



CORR

Data Quality Documentation for Users

Canadian Organ
Replacement Register

2012 to 2021 Data



Canadian Institute
for Health Information

Institut canadien
d'information sur la santé

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Database description

The Canadian Organ Replacement Register (CORR) at the Canadian Institute for Health Information (CIHI) is the national information system for dialysis, donation and transplantation with a mandate to record and analyze the level of activity and outcomes of vital organ transplantation and dialysis. 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 used to inform health care policy regarding end-stage kidney disease (ESKD), organ donation and transplantation across Canada.

Data sources and methodology

Target population: All chronic renal failure patients who have initiated renal replacement therapy since January 1, 1981, and all patients who have received an extra-renal organ transplant since January 1, 1988. CORR does not contain information on patients who have been determined to have acute, but not end-stage, renal failure; recipients of tissue transplants; patients who were listed for but did not receive a vital organ transplant; and potential organ donors (i.e., deceased donors who met the criteria for donation but whose organs were not used for transplantation).

CORR's frame (i.e., the entities that would be expected to contribute data to CORR, given its mandate) includes all the dialysis programs treating end-stage renal failure patients and all the vital organ donation and transplantation programs in Canada. Data from these programs is received from different sources, either directly (from individual dialysis and transplantation programs) or indirectly (regional/provincial programs) through electronic file (eFile), web form or Excel submission. Tables 1 and 2 below identify the number of dialysis and transplantation programs, respectively, that have participated in data submission to CORR.

Table 1 Dialysis programs in CORR frame by province/territory (number)

Dialysis program	B.C.	Alta.	Sask.	Man.	Ont.	Que	N.B.	N.S.	P.E.I.	N.L.	N.W.T.	Total
Full-care dialysis programs	13	9	3	5	34	26	4	5	2	4	0	105
Affiliated community centres	30	27	11	16	67	36	7	11	2	10	0	217
Independent health care facilities offering hemodialysis	0	0	0	0	6	5	0	0	0	0	2	13
Total	43	36	14	21	107	67	11	16	4	14	2	335

Source

Canadian Organ Replacement Register, 2022, Canadian Institute for Health Information.

Table 2 Transplantation programs in CORR frame by province (number)

Organ type	B.C.	Alta.	Sask.	Man.	Ont.	Que.*	N.S.	Total
Kidney	3	3	1	2	7	7	2	25
Liver	1	1	0	0	3	3	1	9
Heart	2	1	0	0	4	4	1	12
Lung/heart–lung	2	1	0	0	2	1	0	6
Pancreas/ kidney–pancreas	1	2	0	0	2	2	1	8
Intestine/ multi-visceral	0	1	0	0	2	0	0	3
Islets	1	1	0	0	0	0	0	2

Note

* Significant under-reporting in Quebec exists between 2012 and 2021.

Source

Canadian Organ Replacement Register, 2022, Canadian Institute for Health Information.

Frame maintenance procedures are updated on an annual basis. Provincial sources alert CORR to new frame facilities. Facility identifiers in CORR (i.e., a province code from 1 to 9, along with a 4-digit identifier) are assigned to align with the Discharge Abstract Database (DAD) and Hospital Morbidity Database (HMDB). Any facility not in the DAD/HMDB is assigned a number similar in format to what is used in the DAD/HMDB. Unique facility identifiers are assigned to satellite centres and organ donation organizations (ODOs) using a consistent notation system. The CORR Directory captures information on participating dialysis centres, transplant centres and ODOs in Canada; it is published annually on CIHI's [CORR Directory web page](#).

Data sources: CORR is composed of demographic, clinical and outcome-related data. Methods of data submission to CORR include the following:

- eFile: Used for submitting dialysis data in files with batch records that conform to CIHI's technical specifications;
- CORR Web-Entry Data Form: Used for submitting individual records to CORR through a secure, online platform; and
- Excel: Use for limited acceptance of spreadsheet submission, in compliance with CORR submission data standards.

Data providers who use eFile must first obtain the *Dialysis Submission Specifications Manual* from CIHI. An instruction manual for data submission is also available. Within CORR, data elements are classified as mandatory, conditionally mandatory or optional. Mandatory elements must be entered (e.g., Recipient Name, Birthdate, Treatment Code), whereas conditionally mandatory elements must be entered only if other specific conditions are satisfied (e.g., Date of Death must be entered if Cause of Death has been entered). Data providers are encouraged to submit information on all data elements, although it should be noted that for the most part reporting to CORR is not provincially mandated.

Data types: The different levels of data capture, as well as the points of data capture within CORR, are summarized in Table 3. Changes in patients' treatment status (whether dialysis or organ transplant) are tracked and treatment outcomes are recorded. Information on organ donors is also collected.

Table 3 Types of data captured and points of data capture in CORR

Level	Type of data	Point of data capture
Patient-level data	Dialysis recipients	<ul style="list-style-type: none"> • When dialysis is initiated • When recipient . . . <ul style="list-style-type: none"> – Transfers to another program – Changes treatment modalities – Has a kidney transplant – Withdraws from dialysis – Recovers kidney function – Dies • At annual follow-up on October 31
	Transplant recipients	<ul style="list-style-type: none"> • When transplanted • When . . . <ul style="list-style-type: none"> – Recipient transfers to another program for follow-up – Graft fails – Recipient receives re-transplantation – Recipient dies
	Donors	When organ(s) are retrieved and utilized from a living or deceased donor for the purposes of transplantation
Facility-level data	Dialysis hospital programs	Hemodialysis facility profile and peritoneal dialysis facility profile at year end
Aggregate-level data	Wait-list, donor and transplant statistics	Counts of patients waiting for transplants, patients who received transplant(s) and organ donations that were utilized; all collected on an annual basis from organ donation organizations

Source

Canadian Organ Replacement Register, 2022, Canadian Institute for Health Information.

The data supply chain for CORR can be found in Table 4.

Table 4 CORR data supply chain

Province/territory of treatment	Dialysis recipients	Organ transplant recipients	Deceased organ donors	Living organ donors	Wait-list statistics
B.C.	BC Renal Agency	BC Transplant	BC Transplant	BC Transplant	BC Transplant
Alta.	Alberta Kidney Care — South (Calgary) Alberta Kidney Care — North (Edmonton)	Hospital transplantation programs	Southern Alberta Organ and Tissue Donation Program — Calgary Human Organ Procurement and Exchange (HOPE) Program — Edmonton	Southern Alberta Transplant Program University of Alberta Hospital Transplant Services	Southern Alberta Organ and Tissue Donation Program — Calgary Human Organ Procurement and Exchange (HOPE) Program — Edmonton
Sask.	Renal programs	Saskatchewan Transplant Program	Saskatchewan Transplant Program Saskatchewan Health Authority Donation Program	Saskatchewan Transplant Program	Saskatchewan Transplant Program
Man.	Manitoba Renal Program	Transplant Manitoba — Gift of Life	Transplant Manitoba — Gift of Life	Transplant Manitoba — Gift of Life	Transplant Manitoba — Gift of Life
Ont.	Ontario Health (Ontario Renal Network)	Ontario Health (Trillium Gift of Life Network)	Ontario Health (Trillium Gift of Life Network)	Ontario Health (Trillium Gift of Life Network)	Ontario Health (Trillium Gift of Life Network)
Que.	Renal programs	Hospital transplantation programs*	Transplant Québec*	Hospital transplantation programs*	Transplant Québec
N.B.	Renal programs	—	New Brunswick Organ and Tissue Procurement Program	—	—
N.S.	Renal programs	Multi-Organ Transplant Program	Multi-Organ Transplant Program Legacy of Life Organ Donation Program	Multi-Organ Transplant Program	Multi-Organ Transplant Program
P.E.I.	P.E.I. Renal Program	—	—	—	—

Province/territory of treatment	Dialysis recipients	Organ transplant recipients	Deceased organ donors	Living organ donors	Wait-list statistics
N.L.	Renal programs	—	Organ Procurement and Exchange of Newfoundland and Labrador (OPEN)	—	—
N.W.T.	Community dialysis programs	—	—	—	—

Notes

* Significant under-reporting of Quebec record-level data occurred between 2012 and 2021. For further information on data completeness, please see Table 5.

— No programs or organizations submit data.

Source

Canadian Organ Replacement Register, 2022, Canadian Institute for Health Information.

Error detection: All data providers receive 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 submission reports that summarize submitted records and errors, direct client support and other feedback. The data entry flow is designed to enhance error detection:

- On the transplant side, data on 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 is entered in chronological order. This helps to identify problematic submissions (e.g., inconsistent submissions regarding a patient’s status).

Upon completion of data entry and processing, reporting centres are forwarded standardized audit reports for the purposes of verification. Following review of the audit report, changes requested by centres are made in the CORR database. A client service associate (CSA) may also liaise with a reporting centre before processing the web forms when verification of the returned forms reveals any data quality issues. A CSA will also liaise with the reporting centre to address any problems with the data uncovered through analysts’ work on ad hoc requests and research projects.

CORR's *Dialysis Submission Specifications Manual* includes a definition field status column that indicates whether the data element is mandatory, required or optional. Definitions of the field status values are as follows:

- **Mandatory:** Records containing fields marked as mandatory and left blank will be rejected by CORR.
- **Conditionally mandatory:** Fields may require a value depending on the selection in an associated field.
- **Required:** Records containing fields marked as required and left blank will result in a warning error in the submission report.
- **Conditionally required:** Similar to conditionally mandatory, except that the associated field is defined as required and not mandatory.
- **Optional:** Records containing fields marked as optional may be left blank; however, data providers are encouraged to enter data for these fields.

CORR incorporates edits as needed to align with current logic-based; consistency-based; and administrative, validity and completeness practices in Canada. These edits are designed to:

- Reduce entry of duplicate records (e.g., matching algorithm used to reduce double entry of patient records);
- Improve consistency of data (e.g., logic checks to ensure entry of treatments in a chronological sequence);
- Minimize entry of incorrect data (e.g., drop-down menus used to minimize the opportunities for incorrect domain values to be inputted; entry of dates in the format YYYY-MO-DD to prevent the transposition of day and month during data entry); and
- Improve data completeness (e.g., 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 (e.g., recipient height and weight), the application employs a warning error in the submission report or, if it is a manual entry, it will alert the data entry personnel to potential entry errors.

In 2010, database functionality was enhanced to allow for the electronic submission and processing of dialysis data using defined submission specifications (eFile). These specifications include the same edit checks and validation rules that are applied to data entered manually. This submission method is used by Ontario Health/Ontario Renal Network (since 2011), Queen Elizabeth II Health Sciences Centre (2014), Alberta Kidney Care — South (2016) and British Columbia Provincial Renal Agency (2016). CORR monitors electronic submissions to ensure that the information submitted to the registry is accurate and complete by producing submission reports once the records have been processed.

In 2015, CORR released a new electronic web-based submission method, the CORR Web-Entry Data Form. This submission method is a secure industry-standard web environment that allows a data provider to enter records online and submit them directly to CORR. This application replaced the paper forms that were mailed prior to the 2015 data year. When first implemented, this submission method had limited edit checks and validation rules. Since then, additional validation rules have been implemented to align with CORR eFile submission.

Imputation: Currently no imputed data is stored in CORR.

Quality evaluation: CIHI's Information Quality Framework, which was implemented in 2000–2001 and most recently revised in 2017, provides a common strategy for assessing data quality across CIHI's databases and registries along 5 general dimensions:

- **Relevance:** The degree to which information meets the current and potential needs of clients, users, stakeholders or the audience.
- **Accuracy and reliability:** The degree to which the information correctly and consistently describes the phenomena it was designed to measure.
- **Comparability and coherence:** The degree to which information is comparable over time and across jurisdictions, produced using common standards and methods, and can be combined with other sources.
- **Timeliness and punctuality:** Timeliness refers to how quickly information is made available after the end of the reference period; punctuality refers to whether information is delivered on the dates announced.
- **Accessibility and clarity:** The degree to which information, including supplementary explanatory information and metadata, is easily obtainable and clearly presented, in a way that can be understood.

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

Under-reporting across Canada

A summary of all known under-reporting issues is presented in Table 5. Data completeness is summarized by province, year and type of data.

Table 5 Data completeness

Type of data	2016	2017	2018	2019	2020	2021
Dialysis	Quebec Missing an undetermined number of new patients and deaths due to incomplete historic data	Quebec Missing an undetermined number of new patients and deaths due to incomplete historic data	Quebec Missing an undetermined number of new patients and deaths due to incomplete historic data	Quebec Missing an undetermined number of new patients and deaths due to incomplete historic data	Quebec Missing an undetermined number of new patients and deaths due to incomplete historic data	Quebec Missing an undetermined number of new patients
	New Brunswick Missing a small number of new patients and deaths from 1 facility due to incomplete historic data	New Brunswick Missing a small number of new patients and deaths from 1 facility due to incomplete historic data	New Brunswick Missing a small number of new patients and deaths from 1 facility due to incomplete historic data	New Brunswick Missing 14 new patients	New Brunswick Missing 16 new patients	New Brunswick Missing 28 new patients
	Ontario Missing dialysis data from 1 pediatric facility	Ontario Missing dialysis data from 1 pediatric facility	Ontario Missing dialysis data from 1 pediatric facility	Ontario Missing dialysis data from 1 pediatric facility	Ontario Missing dialysis data from 1 pediatric facility	Ontario Missing dialysis data from 1 pediatric facility
	Saskatchewan Missing dialysis data from 1 pediatric facility	Saskatchewan Missing dialysis data from 1 pediatric facility	Saskatchewan Missing dialysis data from 1 pediatric facility	Saskatchewan Missing dialysis data from 1 pediatric facility	Saskatchewan Missing dialysis data from 1 pediatric facility	Saskatchewan Missing dialysis data from 1 pediatric facility

Type of data	2016	2017	2018	2019	2020	2021
Transplants	<p>Quebec</p> <p>39% complete</p> <p>Missing transplants include 292 kidney, 6 heart, 1 lung, 38 liver and 8 pancreas</p> <p>Totals are determined from aggregate data from Transplant Québec</p>	<p>Quebec</p> <p>35% complete</p> <p>Missing transplants include 290 kidney, 24 heart, 1 lung, 51 liver and 2 pancreas</p> <p>Totals are determined from aggregate data from Transplant Québec</p>	<p>Quebec</p> <p>14% complete</p> <p>Missing transplants include 293 kidney, 24 heart, 55 lung, 54 liver and 4 pancreas</p> <p>Totals are determined from aggregate data from Transplant Québec</p>	<p>Quebec</p> <p>4% complete</p> <p>Missing transplants include 299 kidney, 23 heart, 70 lung, 121 liver and 5 pancreas</p> <p>Totals are determined from aggregate data from Transplant Québec</p>	<p>Quebec</p> <p>1% complete</p> <p>Missing transplants include 229 kidney, 39 heart, 70 lung, 91 liver and 5 pancreas</p> <p>Totals are determined from aggregate data from Transplant Québec</p>	<p>Quebec</p> <p>2% complete</p> <p>Missing transplants include 292 kidney, 24 heart, 73 lung, 98 liver and 4 pancreas</p> <p>Totals are determined from aggregate data from Transplant Québec</p>
Living donors	<p>Quebec</p> <p>Missing data for 36 living donors</p> <p>Totals are determined from aggregate data from Transplant Québec</p>	<p>Quebec</p> <p>Missing data for 40 living donors</p> <p>Totals are determined from aggregate data from Transplant Québec</p>	<p>Quebec</p> <p>Missing data for 46 living donors</p> <p>Totals are determined from aggregate data from Transplant Québec</p>	<p>Quebec</p> <p>Missing data for 45 living donors</p> <p>Totals are determined from aggregate data from Transplant Québec</p>	<p>Quebec</p> <p>Missing data for 42 living donors</p> <p>Totals are determined from aggregate data from Transplant Québec</p>	<p>Quebec</p> <p>Missing data for 73 living donors</p> <p>Totals are determined from aggregate data from Transplant Québec</p>
Deceased donors	<p>No known missing records</p>	<p>No known missing records</p>	<p>No known missing records</p>	<p>Quebec</p> <p>Totals are supplemented with aggregate data of 179 donors from Transplant Québec</p>	<p>No known missing records</p>	<p>No known missing records</p>

Source

Canadian Organ Replacement Register, 2022, Canadian Institute for Health Information.

Missing incident dialysis data affects the prevalence data in these provinces, as well as the national totals. As a result, trending must be interpreted with care.

Starting in 2020, the province of Quebec resumed submission of record-level dialysis data and deceased donation data to CORR. As a result, the CORR annual statistics now include Quebec in appropriate analyses. CIHI continues to work with Quebec to improve reporting for future years.

Data accuracy

Coverage: There are known coverage errors in CORR, as the program is aware of all hospitals that should report. CORR is missing dialysis data from 2 children's hospitals across Canada. There has also been significant under-reporting of transplantation in Quebec since 2012. Longitudinal dialysis data from Ontario also ceased as of 2018.

Linkage of CORR: Prevalent patients in CORR are linked to the DAD, Continuing Care Reporting System, Home Care Reporting System and Insured Persons Repository for death record verification. If the linkage produces deaths that were not submitted to the registry, CORR staff manually adds these deaths to the database.

Before 2001, duplicate patient records were identified and eliminated in the database manually. Since then, CORR has utilized an application that reduces entry of duplicate records through a matching algorithm. Additionally, the CORR program conducts a standard audit report as part of the annual data verification process to identify any duplicate registrations based on health card number (HCN) or combination of HCN, patient name and date of birth.

Unit non-response: Because CORR is updated continually, unit non-response is addressed on an ongoing basis. Those centres that failed to report to CORR in a timely and complete way are identified, and staff works with them to improve reporting. Strategies to improve reporting include direct client support where needed. The 2 main strategies to evaluate non-response are

1. Trending of incident dialysis patients; and
2. Cross-checking of aggregate-level data sources with patient-level data.

Using this second method, data accuracy for unit response in 2021 is evaluated in tables 6, 7 and 8 for kidney transplant, extra-renal transplant and organ donation, respectively.

Table 6 Comparison of counts of kidney transplants* by data source, 2021 (number)

Data source	B.C.	Alta.	Sask.	Man.	Ont.	Que.	N.S.	Total
Patient-level counts for transplants in CORR	342	217	27	29	685	—	79	1,379
Aggregate counts provided by ODOs at year end	342	216	27	29	686	294	79	1,673

Notes

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

— Due to significant under-reporting, Quebec is excluded from patient-level counts.

CORR: Canadian Organ Replacement Register.

ODO: Organ donation organization.

Source

Canadian Organ Replacement Register, 2022, Canadian Institute for Health Information.

Table 7 Comparison of counts of extra-renal transplants* by data source and province of treatment, 2021 (number)

Organ type	Data source	B.C.	Alta.	Sask.	Man.	Ont.	Que.	N.S.	Total
Liver	Patient-level CORR count	98	74	0	0	287	—	30	489
	Aggregate-level ODO count	98	75	0	0	288	98	30	589
Heart	Patient-level CORR count	22	26	0	0	54	—	3	105
	Aggregate-level ODO count	22	26	0	0	54	32	3	137
Lung/heart–lung	Patient-level CORR count	66	54	0	0	156	—	0	276
	Aggregate-level ODO count	66	53	0	0	160	73	0	352
Pancreas	Patient-level CORR count	3	8	0	0	38	—	0	49
	Aggregate-level ODO count	3	8	0	0	38	4	0	53

Organ type	Data source	B.C.	Alta.	Sask.	Man.	Ont.	Que.	N.S.	Total
Islets	Patient-level CORR count	0	20	0	0	0	—	0	20
	Aggregate-level ODO count	0	20	0	0	0	1	0	21
Intestine/ multi-visceral	Patient-level CORR count	0	5	0	0	1	—	0	6
	Aggregate-level ODO count	0	5	0	0	2	0	0	7

Notes

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

— Due to significant under-reporting, Quebec is excluded from patient-level counts.

Patient-level CORR count: Patient-level data within CORR; Aggregate-level ODO count: Aggregate count provided by ODOs at year end.

CORR: Canadian Organ Replacement Register.

ODO: Organ donation organization.

Source

Canadian Organ Replacement Register, 2022, Canadian Institute for Health Information.

Table 8a Comparison of deceased and living donors registered in CORR and reported by ODOs, Canada (excluding Quebec), 2012 to 2021 (number)

Year	Patient-level CORR count			Aggregate-level ODO count		
	Deceased donors	Living donors	Total donors	Deceased donors	Living donors	Total donors
2012	421	485	906	422	484	906
2013	388	533	921	387	534	921
2014	437	506	943	444	506	950
2015	477	508	985	479	508	987
2016	590	488	1,078	588	489	1,077
2017	621	481	1,102	619	479	1,098
2018	598	509	1,107	598	509	1,107
2019	641	569	1,210	643	569	1,212
2020	588	448	1,036	591	445	1,036
2021	592	517	1,109	590	520	1,110
Total	5,353	5,044	10,397	5,361	5,043	10,404

Notes

Patient-level CORR count: Patient-level data within CORR; Aggregate-level ODO count: Aggregate count provided by ODOs at year end.

CORR: Canadian Organ Replacement Register.

ODO: Organ donation organization.

Source

Canadian Organ Replacement Register, 2022, Canadian Institute for Health Information.

Table 8b Comparison of deceased and living donors registered in CORR and reported by ODOs, Canada (including Quebec), 2012 to 2021 (number)

Year	Patient-level CORR count			Aggregate-level ODO count		
	Deceased donors	Living donors	Total donors	Deceased donors	Living donors	Total donors
2012	421	529	950	542	537	1,079
2013	388	573	961	552	586	1,138
2014	437	526	963	598	553	1,151
2015	649	526	1,175	651	563	1,214
2016	760	506	1,266	758	545	1,303
2017	803	495	1,298	801	533	1,334
2018	762	509	1,271	762	555	1,317
2019	641	569	1,210	822	614	1,436
2020	730	449	1,179	734	487	1,221
2021	736	519	1,255	734	595	1,329
Total	6,327	5,201	11,528	6,954	5,568	12,522

Notes

CORR: Canadian Organ Replacement Register.

ODO: Organ donation organization.

Source

Canadian Organ Replacement Register, 2022, Canadian Institute for Health Information.

Item non-response: While overall item non-response has improved over time, particularly since 1997, some significant province-specific item non-response issues remain.

An examination of sensitivity and specificity found that while comorbidities have a low-to-moderate sensitivity for identifying incident dialysis patients, it is uncommon for comorbidities to be falsely attributed to patients, indicating a high specificity.

Table 9 presents a summary of the proportion of records with null and/or unknown values on key mandatory data elements within CORR for transplant recipients of first grafts for the period from 2012 to 2021, and for donors for the same period. Rates of non-response/unknowns 10% or greater are shaded and marked with a dagger (†).

Table 9 Non-response/unknown values for key analytical data elements related to donors and transplant recipients* in CORR, 2012 to 2021 (percentage)

Data type	Data element	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021
Deceased donor	Age	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
	Sex	0.0	0.3	0.2	0.0	22.4†	0.1	0.0	0.0	0.0	0.1
	Blood Type	0.2	0.0	0.0	0.2	22.4†	0.0	0.0	0.0	0.0	0.0
	Race/Ethnic Origin	5.9	43.0†	6.9	5.2	26.6†	3.4	3.5	5.8	9.0	7.9
	Province of Residence	0.0	0.0	0.2	1.1	2.4	0.2	0.5	0.0	0.5	0.0
	Cause of Death	3.1	1.3	7.6	3.4	3.8	6.4	4.2	0.3	3.4	4.3
Living donor	Age	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
	Sex	0.0	0.7	0.0	0.0	0.4	0.0	0.6	0.0	0.2	0.0
	Blood Type	0.9	2.4	1.0	1.5	0.6	1.6	1.4	1.1	2.9	3.9
	Province of Residence	4.0	0.9	1.7	0.6	3.0	0.4	0.2	1.8	0.9	0.2
Transplant recipients	Sex	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
	Race/Ethnic Origin	18.5†	16.3†	18.1†	17.0†	16.0†	15.5†	17.2†	20.5†	25.7†	30.3†
	Blood Type	3.1	1.5	2.1	2.4	1.9	1.8	2.4	0.9	0.7	0.8
	Residential Postal Code	1.6	0.4	0.4	0.4	0.2	0.3	0.2	0.2	0.9	0.3
	Cause of Death	43.8†	42.4†	42.3†	37.8†	45.4†	39.6†	38.6†	36.7†	31.9†	23.5†
	Diagnosis	5.7	4.7	3.1	2.5	3.5	4.4	7.5	6.6	5.3	6.2
	Medical Status at Listing (heart, liver, lung transplants)	7.1	23.3†	31.1†	29.9†	27.5†	27.4†	32.4†	30.4†	35.9†	37.4†
	Medical Status at Transplant (heart, liver, lung transplants)	13.9†	30.2†	33.8†	29.9†	29.0†	28.1†	47.2†	36.5†	43.6†	40.6†
Cause of Graft Failure (transplants with failed grafts)	61.9†	57.9†	59.7†	60.7†	63.8†	56.4†	58.5†	60.6†	48.8†	66.7†	

Notes

* Recipients of first grafts from 2012 to 2021.

† Rates of non-response/unknowns 10% or greater.

Source

Canadian Organ Replacement Register, 2022, Canadian Institute for Health Information.

Table 10a presents a summary of the proportion of records with null and/or unknown values on key mandatory data elements within CORR for incident dialysis patients for each year in the period 2012 to 2021. Table 10b presents the same information stratified by province of treatment. Rates of non-response/unknowns 10% or greater are shaded and marked with a dagger (†).

Table 10a Non-response/unknown values for key analytical data elements related to incident dialysis patients registered in CORR by year, 2012 to 2021 (percentage)

Data type	Data element	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021	Total
Dialysis patients	Sex	0.1	0.1	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
	Race/Ethnic Origin	5.5	6.4	6.7	5.8	8.7	10.7†	14.3†	15.6†	19.0†	11.2†	10.5†
	Residential Postal Code	2.0	2.0	2.7	2.5	3.7	4.9	5.8	7.0	8.3	2.2	4.2
	Diagnosis	15.4†	14.3†	19.5†	14.3†	14.7†	16.6†	20.4†	25.1†	24.6†	14.0†	18.0†
	Cause of Death	52.6†	54.1†	56.6†	56.0†	55.1†	54.2†	55.7†	55.6†	55.5†	56.4†	55.0†
Comorbidities	Angina	10.0†	9.0	6.9	6.7	7.2	9.4	12.1†	14.0†	15.8†	7.3	9.9
	Coronary Artery Bypass/Angioplasty	8.8	7.8	5.9	5.9	6.8	9.0	11.7†	13.6†	15.6†	6.7	9.3
	Pulmonary Edema	9.4	8.4	7.1	8.0	9.1	10.1†	12.8†	14.5†	16.8†	8.0	10.5†
	Myocardial Infarct	9.3	8.1	6.3	6.2	6.9	9.3	11.8†	13.8†	15.6†	6.8	9.5
	Diabetes	4.9	5.0	4.4	5.0	7.1	8.9	11.9†	14.8†	15.9†	5.4	8.5
	Cerebrovascular Accident	9.0	8.2	6.3	5.6	6.6	8.7	11.5†	13.8†	15.7†	6.7	9.3
	Peripheral Vascular Disease	9.4	8.4	6.6	6.1	7.0	9.0	11.7†	13.5†	15.6†	6.7	9.5
	Malignancy	11.2†	10.0†	9.2	6.6	7.7	9.4	11.9†	14.2†	16.2†	7.1	10.4†
	Chronic Lung Disease	9.2	8.7	6.6	5.7	6.8	9.2	11.6†	13.7†	15.6†	6.2	9.4
	Use of Medications for Hypertension	7.2	5.7	4.6	4.5	6.2	8.5	13.9†	15.0†	16.1†	5.6	8.9
	Presence of Other Serious Illness	25.1†	27.6†	24.6†	25.5†	29.5†	30.8†	32.6†	35.3†	36.0†	27.3†	29.5†
	Current Smoker	12.3†	11.6†	9.7	7.2	9.2	11.2†	14.1†	16.0†	17.0†	8.2	11.7†

Note

† Rates of non-response/unknowns 10% or greater.

Source

Canadian Organ Replacement Register, 2022, Canadian Institute for Health Information.

Table 10b Non-response/unknown values for key analytical data elements related to incident dialysis patients registered in CORR by province, 2012 to 2021 (percentage)

Data type	Data element	B.C.	Alta.	Sask.	Man.	Ont.	Que.	N.B.	N.S.	N.L.	Total
Dialysis patients	Sex	0.0	0.1	0.1	0.0	0.0	0.0	0.2	0.0	0.0	0.0
	Race/Ethnic Origin	2.6	9.1	1.7	11.5†	4.5	56.2†	1.9	5.6	1.6	10.5†
	Residential Postal Code	0.2	0.5	0.4	1.0	0.2	35.2†	5.7	1.6	1.1	4.2
	Diagnosis	20.7†	8.2	7.0	9.0	11.2†	63.0†	9.2	19.7†	24.7†	18.0†
	Cause of Death	74.3†	43.3†	46.8†	42.2†	56.0†	55.8†	44.4†	52.8†	27.0†	55.0†
Comorbidities	Angina	4.7	6.3	4.4	7.9	1.9	61.6†	4.9	5.5	3.2	9.9
	Coronary Artery Bypass/Angioplasty	4.3	5.9	1.2	7.6	1.3	60.8†	5.2	4.9	1.3	9.3
	Pulmonary Edema	4.3	13.1†	7.2	7.8	1.5	61.3†	6.4	5.2	2.1	10.5†
	Myocardial Infarct	4.2	5.6	4.2	8.0	1.5	61.1†	5.6	5.4	1.8	9.5
	Diabetes	7.0	2.1	0.3	6.2	1.1	57.4†	2.0	2.0	0.4	8.5
	Cerebrovascular Accident	4.5	5.4	1.9	7.8	1.5	60.7†	5.4	4.5	0.9	9.3
	Peripheral Vascular Disease	5.1	4.9	1.6	7.7	1.6	61.2†	5.5	6.0	1.9	9.5
	Malignancy	5.0	7.9	2.2	9.9	2.0	62.0†	8.3	8.0	2.9	10.4†
	Chronic Lung Disease	4.9	5.3	3.0	8.4	1.3	60.3†	5.2	6.4	1.8	9.4
	Use of Medications for Hypertension	7.7	2.4	1.5	6.4	1.2	58.5†	2.5	3.1	0.9	8.9
	Presence of Other Serious Illness	97.8†	29.3†	8.3	11.7†	4.4	65.6†	17.9†	18.8†	7.8	29.5†
	Current Smoker	4.6	8.0	17.2†	12.1†	2.8	63.3†	10.1†	10.8†	4.8	11.7†

Note

† Rates of non-response/unknowns 10% or greater.

Source

Canadian Organ Replacement Register, 2022, Canadian Institute for Health Information.

Reliability/response bias: While non-response issues for data elements exist, CORR data as a whole is comprehensive. A formal linkage¹ of CORR data to the DAD and National Ambulatory Care Reporting System (NACRS) completed in 2008 found that patients who received a transplant or who have chronic renal failure are well reported in CORR (98.5% coverage when compared with transplant data in the DAD).

In the same study¹ reliability was found to be moderate, with a re-coding of 2006 data showing a 59% agreement rate between study coder and CORR data for primary renal disease, and a 71% agreement on the type of renal disease.

Finally, the study¹ also observed that, in general, comorbidities were under-reported in CORR. Despite this, hazard ratios for mortality were similar for various primary renal diseases and comorbidities, whether they were calculated using the CORR data or study data. Hazard ratios either remained less than 1 (indicating conditions that were protective of mortality) or remained greater than 1 (indicating conditions that increased the risk of mortality). It should be noted, however, that the extent of the risk sometimes changed in magnitude. Unadjusted hazard ratios were similar when using the CORR data compared with the study data for the various primary renal diseases but were underestimated in CORR for several comorbidities (e.g., myocardial infarction, cardiovascular disease).

The results from the data quality study provided an assessment of the quality of CORR and identified areas for ongoing improvement. While CORR may contain the most comprehensive national data on treatment for end-stage organ failure at the present time, evaluation of completeness and accuracy of data continues. This includes yearly data quality checks to ensure data providers are using the listed diagnosis and cause of death codes. For example, if diagnoses or causes of death are submitted using descriptive text for the code of “other” instead of the listed numeric codes, these are re-coded to the numerical code wherever applicable.

This also includes ongoing investigation into the extent and impact of reporting completeness and accuracy of death status. Deaths on the wait-list are likely to be underestimated in CORR, as counts that ODOs provide do not capture patients who withdraw from the wait-list and subsequently die (even if their death is attributed to lack of medical treatment/organ transplantation). Canada also continues to report higher patient and graft survival rates for transplant recipients than other countries, which is likely the result of this under-reporting of failures and deaths.

Database revisions

The main CORR database changes have included the following:

- 2020: Introduced 2 new codes to capture primary diagnosis and death caused by COVID-19 for renal patients on chronic dialysis.
- 2020: Introduced 3 new codes to capture primary diagnosis, death and graft failure caused by COVID-19 for transplant patients.
- 2018: Updated valid treatment codes to capture assisted home dialysis.
- 2018: Discontinued some data elements for longitudinal data following consultation with stakeholders and with the approval of the CORR board.
- 2017: Revised the hemodialysis and peritoneal dialysis facility profile to discontinue some data elements.
- 2015: Introduced web forms and web-based submission to allow clients to enter data directly in electronic format.
- 2010: Enhanced database functionality to allow for the electronic submission and processing of dialysis data using defined submission specifications (eFile).
- 2004: Created standardized form for living donors.
- 2001: Added data elements relating to cardiac function and inotrope use on deceased donor profile.
- 2001: Added a follow-up survey of all dialysis recipients, designed to capture information on the ways in which current treatment corresponds to the *Clinical Practice Guidelines of the Canadian Society of Nephrology for the Treatment of Recipients With Chronic Renal Failure*.²
- 2001: Revised comorbidities for transplant recipients and donors.

References

1. Canadian Institute for Health Information. *Data Quality Study on the Canadian Organ Replacement Register*. 2009.
2. Canadian Society of Nephrology. *Clinical Practice Guidelines of the Canadian Society of Nephrology for the Treatment of Recipients With Chronic Renal Failure*. 2001.

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