



CORR

# Data Quality Documentation for Users

Canadian Organ  
Replacement Register

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2010 to 2019 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. 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 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 chronic renal failure patients and all the vital organ transplant programs in Canada. Data from these programs is received from different sources, either directly (dialysis and transplant 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 transplant programs, respectively, that participated in data submission to CORR in 2019.

**Table 1** Dialysis programs in CORR frame by province/territory (excluding Quebec), 2019

| Dialysis program   | B.C. | Alta. | Sask. | Man. | Ont. | N.B. | N.S. | P.E.I. | N.L. | N.W.T. | Total |
|--|------|-------|-------|------|------|------|------|--------|------|--------|-------|
| Full-care dialysis programs                              | 13   | 9     | 2     | 5    | 34   | 4    | 5    | 2      | 4    | 0      | 78    |
| Affiliated community centres                             | 29   | 26    | 11    | 16   | 62   | 7    | 9    | 2      | 10   | 0      | 172   |
| Independent health care facilities offering hemodialysis | 0    | 0     | 0     | 0    | 6    | 0    | 0    | 0      | 0    | 2      | 8     |

**Source**

Canadian Organ Replacement Register, Canadian Institute for Health Information.

**Table 2** Transplant programs in CORR frame by province (excluding Quebec), 2019

| Organ type                   | B.C. | Alta. | Sask. | Man. | Ont. | N.S. | Total |
|------------------------------|------|-------|-------|------|------|------|-------|
| Kidney                       | 3    | 3     | 1     | 2    | 7    | 2    | 18    |
| Liver                        | 1    | 1     | 0     | 0    | 3    | 1    | 6     |
| Heart                        | 2    | 1     | 0     | 0    | 4    | 1    | 8     |
| Lung/heart–lung              | 2    | 1     | 0     | 0    | 2    | 0    | 5     |
| Pancreas/<br>kidney–pancreas | 1    | 2     | 0     | 0    | 2    | 1    | 6     |
| Intestine/<br>multi-visceral | 0    | 1     | 0     | 0    | 2    | 0    | 3     |
| Islets                       | 1    | 1     | 0     | 0    | 0    | 0    | 2     |

**Source**

Canadian Organ Replacement Register, Canadian Institute for Health Information.

Frame maintenance procedures are kept up to date on an annual basis. CORR is informed by provincial sources of new facilities and generally aligns with the Discharge Abstract Database (DAD) to assign facility identifiers (i.e., a province code from 1 to 9, along with a 4-digit identifier). Any facility not in the DAD is assigned a number similar in format to what is used in the DAD. Unique facility identifiers are assigned to hospitals in Quebec, satellite centres and organ procurement organizations (OPOs) using a consistent notation system. The CORR Directory captures information on participating dialysis centres, transplant centres and OPOs in Canada; it is published annually at [www.cihi.ca/corr](http://www.cihi.ca/corr).

**Data sources:** CORR comprises retrospectively collected demographic, clinical and outcome-related data. Methods of data submission to CORR include the following:

- eFile: For submitting dialysis data in files with batch records that conform to CIHI's technical specifications;
- CORR Web-Entry Data Form: For submitting individual records to CORR through a secure, online platform; and
- Excel: 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 2019, Version 1* 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 emphasized that reporting to CORR is not provincially or nationally 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 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

| Patient-level data   |  |   | Facility-level data  | Aggregate-level data   |
|--|--|---|--|--|
| Dialysis recipients  | Transplant recipients  | Donors  | Dialysis hospital programs   | Transplant waiting list statistics   |
| 1. When dialysis is initiated<br>2. When recipient . . . <ul style="list-style-type: none"> <li>• Transfers to another program</li> <li>• Changes treatment modalities</li> <li>• Has a kidney transplant</li> <li>• Withdraws from dialysis</li> <li>• Recovers kidney function</li> <li>• Dies</li> </ul> 3. At annual follow-up on October 31 | 1. When transplanted<br>2. When . . . <ul style="list-style-type: none"> <li>• Recipient transfers to another program for follow-up</li> <li>• Graft fails</li> <li>• Re-transplanted</li> <li>• Recipient dies</li> </ul> | When organ(s) are retrieved from a living or deceased donor for the purposes of transplantation | At year-end — hemodialysis facility profile and peritoneal dialysis facility profile | Counts of patients waiting for transplants at each of the transplant programs; reported on an annual basis by the OPOs |

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

Table 4 outlines the data supply chain for CORR.

**Table 4** CORR data supply chain

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

**Note**

— No programs or organizations submit data.

**Source**

Canadian Organ Replacement Register, 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 written instructions and feedback. The data entry flow is designed to enhance error detection:

- On the transplant side, data relating to organ donors is entered first, followed by transplant recipient data. This facilitates identification of transplant recipient–donor links and dialysis recipients who go on to have transplants.
- On the dialysis side, treatment information 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. Changes noted 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 visual scans of the returned forms reveal any data quality issues. A CSA will also liaise with the reporting centre to address any problems with the data uncovered through the course of analysts’ work on ad hoc requests and research projects.

CORR’s *Dialysis Submission Specifications Manual 2019, Version 1* includes a definition field status column that indicates whether the data element is required as part of the record for the specific record type. 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.



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-MON-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), QEII Health Sciences Centre (2014), Alberta Kidney Care — South (2016) and British Columbia Provincial Renal Agency (2016). CORR monitors electronic submissions through submission reports that are produced after the records have been processed to ensure that the information submitted to the registry is accurate and complete.

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 to CIHI prior to the 2015 data year. When first implemented, this submission method had limited edit checks and validation rules. In 2017–2018, additional validation rules were 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 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 2019, Quebec record-level dialysis data was 7% complete, with an estimated 1,025 incident records missing. This estimate of missing records is based on the last known year of complete reporting of 1,100 incident dialysis cases in 2009. Transplant record-level data was 4% 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.

In 2019, there was missing dialysis data from New Brunswick, with an estimated 53 incident dialysis records missing, and 1 centre in Newfoundland and Labrador that had an estimated 10 missing incident dialysis records.

**Table 5** Data completeness

| Type of data       | 2014  | 2015  | 2016  | 2017   | 2018   | 2019   |
|--------------------|---|---|---|--|--|--|
| <b>Dialysis</b>    | <p><b>Quebec*</b></p> <p>Approximately 31% complete</p> <p>Missing an estimated 750 incident cases</p> <p>Missing an undetermined number of death reports</p> | <p><b>Quebec*</b></p> <p>Approximately 21% complete</p> <p>Missing an estimated 874 incident cases</p> <p>Missing an undetermined number of death reports</p> | <p><b>Quebec*</b></p> <p>Approximately 15% complete</p> <p>Missing an estimated 936 incident cases</p> <p>Missing an undetermined number of death reports</p> <p><b>New Brunswick</b></p> <p>Missing an estimated 25 incident cases from 1 facility</p> | <p><b>Quebec*</b></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><b>New Brunswick</b></p> <p>Missing an estimated 53 incident cases from 1 facility</p> | <p><b>Quebec*</b></p> <p>Approximately 9% complete</p> <p>Missing an estimated 1,001 incident cases</p> <p>Missing an undetermined number of death reports</p> <p><b>New Brunswick</b></p> <p>Missing an estimated 53 incident cases from 1 facility</p> | <p><b>Quebec*</b></p> <p>Approximately 7% complete</p> <p>Missing an estimated 1,025 incident cases</p> <p>Missing an undetermined number of death reports</p> <p><b>New Brunswick</b></p> <p>Missing an estimated 53 incident cases from 1 facility</p> <p><b>Newfoundland and Labrador</b></p> <p>Missing an estimated 10 incident cases from 1 facility</p> |
| <b>Transplants</b> | <p><b>Quebec</b></p> <p>80% complete</p> <p>Missing transplants include 94 kidney, 4 heart, 2 lung and 1 pancreas</p>   | <p><b>Quebec</b></p> <p>49% complete</p> <p>Missing transplants include 233 kidney, 2 heart, 41 liver and 6 pancreas</p>                                      | <p><b>Quebec</b></p> <p>39% complete</p> <p>Missing transplants include 292 kidney, 6 heart, 1 lung, 38 liver and 8 pancreas</p>  | <p><b>Quebec</b></p> <p>35% complete</p> <p>Missing transplants include 290 kidney, 24 heart, 1 lung, 51 liver and 2 pancreas</p>  | <p><b>Quebec</b></p> <p>14% complete</p> <p>Missing transplants include 293 kidney, 24 heart, 55 lung, 54 liver and 4 pancreas</p>   | <p><b>Quebec</b></p> <p>4% complete</p> <p>Missing transplants include 299 kidney, 23 heart, 70 lung, 121 liver and 5 pancreas</p>   |

| Type of data           | 2014   | 2015   | 2016   | 2017   | 2018   | 2019   |
|------------------------|--|--|--|--|--|--|
| <b>Living donors</b>   | <b>Quebec</b><br>Missing data for 27 living donors<br><br>Totals are determined from aggregate data from Transplant Québec | <b>Quebec</b><br>Missing data for 37 living donors<br><br>Totals are determined from aggregate data from Transplant Québec | <b>Quebec</b><br>Missing data for 36 living donors<br><br>Totals are determined from aggregate data from Transplant Québec | <b>Quebec</b><br>Missing data for 40 living donors<br><br>Totals are determined from aggregate data from Transplant Québec | <b>Quebec</b><br>Missing data for 46 living donors<br><br>Totals are determined from aggregate data from Transplant Québec | <b>Quebec</b><br>Missing data for 45 living donors<br><br>Totals are determined from aggregate data from Transplant Québec |
| <b>Deceased donors</b> | <b>Quebec</b><br>Totals are supplemented with aggregate data of 154 donors from Transplant Québec                          | <b>Quebec</b><br>No known missing records  | <b>Quebec</b><br>No known missing records  | <b>Quebec</b><br>No known missing records  | <b>Quebec</b><br>No known missing records  | <b>Quebec</b><br>Totals are supplemented with aggregate data of 179 donors from Transplant Québec                          |

**Note**

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

**Source**

Canadian Organ Replacement Register, Canadian Institute for Health Information.

Missing incident dialysis data affects the prevalence data in these provinces as well as the national totals. For Quebec, totals for transplant and organ donor activity are also affected. As a result, 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. Because of significant missing data in Quebec, the province was excluded from portions of CORR products, including all Quick Stats reports and most sections of the annual statistics.

# Data accuracy

A data quality study<sup>1</sup> 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 [HCN], Date of Birth) captured in CORR were generally coded with a high degree of accuracy.

**Coverage:** There are known coverage errors in CORR. The program is aware of all hospitals that should report. CORR is missing dialysis data from 2 children's hospitals in Ontario. CORR also has 35% missing dialysis data in New Brunswick and significant under-coverage for both dialysis and transplant in Quebec since 2011–2012.

**Linkage of CORR to DAD:** Prevalent patients in CORR are linked to the DAD 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.

A formal linkage<sup>1</sup> 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 with data on transplants in the DAD. For coverage of dialysis treatment in Ontario, patients receiving dialysis were comparable between CORR and NACRS.

Duplicate patient records were identified and eliminated in the database for pre-2001 data. The application introduced in 2001 has a matching algorithm in place. The CORR program conducts a standard audit report, as part of the annual data verification process, to identify any duplicate registrations based on 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. 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 is an issue primarily in Quebec and New Brunswick. Since 2011, Quebec has had issues with incident, prevalence and transplant data due to administrative issues. New Brunswick also has under-reporting from 1 dialysis centre for 2013 and 2016 to 2019.

## 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 by province for 2019, and shows that the new patient-level data is comparable to the OPO aggregate counts.

**Table 6** Comparison of counts (number) of kidney transplants\* by data source, 2019

| Data source                                   | B.C. | Alta. | Sask. | Man. | Ont. | Que. | N.S. | Total |
|---|------|-------|-------|------|------|------|------|-------|
| Patient-level data for transplants in CORR    | 333  | 180   | 49    | 50   | 788  | 0    | 90   | 1,490 |
| Aggregate counts provided by OPOs at year-end | 333  | 182   | 49    | 50   | 788  | 299  | 89   | 1,790 |

**Note**

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

**Source**

Canadian Organ Replacement Register, Canadian Institute for Health Information.

### 3. Extra-renal transplants

For extra-renal transplants in 2019, 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 little under-reporting of transplant procedures was observed outside of Quebec.

**Table 7** Comparison of counts (number) of extra-renal transplants\* by data source and province of treatment, 2019

| Organ type               | Data source       | B.C. | Alta. | Sask. | Man. | Ont. | Que. | N.S. | Total |
|--------------------------|-------------------|------|-------|-------|------|------|------|------|-------|
| Liver                    | CORR registration | 69   | 100   | —     | —    | 291  | 0    | 29   | 489   |
|                          | OPO count         | 69   | 99    | —     | —    | 291  | 121  | 29   | 609   |
| Heart                    | CORR registration | 31   | 40    | —     | —    | 93   | 22   | 3    | 189   |
|                          | OPO count         | 31   | 40    | —     | —    | 93   | 45   | 3    | 212   |
| Lung/heart-lung          | CORR registration | 46   | 76    | —     | —    | 212  | 0    | 0    | 334   |
|                          | OPO count         | 46   | 75    | —     | —    | 212  | 70   | 0    | 403   |
| Pancreas                 | CORR registration | 2    | 11    | —     | —    | 50   | 0    | 0    | 63    |
|                          | OPO count         | 2    | 12    | —     | —    | 50   | 5    | 0    | 69    |
| Islets                   | CORR registration | 1    | 30    | —     | —    | 0    | 0    | —    | 31    |
|                          | OPO count         | 1    | 30    | —     | —    | 0    | 2    | —    | 33    |
| Intestine/multi-visceral | CORR registration | 0    | 0     | —     | —    | 1    | 0    | —    | 1     |
|                          | OPO count         | 0    | 0     | —     | —    | 1    | 0    | —    | 1     |

#### Notes

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

— This organ type is not transplanted.

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

#### Source

Canadian Organ Replacement Register, Canadian Institute for Health Information.

#### 4. Donors

The comparison of donors registered in CORR with donor numbers reported by OPOs at year-end is provided in tables 8a and 8b for all of Canada and for Canada excluding Quebec, respectively. With the exception of the unreported deceased and living donors from Quebec between 2012 and 2019 (see Table 5), these tables suggest that no under-reporting of donors has been observed in CORR.

**Table 8a** Comparison of deceased and living donors (number) registered in CORR and reported by OPOs, Canada (including Quebec), 2010 to 2019

| Year         | Registered in CORR |               |               | Reported by OPOs |               |               |
|--------------|--------------------|---------------|---------------|------------------|---------------|---------------|
|              | Deceased donors    | Living donors | Total donors  | Deceased donors  | Living donors | Total donors  |
| 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         | 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         |
| <b>Total</b> | <b>5,842</b>       | <b>5,311</b>  | <b>11,153</b> | <b>6,467</b>     | <b>5,553</b>  | <b>12,020</b> |

**Source**

Canadian Organ Replacement Register, Canadian Institute for Health Information.



**Table 8b** Comparison of deceased and living donors (number) registered in CORR and reported by OPOs, Canada (excluding Quebec), 2010 to 2019

| Year         | Registered in CORR |               |              | Reported by OPOs |               |              |
|--------------|--------------------|---------------|--------------|------------------|---------------|--------------|
|              | Deceased donors    | Living donors | Total donors | Deceased donors  | Living donors | Total donors |
| 2010         | 347                | 502           | 849          | 349              | 498           | 847          |
| 2011         | 378                | 473           | 851          | 376              | 470           | 846          |
| 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        |
| <b>Total</b> | <b>4,898</b>       | <b>5,054</b>  | <b>9,952</b> | <b>4,905</b>     | <b>5,046</b>  | <b>9,951</b> |

**Source**

Canadian Organ Replacement Register, Canadian Institute for Health Information.

**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.

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 2010 to 2019, 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, 2010 to 2019

| Data type   | Data element  | 2010  | 2011  | 2012  | 2013  | 2014  | 2015  | 2016  | 2017  | 2018  | 2019  |
|---|---|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|
| <b>Deceased donor</b>                                   | 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   | 0.3   | 0.2   | 0.0   | 22.4† | 0.1   | 0.0   | 0.0   |
|   | Blood Type  | 0.2   | 0.0   | 0.2   | 0.0   | 0.0   | 0.2   | 22.4† | 0.0   | 0.0   | 0.0   |
|   | Race/Ethnic Origin  | 16.3† | 6.6   | 5.9   | 43.0† | 6.9   | 5.2   | 26.6† | 3.4   | 3.5   | 5.8   |
|   | Province of Residence   | 0.0   | 0.2   | 0.0   | 0.0   | 0.2   | 1.1   | 2.4   | 0.2   | 0.5   | 0.0   |
|   | Cause of Death  | 2.4   | 2.3   | 3.1   | 1.3   | 7.6   | 3.4   | 3.8   | 6.4   | 4.2   | 0.3   |
| <b>Living donor</b>                                     | Age   | 0.0   | 0.0   | 0.0   | 0.0   | 0.0   | 0.0   | 0.0   | 0.0   | 0.0   | 0.0   |
|   | Sex   | 0.0   | 0.2   | 0.0   | 0.7   | 0.0   | 0.0   | 0.4   | 0.0   | 0.6   | 0.0   |
|   | Blood Type  | 1.1   | 1.9   | 0.9   | 2.4   | 1.0   | 1.5   | 0.6   | 1.6   | 1.4   | 1.1   |
|   | Province of Residence   | 0.9   | 0.2   | 4.0   | 0.9   | 1.7   | 0.6   | 3.0   | 0.4   | 0.2   | 1.8   |
| <b>Transplant recipients</b>                            | Sex   | 0.0   | 0.0   | 0.0   | 0.0   | 0.0   | 0.0   | 0.0   | 0.0   | 0.0   | 0.0   |
|   | Race/Ethnic Origin  | 18.1† | 19.0† | 18.5† | 16.3† | 18.2† | 17.0† | 16.1† | 15.5† | 17.1† | 20.3† |
|   | Blood Type  | 1.8   | 4.3   | 3.0   | 1.4   | 2.0   | 1.7   | 1.6   | 1.4   | 2.2   | 0.6   |
|   | Residential Postal Code                                       | 0.9   | 0.8   | 1.5   | 0.4   | 0.4   | 0.3   | 0.1   | 0.3   | 0.0   | 0.0   |
|   | Cause of Death  | 35.6† | 39.1† | 41.8† | 39.3† | 43.4† | 37.9† | 41.6† | 44.4† | 43.3† | 49.3† |
|   | Diagnosis   | 6.1   | 5.5   | 5.6   | 4.9   | 3.1   | 2.5   | 3.5   | 4.4   | 7.5   | 6.6   |
|   | Medical Status at Listing (heart, liver, lung transplants)    | 3.3   | 10.1† | 7.1   | 23.2† | 31.0† | 29.8† | 27.5† | 27.3† | 32.5† | 30.4† |
|   | Medical Status at Transplant (heart, liver, lung transplants) | 4.0   | 7.1   | 13.9† | 30.1† | 33.6† | 29.8† | 28.7† | 28.1† | 47.3† | 36.6† |
| Cause of Graft Failure (transplants with failed grafts) | 55.4†   | 54.1† | 62.2† | 51.7† | 52.3† | 53.8† | 60.5† | 45.8† | 48.3† | 23.8† |       |

**Notes**

\* Recipients of first grafts from 2010 to 2019.

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

**Source**

Canadian Organ Replacement Register, Canadian Institute for Health Information.

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 2010 to 2019. Table 11 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 10** Non-response/unknown values for key analytical data elements related to incident dialysis patients registered in CORR by year, 2010 to 2019

| Data type                | Data element                        | 2010  | 2011  | 2012  | 2013  | 2014  | 2015  | 2016  | 2017  | 2018  | 2019  | Total        |
|--------------------------|-------------------------------------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|--------------|
| <b>Dialysis patients</b> | Sex                                 | 0.0   | 0.0   | 0.1   | 0.1   | 0.0   | 0.0   | 0.0   | 0.0   | 0.0   | 0.0   | <b>0.0</b>   |
|                          | Race/Ethnic Origin                  | 4.3   | 3.6   | 4.6   | 5.2   | 4.3   | 2.5   | 4.1   | 3.8   | 5.4   | 4.8   | <b>4.3</b>   |
|                          | Residential Postal Code             | 0.8   | 0.8   | 1.5   | 1.1   | 1.0   | 0.8   | 0.8   | 0.5   | 0.4   | 0.6   | <b>0.8</b>   |
|                          | Diagnosis                           | 12.6† | 10.6† | 14.6† | 13.1† | 17.6† | 11.2† | 10.5† | 9.9   | 11.6† | 14.6† | <b>12.6†</b> |
|                          | Cause of Death                      | 43.6† | 45.4† | 50.9† | 52.7† | 55.5† | 55.9† | 53.9† | 51.4† | 53.3† | 54.4† | <b>50.8†</b> |
| <b>Risk factors</b>      | Angina                              | 13.0† | 8.6   | 9.1   | 7.6   | 4.4   | 2.9   | 2.3   | 1.8   | 2.4   | 2.1   | <b>5.6</b>   |
|                          | Coronary Artery Bypass/Angioplasty  | 11.8† | 7.0   | 7.9   | 6.3   | 3.3   | 2.3   | 2.1   | 1.5   | 2.0   | 1.6   | <b>4.7</b>   |
|                          | Pulmonary Edema                     | 12.1† | 7.6   | 8.6   | 7.0   | 4.5   | 4.3   | 4.2   | 2.4   | 3.1   | 2.4   | <b>5.7</b>   |
|                          | Myocardial Infarct                  | 12.0† | 7.7   | 8.5   | 6.7   | 3.8   | 2.5   | 2.1   | 1.7   | 2.0   | 1.8   | <b>5.0</b>   |
|                          | Diabetes                            | 6.3   | 4.6   | 4.0   | 3.6   | 1.9   | 1.4   | 2.3   | 1.4   | 2.2   | 3.0   | <b>3.1</b>   |
|                          | Cerebrovascular Accident            | 11.7† | 6.8   | 8.1   | 6.8   | 3.8   | 2.0   | 1.9   | 1.2   | 1.8   | 1.9   | <b>4.7</b>   |
|                          | Peripheral Vascular Disease         | 12.8† | 7.7   | 8.6   | 7.0   | 4.1   | 2.4   | 2.2   | 1.4   | 2.1   | 1.5   | <b>5.1</b>   |
|                          | Malignancy                          | 16.0† | 9.9   | 10.4† | 8.6   | 6.7   | 2.9   | 2.9   | 1.9   | 2.1   | 2.3   | <b>6.5</b>   |
|                          | Chronic Lung Disease                | 14.4† | 7.7   | 8.3   | 7.3   | 4.0   | 2.1   | 2.1   | 1.7   | 1.9   | 1.8   | <b>5.3</b>   |
|                          | Use of Medications for Hypertension | 9.3   | 6.7   | 6.4   | 4.3   | 2.0   | 0.8   | 1.5   | 1.0   | 4.5   | 3.1   | <b>4.0</b>   |
|                          | Presence of Other Serious Illness   | 22.3† | 21.3† | 24.4† | 26.4† | 22.4† | 22.1† | 25.0† | 24.3† | 24.2† | 25.0† | <b>23.7†</b> |
|                          | Current Smoker                      | 17.4† | 12.0† | 11.5† | 10.3† | 7.2   | 3.6   | 4.6   | 3.8   | 4.6   | 4.0   | <b>8.0</b>   |

**Note**

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

**Source**

Canadian Organ Replacement Register, Canadian Institute for Health Information.

**Table 11** Non-response/unknown values for key analytical data elements related to incident dialysis patients registered in CORR by province, 2010 to 2019

| Data type                | Data element                        | B.C.              | Alta.             | Sask.             | Man.              | Ont.              | Que.              | N.B.              | N.S.              | N.L.              | Total                   |
|--------------------------|-------------------------------------|-------------------|-------------------|-------------------|-------------------|-------------------|-------------------|-------------------|-------------------|-------------------|-------------------------|
| <b>Dialysis patients</b> | Sex                                 | 0.0               | 0.1               | 0.1               | 0.0               | 0.0               | 0.0               | 0.1               | 0.0               | 0.0               | <b>0.0</b>              |
|                          | Race/Ethnic Origin                  | 3.5               | 8.3               | 2.1               | 6.6               | 3.5               | 3.8               | 2.4               | 6.8               | 1.9               | <b>4.3</b>              |
|                          | Residential Postal Code             | 0.3               | 0.7               | 0.6               | 1.1               | 0.3               | 4.7               | 4.3               | 2.1               | 0.6               | <b>0.8</b>              |
|                          | Diagnosis                           | 19.2 <sup>†</sup> | 9.2               | 8.4               | 5.7               | 11.8 <sup>†</sup> | 16.6 <sup>†</sup> | 8.9               | 16.9 <sup>†</sup> | 18.9 <sup>†</sup> | <b>12.6<sup>†</sup></b> |
|                          | Cause of Death                      | 74.3 <sup>†</sup> | 42.9 <sup>†</sup> | 49.0 <sup>†</sup> | 31.4 <sup>†</sup> | 51.7 <sup>†</sup> | 34.0 <sup>†</sup> | 38.0 <sup>†</sup> | 48.4 <sup>†</sup> | 21.2 <sup>†</sup> | <b>50.8<sup>†</sup></b> |
| <b>Risk factors</b>      | Angina                              | 9.1               | 8.0               | 7.3               | 5.1               | 3.1               | 11.3 <sup>†</sup> | 5.1               | 4.7               | 2.9               | <b>5.6</b>              |
|                          | Coronary Artery Bypass/Angioplasty  | 8.7               | 7.4               | 2.2               | 4.9               | 2.2               | 10.5 <sup>†</sup> | 5.4               | 3.8               | 1.3               | <b>4.7</b>              |
|                          | Pulmonary Edema                     | 8.2               | 12.1 <sup>†</sup> | 9.2               | 4.8               | 2.7               | 11.7 <sup>†</sup> | 5.8               | 4.3               | 2.0               | <b>5.7</b>              |
|                          | Myocardial Infarct                  | 8.4               | 7.1               | 6.7               | 5.1               | 2.5               | 11.6 <sup>†</sup> | 5.8               | 4.7               | 1.6               | <b>5.0</b>              |
|                          | Diabetes                            | 8.4               | 3.0               | 0.5               | 3.0               | 1.5               | 6.3               | 2.2               | 1.4               | 0.3               | <b>3.1</b>              |
|                          | Cerebrovascular Accident            | 8.7               | 6.9               | 3.6               | 4.8               | 2.5               | 9.7               | 5.5               | 3.2               | 0.8               | <b>4.7</b>              |
|                          | Peripheral Vascular Disease         | 9.5               | 7.2               | 3.3               | 4.7               | 2.7               | 10.8 <sup>†</sup> | 5.3               | 4.6               | 1.7               | <b>5.1</b>              |
|                          | Malignancy                          | 10.1 <sup>†</sup> | 10.2 <sup>†</sup> | 4.0               | 7.3               | 3.6               | 13.4 <sup>†</sup> | 7.6               | 6.0               | 3.5               | <b>6.5</b>              |
|                          | Chronic Lung Disease                | 9.4               | 7.4               | 5.3               | 5.5               | 2.8               | 10.0 <sup>†</sup> | 6.0               | 5.3               | 2.0               | <b>5.3</b>              |
|                          | Use of Medications for Hypertension | 12.3 <sup>†</sup> | 3.4               | 1.6               | 3.2               | 1.6               | 7.5               | 2.9               | 2.3               | 0.7               | <b>4.0</b>              |
|                          | Presence of Other Serious Illness   | 88.7 <sup>†</sup> | 27.2 <sup>†</sup> | 11.1 <sup>†</sup> | 9.6               | 6.9               | 18.2 <sup>†</sup> | 14.0 <sup>†</sup> | 17.8 <sup>†</sup> | 6.7               | <b>23.7<sup>†</sup></b> |
|                          | Current Smoker                      | 8.8               | 10.3 <sup>†</sup> | 19.6 <sup>†</sup> | 9.6               | 4.6               | 17.3 <sup>†</sup> | 12.8 <sup>†</sup> | 9.1               | 4.0               | <b>8.0</b>              |

**Note**

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

**Source**

Canadian Organ Replacement Register, Canadian Institute for Health Information.

**Reliability/response bias:** A formal linkage<sup>1</sup> 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.

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 with 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 continues. Specifically, an investigation of the extent and impact of reporting completeness and accuracy of death status is ongoing 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).

CORR conducts yearly data quality checks to ensure data providers are using the listed diagnosis and cause of death codes. If diagnoses or causes of death are submitted using descriptive text for the code of “other” instead of the listed numeric codes, then these are recoded to the numerical code wherever applicable.

# Database revisions

The main changes have included the following:

- 2018: Updated valid treatment code to capture assisted home dialysis.
- 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*.<sup>2</sup>
- 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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