





Canadian Organ Replacement Register Annual Report

Treatment of End-Stage Organ Failure in Canada, 2000 to 2009

January 2011



Who We Are

Established in 1994, CIHI is an independent, not-for-profit corporation that provides essential information on Canada's health system and the health of Canadians. Funded by federal, provincial and territorial governments, we are guided by a Board of Directors made up of health leaders across the country.

Our Vision

To help improve Canada's health system and the well-being of Canadians by being a leading source of unbiased, credible and comparable information that will enable health leaders to make better-informed decisions.

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Executive Summary

Treatment of End-Stage Organ Failure in Canada, 2000 to 2009 draws on data from the Canadian Institute for Health Information (CIHI) Canadian Organ Replacement Register (CORR), primarily for the years 2000 through 2009 (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.

This report includes information that has not been present in recent reports, including

- An expanded dialysis chapter, including 20 years of data (1990 to 2009) for key indicators;
- Survival data for dialysis and transplant patients; and
- A chapter on organ donors.

Overview

- In 2009, 5,375 patients started renal replacement therapy (RRT).
- Overall, 2,087 transplants of solid organs were performed in Canada in 2009.
- There were 1,003 organ donors (living and deceased) in 2009.

Kidney

- There were an estimated 37,744 people living with end-stage renal disease (ESRD) in Canada at the end of 2009, more than triple the number recorded in 1990. Of these, 22,310 were on dialysis and 15,434 were living with a functioning kidney transplant.
- A total of 5,375 ESRD patients initiated renal replacement therapy (RRT) in 2009, with 78% receiving hemodialysis as their initial treatment. In 1990, 2,272 initiated RRT.
- Of 1,224 kidney recipients during 2009, 187 received pre-emptive transplants,ⁱ which are becoming an increasingly important treatment option in Canada.
- Diabetes continues to be the predominant cause of ESRD in Canada, identified in 34% of new cases in 2009, followed by renal vascular disease (19%).

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

- The aging of the Canadian population is reflected in the demographic profile
 of new ESRD patients, with 54% of those who initiated RRT being age 65 and
 older in 2009, compared to 33% in 1990. However, incidence rates have
 remained stable during the last 10 years and may be starting to decline.
- The proportion of incident dialysis patients that were considered lateⁱⁱ referrals is declining. In 2009, 31% of patients first saw a nephrologist less than three months before starting dialysis, compared to 42% in 2001. Additionally, the average age of incident hemodialysis patients increased from 63.1 in 2000 to 65.4 in 2009.

Liver

- There were 452 liver transplants performed in Canada in 2009, 11% more than in 2000.
- During the 10-year period, 4,285 liver transplants were performed.
- At the end of 2009, 551 patients were waiting for a transplant, a number that has declined from its peak of 723 in 2006.

Heart

- In 2009, 170 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, 1,647 Canadians received a first heart transplant in this time frame, and 55 were re-transplanted.
- In 2009, there were 136 Canadians awaiting a heart transplant, with 30 deaths on the waiting list that year.

Lung

- In 2009, 189 lung transplants were performed, a 52% increase over the 124 that were performed in 2000.
- Bilateral lung transplants accounted for 83% of the lung transplants performed in 2009.
- Bilateral procedures were most commonly performed on recipients with cystic fibrosis (28%). Conversely, the most frequent diagnosis for a single-lung transplant recipient was emphysema (48%).
- In 2009, there were 245 Canadians, compared to 177 in 2000, waiting to receive a lung transplant.

ii. For this report, a late referral is defined as a patient who first sees a nephrologist less than 90 days before starting dialysis. These patients may have fewer treatment options available for slowing disease progression compared to patients who are referred to a nephrologist at an earlier disease stage.

Pancreas

- There were 673 pancreatic transplants performed in Canada between 2000 and 2009.
- Of these, 71% were simultaneous pancreas-kidney transplants.
- The number of Canadians awaiting a simultaneous pancreas–kidney transplant peaked in 2001 (172) and declined to 56 in 2009.

Small Intestine

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 1990 and 2009, there were 51 such procedures
performed in Canada, with more than 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 with decision-making. 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.



Chapter 1—Introduction

1 Introduction

The Canadian Organ Replacement Register (CORR) is a pan-Canadian information system for organ failure 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 Inc. Board of Directors is responsible for providing strategic advice to the register. (For a membership list of the Board of Directors as of October 1, 2010, 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 Donation 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, iii 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 proportion of unknown values reported continues to exceed 10%. In 2009, primary diagnosis was missing or unknown in 14% of incident dialysis patients; 27% of dialysis patients and 26% of transplant recipients were missing cause of death; and cause of graft failure was missing or unknown in half the 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 in 2007, 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.

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.

iii. 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.

Please see Appendix D—CORR Data Quality Documentation: 2000 to 2009, for further detail regarding the completeness and coverage of reporting in CORR.

1.3 Organization of the Report

This report summarizes information on end-stage organ failure treatments in Canada. Sections 2 to 8 report on the following subjects:

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

Appendix A provides a list of members of the CORR Inc. 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 2000 to 2009 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.

A list of the primary diagnosis codes captured by CORR can be found in Appendix G.

1.4 Provincial Data

Throughout this report, province-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 Small Cell Sizes

Due to the nature of the material being reported by CORR, there are instances when cells with fewer than five observations are reported. CORR and CIHI recognize that there is a small risk of re-identification from reporting small cell sizes if they were matched with other external sources of information. Cases where small cells are published are reviewed with CIHI statisticians to ensure the risk of re-identification is minimized.

1.6 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. This report provides the latest summary statistics on transplant, donor and waiting list data, including the number of patients who died while waiting for a vital organ transplant.

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.



Chapter 2—Renal Replacement Therapy for End-Stage Renal Disease

2 Renal Replacement Therapy for End-Stage Renal Disease

This section presents trends about end-stage renal disease (ESRD) patients who are newly diagnosed (incidence) each year, 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, most responsible diagnoses for renal failure and initial treatment. 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.

There were 5,375 newly diagnosed patients with ESRD in 2009, an increase of 12% since 2000 (n = 4,755). However, this was a 58% increase when compared to 1990 (Table 1). Since 1999, the highest RPMP of newly diagnosed ESRD was among 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 772.4. From 1990 until 2001, the rate of incidence among patients age 75 and older increased 74%. Between 2001 and 2005, incidence rates remained relatively constant. Since 2005, rates among older age groups have slowly declined, falling from 760.0 to 699.2 among those age 75 and older, and from 625.6 to 538.2 in the 65-to-74 age group. Incidence rates among those aged 45–64 increased from 161.5 to 196.3 during the 20-year period. Since 1997, the incidence rates in this age group remained relatively stable and declined slightly in recent years. Over the 20-year period considered, incidence rates among those younger than age 45 remained relatively unchanged.

While Figure 1 shows that those age 75 and older had the highest incident rate of ESRD diagnosis, the largest number of new patients was seen in the group of patients age 45 to 64.

Provincially in 2009, the highest incidence RPMP occurred in Newfoundland and Labrador (249.5) and Manitoba (232.4), while the lowest rates were in Quebec and Alberta, at 124.4 and 138.4, respectively.

At the end of 2009, 78% of all new patients initiated treatment on hemodialysis, iv a level that has remained virtually unchanged since 2000 (Table 3). While hemodialysis (HD) was consistently utilized as the primary modality of treatment throughout the decade, the number of new patients receiving peritoneal dialysis (PD) as an initial treatment also remained consistent through the time period. The use of pre-emptive transplants increased over time, from 135 in 1999 to 187 in 2009.

Age of incidence also influences the initial treatment (Table 4). In 2009, 67% of incidence patients age 25 to 44 started with hemodialysis, while among those age 65 to 74 and 75 and older the proportions were 81% and 86%. Pre-emptive transplant as an initial treatment was highest among younger age groups and declined with patient age.

When dialysis was used to treat incident patients in 2009, all provinces used HD the majority of the time, with Newfoundland and Labrador having the highest proportion of HD (94%), followed by Quebec (81%) and New Brunswick (81%). The highest proportion of patients treated by continuous ambulatory peritoneal dialysis (CAPD) was seen in Alberta (24%) (Table 5).

Incidence rates by primary diagnosis are presented in Table 6. Diabetes continued to be the most frequently reported primary cause of ESRD, accounting for 34% of incident patients in Canada.

A patient who first sees a nephrologist less than 90 days before starting dialysis is considered a late referral. This characteristic is considered a measure of how well the early stages of kidney disease are being managed. In 2009, 31% of incident patients were late referrals, down from 42% in 2000 (Table 7). This improvement can be seen in all provinces. Table 8 presents late referral status by primary diagnosis. In 2001, 37% of patients with a primary diagnosis of diabetes were late referrals, while in 2009, only 22% were considered late referrals.

iv. 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.

v. 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 9 presents selected characteristics of HD and PD patients. The average age of both patient groups has been increasing. In 2009, the average age of incident HD patients was 65.4, and the average age of PD patients was 61.8.

Table 1: Incident End-Stage Renal Disease Patients by Age Group, Canada, 1990 to 2009 (Number, Rate per Million Population, Percentage of Total)

Age	0-	-19 Yea	rs	20)–44 Yea	ars	45	5–64 Yea	rs	65	–74 Year	'S	75	5+ Years	;	То	otal
Group	N	RPMP	%	N	RPMP	%	N	RPMP	%	N	RPMP	%	N	RPMP	%	N	RPMP
1990	93	12.1	4.1	559	48.2	24.6	859	161.5	37.8	508	271.7	22.4	253	202.3	11.1	2,272	82.0
1991	83	10.8	3.2	600	51.5	23.0	908	166.8	34.7	694	361.0	26.5	329	254.1	12.6	2,614	93.3
1992	88	11.3	3.2	602	51.6	22.1	983	175.0	36.2	701	356.7	25.8	344	258.6	12.7	2,718	95.8
1993	89	11.3	3.1	607	52.0	20.9	1,020	176.1	35.0	802	399.4	27.6	393	288.6	13.5	2,911	101.5
1994	69	8.7	2.2	629	53.9	20.2	1,111	186.1	35.7	882	431.5	28.4	420	301.3	13.5	3,111	107.3
1995	98	12.3	3.0	636	54.4	19.3	1,117	181.8	33.8	941	454.9	28.5	508	352.6	15.4	3,300	112.6
1996	70	8.8	2.0	639	54.5	18.0	1,237	195.8	34.9	1,003	480.2	28.3	596	399.9	16.8	3,545	119.7
1997	90	11.2	2.3	695	59.2	17.6	1,316	202.2	33.2	1,145	542.9	28.9	714	461.9	18.0	3,960	132.4
1998	86	10.7	2.0	685	58.5	16.2	1,417	211.2	33.5	1,198	563.3	28.3	848	530.9	20.0	4,234	140.4
1999	90	11.3	2.0	717	61.3	15.8	1,483	213.9	32.6	1,253	586.8	27.5	1,008	610.5	22.1	4,551	149.7
2000	103	12.9	2.2	674	57.7	14.2	1,559	217.5	32.8	1,295	603.4	27.2	1,124	658.6	23.6	4,755	154.9
2001	104	13.1	2.1	604	51.6	12.0	1,585	213.9	31.6	1,359	628.9	27.1	1,361	772.4	27.1	5,013	161.6
2002	86	10.8	1.7	632	53.8	12.5	1,567	204.2	31.1	1,377	633.1	27.3	1,381	759.5	27.4	5,043	160.8
2003	87	11.0	1.7	593	50.5	11.6	1,673	210.8	32.6	1,391	635.0	27.1	1,384	737.8	27.0	5,128	162.0
2004	75	9.6	1.4	627	53.3	12.0	1,736	211.9	33.2	1,344	607.3	25.7	1,444	748.9	27.6	5,226	163.6
2005	98	12.5	1.8	607	51.6	11.5	1,690	200.1	31.9	1,399	625.6	26.4	1,506	760.0	28.4	5,300	164.2
2006	85	10.9	1.6	637	54.1	11.8	1,795	206.0	33.1	1,367	601.4	25.2	1,534	751.5	28.3	5,418	166.1
2007	75	9.5	1.4	645	55.4	11.7	1,840	204.7	33.3	1,411	605.0	25.5	1,556	740.5	28.2	5,527	167.8
2008	80	10.2	1.5	627	53.7	11.4	1,846	199.9	33.6	1,389	578.0	25.3	1,549	719.2	28.2	5,491	164.8
2009	78	9.9	1.5	561	47.9	10.4	1,859	196.3	34.6	1,339	538.2	24.9	1,538	699.2	28.6	5,375	159.3

Sources

Figure 1: Incident End-Stage Renal Disease Patients, Age-Specific Rate per Million Population, Canada, 1990 to 2009

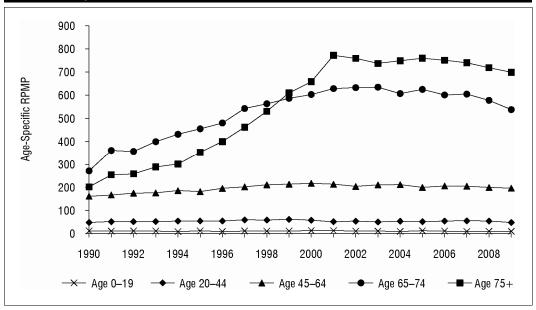


Table 2: Incident End-Stage Renal Disease Patients by Province, Canada, 2000 to 2009 (Number, Rate per Million Population)

		2000	2001	2002	2003	2004	2005	2006	2007	2008	2009
B.C./	N	588	631	652	622	669	636	701	718	694	739
Y.T.	RPMP	144.5	153.6	157.3	148.7	158.2	148.4	161.5	165.4	157.1	164.6
Alta./ N.W.T./	N	381	504	495	558	465	531	483	529	480	521
Nun.	RPMP	124.0	161.2	155.3	172.8	142.0	159.5	140.1	147.4	130.7	138.4
Sask.	N	184	225	166	182	192	171	186	199	176	180
Sask.	RPMP	182.6	225.0	166.7	183.0	192.9	172.0	188.8	199.0	173.6	174.7
Man.	N	236	240	245	239	230	236	298	251	285	284
IVIAII.	RPMP	205.7	208.5	212.0	205.8	196.5	200.4	253.0	210.2	236.3	232.4
Ont.	N	1,935	2,008	2,092	2,102	2,218	2,275	2,316	2,368	2,302	2,289
Ont.	RPMP	165.6	168.8	172.9	171.5	179.0	181.4	182.5	185.1	177.9	175.1
Que.	N	1,001	995	1,009	1,006	1,019	1,049	1,052	1,066	1,098	974
Que.	RPMP	136.1	134.5	135.5	134.3	135.1	138.1	137.5	138.7	141.6	124.4
N D	N	140	145	128	144	161	123	139	111	142	88
N.B.	RPMP	186.5	193.4	170.6	191.8	214.3	163.6	185.5	148.9	190.1	117.4
N.S./	N	192	158	152	176	157	185	161	197	207	173
P.E.I.	RPMP	179.4	147.8	141.9	164.0	146.1	171.9	150.1	183.4	192.4	160.3
N.L.	N	98	107	104	99	115	94	82	88	107	127
IV.L.	RPMP	185.6	205.0	200.2	191.0	222.4	182.2	160.9	173.7	211.3	249.5
Canada	N	4,755	5,013	5,043	5,128	5,226	5,300	5,418	5,527	5,491	5,375
Canada	RPMP	154.9	161.6	160.7	162.0	163.6	164.2	166.1	167.8	164.8	159.3

Table 3: Incident End-Stage Renal Disease Patients by Initial Treatment, Canada, 2000 to 2009 (Number, Rate per Million Population, Percentage of Total)

Type of Treatment		2000	2001	2002	2003	2004	2005	2006	2007	2008	2009
	N	10	5	6	7	9	3	19	17	25	25
HD Home	RPMP	0.3	0.2	0.2	0.2	0.3	0.1	0.6	0.5	0.8	0.7
	%	0.2	0.1	0.1	0.1	0.2	0.1	0.4	0.3	0.5	0.5
ш	Ν	3,651	3,901	4,017	4,116	4,102	4,156	4,304	4,375	4,296	4,155
HD Institutional	RPMP	119.0	125.8	128.0	130.0	128.4	128.8	131.9	132.9	128.9	123.2
	%	76.8	77.8	79.7	80.3	78.5	78.4	79.4	79.2	78.2	77.3
	N	637	616	600	644	732	708	661	686	704	751
CAPD	RPMP	20.8	19.9	19.1	20.3	22.9	21.9	20.3	20.8	21.1	22.3
	%	13.4	12.3	11.9	12.6	14.0	13.4	12.2	12.4	12.8	14.0
	N	322	354	309	242	253	272	271	271	298	257
APD	RPMP	10.5	11.4	9.9	7.6	7.9	8.4	8.3	8.2	8.9	7.6
	%	6.8	7.1	6.1	4.7	4.8	5.1	5.0	4.9	5.4	4.8
	N	135	137	111	119	130	161	163	178	168	187
Pre-Emptive	RPMP	4.4	4.4	3.5	3.8	4.1	5.0	5.0	5.4	5.0	5.5
	%	2.8	2.7	2.2	2.3	2.5	3.0	3.0	3.2	3.1	3.5
Total	N	4,755	5,013	5,043	5,128	5,226	5,300	5,418	5,527	5,491	5,375
- Ulai	RPMP	154.9	161.6	160.8	162.0	163.6	164.2	166.1	167.8	164.8	159.3

Note

HD: hemodialysis; CAPD: continuous ambulatory peritoneal dialysis; APD: automated peritoneal dialysis; pre-emptive: pre-emptive kidney transplant.

Sources

Table 4: Incident End-Stage Renal Disease Patients by Year, Age Group and Initial Treatment Modality, Canada, 2000 to 2009 (Number)

		2000	2001	2002	2003	2004	2005	2006	2007	2008	2009
Age Group	Initial Modality	N = 4,755	N = 5,013	N = 5,043	N = 5,128	N = 5,226	N = 5,300	N = 5,418	N = 5,527	N = 5,491	N = 5,375
	HD	46	45	36	39	34	45	59	39	35	47
0–19	PD	34	45	28	32	29	33	15	16	33	21
	Pre-Emptive	23	14	22	16	12	20	11	20	12	10
	HD	444	404	440	427	417	432	441	441	426	378
20-44	PD	171	133	147	124	155	134	145	134	146	120
	Pre-Emptive	59	67	45	42	55	41	51	70	55	63
	HD	1,153	1,180	1,200	1,274	1,294	1,232	1,342	1,389	1,372	1,348
45-64	PD	356	359	326	344	392	367	368	376	388	415
40 04	Pre-Emptive	50	46	41	55	50	91	85	75	86	96
	HD	1,052	1,117	1,142	1,157	1,120	1,140	1,123	1,169	1,123	1,080
65–74	PD	240	232	232	228	212	250	230	230	251	241
	Pre-Emptive	3	10	3	6	12	9	14	12	15	18
	HD	966	1,160	1,205	1,226	1,246	1,310	1,358	1,354	1,365	1,327
75+	PD	158	201	176	158	197	196	174	201	184	211
	Pre-Emptive	0	0	0	0	1	0	2	1	0	0
	HD	3,661	3,906	4,023	4,123	4,111	4,159	4,323	4,392	4,321	4,180
Total	PD	959	970	909	886	985	980	932	957	1,002	1,008
	Pre-Emptive	135	137	111	119	130	161	163	178	168	187

Note

 $\label{eq:homodialysis} \mbox{ HD: hemodialysis; PD: peritoneal dialysis; pre-emptive: pre-emptive kidney transplant.}$

Source

Canadian Organ Replacement Register, 2010, Canadian Institute for Health Information.

Table 5: Incident Patients by Type of Treatment and Province of Treatment, Canada, 2009 (Number, Percentage of Total)

Type of			Province of Treatment*												
Treatment	Treatment		Alta.	Sask.	Man.	Ont.	Que.	N.B.	N.S.	N.L.	Canada				
HD	N	539	370	139	223	1,793	793	70	134	119	4,180				
חט	%	72.9	71.0	78.1	78.8	78.2	81.4	80.5	76.6	94.4	77.8				
CAPD	Ν	126	124	38	47	252	116	15	26	7	751				
CAPD	%	17.1	23.8	21.3	16.6	11.0	11.9	17.2	14.9	5.6	14.0				
ADD	N	33	7	1	8	188	17	2	1	0	257				
APD	%	4.5	1.3	0.6	2.8	8.2	1.7	2.3	0.6	0.0	4.8				
Pre-	N	41	20	0	5	59	48	0	14	0	187				
Emptive	%	5.5	3.8	0.0	1.8	2.6	4.9	0.0	8.0	0.0	3.5				
Total	N	739	521	178	283	2,292	974	87	175	126	5,375				

Notes

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

Canadian Organ Replacement Register, 2010, Canadian Institute for Health Information.

Table 6: Incident End-Stage Renal Disease Patients by Primary Diagnosis, Canada, 2000 to 2009 (Number, Rate per Million Population)

Diagnosis		2000	2001	2002	2003	2004	2005	2006	2007	2008	2009
Glomerulonephritis	N	651	668	638	657	684	594	618	617	584	588
Gioinerulonepiinus	RPMP	21.2	21.5	20.3	20.8	21.4	18.4	18.9	18.7	17.5	17.4
Diabetes	N	1,527	1,693	1,706	1,755	1,795	1,846	1,856	1,918	1,905	1,814
Diabetes	RPMP	49.8	54.6	54.4	55.4	56.2	57.2	56.9	58.2	57.2	53.8
Renal Vascular Disease	N	964	961	923	952	960	1,024	1,061	994	1,003	1,005
	RPMP	31.4	31.0	29.4	30.1	30.1	31.7	32.5	30.2	30.1	29.8
Polycystic Kidney	N	225	197	202	215	222	268	258	233	217	192
Disease	RPMP	7.3	6.4	6.4	6.8	7.0	8.3	7.9	7.1	6.5	5.7
Davis Indused	N	87	103	104	101	95	103	92	124	107	112
Drug Induced	RPMP	2.8	3.3	3.3	3.2	3.0	3.2	2.8	3.8	3.2	3.3
Dyolonophritio	N	188	206	215	216	231	197	189	213	195	182
Pyelonephritis	RPMP	6.1	6.6	6.9	6.8	7.2	6.1	5.8	6.5	5.9	5.4
Othout	N	547	485	508	493	524	582	626	570	659	621
Other*	RPMP	17.8	15.6	16.2	15.6	16.4	18.0	19.2	17.3	19.8	18.4
Unknown	N	566	700	747	739	715	686	718	858	821	861
	RPMP	18.4	22.6	23.8	23.3	22.4	21.3	22.0	26.1	24.6	25.5

Note

Sources

^{*} 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.

^{*} For a list of primary diagnoses captured by CORR, see Appendix G.

Table 7: Incident End-Stage Renal Disease Renal Replacement Therapy Patients by Late Referral Status,* by Province and Canada, 2001 to 2009 (Percentage)

Province	2001	2002	2003	2004	2005	2006	2007	2008	2009
B.C./Y.T.	42.8	43.4	35.2	34.6	31.2	29.8	31.1	32.7	33.7
Alta./N.W.T./Nun.	36.1	36.1	38.2	40.4	34.1	39.0	30.8	33.1	31.0
Sask.	44.2	44.5	42.9	36.6	34.8	40.9	28.5	29.2	29.3
Man.	48.5	43.7	36.2	38.4	33.7	33.6	32.2	25.3	29.6
Ont.	43.6	40.4	38.5	35.9	36.1	33.6	31.9	32.3	31.8
Que.	42.1	41.6	36.6	38.3	33.3	33.1	32.7	29.4	27.5
N.B.	49.6	43.2	40.3	32.2	37.8	39.4	37.9	30.9	27.4
N.S./P.E.I.	26.7	35.1	32.7	30.6	31.8	25.2	27.1	26.4	25.9
N.L.	38.1	40.0	31.5	36.1	30.2	22.7	25.0	30.8	27.4
Canada	42.2	40.9	37.5	36.5	34.4	33.5	31.6	31.2	30.7

Note

Source

Canadian Organ Replacement Register, 2010, Canadian Institute for Health Information.

Table 8: Incident End-Stage Renal Disease Renal Replacement Therapy Patients by Primary Diagnosis and Late Referral Status,* Canada, 2001 to 2009 (Percentage)

Diagnosis	2001	2002	2003	2004	2005	2006	2007	2008	2009
Glomerulonephritis	36.4	33.8	32.5	32.7	30.8	30.4	28.0	24.0	26.2
Diabetes	37.0	32.4	30.6	27.7	26.0	25.5	23.2	21.7	22.1
Renal Vascular Disease	40.6	44.4	41.3	37.2	32.2	33.2	29.1	27.0	25.4
Polycystic Kidney Disease	16.2	20.0	14.3	15.4	11.1	9.4	8.7	8.6	9.5
Drug Induced	51.7	42.4	40.7	42.7	25.0	33.0	36.8	29.7	24.3
Pyelonephritis	45.2	37.6	32.6	40.1	36.0	30.4	30.9	38.4	32.5
Other [†]	57.0	61.9	54.9	58.7	59.4	56.5	54.5	57.3	54.5
Unknown	57.1	54.5	50.2	50.2	53.6	47.7	47.5	48.2	48.2
All Incident Patients	42.2	40.9	37.5	36.5	34.4	33.5	31.6	31.2	30.7

Notes

Source

Canadian Organ Replacement Register, 2010, Canadian Institute for Health Information.

^{*} Patients with a late referral status started dialysis less than 90 days after first seeing a nephrologist.

^{*} Patients with a late referral status started dialysis less than 90 days after first seeing a nephrologist.

[†] For a complete list of primary diagnoses captured, see Appendix G.

Table 9: Adult Incident Dialysis Patients,	, Selected Characteristics, Canada,
2000 to 2009	

		2000	2001	2002	2003	2004	2005	2006	2007	2008	2009
	Mean Age (Years)	63.1	65.0	64.9	65.1	64.8	65.2	65.1	65.0	65.4	65.4
	Age 65+ (%)	54.8	59.1	58.9	58.5	57.3	59.2	57.7	57.7	58.1	58.1
	Male (%)	64.5	58.9	57.5	60.4	59.1	60.1	59.9	61.8	60.7	60.0
	Mean Comorbidity Index	2.5	2.4	2.2	2.1	2.1	2.0	2.0	2.1	2.1	2.1
	Mean BMI	24.2	26.7	26.8	26.9	27.4	27.5	27.7	27.6	28.2	28.3
HD	Mean eGFR	N/A	9.2	9.3	9.8	9.7	10.0	10.2	10.2	10.4	10.6
	Late Referral (%)	N/A	46.8	44.2	41.1	40.8	39.5	37.8	36.0	35.7	35.6
	Access Type (%)										
	Catheter	N/A	76.8	76.6	77.8	78.9	78.1	78.7	79.4	82.0	82.6
	AV Fistula	N/A	21.1	20.7	19.7	18.8	20.3	19.7	19.1	16.5	16.2
	AV Graft	N/A	2.1	2.7	2.5	2.3	1.6	1.7	1.5	1.5	1.2
	Mean Age (Years)	59.1	61.2	60.4	60.5	60.3	61.3	60.6	61.1	60.8	61.8
	Age 65+ (%)	42.8	46.6	46.2	45.0	42.6	46.9	44.0	45.6	44.8	45.7
	Male (%)	56.3	54.7	55.7	59.8	56.7	60.2	55.0	58.4	57.6	57.3
PD	Mean Comorbidity Index	1.6	1.6	1.3	1.5	1.2	1.4	1.2	1.3	1.1	1.1
	Mean BMI	25.5	25.6	26.0	26.4	26.5	26.8	27.2	27.1	27.6	28.0
	Mean eGFR	N/A	9.3	10.0	9.8	9.9	10.1	10.0	10.5	10.7	10.7
	Late Referral (%)	N/A	22.6	23.6	16.2	15.8	11.4	12.2	11.2	10.4	10.2

Notes

N/A: not available.

HD: hemodialysis; PD: peritoneal dialysis.

Comorbidity index: The index assigns each of the 14 comorbid conditions collected in CORR a weight from

1 to 10. The possible range is from 0 to 32.

BMI: body mass index.

eGFR: estimated glomerular filtration rate as determined by the Modification of Diet in Renal Disease (MDRD) formula ($mL/min/1.73 \text{ m}^2$).

Late referral: patients who first see a nephrologist less than 90 days before starting dialysis.

 $Access\ type:\ catheter-central\ venous\ catheter;\ AV\ fistula-arteriovenous\ fistula;\ AV\ graft-arteriovenous\ graft.$

Source

Canadian Organ Replacement Register, 2010, 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.

As of December 31, 2009, there were 37,744 people in Canada being treated for ESRD, with 59% (n = 22,310) on dialysis and 41% (15,434) living with a functioning kidney transplant (Table 10). Since 1990, the prevalence rate for patients being treated by dialysis has increased 212%, from 211.6 RPMP to 661.2 RPMP (Figure 2). During the same period, the prevalence rate of patients with kidney transplants more than doubled, from 187.1 RPMP to 457.4 RPMP.

Table 11 provides prevalence rates by age. Over the 20-year period prevalence rates increased in all age groups. In 2009, the age distribution of prevalent patients was similar in all provinces and territories (Table 12).

Prevalence rates in 2009 were highest in Manitoba and Newfoundland and Labrador (1,431.3 and 1,389.2 RPMP, Table 13). The lowest RPMPs were observed in Alberta (989.3), Quebec (1,005.6) and Saskatchewan, where the prevalence rate was 1,083.4.

HD provided in an institutional setting was the most common form of RRT across the country (46%), followed by transplant (41%) (Table 14). With the exception of CAPD, the prevalence rate of all treatment types increased over the 10-year period.

In 2009, in Nova Scotia/Prince Edward Island, Alberta/Northwest Territories/ Nunavut and British Columbia/Yukon, transplant was the leading treatment seen in prevalent patients with ESRD (56%, 50% and 44%, respectively) (Table 15). Transplant as a treatment was lowest in Manitoba (33%) and Saskatchewan (32%).

Tables 16 and 17 examine prevalence rates by primary diagnosis. Between 2000 and 2009, the prevalence rate of patients with diabetes as a primary diagnosis increased by 63%. In 2009, diabetic nephropathy accounted for the largest proportion of all prevalent patients (24%), followed by patients with glomerulonephritis (21%).

Among prevalent patients in 2009 with a primary diagnosis of diabetes, 63% were being treated with HD and 24% had transplants (Table 18). Patients with diabetic nephropathy accounted for 34% of HD patients being treated. For patients with a primary diagnosis of glomerulonephritis, 59% had a functioning kidney transplant, representing 30% of all transplant patients.

Table 19 summarizes changes in prevalence by examining flows into and out of treatment.

Table 10: Prevalence Rate for Patients on Dialysis or With a Functioning Transplant in Canada, 1990 to 2009 (Rate per Million Population, Percentage of Total)

		Dialysis		Functi	oning Trans	plants	Total		
	Number	RPMP	%	Number	RPMP	%	Number	RPMP	
1990	5,861	211.6	53.1	5,181	187.1	46.9	11,042	398.7	
1991	6,597	235.3	54.0	5,621	200.5	46.0	12,218	435.9	
1992	7,422	261.6	55.6	5,916	208.6	44.4	13,338	470.2	
1993	8,121	283.1	56.1	6,366	222.0	43.9	14,487	505.1	
1994	8,909	307.2	56.5	6,851	236.3	43.5	15,760	543.5	
1995	9,671	330.0	56.9	7,315	249.6	43.1	16,986	579.7	
1996	10,480	353.9	57.3	7,817	264.0	42.7	18,297	617.9	
1997	11,678	390.5	58.5	8,283	277.0	41.5	19,961	667.4	
1998	12,783	423.9	59.2	8,816	292.3	40.8	21,599	716.2	
1999	13,893	457.0	59.7	9,392	308.9	40.3	23,285	765.9	
2000	14,917	486.1	59.9	9,998	325.8	40.1	24,915	811.9	
2001	16,008	516.0	60.2	10,567	340.6	39.8	26,575	856.7	
2002	16,978	541.2	60.5	11,093	353.6	39.5	28,071	894.8	
2003	17,899	565.3	60.6	11,642	367.7	39.4	29,541	933.1	
2004	18,882	591.1	60.8	12,164	380.8	39.2	31,046	971.8	
2005	19,784	613.1	61.0	12,669	392.6	39.0	32,453	1,005.7	
2006	20,541	629.6	60.7	13,306	407.9	39.3	33,847	1,037.5	
2007	21,157	642.5	60.1	14,045	426.5	39.9	35,202	1,068.9	
2008	21,735	652.2	59.7	14,694	440.9	40.3	36,429	1,093.1	
2009	22,310	661.2	59.1	15,434	457.4	40.9	37,744	1,118.7	

Sources

--- Functioning Transplants ■ Dialysis

Figure 2: Prevalence Rate for Patients on Dialysis or With a Functioning Transplant in Canada, 1990 to 2009 (Rate per Million Population)

Table 11: Prevalent End-Stage Renal Disease Patients by Age Group, Canada, 1990 to 2009 (Number, Rate per Million Population)

	Age 0-19		Age	20–44	Age -	45–64	Age	65–74	Age	75+	Total	
	N	RPMP	N	RPMP	N	RPMP	N	RPMP	N	RPMP	N	RPMP
1990	439	57.2	4,087	352.7	4,184	786.5	1,669	892.5	663	530.1	11,042	398.7
1991	441	57.1	4,387	376.5	4,618	848.3	1,975	1,027.2	797	615.7	12,218	435.9
1992	474	60.8	4,600	394.5	5,071	902.8	2,244	1,141.9	949	713.3	13,338	470.2
1993	483	61.5	4,807	412.0	5,564	960.8	2,541	1,265.4	1,092	801.9	14,487	505.1
1994	475	60.0	5,076	434.7	6,042	1,012.1	2,898	1,417.7	1,269	910.3	15,760	543.5
1995	491	61.7	5,256	449.4	6,493	1,056.9	3,239	1,565.9	1,507	1,045.9	16,986	579.7
1996	486	60.8	5,412	461.9	7,114	1,125.8	3,513	1,682.1	1,772	1,188.9	18,297	617.9
1997	499	62.3	5,638	480.3	7,787	1,196.5	3,897	1,847.9	2,140	1,384.4	19,961	667.4
1998	523	65.3	5,851	499.6	8,436	1,257.2	4,249	1,997.7	2,540	1,590.1	21,599	716.2
1999	535	66.9	6,016	514.6	9,149	1,319.7	4,593	2,150.8	2,992	1,812.1	23,285	765.9
2000	557	69.8	6,133	524.7	9,870	1,376.9	4,939	2,301.3	3,416	2,001.5	24,915	811.9
2001	565	70.9	6,199	529.1	10,527	1,420.4	5,310	2,457.2	3,974	2,255.3	26,575	856.7
2002	564	70.9	6,280	534.4	11,106	1,447.0	5,599	2,574.3	4,522	2,487.0	28,071	894.8
2003	565	71.5	6,307	536.6	11,753	1,481.0	5,968	2,724.6	4,948	2,637.8	29,541	933.1
2004	554	70.5	6,301	535.9	12,480	1,523.3	6,271	2,833.8	5,440	2,821.4	31,046	971.8
2005	560	71.5	6,312	536.1	13,055	1,545.5	6,591	2,947.5	5,935	2,995.0	32,453	1,005.7
2006	557	71.3	6,342	538.3	13,724	1,575.1	6,855	3,015.8	6,369	3,120.3	33,847	1,037.5
2007	554	70.5	6,299	540.6	14,336	1,594.8	7,288	3,125.1	6,725	3,200.4	35,202	1,068.9
2008	544	69.2	6,312	541.0	14,939	1,617.4	7,548	3,141.0	7,086	3,290.0	36,429	1,093.1
2009	548	69.7	6,232	531.8	15,513	1,638.1	7,976	3,205.9	7,475	3,398.4	37,744	1,118.7

Table 12: Prevalent End-Stage Renal Disease Patients by Age and Province, Canada, 2009 (Number, Percentage)

Province		Age 0–19	Age 20–44	Age 45–64	Age 65–74	Age 75+	Total
B.C./Y.T.	N	73	785	1,963	995	948	4,764
B.C./ Y. I .	%	1.5	16.5	41.2	20.9	19.9	100.0
Alta./N.W.T./	N	88	782	1,750	765	590	3,975
Nun.	%	2.2	19.7	44.0	19.2	14.8	100.0
Caale	N	3	232	478	201	203	1,117
Sask.	%	0.3	20.8	42.8	18.0	18.2	100.0
Man.	N	43	363	810	323	235	1,774
wan.	%	2.4	20.5	45.7	18.2	13.2	100.0
Ont.	Ν	197	2,368	6,100	3,311	3,316	15,292
Ont.	%	1.3	15.5	39.9	21.7	21.7	100.0
Que.	Ν	113	1,187	3,129	1,780	1,645	7,854
Que.	%	1.4	15.1	39.8	22.7	20.9	100.0
N.B.	Ν	0	132	361	189	171	853
N.D.	%	0.0	15.5	42.3	22.2	20.0	100.0
N.C./D.E.I	N	28	270	603	278	243	1,422
N.S./P.E.I.	%	2.0	19.0	42.4	19.5	17.1	100.0
N.L.	N	3	113	319	134	124	693
N.L.	%	0.4	16.3	46.0	19.3	17.9	100.0
Canada	N	548	6,232	15,513	7,976	7,475	37,744
Callaua	%	1.5	16.5	41.1	21.1	19.8	100.0

Table 13: Prevalent End-Stage Renal Disease Patients by Province, Canada, 2000 to 2009 (Number, Rate per Million Population)

Province		2000	2001	2002	2003	2004	2005	2006	2007	2008	2009
B.C./	N	3,108	3,342	3,549	3,762	4,031	4,200	4,403	4,580	4,719	4,946
Y.T.	RPMP	763.7	813.4	856.1	899.4	953.5	980.1	1,014.1	1,054.8	1,068.4	1,101.8
Alta./N.W.T./	N	2,280	2,524	2,745	2,967	3,103	3,266	3,376	3,502	3,577	3,723
Nun.	RPMP	742.0	807.5	861.4	918.6	947.7	980.8	979.0	976.1	974.3	989.3
Sask.	N	765	858	893	949	976	948	985	1,046	1,069	1,116
Sask.	RPMP	759.1	857.9	896.7	954.3	980.5	953.6	999.6	1,045.9	1,054.6	1,083.4
Man.	N	1,221	1,245	1,315	1,351	1,388	1,446	1,523	1,574	1,647	1,749
iviaii.	RPMP	1,064.2	1,081.4	1,138.0	1,163.1	1,186.1	1,228.0	1,293.1	1,318.3	1,365.6	1,431.3
Ont.	N	9,866	10,550	11,203	11,798	12,415	13,120	13,719	14,265	14,829	15,347
Ont.	RPMP	844.3	886.7	925.7	962.6	1,001.8	1,046.1	1,081.4	1,114.9	1,146.3	1,174.3
Que.	N	5,397	5,682	5,916	6,174	6,506	6,776	7,090	7,406	7,666	7,873
Que.	RPMP	733.6	768.2	794.6	824.0	862.6	891.8	926.6	963.4	988.7	1,005.6
N.B.	N	678	708	718	742	792	803	849	855	866	858
N.B.	RPMP	903.4	944.1	956.9	988.2	1,054.1	1,067.8	1,133.3	1,146.8	1,159.1	1,144.8
N.S.	N	564	584	603	617	661	664	658	657	667	707
N.S.	RPMP	1,068.1	1,118.8	1,160.9	1,190.3	1,278.5	1,286.9	1,291.0	1,297.1	1,317.0	1,389.2
N.L.	N	1,036	1,082	1,129	1,181	1,174	1,230	1,244	1,317	1,389	1,425
IV.L.	RPMP	967.9	1,012.1	1,053.7	1,100.2	1,092.3	1,143.1	1,159.5	1,226.2	1,290.9	1,320.5
Canada	N	24,915	26,575	28,071	29,541	31,046	32,453	33,847	35,202	36,429	37,744
Callaua	RPMP	811.9	856.7	894.8	933.1	971.8	1,005.7	1,037.5	1,068.9	1,093.1	1,118.7

Table 14: Prevalent End-Stage Renal Disease Patients by Type of Treatment, Canada, 2000 to 2009 (Number, Rate per Million Population, Percentage of Total)

Type of Trea	tment	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009
	N	221	227	259	304	370	486	573	638	715	781
HD Home	RPMP	7.2	7.3	8.3	9.6	11.6	15.1	17.6	19.4	21.5	23.2
	%	0.9	0.9	0.9	1.0	1.2	1.5	1.7	1.8	2.0	2.1
	N	11,385	12,427	13,343	14,213	14,941	15,607	16,192	16,627	17,024	17,486
HD Institutional	RPMP	371.0	400.6	425.3	448.9	467.7	483.6	496.3	504.9	510.8	518.3
oaoa.	%	45.7	46.8	47.5	48.1	48.1	48.1	47.8	47.2	46.7	46.3
	N	2,015	1,886	1,781	1,686	1,659	1,613	1,555	1,582	1,609	1,566
CAPD	RPMP	65.7	60.8	56.8	53.3	51.9	50.0	47.7	48.0	48.3	46.4
	%	8.1	7.1	6.3	5.7	5.3	5.0	4.6	4.5	4.4	4.1
	N	1,296	1,468	1,595	1,696	1,912	2,078	2,221	2,310	2,387	2,477
APD	RPMP	42.2	47.3	50.8	53.6	59.9	64.4	68.1	70.1	71.6	73.4
	%	5.2	5.5	5.7	5.7	6.2	6.4	6.6	6.6	6.6	6.6
	N	9,998	10,567	11,093	11,642	12,164	12,669	13,306	14,045	14,694	15,434
Transplant	RPMP	325.8	340.6	353.6	367.7	380.8	392.6	407.9	426.5	440.9	457.4
	%	40.1	39.8	39.5	39.4	39.2	39.0	39.3	39.9	40.3	40.9
Total	N	24,915	26,575	28,071	29,541	31,046	32,453	33,847	35,202	36,429	37,744
ı olai	RPMP	811.9	856.7	894.8	933.1	971.8	1,005.7	1,037.5	1,068.9	1,093.1	1,118.7

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

Sources

Canadian Organ Replacement Register, 2010, Canadian Institute for Health Information; Statistics Canada.

Table 15: Prevalent End-Stage Renal Disease Patients by Type of Treatment and Province of Treatment, Canada, 2009 (Number, Percentage)

		Province of Treatment												
Type of Treatr	nent	B.C./ Y.T.	Alta./ N.W.T./ Nun.	Sask.	Man.	Ont.	Que.	N.B.	N.S./ P.E.I.	N.L.	Canada			
HD Home	N	129	94	7	17	421	78	12	10	13	781			
пр ноше	%	2.6	2.5	0.6	1.0	2.7	1.0	1.4	0.7	1.8	2.0			
HD	N	1,980	1,405	588	929	7,511	3,765	405	521	382	17,486			
Institutional	%	40.0	37.7	52.7	53.1	48.9	47.8	47.2	36.6	54.0	46.0			
CARD	N	191	103	114	87	590	339	54	64	24	1,566			
CAPD	%	3.9	2.8	10.2	5.0	3.8	4.3	6.3	4.6	3.4	4.0			
ADD	N	471	258	48	135	1,146	279	69	51	20	2,477			
APD	%	9.5	6.9	4.3	7.7	7.5	3.5	8.0	3.7	2.8	7.0			
Transplant	N	2,175	1,863	359	581	5,679	3,412	318	779	268	15,434			
Transplant	%	44.0	50.0	32.2	33.2	37.0	43.3	37.1	56.4	37.9	41.0			
Total	N	4,946	3,723	1,116	1,749	15,347	7,873	858	1,425	707	37,744			

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

Table 16: Prevalent End-Stage Renal Disease Patients by Primary Diagnosis, Canada, 2000 to 2009 (Number, Rate per Million Population, Percentage of Total)

Diagnosis		2000	2001	2002	2003	2004	2005	2006	2007	2008	2009
	N	5,954	6,241	6,482	6,734	7,035	7,205	7,388	7,552	7,715	7,938
Glomerulonephritis	RPMP	194.0	201.2	206.6	212.7	220.2	223.3	226.5	229.3	231.5	235.3
	%	23.9	23.5	23.1	22.8	22.7	22.2	21.8	21.5	21.2	21.0
	N	5,464	6,058	6,590	7,142	7,658	8,143	8,625	9,029	9,414	9,769
Diabetes	RPMP	178.0	195.3	210.1	225.6	239.7	252.3	264.4	274.2	282.5	289.5
	%	21.9	22.8	23.5	24.2	24.7	25.1	25.5	25.6	25.8	25.9
	N	3,253	3,477	3,632	3,828	3,973	4,200	4,419	4,594	4,734	4,906
Renal Vascular Disease	RPMP	106.0	112.1	115.8	120.9	124.4	130.2	135.5	139.5	142.1	145.4
2.000.00	%	13.1	13.1	12.9	13.0	12.8	12.9	13.1	13.1	13.0	13.0
	N	1,782	1,884	1,975	2,078	2,179	2,337	2,461	2,575	2,684	2,775
Polycystic Kidney Disease	RPMP	58.1	60.7	63.0	65.6	68.2	72.4	75.4	78.2	80.5	82.3
2.000.00	%	7.2	7.1	7.0	7.0	7.0	7.2	7.3	7.3	7.4	7.4
	N	319	365	405	434	453	480	496	539	546	574
Drug Induced	RPMP	10.4	11.8	12.9	13.7	14.2	14.9	15.2	16.4	16.4	17.0
	%	1.3	1.4	1.4	1.5	1.5	1.5	1.5	1.5	1.5	1.5
	N	1,848	1,900	1,988	2,034	2,103	2,119	2,152	2,209	2,229	2,248
Pyelonephritis	RPMP	60.2	61.3	63.4	64.2	65.8	65.7	66.0	67.1	66.9	66.6
	%	7.4	7.1	7.1	6.9	6.8	6.5	6.4	6.3	6.1	6.0
	N	2,876	3,016	3,172	3,318	3,458	3,650	3,819	3,964	4,163	4,335
Other*	RPMP	93.7	97.2	101.1	104.8	108.2	113.1	117.1	120.4	124.9	128.5
	%	11.5	11.3	11.3	11.2	11.1	11.2	11.3	11.3	11.4	11.5
	N	3,419	3,634	3,827	3,973	4,187	4,319	4,487	4,740	4,944	5,199
Unknown	RPMP	111.4	117.2	122.0	125.5	131.1	133.8	137.5	143.9	148.4	154.1
	%	13.7	13.7	13.6	13.4	13.5	13.3	13.3	13.5	13.6	13.8
Total	N	24,915	26,575	28,071	29,541	31,046	32,453	33,847	35,202	36,429	37,744
IUIAI	RPMP	811.9	856.7	894.8	933.1	971.8	1,005.7	1,037.5	1,068.9	1,093.1	1,118.7

Sources

Canadian Organ Replacement Register, 2010, Canadian Institute for Health Information; Statistics Canada.

 $^{^{\}star}$ For a list of primary diagnoses captured by CORR, see Appendix G.

Table 17: Prevalent End-Stage Renal Disease Patients by Primary Diagnosis and Province, Canada, 2009 (Number, Rate per Million Population, Percentage of Total)

Province		Glomerulone -phritis	Diabetes	Renal Vascular Disease	Polycystic Kidney Disease	Drug Induced	Pyelone- phritis	Other*	Unknown	Total
TTOVIIIOC	N	961	745	627	341	65	214	541	1,452	4,946
B.C./Y.T.	RPMP	214.1	166.0	139.7	76.0	14.5	47.7	120.5	323.5	1,101.8
<i>5.6.</i> ,	%	19.4	15.1	12.7	6.9	1.3	4.3	10.9	29.4	100
	N	932	997	350	289	63	245	427	420	3,723
Alta./N.W.T./	RPMP	247.7	264.9	93.0	76.8	16.7	65.1	113.5	111.6	989.3
Nun.	%	25.0	26.8	9.4	7.8	1.7	6.6	11.5	11.3	100
	N	205	382	127	61	16	69	154	102	1,116
Sask.	RPMP	199.0	370.8	123.3	59.2	15.5	67.0	149.5	99.0	1,083.4
- Cuom	%	18.4	34.2	11.4	5.5	1.4	6.2	13.8	9.1	100
	N	357	670	135	82	21	96	232	156	1,749
Man.	RPMP	292.2	548.3	110.5	67.1	17.2	78.6	189.9	127.7	1,431.3
	%	20.4	38.3	7.7	4.7	1.2	5.5	13.3	8.9	100
-	N	3,148	4,328	2,291	1,116	221	856	1,634	1,753	15,347
Ont.	RPMP	240.9	331.2	175.3	85.4	16.9	65.5	125.0	134.1	1,174.3
	%	20.5	28.2	14.9	7.3	1.4	5.6	10.6	11.4	100
	N	1,693	1,953	966	579	127	562	996	997	7,873
Que.	RPMP	216.3	249.5	123.4	74.0	16.2	71.8	127.2	127.4	1,005.6
	%	21.5	24.8	12.3	7.4	1.6	7.1	12.7	12.7	100
	N	186	222	140	73	12	52	90	83	858
N.B.	RPMP	248.2	296.2	186.8	97.4	16.0	69.4	120.1	110.8	1,144.8
	%	21.7	25.9	16.3	8.5	1.4	6.1	10.5	9.7	100
	N	282	323	182	173	34	94	183	154	1,425
N.S./P.E.I.	RPMP	261.3	299.3	168.7	160.3	31.5	87.1	169.6	142.7	1,320.5
	%	19.8	22.7	12.8	12.1	2.4	6.6	12.8	10.8	100
	N	174	149	88	61	15	60	78	82	707
N.L.	RPMP	341.9	292.8	172.9	119.9	29.5	117.9	153.3	161.1	1,389.2
	%	24.6	21.1	12.4	8.6	2.1	8.5	11.0	11.6	100
	N	7,938	9,769	4,906	2,775	574	2,248	4,335	5,199	37,744
Canada	RPMP	235.3	289.5	145.4	82.3	17.0	66.6	128.5	154.1	1,118.7
	%	21.0	25.9	13.0	7.4	1.5	6.0	11.5	13.8	100

Sources

Canadian Organ Replacement Register, 2010, Canadian Institute for Health Information; Statistics Canada.

^{*} For a list of primary diagnoses captured by CORR, see Appendix G.

Table 18: Prevalent End-Stage Renal Disease Patients by Treatment, Age Group, Sex and Primary Diagnosis, Canada, December 31, 2009 (Number, Rate per Million Population, Percentage of Total)

		HD	PD	TX	Total
Total	N	18,266	4,043	15,434	37,743
	RPMP	541.4	119.8	457.4	1,118.6
Age Group					
	N	74	48	426	548
0-19 Years	RPMP	9.4	6.1	54.2	69.7
	%	0.4	1.2	2.8	1.5
	N	1,986	557	3,689	6,232
20-44 Years	RPMP	169.5	47.5	314.8	531.8
	%	10.9	13.8	23.9	16.5
	N	5,954	1,584	7,975	15,513
45-64 Years	RPMP	628.7	167.3	842.1	1,638.1
	%	32.6	39.2	51.7	41.1
	N	4,382	995	2,598	7,975
65-74 Years	RPMP	1,761.3	399.9	1,044.3	3,205.5
	%	24.0	24.6	16.8	21.1
	N	5,870	859	746	7,475
75+ Years	RPMP	2,668.7	390.5	339.2	3,398.4
	%	32.1	21.2	4.8	19.8
Sex	•				
	N	7,615	1,775	5,854	15,244
Female	RPMP	447.7	104.4	344.2	896.3
	%	41.7	43.9	37.9	40.4
	N	10,651	2,268	9,580	22,499
Male	RPMP	636.5	135.5	572.5	1,344.6
	%	58.3	56.1	62.1	59.6
Diagnosis					
	N	6,172	1,232	2,365	9,769
Diabetes	RPMP	182.9	36.5	70.1	289.5
	%	33.8	30.5	15.3	25.9
	N	2,504	734	4,699	7,937
Glomerulonephritis	RPMP	74.2	21.8	139.3	235.2
	%	13.7	18.2	30.4	21.0
	N	3,240	703	963	4,906
Renal Vascular Disease	RPMP	96.0	20.8	28.5	145.4
	%	17.7	17.4	6.2	13.0
	N	868	162	1,218	2,248
Pyelonephritis	RPMP	25.7	4.8	36.1	66.6
	%	4.8	4.0	7.9	6.0
	N	802	223	1,750	2,775
Polycystic Kidney Disease	RPMP	23.8	6.6	51.9	82.2
	%	4.4	5.5	11.3	7.4

Table 18: Prevalent End-Stage Renal Disease Patients by Treatment, Age Group, Sex and Primary Diagnosis, Canada, December 31, 2009 (Number, Rate per Million Population, Percentage of Total) (cont'd)

		HD	PD	TX	Total
Total	N	18,266	4,043	15,434	37,743
	RPMP	541.4	119.8	457.4	1,118.6
Diagnosis (cont'd)					
	N	304	67	203	574
Drug Induced	RPMP	9	2	6	17
	%	1.7	1.7	1.3	1.5
	N	1,844	378	2,113	4,335
Other*	RPMP	54.7	11.2	62.6	128.5
	%	10.1	9.3	13.7	11.5
	N	2,532	544	2,123	5,199
Unknown	RPMP	75	16.1	62.9	154.1
	%	13.9	13.5	13.8	13.8

Notes

HD: hemodialysis; PD: peritoneal dialysis; TX: transplant.

Sources

Canadian Organ Replacement Register, 2010, Canadian Institute for Health Information; Statistics Canada.

Table 19: End-Stage Renal Disease Patient Flows by Treatment, Canada, 2000 to 2009

		2000	2001	2002	2003	2004	2005	2006	2007	2008	2009
	January 1, Prevalence	13,893	14,917	16,008	16,978	17,899	18,882	19,784	20,541	21,157	21,735
	Incident Dialysis	4,620	4,876	4,932	5,009	5,096	5,139	5,255	5,349	5,323	5,188
ysis	Deaths	2,692	2,927	3,061	3,170	3,191	3,347	3,478	3,564	3,600	3,389
Dialysis	Net Transplants*	744	686	650	682	655	632	763	815	776	768
_	Net Migrations [†]	160	172	251	236	267	258	257	354	369	456
	December 31, Prevalence	14,917	16,008	16,978	17,899	18,882	19,784	20,541	21,157	21,735	22,310
	January 1, Prevalence	9,392	9,998	10,567	11,093	11,642	12,164	12,669	13,306	14,045	14,694
Ħ	New Transplants	1,158	1,094	1,079	1,093	1,074	1,107	1,252	1,299	1,277	1,175
Transplant	Deaths	237	200	238	230	241	217	283	255	276	213
ans	Return to Dialysis	310	318	295	307	289	377	326	302	345	216
F	Net Migrations [†]	5	7	20	7	22	8	6	3	7	6
	December 31, Prevalence	9,998	10,567	11,093	11,642	12,164	12,669	13,306	14,045	14,694	15,434

Notes

Source

^{*} For a list of primary diagnoses captured by CORR, see Appendix G.

^{*} 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.

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 20).

Saskatchewan had the highest number of patients per station, with 5.0, followed closely by Ontario (4.9), while New Brunswick (3.1), Nova Scotia (3.8) and Newfoundland and Labrador (3.8) had the lowest number of patients per station (Table 20).

Table 20: Point Prevalent Hospital, Independent Health Facility and Community Centre Hemodialysis Patients,* by Stations and Province of Treatment, Canada, 2009 (Number)

Province of Treatment	Stations (N) [†]	Patients (N) [‡]	Patients per Station	Population [§]	Stations per Million Population
B.C.	451	2,158	4.8	4,488,860	100.4
Alta.	383	1,491	3.9	3,763,284	101.7
Sask.	126	625	5.0	1,030,129	122.3
Man.	212	910	4.3	1,221,964	173.5
Ont.	1,564	7,730	4.9	13,069,182	119.7
Que.	850	3,865	4.5	7,828,879	108.6
N.B.	152	466	3.1	749,468	202.8
N.S.	153	589	3.8	1,079,168	141.8
N.L.	107	407	3.8	508,925	210.2
Total	3,998	18,241	4.6	33,739,859	118.4

Notes

- * Data is incomplete for four centres in Canada: one in Ontario, two in Quebec and one in British Columbia.

 Data was estimated based on data for the previous year.
- † The estimated number of missing stations is 228 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 estimated patients is 1,310 for HD.
- § 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.

Sources

Canadian Organ Replacement Register, 2010, Canadian Institute for Health Information; Statistics Canada.

2.4 Outcomes

The factors associated with the survival of patients receiving dialysis treatment are well documented.

Table 21 presents unadjusted patient survival rates by dialysis treatment. Long-term survival rates have been gradually improving.

In general, gender makes little difference to long-term survival, while both age and primary diagnosis do affect survival of dialysis patients (figures 3 to 8).

Eighty-seven percent of dialysis patients younger than 18 will survive for five years, while 24% of patients older than 75 survive for five years (Figure 3).

Patients with renal vascular disease and diabetes have the lowest five-year survival rates, at 35% and 38% (Figure 6). The longest five-year survival rate is seen among patients with a primary diagnosis of glomerulonephritis (63%).

Table 21: Unadjusted Three-Month and One-, Three- and Five-Year Survival Rates in Dialysis Patients, Canada, 2000 to 2009 (Percentage)

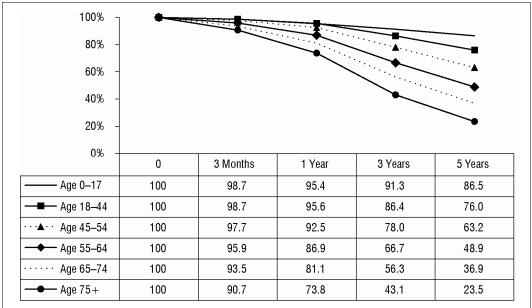
		2000	2001	2002	2003	2004	2005	2006	2007	2008	2009
	N	4,620	4,876	4,932	5,009	5,096	5,139	5,255	5,349	5,323	5,188
	3 Months	94.1	93.9	93.8	94.5	94.6	94.4	94.4	94.7	94.3	94.7
All Dialysis	1 Year	82.2	81.9	82.3	83.4	83.4	83.5	83.7	84.5	84.0	
2 iai, y c i c	3 Years	58.6	57.2	58.1	59.6	60.6	61.6	61.4	_		
	5 Years	40.2	38.9	39.5	40.5	43.2	_	_	_		
	N	3,661	3,906	4,023	4,123	4,111	4,159	4,323	4,392	4,321	4,180
	3 Months	93.0	93.1	93.0	93.7	93.7	93.4	93.7	94.0	93.4	93.8
HD	1 Year	80.2	80.1	80.4	81.6	81.6	81.4	81.8	82.8	82.0	_
	3 Years	56.6	55.5	56.2	57.5	58.3	59.3	59.3	_	_	_
	5 Years	38.3	36.7	37.6	38.7	41.4	_	_	_		
	N	959	970	909	886	985	980	932	957	1,002	1,008
	3 Months	98.1	97.3	97.5	98.2	98.5	98.6	98.1	98.2	98.0	98.4
PD	1 Year	90.0	89.1	90.7	91.7	91.0	92.6	92.6	92.5	92.7	
	3 Years	66.3	64.1	66.4	69.7	70.2	71.4	71.0	_		
	5 Years	47.9	48.3	47.8	49.0	51.0	_	_	_	_	_

Note

HD: hemodialysis; PD: peritoneal dialysis.

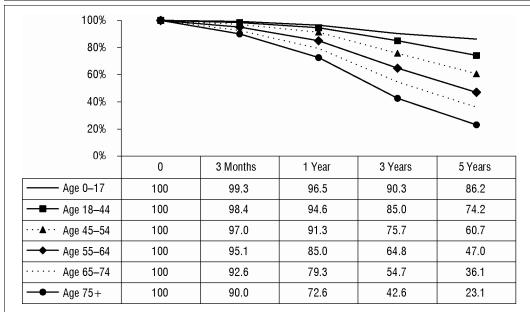
Source

Figure 3: Unadjusted Three-Month and One-, Three- and Five-Year Survival Rates in Dialysis Patients, by Age Group, Canada, 2000 to 2009 (Percentage)



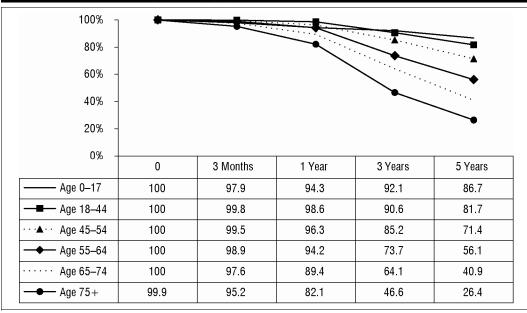
Canadian Organ Replacement Register, 2010, Canadian Institute for Health Information.

Figure 4: Unadjusted Three-Month and One-, Three- and Five-Year Survival Rates in Hemodialysis Patients, by Age Group, Canada, 2000 to 2009 (Percentage)



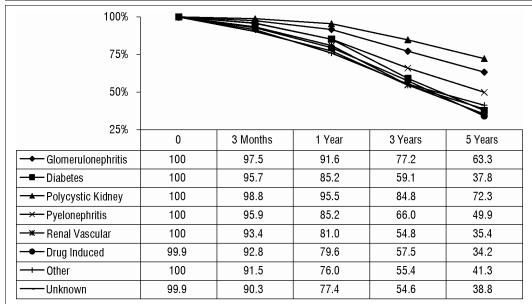
Source

Figure 5: Unadjusted Three-Month and One-, Three- and Five-Year Survival Rates in Peritoneal Dialysis Patients, by Age Group, Canada, 2000 to 2009 (Percentage)



Canadian Organ Replacement Register, 2010, Canadian Institute for Health Information.

Figure 6: Unadjusted Three-Month and One-, Three- and Five-Year Survival Rates in Dialysis Patients, by Etiology* of Renal Failure, Canada, 2000 to 2009 (Percentage)

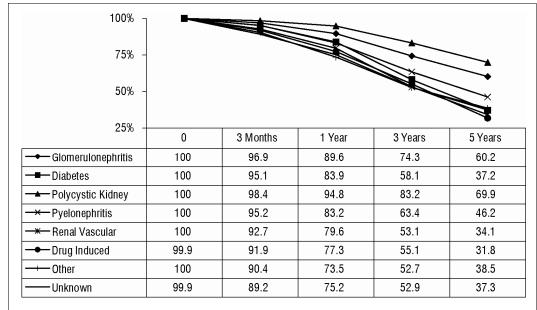


Note

* For a list of primary diagnoses captured by CORR, see Appendix G.

Source

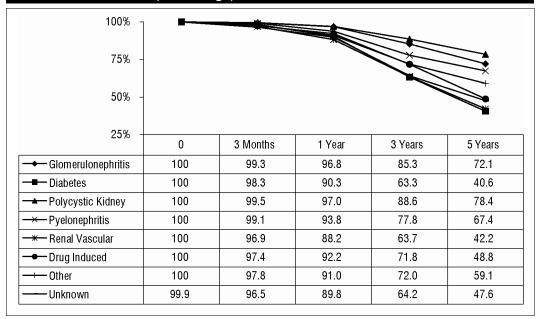
Figure 7: Unadjusted Three-Month and One-, Three- and Five-Year Survival Rates in Hemodialysis Patients, by Etiology* of Renal Failure, Canada, 2000 to 2009 (Percentage)



Source

^{*} For a list of primary diagnoses captured by CORR, see Appendix G.

Figure 8: Unadjusted Three-Month and One-, Three- and Five-Year Survival Rates in Peritoneal Dialysis Patients, by Etiology* of Renal Failure, Canada, 2000 to 2009 (Percentage)



* For a list of primary diagnoses captured by CORR, see Appendix G.

Source

2.5 Kidney Transplantation: Adult Recipients

Kidney transplantation is the preferred treatment for the majority of 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.

In 2009, there were 23 active kidney transplant programs in Canada operating in seven provinces. Between 2000 and 2009 inclusive, there were 10,641 kidney transplant procedures registered in CORR (Table 22). Of these, 1,141 (11%) were re-transplants. Of the 9,430 kidney-only first transplants, 61% utilized deceased-donor kidneys. Ontario and Quebec surgeons performed the most deceased-donor kidney transplants over the decade (2,309 and 2,014, respectively) (Table 23). Ontario (1,783) saw the highest number of living-donor kidney transplants over the decade (Table 24), followed by British Columbia (808). Since 2006, the number of living-donor kidney transplants has been stable, fluctuating between 440 and 461 transplants each year.

For the most recent three-year period, 2007 to 2009, the median wait time for a deceased-donor kidney transplant (excluding pre-emptive transplants) was 3.6 years (Table 25). The longest median wait times were in British Columbia (5.8 years) and Ontario (4.5 years). The shortest median wait time of just more than two years was observed in Nova Scotia.

Since 2000, the proportion of recipients older than age 60 receiving a kidney transplant from a deceased donor increased from 20% to 36%, and the average age of recipients increased from 48.2 to 53.8 (Table 26). A similar trend was observed for living-donor transplants (10% to 22%) (Table 26). Glomerulonephritis continued to be the predominant diagnosis among adults (324) (Table 27).

At five years after transplantation, the unadjusted patient survival rates between 2000 and 2004 were greater than 84% for recipients of living-donor kidneys and greater than 75% for recipients of deceased-donor kidneys (Table 28).

Figures 9 and 10 present graft survival rates comparing living-donor recipients to deceased-donor recipients by age.

Table 22: Kidney Transplants* by Year and Donor Type, Adult Recipients, Canada, 2000 to 2009 (Number)

	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	Total
Kidney Only, First Graft, Deceased Donor	597	546	516	550	514	504	606	631	634	667	5,765
Kidney Only, First Graft, Living Donor	310	340	319	342	345	370	415	413	409	402	3,665
Kidney Combination, First Graft, Deceased Donor [†]	5	6	5	8	3	5	10	8	9	11	70
Re-Transplants	125	123	129	99	104	104	119	133	114	91	1,141
Total	1,037	1,015	969	999	966	983	1,150	1,185	1,166	1,171	10,641

Notes

Source

Canadian Organ Replacement Register, 2010, Canadian Institute for Health Information.

Table 23: Deceased-Donor Kidney Transplants* by Year and Province of Treatment, Adult Recipients, Canada, 2000 to 2009 (Number)

Province of Treatment	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	Total
B.C.	60	59	46	53	52	40	61	61	83	54	569
Alta.	85	85	81	67	67	83	78	71	66	61	744
Sask.	19	28	18	29	18	15	21	21	21	14	204
Man.	28	11	17	17	13	6	22	27	24	22	187
Ont.	213	184	196	192	208	206	243	291	253	323	2,309
Que.	209	207	186	218	196	173	197	204	217	207	2,014
N.S.	79	70	63	51	35	49	67	52	49	50	565
Total	693	644	607	627	589	572	689	727	713	731	6,592

Note

Source

^{*} Excludes simultaneous kidney-pancreas transplants. See Section 6.

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

^{*} Excludes simultaneous kidney-pancreas transplants. See Section 6. Includes first transplants and re-transplants.

Table 24: Living-Donor Kidney Transplants by Year and Province of Treatment, Adult Recipients, Canada, 2000 to 2009 (Number)

Province of Treatment	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	Total
B.C.	78	83	74	69	74	70	98	100	75	87	808
Alta.	37	50	47	52	61	50	46	60	51	40	494
Sask.	6	8	14	10	12	11	9	7	13	1	91
Man.	10	12	15	18	12	19	24	21	17	17	165
Ont.	151	144	149	156	157	186	206	199	211	224	1,783
Que.	22	43	38	43	38	46	47	44	47	39	407
N.S.	40	31	25	24	23	29	31	27	39	32	301
Total	344	371	362	372	377	411	461	458	453	440	4,049

Canadian Organ Replacement Register, 2010, Canadian Institute for Health Information.

Table 25: Dialysis Duration Prior to First Kidney Transplant by Province of Treatment, Adult Kidney Transplant Recipients, Canada, 2007 to 2009

	B.C.	Alta.	Sask.	Man.	Ont.	Que.	N.S.	Canada
Duration on Dialysis (Median Days), Deceased Donor	2,145.5	915	899	1,534	1,618.5	845	765	1,258.5
Duration on Dialysis (Median Days), Deceased Donor, No Pre-Emptive	2,145.5	972	935	1,598	1,630	970	833	1,321
Duration on Dialysis (Median Days), Living Donor	146	344	421	400	387	188.5	135	313.5
Duration on Dialysis (Median Days), Living Donor, No Pre-Emptive	567	517	568	527	625	407	461	534

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 3,184 adult first kidney transplants performed in Canada between 2007 and 2009, 477 of which were pre-emptive transplants.

Source

Table 26: Adult Kidney Transplant Recipients, Selected Characteristics, First Graft, Canada, 2000 to 2009 (Number, Percentage)

Donor	Characteristic	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009
	Percentage Male	63.1	63.9	63.5	64.7	62.1	63.9	61.9	63.8	65.0	63.6
	Percentage Age 60+	19.9	25.7	29.4	26.7	30.6	29.5	29.7	34.9	35.8	37.5
	Average Age	48.2	50.0	50.6	50.4	51.2	51.8	51.9	53.4	53.2	53.8
	Age Standard Deviation	12.2	12.8	13.6	12.6	13.2	12.4	12.7	12.8	13.0	12.9
	Primary Cause of ESRD (%)										
ਰੂ	Diabetes	16.8	17.2	19.0	20.8	14.3	16.3	17.0	21.4	23.5	19.2
Deceased	Renal Vascular	8.3	9.4	9.4	8.1	13.2	10.8	10.9	9.1	10.1	9.6
ခင ်	Glomerulonephritis	31.4	33.9	31.9	36.6	36.6	30.6	31.0	28.3	27.2	30.5
	Other*	34.2	35.5	33.8	29.9	31.9	38.1	37.0	36.8	33.6	33.6
	Unknown Diagnosis	9.3	4.0	6.0	4.7	4.1	4.1	4.1	4.4	5.6	7.1
	Median Peak PRA [†]	0	2	2	2	2	3	0	0	0	2
	Peak PRA >50% (%)	6	5.3	6.8	8.6	7.3	7.5	2.2	6.5	7.2	10.6
	Duration of Dialysis (Median Days)	854	930	973	1,016	1,305	1,261	1,283	1,338	1,199	1,250
	Percentage Male	62.3	55.6	60.5	65.2	59.1	63.2	62.4	63.4	60.1	59.7
	Percentage Age 60+	10.0	12.6	13.8	17.0	14.5	14.6	14.7	18.6	19.3	21.6
	Average Age	43.2	42.7	43.8	46.2	44.6	46.6	45.4	46.0	46.8	47.0
	Age Standard Deviation	12.9	13.3	13.5	13.0	13.2	12.6	13.1	13.8	13.4	13.6
	Primary Cause of ESRD (%)										
	Diabetes	15.5	15.9	16.0	19.0	16.2	16.5	13.3	16.7	14.7	16.2
Living	Renal Vascular	5.8	6.5	5.3	7.6	4.9	5.7	7.2	7.7	7.1	6.7
Ę	Glomerulonephritis	35.5	35.6	32.9	32.5	38.3	31.1	35.4	29.3	29.3	27.6
	Other*	36.8	36.5	39.8	35.4	35.7	41.1	36.1	36.3	41.1	38.8
	Unknown Diagnosis	6.5	5.6	6.0	5.6	4.9	5.7	8.0	9.9	7.8	10.7
	Median Peak PRA [†]	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	1.0
	Peak PRA >50% (%)	3.9	2.0	3.6	2.8	5.0	4.2	1.9	4.5	8.4	8.1
	Duration of Dialysis (Median Days)	248	352	350	380.5	343	286	314	304	356	286

Notes

Source

^{*} For a list of primary diagnoses captured by CORR, see Appendix G.

[†] PRA: panel reactive antibody.

Table 27: Kidney Transplant Recipients* by Age Group and Primary Renal Diagnosis Category, Adult Recipients, First Graft, Canada, 2009 (Number)

	Age 18–39	Age 40–59	Age 60+	Total
Glomerulonephritis	80	163	75	318
Pyelonephritis	13	35	13	61
Polycystic Kidney Disease	10	95	41	146
Hypertension/ Other Vascular	7	35	50	92
Diabetic Nephropathy	21	90	84	195
Other [†]	56	62	59	177
Unknown/Not Reported	24	48	19	91
Total	211	528	341	1,080

Source

Canadian Organ Replacement Register, 2010, Canadian Institute for Health Information.

Table 28: Unadjusted Three-Month and One-, Three- and Five-Year Graft Survival Rates in Adult Kidney Transplant Recipients, First Graft, Canada, 2000 to 2009 (Percentage)

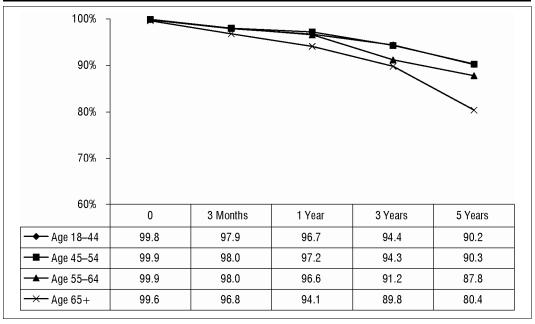
		2000	2001	2002	2003	2004	2005	2006	2007	2008	2009
	N	602	552	521	558	517	509	616	639	643	678
	3 Months	94.5	95.1	93.3	95.2	95.2	96.3	95.6	96.7	95.8	96.3
Deceased Donor	1 Year	93.5	93.1	90.4	91.4	91.9	92.5	93.3	93.4	92.5	_
Donoi	3 Years	89.9	88.9	82.9	85.8	85.9	85.9	86.9	_		_
	5 Years	83	83.7	75.4	79.7	79.1	_	_	_		_
	N	310	340	319	342	345	370	415	413	409	402
	3 Months	95.2	96.2	99.1	98.5	98.6	98.1	97.6	98.8	97.6	98.7
Living Donor	1 Year	94.2	95	98.1	98	98.3	95.9	96.4	96.6	96.3	_
20	3 Years	92.6	90.8	95.3	95.9	94.5	92.4	93.3	_		_
	5 Years	88.7	84.6	92.2	91.5	90.1	_	_	_	_	_

Source

^{*} 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.

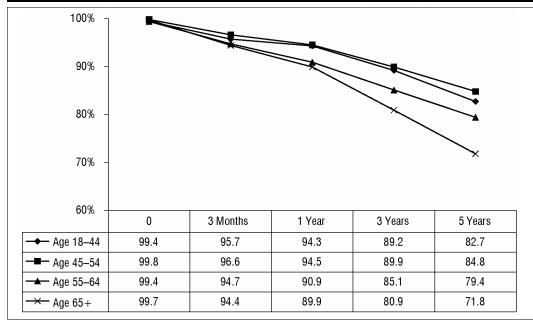
[†] For a list of primary diagnoses captured by CORR, see Appendix G.

Figure 9: Unadjusted Three-Month and One-, Three- and Five-Year Graft Survival Rates in Adult Kidney Transplant Patients, First Graft, Living Donor, by Age at Transplant, Canada, 2000 to 2009 (Percentage)



Canadian Organ Replacement Register, 2010, Canadian Institute for Health Information.

Figure 10: Unadjusted Three-Month and One-, Three- and Five-Year Graft Survival Rates in Adult Kidney Transplant Patients, First Graft, Deceased Donor, by Age at Transplant, Canada, 2000 to 2009 (Percentage)



Source

2.6 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 29 to 33. Throughout the decade, there were 568 first graft transplants and 33 re-transplants on pediatric recipients. There was no distinct trend for transplants utilizing living-donor or deceased-donor organs.

Table 29: Kidney Transplants by Year, Donor Type and Re-Transplants, Pediatric Recipients, Canada, 2000 to 2009 (Number)

	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	Total
First Graft, Deceased Donor	31	18	28	27	19	39	22	42	24	31	281
First Graft, Living Donor	43	26	36	28	37	29	26	21	23	18	287
Re-Transplants	3	3	2	3	5	5	1	4	3	4	33
Total	77	47	66	58	61	73	49	67	50	53	601

Source

Canadian Organ Replacement Register, 2010, Canadian Institute for Health Information.

Table 30: Pediatric Kidney Transplants by Age Group and Province of Treatment, Canada, 2000 to 2009 (Number, Percentage)

		B.C.	Alta.	Sask.	Man.	Ont.	Que.	N.S.	Total
A== 0 4	N	11	11	0	3	29	20	11	85
Age 0–4	%	15.7	15.9	0.0	5.6	13.4	14.0	28.9	14.1
A 5 . 4 O	N	17	17	0	16	42	26	8	126
Age 5-10	%	24.3	24.6	0.0	29.6	19.4	18.2	21.1	21.0
A== 11 17	N	42	41	10	35	146	97	19	390
Age 11-17	%	60.0	59.4	100.0	64.8	67.3	67.8	50.0	64.9
Total	N	70	69	10	54	217	143	38	601

Source

Table 31: Dialysis Duration in Days Prior to First Kidney Transplant, Pediatric Recipients, Canada, 2000 to 2009

	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009
Duration on Dialysis (Median Days), Deceased Donor	379	292	336	460	586	625	631	422	344	265
Duration on Dialysis (Median Days), Deceased Donor, Excluding Pre-Emptive	516	507	436	772	705	770	649	558	373	292
Duration on Dialysis (Median Days), Living Donor	193	137	140	175	267	107	144	137	66	197
Duration on Dialysis (Median Days), Living Donor, Excluding Pre-Emptive	467	295	348	327	414	349	271	483	258	297

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

Source

Table 32: Pediatric Kidney Transplant by Age Group and Primary Renal Diagnosis Category, Canada, 2000 to 2009

	Age	0–4	Age	5–10	Age 1	11–17
Primary Renal Diagnosis Category	N	%	N	%	N	%
Alport Syndrome	0	0.0	<5*		8	2.2
Cystinosis	0	0.0	9	7.3	19	5.3
Dysplasia/Hypoplasia	24	28.9	25	20.2	45	12.5
Posterior Urethral Valves	8	9.6	7	5.6	13	3.6
Obstructive Uropathy	<5*		6	4.8	15	4.2
Vesicoureteric Reflux	<5*		<5*		20	5.5
Polycystic Kidneys	<5*		<5*		11	3.0
Nephronophthisis	<5*		6	4.8	19	5.3
Other Congenital/Hereditary	8	9.6	<5*		8	2.2
Other Pyelonephritis	0	0.0	6	4.8	10	2.8
Glomerulonephritis	11	13.3	13	10.5	47	13.0
Focal Sclerosis	<5*		9	7.3	18	5.0
Autoimmune Disease	0	0.0	<5*		23	6.4
Moschcowitz Syndrome	0	0.0	8	6.5	14	3.9
Other [†]	10	12.0	14	11.3	43	11.9
Unknown	10	12.0	12	9.7	48	13.3
Total Patients	83	100.0	124	100.0	361	100.0

Notes

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

^{..} Number suppressed to ensure confidentiality.

^{*} Value suppressed in accordance with CIHI privacy policy; cell value is from 1 to 4.

[†] For a list of primary diagnoses captured by CORR, see Appendix G.

Table 33: Unadjusted Three-Month and One-, Three- and Five-Year Graft Survival Rates in Pediatric Kidney Transplant Recipients, First Graft, Canada, 2000 to 2009 (Percentage)

		2000	2001	2002	2003	2004	2005	2006	2007	2008	2009
	N	31	18	28	27	19	39	22	42	24	31
	3 Months	96.8	94.4	100.0	92.6	94.7	97.4	95.5	95.2	100.0	100.0
Deceased Donor	1 Year	96.8	88.9	100.0	88.9	94.7	97.4	90.9	95.2	91.7	_
Donoi	3 Years	90.3	88.9	100.0	74.1	94.7	92.3	81.8	_	_	_
	5 Years	80.6	83.3	88.9	70.4	89.5	_	_	_	_	_
	N	43	26	36	28	37	29	26	21	23	18
	3 Months	97.7	100.0	94.4	96.4	100.0	96.6	100.0	100.0	95.7	100.0
Living Donor	1 Year	97.7	100.0	94.4	96.4	100.0	96.6	100.0	100.0	95.7	_
20	3 Years	93.0	96.2	94.4	85.7	100.0	93.1	92.3	_	_	_
	5 Years	90.7	96.2	94.4	85.7	89.2	_	_	_	_	_



Chapter 3—Liver Transplantation

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 2000 to 2009.

The decade spanning 2000 to 2009 saw 4,285 liver transplants registered with CORR, with more than 80% of patients receiving livers from deceased donors (Table 34). However, during that period the proportion of transplants from living donors increased from 5% in 2000 to 12% in 2009. While most of the transplants were liver only, there were also combination transplants performed; the liver–kidney combination was the most frequently observed (n = 67) (Table 35).

Between 2000 and 2009, more males received liver transplants (65%), primarily those age 35 and older (Table 36). Among recipients younger than 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 36).

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 2000, more than 80% of liver transplant recipients receiving a first graft in the past decade were considered non-urgent (Status 1 and 2) (Figure 11).

The crude RPMP of liver transplant recipients was highest in the Atlantic provinces (15.0) and Ontario (14.4). The remaining provinces ranged from 5.8 to 12.5 RPMP (Figure 12).

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 37). In 2009, the waiting list decreased to 551, and deaths on the waiting list also decreased, from 141 to 91 between 2005 and 2009 (Table 37).

Unadjusted patient survival rates for liver transplant patients remained relatively stable over the last decade. Three-year survival varied between 82% and 85%; five-year survival was somewhat lower (between 79% and 80%) (Figure 13). One-year survival reached a peak of 93.3% in 2008.

Table 34: Liver Transplants by Year, Donor Type, Age Group and Re-Transplants, Canada, 2000 to 2009 (Number)

		2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	Total
ic: 17	First Graft, Deceased Donor	30	20	25	33	15	34	25	28	27	31	268
Pediatric: Age 0–17	First Graft, Living Donor	6	13	10	6	12	8	9	15	10	9	98
_ `	Re-Transplants	4	4	3	4	3	9	8	6	7	7	55
:: 8	First Graft, Deceased Donor	336	293	290	302	318	296	324	342	318	324	3,143
Adults: Age 18+	First Graft, Living Donor	13	31	32	29	42	52	58	56	58	48	419
·	Re-Transplants	20	33	26	31	27	24	42	33	33	33	302
Total	All Ages	409	394	386	405	417	423	466	480	453	452	4,285

Source

Canadian Organ Replacement Register, 2010, Canadian Institute for Health Information.

Table 35: Combination Liver Transplants, Canada, 2000 to 2009 (Number)												
2000 2001 2002 2003 2004 2005 2006 2007 2008 2009 Total												
Liver Only	403	383	381	399	414	416	447	468	442	439	4,192	
Liver Combinations	6	11	5	6	3	7	19	12	11	13	93	
Total	409	394	386	405	417	423	466	480	453	452	4,285	

Source

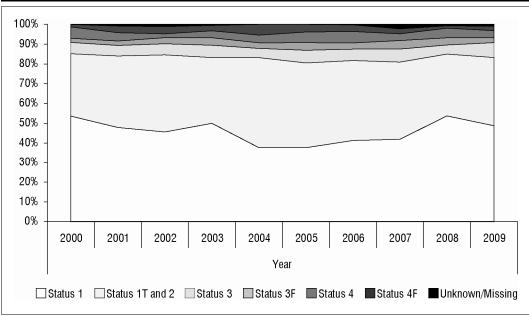
Table 36: Primary Diagnosis for Liver Transplant Recipients, First Graft, by Age Group, Canada, 2000 to 2009 (Number)

	Age <1	Age 1-10	Age 11-17	Age 18–34	Age 35–59	Age 60+	Total
Primary Biliary Atresia	72	53	5	2	2	1	135
Hepatitis C	1	2	1	7	808	164	983
Hepatitis B	_	_	1	20	157	49	227
Other Hepatitis	4	8	8	42	92	29	183
Alcoholic Cirrhosis	_	_	_	3	333	151	487
Cryptogenic Cirrhosis	_	_	3	15	107	74	199
Cancer	2	17	6	10	219	105	359
Metabolic Disorders	8	12	7	20	46	15	108
Cholestatic Liver Disease	5	12	15	77	339	115	563
Unknown/Missing	13	24	7	13	53	22	132
Other*	15	37	28	78	285	109	552
Total	120	165	81	287	2,441	834	3,928

Source

Canadian Organ Replacement Register, 2010, Canadian Institute for Health Information.

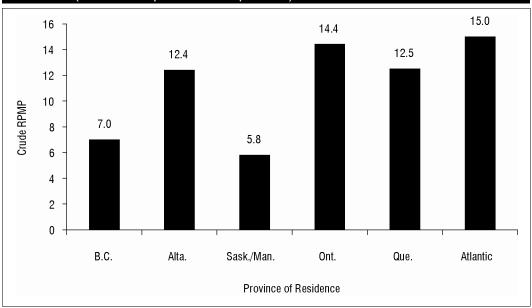
Figure 11: Distribution of Liver Transplants by Medical Status at Transplant, Canada, 2000 to 2009



Source

^{*} For a list of primary diagnoses captured by CORR, see Appendix G.

Figure 12: Liver Transplant Recipients by Province of Residence, Canada, 2009 (Crude Rate per Million Population)



Data from the Atlantic provinces was combined, as was data from Saskatchewan and Manitoba, due to small numbers.

Source

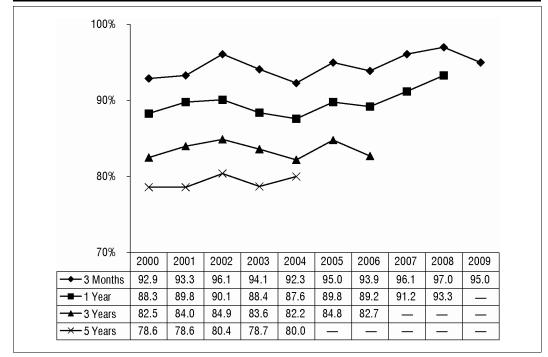
Canadian Organ Replacement Register, 2010, Canadian Institute for Health Information.

Table 37: Liver Transplant Waiting List and Deaths, December 31, Canada, 2000 to 2009

	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	Total
Age 0-17	27	36	31	30	37	32	36	19	17	19	284
Age 18+	311	418	528	539	630	681	687	616	570	532	5,512
Total	338	454	559	569	667	713	723	635	587	551	5,796
Deaths on Waiting List	51	57	82	100	96	141	120	77	92	91	907

Source

Figure 13: Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival Rates for Deceased-Donor Liver Transplant Recipients, First Graft, Canada, 2000 to 2009 (Percentage)





Chapter 4—Heart Transplantation

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 discusses the trends in heart transplantation procedures and outcomes in Canada over the decade from 2000 to 2009.

Between 2000 and 2009, there were 1,647 heart transplants registered in CORR, including 53 re-transplants. The number of transplants performed each year remained fairly stable between 2000 (173) and 2009 (170). The number of children younger than a year old receiving heart transplants fluctuated minimally over the decade (<20 for all years). The largest number of transplants was performed on recipients between age 35 and 59 (799), followed by those age 60 and older (329) (Table 38). The crude RPMP for heart transplants varied from 4 to 6 across Canada (Figure 14).

In each age group, the proportion of male recipients was higher than females; it was highest in those age 60 and older (83%). Over the last decade, males comprised 72.5% of Canadian heart transplant recipients (Table 39).

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 15).

There were 136 people on the waiting list for a heart transplant in 2009. Since 2000, deaths on the waiting list have varied from 14 to 35 per year (Table 40). A total of 258 Canadians died over the last decade while waiting for a heart transplant.

Three-month, one-year and three-year survival rates reached their highest levels in recent years (95%, 94% and 85%, respectively, Figure 16). Five-year survival remained relatively constant, varying between 75% and 82%.

Table 38: Heart Transplants by Year, Age Group and Re-Transplants, Canada, 2000 to 2009 (Number)

		2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	Total
ö ►	First Graft Age <1	10	10	5	6	14	15	17	7	16	17	117
Pediatric: Age 0–17	First Graft Age 1–10	8	8	8	4	7	8	7	9	6	11	76
ďΚ	First Graft Age 11–17	8	9	8	10	9	9	9	11	15	9	97
+	First Graft Age 18–34	17	19	15	16	13	18	27	14	19	18	176
Adults: Age 18+	First Graft Age 35–59	80	71	84	82	66	86	91	85	75	79	799
~ 4	First Graft Age 60+	38	40	41	33	30	33	20	31	30	33	329
Re-Tra	ansplants	12	4	3	6	4	5	7	6	3	3	53
Total		173	161	164	157	143	174	178	163	164	170	1,647

Canadian Organ Replacement Register, 2010, Canadian Institute for Health Information.

Table 39: Primary Diagnosis for Heart Transplant Recipients, Canada, 2000 to 2009 (Number)

	Age <1	Age 1–10	Age 11-17	Age 18–34	Age 35–59	Age 60+	Total
Congenital	56	26	17	20	21	1	141
Cardiomyopathy Unspecified	10	5	22	21	72	27	157
Dilated Cardiomyopathy	11	9	22	49	165	54	310
Idiopathic Cardiomyopathy	4	4	2	21	74	22	127
Ischemic Cardiomyopathy	_	1	2	8	280	180	471
Unknown/Missing	14	13	13	5	27	12	84
Other*	22	18	19	52	160	33	304
Total	117	76	97	176	799	329	1,594

Note

Source

^{*} For a list of primary diagnoses captured by CORR, see Appendix G.

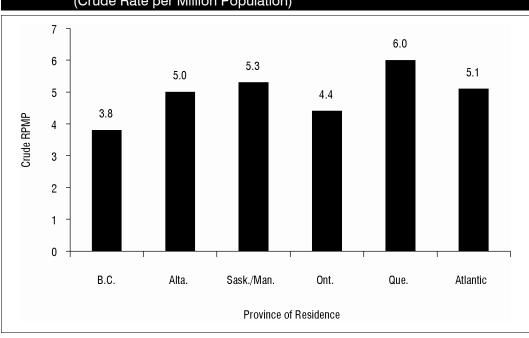


Figure 14: Heart Transplant Recipients by Province of Residence, Canada, 2009 (Crude Rate per Million Population)

Data from the Atlantic provinces was combined, as was data from Saskatchewan and Manitoba, due to small numbers.

Source

2004

Status 3

2005

Year

2006

Status 4

2007

Unknown/Missing

2008

2009

Figure 15: Distribution of Heart Transplants by Medical Status* at Transplant, Canada, 2000 to 2009

Note

2000

2001

2002

☐ Status 1 ☐ Status 2

Source

Canadian Organ Replacement Register, 2010, Canadian Institute for Health Information.

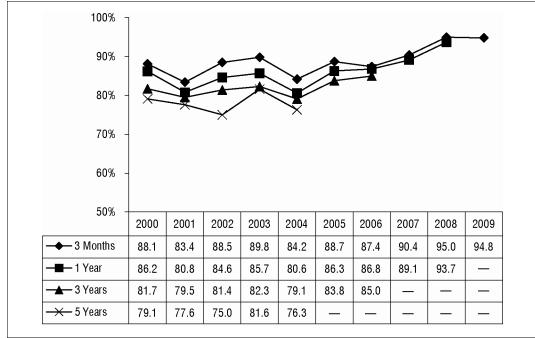
2003

2000 to 2009												
	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	Total	
Age 0-17	9	13	13	37	6	9	7	13	17	12	136	
Age 18+	80	112	90	94	119	87	80	102	114	124	1,002	
Total	89	125	103	131	125	96	87	115	131	136	1,138	
Deaths on Waiting List	30	34	35	30	26	27	13	19	14	30	258	

Source

^{*} 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.

Figure 16: Unadjusted Three-Month and One-, Three-, and Five-Year Patient Survival Rates for Heart Transplant Recipients, First Graft, Canada, 2000 to 2009 (Percentage)





Chapter 5—Lung Transplantation

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 2000 to 2009.

Between 2000 and 2009, there was an increase in the annual number of lung transplants performed in Canada. During the decade, the total number of lung transplants reached 1,499, reflecting an increase of 52% from 2000 (124) to 2009 (189) (Table 41). During the decade, the volume of bilateral lung transplants increased by 84%, from 85 to 156. Single-lung transplant volumes fluctuated somewhat but did not change consistently over time (34 in 2000, 31 in 2009) (Table 42).

In 2009, the Atlantic region had the highest rate of lung transplantation, at 8.6 RPMP, followed by Alberta (8.2 RPMP) and Ontario (5.7 RPMP) (Figure 17).

The number of individuals on the waiting list for a lung transplant continued to grow over the decade, reaching 245 in 2009. Since 2004, the number of people dying annually has remained relatively constant at around 40 (Table 44).

Rates of patient survival for lung transplant generally show an increasing trend (Figure 18). One-year survival increased from 81% to 91% between 2005 and 2008. Similarly, five-year survival increased from 57% to 72% between 2000 and 2004. Three-month and three-year survival made smaller gains (85% to 93% from 2000 to 2009; 69% to 72% from 2000 to 2006).

Table 41: Lung Transplants by Year, Age Group and Re-Transplants, Canada, 2000 to 2009 (Number)

	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	Total
First Graft, Age 18+	121	120	130	112	128	137	166	179	156	178	1,427
First Graft, Age 0–17	2	4	5	2	3	5	4	4	6	4	39
Re-Transplants	1	2	4	4	2	3	1	4	5	7	33
Total	124	126	139	118	133	145	171	187	167	189	1,499

Source

Table 42: Lung Transplants by Ti	ransplant Type,	Canada, 2000 to	b 2009 (Number)
----------------------------------	-----------------	-----------------	-----------------

	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	Total
Bilateral Lung	85	82	96	95	98	119	129	152	135	156	1,147
Single Lung	34	39	36	21	30	19	35	32	28	31	305
Living-Donor Lobar	1	2	0	0	2	1	1	0	0	0	7
Heart-Lung	4	3	7	2	3	6	6	3	4	2	40
Total	124	126	139	118	133	145	171	187	167	189	1,499

Canadian Organ Replacement Register, 2010, Canadian Institute for Health Information.

Table 43: Primary Diagnoses* for Lung Transplant Recipients, First Graft, Canada, 2000 to 2009 (Number, Percentage)

	Bilatera	al Lung	Single	Lung	Heart	–Lung
	N	%	N	%	N	%
Congenital	9	0.8	1	0.3	14	35.0
Alpha Antitrypsin	66	5.9	17	5.4	1	2.5
Cystic Fibrosis	320	28.4	13	4.2	4	10.0
Emphysema/Chronic Obstructive Pulmonary Disease	246	21.8	149	47.6	3	7.5
Idiopathic Pulmonary Fibrosis	240	21.3	94	30.0	3	7.5
Primary Pulmonary Hypertension	51	4.5	3	1.0	5	12.5
Unknown/Missing	39	3.5	5	1.6	1	2.5
Other [†]	157	13.9	31	9.9	9	22.5
Total	1,128	100.0	313	100.0	40	100.0

Note

Source

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

[†] For a list of primary diagnoses captured by CORR, see Appendix G.

10 8.6 9 8.2 8 7 5.7 Crude RPMP 6 4.9 5 4.1 4 2.9 3 2 1 0 B.C. Alta. Sask./Man. Ont. Que. Atlantic Province of Residence

Figure 17: Lung Transplant Recipients by Province of Residence, Canada, 2009 (Crude Rate per Million Population)

Note

Data from the Atlantic provinces was combined, as was data from Saskatchewan and Manitoba, due to small numbers.

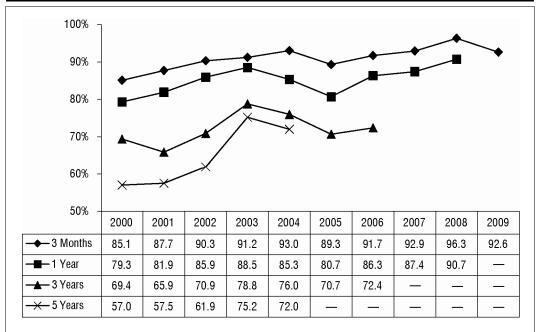
Sources

Canadian Organ Replacement Register, 2010, Canadian Institute for Health Information; Statistics Canada.

Table 44: Lung Transplant Waiting List, December 31, Canada, 2000 to 2009											
	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	Total
Bilateral Lung	108	125	88	131	155	188	147	183	147	137	1,409
Single Lung	58	25	50	29	22	37	94	51	129	104	599
Heart-Lung	11	13	12	12	4	14	11	9	6	4	96
Total	177	163	150	172	181	239	252	243	282	245	2,104
Deaths on Waiting List	21	28	26	29	43	43	36	43	44	44	357

Source

Figure 18: Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Lung Transplant Recipients, First Graft, Deceased-Donor Lungs, Canada, 2000 to 2009 (Percentage)





Chapter 6—Pancreas Transplantation

6 Pancreas Transplantation

ESRD patients with underlying diabetes generally 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. Pancreas transplant after kidney transplant (PAK) and pancreas transplant alone (PTA) are less common. 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 2000 to 2009, there were 673 pancreas transplants performed in Canada (Table 45). The majority of the transplants performed (71%) were SKP procedures. Table 46 summarizes islet cell transplants, a medical procedure that involves replacing the insulin-producing cells of the pancreas (islet cells) that are destroyed in people with type 1 diabetes. Since 2000, 290 procedures have been performed on 209 patients (in general, patients receive two procedures).

More pancreas transplantations in Canada have been performed on men than women (Figure 19). The number of people waiting for a pancreas transplant declined steadily, from 195 in 2005 to 98 in 2009 (Table 47).

Rates of patient survival for simultaneous kidney–pancreas transplant are presented in Figure 20.

Table 45: Pancreas Transplants by Year, Canada, 2000 to 2009 (Number)											
Transplant	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	Total
SKP	47	34	44	38	47	53	55	50	63	48	479
PAK	14	10	17	17	11	12	13	13	18	18	143
PTA	4	3	11	9	3	6	5	6	3	1	51
Total	65	47	72	64	61	71	73	69	84	67	673

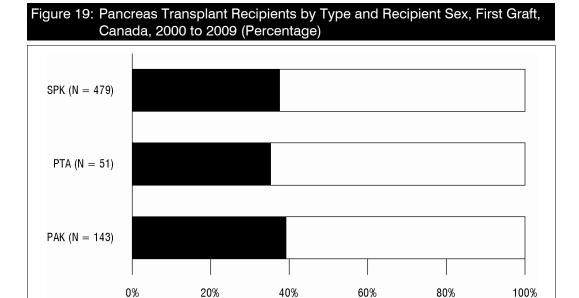
Note

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

Source

Table 46: Islet Cell Transplants in Canada, 2000 to 2009											
2000 2001 2002 2003 2004 2005 2006 2007 2008 2009 Total											
Patients	10	18	26	14	8	27	31	18	28	29	209
Procedures	22	22	41	20	11	37	39	25	35	38	290

Canadian Organ Replacement Register, 2010, Canadian Institute for Health Information.



Note

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

Female

☐ Male

Source

Table 47: Pancreas and Kidney–Pancreas Transplant Waiting List, Canada, 2000 to 2009 (Number)

	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009
PTA/PAK	30	32	37	31	51	63	63	55	49	42
SKP	128	172	122	120	101	132	113	126	98	56
Total	158	204	159	151	152	195	176	181	147	98

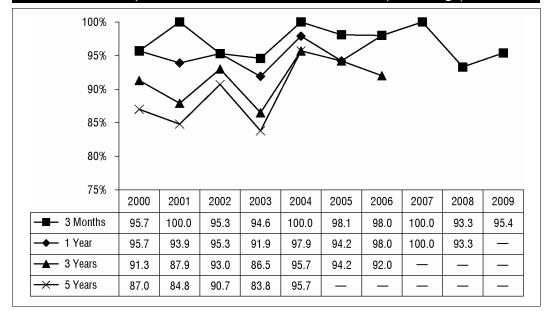
Note

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

Source

Canadian Organ Replacement Register, 2010, Canadian Institute for Health Information.

Figure 20: Unadjusted Three-Month and One-, Three- and Five-Year Graft Survival Rates in Simultaneous Kidney–Pancreas Transplant Recipients, by Year of Transplant, First Graft, Canada, 2000 to 2009 (Percentage)



Source



Chapter 7—Intestinal Transplantation

7 Intestinal Transplantationvi

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.

Since 1990, there have been 51 intestinal transplants reported to CORR (Table 48). The transplants were almost evenly split between pediatric patients and adult recipients (55% versus 45%). The majority of liver–small intestine transplants were performed in those younger than age 18 (84%).

Table 48: Intestinal Transplants by Transplant Period and Age Group, Canada, 1990 to 2009 (Number)

	1990–1999		2000-	-2009	Total				
Type of Graft	Age 0–17	Age 18+	Age 0–17	Age 18+	Age 0-17	Age 18+	All Ages		
Multi-Visceral	1	2	2	9	3	11	14		
Isolated Small Intestine	5	2	3	5	8	7	15		
Liver-Small Intestine	4	2	12	1	16	3	19		
Kidney-Small Intestine	0	2	0	0	0	2	2		
Liver-Kidney- Small Intestine	1	0	0	0	1	0	1		
Total	11	8	17	15	28	23	51		

Source

vi. 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 1990 and 2009.



Chapter 8—Donors

8 Donors

Overall, the number of Canadian organ donors increased from 880 in 2000 to 1,003 in 2009, a relative increase of 14% (Figure 21). Over this same time period, the percentage of living donors increased from 46% to 51%. As a result of this increase in donors, transplant procedures also increased, from 1,879 in 2000 to 2,087 in 2009 (Figure 22).

Although the total number of deceased donors remained stable over the past decade, the age composition of donors changed. Between 2000 and 2009, the number of deceased donors age 55 and older increased 69%, from 110 to 186 (Table 49). Conversely, deceased donors younger than 18 decreased 46% (from 72 to 39). This changing age profile was also reflected in living donors (Table 50). The number of living donors increased among those age 40 and older, particularly among those age 55 to 59 (170%) and 60 or older (233%).

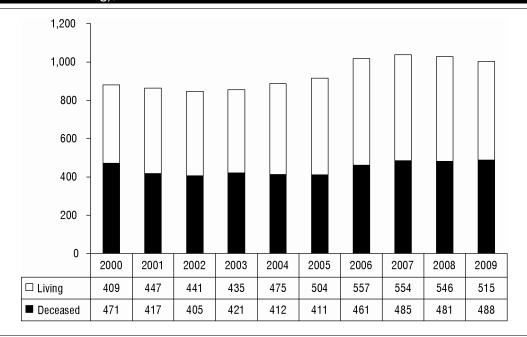
Between 2001 and 2009, 30% of living donors in Canada were unrelated (the definition of unrelated includes spouses). The proportion of unrelated donors has been increasing and, in 2009, accounted for 39% of living donors (Table 51).

A Note About Deceased-Donor Rates

Currently, the deceased donor rate per million population (DRPM) remains the most commonly used metric of deceased organ donation activity in Canada and internationally. The deceased DRPM does not take into account variation in the number of potential organ donors who die in hospital. This number can be influenced by a variety of socio-demographic and non-health system related factors. As such, the deceased DRPM may vary between countries or regions for reasons other than the efficiency of the health care system in identifying and obtaining consent for deceased organ donation. The extent to which socio-demographic and non-health system related factors may influence the deceased DRPM in different regions within the same country has not been well studied. If the population in a given region or country is relatively constant over time, the deceased DRPM may provide valuable information regarding longitudinal changes in organ donation activity within a given region.

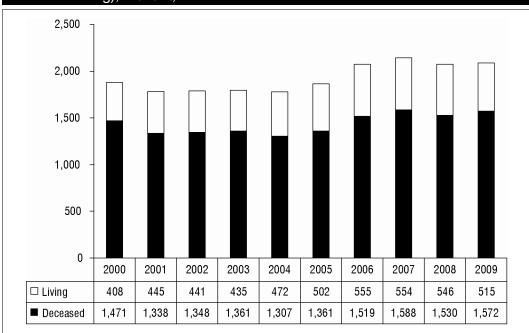
The overall deceased DRPM for Canada in 2009 was 14.5; it remained relatively constant over the past decade (Figure 23). The living DRPM was 15.3. Figures 24 and 25 provide corresponding regional donor rates.

Figure 21: Number of Canadian Organ Donors by Donor Source (Deceased or Living), 2000 to 2009



Canadian Organ Replacement Register, 2010, Canadian Institute for Health Information.

Figure 22: Number of Solid Organ Transplants by Donor Source (Deceased or Living), Canada, 2000 to 2009



Source

Table 49: Number of Deceased Donors by Age Group, Canada, 2000 to 2009											
	2000 2001 2002 2003 2004 2005 2006 2007 2008 2009									2009	Total
Age 0-17	72	54	47	36	29	47	41	53	49	39	467
Age 18-39	145	105	109	128	114	99	115	108	131	126	1,180
Age 40-49	93	112	96	95	86	83	102	101	92	86	946
Age 50- 54	51	46	51	36	43	51	53	60	50	51	492
Age 55-59	38	36	41	35	46	44	48	52	58	53	451
Age 60+	72	64	61	91	94	87	102	111	101	133	916
Total	471	417	405	421	412	411	461	485	481	488	4,452

Canadian Organ Replacement Register, 2010, Canadian Institute for Health Information.

Table 50: Number of Living Donors by Age Group, Canada, 2000 to 2009											
	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	Total
Age 0-39	187	196	191	178	190	180	218	199	188	168	1,895
Age 40-49	132	146	144	139	151	159	164	178	177	171	1,561
Age 50-54	49	48	63	58	61	66	66	78	87	72	648
Age 55-59	20	33	28	26	34	48	49	68	56	54	416
Age 60+	15	24	15	18	22	23	32	31	37	50	267
Unknown	6	0	0	16	17	28	28	0	1	0	96
Total	409	447	441	435	475	504	557	554	546	515	4,883

Source

Canadian Organ Replacement Register, 2010, Canadian Institute for Health Information.

Table 51: Living Donor by Relationship of Donor to Recipient, Canada, 2001 to 2009

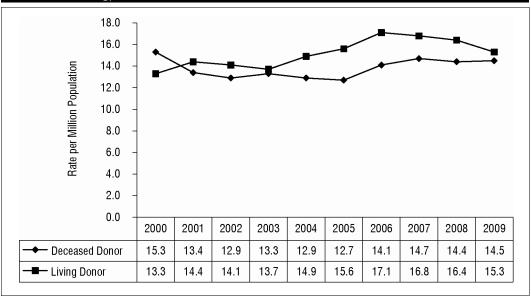
	Parent	Sibling	Offspring	Other Related*	Spouse	Unrelated	Total
	raient	Sibiling	Olispinig	nelateu	Spouse	Officialed	Total
2001	97	164	62	21	43	60	447
2002	86	144	68	27	51	65	441
2003	62	154	71	30	62	56	435
2004	85	149	72	43	58	68	475
2005	79	150	75	39	86	75	504
2006	88	159	86	66	80	78	557
2007	83	149	95	38	91	98	554
2008	78	171	60	37	86	114	546
2009	81	120	75	39	96	104	515

Notes

Source

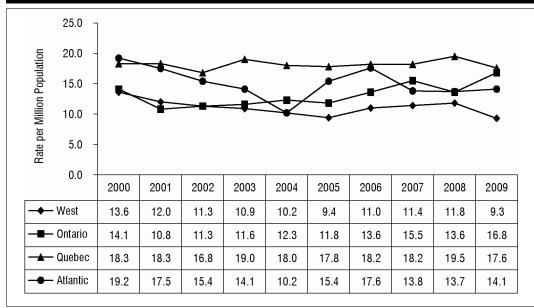
^{*} Other related refers to family members such as aunts, uncles or cousins.

Figure 23: Donor Rate per Million Population, by Donor Source (Deceased or Living), Canada, 2000 to 2009



Canadian Organ Replacement Register, 2010, Canadian Institute for Health Information.

Figure 24: Deceased Donor Rate per Million Population by Region, Canada, 2000 to 2009



Notes

West includes British Columbia, Alberta, Saskatchewan and Manitoba.

Atlantic includes New Brunswick, Nova Scotia, Prince Edward Island and Newfoundland and Labrador.

Source

25.0 Rate per Million Population 20.0 15.0 10.0 5.0 0.0 2000 2001 2002 2003 2004 2005 2006 2007 2008 2009 → West 16.2 18.4 18.5 17.2 19.8 17.9 19.8 21.2 17.4 15.7 Ontario 15.7 16.2 15.9 15.4 17.3 19.8 21.8 20.6 21.2 21.1 → Quebec 4.2 6.2 6.0 7.1 5.8 6.7 6.8 6.0 7.0 5.2 Atlantic 18.7 15.0 12.0 12.0 11.1 12.8 13.7 12.5 16.7 14.1

Figure 25: Living Donor Rate per Million Population, by Region, Canada, 2000 to 2009

Notes

West includes British Columbia, Alberta, Saskatchewan and Manitoba.

Atlantic includes New Brunswick, Nova Scotia, Prince Edward Island and Newfoundland and Labrador.

Source



Appendices

Appendix A—Canadian Organ Replacement Register Board of Directors

CORR Board of Directors (October 1, 2010)

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

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

	Type of Transplants Performed in 2009									Dialysis Programs in 2009			
						Intestine/	Pancreas/			Home		Home	
Heenitel/Equility	Kidnov	Liver	Heart	Heart/	Luna	Multi-	Kidney-	Islet	HD	HD	חח	PD	
Hospital/Facility	Kidney	Liver	пеап	Lung	Lung	Visceral	Pancreas	Cell	חח	Training	PD	Training	
Northwest Territories			I		T				l				
Stanton Territorial Health Authority*									Х				
Hay River Health Authority*									Χ				
British Columbia													
Abbotsford Regional									Χ				
B.C. Children's	Х								Х		Х	Х	
Kelowna General									Х	Х	Х	Х	
Kootenay-Boundary Regional									Х	Х	Х	Х	
Penticton Regional									Χ		Х	Х	
Prince George Regional									Χ	Х	Х	Х	
Royal Columbian									Χ		Х	Х	
Royal Inland									Χ	Х	Х	Х	
Royal Jubilee									Χ	Х	Х	Х	
St. Paul's	Х		Χ						Χ		Х	Х	
Surrey Memorial									Х				
Vancouver General	Х	Χ			Χ		Х	Χ	Х		Х	Х	
Alberta	,						'						
SARP, Foothills Medical	Х						Х		Х	Х	Х	Х	
NARP, University of Alberta	Х	Χ	Χ	Х	Х	Χ	Х	Χ	Х	Х	Х	Х	
Alberta Children's Hospital	Х												
Saskatchewan													
Regina General									Χ		Х	Х	
St. Paul's	Х								Х		Х	Х	
Manitoba	<u>. </u>		•		•								
Brandon Regional									Х				
Children's Hospital of Winnipeg	Х								Х				
Health Sciences Centre	Х				Х				Х	Х			
Seven Oaks General									Х				
St. Boniface General									Х		Χ	Х	

	Type of Transplants Performed in 2009								Dialysis Programs in 2009			
						Intestine/	Pancreas/			Home		Home
				Heart/		Multi-	Kidney-	Islet		HD_		PD
Hospital/Facility	Kidney	Liver	Heart	Lung	Lung	Visceral	Pancreas	Cell	HD	Training	PD	Training
Ontario Bayshore Centre				I								
Dialysis Brockville*									Х			
Bayshore Centre Dialysis Stoney Creek*									Х			
Brantford General*									Χ			
Children's Hospital of Eastern Ontario									х		Χ	
Cornwall Dialysis Clinic*									Х			
Credit Valley									Х	Х	Х	Х
Dialysis Management Clinics Inc.—Pickering*									Х			
Dialysis Management Clinics Inc.—Markham*									Х			
Dialysis Management Clinics Inc.—Peterborough*									Х			
Grand River									Х		Х	Х
Halton Healthcare Services									Х			
McMaster Children's											Х	X
Hospital for Sick Children	Х	Χ	Х			Х			Х	Х	Х	Х
Niagara Health System									Х	Х	Х	Х
Hôtel-Dieu Grace									Х		Х	Х
Humber River Regional									Х	Х	Х	Х
Kingston General	Х								Х	Х	Х	Х
Lakeridge Health Corp. Whitby									Х	Х	Х	Х
LHSC—University and South Street	Х	Х	Х			Х	х		Х			
LHSC—Victoria									Х	Х	Х	Х
North Bay General									Х		Х	
Orillia Soldiers' Memorial									Х		Х	X
Ottawa-Carleton Dialysis Clinic*									Х			
Ottawa Hospital	Х								Х	Х	Х	Х
Peterborough Regional Health									Х		Х	Х
Renfrew Victoria									Х		Х	
Sault Area Hospitals— Plummer Memorial									Х		Х	Х
Scarborough— General Division									Х		Х	Х
Sheppard Centre*									Х			
St. Joseph's (Hamilton)	Χ								Х	Х	Χ	Х
St. Joseph's (Toronto)									Х		Х	Х
St. Michael's	Х								Х	Х	Х	Х
Sudbury Regional— Laurentian Site									Х	Х	Х	Х
Sunnybrook and Women's College									Х	Х	Х	Х
Sussex Centre*									Χ			

		Type of Transplants Performed in 2009							Dialysis Programs in 2009				
						Intestine/	Pancreas/			Home		Home	
Hospital/Facility	Kidney	Liver	Heart	Heart/ Lung	Lung	Multi- Visceral	Kidney- Pancreas	Islet Cell	HD	HD Training	PD	PD Training	
Thunder Bay Regional— McKellar Site				3					Х		Х	Х	
Timmins and District									Х		Х	Х	
Toronto East General									Х				
Toronto General—		.,	.,		.,		.,		.,	.,	.,		
University Health Network	Х	Х	Х	Х	Х	Х	Х		Х	Х	Х	Х	
University of Ottawa Heart Institute			Х										
William Osler									Х				
York Central									Χ		Х	Х	
Quebec	,		,	'						<u> </u>			
Aurores boréales									Х		Х		
Charles-LeMoyne									Χ		Х	Х	
CHUS—Fleurimont	Х								Х		Х	Х	
C.H. de Granby									Х				
C.H. de Verdun									Х		Х	Х	
Chicoutimi									Х		Х		
C.H. de la région de l'Amiante*									х				
CHUM—Notre-Dame	Χ			Х	Х		Х		Х	Х	Х	Х	
CHUM—St-Luc		Х							Х		Х	Х	
C.H. régional de Trois-Rivières									х		Х	Х	
Cité de la Santé de Laval									Х	Х	Х	Х	
CHUQ—Hôtel-Dieu	Х								X	X	X	X	
C.H. régional de Lanaudière									Х	Λ	Х		
CSSS de Gatineau-Hull									Х		Х	Х	
CSSS de Rimouski-Neigette									X		Х	X	
CSSS de la Témiscaminque													
CSSS du Suroît									Х		Х	Х	
CSSS de la Vallée-de-l'Or									X		X	X	
CSSS Haut-Richelieu-Rouville									Х		Х	X	
CSSS de Saint-Jérôme									Х		Х	Х	
CSSS de Sorel-Tracy									Х		Х	Х	
Hôtel-Dieu de Lévis									Х		Х	Х	
Institut de cardiologie de Montréal			Х										
Lakeshore									Х				
Maisonneuve-Rosemont	Х								X	Х	Х	Х	
Montréal Children's, McGill	X								Х		Х	X	
Montréal General, McGill									X	Х	Х	X	
Pierre-Le Gardeur									X				
Royal Victoria, McGill	Х	Х	Х	Х			Х		X		Х	Х	
Sacré-Cœur de Montréal			1						X		Х	X	
Sainte-Croix*									X		Х		
Sainte-Justine	Х	Х	Х						X		X	Х	
Sir Mortimer B. Davis—Jewish		- •							Х		Х	X	
General Hospital												L	

	Type of Transplants Performed in 2009							Dialysis Programs in 2009				
Hospital/Facility	Kidney	Liver	Heart	Heart/ Lung	Lung	Intestine/ Multi- Visceral	Pancreas/ Kidney- Pancreas	Islet Cell	HD	Home HD Training	PD	Home PD Training
St. Mary's									Х		Χ	X
New Brunswick												
Chaleur Regional									Х		Χ	
Edmundston									Х	Х	Χ	Х
Georges L. Dumont									Х	Х	Χ	Х
Saint John Regional									Х	Х	Χ	Х
St. Joseph's*									Х			
Nova Scotia												
Cape Breton Regional									Х		Χ	Х
IWK Grace Health	Х								Х		Χ	Х
Queen Elizabeth II	Х	Χ	Χ						Х	Х	Χ	Х
Yarmouth Regional									Х			
Newfoundland and Labrador												
Central Newfoundland Regional									Х			
Eastern Health									Х	Х	Χ	Х
Western Memorial Regional									Х		Х	

Note

^{*} Independent health facilities.

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=9
2¢erContent.ld.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: 2000 to 2009

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 outcomes 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, ESRD 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 RRT since January 1, 1981, form CORR's target population. CORR does not contain information on patients who have been determined to have acute, but not chronic, renal failure; recipients of tissue transplants; patients who were listed for but did not receive a vital organ transplant; and potential organ donors (that is, deceased donors who met the criteria for donation but from whom no organs were used for transplantation).

CORR's frame (that is, the entities that would be expected to contribute data to CORR, given its mandate) includes all the dialysis programs treating chronic renal failure patients and all the vital organ transplant programs within Canada. Data 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 2009, 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, 2009												
	B.C.	Alta.	Sask.	Man.	Ont.	Que.	N.B.	N.S.	P.E.I.	N.L.	N.W.T.	Total
Full-Care Dialysis Programs	12	3	2	5	31	33	4	4	0	3	0	97
Affiliated Community Centres	25	31	8	12	47	8	5	11	0	7	0	154
Independent Health Care Facilities Offering Hemodialysis	0	0	0	0	11	3	1	0	4	0	2	21

Table D2:Transplant Programs Within CORR Frame by Province, 2009										
	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	4	4	1	11		
Lung	1	1	0	1	2	1	0	6		
Pancreas/ Kidney–Pancreas	1	2	0	0	2	2	1	8		
Intestine/ Multi-Visceral	0	1	0	0	3	0	0	3		
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 that detail the data elements and the domain values are used for the purposes of paper collection. 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						
When initiate dialysis When Transfer to another program Change treatment modalities Have a kidney transplant Withdraw from dialysis Recover kidney function Die Mannually, on October 31 (survey with voluntary participation)	When transplanted When 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)	When organ(s) are retrieved for purposes of transplantation—deceased-donor profile and living-donor profile	At year-end— HD facility profile and PD facility profile	At year-end— renal transplant facility profile	Counts of patients waiting for transplants at each of the transplant programs; reported on a semi-annual basis by the OPOs						

Table D4 outlines the data supply chain for CORR.

Table D4: CORR Data Supply Chain										
Province of Treatment	Dialysis Recipients	Organ Transplant Recipients	Deceased Organ Donors	Living Organ Donors	Waiting List Statistics					
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)							
N.W.T.	Hospital dialysis program									

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

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

Upon completion of data entry, reporting centres are forwarded standardized audit reports for the purposes of verification. Changes noted by centres are made in the database. 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); and
- 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 (HMDB) for the calendar years 1995 to 2000 confirms the transplant hospitals within CORR.

A formal linkage^{vii} 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.

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.

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.

1) Incident ESRD Cases

In 2009, unit non-response for incident ESRD cases (under-reporting) was estimated to be 110 cases from Quebec and 40 cases from New Brunswick.

2) 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 2009, 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, 2009 (Number)											
	B.C.	Alta.	Sask.	Man.	Ont.	Que.	N.S.	Total			
Aggregate Counts Provided by OPOs at Year-End	147	120	15	46	584	261	90	1,263			
Patient-Level Data 147 120 15 45 586 269 90 1,272 for Transplants in CORR											

Note

^{*} Includes SKP and other kidney combination transplants.

3) Extra-Renal Transplants

For the extra-renal transplants in 2009, 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, 2009 (Number)

Organ Type	Data Source [†]	B.C.	Alta.	Man.	Ont.	Que.	N.S.	Total
Liver	CORR Registration	29	62	0	212	111	38	452
Livei	OPO Count	29	65	0	238	111	38	481
Heart	CORR Registration	12	36	0	64	49	11	172
пеан	OPO Count	12	36	0	64	51	11	174
Lung/	CORR Registration	12	39	4	102	32	0	189
Heart-Lung	OPO Count	12	39	4	102	32	0	189
Pancreas	CORR Registration	6	10	0	34	13	5	68
Pancieas	OPO Count	6	10	0	34	16	5	71
Intestine/	CORR Registration	0	1	0	2	0	0	3
Multi-Visceral	OPO Count	0	1	0	1	0	0	2

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.

4) 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 underreporting 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 2000 and 2009 was greater by 77 donors than initially reported by OPOs.

Table D7: Comparison of Deceased and Living Donors Registered in CORR and Reported by OPOs, 2000 to 2009 (Number)

	Re	gistered in CO	RR	Re	eported by OP(Os
Year	Deceased Donors	Living Donors	Total Donors	Deceased Donors	Living Donors	Total Donors
2000	471	409	881	471	409	880
2001	417	447	864	420	447	867
2002	405	441	848	405	440	845
2003	421	435	859	428	431	859
2004	412	475	914	414	468	882
2005	411	504	917	414	504	918
2006	461	557	1,020	468	554	1,022
2007	485	554	1,070	493	549	1,042
2008	481	546	1,045	486	542	1,028
2009	488	515	1,003	487	514	1,001
Total	4,452	4,883	9,421	4,486	4,858	9,344

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^{viii} 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.

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.

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 2000 to 2009, 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, 2000 to 2009

Data Type	Data Element	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009
	Age	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
	Sex	0.2	0.0	0.2	0.2	0.2	0.0	0.2	0.2	0.0	0.2
	Blood Type	0.0	0.2	0.0	0.0	3.0	0.4	0.4	0.6	1.0	19.2
Deceased Donor	Race/Ethnic Origin	20.9	25.4	3.6	22.1	32.0	36.7	34.2	36.6	36.7	45.3
Donor	Province of Residence (Not Formally Collected Until 2001)	85.8	0.0	0.0	0.0	0.0	0.0	0.2	0.4	0.8	0.0
	Cause of Death	1.0	4.8	3.8	2.5	3.2	5.2	6.6	8.4	4.9	4.6
	Age	1.5	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
	Sex	0.5	0.9	0.2	0.0	0.0	0.0	0.5	0.2	0.2	0.0
Living Donor	Blood Type	0.7	0.7	6.8	7.3	12.8	9.5	4.5	0.7	1.5	1.9
	Province of Residence (Not Formally Collected Until 2001)	96.8	0.2	0.2	0.5	1.3	1.2	2.3	1.1	0.5	0.0
	Sex	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.1	0.0	0.0
	Race/Ethnic Origin	14.5	18.5	16.2	20.0	21.3	23.3	22.1	19.8	19.5	19.5
	Blood Type	2.0	3.6	3.1	3.9	2.9	3.2	2.7	4.0	4.5	1.7
	Residential Postal Code	1.8	1.0	0.7	3.4	2.7	1.9	1.1	1.9	1.2	0.8
	Cause of Death	22.9	25.6	23.8	23.0	21.8	22.2	20.9	33.5	20.7	25.8
	Diagnosis	1.8	1.8	0.9	5.1	2.0	3.0	3.6	7.5	4.4	4.1
Transplant Recipients	Medical Status at Listing (Heart, Liver, Lung Transplants)	3.7	7.0	1.5	3.1	1.4	2.3	2.8	3.9	3.9	4.7
	Medical Status at Transplant (Heart, Liver, Lung Transplants)	0.1	1.7	0.6	0.5	0.2	0.4	0.3	2.8	2.0	2.3
	Cause of Graft Failure (Transplants With Failed Grafts)	37.9	40.1	38.4	45.8	44.6	45.2	39.6	52.0	44.7	50.0

Note

^{*} Recipients of first grafts for 2000 to 2009.

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 2000 to 2009. 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, 2000 to 2009										
Data Type Data Element 2000 2001 2002 2003 2004 2005 2006 2007 2008										

Data Type	Data Element	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	Total
	Sex	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.1	0.0
	Race/Ethnic Origin	14.2	6.5	6.7	7.2	6.0	4.9	7.1	5.2	4.2	5.5	6.7
Recipients	Residential Postal Code	1.3	1.2	0.9	1.3	1.3	1.6	1.2	1.6	2.5	1.8	1.5
	Diagnosis	11.9	13.8	14.8	14.4	13.6	13.0	12.9	15.2	14.9	15.8	14.1
	Cause of Death	26.7	26.2	27.9	29.3	25.4	28.0	26.4	28.8	30.2	29.5	27.4
	Angina	8.1	8.1	7.4	9.3	9.5	9.7	11.9	11.0	13.0	14.8	10.3
	Coronary Artery Bypass/Angioplasty	8.2	7.8	8.0	10.0	9.3	9.7	11.1	10.7	12.4	13.3	10.1
	Pulmonary Edema	8.4	7.9	8.0	9.5	9.8	9.8	11.2	11.1	12.2	14.1	10.2
	Myocardial Infarct	8.1	7.6	7.7	9.2	9.6	9.4	10.9	10.6	12.5	13.6	10.0
	Diabetes	6.5	6.6	5.2	6.8	7.0	7.0	8.2	6.6	7.7	7.7	6.9
	Cerebrovascular Accident	8.4	7.2	7.4	8.6	9.2	8.9	10.8	10.4	12.3	13.6	9.7
Risk Factors	Peripheral Vascular Disease	8.4	8.0	8.1	9.5	9.9	9.7	11.3	11.1	12.9	14.7	10.4
	Malignancy	8.4	9.5	9.4	11.8	11.0	12.9	13.4	14.8	16.2	19.4	12.8
	Chronic Lung Disease	8.4	8.3	8.3	9.8	10.2	10.0	11.6	11.5	13.2	15.5	10.7
	Use of Medications for Hypertension	7.7	5.7	5.5	7.0	7.4	7.1	8.2	7.3	7.9	8.3	7.2
	Presence of Other Serious Illness	11.5	17.4	19.0	19.5	19.6	21.7	20.2	18.7	24.6	27.4	20.1
	Current Smoker	9.5	13.3	14.7	13.7	16.0	16.2	15.8	15.4	16.1	17.1	14.8

Table D10: Non-Response/Unknown Values for Key Analytical Data Elements Related to Incident Dialysis Patients Registered in CORR by Province, 2000 to 2009

Data Type	Data Element	B.C.	Alta.	Sask.	Man.	Ont.	Que.	N.B.	N.S.	N.L.	Total
	Sex	0.0	0.0	0.0	0.0	0.0	0.0	0.3	0.0	0.0	0.0
	Race/Ethnic Origin	19.6	7.2	1.3	5.2	5.1	3.3	4.1	9.5	2.1	6.7
Recipients	Residential Postal Code	2.2	1.8	0.5	2.9	1.0	1.6	3.8	1.3	0.9	1.5
	Diagnosis	33.9	9.9	7.2	8.9	10.8	14.6	8.4	8.5	13.7	14.1
	Cause of Death	51.0	37.2	16.0	35.8	21.5	25.6	8.7	22.4	11.8	27.4
	Angina	35.3	7.1	5.7	12.9	6.3	8.1	2.5	2.1	1.5	10.3
	Coronary Artery Bypass/Angioplasty	35.5	7.0	2.7	12.4	6.0	8.0	2.7	1.9	1.6	10.1
	Pulmonary Edema	35.7	6.7	4.0	12.1	6.1	8.3	2.3	2.1	2.4	10.2
	Myocardial Infarct	34.9	6.6	3.5	12.5	5.8	8.2	2.1	2.4	2.2	10.0
	Diabetes	31.3	3.0	0.8	9.5	2.9	4.8	1.4	0.6	0.6	6.9
	Cerebrovascular Accident	35.0	6.2	3.6	12.0	5.8	7.2	2.5	1.4	1.2	9.7
Risk Factors	Peripheral Vascular Disease	36.5	6.9	4.0	12.3	6.4	8.0	2.6	2.4	2.1	10.4
	Malignancy	39.7	10.5	6.0	14.2	8.2	10.9	5.0	2.4	3.8	12.8
	Chronic Lung Disease	38.3	7.9	4.5	12.4	6.4	7.7	3.0	2.4	2.3	10.7
	Use of Medications for Hypertension	30.0	2.8	1.0	9.9	3.6	5.4	2.0	0.8	1.0	7.2
	Presence of Other Serious Illness	52.0	19.6	10.8	16.8	14.9	17.0	19.3	7.8	6.4	20.1
	Current Smoker	46.9	10.4	7.1	15.3	8.0	16.3	7.0	4.3	3.4	14.8

Reliability/Response Bias: A formal linkage^{ix} 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.

ix. 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 for 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

Body mass index (BMI):

Body mass index is a relationship between weight and height that is associated with body fat and health risk. The equation for BMI is body weight in kilograms divided by the square of height in metres.

In the Canadian weight classification system, four categories of BMI ranges are defined:

- Underweight (BMI less than 18.5)
- Normal weight (BMI 18.5 to 24.9)
- Overweight (BMI 25 to 29.9)
- Obese (BMI 30 and higher)

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

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.

Estimated glomerular filtration rate (eGFR): Estimated rate in mL/min/1.73 m² of the volume of plasma filtered by the kidney. Rates of filtration have been calculated from serum creatinine using the Modification of Diet in Renal Disease (MDRD) Study equation. eGFR is used to determine renal function.

Graft survival: Graft survival refers to whether an organ is still functioning at a certain time after 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 code: 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 endstage 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.

Patient Survival

Unadjusted survival probabilities (expressed as percentages from 0 to 100) are calculated using the Kaplan–Meier method. The cohorts are dialysis and transplant patients who started dialysis or received a first graft between 2000 and 2009. For dialysis survival, patients were censored at first kidney transplant, lost to follow-up, left the country or recovered function. For transplant graft survival, patients were censored at graft failure, lost to follow-up or left the country.

Population Estimates Used in Rate Calculations

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

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

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

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

Province	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009
B.C.*	4,069,619	4,108,576	4,145,550	4,182,843	4,227,592	4,285,510	4,341,681	4,342,039	4,417,017	4,488,860
Alta.†	3,072,939	3,125,682	3,186,560	3,229,988	3,274,349	3,329,790	3,448,406	3,587,925	3,671,210	3,763,284
Sask.	1,007,767	1,000,134	995,886	994,428	995,391	994,126	985,386	1,000,139	1,013,620	1,030,129
Man.	1,147,373	1,151,285	1,155,584	1,161,552	1,170,268	1,177,556	1,177,765	1,193,932	1,206,100	1,221,964
Ont.	11,685,380	11,897,647	12,102,045	12,256,645	12,392,721	12,541,410	12,686,952	12,794,689	12,936,296	13,069,182
Que.	7,357,029	7,396,990	7,445,745	7,492,333	7,542,760	7,598,146	7,651,531	7,687,125	7,753,470	7,828,879
Atlantic [‡]	2,348,928	2,340,937	2,341,217	2,342,677	2,343,235	2,343,969	2,331,769	2,326,107	2,329,624	2,337,561

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	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009
N.B.	750,518	749,890	750,327	750,896	751,384	752,006	749,168	745,561	747,147	749,468
N.S./P.E.I.	1,070,367	1,069,061	1,071,441	1,073,431	1,074,824	1,076,002	1,072,924	1,074,016	1,076,036	1,079,168
N.L.	528,043	521,986	519,449	518,350	517,027	515,961	509,677	506,530	506,441	508,925
Total	2,348,928	2,340,937	2,341,217	2,342,677	2,343,235	2,343,969	2,331,769	2,326,107	2,329,624	2,337,561

Source

Statistics Canada.

The following child population (age younger than 18) estimates were used.

Province	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009
B.C.*	907,328	900,396	888,732	877,882	869,646	867,966	864,480	862,756	860,604	857,765
Alta.†	788,193	787,870	789,641	787,376	785,038	788,342	805,279	824,926	830,994	840,911
Sask.	264,349	258,241	252,975	248,051	244,033	240,950	236,225	236,692	237,266	239,553
Man.	289,809	288,338	286,255	284,449	283,608	282,600	279,696	281,967	282,096	283,564
Ont.	2,766,649	2,793,673	2,803,770	2,792,395	2,776,729	2,777,653	2,776,967	2,765,370	2,747,704	2,729,827
Que.	1,596,734	1,580,565	1,567,208	1,553,393	1,543,295	1,538,081	1,534,706	1,542,975	1,536,332	1,530,262
Atlantic	524,716	512,869	501,363	490,679	480,431	472,261	461,433	455,817	448,366	442,578
N.B.	165,611	162,339	159,122	155,947	153,025	150,784	147,483	146,502	144,459	142,627
N.S./P.E.I.	241,738	237,535	233,016	228,696	224,166	220,019	215,333	212,690	208,993	205,667
N.L.	117,367	112,995	109,225	106,036	103,240	101,458	98,617	96,625	94,914	94,284

Notes

- * Includes the Yukon.
- † Includes the Northwest Territories and Nunavut.

Source

Statistics Canada.

Prevalent Patients

Prevalent patient numbers at year-end are based on the patient-level data, which includes registered 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: not all patients will be registered in CORR because they may have started treatment prior to January 1, 1981; incident patients have been under-reported by some reporting centres; and deaths are suspected to be under-reported to CORR, potentially inflating numbers of living patients.

Transplant Recipients

Information presented on transplant recipients in this report looks at recipients of first grafts of a specific organ where transplants occurred at a Canadian transplant facility. Tables and figures presented in sections 3 to 7, inclusive, refer to either 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 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.

Appendix G—Primary Diagnoses Captured by CORR

The tables below list the diagnostic categories that are captured by CORR for primary diagnosis. The tables are organized by organ.

End-Stage Renal Disease

Prima	ry Diagnosis Codes—End-Stage Renal Disease
Gener	ic
00	Chronic renal failure—etiology uncertain
Glome	erulonephritis/Autoimmune Diseases
05	Mesangial proliferative glomerulonephritis
06	Minimal lesion glomerulonephritis
07	Post-strep glomerulonephritis
08	Rapidly progressive glomerulonephritis
09	Focal glomerulosclerosis—adults
10	Glomerulonephritis, histologically NOT examined
11	Severe nephrotic syndrome with focal sclerosis (pediatric patients)
12	IgA nephropathy—proven by immunofluorescence (not code 85)
13	Dense deposit disease—proven by immunofluorescence and/or electron microscopy (MPGN type II)
14	Membranous nephropathy
15	Membranoproliferative mesangiocapillary glomerulonephritis (MPGN type I)
16	Idiopathic crescentic glomerulonephritis (diffuse proliferative)
17	Congenital nephrosis or congenital nephrotic syndrome (pediatric only)
19	Glomerulonephritis, histologically examined—specify
73	Polyarteritis
74	Wegener's granulomatosis
84	Lupus erythematosus
85	Henoch-Schönlein purpura
86	Goodpasture syndrome
87	Scleroderma
88	Hemolytic uremic syndrome (Moschcowitz syndrome)
Nephr	opathy, Drug Induced
30	Nephropathy caused by drugs or nephrotoxic agents, cause not specified
31	Nephropathy due to analgesic drugs
32	Nephropathy due to cisplatin
33	Nephropathy due to cyclosporin A
39	Nephropathy caused by other specific drug—specify

Polyon	stic Kidney
Polycy 11	
+1 12	Polycystic kidneys, adult type (dominant) Polycystic kidneys, infantile and juvenile types (recessive)
	nital/Hereditary Renal Diseases
21	Pyelonephritis/interstitial nephritis associated with neurogenic bladder
22	Pyelonephritis/interstitial nephritis due to congenital obstructive uropathy with or without vesicoureteric reflux
24	Pyelonephritis/interstitial nephritis due to vesicoureteric reflux without obstruction
40	Cystic kidney disease, type unspecified
41	Polycystic kidneys, adult type (dominant)
42	Polycystic kidneys, infantile and juvenile types (recessive)
43	Medullary cystic disease, including nephronophthisis
49	Cystic kidney disease, other type—specify
50	Hereditary familial nephropathy, type unspecified
51	Hereditary nephritis with nerve deafness (Alport syndrome)
52	Cystinosis
53	Oxalosis
54	Fabry disease
55	DRASH syndrome
58	Posterior urethral valves
59	Hereditary nephropathy, other—specify
60	Congenital renal hypoplasia—specify
61	Oligomeganephronic hypoplasia
62	Segmental renal hypoplasia (Ask-Upmark kidney)
63	Congenital renal dysplasia with or without urinary tract malformation
66	Syndrome of agenesis of abdominal muscles (prune belly syndrome)
Diabet	es
80	Diabetic nephropathy associated with type 1
81	Diabetic nephropathy associated with type 2
Renal	Vascular Disease
70	Renal vascular disease, type unspecified
71	Malignant hypertension (no primary renal disease)
72	Renal vascular disease due to hypertension (no primary renal disease)
73	Polyarteritis nodosa
78	Atheroembolic renal disease
79	Renal vascular disease, classified (nephrosclerosis, renal vascular thrombosis)
Other	· · · · · · · · · · · · · · · · · · ·
20	Pyelonephritis/interstitial nephritis, cause not specified
23	Pyelonephritis/interstitial nephritis due to acquired obstructive uropathy—specify
25	Pyelonephritis/interstitial nephritis due to urolithiasis

Primary D	Diagnosis Codes—End-Stage Renal Disease
Other	
29	Pyelonephritis, other causes
56	Sickle cell nephropathy
57	Wilms' tumour
82	Multiple myeloma
83	Amyloid
89	Multi-system disease, other—specify
90	Cortical or acute tubular necrosis
91	Tuberculosis
92	Gout
93	Nephrocalcinosis and hypercalcemic nephropathy
94	Balkan nephropathy
95	Kidney tumour
96	Traumatic or surgical loss of kidney
97	HIV nephropathy
99	Other identified renal disorders—specify

Liver Transplant

Primary	Primary Diagnosis—Liver Transplant						
Acute He	Acute Hepatic Failure (Fulminant)						
01	Hepatitis, type A						
02	Hepatitis, type B						
61	Hepatitis, type C						
58	Hepatitis, type non-A, -B, -C						
35	Hepatitis with delta						
05	Toxics						
04	Drug induced, other						
56	Drug induced, acetaminophen						
47	Other/fulminant hepatic failure (including Budd-Chiari syndrome and Wilson disease)						
Chronic	Chronic Hepatic Failure						
12	Budd-Chiari syndrome						
36	Byler disease (intra-hepatic cholestasis)						
09	Cirrhosis, alcoholic						
10	Cirrhosis, other						
08	Cryptogenic cirrhosis						
49	Post-necrotic cirrhosis						
07	Primary biliary cirrhosis						
14	Secondary biliary cirrhosis						
45	Drug induced, other						

Primai	ry Diagnosis—Liver Transplant
Chron	ic Hepatic Failure
42	Hepatitis, type A
43	Hepatitis, type B
60	Hepatitis, type C
59	Hepatitis, type non-A, -B, -C
51	Neonatal hepatitis
06	Autoimmune chronic active hepatitis
13	Primary biliary atresia
11	Sclerosing cholangitis
46	Toxic
15	Watson-Alagille disease (arterio-hepatic dysplasia)
62	Polycystic liver disease
64	Non-alcoholic steatohepatitis (NASH)
Hepati	c Tumours
50	Angiosarcoma
17	Cholangiocarcinoma
18	Fibrolamellar hepatoma
16	Hepatocellular carcinoma
19	Metastatic tumour
53	Hepatic tumour, other
Metab	olic Disorders
20	Alpha I anti-trypsin deficiency
28	Crigler-Najjar syndrome
21	Glycogen storage disease
23	Hemochromatosis
27	Hyperlipoproteinemia type 2
24	Niemann-Pick
26	Phenylketonuria
25	Protoporphyria
29	Tyrosinemia
22	Wilson disease
34	Metabolic disorder, other
Other	Primary Diagnosis
30	Congenital hepatic fibrosis
31	Caroli disease
32	Cystic disorders
52	Thrombosed hepatic artery
98	Unknown/missing
99	Other

Heart Transplant

Primary D	Diagnosis—Heart Transplant					
32	Cardiomyopathy					
29	Dilated cardiomyopathy					
01	Idiopathic cardiomyopathy					
30	Other dilated cardiomyopathy—specify					
33	Metabolic/genetic cardiomyopathy					
34	Cardiomyopathy related to muscular dystrophy					
35	Drug-induced cardiomyopathy (chemotherapy)					
12	Restrictive cardiomyopathy					
31	Hypertrophic cardiomyopathy					
24	Myocarditis					
07	Coronary artery disease (ischemic cardiomyopathy)					
04	Valvular heart disease					
23	Acute myocardial infarction					
15	Congenital heart disease—specify					
16	Congenital heart disease—acyanotic lesions					
17	Congenital heart disease—cyanotic lesions					
36	Metabolic disorder					
37	Cardiac tumour					
38	Refractive arrhythmia					
39	Muscular dystrophy					
98	Unknown					
99	Other—specify					

Lung, Heart-Lung Transplant

Code	Primary Diagnosis—Lung, Heart–Lung Transplant
08	Eisenmenger syndrome
11	Idiopathic pulmonary fibrosis
13	Emphysema
15	Lung failure due to congenital disease
17	Primary pulmonary hypertension
18	Chronic obstructive lung disease
19	Alpha I antitrypsin deficiency
20	Cystic fibrosis
22	Bronchiectasis
26	Sarcoidosis
27	Asbestosis
28	Bronchiolitis obliterans
32	Cardiomyopathy—not specified
98	Unknown
99	Other—specify

Pancreas Transplant

Code	Primary Diagnosis—Pancreas Transplant
01	Chronic pancreatitis
02	Diabetes type 1
03	Pancreatectomy
04	Cystic fibrosis
05	Trauma
06	Diabetes type 2
07	Pancreatic cancer
08	Bile duct cancer
98	Unknown
99	Other—specify

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