Canadian Organ Replacement Register Annual Report: Treatment of End-Stage Organ Failure in Canada, 2003 to 2012

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

Table of Contents

Acknowledgements

This report was completed through the collaborative efforts and voluntary contributions of nephrology programs, organ procurement organizations, nephrologists, transplant physicians and surgeons, nurses and coordinators across Canada.

Parts of this material are based on data and information compiled and provided by Cancer Care Ontario. However, the analyses, conclusions, opinions and statements expressed herein are those of the author, and not necessarily those of Cancer Care Ontario.

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

The CORR annual report was developed at CIHI by

- Greg Webster, Director, Acute and Ambulatory Care Information Services
- Juliana Wu, Manager, Decision Support Services, CORR and Trauma Registries
- Bob Williams, Program Lead, CORR
- Frank Ivis, Senior Analyst, CORR
- Eric de Sa, Senior Analyst, CORR
- Norma Hall, Analyst, CORR

Summary[i]

Treatment of End-Stage Organ Failure in Canada, 2003 to 2012 reports on data from the Canadian Organ Replacement Register (CORR) at the Canadian Institute for Health Information (CIHI). The report examines dialysis, organ transplantation and donation characteristics and trends in Canada during the decade 2003 to 2012.

In 2012, there were 41,252 Canadians living with end-stage kidney disease (ESKD); 58% were receiving some form of dialysis. The remaining 42% had a functioning kidney transplant.

- Of the 23,814 patients on dialysis, more than three-quarters were receiving institutional hemodialysis, the most expensive treatment option.
- There were 5,431 newly diagnosed ESKD patients reported in 2012.
- More than half (53%) of the newly diagnosed ESKD patients were 65 and older.
- Nearly 38% of the newly diagnosed patients had diabetes as the main cause of their kidney failure.
- The average age of patients receiving a deceased donor kidney transplant was 53.5, and nearly 35% of patients were 60 and older.

In 2012, a total of 2,225 transplant procedures were performed, an increase of nearly 5% over 2011. The number of transplants performed has increased annually over the last four years. The 2,225 transplant procedures performed in 2012 resulted in 2,287 solid organs being transplanted, as highlighted below:

- Kidneys: 1,358
- Livers: 494
- Lungs: 194
- Hearts: 164
- Pancreases: 77

In 2012, there were 540 deceased organ donors in Canada, 26 more than the 514 reported in 2011. In addition, there were 539 living organ donors. This was the first year in which the number of deceased organ donors exceeded living donors.

- While a living donor provides a single organ for transplant, a deceased organ donor can provide up to eight organs.
- The 26 additional deceased organ donors in 2012 resulted in 82 more deceased donor transplants, compared with 2011.
- In 2012, a total of 36% of living organ donors were not related to the transplant recipient. Spouses accounted for 14% of living donors, while the remaining 22% had no relationship to the organ recipient. This latter group has grown from 13% in 2003, possibly reflecting the increased frequency of living donor paired exchange kidney transplants.

i. In 2012, under-reporting of incident ESKD cases from Quebec was estimated to be approximately 560 cases. Counts of organ donors and transplants from Quebec have been supplemented with additional data from Transplant Québec. For additional information, see Chapter 1 and Appendix D.

Highlights[ii]

Treatment of End-Stage Organ Failure in Canada, 2003 to 2012 draws on data from the Canadian Institute for Health Information (CIHI) Canadian Organ Replacement Register (CORR), primarily for the years 2003 through 2012 (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.

2012 Overview

- More than 50,000 Canadians were living with a transplant or were on dialysis.
- In total, 5,431 patients started renal replacement therapy (RRT).
- The 1,079 organ donors (living and deceased) resulted in 2,225 solid organ transplants.
- There were 15.5 deceased organ donors per million population, an increase of 17% since 2003. The living donor rate was 15.5 donors per million population.
- Altogether, 4,612 patients were waiting for a solid organ transplant at the end of the year.
- A total of 230[iii] Canadians died waiting for an organ transplant.

Kidney

- At the end of 2012, 41,252 Canadians were living with end-stage kidney disease (ESKD). Since 2003, this number has grown 40% from 29,540.
- Of these patients, 23,814 were on dialysis and 17,438 were living with a functioning kidney transplant.
- In total, 5,431 patients started RRT in 2012, with just less than 79% receiving hemodialysis as their initial treatment.
- There were 1,358 kidney transplants performed, an increase of 14% over the 1,195 performed in 2003.
- On December 31, there were 3,428 patients waiting for a kidney transplant.
- A total of 84 patients died while waiting for a kidney transplant in 2012.
- Diabetes continued to be the predominant cause of ESKD in Canada, identified in 38% of new cases in 2012, followed by renal vascular disease (15%).

ii. In 2012, under-reporting of incident ESKD cases from Quebec was estimated to be approximately 560 cases. Counts of organ donors and transplants from Quebec have been supplemented with additional data from Transplant Québec. For additional information, see Chapter 1 and Appendix D.

iii. Total includes 69 patient deaths in Quebec, as reported in Transplant Québec's *Statistiques officielles 2012*.

Liver

- There were 5,654 Canadians living with a liver transplant.
- In 2012, 494 liver transplants were performed, 22% more than the 405 performed in 2003.
- On December 31, there were 492 patients waiting for a liver transplant.
- A total of 62 patients died while waiting for a liver transplant in 2012.
- Hepatitis C was the cause of liver failure for 21% of liver transplant patients between 2003 and 2012.

Heart

- There were 2,546 Canadians living with a transplanted heart.
- A total of 161 heart-only transplants were performed.
- On December 31, there were 183 Canadians waiting for a heart transplant.
- A total of 15 Canadians died while on the heart transplant waiting list in 2012.
- Between 2003 and 2012, 23% of heart transplants resulted from narrowing of the coronary arteries (ischemic cardiomyopathy).

Lung

- There were 1,441 Canadians living with a lung transplant.
- In 2012, 194 lung transplants were performed, 82% of which were double lung transplants. Since 2003, the number of lung transplants has grown 62%.
- On December 31, there were 329 Canadians waiting to receive a lung transplant.
- A total of 69 Canadians died while waiting for a lung transplant.
- Between 2003 and 2012, 26% of lung transplants resulted from lung tissue scarring with no known cause (idiopathic pulmonary fibrosis). Emphysema and chronic obstructive pulmonary disease (COPD) were the causes of an additional 25% of lung transplants.

Pancreas

- There were 77 pancreatic transplants performed in 2012. Of these, 40 were simultaneous kidney–pancreas transplants.
- A total of 180 Canadians were waiting for a pancreas transplant.

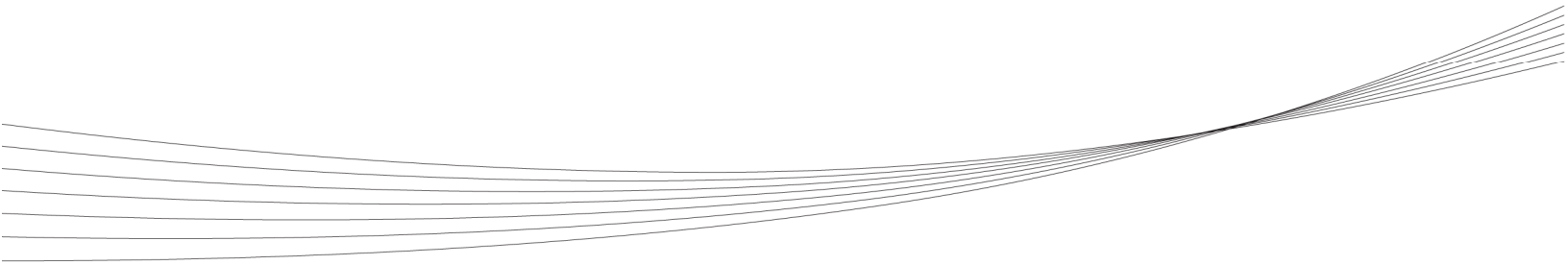
Small Intestine

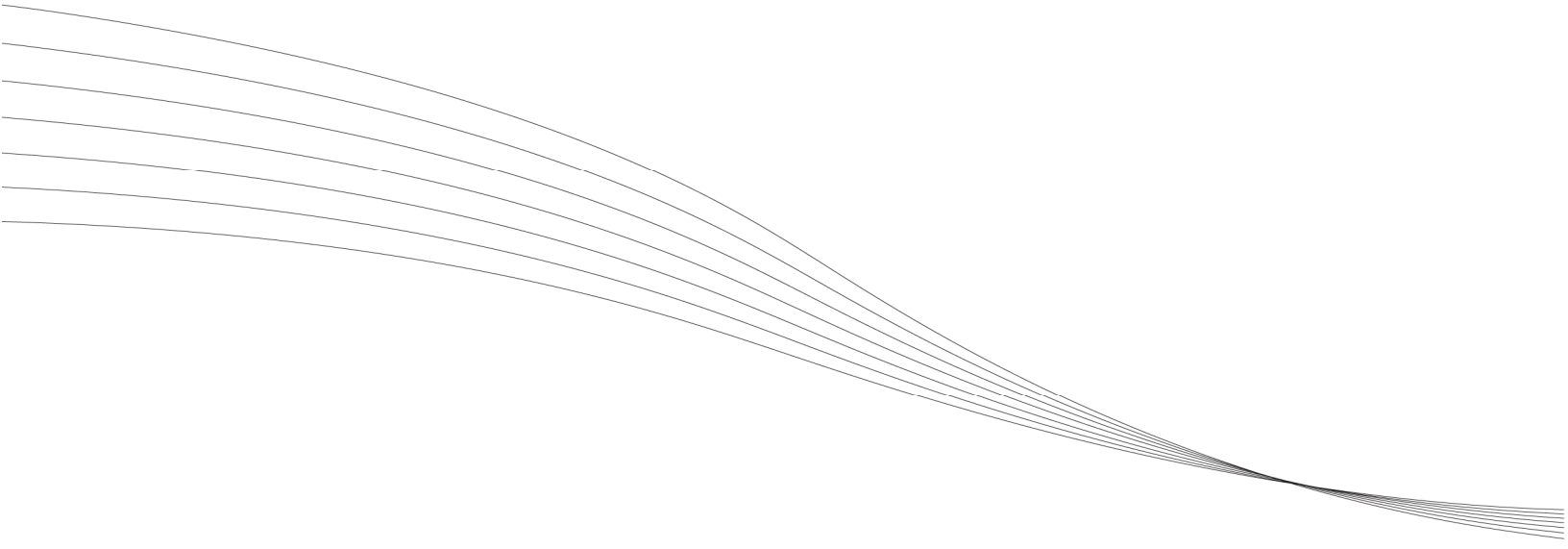
- Small intestine transplantation is an emerging and evolving field with the potential to improve the outcomes of children and adults with intestinal failure in Canada. Between 1993 and 2012, there were 57 such procedures performed in Canada, with more than half (56%) of the recipients younger than age 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 continuously 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 (Analysis in Brief reports) and semi-annual reports from the organ procurement organizations entitled *e-Statistics on Organ Transplants, Waiting Lists and Donors*.

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. 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, 2013, please see Appendix A). The Canadian Institute for Health Information (CIHI) manages CORR operations, data and reporting.

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 CIHI, which maintains numerous health system–related pan-Canadian data holdings. Current and historical CORR data and reports are available from CIHI.

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 in a privacy-secure manner 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 for 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 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 Under-Reporting in Quebec

As noted in the last report, unit non-response (under-reporting) for 2011 incident end-stage kidney disease (ESKD) cases was estimated to be 300 cases from six to eight centres in Quebec. Since that report, additional data has been received; under-reporting for 2011 is now estimated to be approximately 170 cases.

In 2012, Quebec had increased under-reporting due to administrative issues. CIHI is working with Quebec sites to improve reporting for future years.

The table below provides a measure of the completeness of Quebec data for 2011 and 2012.

Data Completeness for Quebec

	2011	2012
Dialysis*	Approximately 84% complete Missing an estimated 170 incident cases In addition, an undetermined number of death reports are missing from Quebec	Approximately 49% complete Missing an estimated 560 incident cases In addition, an undetermined number of death reports are missing from Quebec
Transplants	Complete	95% complete Missing 24 known transplants (21 kidney transplants, 3 lung transplants) Complete data on heart, liver and pancreas transplants
Living Donors	Complete	Supplemented with data from Transplant Québec
Deceased Donors	Complete	Supplemented with data from Transplant Québec
Waiting List	Complete	Supplemented with data from Transplant Québec
Waiting List Deaths	Complete	Unknown

Note

* The estimate of missing incident cases assumes approximately 1,100 incident cases in Quebec annually.

Missing Quebec data affects the incidence dialysis data and, to a lesser extent, the prevalence data in Quebec and Canada overall. Totals for transplant and organ donor activity are also affected. As a result, Quebec and national trends must be interpreted with care.

The impact of the missing Quebec data is most apparent on dialysis incident counts and rates. The impact on overall prevalence counts and rates is difficult to determine, since the undercounts of both Quebec incident cases and deaths partially offset each other. Prevalence reflects the number of persons living with a condition at a specific point in time. The under-reporting of incident cases in Quebec and the unreported number of deaths from Quebec have offsetting effects, resulting in an undetermined true impact on prevalence.

To the extent possible, the numbers reported in selected tables are supplemented with aggregate data obtained from Transplant Québec (as referenced in the notes). For the remainder of the report, no additional adjustments were made to account for the missing data. Notes have been added, where appropriate, to indicate incomplete data.

1.3 Data Quality

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

With the exception of the problems identified in Section 1.2, there are no known coverage issues for 2012 CORR data. The program area is aware of all hospitals that should report to CORR. While completeness has improved over time, the proportion of records with unknown values continues to exceed 10% for selected data fields. In 2012, primary diagnosis was missing or unknown in 14% of incident dialysis patients; 42% of dialysis patients and 15% of transplant recipients were missing cause of death; and cause of graft failure was missing or unknown in nearly half of the cases. Users should consider this when interpreting trends.

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: 2003 to 2012, for further detail regarding the completeness and coverage of reporting in CORR.

1.4 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 ESKD 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 2003 to 2012 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.

1.5 Provincial Data

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

1.6 Small Cell Sizes

Due to the nature of the material reported by CORR, there are instances when cells with fewer than five observations are reported. Published small cells are reviewed with CIHI statisticians to minimize the risk of re-identification.

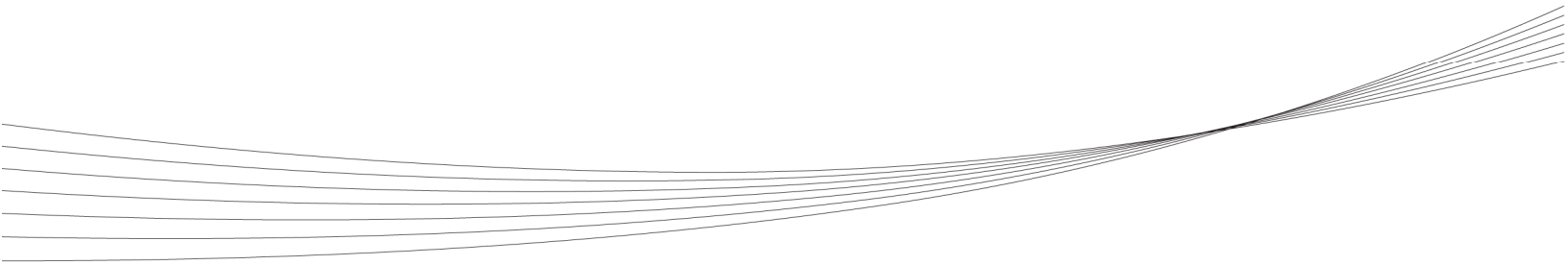
1.7 Age Group Reporting

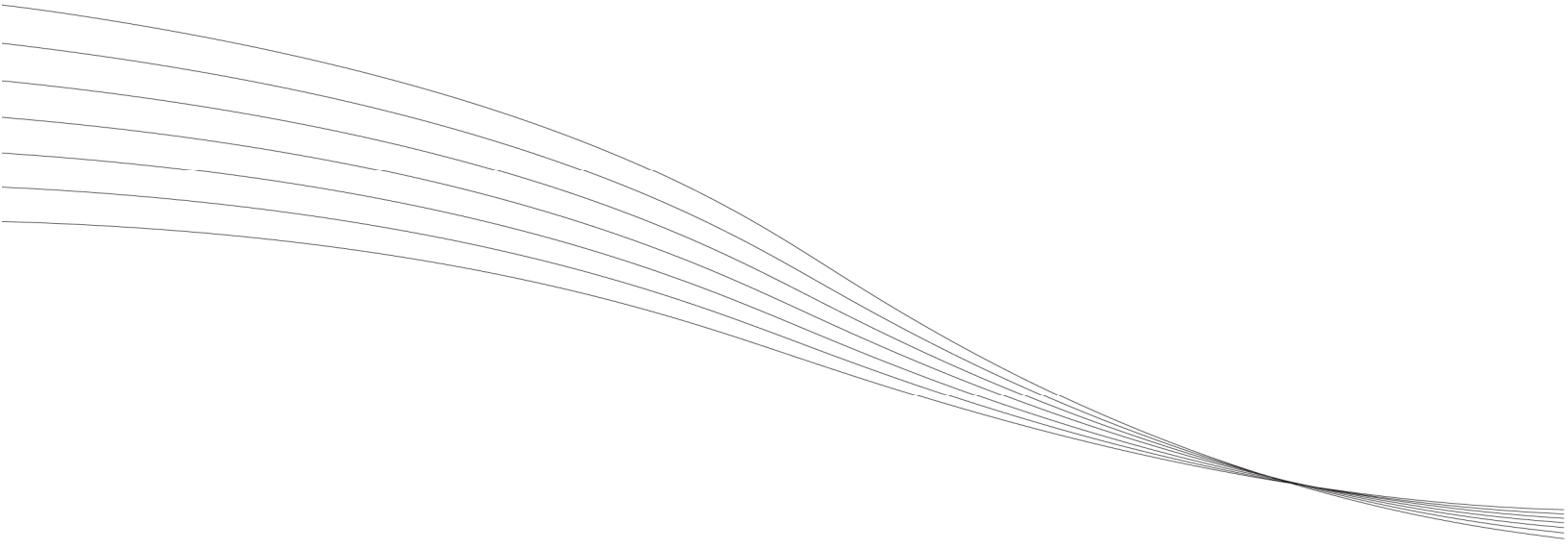
Throughout the report, data is presented by age group. The choice of age groups is not always consistent and may be influenced by therapeutic interest (for example, activity levels or pediatric versus adult) or analytical limitations; age groups may also be chosen to facilitate international comparisons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

1.8 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 (Analysis in Brief reports) and semi-annual reports from the OPOs entitled *e-Statistics on Organ Transplants, Waiting Lists and Donors*. These e-Statistics reports provide 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.

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 Kidney Disease

2 Renal Replacement Therapy for End-Stage Kidney Disease

This section presents trends about end-stage kidney disease (ESKD) patients who are newly diagnosed each year (incidence), as well as the total number of patients being treated for ESKD 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 ESKD patient characteristics, such as age at initiation of treatment, most responsible diagnoses for renal failure and modality of initial treatment. The intent of the information is to support the various programs providing care to ESKD patients in Canada and to help inform decision-making at clinical, facility and health system policy levels.

2.1 Incident ESKD RRT Patients

An *incident patient* refers to a new case within the population with a defined disease that requires treatment. In the case of CORR, these are patients with ESKD who began RRT (either dialysis or kidney transplantation) for the first time during the calendar year. Incidence is usually presented as a rate per million population (RPMP), or the relative proportion of people in the population who are newly diagnosed. The trends in ESKD incident patients in Canada are presented by age groups over time in the figures and tables below.

There were 5,431 newly diagnosed patients with ESKD reported to CORR in 2012, almost double the number reported in 1993 (Table 1).

In 2012, more than half (53%) of incident patients were age 65 and older, and an additional 36% were age 45 to 64.

Provincially, in 2012, the highest incidence RPMP occurred in Newfoundland and Labrador (212.6) and Manitoba (222.6) (Table 2).

The highest RPMP of newly diagnosed ESKD 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 1993 until 2001, the rate of incidence among patients age 75 and older doubled. Starting in 2005, incidence rates among older age groups slowly declined. Incidence rates among those patients age 45 to 64 increased from 176.1 in 1993 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.

At the end of 2012, 79% of all new patients initiated treatment on hemodialysis (HD),[iv] a level that has remained virtually unchanged since 2003 (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 119 in 2003 to 184 in 2012.

Age of incidence also influences the initial treatment (Table 4). In 2012, 72% of incidence patients age 20 to 44 started with hemodialysis, while among those age 65 and older, the proportion was 84%. 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 2012, all provinces used HD the majority of the time, with Newfoundland and Labrador having the highest proportion of HD (94%), followed by Saskatchewan (87%). The highest proportion of patients treated by continuous ambulatory peritoneal dialysis (CAPD) was observed in New Brunswick (20%) (Table 5).

Incidence rates by primary diagnosis are presented in Table 6. Diabetes continued to be the most frequently reported primary cause of ESKD, accounting for 38% 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 managed. An earlier referral allows for better management of the disease and may influence patient survival. In 2012, 27% of incident patients were late referrals, down from 37% in 2003 (Table 7). This improvement can be seen in all provinces. Table 8 presents late referral status by primary diagnosis. In 2003, 31% of patients with a primary diagnosis of diabetes were late referrals, while in 2012 only 16% were considered late referrals.

Table 9 presents selected characteristics of HD and PD patients. In 2012, the average age of incident HD patients was 65.0, and the average age of PD patients was 62.1. Patients 65 or older accounted for 56% of incident HD patients, while males accounted for 63%.

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 Kidney Disease Patients by Age Group, Canada, 1993 to 2012 (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
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	628	53.8	20.2	1,112	186.3	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	686	58.6	16.2	1,416	211.0	33.4	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	103	12.9	2.1	603	51.5	12.0	1,588	214.3	31.7	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	1,738	212.1	33.2	1,344	607.3	25.7	1,445	749.4	27.6	**5,229**	**163.7**
2005	98	12.5	1.9	608	51.6	11.5	1,688	199.8	31.8	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	1,798	206.4	33.1	1,369	602.3	25.2	1,534	751.5	28.3	**5,425**	**166.3**
2007	75	9.5	1.4	648	55.6	11.7	1,844	205.1	33.3	1,413	605.9	25.5	1,563	743.8	28.2	**5,543**	**168.3**
2008	80	10.2	1.4	636	54.5	11.5	1,866	202.0	33.7	1,393	579.7	25.2	1,562	725.2	28.2	**5,537**	**166.1**
2009	81	10.3	1.4	592	50.5	10.4	1,959	206.9	34.4	1,423	572.0	25.0	1,636	743.8	28.8	**5,691**	**168.7**
2010	74	9.4	1.3	619	52.6	10.8	2,004	207.2	34.8	1,424	553.0	24.7	1,636	727.0	28.4	**5,757**	**168.7**
2011*	60	7.7	1.1	639	53.9	11.3	1,937	197.4	34.3	1,423	531.6	25.2	1,583	689.3	28.1	**5,642**	**163.6**
2012*	80	10.2	1.5	567	47.3	10.4	1,933	195.7	35.6	1,350	476.1	24.9	1,501	638.4	27.6	**5,431**	**155.7**

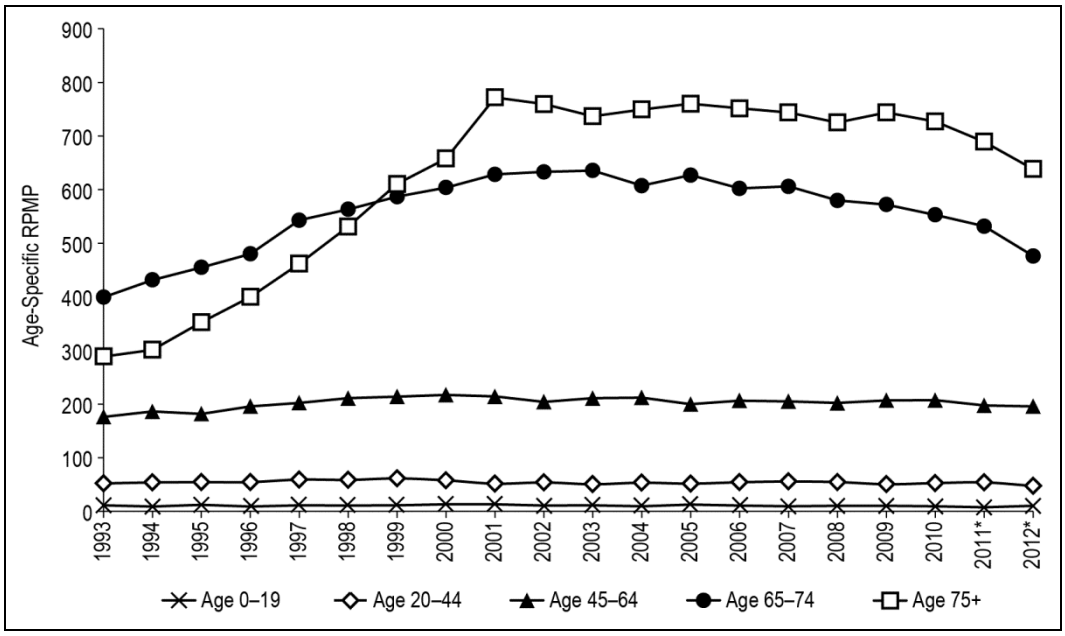
Note

* Under-reporting of incident ESKD cases from Quebec was estimated to be approximately 170 cases in 2011 and 560 cases in 2012. For additional information, see Chapter 1 and Appendix D.

Sources

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information; Statistics Canada.

Figure 1: Incident End-Stage Kidney Disease Patients, Age-Specific Rate per Million Population, Canada, 1993 to 2012*



Note

* Under-reporting of incident ESKD cases from Quebec was estimated to be approximately 170 cases in 2011 and 560 cases in 2012. For additional information, see Chapter 1 and Appendix D.

Sources

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information; Statistics Canada.

Table 2: Incident End-Stage Kidney Disease Patients by Province, Canada, 2003 to 2012 (Number, Rate per Million Population)

		2003	2004	2005	2006	2007	2008	2009	2010	2011*	2012*
B.C./Y.T.	N	623	669	636	701	717	697	771	751	779	891
	RPMP	148.9	158.2	148.4	161.5	165.1	157.8	171.8	164.5	169.1	191.3
Alta./ N.W.T./ Nun.	N	558	465	531	483	529	483	532	495	506	524
	RPMP	172.8	142	159.5	140.1	147.4	131.6	141.4	130.3	131.2	132.6
Sask.	N	182	192	171	186	199	177	200	158	174	193
	RPMP	183.0	192.9	172.0	188.8	199.0	174.6	194.2	151.3	164.5	178.7
Man.	N	239	230	236	298	251	286	288	302	270	282
	RPMP	205.8	196.5	200.4	253.0	210.2	237.1	235.7	244.6	215.9	222.6
Ont.	N	2,102	2,219	2,275	2,316	2,376	2,312	2,379	2,519	2,548	2,591
	RPMP	171.5	179.1	181.4	182.5	185.7	178.7	182	190.4	190.5	191.8
Que.*	N	1,006	1,021	1,049	1,054	1,067	1,102	1,077	1,068	927	540
	RPMP	134.3	135.4	138.1	137.8	138.8	142.1	137.6	135.1	116.2	67.0
N.B.	N	144	161	123	140	112	148	130	134	123	126
	RPMP	191.8	214.3	163.6	186.9	150.2	198.1	173.5	178.0	162.8	166.7
N.S./ P.E.I.	N	176	157	187	165	204	225	188	200	174	175
	RPMP	164.0	146.1	173.8	153.8	189.9	209.1	174.2	183.8	159.4	159.8
N.L.	N	99	115	94	82	88	107	126	130	141	109
	RPMP	191.0	222.4	182.2	160.9	173.7	211.3	247.6	254.3	276.2	212.6
Canada	**N**	**5,129**	**5,229**	**5,302**	**5,425**	**5,543**	**5,537**	**5,691**	**5,757**	**5,642**	**5,431**
	RPMP	**162.0**	**163.7**	**164.3**	**166.3**	**168.3**	**166.1**	**168.7**	**168.7**	**163.6**	**155.7**

Note

* Under-reporting of incident ESKD cases from Quebec was estimated to be approximately 170 cases in 2011 and 560 cases in 2012. For additional information, see Chapter 1 and Appendix D.

Sources

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information; Statistics Canada.

Table 3: Incident End-Stage Kidney Disease Patients by Initial Treatment, Canada, 2003 to 2012 (Number, Rate per Million Population, Percentage of Total)

Initial Treatment		2003	2004	2005	2006	2007	2008	2009	2010	2011*	2012*
HD Home	N	7	9	3	19	17	24	26	21	24	23
	RPMP	0.2	0.3	0.1	0.6	0.5	0.7	0.8	0.6	0.7	0.7
	%	0.1	0.2	0.1	0.4	0.3	0.4	0.5	0.4	0.4	0.4
HD Institutional	N	4,117	4,105	4,159	4,311	4,390	4,344	4,445	4,564	4,498	4,261
	RPMP	130.0	128.5	128.9	132.1	133.3	130.3	131.7	133.7	130.4	122.2
	%	80.3	78.5	78.4	79.5	79.2	78.5	78.1	79.3	79.7	78.5
CAPD	N	644	732	707	661	686	704	777	685	688	645
	RPMP	20.3	22.9	21.9	20.3	20.8	21.1	23	20.1	20	18.5
	%	12.6	14.0	13.3	12.2	12.4	12.7	13.7	11.9	12.2	11.9
APD	N	242	253	272	271	272	297	260	298	240	318
	RPMP	7.6	7.9	8.4	8.3	8.3	8.9	7.7	8.7	7	9.1
	%	4.7	4.8	5.1	5.0	4.9	5.4	4.6	5.2	4.3	5.9
Pre-Emptive	N	119	130	161	163	178	168	183	189	192	184
	RPMP	3.8	4.1	5.0	5.0	5.4	5.0	5.4	5.5	5.6	5.3
	%	2.3	2.5	3.0	3.0	3.2	3.0	3.2	3.3	3.4	3.4
Total	**N**	**5,129**	**5,229**	**5,302**	**5,425**	**5,543**	**5,537**	**5,691**	**5,757**	**5,642**	**5,431**
	RPMP	**162.0**	**163.7**	**164.3**	**166.3**	**168.3**	**166.1**	**168.7**	**168.7**	**163.6**	**155.7**

Notes

* Under-reporting of incident ESKD cases from Quebec was estimated to be approximately 170 cases in 2011 and 560 cases in 2012. For additional information, see Chapter 1 and Appendix D.

HD: Hemodialysis; CAPD: Continuous ambulatory peritoneal dialysis; APD: Automated peritoneal dialysis; Pre-Emptive: Pre-emptive kidney transplant.

Sources

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information; Statistics Canada.

Table 4: Incident End-Stage Kidney Disease Patients by Year, Age Group and Initial Treatment Modality, Canada, 2003 to 2012 (Number)

Age Group	Initial Modality	2003 N = 5,129	2004 N = 5,229	2005 N = 5,302	2006 N = 5,425	2007 N = 5,543	2008 N = 5,537	2009 N = 5.691	2010 N = 5,757	2011* N = 5,642	2012* N = 5,431
0–19	HD	39	34	45	59	39	35	51	39	26	31
	PD	32	29	33	15	16	33	21	19	14	18
	Pre-Emptive	16	12	20	11	20	12	9	16	20	31
20–44	HD	428	417	433	443	444	435	410	428	441	408
	PD	124	155	134	145	134	146	121	136	141	109
	Pre-Emptive	42	55	41	51	70	55	61	55	57	50
45–64	HD	1,275	1,296	1,231	1,345	1,393	1,391	1,435	1,519	1,463	1,443
	PD	344	392	366	368	376	389	429	381	377	399
	Pre-Emptive	55	50	91	85	75	86	95	104	97	91
65–74	HD	1,158	1,120	1,143	1,124	1,171	1,130	1,154	1,177	1,198	1,114
	PD	228	212	250	231	230	248	251	233	208	226
	Pre-Emptive	6	12	9	14	12	15	18	14	17	10
75+	HD	1,224	1,247	1,310	1,359	1,360	1,377	1,421	1,422	1,394	1,288
	PD	158	197	196	173	202	185	215	214	188	211
	Pre-Emptive	0	1	0	2	1	0	0	0	1	2
Total	**HD**	**4,124**	**4,114**	**4,162**	**4,330**	**4,407**	**4,368**	**4,471**	**4,585**	**4,522**	**4,284**
	PD	**886**	**985**	**979**	**932**	**958**	**1,001**	**1,037**	**983**	**928**	**963**
	Pre-Emptive	**119**	**130**	**161**	**163**	**178**	**168**	**183**	**189**	**192**	**184**

Notes

* Under-reporting of incident ESKD cases from Quebec was estimated to be approximately 170 cases in 2011 and 560 cases in 2012. For additional information, see Chapter 1 and Appendix D.

HD: Hemodialysis; PD: Peritoneal dialysis; Pre-Emptive: Pre-emptive kidney transplant.

Source

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information.

Table 5: Incident Patients by Initial Treatment and Province of Treatment, Canada, 2012 (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	637	403	166	217	2,085	445	98	131	102	**4,284**
	%	71.6	76.6	86.5	77.5	80.4	82.1	77.8	75.7	93.6	**78.9**
CAPD	N	139	85	21	53	232	55	25	28	7	**645**
	%	15.6	16.2	10.9	18.9	8.9	10.1	19.8	16.2	6.4	**11.9**
APD	N	81	11	3	6	205	6	3	3	0	**318**
	%	9.1	2.1	1.6	2.1	7.9	1.1	2.4	1.7	0.0	**5.9**
Pre-Emptive	N	33	27	2	4	71	36	0	11	0	**184**
	%	3.7	5.1	1.0	1.4	2.7	6.6	0.0	6.4	0.0	**3.4**
Total	**N**	**890**	**526**	**192**	**280**	**2,593**	**542**	**126**	**173**	**109**	**5,431**

Notes

***** Under-reporting of incident ESKD cases from Quebec was estimated to be approximately 170 cases in 2011 and 560 cases in 2012. For additional information, see Chapter 1 and Appendix D.

† 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;
Pre-Emptive: Pre-emptive kidney transplant.

Source

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information.

Table 6: Incident End-Stage Kidney Disease Patients by Primary Diagnosis, Canada, 2003 to 2012 (Number, Rate per Million Population)

Diagnosis		2003	2004	2005	2006	2007	2008	2009	2010	2011*	2012*
Glomerulonephritis	N	657	683	595	619	619	588	621	619	616	571
	RPMP	20.8	21.4	18.4	19.0	18.8	17.6	18.4	18.1	17.9	16.4
Diabetes	N	1,758	1,799	1,847	1,858	1,926	1,921	1,909	2,020	1,992	2,043
	RPMP	55.5	56.3	57.2	57.0	58.5	57.6	56.6	59.2	57.8	58.6
Renal Vascular Disease	N	952	960	1,024	1,062	996	1,006	1,059	1,041	922	789
	RPMP	30.1	30.1	31.7	32.6	30.2	30.2	31.4	30.5	26.7	22.6
Polycystic Kidney Disease	N	215	222	269	258	233	218	204	234	220	226
	RPMP	6.8	6.9	8.3	7.9	7.1	6.5	6	6.9	6.4	6.5
Drug Induced	N	101	95	103	94	124	109	114	120	104	102
	RPMP	3.2	3.0	3.2	2.9	3.8	3.3	3.4	3.5	3.0	2.9
Pyelonephritis	N	216	231	197	190	215	195	193	186	236	129
	RPMP	6.8	7.2	6.1	5.8	6.5	5.9	5.7	5.5	6.8	3.7
Other†	N	493	525	583	625	572	664	652	717	815	642
	RPMP	15.6	16.4	18.1	19.2	17.4	19.9	19.3	21	23.6	18.4
Unknown	N	737	714	684	719	858	836	939	820	737	929
	RPMP	23.3	22.3	21.2	22.0	26.1	25.1	27.8	24.0	21.4	26.6

Notes

* Under-reporting of incident ESKD cases from Quebec was estimated to be approximately 170 cases in 2011 and 560 cases in 2012. For additional information, see Chapter 1 and Appendix D.

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

Sources

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information; Statistics Canada.

Table 7: Incident End-Stage Kidney Disease Patients by Late Referral Status,† by Province and Canada, 2003 to 2012 (Percentage)

Province	2003	2004	2005	2006	2007	2008	2009	2010	2011*	2012*
B.C./Y.T.	35.1	34.7	31.2	29.8	31.0	32.9	34.2	30.1	34.1	30.4
Alta./N.W.T./Nun.	38.2	40.3	34.1	39.0	30.8	33.0	31.4	30.9	27.7	27.4
Sask.	42.9	36.6	34.5	40.9	28.5	29.6	28.5	31.2	31.5	27.0
Man.	36.2	38.4	33.7	33.6	32.2	25.6	30.1	29.0	27.4	26.1
Ont.	38.5	35.9	36.1	33.6	31.9	32.3	31.9	30.3	30.0	26.4
Que.*	36.6	38.3	33.3	33.0	32.8	29.3	28.5	31.9	27.5	27.2
N.B.	40.3	32.7	37.5	39.1	38.5	32.0	34.4	34.9	32.2	27.4
N.S./P.E.I.	32.7	30.6	31.3	25.2	27.3	26.5	26.7	23.5	20.4	22.6
N.L.	31.5	36.1	30.2	22.7	25.0	30.8	26.8	26.2	27.5	29.5
Canada	**37.4**	**36.5**	**34.3**	**33.5**	**31.6**	**31.2**	**31.2**	**30.3**	**29.6**	**27.2**

Notes

* Under-reporting of incident ESKD cases from Quebec was estimated to be approximately 170 cases in 2011 and 560 cases in 2012. For additional information, see Chapter 1 and Appendix D.

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

Source

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information.

Table 8: Incident End-Stage Kidney Disease Patients by Primary Diagnosis and Late Referral Status,† Canada, 2003 to 2012 (Percentage)

Diagnosis‡	2003	2004	2005	2006	2007	2008	2009	2010	2011*	2012*
Glomerulonephritis	32.3	32.8	30.9	30.3	28.0	24.2	26.8	25.0	29.0	23.2
Diabetes	30.7	27.6	25.9	25.5	23.3	21.9	22.7	22.0	19.3	15.9
Renal Vascular Disease	41.2	37.2	32.1	33.2	29.0	26.5	25.5	23.5	24.2	23.1
Polycystic Kidney Disease	14.2	15.3	11.0	9.4	8.7	8.6	8.8	11.2	8.5	12.8
Drug Induced	40.7	42.7	25.0	33.3	36.8	30.4	24.8	24.8	31.6	31.7
Pyelonephritis	32.6	40.1	36.0	30.2	31.1	38.4	35.1	38.0	37.1	39.8
Other‡	54.9	58.8	59.4	56.6	54.8	57.1	55.2	54.9	52	51.4
Unknown	50.3	50.3	53.7	47.7	47.4	48.5	48.4	48.7	44.7	44.3
All Incident Patients	**37.4**	**36.5**	**34.4**	**33.5**	**31.6**	**31.2**	**31.2**	**30.3**	**29.6**	**27.2**

Notes

* Under-reporting of incident ESKD cases from Quebec was estimated to be approximately 170 cases in 2011 and 560 cases in 2012. For additional information, see Chapter 1 and Appendix D.

† 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, 2013, Canadian Institute for Health Information.

Table 9: Adult Incident Dialysis Patients, Selected Characteristics, Canada, 2003 to 2012

		2003	2004	2005	2006	2007	2008	2009	2010	2011*	2012*
HD	Mean Age (Years)	65.0	65.0	65.2	65.1	65.0	65.3	65.4	65.4	65.3	65.0
	Age 65+ (%)	58.2	57.8	59.4	57.9	57.7	57.8	58.1	57.0	57.5	56.3
	Male (%)	60.3	59.6	60.2	59.6	61.9	61.0	59.9	61.1	62.1	63.2
	Diabetes (%)	44.5	45.0	46.0	47.7	49.3	48.5	49.8	51.2	53.5	53.6
	Mean Comorbidity Index†	2.1	2.0	2.0	2.0	2.1	2.1	2.1	2.1	2.3	2.1
	Mean BMI	27.0	27.4	27.5	27.7	27.6	28.2	28.2	28.3	28.3	28.8
	Mean eGFR‡	9.8	9.7	10.1	10.2	10.2	10.4	10.6	10.6	10.5	10.5
	Late Referral (%)§	41.7	41.3	39.5	37.7	36.0	35.7	35.9	34.8	33.6	31.4
	Access Type (%)										
	Catheter	70.6	73.2	73.4	74.5	76.3	79.0	79.7	77.2	80.9	81.1
	AV Fistula	17.9	17.5	19.1	18.6	18.3	15.8	15.6	16.9	15.6	15.8
	AV Graft	2.3	2.1	1.5	1.6	1.5	1.5	1.2	1.2	0.8	0.9
	Unknown	9.2	7.2	6.0	5.3	3.9	3.7	3.4	4.7	2.6	2.1
PD	Mean Age (Years)	60.5	60.3	61.3	60.6	61.1	60.8	61.9	61.7	60.9	62.1
	Age 65+ (%)	45.0	42.6	47.0	44.0	45.7	44.6	45.7	46.1	43.2	46.1
	Male (%)	59.8	56.7	60.3	55.0	58.5	57.4	57.6	59.4	60.3	60.3
	Diabetes (%)	41.7	43.4	45.1	43.2	43.7	42.7	44.5	47.0	45.4	51.6
	Mean Comorbidity Index†	1.5	1.3	1.4	1.2	1.3	1.1	1.1	1.3	1.2	1.2
	Mean BMI	26.4	26.5	26.8	27.2	27.1	27.5	28.0	27.5	27.3	27.9
	Mean eGFR‡	9.8	9.9	10.1	10.0	10.5	10.7	10.7	10.9	10.1	10.0
	Late Referral (%)§	16.2	15.8	11.4	12.2	11.3	10.4	10.1	8.6	9.1	6.7

Notes

* Under-reporting of incident ESKD cases from Quebec was estimated to be approximately 170 cases in 2011 and 560 cases in 2012. For additional information, see Chapter 1 and Appendix D.

† 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, 2013, Canadian Institute for Health Information.

2.2 Prevalent ESKD 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. For CORR, this is the number of patients who are alive and receiving RRT (dialysis or transplant) for ESKD on December 31 of a given year. Prevalence is usually presented as RPMP, or the relative proportion of people in the population living with the cited disease.

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

As of December 31, 2012, there were 41,252 people in Canada being treated for ESKD, with 58% (23,814) on dialysis and 42% (17,438) living with a functioning kidney transplant (Table 10). Since 1993, the prevalence rate for patients being treated by dialysis has increased nearly 141%, from 283.2 RPMP to 682.7 RPMP (Figure 2). During the same period, the prevalence rate of patients with kidney transplants more than doubled, from 222.3 RPMP to 499.9 RPMP.

Table 11 provides prevalence rates by age. Over the 20-year period, prevalence rates increased in all age groups except among those age 0 to 19.

Prevalence rates in 2012 were highest in Newfoundland and Labrador and Manitoba (1,576.1 and 1,559.6 PMP, Table 13).

HD provided in an institutional setting was the most common form of RRT across the country (45%), followed by transplant (42%) (Table 14).

In 2012, in Nova Scotia/Prince Edward Island, Alberta/Northwest Territories/Nunavut and British Columbia/Yukon, transplant was the leading treatment seen in prevalent patients with ESKD (56%, 49% and 44%, respectively) (Table 15). Transplant as a treatment was lowest in Manitoba (33%).

Tables 16 and 17 examine prevalence rates by primary diagnosis. Between 2003 and 2012, the prevalence rate of patients with diabetes as a primary diagnosis increased by 41%. In 2012, diabetic nephropathy accounted for the largest proportion of all prevalent patients (27%), followed by patients with glomerulonephritis (22%).

Among prevalent patients in 2012 with a primary diagnosis of diabetes, 62% were being treated with HD and 26% had transplants (Table 18). Overall, patients with diabetic nephropathy accounted for 36% of HD patients. For patients with a primary diagnosis of glomerulonephritis, 62% 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, 1993 to 2012 (Rate per Million Population, Percentage of Total)

	Dialysis			Functioning Transplants			Total	
	Number	RPMP	%	Number	RPMP	%	Number	RPMP
1993	8,123	283.2	56.0	6,376	222.3	44.0	**14,499**	**505.5**
1994	8,912	307.3	56.5	6,860	236.6	43.5	**15,772**	**543.9**
1995	9,674	330.1	56.9	7,321	249.8	43.1	**16,995**	**580.0**
1996	10,483	354.0	57.3	7,817	264.0	42.7	**18,300**	**618.0**
1997	11,676	390.4	58.5	8,275	276.7	41.5	**19,951**	**667.1**
1998	12,775	423.6	59.2	8,807	292.0	40.8	**21,582**	**715.7**
1999	13,887	456.8	59.7	9,380	308.5	40.3	**23,267**	**765.3**
2000	14,917	486.1	59.9	9,982	325.3	40.1	**24,899**	**811.3**
2001	16,011	516.1	60.3	10,558	340.3	39.7	**26,569**	**856.5**
2002	16,983	541.3	60.5	11,084	353.3	39.5	**28,067**	**894.6**
2003	17,906	565.6	60.6	11,634	367.5	39.4	**29,540**	**933.0**
2004	18,892	591.4	60.8	12,155	380.5	39.2	**31,047**	**971.8**
2005	19,789	613.2	60.9	12,713	394.0	39.1	**32,502**	**1,007.20**
2006	20,550	629.9	60.6	13,350	409.2	39.4	**33,900**	**1,039.10**
2007	21,170	642.8	60.1	14,081	427.6	39.9	**35,251**	**1,070.40**
2008	21,744	652.4	59.6	14,721	441.7	40.4	**36,465**	**1,094.10**
2009	22,521	667.5	59.4	15,413	456.8	40.6	**37,934**	**1,124.30**
2010	22,908	671.3	58.8	16,073	471.0	41.2	**38,981**	**1,142.30**
2011*	23,480	680.9	58.4	16,729	485.1	41.6	**40,209**	**1,166.10**
2012*	23,814	682.7	57.7	17,438	499.9	42.3	**41,252**	**1,182.70**

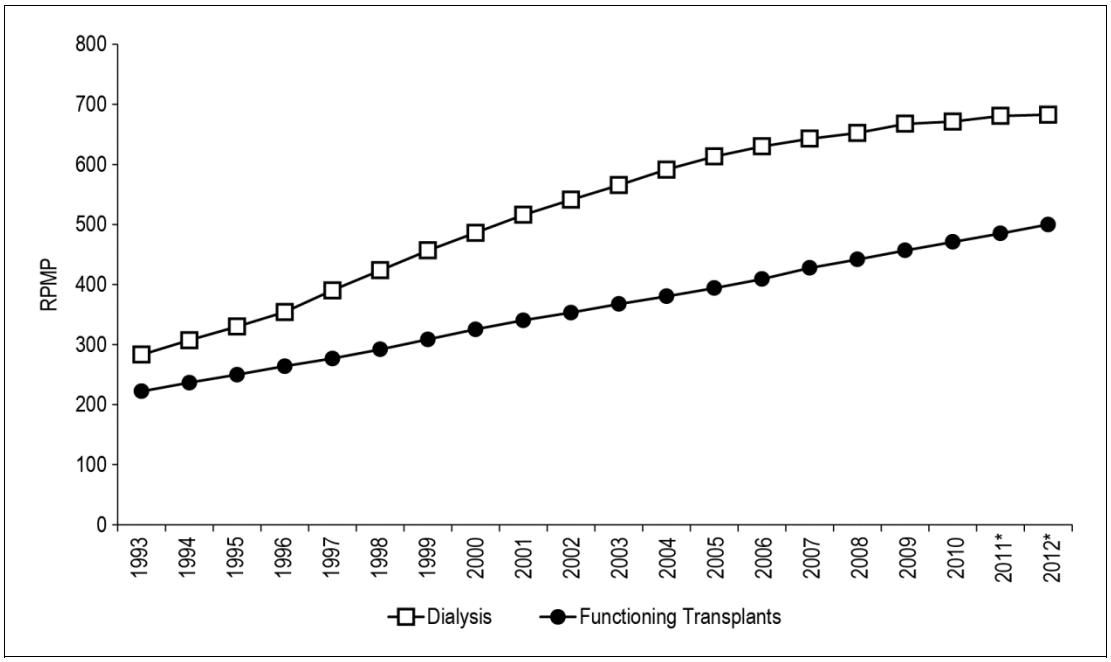
Note

* Reported values for 2011 and 2012 may be slightly lower as a result of unreported incident ESKD cases and deaths from Quebec.

Sources

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information; Statistics Canada.

Figure 2: Prevalence Rate for Patients on Dialysis or With a Functioning Transplant in Canada, 1993 to 2012* (Rate per Million Population)



Note

* Reported values for 2011 and 2012 may be slightly lower as a result of unreported incident ESKD cases and deaths from Quebec.

Sources

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information; Statistics Canada.

Table 11: Prevalent End-Stage Kidney Disease Patients by Age Group, Canada, 1993 to 2012 (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
1993	483	61.5	4,818	413.0	5,566	961.2	2,542	1,265.9	1,090	800.4	**14,499**	**505.5**
1994	475	60.0	5,086	435.5	6,046	1,012.8	2,898	1,417.7	1,267	908.8	**15,772**	**543.9**
1995	491	61.7	5,265	450.2	6,496	1,057.4	3,239	1,565.9	1,504	1,043.8	**16,995**	**580.0**
1996	486	60.8	5,418	462.4	7,116	1,126.1	3,511	1,681.1	1,769	1,186.9	**18,300**	**618.0**
1997	499	62.3	5,641	480.5	7,786	1,196.4	3,889	1,844.1	2,136	1,381.8	**19,951**	**667.1**
1998	524	65.4	5,855	499.9	8,427	1,255.9	4,243	1,994.9	2,533	1,585.7	**21,582**	**715.7**
1999	537	67.2	6,020	514.9	9,138	1,318.1	4,589	2,149.0	2,983	1,806.7	**23,267**	**765.3**
2000	561	70.3	6,136	525.0	9,861	1,375.6	4,933	2,298.5	3,408	1,996.8	**24,899**	**811.3**
2001	566	71.0	6,210	530.1	10,526	1,420.3	5,300	2,452.6	3,967	2,251.4	**26,569**	**856.5**
2002	565	71.0	6,291	535.3	11,105	1,446.8	5,590	2,570.2	4,516	2,483.7	**28,067**	**894.6**
2003	565	71.5	6,321	537.8	11,756	1,481.4	5,961	2,721.4	4,937	2,632.0	**29,540**	**933.0**
2004	555	70.7	6,322	537.6	12,482	1,523.6	6,260	2,828.8	5,428	2,815.2	**31,047**	**971.8**
2005	562	71.8	6,354	539.7	13,081	1,548.5	6,583	2,943.9	5,922	2,988.5	**32,502**	**1,007.2**
2006	558	71.4	6,389	542.3	13,751	1,578.2	6,848	3,012.7	6,354	3,112.9	**33,900**	**1,039.1**
2007	555	70.6	6,349	544.9	14,372	1,598.8	7,269	3,117.0	6,706	3,191.3	**35,251**	**1,070.4**
2008	547	69.5	6,375	546.4	14,989	1,622.8	7,516	3,127.7	7,038	3,267.7	**36,465**	**1,094.1**
2009	551	70.1	6,326	539.8	15,638	1,651.3	7,978	3,206.7	7,441	3,383.0	**37,934**	**1,124.3**
2010	541	68.9	6,302	535.1	16,180	1,673.3	8,310	3,227.1	7,648	3,398.7	**38,981**	**1,142.3**
2011*	505	64.4	6,331	534.0	16,601	1,692.0	8,784	3,281.2	7,988	3,478.5	**40,209**	**1,166.1**
2012*	494	63.1	6,313	526.5	16,923	1,713.5	9,194	3,242.1	8,328	3,542.3	**41,252**	**1,182.7**

Note

* Reported values for 2011 and 2012 may be slightly lower as a result of unreported incident ESKD cases and deaths from Quebec.

Sources

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information; Statistics Canada.

Table 12: Prevalent End-Stage Kidney Disease Patients by Age and Province, Canada, 2012 (Number, Percentage)

Province		Age 0–19	Age 20–44	Age 45–64	Age 65–74	Age 75+	Total
B.C./Y.T.	N	62	826	2,233	1,259	1,171	**5,551**
	%	1.1	14.9	40.2	22.7	21.1	**100.0**
Alta./N.W.T./ Nun.	N	70	801	1,806	814	610	**4,101**
	%	1.7	19.5	44.0	19.8	14.9	**100.0**
Sask.	N	5	263	555	242	220	**1,285**
	%	0.4	20.5	43.2	18.8	17.1	**100.0**
Man.	N	44	375	892	406	259	**1,976**
	%	2.2	19.0	45.1	20.5	13.1	**100.0**
Ont.	N	191	2,425	6,928	3,794	3,608	**16,946**
	%	1.1	14.3	40.9	22.4	21.3	**100.0**
Que.*	N	85	1,110	3,090	1,933	1,896	**8,114**
	%	1.0	13.7	38.1	23.8	23.4	**100.0**
N.B.	N	1	138	387	222	178	**926**
	%	0.1	14.9	41.8	24.0	19.2	**100.0**
N.S./P.E.I.	N	33	251	690	343	228	**1,545**
	%	2.1	16.2	44.7	22.2	14.8	**100.0**
N.L.	N	3	124	342	181	158	**808**
	%	0.4	15.3	42.3	22.4	19.6	**100**
Canada	**N**	**494**	**6,313**	**16,923**	**9,194**	**8,328**	**41,252**
	%	**1.2**	**15.3**	**41.0**	**22.3**	**20.2**	**100.0**

Note

* Reported values may be slightly lower as a result of unreported incident ESKD cases and deaths from Quebec.

Sources

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information; Statistics Canada.

Table 13: Prevalent End-Stage Kidney Disease Patients by Province, Canada, 2003 to 2012 (Number, Rate per Million Population)

Province		2003	2004	2005	2006	2007	2008	2009	2010	2011*	2012*
B.C./Y.T.	N	3,760	4,028	4,196	4,398	4,574	4,711	4,957	5,114	5,286	5,551
	RPMP	898.9	952.8	979.1	1,013	1,053.4	1,066.6	1,104.3	1,120.5	1,147.1	1,191.5
Alta./N.W.T./ Nun.	N	2,965	3,104	3,267	3,379	3,507	3,587	3,720	3,852	3,949	4,101
	RPMP	918.0	948.0	981.1	979.9	977.4	977.1	988.5	1,014.3	1,024.0	1,038.0
Sask.	N	953	980	1,014	1,056	1,117	1,139	1,206	1,199	1,251	1,285
	RPMP	958.3	984.5	1,020.0	1,071.7	1,116.8	1,123.7	1,170.7	1,148.4	1,182.5	1,189.9
Man.	N	1,351	1,388	1,446	1,523	1,574	1,645	1,748	1,847	1,906	1,976
	RPMP	1,163.1	1,186.1	1,228	1,293.1	1,318.3	1,363.9	1,430.5	1,496.1	1,524.1	1,559.6
Ont.	N	11,814	12,438	13,137	13,735	14,284	14,809	15,380	15,892	16,474	16,946
	RPMP	963.9	1,003.7	1,047.5	1,082.6	1,116.4	1,144.8	1,176.8	1,201.4	1,231.9	1,254.7
Que.*	N	6,159	6,487	6,749	7,060	7,371	7,645	7,904	7,979	8,139	8,114
	RPMP	822.0	860.0	888.2	922.7	958.9	986.0	1,009.6	1,009.3	1,020.0	1,007.4
N.B.	N	743	792	801	846	854	869	889	900	904	926
	RPMP	989.5	1,054.1	1,065.2	1,129.3	1,145.4	1,163.1	1,186.2	1,195.5	1,196.6	1,224.9
N.S.	N	1,179	1,170	1,229	1,246	1,314	1,392	1,421	1,453	1,497	1,545
	RPMP	1,098.3	1,088.6	1,142.2	1,161.3	1,223.4	1,293.6	1,316.8	1,335.2	1,371.8	1,411.2
N.L.	N	616	660	663	657	656	668	709	745	803	808
	RPMP	1,188.4	1,276.5	1,285	1,289.1	1,295.1	1,319.0	1,393.1	1,457.1	1,572.7	1,576.1
Canada	**N**	**29,540**	**31,047**	**32,502**	**33,900**	**35,251**	**36,465**	**37,934**	**38,981**	**40,209**	**41,252**
	RPMP	**933.0**	**971.8**	**1,007.2**	**1,039.1**	**1,070.4**	**1,094.1**	**1,124.3**	**1,142.3**	**1,166.1**	**1,182.7**

Note

* Reported values for 2011 and 2012 may be slightly lower as a result of unreported incident ESKD cases and deaths from Quebec.

Sources

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information; Statistics Canada.

Table 14: Prevalent End-Stage Kidney Disease Patients by Type of Treatment, Canada, 2003 to 2012 (Number, Rate per Million Population, Percentage of Total)

Type of Treatment†		2003	2004	2005	2006	2007	2008	2009	2010	2011*	2012*
HD Home	N	303	369	485	572	638	717	786	843	926	967
	RPMP	9.6	11.6	15.0	17.5	19.4	21.5	23.3	24.7	26.9	27.7
	%	1.0	1.2	1.5	1.7	1.8	2.0	2.1	2.2	2.3	2.3
HD Institutional	N	14,218	14,950	15,613	16,204	16,641	17,036	17,654	17,979	18,530	18,671
	RPMP	449.1	468	483.8	496.7	505.3	511.2	523.2	526.8	537.4	535.3
	%	48.1	48.2	48.0	47.8	47.2	46.7	46.5	46.1	46.1	45.3
CAPD	N	1,687	1,658	1,610	1,553	1,576	1,603	1,573	1,525	1,480	1,481
	RPMP	53.3	51.9	49.9	47.6	47.9	48.1	46.6	44.7	42.9	42.5
	%	5.7	5.3	5.0	4.6	4.5	4.4	4.1	3.9	3.7	3.6
APD	N	1,698	1,915	2,081	2,221	2,315	2,388	2,508	2,561	2,544	2,695
	RPMP	53.6	59.9	64.5	68.1	70.3	71.7	74.3	75	73.8	77.3
	%	5.7	6.2	6.4	6.6	6.6	6.5	6.6	6.6	6.3	6.5
Transplant	N	11,634	12,155	12,713	13,350	14,081	14,721	15,413	16,073	16,729	17,438
	RPMP	367.5	380.5	394.0	409.2	427.6	441.7	456.8	471	485.1	499.9
	%	39.4	39.2	39.1	39.4	39.9	40.4	40.6	41.2	41.6	42.3
Total	**N**	**29,540**	**31,047**	**32,502**	**33,900**	**35,251**	**36,465**	**37,934**	**38,981**	**40,209**	**41,252**
	RPMP	**933.0**	**971.8**	**1,007.2**	**1,039.1**	**1,070.4**	**1,094.1**	**1,124.3**	**1,142.3**	**1,166.1**	**1,182.7**

Notes

* Reported values for 2011 and 2012 may be slightly lower as a result of unreported incident ESKD cases and deaths from Quebec.

† HD: Hemodialysis; CAPD: Continuous ambulatory peritoneal dialysis; APD: Automated peritoneal dialysis.

Sources

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information; Statistics Canada.

Table 15: Prevalent End-Stage Kidney Disease Patients by Type of Treatment and Province of Treatment, Canada, 2012 (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	110	134	25	34	551	74	12	15	12	**967**
	%	2.0	3.3	1.9	1.7	3.3	0.9	1.3	1.0	1.5	**2.0**
HD Institutional	N	2,155	1,572	642	1,034	7,915	3,800	485	577	491	**18,671**
	%	38.8	38.3	50.0	52.3	46.7	46.8	52.4	37.3	60.8	**45.0**
CAPD	N	237	118	81	83	547	332	44	23	16	**1,481**
	%	4.3	2.9	6.3	4.2	3.2	4.1	4.8	1.5	2.0	**4.0**
APD	N	582	286	72	171	1,201	233	60	73	17	**2,695**
	%	10.5	7.0	5.6	8.7	7.1	2.9	6.5	4.7	2.1	**7.0**
Transplant	N	2,467	1,991	465	654	6,732	3,675	325	857	272	**17,438**
	%	44.4	48.5	36.2	33.1	39.7	45.3	35.1	55.5	33.7	**42.0**
Total	**N**	**5,551**	**4,101**	**1,285**	**1,976**	**16,946**	**8,114**	**926**	**1,545**	**808**	**41,252**

Notes

* Reported values may be slightly lower as a result of unreported incident ESKD cases and deaths from Quebec.

† HD: Hemodialysis; CAPD: Continuous ambulatory peritoneal dialysis; APD: Automated peritoneal dialysis.

Source

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information.

Table 16: Prevalent End-Stage Kidney Disease Patients by Primary Diagnosis,† Canada, 2003 to 2012 (Number, Rate per Million Population, Percentage of Total)

Diagnosis		2003	2004	2005	2006	2007	2008	2009	2010	2011*	2012*
Glomerulonephritis	N	6,971	7,320	7,510	7,717	7,895	8,083	8,345	8,589	8,795	8,960
	RPMP	220.2	229.1	232.7	236.5	239.7	242.5	247.3	251.7	255.1	256.9
	%	23.6	23.6	23.1	22.8	22.4	22.2	22.0	22.0	21.9	21.7
Diabetes	N	7,220	7,734	8,211	8,692	9,102	9,481	9,901	10,262	10,645	11,190
	RPMP	228.0	242.1	254.4	266.4	276.4	284.5	293.5	300.7	308.7	320.8
	%	24.4	24.9	25.3	25.6	25.8	26.0	26.1	26.3	26.5	27.1
Renal Vascular Disease	N	3,861	4,005	4,243	4,467	4,641	4,754	4,939	5,014	5,090	5,030
	RPMP	122.0	125.4	131.5	136.9	140.9	142.6	146.4	146.9	147.6	144.2
	%	13.1	12.9	13.1	13.2	13.2	13.0	13.0	12.9	12.7	12.2
Polycystic Kidney Disease	N	2,076	2,182	2,360	2,487	2,607	2,723	2,824	2,931	3,026	3,102
	RPMP	65.6	68.3	73.1	76.2	79.2	81.7	83.7	85.9	87.8	88.9
	%	7.0	7.0	7.3	7.3	7.4	7.5	7.4	7.5	7.5	7.5
Drug Induced	N	426	440	468	492	528	539	566	605	614	618
	RPMP	13.5	13.8	14.5	15.1	16.0	16.2	16.8	17.7	17.8	17.7
	%	1.4	1.4	1.4	1.5	1.5	1.5	1.5	1.6	1.5	1.5
Pyelonephritis	N	2,102	2,183	2,209	2,254	2,329	2,353	2,370	2,375	2,446	2,415
	RPMP	66.4	68.3	68.5	69.1	70.7	70.6	70.2	69.6	70.9	69.2
	%	7.1	7.0	6.8	6.6	6.6	6.5	6.2	6.1	6.1	5.9
Other†	N	3,363	3,519	3,763	3,967	4,141	4,362	4,579	4,743	5,062	5,188
	RPMP	106.2	110.2	116.6	121.6	125.7	130.9	135.7	139.0	146.8	148.7
	%	11.4	11.3	11.6	11.7	11.7	12.0	12.1	12.2	12.6	12.6
Unknown	N	3,521	3,664	3,738	3,824	4,008	4,170	4,410	4,462	4,531	4,749
	RPMP	111.2	114.7	115.8	117.2	121.7	125.1	130.7	130.8	131.4	136.2
	%	11.9	11.8	11.5	11.3	11.4	11.4	11.6	11.4	11.3	11.5
Total	**N**	**29,540**	**31,047**	**32,502**	**33,900**	**35,251**	**36,465**	**37,934**	**38,981**	**40,209**	**41,252**
	RPMP	**933.0**	**971.8**	**1,007.2**	**1,039.1**	**1,070.4**	**1,094.1**	**1,124.3**	**1,142.3**	**1,166.1**	**1,182.7**

Notes

* Reported values for 2011 and 2012 may be slightly lower as a result of unreported incident ESKD cases and deaths from Quebec.

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

Sources

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information; Statistics Canada.

Table 17: Prevalent End-Stage Kidney Disease Patients by Primary Diagnosis† and Province, Canada, 2012 (Number, Rate per Million Population, Percentage of Total)

Province		Glomerulo-nephritis	Diabetes	Renal Vascular Disease	Polycystic Kidney Disease	Drug Induced	Pyelo-nephritis	Other†	Unknown	Total
B.C./Y.T.	N	1,176	1,017	716	403	77	242	733	1,187	**5,551**
	RPMP	254.4	220.0	154.9	87.2	16.7	52.4	158.6	256.8	**1,200.8**
	%	21.2	18.3	12.9	7.3	1.4	4.4	13.2	21.4	**100**
Alta./N.W.T./ Nun.	N	1,031	1,160	355	329	51	272	509	394	**4,101**
	RPMP	334.6	390.7	137.3	84.9	13.2	70.2	177	124.5	**1,332.4**
	%	25.1	28.3	8.7	8.0	1.2	6.6	12.4	9.6	**100**
Sask.	N	267	424	117	79	16	100	166	116	**1,285**
	RPMP	247.2	392.6	108.3	73.2	14.8	92.6	153.7	107.4	**1,189.9**
	%	20.8	33.0	9.1	6.1	1.2	7.8	12.9	9.0	**100**
Man.	N	460	766	142	97	28	101	285	97	**1,976**
	RPMP	363.1	604.6	112.1	76.6	22.1	79.7	224.9	76.6	**1,559.6**
	%	23.3	38.8	7.2	4.9	1.4	5.1	14.4	4.9	**100**
Ont.	N	3,508	4,959	2,307	1,260	229	905	1,933	1,845	**16,946**
	RPMP	259.7	367.2	170.8	93.3	17.0	67.0	143.1	136.6	**1,254.7**
	%	20.7	29.3	13.6	7.4	1.4	5.3	11.4	10.9	**100**
Que.*	N	1,815	2,040	997	587	156	570	1,134	815	**8,114**
	RPMP	225.3	253.3	123.8	72.9	19.4	70.8	140.8	101.2	**1,007.4**
	%	22.4	25.1	12.3	7.2	1.9	7.0	14.0	10.0	**100**
N.B.	N	201	253	128	92	13	55	117	67	**926**
	RPMP	265.9	334.7	169.3	121.7	17.2	72.8	154.8	88.6	**1,224.9**
	%	21.7	27.3	13.8	9.9	1.4	5.9	12.6	7.2	**100**
N.S./P.E.I.	N	314	362	167	188	34	105	226	149	**1,545**
	RPMP	371.5	543.7	257.1	221.3	59.0	151.2	296.1	209.2	**2,109.1**
	%	20.3	23.4	10.8	12.2	2.2	6.8	14.6	9.6	**100**
N.L.	N	188	209	101	67	14	65	85	79	**808**
	RPMP	366.7	407.7	197	130.7	27.3	126.8	165.8	154.1	**1,576.1**
	%	23.3	25.9	12.5	8.3	1.7	8.0	10.5	9.8	**100**
Canada	**N**	**8,960**	**11,190**	**5,030**	**3,102**	**618**	**2,415**	**5,188**	**4,749**	**41,252**
	RPMP	**256.9**	**320.8**	**144.2**	**88.9**	**17.7**	**69.2**	**148.7**	**136.2**	**1,182.7**
	%	**21.7**	**27.1**	**12.2**	**7.5**	**1.5**	**5.9**	**12.6**	**11.5**	**100**

Notes

* Reported values may be slightly lower as a result of unreported incident ESKD cases and deaths from Quebec.

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

Sources

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information; Statistics Canada.

Table 18: Prevalent End-Stage Kidney Disease Patients by Treatment, Age Group, Sex and Primary Diagnosis,† Canada, December 31, 2012* (Number, Rate per Million Population, Percentage of Total)

		HD	PD	TX	Total*
Total	**N**	**19,638**	**4,176**	**17,438**	**41,252**
	RPMP	**563.0**	**119.7**	**499.9**	**1,182.7**
Age Group					
Age 0–19	N	58	35	401	**494**
	RPMP	7.4	4.5	51.2	**63.1**
	%	0.3	0.8	2.3	**1.2**
Age 20–44	N	2,031	513	3,769	**6,313**
	RPMP	169.4	42.8	314.3	**526.5**
	%	10.3	12.3	21.6	**15.3**
Age 45–64	N	6,462	1,625	8,836	**16,923**
	RPMP	654.3	164.5	894.7	**1,713.5**
	%	32.9	38.9	50.7	**41.0**
Age 65–74	N	4,784	1,060	3,350	**9,194**
	RPMP	1,687.0	373.8	1,181.3	**3,242.1**
	%	24.4	25.4	19.2	**22.3**
Age 75+	N	6,303	943	1,082	**8,328**
	RPMP	2681	401.1	460.2	**3,542.3**
	%	32.1	22.6	6.2	**20.2**
Sex					
Female	N	7,997	1,750	6,593	**16,340**
	RPMP	455.1	99.6	375.2	**929.9**
	%	40.7	41.9	37.8	**39.6**
Male	N	11,629	2,424	10,845	**24,898**
	RPMP	671.8	140	626.5	**1438.4**
	%	59.3	58.1	62.2	**60.4**
Diagnosis†					
Diabetes	N	6,983	1,317	2,890	**11,190**
	RPMP	200.2	37.8	82.9	**320.8**
	%	35.6	31.5	16.6	**27.1**
Glomerulonephritis	N	2,689	754	5,517	**8,960**
	RPMP	77.1	21.6	158.2	**256.9**
	%	13.7	18.1	31.6	**21.7**
Renal Vascular Disease	N	3,193	673	1,164	**5,030**
	RPMP	91.5	19.3	33.4	**144.2**
	%	16.3	16.1	6.7	**12.2**
Pyelonephritis	N	863	160	1,392	**2,415**
	RPMP	24.7	4.6	39.9	**69.2**
	%	4.4	3.8	8	**5.9**
Polycystic Kidney Disease	N	832	253	2,017	**3,102**
	RPMP	23.9	7.3	57.8	**88.9**
	%	4.2	6.1	11.6	**7.5**

(cont'd on next page)

Table 18: Prevalent End-Stage Kidney Disease Patients by Treatment, Age Group, Sex and Primary Diagnosis,† Canada, December 31, 2012* (Number, Rate per Million Population, Percentage of Total) (cont'd)

		HD	PD	TX	Total*
Total	**N**	**19,638**	**4,176**	**17,438**	**41,252**
	RPMP	**563.0**	**119.7**	**499.9**	**1,182.7**
Diagnosis (cont'd)					
Drug Induced	N	341	57	220	**618**
	RPMP	9.8	1.6	6.3	**17.7**
	%	1.7	1.4	1.3	**1.5**
Other	N	2,056	428	2,704	**5,188**
	RPMP	58.9	12.3	77.5	**148.7**
	%	10.5	10.2	15.5	**12.6**
Unknown	N	2,681	534	1,534	**4,749**
	RPMP	76.9	15.3	44	**136.2**
	%	13.7	12.8	8.8	**11.5**

Notes

* Reported values may be slightly lower as a result of unreported incident ESKD cases and deaths from Quebec.

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

HD: Hemodialysis; PD: Peritoneal dialysis; TX: Transplant.

Sources

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information; Statistics Canada.

Table 19: End-Stage Kidney Disease Patient Flows by Treatment, Canada, 2003 to 2012

		2003	2004	2005	2006	2007	2008	2009	2010	2011*	2012*
Dialysis	January 1, Prevalence	16,983	17,906	18,892	19,789	20,550	21,170	21,744	22,521	22,908	23,480
	Incident Dialysis	5,010	5,099	5,141	5,262	5,365	5,369	5,508	5,568	5,450	5,247
	Deaths	3,208	3,233	3,378	3,513	3,620	3,714	3,582	3,745	3,678	3,400
	Net Transplants†	691	651	643	782	822	794	785	777	789	851
	Net Migrations‡	197	216	218	213	285	315	367	460	456	655
	December 31, Prevalence	17,906	18,892	19,789	20,550	21,170	21,744	22,521	22,908	23,480	23,814
Transplant	January 1, Prevalence	11,084	11,634	12,155	12,713	13,350	14,081	14,721	15,413	16,073	16,729
	New Transplants	992	965	999	1,129	1,164	1,159	1,176	1,168	1,193	1,200
	Deaths	239	250	235	293	274	293	265	284	277	310
	Return to Dialysis	302	294	320	319	316	332	320	333	316	292
	Net Migrations‡	10	23	9	12	6	10	8	7	3	3
	December 31, Prevalence	11,634	12,155	12,713	13,350	14,081	14,721	15,413	16,073	16,729	17,438

Notes

* Reported values for 2011 and 2012 may be slightly lower as a result of unreported incident ESKD cases and deaths from Quebec.

† 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, 2013, 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 ESKD in a facility, region or province (Table 20).

Ontario had the highest number of patients per station, with 5.1, followed closely by Alberta (4.8), while New Brunswick (3.1) and Nova Scotia (3.5) 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, 2012 (Number)

Province of Treatment	Stations (N)	Patients (N)	Patients per Station	Population	Stations per Million Population
B.C.	480	2,265	4.7	4,658,674	103.0
Alta.	354	1,706	4.8	3,950,791	89.6
Sask.	141	667	4.7	1,079,958	130.6
Man.	243	1,068	4.4	1,267,003	191.8
Ont.	1,669	8,466	5.1	13,505,900	123.6
Que.	847	3,967	4.7	8,054,756	105.2
N.B.	160	497	3.1	755,950	211.7
N.S.	171	592	3.5	1,094,800	156.2
N.L.	125	503	4.0	512,659	243.8
Total	**4,190**	**19,731**	**4.7**	**34,880,491**	**120.1**

Notes

* British Columbia provides treatment for patients from Yukon. Alberta provides treatment for patients from the Northwest Territories and Nunavut. Nova Scotia provides treatment for patients from Prince Edward Island.

† Number of stations reported is incomplete 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, 2013, 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, both age and primary diagnosis affect survival of dialysis patients (figures 3 to 8).

Nearly 90% of dialysis patients younger than 18 survive for five years, while 26% 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%, 39% and 41%, respectively (Figure 6). The longest five-year survival rate is seen among patients with a primary diagnosis of polycystic kidney disease (75%) and glomerulonephritis (65%).

Table 21: Unadjusted Three-Month and One-, Three- and Five-Year Survival Rates* in Dialysis Patients, Canada, 2003 to 2012 (Percentage)

		2003	2004	2005	2006	2007	2008	2009	2010	2011*	2012*
All Dialysis	N	5,010	5,099	5,141	5,262	5,365	5,369	5,508	5,568	5,450	5,247
	3 Months	94.4	94.5	94.3	94.3	94.6	94.1	94.5	94.2	93.1	94.4
	1 Year	83.0	83.3	83.3	83.6	84.1	83.4	84.7	84.1	84.3	—
	3 Years	59.2	60.3	61.3	60.7	62.6	61.6	64.4	66.2	—	—
	5 Years	40.0	42.4	43.4	42.8	44.9	43.8	—	—	—	—
HD	N	4,124	4,114	4,162	4,330	4,407	4,368	4,471	4,585	4,522	4,284
	3 Months	93.6	93.6	93.3	93.5	93.8	93.2	93.6	93.1	92.1	93.4
	1 Year	81.3	81.4	81.1	81.6	82.3	81.3	82.6	82.3	82.3	—
	3 Years	57.1	58.0	59.0	58.6	60.4	59.0	62.1	65.3	—	—
	5 Years	38.2	40.6	42.1	40.9	43.3	41.2	—	—	—	—
PD	N	886	985	979	932	958	1,001	1,037	983	928	963
	3 Months	98.1	98.4	98.5	98.0	98.1	98.1	98.6	98.9	98.2	98.5
	1 Year	91.3	90.9	92.4	92.5	92.1	92.5	93.7	92.3	93.7	—
	3 Years	69.2	69.8	71.0	70.5	72.8	73.2	74.8	—	—	—
	5 Years	48.5	50.4	48.9	51.9	52.4	56.9	—	—	—	—

Notes

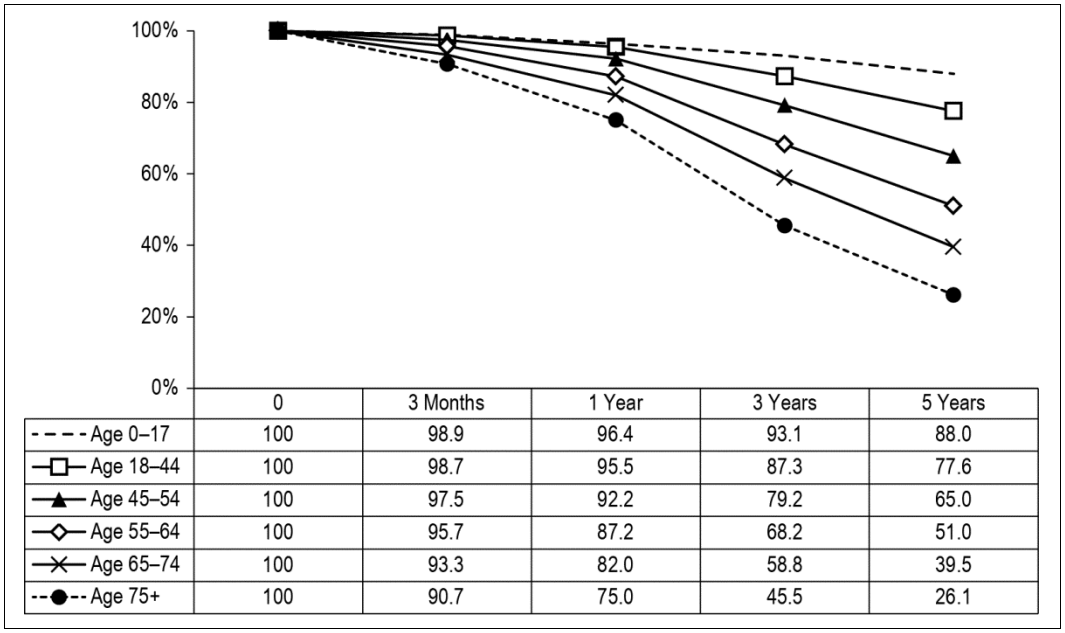
* Survival rates may be affected by unreported incident ESKD cases and deaths from Quebec.

HD: Hemodialysis; PD: Peritoneal dialysis.

Source

Canadian Organ Replacement Register, 2013, 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, 2003 to 2012 (Percentage)



	0	3 Months	1 Year	3 Years	5 Years
Age 0–17	100	98.9	96.4	93.1	88.0
Age 18–44	100	98.7	95.5	87.3	77.6
Age 45–54	100	97.5	92.2	79.2	65.0
Age 55–64	100	95.7	87.2	68.2	51.0
Age 65–74	100	93.3	82.0	58.8	39.5
Age 75+	100	90.7	75.0	45.5	26.1

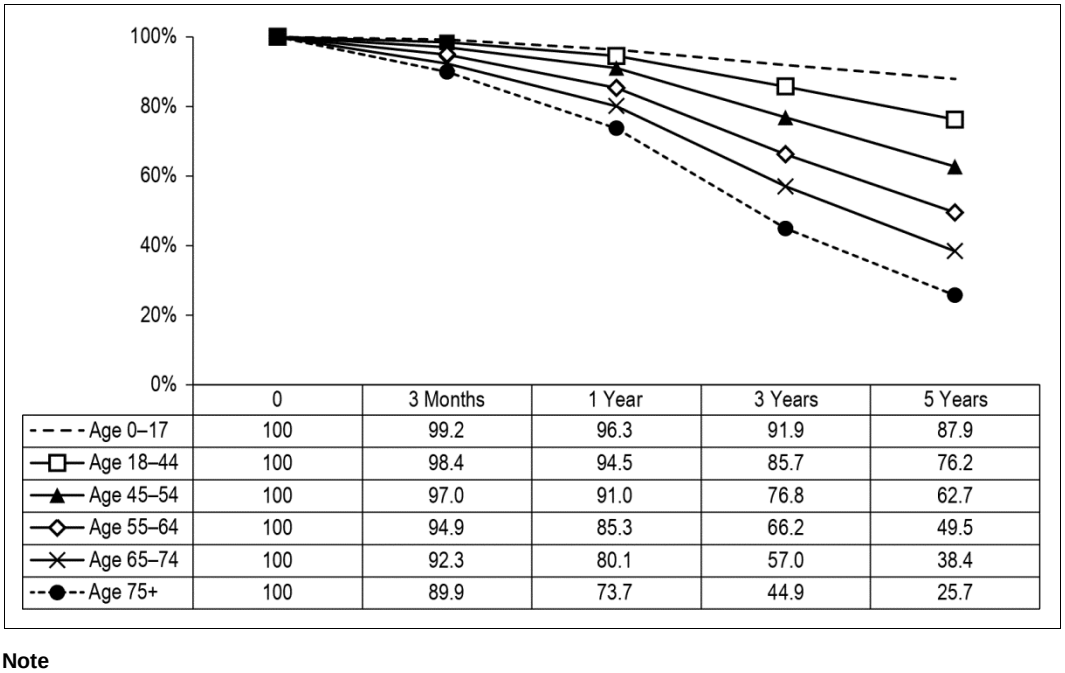
Note

* Survival rates may be affected by unreported incident ESKD cases and deaths from Quebec in 2011 and 2012.

Source

Canadian Organ Replacement Register, 2013, 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, 2003 to 2012 (Percentage)



	0	3 Months	1 Year	3 Years	5 Years
Age 0–17	100	99.2	96.3	91.9	87.9
Age 18–44	100	98.4	94.5	85.7	76.2
Age 45–54	100	97.0	91.0	76.8	62.7
Age 55–64	100	94.9	85.3	66.2	49.5
Age 65–74	100	92.3	80.1	57.0	38.4
Age 75+	100	89.9	73.7	44.9	25.7

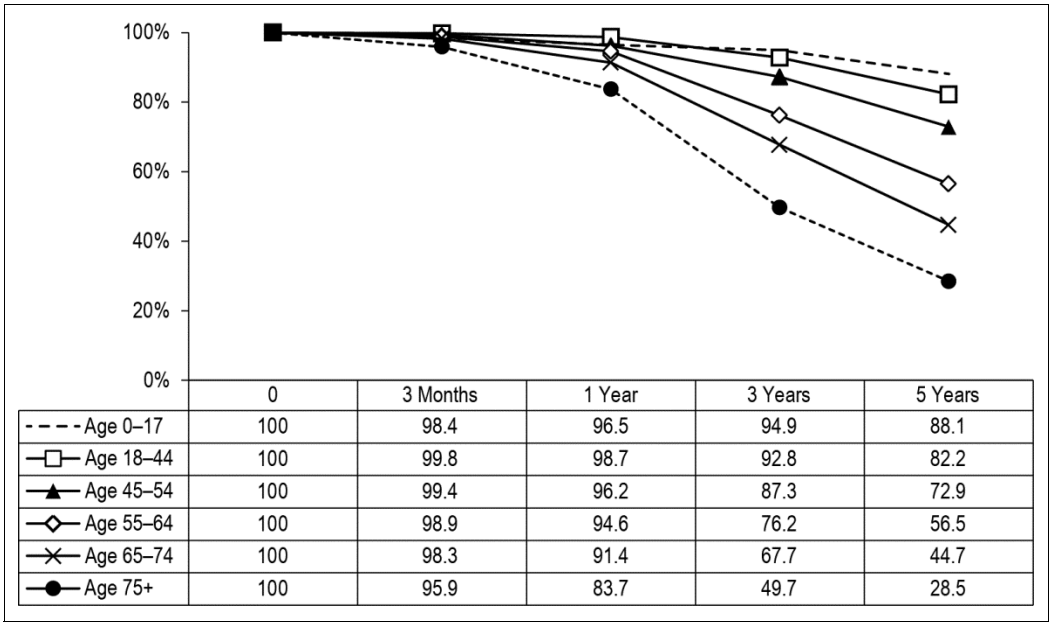
Note

* Survival rates may be affected by unreported incident ESKD cases and deaths from Quebec in 2011 and 2012.

Source

Canadian Organ Replacement Register, 2013, 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, 2003 to 2012 (Percentage)



	0	3 Months	1 Year	3 Years	5 Years
Age 0–17	100	98.4	96.5	94.9	88.1
Age 18–44	100	99.8	98.7	92.8	82.2
Age 45–54	100	99.4	96.2	87.3	72.9
Age 55–64	100	98.9	94.6	76.2	56.5
Age 65–74	100	98.3	91.4	67.7	44.7
Age 75+	100	95.9	83.7	49.7	28.5

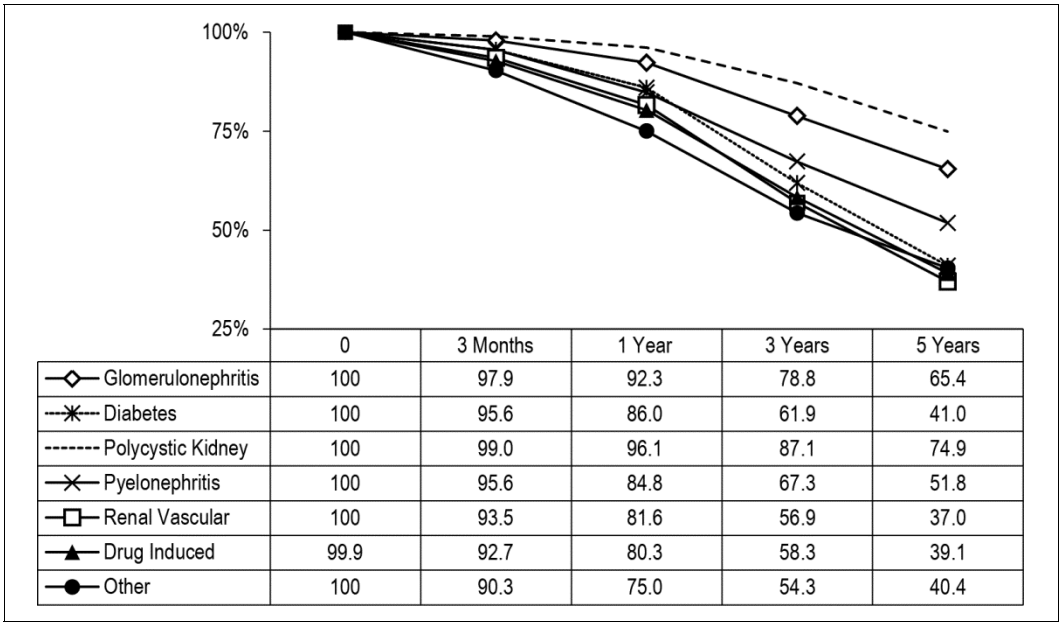
Note

* Survival rates may be affected by unreported incident ESKD cases and deaths from Quebec in 2011 and 2012.

Source

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information.

Figure 6: Unadjusted Three-Month and One-, Three- and Five-Year Survival Rates* in Dialysis Patients, by Cause† of Kidney Failure, Canada, 2003 to 2012 (Percentage)



	0	3 Months	1 Year	3 Years	5 Years
Glomerulonephritis	100	97.9	92.3	78.8	65.4
Diabetes	100	95.6	86.0	61.9	41.0
Polycystic Kidney	100	99.0	96.1	87.1	74.9
Pyelonephritis	100	95.6	84.8	67.3	51.8
Renal Vascular	100	93.5	81.6	56.9	37.0
Drug Induced	99.9	92.7	80.3	58.3	39.1
Other	100	90.3	75.0	54.3	40.4

Notes

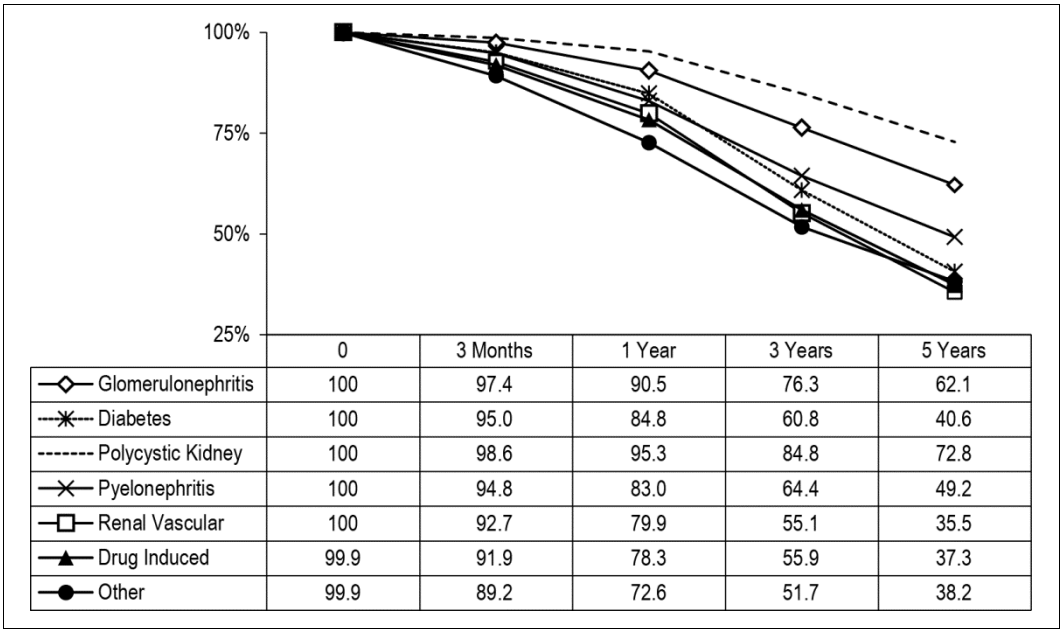
* Survival rates may be affected by unreported incident ESKD cases and deaths from Quebec in 2011 and 2012.

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

Source

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information.

Figure 7: Unadjusted Three-Month and One-, Three- and Five-Year Survival Rates* in Hemodialysis Patients, by Cause† of Kidney Failure, Canada, 2003 to 2012 (Percentage)



	0	3 Months	1 Year	3 Years	5 Years
Glomerulonephritis	100	97.4	90.5	76.3	62.1
Diabetes	100	95.0	84.8	60.8	40.6
Polycystic Kidney	100	98.6	95.3	84.8	72.8
Pyelonephritis	100	94.8	83.0	64.4	49.2
Renal Vascular	100	92.7	79.9	55.1	35.5
Drug Induced	99.9	91.9	78.3	55.9	37.3
Other	99.9	89.2	72.6	51.7	38.2

Notes

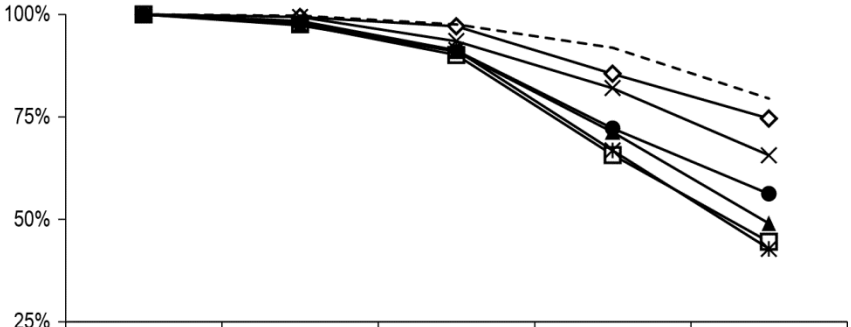
* Survival rates may be affected by unreported incident ESKD cases and deaths from Quebec in 2011 and 2012.

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

Source

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information.

Figure 8: Unadjusted Three-Month and One-, Three- and Five-Year Survival Rates* in Peritoneal Dialysis Patients, by Cause† of Kidney Failure, Canada, 2003 to 2012 (Percentage)



	0	3 Months	1 Year	3 Years	5 Years
Glomerulonephritis	100	99.4	97.1	85.5	74.6
Diabetes	100	98.4	91.3	66.8	42.8
Polycystic Kidney	100	99.7	97.6	91.9	79.5
Pyelonephritis	100	99.4	93.5	82.0	65.6
Renal Vascular	100	97.6	90.1	65.7	44.5
Drug Induced	100	97.4	91.0	71.3	49.0
Other	100	98.0	91.2	72.2	56.2

Notes

* Survival rates may be affected by unreported incident ESKD cases and deaths from Quebec in 2011 and 2012.

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

Source

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information.

2.5 Kidney Transplantation: Adult Recipients

Kidney transplantation is the preferred treatment for the majority of ESKD 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 2012, there were 25 active kidney transplant programs in Canada operating in seven provinces.

At the end of 2012, there were 3,428 people (adult and pediatric) waiting for a deceased donor kidney transplant (Table 22).

Table 22: Kidney Transplant* Waiting List at December 31 and Waiting List Deaths, Canada, 2003 to 2012 (Number)

	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012
Waiting List	2,875	2,872	2,759	2,962	2,963	3,179	2,732	3,362	3,406	3,428†
Deaths on Waiting List	82	55	66	70	46	58	76	82	80	84‡

Notes

* Includes both adult and pediatric patients.

† Includes 923 persons waiting for a kidney transplant in Quebec, as reported in Transplant Québec's *Statistiques officielles 2012*.

‡ Includes 24 deaths for Quebec in 2012, as reported by Transplant Quebec..

Sources

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information.

Transplant Québec. Statistiques officielles 2012. http://www.transplantquebec.ca/sites/default/files/statistiques2012.pdf. Published February 2013. Accessed December 5, 2013.

During the 10-year period, there were 11,252 kidney transplant procedures registered in CORR (Table 23). Of these, 1,126 (10%) were re-transplants. Of the 10,054 kidney-only first transplants, 61% utilized deceased-donor kidneys. Ontario and Quebec surgeons performed the most deceased-donor kidney transplants over the decade (2,691 and 1,962, respectively) (Table 24). Ontario saw the highest number of living-donor kidney transplants (1,935) over the decade (Table 25), followed by British Columbia (836). Since 2006, the number of living-donor kidney transplants has been stable, fluctuating between 435 and 466 transplants each year.

For the most recent three-year period, 2010 to 2012, the median wait time for a deceased-donor kidney transplant (excluding pre-emptive transplants) was 3.9 years (Table 26). The longest median wait times were in Manitoba (5.0 years) and British Columbia (4.8 years). The shortest median wait time of 2.2 years was observed in Saskatchewan.

Since 2003, the proportion of recipients older than age 60 receiving a kidney transplant from a deceased donor has increased from 27% to 35%; a similar trend was observed for living-donor transplants (17% to 22%) (Table 27). The average age of recipients of deceased donor kidneys increased from 50.4 to 53.5 (Table 27). Glomerulonephritis continued to be the predominant diagnosis among adult kidney transplant recipients (281) (Table 28).

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

Table 23: Kidney Transplants† by Year and Donor Type, Adult Recipients, Canada, 2003 to 2012 (Number)

	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012*	Total
Kidney Only, First Graft, Deceased Donor	550	514	504	606	631	634	667	646	683	713	**6,148**
Kidney Only, First Graft, Living Donor	342	345	370	415	413	409	403	413	404	392	**3,906**
Kidney Combination, First Graft, Deceased Donor‡	8	3	5	10	8	9	11	7	6	5	**72**
Re-Transplants	99	104	104	119	133	114	91	125	102	135	**1,126**
Total	**999**	**966**	**983**	**1,150**	**1,185**	**1,166**	**1,172**	**1,191**	**1,195**	**1,245**	**11,252**

Notes

* Missing data for 21 kidney transplants (donor source and recipient age unknown) from Quebec in 2012.

† 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, 2013, Canadian Institute for Health Information.

Table 24: Deceased-Donor Kidney Transplants† by Year and Province of Treatment, Adult Recipients, Canada, 2003 to 2012 (Number)

Province of Treatment	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012*	Total
B.C.	53	52	40	61	61	83	54	89	91	107	**691**
Alta.	67	67	83	78	71	66	61	74	74	60	**701**
Sask.	29	18	15	21	21	21	14			8	**147**
Man.	17	13	6	22	27	24	22	33	17	23	**204**
Ont.	192	208	206	243	291	253	323	308	296	371	**2,691**
Que.*	218	196	173	197	204	217	207	172	206	172	**1,962**
N.S.	51	35	49	67	52	49	50	49	74	69	**545**
Total	**627**	**589**	**572**	**689**	**727**	**713**	**731**	**725**	**758**	**810**	**6,941**

Notes

* Missing data for 21 kidney transplants from Quebec in 2012, the number of which are deceased-donor transplants is unknown.

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

Source

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information.

Table 25: Living-Donor Kidney Transplants by Year and Province of Treatment, Adult Recipients, Canada, 2003 to 2012 (Number)

Province of Treatment	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012*	Total
B.C.	69	74	70	98	100	75	87	89	94	80	**836**
Alta.	52	61	50	46	60	51	40	66	54	64	**544**
Sask.	10	12	11	9	7	13	1	3	2	4	**72**
Man.	18	12	19	24	21	17	18	20	19	24	**192**
Ont.	156	157	186	206	199	211	224	208	199	189	**1,935**
Que.*	43	38	46	47	44	47	39	51	42	44	**441**
N.S.	24	23	29	31	27	39	32	29	27	30	**291**
Total	**372**	**377**	**411**	**461**	**458**	**453**	**441**	**466**	**437**	**435**	**4,311**

Note

* Missing data for 21 kidney transplants from Quebec in 2012, the number of which are living-donor transplants is unknown.

Source

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information.

Table 26: Dialysis Duration Prior to First Kidney Transplant by Province of Treatment, Adult Kidney Transplant Recipients, Canada, 2010 to 2012

	B.C.	Alta.	Sask.	Man.	Ont.	Que.*, †	N.S.	Canada
Duration on Dialysis (Median Days), Deceased Donor	1,736	1,296	629	1,780	1,534	1,054	930	**1,380.5**
Duration on Dialysis (Median Days), Deceased Donor, No Pre-Emptive	1,736	1,312	791	1,809	1,554	1,271	1,019	**1,436**
Duration on Dialysis (Median Days), Living Donor	175	348	591	437	329	164	245	**300**
Duration on Dialysis (Median Days), Living Donor, No Pre-Emptive	648.5	490	594	518	557	560.5	414	**541.5**

Notes

* Missing data for 21 kidney transplants (donor source and recipient age are unknown) from Quebec in 2012.

† In 2012, Quebec introduced a new kidney allocation algorithm. As a result, median times on dialysis are higher than reported in earlier reports.

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 3,269 adult first kidney transplants performed in Canada between 2010 and 2012; of these, 564 were pre-emptive transplants.

Source

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information.

Table 27: Adult Kidney Transplant Recipients, Selected Characteristics, First Graft, Canada, 2003 to 2012 (Number, Percentage)

Donor	Characteristic	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012*
Deceased	Percentage Male	64.7	62.1	63.9	61.7	63.8	65.0	63.6	63.6	64.7	63.9
	Percentage Age 60+	26.7	30.6	29.5	29.7	34.9	35.8	37.5	39.4	42.7	34.7
	Average Age	50.4	51.2	51.8	51.9	53.4	53.2	53.8	54.2	54.5	53.5
	Age Standard Deviation	12.6	13.2	12.4	12.7	12.8	13.0	12.9	12.7	12.9	12.2
	Primary Cause of ESKD† (%)										
	Diabetes	21.1	14.5	17.5	17.0	21.6	23.6	19.8	24.2	26.9	24
	Renal Vascular	7.9	13.2	10.6	10.7	9.1	10.1	9.1	10.0	11.6	11.6
	Glomerulonephritis	36.4	36.4	30.3	31	28.3	27.1	30.5	29.4	24.2	25.3
	Other†	29.9	31.9	37.5	37.2	36.6	33.6	33.6	32.8	33.8	33.6
	Unknown Diagnosis	4.7	4.1	4.1	4.1	4.4	5.6	6.9	3.7	3.5	5.6
	Median Peak PRA	0	0	0	0	0	0	0	0	0	0
	Peak PRA >50% (%)	3.2	2.7	3.1	1.3	2.4	6.1	6.1	8.6	5.6	6.2
	Duration of Dialysis (Median Days)	1,015.5	1,305	1,261	1,282.5	1,338	1,199	1,252	1,381	1,334	1,444
Living	Percentage Male	65.2	59.1	63.0	62.4	63.4	60.1	59.6	65.6	60.4	63.0
	Percentage Age 60+	16.7	14.5	14.6	14.7	18.6	19.3	21.6	26.4	20.5	22.4
	Average Age	46.1	44.6	46.6	45.4	46	46.8	47	48.4	46.5	47.7
	Age Standard Deviation	13.0	13.2	12.6	13.1	13.8	13.4	13.6	14.2	14.1	14.1
	Primary Cause of ESKD† (%)										
	Diabetes	19.6	16.8	16.5	13.3	16.9	14.7	16.6	15.3	16.8	16.6
	Renal Vascular	7.6	4.6	5.7	7.2	7.7	7.1	6.9	6.5	5.9	4.6
	Glomerulonephritis	32.5	38	31.1	35.4	29.1	29.3	28.0	32.0	31.7	25.3
	Other†	35.1	35.7	41.1	36.1	36.3	41.1	38.5	34.4	34.9	41.3
	Unknown Diagnosis	5.3	4.9	5.7	8.0	9.9	7.8	9.9	11.9	10.6	12.2
	Median Peak PRA	0	0	0	0	0	0	0	0	0	0
	Peak PRA >50% (%)	0.9	3.4	1.5	1.1	2.9	5.4	5.1	3.7	5.0	6.2
	Duration of Dialysis (Median Days)	380.5	343	286	314	304	356	285	280	302	319.5

Notes

* Missing data for 21 kidney transplants (donor source and recipient age are unknown) from Quebec in 2012.

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

PRA: Panel reactive antibody.

Source

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information.

Table 28: Kidney Transplant Recipients† by Age Group and Primary Renal Diagnosis‡ Category, Adult Recipients, First Graft, Canada, 2012 (Number)

	Age 18–44	Age 45–54	Age 55–64	Age 65+	Total*
Glomerulonephritis	110	75	58	38	**281**
Pyelonephritis	23	13	12	8	**56**
Polycystic Kidney Disease	20	53	50	21	**144**
Hypertension/Other Vascular	22	19	31	29	**101**
Diabetic Nephropathy	29	59	93	56	**237**
Other‡	78	48	46	31	**203**
Unknown/Not Reported	39	22	16	11	**88**
Total	**321**	**289**	**306**	**194**	**1,110**

Notes

* Missing data for 21 kidney transplants (recipient age and primary renal diagnosis are unknown) from Quebec in 2012.

† 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, 2013, 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, 2003 to 2012 (Percentage)

		2003	2004	2005	2006	2007	2008	2009	2010	2011	2012*
Deceased Donor	N	558	517	509	616	639	643	678	653	689	718
	3 Months	95.2	95.0	96.3	95.5	96.4	95.6	95.3	97.4	97.0	97.5
	1 Year	91.2	91.7	92.7	93.2	93.1	92.4	92.6	94.9	93.3	—
	3 Years	85.5	85.5	86.0	86.2	87.2	87.1	88.2	—	—	—
	5 Years	79.2	78.3	80.5	81.3	82.0	83.2	—	—	—	—
Living Donor	N	342	345	370	415	413	409	403	413	404	392
	3 Months	98.5	98.5	97.8	97.6	98.8	97.8	98.8	98.1	98.3	98.7
	1 Year	98.0	98.3	95.7	96.4	96.6	96.6	97.5	96.1	97.5	—
	3 Years	95.6	94.5	92.1	93.3	93.0	93.9	94.5	—	—	—
	5 Years	91.2	89.8	89.2	88.2	88.4	90.9	—	—	—	—

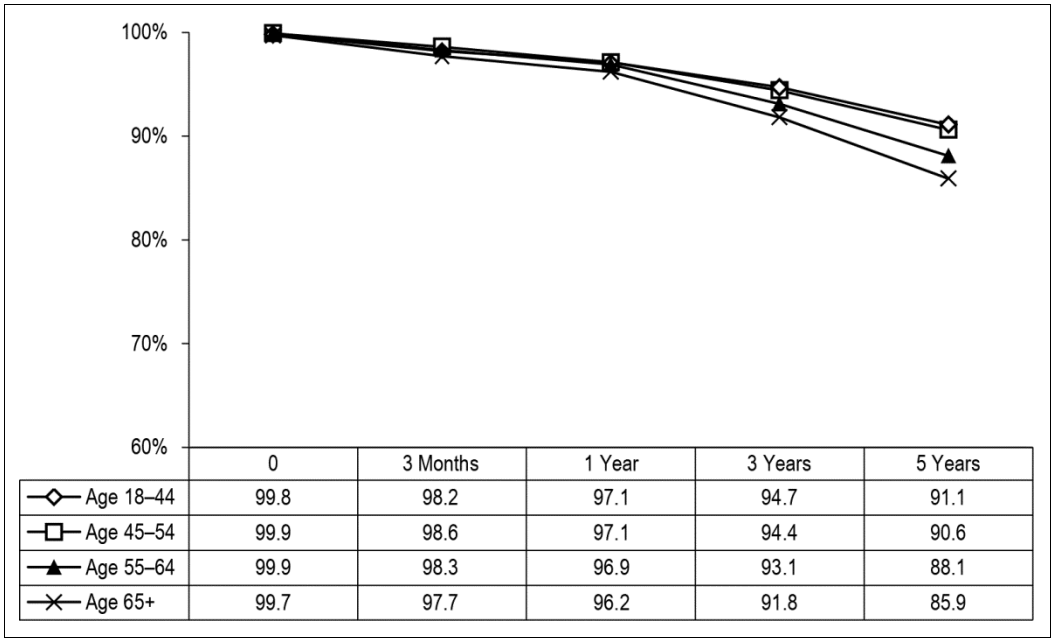
Note

* Survival rates may be affected by unreported kidney transplants and deaths from Quebec in 2012.

Source

Canadian Organ Replacement Register, 2013, 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, 2003 to 2012 (Percentage)



	0	3 Months	1 Year	3 Years	5 Years
Age 18–44	99.8	98.2	97.1	94.7	91.1
Age 45–54	99.9	98.6	97.1	94.4	90.6
Age 55–64	99.9	98.3	96.9	93.1	88.1
Age 65+	99.7	97.7	96.2	91.8	85.9

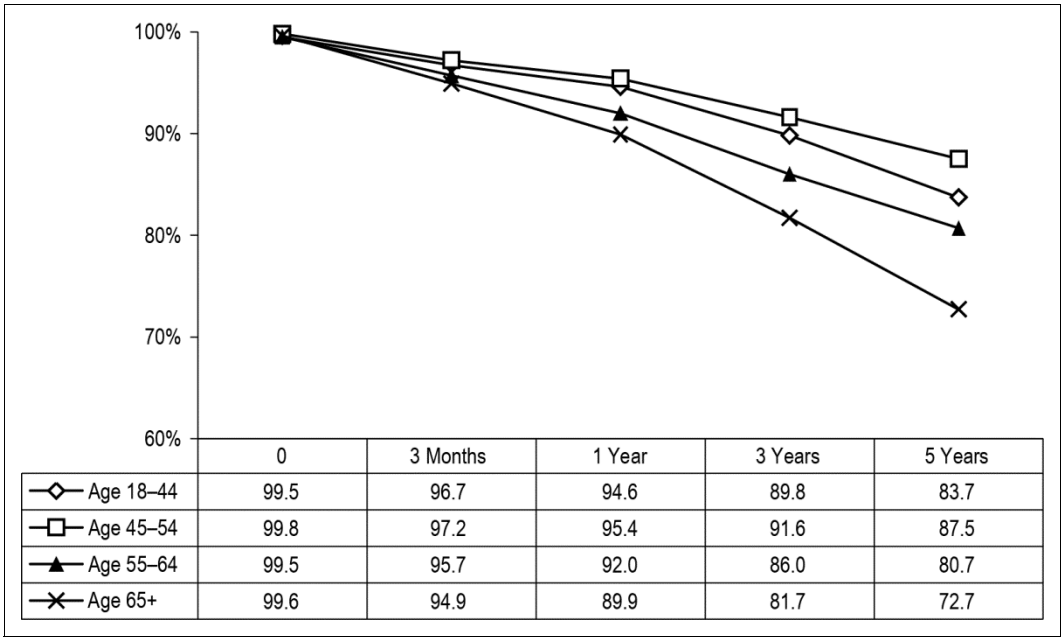
Note

* Survival rates may be affected by unreported kidney transplants and deaths from Quebec in 2012.

Source

Canadian Organ Replacement Register, 2013, 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, 2003 to 2012 (Percentage)



	0	3 Months	1 Year	3 Years	5 Years
Age 18–44	99.5	96.7	94.6	89.8	83.7
Age 45–54	99.8	97.2	95.4	91.6	87.5
Age 55–64	99.5	95.7	92.0	86.0	80.7
Age 65+	99.6	94.9	89.9	81.7	72.7

Note

* Survival rates may be affected by unreported kidney transplants and deaths from Quebec in 2012.

Source

Canadian Organ Replacement Register, 2013, 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 ESKD 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 536 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, 2003 to 2012 (Number)

	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012*	Total
First Graft, Deceased Donor	27	19	39	22	42	24	31	28	29	31	**292**
First Graft, Living Donor	28	37	29	26	21	23	18	25	18	19	**244**
Re-Transplants	3	5	5	1	4	3	4	4	4	2	**35**
Total	**58**	**61**	**73**	**49**	**67**	**50**	**53**	**57**	**51**	**52**	**571**

Note

* Missing data for 21 kidney transplants from Quebec in 2012; the number of pediatric recipients is unknown.

Source

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information.

Table 31: Pediatric Kidney Transplants by Age Group and Province of Treatment, Canada, 2003 to 2012 (Number, Percentage)

		B.C.	Alta.	Sask.	Man.	Ont.	Que.*	N.S.	Total
Age 0–4	N	9	12	—	2	38	18	9	**88**
	%	12.2	18.8	—	5.4	16.6	14.0	27.3	**15.4**
Age 5–10	N	16	11	—	—	40	27	10	**114**
	%	21.6	17.2	—	27.0	17.5	20.9	30.3	**20.0**
Age 11–17	N	49	41	5	25	151	84	14	**369**
	%	66.2	64.1	100	67.6	65.9	65.1	42.4	**64.6**
Total	**N**	**74**	**64**	**5**	**37**	**229**	**129**	**33**	**571**

Note

* Missing data for 21 kidney transplants from Quebec in 2012; the number of pediatric recipients is unknown.

Source

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information.

Table 32: Dialysis Duration in Days Prior to First Kidney Transplant, Pediatric Recipients, Canada, 2003 to 2012

	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012*
Duration on Dialysis (Median Days), Deceased Donor	460	586	625	631	422	344	265	524	599	0†
Duration on Dialysis (Median Days), Deceased Donor, Excluding Pre-Emptive	772	705	770	649	558	373	286	614	762	380
Duration on Dialysis (Median Days), Living Donor	175	264	107	144	137	66	197	228	0†	0†
Duration on Dialysis (Median Days), Living Donor, Excluding Pre-Emptive	327	414	349	271	483	258	297	304	339	396

Notes

* Missing data for 21 kidney transplants from Quebec in 2012; the number of pediatric recipients is unknown.

† More than half of the transplants 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, 2013, Canadian Institute for Health Information.

Table 33: Pediatric Kidney Transplant by Age Group and Primary Renal Diagnosis† Category, Canada, 2003 to 2012*

Primary Renal Diagnosis† Category	Age 0–4		Age 5–10		Age 11–17	
	N	%	N	%	N	%
Alport Syndrome	0	0	0	0	6	1.8
Cystinosis	0	0	5	4.5	20	5.9
Dysplasia/Hypoplasia	24	27.9	22	19.6	39	11.5
Posterior Urethral Valves	8	9.3	6	5.4	10	3
Obstructive Uropathy	<5	..	<5	..	13	3.8
Vesicoureteric Reflux	<5	..	<5	..	15	4.4
Polycystic Kidneys	<5	..	<5	..	8	2.4
Nephronophthisis	<5	..	7	6.3	16	4.7
Other Congenital/Hereditary	9	10.5	<5	..	10	3
Other Pyelonephritis	0	0	<5	..	8	2.4
Glomerulonephritis	9	10.5	12	10.7	34	10.1
Focal Sclerosis	5	5.8	7	6.3	21	6.2
Autoimmune Disease	0	0	0	0	21	6.2
Hemolytic Uremic Syndrome	<5	..	8	7.1	8	2.4
Other†	8	9.3	17	15.2	44	13
Unknown	15	17.4	16	14.3	65	19.2
Total Patients	**86**	**100**	**112**	**100**	**338**	**100**

Notes

* Missing data for 21 kidney transplants from Quebec in 2012; the number of pediatric recipients is unknown.

† 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, 2013, 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, 2003 to 2012 (Percentage)

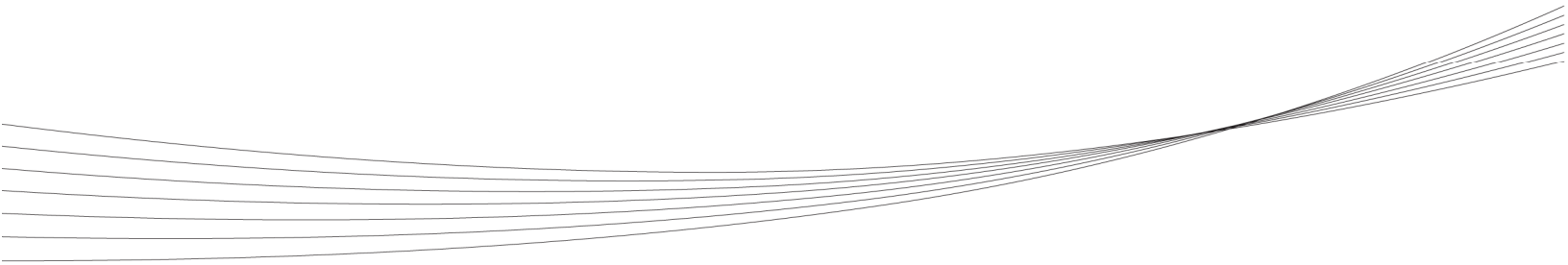
		2003	2004	2005	2006	2007	2008	2009	2010	2011	2012*
Deceased Donor	N	27	19	39	22	42	24	31	28	29	31
	3 Months	92.6	94.7	97.4	95.5	95.2	100	96.8	100	96.6	93.5
	1 Year	88.9	94.7	97.4	90.9	95.2	95.8	96.8	100	96.6	—
	3 Years	74.1	94.7	92.3	77.3	90.4	87.5	90.3	—	—	—
	5 Years	70.4	89.5	89.7	77.3	83.0	—	—	—	—	—
Living Donor	N	28	37	29	26	21	23	18	25	18	19
	3 Months	96.4	100	96.6	100	100	95.7	100	96.0	100	100
	1 Year	96.4	100	96.6	100	100	95.7	100	96.0	100	—
	3 Years	85.7	100	93.1	92.3	100	95.7	100	—	—	—
	5 Years	85.7	89.2	93.1	84.6	100	—	—	—	—	—

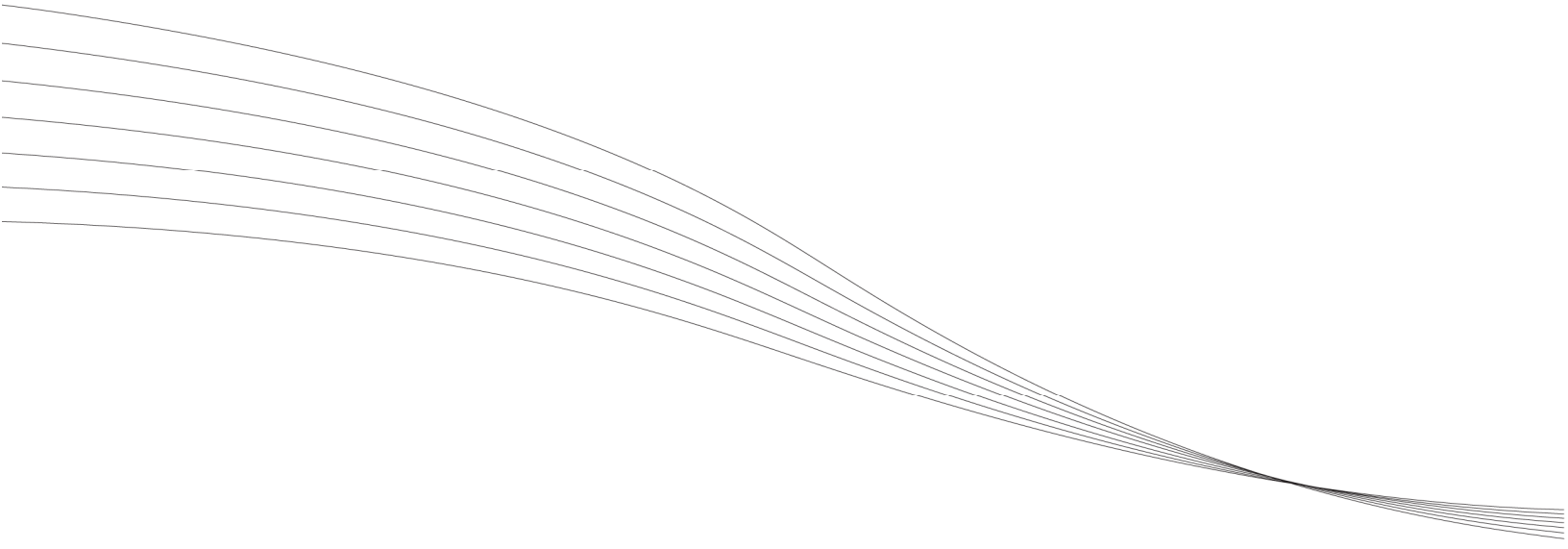
Note

* Survival rates may be affected by unreported kidney transplants and deaths from Quebec in 2012.

Source

Canadian Organ Replacement Register, 2013, 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 2003 to 2012.

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 2012, the waiting list had decreased to 492 (Table 35).

The decade spanning 2003 to 2012 saw 4,527 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 16% in 2012. 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, around 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 (16.8) and British Columbia (14.1). The remaining provinces ranged from 8.9 to 10.3 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 88%; five-year survival was somewhat lower (between 78% and 83%) (Figure 13). One-year survival has been 92% since 2008.

In 2012, there were 5,654 patients in Canada living with a transplanted liver (Table 39).

Table 35: Liver Transplant Waiting List at December 31 and Waiting List Deaths, Canada, 2003 to 2012

	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	Total
Age 0–17	30	37	32	36	19	17	19	22	21	43	**276**
Age 18+	539	630	681	687	616	570	532	479	468	449	**5,651**
Waiting List	569	667	713	723	635	587	551	501	489	492*	**5,927**
Deaths on Waiting List	100	96	141	120	77	92	91	74	93	62†	**946**

Notes

* Includes 118 persons waiting for a liver transplant in Quebec, as reported in Transplant Québec's *Statistiques officielles 2012*.

† Includes 19 deaths in Quebec, as reported by Transplant Québec.

Sources

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information.

Transplant Québec. *Statistiques officielles 2012*. http://www.transplantquebec.ca/sites/default/files/statistiques2012.pdf. Published February 2013. Accessed December 5, 2013.

Table 36: Liver Transplants by Year, Donor Type, Age Group and Re-Transplants, Canada, 2003 to 2012 (Number)

		2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	Total
Pediatric: Age 0–17	First Graft, Deceased Donor	33	15	34	25	28	27	31	22	34	27	**276**
	First Graft, Living Donor	6	12	8	9	15	9	9	14	14	15	**111**
	Re-Transplants	4	3	9	8	6	7	7	6	5	4	**59**
Adults: Age 18+	First Graft, Deceased Donor	302	318	296	324	342	318	324	331	349	350	**3,254**
	First Graft, Living Donor	29	42	52	58	56	59	48	50	50	63	**507**
	Re-Transplants	31	27	24	42	33	33	34	28	33	35	**320**
Total: All Ages		**405**	**417**	**423**	**466**	**480**	**453**	**453**	**451**	**485**	**494**	**4,527**

Source

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information.

Table 37: Combination Liver Transplants, Canada, 2003 to 2012 (Number)

	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	Total
Liver Only	399	414	416	447	468	442	440	442	481	484	**4,433**
Liver Combinations	6	3	7	19	12	11	13	9	4	10	**94**
Total	**405**	**417**	**423**	**466**	**480**	**453**	**453**	**451**	**485**	**494**	**4,527**

Source

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information.

Table 38: Primary Diagnosis* for Liver Transplant Recipients, First Graft, by Age Group, Canada, 2003 to 2012 (Percentage)

	Age <1	Age 1–10	Age 11–17	Age 18–34	Age 35–59	Age 60+	Total
Primary Biliary Atresia	52.5	26.9	4.8	1.2	0.2	0.2	**2.7**
Hepatitis C	0	0	1.2	3.2	28.1	15.8	**21.2**
Hepatitis B	0	0	1.2	6.2	4.8	4.7	**4.5**
Other Hepatitis	2.2	4.6	12.0	12.6	3.2	2.7	**3.9**
Alcoholic Cirrhosis	0	0	0	0.9	16.7	17.7	**14.6**
Cryptogenic Cirrhosis	0	0	1.2	2.9	2.8	5.0	**3.2**
Cancer	1.4	10.3	4.8	6.2	15.3	23.4	**15.9**
Metabolic Disorders	5.8	9.7	6.0	5.6	1.9	2.1	**2.7**
Cholestatic Liver Disease	3.6	6.3	22.9	25.6	10.7	10.1	**11.4**
Unknown/Missing	21.6	21.7	14.5	5.9	2.3	1.9	**3.9**
Other*	12.9	20.6	31.3	29.7	13.9	16.4	**16.1**
Total	**100**	**100**	**100**	**100**	**100**	**100**	**100**

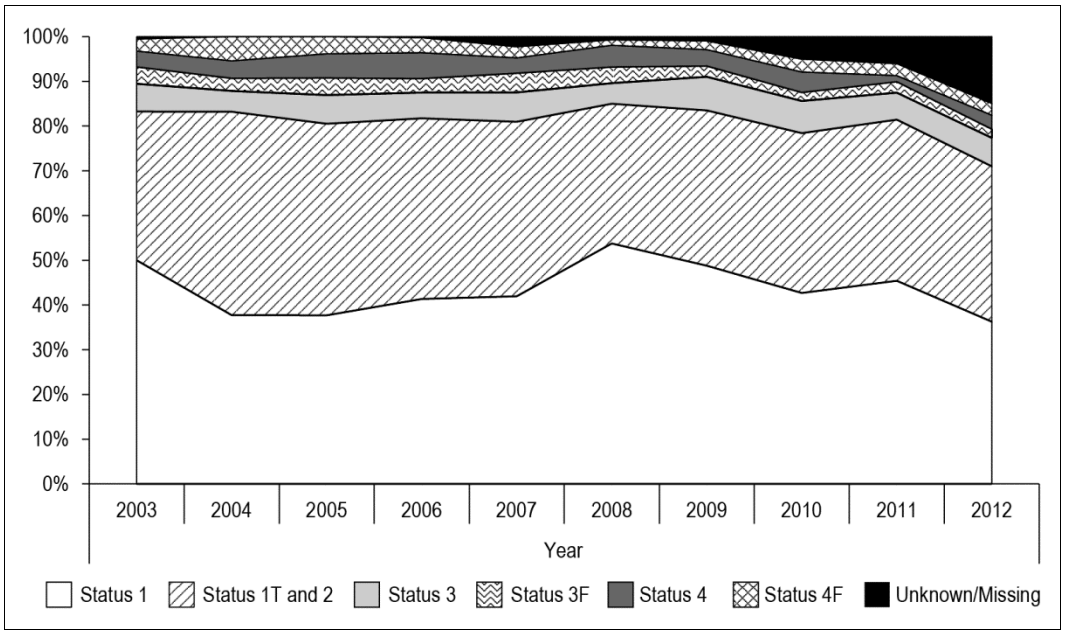
Note

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

Source

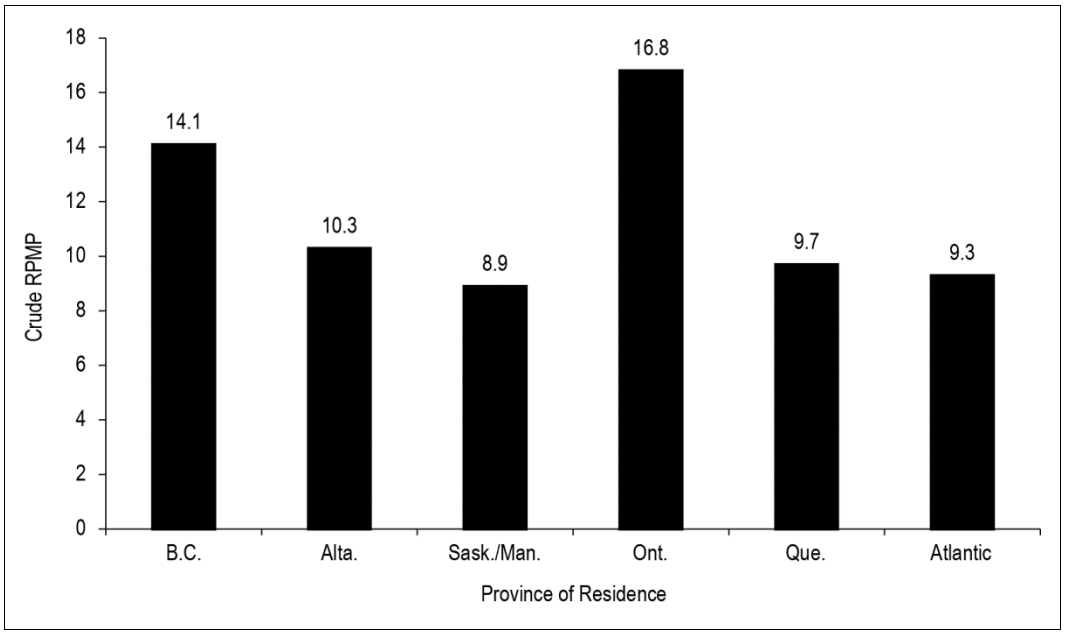
Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information.

Figure 11: Distribution of Liver Transplants by Medical Status at Transplant, Canada, 2003 to 2012



Source
Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information.

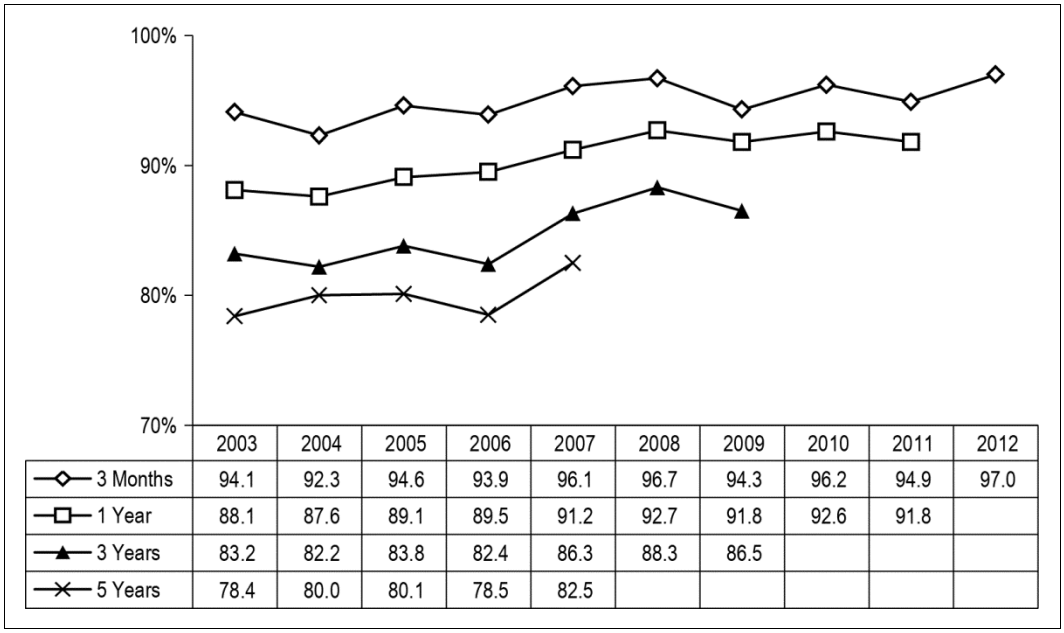
Figure 12: Liver Transplant Recipients by Province of Residence, Canada, 2012 (Crude Rate per Million Population)



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

Source
Canadian Organ Replacement Register, 2013, 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, 2003 to 2012 (Percentage)



	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012
3 Months	94.1	92.3	94.6	93.9	96.1	96.7	94.3	96.2	94.9	97.0
1 Year	88.1	87.6	89.1	89.5	91.2	92.7	91.8	92.6	91.8	
3 Years	83.2	82.2	83.8	82.4	86.3	88.3	86.5			
5 Years	78.4	80.0	80.1	78.5	82.5					

Source

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information.

Table 39: Prevalent Liver Transplant Patients, by Province of Treatment/Follow-Up, 2003 to 2012 (Number)

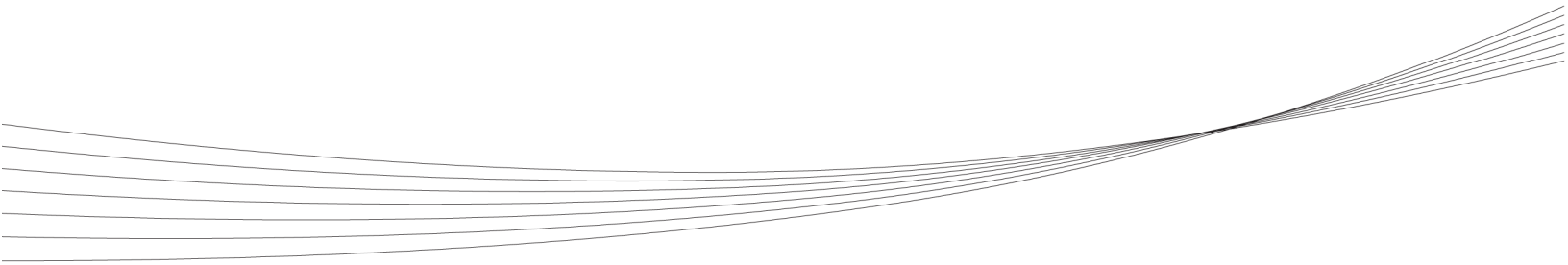
	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012
B.C.	284	307	329	354	384	419	438	479	508	552
Alta.	424	466	491	537	558	575	604	639	672	699
Sask.	35	42	46	51	61	67	75	75	73	69
Man.	<5*	<5*	<5*	<5*	<5*	<5*	<5*	<5*	<5*	<5*
Ont.	1,540	1,653	1,777	1,901	2,052	2,181	2,320	2,463	2,624	2,810
Que.	725	774	826	875	936	1,005	1,068	1,118	1,177	1,217
N.B.	<5*	<5*	<5*	—	<5*	<5*	<5*	<5*	<5*	<5*
N.S.	191	196	210	228	243	260	278	287	300	303
N.L.	<5*	<5*	<5*	<5*	<5*	<5*	<5*	<5*	<5*	—
Canada	**3,205**	**3,444**	**3,685**	**3,951**	**4,238**	**4,511**	**4,787**	**5,066**	**5,359**	**5,654**

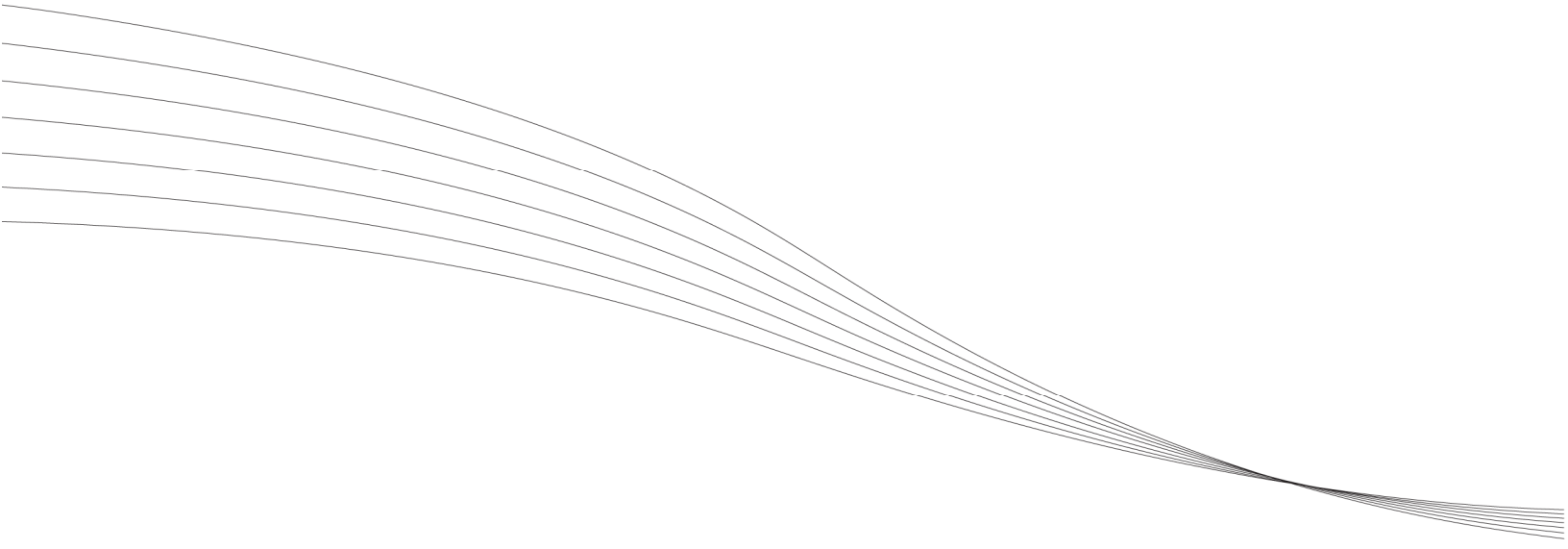
Note

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

Source

Canadian Organ Replacement Register, 2013, 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 2003 to 2012.

There were 183 people on the waiting list for a heart transplant in 2012. Between 2003 and 2012, there were 1,632 heart transplants registered in CORR, including 54 re-transplants. The number of transplants performed each year remained fairly stable between 2003 (157) and 2012 (161). Children accounted for 17% (285) of all heart transplants over the decade. The largest number of transplants was performed on recipients between age 35 and 59 (795), followed by those age 60 and older (325) (Table 41). The crude RPMP for heart transplants varied from 3.0 to 5.0 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, more than 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 2009, 88% of recipients survived the first three years, and five-year survival also improved from 80% to 85% between 2003 and 2007.

In 2012, there were 2,546 Canadians living with a heart transplant.

Table 40: Heart Transplant Waiting List at December 31 and Deaths, 2003 to 2012

	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	Total
Age 0–17	37	6	9	7	13	17	12	14	23	23	**161**
Age 18+	94	119	87	80	102	114	124	121	143	160	**1,144**
Waiting List	131	125	96	87	115	131	136	135	166	183*	**1,305**
Deaths on Waiting List	30	26	27	13	19	14	30	22	25	15†	**221**

Notes

* Includes 60 persons waiting for a heart transplant in Quebec, as reported in Transplant Québec's *Statistiques officielles 2012*.

† Includes 3 deaths in Quebec, as reported by Transplant Québec.

Sources

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information.

Transplant Québec. *Statistiques officielles 2012*. http://www.transplantquebec.ca/sites/default/files/statistiques2012.pdf. Published February 2013. Accessed December 5, 2013.

Table 41: Heart Transplants by Year, Age Group and Re-Transplants, Canada, 2003 to 2012 (Number)

		2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	Total
Pediatric: Age 0–17	First Graft Age <1	6	14	15	17	7	16	17	5	8	5	**110**
	First Graft Age 1–10	4	7	8	7	9	6	11	12	10	5	**79**
	First Graft Age 11–17	10	9	9	9	11	15	9	9	8	7	**96**
Adults: Age 18+	First Graft Age 18–34	16	13	18	27	14	19	17	21	12	16	**173**
	First Graft Age 35–59	82	66	86	91	85	75	78	73	78	81	**795**
	First Graft Age 60+	33	30	33	20	31	30	33	47	27	41	**325**
Re-Transplants		6	4	5	7	6	3	3	2	12	6	**54**
Total		**157**	**143**	**174**	**178**	**163**	**164**	**168**	**169**	**155**	**161**	**1,632**

Source

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information.

Table 42: Primary Diagnosis* for Heart Transplant Recipients, Canada, 2003 to 2012 (Percentage)

	Age <1	Age 1–10	Age 11–17	Age 18–34	Age 35–59	Age 60+	Total
Congenital	36.1	25.9	12.7	12.4	3.2	0	**7.6**
Cardiomyopathy Unspecified	7.6	4.9	14.7	10.8	9.7	10.4	**9.9**
Dilated Cardiomyopathy	10.1	9.9	20.6	23.2	22.1	17.3	**19.7**
Idiopathic Cardiomyopathy	4.2	11.1	5.9	14.1	10.7	11.0	**10.4**
Ischemic Cardiomyopathy	0	0	1	3.2	27.0	43.5	**22.8**
Unknown/Missing	21.0	25.9	23.5	3.2	3.1	3.6	**6.8**
Other*	21.0	22.2	21.6	33.0	24.3	14.3	**22.7**
Total	**100**	**100**	**100**	**100**	**100**	**100**	**100**

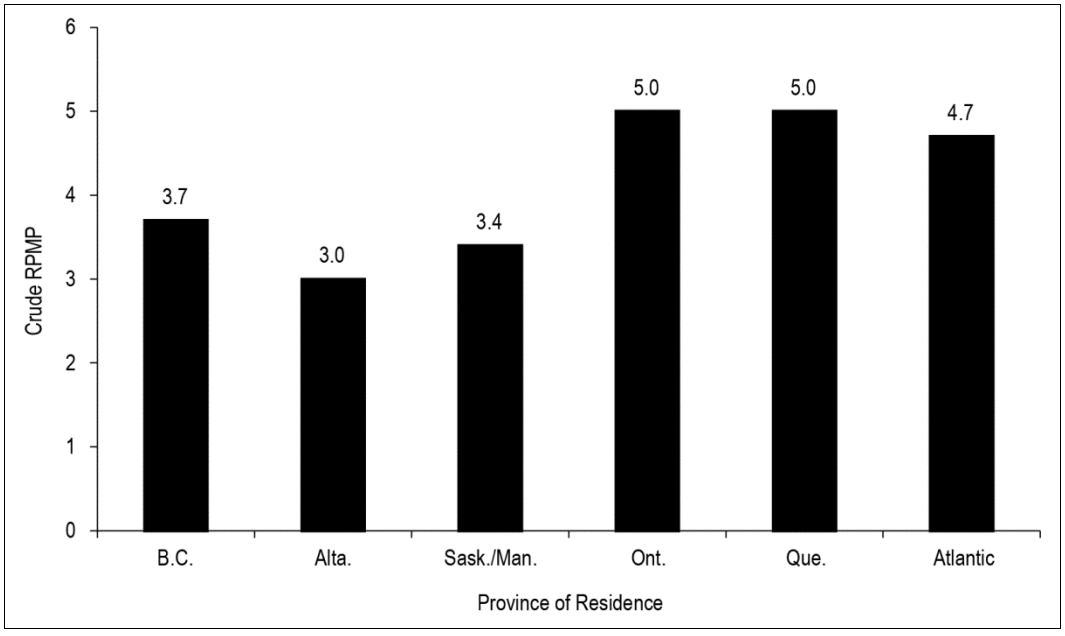
Note

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

Source

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information.

Figure 14: Heart Transplant Recipients by Province of Residence, Canada, 2012 (Crude Rate per Million Population)



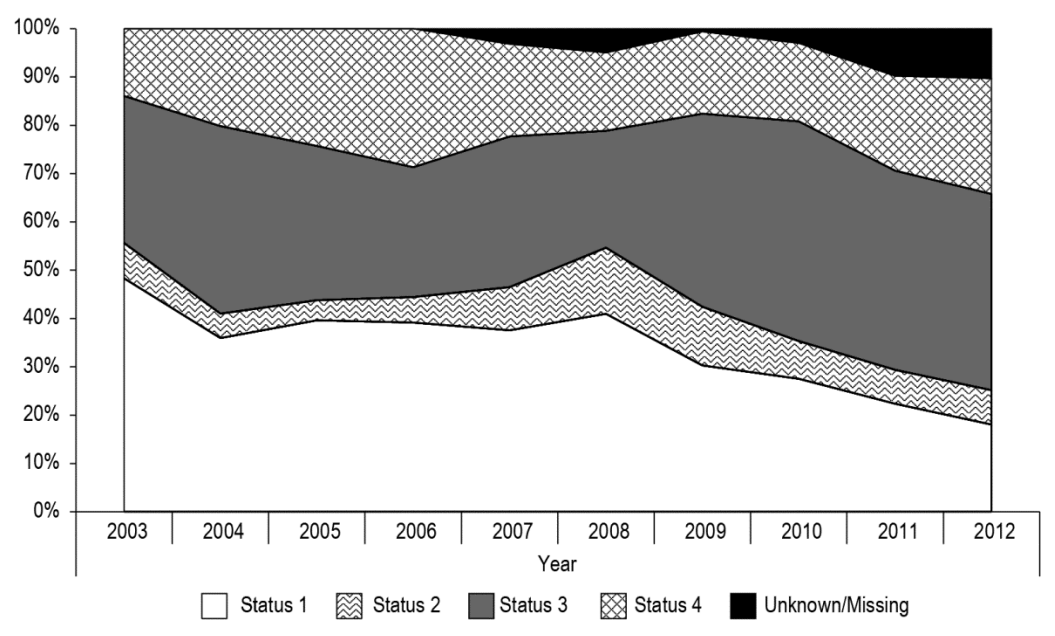
Note

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

Source

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information.

Figure 15: Distribution of Heart Transplants by Medical Status* at Transplant, Canada, 2003 to 2012



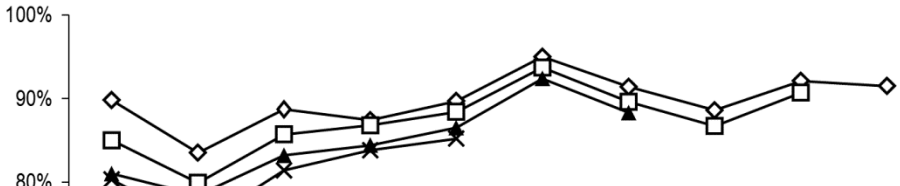
Note

* 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, 2013, 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, 2003 to 2012 (Percentage)



	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012
3 Months	89.8	83.5	88.7	87.4	89.7	95.0	91.4	88.6	92.1	91.5
1 Year	85.0	79.9	85.7	86.8	88.4	93.7	89.6	86.7	90.7	
3 Years	81.0	78.4	83.2	84.4	86.5	92.4	88.3			
5 Years	80.3	74.8	81.4	83.8	85.2					

Source

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information.

Table 43: Prevalent Heart Transplant Patients, by Province of Treatment/Follow-Up, 2003 to 2012 (Number)

	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012
B.C.	178	182	192	200	213	227	229	241	249	257
Alta.	279	292	318	342	356	370	395	413	433	447
Sask.	14	14	14	15	16	20	22	22	21	21
Man.	5	5	<5*	<5*	<5*	<5*	<5*	8	9	8
Ont.	710	726	758	785	820	856	899	942	972	1,019
Que.	482	484	495	508	530	566	602	625	645	663
N.S.	99	103	107	109	112	115	123	125	128	131
Canada†	**1,767**	**1,806**	**1,888**	**1,963**	**2,050**	**2,157**	**2,273**	**2,376**	**2,457**	**2,546**

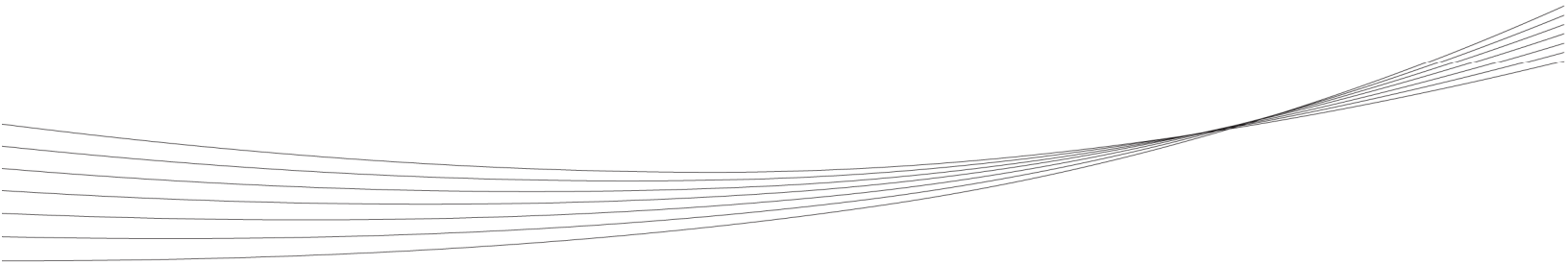
Notes

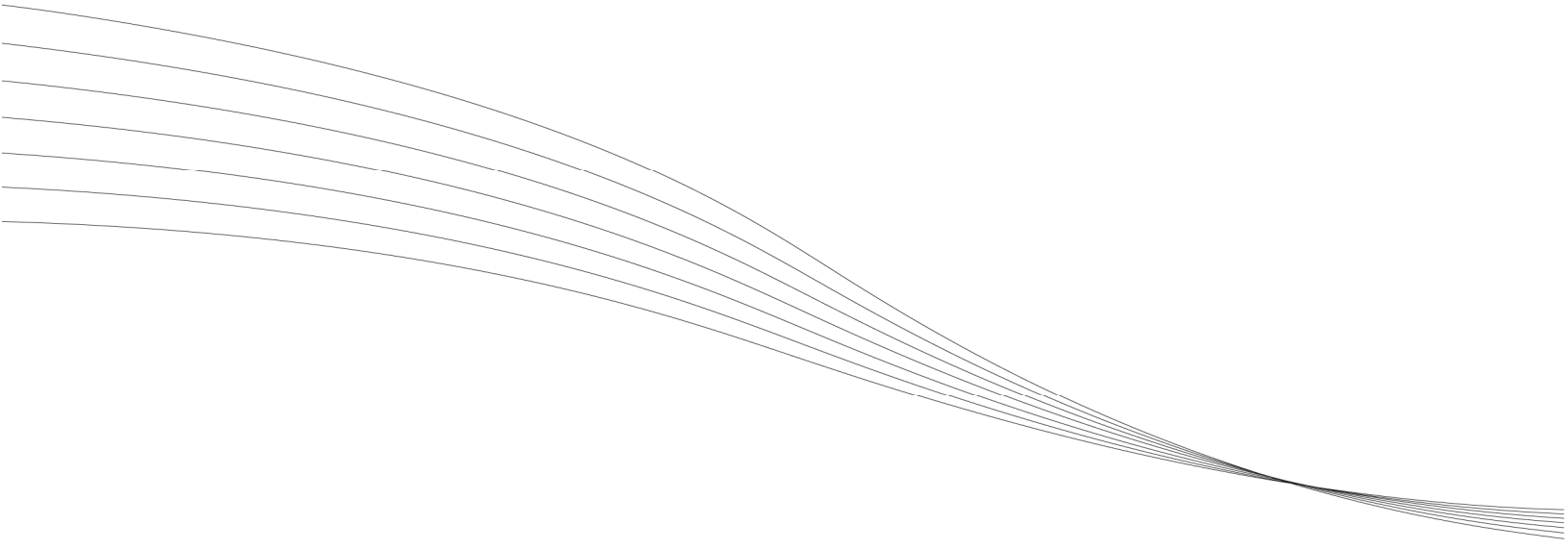
* Value suppressed in accordance with CIHI's privacy policy; cell value is from 1 to 4.

† Totals for Canada do not include suppressed cells.

Source

Canadian Organ Replacement Register, 2013, 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 2003 to 2012.

The number of individuals on the waiting list for a lung transplant continued to grow over the decade, reaching 329 in 2012. Between 2003 and 2012, there was an increase in the annual number of lung transplants performed in Canada. During the decade, there were 1,656 lung transplants, with an average of 180 performed each year since 2006 (Table 45). Of the 191 reported lung transplants performed in 2012, 82% were bilateral lung transplants (Table 46). Since 2003, the number of bilateral lung transplants has increased by 65%, from 95 to 157. Single-lung transplant volumes averaged 27 procedures per year over the 10 years (Table 46).

In 2012, Ontario had the highest rate of lung transplantation, at 6.7 RPMP, followed by Alberta (6.5 RPMP) and British Columbia (5.2 RPMP) (Figure 17).

Rates of patient survival for lung transplant generally show an increasing trend (Figure 18). Three-year survival increased from 66% to 77% between 2003 and 2009. Similarly, five-year survival increased from 58% to 66% between 2003 and 2007. Three-month and one-year survival showed similar improvements (89% to 94% from 2003 to 2012, and 81% to 91% from 2003 to 2011, respectively).

There were 1,441 Canadians living with a transplanted lung in 2012 (Table 48).

Table 44: Lung Transplant Waiting List at December 31 and Waiting List Deaths, Canada, 2003 to 2012

	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	Total
Bilateral Lung	131	155	188	147	183	147	137	178	188	174*	**1,628**
Single Lung	29	22	37	94	51	129	104	125	122	144*	**857**
Heart–Lung	12	4	14	11	9	6	4	7	1	11*	**79**
Total	**172**	**181**	**239**	**252**	**243**	**282**	**245**	**310**	**311**	**329**	**2,564**
Deaths on Waiting List	29	43	43	36	43	44	44	51	67	69†	**469**

Notes

* Includes 106 persons waiting for a bilateral lung transplant, 1 waiting for a single lung transplant and 2 waiting for a heart–lung transplant in Quebec, as reported in Transplant Québec's *Statistiques officielles 2012*.

† Includes 23 deaths in Quebec, as reported by Transplant Québec.

Sources

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information.

Transplant Québec. *Statistiques officielles 2012*. http://www.transplantquebec.ca/sites/default/files/statistiques2012.pdf. Published February 2013. Accessed December 5, 2013.

Table 45: Lung Transplants by Year, Age Group and Re-Transplants, Canada, 2003 to 2012 (Number)

	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012*	Total
First Graft, Age 18+	112	128	137	166	179	156	178	174	167	182	**1,579**
First Graft, Age 0–17	2	3	5	4	4	6	4	3	5	1	**37**
Re-Transplants	4	2	3	1	4	5	7	3	3	8	**40**
Total	**118**	**133**	**145**	**171**	**187**	**167**	**189**	**180**	**175**	**191**	**1,656**

Note

* Missing data for three lung transplants in Quebec in 2012.

Source

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information.

Table 46: Lung Transplants by Transplant Type, Canada, 2003 to 2012 (Number)

	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012*	Total
Bilateral Lung	95	98	119	129	152	135	153	153	159	157	**1,350**
Single Lung	21	30	19	35	32	28	31	25	13	31	**265**
Living-Donor Lobar	0	2	1	1	0	0	0	0	1	0	**5**
Heart–Lung	2	3	6	6	3	4	5	2	2	3	**36**
Total	**118**	**133**	**145**	**171**	**187**	**167**	**189**	**180**	**175**	**191**	**1,656**

Note

* Missing data for three lung transplants in Quebec in 2012.

Source

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information.

Table 47: Primary Diagnoses† for Lung Transplant Recipients, First Graft, Canada, 2003 to 2012* (Number, Percentage)

	Bilateral Lung		Single Lung		Heart–Lung	
	N	%	N	%	N	%
Congenital	9	0.7	0	0	8	21.6
Alpha-1-Antitrypsin Deficiency	57	4.3	11	4.0	0	0
Cystic Fibrosis	352	26.4	11.0	4.0	2	5.4
Emphysema/Chronic Obstructive Pulmonary Disease	298	22.4	110	39.9	5	13.5
Idiopathic Pulmonary Fibrosis	322	24.2	107	38.8	3	8.1
Primary Pulmonary Hypertension	59	4.4	3	1.1	5	13.5
Unknown/Missing	41	3.1	5	1.8	3	8.1
Other‡	194	14.6	29	10.5	11	29.7
Total	1332	100	276	100	37	100

Notes

* Missing data for three lung transplants in Quebec in 2012.

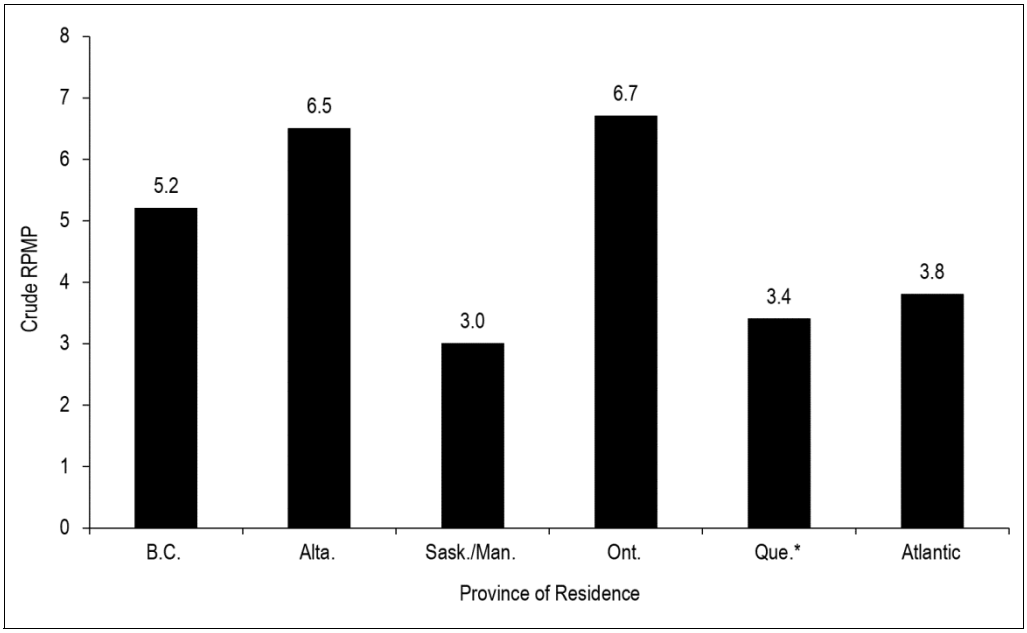
† More than one diagnosis can be reported for a patient.

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

Source

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information.

Figure 17: Lung Transplant Recipients by Province of Residence, Canada, 2012 (Crude Rate per Million Population)



Notes

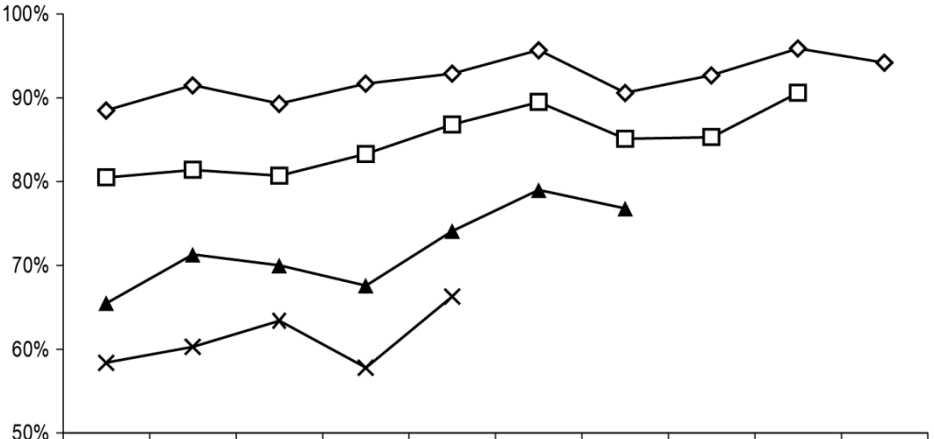
* Missing data for three lung transplants in Quebec in 2012.

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

Sources

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information; Statistics Canada.

Figure 18: Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival Rates* for Lung Transplant Recipients, First Graft, Deceased-Donor Lungs, Canada, 2003 to 2012 (Percentage)



	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012
3 Months	88.5	91.5	89.3	91.7	92.9	95.7	90.6	92.7	95.9	94.2
1 Year	80.5	81.4	80.7	83.3	86.8	89.5	85.1	85.3	90.6	
3 Years	65.5	71.3	70.0	67.6	74.1	79.0	76.8			
5 Years	58.4	60.3	63.4	57.8	66.3					

Note

* Survival rates may be affected by unreported lung transplants and deaths in Quebec in 2012.

Source

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information.

Table 48: Prevalent Lung Transplant Patients, by Province of Treatment/Follow-Up, 2003 to 2012 (Number)

	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012*
B.C.	55	59	63	67	76	85	81	87	94	105
Alta.	133	148	168	187	206	222	225	244	260	272
Sask.	5	5	5	6	8	15	29	28	27	22
Man.	53	60	58	61	65	66	63	66	67	66
Ont.	308	338	370	416	488	530	574	614	671	725
Que.*	143	157	155	168	185	191	210	223	230	251
Canada	**697**	**767**	**819**	**905**	**1,028**	**1,109**	**1,182**	**1,262**	**1,349**	**1,441**

Note

* Missing data for three lung transplants in Quebec in 2012.

Source

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information.

Chapter 6—Pancreas Transplantation

6 Pancreas Transplantation

ESKD 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 ESKD 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 2012 was 180 (Table 49). More than two-thirds were waiting for a simultaneous kidney–pancreas transplant.

During the decade from 2003 to 2012, there were 717 pancreas transplants performed in Canada (Table 50). The majority of the transplants performed (69%) 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 2003, 392 procedures have been performed on 294 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, 2003 to 2012

Transplant	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012
SKP	120	101	132	113	126	98	56	107	108	122*
PAK/PTA	31	51	63	63	55	49	42	68	63	58*
Total	**151**	**152**	**195**	**176**	**181**	**147**	**98**	**175**	**171**	**180**

Notes

* Includes 17 persons waiting for a simultaneous kidney–pancreas transplant and 14 persons waiting for a pancreas transplant alone in Quebec, as reported in Transplant Québec's *Statistiques officielles 2012*.

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

Sources

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information.

Transplant Québec. *Statistiques officielles 2012*. http://www.transplantquebec.ca/sites/default/files/statistiques2012.pdf. Published February 2013. Accessed December 5, 2013.

Table 50: Pancreas Transplants by Year, Canada, 2003 to 2012 (Number)

Transplant	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	Total
SKP	38	47	53	55	50	63	48	50	54	40	**498**
PAK	17	11	12	13	13	18	20	20	16	33	**173**
PTA	9	3	6	5	6	3	2	5	3	4	**46**
Total	**64**	**61**	**71**	**73**	**69**	**84**	**70**	**75**	**73**	**77**	**717**

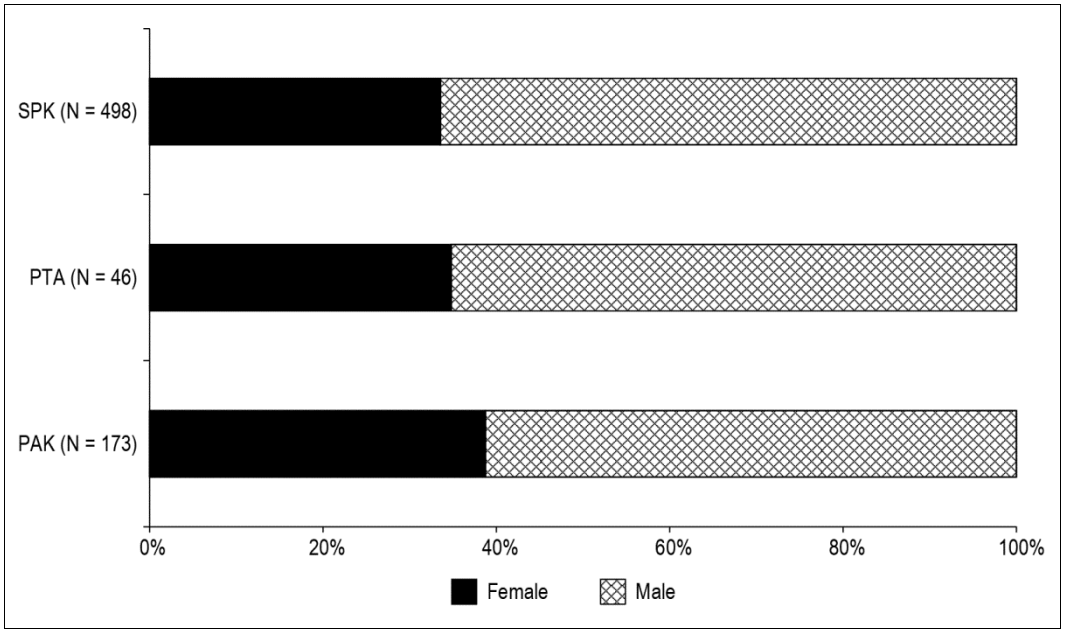
Note
SKP: Simultaneous kidney–pancreas transplant; PAK: Pancreas after kidney transplant; PTA: Pancreas transplant alone.
Source
Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information.

Table 51: Islet Cell Transplants in Canada, 2003 to 2012

	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	Total
Patients	27	25	28	31	18	28	29	32	27	49	**294**
Procedures	35	39	39	39	25	35	38	44	36	62	**392**

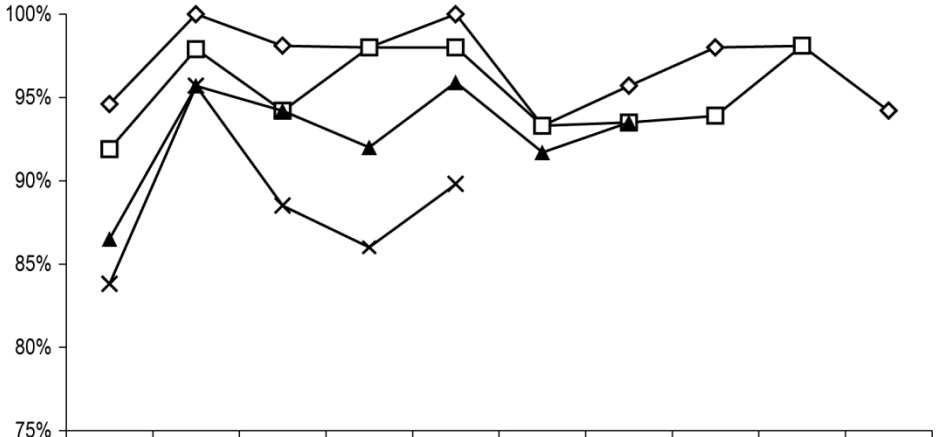
Source
Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information.

Figure 19: Pancreas Transplant Recipients by Type and Recipient Sex, First Graft, Canada, 2003 to 2012 (Percentage)



Note
SKP: Simultaneous kidney–pancreas transplant; PAK: Pancreas after kidney transplant; PTA: Pancreas transplant alone.
Source
Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information.

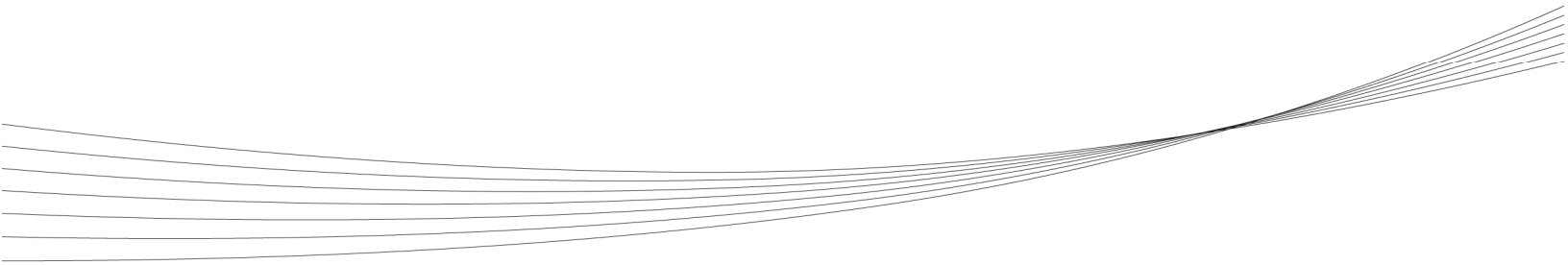
Figure 20: Unadjusted Three-Month and One-, Three- and Five-Year Graft Survival Rates in Simultaneous Kidney–Pancreas Transplant Recipients, by Year of Transplant, First Graft, Canada, 2003 to 2012 (Percentage)

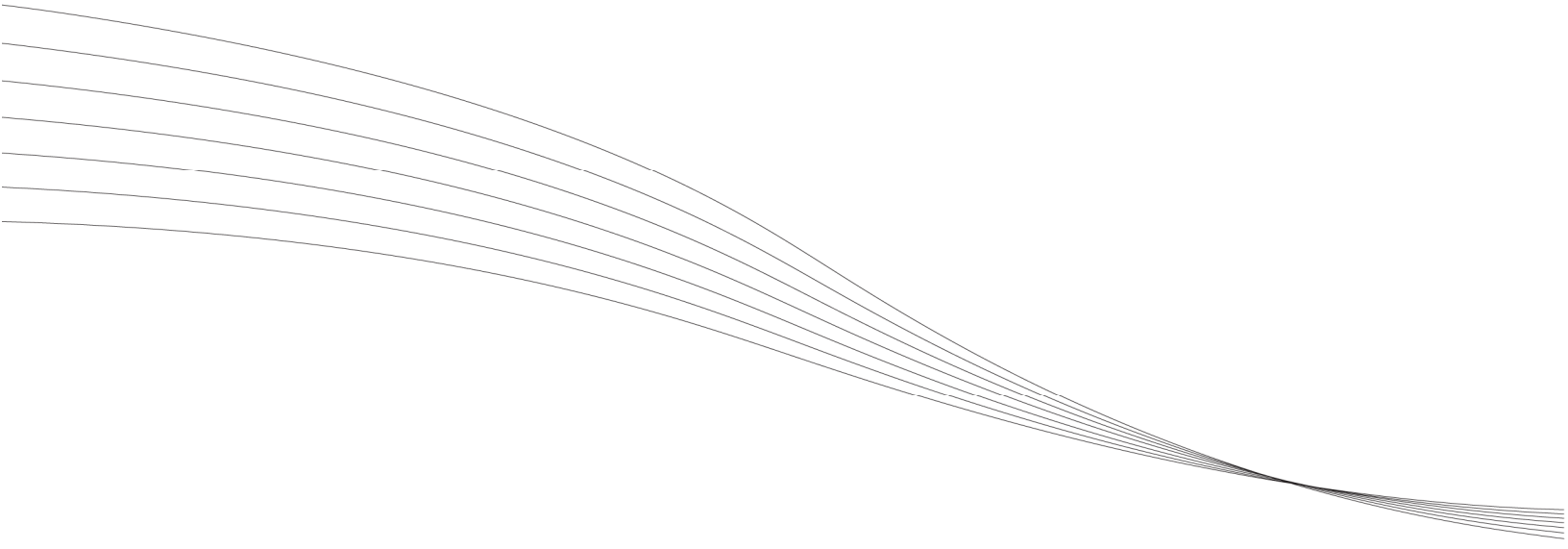


	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012
3 Months	94.6	100.0	98.1	98.0	100.0	93.3	95.7	98.0	98.1	94.2
1 Year	91.9	97.9	94.2	98.0	98.0	93.3	93.5	93.9	98.1	
3 Years	86.5	95.7	94.2	92.0	95.9	91.7	93.5			
5 Years	83.8	95.7	88.5	86.0	89.8					

Source

Canadian Organ Replacement Register, 2013, 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.

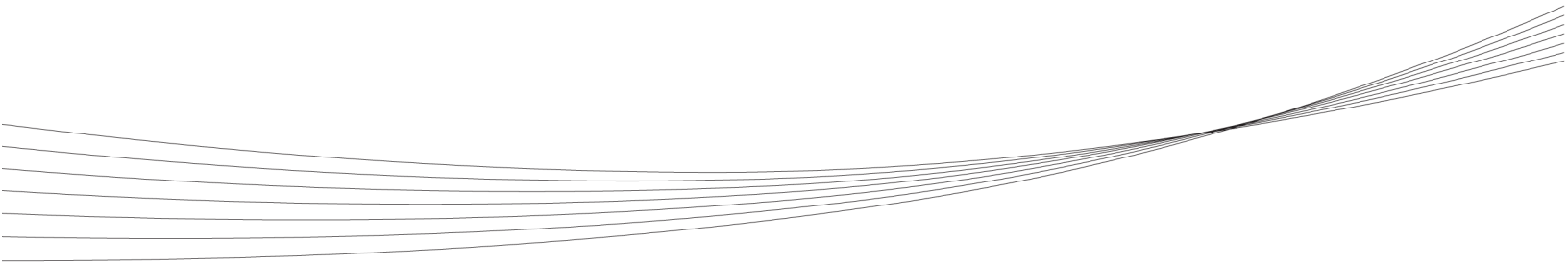
Since 1993, there have been 57 intestinal transplants reported to CORR (Table 52). The transplants were almost evenly split between pediatric patients and adult recipients (56% versus 44%). The majority of liver–small intestine transplants were performed on pediatric patients (85%).

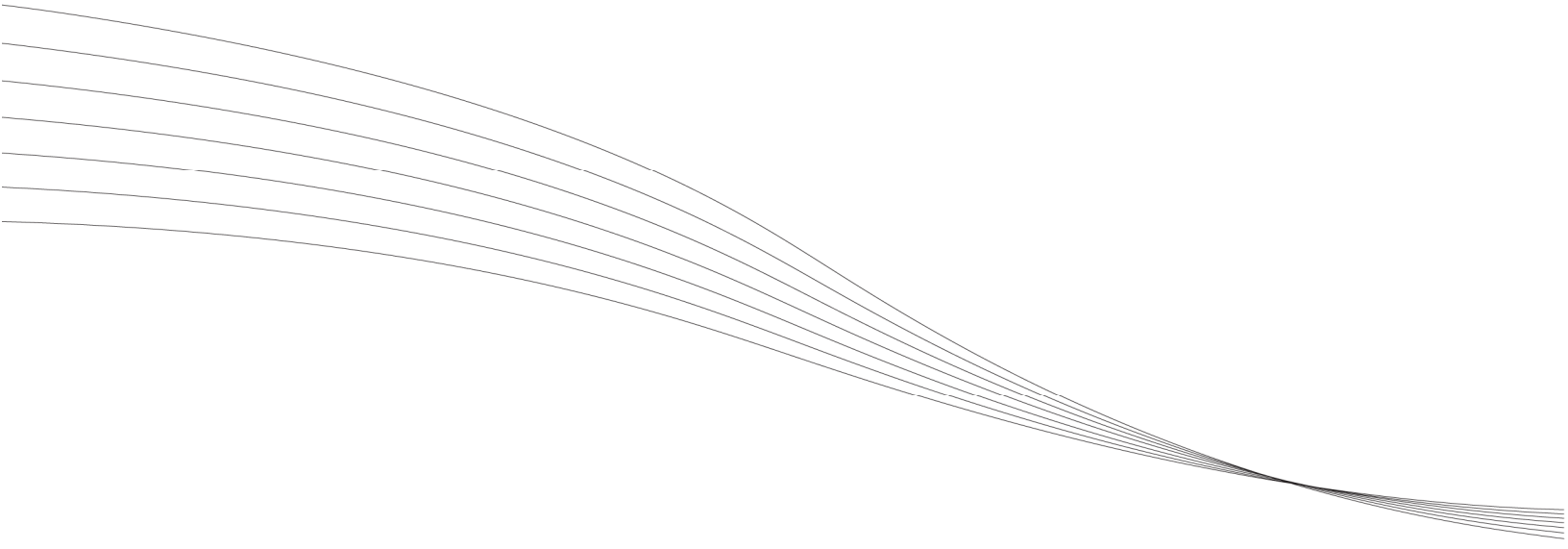
Table 52: Intestinal Transplants by Transplant Period and Age Group, Canada, 1993 to 2012 (Number)

	1993–2002		2003–2012		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	9	**8**	**11**	**19**
Liver–Small Intestine	7	2	10	1	**17**	**3**	**20**
Kidney–Small Intestine	0	2	0	0	**0**	**2**	**2**
Liver–Kidney–Small Intestine	1	0	0	0	**1**	**0**	**1**
Total	**14**	**9**	**18**	**16**	**32**	**25**	**57**

Source
Canadian Organ Replacement Register, 2013, 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 1993 and 2012.





Chapter 8—Donors

8 Donors[vii]

Overall, the number of Canadian organ donors increased from 856 in 2003 to 1,079 in 2012, a relative increase of 26% (Figure 21). During that same period, the number of deceased donors slowly increased, and in 2012 deceased donors outnumbered living donors (540 versus 539). As a result of this increase in donors, transplant procedures increased 24%, from 1,796 in 2003 to 2,225 in 2012 (Figure 22).

Between 2003 and 2012, 34% of living donors in Canada were unrelated (the definition of unrelated includes spouses). The proportion of unrelated donors has increased from 27% of living donors in 2003 to 36% in 2012 (Table 55).

A Note About Deceased-Donor Rates

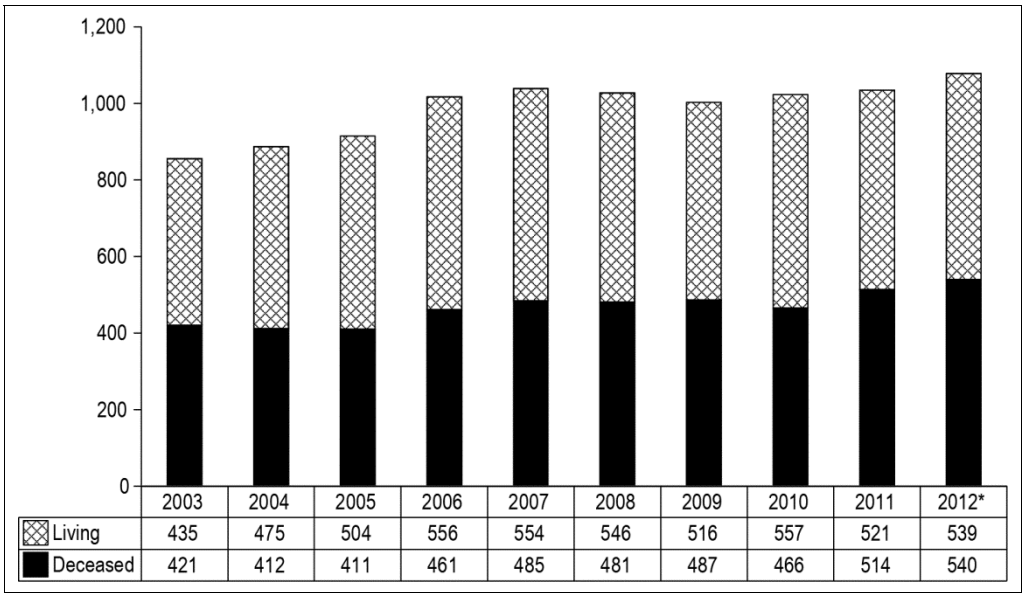
In Canada, deceased organ donors are defined as donors from whom at least one organ was recovered and transplanted. This definition is more conservative than that used in the United States by the United Network of Organ Sharing, which includes donors whose organs were recovered but not transplanted.

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 2012 was 15.5, the highest rate achieved during the 10-year period and 22% above the rate recorded in 2005 (Figure 23). The living DRPM was 15.5. Figures 24 and 25 provide corresponding regional donor rates.

vii. Given the importance of donor numbers and donor rates, some of the tables in this chapter have been supplemented with numbers from Transplant Québec's *Statistiques officielles 2012*.

Figure 21: Number of Canadian Organ Donors by Donor Source (Deceased or Living), 2003 to 2012



	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012*
Living	435	475	504	556	554	546	516	557	521	539
Deceased	421	412	411	461	485	481	487	466	514	540

Note

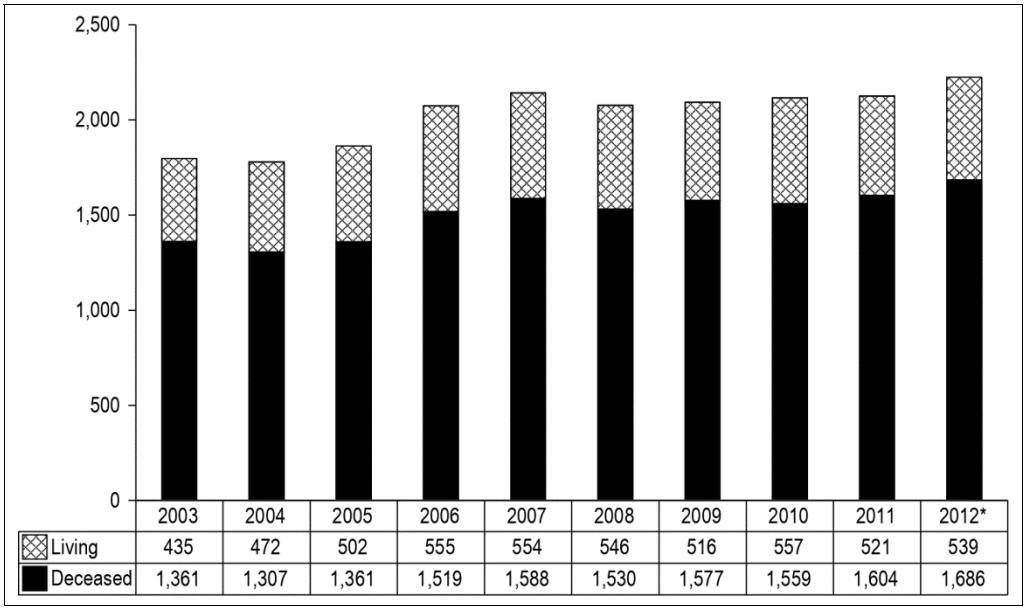
* Includes 54 living donors and 120 deceased donors in Quebec, as reported in Transplant Québec's *Statistiques officielles 2012*.

Sources

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information.

Transplant Québec. *Statistiques officielles 2012*. http://www.transplantquebec.ca/sites/default/files/statistiques2012.pdf. Published February 2013. Accessed December 5, 2013.

Figure 22: Number of Solid Organ Transplants by Donor Source (Deceased or Living), Canada, 2003 to 2012



	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012*
Living	435	472	502	555	554	546	516	557	521	539
Deceased	1,361	1,307	1,361	1,519	1,588	1,530	1,577	1,559	1,604	1,686

Note

* Includes 12 unreported living transplants and 12 unreported deceased donor transplants. Missing counts were derived by comparing totals reported in Transplant Québec's *Statistiques officielles 2012* and available data in CORR.

Sources

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information.

Transplant Québec. *Statistiques officielles 2012*. http://www.transplantquebec.ca/sites/default/files/statistiques2012.pdf. Published February 2013. Accessed December 5, 2013.

Table 53: Number of Deceased Donors by Age Group, Canada, 2003 to 2012

	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012*	Total
Age 0–17	36	29	47	41	53	49	39	34	43	50	**421**
Age 18–39	128	114	99	115	108	131	125	138	128	146	**1,232**
Age 40–49	95	86	83	102	101	92	86	82	97	101	**925**
Age 50–54	36	43	51	53	60	50	51	74	55	60	**533**
Age 55–59	35	46	44	48	52	58	53	42	60	69	**507**
Age 60+	91	94	87	102	111	101	133	96	131	114	**1,060**
Total	**421**	**412**	**411**	**461**	**485**	**481**	**487**	**466**	**514**	**540**	**4,678**

Note

***** Includes 120 deceased donors in Quebec, as reported by Transplant Québec.

Sources

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information.

Transplant Québec. *Statistiques officielles 2012*. http://www.transplantquebec.ca/sites/default/files/statistiques2012.pdf. Published February 2013. Accessed December 5, 2013.

Table 54: Number of Living Donors by Age Group, Canada, 2003 to 2012

	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012*	Total
Age 0–39	178	190	180	218	199	188	169	192	189	205	**1,908**
Age 40–49	139	151	159	163	178	177	171	170	144	129	**1,581**
Age 50–54	58	61	66	66	78	87	72	73	85	75	**721**
Age 55–59	26	34	48	49	68	56	54	64	60	66	**525**
Age 60+	18	22	23	32	31	37	50	58	43	52	**366**
Unknown	16	17	28	28	—	1	—	—	—	12	**102**
Total	**435**	**475**	**504**	**556**	**554**	**546**	**516**	**557**	**521**	**539**	**5,203**

Note

***** Includes 12 unreported living donors from Quebec where age was unknown.

Sources

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information.

Transplant Québec. *Statistiques officielles 2012*. http://www.transplantquebec.ca/sites/default/files/statistiques2012.pdf. Published February 2013. Accessed December 5, 2013.

Table 55: Living Donor by Relationship of Donor to Recipient, Canada, 2003 to 2012

	Parent	Sibling	Offspring	Other Related†	Spouse	Unrelated	Unknown*	Total
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	132	54	44	85	140	—	**521**
2012*	85	106	86	57	73	120	12	**539**

Notes

* Includes 12 unreported living donors from Quebec where the relationship was unknown.

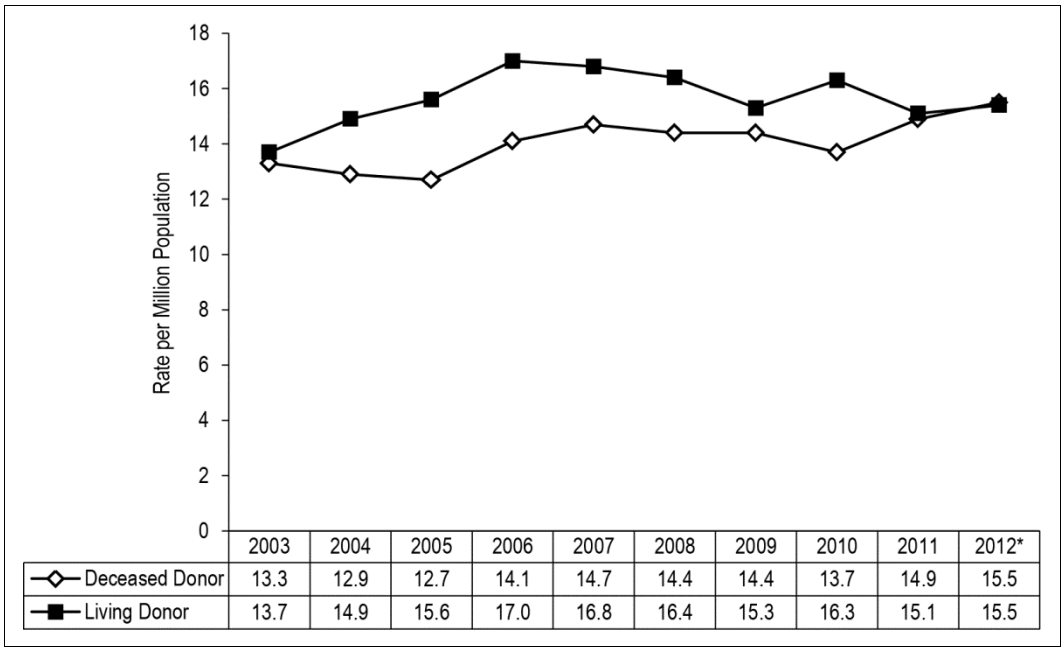
† Family members such as aunts, uncles or cousins.

Sources

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information.

Transplant Québec. *Statistiques officielles 2012*. http://www.transplantquebec.ca/sites/default/files/statistiques2012.pdf. Published February 2013. Accessed December 5, 2013.

Figure 23: Donor Rate per Million Population, by Donor Source (Deceased or Living), Canada, 2003 to 2012



	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012*
Deceased Donor	13.3	12.9	12.7	14.1	14.7	14.4	14.4	13.7	14.9	15.5
Living Donor	13.7	14.9	15.6	17.0	16.8	16.4	15.3	16.3	15.1	15.5

Note

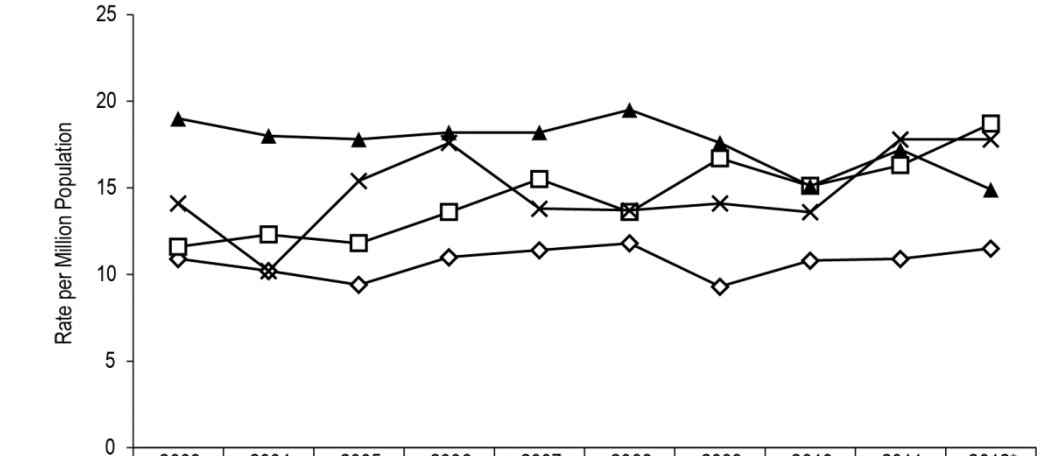
* Donor counts include 120 deceased donors and 54 living donors in Quebec, as reported in Transplant Québec's *Statistiques officielles 2012*.

Sources

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information.

Transplant Québec. *Statistiques officielles 2012*. http://www.transplantquebec.ca/sites/default/files/statistiques2012.pdf. Published February 2013. Accessed December 5, 2013.

Figure 24: Deceased Donor Rate per Million Population by Region, Canada, 2003 to 2012



	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012*
West	10.9	10.2	9.4	11.0	11.4	11.8	9.3	10.8	10.9	11.5
Ontario	11.6	12.3	11.8	13.6	15.5	13.6	16.7	15.1	16.3	18.7
Quebec*	19.0	18.0	17.8	18.2	18.2	19.5	17.6	15.1	17.2	14.9
Atlantic	14.1	10.2	15.4	17.6	13.8	13.7	14.1	13.6	17.8	17.8

Notes

* Rate based on 120 deceased donors in Quebec, as reported in Transplant Québec's *Statistiques officielles 2012*.

West includes British Columbia, Alberta, Saskatchewan and Manitoba.

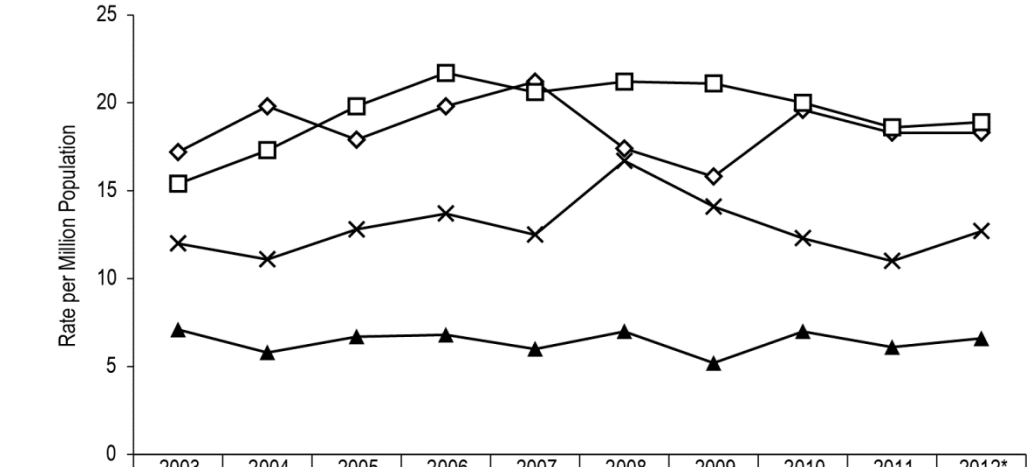
Atlantic includes New Brunswick, Nova Scotia, Prince Edward Island and Newfoundland and Labrador.

Sources

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information.

Transplant Québec. *Statistiques officielles 2012*. http://www.transplantquebec.ca/sites/default/files/statistiques2012.pdf. Published February 2013. Accessed December 5, 2013.

Figure 25: Living Donor Rate per Million Population, by Region, Canada, 2003 to 2012



	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012*
West	17.2	19.8	17.9	19.8	21.2	17.4	15.8	19.6	18.3	18.3
Ontario	15.4	17.3	19.8	21.7	20.6	21.2	21.1	20.0	18.6	18.9
Quebec*	7.1	5.8	6.7	6.8	6.0	7.0	5.2	7.0	6.1	6.7
Atlantic	12.0	11.1	12.8	13.7	12.5	16.7	14.1	12.3	11.0	12.7

Notes

* Rate based on 54 living donors in Quebec, as reported in Transplant Québec's *Statistiques officielles 2012*.

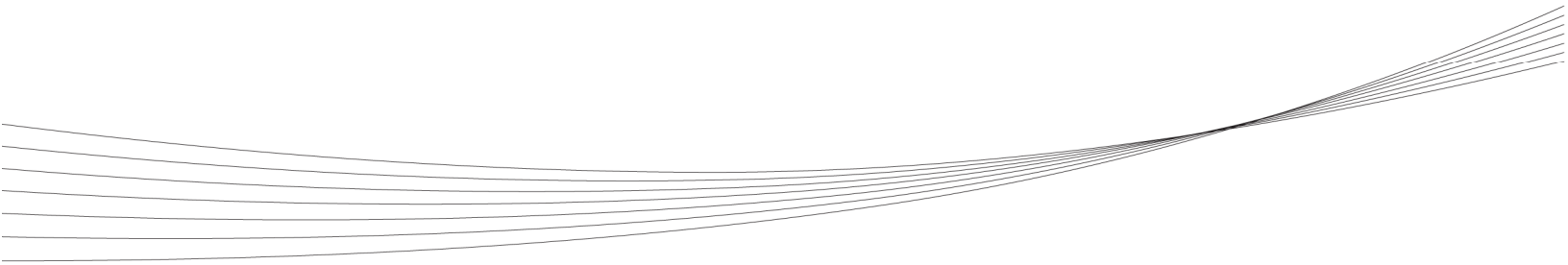
West includes British Columbia, Alberta, Saskatchewan and Manitoba.

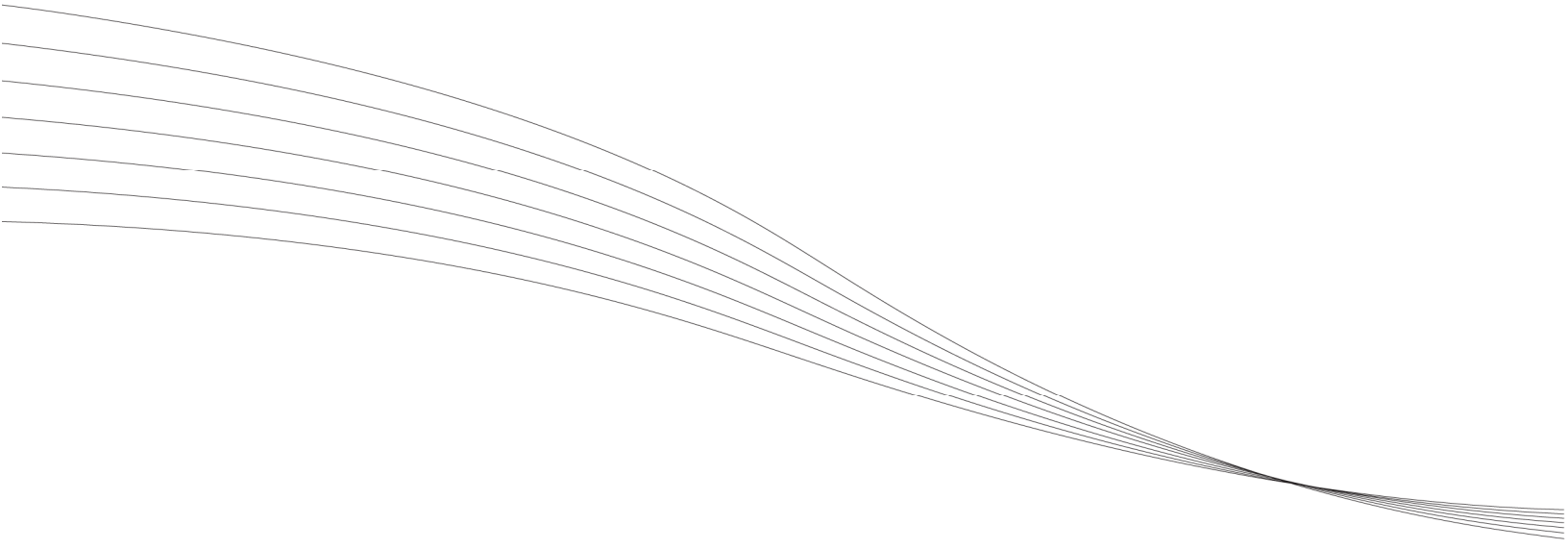
Atlantic includes New Brunswick, Nova Scotia, Prince Edward Island and Newfoundland and Labrador.

Sources

Canadian Organ Replacement Register, 2013, Canadian Institute for Health Information.

Transplant Québec. *Statistiques officielles 2012*. http://www.transplantquebec.ca/sites/default/files/statistiques2012.pdf. Published February 2013. Accessed December 5, 2013.





Appendices

Appendix A—Canadian Organ Replacement Register Board of Directors

CORR Board of Directors (October 1, 2013)

- Dr. Joseph Kim, Canadian Society of Transplantation—President
- Dr. Scott Klarenbach, Canadian Society of Nephrology—Vice President
- Dr. Louise Moist, 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. 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 2012								Dialysis Programs in 2012			
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		X	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	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

(cont'd on next page)

Hospital/Facility	Types of Transplants Performed in 2012								Dialysis Programs in 2012			
	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	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

(cont'd on next page)

Hospital/Facility	Types of Transplants Performed in 2012								Dialysis Programs in 2012			
	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 du lac Témiscaminque									X			
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 Rouyn-Noranda									X			
CSSS de Saint-Jérôme									X		X	X
CSSS de Sorel-Tracy									X		X	X
Hôtel-Dieu d'Arthabaska*									X			
Hôtel-Dieu de Lévis									X		X	X
Institut de cardiologie de Montréal			X									
IUCPQ			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			
Rivière-Rouge*									X			
Royal Victoria, McGill	X	X	X				X		X		X	X
Sacré-Cœur de Montréal									X		X	X
Sainte-Croix*									X		X	

(cont'd on next page)

Hospital/Facility	Types of Transplants Performed in 2012								Dialysis Programs in 2012			
	Kidney	Liver	Heart	Heart/ Lung	Lung	Intestine/ Multi-Visceral	Pancreas/ Kidney–Pancreas	Islet Cell	HD	Home HD Training†	PD	Home PD Training
Quebec (cont'd)												
Sainte-Justine	X	X	X						X		X	X
Sir Mortimer B. Davis—Jewish General Hospital									X		X	X
St. Mary's									X		X	X
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	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: 2003 to 2012

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, ESKD 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, 2012

	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	8	2	6	31	35	4	5	0	3	0	**107**
Affiliated Community Centres	26	27	10	16	56	6	6	9	0	9	0	**165**
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, 2012

	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. Since 2011, data reported by the Ontario Renal Network has been 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.

Under-Reporting in Quebec

As noted in the last report, unit non-response (under-reporting) for 2011 incident ESKD cases was estimated to be 300 cases from six to eight centres in Quebec. Since that report, additional data has been received; under-reporting for 2011 is now estimated to be approximately 170 cases.

In 2012, Quebec had increased under-reporting due to administrative issues. CIHI is working with Quebec sites to improve reporting for future years.

The table below provides a measure of the completeness of Quebec data for 2011 and 2012.

Table D5: Data Completeness for Quebec

	2011	2012
Dialysis	Approximately 84% complete Missing an estimated 170 incident cases In addition, an undetermined number of death reports are missing from Quebec	Approximately 49% complete Missing an estimated 560 incident cases In addition, an undetermined number of death reports are missing from Quebec
Transplants	Complete	95% complete Missing 24 known transplants (21 kidney transplants, 3 lung transplants) Complete data on heart, liver and pancreas transplants
Living Donors	Complete	Supplemented with data from Transplant Québec
Deceased Donors	Complete	Supplemented with data from Transplant Québec
Waiting List	Complete	Supplemented with data from Transplant Québec
Waiting List Deaths	Complete	Unknown

Missing Quebec data affects the incidence dialysis data and, to a lesser extent, the prevalence data. Totals for transplant and organ donor activity are also affected. As a result, national trends must be interpreted with care.

The impact of the missing Quebec data is most apparent on dialysis incident counts and rates. The true impact on overall prevalence counts is difficult to determine. Prevalence reflects the number of persons living with a condition at a specific point in time. The under-reporting of incident cases in Quebec and the unreported number of deaths from Quebec have offsetting effects, resulting in an undetermined true impact on prevalence.

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[1] 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 ESKD Cases

As noted above, unit non-response in Quebec for incident ESKD cases (under-reporting) was estimated to be approximately 170 cases in 2011 and 560 cases in 2012.

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 D6 presents a comparison of these sources and the respective transplant counts per province for 2012, and shows that the new patient-level data is marginally less than the OPO aggregate counts. This suggests 99% reporting of aggregate data.

Table D6: Comparison of Counts of Kidney Transplants* by Data Source, 2012 (Number)

	B.C.	Alta.	Sask.	Man.	Ont.	Que.	N.S.	Total
Patient-Level Data for Transplants in CORR	196	132	12	50	610	232	105	**1,337**
Aggregate Counts Provided by OPOs at Year-End	196	134	10	50	605	253	105	**1,353**

Note

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

3) Extra-Renal Transplants

For the extra-renal transplants in 2012, the transplants registered in the database were compared against the aggregate counts reported by the OPOs. The results are provided in Table D7 and suggest that little under-reporting of transplant procedures was observed in the last decade.

Table D7: Comparison of Counts of Extra-Renal Transplants* by Data Source and Province of Treatment, 2012 (Number)

Organ Type	Data Source†	B.C.	Alta.	Sask.	Man.	Ont.	Que.	N.S.	Total
Liver	CORR Registration	65	64	—	—	253	92	20	**494**
	OPO Count	65	64	—	—	247	92	20	**488**
Heart	CORR Registration	16	24	—	—	74	40	10	**164**
	OPO Count	16	29	—	—	74	40	10	**169**
Lung/ Heart–Lung	CORR Registration	25	30	—	2	104	30	—	**191**
	OPO Count	25	29	—	2	104	33	—	**193**
Pancreas	CORR Registration	5	5	—	—	43	12	5	**70**
	OPO Count	5	7	1	—	43	12	4	**72**
Islets	CORR Registration	1	61	—	—	—	—	—	**62**
	OPO Count	1	61	—	—	—	—	—	**62**
Intestine/ Multi-Visceral	CORR Registration	—	1	—	—	2	—	—	**3**
	OPO Count	—	1	—	—	1	—	—	**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 D8. With the exception of the 120 unreported deceased and 11 living donors from Quebec in 2012, this table suggests that no under-reporting of donors has been observed in CORR.

Table D8: Comparison of Deceased and Living Donors Registered in CORR and Reported by OPOs, 2003 to 2012 (Number)

	Registered in CORR			Reported by OPOs		
Year	Deceased Donors	Living Donors	Total Donors	Deceased Donors	Living Donors	Total Donors
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	521	**1,035**	514	518	**1,032**
2012	420	527	**947**	542	537	**1,079**
Total	**4,558**	**5,191**	**9,749**	**4,567**	**5,174**	**9,861**

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[1] 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.

Table D9 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 2003 to 2012, and for donors for the same period. Rates of non-response/unknowns greater than 10% are shaded.

Table D9: Non-Response/Unknown Values for Key Analytical Data Elements Related to Donors and Transplant Recipients* in CORR, 2003 to 2012

Data Type	Data Element	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012
Deceased Donor	Age	0	0	0	0	0	0	0	0	0	0
	Sex	0.2	0.2	0	0.2	0.2	0	0	0	0	0
	Blood Type	0	2.4	0.2	0	0.4	0.2	0.4	0.2	0	0.2
	Race/Ethnic Origin	22.1	31.6	36.7	34.7	36.3	36.6	31.6	16.3	5.8	5.5
	Province of Residence	0	0	0	0	0.2	0.2	0	0	0.2	0
	Cause of Death	2.4	2.9	2.9	6.3	5.8	3.3	4.1	2.4	1	1.2
Living Donor	Age	0	0	0	0	0	0	0	0	0	0
	Sex	0	0	0	0.5	0.2	0.2	0	0	0.2	0
	Blood Type	7.4	12.4	9.5	4.5	0.7	1.5	1.9	1.1	1.9	0.9
	Province of Residence	0.2	1.3	1.2	2.2	1.1	0.5	0	0.9	0.2	4
Transplant Recipients	Sex	0	0	0	0	0.1	0	0	0	0	0
	Race/Ethnic Origin	20.1	21.1	23.6	22	19.8	19.3	19.4	18.3	19.3	18.9
	Blood Type	4.1	3.1	3.7	3	4.3	4.9	2	1.6	4.2	2.7
	Residential Postal Code	3.1	2.4	1.7	0.9	1.9	1	0.8	0.9	0.8	1.4
	Cause of Death	28.4	23.6	29.3	23.5	32.1	23.5	27	22.3	27.8	15
	Diagnosis	5.1	2.1	2.8	3.6	7.5	4.2	4.1	6.1	5.6	5.7
	Medical Status at Listing (Heart, Liver, Lung Transplants)	3.2	1.4	3.1	3.9	2.6	2.9	4.7	3.2	10.1	7.1
	Medical Status at Transplant (Heart, Liver, Lung Transplants)	0.8	0.4	1.4	1	2.9	2.2	2.5	3.7	6.5	14
	Cause of Graft Failure (Transplants With Failed Grafts)	53.6	52.9	45.7	50	57.4	46.5	55.5	44.7	50	48.7

Note

* Recipients of first grafts for 2002 to 2011.

Table D10 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 2003 to 2012. Table D11 presents the same information stratified by province of treatment. Rates of non-response/unknowns greater than 10% are shaded.

Table D10: Non-Response/Unknown Values for Key Analytical Data Elements Related to Incident Dialysis Patients Registered in CORR by Year, 2003 to 2012

Data Type	Data Element	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	Total
Recipients	Sex	0	0	0	0	0	0	0	0	0.1	0.2	**0**
	Race/Ethnic Origin	6.8	5.4	4.8	6.7	5.2	4.5	5.9	4.6	4	4.4	**5.3**
	Residential Postal Code	1	1	1.1	0.9	1.1	1.8	1.1	0.9	0.9	1.2	**1.1**
	Diagnosis	14.3	13	12.6	13	14.8	14.8	16.3	13.6	11.7	16.7	**14**
	Cause of Death	30.5	26.7	30.6	29	30.2	30.2	30.6	32	29.4	41.9	**29.9**
Risk Factors	Angina	9.1	9.1	9.2	11.7	11.2	13.2	15.4	13.4	8.7	7.9	**11**
	Coronary Artery Bypass/Angioplasty	9.7	8.9	9.4	10.9	10.8	12.4	13.7	12	7	6.8	**10.3**
	Pulmonary Edema	9.3	9.4	9.3	11	11.1	12.4	14.4	12.4	7.7	7.3	**10.5**
	Myocardial Infarct	8.8	9.2	9	10.9	10.6	12.5	14.2	12.1	7.8	7.3	**10.3**
	Diabetes	6.4	6.5	6.4	8.1	6.6	8.1	8.1	6.5	4.8	2.9	**6.6**
	Cerebrovascular Accident	8.3	8.8	8.5	10.8	10.2	12.3	14.1	11.9	6.8	6.9	**10**
	Peripheral Vascular Disease	9.3	9.4	9.2	11.3	11.1	12.9	15.1	12.9	7.6	7.4	**10.7**
	Malignancy	11.2	10.6	12.7	13.2	14.6	16.3	19.8	16.3	9.9	9	**13.5**
	Chronic Lung Disease	9.3	9.7	9.4	11.6	11.6	13.4	16.5	14.6	7.8	7.3	**11.2**
	Use of Medications for Hypertension	6.7	7.1	6.6	8.1	7.1	8.2	8.7	9.5	6.9	5	**7.4**
	Presence of Other Serious Illness	19.3	18.9	21.3	20	18.6	25.1	28	22.8	21.1	22.8	**21.8**
	Current Smoker	13.2	15.4	15.2	15.6	15.2	16	18.1	18	12	10.1	**15**

Table D11: Non-Response/Unknown Values for Key Analytical Data Elements Related to Incident Dialysis Patients Registered in CORR by Province, 2003 to 2012

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	0.4	0	0	0
	Race/Ethnic Origin	14.5	5.8	2.6	5.5	3.6	2.8	3.1	9.1	2.0	5.3
	Residential Postal Code	1.4	1.4	0.5	1.4	0.7	1.3	3.6	1.4	0.7	1.1
	Diagnosis	33.2	10.9	8.3	6.8	11.6	13.3	9.3	9.0	12.5	14
	Cause of Death	60.1	39.1	26.3	25.2	23.4	25.5	17	27.8	15.4	29.9
Risk Factors	Angina	34.3	9.1	9.7	10.8	6.5	9.6	3.9	2.7	1.8	11
	Coronary Artery Bypass/Angioplasty	34.2	8.8	3.4	10.5	5.9	9.0	4.0	1.7	2.0	10.3
	Pulmonary Edema	33.7	8.0	6.4	10.2	6.2	9.9	3.7	2.2	2.0	10.5
	Myocardial Infarct	33.2	8.3	6.6	10.5	5.8	9.7	3.3	2.7	1.7	10.3
	Diabetes	27.2	3.4	1	7.5	2.8	5.8	1.6	0.5	0.6	6.6
	Cerebrovascular Accident	33.5	7.8	5.1	10.1	5.9	8.3	3.5	1.5	1.1	10.0
	Peripheral Vascular Disease	35.2	8.7	5.4	10.3	6.4	9.2	3.0	2.6	2.0	10.7
	Malignancy	38.6	13.7	7.7	11.4	8.8	12.7	5.3	2.4	4.2	13.5
	Chronic Lung Disease	36.6	9.5	6.9	10.5	6.8	8.9	4.4	3.1	2.8	11.2
	Use of Medications for Hypertension	31.3	3.3	1.2	7.5	3.4	6.2	2.3	0.9	0.8	7.4
	Presence of Other Serious Illness	56.6	23.8	13.2	13.7	15.9	18.3	18.9	9.7	7.2	21.8
	Current Smoker	42.2	10.8	10.3	14.2	8.7	17.4	12.6	5.2	3.5	15.0

Reliability/Response Bias: A formal linkage[1] 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.

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 kidney 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
ESKD: end-stage kidney 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 kidney 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 kidney 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 kidney 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 kidney disease. Not all persons with end-stage kidney disease are candidates for kidney transplantation. Most people with end-stage kidney 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 kidney 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 kidney 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 ESKD 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 ESKD in a Canadian facility. Patients who began RRT for ESKD 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 and Graft 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 2003 and 2012. 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 if they withdrew, were 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	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012
B.C.*	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	4,658,674
Alta.†	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	3,950,791
Sask.	994,428	995,391	994,126	985,386	1,000,139	1,013,620	1,030,129	1,044,028	1,057,884	1,079,958
Man.	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	1,267,003
Ont.	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	13,505,900
Que.	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	8,054,756
Atlantic‡	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	2,363,409
Canada	**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**	**34,880,491**

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	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012
N.B.	750,896	751,384	752,006	749,168	745,561	747,147	749,468	752,838	755,455	755,950
N.S./P.E.I.	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	1,094,800
N.L.	518,350	517,027	515,961	509,677	506,530	506,441	508,925	511,281	510,578	512,659
Total	**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**	**2,363,409**

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 ESKD 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 ESKD 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 Kidney Disease

Primary Diagnosis Codes—End-Stage Kidney 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

(cont’d on next page)

Primary Diagnosis Codes—End-Stage Kidney 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

(cont'd on next page)

Primary Diagnosis Codes—End-Stage Kidney 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

(cont'd on next page)

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

Reference

1. Canadian Institute for Health Information. *Data Quality Study on the Canadian Organ Replacement Register*. Ottawa, ON: CIHI; 2009. http://www.cihi.ca/cihi-ext-portal/internet/en/tabbedcontent/types+of+care/specialized+services/organ+replacements/cihi021362.

Production of this report is made possible by financial contributions from Health Canada and provincial and territorial governments. The views expressed herein do not necessarily represent the views of Health Canada or any provincial or territorial government.

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

Phone: 613-241-7860
Fax: 613-241-8120
www.cihi.ca
copyright@cihi.ca

ISBN 978-1-77109-264-7 (PDF)

How to cite this document:
Canadian Institute for Health Information. *Canadian Organ Replacement Register Annual Report: Treatment of End-Stage Organ Failure in Canada, 2003 to 2012*. Ottawa, ON: CIHI; 2014.

Cette publication est aussi disponible en français sous le titre *Traitement du stade terminal de l'insuffisance organique au Canada, de 2003 à 2012 — rapport annuel du Registre canadien des insuffisances et des transplantations d'organes*.
ISBN 978-1-77109-265-4 (PDF)

Talk to Us

CIHI Ottawa
495 Richmond Road, Suite 600
Ottawa, Ontario K2A 4H6
Phone: 613-241-7860

CIHI Toronto
4110 Yonge Street, Suite 300
Toronto, Ontario M2P 2B7
Phone: 416-481-2002

CIHI Victoria
880 Douglas Street, Suite 600
Victoria, British Columbia V8W 2B7
Phone: 250-220-4100

CIHI Montréal
1010 Sherbrooke Street West, Suite 300
Montréal, Quebec H3A 2R7
Phone: 514-842-2226

CIHI St. John's
140 Water Street, Suite 701
St. John's, Newfoundland and Labrador A1C 6H6
Phone: 709-576-7006

www.cihi.ca
At the heart of data

Canadian Institute
for Health Information

Institut canadien
d'information sur la santé