



CORR

Data Quality Documentation for Users

Canadian Organ
Replacement Register

2008 to 2017 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) of the Canadian Institute for Health Information (CIHI) is the national information system for organ failure, transplantation and donation, and renal dialysis, with a mandate to record and analyze the level of activity and outcomes of vital organ transplantation and dialysis activities. It is a longitudinal database, following recipients with end-stage organ failure from their first treatment to their death. The national scope of CORR has been useful in informing health care policy vis-à-vis organ donation across Canada, end-stage kidney disease (ESKD) and organ transplantation.

Data sources and methodology

Target population: All patients who have received an extra-renal organ transplant since January 1, 1988, and all chronic renal failure patients who have initiated renal replacement therapy (RRT) since January 1, 1981. CORR does not contain information on patients who have been determined to have acute, but not chronic, renal failure; recipients of tissue transplants; patients who were listed for but did not receive a vital organ transplant; and potential organ donors (i.e., deceased donors who met the criteria for donation but from whom no organs were 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 chronic renal failure patients and all the vital organ transplant programs within Canada. Data is received either directly or indirectly from these programs. Tables 1 and 2 below identify the number of dialysis programs and transplant programs, respectively, in 2017, that participated in CORR directly or through a regional or provincial registry or organ procurement program.

Table 1 Dialysis programs within CORR frame by province/territory, 2017

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	2	5	31	34	4	4	2	3	0	107
Affiliated community centres	29	27	10	16	55	12	6	9	2	10	0	176
Independent health care facilities offering hemodialysis	0	0	0	0	10	0	1	0	0	0	2	13

Table 2 Transplant programs within CORR frame by province, 2017

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/heart–lung	1	1	0	0	4	4	1	11
Lung	1	1	0	1	2	1	0	6
Pancreas/ kidney–pancreas	1	2	0	0	2	2	1	8
Intestine/ multi-visceral	0	1	0	0	3	0	0	4
Islets	1	1	0	0	0	0	0	2

Frame maintenance procedures are currently in place for CORR. 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 (i.e., a province code from 1 to 9, along with a 4-digit identifier). Unique facility identifiers are assigned to hospitals in Quebec, satellite centres and organ procurement organizations (OPOs) using a consistent notation system. All facility identifiers are identified in the CORR e-Directory of Participating Dialysis Centres, Transplant Centres and Organ Procurement Organizations in Canada, which is published annually at www.cihi.ca/corr. In addition, a formal review process was undertaken in April and May 2002 to formally verify CORR's frame.

Data sources: CORR comprises retrospectively collected demographic, clinical and outcome-related data. Data is received via electronic file submission and standardized paper forms.ⁱ These forms, and the accompanying instruction manuals, also guide spreadsheet submissions.

Within CORR, data elements are classified as mandatory, conditionally mandatory or optional. Mandatory elements must be submitted and entered (e.g., Recipient Name, Birthdate, Treatment Code), whereas conditionally mandatory elements are entered only if other specific conditions are satisfied (e.g., Date of Death must be entered if a Cause of Death is given). Before 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.

i. Paper-based data submission ended in 2015 and has been replaced with a web-based data submission method.

The types of data captured, as well as the points of data capture within CORR, are summarized in Table 3. Changes in patients' treatment status are tracked and treatment outcomes are recorded. Information on organ donors is also collected. Facility-level data on clinical practices and policies is collected from dialysis hospitals and independent health facilities. Counts of patients waiting for a transplant are collected from OPOs.

Table 3 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 statistic
1) When dialysis is initiated 2) 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 3) At annual follow-up on October 31 (surveywithvoluntary participation)	1) When transplanted 2) When . . . <ul style="list-style-type: none"> • Recipient transfers to another program for follow-up • Graft fails • Re-transplanted • Recipient dies 	When organ(s) are retrieved for purposes of transplantation — deceased donor profile and living donor profile	At year-end — hemodialysis facility profile and peritoneal dialysis facility profile	At year-end — renal transplant facility profile	Counts of patients waiting for transplants at each of the transplant programs; reported on a semi-annual basis by the OPOs

Table 4 outlines the data supply chain for CORR.

Table 4 CORR data supply chain

Province/ territory of treatment	Dialysis recipients	Organ transplant recipients	Deceased organ donors	Living organ donors	Waiting list statistics
B.C.	BC Renal Agency, renal programs	BC Transplant	BC Transplant	BC Transplant	BC Transplant
Alta.	Southern Alberta Renal Program (Calgary) and Northern Alberta Renal Program (Edmonton)	Hospital transplant programs	Southern Alberta Organ and Tissue Donation Program — Calgary, HOPE Edmonton	Hospital transplant programs	Southern Alberta Organ and Tissue Donation Program — Calgary, HOPE Edmonton
Sask.	Renal programs	Saskatchewan Transplant Program	Saskatchewan Transplant Program	Saskatchewan Transplant Program	Saskatchewan Transplant Program
Man.	Manitoba renal program	Hospital transplant program	Transplant Manitoba — Gift of Life	Hospital transplant program	Transplant Manitoba — Gift of Life
Ont.	Ontario Renal Network	Trillium Gift of Life Network	Trillium Gift of Life Network	Trillium Gift of Life Network	Trillium Gift of Life Network
Que.	Renal programs	Hospital transplant programs	Transplant Québec	Hospital transplant programs	Transplant Québec
N.B.	Renal programs	—	New Brunswick Organ and Tissue Procurement Program	—	—
N.S.	Renal programs	Multi-Organ Transplant Program	Multi-Organ Transplant Program	Multi-Organ Transplant Program	Multi-Organ Transplant Program
P.E.I.	P.E.I. renal program	—	—	—	—
N.L.	Renal programs	—	Organ Procurement and Exchange of Newfoundland and Labrador (OPEN)	—	—
N.W.T.	Community dialysis program	—	—	—	—

Note

— No programs submit data.

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 submission reports that summarize submitted records and errors; telephone support; site visits; and written instructions and feedback. The data processing 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 (e.g., inconsistent submissions regarding a patient’s status).

Upon completion of data processing, reporting centres are forwarded standardized audit reports for the purposes of verification. Changes noted by centres are made in the database. CORR staff may also liaise with a reporting centre prior to data processing when visual scans of the returned forms reveal problems or when problems in the data have been identified through the course of analysts’ work on ad hoc requests and research projects.

In 2001, a number of new hard and soft edits were introduced

- To reduce processing of duplicate records (e.g., matching algorithm used to reduce double processing of patient records);
- To improve consistency of data (e.g., logic checks to ensure processing of treatments in a chronological sequence);
- To minimize processing 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–MON–DD to prevent the transposition of day and month during data processing); and
- To improve data completeness (e.g., mandatory data elements cannot be bypassed; some data elements are autopopulated; 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 soft edits, which alert CORR personnel to potential processing 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. The Ontario Renal Network and QEII Health Sciences Centre have been submitting data using this eFile method since 2011 and 2014, respectively. The Southern Alberta Renal Program and British Columbia Provincial Renal Agency started submitting data using the eFile method in 2016. CORR monitors electronic submissions to ensure that no changes in completeness or quality are detected.

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 data online and submit it directly to CORR. This application replaced the paper forms that were mailed to CIHI prior to the 2015 data year. This submission method includes the same edit checks and validation rules that were applied to data entered manually via paper submission.

Imputation: As of December 2006, no imputed data is stored in CORR.

Quality evaluation: CIHI's Information Quality Framework, which was implemented in 2000–2001, and revised in 2009 and 2017, provides a common strategy for assessing data quality across CIHI 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. Each CIHI data holding is evaluated for each annual release of data.

Under-reporting across Canada

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

Since 2011, Quebec has had increased under-reporting due to administrative issues. CIHI is working with the province of Quebec to improve reporting for future years.

In 2017, Quebec dialysis data was 7% complete, with an estimated 1,018 incident records missing. This estimate of missing records is based on a historical average of 1,100 incident dialysis cases per year. Transplant record-level data was 35% complete. A summary of missing dialysis and transplant records is provided in Table 5. Missing transplant records were determined by comparing records received by CORR against aggregate-level reporting by OPOs.

Also in 2017, there was missing dialysis data from New Brunswick, with an estimated 47 incident dialysis records missing.

Table 5 Data completeness

Type of data	2012	2013	2014	2015	2016	2017
Dialysis	<p>Quebec*</p> <p>Approximately 49% complete</p> <p>Missing an estimated 560 incident cases</p> <p>Missing an undetermined number of death reports</p>	<p>Quebec*</p> <p>Approximately 40% complete</p> <p>Missing an estimated 600 incident cases</p> <p>Missing an undetermined number of death reports</p> <p>New Brunswick</p> <p>Missing 27 incident cases from 1 facility</p>	<p>Quebec*</p> <p>Approximately 31% complete</p> <p>Missing an estimated 750 incident cases</p> <p>Missing an undetermined number of death reports</p>	<p>Quebec*</p> <p>Approximately 21% complete</p> <p>Missing an estimated 874 incident cases</p> <p>Missing an undetermined number of death reports</p>	<p>Quebec*</p> <p>Approximately 15% complete</p> <p>Missing an estimated 936 incident cases</p> <p>Missing an undetermined number of death reports</p> <p>New Brunswick</p> <p>Missing an estimated 25 incident cases from 1 facility</p>	<p>Quebec*</p> <p>Approximately 7% complete</p> <p>Missing an estimated 1,018 incident cases</p> <p>Missing an undetermined number of death reports</p> <p>New Brunswick</p> <p>Missing an estimated 47 incident cases from 1 facility</p>
Transplants	<p>Quebec</p> <p>95% complete</p> <p>Missing 21 kidney transplants and 3 lung transplants</p>	<p>Quebec</p> <p>89% complete</p> <p>Missing 58 kidney transplants, 5 kidney–pancreas transplants and 1 pancreas-only transplant</p>	<p>Quebec</p> <p>80% complete</p> <p>Missing transplants include 94 kidney, 4 heart, 2 lung and 1 pancreas</p>	<p>Quebec</p> <p>49% complete</p> <p>Missing transplants include 233 kidney, 2 heart, 41 liver and 6 pancreas</p>	<p>Quebec</p> <p>39% complete</p> <p>Missing transplants include 292 kidney, 6 heart, 1 lung, 38 liver and 8 pancreas</p>	<p>Quebec</p> <p>35% complete</p> <p>Missing transplants include 290 kidney, 24 heart, 1 lung, 51 liver and 2 pancreas</p>

Type of data	2012	2013	2014	2015	2016	2017
Living donors	Quebec Missing data for 9 living donors Totals are determined from aggregate data from Transplant Québec	Quebec Missing data for 12 living donors Totals are determined from aggregate data from Transplant Québec	Quebec Missing data for 27 living donors Totals are determined from aggregate data from Transplant Québec	Quebec Missing data for 37 living donors Totals are determined from aggregate data from Transplant Québec	Quebec Missing data for 36 living donors Totals are determined from aggregate data from Transplant Québec	Quebec Missing data for 40 living donors Totals are determined from aggregate data from Transplant Québec
Deceased donors	Quebec Totals are supplemented with aggregate data of 120 donors from Transplant Québec	Quebec Totals are supplemented with aggregate data of 165 donors from Transplant Québec	Quebec Totals are supplemented with aggregate data of 154 donors from Transplant Québec	Quebec No known missing records	Quebec No known missing records	Quebec No known missing records

Note

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

Missing incident dialysis data affects the prevalence data in these provinces and Canada overall. For Quebec, totals for transplant and organ donor activity are also affected. As a result, any trending must be interpreted with care.

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

Data accuracy

Coverage: There are no known coverage errors within CORR. The program is aware of all hospitals that should report. An analysis of transplant procedures as captured in the Hospital Morbidity Database (HMDB) for the calendar years 1995 to 2000 confirms the transplant hospitals within CORR.

A formal linkage¹ of CORR data to the DAD and the National Ambulatory Care Reporting System (NACRS) completed in 2008 found that patients who received a transplant or who have chronic renal failure are well reported in CORR. The coverage of transplants in CORR is 98.5% when compared to data on transplants in the DAD. For coverage of dialysis treatment in Ontario, the patients receiving dialysis were comparable between CORR and NACRS.

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

Unit non-response: Because CORR is updated continually, unit non-response is addressed on an ongoing basis. Those centres that failed to report to CORR in a timely and complete way are identified, and staff works with them to improve reporting. Strategies to improve reporting include telephone support and on-site support, where needed. Trending of incident dialysis patients and cross-checking of aggregate-level data sources with patient-level data are 2 main approaches used to evaluate unit non-response. In this section, unit non-response is described for the data used in this report.

1) Incident dialysis cases

As noted in Table 5, unit non-response was an issue for 2 provinces for incident dialysis cases (under-reporting).

2) Kidney transplants

Since the 1990s, patient-level data submitted by hospitals and OPOs is reconciled with aggregate-level counts received from OPOs, which are received in advance of patient-level data submissions. For under-reporting in Quebec, see Table 5. Table 6 presents a comparison of these sources and the respective transplant counts per province for 2017, and shows that the new patient-level data is comparable to the OPO aggregate counts.

Table 6 Comparison of counts of kidney transplants* by data source 2017 (number)

Data source	B.C.	Alta.	Sask.	Man.	Ont.	Que.	N.S.	Total
Patient-level data for transplants in CORR	324	208	32	77	722	52	66	1,481
Aggregate counts provided by OPOs at year-end	324	208	33	77	721	342	66	1,771

Note

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

3) Extra-renal transplants

For the extra-renal transplants in 2017, the transplants registered in the database were compared against the aggregate counts reported by the OPOs. The results are provided in Table 7 and suggest that little under-reporting of transplant procedures was observed outside of Quebec.

Table 7 Comparison of counts of extra-renal transplants* by data source and province of treatment, 2017 (number)

Organ type	Data source [†]	B.C.	Alta.	Sask.	Man.	Ont.	Que.	N.S.	Total
Liver	CORR registration	80	92	—	—	268	69	24	533
	OPO count	80	92	—	—	269	120	24	585
Heart	CORR registration	20	45	—	—	95	25	6	191
	OPO count	20	43	—	—	93	49	6	211
Lung/ heart–lung	CORR registration	52	73	—	0	170	52	0	347
	OPO count	52	73	—	0	170	53	0	348
Pancreas	CORR registration	1	21	—	—	50	1	0	73
	OPO count	1	21	—	—	51	3	0	76
Islets	CORR registration	4	33	—	—	0	0	0	37
	OPO count	4	33	—	—	0	2	0	39
Intestine/ multi-visceral	CORR registration	0	1	—	—	1	0	0	2
	OPO count	0	0	—	—	1	0	0	1

Notes

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

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

— This organ type is not transplanted.

4) Donors

A comparison of donors registered in CORR with donor numbers reported by OPOs at year-end is provided in Table 8. With the exception of the unreported deceased and living donors from Quebec between 2012 and 2017, included in Table 5, this table suggests that no under-reporting of donors has been observed in CORR.

Table 8 Comparison of deceased and living donors registered in CORR and reported by OPOs, 2008 to 2017 (number)

Year	Registered in CORR			Reported by OPO		
	Deceased donors	Living donors	Total donors	Deceased donors	Living donors	Total donors
2008	481	546	1,027	486	542	1,028
2009	487	516	1,003	487	516	1,003
2010	466	557	1,023	468	549	1,017
2011	515	521	1,036	513	518	1,031
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	652	563	1,215
2016	760	506	1,266	758	545	1,303
2017	803	495	1,298	802	533	1,335
Total	5,407	5,295	10,702	5,858	5,442	11,300

Linkage of CORR to the DAD for completeness of death reporting: Prevalent patients in CORR are linked to the DAD to verify the completeness of death reporting for patients in CORR. If the linkage produces deaths that were not submitted to the registry, CORR staff manually adds these deaths into CORR.

Item non-response: Overall, item non-response has improved over time, particularly since 1997. There are, however, some significant province-specific item non-response issues.

A data quality study¹ completed in 2008 that included a recoding of 2006 data found that, with the exception of Race/Ethnic Origin, demographic data elements (Health Care Number, Date of Birth) captured in CORR were generally coded with a high degree of accuracy.

An examination of risk factors for incident dialysis patients found that there was a low-to-moderate sensitivity observed for most risk factors, indicating a tendency to under-report. However, it is uncommon for conditions to be falsely attributed to patients, indicating a high specificity.

Table 9 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 2008 to 2017, and for donors for the same period. Rates of non-response/unknowns greater than 10% are shaded.

Table 9 Non-response/unknown values for key analytical data elements related to donors and transplant recipients* in CORR, 2008 to 2017

Data type	Data element	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017
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	0.0	0.0	0.0	0.0	0.3	0.2	0.0	22.4	0.1
	Blood Type	0.2	0.4	0.2	0.0	0.2	0.0	0.0	0.2	22.4	0.0
	Race/Ethnic Origin	36.6	31.6	16.3	6.6	5.9	43.0	6.9	5.2	26.6	3.4
	Province of Residence	0.2	0.0	0.0	0.2	0.0	0.0	0.2	1.1	2.4	0.2
	Cause of Death	3.3	4.1	2.4	2.3	3.1	1.3	7.6	3.4	3.8	6.4
Living donor	Age	0.2	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
	Sex	0.2	0.0	0.0	0.2	0.0	0.7	0.0	0.0	0.4	0.0
	Blood Type	1.5	1.9	1.1	1.9	0.9	2.4	1.0	1.5	0.6	1.6
	Province of Residence	0.5	0.0	0.9	0.2	4.0	0.9	1.7	0.6	3.0	0.4
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	19.3	19.2	18.2	19.1	18.6	16.3	18.2	17.0	16.1	15.6
	Blood Type	5.1	2.4	1.8	4.4	2.9	1.4	1.7	1.4	1.4	1.3
	Residential Postal Code	1.0	0.8	0.9	0.8	1.4	0.4	0.3	0.2	0.1	0.2
	Cause of Death	36.7	39.5	32.5	35.9	36.4	36.5	38.0	36.6	45.7	46.1
	Diagnosis	4.2	4.1	6.1	5.5	5.6	4.9	3.2	2.5	3.5	4.4
	Medical Status at Listing (heart, liver, lung transplants)	3.0	5.4	3.3	10.1	7.1	23.3	30.9	29.6	27.5	27.9
	Medical Status at Transplant (heart, liver, lung transplants)	2.5	2.5	4.1	7.2	13.9	30.2	33.4	29.6	28.7	28.6
Cause of Graft Failure (transplants with failed grafts)	52.0	58.2	54.1	52.6	62.1	50.4	54.3	55.8	70.0	44.4	

Note

* Recipients of first grafts for 2008 to 2017.

Table 10 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 2008 to 2017. Table 11 presents the same information stratified by province of treatment. Rates of non-response/unknowns greater than 10% are shaded.

Table 10 Non-response/unknown values for key analytical data elements related to incident dialysis patients registered in CORR by year, 2008 to 2017

Data type	Data element	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017	Total
Recipients	Sex	0.0	0.0	0.0	0.0	0.1	0.1	0.0	0.0	0.0	0.0	0.0
	Race/Ethnic Origin	4.2	5.5	4.3	3.8	4.7	5.2	4.6	2.6	4.2	4.0	4.3
	Residential Postal Code	1.7	1.0	0.8	0.8	1.5	1.1	1.1	0.9	0.9	0.6	1.0
	Diagnosis	13.4	14.1	12.6	10.7	14.6	13.2	17.9	11.5	10.6	9.8	12.9
	Cause of Death	36.9	40.5	40.6	42.2	49.6	51.9	53.6	55.0	50.7	51.4	44.9
Risk factors	Angina	13.1	15.4	13.1	8.7	9.3	7.7	4.5	2.9	2.3	1.6	8.1
	Coronary Artery Bypass/Angioplasty	12.3	13.7	11.9	7.0	8.0	6.4	3.3	2.3	2.1	1.3	7.1
	Pulmonary Edema	12.4	14.5	12.2	7.6	8.7	7.0	4.4	4.4	4.2	2.3	8.0
	Myocardial Infarct	12.4	14.1	12.1	7.8	8.5	6.7	3.8	2.6	2.1	1.5	7.4
	Diabetes	7.9	7.7	6.4	4.7	4.1	3.7	1.9	1.4	2.3	1.4	4.3
	Cerebrovascular Accident	12.3	14.1	11.8	6.8	8.2	6.8	3.8	2.0	1.9	1.1	7.2
	Peripheral Vascular Disease	12.8	15.2	12.9	7.6	8.7	6.9	4.1	2.4	2.1	1.2	7.7
	Malignancy	16.2	19.7	16.1	10.0	10.4	8.6	6.7	2.9	2.9	1.8	9.9
	Chronic Lung Disease	13.4	16.5	14.5	7.8	8.4	7.3	4.1	2.1	2.1	1.6	8.1
	Use of Medications for Hypertension	8.0	8.8	9.3	6.7	6.4	4.3	2.1	0.8	1.5	0.9	5.1
	Presence of Other Serious Illness	24.8	27.9	22.4	21.3	24.5	26.4	22.3	21.8	24.7	23.7	24.0
	Current Smoker	16.1	18.0	17.5	11.9	11.6	10.3	7.0	3.6	4.5	3.5	10.7

Table 11 Non-response/unknown values for key analytical data elements related to incident dialysis patients registered in CORR by year, 2008 to 2017

Data type	Data element	B.C.	Alta.	Sask.	Man.	Ont.	Que.	N.B.	N.S.	N.L.	Total
Recipients	Sex	0.0	0.1	0.1	0.0	0.0	0.0	0.1	0.0	0.0	0.0
	Race/Ethnic Origin	4.4	7.4	3.4	7.2	3.3	3.6	3.5	8.8	2.0	4.3
	Residential Postal Code	0.5	1.2	0.6	1.3	0.5	3.1	4.3	2.4	0.6	1.0
	Diagnosis	19.1	10.4	9.6	4.8	12.6	16.0	8.9	12.8	12.7	12.9
	Cause of Death	73.4	39.6	47.7	23.9	44.2	29.5	37.3	41.4	15.6	44.9
Risk factors	Angina	19.2	8.8	9.9	7.4	4.6	10.7	4.4	3.8	2.3	8.1
	Coronary Artery Bypass/Angioplasty	18.9	8.1	3.1	7.0	3.5	10.2	4.7	2.5	1.2	7.1
	Pulmonary Edema	18.3	11.8	9.9	6.8	3.9	11.4	4.5	3.3	2.2	8.0
	Myocardial Infarct	18.4	7.7	7.6	7.2	3.8	11.0	4.7	3.6	1.5	7.4
	Diabetes	14.3	3.3	0.8	3.9	1.9	6.0	2.0	1.0	0.2	4.3
	Cerebrovascular Accident	18.9	7.4	5.1	6.8	3.9	9.2	4.3	2.3	0.9	7.2
	Peripheral Vascular Disease	20.0	8.2	5.1	6.7	4.2	10.3	4.1	3.7	1.2	7.7
	Malignancy	21.9	11.6	7.1	9.4	5.9	13.5	6.7	5.0	3.9	9.9
	Chronic Lung Disease	20.4	8.4	7.6	7.7	4.5	9.6	5.2	4.6	2.3	8.1
	Use of Medications for Hypertension	17.3	3.5	1.8	3.7	2.2	6.9	2.4	2.0	0.6	5.1
	Presence of Other Serious Illness	82.4	26.0	15.6	12.3	10.2	18.0	17.8	15.8	5.6	24.0
	Current Smoker	19.7	10.7	18.3	11.3	6.2	17.5	15.0	6.9	2.4	10.7

Reliability/response bias: A formal linkage¹ of CORR data to the DAD and NACRS completed in 2008 found that patients who received a transplant or who have chronic renal failure are well reported in CORR. The coverage of transplants in CORR is 98.5% when compared with data on transplants in the DAD. For coverage of dialysis treatment in Ontario, patients receiving dialysis were comparable between CORR and NACRS.

In the same study, a recoding of 2006 data found the agreement rate between study coder and the CORR data on the primary renal disease was 59%, and the agreement on the type of renal disease was 71%. The study also observed that, in general, risk factors were under-reported in CORR.

However, in general, hazard ratios for various primary renal disease and risk factors were similar whether these were calculated using the CORR data or study data. Hazard ratios either remained less than 1 (indicating conditions that were protective of mortality) or remained greater than 1 (indicating conditions that increased the risk of mortality). However, the extent of the risk sometimes changed in magnitude. Unadjusted hazard ratios were similar when using the CORR data compared to the study data for the various primary renal diseases but were underestimated in CORR for several risk factors.

The results from the data quality study provided an understanding of the quality of CORR and identified areas for ongoing improvement. While CORR may contain the most comprehensive national data on treatment for end-stage organ failure at the present time, evaluation of completeness and accuracy of data will continue. Specifically, an investigation of the extent and impact of reporting completeness and accuracy of death status will be performed in the coming year, as patient and graft survival rates for transplant recipients in Canada continue to be higher than rates reported in other countries, likely due to under-reporting of failures and deaths.

Deaths on the waiting list, which are provided in the form of counts by OPOs, are likely to be underestimated because high-risk (medically urgent) patients are more likely to receive a transplant, and patients who are withdrawn from the list and subsequently die are not included within the death count, even if their deaths were attributable to lack of medical treatment (i.e., organ transplantation).

Major database revisions

In 2000, the database underwent a major review involving a number of expert working groups. Data elements were in some cases eliminated or refined, and new data elements and reporting requirements were added. These changes became effective for reporting year 2001.

The main changes included the following:

- Expanded the treatment modalities for dialysis.
- Added data elements on pre-dialysis contact.
- Added data elements relating to cardiac function and inotrope use on the deceased donor profile.
- Created a standardized form for living donors.
- Added a follow-up survey of all dialysis recipients, designed to capture information on the ways in which current treatment corresponds to the *Clinical Practice Guidelines of the Canadian Society of Nephrology for the Treatment of Recipients With Chronic Renal Failure*.
- Refined the dialysis and renal facility profiles.
- Added data elements pertaining to liver tumours in liver transplant recipients.
- Added a follow-up questionnaire for all liver transplant recipients with diagnoses of hepatitis B, hepatitis C or liver tumours.
- Added comorbidities for transplant recipients and donors.
- Added data elements relating to transplant procedures.

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

In 2010, database functionality was enhanced to allow for the electronic submission and processing of dialysis data using defined submission specifications.

Reference

1. Canadian Institute for Health Information. *Data Quality Study on the Canadian Organ Replacement Register*. 2009.

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