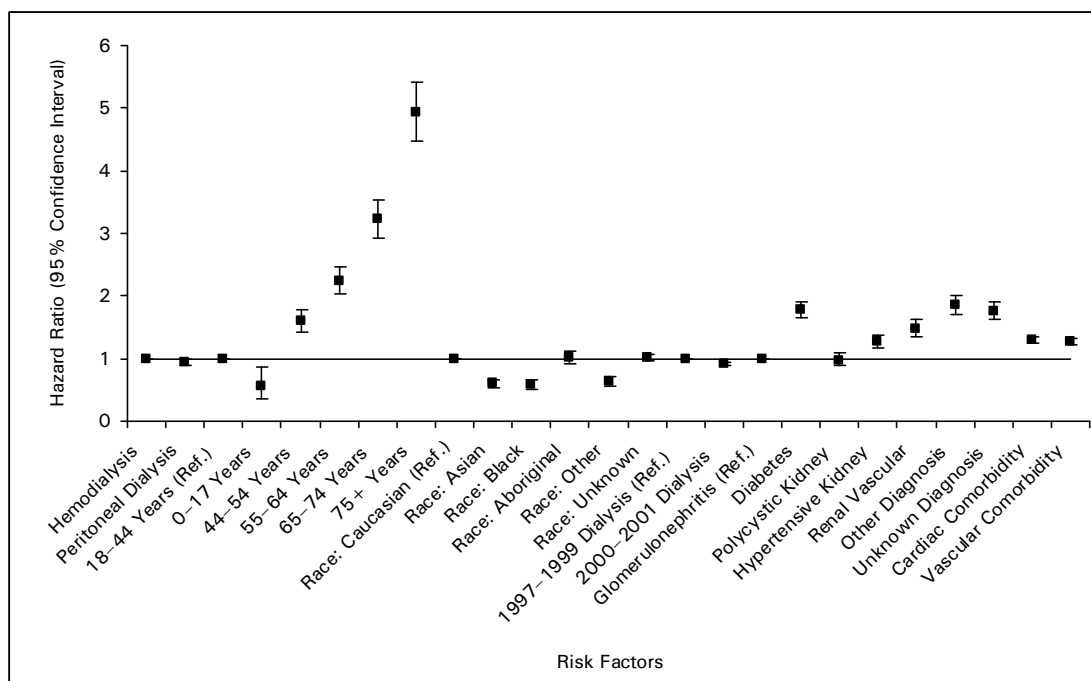
\* Includes total and limited self-care.

† Total care only.

## 2.3 Outcomes of Dialysis Treatment in Canada

There are known factors associated with survival for those receiving dialysis treatment. Figure 4 shows the results of analysis that explores the impact of these factors during the decade in Canada. Points located above the horizontal line, at 1, indicate increased risk and, conversely, points below the line are more likely to have better survival outcomes. The most important associated factors, resulting in less favourable outcomes, are seen with advancing age and the diagnosis of diabetes.

**Figure 4 Adjusted Mortality Risk of Patients Who Initiated RRT With Dialysis, Canada, 1997 to 2001 (Followed to 2006)**



## 2.4 Kidney Transplantation: Adult Recipients

Kidney transplantation is the preferred treatment for the majority of ESRD patients. There has been improvement in both the short- and long-term survival of the kidney allografts and improved patient survival; however, kidney transplant activity is dependent on the availability of organs. Living organ donation has become an important component of the solution to limited availability of deceased-donor organs and has played an increasingly important role in kidney transplantation over the decade studied.

This section presents transplantation activity among adult kidney recipients (18 years of age and older) in the decade from 1997 to 2006 in Canada. Outcomes of kidney transplantation are examined using an adjusted regression analysis, which points out the risk factors associated with patient survival after kidney transplant.



### 2.4.1 Activity

In 2006, there were 23 active kidney transplant programs in Canada operating in seven provinces. Between 1997 and 2006, inclusive, there were 9,937 kidney transplant procedures registered in CORR. Of these, 1,169 (11.8%) were retransplants. Of the 8,709 kidney-only first transplants, 62.1% utilized deceased-donor kidneys (Table 9). Ontario and Quebec surgeons performed the most deceased-donor kidney transplants over the decade (2,073 and 1,896, respectively) (Table 10). Ontario saw the highest number of living-donor kidney transplants over the decade, followed by B.C., where the largest increase was seen (35 in 1997 to 98 in 2006) (Table 11).

Days on dialysis provides some indication of access to kidney transplantation. Pre-emptive transplants, by virtue of the definition, have zero days on dialysis. When pre-emptive transplants are removed from the analysis of time on dialysis, recipients in Nova Scotia had the shortest time on dialysis prior to transplant, both for deceased-donor transplants (median of 909 days) and for living-donor transplants (median of 377 days) (Table 12). There were 70 deaths of those waiting for a kidney transplant in 2006.

**Table 9 Kidney Transplants\* by Year, Donor Type, Adult Recipients, Canada, 1997 to 2006 (Number)**

	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	Total
Kidney Only First Graft, Deceased Donor	548	526	502	596	546	517	550	514	503	607	5,409
Kidney Only First Graft, Living Donor	236	300	323	309	340	319	346	345	368	414	3,300
Kidney Combination First Graft, Deceased Donor†	8	4	5	5	6	5	8	3	5	10	59
Retransplants	122	119	128	125	123	129	95	104	105	119	1,169
<b>Total</b>	<b>914</b>	<b>949</b>	<b>958</b>	<b>1,035</b>	<b>1,015</b>	<b>970</b>	<b>999</b>	<b>966</b>	<b>981</b>	<b>1,150</b>	<b>9,937</b>

#### Notes

\* Excludes simultaneous kidney-pancreas transplants. See Section 6.

† Includes kidney-liver, kidney-lung, kidney-heart and kidney-bowel combination transplants.

**Table 10 Deceased Donor Kidney Transplants\* by Year and Province of Treatment, Adult Recipients, Canada, 1997 to 2006 (Number)**

Province of Treatment	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	Total
British Columbia	77	52	64	60	59	46	53	52	40	61	<b>564</b>
Alberta	90	74	72	84	85	81	67	67	83	78	<b>781</b>
Saskatchewan	16	35	35	19	28	18	29	18	15	21	<b>234</b>
Manitoba	16	14	14	28	11	17	17	13	6	22	<b>158</b>
Ontario	220	238	173	213	184	196	192	208	206	243	<b>2,073</b>
Quebec	149	165	194	209	207	187	218	196	173	198	<b>1,896</b>
Nova Scotia	86	36	57	79	70	63	51	35	49	67	<b>593</b>
<b>Total</b>	<b>654</b>	<b>614</b>	<b>609</b>	<b>692</b>	<b>644</b>	<b>608</b>	<b>627</b>	<b>589</b>	<b>572</b>	<b>690</b>	<b>6,299</b>

**Note**

\* Excludes simultaneous kidney–pancreas transplants. See Section 6. Includes first transplants and retransplants.

**Table 11 Living-Donor Kidney Transplants by Year and Province of Treatment, Adult Recipients, Canada, 1997 to 2006 (Number)**

Province of Treatment	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	Total
British Columbia	35	38	70	77	83	74	69	74	70	98	<b>688</b>
Alberta	29	55	48	37	50	47	52	61	50	46	<b>475</b>
Saskatchewan	16	26	15	6	8	14	10	12	11	9	<b>127</b>
Manitoba	9	6	14	10	12	15	18	12	19	23	<b>138</b>
Ontario	123	144	140	151	144	149	156	157	185	206	<b>1,555</b>
Quebec	12	29	24	22	43	38	43	38	45	47	<b>341</b>
Nova Scotia	36	37	38	40	31	25	24	23	29	31	<b>314</b>
<b>Total</b>	<b>260</b>	<b>335</b>	<b>349</b>	<b>343</b>	<b>371</b>	<b>362</b>	<b>372</b>	<b>377</b>	<b>409</b>	<b>460</b>	<b>3,638</b>

**Table 12 Dialysis Duration Prior to First Kidney Transplant by Province of Treatment, Adult Kidney Transplant Recipients, Canada, 2004 to 2006 (Number)**

	<b>British Columbia</b>	<b>Alberta</b>	<b>Saskatchewan</b>	<b>Manitoba</b>	<b>Ontario</b>	<b>Quebec</b>	<b>Nova Scotia</b>	<b>Canada</b>
Duration on Dialysis (Median Days), Deceased Donor	2,032	1,128	944	1,495	1,843	820	856	<b>1,282</b>
Duration on Dialysis (Median Days), Deceased Donor, No Pre-emptive	2,071	1,148	970	1,495	1,873	912	909	<b>1,320</b>
Duration on Dialysis (Median Days), Living Donor	222	394	248	553	345	294	184	<b>318</b>
Duration on Dialysis (Median Days), Living Donor, No Pre-emptive	387	481	711	613	541	651	377	<b>505</b>

**Notes**

In the calculation of median days on dialysis, pre-emptive kidney transplant recipients were given a value of 0 for their wait time.

There were 2,769 adult first kidney transplants performed in Canada between 2004 and 2006, 409 of which were pre-emptive transplants (83 deceased, 326 living donor).

**2.4.2 Recipient Characteristics**

As the Canadian population ages, so does the group of patients living with a kidney transplant. The proportion of recipients over age 60 with transplants from a deceased donor rose from 19.1% to 29.7%, while the percentage over age 60 receiving an organ from a living donor was much smaller, but also increased (6.4% to 14.7%) (Table 13). The most common primary renal diagnosis continued to be glomerulonephritis in adults (380) (Table 14).

**Table 13 Adult Kidney Transplant Recipients, Selected Characteristics, First Graft, Canada, 1997 to 2006 (Number, Percent)**

Donor	Characteristic	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006
Deceased	Percentage Male	65.1	67	60.2	63.2	63.9	63.6	64.7	62.1	63.8	61.8
	Percentage Age 60+ Years	19.1	20.8	18.1	20	25.7	29.5	26.7	30.6	29.5	29.7
	Average Age in Years (SD*)	47.5 (12.7)	47.5 (13)	47.8 (12.9)	48.2 (12.1)	50 (12.8)	50.7 (13.6)	50.4 (12.6)	51.2 (13.2)	51.8 (12.5)	51.9 (12.7)
	Percentage Diabetes	17.3	17.2	22.3	20	21.4	23.2	25.4	19.1	25.4	25.3
Living	Percentage Male	63.6	63.3	61.9	62.1	55.6	60.5	64.5	59.1	63	62.6
	Percentage Age 60+ Years	6.4	12.3	10.2	10	12.6	13.8	16.8	14.5	14.7	14.7
	Average Age in Years (SD*)	40.5 (12.1)	43.4 (12.6)	42.6 (13)	43.3 (12.8)	42.7 (13.3)	43.8 (13.5)	46.2 (12.9)	44.6 (13.2)	46.7 (12.5)	45.4 (13.1)
	Percentage Diabetes	16.9	21.7	18.6	17.5	18.2	18.8	23.7	22	22.6	18.1

**Note**

\* SD = standard deviation.

**Table 14 Kidney Transplant Recipients\* by Age Group, Primary Renal Diagnosis Category, Adult Recipients, First Graft, Canada, 2006 (Number)**

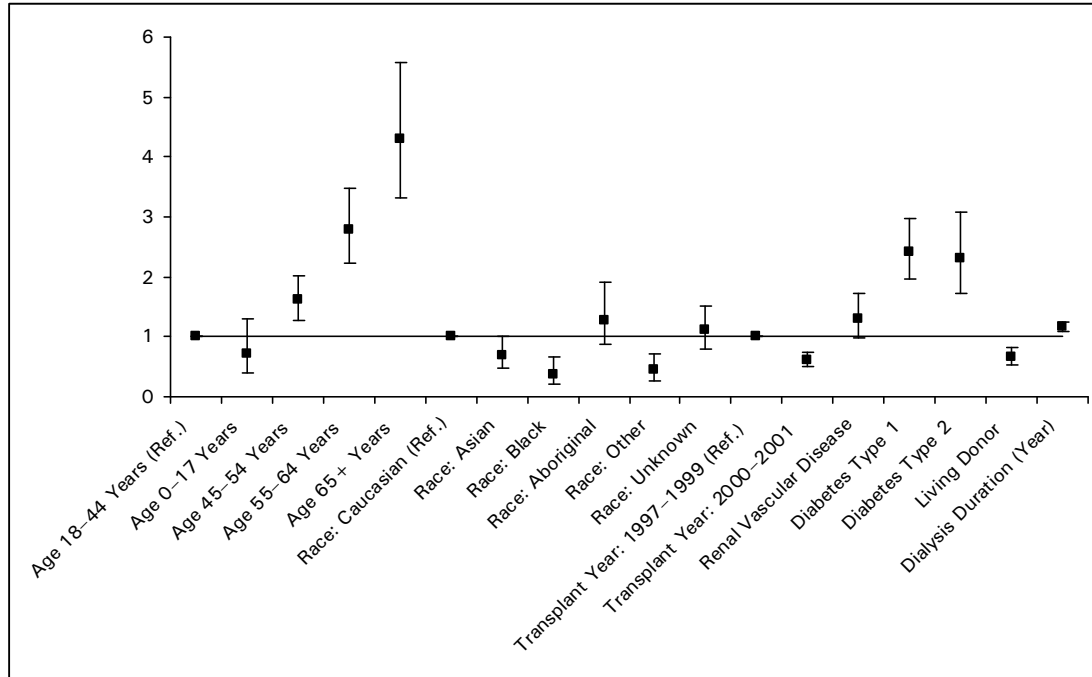
	18–39 Years	40–59 Years	60+ Years	Total
Glomerulonephritis	110	192	78	380
Pyelonephritis	20	46	5	71
Nephropathy—Drug-Induced	2	16	8	26
Polycystic Kidney Disease	15	104	34	153
Hypertension/Other Vascular	16	59	52	127
Diabetic Nephropathy	24	92	63	179
Other	68	73	24	165
Unknown/Not Reported	12	29	18	59
<b>Total Diagnoses</b>	<b>267</b>	<b>611</b>	<b>282</b>	<b>1,160</b>
<b>Total Patients</b>	<b>245</b>	<b>542</b>	<b>244</b>	<b>1,031</b>

**Note**

\* Based on patients with first grafts. Both diagnoses provided at incident dialysis treatment and subsequent diagnoses at time of kidney transplant are included in this table.

When survival analyses are conducted through the use of multivariate modeling techniques—in this case a Cox model—the largest risks for compromised survival are associated with increasing age, followed by a diagnosis of diabetes (Figure 5).

**Figure 5 Cox-Adjusted Mortality Risk for Kidney Adult Transplant Patients, Canada, 1997 to 2001 (Followed to 2006)**



## 2.5 Kidney Transplantation: Pediatric Recipients

In an effort to more accurately capture patients who would be considered pediatric according to the health care delivery system throughout Canada, the upper age limit defining pediatric patients in CORR was changed from 14 to 17 years in 2002.

Pediatric ESRD patients present different treatment challenges than adult patients. Transplantation has become the treatment of choice for this patient population. This section presents the trends in kidney transplantation for pediatric patients in Canada (tables 15 to 18). Throughout the decade, there were 576 first graft transplants and 38 retransplants on pediatric recipients. Numbers for transplants utilizing living-donor organs have fluctuated over time, showing no distinct trend. Similarly, the number of transplants in pediatric recipients using deceased organs has fluctuated over time (Table 15). The majority of transplants are performed for recipients in the 11- to 17-year age group (64.5%).

**Table 15 Kidney Transplants by Year, Donor Type and Retransplants, Pediatric Recipients, Canada, 1997 to 2006 (Number)**

	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	Total
First Graft, Deceased Donor	40	19	27	32	18	28	27	19	39	22	271
First Graft, Living Donor	25	25	30	43	26	36	28	37	29	26	305
Retransplants	3	6	7	3	3	2	3	5	5	1	38
<b>Total</b>	<b>68</b>	<b>50</b>	<b>64</b>	<b>78</b>	<b>47</b>	<b>66</b>	<b>58</b>	<b>61</b>	<b>73</b>	<b>49</b>	<b>614</b>

**Table 16 Pediatric Kidney Transplants by Age Group and Province of Treatment, Canada, 1997 to 2006 (Number, Percent)**

Age Group		B.C.	Alta.	Sask.	Man.	Ont.	Que.	N.S.	Total
0–4 Years	N	13	9	0	2	31	18	12	85
	%	19.1	12.0	0.0	4.0	14.6	12.3	24.5	13.8
5–10 Years	N	18	22	0	18	35	33	7	133
	%	26.5	29.3	0.0	36.0	16.4	22.6	14.3	21.7
11–17 Years	N	37	44	13	30	147	95	30	396
	%	54.4	58.7	100.0	60.0	69.0	65.1	61.2	64.5
<b>Total</b>	<b>N</b>	<b>68</b>	<b>75</b>	<b>13</b>	<b>50</b>	<b>213</b>	<b>146</b>	<b>49</b>	<b>614</b>

**Table 17 Dialysis Duration Prior to First Kidney Transplant, Pediatric Recipients, Canada, 1997 to 2006 (Number)**

	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006
Duration on Dialysis (Median Days), Deceased Donor	526	453	548	448	292	385	427	586	557	633
Duration on Dialysis (Median Days), Deceased Donor, No Pre-emptive	573	474	632	566	508	452	874	705	786	653
Duration on Dialysis (Median Days), Living Donor	278	131	241	193	109	75	87	264	107	125
Duration on Dialysis (Median Days), Living Donor, No Pre-emptive	338	281	461	467	303	411	327	420	396	236

**Note**

In 2006 there were 48 pediatric first kidney transplants performed in Canada, 11 of which were pre-emptive transplants.

**Table 18 Pediatric Kidney Transplant Recipients\* by Age Group and Primary Renal Diagnosis Category, First Graft, Canada, 1997 to 2006 (Number, Percent)**

Primary Renal Diagnosis Category	0–4 Years		5–10 Years		11–17 Years		Total
	N	%	N	%	N	%	N
Alport's Syndrome	0	0	2	1.4	10	2.5	12
Cystinosis	0	0	13	9.2	17	4.3	30
Dysplasia/Hypoplasia	24	24.7	34	23.9	53	13.4	111
Posterior Urethral Valves	9	9.3	9	6.3	14	3.5	32
Obstructive Uropathy	9	9.3	7	4.9	23	5.8	39
Vesico-Ureteric Reflux	3	3.1	3	2.1	22	5.6	28
Polycystic Kidneys	3	3.1	2	1.4	16	4.1	21
Nephronophthisis	1	1	7	4.9	17	4.3	25
Other Congenital/Hereditary	12	12.4	3	2.1	9	2.3	24
Other Pyelonephritis	0	0	4	2.8	8	2	12
Glomerulonephritis	11	11.3	12	8.5	60	15.2	83
Focal Sclerosis	6	6.2	14	9.9	23	5.8	43
Autoimmune Disease	1	1	2	1.4	23	5.8	26
Hemolytic-Uremic Syndrome	0	0	9	6.3	14	3.5	23
Other	10	10.3	11	7.7	44	11.1	65
Unknown	8	8.2	10	7	42	10.6	60
<b>Total</b>	<b>97</b>	<b>100</b>	<b>142</b>	<b>100</b>	<b>395</b>	<b>100</b>	<b>634</b>

**Note**

\* Based on patients with first grafts. Both diagnoses provided at incident dialysis treatment and subsequent diagnoses at time of kidney transplant are included in this table.





### 3 Liver Transplantation

The science of liver transplantation experienced a paradigm shift in 1989 when the first living-donor liver transplant was performed in the United States. In Canada, the first living-donor, parent-to-child liver transplant took place in 1993, followed by the first living-donor, adult-to-adult liver transplant in Canada in 2000. The introduction of advances in immunosuppression dramatically enhanced patient survival. In addition, improvements in organ preservation and surgical techniques beginning in the 1980s have worked together to continue to improve graft and patient survival. With these advances, liver transplantation is now considered the optimal form of therapy for end-stage liver disease. This section presents liver transplantation activity over the decade from 1997 to 2006 in Canada.

The decade spanning 1997 to 2006 saw 3,976 liver transplants registered with CORR, with the majority of those utilizing deceased-donor livers in patients age 18 and older (75.9%) (Table 19). While most of the transplants were liver only, there were combination transplants performed, with the liver–kidney combination the most frequently observed ( $n=57$ ) (Table 20).

Between 1997 and 2006, more males received liver transplants (63.1%) than females, but the male-to-female ratio differed between age groups (Table 21). For recipients age 10 and younger, biliary atresia was the predominant cause of end-stage liver failure, while for recipients age 35 and older, where a specific cause was recorded, hepatitis C was the most common diagnosis (Table 21).

The medical status of liver disease patients is part of the clinical decision-making algorithm. Status 1, 1T and 2 patients are considered non-urgent, with Status 1 individuals being at home, 1T being at home with tumour and Status 2 individuals being hospitalized at the time of transplant. Status 3 and upward are considered urgent, with Status 3 patients being in the intensive care unit (ICU), Status 3F are in the ICU and fulminant, Status 4 are in the ICU intubated and ventilated, while Status 4F are in the ICU intubated, ventilated and fulminant. In terms of the distribution of patient medical status at the time of transplantation, there was little change over the decade (Figure 6). The highest rate of liver transplant by RPMP was seen in Alberta, at 16.4 RPMP (Figure 7). More than 80% of liver transplant recipients receiving a first graft in 2006 were considered non-urgent (Status 1 and 2) (Figure 6).

The number of people waiting for a liver transplant climbed each year, with the highest number in 2006, at 723 patients. There were 120 deaths of those on the waiting list for a liver transplant in 2006 (Table 22), a rate similar to that for heart transplants.

**Table 19 Liver Transplants by Year, Donor Type, Age Group and Retransplants, Canada, 1997 to 2006 (Number)**

	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	Total
First Graft < 18, Deceased Donor	27	24	39	30	20	25	33	15	34	25	272
First Graft < 18, Living Donor	0	3	6	6	13	10	6	12	8	9	73
Retransplants < 18	9	5	13	4	4	3	4	3	9	8	62
First Graft 18 +, Deceased Donor	279	281	300	336	293	290	302	318	297	324	3,020
First Graft 18 +, Living Donor	0	0	3	13	31	32	29	42	52	58	260
Retransplants 18 +	35	29	23	20	33	26	31	27	23	42	289
<b>Total</b>	<b>350</b>	<b>342</b>	<b>384</b>	<b>409</b>	<b>394</b>	<b>386</b>	<b>405</b>	<b>417</b>	<b>423</b>	<b>466</b>	<b>3,976</b>

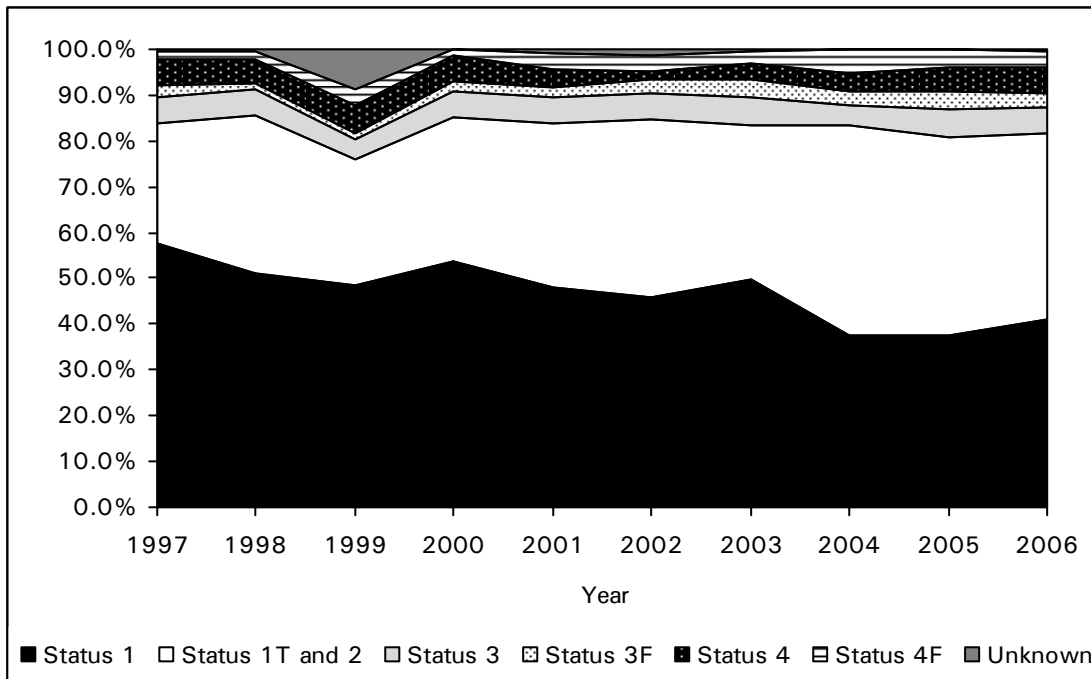
**Table 20 Combination Liver Transplants, Canada, 1997 to 2006 (Number)**

	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	Total
Liver Only	340	338	378	403	383	381	399	414	416	447	3,899
Liver–Kidney	8	4	5	4	9	3	5	3	5	11	57
Liver–Small Bowel	1	0	1	1	1	1	1	0	1	4	11
Other Combination	1	0	0	1	1	1	0	0	1	4	9
<b>Total</b>	<b>350</b>	<b>342</b>	<b>384</b>	<b>409</b>	<b>394</b>	<b>386</b>	<b>405</b>	<b>417</b>	<b>423</b>	<b>466</b>	<b>3,976</b>

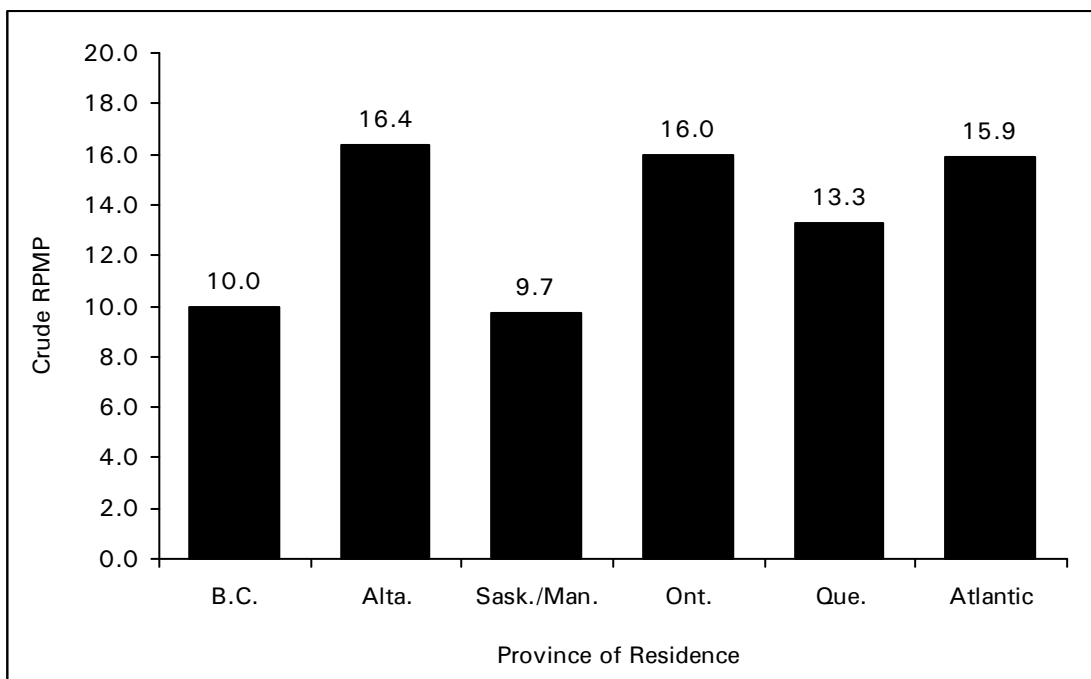
**Table 21 Primary Diagnoses for Liver Transplant Recipients, First Grafts by Age Group, Canada, 1997 to 2006 (Number, Percent)**

Age Group (Years)	N	Percent Male	Primary Diagnosis									
			Primary Biliary Atresia	Hepatitis C	Hepatitis B	Other Hepatitis	Alcoholic Cirrhosis	Cryptogenic Cirrhosis	Cancer	Metabolic Disorders	Unknown/Missing	Other
< 1	169	40.8	56.5	0.6	0	4.7	0	1.2	1.2	5.9	5.9	24.1
1–10	103	59.2	23.6	0.9	0	7.5	0	0	10.4	10.4	6.6	40.6
11–17	73	53.4	3.9	2.6	1.3	15.6	0	3.9	5.2	7.8	6.5	53.2
18–34	274	50.7	0.3	3.0	6.8	13.2	1.0	3.4	4.4	7.4	2.7	57.8
35–59	2,258	66.8	0.1	28.6	7.3	3.9	18.2	4.4	9.5	2.3	1.6	24.2
60+	748	63.0	0.2	17.9	7.7	3.6	16.8	9.8	15.4	3.5	1.5	23.7
<b>Total</b>	<b>3,625</b>	<b>63.1</b>	<b>3.1</b>	<b>22.3</b>	<b>6.7</b>	<b>4.8</b>	<b>15.2</b>	<b>5.2</b>	<b>10.0</b>	<b>3.4</b>	<b>2.0</b>	<b>27.4</b>

**Figure 6** Distribution of Liver Transplants by Medical Status at Transplant, Canada, 1997 to 2006 (Percent)



**Figure 7** Liver Transplant Recipients by Province of Residence, Canada, 2005 (Crude RPMP)



**Note**

Data from Saskatchewan and Manitoba were combined due to small numbers.

**Table 22 Liver Transplant Waiting List and Deaths, on December 31, Canada, 1997 to 2006, (Number of People)**

	<b>1997</b>	<b>1998</b>	<b>1999</b>	<b>2000</b>	<b>2001</b>	<b>2002</b>	<b>2003</b>	<b>2004</b>	<b>2005</b>	<b>2006</b>	<b>Total</b>
< 18 Years	24	26	20	27	36	31	30	37	32	36	<b>299</b>
18+ Years	206	260	298	311	418	528	539	630	681	687	<b>4,558</b>
<b>Total</b>	<b>230</b>	<b>286</b>	<b>318</b>	<b>338</b>	<b>454</b>	<b>559</b>	<b>569</b>	<b>667</b>	<b>713</b>	<b>723</b>	<b>4,857</b>
Deaths on Waiting List	42	30	70	51	57	82	100	96	141	120	<b>789</b>

## 4 Heart Transplantation

Heart transplantation is the treatment of last resort for people with heart failure when all other treatments have failed. Heart transplants are now the third most common organ transplant operation in Canada. This section shows the trends in heart transplantation procedures and outcomes in Canada over the decade from 1997 to 2006.

Between 1997 and 2006, there were 1,633 heart transplants registered in CORR, which included 58 retransplants. The number of transplants performed each year remained fairly stable, with a 9.2% increase in the decade (163 to 178). While the number of children under a year old receiving heart transplants fluctuated minimally over the decade, it peaked in 2006 at 17. The largest number of transplants were performed for recipients between age 35 and 59 (848), followed by those age 60 and older (321) (Table 23).

In each age group, the proportion of male recipients was higher than females, with the highest male–female ratio being seen in those 60 years of age and older (84.1%). Over the decade, males comprised 73.6% of Canadian heart transplant recipients (Table 24). When sex of recipient was examined using sex-specific RPMP, males had substantially higher rates in all regions, with the highest rate in Alberta (9.1) and the lowest rate of male recipients in Manitoba/Saskatchewan (5.6) (Figure 8).

Each person on the waiting list for a heart transplant is categorized according to medical status. Status 1 and 2 patients are classified as non-urgent and may be at home or in hospital. Status 3 and 4 patients are in the most urgent need of a transplant. Status 3 patients may be in the ICU or require inotropic support, while Status 4 patients are already in the ICU with ventilator support. Just over half of the patients transplanted in 2006 were classified as having an urgent medical status, which differs from 1997, when the majority of recipients were classified as non-urgent (Figure 9).

There were 87 people on the waiting list for a heart transplant in 2006, and there were 13 deaths, down substantially from previous years (27 deaths in 2005) (Table 25). A total of 292 Canadians died over the decade while on the waiting list for a heart transplant.

**Table 23 Heart Transplants by Year, Age Group and Retransplants, Canada, 1997 to 2006 (Number)**

	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	Total
First Graft, <1 Year	5	2	9	10	10	5	6	14	15	17	93
First Graft, 1–10 Years	8	7	10	8	8	8	4	7	8	7	75
First Graft, 11–17 Years	7	7	7	8	9	8	10	9	9	9	83
First Graft, 18–34 Years	12	6	12	17	19	15	16	13	18	27	155
First Graft, 35–59 Years	100	105	83	80	71	84	82	66	86	91	848
First Graft, 60+ Years	25	21	40	38	40	41	33	30	33	20	321
Retransplants	6	6	5	12	4	3	6	4	5	7	58
<b>Total</b>	<b>163</b>	<b>154</b>	<b>166</b>	<b>173</b>	<b>161</b>	<b>164</b>	<b>157</b>	<b>143</b>	<b>174</b>	<b>178</b>	<b>1,633</b>

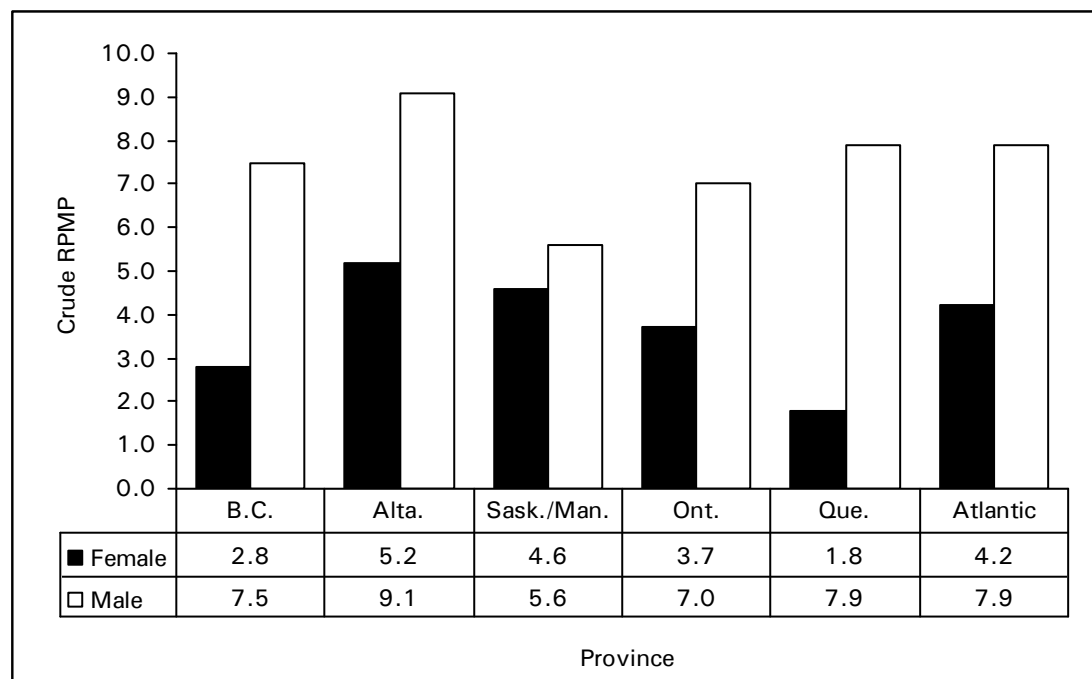
**Table 24 Primary Diagnoses for Heart Transplant Recipients, Canada, 1997 to 2006 (Number, Percent)**

Age (Years)	Number	Percent Male	Primary Diagnosis						
			Congenital	C. Unspecified	Dilated C.	Idiopathic C.	Ischemic C.	Unknown/Missing	Other
<1	107	60.8	52.8	12.0	11.1	2.8	0.9	4.6	15.7
1–10	61	52.5	35.5	11.3	14.5	3.2	1.6	4.8	29.0
11–17	83	59.0	24.4	27.9	22.1	4.7	1.2	3.5	16.3
18–34	155	67.1	9.9	14.9	26.1	11.8	3.1	1.9	32.3
35–59	843	75.4	1.8	10.3	16.0	10.0	40.2	2.1	19.6
60+	321	84.1	0.3	9.5	14.6	4.9	58.2	1.8	10.7
<b>Total</b>	<b>1,570</b>	<b>73.6</b>	<b>8.2</b>	<b>11.7</b>	<b>16.6</b>	<b>8.1</b>	<b>34.0</b>	<b>2.4</b>	<b>19.0</b>

**Note**

C = cardiomyopathy.

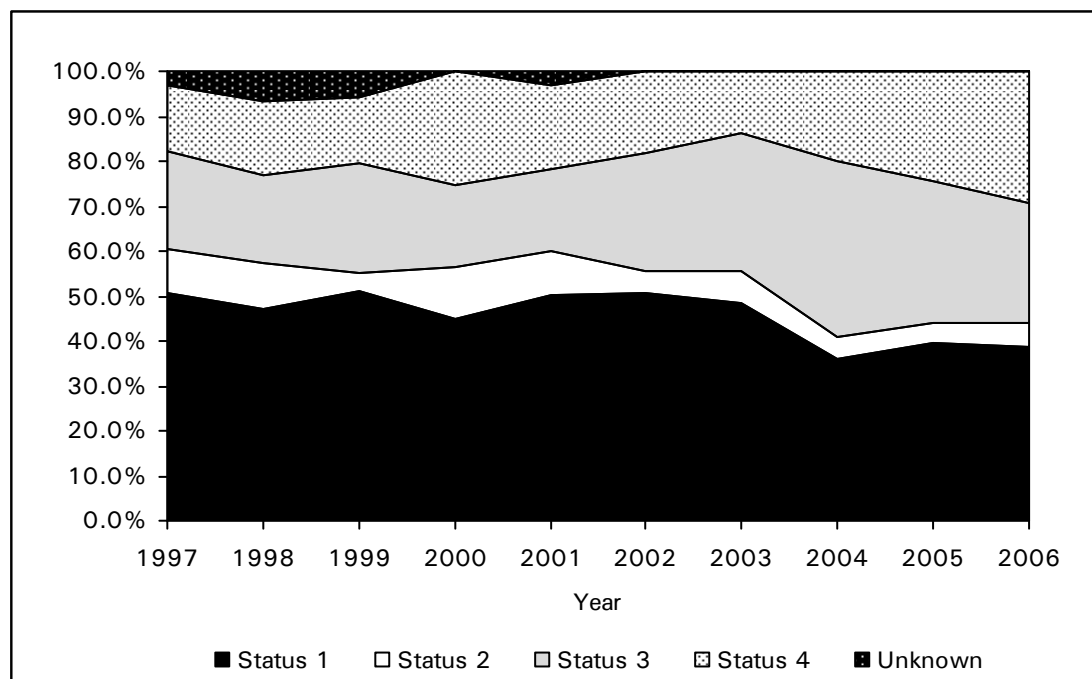
**Figure 8 Heart Transplant Recipients by Province of Residence, Canada, 2006  
(Sex-Specific Crude Rate PMP)**



**Note**

Data from Saskatchewan and Manitoba are combined due to small numbers.

**Figure 9** Distribution of Heart Transplants by Medical Status\* at Transplant, Canada, 1997 to 2006 (Percent)



**Note**

\* Status 1 = at home; status 2 = hospitalized; status 3 = hospitalized in ICU receiving inotropes or less than 6 months of age, or with rapid deterioration; status 4 = in ICU with mechanical/ventilatory support; unknown = status not provided.

**Table 25** Waiting Lists and Deaths on the Waiting List for Heart Transplant, 1997 to 2006 (Number of People)

	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	Total
< 18 Years	9	21	13	9	13	13	37	6	9	7	137
18+ Years	88	99	88	80	112	90	94	119	87	80	937
<b>Total</b>	<b>97</b>	<b>120</b>	<b>101</b>	<b>89</b>	<b>125</b>	<b>103</b>	<b>131</b>	<b>125</b>	<b>96</b>	<b>87</b>	<b>1,074</b>
Deaths on Waiting List	28	28	41	30	34	35	30	26	27	13	292



## 5 Lung Transplantation

The first single lung transplant procedure in Canada was performed in 1983, followed by the first bilateral lung transplant in 1986. Since that time, outcomes for lung-transplant recipients have continued to improve for several reasons: better organ preservation techniques, improvements in pre- and peri-operative care, better follow-up medical management of recipients and advances in immunosuppression. In Canada, lung transplant activity almost doubled in the decade. This section presents the evolving landscape of lung transplant procedures in Canada between 1997 and 2006.

In the decade spanning 1997 to 2006, there was an increase in the number of lung transplants performed in Canada annually. During the decade, the total number of lung transplants reached 1,222, reflecting an increase of 83.9% from 1997 (93) to 2006 (171) (Table 26). There was a 148% increase in the volume of bilateral lung transplants during the decade, while single lung transplant volumes fluctuated somewhat over time (34 in 1997, 35 in 2006) (Table 27).

Emphysema and chronic obstructive pulmonary disease (COPD) are the primary diagnoses in the majority of single lung transplants (50.5%), while cystic fibrosis accounts for the largest proportion of bilateral lung transplants (31.4%), and congenital diseases represent the leading cause of heart–lung transplants (39.6%) (Table 28).

When considering the population by province, in 2006 Alberta had the highest rate of lung transplant, at 8.0 RPMP, followed closely by Atlantic Canada, with 7.3 RPMP (Figure 10).

The number of individuals on the waiting list for a lung transplant continued to grow over the decade, with 252 in 2006, up from 239 the previous year (5.4% annual increase); the number of deaths while waiting dropped in 2006 to 36 (from 43 in 2005) (Table 29).

**Table 26 Lung Transplants by Year, Age Group and Retransplants, Canada, 1997 to 2006 (Number)**

	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	Total
First Graft, 18+	86	75	84	121	120	130	112	128	137	166	1,159
First Graft, <18	4	4	5	2	4	5	2	3	5	4	38
Retransplants	3	4	1	1	2	4	4	2	3	1	25
<b>Total</b>	<b>93</b>	<b>83</b>	<b>90</b>	<b>124</b>	<b>126</b>	<b>139</b>	<b>118</b>	<b>133</b>	<b>145</b>	<b>171</b>	<b>1,222</b>

**Table 27 Lung Transplants by Transplant Type, Canada, 1997 to 2006 (Number)**

	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	Total
Bilateral Lung	52	46	54	85	82	96	95	98	119	129	856
Single Lung	34	30	30	34	39	36	21	30	19	35	308
Living Donor Lobar	0	0	1	1	2	0	0	2	1	1	8
Heart–Lung	7	7	5	4	3	7	2	3	6	6	50
<b>Total</b>	<b>93</b>	<b>83</b>	<b>90</b>	<b>124</b>	<b>126</b>	<b>139</b>	<b>118</b>	<b>133</b>	<b>145</b>	<b>171</b>	<b>1,222</b>

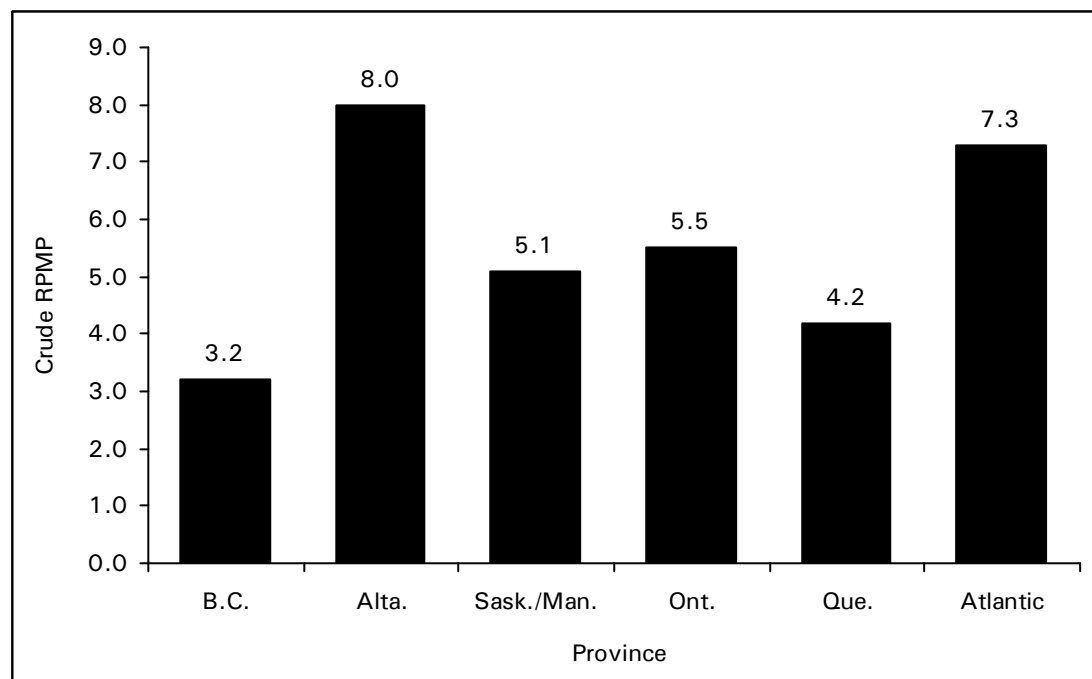
**Table 28 Primary Diagnoses\* for Lung Transplant Recipients, First Grafts, Canada, 1997 to 2006 (Number, Percent)**

	Bilateral Lung		Single Lung		Heart–Lung	
	N	%	N	%	N	%
Congenital	11	1.3	1	0.3	19	39.6
Alpha Antitrypsin	67	8.0	24	7.6	1	2.1
Cystic Fibrosis	264	31.4	14	4.4	3	6.3
Emphysema/COPD	163	19.4	159	50.5	6	12.5
Idiopathic Pulmonary Fibrosis	157	18.7	69	21.9	1	2.1
Primary Pulmonary Hypertension	43	5.1	3	1.0	8	16.7
Unknown/Missing	12	1.4	5	1.6	2	4.2
Other	123	14.6	40	12.7	8	16.7
<b>Total</b>	<b>840</b>	<b>100.0</b>	<b>315</b>	<b>100.0</b>	<b>48</b>	<b>100.0</b>

**Note**

\* More than one diagnosis can be reported for a patient.

**Figure 10 Lung Transplant Recipients by Province of Residence, Canada, 2006  
(Crude Rate PMP)**



**Table 29 Lung Transplant Waiting List on December 31, Canada, 1997 to 2006  
(Number of People)**

	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	Total
Bilateral Lung	44	66	93	108	125	88	131	155	188	147	1,145
Single Lung	60	61	64	58	25	50	29	22	37	94	500
Heart-Lung	15	15	11	11	13	12	12	4	14	11	118
<b>Total</b>	<b>119</b>	<b>142</b>	<b>168</b>	<b>177</b>	<b>163</b>	<b>150</b>	<b>172</b>	<b>181</b>	<b>239</b>	<b>252</b>	<b>1,763</b>
Deaths on Waiting List	22	24	27	21	28	26	29	43	43	36	299



## 6 Pancreas Transplantation

ESRD patients with underlying diabetes have two serious conditions, each of which may require different treatments. For kidney failure, patients need RRT. For diabetes, therapy must regulate glycemia. Pancreas transplantation offers those with type 1 diabetes the prospect of insulin independence and the stabilization of some diabetes-related complications. Pancreas transplantation provides stable, long-term normoglycemia with normal or near-normal glucose tolerance, while avoiding hypoglycemic episodes. Three types of pancreas transplant have been utilized. The most common is a simultaneous kidney–pancreas transplantation (SKP) for ESRD recipients. Less common are pancreas transplants performed after kidney transplant (PAK), or alone (PTA). When these are performed (PAK, PTA) they are usually performed using a live donor kidney. The introduction of cyclosporin and anti-T-cell agents, new surgical techniques and refined patient-selection criteria have all contributed to improved results for pancreatic transplantation.

This section presents data on pancreas only or simultaneous pancreas and kidney transplant activity in Canada between 1997 and 2006.

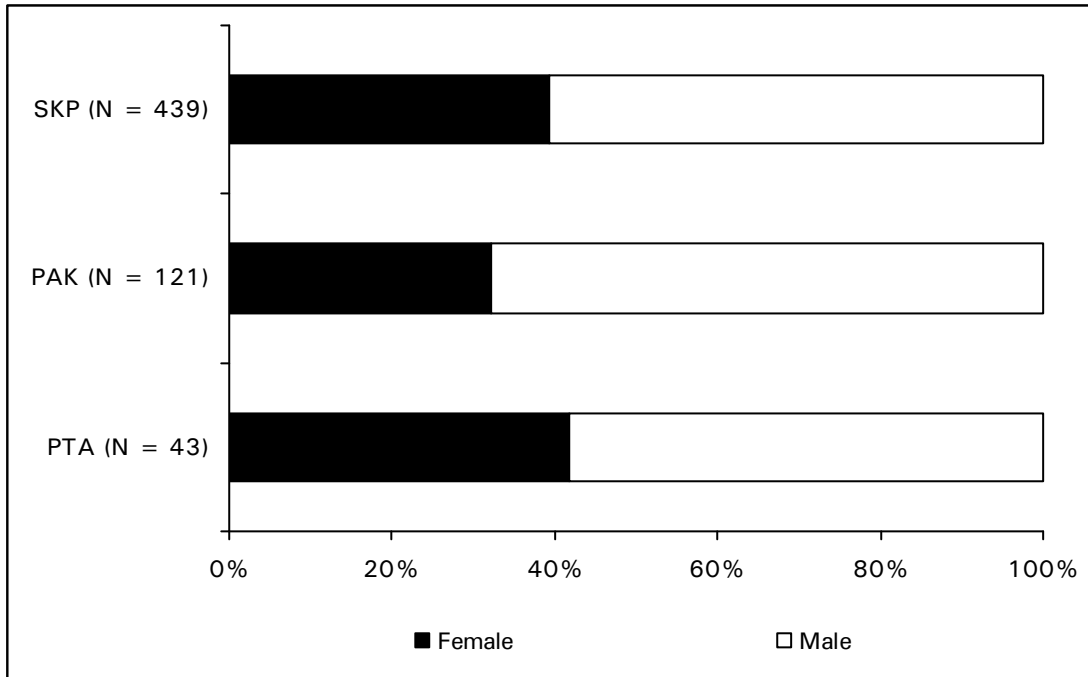
Between 1997 and 2006, there were 603 pancreas transplants performed in Canada (Table 30). The majority of the transplants performed (73.4%) were SKP procedures. The majority of pancreas transplantations in Canada were performed on male recipients (Figure 11).

The number of people waiting for pancreas transplant fluctuated over time; the number waiting for a PTA/PAK procedure increased consistently over time (Table 31), while the number waiting for a SKP procedure spiked in 2001 and has fluctuated since then, decreasing to 113 people in 2006 (from 132 in 2005).

**Table 30 Pancreas Transplants by Year, Canada, 1997 to 2006 (Number)**

	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	Total
Simultaneous Kidney–Pancreas (SKP)	30	40	51	47	34	44	38	47	54	54	439
Pancreas After Kidney (PAK)	2	8	18	14	11	15	16	11	12	14	121
Pancreas Transplant Alone (PTA)	0	1	0	5	3	11	9	3	6	5	43
<b>Total</b>	<b>32</b>	<b>49</b>	<b>69</b>	<b>66</b>	<b>48</b>	<b>70</b>	<b>63</b>	<b>61</b>	<b>72</b>	<b>73</b>	<b>603</b>

**Figure 11 Pancreas Transplant Recipients by Type and Recipient Sex, First Grafts, Canada, 1997 to 2006 (Percent)**



**Table 31 Pancreas and Kidney–Pancreas Transplant Waiting List, Canada, 1997 to 2006 (Number of People)**

	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006
PTA/PAK	8	9	17	30	32	37	31	51	63	63
SKP	35	86	100	128	172	122	120	101	132	113
<b>Total</b>	<b>43</b>	<b>95</b>	<b>117</b>	<b>158</b>	<b>204</b>	<b>159</b>	<b>151</b>	<b>152</b>	<b>195</b>	<b>176</b>

## 7 Intestinal Transplantation<sup>iv</sup>

Small intestine transplantation is an evolving surgical procedure used in the management of intestinal failure in children and adults. In spite of recent advances, intestinal transplantation is currently a therapeutic option only for patients with intestinal failure whose condition continues to decline in spite of total parenteral nutrition (TPN). It is not yet an alternative for patients who are doing well on TPN.

From the inception of CORR, 45 intestinal transplants have been registered (Table 32). The transplants have been almost evenly split between pediatric patients and adult recipients. The majority of liver–small intestine transplants have been performed in those under age 18 (66.6%).

**Table 32 Intestinal Transplants by Transplant Period and Age Group, Canada, 1988 to 2006 (Number)**

Type of Graft	1988 to 1996		1997 to 2006		Total	
	< 18 Years	18+ Years	< 18 Years	18+ Years	< 18 Years	18+ Years
Multivisceral	0	2	3	7	3	9
Isolated Small Intestine	6	2	2	2	8	4
Liver–Small Intestine	3	4	9	2	12	6
Kidney–Small Intestine	0	1	0	1	0	2
Liver–Kidney–Small Intestine	0	0	1	0	1	0

iv. The information on intestinal transplantation is restricted in content by the small number of intestinal transplants and by data completeness concerns. In this section, the time period of observation differs from the remainder of the report in that it is expanded to include the years between 1988 and 2006.





## **There's More on the Web!**

What you see in the print version of this report is only a fraction of the available information from CORR. Please see Appendix G and go to [www.cihi.ca/corr](http://www.cihi.ca/corr) for additional information and a full set of tables and figures on outcomes and clinical indicators, as well as international comparisons, for the period between 1997 and 2006. In addition, there are presentations, previous reports, analyses and statistics on the subject of end-stage organ failure.



## **Appendix A—Canadian Organ Replacement Register (CORR) Board of Directors and Members of the Advisory Committee**

### **CORR Board of Directors (July 1, 2008)**

- Dr. John Gill, Canadian Society of Transplantation/Canadian Society of Nephrology, President
- Dr. Louise Moist, Canadian Society of Nephrology, Vice-President
- Dr. Joanne Kappel, Canadian Society of Nephrology, Past-President
- Mr. Peter Hault, Kidney Foundation of Canada (Secretary/Treasurer)
- Dr. Marie-Josée Clermont, Canadian Society of Nephrology
- Ms. Jane Njiha, Public Health Agency of Canada
- Dr. Vivian McAlister, Canadian Society of Transplantation
- Dr. Rosalie Starzomski, Canadian Association of Nephrology Nurses and Technicians
- Dr. Charles Poirier, Quebec Society of Transplantation
- Dr. Semeena Iqbal, Quebec Society of Nephrology
- Dr. Paul Sohi, Canadian Society of Nephrology
- Ms. Kim Young, Canadian Blood Services

### **CORR Advisory Committee (July 1, 2008)**

- Dr. John Gill, Kidney Transplantation (British Columbia), Chair
- Dr. Stanley Fenton, Nephrology (Ontario)
- Dr. Joanne Kappel, Nephrology (Saskatchewan)
- Dr. Vivian McAlister, Liver Transplantation (Ontario)
- Dr. Louise Moist, Nephrology (Ontario)
- Dr. Beth Foster, Pediatric Nephrology (Quebec)
- Dr. Jean-François Légaré, Heart Transplantation (Quebec)
- Dr. Brenda Hemmelgarn, Nephrology (Alberta)
- Dr. Tom Blydt-Hansen, Pediatric Nephrology (Manitoba)
- Ms. Raylene Matlock, Out-of-Province Transplant Coordinator (Saskatchewan)
- Dr. Tammy Keough-Ryan, Kidney Transplantation (Nova Scotia)
- Dr. Steven Paraskevas, Pancreas Transplantation (Quebec)



# Appendix B—Canadian Transplant Hospitals, Canadian Hospitals and Independent Health Facilities Providing Dialysis to Chronic Renal Failure Patients as Reported to CORR

Independent health facilities are in italics.

Hospital/Facility	Type of Transplants Performed in 2006							Dialysis Programs in 2006				
	Kidney	Liver	Heart	Heart–Lung	Lung	Intestine/ Multivisceral	Pancreas/ Kidney– Pancreas	Islet Cell	HD	Home HD Training	PD	Home PD Training
<b>Northwest Territories</b>												
<i>Stanton Territorial Health Authority</i>									X			
<b>British Columbia</b>												
B.C. Children’s	X								X		X	X
Kelowna General									X	X	X	X
Kootenay-Boundary Regional									X	X	X	X
Penticton Regional									X		X	X
Prince George Regional									X	X	X	X
Royal Columbian									X		X	X
Royal Inland									X	X	X	X
Royal Jubilee									X	X	X	X
St. Paul’s	X		X						X		X	X
Surrey Memorial									X			
Vancouver	X	X			X		X	X	X		X	X
<b>Alberta</b>												
Foothills Medical	X						X		X	X	X	X
University of Alberta	X	X	X	X	X	X	X	X	X	X	X	X
Alberta Children’s Hospital	X											
<b>Saskatchewan</b>												
Regina General									X		X	X
St. Paul’s	X								X		X	X
<b>Manitoba</b>												
Brandon Regional									X			
Health Sciences	X				X				X	X		
Seven Oaks General									X			
St. Boniface General									X		X	X

Hospital/Facility	Type of Transplants Performed in 2006							Dialysis Programs in 2006				
	Kidney	Liver	Heart	Heart–Lung	Lung	Intestine/Multivisceral	Pancreas/Kidney–Pancreas	Islet Cell	HD	Home HD Training	PD	Home PD Training
<b>Ontario</b>												
<i>Bayshore Dialysis Clinic—Brockville</i>									X			
<i>Bayshore Dialysis Clinic—Stoney Creek</i>									X			
<i>Brantford General</i>									X			
Children’s Hospital of Eastern Ontario									X		X	
<i>Cornwall Dialysis Clinic</i>									X			
Credit Valley									X	X	X	X
<i>Dialysis Mgmt. Clinics Inc.—Pickering</i>									X			
<i>Dialysis Mgmt. Clinics Inc.—Markham</i>									X			
<i>Dialysis Mgmt. Clinics Inc.—Peterborough</i>									X			
Grand River									X		X	X
Halton Healthcare Services									X			
Hamilton Health Services Corp. McMaster Children’s											X	X
Hospital for Sick Children	X	X	X			X			X	X	X	X
Hotel Dieu Health Sciences									X	X	X	X
Hôtel-Dieu Grace									X		X	X
Humber River Regional									X	X	X	X
Kingston General	X								X	X	X	X
Lakeridge Health Corp. Whitby									X	X	X	X
LHSC—University and South Street	X	X	X		X	X			X			
LHSC—Westminster									X	X	X	X
North Bay General									X			
Orillia Soldiers’ Memorial									X		X	X
<i>Ottawa–Carleton Dialysis Clinic</i>									X			
Ottawa Hospital	X								X	X	X	X
Peterborough Regional Health									X		X	X
Renfrew Victoria									X			
Sault Area Hospitals Plummer Memorial									X		X	X

*Appendix B—Canadian Transplant Hospitals, Canadian Hospitals and Independent Health Facilities Providing Dialysis to Chronic Renal Failure Patients as Reported to CORR*

Hospital/Facility	Type of Transplants Performed in 2006								Dialysis Programs in 2006			
	Kidney	Liver	Heart	Heart–Lung	Lung	Intestine/Multivisceral	Pancreas/Kidney–Pancreas	Islet Cell	HD	Home HD Training	PD	Home PD Training
Scarborough—General Division									X		X	X
<i>Sheppard Centre</i>									X			
St. Joseph’s (Hamilton)	X								X	X	X	X
St. Joseph’s (Toronto)									X		X	X
St. Michael’s	X								X	X	X	X
Sudbury Regional Laurentian Site									X	X	X	X
Sunnybrook and Women’s College									X	X	X	X
<i>Sussex Centre</i>									X			
Thunder Bay Regional McKellar Site									X		X	X
Timmins and District									X		X	X
Toronto East General									X			
Toronto General—University Health Network	X	X	X	X	X	X	X		X	X	X	X
University of Ottawa Heart Institute			X									
York Central									X		X	X
<b>Quebec</b>												
Aurores Boréales											X	
CHUS—Fleurimont	X								X		X	X
C.H. de Granby									X			
C.H. de Verdun									X		X	X
Chicoutimi									X		X	
CHUM—Hôtel-Dieu									X			
<i>C.H. de la région de l’amiante</i>									X			
CHUM—Notre-Dame	X			X	X		X		X	X	X	X
CHUM—St-Luc		X							X		X	X
C.H. des Vallées de l’Outaouais, Pavillon de Hull									X		X	X
C.H. régional de Trois-Rivières—Pavillon St. Joseph									X		X	X
CHUQ—Hôtel-Dieu	X								X	X	X	X
C.H régional de Lanaudière									X		X	
C.H. régional de Rimouski									X		X	X

Hospital/Facility	Type of Transplants Performed in 2006							Dialysis Programs in 2006				
	Kidney	Liver	Heart	Heart–Lung	Lung	Intestine/ Multivisceral	Pancreas/ Kidney– Pancreas	Islet Cell	HD	Home HD Training	PD	Home PD Training
C.H. régional du Suroît									X		X	X
C.H. Vallée-de-l'Or									X		X	X
Charles Lemoyne									X		X	X
Haut-Richelieu									X		X	X
Hôtel-Dieu d'Arthabaska									X			
Hôtel-Dieu de Lévis									X		X	X
Hôtel-Dieu de Saint-Jérôme									X		X	X
Hôtel-Dieu de Sorel									X		X	X
Institut de cardiologie de Montréal			X									
Lakeshore									X			
Laval			X						X	X	X	X
Maisonneuve-Rosemont	X								X	X	X	X
Montréal Children's – McGill	X								X		X	X
Montréal General – McGill									X	X	X	X
Royal Victoria – McGill	X	X	X	X			X		X		X	X
Sacré Coeur de Montréal									X		X	X
<i>Sainte-Croix</i>									X		X	
Sainte-Justine	X	X	X						X		X	X
Sir Mortimer B. Davis Hospital – Jewish General									X		X	X
St. Mary's									X		X	X
<b>Nova Scotia</b>												
Cape Breton Regional									X		X	X
IWK Grace Health	X								X		X	X
Queen Elizabeth II	X	x	X						X	X	X	X
Yarmouth Regional									X			
<b>New Brunswick</b>												
Chaleur Regional Hospital									X			
Edmundston									X	X	X	X
Georges L. Dumont									X	X	X	X
Saint John Regional									X	X	X	X



*Appendix B—Canadian Transplant Hospitals, Canadian Hospitals and Independent Health Facilities Providing Dialysis to Chronic Renal Failure Patients as Reported to CORR*

Hospital/Facility	Type of Transplants Performed in 2006							Dialysis Programs in 2006				
	Kidney	Liver	Heart	Heart–Lung	Lung	Intestine/Multivisceral	Pancreas/Kidney–Pancreas	Islet Cell	HD	Home HD Training	PD	Home PD Training
<b>Newfoundland and Labrador</b>												
Central Newfoundland Regional									X			
St. John’s Health Sciences									X	X	X	X
Western Memorial Regional									X			



## Appendix C—Canadian Organ Procurement Organizations

### British Columbia

British Columbia Transplant Society (BCTS)  
3rd Floor, West Tower  
555 West 12th Avenue  
Vancouver, British Columbia V5Z 3X7  
[www.transplant.bc.ca](http://www.transplant.bc.ca)

### Alberta

HOPE Program—Calgary  
Foothills Medical Centre  
1403 29th Street North West  
Calgary, Alberta T2N 2T9  
[www.crha-health.ab.ca/hlthconn/items/orgtiss.htm](http://www.crha-health.ab.ca/hlthconn/items/orgtiss.htm)

HOPE Program—Edmonton  
University of Alberta Hospital  
11402 University Avenue  
ABC1 9120a  
Edmonton, Alberta T6G 2J3

### Saskatchewan

The Saskatchewan Transplant Program  
Provincial Office  
St. Paul's Hospital  
1702 20th Street West  
Saskatoon, Saskatchewan S7M 0Z9

The Saskatchewan Transplant Program  
Regina Office  
Regina General Hospital  
1440 14th Avenue  
Regina, Saskatchewan S4P 0W5

### Manitoba

Transplant Manitoba  
Gift of Life Program  
Health Sciences Centre  
820 Sherbrooke Street, Room GE441  
Winnipeg, Manitoba R3A 1R9

## **Ontario**

Trillium Gift of Life Network  
522 University Avenue, Suite 900  
Toronto, Ontario M5G 1W7  
[www.giftoflife.on.ca](http://www.giftoflife.on.ca)

## **Quebec**

Québec-Transplant  
Head Office  
4101 Molson Street, Suite 101  
Montréal, Quebec H3Y 1L1  
[www.quebec-transplant.qc.ca](http://www.quebec-transplant.qc.ca)

Québec-Transplant  
Québec Office  
2700 Jean-Pierre Street, Suite 170  
Québec, Quebec G2C 1S9

## **Nova Scotia**

Multi-Organ Transplant Program  
Queen Elizabeth II Health Sciences Centre  
Mackenzie Building  
5788 University Avenue  
Halifax, Nova Scotia B3H 1V7  
[www.cdha.nshealth.ca/transplantservices/](http://www.cdha.nshealth.ca/transplantservices/)

## **New Brunswick**

Multiple Organ Retrieval and Exchange Program  
Department of Health and Wellness Hospital Services Branch  
PO Box 5100  
Fredericton, New Brunswick E3B 5G8  
[www.gnb.ca/0217/organ-e.asp](http://www.gnb.ca/0217/organ-e.asp)

## **Newfoundland and Labrador**

Organ Procurement and Exchange of Newfoundland and Labrador (O.P.E.N. Program)  
Health Sciences Centre  
300 Prince Phillip Parkway  
St. John's, Newfoundland and Labrador A1B 3V6

## Appendix D—CORR Data Quality Documentation: 1997 to 2006

The information in this appendix should be used in conjunction with the information presented in Section 1 of this report, Appendix E (Glossary and Commonly Used Acronyms) and Appendix F (Analytical Methods). Documentation is just one part of the comprehensive data quality program operating at CIHI. Users who require additional information are encouraged to contact CORR by sending an email message to [corr@cihi.ca](mailto:corr@cihi.ca).

### Database Description

The Canadian Organ Replacement Register (CORR) is the national information system for organ failure, transplantation, organ donation and renal dialysis, with a mandate to record and analyze the level of activity and outcome of vital organ transplantation and dialysis activities. It is a longitudinal database, following recipients with end-stage organ failure from their first treatment to their death. The national scope of CORR has been useful in informing health care policy vis-à-vis the decline in organ donation across Canada, the rise in end-stage renal disease and the evolution of organ transplantation from experimental to mainstream treatment. For a brief history of the database, please refer to Section 1 of this report.

### Data Sources and Methodology

**Target Population:** All patients who have received an extra-renal organ transplant since January 1, 1988, and all chronic renal failure patients who have initiated renal replacement therapy since January 1, 1981, form CORR's target population.

CORR does not contain information on:

- Patients who have been determined to have acute, but not chronic, renal failure;
- Recipients of tissue transplants;
- Patients who were listed for but did not receive a vital organ transplant; and
- Potential organ donors (that is, deceased donors who met the criteria for donation but from whom no organs were used for transplantation).

CORR's frame (that is, the entities that would be expected to contribute data to CORR, given its mandate) includes all the dialysis programs treating chronic renal failure patients and all the vital organ transplant programs within Canada. Data are received either directly or indirectly from these programs. Tables D1 and D2 below identify the number of dialysis programs and transplant programs in 2006, respectively, that participated in CORR directly or through a regional or provincial registry or organ procurement program.

**Table D1 Dialysis Programs Within CORR Frame by Province, 2006**

	Alta.	B.C.	Man.	N.B.	N.L.	N.W.T.	N.S.	Ont.	Que.	Sask.	Total
Full-Care Dialysis Programs	2	11	4	4	3	0	4	31	31	2	92
Affiliated Community Centres	28	24	12	4	4	0	15	42	11	6	146
Independent Health Care Facilities Offering Hemodialysis	0	0	0	0	0	1	0	10	2	0	13

**Table D2 Transplant Programs Within CORR Frame by Province, 2006**

	Alta.	B.C.	Man.	N.S.	Ont.	Que.	Sask.	Total
Kidney	3	3	1	1	7	7	1	23
Liver	1	1	0	1	3	3	0	9
Heart/Heart–Lung	1	1	0	1	4	5	0	12
Lung	1	1	1	0	2	1	0	6
Pancreas/Kidney–Pancreas	2	1	0	0	1	2	0	6
Intestine/Multivisceral	1	0	0	0	3	0	0	4

Frame maintenance procedures have been in place for several years. CORR staff is informed by provincial sources of new dialysis hospitals and generally follows the Discharge Abstract Database (DAD) in terms of assigning facility identifiers (that is, a province code from 1 to 9, along with a four-digit identifier). Unique facility identifiers are assigned to hospitals in Quebec, satellite centres and organ procurement organizations (OPOs) using a consistent notation system. All facility identifiers are identified in the *CORR Directory of Participating Dialysis Centres, Transplant Centres and Organ Procurement Organizations in Canada*, which is published annually. In addition, a formal review process was undertaken in April and May of 2002 to formally verify CORR's frame.

**Data Sources:** CORR comprises retrospectively collected demographic, clinical and outcome-related data. Data are currently received via paper forms or spreadsheets. Standardized forms are used for the purposes of paper collection, which detail the data elements and the domain values. These forms, and the accompanying instruction manuals, also guide spreadsheet submissions. Specially trained staff enters all the data received.

The CORR data model consists of 119 relational tables:

- 34 data tables;
- 68 code tables;
- 3 population tables derived from Statistics Canada; and
- 14 system tables.

The data tables contain information on 579 data elements. One of these variables is derived (MELD\_SCORE) and five are system-generated (RECIPIENT\_ID, RECIPIENT\_TREATMENT\_ID, DONOR\_ID, COMMUNITY\_CENTRE\_ID and ORGAN\_FAILURE\_CAUSE\_ID). Twelve data elements are used either alone or in combination to link the various tables.

Within CORR, data elements are classified as mandatory, conditionally mandatory or optional. Mandatory elements must be submitted and entered (for example, *recipient name, birthdate, treatment code*), whereas conditionally mandatory elements are entered only if other specific conditions are satisfied (for example, *date of death* must be entered if a *cause of death* is given). Prior to 2001, mandatory items within CORR were limited to 19 data elements. Since 2001, major changes have occurred with CORR. Data providers are encouraged to submit information on all data elements, although it should be emphasized that reporting to CORR is not provincially or nationally mandated.

The types of data captured, as well as the points of data capture within CORR, are summarized in Table D3. Changes in patients' treatment status are tracked and treatment outcomes are recorded. Information on organ donors is also collected. Facility-level data on clinical practices and policies are collected from dialysis hospitals and independent health facilities. Counts of patients waiting for a transplant are collected from OPOs.

**Table D3 Types of Data Captured and Points of Data Capture in CORR**

Dialysis Recipients	Transplant Recipients	Donors	Dialysis Hospital Programs	Hospital Transplant Programs Following Kidney Transplant Recipients	Transplant Waiting List Statistics
When initiate dialysis ↓ When: <ul style="list-style-type: none"> <li>• Transfer to another program</li> <li>• Change treatment modalities</li> <li>• Have a kidney transplant</li> <li>• Withdraw from dialysis</li> <li>• Recover kidney function</li> <li>• Die</li> </ul> ↓ Annually, on October 31 (survey with voluntary participation)	When transplanted ↓ When: <ul style="list-style-type: none"> <li>• Transfer to another program for follow-up</li> <li>• Graft fails</li> <li>• Retransplanted</li> <li>• Die</li> <li>• For liver transplant recipients only—annual follow-up to record recurrent hepatitis B, hepatitis C and liver tumour(s)</li> </ul>	When organ(s) retrieved for purposes of transplantation—deceased donor profile and living donor profile	At year-end—HD facility profile; peritoneal dialysis facility profile	At year-end—renal transplant facility profile	Counts of patients waiting for transplants at each of the transplant programs; reported on a semi-annual basis by the OPOs

Table D4 outlines the data supply chain for CORR.

**Table D4 CORR Data Supply Chain**

Province of Treatment	Dialysis Recipients	Organ Transplant Recipients	Deceased Organ Donors	Living Organ Donors	Waiting List Statistics
Alta.	Southern Alberta Renal Program (Calgary) and Northern Alberta Renal Program (Edmonton)	Hospital transplant programs	HOPE Calgary, HOPE Edmonton	Hospital transplant programs	HOPE Calgary, HOPE Edmonton
B.C.	B.C. Renal Agency, Hospital dialysis programs	B.C. Transplant Society	B.C. Transplant Society	B.C. Transplant Society	B.C. Transplant Society
Man.	Hospital dialysis programs	Hospital transplant program	Transplant Manitoba—Gift of Life Program	Hospital transplant program	Transplant Manitoba—Gift of Life Program
N.B.	Hospital dialysis programs		Multiple Organ Retrieval and Exchange Program		
N.L.	Hospital dialysis programs		O.P.E.N. Program		
N.W.T.	Hospital dialysis program				
N.S.	Hospital dialysis programs	Multi-Organ Transplant Program	Multi-Organ Transplant Program	Multi-Organ Transplant Program	Multi-Organ Transplant Program
Ont.	Hospital dialysis programs, Toronto Region Dialysis Registry	Trillium Gift of Life Network	Trillium Gift of Life Network	Trillium Gift of Life Network	Trillium Gift of Life Network
Que.	Hospital dialysis programs	Hospital transplant programs	Québec-Transplant	Hospital transplant programs	Québec-Transplant
Sask.	Hospital dialysis programs	Saskatchewan Transplant Program	Saskatchewan Transplant Program	Saskatchewan Transplant Program	Saskatchewan Transplant Program



**Error Detection:** All dialysis and transplant programs and the OPOs are provided with coding instruction manuals, which provide definitions and descriptions of each data element contained in CORR and information on how to appropriately record data. Other measures designed to help improve the consistency and quality of the data submissions include providing telephone support, conducting site visits and sending written instructions and feedback.

The data entry flow is designed to enhance error detection. On the transplant side, data relating to organ donors are entered first, followed by transplant recipient data. This facilitates identification of transplant recipient–donor links and dialysis recipients who go on to have transplants. On the dialysis side, treatment information must be entered in chronological order. This helps to identify problematic submissions (for example, inconsistent submissions regarding a patient’s status).

Upon completion of data entry, reporting centres are forwarded standardized audit reports for the purposes of verification. Changes noted by centres are made in the database. Data entry staff may also liaise with a reporting centre prior to data entry when visual scans of the returned forms reveal problems or when problems in the data have been identified through the course of analysts’ work on ad hoc requests and research projects.

In 2001, the data entry application underwent a complete redesign. CORR was converted from a Microsoft SQL server two-tier client/server architecture running on a Windows NT platform to an Oracle database with a multi-tier client/server architecture. Within the new web-based application, a number of new hard and soft edits were introduced in order to:

- Reduce entry of duplicate records (for example, matching algorithm used to reduce double entry of patient records);
- Improve consistency of data (for example, logic checks to ensure entry of treatments in a chronological sequence);
- Minimize entry of incorrect data (for example, drop-down menus used to minimize the opportunities for incorrect domain values to be inputted; entry of dates in the format YYYY-MON-DD to prevent the transposition of day and month during data entry); and
- Improve data completeness (for example, mandatory data elements cannot be bypassed; some data elements are auto populated; conditionally mandatory data elements are triggered on/off based on responses to other data elements).

In some cases where data elements are optional (for example, recipient height and weight), the new application employs soft edits, which alert data entry personnel to potential entry errors.

**Imputation:** As of December 2006, no imputed data are stored in CORR.

**Quality Evaluation:** CIHI's *Data Quality Framework*, which was implemented in 2000–2001, is based on a similar framework used at Statistics Canada and provides a common strategy for assessing data quality across CIHI databases and registries along five general dimensions:

- **Accuracy:** how well information within a database reflects what was supposed to be collected.
- **Comparability:** the extent to which a database can be properly integrated within the entire health information system at CIHI.
- **Timeliness:** whether the data are available for user needs within a reasonable time period.
- **Usability:** how easily the storage and documentation of data allow one to make intelligent use of the data.
- **Relevance:** incorporates all of the above dimensions to some degree, but focuses specifically on value and adaptability.

The framework implementation is part of the larger quality cycle in which problems are identified, addressed, documented and reviewed on a regular basis. Each CIHI data holding is evaluated for each annual release of data.

## Data Accuracy

**Coverage:** There are no known coverage errors within CORR. The program is aware of all hospitals that should report. Hospitals not included in the frame do not report to CORR. An analysis of transplant procedures as captured in the Hospital Morbidity Database (HMDB) for the calendar years 1995 to 2000 confirmed the transplant hospitals within CORR.

Duplicate patient records were identified and eliminated from the database for pre-2001 data. The new application introduced in 2001 has a matching algorithm in place that prevents duplicate entry of patients.

**Unit Non-Response:** Because CORR is updated continually, unit non-response is addressed on an ongoing basis. Those centres that fail to report to CORR in a timely and complete way are identified, and staff works with them to improve reporting. Strategies to improve reporting include telephone support and on-site support, where needed. Trending of incident dialysis patients and cross-checking of aggregate-level data sources with patient-level data are two main analytical approaches used to evaluate unit non-response. In this section, unit non-response is described for the data used in this report.

### (1) Prevalent ESRD Cases

Prevalent number of registered ESRD cases depends on new cases reporting and number of deaths. The prevalent ESRD numbers from the facility profile questionnaire were incompletely reported for the period 1997 to 2006. Hemodialysis facility profiles, from which the count of prevalent hemodialysis patients is obtained, were not provided by Montréal General Hospital (Que.) for 2000; Hôpital Charles-LeMoyne (Que.) for 2000; Hôpital du Haut-Richelieu (Que.) for 2001; and Royal Inland Hospital (B.C.) for 2002. Peritoneal dialysis facility profiles, from which the count of prevalent peritoneal dialysis patients is obtained, were not provided by Montréal General Hospital (Que.) for 2000 and

2001; Hôpital Charles-LeMoyne (Que.) for 2000; Hôpital du Haut-Richelieu (Que.) for 2001; and Royal Inland Hospital (B.C.) for 2002. In addition, there was suspected under-reporting on the peritoneal dialysis facility profiles for Wellesley Hospital (Ont.) for 1996; St. Joseph's Health Care System (Ont.) for 2000 and 2001; and Hôpital Fleurimont (Que.) for 1995 and 1996. In 2005, six facilities did not provide facility profile data to CORR; their number of cases was imputed based on patient-level data. The following hospitals were missing the hemodialysis facility profiles: CSSS de Gatineau (Que.), Ottawa-Carleton Dialysis Clinic (Ont.), Alberta Children's Hospital and Foothills Hospital (Alta.) and Surrey Memorial and Kelowna General Hospital (B.C.). Four hospitals were missing peritoneal facility profile data in 2005: CSSS de Gatineau (Que.), Alberta Children's Hospital (Alta.) and Surrey Memorial and Kelowna General Hospital (B.C.). In 2006, facility profile numbers were missing from Montréal General Hospital (Que.); Hôpital Charles-LeMoyne (Que.); Hôpital du Haut-Richelieu (Que.) and Royal Victoria (Que.); York Central and Scarborough General Hospital (Ont.); and hemodialysis numbers were missing from Capital Health in Alberta. Renal facility profiles, from which the count of functioning kidney transplants were obtained, were not provided by the Health Science Centre, Health Care Corporation of St. John's (N.L.) for 2002. For 2001, The Ottawa Hospital (Ont.) under-reported by an estimated 148 functioning kidney transplants. Data were adjusted for the unit non-response and under-reporting presented in Section 2.3 of this report.

## (2) Incident ESRD Cases

In terms of unit non-response for incident ESRD cases, under-reporting of incident ESRD cases is estimated to be 69 cases from Quebec in 2001, 115 cases from Quebec in 2002 and 15 cases from Nova Scotia in 2002. In 2005, under-reporting of incident cases for dialysis cases is estimated to be 60; and in 2006, it is estimated at around 20 cases. Chronic under-reporting of incident cases is more difficult to ascertain.

## (3) Kidney Transplants

Since the 1990s, patient-level data submitted by hospitals and OPOs are reconciled with aggregate-level counts received from OPOs, which are received in advance of patient-level data submissions. Table D5 presents a comparison of these sources, and the respective transplant counts per province for the period from 1997 to 2006, and shows that the new patient-level data are higher than the OPO aggregate counts for about 69 cases. This suggests 100% reporting and slight mis-reporting of aggregate data.

**Table D5 Comparison of Counts of Kidney Transplants\* by Data Source, 1997 to 2006 (Number)**

	Alta.	B.C.	Man.	N.S.	Ont.	Que.	Sask.	Total
Aggregate Counts Provided by OPOs at Year-End	1,352	1,293	345	947	3,829	2,339	377	10,459
Patient-Level Data for New Transplants Within CORR	1,331	1,320	346	956	3,841	2,383	374	10,551

### Note

\* Includes SKP and other kidney combination transplants.

**(4) Extra-Renal Transplants**

For the extra-renal transplants for the period from 1997 to 2006, the transplants registered in the database were compared against the aggregate counts reported by the OPOs. The results are provided in Table D6 and suggest that no under-reporting of transplant procedures was observed in the last decade.

**Table D6 Comparison of Counts of Extra-Renal Transplants\* by Data Source, 1997 to 2006 (Number)**

Organ Type	Data Source <sup>†</sup>	Alta.	B.C.	Man.	N.S.	Ont.	Que.	Total
Liver	CORR Registration	667	341	N/A	164	1,784	1,020	<b>3,976</b>
	OPO Count	590	326	4	142	1,714	897	<b>3,673</b>
Heart	CORR Registration	344	160	N/A	92	633	404	<b>1,633</b>
	OPO Count	322	170	N/A	68	589	357	<b>1,506</b>
Lung and Heart-Lung	CORR Registration	275	86	68	N/A	547	256	<b>1,199</b>
	OPO Count	223	105	40	N/A	441	205	<b>1,014</b>
Pancreas	CORR Registration	128	97	N/A	31	202	188	<b>646</b>
	OPO Count	108	60	N/A	22	203	176	<b>569</b>
Intestine/ Multivisceral	CORR Registration	5	N/A	N/A	N/A	22	N/A	<b>27</b>
	OPO Count	1	N/A	N/A	N/A	13	N/A	<b>11</b>

**Notes**

\* Includes combination transplants; combination transplants are counted under their respective organ types.

† CORR registration = patient-level data within CORR; OPO count = aggregate count provided by OPOs at year-end.

**(5) Donors**

A comparison of donors registered in CORR contrasted with donor numbers reported by OPOs at year-end is provided in Table D7. This table suggests that no under-reporting of donors has been observed in CORR; however, under-reporting by OPOs of 30 cases occurred in 2004. Overall, the number of donors collected by CORR between 1997 and 2006 was greater by 37 donors than initially reported by OPOs.

**Table D7 Comparison of Deceased and Living Donors Registered in CORR and Reported by OPOs, 1997 to 2006 (Number)**

Year	Registered in CORR			Reported by OPOs		
	Deceased Donors	Living Donors	Total Donors	Deceased Donors	Living Donors	Total Donors
1997	426	288	714	429	283	712
1998	415	369	784	415	368	783
1999	420	393	813	421	392	813
2000	472	409	881	471	409	880
2001	416	448	864	420	447	867
2002	407	441	848	405	440	845
2003	423	438	859	428	431	859
2004	417	474	914	414	468	882
2005	414	503	917	414	504	918
2006	464	556	1,020	464	554	1,018
<b>Total</b>	<b>4,274</b>	<b>4,319</b>	<b>8,593</b>	<b>4,281</b>	<b>3,828</b>	<b>7,559</b>

**Item Non-Response:** Overall, item non-response has improved over time, particularly since 1997. There are, however, some significant province-specific item non-response issues.

Table D8 presents a summary of the proportion of records with null and unknown values on key mandatory data elements within CORR for transplant recipients of first grafts for the period from 1997 to 2006, and for donors for the same period. Rates of non-response/unknowns greater than 10% are shaded.

**Table D8 Non-Response/Unknown Values for Key Analytical Data Elements Related to Donors and Transplant Recipients\* in CORR, 1997 to 2006**

Data Type	Data Element	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006
Deceased Donor	Age	0.5	0	0.7	0	0	0	0	0	0	0
	Sex	0	0	0.5	0.2	0	0.2	0.2	0.2	0	0.2
	Blood Type	0.2	0	0.5	0	0.2	0	0	3.0	0.4	0.4
	Race/Ethnic Origin	13.9	5.5	11.9	20.9	25.4	3.6	22.1	32.0	36.6	34.2
	Province of Residence (Not Formally Collected Until 2001)	80.4	88.8	83.7	85.8	0	0	0	0	0	0.2
	Cause of Death	2.8	0.5	0.7	1.0	4.8	3.8	2.5	3.2	5.4	6.6
Living Donor	Age	26.9	9.2	25.7	1.5	0	0	0	0	0	0
	Sex	48.4	4.9	20.1	0.5	0.9	0.2	0	0	0	0.5
	Blood Type	1.4	6.5	24.9	0.7	0.7	6.8	7.3	12.8	9.5	4.5
	Province of Residence (Not Formally Collected Until 2001)	98.9	99.7	98.0	99.0	0.2	0.2	0.5	1.3	1.2	2.3
Transplant Recipients	Sex	0	0	0	0	0	0	0	0	0	0
	Race/Ethnic Origin	13.5	12.1	13.7	14.6	18.7	16.6	20.0	21.3	23.8	22.3
	Blood Type	7.7	2.2	3.8	1.8	3.5	2.9	3.8	2.8	2.9	2.4
	Residential Postal Code	3.2	2.7	3.0	1.8	0.9	0.7	3.3	2.7	1.9	1.1
	Cause of Death	24.0	21.2	24.7	22.0	21.0	21.9	22.0	16.0	22.0	20.8
	Diagnosis	0.9	0.8	2.0	1.7	1.6	0.9	5.1	1.8	2.9	3.6
	Medical Status at Listing (Heart, Liver, Lung Transplants)	11.1	5.8	12.3	3.7	8.7	1.4	2.8	0.9	4.1	4.4
	Medical Status at Transplant (Heart, Liver, Lung Transplants)	5.4	2.6	6.6	0	1.7	0.5	0.3	0	0.1	0.3
Cause of Graft Failure (Transplants With Failed Grafts)	34.4	28.1	31.5	33.2	39.1	37.4	42.3	37.7	44.3	35.6	

**Note**

\* Recipients of first grafts for the period from 1997 to 2006.

Table D9 presents a summary of the proportion of records with null and unknown values on key mandatory data elements within CORR for incident dialysis patients for each year in the period from 1997 to 2006. Table D10 presents the same information stratified by province of treatment. Rates of non-response/unknowns greater than 10% are shaded.

**Table D9 Non-Response/Unknown Values for Key Analytical Data Elements Related to Incident Dialysis Patients Registered in CORR by Year, 1997 to 2006**

Data Type	Data Element	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	Total
Recipients	Sex	0	0	0	0	0	0	0	0	0.0	0.0	0.0
	Race/Ethnic Origin	12.2	12.6	13.6	14.3	6.7	6.8	7.3	6.1	4.9	7.3	8.9
	Residential Postal Code	0.9	1.4	2.4	1.3	1.2	0.9	1.4	1.3	1.7	1.3	1.4
	Diagnosis	15.7	13.0	12.5	11.9	13.9	14.7	14.3	13.6	12.7	12.5	13.5
	Cause of Death	23.2	21.8	23.1	26.3	26.2	27.2	28.8	23.5	23.7	22.8	24.9
Risk Factors	Angina	12.9	7.4	6.4	8.1	7.9	7.3	9.1	9.2	9.5	11.6	8.9
	Coronary Artery Bypass/Angioplasty	13.8	7.4	6.3	8.2	7.7	7.8	9.8	9.1	9.5	10.8	9.0
	Pulmonary Edema	13.0	7.8	6.5	8.4	7.8	7.8	9.3	9.6	9.5	11.0	9.0
	Myocardial Infarct	12.8	7.6	6.2	8.1	7.5	7.5	8.9	9.4	9.2	10.7	8.8
	Diabetes Type 1	11.5	6.8	5.3	6.5	6.5	5.0	6.6	6.8	6.7	8.0	6.9
	Diabetes Type 2	11.5	6.8	5.3	6.5	6.5	5.0	6.6	6.8	6.7	8.0	6.9
	Cerebrovascular Accident	13.1	7.4	6.5	8.4	7.1	7.3	8.4	9.0	8.6	10.6	8.6
	Peripheral Vascular Disease	13.1	7.5	6.4	8.4	7.9	8.0	9.3	9.7	9.5	11.0	9.0
	Malignancy	13.3	7.7	6.8	8.4	9.4	9.2	11.5	10.8	12.6	13.1	10.3
	Chronic Lung Disease	13.4	7.8	6.5	8.4	8.2	8.2	9.6	10.0	9.7	11.4	9.3
	Use of Medications for Hypertension	11.2	7.1	5.6	7.6	5.6	5.4	6.8	7.2	6.8	8.0	7.1
	Presence of Other Serious Illness	18.3	11.1	9.8	11.5	17.3	18.9	19.3	19.5	21.5	20.0	16.9
Current Smoker	16.7	11.1	8.1	9.5	13.2	14.5	13.5	15.7	15.9	15.6	13.4	

**Table D10 Non-Response/Unknown Values for Key Analytical Data Elements Related to Incident Dialysis Patients Registered in CORR by Province, 1997 to 2006**

Data Type	Data Element	B.C.	Alta.	Sask.	Man.	Ont.	Que.	N.B.	N.S.	N.L.	Total
Recipients	Sex	0	0	0	0	0	0.0	0.2	0	0	0.0
	Race/Ethnic Origin	25.2	11.1	1.1	3.2	7.9	3.4	4.2	15.9	3.6	8.9
	Residential Postal Code	3.4	1.1	0.6	3.9	0.6	1.3	1.9	1.3	1.3	1.4
	Diagnosis	31.0	13.6	6.6	10.6	10.4	12.7	6.6	7.5	16.2	13.5
	Cause of Death	50.2	36.6	13.3	36.0	18.8	23.6	7.3	16.9	13.0	24.9
Risk Factors	Angina	28.6	7.5	2.8	11.4	6.5	6.0	2.6	2.7	2.0	8.9
	Coronary Artery Bypass/Angioplasty	29.0	7.2	1.8	11.0	6.7	6.1	2.4	2.7	3.6	9.0
	Pulmonary Edema	29.4	7.3	1.9	10.9	6.7	6.0	2.4	3.0	3.6	9.0
	Myocardial Infarct	28.6	7.1	2.0	11.1	6.3	5.9	2.3	3.5	2.9	8.8
	Diabetes Type 1	28.2	3.9	0.9	9.9	4.2	3.6	1.8	1.5	2.0	6.9
	Diabetes Type 2	28.2	3.9	0.9	9.9	4.2	3.6	1.8	1.5	2.0	6.9
	Cerebrovascular Accident	28.3	6.7	2.0	10.9	6.4	5.2	2.3	3.1	2.3	8.6
	Peripheral Vascular Disease	29.4	6.9	2.0	11.0	6.7	5.9	2.5	3.5	3.0	9.0
	Malignancy	30.7	9.9	2.9	13.2	7.6	7.4	4.0	3.1	3.8	10.3
	Chronic Lung Disease	30.4	8.3	2.3	11.0	6.9	5.6	2.5	3.0	2.9	9.3
	Use of Medications for Hypertension	26.0	3.8	1.1	10.6	4.8	4.2	2.1	2.3	1.9	7.1
	Presence of Other Serious Illness	44.6	17.4	6.0	14.8	13.0	14.1	12.6	7.1	7.7	16.9
	Current Smoker	39.2	12.0	4.1	13.9	8.6	13.7	4.7	5.2	5.1	13.4

**Reliability/Response Bias:** No formal reliability or linkage studies with other external data sources have been undertaken to assess bias or data reliability. Based on record linkage of transplant records in the HMDB, preliminary estimates of overall error (expressed as a percentage of total non-agreement) appear to be in the range of 5% to 10%. This linkage was based on data from 1995 to 2000 for provinces other than Quebec and applied to a few core variables, including birthdate, sex and health card number.



A complete investigation of the extent and impact of reporting bias has not yet been undertaken, and users are warned that while CORR may contain the most comprehensive national data on treatment for end-stage organ failure at the present time, completeness and accuracy of data are significant issues. Bias is suspected for a number of variables, including death status, cause of death, comorbidities and treatment status. Timely updating of patients' status has not been done in a number of centres, most notably from centres in British Columbia and southern Alberta. Patient and graft survival rates for transplant recipients in Canada continue to be higher than rates reported in other countries, also likely due to under-reporting of failures and deaths.

Deaths on the waiting list, which are provided in the form of counts by OPOs, are likely to be underestimated because high-risk (medically urgent) patients are more likely to receive a transplant, and patients who are withdrawn from the list and subsequently die are not included within the death count, even if their death was attributable to lack of medical treatment (that is, organ transplantation).

## Recent Database Revisions

In 2000, the database underwent a major review involving a number of expert working groups. Data elements were in some cases eliminated or refined, and new data elements and reporting requirements were added. These changes became effective for reporting year 2001.

The main changes included:

- An expansion of the treatment modalities for dialysis;
- Addition of data elements on pre-dialysis contact;
- Addition of data elements relating to cardiac function and inotrope use on the deceased-donor profile;
- Creation of a standardized form on living donors;
- Addition of a follow-up survey of all dialysis recipients, designed to capture information on the ways in which current treatment corresponds to the *Clinical Practice Guidelines of the Canadian Society of Nephrology for the Treatment of Recipients With Chronic Renal Failure*;
- Refinement of the dialysis and renal facility profiles;
- Addition of data elements pertaining to liver tumours in liver transplant recipients;
- Addition of a follow-up questionnaire for all liver transplant recipients with diagnoses of hepatitis B, hepatitis C or liver tumours;
- Addition of comorbidities for transplant recipients and donors; and
- Addition of data elements relating to transplant procedures.

A new data model was created, which was designed to improve the flexibility of the database for analysis and facilitate the accommodation of future changes.



## Appendix E—Glossary and Commonly Used Acronyms

**Diabetes:** A disease caused by the lack of insulin in the body or the body's inability to properly use normal amounts of insulin.

- **Type 1:** Occurs when the pancreas no longer produces any or produces very little insulin. The body needs insulin to use sugar for energy. Approximately 10% of people with diabetes have type 1 diabetes.
- **Type 2:** Occurs when the pancreas does not produce enough insulin or when the body does not use the insulin that is produced effectively. Approximately 90% of people with diabetes have type 2 diabetes.

**Dialysis:** A type of renal replacement therapy, whereby the blood is cleaned and wastes and excess water are removed from the body. Sometimes dialysis is a temporary treatment. However, when the loss of kidney function is permanent, as in end-stage renal disease, dialysis must be continued on a regular basis. The only other treatment for kidney failure is kidney transplantation. There are two kinds of dialysis: hemodialysis and peritoneal dialysis.

- **Hemodialysis:** The blood is cleaned by being passed through a machine that contains a dialyser. The dialyser has two spaces separated by a thin membrane. Blood passes on one side of the membrane and dialysis fluid passes on the other. The wastes and excess water pass from the blood through the membrane into the dialysis fluid, which is then discarded. The cleaned blood is returned to the bloodstream.
- **Peritoneal dialysis:** The peritoneal cavity inside the abdomen is filled with dialysis fluid, which enters the body through a permanently implanted catheter. Excess water and wastes pass from the blood through the lining of the peritoneal cavity (the peritoneum) into the dialysis fluid. This fluid is then drained from the body and discarded. In most cases, this treatment can be performed without assistance from hospital personnel.

**End-stage renal disease (ESRD):** A condition in which the kidneys are permanently impaired and can no longer function normally to maintain life.

### Commonly Used Acronyms

**APD:** automated peritoneal dialysis  
**CAPD:** continuous ambulatory peritoneal dialysis  
**COPD:** chronic obstructive pulmonary disease  
**CORR:** Canadian Organ Replacement Register  
**CSN:** Canadian Society of Nephrology  
**CST:** Canadian Society of Transplantation  
**ESRD:** end-stage renal disease  
**HD:** hemodialysis  
**ICU:** intensive care unit  
**OPO:** organ procurement organization  
**PAK:** pancreas after kidney transplantation  
**PD:** peritoneal dialysis  
**PMP:** per million population  
**PTA:** pancreas transplant alone (isolated pancreas transplantation)  
**RRT:** renal replacement therapy  
**SD:** standard deviation  
**SKP:** simultaneous kidney–pancreas transplantation

**Graft survival:** Graft survival refers to whether an organ is still functioning at a certain time after transplantation. The four time points used in this report are three months, one year, three years and five years.

**Median waiting time:** This statistic reports the middle waiting time value for recipients of an extra-renal transplant. It means that half the recipients waited less than this value, and the remaining half waited more than the value. CORR does not have patient-level data for patients who were listed for a transplant but did not receive a transplant. Thus, these waiting times provide only a partial picture. For kidney transplant patients, time between first dialysis and first kidney transplant is used.

**Medical urgency status codes:** Liver, heart and lung patients are assigned a status code at the time of their listing for a transplant. This status code corresponds to their medical condition and how urgently they require transplantation. The status codes are updated regularly until a patient is transplanted. CORR collects the initial listing status and the status at the time of transplant.

**New patient:** A patient with end-stage renal disease who began renal replacement therapy for the first time (either dialysis or renal transplantation) in the calendar year. Also known as an incident patient (see Section 2.1).

**Organ donor:** A person who donates one or more organs that are used for transplantation. Organ donors may be deceased or living.

- **Deceased donor:** A person for whom neurological death has been determined, consent has been obtained and organs are offered for transplantation. Neurological determination of death means that there is an irreversible absence of clinical neurological function as determined by definite clinical and/or neuro-imaging evidence. Within CORR, deceased donors are defined as those donors who originated in Canada and who have had at least one solid organ used for transplantation. Solid organs that can be donated after death include the heart, liver, kidneys, pancreata, lungs, intestine and stomach.
- **Living donor:** A donor with a biological (related) and/or emotional relationship (unrelated) to the transplant recipient. Living donors most commonly donate one of their kidneys. A lobe of the liver, a lobe of the lung or a segment of the pancreata or the intestine may also be donated by a living donor. At the time of this report, living pancreas and intestine transplants had not been performed in Canada.

**Organ procurement organization (OPO):** An organization responsible for coordinating the recovery and distribution of organs from deceased donors in its province or region. Since not all provinces in Canada perform extra-renal transplants, OPOs from across the country coordinate their activities to ensure that those patients on the extra-renal organ transplant waiting lists who most urgently require a transplant are offered a suitable organ first.

**Organ transplantation:** Surgical procedure that involves transplantation of organs or parts of organs recovered from deceased or living donors to recipients with end-stage organ failure. Organs that can be transplanted include the heart, liver, kidneys, pancreas, lungs, intestine and stomach. The single-organ kidney transplant is the most commonly performed transplant procedure. In rare cases, two or more organs may be transplanted. Organs used in these transplants may be from one or more donors.

- **Combination organ transplantation:** Surgical procedure that involves transplantation of organs or parts of organs to recipients who have more than one organ with end-stage organ failure. The most frequent examples of combination transplants in Canada are kidney–liver and kidney–heart transplants, where patients have end-stage renal failure along with liver or heart failure. Organs used in these transplants are usually from the same donor.
- **Islet cell transplantation:** A medical procedure that involves replacing the insulin-producing cells of the pancreas (islet cells), which are destroyed in people with type 1 diabetes. In Canada, islet cells are retrieved from the pancreas of deceased organ donors, although they may be preserved for a period of time prior to being used for transplantation. Islet cell transplants are currently not captured within CORR.
- **Kidney transplantation:** A procedure during which one or two kidneys from a deceased organ donor, or one kidney from a living organ donor, are surgically recovered and implanted into a person with end-stage renal disease. Not all persons with end-stage renal disease are candidates for kidney transplantation. Most people with end-stage renal disease receive dialysis prior to a kidney transplant.
- **Multivisceral transplantation:** A rare surgical procedure that involves transplantation of the liver, small intestine, pancreas, stomach and duodenum (also known as a cluster transplant).
- **Pre-emptive kidney transplant:** An organ transplant that includes a kidney, where the patient has not been treated with dialysis prior to the transplant.

**Organ transplant waiting list:** A list of patients awaiting organ transplantation. Lists are maintained by the OPOs. Information on urgent liver and heart patients is shared across provinces. Each list identifies active and on-hold patients.

- **Active patient:** A patient on the organ transplant waiting list who can receive a transplant at any time.
- **On-hold patient:** A patient on the organ transplant waiting list who cannot receive a transplant for medical or other reasons for a short period of time.

**Patient survival:** Patient survival refers to whether a transplant recipient is still alive at a certain time after transplantation. The four time points used in this report are three months, one year, three years and five years.

**Prevalent patient:** A patient who is alive and receiving renal replacement therapy for end-stage renal disease on December 31 of a given year, regardless of date of initiation of treatment. Counts of prevalent patients are obtained from treatment hospitals providing patient status change data and facilities on the year-end hemodialysis facility profile and peritoneal facility profile (see sections 2.2. and 2.3).

**Registered patient:** A patient who began renal replacement therapy for end-stage renal disease for the first time in 1981 or thereafter and is registered in CORR. The progress of registered patients is monitored each year (see Section 2.2).

**Renal replacement therapy (RRT):** Procedures of hemodialysis, peritoneal dialysis and kidney transplantation, which in part temporarily or permanently replace a person's failed kidneys.

## Appendix F—Analytical Methods

### Age Calculation

The computation of patient age is based on a count of months between birthdate and treatment date, which is then divided by 12. This calculation yields a whole number in years. For donors, age is collected in terms of a code (for example, *newborn, days, months, years*) and unit (for example, *2, 12, 35*) as birthdate is not part of the donor data set. For the purposes of this report, donor age is converted to a year-based whole number.

### Deceased Organ Donors

Deceased organ donors, as described in Section 8, are defined as donors identified in Canadian hospitals where at least one organ was recovered and used for transplantation. A donor is different from a donated organ. Donors described under the organ-specific transplant sections of the report, however, include donors from the United States.

### Graft Survival

The SAS® procedure, PROC LIFETEST method (also known as actuarial survival) is used in the calculation of unadjusted (crude) graft survival rates. The graft survival rates are computed for first organ-specific grafts for patients who are transplanted in each year from 1997 to 2006 at four intervals: three months, one year, three years and five years. Patients are followed until graft failure, death (with or without a functioning graft) or the end of observation (December 31, 2006). Five-year graft survival is reported for patients transplanted in years 1997 to 2001; three-year survival is reported for patients transplanted in years 1997 to 2003. For all years, three-month and one-year survival rates are presented.

### Incident ESRD RRT Patients

Counts and rates are based on patients registered during a given calendar year (January 1 to December 31). An incident patient must start RRT for ESRD in a Canadian facility. Patients who began RRT for ESRD outside of Canada, but are subsequently treated in Canada, are included in registered and prevalent counts, but not incident counts.

### Cause of Death

In Table 5, the following CORR codes are used for the cause of death categories: cardiac—codes 11, 12, 13, 14, 15, 16, 17, 18; social—codes 50, 51, 52, 53, 54 (includes patients who withdrew from dialysis, but for whom no cause of death or date of death was specified); infections—codes 03, 04, 05, 06, 07, 08, 09, 10, 31, 32, 33, 34, 35, 36, 37, 38, 39, 77; vascular—codes 21, 22, 24, 25, 26, 27, 28, 30, 55, 56, 57; gastrointestinal—codes 02, 20, 23, 29, 62, 68, 70, 72; malignancy—codes 66, 67; accidental—codes 81, 82; other—codes 19, 40, 41, 42, 43, 44, 45, 46, 49, 59, 61, 63, 64, 69, 71, 73, 74, 75, 76, 90, 99; unknown—codes 00, 47, 48. This categorization varies slightly from previously reported data.

### Organ Recovery Rates

Organ recovery rates (deceased) described in the report are based on organs recovered and transplanted from deceased donors identified in Canadian hospitals.

## Adjusted Mortality Risk

The adjusted mortality risk analysis (Cox regression) was used to determine whether or not certain risk factors may be influencing survival or failure times in dialysis and kidney transplant patients.

For the Cox regression analysis, the cohort of dialysis and transplant patients starting dialysis or receiving first grafts between 1997 and 2001 was used. The cohort members were followed until second transplant, death, loss to follow-up or the end of the observation period (December 31, 2006).

Hazard ratio with upper and lower confidence intervals are presented in the following tables, which were used for creating figures 4 and 5.

### Adjusted Mortality Risk for Dialysis Patients, Canada, 1997 to 2001, Followed to 2006 (N = 20,484), Pertaining to Figure 4

Parameter	Estimate	Standard Error	Hazard Ratio (HR)	HR Lower Confidence Limit	HR Upper Confidence Limit
Hemodialysis			1.00	1.00	1.00
Peritoneal Dialysis	-0.0690	0.0249	0.93	0.89	0.98
18–44 Years (Ref.)			1.00	1.00	1.00
0–17 Years	-0.5987	0.2339	0.55	0.35	0.87
44–54 Years	0.4674	0.0548	1.60	1.43	1.78
55–64 Years	0.8040	0.0498	2.24	2.03	2.46
65–74 Years	1.1704	0.0476	3.22	2.94	3.54
75+ Years	1.5940	0.0483	4.92	4.48	5.41
Race: Caucasian (Ref.)			1.00	1.00	1.00
Race: Asian	-0.5145	0.0516	0.60	0.54	0.66
Race: Black	-0.5416	0.0724	0.58	0.51	0.67
Race: Aboriginal	0.0160	0.0491	1.02	0.92	1.12
Race: Other	-0.4606	0.0546	0.63	0.57	0.70
Race: Unknown	0.0164	0.0291	1.02	0.96	1.08
1997–1999 Dialysis (Ref.)			1.00	1.00	1.00
2000–2001 Dialysis	-0.0904	0.0190	0.91	0.88	0.95
Glomerulonephritis (Ref.)			1.00	1.00	1.00
Diabetes	0.5738	0.0372	1.78	1.65	1.91
Polycystic Kidney	-0.0217	0.0538	0.98	0.88	1.09
Hypertensive Kidney	0.2341	0.0426	1.26	1.16	1.37
Renal Vascular	0.3917	0.0448	1.48	1.36	1.62
Other Diagnosis	0.6174	0.0438	1.85	1.70	2.02
Unknown Diagnosis	0.5643	0.0417	1.76	1.62	1.91
Cardiac Comorbidity	0.2521	0.0202	1.29	1.24	1.34
Vascular Comorbidity	0.2439	0.0211	1.28	1.22	1.33



### Cox Mortality Model for Kidney Adult Transplant Patients, 1997 to 2001, Followed to 2006, Pertaining to Figure 5

Parameter	Estimate	Standard Error	Hazard Ratio (HR)	HR Lower Confidence Limit	HR Upper Confidence Limit
Age 18–44 Years (Ref.)			1.00	1.00	1.00
Age 0–17 Years	-0.3392	0.3027	0.71	0.39	1.29
Age 45–54 Years	0.4779	0.1168	1.61	1.28	2.03
Age 55–64 Years	1.0262	0.1139	2.79	2.23	3.49
Age 65+ Years	1.4582	0.1317	4.30	3.32	5.56
Race: Caucasian (Ref.)			1.00	1.00	1.00
Race: Asian	-0.3639	0.1956	0.70	0.47	1.02
Race: Black	-1.0069	0.3071	0.37	0.20	0.67
Race: Aboriginal	0.2515	0.2017	1.29	0.87	1.91
Race: Other	-0.8162	0.2479	0.44	0.27	0.72
Race: Unknown	0.0988	0.1627	1.10	0.80	1.52
Transplant year: 1997–1999 (Ref.)			1.00	1.00	1.00
Transplant year: 2000–2001	-0.4973	0.0968	0.61	0.50	0.74
Renal Vascular Disease	0.2598	0.1446	1.30	0.98	1.72
Diabetes Type 1	0.8805	0.1053	2.41	1.96	2.97
Diabetes Type 2	0.8321	0.1493	2.30	1.72	3.08
Living Donor	-0.4050	0.1063	0.67	0.54	0.82
Dialysis Duration (Year)	0.1467	0.0351	1.16	1.08	1.24

### Population Estimates Used in Rate Calculations

Rates presented in this report are either crude or age-specific, and are not age-standardized.

Crude rate = (number of cases/population) x 1,000,000

Age-specific rate = (number of cases in age group/population of age group) x 1,000,000

All Canadian population estimates are from the Statistics Canada report, Statistics Canada, CANSIM, table 051-0001, and are based on total population figures for July 1. Population estimates for the United States and France are total mid-year population estimates from the United States Census Bureau, International Data Base, at [www.census.gov/ipc/www/idbnew.html](http://www.census.gov/ipc/www/idbnew.html).

Province	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006
B.C.*	3,980,335	4,014,219	4,042,119	4,069,619	4,108,576	4,145,550	4,182,843	4,227,592	4,285,510	4,341,681
Alta.†	2,897,575	2,966,642	3,020,731	3,072,939	3,125,682	3,186,560	3,229,988	3,274,349	3,329,790	3,448,406
Sask.	1,018,067	1,017,506	1,014,707	1,007,767	1,000,134	995,886	994,428	995,391	994,126	985,386
Man.	1,136,137	1,137,515	1,142,491	1,147,373	1,151,285	1,155,584	1,161,552	1,170,268	1,177,556	1,177,765
Ont.	11,228,284	11,367,018	11,506,359	11,685,380	11,897,647	12,102,045	12,256,645	12,392,721	12,541,410	12,686,952
Que.	7,274,630	7,295,973	7,323,308	7,357,029	7,396,990	7,445,745	7,492,333	7,542,760	7,598,146	7,651,531
Atlantic‡	2,372,144	2,358,209	2,354,163	2,348,928	2,340,937	2,341,217	2,342,677	2,343,235	2,343,969	2,331,769

**Notes**

\* Includes the Yukon.

† Includes the Northwest Territories and Nunavut.

‡ Includes New Brunswick, Newfoundland and Labrador, Nova Scotia and Prince Edward Island (see breakdown below).

Atlantic Provinces	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006
N.B.	752,543	750,551	750,611	750,518	749,890	750,327	750,896	751,384	752,006	749,168
N.L.	551,011	539,932	533,409	528,043	521,986	519,449	518,350	517,027	515,961	509,677
N.S./P.E.I.	1,068,590	1,067,726	1,070,143	1,070,367	1,069,061	1,071,441	1,073,431	1,074,824	1,076,002	1,072,924
<b>Total</b>	<b>2,372,144</b>	<b>2,358,209</b>	<b>2,354,163</b>	<b>2,348,928</b>	<b>2,340,937</b>	<b>2,341,217</b>	<b>2,342,677</b>	<b>2,343,235</b>	<b>2,343,969</b>	<b>2,331,769</b>

For Table 35, the following child population (< 18 years) estimates were used.

	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006
B.C.*	922,209	920,129	914,437	907,328	900,396	888,732	877,882	869,646	867,966	864,480
Alta.†	776,805	785,075	787,012	788,193	787,870	789,641	787,376	785,038	788,342	805,279
Sask.	277,114	273,975	269,649	264,349	258,241	252,975	248,051	244,033	240,950	236,225
Man.	293,056	291,355	290,694	289,809	288,338	286,255	284,449	283,608	282,600	279,696
Ont.	2,709,476	2,731,584	2,744,445	2,766,649	2,793,673	2,803,770	2,792,395	2,776,729	2,777,653	2,776,967
Que.	1,664,663	1,642,069	1,616,863	1,596,734	1,580,565	1,567,208	1,553,393	1,543,295	1,538,081	1,534,706
N.B.	174,592	171,255	168,464	165,611	162,339	159,122	155,947	153,025	150,784	147,483
N.L.	131,533	125,831	121,353	117,367	112,995	109,225	106,036	103,240	101,458	98,617
N.S./P.E.I.	252,244	248,322	245,024	241,738	237,535	233,016	228,696	224,166	220,019	215,333
<b>Total</b>	<b>7,201,692</b>	<b>7,189,595</b>	<b>7,157,941</b>	<b>7,137,778</b>	<b>7,121,952</b>	<b>7,089,944</b>	<b>7,034,225</b>	<b>6,982,780</b>	<b>6,967,853</b>	<b>6,958,786</b>

**Notes**

\* Includes the Yukon.

† Includes the Northwest Territories and Nunavut.

## Prevalent Patients

Prevalent patient numbers at year-end are based on patient-level data, which include registering patients with CORR. These are called prevalent-registered patients, while prevalent ESRD patients present facility numbers, which are obtained on year-end when the facility profiles are provided by Canadian renal programs. Within these questionnaires, centres are asked to record the number of patients by their modality at year-end. These counts are compared against registered patients within CORR. Over time, the numbers yielded from the facility profiles and patient-level data within CORR have become nearly identical to the dialysis counts. Although converging over time, the counts of patients with a functioning kidney transplant from the facility profiles and the patient-level data are still divergent. As such, the facility profiles might continue to provide the most comprehensive picture of the burden of ESRD on the health care system.

## Primary Diagnosis

For extra-renal transplant recipients, primary diagnosis is based on the diagnosis made at the time of the patient's first transplant. In some cases, most usually for liver transplant recipients, more than one diagnosis may be recorded. For kidney transplant recipients, primary diagnosis is based on the diagnosis provided at the time of incident dialysis treatment, as well as diagnosis at the time of kidney transplant for non-pre-emptive kidney transplants.

## Registered Patients

Registered patients are patients for whom CORR has patient-level information; the term includes patients who are being treated at a Canadian renal program with dialysis at year-end or who have a functioning kidney transplant at year-end. Prevalent registered patients were presented in Section 2.2.

The prevalent number of registered patients in CORR may vary from prevalent counts provided in the annual facility profiles for the following reasons:

- Not all patients will be registered in CORR because they may have started treatment prior to January 1, 1981;
- Incident patients have been under-reported by some reporting centres; and
- Deaths are suspected to be under-reported to CORR, potentially inflating numbers of living patients.

## Transplant Recipients

Information presented on transplant recipients in this report looks at recipients of first grafts of a specific organ where transplants occurred at a Canadian transplant facility. Tables and figures presented in sections 3 to 7, inclusive, refer either to transplant procedures or recipients, with the latter counting patients only one time for their first organ-specific graft. Recipient characteristics and province-specific rates are based on transplant recipients.

## **Waiting List**

Data reported on patients waiting for transplants come from counts provided by provincial and regional OPOs. Patient-level data are not available. For patients waiting for a kidney transplant, the definition of a pediatric patient was changed in 2002 from younger than age 15 to younger than age 18. This definition is now in line with the definition of pediatric patient used for extra-renal transplants.

## **Waiting Times**

Waiting list times are calculated for patients who received extra-renal transplants; they do not include patients who died while waiting or those patients withdrawn from the list because they became too sick to undergo a transplant. There is currently no national source of information on wait times for all patients listed for transplantation.

For patients who received a kidney transplant, a proxy measure of waiting time (that is, time spent on dialysis pre-transplant) is used. While this approach avoids the problem of incomplete data on waiting list start dates for prospective kidney transplant recipients within CORR, it does not factor in the waiting time for patients who were listed for a kidney transplant but for whom no transplant occurred. A wait time of 0 is allocated to patients who received a pre-emptive kidney transplant.

## Appendix G—Treatment of End-Stage Organ Failure in Canada, 1997 to 2006: Outcomes, Clinical Indicators and International Comparisons

### List of Tables Found on the CIHI Website ([www.cihi.ca](http://www.cihi.ca))

- |          |   |
|----------|---|
| Table 1  | Unadjusted Three-Month and One-, Three- and Five-Year Survival in Dialysis Patients, Canada, 1997 to 2001, With Follow-Up Until 2006                                    |
| Table 2  | Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Adult Kidney Transplant Recipients, First Graft, Canada, 1997 to 2001 (Followed to 2006)     |
| Table 3  | Unadjusted Three-Month and One-, Three- and Five-Year Graft Survival for Adult Kidney Transplant Recipients, First Graft, Canada, 1997 to 2001 (Followed to 2006)       |
| Table 4  | Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Pediatric Kidney Transplant Recipients, First Graft, Canada, 1997 to 2006                    |
| Table 5  | Unadjusted Three-Month and One-, Three- and Five-Year Graft Survival for Pediatric Kidney Transplant Recipients, First Graft, Canada, 1997 to 2006                      |
| Table 6  | Unadjusted Three-Month and One-, Three- and Five-Year Patient and Pancreas Graft Survival Rates, First SKP Grafts, Canada, 1997 to 2001 (Percentage) (Followed to 2006) |
| Table 7  | Incident ESRD RRT Patients by Age Group and Cause of Death, 1997 to 2006 (Number and Percentage)  |
| Table 8  | Type of Access for Point Prevalent Hemodialysis Patients by Province of Treatment, Canada, December 31, 2006 (Number and Percentage)                                    |
| Table 9  | Average eGFR (MDRD Formula) at the Initiation of Dialysis Treatment, Canada, 2002 to 2006 (Number and Average)  |
| Table 10 | Follow-Up Average Hemoglobin by Treatment Type and Year; Follow-Up Hemoglobin Range by Treatment Type and Year  |
| Table 11 | Follow-Up Erythropoietin Usage by Treatment and Year (Percentage)   |
| Table 12 | Follow-Up Average Albumin by Treatment Type; Follow-up Albumin Range by Treatment Type (Percentage)   |

### List of Figures Found on the CIHI Website ([www.cihi.ca](http://www.cihi.ca))

- |          |  |
|----------|--|
| Figure 1 | Unadjusted Three-Month and One-, Three- and Five-Year Survival in Dialysis Patients, by Age Group, Canada, 1997 to 2001 (Followed to 2006) |
| Figure 2 | Unadjusted Three-Month and One-, Three- and Five-Year Survival in HD Patients, by Age Group, Canada, 1997 to 2001 (Followed to 2006)       |

- Figure 3 Unadjusted Three-Month and One-, Three- and Five-Year Survival in Patients Treated With PD, by Age Group, Canada, 1997 to 2001 (Followed to 2006)
- Figure 4 Unadjusted Three-Month and One-, Three- and Five-Year Survival in Dialysis Patients, by Treatment Type and Sex, Canada, 1997 to 2001 (Followed to 2006)
- Figure 5 Unadjusted Three-Month and One-, Three- and Five-Year Survival in Dialysis Patients (All), by Race, Canada, 1997 to 2001 (Followed to 2006)
- Figure 6 Unadjusted Three-Month and One-, Three- and Five-Year Survival in HD Patients, by Race, Canada, 1997 to 2001 (Followed to 2006)
- Figure 7 Unadjusted Three-Month and One-, Three- and Five-Year Survival in Patients Treated With PD, by Race, Canada, 1997 to 2001 (Followed to 2006)
- Figure 8 Unadjusted Three-Month and One-, Three- and Five-Year Survival in Dialysis Patients, by Etiology of Renal Failure, Canada, 1997 to 2001 (Followed to 2006)
- Figure 9 Unadjusted Three-Month and One-, Three- and Five-Year Survival in HD Patients, by Etiology of Renal Failure, Canada, 1997 to 2001 (Followed to 2006)
- Figure 10 Unadjusted Three-Month and One-, Three- and Five-Year Survival in PD Patients, by Etiology of Renal Failure, Canada, 1997 to 2001 (Followed to 2006)
- Figure 11 Adjusted Mortality Risk for Dialysis Patients, Canada 1997 to 2001 (Followed to 2006)
- Figure 12 Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Adult Kidney Transplant Recipients, First Graft, Deceased Donor, by Age at Transplant, Canada, 1997 to 2001 (Followed to 2006)
- Figure 13 Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Adult Kidney Transplant Recipients, First Graft, Living Donor by Age at Transplant, Canada, 1997 to 2001 (Followed to 2006)
- Figure 14 Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Adult Kidney Transplant Recipients, First Graft, Deceased Donor, by Diagnosis, Canada, 1997 to 2001 (Followed to 2006)
- Figure 15 Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Adult Kidney Transplant Recipients, First Graft, Living Donor, by Diagnosis, Canada, 1997 to 2001 (Followed to 2006)
- Figure 16 Unadjusted Three-Month and One-, Three- and Five-Year Graft Survival for Adult Kidney Transplant Recipients, First Graft, Deceased Donor, by Age Groups, Canada, 1997 to 2001 (Followed to 2006)
- Figure 17 Unadjusted Three-Month and One-, Three- and Five-Year Graft Survival for Adult Kidney Transplant Recipients, First Graft, Living Donor, by Age Groups, Canada, 1997 to 2001 (Followed to 2006)
- Figure 18 Unadjusted Three-Month and One-, Three- and Five-Year Graft Survival for Adult Kidney Transplant Recipients, First Graft, Deceased Donor, by Primary Diagnosis, Canada, 1997 to 2001 (Followed to 2006)

- Figure 19 Unadjusted Three-Month and One-, Three- and Five-Year Graft Survival for Adult Kidney Transplant Recipients, First Graft, Living Donor, by Primary Diagnosis, Canada, 1997 to 2001 (Followed to 2006)
- Figure 20 Cox-Adjusted Mortality Rates for Adult Kidney Transplant Patients, Canada, 1997 to 2001 (Followed to 2006)
- Figure 21 Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Deceased-Donor Liver Transplant Recipients, First Graft, Canada, 1997 to 2006
- Figure 22 Unadjusted Three-Month and One-, Three- and Five-Year Graft Survival for Deceased-Donor Liver Transplant Recipients, First Graft, Canada, 1997 to 2006
- Figure 23 Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Deceased-Donor Liver Transplant Recipients by Age Group, First Graft, Canada, 1997 to 2001 (Followed to 2006)
- Figure 24 Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Deceased-Donor Liver Transplant Recipients by Medical Status at Transplant, First Graft, Canada, 1997 to 2001 (Followed to 2006)
- Figure 25 Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Heart Transplant Recipients, First Graft, Canada, 1997 to 2006
- Figure 26 Unadjusted Three-Month and One-, Three- and Five-Year Graft Survival for Heart Transplant Recipients, First Graft, Canada, 1997 to 2006
- Figure 27 Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Heart Transplant Recipients by Age Group, First Graft, Canada, 1997 to 2006
- Figure 28 Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Heart Transplant Recipients by Primary Diagnosis, First Graft, Canada, 1997 to 2006
- Figure 29 Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Heart Transplant Recipients by Medical Status at Transplant, First Graft, Canada, 1997 to 2001 (Followed to 2006)
- Figure 30 Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Lung Transplant Recipients, First Graft, Deceased-Donor Lungs, Canada, 1997 to 2006
- Figure 31 Unadjusted Three-Month and One-, Three- and Five-Year Graft Survival for Lung Transplant Recipients, First Graft, Deceased-Donor Lungs, Canada, 1997 to 2006
- Figure 32 Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Lung Transplant Recipients by Primary Diagnosis, First Graft, Deceased-Donor Lungs, Canada, 1997 to 2001 (Followed to 2006)
- Figure 33 Deceased-Donor Kidney Transplants, Canada, France and United States, 1997 to 2006 (Crude Rate PMP)

- Figure 34 Living-Donor Kidney Transplants, Canada, France and United States, 1997 to 2006 (Crude Rate PMP)
- Figure 35 Liver Transplants, Canada, France and United States, 1997 to 2006 (Crude Rate PMP)
- Figure 36 Heart Transplants, Canada, France and United States, 1997 to 2006 (Crude Rate PMP)
- Figure 37 Lung Transplants, Canada and the United States, 1997 to 2006, France, 2002 to 2006 (Crude Rate PMP)



