Canadian Organ Replacement Register Annual Report: Treatment of End-Stage Organ Failure in Canada, 2002 to 2011

Types of Care

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

Our Vision

Better data. Better decisions.
Healthier Canadians.

Our Mandate

To lead the development and maintenance of comprehensive and integrated health information that enables sound policy and effective health system management that improve health and health care.

Our Values

Respect, Integrity, Collaboration, Excellence, Innovation

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Acknowledgements

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Executive Summary

Treatment of End-Stage Organ Failure in Canada, 2002 to 2011 draws on data from the Canadian Institute for Health Information (CIHI) Canadian Organ Replacement Register (CORR), primarily for the years 2002 through 2011 (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.

Overview

- In 2011, 5,489 patients started renal replacement therapy (RRT).
- The number of patients waiting for a solid organ transplant at the end of 2011 was 4,543, a number that has been slowly increasing since 2005.
- Overall, 2,124 transplants of solid organs were performed in Canada in 2011.
- There were 1,033 organ donors (living and deceased) in 2011.

Kidney

- There were an estimated 40,385 people living with end-stage renal disease (ESRD) in Canada at the end of 2011, more than triple the number recorded in 1992. Of these, 23,423 were on dialysis and 16,962 were living with a functioning kidney transplant.
- A total of 5,489 ESRD patients initiated RRT in 2011, with just less than 80% receiving hemodialysis as their initial treatment. In 1992, 2,719 initiated RRT.
- At the end of 2011, there were 3,406 patients waiting for a kidney transplant, an increase of 23% since 2005.
- Of 1,247 kidney recipients during 2011, 194 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 2011, followed by renal vascular disease (16%).
- 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 2011, compared with 38% in 1992. However, incidence rates have remained stable during the last 10 years and may be starting to decline.

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

- The proportion of incident dialysis patients that were considered late referrals[ii] is declining. In 2011, 30% of patients first saw a nephrologist less than three months before starting dialysis, compared with 41% in 2002.
- The average age of incident hemodialysis patients was 65.2 in 2011; more than half of these patients reported having diabetes.

Liver

- At the end of 2011, 489 patients were waiting for a transplant, a number that has declined from its peak of 723 in 2006.
- There were 485 liver transplants performed in Canada in 2011.
- During the 10-year period from 2002 to 2011, 4,419 liver transplants were performed.

Heart

- There were 166 Canadians awaiting a heart transplant, with 25 deaths on the waiting list during 2011.
- In 2011, 152 heart transplants were performed in Canada.
- Over the decade, the annual number of transplants performed fluctuated between 143 and 178, averaging 163 transplants per year.
- Overall, 1,632 Canadians received a heart transplant between 2002 and 2011.

Lung

- In 2011, there were 311 Canadians, compared with 150 in 2002, waiting to receive a lung transplant.
- In 2011, 175 lung transplants were performed, a 26% increase over the 139 that were performed in 2002.
- Bilateral lung transplants accounted for 91% of the lung transplants performed in 2011.
- Bilateral procedures were most commonly performed on recipients with cystic fibrosis (27%). Conversely, the most frequent diagnosis for a single-lung transplant recipient was emphysema (43%).

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

- Simultaneous kidney–pancreas transplants accounted for 53 of the 72 pancreatic transplants performed in 2011.
- There were 711 pancreatic transplants performed in Canada between 2002 and 2011.
- Of these, 70% were simultaneous kidney–pancreas transplants.
- The number of Canadians awaiting a simultaneous kidney–pancreas transplant in 2011 was 108.

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 1992 and 2011, there were 54 such procedures performed in Canada, with more than half (57%) 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, 2012, 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. In 2011, CORR also began receiving dialysis data through electronic submissions using a recently implemented standard file format. The Ontario Renal Network was the first organization to submit data electronically using the new standard. Currently, all data is processed 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.

Annual 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.

Note: In 2011, the number of incident dialysis patients reported by Quebec was lower than in previous years due to suspected under-reporting involving six to eight centres. As a result, 2011 national data and trends for dialysis should be interpreted with care. This affects the incidence data and, to a lesser extent, the prevalence data.

There are no known additional 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%

The same study found the agreement rate between the study coder and the CORR data on the primary renal disease code to be 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.

While completeness of key data elements has improved over time, the proportion of unknown values reported continues to exceed 10%. In 2011, primary diagnosis was missing or unknown in 11% of incident dialysis patients; 25% of dialysis patients and 19% of transplant recipients were missing cause of death; and cause of graft failure was missing or unknown in more than 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.

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

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.

CORR is a longitudinal database that monitors patient treatment changes over time. It is therefore 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: 2002 to 2011, for further detail regarding the completeness and coverage of reporting in CORR.

1.3 Organization of the Report

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

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

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

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

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

The CORR data quality documentation for the years 2002 to 2011 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 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 5,489 newly diagnosed patients with ESRD reported to CORR in 2011, double the number reported in 1992 (Table 1).

The highest RPMP of newly diagnosed ESRD continued to be 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 1992 until 2001, the rate of incidence among patients age 75 and older doubled. Between 2001 and 2005, incidence rates remained relatively constant. Since 2005, rates among older age groups have slowly declined. Incidence rates among those age 45 to 64 increased from 175.0 in 1992 to a peak of 217.3 in 2000. 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 2011, 53% of incident patients were age 65 or older, and an additional 34% were age 45 to 64.

Provincially in 2011, the highest incidence RPMP occurred in Newfoundland and Labrador (276.2) and Manitoba (201.5) (Table 2).

At the end of 2011, slightly less than 80% of all new patients initiated treatment on hemodialysis (HD),[iv] a level that has remained virtually unchanged since 2002 (Table 3). While HD was consistently utilized as the primary modality of treatment, 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 111 in 2002 to 194 in 2011.

Age of incidence also influences the initial treatment (Table 4). In 2011, 69% of incidence patients age 20 to 44 started with hemodialysis, while among those age 65 and older, the proportion was 86%. Pre-emptive transplant as an initial treatment was highest among younger age groups and declined with patient age.

When dialysis was used to treat incident patients in 2011, all provinces used HD the majority of the time, with Newfoundland and Labrador having the highest proportion of HD (93%), followed by New Brunswick (87%). The highest proportion of patients treated by continuous ambulatory peritoneal dialysis (CAPD) was seen in Manitoba (21%) (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 starts dialysis less than 90 days after first seeing a nephrologist is considered a late referral patient. This characteristic is considered a measure of how well the early stages of kidney disease are being managed. An earlier referral allows for better management of the disease and may influence patient survival. In 2011, 30% of incident patients were late referrals, down from 41% in 2002 (Table 7). This improvement can be seen in all provinces. Table 8 presents late referral status by primary diagnosis. In 2002, 32% of patients with a primary diagnosis of diabetes were late referrals, while in 2011, only 19% were considered late referrals.

Table 9 presents selected characteristics of HD and PD patients. In 2011, the average age of incident HD patients was 65.2, and the average age of PD patients was 61.0. Patients 65 or older accounted for 58% of incident HD patients, while males accounted for 62%.

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. In general, this form of dialysis is 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 1: Incident End-Stage Renal Disease Patients by Age Group, Canada, 1992 to 2011 (Number, Rate per Million Population, Percentage of Total)

	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
1992	88	11.3	3.2	603	51.7	22.2	983	175.0	36.2	701	356.7	25.8	344	258.6	12.7	**2,719**	**95.9**
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	676	57.8	14.2	1,558	217.3	32.8	1,296	603.9	27.3	1,123	658.0	23.6	**4,756**	**155.0**
2001	104	13.0	2.1	605	51.6	12.1	1,585	213.9	31.6	1,358	628.4	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	1,445	749.4	27.6	**5,229**	**163.7**
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	639	54.2	11.8	1,797	206.2	33.1	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	1,414	606.3	25.5	1,563	743.8	28.2	**5,542**	**168.3**
2008	80	10.2	1.5	634	54.3	11.5	1,863	201.7	33.7	1,392	579.3	25.2	1,562	725.2	28.2	**5,531**	**166.0**
2009	81	10.3	1.4	591	50.4	10.4	1,953	206.2	34.4	1,420	570.8	25.0	1,633	742.4	28.8	**5,678**	**168.3**
2010	73	9.3	1.3	622	52.8	10.8	2,007	207.6	34.9	1,424	553.0	24.7	1,631	724.8	28.3	**5,757**	**168.7**
2011	59	7.5	1.1	628	53.0	11.4	1,883	191.9	34.3	1,385	517.4	25.2	1,534	668.0	28.0	**5,489**	**159.2**

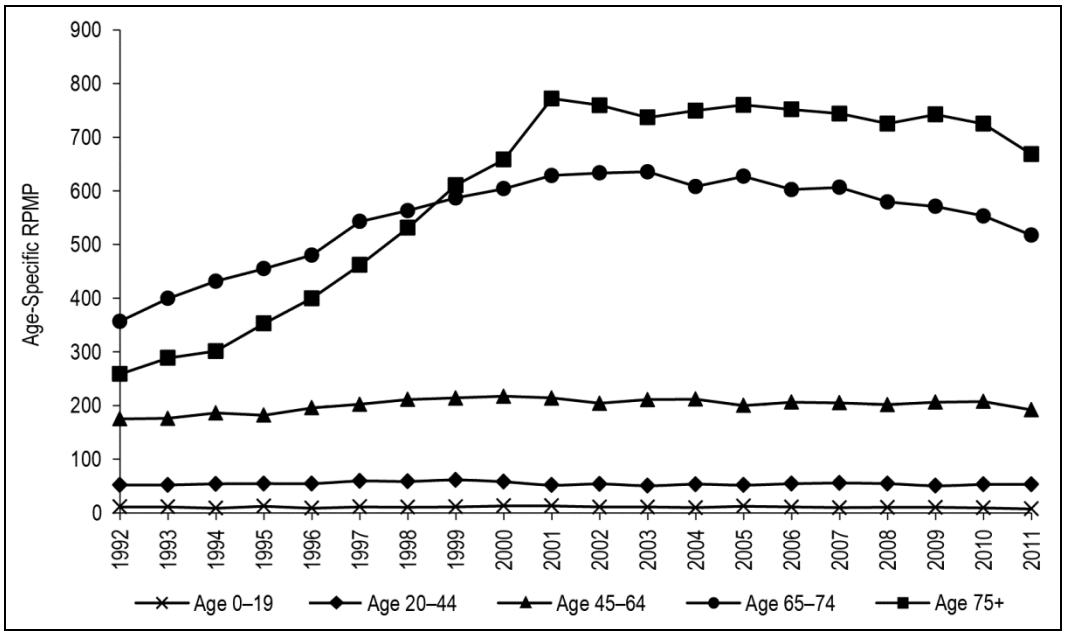
Note

In 2011, under-reporting of incident ESRD cases was estimated to be approximately 300 cases.

Sources

Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information; Statistics Canada.

Figure 1: Incident End-Stage Renal Disease Patients, Age-Specific Rate per Million Population, Canada, 1992 to 2011



Note

In 2011, under-reporting of incident ESRD cases was estimated to be approximately 300 cases. For additional information, see Appendix D.

Sources

Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information; Statistics Canada.

Table 2: Incident End-Stage Renal Disease Patients by Province, Canada, 2002 to 2011 (Number, Rate per Million Population)

		2002	2003	2004	2005	2006	2007	2008	2009	2010	2011
B.C./Y.T.	N	652	623	669	636	701	717	697	771	751	773
	RPMP	157.3	148.9	158.2	148.4	161.5	165.1	157.8	171.8	164.5	167.8
Alta./ N.W.T./ Nun.	N	495	558	465	531	483	529	482	530	512	497
	RPMP	155.3	172.8	142.0	159.5	140.1	147.4	131.3	140.8	134.8	128.9
Sask.	N	166	182	192	171	186	199	177	200	158	174
	RPMP	166.7	183.0	192.9	172.0	188.8	199.0	174.6	194.2	151.3	164.5
Man.	N	245	239	230	236	298	251	286	288	302	252
	RPMP	212.0	205.8	196.5	200.4	253.0	210.2	237.1	235.7	244.6	201.5
Ont.	N	2,092	2,102	2,219	2,275	2,316	2,376	2,312	2,379	2,520	2,548
	RPMP	172.9	171.5	179.1	181.4	182.5	185.7	178.7	182.0	190.5	190.5
Que.	N	1,009	1,006	1,021	1,050	1,053	1,067	1,101	1,067	1,050	815
	RPMP	135.5	134.3	135.4	138.2	137.6	138.8	142.0	136.3	132.8	102.1
N.B.	N	128	144	161	123	140	112	147	130	134	119
	RPMP	170.6	191.8	214.3	163.6	186.9	150.2	196.7	173.5	178.0	157.5
N.S./ P.E.I.	N	152	176	157	186	165	203	222	187	200	170
	RPMP	141.9	164.0	146.1	172.9	153.8	189.0	206.3	173.3	183.8	155.8
N.L.	N	104	99	115	94	82	88	107	126	130	141
	RPMP	200.2	191.0	222.4	182.2	160.9	173.7	211.3	247.6	254.3	276.2
Canada	**N**	**5,043**	**5,129**	**5,229**	**5,302**	**5,424**	**5,542**	**5,531**	**5,678**	**5,757**	**5,489**
	RPMP	**160.7**	**162.0**	**163.7**	**164.3**	**166.3**	**168.3**	**166.0**	**168.3**	**168.7**	**159.2**

Note

In 2011, under-reporting of incident ESRD cases was estimated to be approximately 300 cases. For additional information, see Appendix D.

Sources

Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information; Statistics Canada.

Table 3: Incident End-Stage Renal Disease Patients by Initial Treatment, Canada, 2002 to 2011 (Number, Rate per Million Population, Percentage of Total)

Initial Treatment		2002	2003	2004	2005	2006	2007	2008	2009	2010	2011
HD Home	N	6	7	9	3	19	17	25	26	21	24
	RPMP	0.2	0.2	0.3	0.1	0.6	0.5	0.8	0.8	0.6	0.7
	%	0.1	0.1	0.2	0.1	0.4	0.3	0.5	0.5	0.4	0.4
HD Institutional	N	4,017	4,117	4,105	4,158	4,310	4,389	4,337	4,431	4,564	4,361
	RPMP	128.0	130.0	128.5	128.8	132.1	133.3	130.1	131.3	133.7	126.5
	%	79.7	80.3	78.5	78.4	79.5	79.2	78.4	78.0	79.3	79.5
CAPD	N	600	644	732	708	661	686	704	778	685	674
	RPMP	19.1	20.3	22.9	21.9	20.3	20.8	21.1	23.1	20.1	19.5
	%	11.9	12.6	14.0	13.4	12.2	12.4	12.7	13.7	11.9	12.3
APD	N	309	242	253	272	271	272	297	260	297	236
	RPMP	9.8	7.6	7.9	8.4	8.3	8.3	8.9	7.7	8.7	6.8
	%	6.1	4.7	4.8	5.1	5.0	4.9	5.4	4.6	5.2	4.3
Pre-Emptive	N	111	119	130	161	163	178	168	183	190	194
	RPMP	3.5	3.8	4.1	5.0	5.0	5.4	5.0	5.4	5.6	5.6
	%	2.2	2.3	2.5	3.0	3.0	3.2	3.0	3.2	3.3	3.5
Total	**N**	**5,043**	**5,129**	**5,229**	**5,302**	**5,424**	**5,542**	**5,531**	**5,678**	**5,757**	**5,489**
	RPMP	**160.7**	**162.0**	**163.7**	**164.3**	**166.3**	**168.3**	**166.0**	**168.3**	**168.7**	**159.2**

Notes

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

In 2011, under-reporting of incident ESRD cases was estimated to be approximately 300 cases. For additional information, see Appendix D.

Sources

Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information; Statistics Canada.

Table 4: Incident End-Stage Renal Disease Patients by Year, Age Group and Initial Treatment Modality, Canada, 2002 to 2011 (Number)

Age Group	Initial Modality	2002 N = 5,043	2003 N = 5,129	2004 N = 5,229	2005 N = 5,302	2006 N = 5,424	2007 N = 5,542	2008 N = 5,531	2009 N = 5,678	2010 N = 5,757	2011 N = 5,489
0–19	HD	36	39	34	45	59	39	35	51	39	25
	PD	28	32	29	33	15	16	33	21	18	14
	Pre-Emptive	22	16	12	20	11	20	12	9	16	20
20–44	HD	440	428	417	432	443	443	433	409	431	433
	PD	147	124	155	134	145	134	146	121	136	137
	Pre-Emptive	45	42	55	41	51	70	55	61	55	58
45–64	HD	1,200	1,275	1,295	1,231	1,344	1,392	1,388	1,428	1,521	1,416
	PD	326	344	392	367	368	376	389	430	381	369
	Pre-Emptive	41	55	50	91	85	75	86	95	105	98
65–74	HD	1,142	1,158	1,121	1,143	1,124	1,172	1,129	1,151	1,177	1,165
	PD	232	228	212	250	231	230	248	251	233	203
	Pre-Emptive	3	6	12	9	14	12	15	18	14	17
75+	HD	1,205	1,224	1,247	1,310	1,359	1,360	1,377	1,418	1,417	1,346
	PD	176	158	197	196	173	202	185	215	214	187
	Pre-Emptive	0	0	1	0	2	1	0	0	0	1
Total	**HD**	**4,023**	**4,124**	**4,114**	**4,161**	**4,329**	**4,406**	**4,362**	**4,457**	**4,585**	**4,385**
	PD	**909**	**886**	**985**	**980**	**932**	**958**	**1,001**	**1,038**	**982**	**910**
	Pre-Emptive	**111**	**119**	**130**	**161**	**163**	**178**	**168**	**183**	**190**	**194**

Notes

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

In 2011, under-reporting of incident ESRD cases was estimated to be approximately 300 cases. For additional information, see Appendix D.

Source

Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information.

Table 5: Incident Patients by Initial Treatment and Province of Treatment, Canada, 2011 (Number, Percentage of Total)

Initial Treatment		Province of Treatment*									
		B.C.	Alta.	Sask.	Man.	Ont.	Que.	N.B.	N.S.	N.L.	**Canada**
HD	N	557	396	137	191	2,075	660	102	138	129	**4,385**
	%	72.2	79.0	80.6	76.1	81.4	80.9	87.2	79.8	92.8	**80.0**
CAPD	N	131	84	30	52	240	93	14	20	10	**674**
	%	17.0	16.8	17.6	20.7	9.4	11.4	12.0	11.6	7.2	**12.0**
APD	N	48	4	3	3	168	5	1	4	0	**236**
	%	6.2	0.8	1.8	1.2	6.6	0.6	0.9	2.3	0.0	**4.0**
Pre-Emptive	N	36	17	0	5	67	58	0	11	0	**194**
	%	4.7	3.4	0.0	2.0	2.6	7.1	0.0	6.4	0.0	**4.0**
Total	**N**	**772**	**501**	**170**	**251**	**2,550**	**816**	**117**	**173**	**139**	**5,489**

Notes

* 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.

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

In 2011, under-reporting of incident ESRD cases was estimated to be approximately 300 cases. For additional information, see Appendix D.

Source

Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information.

Table 6: Incident End-Stage Renal Disease Patients by Primary Diagnosis, Canada, 2002 to 2011 (Number, Rate per Million Population)

Diagnosis		2002	2003	2004	2005	2006	2007	2008	2009	2010	2011
Glomerulonephritis	N	638	657	683	595	619	619	585	619	619	599
	RPMP	20.3	20.8	21.4	18.4	19.0	18.8	17.6	18.4	18.1	17.4
Diabetes	N	1,708	1,758	1,799	1,847	1,857	1,926	1,919	1,909	2,018	1,943
	RPMP	54.4	55.5	56.3	57.2	56.9	58.5	57.6	56.6	59.1	56.4
Renal Vascular Disease	N	922	952	960	1,024	1,062	995	1,006	1,058	1,042	903
	RPMP	29.4	30.1	30.1	31.7	32.6	30.2	30.2	31.4	30.5	26.2
Polycystic Kidney Disease	N	202	215	222	268	258	233	218	204	234	218
	RPMP	6.4	6.8	7.0	8.3	7.9	7.1	6.5	6.1	6.9	6.3
Drug Induced	N	103	101	95	103	93	124	108	114	118	100
	RPMP	3.3	3.2	3.0	3.2	2.9	3.8	3.2	3.4	3.5	2.9
Pyelonephritis	N	215	216	231	197	190	215	195	193	184	227
	RPMP	6.9	6.8	7.2	6.1	5.8	6.5	5.9	5.7	5.4	6.6
Other*	N	508	493	525	583	626	573	664	651	725	802
	RPMP	16.2	15.6	16.4	18.1	19.2	17.4	19.9	19.3	21.2	23.3
Unknown	N	747	737	714	685	719	857	836	930	817	697
	RPMP	23.8	23.3	22.4	21.2	22.0	26.0	25.1	27.6	23.9	20.2

Notes

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

In 2011, under-reporting of incident ESRD cases was estimated to be approximately 300 cases. For additional information, see Appendix D.

Sources

Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information; Statistics Canada.

Table 7: Incident End-Stage Renal Disease Patients by Late Referral Status,* by Province and Canada, 2002 to 2011 (Percentage)

Province	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011
B.C./Y.T.	43.3	35.1	34.7	31.2	29.8	31.0	32.9	34.2	30.1	34.1
Alta./N.W.T./Nun.	36.1	38.2	40.3	34.1	39.0	30.8	33.0	31.2	33.3	27.4
Sask.	44.5	42.9	36.6	34.5	40.9	28.5	29.6	28.5	31.2	31.5
Man.	43.7	36.2	38.4	33.7	33.6	32.2	25.6	30.1	29.0	27.2
Ont.	40.5	38.5	35.9	36.1	33.6	31.9	32.3	31.9	30.2	30.0
Que.	41.5	36.6	38.3	33.3	33.1	32.8	29.3	28.4	32.0	29.1
N.B.	42.4	40.3	32.7	37.5	39.1	38.5	32.3	34.4	34.9	32.4
N.S./P.E.I.	35.1	32.7	30.6	31.4	25.2	26.9	26.3	26.3	23.0	19.8
N.L.	40.0	31.5	36.1	30.2	22.7	25.0	30.8	26.8	26.2	27.5
Canada	**40.8**	**37.4**	**36.5**	**34.3**	**33.5**	**31.6**	**31.2**	**31.1**	**30.5**	**29.8**

Note

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

Source

Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information.

Table 8: Incident End-Stage Renal Disease Patients by Primary Diagnosis and Late Referral Status,* Canada, 2002 to 2011 (Percentage)

Diagnosis	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011
Glomerulonephritis	33.8	32.3	32.8	30.9	30.3	28	23.9	26.6	25	29
Diabetes	32.4	30.7	27.6	25.9	25.5	23.3	21.9	22.7	22.0	19.4
Renal Vascular Disease	44.4	41.2	37.2	32.1	33.2	29.1	26.5	25.5	23.5	24.5
Polycystic Kidney Disease	20.0	14.2	15.3	11.0	9.4	8.7	8.6	8.8	11.2	8.6
Drug Induced	42.4	40.7	42.7	25.0	33.7	36.8	29.7	24.8	25.2	32.6
Pyelonephritis	37.6	32.6	40.1	36.0	30.2	31.1	38.4	35.1	37.8	36.4
Other†	61.8	54.9	58.8	59.4	56.5	54.7	57.3	55.3	55.5	52.1
Unknown	54.4	50.3	50.3	53.7	47.7	47.3	48.5	48.2	49.6	46.2
All Incident Patients	**40.8**	**37.4**	**36.5**	**34.4**	**33.5**	**31.6**	**31.2**	**31.1**	**30.5**	**29.8**

Notes

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

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

Source

Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information.

Table 9: Adult Incident Dialysis Patients, Selected Characteristics, Canada, 2002 to 2011

		2002	2003	2004	2005	2006	2007	2008	2009	2010	2011
HD	Mean Age (Years)	64.8	65.0	65.0	65.3	65.1	65.0	65.3	65.4	65.3	65.2
	Age 65+ (%)	58.8	58.2	57.9	59.4	57.9	57.8	57.8	58.1	56.9	57.5
	Male (%)	57.8	60.3	59.6	60.2	59.6	61.9	61.0	59.8	61.1	62.2
	Diabetes (%)	44.3	44.5	45.0	46.0	47.2	49.0	48.5	49.8	50.9	53.6
	Mean Comorbidity Index*	2.1	2.1	2.0	2.0	2.0	2.0	2.1	2.1	2.0	2.2
	Mean BMI	26.8	27.0	27.4	27.5	27.7	27.6	28.2	28.2	28.3	28.3
	Mean eGFR†	9.4	9.8	9.7	10.1	10.2	10.2	10.4	10.6	10.7	10.5
	Late Referral (%)‡	44.8	41.7	41.3	39.6	37.8	36.0	35.7	35.9	35.1	33.9
	Access Type (%)										
	Catheter	70.4	70.6	73.2	73.4	74.5	76.3	79.0	79.7	77.4	81.1
	AV Fistula	19.0	17.9	17.5	19.1	18.6	18.3	15.9	15.7	16.8	15.7
	AV Graft	2.5	2.3	2.1	1.5	1.6	1.5	1.5	1.2	1.2	0.8
	Unknown	8.1	9.2	7.2	6.0	5.3	3.9	3.7	3.4	4.6	2.5
PD	Mean Age (Years)	60.4	60.5	60.3	61.3	60.6	61.1	60.8	61.9	61.7	61.0
	Age 65+ (%)	46.2	45.0	42.6	46.9	44.0	45.7	44.6	45.7	46.1	43.4
	Male (%)	55.4	59.8	56.8	60.2	55.0	58.4	57.5	57.5	59.4	60.4
	Diabetes (%)	41.4	41.7	43.4	45.1	43.1	43.4	42.7	44.5	47.0	45.5
	Mean Comorbidity Index*	1.4	1.5	1.3	1.4	1.2	1.3	1.1	1.1	1.3	1.2
	Mean BMI	26.0	26.4	26.5	26.8	27.2	27.1	27.5	28.0	27.5	27.3
	Mean eGFR†	10.0	9.8	9.9	10.1	10.0	10.5	10.7	10.7	10.9	10.1
	Late Referral (%)‡	23.5	16.2	15.8	11.4	12.2	11.3	10.4	10.2	8.6	9.3

Notes

* 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.

† Estimated glomerular filtration rate as determined by the Modification of Diet in Renal Disease (MDRD) formula (mL/min/1.73 m^2).

‡ Patients who first see a nephrologist less than 90 days before starting dialysis.

HD: hemodialysis; PD: peritoneal dialysis; BMI: body mass index; catheter: central venous catheter; AV fistula: arteriovenous fistula; AV graft: arteriovenous graft.

Source

Canadian Organ Replacement Register, 2012, 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, 2011, there were 40,385 people in Canada being treated for ESRD, with 58% (23,423) on dialysis and 42% (16,962) living with a functioning kidney transplant (Table 10). Since 1992, the prevalence rate for patients being treated by dialysis has increased nearly 160%, from 261.7 RPMP to 679.3 RPMP (Figure 2). During the same period, the prevalence rate of patients with kidney transplants more than doubled, from 209.0 RPMP to 491.9 RPMP.

Table 11 provides prevalence rates by age. Over the 20-year period, prevalence rates increased in all age groups. In 2011, the age distribution of prevalent patients was similar in all provinces and territories (Table 12).

Prevalence rates in 2011 were highest in Newfoundland and Labrador and Manitoba (1,578.6 and 1,516.9 RPMP, Table 13).

HD provided in an institutional setting was the most common form of RRT across the country (46%), followed by transplant (42%) (Table 14).

In 2011, 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 (55%, 49% and 45%, respectively) (Table 15). Transplant as a treatment was lowest in Manitoba (33%).

Tables 16 and 17 examine prevalence rates by primary diagnosis. Between 2002 and 2011, the prevalence rate of patients with diabetes as a primary diagnosis increased by 46%. In 2011, diabetic nephropathy accounted for the largest proportion of all prevalent patients (26%), followed by patients with glomerulonephritis (22%).

Among prevalent patients in 2011 with a primary diagnosis of diabetes, 63% were being treated with HD and 26% had transplants (Table 18). Overall, patients with diabetic nephropathy accounted for 35% 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.

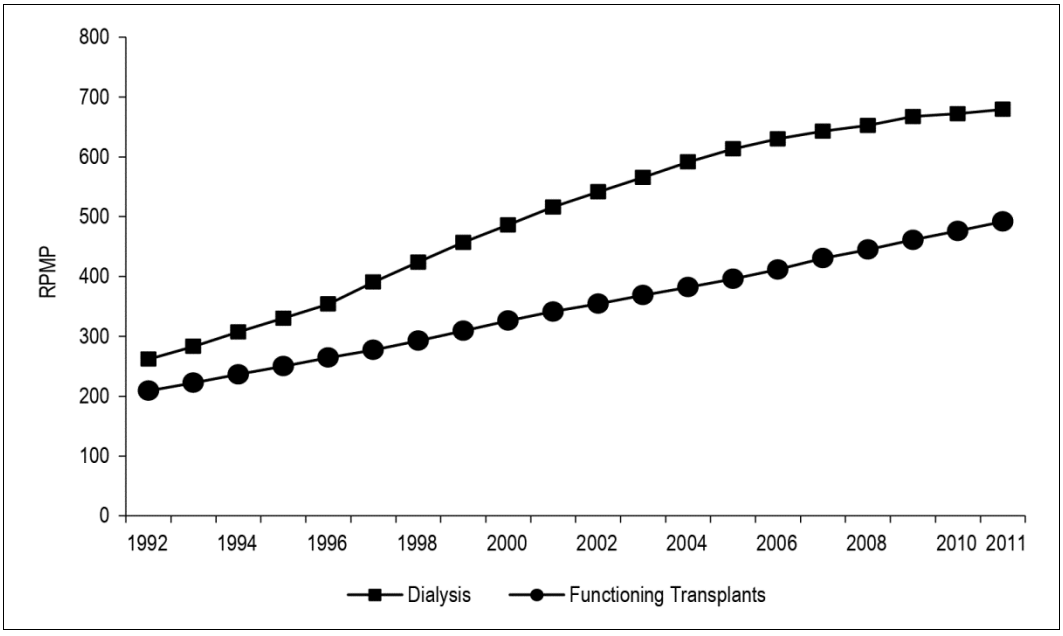
Table 19 summarizes changes in prevalence by examining flows into and out of treatment.

Table 10: Prevalence Rate for Patients on Dialysis or With a Functioning Transplant in Canada, 1992 to 2011 (Rate per Million Population, Percentage of Total)

	Dialysis			Functioning Transplants			Total	
	Number	RPMP	%	Number	RPMP	%	Number	RPMP
1992	7,424	261.7	55.6	5,928	209.0	44.4	**13,352**	**470.7**
1993	8,123	283.2	56.0	6,377	222.3	44.0	**14,500**	**505.5**
1994	8,912	307.3	56.5	6,862	236.6	43.5	**15,774**	**543.9**
1995	9,674	330.1	56.9	7,326	250.0	43.1	**17,000**	**580.2**
1996	10,482	354.0	57.2	7,828	264.4	42.8	**18,310**	**618.4**
1997	11,682	390.6	58.5	8,292	277.3	41.5	**19,974**	**667.9**
1998	12,786	424.0	59.2	8,828	292.7	40.8	**21,614**	**716.7**
1999	13,896	457.0	59.6	9,404	309.3	40.4	**23,300**	**766.3**
2000	14,921	486.2	59.8	10,011	326.2	40.2	**24,932**	**812.4**
2001	16,011	516.1	60.2	10,594	341.5	39.8	**26,605**	**857.6**
2002	16,982	541.3	60.4	11,123	354.5	39.6	**28,105**	**895.8**
2003	17,905	565.5	60.5	11,681	368.9	39.5	**29,586**	**934.5**
2004	18,890	591.3	60.7	12,209	382.2	39.3	**31,099**	**973.5**
2005	19,788	613.2	60.8	12,783	396.1	39.2	**32,571**	**1,009.3**
2006	20,548	629.9	60.5	13,432	411.7	39.5	**33,980**	**1,041.6**
2007	21,172	642.9	59.9	14,181	430.6	40.1	**35,353**	**1,073.5**
2008	21,742	652.4	59.5	14,829	445.0	40.5	**36,571**	**1,097.3**
2009	22,515	667.3	59.1	15,560	461.2	40.9	**38,075**	**1,128.5**
2010	22,936	672.1	58.5	16,244	476.0	41.5	**39,180**	**1,148.1**
2011	23,423	679.3	58.0	16,962	491.9	42.0	**40,385**	**1,171.2**

Sources
Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information; Statistics Canada.

Figure 2: Prevalence Rate for Patients on Dialysis or With a Functioning Transplant in Canada, 1992 to 2011 (Rate per Million Population)



Sources
Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information; Statistics Canada.

Table 11: Prevalent End-Stage Renal Disease Patients by Age Group, Canada, 1992 to 2011 (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
1992	474	60.8	4,611	395.5	5,074	903.3	2,244	1,141.9	949	713.3	**13,352**	**470.7**
1993	483	61.5	4,816	412.8	5,568	961.5	2,541	1,265.4	1,092	801.9	**14,500**	**505.5**
1994	475	60.0	5,084	435.4	6,048	1,013.1	2,898	1,417.7	1,269	910.3	**15,774**	**543.9**
1995	491	61.7	5,264	450.1	6,498	1,057.7	3,240	1,566.4	1,507	1,045.9	**17,000**	**580.2**
1996	486	60.8	5,419	462.5	7,119	1,126.5	3,514	1,682.5	1,772	1,188.9	**18,310**	**618.4**
1997	499	62.3	5,646	481.0	7,791	1,197.1	3,897	1,847.9	2,141	1,385.0	**19,974**	**667.9**
1998	523	65.3	5,860	500.4	8,441	1,257.9	4,250	1,998.2	2,540	1,590.1	**21,614**	**716.7**
1999	536	67.1	6,023	515.2	9,155	1,320.5	4,594	2,151.3	2,992	1,812.1	**23,300**	**766.3**
2000	560	70.2	6,141	525.4	9,874	1,377.4	4,941	2,302.2	3,416	2,001.5	**24,932**	**812.4**
2001	566	71.0	6,215	530.5	10,540	1,422.2	5,311	2,457.6	3,973	2,254.8	**26,605**	**857.6**
2002	565	71.0	6,294	535.6	11,123	1,449.2	5,600	2,574.8	4,523	2,487.6	**28,105**	**895.8**
2003	566	71.6	6,325	538.1	11,776	1,483.9	5,971	2,726.0	4,948	2,637.8	**29,586**	**934.5**
2004	555	70.7	6,326	538.0	12,502	1,526.0	6,277	2,836.5	5,439	2,820.9	**31,099**	**973.5**
2005	562	71.8	6,358	540.0	13,106	1,551.5	6,607	2,954.6	5,938	2,996.5	**32,571**	**1,009.3**
2006	558	71.4	6,394	542.7	13,783	1,581.9	6,875	3,024.5	6,370	3,120.8	**33,980**	**1,041.6**
2007	555	70.6	6,356	545.5	14,406	1,602.6	7,308	3,133.7	6,728	3,201.8	**35,353**	**1,073.5**
2008	547	69.5	6,379	546.7	15,021	1,626.3	7,559	3,145.6	7,065	3,280.2	**36,571**	**1,097.3**
2009	551	70.1	6,326	539.8	15,679	1,655.7	8,034	3,229.2	7,485	3,403.0	**38,075**	**1,128.5**
2010	540	68.8	6,310	535.7	16,239	1,679.4	8,381	3,254.7	7,710	3,426.2	**39,180**	**1,148.1**
2011	503	64.1	6,322	533.2	16,645	1,696.5	8,852	3,306.6	8,063	3,511.2	**40,385**	**1,171.2**

Sources

Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information; Statistics Canada.

Table 12: Prevalent End-Stage Renal Disease Patients by Age and Province, Canada, 2011 (Number, Percentage)

Province		Age 0–19	Age 20–44	Age 45–64	Age 65–74	Age 75+	Total
B.C./Y.T.	N	70	817	2,174	1,153	1,082	**5,296**
	%	1.3	15.4	41.0	21.8	20.4	**100.0**
Alta./N.W.T./ Nun.	N	73	785	1,741	801	605	**4,005**
	%	1.8	19.6	43.5	20.0	15.1	**100.0**
Sask.	N	4	248	553	232	205	**1,242**
	%	0.3	20.0	44.5	18.7	16.5	**100.0**
Man.	N	44	370	865	377	241	**1,897**
	%	2.3	19.5	45.6	19.9	12.7	**100.0**
Ont.	N	187	2,419	6,735	3,660	3,560	**16,561**
	%	1.1	14.6	40.7	22.1	21.5	**100.0**
Que.	N	89	1,174	3,140	1,922	1,788	**8,113**
	%	1.1	14.5	38.7	23.7	22.0	**100.0**
N.B.	N	3	131	396	218	185	**933**
	%	0.3	14.0	42.4	23.4	19.8	**100.0**
N.S./P.E.I.	N	31	253	683	317	248	**1,532**
	%	2.0	16.5	44.6	20.7	16.2	**100.0**
N.L.	N	2	125	358	172	149	**806**
	%	0.2	15.5	44.4	21.3	18.5	**100.0**
Canada	**N**	**503**	**6,322**	**16,645**	**8,852**	**8,063**	**40,385**
	%	**1.2**	**15.7**	**41.2**	**21.9**	**20.0**	**100.0**

Sources
Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information; Statistics Canada.

Table 13: Prevalent End-Stage Renal Disease Patients by Province, Canada, 2002 to 2011 (Number, Rate per Million Population)

Province		2002	2003	2004	2005	2006	2007	2008	2009	2010	2011
B.C./Y.T.	N	3,549	3,764	4,032	4,199	4,403	4,580	4,719	4,965	5,123	5,296
	RPMP	856.1	899.9	953.7	979.8	1,014.1	1,054.8	1,068.4	1,106.1	1,122.4	1,149.3
Alta./N.W.T./ Nun.	N	2,745	2,967	3,105	3,268	3,380	3,509	3,589	3,741	3,901	4,005
	RPMP	861.4	918.6	948.3	981.4	980.2	978.0	977.6	994.1	1,027.2	1,038.5
Sask.	N	895	951	978	1,014	1,056	1,117	1,138	1,203	1,193	1,242
	RPMP	898.7	956.3	982.5	1,020.0	1,071.7	1,116.8	1,122.7	1,167.8	1,142.7	1,174.0
Man.	N	1,315	1,351	1,388	1,446	1,523	1,574	1,647	1,750	1,850	1,897
	RPMP	1,138.0	1,163.1	1,186.1	1,228.0	1,293.1	1,318.3	1,365.6	1,432.1	1,498.5	1,516.9
Ont.	N	11,234	11,837	12,461	13,171	13,773	14,334	14,861	15,440	15,972	16,561
	RPMP	928.3	965.8	1,005.5	1,050.2	1,085.6	1,120.3	1,148.8	1,181.4	1,207.5	1,238.4
Que.	N	5,917	6,176	6,510	6,778	7,093	7,409	7,681	7,939	8,007	8,113
	RPMP	794.7	824.3	863.1	892.1	927	963.8	990.7	1,014.1	1,012.8	1,016.7
N.B.	N	718	742	791	801	846	854	870	895	920	933
	RPMP	956.9	988.2	1,052.7	1,065.2	1,129.3	1,145.4	1,164.4	1,194.2	1,222.0	1,235.0
N.S.	N	1,130	1,182	1,174	1,231	1,249	1,320	1,399	1,432	1,468	1,532
	RPMP	1,054.7	1,101.1	1,092.3	1,144.0	1,164.1	1,229.0	1,300.1	1,326.9	1,349.0	1,403.8
N.L.	N	602	616	660	663	657	656	667	710	746	806
	RPMP	1,158.9	1,188.4	1,276.5	1,285.0	1,289.1	1,295.1	1,317.0	1,395.1	1,459.1	1,578.6
Canada	**N**	**28,105**	**29,586**	**31,099**	**32,571**	**33,980**	**35,353**	**36,571**	**38,075**	**39,180**	**40,385**
	RPMP	**895.8**	**934.5**	**973.5**	**1,009.3**	**1,041.6**	**1,073.5**	**1,097.3**	**1,128.5**	**1,148.1**	**1,171.2**

Sources
Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information; Statistics Canada.

Table 14: Prevalent End-Stage Renal Disease Patients by Type of Treatment, Canada, 2002 to 2011 (Number, Rate per Million Population, Percentage of Total)

Type of Treatment		2002	2003	2004	2005	2006	2007	2008	2009	2010	2011
HD Home	N	258	303	369	485	572	638	717	787	844	929
	RPMP	8.2	9.6	11.6	15.0	17.5	19.4	21.5	23.3	24.7	26.9
	%	0.9	1.0	1.2	1.5	1.7	2	2.0	2.1	2.2	2.3
HD Institutional	N	13,345	14,216	14,947	15,611	16,200	16,641	17,032	17,642	17,997	18,480
	RPMP	425.4	449.0	467.9	483.8	496.6	505.3	511.1	522.9	527.4	535.9
	%	47.5	48.0	48.1	47.9	47.7	47.1	46.6	46.3	45.9	45.8
CAPD	N	1,781	1,688	1,659	1,611	1,554	1,578	1,605	1,583	1,542	1,482
	RPMP	56.8	53.3	51.9	49.9	47.6	47.9	48.2	46.9	45.2	43.0
	%	6.3	5.7	5.3	4.9	4.6	4.5	4.4	4.2	3.9	3.7
APD	N	1,598	1,698	1,915	2,081	2,222	2,315	2,388	2,503	2,553	2,532
	RPMP	50.9	53.6	59.9	64.5	68.1	70.3	71.7	74.2	74.8	73.4
	%	5.7	5.7	6.2	6.4	6.5	6.5	6.5	6.6	6.5	6.3
Transplant	N	11,123	11,681	12,209	12,783	13,432	14,181	14,829	15,560	16,244	16,962
	RPMP	354.5	368.9	382.2	396.1	411.7	430.6	445.0	461.2	476.0	491.9
	%	39.6	39.5	39.3	39.2	39.5	40.1	40.5	40.9	41.5	42.0
Total	**N**	**28,105**	**29,586**	**31,099**	**32,571**	**33,980**	**35,353**	**36,571**	**38,075**	**39,180**	**40,385**
	RPMP	**895.8**	**934.5**	**973.5**	**1,009.3**	**1,041.6**	**1,073.5**	**1,097.3**	**1,128.5**	**1,148.1**	**1,171.2**

Note

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

Sources

Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information; Statistics Canada.

Table 15: Prevalent End-Stage Renal Disease Patients by Type of Treatment and Province of Treatment, Canada, 2011 (Number, Percentage)

		Province of Treatment									
Type 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	119	126	20	32	514	75	14	16	13	**929**
	%	2.2	3.1	1.6	1.7	3.1	1	1.5	1.0	1.6	**2.0**
HD Institutional	N	2,078	1,526	601	990	7,937	3,810	482	589	467	**18,480**
	%	39.2	38.1	48.4	52.2	47.9	47.0	51.7	38.4	57.9	**46.0**
CAPD	N	187	123	93	87	547	337	51	30	27	**1,482**
	%	3.5	3.1	7.5	4.6	3.3	4.2	5.5	2.0	3.3	**4.0**
APD	N	530	280	68	159	1,132	237	53	62	11	**2,532**
	%	10.0	7.0	5.5	8.4	6.8	2.9	5.7	4.0	1.4	**6.0**
Transplant	N	2,382	1,950	460	629	6,431	3,654	333	835	288	**16,962**
	%	45.0	48.7	37.0	33.2	38.8	45.0	35.7	54.5	35.7	**42.0**
Total	**N**	**5,296**	**4,005**	**1,242**	**1,897**	**16,561**	**8,113**	**933**	**1,532**	**806**	**40,385**

Note

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

Source

Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information.

Table 16: Prevalent End-Stage Renal Disease Patients by Primary Diagnosis,* Canada, 2002 to 2011 (Number, Rate per Million Population, Percentage of Total)

Diagnosis		2002	2003	2004	2005	2006	2007	2008	2009	2010	2011
Glomerulonephritis	N	6,690	6,987	7,337	7,530	7,741	7,924	8,109	8,378	8,628	8,833
	RPMP	213.2	220.7	229.7	233.3	237.3	240.6	243.3	248.3	252.8	256.2
	%	23.8	23.6	23.6	23.1	22.8	22	22.2	22.0	22.0	21.9
Diabetes	N	6,663	7,224	7,738	8,218	8,701	9,116	9,500	9,931	10,304	10,678
	RPMP	212.4	228.2	242.2	254.7	266.7	276.8	285.1	294.3	301.9	309.7
	%	23.7	24.4	24.9	25.2	25.6	25.8	26.0	26.1	26.3	26.4
Renal Vascular Disease	N	3,666	3,863	4,009	4,250	4,475	4,649	4,765	4,957	5,041	5,117
	RPMP	116.9	122.0	125.5	131.7	137.2	141.2	143.0	146.9	147.7	148.4
	%	13.0	13.1	12.9	13.0	13.2	13.2	13.0	13.0	12.9	12.7
Polycystic Kidney Disease	N	1,976	2,082	2,190	2,368	2,497	2,621	2,738	2,844	2,959	3,062
	RPMP	63.0	65.8	68.6	73.4	76.5	79.6	82.2	84.3	86.7	88.8
	%	7.0	7.0	7.0	7.3	7.3	7.4	7.5	7.5	7.6	7.6
Drug Induced	N	401	427	441	469	492	531	542	571	608	619
	RPMP	12.8	13.5	13.8	14.5	15.1	16.1	16.3	16.9	17.8	18.0
	%	1.4	1.4	1.4	1.4	1.4	1.5	1.5	1.5	1.6	1.5
Pyelonephritis	N	2,047	2,100	2,181	2,210	2,257	2,334	2,357	2,377	2,386	2,462
	RPMP	65.2	66.3	68.3	68.5	69.2	70.9	70.7	70.5	69.9	71.4
	%	7.3	7.1	7.0	6.8	6.6	6.6	6.4	6.2	6.1	6.1
Other*	N	3,218	3,369	3,527	3,774	3,978	4,154	4,376	4,598	4,781	5,103
	RPMP	102.6	106.4	110.4	116.9	121.9	126.1	131.3	136.3	140.1	148.0
	%	11.4	11.4	11.3	11.6	11.7	11.8	12.0	12.1	12.2	12.6
Unknown	N	3,444	3,534	3,676	3,752	3,839	4,024	4,184	4,419	4,473	4,511
	RPMP	109.8	111.6	115.1	116.3	117.7	122.2	125.5	131.0	131.1	130.8
	%	12.3	11.9	11.8	11.5	11.3	11.4	11.4	11.6	11.4	11.2
Total	**N**	**28,105**	**29,586**	**31,099**	**32,571**	**33,980**	**35,353**	**36,571**	**38,075**	**39,180**	**40,385**
	RPMP	**895.8**	**934.5**	**973.5**	**1,009.3**	**1,041.6**	**1,073.5**	**1,097.3**	**1,128.5**	**1,148.1**	**1,171.2**

Note

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

Sources

Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information; Statistics Canada.

Table 17: Prevalent End-Stage Renal Disease Patients by Primary Diagnosis* and Province, Canada, 2011 (Number, Rate per Million Population, Percentage of Total)

Province		Glomerulone-phritis	Diabetes	Renal Vascular Disease	Polycystic Kidney Disease	Drug Induced	Pyelone-phritis	Other*	Unknown	Total
B.C./Y.T.	N	1,150	939	721	391	71	240	720	1,064	**5,296**
	RPMP	251.5	205.3	157.7	85.5	15.5	52.5	157.4	232.7	**1,158.0**
	%	21.7	17.7	13.6	7.4	1.3	4.5	13.6	20.1	**100**
Alta./N.W.T./ Nun.	N	999	1,096	370	316	56	282	514	372	**4,005**
	RPMP	309.6	380.5	143.2	83.6	14.8	97.2	181.3	143.7	**1,353.9**
	%	24.9	27.4	9.2	7.9	1.4	7.0	12.8	9.3	**100**
Sask.	N	252	400	117	77	18	100	168	110	**1,242**
	RPMP	238.2	378.1	110.6	72.8	17.0	94.5	158.8	104.0	**1,174.0**
	%	20.3	32.2	9.4	6.2	1.4	8.1	13.5	8.9	**100**
Man.	N	439	724	134	91	26	102	275	106	**1,897**
	RPMP	351.0	578.9	107.2	72.8	20.8	81.6	219.9	84.8	**1,516.9**
	%	23.1	38.2	7.1	4.8	1.4	5.4	14.5	5.6	**100**
Ont.	N	3,469	4,670	2,343	1,249	229	933	1,934	1,734	**16,561**
	RPMP	259.4	349.2	175.2	93.4	17.1	69.8	144.6	129.7	**1,238.4**
	%	20.9	28.2	14.1	7.5	1.4	5.6	11.7	10.5	**100**
Que.	N	1,820	2,032	1,008	601	155	577	1,091	829	**8,113**
	RPMP	228.1	254.6	126.3	75.3	19.4	72.3	136.7	103.9	**1,016.7**
	%	22.4	25.0	12.4	7.4	1.9	7.1	13.4	10.2	**100**
N.B.	N	200	252	144	91	11	57	107	71	**933**
	RPMP	264.7	333.6	190.6	120.5	14.6	75.5	141.6	94.0	**1,235.0**
	%	21.4	27.0	15.4	9.8	1.2	6.1	11.5	7.6	**100**
N.S./P.E.I.	N	311	367	178	183	36	105	209	143	**1,532**
	RPMP	381.1	521.5	234.7	205.2	61.3	169.0	267.4	209.2	**2,049.5**
	%	20.3	24.0	11.6	11.9	2.3	6.9	13.6	9.3	**100**
N.L.	N	193	198	102	63	17	66	85	82	**806**
	RPMP	378.0	387.8	199.8	123.4	33.3	129.3	166.5	160.6	**1,578.6**
	%	23.9	24.6	12.7	7.8	2.1	8.2	10.5	10.2	**100**
Canada	**N**	**8,833**	**10,678**	**5,117**	**3,062**	**619**	**2,462**	**5,103**	**4,511**	**40,385**
	RPMP	**256.2**	**309.7**	**148.4**	**88.8**	**18.0**	**71.4**	**148.0**	**130.8**	**1,171.2**
	%	**21.9**	**26.4**	**12.7**	**7.6**	**1.5**	**6.1**	**12.6**	**11.2**	**100**

Note

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

Sources

Canadian Organ Replacement Register, 2012, 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, 2011 (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					
Age 0–19	N	54	36	413	**503**
	RPMP	6.9	4.6	52.7	**64.1**
	%	0.3	0.9	2.4	**1.2**
Age 20–44	N	2,051	546	3,725	**6,322**
	RPMP	173.0	46.0	314.2	**533.2**
	%	10.6	13.6	22.0	**15.7**
Age 45–64	N	6,419	1,568	8,658	**16,645**
	RPMP	654.2	159.8	882.4	**1,696.5**
	%	33.1	39.1	51.0	**41.2**
Age 65–74	N	4,713	984	3,155	**8,852**
	RPMP	1,760.5	367.6	1,178.5	**3,306.6**
	%	24.3	24.5	18.6	**21.9**
Age 75+	N	6,172	880	1,011	**8,063**
	RPMP	2,687.7	383.2	440.3	**3,511.2**
	%	31.8	21.9	6.0	**20.0**
Sex					
Female	N	7,968	1,731	6,428	**16,127**
	RPMP	458.5	99.6	369.9	**928.0**
	%	41.1	43.1	37.9	**39.9**
Male	N	11,436	2,282	10,534	**24,252**
	RPMP	668.6	133.4	615.9	**1,417.9**
	%	58.9	56.9	62.1	**60.1**
Diagnosis					
Diabetes	N	6,694	1,208	2,776	**10,678**
	RPMP	194.1	35	80.5	**309.7**
	%	34.5	30.1	16.4	**26.4**
Glomerulonephritis	N	2,676	733	5,424	**8,833**
	RPMP	77.6	21.3	157.3	**256.2**
	%	13.8	18.3	32	**21.9**
Renal Vascular Disease	N	3,305	690	1,122	**5,117**
	RPMP	95.8	20	32.5	**148.4**
	%	17.0	17.2	6.6	**12.7**
Pyelonephritis	N	863	243	1,956	**3,062**
	RPMP	25.0	7.0	56.7	**88.8**
	%	4.4	6.1	11.5	**7.6**
Polycystic Kidney Disease	N	347	51	221	**619**
	RPMP	10.1	1.5	6.4	**18**
	%	1.8	1.3	1.3	**1.5**

(continued on next page)

Table 18: Prevalent End-Stage Renal Disease Patients by Treatment,* Age Group, Sex and Primary Diagnosis,† Canada, December 31, 2011 (Number, Rate per Million Population, Percentage of Total) (cont'd)

		HD	PD	TX	Total
Total	**N**	**19,409**	**4,014**	**16,962**	**40,385**
	RPMP	**562.9**	**116.4**	**491.9**	**1,171.2**
Diagnosis (cont'd)					
Drug Induced	N	889	180	1,393	**2,462**
	RPMP	25.8	5.2	40.4	**71.4**
	%	4.6	4.5	8.2	**6.1**
Other	N	2,083	431	2,589	**5,103**
	RPMP	60.4	12.5	75.1	**148**
	%	10.7	10.7	15.3	**12.6**
Unknown	N	2,552	478	1,481	**4,511**
	RPMP	74	13.9	42.9	**130.8**
	%	13.1	11.9	8.7	**11.2**

Notes

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

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

Sources

Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information; Statistics Canada.

Table 19: End-Stage Renal Disease Patient Flows by Treatment, Canada, 2002 to 2011

		2002	2003	2004	2005	2006	2007	2008	2009	2010	2011
Dialysis	January 1, Prevalence	16,011	16,982	17,905	18,890	19,788	20,548	21,172	21,742	22,515	22,936
	Incident Dialysis	4,932	5,010	5,099	5,141	5,261	5,364	5,363	5,495	5,567	5,295
	Deaths	3,061	3,175	3,195	3,353	3,485	3,585	3,672	3,529	3,669	3,542
	Net Transplants*	653	683	659	637	766	828	759	765	734	794
	Net Migrations†	247	229	260	253	250	327	362	428	743	472
	December 31, Prevalence	16,982	17,905	18,890	19,788	20,548	21,172	21,742	22,515	22,936	23,423
Transplant	January 1, Prevalence	10,594	11,123	11,681	12,209	12,783	13,432	14,181	14,829	15,560	16,244
	New Transplants	1,094	1,097	1,084	1,120	1,254	1,325	1,271	1,278	1,269	1,193
	Deaths	238	231	243	220	284	256	281	227	251	222
	Return to Dialysis	307	302	294	319	319	316	331	316	322	252
	Net Migrations†	20	6	19	7	2	4	11	4	12	1
	December 31, Prevalence	11,123	11,681	12,209	12,783	13,432	14,181	14,829	15,560	16,244	16,962

Notes

* Transplants minus patients 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, 2012, 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 5.1, followed closely by Alberta (4.9), while New Brunswick (3.1) and Nova Scotia (3.9) had the lowest number of patients per station (Table 20).

Table 20: Point Prevalent Hospital, Independent Health Facility and Community Centre Hemodialysis Patients, by Province of Treatment* and Stations,† Canada, 2011 (Number)

Province of Treatment	Stations (N)	Patients (N)	Patients per Station	Population	Stations per Million Population
B.C.	480	2,197	4.6	4,607,987	104.2
Alta.	340	1,652	4.9	3,856,350	88.2
Sask.	138	621	4.5	1,057,884	130.4
Man.	243	1,022	4.2	1,250,574	194.3
Ont.	1,669	8,451	5.1	13,372,996	124.8
Que.	847	3,885	4.6	7,979,663	106.1
N.B.	160	496	3.1	755,455	211.8
N.S.	155	605	3.9	1,091,292	142.0
N.L.	118	480	4.1	510,578	231.1
Total	**4,150**	**19,409**	**4.7**	**34,482,779**	**120.3**

Notes

* 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.

† Stations are missing from Alberta, Ontario and Quebec. 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.

Sources

Canadian Organ Replacement Register, 2012, 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).

Nearly 90% of dialysis patients younger than 18 survive for five years, while 25% of patients older than 75 survive for five years (Figure 3).

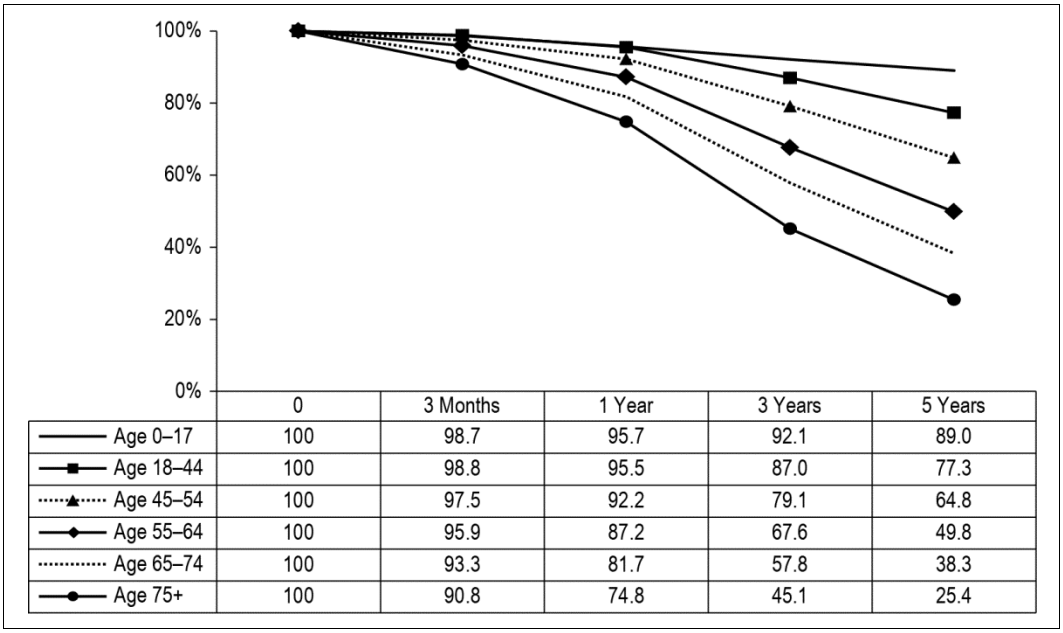
Patients with renal vascular disease, drug-induced renal failure and diabetes have the lowest five-year survival rates, at 37%, 40% and 40%, respectively (Figure 6). The longest five-year survival rate is seen among patients with a primary diagnosis of polycystic kidney disease (75%) and glomerulonephritis (64%).

Table 21: Unadjusted Three-Month and One-, Three- and Five-Year Survival Rates in Dialysis Patients, Canada, 2002 to 2011 (Percentage)

		2002	2003	2004	2005	2006	2007	2008	2009	2010	2011
All Dialysis	N	4,932	5,010	5,099	5,141	5,261	5,364	5,363	5,495	5,567	5,295
	3 Months	93.8	94.4	94.6	94.4	94.4	94.7	94.3	94.6	94.4	93.2
	1 Year	82.3	83.3	83.4	83.5	83.8	84.4	83.8	85.0	84.6	—
	3 Years	58.1	59.5	60.6	61.5	61.0	63.0	62.3	—	—	—
	5 Years	39.4	40.3	42.8	43.8	43.2	—	—	—	—	—
HD	N	4,023	4,124	4,114	4,161	4,329	4,406	4,362	4,457	4,585	4,385
	3 Months	93.0	93.7	93.7	93.4	93.6	93.9	93.4	93.7	93.4	92.2
	1 Year	80.4	81.5	81.6	81.4	81.8	82.6	81.7	82.9	82.9	—
	3 Years	56.2	57.4	58.4	59.3	58.9	60.8	59.8	—	—	—
	5 Years	37.6	38.6	41.0	42.5	41.3	—	—	—	—	—
PD	N	909	886	985	980	932	958	1,001	1,038	982	910
	3 Months	97.5	98.1	98.5	98.5	98.1	98.1	98.1	98.6	98.9	98.2
	1 Year	90.7	91.6	91.0	92.5	92.6	92.3	92.7	93.8	92.6	—
	3 Years	66.4	69.6	70.1	71.1	70.8	73.2	73.6	—	—	—
	5 Years	47.7	48.9	50.9	49.4	52.6	—	—	—	—	—

Note
HD: hemodialysis; PD: peritoneal dialysis.
Source
Canadian Organ Replacement Register, 2012, 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, 2002 to 2011 (Percentage)

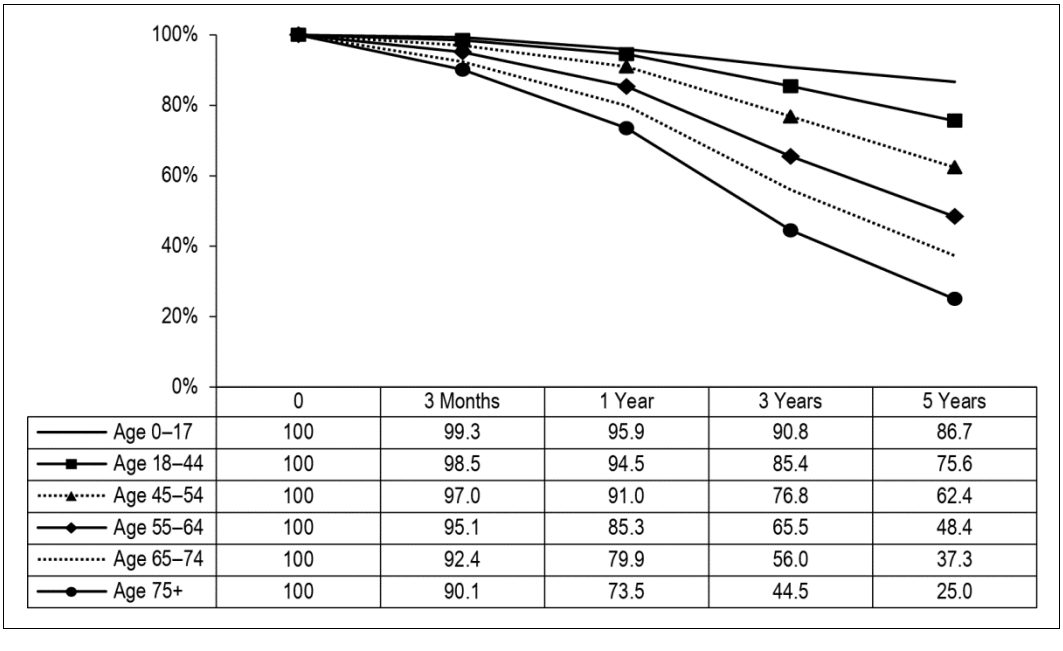


	0	3 Months	1 Year	3 Years	5 Years
Age 0–17	100	98.7	95.7	92.1	89.0
Age 18–44	100	98.8	95.5	87.0	77.3
Age 45–54	100	97.5	92.2	79.1	64.8
Age 55–64	100	95.9	87.2	67.6	49.8
Age 65–74	100	93.3	81.7	57.8	38.3
Age 75+	100	90.8	74.8	45.1	25.4

Source

Canadian Organ Replacement Register, 2012, 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, 2002 to 2011 (Percentage)

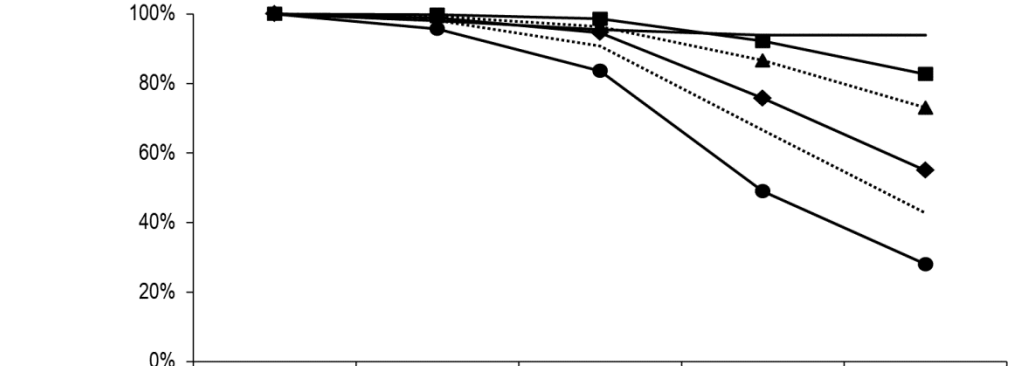


	0	3 Months	1 Year	3 Years	5 Years
Age 0–17	100	99.3	95.9	90.8	86.7
Age 18–44	100	98.5	94.5	85.4	75.6
Age 45–54	100	97.0	91.0	76.8	62.4
Age 55–64	100	95.1	85.3	65.5	48.4
Age 65–74	100	92.4	79.9	56.0	37.3
Age 75+	100	90.1	73.5	44.5	25.0

Source

Canadian Organ Replacement Register, 2012, 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, 2002 to 2011 (Percentage)

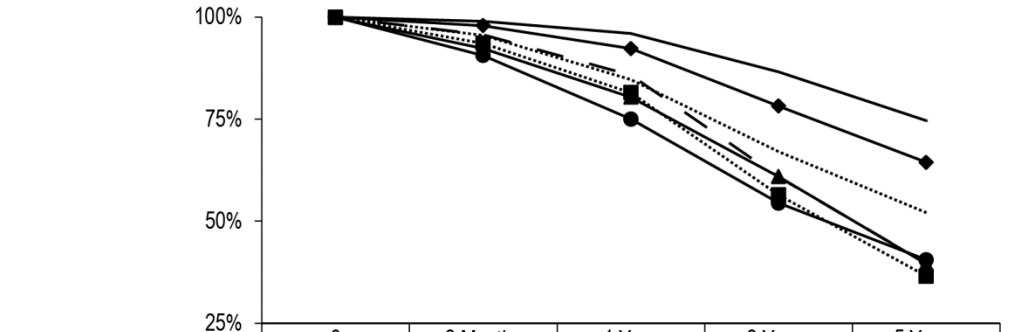


	0	3 Months	1 Year	3 Years	5 Years
Age 0–17	100	98.0	95.5	93.9	93.9
Age 18–44	100	99.8	98.6	92.2	82.7
Age 45–54	100	99.3	96.3	86.6	73.0
Age 55–64	100	98.9	94.6	75.7	55.0
Age 65–74	100	98.1	90.8	66.5	42.7
Age 75+	100	95.7	83.6	49.0	28.0

Source

Canadian Organ Replacement Register, 2012, 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, 2002 to 2011 (Percentage)



	0	3 Months	1 Year	3 Years	5 Years
Glomerulonephritis	100	97.9	92.3	78.2	64.4
Diabetes	100	95.7	85.8	60.8	39.6
Polycystic Kidney	100	99	96	86.6	74.6
Pyelonephritis	100	95.5	84.7	67	52.1
Renal Vascular	100	93.6	81.5	56.4	36.5
Drug Induced	99.9	92.3	80.4	60.9	39.5
Other	100	90.6	75	54.4	40.5

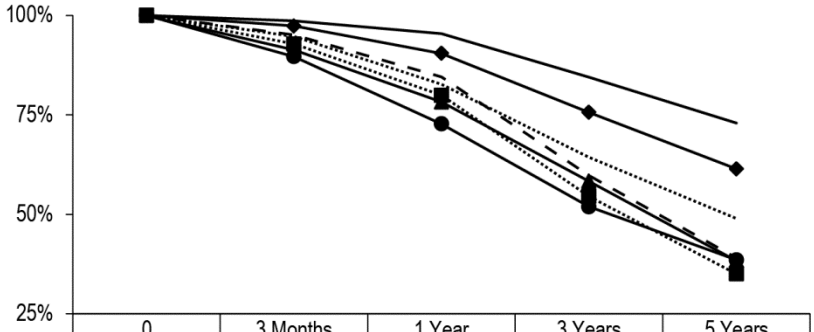
Note

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

Source

Canadian Organ Replacement Register, 2012, 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, 2002 to 2011 (Percentage)



	0	3 Months	1 Year	3 Years	5 Years
Glomerulonephritis	100	97.3	90.4	75.6	61.4
Diabetes	100	95.1	84.5	59.7	39.0
Polycystic Kidney	100	98.6	95.4	84.4	72.9
Pyelonephritis	100	94.7	82.7	64.3	48.9
Renal Vascular	100	92.8	79.9	54.5	35.0
Drug Induced	99.9	91.3	78.2	58.3	38.3
Other	100	89.6	72.7	51.9	38.5

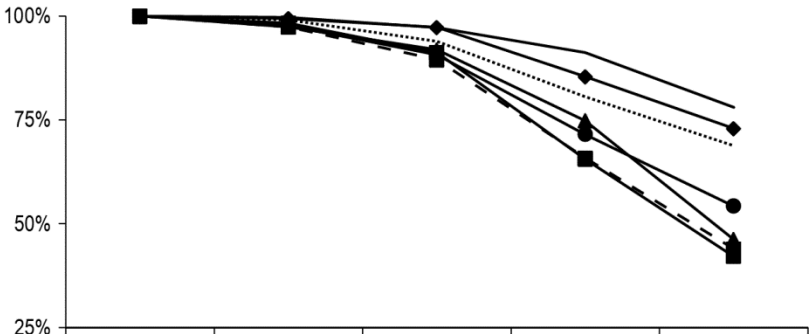
Note

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

Source

Canadian Organ Replacement Register, 2012, 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, 2002 to 2011 (Percentage)



	0	3 Months	1 Year	3 Years	5 Years
Glomerulonephritis	100	99.4	97.3	85.4	72.9
Diabetes	100	98.3	91.2	65.5	42.1
Polycystic Kidney	100	99.7	97.2	91.2	78.0
Pyelonephritis	100	99.1	93.9	80.6	68.8
Renal Vascular	100	97.4	89.5	65.8	43.9
Drug Induced	100	97.4	91.9	74.8	46.2
Other	100	97.7	90.7	71.5	54.2

Note

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

Source

Canadian Organ Replacement Register, 2012, 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 2011, there were 25 active kidney transplant programs in Canada operating in seven provinces.

At the end of 2011, there were 3,406 people (adult and pediatric) waiting for a deceased donor kidney transplant (Table 22). Between 2002 and 2011, there was an average of 70 deaths per year involving people on the waiting list.

During the 10-year period, there were 10,977 kidney transplant procedures registered in CORR (Table 23). Of these, 1,119 (10%) were re-transplants. Of the 9,788 kidney-only first transplants, 61% utilized deceased-donor kidneys. Ontario and Quebec surgeons performed the most deceased-donor kidney transplants over the decade (2,516 and 1,977, respectively) (Table 24). Ontario saw the highest number of living-donor kidney transplants (1,895) over the decade (Table 25), followed by British Columbia (830). Since 2006, the number of living-donor kidney transplants has been stable, fluctuating between 437 and 466 transplants each year.

For the most recent three-year period, 2009 to 2011, the median wait time for a deceased-donor kidney transplant (excluding pre-emptive transplants) was 3.8 years (Table 26). The longest median wait times were in British Columbia (5.4 years) and Manitoba (5.1 years). The shortest median wait time of 2.3 years was observed in Saskatchewan.

Since 2002, the proportion of recipients older than age 60 receiving a kidney transplant from a deceased donor increased from 29% to 43%, and the average age of recipients increased from 50.7 to 54.5 (Table 27). A similar trend was observed for living-donor transplants (14% to 21%) (Table 27). Glomerulonephritis continued to be the predominant diagnosis among adult kidney transplant recipients (295) (Table 28).

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

Table 22: Kidney Transplant* Waiting List at December 31 and Waiting List Deaths, Canada, 2002 to 2011 (Number)

	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011
Waiting List	2,963	2,875	2,872	2,759	2,962	2,963	3,179	2,732	3,362	3,406
Deaths on Waiting List	86	82	55	66	70	46	58	76	82	80

Note

* Includes both adult and pediatric patients.

Source

Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information.

Table 23: Kidney Transplants* by Year and Donor Type, Adult Recipients, Canada, 2002 to 2011 (Number)

	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	Total
Kidney Only, First Graft, Deceased Donor	516	550	514	504	606	631	634	667	647	686	**5,955**
Kidney Only, First Graft, Living Donor	319	342	345	370	415	413	409	403	413	404	**3,833**
Kidney Combination, First Graft, Deceased Donor†	5	8	3	5	10	8	9	11	7	4	**70**
Re-Transplants	129	99	104	104	119	133	114	91	124	102	**1,119**
Total	**969**	**999**	**966**	**983**	**1,150**	**1,185**	**1,166**	**1,172**	**1,191**	**1,196**	**10,977**

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, 2012, Canadian Institute for Health Information.

Table 24: Deceased-Donor Kidney Transplants* by Year and Province of Treatment, Adult Recipients, Canada, 2002 to 2011 (Number)

Province of Treatment	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	Total
B.C.	46	53	52	40	61	61	83	54	89	91	**630**
Alta.	81	67	67	83	78	71	66	61	74	74	**722**
Sask.	18	29	18	15	21	21	21	14	—	—	**157**
Man.	17	17	13	6	22	27	24	22	33	17	**198**
Ont.	196	192	208	206	243	291	253	323	308	296	**2,516**
Que.	186	218	196	173	197	204	217	207	172	207	**1,977**
N.S.	63	51	35	49	67	52	49	50	49	74	**539**
Total	**607**	**627**	**589**	**572**	**689**	**727**	**713**	**731**	**725**	**759**	**6,739**

Note

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

Source

Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information.

Table 25: Living-Donor Kidney Transplants by Year and Province of Treatment, Adult Recipients, Canada, 2002 to 2011 (Number)

Province of Treatment	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	Total
B.C.	74	69	74	70	98	100	75	87	89	94	**830**
Alta.	47	52	61	50	46	60	51	40	66	54	**527**
Sask.	14	10	12	11	9	7	13	1	3	2	**82**
Man.	15	18	12	19	24	21	17	18	20	19	**183**
Ont.	149	156	157	186	206	199	211	224	208	199	**1,895**
Que.	38	43	38	46	47	44	47	39	51	42	**435**
N.S.	25	24	23	29	31	27	39	32	29	27	**286**
Total	**362**	**372**	**377**	**411**	**461**	**458**	**453**	**441**	**466**	**437**	**4,238**

Source

Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information.

Table 26: Dialysis Duration Prior to First Kidney Transplant by Province of Treatment, Adult Kidney Transplant Recipients, Canada, 2009 to 2011

	B.C.	Alta.	Sask.	Man.	Ont.	Que.	N.S.	Canada
Duration on Dialysis (Median Days), Deceased Donor	1,954	1,186	849.5	1,839	1,578	863.5	882.5	**1,325**
Duration on Dialysis (Median Days), Deceased Donor, No Pre-Emptive	1,954	1,265	849.5	1,861.5	1,598	1,028.5	981	**1,382**
Duration on Dialysis (Median Days), Living Donor	212	309	564	380	367.5	48	217	**293.5**
Duration on Dialysis (Median Days), Living Donor, No Pre-Emptive	628.5	460	564	470	624	438	413.5	**525**

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 3,242 adult first kidney transplants performed in Canada between 2009 and 2011; of these, 408 were pre-emptive transplants.

Source

Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information.

Table 27: Adult Kidney Transplant Recipients, Selected Characteristics, First Graft, Canada, 2002 to 2011 (Number, Percentage)

Donor	Characteristic	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011
Deceased	Percentage Male	63.5	64.7	62.1	63.9	61.7	63.8	65.0	63.6	63.6	64.8
	Percentage Age 60+	29.4	26.7	30.6	29.5	29.7	34.9	35.8	37.5	39.4	42.6
	Average Age	50.7	50.4	51.2	51.8	51.9	53.4	53.2	53.8	54.2	54.5
	Age Standard Deviation	13.6	12.6	13.2	12.4	12.7	12.8	13.0	12.9	12.6	12.9
	Primary Cause of ESRD* (%)										
	Diabetes	19.0	21.1	14.5	17.3	17.0	21.6	23.6	19.8	24.2	27.0
	Renal Vascular	9.4	7.9	13.2	10.6	10.7	9.1	10.1	9.1	9.9	11.6
	Glomerulonephritis	31.9	36.4	36.4	30.3	31.0	28.3	27.1	30.5	29.5	24.2
	Other*	33.8	29.9	31.9	37.7	37.2	36.6	33.6	33.6	32.7	33.8
	Unknown Diagnosis	6.0	4.7	4.1	4.1	4.1	4.4	5.6	6.9	3.7	3.5
	Median Peak PRA	0	0	0	0	0	0	0	0	0	0
	Peak PRA >50% (%)	2.3	3.2	2.7	3.1	1.3	2.4	6.1	6.1	8.6	5.6
	Duration of Dialysis (Median Days)	973	1,015.5	1,305	1,261	1,282.5	1,338	1,199	1,252	1,381.5	1,330.5
Living	Percentage Male	60.5	65.2	59.1	63.2	62.4	63.4	60.1	59.6	65.6	60.4
	Percentage Age 60+	13.8	16.7	14.5	14.6	14.7	18.6	19.3	21.6	26.4	20.5
	Average Age	43.8	46.1	44.6	46.6	45.4	46	46.8	47	48.4	46.5
	Age Standard Deviation	13.5	13	13.2	12.6	13.1	13.8	13.4	13.6	14.2	14.1
	Primary Cause of ESRD* (%)										
	Diabetes	16	19.6	16.8	16.5	13.3	16.9	14.7	16.6	15.3	16.8
	Renal Vascular	5.3	7.6	4.6	5.7	7.2	7.7	7.1	6.9	6.5	5.9
	Glomerulonephritis	32.9	32.5	38	31.1	35.4	29.1	29.3	28	32	31.7
	Other*	39.8	35.1	35.7	41.1	36.1	36.3	41.1	38.5	34.4	34.9
	Unknown Diagnosis	6	5.3	4.9	5.7	8	9.9	7.8	9.9	11.9	10.6
	Median Peak PRA	0	0	0	0	0	0	0	0	0	0
	Peak PRA >50% (%)	1.9	0.9	3.4	1.5	1.1	2.9	5.4	5.1	3.7	5.0
	Duration of Dialysis (Median Days)	350	380.5	343	286	314	304	356	285	280	302

Notes

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

PRA: panel reactive antibody.

Source

Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information.

Table 28: Kidney Transplant Recipients* by Age Group and Primary Renal Diagnosis† Category, Adult Recipients, First Graft, Canada, 2011 (Number)

	Age 18–44	Age 45–54	Age 55–64	Age 65+	Total
Glomerulonephritis	118	74	69	34	**295**
Pyelonephritis	21	15	14	10	**60**
Polycystic Kidney Disease	15	47	50	21	**133**
Hypertension/ Other Vascular	25	17	33	29	**104**
Diabetic Nephropathy	44	55	88	67	**254**
Other†	74	39	41	27	**181**
Unknown/Not Reported	23	11	20	13	**67**
Total	**320**	**258**	**315**	**201**	**1,094**

Notes

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

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

Source

Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information.

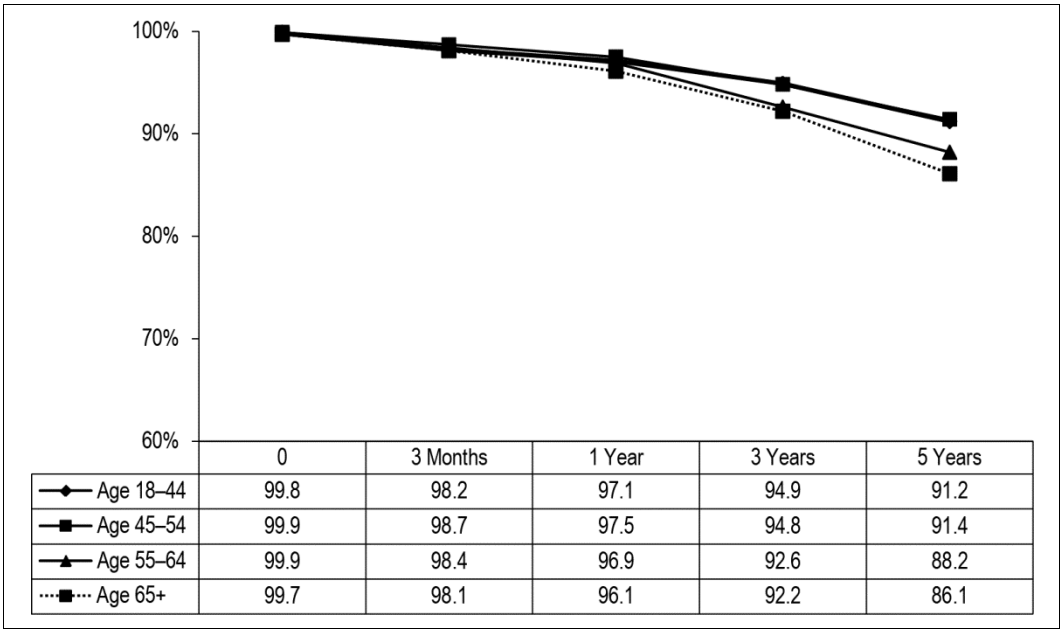
Table 29: Unadjusted Three-Month and One-, Three- and Five-Year Graft Survival Rates in Adult Kidney Transplant Recipients, First Graft, Canada, 2002 to 2011 (Percentage)

		2002	2003	2004	2005	2006	2007	2008	2009	2010	2011
Deceased Donor	N	521	558	517	509	616	639	643	678	654	690
	3 Months	93.3	95.2	95.2	96.3	95.6	96.6	95.6	95.7	97.4	97.4
	1 Year	90.4	91.4	91.9	92.5	93.3	93.3	92.5	93.2	95	—
	3 Years	82.9	85.8	85.9	85.9	86.7	87.5	87.2	—	—	—
	5 Years	75.4	79.7	79.1	80.7	82.1	—	—	—	—	—
Living Donor	N	319	342	345	370	415	413	409	403	413	404
	3 Months	99.1	98.5	98.6	98.1	97.6	98.8	97.8	98.8	98.3	98.5
	1 Year	98.1	98.0	98.3	95.9	96.4	96.6	96.6	97.5	96.9	—
	3 Years	95.3	95.9	94.5	92.4	93.3	93.0	94.4	—	—	—
	5 Years	92.2	91.5	90.1	89.7	88.2	—	—	—	—	—

Source

Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information.

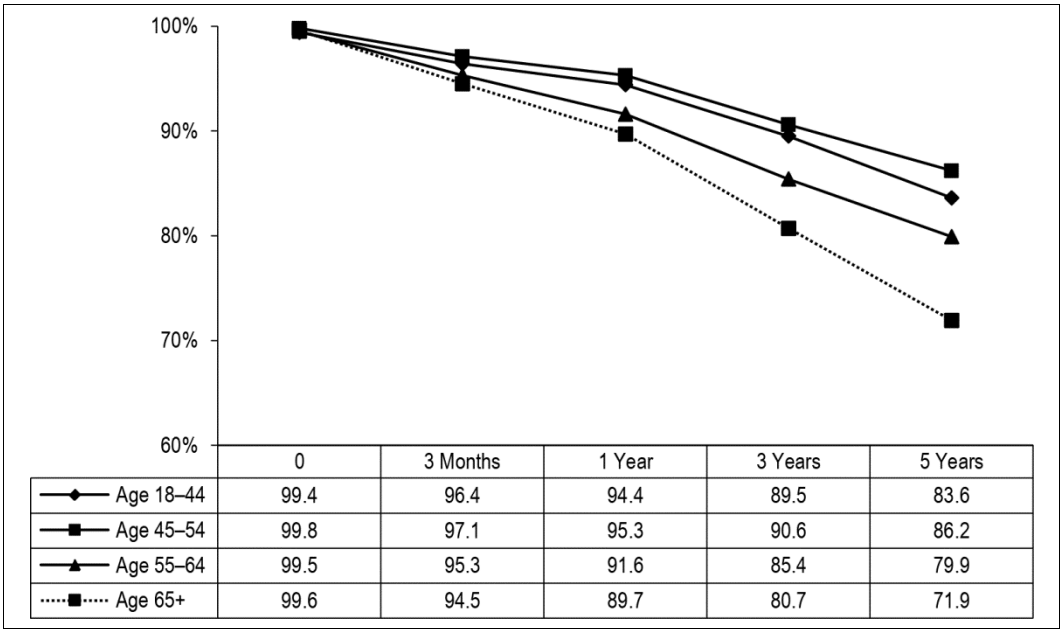
Figure 9: Unadjusted Three-Month and One-, Three- and Five-Year Graft Survival Rates in Adult Kidney Transplant Patients, First Graft, Living Donor, by Age at Transplant, Canada, 2002 to 2011 (Percentage)



	0	3 Months	1 Year	3 Years	5 Years
Age 18–44	99.8	98.2	97.1	94.9	91.2
Age 45–54	99.9	98.7	97.5	94.8	91.4
Age 55–64	99.9	98.4	96.9	92.6	88.2
Age 65+	99.7	98.1	96.1	92.2	86.1

Source
Canadian Organ Replacement Register, 2012, 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, 2002 to 2011 (Percentage)



	0	3 Months	1 Year	3 Years	5 Years
Age 18–44	99.4	96.4	94.4	89.5	83.6
Age 45–54	99.8	97.1	95.3	90.6	86.2
Age 55–64	99.5	95.3	91.6	85.4	79.9
Age 65+	99.6	94.5	89.7	80.7	71.9

Source
Canadian Organ Replacement Register, 2012, 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 550 first graft transplants and 35 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, 2002 to 2011 (Number)

	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	Total
First Graft, Deceased Donor	28	27	19	39	22	42	24	31	28	29	**289**
First Graft, Living Donor	36	28	37	29	26	21	23	18	25	18	**261**
Re-Transplants	2	3	5	5	1	4	3	4	4	4	**35**
Total	**66**	**58**	**61**	**73**	**49**	**67**	**50**	**53**	**57**	**51**	**585**

Source
Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information.

Table 31: Pediatric Kidney Transplants by Age Group and Province of Treatment, Canada, 2002 to 2011 (Number, Percentage)

		B.C.	Alta.	Sask.	Man.	Ont.	Que.	N.S.	Total
Age 0–4	N	12	12	—	3	33	16	10	**86**
	%	15.8	17.9	—	7.0	14.9	11.9	28.6	**14.7**
Age 5–10	N	17	16	—	12	44	30	8	**127**
	%	22.4	23.9	—	27.9	19.8	22.2	22.9	**21.7**
Age 11–17	N	47	39	7	28	145	89	17	**372**
	%	61.8	58.2	100.0	65.1	65.3	65.9	48.6	**63.6**
Total	**N**	**76**	**67**	**7**	**43**	**222**	**135**	**35**	**585**

Source
Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information.

Table 32: Dialysis Duration in Days Prior to First Kidney Transplant, Pediatric Recipients, Canada, 2002 to 2011

	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011
Duration on Dialysis (Median Days), Deceased Donor	336	460	586	625	631	422	344	265	524	599
Duration on Dialysis (Median Days), Deceased Donor, Excluding Pre-Emptive	436	772	705	770	649	558	373	286	614	762
Duration on Dialysis (Median Days), Living Donor	140	175	264	107	144	137	66	197	228	0*
Duration on Dialysis (Median Days), Living Donor, Excluding Pre-Emptive	348	327	414	349	271	483	258	297	304	339

Notes

* In 2011, more than half of the living donor tranplants were pre-emptive.

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, 2012, Canadian Institute for Health Information.

Table 33: Pediatric Kidney Transplant by Age Group and Primary Renal Diagnosis* Category, Canada, 2002 to 2011

Primary Renal Diagnosis* Category	Age 0–4		Age 5–10		Age 11–17	
	N	%	N	%	N	%
Alport Syndrome	0	0.0	0	0.0	7	2.1
Cystinosis	0	0.0	9	7.2	17	5.0
Dysplasia/Hypoplasia	25	29.8	23	18.4	44	12.9
Posterior Urethral Valves	8	9.5	8	6.4	10	2.9
Obstructive Uropathy	<5	..	5	4.0	13	3.8
Vesicoureteric Reflux	<5	..	<5	..	18	5.3
Polycystic Kidneys	<5	..	<5	..	7	2.1
Nephronophthisis	<5	..	7	5.6	15	4.4
Other Congenital/Hereditary	7	8.3	<5	..	10	2.9
Other Pyelonephritis	0	0.0	5	4.0	8	2.3
Glomerulonephritis	11	13.1	15	12.0	40	11.7
Focal Sclerosis	5	6.0	8	6.4	22	6.5
Autoimmune Disease	0	0.0	0	0.0	23	6.7
Hemolytic Uremic Syndrome	<5	..	7	5.6	8	2.3
Other*	8	9.5	18	14.4	41	12.0
Unknown	12	14.3	15	12.0	58	17.0
Total Patients	**84**	**100.0**	**125**	**100.0**	**341**	**100.0**

Notes

* For a list of all 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, 2012, 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, 2002 to 2011 (Percentage)

		2002	2003	2004	2005	2006	2007	2008	2009	2010	2011
Deceased Donor	N	28	27	19	39	22	42	24	31	28	29
	3 Months	100	92.6	94.7	97.4	95.5	95.2	100	96.8	100	100
	1 Year	100	88.9	94.7	97.4	90.9	95.2	95.8	96.8	100	—
	3 Years	100	74.1	94.7	92.3	77.3	90.4	87.5	—	—	—
	5 Years	88.9	70.4	89.5	89.7	77.3	—	—	—	—	—
Living Donor	N	36	28	37	29	26	21	23	18	25	18
	3 Months	94.4	96.4	100	96.6	100	100	95.7	100	96	100
	1 Year	94.4	96.4	100	96.6	100	100	95.7	100	96	—
	3 Years	94.4	85.7	100	93.1	92.3	100	95.7	—	—	—
	5 Years	94.4	85.7	89.2	93.1	84.6	—	—	—	—	—

Source

Canadian Organ Replacement Register, 2012, 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 2002 to 2011.

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 2011, the waiting list had decreased to 489, and deaths on the waiting list also decreased, from 141 to 93 between 2005 and 2011 (Table 35).

The decade spanning 2002 to 2011 saw 4,419 liver transplants registered with CORR, with 78% of patients receiving their first liver from deceased donors (Table 36). During that period the proportion of first 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 (15.7) and Alberta (14.4). The remaining provinces ranged from 5.6 to 12.7 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 89%; five-year survival was somewhat lower (between 79% and 81%) (Figure 13). One-year survival reached a peak of 93% in 2008 and 2010.

In 2011, there were 5,436 patients in Canada living with a transplanted liver (Table 39).

Table 35: Liver Transplant Waiting List at December 31 and Waiting List Deaths, Canada, 2002 to 2011

	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	Total
Age 0–17	31	30	37	32	36	19	17	19	22	21	**264**
Age 18+	528	539	630	681	687	616	570	532	479	468	**5,730**
Total	**559**	**569**	**667**	**713**	**723**	**635**	**587**	**551**	**501**	**489**	**5,994**
Deaths on Waiting List	82	100	96	141	120	77	92	91	74	93	**966**

Source
Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information.

Table 36: Liver Transplants by Year, Donor Type, Age Group and Re-Transplants, Canada, 2002 to 2011 (Number)

		2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	Total
Pediatric: Age 0–17	First Graft, Deceased Donor	25	33	15	34	25	28	27	31	22	34	**274**
	First Graft, Living Donor	10	6	12	8	9	15	9	9	14	14	**106**
	Re-Transplants	3	4	3	9	8	6	7	7	6	5	**58**
Adults: Age 18+	First Graft, Deceased Donor	290	302	318	296	324	342	318	324	331	349	**3,194**
	First Graft, Living Donor	32	29	42	52	58	56	59	48	50	50	**476**
	Re-Transplants	26	31	27	24	42	33	33	34	28	33	**311**
Total: All Ages		**386**	**405**	**417**	**423**	**466**	**480**	**453**	**453**	**451**	**485**	**4,419**

Source
Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information.

Table 37: Combination Liver Transplants, Canada, 2002 to 2011 (Number)

	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	Total
Liver Only	381	399	414	416	447	468	442	440	442	482	**4,331**
Liver Combinations	5	6	3	7	19	12	11	13	9	3	**88**
Total	**386**	**405**	**417**	**423**	**466**	**480**	**453**	**453**	**451**	**485**	**4,419**

Source
Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information.

Table 38: Primary Diagnosis* for Liver Transplant Recipients, First Graft, by Age Group, Canada, 2002 to 2011 (Percentage)

	Age <1	Age 1–10	Age 11–17	Age 18–34	Age 35–59	Age 60+	Total
Primary Biliary Atresia	58.6	28.2	4.7	0.9	0.1	0.1	**2.8**
Hepatitis C	0	0	1.2	3.7	28.5	16.0	**21.7**
Hepatitis B	0	0	1.2	5.9	5.1	5.1	**4.7**
Other Hepatitis	3	4.1	11.6	12.8	3.3	2.7	**3.9**
Alcoholic Cirrhosis	0	0	0	0.6	17.0	17.4	**14.7**
Cryptogenic Cirrhosis	0	0	2.3	4.0	3.4	6.0	**3.8**
Cancer	1.5	11.2	4.7	5.9	14.5	22.8	**15.3**
Metabolic Disorders	4.5	9.4	9.3	5.0	1.9	2.1	**2.6**
Cholestatic Liver Disease	3.8	7.6	18.6	26.8	10.9	10.7	**11.7**
Unknown/Missing	16.5	16.5	12.8	6.2	2.2	1.9	**3.5**
Other*	12.0	22.9	33.7	28.0	13.2	15.3	**15.3**
Total	**100**	**100**	**100**	**100**	**100**	**100**	**100**

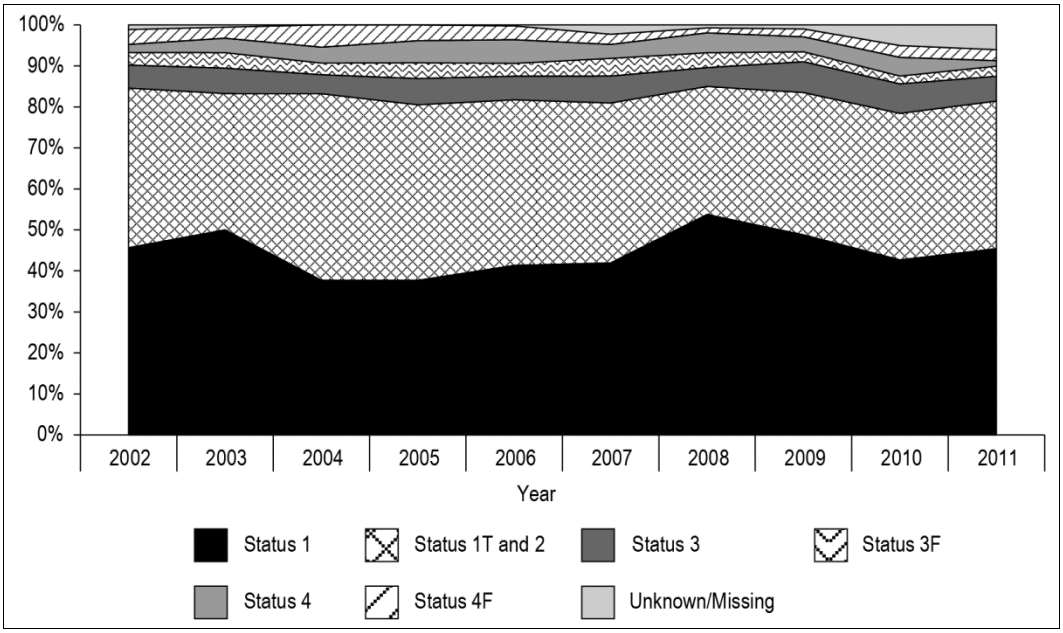
Note

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

Source

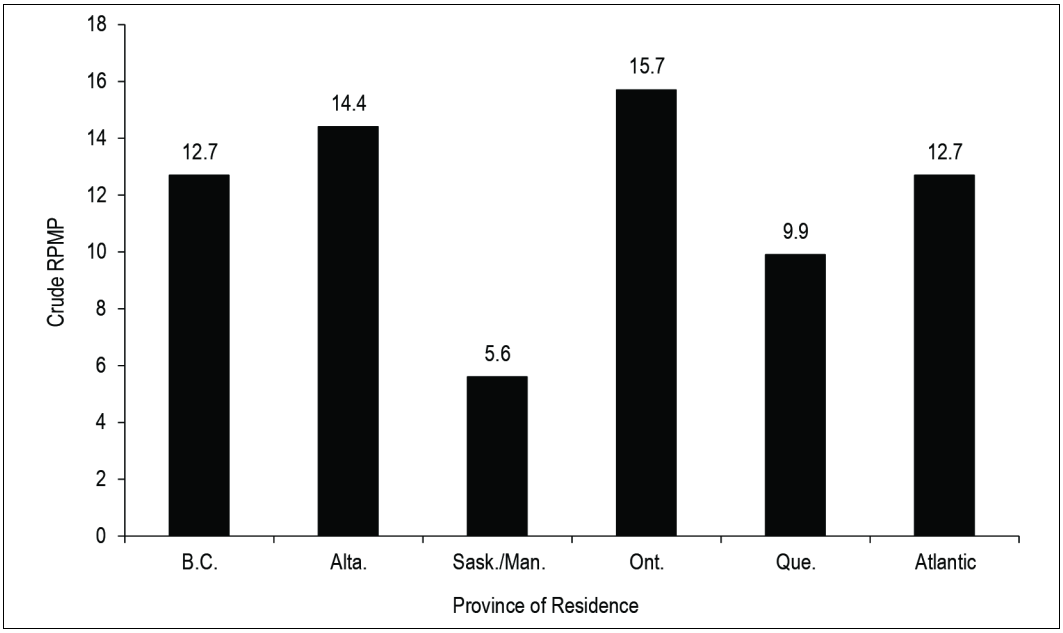
Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information.

Figure 11: Distribution of Liver Transplants by Medical Status at Transplant, Canada, 2002 to 2011



Source
Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information.

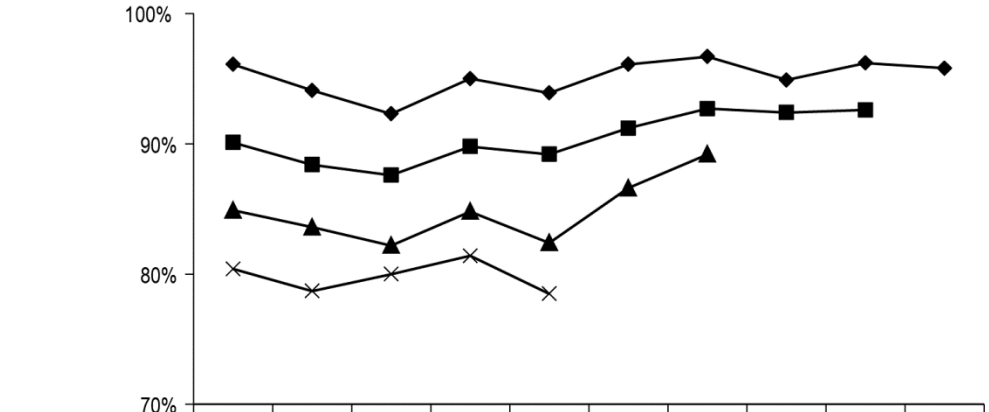
Figure 12: Liver Transplant Recipients by Province of Residence, Canada, 2011 (Crude Rate per Million Population)



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

Source
Canadian Organ Replacement Register, 2012, 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, 2002 to 2011 (Percentage)



	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011
3 Months	96.1	94.1	92.3	95	93.9	96.1	96.7	94.9	96.2	95.8
1 Year	90.1	88.4	87.6	89.8	89.2	91.2	92.7	92.4	92.6	—
3 Years	84.9	83.6	82.2	84.8	82.4	86.6	89.2	—	—	—
5 Years	80.4	78.7	80	81.4	78.5	—	—	—	—	—

Source

Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information.

Table 39: Prevalent Liver Transplant Patients, by Province of Treatment/Follow-Up, 2002 to 2011 (Number)

	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011
B.C.	264	284	307	330	356	388	422	442	483	512
Alta.	393	427	469	492	538	561	579	610	645	680
Sask.	25	35	42	47	51	61	66	74	74	73
Man.	<5*	<5*	<5*	<5*	<5*	<5*	<5*	<5*	<5*	<5*
Ont.	1,439	1,553	1,672	1,798	1,924	2,078	2,214	2,360	2,508	2,675
Que.	663	724	774	826	873	937	1,005	1,070	1,118	1,178
N.B.	<5*	<5*	<5*	<5*	0	<5*	<5*	<5*	<5*	<5*
N.S.	182	191	196	212	230	245	262	280	289	313
N.L.	<5*	<5*	<5*	<5*	<5*	<5*	<5*	<5*	<5*	<5*
Canada	**2,972**	**3,220**	**3,466**	**3,711**	**3,977**	**4,274**	**4,552**	**4,840**	**5,122**	**5,436**

Note

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

Source

Canadian Organ Replacement Register, 2012, 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 2002 to 2011.

There were 166 people on the waiting list for a heart transplant in 2011. Since 2002, deaths on the waiting list have varied from 14 to 35 per year (Table 40). A total of 241 Canadians died over the last decade while waiting for a heart transplant.

Between 2002 and 2011, there were 1,632 heart transplants registered in CORR, including 51 re-transplants. The number of transplants performed each year remained fairly stable between 2002 (164) and 2011 (152). 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 (796), followed by those age 60 and older (325) (Table 41). The crude RPMP for heart transplants varied from 3.5 to 4.9 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).

Longer-term survival rates showed continued improvement for much of the period under examination (Figure 16). In 2008, 93% of recipients survived the first three years, and five-year survival also improved from 75% to 85% between 2002 and 2006.

In 2011, there were 2,533 Canadians living with a heart transplant.

Table 40: Heart Transplant Waiting List at December 31 and Deaths, 2002 to 2011

	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	Total
Age 0–17	13	37	6	9	7	13	17	12	14	23	**151**
Age 18+	90	94	119	87	80	102	114	124	121	143	**1,074**
Total	103	131	125	96	87	115	131	136	135	166	**1,225**
Deaths on Waiting List	35	30	26	27	13	19	14	30	22	25	**241**

Source
Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information.

Table 41: Heart Transplants by Year, Age Group and Re-Transplants, Canada, 2002 to 2011 (Number)

		2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	Total
Pediatric: Age 0–17	First Graft Age <1	5	6	14	15	17	7	16	17	5	8	**110**
	First Graft Age 1–10	8	4	7	8	7	9	6	11	12	9	**81**
	First Graft Age 11–17	8	10	9	9	9	11	15	9	9	8	**97**
Adults: Age 18+	First Graft Age 18–34	15	16	13	18	27	14	19	17	21	12	**172**
	First Graft Age 35–59	84	82	66	86	91	85	75	78	73	76	**796**
	First Graft Age 60+	41	33	30	33	20	31	30	33	47	27	**325**
Re-Transplants		3	6	4	5	7	6	3	3	2	12	**51**
Total		**164**	**157**	**143**	**174**	**178**	**163**	**164**	**168**	**169**	**152**	**1,632**

Source
Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information.

Table 42: Primary Diagnosis* for Heart Transplant Recipients, Canada, 2002 to 2011 (Percentage)

	Age <1	Age 1–10	Age 11–17	Age 18–34	Age 35–59	Age 60+	Total
Congenital	40.3	25.3	15.5	12.9	2.6	0	**7.8**
Cardiomyopathy Unspecified	7.6	6.0	14.6	9.7	10.1	10.5	**10**
Dilated Cardiomyopathy	10.1	9.6	20.4	26.3	22.5	17.4	**20.2**
Idiopathic Cardiomyopathy	4.2	7.2	5.8	13.4	10.8	11.1	**10.2**
Ischemic Cardiomyopathy	0	1.2	1.0	3.2	28.6	45.5	**24.1**
Unknown/Missing	16.8	22.9	20.4	3.2	2.8	3.0	**6**
Other*	21.0	27.7	22.3	31.2	22.6	12.6	**21.7**
Total	**100**	**100**	**100**	**100**	**100**	**100**	**100**

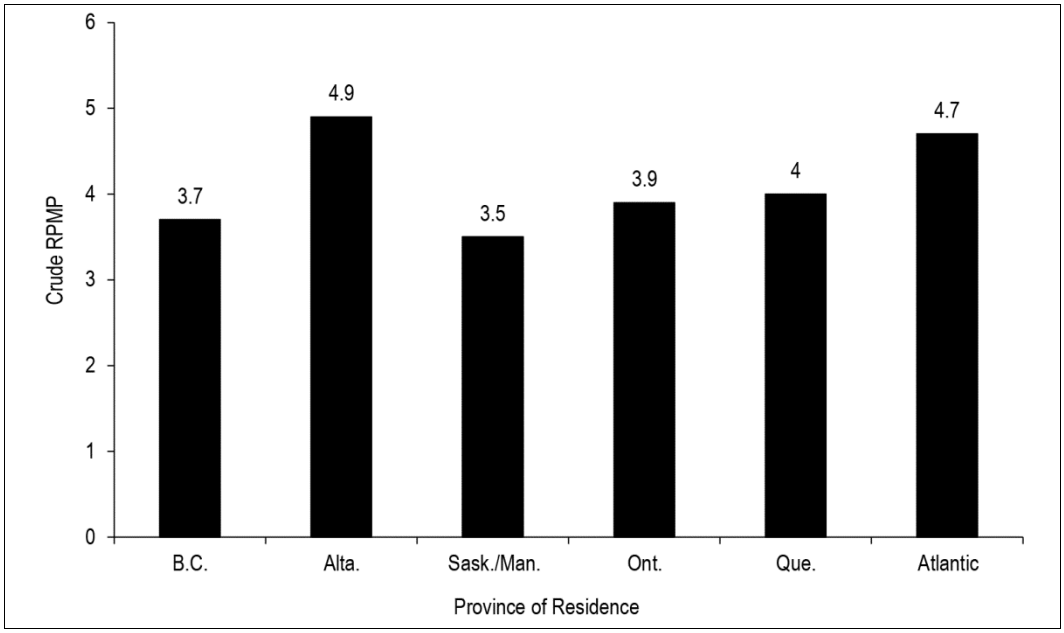
Note

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

Source

Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information.

Figure 14: Heart Transplant Recipients by Province of Residence, Canada, 2011 (Crude Rate per Million Population)



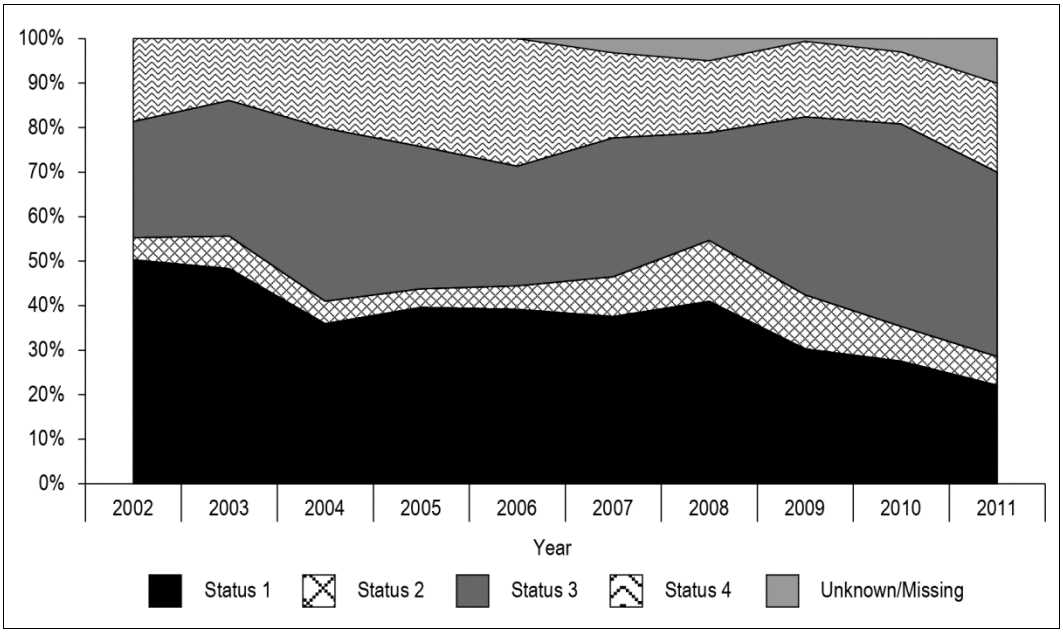
Note

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

Source

Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information.

Figure 15: Distribution of Heart Transplants by Medical Status* at Transplant, Canada, 2002 to 2011



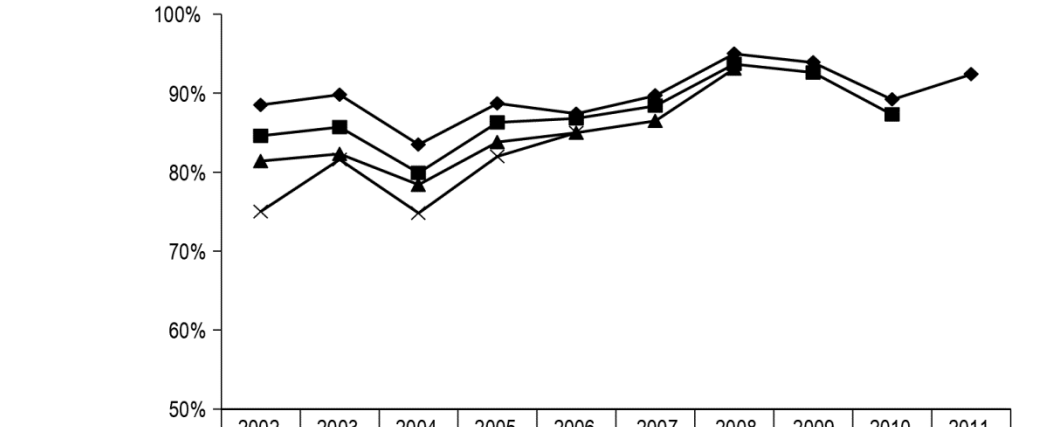
Note

* 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, 2012, 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, 2002 to 2011 (Percentage)



	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011
3 Months	88.5	89.8	83.5	88.7	87.4	89.7	95	93.9	89.2	92.4
1 Year	84.6	85.7	79.9	86.3	86.8	88.4	93.7	92.6	87.3	—
3 Years	81.4	82.3	78.4	83.8	85	86.5	93.1	—	—	—
5 Years	75	81.6	74.8	82	85	—	—	—	—	—

Source

Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information.

Table 43: Prevalent Heart Transplant Patients, by Province of Treatment/Follow-Up, 2002 to 2011 (Number)

	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011
B.C.	163	178	182	192	200	213	227	230	242	250
Alta.	269	285	298	324	350	365	383	411	435	459
Sask.	13	14	14	14	15	16	20	22	22	21
Man.	5	5	5	<5*	<5*	<5*	<5*	<5*	8	9
Ont.	692	731	754	789	819	855	891	935	981	1,011
Que.	460	482	485	496	509	531	567	605	629	647
N.S.	96	99	103	108	110	113	116	126	128	136
Canada†	**1,698**	**1,794**	**1,841**	**1,927**	**2,007**	**2,096**	**2,207**	**2,332**	**2,445**	**2,533**

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, 2012, 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 2002 to 2011.

The number of individuals on the waiting list for a lung transplant continued to grow over the decade, reaching 311 in 2011. Since 2002, the number of people dying annually more than doubled from 26 to 67 in 2011 (Table 44).

Between 2002 and 2011, there was an increase in the annual number of lung transplants performed in Canada. During the decade, the total number of lung transplants reached 1,604, with an average of 178 performed each year since 2006 (Table 45). Between 2002 and 2011, the volume of bilateral lung transplants increased by 66%, from 96 to 159. Single-lung transplant volumes averaged 27 procedures per year over the 10 years (Table 46).

In 2011, Ontario had the highest rate of lung transplantation, at 6.5 RPMP, followed by Alberta (5.7 RPMP) and British Columbia (3.7 RPMP) (Figure 17).

Rates of patient survival for lung transplant generally show an increasing trend (Figure 18). Three-year survival increased from 71% to 82% between 2002 and 2008. Similarly, five-year survival increased from 62% to 66% between 2002 and 2006. Three-month and one-year survival showed similar improvements (90% to 98% from 2002 to 2011, and 86% to 90% from 2002 to 2010, respectively).

There were 1,500 Canadians living with a transplanted lung in 2011 (Table 47).

Table 44: Lung Transplant Waiting List at December 31 and Waiting List Deaths, Canada, 2002 to 2011

	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	Total
Bilateral Lung	88	131	155	188	147	183	147	137	178	188	**1,542**
Single Lung	50	29	22	37	94	51	129	104	125	122	**763**
Heart–Lung	12	12	4	14	11	9	6	4	7	1	**80**
Total	**150**	**172**	**181**	**239**	**252**	**243**	**282**	**245**	**310**	**311**	**2,385**
Deaths on Waiting List	26	29	43	43	36	43	44	44	51	67	**426**

Source
Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information.

Table 45: Lung Transplants by Year, Age Group and Re-Transplants, Canada, 2002 to 2011 (Number)

	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	Total
First Graft, Age 18+	130	112	128	137	166	179	156	178	174	167	**1,527**
First Graft, Age 0–17	5	2	3	5	4	4	6	4	3	5	**41**
Re-Transplants	4	4	2	3	1	4	5	7	3	3	**36**
Total	**139**	**118**	**133**	**145**	**171**	**187**	**167**	**189**	**180**	**175**	**1,604**

Source
Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information.

Table 46: Lung Transplants by Transplant Type, Canada, 2002 to 2011 (Number)

	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	Total
Bilateral Lung	96	95	98	119	129	152	135	153	153	159	**1,289**
Single Lung	36	21	30	19	35	32	28	31	25	13	**270**
Living-Donor Lobar	0	0	2	1	1	0	0	0	0	1	**5**
Heart–Lung	7	2	3	6	6	3	4	5	2	2	**40**
Total	**139**	**118**	**133**	**145**	**171**	**187**	**167**	**189**	**180**	**175**	**1,604**

Source
Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information.

Table 47: Primary Diagnoses* for Lung Transplant Recipients, First Graft, Canada, 2002 to 2011 (Number, Percentage)

	Bilateral Lung		Single Lung		Heart–Lung	
	N	%	N	%	N	%
Congenital	8	0.6	0	0.0	13	31.7
Alpha-1-Antitrypsin Deficiency	59	4.6	12	4.3	0	0.0
Cystic Fibrosis	348	27.4	11	3.9	3	7.3
Emphysema/Chronic Obstructive Pulmonary Disease	281	22.1	120	42.9	4	9.8
Idiopathic Pulmonary Fibrosis	287	22.6	100	35.7	3	7.3
Primary Pulmonary Hypertension	54	4.3	2	0.7	6	14.6
Unknown/Missing	48	3.8	5	1.8	3	7.3
Other†	184	14.5	30	10.7	9	22.0
Total	**1,269**	**100.0**	**280**	**100.0**	**41**	**100.0**

Notes

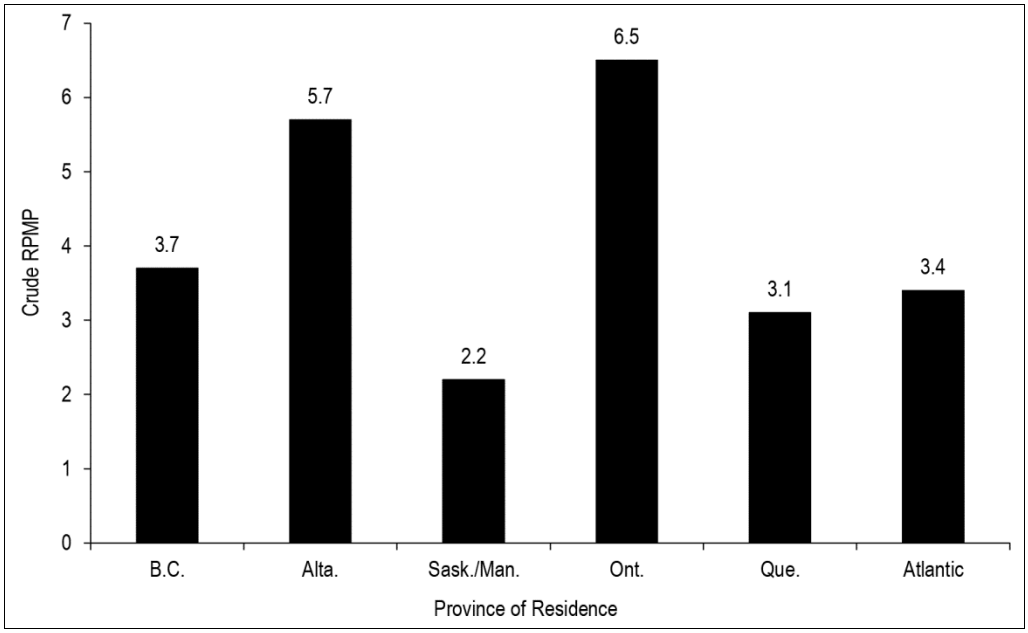
* More than one diagnosis can be reported for a patient.

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

Source

Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information.

Figure 17: Lung Transplant Recipients by Province of Residence, Canada, 2011 (Crude Rate per Million Population)



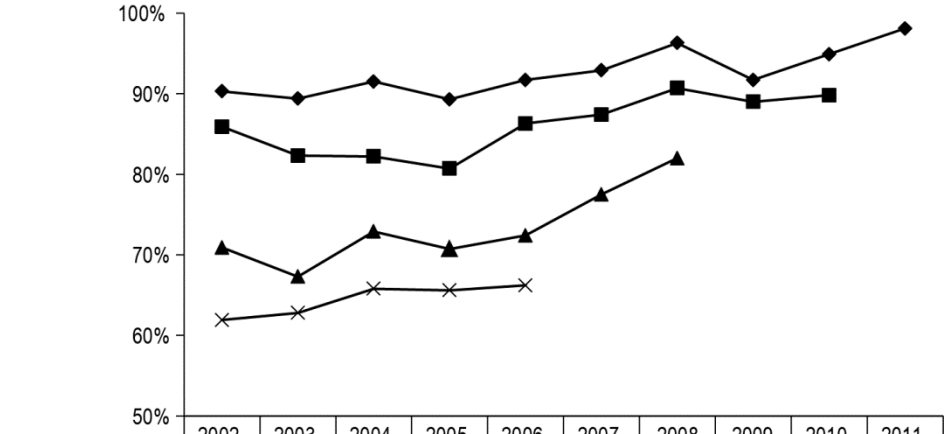
Note

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

Sources

Canadian Organ Replacement Register, 2012, 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, 2002 to 2011(Percentage)



	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011
3 Months	90.3	89.4	91.5	89.3	91.7	92.9	96.3	91.7	94.9	98.1
1 Year	85.9	82.3	82.2	80.7	86.3	87.4	90.7	89	89.8	—
3 Years	70.9	67.3	72.9	70.7	72.4	77.5	82	—	—	—
5 Years	61.9	62.8	65.8	65.6	66.2	—	—	—	—	—

Source
Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information.

Table 48: Prevalent Lung Transplant Patients, by Province of Treatment/Follow-Up, 2002 to 2011 (Number)

	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011
B.C.	54	55	59	63	67	76	86	82	88	95
Alta.	123	132	147	167	186	205	232	253	293	325
Sask.	5	5	5	5	6	8	15	29	29	29
Man.	55	63	71	71	74	79	85	87	91	94
Ont.	289	311	342	376	424	495	539	585	630	695
Que.	127	143	157	155	175	200	207	233	255	262
Canada	**653**	**709**	**781**	**837**	**932**	**1,063**	**1,164**	**1,269**	**1,386**	**1,500**

Source
Canadian Organ Replacement Register, 2012, 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 2011 was 171 (Table 49). More than 60% were waiting for a simultaneous kidney–pancreas transplant.

During the decade from 2002 to 2011, there were 711 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 2002, 357 procedures have been performed on 259 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 at December 31, Canada, 2002 to 2011

Transplant	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011
SKP	122	120	101	132	113	126	98	56	107	108
PAK/PTA	37	31	51	63	63	55	49	42	68	63
Total	**159**	**151**	**152**	**195**	**176**	**181**	**147**	**98**	**175**	**171**

Note
SKP: simultaneous kidney–pancreas transplant; PAK: pancreas after kidney transplant; PTA: pancreas transplant alone.
Source
Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information.

Table 50: Pancreas Transplants by Year, Canada, 2002 to 2011 (Number)

Transplant	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	Total
SKP	44	38	47	53	55	50	63	48	50	53	**501**
PAK	17	17	11	12	13	13	18	20	20	16	**157**
PTA	11	9	3	6	5	6	3	2	5	3	**53**
Total	**72**	**64**	**61**	**71**	**73**	**69**	**84**	**70**	**75**	**72**	**711**

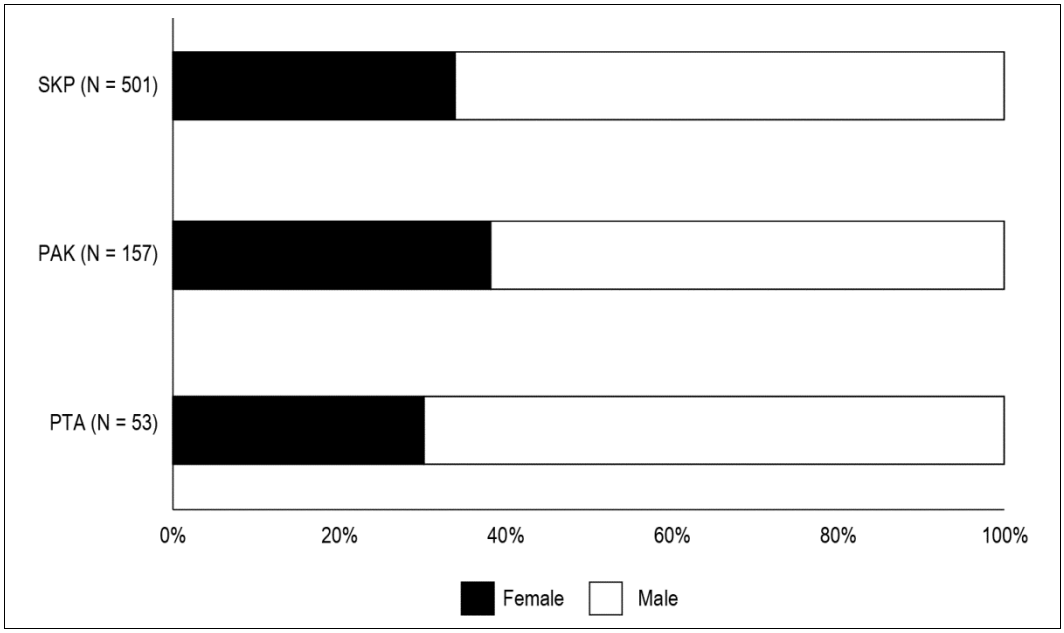
Note
SKP: simultaneous kidney–pancreas transplant; PAK: pancreas after kidney transplant; PTA: pancreas transplant alone.
Source
Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information.

Table 51: Islet Cell Transplants in Canada, 2002 to 2011

	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	Total
Patients	26	15	25	28	31	18	28	29	32	27	**259**
Procedures	41	21	39	39	39	25	35	38	44	36	**357**

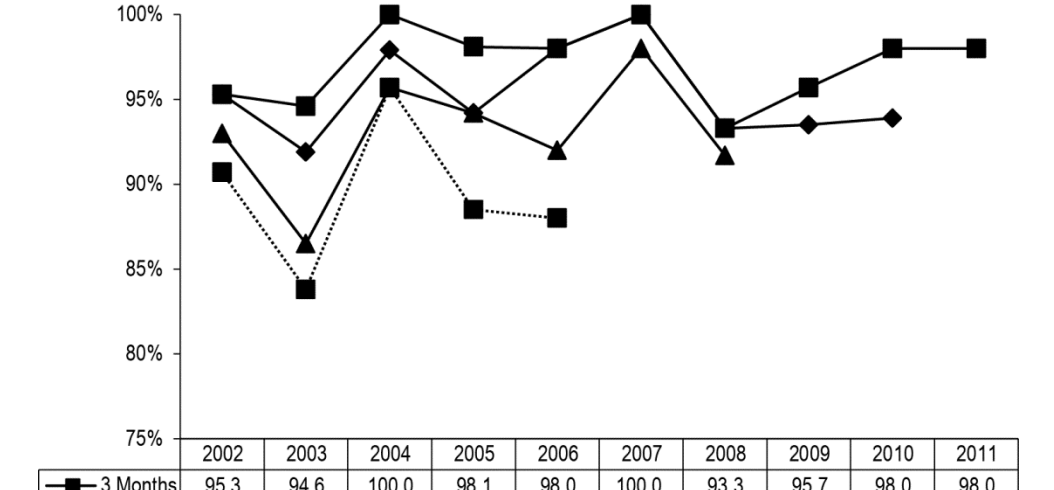
Source
Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information.

Figure 19: Pancreas Transplant Recipients by Type and Recipient Sex, First Graft, Canada, 2002 to 2011 (Percentage)



Note
SKP: simultaneous kidney–pancreas transplant; PAK: pancreas after kidney transplant; PTA: pancreas transplant alone.
Source
Canadian Organ Replacement Register, 2012, 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, 2002 to 2011 (Percentage)



	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011
3 Months	95.3	94.6	100.0	98.1	98.0	100.0	93.3	95.7	98.0	98.0
1 Year	95.3	91.9	97.9	94.2	98.0	100.0	93.3	93.5	93.9	—
3 Years	93.0	86.5	95.7	94.2	92.0	98.0	91.7	—	—	—
5 Years	90.7	83.8	95.7	88.5	88.0	—	—	—	—	—

Source

Canadian Organ Replacement Register, 2012, 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 1992, there have been 54 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, 1992 to 2011 (Number)

	1992–2001		2002–2011		Total		
Type of Transplant	Age 0–17	Age 18+	Age 0–17	Age 18+	Age 0–17	Age 18+	All Ages
Multi-Visceral	1	3	5	6	6	9	15
Isolated Small Intestine	5	2	3	7	8	9	17
Liver–Small Intestine	6	2	10	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	**13**	**9**	**18**	**14**	**31**	**23**	**54**

Source
Canadian Organ Replacement Register, 2012, 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 1992 and 2011.

Chapter 8—Donors

8 Donors

Overall, the number of Canadian organ donors increased from 846 in 2002 to 1,033 in 2011, a relative increase of 22% (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, transplant procedures increased 18%, from 1,789 in 2002 to 2,124 in 2011 (Figure 22).

Although the total number of deceased donors remained stable over the past decade, the age composition of donors changed. In 2002, deceased donors age 55 and older accounted for 25% of donors, while in 2011 they accounted for 37% (Table 53). Conversely, in 2011, 8% of deceased donors were younger than 18, compared with 12% of donors in 2002. This changing age profile was also reflected in living donors (Table 54). The number of living donors increased among those age 55 and older. This age group accounted for 20% of living donors in 2011, compared with 10% in 2002.

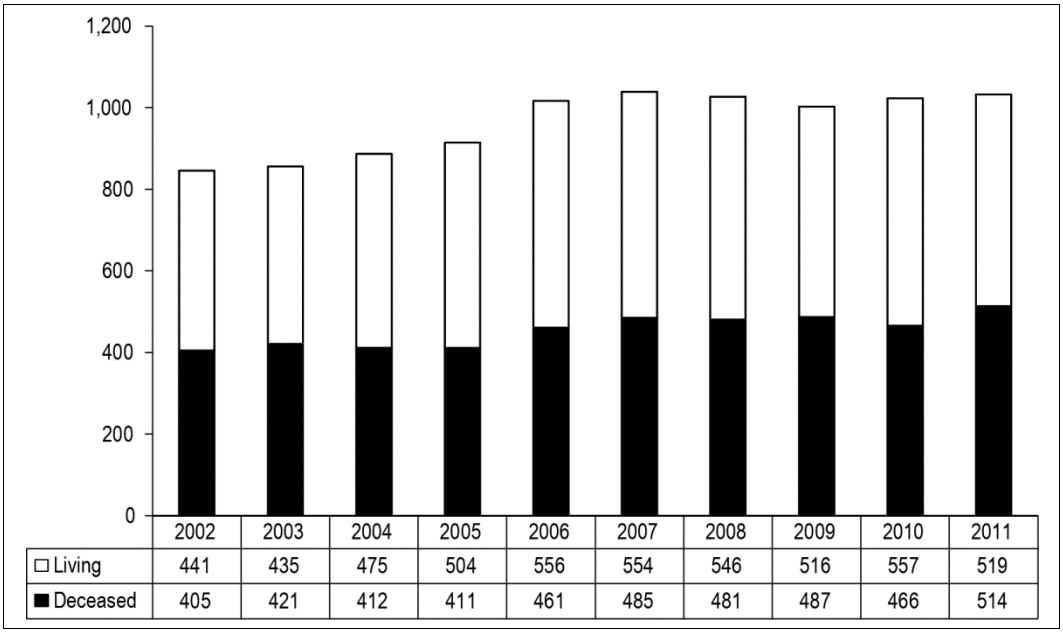
Between 2002 and 2011, 34% of living donors in Canada were unrelated (the definition of unrelated includes spouses). The proportion of unrelated donors has increased from 26% of living donors in 2002 to 43% in 2011 (Table 55).

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 2011 was 14.9, the highest rate achieved during the 10-year period and 17% above the rate recorded in 2005 (Figure 23). The living DRPM was 15.1. Figures 24 and 25 provide corresponding regional donor rates.

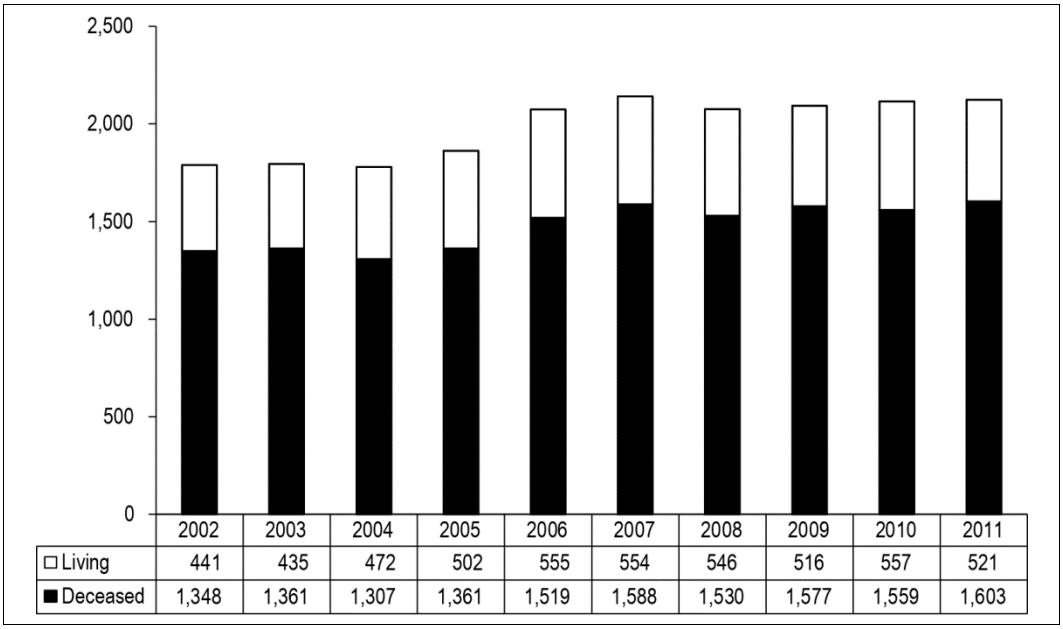
Figure 21: Number of Canadian Organ Donors by Donor Source (Deceased or Living), 2002 to 2011



	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011
□ Living	441	435	475	504	556	554	546	516	557	519
■ Deceased	405	421	412	411	461	485	481	487	466	514

Source
Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information.

Figure 22: Number of Solid Organ Transplants by Donor Source (Deceased or Living), Canada, 2002 to 2011



	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011
□ Living	441	435	472	502	555	554	546	516	557	521
■ Deceased	1,348	1,361	1,307	1,361	1,519	1,588	1,530	1,577	1,559	1,603

Source
Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information.

Table 53: Number of Deceased Donors by Age Group, Canada, 2002 to 2011

	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	Total
Age 0–17	47	36	29	47	41	53	49	39	34	43	**418**
Age 18–39	109	128	114	99	115	108	131	125	138	128	**1,195**
Age 40–49	96	95	86	83	102	101	92	86	82	97	**920**
Age 50–54	51	36	43	51	53	60	50	51	74	55	**524**
Age 55–59	41	35	46	44	48	52	58	53	42	60	**479**
Age 60+	61	91	94	87	102	111	101	133	96	131	**1,007**
Total	**405**	**421**	**412**	**411**	**461**	**485**	**481**	**487**	**466**	**514**	**4,543**

Source
Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information.

Table 54: Number of Living Donors by Age Group, Canada, 2002 to 2011

	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	Total
Age 0–39	191	178	190	180	218	199	188	169	192	188	**1,893**
Age 40–49	144	139	151	159	163	178	177	171	170	144	**1,596**
Age 50–54	63	58	61	66	66	78	87	72	73	85	**709**
Age 55–59	28	26	34	48	49	68	56	54	64	59	**486**
Age 60+	15	18	22	23	32	31	37	50	58	43	**329**
Unknown	0	16	17	28	28	0	1	0	0	0	**90**
Total	**441**	**435**	**475**	**504**	**556**	**554**	**546**	**516**	**557**	**519**	**5,103**

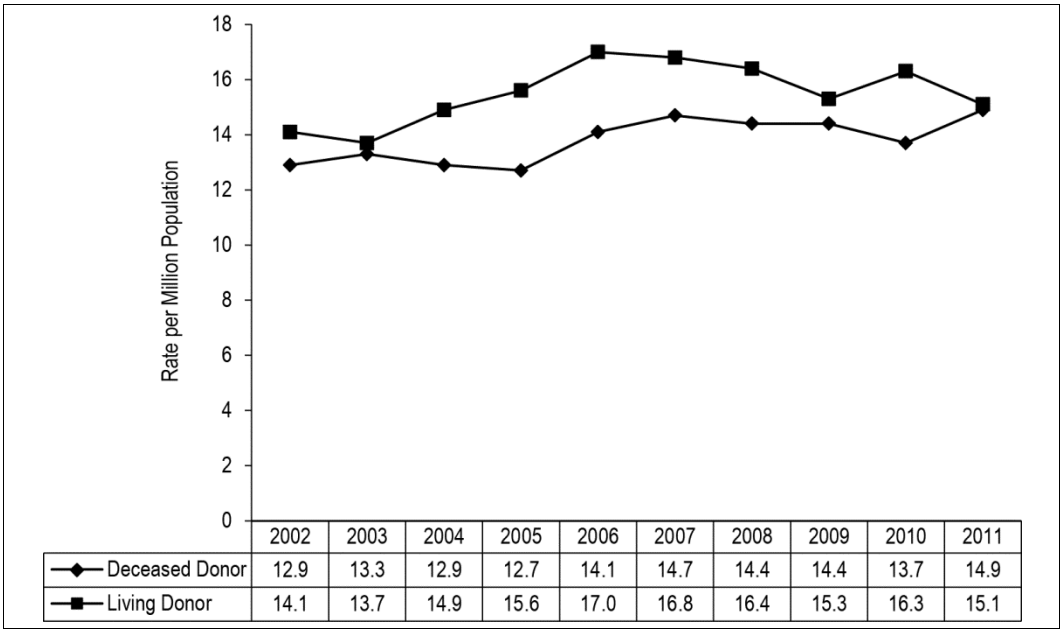
Source
Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information.

Table 55: Living Donor by Relationship of Donor to Recipient, Canada, 2002 to 2011

	Parent	Sibling	Offspring	Other Related*	Spouse	Unrelated	Total
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	76	39	96	104	**516**
2010	79	126	86	43	80	143	**557**
2011	66	131	54	43	85	140	**519**

Note
* Family members such as aunts, uncles or cousins.
Source
Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information.

Figure 23: Donor Rate per Million Population, by Donor Source (Deceased or Living), Canada, 2002 to 2011

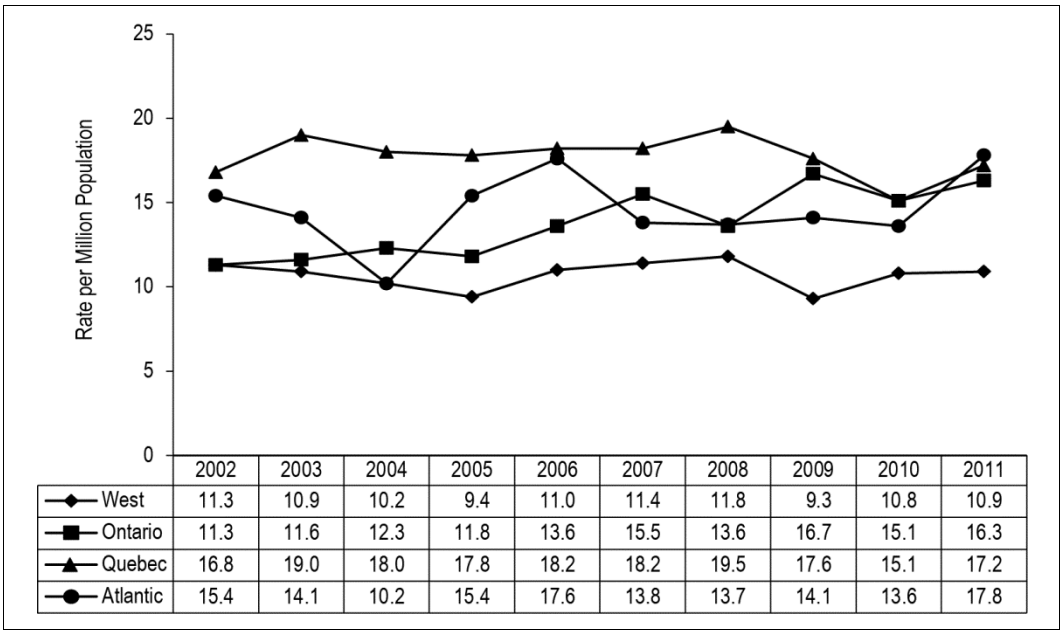


	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011
Deceased Donor	12.9	13.3	12.9	12.7	14.1	14.7	14.4	14.4	13.7	14.9
Living Donor	14.1	13.7	14.9	15.6	17.0	16.8	16.4	15.3	16.3	15.1

Source

Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information.

Figure 24: Deceased Donor Rate per Million Population by Region, Canada, 2002 to 2011



	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011
West	11.3	10.9	10.2	9.4	11.0	11.4	11.8	9.3	10.8	10.9
Ontario	11.3	11.6	12.3	11.8	13.6	15.5	13.6	16.7	15.1	16.3
Quebec	16.8	19.0	18.0	17.8	18.2	18.2	19.5	17.6	15.1	17.2
Atlantic	15.4	14.1	10.2	15.4	17.6	13.8	13.7	14.1	13.6	17.8

Notes

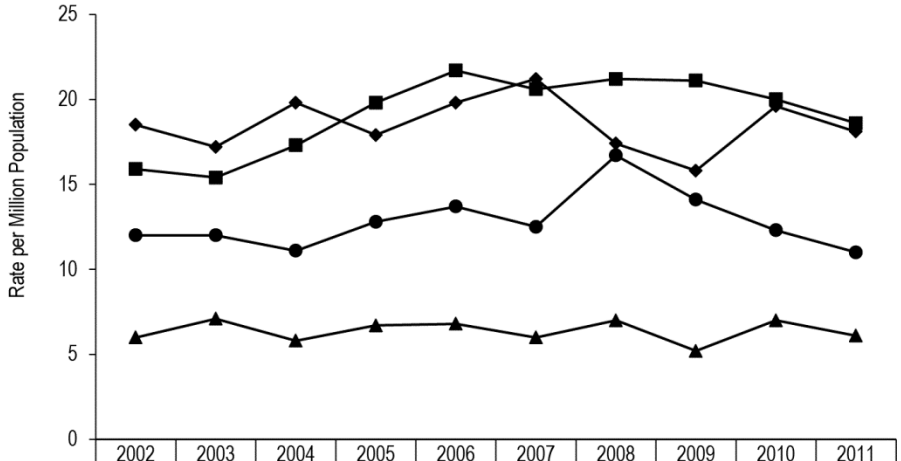
West includes British Columbia, Alberta, Saskatchewan and Manitoba.

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

Source

Canadian Organ Replacement Register, 2012, Canadian Institute for Health Information.

Figure 25: Living Donor Rate per Million Population, by Region, Canada, 2002 to 2011



	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011
West	18.5	17.2	19.8	17.9	19.8	21.2	17.4	15.8	19.6	18.1
Ontario	15.9	15.4	17.3	19.8	21.7	20.6	21.2	21.1	20.0	18.6
Quebec	6.0	7.1	5.8	6.7	6.8	6.0	7.0	5.2	7.0	6.1
Atlantic	12.0	12.0	11.1	12.8	13.7	12.5	16.7	14.1	12.3	11.0

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, 2012, Canadian Institute for Health Information.

Appendices

Appendix A—Canadian Organ Replacement Register Board of Directors

CORR Board of Directors (October 1, 2012)

- 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
- Mr. Peter Hoult, Kidney Foundation of Canada—Secretary/Treasurer
- Dr. Brenda Hemmelgarn, Canadian Society of Nephrology
- Dr. Joanne Kappel, Canadian Society of Nephrology
- Dr. Daniel H. Kim
- Dr. Scott Klarenbach
- Dr. Jean-Philippe Lafrance, Quebec Society of Nephrology
- Dr. Susan M. Samuel
- Dr. Lianne Singer
- Dr. Rosalie Starzomski, Canadian Association of Nephrology Nurses and Technicians
- Dr. Jean Tchervenkov, Quebec Society of Transplant
- 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

	Types of Transplants Performed in 2011								Dialysis Programs in 2011			
Hospital/Facility	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			
Kootenay-Boundary Regional									X	X	X	X
Penticton Regional									X		X	X
University of Northern B.C.									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	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	X
St. Paul's	X								X	X	X	X
Manitoba												
Brandon Regional									X			
Children's Hospital of Winnipeg	X								X		X	X
Health Sciences Centre	X			X	X				X	X		
Seven Oaks General									X	X	X	X
St. Boniface General									X		X	X

Hospital/Facility	Types of Transplants Performed in 2011								Dialysis Programs in 2011			
	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	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	X
Humber River Regional									X	X	X	X
Kingston General	X								X	X	X	X
Lake of the Woods*									X			
Lakeridge Health									X	X	X	X
LHSC—University and South Street	X	X	X				X		X			
LHSC—Victoria									X	X	X	X
North Bay General									X		X	
Orillia Soldiers' Memorial									X	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
Health Sciences North									X	X	X	X
Sunnybrook Health Centre									X	X	X	X
Sussex Centre*									X			
Thunder Bay Regional—McKellar Site									X	X	X	X
Timmins and District									X		X	X

Hospital/Facility	Types of Transplants Performed in 2011								Dialysis Programs in 2011			
	Kidney	Liver	Heart	Heart/ Lung	Lung	Intestine/ Multi-Visceral	Pancreas/ Kidney–Pancreas	Islet Cell	HD	Home HD Training†	PD	Home PD Training
Ontario (cont'd)												
Toronto East General									X	X		
Toronto General—University Health Network	X	X	X		X	X	X		X	X	X	X
University of Ottawa Heart Institute			X									
William Osler									X			
Mckenzie Richmond Hill									X		X	X
Quebec												
Aurores boréales									X		X	
Charles-LeMoyne									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
CHUM—Saint-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 Témiscaminque												
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			
Maisonneuve-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
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 2011								Dialysis Programs in 2011			
	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
Dr.-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.

HD: hemodialysis; PD: peritoneal dialysis.

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 Sherbrook 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.motphalifax.net

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: 2002 to 2011

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/Territory, 2011

	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	33	4	4	0	3	0	**98**
Affiliated Community Centres	27	32	9	14	53	6	6	10	0	9	0	**166**
Independent Health Care Facilities Offering Hemodialysis	0	0	0	0	11	6	1	0	4	0	2	**24**

Table D2: Transplant Programs Within CORR Frame by Province, 2011

	B.C.	Alta.	Sask.	Man.	Ont.	Que.	N.S.	Total
Kidney	3	3	1	2	7	7	2	**25**
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/ Territory 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.

In 2010, database functionality was enhanced to allow for the electronic submission and processing of dialysis data using defined submission specifications.These specifications include the same edit checks and validation rules that are applied to data entered manually. For this report, 2011 data reported by the Ontario Renal Network was submitted using this method. CORR monitors electronic submissions to ensure that no changes in completeness or quality are detected.

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 the DAD. For coverage of dialysis treatment in Ontario, the patients receiving dialysis were comparable between CORR and NACRS.

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

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

1) Incident ESRD Cases
In 2011, unit non-response for incident ESRD cases (under-reporting) was estimated to be approximately 300 cases from six to eight centres in 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 2011, and shows that the new patient-level data is marginally less than the OPO aggregate counts. This suggests 99.9% reporting of aggregate data.

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

Table D5: Comparison of Counts of Kidney Transplants* by Data Source, 2011 (Number)

	B.C.	Alta.	Sask.	Man.	Ont.	Que.	N.S.	Total
Aggregate Counts Provided by OPOs at Year-End	194	139	2	39	550	268	107	**1,299**
Patient-Level Data for Transplants in CORR	193	139	2	39	550	270	107	**1,300**

Note

* Includes simultaneous kidney–pancreas and other kidney combination transplants.

3) Extra-Renal Transplants

For the extra-renal transplants in 2011, 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, 2011 (Number)

Organ Type	Data Source†	B.C.	Alta.	Sask.	Man.	Ont.	Que.	N.S.	Total
Liver	CORR Registration	56	70	0	0	231	98	30	**485**
	OPO Count	56	70	0	0	231	98	30	**485**
Heart	CORR Registration	15	34	0	1	61	35	8	**154**
	OPO Count	15	34	0	0	61	38	8	**156**
Lung/ Heart–Lung	CORR Registration	12	33	0	6	102	22	0	**175**
	OPO Count	12	33	0	6	102	28	0	**181**
Pancreas	CORR Registration	8	11	0	0	34	12	3	**68**
	OPO Count	8	11	0	0	34	13	3	**69**
Islets	CORR Registration	2	34	0	0	0	0	0	**36**
	OPO Count	3	34	0	0	0	0	0	**37**
Intestine/ Multi-Visceral	CORR Registration	0	1	0	0	1	0	0	**2**
	OPO Count	0	1	0	0	1	0	0	**2**

Notes

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

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

4) Donors

A comparison of donors registered in CORR with donor numbers reported by OPOs at year-end is provided in Table D7. This table suggests that no under-reporting of donors has been observed in CORR. Overall, the number of donors collected by CORR between 2002 and 2011 was greater by 26 donors than initially reported by OPOs.

Table D7: Comparison of Deceased and Living Donors Registered in CORR and Reported by OPOs, 2002 to 2011(Number)

Year	Registered in CORR			Reported by OPOs		
	Deceased Donors	Living Donors	Total Donors	Deceased Donors	Living Donors	Total Donors
2002	405	441	**846**	405	433	**838**
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	516	**1,003**	487	516	**1,003**
2010	466	557	**1,023**	468	549	**1,017**
2011	514	519	**1,033**	514	518	**1,032**
Total	**4,543**	**5,103**	**9,646**	**4,550**	**5,070**	**9,620**

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, ON: 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 2002 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, 2002 to 2011

Data Type	Data Element	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011
Deceased Donor	Age	0	0	0	0	0	0	0	0	0	0
	Sex	0.2	0.2	0.2	0	0.2	0.2	0	0	0	0
	Blood Type	0	0	2.4	0.2	0	0.4	0.2	0.4	0.2	0
	Race/Ethnic Origin	3.5	22.1	31.6	36.7	34.7	36.3	36.6	31.6	16.3	5.8
	Province of Residence	0	0	0	0	0	0.2	0.2	0	0	0.2
	Cause of Death	2.2	2.4	2.9	2.9	6.3	5.8	3.3	4.1	2.4	1
Living Donor	Age	0	0	0	0	0	0	0	0	0	0
	Sex	0.2	0	0	0	0.5	0.2	0.2	0	0	0.2
	Blood Type	6.8	7.4	12.4	9.5	4.5	0.7	1.5	1.9	1.1	1.9
	Province of Residence	0.2	0.2	1.3	1.2	2.2	1.1	0.5	0	0.9	0.2
Transplant Recipients	Sex	0	0	0	0	0	0.1	0	0	0	0
	Race/Ethnic Origin	16.1	20.1	21.1	23.6	22.1	19.8	19.4	19.4	18.3	20.0
	Blood Type	3.2	4.1	3.1	3.6	2.9	4.2	4.7	2	1.5	4.4
	Residential Postal Code	0.7	3.2	2.4	1.7	0.9	1.9	1	0.8	0.9	1.2
	Cause of Death	24.2	24.3	21.6	24.4	22.0	30.8	18.5	21.3	13.5	18.6
	Diagnosis	0.8	5.1	2.1	3	3.5	7.5	4.2	4.1	6.1	6.8
	Medical Status at Listing (Heart, Liver, Lung Transplants)	1.9	3.4	1.6	3.1	4.5	4	4	4.8	3.9	10.2
	Medical Status at Transplant (Heart, Liver, Lung Transplants)	1.0	0.8	0.4	1.4	1.0	2.9	2.2	2.5	3.7	7.7
	Cause of Graft Failure (Transplants With Failed Grafts)	43.9	53.2	53.5	44.7	51.9	57.0	46.7	59.0	52.7	58.3

Note

* Recipients of first grafts for 2002 to 2011.

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 2002 to 2011. 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, 2002 to 2011

Data Type	Data Element	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	Total
Recipients	Sex	0	0	0	0	0	0	0	0	0	0.1	**0**
	Race/Ethnic Origin	6.0	6.7	5.5	4.8	6.8	5.2	4.6	5.8	4.8	3.7	**5.4**
	Residential Postal Code	0.6	1.0	1.0	1.1	0.9	1.2	1.8	1.1	1.0	1.0	**1.1**
	Diagnosis	13.6	14.3	12.9	12.6	13.0	14.8	14.7	16.1	13.6	11.3	**13.7**
	Cause of Death	27.1	29.6	25.4	28.4	28.1	28.7	27.6	26.3	27.7	24.5	**27.7**
Risk Factors	Angina	6.8	9.1	9.1	9.3	11.7	11.1	13.1	15.1	13.6	8.3	**10.7**
	Coronary Artery Bypass/Angioplasty	7.4	9.6	8.9	9.4	10.9	10.8	12.3	13.4	12.1	6.7	**10.2**
	Pulmonary Edema	7.3	9.3	9.3	9.3	11.0	11.0	12.2	14.1	12.4	7.2	**10.4**
	Myocardial Infarct	6.9	8.8	9.1	9.0	10.8	10.5	12.4	13.9	12.2	7.3	**10.1**
	Diabetes	4.3	6.4	6.5	6.4	8.0	6.6	8.0	8.0	6.6	4.7	**6.6**
	Cerebrovascular Accident	6.7	8.2	8.8	8.5	10.8	10.2	12.2	13.9	12.2	6.5	**9.8**
	Peripheral Vascular Disease	7.4	9.3	9.4	9.2	11.3	11.0	12.8	14.9	13.1	7.3	**10.6**
	Malignancy	8.7	11.2	10.6	12.7	13.2	14.5	16.2	19.5	16.4	9.5	**13.3**
	Chronic Lung Disease	7.8	9.3	9.7	9.4	11.5	11.5	13.2	16.2	14.8	7.6	**11.1**
	Use of Medications for Hypertension	4.9	6.7	7.0	6.6	8.1	7.2	8.1	8.6	9.6	6.7	**7.3**
	Presence of Other Serious Illness	18.2	19.3	18.8	21.3	20.0	18.6	24.7	27.8	23.0	20.2	**21.2**
	Current Smoker	13.7	13.2	15.4	15.3	15.6	15.0	15.9	17.8	18.0	11.2	**15.1**

Table D10: Non-Response/Unknown Values for Key Analytical Data Elements Related to Incident Dialysis Patients Registered in CORR by Province, 2002 to 2011

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	15.9	6.3	1.8	5.0	3.7	3.2	3.1	7.9	1.8	**5.4**
	Residential Postal Code	1.5	1.3	0.4	1.5	0.7	1.4	3.2	1.5	0.7	**1.1**
	Diagnosis	32.1	10.4	7.7	7.0	11.4	13.8	8.7	8.6	12.8	**13.7**
	Cause of Death	55.1	37.5	20.6	28.6	21.9	24.5	9.8	23.8	11.9	**27.7**
Risk Factors	Angina	34.3	8.5	8.9	10.9	6.8	9.0	3.2	2.4	1.5	**10.7**
	Coronary Artery Bypass/Angioplasty	34.3	8.2	3.3	10.5	6.3	9.0	3.4	1.8	1.8	**10.2**
	Pulmonary Edema	33.9	7.6	5.9	10.1	6.6	9.2	3.0	2.2	1.8	**10.4**
	Myocardial Infarct	33.4	7.7	6.0	10.4	6.2	9.1	2.8	2.8	1.8	**10.1**
	Diabetes	28.6	3.4	0.9	7.5	2.8	5.7	1.6	0.6	0.5	**6.6**
	Cerebrovascular Accident	33.7	7.3	4.9	10.0	6.2	8.1	3.0	1.5	1.1	**9.8**
	Peripheral Vascular Disease	35.2	8.2	5.4	10.5	6.8	8.8	2.6	2.6	2.1	**10.6**
	Malignancy	38.9	12.6	7.4	10.9	9.1	12.3	5.1	2.3	4.1	**13.3**
	Chronic Lung Disease	36.7	8.9	6.5	10.4	7.3	8.7	4.0	2.8	2.3	**11.1**
	Use of Medications for Hypertension	31.3	3.3	1.0	7.6	3.5	6.2	2.1	0.9	0.9	**7.3**
	Presence of Other Serious Illness	52.8	22.5	12.7	13.5	16.6	18.2	19.5	9.1	6.6	**21.2**
	Current Smoker	43.8	10.7	9.9	13.9	9.2	17.3	11.2	5.1	3.3	**15.1**

Reliability/Response Bias: A formal linkage[ix] of CORR data to the 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 the 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.

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.

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

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)

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.

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

- **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 m^2 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 2002 and 2011. 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) × 1,000,000

Age-specific rate = (number of cases in age group／population of age group) × 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	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011
B.C.*	4,145,550	4,182,843	4,227,592	4,285,510	4,341,681	4,342,039	4,417,017	4,488,860	4,564,233	4,607,987
Alta.†	3,186,560	3,229,988	3,274,349	3,329,790	3,448,406	3,587,925	3,671,210	3,763,284	3,797,591	3,856,350
Sask.	995,886	994,428	995,391	994,126	985,386	1,000,139	1,013,620	1,030,129	1,044,028	1,057,884
Man.	1,155,584	1,161,552	1,170,268	1,177,556	1,177,765	1,193,932	1,206,100	1,221,964	1,234,535	1,250,574
Ont.	12,102,045	12,256,645	12,392,721	12,541,410	12,686,952	12,794,689	12,936,296	13,069,182	13,227,791	13,372,996
Que.	7,445,745	7,492,333	7,542,760	7,598,146	7,651,531	7,687,125	7,753,470	7,828,879	7,905,679	7,979,663
Atlantic‡	2,341,217	2,342,677	2,343,235	2,343,969	2,331,769	2,326,107	2,329,624	2,337,561	2,352,324	2,357,325
Canada	**31,372,587**	**31,660,466**	**31,946,316**	**32,270,507**	**32,623,490**	**32,931,956**	**33,327,337**	**33,739,859**	**34,126,181**	**34,482,779**

Notes

* Includes 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	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011
N.B.	750,327	750,896	751,384	752,006	749,168	745,561	747,147	749,468	752,838	755,455
N.S./P.E.I.	1,071,441	1,073,431	1,074,824	1,076,002	1,072,924	1,074,016	1,076,036	1,079,168	1,088,205	1,091,292
N.L.	519,449	518,350	517,027	515,961	509,677	506,530	506,441	508,925	511,281	510,578
Total	**2,341,217**	**2,342,677**	**2,343,235**	**2,343,969**	**2,331,769**	**2,326,107**	**2,329,624**	**2,337,561**	**2,352,324**	**2,357,325**

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 (Moschcowitz 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 Codes—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 Codes—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-1-antitrypsin deficiency
28	Crigler–Najjar syndrome
21	Glycogen storage disease
23	Hemochromatosis
27	Hyperlipoproteinemia type 2
24	Niemann–Pick
26	Phenylketonuria
25	Protoporphyria
29	Tyrosinemia
22	Wilson disease
34	Metabolic disorder, other
Other Primary Diagnosis	
30	Congenital hepatic fibrosis
31	Caroli disease
32	Cystic disorders
52	Thrombosed hepatic artery
98	Unknown/missing
99	Other

Heart Transplant

Primary Diagnosis Codes—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

Primary Diagnosis Codes—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

Primary Diagnosis Codes—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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