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Treatment of End-Stage Organ Failure in Canada 1999 to 2008

2010 Annual Report

Canadian Organ Replacement Register



Canadian Institute
for Health Information

Institut canadien
d'information sur la santé

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Requests for permission should be addressed to:

Canadian Institute for Health Information
495 Richmond Road, Suite 600
Ottawa, Ontario K2A 4H6

Phone: 613-241-7860

Fax: 613-241-8120

www.cihi.ca

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Treatment of End-Stage Organ Failure in Canada, 1999 to 2008

CORR 2010 Annual Report

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The 2010 CORR annual report was developed at CIHI by

- Claire Marie Fortin, Manager, Clinical Registries
- Bob Williams, Program Lead, CORR
- Frank Ivis, Senior Analyst, CORR
- Yingbo Na, Senior Analyst, CORR
- Norma Hall, Analyst, CORR

Executive Summary

Treatment of End-Stage Organ Failure in Canada, 1999 to 2008 draws on data from the Canadian Institute for Health Information (CIHI) Canadian Organ Replacement Register (CORR) for the years 1999 through 2008 (the most current year available). The report examines dialysis and transplantation characteristics and trends in Canada during that period.

The information presented is relevant to a wide array of stakeholders. Individuals interested in health system policy, as well as clinical and service management related to end-stage organ failure, will find the report useful, as will individuals and groups generally interested in end-stage organ failure in Canada.

Overall, 2,080 transplants of solid organs were performed in Canada in 2008. These included kidney, liver, lung, heart and pancreas transplants.

There were an estimated 36,638 people living with end-stage renal disease (ESRD) in Canada at the end of 2008, an increase of 57% since 1999. Of these, 21,754 were on dialysis and 14,884 were living with a functioning kidney transplant. There were 5,431 ESRD patients who initiated renal replacement therapy (RRT) in 2008, representing an increase of 1% over the previous year. Of 1,216 kidney transplants during 2008, 169 received pre-emptive transplants,ⁱ which are becoming an increasingly important treatment option in Canada. The proportion of new patients receiving this treatment remains low. Diabetes continues to be the predominant cause of ESRD in Canada, identified in 35% of new cases in 2008, followed by renal vascular disease (18%). The aging of the Canadian population is reflected in the demographic profile of new ESRD patients, with 53% of those who initiated RRT being age 65 and older in 2008, compared to 49% in 1999.

Liver transplantation has undergone tremendous innovation in technique as well as pre- and post-surgical care. As a result, the procedure has vaulted to the forefront as the treatment of choice for end-stage liver disease in Canada. There were 453 liver transplants performed in Canada in 2008, and 587 patients were waiting for a transplant in 2008, a number that has declined from its peak of 723 in 2006.

In 2008, 164 heart transplants were performed in Canada. Over the decade, the annual number of transplants performed fluctuated between 147 and 178, averaging 164 transplants per year. Overall, 1,588 Canadians received a first heart transplant in this time frame, and 55 were re-transplanted. In 2008, there were 131 Canadians awaiting a heart transplant, with 14 deaths on the waiting list that year.

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

Among adult Canadians, end-stage lung disease treated by lung transplant increased by 82% between 1999 and 2008. In 2008, 165 lung transplants were performed, down from the 187 performed in 2007. Bilateral lung transplants accounted for 81% of the lung transplants performed. Bilateral procedures were most commonly performed on recipients with cystic fibrosis (29%). Conversely, the most frequent diagnosis for a single-lung transplant recipient was emphysema (49%). In 2008, there were 282 Canadians waiting to receive a lung transplant, up from 168 in 1999, representing a 68% increase over time. Of note, the number of people waiting for a single lung transplant more than doubled, from 51 in 2007 to 129 in 2008.

Transplantation for pancreatic disease was first performed in 1996 in the United States. Since then, it has evolved to become a well-recognized treatment for pancreatic disease. There were 671 pancreatic transplants performed in Canada between 1999 and 2008; of these, almost three-quarters (72%) were simultaneous pancreas–kidney transplants. Islet cell transplants are also performed in Canada and, over the decade, there were 265 procedures involving 135 patients. The number of Canadians awaiting a simultaneous pancreas–kidney transplant peaked in 2001 (172) and declined to 98 in 2008. Over the decade, the number of individuals waiting for a single pancreas transplant went from 17 to 49 per year.

Small intestine transplantation is an emerging and evolving field with the potential to improve the outcomes of children and adults with intestinal failure in Canada. Between 1999 and 2008, there were 51 such procedures performed in Canada, with half of recipients younger than age 18.

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

In addition to this annual summary report, more information and data tables are available online at www.cihi.ca/corr, in the form of special reports (Analyses in Brief) and semi-annual reports from the organ procurement organizations called *e-Statistics on Organ Transplants, Waiting Lists and Donors*. The website also features PowerPoint presentations with summary data.

If you have questions about this report or would like further information, please write to CORR at corr@cihi.ca.

1 Introduction

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

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

In 1987, the register was expanded to include data on extra-renal organ transplants. In 1995, responsibility for CORR transferred to the Canadian Institute for Health Information (CIHI), which maintains numerous health system-related pan-Canadian data holdings.

The current mission of CORR is to provide pan-Canadian information on vital organ replacement therapy in Canada, with the goal of enhancing treatment, research and patient care. The CORR Board of Directors is responsible for providing strategic advice to the register. (For a membership list of the Board of Directors as of November 1, 2009, please see Appendix A.)

1.1 Data Sources

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

Patients are tracked from their first treatment for end-stage organ failure (dialysis or transplantation) to their death, unless they become lost to follow-up. Only treatments provided in Canada are included in this report. For the purposes of recording continuity of care, however, CORR does capture out-of-country transfers when informed by reporting facilities.

At present, CORR does not receive individual patient data on those wait-listed for transplant. Aggregate counts of patients waiting for solid organ transplants are provided on a semi-annual basis by the eight OPOs that are responsible for maintaining wait lists. The OPOs that contribute wait-list counts are BC Transplant, Southern Alberta Organ and Tissue Donations Program (Calgary), HOPE Edmonton, the Saskatchewan Transplant Program (Saskatoon and Regina), Transplant Manitoba—Gift of Life, 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 the OPOs is provided in Appendix C.

Population estimates used for calculating age- and province-specific rates were obtained from Statistics Canada.

1.2 Data Quality

Ensuring data quality is an ongoing CORR activity. This includes the annual completion of the CIHI Data Quality Framework and the subsequent production of a data quality report, which can be found in Appendix D.

There are no known coverage errors within CORR; the program area is aware of all hospitals that should report. In 2007, the coverage of CORR against other CIHI data holdings was assessed as part of a data quality study,ⁱⁱ where results confirmed that more than 98% of transplant patients recorded in CORR were also represented in the Discharge Abstract Database. A second analysis compared Ontario's renal dialysis patients in the National Ambulatory Care Reporting System (NACRS) to those in CORR. NACRS reports ambulatory care visits to emergency departments and outpatient clinic visits for all dialysis patients (acute and chronic). This linkage found 93% of patients in CORR were matched perfectly to patients in NACRS.

While completeness of key data elements has improved over time, the proportions of unknown values reported for primary diagnosis, cause of death and cause of graft failure continue to exceed 10% in many cases. Users should consider this when interpreting trends. In the case of primary diagnosis, a chart review, conducted as part of the data quality study, found that there was lower-than-expected agreement with data reported to CORR. The agreement rate between the study coder and the CORR data on the primary renal disease code was 59%, while the agreement rate on the broader type of renal disease was 71%. Despite these coding issues, the resulting hazard ratios for various primary renal diseases and risk factors were similar, whether calculated using the CORR data or study data.

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 in the United States by the United Network of Organ Sharing, which includes donors whose organs were recovered but not transplanted. This is an important distinction to consider when making comparisons of deceased donor rates between countries.

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

Please see Appendix D—CORR Data Quality Documentation: 1999 to 2008, for further detail regarding the completeness and coverage of reporting in CORR.

ii. Canadian Institute for Health Information, *Data Quality Study on the Canadian Organ Replacement Register* (Ottawa, Ont.: CIHI, 2009). This study is available for download as a PDF document at www.cihi.ca/corr.

1.3 Organization of the Report

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

- Renal replacement therapy for end-stage renal disease patients (dialysis and renal transplant)
- Liver transplantation
- Heart transplantation
- Lung transplantation
- Pancreas transplantation
- Intestinal transplantation

Appendix A provides a list of members of the CORR Board of Directors.

Appendix B provides information on Canadian transplant programs, including which solid organ transplants they perform; it also lists the Canadian hospitals and independent health care facilities that provide dialysis treatment in Canada.

The OPOs that provide organ donation statistics to CORR are listed in Appendix C.

The CORR data quality documentation for the years 1999 to 2008 is outlined in Appendix D.

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

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

1.4 Provincial Data

Throughout this report, provincial-level data is presented. Users should note the distinctions between province of treatment, generally reflecting service availability, and province of patient residence. In general, dialysis patients from the Yukon are managed by British Columbia; those in the Northwest Territories and Nunavut are managed through Alberta; and Prince Edward Island patients are managed in Nova Scotia.

1.5 Additional Information

In addition to this annual summary report, more information and data tables are available online at www.cihi.ca/corr, in the form of special reports (Analyses in Brief) and semi-annual reports from the OPOs called *e-Statistics on Organ Transplants, Waiting Lists and Donors*. The website also features PowerPoint presentations with summary data.

If you have questions about this report or would like further information, please write to CORR at corr@cihi.ca.

2 Renal Replacement Therapy for End-Stage Renal Disease

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

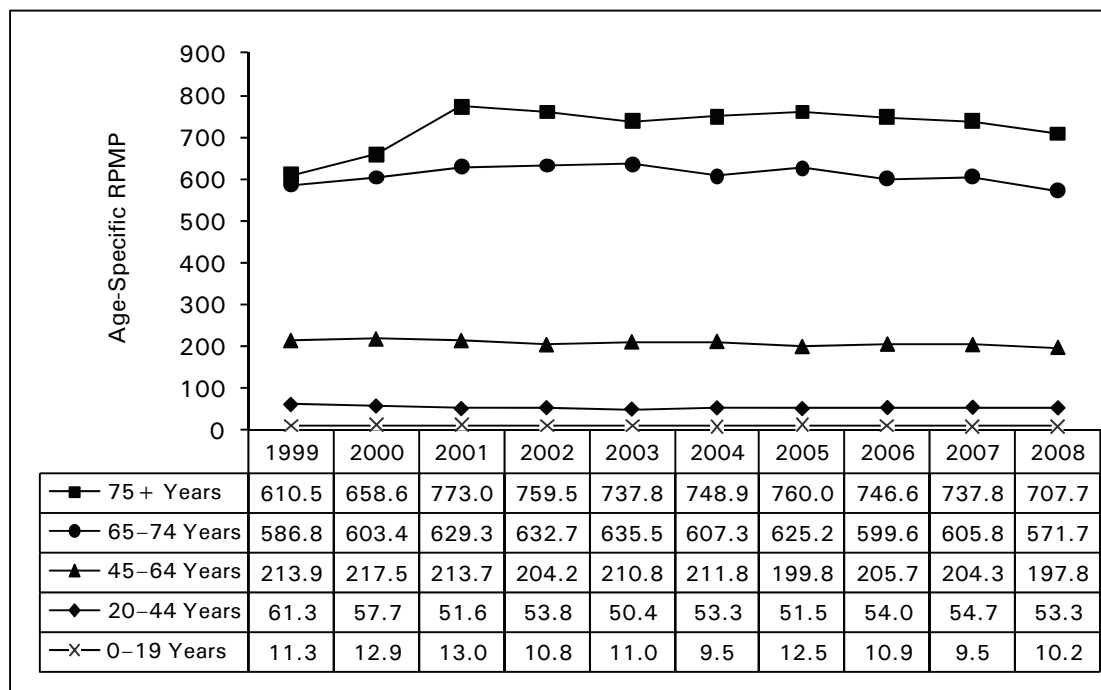
2.1 Incident ESRD RRT Patients

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

2.1.1 Activity

There were 5,431 newly diagnosed patients with ESRD in 2008, an increase of 19% since 1999 ($n = 4,551$). Throughout the period from 1999 to 2008, the highest rate per million population of newly diagnosed ESRD was in those age 75 and older (Figure 1). This age group also had the largest rate increase over the reporting period, a trend that began in the 1980s and continued until 2001, when the incident RPMP reached 773.0. Between 2001 and 2005, incidence rates remained relatively constant. Since 2005, rates among older age groups have slowly declined, falling from 760.0 to 707.7 among those age 75 and older, and from 625.2 to 571.7 in the 65-to-74 age group. Those age 20 to 44 saw a slight decline in new diagnoses of ESRD over the 10 years, with the RPMP declining from 61.3 in 1999 to 53.3 in 2008 (a 13% decline).

Figure 1 Incident End-Stage Renal Disease Patients, Age-Specific Rate per Million Population, Canada, 1999 to 2008



Sources

Canadian Organ Replacement Register, 2009, Canadian Institute for Health Information; and Statistics Canada.

2.1.2 Patient and Treatment Characteristics

The patient and treatment characteristics of newly diagnosed patients with ESRD in Canada have changed over time. At the end of 2008, the largest proportion of all new patients initiated treatment on hemodialysisⁱⁱⁱ (79%), up from 76% in 1999.

iii. Hemodialysis works by circulating the blood through special filters outside the body. The blood flows across a filter, along with solutions that help remove toxins. This form of dialysis must be performed in a health care facility.

While Figure 1 shows that those age 75 and older had the highest rate of ESRD diagnosis, the largest number of new patients was seen in the group of patients age 45 to 64 (Table 1). As Table 2 shows, hemodialysis (HD) was consistently utilized as the primary modality of treatment throughout the decade, while the number of new patients receiving peritoneal dialysis (PD)^{iv} as an initial treatment remained consistent through the time period. The use of pre-emptive transplants increased over time, from 127 in 1998 to 169 in 2008. When dialysis was used to treat incident patients in 2008, all provinces used HD the majority of the time, with Newfoundland and Labrador having the highest proportion of HD (97%), followed by Saskatchewan (85%) and New Brunswick (84%). The highest proportion of patients treated by continuous ambulatory peritoneal dialysis (CAPD) was seen in Alberta (16%) (Table 3). Diabetes continued to be the most frequently reported primary cause of ESRD, accounting for 35% of incident patients in Canada (Figure 2).

Table 1 Distribution of Incident End-Stage Renal Disease Patients by Age Group, Canada, 1999 to 2008 (Number, Percent of Total)

Age Group		1999	2000	2001	2002	2003	2004	2005	2006	2007	2008
0–19 Years	N	90	103	104	86	87	75	98	85	74	80
	%	2.0	2.2	2.2	1.7	1.7	1.4	1.9	1.6	1.3	1.5
20–44 Years	N	717	674	604	632	592	627	606	636	644	622
	%	15.8	14.2	12.0	12.5	11.5	12.0	11.4	11.8	11.7	11.5
45–64 Years	N	1,483	1,559	1,584	1,567	1,673	1,735	1,688	1,792	1,831	1,827
	%	32.6	32.8	31.6	31.1	32.6	33.2	31.9	33.1	33.3	33.6
65–74 Years	N	1,253	1,295	1,360	1,377	1,392	1,344	1,398	1,363	1,407	1,376
	%	27.5	27.2	27.1	27.3	27.1	25.7	26.4	25.2	25.6	25.3
75+ Years	N	1,008	1,124	1,362	1,380	1,384	1,444	1,506	1,534	1,550	1,526
	%	22.2	23.6	27.2	27.4	27.0	27.6	28.4	28.4	28.2	28.1
Total	N	4,551	4,755	5,014	5,042	5,128	5,225	5,296	5,410	5,506	5,431

Source

Canadian Organ Replacement Register, 2009, Canadian Institute for Health Information.

iv. Peritoneal dialysis filters waste using a peritoneal membrane inside the abdomen. The abdomen is filled with special solutions that help remove toxins. The solutions remain in the abdomen for a time and are then drained out. There are two types of peritoneal dialysis—continuous ambulatory peritoneal dialysis and automated peritoneal dialysis. This form of dialysis can be performed at home.

Table 2 Incident End-Stage Renal Disease Patients by Year, Age Group and Initial Treatment Modality, Canada, 1999 to 2008 (Number)

Age Group	Initial Modality*	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008
		N = 4,551	N = 4,755	N = 5,014	N = 5,042	N = 5,128	N = 5,225	N = 5,296	N = 5,410	N = 5,506	N = 5,431
0–19 Years	HD	37	46	45	36	39	34	45	59	38	36
	PD	38	34	45	28	32	29	33	15	16	32
	Pre-Emptive	15	23	14	22	16	12	20	11	20	12
20–44 Years	HD	472	444	404	440	427	417	431	441	440	422
	PD	180	171	133	147	123	155	134	144	134	145
	Pre-Emptive	65	59	67	45	42	55	41	51	70	55
45–64 Years	HD	1,120	1,153	1,179	1,200	1,274	1,293	1,230	1,339	1,384	1,358
	PD	321	356	359	326	344	392	367	368	372	382
	Pre-Emptive	42	50	46	41	55	50	91	85	75	87
65–74 Years	HD	995	1,052	1,118	1,141	1,157	1,120	1,139	1,119	1,164	1,109
	PD	253	240	232	233	229	212	250	230	231	252
	Pre-Emptive	5	3	10	3	6	12	9	14	12	15
75+ Years	HD	828	966	1,161	1,205	1,226	1,246	1,310	1,358	1,349	1,348
	PD	180	158	201	175	158	197	196	174	200	178
	Pre-Emptive	0	0	0	0	0	1	0	2	1	0
Total	HD	3,452	3,661	3,907	4,022	4,123	4,110	4,155	4,316	4,375	4,273
	PD	972	959	970	909	886	985	980	931	953	989
	Pre-Emptive	127	135	137	111	119	130	161	163	178	169

Note

* HD: hemodialysis; PD: peritoneal dialysis; Pre-Emptive: pre-emptive kidney transplant.

Source

Canadian Organ Replacement Register, 2009, Canadian Institute for Health Information.

Table 3 Incident Patients on Dialysis, by Type of Treatment and Province of Treatment, Canada, 2008 (Number, Percent of Total)

Type of Treatment*		Province of Treatment†									
		B.C.	Alta.	Sask.	Man.	Ont.	Que.	N.B.	N.S.	N.L.	Canada
HD	N	512	382	142	224	1,742	899	119	151	102	4,273
	%	77.0	82.7	85.0	79.7	78.2	87.2	84.4	83.4	97.1	81.2
CAPD	N	105	75	21	45	275	114	21	28	3	687
	%	15.8	16.2	12.6	16.0	12.3	11.1	14.9	15.5	2.9	13.1
APD	N	48	5	4	12	212	18	1	2	0	302
	%	7.2	1.1	2.4	4.3	9.5	1.7	0.7	1.1	0.0	5.7
Total	N	665	462	167	281	2,229	1,031	141	181	105	5,262

Notes

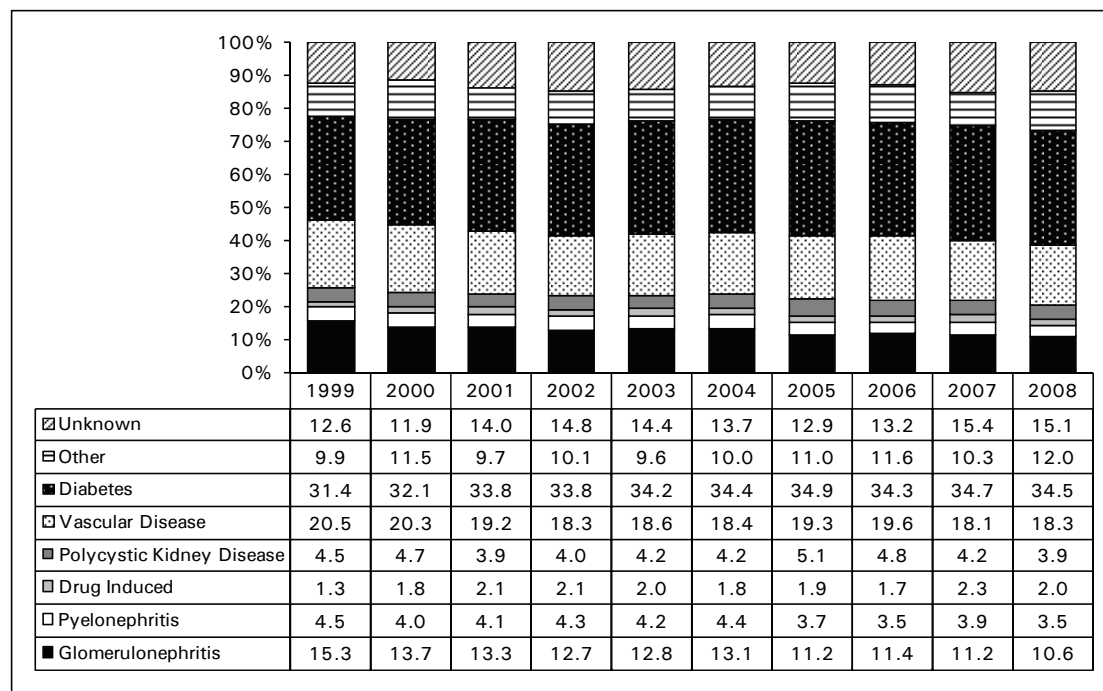
* HD: hemodialysis; CAPD: continuous ambulatory peritoneal dialysis; APD: automated peritoneal dialysis.

† British Columbia includes the population of the Yukon; Alberta includes the populations of the Northwest Territories and Nunavut; Nova Scotia includes the population of Prince Edward Island.

Source

Canadian Organ Replacement Register, 2009, Canadian Institute for Health Information.

Figure 2 Distribution of Incident End-Stage Renal Disease Patients by Primary Diagnosis Category, Canada, 1999 to 2008 (Percentage)



Source

Canadian Organ Replacement Register, 2009, Canadian Institute for Health Information.

2.2 Prevalent ESRD RRT Patients

Prevalence, by definition, is the number of people or proportion of people in the entire population who are found with a defined disease at a specified point in time, in this case ESRD. Prevalence is usually presented as RPMP, or the relative proportion of people in the population living with the cited disease. In CORR, prevalence is measured as of December 31 each year.

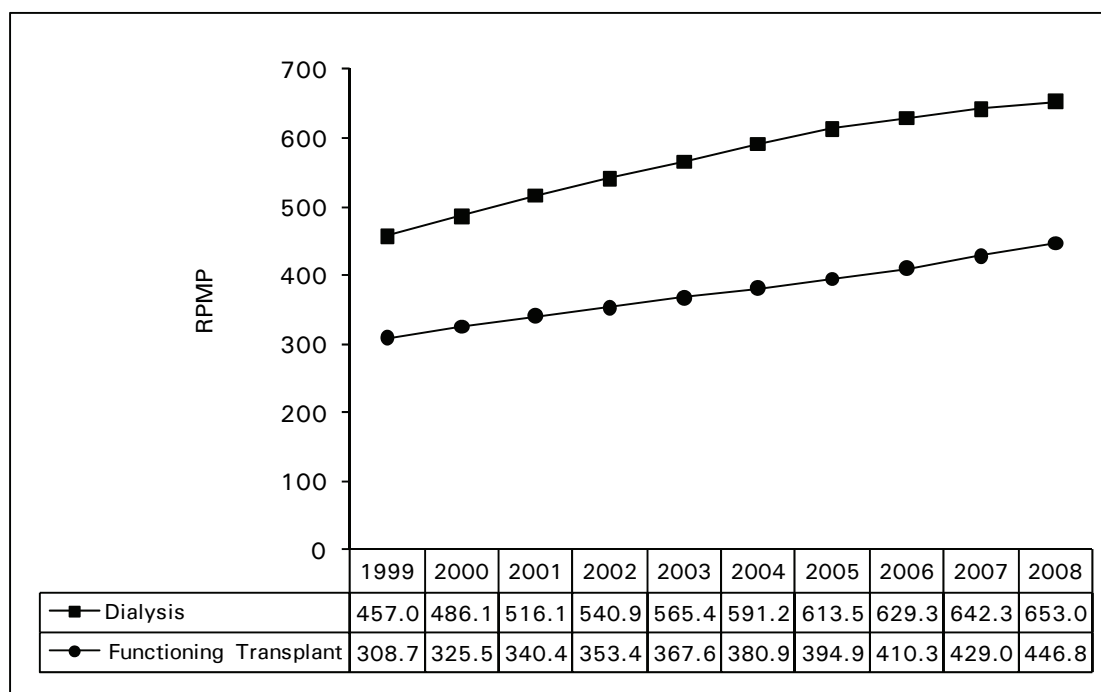
In this section, the trends in ESRD prevalent patients in Canada are presented over time in the following figures and tables.

2.2.1 Activity

As of December 31, 2008, there were 36,638 people in Canada being treated for ESRD, with almost half (48%, n = 17,765) receiving hemodialysis (HD), followed by 41% (14,884) living with a functioning kidney transplant and 3,989 (11%) being treated with peritoneal dialysis (PD).

The prevalence rates for people being treated by dialysis and through a transplanted organ both increased steadily over time. There was a 43% increase in the prevalent rate for dialysis and a corresponding 45% increase in the rate of people living with a transplant between 1999 and 2008 (Figure 3).

Figure 3 Prevalence Rate for Patients on Dialysis or With Functioning Transplant in Canada, 1999 to 2008 (Rate per Million Population)



Sources

Canadian Organ Replacement Register, 2009, Canadian Institute for Health Information; and Statistics Canada.

2.2.2 Patient and Treatment Characteristics

The profile of prevalent ESRD patients in Canada has changed over time. At the end of 2008, the largest proportion of all patients was receiving HD (48%). This was followed closely by the number of ESRD patients living with a functioning kidney transplant (41%) (Table 4). The highest prevalence rate of any treatment, at 2,620.5 RPMP, was seen for those age 75 and older being treated with HD (Table 5).

HD provided in an institutional setting is the most common form of renal replacement therapy (RRT) across the country (47%), followed by transplant (41%). However, in Nova Scotia/Prince Edward Island, Alberta/Northwest Territories/Nunavut and British Columbia/Yukon, transplant is the leading treatment seen in prevalent patients with ESRD (53%, 50% and 50%, respectively) (Table 6). Table 7 summarizes changes in prevalence by examining flows into and out of treatment.

Table 4 Prevalent End-Stage Renal Disease Patients by Treatment, Age Group, Sex and Primary Diagnosis, Canada, December 31, 2008 (Number, Percent)

		Type of Treatment*			Total
		HD	PD	Tx	
Total	N	17,765	3,989	14,884	36,638
	%	48.5	10.9	40.6	
Age Group					
0–19 Years	N	72	46	426	544
	%	0.4	1.2	2.9	1.5
20–44 Years	N	1,958	612	3,766	6,336
	%	11	15.3	25.3	17.3
45–64 Years	N	5,797	1,538	7,665	15,000
	%	32.6	38.6	51.5	40.9
65–74 Years	N	4,287	970	2,362	7,619
	%	24.1	24.3	15.9	20.8
75 + Years	N	5,651	823	665	7,139
	%	31.8	20.6	4.5	19.5
Sex					
Female	N	7,403	1,741	5,650	14,794
	%	41.7	43.6	38.0	40.4
Male	N	10,360	2,248	9,234	21,842
	%	58.3	56.4	62.0	59.6
Other	N	2	0	0	2
	%	0.0	0.0	0.0	0.0
Diagnosis					
Glomerulonephritis	N	2,474	732	4,479	7,685
	%	13.9	18.4	30.1	21.0
Diabetes	N	5,973	1,200	2,269	9,442
	%	33.6	30.1	15.2	25.8
Renal Vascular Disease	N	3,157	681	917	4,755
	%	17.8	17.1	6.2	13.0
Polycystic Kidney Disease	N	798	231	1,669	2,698
	%	4.5	5.8	11.2	7.4
Drug Induced	N	296	62	194	552
	%	1.7	1.6	1.3	1.5
Pyelonephritis	N	866	156	1,195	2,217
	%	4.9	3.9	8.2	6.1
Other	N	1,754	397	1,998	4,149
	%	9.9	10.0	13.4	11.3
Unknown	N	2,447	530	2,163	5,140
	%	13.8	13.3	14.5	14.0

Note

* HD: hemodialysis; PD: peritoneal dialysis; Tx: transplant.

Source

Canadian Organ Replacement Register, 2009, Canadian Institute for Health Information.

Table 5 Prevalent Patients by Treatment,* Age Group, Sex and Primary Diagnosis, Canada, December 31, 2008 (Rate per Million Population, Percent Change)

	Rate per Million Population			Percent Change, 2004 to 2008		
	HD	PD	Tx	HD	PD	Tx
Age Group						
0–19 Years	9.2	5.9	54.2	-1.9	-5.2	0.5
20–44 Years	167.9	52.5	323.0	0.9	-0.4	-0.1
45–64 Years	627.8	166.6	830.1	3.6	2.8	6.7
65–74 Years	1,781.3	403.0	981.4	2.8	3.4	12.8
75+ Years	2,620.5	381.7	308.4	6.9	6.4	20.8
Sex						
Female	634.3	137.6	537.9	3.9	4.1	4.0
Male	444.8	104.6	322.1	4.2	1.6	4.1
Diagnosis						
Diabetes	179.3	36.0	68.1	5.5	3.5	8.3
Glomerulonephritis	74.3	22.0	134.5	0.8	0.1	4.6
Vascular Disease	94.8	20.4	27.5	4.3	5.0	7.6
Pyelonephritis	26.0	4.7	35.9	2.1	-4.7	3.0
Polycystic Kidney Disease	24.0	6.9	50.1	3.5	5.1	7.7
Drug Induced	8.9	1.9	5.8	2.2	11.9	9.9
Other	52.7	11.9	60.0	6.2	2.9	5.1
Unknown	73.5	15.9	64.9	3.4	5.3	4.5

Note

* HD: hemodialysis; PD: peritoneal dialysis; Tx: transplant.

Sources

Canadian Organ Replacement Register, 2009, Canadian Institute for Health Information; and Statistics Canada.

Table 6 Prevalent End-Stage Renal Disease Patients, by Type of Treatment and Province of Treatment, Canada, 2008 (Number, Percent)

Type of Treatment*		Province of Treatment†									Canada
		B.C./ Yukon	Alta./ N.W.T./ Nun.	Sask.	Man.	Ont.	Que.	N.B.	N.S./ P.E.I.	N.L.	
HD Home	N	141	86	7	0	382	83	9	2	11	721
	%	3.0	2.4	0.4	0.0	2.6	1.1	1.0	0.1	1.6	2.0
HD Institutional	N	1,850	1,412	899	557	7,322	3,712	422	533	337	17,044
	%	39.2	39.2	54.1	49.1	49.1	48.4	49.2	37.6	50.2	46.5
CAPD	N	156	118	84	100	639	349	60	90	26	1,622
	%	3.3	3.3	5.1	8.8	4.3	4.6	7.0	6.3	3.9	4.4
APD	N	467	190	124	52	1,164	253	63	38	16	2,367
	%	9.9	5.3	7.5	4.6	7.8	3.3	7.3	2.7	2.4	6.5
Transplant	N	2,102	1,794	548	425	5,409	3,265	304	756	281	14,884
	%	44.6	49.8	33.0	37.5	36.3	42.6	35.4	53.3	41.9	41.0
Total	N	4,716	3,600	1,662	1,134	14,916	7,662	858	1,419	671	36,638

Notes

* HD: hemodialysis; CAPD: continuous ambulatory peritoneal dialysis; APD: automated peritoneal dialysis.

† British Columbia includes the population of the Yukon; Alberta includes the populations of the Northwest Territories and Nunavut; Nova Scotia includes the population of Prince Edward Island.

Source

Canadian Organ Replacement Register, 2009, Canadian Institute for Health Information.

Table 7 End-Stage Renal Disease Patient Flows by Treatment, Canada, 1999 to 2008

		1999	2000	2001	2002	2003	2004	2005	2006	2007	2008
Dialysis	January 1, Prevalence	12,783	13,894	14,918	16,010	16,981	17,901	18,886	19,797	20,560	21,182
	Incident Dialysis	4,424	4,620	4,877	4,931	5,009	5,095	5,135	5,247	5,328	5,262
	Deaths	2,530	2,692	2,927	3,059	3,171	3,188	3,338	3,466	3,543	3,543
	Net Transplants*	629	742	684	648	683	656	624	757	803	771
	Net Migrations [†]	154	162	174	253	235	266	262	261	360	376
	December 31, Prevalence	13,894	14,918	16,010	16,981	17,901	18,886	19,797	20,560	21,182	21,754
Transplant	January 1, Prevalence	8,812	9,386	9,990	10,561	11,086	11,637	12,168	12,745	13,387	14,147
	New Transplants	1,071	1,158	1,094	1,079	1,093	1,074	1,107	1,252	1,299	1,277
	Deaths	198	238	198	238	227	235	216	276	234	201
	Return to Dialysis	293	310	317	296	308	289	307	328	302	336
	Net Migrations [†]	6	6	8	20	7	19	7	6	3	3
	December 31, Prevalence	9,386	9,990	10,561	11,086	11,637	12,168	12,745	13,387	14,147	14,884

Notes

* Transplants minus those returning to dialysis due to failed transplants.

† Includes patients who left the country, recovered function, were lost to follow-up or withdrew from treatment.

Source

Canadian Organ Replacement Register, 2009, Canadian Institute for Health Information.

2.2.3 Facility Profiles

Each HD treatment is provided at a dialysis station, which treats one patient at a time. The number of HD stations available for treatment is a relatively crude indicator of the system's capacity to treat those with ESRD in a facility, region or province (Table 8). Ontario has the highest number of patients per station with 5.1, while New Brunswick has the lowest at 2.9 per station (Table 8).

Peritoneal dialysis includes total care as well as limited self-care treatments. Some patients may have also received a combined HD and PD regimen of treatment. There were 3,941 patients being treated with PD in 2008, with the majority (61%) being treated with home automated peritoneal dialysis (APD), followed by home CAPD (37%) (Table 9).

Table 8 Point Prevalent Hospital, Independent Health Facility and Community Centre Hemodialysis (HD) Patients,* by Stations and Province of Treatment, Canada, 2008 (Number)

Province of Treatment	Stations (N) [†]	Patients (N) [‡]	Patients per Station	Population [§]	Stations per Million Population
B.C.	451	1,777	3.9	4,414,747	102.2
Alta.	383	1,496	3.9	3,659,873	104.6
Sask.	127	573	4.5	1,015,985	125.0
Man.	199	708	3.6	1,207,959	164.7
Ont.	1,483	7,544	5.1	12,928,996	114.7
Que.	791	3,602	4.6	7,750,504	102.1
N.B.	152	437	2.9	747,302	203.4
N.S.	139	519	3.7	1,078,128	128.9
N.L.	96	327	3.4	507,895	189.0
Total	3,821	16,983	4.4	33,311,389	114.7

Notes

* Data is incomplete for four centres in Canada: one in Ontario, two in Quebec and one in British Columbia. Data was imputed based on data for the previous year.

† It is estimated that for stations, the number imputed is 51 for HD. This table includes information about stations located in and patients being treated at full-care hospitals, independent health facilities and community centres. Satellite stations refer to a facility where nephrology inpatient services are *not* on site. This includes mobile dialysis services and dialysis services provided at independent health facilities.

‡ The number of imputed patients is 294 for HD and 304 for PD.

§ 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.

Sources

Canadian Organ Replacement Register, 2009, Canadian Institute for Health Information; and Statistics Canada.

Table 9 Point Prevalent Peritoneal Dialysis Patients, by Type of Treatment* and Province of Treatment, Canada, 2008 (Number, Percent of Province Total)

Province of Treatment [†]		Home CAPD	Home APD	Chronic Care CAPD [‡]	Chronic Care APD	Hospital CAPD [§]	Hospital APD [§]	Combined PD and HD	Total
B.C.	N	137	454	2	12	2	2	5	614
	%	22.3	73.9	0.3	2.0	0.3	0.3	0.8	100
Alta.	N	115	188	2	1	0	0	0	306
	%	37.6	61.4	0.7	0.3	0.0	0.0	0.0	100
Sask.	N	100	53	0	0	0	1	4	158
	%	63.3	33.5	0.0	0.0	0.0	0.6	2.5	100
Man.	N	70	145	0	2	1	1	1	220
	%	31.8	65.9	0.0	0.9	0.5	0.5	0.5	100
Ont.	N	572	1,087	6	10	6	19	14	1,714
	%	33.4	63.4	0.4	0.6	0.4	1.1	0.8	100
Que.	N	295	319	4	1	2	1	0	622
	%	47.4	51.3	0.6	0.2	0.3	0.2	0.0	100
N.B.	N	51	67	0	0	0	0	1	119
	%	42.9	56.3	0.0	0.0	0.0	0.0	0.8	100
N.S.	N	86	58	0	0	0	0	1	145
	%	59.3	40.0	0.0	0.0	0.0	0.0	0.7	100
N.L.	N	22	19	0	0	0	0	2	43
	%	51.2	44.2	0.0	0.0	0.0	0.0	4.7	100
Total	N	1,448	2,390	14	26	11	24	28	3,941
	%	36.7	60.6	0.4	0.7	0.3	0.6	0.7	100

Notes

* CAPD: continuous ambulatory peritoneal dialysis; APD: automated peritoneal dialysis; PD: peritoneal dialysis; HD: hemodialysis.

† British Columbia includes the population of the Yukon; Alberta includes the populations of the Northwest Territories and Nunavut; Nova Scotia includes the population of Prince Edward Island.

‡ Includes total and limited self-care.

§ Total care only.

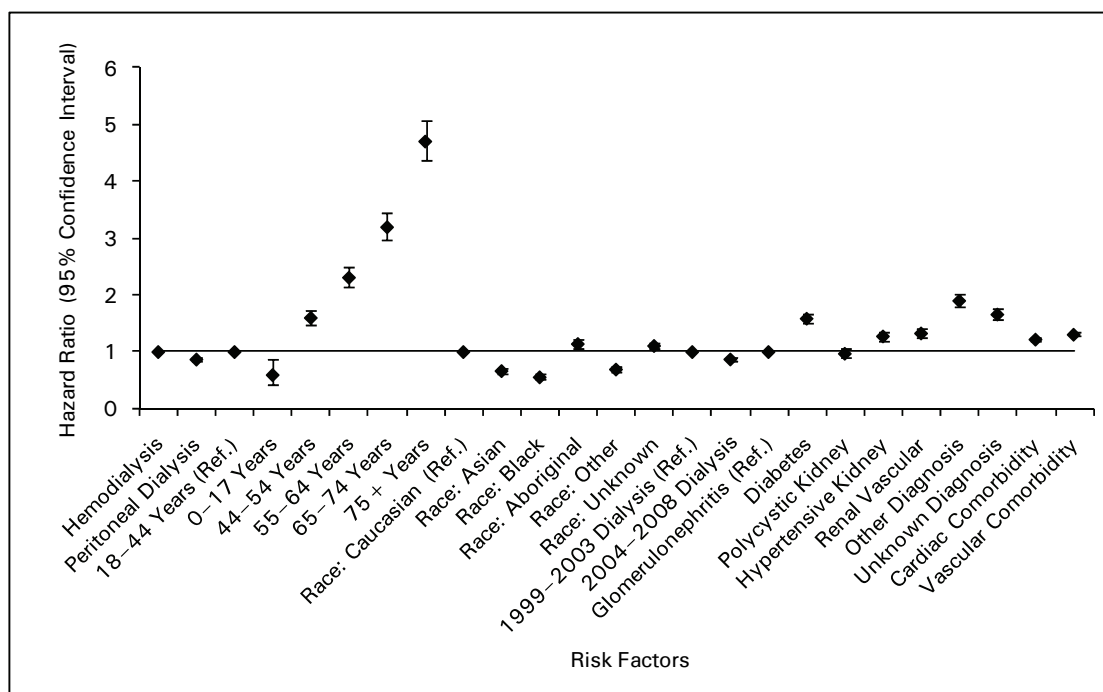
Source

Canadian Organ Replacement Register, 2009, Canadian Institute for Health Information.

2.3 Outcome of Dialysis Treatment in Canada

The factors associated with the survival of patients receiving dialysis treatment are well documented. Figure 4 illustrates the impact of these factors during the last decade in Canada. Points located above the horizontal line, at 1, indicate increased risk of death; conversely, points below the line indicate better survival outcomes. The most significant associated factors, resulting in less favourable outcomes, are seen with advancing age and the diagnosis of diabetes.

Figure 4 Cox Proportional-Hazards Model for Mortality Risk for Patients Who Initiated RRT With Dialysis, Canada, 1999 to 2008



Source

Canadian Organ Replacement Register, 2009, Canadian Institute for Health Information.

2.4 Kidney Transplantation: Adult Recipients

Kidney transplantation is the preferred treatment for the majority of end-stage renal disease (ESRD) patients. There have been improvements in both the short- and long-term survival of the kidney allograft and overall improved patient survival; however, kidney transplant activity is dependent on the availability of organs. Living organ donation has greatly improved the situation of limited availability of deceased donor organs. It has played an increasingly important role in kidney transplantation over the last decade.

This section presents transplantation activity among adult kidney recipients (age 18 and older) in the last decade in Canada. Outcomes of kidney transplantation are examined using an adjusted regression analysis, which helps identify risk factors associated with an increased risk of death after kidney transplant.

2.4.1 Activity

In 2008, there were 23 active kidney transplant programs in Canada operating in seven provinces. Between 1999 and 2008 inclusive, there were 10,425 kidney transplant procedures registered in CORR. Of these, 1,179 (11%) were re-transplants. Of the 9,182 kidney-only first transplants, 61% utilized deceased-donor kidneys (Table 10). Ontario and Quebec surgeons performed the most deceased-donor kidney transplants over the decade (2,159 and 2,001, respectively) (Table 11). Ontario saw the highest number of living-donor kidney transplants over the decade, followed by British Columbia. Since 2006, the number of living-donor kidney transplants has been stable, fluctuating between 453 and 461 transplants each year (Table 12).

Table 10 Kidney Transplants* by Year and Donor Type, Adult Recipients, Canada, 1999 to 2008 (Number)

	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	Total
Kidney Only, First Graft, Deceased Donor	501	596	546	516	550	514	503	606	631	634	5,597
Kidney Only, First Graft, Living Donor	323	309	340	319	342	345	370	415	413	409	3,585
Kidney Combination, First Graft, Deceased Donor [†]	5	5	6	5	8	3	5	10	8	9	64
Re-Transplants	128	125	123	129	99	104	105	119	133	114	1,179
Total	957	1,035	1,015	969	999	966	983	1,150	1,185	1,166	10,425

Notes

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

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

Source

Canadian Organ Replacement Register, 2009, Canadian Institute for Health Information.

Table 11 Deceased-Donor Kidney Transplants* by Year and Province of Treatment, Adult Recipients, Canada, 1999 to 2008 (Number)

Province of Treatment	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	Total
B.C.	63	60	59	46	53	52	40	61	61	83	578
Alta.	72	84	85	81	67	67	83	78	71	66	754
Sask.	35	19	28	18	29	18	15	21	21	21	225
Man.	14	28	11	17	17	13	6	22	27	24	179
Ont.	173	213	184	196	192	208	206	243	291	253	2,159
Que.	194	209	207	186	218	196	173	197	204	217	2,001
N.S.	57	79	70	63	51	35	49	67	52	49	572
Total	608	692	644	607	627	589	572	689	727	713	6,468

Note

* Excludes simultaneous kidney–pancreas transplants. See Section 6. Includes first transplants and re-transplants.

Source

Canadian Organ Replacement Register, 2009, Canadian Institute for Health Information.

Table 12 Living-Donor Kidney Transplants by Year and Province of Treatment, Adult Recipients, Canada, 1999 to 2008 (Number)

Province of Treatment	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	Total
B.C.	70	77	83	74	69	74	70	98	100	75	790
Alta.	48	37	50	47	52	61	50	46	60	51	502
Sask.	15	6	8	14	10	12	11	9	7	13	105
Man.	14	10	12	15	18	12	19	24	21	17	162
Ont.	140	151	144	149	156	157	186	206	199	211	1,699
Que.	24	22	43	38	43	38	46	47	44	47	392
N.S.	38	40	31	25	24	23	29	31	27	39	307
Total	349	343	371	362	372	377	411	461	458	453	3,957

Source

Canadian Organ Replacement Register, 2009, Canadian Institute for Health Information.

Table 13 Dialysis Duration Prior to First Kidney Transplant by Province of Treatment, Adult Kidney Transplant Recipients, Canada, 2006 to 2008

	B.C.	Alta.	Sask.	Man.	Ont.	Que.	N.S.	Canada
Duration on Dialysis (Median Days), Deceased Donor	2,266	1,073	1,001	1,599	1,778	824	756	1,283
Duration on Dialysis (Median Days), Deceased Donor, No Pre-Emptive	2,286	1,095	1,007	1,599	1,789	955	794	1,324
Duration on Dialysis (Median Days), Living Donor	212	390	465	532	344	283	208	323
Duration on Dialysis (Median Days), Living Donor, No Pre-Emptive	536	561	735	575	595	431	458	549

Notes

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

There were 3,135 adult first kidney transplants performed in Canada between 2006 and 2008, 459 of which were pre-emptive transplants.

Source

Canadian Organ Replacement Register, 2009, Canadian Institute for Health Information.

2.4.2 Recipient Characteristics

As the Canadian population ages, so does the group of patients receiving a kidney transplant. The proportion of recipients older than age 60 receiving a transplant from a deceased donor has doubled from 18% to 36% since 1999. A similar trend is observed for living-donor transplants (10% to 19%) (Table 14). Glomerulonephritis continues to be the predominant diagnosis among adults (324) (Table 15).

Table 14 Adult Kidney Transplant Recipients, Selected Characteristics, First Graft, Canada, 1999 to 2008 (Number, Percentage)

Donor	Characteristic	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008
Deceased	Percentage Male	60.1	63.2	63.9	63.5	64.7	62.1	63.8	61.9	63.8	65.0
	Percentage Age 60 +	18.2	20.0	25.7	29.4	26.7	30.6	29.5	29.7	34.9	35.8
	Average Age in Years (SD*)	47.8 (12.9)	48.2 (12.1)	50.0 (12.8)	50.6 (13.6)	50.4 (12.6)	51.2 (13.2)	51.8 (12.5)	51.9 (12.7)	53.4 (12.8)	53.2 (13.0)
	Percentage Diabetes	22.3	20.0	21.4	23.2	25.4	19.1	25.4	25.2	28.2	30.6
Living	Percentage Male	61.9	62.1	55.6	60.5	65.2	59.1	63.2	62.4	63.4	60.1
	Percentage Age 60 +	10.2	10.0	12.6	13.8	17.0	14.5	14.6	14.7	18.6	19.3
	Average Age in Years (SD*)	42.6 (13.0)	43.3 (12.8)	42.7 (13.3)	43.8 (13.5)	46.2 (13.0)	44.6 (13.2)	46.6 (12.6)	45.4 (13.1)	46.0 (13.8)	46.8 (13.4)
	Percentage Diabetes	18.6	17.5	18.2	18.8	23.7	22.0	22.4	18.1	21.5	17.6

Note

* SD: standard deviation.

Source

Canadian Organ Replacement Register, 2009, Canadian Institute for Health Information.

Table 15 Kidney Transplant Recipients* by Age Group and Primary Renal Diagnosis Category, Adult Recipients, First Graft, Canada, 2008 (Number)

	18–39 Years	40–59 Years	60+ Years	Total
Glomerulonephritis	93	155	76	324
Pyelonephritis	29	36	12	77
Nephropathy, Drug Induced	5	16	11	32
Polycystic Kidney Disease	9	97	42	148
Hypertension/Other Vascular	10	48	63	121
Diabetic Nephropathy	16	114	91	221
Other	64	78	35	177
Unknown/Not Reported	24	28	17	69
Total Diagnoses	250	572	347	1,169
Total Patients	227	516	309	1,052

Note

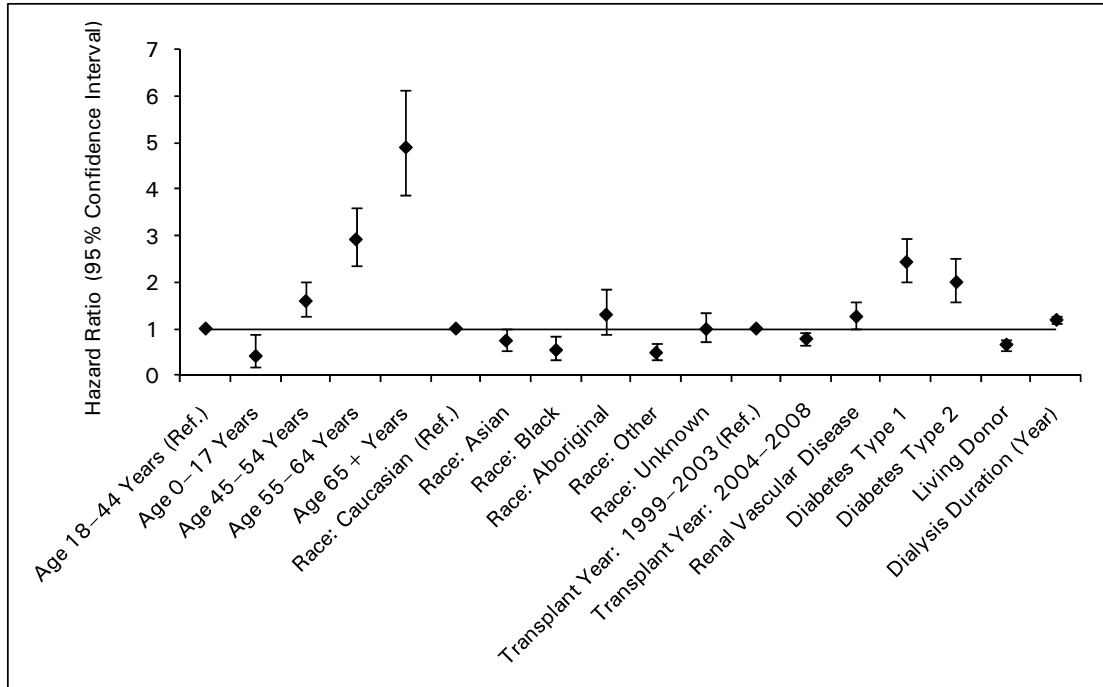
* Based on patients with first grafts. Both diagnoses provided at incident dialysis treatment and subsequent diagnoses at time of kidney transplant are included in this table.

Source

Canadian Organ Replacement Register, 2009, Canadian Institute for Health Information.

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

Figure 5 Cox Proportional-Hazards Model for Mortality Risk After Kidney Transplant, Patients, Canada, 1999 to 2008



Source

Canadian Organ Replacement Register, 2009, Canadian Institute for Health Information.

2.5 Kidney Transplantation: Pediatric Kidney Transplants

In this section pediatric patients are defined as those age 17 and younger.

Pediatric ESRD patients present different treatment challenges than adult patients. Transplantation has become the treatment of choice for this patient population. The trends in kidney transplantation for pediatric patients in Canada are presented in tables 16 to 19. Throughout the decade, there were 577 first graft transplants and 36 re-transplants on pediatric recipients. There was no distinct trend for transplants utilizing living-donor or deceased-donor organs.

Table 16 Kidney Transplants by Year, Donor Type and Re-Transplants, Pediatric Recipients, Canada, 1999 to 2008 (Number)

	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	Total
First Graft, Deceased Donor	27	32	18	28	27	19	39	22	42	24	278
First Graft, Living Donor	30	43	26	36	28	37	29	26	21	23	299
Re-Transplants	7	3	3	2	3	5	5	1	4	3	36
Total	64	78	47	66	58	61	73	49	67	50	613

Source

Canadian Organ Replacement Register, 2009, Canadian Institute for Health Information.

Table 17 Pediatric Kidney Transplants by Age Group and Province of Treatment, Canada, 1999 to 2008 (Number, Percentage)

		B.C.	Alta.	Sask.	Man.	Ont.	Que.	N.S.	Total
0–4 Years	N	10	9	0	3	34	18	10	84
	%	13.5	13.2	0.0	5.8	15.5	12.4	23.3	13.7
5–10 Years	N	18	20	0	15	40	30	8	131
	%	24.3	29.4	0.0	28.8	18.2	20.7	18.6	21.4
11–17 Years	N	46	39	11	34	146	97	25	398
	%	62.2	57.4	100.0	65.4	66.4	66.9	58.1	64.9
Total	N	74	68	11	52	220	145	43	613

Source

Canadian Organ Replacement Register, 2009, Canadian Institute for Health Information.

Table 18 Dialysis Duration Prior to First Kidney Transplant, Pediatric Recipients, Canada, 1999 to 2008

	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008
Duration on Dialysis (Median Days), Deceased Donor	548	448	292	430	460	586	625	633	398	344
Duration on Dialysis (Median Days), Deceased Donor, No Pre-Emptive	632	566	508	507	772	705	770	653	565	373
Duration on Dialysis (Median Days), Living Donor	241	193	137	140	175	267	107	144	137	66
Duration on Dialysis (Median Days), Living Donor, No Pre-Emptive	461	467	295	348	327	414	349	271	483	258

Note

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

Source

Canadian Organ Replacement Register, 2009, Canadian Institute for Health Information.

Table 19 Pediatric Kidney Transplant by Age Group and Primary Renal Diagnosis Category, Canada, 1999 to 2008

Primary Renal Diagnosis Category	0–4 Years		5–10 Years		11–17 Years		Total
	N	%	N	%	N	%	N
Alport’s Syndrome	0	0.0	1	0.7	11	2.7	12
Cystinosis	0	0.0	11	7.6	19	4.6	30
Dysplasia/Hypoplasia	25	25.5	34	23.6	49	11.9	108
Posterior Urethral Valves	9	9.2	8	5.6	16	3.9	33
Obstructive Uropathy	8	8.2	7	4.9	21	5.1	36
Vesico–Ureteric Reflux	2	2.0	3	2.1	20	4.8	25
Polycystic Kidneys	2	2.0	2	1.4	17	4.1	21
Nephronophthisis	1	1.0	8	5.6	18	4.4	27
Other Congenital/Hereditary	13	13.3	3	2.1	9	2.2	25
Other Pyelonephritis	0	0.0	5	3.5	10	2.4	15
Glomerulonephritis	12	12.2	15	10.4	64	15.5	91
Focal Sclerosis	5	5.1	10	6.9	24	5.8	39
Autoimmune Disease	1	1.0	1	0.7	24	5.8	26
Hemolytic–Uremic Syndrome	0	0.0	8	5.6	15	3.6	23
Other	10	10.2	16	11.1	49	11.9	75
Unknown	10	10.2	12	8.3	47	11.4	69
Total	98	100.0	144	100.0	413	100.0	655

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.

Source

Canadian Organ Replacement Register, 2009, Canadian Institute for Health Information.

3 Liver Transplantation

The science of liver transplantation experienced a paradigm shift in 1989, when the first living-donor partial liver transplant was performed in the United States. In Canada, the first living-donor parent-to-child liver transplant followed in 1993, with the first living-donor adult-to-adult liver transplant in Canada in 2000. Advances in immunosuppression have dramatically enhanced patient survival. Beginning in the 1980s, improvements in organ preservation and surgical techniques worked together to improve graft and patient survival. Given these developments, liver transplantation is now considered the optimal form of therapy for end-stage liver disease. This section presents Canadian liver transplantation activity in the last decade, from 1999 to 2008.

The decade spanning 1999 to 2008 saw 4,217 liver transplants registered with CORR, with over 81% of patients overall receiving livers from deceased donors (Table 20). However, during that period the proportion of transplants from living donors increased from 2% in 1999 to 15% in 2008. While most of the transplants were liver only, there were also combination transplants performed; the liver–kidney combination was the most frequently observed (n = 63) (Table 21).

Between 1999 and 2008, more males received liver transplants (64%), primarily those age 35 and older (Table 22). Among recipients younger than age 10, biliary atresia was the predominant cause of end-stage liver failure. Among recipients age 35 and older, the most commonly reported diagnosis was hepatitis C (Table 22).

The medical status of liver disease patients is part of the clinical decision-making algorithm. Status 1 (at home), 1T (at home with tumour) and 2 (hospitalized) patients are considered non-urgent. In contrast, Status 3 (in ICU), 3F (in ICU and fulminant) and 4 (in ICU intubated, ventilated and fulminant) are considered urgent. There has been little change over the decade in the distribution of patient medical status at the time of transplantation. Excepting 1999, more than 80% of liver transplant recipients receiving a first graft in the past decade were considered non-urgent (Status 1 and 2) (Figure 6).

The crude RPMP of liver transplant recipients is highest in Ontario (15.0) and Alberta (11.7). The remaining provinces range from 8.1 to 10.7 RPMP (Figure 7).

Prior to 2007, the number of people waiting for a liver transplant climbed each year, with the highest number in 2006, at 723 patients (Table 23). In 2008, the waiting list decreased to 587, and deaths on the waiting list also decreased, from 141 to 92 between 2005 and 2008 (Table 23).

Table 20 Liver Transplants by Year, Donor Type, Age Group and Re-Transplants, Canada, 1999 to 2008 (Number)

	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	Total
First Graft < 18, Deceased Donor	39	30	20	25	33	15	34	25	28	27	276
First Graft < 18, Living Donor	6	6	13	10	6	12	8	9	15	10	95
Re-Transplants < 18	13	4	4	3	4	3	9	8	6	7	61
First Graft 18+, Deceased Donor	301	336	293	290	302	318	297	324	342	318	3,121
First Graft 18+, Living Donor	2	13	31	32	29	42	52	58	56	58	373
Re-Transplants 18+	23	20	33	26	31	27	23	42	33	33	291
Total	384	409	394	386	405	417	423	466	480	453	4,217

Source

Canadian Organ Replacement Register, 2009, Canadian Institute for Health Information.

Table 21 Combination Liver Transplants, Canada, 1999 to 2008 (Number)

	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	Total
Liver Only	378	403	383	381	399	414	416	447	468	442	4,131
Liver-Kidney	5	4	9	3	5	3	5	11	9	9	63
Liver-Small Bowel	1	1	1	1	1	0	1	4	2	1	13
Other Combination	0	1	1	1	0	0	1	4	1	1	10
Total	384	409	394	386	405	417	423	466	480	453	4,217

Source

Canadian Organ Replacement Register, 2009, Canadian Institute for Health Information.

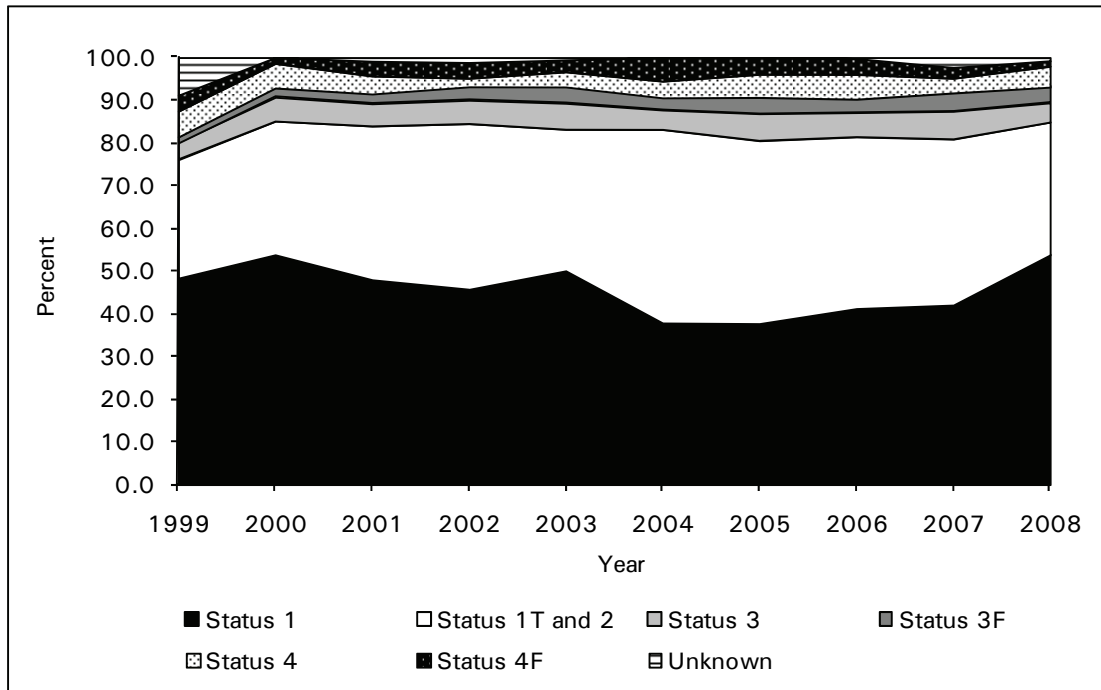
Table 22 Primary Diagnoses for Liver Transplant Recipients, First Grafts by Age Group, Canada, 1999 to 2008 (Number, Percentage of Age Group)

Age Group (Years)	N	Percent Male	Primary Biliary Atresia	Hepatitis C	Hepatitis B	Other Hepatitis	Alcoholic Cirrhosis	Cryptogenic Cirrhosis	Cancer	Metabolic Disorders	Unknown/Missing	Other
<1	179	41.9	56.1	1.1	0.0	4.4	0.0	0.6	1.7	5.6	11.1	19.4
1-10	110	55.5	27.4	0.9	0.0	5.3	0.0	0.0	11.5	11.5	11.5	31.9
11-17	82	48.8	5.8	2.3	1.2	14.0	0.0	3.5	7.0	8.1	7.0	51.2
18-34	282	50.7	0.7	4.3	6.6	12.8	1.0	4.3	5.6	7.2	3.6	54.1
35-59	2,396	68.1	0.1	29.6	6.4	3.6	17.5	4.0	11.5	2.0	1.8	23.7
60+	816	64.5	0.1	17.6	6.6	3.4	17.7	8.0	19.0	2.6	1.7	23.1
Total	3,865	64.1	3.1	22.9	5.9	4.4	15.0	4.7	12.3	3.0	2.6	26.1

Source

Canadian Organ Replacement Register, 2009, Canadian Institute for Health Information.

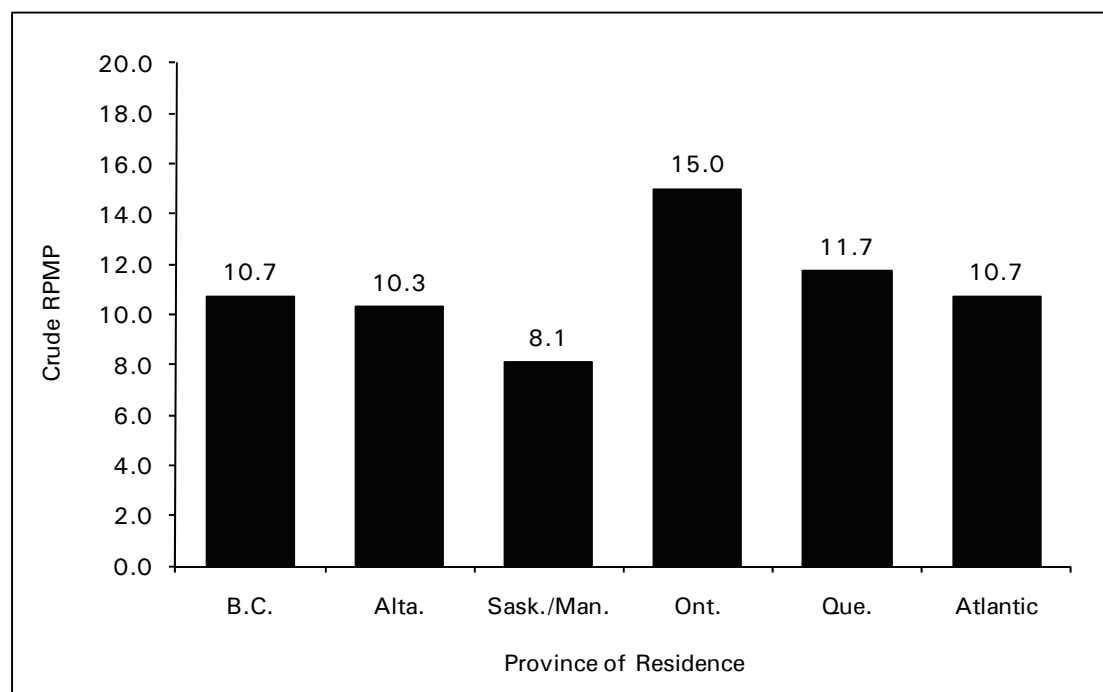
Figure 6 Distribution of Liver Transplants by Medical Status at Transplant, Canada, 1999 to 2008



Source

Canadian Organ Replacement Register, 2009, Canadian Institute for Health Information.

Figure 7 Liver Transplant Recipients by Province of Residence, Canada, 2008 (Crude RPMP)



Note

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

Source

Canadian Organ Replacement Register, 2009, Canadian Institute for Health Information.

Table 23 Liver Transplant Waiting List and Deaths, December 31, Canada, 1999 to 2008

	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	Total
< 18 Years	20	27	36	31	30	37	32	36	19	17	285
18+ Years	298	311	418	528	539	630	681	687	616	570	5,278
Total	318	338	454	559	569	667	713	723	635	587	5,563
Deaths on Waiting List	70	51	57	82	100	96	141	120	77	92	886

Source

Canadian Organ Replacement Register, 2009, Canadian Institute for Health Information.

4 Heart Transplantation

Heart transplantation is the treatment of last resort for people with heart failure. In Canada, heart transplants are the third most common organ transplant operation, after kidney and liver transplants. This section shows the trends in heart transplantation procedures and outcomes in Canada over the decade 1999 to 2008.

Between 1999 and 2008, there were 1,643 heart transplants registered in CORR, including 55 re-transplants. The number of transplants performed each year remained fairly stable between 1999 (164) and 2008 (166). While the number of children younger than a year old receiving heart transplants fluctuated minimally over the decade, it peaked in 2006 at 17. The largest number of transplants was performed on recipients between age 35 and 59 (803), followed by those age 60 and older (336) (Table 24).

In each age group, the proportion of male recipients was higher than females; it was highest in those age 60 and older (84%). Over the last decade, males comprised 74% of Canadian heart transplant recipients (Table 25).

Persons on the waiting list for a heart transplant are categorized according to their medical status at the time of transplant. Status 1 and 2 patients are classified as non-urgent and may be at home or in hospital. Status 3, 3B and 4 patients are in the most urgent need of a transplant. Status 3A and 3B patients may be in the ICU or on inotropic drugs to strengthen heart muscle contractions, while Status 4 patients are already in the ICU with ventilator support. Since 2004, about half of all heart transplants have been classified as urgent (Figure 9).

There were 131 people on the waiting list for a heart transplant in 2008. Since 1999, deaths on the waiting list have declined from 41 in 1999 to 14 in 2008 (Table 26). A total of 269 Canadians died over the last decade while waiting for a heart transplant.

Table 24 Heart Transplants by Year, Age Group and Re-Transplants, Canada, 1999 to 2008 (Number)

	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	Total
First Graft <1 Year	9	10	10	5	6	14	15	17	7	16	109
First Graft 1–10 Years	10	8	8	8	4	7	8	7	9	6	75
First Graft 11–17 Years	7	8	9	8	10	9	9	9	11	15	95
First Graft 18–34 Years	12	17	19	15	16	13	18	27	14	19	170
First Graft 35–59 Years	83	80	71	84	82	66	86	91	85	75	803
First Graft 60+ Years	40	38	40	41	33	30	33	20	31	30	336
Re-Transplants	5	12	4	3	6	4	5	7	6	3	55
Total	166	173	161	164	157	143	174	178	163	164	1,643

Source

Canadian Organ Replacement Register, 2009, Canadian Institute for Health Information.

Table 25 Primary Diagnoses for Heart Transplant Recipients, Canada, 1999 to 2008 (Percentage of Age Group)

Age Group (Years)	N	Percent Male	Congenital	C Unspecified	Dilated C	Idiopathic C	Ischemic C	Unknown/Missing	Other
<1	122	58.2	50.0	10.9	10.2	2.3	0.8	9.4	16.4
1–10	62	58.1	34.9	9.5	12.7	3.2	1.6	12.7	25.4
11–17	95	57.9	18.2	22.2	23.2	5.1	2.0	9.1	20.2
18–34	170	68.8	11.0	11.5	27.5	11.0	3.3	2.7	33.0
35–59	803	76.7	1.8	8.8	19.9	9.4	35.8	3.0	21.4
60+	336	83.6	0.3	8.4	15.1	7.2	55.7	2.3	11.0
Total	1,588	74.1	8.4	10.0	18.9	8.1	30.3	4.0	20.2

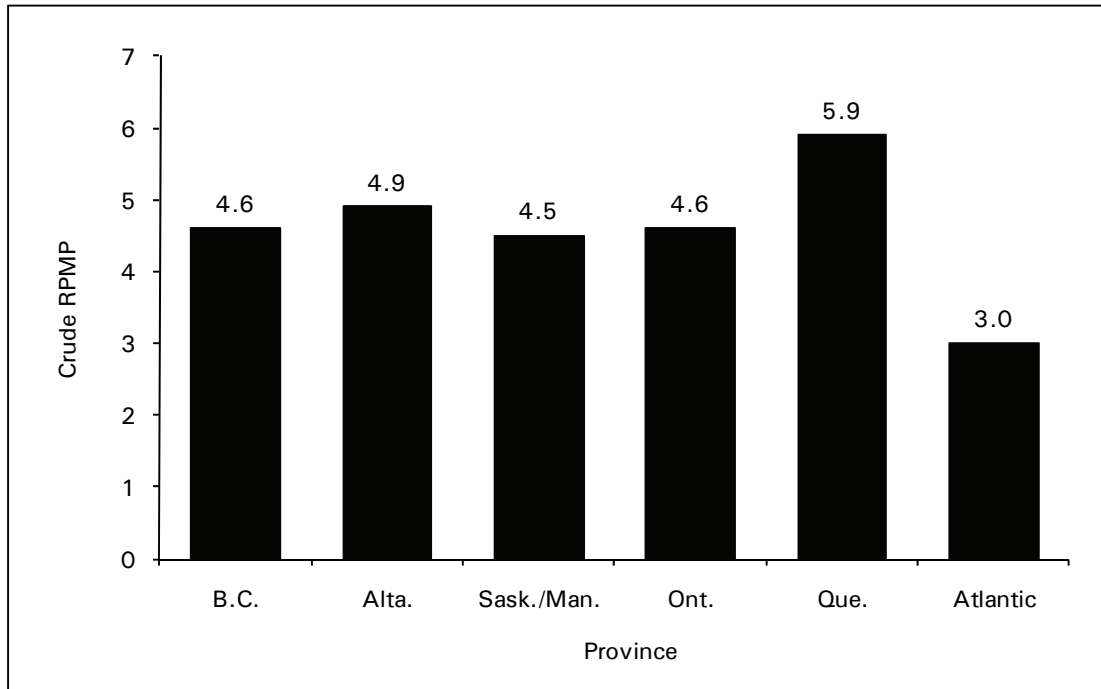
Note

C: cardiomyopathy.

Source

Canadian Organ Replacement Register, 2009, Canadian Institute for Health Information.

Figure 8 Heart Transplant Recipients by Province of Residence, Canada, 2008 (Crude RPMP)



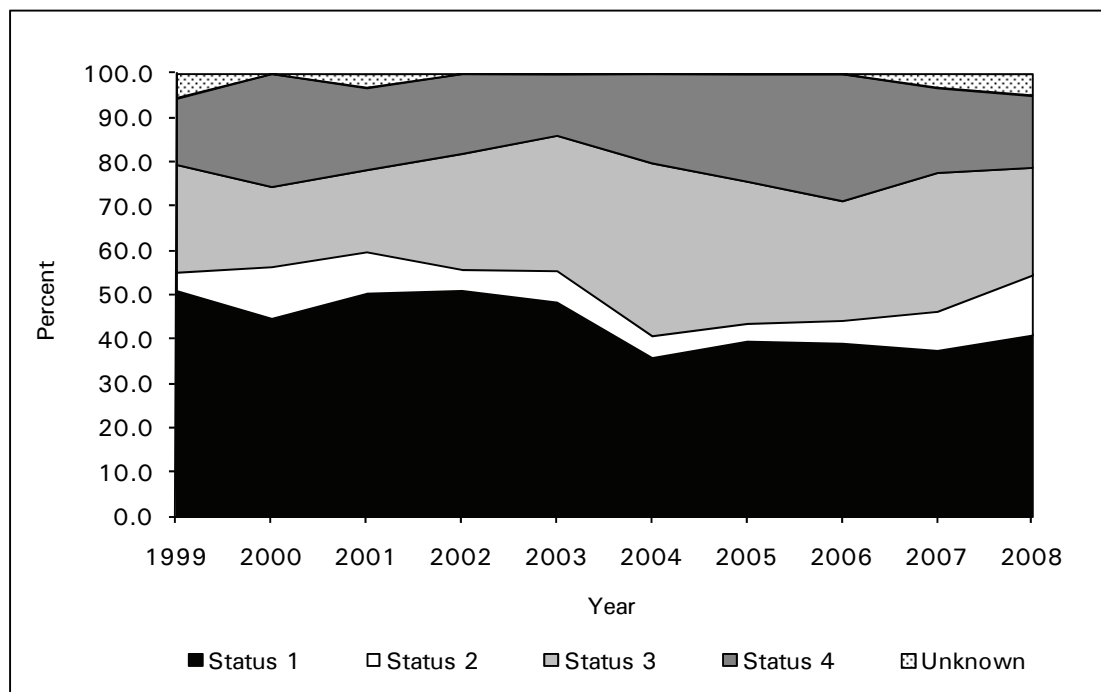
Note

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

Source

Canadian Organ Replacement Register, 2009, Canadian Institute for Health Information.

Figure 9 Distribution of Heart Transplants by Medical Status* at Transplant, Canada, 1999 to 2008



Note

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

Source

Canadian Organ Replacement Register, 2009, Canadian Institute for Health Information.

Table 26 Waiting Lists and Deaths on the Waiting List for Heart Transplant, 1999 to 2008

	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	Total
< 18 Years	13	9	13	13	37	6	9	7	13	17	137
18+ Years	88	80	112	90	94	119	87	80	102	114	966
Total	101	89	125	103	131	125	96	87	115	131	1,103
Deaths on Waiting List	41	30	34	35	30	26	27	13	19	14	269

Source

Canadian Organ Replacement Register, 2009, Canadian Institute for Health Information.

5 Lung Transplantation

The first single-lung transplant procedure in Canada was performed in 1983, followed by the first bilateral lung transplant in 1986. Since then, outcomes for lung transplant recipients have continued to improve for several reasons: better organ preservation techniques, improvements in pre- and peri-operative care, better follow-up medical management of recipients and advances in immunosuppression. Lung transplant activity almost doubled in the last decade in Canada. This section presents the evolving landscape of lung transplant procedures in Canada during the decade from 1999 to 2008.

Between 1999 and 2008, there was an increase in the annual number of lung transplants performed in Canada. During the decade, the total number of lung transplants reached 1,399, reflecting an increase of 81% from 1999 (91) to 2008 (165) (Table 27). During the decade, the volume of bilateral lung transplants increased by 142%, from 55 to 133. Single-lung transplant volumes fluctuated somewhat but did not change consistently over time (30 in 1999, 27 in 2008) (Table 28).

In 2008, Alberta had the highest rate of lung transplantation at 7.0 RPMP, followed by Ontario and Saskatchewan/Manitoba with 5.4 RPMP (Figure 10).

The number of individuals on the waiting list for a lung transplant continued to grow over the decade, with 282 in 2008, up from 243 in the previous year. Since 2004, the number of people dying annually has remained relatively constant at around 40 (Table 30).

Table 27 Lung Transplants by Year, Age Group and Re-Transplants, Canada, 1999 to 2008 (Number)

	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	Total
First Graft 18 +	85	121	120	130	112	128	137	166	179	155	1,333
First Graft < 18	5	2	4	5	2	3	5	4	4	5	39
Re-Transplants	1	1	2	4	4	2	3	1	4	5	27
Total	91	124	126	139	118	133	145	171	187	165	1,399

Source

Canadian Organ Replacement Register, 2009, Canadian Institute for Health Information.

Table 28 Lung Transplants by Transplant Type, Canada, 1999 to 2008 (Number)

	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	Total
Bilateral Lung	55	85	82	96	95	98	119	129	152	133	1,044
Single Lung	30	34	39	36	21	30	19	35	32	27	303
Living-Donor Lobar	1	1	2	0	0	2	1	1	0	0	8
Heart–Lung	5	4	3	7	2	3	6	6	3	5	44
Total	91	124	126	139	118	133	145	171	187	165	1,399

Source

Canadian Organ Replacement Register, 2009, Canadian Institute for Health Information.

Table 29 Primary Diagnoses* for Lung Transplant Recipients, First Grafts, Canada, 1999 to 2008 (Number, Percent)

	Bilateral Lung		Single Lung		Heart–Lung	
	N	%	N	%	N	%
Congenital	8	0.8	1	0.3	15	34.1
Alpha Antitrypsin	61	5.9	18	5.8	1	2.3
Cystic Fibrosis	293	28.5	13	4.2	3	6.8
Emphysema/COPD	224	21.8	155	49.5	4	9.1
Idiopathic Pulmonary Fibrosis	211	20.5	88	28.1	3	6.8
Primary Pulmonary Hypertension	50	4.9	2	0.6	7	15.9
Unknown/Missing	35	3.4	4	1.3	2	4.5
Other	145	14.1	32	10.2	9	20.5
Total	1,027	100.0	313	100.0	44	100.0

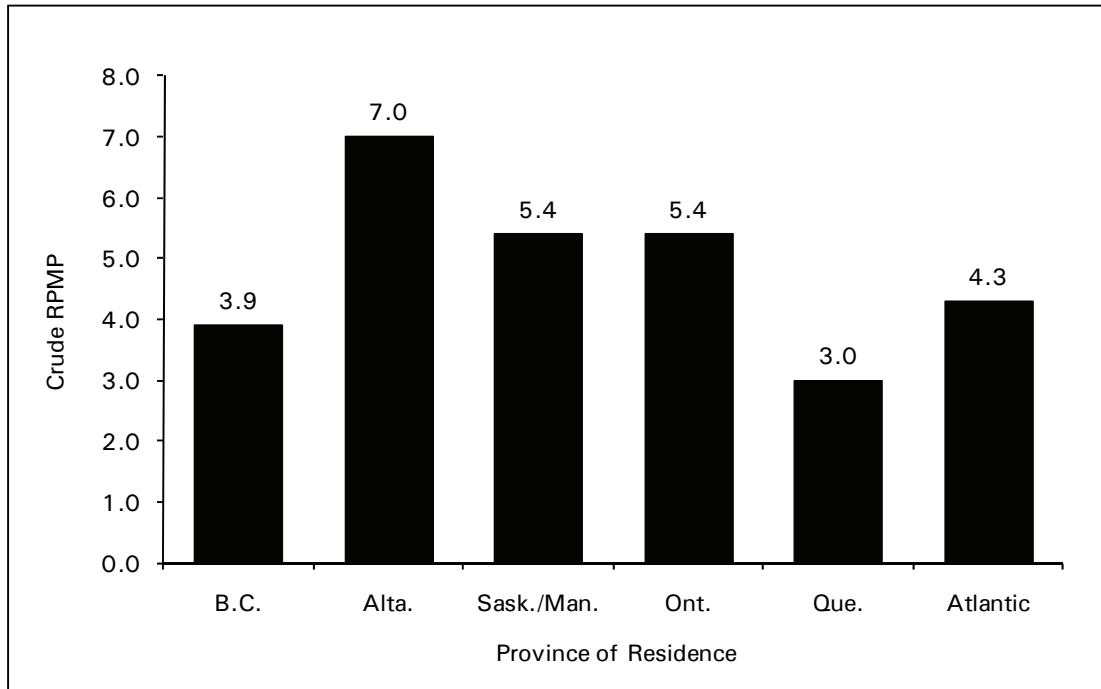
Note

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

Source

Canadian Organ Replacement Register, 2009, Canadian Institute for Health Information.

**Figure 10 Lung Transplant Recipients by Province of Residence, Canada, 2008
(Crude Rate per Million Population)**



Note

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

Sources

Canadian Organ Replacement Register, 2009, Canadian Institute for Health Information; and Statistics Canada.

Table 30 Lung Transplant Waiting List, December 31, Canada, 1999 to 2008

	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	Total
Bilateral Lung	93	108	125	88	131	155	188	147	183	147	1,365
Single Lung	64	58	25	50	29	22	37	94	51	129	559
Heart–Lung	11	11	13	12	12	4	14	11	9	6	103
Total	168	177	163	150	172	181	239	252	243	282	2,027
Deaths on Waiting List	27	21	28	26	29	43	43	36	43	44	340

Source

Canadian Organ Replacement Register, 2009, Canadian Institute for Health Information.

6 Pancreas Transplantation

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

Over the decade from 1999 to 2008, there were 671 pancreas transplants performed in Canada (Table 31). The majority of the transplants performed (72%) were SKP procedures. Table 32 summarizes islet cell transplants, a medical procedure that involves replacing the insulin-producing cells of the pancreas (islet cells), which are destroyed in people with type 1 diabetes. Since 1999, 265 procedures have been performed on 135 patients (in general, patients receive two procedures).

More pancreas transplantations in Canada have been performed on men than women (Figure 11). The number of people waiting for pancreas transplant fluctuated over time. The number awaiting a PTA/PAK procedure increased over time, while the number awaiting an SKP procedure spiked in 2001 and fluctuated since then, decreasing to 98 people in 2008 (from 132 in 2005, Table 33).

Table 31 Pancreas Transplants by Year, Canada, 1999 to 2008 (Number)

Transplant*	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	Total
SKP	51	47	34	44	38	47	53	55	50	63	482
PAK	18	14	11	15	16	11	12	14	12	16	139
PTA	0	4	3	11	9	3	6	5	6	3	50
Total	69	65	48	70	63	61	71	74	68	82	671

Note

* SKP: simultaneous kidney–pancreas transplant; PAK: pancreas after kidney transplant; PTA: pancreas transplant alone.

Source

Canadian Organ Replacement Register, 2009, Canadian Institute for Health Information.

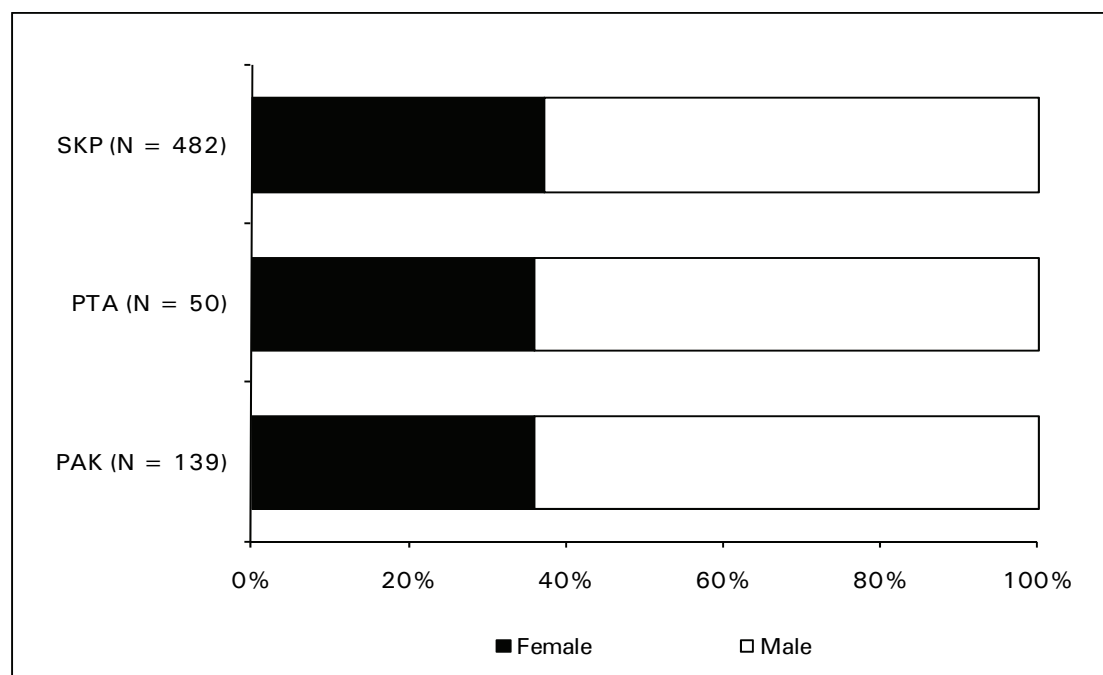
Table 32 Islet Cell Transplants in Canada, 1999 to 2008

	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	Total
Patients	6	10	16	20	11	6	26	17	8	15	135
Procedures	13	22	22	41	20	11	37	39	25	35	265

Source

Canadian Organ Replacement Register, 2009, Canadian Institute for Health Information.

Figure 11 Pancreas Transplant Recipients by Type* and Recipient Sex, First Grafts, Canada, 1999 to 2008 (Percent)



Note

* SKP: simultaneous kidney–pancreas transplant; PAK: pancreas after kidney transplant; PTA: pancreas transplant alone.

Source

Canadian Organ Replacement Register, 2009, Canadian Institute for Health Information.

Table 33 Pancreas and Kidney–Pancreas Transplant Waiting List, Canada, 1999 to 2008 (Number)

	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008
PTA/PAK	17	30	32	37	31	51	63	63	55	49
SKP	100	128	172	122	120	101	132	113	126	98
Total	117	158	204	159	151	152	195	176	181	147

Note

* SKP: simultaneous kidney–pancreas transplant; PAK: pancreas after kidney transplant; PTA: pancreas transplant alone.

Source

Canadian Organ Replacement Register, 2009, Canadian Institute for Health Information.

7 Intestinal Transplantation^v

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

From the inception of CORR until 2008, there were 51 intestinal transplants recorded (Table 34). The transplants were almost evenly split between pediatric patients and adult recipients. The majority of liver–small intestine transplants were performed in those younger than age 18 (75%).

Table 34 Intestinal Transplants by Transplant Period and Age Group, Canada, 1989 to 2008 (Number)

Type of Graft	1989–1998		1999–2008		Total		
	<18 Years	18+ Years	<18 Years	18+ Years	<18 Years	18+ Years	All Ages
Multi-Visceral	1	2	2	9	3	11	14
Isolated Small Intestine	5	2	3	4	8	6	14
Liver–Small Intestine	3	4	12	1	15	5	20
Kidney–Small Intestine	0	2	0	0	0	2	2
Liver–Kidney–Small Intestine	0	0	1	0	1	0	1
Total	9	10	18	14	27	24	51

Source

Canadian Organ Replacement Register, 2009, Canadian Institute for Health Information.

v. The information on intestinal transplantation is restricted in content by the small number of intestinal transplants. 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 1989 and 2008.

Appendix A—Canadian Organ Replacement Register Board of Directors and Advisory Committee

CORR Board of Directors (November 1, 2009)

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

CORR Advisory Committee (November 1, 2009)

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

Appendix B—Canadian Transplant Hospitals 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 2008							Dialysis Programs in 2008				
	Kidney	Liver	Heart	Heart–Lung	Lung	Intestine/ Multi-Visceral	Pancreas/ Kidney–Pancreas	Islet Cell	HD	Home HD Training	PD	Home PD Training
Northwest Territories												
* Stanton Territorial Health Authority									X			
* Hay River 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 General	X	X			X		X	X	X		X	X
Alberta												
SARP, Foothills Medical	X						X		X	X	X	X
NARP, University of Alberta	X	X	X	X	X	X	X	X	X	X	X	X
Alberta Children’s Hospital	X											
Saskatchewan												
Regina General									X		X	X
St. Paul’s	X								X		X	X
Manitoba												
Brandon Regional									X			
Children’s Hospital of Winnipeg	X								X			
Health Sciences Centre	X				X				X	X		
Seven Oaks General									X			
St. Boniface General									X		X	X
Ontario												
* Bayshore Centre Dialysis Brockville									X			
* Bayshore Centre Dialysis Stoney Creek									X			
* Brantford General									X			

Hospital/Facility	Type of Transplants Performed in 2008								Dialysis Programs in 2008			
	Kidney	Liver	Heart	Heart-Lung	Lung	Intestine/ Multi-Visceral	Pancreas/ Kidney-Pancreas	Islet Cell	HD	Home HD Training	PD	Home PD Training
Children's Hospital of Eastern Ontario									X		X	
* Cornwall Dialysis Clinic									X			
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
Niagara Health System									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		X			
LHSC—Victoria									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
Toronto East General									X			

Hospital/Facility	Type of Transplants Performed in 2008								Dialysis Programs in 2008			
	Kidney	Liver	Heart	Heart-Lung	Lung	Intestine/ Multi-Visceral	Pancreas/ Kidney-Pancreas	Islet Cell	HD	Home HD Training	PD	Home PD Training
Toronto General—University Health Network	X	X	X	X	X	X	X		X	X	X	X
University of Ottawa Heart Institute			X									
William Osler									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-LeMoynes									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
Maisonneuve-Rosemont	X								X	X	X	X
Montreal Children's, McGill	X								X		X	X
Montreal General, McGill									X	X	X	X
Royal Victoria, McGill	X	X	X	X			X		X		X	X
Sacré-Cœur de Montréal									X		X	X
* Sainte-Croix									X		X	
Sainte-Justine	X	X	X						X		X	X
Sir Mortimer B. Davis—Jewish General Hospital									X		X	X
St. Mary's									X		X	X

Hospital/Facility	Type of Transplants Performed in 2008								Dialysis Programs in 2008			
	Kidney	Liver	Heart	Heart-Lung	Lung	Intestine/ Multi-Visceral	Pancreas/ Kidney-Pancreas	Islet Cell	HD	Home HD Training	PD	Home PD Training
New Brunswick												
Chaleur Regional									X			
Edmundston									X	X	X	X
Georges L. Dumont									X	X	X	X
Saint John Regional									X	X	X	X
St. Joseph's									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			
Newfoundland and Labrador												
Central Newfoundland Regional									X			
Eastern Health									X	X	X	X
Western Memorial Regional									X			

Appendix C—Canadian Organ Procurement Organizations

British Columbia

BC Transplant
West Tower, 3rd Floor
555 12th Avenue West
Vancouver, British Columbia V5Z 3X7
www.transplant.bc.ca

Alberta

Southern Alberta Organ and Tissue Donation Program—Calgary
SAOTDP
Foothills Medical Centre Site
1403 29th Street North West
Calgary, Alberta T2N 2T9

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

Saskatchewan

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

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

Manitoba

Transplant Manitoba—Gift of Life
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
Head Office
4100 Molson Street, Suite 200
Montréal, Quebec H1Y 3N1
www.quebec-transplant.qc.ca

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

New Brunswick

New Brunswick Organ and Tissue Procurement Program
Department of Health, Hospital Services Branch
P.O. Box 5100
Fredericton, New Brunswick E3B 5G8
www.gnb.ca/0051/0217/organ/index-e.asp

Nova Scotia

Multi-Organ Transplant Program
Queen Elizabeth II Health Sciences Centre
1278 Tower Road, P.O. Box 9000
6 South, Room 291
Victoria Building
Halifax, Nova Scotia B3H 2Y9
www.cdha.nshealth.ca/default.aspx?page=SubPage&category.Categories.1=92¢erContent.Id.0=5279

Newfoundland and Labrador

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

Appendix D—CORR Data Quality Documentation: 1999 to 2008

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

Database Description

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

Data Sources and Methodology

Target Population: All patients who have received an extra-renal organ transplant since January 1, 1988, and all chronic renal failure patients who have initiated renal replacement therapy since January 1, 1981, form CORR's target population. CORR does not contain information on 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; and 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 is received either directly or indirectly from these programs. Tables D1 and D2 below identify the number of dialysis programs and transplant programs, respectively, in 2008 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, 2008

	N.W.T.	B.C.	Alta.	Sask.	Man.	Ont.	Que.	N.B.	N.S.	N.L.	Total
Full-Care Dialysis Programs	0	12	2	2	4	31	31	4	4	3	93
Affiliated Community Centres	0	24	31	8	12	47	8	5	15	7	157
Independent Health Care Facilities Offering Hemodialysis	2	0	0	0	0	11	2	1	0	0	16

Table D2 Transplant Programs Within CORR Frame by Province, 2008

	B.C.	Alta.	Sask.	Man.	Ont.	Que.	N.S.	Total
Kidney	3	3	2	2	7	7	2	26
Liver	1	1	0	0	3	3	1	9
Heart/Heart–Lung	1	1	0	0	6	7	1	16
Lung	1	1	0	1	2	1	0	6
Pancreas/ Kidney–Pancreas	1	2	0	0	2	4	2	11
Intestine/ Multi-Visceral	0	1	0	0	5	0	0	6
Islets	1	1	0	0	0	0	0	2

Frame maintenance procedures have been in place for several years. CORR staff is informed by provincial sources of new dialysis hospitals and generally follows the Discharge Abstract Database 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 2002 to formally verify CORR's frame.

Data Sources: CORR comprises retrospectively collected demographic, clinical and outcome-related data. Data is 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.

Within CORR, data elements are classified as mandatory, conditionally mandatory or optional. Mandatory elements must be submitted and entered (for example, Recipient Name, Birthdate, Treatment Code), whereas conditionally mandatory elements are entered only if other specific conditions are satisfied (for example, Date of Death must be entered if a Cause of Death is given). Prior to 2001, mandatory items within CORR were limited to 19 data elements. Since 2001, major changes have occurred with CORR. Data providers are encouraged to submit information on all data elements, although it should be emphasized that reporting to CORR is not provincially or nationally mandated. The types of data captured, as well as the points of data capture within CORR, are summarized in Table D3. Changes in patients' treatment status are tracked and treatment outcomes are recorded. Information on organ donors is also collected. Facility-level data on clinical practices and policies is 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
<p>When initiate dialysis</p> <p>↓</p> <p>When:</p> <ul style="list-style-type: none"> • Transfer to another program • Change treatment modalities • Have a kidney transplant • Withdraw from dialysis • Recover kidney function • Die <p>↓</p> <p>Annually, on October 31 (survey with voluntary participation)</p>	<p>When transplanted</p> <p>↓</p> <p>When:</p> <ul style="list-style-type: none"> • Transfer to another program for follow-up • Graft fails • Re-transplanted • Die • For liver transplant recipients only—annual follow-up to record recurrent hepatitis B, hepatitis C and liver tumour(s) 	<p>When organ(s) are retrieved for purposes of transplantation—deceased donor profile and living donor profile</p>	<p>At year-end—HD facility profile and PD facility profile</p>	<p>At year-end—renal transplant facility profile</p>	<p>Counts of patients waiting for transplants at each of the transplant programs; reported on a semi-annual basis by the OPOs</p>

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
N.W.T.	Hospital dialysis program				
B.C.	BC Renal Agency, hospital dialysis programs	BC Transplant	BC Transplant	BC Transplant	BC Transplant
Alta.	Southern Alberta Renal Program (Calgary) and Northern Alberta Renal Program (Edmonton)	Hospital transplant programs	Southern Alberta Organ and Tissue Donation Program Calgary, HOPE Edmonton	Hospital transplant programs	Southern Alberta Organ and Tissue Donation Program Calgary, HOPE Edmonton
Sask.	Hospital dialysis programs	Saskatchewan Transplant Program	Saskatchewan Transplant Program	Saskatchewan Transplant Program	Saskatchewan Transplant Program
Man.	Manitoba renal program	Hospital transplant program	Transplant Manitoba—Gift of Life	Hospital transplant program	Transplant Manitoba—Gift of Life
Ont.	Hospital dialysis programs, The Renal Disease 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
N.B.	Hospital dialysis programs		New Brunswick Organ and Tissue Procurement Program		
N.S.	Hospital dialysis programs	Multi-Organ Transplant Program	Multi-Organ Transplant Program	Multi-Organ Transplant Program	Multi-Organ Transplant Program
N.L.	Hospital dialysis programs		Organ Procurement and Exchange of Newfoundland and Labrador (OPEN)		

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. Data entry staff may also liaise with a reporting centre prior to data entry when visual scans of the returned forms reveal problems or when problems in the data have been identified through the course of analysts’ work on ad hoc requests and research projects.

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

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

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

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

Quality Evaluation: CIHI's Data Quality Framework, which was implemented in 2000–2001, provides a common strategy for assessing data quality across CIHI databases and registries along five general dimensions:

- **Accuracy:** how well information within a database reflects what was supposed to be collected
- **Comparability:** the extent to which a database can be properly integrated within the entire health information system at CIHI
- **Timeliness:** whether the data is 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. An analysis of transplant procedures as captured in the Hospital Morbidity Database for the calendar years 1995 to 2000 confirms the transplant hospitals within CORR.

A formal linkage^{vi} of CORR data to the Discharge Abstract Database (DAD) and the National Ambulatory Care Reporting System (NACRS) completed in 2008 found that patients who received a transplant or who have chronic renal failure are well reported in CORR. The coverage of transplants in CORR is 98.5% when compared to data on transplants in DAD. For coverage of dialysis treatment in Ontario, the patients receiving dialysis were comparable between CORR and NACRS.

Duplicate patient records were 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 failed to report to CORR in a timely and complete way are identified and staff works with them to improve reporting. Strategies to improve reporting include telephone support and on-site support, where needed. Trending of incident dialysis patients and cross-checking of aggregate-level data sources with patient-level data are two main analytical approaches used to evaluate unit non-response. In this section, unit non-response is described for the data used in this report.

vi. Canadian Institute for Health Information, *Data Quality Study on the Canadian Organ Replacement Register* (Ottawa, Ont.: CIHI, 2009). This study is available for download as a PDF document at www.cihi.ca/corr.

1) Prevalent ESRD Cases

In 2008, unit non-response among prevalent ESRD patients was estimated to be 45 cases from Quebec and 25 cases from Alberta.

2) Incident ESRD Cases

In 2008, unit non-response for incident ESRD cases (under-reporting) was estimated to be 45 cases from Quebec and 25 cases from Alberta.

3) Kidney Transplants

Since the 1990s, patient-level data submitted by hospitals and OPOs is reconciled with aggregate-level counts received from OPOs, which are received in advance of patient-level data submissions. Table D5 presents a comparison of these sources and the respective transplant counts per province for 2008, and shows that the new patient-level data is marginally less than the OPO aggregate counts. This suggests 99.7% reporting of aggregate data.

Table D5 Comparison of Counts of Kidney Transplants* by Data Source, 2008 (Number)

	B.C.	Alta.	Sask.	Man.	Ont.	Que.	N.S.	Total
Aggregate Counts Provided by OPOs at Year-End	167	130	35	47	506	297	97	1,279
Patient-Level Data for Transplants in CORR	168	131	35	47	506	292	96	1,275

Note

* Includes SKP and other kidney combination transplants.

4) Extra-Renal Transplants

For the extra-renal transplants in 2008, 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 and Province of Treatment, 2008 (Number)

Organ Type	Data Source [†]	B.C.	Alta.	Man.	Ont.	Que.	Total
Liver	CORR Registration	47	65	0	203	112	427
	OPO Count	47	66	0	201	111	425
Heart	CORR Registration	17	32	0	63	47	159
	OPO Count	17	33	0	66	47	163
Lung/Heart–Lung	CORR Registration	14	35	6	85	25	165
	OPO Count	14	37	6	52	26	135
Pancreas	CORR Registration	6	13	0	34	23	76
	OPO Count	6	13	0	34	23	76
Intestine/ Multi-Visceral	CORR Registration	0	2	0	2	0	4
	OPO Count	0	2	0	2	0	4

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 with donor numbers reported by OPOs at year-end is provided in Table D7. This table suggests that no under-reporting of donors has been observed in CORR; however, under-reporting by OPOs of 32 cases in 2004 and 28 cases in 2007 occurred. Overall, the number of donors collected by CORR between 1999 and 2008 was greater by 75 donors than initially reported by OPOs.

Table D7 Comparison of Deceased and Living Donors Registered in CORR and Reported by OPOs, 1999 to 2008 (Number)

Year	Registered in CORR			Reported by OPOs		
	Deceased Donors	Living Donors	Total Donors	Deceased Donors	Living Donors	Total Donors
1999	420	393	813	421	392	813
2000	472	409	881	471	409	880
2001	416	448	864	420	447	867
2002	407	441	848	405	440	845
2003	423	438	859	428	431	859
2004	417	474	914	414	468	882
2005	414	503	917	414	504	918
2006	464	556	1,020	468	554	1,022
2007	516	554	1,070	493	549	1,042
2008	499	546	1,045	486	542	1,028
Total	4,448	4,762	9,231	4,420	4,268	9,156

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.

A data quality study^{vii} completed in 2008 that included a recoding of 2006 data found that with the exception of Race/Ethnic Origin, demographic data elements (Health Care Number, Date of Birth) captured in CORR were generally coded with a high degree of accuracy.

An examination of risk factors for incident dialysis patients found that there was a low-to-moderate sensitivity observed for most risk factors, indicating a tendency to under-report. However, it is uncommon for conditions to be falsely attributed to patients, indicating a high specificity.

vii. Canadian Institute for Health Information, *Data Quality Study on the Canadian Organ Replacement Register* (Ottawa, Ont.: CIHI, 2009). This study is available for download as a PDF document at www.cihi.ca/corr.

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 1999 to 2008, 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, 1999 to 2008

Data Type	Data Element	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008
Deceased Donor	Age	0.7	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
	Sex	0.7	0.2	0.0	0.2	0.2	0.2	0.0	0.2	0.2	0.0
	Blood Type	0.7	0.0	0.2	0.0	0.0	3.0	0.4	0.4	0.6	0.6
	Race/Ethnic Origin	12.1	20.9	25.4	3.6	22.1	32	36.6	34.2	36.7	37.3
	Province of Residence (Not Formally Collected Until 2001)	83.5	85.8	0.0	0.0	0.0	0.0	0.0	0.2	0.4	0.6
	Cause of Death	0.9	1.0	4.8	3.8	2.5	3.2	5.4	6.6	8.4	5.3
Living Donor	Age	25.8	1.5	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
	Sex	19.9	0.5	0.9	0.2	0.0	0.0	0.0	0.5	0.2	0.2
	Blood Type	24.8	0.7	0.7	6.8	7.3	12.8	9.5	4.5	0.7	1.5
	Province of Residence (Not Formally Collected Until 2001)	96.4	96.8	0.2	0.2	0.5	1.3	1.2	2.3	1.1	0.5
Transplant Recipients	Sex	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.1	0.0
	Race/Ethnic Origin	13.4	14.5	18.5	16.2	20.0	21.3	23.3	22.1	19.8	19.5
	Blood Type	3.7	2.0	3.6	3.1	3.9	2.9	3.2	2.7	4.0	4.5
	Residential Postal Code	3.1	1.8	1.0	0.8	3.3	2.7	2.0	1.1	2.0	1.3
	Cause of Death	25.5	22.2	22.3	23.0	23.1	19.8	27.0	23.6	36.0	28.6
	Diagnosis	2.4	1.7	1.8	0.9	5.0	2.0	3.0	3.6	7.5	4.4
	Medical Status at Listing (Heart, Liver, Lung Transplants)	12.1	3.7	7.0	1.5	3.1	1.2	2.3	2.8	3.9	3.8
	Medical Status at Transplant (Heart, Liver, Lung Transplants)	6.8	0.0	1.7	0.6	0.5	0.2	0.4	0.3	2.8	2.0
Cause of Graft Failure (Transplants With Failed Grafts)	35.0	37.2	41.0	38.0	46.1	42.7	47.0	43.4	53.8	45.6	

Note

* Recipients of first grafts for the period from 1999 to 2008.

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 1999 to 2008. Table D10 presents the same information stratified by province of treatment. Rates of non-response/unknowns greater than 10% are shaded.

Table D9 Non-Response/Unknown Values for Key Analytical Data Elements Related to Incident Dialysis Patients Registered in CORR by Year, 1999 to 2008

Data Type	Data Element	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	Total
Recipients	Sex	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
	Race/Ethnic Origin	13.6	14.2	6.5	6.8	7.2	6.1	4.9	7.1	5.1	4.2	7.4
	Residential Postal Code	2.3	1.3	1.2	0.9	1.4	1.3	1.7	1.2	1.6	2.4	1.5
	Diagnosis	12.5	11.9	13.9	14.8	14.4	13.6	12.9	12.9	15.1	15.1	13.7
	Cause of Death	23.3	26.4	26.2	28.0	29.1	24.7	26.6	25.9	29.1	28.9	26.5
Risk Factors	Angina	6.4	8.1	8.1	7.4	9.3	9.4	9.7	11.8	10.9	12.8	9.5
	Coronary Artery Bypass/Angioplasty	6.4	8.2	7.8	8.0	10.0	9.3	9.7	11.0	10.5	12.1	9.4
	Pulmonary Edema	6.6	8.4	7.9	8.0	9.5	9.8	9.8	11.1	10.9	12.0	9.5
	Myocardial Infarct	6.3	8.1	7.7	7.7	9.2	9.6	9.4	10.9	10.4	12.3	9.2
	Diabetes	5.4	6.5	6.6	5.2	6.8	7.0	6.9	8.1	6.5	7.8	6.7
	Cerebrovascular Accident	6.6	8.4	7.2	7.4	8.6	9.2	8.9	10.8	10.2	12.0	9.0
	Peripheral Vascular Disease	6.4	8.4	8.1	8.1	9.5	9.9	9.7	11.2	10.9	12.6	9.6
	Malignancy	6.8	8.4	9.6	9.4	11.8	11.0	12.8	13.3	14.6	16.0	11.5
	Chronic Lung Disease	6.6	8.4	8.3	8.3	9.8	10.2	9.9	11.6	11.3	12.9	9.8
	Use of Medications for Hypertension	5.7	7.7	5.7	5.5	7.0	7.4	7.0	8.2	7.2	7.8	6.9
	Presence of Other Serious Illness	9.8	11.5	17.4	19.0	19.5	19.6	21.7	20.1	18.5	24.4	18.4
	Current Smoker	8.1	9.5	13.3	14.7	13.7	16.0	16.1	15.8	15.3	15.8	14.0

Table D10 Non-Response/Unknown Values for Key Analytical Data Elements Related to Incident Dialysis Patients Registered in CORR by Province, 1999 to 2008

Data Type	Data Element	B.C.	Alta.	Sask.	Man.	Ont.	Que.	N.B.	N.S.	N.L.	Total
Recipients	Sex	0.0	0.0	0.0	0.0	0.0	0.0	0.3	0.0	0.0	0.0
	Race/Ethnic Origin	21.7	8.5	1.1	3.9	6.2	3.0	4.1	11.5	1.7	7.4
	Residential Postal Code	3.0	1.4	0.7	3.6	0.8	1.5	3.6	1.6	1.0	1.5
	Diagnosis	32.5	10.9	6.5	9.6	10.6	13.8	8.2	8.6	15.1	13.7
	Cause of Death	50.2	36.9	14.7	36.4	20.6	25.3	8.2	19.7	12.0	26.5
Risk Factors	Angina	32.5	7.4	3.9	11.8	5.7	7.6	2.4	2.1	1.3	9.5
	Coronary Artery Bypass/Angioplasty	32.7	7.0	1.9	11.3	5.7	7.5	2.4	2.2	1.4	9.4
	Pulmonary Edema	33.0	7.0	2.9	11.3	5.6	7.7	2.4	2.3	2.2	9.5
	Myocardial Infarct	32.1	6.8	2.5	11.5	5.4	7.6	2.1	2.8	2.1	9.2
	Diabetes	29.8	3.2	0.8	9.7	3.0	4.6	1.2	0.8	0.9	6.7
	Cerebrovascular Accident	32.1	6.6	2.4	11.2	5.4	6.7	2.4	1.8	1.3	9.0
	Peripheral Vascular Disease	33.5	6.9	2.5	11.3	5.8	7.5	2.4	2.6	2.1	9.6
	Malignancy	36.1	10.6	3.6	13.3	7.2	9.9	4.4	2.4	3.2	11.5
	Chronic Lung Disease	35.2	8.2	2.5	11.3	5.8	7.2	2.8	2.5	2.1	9.8
	Use of Medications for Hypertension	27.8	3.0	1.0	10.5	3.6	5.1	1.9	1.1	1.1	6.9
	Presence of Other Serious Illness	47.9	19.6	7.3	15.6	13.2	16.1	17.3	7.3	6.3	18.4
	Current Smoker	44.2	10.9	5.4	13.7	7.6	15.2	6.5	4.3	3.6	14.0

Reliability/Response Bias: A formal linkage^{viii} of CORR data to DAD and NACRS completed in 2008 found that patients who received a transplant or who have chronic renal failure are well reported in CORR. The coverage of transplants in CORR is 98.5% when compared with data on transplants in DAD. For coverage of dialysis treatment in Ontario, patients receiving dialysis were comparable between CORR and NACRS.

In the same study, a recoding of 2006 data found the agreement rate between study coder and the CORR data on the primary renal disease was 59%, and the agreement on the type of renal disease was 71%. The study also observed that, in general, risk factors were under-reported in CORR.

viii. Canadian Institute for Health Information, *Data Quality Study on the Canadian Organ Replacement Register* (Ottawa, Ont.: CIHI, 2009). This study is available for download as a PDF document at www.cihi.ca/corr.

However, in general, hazard ratios for various primary renal disease and risk factors were similar whether these were calculated using the CORR data or study data. Hazard ratios either remained less than one (indicating conditions that were protective of mortality) or remained greater than one (indicating conditions that increased the risk of mortality). However, the extent of the risk sometimes changed in magnitude. Unadjusted hazard ratios were similar when using the CORR data compared to the study data for the various primary renal diseases but were underestimated in CORR for several risk factors.

The results from the data quality study provided an understanding of the quality of CORR and identified areas for ongoing improvement. While CORR may contain the most comprehensive national data on treatment for end-stage organ failure at the present time, evaluation of completeness and accuracy of data will continue. Specifically, an investigation of the extent and impact of reporting completeness and accuracy of death status will be performed in the coming year, as patient and graft survival rates for transplant recipients in Canada continue to be higher than rates reported in other countries, 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 the following:

- Expanded the treatment modalities for dialysis.
- Added data elements on pre-dialysis contact.
- Added data elements relating to cardiac function and inotrope use on the deceased donor profile.
- Created a standardized form on living donors.
- Added 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*.
- Refined the dialysis and renal facility profiles.
- Added data elements pertaining to liver tumours in liver transplant recipients.
- Added a follow-up questionnaire for all liver transplant recipients with diagnoses of hepatitis B, hepatitis C or liver tumours.
- Added comorbidities for transplant recipients and donors.
- Added data elements relating to transplant procedures.

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

Appendix E—Glossary and Commonly Used Acronyms

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

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

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

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

End-stage renal disease: 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.

Commonly Used Acronyms

APD: automated peritoneal dialysis

CAPD: continuous ambulatory peritoneal dialysis

COPD: chronic obstructive pulmonary disease

CORR: Canadian Organ Replacement Register

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

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

Medical urgency status codes: Liver, heart and lung patients are assigned a status code at the time of their listing for a transplant. This status code corresponds to their medical condition and how urgently they require transplantation. The status codes are updated regularly until a patient receives a transplant. 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 had at least one solid organ used for transplantation. Solid organs that can be donated after death include the heart, liver, kidneys, pancreas, 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 pancreas or the intestine may also be donated by a living donor. At the time of this report, living pancreas and intestine transplants have not been performed in Canada.

Organ procurement organization: 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 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.

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 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.
- **Multi-visceral 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.

Patient survival: Patient survival refers to whether a transplant recipient is still alive at a certain time after transplantation.

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

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

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

Appendix F—Analytical Methods

Age Calculation

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

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.

Organ Recovery Rates

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

Adjusted Mortality Risk

The mortality risk factor analysis (Cox proportional-hazards 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 1999 and 2008 was used. The cohort members were followed until second transplant, death, loss to follow-up or the end of the observation (December 31, 2008).

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

Mortality Risk Factors for Dialysis Patients, Canada, 1999 to 2008, Pertaining to Figure 4

Parameter	Estimate	Standard Error	Hazard Ratio	Lower Confidence Limit	Upper Confidence Limit
Hemodialysis			1.00	1.00	1.00
Peritoneal Dialysis	-0.1425	0.0188	0.86	0.83	0.90
18–44 Years (Reference)			1.00	1.00	1.00
0–17 Years	-0.5202	0.1831	0.59	0.42	0.85
45–54 Years	0.4710	0.0419	1.60	1.48	1.74
55–64 Years	0.8376	0.0379	2.31	2.15	2.49
65–74 Years	1.1630	0.0366	3.20	2.98	3.44
75+ Years	1.5500	0.0368	4.71	4.38	5.06
Race: Caucasian (Reference)			1.00	1.00	1.00
Race: Asian	-0.4087	0.0338	0.66	0.62	0.71
Race: Black	-0.5905	0.0504	0.55	0.50	0.61
Race: Aboriginal	0.1322	0.0326	1.14	1.07	1.22
Race: Other	-0.3700	0.0344	0.69	0.65	0.74
Race: Unknown	0.1019	0.0231	1.11	1.06	1.16
1999–2003 Dialysis (Reference)			1.00	1.00	1.00
2004–2008 Dialysis	-0.1400	0.0151	0.87	0.84	0.90
Glomerulonephritis (Reference)			1.00	1.00	1.00
Diabetes	0.4625	0.0276	1.59	1.50	1.68
Polycystic Kidney	-0.0300	0.0393	0.97	0.90	1.05
Hypertensive Kidney	0.2432	0.0312	1.28	1.20	1.36
Renal Vascular	0.2837	0.0342	1.33	1.24	1.42
Other Diagnosis	0.6427	0.0317	1.90	1.79	2.02
Unknown Diagnosis	0.5072	0.0307	1.66	1.56	1.76
Cardiac Comorbidity	0.1979	0.0145	1.22	1.19	1.25
Vascular Comorbidity	0.2661	0.0151	1.31	1.27	1.34

Mortality Risk Factors for Kidney Transplant Patients, 1999 to 2008, Pertaining to Figure 5

Parameter	Estimate	Standard Error	Hazard Ratio	Lower Confidence Limit	Upper Confidence Limit
18–44 Years (Reference)			1.00	1.00	1.00
0–17 Years	-0.8863	0.3892	0.41	0.19	0.88
45–54 Years	0.4630	0.1165	1.59	1.26	2.00
55–64 Years	1.0680	0.1081	2.91	2.35	3.60
65+ Years	1.5852	0.1173	4.88	3.88	6.14
Race: Caucasian (Reference)			1.00	1.00	1.00
Race: Asian	-0.3002	0.1624	0.74	0.54	1.02
Race: Black	-0.6172	0.2286	0.54	0.35	0.84
Race: Aboriginal	0.2610	0.1838	1.30	0.91	1.86
Race: Other	-0.7250	0.1856	0.48	0.34	0.70
Race: Unknown	-0.0123	0.1609	0.99	0.72	1.35
Transplant Year: 1999–2003 (Reference)			1.00	1.00	1.00
Transplant Year: 2004–2008	-0.2472	0.0969	0.78	0.65	0.94
Renal Vascular Disease	0.2283	0.1187	1.26	1.00	1.59
Diabetes Type 1	0.8858	0.0960	2.43	2.01	2.93
Diabetes Type 2	0.6898	0.1160	1.99	1.59	2.50
Living Donor	-0.4222	0.0952	0.66	0.54	0.79
Dialysis Duration (Year)	0.1709	0.0323	1.19	1.11	1.26

Population Estimates Used in Rate Calculations

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

$$\text{Crude rate} = (\text{number of cases} / \text{population}) \times 1,000,000$$

$$\text{Age-specific rate} = (\text{number of cases in age group} / \text{population of age group}) \times 1,000,000$$

All Canadian population estimates are from the Statistics Canada CANSIM Table 051-0001 and are based on total population figures for July 1.

Province	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008
B.C.*	4,042,119	4,069,619	4,108,576	4,145,550	4,182,843	4,227,592	4,285,510	4,341,681	4,411,245	4,414,747
Alta.†	3,020,731	3,072,939	3,125,682	3,186,560	3,229,988	3,274,349	3,329,790	3,448,406	3,547,734	3,659,873
Sask.	1,014,707	1,007,767	1,000,134	995,886	994,428	995,391	994,126	985,386	996,869	1,015,985
Man.	1,142,491	1,147,373	1,151,285	1,155,584	1,161,552	1,170,268	1,177,556	1,177,765	1,186,679	1,207,959
Ont.	11,506,359	11,685,380	11,897,647	12,102,045	12,256,645	12,392,721	12,541,410	12,686,952	12,803,861	12,928,996
Que.	7,323,308	7,357,029	7,396,990	7,445,745	7,492,333	7,542,760	7,598,146	7,651,531	7,700,807	7,750,504
Atlantic‡	2,354,163	2,348,928	2,340,937	2,341,217	2,342,677	2,343,235	2,343,969	2,331,769	2,328,831	2,333,325

Notes

* Includes the Yukon.

† Includes the Northwest Territories and Nunavut.

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

Source

Statistics Canada.

Atlantic Provinces	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008
N.B.	750,611	750,518	749,890	750,327	750,896	751,384	752,006	749,168	749,782	747,302
N.S./P.E.I.	1,070,143	1,070,367	1,069,061	1,071,441	1,073,431	1,074,824	1,076,002	1,072,924	1,072,774	1,078,128
N.L.	533,409	528,043	521,986	519,449	518,350	517,027	515,961	509,677	506,275	507,895
Total	2,354,163	2,348,928	2,340,937	2,341,217	2,342,677	2,343,235	2,343,969	2,331,769	2,328,831	2,333,325

Source

Statistics Canada.

The following child population (< 18 years) estimates were used.

Province	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008
B.C.*	914,437	907,328	900,396	888,732	877,882	869,646	867,966	864,480	864,424	860,480
Alta.†	787,012	788,193	787,870	789,641	787,376	785,038	788,342	805,279	816,518	823,643
Sask.	269,649	264,349	258,241	252,975	248,051	244,033	240,950	236,225	235,904	238,069
Man.	290,694	289,809	288,338	286,255	284,449	283,608	282,600	279,696	280,015	282,101
Ont.	2,744,445	2,766,649	2,793,673	2,803,770	2,792,395	2,776,729	2,777,653	2,776,967	2,760,232	2,742,371
Que.	1,616,863	1,596,734	1,580,565	1,567,208	1,553,393	1,543,295	1,538,081	1,534,706	1,531,388	1,535,399
Atlantic	534,841	524,716	512,869	501,363	490,679	480,431	472,261	461,433	452,530	448,981
N.B.	168,464	165,611	162,339	159,122	155,947	153,025	150,784	147,483	144,687	144,647
N.S./P.E.I.	245,024	241,738	237,535	233,016	228,696	224,166	220,019	215,333	211,446	209,025
N.L.	121,353	117,367	112,995	109,225	106,036	103,240	101,458	98,617	96,397	95,309

Notes

* Includes the Yukon.

† Includes the Northwest Territories and Nunavut.

Prevalent Patients

Prevalent patient numbers at year-end are based on the patient-level data, which includes 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; 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. 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 comes from counts provided by provincial and regional OPOs. Patient-level data is not available. For patients waiting for a kidney transplant, the definition of a pediatric patient was changed in 2002 from younger than 15 to younger than 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 who withdrew 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.

