

Canadian Organ Replacement Register

Methodology Notes and Supplementary Information

2011 to 2020



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

Unless otherwise indicated, this product uses data provided by Canada's provinces and territories.

All rights reserved.

The contents of this publication may be reproduced unaltered, in whole or in part and by any means, solely for non-commercial purposes, provided that the Canadian Institute for Health Information is properly and fully acknowledged as the copyright owner. Any reproduction or use of this publication or its contents for any commercial purpose requires the prior written authorization of the Canadian Institute for Health Information. Reproduction or use that suggests endorsement by, or affiliation with, the Canadian Institute for Health Information is prohibited. For permission or information, please contact CIHI:

Canadian Institute for Health Information

495 Richmond Road, Suite 600 Ottawa, Ontario K2A 4H6 Phone: 613-241-7860 Fax: 613-241-8120 <u>cihi.ca</u> <u>copyright@cihi.ca</u>

ISBN 978-1-77479-080-9 (PDF)

© 2021 Canadian Institute for Health Information

How to cite this document:

Canadian Institute for Health Information. *Canadian Organ Replacement Register* — *Methodology Notes and Supplementary Information, 2011 to 2020.* Ottawa, ON: CIHI; 2021.

Cette publication est aussi disponible en français sous le titre *Registre canadien des insuffisances et des transplantations d'organes* — *notes méthodologiques et information supplémentaire, 2011 à 2020.* ISBN 978-1-77479-081-6 (PDF)

Table of contents

Section 1: Canadian Organ Replacement Register board of directors	4
Section 2: Canadian transplant hospitals, renal programs and independent centres	5
Section 3: Canadian organ donation organizations	9
Section 4: Acronyms and glossary	1
Section 5: Analytical methods	6
Section 6: Primary diagnoses captured by CORR	9

Section 1: Canadian Organ Replacement Register board of directors

CORR board of directorsⁱ

- Dr. Jagbir Gill, University of British Columbia and Providence Health Care CORR Board President
- Dr. Karthik K. Tennankore, Dalhousie University and Nova Scotia Health Authority CORR Board Vice President
- Dr. Scott Klarenbach, University of Alberta and University of Alberta Hospital CORR Board Past President
- Ms. Catherine Butler, Canadian Blood Services
- Dr. Allison Dart, University of Manitoba and Health Sciences Centre Winnipeg
- Dr. Daniel H. Kim, University of Alberta and University of Alberta Hospital
- Dr. Joseph Kim, University of Toronto and University Health Network Toronto General Hospital
- Ms. Lydia Lauder, Kidney Foundation of Canada
- Dr. Louise Moist, University of Western Ontario and London Health Sciences Centre Victoria Hospital
- Dr. Annie-Claire Nadeau-Fredette, Université de Montréal and Hôpital Maisonneuve-Rosemont
- Dr. Jeffrey Perl, University of Toronto and St. Michael's Hospital
- Dr. Jean Tchervenkov, McGill University and McGill University Health Centre
- Ms. Alison Thomas, Unity Health Toronto St. Michael's Hospital

i. Reflects membership as of October 15, 2021.

Section 2: Canadian transplant hospitals, renal programs and independent centres*

	Types of transplants performed in 2020								orograms 020
				Lung/ heart–	Intestine/ multi-	Pancreas/ kidney–	Islet		
Hospital/facility	Kidney	Liver	Heart	lung	visceral	pancreas	cell	HD	PD
Northwest Territorie	es								
Hay River Health Authority*	n/a	n/a	n/a	n/a	n/a	n/a	n/a	X	n/a
Stanton Territorial Health Authority*	n/a	n/a	n/a	n/a	n/a	n/a	n/a	X	n/a
British Columbia									
Abbotsford Regional	n/a	n/a	n/a	n/a	n/a	n/a	n/a	X	Х
B.C. Children's	X	n/a	Х	n/a	n/a	n/a	n/a	X	X
Kelowna General	n/a	n/a	n/a	n/a	n/a	n/a	n/a	X	Х
Kootenay- Boundary Regional	n/a	n/a	n/a	n/a	n/a	n/a	n/a	X	X
Nanaimo Regional	n/a	n/a	n/a	n/a	n/a	n/a	n/a	x	х
Penticton Regional	n/a	n/a	n/a	n/a	n/a	n/a	n/a	x	Х
Royal Columbian	n/a	n/a	n/a	n/a	n/a	n/a	n/a	X	Х
Royal Inland	n/a	n/a	n/a	n/a	n/a	n/a	n/a	X	Х
Royal Jubilee	n/a	n/a	n/a	n/a	n/a	n/a	n/a	X	Х
St. Paul's	X	n/a	Х	n/a	n/a	n/a	n/a	X	Х
Surrey Memorial	n/a	n/a	n/a	n/a	n/a	n/a	n/a	X	Х
University of Northern B.C.	n/a	n/a	n/a	n/a	n/a	n/a	n/a	X	Х
Vancouver General	X	X	n/a	Х	n/a	Х	Х	X	Х
Alberta									
Alberta Children's	Х	n/a	n/a	n/a	n/a	n/a	n/a	X	Х
Foothills Medical Centre/AKC-South	Х	n/a	n/a	n/a	n/a	Х	n/a	X	х
University of Alberta/ AKC-North	Х	Х	х	Х	Х	Х	х	X	Х

		Ту	pes of t	ransplants	performed i	n 2020		Dialysis in 2	program 2020
				Lung/ heart–	Intestine/ multi-	Pancreas/ kidney–	Islet		
Hospital/facility	Kidney	Liver	Heart	lung	visceral	pancreas	cell	HD	PD
Saskatchewan	1.								
Regina General	n/a	n/a	n/a	n/a	n/a	n/a	n/a	X	X
St. Paul's	X	n/a	n/a	n/a	n/a	n/a	n/a	X	X
Manitoba	1 .								
Brandon Regional	n/a	n/a	n/a	n/a	n/a	n/a	n/a	X	X
Children's Hospital of Winnipeg	X	n/a	n/a	n/a	n/a	n/a	n/a	X	X
Health Sciences Centre	X	n/a	n/a	n/a	n/a	n/a	n/a	X	n/a
Seven Oaks General	n/a	n/a	n/a	n/a	n/a	n/a	n/a	x	X
St. Boniface General	n/a	n/a	n/a	n/a	n/a	n/a	n/a	x	X
Ontario									
Brockville Dialysis Clinic*	n/a	n/a	n/a	n/a	n/a	n/a	n/a	x	n/a
Children's Hospital of Eastern Ontario	n/a	n/a	n/a	n/a	n/a	n/a	n/a	x	X
Dialysis Management Clinics Inc. — Markham*	n/a	n/a	n/a	n/a	n/a	n/a	n/a	x	n/a
Dialysis Management Clinics Inc. — Peterborough*	n/a	n/a	n/a	n/a	n/a	n/a	n/a	X	n/a
Dialysis Management Clinics Inc. — Pickering*	n/a	n/a	n/a	n/a	n/a	n/a	n/a	X	n/a
Grand River	n/a	n/a	n/a	n/a	n/a	n/a	n/a	X	X
Halton Healthcare Services	n/a	n/a	n/a	n/a	n/a	n/a	n/a	X	X
Health Sciences North	n/a	n/a	n/a	n/a	n/a	n/a	n/a	x	X
Hospital for Sick Children	Х	x	Х	Х	n/a	n/a	n/a	n/a	n/a
Humber River	n/a	n/a	n/a	n/a	n/a	n/a	n/a	Х	Х
Kingston Health Sciences Centre	х	n/a	n/a	n/a	n/a	n/a	n/a	X	X

		Ту	pes of t	ransplants	performed i	n 2020		-	program 2020
Hospital/facility	Kidney	Liver	Heart	Lung/ heart– lung	Intestine/ multi- visceral	Pancreas/ kidney– pancreas	lslet cell	HD	PD
Ontario (continued)	[1		[1	T	[1	1
Lakeridge Health	n/a	n/a	n/a	n/a	n/a	n/a	n/a	X	X
LHSC — University	X	X	Х	n/a	n/a	X	n/a	X	n/a
LHSC — Victoria	n/a	n/a	n/a	n/a	n/a	n/a	n/a	X	X
Mackenzie Richmond Hill	n/a	n/a	n/a	n/a	n/a	n/a	n/a	X	X
McMaster Children's	n/a	n/a	n/a	n/a	n/a	n/a	n/a	x	X
Michael Garron	n/a	n/a	n/a	n/a	n/a	n/a	n/a	х	n/a
Niagara Health System	n/a	n/a	n/a	n/a	n/a	n/a	n/a	х	X
North Bay General	n/a	n/a	n/a	n/a	n/a	n/a	n/a	х	X
Orillia Soldiers' Memorial	n/a	n/a	n/a	n/a	n/a	n/a	n/a	x	X
Ottawa–Carleton Dialysis Clinic*	n/a	n/a	n/a	n/a	n/a	n/a	n/a	x	n/a
Ottawa Hospital	X	n/a	n/a	n/a	n/a	n/a	n/a	X	X
Peterborough Regional Health	n/a	n/a	n/a	n/a	n/a	n/a	n/a	X	X
Renfrew Victoria	n/a	n/a	n/a	n/a	n/a	n/a	n/a	X	X
Sault Area Hospitals — Plummer Memorial	n/a	n/a	n/a	n/a	n/a	n/a	n/a	x	X
Scarborough and Rouge	n/a	n/a	n/a	n/a	n/a	n/a	n/a	x	X
St. Joseph's (Hamilton)	Х	n/a	n/a	n/a	n/a	n/a	n/a	x	x
St. Joseph's (Toronto)	n/a	n/a	n/a	n/a	n/a	n/a	n/a	x	X
St. Michael's	Х	n/a	n/a	n/a	n/a	n/a	n/a	х	X
Sunnybrook Health Centre	n/a	n/a	n/a	n/a	n/a	n/a	n/a	Х	X
Thunder Bay Regional	n/a	n/a	n/a	n/a	n/a	n/a	n/a	x	x
Timmins and District	n/a	n/a	n/a	n/a	n/a	n/a	n/a	Х	X
Toronto General — University Health Network	Х	X	х	Х	X	X	n/a	X	X

		Ту	pes of t	ransplants	performed i	n 2020			programs 2020
Hospital/facility	Kidney	Liver	Heart	Lung/ heart– lung	Intestine/ multi- visceral	Pancreas/ kidney– pancreas	Islet cell	HD	PD
Ontario (continued)									
Trillium Health Partners — Credit Valley	n/a	n/a	n/a	n/a	n/a	n/a	n/a	x	Х
University of Ottawa Heart Institute	n/a	n/a	Х	n/a	n/a	n/a	n/a	n/a	n/a
William Osler	n/a	n/a	n/a	n/a	n/a	n/a	n/a	X	X
Windsor Regional	n/a	n/a	n/a	n/a	n/a	n/a	n/a	X	X
New Brunswick									
Chaleur Regional	n/a	n/a	n/a	n/a	n/a	n/a	n/a	X	X
DrGeorges-L Dumont	n/a	n/a	n/a	n/a	n/a	n/a	n/a	X	x
Edmundston	n/a	n/a	n/a	n/a	n/a	n/a	n/a	X	X
Saint John Regional	n/a	n/a	n/a	n/a	n/a	n/a	n/a	X	X
Nova Scotia									
Cape Breton Regional	n/a	n/a	n/a	n/a	n/a	n/a	n/a	x	×
IWK Grace Health	X	n/a	n/a	n/a	n/a	n/a	n/a	X	X
Queen Elizabeth II	X	X	Х	n/a	n/a	n/a	n/a	X	X
Yarmouth Regional	n/a	n/a	n/a	n/a	n/a	n/a	n/a	X	n/a
Prince Edward Islan	d							-	
P.E.I. Renal Program	n/a	n/a	n/a	n/a	n/a	n/a	n/a	X	×
Newfoundland and	Labrador								
Central Newfoundland Regional	n/a	n/a	n/a	n/a	n/a	n/a	n/a	x	X
Eastern Health and Labrador–Grenfell Health	n/a	n/a	n/a	n/a	n/a	n/a	n/a	X	X
Western Memorial Regional	n/a	n/a	n/a	n/a	n/a	n/a	n/a	X	Х

Notes

* Independent centres provide dialysis to chronic renal failure patients.

HD: Hemodialysis; PD: Peritoneal dialysis.

n/a: Not applicable.

Hospital/facility information from Quebec was excluded from this table because of significant under-reporting between 2011 and 2020.

Section 3: Canadian organ donation organizations

British Columbia

BC Transplant 260-1770 West 7th Avenue Vancouver, BC V6J 4Y6 www.transplant.bc.ca

Alberta

Southern Alberta Organ and Tissue Donation Program — Calgary (SAOTDP) Foothills Medical Centre Site 1403 29th Street North West Calgary, Alberta T2N 2T9 https://www.albertahealthservices.ca/services/page13174.aspx

HOPE Program — Edmonton University of Alberta Hospital Transplant Services Walter C. Mackenzie Centre 8440 112th Street Edmonton, Alberta T6G 2B7 https://www.albertahealthservices.ca/services/page13174.aspx

Saskatchewan

Saskatchewan Transplant Program Provincial Office St. Paul's Hospital 1702 20th Street West Saskatoon, Saskatchewan S7M 0Z9 https://www.saskhealthauthority.ca/your-health/conditions-diseases-services/all-z/ tissue-organ-donation/saskatchewan-transplant

Saskatchewan Transplant Program Regina Office Regina General Hospital 1440 14th Avenue Regina, Saskatchewan S4P 0W5

Manitoba

Transplant Manitoba — Gift of Life Program Health Sciences Centre 820 Sherbrook Street, Room GE441 Winnipeg, Manitoba R3A 1R9 <u>https://www.transplantmanitoba.ca/</u>

Ontario

Trillium Gift of Life Network 483 Bay Street, South Tower, 4th Floor Toronto, Ontario M5G 2C9 www.giftoflife.on.ca

Quebec

Transplant Québec Head Office 4100 Molson Street, Suite 200 Montréal, Quebec H1Y 3N1 www.transplantquebec.ca/en

Transplant Québec Québec Site 1305 du Blizzard Street, Suite 100 Québec, Quebec G2K 0A1

New Brunswick

New Brunswick Organ and Tissue Procurement Program The Moncton Hospital 135 MacBeath Avenue Moncton, New Brunswick E1C 6Z8 www.gnb.ca/0051/0217/organ/index-e.asp

Nova Scotia

Multi-Organ Transplant Program Queen Elizabeth II Health Sciences Centre 1276 South Park Street 6 South, Room 291 Victoria Building Halifax, Nova Scotia B3H 2Y9 www.motpatlantic.ca

Newfoundland and Labrador

Organ Procurement and Exchange of Newfoundland and Labrador (OPEN) Health Sciences Centre 300 Prince Phillip Parkway St. John's, Newfoundland and Labrador A1B 3V6 https://www.easternhealth.ca/find-health-care/organ-donation/

Section 4: Acronyms and glossary

Acronyms

APD: automated peritoneal dialysis

- CAPD: continuous ambulatory peritoneal dialysis
- COPD: chronic obstructive pulmonary disease
- **CORR:** Canadian Organ Replacement Register
- ESKD: end-stage kidney disease
- HD: hemodialysis
- ICU: intensive care unit
- **ODO:** organ donation 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

Glossary

body mass index (BMI): Body mass index is a relationship between weight and height that is associated with body fat and health risk. The equation for BMI is body weight in kilograms divided by the square of height in metres. In the Canadian weight classification system, 4 categories of BMI ranges are defined:

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

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

- **type 1:** Occurs when the pancreas no longer produces any insulin or produces very little insulin. The body needs insulin to use sugar for energy.
- **type 2:** Occurs when the pancreas does not produce enough insulin or when the body does not use insulin that is produced effectively.

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, but when the loss of kidney function is permanent as in end-stage kidney disease, dialysis must be continued on a regular basis. The only other treatment for kidney failure is kidney transplantation. There are 2 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 2 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 kidney disease: A condition in which the kidneys are permanently impaired and can no longer function normally to maintain life.

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

graft survival: A measure of whether an organ is still functioning at a certain time after transplantation.

median wait time: This statistic reports the middle wait time value for recipients of an extra-renal transplant. It means that half the recipients waited less than this value and the remaining half waited more than the value. CORR does not have patient-level data for patients who were listed for a transplant but ultimately did not receive a transplant, and therefore these wait times provide only a partial picture. For kidney transplant patients, this statistic reports the middle wait time between first dialysis and first kidney transplant.

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

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

organ donor: A person who donates 1 or more organs that are used for transplantation. Organ donors may be deceased or living.

- **deceased donor:** A person for whom neurological or cardiac death has been determined, consent has been obtained and organs are offered for transplantation. Within CORR, deceased donors are defined as those donors who originated in Canada and who had at least one solid organ used for transplantation. Solid organs that can be donated after death include the heart, liver, kidneys, pancreas, lungs, intestine and stomach.
 - Neurological determination of death means that there is an irreversible absence of clinical neurological function as determined by definite clinical and/or neuro-imaging evidence.
 - Non-heart beating donor refers to the donation of organs for transplantation from an individual who is declared dead after cardiac arrest; also known as "donation after cardiocirculatory death" (DCD). There are 2 types of DCD:
 - Controlled DCD refers to circumstances where donation may be considered when death is anticipated but has not yet occurred; death may take place in an intensive care unit (ICU) following a consensual decision to withdraw life-sustaining therapy.
 - Uncontrolled DCD may occur when donation is considered after death has occurred but was not anticipated; death may occur in the emergency department, hospital ward, ICU, special care unit or pre-hospital location. The deceased will have had a witnessed cardiocirculatory arrest of known duration, and there should already be an established decision to terminate or not initiate cardiopulmonary resuscitation.

• **living donor:** A donor with a biological (related) or emotional (unrelated) relationship to the transplant recipient. Living donors most commonly donate one of their kidneys. A lobe of the liver, a lobe of the lung or a segment of the pancreas or the intestine may also be donated by a living donor. At the time of this report, living pancreas and intestine transplants have not been performed in Canada.

organ donation organization: An organization responsible for coordinating the recovery and distribution of organs from deceased donors in its province or region. Since not all provinces in Canada perform extra-renal transplants, ODOs from across the country coordinate their activities to ensure that those patients on the extra-renal organ transplant wait-lists who most urgently require a transplant are offered a suitable organ first.

organ transplant wait-list: A list of patients awaiting organ transplantation. Lists are maintained by the ODOs. 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 wait-list who can receive a transplant at any time.
- **on-hold patient:** A patient on the organ transplant wait-list who cannot receive a transplant for medical or other reasons for a short period of time.

organ transplantation: Surgical procedure that involves transplantation of organs or parts of organs recovered from deceased or living donors to recipients with end-stage organ failure. Organs that can be transplanted include the heart, liver, kidneys, pancreas, lungs, intestine and stomach. The single-organ kidney transplant is the most commonly performed transplant procedure. In rare cases, 2 or more organs may be transplanted. Organs used in these transplants may be from 1 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 in end-stage organ failure. The most frequent examples of combination transplants in Canada are kidney–liver and kidney–heart transplants, where patients have end-stage kidney failure along with liver or heart failure. Organs used in these transplants are usually from the same donor.
- islet cell transplantation: A medical procedure that involves replacing the insulin-producing cells of the pancreas (islet cells), which are destroyed in people with type 1 diabetes. In Canada, islet cells are retrieved from the pancreas of deceased organ donors, although they may be preserved for a period of time prior to being used for transplantation. Islet cell transplants are captured within CORR.
- **kidney transplantation:** A procedure during which 1 or 2 kidneys from a deceased organ donor or 1 kidney from a living organ donor are surgically recovered and implanted into a person with end-stage kidney disease. Not all persons with end-stage kidney disease are candidates for kidney transplantation. Most people with end-stage kidney disease receive dialysis prior to a kidney transplant.

- **multi-visceral transplantation:** A rare surgical procedure that involves transplantation of the liver, small intestine, pancreas, stomach and duodenum (also known as a cluster transplant).
- **pre-emptive kidney transplant:** An organ transplant that includes a kidney, where the patient has not been treated with dialysis prior to the transplant.

patient survival: A measure of whether a transplant recipient is still alive at a certain time after transplantation.

pediatric patient: A patient who is age 17 or younger.

prevalent patient: A patient who is alive and receiving renal replacement therapy for end-stage kidney disease on December 31 of a given year, regardless of date of initiation of treatment. Counts of prevalent patients are obtained from treatment hospitals providing patient status change data, and from facilities through the CORR year-end hemodialysis facility profile and peritoneal facility profile.

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

renal replacement therapy: Procedures of hemodialysis, peritoneal dialysis and kidney transplantation, which in part temporarily or permanently replace a person's failed kidneys.

Section 5: Analytical methods

Age calculation

The computation of patient age is based on a count of months between birthdate and treatment date, which is then divided by 12. This calculation yields a number that is rounded to a whole number in years. For donors, age is collected in terms of a code (e.g., *newborn*, *days, months, years*) and unit (e.g., *2*, *12*, *35*), as birthdate is not part of the donor data set. For the purposes of this report, donor age is converted to a year-based whole number.

Incident ESKD renal replacement therapy patients

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

Organ recovery rates

Organ recovery rates (deceased) are based on organs recovered and transplanted from deceased donors identified in Canadian hospitals.

Patient and graft survival

Unadjusted survival probabilities (expressed as percentages from 0 to 100) are calculated using the Kaplan–Meier method. The cohorts are dialysis and transplant patients who started dialysis or received a first graft between 2009 and 2020. For dialysis survival, patients were censored at first kidney transplant, lost to follow-up, left the country or recovered function. For transplant graft survival, patients were censored if they withdrew, were lost to follow-up or left the country.

Population estimates used in rate calculations

Rates presented are either crude or age-specific and are not age-standardized.

Crude rate = (Number of cases ÷ Population) × 1,000,000

Age-specific rate = (Number of cases in age group ÷ Population of age group) × 1,000,000

All Canadian population estimates are from Statistics Canada and are based on total population figures for July 1 of the respective year.

Province	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020
B.C.*	4,537,515	4,603,003	4,666,598	4,744,240	4,814,078	4,897,797	4,969,053	5,051,089	5,132,432	5,189,764
Alta. ⁺	3,866,726	3,952,868	4,060,153	4,163,503	4,225,216	4,277,685	4,323,537	4,381,399	4,445,336	4,506,390
Sask.	1,066,026	1,083,755	1,099,736	1,112,979	1,120,967	1,135,987	1,150,331	1,161,767	1,172,302	1,178,681
Man.	1,233,649	1,249,975	1,264,620	1,279,014	1,292,227	1,314,139	1,334,790	1,352,825	1,369,540	1,379,263
Ont.	13,261,381	13,390,632	13,510,781	13,617,553	13,707,118	13,875,394	14,070,141	14,308,697	14,544,718	14,734,014
Que.	8,005,090	8,061,101	8,110,880	8,150,183	8,175,272	8,225,950	8,302,063	8,401,738	8,501,703	8,574,571
Atlantic [‡]	2,368,941	2,372,888	2,370,186	2,369,963	2,368,030	2,382,535	2,395,380	2,407,663	2,427,353	2,442,555
Canada (excl. Que.)	26,334,238	26,653,121	26,972,074	27,287,252	27,527,636	27,883,537	28,243,232	28,663,440	29,091,681	29,430,667
Canada (incl. Que.)	34,339,328	34,714,222	35,082,954	35,437,435	35,702,908	36,109, 487	36,545, 295	37,065,178	37,593,384	38,005,238

Notes

* Includes Yukon.

† Includes the Northwest Territories and Nunavut.

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

Source

Statistics Canada, Demography Division. Estimates of population (2016 Census and administrative data), by age group and sex for July 1, Canada, provinces, territories, health regions (2020 boundaries).

Atlantic provinces	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020
N.B.	755,705	758,378	758,544	758,976	758,842	763,350	766,621	770,301	776,868	781,476
N.S./P.E.I.	1,088,237	1,088,165	1,084,528	1,082,828	1,081,071	1,089,759	1,100,510	1,111,802	1,127,009	1,138,976
N.L.	524,999	526,345	527,114	528,159	528,117	529,426	528,249	525,560	532,476	522,103
Total	2,368,941	2,372,888	2,370,186	2,369,963	2,368,030	2,382,535	2,395,380	2,407,663	2,436,353	2,442,555

Source

Statistics Canada, Demography Division. Estimates of population (2016 Census and administrative data), by age group and sex for July 1, Canada, provinces, territories, health regions (2020 boundaries).

Prevalent patients

Prevalent patient numbers at year-end are based on the record-level data for patients registered in CORR.

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.

Province of treatment

Patients residing in the territories are required to start, and often continue, their dialysis in the provinces. As a result, statistical analyses of patients are presented by province of treatment, with Yukon being combined with British Columbia, and the Northwest Territories and Nunavut being combined with Alberta.

Registered patients

A patient who commenced treatment (dialysis or transplantation) for the first time in 1981 or thereafter. This patient has been registered in CORR and their progress is monitored each year.

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. The tables and figures refer to either transplant procedures or recipients, with the latter counting patients only 1 time for their first organ-specific graft. Recipient characteristics and province-specific rates are based on transplant recipients.

Wait-list

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

Wait times

Wait times are calculated for patients who received extra-renal transplants and do not include patients who died while waiting or who withdrew from the list because they became too sick to undergo a transplant. There is currently no national source of information on wait times for all patients listed for transplantation.

For patients who received a kidney transplant, a proxy measure of wait time (i.e., time spent on dialysis pre-transplant) is used. While this approach avoids the problem of incomplete data on wait-list start dates for prospective kidney transplant recipients within CORR, it does not factor in the wait 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.

Section 6: Primary diagnoses captured by CORR

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

End-stage kidney disease

Prima	ary diagnosis codes — End-stage kidney disease						
Gene	Generic						
00	Chronic renal failure — etiology uncertain						
Glom	erulonephritis/autoimmune diseases						
05	Mesangial proliferative glomerulonephritis						
06	Minimal lesion glomerulonephritis						
07	Post-strep glomerulonephritis						
08	Rapidly progressive glomerulonephritis						
09	Focal glomerulosclerosis — adults						
10	Glomerulonephritis, histologically not examined						
11	Severe nephrotic syndrome with focal sclerosis (pediatric patients)						
12	IgA nephropathy — proven by immunofluorescence (not code 85)						
13	Dense deposit disease — proven by immunofluorescence and/or electron microscopy (MPGN type II)						
14	Membranous nephropathy						
15	Membranoproliferative mesangiocapillary glomerulonephritis (MPGN type I)						
16	Idiopathic crescentic glomerulonephritis (diffuse proliferative)						
17	Congenital nephrosis or congenital nephrotic syndrome (pediatric only)						
19	Glomerulonephritis, histologically examined — specify						

Prima	ary diagnosis codes — End-stage kidney disease
Glom	erulonephritis/autoimmune diseases (continued)
73	Polyarteritis
74	Wegener's granulomatosis
84	Lupus erythematosus
85	Henoch–Schönlein purpura
86	Goodpasture syndrome
87	Scleroderma
88	Hemolytic uremic syndrome (Moschcowitz syndrome)
Neph	ropathy, drug-induced
30	Nephropathy caused by drugs or nephrotoxic agents, cause not specified
31	Nephropathy due to analgesic drugs
32	Nephropathy due to cisplatin
33	Nephropathy due to cyclosporin A
39	Nephropathy caused by other specific drug — specify
Polyc	ystic kidney
41	Polycystic kidneys, adult type (dominant)
42	Polycystic kidneys, infantile and juvenile types (recessive)
Cong	enital/hereditary renal diseases
21	Pyelonephritis/interstitial nephritis associated with neurogenic bladder
22	Pyelonephritis/interstitial nephritis due to congenital obstructive uropathy with or without vesicoureteric reflux
24	Pyelonephritis/interstitial nephritis due to vesicoureteric reflux without obstruction
40	Cystic kidney disease, type unspecified
41	Polycystic kidneys, adult type (dominant)
42	Polycystic kidneys, infantile and juvenile types (recessive)
43	Medullary cystic disease, including nephronophthisis
49	Cystic kidney disease, other type — specify
50	Hereditary familial nephropathy, type unspecified
51	Hereditary nephritis with nerve deafness (Alport syndrome)
52	Cystinosis
53	Oxalosis
54	Fabry disease
55	DRASH syndrome
58	Posterior urethral valves
59	Hereditary nephropathy, other — specify
60	Congenital renal hypoplasia — specify
61	Oligomeganephronic hypoplasia
62	Segmental renal hypoplasia (Ask–Upmark kidney)
63	Congenital renal dysplasia with or without urinary tract malformation
66	Syndrome of agenesis of abdominal muscles (prune belly syndrome)

Prima	ary diagnosis codes — End-stage kidney disease
Diabe	etes
80	Diabetic nephropathy associated with type 1
81	Diabetic nephropathy associated with type 2
Rena	l vascular disease
70	Renal vascular disease, type unspecified
71	Malignant hypertension (no primary renal disease)
72	Renal vascular disease due to hypertension (no primary renal disease)
73	Polyarteritis nodosa
78	Atheroembolic renal disease
79	Renal vascular disease, classified (nephrosclerosis, renal vascular thrombosis)
Othe	r
20	Pyelonephritis/interstitial nephritis, cause not specified
23	Pyelonephritis/interstitial nephritis due to acquired obstructive uropathy — specify
25	Pyelonephritis/interstitial nephritis due to urolithiasis
29	Pyelonephritis, other causes
56	Sickle cell nephropathy
57	Wilms' tumour
82	Multiple myeloma
83	Amyloid
89	Multi-system disease, other — specify
90	Cortical or acute tubular necrosis
91	Tuberculosis
92	Gout
93	Nephrocalcinosis and hypercalcemic nephropathy
94	Balkan nephropathy
95	Kidney tumour
96	Traumatic or surgical loss of kidney
97	HIV nephropathy
99	Other identified renal disorders — specify

Liver transplant

Prima	ry diagnosis codes — Liver transplant
Acute	hepatic failure (fulminant)
01	Hepatitis, type A
02	Hepatitis, type B
61	Hepatitis, type C
58	Hepatitis, type non-A, -B, -C
35	Hepatitis with delta
05	Toxics
04	Drug-induced, other
56	Drug-induced, acetaminophen
47	Other/fulminant hepatic failure (including Budd–Chiari syndrome and Wilson disease)
Chron	ic hepatic failure
12	Budd–Chiari syndrome
36	Byler disease (intra-hepatic cholestasis)
09	Cirrhosis, alcoholic
10	Cirrhosis, other
08	Cryptogenic cirrhosis
49	Post-necrotic cirrhosis
07	Primary biliary cirrhosis
14	Secondary biliary cirrhosis
45	Drug-induced, other
42	Hepatitis, type A
43	Hepatitis, type B
60	Hepatitis, type C
59	Hepatitis, type non-A, -B, -C
51	Neonatal hepatitis
06	Autoimmune chronic active hepatitis
13	Primary biliary atresia
11	Sclerosing cholangitis
46	Тохіс
15	Watson–Alagille disease (arterio-hepatic dysplasia)
62	Polycystic liver disease
64	Non-alcoholic steatohepatitis (NASH)

Hepaticitumours 50 Angiosarcoma 51 Angiosarcoma 17 Cholangiocarcinoma 18 Fibrolamellar hepatoma 16 Hepatocellular carcinoma 19 Metastatic tumour 53 Hepatic tumour, other Metastatic tumour, other <	Prima	ry diagnosis codes — Liver transplant
17Cholangiocarcinoma18Fibrolamellar hepatoma16Hepatocellular carcinoma19Metastatic tumour53Hepatic tumour, otherMetabolic disorders20Alpha-1-antitrypsin deficiency28Crigler-Najjar syndrome21Glycogen storage disease23Hemochromatosis24Niemann-Pick25Protoporphyria26Phenylketonuria27Hyperlipoproteinemia type 224Niemann-Pick25Protoporphyria29Tyrosinemia21Gliscase34Metabolic disorder, other0ther primary diagnosis30Congenital hepatic fibrosis31Caroli disease32Cystic disorders33Unknown/missing	Hepat	ic tumours
18Fibrolamellar hepatoma16Hepatocellular carcinoma19Metastatic tumour53Hepatic tumour, otherMetastatic tumour, otherOfficiencyAlpha-1-antitrypsin deficiency20Alpha-1-antitrypsin deficiency28Crigler-Najjar syndromeClisper-Najjar syndrome21Glycogen storage disease23Hemochromatosis27Hyperlipoproteinemia type 224Nieman-Pick28Protoporphyria29Tyrosinemia22Wilson disease30Congenital hepatic fibrosis31Caroli disease32Cystic disorders52Thrombosed hepatic artery98Unknown/missing <td>50</td> <td>Angiosarcoma</td>	50	Angiosarcoma
16Hepatocellular carcinoma19Metastatic tumour53Hepatic tumour, otherMetastatic tumour, otherOfficiency20Alpha-1-antitrypsin deficiency28Crigler-Najjar syndrome21Glycogen storage disease23Hemochromatosis27Hyperlipoproteinemia type 224Niemann-Pick26Phenylketonuria29Tyrosinemia22Wilson disease34Metabolic disorder, otherOther primary diagnosis30Congenital hepatic fibrosis31Caroli disease32Cystic disorders52Thrombosed hepatic artery98Uhknown/missing	17	Cholangiocarcinoma
19Metastatic tumour53Hepatic tumour, otherMetastic disorders20Alpha-1-antitrypsin deficiency28Crigler-Najjar syndrome21Glycogen storage disease23Hemochromatosis24Niemann-Pick26Phenylketonuria27Pytoporphyria28Tryrosinemia29Tyrosinemia20Vilson disease34Metabolic disorder, other0ther primary diagnosis30Congenital hepatic fibrosis31Caroli disease32Cystic disorders52Thrombosed hepatic artery98Unknown/missing	18	Fibrolamellar hepatoma
53Hepatic tumour, otherMetabulaMetabula20Alpha-1-antitrypsin deficiency28Crigler-Najjar syndrome21Glycogen storage disease23Hemochromatosis24Hemochromatosis27Hyperlipoproteinemia type 224Niemann-Pick26Phenylketonuria29Tyrosinemia29Tyrosinemia20Vilson disease34Metabolic disorder, other0ther primary diagnosis30Congenital hepatic fibrosis31Caroli disease32Cystic disorders52Thrombosed hepatic artery98Unknown/missing	16	Hepatocellular carcinoma
Metabolic disorders20Alpha-1-antitrypsin deficiency28Crigler–Najjar syndrome21Glycogen storage disease23Hemochromatosis27Hyperlipoproteinemia type 224Niemann–Pick26Phenylketonuria25Protoporphyria29Tyrosinemia22Wilson disease34Metabolic disorder, otherOther primary diagnosis30Congenital hepatic fibrosis31Caroli disease32Cystic disorders33Likonders34Unknown/missing	19	Metastatic tumour
20Alpha-1-antitrypsin deficiency28Crigler-Najjar syndrome21Glycogen storage disease23Hemochromatosis24Hemochromatosis27Hyperlipoproteinemia type 224Niemann-Pick26Phenylketonuria27Protoporphyria29Tyrosinemia20Wilson disease34Metabolic disorder, otherOther primary diagnosis30Congenital hepatic fibrosis31Caroli disease32Cystic disorders33Thrombosed hepatic artery98Unknown/missing	53	Hepatic tumour, other
28Crigler-Najjar syndrome21Glycogen storage disease23Hemochromatosis27Hyperlipoproteinemia type 224Niemann-Pick26Phenylketonuria27Protoporphyria29Tyrosinemia20Wilson disease34Metabolic disorder, other0ther primary diagnosis30Congenital hepatic fibrosis31Caroli disease32Cystic disorders33Thrombosed hepatic artery98Unknown/missing	Metal	polic disorders
21 Glycogen storage disease 23 Hemochromatosis 27 Hyperlipoproteinemia type 2 24 Niemann-Pick 26 Phenylketonuria 25 Protoporphyria 29 Tyrosinemia 22 Wilson disease 34 Metabolic disorder, other Other primary diagnosis 0 30 Congenital hepatic fibrosis 31 Caroli disease 32 Cystic disorders 52 Thrombosed hepatic artery 98 Unknown/missing	20	Alpha-1-antitrypsin deficiency
23Hemochromatosis27Hyperlipoproteinemia type 224Niemann–Pick26Phenylketonuria25Protoporphyria29Tyrosinemia22Wilson disease34Metabolic disorder, otherOther primary diagnosis30Congenital hepatic fibrosis31Caroli disease32Cystic disorders52Thrombosed hepatic artery98Unknown/missing	28	Crigler–Najjar syndrome
27Hyperlipoproteinemia type 224Niemann-Pick26Phenylketonuria25Protoporphyria29Tyrosinemia21Wilson disease34Metabolic disorder, otherOther primary diagnosis30Congenital hepatic fibrosis31Caroli disease32Cystic disorders33Thrombosed hepatic artery98Unknown/missing	21	Glycogen storage disease
24 Niemann-Pick 26 Phenylketonuria 25 Protoporphyria 29 Tyrosinemia 22 Wilson disease 34 Metabolic disorder, other Other primary diagnosis 30 Congenital hepatic fibrosis 31 Caroli disease 32 Cystic disorders 52 Thrombosed hepatic artery 98 Unknown/missing	23	Hemochromatosis
26Phenylketonuria25Protoporphyria29Tyrosinemia22Wilson disease34Metabolic disorder, otherOther primary diagnosis30Congenital hepatic fibrosis31Caroli disease32Cystic disorders52Thrombosed hepatic artery98Unknown/missing	27	Hyperlipoproteinemia type 2
 Protoporphyria Tyrosinemia Wilson disease Metabolic disorder, other Other primary diagnosis Congenital hepatic fibrosis Caroli disease Cystic disorders Thrombosed hepatic artery Uhknown/missing 	24	Niemann-Pick
29 Tyrosinemia 22 Wilson disease 34 Metabolic disorder, other Other primary diagnosis 30 Congenital hepatic fibrosis 31 Caroli disease 32 Cystic disorders 52 Thrombosed hepatic artery 98 Unknown/missing	26	Phenylketonuria
22 Wilson disease 34 Metabolic disorder, other Other primary diagnosis 30 Congenital hepatic fibrosis 31 Caroli disease 32 Cystic disorders 52 Thrombosed hepatic artery 98 Unknown/missing	25	Protoporphyria
34 Metabolic disorder, other Other primary diagnosis 30 Congenital hepatic fibrosis 31 Caroli disease 32 Cystic disorders 52 Thrombosed hepatic artery 98 Unknown/missing	29	Tyrosinemia
Other primary diagnosis 30 Congenital hepatic fibrosis 31 Caroli disease 32 Cystic disorders 52 Thrombosed hepatic artery 98 Unknown/missing	22	Wilson disease
30 Congenital hepatic fibrosis 31 Caroli disease 32 Cystic disorders 52 Thrombosed hepatic artery 98 Unknown/missing	34	Metabolic disorder, other
31 Caroli disease 32 Cystic disorders 52 Thrombosed hepatic artery 98 Unknown/missing	Other	primary diagnosis
32 Cystic disorders 52 Thrombosed hepatic artery 98 Unknown/missing	30	Congenital hepatic fibrosis
52 Thrombosed hepatic artery 98 Unknown/missing	31	Caroli disease
98 Unknown/missing	32	Cystic disorders
	52	Thrombosed hepatic artery
99 Other	98	Unknown/missing
	99	Other

Heart transplant

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

Lung, heart-lung transplant

Primary diagnosis codes — Lung, heart-lung transplant		
08	Eisenmenger syndrome	
11	Idiopathic pulmonary fibrosis	
13	Emphysema	
15	Lung failure due to congenital disease	
17	Primary pulmonary hypertension	
18	Chronic obstructive lung disease	
19	Alpha-1-antitrypsin deficiency	
20	Cystic fibrosis	
22	Bronchiectasis	
26	Sarcoidosis	
27	Asbestosis	
28	Bronchiolitis obliterans	
32	Cardiomyopathy — not specified	
98	Unknown	
99	Other — specify	

Pancreas transplant

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



CIHI Ottawa

495 Richmond Road Suite 600 Ottawa, Ont. K2A 4H6 **613-241-7860**

CIHI Toronto

4110 Yonge Street Suite 300 Toronto, Ont. M2P 2B7

416-481-2002

CIHI Victoria

880 Douglas Street Suite 600 Victoria, B.C. V8W 2B7 **250-220-4100**

CIHI Montréal

1010 Sherbrooke Street West Suite 602 Montréal, Que. H3A 2R7

514-842-2226



