Treatment of End-Stage Organ Failure in Canada

1996 to 2005

2007 Annual Report

Canadian Organ Replacement Register

Canadian Institute for Health Information
Institut canadien d'information sur la santé

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Acknowledgements

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Report Highlights

End-Stage Renal Disease

- Between 1999 and 2005, the rate of incident renal replacement therapy rose 36% in Canada from 119 to 162 per million population (PMP).
- At the end of 2005, a total of 32,375 Canadians with end-stage renal disease (ESRD) were registered in CORR, with 19,721 patients on dialysis and 12,654 living with a functioning kidney transplant.
- In 2005, more than half of the new ESRD patients (54.7%) initiated renal replacement therapy at age 65 years or older.
- The mortality risk over a 10-year time span was reduced by 10%.
- The number of living-donor kidneys for adult patients increased by 65.6% between 1996 and 2005.
- The five-year survival rate for recipients of living-donor kidneys was 95.1%, compared to 92.3% for those receiving a kidney from a deceased donor.
- The largest mortality risk was found for patients aged 65 years and older, the second largest was for those in the 55-to-64-year age group and the third largest was for those with type 2 diabetes.

End-Stage Liver Disease

- The number of liver transplants performed on pediatric patients increased by 23.5% annually between 1996 and 2005, while the number of liver transplants in those aged 18 years and older increased by 21.2%.
- Less than 2% of liver transplants in Canada were combination transplants.
- The number of patients waiting for a liver transplant grew steadily over the 10 years, with an overall increase of 245%.
- The majority of patients (70%) received their liver transplant after being placed on the waiting list as Status 1 (non-urgent).
- Between 1996 and 2005, the highest five-year survival rate was among those patients aged 11 to 17 years.

End-Stage Heart Disease

- Between 1996 and 2005, 1,622 patients received a first heart transplant and 58 were retransplanted.
- The number of heart transplants per year increased by 4%, from a low of 167 in 1996 to a high of 174 in 2005.
- Between 1996 and 2005, the unadjusted patient survival rates for those with first heart transplants improved for all observation times (three months, one year, three years and four years).
- Compared to those with coronary artery disease or congenital heart diseases, those with cardiomyopathy as the cause of end-stage heart disease had improved survival at all time points. The proportion of hearts recovered for transplant from deceased donors showed a steady decline over the decade, with an overall relative decline of 14.3%.

End-Stage Lung Disease

- The number of adult lung transplants increased by 92% between 1996 and 2005.
- Bilateral lung transplants accounted for 82.1% of the lung transplants performed in Canada in 2005, which more than doubled between 1996 and 2005.
- Among all solid organ transplantations, lung transplantation is the only procedure where Canadian rates have not been consistently below those reported in the United States.
- Despite a 17% increase in the number of donors from whom both lungs were retrieved, the rate of lung recovery from deceased donors was 32.6% in 2005.
- There was improved patient survival rate throughout the decade, with the largest improvement seen in one- and three-year survival rates, or a 10% and 23.4% improvement respectively.

End-Stage Pancreas Disease

- Out of 553 pancreas transplants performed in Canada between 1996 and 2005, two-thirds were simultaneous pancreas–kidney transplants.
- The average age of first pancreas transplant recipient during the decade was 40.3 years.
- The number of patients waiting for a simultaneous pancreas–kidney transplant peaked in 2001 at 172, dropping to 113 in 2005.
- After having received a simultaneous pancreas–kidney transplant, patient survival at the five-year mark was 90.9%.
- The average age of pancreas donors was relatively low at 30 years of age.

End-Stage Intestinal Disease

- Intestine transplantation was performed infrequently in Canada, with only 38 transplants performed between 1988 and 2005.
- The cause of intestinal failure that was most commonly reported was a metabolic disorder which includes short-gut syndrome.
- Two-thirds of the recipients who received only the intestine, or a combined intestine/liver or kidney, were younger than 18 years of age.
- Thirteen graft failures were reported between 1988 and 2005.
- Small intestines were recovered for transplantation in less than 1% of all deceased donors in Canada.

Deceased-Organ Donation

- There were 4,238 deceased-organ donors between 1996 and 2005.
- The mean age of donors increased from 36.8 years in 1996 to 45.0 years in 2005.
- The most frequently observed cause of death in donors in 2005 was cerebrovascular accident/stroke.
- The average number of organs transplanted from each deceased donor in 2005 was 3.7.
- The highest number of organs transplanted per donor (4.6) was in the donor age group of 15 to 39 years.

Pediatric End-Stage Renal Disease

- There has been a slight drop in the incidence of children with a new diagnosis of ESRD over the past 25 years.
- The number of children being treated for ESRD in Canada has grown by 65% over the 25-year period of study.
- The proportion of children and youth being treated through transplantation over the 25-year period has doubled.
- The growth indicators for children with ESRD have not changed over the period under study.
- Overall, there has been improved survival rate for children and youth with ESRD in Canada, particularly in the youngest age group (birth to 4 years).

1. Introduction

The Canadian Organ Replacement Register (CORR) is the national information system for renal and extra-renal organ failure and transplantation in Canada. It has a mandate to record and analyze the level of activity and outcomes of solid organ transplantation and renal dialysis activities.

Since the early 1970s, there has been a Canadian register of renal failure statistics in various forms. The first registry in Canada was started in 1972 under the leadership of Dr. Arthur Shimizu. Known as the Canadian Renal Failure Registry, it was transferred to Statistics Canada in 1973 in collaboration with The Kidney Foundation of Canada. Its first report was produced in 1974, and in the mid-1970s a more detailed report of annual dialysis and kidney transplantation activity was developed. The project faltered briefly in the late 1970s, but was revived in 1980 under a new partnership between The Kidney Foundation of Canada, Health Canada and Statistics Canada, under 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, CORR became fully integrated with CIHI, which maintains numerous health-related national registries and data holdings.

The mission of CORR is to provide a national database on vital organ replacement therapy in Canada, with the goal of enhancing treatment, research and patient care. Major stakeholders include the Canadian Society of Transplantation, the Canadian Society of Nephrology, the Canadian Association of Transplantation, Health Canada, The Kidney Foundation of Canada and the Canadian Association of Nephrology Nurses and Technologists. The CORR Board of Directors is responsible for providing strategic advice to the register. The Advisory Committee provides advice on analytical issues and reporting. (For a membership list of the Board of Directors and the Advisory Committee as of August 1, 2007, please see Appendix A.)

1.1 Data Sources

CORR collects data from hospital dialysis programs, regional transplant programs, organ procurement organizations 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, which are entered at CIHI by specially trained staff. As in other international registries reporting on end-stage organ failure, data within the database are collected and reported by calendar year (January 1 to December 31) in order to ensure comparative reporting.

Only treatments provided in Canada are included in this report. Patients are tracked from their first treatment (dialysis or transplantation) to their death. For the purpose of recording continuity of care, CORR does capture out-of-country transfers when they are provided by reporting facilities. Information on organ donors is linked to recipient information. At the present time, CORR does not collect information on patients who have been listed for transplant, but have not received an organ.

1.2 Data Quality

The collection of patient-level extra-renal transplant data commenced formally on January 1, 1989. Previously these data had been collected retrospectively for the years 1981 to 1988 in the *Canadian Organ Replacement Register 1989 Report*. Only kidney transplants for patients who had their initial renal replacement therapy on or after January 1, 1981, were originally registered in CORR. As a consequence, not all kidney transplants occurring during the period from 1981 to 1989 are registered in CORR.

While the extent of under-reporting of extra-renal transplant activity is unknown, CIHI continues to work with transplant programs to improve the completeness and quality of historical data. Although completeness of key data elements has improved over time, one notable problem is that the proportion of unknown values reported for primary diagnosis, cause of death and cause of graft failure exceeds 10% in many cases. Users should consider this when interpreting trends in diagnoses, causes of death and causes of graft failure.

At present, CORR does not collect individual patient data for those who are awaiting transplants. However, the number of patients waiting for solid organ transplants is provided on a quarterly basis by organ procurement organizations (OPOs) including the British Columbia Transplant Society, H.O.P.E. Calgary, H.O.P.E. Edmonton, the Saskatchewan Transplant Program (Saskatoon and Regina), the Manitoba Transplant 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. For further details regarding the completeness and coverage of reporting in CORR, please see Appendix D, *CORR Data Quality Documentation: 1996 to 2005*.

1.3 This Report

This report highlights key data on end-stage organ failure treatments in Canada. Data and analysis on renal replacement therapy, transplantation and organ donation in this report cover the decade from 1996 to 2005. The main sections of the report are:

- renal replacement therapy for end-stage renal disease (ESRD) patients (dialysis and renal transplant)
- liver transplantation
- heart transplantation
- lung transplantation
- pancreas transplantation
- intestinal transplantation
- deceased organ donors

There is also a special section that provides detailed information on the evolution of pediatric end-stage renal failure and its treatment in Canada. (See Chapter 9: *Pediatric ESRD in Canada: A Review of the Last Quarter Century.)*

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 report, this information is available online at www.cihi.ca/corr, in the form of special reports (Analysis in Brief documents) and semi-annual reports from the OPOs (E-Statistics on Organ Transplants, Waiting Lists and Donors). The website also features PowerPoint presentations with summary data.

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

In addition, analytical conventions used in this report may vary from previously published reports. If you have questions about this report or would like further information, please email CORR at corr@cihi.ca.

2. Renal Replacement Therapy (RRT) for End-Stage Renal Disease (ESRD)

2.1 Incident ESRD RRT Patients

2.1.1 Activity

In 2005, there were 92 facilities that registered incident (newly diagnosed) ESRD RRT patients in CORR (Table 1).[i] The vast majority of patients started RRT in hospital-based programs where full renal care services[ii] were delivered. A small number of patients started treatment at two community-based centres in Ontario.

Table 1 Facilities Registering Incident ESRD RRT Patients in CORR for 2005

Province	Full-Care Hospitals* (N)
British Columbia	11
Alberta/Northwest Territories	2
Saskatchewan	2
Manitoba	4
Ontario	31
Quebec	31
New Brunswick	4
Nova Scotia/Prince Edward Island	4
Newfoundland and Labrador	3

Note:

* Hospital-based programs with full renal care services.

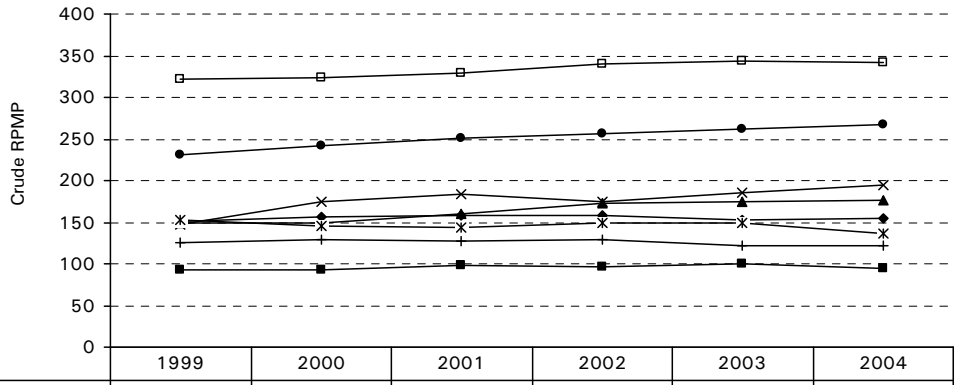
i. The way in which nephrology services are organized in each of the provinces dictates, in part, the way in which centres report to CORR. For example, in Alberta, the Northern and Southern Alberta Renal Programs report as two distinct entities, while in most other provinces, hospitals providing incident treatment to ESRD patients report directly to CORR.

ii. Services provided under the care of nephrologists include social work and dietary consultation, as well as inpatient back-up care.

2.1.2 International Comparison

The rate of incident ESRD RRT patients in Canada increased by 29%, from 119 in 1996 to 154 in 2004, per million population (PMP). Since many registries throughout the world recorded growth in ESRD RRT rates, this reflects the global increase. From 1999 to 2004, annual rates of incident ESRD RRT in Canada were comparable to those in Belgium and Germany, but were higher than in Sweden, Australia and Spain/Catalonia, and lower than in the United States and Japan (Figure 1).

Figure 1 Incident ESRD RRT Patients, Selected Countries, 1999 to 2004 (Crude Rate PMP)



	1999	2000	2001	2002	2003	2004
Canada	150	156	159	158	152	154
Australia	92	92	98	97	100	95
Belgium	150	149	160	172	174	177
Germany	148	175	184	174	186	194
Japan	231	242	251	256	262	267
Spain/Catalonia	152	145	144	149	149	136
Sweden	125	130	127	129	122	122
United States	321	324	329	340	343	342

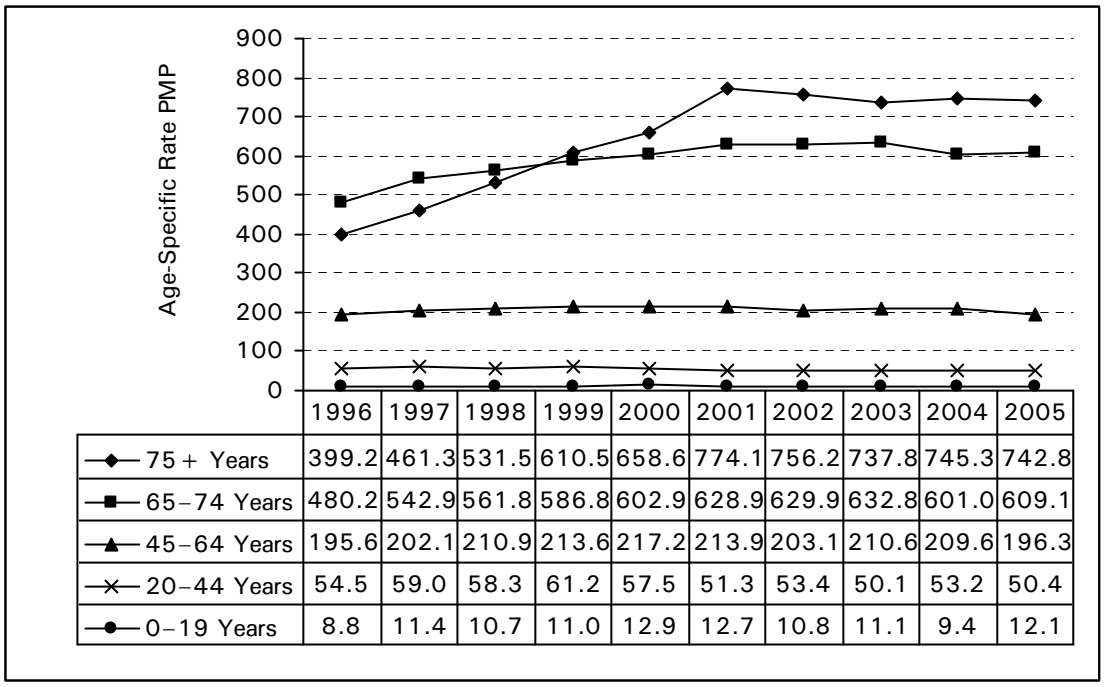
Source of international data: U.S. Renal Data System, *USRDS 2006 Annual Data Report: Atlas of End-Stage Renal Disease in the United States* (Bethesda, MD: National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, 2006).

2.1.3 Patient Characteristics

The examination of trends in both rates and crude numbers must be done within the context and framework of demographic changes in the population over the given time period. For example, from 1996 to 2005, there were changes in the composition of the Canadian population by age group. For those 19 years of age and younger, the population was relatively stable, with a decrease of about 2% in the decade under consideration. For the young adult group (20 to 39 years), the Canadian population decreased by 3.4%, while the age group between 40 and 59 years increased by 29%. At the upper end of the age spectrum (aged 60 years of age and older), the number of Canadians increased by 20% but has been relatively stable since 2001.[1]

Considering incident ESRD RRT patients in Canada in terms of age-specific rates, the magnitude and direction of change differed between age groups. There was considerable growth in incident ESRD RRT treatment among patients age 75 years and older, where the rate more than doubled from 1996 to 2005. For those patients in the range of 65 to 74 years of age, the rate also increased but to a lesser degree (27%). Those patients in the range of 0 to19 years saw an incremental increase in rate of 37%. Finally, for the young adult age group, rates declined slightly but were essentially stable (Figure 2).

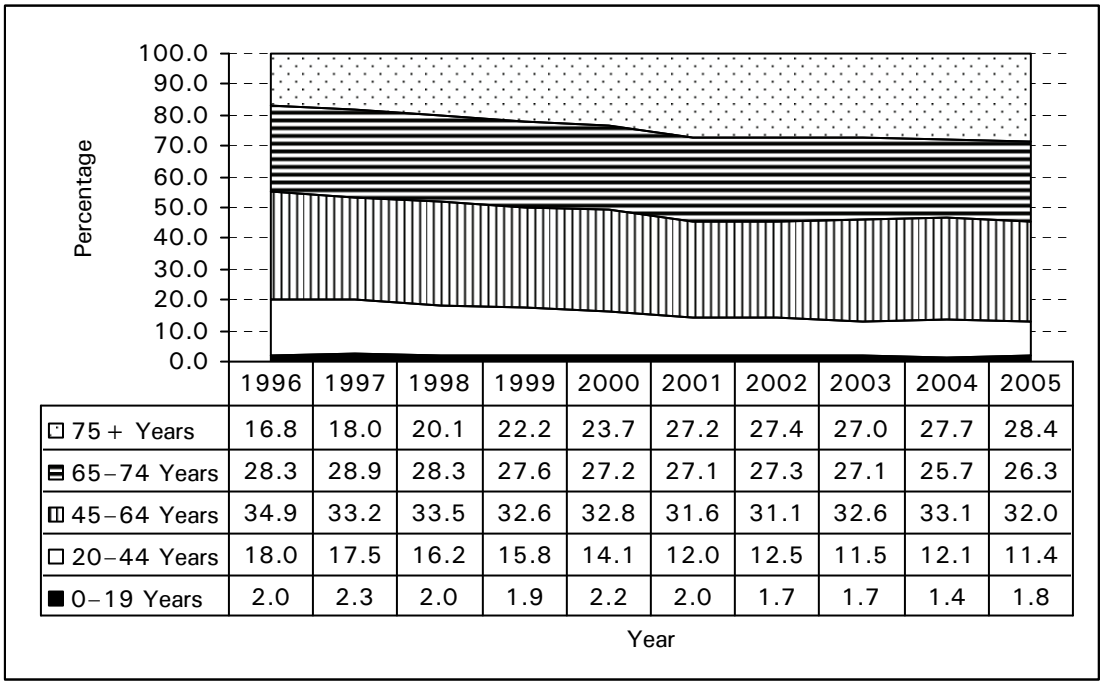
Figure 2 Incident ESRD Patients, Age-Specific Rate PMP, Canada, 1996 to 2005



	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
75 + Years	399.2	461.3	531.5	610.5	658.6	774.1	756.2	737.8	745.3	742.8
65–74 Years	480.2	542.9	561.8	586.8	602.9	628.9	629.9	632.8	601.0	609.1
45–64 Years	195.6	202.1	210.9	213.6	217.2	213.9	203.1	210.6	209.6	196.3
20–44 Years	54.5	59.0	58.3	61.2	57.5	51.3	53.4	50.1	53.2	50.4
0–19 Years	8.8	11.4	10.7	11.0	12.9	12.7	10.8	11.1	9.4	12.1

In 2005, more than half of the incident patients (54.7%) initiated RRT treatment at age 65 years or older, an increase of 9.6% for this age group since 1996 (Figure 3).

Figure 3 Distribution of Incident ESRD RRT Patients by Age Group, Canada, 1996 to 2005 (Percentage)



	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
75 + Years	16.8	18.0	20.1	22.2	23.7	27.2	27.4	27.0	27.7	28.4
65–74 Years	28.3	28.9	28.3	27.6	27.2	27.1	27.3	27.1	25.7	26.3
45–64 Years	34.9	33.2	33.5	32.6	32.8	31.6	31.1	32.6	33.1	32.0
20–44 Years	18.0	17.5	16.2	15.8	14.1	12.0	12.5	11.5	12.1	11.4
0–19 Years	2.0	2.3	2.0	1.9	2.2	2.0	1.7	1.7	1.4	1.8

There was considerable variation in age-specific rates of ESRD by province of initial treatment for 2005 (Table 2). The highest rate of treatment for new patients in the pediatric population (from birth to 19 years) was in Nova Scotia and Prince Edward Island (24.0 PMP). The highest rate for those 65 to 74 years of age was in Newfoundland and Labrador and Ontario, with 816.9 PMP for patients aged 65 to 74 years, and 950.9 PMP for patients aged 75 and older years, respectively.

The adult group of 20 to 65 years is normally considered to be the working/career years. For this group, the highest rates were in Manitoba, with 77.7 PMP in the 20-to-44-year age group, and a considerably higher rate of 292.4 PMP in the 45-to-65-year age group.

Table 2 Incident ESRD Patients, Age-Specific Rate PMP, by Province, 2005

Province of Treatment		Age Group				
		0–19	20–44	45–64	65–74	75+
British Columbia*	N	18	84	192	160	176
	PMP	18.3	54.1	165.5	522.1	623.1
Alberta/Northwest Territories	N	9	80	182	142	117
	PMP	14.6	52.8	204.5	670.6	629.3
Saskatchewan	N	4	26	61	47	32
	PMP	14.7	78.1	252.0	675.6	412.7
Manitoba	N	3	32	85	55	61
	PMP	9.5	77.7	292.4	712.8	749.2
Ontario	N	40	238	682	559	716
	PMP	12.8	51.1	215.7	653.2	950.9
Quebec	N	14	89	331	286	267
	PMP	8.1	32.9	156.0	503.6	558.9
New Brunswick	N	0	10	39	31	37
	PMP	0.0	37.7	184.8	568.0	738.1
Nova Scotia/ Prince Edward Island	N	6	26	58	51	43
	PMP	24.0	69.6	193.7	629.8	596.9
Newfoundland and Labrador	N	1	8	28	31	23
	PMP	8.7	44.1	184.9	816.9	771.9
Total	**N**	**95**	**593**	**1,658**	**1,362**	**1,472**
	PMP	**12.1**	**50.4**	**196.3**	**609.1**	**742.8**

Note:

* British Columbia includes the population of the Yukon.

In 2005, hemodialysis (HD) remained the predominant RRT for new ESRD patients (Table 3). The majority of incident patients (80.7%) started RRT on HD, compared to 70.8% in 1996 (Table 4). Conversely, 19.3% of incident patients started on peritoneal dialysis (PD), a decrease from 24.0% in 1996.

The number of pre-emptive kidney transplants[iii] performed as RRT in incident ESRD patients has increased during the decade, peaking at 163 patients in 2005. This represents a 79% increase over the number in 1996 (86).

In terms of the number of patients by age group, there was a 33% increase in the number of incident ESRD patients aged 65 to 74 years (from 1,003 in 1996 to 1,362 in 2005) and more than double the number of patients age 75 years and older, from 595 in 1996 to 1,437 in 2005 (Table 4).

iii. Pre-emptive kidney transplant recipients are patients who have not been treated with dialysis prior to transplantation.

Table 3 Initial Dialysis Treatment, Canada and Provinces, 2005 (Number, Percentage)

Treatment Type	Canada	B.C.	Alta./ N.W.T	Sask.	Man.	Ont.	Que.	N.S./ P.E.I.	N.B.	N.L.
HD*	4,043	459	401	128	174	1,739	836	130	95	81
Percentage	80.7	77.3	78.3	76.6	76.3	79.4	88.0	78.8	81.9	90.0
PD†	969	135	111	39	54	451	114	35	21	9
Percentage	19.3	22.7	21.7	23.4	23.7	20.6	12.0	21.2	18.1	10.0
Total	**5,012**	**594**	**512**	**167**	**228**	**2,190**	**950**	**165**	**116**	**90**

Notes:
*** Hemodialysis.**
† Peritoneal dialysis.

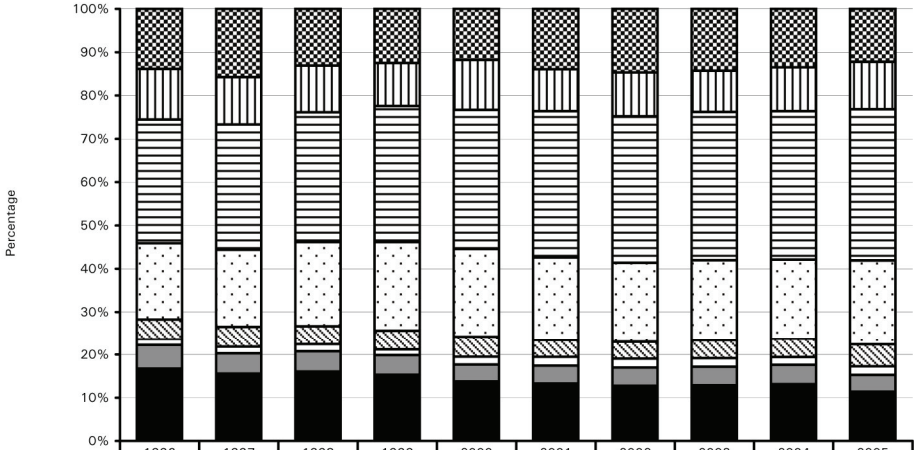
Table 4 Incident ESRD RRT Patients by Year, Age Group and Initial Treatment Modality, Canada, 1996 to 2005 (Number)

Age Group	Initial Modality*	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
		N = 3,543	N = 3,957	N = 4,228	N = 4,546	N = 4,750	N = 5,010	N = 5,018	N = 5,118	N = 5,184	N = 5,180
0–19 Years	HD	34	52	40	37	46	45	36	40	32	43
	PD	30	28	33	36	34	40	24	29	28	30
	Pre-empt	6	11	13	15	23	16	26	19	14	22
20–44 Years	HD	393	487	462	472	445	400	437	427	417	419
	PD	198	162	176	180	170	133	147	120	153	133
	Pre-empt	48	44	45	64	57	68	44	42	56	41
45–64 Years	HD	857	948	1,058	1,118	1,152	1,181	1,192	1,272	1,280	1,195
	PD	348	326	322	321	357	359	326	342	387	366
	Pre-empt	31	41	35	42	48	45	41	57	50	97
65–74 Years	HD	756	919	935	995	1,051	1,117	1,136	1,151	1,110	1,107
	PD	246	221	257	253	240	232	231	229	208	247
	Pre-empt	1	5	3	5	3	10	3	6	12	8
75+ Years	HD	469	585	719	828	966	1,163	1,200	1,227	1,241	1,279
	PD	126	128	130	180	158	201	175	157	195	193
	Pre-empt	0	0	0	0	0	0	0	0	1	0
Total	**HD**	**2,509**	**2,991**	**3,214**	**3,450**	**3,660**	**3,906**	**4,001**	**4,117**	**4,080**	**4,043**
	PD	**948**	**865**	**918**	**970**	**959**	**965**	**903**	**877**	**971**	**969**
	Pre-empt	**86**	**101**	**96**	**126**	**131**	**139**	**114**	**124**	**133**	**168**

Note:
* HD = hemodialysis; PD = peritoneal dialysis; pre-empt = pre-emptive kidney transplant.

Diabetic nephropathy was the leading cause of renal failure from 1996 to 2005, and the incidence of this diagnosis increased with each successive year during the decade (Figure 4). A declining trend in the diagnoses of pyelonephritis and glomerulonephritis as the cause of renal failure in incident patients emerged throughout the same period. The proportion of unknown diagnoses remained stable between 1996 and 2004 at 13.5%, declining to 12.2% in 2005.

Figure 4 Distribution of Incident ESRD RRT Patients by Primary Diagnosis Category, Canada, 1996 to 2005 (Percentage)



	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
Unknown	13.9	15.8	13.1	12.5	11.8	14.0	14.7	14.3	13.5	12.2
Other	11.7	10.9	10.8	9.9	11.5	9.7	10.1	9.5	10.1	10.9
Diabetes	28.6	28.9	29.9	31.4	32.1	33.8	33.8	34.2	34.3	35.0
Vascular Disease	17.7	17.8	19.5	20.5	20.3	19.2	18.4	18.6	18.4	19.5
Polycystic Kidney Disease	4.6	4.7	4.3	4.5	4.7	3.9	4.0	4.2	4.3	5.1
Drug-Induced	1.4	1.6	1.7	1.3	1.8	2.1	2.1	2.0	1.8	2.0
Pyelonephritis	5.5	4.7	4.7	4.5	4.0	4.1	4.2	4.3	4.5	3.9
Glomerulonephritis	16.7	15.5	16.0	15.3	13.7	13.3	12.7	12.9	13.1	11.4

The cause of death was unknown for 24.6% of incident ESRD RRT patients who died between 1996 and 2005 (Table 5). Where the cause was known, cardiac failure was the leading cause of death for all age groups, although social causes (which include treatment withdrawals, treatment refusals and suicides) were a close second overall. When examined by age group, the profiles differed. In the oldest patient group (75 years of age and older), cardiac deaths were the most prominent, followed by social causes. As a proportion of the number of deaths in each age group, deaths from infections tended to be higher in younger age groups (44 years of age and younger). Accidental deaths, including incidents related and unrelated to treatment, formed a small proportion of the reported causes of death overall and by age group.

Table 5 Incident ESRD RRT Patients by Age Group* and Cause of Death† 1996 to 2005 (Number and Percentage)

Age Group		Cardiac	Social	Infections	Vascular	Gastro-Intestinal	Malignancy	Accidental	Other	Unknown	Total
0–19 Years	N	8	6	4	3	2	3	0	5	11	42
	%	19.0	14.3	9.5	7.1	4.8	7.1	0.0	11.9	26.2	0.2
20–44 Years	N	265	94	131	69	15	43	12	102	276	1,007
	%	26.3	9.3	13.0	6.9	1.5	4.3	1.2	10.1	27.4	4.9
45–64 Years	N	1,679	520	514	335	146	375	31	471	1,367	5,438
	%	30.9	9.6	9.5	6.2	2.7	6.9	0.6	8.7	25.1	26.7
65–74 Years	N	1,917	976	570	497	251	425	27	598	1,721	6,982
	%	27.5	14.0	8.2	7.1	3.6	6.1	0.4	8.6	24.6	34.2
75 + Years	N	1,689	1,332	579	452	220	333	29	638	1,648	6,920
	%	24.4	19.2	8.4	6.5	3.2	4.8	0.4	9.2	23.8	33.9
Total	**N**	**5,558**	**2,928**	**1,798**	**1,356**	**634**	**1,179**	**99**	**1,814**	**5,023**	**20,389**
	%	**27.3**	**14.4**	**8.8**	**6.7**	**3.1**	**5.8**	**0.5**	**8.9**	**24.6**	**100.0**

Notes:

* Age at incident treatment.

† For a breakdown of CORR cause-of-death codes used in this categorization, refer to Appendix F.

For the years 2004 and 2005, there were differences observed in key treatment and patient characteristics for incident dialysis patients, depending on the initial province of treatment (Table 6). Newfoundland and Labrador had the lowest proportion of males starting dialysis treatment (54.9%), while Ontario had the highest percentage of incident dialysis patients 75 years of age and older (32.3%). The largest proportion of Aboriginal patients was in Manitoba (30.9%), followed by Saskatchewan (22.4%). The presence of diabetes among new patients was also highest in Manitoba, at 54.3%. In British Columbia, 77.3% of patients started dialysis on HD (the lowest proportion of the provinces). The highest proportional utilization of HD as the incident treatment modality was in Newfoundland and Labrador (90.3%) and Quebec (87.4%). More than three quarters of incident dialysis patients had been followed by nephrologists before they began receiving dialysis. This varied from a low of 71.1% in Alberta/Northwest Territories to a high of 79.9% in British Columbia. The proportion of patients diagnosed with glomerulonephritis ranged from a low of 8.7% in New Brunswick, to a high of 13.1% in Alberta/Northwest Territories. The proportion of patients with vascular disease as the cause of their renal failure was highest in the Atlantic provinces.

As in the case of other chronic diseases, comorbid conditions existing at the time of initial dialysis treatment increased the complexity of patient care.[2, 3] The proportion of incident ESRD patients with co-existing heart disease and peripheral vascular disease was highest in New Brunswick, while Newfoundland and Labrador had the highest proportion of cerebrovascular disease (Table 6). Quebec had the highest incidence of chronic lung disease as a comorbid condition in ESRD dialysis patients, with one in five incident dialysis patients diagnosed accordingly. The proportion of patients with malignancies was highest in New Brunswick and Newfoundland and Labrador, at 14.1% and 13.6% respectively.

Table 6 Incident Dialysis Patients by Selected Indicators and Initial Province of Treatment, Canada, 2004–2005*

Indicator	Province of Treatment									Total
	B.C.	Alta./N.W.T.	Sask.	Man.	Ont.	Que.	N.B.	N.S./ P.E.I.	N.L.	
Centres Reporting 2004 (N)	11	3	2	4	31	30	4	4	3	**92**
Centres Reporting 2005 (N)	11	3	2	4	31	30	4	4	3	**92**
Incident Dialysis Patients 2004 (N)	642	449	184	224	2,161	967	159	150	115	**5,051**
Incident Dialysis Patients 2005 (N)	597	511	168	229	2,181	951	117	167	91	**5,012**
Percentage Male	62.8	57.9	55.4	58.9	59.1	61.3	57.6	59.3	54.9	**59.6**
Percentage Aboriginal†	4.0	9.1	22.4	30.9	2.5	1.0	3.3	3.2	1.0	**5.0**
Median Age (Years)	63	61	61	62	65	64	65	63	66	**63**
Percentage 75+ Years	28.7	22.2	21.0	23.4	32.3	27.5	30.4	27.1	29.1	**28.9**
Percentage Hemodialysis as Incident Modality	77.3	80.1	78.4	79.0	79.0	87.4	80.4	78.5	90.3	**80.7**
Percentage Followed by Nephrologist Before Starting Dialysis	79.9	71.5	73.5	76.7	76.7	75.9	74.7	76.1	71.7	**76.2**
Percentage Glomerunephritis as Primary Diagnosis	9.5	13.1	9.9	12.4	12.3	12.5	8.7	12.3	11.2	**11.9**
Percentage Vascular Disease as Primary Diagnosis	19.6	11.7	19.6	11.3	21.5	19.7	23.9	20.8	19.4	**19.4**
Percentage Diabetic‡	32.0	49.2	48.0	54.3	43.7	46.6	44.9	39.4	42.7	**43.8**
Percentage With Heart Disease§	21.8	29.6	31.8	20.5	35.0	35.7	41.3	29.7	41.7	**32.3**
Percentage With Peripheral Vascular Disease	12.1	15.0	16.2	13.9	18.1	20.9	30.4	20.2	28.6	**18.0**
Percentage With Cerebrovascular Disease	9.2	14.1	13.9	14.3	14.2	12.9	13.8	14.5	16.5	**13.3**
Percentage With Malignancies	7.7	11.1	11.6	9.9	11.5	10.2	14.1	13.2	13.6	**10.8**
Percentage With Chronic Lung Disease	5.1	10.5	17.6	2.4	9.6	19.7	16.3	12.9	11.7	**11.3**

Notes:

* Information presented is based on patients with reported data.

† Proportion of Aboriginal patients is reported due to the high rate of diabetic nephropathy among Aboriginal Peoples.

‡ The proportion of diabetic patients is based on primary diagnosis and comorbid disease.

§ Heart disease includes patients with one or more of the following: history of angina, previous myocardial infarction, previous coronary artery bypass or previous angioplasty.

2.1.4. Estimated Glomerular Filtration Rate for Adult Patients at Initiation of RRT

The estimated glomerular filtration rate (eGFR) is one of the standard biochemical methods of measuring the level of kidney function and thereby determining the stage of kidney disease. The eGFR is determined by the serum creatinine levels in adult patients. There are two prominent formulae used to calculate an eGFR: i) the MDRD equation[4] (used in many programs currently) and ii) the Cockcroft-Gault formula.[5] Results presented in this report are based on both formulae.

i) The MDRD formula is calculated as follows:

- eGFR = 32788 x creatinine$^{-1.154}$ x age$^{-0.203}$ x multiplier

Using the MDRD formula, the average eGFR estimates in ESRD patients in Canada by province are presented in Table 7. Overall, the national average eGFR increased from 9.5 ml/min in 2002 to 10.1 ml/min in 2005. The highest average eGFR, at a level of greater than 11.2 ml/min, was in patients initiating dialysis treatment in New Brunswick beginning in 2003 (Table 7). The varying results based on these two formulae point to the need for further research and consensus about the most appropriate method to calculate eGFR.

Table 7 Average eGFR (MDRD Formula) at the Initiation of Dialysis Treatment, Canada, 2002 to 2005 (Number and Average)

		B.C.	Alta./N.W.T.	Sask.	Man.	Ont.	Que.	N.B.	N.S./P.E.I.	N.L.	Canada
2002	N	556	448	162	219	1,814	872	124	120	103	4,418
	Mean	9.7	9.7	9.6	8.5	9.5	9.4	10.4	8.7	9.0	9.5
2003	N	530	500	177	198	1,794	846	141	142	95	4,423
	Mean	10.2	9.5	10.0	8.4	9.8	10.0	11.2	8.7	9.6	9.8
2004	N	600	427	180	212	1,895	862	146	138	113	4,573
	Mean	10.1	9.6	9.8	8.3	9.8	9.9	11.2	8.7	9.1	9.8
2005	N	555	477	163	202	1,944	874	109	152	87	4,563
	Mean	10.7	9.9	10.3	8.3	10.2	10.4	11.7	8.1	8.8	10.1

ii) The Cockcroft-Gault formula is calculated as follows:

- GFR = ((140-age)*initial weight)/(0.82*creatinine result) for males
- GFR = ((140-age)*initial weight)/(0.82*creatinine result)*0.85 for females

Using the Cockcroft-Gault formula, the average eGFR estimates in ESRD patients in Canada by province of initial treatment are presented in Table 8. Overall, the national average eGFR increased from 12.3 ml/min in 2002 to 13.3 ml/min in 2005. The highest average eGFR from 2002 to 2005 was observed in patients initiating dialysis treatment in New Brunswick. In contrast, the lowest average eGFR level (below 12 ml/min), was in the provinces of Nova Scotia/Prince Edward Island for the same period.

Table 8 Average Adult eGFR (Cockcroft-Gault Formula) at the Initiation of Dialysis Treatment, by Province, Canada, 2002 to 2005 (Number and Average)

		B.C.	Alta./ N.W.T.	Sask.	Man.	Ont.	Que.	N.B.	N.S./ P.E.I.	N.L.	Canada
2002	N	514	431	160	219	1,794	832	124	118	101	4,293
	Mean	12.5	12.9	13.4	11.9	12.2	12.0	14.5	11.3	12.1	12.3
2003	N	480	480	172	192	1,767	817	140	139	95	4,282
	Mean	13.1	13.2	14.1	12.2	12.6	12.8	14.4	11.2	12.7	12.8
2004	N	533	421	178	205	1,871	839	144	133	112	4,436
	Mean	13.5	13.5	13.8	12.6	12.5	12.7	14.9	11.8	12.4	12.9
2005	N	509	473	163	197	1,912	855	107	150	87	4,453
	Mean	14.2	14.2	14.3	11.6	12.9	13.3	15.5	11.8	12.5	13.3

Further exploration of the various formulae and their utilization is planned, and future reports will present more in-depth analysis on the role of eGFR.

2.1.5 Outcomes

Despite continuing efforts to improve RRT, there were no appreciable changes observed in survival benefits associated with RRT over time (1996 to 2005). The five-year survival rates for incident patients on dialysis remained stable at approximately 40% for the inception cohorts between 1996 and 2000. A possible explanation for the stable survival rate during this time period is the changes in the profile of patients who are initiated on RRT therapy. There was an increase in the frequency with which dialysis treatment was offered to older and more medically frail patients. During this time period, the survival rates appear to have been slightly better in patients who initiated treatment with PD, compared to those initiating treatment with HD (Table 9).

Table 9 Unadjusted Three-Month, One-, Three- and Five-Year Survival in Dialysis Patients, Canada, 1996 to 2000, With Follow-up Until 2005

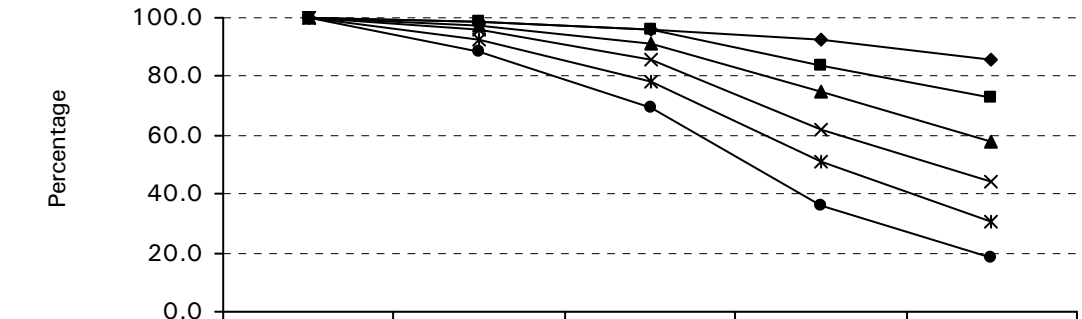
	Survival Time	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
All Dialysis	N	3,457	3,856	4,132	4,420	4,619	4,871	4,904	4,994	5,051	5,012
	3 Months	94.2	94.1	94.3	94.2	94.1	93.9	93.8	94.5	94.7	94.7
	1 Year	82.4	82.8	82.5	81.9	82.3	81.9	82.3	83.4	83.5	
	3 Years	57.2	57.9	58.1	56.4	58.6	57.2	58.1	60.1		
	5 Years	37.1	38.8	39.6	37.7	40.5	39.5				
HD	N	2,509	2,991	3,214	3,450	3,660	3,906	4,001	4,117	4,080	4,043
	3 Months	93.3	93.2	93.4	93.1	93.0	93.1	93.0	93.7	93.7	93.7
	1 Year	80.3	81.5	80.7	80.1	80.3	80.1	80.4	81.6	81.7	
	3 Years	56.2	56.6	56.8	55.3	56.7	55.5	56.2	57.7		
	5 Years	36.0	37.6	38.4	36.3	38.7	37.7				
PD	N	948	865	918	970	959	965	903	877	971	969
	3 Months	96.8	97.1	97.5	98.0	98.1	97.3	97.4	98.3	98.5	98.6
	1 Year	88.3	87.2	88.6	88.1	90.0	89.3	90.7	91.7	90.9	
	3 Years	59.6	62.3	62.8	60.0	66.1	64.3	66.4	71.3		
	5 Years	40.1	42.8	43.7	42.8	47.7					

Note:

* Patients are censored at the time of their first kidney transplant or when it is determined that they are lost to follow-up.

Short-term survival periods (three months or one year) fluctuated with age, with a slight decrease as age increased in all dialysis patients, regardless of the type (HD or PD) of initial treatment (Figure 5). However, age became a significant factor in the analysis of long-term survival (three- or five-year periods) when a steep decrease in survival is noted with an increase in the patient's age. The most marked differences exist between those at both ends of the age spectrum. This decrease is marked by a reduction from an 85.6% survival rate at five years (in patients from birth to 18 years of age) to an 18.2% survival rate at five years in patients aged 75 years and older. The survival analysis indicated that patients who initiated treatment with PD between the ages of 18 and 75 years had superior rates of survival, compared to their counterparts (18 to 75 years of age) who initiated treatment on HD (figures 6 and 7).

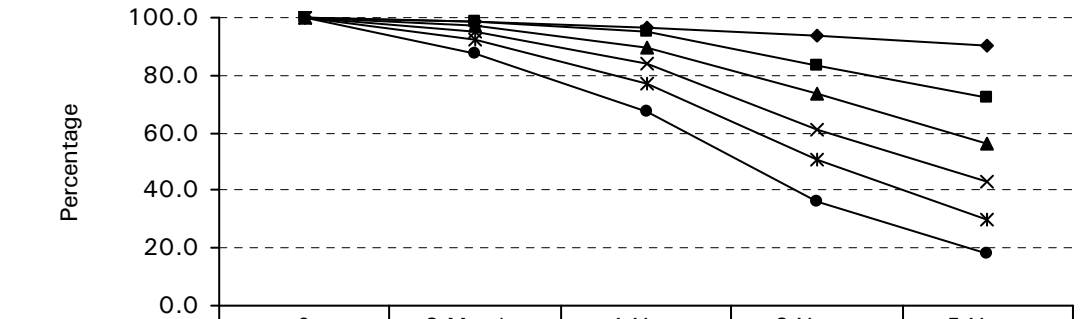
Figure 5 Unadjusted Three-Month and One-, Three- and Five-Year Survival in Dialysis Patients, by Age Group, Canada, 1996 to 2000 (Followed to 2005)



	0	3 Months	1 Year	3 Years	5 Years
<18 Years	100.0	98.6	95.8	92.2	85.6
18–44 Years	100.0	98.6	95.7	83.9	72.8
45–54 Years	100.0	97.5	91.2	75.0	57.5
55–64 Years	100.0	95.8	85.5	62.1	44.3
65–74 Years	100.0	92.8	78.3	51.0	30.4
75+ Years	100.0	88.7	69.2	36.3	18.2

Survival Time

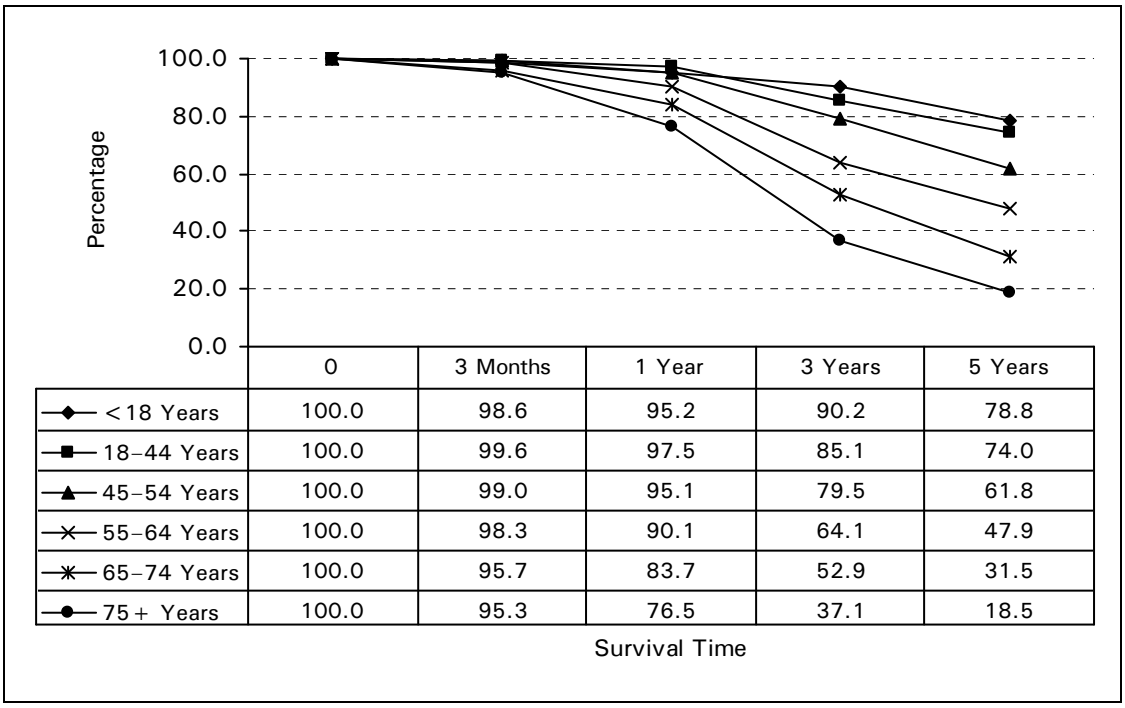
Figure 6 Unadjusted Three-Month and One-, Three- and Five-Year Survival in HD Patients, by Age Group, Canada, 1996 to 2000 (Followed to 2005)



	0	3 Months	1 Year	3 Years	5 Years
<18 Years	100.0	98.7	96.4	93.8	90.0
18–44 Years	100.0	98.3	94.9	83.5	72.4
45–54 Years	100.0	97.0	89.9	73.5	56.1
55–64 Years	100.0	95.0	84.0	61.4	43.2
65–74 Years	100.0	92.1	76.9	50.5	30.2
75+ Years	100.0	87.4	67.7	36.2	18.1

Survival Time

Figure 7 Unadjusted Three-Month and One-, Three- and Five-Year Survival in Patients Treated with PD, by Age Group, Canada, 1996 to 2000 (Followed to 2005)

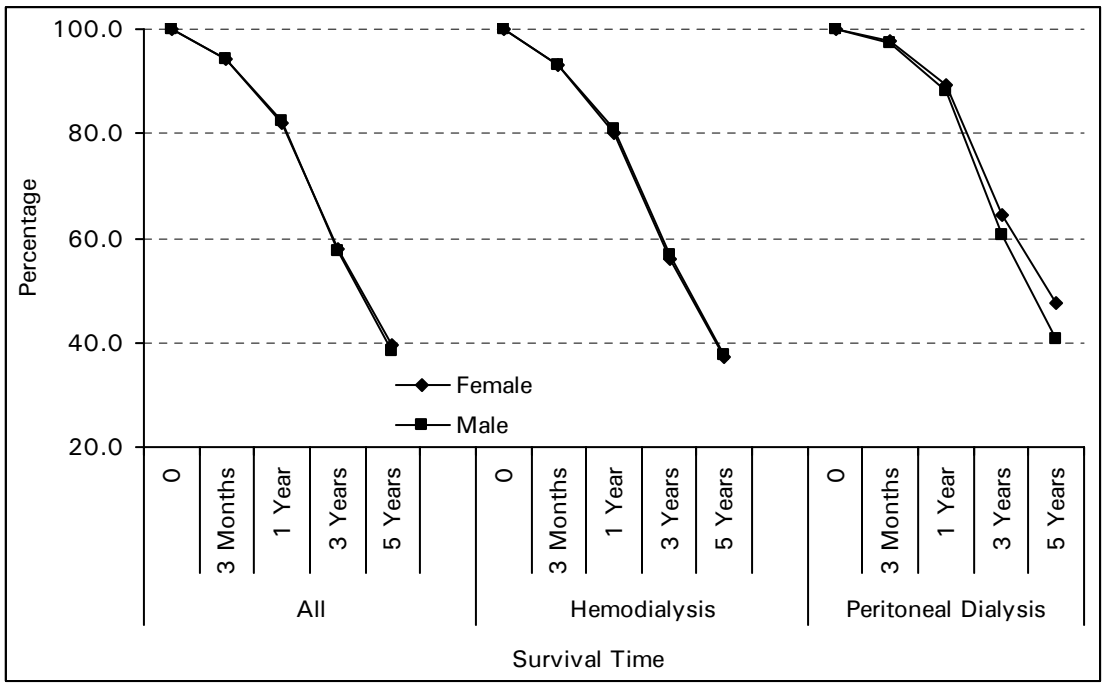


	0	3 Months	1 Year	3 Years	5 Years
< 18 Years	100.0	98.6	95.2	90.2	78.8
18–44 Years	100.0	99.6	97.5	85.1	74.0
45–54 Years	100.0	99.0	95.1	79.5	61.8
55–64 Years	100.0	98.3	90.1	64.1	47.9
65–74 Years	100.0	95.7	83.7	52.9	31.5
75 + Years	100.0	95.3	76.5	37.1	18.5

Survival Time

When the survival rates were compared for females and males starting dialysis treatment, the overall rates were similar (Figure 8). When examined by treatment modality, the survival rates were similar for females and males starting treatment on HD. However, when PD was the incident treatment modality, differences in five-year survival rates were seen between males (40.5%) and females (47.4%).

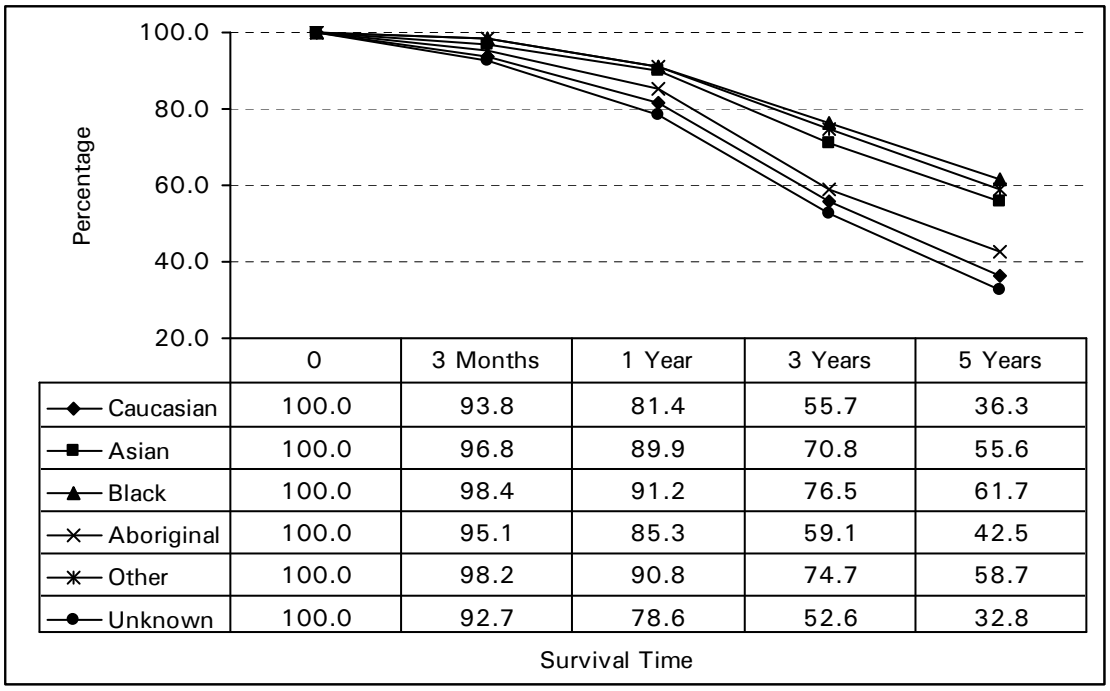
Figure 8 Unadjusted Three-Month and One-, Three- and Five-Year Survival in Dialysis Patients, by Treatment Type and Sex, Canada, 1996 to 2000 (Followed to 2005)



Ethnicity may be a factor in the differing mortality rates associated with treatment of ESRD through dialysis. However, the factors involved are complex and multi-faceted. When patient ethnicity is a variable for the analysis of patients receiving dialysis treatment in Canada, differences in outcomes can be seen, particularly in the survival rate beyond one year. Overall, the five-year survival rate was superior in patients of Black origin, as well as "other race" (including Philippine, Arabic and Indian) and Asian origin. Caucasians and the Aboriginal population had the lowest five-year survival rates, at 36.3% and 42.5% respectively (Figure 9).

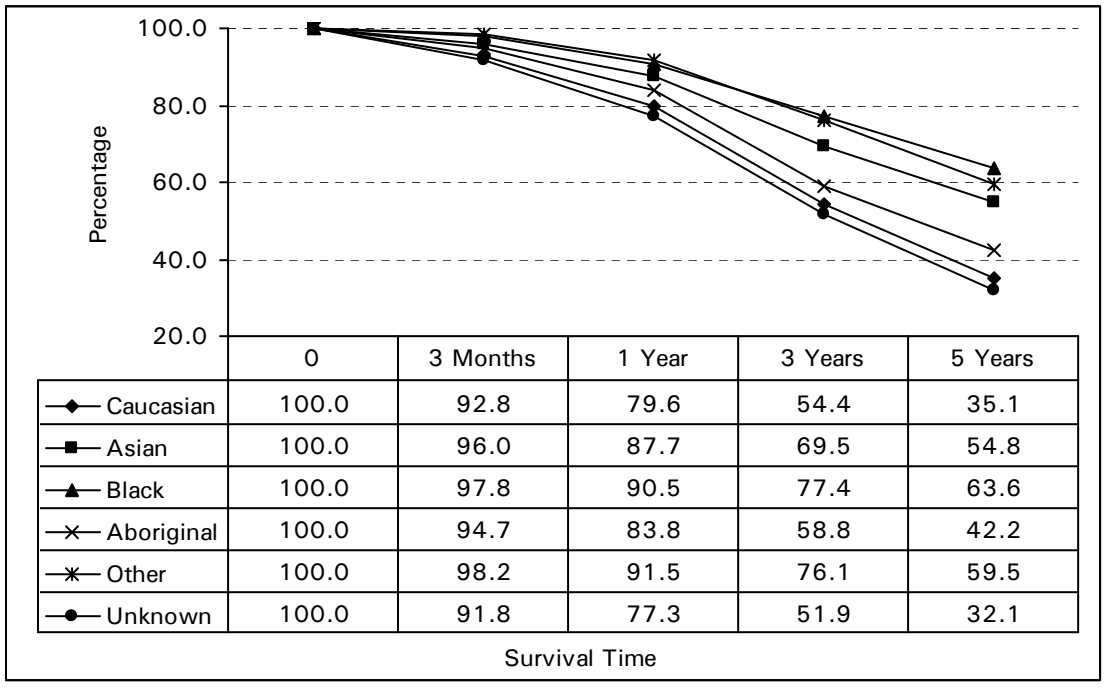
These findings are similar for both the HD and PH modalities of dialysis (figure 10 and 11) and are consistent with published literature.[6, 7] As noted, Canada's Aboriginal Peoples (First Nations, Inuit and Métis) have relatively low five-year survival rates. Aboriginal Peoples form an important ethnic sub-population in Canada, and it must be recognized that this group of Canadians face additional challenges including a higher incidence of chronic health conditions such as diabetes, heart disease, hypertension, cancer and arthritis.[8, 9, 10] As well, members of Canada's Aboriginal population experience a higher mortality rate compared to their non-Aboriginal counterparts due to these conditions.[11, 12, 13]

Figure 9 Unadjusted Three-Month and One-, Three- and Five-Year Survival in Dialysis Patients (All), by Race, Canada, 1996 to 2000 (Followed to 2005)



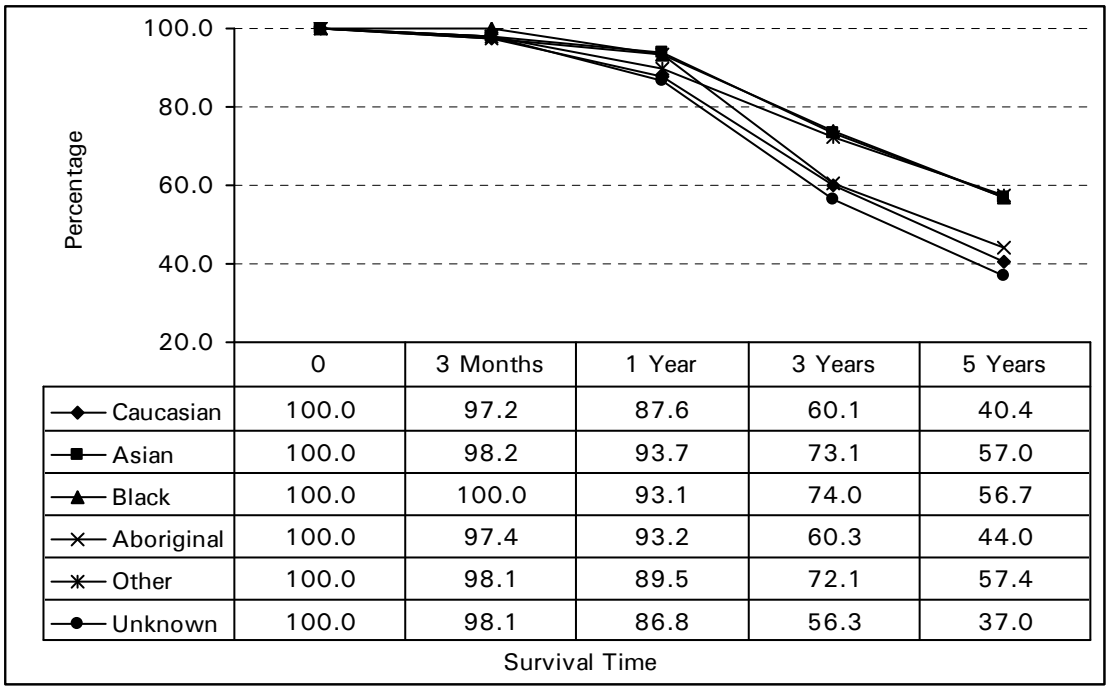
	0	3 Months	1 Year	3 Years	5 Years
Caucasian	100.0	93.8	81.4	55.7	36.3
Asian	100.0	96.8	89.9	70.8	55.6
Black	100.0	98.4	91.2	76.5	61.7
Aboriginal	100.0	95.1	85.3	59.1	42.5
Other	100.0	98.2	90.8	74.7	58.7
Unknown	100.0	92.7	78.6	52.6	32.8

Figure 10 Unadjusted Three-Month and One-, Three- and Five-Year Survival in HD Patients, by Race, Canada, 1996 to 2000 (Followed to 2005)



	0	3 Months	1 Year	3 Years	5 Years
Caucasian	100.0	92.8	79.6	54.4	35.1
Asian	100.0	96.0	87.7	69.5	54.8
Black	100.0	97.8	90.5	77.4	63.6
Aboriginal	100.0	94.7	83.8	58.8	42.2
Other	100.0	98.2	91.5	76.1	59.5
Unknown	100.0	91.8	77.3	51.9	32.1

Figure 11 Unadjusted Three-Month and One-, Three- and Five-Year Survival in Patients Treated With PD, by Race, Canada, 1995 to 1999 (Followed to 2004)

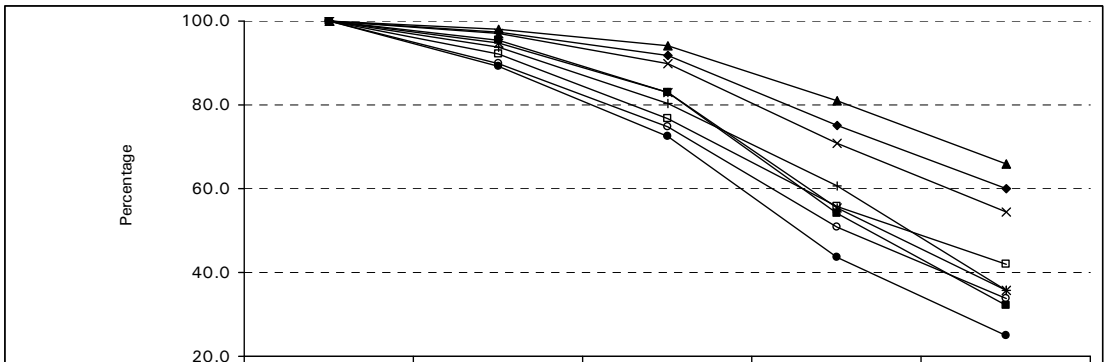


	0	3 Months	1 Year	3 Years	5 Years
Caucasian	100.0	97.2	87.6	60.1	40.4
Asian	100.0	98.2	93.7	73.1	57.0
Black	100.0	100.0	93.1	74.0	56.7
Aboriginal	100.0	97.4	93.2	60.3	44.0
Other	100.0	98.1	89.5	72.1	57.4
Unknown	100.0	98.1	86.8	56.3	37.0

The etiology of renal failure was seen to have an effect on patient survival (figures 12 to 14). In particular, patient survival was compromised with primary diagnoses of renal vascular disease and diabetes, both of which showed relatively poor long-term survival (five years), of 24.8% and 32.2% respectively. Patients whose renal failure was due to polycystic disease, glomerulonephritis and pyelonephritis had improved five-year survival rates (65.9%, 60.1% and 54.5% respectively) compared to other etiologies (Figure 12). When diabetes and renal vascular disease were the primary diagnosis in renal failure, PD patients had higher rates (33.5% and 27.8% at five years) than HD patients (31.8% and 24.3% at five years) (figures 13 and 14).

Note: These survival analyses are based on an unadjusted intent-to-treat methodology, and caution must be exercised when interpreting the results.

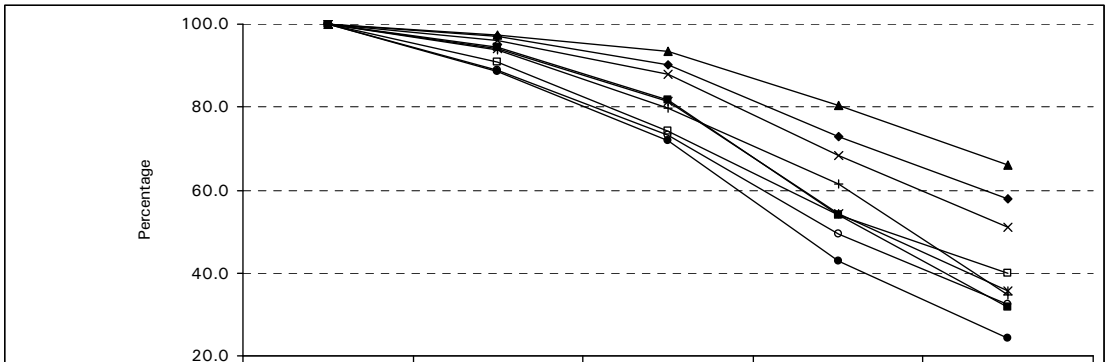
Figure 12 Unadjusted Three-Month and One-, Three- and Five-Year Survival in Dialysis Patients, by Etiology of Renal Failure, Canada, 1996 to 2000 (Followed to 2005)



	0	3 Months	1 Year	3 Years	5 Years
Glomerulonephritis	100.0	97.4	91.7	75.2	60.1
Diabetes	100.0	95.3	83.0	54.1	32.2
Polycystic Kidneys	100.0	98.0	94.2	80.9	65.9
Pyelonephritis	100.0	97.0	89.8	70.9	54.5
Hypertensive Kidneys	100.0	94.8	82.8	55.3	35.9
Renal Vascular Disease	100.0	89.3	72.6	43.5	24.8
Drug-Induced	100.0	93.8	80.2	60.7	35.7
Other	100.0	92.1	76.7	55.6	42.1
Unknown	100.0	90.0	74.9	50.7	33.8

Survival Time

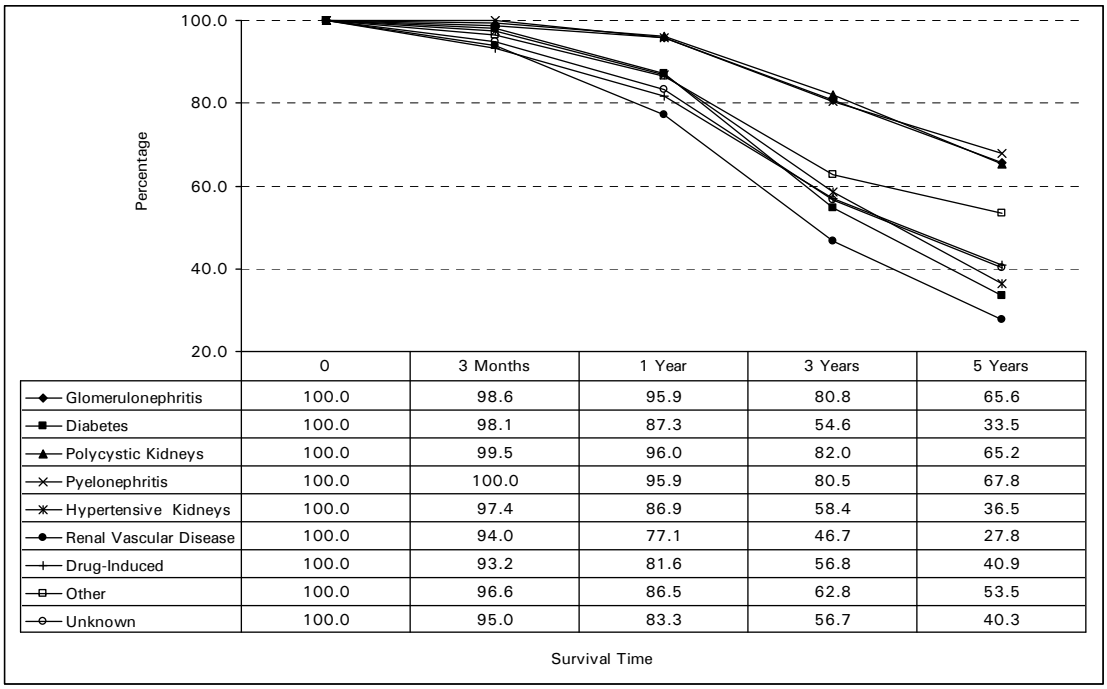
Figure 13 Unadjusted Three-Month and One-, Three- and Five-Year Survival in HD Patients, by Etiology of Renal Failure, Canada, 1996 to 2000 (Followed to 2005)



	0	3 Months	1 Year	3 Years	5 Years
Glomerulonephritis	100.0	96.9	90.1	73.0	58.0
Diabetes	100.0	94.4	81.6	53.8	31.8
Polycystic Kidneys	100.0	97.5	93.6	80.5	66.1
Pyelonephritis	100.0	96.1	88.0	68.2	50.9
Hypertensive Kidneys	100.0	94.0	81.4	54.3	35.7
Renal Vascular Disease	100.0	88.6	71.9	43.0	24.3
Drug-Induced	100.0	93.9	79.9	61.4	34.6
Other	100.0	91.0	74.3	53.9	39.8
Unknown	100.0	88.9	73.1	49.3	32.4

Survival Time

Figure 14 Unadjusted Three-Month and One-, Three- and Five-Year Survival in PD Patients, by Etiology of Renal Failure, Canada, 1995 to 1999 (Followed to 2004)



	0	3 Months	1 Year	3 Years	5 Years
Glomerulonephritis	100.0	98.6	95.9	80.8	65.6
Diabetes	100.0	98.1	87.3	54.6	33.5
Polycystic Kidneys	100.0	99.5	96.0	82.0	65.2
Pyelonephritis	100.0	100.0	95.9	80.5	67.8
Hypertensive Kidneys	100.0	97.4	86.9	58.4	36.5
Renal Vascular Disease	100.0	94.0	77.1	46.7	27.8
Drug-Induced	100.0	93.2	81.6	56.8	40.9
Other	100.0	96.6	86.5	62.8	53.5
Unknown	100.0	95.0	83.3	56.7	40.3

Survival analysis by multi-variable modelling was employed to estimate the effect of several variables simultaneously. In this section the regression modelling is employed using a COX model. Separate models were fit to "all" dialysis and for each initial treatment modality. Details of the model inputs are found in Appendix F.

Based on the analysis, dialysis patients older than 75 years of age had a mortality risk that was five times greater than that for younger adults (ages 18 to 45 years).

The mortality risk over a 10-year time span was reduced by 6% to 12% for dialysis treatments in Canada ($p < 0.01$). There was a similar but slightly lower mortality risk calculated in the model for those treated with PD, compared to those receiving HD treatment (HR: 0.97; C.I.: 0.92,1.02).

Continual ambulatory peritoneal dialysis (CAPD) treatment among PD patients appeared to marginally decrease the risk of mortality (HR: 0.93; C.I.: 0.84, 1.03) compared to that calculated for automated peritoneal dialysis (APD) treatment.

Diabetes was determined to be one of the most influential risk factors among all primary diseases causing ESRD in the multi-variable adjusted analysis. When the race of dialysis patients was included as a variable in the model, patients of Black and Asian origins had improved survival outcomes.

Figure 15 Adjusted Mortality Risk for Dialysis Patients, Canada 1996 to 2000 (Followed to 2005)

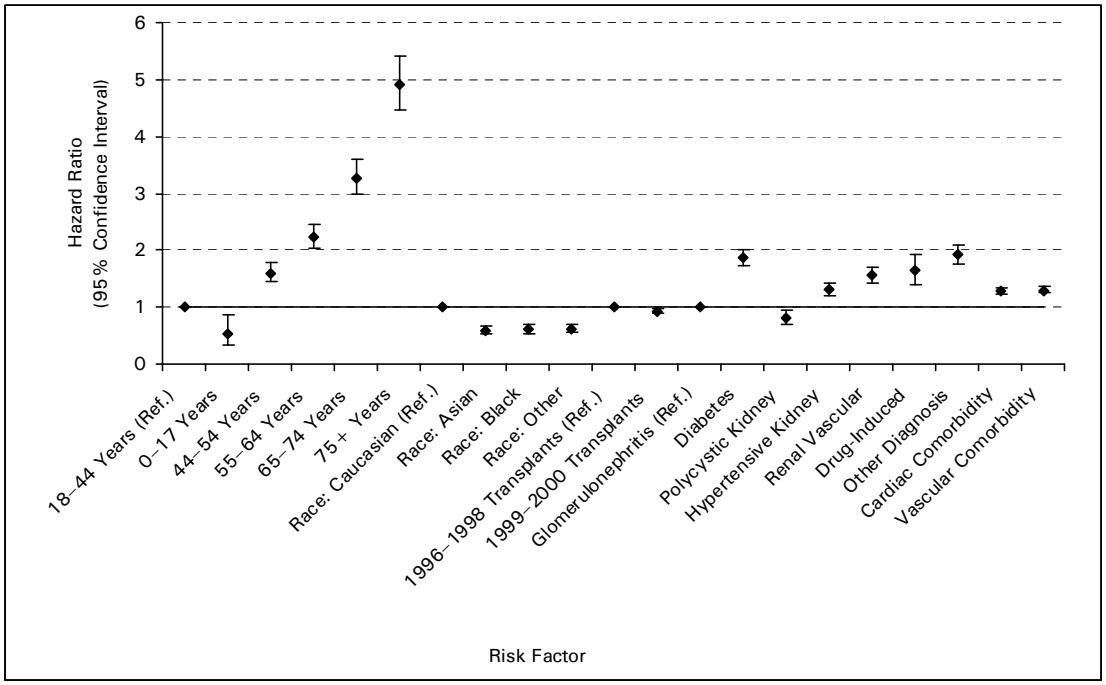


Figure 16 Adjusted Mortality Risk of Patients Who Initiated RRT With HD, Canada 1996 to 2000 (Followed to 2005)

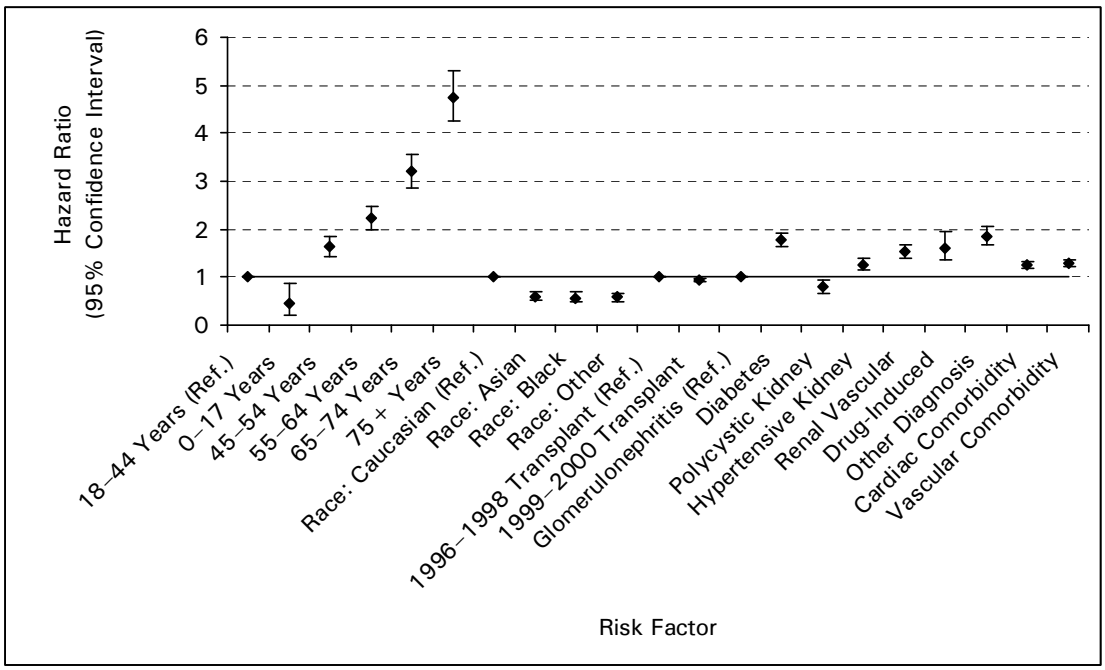
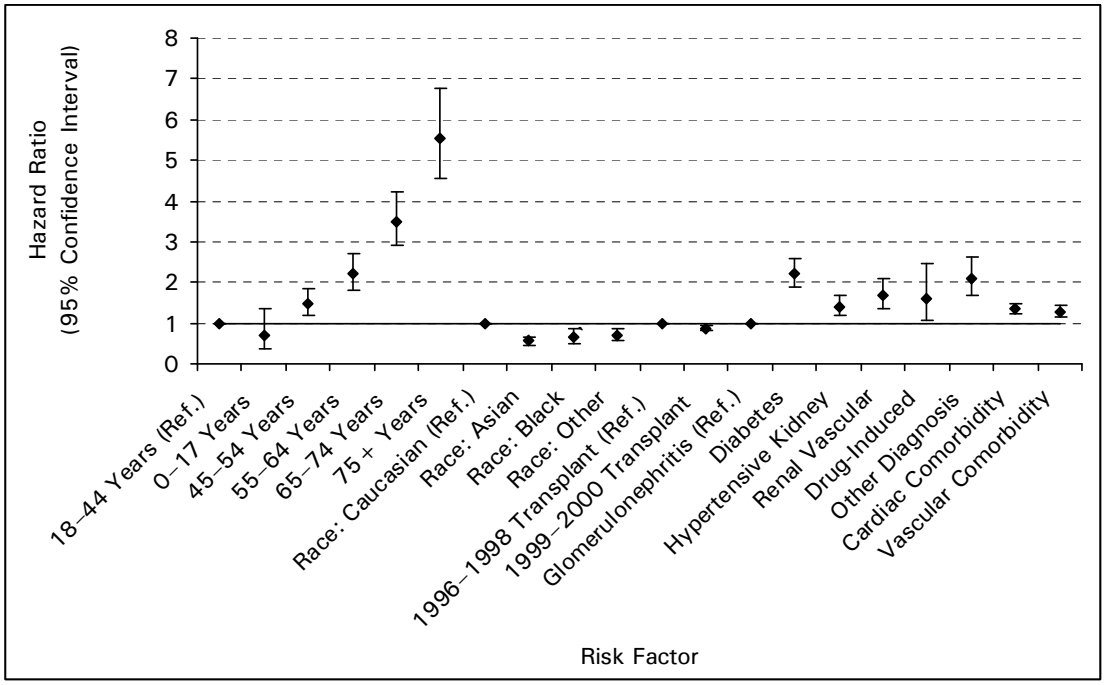


Figure 17 Adjusted Mortality Risk of Patients Who Initiated RRT With PD, Canada 1996 to 2000 (Followed to 2005)



2.2 Prevalent ESRD RRT Patients (Registered)

One of the measures utilized to assess the growth of an ESRD program is prevalence: the total patient count at a specified point in time. By definition, prevalence is the proportion of people in the entire population who are found to have the cited disease at a certain point in time. The prevalent counts of ESRD patients can be calculated from two data sources: i) the patient-level data representing registered patients and ii) a facility survey, which collects aggregate numbers of patients receiving treatment by each facility at the end of each calendar year. In this section of the report, patient-level data (registered patients) will be used for the analysis of prevalent patient trends and characteristics in Canada.

2.2.1 Activity

CIHI gathers data annually from all reporting centres on patients with functioning transplants, as well as those on dialysis, As of December 31, 2005, there were 32,375 Canadians registered in the database with ESRD (Table 10) of which 19,721 (60.8%) were receiving dialysis and 12,654 (39.2%) were living with a functioning kidney transplant.

2.2.2 Patient Characteristics

Table 10 provides the characteristics of prevalent ESRD patients, by age, sex, race and primary diagnosis. In 2005, the largest proportion of prevalent patients by treatment was found in the age group of 45 to 64 years. Rates were at 32.8%, 38.5% and 49.9% for the HD, PD and functioning transplant (TX) groups respectively. Regardless of age group, male patients were predominant in all three groups (HD: 58.4%, PD: 56.3% and TX: 62.1%). For all prevalent HD, PD and TX patients combined, two-thirds were Caucasian, 6.1% were Asian, 4.4% were Aboriginal, 3.7% were Black and 14.0% were "other" origin.

In 2005, diabetic nephropathy accounted for the largest proportion of all prevalent patients (25.1%), followed by patients with glomerulonephritis (22.4%). While a diagnosis of diabetes was most common in patients being treated with HD (32.4%) and PD (29.8%), a diagnosis of glomerulonephritis as the cause of ESRD was more common in patients with a functioning kidney transplant, accounting for 32.3% of transplant patients.

Table 10 Prevalent ESRD Patients at Year-End, by Treatment, Age Group, Sex, Race and Primary Diagnosis, Canada, 2005 (Number, Percentage)

	Number			Percent of Total		
	HD	PD	TX	HD	PD	TX
Total	16,047	3,674	12,654	49.5	11.3	39.2
Age Group						
0–19	72	50	427	0.4	1.4	3.4
20–44	1,937	605	3,734	12.1	16.5	29.5
45–64	5,262	1,416	6,318	32.8	38.5	49.9
65–74	3,957	898	1,738	24.7	24.4	13.7
75+	4,819	705	437	30.0	19.2	3.5
Sex						
Male	9,367	2,069	7,860	58.4	56.3	62.1
Female	6,679	1,605	4,794	41.6	43.7	37.9
Race						
White (Caucasian)	11,194	2,488	9,545	69.8	67.7	75.4
Asian	977	338	679	6.1	9.2	5.4
Black	736	109	341	4.6	3.0	2.7
Indigenous (Aboriginal)	881	172	364	5.5	4.7	2.9
Other	2,259	567	1,725	14.1	15.4	13.6
Diagnosis						
Diabetes	5,206	1,095	1,829	32.4	29.8	14.5
Glomerulonephritis	2,437	749	4,088	15.2	20.4	32.3
Vascular Disease	2,865	628	741	17.9	17.1	5.9
Pyelonephritis	834	183	1,154	5.2	5.0	9.1
Polycystic Kidney Disease	747	215	1,381	4.7	5.9	10.9
Drug-Induced	233	37	117	1.5	1.0	0.9
Other	1,544	350	1,776	9.6	9.5	14.0
Unknown	2,181	417	1,568	13.6	11.4	12.4

In regard to age-specific rates for prevalent ESRD patients in 2005, the highest rate was found among HD patients 75 years of age and older (2,431.9 PMP). Among PD patients, the highest rate was among those 65 to 74 years of age (401.6 PMP), and among living transplant patients, the highest rate was also among those 65 to 74 years of age (777.2 PMP) (Table 11). The treatment rates for male patients were higher than for females for all three types of treatments. The largest average annual growth (percentage of total) was in HD treatment, reflecting a 6.3% increase for males and a 7.5% increase for females. The largest annual percent change was for patients with kidney transplant who were over 75 years old (29.4%).

With respect to ethnicity, the prevalence of ESRD was 58.4% higher among Aboriginals compared to non-Aboriginals on HD. However, the rate for kidney transplant was lower (346.1 PMP), compared to the rate for patients of non-Aboriginal origin (396.6 PMP).

The number of prevalent ESRD patients with diabetes as their primary diagnosis increased over time. For HD patients, the average annual increase was 10.5%, while for those with a functioning kidney transplant, the average annual increase was 7.5%. For those receiving PD treatment, the average annual change was smaller at 3.2% (Table 11).

Table 11 Prevalent Patients at Year-End, by Treatment, Age Groups, Sex, Aboriginal Status, Primary Diagnosis, Canada, 2005 (PMP and Percent Change)

	RPM			Annual Percent Change 2001 to 2005		
	HD	PD	TX	HD	PD	TX
Age Group						
0–19	9.2	6.4	54.5	-5.0	-6.3	1.6
20–44	164.5	51.4	317.1	1.9	-0.9	0.0
45–64	622.9	167.6	747.9	6.1	3.2	6.7
65–74	1,769.5	401.6	777.2	4.8	2.0	12.5
75+	2,431.9	355.8	220.5	12.6	5.9	29.4
Sex						
Male	586.2	129.5	491.9	6.3	3.8	5.0
Female	410.0	98.5	294.3	7.4	0.8	5.6
Race						
(Indigenous) Aboriginal	837.7	163.5	346.1	7.1	1.8	4.9
Non Indigenous	489.4	113.0	396.6	10.8	4.2	7.0
Diagnosis						
Diabetes	161.3	33.9	56.7	10.5	3.2	7.5
Glomerulonephritis	75.5	23.2	126.7	3.4	0.9	4.7
Vascular Disease	88.8	19.5	23.0	5.8	2.3	6.7
Pyelonephritis	25.8	5.7	35.8	4.3	-1.2	3.0
Polycystic Kidney Disease	23.1	6.7	42.8	5.1	12.1	5.7
Drug-Induced	7.2	1.1	3.6	4.9	1.4	10.7
Other	47.8	10.8	55.0	6.6	0.6	5.2
Unknown	67.6	12.9	48.6	5.9	3.4	4.6

Age-specific rates in prevalent patients on dialysis increased over time for all age groups except the pediatric group where the rate was 15.6 PMP in 2005, down from 20.1 PMP in 1996 (Table 12). The greatest change was observed in patients older than 75 years where the rate more than doubled to 2,787 PMP in 2005, compared to 1,133.2 PMP in 1996.

Table 12 Prevalent ESRD Patients on Dialysis at Year-End, by Age Group, 1996 to 2005, Canada (Number and Rate PMP)

Age Group		1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
0–19	N	161	160	162	159	151	157	144	140	130	122
	PMP	20.1	20.0	20.2	19.9	18.9	19.7	18.1	17.7	16.6	15.6
20–44	N	2,153	2,274	2,380	2,412	2,437	2,425	2,467	2,499	2,503	2,542
	PMP	183.7	193.7	203.2	206.3	208.5	207.0	209.9	212.6	212.9	215.9
45–64	N	3,682	4,081	4,438	4,838	5,167	5,490	5,759	6,050	6,421	6,678
	PMP	582.7	627.1	661.4	697.8	720.8	740.8	750.3	762.4	783.8	790.5
65–74	N	2,788	3,106	3,362	3,622	3,898	4,153	4,304	4,535	4,703	4,855
	PMP	1,334.9	1,472.8	1,580.7	1,696.1	1,816.2	1,921.8	1,978.9	2,070.4	2,125.2	2,171.1
75 +	N	1,689	2,044	2,424	2,843	3,249	3,772	4,276	4,644	5,073	5,524
	PMP	1,133.2	1,322.3	1,517.5	1,721.9	1,903.6	2,140.7	2,351.7	2,475.8	2,631.1	2,787.6
Total	**N**	**10,473**	**11,665**	**12,766**	**13,874**	**14,902**	**15,997**	**16,950**	**17,868**	**18,830**	**19,721**
	PMP	**353.7**	**390.0**	**423.3**	**456.3**	**485.6**	**515.7**	**540.3**	**564.4**	**589.4**	**611.1**

There was variation in the sex- and age-specific rates for prevalent ESRD patients by province (Table 13). The highest rate for females of all age groups (except for those under 20 years of age and for those 75 years of age and older), was in Manitoba. The highest rate for females under age 20 years was in Saskatchewan (30.2). The lowest rate for females aged 65 to 74 was in Newfoundland and Labrador. In contrast, British Columbia showed the highest rates in the elderly group for both sexes with females at 2,944.6 PMP and males at 5,874.7 PMP. For the young adult group (20 to 44 years) the lowest rates for females were observed in Quebec (118.4) and for males in Alberta (169.6).

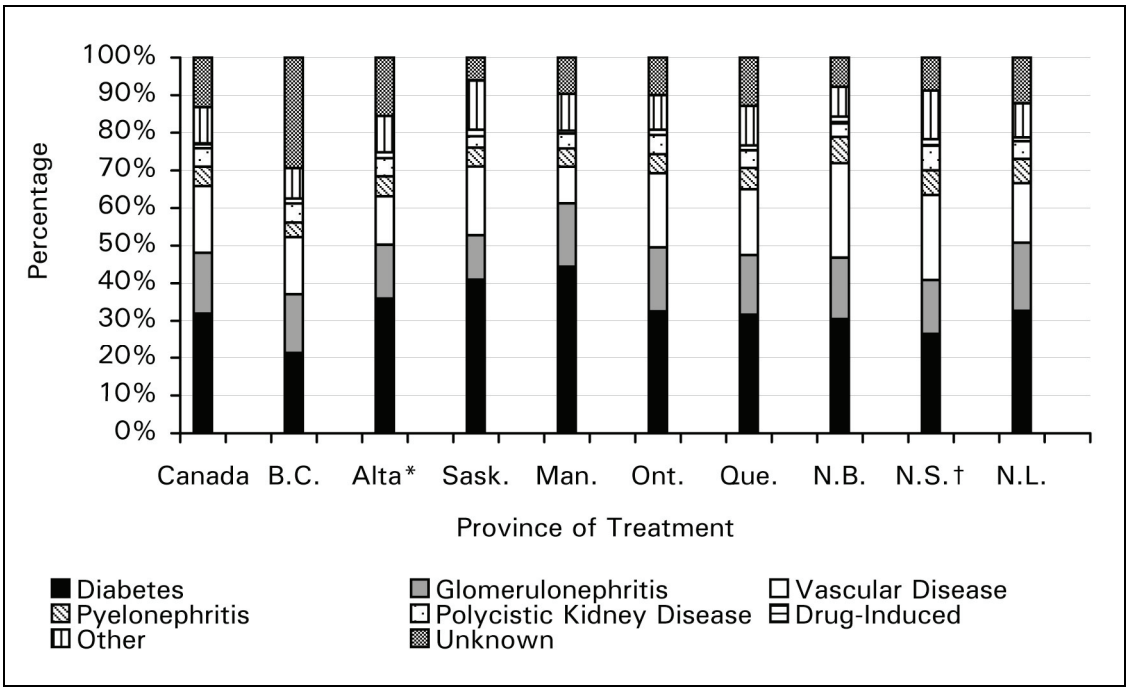
Table 13 Prevalent ESRD Patients at Year-End, by Age and Sex, Canada and Provinces, 2005 (Number and Rate PMP)

Province of Treatment		Female						Male					
		0–19	20–44	45–64	65–74	75+	Total	0–19	20–44	45–64	65–74	75+	Total
British Columbia*	N	9	122	294	213	277	915	16	191	498	348	373	1,426
	PMP	20.9	194.9	735.9	2,226.4	2,944.6	555.7	35.2	287.2	1,215.3	3,862.0	5,874.7	847.1
Alberta/Northwest Territories	N	12	115	249	185	201	762	5	132	353	248	272	1010
	PMP	25.1	148.3	425.7	1,189.6	1,205.5	352.7	9.9	169.6	614.0	1,643.2	2,350.2	475.4
Saskatchewan	N	4	68	84	57	64	277	0	45	131	104	78	358
	PMP	30.2	413.8	697.4	1,567.8	1,368.0	553.6	0.0	266.8	1,077.1	3,131.5	2,536.5	725.0
Manitoba	N	0	94	200	103	83	480	0	91	218	109	95	513
	PMP	0.0	466.4	1,372.8	2,541.1	1,649.2	809.8	0.0	433.1	1,503.0	2,975.6	3,054.9	877.2
Ontario	N	21	436	1,157	915	1,118	3,647	32	654	1,701	1,184	1,399	4,970
	PMP	13.8	188.1	722.0	2,033.6	2,447.9	574.3	20.1	279.8	1,090.9	2,917.6	4,722.9	802.7
Quebec	N	7	157	509	410	490	1,573	10	249	815	609	639	2,322
	PMP	8.3	118.4	473.6	1,345.9	1,622.4	408.8	11.3	180.1	778.4	2,312.7	3,637.2	619.2
New Brunswick†	N	0	20	78	53	69	220	0	36	85	65	95	281
	PMP	0.0	152.0	734.0	1,848.6	2,212.7	577.7	0.0	269.0	811.1	2,508.5	5,014.5	757.1
Nova Scotia/ Prince Edward Island	N	2	26	65	65	73	231	3	52	110	80	104	349
	PMP	16.3	138.2	427.9	1,532.0	1,635.2	420.4	23.5	280.5	745.8	2,074.9	3,796.2	662.9
Newfoundland/ Labrador	N	1	32	55	41	50	179	0	22	76	65	44	207
	PMP	8.2	170.0	362.1	966.4	1,120.0	325.7	0.0	246.8	1,014.1	3,507.8	3,733.9	816.8
Canada	**N**	**56**	**1,070**	**2,691**	**2,042**	**2,425**	**8,284**	**66**	**1,472**	**3,987**	**2,812**	**3,099**	**11,436**
	PMP	**14.7**	**183.7**	**631.3**	**1,740.6**	**2,003.3**	**508.5**	**16.5**	**247.4**	**952.7**	**2,645.3**	**4,018.9**	**715.7**

Notes:
Age was calculated on December 31, 2005.
* British Columbia includes the population of the Yukon.
† Data for one patient in New Brunswick is not included in the table.

In 2005, the primary cause of ESRD among prevalent patients varied between provinces.[iv] Diabetes was the most common cause of ESRD among patients on dialysis, accounting for the largest proportion of prevalent patients in Manitoba (44.0%) and the smallest proportion in Nova Scotia (26.0%). Renal vascular disease was the second most common cause of prevalent ESRD and accounted for 17.7% nationally, with the highest proportions in Nova Scotia (23.0%).

Figure 18 Primary Renal Diagnosis in Prevalent Patients on Dialysis, by Province of Treatment, Canada, 2005



Notes:

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

† Nova Scotia includes the population of Prince Edward Island.

iv. Data for British Columbia are presented, although there is a large proportion of cases with an unknown primary diagnosis, and the data should therefore be used with caution.

2.3 Prevalent ESRD RRT Patients (Facility Profile Data)

As noted in Section 2.2, the prevalent counts of ESRD patients can be calculated from two data sources: the patient-level data or a facility survey. In this section of the report, facility-level data (aggregate facility numbers) will be used for the analysis of prevalent patient trends and characteristics in Canada.

At the end of the calendar year, CIHI gathers data on patients with functioning transplants and patients on dialysis from all reporting centres. These data are compared against registered patients in the database and used as a data quality check, found in Appendix D at the end of this report. In this section, these counts are used to illustrate the volume of treated ESRD cases in Canada.[v]

As of December 31, 2005, there were 13,441 patients surviving with a functioning kidney transplant (Table 14). This represented a 61.0% increase from 1996 and an average increase of 6.1% per year. As a proportion of the population, the number of transplant patients in Canada rose by 47.96%, or from 281.5 PMP in 1996 to 416.5 PMP in 2005. When examining the rate by province of treatment, sizeable variations occurred between provinces. The highest rate of patients was in Nova Scotia/Prince Edward Island (558.5 PMP) and the lowest in Manitoba (368.6 PMP).

v. CORR Dialysis Facility Profile contains counts of all patients living and on dialysis at year-end, including patients who initiated treatment prior to 1981 and who may not be registered in CORR. In addition, it would be affected by under-reporting of deaths as are the patient-level data within CORR. Please see Appendix F for further information.

Table 14 Patients With Functioning Kidney Transplants* at Year-End by Province of Follow-up, Canada, 1996 to 2005 (Number, Rate PMP)

Province of Treatment		1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
British Columbia	N	1,140	1,199	1,246	1,282	1,366	1,444	1,511	1,583	1,580	1,761
	RPMP	294.2	303.7	312.8	319.6	338.2	354.1	367.2	381.2	376.5	410.9
Alberta	N	857	926	1,027	1,137	1,180	1,287	1,331	1,437	1,554	1,643
	RPMP	298.2	316.1	342.6	372.6	380.2	407.8	413.8	440.7	470.1	493.4
Saskatchewan	N	225	232	273	303	319	337	450	384	390	408
	RPMP	220.8	227.9	268.3	298.6	316.5	337.0	451.9	386.2	391.8	410.4
Manitoba	N	377	382	371	370	387	398	415	438	446	434
	RPMP	332.4	336.2	326.1	323.9	337.3	345.7	359.1	377.1	381.1	368.6
Ontario	N	3,201	3,228	3,333	3,675	3,811	3,765	4,238	4,426	4,905	5,147
	RPMP	288.8	287.5	293.2	319.4	326.1	328.9	350.2	361.1	395.8	410.4
Quebec	N	1,673	1,784	1,830	1,982	2,158	2,330	2,553	2,601	2,582	2,846
	RPMP	230.9	245.2	250.8	270.6	293.3	315.0	342.9	347.2	342.3	374.6
New Brunswick	N	208	220	220	235	239	266	273	287	293	313
	RPMP	276.5	292.3	293.1	313.1	318.4	354.7	363.8	382.2	389.9	416.2
Nova Scotia†	N	417	455	455	543	606	914	1,000	1,082	572	601
	RPMP	390.8	425.8	426.1	507.4	566.2	855.0	936.1	1008.0	532.2	558.5
Newfoundland and Labrador‡	N	237	237	244	254	264	270	272	279	284	288
	RPMP	423.4	430.1	451.9	476.2	500.0	517.3	523.6	538.2	549.3	558.2
Total	**N**	**8,335**	**8,663**	**8,999**	**9,781**	**10,330**	**11,011**	**12,043**	**12,517**	**12,606**	**13,441**
	RPMP	**281.5**	**289.7**	**298.4**	**321.7**	**336.6**	**355.0**	**383.9**	**395.4**	**394.6**	**416.5**

Notes:

* Data come from the year-end CORR Renal Transplant Facility Profile and represent point prevalent counts of patients for December 31 of each year.

† Nova Scotia data were calculated from the East Coast cumulative data report by subtracting other provinces.

‡ Newfoundland and Labrador data for 2002 have been estimated on the basis of the previous years.

At the end of 2005, there were 19,680 dialysis patients in Canada (Table 15), of which 15,938 received HD treatment, compared to 3,742 (Table 16) on PD treatment. The number of patients on HD grew by 124.5% in the decade since 1996, with an average annual growth of 12.4%. In contrast, the number of patients on PD showed an average annual increase of 1.1%.

As a proportion of the population of patients on HD in Canada, there was an increase from 239.7 PMP (1996) to 493.9 PMP (2005), or more than double. In regard to differences in rates for patients on HD by province, there are more noticeable differences observed between provinces in 2005, compared to the higher degree of homogeneity in rates between provinces reported in 1996. The highest rate of patients on HD treatment was in Manitoba (661.5 PMP) while the lowest was in Alberta (419.2 PMP).

Table 15 Patients on HD* at Year-End by Province of Treatment, Canada, 1996 to 2005 (Number, Rate PMP)

Province of Treatment		1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
British Columbia†	N	747	788	921	1,119	1,306	1,258	1,471	1,449	1,613	1,812
	RPMP	192.8	199.6	231.2	279.0	323.3	308.5	357.4	349.0	384.4	422.8
Alberta	N	516	666	770	916	982	1,084	1,199	1,332	1,361	1,396
	RPMP	179.5	227.4	256.9	300.2	316.4	343.5	372.7	408.5	411.7	419.2
Saskatchewan	N	230	284	286	327	355	382	442	485	486	505
	RPMP	225.7	279.0	281.1	322.3	352.3	381.9	443.8	487.7	488.3	508.0
Manitoba	N	385	444	529	575	617	660	718	716	762	779
	RPMP	339.4	390.8	465.0	503.3	537.8	573.3	621.3	616.4	651.1	661.5
Ontario†	N	2,930	3,498	3,975	4,512	5,020	5,357	5,872	6,369	6,787	7,086
	RPMP	264.4	311.5	349.7	392.1	429.6	450.3	485.2	519.6	547.7	565.0
Quebec†	N	1,720	1,955	2,216	2,409	2,361	2,770	2,922	3,092	3,228	3,207
	RPMP	237.3	268.7	303.7	328.9	320.9	374.5	392.4	412.7	428.0	422.1
New Brunswick	N	193	199	220	236	264	284	300	328	373	372
	RPMP	256.5	264.4	293.1	314.4	351.8	378.7	399.8	436.8	496.4	494.7
Nova Scotia	N	219	278	304	329	332	369	385	467	405	456
	RPMP	205.2	260.2	284.7	307.4	310.2	345.2	359.3	435.1	376.8	423.8
Newfoundland and Labrador	N	158	138	149	192	216	232	251	273	327	325
	RPMP	282.2	250.4	276.0	359.9	409.1	444.5	483.2	526.7	632.5	629.9
Total	**N**	**7,098**	**8,250**	**9,370**	**10,615**	**11,453**	**12,396**	**13,560**	**14,511**	**15,342**	**15,938**
	RPMP	**239.7**	**275.9**	**310.7**	**349.1**	**373.2**	**399.6**	**432.2**	**458.3**	**480.2**	**493.9**

Notes:

* Data come from the year-end CORR Hemodialysis Facility Profile and represent point prevalent counts of patients for December 31 of each year. Data have been imputed based on data of previous years. It is estimated that the number imputed is 1,089 on HD.

† Data are incomplete for year 2005 for two centres in British Columbia, one centre in Ontario and one centre in Quebec.

In contrast, the rate for patients undergoing PD treatment has remained stable, increasing from 114.8 (1996) to 116.0 PMP (2005) (Table 16). However, once again there is considerable variation between provinces. In 2005, the rate was as low as 79.9 PMP in Quebec and as high as 178.2 PMP in New Brunswick.

Table 16 Patients on PD* at Year-End and Province of Treatment, Canada, 1996 to 2005 (Number, Rate PMP)

Province of Treatment		1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
British Columbia†	N	375	377	417	440	443	503	536	590	616	632
	RPMP	96.8	95.5	104.7	109.7	109.7	123.3	130.2	142.1	146.8	147.5
Alberta	N	315	282	265	217	206	228	235	247	239	310
	RPMP	109.6	96.3	88.4	71.1	66.4	72.2	73.1	75.8	72.3	93.1
Saskatchewan	N	94	88	95	79	85	96	95	110	119	124
	RPMP	92.2	86.4	93.4	77.9	84.3	96.0	95.4	110.6	119.6	124.7
Manitoba	N	136	169	184	206	201	199	200	193	189	208
	RPMP	119.9	148.7	161.8	180.3	175.2	172.9	173.1	166.2	161.5	176.6
Ontario	N	1,375	1,311	1,194	1,231	1,236	1,287	1,324	1,342	1,490	1,549
	RPMP	124.1	116.8	105.0	107.0	105.8	108.2	109.4	109.5	120.2	123.5
Quebec†	N	712	813	809	748	690	654	654	614	657	607
	RPMP	98.2	111.8	110.9	102.1	93.8	88.4	87.8	82.0	87.1	79.9
New Brunswick	N	144	159	191	185	180	173	156	163	181	134
	RPMP	191.4	211.3	254.5	246.5	239.8	230.7	207.9	217.1	240.9	178.2
Nova Scotia	N	159	147	150	147	163	154	156	131	127	136
	RPMP	149.0	137.6	140.5	137.4	152.3	144.1	145.6	122.0	118.2	126.4
Newfoundland and Labrador	N	89	100	99	100	84	76	66	54	47	42
	RPMP	159.0	181.5	183.4	187.5	159.1	145.6	127.1	104.2	90.9	81.4
Total	**N**	**3,399**	**3,446**	**3,404**	**3,353**	**3,288**	**3,370**	**3,422**	**3,444**	**3,665**	**3,742**
	RPMP	**114.8**	**115.2**	**112.9**	**110.3**	**107.1**	**108.6**	**109.1**	**108.8**	**114.7**	**116.0**

Notes:

* Data come from the year-end CORR Peritoneal Dialysis Facility Profile and represent point prevalent counts of patients for December 31 of each year. Data have been imputed based on data of previous years. It is estimated that the number imputed is 76 on PD.

† Data are incomplete for 2005 for one centre in British Columbia and one centre in Quebec.

As of December 31, 2005, the majority of HD patients (71.8%) were receiving conventional HD treatment in a full-care hospital setting or independent health facility (Table 17). The proportion of patients receiving HD in a community centre or independent health care facility varied by province, from a high of 54.6% in Alberta, to as low as 7.6% in Quebec. The rate for patients receiving dialysis using HD and being treated in the home setting was only 3.2% (1.0% higher than in 2004).

Table 17 Point Prevalent HD Patients* by Treatment and Province of Treatment, Canada, 2005 (Number and Percent)

Province of Treatment		Full-Care Hospital			Chronic Care†	Community Centre and Independent Health Facility		Home‡	Total
		Conventional	Short Daily	Slow Nocturnal		Conventional	Short Daily		
British Columbia	N	1,039	6	1	16	652	0	98	1,812
	%	57.3	0.3	0.1	0.9	36.0	0	5.4	100
Alberta§	N	550	0	0	30	762	0	54	1,396
	%	39.4	0.0	0.0	2.1	54.6	0	3.9	100
Saskatchewan	N	390	0	0	0	115	0	0	505
	%	77.2	0.0	0	0	22.8	0	0	100
Manitoba	N	605	0	0	0	170	0	4	779
	%	77.7	0.0	0	0	21.8	0	0.5	100
Ontario	N	5,097	68	24	51	1,559	12	275	7,086
	%	71.9	1.0	0.3	0.7	22.0	0.2	3.9	100
Quebec	N	2,898	7	0	0	245	0	57	3,207
	%	90.4	0.2	0	0	7.6	0	1.8	100
New Brunswick	N	300	0	0	0	65	0	7	372
	%	80.6	0.0	0	0	17.5	0	1.9	100
Nova Scotia	N	301	1	0	0	151	0	3	456
	%	66.0	0.2	0	0	33.1	0	0.7	100
Newfoundland and Labrador	N	269	0	0	0	51	0	5	325
	%	82.8	0.0	0	0	15.7	0	1.5	100
Total	**N**	**11,449**	**82**	**25**	**97**	**3,770**	**12**	**503**	**15,938**
	%	**71.8**	**0.5**	**0.2**	**0.6**	**23.7**	**0.1**	**3.2**	**100**

Notes:

* Data are incomplete for two centres in British Columbia, one center in Ontario and one center in Quebec. Data have been imputed based on data of previous year. It is estimated that the number imputed is 1,089 on HD.

† May include conventional or slow nocturnal dialysis.

‡ May include conventional, short daily or slow nocturnal dialysis.

§ Alberta includes the population of the Northwest Territories.

As of December 31, 2005, there was a total of 3,580 HD stations in Canadian hospitals and affiliated centres (Table 18). New Brunswick had the highest availability of stations for treatment at 182.2 PMP, while Ontario had the highest ratio of patients treated at each station (at 5.2 per station).

Table 18 Point Prevalent Hospital, Independent Health Facility and Community Centre HD Patients* by Stations and Province of Treatment, Canada, 2005 (Number)

Province of Treatment	Stations† (N)	Patients† (N)	Patients per Stations	Population‡	Stations per Million Population
British Columbia	385	1,812	4.7	4,285,510	89.8
Alberta	343	1,396	4.1	3,329,790	103.0
Saskatchewan	103	505	4.9	994,126	103.6
Manitoba	176	779	4.4	1,177,556	149.5
Ontario	1,356	7,086	5.2	12,541,410	108.1
Quebec	822	3,207	3.9	7,598,146	108.2
New Brunswick	137	372	2.7	752,006	182.2
Nova Scotia	175	456	2.6	1,076,002	162.6
Newfoundland and Labrador	83	325	3.9	515,961	160.9
Total	**3,580**	**15,938**	**4.5**	**32,270,507**	**110.9**

Notes:

* Data are incomplete for 2005 for two centres in British Columbia, one centre in Ontario and one centre in Quebec. Data have been imputed based on data of previous year. It is estimated that the number imputed is 1,089 on HD.

† Includes stations located in, and patients being treated at, full-care hospitals, independent health facilities and community centres.

‡ 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.

Overall, 45.4% of HD patients received their dialysis through a natural AV fistula, although there were observed differences in the distribution of access types by province. The utilization rate for the fistula ranged from 40.2 % in Saskatchewan, to 66.9% in Nova Scotia (Table 19). Permanent (tunnelled) central venous catheters were the second most commonly used access type (41.8%).

Table 19 Type of Access for Point Prevalent HD Patients* by Province of Treatment, Canada, December 31, 2005 (Number and Percent)

Province of Treatment		Natural Vein Fistula	Graft		Catheter				Other	Total
			Synthetic Arteriovenous	Saphenous Vein	Permanent Central Venous	Temporary Subclavian Vein	Temporary Internal Jugular Vein	Temporary Femoral Vein		
British Columbia	N	824	190	22	478	6	18	1	2	**1,541**
	%	53.5	12.3	1.4	31.0	0.4	1.2	0.1	0.1	**100**
Alberta	N	306	96	0	302	0	7	0	0	**711**
	%	43.0	13.5	0.0	42.5	0.0	1.0	0.0	0.0	**100**
Saskatchewan	N	181	75	0	193	0	1	0	0	**450**
	%	40.2	16.7	0.0	42.9	0.0	0.2	0.0	0.0	**100**
Manitoba	N	462	16	1	329	6	18	4	5	**841**
	%	54.9	1.9	0.1	39.1	0.7	2.1	0.5	0.6	**100**
Ontario	N	3,110	530	23	3,147	95	177	19	36	**7,137**
	%	43.6	7.4	0.3	44.1	1.3	2.5	0.3	0.5	**100**
Quebec	N	1,424	215	91	1,134	14	76	9	2	**2,965**
	%	48.0	7.3	3.1	38.2	0.5	2.6	0.3	0.1	**100**
New Brunswick	N	138	22	92	626	5	1	0	0	**884**
	%	15.6	2.5	10.4	70.8	0.6	0.1	0.0	0.0	**100**
Nova Scotia	N	303	3	1	84	12	50	0	0	**453**
	%	66.9	0.7	0.2	18.5	2.6	11.0	0.0	0.0	**100**
Newfoundland and Labrador	N	197	15	0	111	0	0	0	1	**324**
	%	60.8	4.6	0.0	34.3	0.0	0.0	0.0	0.3	**100**
Total	**N**	**6,945**	**1,162**	**230**	**6,404**	**138**	**348**	**33**	**46**	**15,306**
	%	**45.4**	**7.6**	**1.5**	**41.8**	**0.9**	**2.3**	**0.2**	**0.3**	**100**

Note:

* Of patients, 632 are missing information about accesses and 98 were reported with more than one type of access.

The majority of PD patients in Canada (96.6%) were receiving continuous ambulatory peritoneal dialysis (CAPD) or automated peritoneal dialysis (APD) at home in 2005, or 40.8% and 55.8% respectively (Table 20). Significant differences were observed among the provinces with the largest proportion of patients on APD in Manitoba (73.6%), and on CAPD in Nova Scotia (71.3%).

Table 20 Point Prevalent Peritoneal Dialysis Patients by Treatment and Province of Treatment, Canada, 2005 (Number and 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	216	385	8	1	0	11	11	632
	%	34.2	60.9	1.3	0.2	0.0	1.7	1.7	100
Alberta	N	154	150	4	2	0	0	0	310
	%	49.7	48.4	1.3	0.6	0.0	0.0	0.0	100
Saskatchewan	N	76	45	0	1	0	0	2	124
	%	61.3	36.3	0.0	0.8	0.0	0.0	1.6	100
Manitoba	N	50	153	3	0	1	1	0	208
	%	24.0	73.6	1.4	0.0	0.5	0.5	0.0	100
Ontario	N	567	950	1	10	5	4	12	1,549
	%	36.6	61.3	0.1	0.6	0.3	0.3	0.8	100
Quebec	N	286	279	3	1	24	11	3	607
	%	47.1	46.0	0.5	0.2	4.0	1.8	0.5	100
New Brunswick	N	58	72	0	0	2	2	0	134
	%	43.3	53.7	0.0	0.0	1.5	1.5	0.0	100
Nova Scotia	N	97	36	0	0	0	2	1	136
	%	71.3	26.5	0.0	0.0	0.0	1.5	0.7	100
Newfoundland and Labrador	N	24	18	0	0	0	0	0	42
	%	57.1	42.9	0.0	0.0	0.0	0.0	0.0	100
Total	**N**	**1,528**	**2,088**	**19**	**15**	**32**	**31**	**29**	**3,742**
	%	**40.8**	**55.8**	**0.5**	**0.4**	**0.9**	**0.8**	**0.8**	**100**

Notes:

* Includes total and limited self-care.

† Total care only.

2.4 Kidney Transplantation: Adult Recipients

The first kidney transplant was performed by Drs. Murray and Harrison in 1954. The ground-breaking operation grafted a kidney from one identical twin to another. However, it was not until the end of the 1950s that kidney transplants from deceased donors were successfully performed and became a relatively routine procedure. This path-finding work established the foundation for eventual and continuing developments in extra-renal transplantation. Today, kidney transplantation is the most commonly performed solid organ transplant in Canada.

2.4.1 Activity

In 2005, there were 23 active kidney transplant programs in Canada operating in seven provinces: British Columbia (3), Alberta (2), Saskatchewan (1), Manitoba (1), Ontario (7), Quebec (7) and Nova Scotia (2). Among patients 18 years of age and older, there were 9,683 kidney transplant procedures registered in CORR between 1996 and 2005. During the same time, an additional 604 kidney transplant procedures were performed involving pediatric recipients. (The details on pediatric recipients are provided in Section 9 of this report.) There were also 406 simultaneous kidney–pancreas (SKP) transplants during this period. (SPK transplants are described more fully in Section 2.5 and are excluded from the data and analysis provided in this section.)

In this time period, 9,683 kidney transplant procedures were performed among adult recipients in Canada (Table 21), of which 12.2% were retransplants. A small number of kidney combination transplants were performed each year, mostly kidney–liver transplants. A total of 8,451 patients received a first kidney transplant, with 63.3% of these first grafts utilizing deceased-donor kidneys.

Table 21 Kidney Transplants* by Year, Donor Type and Retransplants, Adult Recipients, Canada, 1996 to 2005 (Number)

	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	Total
Kidney Only First Graft, Deceased Donor	560	547	525	500	592	546	515	549	514	501	5,349
Kidney Only First Graft, Living Donor	216	236	300	323	309	340	319	346	345	368	3,102
Kidney Combination First Graft, Deceased Donor	5	8	4	5	5	6	5	8	3	5	54
Retransplants	128	122	119	128	125	123	129	95	104	105	1,178
Total	**909**	**913**	**948**	**956**	**1,031**	**1,015**	**968**	**998**	**966**	**979**	**9,683**

Note:

* Excludes simultaneous kidney–pancreas transplants. See Section 2.6.

Over the decade, the number of adult deceased-donor kidney transplants declined in Manitoba, Ontario and British Columbia (Table 22), with the largest percentage decline in Manitoba (82.4%). Although there was a 56.8% decline in British Columbia over the period, the number remained stable for 2003 and 2004. The number of deceased-donor kidney transplants in Ontario was 9.6% fewer in 2005 (206) than in 1996; an upward movement beginning after 2001 resulted in an increase of 12.0% by 2005. The largest number of deceased-donor kidney transplants in Canada (36.1%) were performed in Ontario (206), followed by Quebec, with 173 cases or 30.4% of all Canadian renal transplants performed in 2005. The number of deceased-donor transplants for adult recipients is notable in Saskatchewan, where it is considerably higher than it was 10 years ago (representing a 66.7% increase). The numbers of deceased donor transplants in Alberta, Nova Scotia and Quebec have remained stable throughout the decade (Table 22).

Table 22 Deceased-Donor Kidney Transplants* by Year and Province of Treatment, Adult Recipients, Canada, 1996 to 2005 (Number)

Province of Treatment	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	Total
British Columbia	88	77	51	62	56	59	45	52	52	38	580
Alberta	84	90	74	72	84	85	81	67	67	83	787
Saskatchewan	9	16	35	35	19	28	18	29	18	15	222
Manitoba	34	16	14	14	28	11	17	17	13	6	170
Ontario	228	220	238	173	213	184	196	192	208	206	2,058
Quebec	172	148	165	194	209	207	186	218	196	173	1,868
Nova Scotia	47	86	36	57	79	70	63	51	35	49	573
Total	**662**	**653**	**613**	**607**	**688**	**644**	**606**	**626**	**589**	**570**	**6,258**

Note:

* Excludes simultaneous kidney–pancreas transplants. See Section 6.

Approximately 1,000 kidney transplants are performed annually in Canada. Over the last four years, this level was influenced by a steady rise in living-donor kidney transplants (Table 23). While the data suggest a levelling-off of living-donor numbers between 2001 and 2003, the number of living-donor kidneys for adult patients increased by 65.6% to a total of 409 in 2005. The largest proportion was in Ontario (45.2%), followed by British Columbia (17.1%).

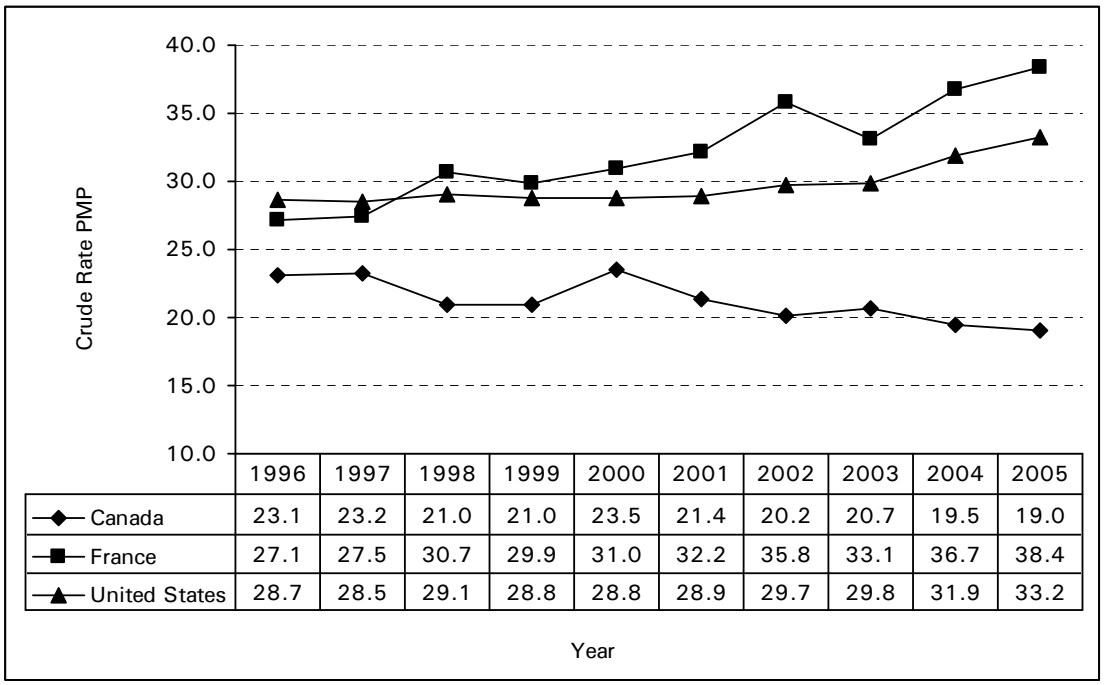
Table 23 Living-Donor Kidney Transplants by Year and Province of Treatment, Adult Recipients, Canada, 1996 to 2005 (Number)

Province of Treatment	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	Total
British Columbia	34	35	38	70	77	83	74	69	74	70	624
Alberta	31	29	55	48	37	50	47	52	61	50	460
Saskatchewan	13	16	26	15	6	8	14	10	12	11	131
Manitoba	8	9	6	14	10	12	15	18	12	19	123
Ontario	121	123	144	140	151	144	149	156	157	185	1,470
Quebec	13	12	29	24	22	43	38	43	38	45	307
Nova Scotia	27	36	37	38	40	31	25	24	23	29	310
Total	**247**	**260**	**335**	**349**	**343**	**371**	**362**	**372**	**377**	**409**	**3,425**

2.4.2 International Comparison

The deceased-donor kidney transplantation rate PMP is a crude rate that excludes SPK transplants and includes patients of all ages. Over the decade, it declined from 23.1 PMP (1996) to 19.0 PMP (2005). During the same period, the rate in the United States and in France increased from 28.7% to 33.2 PMP and from 27.1 to 38.4 PMP respectively (Figure 19).

Figure 19 Deceased-Donor Kidney Transplants, Canada, France and United States, 1996 to 2005 (Crude Rate PMP)



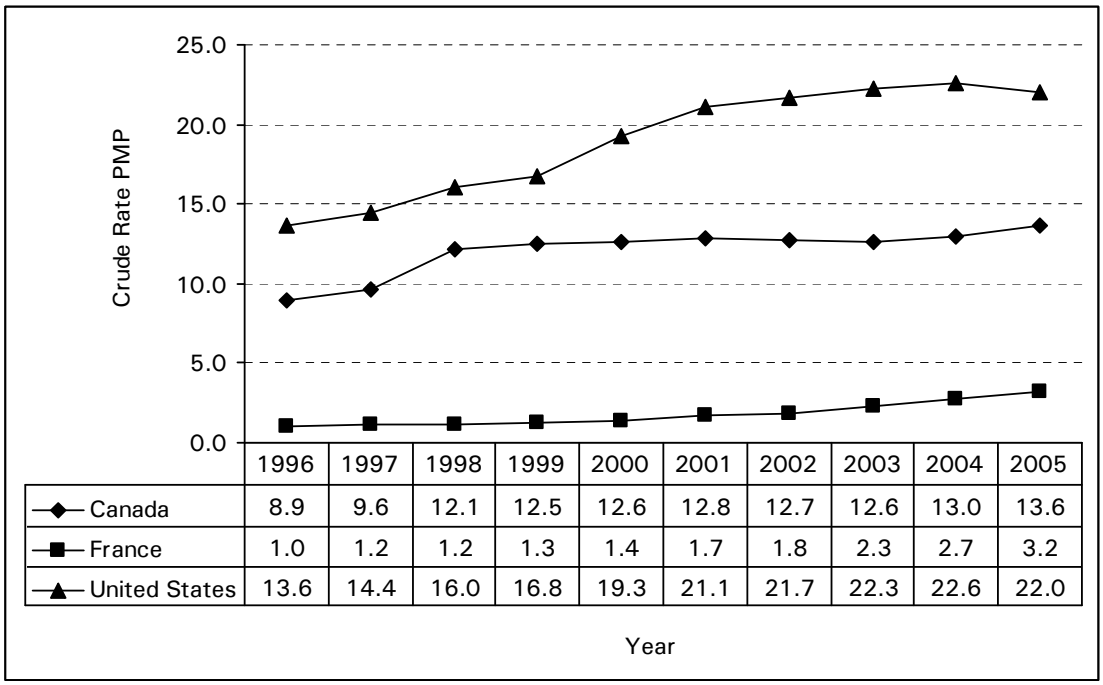
	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
Canada	23.1	23.2	21.0	21.0	23.5	21.4	20.2	20.7	19.5	19.0
France	27.1	27.5	30.7	29.9	31.0	32.2	35.8	33.1	36.7	38.4
United States	28.7	28.5	29.1	28.8	28.8	28.9	29.7	29.8	31.9	33.2

Data source for France: l'Établissement français des Greffes, *Rapport d'activité et Bilan des activités de prélèvement et de greffe en France Année 2005* (Paris: l'Établissement français des Greffes, Agence de la biomédecine, 2006).

Data source for the U.S.: Department of Health and Human Services (Health Resources and Services Administration, Healthcare Systems Bureau, Division of Transplantation), United Network for Organ Sharing and University Renal Research and Education Association, *2006 Annual Report of the U.S. Organ Procurement and Transplantation Network and the Scientific Registry of Transplant Recipients: Transplant Data 1996–2005* (Richmond, VA: United Network for Organ Sharing, 2006).

In terms of living-donor kidney transplant rates, there are distinct differences between Canada, France and the United States. As well, there are changing trends within each country. Over the decade, the rates in Canada were up to 10 times higher than those in France. In 2005, the living-donor rate in Canada was 13.6 PMP, just over four times greater than in France. In contrast, the rate in Canada was 61.8% that for the United States, or 22.0 PMP in 2005 (Figure 20). The rate for living kidney donors in Canada has remained fairly stable, increasing slightly between 1998 and 2005 (12.1 to 13.6), while in the United States, it has increased consistently during the period, from 16.0 to 22.6 PMP with a slight decline between 2004 and 2005.

Figure 20 Living Donor Kidney Transplants, Canada, France and United States, 1996 to 2005 (Crude Rate PMP)



	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
Canada	8.9	9.6	12.1	12.5	12.6	12.8	12.7	12.6	13.0	13.6
France	1.0	1.2	1.2	1.3	1.4	1.7	1.8	2.3	2.7	3.2
United States	13.6	14.4	16.0	16.8	19.3	21.1	21.7	22.3	22.6	22.0

Data source for France: l'Établissement français des Greffes, *Rapport d'activité et Bilan des activités de prélèvement et de greffe en France Année 2005* (Paris: l'Établissement français des Greffes, Agence de la biomédecine, 2006).
Data source for the U.S.: Department of Health and Human Services (Health Resources and Services Administration, Healthcare Systems Bureau, Division of Transplantation), United Network for Organ Sharing and University Renal Research and Education Association, *2006 Annual Report of the U.S. Organ Procurement and Transplantation Network and the Scientific Registry of Transplant Recipients: Transplant Data 1996–2005* (Richmond, VA: United Network for Organ Sharing, 2006).

2.4.3 Recipient Characteristics

Three out of every five adult kidney transplant recipients were males, regardless of whether the transplant involved a living- or a deceased-donor kidney (Table 24). Between 2004 and 2005, the proportion of male recipients of deceased-donor kidneys increased by 1.5%, and those of living-donor organs increased by 3.9%. However, between 1996 and 2005, the proportion of male recipients of deceased-donor kidneys (6.9%) and living-donor kidneys (less than 1%) has decreased. Among patients who received first kidney grafts, the proportion of recipients with diabetes who received kidneys from living donors increased by 5%, from 17.6% (1996) to 22.6% (2005). For those recipients receiving kidneys from deceased donors, the proportion of those with diabetes rose steadily in the 10-year period, for a total increase of 10.1%.

The literature notes that the number of patients referred for transplantation who are both older and who have complex comorbidities is increasing.[14] Within CORR, the average age of recipients has gradually increased over the decade. The age of deceased-donor recipients rose to 51.8 years (from 47.0 years), and for living-donor recipients to 46.7 years (from 42.0 years).

Table 24 Adult Kidney Transplant Recipients, Selected Characteristics, First Graft, Canada, 1996 to 2005 (Number)

Donor Type	Characteristic	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
Deceased	Percentage Male	68.3	65.2	67.1	60.0	63.1	63.9	63.5	64.8	62.1	63.6
	Percentage Age 60+ Years	19.1	19.1	20.8	18.2	20.1	25.7	29.4	26.8	30.6	29.4
	Average Age	47.0	47.5	47.5	47.8	48.3	50.0	50.7	50.4	51.2	51.8
	(Std*)	12.7	12.8	13.0	12.9	12.1	12.8	13.6	12.6	13.2	12.4
	Percentage Diabetic†	15.6	17.3	17.2	22.4	20.1	21.4	23.3	25.5	19.1	25.5
Living	Percentage Male	63.9	63.6	63.3	61.9	62.1	55.6	60.5	64.5	59.1	63.0
	Percentage Age 60+ Years	8.8	6.4	12.3	10.2	10.0	12.6	13.8	16.8	14.5	14.7
	Average Age	42.0	40.5	43.4	42.6	43.3	42.6	43.8	46.2	44.6	46.7
	(Std*)	12.2	12.1	12.6	13.0	12.8	13.2	13.5	12.9	13.2	12.5
	Percentage Diabetic†	17.6	16.9	21.7	18.6	17.5	18.2	18.5	23.7	22.0	22.6

Notes:

* Std = standard deviation.

† Determination of diabetic status is based on primary diagnosis and comorbidity data at time of incident dialysis treatment and/or initial kidney transplant.

Since 2005, the most frequent cause of kidney failure cited in adult kidney transplant diagnoses, regardless of age, was glomerulonephritis (651), followed by diabetic nephropathy (311) (Table 25). Polycystic kidney disease (251) was the third leading specified cause of kidney failure resulting in transplant, and the second leading cause for those aged 40 to 59 years of age (180 recipients). Diabetic nephropathy was the third most frequent cause of kidney failure for the 40-to-59-year age group, or 173 recipients. A diagnosis of diabetic nephropathy was also the second leading cause of kidney failure for those 60 years of age and older (84 recipients).

Table 25 Kidney Transplant Recipients* by Age Group and Primary Renal Diagnosis Category, Adult Recipients, First Graft, Canada, 2005 (Number)

Primary Renal Diagnosis Category	Age Group			
	18–39 Years	40–59 Years	60+ Years	Total
Glomerulonephritis	224	293	134	651
Pyelonephritis	40	76	34	150
Nephropathy—Drug-Induced	6	17	14	37
Polycystic Kidney Disease	18	180	53	251
Hypertension/Other Vascular	30	90	81	201
Diabetic Nephropathy	54	173	84	311
Other	82	130	71	283
Unknown/Not Reported	23	44	10	77
Total Diagnoses	**477**	**1,003**	**481**	**1,961**
Total Patients	**427**	**898**	**411**	**1,736**

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.

2.4.4 Waiting List and Waiting Times

A change in the definition of pediatric patients from "birth to 14 years" to "birth to 17 years" was implemented in 2002. As anticipated, this change affected the trend line for the adult kidney transplant waiting list, since fewer patients meet the definition of "adult" under the new definition (Table 26).

Table 26 Adult Kidney Transplant Waiting List on December 31, Canada, 1996 to 2005 (Number)

	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
≥14 Years	2,331	2,341	2,541	2,760	2,989	2,987				
18+ Years							2,927	2,845	2,840	2,920

For the most recent three-year period (2003 to 2005), patients receiving a kidney transplant in British Columbia had the longest wait times for deceased-donor transplants, with half of the patients waiting for more than five years (Table 27). The shortest median wait time, just under two years, was reported in Saskatchewan. As a proportion of all kidney transplants performed in a province, pre-emptive transplants for adult recipients were most frequently performed in Nova Scotia (17.7%) and less frequently in Ontario (12.1%).

Table 27 Dialysis Duration Prior to First Kidney Transplant, Adult Kidney Transplant Recipients, Canada, 2003 to 2005 (Number)

	B.C.	Alta.	Sask.	Man.	Ont.	Que.	N.S.
Recipients (N)	320	344	89	79	994	632	181
Pre-emptive Transplants, Deceased Donor (N)	3	16	4	0	4	45	10
Pre-emptive Transplants, Living Donor (N)	53	35	9	11	116	36	22
Duration on Dialysis (Median Days)—Deceased Donor	1,912.5	1,050.0	664.0	1,177.0	1,734.0	836.0	865.0
Duration on Dialysis (Median Days)—Living Donor	224.5	365.0	556.0	498.0	374.5	406.0	137.0

Note:

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

2.4.5 Outcomes

At five years after transplantation, the unadjusted patient survival rates for the single years spanning 1996 to 2005 were greater than 90% for recipients of living-donor kidneys, and greater than 85% for recipients of deceased-donor kidneys. The trend in five-year survival rates has steadily improved over time for recipients of organs from deceased donors (85.9% in 1996 to 92.3% in 2005). While the trend for survival with living-donor organ recipients has shown more variation between years, there is a relatively stable overall trend in the survival rate (94.9% in 1996 to 95.1% in 2000) (Table 28).

Table 28 Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Adult Kidney Transplant Recipients, First Graft, Canada, 1996 to 2000 (Followed to 2005)

		1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
Deceased Donor	N	565	555	529	505	597	552	520	557	517	506
	3 Months	97.3	98.6	97.5	97.0	98.7	98.9	98.1	97.7	98.6	98.9
	1 Year	93.8	96.8	95.1	95.4	98.0	98.0	96.5	96.0	95.9	
	3 Years	91.1	93.3	90.7	92.0	95.8	94.9	91.1			
	5 Years	85.9	87.1	87.2	86.8	92.3					
Living Donor	N	216	236	300	323	309	340	319	346	345	368
	3 Months	98.6	99.6	99.0	98.5	98.4	100.0	100.0	99.7	99.7	99.7
	1 Year	96.8	98.3	99.0	97.5	98.1	99.7	100.0	99.4	99.7	
	3 Years	96.3	97.5	96.0	96.3	97.1	98.2	97.8			
	5 Years	94.9	95.7	92.9	95.3	95.1					

The five-year graft survival rate was over 70% for deceased-donor grafts for transplants performed between 1996 and 2000, with a substantial improvement in the survival rates for transplants performed in 2000. Between 1996 and 1999, the graft survival went from 71.8 to 75.8% (a 4.0% increase over three years). However, in 2000, the rate increased by 8.1% to 83.9% in one year. For living-donor grafts in the same time period, survival at five years increased by 4.3% to 89.0% in 2000 (Table 29).

Table 29 Unadjusted Three-Month and One-, Three- and Five-Year Graft Survival* for Adult Kidney Transplant Recipients, First Graft, Canada, 1996 to 2000 (Followed to 2005)

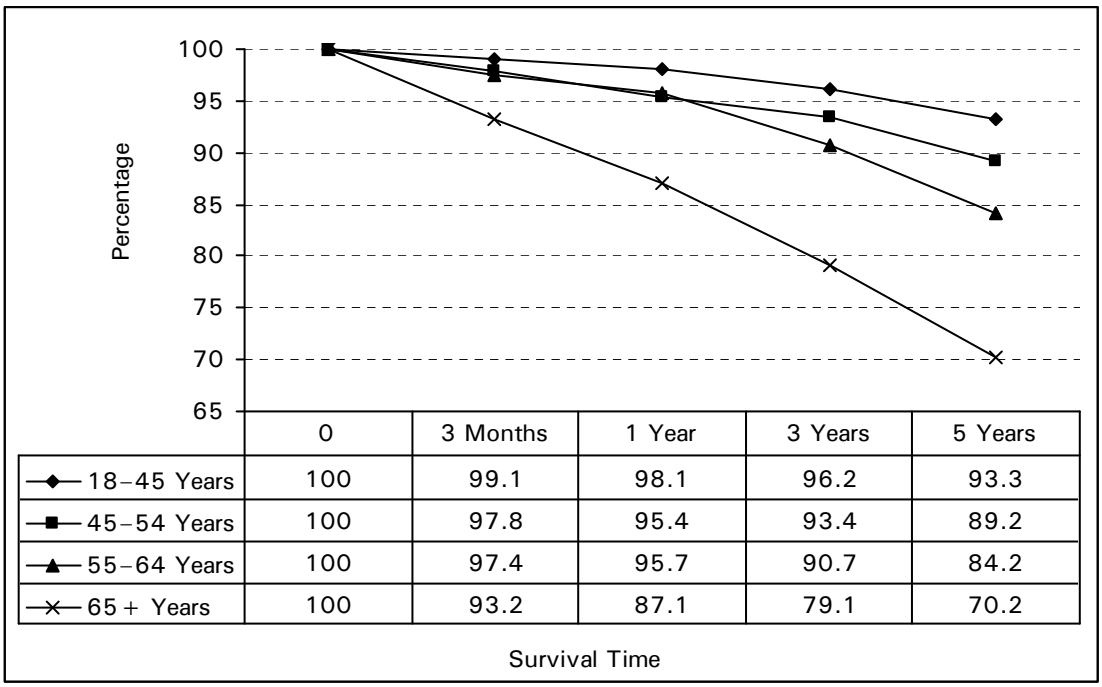
		1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
Deceased Donor	N	565	555	529	505	597	552	520	557	517	506
	3 Months	90.6	92.1	93.0	92.3	94.5	95.1	92.9	95.3	95.6	95.6
	1 Year	85.5	87.9	89.2	88.7	93.5	93.1	90.2	91.7	92.3	
	3 Years	80.0	81.3	83.4	84.2	90.1	89.1	82.9			
	5 Years	71.8	73.3	76.0	75.8	83.9					
Living Donor	N	216	236	300	323	309	340	319	346	345	368
	3 Months	95.4	97.0	96.7	96.9	95.1	96.2	99.1	98.6	98.6	98.1
	1 Year	91.7	94.9	96.0	95.4	94.2	95.6	98.1	98.0	98.3	
	3 Years	88.4	92.8	90.7	91.9	92.5	91.4	95.3			
	5 Years	84.7	88.1	86.0	88.5	89.0					

Note:

* Graft survival is computed from first kidney transplant date to first graft failure date, death date or end of observation (December 31, 2005). In this analysis, patients who died with a functioning graft are considered as failed grafts.

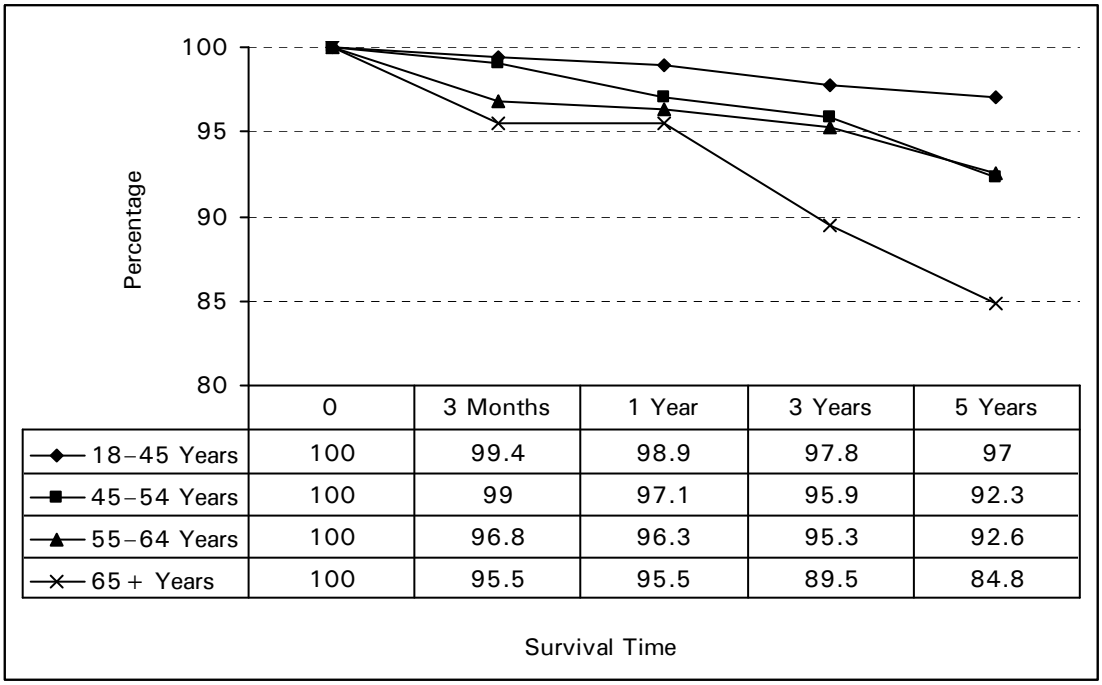
When analyzed by age group, there were notable differences between unadjusted patient survival rates for recipients of kidneys from living donors, compared to deceased donors. The most marked differences are in long-term survival (defined here as five years) at the upper end of the age continuum. Those in the 65-years-of-age-and-older group had a 14.6% improvement in survival when the transplanted kidney was from a living donor, compared to a deceased donor (figures 21 and 22). The second-largest difference in long-term survival of patients was seen in those in the 55-to-64-year age group. For recipients of a kidney from a living donor, there was an 8.4% improvement in survival at the five-year mark, compared to those in the same age group who had received a donor kidney from a deceased donor.

Figure 21 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, 1996 to 2000, (Followed to 2005)



	0	3 Months	1 Year	3 Years	5 Years
18–45 Years	100	99.1	98.1	96.2	93.3
45–54 Years	100	97.8	95.4	93.4	89.2
55–64 Years	100	97.4	95.7	90.7	84.2
65 + Years	100	93.2	87.1	79.1	70.2

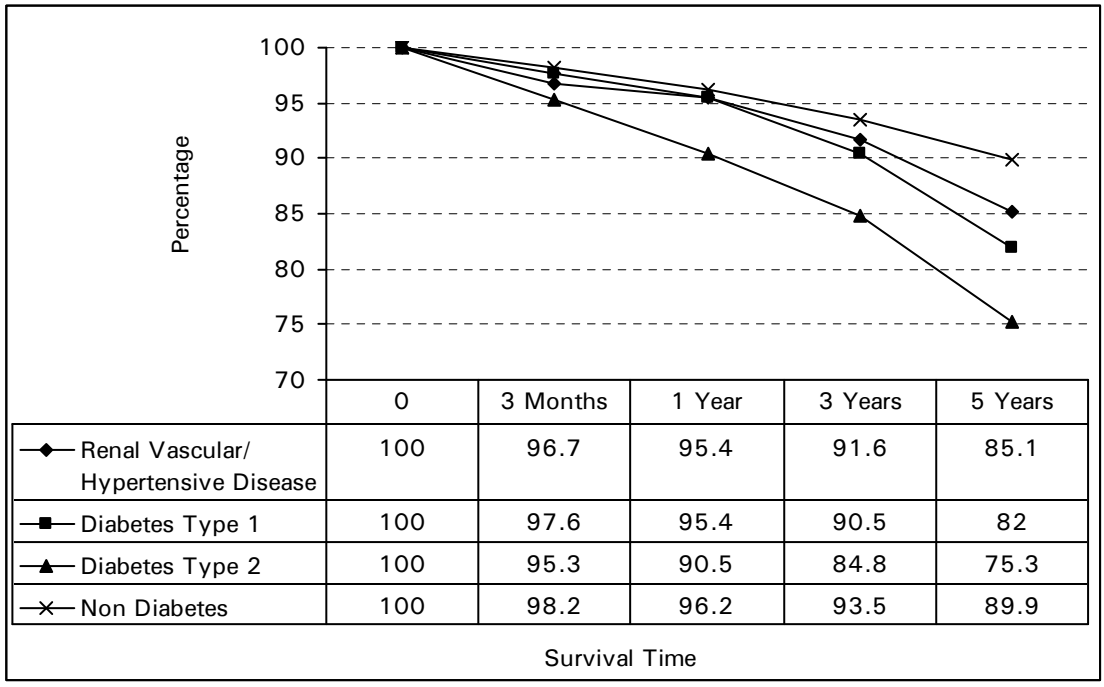
Figure 22 Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Adult Kidney Transplant Recipients, First Graft, Living Donor by Age at Transplant, Canada, 1996 to 2000 (Followed to 2005)



	0	3 Months	1 Year	3 Years	5 Years
18–45 Years	100	99.4	98.9	97.8	97
45–54 Years	100	99	97.1	95.9	92.3
55–64 Years	100	96.8	96.3	95.3	92.6
65 + Years	100	95.5	95.5	89.5	84.8

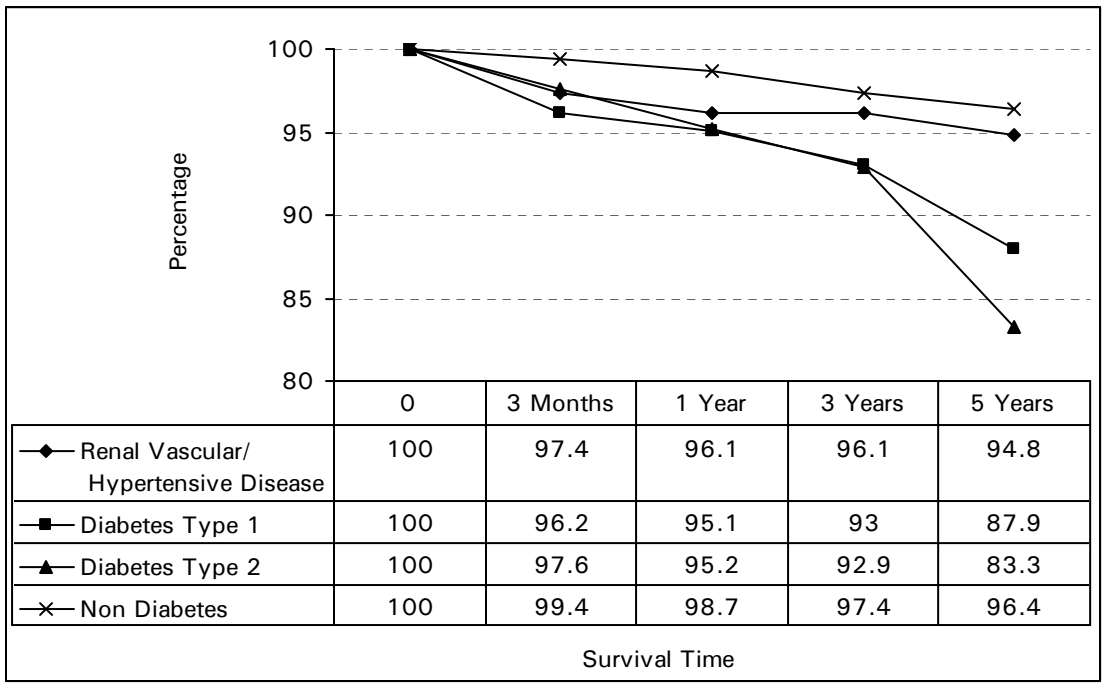
Patient survival after kidney transplantation is affected by the cause of renal failure (figures 23 and 24). The most compromised five-year survival rate (75.3%) was for those patients who received a transplanted organ from a deceased donor and who also had any type of diabetes (types and 1 and 2, but most markedly those with type 2).

Figure 23 Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Adult Kidney Transplant Recipients, First Graft, Deceased Donor, by Diagnosis, Canada, 1996 to 2000 (Followed to 2005)



	0	3 Months	1 Year	3 Years	5 Years
Renal Vascular/ Hypertensive Disease	100	96.7	95.4	91.6	85.1
Diabetes Type 1	100	97.6	95.4	90.5	82
Diabetes Type 2	100	95.3	90.5	84.8	75.3
Non Diabetes	100	98.2	96.2	93.5	89.9

Figure 24 Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival* for Adult Kidney Transplant Recipients, First Graft, Living Donor, by Diagnosis, Canada, 1996 to 2000 (Followed to 2005)



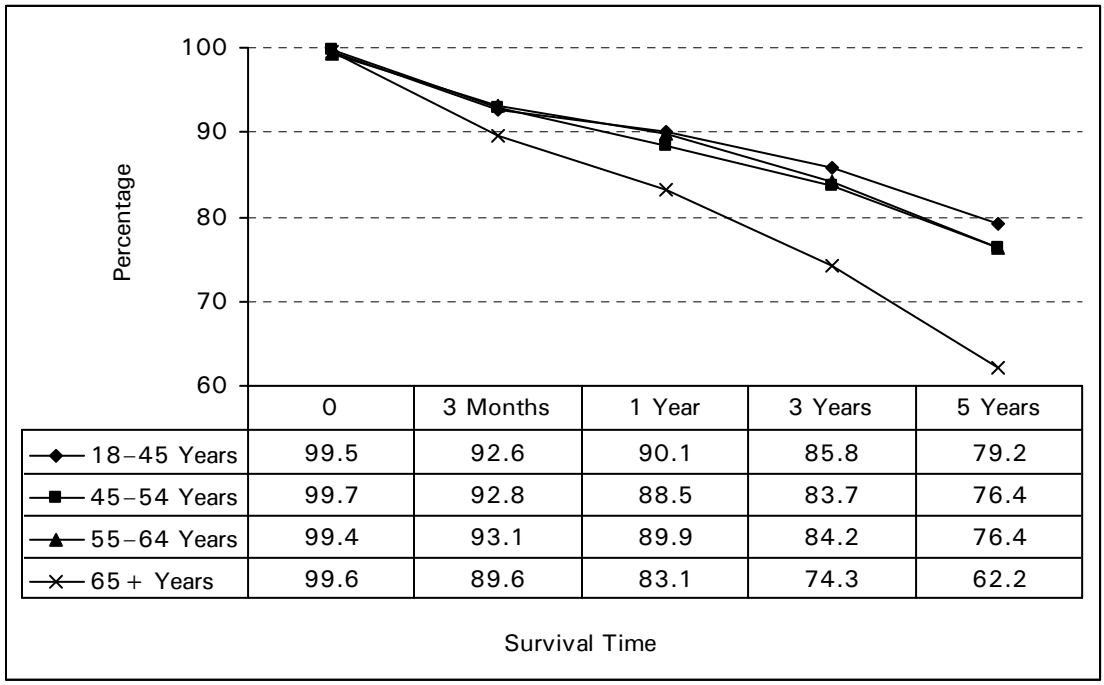
	0	3 Months	1 Year	3 Years	5 Years
Renal Vascular/ Hypertensive Disease	100	97.4	96.1	96.1	94.8
Diabetes Type 1	100	96.2	95.1	93	87.9
Diabetes Type 2	100	97.6	95.2	92.9	83.3
Non Diabetes	100	99.4	98.7	97.4	96.4

Survival Time

Note:

* Graft survival is computed from first kidney transplant date to first graft failure date, death date or end of observation (December 31, 2005). In this analysis, patients who died with a functioning graft are considered as failed grafts.

Figure 25 Unadjusted Three-Month and One-, Three- and Five-Year Graft Survival* for Adult Kidney Transplant Recipients, First Graft, Deceased Donor, by Age Groups, Canada, 1996 to 2000 (Followed until 2005)

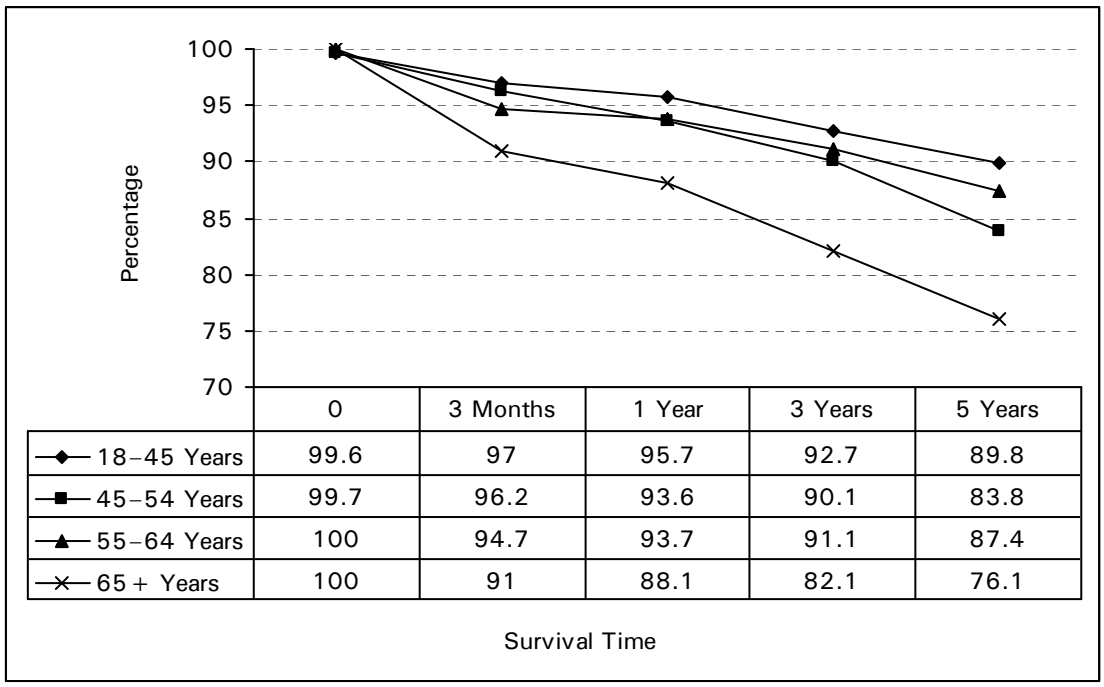


	0	3 Months	1 Year	3 Years	5 Years
18–45 Years	99.5	92.6	90.1	85.8	79.2
45–54 Years	99.7	92.8	88.5	83.7	76.4
55–64 Years	99.4	93.1	89.9	84.2	76.4
65 + Years	99.6	89.6	83.1	74.3	62.2

Note:

* Graft survival is computed from first kidney transplant date to first graft failure date, death date or end of observation (December 31, 2005). In this analysis, patients who died with a functioning graft are considered as failed grafts.

Figure 26 Unadjusted Three-Month and One-, Three- and Five-Year Graft Survival* for Adult Kidney Transplant Recipients, First Graft, Living Donor, by Age Groups, Canada, 1996 to 2000 (Followed to 2005)

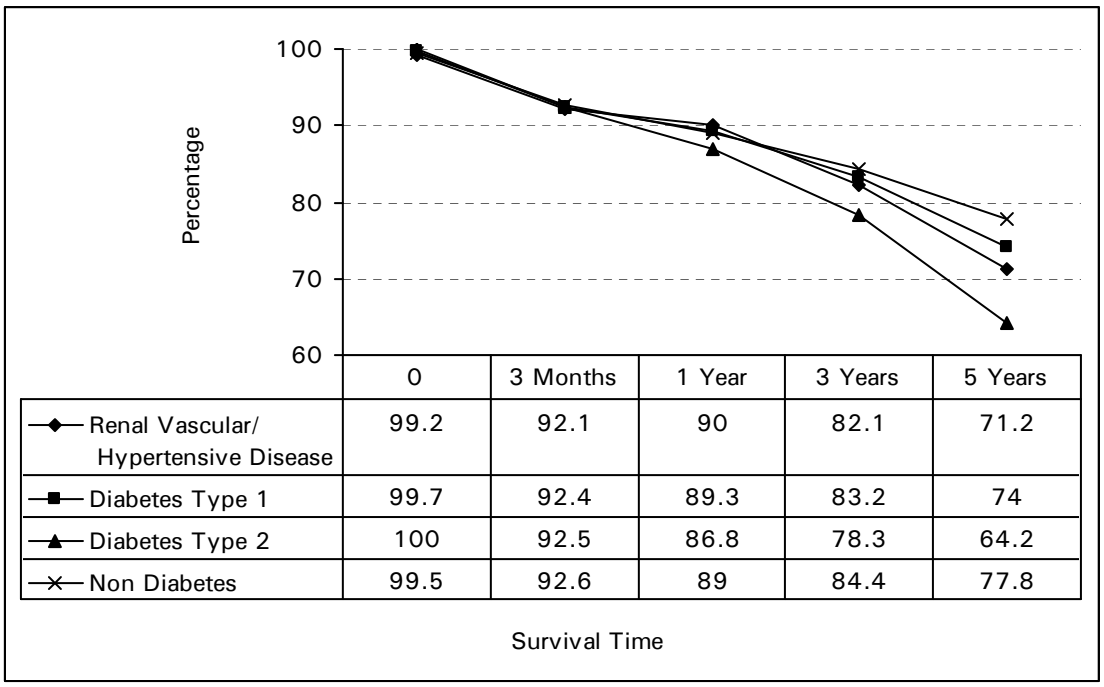


	0	3 Months	1 Year	3 Years	5 Years
18–45 Years	99.6	97	95.7	92.7	89.8
45–54 Years	99.7	96.2	93.6	90.1	83.8
55–64 Years	100	94.7	93.7	91.1	87.4
65 + Years	100	91	88.1	82.1	76.1

Note:

* Graft survival is computed from first kidney transplant date to first graft failure date, death date or end of observation (December 31, 2005). Patients who died with a functioning graft were considered as failed grafts.

Figure 27 Unadjusted Three-Month and One-, Three- and Five-Year Graft Survival* for Adult Kidney Transplant Recipients, First Graft, Deceased Donor, by Primary Diagnosis, Canada, 1996 to 2000 (Followed to 2005)



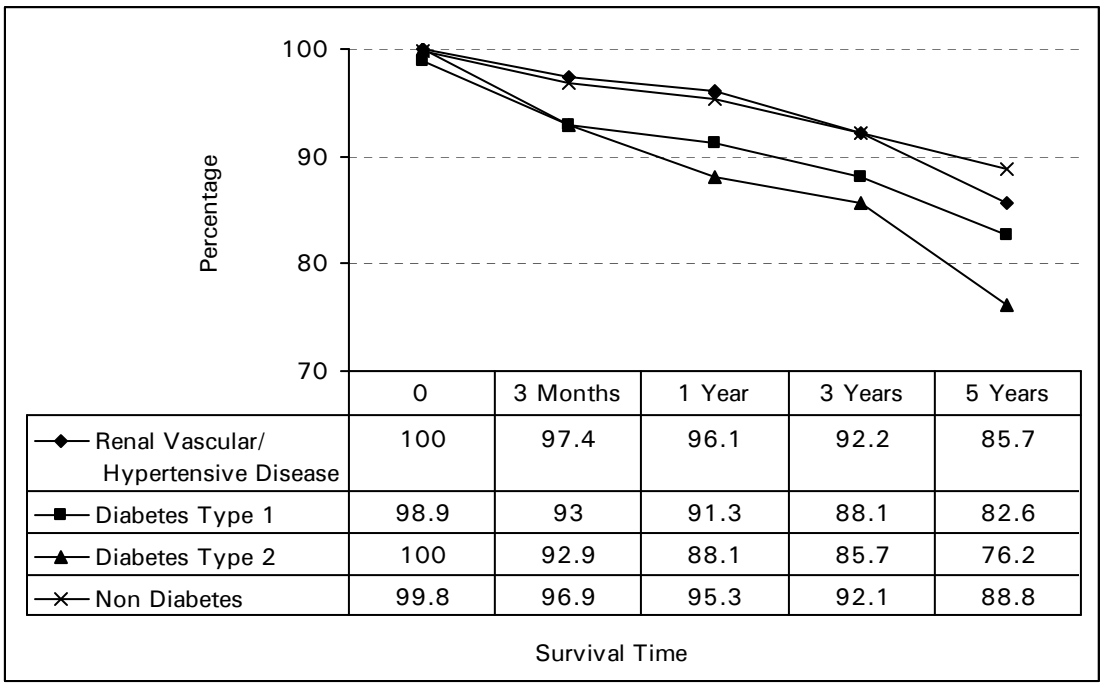
	0	3 Months	1 Year	3 Years	5 Years
Renal Vascular/ Hypertensive Disease	99.2	92.1	90	82.1	71.2
Diabetes Type 1	99.7	92.4	89.3	83.2	74
Diabetes Type 2	100	92.5	86.8	78.3	64.2
Non Diabetes	99.5	92.6	89	84.4	77.8

Note:

* Graft survival is computed from first kidney transplant date to first graft failure date, death date or end of observation (December 31, 2005). Patients who died with a functioning graft were considered as failed grafts.

Graft survival was also seen to be related to the etiology of the patient's renal failure. For those patients without diabetes, graft survival was superior to the other groups, ranging from 96.9% (at three months) to 88.8% (at five years). The grafts of those with type 2 diabetes had the most compromised status, with graft survival of 92.9% (at three months), dropping to 76.2% (at five years) (Figure 28).

Figure 28 Unadjusted Three-Month and One-, Three- and Five-Year Graft Survival* for Adult Kidney Transplant Recipients, First Graft, Living Donor, by Primary Diagnosis Canada, 1996 to 2000 (Followed Until 2005)



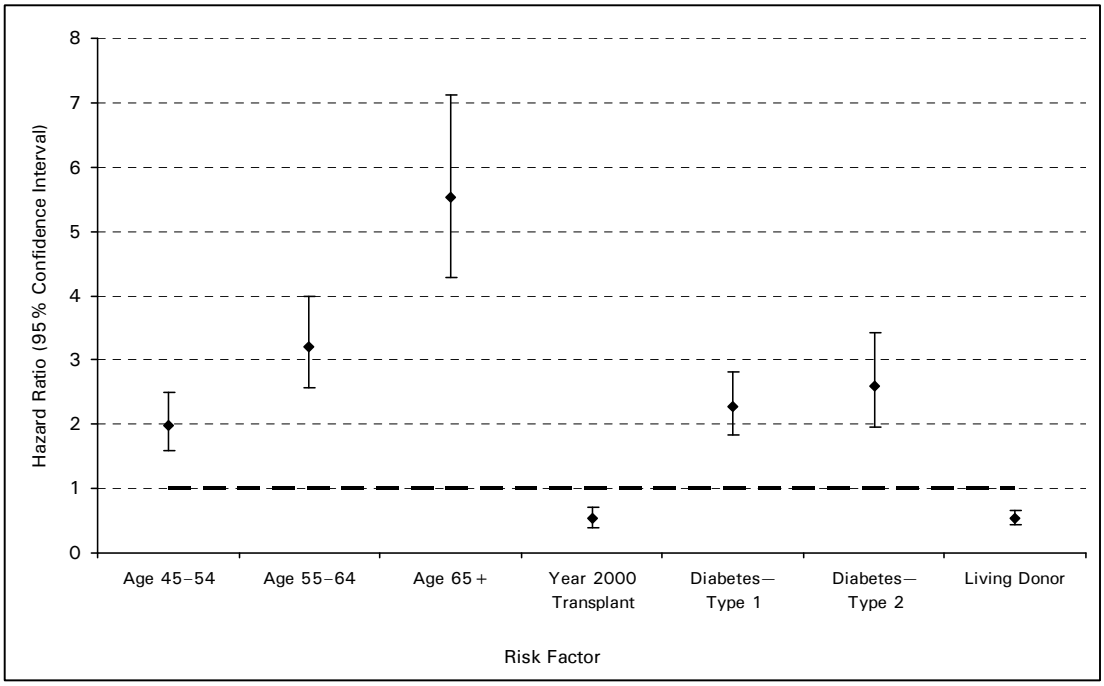
	0	3 Months	1 Year	3 Years	5 Years
Renal Vascular/ Hypertensive Disease	100	97.4	96.1	92.2	85.7
Diabetes Type 1	98.9	93	91.3	88.1	82.6
Diabetes Type 2	100	92.9	88.1	85.7	76.2
Non Diabetes	99.8	96.9	95.3	92.1	88.8

Note:

* Graft survival is computed from first kidney transplant date to first graft failure date, death date or end of observation (December 31, 2005). Patients who died with a functioning graft are considered as failed grafts.

Survival analyses were conducted through the use of multi-variable modelling techniques, which were developed to estimate the effect of several factors simultaneously on patient survival in kidney transplant recipients. The regression modelling employed a Cox model (see Appendix F). The largest and second-largest mortality risk of 5.5 (CI: 4.3 to 7.1) and 3.2 (CI: 2.6 to 4.0) were found for the patients aged 65 and over, and aged 55 to 64, respectively. The third-largest mortality risk (2.6) was for those patients with type 2 diabetes (CI: 2.0 to 3.4) (Figure 29).

Figure 29 Cox Adjusted Mortality Rates for Kidney Adult Transplants Patients, Canada, 1996 to 2000 (Followed to 2005)



2.4.6 Organ Donors

The age of recipients and the age of donors showed a correlation (Table 30). The median age of donors ranged between 41, 44 and 47 years for kidney transplant recipients in the 18-to-39-year age group, the 40-to-59-year age group and the 60-years-and-older group respectively (Table 30). Almost half of the recipients between the ages of 18 and 39 years (46.6%) or 40 and 59 years (44.6%) received a living-donor kidney transplant from a sibling, compared to 13.5% of patients 60 years of age and older who received a living-donor kidney from a sibling. The largest number of unrelated donors (23.1%) of all living donors was for recipients in the 40-to-59-year age group.

Table 30 Selected Donor Characteristics, Adult Kidney Transplants, Canada, 1996 to 2005

		Recipient Age Group		
		18–39 Years	40–59 Years	60+ Years
Deceased Donor*	N	1,637	3,248	1,373
	Percentage Male	56.5	56.0	52.1
	Median Age	41	44	47
Living Donor	N	1,387	1,645	393
	Percentage Parent as Donor (N)	27.8 (385)	1.5 (25)	2.0 (8)
	Percentage Sibling as Donor (N)	46.6 (647)	44.6 (734)	13.5 (53)
	Percentage Other Relative as Donor (N)	12.3 (170)	30.8 (506)	67.9 (267)
	Percentage Unrelated Donor (N)	13.3 (185)	23.1 (380)	16.5 (65)

Note:

* A deceased donor will be counted twice if both kidneys are used for transplantation in different recipients.

3. Liver Transplantation

An exciting era in transplant medicine began in 1963 when Dr. Thomas Starzl performed the first human liver transplant in Denver, Colorado. In 1970, the first liver transplant in Canada was performed by Dr. Pierre Daloze in Montréal, Quebec. The introduction of advances in immunosuppression dramatically enhanced patient survival As well, 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.

The science of liver transplantation experienced a paradigm shift in 1989 when the first living-donor liver transplant was performed at the University of Chicago. In Canada, the first-living donor, parent-to-child liver transplant took place in 1993 at the London Health Sciences Centre, followed by the first living-donor, adult-to-adult liver transplant in Canada in 2000.

3.1 Activity

In 2005, there were nine active surgical liver transplant programs in Canada: British Columbia (1), Alberta (1), Ontario (3), Quebec (3) and Nova Scotia (1). Most patients from Saskatchewan were treated in Alberta, while most patients from Manitoba were treated in Ontario. Between May of 2001 and December 2004, the London Health Sciences Liver Program performed the transplants for patients from the Atlantic region until the program resumed in December 2004.

Pediatric liver transplants were performed at the Hôpital Sainte-Justine (Montréal), the Hospital for Sick Children (Toronto) and the University of Alberta (Edmonton). As of December 31, 2005 there were five living donor liver transplant programs operating in Canada (British Columbia, Alberta and Ontario).

Between 1996 and 2005, there were 3,866 liver transplants registered in CORR, of which 3,531 recipients received first liver transplants (Table 31). While liver transplants in pediatric recipients account for 10.5% of liver transplants performed in Canada during the decade, the annual number of first liver transplants performed on pediatric patients has increased by 23.5% since 1996. In recipients 18 years of age and older, the annual number increased by 21.2% in the same period. A total of 267 living-donor liver transplants were performed in Canada during the decade. The number of recipients receiving livers from living donors increased from 1 in 1996 to 60 in 2005. During the 10 years, there were 335 retransplants performed, with the majority of those undertaken in recipients 18 years of age and older (82.1%).

Table 31 Liver Transplants by Year, Donor Type, Age Group and Retransplants, Canada, 1996 to 2005 (Number)

	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	Total
First Graft <18, Deceased Donor	33	27	24	39	30	20	25	33	15	34	280
First Graft <18, Living Donor	1	0	3	6	6	13	10	6	12	8	65
Retransplants <18	6	9	5	13	4	4	3	4	3	9	60
First Graft 18+, Deceased Donor	288	279	281	300	336	293	290	302	318	297	2,984
First Graft 18+, Living Donor	0	0	0	3	13	31	32	29	42	52	202
Retransplants 18+	28	35	29	23	20	33	26	31	27	23	275
Total	**356**	**350**	**342**	**384**	**409**	**394**	**386**	**405**	**417**	**423**	**3,866**

Combination transplants involving the liver are rare in Canada, constituting less than 2% of the liver transplants performed between 1996 and 2005. The vast majority (81.0%) was liver–kidney transplants (Table 32) and liver–small bowel or other combinations were few and sporadic throughout the period of study.

Table 32 Liver Transplants by Combination Transplants, Canada, 1996 to 2005 (Number)

Procedure	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	Total
Liver Only	351	340	338	378	403	383	381	399	414	416	3,803
Liver–kidney	5	8	4	5	4	9	3	5	3	5	51
Liver–Small Bowel	0	1	0	1	1	1	1	1	0	1	7
Other Combination	0	1	0	0	1	1	1	0	0	1	5
Total	**356**	**350**	**342**	**384**	**409**	**394**	**386**	**405**	**417**	**423**	**3,866**

The majority of liver transplants were performed in the province of Ontario (45.0%), followed by Quebec (26.0%) and Alberta (16.3%) during the 10-year period (Table 33).

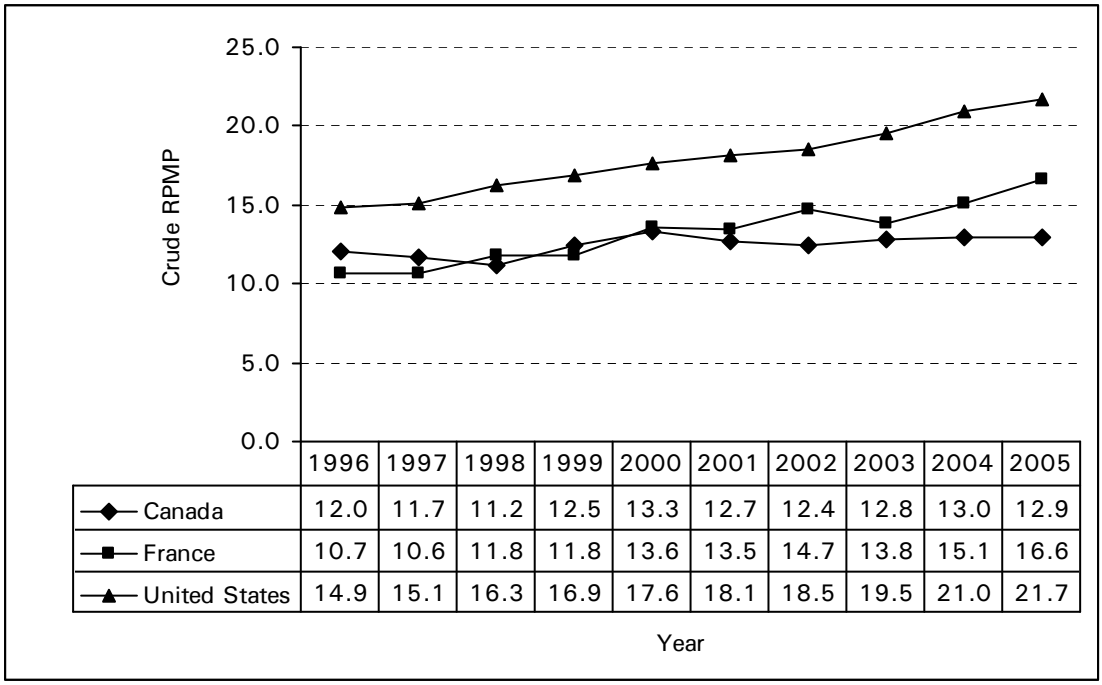
Table 33 Liver Transplants by Year and Province of Treatment, Canada, 1996 to 2005 (Number)

Province of Treatment	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	Total
British Columbia	33	38	24	32	34	39	34	35	36	34	339
Alberta	42	56	55	69	65	63	69	64	71	78	632
Ontario	169	150	155	142	173	176	184	193	202	195	1,739
Quebec	95	85	90	112	111	100	99	113	107	97	1,009
Nova Scotia	17	21	18	29	26	16	0	0	1	19	147
Total	**356**	**350**	**342**	**384**	**409**	**394**	**386**	**405**	**417**	**423**	**3,866**

3.2 International Comparison

The crude rate for liver transplantation in Canada has remained fairly stable, from a high of 13.3 PMP in 2000 to 12.9 PMP in 2005, and has been lower than in the United States and France (Figure 30). Between 1996 and 2005, the rate has increased by 0.9 PMP. This situation differs substantially in the United States, where the rate has increased steadily each year, from 14.9 PMP in 1996 to 21.7 PMP in 2005, for a total increase of 6.8 PMP over the decade. Between 1996 and 2000, the rates in Canada and France were quite similar, but beginning in 2001 a divergence began to appear, in which France's rate continued to increase, while Canada's rate remained consistent.

Figure 30 Liver Transplants, Canada, France and United States, 1996 to 2005 (Crude Rate PMP)



	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
Canada	12.0	11.7	11.2	12.5	13.3	12.7	12.4	12.8	13.0	12.9
France	10.7	10.6	11.8	11.8	13.6	13.5	14.7	13.8	15.1	16.6
United States	14.9	15.1	16.3	16.9	17.6	18.1	18.5	19.5	21.0	21.7

Data source for France: l'Établissement français des Greffes, *Rapport d'activité et Bilan des activités de prélèvement et de greffe en France Année 2005* (Paris: l'Établissement français des Greffes, Agence de la biomédecine, 2006).
Data source for the U.S.: Department of Health and Human Services (Health Resources and Services Administration, Healthcare Systems Bureau, Division of Transplantation), United Network for Organ Sharing and University Renal Research and Education Association, *2006 Annual Report of the U.S. Organ Procurement and Transplantation Network and the Scientific Registry of Transplant Recipients: Transplant Data 1996–2005* (Richmond, VA: United Network for Organ Sharing, 2006).

3.3 Recipient Characteristics

Between 1996 and 2005, the average age of liver transplant recipients ranged between 43 and 48 years. Overall, more males (62.2%) received first liver grafts in these years than females, but the male-to-female ratio differed between age groups (Table 34), with those between the ages of 35 and 59 years having the highest proportion of males (65.9%). In contrast, for the age group of less than one year, there were more female liver transplant recipients (60.6 %).

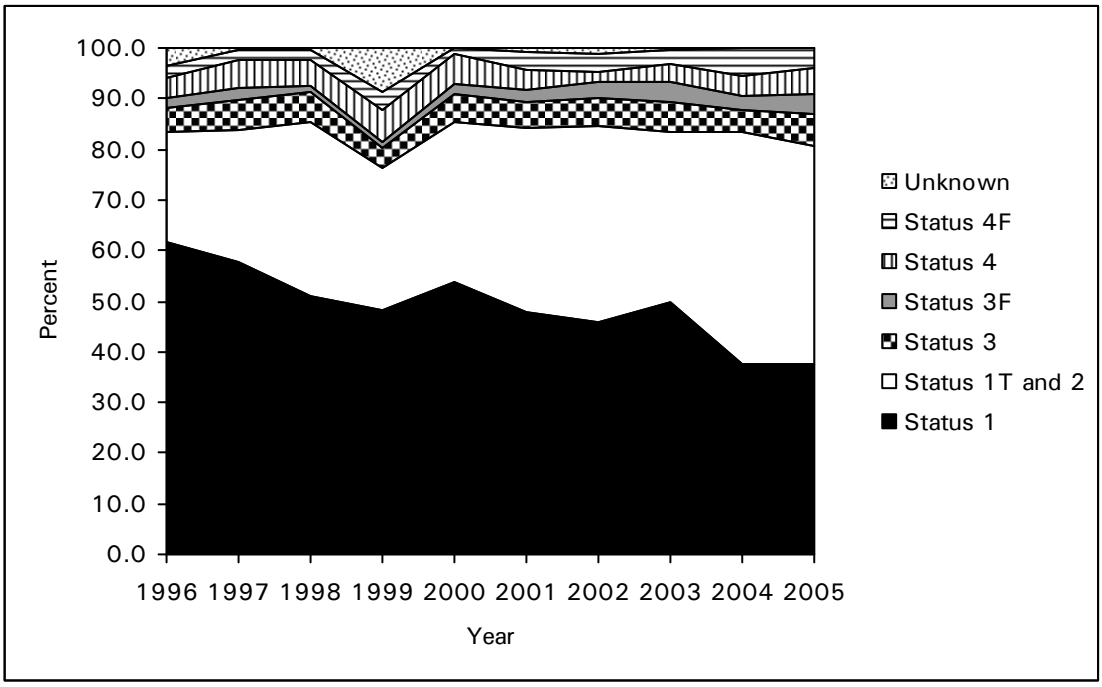
For recipients 10 years of age and younger, biliary atresia was the predominant cause of end-stage liver failure. For those 11 to 34 years of age, where specific diagnoses were recorded, "other hepatitis" was the primary diagnosis. For recipients aged 35 years and older, where specific diagnoses were recorded, hepatitis C, alcoholic cirrhosis and cancer were the major causes of end-stage liver failure cited during the decade.

Table 34 Distribution of Primary Diagnoses for Liver Transplant Recipients, First Grafts by Age Group, Canada, 1996 to 2005

	N	Percentage Male	Primary Biliary Atresia	Hepatitis C	Hepatitis B	Other Hepatitis	Alcoholic Cirrhosis	Cryptogenic Cirrhosis	Cancer	Metabolic Disorders	Unknown	Other
<1	170	39.4	59.6	0.6	0	5.3	0	1.2	1.8	6.4	3.5	21.6
1–10	100	59.0	22.3	1.0	0	6.8	0	0	10.7	12.6	7.8	38.8
11–17	75	52.0	5.1	2.5	1.3	15.2	0	3.8	5.1	7.6	8.9	50.6
18–34	283	51.9	0	3.3	6.9	14.1	1.0	3.6	3.9	7.9	3.9	55.3
35–59	2,183	65.9	0.2	28.2	7.1	4.3	18.2	4.7	8.1	2.4	2.1	24.6
60+	720	62.1	0.2	18.9	7.0	3.5	16.7	10.1	13.8	3.8	1.3	24.6
Total	**3,531**	**62.2**	**3.4**	**22.0**	**6.4**	**5.2**	**15.0**	**5.5**	**8.7**	**3.7**	**2.4**	**27.7**

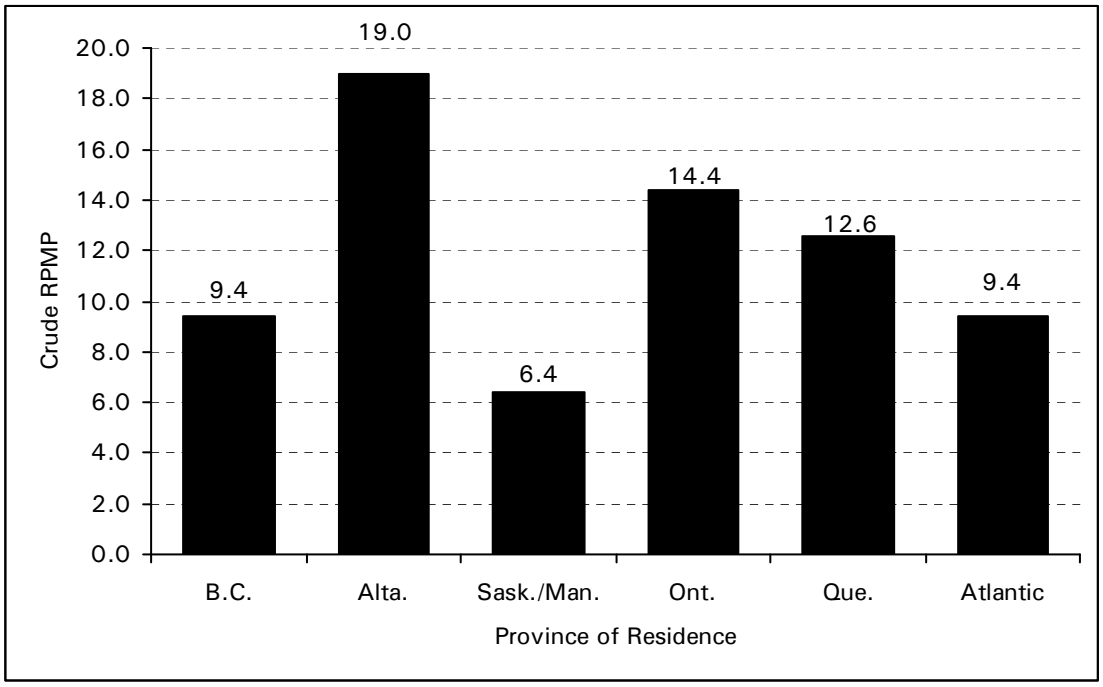
In terms of the distribution of patient medical status at the time of transplantation, there has been little change observed over the decade (Figure 31). More than 70% of liver transplant recipients receiving a first graft were considered as non-urgent, meaning they had a status of 1 (at home), 1T (with tumour), or 2 (hospitalized) at the time they received their transplant.

Figure 31 Distribution of Liver Transplants by Medical Status at Transplant, Canada, 1996 to 2005



There was variation between the crude rates PMP when examined by the patient's province of residence for 2005 (Figure 32). The rates for Alberta were the highest (19.0 PMP) followed by Ontario (14.4 PMP). The lowest crude rates were seen in Saskatchewan and in Manitoba at 6.4 PMP. It is important to note that crude rates do not take factors such as potential provincial differences in the prevalence of end-stage liver failure into consideration.

Figure 32 Liver Transplant Recipients by Province of Residence, Canada, 2005 (Crude Rate PMP)



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

3.4 Waiting List and Waiting Times

As of December 31, 2005, there were 713 people waiting for a liver transplant in Canada (Table 35). The number has grown steadily over the last 10 years for an overall increase of 241.2%. The increase was in both pediatric and adult patients, although the largest increase was seen in the adult group (18 years and older).

Table 35 Liver Transplant Waiting List, on December 31, Canada, 1996 to 2005

	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	Total
<18 Years	22	24	26	20	27	36	31	30	37	32	263
18+ Years	231	206	260	298	311	418	528	539	630	681	4,102
Total	**209**	**230**	**286**	**318**	**338**	**454**	**559**	**569**	**667**	**713**	**4,365**

A total of 670 patients died while waiting for a liver transplant between 1996 and 2005. Most deaths were patients in the 18-years-of-age-and-older group (Table 36). For those under the age of 18 years, the number fluctuated from year to year, demonstrating no real trend. For adult patients, there was an upward trend in deaths on the waiting list, most notably between 2004 and 2005, with a 46.9% increase from 96 to 141 deaths.

Table 36 Deaths Among Patients Waiting for a Liver Transplant, Canada, 1996 to 2005

	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	Total
<18 Years	1	3	9	7	5	1	4	6	8	9	**53**
18+ Years	22	39	21	63	46	56	78	94	88	132	**617**
Total	**23**	**42**	**30**	**70**	**51**	**57**	**82**	**100**	**96**	**141**	**670**

The median wait times showed that over the most recent three-year period (2003 to 2005) for deceased-donor liver transplant recipients of first grafts, those listed as urgent had the shortest wait times (Table 37). For non-urgent patients (status 1, 1T and 2), patients in blood group O had the longest median wait times.[†] For status 3 patients (in the ICU), patients with blood type B had the longest median wait and those with type A blood had the shortest.

Table 37 Wait Time* From Listing to Transplant for Deceased Donor Liver Transplant Recipients, First Grafts, Canada, 2003 to 2005

Medical Status as Listing	Blood Group	Wait (in Days)			
		N	Min.	Max.	Median
Status 1	A	259	1	1,210	229.0
	AB	37	4	424	16.0
	B	65	21	1,251	308.0
	O	236	6	1,747	337.5
	U	3	20	535	88.0
Status 1T/2	A	104	2	716	34.0
	AB	14	4	368	41.0
	B	31	1	568	62.0
	O	101	0	1,119	89.0
	U	1	150	150	150.0
Status 3	A	4	1	29	6.5
	B	6	7	91	42.0
	O	14	1	252	14.0
Status 3F/4/4F	A	39	0	19	1.0
	AB	3	1	5	2.0
	B	9	1	4	2.0
	O	26	0	47	3.0
	U	2	1	71	36.0

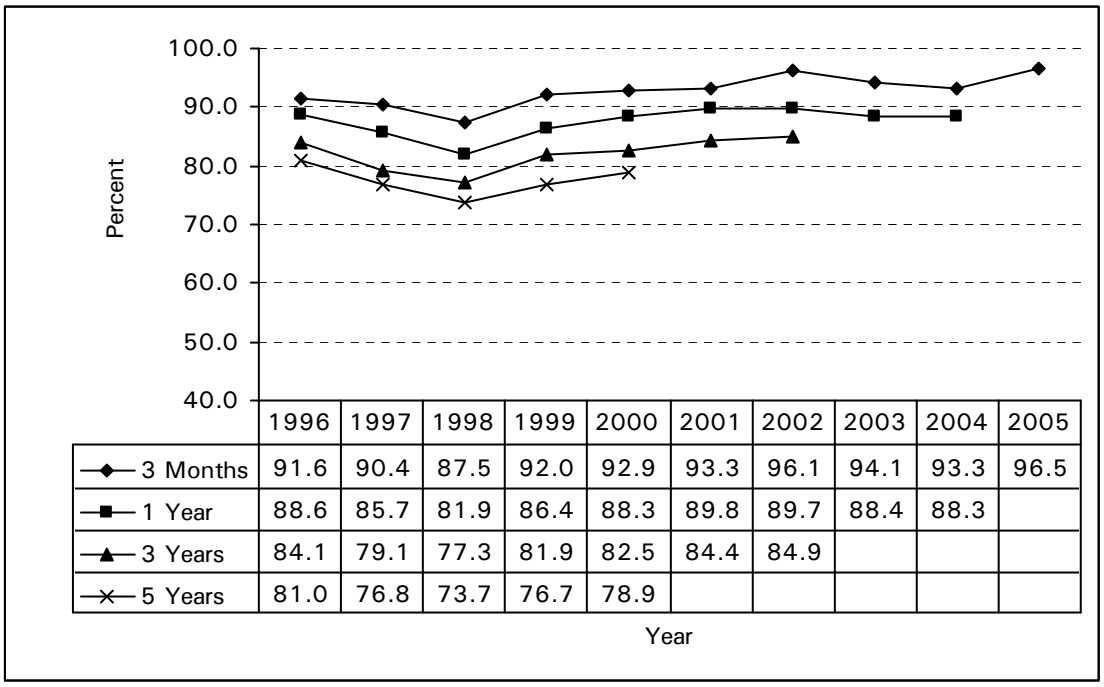
Note:

* Calculated on the basis of actual wait times. Outliers are not excluded.

3.5 Outcomes

Unadjusted patient survival rates for those with deceased-donor liver transplants (first grafts) showned incremental improvements, most notably between 1998 and 2002. However, for 2003 and 2004, the proportion of those surviving at three months and one year declined slightly (Figure 33). In 2005, the three-month survival rose to 96.5%, reflecting the highest three-month survival in the decade of study.

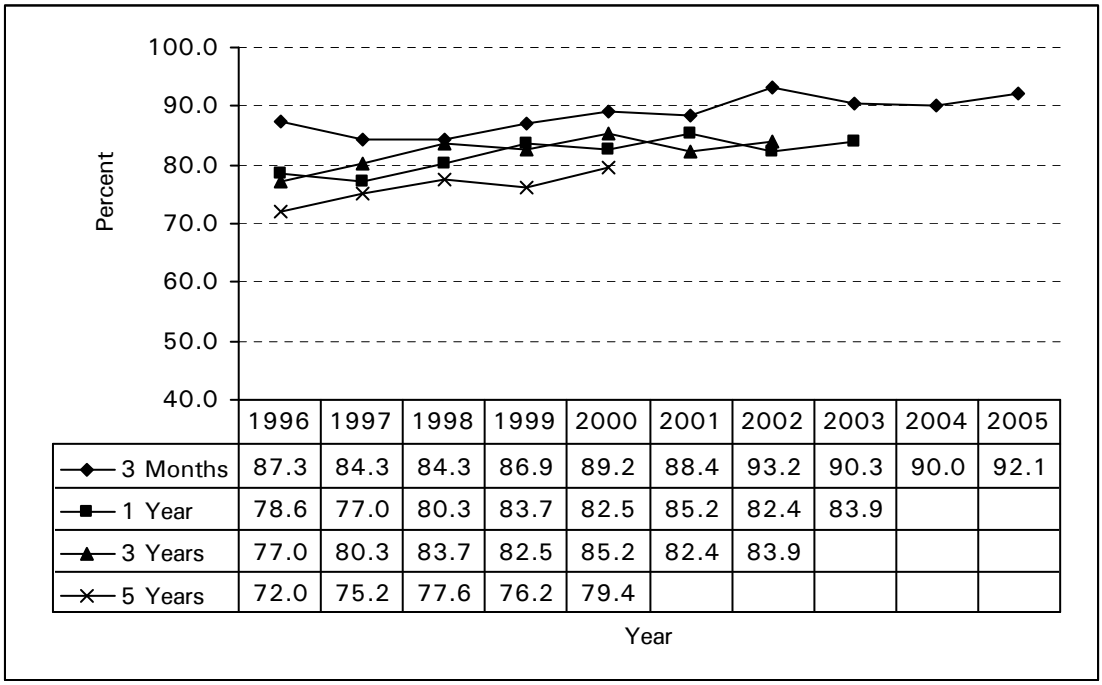
Figure 33 Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Deceased Donor Liver Transplant Recipients, First Graft, Canada, 1996 to 2005



	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
3 Months	91.6	90.4	87.5	92.0	92.9	93.3	96.1	94.1	93.3	96.5
1 Year	88.6	85.7	81.9	86.4	88.3	89.8	89.7	88.4	88.3	
3 Years	84.1	79.1	77.3	81.9	82.5	84.4	84.9			
5 Years	81.0	76.8	73.7	76.7	78.9					

Similar to the trend that was observed in patient survival after a first liver transplant, graft survival rates showed an incremental increase until 2002, after which time the three-month graft survival rates began to decrease slightly, but rose again in 2005 (Figure 34).

Figure 34 Unadjusted Three-Month and One-, Three- and Five-Year Graft Survival* for Deceased Donor Liver Transplant Recipients, First Graft, Canada, 1996 to 2005



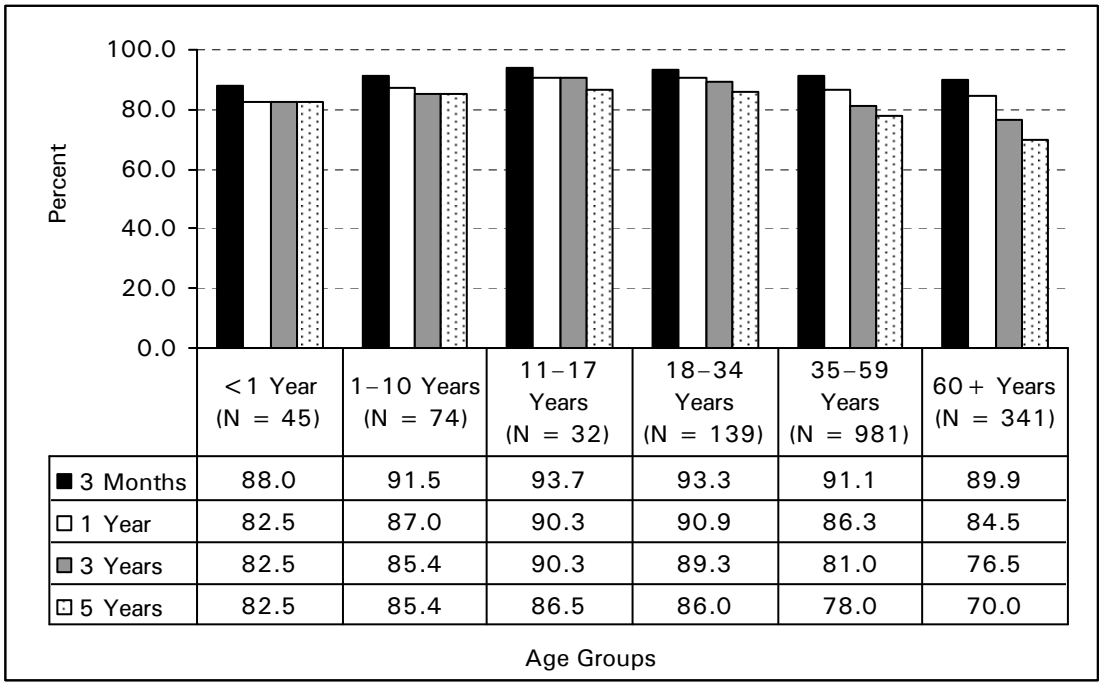
	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
3 Months	87.3	84.3	84.3	86.9	89.2	88.4	93.2	90.3	90.0	92.1
1 Year	78.6	77.0	80.3	83.7	82.5	85.2	82.4	83.9		
3 Years	77.0	80.3	83.7	82.5	85.2	82.4	83.9			
5 Years	72.0	75.2	77.6	76.2	79.4					

Note:

* Graft survival is computed from first liver transplant date to first graft failure date, death date or end of observation (December 31, 2005). In this analysis, patients who died with a functioning graft are considered as failed grafts.

The unadjusted patient survival rate by age group for liver transplants between 1996 and 2000 showed the highest survival rates for three months, three and five years after transplantation for recipients aged 11 to 17 years (Figure 35). Survival at one year was the highest in those aged 18 to 34 years of age. The five-year survival was lowest among the oldest liver transplant recipient group (age 60 years and older).

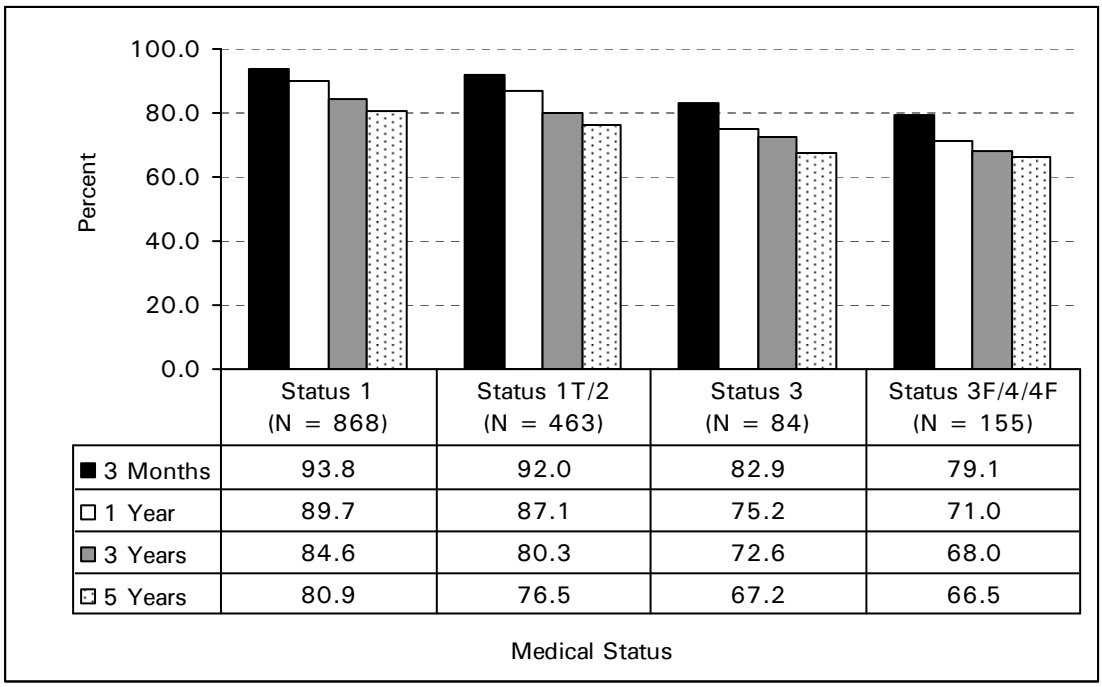
Figure 35 Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Deceased Donor Liver Transplant Recipients by Age Group, First Graft, Canada, 1996 to 2000



	<1 Year (N = 45)	1–10 Years (N = 74)	11–17 Years (N = 32)	18–34 Years (N = 139)	35–59 Years (N = 981)	60+ Years (N = 341)
3 Months	88.0	91.5	93.7	93.3	91.1	89.9
1 Year	82.5	87.0	90.3	90.9	86.3	84.5
3 Years	82.5	85.4	90.3	89.3	81.0	76.5
5 Years	82.5	85.4	86.5	86.0	78.0	70.0

Unadjusted patient survival for deceased-donor liver transplant recipients who received their first liver transplant between 1996 and 2000 clearly demonstrated that medical status at the time of transplant is related to outcome. Recipients with an urgent medical status (3F, 4, or 4F) had lower survival rates at all four follow-up time points, compared to patients who received their liver transplant who were non-urgent in status (Figure 36). The best survival at all four time points measured was seen in those patients who received their transplant who were status 1 (non-urgent) when they received the transplant. The majority of patients (55%) received their liver transplant when listed as status 1.

Figure 36 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, 1996 to 2000



	Status 1 (N = 868)	Status 1T/2 (N = 463)	Status 3 (N = 84)	Status 3F/4/4F (N = 155)
3 Months	93.8	92.0	82.9	79.1
1 Year	89.7	87.1	75.2	71.0
3 Years	84.6	80.3	72.6	68.0
5 Years	80.9	76.5	67.2	66.5

3.6 Organ Donors

The majority of liver donors (55.9%) were male. While the average age of Canadian liver donors was 41.0 years, they ranged in age from newborns to donors 89 years old. There has been little change in the age of donors over the decade. (Additional information about deceased organ donors is provided in Section 8.)

The recovery of donors who received livers from deceased organ donors ranged from 80.6% in 1998, to a high of 87.1% in 1999 (Table 38). After a drop in recovery in 2000, the rates show a consistent, albeit modest annual increase in the years following until 2005, when a 1% decrease from the previous year was noted. This increase over the decade occurred in tandem with the maturation of liver transplant programs across Canada.

Table 38 Proportion of Livers Transplanted From Deceased Donors, 1996 to 2005 (Percentage)

	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
Recovery Rate	84.0	80.9	80.6	87.1	81.1	81.4	83.6	85.8	86.3	85.3

Donor livers were shared among programs based on medical urgency. Donor livers from Saskatchewan were typically provided to the Edmonton program, while donor livers from Manitoba were provided to the London (Ontario) program. For the period of 2002 to 2004, liver transplant recipients from the Atlantic provinces had their transplants in London, and donor livers were brought to London for these patients. When looking at the ways in which liver organs were used among recipients who were listed as non-urgent, the majority of livers originated from the OPO within the province of the transplant program (Table 39).

Table 39 Origin and Destination of Transplanted Livers for Recipients Who Were Listed as Status 1/1T/2/3, Canada, 2003 to 2005

Retrieval Province	Treated Province					Total
	B.C.	Alta.	Ont.	Que.	N.S.	
British Columbia	61	3	5	3	0	72
Alberta	2	104	2	0	0	108
Saskatchewan	1	35	0	0	0	36
Manitoba	0	2	16	0	0	18
Ontario	5	6	331	4	0	346
Quebec	1	9	23	256	0	289
New Brunswick	0	0	20	2	9	31
Nova Scotia	1	1	16	1	6	25
Newfoundland and Labrador	0	1	13	1	3	18
Total	**71**	**161**	**426**	**267**	**18**	**943**

Note:
Shaded cells show local organs used for transplantation.

The need to share livers arose when patients were considered medically urgent, such as status 3F, 4 or 4F (Table 40). The highest numbers of shared organs originated in Ontario and Quebec.

Table 40 Origin and Destination of Transplanted Livers for Recipients Who Were Listed as Status 3F/4/4F, Canada, 2003 to 2005

Retrieval Province	Treated Province					Total
	B.C.	Alta.	Ont.	Que.	N.S.	
British Columbia	1	2	1	2	0	6
Alberta	2	6	2	2	0	12
Saskatchewan	1	0	2	0	0	3
Manitoba	0	0	1	0	0	1
Ontario	8	8	24	7	1	48
Quebec	4	5	15	21	0	45
New Brunswick	0	1	0	2	0	3
Newfoundland and Labrador	0	0	1	0	0	1
Total	**16**	**22**	**46**	**34**	**1**	**119**

Note:
Shaded cells show local organs used for transplantation.

4. Heart Transplantation[vi]

With the advent of pioneering techniques for successful heart transplant procedures in the 1950s, world attention was focused on heart transplantation. The first human heart transplant was performed in 1967 by Dr. Christian Barnard in Capetown, South Africa. However, the low one-year patient survival for heart transplant recipients at the time resulted in dwindling enthusiasm for heart transplantation.[15] The discovery of the drug cyclosporin and its introduction to clinical transplantation in the early 1980s resulted in the beginning of substantial improvements in patient survival rates. It was at this juncture that heart transplantation became a mainstream treatment for end-stage heart failure.

4.1 Activity

From 1996 to 2005, there were 1,622 heart transplants registered in CORR, which included 17 heart combination transplants, of which 15 were heart–kidney combinations (Table 41). The number of children receiving donor hearts under the age of 1 year fluctuated from year to year, with the highest number recorded in 2005 (15). The number of heart transplants in children between the ages of 1 and 10 years also fluctuated between 7 and 10 per year. The majority of heart transplants were performed on those between 35 to 59 years of age (52.2%), followed by those aged 60 and older (20.9%).

The number of heart transplants performed in Canada increased during the decade, reaching 174 in 2005, up from the lowest level in 2004 (143) or an increase of 21.7%. In total, 1,564 patients received a first heart transplant, while 58 were retransplanted.

vi. For the purpose of this report, heart–lung transplants are included in Section 5, Lung Transplantation, given that the same data elements are collected for heart–lung and lung transplants.

Table 41 Heart Transplants by Year, Age Group and Retransplants Canada, 1996 to 2005 (Number)

	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	Total
First Graft <1	3	5	2	9	10	10	5	6	14	15	79
First Graft 1–10	6	8	7	10	8	8	8	4	7	8	74
First Graft 11–17	9	7	7	7	8	9	8	10	9	9	83
First Graft 18–34	14	12	6	12	17	19	15	16	13	18	142
First Graft 35–59	90	100	105	83	80	71	84	82	66	86	847
First Graft 60+	38	25	21	40	38	40	41	33	30	33	339
Retransplants	7	6	6	5	12	4	3	6	4	5	58
Total	**167**	**163**	**154**	**166**	**173**	**161**	**164**	**157**	**143**	**174**	**1,622**

Heart transplant procedures are highly specialized and recipients require multi-disciplinary and complex care before and after surgery. During this period, heart transplants were performed in a relatively small number of hospitals in Canada (10) and heart transplant programs existed in Halifax, Montréal, Quebec City, Toronto, London, Ottawa, Edmonton and Vancouver. Infant and child heart transplants were performed at the Hospital for Sick Children (Toronto), the Hôpital Sainte-Justine (Montréal), Montréal Children's Hospital and the University of Alberta Hospital (Edmonton). The heart transplant programs located in Ontario (39.4%), Quebec (24.9%) and Alberta (20.3%) performed a combined total of 84.6% of all heart transplants in Canada during this period (Table 42).

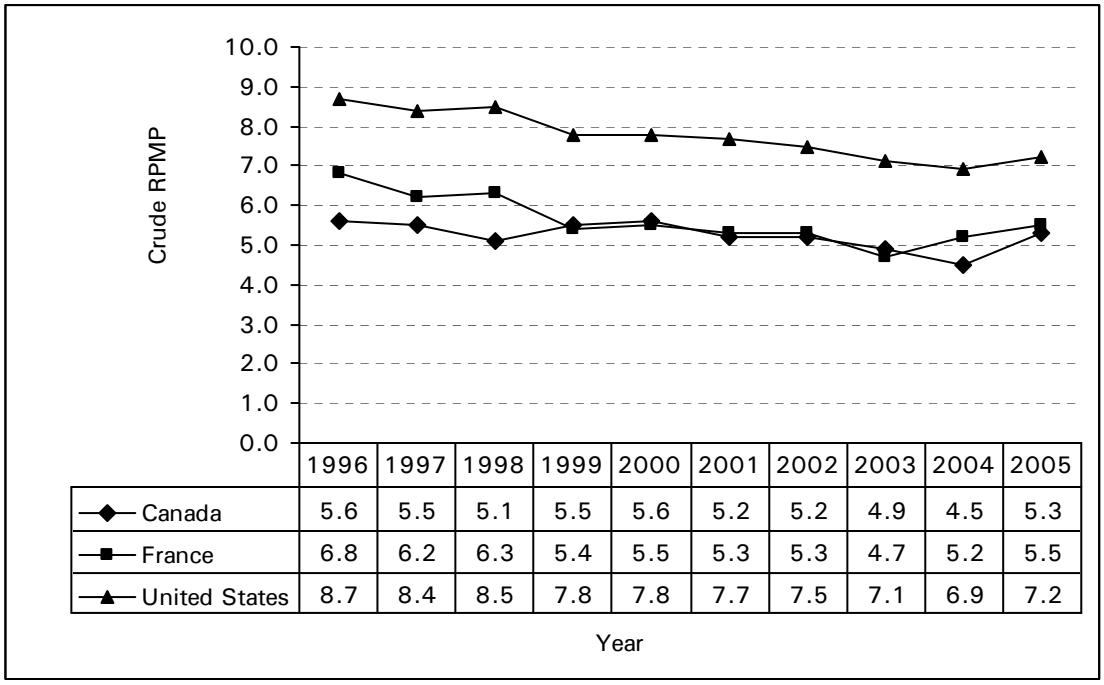
Table 42 Heart Transplants by Year and Province of Treatment, Canada, 1996 to 2005 (Number)

Province of Treatment	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	Total
British Columbia	18	20	14	16	11	14	21	18	14	16	162
Alberta	23	24	32	29	41	42	39	21	28	51	330
Ontario	83	64	63	74	64	58	55	63	56	59	639
Quebec	37	44	36	38	44	39	43	47	36	40	404
Nova Scotia	6	11	9	9	13	8	6	8	9	8	87
Total	**167**	**163**	**154**	**166**	**173**	**161**	**164**	**157**	**143**	**174**	**1,622**

4.2 International Comparison

The heart transplantation rate for Canada was lower than that for the United States, but similar to France for the years 1999 to 2003 (Figure 37). Between 1996 and 2004, the heart transplantation rate generally declined in Canada and the United States, culminating in an increase of 0.8 and 0.3 respectively in 2005. Similarly, heart transplantation was on the decline in France between 1996 and 2003, but saw an upswing beginning in 2004 and continuing in 2005.

Figure 37 Heart Transplants, Canada, France and United States, 1996 to 2005, (Crude Rate PMP)



	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
Canada	5.6	5.5	5.1	5.5	5.6	5.2	5.2	4.9	4.5	5.3
France	6.8	6.2	6.3	5.4	5.5	5.3	5.3	4.7	5.2	5.5
United States	8.7	8.4	8.5	7.8	7.8	7.7	7.5	7.1	6.9	7.2

Data source for France: l'Établissement français des Greffes, *Rapport d'activité et Bilan des activités de prélèvement et de greffe en France Année 2005* (Paris: l'Établissement français des Greffes, Agence de la biomédecine, 2006).
Data source for the U.S.: Department of Health and Human Services (Health Resources and Services Administration, Healthcare Systems Bureau, Division of Transplantation), United Network for Organ Sharing and University Renal Research and Education Association, *2006 Annual Report of the U.S. Organ Procurement and Transplantation Network and the Scientific Registry of Transplant Recipients: Transplant Data 1996–2005* (Richmond, VA: United Network for Organ Sharing, 2006).

4.3 Recipient Characteristics

The mean age of heart transplant recipients fluctuated slightly throughout the decade, ranging from 40 to 46 years. Males outnumbered female recipients in all age groups, with the largest proportion in the 60-years-and-older age group (85.3% male) and the lowest in the 1-to-10-year age group (56.7%) (Table 43). Congenital diseases and unspecified cardiomyopathy were the most frequently observed diagnoses for patients 17 years of age and younger. For those 18 to 34 years of age, the leading diagnosis reported was dilated cardiomyopathy or cardiomyopathy of unspecified origin.

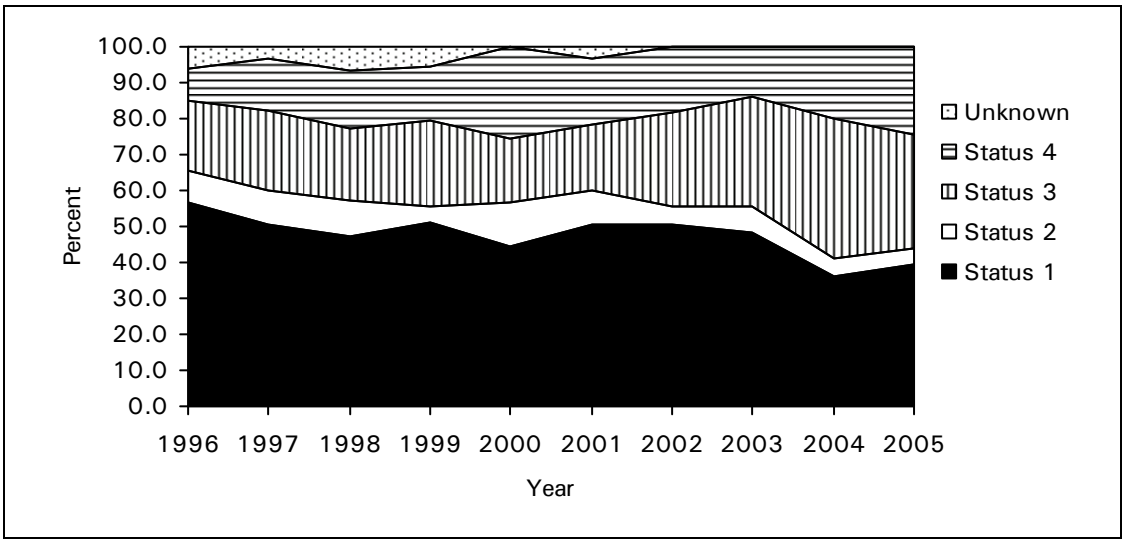
Table 43 Distribution of Primary Diagnoses for Heart Transplant Recipients First Grafts by Age Group, Canada, 1996 to 2005

Age (Years)	Total	Percentage Male	Congenital	Cardio-myopathy Unspecified	Dilated Cardio-myopathy	Idiopathic Cardio-myopathy	Ischemic Cardio-myopathy	Unknown	Other
<1	93	59.1	57.4	14.9	7.4	2.1	1.1	2.1	14.9
1–10	60	56.7	37.7	11.5	14.8	3.3	1.6	6.6	24.6
11–17	83	59.0	26.7	26.7	19.8	4.7	1.2	4.7	16.3
18–34	142	66.2	11.5	14.9	22.3	10.8	5.4	2.0	33.1
35–59	845	77.5	1.7	10.8	15.1	9.4	42.4	2.4	18.1
60+	339	85.3	0.3	9.8	13.9	4.0	60.7	2.3	9.0
Total	**1,562**	**75.3**	**8.5**	**12.2**	**14.1**	**7.7**	**37.7**	**2.7**	**17.2**

The diagnosis most frequently reported (42.4%) for heart transplant recipients over 35 years of age was coronary heart disease (ischemic cardiomyopathy), while in patients over 60 years of age, 60.7% were diagnosed with coronary artery disease as the primary diagnosis.

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 3A, 3B and 4 patients are in the most urgent need of a transplant. Status 3A and 3B patients may be in the ICU or require inotropic support, while status 4 patients and are already in the ICU with ventilator support. Examination of the distribution of heart transplant recipients by medical status revealed an increasing proportion of patients who were in the ICU and receiving inotropic support (status 3) (Figure 38). There was no clear trend in regard to patients with “other” medical status.

Figure 38 Distribution of Heart Transplants by Medical Status* at Transplant, Canada, 1996 to 2005

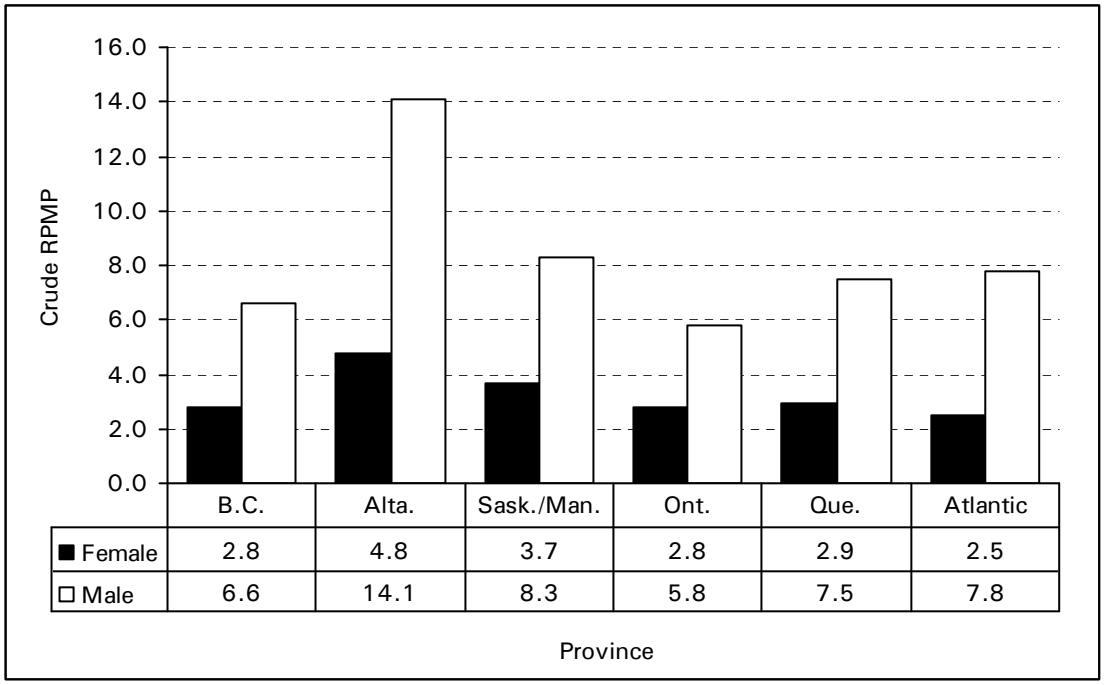


Note:

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

Over this decade, the heart transplant rates for females by province of residence have begun to change. When the decade was assessed at the end of 2003, the rate ranged between 1.8 and 2.9 PMP in each province, showing very little variation. However, when the assessment incorporates 2005 data, both the rate for female heart transplant recipients has risen overall and the variation between provinces has increased (Figure 39). The rate now ranges from a low of 2.5 PMP (Atlantic region) to 4.8 PMP (Alberta). For male recipients, the highest rate was in Alberta (14.1 PMP), and the lowest (5.8) in Ontario. These analyses do not take into consideration other potential factors such as provincial differences in the prevalence of end-stage heart failure.

Figure 39 Heart Transplant Recipients by Province of Residence, Canada, 2005 (Sex-Specific Crude Rate PMP)



	B.C.	Alta.	Sask./Man.	Ont.	Que.	Atlantic
■ Female	2.8	4.8	3.7	2.8	2.9	2.5
□ Male	6.6	14.1	8.3	5.8	7.5	7.8

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

4.4 Waiting List and Waiting Times

While the number of Canadians on the waiting list for heart transplantation fluctuated from year to year, there was an overall increase of 27.6% from 1996 to 2004 (Table 44). However, in 2005, the number was 96, the lowest it has been since 2000 (89), and reflected a 23% decrease from 2004. Throughout the 10 years, the number of people who died while waiting fluctuated between 26 to 41 per year, with an annual average of 31 patients. The lowest number of patients who died awaiting for the transplant throughout the decade was 27 in 2005.

Table 44 Heart Transplant, Number Waiting, Canada, 1996 to 2005

	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	Total
<18 Years	--	9	21	13	9	13	13	37	6	9	130
18+ Years	--	88	99	88	80	112	90	94	119	87	857
Total	**96**	**97**	**120**	**101**	**89**	**125**	**103**	**131**	**125**	**96**	**1,083**
Number Died	29	28	28	41	30	34	35	30	26	27	308

The median wait times for people requiring first heart transplants between 2003 and 2005 show that those with an urgent need had the shortest wait times (Table 45). For groups with a medical status of 1, 2, 3A or 3B, recipients in the blood group O had the longest wait times, while those with status 4 in blood group B had the longest wait for an organ.

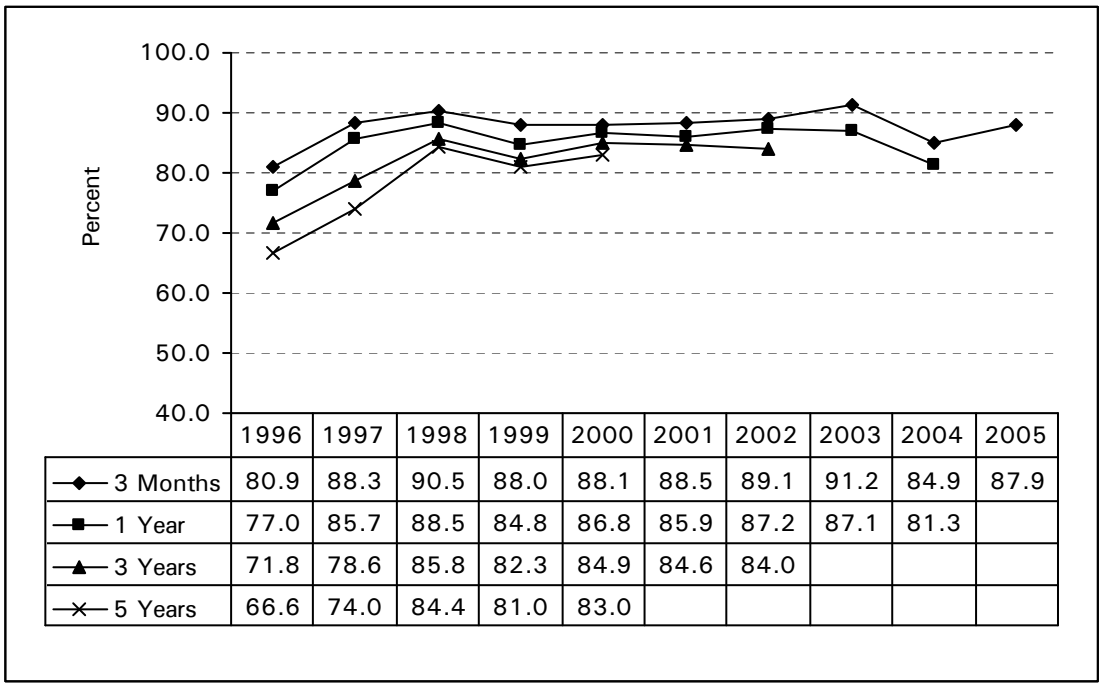
Table 45 Wait Time From Listing to Transplant for Deceased-Donor Heart Transplant Recipients First Grafts, Canada, 2003 to 2005

Medical Status as Listing	Blood Group	Wait (in Days)			
		N	Min.	Max.	Median
Status 1 (at home) and 2 (hospitalized)	A	124	0	641	70.5
	AB	15	7	560	79.0
	B	34	0	1,399	79.0
	O	84	0	1,917	243.5
	U	1	51	51	51.0
Status 3A and 3B (ICU or inotropic support required)	A	48	1	365	23.5
	AB	10	0	129	5.0
	B	19	1	283	41.0
	O	33	0	693	62.0
	U	1	12	12	12.0
Status 4 (ICU with mechanical/ ventilator support) and in utero	A	28	0	211	15.0
	AB	7	1	96	10.0
	B	8	1	77	25.0
	O	29	0	174	16.0
	U	2	0	2	1.0

4.5 Outcomes

In general, over the 10-year period, the unadjusted patient survival rates for those with first heart grafts improved. However, the early survival rate (three months) for first-time heart transplant recipients declined by 6.3% from 91.2% (2003) to 84.9% (2004), but improved in 2005 to 87.9% (Figure 40).

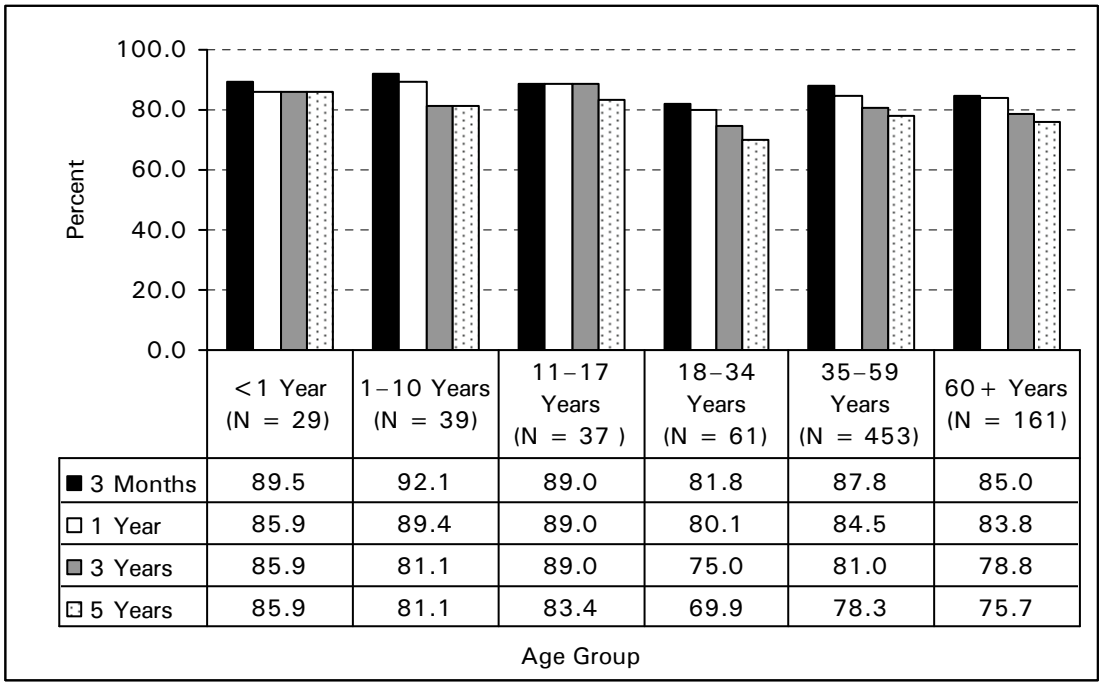
Figure 40 Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Heart Transplant Recipients, First Graft, Canada, 1996 to 2005



	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
3 Months	80.9	88.3	90.5	88.0	88.1	88.5	89.1	91.2	84.9	87.9
1 Year	77.0	85.7	88.5	84.8	86.8	85.9	87.2	87.1	81.3	
3 Years	71.8	78.6	85.8	82.3	84.9	84.6	84.0			
5 Years	66.6	74.0	84.4	81.0	83.0					

When examined by age group, patient survival rates at first transplant vary somewhat (Figure 41). Patients in the 1-to-10-year age group had the highest survival rate at three months (92.1%) and one year (89.4%). However, the three-year survival rate was highest among those aged 11 to 17 (89.0%) and the five-year rate was highest among those less than one year (85.9%). It is important to note that the three pediatric age groups used in this analysis involve a small number of patients.

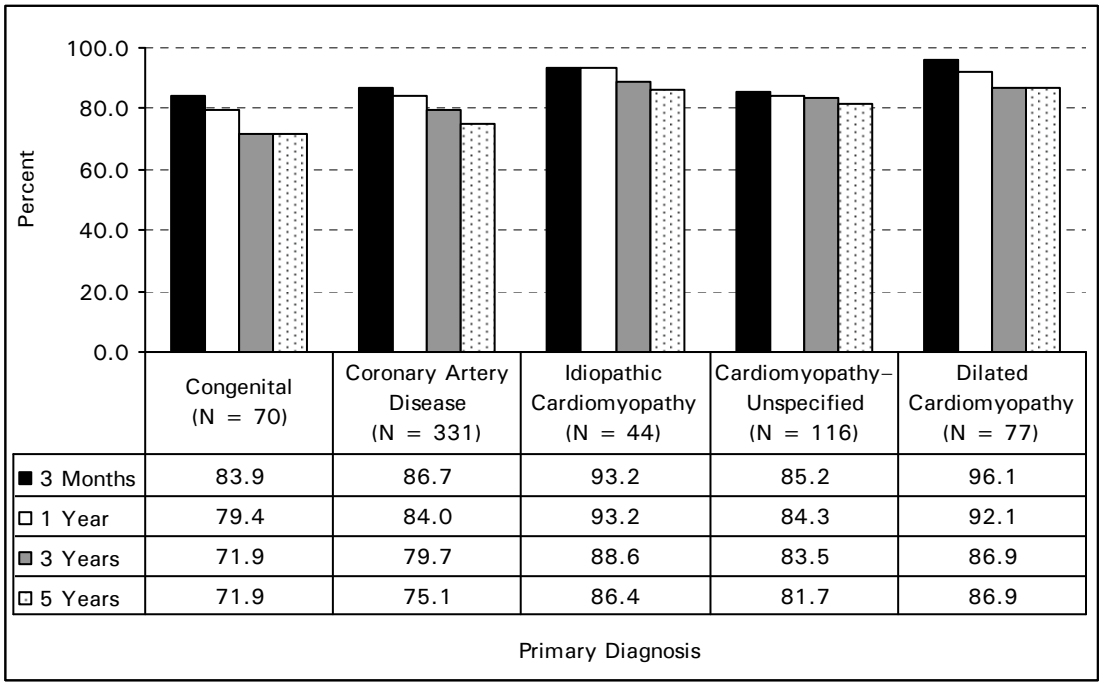
Figure 41 Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Heart Transplant Recipients by Age Group, First Graft, Canada, 1996 to 2000



	<1 Year (N = 29)	1–10 Years (N = 39)	11–17 Years (N = 37)	18–34 Years (N = 61)	35–59 Years (N = 453)	60+ Years (N = 161)
■ 3 Months	89.5	92.1	89.0	81.8	87.8	85.0
□ 1 Year	85.9	89.4	89.0	80.1	84.5	83.8
▩ 3 Years	85.9	81.1	89.0	75.0	81.0	78.8
⊡ 5 Years	85.9	81.1	83.4	69.9	78.3	75.7

When the etiology of end-stage heart failure is considered, those recipients diagnosed with cardiomyopathy as the cause of heart failure have improved survival rates at three months, one year, three years and five years, compared to those with either coronary artery disease or congenital heart disease (Figure 42). The most compromised unadjusted patient survival rate was observed at three years and at five years after transplantation, in patients diagnosed with congenital heart disease (71.9%).

Figure 42 Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Heart Transplant Recipients by Primary Diagnosis, First Graft, Canada, 1996 to 2000

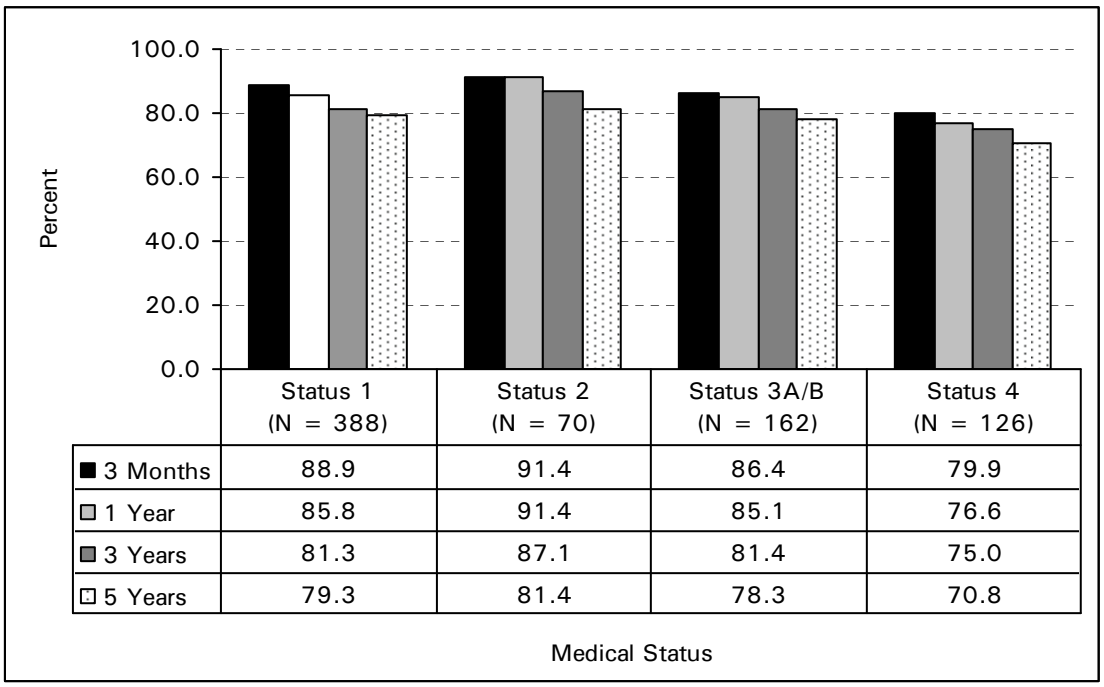


	Congenital (N = 70)	Coronary Artery Disease (N = 331)	Idiopathic Cardiomyopathy (N = 44)	Cardiomyopathy–Unspecified (N = 116)	Dilated Cardiomyopathy (N = 77)
3 Months	83.9	86.7	93.2	85.2	96.1
1 Year	79.4	84.0	93.2	84.3	92.1
3 Years	71.9	79.7	88.6	83.5	86.9
5 Years	71.9	75.1	86.4	81.7	86.9

Primary Diagnosis

Medical status at the time of transplant was an important factor in the analysis of patient outcomes. Consistently, at all time points, those in the status 4 category had the poorest survival rates. Similarly, consistently at all time points, those in status 2 had the best survival rates.[vii] For short-term survival (three months and one year) those assigned to status 2 had the highest survival rate (91.4%), while the lowest, at 79.9% and 76.6% respectively, was seen in status 4 recipients. The three-year survival rate varied considerably, from a low of 75.0% for status 4 patients to a high of 87.1% for status 2. Long-term survival at five years was best for status 2 recipients (81.4%), followed closely by status 1 (79.3%) and status 3 (78.3%). Those determined to be status 4 at the time of the operation had a 70.8% survival rate at five years (Figure 43).

Figure 43 Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Heart Transplant Recipients by Medical Status at Transplant, First Graft, Canada, 1996 to 2000

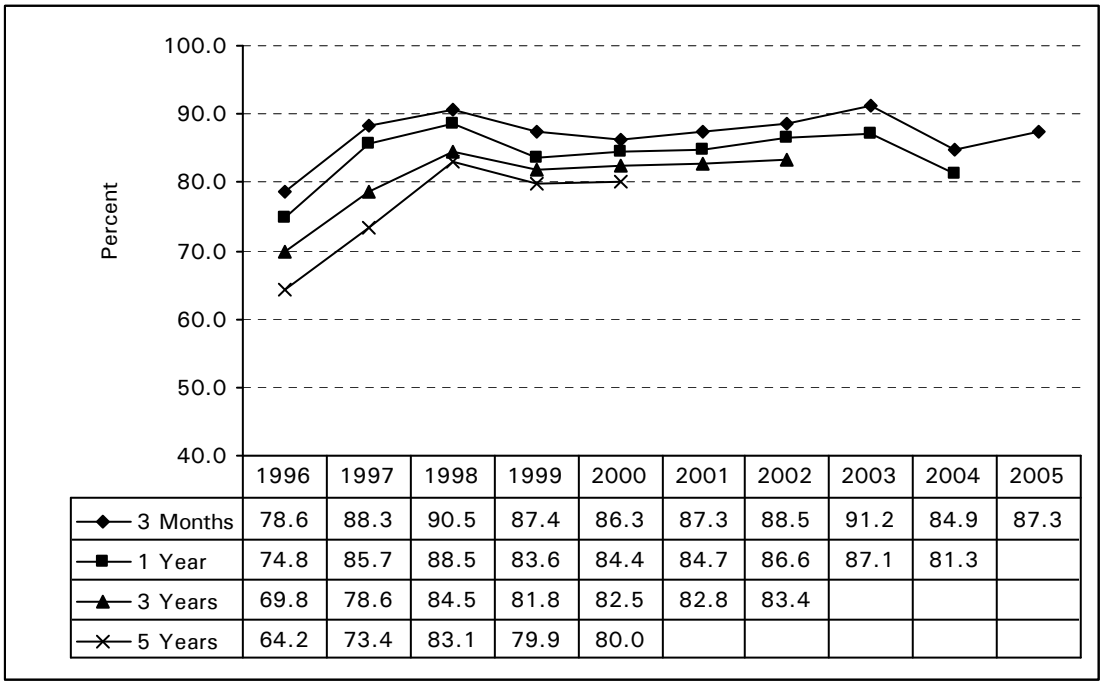


	Status 1 (N = 388)	Status 2 (N = 70)	Status 3A/B (N = 162)	Status 4 (N = 126)
3 Months	88.9	91.4	86.4	79.9
1 Year	85.8	91.4	85.1	76.6
3 Years	81.3	87.1	81.4	75.0
5 Years	79.3	81.4	78.3	70.8

vii. Note that the Status 2 group used in this analysis (1995 to 1999) involved a small number of patients, relative to the other groups.

Graft survival for heart transplants showed similar trends with improvement over time. Between 2003 and 2004, there was a drop of 6.3% in the three-month category (from 91.2% to 84.9%), which then improved to 87.3% in 2005 (Figure 44).

Figure 44 Unadjusted One-Month, One-, Three- and Five-Year Graft Survival* for Heart Transplant Recipients, First Graft, Canada, 1996 to 2005



	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
3 Months	78.6	88.3	90.5	87.4	86.3	87.3	88.5	91.2	84.9	87.3
1 Year	74.8	85.7	88.5	83.6	84.4	84.7	86.6	87.1	81.3	
3 Years	69.8	78.6	84.5	81.8	82.5	82.8	83.4			
5 Years	64.2	73.4	83.1	79.9	80.0					

Note:

* Graft survival is computed from first heart transplant date to first graft failure date, death date or end of observation (December 31, 2005). In this analysis, patients who died with a functioning graft are considered as failed grafts.

4.6 Organ Donors[viii]

The rate of recovery for hearts used for both heart and heart–lung transplants gained some momentum in 2005, reaching 33.3%, an improvement over 2004 when it was at its lowest for the decade at 30.5%. The proportion of hearts recovered for transplant from deceased donors fluctuated from year to year, but generally declined between 1996 and 2005, for an overall decrease of 14.4% during the 10-year period (Table 46). The overall number of hearts recovered for donation also declined by 18.2% over the decade (Table 49).

viii. For details related to heart–lung donors, please refer to Section 5. The remainder of this section excludes donated heart–lungs.

Table 46 Proportion of Hearts Transplanted from Deceased Donors, 1996 to 2005 (Percentage)

	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
Recovery Rate	38.9	37.5	36.5	37.6	34.0	34.5	35.3	34.0	30.5	33.3

In Canada, donor hearts are shared between provinces based on the urgency of a patient's medical need for the organ. Donor hearts from Saskatchewan were typically provided to the Edmonton program, while donor hearts from Manitoba were provided to the London program. In terms of medical status, 59.1% (273) of those listed for heart transplant from 2003 to 2005 were deemed to be status 1 or 2, while the remainder (189) were listed as status 3A, 3B and 4 (tables 47 and 48).

When examining the ways in which hearts were utilized among recipients who were listed as non-urgent (status 1 and 2), the Halifax heart transplant program used only hearts recovered from donors at facilities in the Atlantic provinces (Table 47). The Atlantic provinces shared more organs with programs in other provinces outside the region than it received from other parts of Canada. The United States sent 27 hearts for transplant to Canada over the decade, 17.9% of which were used by the Vancouver and Edmonton programs. The Halifax program is the only program which did not utilize donated hearts from the United States.

Table 47 Origin and Destination of Transplanted Hearts for Recipients Who Were Listed as Status 1/2, Canada, 2003 to 2005

Retrieval Province	Treated Province					Total
	B.C.	Alta.	Ont.	Que.	N.S.	
British Columbia	23	3	1	0	0	27
Alberta	10	24	1	0	0	35
Saskatchewan	3	5	0	0	0	8
Manitoba	0	0	5	0	0	5
Ontario	0	1	74	2	0	77
Quebec	0	0	9	54	0	63
New Brunswick	0	0	3	2	10	15
Nova Scotia	0	0	2	5	2	9
Newfoundland and Labrador	0	0	2	1	4	7
United States	6	9	9	3	0	27
Total	**42**	**42**	**106**	**67**	**16**	**273**

Note:
Shaded cells show local organs used for transplantation.

While donor heart organs are shared by patients from status 1 through to 4, the most extensive sharing was seen for patients who were placed on the wait list for transplant when they were in the ICU and deemed to be urgently in need of a transplant (Table 48). In Canada, Ontario was most reliant on donor hearts from the United States, requiring organs for 22.4% of its urgent heart transplant recipients.

Table 48 Origin and Destination of Transplanted Hearts for Recipients Who Were Listed as Status 3A/3B/4, Canada, 2003 to 2005

Retrieval Province	Treated Province					Total
	B.C.	Alta.	Ont.	Que.	N.S.	
British Columbia	2	1	2	0	0	5
Alberta	0	18	3	0	0	21
Saskatchewan	0	9	0	0	0	9
Manitoba	1	1	2	0	0	4
Ontario	0	8	37	9	2	56
Quebec	1	3	6	41	0	51
New Brunswick	0	1	1	0	5	7
Nova Scotia	0	1	1	1	1	4
Newfoundland and Labrador	0	0	0	1	1	2
United States	2	10	15	3	0	30
Total	**6**	**52**	**67**	**55**	**9**	**189**

Note:
Shaded cells show local organs used for transplantation.

Between 1996 and 2005, the average age of heart donors in Canada remained virtually unchanged, varying between 31 and 35 years of age. As the decade progressed, there has been a small increase in the number of infant hearts utilized towards the end of the period. Overall, there were fewer female Canadian heart donors (36.3%) than males. In Canada, the proportion of donors who died as a result of motor vehicle collisions declined over the course of decade, likely reflecting the implementation of effective vehicle safety and injury-prevention strategies. This proportion of donors dropped by 8.2% between 1996 and 2005. There was a significant one-year decrease of 5.5% from 2003 to 2004. There were also decreases in CVA/stroke and gunshot as the cause of death in donors. However, while motor vehicle collisions declined as a cause of death, the proportion of donors dying from other causes of trauma climbed steadily throughout the decade, with a 10.8% increase between 1996 and 2005 (Table 49).

Table 49 Cause of Death Among Donors of Transplanted Hearts, 1996 to 1997 and 2004 to 2005

Cause of Death	1996 to 1997		2004 to 2005	
	N	Percentage	N	Percentage
CVA/Stroke	138	42.6	102	38.5
Motor Vehicle Collision	84	25.9	47	17.7
Other Trauma	42	13.0	63	23.8
Other	17	5.2	27	10.2
Anoxia/Hypoxia	17	5.2	16	6.0
Gunshot	18	5.6	4	1.5
Unknown	8	2.5	6	2.3
Total	**324**	**100.0**	**265**	**100.0**

5. Lung Transplantation

The first human lung transplant was performed by Dr. James Hardy at the University of Mississippi, in 1963. The patient had an isolated lung malignancy and lived for 18 days after the transplant. Between 1963 and 1980, only a small number of lung transplants were performed around the world, and there was no long-term survival for any of the patients during this period. With the introduction of cyclosporin in the early 1980s, the landscape for lung transplantation began to change.

The first single-lung transplant operation was performed by the Toronto Thoracic Surgical Group, under the leadership of Dr. Joel Cooper in 1983. With it, Canada made a dramatic mark on the lung transplant landscape. Dr. Cooper continued to make strides in lung transplant history, performing the first successful bilateral lung transplant in 1986. The first successful heart–lung transplant had been performed in 1981 at Stanford University. Since that time, results have continued to improve for several reasons, including better organ preservation techniques, improvements in pre- and peri-operative care, better follow-up in medical management of recipients and advances in immunosuppression.

5.1 Activity

In the decade from 1996 to 2005, there was both an increase in the numbers of lung transplants being performed annually in Canada and an improvement in outcomes. Throughout the period, lung transplantation procedures in Canada were performed in 10 facilities: the Montréal General Hospital, Royal Victoria Hospital, Notre-Dame Hospital (Montréal), Hospital for Sick Children (Toronto), The University Health Network (Toronto General Hospital), London Health Sciences Centre, the Health Sciences Centre (Winnipeg), the University of Alberta Hospital (Edmonton), Vancouver General Hospital and Health Sciences Centre and British Columbia Children's Hospital (Vancouver). In the fall of 1997, the programs at the Montréal General Hospital and at the Royal Victoria Hospital (now both part of the McGill University Health Centre in Montréal) ended, while the London Health Sciences Centre program ended in 2003.

During the period of study, the aggregate number of lung transplants reached 1,128, reflecting an increase of 90.8% from 1996 (76) to 2005 (145) (Table 50).

Table 50 Lung Transplants by Year, Age Group and Retransplants, Canada, 1996 to 2005 (Number)

	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	Total
First Graft 18+	67	86	75	85	121	121	130	112	128	137	1,062
First Graft <18	4	4	4	5	2	4	5	2	3	5	38
Retransplants	5	3	4	1	1	1	4	4	2	3	28
Total	**76**	**93**	**83**	**91**	**124**	**126**	**139**	**118**	**133**	**145**	**1,128**

The Toronto Lung Transplant Program includes lung transplant surgeries performed at the University Health Network sites (Hospital for Sick Children and The Toronto Hospital). It performed 390 lung transplant procedures during the period (or 34.6%), followed by Notre Dame Hospital (244 procedures or 21.6%) and the University of Alberta Hospital (224 procedures or 19.9%).

Bilateral lung transplants were the leading type of lung transplant performed each year, with the number almost tripling between 1996 and 2005 (Table 51). Bilateral procedures represented 68.4% of the total number of lung transplants in Canada over the decade, accounting for 82.1% in 2005. The number of heart–lung transplants performed remained relatively small throughout the decade, fluctuating between a high of seven to a low of three during the period. Six procedures were performed in 2005. In 1999, the Winnipeg transplant program pioneered the first living-donor lobar lung transplant in Canada and since that time, an additional six procedures have been performed, including one in 2005.

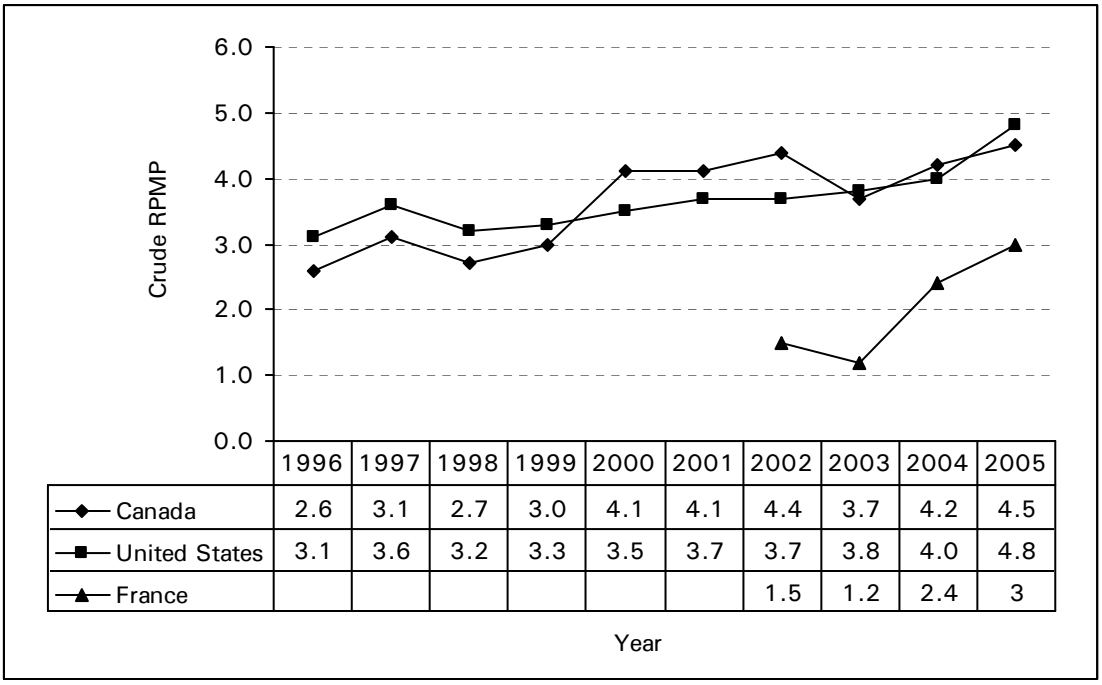
Table 51 Lung Transplants by Transplant Type, Canada, 1996 to 2005 (Number)

	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	Total
Bilateral Lung	43	52	46	55	85	82	96	95	98	119	771
Single Lung	29	34	30	30	34	39	36	21	30	19	302
Living-Donor Lobar	0	0	0	1	1	2	0	0	2	1	7
Heart–Lung	4	7	7	5	4	3	7	2	3	6	48
Total	**76**	**93**	**83**	**91**	**124**	**126**	**139**	**118**	**133**	**145**	**1,128**

5.2 International Comparison

Advances in lung transplantation procedures in Canada resulted in Canada surpassing the United States between 2000 and 2002; the Canadian rate peaked in 2005 (Figure 45). Lung transplantation is the only solid organ transplantation procedure where Canadian rates have not been consistently below those reported in the United States. While the rate in France is relatively low compared to Canada and the United States, there was a substantial rate increase recorded between 2003 and 2005.

Figure 45 Lung Transplants, Canada and the United States, 1996 to 2005, France, 2002 to 2005 (Crude Rate PMP)



	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
Canada	2.6	3.1	2.7	3.0	4.1	4.1	4.4	3.7	4.2	4.5
United States	3.1	3.6	3.2	3.3	3.5	3.7	3.7	3.8	4.0	4.8
France							1.5	1.2	2.4	3

Data source for France: l'Établissement français des Greffes, *Rapport d'activité et Bilan des activités de prélèvement et de greffe en France Année 2005* (Paris: l'Établissement français des Greffes, Agence de la biomédecine, 2006).
Data source for the U.S.: Department of Health and Human Services (Health Resources and Services Administration, Healthcare Systems Bureau, Division of Transplantation), United Network for Organ Sharing and University Renal Research and Education Association, *2006 Annual Report of the U.S. Organ Procurement and Transplantation Network and the Scientific Registry of Transplant Recipients: Transplant Data 1996–2005* (Richmond, VA: United Network for Organ Sharing, 2006).

5.3 Recipient Characteristics

The number of adult lung transplants performed in Canada increased by 104%, from 67 (1996) to 137 (2005) for patients age 18 years and older. It was closely split between genders, with males receiving 576 (54.2%). The number of lung transplants performed annually doubled from 32 (1996) to 65 (2005) for adults 50 years and older. In the recipients aged 50 years and older, there was a similar increase in the annual number of lung transplants performed, from a low of 35 in 1996 to 71 in 2005.

The etiology of lung or heart–lung failures differed for each type of transplant. The diagnostic grouping of congenital diseases (44.4%) and primary pulmonary hypertension (13.3%) were the two most commonly reported causes in heart–lung recipients. Emphysema/COPD (51.6%) and idiopathic pulmonary fibrosis (20.4%) were the causes most frequently reported in single lung recipients, while cystic fibrosis (31.9%) and emphysema/COPD (18.1%) were most often noted as the etiology of failure for double lung transplant recipients (Table 52).

Table 52 Distribution of Primary Diagnoses* for Lung Transplant Recipients, First Grafts, Canada, 1996 to 2005

	Bilateral Lung		Single Lung		Heart–Lung	
	N	Percentage	N	Percentage	N	Percentage
Congenital	12	1.6	1	0.3	20	44.4
Alpha Antitrypsin	66	8.7	25	8.2	1	2.2
Cystic Fibrosis	241	31.9	8	2.6	4	8.9
Emphysema/COPD	137	18.1	157	51.6	5	11.1
Idiopathic Pulmonary fibrosis	130	17.2	62	20.4	0	0
Primary Pulmonary Hypertension	38	5.0	4	1.3	6	13.3
Unknown/Missing	12	1.6	7	2.3	1	2.2
Other	120	15.9	40	13.2	8	17.8
Total	**756**	**100.0**	**304**	**100.0**	**45**	**100.0**

Note:

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

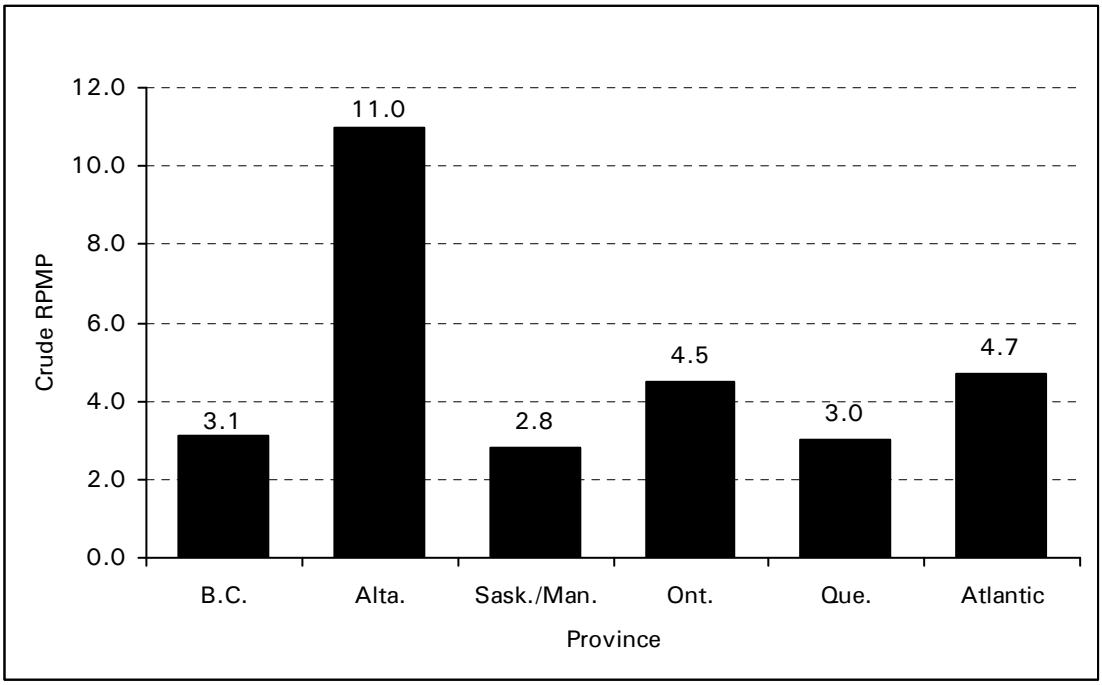
Between 1996 and 2005, there were 38 pediatric recipients, ranging in age from 8 to 17 years, with an even split between the genders. Out of 31 pediatric patients who received bilateral lung transplants, 22 recipients (71%) had cystic fibrosis as the etiology of end-stage disease which necessitated the transplant (Table 53).

Table 53 Lung Diagnosis for Pediatric Patients, Canada, 1996 to 2005

	Bilateral Lung		Single Lung		Heart–Lung	
	N	Percentage	N	Percentage	N	Percentage
Congenital	0	0	0	0	2	100.0
Cystic Fibrosis	22	71.0	1	20.0	0	0
Emphysema/COPD	0	0	1	20.0	0	0
Primary Pulmonary Hypertension	4	12.9	2	40.0	0	0
Other	5	16.1	1	20.0	0	0
Total	**31**	**100.0**	**5**	**100.0**	**2**	**100.0**

In 2005, the rates of transplant by province of residence showed Alberta with the highest rate at 11.0 PMP, up 59% from the previous year, followed by the Atlantic region with 4.7 PMP. Saskatchewan and Manitoba had the lowest rate of lung transplant for the decade with 2.8 PMP (Figure 46).

Figure 46 Lung Transplant Recipients by Province of Residence, Canada, 2005 (Crude Rate PMP)



5.4 Waiting List and Waiting Times

The waiting list for lung transplants fluctuated from year to year. Between 1996 and 2005, it more than doubled from 99 to 239 people, while the number of those waiting for a bilateral lung transplant increased nearly ten times, from 19 (1996) to 188 people (2005) (Table 54). In contrast, the number waiting for a single lung transplant decreased considerably, from 66 to 37 during the same period.

Table 54 Lung Transplant Waiting List on December 31, Canada, 1996 to 2005

	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	Total
Bilateral Lung	19	44	66	93	108	125	88	131	155	188	1,017
Single Lung	66	60	61	64	58	25	50	29	22	37	472
Heart–Lung	14	15	15	11	11	13	12	12	4	14	121
Total	99	119	142	168	177	163	150	172	181	239	1,610

In 2005, a total of 43 patients died while waiting for a lung transplant in Canada, and in total, 295 people have died while on the waiting list since 1996. Recipients who received their first lung transplant in 2005 waited a median of 163 days, based on a range of 3 to 1,615 days (Table 55). The duration of time was influenced by medical status at the time of listing. Status 2, defined as rapidly deteriorating patients, experienced a median wait time of 68 days, based on a range of 3 to 1,231 days. The median wait for status 2 patients was reduced by 28 days from 2004. For those listed as status 1 defined as stable, the median wait time was 244 days, based on a range of 11 to 1,235 days. Status 0 patients, defined as on hold/inactive, experienced a wide range of wait times, from 19 to 1,615 days, with a median of 172 days.

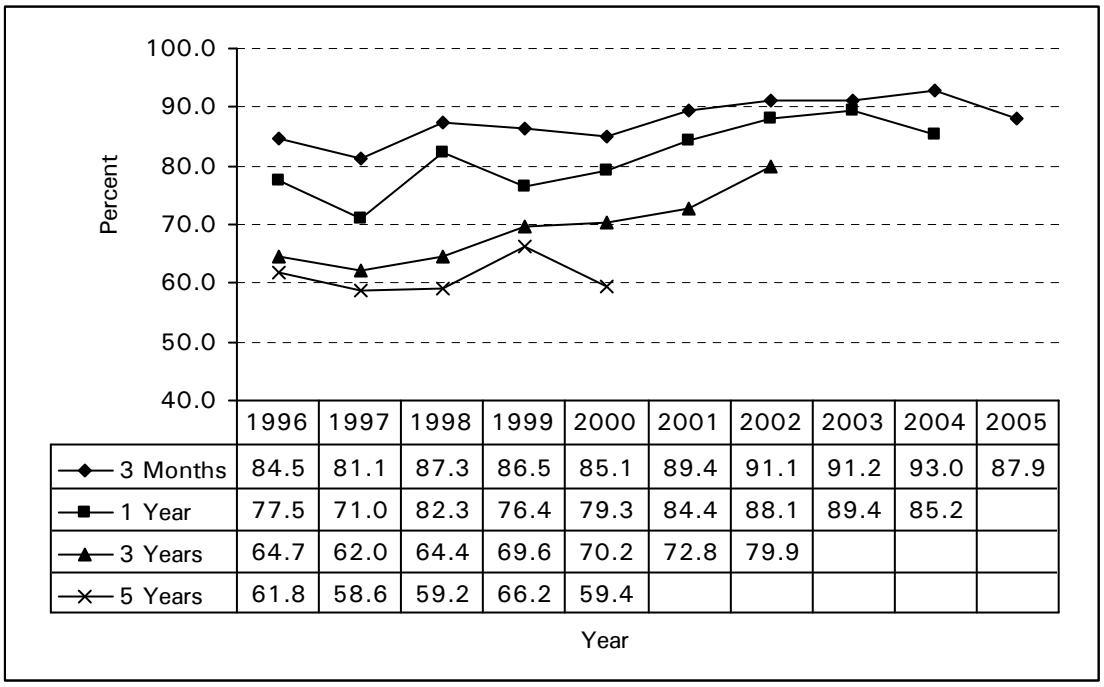
Table 55 Wait Time From Listing to Transplant for Deceased-Donor Adult Lung Transplant Recipients, First Grafts, Canada, 2005

Medical Status at Listing	Waiting Time (Days)			
	N	Min	Max	Median
Status 0	34	19	1,615	172.0
Status 1	67	11	1,235	244.0
Status 2	30	3	1,231	68.0
Total	**131**	**3**	**1,615**	**163.0**

5.5 Outcomes

Both short- and long-term patient survival improved for Canadian lung transplant patients throughout the decade (Figure 47). The largest improvement was seen in the three-year survival rate which improved by 15.2% over 1996. The one-year survival rate also showed considerable improvement (7.7%), while the most modest improvement was seen in the shortest term (survival at three months), which was only 3.4%.

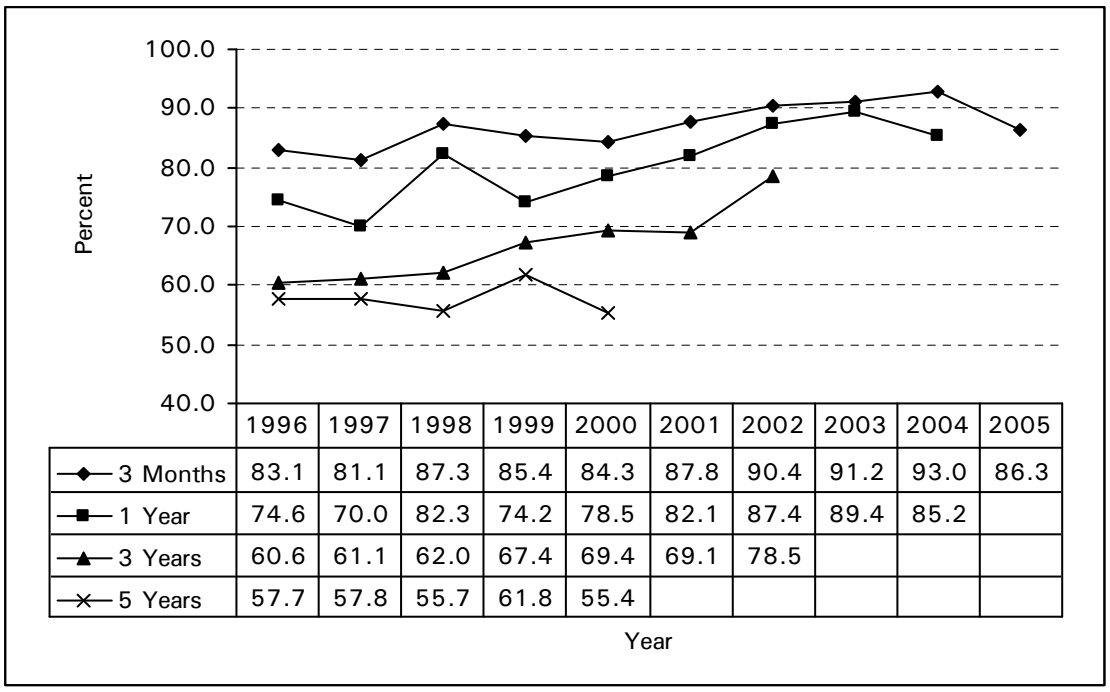
Figure 47 Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Lung Transplant Recipients, First Graft, Deceased Donor Lungs, Canada, 1996 to 2005



	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
3 Months	84.5	81.1	87.3	86.5	85.1	89.4	91.1	91.2	93.0	87.9
1 Year	77.5	71.0	82.3	76.4	79.3	84.4	88.1	89.4	85.2	
3 Years	64.7	62.0	64.4	69.6	70.2	72.8	79.9			
5 Years	61.8	58.6	59.2	66.2	59.4					

Reflecting the improvement in patient survival outcomes over the decade, there was similar improvement in terms of graft survival over the same time period (Figure 48). With the exception of the five-year graft survival rates, improvements were seen at all time points of measurement. The smallest gains were in the short-term graft survival, with an improvement of 3.2% over 10 years. The largest improvement was in the three-year graft survival rate, which showed a 17.9% increase between 1996 and 2002.

Figure 48 Unadjusted Three-Month and One-, Three- and Five-Year Graft Survival* for Lung Transplant Recipients, First Graft, Deceased Donor Lungs, Canada, 1996 to 2005



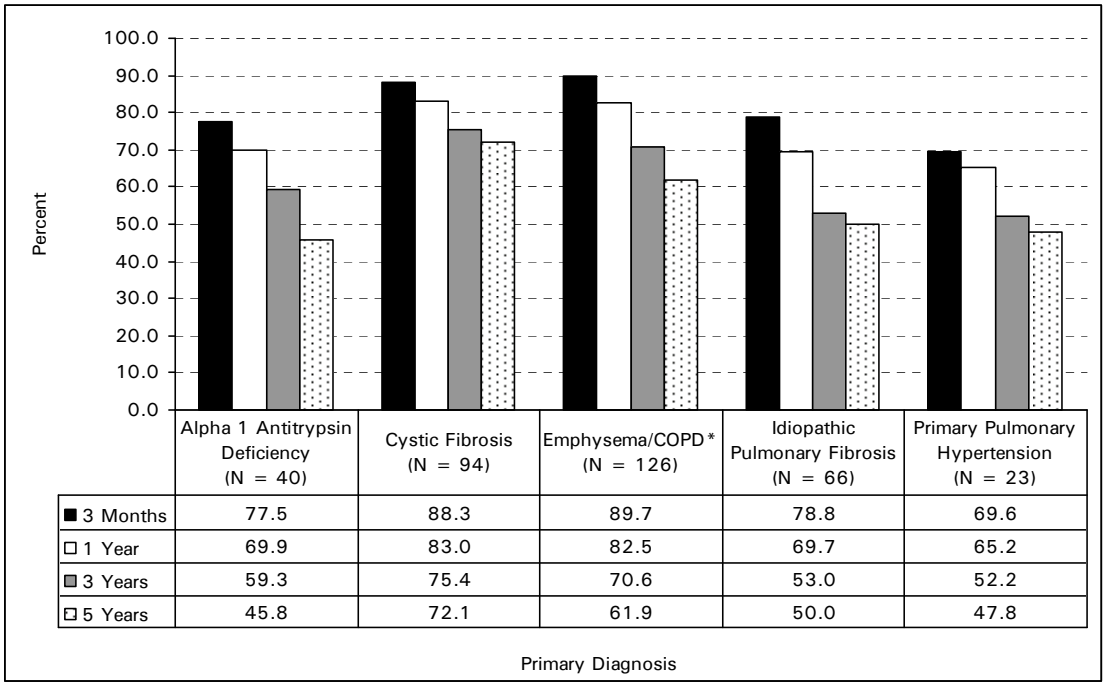
	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
3 Months	83.1	81.1	87.3	85.4	84.3	87.8	90.4	91.2	93.0	86.3
1 Year	74.6	70.0	82.3	74.2	78.5	82.1	87.4	89.4	85.2	
3 Years	60.6	61.1	62.0	67.4	69.4	69.1	78.5			
5 Years	57.7	57.8	55.7	61.8	55.4					

Note:

* Graft survival is computed from first lung transplant date to first graft failure date, death date or end of observation (December 31, 2005). In this analysis, patients who died with a functioning graft are considered as failed grafts.

An analysis was conducted using the diagnosis associated with patient lung failure as the test variable. Among patients who received their first lung graft between 1996 and 2000, survival was lowest for those with a diagnosis of pulmonary hypertension at three months (69.6%), one year (65.2%) and three years (52.2%) (Figure 49). When longer-term survival is examined, those with alpha 1 antitrypsin deficiency had the most compromised survival, 45.8% at five years. The best patient survival at all time points measured, except the three-month mark, was observed in those with a diagnosis of cystic fibrosis. These results are consistent with the survival trends reported by the International Society of Heart and Lung Transplantation.[16, 17]

Figure 49 Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Lung Transplant Recipients by Primary Diagnosis,* First Graft, Deceased Donor Lungs, Canada, 1996 to 2000



	Alpha 1 Antitrypsin Deficiency (N = 40)	Cystic Fibrosis (N = 94)	Emphysema/COPD* (N = 126)	Idiopathic Pulmonary Fibrosis (N = 66)	Primary Pulmonary Hypertension (N = 23)
3 Months	77.5	88.3	89.7	78.8	69.6
1 Year	69.9	83.0	82.5	69.7	65.2
3 Years	59.3	75.4	70.6	53.0	52.2
5 Years	45.8	72.1	61.9	50.0	47.8

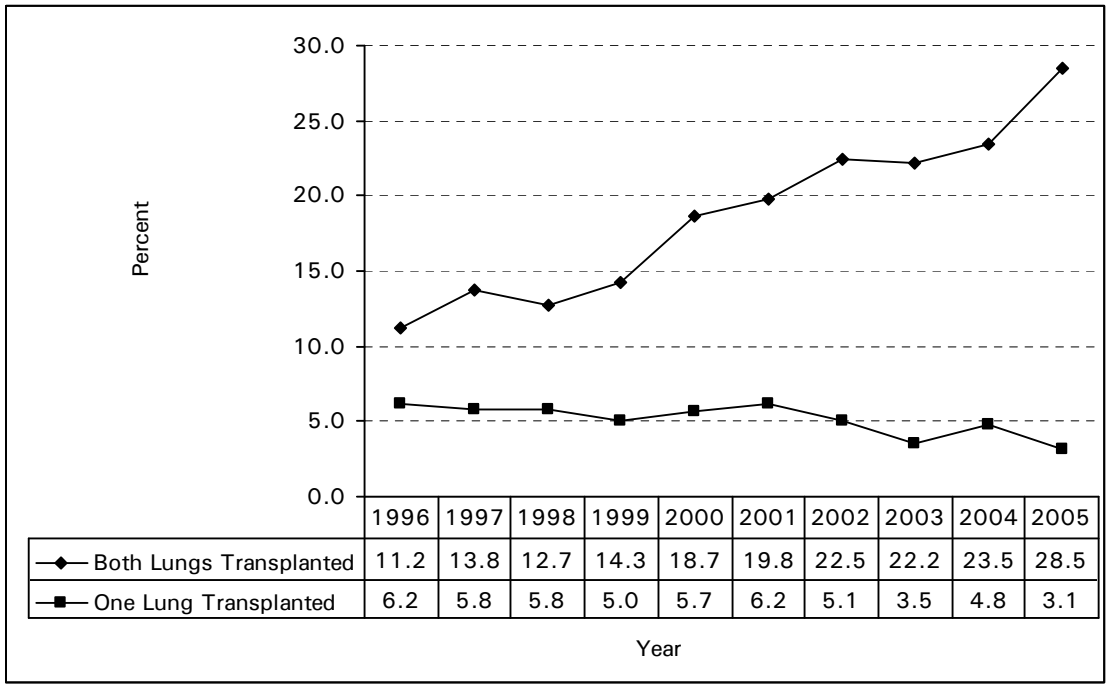
Note:

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

5.6 Organ Donors

The recovery of lungs used for transplantation in Canada demonstrated a distinct pattern of activity throughout the decade. While the recovery of single lungs for transplant has decreased through the 10-year span (from 6.2% in 1996 to 3.1% in 2005), there was considerable growth in the recovery where both organs were transplanted, going from 11.2% in 1996 to 28.5% in 2005 (Figure 50). This translates to a total increase of 17% during the time period. The peak (28.5%) was reached in 2005, representing a 5% increase over 2004. This increase mirrors the increase in the utilization of bilateral lung transplants throughout the decade. However, it is important to note that despite this encouraging growth, even in the year with the highest rate of lung recovery (2005), one or both lungs were recovered in only 31.6% of all deceased donors.

Figure 50 Proportion of Lungs Transplanted From Deceased Donors, Canada, 1996 to 2005 (Percentage)



	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
Both Lungs Transplanted	11.2	13.8	12.7	14.3	18.7	19.8	22.5	22.2	23.5	28.5
One Lung Transplanted	6.2	5.8	5.8	5.0	5.7	6.2	5.1	3.5	4.8	3.1

There is no nationally applied algorithm for the sharing of donor lungs across Canada. In most provinces, lungs used by transplant programs were recovered from the OPOs in that province (Table 56). The Edmonton Lung Transplant Program (Alberta) continued to utilize the highest proportion of lungs from OPOs in the United States. In contrast, Quebec transplant programs were most likely to utilize lungs recovered from donors identified by Quebec Transplant. The Quebec transplant programs also shared the highest number of organs with other lung transplant programs across Canada.

Table 56 Origin and Destination of Transplanted Lungs, Canada, 2003 to 2005

Retrieval Province	Treated Province					Total
	B.C.	Alta.	Man.	Ont.	Que.	
British Columbia	20	7	1	5	0	33
Alberta	4	43	3	3	0	53
Saskatchewan	0	19	2	0	0	21
Manitoba	0	0	10	0	0	10
Ontario	1	5	4	127	4	141
Quebec	0	0	0	19	69	88
New Brunswick	0	1	0	13	1	15
Nova Scotia	0	0	0	7	1	8
Newfoundland and Labrador	0	0	0	5	0	5
United States	1	10	0	8	0	19
Total	**26**	**85**	**20**	**187**	**75**	**393**

Note:
Shaded cells show local organs used for transplantation.

As previously noted, the age of deceased donors increased over the decade. The sex distribution and age characteristics of deceased lung donors varied according to the use of the organs for transplantation (Table 57). Donors used for single-lung transplants were more likely to be male. Where both lungs were transplanted into the same recipient, there was a fairly even distribution between male (50.5%) and female (49.5%) donors. The heart–lung donors were also the youngest in average age (31.4 years), compared to the oldest average age donor group, comprised of those donors where both lungs were utilized for transplant into different recipients (39.3 years).

Table 57 Deceased Lung Donors by Lungs Used for Transplantation, Donor and Age, Canada 1996 to 2005

	Percentage Male	Mean	Std.	Min.	Max.
Both Lungs—Different Recipients	55.6	39.3	15.5	12	62
Both Lungs—Same Recipient	50.5	38.6	16.1	5	77
One Lung	60.7	36.4	13.1	14	65
Heart–Lung	49.0	31.4	13.7	10	62

As noted in Section 8, the causes of death for donors have changed over time, with an increase in the number of donor organs transplanted after death caused by cerebrovascular accidents and strokes. Concurrently, there was a decrease in the number of organs from donors whose death was caused by motor vehicle collisions. When examined by the mode of use of the lungs for transplant, there were differences observed in the cause of donor death (Table 58). The smallest proportion of organs utilized in each of the transplant uses were when death was caused by gunshot, or "other" causes. Notably, heart–lung donors had proportionately fewer deaths from cerebrovascular accidents and strokes than those in the other utilization groups.

Table 58 Deceased Lung Donors by Lungs Used for Transplantation and Donor Cause of Death, Canada, 1996 to 2005

Cause of Death	Both Lungs—Different Recipients		Both Lungs—Same Recipient		One Lung		Heart–Lung	
	N	%	N	%	N	%	N	%
Anoxia/Hypoxia	7	11	40	5	10	6	2	4
CVA/Stroke	38	60	393	53	71	46	19	39
Other Trauma	7	11	92	12	25	16	7	14
Motor Vehicle Collision	4	6	146	20	40	26	15	31
Other	3	5	34	5	4	3	3	6
Gunshot	3	5	25	3	4	3	2	4
Unknown	1	2	13	2	1	1	1	2
Total	**63**	**100**	**743**	**100**	**155**	**100**	**49**	**100**

6. Pancreas Transplantation

ESRD patients with underlying diabetes have two serious conditions, each of which may require different treatments. For kidney failure, patients need renal replacement therapy. For diabetes, therapy must regulate glycemia. Pancreas transplantation offers those with type 1 diabetes the prospect of complete insulin independence and the stabilization of some diabetes-related complications.[18, 19] While novel therapies such as the insulin pump and islet cell transplants have received much attention, pancreas transplantation provides stable long-term normoglycemia with normal or near-normal glucose tolerance, while avoiding hypoglycemic episodes.[20, 21] Pancreatic transplantation was first performed in 1996 at University of Minnesota. Since that time, it has evolved from an experimental alternative to a well-recognized treatment for diabetic patients on dialysis who have difficulty maintaining control of insulin levels through other medical means.[22]

Three types of pancreas transplant related to recipient indications have been defined. The most common is a combined kidney–pancreas transplantation (SKP) for ESRD recipients. Less common are pancreas transplants performed after kidney transplant, usually with a live donor kidney (PAK) or alone, for early complications or hypoglycemia unawareness (PTA). In Canada, the transplant rate to date has generally lagged behind that of the United States and some European countries.[23] 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.

6.1 Activity

As of December 31, 2005, 19,000 pancreas transplants had been performed in the United States and almost 6,000 in other countries.[25] Between 1996 and 2005, there were 553 pancreas transplants recorded in Canada (Table 59). Over two-thirds of these transplant procedures involved SKP transplantation (406), about 5.8% were performed as single (alone—PTA) pancreas transplantations (32), and in 115 patients, a pancreas transplant was performed following a kidney transplant (PAK). Five transplants involved second pancreas grafts.

Table 59 Pancreas Transplants by Year, Canada, 1996 to 2005 (Number)

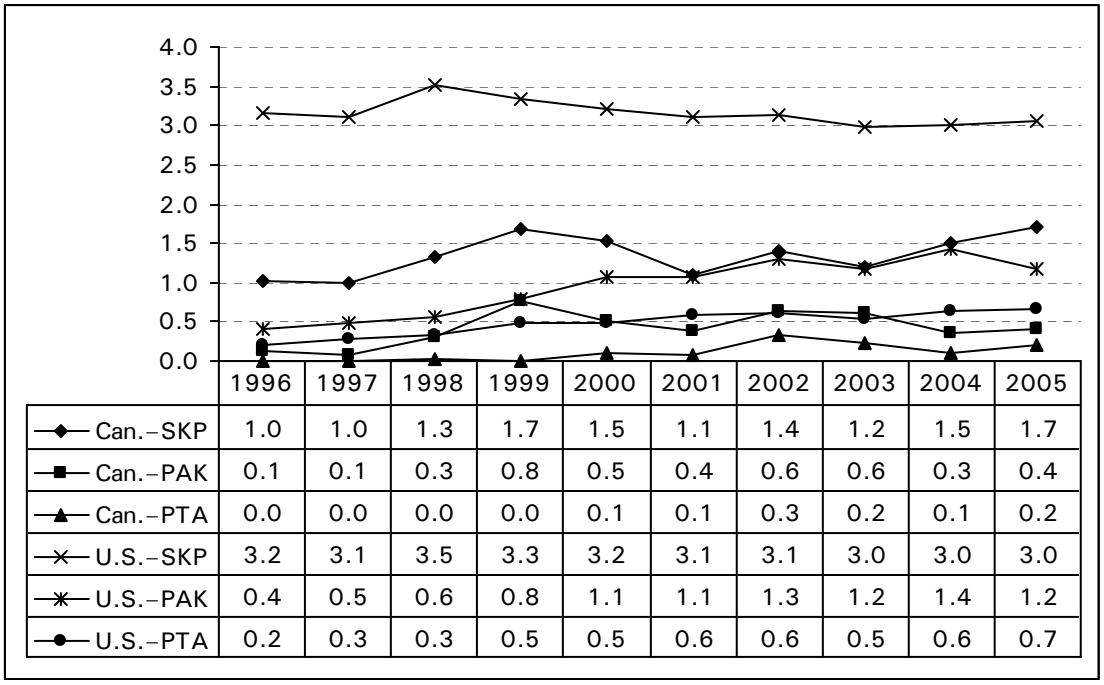
	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	Total
Simultaneous Pancreas—Kidney (SKP)	19	30	40	51	47	34	44	39	47	55	406
Pancreas After Kidney (PAK)	2	3	8	18	14	12	18	17	11	12	115
Pancreas Transplant Alone (PTA)	0	0	1	0	3	2	10	7	3	6	32
Total	**21**	**33**	**50**	**74**	**66**	**48**	**76**	**65**	**61**	**74**	**553**

Pancreas transplant programs were in existence in five provinces during the period: Nova Scotia, Quebec, Ontario, Alberta and British Columbia. For the years 2002 and 2003, pancreas transplants for residents of the Atlantic provinces were performed in either Quebec or Ontario. The majority of pancreas transplants over the decade were performed in either Ontario (184) or Quebec (157), accounting for 62% of the total number. In terms of the type of pancreas transplantation performed, 65.0% of the pancreas transplants in Quebec were PAK or PTA transplants, in contrast to the other provinces where up to 90.0% of transplants were SKPs.

6.2 International Comparison

The transplant rate in Canada has generally lagged behind that of the United States and some European countries. Over the decade, SKP, PAK and PTA transplant rates in Canada were lower than rates in the United States (Figure 51). In 2005, the rate in the United States was 4.9 PMP, compared to 2.3 PMP in Canada. The type of pancreas transplant procedure varied somewhat between the two countries with 73.4% (SKP), 20.7% (PAK) and 5.8% (PTA) in Canada, compared to 65.5% (SKP), 25.1% (PAK) and 9.4% (PTA) in the United States.

Figure 51 Pancreas Transplants by Type, Canada and United States, 1996 to 2005 (Crude Rate PMP) AK performed in the United States



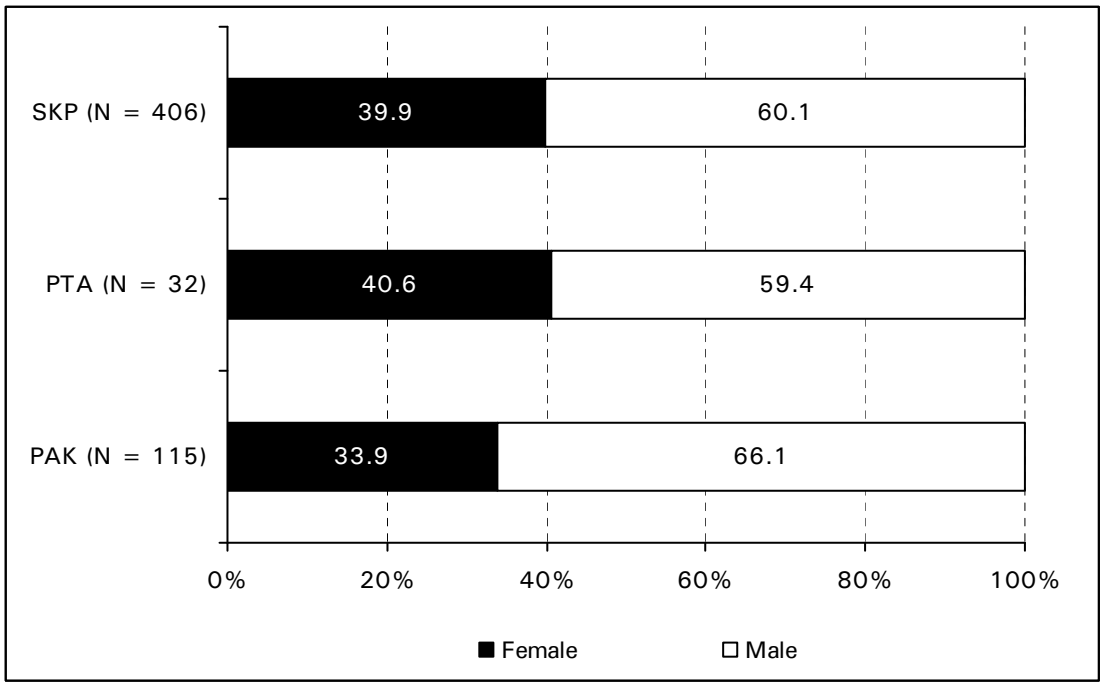
	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
Can.–SKP	1.0	1.0	1.3	1.7	1.5	1.1	1.4	1.2	1.5	1.7
Can.–PAK	0.1	0.1	0.3	0.8	0.5	0.4	0.6	0.6	0.3	0.4
Can.–PTA	0.0	0.0	0.0	0.0	0.1	0.1	0.3	0.2	0.1	0.2
U.S.–SKP	3.2	3.1	3.5	3.3	3.2	3.1	3.1	3.0	3.0	3.0
U.S.–PAK	0.4	0.5	0.6	0.8	1.1	1.1	1.3	1.2	1.4	1.2
U.S.–PTA	0.2	0.3	0.3	0.5	0.5	0.6	0.6	0.5	0.6	0.7

Data source for the U.S.: Department of Health and Human Services (Health Resources and Services Administration, Healthcare Systems Bureau, Division of Transplantation), United Network for Organ Sharing and University Renal Research and Education Association, *2006 Annual Report of the U.S. Organ Procurement and Transplantation Network and the Scientific Registry of Transplant Recipients: Transplant Data 1996–2005* (Richmond, VA: United Network for Organ Sharing, 2006).

6.3 Recipient Characteristics

The average age of a recipient of first pancreas grafts during the decade was 40.3 years (based on a range of 19 to 75 years). While more males received pancreas transplants, the gender distribution varied by transplant type (Figure 52).

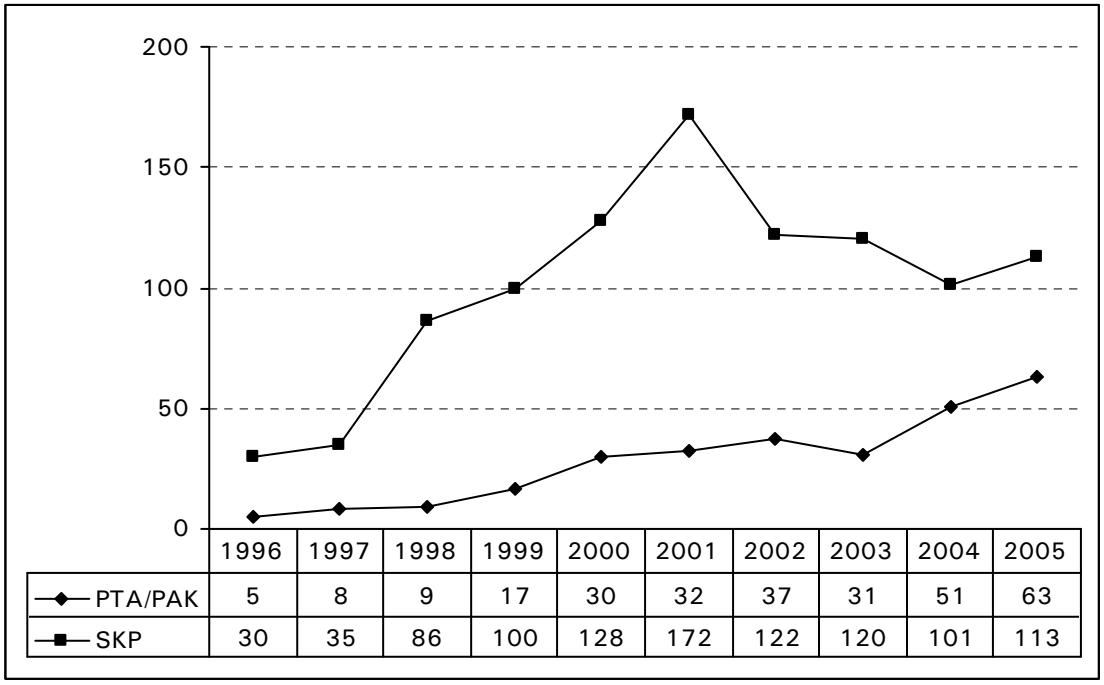
Figure 52 Pancreas Transplant Recipients by Type and Recipient Sex, First Grafts, Canada, 1996 to 2005 (Percent)



6.4 Waiting List and Waiting Times

The number of patients waiting for an SKP transplant spiked at 172 cases at the end of 2001, tapering off to as low as 101 people and back up to 113 in 2005 (Figure 53). The number of patients waiting for a PTA/PAK transplant increased to 63 in 2005, a one-year increase of 23.5%. Over the period, only 18 deaths were recorded for patients on the waiting list for a pancreas or SKP transplant.

Figure 53 Pancreas and Kidney–Pancreas Transplant Waiting List on December 31, Canada, 1996 to 2005 (Number)



	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
PTA/PAK	5	8	9	17	30	32	37	31	51	63
SKP	30	35	86	100	128	172	122	120	101	113

6.5 Outcomes

As a result of the small annual number of PTA and PAK transplants for the years 1996 to 2000, unadjusted patient and graft survival rates were examined only for SKP recipients who received a first transplant in the first five years of the decade (187). Patient survival was 90.9% at five years, and graft survival was lower at 86.4% at five years (Table 60).

Table 60 Unadjusted Three-Month and One-, Three- and Five-Year Patient and Pancreas Graft Survival Rates, First SKP Grafts, Canada, 1996 to 2000

	90-Day	1 Year	3 Years	5 Years
Patient Survival	97.9	96.6	93.1	90.9
Pancreas Graft Survival*	96.1	95.5	90.9	86.4

Note:

* Graft survival is computed from first SKP transplant date to first pancreas graft failure date, death date or end of observation (December 31, 2005). In this analysis, patients who died with a functioning graft are considered as failed grafts.

6.6 Organ Donors

The recovery rates of donor pancreata are imprecise in the register and no mechanism currently exists to comprehensively track islet cell transplants.

The sharing of pancreata for the purposes of solid organ transplantation was minimal from 2001 to 2005. For the vast majority of SKP transplants (94%) and PAK and PTA transplants (90%), the OPO and transplant program were in the same province.

The majority of pancreas donors were males who had died from cerebrovascular accidents/strokes or head trauma caused by involvement in motor vehicle collisions or similar circumstances (Table 61). The average age of pancreas donors was similar for SKP and PAK/PTA transplants at 30 years of age and lower than the average age of recipients (40 years).

Table 61 Pancreas Donor Characteristics by Transplant Type, Canada, 1996 to 2005

	PAK and PTA (N = 147)	SKP (N = 406)
Percentage Male	64.5	63.4
Average Age (Years) (SD)*	28.7 (11.5)	30.2 (11.4)
Age Range	10–53	3–57
Percentage Died From Cerebrovascular Accident/Stroke	49.1	38.3
Percentage Died From Motor Vehicle Collision	22.7	29.5
Percentage Died From Other Head Trauma	17	18.2

Note:
* SD = standard deviation.

7. Intestinal Transplantation[ix]

Intestinal transplantation was first attempted in humans during the 1960s. Early intestinal transplant patients died from technical complications, rejection or infection. At the time, intravenous feeding through total parenteral nutrition (TPN) therapy was not yet available. A new era began in the mid-1980s. The first successful multi-visceral transplant was performed in Pittsburgh in 1987, followed a year later by the first successful small bowel segment performed in Cologne, Germany, and the first successful complete small bowel transplant in Paris, France, in 1989. In Canada, the first successful liver–bowel transplantation was performed in London, Ontario, in 1988.

The advent of tacrolimus in 1990 saw the emergence of intestinal transplantation as a viable treatment for intestinal failure. However, in spite of recent advances, intestinal transplantation is a therapeutic option only for patients with intestinal failure whose condition continues to decline in spite of TPN. It is not yet an alternative for patients who are doing well on TPN.

7.1 Activity

In 2005, there were four active intestine transplant programs for patients from across Canada at the following hospitals: the Toronto General Hospital—University Health Network, the Hospital for Sick Children, the London Health Sciences Centre—University Campus and the University of Alberta Hospital—Capital Health.

From the inception of the Canadian register until 2005, there were 38 intestinal transplants registered among 37 recipients (with one patient requiring a retransplant). The transplants occurred between 1988 and 2005 and included 10 multi-visceral, 11 isolated small intestine, 14 liver–small intestine, 2 kidney–small intestine and 1 liver–kidney–small intestine transplants. Nearly two-thirds (or 24 out of 38) were performed in London, Ontario. Two-thirds of the recipients of the solitary small intestine procedures or combined small intestine (with liver or kidney) were younger than 18 years of age (Table 62). However, a cluster transplant (including a small intestine, liver, pancreas and stomach, also known as a multi-visceral transplant), was more likely in patients over 18 years of age. All of the intestinal transplants reported were performed with organs from deceased donors.

ix. 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 1998 and 2005.

Table 62 Intestinal Transplants by Transplant Period and Age Group, Canada, 1988 to 2005 (Number)

Type of Graft	1988 to 1993		1994 to 1998		1999 to 2005		Total	
	<18 Years	18+ Years	<18 Years	18+ Years	<18 Years	18+ Years	<18 Years	18+ Years
Multivisceral (N = 9)	0	2	1	0	1	5	2	7
Isolated Small Intestine (N = 11)	1	0	5	2	2	1	8	3
Liver–Small Intestine (N = 14)	1	4	2	1	6	0	9	5
Kidney–Small Intestine (N = 2)	0	1	0	1	0	0	0	2
Liver–Kidney–Small Intestine (N = 1)	0	0	0	0	1	0	1	0
Total (N = 37)	**2**	**7**	**8**	**4**	**9**	**5**	**20**	**17**

7.2 International Comparison

In 2005, 176 intestinal transplants were performed in the United States,[25] compared to only one in Canada.

7.3 Recipient Characteristics

For the years between 1988 and 2005, the underlying cause of intestinal failure was reported in 31 cases (83.8%). The most frequently reported underlying condition was a metabolic disorder (14 cases), a diagnosis that includes short-gut syndrome.

7.4 Waiting List and Waiting Times

Waiting list data for intestinal transplantation and deaths among patients listed are reported as "other" organ combinations and are therefore considered to be incomplete. Currently, various ways to improve reporting are being investigated with the goal of achieving more comprehensive information.

7.5 Outcomes

Thirteen graft failures were reported from 1988 to 2005. However, causes of graft failure were specified for only three patients. Nineteen intestinal transplant recipients died during the same period, 40% of whom had chronic renal failure reported as the cause of death, while for six patients it was unknown.

7.6 Organ Donors

Small bowels were recovered for transplantation in less than 1% of all deceased donors in Canada. Within the register, donor information was available for 35 out of the 37 intestinal transplants. The age profiles of donors were as follows: aged 1 year or younger (7), age 1 to 17 years (16) and 18 years of age and older (13). Twenty-one donors were female. Twenty of the donors (62%) were identified by the Ontario OPOs.

The cause of death was available for 35 out of the 37 donors, with 11 having died as a result of head injuries sustained from motor vehicle collisions and another 12 after cerebrovascular accidents/strokes.

8. Deceased Organ Donors

Regardless of the location where the organs will be transplanted, a donor is determined by the OPO that recovers the donor organ. 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, which includes donors where organs were recovered, but not transplanted.[24] This distinction is important when making comparisons of deceased-donor rates between countries. The characteristics of deceased organ donors in terms of organs donated are discussed in the organ-specific sections of this report.

As a measure of organ donation activity, "rate PMP" is less than optimal, and its role as an accurate reflection of organ donation activity has been much debated. Calculating a rate using a denominator that reflects the number of potential donors would be a more desired method. Unfortunately, Canada does not yet have a national information system from which the number of potential donors from each province can be reliably identified. Medical chart reviews done at individual hospitals and the much broader work conducted by the Collège des médicins du Québec[25] suggest that there is room to improve the way in which Canada's deceased organ donor rates are determined.

The number of deceased organ donors in Canada has changed very little between 1996 and 2005 (Table 63).[x] Dramatic annual fluctuations may be seen in the number of donors in provinces or ies with populations of less than 2 million.

Table 63 Deceased Organ Donors, Canada and OPO Province, 1996 to 2005

OPO Province	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	Total
British Columbia	48	49	36	41	38	37	30	39	31	25	374
Alberta	53	52	49	54	55	54	54	38	56	46	511
Saskatchewan*	4	13	22	19	13	16	13	17	9	15	141
Manitoba*	27	18	15	9	20	9	11	12	7	6	134
Ontario	150	154	152	133	165	128	137	142	153	148	1,462
Quebec	113	95	120	131	135	135	126	142	137	136	1,270
New Brunswick*	7	13	11	17	11	17	11	12	10	17	126
Nova Scotia*	11	27	9	12	19	9	11	11	9	14	132
Newfoundland and Labrador*	6	8	3	4	15	15	15	10	5	7	88
Total	**419**	**429**	**417**	**420**	**471**	**420**	**408**	**423**	**417**	**414**	**4,238**

Note:

* Denotes province with population of less than 2 million.

x. In this section, "donor data" refers to donors registered within the register from whom at least one organ has been used for transplantation. This may differ slightly from aggregate annual counts provided by OPOs.

The number and characteristics of deceased donors have been affected by socio-demographic factors, such as Canada's aging population and a marked reduction in fatal motor vehicle collisions. The mean age of donors in 1996 was 38.0 years, which rose to 43.7 years in 2005. For the period from 2003 to 2005, the oldest average age for donors was reported in Quebec (47.9 years) and the youngest average age was reported in Manitoba (31.8 years) (Table 64).

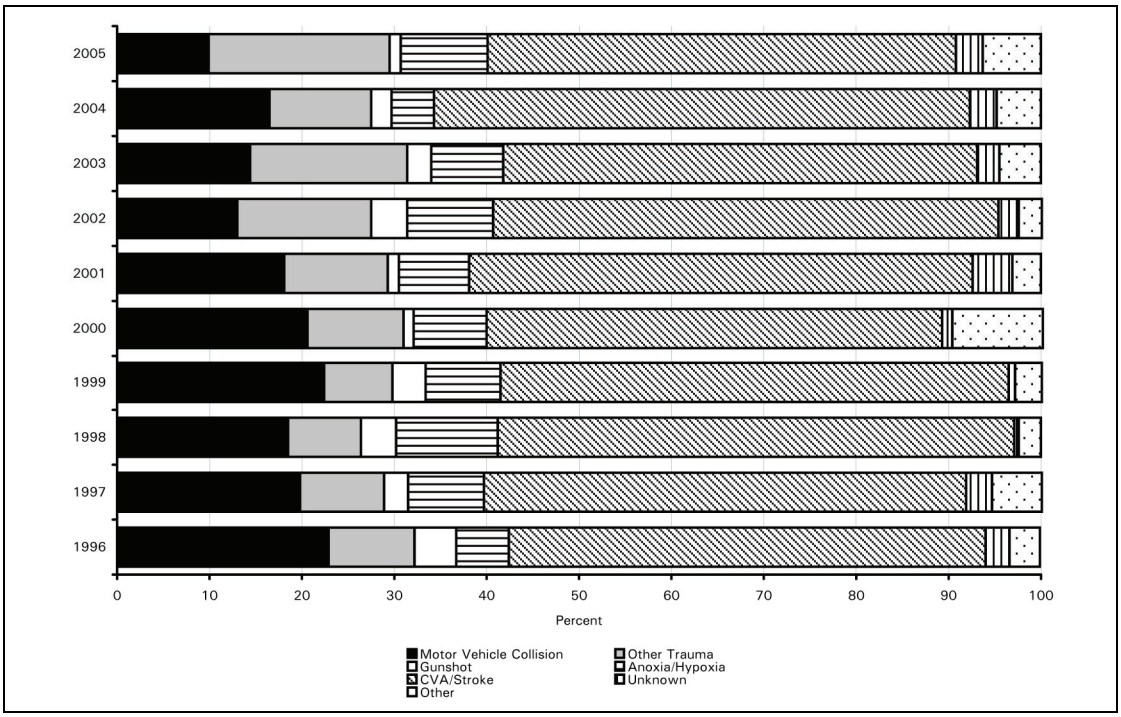
Table 64 Deceased Organ Donors by Age (in Years), OPO Province, 2003 to 2005

	B.C.	Calgary, Alta.	Edmonton, Alta.	Sask.	Man.	Ont.	Que.	N.B.	N.S.	N.L.	Total
Range	<1–79	<1–85	<1–70	3–64	<1–72	<1–89	1–88	8–79	<1–71	14–71	<1–89
Median	44.0	35.5	41.0	42.0	30.0	47.0	50.0	40.0	44.0	38.0	46.0
Mean	39.6	36.8	38.6	37.9	31.8	45.3	47.9	40.5	37.6	41.2	44.0
Std.*	17.9	19.6	18.4	16.5	18.7	18.0	18.9	16.9	18.7	16.2	18.7

Note:
* Std. = standard deviation.

In keeping with the socio-demographic changes and the success of injury prevention programs in Canada, the distribution of the cause of death for donors has changed over the decade. In 2005, cerebrovascular accident/stroke was the most frequent cause of death (50.7%), with a declining proportion of donor deaths due to head injuries sustained from motor vehicle collisions (9.9%). In 1996, these figures had been 51.6% and 22.9% respectively. Between 2004 and 2005, the change in donor deaths due to motor vehicle collisions decreased by 51.4%.

Figure 54 Deceased Organ Donors by Cause of Death, Canada, 1996 to 2005 (Percent)



There was some minor fluctuation in the number of organs transplanted from each deceased donor over the years of the study (Table 65). The peak occurred in 2002, then in 2003 and again in 2005, with 3.7 organs per donor used for transplantation. During the 10-year period, between 3.3 and 3.7 organs were donated per deceased donor. The highest number of organs transplanted per donor was in the donor age group of 15 to 39 years, with 4.6 organs per donor in 2005. The smallest number of organs transplanted per donor was seen in the less-than-one-year-of-age-group, with a rate of one organ (or a partial organ) per donor in 2005.

Table 65 Organs Donated per Deceased Donor by Age Group, Canada, 1996 to 2005

Age Group	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
<1	0	1.0	1.0	2.0	1.3	1.7	0	2.3	1.0	1.0
1–14	3.3	3.3	3.2	3.7	3.3	3.2	3.4	3.6	4.1	3.5
15–39	3.7	3.8	4.2	4.2	4.2	4.4	4.3	4.4	4.5	4.6
40–54	3.5	3.5	3.2	3.6	3.4	3.5	3.8	3.9	3.7	3.9
55–69	2.7	2.7	2.5	2.7	2.7	2.9	3.1	3.0	3.0	3.2
70+	1.2	1.3	1.4	2.1	1.5	1.7	2.0	2.1	1.9	1.9
Total	**3.4**	**3.4**	**3.3**	**3.5**	**3.4**	**3.5**	**3.7**	**3.7**	**3.6**	**3.7**

Note:

* Organ count divided by number of donors per age group. Includes pancreata used for islet cells and organs exported to the United States. Excludes donors where age is missing (less than 0.3% of the data).

9. Pediatric ESRD in Canada: A Review of the Last Quarter Century

ESRD occurring during childhood and adolescence is uncommon, but nevertheless it is an important chronic condition in that it imposes specific challenges for the patient, the family and the health care provider. Research into the psychosocial and socio-economic impacts of ESRD in children concludes that these impacts are substantial and different than those seen in adult patients.[26] In order to appropriately plan for the treatment of these children and to optimize outcomes, knowledge about this particular group is important. While conceptually similar, treatment of ESRD (dialysis and renal transplantation) in children and youth differs in several aspects from dialysis and transplantation in adults. Etiology of disease, pretransplant and surgical considerations and measures of outcome can differ in the pediatric population.[27]

This chapter explores demographic and clinical information about children and youth with ESRD over the last 25 years in Canada. This chapter focuses on the incidence and etiology of ESRD leading to dialysis and/or transplant in the pediatric population, as well as trends in treatment and the outcomes associated with pediatric ESRD, measured by length of time on dialysis, impacts on growth, as well as graft and patient survival rates.

Although many technological and clinical advances have been made in the treatment of ESRD during this period, there are barriers to assessing their use and outcomes in children and youth. They include the need for effectiveness measures that reflect the specifics of a smaller and younger population, as well as differing etiologies of disease compared to adults. The analyses below are performed by age group and include patients from birth to age 19 years undergoing treatment between 1981 and 2005.

The information in this chapter presents the continuum of patient care in pediatric ESRD, beginning with a section on new (incident) patients initiating dialysis treatment, followed by information on the prevalence of ESRD in the pediatric population. The chapter then examines the trends in transplants that are specific to the pediatric population in Canada.

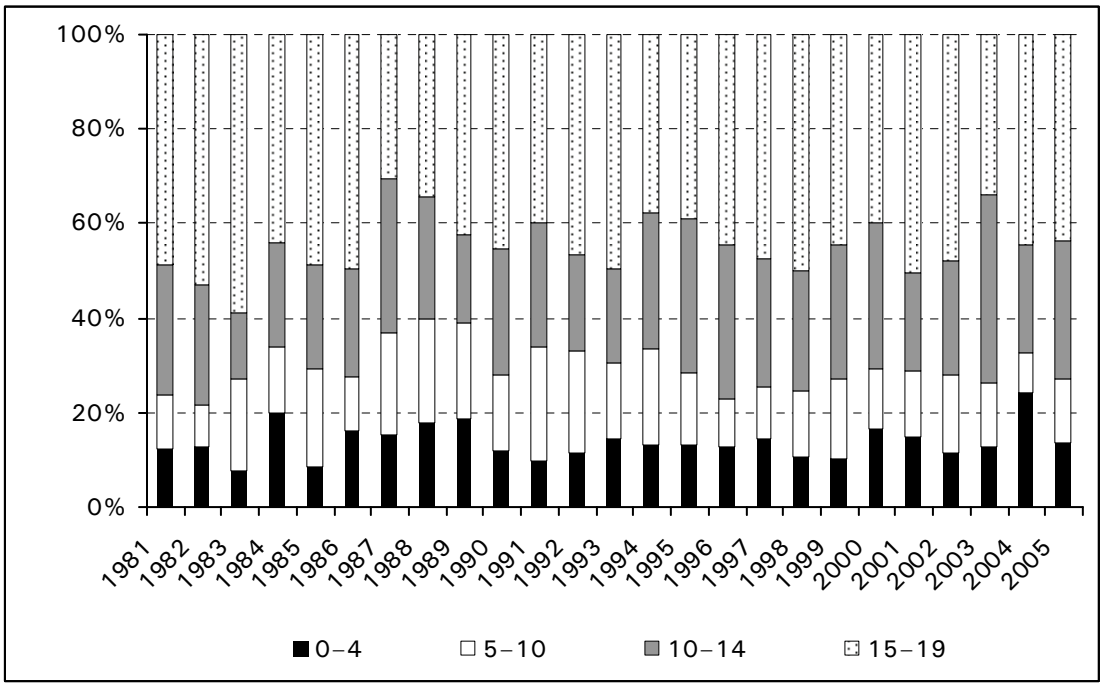
9.1 Incident Pediatric RRT Treatment

Incident treatment for ESRD refers to new cases diagnosed and initiating RRT each year. The period of observation for children and youth (aged birth to 19 years) has shown considerable stability, with an average of 85 (SD 10.1) incident cases initiating treatment each year. In 1981, the number of new cases, which was 80, increased to 96 by 2005. Of the newly diagnosed pediatric patients, 54% were male. The number of newly diagnosed children and youth has remained quite stable over the entire period. It has fluctuated from year to year showing no apparent trend in either direction or magnitude, with a range of new pediatric patients between a low of 66 and a high of 103 per year (Table 66).

Table 66 Number of New ESRD Patients, Birth to 19 Years, Canada, 1981 to 2005

Year	Age Groups				
	0–4	5–10	10–14	15–19	Total
1981	10	9	22	39	80
1982	9	6	18	37	70
1983	5	13	9	39	66
1984	17	12	19	38	86
1985	6	15	16	35	72
1986	14	10	20	43	87
1987	12	17	26	24	79
1988	15	19	22	29	85
1989	16	17	16	36	85
1990	11	15	25	42	93
1991	8	20	22	33	83
1992	10	19	18	41	88
1993	13	14	18	44	89
1994	9	14	20	26	69
1995	13	15	32	38	98
1996	9	7	23	31	70
1997	13	10	25	43	91
1998	9	12	22	43	86
1999	9	15	25	39	88
2000	17	13	32	41	103
2001	15	14	21	51	101
2002	10	14	21	41	86
2003	11	12	35	30	88
2004	18	6	17	33	74
2005	13	13	28	42	96
Total	**292**	**331**	**552**	**938**	**2,113**

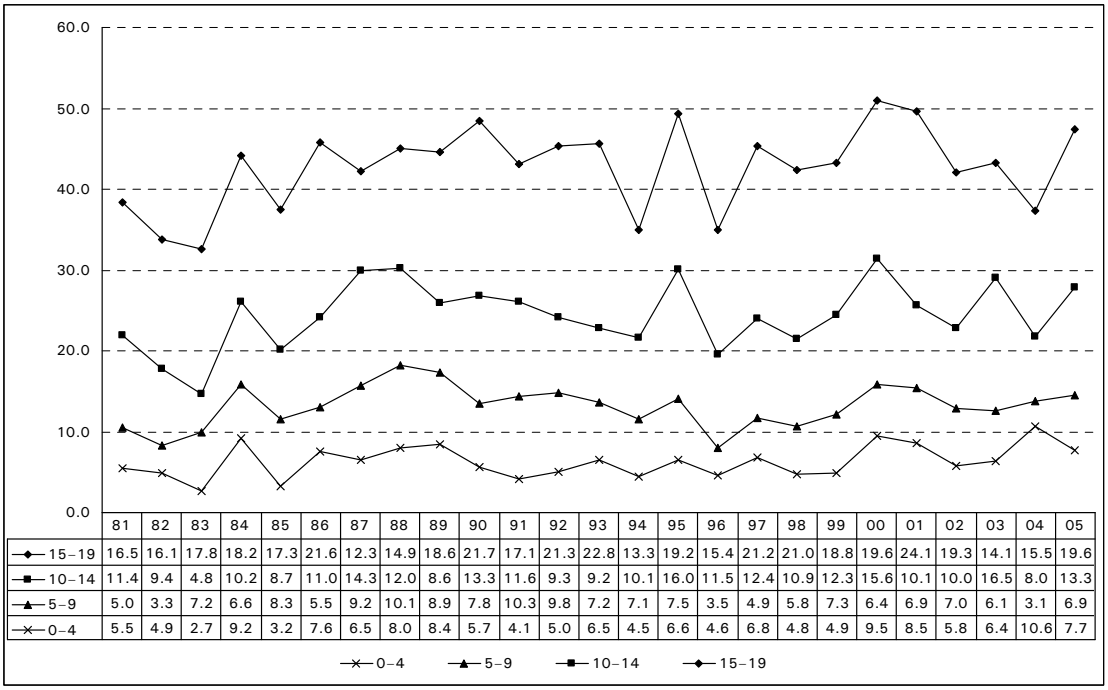
Figure 55 Proportion of New ESRD Patients, Birth to 19 Years, Canada, 1981 to 2005



Demographic changes in the entire Canadian population over the time of study must be considered when trends in both rates and crude numbers are examined. During the 25 years of study (1981 to 2005), there were changes in the composition of the Canadian population by age group. In regard to the age group under 19 years, the Canadian population was relatively stable, with a decrease of about 0.9% in the 25-year period.

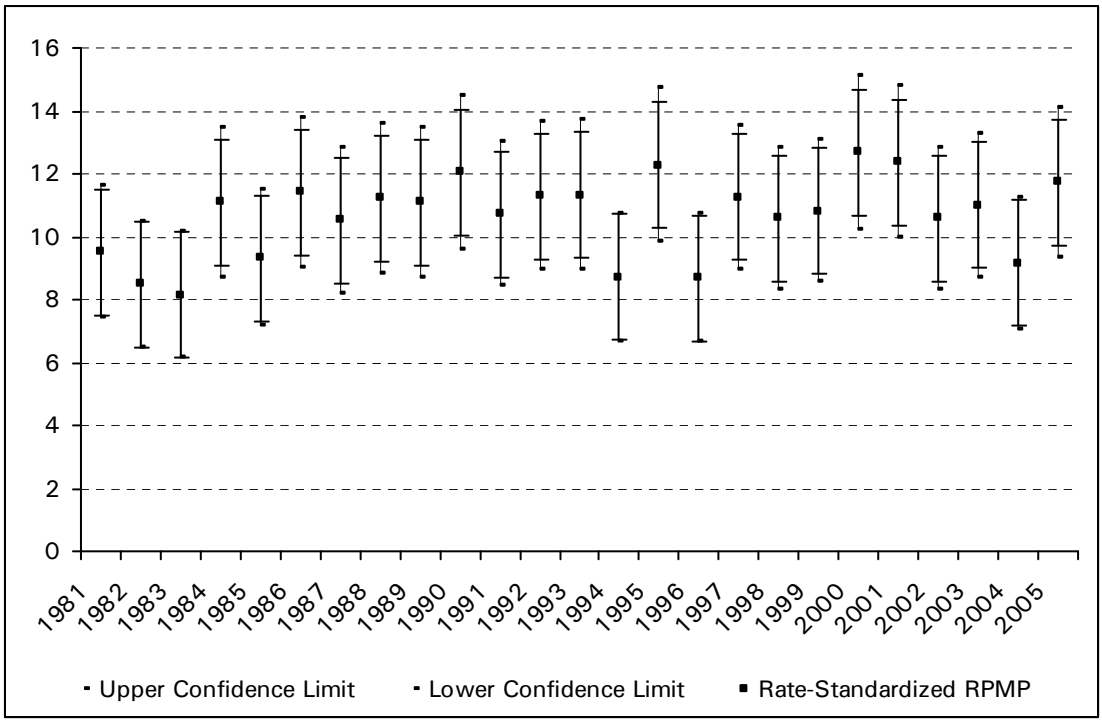
Over this period, the rate per million population (PMP) of incident ESRD patients initiating treatment have remained relatively stable for most age groups (figure 56 and 57).

Figure 56 Age-Specific Incident RPMP in ESRD Patients (Birth to 19 Years) in Canada, 1981 to 2005



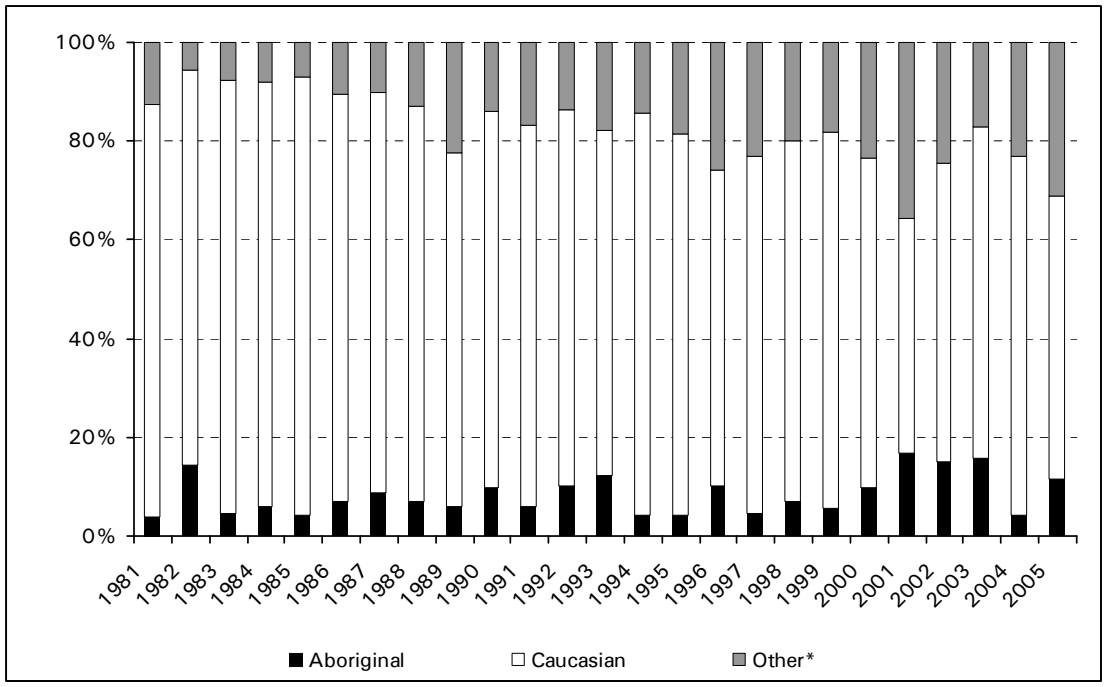
	81	82	83	84	85	86	87	88	89	90	91	92	93	94	95	96	97	98	99	00	01	02	03	04	05
15–19	16.5	16.1	17.8	18.2	17.3	21.6	12.3	14.9	18.6	21.7	17.1	21.3	22.8	13.3	19.2	15.4	21.2	21.0	18.8	19.6	24.1	19.3	14.1	15.5	19.6
10–14	11.4	9.4	4.8	10.2	8.7	11.0	14.3	12.0	8.6	13.3	11.6	9.3	9.2	10.1	16.0	11.5	12.4	10.9	12.3	15.6	10.1	10.0	16.5	8.0	13.3
5–9	5.0	3.3	7.2	6.6	8.3	5.5	9.2	10.1	8.9	7.8	10.3	9.8	7.2	7.1	7.5	3.5	4.9	5.8	7.3	6.4	6.9	7.0	6.1	3.1	6.9
0–4	5.5	4.9	2.7	9.2	3.2	7.6	6.5	8.0	8.4	5.7	4.1	5.0	6.5	4.5	6.6	4.6	6.8	4.8	4.9	9.5	8.5	5.8	6.4	10.6	7.7

Figure 57 Age and Sex Standardized Pediatric Incident ESRD (Birth to 19) RPMP in Canada, 1981 to 2005



As in the case of adult ESRD patients, ethnicity is a factor in the etiology of ESRD and may be a factor in differing outcomes. It is important to recognize that the factors associated are complex and multi-faceted. Of interest is the ethnic composition of incident pediatric patients, which has changed over time in that the proportion of Caucasian patients has decreased while the proportion of Aboriginal patients has increased. The most significant change over the 25-year period is in the increasing proportion of ethnic background categorized as "other" that constitutes more than 30% of the total (Figure 58). The high proportion of children classified as "other" is likely to be a reflection of Canada's increasingly multi-cultural population and the fact that the register currently captures a limited number of specified ethnic origins. The different causes of ESRD related to ethnicity will make this information increasingly important.

Figure 58 Incident ESRD Pediatric Patients by Ethnicity, Canada, 1981 to 2005 (Proportion)

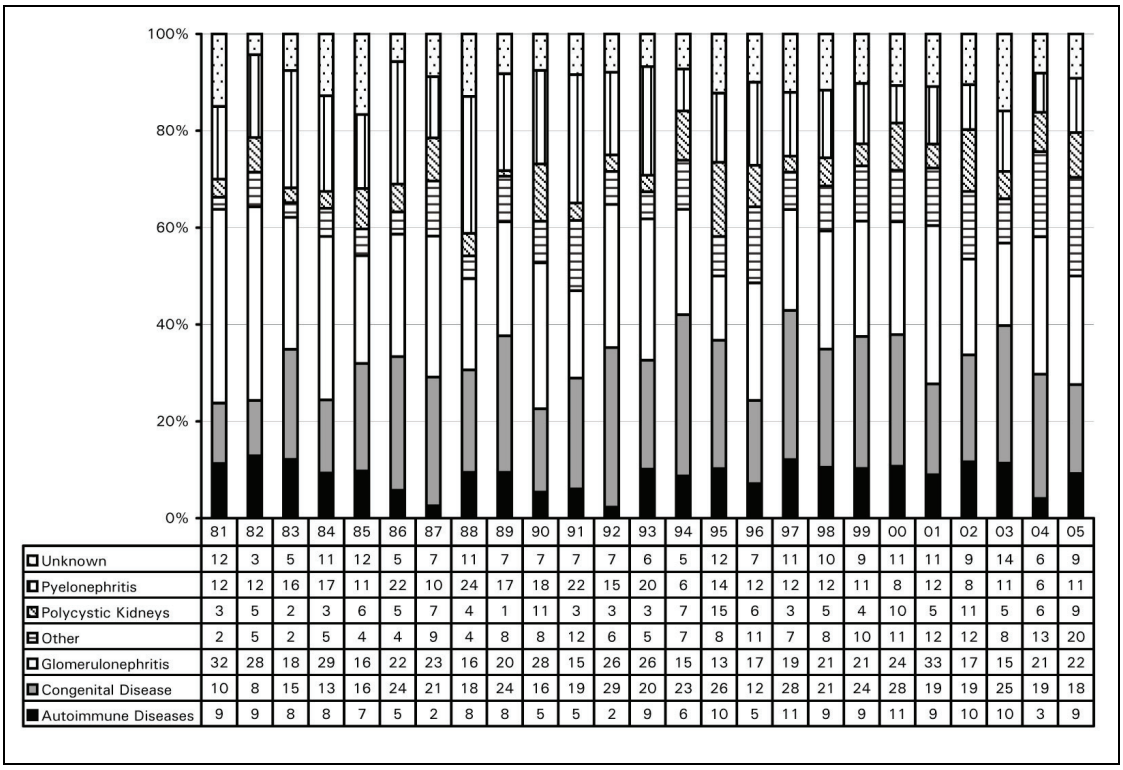


Note:

* "Other" includes Blacks, people with Indian subcontinent origins, Asians, Pacific Islanders, Middle Eastern/Arabians and people with other, multicultural or unknown ethnicity.

The reported causes of ESRD in children and youth have been analyzed. Diagnoses were grouped into seven categories (autoimmune diseases, congenital diseases, glomerulonephritis, polycystic kidney, pyelonephritis, other or unknown), and were analyzed by gender and over time (figures 59 and 60). As in the adult population, the proportion of incident pediatric patients with a diagnosis of glomerulonephritis has dropped considerably since 1981.

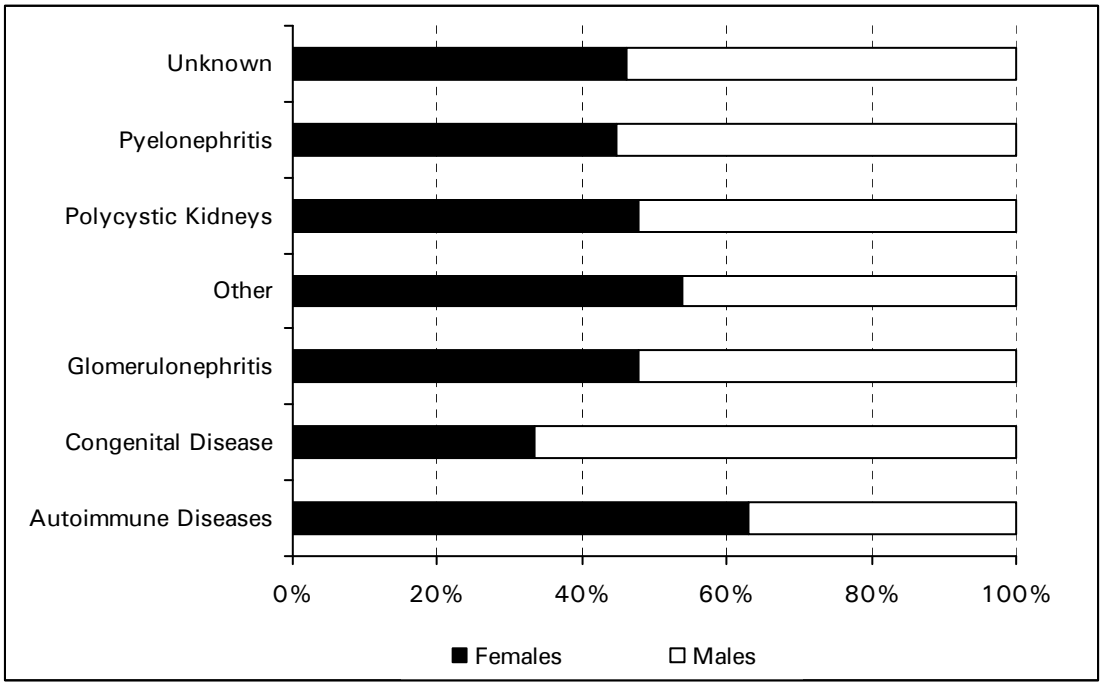
Figure 59 Distribution of Diagnoses in ESRD Patients (Birth to 19 Years), Canada, 1981 to 2005



	81	82	83	84	85	86	87	88	89	90	91	92	93	94	95	96	97	98	99	00	01	02	03	04	05
Unknown	12	3	5	11	12	5	7	11	7	7	7	7	6	5	12	7	11	10	9	11	11	9	14	6	9
Pyelonephritis	12	12	16	17	11	22	10	24	17	18	22	15	20	6	14	12	12	12	11	8	12	8	11	6	11
Polycystic Kidneys	3	5	2	3	6	5	7	4	1	11	3	3	3	7	15	6	3	5	4	10	5	11	5	6	9
Other	2	5	2	5	4	4	9	4	8	8	12	6	5	7	8	11	7	8	10	11	12	12	8	13	20
Glomerulonephritis	32	28	18	29	16	22	23	16	20	28	15	26	26	15	13	17	19	21	21	24	33	17	15	21	22
Congenital Disease	10	8	15	13	16	24	21	18	24	16	19	29	20	23	26	12	28	21	24	28	19	19	25	19	18
Autoimmune Diseases	9	9	8	8	7	5	2	8	8	5	5	2	9	6	10	5	11	9	9	11	9	10	10	3	9

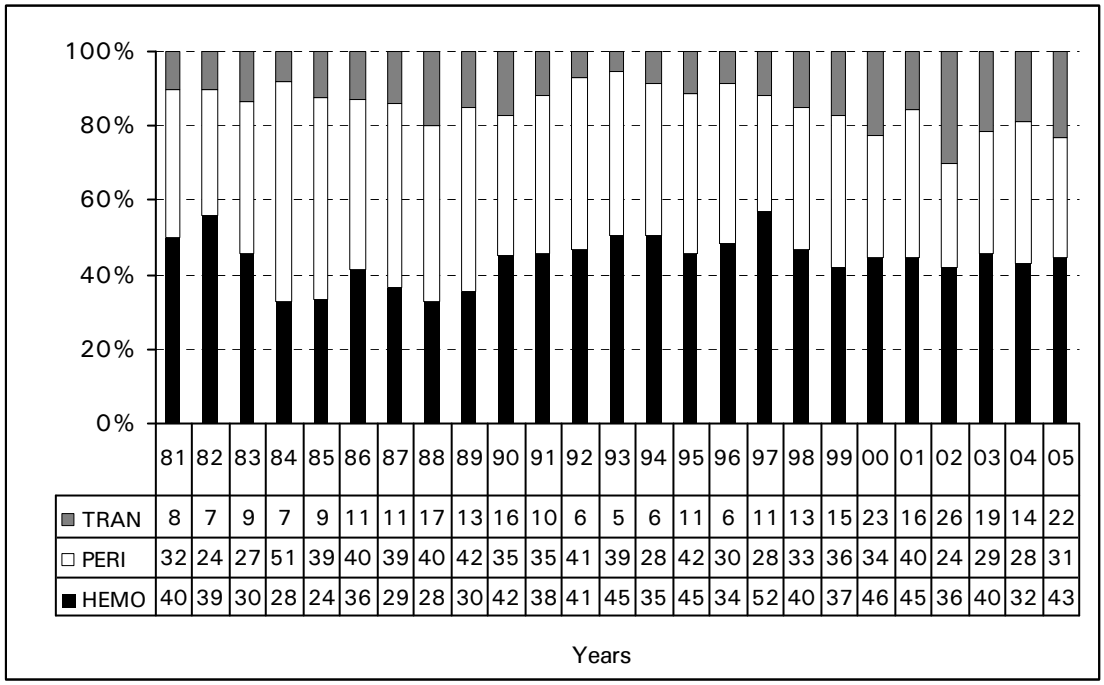
The distribution of diagnosis by gender is similar between males and females for pyelonephritis, polycystic kidney, glomerulonephritis and "other." There is a male predominance in congenital diseases, while females are more highly represented in the autoimmune disease category.

Figure 60 Sex Distribution of ESRD Patients (Birth to 19 Years), Diagnostic Groups, Canada, 1981 to 2005



The majority of pediatric patients start treatment with HD, followed by PD, with a relatively low but growing number of children and youth (175% over the period), being treated with pre-emptive transplantation (Figure 61).

Figure 61 Number and Proportion of Pediatric Patients (Birth to 19 Years) Starting HD, PD and Pre-Emptive Transplantation in Canada, 1981 to 2005



	81	82	83	84	85	86	87	88	89	90	91	92	93	94	95	96	97	98	99	00	01	02	03	04	05
TRAN	8	7	9	7	9	11	11	17	13	16	10	6	5	6	11	6	11	13	15	23	16	26	19	14	22
PERI	32	24	27	51	39	40	39	40	42	35	35	41	39	28	42	30	28	33	36	34	40	24	29	28	31
HEMO	40	39	30	28	24	36	29	28	30	42	38	41	45	35	45	34	52	40	37	46	45	36	40	32	43

In parallel with the growth in pre-emptive transplants and the increase in transplantation as treatment for children with ESRD, there have been considerable changes in the amount of time that children now wait for a transplant. Increasing by 201.6% over the period, the median wait for transplant was just over one year in 2005 (Table 67).

Table 67 Median Days on Dialysis Before the First Kidney Transplant in Patients, Birth to 19 Years, by Year of Dialysis, 1981 to 2005

Year	N	Days on Dialysis (Median)
1981	37	123.0
1982	45	187.0
1983	52	192.5
1984	53	217.0
1985	60	217.0
1986	63	124.0
1987	64	287.0
1988	68	235.5
1989	66	311.0
1990	71	202.0
1991	58	276.0
1992	56	277.5
1993	61	379.0
1994	54	432.5
1995	64	265.5
1996	40	322.5
1997	75	407.0
1998	55	316.0
1999	70	428.0
2000	88	324.0
2001	64	274.5
2002	74	182.5
2003	64	276.0
2004	64	403.0
2005	76	371.0

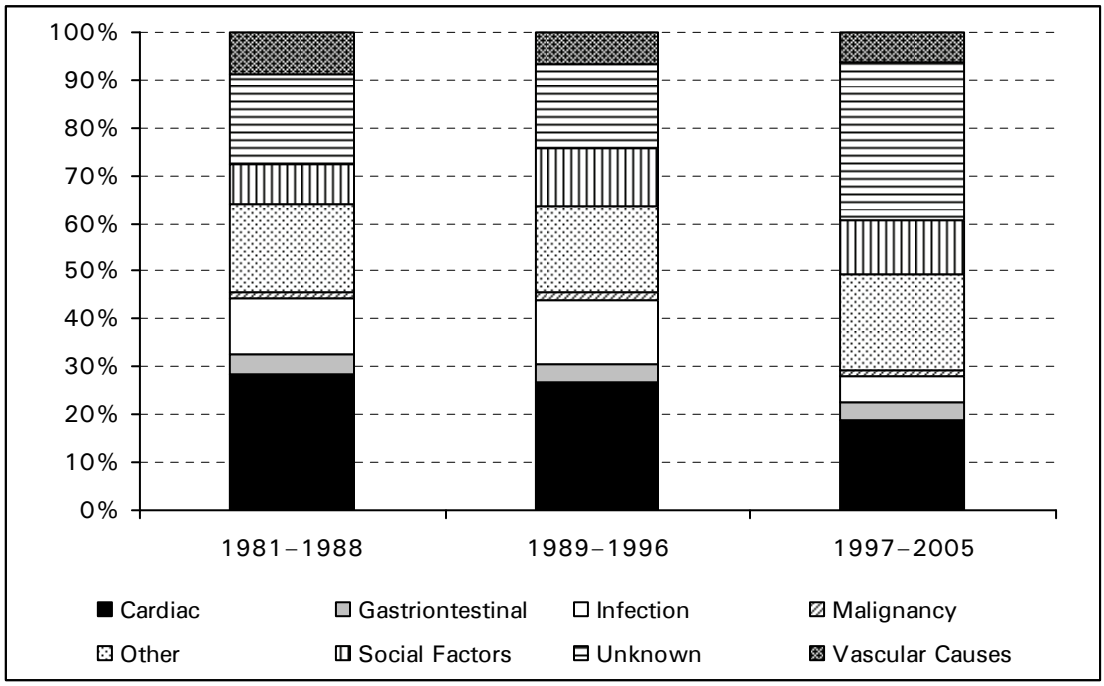
Out of 2,114 cases receiving treatment for ESRD in the 25-year period, there were 381 deaths in the children and youth group. When the causes of death were specified, the leading cause was cardiac, accounting for nearly one quarter of the deaths. Vascular causes, infection and social factors remained as important causes of death in this patient population (Table 68).

Table 68 Cause of Death in Incident ESRD Patients (Birth to 19 Years), Canada, 1981 to 2005

Cause of Death	N	Percentage
Cardiac	95	24.9
Vascular Causes	77	20.2
Other	66	17.3
Infection	47	12.3
Social Factors	46	12.1
Unknown	30	7.9
Gastrointestinal	14	3.7
Malignancy	6	1.6

When the cause of death was specified, the proportion of children and youth who died as a result of cardiac causes decreased over the time studied, along with the proportion of deaths resulting from infection. However, there were a large and growing proportion of deaths from unknown causes.

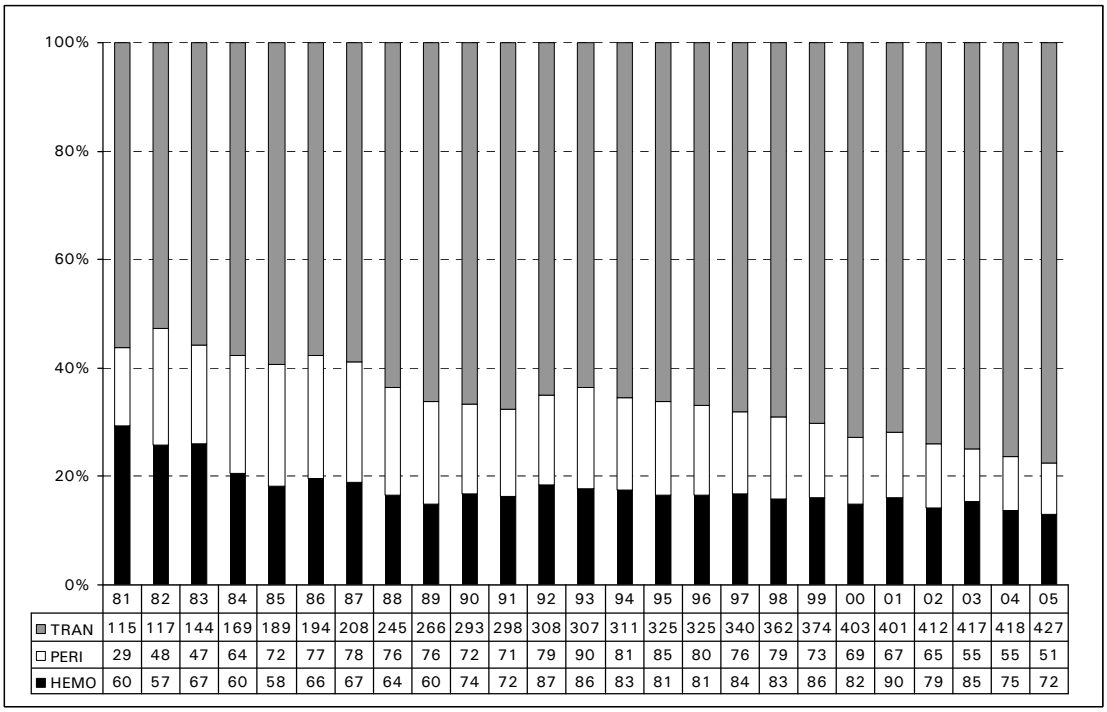
Figure 62 Causes of Death in Incident Pediatric ESRD Patients Over Time, 1981 to 2005 (Proportion)



9.2. Prevalent Pediatric Patients

Between 1981 and 2005, the number of children and youth being treated for ESRD continued to climb each year, from 204 in 1981 to 550 in 2005. In 2005, the largest proportion, just under 80% of prevalent patients in this age group, were treated through transplantation. As a proportion of pediatric ESRD patients, the number receiving transplants more than tripled between 1981 and 2005. In contrast, the proportion of those prevalent pediatric patients being treated with dialysis (HD and PD) decreased significantly from 43.6% (1981) to 22.4% (2005) (Figure 63).

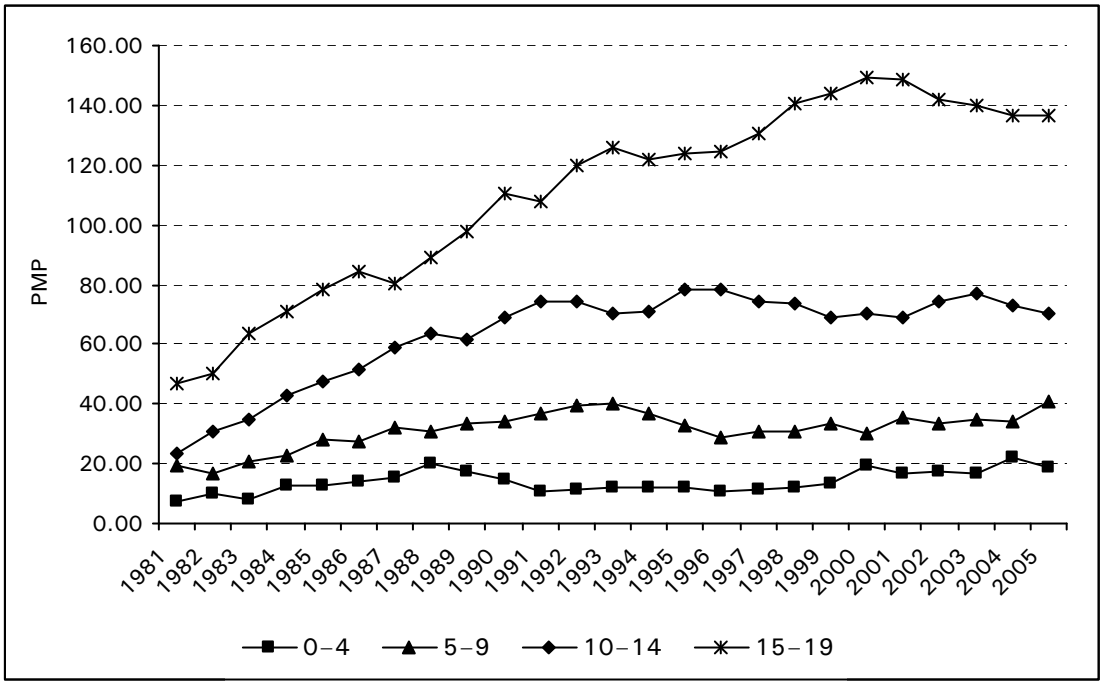
Figure 63 Prevalent Patients, Birth to 19 Years, Type of Treatment by Year, Canada, 1981 to 2005 (Number, Percentage)



	81	82	83	84	85	86	87	88	89	90	91	92	93	94	95	96	97	98	99	00	01	02	03	04	05
TRAN	115	117	144	169	189	194	208	245	266	293	298	308	307	311	325	325	340	362	374	403	401	412	417	418	427
PERI	29	48	47	64	72	77	78	76	76	72	71	79	90	81	85	80	76	79	73	69	67	65	55	55	51
HEMO	60	57	67	60	58	66	67	64	60	74	72	87	86	83	81	81	84	83	86	82	90	79	85	75	72

The rates measuring the prevalence of ESRD in the pediatric age groups fluctuated throughout the period, with the most pronounced increase in the oldest age group of 15 to 19 years of age (Figure 64).

Figure 64 Age-Specific Prevalent RPMP in ESRD Patients (Birth to 19 Years), Canada, 1981 to 2005



When examined by treatment type, the RPMP for prevalent pediatric patients on dialysis rose through the 25-year period, peaking in 1993 and then decreasing through the latter part (Figure 65). In contrast, the RPMP for transplant in this population showed a steady and continuing upward trend throughout the entire period, with a more than four-fold increase (Figure 66).

Figure 65 Age and Sex Standardized RPMP of Prevalent Patients on Dialysis, Birth to 19 Years, Canada, 1981 to 2005

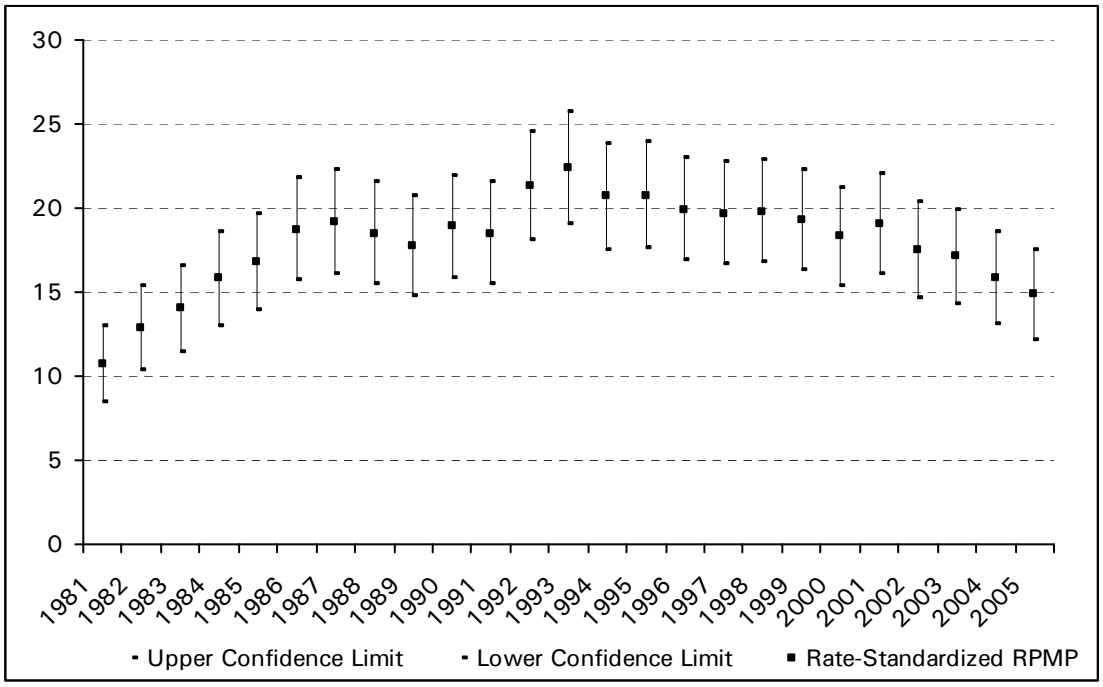
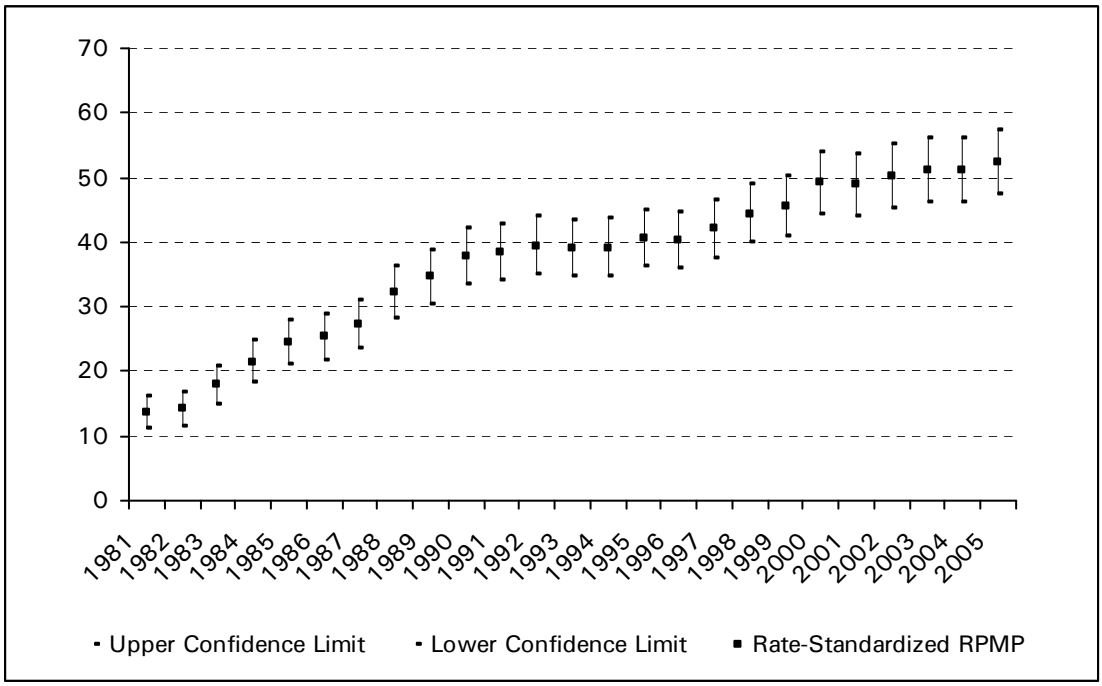
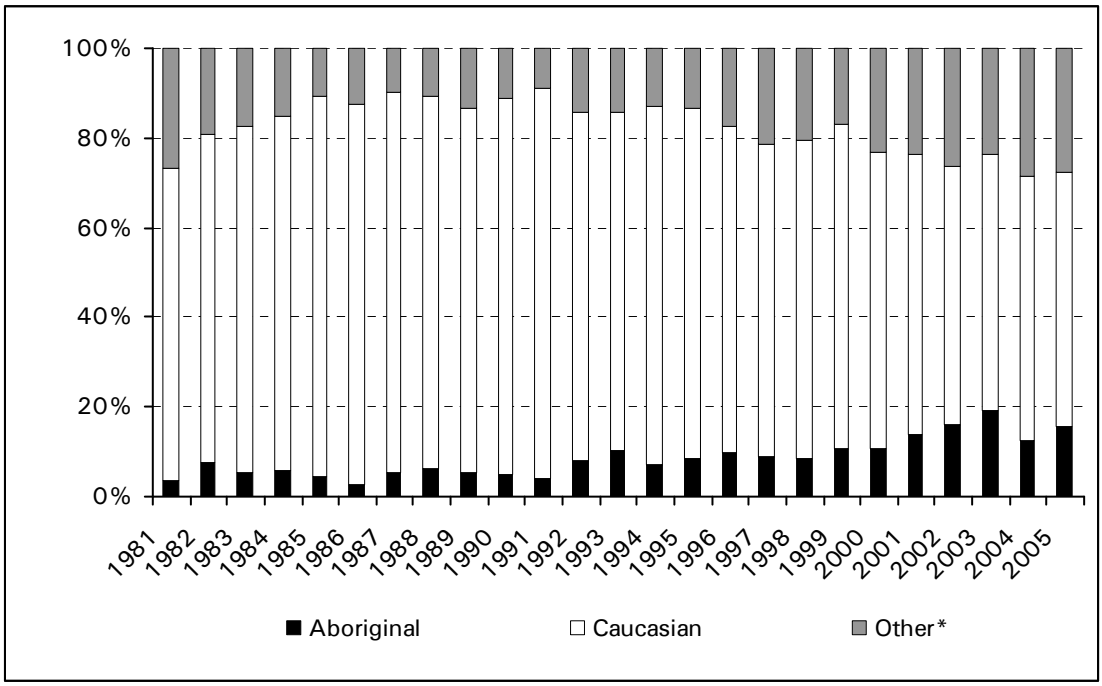


Figure 66 Age and Sex Standardized RPMP of Prevalent Patients, Birth to 19 Years, With Functioning Transplant, Canada, 1981 to 2005



Figures 67 and 68 illustrate the proportion of pediatric patients by ethnicity who received either dialysis or transplant during the time of study. While Caucasian patients continued to make up the majority of patients, the proportion dropped both for dialysis and transplant. The proportion of Aboriginal patients on dialysis increased to 15% of the pediatric dialysis population in 2005, while this group increased only marginally as a proportion of those being treated by transplant. Although there was a rise in incident Aboriginal ESRD pediatric patients in 2001 to 2003 (Figure 58), a corresponding rise in functional transplants in Aboriginal ESRD pediatric patients was not observed (Figure 68).

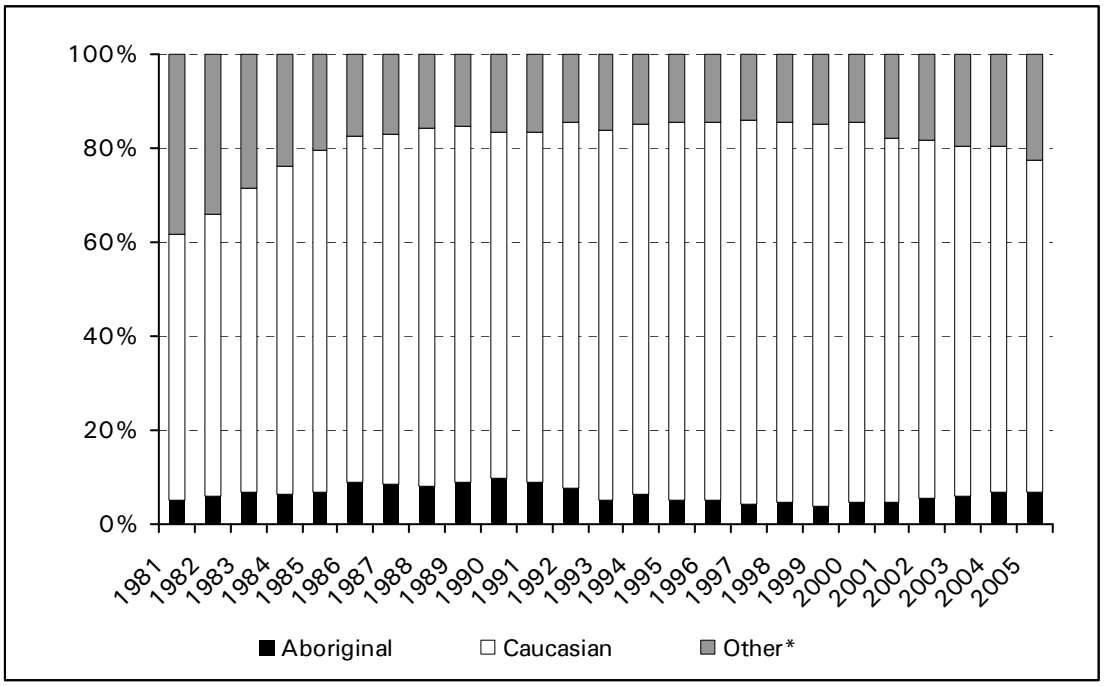
Figure 67 Prevalent Pediatric Patients on Dialysis by Ethnicity in Canada, 1981 to 2005 (Proportion)



Note:

* "Other" includes Blacks, people with Indian subcontinent origins, Asians, Pacific Islanders, Middle Eastern/Arabians and people with other, multicultural or unknown ethnicity.

Figure 68 Prevalent Pediatric Patients With Functioning Kidney Transplant by Ethnicity in Canada, 1981 to 2005 (Proportion)



Note:

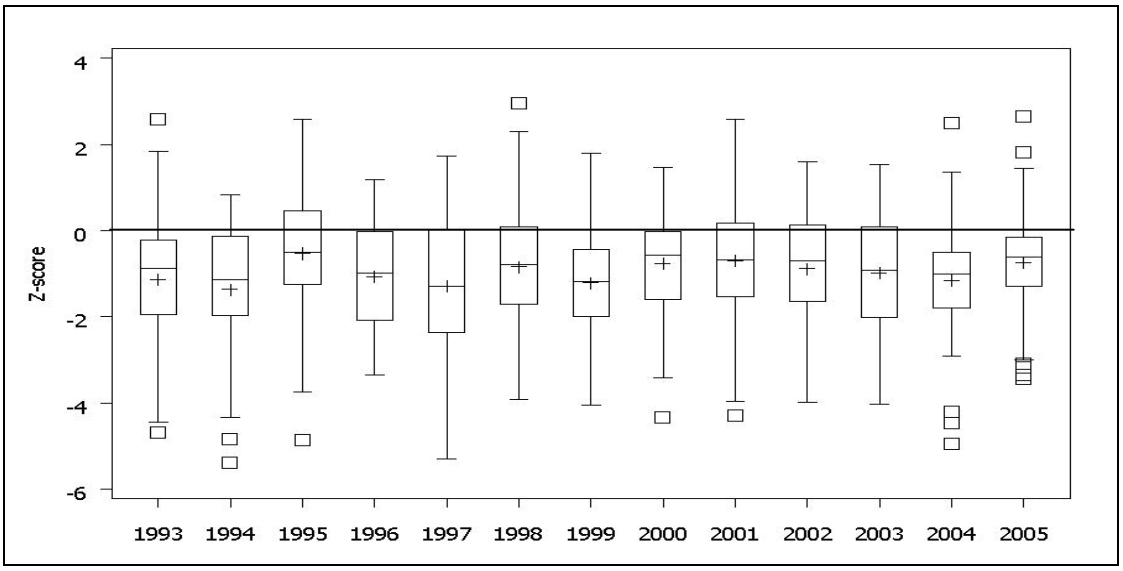
* "Other" includes Blacks, people with Indian subcontinent origins, Asians, Pacific Islanders, Middle Eastern/Arabians and people with other, multicultural or unknown ethnicity.

9.2.1 Trends in Growth in Pediatric Kidney Failure in Canada

One of the important issues facing both pediatric ESRD patients and their health care providers is that of compromised linear growth. Although growth hormone therapy has been demonstrated to be effective in improving growth in pediatric ESRD, according to the literature it is not optimally utilized.[28, 29] In addition, numerous other factors, including acid-base disturbances, inadequate nutrition, anemia and renal osteodystrophy, may impair growth.[30] As a result, growth retardation remains a serious problem for Canadian children with chronic kidney disease.

Figure 69 shows the distribution of height-for-age z-scores at the time of initial treatment for ESRD in pediatric dialysis patients in Canada, and therefore reflects growth prior to starting dialysis. This information is not available prior to 1993. A z-score of zero indicates the mean for a normal, healthy population. A population with a mean significantly lower than zero, such as the Canadian pediatric dialysis population, demonstrates significant growth retardation. Despite the widespread availability of recombinant human growth hormone since the mid-1990s, there is no evidence of improvements in growth since that time.

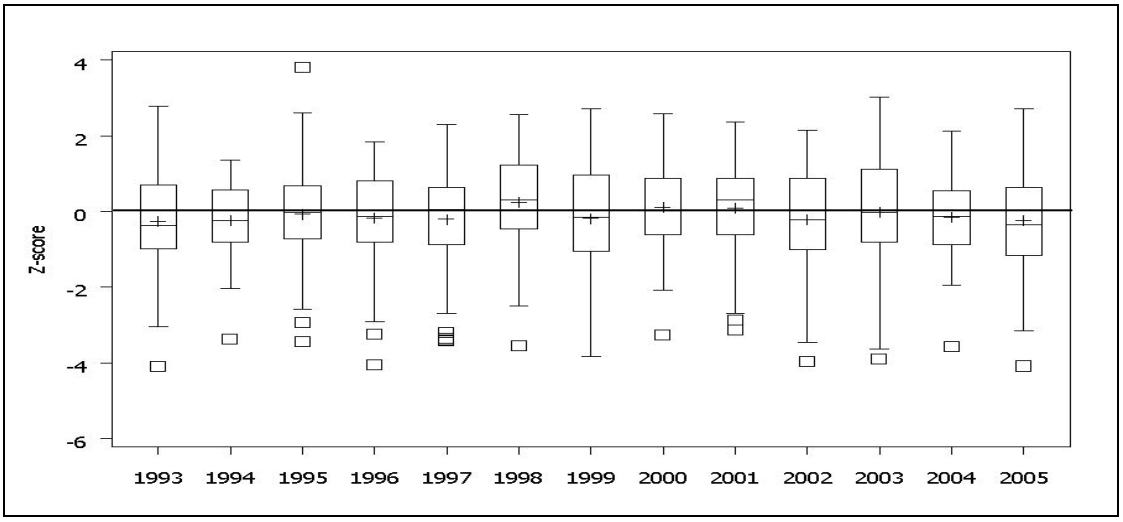
Figure 69 Scores for Height (Age and Sex-Adjusted) in Pediatric Dialysis Patients in Canada, 1993 to 2005



Note:
Relative to the American National Center for Health Statistics reference data.

Body mass index (BMI) provides an estimate of nutritional status. Since normal BMI varies by age, BMI in children is expressed as a z-score, relative to age. The mean BMI z-score for Canadian pediatric dialysis patients has consistently been slightly below zero during the past 13 years (Figure 70). This may suggest that the nutritional status for these patients is relatively good. There is no substantive difference between the BMI z-scores for pediatric dialysis versus transplant patients.

Figure 70 Scores for BMI (Age and Sex-Adjusted) in Pediatric Dialysis Patients in Canada, 1993 to 2005

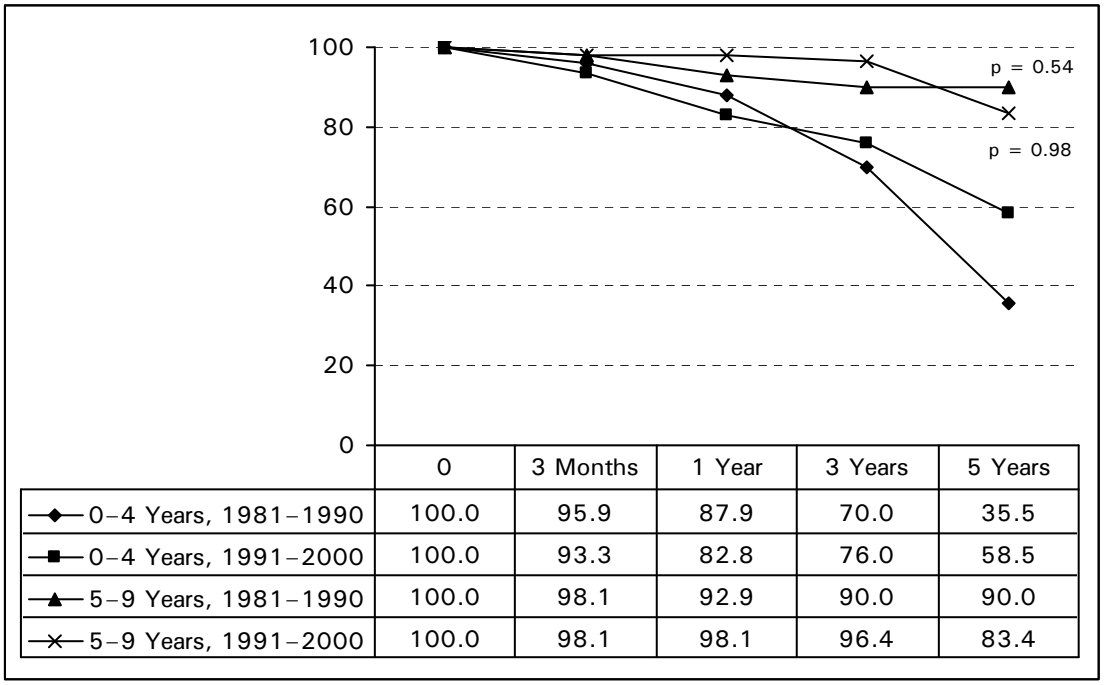


Note:
Relative to the American National Center for Health Statistics reference data.

9.2.2 Outcomes in ESRD Patients Receiving Initial Dialysis Treatment Between 1981 and 2000

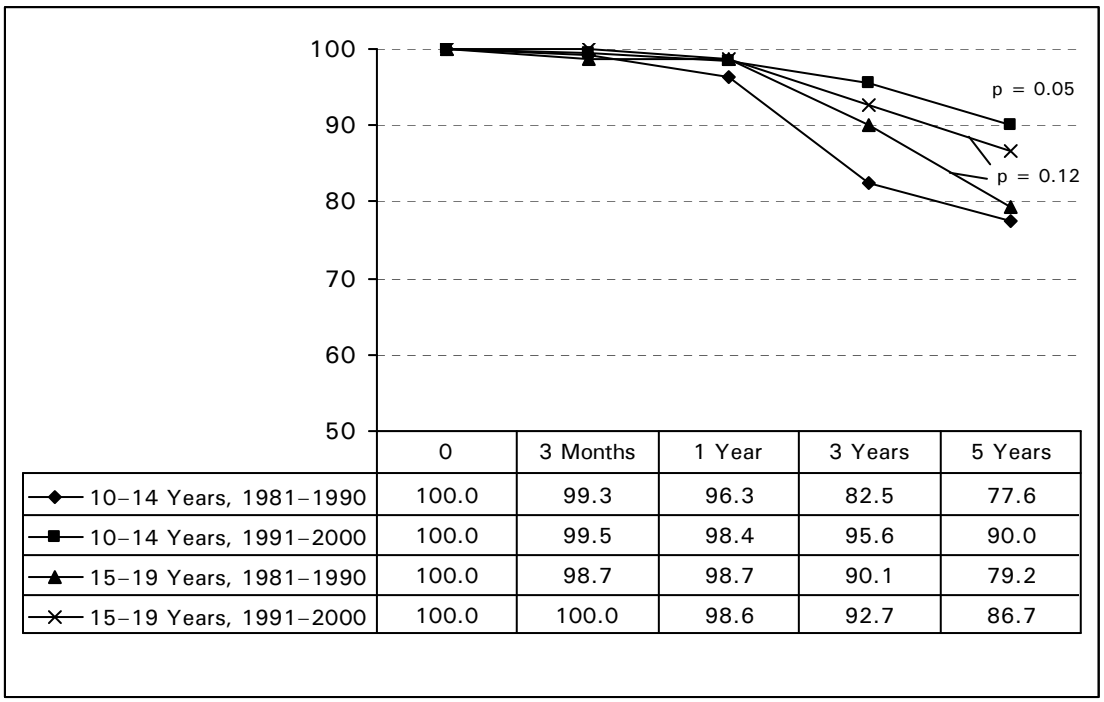
When examined by 10-year periods based on when initial dialysis treatment began (1981 to 1990 and 1991 to 2000), there are slight fluctuations in short-term survival for all age groups and more pronounced differences in long-term survival (three- and five-year periods). Figures 71 and 72 illustrate the survival for the birth-to-9-years age group (Figure 71), and for those 10 to 19 years of age (Figure 72). These are patients who initiated treatment between 1981 and 2000 and who were followed to 2005. The most compromised long-term survival is seen in the youngest age group. While there was a 23% increase in five-year survival between the two decades, this age group continueds to have the lowest survival of any age group (58.5%). The best long-term survival was 90% for those 5 to 9 years of age, initially treated between 1981 and 1990, and for those 10 to 14 years of age, treated between 1991 and 2000. Overall, for this group of patients, the average five-year survival rate in the decade spanning 1981 to 1990 was 72.4%, improving to 83.7% between 1991 and 2000. Other than for the group aged 5 to 9 years of age, all other age groups had improved five-year survival rates in the second decade (1991 to 2000), compared to that achieved in those treated between 1981 and 1990.

Figure 71 Unadjusted Three-Month and One-, Three- and Five-Year Survival in Dialysis Patients, Birth to 9 Years, by Treatment Intervals, 1981 to 2000 (Followed to 2005)



	0	3 Months	1 Year	3 Years	5 Years
0–4 Years, 1981–1990	100.0	95.9	87.9	70.0	35.5
0–4 Years, 1991–2000	100.0	93.3	82.8	76.0	58.5
5–9 Years, 1981–1990	100.0	98.1	92.9	90.0	90.0
5–9 Years, 1991–2000	100.0	98.1	98.1	96.4	83.4

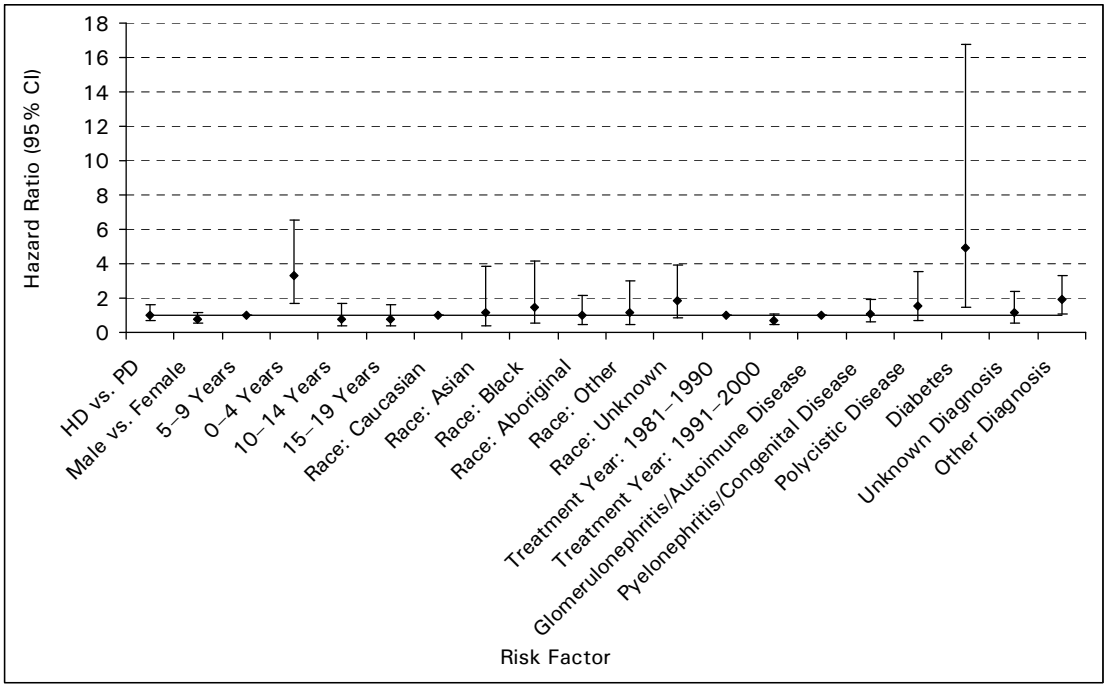
Figure 72 Unadjusted Three-Month and One-, Three- and Five-Year Survival in Dialysis Patients, 10 to 19 years, by Treatment Intervals, 1981 to 2000 (Followed to 2005)



	0	3 Months	1 Year	3 Years	5 Years
10–14 Years, 1981–1990	100.0	99.3	96.3	82.5	77.6
10–14 Years, 1991–2000	100.0	99.5	98.4	95.6	90.0
15–19 Years, 1981–1990	100.0	98.7	98.7	90.1	79.2
15–19 Years, 1991–2000	100.0	100.0	98.6	92.7	86.7

Survival analysis utilizing multi-variate modelling was undertaken to estimate the effect of several variables simultaneously. The regression modelling was employed using a Cox model. The model presented in Figure 73 was fit to "all" dialysis. Details of the model inputs are found in Appendix F. Age (birth to 4 years) and diabetes appear to be the most influential factors in the multi-variate adjusted analysis. Treatment in the years between 1991 and 2000 was predictive of improved survival outcomes.

Figure 73 Mortality Risk Factors in Patients, Birth to 19 Years, on Dialysis Who Initiated Treatment Between 1981 to 2000 (Followed to 2005)



9.3 Kidney Transplantation: Pediatric Recipients

9.3.1 Activity

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.

In the decade from 1996 to 2005, eight centres provided kidney transplants to pediatric renal failure patients throughout Canada: Halifax, Montréal, Toronto, Winnipeg, Saskatoon, Edmonton, Calgary and Vancouver. The annual number of pediatric kidney transplant procedures ranged from 50 to 93 throughout the decade of observation, with an overall total of 733 procedures (Table 69). During this period, 670 pediatric recipients received first grafts.

In the two consecutive decades spanning 1981 to 2005, there was considerable fluctuation, with an overall twofold increase since 1981. There were 41 transplants performed in 1981, peaking with 93 transplants in 2000 (Table 69). Over the last 10 years, there was a trend towards a decrease in the number of deceased-donor transplants (first graft) and an increase in living-donor transplants, compared to the decade spanning 1981 to 1995.

Table 69 Kidney Transplants* by Year, Donor Type and Retransplants, Pediatric Recipients, Canada, 1981 to 2005 (Number)

	First Graft, Deceased Donor	First Graft, Living Donor	Retransplants	Total
1981	30	7	4	41
1982	35	10	7	52
1983	42	10	12	64
1984	50	3	17	70
1985	48	12	12	72
1986	50	13	16	79
1987	49	15	13	77
1988	51	17	18	86
1989	51	15	7	73
1990	62	9	8	79
1991	39	19	12	70
1992	48	8	9	65
1993	47	14	7	68
1994	34	20	12	66
1995	41	23	16	80
1996	20	20	10	50
1997	44	31	3	78
1998	26	29	7	62
1999	34	36	10	80
2000	36	52	5	93
2001	26	38	6	70
2002	32	42	3	77
2003	33	31	6	70
2004	22	42	7	71
2005	43	33	6	82
Total	**993**	**549**	**233**	**1,775**

Note:

* Includes kidney-combination transplants.

When examining subgroups by age of pediatric recipients, the majority (44.2%) were between 15 and 19 years old at the time of transplantation (Table 70), while the smallest number of recipients was in the birth-to-age-4-years group (10.4%). Statistics on provincial distribution showed the largest proportion of patients in Nova Scotia (13.8%) for patients between birth and 4 years of age, followed closely by Ontario (13.3%). In the next two age groups, 5 to 9 years and 10 to 14 years, the largest proportion was found in Manitoba at 28% and 35.5% respectively. Throughout the 25-year period, a combined total of 1,042 pediatric kidney transplants (58.7%) were performed in Ontario and Quebec (Table 70).

Table 70 Pediatric Kidney Transplants* by Age Group and Province of Treatment, Canada, 1981 to 2005 (Number and Percent)

Age Group at Transplant		B.C.	Alta.	Sask.	Man.	Ont.	Que.	N.S.	Total
0–4 Years	N	25	10	0	3	86	35	26	185
	%	12.6	5.3	0.0	2.8	13.3	8.9	13.8	10.4
5–9 Years	N	32	26	1	30	119	69	28	305
	%	16.2	13.8	1.9	28.0	18.4	17.5	14.9	17.2
10–14 Years	N	49	63	11	38	170	116	53	500
	%	24.7	33.5	21.2	35.5	26.3	29.4	28.2	28.2
15–19 Years	N	92	89	40	36	272	175	81	785
	%	46.5	47.3	76.9	33.6	42.0	44.3	43.1	44.2
Total	**N**	**198**	**188**	**52**	**107**	**647**	**395**	**188**	**1,775**

Note:
* Includes kidney-combination transplants.

On a national basis during this interval, the number of deceased–kidney donor transplantations (1,176) out-numbered living-donor donations in the pediatric population. However, there were differences observed between provinces with the highest proportion of living-donor procedures performed in Alberta (55%) (Table 71).

Table 71 Pediatric Kidney Transplants* by Donor Type and Province of Treatment, Canada, 1981 to 2005 (Number and Percent)

Donor Type		B.C.	Alta.	Sask.	Man.	Ont.	Que.	N.S.	Total
Deceased	N	155	84	28	57	428	317	107	1,176
	%	78	45	53.8	53.3	66	80.3	57	66.3
Living	N	43	104	24	50	219	78	81	599
	%	22	55	46.2	46.7	34	19.7	43	33.7
Total	**N**	**198**	**188**	**52**	**107**	**647**	**395**	**188**	**1,775**

Note:
* Includes kidney-combination transplants.

9.3.2 Recipient Characteristics

In the 10-year period from 1996 to 2005, there were slightly more male recipients (53.0%) than female, although the proportion of males was higher in the group aged from birth to 4 years (65.0%), likely due to the fact that more males have congenital diseases. The overall profile reflects the initial dialysis cohort for pediatric patients (54% male). The male/female split differs from adult kidney transplant recipients in that three of every five (63.3%) were males, regardless of whether the transplanted kidney was from a deceased or living donor.

When looking at the cause of renal failure among pediatric transplant recipients during this 25-year period, the spectrum of causes is wide and differs substantially from adult recipients. In pediatric patients, the predominant cause of renal failure included various congenital diseases, which were largely related to the patient's age (Table 72). The most frequent cause observed in all age groups was congenital disease, specifically dysplasia/hypoplasia (221). Just under one in four kidney transplant recipients was reported to have renal failure caused by dysplasia/hypoplasia in patients under the age of 11 years. Other diseases such as cystinosis, glomerulonephritis and focal sclerosis, played a larger role in patients aged 11 years and older.

Table 72 Kidney Transplant Recipients* by Age Group and Primary Renal Diagnosis Category, Pediatric Recipients, First Graft, Canada, 1981 to 2005 (Numbers, Percentage)

	0–4 Years				5–9 Years				10–14 Years				15–19 Years			
	1981 to 1990		1991 to 2005		1981 to 1990		1991 to 2005		1981 to 1990		1991 to 2005		1981 to 1990		1991 to 2005	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Alport's Syndrome	0	0	0	0	0	0	3	1.9	4	2.7	4	1.3	17	6.6	25	5.5
Cystinosis	2	3.2	0	0	18	16	13	8.1	3	2	28	9.3	2	0.8	5	1.1
Dysplasia/ Hypoplasia	19	30	31	27	14	12	39	24	14	9.5	56	19	15	5.9	33	7.3
Posterior Urethral Valves	0	0	11	9.6	2	1.8	12	7.5	4	2.7	13	4.3	3	1.2	5	1.1
Obstructive Uropathy	4	6.3	11	9.6	12	11	10	6.2	20	14	21	7	16	6.3	34	7.5
Vesico-Ureteric Reflux	2	3.2	3	2.6	6	5.3	5	3.1	13	8.8	18	6	28	11	26	5.8
Polycystic Kidneys	4	6.3	4	3.5	5	4.4	4	2.5	1	0.7	10	3.3	3	1.2	13	2.9
Nephronophthisis	0	0	1	0.9	3	2.6	5	3.1	10	6.8	16	5.3	7	2.7	18	4
Other Congenital/ Hereditary	2	3.2	18	16	1	0.9	6	3.7	2	1.4	5	1.7	5	2	15	3.3
Other Pyelonephritis	0	0	0	0	3	2.6	4	2.5	5	3.4	8	2.6	14	5.5	12	2.7
Glomerulonephritis	5	7.9	10	8.8	9	7.9	14	8.7	30	20	38	13	84	33	109	24
Focal Sclerosis	3	4.8	6	5.3	12	11	18	11	8	5.4	17	5.6	8	3.1	22	4.9
Autoimmune Disease	0	0	0	0	8	7	2	1.2	9	6.1	8	2.6	18	7	27	6
Hemolytic-uremic Syndrome	4	6.3	1	0.9	2	1.8	10	6.2	2	1.4	8	2.6	0	0	11	2.4
Other	6	9.5	11	9.6	9	7.9	12	7.5	8	5.4	23	7.6	9	3.5	49	11
Unknown	12	19	7	6.1	10	8.8	4	2.5	14	9.5	29	9.6	27	11	47	10
Total	63	100	114	100	114	100	161	100	147	100	302	100	256	100	451	100

Note:

* Based on patients with first grafts. Diagnoses provided at incident dialysis treatment and subsequent diagnoses at time of kidney transplant are included in this table. Sixty-six patients had a diagnosis in more than one category.

The number of pediatric kidney transplants by province during this period showed that children and youth received transplants in every province, with the lowest average rate in Ontario (6.3 PMP) and the highest in Saskatchewan, at 10.2 per million child population (Table 73).

Table 73 Pediatric Kidney Transplant Recipients* by Year and Province of Residence, First Graft, Canada, 1981 to 2005 (Number and Average Rate† per Million Pediatric Population‡)

	B.C.	Alta.	Sask.	Man.	Ont.	Que.	N.B.	N.S. and P.E.I.	N.L.	Total
1981–1985	13	15	7	8	52	40	8	6	7	156
1986–1990	44	27	19	20	89	53	8	22	11	293
1991–1995	30	37	9	14	101	74	9	8	11	293
1996–2000	37	47	20	14	106	70	9	20	5	328
2001–2005	42	33	22	21	114	87	4	14	2	339
Total	**166**	**159**	**77**	**77**	**462**	**324**	**38**	**70**	**36**	**1,409**
Average RPM	7.1	7.6	10.2	9.5	6.3	7.1	7.3	9.9	8.1	7.2

Notes:

* Includes kidney-combination transplants. Excludes 133 patients for whom residence was unknown.

† Pediatric population used to compute rates is provided in Appendix F.

‡ Crude rate.

9.3.3 Waiting List and Waiting Times

Comprehensive information on number of children waiting for a transplant is available only for the 10-year period from 1996 to 2005. As previously noted, in 2002, the age range for pediatric patients in CORR was changed from "birth to 14 years," to "birth to 17 years." Despite this increase in the age, the number of patients waiting for kidney transplantation declined to 23 cases in 2005, compared to 59 in 1996. Given the change in definition, an increase in the number of pediatric patients on the wait list would not have been surprising (Table 74). This consistent reduction differs from the pattern seen in adult kidney transplant recipients, where the number increased from 2,331 in 1996 to 2,920 in 2005. There were no recorded deaths of pediatric patients while waiting for a kidney transplant at the end of 2005.

Table 74 Pediatric* Kidney Transplant Waiting List on December 31, Canada, 1996 to 2005 (Number)

	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
<15 Years	59	42	48	48	38	36				
<18 Years							36	30	32	23

Note:

* From 1995 to 2001, pediatric recipients were defined as patients under the age of 15. In 2002, this definition was changed to patients under the age of 18.

The duration of time on dialysis provides a proxy for the waiting time for kidney transplant in most kidney-failure patients on dialysis. When examining the time on dialysis prior to transplant in 2005, the median number of days on dialysis prior to the transplant was much shorter for pediatric recipients who had a living-donor graft (98 days), compared to recipients receiving a deceased-donor graft (493 days) (Table 75). While this pattern is consistent with that seen in adult recipients, the average median wait time for transplants differs considerably. In 2005, the wait for adult deceased-donor recipients was twice as long as that for pediatric patients and 2.5 times longer for adults receiving living-donor transplants than for pediatric patients. These differences can be explained by the organ allocation algorithms in Canada, which are designed to ensure rapid transplantation for children.

When reviewing the trends over time, the time on dialysis prior to a first transplant (both pre-emptive and non pre-emptive) fluctuated from year to year for young Canadians throughout the 25-year period, but overall it increased threefold from 153 to 416 days.

With the exception of 1992, recipients of deceased-donor organs wait longer for a transplant based on the length of time on dialysis. While there is considerable fluctuation on an annual basis, waiting time increased from 134 days (including pre-emptive) in 1981 to a high of 741 days (including pre-emptive) in 2004. In regard to living-donor grafts, the median also fluctuated considerably from year to year, with no distinct trend and the longest lasting more than one year (Including pre-emptive) in 1994.

Table 75 Dialysis Duration Prior to First Kidney Transplant, Pediatric Kidney Transplant Recipients, Canada, 1981 to 2005

Year	Recipients (N)	Pre-Emptive Deceased Donor (N)	Pre-Emptive Living Donor (N)	Duration on Dialysis (Median Days) Deceased Donor		Duration on Dialysis (Median Days) Living Donor	
				Including Pre-Emptive	No Pre-Emptive	Including Pre-Emptive	No Pre-Emptive
1981	37	8	0	134	231	123	123
1982	45	5	2	218	285	156	168
1983	52	8	1	199	430	173	175
1984	53	6	1	228	291	44	76
1985	60	6	3	220	316	162	242
1986	63	8	3	212	286	50	82
1987	64	7	4	314	398	167	231
1988	68	10	7	293	374	101	311
1989	66	7	6	379	466	76	299
1990	71	10	6	219	246	0	202
1991	58	5	5	316	371	187	240
1992	56	6	0	278	354	296	296
1993	61	2	3	396	469	112	311
1994	54	2	4	468	512	320	444
1995	64	4	7	295	376	193	280
1996	40	1	5	474	490	204	303
1997	75	4	7	563	630	268	325
1998	55	1	12	517	538	101	247
1999	70	3	12	632	817	122	325
2000	88	5	18	482	566	188	467
2001	64	3	13	530	553	160	361
2002	74	8	18	430	569	75	365
2003	64	7	12	582	827	131	321
2004	64	2	12	741	793	266	403
2005	76	11	11	493	722	98	349

From 2003 to 2005, there was considerable variation by province for patients in the age group from birth to 19 years (Table 76). While some of these variations may be driven by small numbers, there are several other possible factors contributing to the differences between provinces, such as differing proportions of living- versus deceased-donor transplants. As well, an increase in the number of pre-emptive transplants may reduce the wait times.

Table 76 Median Days on Dialysis Before the First Kidney Transplant in Patients, Birth to 19 Years, by Region, 2003 to 2005

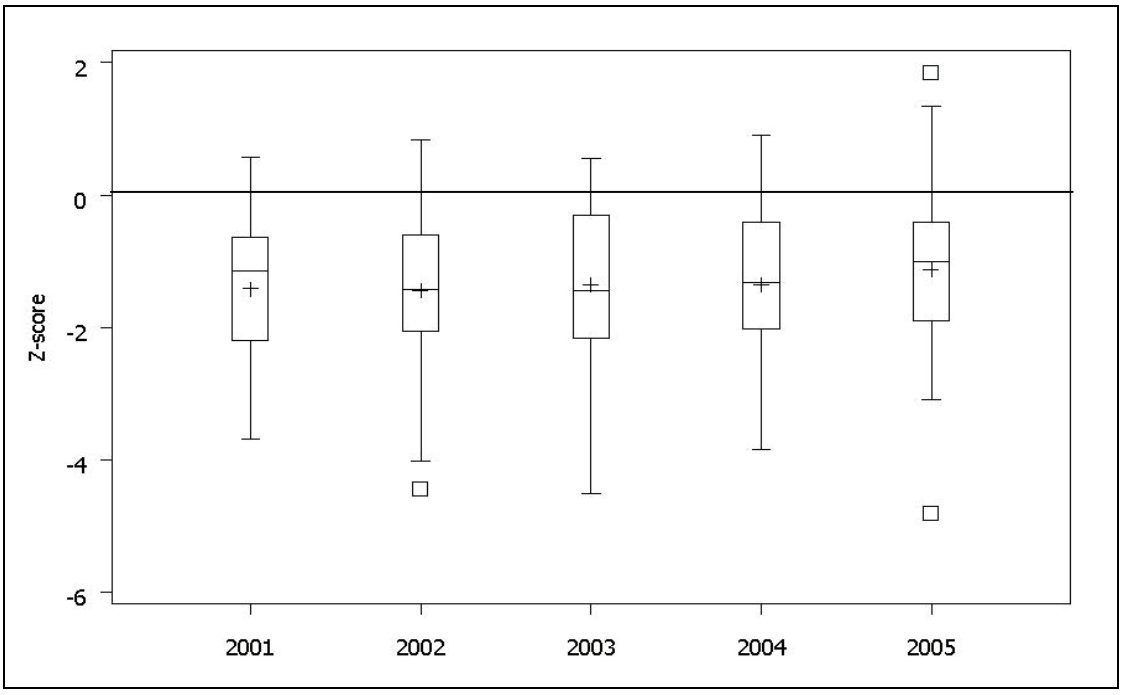
Region	Year	Donor	N	Median
B.C., Alta., Sask., Man.	2003	Living	9	0.0
		Deceased	12	193.5
	2004	Living	17	264.0
		Deceased	6	665.5
	2005	Living	12	136.5
		Deceased	10	241.0
Ont.	2003	Living	7	275.0
		Deceased	6	592.0
	2004	Living	19	255.0
		Deceased	6	681.0
	2005	Living	17	71.0
		Deceased	11	835.0
Que.	2003	Living	11	292.0
		Deceased	15	1149.0
	2004	Living	5	290.0
		Deceased	10	825.5
	2005	Living	3	396.0
		Deceased	17	431.0
N.S.	2003	Living	< 5	24.0
		Deceased	0	--
	2004	Living	< 5	463.0
		Deceased	0	--
	2005	Living	< 5	460.0
		Deceased	5	0.0

Note:
Cell sizes less than 5 have been suppressed for privacy reasons.

9.3.4. Growth in Pediatric Kidney Transplant Patients

The height z-score that a child attains by the time of transplant reflects his/her growth during early chronic kidney disease and dialysis. Clinical evidence indicates that the height z-score is unlikely to change substantially after transplant. The data available for this analysis spans the years between 2001 and 2005. During this period, the average height-for-age z-scores at the time of transplant were somewhat lower than those at the time dialysis was initiated. This may be related to the fact that, at the time of transplant, patients have had longer disease duration and therefore a longer time to deviate from the growth curves prior to transplant. The average scores have remained relatively stable over the past five years (Figure 74).

Figure 74 Height-for-Age Z-Scores in Pediatric Kidney Transplants Patients in Canada, 2001 to 2005



Note: Relative to the American National Center for Health Statistics reference data.

9.3.5. Outcomes

The unadjusted five-year patient survival rate for pediatric kidney transplant recipients exceeded 92% for all years that were examined (Table 77). There was little difference in patient survival rates observed when living-donor recipients were compared to deceased-donor recipients.

For transplants utilizing kidneys from deceased donors, the recipients had a five-year survival rate ranging from 92.6% to 100%. In the pediatric population, the rate was between 85.9% and 92.3%.

The average five-year patient survival rate for transplants using kidneys from living donors was very similar in pediatric and adult patients, ranging from 93.8% to 100% for an average of 97.8%, compared to 92.9% to 95.7% respectively (Table 28, 77).

Table 77 Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Pediatric Kidney Transplant Recipients, First Graft, Canada, 1996 to 2005

	Survival Time	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
Deceased Donor	N	16	40	19	27	32	17	28	27	19	39
	3 Months	100.0	100.0	100.0	96.3	100.0	94.1	100.0	100.0	100.0	100.0
	1 Year	100.0	97.5	100.0	92.6	100.0	94.1	100.0	100.0	100.0	
	3 Years	100.0	97.5	100.0	92.6	100.0	94.1	100.0			
	5 Years	100.0	97.5	94.4	92.6	100.0					
Living Donor	N	17	25	25	30	43	26	36	28	37	29
	3 Months	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
	1 Year	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	
	3 Years	93.8	100.0	100.0	100.0	97.7	100.0	100.0			
	5 Years	93.8	100.0	95.8	100.0	97.7					

The unadjusted five-year graft survival rate was somewhat lower by comparison, ranging from 75.0% (1996) to 90.7% (2000) (tables 77 and 78). Living-donor grafts were somewhat higher (between 76.5% and 90.7%) than deceased-donor grafts (between 75.0% and 84.2%) up to 2000, but varied on a year-to-year basis (Table 78.)

For all time points measured, graft survival rates in the pediatric population were different from those observed in the adult population. The short-term (three month) graft survival rate for pediatric recipients was 100% for both living- and deceased-donor kidneys, with the exception of 1999 and 2001 when it dropped to 96.3% and 94.1% respectively.

The short-term graft survival rate for adults ranged from 90.6% (from living donors) to 95.6% (from deceased donors). The long-term rate was different in adults, ranging from 71.8% to 83.9% for deceased-donor grafts, and from 84.7% to 89.1% for living-donor grafts (Table 78).

Table 78 Unadjusted Three-Month and One-, Three- and Five-Year Graft Survival* for Pediatric Kidney Transplant Recipients, First Graft, Canada, 1996 to 2005

	Survival Time	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
Deceased Donor	N	16	40	19	27	32	17	28	27	19	39
	3 Months	93.8	90.0	94.7	96.3	96.9	94.1	100.0	92.6	94.7	97.4
	1 Year	93.8	85.0	94.7	92.6	96.9	88.2	100.0	88.9	94.7	
	3 Years	87.5	82.5	89.5	85.2	90.6	88.2	100.0			
	5 Years	75.0	77.5	84.2	77.8	81.3					
Living Donor	N	17	25	25	30	43	26	36	28	37	29
	3 Months	82.4	92.0	96.0	93.3	97.7	100.0	94.4	96.4	100.0	96.6
	1 Year	82.4	92.0	96.0	93.3	97.7	100.0	94.4	96.4	100.0	
	3 Years	76.5	88.0	92.0	90.0	93.0	96.2	94.4			
	5 Years	76.5	84.0	88.0	90.0	90.7					

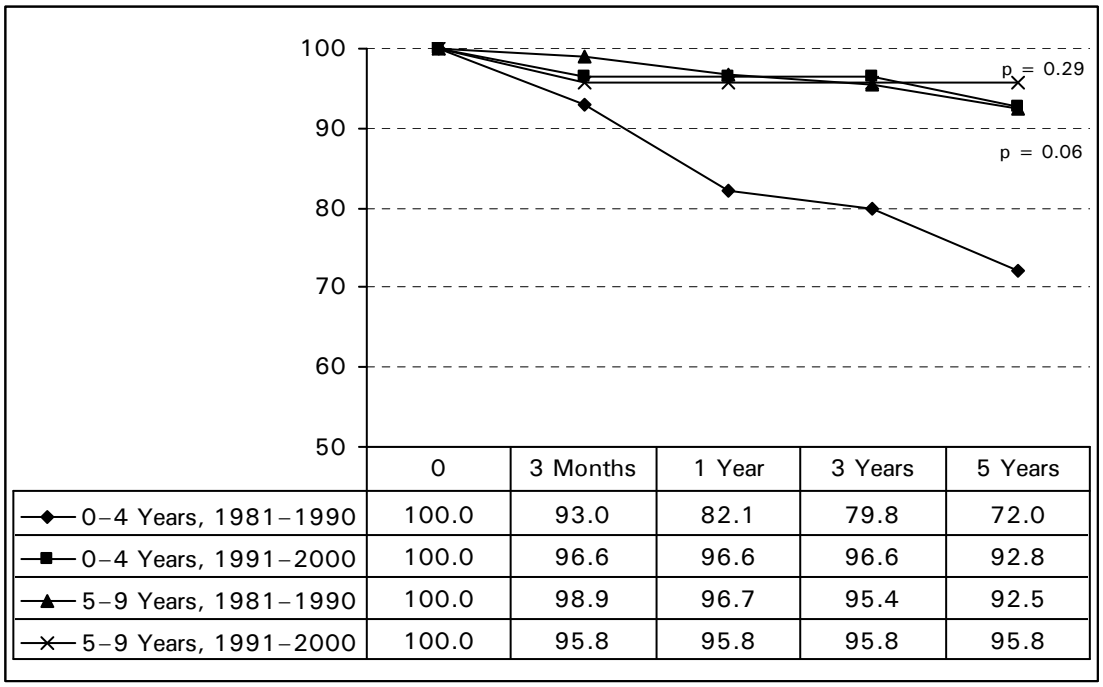
Note:

* Graft survival is computed from first kidney transplant date to first graft failure date, death date or end of observations (December 31, 2005). In this analysis, patients who died with a functioning graft are considered as failed grafts.

9.3.6 Survival in Pediatric ESRD Patients Who Received First Kidney Transplants Between 1981 and 2000

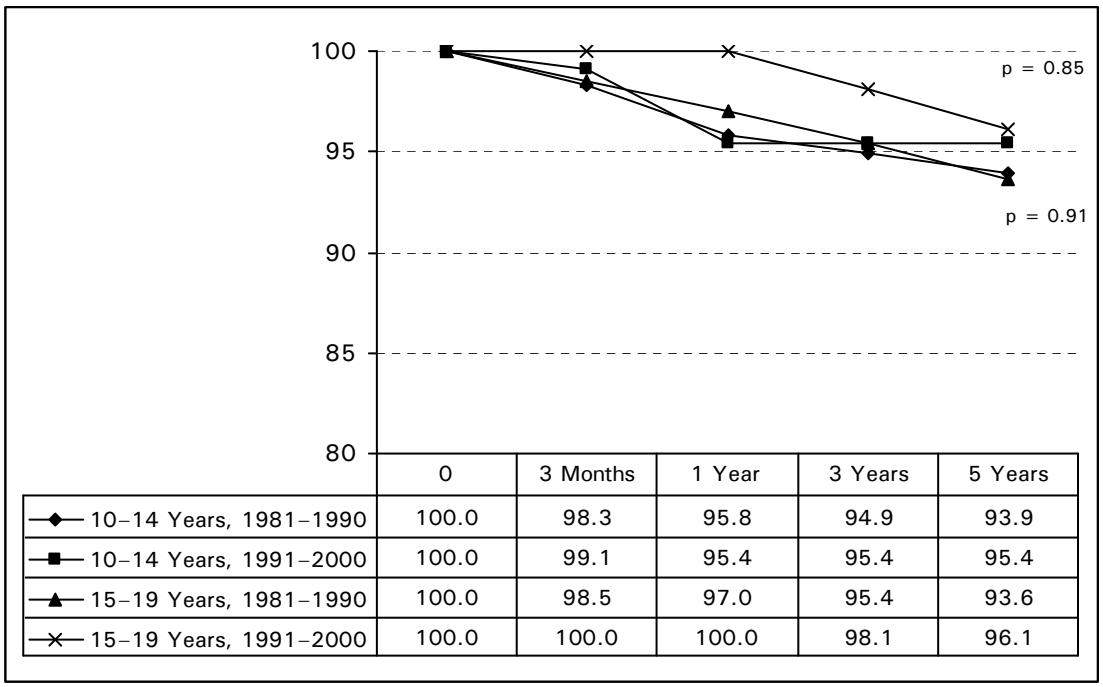
The unadjusted patient survival rate for those patients aged birth to 4 years who received a donor kidney from a deceased donor improved considerably over the two 10-year periods—reflecting a 20% improvement in the five-year survival rate. For those aged 5 to 9 years, there was decreased short-term survival (three-month and one-year), and there was also some improvement in three- and five-year survival (Figure 75). A similar pattern was seen in those aged 10 through to 19 years, with small improvements between the two time periods (Figure 76). However, due to the small numbers, caution must be exercised in interpreting these results.

Figure 75 Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Transplant Patients, Birth to 9 Years, Deceased Donor, by Treatment Intervals, 1981 to 2000 (Followed to 2005)



	0	3 Months	1 Year	3 Years	5 Years
0–4 Years, 1981–1990	100.0	93.0	82.1	79.8	72.0
0–4 Years, 1991–2000	100.0	96.6	96.6	96.6	92.8
5–9 Years, 1981–1990	100.0	98.9	96.7	95.4	92.5
5–9 Years, 1991–2000	100.0	95.8	95.8	95.8	95.8

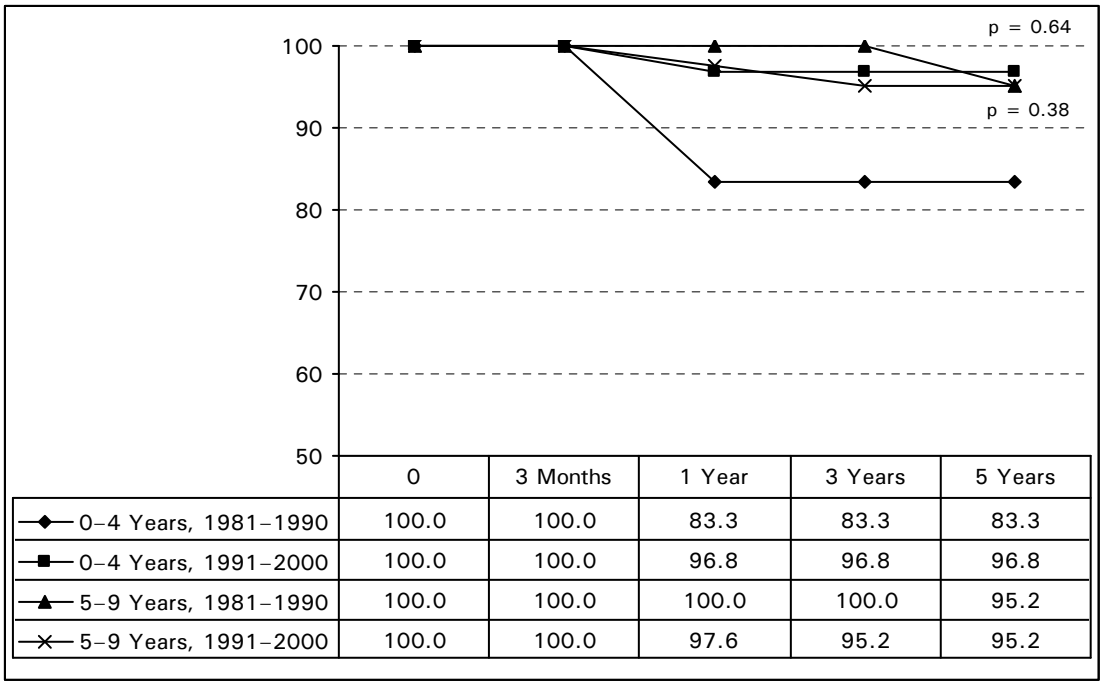
Figure 76 Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Transplant Patients, 10 to 19 Years, Deceased Donor, by Treatment Intervals, 1981 to 2000 (Followed to 2005)



	0	3 Months	1 Year	3 Years	5 Years
10–14 Years, 1981–1990	100.0	98.3	95.8	94.9	93.9
10–14 Years, 1991–2000	100.0	99.1	95.4	95.4	95.4
15–19 Years, 1981–1990	100.0	98.5	97.0	95.4	93.6
15–19 Years, 1991–2000	100.0	100.0	100.0	98.1	96.1

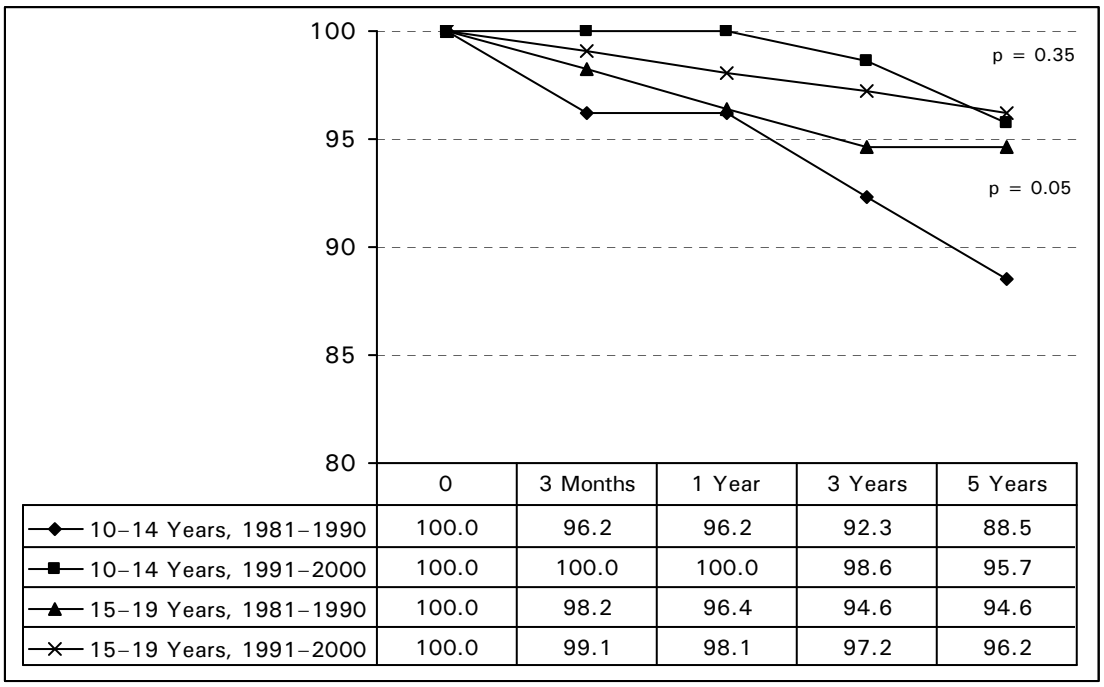
In the children who received a living-donor transplant, there were changes in survival rates between the two 10-year periods, showing substantial improvements in long-term survival for those patients in the birth-to-age-4 group. It increased from 83.3% in the first period to 96.8% survival at five years in the second decade. For those aged between 5 and 9 years, the five-year survival rate remained exactly the same between the two time periods. For those patients aged 10 to 14 years, there was a similar improvement in the five-year survival rate as that for patients in the birth-to-4-years-old group (figures 77 and 78).

Figure 77 Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Transplant Patients, Birth to 9 Years, Living Donor, by Treatment Modality, 1981 to 2000 (Followed to 2005)



	0	3 Months	1 Year	3 Years	5 Years
0–4 Years, 1981–1990	100.0	100.0	83.3	83.3	83.3
0–4 Years, 1991–2000	100.0	100.0	96.8	96.8	96.8
5–9 Years, 1981–1990	100.0	100.0	100.0	100.0	95.2
5–9 Years, 1991–2000	100.0	100.0	97.6	95.2	95.2

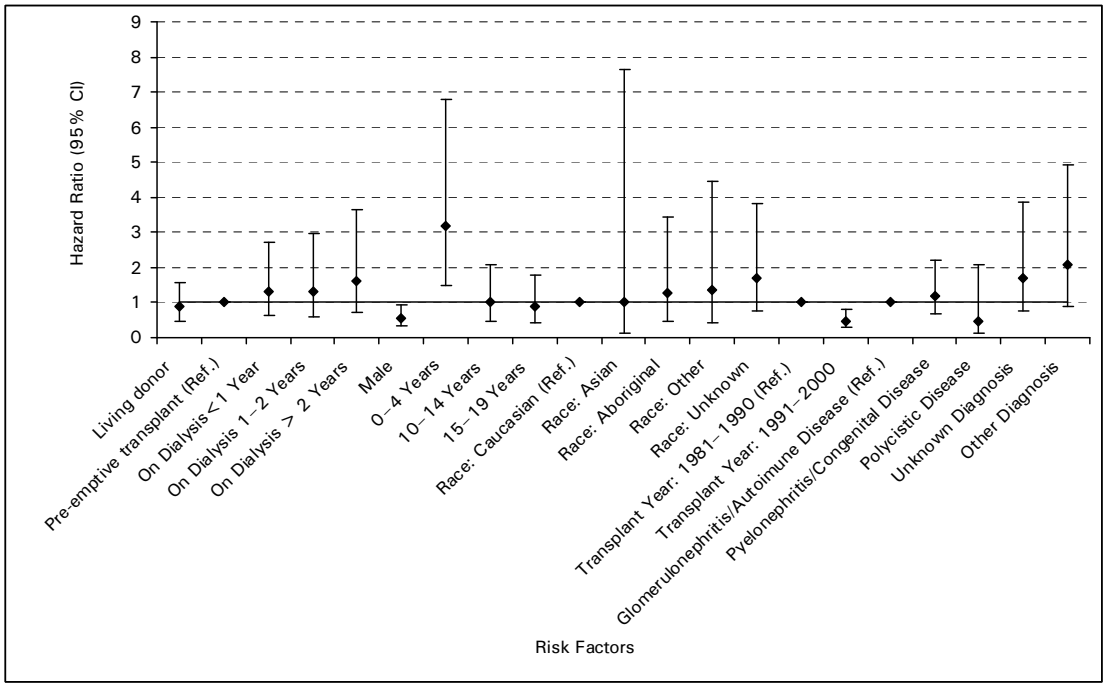
Figure 78 Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Transplant Patients, 10 to 19 Years, Living Donor, by Treatment Modality, 1981 to 2000 (Followed to 2005)



	0	3 Months	1 Year	3 Years	5 Years
10–14 Years, 1981–1990	100.0	96.2	96.2	92.3	88.5
10–14 Years, 1991–2000	100.0	100.0	100.0	98.6	95.7
15–19 Years, 1981–1990	100.0	98.2	96.4	94.6	94.6
15–19 Years, 1991–2000	100.0	99.1	98.1	97.2	96.2

When a Cox model (Figure 79) is utilized to examine the influence of several factors on mortality among pediatric transplant patients, the largest negative influence is for those patients aged birth to 4 years. There are three factors related to mortality: age (birth to 4 years), gender (female) and the possibility of having had a transplant in the previous decade (1981 to 1990).

Figure 79 Mortality Risk Factors for Transplant Patients, (Birth to 19 Years), First Graft and Year, 1981 to 2000 (Followed to 2005)



9.3.7 Organ Donors

The age of deceased organ donors for pediatric kidney recipients ranged from 1 year to 77 years. During the period, the most common living-donor relationship for patients receiving kidneys from living donors were parents (467 out of 599 cases), or 77.9% (Table 79). The number of "other relative and unrelated living donor" kidney transplants was largest (29) in the oldest pediatric age group. The proportion of unrelated donors and other relatives was the second-largest living-donor group in kids younger then 15 years of age, representing 7.5%, 6.7% and 9.4% in the age groups of birth to 4 years, 5 to 9 years and 10 to 15 years of age, respectively. However, the second-largest living donor group in youth (15-to-18 age group) was from siblings (18.7%).

The smallest proportion of living donations in those younger than 15 years was from siblings, with 3.0% (in the birth-to-4-year recipients), 4.5% (5- to 9-year age group) and 6.9% (10- to 15-year-old recipients). This is in contrast to what is observed in the pattern of living donors for adult recipients, where sibling donations are the most prevalent relationship in recipients who are between 18 and 59 years of age. This difference is largely explained by legal restrictions that do not allow children to donate organs. It is expected that young children, whose siblings would also likely be young in age, would not receive organs from them.

Table 79 Selected Donor Characteristics, Pediatric Kidney Transplants, Canada, 1981 to 2005

		Recipient Age Group			
		0–4 Years	5–9 Years	10–14 Years	15–19 Years
Deceased Donor	N	118	216	340	502
	Percentage Male	63.2	60	55.4	58
	Median age	13	19	20	24
Living Donor	N	67	89	160	283
	Percentage Parent as Donor (N)	89.6 (60)	86.5 (77)	80.6 (129)	71 (201)
	Percentage Sibling as Donor (N)	3 (2)	4.5 (4)	6.9 (11)	18.7 (53)
	Percentage Other Relative as Donor (N)	7.5 (5)	6.7 (6)	9.4 (15)	8.5 (24)
	Percentage Unrelated Donor (N)	0.0 (0)	2.2 (2)	3.1 (5)	1.8 (5)

Note:

* Deceased donors will be counted twice if both kidneys were used for transplantation in different recipients.

10. Conclusion

This comprehensive review encompasses 25 years of ESRD care in children and youth across Canada, and reflects changes in epidemiology and care delivery. It provides the framework to allow future comparisons between different regions and with international registries. However, since the numbers are small, care must be taken in the interpretation of the data.

In terms of new cases of ESRD in the incident pediatric (0 to 18) age group, there has been stability over the 25-year period.

The prevalent number of children and youth being treated at the end of calendar year for ESRD in Canada has grown considerably, from 204 to 550 cases, with just under 80% being treated through transplantation in 2005. The tripling of the number of patients being treated with transplant is directly the opposite of the profile at the start of the study, when the vast majority of pediatric patients were being treated through dialysis.

The improved survival rate is most notable in the very young age group (birth to 4 years of age). When examined by decade of study where dialysis is the initial treatment, all age groups (except 5 to 9 years of age) had improved five-year survival in the second decade, compared to the first. Unadjusted long-term survival (five years) for pediatric kidney transplant recipients was above 92% for all years, with little difference observed between deceased and living donors. As well, a growing number of pediatric patients are being treated through pre-emptive transplant.

When a child has ESRD and requires treatment, there is a personal and financial impact on the child, the caregivers, the family and the health care provider. It is through comprehensive information that clarity can be achieved and the framework provided to guide optimal treatments and outcomes. This chapter has presented information on the evolution of ESRD and its treatment in Canadian children and youth from 1981 through to 2005. It is our hope that it will advance our knowledge about the causative diagnoses, treatment modalities, access to transplantation and the overall success of treatment in Canada.

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Appendix A

Canadian Organ Replacement Register (CORR) Board of Directors and Members of the Advisory Committee

CORR Board of Directors (July 1, 2007)

Dr. Joanne Kappel, Canadian Society of Nephrology (CSN), Chair/President

Dr. Stanley Fenton, Canadian Society of Nephrology (CSN), Past President

Dr. John Gill, Canadian Society of Transplantation (CST)/CSN, Vice-President

Mr. Peter Hoult, Kidney Foundation of Canada (Secretary/Treasurer)

Dr. Marie-Josée Clermont, (CSN)

Ms. Cindy Hyson, (PHAC)

Dr. Vivian McAlister, (CST)

Dr. Louise Moist, (CSN)

Dr. Rosalie Starzomski, Canadian Association of Nephrology Nurses and Technicians (CANNT)

Dr. Charles Poirier (QST)

Dr. Semeena Iqbal (QSN)

Dr. Paul Sohi (CSN)

Ms. Kim Young (CCDT)

CORR Advisory Committee (July 1, 2007)

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. 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 and Canadian Hospitals and Independent Health Facilities Providing Dialysis to Chronic Renal Failure Patients as Reported to CORR

Independent health facilities are noted with an asterisk (*).

Hospital/Facility	Type of Transplants Performed in 2005								Dialysis Programs in 2005			
	Kidney	Liver	Heart	Heart–Lung	Lung	Intestine/ Multivisceral	Pancreas/Kidney–Pancreas	Islet Cell	HD	Home HD Training	PD	Home PD Training
Northwest Territories												
*Stanton Territorial Health Authority									X			
British Columbia												
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
Alberta												
Foothills Medical	X						X		X	X	X	X
Alberta Children's Hospital	X											
University of Alberta	X	X	X	X	X	X	X	X	X	X	X	X
Saskatchewan												
Regina General									X		X	X
St. Paul's	X								X		X	X
Manitoba												
Brandon Regional									X			
Health Sciences	X				X				X	X		
Seven Oaks General									X			
St. Boniface General									X		X	X
Ontario												
*Bayshore Dialysis Clinic—Brockville									X			
*Bayshore Dialysis Clinic—Stoney Creek									X			
*Brantford General									X			
Children's Hospital of Eastern Ontario									X		X	
*Cornwall Dialysis Clinic									X			

Hospital/Facility	Type of Transplants Performed in 2005								Dialysis Programs in 2005			
	Kidney	Liver	Heart	Heart–Lung	Lung	Intestine/ Multivisceral	Pancreas/Kidney–Pancreas	Islet Cell	HD	Home HD Training	PD	Home PD Training
Credit Valley									X	X	X	X
*Dialysis Mgmt. Clinics Inc.—Pickering									X			
*Dialysis Mgmt. Clinics Inc.—Markham									X			
*Dialysis Mgmt. Clinics Inc.—Peterborough									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
*Ottawa–Carleton Dialysis Clinic									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
Scarborough—General Division									X		X	X
*Sheppard Centre									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
*Sussex Centre									X			
Thunder Bay Regional McKellar Site									X		X	X
Timmins and District									X		X	X

Hospital/Facility	Type of Transplants Performed in 2005								Dialysis Programs in 2005			
	Kidney	Liver	Heart	Heart–Lung	Lung	Intestine/ Multivisceral	Pancreas/Kidney–Pancreas	Islet Cell	HD	Home HD Training	PD	Home PD Training
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
Quebec												
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			
*C.H. de la région de l'amiante									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
C.H. régional du Suroît									X		X	X
C.H. de Santé Val-D'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

Hospital/Facility	Type of Transplants Performed in 2005								Dialysis Programs in 2005			
	Kidney	Liver	Heart	Heart–Lung	Lung	Intestine/ Multivisceral	Pancreas/Kidney–Pancreas	Islet Cell	HD	Home HD Training	PD	Home PD Training
*Sainte-Croix									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
Nova Scotia												
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			
New Brunswick												
Chaleur Regional									X			
Edmundston									X	X	X	X
Georges L. Dumont									X	X	X	X
Saint John Regional									X	X	X	X
Newfoundland and Labrador												
Central Nfld. 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)
555 West 12th Avenue
3rd Floor, West Tower
Vancouver, British Columbia V5Z 3X7
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

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

Quebec
Québec-Transplant
Siège Social/Head Office
4101 rue Molson, Bureau 101
Montréal, Quebec H3Y 1L1
www.quebec-transplant.qc.ca

Québec-Transplant
Bureau de Quebec
2700 Jean-Pierre Street
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/

New Brunswick
Multiple Organ Retrieval and Exchange Program
Health and Wellness Hospital Services Branch
PO Box 5100
Fredericton, New Brunswick E3B 5G8
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: 1996 to 2005

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 at 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 deaths. 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 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 (1) patients who have been determined to have acute, but not chronic, renal failure; (2) recipients of tissue transplants; (3) patients who were listed for but did not receive a vital organ transplant; or (4) 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 in 2005 and transplant programs in 2005, 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, 2005

	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	24	14	11	2	1	0	15	37	10	6	**117**
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, 2005

	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 are informed by provincial sources of new dialysis hospitals and generally follow 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 enter 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, 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*, *birth date*, *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: • transfer to another program • change treatment modalities • have a kidney transplant • withdraw from dialysis • recover kidney function • die ⬇ Annually, on October 31 (survey with voluntary participation)	When transplanted ⬇ When: • transfer to another program for follow-up • graft fails • retransplanted • die • for liver transplant recipients only—annual follow-up to record recurrent hepatitis B, hepatitis C and liver tumour(s)	When organ(s) retrieved for purposes of transplantation—Deceased Donor Profile and Living Donor Profile	At year-end—hemodialysis 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 is 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. Quality assurance 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 juxtaposition 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 2007, 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 into 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 confirms the transplant hospitals within CORR.

Duplicate patient records have been identified and eliminated in 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 have failed to report to CORR in a timely and complete way are identified, and staff work 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 ESRD cases were incompletely reported for the period from 1996 to 2005. 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 (Hamilton, Ont.) for 2000 and 2001; and Hôpital Fleurimont (Que.) for 1995 and 1996. In 2005, six facilities have not provided facility profile data to CORR, and their number of cases have been imput based on patient-level data. The following hospitals have been missing the hemodialysis facility profiles: CSSS de Gatineau, Ottawa-Carleton Dialysis Clinic (Ont.), Alberta Children's Hospital and Foothils Hospital (Alt.), Surrey Memorial and Kelowna General Hospital (B.C.). Four hospitals have been missing peritoneal facility profile data in 2005: CSSS de Gatineau (Que.), Alberta Children's Hospital (Alt.) and Surrey Memorial and Kelowna General Hospital (B.C.). Renal facility profiles, from which the count of functioning kidney

transplants was 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 in Section 2.3 of this report.

(2) Incident End-Stage Renal Disease (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, underreporting of incident cases on dialysis is estimated to be 60. 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 have been reconciled with aggregate-level counts received from OPOs, which are received in advance of patient-level data submissions. In addition, the *Renal Transplant Facility Profile* provides another check of the kidney transplant data. Table D5 presents a comparison of these sources, and the respective transplant counts per province for the period from 1996 to 2005, and shows that the patient-level data are higher than the OPO aggregate counts, but the prevalent patient-level data are lower than the counts provided on the *Renal Transplant Facility Profile*. This may suggest some under-reporting of kidney transplants within CORR in the years prior to 1996.

Table D5 Comparison of Counts of Kidney Transplants* by Data Source, 1996 to 2005 (Number)

	Alta.	B.C.	Man.	N.S.	Ont.	Que.	Sask.	Total
Patient-Level Data Within CORR	1,589	1,683	462	1,121	4,482	2,829	388	**12,654**
Aggregate Counts Provided in *Renal Transplant Facility Profile*	1,643	1,761	434	1,202	5,147	2,846	408	**13,441**
Aggregate Counts Provided by OPOs at Year-End	1,253	1,335	337	923	3,725	2,289	371	**10,239**
Patient-Level Data for New Transplants Within CORR	1,417	1,332	341	963	3,893	2,380	366	**10,692**

Note:

* Includes SKP and other kidney combination transplants.

(4) Extra-Renal Transplants

For the extra-renal transplants for the period from 1996 to 2005, 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, 1996 to 2005 (Number)

Organ Type	Data Source†	Alta.	B.C.	Man.	N.S.	Ont.	Que.	Total
Liver	CORR registration	619	341	na	147	1,739	1,009	**3,886**
	OPO count	590	326	na	142	1,714	897	**3,673**
Heart	CORR registration	330	132	na	87	639	404	**1,622**
	OPO count	299	157	na	86	595	366	**1,503**
Lung and Heart–Lung	CORR registration	276	84	66	na	519	254	**1,199**
	OPO count	221	82	41	na	401	187	**932**
SKP	CORR registration	97	62	na	27	177	167	**530**
	OPO count	79	52	na	32	148	56	**367**
PTA/PAK	CORR registration	18	9	na	7	34	93	**161**
	OPO count	16	4	na	8	15	102	**145**
Intestine/Multivisceral	CORR registration	3	na	na	na	20	na	**23**
	OPO count	1	na	na	na	10	na	**11**

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, the under-reporting by OPOs of 30 cases occurred in 2005. Overall, the number of donors collected by CORR between 1996 and 2005 was greater by 16 donors than initially reported by OPOs.

Table D7 Comparison of Deceased and Living Donors Registered in CORR and Reported by OPOs, 1996 to 2005 (Number)

Year	Registered in CORR			Reported by OPOs		
	Deceased Donors	Living Donors	Total Donors	Deceased Donors	Living Donors	Total Donors
1996	418	269	**687**	420	265	**685**
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	421	438	**859**	428	431	**859**
2004	440	474	**914**	414	468	**882**
2005	414	503	**917**	414	504	**918**
Total	**4,228**	**4,032**	**8,260**	**4,237**	**3,539**	**8,224**

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 1996 to 2005, 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, 1996 to 2005

Data Type	Data Element	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
Deceased Donor	Age	0.2	0.5	0	0.7	0	0	0	0	0	0
	Sex	0	0	0	0.5	0.2	0	0.2	0.2	0.2	0
	Blood Type	1.2	0.2	0	0.5	0	0.2	0	0	3.0	0.4
	Race/Ethnic Origin	10.9	13.9	5.5	11.9	20.9	25.4	3.6	22.1	32.0	36.6
	Province of Residence (not formally collected until 2001)	78.7	80.4	88.8	83.7	85.8	0	0	0	0	0
	Cause of Death	2.6	2.8	0.5	0.7	1.0	4.8	3.8	2.5	3.2	5.4
Living Donor	Age	49.1	26.9	9.2	25.7	1.5	0	0	0	0	0
	Sex	1.1	48.4	4.9	20.1	0.5	0.9	0.2	0	0	0
	Blood Type	3.0	1.4	6.5	24.9	0.7	0.7	6.8	7.3	12.8	9.5
	Province of Residence (not formally collected until 2001)	98.9	98.9	99.7	98.0	99.0	0.2	0.2	0.5	1.3	1.2
Transplant Recipients	Sex	0	0	0	0	0	0	0	0	0	0
	Race/Ethnic Origin	14.0	13.4	12.1	13.5	14.4	18.5	16.6	19.9	21.4	23.8
	Blood Type	11.2	7.7	2.1	3.6	1.4	3.2	2.7	3.4	2.7	2.8
	Residential Postal Code	6.1	3.0	2.7	2.9	1.4	0.7	0.6	3.2	2.9	1.8
	Cause of Death	0	0	0	0	0	0	0	0	0	0
	Diagnosis	7.6	0.9	0.8	2.0	1.7	1.6	0.9	5.1	1.8	3.0
	Medical Status at Listing (heart, liver, lung transplants)	9.9	11.1	5.8	12.3	3.7	8.7	1.4	2.8	0.9	4.1
	Medical Status at Transplant (heart, liver, lung transplants)	5.0	5.4	2.6	6.6	0	1.7	0.5	0.3	0	0.1
	Cause of Graft Failure (transplants with failed grafts)	33.6	34.4	27.2	29.7	33.3	39.5	37.0	38.3	41.5	51.9

Note:

* Recipients of first grafts for the period from 1996 to 2005.

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 1996 to 2005. 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 Incident Dialysis Patients Registered in CORR by Year, 1996 to 2005

Data Type	Data Element	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	Total
Recipients	Sex	0	0	0	0	0	0	0	0	0	0.0	0.0
	Race/Ethnic Origin	9.2	12.2	12.7	13.9	14.6	6.7	6.7	7.4	6.1	5.0	9.2
	Residential Postal Code	1.2	0.9	1.5	2.6	1.4	1.3	0.6	1.4	1.4	1.7	1.4
	Diagnosis	13.9	15.7	13.0	12.5	11.9	13.9	14.7	14.3	13.5	12.3	13.5
	Cause of Death	22.1	23.1	21.7	23.0	25.6	26.0	26.7	29.0	22.2	21.0	24.2
Risk Factors	Angina	7.5	12.9	7.4	6.4	8.1	7.9	7.2	9.1	9.1	8.7	8.4
	Coronary Artery Bypass/ Angioplasty	31.0	13.8	7.4	6.3	8.2	7.6	7.7	9.8	9.0	8.8	10.4
	Pulmonary Edema	7.8	13.0	7.8	6.5	8.4	7.7	7.7	9.3	9.4	8.9	8.6
	Myocardial Infarct	8.2	12.8	7.6	6.2	8.1	7.5	7.5	9.0	9.3	8.5	8.4
	Diabetes Type 1	6.3	11.5	6.8	5.3	6.5	6.4	5.0	6.5	6.7	6.0	6.6
	Diabetes Type 2	6.3	11.5	6.8	5.3	6.5	6.4	5.0	6.5	6.7	6.0	6.6
	Cerebrovascular Accident	7.9	13.1	7.4	6.5	8.4	7.0	7.2	8.3	8.9	7.9	8.2
	Peripheral Vascualr Disease	7.9	13.1	7.5	6.4	8.4	7.9	7.9	9.2	9.6	8.8	8.6
	Malignancy	8.0	13.3	7.7	6.8	8.4	9.4	9.2	11.5	10.7	12.0	9.7
	Chronic Lung Disease	8.0	13.4	7.8	6.5	8.4	8.2	8.1	9.6	9.8	9.1	8.9
	Use of Medications for Hypertension	5.9	11.2	7.1	5.6	7.6	5.5	5.3	6.8	7.1	6.1	6.8
	Presence of Other Serious Illness	11.4	18.3	11.1	9.8	11.4	17.3	18.9	19.3	19.3	21.0	16.1
	Current Smoker	12.3	16.7	11.1	8.0	9.5	13.2	14.4	13.5	15.7	15.3	13.0

Table D10 Non-Response/Unknown Values for Key Analytical Data Elements Related Incident Dialysis Patients Registered in CORR by Province of Treatment, 1996 to 2005

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	0.1	0	0	0.0
	Race/Ethnic Origin	22.1	12.1	1.5	3.0	8.9	4.0	4.4	18.4	4.7	9.2
	Residential Postal Code	3.4	1.2	0.7	5.4	0.6	1.0	1.3	1.4	2.0	1.4
	Diagnosis	30.2	15.1	7.0	11.3	10.2	13.0	7.6	8.0	17.2	13.5
	Cause of Death	49.7	36.1	14.4	34.4	18.3	22.2	7.4	15.8	14.0	24.2
Risk Factors	Angina	26.5	7.1	2.3	10.6	6.4	5.3	3.0	3.6	3.1	8.4
	Coronary Artery Bypass/Angioplasty	28.3	9.5	3.2	10.7	8.4	7.5	5.9	5.3	6.5	10.4
	Pulmonary Edema	27.4	7.3	1.9	10.2	6.5	5.5	3.2	3.8	4.6	8.6
	Myocardial Infarct	26.9	7.0	1.7	10.4	6.2	5.5	2.9	4.5	4.0	8.4
	Diabetes Type 1	26.1	4.1	0.9	9.2	4.2	3.5	2.3	2.3	3.2	6.6
	Diabetes Type 2	26.1	4.1	0.9	9.2	4.2	3.5	2.3	2.3	3.2	6.6
	Cerebrovascular Accident	26.6	6.4	2.1	10.0	6.3	4.9	2.7	3.8	3.5	8.2
	Peripheral Vascualr Disease	27.6	6.7	2.0	10.2	6.6	5.5	3.0	4.2	4.3	8.6
	Malignancy	28.9	9.3	2.8	12.3	7.4	6.5	4.3	4.0	4.3	9.7
	Chronic Lung Disease	28.6	7.8	1.9	10.2	6.8	5.1	3.0	3.8	3.9	8.9
	Use of Medications for Hypertension	23.9	3.9	1.1	9.7	4.8	4.1	2.1	3.1	3.1	6.8
	Presence of Other Serious Illness	43.6	15.4	5.2	14.0	12.5	13.0	11.3	7.6	8.0	16.1
	Current Smoker	36.6	12.5	4.0	13.0	8.5	13.2	6.3	5.6	6.1	13.0

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 HMDB, preliminary estimates of overall error (expressed as a percentage of total non-agreement) appear to be in the 5% to 10% range. This linkage was based on data from 1995 to 2000 for provinces other than Quebec and applied to a few core variables, including birth date, 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 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 deaths were 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
- 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.

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

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.

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 are 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 (unrelated) relationship 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 at 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 birth date 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 birth date is not part of the donor data set. For the purposes of this report, donor age is converted to a year-based whole number.

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.

Deceased Organ Donors

Deceased organ donors, as described in Section 8, are defined as donors identified in Canadian hospitals from whom 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® PROC LIFETEST method (also known as actuarial survival) is used in the calculation of unadjusted (crude) graft survival rates. The graft survival rates were computed for first organ-specific grafts for patients who were transplanted in each year from 1996 to 2005 at four intervals: three months, one year, three years and five years. Patients were followed until graft failure, death (with or without a functioning graft) or the end of observation (December 31, 2005). Five-year graft survival is reported for patients transplanted in years 1996 to 2000; three-year survival for patients transplanted in years 1996 to 2002. 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, but not incident counts.

International Comparisons
Figure 1 is based on selected countries as reported by the U.S. Renal Data System. Figures 19 (kidney transplant), 30 (liver transplant) and 37 (heart transplant) compare crude transplant rates for Canada with those for France and the United States. These two countries are used because of the fact that data from these countries were readily available for the entire reporting period used in this report, because of Canada's geographic proximity to the United States and its parallel development in terms of transplantation advances, and because of the close cultural ties of Quebec to France. Figures 46 (lung transplant) and 51 (pancreas transplants) compared Canada transplant rates to the U.S. only.

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.

Patient Survival
The SAS® PROC LIFETEST method (also known as actuarial survival) is used in the calculation of unadjusted (crude) patient survival rates. For figures 5 to 14 and 21 to 24, patient survival was computed for RRT recipients who started dialysis between the years 1996 and 2000 and followed to 2005 at four intervals: three months, one year, three years and five years. Patients were followed to their first kidney transplant or until they were lost to follow-up, recovered function or died or the end of observation (December 31, 2005).

For dialysis and transplant patient survival trend analyses, patients starting dialysis or receiving first grafts between 1996 and 2005 were followed for the same four time periods until their deaths, they were lost to follow-up or the end of the observation (December 31, 2005). In addition, patient survival rates for specific patient cohorts receiving liver, heart, lung or pancreas transplants during the period from 1996 to 2000 are also provided. The latter method was used so that each patient in the cohort would have a minimum five-year follow-up period. Titles of the figures/tables identify the cohort used in the analysis.

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 1996 and 2000 was used. The cohort members were followed until second transplant, their death, loss to follow-up or the end of the observation (December 31, 2005).

Hazard ratios with upper and lower confidence intervals are presented in the following tables, which were used for creating figures 15, 16, 17 and 29.

Adjusted Mortality Risk for Dialysis Patients, Canada, 1996 to 2000, Followed to 2005 (N = 20,484), Pertaining to Figure 15 in Text

Parameter	Class Value	Estimate	Std. Error	Chi-Square	Chi-Square Probability	Hazard Ratio (HR)	HR Lower CL	HR Upper CL
Peritoneal Dialysis		-0.0331	0.0249	1.7676	0.1837	0.97	0.92	1.02
Male		0.0154	0.0200	0.5916	0.4418	1.02	0.98	1.06
Age: 0–18		-0.6262	0.2401	6.8000	0.0091	0.54	0.33	0.86
Age: 45–54		0.4705	0.0547	74.0388	<0.0001	1.60	1.44	1.78
Age: 55–64		0.8023	0.0498	260.1074	<0.0001	2.23	2.02	2.46
Age: 65–74		1.1860	0.0474	626.3392	<0.0001	3.27	2.98	3.59
Age: 75+		1.5923	0.0485	1,077.4345	<0.0001	4.92	4.47	5.41
Race: Asian		-0.5214	0.0547	90.7949	<0.0001	0.59	0.53	0.66
Race: Black		-0.5052	0.0742	46.3512	<0.0001	0.60	0.52	0.70
Race: Aborginal		0.0024	0.0510	0.0022	0.9622	1.00	0.91	1.11
Race: Other		-0.4696	0.0580	65.4669	<0.0001	0.63	0.56	0.70
Race: Unknown		0.0322	0.0292	1.2143	0.2705	1.03	0.98	1.09
Treatment Year: 1996—1998		-0.0709	0.0197	13.0064	0.0003	0.93	0.90	0.97
Province	Alta.	-0.0757	0.0400	3.5792	0.0585	0.93	0.86	1.00
Province	B.C.	0.0592	0.0341	3.0091	0.0828	1.06	0.99	1.13
Province	Man.	0.1883	0.0451	17.4183	<0.0001	1.21	1.11	1.32
Province	N.B.	0.1986	0.0540	13.5572	0.0002	1.22	1.10	1.36
Province	N.L.	0.2795	0.0602	21.5869	<0.0001	1.32	1.18	1.49
Province	N.S.	0.0119	0.0520	0.0519	0.8198	1.01	0.91	1.12
Province	Que.	-0.0517	0.0267	3.7430	0.0530	0.95	0.90	1.00
Province	Sask.	0.2734	0.0511	28.6271	<0.0001	1.31	1.19	1.45
Diabetes		0.6236	0.0381	267.5746	<0.0001	1.87	1.73	2.01
Polycystic Kidney		-0.2113	0.0779	7.3640	0.0067	0.81	0.70	0.94
Pyelonephritis		0.0736	0.0654	1.2648	0.2607	1.08	0.95	1.22
Hypertensivd Kidney		0.2651	0.0437	36.7955	<0.0001	1.30	1.20	1.42
Renal Vascular		0.4483	0.0455	97.0041	<0.0001	1.57	1.43	1.71
Drug Induced		0.4956	0.0835	35.2190	<0.0001	1.64	1.39	1.93
Other		0.6491	0.0462	197.8696	<0.0001	1.91	1.75	2.10
Unknown		0.5622	0.0428	172.4483	<0.0001	1.76	1.61	1.91
Cardiac Comorbidity		0.2435	0.0210	134.7632	<0.0001	1.28	1.22	1.33
Vascular Comorbidity		0.2603	0.0222	137.3837	<0.0001	1.30	1.24	1.36

Cox Model of Mortality for HD Patients, 1996 to 2000, Followed to 2005 (N = 15,824), Pertaining to Figure 16

Parameter	Class Value	Estimate	Std. Error	Chi-Square	Chi-Square Probability	Hazard Ratio (HR)	HR Lower CL	HR Upper CL
Male		0.0073	0.0224	0.1079	0.7425	1.01	0.96	1.05
Age: 0–18		-0.8195	0.3569	5.2718	0.0217	0.44	0.22	0.89
Age: 45–54		0.4902	0.0627	61.1727	<0.0001	1.63	1.44	1.85
Age: 55–64		0.7999	0.0573	194.9083	<0.0001	2.23	1.99	2.49
Age: 65–74		1.1611	0.0546	452.0554	<0.0001	3.19	2.87	3.55
Age: 75+		1.5576	0.0556	786.1601	<0.0001	4.75	4.26	5.29
Race: Asian		-0.5093	0.0672	57.4876	<0.0001	0.60	0.53	0.69
Race: Black		-0.5535	0.0884	39.1606	<0.0001	0.58	0.48	0.68
Race: Aborginal		-0.0389	0.0559	0.4859	0.4858	0.96	0.86	1.07
Race: Other		-0.5420	0.0723	56.1839	<0.0001	0.58	0.51	0.67
Race: Unknown		0.0293	0.0317	0.8578	0.3544	1.03	0.97	1.10
Treatment Year: 1996–1998		-0.0577	0.0219	6.9594	0.0083	0.94	0.90	0.99
Province	Alta.	-0.0513	0.0426	1.4462	0.2291	0.95	0.87	1.03
Province	B.C.	0.0343	0.0399	0.7381	0.3903	1.04	0.96	1.12
Province	Man.	0.2217	0.0491	20.3762	<0.0001	1.25	1.13	1.37
Province	N.B.	0.2026	0.0640	10.0088	0.0016	1.23	1.08	1.39
Province	N.L.	0.3234	0.0659	24.0885	<0.0001	1.38	1.21	1.57
Province	N.S.	0.0197	0.0585	0.1127	0.7370	1.02	0.91	1.14
Province	Que.	-0.0272	0.0295	0.8536	0.3555	0.97	0.92	1.03
Province	Sask.	0.3022	0.0558	29.3661	<0.0001	1.35	1.21	1.51
Diabetes		0.5747	0.0434	175.5790	<0.0001	1.78	1.63	1.93
Polycystic Kidney		-0.2418	0.0890	7.3911	0.0066	0.79	0.66	0.94
Pyelonephritis		0.1218	0.0717	2.8865	0.0893	1.13	0.98	1.30
Hypertensivd Kidney		0.2397	0.0498	23.1440	<0.0001	1.27	1.15	1.40
Renal Vascular		0.4237	0.0505	70.4760	<0.0001	1.53	1.38	1.69
Drug Induced		0.4837	0.0908	28.3980	<0.0001	1.62	1.36	1.94
Other		0.6229	0.0511	148.7894	<0.0001	1.86	1.69	2.06
Unknown		0.5643	0.0478	139.2124	<0.0001	1.76	1.60	1.93
Cardiac Comorbidity		0.2293	0.0234	96.0394	<0.0001	1.26	1.20	1.32
Vascular Comorbidity		0.2618	0.0247	112.3643	<0.0001	1.30	1.24	1.36

Cox Model of Mortality for PD Patients, 1996 to 2000, Followed to 2005 (N = 4,660), Pertaining to Figure 18

Parameter	Class Value	Estimate	Std. Error	Chi-Square	Chi-Square Probability	Hazard Ratio (HR)	HR Lower CL	HR Upper CL
CAPD		-0.0781	0.0523	2.2350	0.1349	0.93	0.84	1.03
Male		0.0264	0.0453	0.3401	0.5598	1.03	0.94	1.12
Age: 0–18		-0.3509	0.3341	1.1026	0.2937	0.70	0.37	1.36
Age: 45–54		0.3883	0.1129	11.8385	0.0006	1.48	1.18	1.84
Age: 55–64		0.7977	0.1009	62.5154	<0.0001	2.22	1.82	2.71
Age: 65–74		1.2516	0.0962	169.3685	<0.0001	3.50	2.90	4.22
Age: 75+		1.7107	0.1015	284.3031	<0.0001	5.53	4.54	6.75
Race: Asian		-0.5807	0.0956	36.8793	<0.0001	0.56	0.46	0.68
Race: Black		-0.4173	0.1380	9.1395	0.0025	0.66	0.50	0.86
Race: Aborginal		0.2044	0.1262	2.6231	0.1053	1.23	0.96	1.57
Race: Other		-0.3491	0.0988	12.4900	0.0004	0.71	0.58	0.86
Race: Unknown		0.0914	0.0784	1.3574	0.2440	1.10	0.94	1.28
Treatment Year: 1996–1998		-0.1264	0.0450	7.8928	0.0050	0.88	0.81	0.96
Province	Alta.	-0.2224	0.1227	3.2842	0.0700	0.80	0.63	1.02
Province	B.C.	0.1411	0.0675	4.3668	0.0366	1.15	1.01	1.31
Province	Man.	0.0811	0.1192	0.4629	0.4963	1.08	0.86	1.37
Province	N.B.	0.2088	0.1023	4.1654	0.0413	1.23	1.01	1.51
Province	N.L.	0.1375	0.1501	0.8396	0.3595	1.15	0.86	1.54
Province	N.S.	0.0113	0.1162	0.0094	0.9229	1.01	0.81	1.27
Province	Que.	-0.1307	0.0674	3.7634	0.0524	0.88	0.77	1.00
Province	Sask.	0.1709	0.1298	1.7334	0.1880	1.19	0.92	1.53
Diabetes		0.7890	0.0802	96.8716	<0.0001	2.20	1.88	2.58
Polycystic Kidney		-0.0978	0.1617	0.3656	0.5454	0.91	0.66	1.25
Pyelonephritis		-0.1929	0.1645	1.3756	0.2408	0.83	0.60	1.14
Hypertensivd Kidney		0.3390	0.0917	13.6601	0.0002	1.40	1.17	1.68
Renal Vascular		0.5236	0.1082	23.4047	<0.0001	1.69	1.37	2.09
Drug Induced		0.4782	0.2175	4.8332	0.0279	1.61	1.05	2.47
Other		0.7420	0.1118	44.0198	<0.0001	2.10	1.69	2.62
Unknown		0.5016	0.0981	26.1628	<0.0001	1.65	1.36	2.00
Cardiac Comorbidity		0.3103	0.0476	42.5499	<0.0001	1.36	1.24	1.50
Vascular Comorbidity		0.2557	0.0511	25.0356	<0.0001	1.29	1.17	1.43

Cox Mortality Model for Kidney Adult Transplant Patients, 1996 to 2000, Followed to 2005, Pertaining to Figure 29

Parameter	Class Value	Estimate	Std. Error	Chi-Square	Chi-Square Probability	Hazard Ratio (HR)	HR Lower CL	HR Upper CL
Male		0.0124	0.0866	0.0204	0.8865	1.01	0.85	1.20
Age: 45–54		0.6873	0.1162	35.0163	<0.0001	1.99	1.58	2.50
Age: 55–64		1.1617	0.1121	107.4090	<0.0001	3.20	2.57	3.98
Age: 65+		1.7097	0.1289	175.8784	<0.0001	5.53	4.29	7.12
Transplant Year	1997	-0.0666	0.1167	0.3252	0.5685	0.94	0.74	1.18
Transplant Year	1998	-0.0715	0.1210	0.3496	0.5543	0.93	0.73	1.18
Transplant Year	1999	-0.1426	0.1303	1.1963	0.2741	0.87	0.67	1.12
Transplant Year	2000	-0.6335	0.1529	17.1630	<0.0001	0.53	0.39	0.72
Province	Alta.	-0.2699	0.1450	3.4619	0.0628	0.76	0.58	1.02
Province	B.C.	0.1334	0.1310	1.0373	0.3084	1.14	0.88	1.48
Province	Man.	0.5883	0.1880	9.7914	0.0018	1.80	1.25	2.60
Province	N.S.	0.0749	0.1465	0.2610	0.6094	1.08	0.81	1.44
Province	Que.	-0.1208	0.1133	1.1376	0.2862	0.89	0.71	1.11
Province	Sask.	0.0359	0.2010	0.0318	0.8585	1.04	0.70	1.54
Renal Vascular Disease		0.1928	0.1397	1.9054	0.1675	1.21	0.92	1.59
Diabetes: Type 1		0.8203	0.1086	57.0516	<0.0001	2.27	1.84	2.81
Diabetes: Type 2		0.9516	0.1434	44.0393	<0.0001	2.59	1.96	3.43
Living Donor		-0.6190	0.1057	34.2854	<0.0001	0.54	0.44	0.66

Mortality Risk Factors for Pediatric Dialysis Patients, 1981–2000 (Followed to 2005), Pertaining to Figure 72

Parameter	Estimate	Std. Error	Chi-Square	Chi-Square Probability	Hazard Ratio (HR)	HR Lower CL	HR Upper CL
PD vs. HD	0.02	0.22	0.01	0.93	1.02	0.66	1.58
Male vs. Female	-0.27	0.20	1.87	0.17	0.76	0.52	1.12
0–4 Years	1.20	0.35	11.80	0.00	3.31	1.67	6.56
10–14 Years	-0.21	0.39	0.31	0.58	0.81	0.38	1.72
15–19 Years	-0.25	0.36	0.47	0.49	0.78	0.38	1.59
Race: Asian	0.15	0.61	0.06	0.81	1.16	0.35	3.85
Race: Black	0.38	0.53	0.51	0.47	1.46	0.52	4.14
Race: Aboriginal	0.01	0.39	0.00	0.99	1.01	0.47	2.18
Race: Other	0.17	0.48	0.13	0.72	1.19	0.46	3.03
Race: Unknown	0.60	0.39	2.41	0.12	1.83	0.85	3.91
Treatment Year: 1991–2000	-0.35	0.20	3.01	0.08	0.71	0.48	1.05
Province: Alt.	0.93	0.32	8.42	0.00	2.55	1.35	4.78
Province: B.C.	0.48	0.33	2.16	0.14	1.62	0.85	3.08
Province: Man.	0.69	0.42	2.74	0.10	1.99	0.88	4.51
Province: N.L.	0.55	0.75	0.54	0.46	1.73	0.40	7.52
Province: N.S.	1.00	0.37	7.12	0.01	2.72	1.30	5.66
Province: Que.	0.21	0.29	0.51	0.48	1.23	0.69	2.19
Province: Sask.	0.85	0.41	4.26	0.04	2.35	1.04	5.29
Pyelonephritis/ Congenital Disease	0.10	0.28	0.14	0.71	1.11	0.65	1.91
Polycystic Kidney Disease	0.44	0.41	1.13	0.29	1.55	0.69	3.50
Diabetes	1.59	0.63	6.39	0.01	4.90	1.43	16.81
Unknown Diagnosis	0.13	0.38	0.11	0.74	1.14	0.54	2.38
Other Diagnosis	0.64	0.28	5.34	0.02	1.91	1.10	3.29

Mortality Risk Factors for Pediatric Transplant Patients, First Graft, 1981–2000 (Followed to 2005), Pertaining to Figure 77

Parameter	Estimate	Std. Error	Chi-Square	Chi-Square Probability	Hazard Ratio (HR)	HR Lower CL	HR Upper CL
Living Donor	-0.1327	0.3005	0.1949	0.6589	0.88	0.49	1.58
On Dialysis <1 Year vs. Pre-Emptive	0.2763	0.3666	0.5678	0.4511	1.32	0.64	2.70
On Dialysis 1–2 Years vs. Pre-Emptive	0.2799	0.4107	0.4643	0.4956	1.32	0.59	2.96
On Dialysis >2 Years vs. Pre-Emptive	0.4717	0.4190	1.2673	0.2603	1.60	0.71	3.64
Male vs. Female	-0.5595	0.2464	5.1559	0.0232	0.57	0.35	0.93
0–4 Years	1.1596	0.3874	8.9613	0.0028	3.19	1.49	6.81
10–14 Years	-0.0007	0.3782	0.0000	0.9985	1.00	0.48	2.10
15–19 Years	-0.1225	0.3593	0.1162	0.7332	0.89	0.44	1.79
Asian vs. Caucasian	0.0276	1.0244	0.0007	0.9785	1.03	0.14	7.66
Black vs. Caucasian	-12.1119	499.5434	0.0006	0.9807	0.00	0.00	.
Aboriginal vs. Caucasian	0.2421	0.5081	0.2270	0.6337	1.27	0.47	3.45
Other Race vs. Caucasian	0.2928	0.6111	0.2295	0.6319	1.34	0.41	4.44
Unknown Race vs. Caucasian	0.5374	0.4121	1.7011	0.1921	1.71	0.76	3.84
Transplant Year 1991–2000 vs. 1981–1990	-0.7400	0.2698	7.5259	0.0061	0.48	0.28	0.81
Province Alta. vs. Ont.	0.0751	0.4411	0.0290	0.8648	1.08	0.45	2.56
Province B.C. vs. Ont.	-0.6116	0.5038	1.4738	0.2247	0.54	0.20	1.46
Province M.B. vs. Ont.	0.1057	0.5770	0.0335	0.8547	1.11	0.36	3.44
Province N.S. vs. Ont.	0.2215	0.3677	0.3628	0.5469	1.25	0.61	2.57
Province Que. vs. Ont.	0.2177	0.3144	0.4794	0.4887	1.24	0.67	2.30
Province Sask. vs. Ont.	-0.1821	0.7527	0.0586	0.8088	0.83	0.19	3.64
Pyelonephritis/ Congenital Disease	0.1895	0.3052	0.3856	0.5346	1.21	0.67	2.20
Polycistic Disease	-0.7352	0.7510	0.9583	0.3276	0.48	0.11	2.09
Unknown Diagnosis	0.5400	0.4154	1.6899	0.1936	1.72	0.76	3.87
Other Diagnosis	0.7361	0.4389	2.8130	0.0935	2.09	0.88	4.94

Population Estimates Used in Rate Calculations

Rates presented in this report are either crude or age-specific, and 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 U.S. 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.

Country	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
Canada	29,610,757	29,907,172	30,157,082	30,403,878	30,689,035	31,021,251	31,361,611	31,629,677	31,974,400	32,270.51
U.S.	269,667,391	272,911,760	276,115,288	279,294,713	282,338,631	285,023,886	287,675,526	290,342,554	293,656,824	295,507,000
France	58,388,408	58,623,428	58,866,290	59,116,128	59,381,628	59,658,144	59,925,035	60,180,529	60,424,213	61,045,000

Province	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
Alta.*	2,842,579	2,897,575	2,966,642	3,020,731	3,072,938	3,125,682	3,184,564	3,224,979	3,274.349	3,329,790
B.C.†	3,905,659	3,980,335	4,014,219	4,042,119	4,069,619	4,108,576	4,145,104	4,177,640	4,227,592	4,285,410
Man.	1,134,188	1,136,137	1,137,515	1,142,491	1,147,373	1,151,285	1,155,492	1,162,776	1,170,268	1,177,556
Atlantic Provinces‡	2,379,283	2,372,144	2,358,209	2,354,163	2,348,928	2,340,937	2,340,843	2,343,970	2,343,235	2,343,969
Ont.	11,083,052	11,228,284	11,367,018	11,506,359	11,685,380	11,897,647	12,096,627	12,238,300	12,392,721	12,541,410
Que.	7,246,896	7,274,630	7,295,973	7,323,308	7,357,029	7,396,990	7,443,491	7,487,169	7,542,760	7,598,146
Sask.	1,019,100	1,018,067	1,017,506	1,014,707	1,007,767	1,000,134	995,490	994,843	995,391	994,126

Notes:

* Includes Northwest Territories and Nunavut.
† Includes the Yukon.
‡ Includes New Brunswick, Newfoundland and Labrador, Nova Scotia and Prince Edward Island (see breakdown below).

Atlantic Provinces	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
N.B.	752,312	752,543	750,551	750,611	750,518	749,890	750,183	750,594	751,384	752,006
N.L.	559,807	551,011	539,932	533,409	528,043	521,986	519,270	519,570	517,027	515,961
N.S.	931,413	932,481	931,907	933,847	933,881	932,389	934,392	936,025	936,960	937,889
P.E.I.	135,751	136,109	135,819	136,296	136,486	136,672	136,998	137,781	137,864	138,113
Total—Atlantic Provinces	**2,379,283**	**2,372,144**	**2,358,209**	**2,354,163**	**2,348,928**	**2,340,937**	**2,340,843**	**2,343,970**	**2,343,235**	**2,343,969**

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

Province	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
Alta.*	770,292	776,805	785,075	787,012	788,193	787,870	789,420	785,414	795,515	867,966
B.C.†	912,324	922,209	920,129	914,437	907,328	900,396	889,176	876,470	901,012	788,342
Man.	294,295	293,056	291,355	290,694	289,809	288,338	286,374	284,931	289,581	240,950
N.B.	177,305	174,592	171,255	168,464	165,611	162,339	159,210	156,197	166,724	282,600
N.L.	137,203	131,533	125,831	121,353	117,367	112,995	109,188	106,258	120,738	2,777,653
N.S. and P.E.I.	255,385	252,244	248,322	245,024	241,738	237,535	233,152	228,860	275,740	1,538,081
Ont.	2,687,527	2,709,476	2,731,584	2,744,445	2,766,649	2,793,673	2,805,072	2,793,643	2,745,893	150,784
Que.	1,683,129	1,664,663	1,642,069	1,616,863	1,596,734	1,580,565	1,566,619	1,551,727	1,613,809	220,019
Sask.	280,587	277,114	273,975	269,649	264,349	258,241	253,096	249,097	265,061	101,458
Total	**7,198,047**	**7,201,692**	**7,189,595**	**7,157,941**	**7,137,778**	**7,121,952**	**7,091,307**	**7,032,597**	**7,174,073**	**6,967,853**

Notes:

* Includes Northwest Territories and Nunavut.

† Includes the Yukon.

Prevalent Patients

Prevalent patient numbers at year-end are based on the 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 Profile 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, and 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: (1) not all patients will be registered in CORR because they may have started treatment prior to January 1, 1981; (2) incident patients have been under-reported by some reporting centres; and (3) 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. For example, if a patient has a combination liver–kidney transplant and has no previous transplant history, she would be included as a first graft recipient for both liver (Section 3) and kidney (Section 2). 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 under the age of 15 to under the age of 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, and 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.