



Treatment of End-Stage Organ Failure in Canada

2002 and 2003

C a n a d i a n O r g a n R e p l a c e m e n t R e g i s t e r



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This report is dedicated to Dr. John Jeffery, a well-known Canadian kidney transplant physician from Winnipeg. Dr. Jeffery spent nearly a quarter of a century as a volunteer with CORR, working to facilitate the growth of the database, to develop a standardized reporting process and to bring about the transition of the database from Statistics Canada to CIHI's predecessor organization in the late 1980s. He resigned from the CORR Advisory Committee in 2004.

Treatment of End-Stage Organ Failure in Canada, 2002 and 2003

CORR Report

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1 Introduction

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

The first Renal Failure Register was started in 1972 under the leadership of Dr. Arthur Shimizu. In 1973, the Register was transferred to Statistics Canada, in collaboration with The Kidney Foundation of Canada. Its first report was produced in 1974. In the mid-1970s, 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 revived 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, including extensive assistance from Drs. Gerald Posen, John Jeffery and Gerald Arbus.

In 1987, with the support of the Federal/Provincial Advisory Committee on the Institutional Medical Services (ACIMS), the Register was expanded to include data on extra-renal organ transplants. The expanded register was operated by the Hospital Medical Records Institute, and renamed the Canadian Organ Replacement Register (CORR). In 1995, CORR became fully integrated with the Canadian Institute for Health Information, which maintains numerous registries and data holdings.

The mission of CORR is to provide a national database on vital organ replacement therapy in Canada and to enhance treatment, research and patient care. Major stakeholders include the Canadian Society of Transplantation, the Canadian Society of Nephrology, the Canadian Association of Transplantation, Health Canada, The Kidney Foundation of Canada and the Canadian Association of Nephrology Nurses and Technologists. The CORR Board of Directors is responsible for providing strategic advice to the Register. The CORR Advisory Committee provides advice on analytical issues and reporting. (For a membership list of the Board of Directors and the Advisory Committee as of April 1, 2005, please see Appendix A.)

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 hospitals and facilities with transplant and dialysis activity reporting to CORR, please refer to Appendix B. CORR receives data on standardized paper forms or spreadsheets. At the present time, all data are entered at CIHI by specially trained staff. Data within the database is collected and reported on a calendar year basis (January 1 to December 31) as is done by other international registries reporting on end-stage organ failure.

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. Information on organ donors is linked to recipient information. At the present time, CORR does not collect information on patients who have been listed for transplant, but not transplanted.

Since the fall of 2002, CORR has operated in a multi-tier environment using an Internet browser. CORR is an Oracle relational database, with over 100 data and code tables included in its architecture. Application services run on IBM AIX.

Data Quality

The collection of patient-level extra-renal transplant data commenced formally on January 1, 1989. These data were collected retrospectively for the years 1981 to 1988 in the *Canadian Organ Replacement Register 1989 Report*. The extent of underreporting of extra-renal transplant activity is unknown. The CORR team continues to work with transplant programs to improve this historical data. Only kidney transplants for patients who had their initial renal replacement therapy on or after January 1, 1981, were originally registered within CORR. As a consequence, not all kidney transplants occurring during the period from 1981 to 1989 are registered in CORR.

While completeness of key data elements has improved over time, one notable problem is that the proportion of unknown values reported for primary diagnosis, cause of death and cause of graft failure exceeds 10% in many cases. Users should consider this when interpreting trends in diagnoses, causes of death and causes of graft failure.

At present, CORR does not collect individual patient data on patients listed for transplant. Counts of patients waiting for solid organ transplants are provided on a quarterly basis by 8 of the 10 OPOs. The OPOs that contribute waiting list counts are BC Transplant Society, H.O.P.E. Calgary, H.O.P.E. Edmonton, Saskatchewan Transplant Program (Saskatoon and Regina), Manitoba Transplant Program, Trillium Gift of Life Network (Ontario), Québec-Transplant and Nova Scotia Multi-Organ Transplant Program (for Atlantic region). A complete list of OPOs is provided in Appendix C.

Please see Appendix D, CORR Data Quality Documentation: 1993 to 2003, for further detail regarding the completeness and coverage of reporting in CORR.

This Report

This is a new report from CORR, highlighting key data on end-stage organ failure treatments in Canada. Its eight main sections deal with

- renal replacement therapy for end-stage renal disease patients
- liver transplantation
- heart transplantation
- lung transplantation
- pancreas transplantation
- intestinal transplantation
- deceased organ donors

Data on transplantation and organ donation cover the decade from 1994 to 2003; data on patients receiving renal replacement therapy cover the decade from 1993 to 2002. The difference in the time periods reflects the fact that dialysis data for 2003 were not sufficiently complete to report at the time of this document's production.

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 and other countries, are provided in Appendix F.

In addition to this annual summary, information is also available online at www.cihi.ca/corr, in the form of special reports called *CORR inSITES* and semi-annual reports from the OPOs called *E- Statistics on Organ Transplants, Waiting Lists and Donors*. The Web site also features PowerPoint presentations with summary data.

It is important to note that all data presented in this report are 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.

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

2 Renal Replacement Therapy (RRT) for End-Stage Renal Disease (ESRD) Patients

2.1 Incident ESRD RRT Patients

In 2002, there were 92 facilities that registered incident ESRD RRT patients in CORR (Table 2.1.1).[†] The vast majority of patients started renal replacement therapy (RRT) in hospital-based programs where full renal care services[‡] were delivered. A few patients, however, started at community centres in Ontario.

In 1945, Dr. Willem Kolff invented the first artificial kidney machine. Due to limited availability of equipment and difficulty obtaining long-term vascular access for catheters, only patients in acute renal failure were dialyzed. With the invention of the Scribner shunt by Dr. Belding Scribner in 1960, the vascular access problem was largely resolved, and long-term dialysis for patients with end-stage kidney failure became possible.

Table 2.1.1 Facilities Registering Incident ESRD RRT Patients in CORR for 2002

Province	Full-Care Hospitals* (N)	Community Centres** (N)	Range of Incident Patients Registered per Centre in 2002
Alberta	2	0	188–284
British Columbia	11	0	9–127
Manitoba	4	0	6–107
New Brunswick	4	0	1–66
Newfoundland and Labrador	3	0	10–75
Nova Scotia	4	0	2–110
Ontario	31	2	2–210
Quebec	29	0	1–99
Saskatchewan	2	0	79–86

* Hospital-based programs with full renal care services.

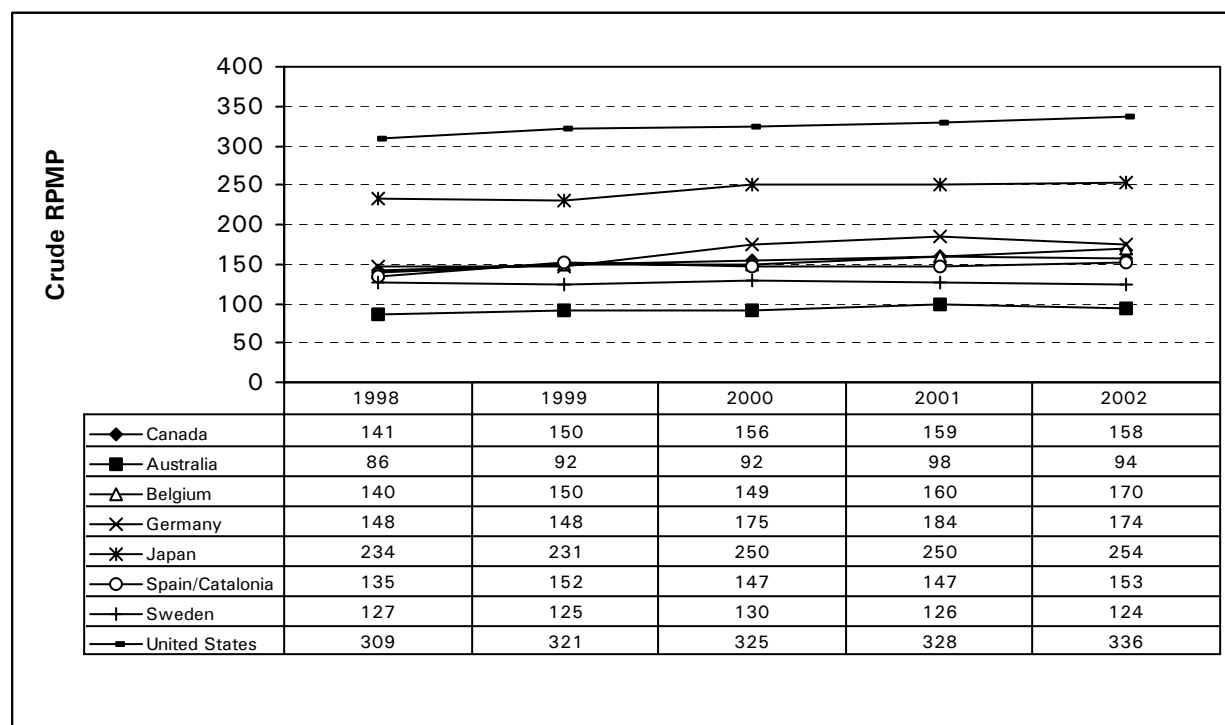
** Centres affiliated with hospital-based programs where, on an infrequent basis, patients may initiate hemodialysis.

[†] The way in which nephrology services are organized in each of the provinces dictates in part the way in which centres report to CORR. For example, in Alberta, the Northern and Southern Alberta Renal Programs report as two distinct entities, while in most other provinces, hospitals providing incident treatment to ESRD patients report directly to CORR.

[‡] Services provided under the care of nephrologist(s), which include social work and dietary consultation, as well as inpatient back-up care.

The rate of incident ESRD RRT patients in Canada rose from 102 per million population in 1993 to 158 in 2002, a 55% increase. Many registries throughout the world have recorded growth in ESRD RRT rates. From 1998 to 2002, the annual rates of incident ESRD RRT patients in Canada were comparable to those in Belgium, Germany and Spain/Catalonia, higher than those in Sweden and Australia and lower than those in the United States and Japan (Figure 2.1.1).

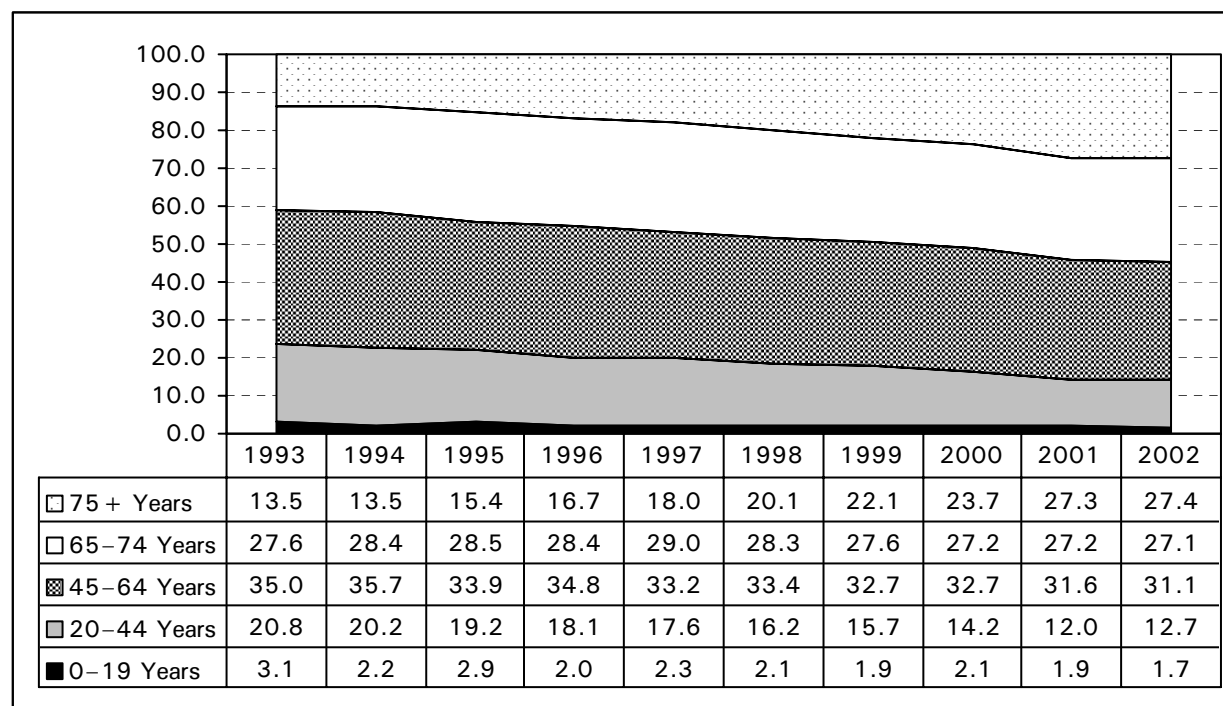
Figure 2.1.1 Incident ESRD RRT Patients, Selected Countries, 1998 to 2002
(Crude Rate per Million Population)



Source of international data: U.S. Renal Data System, *USRDS 2004 Annual Data Report: Atlas of End-Stage Renal Disease in the United States* (Bethesda, MD: National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, 2004).

Considering incident ESRD RRT patients in Canada in terms of age-specific rates, incremental growth was found among patients 75+. For other age groups, rates remained stable or declined slightly (Figure 2.1.2). In terms of numbers, there was a 67% increase in the number of incident ESRD patients 65–74 years of age from 1993 to 2002, and a more than twofold increase in the number of patients 75+ years old (Table 2.1.2).

Figure 2.1.2 Distribution of Incident ESRD RRT Patients by Age Group, Canada, 1993 to 2002 (Age-Specific Rate per Million Population)



Hemodialysis remained the predominant renal replacement therapy for new ESRD patients in 2002 (Table 2.1.2). Four of every five (80%) incident patients in 2002 started on hemodialysis, compared to 63% in 1993. Conversely, 18% of patients in 2002 started on peritoneal dialysis, down from 36% in 1993.

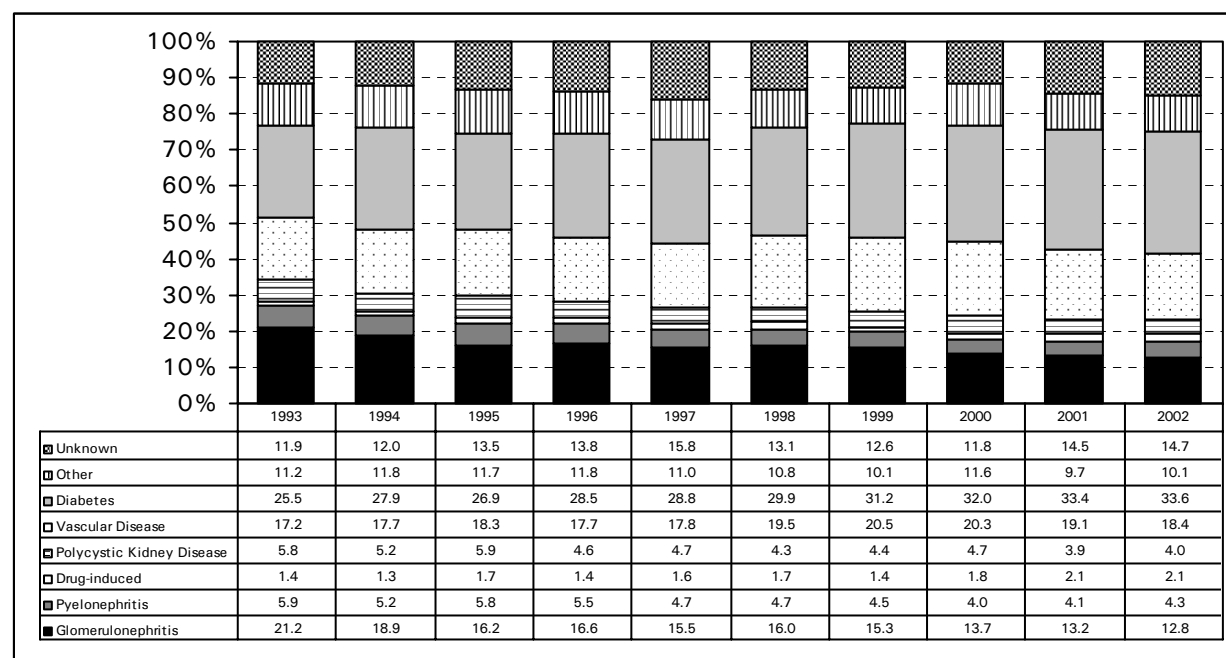
Table 2.1.2 Incident ESRD RRT Patients by Year, Age Group and Initial Modality, Canada, 1993 to 2002 (Number)

Age Group	Initial Modality*	1993 N = 2,917	1994 N = 3,115	1995 N = 3,304	1996 N = 3,556	1997 N = 3,971	1998 N = 4,245	1999 N = 4,572	2000 N = 4,777	2001 N = 4,940	2002 N = 4,962
0–19 Years	HD	45	35	45	35	52	42	37	45	43	36
	PD	39	28	42	30	28	33	36	34	36	22
	Pre-empt	5	6	10	6	11	13	15	23	17	27
20–44 Years	HD	340	393	411	396	491	466	475	452	394	433
	PD	235	212	188	198	162	176	180	170	132	147
	Pre-empt	31	25	36	48	44	44	64	57	68	48
45–64 Years	HD	639	703	750	859	950	1,059	1,131	1,156	1,158	1,177
	PD	367	381	345	348	326	322	321	358	358	322
	Pre-empt	16	29	24	31	41	35	42	49	45	45
65–74 Years	HD	520	603	680	762	925	942	1,002	1,058	1,100	1,113
	PD	284	280	259	247	222	257	253	239	232	229
	Pre-empt	1	0	4	1	5	3	5	3	10	3
75+ Years	HD	278	295	376	470	586	723	831	974	1,145	1,186
	PD	117	125	134	125	128	130	180	159	202	174
Total	HD	1,822	2,029	2,262	2,522	3,004	3,232	3,476	3,685	3,840	3,945
	PD	1,042	1,026	968	948	866	918	970	960	960	894
	Pre-empt	53	60	74	86	101	95	126	132	140	123

*HD = hemodialysis; PD = peritoneal dialysis; pre-empt = pre-emptive kidney transplant.

Diabetic nephropathy was the leading cause of renal failure from 1993 to 2002, and increased with each successive year during this decade (Figure 2.1.3). There appeared to be a falling trend in polycystic kidney disease, pyelonephritis and glomerulonephritis. The proportion of unknown diagnoses rose in 2001 and 2002, largely due to underreporting of primary diagnoses by programs in British Columbia.[§]

§ Details of data quality issues are provided in Appendix D.

Figure 2.1.3 Distribution of Incident ESRD RRT Patients by Primary Diagnosis Category, Canada, 1993 to 2002 (Percent)

For nearly 20% of incident ESRD RRT patients who died between 1993 and 2002, the cause of death was unknown (Table 2.1.3). Cardiac failure was the leading cause of death for all age groups, although social causes (which included treatment withdrawals, treatment refusals and suicides) were a close second in the oldest patient group (75+). The number of deaths from infections tended to be higher in younger age groups. Accidental deaths, which included accidents related and unrelated to treatment, formed a very small proportion of all reported causes of death.

Table 2.1.3 Incident ESRD RRT Patients by Age Group* and Cause of Death, 1993 to 2002 (Number and Percent)**

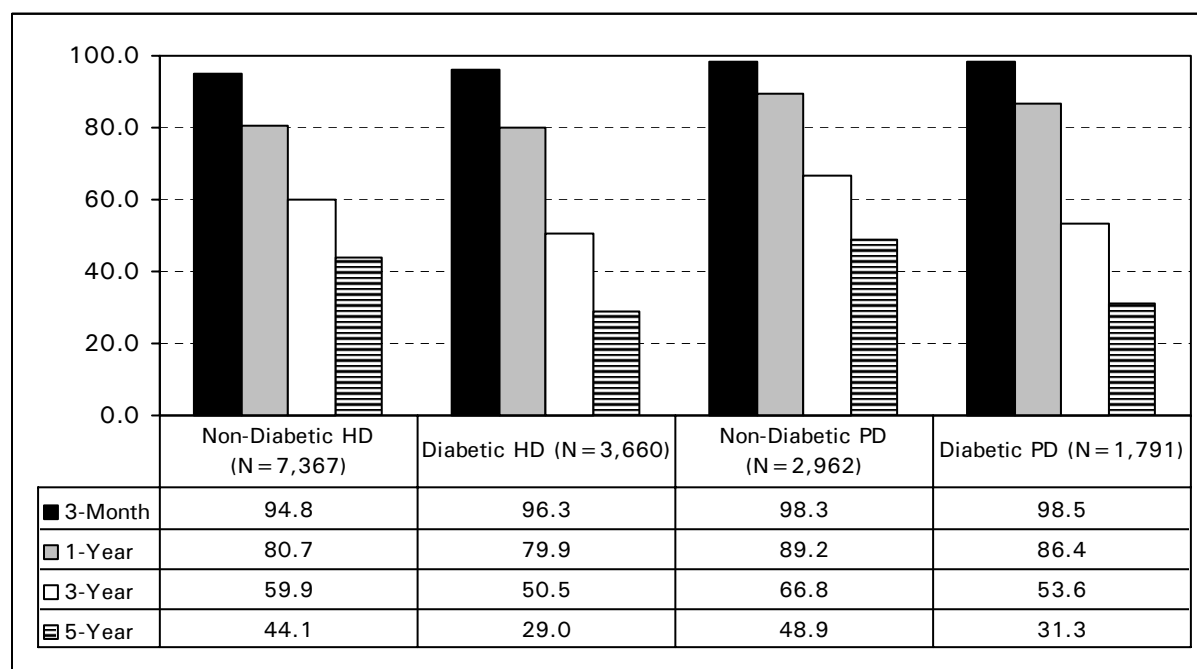
Age Group		Cardiac	Social	Infections	Vascular	Gastro-Intestinal	Malignancy	Accidental	Other	Unknown	Total
0-19 Years	N	15	13	11	7	4	4	1	5	10	70
	%	21.4	18.6	15.7	10.0	5.7	5.7	1.4	7.1	14.3	100.0
20-44 Years	N	331	128	147	88	23	42	10	80	232	1,081
	%	30.6	11.8	13.6	8.1	2.1	3.9	0.9	7.4	21.5	100.0
45-64 Years	N	1,672	619	517	360	137	316	33	371	961	4,986
	%	33.5	12.4	10.4	7.2	2.7	6.3	0.7	7.4	19.3	100.0
65-74 Years	N	1,906	1,043	512	520	218	349	31	483	1,194	6,256
	%	30.5	16.7	8.2	8.3	3.5	5.6	0.5	7.7	19.1	100.0
75+ Years	N	1,293	1,217	427	387	152	202	19	402	957	5,056
	%	25.6	24.1	8.4	7.7	3.0	4.0	0.4	8.0	18.9	100.0
Total	N	5,217	3,020	1,614	1,362	534	913	94	1,341	3,354	17,449
	%	29.9	17.3	9.2	7.8	3.1	5.2	0.5	7.7	19.2	100.0

* Age at incident treatment.

** For a breakdown of CORR cause of death codes used in this categorization, refer to Appendix F.

Survival rates for patients by incident dialytic modality and diabetic status revealed a survival advantage for patients initiating peritoneal dialysis, regardless of their diabetic status (Figure 2.1.4). The survival of diabetic patients was found to be worse for all age groups, except patients who were 75 + at the time of their initial treatment (Figure 2.1.5).

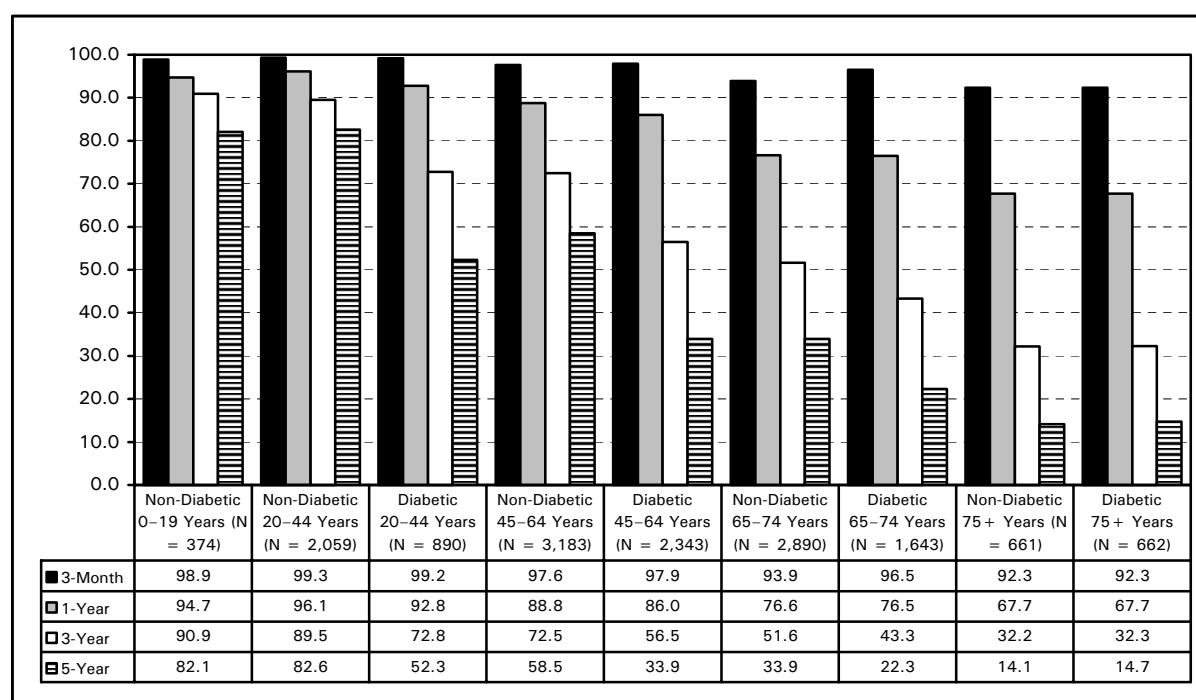
Figure 2.1.4 Unadjusted 3-Month, 1-Year, 3-Year and 5-Year Patient Survival* for Incident Dialysis Patients by Incident Dialytic Modality and Diabetic Status, Canada, 1993 to 1997**



* Patients are censored at the time of their first kidney transplant.

** Diabetic status is based on primary diagnosis and comorbidity status.

Figure 2.1.5 Unadjusted 3-Month, 1-Year, 3-Year and 5-Year Patient Survival* for Incident Dialysis Patients by Age Group at Dialysis Start and Diabetic Status, Canada, 1993 to 1997**



* Patients are censored at the time of their first kidney transplant.

** Diabetic status is based on primary diagnosis and comorbidity status. There were no patients aged 0 to 19 years old with diabetes.

There were differences in key treatment and patient characteristics for incident dialysis patients for the years 2001–2002 according to their initial province of treatment (Table 2.1.4). New Brunswick had the lowest percentage of males starting dialysis (51%); Nova Scotia had the highest percentage of incident dialysis patients 75+ years of age (35%). The largest proportion of Aboriginal patients was observed in Manitoba (29%), followed by Saskatchewan (20%). The presence of diabetes among new patients was also highest in these two provinces, at 52% and 45%, respectively. In Newfoundland and Labrador, 88% of patients started dialysis on hemodialysis; in British Columbia and New Brunswick, hemodialysis was the incident dialytic modality in 74% of patients. Nearly three-quarters of incident dialysis patients were followed by nephrologists before they began receiving dialysis. This varied from a low of 66% in Saskatchewan to a high of 78% in Nova Scotia. The proportion of patients diagnosed with glomerulonephritis ranged from 10% (Nova Scotia) to 15% (Alberta). The proportion of patients with vascular disease as the cause of their renal failure was highest in the Atlantic provinces.

Comorbid conditions existing at the time of initial dialysis increase the complexity of patient care.¹ The percentage of incident patients with heart disease and cerebrovascular disease was highest in Newfoundland and Labrador, while proportionately more patients in New Brunswick had peripheral vascular disease. One in every five incident dialysis patients in Quebec had chronic lung disease. The proportion of patients with malignancies was highest in Nova Scotia and Saskatchewan, at 14%.

Table 2.1.4 Incident Dialysis Patients by Selected Indicators and Initial Province of Treatment, Canada, 2001–2002*

Indicator	Province of Treatment									Total
	Alta.	B.C.	Man.	N.B.	N.L.	N.S.	Ont.	Que.	Sask.	
Centres Reporting 2001 (N)	2	11	3	3	3	3	32	30	3	90
Centres Reporting 2002 (N)	2	11	4	4	3	3	33	29	2	91
Incident Dialysis Patients 2001 (N)	424	615	217	145	106	142	1,964	966	221	4,800
Incident Dialysis Patients 2002 (N)	442	622	223	128	104	133	2,050	972	165	4,839
% Male	56.4	58.5	53.6	50.9	59.1	56.0	57.9	58.4	58.6	57.5
% Aboriginal**	na	na	28.6	0.7	0.0	1.5	2.5	1.3	19.7	4.7
Median Age (Years)	65	66	61.5	67	68	70	68	67	65	67
% 75 + Years	26.3	25.6	20.2	31.5	31.4	34.9	30.7	25.2	27.2	28.1
% Hemodialysis as Incident Modality	84.5	73.6	86.4	74.4	88.1	80.4	79.2	85.5	82.6	80.8
% Followed by Nephrologist Before Starting Dialysis	76.1	68.2	68.3	70.0	71.1	78.2	74.2	na	65.5	72.3
% Glomerulonephritis as Primary Diagnosis	14.7	12.9	13.9	11.7	12.3	10.2	11.7	13.9	10.6	12.6
% Vascular Disease as Primary Diagnosis	15.5	12.5	10.9	30.0	24.2	28.7	21.9	17.9	20.7	19.2
% Diabetic***	46.9	36.7	51.8	41.0	46.2	36.0	43.4	41.0	45.3	42.6
% With Heart Disease****	33.4	na	30.9	39.4	42.9	39.9	39.2	37.5	29.5	37.1
% With Peripheral Vascular Disease	16.3	na	22.5	33.0	26.0	30.7	22.8	23.8	26.7	22.9
% With Cerebrovascular Disease	15.4	na	17.8	16.3	18.8	14.8	14.5	14.3	14.8	14.8

Table 2.1.4 Incident Dialysis Patients by Selected Indicators and Initial Province of Treatment, Canada, 2001–2002* (cont'd)

Indicator	Province of Treatment									Total
	Alta.	B.C.	Man.	N.B.	N.L.	N.S.	Ont.	Que.	Sask.	
% With Malignancies	10.8	na	na	7.9	7.2	13.7	11.5	9.9	13.6	11.8
% With Chronic Lung Disease	8.4	na	13.6	18.3	16.2	15.9	11.9	21.5	8.7	14.0

* Cells are suppressed ("na") if data are missing for more than 10% of patients. Data are based on patients with reported data.

** Proportion of Aboriginal patients is reported given the high rate of diabetic nephropathy among these peoples.

*** Proportion of diabetic patients is based on primary diagnosis and comorbid disease.

**** Heart disease includes patients with one or more of the following: history of angina, previous myocardial infarction, previous coronary artery bypass or angioplasty.

2.2 Registered Dialysis Patients

There were 17,116 patients registered in CORR who were recorded as being on dialysis on December 31, 2002. This represented a 111% increase in the number of patients from 1993, or a 93% increase in the crude rate per million population. The greatest growth in registered patients occurred among the oldest age group (75+), with an averaged rate of annual growth of 13% (Table 2.2.1).

Table 2.2.1 Registered Dialysis Patients by Age Group at Year-End, Canada, 1993 to 2002 (Number and Age-Specific Rate per Million Population)

Age Group		1993	1994	1995	1996	1997	1998	1999	2000	2001	2002
0–19 Years	N	176	164	166	162	160	163	160	150	155	142
	pmp	22.4	20.7	20.9	20.3	20.0	20.3	20.0	18.8	19.4	17.9
20–44 Years	N	1,896	1,994	2,063	2,155	2,274	2,379	2,408	2,436	2,417	2,460
	pmp	162.5	170.8	176.4	183.9	193.7	203.1	206.0	208.4	206.3	209.5
45–64 Years	N	2,909	3,173	3,395	3,683	4,084	4,445	4,851	5,179	5,477	5,773
	pmp	502.3	531.5	552.6	582.8	627.5	662.4	699.7	722.5	739.0	752.3
65–74 Years	N	2,079	2,348	2,587	2,791	3,110	3,368	3,629	3,915	4,171	4,353
	pmp	1,035.4	1,148.6	1,250.7	1,336.4	1,474.7	1,583.5	1,699.4	1,824.1	1,930.1	2,003.0
75+ Years	N	1,057	1,228	1,450	1,690	2,045	2,429	2,857	3,279	3,802	4,388
	pmp	776.2	880.9	1,006.3	1,133.8	1,322.9	1,520.6	1,730.4	1,921.2	2,157.7	2,414.7
Total	N	8,117	8,907	9,661	10,481	11,673	12,784	13,905	14,959	16,022	17,116
	pmp	283.0	307.1	329.7	354.0	390.3	423.9	457.3	487.4	516.5	545.8

Sex-age specific rates of registered patients varied with the province of treatment (Table 2.2.2). Manitoba had the highest rates for females of all age groups except 75+. Saskatchewan had the lowest rates for both males and females 75+. In contrast, Newfoundland and Labrador had the highest rate for females 75+, while Alberta had the highest rate for males 75+. Nova Scotia had the lowest rates for males aged 20–44 and 45–64, and females 20–44 and 65–74.

Table 2.2.2 Registered Dialysis Patients by Sex, Age Group* and Province of Treatment, Canada, December 31, 2002 (Number and Sex-Age Specific Rate per Million Population)**

Province of Treatment		Female						Male					
		0-19	20-44	45-64	65-74	75+	Total	0-19	20-44	45-64	65-74	75+	Total
Alberta	N	13	97	203	167	173	653	6	113	263	206	227	815
	pmp	30.2	158.3	574.9	1,821.3	2,006.1	414.9	13.2	173.8	725.5	2,378.2	4,052.5	506.0
British Columbia	N	6	131	265	214	195	811	8	193	421	274	275	1,171
	pmp	12.3	170.2	504.1	1,430.0	1,256.9	388.2	15.5	250.8	807.6	1,895.6	2,682.9	569.6
Manitoba	N	6	86	177	101	71	441	3	83	186	99	83	454
	pmp	38.5	426.3	1,318.8	2,446.6	1,435.6	756.9	18.4	394.8	1,403.1	2,681.5	2,781.3	792.6
New Brunswick	N	0	30	67	46	71	214	2	42	83	50	63	240
	pmp	0.0	219.8	684.1	1,640.4	2,375.0	563.8	21.6	303.6	856.5	2,024.3	3,510.9	647.6
Newfoundland and Labrador	N	2	22	39	38	41	142	1	41	64	44	37	187
	pmp	32.8	228.7	550.1	2,051.6	2,386.9	538.4	15.6	441.7	915.2	2,547.3	3,274.6	731.8
Nova Scotia	N	2	19	66	50	85	222	0	23	89	78	97	287
	pmp	15.6	98.1	471.8	1,224.6	1,926.0	406.0	0.0	120.4	651.9	2,115.7	3,743.0	547.1
Ontario	N	24	424	980	840	880	3,148	24	592	1482	1065	1048	4,211
	pmp	15.7	186.1	676.3	1,913.8	2,085.0	514.4	15.0	256.6	1,051.2	2,700.8	3,983.7	704.6
Quebec	N	20	185	461	407	396	1,469	18	280	749	548	517	2,112
	pmp	23.4	136.8	466.0	1,361.4	1,433.1	389.4	20.0	199.5	779.7	2,173.0	3,349.2	575.3
Saskatchewan	N	4	54	62	47	52	219	0	48	116	79	77	320
	pmp	29.0	321.6	558.0	1,251.7	1,132.3	437.5	0.0	279.4	1,033.7	2,298.7	2,572.6	646.5
Total	N	77	1,048	2,320	1,910	1,964	7,319	62	1,415	3,453	2,443	2,424	9,797
	pmp	19.9	180.4	599.3	1,667.5	1,743.7	462.4	15.2	238.4	908.1	2,376.9	3,508.6	630.7

* Age on December 31, 2002.

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

2.3 Prevalent ESRD RRT Patients

At year-end, CIHI gathers counts of patients with functioning transplants and patients on dialysis from all reporting centres. These data are compared against registered patients in the database, and are used as a data quality check. In this section, these counts are used to illustrate the extent of treated ESRD cases in Canada.**

On December 31, 2002, 12,046 patients were reported to be alive with a functioning kidney transplant (Table 2.3.1). This represents a 73% increase from 1993, and an averaged increase of 6% per year.

Table 2.3.1 Patients With Functioning Kidney Transplants* at Year-End by Province of Follow-up Care, Canada, 1993 to 2002 (Number)

Province of Follow-up	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002
Alberta	692	759	804	857	926	1,027	1,137	1,180	1,287	1,331
British Columbia	920	991	1,123	1,140	1,199	1,246	1,282	1,366	1,444	1,511
Manitoba	327	351	369	377	382	371	370	387	398	415
New Brunswick	194	205	209	208	220	220	235	239	266	273
Newfoundland and Labrador	213	221	222	237	237	244	254	264	270	272
Nova Scotia	339	370	393	417	455	455	543	606	914	1,003
Ontario	2,651	2,869	2,984	3,201	3,228	3,333	3,675	3,811	3,913	4,238
Quebec	1,419	1,492	1,624	1,673	1,784	1,830	1,982	2,158	2,330	2,553
Saskatchewan	207	212	215	225	232	273	303	319	337	450
Total	6,962	7,470	7,942	8,335	8,663	8,999	9,781	10,330	11,159	12,046

* Data come from the year-end *CORR Renal Transplant Facility Profile* and represent point prevalent counts of patients for December 31 of each year. Data have been adjusted for underreporting. Please see Appendix F for details on underreporting.

Patients on hemodialysis at 2002 year-end numbered 13,620 (Table 2.3.2), while those on peritoneal dialysis numbered 3,421 (Table 2.3.3), for a total of 17,041.^{††} The number of patients on hemodialysis grew by 162%, with an averaged annual growth of 10%. In contrast, the annual number of patients on peritoneal dialysis showed only minor variations, spiking in 1996 at 3,567, and averaging 3,389 patients per year.

** The *CORR Dialysis Facility Profiles* contains counts of all patients living and on dialysis at year-end, including patients who initiated treatment prior to 1981, and who may not be registered in CORR. As well, it would not be affected by underreporting of deaths as is the patient-level data within CORR. Please see Appendix F for more information.

†† The difference in numbers of registered patients reported in Sections 2.2 and 2.3 may reflect incomplete reporting of deaths of registered patients.

Table 2.3.2 Patients on Hemodialysis* at Year-End by Province of Treatment, Canada, 1993 to 2002 (Number)

Province of Treatment	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002
Alberta	451	460	498	516	666	770	916	982	1,084	1,199
British Columbia	545	601	672	747	788	921	1,119	1,306	1,258	1,467
Manitoba	343	346	357	385	444	529	575	617	658	695
New Brunswick	126	127	150	193	199	220	236	264	284	300
Newfoundland and Labrador	92	103	116	158	138	149	192	216	232	251
Nova Scotia	165	174	202	219	278	304	329	332	369	385
Ontario	1,929	2,234	2,592	2,930	3,498	3,975	4,512	5,031	5,378	5,967
Quebec	1,361	1,481	1,602	1,720	1,955	2,216	2,409	2,610	2,854	2,914
Saskatchewan	178	202	219	230	284	286	327	355	382	442
Total	5,190	5,728	6,408	7,098	8,250	9,370	10,615	11,713	12,499	13,620

* Data come from the year-end *CORR Hemodialysis Facility Profile* and represent point prevalent counts of patients for December 31 of each year. Data have been adjusted for underreporting. Please see Appendix F for details on underreporting.

Table 2.3.3 Patients on Peritoneal Dialysis* at Year-End and Province of Treatment, Canada, 1993 to 2002 (Number)

Province of Treatment	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002
Alberta	262	283	297	315	282	265	217	206	228	235
British Columbia	318	372	381	375	377	417	440	443	503	535
Manitoba	116	133	139	136	169	184	206	201	199	200
New Brunswick	119	125	143	144	159	191	185	180	173	156
Newfoundland and Labrador	68	86	94	89	100	99	100	84	76	66
Nova Scotia	129	128	142	159	147	150	147	163	154	156
Ontario	1,365	1,426	1,425	1,497	1,311	1,194	1,231	1,278	1,318	1,324
Quebec	602	692	714	758	813	809	748	741	685	654
Saskatchewan	112	108	111	94	88	95	79	85	96	95
Total	3,091	3,353	3,446	3,567	3,446	3,404	3,353	3,381	3,432	3,421

* Data come from the year-end *CORR Peritoneal Dialysis Facility Profile* and represent point prevalent counts of patients for December 31 of each year. Data have been adjusted for underreporting. Please see Appendix F for details on underreporting.

On December 31, 2002, one in five hemodialysis patients were receiving conventional hemodialysis in a full-care hospital setting or independent health facility (Table 2.3.4). The proportion of patients receiving hemodialysis in a community centre varied per province, from a high of 34% in British Columbia to a low of 2% in Quebec. Less than 2% of patients were being dialyzed in their homes.

Table 2.3.4 Point Prevalent Hemodialysis Patients* by Treatment and Province of Treatment, Canada, 2002 (Number and Percent)

Province of Treatment		Full-Care Hospital and Independent Health Facility			Chronic Care**	Community Centre		Home***	Total
		Conventional	Short Daily	Slow Nocturnal		Conventional	Short Daily		
Alberta	N	823	0	0	0	350	0	26	1,199
	%	68.6	0.0	0.0	0.0	29.2	0.0	2.2	100.0
British Columbia	N	946	0	0	0	497	0	24	1,467
	%	64.5	0.0	0.0	0.0	33.9	0.0	1.6	100.0
Manitoba	N	538	0	0	0	153	0	4	695
	%	77.4	0.0	0.0	0.0	22.0	0.0	0.6	100.0
New Brunswick	N	261	0	0	0	32	0	7	300
	%	87.0	0.0	0.0	0.0	10.7	0.0	2.3	100.0
Newfoundland and Labrador	N	228	0	0	6	14	0	3	251
	%	90.8	0.0	0.0	2.4	5.6	0.0	1.2	100.0
Nova Scotia	N	293	4	0	0	87	0	1	385
	%	76.1	1.0	0.0	0.0	22.6	0.0	0.3	100.0
Ontario	N	4,877	91	32	14	814	18	121	5,967
	%	81.7	1.5	0.5	0.2	13.6	0.3	2.0	100.0
Quebec	N	2,821	0	0	0	53	0	40	2,914
	%	96.8	0.0	0.0	0.0	1.8	0.0	1.4	100.0
Saskatchewan	N	360	0	0	0	82	0	0	442
	%	81.4	0.0	0.0	0.0	18.6	0.0	0.0	100.0
Total	N	11,147	95	32	20	2,082	18	226	13,620
	%	81.8	0.7	0.2	0.1	15.3	0.1	1.7	100.0

* Corrected for underreporting. Level of care is not indicated in this table.

** May include conventional or slow nocturnal.

*** May include conventional, short daily or slow nocturnal.

There were a total of 3,015 hemodialysis stations in hospitals and affiliated centres on December 31, 2002 (Table 2.3.5). Manitoba had the highest rate of stations per million population; however, Saskatchewan had the highest ratio of patients per station.

Table 2.3.5 Point Prevalent Hospital, Independent Health Facility and Community Centre Hemodialysis Patients* by Stations and Province of Treatment, Canada, 2002 (Number)

Province of Treatment	Stations** (N)	Patients** (N)	Patients per Stations	Population***	Stations per Million Population
Alberta	260	1,173	4.5	3,184,564	81.6
British Columbia	331	1,443	4.4	4,145,104	79.9
Manitoba	164	691	4.2	1,155,492	141.9
New Brunswick	100	293	2.9	750,183	133.3
Newfoundland and Labrador	72	248	3.4	519,270	138.7
Nova Scotia	116	384	3.3	1,071,390	108.3
Ontario	1,205	5,846	4.9	12,096,627	99.6
Quebec	687	2,874	4.2	7,443,491	92.3
Saskatchewan	80	442	5.5	995,490	80.4
Total	3,015	13,394	4.4	31,361,611	96.1

* Corrected for underreporting.

** Includes stations located in and patients being treated at full-care hospitals, independent health facilities and community centres.

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

Overall, 49% of hemodialysis patients on December 31, 2002, received their dialysate through a natural vein fistula, although there were significant differences in the distribution of access types by province (Table 2.3.6). Permanent central venous catheters were the second most commonly used access type (32%). For 5% of patients, some form of temporary catheter was used.

Table 2.3.6 Type of Access for Point Prevalent Hemodialysis Patients by Province of Treatment, Canada, December 31, 2002 (Number and Percent)

Province of Treatment		Natural Vein Fistula	Graft		Catheter				Other	Total
			Synthetic Arteriovenous	Saphenous Vein	Permanent Central Venous	Temporary Subclavian Vein	Temporary Internal Jugular Vein	Temporary Femoral Vein		
Alberta	N	526	198	0	436	1	23	3	0	1,187
	%	44.3	16.7	0.0	36.7	0.1	1.9	0.3	0.0	100.0
British Columbia	N	795	198	0	309	30	47	5	0	1,384
	%	57.4	14.3	0.0	22.3	2.2	3.4	0.4	0.0	100.0
Manitoba	N	417	62	0	147	3	44	13	13	699
	%	59.7	8.9	0.0	21.0	0.4	6.3	1.9	1.9	100.0
New Brunswick	N	104	16	0	150	35	2	0	1	308
	%	33.8	5.2	0.0	48.7	11.4	0.6	0.0	0.3	100.0
Newfoundland and Labrador	N	131	33	0	61	12	0	0	0	237
	%	55.3	13.9	0.0	25.7	5.1	0.0	0.0	0.0	100.0
Nova Scotia	N	247	7	0	2	107	13	3	0	379
	%	65.2	1.8	0.0	0.5	28.2	3.4	0.8	0.0	100.0
Ontario	N	2,544	711	47	2,033	183	92	10	74	5,694
	%	44.7	12.5	0.8	35.7	3.2	1.6	0.2	1.3	100.0
Quebec	N	1,476	316	17	957	9	41	7	1	2,824
	%	52.3	11.2	0.6	33.9	0.3	1.5	0.2	0.0	100.0
Saskatchewan	N	212	65	0	160	0	0	2	0	439
	%	48.3	14.8	0.0	36.4	0.0	0.0	0.5	0.0	100.0
Total	N	6,452	1,606	64	4,255	380	262	43	89	13,151
	%	49.1	12.2	0.5	32.4	2.9	2.0	0.3	0.7	100.0

* Corrected for underreporting. Access type was missing for 3% of hemodialysis patients.

Of recent peritoneal dialysis patients, 97% were receiving continuous ambulatory peritoneal dialysis (CAPD) or automated peritoneal dialysis (APD) at home, with the numbers for each being nearly equal for the country as a whole (Table 2.3.7). Significant differences, however, were observed among the provinces in the distribution of patients on home CAPD and home APD.

Table 2.3.7 Point Prevalent Peritoneal Dialysis Patients* by Treatment and Province of Treatment, Canada, 2002 (Number and Percent)

Province of Treatment		Home CAPD	Home APD	Chronic Care CAPD**	Chronic Care APD***	Hospital CAPD***	Hospital APD***	Combined PD and HD	Total
Alberta	N	150	77	4	0	0	0	4	235
	%	63.8	32.8	1.7	0.0	0.0	0.0	1.7	100.0
British Columbia	N	260	240	2	5	8	6	14	535
	%	48.6	44.9	0.4	0.9	1.5	1.1	2.6	100.0
Manitoba	N	70	130	0	0	0	0	0	200
	%	35.0	65.0	0.0	0.0	0.0	0.0	0.0	100.0
New Brunswick	N	89	66	1	1	0	0	0	157
	%	56.7	42.0	0.6	0.6	0.0	0.0	0.0	100.0
Newfoundland and Labrador	N	41	20	2	0	2	0	0	65
	%	63.1	30.8	3.1	0.0	3.1	0.0	0.0	100.0
Nova Scotia	N	106	47	0	1	1	0	1	156
	%	67.9	30.1	0.0	0.6	0.6	0.0	0.6	100.0
Ontario	N	457	833	1	1	13	14	5	1,324
	%	34.5	62.9	0.1	0.1	1.0	1.1	0.4	100.0
Quebec	N	394	240	10	0	9	0	1	654
	%	60.2	36.7	1.5	0.0	1.4	0.0	0.2	100.0
Saskatchewan	N	58	33	0	0	0	2	2	95
	%	61.1	34.7	0.0	0.0	0.0	2.1	2.1	100.0
Total	N	1,625	1,686	20	8	33	22	27	3,421
	%	47.5	49.3	0.6	0.2	1.0	0.6	0.8	100.0

* Corrected for underreporting. CAPD = continuous ambulatory peritoneal dialysis; APD = automated peritoneal dialysis.

** Includes total and limited self-care.

*** Total care only.

2.4 Kidney Transplantation: Adult Recipients

Activity

In 2003, there were 24 active kidney transplant programs in Canada operating in seven provinces: British Columbia (3 programs), Alberta (2 programs), Saskatchewan (1 program), Manitoba (1 program), Ontario (7 programs), Quebec (8 programs) and Nova Scotia (2 programs). Among patients 18+ years of age, there were 9,809 kidney transplants registered in CORR between 1994 and 2003. An additional 586 kidney transplants involved pediatric recipients. The details on pediatric recipients are provided in Section 2.5. There were 325 simultaneous kidney-pancreas (SKP) transplants during this period. SKP transplants are described in full in Section 6, and excluded from the data provided in this section.

At the end of 1954, Drs. Murray and Harrison performed the first kidney transplant, grafting a kidney from one identical twin to another. Deceased-donor kidney transplants were not, however, successfully performed until the end of the 1950s. This "pathfinding" work established the foundation for eventual developments in extra-renal transplantation.²

Among patients 18+ years of age, there were 9,809 kidney transplants registered in CORR between 1994 and 2003. An additional 586 kidney transplants involved pediatric recipients. The details on pediatric recipients are provided in Section 2.5. There were 325 simultaneous kidney-pancreas (SKP) transplants during this period. SKP transplants are described in full in Section 6, and excluded from the data provided in this section.

In the decade of observation, there were 9,484 kidney transplants among adult recipients (Table 2.4.1). Re-transplants comprised 13% of the transplants performed. A small number of kidney combination transplants were performed each year, mostly kidney-liver transplants. A total of 8,279 patients received a first transplant between 1994 and 2003. Two-thirds of these first grafts were deceased-donor kidneys.

Table 2.4.1 Kidney Transplants* by Year, Donor Type and Re-Transplants, Adult Recipients, Canada, 1994 to 2003 (Number)

	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	Total
Kidney Only First Grafts; Deceased Donor	574	558	560	547	524	500	592	548	516	549	5,468
Kidney Only First Grafts; Living Donor	177	187	216	236	301	323	311	339	320	345	2,755
Kidney Combinations First Grafts: Deceased Donors	5	5	5	8	4	5	5	6	5	8	56
Re-Transplants	112	128	128	122	118	128	124	123	127	95	1,205
Total	868	878	909	913	947	956	1,032	1,016	968	997	9,484

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

The number of adult deceased-donor kidney transplants declined over the decade for most treatment provinces, with the exception of Quebec (Table 2.4.2). Deceased donor transplants performed in Quebec represented 35% of all deceased donor kidney transplants performed in 2003.

Table 2.4.2 Deceased Donor Kidney Transplants* by Year and Province of Treatment, Adult Recipients, Canada, 1994 to 2003 (Number)

Province of Treatment	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	Total
Alberta	83	61	84	90	74	72	84	85	82	67	782
British Columbia	73	90	88	77	51	62	56	59	45	52	653
Manitoba	31	35	34	16	14	14	28	11	17	17	217
Nova Scotia	87	50	47	86	36	57	79	72	63	51	628
Ontario	237	233	228	220	238	173	213	184	196	192	2,114
Quebec	139	183	172	148	165	194	209	207	186	218	1,821
Saskatchewan	21	22	9	16	34	35	19	28	18	29	231
Total	671	674	662	653	612	607	688	646	607	626	6,446

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

Canada's capacity to maintain a level of approximately 1,000 kidney transplants over the last four years for adult recipients was largely fuelled by a steady rise in living-donor kidney transplants (Table 2.4.3). The data from 2001 to 2003, however, hint at a possible plateauing of the living-donor numbers. In 2003, living-donor kidney transplants among adult recipients performed in Ontario represented 42% of all living-donor kidney transplants performed in Canada that year.

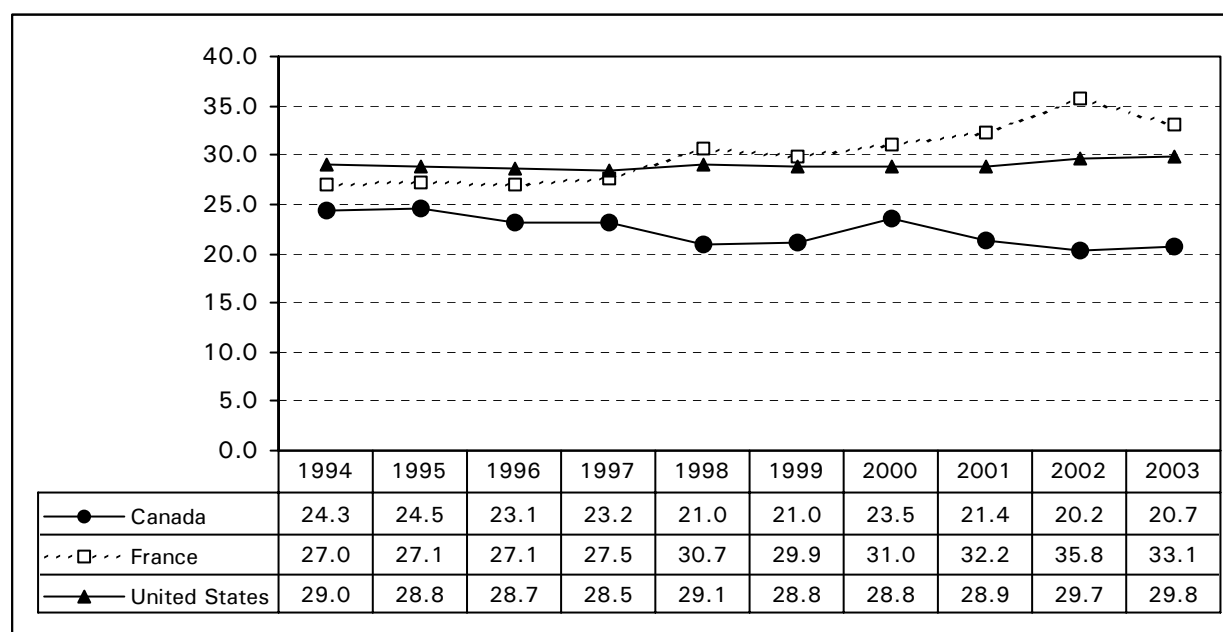
Table 2.4.3 Living-Donor Kidney Transplants by Year and Province of Treatment, Adult Recipients, Canada, 1994 to 2003 (Number)

Province of Treatment	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	Total
Alberta	26	29	31	29	55	48	37	50	47	52	404
British Columbia	24	27	34	35	38	70	78	83	74	69	532
Manitoba	12	9	8	9	6	14	10	12	15	18	113
Nova Scotia	18	22	27	36	37	38	40	30	25	24	297
Ontario	97	94	121	123	144	140	151	144	148	155	1,317
Quebec	12	19	13	12	29	24	22	43	38	43	255
Saskatchewan	8	4	13	16	26	15	6	8	14	10	120
Total	197	204	247	260	335	349	344	370	361	371	3,038

International Comparison

The deceased donor kidney transplantation rate per million population, a crude rate which excludes SKP transplants and includes patients of all ages, declined over the decade in Canada, while the U.S. rate stayed static and the rate in France inched upward (Figure 2.4.1).

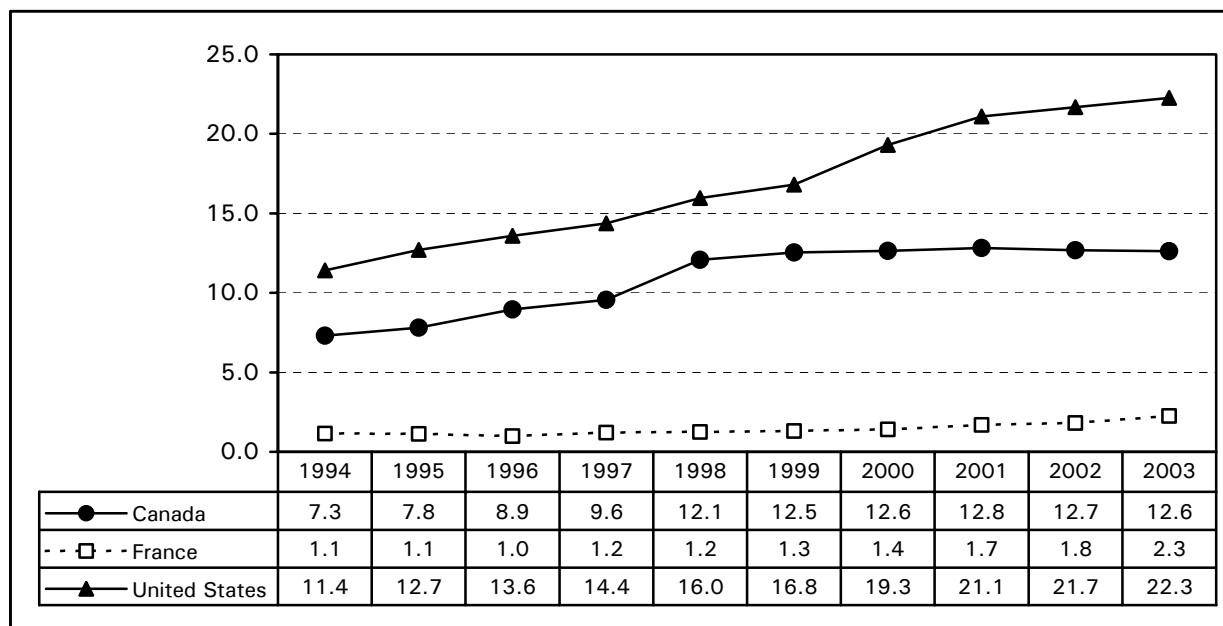
Figure 2.4.1 Deceased Donor Kidney Transplants, Canada, France and United States, 1993 to 2003 (Crude Rate per Million Population)



Data source for France: l'Établissement français des Greffes, *Rapport d'activité et Bilan des activités de prélèvement et de greffe en France Année 2003* (Paris: l'Établissement français des Greffes, Agence de la biomédecine, 2004). Data source for the U.S.: Department of Health and Human Services (Health Resources and Services Administration, Healthcare Systems Bureau, Division of Transplantation), United Network for Organ Sharing and University Renal Research and Education Association, *2004 Annual Report of the U.S. Organ Procurement and Transplantation Network and the Scientific Registry of Transplant Recipients: Transplant Data 1994-2003* (Richmond, VA: United Network for Organ Sharing, 2004).

In terms of living-donor kidney transplant rates, rates in Canada were much higher than in France, but lower than in the U.S. (Figure 2.4.2). The rate in Canada was flat from 1998 to 2003, in contrast to the U.S. rate, which did show some increase during those years.

Figure 2.4.2 Living Donor Kidney Transplants, Canada, France and United States, 1993 to 2003 (Crude Rate per Million Population)



Data source for France: l'Établissement français des Greffes, *Rapport d'activité et Bilan des activités de prélèvement et de greffe en France Année 2003* (Paris: l'Établissement français des Greffes, Agence de la biomédecine, 2004). Data source for the U.S.: Department of Health and Human Services (Health Resources and Services Administration, Healthcare Systems Bureau, Division of Transplantation), United Network for Organ Sharing and University Renal Research and Education Association, *2004 Annual Report of the U.S. Organ Procurement and Transplantation Network and the Scientific Registry of Transplant Recipients: Transplant Data 1994-2003* (Richmond, VA: United Network for Organ Sharing, 2004).

Recipient Characteristics

Three of every five adult kidney transplant recipients were males, regardless of whether the transplant involved a living- or deceased-donor kidney (Table 2.4.4). Among patients who received first kidney grafts, there was an increase in the proportion of diabetics during the period of observation. The average age of recipients also rose over the decade.

Table 2.4.4 Adult Kidney Transplant Recipients, Selected Characteristics, First Graft, Canada, 1994 to 2003 (Number)

Donor Type	Characteristic	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003
Deceased	% Male	65.1	63.4	68.3	65.2	67.2	60.0	63.2	63.8	63.3	64.8
	Average Age (SD)**	45.6 (12.3)	45.6 (12.9)	47.0 (12.7)	47.5 (12.8)	47.5 (13.0)	47.8 (12.9)	48.3 (12.1)	50.0 (12.9)	50.7 (13.5)	50.4 (12.6)
	% 60+ Years	14.3	16.0	19.1	19.3	20.8	18.2	20.1	25.7	29.4	26.9
	% Diabetic*	8.1	7.3	7.4	9.1	8.1	10.1	8.5	20.3	21.9	24.2
Living	% Male	62.7	57.8	63.9	63.6	63.5	61.9	62.1	55.6	60.3	64.4
	Average Age (SD)**	38.4 (11.5)	41.1 (12.0)	42.0 (12.2)	40.5 (12.1)	43.4 (12.6)	42.6 (13.0)	43.2 (12.9)	42.6 (13.3)	43.9 (13.4)	46.2 (12.9)
	% 60+ Years	6.2	7.5	8.8	6.4	12.3	10.2	10.0	12.7	13.8	16.8
	% Diabetic*	7.9	13.4	6.9	7.2	9.6	9.3	9.0	17.4	16.9	22.9

* Diabetic status was based on primary diagnosis and comorbidity data at time of incident dialysis treatment and/or initial kidney transplant.

** SD = standard deviation.

For the most recent period, 2001 to 2003, glomerulonephritis was the most frequent cause of kidney failure for adult kidney transplant recipients, regardless of age, followed by diabetic nephropathy (Table 2.4.5). Polycystic kidney disease was also a frequent cause of kidney failure among recipients 40–59 years of age. Diabetic nephropathy was the second most frequent cause of kidney failure for the 40–59 and 60+ age groups.

Table 2.4.5 Kidney Transplant Recipients* by Age Group and Primary Renal Diagnosis Category, Adult Recipients, First Graft, Canada, 2001 to 2003 (Number)

Primary Renal Diagnosis Category	Age Group			Total
	18–39 Years	40–59 Years	60+ Years	
Glomerulonephritis	299	477	193	969
Pyelonephritis	95	88	42	225
Drug-Induced	16	41	18	75
Polycystic Kidney Disease	31	224	80	335
Hypertension/Other Vascular	45	125	105	275
Diabetic Nephropathy	87	278	145	510
Other	167	189	63	419
Unknown/Not Reported	46	64	25	135
Total Diagnoses	765	1,467	671	2,943
Total Patients	707	1,339	590	2,636

* Based on patients with first grafts. Diagnoses provided at incident dialysis treatment and subsequent diagnoses at time of kidney transplant are included in this table. Twelve percent of patients had a diagnosis in more than one category.

Waiting List and Waiting Times

Although a change in the definition of pediatric patients from 0–14 years to 0–17 years affects the trend line for the adult kidney transplant waiting list (Table 2.4.6), there appeared to be a reduction in the listing of prospective recipients.^{‡‡}

Table 2.4.6 Adult* Kidney Transplant Waiting List on December 31, Canada, 1994 to 2003 (Number)

	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003
> 14 Years	1,808	2,069	2,331	2,341	2,541	2,760	2,989	2,978		
> 17 Years									2,927	2,845

* From 1994 to 2001, adult recipients were defined as patients 15 + years of age. In 2002, this definition was changed to patients 18 + years of age.

For the most recent three-year period, 2001 to 2003, patients transplanted in British Columbia had the longest waits, with half of patients waiting for more than 4.5 years (Table 2.4.7). The shortest median wait times occurred in Saskatchewan and Manitoba. Pre-emptive kidney transplants for adult recipients were most frequent in Alberta (20%) and least frequent in Saskatchewan (7%).^{§§}

Table 2.4.7 Dialysis Duration Prior to First Kidney Transplant, Adult Kidney Transplant Recipients, Canada, 2001 to 2003 (Number)

	Alta.	B.C.	Man.	N.S.	Ont.	Que.	Sask.
Recipients (N)	339	330	86	230	908	644	99
Pre-Emptive Transplants, Deceased Donor (N)	23	4	3	11	6	37	4
Pre-Emptive Transplants, Living Donor (N)	45	49	8	26	87	16	3
Duration on Dialysis (Median Days)* — Deceased Donor	759	1,734	602	796	1,432.5	838	561.5
Duration on Dialysis (Median Days)* — Living Donor	245	333	528	135	421	406	473

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

‡‡ Kidney transplant physicians at a recent meeting of the Canadian Society of Transplantation anecdotally confirmed that due to longer wait times for kidney transplants, programs were listing fewer patients.

§§ Pre-emptive kidney transplant recipients are patients who have not been treated with dialysis prior to transplantation.

Outcomes

At five years post-transplant, unadjusted patient survival rates for the single years 1994 to 2002 were greater than 90% for recipients of living-donor kidneys, and, for most years, greater than 85% for recipients of deceased-donor kidneys (Table 2.4.8). Graft survival was somewhat lower, but showed improvements over time (Table 2.4.9).

Table 2.4.8 Unadjusted 3-Month, 1-Year, 3-Year and 5-Year Patient Survival for Adult Kidney Transplant Recipients, First Graft, Canada, 1994 to 2002

		1994	1995	1996	1997	1998	1999	2000	2001	2002
Deceased Donor	N	579	563	565	555	528	505	597	553	521
	3-Month	98.3	98.9	99.1	99.3	98.5	99.4	99.0	99.3	98.9
	1-Year	95.3	93.3	93.8	96.8	95.1	95.5	98.0	98.0	96.7
	3-Year	91.2	89.3	91.2	93.2	90.9	92.3	95.6		
	5-Year	86.2	83.8	86.2	87.6	87.9				
Living Donor	N	177	187	216	236	301	323	311	340	320
	3-Month	100.0	100.0	99.5	100.0	99.7	99.7	99.0	100.0	100.0
	1-Year	99.4	98.9	96.8	98.3	99.0	97.5	98.1	99.7	100.0
	3-Year	97.7	96.8	96.3	97.5	96.0	96.3	97.1		
	5-Year	94.9	93.6	94.0	95.8	93.0				

Table 2.4.9 Unadjusted 3-Month, 1-Year, 3-Year and 5-Year Graft Survival* for Adult Kidney Transplant Recipients, First Graft, Canada, 1994 to 2002

		1994	1995	1996	1997	1998	1999	2000	2001	2002
Deceased Donor	N	579	563	565	555	528	505	597	553	521
	3-Month	93.4	90.8	94.0	94.8	95.1	95.3	95.3	96.4	95.8
	1-Year	86.0	82.8	85.5	87.9	89.2	88.7	93.5	93.3	90.6
	3-Year	78.4	76.2	80.0	81.3	83.3	84.4	90.1		
	5-Year	70.6	68.7	71.9	73.5	76.3				
Living Donor	N	177	187	216	236	301	323	311	340	320
	3-Month	94.7	96.8	98.3	97.3	97.8	95.8	96.8	99.4	99.1
	1-Year	93.1	91.7	94.9	96.0	95.4	94.2	95.9	97.8	
	3-Year	89.3	88.4	92.8	90.7	92.0	92.6			
	5-Year	84.5	84.3	88.1	86.1					

* Graft survival is computed from first kidney transplant date to first graft failure date, death date or end of observation (December 31, 2003). In this analysis, patients who died with a functioning graft are considered as failed grafts.

Organ Donors

Older recipients received kidneys from older deceased donors (Table 2.4.10). Living donation was less likely to occur as recipients aged: 39% of recipients 18–39 received a living-donor kidney transplant, compared to 29% for patients 40–59 and 20% for patients 60+. Living donors were most likely to be siblings of kidney transplant recipients aged 18–39 and 40–59, and more likely to be other relatives of patients 60+.

Table 2.4.10 Selected Donor Characteristics, Adult Kidney Transplants, Canada, 1994 to 2003

		Recipient Age Group		
		18–39 Years	40–59 Years	60+ Years
Deceased Donor*	N	2,048	3,483	1,237
	% Male	56.6	56.6	51.6
	Median Age	32	42	45
Living Donor	N	1,332	1,398	311
	% Parent as Donor (n)	25.9 (345)	2.4 (34)	0.0 (0)
	% Sibling as Donor (n)	51.0 (679)	47.3 (661)	3.7 (46)
	% Other Relative as Donor (n)	7.0 (93)	19.4 (276)	14.3 (177)
	% Unrelated Donor (n)	16.1 (215)	30.5 (427)	6.4 (79)

* Deceased donor will be counted for up to two times if both kidneys were used for transplantation in different recipients.

2.5 Kidney Transplantation: Pediatric Recipients

Activity

Pediatric kidney transplant centres exist in Halifax, Montréal, Toronto, Winnipeg, Saskatoon, Edmonton, Calgary and Vancouver. The annual number of pediatric kidney transplants ranged from 40 to 78 throughout the decade of observation, with an overall total of 586 (Table 2.5.1). During this decade, 528 recipients received first grafts.

Table 2.5.1 Kidney Transplants* by Year, Donor Type and Re-transplants, Pediatric Recipients, Canada, 1994 to 2003 (Number)

	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	Total
First Grafts; Deceased Donor	29	34	16	39	19	26	32	17	27	26	265
First Grafts; Living Donor	14	20	17	25	25	30	42	26	36	28	263
Re-Transplants	7	14	7	4	6	8	4	3	2	3	58
Total	50	68	40	68	50	64	78	46	65	57	586

* Includes kidney-combination transplants.

Overall, most pediatric recipients (63%) were aged 11–17 years at the time of their transplant (Table 2.5.2). The largest proportion of patients 0–4 years of age was found in British Columbia (22%), followed closely by Nova Scotia (20%). A total of 339 pediatric transplants (58%) were performed in Ontario and Quebec combined.

Table 2.5.2 Pediatric Kidney Transplants* by Age Group and Province of Treatment, Canada, 1994 to 2004 (Number and Percent)

Age Group at Transplant		Alta.	B.C.	Man.	N.S.	Ont.	Que.	Sask.	Total
0–4 Years	N	3	15	3	11	27	11	0	70
	%	4.5	22.4	5.9	20.4	13.8	7.7	0.0	12.0
5–10 Years	N	22	17	20	8	47	35	0	149
	%	33.3	25.4	39.2	14.8	24.0	24.5	0.0	25.4
11–17 Years	N	41	35	28	35	122	97	9	367
	%	62.1	52.2	54.9	64.8	62.2	67.8	100.0	62.6
Total	N	66	67	51	54	196	143	9	586
	%	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

* Includes kidney-combination transplants.

Overall, there were slightly more deceased-donor than living-donor kidney transplants among pediatric recipients; in British Columbia and Quebec, there were proportionately more deceased-donor transplants (Table 2.5.3).

Table 2.5.3 Pediatric Kidney Transplants* by Donor Type and Province of Treatment, Canada, 1994 to 2004 (Number and Percent)

Donor Type		Alta.	B.C.	Man.	N.S.	Ont.	Que.	Sask.	Total
Deceased	N	26	43	23	22	96	90	4	304
	%	39.4	64.2	45.1	40.7	49.0	62.9	44.4	51.9
Living	N	40	24	28	32	100	53	5	282
	%	60.6	35.8	54.9	59.3	51.0	37.1	66.6	48.1
Total	N	66	67	51	54	196	143	9	586
	%	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

* Includes kidney-combination transplants.

International Comparison

Please refer to Figure 2.4.2.

Recipient Characteristics

Among pediatric kidney transplant recipients, there were slightly more males (56%) than females, although the proportion of males did predominate among patients aged 0–4 years (74%).

Kidney failure among pediatric recipients was due to varied causes, and highly dependent on the patient's age (Table 2.5.4). Congenital disease, specifically dysplasia/hypoplasia, was most common among the youngest patients (0–4 years). Other diseases, like cystinosis, glomerulonephritis and focal sclerosis, played a larger role in the kidney failure of patients aged 5 + .

Table 2.5.4 Kidney Transplant Recipients* by Age Group and Primary Renal Diagnosis Category, Pediatric Recipients, First Graft, Canada, 1994 to 2003 (Number)

Primary Renal Diagnosis Category	Age Group			Total
	0–4 Years	5–10 Years	11–17 Years	
Alport's Syndrome	0	3	10	13
Cystinosis	0	14	18	32
Dysplasia/Hypoplasia	22	35	46	103
Posterior Urethral Valves	5	8	14	27
Obstructive Uropathy	6	6	25	37
Vesico-Ureteric Reflux	2	3	19	24
Polycystic Kidneys	2	6	15	23
Nephronophthisis	0	6	12	18
Other Congenital/Hereditary	11	5	14	30
Other Pyelonephritis	0	3	9	12
Glomerulonephritis	6	12	52	70
Focal Sclerosis	5	16	17	38
Autoimmune Disease	0	3	14	17
Moschowitz Syndrome	1	7	15	23
Other	4	4	15	23
Unknown	4	9	28	41
Total	64	135	317	531

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

Children from all provinces were transplanted, with the lowest averaged rates of transplantation being in Newfoundland and Labrador, at 6 per million child population, and the highest being in Manitoba, at 11 per million child population (Table 2.5.5).

Table 2.5.5 Kidney Transplant Recipients* by Year and Province of Residence, Pediatric Recipients, First Graft, Canada, 1994 to 2003 (Number and Averaged Rate per Million Child Population)

	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	Total	Averaged Rate per Million Child Population***
Alberta, the Northwest Territories and Nunavut	2	4	6	11	10	5	8	2	7	3	57	7.4
British Columbia and the Yukon	3	9	3	6	7	7	8	3	9	9	64	7.1
Manitoba	4	3	0	1	5	2	5	5	4	4	33	11.4
New Brunswick	2	1	5	2	0	0	2	0	0	1	13	7.5
Newfoundland and Labrador	0	3	1	0	0	3	0	0	0	0	7	5.3
Nova Scotia and Prince Edward Island	2	1	2	2	3	4	4	2	3	2	23	10.2
Ontario	18	12	8	20	10	21	25	21	21	12	168	6.1
Quebec	11	18	8	20	7	9	16	8	13	22	132	8.1
Saskatchewan	1	3	0	3	2	6	7	2	6	0	30	11.2
Total	43	54	33	65	44	57	75	43	63	53	530	7.4

* Includes kidney-combination transplants. Excludes 1 patient for whom residence was unknown.

** Child population used to compute rates is provided in Appendix F.

*** Crude rate.

Waiting List and Waiting Times

Although the age definition for pediatric patients was not consistent over the period of observation, the waiting list for kidney transplantation declined over time, despite an increase in the age range defined as pediatric patients within CORR (Table 2.5.6). There were three deaths of pediatric patients who were waiting for a kidney transplant recorded from 1994–2003.

Table 2.5.6 Pediatric* Kidney Transplant Waiting List on December 31, Canada, 1994 to 2003 (Number)

	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003
< 15 Years	57	57	59	42	44	48	38	36		
< 18 Years									36	30

* From 1994 to 2001, pediatric recipients were defined as patients under the age of 15. In 2002, this definition was changed to patients under the age of 18 to more accurately capture patients who would be considered pediatric according to the health care delivery system.

The number of median days on dialysis prior to first kidney transplant was much shorter for pediatric recipients who had a living-donor graft than for recipients of a deceased-donor graft (Table 2.5.7).

Table 2.5.7 Dialysis Duration Prior to First Kidney Transplant, Pediatric Kidney Transplant Recipients, Canada, 2001 to 2003 (Number)

	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003
Recipients (N)	43	54	33	64	54	57	74	43	63	54
Pre-emptive Transplants, Deceased Donor (N)	2	4	0	3	1	3	5	3	7	7
Pre-emptive Transplants, Living Donor (N)	4	5	5	6	10	10	14	11	17	12
Duration on Dialysis (Median Days)* — Deceased Donor	693	390	459.5	525.5	453	548	448	321	354	373.5
Duration on Dialysis (Median Days)* — Living Donor	351	194.5	143	278	131	240.5	193	108.5	62.5	69

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

Outcomes

Unadjusted five-year patient survival for pediatric kidney transplant recipients exceeded 90% for most years (Table 2.5.8). Unadjusted graft survival, although somewhat lower, was in the 75–95% range from 1994 to 1998 (Table 2.5.9). Living-donor grafts seemed to have better survival rates than deceased-donor grafts, but were variable from year to year.

Table 2.5.8 Unadjusted 3-Month, 1-Year, 3-Year and 5-Year Patient Survival for Pediatric Kidney Transplant Recipients, First Graft, Canada, 1994 to 2002

		1994	1995	1996	1997	1998	1999	2000	2001	2002
Deceased Donor	N	29	31	16	38	19	26	32	17	27
	3-Month	100.0	100.0	100.0	100.0	100.0	100.0	100.0	94.1	100.0
	1-Year	100.0	93.6	100.0	97.4	100.0	96.2	100.0	94.1	100.0
	3-Year	93.1	93.6	100.0	97.4	100.0	96.2	100.0		
	5-Year	93.1	93.6	100.0	97.4	94.7				
Living Donor	N	14	20	17	25	25	30	43	26	36
	3-Month	100.0	100.0	94.1	100.0	100.0	100.0	100.0	100.0	100.0
	1-Year	85.7	100.0	94.1	100.0	100.0	100.0	100.0	100.0	100.0
	3-Year	85.7	95.0	88.2	100.0	100.0	100.0	100.0		
	5-Year	78.6	95.0	88.2	100.0	96.0				

Table 2.5.9 Unadjusted 3-Month, 1-Year, 3-Year and 5-Year Graft Survival* for Pediatric Kidney Transplant Recipients, First Graft, Canada, 1994 to 2002

		1994	1995	1996	1997	1998	1999	2000	2001	2002
Deceased Donor	N	29	31	16	38	19	26	32	17	27
	3-Month	89.7	93.6	93.8	89.5	94.7	100.0	96.9	94.1	100.0
	1-Year	89.7	87.1	93.8	84.2	94.7	96.2	96.9	88.2	100.0
	3-Year	82.8	87.1	87.5	81.6	89.5	88.5	90.6		
	5-Year	79.3	80.7	75.0	76.3	84.2				
Living Donor	N	14	20	17	25	25	30	43	26	36
	3-Month	85.7	100.0	82.4	92.0	96.0	93.3	97.7	100.0	94.4
	1-Year	85.7	100.0	82.4	92.0	96.0	93.3	97.7	100.0	94.4
	3-Year	85.7	95.0	76.5	88.0	92.0	90.0	95.4		
	5-Year	78.6	95.0	76.5	84.0	88.0				

* Graft survival is computed from first kidney transplant date to first graft failure date, death date or end of observation (December 31, 2003). In this analysis, patients who died with a functioning graft are considered as failed grafts.

Organ Donors

Deceased organ donors for pediatric kidney recipients ranged in age from 1 to 69 years. Deceased donor age was positively correlated with recipient age (Table 2.5.10). Parents were the organ donors in 84% (236/282) of pediatric living-donor kidney transplants during the decade of observation.

Table 2.5.10 Selected Donor Characteristics, Pediatric Kidney Transplants, Canada, 1994 to 2003

		Recipient Age Group		
		0–4 Years	5–10 Years	11–17 Years
Deceased Donor*	N	26	79	199
	% Male	57.7	60.8	53.8
	Median Age	13.5	19	20
Living Donor	N	44	70	168
	% Parent as Donor (n)	95.5 (42)	82.9 (58)	81.0 (136)
	% Sibling as Donor (n)	0.0 (0)	4.3 (3)	7.7 (13)
	% Other Relative/Unrelated Donor (n)	4.5 (2)	12.9 (9)	11.3 (19)

* Deceased donor will be counted for up to two times if both kidneys were used for transplantation in different recipients.

3 Liver Transplantation

Activity

In 2003, there were eight active surgical liver transplant programs in Canada operating in the following provinces: British Columbia (one program), Alberta (one program), Ontario (three programs), and Quebec (three programs). Most patients from Saskatchewan were treated in Alberta, while most patients from Manitoba were treated in Ontario. Since May 2001, the Atlantic liver transplant program has had an arrangement with London Health Sciences Centre in Ontario to perform transplants for its patients. ***

Liver transplantation became a reality in 1963 when the first case was performed in Denver, Colorado by Dr. Thomas Starzl. The first liver transplant in Canada was performed by Dr. Pierre Daloze in Montréal, Quebec in 1970. With the dramatically enhanced patient survival rates largely due to improvements in immunosuppression and organ preservation techniques in the 1980s, liver transplantation is now considered the best form of therapy for end-stage liver disease.

A new era in liver transplantation began in 1989 when the University of Chicago performed the first living donor liver transplant. The London Health Sciences Centre performed the first living-donor parent-to-child liver transplant in Canada in 1993 and the first living-donor adult-to-adult liver transplant in Canada in 1999.

Pediatric liver transplants were performed at the Hôpital Sainte-Justine (Montréal), the Hospital for Sick Children (Toronto) and the University of Alberta (Edmonton). As of December 31, 2003, there were five living-donor liver transplant programs operating in Canada (in the British Columbia, Alberta and Ontario centres).

Of the total 3,658 liver transplants registered in CORR, 3,319 recipients received first liver grafts between 1994 and 2003 (Table 3.1). Of all livers transplanted during this period, 11% involved pediatric recipients and 5% were living-donor transplants. There were 339 re-transplants performed.

Table 3.1 Liver Transplants by Year, Donor Type, Age Group and Re-Transplants, Canada, 1994 to 2003 (Number)

	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	Total
First Grafts; Deceased Donor < 18 Years	35	49	33	28	24	39	30	20	25	33	316
First Grafts; Living Donor < 18 Years	0	0	1	0	3	6	6	13	10	6	45
Re-transplants < 18 Years	6	8	6	9	5	13	4	4	3	4	62
First Grafts; Deceased Donor 18+ Years	239	244	287	278	281	300	336	293	290	302	2,850
First Grafts; Living Donor 18+ Years	0	0	0	0	0	3	13	31	32	29	108
Re-Transplants 18+ Years	28	24	28	35	29	23	20	33	26	31	277
Total	308	325	355	350	342	384	409	394	386	405	3,658

*** The Atlantic liver program resumed liver transplant surgeries in December 2004.

Less than 2% of liver transplants were combination transplants; most of these were liver-kidney transplants (Table 3.2).

Table 3.2 Liver Transplants by Combination Transplants, Canada, 1994 to 2003 (Number)

	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	Total
Liver Only	300	319	350	340	338	378	403	383	381	399	3,591
Liver-Kidney	4	6	5	8	4	3	4	9	3	5	51
Liver-Small Bowel	2	0	0	1	0	1	1	1	1	1	8
Other Combination*	2	0	0	1	0	2	1	1	1	0	8
Total	308	325	355	350	342	384	409	394	386	405	3,658

* Excludes multivisceral transplants (see Section 7).

Most of the liver transplants were performed in Ontario (45%), followed by Quebec (26%) (Table 3.3).

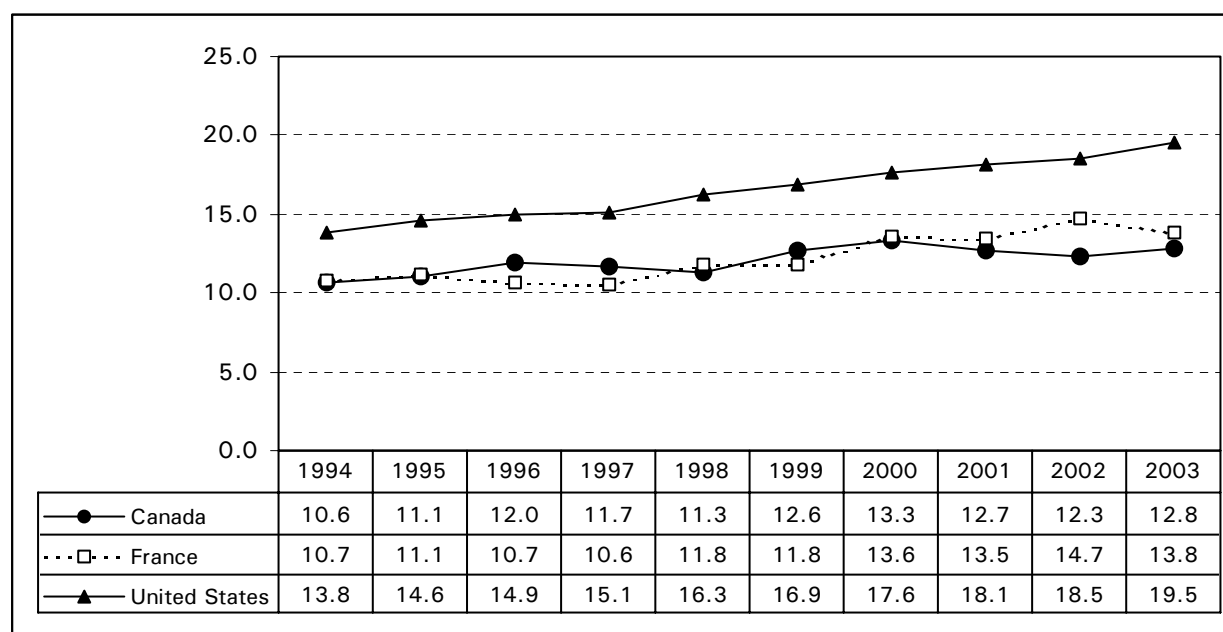
Table 3.3 Liver Transplants by Year and Province of Treatment, Canada, 1994 to 2003 (Number)

Province of Treatment	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	Total
Alberta	37	38	42	56	55	69	65	63	69	64	558
British Columbia	25	23	33	38	24	32	34	39	34	35	317
Nova Scotia	23	17	17	21	18	29	26	16	0	0	167
Ontario	150	161	169	150	155	142	173	176	184	193	1,653
Quebec	73	86	94	85	90	112	111	100	99	113	963
Total	308	325	355	350	342	384	409	394	386	405	3,658

International Comparison

Canada's liver transplantation crude rate per million population was lower than that of the U.S., but similar to that of France (Figure 3.1). Unlike Canada's fairly stable liver transplantation rates, the rates in France and, to a greater degree in the U.S., showed an increase over time.

Figure 3.1 Liver Transplants, Canada, France and United States, 1993 to 2003 (Crude Rate per Million Population)



Data source for France: l'Établissement français des Greffes, *Rapport d'activité et Bilan des activités de prélèvement et de greffe en France Année 2003* (Paris: l'Établissement français des Greffes, Agence de la biomédecine, 2004). Data source for the U.S.: Department of Health and Human Services (Health Resources and Services Administration, Healthcare Systems Bureau, Division of Transplantation), United Network for Organ Sharing and University Renal Research and Education Association, *2004 Annual Report of the U.S. Organ Procurement and Transplantation Network and the Scientific Registry of Transplant Recipients: Transplant Data 1994-2003* (Richmond, VA: United Network for Organ Sharing, 2004).

Recipient Characteristics

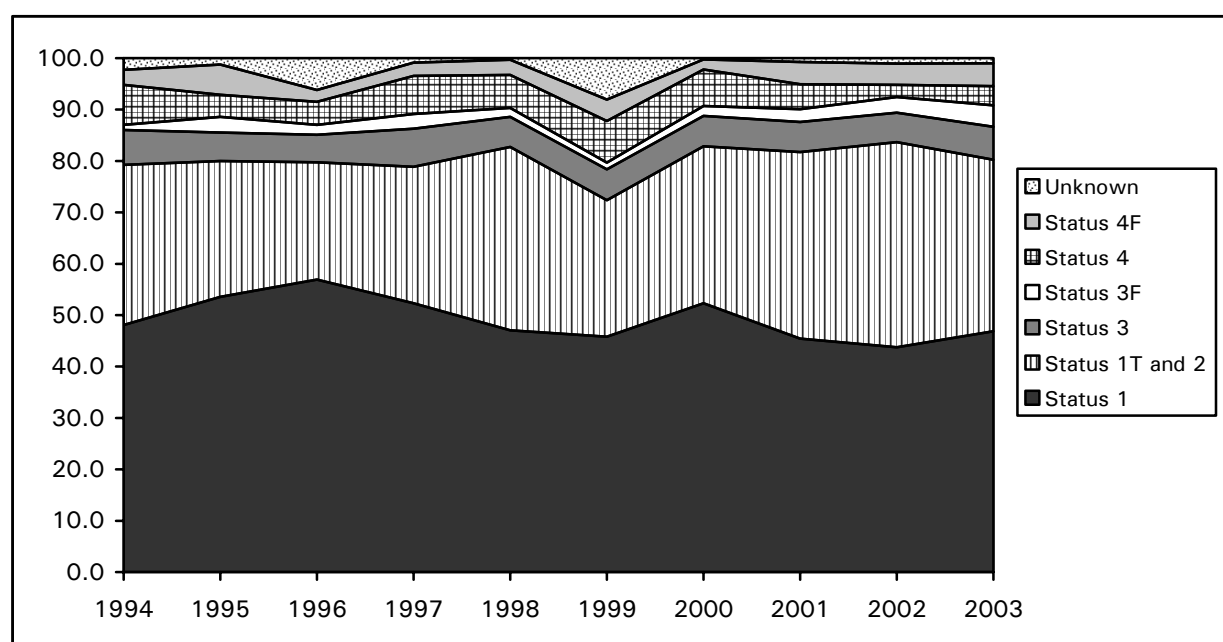
The average age of liver transplant recipients was between 43 and 48. Overall, more males (61%) received first liver grafts from 1994 to 2003 than females, but the male to female ratio varied among recipient age groups (Table 3.4). Primary biliary atresia was a major cause of end-stage liver failure for the youngest transplant recipients (< 11 years), while hepatitis C, alcoholic cirrhosis and cholestatic liver disease were the major causes of end-stage liver failure for recipients 35+ years old.

Table 3.4 Distribution of Primary Diagnoses for Liver Transplant Recipients, First Grafts by Age Group, Canada, 1994 to 2003

Age Group	Number	% Male	Primary Diagnosis Category*										
			Primary Biliary Atresia	Hepatitis C	Hepatitis B	Other Hepatitis	Cholestatic Liver Disease	Alcoholic Cirrhosis	Cryptogenic Cirrhosis	Cancer	Metabolic Disorders	Other	Unknown
< 1 Year	103	42.7	68.3	1.0	0.0	5.8	3.9	0.0	1.0	1.0	8.7	6.7	3.9
1–10 Years	171	51.5	39.3	1.2	0.0	7.5	6.9	0.0	0.6	7.5	11.0	21.4	4.6
11–17 Years	87	55.2	6.7	3.4	1.1	18.0	12.4	0.0	2.3	4.5	4.5	39.3	7.9
18–34 Years	283	49.5	0.0	4.0	5.7	16.6	25.3	1.7	4.3	3.3	7.6	27.2	4.3
35–59 Years	1,997	64.8	0.2	26.3	7.6	4.8	14.9	18.6	4.8	6.9	3.1	10.9	2.0
60+ Years	678	59.3	0.3	20.8	7.5	4.1	15.7	16.4	10.1	11.6	3.9	8.9	0.9

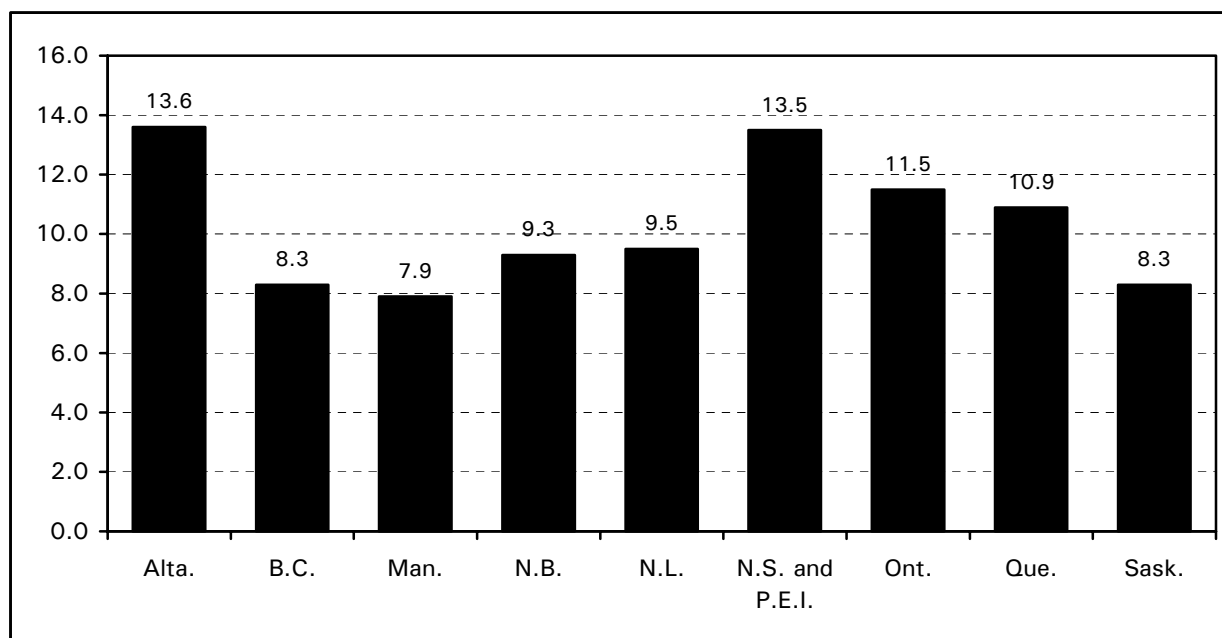
*Up to 4 diagnoses may be reported per recipient.

The distribution of patient medical status at time of transplantation did not change over the period from 1994 to 2003 (Figure 3.2). More than 70% of liver transplant recipients receiving a first graft were considered non-urgent—that is, they had a status of 1 (at home), 1T (with tumour) or 2 (hospitalized) at the time of receiving their transplant.

Figure 3.2 Distribution of Liver Transplants by Medical Status at Transplant, Canada, 1994 to 2003

Liver transplants performed according to patients' province of residence showed some differences when expressed as averaged crude rates per million population (Figure 3.3). The rates for Alberta and Nova Scotia (including Prince Edward Island) were the highest; rates in Manitoba, British Columbia and Saskatchewan were the lowest. These crude rates do not take into consideration potential provincial differences in the prevalence of end-stage liver failure.

Figure 3.3 Liver Transplant Recipients by Province of Residence, Canada, 1994 to 2003 (Crude Rate per Million Population)



Waiting List and Waiting Times

On December 31, 2003, there were 569 patients waiting for a liver transplant (Table 3.5). The number of patients waiting for a liver transplant grew 400% over the past decade.

Table 3.5 Liver Transplant Waiting List on December 31, Canada, 1994 to 2003

	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003
< 18 Years	20	23	22	24	26	20	27	36	31	30
18+ Years	90	126	231	206	260	298	311	418	528	539
Total	110	149	209	230	286	318	338	454	559	569

A total of 503 patients died while waiting for a liver transplant from 1994 to 2003, most being patients aged 18+ (Table 3.6). For adult patients, there was an upward trend in deaths on the waiting list over the decade of observation.

Table 3.6 Deaths Among Patients Waiting for a Liver Transplant, Canada, 1994 to 2003

	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	Total
< 18 Years	3	1	1	3	9	7	5	1	4	6	40
18+ Years	31	19	22	39	21	63	46	56	78	88	463
Total	34	20	23	42	30	70	51	57	82	94	503

An examination of median wait times over the most recent three-year period (2001 to 2003) for deceased-donor liver transplant recipients of first grafts showed that patients listed as urgent had the shortest median waiting times (Table 3.7). For non-urgent patients (Statuses 1, 1T, 2 and 3), patients in blood group O had the longest median wait times.^{†††}

Table 3.7 Wait Time From Listing to Transplant for Deceased Donor Liver Transplant Recipients, First Grafts, Canada, 2001 to 2003

Medical Status at Listing	Blood Group	N	Wait Time* (in days)		
			Minimum	Maximum	Median
1 (at Home)	A	266	0	1,325	194
	AB	44	1	273	50
	B	62	20	1,180	230.5
	O	223	7	1,335	273
1T (Tumour), 2 (Hospitalized)	A	89	1	588	24
	AB	12	0	94	29.5
	B	27	1	294	38
	O	83	3	1,119	100
3 (Intensive Care Unit)	A	11	0	50	7
	B	4	2	45	9
	O	17	2	252	24
Urgent (3F, 4, 4F)	A	30	0	17	1
	AB	5	1	3	1
	B	7	1	147	4
	O	19	0	11	2

*Calculated on the basis of actual wait times. Outliers are not excluded.

††† Type O blood group patients can receive organs only from type O donors. Type O donors, however, are universal donors, with the capacity to donate to patients of all blood groups.

Outcomes

Unadjusted patient survival rates for patients with deceased donor liver transplants (first grafts) over the period from 1994 to 2002 showed incremental improvements in survival over time (Figure 3.4). Graft survival, although somewhat lower, mirrored the trend in patient survival (Figure 3.5).

Figure 3.4 Unadjusted 3-Month, 1-Year, 3-Year and 5-Year Patient Survival for Deceased Donor Liver Transplant Recipients, First Graft, Canada, 1994 to 2002

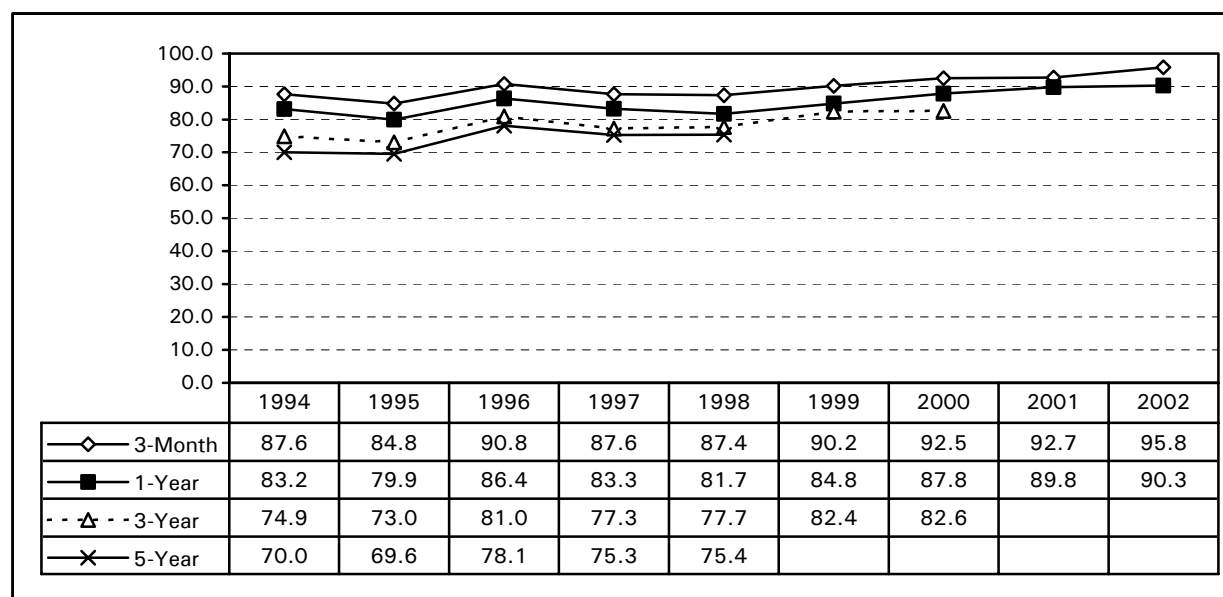
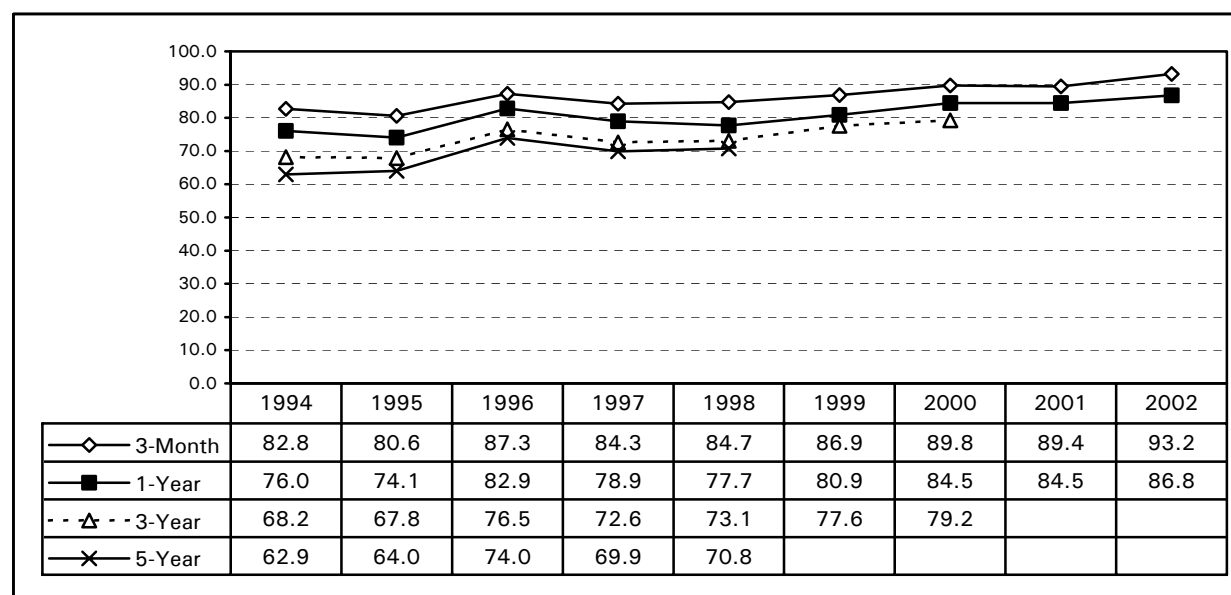


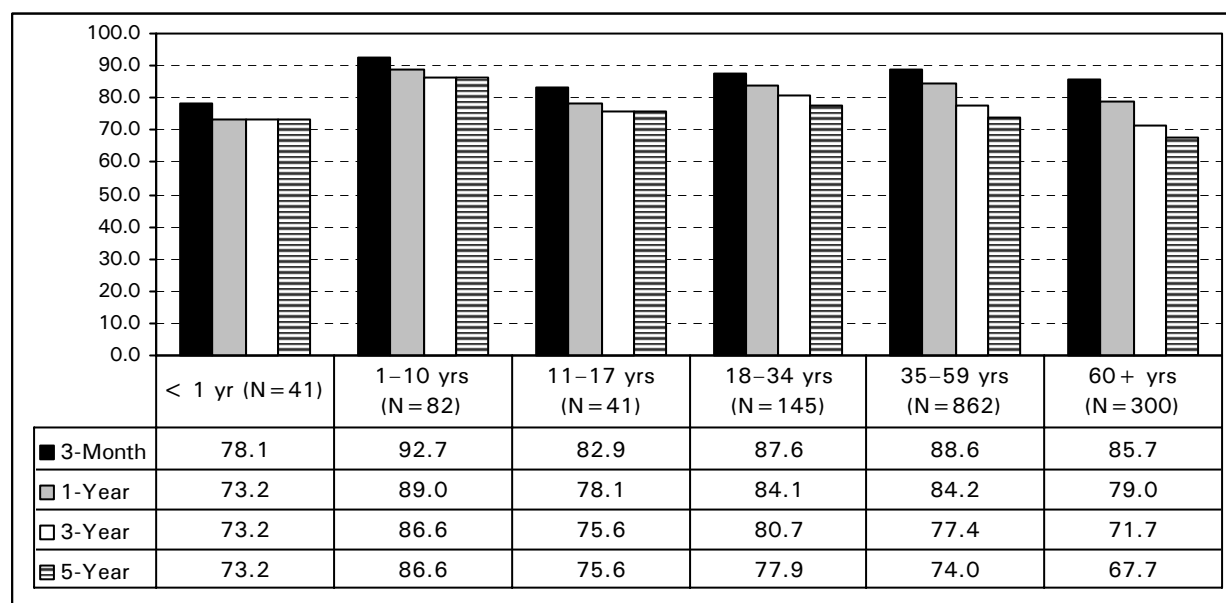
Figure 3.5 Unadjusted 3-Month, 1-Year, 3-Year and 5-Year Graft Survival* for Deceased Donor Liver Transplant Recipients, First Graft, Canada, 1994 to 2002



* Graft survival is computed from first liver transplant date to first graft failure date, death date or end of observation (December 31, 2003). In this analysis, patients who died with a functioning graft are considered as failed grafts.

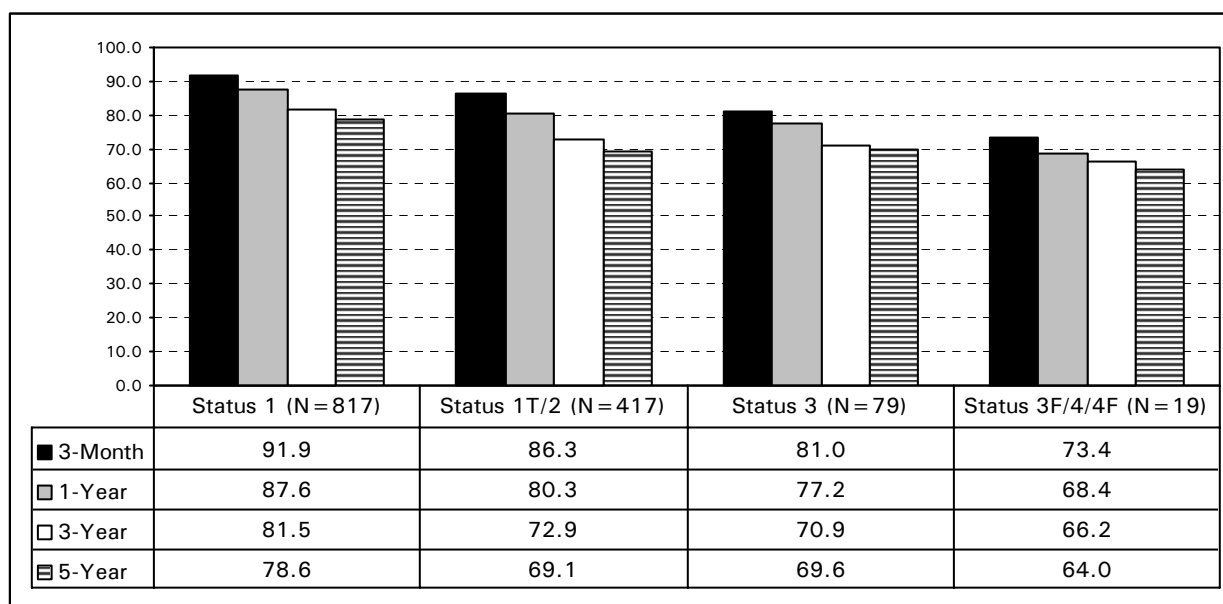
Unadjusted patient survival by age groups for the period from 1994 to 1998 showed the highest survival rates at three months, and one, three and five years post-transplant for recipients aged 1–10 (Figure 3.6). Five-year survival was lowest for the oldest age group (60+).

Figure 3.6 Unadjusted 3-Month, 1-Year, 3-Year and 5-Year Patient Survival for Deceased Donor Liver Transplant Recipients by Age Group, First Graft, Canada, 1994 to 1998



Unadjusted patient survival for deceased–donor liver transplant recipients who received their first liver transplant between 1994 and 1998 showed that medical status was related to outcome. Patients with urgent medical statuses (statuses 3F, 4 or 4F) had lower survival rates at all four time points than patients who were non-urgent (Figure 3.7).

Figure 3.7 Unadjusted 3-Month, 1-Year, 3-Year and 5-Year Patient Survival for Deceased Donor Liver Transplant Recipients by Medical Status at Transplant, First Graft, Canada, 1994 to 1998



Organ Donors

Recovery of livers used for transplantation from deceased organ donors ranged from 78% to 87% (Table 3.8). Recovery rates showed a slight increasing trend over the decade concurrent with the maturation of liver transplant programs across the country.

Table 3.8 Proportion of Livers Transplanted From Deceased Donors, Canada, 1994 to 2003 (Percent)

	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003
Recovery Rate	77.8	79.0	85.4	82.2	81.9	87.4	80.9	82.2	84.0	86.7

Donor livers were shared among programs on the basis of patients' medical urgency. Donor livers from Saskatchewan were typically provided to the Edmonton program, while donor livers from Manitoba were provided to the London program. For the period of 2001 to 2003, liver transplant recipients from the Atlantic provinces were transplanted in London, and donor livers were imported to London for these patients. When looking at the ways in which liver organs were used among recipients who were listed as non-urgent at the time of their wait listing, the majority of livers originated from OPOs within the province of the transplant program (Table 3.9).

Table 3.9 Origin and Destination of Transplanted Livers for Recipients Who Were Listed as Status 1/1T/2/3, Canada 2001 to 2003*

Province of Organ Procurement Organization	Province of Treatment					Total
	Alta.	B.C.	N.S.	Ont.	Que.	
Alberta	113	5	0	5	2	124
British Columbia	4	77	0	6	3	90
Manitoba	1	0	0	18	0	19
New Brunswick	0	0	7	25	3	35
Newfoundland and Labrador	1	1	6	23	2	33
Nova Scotia	1	1	1	19	3	25
Ontario	4	7	0	299	7	317
Quebec	7	1	0	25	258	291
Saskatchewan	32	1	0	2	0	35
United States	1	0	0	0	0	1
Total	164	93	14	422	278	971

* Shaded cells show local organs used for transplantation.

The sharing of livers was most evident when looking at patients who were wait listed when they were medically urgent (that is, Status 3F, 4 or 4F) (Table 3.10).

Table 3.10 Origin and Destination of Transplanted Livers for Recipients Who Were Listed as Status 3F/4/4F, Canada 2001 to 2003*

Province of Organ Procurement Organization	Province of Treatment					Total
	Alta.	B.C.	N.S.	Ont.	Que.	
Alberta	2	0	0	2	1	5
British Columbia	1	0	1	1	1	4
Manitoba	0	0	0	3	0	3
New Brunswick	2	0	0	0	1	3
Newfoundland and Labrador	1	0	0	0	0	1
Nova Scotia	0	0	0	1	2	3
Ontario	3	3	0	18	12	36
Quebec	4	3	1	12	17	37
Saskatchewan	0	0	0	1	0	1
Total	13	6	2	38	34	93

* Shaded cells show local organs used for transplantation.

The vast majority of liver donors were males (62%). The average age of domestic liver donors was 32.5 (standard deviation 14.8), ranging from newborns to patients aged 65 years. There was little change in donor age over the decade. For more information about deceased organ donors, please consult Section 8.

4 Heart Transplantation^{†††}

Activity

During the period 1994 to 2003, 1,657 heart transplants were registered in CORR (Table 4.1). This total included 20 heart-combination transplants, of which 18 were heart-kidney and 2 were heart-liver transplants. The number of infant (< 1 year) and child (aged 1–10 years) heart transplant recipients varied from year to year. In total, 1,598 patients received a first heart transplant during this period.

With the advent of techniques for successful heart surgery in the 1950s, major attention was focused on heart transplantation. The first human heart transplant was performed in 1967 by Dr. Christian Barnard in Capetown, South Africa. Enthusiasm for heart transplantation quickly waned, however, given low one-year patient survival rates among the earliest heart transplant recipients.³ It was not until the discovery and introduction of the drug cyclosporin to clinical transplantation in the early 1980s that patient survival rates began to substantially improve, and heart transplantation became a mainstream treatment for end-stage heart failure.

Table 4.1 Heart Transplants by Year, Age Group and Re-Transplants, Canada, 1994 to 2003 (Number)

	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	Total
First Grafts; Infants < 1 Year	2	4	3	5	2	9	10	10	5	6	56
First Grafts; Recipients 1–10 Years	7	8	6	8	7	10	8	8	8	4	74
First Grafts; Recipients 11–17 Years	7	11	9	7	7	7	8	9	8	10	83
First Grafts; Recipients 18–34 Years	18	22	14	12	6	12	17	19	15	16	151
First Grafts; Recipients 35–59 Years	104	96	90	100	105	83	80	71	84	82	895
First Grafts; Recipients 60+ Years	28	35	38	25	21	40	38	40	41	33	339
Re-Transplants	5	5	7	6	6	5	12	4	3	6	58
Total	171	181	167	163	154	166	173	161	164	157	1,657

Heart transplants were performed in 15 hospitals over this decade. Programs existed in the following major cities in Canada: Halifax, Montréal, Quebec City, Toronto, London, Ottawa, Edmonton and Vancouver. Infant heart transplants were performed at the Hospital for Sick Children (Toronto), the Hôpital Sainte-Justine (Montréal) and the University of Alberta Hospital (Edmonton). Nearly 85% of all heart transplants were performed at centres in Ontario, Quebec and Alberta (Table 4.2).

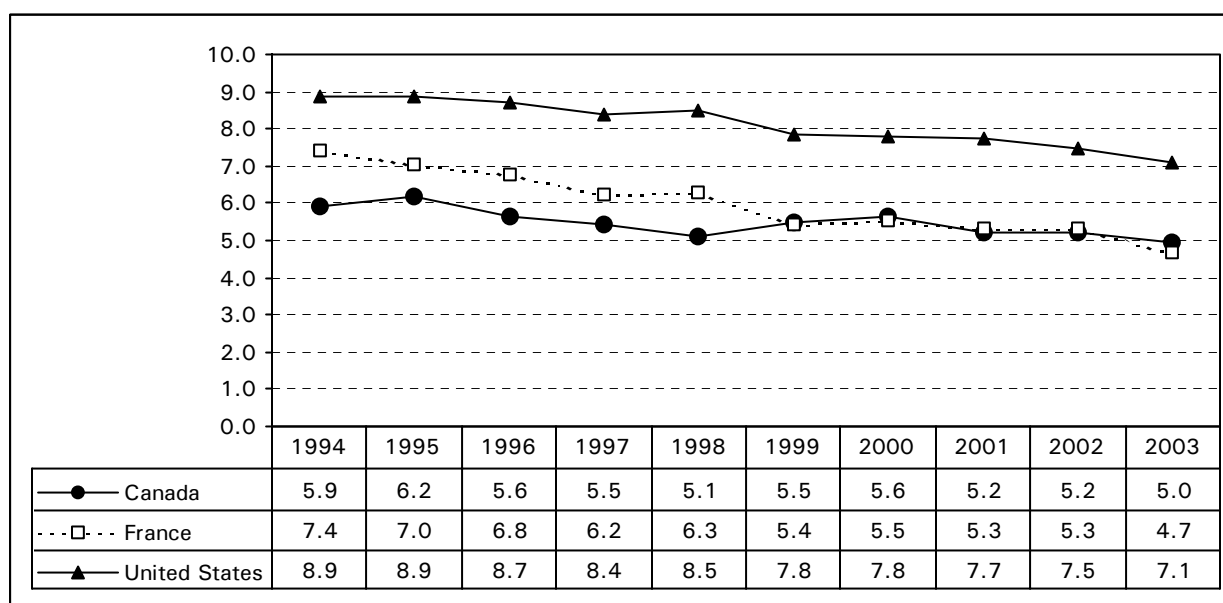
^{†††} For the purpose of this report, heart-lung transplants are included in Section 5, Lung Transplantation, given that the same data elements are collected for heart-lung and lung transplants.

Table 4.2 Heart Transplants by Year and Province of Treatment, Canada, 1994 to 2003 (Number)

Province of Treatment	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	Total
Alberta	26	21	23	24	32	29	41	42	39	21	298
British Columbia	10	14	18	20	14	16	11	14	21	18	156
Nova Scotia	18	9	6	11	9	9	13	8	6	8	97
Ontario	71	86	83	64	63	74	64	58	55	63	681
Quebec	46	51	37	44	36	38	44	39	43	47	425
Total	171	181	167	163	154	166	173	161	164	157	1,657

International Comparison

Canada's heart transplantation rate was lower than that of the U.S., but similar to France's for the years 1999 to 2003 (Figure 4.1). While heart transplantation was on the decline in Canada over the period of 1994 to 2003, the fall in heart transplantation rates in the U.S. and France was even more pronounced.

Figure 4.1 Heart Transplants, Canada, France and US, 1994 to 2003 (Crude Rate per Million Population)

Data source for France: l'Établissement français des Greffes, *Rapport d'activité et Bilan des activités de prélèvement et de greffe en France Année 2003* (Paris: l'Établissement français des Greffes, Agence de la biomédecine, 2004). Data source for the U.S.: Department of Health and Human Services (Health Resources and Services Administration, Healthcare Systems Bureau, Division of Transplantation), United Network for Organ Sharing and University Renal Research and Education Association, *2004 Annual Report of the U.S. Organ Procurement and Transplantation Network and the Scientific Registry of Transplant Recipients: Transplant Data 1994-2003* (Richmond, VA: United Network for Organ Sharing, 2004).

Recipient Characteristics

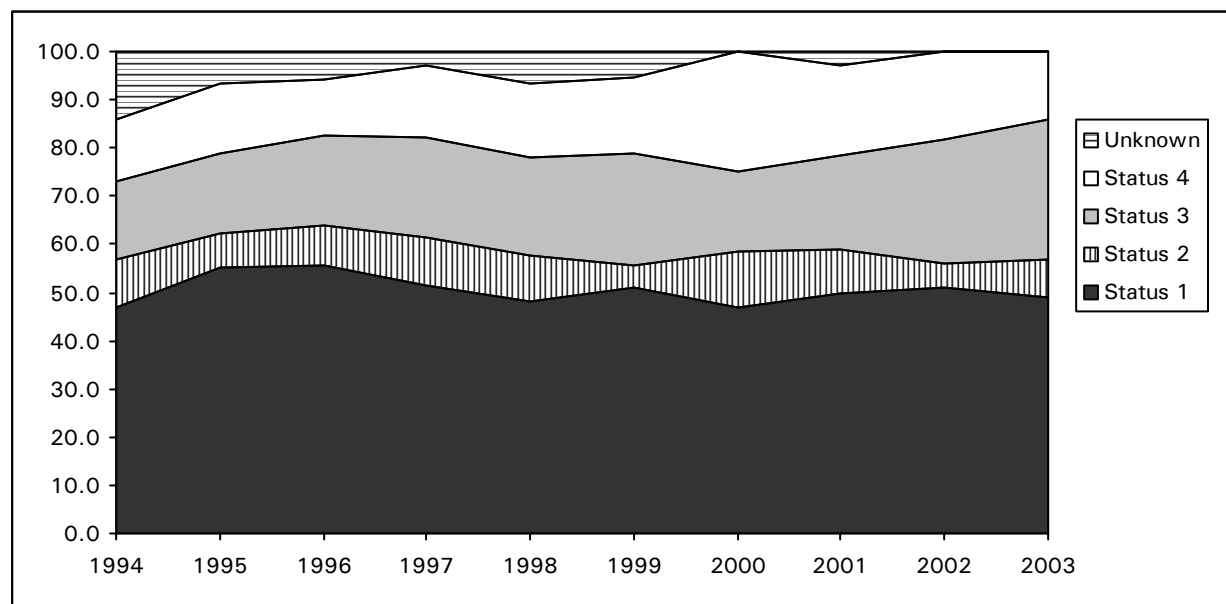
Mean age of heart transplant recipients ranged from 43 to 47 years, with no clear pattern of increase from 1994 to 2003. Most heart transplant recipients were male, with the highest proportion of males being among recipients 60+ years and the lowest proportion of males among recipients 1 to 10 years of age (Table 4.3). Congenital diseases and unspecified cardiomyopathy were the most frequent diagnoses for patients under the age of 11. Cardiomyopathy and coronary artery disease were the most frequent diagnoses for heart transplant recipients aged 35+. Nearly two-thirds of patients 60+ years were diagnosed with coronary artery disease.

Table 4.3 Heart Transplant Recipients, First Grafts by Sex Distribution and Distribution of Primary Diagnosis Category, Canada, 1994 to 2003

Age Group	Total	% Male	Primary Diagnosis Category						
			Congenital	Cardiomyopathy Unspecified	Dilated Cardiomyopathy	Idiopathic Cardiomyopathy	Coronary Artery Disease	Other	Unknown
< 1 Year	56	64.3	66.1	17.9	3.6	1.80	1.8	7.2	1.8
1–10 Years	74	54.1	43.2	21.6	10.8	0.0	1.4	16.2	6.8
11–17 Years	83	63.9	33.7	31.3	9.6	6.0	2.4	12.0	4.8
18–34 Years	151	69.5	13.9	18.5	17.9	11.9	6.6	28.5	2.0
35–59 Years	895	79.7	1.6	9.9	12.0	10.2	48.6	14.2	2.5
60+ Years	339	87.0	0.3	10.6	10.9	4.4	66.1	5.3	1.8

Examination of the distribution of heart transplant recipients by medical status for the period from 1994 to 2003 showed an increasing proportion over time of patients who were in the intensive care unit (ICU) and receiving inotropic support (Status 3) (Figure 4.2). There was no clear trend over time for the other medical statuses.

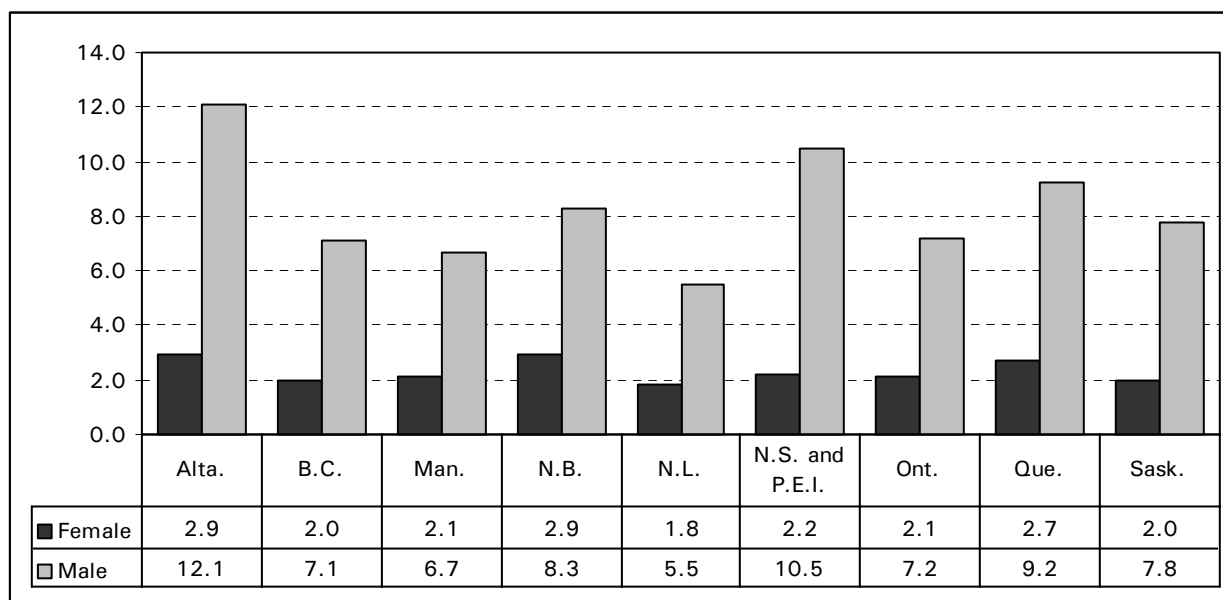
Figure 4.2 Distribution of Heart Transplants by Medical Status* at Transplant, Canada, 1994 to 2003



* Medical statuses 3A and 3B are grouped for the purposes of this analysis.

Heart transplants by province of residence showed similar rates for females over this decade (Figure 4.3). The highest heart transplant rates for males were found in Alberta (12 pmp) and Nova Scotia (including Prince Edward Island) (11 pmp), with the lowest rate in Newfoundland and Labrador (6 pmp). These rates do not take into consideration potential provincial differences in the prevalence of end-stage heart failure.

Figure 4.3 Heart Transplant Recipients by Province of Residence, Canada, 1994 to 2003 (Sex-Specific Crude Rate per Million Population)



Waiting List and Waiting Times

The waiting list for heart transplants showed annual fluctuations from 1998 to 2003, with a sizeable increase in the number of patients under the age of 18 waiting in 2003 (Table 4.4). The number of patients who died while waiting ranged from 28 to 46 per year, with an annual average of 34 patients. While patients under the age of 18 represented 20% of deaths on the waiting list from 1997 to 2003, there appeared to be a trend of fewer deaths among these patients.

Table 4.4 Heart Transplant Waiting List on December 31, Canada, 1994 to 2003

	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003
< 18 Years	--	--	--	9	21	13	9	13	13	37
18+ Years	--	--	--	88	99	88	80	112	90	94
Total	99	98	96	97	120	101	89	125	103	131

Median waiting times over the most recent three-year period (2001 to 2003) for recipients of first heart grafts revealed a trend towards shorter wait times for patients with an urgent need for a transplant (Table 4.5). Recipients within blood group O had the longest waits regardless of medical status at listing.

Table 4.5 Wait Time From Listing to Transplant for Heart Transplant Recipients, First Grafts, Canada, 2001 to 2003

Medical Status at Listing	Blood Group	N	Wait (in Days)		
			Minimum	Maximum	Median
1 (at Home) and 2 (Hospitalized)	O	96	0	1,439	193.5
	A	139	0	1,099	91
	AB and B	53	0	580	70
3A and 3B (ICU or Inotropic Support)	O	31	0	451	44
	A	52	1	526	22.5
	AB and B	22	0	289	37
4 (ICU and Mechanical/Ventilator Support) and in Utero	O	27	0	146	10
	A	27	1	137	8
	AB and B	12	1	85	4.5

Outcomes

Unadjusted patient survival rates for patients with first grafts over the period from 1994 to 2002 showed improvements over time (Figure 4.4). Graft survival showed a similar trend (Figure 4.5).

Figure 4.4 Unadjusted 3-Month, 1-Year, 3-Year and 5-Year Patient Survival for Heart Transplant Recipients, First Graft, Canada, 1994 to 2002

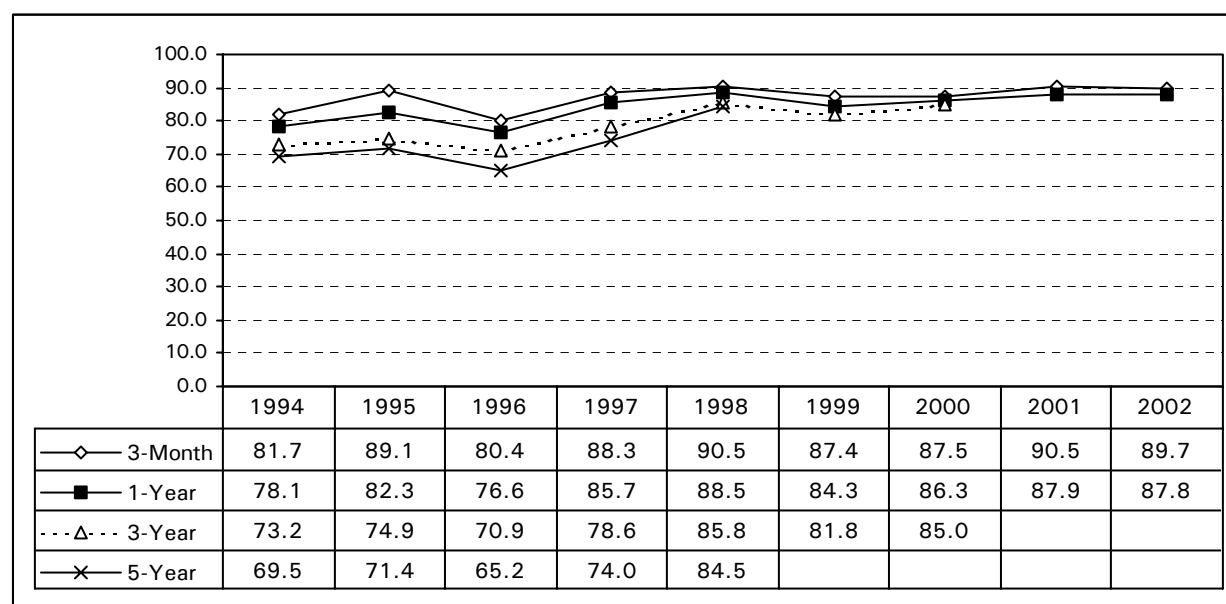
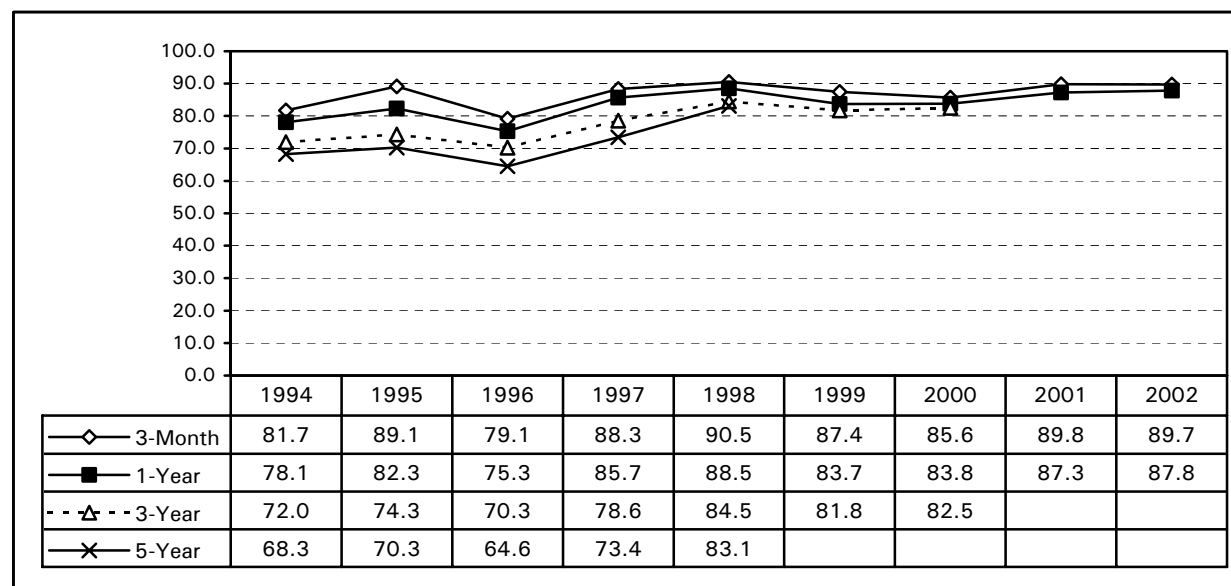


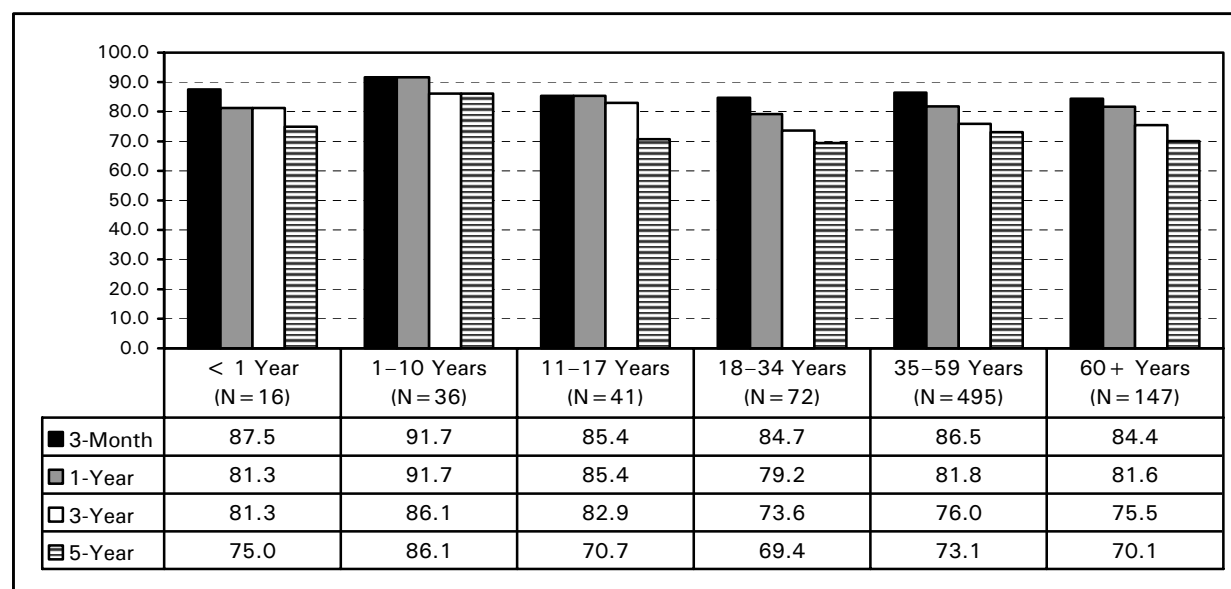
Figure 4.5 Unadjusted 3-Month, 1-Year, 3-Year and 5-Year Graft Survival* for Heart Transplant Recipients, First Graft, Canada, 1994 to 2002



* Graft survival is computed from first heart transplant date to first graft failure date, death date or end of observation (December 31, 2003). In this analysis, patients who died with a functioning graft are considered as failed grafts.

Patient survival rates varied somewhat by patient age group^{§§§} at first transplant, with patients in the 1–10 year age group having the highest survival rates at three months, one year, three years and five years (Figure 4.6).

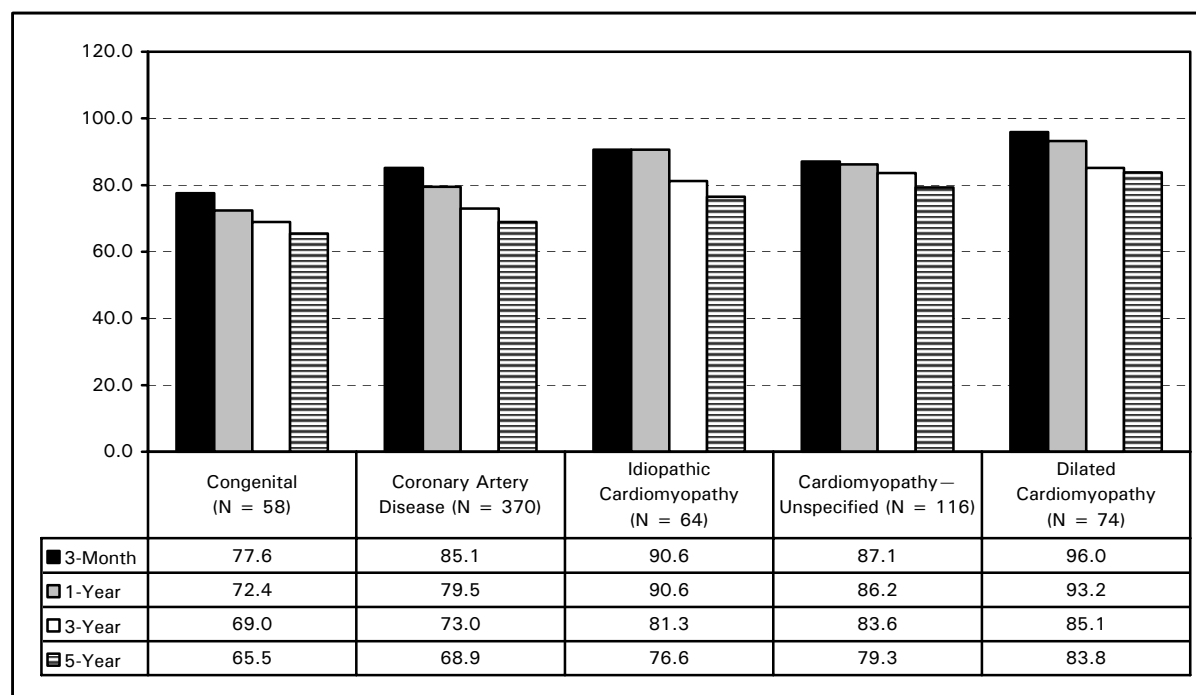
Figure 4.6 Unadjusted 3-Month, 1-Year, 3-Year and 5-Year Patient Survival for Heart Transplant Recipients by Age Group, First Graft, Canada, 1994 to 1998



§§§ The three pediatric age groups used in this analysis (1994 to 1998) involved small numbers of patients.

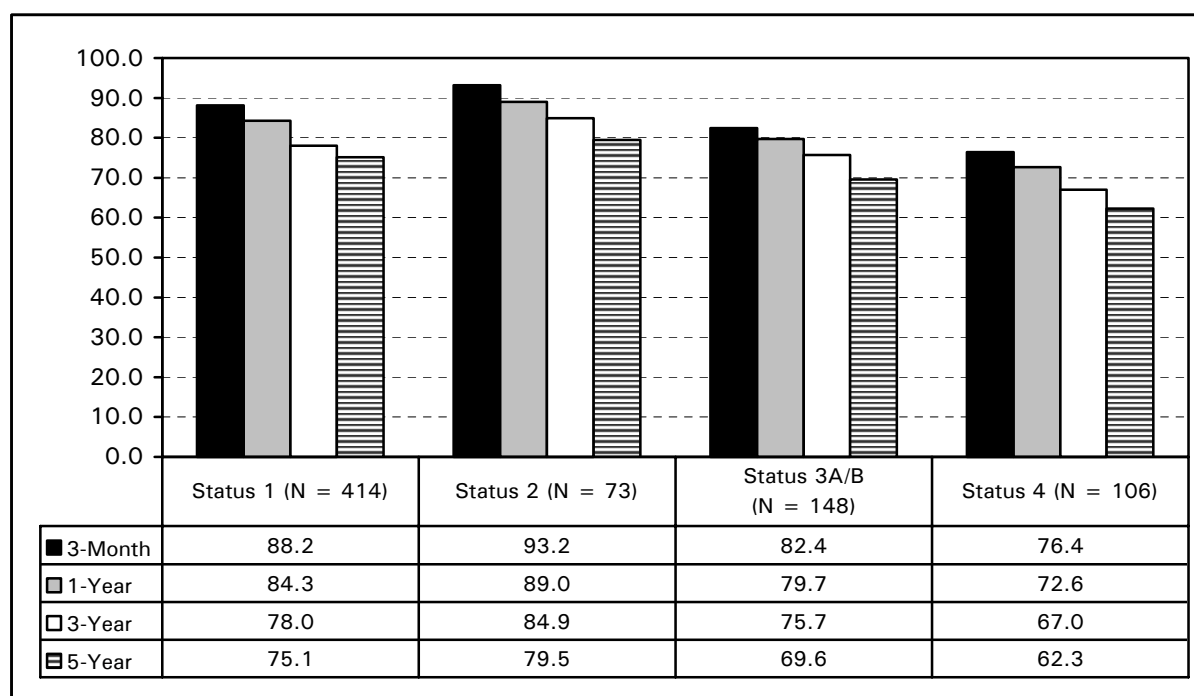
Better patient survival was found for heart transplant recipients with cardiomyopathy than with coronary artery disease or congenital heart diseases (Figure 4.7).

Figure 4.7 Unadjusted 3-Month, 1-Year, 3-Year and 5-Year Patient Survival for Heart Transplant Recipients by Primary Diagnosis, First Graft, Canada, 1994 to 1998



Patients with their first heart transplant during the years 1994 to 1998 who were in ICU and on mechanical/ventilator support at the time of their transplant (Status 4) had the poorest unadjusted patient survival (Figure 4.8). Hospitalized patients (Status 2) had higher patient survival than patients who were not hospitalized (Status 1) at the time of their transplant.

Figure 4.8 Unadjusted 3-Month, 1-Year, 3-Year and 5-Year Patient Survival for Heart Transplant Recipients by Medical Status at Transplant, First Graft, Canada, 1994 to 1998



Organ Donors

Recovery of hearts used for heart and heart-lung transplantation ranged from 35% to 45%, and showed a declining trend from 1994 to 2000 (Table 4.6). This trend was affected by the increased age of deceased donors, as described in Section 8. For further detail related to heart-lung donors, please refer to Section 5. The rest of this section excludes donated heart-lungs.

Table 4.6 Proportion of Hearts Transplanted from Deceased Donors, Canada, 1994 to 2003 (Percent)

	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003
Recovery Rate	44.8	45.2	41.2	39.9	38.6	39.1	34.8	35.6	37.6	35.6

Donor hearts were shared across provinces on the basis of patients' medical urgency. Donor hearts from Saskatchewan were typically provided to the Edmonton program, while donor hearts from Manitoba were provided to the London program. When looking at the ways in which heart organs were used among recipients who were listed as non-urgent at the time of their wait listing, the Halifax program used only hearts recovered from donors at hospitals in the Atlantic provinces (Table 4.7). The Atlantic provinces sent out proportionately more organs to programs outside the region than it received from other parts of Canada. Over 10% of hearts used by the Vancouver and Edmonton programs were from U.S. donors.

Table 4.7 Origin and Destination of Transplanted Hearts for Recipients Who Were Listed as Non-Urgent (Status 1 and 2), Canada 2001 to 2003*

Province of Organ Procurement Organization	Province of Treatment					Total
	Alta.	B.C.	N.S.	Ont.	Que.	
Alberta	36	7	0	2	0	45
British Columbia	8	25	0	0	0	33
Manitoba	1	0	0	7	0	8
New Brunswick	0	0	5	3	2	10
Newfoundland and Labrador	0	0	7	0	0	7
Nova Scotia	0	0	4	1	2	7
Ontario	3	0	0	82	1	86
Quebec	0	0	0	3	63	66
Saskatchewan	10	4	0	0	0	14
United States	7	6	0	9	3	25
Total	65	42	16	107	71	301

* Shaded cells show local organs used for transplantation.

The extent of sharing of heart organs was most evident for patients who were wait listed when they were in an ICU (Table 4.8). Ontario relied on U.S. donor hearts for nearly 22% of its urgent heart transplant recipients. These were all pediatric hearts for pediatric transplant recipients at the Hospital for Sick Children in Toronto. Similar to the trend in non-urgent heart sharing, the Atlantic region sent out more organs to other programs than it received from other programs.

Table 4.8 Origin and Destination of Transplanted Hearts for Recipients Who Were Listed as Urgent (Status 3A, 3B and 4), Canada 2001 to 2003*

Province of Organ Procurement Organization	Province of Treatment					Total
	Alta.	B.C.	N.S.	Ont.	Que.	
Alberta	16	1	0	5	1	23
British Columbia	4	6	0	2	1	13
Manitoba	0	0	1	4	0	5
New Brunswick	0	0	2	0	3	5
Newfoundland and Labrador	0	0	2	2	2	6
Nova Scotia	0	0	0	1	2	3
Ontario	5	0	1	35	8	49
Quebec	0	2	0	4	38	44
Saskatchewan	6	0	0	1	0	7
United States	6	2	0	15	1	24
Total	37	11	6	69	56	179

* Shaded cells show local organs used for transplantation.

The average age of domestic heart donors did not change from 1994 to 2003, being 32.6 (standard deviation 14.8). Slightly more infant hearts were recovered in the later part of the decade. Overall, there were fewer female domestic heart donors than male (37% to 63%). The proportion of donors who died from motor vehicle collisions dropped 11% from 1994–1995 to 2002–2003, while the proportion dying from other sources of head trauma rose by nearly 10% (Table 4.9).

Table 4.9 Cause of Death Among Donors of Transplanted Hearts, Canada, 1994–1995 and 2002–2003

Cause of Death	1994–1995		2002–2003	
	N	%	N	%
Cerebrovascular Accident/Stroke	131	37.4	106	36.8
Motor Vehicle Collision	109	31.1	58	20.1
Other Head Trauma	40	11.4	61	21.2
Gunshot	18	5.1	16	5.6
Anoxia/Hypoxia	27	7.7	20	6.9
Other	21	6.0	18	6.3
Unknown	4	1.1	9	3.1
Total	350	100.0	288	100.0

5 Lung Transplantation

Activity

During the period from 1994 to 2003, 1,001 lung transplants were registered in CORR. These surgeries were performed in 10 hospitals over this decade: the Montreal General Hospital and Royal Victoria Hospital (both now part of the McGill University Health Centre in Montréal), Notre-Dame Hospital (Montréal); Hospital for Sick Children (Toronto), Toronto General Hospital—University Health Network, the London Health Sciences Centre, the Health Sciences Centre (Winnipeg), the University of Alberta Hospital (Edmonton), Vancouver General Hospital and Health Sciences Centre and B.C. Children's Hospital (Vancouver). The London Health Sciences Centre program closed in the spring of 2003. During this time, 975 patients received first grafts (Table 5.1).

The first human lung transplant was performed by Dr. James Hardy at the University of Mississippi in 1963 on a patient with an isolated lung cancer.³ This patient lived for 18 days. A small number of transplants were performed around the world between 1963 and 1980 with no long-term survival being achieved for patients. It was not until cyclosporin was introduced in the early 1980s that real progress began to be made.

The first "successful" heart-lung transplantation was performed in 1981 at Stanford University. In 1983, the Toronto Thoracic Surgical Group, under the leadership of Dr. Joel Cooper, performed the first single lung transplant operation. In 1986, Dr. Cooper performed the first successful bilateral lung transplant. Results have continued to improve since that time because of advances in immunosuppression, improved pre- and perioperative care of recipients and better organ preservation techniques and medical management of donors.

Table 5.1 Lung Transplants by Year, Age Group and Re-Transplants, Canada, 1994 to 2003 (Number)

	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	Total
First Grafts; Recipients 18+ Years	68	78	67	86	75	85	121	121	130	112	943
First Grafts; Recipients < 18 Years	1	1	4	4	4	5	2	4	5	2	32
Re-Transplants	2	1	5	3	4	1	1	1	4	4	26
Total	71	80	76	93	83	91	124	126	139	118	1,001

The Toronto Lung Transplant Program, which encompasses surgeries performed at both the Hospital for Sick Children and Toronto General Hospital—University Health Network, performed 39% (388) of all transplant procedures during the decade. University of Alberta Hospital and Notre-Dame Hospital each performed 19% of all procedures (189 and 186, respectively).

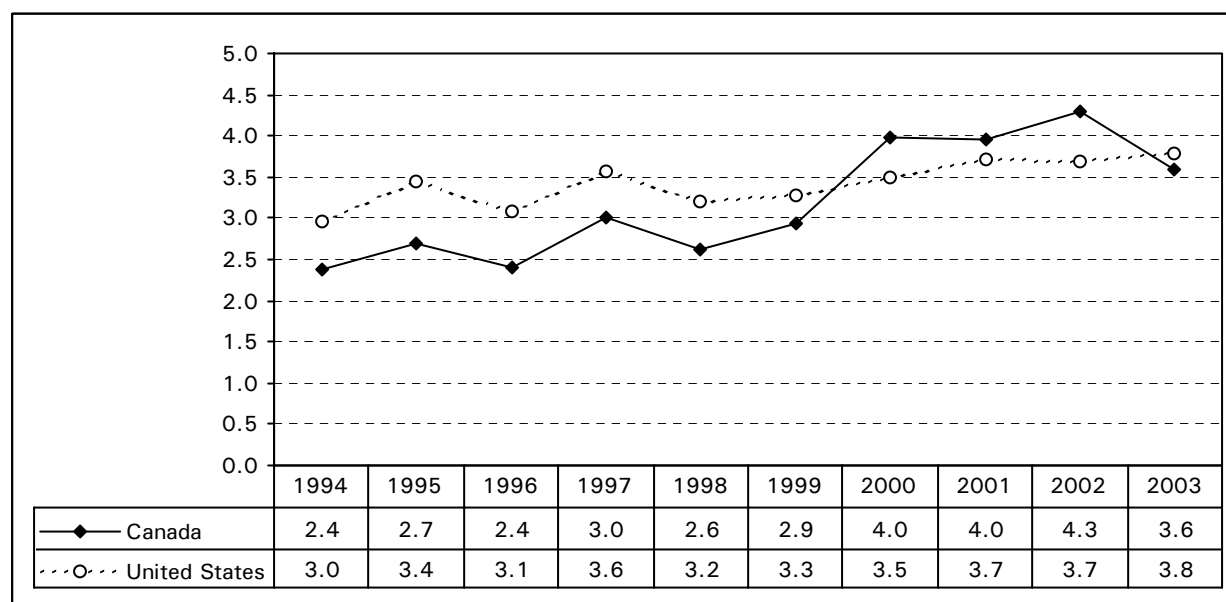
Bilateral lung transplants were the predominant type of lung transplant performed in Canada, increasing more than twofold over the decade and representing 64% of all lung transplants performed from 1994 to 2003 (Table 5.2). Most pediatric patients (27 out of 32) received bilateral lung transplants. Heart-lung transplants represented 5% of the lung transplants performed during the decade. The Winnipeg program performed the first living-donor lobar lung transplantation in Canada in 1999. Three additional living-donor lobar lung transplants were performed in the 2000 to 2003 period.

Table 5.2 Lung Transplants by Transplant Type, Canada, 1994 to 2003 (Number)

	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	Total
Bilateral Lung	41	45	43	52	46	55	85	82	96	95	640
Single Lung	24	27	29	34	30	30	34	39	36	21	304
Living-Donor Lobar	0	0	0	0	0	1	1	2	0	0	4
Heart-Lung	6	8	4	7	7	5	4	3	7	2	53
Total	71	80	76	93	83	91	124	126	139	118	1,001

International Comparison

With the increase in lung transplantation (single, bilateral, heart-lung) in Canada over the 1994 to 2003 period, the lung transplantation rate in Canada surpassed the U.S. rate in 2000, although there was a small drop in 2003 (Figure 5.1). Lung transplantation is the only type of solid organ transplantation where Canadian rates were not consistently lower than U.S. rates.

Figure 5.1 Lung Transplants, Canada and United States, 1994 to 2003 (Crude Rate per Million Population)

Data source for US: l'Établissement français des Greffes, *Rapport d'activité et Bilan des activités de prélèvement et de greffe en France Année 2003* (Paris: l'Établissement français des Greffes, Agence de la biomédecine, 2004). Data source for the U.S.: Department of Health and Human Services (Health Resources and Services Administration, Healthcare Systems Bureau, Division of Transplantation), United Network for Organ Sharing and University Renal Research and Education Association, *2004 Annual Report of the U.S. Organ Procurement and Transplantation Network and the Scientific Registry of Transplant Recipients: Transplant Data 1994-2003* (Richmond, VA: United Network for Organ Sharing, 2004).

Recipient Characteristics

There were 32 pediatric patients, ranging in age from 8 to 17 years at the time of their initial transplant. Over half (53%, $n = 17$) were male. Twenty-seven pediatric patients received bilateral lung transplants, with 19 of these patients having cystic fibrosis.

Although there were slightly more men than women transplanted with lungs over the decade (491 to 452), there was no clear trend from one year to the next in terms of the sex distribution. While the average age of adult recipients increased only slightly over the decade, from 45 in 1994 to 48 in 2003, the proportion of adult lung transplant recipients 50+ years old rose to 52% in 2003 from 40% in 1994.

Eisenmenger's disease and primary pulmonary hypertension were the two most common causes of end-stage lung disease for recipients of heart-lung transplants (Table 5.3). Cystic fibrosis, emphysema/chronic obstructive pulmonary disease and idiopathic pulmonary fibrosis were the three most frequent primary diagnoses for recipients of bilateral lung transplants during the period. Over half of single lung transplant recipients had emphysema/chronic obstructive pulmonary disease, and an additional 23% had idiopathic pulmonary fibrosis.

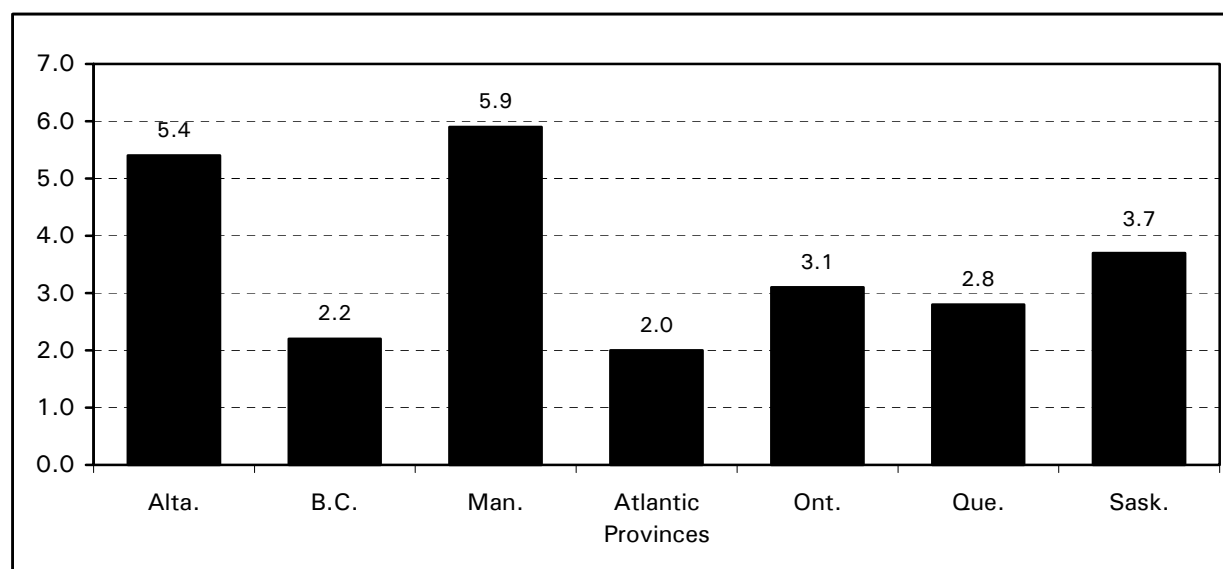
Table 5.3 Primary Diagnosis for Adult Lung Transplant Recipients, Canada, 1994 to 2003

Primary Diagnosis Category	Bilateral Lung		Single Lung		Heart-Lung	
	N	%	N	%	N	%
Alpha 1 Antitrypsin Deficiency	59	9.8	26	8.9	1	2.1
Congenital	3	0.5	2	0.7	5	10.4
Cystic Fibrosis	188	31.2	2	0.7	3	6.3
Eisenmenger's Disease	10	1.7	0	0.0	15	31.3
Emphysema/COPD*	120	19.9	157	53.8	4	8.3
Idiopathic Pulmonary Fibrosis	92	15.3	66	22.6	2	4.2
Primary Pulmonary Hypertension	31	5.1	5	1.7	13	27.1
Other	92	15.1	27	9.3	4	8.3
Unknown	8	1.5	7	2.4	1	2.1
Total	603	100.0	292	100.0	48	100.0

* COPD = chronic obstructive pulmonary disease

Rates of lung transplants by province of residence showed that Manitobans and Albertans had the highest rates and the combined Atlantic provinces had the lowest rate. This is a crude rate calculation and does not take into consideration potential provincial differences in the prevalence of end-stage lung disease.

Figure 5.2 Lung Transplant Recipients by Province of Residence, Canada, 1994 to 2003 (Crude Rate per Million Population)



Waiting List and Waiting Times

The lung transplant waiting list grew during the period from 1993 to 2004, largely due to increased listings for bilateral lung transplants (Table 5.4).

Table 5.4 Lung Transplant Waiting List on December 31, Canada, 1994 to 2003

	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003
Bilateral Lung	21	83	19	44	66	93	108	125	88	131
Single Lung	32	98	66	60	61	64	58	25	50	29
Heart-Lung	11	14	14	15	15	11	11	13	12	12
Total	64	195	99	119	142	168	177	163	150	172

A total of 248 patients died while listed for a lung transplant from 1994 to 2003, with an average of 25 deaths per year.

Adult single and bilateral lung transplant recipients receiving their first lung transplant in 2003 ($n = 110$) waited a median of 165.5 days (range 0 to 1,332 days). Wait time was influenced by patients' medical status at the time of listing, with Status 2 (rapidly deteriorating) patients ($n = 34$) having a median wait time of 38 days, and Status 1 (stable) patients ($n = 70$) having a median wait time of 320.5 days.

Outcomes

Unadjusted patient survival for recipients of deceased-donor first grafts in the years 1994 to 2002 showed modest improvements over time (Figure 5.3). Similar trends were found for unadjusted graft survival (Figure 5.4).

Figure 5.3 Unadjusted 3-Month, 1-Year, 3-Year and 5-Year Patient Survival for Lung Transplant Recipients, First Graft, Deceased Donor Lungs, Canada, 1994 to 2002

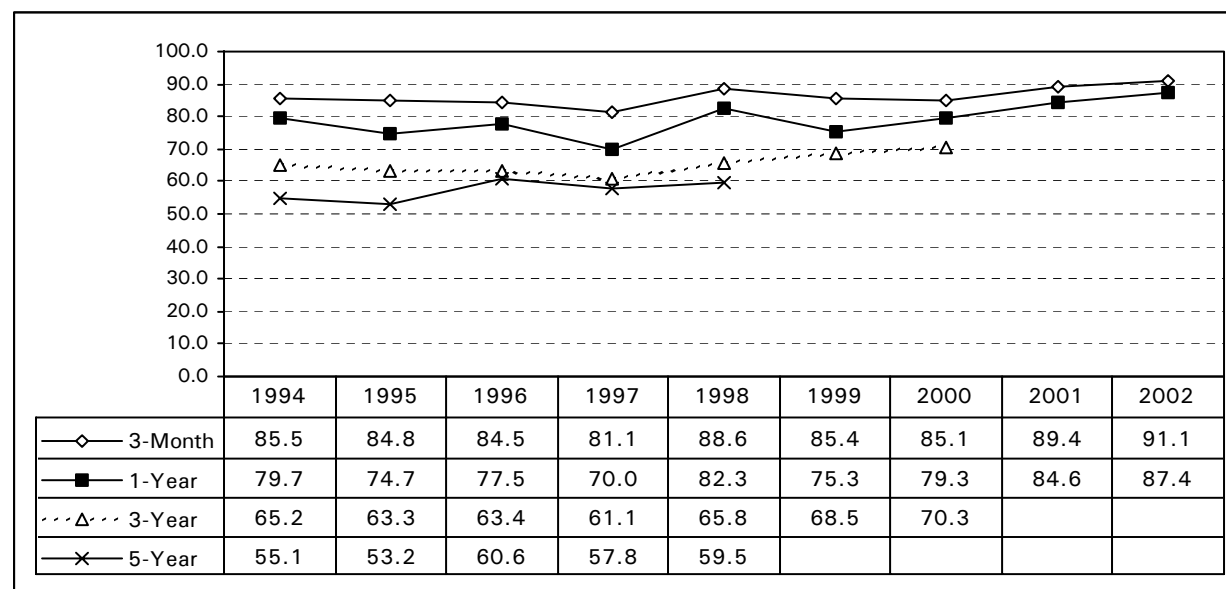
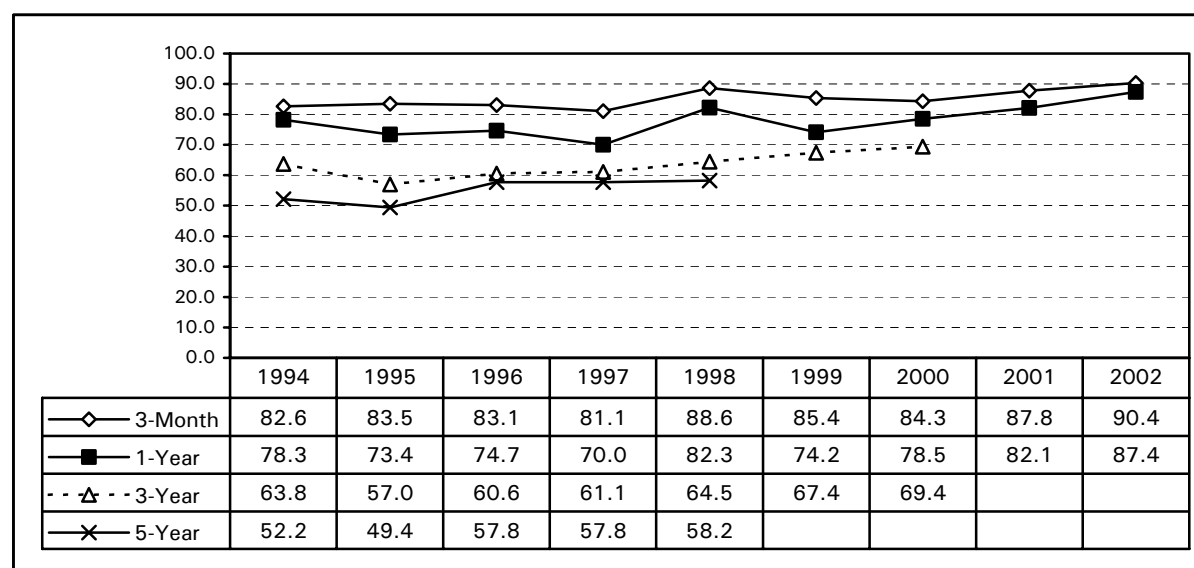


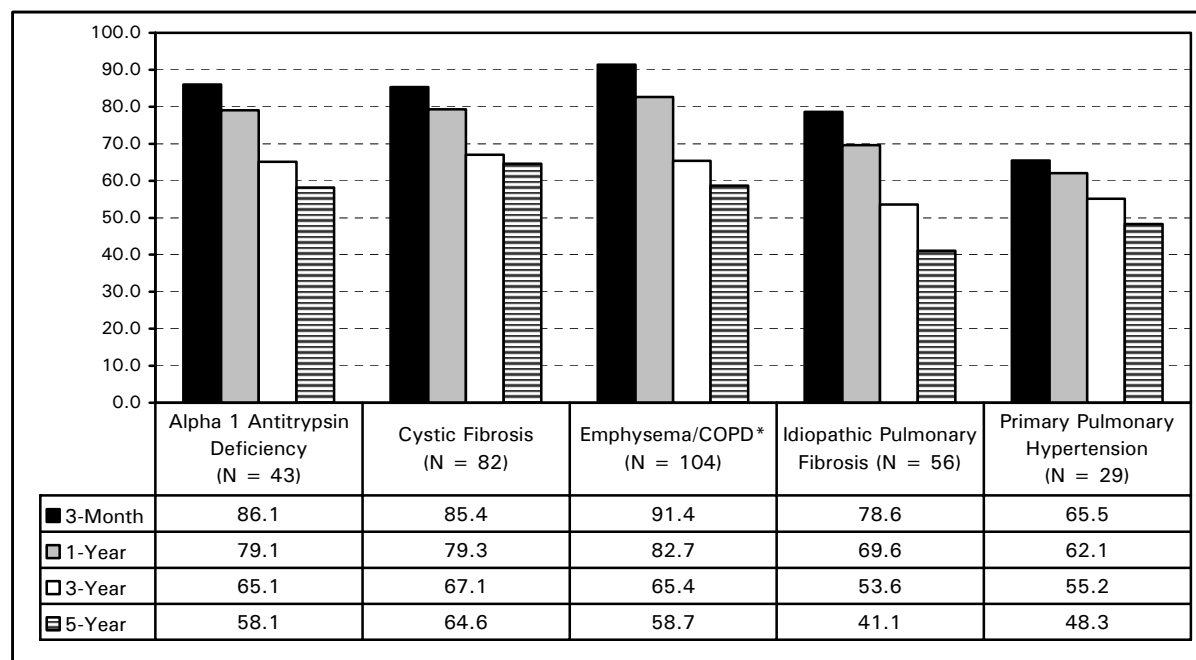
Figure 5.4 Unadjusted 3-Month, 1-Year, 3-Year and 5-Year Graft Survival* for Lung Transplant Recipients, First Graft, Deceased Donor Lungs, Canada, 1994 to 2002



* Graft survival is computed from first lung transplant date to first graft failure date, death date or end of observation (December 31, 2003). In this analysis, patients who died with a functioning graft are considered as failed grafts.

For patients receiving their first graft between 1994 and 1998, patient survival was lowest at three months and one year post-transplant for patients with primary pulmonary hypertension (Figure 5.5). At three and five years post-transplant, patient survival was lowest for patients with idiopathic pulmonary fibrosis. Patients with cystic fibrosis had the highest five-year patient survival. These results are consistent with those reported by the International Society of Heart and Lung Transplantation.⁴

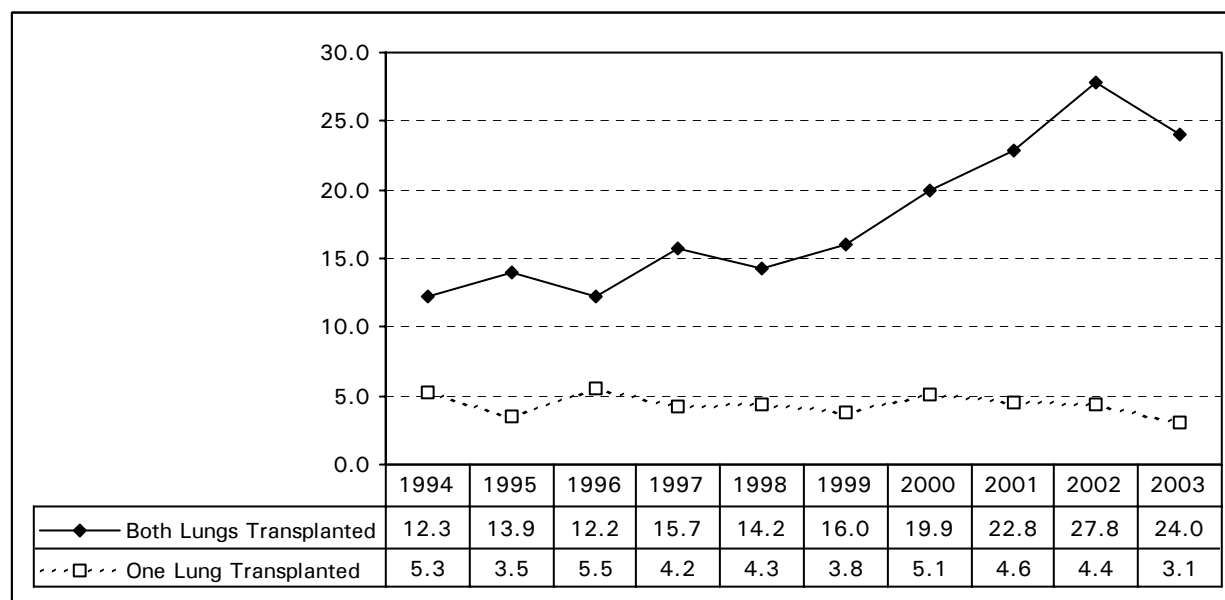
Figure 5.5 Unadjusted 3-Month, 1-Year, 3-Year and 5-Year Patient Survival for Lung Transplant Recipients by Primary Diagnosis, First Graft, Deceased Donor Lungs, Canada, 1994 to 1998



* COPD = chronic obstructive pulmonary disease

Organ Donors

Recovery of lungs used for transplantation showed two distinct patterns. Single lungs were recovered at a fairly constant rate, whereas the recovery of both organs climbed over the period from 1994 to 2003 (Figure 5.6). This growth mirrored the increase in bilateral lung transplants over the period. Despite this growth, even in 2002, the year with the highest rate of lung recovery, one or both lungs were recovered in only 32% of all deceased donors.

Figure 5.6 Proportion of Lungs Transplanted from Deceased Donors, Canada, 1994 to 2003 (Percent)

There is no national algorithm for sharing of donor lungs in Canada. In most provinces, lungs used by transplant programs were recovered from their own provincial procurement programs (Table 5.5). The Edmonton lung transplant program had the highest proportion of lungs from U.S. OPOs for the 2001 to 2003 period. In contrast, Quebec transplant programs were most likely to use lungs recovered from donors identified by Québec-Transplant, and were also more likely to share organs with other lung transplant programs.

Table 5.5 Origin and Destination of Transplanted Lungs, Canada 2001 to 2003*

Province of Organ Procurement Organization	Province of Treatment					Total
	Alta.	B.C.	Man.	Ont.	Que.	
Alberta	40	0	2	0	0	42
British Columbia	11	22	1	0	0	34
Manitoba	1	0	12	0	0	13
New Brunswick	0	0	0	13	2	15
Newfoundland and Labrador	0	0	0	6	0	6
Nova Scotia	0	0	0	2	0	2
Ontario	5	1	5	114	6	131
Quebec	6	0	0	20	67	93
Saskatchewan	12	0	3	0	0	15
United States	24	3	0	3	0	30
Total	99	26	23	158	75	381

* Shaded cells show local organs used for transplantation.

As noted in Section 8, deceased donors have aged over the decade of observation. The sex distribution and age characteristics of deceased lung donors varied according to the lungs used for transplantation. Heart-lung donors were more likely to be female, and had a younger overall age, while single lung donors where both lungs were used but transplanted into different recipients had the oldest average age (Table 5.6).

Table 5.6 Deceased Lung Donors by Lungs Used for Transplantation, Donor Sex and Age Statistics, Canada, 1994 to 2003

	% Male	Mean Age (Standard Deviation)	Age Range
Both Lungs—Different Recipients	55.0	39.2 (15.4)	12–62
Both Lungs—Same Recipient	50.8	37.4 (15.7)	5–77
One Lung	57.9	35.5 (13.4)	14–65
Heart-Lung	39.6	31.7 (13.2)	10–62

As noted in Section 8, causes of death for donors changed over the decade with a rise in deaths from cerebrovascular accidents and strokes and a concomitant fall in deaths from motor vehicle collisions. Causes of donor death varied for lung donors according to the way the lungs were used for transplantation (Table 5.7). Notably, heart-lung donors had proportionately fewer deaths from cerebrovascular accidents and strokes.

Table 5.7 Deceased Lung Donors by Lungs Used for Transplantation and Donor Cause of Death, Canada, 1994 to 2003

Cause of Death	Both Lungs— Different Recipients		Both Lungs—Same Recipient		One Lung		Heart-Lung	
	N	%	N	%	N	%	N	%
Motor Vehicle Collision	5	8.3	144	22.5	52	28.3	18	34.0
Other Head Trauma	6	10.0	70	10.9	25	13.6	6	11.3
Gunshot	5	8.3	26	4.1	4	2.2	2	3.8
Anoxia/Hypoxia	7	11.7	37	5.8	11	6.0	3	5.7
Cerebrovascular Accident/Stroke	33	55.0	322	50.3	84	45.6	21	39.6
Other	3	5.0	28	4.4	6	3.3	2	3.8
Unknown	1	1.7	13	2.0	2	1.1	1	1.9
Total	60	100.0	640	100.0	184	100.0	53	100.0

6 Pancreas Transplantation

Activity

There were 446 pancreas transplants registered in CORR between 1994 and 2003 (Table 6.1). Over two-thirds of these transplant procedures involved simultaneous kidney-pancreas (SKP) transplantation. Ten transplants involved second pancreas grafts. A total of 436 patients received their first pancreas grafts during this decade.

Pancreatic transplantation is a procedure reserved for patients who have difficulty maintaining control of insulin levels through other medical means. Drs. Richard Lillehei and William Kelly performed the first simultaneous kidney-pancreas transplant in 1966 at the University of Minnesota.⁵ The first pancreas-only transplant, again by Dr. Lillehei in Minneapolis, occurred in 1968. In the early years of the procedure, rates of graft and patient survival were low. The introduction of cyclosporin and anti-T-cell agents, new surgical techniques and refined patient selection criteria all contributed to improved surgical results.

Table 6.1 Pancreas Transplants by Year, Canada, 1994 to 2003 (Number)

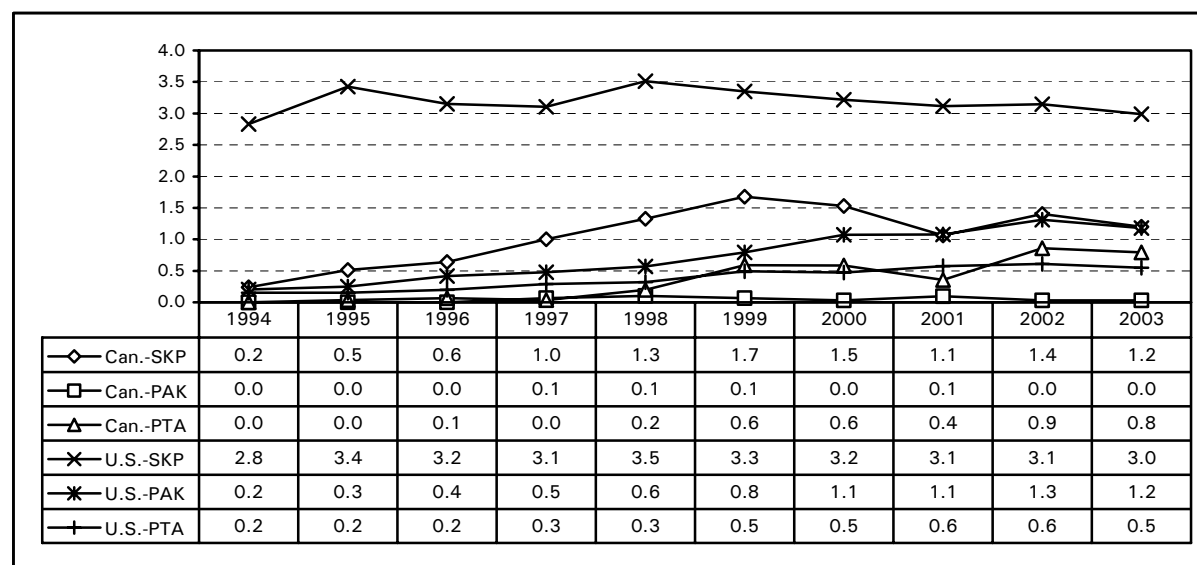
	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	Total
Simultaneous Kidney-Pancreas (SKP)	7	15	19	30	40	51	47	33	44	38	324
Pancreas After Kidney (PAK)	0	0	0	2	3	2	1	3	1	1	13
Pancreas Transplant Alone (PTA)	0	1	2	1	6	18	18	11	27	25	109
Total	7	16	21	33	49	71	66	47	72	64	446

Pancreas transplant programs were performed in five provinces during the period from 1994 to 2003: Nova Scotia, Quebec, Ontario, Alberta and British Columbia. For years 2002 and 2003, pancreas transplants for residents of the Atlantic provinces were performed in either Quebec or Ontario. The Quebec and Ontario programs performed the same number of surgeries over the decade, 132 in each province, accounting for nearly 60% of all pancreas transplants performed. In Quebec, nearly 71% of the pancreas transplants were PAK or PTA transplants, in contrast to the other treatment provinces, where between 83 to 87% of transplants were SKPs.

International Comparison

SKP and PAK transplant rates in Canada were lower than rates in the U.S. over the decade (Figure 6.1). In 2002 and 2003, the crude PTA transplant rate in Canada was slightly higher than the U.S., although for most of the rest of the decade it was lower. The overall pancreas transplant rate of 5 pmp in the U.S. in 2003 compared with a 2 pmp rate in Canada. While the proportion of SKP transplants was similar in both countries, proportionately more PTA were performed in Canada, while proportionately more PAK were performed in the U.S.

Figure 6.1 Pancreas Transplants by Type, Canada and United States, 1994 to 2003 (Crude Rate per Million Population)

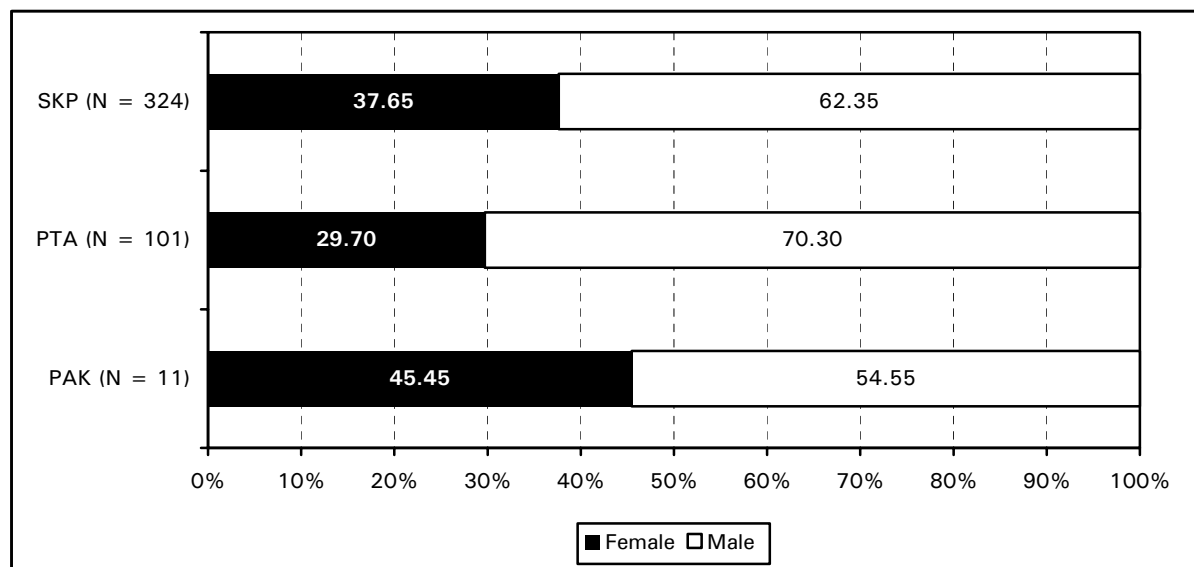


Data source for US: l'Établissement français des Greffes, *Rapport d'activité et Bilan des activités de prélèvement et de greffe en France Année 2003* (Paris: l'Établissement français des Greffes, Agence de la biomédecine, 2004). Data source for the U.S.: Department of Health and Human Services (Health Resources and Services Administration, Healthcare Systems Bureau, Division of Transplantation), United Network for Organ Sharing and University Renal Research and Education Association, *2004 Annual Report of the U.S. Organ Procurement and Transplantation Network and the Scientific Registry of Transplant Recipients: Transplant Data 1994-2003* (Richmond, VA: United Network for Organ Sharing, 2004).

Recipient Characteristics

The average age of recipients of first pancreas grafts during the decade was 39.2 years (standard deviation 7.6; age range 19–75). While more males received a pancreas transplant, the sex distribution varied by transplant type (Figure 6.2).

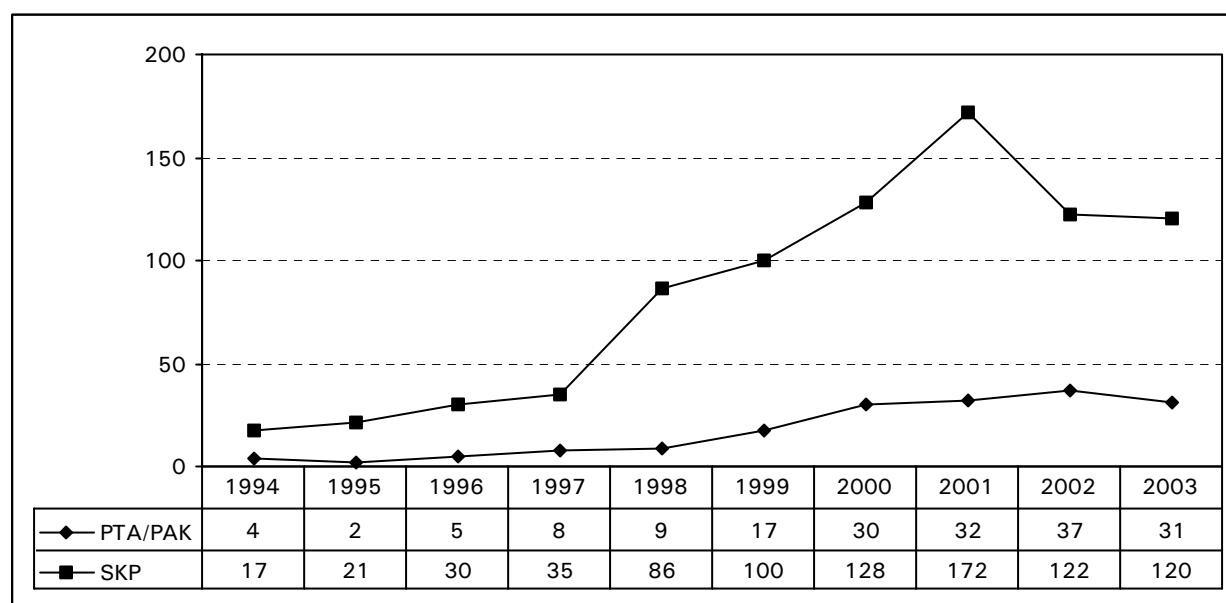
Figure 6.2 Pancreas Transplant Recipients by Type and Recipient Sex, First Grafts, Canada, 1994 to 2003 (Percent)



Waiting List and Waiting Times

The number of patients waiting for an SKP transplant at year-end spiked in 2001 and then tapered off in years 2002 and 2003 (Figure 6.3). The number of patients waiting for a PTA/PAK transplant showed a similar pattern. Number of deaths among patients waiting for a pancreas or SKP totaled 23 over the decade.

Figure 6.3 Pancreas and Kidney-Pancreas Transplant Waiting List on December 31, Canada, 1994 to 2003 (Number)



Outcomes

Because of the small annual number of PTA and PAK transplants for the years 1994 to 1998, unadjusted patient and graft survival rates were examined only for SKP recipients who received a first SKP transplant in the first five years of the decade (N = 111). Patient survival was over 90% at five years, and graft survival was about 10% lower (Table 6.2).

Table 6.2 Unadjusted 90-Day, 1-Year, 3-Year and 5-Year Patient and Pancreas Graft Survival Rates, First SKP Grafts, Canada, 1994 to 1998

	90-Day	1-Year	3-Year	5-Year
Patient Survival	98.2	96.4	92.8	91.9
Pancreas Graft Survival*	95.5	94.6	88.3	82.9

* Graft survival is computed from first SKP transplant date to first pancreas graft failure date, death date or end of observation (December 31, 2003). In this analysis, patients who died with a functioning graft are considered as failed grafts.

Organ Donors

Recovery rates of donor pancreata are imprecise in CORR, as no mechanism currently exists to completely track islet cell transplants.

Sharing of pancreata for the purposes of solid organ transplantation was minimal during the period 2001 to 2003. For 94% of SKP transplants and 90% of PAK and PTA transplants, the OPO and transplant program were in the same province.

The majority of pancreas donors were males who had died from cerebrovascular accidents/strokes or head traumas caused by involvement in motor vehicle collisions or other circumstances (Table 6.3).

Table 6.3 Pancreas Donor Characteristics by Transplant Type, Canada, 1994 to 2003

	PAK and PTA (N = 122)	SKP (N = 322)
% Male	64.8	62.7
Average Age (SD)*	29.9 (11.4)	29.9 (11.7)
Age Range	10–53	3–57
% Died From Cerebrovascular Accident/Stroke	43.3	38.9
% Died From Motor Vehicle Collision	22.5	28.8
% Died From Other Head Trauma	18.3	17.9

* SD = Standard Deviation

7 Intestinal Transplantation^{****}

Activity

Intestine transplantation is a low-volume procedure in Canada. In 2003, there were four active intestine transplant programs at the following hospitals: the Toronto General Hospital—University Health Network; the Hospital for Sick Children; the London Health Sciences Centre—University Campus, and the University of Alberta Hospital—Capital Health. Patients from across Canada were listed at one of these transplant programs.

There have been 35 intestinal transplants registered in CORR among 34 recipients (one patient had two transplants). The transplants occurred during the years 1988 to 2003, and included 8 multivisceral, 11 isolated small bowel, 13 liver-small bowel, 2 kidney-bowel and 1 liver-kidney-bowel transplants. Nearly two-thirds (22 out of 35) of these transplants were performed in London (Table 7.1). All of the intestinal transplants within CORR were performed with organs from deceased donors.

Intestinal transplantation was first attempted in humans during the 1960s. At that time, total parenteral nutrition (TPN) therapy (intravenous feeding) was not yet available. These first intestinal transplant patients died from technical complications, rejection, or infection. Successful intestinal transplants were not performed until the mid-1980s, with the first successful multivisceral transplant performed in Pittsburgh, in the U.S. in 1987, the first successful small bowel segment performed in Cologne, Germany in 1988; the first successful liver-bowel in London, Canada in 1988; and the first successful total small bowel in Paris, France in 1989.⁶

It was not really until the advent of tacrolimus in 1990 that intestinal transplantation emerged as a full-fledged treatment for intestinal failure.⁵ Despite recent advances, intestinal transplantation is a therapeutic option only for patients with intestinal failure whose condition continues to decline in spite of TPN; it is not yet an alternative for patients who are doing well on TPN.⁷

Table 7.1 Intestinal Transplants by Transplant Period and Age Group, Canada, 1988 to 2003 (Number)

Type of Graft	1988 to 1993		1994 to 1998		1999 to 2003		Total	
	< 18 Years	18+ Years	< 18 Years	18+ Years	< 18 Years	18+ Years	< 18 Years	18+ Years
Multivisceral (N = 8)	0	2	1	0	1	4	2	6
Isolated Small Bowel (N = 11)	1	0	5	2	2	1	8	3
Liver-Small Bowel (N = 13)	1	4	2	1	5	0	8	5
Kidney-Small Bowel (N = 2)	0	1	0	1	0	0	0	2
Liver-Kidney-Small Bowel (N = 1)	0	0	0	0	1	0	1	0
Total (N = 35)	2	7	8	4	9	5	19	16

**** The information on intestinal transplantation is the first of its kind reported by CORR. It is restricted in content by the small number of intestinal transplants and by data completeness issues. In this section, the time period of observation was expanded, from 1994 to 2003 to 1988 to 2003.

International Comparison

The Canadian data represented 3.5% of all worldwide intestinal transplants reported from April 1985 to May 2003 to the Intestinal Transplant Registry (ITR), according to its May 31, 2003 report.⁸

Recipient Characteristics

Underlying causes of intestinal failure were poorly reported to CORR—for six patients, no primary diagnosis was provided. Eight patients were diagnosed with short gut syndrome, and an additional 14 had a diagnosis of an unspecified metabolic disorder.

Waiting List and Waiting Times

Waiting list data for intestinal transplantation and deaths among patients listed are considered to be incomplete. Ways to improve reporting are currently being investigated.

Outcomes

Twelve graft failures were reported from 1988 to 2003. Causes of graft failure, however, were specified for only three patients. Sixteen patients died, with no discernable pattern in causes of death. Among reported deaths, cause of death was not specified for six patients.

Organ Donors

Small bowels were recovered in less than 1% of all deceased donors in Canada. Within CORR, donor information was available for 33 of the 35 intestinal transplants. Donor age data were available for 31 of the 33 donors. There were 6 donors aged > 1 year, 14 aged 1–17 and 11 18+ years old. Twenty-one donors were female; 20 donors were identified by the Ontario OPOs.

Cause of death was available for 30 of the 33 donors. Of these, 10 died from head injuries sustained from motor vehicle collisions, another 10 died from cerebrovascular accidents/strokes.

8 Deceased Organ Donors

The 10 organ procurement organizations (OPOs) in Canada submit data to CORR on deceased organ donors identified within provincial hospitals even when the organs recovered by one OPO may be used in another province in Canada. Deceased organ donors are defined as donors where at least one organ was recovered and transplanted, a definition more conservative than that of the U.S., which includes donors where organs were recovered, but not transplanted. The characteristics of deceased organ donors in terms of organs donated are discussed in the organ-specific sections of this report.

Deceased organ donation expressed in terms of rate per million population has been a much-debated measure of organ donation activity. Calculating a rate using a denominator that reflects the number of potential donors would be a more desired method.

Unfortunately, Canada does not yet have a national information system from which the number of potential donors per hospital can be reliably identified. Medical chart reviews done at individual hospitals and the much broader work conducted by the Collège des médecins du Québec⁹ for the province of Quebec suggest that there is some room to improve Canada's deceased organ donor rates.

The number of Canada's deceased organ donors changed very little from 1994 to 2003 (Table 8.1).^{†††} Dramatic annual fluctuations were found in the number of donors in provinces with populations of less than 2 million.

Table 8.1 Deceased Organ Donors, Canada and OPO Province, 1994 to 2003

OPO Province	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	Total
Alberta	40	35	53	52	49	54	56	52	54	36	481
British Columbia	38	51	48	49	36	41	38	37	31	39	408
Manitoba	26	24	26	17	14	9	20	9	11	12	168
New Brunswick	20	13	7	13	11	17	11	17	11	12	132
Newfoundland and Labrador	12	5	6	8	2	4	15	15	14	10	91
Nova Scotia	21	15	11	27	9	12	19	9	11	11	145
Ontario	140	153	150	154	152	133	165	128	137	142	1,454
Quebec	92	117	113	95	120	131	135	134	126	142	1,205
Saskatchewan	11	10	4	11	22	19	13	15	12	17	134
Total	400	423	418	426	415	420	472	416	407	421	4,218

††† In this section, donor data refer to donors registered within CORR where at least one organ has been used for transplantation. This may differ from slightly from aggregate annual counts provided by organ procurement organizations.

Socio-demographic factors, such as Canada's aging population and the reduction in fatal motor vehicle collisions, have had an impact on both the number and the characteristics of deceased donors. The median age of donors in 1994 was 38; in 2003, it was 44. For the period from 2001 to 2003, the oldest donors were in Quebec and the youngest in Alberta.

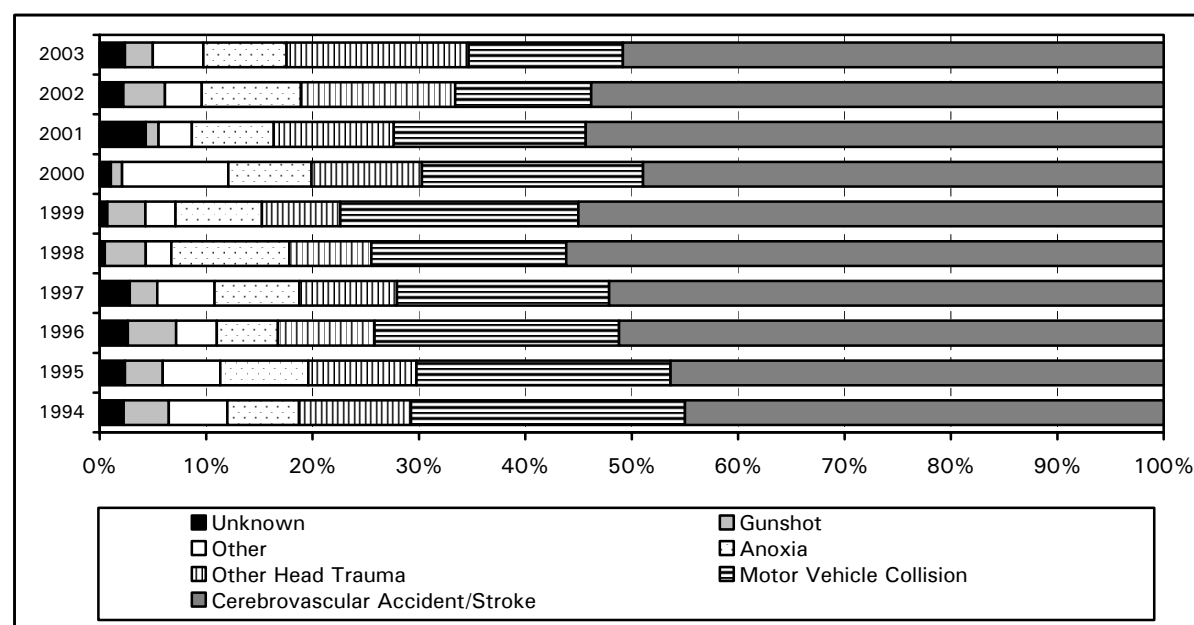
Table 8.2 Deceased Organ Donors by Median Age, OPO Province, 2001 to 2003

	Alta.	B.C.	Man.	N.B.	N.L.	N.S.	Ont.	Que.	Sask.	Total
Age Range	<1-74	<1-74	<1-72	8-68	4-72	1-64	<1-86	<1-88	<1-86	<1-80
Median Age	38.5	41	40.5	39	47	46	44	48.5	42.5	44
Mean Age (SD)*	34.8 (17.6)	38.1 (17.8)	35.9 (19.4)	37.1 (16.5)	46.1 (14.8)	44.7 (15.7)	42.6 (17.8)	46.6 (18.0)	38.0 (19.1)	42.3 (18.2)

* SD = standard deviation

The distribution of causes of death for donors also changed over the decade. The majority of donors in 2003 died from cerebrovascular accidents/strokes (52%), with a declining proportion dying from head injuries sustained from motor vehicle collisions (15%). In 1994, these figures were 45% and 26%, respectively.

Figure 8.1 Deceased Organ Donors by Cause of Death, Canada, 1994 to 2003 (Percent)



The other notable trend in deceased organ donation from 1994 to 2003 in Canada was the increase in organs donated per donor (Table 8.3).

Table 8.3 Organs Donated per Deceased Donor* by Age Group, Canada, 1994 to 2003

Age Group	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003
< 1 year	0.0	0.0	0.0	1.0	1.0	3.0	1.3	2.0	2.0	2.7
1–14 years	3.1	3.0	3.4	3.4	3.1	3.7	3.3	3.2	3.7	3.7
15–39 years	3.8	3.8	3.7	3.8	4.2	4.3	4.2	4.4	4.3	4.4
40–54 years	3.6	3.6	3.5	3.5	3.2	3.6	3.5	3.5	3.8	3.9
55–69 years	2.8	2.8	2.7	2.7	2.6	2.7	2.7	2.9	3.1	3.1
70+ years	2.5	1.4	1.2	1.3	1.5	2.1	1.5	1.7	2.0	2.1
Total	3.5	3.5	3.4	3.4	3.3	3.6	3.5	3.6	3.7	3.7

* Organ count divided by number of donors per age group. Includes pancreata used for islet cells and organs exported to the U.S. Excludes donors where age is missing, which is less than 0.3% of the data.

References

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Appendix A

CORR Board of Directors and Members of the Advisory Committee

CORR Board of Directors (April 1, 2005)

Dr. Stanley Fenton, Canadian Society of Nephrology (CSN), Chair/President

Dr. Marie-Josée Clermont—CSN

Dr. John Gill—Canadian Society of Transplantation (CST)/CSN

Dr. Antonio Giulivi—Health Canada

Mr. Peter Houtt—The Kidney Foundation of Canada (Secretary/Treasurer)

Mr. Greg Kalyta—Canadian Association of Transplantation (CAT)

Dr. Joanne Kappel—CSN, Vice-President

Dr. Vivian McAlister—CST, Past-President

Dr. Louise Moist—CSN

Dr. Rosalie Starzomski—Canadian Association of Nephrology Nurses and Technicians (CANNT)

CORR Advisory Committee (April 1, 2005)

Dr. John Gill—Kidney transplantation (B.C.), Chair

Dr. Stanley Fenton—Nephrology (Ont.)

Dr. Joanne Kappel—Nephrology (Sask.)

Dr. Vivian McAlister—Liver transplantation (Ont.)

Dr. Louise Moist—Nephrology (Ont.)

Dr. Karen Yeates—Nephrology (Ont.)

Dr. Verna Yiu—Pediatric Nephrology (Alta.)

Appendix B

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

Independent health facilities are noted with an asterisk (*).

Hospital/Facility	Type of Transplants Performed in 2003						Dialysis Programs in 2002					
	Kidney	Liver	Heart	Heart-Lung	Lung	Intestine/Multivisceral	Pancreas/Kidney-Pancreas	Islet Cell	HD	Home HD Training	PD	Home PD Training
N.W.T.												
*Stanton Territorial Health Authority									X			
B.C.												
B.C. Children's	X								X		X	X
Kelowna General									X	X	X	X
Kootenay-Boundary Regional									X	X	X	X
Penticton Regional									X		X	X
Prince George Regional									X	X	X	X
Royal Columbian									X		X	X
Royal Inland									X	X	X	X
Royal Jubilee									X	X	X	X
St. Paul's	X		X						X		X	X
Surrey Memorial									X			
Vancouver	X	X			X		X	X	X		X	X
Alta.												
Foothills Medical	X						X		X	X	X	X
University of Alberta	X	X	X	X	X	X	X	X	X	X	X	X
Sask.												
Regina General									X		X	X
St. Paul's	X								X		X	X
Man.												
Brandon Regional									X			
Health Sciences	X				X				X	X		
Seven Oaks General									X			
St. Boniface General									X		X	X
Ont.												
*Bayshore Dialysis Clinic—Brockville									X			
*Bayshore Dialysis Clinic—Stoney Ck									X			
*Brantford General									X			
Children's Hospital of Eastern Ontario									X		X	
*Cornwall Dialysis Clinic									X			
Credit Valley									X	X	X	X

Hospital/Facility	Type of Transplants Performed in 2003						Dialysis Programs in 2002					
	Kidney	Liver	Heart	Heart-Lung	Lung	Intestine/Multivisceral	Pancreas/Kidney-Pancreas	Islet Cell	HD	Home HD Training	PD	Home PD Training
*Dialysis Mgmt Clinics Inc. — Pickering									X			
*Dialysis Mgmt Clinics Inc. — Markham									X			
*Dialysis Mgmt Clinics Inc. — Peterborough									X			
Grand River									X		X	X
Halton Healthcare Services									X			
Hamilton Health Services Corp. McMaster Children's											X	X
Hospital for Sick Children	X	X	X			X			X	X	X	X
Hotel Dieu Health Sciences									X	X	X	X
Hôtel-Dieu Grace									X		X	X
Humber River Regional									X	X	X	X
Kingston General	X								X	X	X	X
Lakeridge Health Corp. Whitby									X	X	X	X
LHSC — University and South Street	X	X	X		X	X			X			
LHSC — Westminster									X	X	X	X
North Bay General									X			
Orillia Soliders' Memorial									X		X	X
*Ottawa-Carleton Dialysis Clinic									X			
Ottawa Hospital	X								X	X	X	X
Peterborough Regional Health									X		X	X
Renfrew Victoria									X			
Sault Area Hospitals Plummer Memorial									X		X	X
Scarborough — General Division									X		X	X
*Sheppard Centre									X			
St. Joseph's (Hamilton)	X								X	X	X	X
St. Joseph's (Toronto)									X		X	X
St. Michael's	X								X	X	X	X
Sudbury Regional Laurentian Site									X	X	X	X
Sunnybrook and Women's College									X	X	X	X
*Sussex Centre									X			
Thunder Bay Regional McKellar Site									X		X	X
Timmins and District									X		X	X
Toronto East General									X			
Toronto General — Univ. Health Netwk.	X	X	X	X	X	X	X		X	X	X	X
Univ. of Ottawa Heart Institute			X									
York Central									X		X	X

Hospital/Facility	Type of Transplants Performed in 2003						Dialysis Programs in 2002					
	Kidney	Liver	Heart	Heart-Lung	Lung	Intestine/Multivisceral	Pancreas/Kidney-Pancreas	Islet Cell	HD	Home HD Training	PD	Home PD Training
Que.												
Aurores Boréales											X	
CHUS – Fleurimont	X								X		X	X
C.H. de Granby									X			
C.H. de Verdun									X		X	X
Chicoutimi									X		X	
CHUM – Hôtel-Dieu									X			
*C.H. de la région de l'amiante									X			
CHUM – Notre-Dame	X			X	X		X		X	X	X	X
CHUM – St-Luc		X							X		X	X
C.H. Des Vallées de l'Outaouais Pav. de Hull									X		X	X
C.H. Régional de Trois-Rivières – Pavillon St. Joseph									X		X	X
CHUQ – Hôtel-Dieu	X								X	X	X	X
C.H Régional de Lanaudière									X		X	
C.H. Régional de Rimouski									X		X	X
C.H. régional du Suroît									X		X	X
C.H. de Santé Val-D'Or									X		X	X
Charles Lemoyne									X		X	X
Haut-Richelieu									X		X	X
Hôtel-Dieu d'Arthabaska									X			
Hôtel-Dieu de Lévis									X		X	X
Hôtel-Dieu de Saint-Jérôme									X		X	X
Hôtel-Dieu de Sorel									X		X	X
Institut de Cardiologie de Montréal			X									
Lakeshore									X			
Laval			X						X	X	X	X
Maisonnette-Rosemont	X								X	X	X	X
Montréal Children's – McGill	X								X		X	X
Montréal General – McGill									X	X	X	X
Royal Victoria – McGill	X	X	X	X			X		X		X	X
Sacré Coeur de Montréal									X		X	X
*Sainte-Croix									X		X	
Sainte-Justine	X	X	X						X		X	X
Sir Mortimer B. Davis Hospital – Jewish General									X		X	X
St. Mary's									X		X	X
N.S.												
Cape Breton Regional									X		X	X
IWK Grace Health	X								X		X	X
Queen Elizabeth II	X		X						X	X	X	X
Yarmouth Regional									X			

Hospital/Facility	Type of Transplants Performed in 2003						Dialysis Programs in 2002					
	Kidney	Liver	Heart	Heart-Lung	Lung	Intestine/Multivisceral	Pancreas/Kidney-Pancreas	Islet Cell	HD	Home HD Training	PD	Home PD Training
N.B.												
Chaleur Regional									X			
Edmundston									X	X	X	X
Georges L. Dumont									X	X	X	X
Saint John Regional									X	X	X	X
N.L.												
Central Nfld. Regional									X			
St. John's Health Sciences									X	X	X	X
Western Memorial Regional									X			

Appendix C

Canadian Organ Procurement Organizations

British Columbia

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

Alberta

HOPE Program—Calgary
Foothills Medical Centre
1403 29th Street North West
Calgary, Alberta T2N 2T9
www.crha-health.ab.ca/hlthconn/items/orgtiss.htm

HOPE Program—Edmonton

University of Alberta Hospital
8440–112th Street
Edmonton, Alberta T6G 2B7

Saskatchewan

The Saskatchewan Transplant Program
Royal University Hospital
108 Hospital Drive, P.O. Box 86
Saskatoon, Saskatchewan S7N 0W8

Manitoba

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

Ontario

Trillium Gift of Life Network
155 University Avenue, Suite 1440
Toronto, Ontario M5H 3B7
www.giftoflife.on.ca

Québec—Bureau de Montréal

Québec Transplant
4200 St-Laurent Boulevard
Montréal, Quebec H2W 2R2
www.quebec-transplant.qc.ca

Québec—Bureau de Québec

Québec Transplant
2601 de la Canardiere
Beauport, Quebec G1J 2G3

Nova Scotia

Multi-Organ Transplant Program
Queen Elizabeth II Health Sciences Centre
Mackenzie Building
5788 University Avenue
Halifax, Nova Scotia B3H 1V7
www.cdha.nshealth.ca/transplantservices/

New Brunswick

Multiple Organ Retrieval and Exchange Program
Health and Wellness Hospital Services Branch
PO Box 5100
Fredericton, New Brunswick E3B 5G8
www.gnb.ca/0217/organ-e.asp

Newfoundland and Labrador

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

Appendix D

CORR Data Quality Documentation: 1993 to 2003

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

Database Description

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

Data Sources and Methodology

Target Population: All patients who have received an extra-renal organ transplant and all chronic renal failure patients who initiated renal replacement therapy from January 1, 1981 on form CORR's target population. CORR does not contain information on (1) patients who have been determined to have acute, but not chronic renal failure; (2) recipients of tissue transplants; (3) patients who were listed for but did not receive a vital organ transplant; and (4) potential organ donors (that is, deceased donors who met the criteria for donation but from whom no organs are 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 are received either directly or indirectly from these programs. Tables D1 and D2 below identify the number of dialysis programs in 2002 and transplant programs in 2003, respectively, 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, 2002

	Alta.	B.C.	Man.	N.B.	N.L.	N.W.T.	N.S.	Ont.	Que.	Sask.	Total
Full-Care Dialysis Programs	2	11	4	4	3	0	3	30	31	2	90
Affiliated Community Centres	7	20	11	2	2	0	14	37	7	4	104
Independent Health Care Facilities Offering Hemodialysis	0	0	0	0	0	1	0	10	2	0	13

Table D2 Transplant Programs Within CORR Frame by Province, 2003

	Alta.	B.C.	Man.	N.S.	Ont.	Que.	Sask.	Total
Kidney	2	3	1	1	7	7	2	23
Liver	1	1	0	0	3	3	0	8
Heart/ Heart-Lung	1	1	0	1	4	5	0	12
Lung	1	1	1	0	2	1	0	6
Pancreas/Kidney-Pancreas	2	1	0	0	1	2	0	6
Intestine/Multivisceral	1	0	0	0	3	0	0	4

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 (DAD) in terms of assigning facility identifiers (that is, a province code from 1 to 9, along with four-digit identifier). Unique facility identifiers are assigned to hospitals in Quebec, satellite centres and 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-May 2002 to formally verify CORR's frame.

Data Sources: CORR is comprised of retrospectively collected demographic, clinical and outcome-related data. Data are currently received via paper forms or spreadsheets. Standardized forms are used for the purposes of paper collection, which detail the data elements and the domain values. These forms, and the accompanying instruction manuals, also guide spreadsheet submissions. Specially trained staff enters all the data received.

The CORR data model consists of 119 relational tables: 34 data tables; 68 code tables; 3 population tables derived from Statistics Canada; and 14 system tables. The data tables contain information on 579 data elements. One of these variables is derived (MELD_SCORE) and five are system-generated (RECIPIENT_ID, RECIPIENT_TREATMENT_ID, DONOR_ID, COMMUNITY_CENTRE_ID, ORGAN_FAILURE_CAUSE_ID). Twelve data elements are used either alone or in combination to link the various tables.

Within CORR, data elements are classified as mandatory, conditionally mandatory, or optional. Mandatory^{††††} elements must be submitted and entered (for example, *recipient name*, *birth date*, *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 are collected from dialysis hospitals and independent health facilities. Counts of patients waiting for a transplant are collected from OPOs.

†††† Mandatory data elements do include domain values for unknown values.

Table D3 Types of Data Captured and Points of Data Capture in CORR

Dialysis Recipients	Transplant Recipients	Donors	Dialysis Hospital Programs	Hospital Transplant Programs Following Kidney Transplant Recipients	Transplant Waiting List Statistics
<p>When initiate dialysis</p> <p>↓</p> <p>When: transfer to another program change treatment modalities have a kidney transplant withdraw from dialysis recover kidney function die</p> <p>↓</p> <p>Annually on October 31 (survey with voluntary participation)</p>	<p>When transplanted</p> <p>↓</p> <p>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)</p>	<p>When organ(s) retrieved for purposes of transplantation— <i>Deceased Donor Profile</i> and <i>Living Donor Profile</i></p>	<p>At year end—hemodialysis facility profile; peritoneal dialysis facility profile</p>	<p>At year end—renal transplant facility profile</p>	<p>Counts of patients waiting for transplants at each of the transplant programs; reported on a quarterly basis by the OPOs.</p>

Table D4 outlines the data supply chain for CORR.

Table D4 CORR Data Supply Chain

Province of Treatment	Dialysis Recipients	Organ Transplant Recipients	Deceased Organ Donors	Living Organ Donors	Waiting List Statistics
Alberta	Southern Alberta Renal Program (Calgary) and Northern Alberta Renal Program (Edmonton)	Hospital transplant programs	HOPE Calgary, HOPE Edmonton	Hospital transplant programs	HOPE Calgary, HOPE Edmonton
British Columbia	BC Renal Agency, Hospital Dialysis Programs	BC Transplant Society	BC Transplant Society	BC Transplant Society	BC Transplant Society
Manitoba	Hospital dialysis programs	Hospital transplant program	Manitoba OPO	Hospital transplant program	Manitoba OPO
New Brunswick	Hospital dialysis programs		Multiple Organ Retrieval and Exchange Program		
Newfoundland and Labrador	Hospital dialysis programs		O.P.E.N. Program		
Northwest Territories	Hospital dialysis program				
Nova Scotia	Hospital dialysis programs	Multi-Organ Transplant Program	Multi-Organ Transplant Program	Multi-Organ Transplant Program	Multi-Organ Transplant Program
Ontario	Hospital dialysis programs, Toronto Region Dialysis Registry	Trillium Gift of Life Network	Trillium Gift of Life Network	Trillium Gift of Life Network	Trillium Gift of Life Network
Quebec	Hospital dialysis programs	Hospital transplant programs	Québec-Transplant	Hospital transplant programs	Québec-Transplant
Saskatchewan	Hospital dialysis programs	Saskatchewan Transplant Program	Saskatchewan Transplant Program	Saskatchewan Transplant Program	Saskatchewan Transplant 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 reveals 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 in order to:

- reduce entry of duplicate records (for example, matching algorithm used to reduce double entry of patient records)
- improve consistency of data (for example, logic checks to ensure entry of treatments in a chronological sequence)
- 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 juxtaposition of day and month during data entry)
- improve data completeness (for example, mandatory data elements cannot be bypassed; some data elements are auto populated; conditionally mandatory data elements are triggered on/off based on responses to other data elements).

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

Imputation: No imputed data are stored in CORR.

Quality Evaluation: CIHI's *Data Quality Framework*, which was implemented in 2000–2001, is based on a similar framework used at Statistics Canada and 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 allows one to make intelligent use of the data
- *Relevance:* incorporates all of the above dimensions to some degree, but focuses specifically on value and adaptability

The framework implementation is part of the larger quality cycle in which problems are identified, addressed, documented and reviewed on a regular basis. Each CIHI data holding is evaluated for each annual release of data.

Data Accuracy

Coverage: There are no known coverage errors within CORR. The program is aware of all hospitals that should report. Hospitals not included in the frame do not report to CORR. 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.

Duplicate patient records have been 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 have 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 onsite 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) Prevalent ESRD Cases

Prevalent ESRD cases were incompletely reported for the period from 1993 to 2002. Hemodialysis facility profiles, from which the count of prevalent hemodialysis patients is obtained, were not provided by Montréal General Hospital (Que.) for year 2000; Hôpital Charles-LeMoyne (Que.) for year 2000; Hôpital du Haut-Richelieu (Que.) for year 2001; and Royal Inland Hospital (B.C.) for year 2002. Peritoneal dialysis facility profiles, from which the count of prevalent peritoneal dialysis patients is obtained, were not provided by Montréal General Hospital (Que.) for year 2000 and 2001; Hôpital Charles-LeMoyne (Que.) for year 2000; Hôpital du Haut-Richelieu (Que.) for year 2001; and Royal Inland Hospital (B.C.) for year 2002. In addition, there was suspected underreporting on the peritoneal dialysis facility profiles for Wellesley Hospital (Ont.) for year 1996; St. Joseph's Health Care System (Hamilton, Ont.) for years 2000 and 2001; and Hôpital Fleurimont (Que.) for years 1995 and 1996. Renal facility profiles, from which the count of functioning kidney transplants were obtained, were not provided by the Health Science Centre, Health Care Corporation of St. John's (N.L.) for year 2002. For year 2001, The Ottawa Hospital (Ont.) underreported by an estimated 148 functioning kidney transplants. Data were adjusted for the unit non-response and under-reporting presented in Section 2.3 of this report.

(2) Incident ESRD Cases

In terms of unit non-response for incident ESRD cases, underreporting of incident ESRD cases is estimated to be 69 cases from Quebec in 2001, 115 cases from Quebec in 2002 and 15 cases from Nova Scotia in 2002. Chronic underreporting of incident cases is more difficult to ascertain.

(3) Kidney Transplants

Since the 1990s, patient-level data submitted by hospitals and OPOs are reconciled with aggregate-level counts received from OPOs, which are received in advance of patient-level data submissions. In addition, the *Renal Transplant Facility Profile* also provides another check of the kidney transplant data. Table D5 presents a comparison of these sources, and the respective transplant counts per province for the period from 1994 to 2003, and shows that the patient-level data are higher than the OPO aggregate counts, but lower than the counts provided on the *Renal Transplant Facility Profile*. This may suggest some underreporting of kidney transplants within CORR.

Table D5 Comparison of Counts of Kidney Transplants* by Data Source, 1994 to 2003 (Number)

	Alta.	B.C.	Man.	N.S.	Ont.	Que.	Sask.	Total
Patient-Level Data Within CORR	1,319	1,315	381	1,012	3,750	2,258	360	10,395
Aggregate Counts Provided in <i>Renal Transplant Facility Profile</i>	1,427	1,374	379	1,031	3,909	2,305	361	10,786
Aggregate Counts Provided by OPOs at Year-End	1,306	1,306	364	1,006	3,713	2,235	360	10,290

* Includes SKP and other kidney combination transplants.

(4) Extra-Renal Transplants

For the extra-renal transplants for the period from 1994 to 2003, the transplants registered in the database were compared against the aggregate counts reported by the OPOs. The results are provided in Table D6, and suggest that there may be some underreporting of liver and lung transplants, particularly in Ontario and Alberta.

Table D6 Comparison of Counts of Extra-Renal Transplants* by Data Source, 1994 to 2003 (Number)

Organ Type	Data Source**	Alta.	B.C.	Man.	N.S.	Ont.	Que.	Total
Liver	CORR registration	558	317	na	167	1,653	963	3,658
	OPO count	569	319	na	166	1,660	960	3,674
Heart	CORR registration	298	156	na	97	681	425	1,657
	OPO count	306	153	na	98	680	413	1,650
Heart-Lung	CORR registration	10	6	na	na	20	17	53
	OPO count	10	6	na	na	18	18	52
Lung	CORR registration	179	78	81	na	416	194	948
	OPO count	182	82	83	na	424	195	966
SKP	CORR registration	66	63	na	33	123	39	324
	OPO count	61	63	na	35	118	37	314
PTA/PAK	CORR registration	11	2	na	7	9	93	122
	OPO count	16	3	na	9	11	85	124
Intestine/Multivisceral	CORR registration	3	na	na	na	23	na	26
	OPO count	1	na	na	na	20	na	21

* 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; na = not applicable

(5) Donors

A comparison of donors registered in CORR contrasted with donor numbers reported by OPOs at year-end is provided in Table D7. This suggests some minor underreporting of donors (n = 10) within CORR from 1994 to 2003.

Table D7 Comparison of Deceased and Living Donors Registered in CORR and Reported by OPOs, 1994 to 2003 (Number)

Year	Registered in CORR			Reported by OPOs		
	Deceased Donors	Living Donors	Total Donors	Deceased Donors	Living Donors	Total Donors
1994	400	215	615	407	210	617
1995	423	230	653	437	230	667
1996	418	269	687	420	265	685
1997	426	288	714	429	283	712
1998	415	369	784	415	368	783
1999	420	393	813	421	392	813
2000	472	409	881	471	409	880
2001	416	448	864	420	447	867
2002	407	441	848	405	440	845
2003	421	438	859	428	431	859
Total	4,218	3,500	7,718	4,253	3,475	7,728

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.

Table D8 presents a summary of the proportion of records with null and unknown values on key mandatory data elements within CORR for transplant recipients of first grafts for the period from 1994 to 2003, and for donors for the same period. Rates of non-response/ unknowns greater than 10% are shaded.

Table D8 Non-Response/Unknown Values for Key Analytical Data Elements Related to Donors and Transplant Recipients* in CORR, 1994 to 2003

Data Type	Data Element	% Non-Response/Unknowns									
		1994	1995	1996	1997	1998	1999	2000	2001	2002	2003
Deceased Donor	Age	2%	0.5%	0%	0.5%	0.2%	0.2%	0%	0%	0%	0.2%
	Sex	0%	0%	0%	0%	0%	0.5%	0%	0%	0.3%	0.2%
	Blood type	5%	1%	1%	0%	0%	0.2%	0%	0%	0%	0%
	Race/ethnic origin	14%	7%	11%	14%	6%	12%	20%	24%	3%	22%
	Province of residence (not formally collected until 2001)	87%	61%	79%	81%	89%	84%	87%	0%	0%	0%
	Cause of death	2%	2%	3%	3%	0.5%	0.7%	1%	4%	2%	2%
Living Donor	Age	1%	44%	49%	28%	9%	26%	2%	0%	0%	0%
	Sex	0%	1%	2%	49%	5%	21%	0.5%	0.7%	0.2%	0.0%
	Blood type	2%	4%	3%	2%	7%	26%	0.7%	0.5%	7%	7%
	Province of residence (not formally collected until 2001)	100%	100%	99%	99%	99%	99%	99%	0%	0.2%	0.2%

Table D8 Non-Response/Unknown Values for Key Analytical Data Elements Related to Donors and Transplant Recipients* in CORR, 1994 to 2003 (cont'd)

Data Type	Data Element	% Non-Response/Unknowns									
		1994	1995	1996	1997	1998	1999	2000	2001	2002	2003
Transplant Recipients	Sex	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
	Race/ethnic origin	17%	15%	14%	14%	12%	13%	14%	19%	16%	20%
	Blood type	7%	10%	13%	8%	2%	3%	1%	3%	2%	3%
	Residential postal code	6%	6%	6%	3%	3%	3%	2%	1%	1%	3%
	Diagnosis	5%	5%	8%	7%	6%	6%	5%	7%	9%	9%
	Cause of death (deceased recipients only)	17%	24%	23%	23%	17%	20%	21%	14%	17%	18%
	Medical status at listing (heart, liver, lung transplants)	52%	14%	10%	13%	7%	9%	3%	6%	1%	2%
	Medical status at transplant (heart, liver, lung transplants)	6%	3%	5%	5%	3%	7%	0.2%	2%	0.6%	0.3%
	Cause of graft failure (transplants with failed grafts)	24%	28%	32%	31%	22%	27%	30%	36%	31%	13%

* Recipients of first grafts for the period from 1994 to 2003.

Table D9 presents a summary of the proportion of records with null and unknown values on key mandatory data elements within CORR for incident dialysis patients for each year in the period from 1993 to 2002. Table D10 presents the same information stratified by province of treatment. Rates of non-response/unknowns greater than 10% are shaded.

Table D9 Non-Response/Unknown Values for Key Analytical Data Elements Related Incident Dialysis Patients Registered in CORR by Year, 1993 to 2002

Data Type	Data Element	% Non-Response/Unknowns									
		1993	1994	1995	1996	1997	1998	1999	2000	2001	2002
Recipient	Sex	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
	Race/ethnic origin	6%	8%	9%	9%	13%	13%	14%	15%	7%	7%
	Residential postal code	5%	7%	3%	1%	0.9%	2%	3%	2%	1%	0.4%
	Diagnosis	12%	12%	13%	14%	16%	13%	13%	12%	14%	15%
	Cause of death (deceased recipients only)	17%	18%	18%	21%	22%	19%	21%	23%	22%	23%
Risk Factors at Start of Dialysis	Angina	10%	7%	10%	8%	13%	7%	6%	8%	8%	7%
	Coronary artery bypass/angioplasty	34%	35%	35%	31%	14%	8%	6%	8%	8%	8%
	Pulmonary edema	10%	7%	10%	8%	13%	8%	7%	8%	8%	7%
	Myocardial infarct	10%	7%	10%	8%	13%	8%	6%	8%	7%	7%
	Diabetes	9%	7%	9%	6%	12%	7%	5%	7%	7%	5%
	Cerebrovascular accident	10%	7%	10%	8%	13%	8%	7%	8%	7%	7%
	Peripheral vascular disease	10%	7%	10%	8%	13%	8%	6%	8%	8%	8%
	Malignancy	10%	7%	10%	8%	13%	8%	7%	8%	10%	9%
	Chronic lung disease	10%	7%	11%	8%	13%	8%	7%	8%	8%	8%
	Use of medications for hypertension	9%	6%	9%	6%	11%	7%	6%	8%	5%	5%
	Presence of other serious illness	13%	11%	16%	11%	18%	11%	10%	11%	17%	18%
	Current smoker	12%	10%	14%	12%	17%	11%	8%	10%	13%	14%

Table D10 Non-Response/Unknown Values for Key Analytical Data Elements Related Incident Dialysis Patients Registered in CORR by Province of Treatment, 1993 to 2002

Data Type	Data Element	% Non-Response/Unknowns									
		Alta.	B.C.	Man.	N.B.	N.L.	N.S.	Ont.	Que.	Sask.	Total
Recipient	Sex	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
	Race/ethnic origin	12%	19%	3%	5%	5%	26%	11%	5%	3%	10%
	Residential postal code	1%	4%	12%	0.9%	2%	3%	1%	0.9%	2%	2%
	Diagnosis	18%	26%	14%	7%	17%	8%	11%	12%	9%	14%
	Cause of death (deceased recipients only)	22%	42%	23%	7%	17%	15%	17%	19%	12%	20%
Risk Factors at Start of Dialysis	Angina	7%	22%	14%	3%	3%	7%	7%	4%	3%	8%
	Coronary artery bypass/angioplasty	16%	29%	17%	15%	14%	15%	16%	13%	9%	17%
	Pulmonary edema	7%	23%	13%	4%	5%	7%	7%	4%	3%	8%
	Myocardial infarct	7%	23%	14%	3%	4%	7%	7%	5%	2%	8%
	Diabetes	5%	21%	13%	4%	4%	6%	6%	3%	2%	7%
	Cerebrovascular accident	6%	23%	13%	3%	4%	7%	7%	4%	3%	8%
	Peripheral vascular disease	6%	23%	14%	3%	5%	7%	7%	4%	3%	8%
	Malignancy	7%	24%	16%	4%	4%	7%	8%	5%	4%	9%
	Chronic lung disease	7%	24%	14%	3%	4%	7%	8%	4%	3%	9%
	Use of medications for hypertension	4%	20%	13%	2%	4%	7%	6%	4%	3%	7%
	Presence of other serious illness	11%	33%	17%	9%	8%	10%	12%	10%	5%	14%
	Current smoker	13%	27%	15%	10%	6%	9%	9%	11%	5%	12%

Reliability/Response Bias: No formal reliability or linkage studies with other external data sources have been undertaken to assess bias or data reliability. Based on record linkage of transplant records in HMDB, preliminary estimates of overall error (expressed as a percentage of total non-agreement) appear to be in the 5 to 10% range. This linkage was based on data from 1995 to 2000 for provinces other than Quebec and applied to a few core variables including birth date, sex and health card number.

A complete investigation of the extent and impact of reporting bias has not yet been undertaken, and users are warned that while CORR may contain the most comprehensive national data on treatment for end-stage organ failure at the present time, completeness and accuracy of data are significant issues. Bias is suspected for a number of variables, including death status, cause of death, comorbidities and treatment status. Timely updating of patients' status has not been done in a number of centres, most notably from centres in British Columbia and southern Alberta. Patient and graft survival rates for transplant recipients in Canada continue to be higher than rates reported in other countries, also likely due to underreporting 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 death was 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:

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

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

Appendix E

Glossary and Commonly Used Acronyms

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

- *Type 1:* Occurs when the pancreas no longer produces any or 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.

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

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

End-stage renal disease (ESRD): A condition in which the kidneys are permanently impaired and can no longer function normally to maintain life.

Graft survival: Graft survival refers to whether an organ is still functioning at a certain time after transplantation. The four time points used in this report are three months, one year, three years and five years.

Commonly Used Acronyms

APD: automated peritoneal dialysis
 CAPD: continuous ambulatory peritoneal dialysis
 COPD: chronic obstructive pulmonary disease
 CORR: Canadian Organ Replacement Register
 CSN: Canadian Society of Nephrology
 CST: Canadian Society of Transplantation
 ESRD: end-stage renal disease
 HD: hemodialysis
 ICU: intensive care unit
 OPO: organ procurement organization
 PAK: pancreas after kidney transplantation
 PD: peritoneal dialysis
 PMP: per million population
 PTA: pancreas transplant alone (isolated pancreas transplantation)
 RRT: renal replacement therapy
 SD: standard deviation
 SKP: simultaneous kidney-pancreas transplantation

Median waiting time: This statistic reports the middle waiting time value for recipients of an extra-renal transplant. It means that half the recipients waited less than this value, and the remaining half waiting 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 are used.

Medical urgency status codes: Liver, heart and lung patients are assigned a status code at the time of their listing for a transplant. This status code corresponds to their medical condition and how urgently they require transplantation. The status codes are updated regularly until a patient is transplanted. CORR collects the initial listing status and the status at the time of transplant.

New patient: A patient with end-stage renal disease who began renal replacement therapy for the first time (either dialysis or renal transplantation) in the calendar year. Also known as an incident patient (see Section 2.1).

Organ donor: A person from whom one or more organ is donated and 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 neuroimaging evidence. Within CORR, deceased donors are defined as those donors who originated in Canada and who have had at least one solid organ used for transplantation. Solid organs that can be donated after death include the heart, liver, kidneys, pancreata, lungs, intestine and stomach.
- *Living donor:* A donor with a biological (related) and/or emotional relationship (unrelated) to the transplant recipient. Living donors most commonly donate one of their kidneys. A lobe of the liver, a lobe of the lung, a segment of the pancreata or the intestine may also be donated by a living donor. At the time of this report, living pancreas and intestine transplants had not been performed in Canada.

Organ procurement organization (OPO): 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 transplantation: Surgical procedure that involves transplantation of organs or parts of organs recovered from deceased or living donors to recipients with end-stage organ failure. Organs that can be transplanted include the heart, liver, kidneys, pancreas, lungs, intestine, and stomach. The single-organ kidney transplant is the most commonly performed transplant procedure. In rare cases, two or more organs may be transplanted. Organs used in these transplants may be from one or more donors.

- *Combination organ transplantation:* Surgical procedure that involves transplantation of organs or parts of organs to recipients who have more than one organ with end-stage organ failure. The most frequent examples of combination transplants in Canada are kidney-liver and kidney-heart transplants where patients have end-stage renal failure along with liver or heart failure. Organs used in these transplants are usually from the same donor.

- *Islet cell transplantation:* A medical procedure that involves replacing the insulin-producing cells of the pancreas (islet cells), which are destroyed in people with Type 1 diabetes. In Canada, islet cells are retrieved from the pancreas of deceased organ donors, although they may be preserved for a period of time prior to being used for transplantation. Islet cell transplants are currently not captured within CORR.
- *Kidney transplantation:* A procedure where one or two kidneys from a deceased organ donor or one kidney from a living organ donor are surgically recovered and implanted in a person with end-stage renal disease. Not all persons with end-stage renal disease are candidates for kidney transplantation. Most people with end-stage renal disease receive dialysis prior to a kidney transplant.
- *Multivisceral 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 transplantation:* An organ transplant that includes a kidney, where the patient has not been treated with dialysis prior to the transplant.

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.

Patient survival: Patient survival refers to whether a transplant recipient is still alive at a certain time after transplantation. The four time points used in this report are three months, one year, three years and five years.

Prevalent patient: A patient who is alive and receiving renal replacement therapy for end-stage renal disease on December 31 of a given year, regardless of date of initiation of treatment. Counts of prevalent patients are obtained from treatment hospitals and facilities at the year-end *Hemodialysis Facility Profile* and *Peritoneal Facility Profile* (see Section 2.3).

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

Renal replacement therapy (RRT): 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 birth date 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 birth date is not part of the donor data set. For the purposes of this report, donor age is converted to a year-based whole number.

Cause of Death

In Table 2.1.3, the following CORR codes are used for the cause of death categories: cardiac—codes 11, 12, 13, 14, 15, 16, 17, 18; social—codes 50, 51, 52, 53, 54 (includes patients who withdrew from dialysis, but for whom no cause of death or date of death was specified); infections—codes 03, 04, 05, 06, 07, 08, 09, 10, 31, 32, 33, 34, 35, 36, 37, 38, 39, 77; vascular—codes 21, 22, 24, 25, 26, 27, 28, 30, 55, 56, 57; gastrointestinal—codes 02, 20, 23, 29, 62, 68, 70, 72; malignancy—codes 66, 67; accidental—codes 81, 82; other—codes 19, 40, 41, 42, 43, 44, 45, 46, 49, 59, 61, 63, 64, 69, 71, 73, 74, 75, 76, 90, 99; unknown—codes 00, 47, 48. This categorization varies slightly from previously reported data.

Deceased Organ Donors

Deceased organ donors, as described in Section 8, are defined as donors identified in Canadian hospitals where at least one organ was recovered and used for transplantation. A donor is different from a donated organ. Donors described under the organ-specific transplant sections of the report, however, include U.S. donors.

Graft Survival

The SAS[®] PROC LIFETEST method (also known as actuarial survival) is used in the calculation of unadjusted (crude) graft survival rates. The graft survival rates are computed for first organ-specific grafts for patients who are transplanted in each year from 1993 to 2002 at four intervals: three months, one year, three years and five years. Patients are followed until graft failure, death (with or without a functioning graft), or the end of observation (December 31, 2003). Five-year graft survival is reported for patients transplanted in years 1994 to 1998; three-year survival for patients transplanted in years 1994 to 2000. For all years, three-month and one-year survival rates are presented.

Incident ESRD RRT Patients

Counts and rates are based on patients registered during a given calendar year (January 1 to December 31). An incident patient must start RRT for ESRD in a Canadian facility. Patients who began RRT for ESRD outside of Canada, but are subsequently treated in Canada, are included in registered and prevalent, but not incident counts.

International Comparisons

Figure 2.1.1 is based on selected countries as reported by the U.S. Renal Data System. Figures 2.4.2 (kidney transplant), 3.1 (liver transplant) and 4.1 (heart transplant) compare crude transplant rates for Canada with those for France and the U.S. These two countries are used because of the fact that data from these countries were readily available for the entire reporting period used in this report, because of Canada's geographic proximity to the U.S. and its parallel development in terms of transplantation advances, and because of the close cultural ties of Quebec to France. Figures 5.1 (lung transplant) and 6.1 (pancreas transplants) compared Canada transplant rates to the U.S. only.

Organ Recovery Rates

Organ recovery rates described in Sections 3 to 7 are based on organs recovered and transplanted from deceased donors identified in Canadian hospitals.

Patient Survival

The SAS[®] PROC LIFETEST method (also known as actuarial survival) is used in the calculation of unadjusted (crude) patient survival rates. For Figures 2.1.4 and 2.1.5, patient survival is computed for RRT recipients who started dialysis between the years 1993 and 1997 at four intervals: three months; one year; three years and five years. Patients are followed to their first kidney transplant, lost to follow-up, recovered function, death or the end of observation (December 31, 2002).

For transplant patient survival analyses, patients receiving first grafts between 1993 and 2002 are followed for the same four time periods until their death, lost to follow-up or the end of the observation (December 31, 2003). In addition, patient survival rates for specific patient cohorts receiving liver, heart, lung or pancreas transplants during the period from 1994 to 1998 are also provided. The latter method was used so that each patient in the cohort would have a minimum five-year follow-up period. Titles of the figures/tables identify the cohort used in the analysis.

Population Estimates Used in Rate Calculations

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

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

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

All Canadian population estimates are from the Statistics Canada report, *Annual Demographic Statistics 2003* (cat. no. 91-213-XIB), and are based on total population figures for July 1.

Population estimates for the U.S. and France are total mid-year population estimates from the U.S. Census Bureau, International Data Base, at www.census.gov/ipc/www/idbnew.html.

Country	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003
Canada	28,999,006	29,302,091	29,610,757	29,907,172	30,157,082	30,403,878	30,689,035	31,021,251	31,361,611	31,629,677
U.S.	263,435,673	266,557,091	269,667,391	272,911,760	276,115,288	279,294,713	282,338,631	285,023,886	287,675,526	290,342,554
France	57,906,847	58,149,727	58,388,408	58,623,428	58,866,290	59,116,128	59,381,628	59,658,144	59,925,035	60,180,529

Province	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003
Alta.*	2,730,852	2,765,680	2,800,927	2,842,579	2,897,575	2,966,642	3,020,731	3,072,938	3,125,682	3,184,564	3,224,979
B.C.**	3,597,763	3,705,394	3,807,449	3,905,659	3,980,335	4,014,219	4,042,119	4,069,619	4,108,576	4,145,104	4,177,640
Man.	1,117,621	1,123,229	1,129,146	1,134,188	1,136,137	1,137,515	1,142,491	1,147,373	1,151,285	1,155,492	1,162,776
Atlantic Provinces***	2,384,922	2,385,047	2,381,021	2,379,283	2,372,144	2,358,209	2,354,163	2,348,928	2,340,937	2,340,843	2,343,970
Ont.	10,688,391	10,818,251	10,949,976	11,083,052	11,228,284	11,367,018	11,506,359	11,685,380	11,897,647	12,096,627	12,238,300
Que.	7,155,273	7,191,884	7,219,446	7,246,896	7,274,630	7,295,973	7,323,308	7,357,029	7,396,990	7,443,491	7,487,169
Sask.	1,006,854	1,009,521	1,014,126	1,019,100	1,018,067	1,017,506	1,014,707	1,007,767	1,000,134	995,490	994,843

* Includes Northwest Territories and Nunavut.

** Includes the Yukon.

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

Atlantic Provinces	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003
N.B.	748,812	750,203	750,979	752,312	752,543	750,551	750,611	750,518	749,890	750,183	750,594
N.L.	579,939	574,469	567,442	559,807	551,011	539,932	533,409	528,043	521,986	519,270	519,570
N.S.	924,029	926,959	928,193	931,413	932,481	931,907	933,847	933,881	932,389	934,392	936,025
P.E.I.	132,142	133,416	134,407	135,751	136,109	135,819	136,296	136,486	136,672	136,998	137,781
Total—Atlantic Provinces	2,384,922	2,385,047	2,381,021	2,379,283	2,372,144	2,358,209	2,354,163	2,348,928	2,340,937	2,340,843	2,343,970

For Table 2.5.5, the following child population (< 18 years) estimates were used.

Province	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003
Alta.*	763,460	766,725	770,292	776,805	785,075	787,012	788,193	787,870	789,420	785,414
B.C.**	879,089	897,046	912,324	922,209	920,129	914,437	907,328	900,396	889,176	876,470
Man.	292,654	293,954	294,295	293,056	291,355	290,694	289,809	288,338	286,374	284,931
N.B.	182,059	179,589	177,305	174,592	171,255	168,464	165,611	162,339	159,210	156,197
N.L.	147,756	142,602	137,203	131,533	125,831	121,353	117,367	112,995	109,188	106,258
N.S. and P.E.I.	257,621	256,210	255,385	252,244	248,322	245,024	241,738	237,535	233,152	228,860
Ont.	2,621,643	2,652,689	2,687,527	2,709,476	2,731,584	2,744,445	2,766,649	2,793,673	2,805,072	2,793,643
Que.	1,697,831	1,690,171	1,683,129	1,664,663	1,642,069	1,616,863	1,596,734	1,580,565	1,566,619	1,551,727
Sask.	282,699	281,640	280,587	277,114	273,975	269,649	264,349	258,241	253,096	249,097
Total	7,124,812	7,160,626	7,198,047	7,201,692	7,189,595	7,157,941	7,137,778	7,121,952	7,091,307	7,032,597

* Includes Northwest Territories and Nunavut.

** Includes the Yukon.

Prevalent Patients

Prevalent patient numbers (Section 2.3) are based on the year-end *Facility Profiles* 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 yielding from the *Facility Profiles* and patient-level data within CORR have become nearly identical for 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* continue to provide the most comprehensive picture of the burden of ESRD on the health care system.

Primary Diagnosis

For extra-renal transplant recipients, primary diagnosis is based on the diagnosis made at the time of the patient's first transplant. In some cases, most usually for liver transplant recipients, more than one diagnosis may be recorded. For kidney transplant recipients, primary diagnosis is based on the diagnosis provided at the time of incident dialysis treatment, as well as diagnosis at the time of kidney transplant for non-pre-emptive kidney transplants.

Registered Patients

Registered patients are patients for whom CORR has patient-level information, and 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. The number of registered patients in CORR may vary from prevalent counts provided in the annual *Facility Profiles* for the following reasons: (1) not all patients will be registered in CORR because they may have started treatment prior to January 1, 1981; (2) incident patients have been underreported by some reporting centres; and (3) deaths are suspected to be underreported 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. By way of example, if a patient has a combination liver-kidney transplant, and has no previous transplant history, she would be included as a first graft recipient for both liver (Section 3) and kidney (Section 2). Tables and figures presented in Sections 3 to 7 inclusive refer either to transplant procedures or recipients, with the latter counting a patient only one time for their first organ-specific graft. Recipient characteristics and provincial-specific rates are based on transplant recipients.

Waiting List

Data reported on patients waiting for transplants come from counts provided by provincial and regional OPOs. Patient-level data are not available. For patients waiting for a kidney transplant, the definition of a pediatric patient was changed in 2002 from under the age of 15 to under the age of 18. This definition is now in line with the definition of pediatric patient used for extra-renal transplants.

Waiting Times

Waiting list times are calculated for patients who received extra-renal transplants, and do not include patients who died while waiting, or those patients withdrawn 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.

