



Canadian Organ Replacement Register Annual
Report: Treatment of End-Stage Organ Failure
in Canada, 2001 to 2010



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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The Canadian Institute for Health Information (CIHI) would like to thank the Canadian Organ Replacement Register Inc. (CORR) Board of Directors and Advisory Committee for their invaluable advice and support (see Appendix A for a list of the members of the Board of Directors).

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Executive Summary

Treatment of End-Stage Organ Failure in Canada, 2001 to 2010 draws on data from the Canadian Institute for Health Information (CIHI) Canadian Organ Replacement Register (CORR), primarily for the years 2001 through 2010 (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 (1991 to 2010) for key indicators;
- Survival data for dialysis and transplant patients; and
- A chapter on organ donors.

Overview

- In 2010, 5,646 patients started renal replacement therapy (RRT).
- Overall, 2,103 transplants of solid organs were performed in Canada in 2010.
- There were 1,022 organ donors (living and deceased) in 2010.

Kidney

- There were an estimated 39,352 people living with end-stage renal disease (ESRD) in Canada at the end of 2010, more than triple the number recorded in 1991. Of these, 23,188 were on dialysis and 16,164 were living with a functioning kidney transplant.
- A total of 5,646 ESRD patients initiated renal replacement therapy (RRT) in 2010, with just less than 80% receiving hemodialysis as their initial treatment. In 1991, 2,614 initiated RRT.
- Of 1,197 kidney recipients during 2010, 198 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 35% of new cases in 2010, followed by renal vascular disease (18%).

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 53% of those who initiated RRT being age 65 and older in 2010, compared to 39% in 1991. 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 2010, 31% of patients first saw a nephrologist less than three months before starting dialysis, compared to 42% in 2001.
- The average age of incident hemodialysis patients was 65.3 in 2010; more than half of these patients reported having diabetes.

Liver

- At the end of 2010, 501 patients were waiting for a transplant, a number that has declined from its peak of 723 in 2006.
- There were 442 liver transplants performed in Canada in 2010, 12% more than in 2001.
- During the 10-year period, 4,319 liver transplants were performed.

Heart

- There were 135 Canadians awaiting a heart transplant, with 22 deaths on the waiting list during 2010.
- In 2010, 167 heart transplants were performed in Canada.
- Over the decade, the annual number of transplants performed fluctuated between 143 and 178, averaging 164 transplants per year.
- Overall, 1,596 Canadians received a first heart transplant in this time frame, and 43 were re-transplanted.

Lung

- In 2010, there were 310 Canadians, compared with 163 in 2001, waiting to receive a lung transplant.
- In 2010, 179 lung transplants were performed, a 42% increase over the 126 that were performed in 2001.
- Bilateral lung transplants accounted for 85% of the lung transplants performed in 2010.
- 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 (45%).

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 685 pancreatic transplants performed in Canada between 2001 and 2010.
- Of these, 70% were simultaneous pancreas–kidney transplants.
- The number of Canadians awaiting a simultaneous pancreas–kidney transplant 2010 was 107.

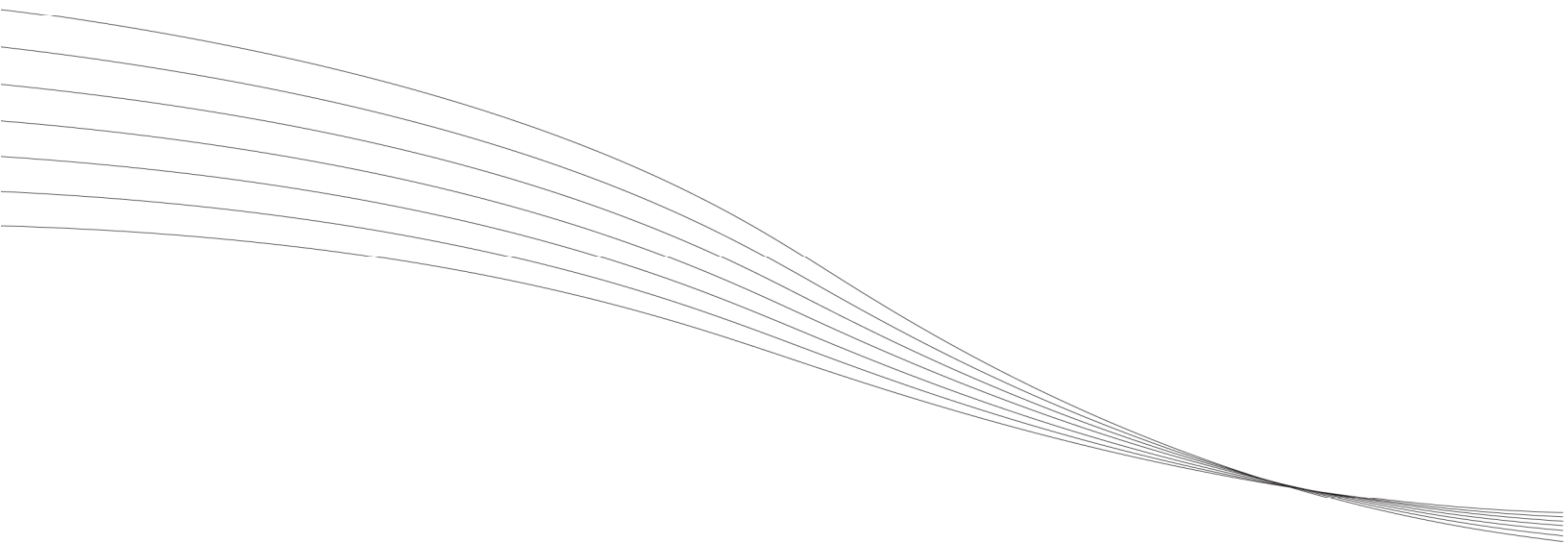
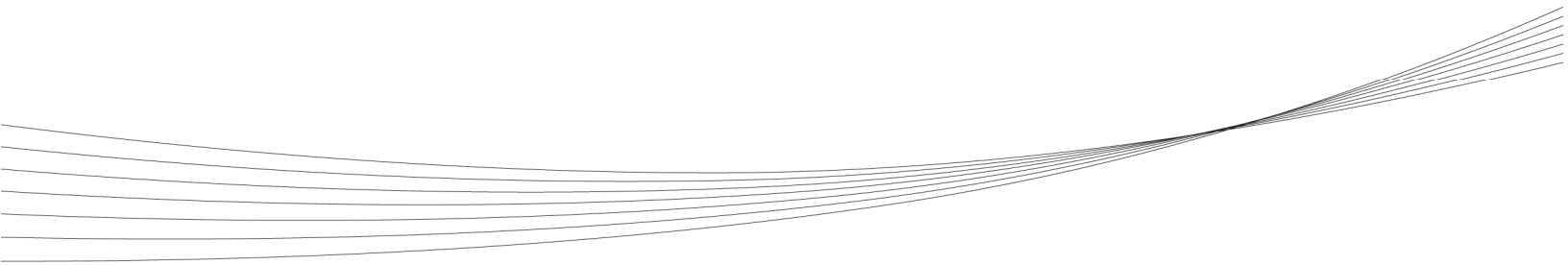
Small Intestine


- 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 1991 and 2010, there were 53 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.

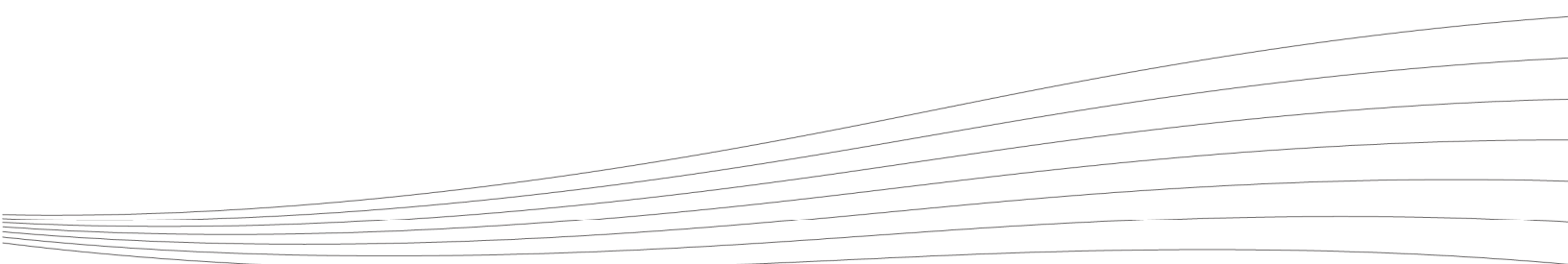
In addition to this annual summary report, more information and data tables are available online at www.cihi.ca/corr, in the form of special reports (Analyses in Brief) and semi-annual reports from the organ procurement organizations called *e-Statistics on Organ Transplants, Waiting Lists and Donors*. 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, 2011, 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), Transplant Québec 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 The table below shows the results of those comparisons.

Percentage of CORR transplant patients also recorded in the Discharge Abstract Database (DAD)	98%
Percentage of CORR's Ontario renal dialysis patients that matched perfectly to the National Ambulatory Care Reporting System (NACRS)	93%

While completeness of key data elements has improved over time, the proportion of unknown values reported continues to exceed 10%. In 2010, primary diagnosis was missing or unknown in 15% of incident dialysis patients; 26% of dialysis patients and 9% 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.

Please see Appendix D—CORR Data Quality Documentation: 2001 to 2010, for further detail regarding the completeness and coverage of reporting in CORR.

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.

1.3 Organization of the Report

This report summarizes information on end-stage organ failure treatments in Canada. Chapters 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 Incorporated 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 2001 to 2010 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. Published small cells are reviewed with CIHI statisticians to ensure the risk of re-identification is minimized.

1.6 Age Group Reporting

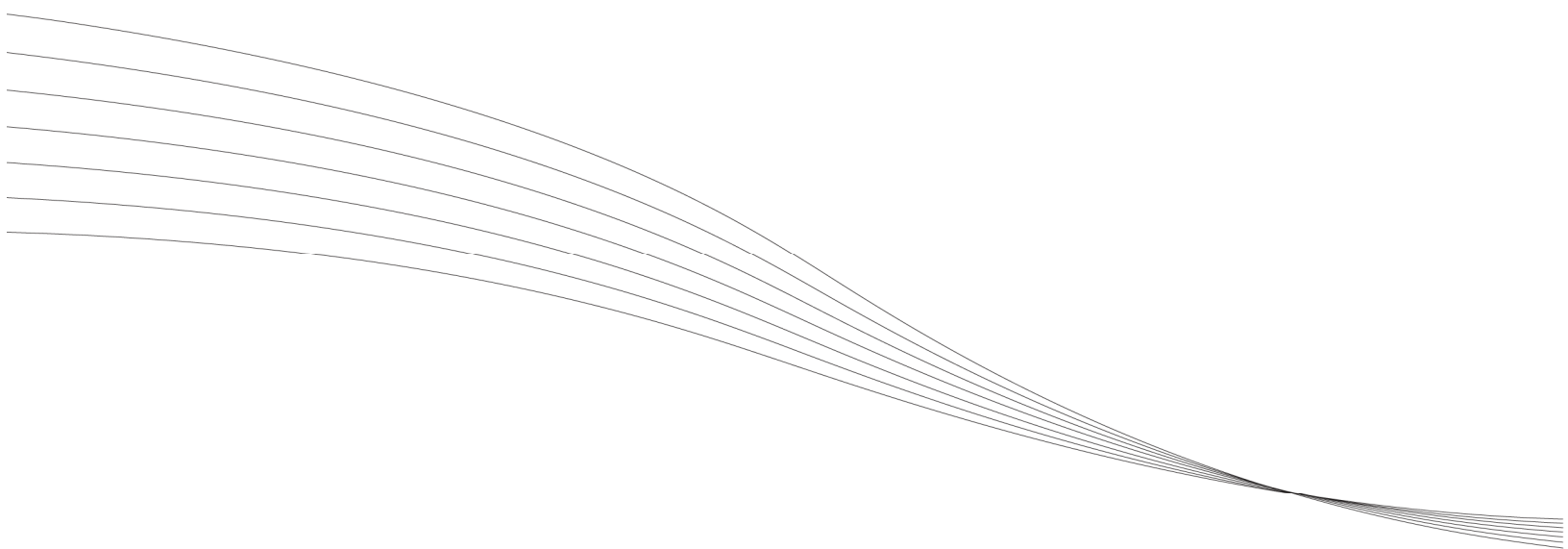
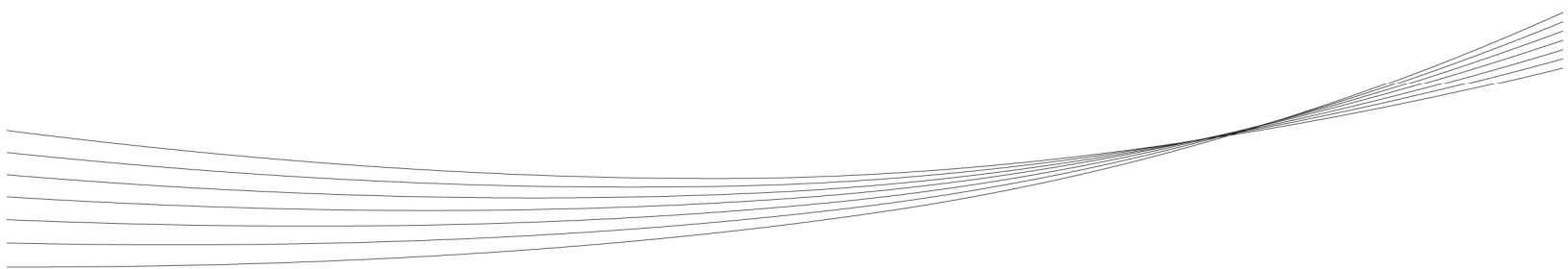
Throughout the report, data is presented by age group. The choice of age groups is not always consistent and may be influenced by therapeutic interest (for example, activity levels or pediatric versus adult) or analysis limitations; age groups may also be chosen to facilitate international comparisons (for example, incidence and prevalence rates). As used in this report, pediatric patients are those patients younger than age 18.

1.7 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 5,646 newly diagnosed patients with ESRD in 2010, an increase of 13% since 2001 ($n = 5,012$). However, this was a 116% increase when compared to 1991 (Table 1).

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 771.8. From 1991 until 2001, the rate of incidence among patients age 75 and older increased more than 200%. Between 2001 and 2005, incidence rates remained relatively constant. Since 2005, the midpoint of the last decade, rates among older age groups have slowly declined, falling from 760.0 to 709.7 among those age 75 and older, and from 627.0 to 543.6 in the 65-to-74 age group. Incidence rates among those age 45 to 64 increased from 166.8 to 203.6 during the 20-year period. Since 1997, the incidence rates in this age group have 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.

In 2010, 53% of incident patients were age 65 or older, and an additional 35% were age 45 to 64.

Provincially in 2010, the highest incidence RPMP occurred in Newfoundland and Labrador (255.1) and Manitoba (241.2), while the lowest rates were in Quebec and Alberta, at 124.7 and 133.2, respectively.

At the end of 2010, slightly fewer than 80% of all new patients initiated treatment on hemodialysis (HD),^{iv} a level that has remained virtually unchanged since 2001 (Table 3). While HD was consistently utilized as the primary modality of treatment throughout the decade, the number of new patients receiving peritoneal dialysis (PD)^v as an initial treatment also remained consistent through the time period. The use of pre-emptive transplants increased over time, from 137 in 2001 to 198 in 2010.

Age of incidence also influences the initial treatment (Table 4). In 2010, 69% of incidence patients age 25 to 44 started with hemodialysis, while among those age 65 to 74 and 75 and older, the proportions were 83% and 87%. 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 2010, all provinces used HD the majority of the time, with Newfoundland and Labrador having the highest proportion of HD (97%), followed by New Brunswick (89%) and Quebec (85%). The highest proportion of patients treated by continuous ambulatory peritoneal dialysis (CAPD) was seen in Saskatchewan (23%) (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 35% 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 2010, 31% of incident patients were late referrals, down from 42% in 2001 (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 2010, 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 2010, the average age of incident HD patients was 65.3, and the average age of PD patients was 61.7. Patients 65 or older accounted for 58% of incident patients, while males accounted for 60%.

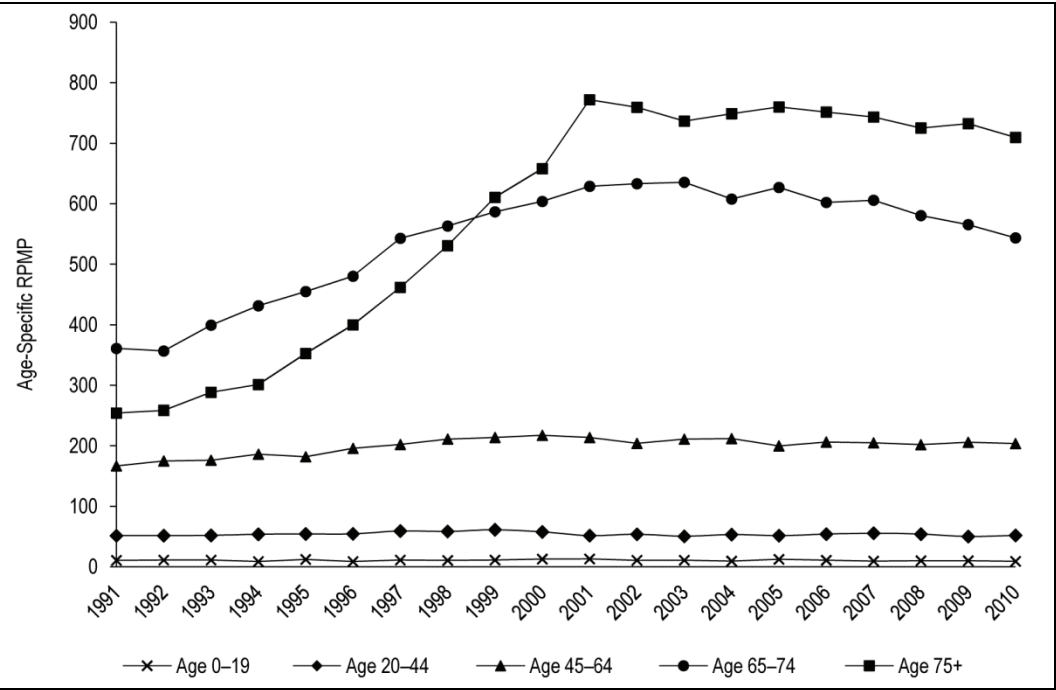
**Table 1: Incident End-Stage Renal Disease Patients by Age Group, Canada, 1991 to 2010
(Number, Rate per Million Population, Percentage of Total)**

Age Group	0–19 Years			20–44 Years			45–64 Years			65–74 Years			75+ Years			Total	
	N	RPMP	%	N	RPMP	%	N	RPMP	%	N	RPMP	%	N	RPMP	%	N	RPMP
1991	83	10.8	3.2	600	51.5	23.0	908	166.8	34.7	694	360.9	26.6	329	254.1	12.6	2,614	93.3
1992	88	11.3	3.2	602	51.6	22.2	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	33.9	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	195.7	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	563.2	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	22.2	4,551	149.7
2000	103	12.9	2.2	675	57.7	14.2	1,558	217.3	32.8	1,296	603.9	27.3	1,123	658.0	23.6	4,755	154.9
2001	104	13.0	2.1	605	51.6	12.1	1,584	213.7	31.6	1,359	628.9	27.1	1,360	771.8	27.1	5,012	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	160.7
2003	87	11.0	1.7	594	50.5	11.6	1,674	210.9	32.6	1,392	635.5	27.1	1,382	736.8	26.9	5,129	162.0
2004	75	9.5	1.4	627	53.3	12.0	1,737	212.0	33.2	1,345	607.8	25.7	1,444	748.9	27.6	5,228	163.6
2005	98	12.5	1.9	607	51.6	11.5	1,689	199.9	31.9	1,402	627.0	26.4	1,506	760.0	28.4	5,302	164.3
2006	85	10.9	1.6	638	54.2	11.8	1,798	206.4	33.2	1,369	602.3	25.2	1,534	751.5	28.3	5,424	166.3
2007	75	9.5	1.4	647	55.5	11.7	1,843	205.0	33.3	1,413	605.9	25.5	1,562	743.3	28.2	5,540	168.2
2008	80	10.2	1.5	631	54.1	11.4	1,866	202.0	33.7	1,395	580.5	25.2	1,562	725.2	28.2	5,534	166.0
2009	80	10.2	1.4	587	50.1	10.4	1,950	205.9	34.6	1,407	565.5	25.0	1,611	732.4	28.6	5,635	167.0
2010	72	9.2	1.3	612	52.0	10.8	1,969	203.6	34.9	1,399	543.6	24.8	1,594	709.7	28.2	5,646	165.5

Sources

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information; Statistics Canada.

Figure 1: Incident End-Stage Renal Disease Patients, Age-Specific Rate per Million Population, Canada, 1991 to 2010



Sources
Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information; Statistics Canada.

Table 2: Incident End-Stage Renal Disease Patients by Province, Canada, 2001 to 2010 (Number, Rate per Million Population)

		2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
B.C./ Y.T.	N	630	652	623	669	636	701	717	697	770	752
	RPMP	153.3	157.3	148.9	158.2	148.4	161.5	165.1	157.8	171.5	164.7
Alta./ N.W.T./ Nun.	N	504	495	558	465	531	483	529	482	530	506
	RPMP	161.2	155.3	172.8	142.0	159.5	140.1	147.4	131.3	140.8	133.2
Sask.	N	225	166	182	192	171	186	199	177	200	154
	RPMP	225.0	166.7	183.0	192.9	172.0	188.8	199.0	174.6	194.2	147.3
Man.	N	240	245	239	230	236	298	251	285	286	298
	RPMP	208.5	212.0	205.8	196.5	200.4	253.0	210.2	236.3	234.0	241.2
Ont.	N	2,008	2,092	2,102	2,218	2,275	2,316	2,374	2,320	2,386	2,492
	RPMP	168.8	172.9	171.5	179.0	181.4	182.5	185.5	179.3	182.6	188.6
Que.	N	995	1,009	1,006	1,021	1,050	1,053	1,067	1,099	1,024	986
	RPMP	134.5	135.5	134.3	135.4	138.2	137.6	138.8	141.7	130.8	124.7
N.B.	N	145	128	144	161	123	140	112	146	128	131
	RPMP	193.4	170.6	191.8	214.3	163.6	186.9	150.2	195.4	170.8	174.2
N.S./ P.E.I.	N	158	152	176	157	186	165	203	221	185	197
	RPMP	147.8	141.9	164.0	146.1	172.9	153.8	189.0	205.4	171.4	181.6
N.L.	N	107	104	99	115	94	82	88	107	126	130
	RPMP	205.0	200.2	191.0	222.4	182.2	160.9	173.7	211.3	247.6	255.1
Canada	N	5,012	5,043	5,129	5,228	5,302	5,424	5,540	5,534	5,635	5,646
	RPMP	161.6	160.7	162.0	163.6	164.3	166.3	168.2	166.0	167.0	165.5

Sources

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information; Statistics Canada.

Table 3: Incident End-Stage Renal Disease Patients by Initial Treatment, Canada, 2001 to 2010 (Number, Rate per Million Population, Percentage of Total)

Type of Treatment		2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
HD Home	N	5	6	7	9	3	19	17	25	26	21
	RPMP	0.2	0.2	0.2	0.3	0.1	0.6	0.5	0.8	0.8	0.6
	%	0.1	0.1	0.1	0.2	0.1	0.4	0.3	0.5	0.5	0.4
HD Institutional	N	3,900	4,017	4,117	4,104	4,158	4,310	4,387	4,340	4,387	4,470
	RPMP	125.7	128.0	130.0	128.5	128.8	132.1	133.2	130.2	130.0	131.1
	%	77.8	79.7	80.3	78.5	78.4	79.5	79.2	78.4	77.9	79.2
CAPD	N	616	600	644	732	708	661	686	704	777	660
	RPMP	19.9	19.1	20.3	22.9	21.9	20.3	20.8	21.1	23.0	19.3
	%	12.3	11.9	12.6	14.0	13.4	12.2	12.4	12.7	13.8	11.7
APD	N	354	309	242	253	272	271	272	297	260	297
	RPMP	11.4	9.8	7.6	7.9	8.4	8.3	8.3	8.9	7.7	8.7
	%	7.1	6.1	4.7	4.8	5.1	5.0	4.9	5.4	4.6	5.3
Pre-Emptive	N	137	111	119	130	161	163	178	168	185	198
	RPMP	4.4	3.5	3.8	4.1	5.0	5.0	5.4	5.0	5.5	5.8
	%	2.7	2.2	2.3	2.5	3.0	3.0	3.2	3.0	3.3	3.5
Total	N	5,012	5,043	5,129	5,228	5,302	5,424	5,540	5,534	5,635	5,646
	RPMP	161.6	160.7	162.0	163.6	164.3	166.3	168.2	166.0	167.0	165.5

Note

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

Sources

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information; Statistics Canada.

Table 4: Incident End-Stage Renal Disease Patients by Year, Age Group and Initial Treatment Modality, Canada, 2001 to 2010 (Number)

Age Group	Initial Modality	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
		N = 5,012	N = 5,043	N = 5,129	N = 5,228	N = 5,302	N = 5,424	N = 5,540	N = 5,534	N = 5,635	N = 5,646
0–19	HD	45	36	39	34	45	59	39	35	50	38
	PD	45	28	32	29	33	15	16	33	21	18
	Pre-Emptive	14	22	16	12	20	11	20	12	9	16
20–44	HD	405	440	428	417	432	442	443	430	403	424
	PD	133	147	124	155	134	145	134	146	121	130
	Pre-Emptive	67	45	42	55	41	51	70	55	63	58
45–64	HD	1,179	1,200	1,275	1,295	1,231	1,345	1,392	1,392	1,425	1,487
	PD	359	326	344	392	367	368	376	388	430	373
	Pre-Emptive	46	41	55	50	91	85	75	86	95	109
65–74	HD	1,117	1,142	1,158	1,121	1,143	1,124	1,171	1,130	1,138	1,156
	PD	232	232	228	212	250	231	230	250	251	228
	Pre-Emptive	10	3	6	12	9	14	12	15	18	15
75+	HD	1,159	1,205	1,224	1,246	1,310	1,359	1,359	1,378	1,397	1,386
	PD	201	176	158	197	196	173	202	184	214	208
	Pre-Emptive	0	0	0	1	0	2	1	0	0	0
Total	HD	3,905	4,023	4,124	4,113	4,161	4,329	4,404	4,365	4,413	4,491
	PD	970	909	886	985	980	932	958	1,001	1,037	957
	Pre-Emptive	137	111	119	130	161	163	178	168	185	198

Note

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

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

Table 5: Incident Patients by Type of Treatment and Province of Treatment, Canada, 2010 (Number, Percentage of Total)

Type of Treatment		Province of Treatment*									
		B.C.	Alta.	Sask.	Man.	Ont.	Que.	N.B.	N.S.	N.L.	Canada
HD	N	521	418	115	239	1,968	834	115	157	124	4,491
	%	69.4	82.0	75.2	80.7	78.9	84.7	88.5	79.3	96.9	79.5
CAPD	N	129	69	35	50	250	87	15	21	4	660
	%	17.2	13.5	22.9	16.9	10.0	8.8	11.5	10.6	3.1	11.7
APD	N	61	9	3	5	208	6	0	5	0	297
	%	8.1	1.8	2.0	1.7	8.3	0.6	0.0	2.5	0.0	5.3
Pre-Emptive	N	40	14	0	2	69	58	0	15	0	198
	%	5.3	2.7	0.0	0.7	2.8	5.9	0.0	7.6	0.0	3.5
Total	N	751	510	153	296	2,495	985	130	198	128	5,646

Notes

* 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.

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

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

Table 6: Incident End-Stage Renal Disease Patients by Primary Diagnosis, Canada, 2001 to 2010 (Number, Rate per Million Population)

Diagnosis		2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
Glomerulonephritis	N	668	638	658	684	595	619	618	586	618	591
	RPMP	21.5	20.3	20.8	21.4	18.4	19.0	18.8	17.6	18.3	17.3
Diabetes	N	1,693	1,706	1,756	1,795	1,846	1,857	1,925	1,920	1,890	1,956
	RPMP	54.6	54.4	55.5	56.2	57.2	56.9	58.5	57.6	56.0	57.4
Renal Vascular Disease	N	961	923	952	960	1,024	1,062	995	1,010	1,048	1,002
	RPMP	31.0	29.4	30.1	30.1	31.7	32.6	30.2	30.3	31.1	29.4
Polycystic Kidney Disease	N	197	202	215	222	268	258	233	218	202	222
	RPMP	6.4	6.4	6.8	7.0	8.3	7.9	7.1	6.5	6.0	6.5
Drug Induced	N	103	104	101	95	103	93	124	108	113	119
	RPMP	3.3	3.3	3.2	3.0	3.2	2.9	3.8	3.2	3.4	3.5
Pyelonephritis	N	206	215	216	231	197	190	215	196	191	180
	RPMP	6.6	6.9	6.8	7.2	6.1	5.8	6.5	5.9	5.7	5.3
Other*	N	486	508	493	524	582	626	573	666	648	712
	RPMP	15.7	16.2	15.6	16.4	18.0	19.2	17.4	20.0	19.2	20.9
Unknown	N	698	747	738	717	687	719	857	830	925	864
	RPMP	22.5	23.8	23.3	22.4	21.3	22.0	26.0	24.9	27.4	25.3

Note

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

Sources

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information; Statistics Canada.

Table 7: Incident End-Stage Renal Disease Patients by Late Referral Status,* by Province and Canada, 2001 to 2010 (Percentage)

Province	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
B.C./Y.T.	42.7	43.4	35.1	34.6	31.2	29.8	31.0	32.9	34.2	30.2
Alta./N.W.T./Nun.	36.1	36.1	38.2	40.4	34.1	39.0	30.8	33.0	31.2	33.4
Sask.	44.2	44.5	42.9	36.6	34.8	40.9	28.5	29.6	28.5	30.0
Man.	48.5	43.7	36.2	38.4	33.7	33.6	32.2	25.3	30.2	29.3
Ont.	43.6	40.4	38.5	35.9	36.1	33.6	32.0	32.5	32.1	31.5
Que.	42.1	41.6	36.6	38.3	33.3	33.1	32.8	29.4	27.7	31.5
N.B.	49.6	43.2	40.3	32.2	37.8	39.1	38.5	32.3	34.2	36.0
N.S./P.E.I.	26.7	35.1	32.7	30.6	31.6	25.2	26.9	26.3	26.0	23.3
N.L.	38.1	40.0	31.5	36.1	30.2	22.7	25.0	30.8	26.8	26.2
Canada	42.1	40.9	37.5	36.5	34.4	33.5	31.6	31.3	31.1	31.0

Note

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

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

Table 8: Incident End-Stage Renal Disease Patients by Primary Diagnosis and Late Referral Status,* Canada, 2001 to 2010 (Percentage)

Diagnosis	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
Glomerulonephritis	36.4	33.8	32.5	32.7	30.9	30.3	28.0	24.1	26.5	25.7
Diabetes	37.0	32.4	30.6	27.7	26.0	25.5	23.3	21.9	22.6	22.2
Renal Vascular Disease	40.6	44.4	41.3	37.2	32.2	33.2	29.1	26.8	25.4	23.6
Polycystic Kidney Disease	16.2	20.0	14.3	15.4	11.1	9.4	8.7	8.6	9.0	11.3
Drug Induced	51.7	42.4	40.7	42.7	25.0	33.7	36.8	29.7	24.0	28.3
Pyelonephritis	45.2	37.6	32.6	40.1	36.0	30.2	31.1	38.7	34.9	38.1
Other†	57.0	61.9	54.9	58.7	59.4	56.5	54.7	57.4	55.1	56.6
Unknown	57.1	54.5	50.2	50.2	53.6	47.7	47.3	48.4	48.1	49.9
All Incident Patients	42.1	40.9	37.5	36.5	34.4	33.5	31.6	31.3	31.1	31.0

Notes

* 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.

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

Table 9: Adult Incident Dialysis Patients, Selected Characteristics, Canada, 2001 to 2010

		2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
HD	Mean Age (Years)	64.9	64.8	65.0	65.0	65.3	65.1	65.0	65.3	65.4	65.3
	Age 65+ (%)	58.7	58.8	58.2	57.8	59.4	57.9	57.8	57.8	57.9	56.9
	Male (%)	58.8	57.8	60.3	59.6	60.2	59.6	61.9	61.0	59.9	60.8
	Diabetes (%)	43.4	43.8	43.3	43.5	45.4	47.2	49.0	48.6	49.9	50.4
	Mean Comorbidity Index	2.3	2.1	2.0	2.0	2.0	2.0	2.0	2.1	2.1	2.0
	Mean BMI	26.7	26.8	27.0	27.4	27.5	27.7	27.6	28.2	28.3	28.4
	Mean eGFR	9.3	9.4	9.8	9.7	10.1	10.2	10.2	10.4	10.6	10.7
	Late Referral (%)	47.0	44.8	41.7	41.2	39.6	37.8	36.0	35.8	35.8	35.7
	Access Type (%)										
	Catheter	72.0	70.4	70.7	73.2	73.4	74.5	76.3	79.1	79.9	76.9
	AV Fistula	19.8	19.1	17.9	17.5	19.1	18.6	18.3	15.8	15.6	16.4
	AV Graft	2.0	2.5	2.3	2.2	1.5	1.6	1.5	1.5	1.2	1.1
	Unknown	6.2	8.1	9.2	7.2	6.0	5.3	3.9	3.6	3.3	5.6
PD	Mean Age (Years)	61.2	60.4	60.5	60.3	61.3	60.6	61.1	60.8	61.9	61.7
	Age 65+ (%)	46.6	46.2	45.0	42.6	46.9	44.0	45.7	44.7	45.6	46.2
	Male (%)	54.7	55.7	59.8	56.8	60.2	55.0	58.4	57.5	57.5	59.4
	Diabetes (%)	43.2	40.7	40.8	41.8	44.8	43.1	43.4	42.7	44.6	46.8
	Mean Comorbidity Index	1.6	1.3	1.5	1.2	1.4	1.2	1.3	1.1	1.1	1.3
	Mean BMI	25.6	26.0	26.4	26.5	26.8	27.2	27.1	27.5	28.0	27.3
	Mean eGFR	9.3	10.0	9.8	9.9	10.1	10.0	10.5	10.7	10.7	10.9
	Late Referral (%)	22.6	23.6	16.2	15.8	11.4	12.2	11.3	10.4	10.2	8.6

Notes

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 m²).

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, 2011, 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, 2010, there were 39,352 people in Canada being treated for ESRD, with 59% ($n = 23,188$) on dialysis and 41% (16,164) living with a functioning kidney transplant (Table 10). Since 1991, the prevalence rate for patients being treated by dialysis has increased 189%, from 235.4 RPMP to 679.8 RPMP (Figure 2). During the same period, the prevalence rate of patients with kidney transplants more than doubled, from 200.7 RPMP to 473.9 RPMP.

Table 11 provides prevalence rates by age. Over the 20-year period prevalence rates increased in all age groups. In 2010, the age distribution of prevalent patients was similar in all provinces and territories (Table 12).

Prevalence rates in 2010 were highest in Manitoba and Newfoundland and Labrador (1,496.7 and 1,463.6 RPMP, Table 13). The lowest RPMPs were observed in Alberta (1,025.6), Quebec (1,031.1) and Saskatchewan, where the prevalence rate was 1,071.2.

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 2010, 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 (53%, 49% and 45%, respectively) (Table 15). Transplant as a treatment was lowest in Manitoba (33%) and Saskatchewan (33%).

Tables 16 and 17 examine prevalence rates by primary diagnosis. Between 2001 and 2010, the prevalence rate of patients with diabetes as a primary diagnosis increased by 54%. In 2010, diabetic nephropathy accounted for the largest proportion of all prevalent patients (26%), followed by patients with glomerulonephritis (22%).

Among prevalent patients in 2010 with a primary diagnosis of diabetes, 63% were being treated with HD and 25% had transplants (Table 18). Patients with diabetic nephropathy accounted for 34% of HD patients being treated. For patients with a primary diagnosis of glomerulonephritis, 61% had a functioning kidney transplant, representing 32% of all transplant patients.

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

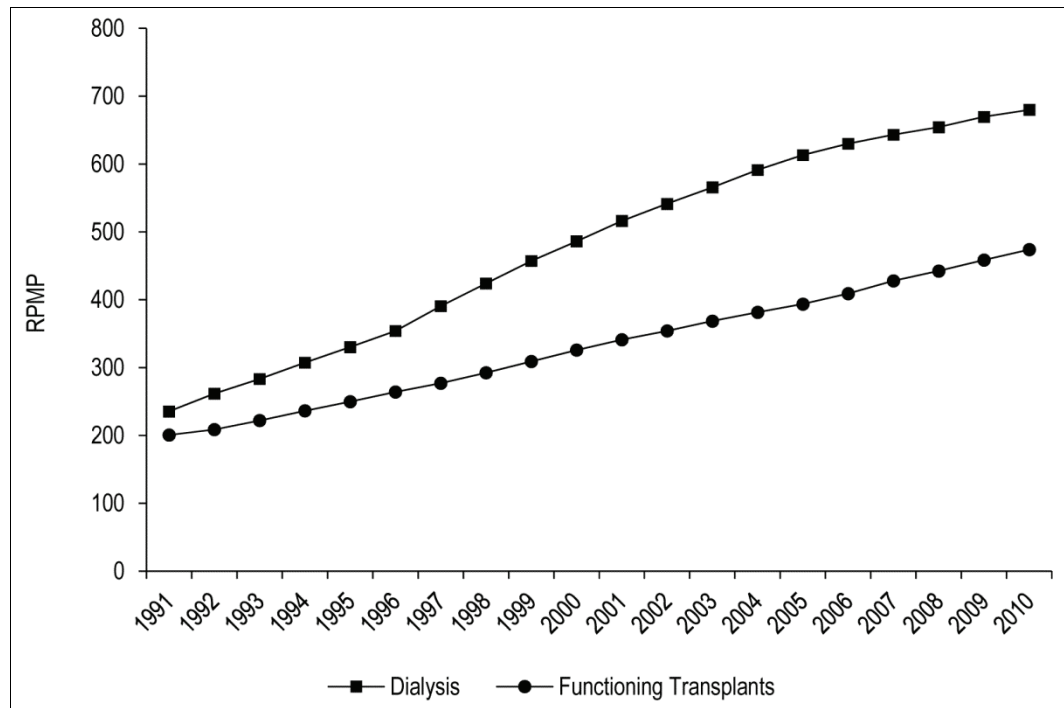
Table 10: Prevalence Rate for Patients on Dialysis or With a Functioning Transplant in Canada, 1991 to 2010 (Rate per Million Population, Percentage of Total)

	Dialysis			Functioning Transplants			Total	
	Number	RPMP	%	Number	RPMP	%	Number	RPMP
1991	6,598	235.4	54.0	5,626	200.7	46.0	12,224	436.1
1992	7,424	261.7	55.6	5,921	208.7	44.4	13,345	470.4
1993	8,123	283.2	56.0	6,370	222.1	44.0	14,493	505.3
1994	8,911	307.3	56.5	6,855	236.4	43.5	15,766	543.7
1995	9,673	330.1	56.9	7,319	249.8	43.1	16,992	579.9
1996	10,482	354.0	57.3	7,821	264.1	42.7	18,303	618.1
1997	11,681	390.6	58.5	8,285	277.0	41.5	19,966	667.6
1998	12,785	423.9	59.2	8,819	292.4	40.8	21,604	716.4
1999	13,895	457.0	59.7	9,395	309.0	40.3	23,290	766.0
2000	14,919	486.1	59.9	10,000	325.8	40.1	24,919	812.0
2001	16,010	516.1	60.2	10,580	341.1	39.8	26,590	857.2
2002	16,981	541.3	60.5	11,109	354.1	39.5	28,090	895.4
2003	17,904	565.5	60.5	11,666	368.5	39.5	29,570	934.0
2004	18,888	591.2	60.8	12,189	381.5	39.2	31,077	972.8
2005	19,786	613.1	60.9	12,700	393.5	39.1	32,486	1,006.7
2006	20,547	629.8	60.6	13,342	409.0	39.4	33,889	1,038.8
2007	21,175	643.0	60.0	14,090	427.9	40.0	35,265	1,070.8
2008	21,799	654.1	59.7	14,740	442.3	40.3	36,539	1,096.4
2009	22,585	669.4	59.3	15,470	458.5	40.7	38,055	1,127.9
2010	23,188	679.8	58.9	16,164	473.9	41.1	39,352	1,153.7

Sources

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information; Statistics Canada.

Figure 2: Prevalence Rate for Patients on Dialysis or With a Functioning Transplant in Canada, 1991 to 2010 (Rate per Million Population)



Sources

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information; Statistics Canada.

Table 11: Prevalent End-Stage Renal Disease Patients by Age Group, Canada, 1991 to 2010 (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
1991	441	57.1	4,391	376.8	4,620	848.7	1,975	1,027.2	797	615.6	12,224	436.1
1992	474	60.8	4,606	395.0	5,072	903.0	2,244	1,141.9	949	713.3	13,345	470.4
1993	483	61.5	4,812	412.4	5,565	961.0	2,541	1,265.4	1,092	801.9	14,493	505.3
1994	475	60.0	5,080	435.0	6,044	1,012.4	2,898	1,417.7	1,269	910.3	15,766	543.7
1995	491	61.7	5,260	449.7	6,494	1,057.0	3,240	1,566.4	1,507	1,045.9	16,992	579.9
1996	486	60.8	5,416	462.2	7,115	1,125.9	3,514	1,682.5	1,772	1,188.9	18,303	618.1
1997	499	62.3	5,643	480.7	7,786	1,196.4	3,897	1,847.9	2,141	1,385.0	19,966	667.6
1998	523	65.3	5,856	500.0	8,435	1,257.1	4,250	1,998.2	2,540	1,590.1	21,604	716.4
1999	535	66.9	6,021	515.0	9,148	1,319.5	4,594	2,151.3	2,992	1,812.1	23,290	766.0
2000	557	69.8	6,138	525.1	9,868	1,376.6	4,940	2,301.7	3,416	2,001.5	24,919	812.0
2001	565	70.9	6,208	529.9	10,532	1,421.1	5,312	2,458.1	3,973	2,254.8	26,590	857.2
2002	564	70.9	6,287	535.0	11,115	1,448.1	5,601	2,575.3	4,523	2,487.6	28,090	895.4
2003	565	71.5	6,318	537.5	11,767	1,482.7	5,972	2,726.4	4,948	2,637.8	29,570	934.0
2004	554	70.5	6,315	537.1	12,493	1,524.9	6,277	2,836.5	5,438	2,820.4	31,077	972.8
2005	561	71.6	6,328	537.5	13,070	1,547.2	6,595	2,949.2	5,932	2,993.5	32,486	1,006.7
2006	557	71.3	6,363	540.1	13,743	1,577.3	6,861	3,018.4	6,365	3,118.3	33,889	1,038.8
2007	554	70.5	6,325	542.9	14,366	1,598.2	7,295	3,128.1	6,725	3,200.4	35,265	1,070.8
2008	545	69.3	6,350	544.2	14,985	1,622.4	7,568	3,149.3	7,091	3,292.3	36,539	1,096.4
2009	549	69.8	6,296	537.3	15,647	1,652.3	8,036	3,230.0	7,527	3,422.1	38,055	1,127.9
2010	536	68.3	6,281	533.4	16,234	1,679.0	8,431	3,276.1	7,870	3,504.0	39,352	1,153.7

Sources

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information; Statistics Canada.

Table 12: Prevalent End-Stage Renal Disease Patients by Age and Province, Canada, 2010 (Number, Percentage)

Province		Age 0–19	Age 20–44	Age 45–64	Age 65–74	Age 75+	Total
B.C./Y.T.	N	76	827	2,108	1,097	1,003	5,111
	%	1.5	16.2	41.2	21.5	19.6	100.0
Alta./N.W.T./Nun.	N	81	763	1,709	747	595	3,895
	%	2.1	19.6	43.9	19.2	15.3	100.0
Sask.	N	4	228	490	212	186	1,120
	%	0.4	20.4	43.8	18.9	16.6	100.0
Man.	N	41	359	873	338	238	1,849
	%	2.2	19.4	47.2	18.3	12.9	100.0
Ont.	N	196	2,410	6,496	3,456	3,509	16,067
	%	1.2	15.0	40.4	21.5	21.8	100.0
Que.	N	104	1,179	3,163	1,941	1,766	8,153
	%	1.3	14.5	38.8	23.8	21.7	100.0
N.B.	N	2	141	393	199	182	917
	%	0.2	15.4	42.9	21.7	19.8	100.0
N.S./P.E.I.	N	30	254	655	294	261	1,494
	%	2.0	17.0	43.8	19.7	17.5	100.0
N.L.	N	2	120	347	147	130	746
	%	0.3	16.1	46.5	19.7	17.4	100.0
Canada	N	536	6,281	16,234	8,431	7,870	39,352
	%	1.4	16.0	41.3	21.4	20.0	100.0

Sources

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information; Statistics Canada.

**Table 13: Prevalent End-Stage Renal Disease Patients by Province, Canada, 2001 to 2010
(Number, Rate per Million Population)**

Province		2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
B.C./Y.T.	N	3,341	3,547	3,762	4,030	4,198	4,400	4,576	4,714	4,957	5,111
	RPMP	813.2	855.6	899.4	953.3	979.6	1,013.4	1,053.9	1,067.2	1,104.3	1,119.5
Alta./N.W.T./Nun.	N	2,524	2,745	2,967	3,103	3,266	3,377	3,505	3,586	3,738	3,895
	RPMP	807.5	861.4	918.6	947.7	980.8	979.3	976.9	976.8	993.3	1,025.6
Sask.	N	859	894	950	977	950	987	1,048	1,069	1,134	1,120
	RPMP	858.9	897.7	955.3	981.5	955.6	1,001.6	1,047.9	1,054.6	1,100.8	1,071.2
Man.	N	1,245	1,315	1,351	1,388	1,446	1,523	1,574	1,647	1,750	1,849
	RPMP	1,081.4	1,138.0	1,163.1	1,186.1	1,228.0	1,293.1	1,318.3	1,365.6	1,432.1	1,496.7
Ont.	N	10,564	11,223	11,825	12,446	13,155	13,757	14,317	14,900	15,510	16,067
	RPMP	887.9	927.4	964.8	1,004.3	1,048.9	1,084.3	1,119.0	1,151.8	1,186.8	1,216.2
Que.	N	5,684	5,917	6,176	6,509	6,777	7,093	7,409	7,675	7,914	8,153
	RPMP	768.4	794.7	824.3	862.9	891.9	927.0	963.8	989.9	1,010.9	1,031.1
N.B.	N	708	718	742	791	801	846	854	869	893	917
	RPMP	944.1	956.9	988.2	1,052.7	1,065.2	1,129.3	1,145.4	1,163.1	1,191.5	1,219.7
N.S.	N	1,082	1,129	1,181	1,173	1,230	1,249	1,326	1,412	1,449	1,494
	RPMP	1,012.1	1,053.7	1,100.2	1,091.3	1,143.1	1,164.1	1,234.6	1,312.2	1,342.7	1,377.2
N.L.	N	583	602	616	660	663	657	656	667	710	746
	RPMP	1,116.9	1,158.9	1,188.4	1,276.5	1,285.0	1,289.1	1,295.1	1,317.0	1,395.1	1,463.6
Canada	N	26,590	28,090	29,570	31,077	32,486	33,889	35,265	36,539	38,055	39,352
	RPMP	857.2	895.4	934.0	972.8	1,006.7	1,038.8	1,070.8	1,096.4	1,127.9	1,153.7

Sources

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information; Statistics Canada.

Table 14: Prevalent End-Stage Renal Disease Patients by Type of Treatment, Canada, 2001 to 2010 (Number, Rate per Million Population, Percentage of Total)

Type of Treatment		2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
HD Home	N	226	258	303	369	485	572	638	718	786	834
	RPMP	7.3	8.2	9.6	11.6	15.0	17.5	19.4	21.5	23.3	24.5
	%	0.8	0.9	1.0	1.2	1.5	1.7	1.8	2.0	2.1	2.1
HD Institutional	N	12,430	13,346	14,217	14,947	15,611	16,201	16,645	17,081	17,712	18,244
	RPMP	400.7	425.4	449.0	467.9	483.8	496.6	505.4	512.5	525.0	534.9
	%	46.7	47.5	48.1	48.1	48.1	47.8	47.2	46.7	46.5	46.4
CAPD	N	1,886	1,779	1,686	1,657	1,609	1,552	1,578	1,608	1,586	1,563
	RPMP	60.8	56.7	53.3	51.9	49.9	47.6	47.9	48.2	47.0	45.8
	%	7.1	6.3	5.7	5.3	5.0	4.6	4.5	4.4	4.2	4.0
APD	N	1,468	1,598	1,698	1,915	2,081	2,222	2,314	2,392	2,501	2,547
	RPMP	47.3	50.9	53.6	59.9	64.5	68.1	70.3	71.8	74.1	74.7
	%	5.5	5.7	5.7	6.2	6.4	6.6	6.6	6.5	6.6	6.5
Transplant	N	10,580	11,109	11,666	12,189	12,700	13,342	14,090	14,740	15,470	16,164
	RPMP	341.1	354.1	368.5	381.5	393.5	409.0	427.9	442.3	458.5	473.9
	%	39.8	39.5	39.5	39.2	39.1	39.4	40.0	40.3	40.7	41.1
Total	N	26,590	28,090	29,570	31,077	32,486	33,889	35,265	36,539	38,055	39,352
	RPMP	857.2	895.4	934.0	972.8	1,006.7	1,038.8	1,070.8	1,096.4	1,127.9	1,153.7

Note

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

Sources

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information; Statistics Canada.

Table 15: Prevalent End-Stage Renal Disease Patients by Type of Treatment and Province of Treatment, Canada, 2010 (Number, Percentage)

Type of Treatment		Province of Treatment									
		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	127	106	9	20	455	77	12	15	13	834
	%	2.5	2.7	0.8	1.1	2.8	0.9	1.3	1.0	1.7	2.0
HD Institutional	N	2,005	1,496	578	979	7,772	3,947	474	575	418	18,244
	%	39.2	38.4	51.6	52.9	48.4	48.4	51.7	38.5	56.0	46.0
CAPD	N	202	116	106	83	608	327	47	47	27	1,563
	%	4.0	3.0	9.5	4.5	3.8	4.0	5.1	3.1	3.6	4.0
APD	N	503	262	58	158	1,153	271	65	61	16	2,547
	%	9.8	6.7	5.2	8.5	7.2	3.3	7.1	4.1	2.1	6.0
Transplant	N	2,274	1,915	369	609	6,079	3,531	319	796	272	16,164
	%	44.5	49.2	32.9	32.9	37.8	43.3	34.8	53.3	36.5	41.0
Total	N	5,111	3,895	1,120	1,849	16,067	8,153	917	1,494	746	39,352

Note

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

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

Table 16: Prevalent End-Stage Renal Disease Patients by Primary Diagnosis, Canada, 2001 to 2010 (Number, Rate per Million Population, Percentage of Total)

Diagnosis		2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
Glomerulonephritis	N	6,415	6,684	6,982	7,332	7,505	7,714	7,897	8,088	8,358	8,609
	RPMP	206.8	213.1	220.5	229.5	232.6	236.5	239.8	242.7	247.7	252.4
	%	24.1	23.8	23.6	23.6	23.1	22.8	22.4	22.1	22.0	21.9
Diabetes	N	6,124	6,660	7,219	7,728	8,200	8,684	9,099	9,507	9,940	10,366
	RPMP	197.4	212.3	228.0	241.9	254.1	266.2	276.3	285.3	294.6	303.9
	%	23.0	23.7	24.4	24.9	25.2	25.6	25.8	26.0	26.1	26.3
Renal Vascular Disease	N	3,506	3,667	3,864	4,009	4,245	4,469	4,648	4,781	4,979	5,083
	RPMP	113.0	116.9	122.0	125.5	131.5	137.0	141.1	143.5	147.6	149.0
	%	13.2	13.1	13.1	12.9	13.1	13.2	13.2	13.1	13.1	12.9
Polycystic Kidney Disease	N	1,949	2,046	2,098	2,179	2,195	2,243	2,321	2,347	2,369	2,386
	RPMP	62.8	65.2	66.3	68.2	68.0	68.8	70.5	70.4	70.2	70.0
	%	7.3	7.3	7.1	7.0	6.8	6.6	6.6	6.4	6.2	6.1
Drug Induced	N	1,886	1,976	2,082	2,190	2,360	2,486	2,609	2,725	2,826	2,938
	RPMP	60.8	63.0	65.8	68.6	73.1	76.2	79.2	81.8	83.8	86.1
	%	7.1	7.0	7.0	7.0	7.3	7.3	7.4	7.5	7.4	7.5
Pyelonephritis	N	370	402	428	441	468	491	530	541	571	613
	RPMP	11.9	12.8	13.5	13.8	14.5	15.1	16.1	16.2	16.9	18.0
	%	1.4	1.4	1.4	1.4	1.4	1.4	1.5	1.5	1.5	1.6
Other*	N	3,050	3,214	3,365	3,521	3,765	3,969	4,145	4,373	4,595	4,813
	RPMP	98.3	102.4	106.3	110.2	116.7	121.7	125.9	131.2	136.2	141.1
	%	11.5	11.4	11.4	11.3	11.6	11.7	11.8	12.0	12.1	12.2
Unknown	N	3,290	3,441	3,532	3,677	3,748	3,833	4,016	4,177	4,417	4,544
	RPMP	106.1	109.7	111.6	115.1	116.1	117.5	121.9	125.3	130.9	133.2
	%	12.4	12.2	11.9	11.8	11.5	11.3	11.4	11.4	11.6	11.5
Total	N	26,590	28,090	29,570	31,077	32,486	33,889	35,265	36,539	38,055	39,352
	RPMP	857.2	895.4	934.0	972.8	1,006.7	1,038.8	1,070.8	1,096.4	1,127.9	1,153.7

Note

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

Sources

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information; Statistics Canada.

Table 17: Prevalent End-Stage Renal Disease Patients by Primary Diagnosis and Province, Canada, 2010 (Number, Rate per Million Population, Percentage of Total)

Province		Glomerulonephritis	Diabetes	Renal Vascular Disease	Polycystic Kidney Disease	Drug Induced	Pyelonephritis	Other*	Unknown	Total
B.C./Y.T.	N	1,113	868	683	372	66	227	657	1,125	5,111
	RPMP	245.6	191.6	150.7	82.1	14.6	50.1	145.0	248.3	1,128.0
	%	21.8	17.0	13.4	7.3	1.3	4.4	12.9	22.0	100
Alta./N.W.T./Nun.	N	977	1,051	362	301	63	272	496	373	3,895
	RPMP	307.7	327.6	142.4	80.9	16.9	95.7	178.4	122.8	1,272.4
	%	25.1	27.0	9.3	7.7	1.6	7.0	12.7	9.6	100
Sask.	N	228	372	116	61	14	74	162	93	1,120
	RPMP	218.1	355.8	110.9	58.3	13.4	70.8	154.9	88.9	1,071.1
	%	20.4	33.2	10.4	5.4	1.3	6.6	14.5	8.3	100
Man.	N	428	714	136	84	24	99	262	102	1,849
	RPMP	346.4	578.0	110.1	68.0	19.4	80.1	212.1	82.6	1,496.7
	%	23.1	38.6	7.4	4.5	1.3	5.4	14.2	5.5	100
Ont.	N	3,356	4,549	2,366	1,203	233	918	1,779	1,663	16,067
	RPMP	254.0	344.3	179.1	91.1	17.6	69.5	134.7	125.9	1,216.2
	%	20.9	28.3	14.7	7.5	1.5	5.7	11.1	10.4	100
Que.	N	1,831	2,045	1,010	594	144	574	1,068	887	8,153
	RPMP	231.6	258.6	127.7	75.1	18.2	72.6	135.1	112.2	1,031.1
	%	22.5	25.1	12.4	7.3	1.8	7.0	13.1	10.9	100
N.B.	N	202	250	139	88	12	56	100	70	917
	RPMP	268.7	332.5	184.9	117.1	16.0	74.5	133.0	93.1	1,219.8
	%	22.0	27.3	15.2	9.6	1.3	6.1	10.9	7.6	100
N.S./P.E.I.	N	287	348	188	178	39	105	204	145	1,494
	RPMP	322.4	488.6	247.2	194.8	71.2	165.1	234.3	213.5	1,937.1
	%	19.2	23.3	12.6	11.9	2.6	7.0	13.7	9.7	100
N.L.	N	187	169	84	58	18	61	85	84	746
	RPMP	366.9	331.6	164.8	113.8	35.3	119.7	166.8	164.8	1,463.7
	%	25.1	22.7	11.3	7.8	2.4	8.2	11.4	11.3	100
Canada	N	8,609	10,366	5,084	2,939	613	2,386	4,813	4,542	39,352
	RPMP	252.4	303.9	149.1	86.2	18.0	70.0	141.1	133.2	1,153.9
	%	21.9	26.3	12.9	7.5	1.6	6.1	12.2	11.5	100

Note

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

Sources

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information; Statistics Canada.

Table 18: Prevalent End-Stage Renal Disease Patients by Treatment, Age Group, Sex and Primary Diagnosis, Canada, December 31, 2010 (Number, Rate per Million Population, Percentage of Total)

		HD	PD	TX	Total
Total	N	19,076	4,110	16,164	39,350
	RPMP	559.3	120.5	473.9	1,153.7
Age Group					
0–19 Years	N	72	42	422	536
	RPMP	9.2	5.4	53.8	68.3
	%	0.4	1.0	2.6	1.4
20–44 Years	N	2,049	552	3,680	6,281
	RPMP	174	46.9	312.5	533.4
	%	10.7	13.4	22.8	16.0
45–64 Years	N	6,273	1,598	8,363	16,234
	RPMP	648.8	165.3	864.9	1,679
	%	32.9	38.9	51.7	41.3
65–74 Years	N	4,560	1,029	2,840	8,429
	RPMP	1,771.9	399.8	1,103.6	3,275.3
	%	23.9	25.0	17.6	21.4
75+ Years	N	6,122	889	859	7,870
	RPMP	2,725.7	395.8	382.5	3,504
	%	32.1	21.6	5.3	20.0
Sex					
Female	N	7,928	1,783	6,108	15,819
	RPMP	461.2	103.7	355.3	920.2
	%	41.6	43.4	37.8	40.2
Male	N	11,148	2,327	10,056	23,531
	RPMP	659	137.6	594.4	1,390.9
	%	58.4	56.6	62.2	59.8
Diagnosis					
Diabetes	N	6,550	1,240	2,577	10,367
	RPMP	192	36.4	75.6	303.9
	%	34.3	30.2	15.9	26.3
Glomerulonephritis	N	2,627	745	5,236	8,608
	RPMP	77	21.8	153.5	252.4
	%	13.8	18.1	32.4	21.9
Renal Vascular Disease	N	3,294	743	1,046	5,083
	RPMP	96.6	21.8	30.7	149
	%	17.3	18.1	6.5	12.9
Pyelonephritis	N	867	167	1,352	2,386
	RPMP	25.4	4.9	39.6	70
	%	4.5	4.1	8.4	6.1
Polycystic Kidney Disease	N	858	221	1,860	2,939
	RPMP	25.2	6.5	54.5	86.2
	%	4.5	5.4	11.5	7.5

Table 18: Prevalent End-Stage Renal Disease Patients by Treatment, Age Group, Sex and Primary Diagnosis, Canada, December 31, 2010 (Number, Rate per Million Population, Percentage of Total) (cont'd)

		HD	PD	TX	Total
Total	N	19,076	4,110	16,164	39,350
	RPMP	559.3	120.5	473.9	1,153.7
Diagnosis (cont'd)					
Drug Induced	N	337	67	209	613
	RPMP	9.9	2	6.1	18
	%	1.8	1.6	1.3	1.6
Other*	N	1,966	393	2,454	4,813
	RPMP	57.6	11.5	71.9	141.1
	%	10.3	9.6	15.2	12.2
Unknown	N	2,577	534	1,430	4,541
	RPMP	75.6	15.7	41.9	133.1
	%	13.5	13.0	8.8	11.5

Notes

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

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

Sources

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information; Statistics Canada.

Table 19: End-Stage Renal Disease Patient Flows by Treatment, Canada, 2001 to 2010

		2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
Dialysis	January 1, Prevalence	14,919	16,010	16,981	17,904	18,888	19,786	20,547	21,175	21,799	22,585
	Incident Dialysis	4,875	4,932	5,010	5,098	5,141	5,261	5,362	5,366	5,450	5,448
	Deaths	2,927	3,061	3,170	3,192	3,352	3,481	3,568	3,607	3,453	3,520
	Net Transplants*	691	653	683	659	637	766	828	759	765	734
	Net Migrations†	166	247	234	263	254	253	338	376	446	591
	December 31, Prevalence	16,010	16,981	17,904	18,888	19,786	20,547	21,175	21,799	22,585	23,188
Transplant	January 1, Prevalence	10,000	10,580	11,109	11,666	12,189	12,700	13,342	14,090	14,740	15,470
	New Transplants	1,091	1,094	1,097	1,084	1,057	1,254	1,325	1,271	1,278	1,269
	Deaths	200	238	231	243	220	284	256	281	227	251
	Return to Dialysis	303	307	302	294	319	319	316	331	316	322
	Net Migrations†	8	20	7	24	7	9	5	9	5	2
	December 31, Prevalence	10,580	11,109	11,666	12,189	12,700	13,342	14,090	14,740	15,470	16,164

Notes

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

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

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

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).

Ontario had the highest number of patients per station, with 4.9, followed closely by Quebec (4.7), while New Brunswick (3.1) and Nova Scotia (3.7) 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, 2010 (Number)

Province of Treatment	Stations (N) [†]	Patients (N) [‡]	Patients per Station	Population [§]	Stations per Million Population
B.C.	451	2,178	4.8	4,565,500	98.7
Alta.	395	1,602	4.1	3,797,900	104.0
Sask.	135	604	4.5	1,045,600	129.1
Man.	216	1,000	4.6	1,235,400	174.8
Ont.	1,673	8,227	4.9	13,210,700	126.6
Que.	852	4,024	4.7	7,907,400	107.7
N.B.	151	473	3.1	751,800	200.9
N.S.	155	571	3.7	1,084,800	142.9
N.L.	107	441	4.1	509,700	209.9
Total	4,135	19,120	4.7	34,108,800	117.8

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 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, 2011, 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).

Ninety percent of dialysis patients younger than 18 will survive for five years, while 25% of patients older than 75 survive for five years (Figure 3).

Patients with renal vascular disease, drug-induced renal failure and diabetes have the lowest five-year survival rates, at 36%, 38% and 39%, respectively (Figure 6). The longest five-year survival rate is seen among patients with a primary diagnosis of glomerulonephritis (64%).

Table 21: Unadjusted Three-Month and One-, Three- and Five-Year Survival Rates in Dialysis Patients, Canada, 2001 to 2010 (Percentage)

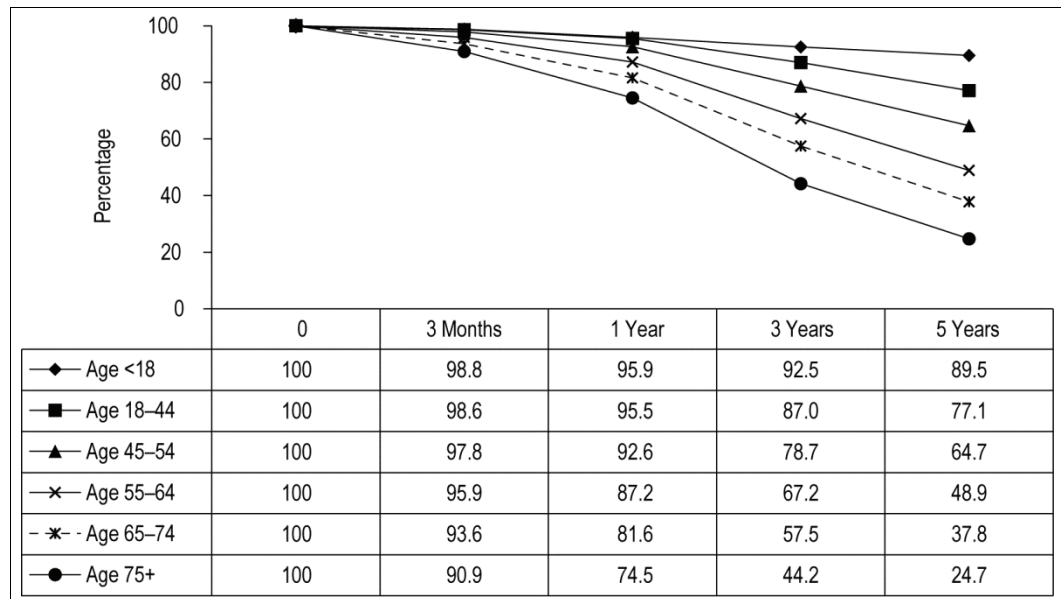
		2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
All Dialysis	N	4,875	4,932	5,010	5,098	5,141	5,261	5,362	5,366	5,450	5,448
	3 Months	93.9	93.8	94.5	94.6	94.4	94.4	94.7	94.3	94.7	94.9
	1 Year	81.9	82.3	83.4	83.4	83.5	83.8	84.6	84.0	85.3	—
	3 Years	57.2	58.1	59.6	60.6	61.6	61.3	63.8	—	—	—
	5 Years	38.9	39.5	40.5	43.2	44.3	—	—	—	—	—
HD	N	3,905	4,023	4,124	4,113	4,161	4,329	4,404	4,365	4,413	4,491
	3 Months	93.1	93.0	93.7	93.7	93.4	93.7	94.0	93.4	93.8	94.0
	1 Year	80.1	80.4	81.6	81.6	81.4	81.8	82.8	82.0	83.3	—
	3 Years	55.5	56.2	57.5	58.4	59.3	59.2	61.6	—	—	—
	5 Years	36.7	37.7	38.7	41.4	42.9	—	—	—	—	—
PD	N	970	909	886	985	980	932	958	1,001	1,037	957
	3 Months	97.3	97.5	98.2	98.5	98.5	98.1	98.2	98.1	98.6	99.1
	1 Year	89.1	90.7	91.7	91.0	92.5	92.6	92.5	92.7	93.7	—
	3 Years	64.1	66.4	69.6	70.2	71.2	71.0	74.1	—	—	—
	5 Years	48.3	47.8	49.0	51.0	50.3	—	—	—	—	—

Note

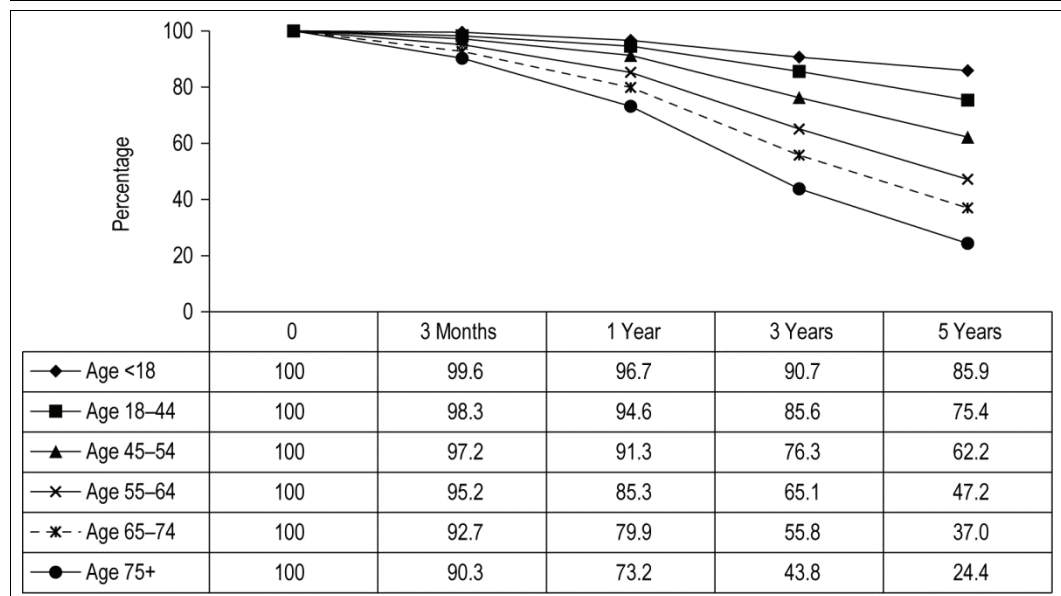
HD: hemodialysis; PD: peritoneal dialysis.

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

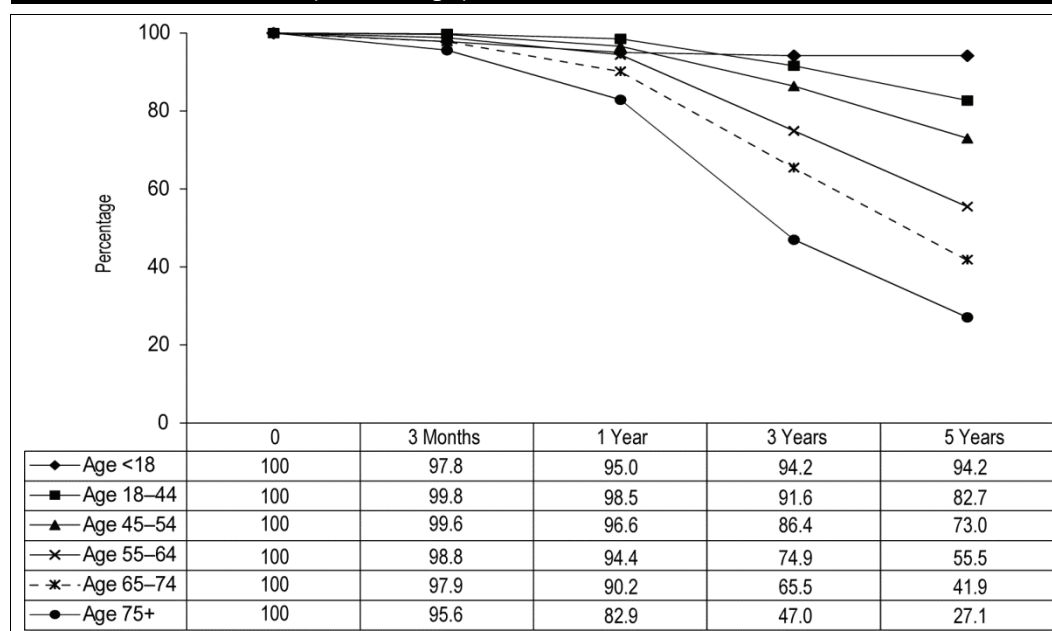
Figure 3: Unadjusted Three-Month and One-, Three- and Five-Year Survival Rates in Dialysis Patients, by Age Group, Canada, 2001 to 2010 (Percentage)**Source**

Canadian Organ Replacement Register, 2011, 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, 2001 to 2010 (Percentage)**Source**

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

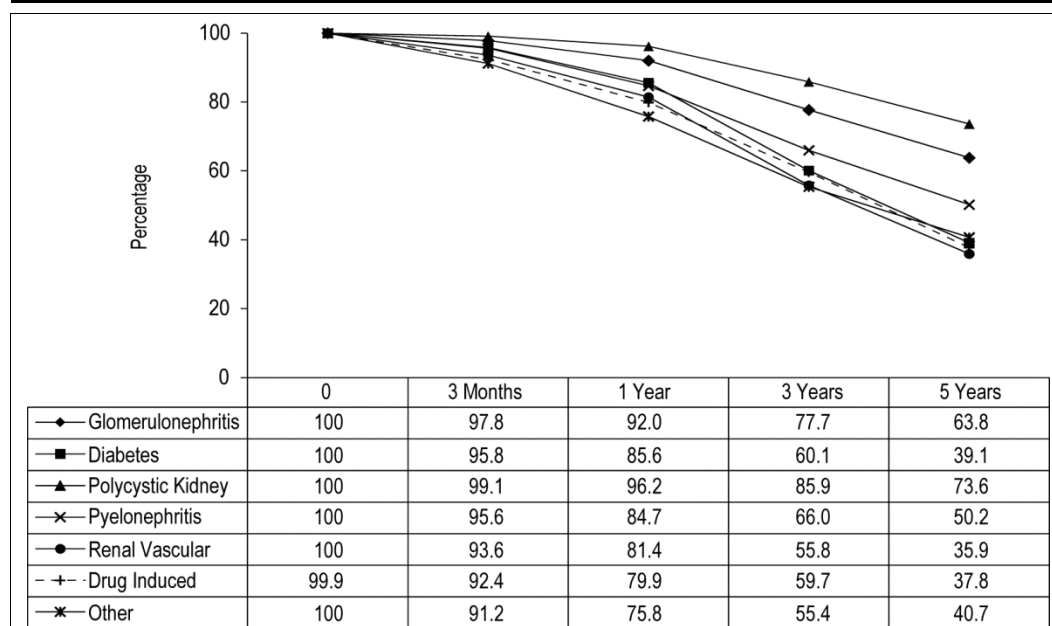
Figure 5: Unadjusted Three-Month and One-, Three- and Five-Year Survival Rates in Peritoneal Dialysis Patients, by Age Group, Canada, 2001 to 2010 (Percentage)



Source

Canadian Organ Replacement Register, 2011, 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, 2001 to 2010 (Percentage)



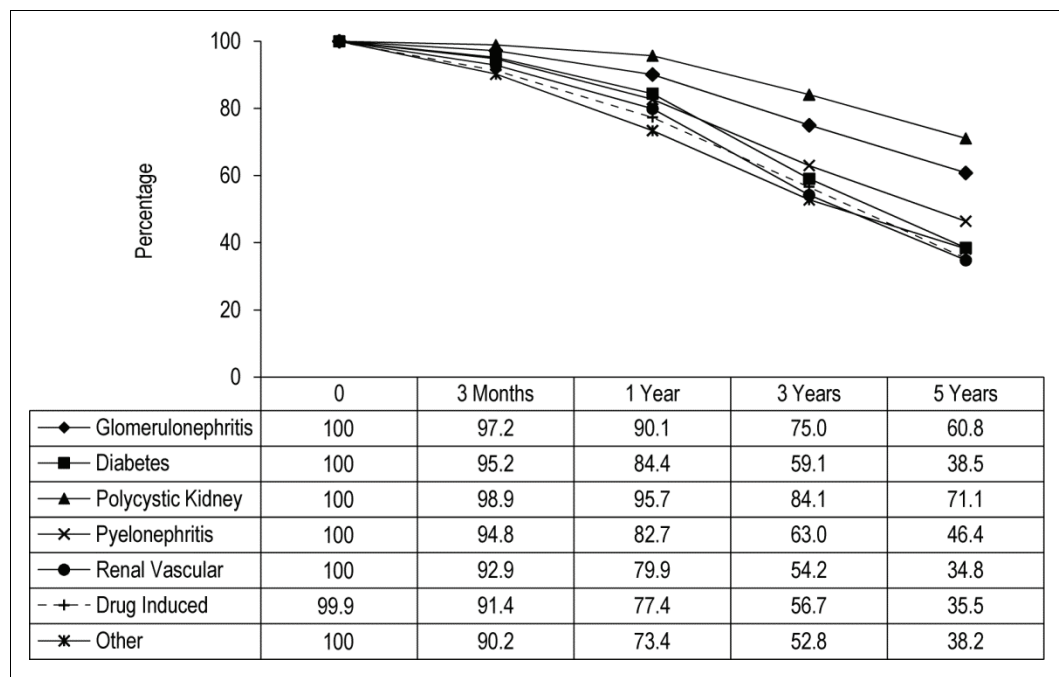
Note

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

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

Figure 7: Unadjusted Three-Month and One-, Three- and Five-Year Survival Rates in Hemodialysis Patients, by Etiology* of Renal Failure, Canada, 2001 to 2010 (Percentage)



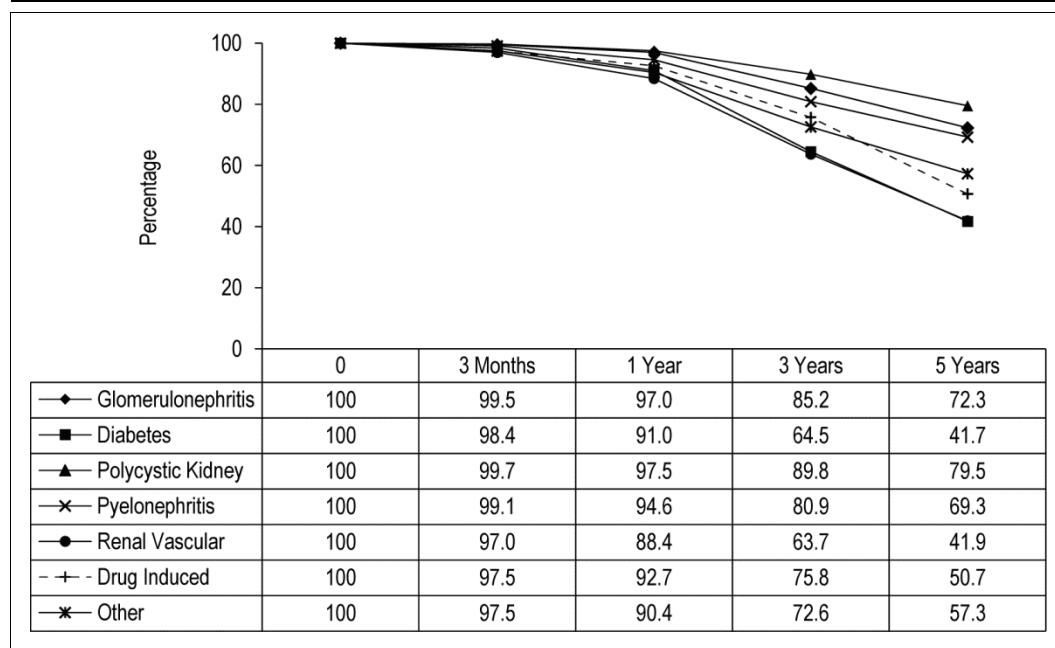
Note

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

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

Figure 8: Unadjusted Three-Month and One-, Three- and Five-Year Survival Rates in Peritoneal Dialysis Patients, by Etiology* of Renal Failure, Canada, 2001 to 2010 (Percentage)



Note

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

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

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 2010, there were 23 active kidney transplant programs in Canada operating in seven provinces.

At the end of 2010, there were 3,362 people (adult and pediatric) waiting for a deceased donor kidney transplant (Table 22). Between 2001 and 2010, there was an average of 68 deaths per year involving people on the waiting list.

Between 2001 and 2010 inclusive, there were 10,795 kidney transplant procedures registered in CORR (Table 23). Of these, 1,140 (11%) were re-transplants. Of the 9,583 kidney-only first transplants, 61% utilized deceased-donor kidneys. Ontario and Quebec surgeons performed the most deceased-donor kidney transplants over the decade (2,404 and 1,977, respectively) (Table 24). Ontario (1,840) saw the highest number of living-donor kidney transplants over the decade (Table 25), followed by British Columbia (819). Since 2006, the number of living-donor kidney transplants has been stable, fluctuating between 440 and 466 transplants each year.

For the most recent three-year period, 2008 to 2010, the median wait time for a deceased-donor kidney transplant (excluding pre-emptive transplants) was 3.5 years (Table 26). The longest median wait times were in British Columbia (5.5 years) and Manitoba (5.2 years). The shortest median wait time of just more than two years was observed in Nova Scotia.

Since 2001, the proportion of recipients older than age 60 receiving a kidney transplant from a deceased donor increased from 26% to 39%, and the average age of recipients increased from 50.0 to 54.2 (Table 27). A similar trend was observed for living-donor transplants (13% to 26%) (Table 27). Glomerulonephritis continued to be the predominant diagnosis among adult kidney transplant recipients (325) (Table 28).

At five years after transplantation, the unadjusted patient survival rates between 2001 and 2005 were greater than 89% for recipients of living-donor kidneys and greater than 80% for recipients of deceased-donor kidneys (Table 29).

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

Table 22: Kidney Transplant Waiting List and Deaths, December 31, Canada, 2001 to 2010 (Number)

	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
Waiting List	3,014	2,963	2,875	2,872	2,759	2,962	2,963	3,179	2,732	3,362
Deaths on Waiting List	62	86	82	55	66	70	46	58	76	82

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

Table 23: Kidney Transplants* by Year and Donor Type, Adult Recipients, Canada, 2001 to 2010 (Number)

	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	Total
Kidney Only, First Graft, Deceased Donor	546	516	550	514	504	606	631	634	667	647	5,815
Kidney Only, First Graft, Living Donor	340	319	342	345	370	415	413	409	402	413	3,768
Kidney Combination, First Graft, Deceased Donor[†]	6	5	8	3	5	10	8	9	11	7	72
Re-Transplants	123	129	99	104	104	119	133	114	91	124	1,140
Total	1,015	969	999	966	983	1,150	1,185	1,166	1,171	1,191	10,795

Notes

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

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

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

Table 24: Deceased-Donor Kidney Transplants* by Year and Province of Treatment, Adult Recipients, Canada, 2001 to 2010 (Number)

Province of Treatment	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	Total
B.C.	59	46	53	52	40	61	61	83	54	89	598
Alta.	85	81	67	67	83	78	71	66	61	74	733
Sask.	28	18	29	18	15	21	21	21	14	0	185
Man.	11	17	17	13	6	22	27	24	22	33	192
Ont.	184	196	192	208	206	243	291	253	323	308	2,404
Que.	207	186	218	196	173	197	204	217	207	172	1,977
N.S.	70	63	51	35	49	67	52	49	50	49	535
Total	644	607	627	589	572	689	727	713	731	725	6,624

Note

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

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

Table 25: Living-Donor Kidney Transplants by Year and Province of Treatment, Adult Recipients, Canada, 2001 to 2010 (Number)

Province of Treatment	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	Total
B.C.	83	74	69	74	70	98	100	75	87	89	819
Alta.	50	47	52	61	50	46	60	51	40	66	523
Sask.	8	14	10	12	11	9	7	13	1	3	88
Man.	12	15	18	12	19	24	21	17	17	20	175
Ont.	144	149	156	157	186	206	199	211	224	208	1,840
Que.	43	38	43	38	46	47	44	47	39	51	436
N.S.	31	25	24	23	29	31	27	39	32	29	290
Total	371	362	372	377	411	461	458	453	440	466	4,171

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

Table 26: Dialysis Duration Prior to First Kidney Transplant by Province of Treatment, Adult Kidney Transplant Recipients, Canada, 2008 to 2010

	B.C.	Alta.	Sask.	Man.	Ont.	Que.	N.S.	Canada
Duration on Dialysis (Median Days), Deceased Donor	2,017	1,034	832	1,910	1,580	844	754	1,280
Duration on Dialysis (Median Days), Deceased Donor, No Pre-Emptive	2,017	1,054	843	1,915	1,602	992	833	1,340
Duration on Dialysis (Median Days), Living Donor	166	319	383	363	404	102	217	308
Duration on Dialysis (Median Days), Living Donor, No Pre-Emptive	647	473	384	393	660	400	465	532.5

Notes

In the calculation of median days on dialysis, pre-emptive kidney transplant recipients were given a value of 0 for their wait time. A patient who receives a pre-emptive transplant has not been treated with dialysis prior to the transplant. There were 3,528 adult first kidney transplants performed in Canada between 2008 and 2010, 514 of which were pre-emptive transplants.

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

Table 27: Adult Kidney Transplant Recipients, Selected Characteristics, First Graft, Canada, 2000 to 2009 (Number, Percentage)

Donor	Characteristic	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
Deceased	Percentage Male	63.9	63.5	64.7	62.1	63.9	61.9	63.8	65.0	63.6	63.6
	Percentage Age 60+	25.7	29.4	26.7	30.6	29.5	29.7	34.9	35.8	37.5	39.4
	Average Age	50.0	50.7	50.4	51.2	51.8	51.9	53.4	53.2	53.8	54.2
	Age Standard Deviation	12.8	13.6	12.6	13.2	12.4	12.7	12.8	13.0	12.9	12.6
	Primary Cause of ESRD (%)										
	Diabetes	17.4	19.0	21.1	14.5	17.3	17.0	21.6	23.6	19.8	24.2
	Renal Vascular	9.4	9.4	7.9	13.2	10.6	10.7	9.1	10.1	9.1	9.9
	Glomerulonephritis	33.7	31.9	36.4	36.4	30.3	31.0	28.3	27.1	30.5	29.5
	Other*	35.5	33.8	29.9	31.9	37.7	37.2	36.6	33.6	33.6	32.7
	Unknown Diagnosis	4.0	6.0	4.7	4.1	4.1	4.1	4.4	5.6	6.9	3.7
	Median Peak PRA [†]	2	2	2	2	3	0	0	0	2	1
	Peak PRA >50% (%)	5.3	6.8	8.6	7.3	7.5	2.2	6.5	7.2	10.6	11.1
	Duration of Dialysis (Median Days)	929.5	973	1,015.5	1,305	1,261	1,282.5	1,338	1,199	1,250	1,383
Living	Percentage Male	55.6	60.5	65.2	59.1	63.2	62.4	63.4	60.1	59.7	65.6
	Percentage Age 60+	12.6	13.8	16.7	14.5	14.6	14.7	18.6	19.3	21.6	26.4
	Average Age	42.7	43.8	46.1	44.6	46.6	45.4	46.0	46.8	47.0	48.3
	Age Standard Deviation	13.3	13.5	13.0	13.2	12.6	13.1	13.8	13.4	13.6	14.2
	Primary Cause of ESRD (%)										
	Diabetes	15.9	16.0	19.6	16.8	16.5	13.3	16.9	14.7	16.7	15.3
	Renal Vascular	6.5	5.3	7.6	4.6	5.7	7.2	7.7	7.1	6.7	6.5
	Glomerulonephritis	35.6	32.9	32.5	38.0	31.1	35.4	29.1	29.3	28.1	32.0
	Other*	36.5	39.8	35.1	35.7	41.1	36.1	36.3	41.1	38.6	34.1
	Unknown Diagnosis	5.6	6.0	5.3	4.9	5.7	8.0	9.9	7.8	10.0	12.1
	Median Peak PRA [†]	0	0	0	0	0	0	0	0	1	0
	Peak PRA >50% (%)	2.0	3.6	2.8	5.0	4.2	1.9	4.5	8.4	8.1	5.9
	Duration of Dialysis (Median Days)	352	350	380.5	343	286	314	304	356	286	268

Notes

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

† PRA: panel reactive antibody.

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

Table 28: Kidney Transplant Recipients* by Age Group and Primary Renal Diagnosis Category, Adult Recipients, First Graft, Canada, 2010 (Number)

	Age 18–44	Age 45–54	Age 55–64	Age 65+	Total
Glomerulonephritis	120	70	93	42	325
Pyelonephritis	17	11	14	13	55
Polycystic Kidney Disease	13	45	52	14	124
Hypertension/ Other Vascular	13	20	28	31	92
Diabetic Nephropathy	36	47	88	50	221
Other†	65	34	48	29	176
Unknown/Not Reported	33	16	20	5	74
Total	297	243	343	184	1,067

Note

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

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

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

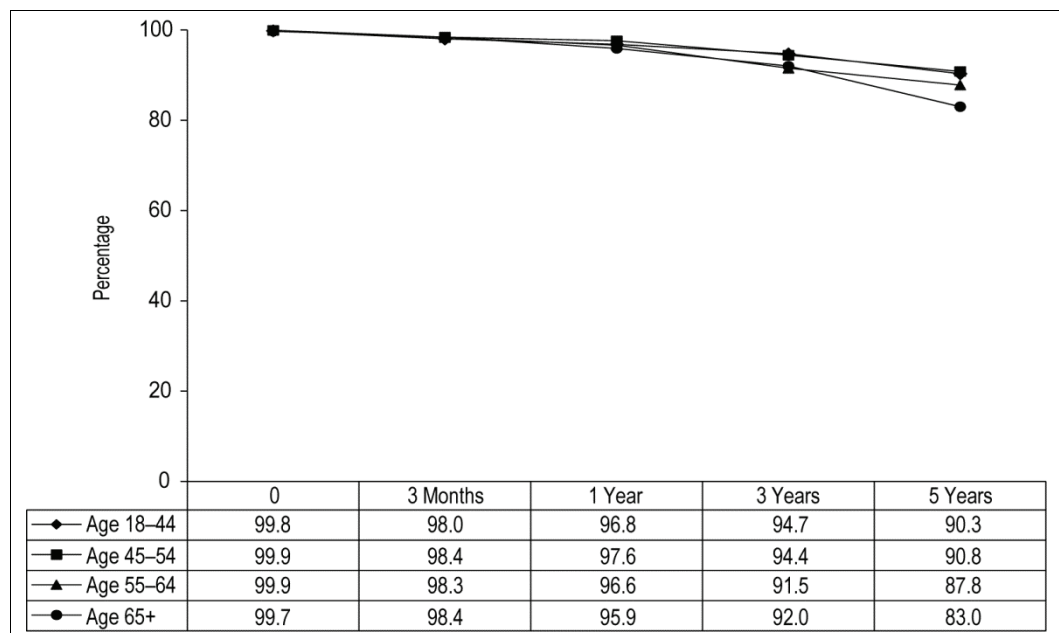
Table 29: Unadjusted Three-Month and One-, Three- and Five-Year Graft Survival Rates in Adult Kidney Transplant Recipients, First Graft, Canada, 2001 to 2010 (Percentage)

		2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
Deceased Donor	N	552	521	558	517	509	616	639	643	678	654
	3 Months	95.1	93.3	95.2	95.2	96.3	95.6	96.7	95.6	95.9	97.3
	1 Year	93.1	90.4	91.4	91.9	92.5	93.3	93.4	92.4	93.5	—
	3 Years	88.8	82.9	85.8	85.9	85.9	86.7	87.6	—	—	—
	5 Years	83.2	75.4	79.7	79.1	80.7	—	—	—	—	—
Living Donor	N	340	319	342	345	370	415	413	409	402	413
	3 Months	96.5	99.1	98.5	98.6	98.1	97.6	98.8	97.8	98.8	98.3
	1 Year	95.3	98.1	98	98.3	95.9	96.4	96.6	96.6	97.5	—
	3 Years	91.1	95.3	95.9	94.5	92.4	93.3	93	—	—	—
	5 Years	84.9	92.2	91.5	90.1	89.7	—	—	—	—	—

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

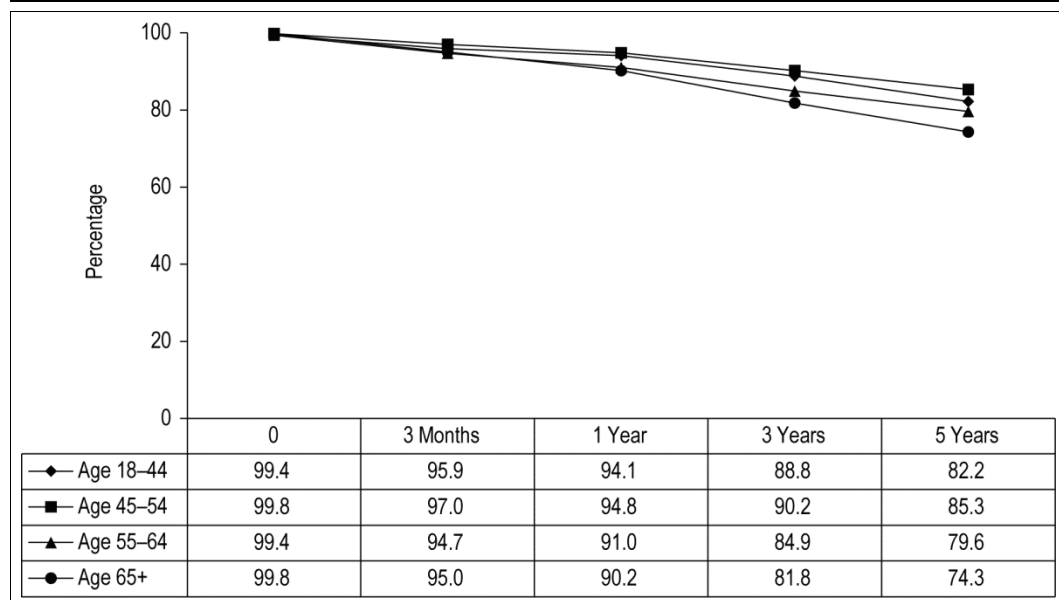
Figure 9: Unadjusted Three-Month and One-, Three- and Five-Year Graft Survival Rates in Adult Kidney Transplant Patients, First Graft, Living Donor, by Age at Transplant, Canada, 2001 to 2010 (Percentage)



Source

Canadian Organ Replacement Register, 2011, 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, 2001 to 2010 (Percentage)



Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

2.6 Kidney Transplantation: Pediatric Kidney Transplants

In this section, pediatric patients are defined as those younger than age 18.

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 30 to 34. Throughout the decade, there were 547 first graft transplants and 34 re-transplants on pediatric recipients. There was no distinct trend for transplants utilizing living-donor or deceased-donor organs.

Table 30: Kidney Transplants by Year, Donor Type and Re-Transplants, Pediatric Recipients, Canada, 2001 to 2010 (Number)

	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	Total
First Graft, Deceased Donor	18	28	27	19	39	22	42	24	31	28	278
First Graft, Living Donor	26	36	28	37	29	26	21	23	18	25	269
Re-Transplants	3	2	3	5	5	1	4	3	4	4	34
Total	47	66	58	61	73	49	67	50	53	57	581

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

Table 31: Pediatric Kidney Transplants by Age Group and Province of Treatment, Canada, 2001 to 2010 (Number, Percentage)

		B.C.	Alta.	Sask.	Man.	Ont.	Que.	N.S.	Total
Age 0–4	N	13	11	—	3	31	17	10	85
	%	17.6	16.2	—	6.5	14.2	12.9	27.8	14.6
Age 5–10	N	16	16	—	14	44	28	7	125
	%	21.6	23.5	—	30.4	20.2	21.2	19.4	21.5
Age 11–17	N	45	41	7	29	143	87	19	371
	%	60.8	60.3	100	63	65.6	65.9	52.8	63.9
Total	N	74	68	7	46	218	132	36	581

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

Table 32: Dialysis Duration in Days Prior to First Kidney Transplant, Pediatric Recipients, Canada, 2001 to 2010

	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
Duration on Dialysis (Median Days), Deceased Donor	292	336	460	586	625	631	422	344	265	524
Duration on Dialysis (Median Days), Deceased Donor, Excluding Pre-Emptive	507	436	772	705	770	649	558	373	286	614
Duration on Dialysis (Median Days), Living Donor	137	140	175	267	107	144	137	66	197	228
Duration on Dialysis (Median Days), Living Donor, Excluding Pre-Emptive	295	348	327	414	349	271	483	258	297	304

Note

In the calculation of median days on dialysis, pre-emptive kidney transplant recipients were given a value of 0 for their wait time. A patient who receives a pre-emptive transplant has not been treated with dialysis prior to the transplant.

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

Table 33: Pediatric Kidney Transplant by Age Group and Primary Renal Diagnosis Category, Canada, 2001 to 2010

Primary Renal Diagnosis Category	Age 0–4		Age 5–10		Age 11–17	
	N	%	N	%	N	%
Alport Syndrome	0	0	<5*	..	7	2.1
Cystinosis	0	0	8	6.5	17	5.0
Dysplasia/Hypoplasia	23	27.7	22	17.9	42	12.3
Posterior Urethral Valves	8	9.6	9	7.3	11	3.2
Obstructive Uropathy	<5*	..	5	4.1	14	4.1
Vesicoureteric Reflux	<5*	..	<5*	..	20	5.9
Polycystic Kidneys	<5*	..	<5*	..	8	2.3
Nephronophthisis	<5*	..	7	5.7	17	5.0
Other Congenital/Hereditary	8	9.6	<5*	..	9	2.6
Other Pyelonephritis	0	0	5	4.1	8	2.3
Glomerulonephritis	12	14.5	13	10.6	44	12.9
Focal Sclerosis	<5*	..	9	7.3	21	6.2
Autoimmune Disease	0	0	0	0	21	6.2
Hemolytic Uremic Syndrome	<5*	..	8	6.5	11	3.2
Other[†]	8	9.6	17	13.8	41	12.0
Unknown	10	12.0	13	10.6	50	14.7
Total Patients	83	100	123	100	341	100

Notes

* 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.

.. Percentage suppressed to ensure confidentiality.

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

Source

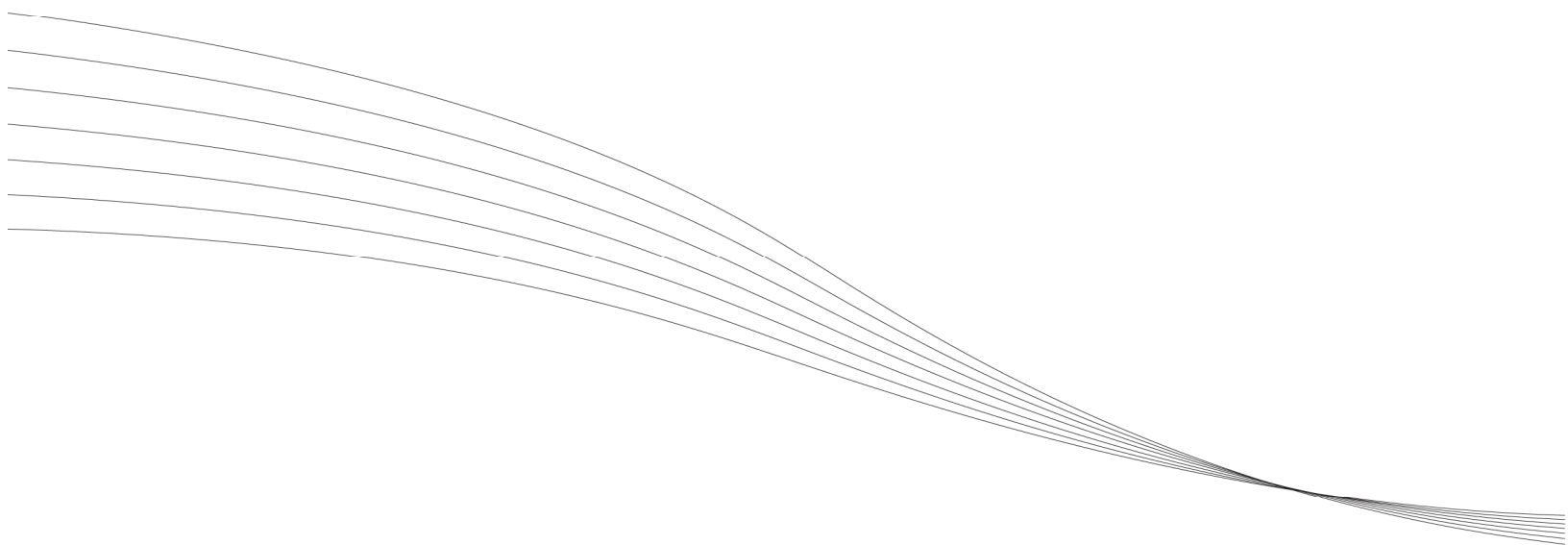
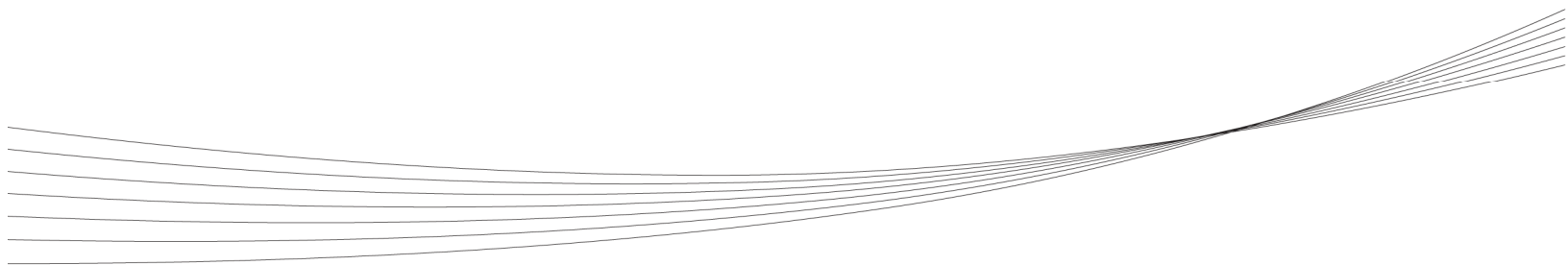
Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

Table 34: Unadjusted Three-Month and One-, Three- and Five-Year Graft Survival Rates in Pediatric Kidney Transplant Recipients, First Graft, Canada, 2001 to 2010 (Percentage)

		2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
Deceased Donor	N	18	28	27	19	39	22	42	24	31	28
	3 Months	94.4	100	92.6	94.7	97.4	95.5	95.2	100	96.8	100
	1 Year	88.9	100	88.9	94.7	97.4	90.9	95.2	91.7	96.8	—
	3 Years	88.9	100	74.1	94.7	92.3	77.3	90.4	—	—	—
	5 Years	83.3	88.9	70.4	89.5	89.7	—	—	—	—	—
Living Donor	N	26	36	28	37	29	26	21	23	18	25
	3 Months	100	94.4	96.4	100	96.6	100	100	95.7	100	95
	1 Year	100	94.4	96.4	100	96.6	100	100	95.7	100	—
	3 Years	96.2	94.4	85.7	100	93.1	92.3	100	—	—	—
	5 Years	96.2	94.4	85.7	89.2	93.1	—	—	—	—	—

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.





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 2001 to 2010.

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 35). In 2010, the waiting list decreased to 501, and deaths on the waiting list also decreased, from 141 to 74 between 2005 and 2010 (Table 35).

The decade spanning 2001 to 2010 saw 4,319 liver transplants registered with CORR, with 87% of patients receiving livers from deceased donors (Table 36). During that period the proportion of transplants from living donors fluctuated between a low of 9% in 2003 to 15% in 2007 and 2008. While most of the transplants were liver only, combination transplants accounted for 2% of the performed transplants (Table 37).

Among recipients younger than 10, biliary atresia was the predominant cause of end-stage liver failure. Among recipients age 35 to 59, the most commonly reported diagnosis was hepatitis C (Table 38).

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. In general, 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 Ontario (14.8) and Alberta (12.5). The remaining provinces ranged from 8.7 to 11.7 RPMP (Figure 12).

Unadjusted patient survival rates for liver transplant patients remained relatively stable over the last decade. Three-year survival varied between 82% and 87%; five-year survival was somewhat lower (between 79% and 81%) (Figure 13). One-year survival reached a peak of 93% in 2008.

In 2010, there were 5,097 patients in Canada living with a transplanted liver (Table 39).

Table 35: Liver Transplant Waiting List and Deaths, December 31, Canada, 2001 to 2010

	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	Total
Age 0–17	36	31	30	37	32	36	19	17	19	22	279
Age 18+	418	528	539	630	681	687	616	570	532	479	5,680
Total	454	559	569	667	713	723	635	587	551	501	5,959
Deaths on Waiting List	57	82	100	96	141	120	77	92	91	74	930

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

Table 36: Liver Transplants by Year, Donor Type, Age Group and Re-Transplants, Canada, 2001 to 2010 (Number)

		2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	Total
Pediatric: Age 0–17	First Graft, Deceased Donor	20	25	33	15	34	25	28	27	31	22	260
	First Graft, Living Donor	13	10	6	12	8	9	15	9	9	14	105
	Re-Transplants	4	3	4	3	9	8	6	7	7	6	57
Adults: Age 18+	First Graft, Deceased Donor	293	290	302	318	296	324	342	318	324	323	3,130
	First Graft, Living Donor	31	32	29	42	52	58	56	59	48	50	457
	Re-Transplants	33	26	31	27	24	42	33	33	34	27	310
Total All Ages		394	386	405	417	423	466	480	453	453	442	4,319

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

Table 37: Combination Liver Transplants, Canada, 2001 to 2010 (Number)

	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	Total
Liver Only	383	381	399	414	416	447	468	442	440	433	4,223
Liver Combinations	11	5	6	3	7	19	12	11	13	9	96
Total	394	386	405	417	423	466	480	453	453	442	4,319

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

Table 38: Primary Diagnosis for Liver Transplant Recipients, First Graft, by Age Group, Canada, 2001 to 2010 (Percentage)

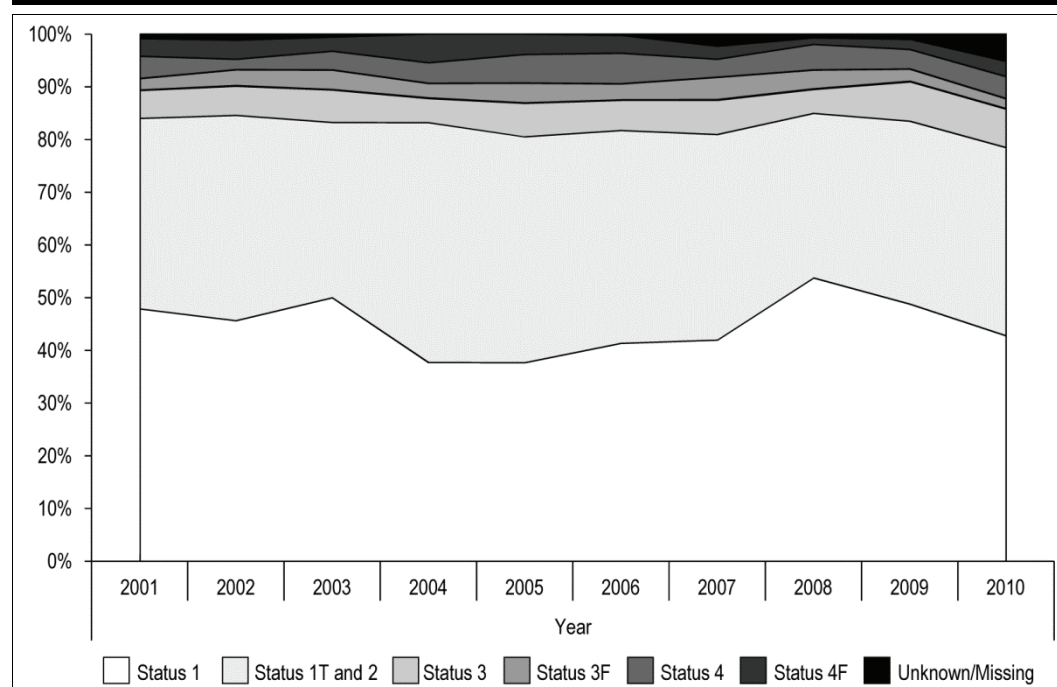
	Age <1	Age 1–10	Age 11–17	Age 18–34	Age 35–59	Age 60+	Total
Primary Biliary Atresia	60.0	30.2	5.8	0.9	0.1	0.2	2.9
Hepatitis C	0.0	0.0	1.2	4.4	28.9	16.5	22.2
Hepatitis B	0.0	0.0	1.2	6.6	5.8	5.6	5.4
Other Hepatitis	3.2	4.9	12.8	13.2	3.4	2.9	4.2
Alcoholic Cirrhosis	0.0	0.0	0.0	0.9	17.2	17.0	14.7
Cryptogenic Cirrhosis	0.0	0.0	2.3	5.0	3.7	6.3	4.1
Cancer	1.6	11.1	3.5	5.3	13.6	22.1	14.4
Metabolic Disorders	5.6	9.3	8.1	5.7	2.0	1.9	2.7
Cholestatic Liver Disease	4.0	8.0	19.8	24.2	11.1	11.3	11.9
Unknown/Missing	12.0	13.6	10.5	5.7	2.1	2.0	3.1
Other*	13.6	22.8	34.9	28.0	12.1	14.1	14.5
Total	100	100	100	100	100	100	100

Note

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

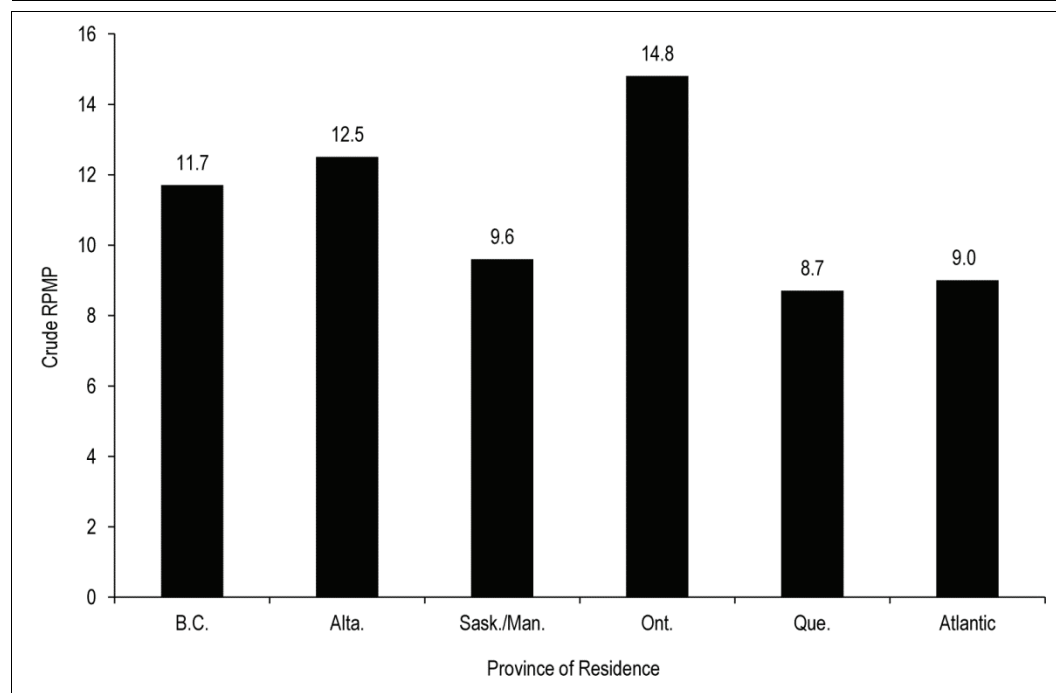
Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

Figure 11: Distribution of Liver Transplants by Medical Status at Transplant, Canada, 2001 to 2010**Source**

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

Figure 12: Liver Transplant Recipients by Province of Residence, Canada, 2010
(Crude Rate per Million Population)



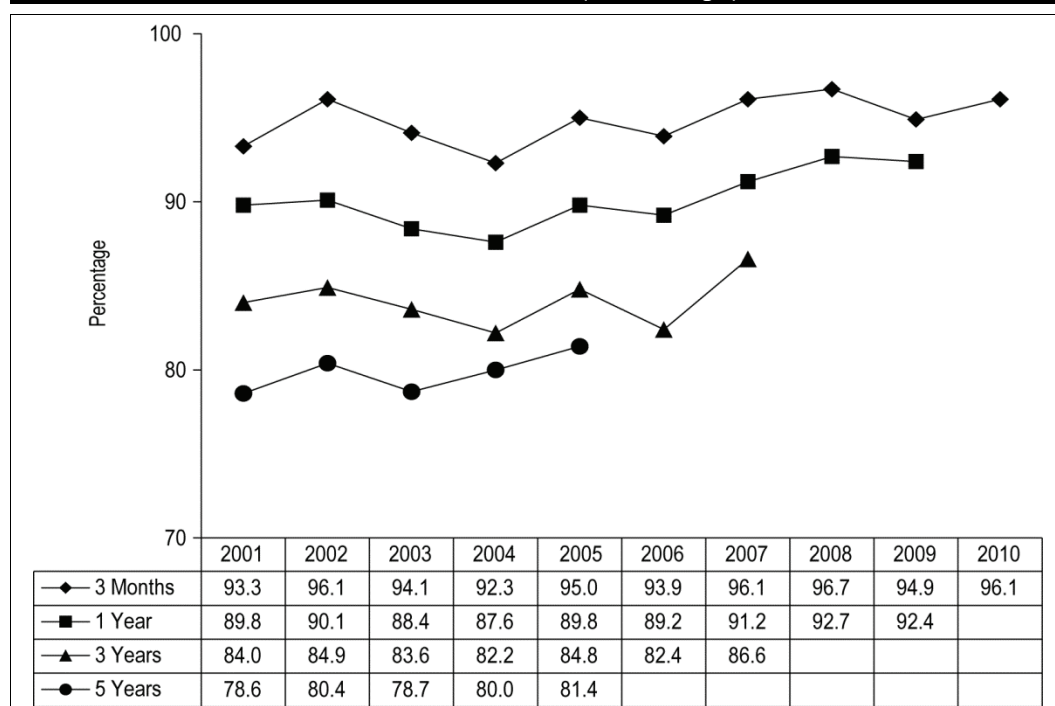
Note

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

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

Figure 13: Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival Rates for Deceased-Donor Liver Transplant Recipients, First Graft, Canada, 2001 to 2010 (Percentage)



Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

Table 39: Prevalent Liver Transplant Patients, by Province of Treatment/Follow-Up, 2001 to 2010 (Number)

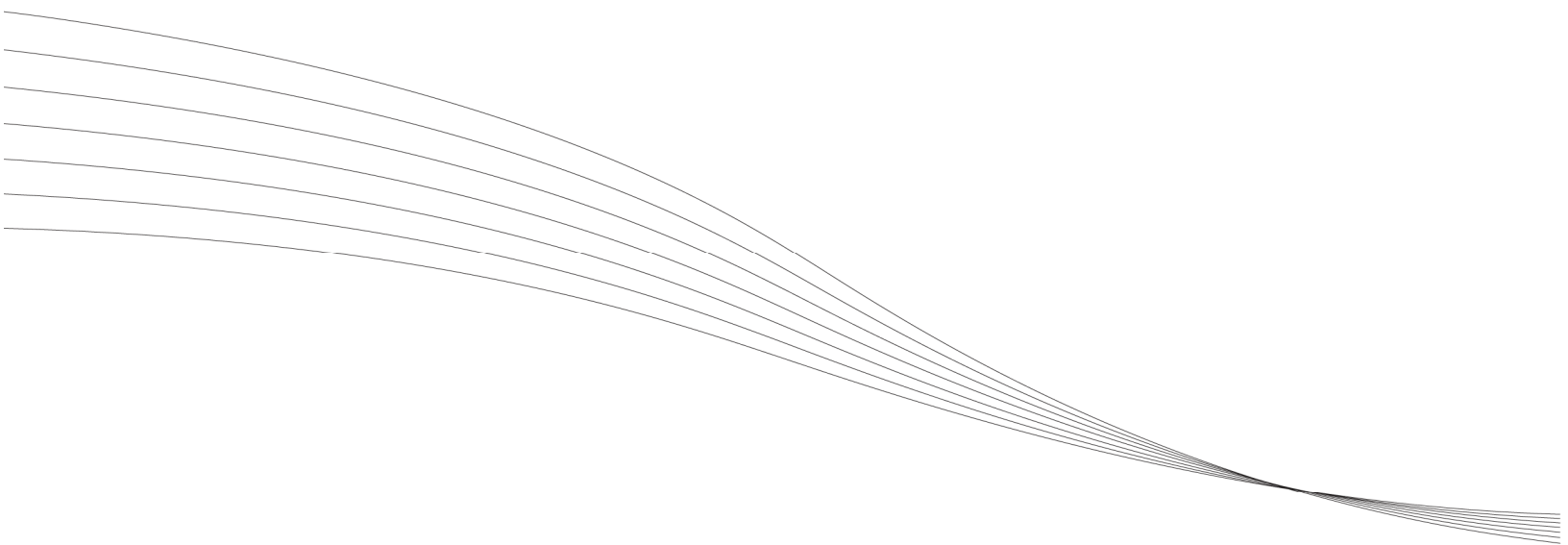
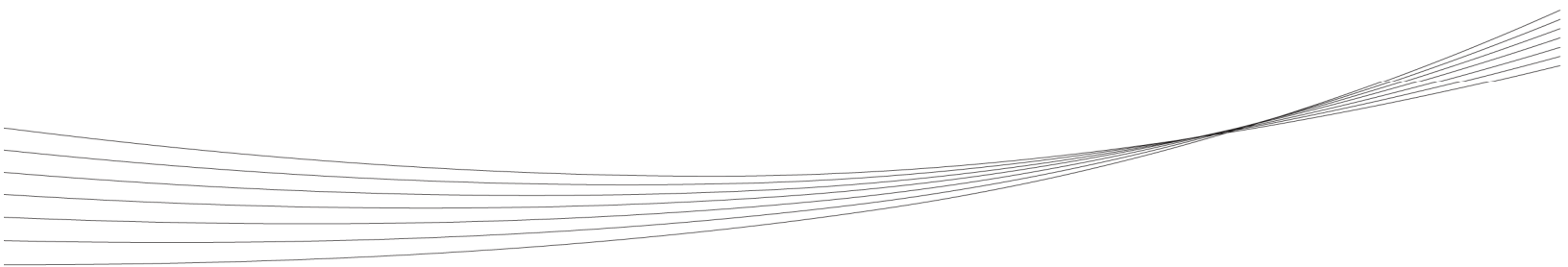
	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
B.C.	237	264	284	306	329	354	387	422	440	480
Alta.	346	393	427	469	492	538	562	582	613	648
Sask.	23	25	35	42	47	51	61	65	73	73
Man.	<5*	<5*	<5*	<5*	<5*	<5*	<5*	<5*	<5*	<5*
Ont.	1,331	1,434	1,548	1,666	1,790	1,915	2,068	2,201	2,346	2,496
Que.	609	661	723	772	824	871	932	1,000	1,065	1,106
N.B.	<5*	<5*	<5*	<5*	<5*	0	<5*	<5*	<5*	<5*
N.S.	166	182	191	196	212	230	245	262	280	289
N.L.	<5*	<5*	<5*	<5*	<5*	<5*	<5*	<5*	<5*	<5*
Canada	2,718	2,965	3,214	3,457	3,700	3,964	4,259	4,536	4,821	5,097

Note

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

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.





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 2001 to 2010.

There were 135 people on the waiting list for a heart transplant in 2010. Since 2000, deaths on the waiting list have varied from 14 to 35 per year (Table 40). A total of 250 Canadians died over the last decade while waiting for a heart transplant.

Between 2001 and 2010, there were 1,639 heart transplants registered in CORR, including 43 re-transplants. The number of transplants performed each year remained fairly stable between 2001 (161) and 2010 (167). The number of children younger than a year old receiving heart transplants fluctuated minimally over the decade (less than 20 for all years). The largest number of transplants was performed on recipients between age 35 and 59 (791), followed by those age 60 and older (336) (Table 41). The crude RPMP for heart transplants varied from 3.0 to 5.7 across Canada (Figure 14).

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).

Survival rates showed continued improvement for much of the period under examination (Figure 16). In 2001, 81% of heart transplant recipients survived one year, whereas in 2009, 93% of recipients survived the first year. Three-year survival was 87%, and five-year survival was 82%.

In 2010, there were 2,447 Canadians living with a heart transplant.

Table 40: Waiting Lists and Deaths on the Waiting List for Heart Transplant, 2001 to 2010

	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	Total
Age 0–17	13	13	37	6	9	7	13	17	12	14	141
Age 18+	112	90	94	119	87	80	102	114	124	121	1,043
Total	125	103	131	125	96	87	115	131	136	135	1,184
Deaths on Waiting List	34	35	30	26	27	13	19	14	30	22	250

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

Table 41: Heart Transplants by Year, Age Group and Re-Transplants, Canada, 2001 to 2010 (Number)

		2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	Total
Pediatric: Age 0–17	First Graft Age <1	10	5	6	14	15	17	7	16	17	5	112
	First Graft Age 1–10	8	8	4	7	8	7	9	6	11	12	80
	First Graft Age 11–17	9	8	10	9	9	9	11	15	9	9	98
Adults: Age 18+	First Graft Age 18–34	19	15	16	13	18	27	14	19	17	21	179
	First Graft Age 35–59	71	84	82	66	86	91	85	75	78	73	791
	First Graft Age 60+	40	41	33	30	33	20	31	30	33	45	336
Re-Transplants		4	3	6	4	5	7	6	3	3	2	43
Total		161	164	157	143	174	178	163	164	168	167	1,639

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

Table 42: Primary Diagnosis for Heart Transplant Recipients, Canada, 2001 to 2010 (Percentage)

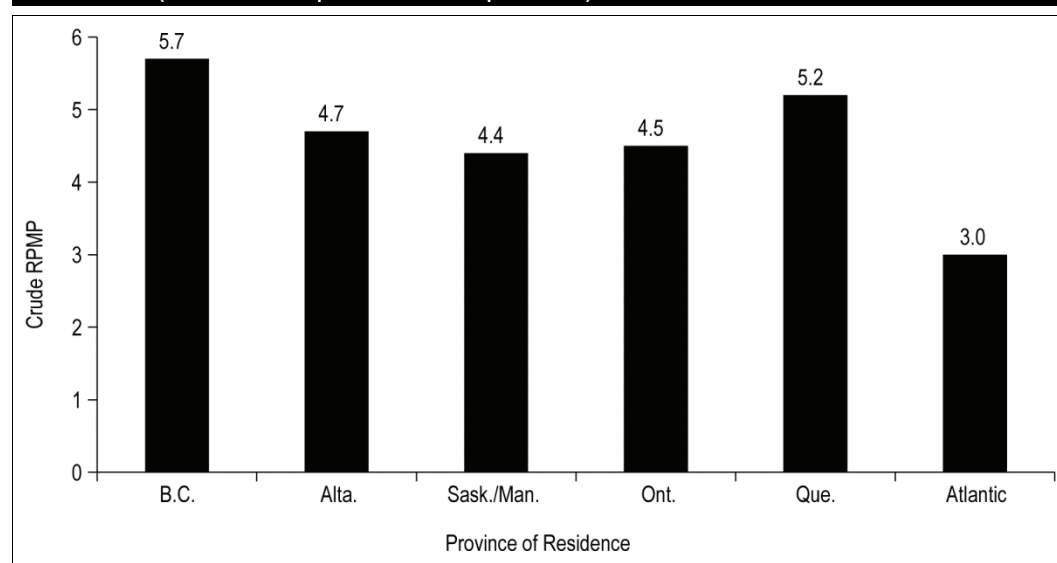
	Age <1	Age 1–10	Age 11–17	Age 18–34	Age 35–59	Age 60+	Total
Congenital	44.5	27.2	16.5	13.4	2.9	0	8.4
Cardiomyopathy Unspecified	7.6	7.4	16.5	9.3	9.1	10.9	9.8
Dilated Cardiomyopathy	10.1	11.1	21.4	26.3	21.6	16.4	19.7
Idiopathic Cardiomyopathy	4.2	4.9	4.9	12.9	11.3	10.1	10
Ischemic Cardiomyopathy	0	1.2	1.9	3.6	30.0	48	25.5
Unknown/Missing	14.3	21.0	16.5	3.1	3.0	3.2	5.5
Other*	19.3	27.2	22.3	31.4	22.1	11.5	21
Total	100	100	100	100	100	100	100

Note

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

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

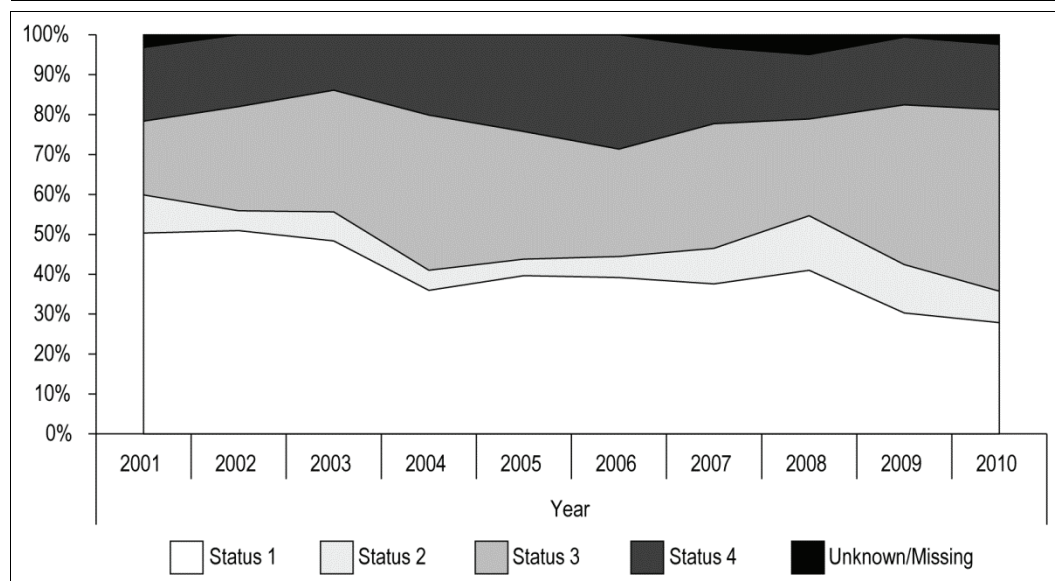
Figure 14: Heart Transplant Recipients by Province of Residence, Canada, 2010 (Crude Rate per Million Population)**Note**

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

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

Figure 15: Distribution of Heart Transplants by Medical Status* at Transplant, Canada, 2001 to 2010



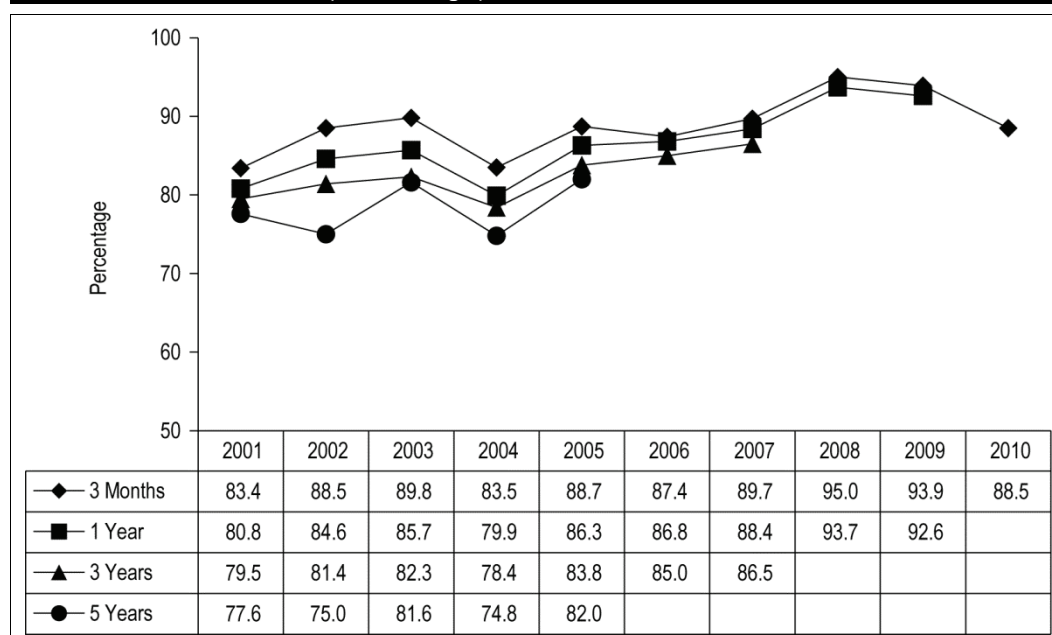
Note

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

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

Figure 16: Unadjusted Three-Month and One-, Three-, and Five-Year Patient Survival Rates for Heart Transplant Recipients, First Graft, Canada, 2001 to 2010 (Percentage)



Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

Table 43: Prevalent Heart Transplant Patients, by Province of Treatment/Follow-Up, 2001 to 2010 (Number)

	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
B.C.	143	163	178	182	192	200	213	227	230	242
Alta.	243	269	285	298	324	350	365	383	411	433
Sask.	11	13	14	14	14	15	16	20	22	22
Man.	6	5	5	5	<5*	<5*	<5*	<5*	<5*	8
Ont.	671	693	732	755	790	820	856	893	937	983
Que.	445	460	482	484	495	510	533	569	607	631
N.S.	91	96	99	103	108	110	113	116	126	128
Canada†	1,610	1,699	1,795	1,841	1,923	2,005	2,096	2,208	2,333	2,447

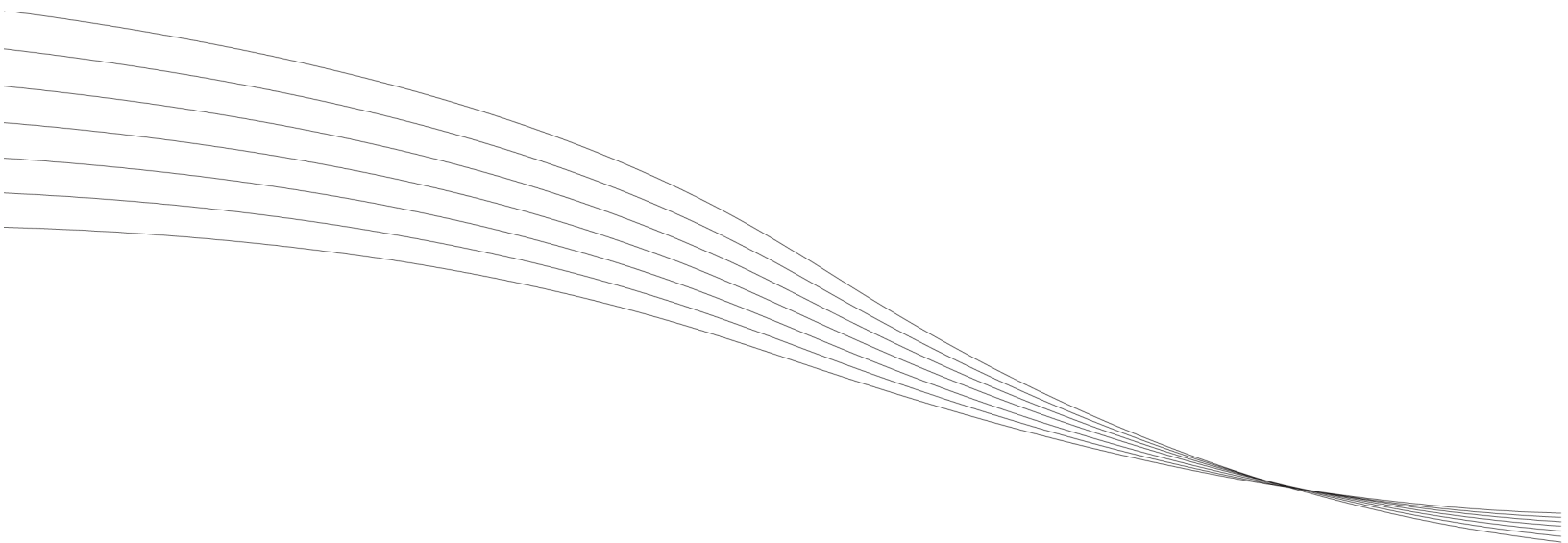
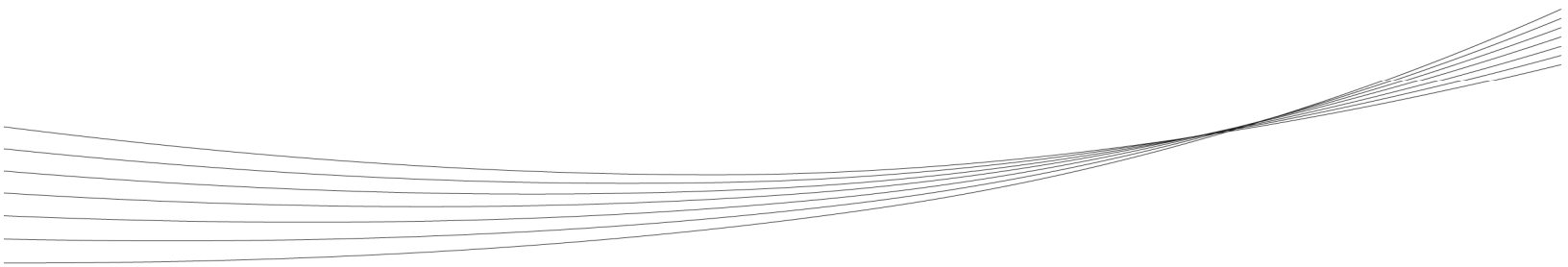
Notes

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

† Totals for Canada do not include suppressed cells.

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.





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 2001 to 2010.

The number of individuals on the waiting list for a lung transplant continued to grow over the decade, reaching 310 in 2010. Since 2004, the number of people dying annually has remained relatively constant at around 44 (Table 44).

Between 2001 and 2010, there was an increase in the annual number of lung transplants performed in Canada. During the decade, the total number of lung transplants reached 1,554, with an average of 179 performed each year since 2006 (Table 45). Between 2001 and 2010, the volume of bilateral lung transplants increased by 85%, from 82 to 152. Single-lung transplant volumes averaged 30 procedures per year over the 10 years (Table 46).

In 2010, the Alberta had the highest rate of lung transplantation, at 8.1 RPMP, followed by Saskatchewan/Manitoba (6.6 RPMP) and Ontario (5.4 RPMP) (Figure 17).

Rates of patient survival for lung transplant generally show an increasing trend (Figure 18). Three-year survival increased from 64% to 78% between 2001 and 2007. Similarly, five-year survival increased from 56% to 66% between 2001 and 2005. Three-month and one-year survival made smaller gains (88% to 94% from 2001 to 2010, and 81% to 89% from 2001 to 2009, respectively).

There were 1,387 Canadians living with a transplanted lung in 2010 (Table 47).

Table 44: Lung Transplant Waiting List, December 31, Canada, 2001 to 2010

	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	Total
Bilateral Lung	125	88	131	155	188	147	183	147	137	178	1,479
Single Lung	25	50	29	22	37	94	51	129	104	125	666
Heart–Lung	13	12	12	4	14	11	9	6	4	7	92
Total	163	150	172	181	239	252	243	282	245	310	2,237
Deaths on Waiting List	28	26	29	43	43	36	43	44	44	51	387

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

Table 45: Lung Transplants by Year, Age Group and Re-Transplants, Canada, 2001 to 2010 (Number)

	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	Total
First Graft, Age 18+	120	130	112	128	137	166	179	156	178	173	1,479
First Graft, Age 0–17	4	5	2	3	5	4	4	6	4	3	40
Re-Transplants	2	4	4	2	3	1	4	5	7	3	35
Total	126	139	118	133	145	171	187	167	189	179	1,554

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

Table 46: Lung Transplants by Transplant Type, Canada, 2001 to 2010 (Number)

	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	Total
Bilateral Lung	82	96	95	98	119	129	152	135	153	152	1,211
Single Lung	39	36	21	30	19	35	32	28	31	25	296
Living-Donor Lobar	2	0	0	2	1	1	0	0	0	0	6
Heart–Lung	3	7	2	3	6	6	3	4	5	2	41
Total	126	139	118	133	145	171	187	167	189	179	1,554

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

Table 47: Primary Diagnoses* for Lung Transplant Recipients, First Graft, Canada, 2001 to 2010 (Number, Percentage)

	Bilateral Lung		Single Lung		Heart–Lung	
	N	%	N	%	N	%
Congenital	7	0.6	0	0.0	14	33.3
Alpha Antitrypsin	64	5.4	15	4.9	1	2.4
Cystic Fibrosis	335	28.1	13	4.2	3	7.1
Emphysema/Chronic Obstructive Pulmonary Disease	265	22.3	138	45.0	3	7.1
Idiopathic Pulmonary Fibrosis	271	22.8	101	32.9	3	7.1
Primary Pulmonary Hypertension	53	4.5	3	1.0	5	11.9
Unknown/Missing	38	3.2	5	1.6	3	7.1
Other[†]	158	13.3	32	10.4	10	23.8
Total	1,191	100.0	307	100.0	42	100.0

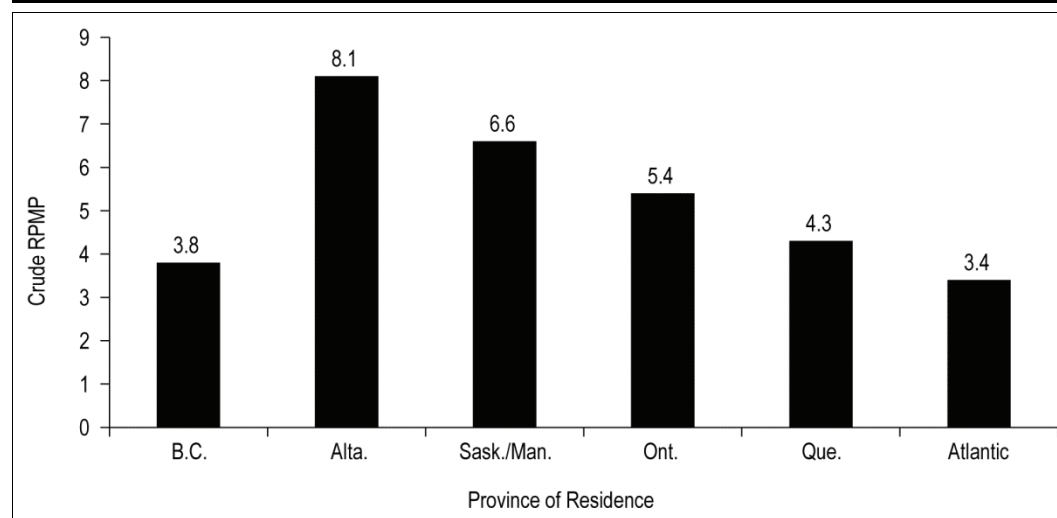
Note

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

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

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

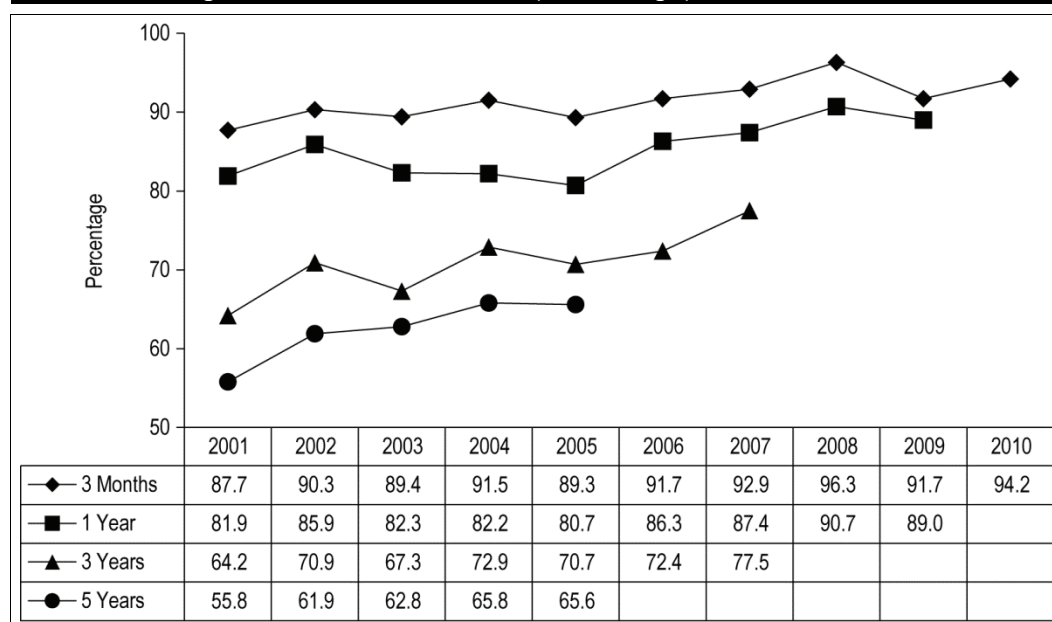
Figure 17: Lung Transplant Recipients by Province of Residence, Canada, 2010 (Crude Rate per Million Population)**Note**

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

Sources

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information; Statistics Canada.

Figure 18: Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Lung Transplant Recipients, First Graft, Deceased-Donor Lungs, Canada, 2001 to 2010 (Percentage)



Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

Table 48: Prevalent Lung Transplant Patients, by Province of Treatment/Follow-Up, 2001 to 2010 (Number)

	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
B.C.	51	54	55	59	63	67	76	86	82	89
Alta.	93	123	132	147	167	186	205	232	253	292
Sask.	<5*	5	5	5	5	6	8	15	29	29
Man.	52	55	63	71	71	74	79	85	87	91
Ont.	254	290	312	343	377	425	497	541	588	633
Que.	123	127	143	157	155	175	200	206	232	253
Canada†	573	654	710	782	838	933	1,065	1,165	1,271	1,387


Notes

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

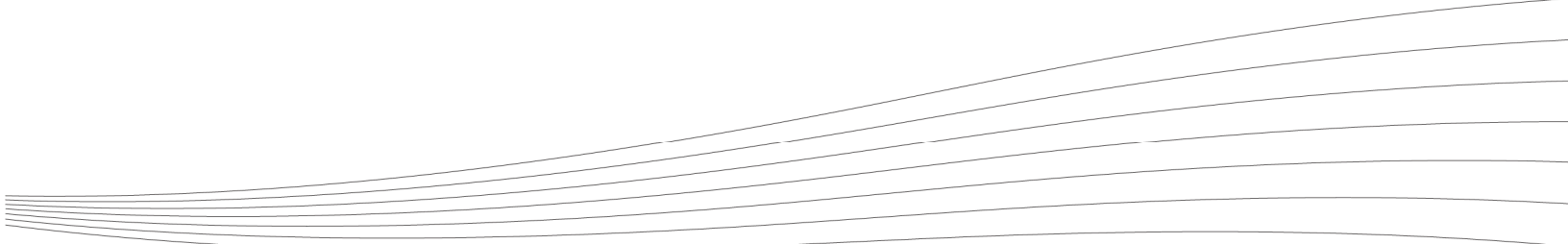
† Totals for Canada do not include suppressed cells.

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.



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.

The number of individuals on the waiting list for a pancreas transplant in 2010 was 175 (Table 44). About 60% were waiting for a simultaneous kidney–pancreas transplant.

Over the decade from 2001 to 2010, there were 685 pancreas transplants performed in Canada (Table 50). The majority of the transplants performed (70%) were SKP procedures. Table 51 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 2001, 343 procedures have been performed on 250 patients (in general, patients receive two procedures).

More pancreas transplantations in Canada have been performed on men than women (Figure 19).

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

Table 49: Pancreas Transplant Waiting List, December 31, Canada, 2001 to 2010

Transplant	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
SKP	172	122	120	101	132	113	126	98	56	107
PAK/PTA	32	37	31	51	63	63	55	49	42	68
Total	204	159	151	152	195	176	181	147	98	175

Note

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

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

Table 50: Pancreas Transplants by Year, Canada, 2001 to 2010 (Number)

Transplant	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	Total
SKP	34	44	38	47	53	55	50	63	48	50	482
PAK	10	17	17	11	12	13	13	18	20	19	150
PTA	3	11	9	3	6	5	6	3	2	5	53
Total	47	72	64	61	71	73	69	84	70	74	685

Note

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

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

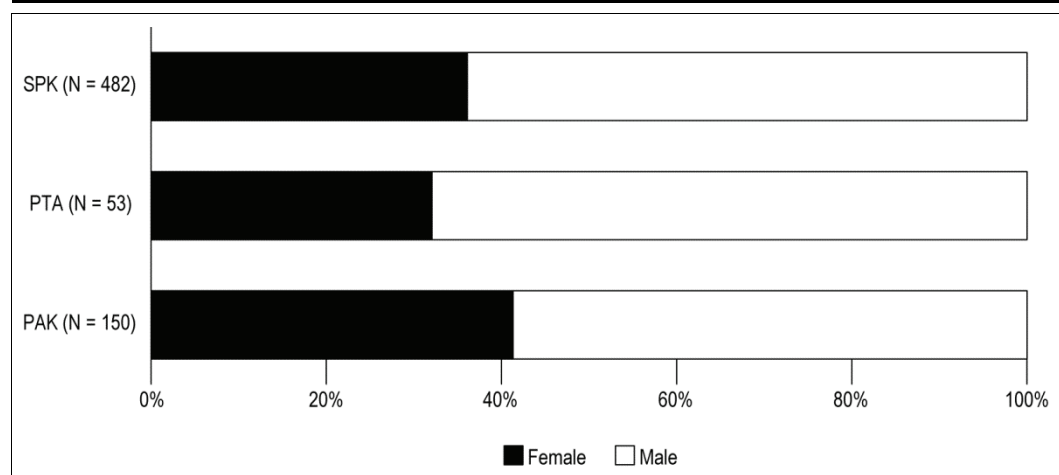
Table 51: Islet Cell Transplants in Canada, 2001 to 2010

	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	Total
Patients	18	26	15	25	28	31	18	28	29	32	250
Procedures	22	41	21	39	39	39	25	35	38	44	343

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

Figure 19: Pancreas Transplant Recipients by Type and Recipient Sex, First Graft, Canada, 2001 to 2010 (Percentage)



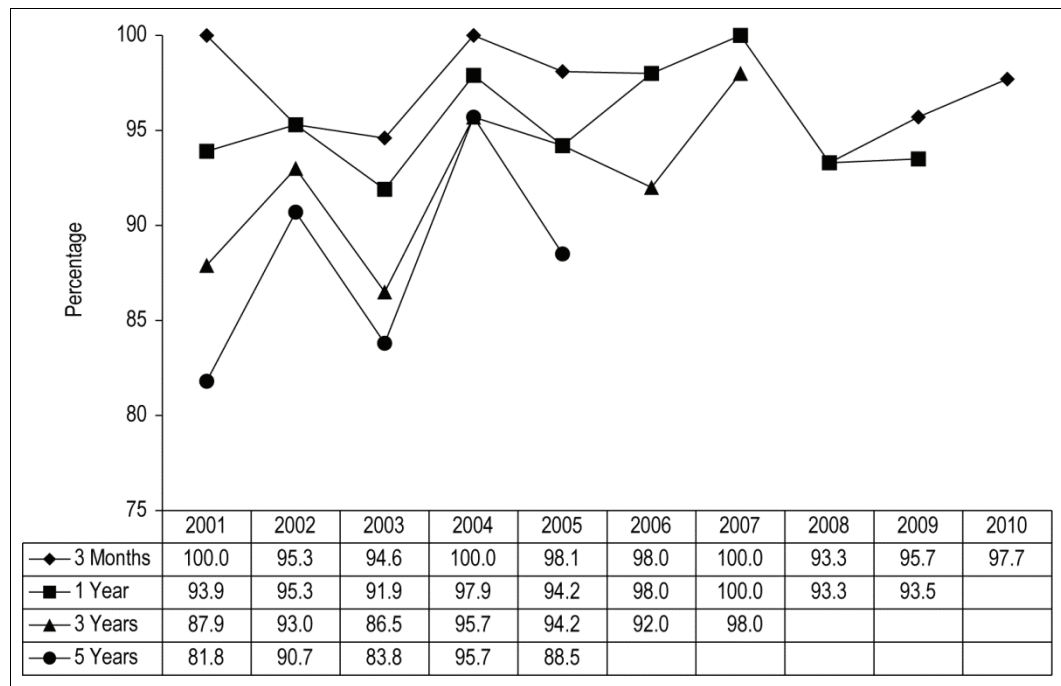
Note

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

Source

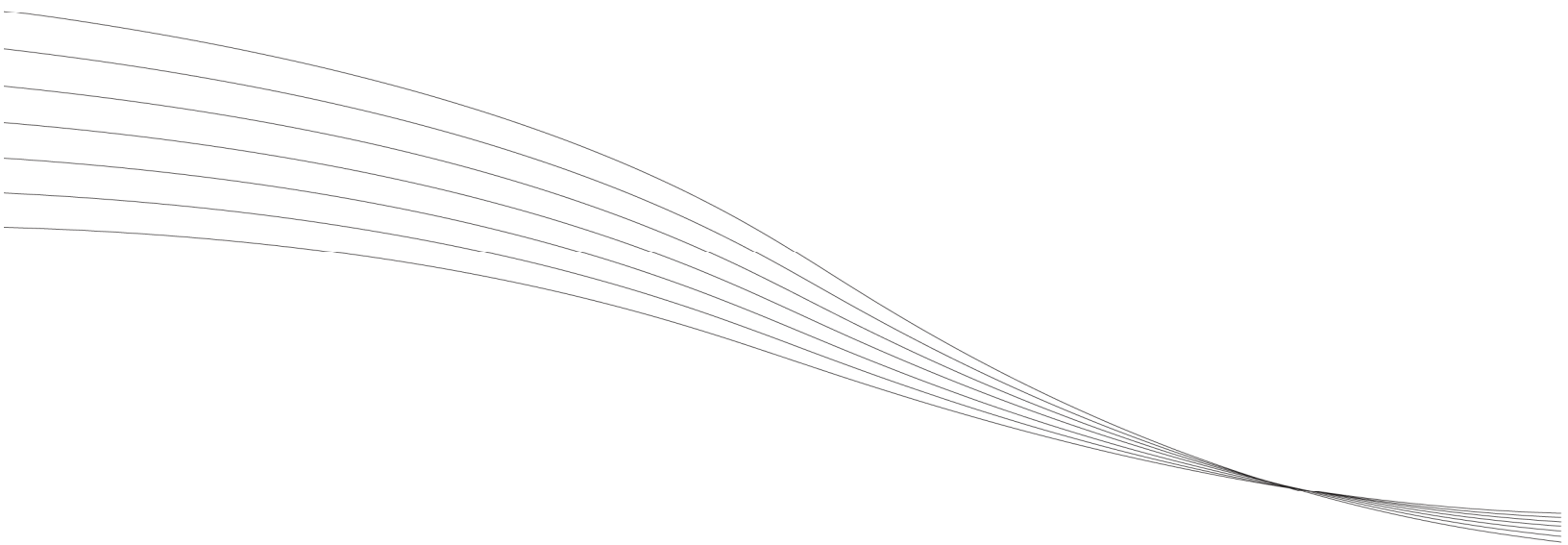
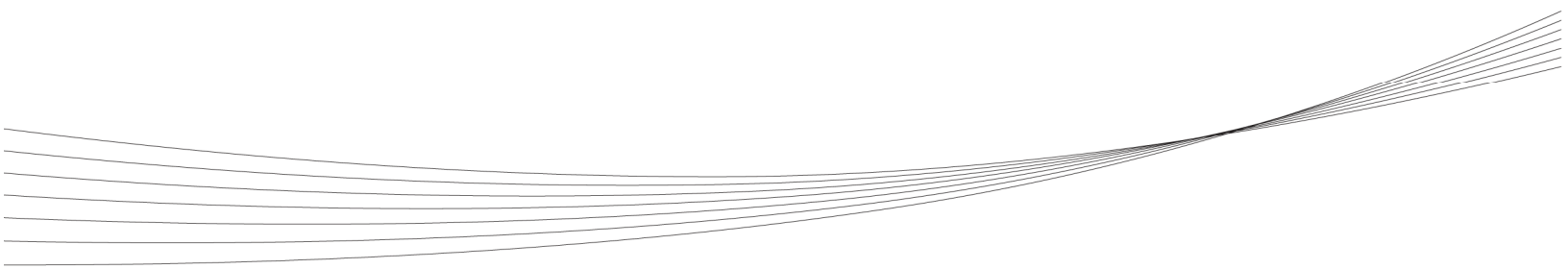
Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.


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, 2001 to 2010 (Percentage)



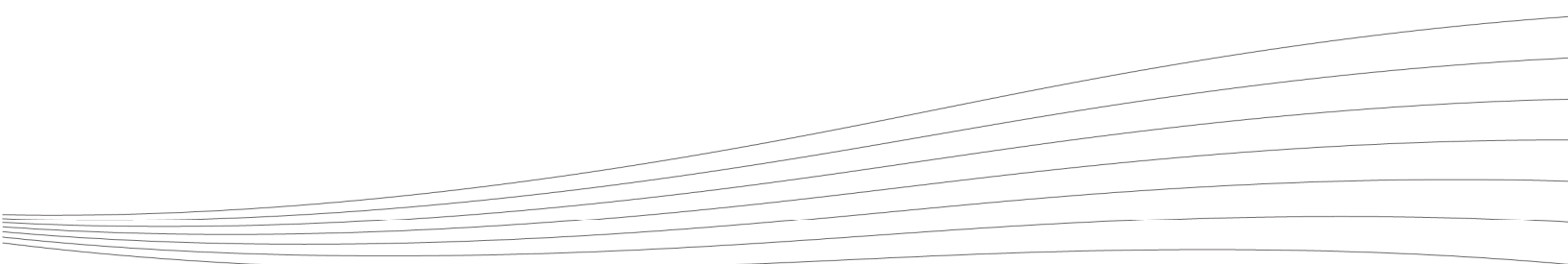
Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.





Chapter 7—Intestinal Transplantation



7 Intestinal Transplantation^{vi}

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 1991, there have been 53 intestinal transplants reported to CORR (Table 52). The transplants were almost evenly split between pediatric patients and adult recipients (57% versus 43%). The majority of liver–small intestine transplants were performed on pediatric patients (84%).

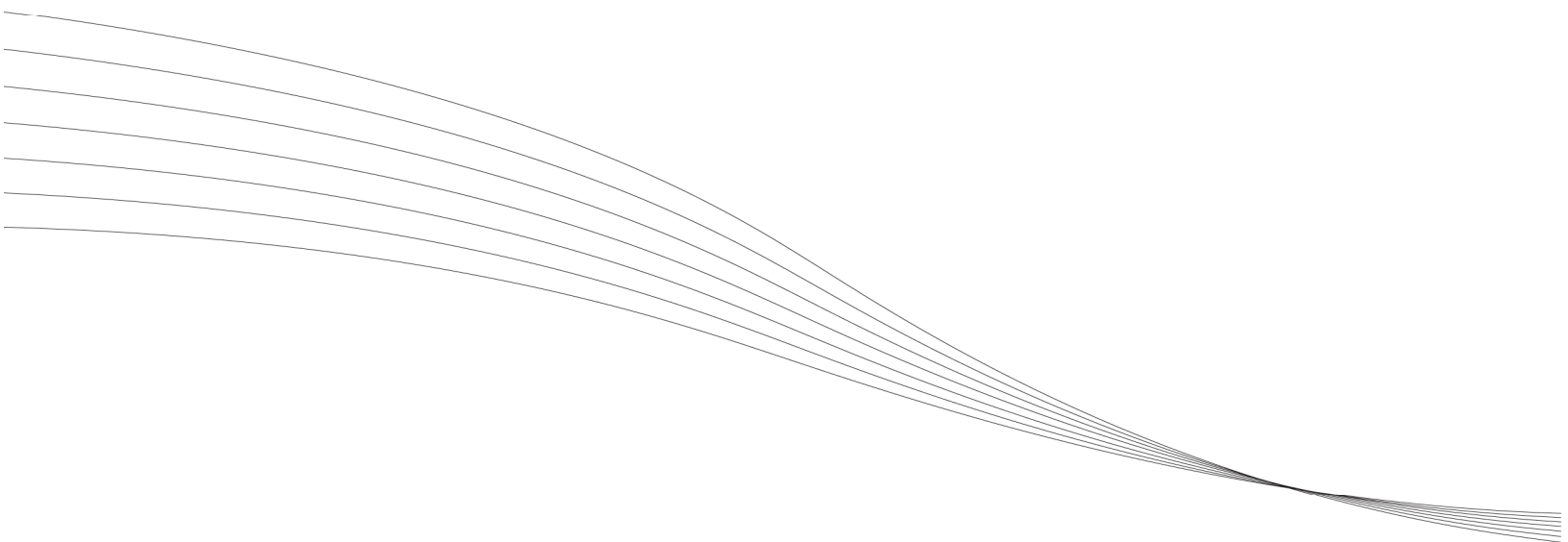
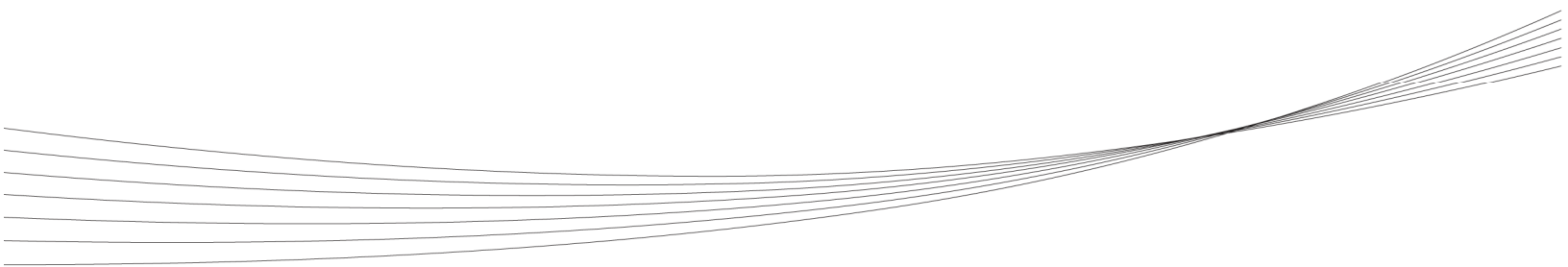
Table 52: Intestinal Transplants by Transplant Period and Age Group, Canada, 1991 to 2010 (Number)


Type of Graft	1991–2000		2001–2010		Total		
	Age 0–17	Age 18+	Age 0–17	Age 18+	Age 0–17	Age 18+	All Ages
Multi-Visceral	1	2	4	8	5	10	15
Isolated Small Intestine	5	2	3	6	8	8	16
Liver–Small Intestine	5	2	11	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	12	8	18	15	30	23	53

Source

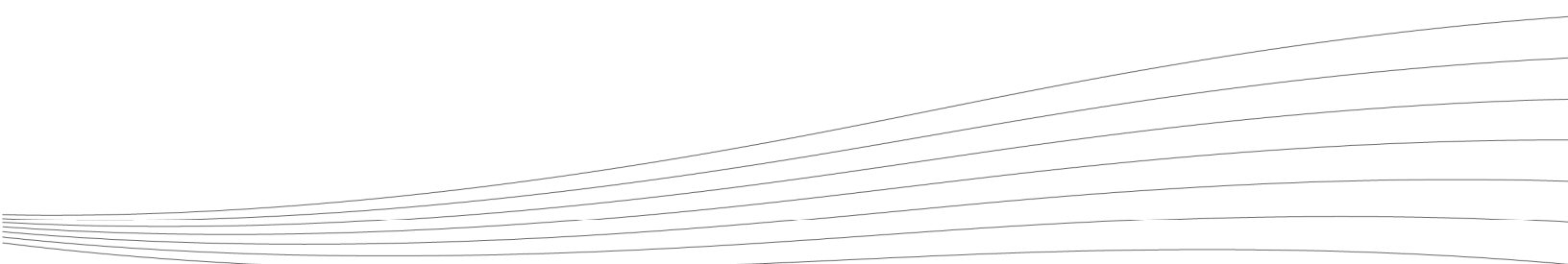
Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

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 1991 and 2010.





Chapter 8—Donors



8 Donors

Overall, the number of Canadian organ donors increased from 864 in 2001 to 1,022 in 2010, a relative increase of 18% (Figure 21). Over this same time period, the percentage of living donors ranged between 51% and 55%. As a result of this increase in donors, solid organ transplant procedures increased 18%, from 1,783 in 2001 to 2,103 in 2010 (Figure 22).

Although the total number of deceased donors remained stable over the past decade, the age composition of donors changed. Between 2001 and 2010, deceased donors age 55 and older represented between 24% and 38% of donors (Table 53). Conversely, in 2010, 7% of deceased donors were younger than 18, compared with 13% of donors in 2001. This changing age profile was also reflected in living donors (Table 54). The number of living donors increased among those age 40 and older. This age group accounted for two-thirds of living donors in 2010, compared with 56% in 2001.

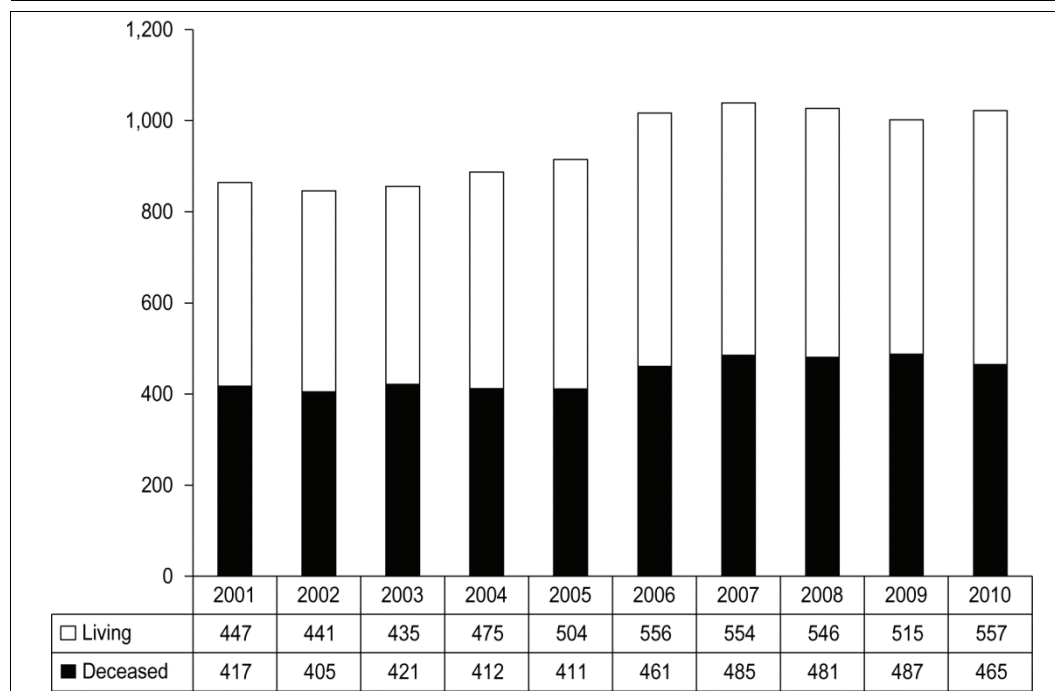
Between 2001 and 2010, 32% of living donors in Canada were unrelated (the definition of unrelated includes spouses). The proportion of unrelated donors has been increasing and, in 2010, accounted for 40% of living donors (Table 55).

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 2010 was 13.6; it remained relatively constant over the past decade (Figure 23). The living DRPM was 16.3. Figures 24 and 25 provide corresponding regional donor rates.

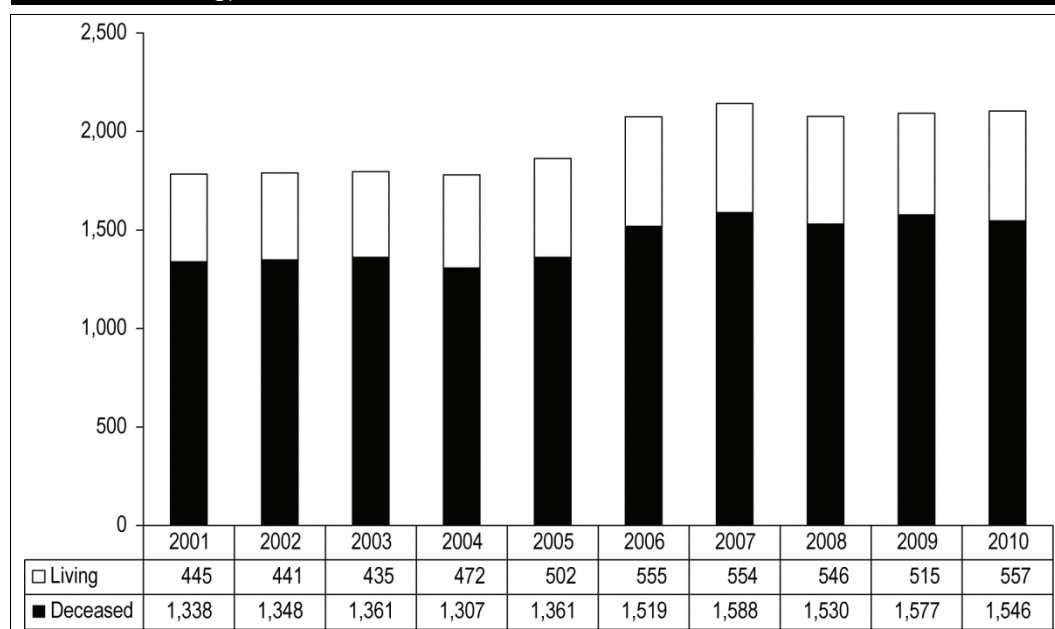
Figure 21: Number of Canadian Organ Donors by Donor Source (Deceased or Living), 2001 to 2010



Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

Figure 22: Number of Solid Organ Transplants by Donor Source (Deceased or Living), Canada, 2001 to 2010



Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

Table 53: Number of Deceased Donors by Age Group, Canada, 2001 to 2010

	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	Total
Age 0–17	54	47	36	29	47	41	53	49	39	34	429
Age 18–39	105	109	128	114	99	115	108	131	125	138	1,172
Age 40–49	112	96	95	86	83	102	101	92	86	82	935
Age 50–54	46	51	36	43	51	53	60	50	51	74	515
Age 55–59	36	41	35	46	44	48	52	58	53	41	454
Age 60+	64	61	91	94	87	102	111	101	133	96	940
Total	417	405	421	412	411	461	485	481	487	465	4,445

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

Table 54: Number of Living Donors by Age Group, Canada, 2001 to 2010

	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	Total
Age 0–39	196	191	178	190	180	218	199	188	168	192	1,900
Age 40–49	146	144	139	151	159	163	178	177	171	170	1,598
Age 50–54	48	63	58	61	66	66	78	87	72	73	672
Age 55–59	33	28	26	34	48	49	68	56	54	64	460
Age 60+	24	15	18	22	23	32	31	37	50	58	310
Unknown	0	0	16	17	28	28	0	1	0	0	90
Total	447	441	435	475	504	556	554	546	515	557	5,030

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

Table 55: Living Donor by Relationship of Donor to Recipient, Canada, 2001 to 2010

	Parent	Sibling	Offspring	Other Related*	Spouse	Unrelated	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	89	159	84	66	80	78	556
2007	84	149	94	38	91	98	554
2008	78	171	60	37	86	114	546
2009	81	120	75	39	96	104	515
2010	79	126	86	43	80	143	557

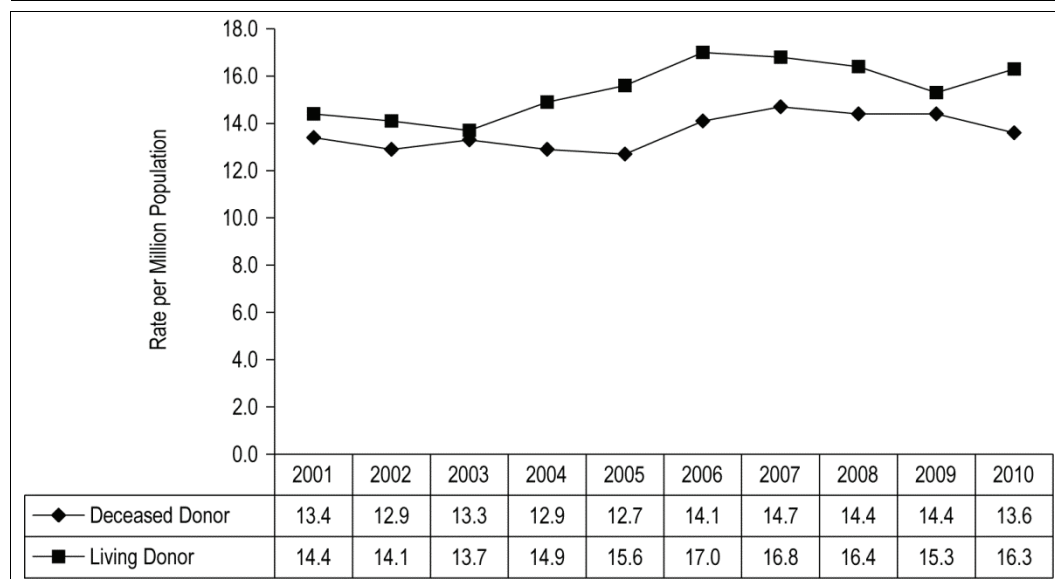
Note

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

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

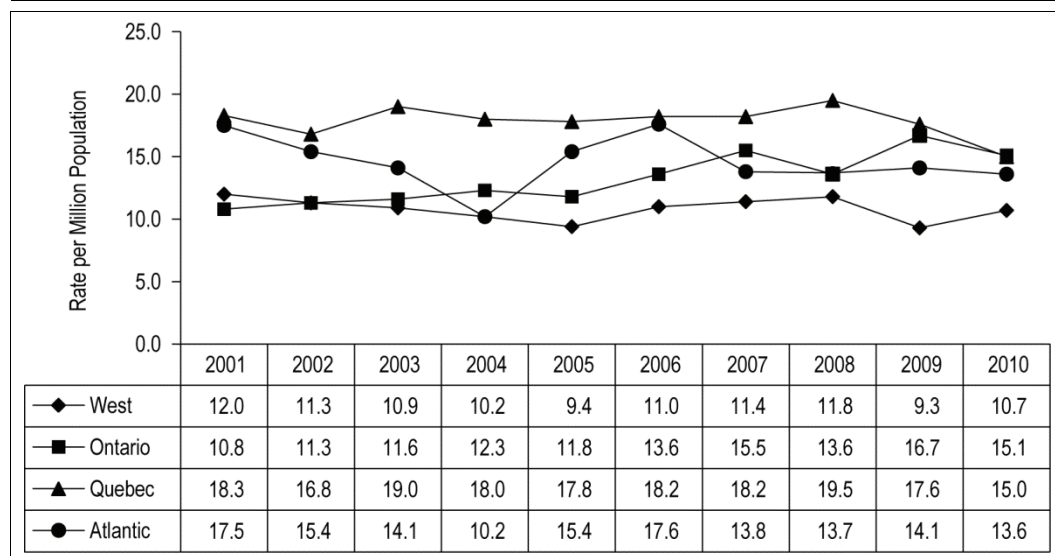
Figure 23: Donor Rate per Million Population, by Donor Source (Deceased or Living), Canada, 2001 to 2010



Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

Figure 24: Deceased Donor Rate per Million Population by Region, Canada, 2001 to 2010



Notes

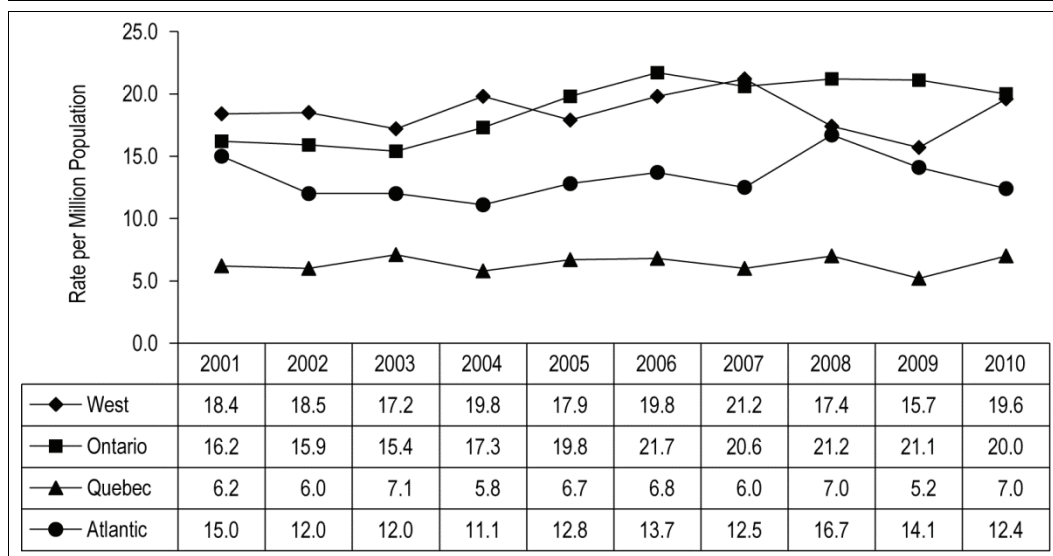
West includes British Columbia, Alberta, Saskatchewan and Manitoba.

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

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

Figure 25: Living Donor Rate per Million Population, by Region, Canada, 2001 to 2010



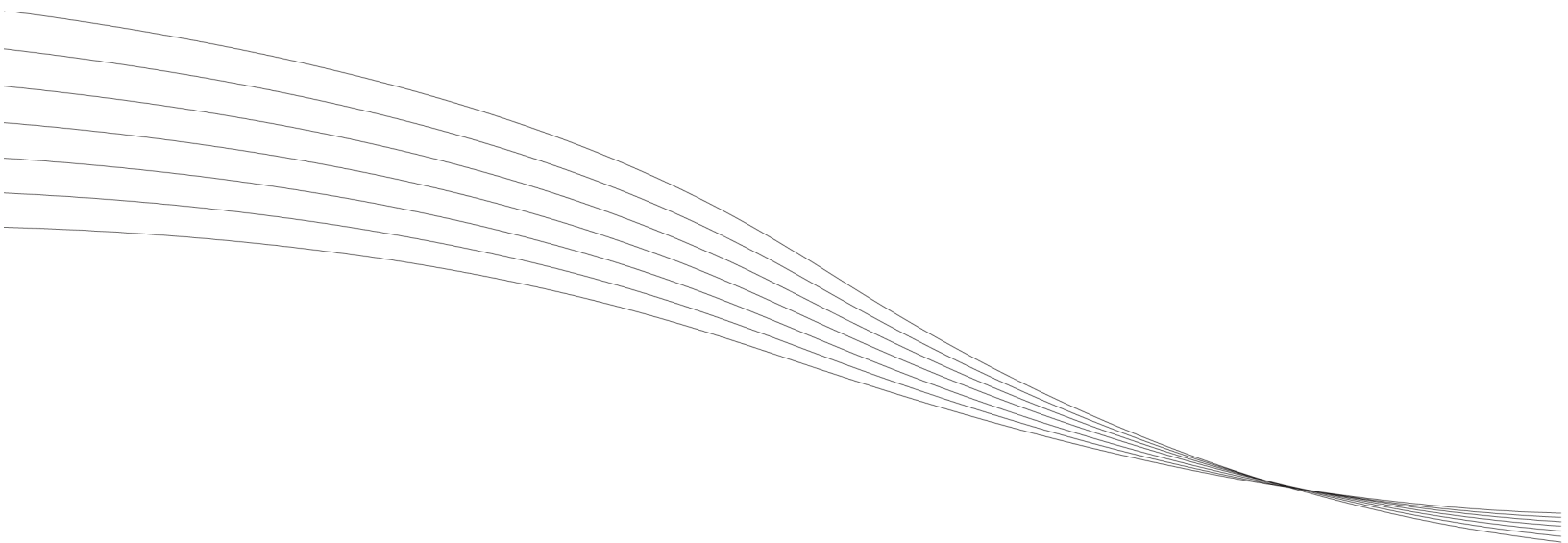
Notes

West includes British Columbia, Alberta, Saskatchewan and Manitoba.

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

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.





Appendices



Appendix A—Canadian Organ Replacement Register Board of Directors

CORR Board of Directors (October 1, 2011)

- 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, Renal Programs and Independent Health Facilities Providing Dialysis to Chronic Renal Failure Patients as Reported to CORR

Hospital/Facility	Types of Transplants Performed in 2010								Dialysis Programs in 2010			
	Kidney	Liver	Heart	Heart/ Lung	Lung	Intestine/ Multi- Visceral	Pancreas/ Kidney– Pancreas	Islet Cell	HD	Home HD Training [†]	PD	Home PD Training
Northwest Territories												
Stanton Territorial Health Authority*									X			
Hay River Health Authority*									X			
British Columbia												
Abbotsford Regional									X		X	X
B.C. Children's	X								X		X	X
Kelowna General									X	X	X	X
Nanaimo Regional									X			
Northern Independent HD Program*												
Kootenay-Boundary Regional									X	X	X	X
Penticton Regional									X		X	X
Prince George Regional									X	X	X	X
Royal Columbian									X		X	X
Royal Inland									X	X	X	X
Royal Jubilee									X	X	X	X
St. Paul's	X		X						X		X	X
Surrey Memorial									X			
Vancouver General	X	X			X		X	X	X		X	X
Alberta												
SARP, Foothills Medical	X						X		X	X	X	X
NARP, University of Alberta	X	X	X	X	X	X	X	X	X	X	X	X
Alberta Children's Hospital	X								X		X	X
Saskatchewan												
Regina General									X		X	X
St. Paul's	X								X		X	X
Manitoba												
Brandon Regional									X			
Children's Hospital of Winnipeg	X								X		X	X
Health Sciences Centre	X				X				X	X		
Seven Oaks General									X	X	X	X
St. Boniface General									X		X	X

Hospital/Facility	Types of Transplants Performed in 2010								Dialysis Programs in 2010			
	Kidney	Liver	Heart	Heart/ Lung	Lung	Intestine/ Multi- Visceral	Pancreas/ Kidney– Pancreas	Islet Cell	HD	Home HD Training [†]	PD	Home PD Training
Ontario												
Bayshore Centre Dialysis Brockville*									X			
Bayshore Centre Dialysis Stoney Creek*									X			
Brantford General*									X			
Children's Hospital of Eastern Ontario									X		X	X
Cornwall Dialysis Clinic*									X			
Credit Valley									X	X	X	X
Dialysis Management Clinics Inc.—Pickering*									X			
Dialysis Management Clinics Inc.—Markham*									X			
Dialysis Management Clinics Inc.—Peterborough*									X			
Grand River									X		X	X
Halton Healthcare Services									X			
McMaster Children's									X		X	X
Hospital for Sick Children	X	X	X			X			X	X	X	X
Niagara Health System									X	X	X	X
Hôtel-Dieu Grace									X		X	X
Humber River Regional									X	X	X	X
Kingston General	X								X	X	X	X
Lake of the Woods									X			
Lakeridge Health Corp. Whitby									X	X	X	X
LHSC—University and South Street	X	X	X			X	X		X			
LHSC—Victoria									X	X	X	X
North Bay General									X		X	
Orillia Soldiers' Memorial									X		X	X
Ottawa—Carleton Dialysis Clinic*									X			
Ottawa Hospital	X								X	X	X	X
Peterborough Regional Health									X		X	X
Renfrew Victoria									X		X	
Sault Area Hospitals— Plummer Memorial									X		X	X
Scarborough— General Division									X		X	X
Sheppard Centre*									X			
St. Joseph's (Hamilton)	X								X	X	X	X
St. Joseph's (Toronto)									X		X	X
St. Michael's	X								X	X	X	X
Sudbury Regional— Laurentian Site									X	X	X	X
Sunnybrook Health Centre									X	X	X	X
Sussex Centre*									X			
Thunder Bay Regional— McKellar Site									X		X	X

Hospital/Facility	Types of Transplants Performed in 2010								Dialysis Programs in 2010			
	Kidney	Liver	Heart	Heart/ Lung	Lung	Intestine/ Multi- Visceral	Pancreas/ Kidney– Pancreas	Islet Cell	HD	Home HD Training [†]	PD	Home PD Training
Timmins and District									X		X	X
Toronto East General									X			
Toronto General— University Health Network	X	X	X	X	X	X	X		X	X	X	X
University of Ottawa Heart Institute			X									
William Osler									X			
York Central									X		X	X
Quebec												
Aurores boréales									X		X	
Charles-LeMoine									X		X	X
CHUS—Fleurimont	X								X		X	X
C.H. de Granby									X			
C.H. de Verdun									X		X	X
Chicoutimi									X		X	
C.H. de la région de l'Amiante*									X			
CHUM—Notre-Dame	X			X	X		X		X	X	X	X
CHUM—St-Luc		X							X		X	X
C.H. régional de Trois-Rivières									X		X	X
Cité de la Santé de Laval									X	X	X	X
CHUQ—Hôtel-Dieu	X								X	X	X	X
C.H. régional de Lanaudière									X		X	
CSSS de Gatineau-Hull									X		X	X
CSSS de Rimouski-Neigette									X		X	X
CSSS de la Témiscamisque												
CSSS du Suroît									X		X	X
CSSS de la Vallée-de-l'Or									X		X	X
CSSS Haut-Richelieu-Rouville									X		X	X
CSSS de Saint-Jérôme									X		X	X
CSSS de Sorel-Tracy									X		X	X
Hôtel-Dieu de Lévis									X		X	X
Institut de cardiologie de Montréal			X									
Lakeshore									X			
Maisonnette-Rosemont	X								X	X	X	X
Montréal Children's, McGill	X								X		X	X
Montréal General, McGill									X	X	X	X
Pierre-Le Gardeur									X			
Royal Victoria, McGill	X	X	X	X			X		X		X	X
Sacré-Cœur de Montréal									X		X	X
Sainte-Croix*									X		X	
Sainte-Justine	X	X	X						X		X	X
Sir Mortimer B. Davis—Jewish General Hospital									X		X	X
St. Mary's									X		X	X

Hospital/Facility	Types of Transplants Performed in 2010								Dialysis Programs in 2010			
	Kidney	Liver	Heart	Heart/ Lung	Lung	Intestine/ Multi- Visceral	Pancreas/ Kidney– Pancreas	Islet Cell	HD	Home HD Training [†]	PD	Home PD Training
New Brunswick												
Chaleur Regional									X		X	
Edmundston									X	X	X	X
Georges L. Dumont									X	X	X	X
Saint John Regional									X	X	X	X
St. Joseph's*									X			
Nova Scotia												
Cape Breton Regional									X		X	X
IWK Grace Health	X								X		X	X
Queen Elizabeth II	X	X	X						X	X	X	X
Yarmouth Regional									X			
Newfoundland and Labrador												
Central Newfoundland Regional									X			
Eastern Health									X	X	X	X
Western Memorial Regional									X		X	

Notes

* Independent health facilities.

† Home HD training is provided at the main dialysis facility or affiliated community dialysis centres.

Appendix C—Canadian Organ Procurement Organizations

British Columbia

BC Transplant Society
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
Walter C. Mackenzie Centre
8440 112th Street
Edmonton, Alberta T6G 2B7

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 Program
Health Sciences Centre
820 Sherbrooke Street, Room GE441
Winnipeg, Manitoba R3A 1R9

Ontario

Trillium Gift of Life Network
522 University Avenue, Suite 900
Toronto, Ontario M5G 1W7
www.giftoflife.on.ca

Quebec

Transplant Québec
Head Office
4100 Molson Street, Suite 200
Montréal, Quebec H1Y 3N1
www.quebec-transplant.qc.ca

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

New Brunswick

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

Nova Scotia

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

Newfoundland and Labrador

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

Appendix D—CORR Data Quality Documentation: 2001 to 2010

The information in this appendix should be used in conjunction with the information presented in Chapter 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 Chapter 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, 2010

	B.C.	Alta.	Sask.	Man.	Ont.	Que.	N.B.	N.S.	P.E.I.	N.L.	N.W.T.	Total
Full-Care Dialysis Programs	13	3	2	5	31	32	4	4	0	3	0	97
Affiliated Community Centres	26	32	9	13	52	6	5	10	0	7	0	160
Independent Health Care Facilities Offering Hemodialysis	1	0	0	0	11	7	1	0	4	0	2	26

Table D2: Transplant Programs Within CORR Frame by Province, 2010

	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 ↓ Annual follow-up 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, renal 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.	Renal 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.	Ontario Renal Network	Trillium Gift of Life Network	Trillium Gift of Life Network	Trillium Gift of Life Network	Trillium Gift of Life Network
Que.	Renal programs	Hospital transplant programs	Transplant Québec	Hospital transplant programs	Transplant Québec
N.B.	Renal programs		New Brunswick Organ and Tissue Procurement Program		
N.S.	Renal programs	Multi-Organ Transplant Program	Multi-Organ Transplant Program	Multi-Organ Transplant Program	Multi-Organ Transplant Program
P.E.I.	P.E.I. renal program				
N.L.	Renal programs		Organ Procurement and Exchange of Newfoundland and Labrador (OPEN)		
N.W.T.	Community 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 2010, unit non-response for incident ESRD cases (under-reporting) was estimated to be 100 cases from Quebec.

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 2010, 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, 2010 (Number)

	B.C.	Alta.	Sask.	Man.	Ont.	Que.	N.S.	Total
Aggregate Counts Provided by OPOs at Year-End	191	159	3	53	562	245	85	1,298
Patient-Level Data for Transplants in CORR	191	159	2	53	559	243	85	1,292

Note

* Includes SKP and other kidney combination transplants.

3) Extra-Renal Transplants

For the extra-renal transplants in 2010, 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 little 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, 2010 (Number)

Organ Type	Data Source [†]	B.C.	Alta.	Man.	Ont.	Que.	N.S.	Total
Liver	CORR Registration	53	70	0	214	85	20	442
	OPO Count	53	70	0	214	94	20	451
Heart	CORR Registration	22	33	0	70	39	5	169
	OPO Count	22	33	0	69	39	5	168
Lung/ Heart-Lung	CORR Registration	16	41	5	84	33	0	179
	OPO Count	16	41	5	84	34	0	180
Pancreas	CORR Registration	5	13	0	32	19	4	73
	OPO Count	13	35	0	14	3	1	66
Intestine/ Multi-Visceral	CORR Registration	0	3	0	0	0	0	3
	OPO Count	0	2	0	0	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 under-reporting of donors has been observed in CORR. Overall, the number of donors collected by CORR between 2001 and 2010 was greater by 71 donors than initially reported by OPOs.

Table D7: Comparison of Deceased and Living Donors Registered in CORR and Reported by OPOs, 2001 to 2010 (Number)

Year	Registered in CORR			Reported by OPOs		
	Deceased Donors	Living Donors	Total Donors	Deceased Donors	Living Donors	Total Donors
2001	417	447	864	420	443	863
2002	405	441	846	405	440	845
2003	421	435	856	428	438	866
2004	412	475	887	387	468	855
2005	411	504	915	414	503	917
2006	461	556	1,017	468	554	1,022
2007	485	554	1,039	493	549	1,042
2008	481	546	1,027	486	542	1,028
2009	487	515	1,002	487	516	1,003
2010	465	557	1,022	468	549	1,017
Total	4,445	5,030	9,475	4,456	5,002	9,458

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 2001 to 2011, 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, 2001 to 2010											
Data Type	Data Element	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
Deceased Donor	Age	0	0	0	0	0	0	0	0	0	0
	Sex	0	0.2	0.2	0.2	0	0.2	0.2	0	0	0
	Blood Type	0	0	0	2.4	0.2	0	0.4	0.2	0.4	0.2
	Race/Ethnic Origin	24	3.5	22.1	31.6	36.7	34.7	36.3	36.6	31.6	16.3
	Province of Residence (Not Formally Collected Until 2001)	0	0	0	0	0	0	0.2	0.2	0	0
	Cause of Death	4.3	2.2	2.4	2.9	2.9	6.3	5.8	3.3	4.1	2.4
Living Donor	Age	0	0	0	0	0	0	0	0	0	0
	Sex	0.7	0.2	0	0	0	0.5	0.2	0.2	0	0
	Blood Type	0.4	6.8	7.4	12.4	9.5	4.5	0.7	1.5	1.9	1.1
	Province of Residence (Not Formally Collected Until 2001)	0	0.2	0.2	1.3	1.2	2.2	1.1	0.5	0	0.9
Transplant Recipients	Sex	0	0	0	0	0	0	0.1	0	0	0
	Race/Ethnic Origin	18.4	16.2	20.1	21.1	23.6	22.2	19.8	19.4	19.5	18.5
	Blood Type	3.9	3.2	4	3.1	3.5	3	4.3	4.7	1.9	1.4
	Residential Postal Code	1	0.7	3.2	2.5	1.7	0.9	1.9	1	0.8	0.9
	Cause of Death	25.2	24.4	23.4	20.3	23.9	21.3	29	16.9	21.6	9
	Diagnosis	1.9	0.8	5.2	2.1	3	3.5	7.4	4.4	4.2	6.1
	Medical Status at Listing (Heart, Liver, Lung Transplants)	6.9	1.9	3.4	1.6	2.9	4.5	4	4	4.8	3.9
	Medical Status at Transplant (Heart, Liver, Lung Transplants)	1.8	1	0.8	0.4	1.3	1	2.9	2.2	2.5	3.5
	Cause of Graft Failure (Transplants With Failed Grafts)	43.6	40.9	51.4	51.1	44.3	52	56.6	43.9	50.7	43.4

Note

* Recipients of first grafts for 2001 to 2010.

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 2001 to 2010. 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, 2001 to 2010												
Data Type	Data Element	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	Total
Recipients	Sex	0	0	0	0	0	0	0	0	0	0	0
	Race/Ethnic Origin	6.8	6.1	6.8	5.6	4.8	6.8	5.2	4.5	6	4.6	5.7
	Residential Postal Code	0.9	0.6	1	1	1.2	0.9	1.3	2.2	1.5	1.3	1.2
	Diagnosis	13.5	13.7	14.4	13.1	12.6	12.9	14.8	14.6	16.2	14.6	14
	Cause of Death	25.6	27.2	29.2	25	28.3	27.5	28.9	29.3	27.5	25.9	27.4
Risk Factors	Angina	7.6	6.9	9.1	9.2	9.4	11.9	11.2	13.1	15.3	14.7	10.7
	Coronary Artery Bypass/Angioplasty	7.4	7.5	9.7	9	9.5	11	10.8	12.2	13.5	13.1	10.3
	Pulmonary Edema	7.8	7.4	9.4	9.5	9.4	11.1	11.1	12.2	14.2	13.6	10.5
	Myocardial Infarct	7.1	7.1	8.9	9.3	9.1	11	10.6	12.3	14	13.1	10.2
	Diabetes	6.2	4.4	6.4	6.7	6.6	8.1	6.6	7.9	7.9	7.6	6.8
	Cerebrovascular Accident	6.9	6.9	8.3	9	8.6	10.9	10.2	12.2	13.9	12.9	9.9
	Peripheral Vascular Disease	7.9	7.6	9.4	9.6	9.3	11.4	11.1	12.8	15	14	10.7
	Malignancy	9.3	8.7	11.3	10.7	12.8	13.4	14.7	16.1	19.6	17.4	13.3
	Chronic Lung Disease	8.1	7.9	9.4	9.8	9.6	11.7	11.5	13.1	16.1	15.7	11.2
	Use of Medications for Hypertension	5.5	5	6.8	7.1	6.7	8.1	7.2	8	8.6	10.5	7.3
	Presence of Other Serious Illness	17	18.4	19.5	19.1	21.5	20.2	18.9	24.7	27.9	23.7	21
	Current Smoker	12.8	13.8	13.3	15.5	15.5	15.8	15.1	16	18.2	18.7	15.4

Table D10: Non-Response/Unknown Values for Key Analytical Data Elements Related to Incident Dialysis Patients Registered in CORR by Province, 2001 to 2010

Data Type	Data Element	B.C.	Alta.	Sask.	Man.	Ont.	Que.	N.B.	N.S.	N.L.	Total
Recipients	Sex	0	0	0	0	0	0	0.2	0	0	0
	Race/Ethnic Origin	16.9	7.4	1.4	4.4	4.1	3.2	3.9	7.3	1.4	5.7
	Residential Postal Code	1.7	1.3	0.4	1.8	0.9	1.3	2.9	1	0.7	1.2
	Diagnosis	32.4	10.8	7.2	7.9	11.5	14.8	8.2	8.3	12.5	14
	Cause of Death	52.5	38.4	18.3	30.9	21.8	24.7	9.7	21.2	11.2	27.3
Risk Factors	Angina	33.4	8.6	7.6	11.7	7.1	9.3	2.9	2.3	1.2	10.7
	Coronary Artery Bypass/Angioplasty	33.5	8.4	3	11	6.6	9.3	3.1	1.6	1.5	10.3
	Pulmonary Edema	33.6	8	5.1	10.8	6.9	9.5	2.7	1.9	2	10.5
	Myocardial Infarct	32.8	8	4.7	11.1	6.4	9.3	2.5	3.1	1.6	10.2
	Diabetes	28.9	3.9	0.9	8.2	3	5.9	1.5	0.6	0.4	6.8
	Cerebrovascular Accident	32.8	7.5	4.3	10.6	6.5	8.3	2.8	1.8	1.1	9.9
	Peripheral Vascular Disease	34.5	8.4	4.6	11.1	7.1	9.2	2.5	3	2.1	10.7
	Malignancy	38	12.6	6.7	12.5	9.4	12.2	5.1	2	3.6	13.3
	Chronic Lung Disease	36.1	9.4	5.7	11	7.6	8.9	3.4	2.8	2.2	11.2
	Use of Medications for Hypertension	29.2	3.7	1	8.5	3.8	6.5	2	0.7	0.9	7.3
	Presence of Other Serious Illness	49.2	22.2	11.7	15.1	17	18.7	19.8	8.5	6.5	21
	Current Smoker	44.4	11.9	8.3	14.3	9.4	17.8	9.4	4.8	3.3	15.4

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.

In 2010, database functionality was enhanced to allow for the electronic submission and processing of dialysis data using defined submission specifications.

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.

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

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 2001 and 2010. 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	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
B.C.*	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	4,565,500
Alta.†	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	3,797,900
Sask.	1,000,134	995,886	994,428	995,391	994,126	985,386	1,000,139	1,013,620	1,030,129	1,045,600
Man.	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	1,235,400
Ont.	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	13,210,700
Que.	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	7,907,400
Atlantic‡	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	2,346,300
Canada	31,021,251	31,372,587	31,660,466	31,946,316	32,270,507	32,623,490	32,931,956	33,327,337	33,739,859	34,108,800

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	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
N.B.	749,890	750,327	750,896	751,384	752,006	749,168	745,561	747,147	749,468	749,468
N.S./P.E.I.	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	1,079,168
N.L.	521,986	519,449	518,350	517,027	515,961	509,677	506,530	506,441	508,925	508,925
Total	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	2,346,300

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 chapters 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

Primary Diagnosis Codes—End-Stage Renal Disease	
Generic	
00	Chronic renal failure—etiology uncertain
Glomerulonephritis/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 (Moscowitz syndrome)
Nephropathy, 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

Primary Diagnosis Codes—End-Stage Renal Disease (cont'd)	
Polycystic Kidney	
41	Polycystic kidneys, adult type (dominant)
42	Polycystic kidneys, infantile and juvenile types (recessive)
Congenital/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)
Diabetes	
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 Diagnosis Codes—End-Stage Renal Disease (cont'd)	
Other (cont'd)	
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 Diagnosis—Liver Transplant	
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 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

Primary Diagnosis—Liver Transplant (cont'd)	
Chronic Hepatic Failure (cont'd)	
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)
Hepatic Tumours	
50	Angiosarcoma
17	Cholangiocarcinoma
18	Fibrolamellar hepatoma
16	Hepatocellular carcinoma
19	Metastatic tumour
53	Hepatic tumour, other
Metabolic 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	Protoporphyrria
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 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 1 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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