Canadian Organ Replacement Register
Privacy Impact Assessment

September 2010
Who We Are
Established in 1994, CIHI is an independent, not-for-profit corporation that provides essential information on Canada’s health system and the health of Canadians. Funded by federal, provincial and territorial governments, we are guided by a Board of Directors made up of health leaders across the country.

Our Vision
To help improve Canada’s health system and the well-being of Canadians by being a leading source of unbiased, credible and comparable information that will enable health leaders to make better-informed decisions.
CIHI is pleased to publish the following Privacy Impact Assessment pursuant to its Privacy Impact Assessment Policy:

CANADIAN ORGAN REPLACEMENT REGISTER
PRIVACY IMPACT ASSESSMENT

Approved by:

Jean-Marie Berthelot
Vice-President, Programs

Mimi Lepage
Chief Privacy Officer & General Counsel

Ottawa—June 2010
Table of Contents

Executive Summary ............................................................................................................ iii
1 Introduction .................................................................................................................... 1
  1.1 PIA Objectives and Scope ....................................................................................... 1
2 Background and Context ............................................................................................... 2
  2.1 Background .............................................................................................................. 2
  2.2 Description of CORR .............................................................................................. 3
    2.2.1 Description of CORR Data .............................................................................. 3
    2.2.2 Limits on Data Collected for CORR ............................................................... 4
    2.2.3 Personal Information in CORR ....................................................................... 4
  2.3 Users of CORR ......................................................................................................... 5
    2.3.1 General Public ................................................................................................ 5
    2.3.2 User Community (Data Providers) ................................................................. 5
    2.3.3 Third-Party Data Requests ............................................................................. 6
  2.4 Organization and Governance ................................................................................. 6
    2.4.1 Organization ................................................................................................... 6
    2.4.2 Governance .................................................................................................... 6
  2.5 Authorities Governing CIHI ...................................................................................... 7
    2.5.1 Legislation and Agreements ........................................................................... 7
    2.5.2 Committees .................................................................................................... 8
    2.5.3 CIHI Policies ................................................................................................... 8
3 Data Collection and Verification Process ....................................................................... 9
4 Privacy Analysis ........................................................................................................... 11
  4.1 Principle 1: Accountability for Personal Health Information .................................. 11
  4.2 Principle 2: Identifying Purposes for Personal Health Information ....................... 11
  4.3 Principle 3: Consent for the Collection, Use or Disclosure of Personal Health Information ................................................................................................. 12
  4.4 Principle 4: Limiting Collection of Personal Health Information ............................ 12
    4.5.1 Limiting Use .................................................................................................. 12
    4.5.2 Limiting Disclosure ....................................................................................... 13
    4.5.3 Limiting Retention ......................................................................................... 14
  4.5 Principle 5: Limiting Use, Disclosure and Retention of Personal Health Information ................................................................................................. 12
  4.6 Principle 6: Accuracy of Personal Health Information............................................. 14
  4.7 Principle 7: Safeguards for Personal Health Information ......................................... 15
  4.8 Principle 8: Openness About the Management of Personal Health Information ................................................................. 16
  4.9 Principle 9: Individual Access to, and Amendment of, Personal Health Information ................................................................................................. 16
    4.10 Principle 10: Complaints About CIHI’s Handling of Personal Health Information ................................................................................................. 17
5 Conclusion ................................................................................................................. 17
Appendix A—Glossary of Terms ....................................................................................... 19
Appendix B—Data Collection Forms ................................................................................ 21
Appendix C—Data Flow Diagram ..................................................................................... 69
Executive Summary

The purpose of this privacy impact assessment (PIA) is to examine the privacy, confidentiality and security risks associated with the Canadian Organ Replacement Register (CORR) at the Canadian Institute for Health Information (CIHI). CORR is a pan-Canadian information system for renal and extra-renal organ failure and transplantation in Canada. Through CORR, CIHI records and analyzes the level of activity and outcomes of solid organ transplantation and renal dialysis activities. Data comes from participating dialysis centres, transplant centres and organ procurement organizations in Canada. CORR receives advice from a board of directors that has representation from the Canadian Society of Transplantation, the Canadian Society of Nephrology, Canadian Blood Services, The Kidney Foundation of Canada and the Public Health Agency of Canada.

A review of the 10 privacy principles set out in the Canadian Standards Association’s Model Code for the Protection of Personal Information as they apply to CORR was undertaken. This assessment concludes that CORR is managed in a privacy-sensitive, confidential and secure manner. Except for the recommendation identified below, the mitigation measures currently in place are such that CIHI and its data providers are prepared to accept and manage any remaining risks.

The PIA sets out the following recommendation:

- CORR should review the practices around retaining paper questionnaires and, in consultation with Records Management, establish a retention and disposal schedule that takes into account any legal requirements or restrictions and redress mechanisms. CORR should dispose of documents that no longer have a specific purpose in a way that prevents improper or unauthorized use, access, copying, modification or disclosure and that is in accordance with CIHI’s policies and procedures.
1 Introduction

CIHI collects and analyzes information on health and health care in Canada. Its goal is to provide timely, accurate and comparable information to inform health policies, support the effective delivery of health services and raise awareness among Canadians of the factors that contribute to good health. CIHI obtains data directly from hospitals, regional health authorities and ministries of health, including personal health information about recipients of health services, registration and practice information about health professionals and health facility information.

CORR is Canada’s national database on patients treated for end-stage organ failure. It captures demographic information on treated patients and the specifics of the treatment. It also captures information about organ donors, transplant and dialysis facilities, and transplant waiting lists. Aggregated statistics are collected from organ procurement organizations. Through CORR, CIHI provides pan-Canadian information on vital organ replacement therapy in Canada, with the goal of enhancing research, treatment and patient care.

1.1 PIA Objectives and Scope

The purpose of this PIA is to examine the privacy, confidentiality and security risks associated with CORR. It includes

a) A review of the 10 privacy principles set out in Canadian Standards Association’s *Model Code for the Protection of Personal Information* as they apply to CORR;

b) A summary of potential privacy risks that were identified; and

c) Measures currently implemented or to be implemented to avoid or mitigate identified risks.

This PIA is specific to CORR. It builds on a PIA carried out in 2001 that evaluated and addressed key data protection issues.
2 Background and Context

2.1 Background

CORR is a national database on patients treated for end-stage organ failure that records, analyzes and reports the level of activity and outcomes of vital organ transplantation and renal dialysis. While it is managed by CIHI, an external, independent board of directors provides strategic advice.

Through CORR, CIHI records and analyzes the level of activity and outcomes of solid organ transplantation i and renal dialysis activities in Canada. More specifically, it

- Provides a national view of end-stage organ failure statistics for comparative analyses and research;
- Increases the availability of comparative data to facilitate better treatment decisions;
- Provides statistics that track long-term trends for organ transplantation, organ donation and dialysis activities that can be used for planning and optimizing programs;
- Enables feedback to centres as a quality assurance function for treatment; and
- Provides statistics to the health care community to support decision-making.

The first renal failure registry in Canada was started in 1972 under the leadership of Dr. Arthur Shimizu. In 1973, the registry was transferred to Statistics Canada, with the collaboration of the Kidney Foundation of Canada. In 1987, with the support of the Federal/Provincial Advisory Committee on Institutional and Medical Services, the registry was expanded to include data on extra-renal organ transplants. The expanded registry was originally maintained by the Hospital Medical Records Institute. In 1995, responsibility for CORR transferred to CIHI.

The number of solid organ transplants performed in Canada continues to grow and, since 1972, there has been tremendous innovation in technique as well as pre- and post-surgical care. CORR’s wealth of current and historical data has over time increased in its research potential. As a result, CORR has also seen an increased demand for data access on the part of data providers and third-party researchers in Canada.

---

i. Solid organ transplants include transplants of the heart, liver and kidney (in contrast to transplanted tissues, including bones, tendons, corneas, heart valves, veins, arms and skin).
2.2 Description of CORR

2.2.1 Description of CORR Data

CORR is a pan-Canadian information system for renal and extra-renal organ failure and transplantation in Canada. Its mandate is to record and analyze the level of activity and outcomes of solid organ transplantation and renal dialysis activities. In various forms, there has been a Canadian register of renal failure statistics since the early 1970s. In 1987, the register was expanded to include data on extra-renal organ transplants. In 1995, responsibility for CORR transferred to CIHI, which maintains numerous health system–related pan-Canadian data holdings.

The current mission of CORR is to provide pan-Canadian information on vital organ replacement therapy in Canada, with the goal of enhancing treatment, research and patient care.

CORR obtains data directly from hospital dialysis programs, regional transplant programs, organ procurement organizations and kidney dialysis services offered at independent health facilities. In 2009, 155 facilities in Canada reported data to CORR, covering all 13 jurisdictions. The number of facilities submitting data varies from one year to another because of site mergers or implementation of new sites for dialysis, for example.

Fifteen different forms are used to collect information about patients, donors and facilities. CORR does not collect full medical treatment records of persons. Only information relevant to the goals of CORR is gathered.

Patients are tracked from their first treatment for end-stage organ failure (dialysis or transplantation) to their death, unless they become lost to follow-up. CORR does capture out-of-country transfers when informed by reporting facilities. Information on organ donors as shown in Table 1 below is linked to recipient information. At present, CORR does not collect patient-level information on those who have been listed for transplant but do not receive a transplant.

CORR collects information on three types of people: 1) recipients and their specific treatments, 2) living organ donors and 3) deceased organ donors. In addition to recipient-specific information, the facility profile form captures information on the facility, including aggregated patient statistics. The wait list summary form provides statistical information from organ procurement organizations on numbers of patients waiting for organ transplants and the number who have died while on the waiting list.

Data is collected for recipients of liver, pancreas, lung/heart–lung, heart and kidney transplants, as well as for chronic renal failure patients and renal replacement treatments. The same personal information is collected for all recipients, while the clinical details are specific to the type of transplant. A copy of the collection forms is found in Appendix B. The chart below summarizes the data elements found in CORR.

ii. Provincial organizations such as Ontario’s Trillium Gift of Life Network and Alberta’s HOPE Program.
Table 1

<table>
<thead>
<tr>
<th>Personal Health Information</th>
<th>Recipient</th>
<th>Living Donor</th>
<th>Deceased Donor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital Name</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Name</td>
<td>Y, complete name (first and last)</td>
<td>First three characters of last name</td>
<td>First three characters of last name</td>
</tr>
<tr>
<td>Province of Residence</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Postal Code</td>
<td>Y</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Birthdate</td>
<td>Y</td>
<td>Age in years</td>
<td>Age in years, months (infants only), days (infants only)</td>
</tr>
<tr>
<td>Sex</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Provincial Health Card Number</td>
<td>Y</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Blood Type</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Race</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Height</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Weight</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Clinical Information Detailed According to Type of Transplant</td>
<td>• Transplant information • Wait time • Risk factors • Serology status • Outcome • Post-transplant follow-up information</td>
<td>• Hospital information • Serology • Risk factors • Organ-specific information</td>
<td>• Province of death • Cause of death • Serology • Risk factors • Organ-specific information</td>
</tr>
</tbody>
</table>

Note
Y = yes, information is collected; N = no, information is not collected.

2.2.2 Limits on Data Collected for CORR

CORR collects and receives only identification, demographic, medical and technical information about recipients, donors and facilities that CIHI has identified as relevant to the goals of CORR, in consultation with the CORR Board of Directors.

2.2.3 Personal Information in CORR

CORR captures detailed recipient identification information (summarized in Table 1 above) to review data quality and track recipients over time to study the effectiveness of surgical methods. Each donor is identified by a recovery program donor number; this number is recorded as part of each organ recipient’s profile. This number is used when linking recipient information to donor profile information and also when requesting clarification of donor information from the local centre.
2.3 Users of CORR

Data products and services have been developed to address three categories of users based on their information needs.

2.3.1 General Public

CORR provides a national view of end-stage organ failure statistics for comparative analyses and research studies that benefit the knowledge base of professionals, patients and the general population. The general public has access to published reports containing aggregated findings, such as an annual report, special analytical products and various data tables. The annual publication is titled *Treatment of End-Stage Organ Failure in Canada*.

Due to the nature of the material being reported by CORR, there are instances when cells with fewer than five observations are reported. CORR and CIHI recognize that there is a small risk of re-identification from reporting small cell sizes if they were to be matched with other external sources of information. Cases where small cells are published are reviewed with CIHI statisticians to ensure that the risk of re-identification is minimized. Small cells are typically reported at a provincial or national level to reduce the risk of re-identification.

In addition, it may be possible to identify hospitals or physicians where there are small cell sizes or where only one hospital or physician provides a given procedure in a province. CIHI policies call for protecting organization and provider identities in most situations, unless the hospital or physician has provided authorization or consent. In 2000, CORR asked CEOs of hospitals that submit data to CORR for authorization for activities such as the release of small cell sizes and data linkages. They unanimously authorized CIHI to include small cell sizes in reports and to perform data linkage (between CORR and the Discharge Abstract Database).

The availability of small cell sizes is considered vital to providing clinical information needed by the participating centres. For example, the small cell information on pediatric patients is particularly important as these patients have different diagnoses, comorbid conditions and outcomes. Small cells also arise in relation to infrequent transplantation procedures (combination transplants). The incidence of these procedures is important because of their rarity. If Canadian practitioners cannot obtain Canadian information from CORR, they have to rely on sources from the United States, which have less clinical relevance.

2.3.2 User Community (Data Providers)

CIHI has a user community of data providers. Treatment centres rely on comparative information to facilitate better treatment decisions. Hospitals, organ procurement organizations and treatment centres use the data to ensure quality of treatment and as a national standard for comparison.

Organizations providing data to CORR receive summary edited files of their own data for data quality updating and review. Comparative reports are produced at the provincial level. Currently, there are no comparative reports published at the facility level.
As the national database for dialysis and transplantation, CORR reports national and provincial aggregated results of dialysis and transplantation activity to the Canadian Society of Nephrology and the Canadian Society of Transplantation. CORR also provides aggregated information to a large constituency of health care workers, including dialysis and transplant nurses, transplant coordinators, organ procurement organizations, hospital administrators, government officials, the Kidney Foundation of Canada and the Canadian Cystic Fibrosis Foundation.

2.3.3 Third-Party Data Requests

CIHI also administers a third-party data request program to facilitate and support statistical health research in Canada. Aggregated data addresses many but not all research needs. As such, CIHI discloses de-identified record-level data for approved research purposes, subject to CIHI’s standard practices for avoiding residual disclosure and the requisite security mechanisms outlined in CIHI’s third-party data request process.

2.4 Organization and Governance

2.4.1 Organization

CORR is a program under the Health Resources Information branch at CIHI. As previously indicated, CORR works with an external, independent board of directors that provides strategic advice on the register, such as what data elements need to be collected and priority areas for analysis.

2.4.2 Governance

<table>
<thead>
<tr>
<th>Position/Group</th>
<th>Role/Responsibilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vice President, Programs</td>
<td>The vice president is responsible for the overall operations and strategic direction of CORR.</td>
</tr>
<tr>
<td>Director, Health Resources</td>
<td>The director is responsible for strategic and operational decisions about CORR, ensuring its continued successful development and managing the strategic relationship with the CORR Board of Directors and other stakeholders.</td>
</tr>
<tr>
<td>Information</td>
<td></td>
</tr>
<tr>
<td>Manager, Clinical Registries</td>
<td>The manager is responsible for ongoing management, development and dissemination of CORR. The manager makes operational decisions about CORR, supports the CORR Board of Directors and consults internally and with CORR clients as appropriate.</td>
</tr>
<tr>
<td>CORR Board of Directors</td>
<td>The CORR Board of Directors is composed of representatives from the data-providing organizations and other key stakeholders. These include the Canadian Society of Transplantation, the Canadian Society of Nephrology, the Kidney Foundation of Canada, the Canadian Association of Nephrology Nurses and Technicians, the Quebec Society of Transplantation, the Quebec Society of Nephrology, Canadian Blood Services and the Public Health Agency of Canada. The CORR Board of Directors provides guidance and advice either directly or through the establishment of temporary advisory groups.</td>
</tr>
<tr>
<td>Position/Group</td>
<td>Role/Responsibilities</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>CORR Program Lead</td>
<td>The program lead coordinates activities related to the functioning of CORR and serves as the main day-to-day contact for stakeholders. He or she ensures the timely delivery of results and services that satisfy business and user requirements.</td>
</tr>
<tr>
<td>Chief Technology Officer</td>
<td>The chief technology officer is responsible for the strategic direction and overall operations/implementation of CIHI’s technological and security solutions.</td>
</tr>
<tr>
<td>Chief Privacy Officer</td>
<td>The chief privacy officer is responsible for the strategic direction and the overall implementation of CIHI’s privacy program.</td>
</tr>
<tr>
<td>Manager, Analytical Systems</td>
<td>The manager is responsible for ensuring that technical requirements for the ongoing development and maintenance of CORR are met. The Analytical Systems team is responsible for acting as the system administrator for CORR.</td>
</tr>
</tbody>
</table>

### 2.5 Authorities Governing CIHI

CIHI adheres to its *Privacy Policy on the Collection, Use, Disclosure and Retention of Personal Health Information and De-Identified Data, 2010* (Privacy Policy, 2010) and to any applicable privacy legislation and/or agreements.

#### 2.5.1 Legislation and Agreements

**Legislation**

CIHI is a secondary data collector of health information, specifically for the planning and management of the health system, including statistical analysis and reporting. Data providers are responsible for meeting the statutory requirements in their respective jurisdictions, where applicable, at the time data is collected.

All provinces and territories have public-sector privacy legislation in place. Canadian privacy legislation includes provisions that authorize public bodies covered by the acts to disclose person-identifiable data, without the consent of the individual, for statistical purposes. Alberta, Saskatchewan, Manitoba and Ontario (legislation pending in Newfoundland and Labrador and New Brunswick) also have health information–specific privacy legislation with express lawful authority to use and disclose personal health information, without individual consent, for the purposes of managing the health system, including statistical analysis and reporting.

For example, CIHI is recognized as a prescribed entity under the *Personal Health Information Protection Act* of Ontario. Custodians in Ontario may disclose personal health information to CIHI without patient consent pursuant to Section 29, as permitted by Section 45(1) of the act.
Agreements

CIHI has in place the following types of agreements:

- Bilateral and data-sharing agreements between the provinces and territories and CIHI in support of data collection and any subsequent data sharing with authorized users.
- Data-sharing and other types of agreements negotiated between other data providers and CIHI, which set out the purpose, use, disclosure and retention requirements and any subsequent data sharing that may be permitted.

2.5.2 Committees

- The CORR Board of Directors is an independent body chaired by a representative of the Canadian Society of Transplantation or the Canadian Society of Nephrology. The CORR Board of Directors is made up of provincial transplantation and nephrology representatives and is constituted to provide advice to CIHI with respect to which data needs to be collected and how to report it; it is not restricted to this role.

2.5.3 CIHI Policies

- CIHI has a suite of privacy and security policies, procedures and guidelines designed to protect personal health information from unauthorized or unintentional loss, theft, access, use, modification or disclosure and which outlines the roles and responsibilities of management and staff at CIHI.
3 Data Collection and Verification Process

CORR is a patient-based tracking system that follows a patient’s treatment for organ failure until the patient dies or is lost to follow-up. CIHI is a secondary data collector, and patient information is abstracted from patient records maintained by individual transplant centres, provincial organ procurement organizations and centres providing dialysis services; these centres are typically located in hospital settings but sometimes function as satellite or stand-alone facilities. Data is submitted annually or at more frequent intervals throughout the year. In 2009, 155 facilities in Canada reported data to CORR, covering all 13 jurisdictions.

Table 2

<table>
<thead>
<tr>
<th>Type of Facility</th>
<th>Province</th>
<th>Number of Facilities Providing Data</th>
<th>Number of Facilities for Each Province and Territory</th>
<th>Data Submission: Quarterly, Annually, etc.</th>
<th>Number of Forms Used by Data Providers (2009)</th>
<th>Most Recent Data Year (Currently Submitting)</th>
<th>Submission: Paper Based, Electronic or Mixed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transplant Centres</td>
<td></td>
<td>28</td>
<td>B.C.: 3 Alta.: 3 Sask.: 1 Man.: 2 Ont.: 8 Que.: 9 N.S.: 2</td>
<td>Mix; at least semi-annually</td>
<td>Transplant registration: 2,200 Outcome: 500 Liver follow-up: 550</td>
<td>2009</td>
<td>Mix; paper and electronic (Excel)</td>
</tr>
<tr>
<td>Total (Where Applicable)</td>
<td></td>
<td>155</td>
<td>155</td>
<td>47,600</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note
Number of forms is a count of records processed (paper and electronic) for 2009.
Data is collected using either paper questionnaires that are mailed in to CIHI or Excel files that are submitted electronically through a combination of two secure applications: CIHI’s electronic Data Submission Services (eDSS) and Client Services. Both are accessed through industry-standard HTTPS protocol over SSL using trusted secure certificates.

Patients that are entered into the CORR database are tracked as they use various facilities or treatment options. This means that a renal transplant record, for example, will be added to existing patient records if the patient received prior dialysis treatments. Follow-up information for dialysis patients is collected annually; for transplant patients, it is limited to date and cause of graft failure. Follow-up records are added and linked to existing records by matching health card number, patient name and date of birth.

Data is checked by CORR staff for errors and inconsistencies, and questionable information is fed back to individual transplant centres, organ procurement organizations and dialysis centres by CORR staff for follow-up and revision.

In May 2007, CIHI adopted the Policy on Methods of Disseminating Record-Level Data to External Clients and Data Providers, which introduced improved safeguards in transmitting data back to providers for follow-up and validation. Prior to 2007, incomplete paper collection forms were mailed or couriered back to the providers for updates. Paper records in the mail pose a significant risk and, in fact, if lost in transit would amount to a privacy breach. Rather than mailing paper copies of transcripts back to data submitters, data files are sent on CD. The data must now be encrypted, password protected and accompanied by a cover letter. The CDs are sent to the authorized registered data users for updating via courier, and confirmation of receipt must be obtained by the program area.

In the spring of 2009, a new mechanism and infrastructure to electronically disseminate information back to data providers was launched to enhance the validation process by minimizing the use of CDs. The automated approach has data loaded to a web interface with access granted to only those appropriately authorized. Updating the data is done directly online and then resubmitted to CORR with stringent security features built in as part of the system architecture.

In the fall of 2010, CORR will be enhanced to permit electronic processing of data submitted via eDSS according to prescribed file specifications. Data will be verified and processed by the CORR application and problems communicated back to data providers on system-generated submission reports via the previously mentioned electronic dissemination mechanisms. Data providers will then have an opportunity to correct or update data and resubmit.

Two data flow diagrams are found in Appendix C depicting the dialysis patient flow and the donor data flow.
4 Privacy Analysis

4.1 Principle 1: Accountability for Personal Health Information

CIHI’s president and chief executive officer is ultimately accountable for privacy and security at CIHI. The day-to-day responsibility has been delegated to CIHI’s chief privacy officer (CPO). Furthermore, CIHI has a corporate Privacy, Confidentiality and Security team mandated to review and, where appropriate, approve internal data linkages across data holdings and external data requests that involve 1) data linkages, 2) disclosure outside of Canada and 3) retention periods beyond three years. CIHI also has a Privacy and Data Protection Subcommittee of its Board of Directors and an external chief privacy advisor to advise the CPO and the organization as a whole on any given privacy or security matter, as the need arises.

As previously indicated, strategic direction for CORR is achieved through collaboration with a Board of Directors that represents the data providers and other stakeholders. Functional responsibility for CORR falls under the Health Resources Information branch. The manager responsible for CORR ensures adherence to CIHI procedures around protecting personal information, receiving and responding to complaints and inquiries, and training staff about procedures. CORR clients are subject to the requirements of data protection laws in their respective jurisdictions and the independent oversight of privacy commissioners or their equivalents.

4.2 Principle 2: Identifying Purposes for Personal Health Information

CIHI collects only personal health information required for purposes specific to CORR:

- The patient’s full name, postal code, health card number and date of birth are collected to correctly identify the patient and allow year-to-year analysis of the outcome of procedures for the individual.
- The patient’s racial origin is collected to monitor incidence and patterns of disease that may affect patient outcomes and which research has shown to vary among racial groups.
- For the donor profile, the donor’s name and province of residence are collected to link donor demographic and health status information with transplant recipients. This is required to analyze the effects of donor health status and donor–recipient matches on transplant outcomes. Province of residence was not formally collected until 2001 and is used for provincial reporting.

Data dictionaries and data users’ manuals that are currently referenced list data elements and describe their purpose. These documents are currently being reviewed and revised to conform to CIHI standards and will be made publicly available during 2010.
4.3 Principle 3: Consent for the Collection, Use or Disclosure of Personal Health Information

Privacy laws in Canada recognize the principle that personal health information may be disclosed without the individual’s consent where the disclosures are for planning purposes, research or statistical analysis. That said, every privacy code uses unique language and may have different requirements embodied in the law itself and in its regulations.

CIHI may collect personal health information from data providers without the consent of individuals for the planning and management of the health system, including statistical analysis and reporting.

4.4 Principle 4: Limiting Collection of Personal Health Information

CIHI limits the collection of personal health information for CORR to that which is necessary for its identified purposes and collects information by fair and lawful means. The required data elements have been suggested by the CORR Board of Directors, representing data providers, along with CIHI. The last full review was undertaken in 2001. Every year, a partial review is completed and minor adjustments included. A full review of the data variables will be undertaken in 2010–2011.

4.5 Principle 5: Limiting Use, Disclosure and Retention of Personal Health Information

4.5.1 Limiting Use

CIHI publishes a wealth of publicly available aggregate-level data. Considerable information is made available through analytic reports as a means to address a broad base of information needs. CIHI limits access to and use of CORR data to authorized purposes, and only authorized users have access. CORR staff is permitted to access and use data holdings containing personal information on a need-to-know basis.

Access to and use of data by other CIHI staff outside of CIHI’s Clinical Registries Unit, which may be required to prepare reports or publications, is done in compliance with CIHI’s Privacy Policy and related procedures. Prior to granting access to other staff, justification for use, manager approval and auditing is required. Employee access to specific data holdings is frequently reviewed and validated by the program manager.

At CIHI, sensitive data elements such as the health card number are encrypted before the data set is used for analysis or report production. Health card numbers in an unencrypted form are rarely available to staff and, more often than not, access is limited to performing data submission and data quality assessments, such as verification and validation activities. Since 2009, data sets used for analysis purposes do not contain unencrypted health card numbers or patient names. These data sets are maintained separately from the main CORR application.
4.5.2 Limiting Disclosure

CORR data is used for analysis and statistical reporting purposes. As part of its mandate, CIHI publishes aggregated health information only in a manner designed to minimize any risk of re-identification and residual disclosure. This generally requires a minimum of five observations per cell. Due to the nature of the material being reported by CORR, there are instances when cells with fewer than five observations are reported. It is recognized that there is a small risk of re-identification from reporting small cell sizes, if they were to be matched with other external sources of information. Cases where small cells are published are reviewed with CIHI statisticians to ensure the risk of re-identification is minimized. Small cells are typically reported at a provincial level and more often at a national level to reduce the risk of re-identification.

The availability of small cell sizes is considered vital to providing clinical information needed by the participating centres. For example, the small cell information on pediatric patients is particularly important as these patients have different diagnoses, comorbid conditions and outcomes. Small cells also arise in relation to infrequent transplantation procedures (combination transplants). The incidence of these procedures is important because of their rarity. If Canadian practitioners cannot obtain Canadian information from CORR, they have to rely on sources from the United States, which have less clinical relevance.

In addition, it may be possible to identify hospitals or physicians where there are small cell sizes or where only one hospital or physician provides a given procedure in a province. CIHI policies call for protecting organization and provider identities in most situations, unless the hospital or physician has provided authorization or consent. In 2000, CORR and CIHI asked CEOs of hospitals that submit data to CORR for authorization for activities such as the release of small cell sizes and data linkages. They unanimously authorized CIHI to include small cell sizes in reports.

CIHI may disclose de-identified record-level data to third parties on a case-by-case basis. For each request, a Third-Party Record-Level Data Request Form is completed that addresses all the requirements to be satisfied prior to the disclosure of data for research purposes. The researchers must also sign a Non-Disclosure/Confidentiality Agreement that requires the individuals to agree to comply with the conditions and restrictions imposed by CIHI relating to the use, security, disclosure, return or destruction of data. This agreement also grants CIHI the right to audit the data recipient and organization. CIHI data disclosures are made at the highest degree of anonymity possible to meet the needs of the request. This means that, whenever possible, data is aggregated. Where aggregate data is not sufficiently detailed for the research purposes, de-identified record-level data may be disclosed. Personal identifiers such as health card number are suppressed or de-identified through techniques such as encryption or truncation. For each record-level request, a unique data file is cut from CORR, and only those data elements required for the research are included in the file. In other words, CIHI applies the minimal data disclosure principle to data sets it prepares for researchers.
4.5.3 Limiting Retention

CORR electronic data is retained permanently to permit relational retrospective and trend analysis. Patients in CORR are tracked from their first treatment for end-stage organ failure (dialysis or transplantation) until they die or are lost to follow-up. The most recent paper forms are retained in a secure storage facility located on site to facilitate follow-up reference. Older questionnaires are retained off site in a secure storage facility. While CORR has destroyed paper forms in the past, minimally after five years, there is currently no retention guideline in place and forms have not been destroyed for several years.

Risk: There are no guidelines in place for retaining paper questionnaires that contain personal information. Paper questionnaires stored over a long period of time increase the risk of improper access to personal information.

Recommendation: CORR should review the practices around retaining paper questionnaires and, in consultation with Records Management, establish a retention and disposal schedule that takes into account any legal requirements or restrictions and redress mechanisms. CORR should dispose of documents that no longer have a specific purpose in a way that prevents improper or unauthorized use, access, copying, modification or disclosure and that is in accordance with CIHI’s policies and procedures.

4.6 Principle 6: Accuracy of Personal Health Information

CIHI has a comprehensive data quality program. Any known data quality issues are addressed with the data provider and/or documented in data limitations documentation that is made available to all users.

Data quality is ongoing within CORR, including the annual completion of the CIHI Data Quality Framework and the subsequent production of data quality reports. There are no known coverage errors within CORR (that is, there are no programs that are not reporting). While completeness of key data elements has improved over time, the proportions of unknown values reported for primary diagnosis, cause of death and cause of graft failure continue to exceed 10% in many cases. A reabstraction study was completed in 2008–2009 to look at the quality of coding comorbid conditions and certain demographic variables. As a result of lessons learned, adjustments are being made to the CORR coding manual, and an education program for data providers was introduced to ensure that the data contained therein is as accurate as possible.

For more information, please see the Canadian Organ Replacement Register (CORR) Data Quality Study.

In 2009, CORR began participating in CIHI’s annual data quality reporting system for provincial deputy ministers of health. These data quality reports are designed to assist deputy ministers to better understand the quality of data submitted to CIHI by their respective jurisdictions. The objectives of this report are to highlight findings from data quality assessments, identify emerging data quality issues and elevate the priority with which issues are addressed by individual jurisdictions.
4.7 Principle 7: Safeguards for Personal Health Information

CIHI has established physical, technical and administrative security practices to ensure the confidentiality and security of its data holdings.

While paper forms submitted to CORR are stored in CIHI’s controlled-access office in locked cabinets, accessible only to certain CORR staff, this PIA recommends implementing best-practice retention guidelines for paper records. Electronic data is stored on a server, which is part of CIHI’s in-house network. Data entry is done by authorized CORR staff. Access to the database by CIHI staff is restricted electronically and requires authorization by the manager responsible for CORR.

The database used for CORR has various features beneficial for both data protection and security. The database is password-protected and can be accessed only by programming languages that require specialized expertise.

Firewalls and/or other appropriate security technologies are employed to protect the system and the data from unauthorized access. Session time-outs are in place that automatically log a user out after 10 minutes of inactivity. Automated auditing is in place to record and track what changes are made by all users of the system within CIHI.

A 2007 CIHI initiative introduced the de-identification of patient health card numbers in the internal analytical environment. This project now prevents routine access to, or view of, the health card numbers among internal CIHI users and analysts. Exceptional access to the health card numbers requires a formal review and approval process to determine where temporary access should be granted. As a result, all health card numbers contained in CORR have been encrypted. This initiative began in the spring of 2007 and was completed in March 2009.

Furthermore and as previously indicated, new procedures were implemented in 2008 to improve the transmission of data back to providers for follow-up and validation purposes. CIHI no longer mails out paper copies of transcripts. Rather, data files are created on CDs, and the data is encrypted, password protected and accompanied by a cover letter. The CDs are sent to the authorized registered data users via courier, and confirmation of receipt is obtained by the program area. In the spring of 2009, CIHI implemented a new mechanism and infrastructure to electronically disseminate information. Data is loaded onto a web-based application, and users have electronic access to their own data for verification and updating.

This data dissemination mechanism, which uses an interface option, allows CIHI to securely post reports that contain sensitive data and allows data providers to receive these reports. Health card numbers are not included in the reports. The interface includes a screen consisting of a listing of external client contact information completed by CIHI. Another screen allows CIHI users to load files to be posted onto Client Services. A third screen consists of a listing of all files posted, which is available to CIHI, and allows users to delete files. Once a report is posted, the external client receives an email inviting him or her to pick up the report.
Once external CORR clients receive an email indicating a report is available, they must log into CIHI’s Client Services site with a username and password and select the report. The report is available to the client for a defined period of time.

With the introduction of the web-based data dissemination mechanism, the process of returning data back to the provider for purposes of data quality follow-up (review and update or correction of errors) could result in reports for one facility being mistakenly posted for access by another facility. Although care is taken to ensure the correct file is chosen and posted, the process is not fool-proof and inappropriate disclosure could result.

To address this, the design of the new web-based data dissemination mechanism for data quality follow-up reports uses an interface option. Measures that have been implemented to ensure the wrong file is not inadvertently posted for access by a facility include:

- Implementing a file naming convention that checks the client ID in the file name against the client ID in the contact list prior to sending a file to the client. Files that do not meet this naming convention will not be sent.
- Auto-populating the Client Services user ID in the contacts page. The means of linking this data dissemination mechanism to Client Services (where the files are picked up by the client) is the Client Services user ID.
- Confirming with a pop-up message that the user wishes to upload the file selected.

Additionally, even after the file has been sent, CIHI staff has the ability to delete files from the dissemination mechanism.

### 4.8 Principle 8: Openness About the Management of Personal Health Information

CIHI makes information available about its privacy policies, data practices and programs relating to the management of personal health information on its corporate website. As well, this PIA is accessible on CIHI’s website (www.cihi.ca).

### 4.9 Principle 9: Individual Access to, and Amendment of, Personal Health Information

CIHI recognizes that individuals have a right to access their personal health information. Sections 60 to 63 of the *CIHI Privacy Policy on the Collection, Use, Disclosure and Retention of Personal Health Information and De-Identified Data, 2010* state that when an individual requests an amendment or correction to his or her personal health information, CIHI refers the individual to the data provider. When a data provider notifies CIHI that the individual has successfully demonstrated the inaccuracy or incompleteness of the personal health information, CIHI amends the information as required. To date there have been no requests for access to personal information.
4.10 Principle 10: Complaints About CIHI’s Handling of Personal Health Information

As set out in CIHI’s Privacy Policy on the Collection, Use, Disclosure and Retention of Personal Health Information and De-Identified Data, 2010, complaints about CIHI’s handling of personal health information are investigated by its Chief Privacy Officer. If an individual does not believe that his or her complaint has been satisfactorily resolved, he or she may appeal to CIHI’s Chief Privacy Advisor, who will report his findings to CIHI’s President and Chief Executive Officer. If a complaint is found to be justified, CIHI takes appropriate corrective measures.

5 Conclusion

This PIA summarizes CIHI’s assessment of the privacy implications of CORR. It makes only one recommendation, which relates to establishing a retention and disposal schedule for the paper questionnaires submitted to CORR. It is felt that this recommendation can be met with minimal impact on the operations of CORR.
# Appendix A—Glossary of Terms

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>data provider</td>
<td>An organization or individual that discloses health information to CIHI.</td>
</tr>
<tr>
<td>de-identified data</td>
<td>Personal health information that has been modified to the fullest extent possible using appropriate methodologies so the identity of the individual cannot be determined by a reasonably foreseeable method.</td>
</tr>
<tr>
<td>health information</td>
<td>A broad term encompassing information of all types about health and health care, including personal health information, health facility information and health expenditure information.</td>
</tr>
<tr>
<td>meta data</td>
<td>Summary information that assists data users in interpreting and using data.</td>
</tr>
<tr>
<td>micro data</td>
<td>Detailed individual record-level information pertaining to a specific patient.</td>
</tr>
<tr>
<td>mitigation measures</td>
<td>Means of reducing the possibility of privacy risks.</td>
</tr>
<tr>
<td>organization-identifiable information</td>
<td>Information that includes the identity (name or number) of any health organization, health facility, local health integration network, government ministry, continuing care facility, acute care hospital, specialty hospital, long-term care home, ambulatory agency (such as an outpatient clinic), rehabilitation centre, community health centre, home care agency, mental health facility, regional health authority or local health authority.</td>
</tr>
<tr>
<td>personal health information</td>
<td>Health information about an individual that identifies the individual or may be used or manipulated by a reasonably foreseeable method to identify the individual or may be linked by a reasonably foreseeable method to other information that identifies the individual. Personal health information does not include health facility information, as defined in CIHI’s Policy on Health Facility–Identifiable Information, or provider information.</td>
</tr>
<tr>
<td>privacy impact assessment</td>
<td>A tool used to assess the possible privacy-related consequences of systems and practices for the collection, use and disclosure of personal information, including personal health information.</td>
</tr>
<tr>
<td>privacy risk</td>
<td>An undesirable event with the potential to compromise privacy or breach data confidentiality.</td>
</tr>
<tr>
<td>record-level data</td>
<td>Data in which each record is related to a single individual or organization (sometimes referred to as micro data).</td>
</tr>
<tr>
<td>residual disclosure</td>
<td>Situations in which the identity of an individual could be determined by reasonably foreseeable methods from personal health information (including when the data has been aggregated or has had direct identifiers stripped, encrypted or masked).</td>
</tr>
<tr>
<td>secondary use</td>
<td>For the purposes of CORR, the use of personal health information for purposes that fall outside of direct health care delivery, such as for statistical and analytical purposes.</td>
</tr>
<tr>
<td>residual risk</td>
<td>The remaining risk after the mitigation measures have been applied to the identified privacy risks.</td>
</tr>
</tbody>
</table>
Appendix B—Data Collection Forms
Complete this form to reflect the situation at your facility on December 31, 2010. Please keep a copy for your records.

Hospital Name: __________________________
Hospital City: __________________________
Hospital Number: _______________________

**SECTION A—FACILITY RESOURCES**

1. Does your facility re-use dialysers?
   - [ ] No  [ ] Yes  ➔ What type of system is used?
     - [ ] Manual (M)  [ ] Automated (A)
   - What number patients were on re-used dialysers on December 31, 2010?
   - What method is used for sterilizing re-used dialysers? *(Please check one.)*
     - [ ] Heat (H)
     - [ ] Formaldehyde (F)
     - [ ] Renalin (R)
     - [ ] Glutaraldehyde (G)
     - [ ] Other chemical (specify) (O)

2. a) What is the total number of haemodialysis stations at your facility? *(Note: This does not include stations at community centres.)*
   - [ ] No (0)  [ ] Yes ➔ Who is responsible for CRRT?
     - [ ] Nephrologist only (1)
     - [ ] Intensivist only (2)
     - [ ] Nephrologist/Intensivist share care (3)

3. Is continuous renal replacement therapy (CRRT) used?
   - [ ] No (0)  [ ] Yes ➔ How many haemodialysis patients are being dialysed using the following accesses? *(Please report the number of patients.)*

<table>
<thead>
<tr>
<th>Access</th>
<th>At Hospital</th>
<th>At Home</th>
<th>At Community Centre</th>
</tr>
</thead>
<tbody>
<tr>
<td>Natural vein fistula</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Synthetic arteriovenous graft (PTFE)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Saphenous vein graft</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Permanent central venous catheters</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Temporary subclavian vein catheters</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Temporary internal jugular vein catheters</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Temporary femoral vein catheters</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other (specify)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

4. b) How many haemodialysis patients are on more than one access on December 31, 2010?

5. a) Does your facility provide dialysis facilities to temporary visitors (including holidays)?
   - [ ] No  [ ] Yes

   b) Is your facility always able to provide dialysis facilities to temporary visitors?
   - [ ] No  [ ] Yes

6. a) Does your facility have adequate haemodialysis facilities (e.g., in terms of space/physical capacity, human resources)?
   - [ ] No ➔ If not, select the top 2 reasons why facilities are inadequate:
     - [ ] inadequate space for patients (1)
     - [ ] inadequate space for machines (2)
     - [ ] inadequate space for training facilities (3)
     - [ ] lack of physical capacity to expand (4)
     - [ ] lack of qualified registered nurses (5)
     - [ ] lack of dieticians, social workers, pharmacists or other allied health professionals (6)
     - [ ] lack of technicians/technologists (7)
     - [ ] lack of dedicated nephrologist(s) (8)
     - [ ] other—please specify: _______________

   b) Do staff and patients have free choices as to which modality is selected?
   - [ ] No ➔ If not, select the top 2 reasons why patients do not have free choice:
     - [ ] other modality not supported at centre (1)
     - [ ] space restrictions limit options (2)
     - [ ] geographic access to centre by patients limits options (3)
     - [ ] other—please specify: _______________
SECTION B—TREATMENT AVAILABLE

7. a) What types of haemodialysis treatment are supported by your facility? (Please check all that apply.)

<table>
<thead>
<tr>
<th>Treatment Type</th>
<th>Acute Care Hospital</th>
<th>Community Centre</th>
<th>Chronic Care Facility</th>
<th>Home</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total Care</td>
<td>Limited Self Care</td>
<td>Total Self Care</td>
<td>Total Self Care</td>
</tr>
<tr>
<td>Conventional HD</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Short Daily HD</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Slow Nocturnal HD</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

b) Please indicate the number of patients on each form of treatment as of December 31, 2010

<table>
<thead>
<tr>
<th>Treatment Type</th>
<th>Acute Care Hospital</th>
<th>Community Centre</th>
<th>Chronic Care Facility</th>
<th>Home</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total Care</td>
<td>Limited Self Care</td>
<td>Total Self Care</td>
<td>Total Self Care</td>
</tr>
<tr>
<td>Conventional HD</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Short Daily HD</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Slow Nocturnal HD</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

SECTION C—ADEQUACY/CLEARANCE

8. a) Is urea kinetic modelling used to monitor haemodialysis prescription?

- □ No □ Yes → What percentage of patients are routinely monitored?
  - □ 0-49% of patients (0)
  - □ 50-75% of patients (1)
  - □ 76-100% of patients (2)

→ What is the target Kt/V or percent reduction in the urea (PRU)?

<table>
<thead>
<tr>
<th>Kt/V</th>
<th>PRU</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.2</td>
<td>0-64% (0)</td>
</tr>
<tr>
<td>1.4</td>
<td>65-69% (1)</td>
</tr>
<tr>
<td>Other (specify)</td>
<td>70-74% (2)</td>
</tr>
</tbody>
</table>

→ How frequently is urea kinetic modelling used per haemodialysis patient? (Please approximate by location.)

<table>
<thead>
<tr>
<th>Frequency</th>
<th>(0)</th>
<th>(1)</th>
<th>(2)</th>
<th>(3)</th>
<th>(4)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Once per mo.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Once every 3 mos.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Once every 6 mos.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Once every 12 mos.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

SECTION D—NURSING HOME/CHRONIC CARE

9. How many haemodialysis patients reside or are awaiting placement in a nursing home or chronic care facility?

<table>
<thead>
<tr>
<th>Type of Placement</th>
<th>Total Care</th>
<th>Limited Self Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conventional HD</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Short Daily HD</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Slow Nocturnal HD</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

Nursing home: A facility where residents require personal care assistance and/or assistance with activities of daily living.

Chronic Care Facility: A facility where, due to the health needs of residents, ongoing medical intervention is provided.

10. Does your facility have a home haemodialysis training program?

- □ No □ Yes → How many home haemodialysis patients were trained for home haemo during the year 2010?

→ Do you have dedicated home training station(s)?

- □ No □ Yes → How many?

11. How many home haemodialysis patients are assisted with their dialysis by a paid assistant?

12. How many haemodialysis patients were receiving erythropoietin on December 31, 2010?

- □ Eprex □ Aranesp □ Other—please specify:

13. How many haemodialysis patients were receiving growth hormone on December 31, 2010? (For paediatric patients only.)

SECTION E—SCREENING

14. Does your facility screen new haemodialysis patients for:

- Hepatitis B? □ No □ Yes
- Hepatitis C? □ No □ Yes

15. Are haemodialysis patients routinely vaccinated against Hepatitis B?

- □ No □ Yes

16. Does your facility have an isolation room for patients who require isolation?

- □ No □ Yes

17a) Which of the following best describes the policy of your facility regarding HIV antibodies (HTLV-III/LAV) among haemodialysis patients with end-stage renal disease? (Please check all that apply.)

- □ All patients are tested
- □ New patients are tested
- □ Only patients with specific indications are tested
- □ No patients are tested

17b) How many haemodialysis patients in your program were HIV positive in 2010?

17c) How many haemodialysis patients in your program died due to AIDS in 2010?
Hospital Name: _______________________________

List of Community Centres *(See question 2b on page 1.)*

<table>
<thead>
<tr>
<th>Community Centre Name/Satellite Unit Name</th>
<th>Location</th>
<th># of Stations</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(5)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(6)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(7)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(8)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(9)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(10)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(11)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(12)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(13)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(14)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(15)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(16)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(17)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(18)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(19)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(20)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Completed by: _______________________________________________ Date: _______________________________________________________

Print Name: __________________________________________________ Tel.: _______________________________________________________

Fax: __________________________________________ Email: _______________________________________________________________________

Name of contact person *(if different from above):* __________________________________________________________________________________

Tel.: __________________________________________ Fax: _________________________________________________________________________

Email: ________________________________________________________

In which language would you prefer to receive feedback? □ English  □ French

*Thank you for completing this questionnaire. Please take a few moments to ensure that all the questions are answered.*
Complete this form to reflect the situation at your facility on December 31, 2010. Please keep a copy for your records.

Hospital Name: __________________________  Hospital City: _________________________________

Hospital Number: _________________

SECTION A—FACILITY RESOURCES

1. a) Does your facility have adequate peritoneal dialysis facilities (e.g., in terms of space/physical capacity, human resources)?
   - □ No ➔ If not, select the top 2 reasons why facilities are inadequate.
   - □ Yes
   - □ inadequate space for patients (1)
   - □ inadequate space for machines (2)
   - □ inadequate space for training facilities (3)
   - □ lack of physical capacity to expand (4)
   - □ lack of qualified registered nurses (5)
   - □ lack of diabetics, social workers, pharmacists or other allied health professionals (6)
   - □ lack of technicans/technologist(s) (7)
   - □ lack of dedicated nephrologist(s) (8)
   - □ other—please specify: __________________________ (9)

b) Do staff and patients have free choices as to which modality is selected?
   - □ No ➔ If, not select the 2 top reasons why patients do not have free choices
   - □ Yes
   - □ other modality not supported at centre (1)
   - □ space restrictions limit options (2)
   - □ geographic access to centre by patients limits options (3)
   - □ other—please specify: __________________________ (9)

SECTION B—TREATMENT AVAILABLE

2. a) What types of peritoneal dialysis treatment are supported by your facility? (Please check all that apply.)
   - □ PD combined with haemodialysis
   - □ CAPD (Continuous Ambulatory)
   - □ APD (Automated PD)

b) Please indicate the number of patients on each form of treatment as of December 31, 2010.
   - PD combined with haemodialysis
   - □ Acute Care Hospital
   - □ Chronic care Hospital
   - □ Home
   - □ CAPD (Continuous Ambulatory)
   - □ Limited Care
   - □ Limited Care
   - □ Home
   - □ APD (Automated PD)

SECTION C—ADEQUACY/CLEARANCE

3. a) Are Peritoneal Equilibration Tests (PETs) done on PD patients?
   - □ No ➔ □ Yes ➔ What proportion of patients have a PET within three months of initiating PD?
   - □ < 25% of patients (0)
   - □ 25–50% of patients (1)
   - □ 51–75% of patients (2)
   - □ 76–100% of patients (3)
   - □ □ Yes ➔ □ No

b) Are adequacy/clearance measurements done on PD patients?
   - □ No ➔ □ Yes ➔ What proportion of PD patients have Kt/V urea or creatinine clearance done at least once a year?
   - □ < 25% of patients (0)
   - □ 25–50% of patients (1)
   - □ 51–75% of patients (2)
   - □ 76–100% of patients (3)
   - □ □ Yes ➔ □ No

Which of the following are routinely done and how many times during the year are they usually done?

- 24-hr dialysate creatinine clearance
  - □ No ➔ □ Yes ➔ # times per year: ___
- 24-hr urinary creatinine clearance
  - □ No ➔ □ Yes ➔ # times per year: ___
- 24-hr dialysate Kt/V urea
  - □ No ➔ □ Yes ➔ # times per year: ___
- 24-hr urinary Kt/V urea
  - □ No ➔ □ Yes ➔ # times per year: ___

C) Is this information used within a computer modeling program to validate the initial (i.e., within three months) peritoneal dialysis prescription?
   - □ No ➔ □ Yes ➔ What program? (specify) ___________
SECTION D—NURSING HOME/CHRONIC CARE

4. How many peritoneal dialysis patients reside or are awaiting placement in a nursing home or chronic care facility?

- # patients residing in a nursing home ______
- # patients awaiting placement in a nursing home ______
- # patients residing in a chronic care facility ______
- # patients awaiting placement in a chronic care facility ______

Nursing home: A facility where residents require personal care assistance and/or assistance with activities of daily living.
Chronic Care Facility: A facility where, due to the health needs of residents, ongoing medical intervention is provided.

5. Does your facility have a home PD training program?

□ No  □ Yes → How many home patients were trained for home peritoneal dialysis during the year 2010? ______

6. How many PD patients were receiving erythropoietin on December 31, 2010?

____ Eprex  ____ Aranesp  ____ Other—please specify:

7. How many PD patients were receiving growth hormone on December 31, 2010? (For paediatric patients only.) ______

SECTION E—SCREENING

8. Does your facility screen new PD patients for:

Hepatitis B?  □ No  □ Yes
Hepatitis C?  □ No  □ Yes

9. Are PD patients routinely vaccinated against Hepatitis B?

□ No  □ Yes

10. Does your facility have an isolation room for patients who require isolation?

□ No  □ Yes

11. a) Which of the following best describes the policy of your facility regarding testing of HIV antibodies (HTLV-III/LAV) among PD patients with end-stage renal disease? (Please check all that apply.)

□ All patients are tested
□ New patients are tested
□ Only patients with specific indications are tested
□ No patients are tested

b) How many PD patients on dialysis in your program were HIV-positive in 2010? ______

c) How many PD patients in your program died due to AIDS in 2010? ______

Completed by: _______________________________
Date: _______________________________
Print Name: _______________________________
Telephone: _______________________________
Fax: _______________________________
Email: _______________________________

Name of contact person (if different from above):

Telephone: _______________________________
Fax: _______________________________
Email: _______________________________

In which language would you prefer to receive feedback?

□ English  □ French

Thank you for completing this questionnaire. Please take a few moments to ensure that all the questions are answered.
Canadian Organ Replacement Register
Chronic Renal Failure Patients on Renal Replacement Therapy

INITIAL REGISTRATION—2010

Hospital Name: __________________________

SECTION A—PERSONAL IDENTIFICATION

(Patient label may be attached if same information is provided.)

Patient Last Name: ____________________________
Patient Former Name: __________________________
Patient First and Middle Names: __________________________
Patient Address (city and province only): __________________________
Patient Postal Code: |___|___|___|   |___|___|___|
Health Card Number: ____________________________
Province of Health Card: ____________________________

Date of Birth: |___|___|/|___|___|___|/|___|___|___|___| (DD/MON/YYYY)

Sex (check one): ☐ Male ☐ Female ☐ Other
Race (check one): ☐ Caucasian/white (01) ☐ Asian (02)
☐ Black (03) ☐ Indian Sub-continent (05) ☐ Pacific Islander (08)
☐ Aboriginal (09) ☐ Mid-East/Arabian (10) ☐ Latin American (11)
☐ Unknown (98) ☐ Other/Multiracial (99)

Date of first renal replacement therapy: |___|___|/|___|___|___|/|___|___|___|___| (DD/MON/YYYY)

Was patient followed by a nephrologist prior to initiating dialysis? (check one): ☐ no pre-dialysis follow-up (0)
☐ yes followed in nephrologist’s office (1)
☐ yes followed in speciality clinic (2)
☐ yes followed in both office and clinic (3)
☐ unknown (9)

Was the patient receiving erythropoietin (i.e. Eprex, Aranesp) prior to initial dialysis treatment?
☐ no ☐ yes ☐ unknown
If yes:
☐ Eprex ☐ Aranesp ☐ Other

Last blood work before initial dialysis treatment: (Indicate NA if not available)

Haemoglobin (g/L) ___________ Creatinine (μmol/L) ___________
Urea (mmol/L) ___________ Serum Bicarbonate/CO₂ (mmol/L) ___________
Serum Calcium (mmol/L) ___________ uncorrected ☐ corrected ☐ ionized
Serum Phosphate (mmol/L) ___________ Serum Albumin (g/L) ___________
Serum Parathormone (PTH) ___________ pmol/L ☐ ng/L ☐ pg/ml

SECTION B—PRE-DIALYSIS AND INITIAL BLOOD WORK

Date when patient first seen by nephrologist: |___|___|/|___|___|___|/|___|___|___|___| (DD/MON/YYYY)

LOCATION:
☐ Acute care hospital ☐ Chronic care hospital ☐ Community centre ☐ Home

TYPE:
☐ Conventional haemo ☐ Short daily haemo ☐ Slow nocturnal haemo
☐ CAPD ☐ APD ☐ Peritoneal dialysis combined with haemo

ASSISTANCE/CARE:
☐ Total care ☐ Limited self care ☐ Total self care

Is this initial treatment the intended long-term dialysis treatment for this patient?
☐ Unknown
☐ Yes

If not, why not?
☐ no facilities/space available (1)
☐ no mature access (2)
☐ unforeseen change in patient status leading to sudden dialysis start (3)
☐ other (specify) ___________________________ (4)

If not, what is the long-term intended treatment for this patient? (Specify location, type and level of assistance/care.)

LOCATION:
☐ Acute care hospital ☐ Chronic care hospital ☐ Community centre ☐ Home

TYPE:
☐ Conventional haemo ☐ Short daily haemo ☐ Slow nocturnal haemo
☐ CAPD ☐ APD ☐ Peritoneal dialysis combined with haemo

ASSISTANCE/CARE:
☐ Total care ☐ Limited self care ☐ Total self care
SECTION D—HEIGHT AND WEIGHT

Height/weight cannot be provided because patient is:

☐ A double-leg amputee

Record patient’s height (cm) at the start of the first dialysis treatment this year:

|___|___|___|•|___|___|___|

Record patient’s actual weight (kg) within the first month of treatment:

|___|___|___|•|___|___|___|

Conversion factors: 1 inch = 2.54 cm; 1 lb = 0.454 kg

SECTION E—PRIMARY DIAGNOSIS AND RISK FACTOR HISTORY

Primary renal disease (see codes on page 3): |___|___|

Specify: _____________________________

Risk Factors/Co-morbid Conditions (check one response per condition):

|☐|☐|Unknown

a) Angina

b) Myocardial infarct

c) Coronary artery bypass grafts/angioplasty

d) Recent history of pulmonary edema (i.e. episode(s) of congestive heart failure or pulmonary edema within 6 months prior to dialysis)

e) Cerebrovascular disease (i.e. stroke, transient ischemic attack, carotid surgery)

f) Peripheral vascular disease (i.e. previous surgery such as femoropopliteal bypass graft, iliac or femoral endarterectomy, angioplasty, etc.; ischemic muscle pain precipitated by exercise; ischemic ulcers; gangrene; amputation)

g) Diabetes Type 1

h) Diabetes Type 2

i) Malignancy existing prior to first treatment

If yes, specify site using the codes listed on page 3 or specify:

|___|___|

j) Chronic obstructive lung disease (i.e. emphysema or chronic bronchitis)

k) Receiving medication for hypertension

l) Other serious illness that could shorten life expectancy to less than 5 years

If yes, specify condition: _____________________________

m) Current smoker (i.e. has smoked cigarettes, cigars or a pipe in the last three months)

TREATMENT CODES

Consists of treatment location, treatment type and level of assistance/care required.

LOCATION

1 = Acute Care Hospital: Treatments carried out in a dialysis facility located in or on the grounds of a hospital that provides full renal care services (i.e. services provided under the care of nephrologist(s), which include social work and dietary consultation and inpatient back-up care).

2 = Chronic Care Hospital: Treatments carried out in a facility where ongoing medical intervention is provided and residents require assistance. Includes chronic care facilities and nursing homes.

3 = Community Centre: Dialysis done outside a hospital. Treatment may occur in an office building, shopping plaza or other place where nephrology inpatient services are not onsite. This includes mobile dialysis services, and dialysis provided at independent health facilities.

4 = Home: Treatments carried out in the patient’s home by the patient and/or family member(s).

TYPE

1 = Conventional Haemodialysis: Given 3–6 hours two to four times a week.

2 = Short Daily Haemodialysis: Given during the day or evening for 2–3 hours 5 to 7 days per week.

3 = Slow Nocturnal Haemodialysis: Given 5–6 nights per week.

4 = CAPD (Continuous Ambulatory Peritoneal Dialysis): Patient receives peritoneal dialysis treatments through an implanted peritoneal catheter continuously throughout the day and night. The fluid held in the abdominal cavity is exchanged an average of 4 times per 24 hours, with a usual volume of 2 litres (includes enhanced CAPD).

5 = APD (Automated Peritoneal Dialysis): An automated cycler is used to effect the dialysate exchanges while the patient sleeps at night with or without additional exchanges during the day. Excludes night manual exchanges and non-automated night exchanges.

6 = Peritoneal Dialysis Combined with Haemodialysis: Patient is receiving a combination of any type of peritoneal dialysis and haemodialysis.

For Type of Treatment code 6 only, location and level of assistance are to be coded as 0 (i.e. 0-6-0).

ASSISTANCE/CARE REQUIRED

1 = Total Care: Patient is under the full care of trained staff affiliated with a nephrology unit.

2 = Limited Self Care: Patient receives a minimal amount of assistance from trained staff affiliated with a nephrology unit. This does not include family member(s).

3 = Total Self Care: Patient is completely responsible for his/her own treatment, with no assistance from nephrology trained staff. A patient may be classified as total self care if he/she receives assistance from family member(s) or home care worker who is not a trained staff affiliated with a nephrology unit.

Examples:

An elderly, infirmed patient waiting for a chronic care bed but being treated at an acute care hospital with conventional haemodialysis would be coded: 1/2/1.

A patient on short daily haemodialysis who is being treated at the acute care hospital with only some care provided by trained staff would be coded: 1/2/2.

A patient on home CAPD receiving no assistance from trained staff would be coded: 4/4/1.

Formulaire disponible en français.
### Primary Renal Diagnosis Codes

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>00</td>
<td>Chronic renal failure—etiology uncertain</td>
</tr>
<tr>
<td>05</td>
<td>Mesangial proliferative glomerulonephritis</td>
</tr>
<tr>
<td>06</td>
<td>Minimal lesion glomerulonephritis</td>
</tr>
<tr>
<td>07</td>
<td>Post-strept glomerulonephritis</td>
</tr>
<tr>
<td>08</td>
<td>Rapidly progressive glomerulonephritis</td>
</tr>
<tr>
<td>09</td>
<td>Focal glomerulonephritis (adults)</td>
</tr>
<tr>
<td>10</td>
<td>Glomerulonephritis, histologically NOT examined</td>
</tr>
<tr>
<td>11</td>
<td>Severe nephrotic syndrome with focal sclerosis (paediatric patients)</td>
</tr>
<tr>
<td>12</td>
<td>IgA nephropathy—proven by immunofluorescence (not code 85)</td>
</tr>
<tr>
<td>13</td>
<td>Dense deposit disease—proven by immunofluorescence and/or electron microscopy (MPGN Type II)</td>
</tr>
<tr>
<td>14</td>
<td>Membranous nephropathy</td>
</tr>
<tr>
<td>15</td>
<td>Membranoproliferative mesangiocapillary glomerulonephritis (MPGN Type I)</td>
</tr>
<tr>
<td>16</td>
<td>Idiopathic crescentic glomerulonephritis (diffuse proliferative)</td>
</tr>
<tr>
<td>17</td>
<td>Congenital nephrosis or congenital nephrotic syndrome</td>
</tr>
<tr>
<td>19</td>
<td>Glomerulonephritis, histologically examined—specify</td>
</tr>
<tr>
<td>73</td>
<td>Polycystic kidney disease</td>
</tr>
<tr>
<td>74</td>
<td>Wegener’s granulomatosis</td>
</tr>
<tr>
<td>84</td>
<td>Lupus erythematosus</td>
</tr>
<tr>
<td>85</td>
<td>Henoch-Schönlein purpura</td>
</tr>
<tr>
<td>86</td>
<td>Goodpasture’s syndrome</td>
</tr>
<tr>
<td>87</td>
<td>Scleroderma</td>
</tr>
<tr>
<td>88</td>
<td>Haemolytic uraemic syndrome</td>
</tr>
</tbody>
</table>

### Site of Primary Malignancy Codes

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>11</td>
<td>Two or more primary malignancies</td>
</tr>
<tr>
<td>16</td>
<td>Urological tract</td>
</tr>
<tr>
<td>25</td>
<td>Myeloma</td>
</tr>
<tr>
<td>26</td>
<td>Acute leukaemia</td>
</tr>
<tr>
<td>27</td>
<td>Chronic leukaemia</td>
</tr>
<tr>
<td>29</td>
<td>Retinoblastoma</td>
</tr>
<tr>
<td>30</td>
<td>Kaposi sarcoma</td>
</tr>
<tr>
<td>31</td>
<td>Plasma cell lymphoma</td>
</tr>
<tr>
<td>33</td>
<td>Hodgkin’s disease</td>
</tr>
<tr>
<td>34</td>
<td>Lymphoreticular tumours</td>
</tr>
<tr>
<td>36</td>
<td>Gastro-intestinal tract</td>
</tr>
<tr>
<td>39</td>
<td>Lymphoma, other types</td>
</tr>
<tr>
<td>40</td>
<td>Oesophagus</td>
</tr>
<tr>
<td>41</td>
<td>Colon</td>
</tr>
<tr>
<td>42</td>
<td>Rectum</td>
</tr>
<tr>
<td>43</td>
<td>Anus</td>
</tr>
<tr>
<td>45</td>
<td>Liver—primary hepatoma</td>
</tr>
<tr>
<td>49</td>
<td>Liver—primary lymphoma</td>
</tr>
<tr>
<td>50</td>
<td>Gallbladder and bile duct</td>
</tr>
<tr>
<td>51</td>
<td>Pancreas</td>
</tr>
</tbody>
</table>

### NECK AND THROAT

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>53</td>
<td>Larynx</td>
</tr>
<tr>
<td>54</td>
<td>Thyroid</td>
</tr>
<tr>
<td>55</td>
<td>Parotid</td>
</tr>
<tr>
<td>56</td>
<td>Bronchus</td>
</tr>
<tr>
<td>58</td>
<td>Lung, primary tumour</td>
</tr>
</tbody>
</table>

### UROGENITAL TRACT

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>60</td>
<td>Kidney—Wilms’ tumour</td>
</tr>
<tr>
<td>61</td>
<td>Kidney—Hypernephroma of host kidney</td>
</tr>
<tr>
<td>62</td>
<td>Kidney—Hypernephroma of graft kidney</td>
</tr>
<tr>
<td>63</td>
<td>Renal pelvis</td>
</tr>
<tr>
<td>64</td>
<td>Ureter</td>
</tr>
<tr>
<td>65</td>
<td>Urinary bladder</td>
</tr>
<tr>
<td>66</td>
<td>Urethra</td>
</tr>
<tr>
<td>67</td>
<td>Prostate</td>
</tr>
<tr>
<td>68</td>
<td>Testis</td>
</tr>
<tr>
<td>69</td>
<td>Penis</td>
</tr>
<tr>
<td>70</td>
<td>Scrotum</td>
</tr>
<tr>
<td>71</td>
<td>Perineum</td>
</tr>
<tr>
<td>72</td>
<td>Vulva</td>
</tr>
<tr>
<td>73</td>
<td>Vagina</td>
</tr>
<tr>
<td>74</td>
<td>Uterus—cervix</td>
</tr>
<tr>
<td>75</td>
<td>Uterus—body</td>
</tr>
<tr>
<td>76</td>
<td>Ovary</td>
</tr>
</tbody>
</table>

### MISCELLANEOUS

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>80</td>
<td>Breast</td>
</tr>
<tr>
<td>81</td>
<td>Muscle</td>
</tr>
<tr>
<td>82</td>
<td>Bone</td>
</tr>
<tr>
<td>83</td>
<td>Brain—primary lymphoma</td>
</tr>
<tr>
<td>84</td>
<td>Brain—other primary tumour</td>
</tr>
<tr>
<td>85</td>
<td>Other tumour of central nervous system</td>
</tr>
<tr>
<td>90</td>
<td>Metastatic carcinoma, primary site unknown</td>
</tr>
</tbody>
</table>

### Polycystic Kidney

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>41</td>
<td>Polycystic kidneys, adult type (dominant)</td>
</tr>
<tr>
<td>42</td>
<td>Polycystic kidneys, infantile and juvenile types (recessive)</td>
</tr>
</tbody>
</table>

### Diabetes

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>80</td>
<td>Diabetic nephropathy associated with Type 1 diabetes</td>
</tr>
<tr>
<td>81</td>
<td>Diabetic nephropathy associated with Type 2 diabetes</td>
</tr>
</tbody>
</table>

### Congenital/Hereditary Renal Diseases

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>21</td>
<td>Pyelonephritis/Interstitial nephritis associated with neurogenic bladder</td>
</tr>
<tr>
<td>22</td>
<td>Pyelonephritis/Interstitial nephritis due to congenital obstructive uropathy with or without vesico-ureteric reflux</td>
</tr>
<tr>
<td>24</td>
<td>Pyelonephritis/Interstitial nephritis due to vesico-ureteric reflux without obstruction</td>
</tr>
</tbody>
</table>

### Other

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>90</td>
<td>Cortical or acute tubular necrosis</td>
</tr>
<tr>
<td>91</td>
<td>Tuberculosis</td>
</tr>
<tr>
<td>92</td>
<td>Gout</td>
</tr>
<tr>
<td>93</td>
<td>Nephrocalcinosis and hypercalcaemic nephropathy</td>
</tr>
<tr>
<td>94</td>
<td>Bacterial nephropathy</td>
</tr>
<tr>
<td>95</td>
<td>Kidney tumour</td>
</tr>
<tr>
<td>96</td>
<td>Traumatic or surgical loss of kidney</td>
</tr>
<tr>
<td>97</td>
<td>HIV nephropathy</td>
</tr>
<tr>
<td>99</td>
<td>Other identified renal disorder—specify</td>
</tr>
</tbody>
</table>

---

*Formulaire disponible en français.*
**Canadian Organ Replacement Register**  
**Chronic Renal Failure Patients on Renal Replacement Therapy**

**FOLLOW-UP (HEMODIALYSIS)—2010**

Please complete one follow-up form for every living hemodialysis patient being treated at your centre on October 31, 2010. (Patient label may be attached if same information is provided.)

<table>
<thead>
<tr>
<th>Hospital City:</th>
<th>Hospital Number:</th>
</tr>
</thead>
</table>

**Patient Details:**

<table>
<thead>
<tr>
<th>Field</th>
<th>Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital Name</td>
<td>___________________</td>
</tr>
<tr>
<td>Patient Last Name</td>
<td>___________________</td>
</tr>
<tr>
<td>Patient First and Middle Names</td>
<td>___________________</td>
</tr>
<tr>
<td>Current Health Card Number</td>
<td>___________________</td>
</tr>
<tr>
<td>Province of Health Card</td>
<td>___________________</td>
</tr>
<tr>
<td>Current Postal Code</td>
<td></td>
</tr>
<tr>
<td>Date of Birth</td>
<td></td>
</tr>
</tbody>
</table>

**Laboratory Results:**

<table>
<thead>
<tr>
<th>Test</th>
<th>Usual Clinical Range of Values*</th>
<th>Laboratory Results</th>
<th>Date of Test (MON/YYYY)</th>
<th>Test Not Done</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hemoglobin (g/L) (pre-dialysis)</td>
<td>60–140 g/L</td>
<td>__________ g/L</td>
<td></td>
<td>___</td>
</tr>
<tr>
<td>Ferritin (within nearest six months) (mol/L or μg/L)</td>
<td>50–500 mol/L</td>
<td>__________</td>
<td></td>
<td>___</td>
</tr>
<tr>
<td>Males 14–610 μg/L</td>
<td>Females 8–125 μg/L</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transferrin saturation (for example, iron saturation index, serum iron range, g/L)</td>
<td>Various ranges—please specify index:</td>
<td>__________</td>
<td></td>
<td>___</td>
</tr>
<tr>
<td>□ Iron saturation (25%–50%)</td>
<td>□ Serum iron 9–32 (μmol/L)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ Transferrin 2.0–4.0 (g/L)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Creatinine (μmol/L) (pre-dialysis)</td>
<td>300–1,500 μmol/L</td>
<td>__________ μmol/L</td>
<td></td>
<td>___</td>
</tr>
<tr>
<td>Urea (mmol/L) (pre-dialysis)</td>
<td>15–40 mmol/L</td>
<td>__________ mmol/L</td>
<td></td>
<td>___</td>
</tr>
<tr>
<td>Urea (mmol/L) (post-dialysis)</td>
<td>5–20 mmol/L</td>
<td>__________ mmol/L</td>
<td></td>
<td>___</td>
</tr>
<tr>
<td>□ Serum bicarbonate (mmol/L) (pre-dialysis) OR</td>
<td>20–30 mmol/L</td>
<td>__________ mmol/L</td>
<td></td>
<td>___</td>
</tr>
<tr>
<td>□ Serum CO₂ (mmol/L) (pre-dialysis)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Serum calcium (mmol/L) (pre-dialysis)</td>
<td>Various ranges—please specify:</td>
<td>__________ mmol/L</td>
<td></td>
<td>___</td>
</tr>
<tr>
<td>□ 2.10–2.60 mmol/L uncorrected</td>
<td>□ 2.22–2.62 mmol/L corrected</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ 1.19–1.29 mmol/L ionized</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Serum phosphate (mmol/L) (pre-dialysis)</td>
<td>1.5–1.8 mmol/L</td>
<td>__________ mmol/L</td>
<td></td>
<td>___</td>
</tr>
<tr>
<td>Serum parathormone (PTH) (pmol/L; ng/L or pg/ml)</td>
<td>Various ranges—please specify:</td>
<td>__________</td>
<td></td>
<td>___</td>
</tr>
<tr>
<td>□ 1.3–7.6 pmol/L</td>
<td>□ 18–73 ng/L</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ 10–65 pg/ml</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HbA₁c (if patient diabetic)</td>
<td>4%–12% (0.04–0.12)</td>
<td>__________ %</td>
<td></td>
<td>___</td>
</tr>
<tr>
<td>Serum albumin (g/L)</td>
<td>25–50 g/L</td>
<td>__________ g/L</td>
<td></td>
<td>___</td>
</tr>
</tbody>
</table>

**Erythropoietin:**

□ No □ Yes  ➔ if yes: Product used:

- □ Eprex
- □ Aranesp
- □ Other:

- Route of administration: □ IV □ Subcutaneously
- Frequency of administration: □ Weekly □ Every two weeks □ Every three weeks □ Monthly □ Other: __________

**Total dose within a 7-day period of administration:** ____________________

* Will depend on laboratory procedures.
### Iron Supplementation:

3. a) Is the patient currently on iron?
- No (1)  Yes (2)  Specify:  Oral (3)  IV (4)  Both (5)

b) Has the patient been on iron during the past three months?
- No (1)  Yes (2)  Specify:  Oral (3)  IV (4)  Both (5)  On dialysis less than three months (6)

c) If the patient has been on dialysis for 12 months or more, has the patient been on iron during the past year?
- No (1)  Yes (2)  Specify:  Oral (3)  IV (4)  Both (5)  On dialysis less than one year (6)

4. a) Patient pre-dialysis weight (kg):  
-  
Patient post-dialysis weight (kg):  
-  

Date taken:  
- 

b) For pediatric patients only (patients younger than 18):
- Height (cm):  
-  

Date taken:  
- 

Conversion factors: 1 lb = 0.454 kg; 1 inch = 2.54 cm

5. a) Hemodialysis frequency (treatments per week):  
-  

b) Number of hours per treatment:  
-  

### Additional Questions:

6. Which access was the patient using on the date the laboratory results were obtained?
- Temporary catheter non-cuffed (1)
- Temporary catheter cuffed (2)
- Permanent catheter non-cuffed (3)
- Permanent catheter cuffed (4)
- Fistula (5)  How do you monitor the fistula function in this patient?
- Not monitored
- Total access blood flow (1)  Last flow (mL/min):  
  Date:  
- Re-circulation (2)  Last re-circulation (%):  
  Date:  
- Graft (6)  How do you monitor the graft function in this patient?
- Not monitored
- Total access blood flow (1)  Last flow (mL/min):  
  Date:  
- Venous pressure (2)  Last dynamic venous pressure (mmHg) at a blood flow of 200 mL/min:  
  Date:  

7. Is the patient currently active on the renal transplant waiting list?
- No  Yes  Unknown
Canadian Organ Replacement Register
Chronic Renal Failure Patients on
Renal Replacement Therapy

FOLLOW-UP (PERITONEAL DIALYSIS)—2010

Please complete one follow-up form for every living hemodialysis patient being treated at your centre on October 31, 2010.
(Patient label may be attached if same information is provided.)

Hospital City: ________________________________________________
Hospital Number: ____________________________________________

| Hospital Name: ______________________________________________ |
| Patient Last Name: ____________________________________________ |
| Patient First and Middle Names: ________________________________ |
| Current Health Card Number: ____________________________________ |
| Province of Health Card: _______________________________________ |
| Current Postal Code: |___|___|___|  |___|___|___| ____________________________ |
| Date of Birth: |___|___|/|___|___|___|/|___|___|___|___| (DD/MON/YYYY) |

1. Provide the details on the latest available laboratory results for this patient. Date cannot exceed December 31, 2010.

<table>
<thead>
<tr>
<th>Test</th>
<th>Usual Clinical Range of Values*</th>
<th>Laboratory Results</th>
<th>Date of Test (MON/YYYY)</th>
<th>Test Not Done</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hemoglobin (g/L)</td>
<td>60–140 g/L</td>
<td>_________ g/L</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ferritin (within nearest six months) (mol/L or μg/L)</td>
<td>50–500 mol/L</td>
<td>_________</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Males 14–610 μg/L</td>
<td>Females 8–125 μg/L</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transferrin saturation (for example, iron saturation index, serum iron range, g/L)</td>
<td>Various ranges—please specify index:</td>
<td>_________</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Iron saturation index (25%–50%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Serum iron (mmol/L)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transferrin (g/L)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Creatinine (μmol/L)</td>
<td>300–1,500 μmol/L</td>
<td>_________ μmol/L</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urea (mol/L)</td>
<td>15–40 mmol/L</td>
<td>_________ mmol/L</td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ Serum bicarbonate (mmol/L) OR</td>
<td>□ Serum CO₂ (mmol/L)</td>
<td>20–30 mmol/L</td>
<td>_________ mmol/L</td>
<td></td>
</tr>
<tr>
<td>□ Serum phosphate (mmol/L)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Serum calcium (mmol/L)</td>
<td>Various ranges—please specify:</td>
<td>_________ mmol/L</td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ 2.10–2.60 mmol/L uncorrected</td>
<td>□ 2.22–2.62 mmol/L corrected</td>
<td>□ 1.19–1.29 mmol/L ionized</td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ 1.5–1.8 mmol/L</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Serum parathormone (PTH) (pmol/L; ng/L or pg/ml)</td>
<td>Various ranges—please specify:</td>
<td>_________</td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ 1.3–7.6 pmol/L</td>
<td>□ 18–73 ng/L</td>
<td>□ 10–65 pg/ml</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HbA₁c (if patient diabetic)</td>
<td>4%–12% (0.04–0.12)</td>
<td>_________ %</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Serum albumin (g/L)</td>
<td>25–50 g/L</td>
<td>_________ g/L</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2. Is the patient currently receiving erythropoietin? (If patient is temporarily on hold from erythropoietin on October 31 but typically receives it, check "Yes.")

□ No □ Yes ▸ If yes: Product used:
□ Eprex □ Aranesp □ Other:

Route of administration:
□ IV □ Subcutaneously
Frequency of administration:
□ Weekly □ Every two weeks □ Every three weeks □ Monthly □ Other: ____________

Total dose within a 7-day period of administration: ________________

* Will depend on laboratory procedures.
Form FUD-P2010

5. a) Weekly creatinine clearance (L/1.73 m²/week)

Residual renal (R) __________
Peritoneal (P) __________
Total (R + P) __________

Date taken: __/__/__/____ (DD/MON/YYYY)

☐ Patient not yet tested ☐ Not routinely done

b) Weekly Kt/V (Urea)

Residual renal (R) __________
Peritoneal (P) __________
Total (R + P) __________

Date taken: __/__/__/____ (DD/MON/YYYY)

☐ Patient not yet tested ☐ Not routinely done

c) Peritoneal membrane transport status
(Please use results of first PET.)

☐ Low (1) ☐ Low Average (2)
☐ High (3) ☐ High Average (4)

☐ Patient not yet tested ☐ Patient declined test
☐ Test not routinely done

6. Type of peritoneal dialysis:

☐ CAPD

(Includes manual exchanges. It can also include the use of a night exchange device to do one automated exchange per 24 hours. If more than one automated exchange is done, it should be considered APD.)

If CAPD  ➔ Volume of fluid per exchange (mL): ______
         ➔ Number of exchanges per day: ______
         ➔ Total volume per day (mL): ______
         ➔ Is a night exchange device used?
                      ☐ No ☐ Yes

☐ APD (includes all other types of PD)

If APD  ➔ Volume cycled per night (mL):_____
         ➔ Dwell volume on cycler (mL):_____
         ➔ Volume of individual day dwells (mL):_____
         ➔ Number of day dwells:_____

7. Is this patient using amino acid dialysate?

☐ No ☐ Yes

8. Is this patient using non-dextrose (that is, icodextrin, no amino acid added) dialysate?

☐ No ☐ Yes

9. Is the patient currently active on the renal transplant waiting list?

☐ No ☐ Yes ☐ Unknown
Canadian Organ Replacement Register  
Chronic Renal Failure Patients on Renal Replacement Therapy  

CHANGE OF STATUS—2010

SECTION A—PERSONAL IDENTIFICATION

(Patient label may be attached if same information is provided.)

Patient last name: ____________________________________________

Patient first and middle names: ________________________________

Health card number: _________________________________________

Prov. or terr. of health card: ________________________________

Prov. or terr. of birth: ________________________________

Date of birth: [__] [__] / [__] [__] / [__] [__] [__] (DD/MON/YYYY)

Patient label may be attached if same information is provided.

Patient last name: ____________________________________________

Patient first and middle names: ________________________________

Health card number: _________________________________________

Prov. or terr. of health card: ________________________________

Prov. or terr. of birth: ________________________________

Date of birth: [__] [__] / [__] [__] / [__] [__] [__] (DD/MON/YYYY)

SECTION B—TREATMENT AND CHANGES

Record treatment changes for this patient during the calendar year, including transfers. When applicable, circle appropriate transfer, withdrew and died codes in column one. Please enter name and city of hospital for each transfer-in and transfer-out. All treatment/transfer change codes are listed below and are defined on the reverse. Treatment location, type and level of assistance/care must be specified when there is a treatment change.

<table>
<thead>
<tr>
<th>Treatment Location</th>
<th>Type</th>
<th>Care</th>
<th>Location</th>
<th>Type</th>
<th>Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>1st treatment</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2nd change</td>
<td>T R</td>
<td></td>
<td>W D</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3rd change</td>
<td>T R</td>
<td></td>
<td>W D</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4th change</td>
<td>T R</td>
<td></td>
<td>W D</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5th change</td>
<td>T R</td>
<td></td>
<td>W D</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

If transplant, specify organ(s):

Major Reason for Change Codes

<table>
<thead>
<tr>
<th>HD Specific</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>16 Hemodialysis access failure</td>
<td>03 Inadequate dialysis</td>
</tr>
<tr>
<td>17 Cardiovascular instability</td>
<td>08 Transferred to originally intended treatment</td>
</tr>
<tr>
<td>14 Patient/family unable to cope with current treatment (patient/family initiated change)</td>
<td></td>
</tr>
<tr>
<td>01 Peritonitis</td>
<td>18 Resource/geographical (non-medical)</td>
</tr>
<tr>
<td>02 Other abdominal complications</td>
<td>09 Transplanted</td>
</tr>
<tr>
<td>10 Other complications related to PD</td>
<td>19 Failed transplant</td>
</tr>
<tr>
<td>11 Lost to follow-up</td>
<td>20 Left country</td>
</tr>
<tr>
<td>99 Other, specify</td>
<td></td>
</tr>
</tbody>
</table>

SECTION C—CAUSE OF DEATH

If patient died, enter the cause of death. (See reverse for codes.)

<table>
<thead>
<tr>
<th>LOCATION</th>
<th>TYPE</th>
<th>ASSISTANCE/CARE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Conventional hemodialysis</td>
<td>Total care</td>
</tr>
<tr>
<td>2</td>
<td>Short daily hemodialysis</td>
<td>Limited self care</td>
</tr>
<tr>
<td>3</td>
<td>Slow nocturnal hemodialysis</td>
<td>Total self care</td>
</tr>
<tr>
<td>4</td>
<td>Continuous ambulatory peritoneal dialysis (CAPD)</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Automated peritoneal dialysis (APD)</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Peritoneal dialysis combined with hemodialysis (code 060)</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Transplantation (code 171)</td>
<td></td>
</tr>
</tbody>
</table>

Examples:

An elderly, infirm patient waiting for a chronic care bed but being treated at an acute care hospital with conventional hemodialysis would be coded [1/1/1].

A patient on short daily hemodialysis, who is being treated at the acute care hospital with only some care provided by trained staff, would be coded [1/2/2].

A patient on home CAPD receiving no assistance from trained staff would be coded [1/4/2].

SECTION D—REASON FOR WITHDRAWAL

If this patient has withdrawn from renal replacement therapy (even if he /she has died), please check the major reason for withdrawal:

- Psychosocial (1)
- Vascular (stroke, peripheral vascular disease, etc.) (2)
- Heart disease (3)
- Infection (4)
- Cancer (6)
- Dementia (6)
- Other (specify) [7]
- Unknown (9)

Date of death: [__] [__] / [__] [__] / [__] [__] [__] (DD/MON/YYYY)
Treatment Codes
Consists of treatment location, treatment type and level of assistance/care required.

LOCATION
1 = Acute care hospital: Treatments carried out in a dialysis facility located in or on the grounds of a hospital that provides full renal care services (i.e. services provided under the care of nephrologists, including social work, dietary consultation and inpatient back-up care).
2 = Chronic care hospital: Treatments carried out in a facility where ongoing medical intervention is provided and residents require assistance. Includes chronic care facilities and nursing homes.
3 = Community centre: Dialysis done outside a hospital. Treatment may occur in an office building, shopping plaza or other place where nephrology inpatient services are not onsite. This includes mobile dialysis services and dialysis provided at independent health facilities.
4 = Home: Treatments carried out in the patient’s home by the patient and/or family member(s).

TYPE
1 = Conventional hemodialysis: Given 3 to 6 hours 2 to 4 times a week.
2 = Short daily hemodialysis: Given during the day or evening for 2 to 3 hours 5 to 7 days per week.
3 = Slow nocturnal hemodialysis: Given 5 to 6 nights per week.
4 = CAPD (continuous ambulatory peritoneal dialysis): Patient receives peritoneal dialysis treatments through an implanted peritoneal catheter continuously throughout the day and night. The fluid held in the abdominal cavity is exchanged an average of 4 times per 24 hours, with a usual volume of 2 litres (includes enhanced CAPD).
5 = APD (automated peritoneal dialysis): An automated cycler is used to affect the dialysate exchanges while the patient sleeps at night with or without additional exchanges during the day. Excludes night manual exchanges and non-automated night exchanges.
6 = Peritoneal dialysis combined with hemodialysis: Patient is receiving a combination of any type of peritoneal dialysis and hemodialysis (code 060).
7 = Transplantation (code 171).

ASSISTANCE/CARE REQUIRED
1 = Total care: Patient is under the full care of trained staff affiliated with a nephrology unit.
2 = Limited self care: Patient receives a minimal amount of assistance from trained staff affiliated with a nephrology unit.
3 = Total self care: Patient is completely responsible for his/her own treatment, with no assistance from trained nephrology staff. A patient may be classified as total self care if he/she receives assistance from family members or a home care worker who is not a trained staff member affiliated with a nephrology unit.

Cause of Death Codes
GENERIC
00 Cause of death uncertain, not determined

ACCIDENT
81 Accident related to treatment
82 Accident unrelated to treatment

CARDIAC
11 Myocardial ischemia and infarction
12 Hyperkalemia
13 Hemorrhagic pericarditis
14 Other causes of cardiac failure
15 Cardiac arrest, cause unknown
16 Hypertensive cardiac failure
17 Hypokalemia
18 Fluid overload

GASTROINTESTINAL
02 Gastrointestinal tumour with or without perforation
03 Acute gastroenteritis with dehydration
23 Gastrointestinal hemorrhage
29 Mesenteric infarction
62 Pancreatitis
68 Perforation of peptic ulcer
70 Sclerosing (or adhesive) peritoneal disease
72 Perforation of colon/small bowel

HEMATOLOGIC
63 Bone marrow depression
71 Thrombocytopenia
73 Thrombosis—specify

INFECTION
04 Infection (bacterial)—specify site
05 Infection (fungi)—specify site
06 Infection (fungi)—specify site
24 Infections elsewhere (except viral hepatitis codes 41 and 42)—specify infectious agent

LIVER
41 Liver, due to hepatitis B virus
42 Liver, due to other viral hepatitis
43 Liver, drug toxicity—specify drug
44 Cirrhosis, not viral
45 Cystic liver disease
46 Liver failure, cause unknown
74 Liver, due to hepatitis C virus

METABOLIC
50 Drug-related toxicity—specify drug

SOCIAL
50 Drug abuse (excludes alcohol abuse)
51 Patient refused further treatment
52 Suicide

RESPIRATORY
19 Acute respiratory distress syndrome (ARDS)
31 Pulmonary infection (bacterial)
32 Pulmonary infection (viral)
33 Pulmonary infection (fungal)
49 Bronchiolitis obliterans

VASCULAR
21 Pulmonary embolus
22 Cerebrovascular accident
24 Hemorrhage from graft site—specify
25 Hemorrhage from vascular access or dialysis circuit
26 Ruptured vascular aneurysm (not codes 22 or 25)
27 Hemorrhage from surgery (not codes 23, 24 or 26)—specify

28 Other hemorrhage (not codes 23 to 27)
55 Vascular thrombosis
56 Pulmonary vein stenosis
57 Stent/balloon complication

MISCELLANEOUS
30 Hypertension
40 Diabetic keto acidosis (DKA)
44 Cachexia
66 Malignant disease possibly induced by immunosuppressive therapy—specify primary site
67 Malignant disease (not code 66)—specify primary source
69 Dementia
90 Multi-system failure
99 Other identified cause of death—specify

FORMULAIRE DISPONIBLE EN FRANÇAIS.
Please complete this form to reflect the situation in your facility on December 31, 2010. Please keep a copy for your records.

SEND THIS CONFIDENTIAL INFORMATION TO:
Canadian Organ Replacement Register
Canadian Institute for Health Information
4110 Yonge Street, Suite 300
Toronto, ON M2P 2B7
Fax: 416-481-2950

NAME AND CITY OF HOSPITAL ______________________________________________________________________________
HOSPITAL NUMBER ________________________________________________________________________________________
(to be completed by CORR)

A. ANNUAL TRANSPLANTS

1. How many kidney transplants were performed at your hospital in 2010?  
   (Note: Please include kidney combinations such as kidney-pancreas or kidney-liver transplants.)

<table>
<thead>
<tr>
<th></th>
<th>Adult Patients</th>
<th>Pediatric Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(18+)</td>
<td>(Under 18)</td>
</tr>
<tr>
<td>a)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Deceased donor)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>b)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Living related donor)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>c)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Living unrelated donor)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2. How many kidney combination transplants were performed at your hospital in 2010?

<table>
<thead>
<tr>
<th></th>
<th>Adult Patients</th>
<th>Pediatric Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(18+)</td>
<td>(Under 18)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

B. FOLLOW-UP

(Note: Please include all patients who underwent transplants during or before 2010.)

3. How many patients alive with a functioning transplant, regardless of where they had their transplant, were being followed at your hospital on December 31?  
   (Note: If patients are also followed at another centre, please include them here only if your centre is the PRIMARY follow-up centre.)

4. How many patients returned to dialysis in 2010?

5. How many transplant patients followed at your hospital died in 2010?
   a) With a functioning graft?
   b) With a failed graft (i.e. did not return to dialysis)?

Completed by _____________________________________________________________ Date __________________________
Name (please print) ________________________________________________________ Tel. __________________________
Name of contact person if different from above _______________________________ Tel. __________________________

Thank you for filling out this questionnaire.  
Please take a few minutes to ensure that all questions are answered.
# Canadian Organ Replacement Register

## Deceased Donor Profile

**Instructions**
To be completed for all referrals, potential, and deceased donors.

**Definitions**
**REFERRAL**—Consultation/communication to a donor program about a deceased or dying patient who may be a potential organ donor. This patient will be assigned a unique identification number.

**POTENTIAL DONOR**—A referral who fulfills the general acceptance criteria for organ donation, for whom neurological death has been determined and consent for organ procurement has been obtained. Organ recovery may occur, but no recovered organs are transplanted.

**ACTUAL DONOR**—A donor from whom at least one organ or tissue has been transplanted.

**DECEASED DONOR**—A donor from whom at least one organ or tissue has been transplanted.

**CODES—Reasons Patient Did Not Become Donor/Organs Not Recovered**

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
<th>Reason</th>
</tr>
</thead>
<tbody>
<tr>
<td>03</td>
<td>Team/hospital logistics (team, hospital, transplantation resource issues)</td>
<td>Consent requested and denied</td>
</tr>
<tr>
<td>04</td>
<td>Medical reasons (instability, infection, etc.)</td>
<td>Unknown/not available</td>
</tr>
<tr>
<td>07</td>
<td>Consent not requested</td>
<td>Other reason: specify</td>
</tr>
<tr>
<td>08</td>
<td>Neurological death not determined</td>
<td></td>
</tr>
<tr>
<td>09</td>
<td>Refusal by medical examiner</td>
<td></td>
</tr>
</tbody>
</table>

**SECTION A—REFERRAL/DONOR INFORMATION**

- Program organizing organ recovery (please check one):
  - 01 Halifax, N.S.
  - 07 Montréal, Que.
  - 05 London, Ont.
  - 16 Toronto, Ont.
  - 17 Regina, Sask.
  - 12 Vancouver, B.C.

- Recovered hospital ___________________________________________________________________________

- Date of cross clamp (DD/MON/YYYY) |___|___|/|___|___|___|/|___|___|___|___| (Cross-clamp date is the same as the date of organ recovery.)

- Cross-clamp time (HH/MM) |___|___|/|___|___|

**SECTION B—HOSPITAL INFORMATION**

- Identifying hospital ___________________________ Date of admission (DD/MON/YYYY) |___|___|/|___|___|___|/|___|___|___|___|___|

- Date death is determined (DD/MON/YYYY) |___|___|/|___|___|___|/|___|___|___|___|

- Time of death is determined (HH/MM) |___|___|/|___|___|

- Recovered hospital _____________________________

- Date of cross clamp (DD/MON/YYYY) |___|___|/|___|___|/|___|___|/|___|___|/|___|___|/|___|___|/|___|___|/|___|___|/|___|___|/|___|___|/|___|___|/|___|___|/|___|___|

- Cross-clamp time (HH/MM) |___|___|/|___|___|

**Definitions**

- Consent not requested
- Refusal by medical examiner
- Medical reasons (instability, infection, etc.)
- Neurological death not determined
- Consent requested and denied
- Unknown/not available
- Other reason: specify
- Consent not requested
- Other reason: specify

**Instructions**

Please provide all available information for referred organ donors. To be completed for all referrals, potential, and deceased donors.

**Definitions**

- Consent not requested
- Refusal by medical examiner
- Medical reasons (instability, infection, etc.)
- Neurological death not determined
- Consent requested and denied
- Unknown/not available
- Other reason: specify

**Instructions**

Please enter the first 3 letters of the donor surname.

**Conversion factors:** 1 in. = 2.54 cm; 1 lb. = 0.45 kg

**Reasons Patient Did Not Become Donor/Organs Not Recovered**

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
<th>Reason</th>
</tr>
</thead>
<tbody>
<tr>
<td>03</td>
<td>Team/hospital logistics (team, hospital, transplantation resource issues)</td>
<td>Consent requested and denied</td>
</tr>
<tr>
<td>04</td>
<td>Medical reasons (instability, infection, etc.)</td>
<td>Unknown/not available</td>
</tr>
<tr>
<td>07</td>
<td>Consent not requested</td>
<td>Other reason: specify</td>
</tr>
<tr>
<td>08</td>
<td>Neurological death not determined</td>
<td></td>
</tr>
<tr>
<td>09</td>
<td>Refusal by medical examiner</td>
<td></td>
</tr>
</tbody>
</table>

**Cause of Donor Death**

Please enter more specific information where applicable (e.g. type of drug overdose or cause of trauma).

- Anoxia/hypoxia
- CVA (stroke)
- Trauma (not MVC)—describe
- Motor vehicle collision
- Overdose—describe
- Primary CNS tumour
- Ruptured cerebral aneurysm
- Spontaneous intracranial hemorrhage
- Gunshot
- Intracranial event—describe
- CNS infection
- Carbon monoxide poisoning
- Cerebral edema
- Asthma, unspecified
- SIDS (sudden infant death syndrome)
- Other—describe

**Other (transsexual, hermaphrodite)**

<table>
<thead>
<tr>
<th>Race</th>
<th>Died</th>
<th>Died</th>
<th>Died</th>
</tr>
</thead>
<tbody>
<tr>
<td>01</td>
<td>Caucasian</td>
<td>02 Asian</td>
<td>03 Black</td>
</tr>
<tr>
<td>08</td>
<td>Pacific islander</td>
<td>09 Aboriginal</td>
<td>10 Mid East/Arabian</td>
</tr>
</tbody>
</table>

**Country of death_____**

**Country of residence_____**

**Province, territory or state of death_____**

**Province, territory or state of residence_____**

**Surnames stem (Please enter the first 3 letters of the donor surname.)**

**Sex**

- Male
- Female
- Other (transsexual, hermaphrodite)

**Blood Type**

- A
- B
- AB
- O
- U

**Race**

- Caucasian
- Asian
- Black
- Indian subcontinent
- Pacific islander
- Aboriginal
- Mid East/Arabian
- Latin American
- Unknown
- Other/multiracial

**Age**

- Years (002–130) _______ Months (001–023) _______

- Days (001–030) _______ Newborn (000) _______

**Sex**

- Male
- Female
- Other (transsexual, hermaphrodite)

**Blood Type**

- A
- B
- AB
- O
- U

**Race**

- Caucasian
- Asian
- Black
- Indian subcontinent
- Pacific islander
- Aboriginal
- Mid East/Arabian
- Latin American
- Unknown
- Other/multiracial

**Age**

- Years (002–130) _______ Months (001–023) _______

- Days (001–030) _______ Newborn (000) _______

**Note**

Please enter the first 3 letters of the donor surname.
### SECTION C—DONOR SEROLOGY AND RISK FACTORS (for actual donors only)

**Donor Serology Status**
(Check those that apply by answering: P = positive, N = negative, U = unknown.)

- Hepatitis BsAg  [ ] P  [ ] N  [ ] U  Epstein-Barr virus  [ ] P  [ ] N  [ ] U
- Hepatitis BsAb  [ ] P  [ ] N  [ ] U  HIV  [ ] P  [ ] N  [ ] U
- Hepatitis C  [ ] P  [ ] N  [ ] U  CMV  [ ] P  [ ] N  [ ] U
- HTLV type I and II (human T-cell lymphotropic virus)  [ ] P  [ ] N  [ ] U
- Donor HLA  A[ ] B[ ] C[ ] DR[ ] DO[ ]

**Donor Risk Factors**
(Check those that apply by answering: Y = yes, N = no, U = unknown.)

- Smoker  [ ] Y  [ ] N  [ ] U  Diabetes  [ ] Y  [ ] N  [ ] U
- Hypertension  [ ] Y  [ ] N  [ ] U  Hyperlipidemia  [ ] Y  [ ] N  [ ] U
- Coronary artery disease  [ ] Y  [ ] N  [ ] U  Creatinine at death > 1.5 mg/dl  [ ] Y  [ ] N  [ ] U

### SECTION D—ADDITIONAL ORGAN INFORMATION (Please complete for all donors)

- Coronary angiogram:  [ ] Not done  [ ] Done (If done, please check): [ ] Normal function  [ ] Abnormal function  [ ] Unknown
- ECG:  [ ] Not done  [ ] Done (If done, please check): [ ] Normal  [ ] Abnormal  [ ] Unknown
- Coronary angiogram:  [ ] Not done  [ ] Done (If done, please check): [ ] Normal  [ ] Abnormal  [ ] Unknown

### SECTION E—ORGAN-SPECIFIC INFORMATION

(Please answer for all organs.)

**CODES—Reasons Donors or Organs Not Recovered/Transplanted**

<table>
<thead>
<tr>
<th>Code</th>
<th>Reason</th>
<th>Organ Sent to (Indicate hospital or program.)</th>
<th>Recipient Name (Indicate if known.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>01</td>
<td>No consent for a particular organ</td>
<td>06 No program</td>
<td>10 Recipient not looked for</td>
</tr>
<tr>
<td>02</td>
<td>No recipient (no suitability matched recipient)</td>
<td>07 Used for research</td>
<td></td>
</tr>
<tr>
<td>03</td>
<td>Team/hospital logistics (team, hospital, transplantation resources issues)</td>
<td>08 Used for heart valves</td>
<td></td>
</tr>
<tr>
<td>04</td>
<td>Medical reasons (instability, infection, etc.)</td>
<td>09 Stored/preserved</td>
<td></td>
</tr>
<tr>
<td>05</td>
<td>Retrieval injury</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Recipient not looked for</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Organ exported to U.S.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>98</td>
<td>Unknown/not available</td>
<td></td>
<td></td>
</tr>
<tr>
<td>99</td>
<td>Other reason: specify _____________________</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Donor Organ</th>
<th>Recovered</th>
<th>Transplanted</th>
<th>Reason Not Recovered/Transplanted (See codes above.)</th>
<th>Organ Sent to</th>
<th>Recipient Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>Double kidney/embloc</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Right Kidney</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Left Kidney</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Heart</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Liver (whole organ)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Liver, right lobe</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Liver, left lobe</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Liver, lateral segment</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pancreas—whole</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pancreas—segment</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pancreas—islet cells</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Heart lung</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bilateral lungs/embloc</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Right lung</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Left lung</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intestine</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cluster (liver, sm. intestine, pancreas, stomach)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other multivisceral/bowel combination (specify organs):</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td></td>
</tr>
</tbody>
</table>
# Canadian Organ Replacement Register

## Living Donor Profile

**SEND THIS CONFIDENTIAL INFORMATION TO:**

Canadian Organ Replacement Register (CORR)  
Canadian Institute for Health Information  
4110 Yonge Street, Suite 300  
Toronto, ON M2P 2B7  
Tel.: 416-481-2002

---

### Instructions:

To be completed by the transplant program. Please attach this form to the relevant transplant recipient form.

---

## SECTION A—DONOR INFORMATION

**Donor Type**

13 □ Autograft (islet)

**Living, biologically related**

03 □ Sibling  
02 □ Parent

**Living, biologically unrelated**

07 □ Spouse  
12 □ Domino  
13 □ Autograft  
14 □ Fetal Tissue (islet cells)

**Transplant hospital**

__________________________________________________________

**Hospital’s donor code**

__________________________________________________________

**Donor last name stem (first 3 letters)**

__________________________________________________________

**Province, territory or state of residence**

__________________________________________________________

**Age**

________ years

**Sex**

□ Male  □ Female  □ Other

**Blood Type**

□ A  □ B  □ AB  □ O  □ U

**Race**

01 □ Caucasian  
02 □ Asian  
03 □ Black  
05 □ Indian subcontinent  
08 □ Pacific islander  
09 □ Aboriginal  
10 □ Mid East /Arabian  
11 □ Latin American  
98 □ Unknown  
99 □ Other/multiracial ______

**Height**

□ □ □ □ □ (cm)

(Conversion factor: 1 in. = 2.54 cm)

**Weight**

□ □ □ □ □ (kg)

(Conversion factor: 1 lb. = 0.45 kg)

---

## SECTION B—HOSPITAL INFORMATION

**Recipient last name**

__________________________________________________________

**Date of admission**

|___|___|/|___|___|___|/|___|___|___|___| (DD/MON/YYYY)

**Date of cross clamp**

|___|___|/|___|___|___|/|___|___|___|___| (DD/MON/YYYY)

**Time of cross clamp**

|___|___|/|___|___| (HH/MM)

---

## SECTION C—DONOR SEROLOGY AND RISK FACTORS

**Donor Serology Status**

(Check those that apply: P = positive, N = negative, U = unknown.)

Hepatitis BsAg  
P □  N □  U □  Epstein-Barr virus  
P □  N □  U □

Hepatitis BcAb  
P □  N □  U □  HIV  
P □  N □  U □

Hepatitis C  
P □  N □  U □  CMV  
P □  N □  U □

HTLV type I and II  
(people T-cell lymphotrophic virus)  
P □  N □  U □

*Donor HLA  
A____ ____  B____ ____  C____ ____  DR____ ____  DQ____ ____(Note: CORR enters the lowest haplotype first.)

**Donor Risk Factors**

(Check those that apply: Y = yes, N = no, U = unknown.)

Smoker  
Y □  N □  U □  Hyperlipidemia  
Y □  N □  U □

Diabetes  
Y □  N □  U □  Coronary artery disease  
Y □  N □  U □

Hypertension  
Y □  N □  U □

---

## SECTION D—ORGAN SPECIFIC INFORMATION

**Organ recovered:**

11 □ Left kidney  
12 □ Right kidney

21 □ Liver left lobe  
22 □ Liver right lobe

23 □ Liver lateral segment  
41 □ Lung left lobe  
42 □ Lung right lobe

**Recipient last name**

__________________________________________________________

**Recipient date of birth**

|___|___|/|___|___|___|/|___|___|___|___| (DD/MON/YYYY)
SECTION A—RECIPIENT INFORMATION

Transplant hospital _______________________________ (name and city)

Patient ID ____________________________

Last name ____________ First/middle name __________

Sex     □ Male     □ Female     □ Other

Blood type □ A □ B □ AB □ O □ U

Race

□ Caucasian    □ Asian    □ Black    □ Indian subcontinent
□ Pacific islander □ Aboriginal □ Mid East/Arabian
□ Latin American □ Unknown  □ Other/multiracial ______

Date of birth |___|___|/|___|___|___|/|___|___|___|___| (DD/MON/YYYY)

Health card number ________________________

Prov. or terr. of health card ________________________

Address (city) ______________________________________

Provinces or territory ________________________ Postal code ___________

SECTION B—TRANSPLANT INFORMATION

Waiting List Information

Date patient first placed on waiting list

[for this transplant] |___|___|/|___|___|___|/|___|___|___|___| (DD/MON/YYYY)

Date of Transplant |___|___|/|___|___|___|/|___|___|___|___| (DD/MON/YYYY)

Graft number ________________________

□ Single kidney transplant □ Double kidney/enbloc

□ Combination transplant

If combination, specify other organ(s) ______________________________________

Please complete section B of relevant transplant recipient registration form for other organ(s).

Recipient Serology Status at Time of Transplant

[Please check one of the acceptable values: P, N, U, or Unknown]

Hepatitis BsAg □ P □ N □ U □

Hepatitis BcAb □ P □ N □ U □

Hepatitis C □ P □ N □ U □

Donor specific antibodies □ Y □ N □

Class I PRA current__ %    Class I PRA peak__ %

Class II PRA current__ %    Class II PRA peak__ %

* Methods: CDC □ ELISA □ Flow □ Luminex □ Other □

* The most sensitive method should be entered if more than one method

* Recipient HLA A____ ____ B____ ____ C____ ____ DR____ ____ DQ____ __

* Note: CORR enters the lowest haplotype first.

SECTION B—TRANSPLANT INFORMATION (continued)

Primary Renal Disease (diagnosis reported at first treatment)

Code ________ (See codes on back of form.) □ Retransplant

Describe ________________________

Diagnosis at time of first transplant

Code ________ (See codes on back of form.)

Describe ________________________

Donor organ kidney □ Right kidney □ Left kidney □ Both kidneys

Laparoscopic nephrectomy used? □ Yes □ No □ Unknown

At time of transplant

Recipient height ________ cm (Conversion factor: 1 in. = 2.54 cm)

Recipient weight ________ kg (Conversion factor: 1 lb. = 0.45 kg)

Was patient on dialysis for ESRD pre-transplant? □ Yes □ No □ Unknown

Delayed graft function? □ Yes □ No □ Unknown

Did patient receive dialysis treatment within the first week of transplantation? □ Yes □ No □ Unknown

Risk Factors Existing at Time of Transplant

(Please check one of the acceptable values: Y = yes, N = no or U = unknown)

Angina □ Y □ N □ U □

Malignancy □ Y □ N □ U □

Pulmonary edema □ Y □ N □ U □

Diabetes type 1 □ Y □ N □ U □

Hypertension □ Y □ N □ U □

Cold ischemic time ________ min

SECTION C—DONOR INFORMATION

□ Living    □ Deceased donor    □ Domino donor

For a living or domino donor, please complete

a living donor profile and attach to this form.

□ Living    □ Deceased donor    □ Domino donor

01 □ Unknown out of country transplant

To facilitate matching, please complete the following:

Program organizing organ recovery ________________________

Originating OPO donor number ________________________

Surname stem (first 3 letters of donor surname) __________

Age Years (002–130) _____ Months (001–023) _____

Days (001–030) ______ Newborn (000) ______

Sex □ Male □ Female □ Other

* Donor HLA A____ ____ B____ ____ C____ ____ DR____ ____ DQ____ __

* Note: CORR enters the lowest haplotype first.

Date of cross clamp (DD/MON/YYYY) |___|___|/|___|___|___|/|___|___|___|___| (Cross-clamp date is the same as the date of organ recovery.)

Cross-clamp time (HH/MM) |___|___|/|___|___|___|/|___|___|___|___|
<table>
<thead>
<tr>
<th>CODE</th>
<th>DESCRIPTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>00</td>
<td>Chronic renal failure, etiology uncertain</td>
</tr>
<tr>
<td>05</td>
<td>Mesangial proliferative glomerulonephritis</td>
</tr>
<tr>
<td>06</td>
<td>Minimal lesion glomerulonephritis</td>
</tr>
<tr>
<td>07</td>
<td>Post-strep glomerulonephritis</td>
</tr>
<tr>
<td>08</td>
<td>Rapidly progressive glomerulonephritis</td>
</tr>
<tr>
<td>09</td>
<td>Focal glomerulonephritis—adults</td>
</tr>
<tr>
<td>10</td>
<td>Glomerulonephritis, histologically not examined</td>
</tr>
<tr>
<td>11</td>
<td>Severe nephrotic syndrome with focal sclerosis (pediatric patients only)</td>
</tr>
<tr>
<td>12</td>
<td>IgA nephropathy (proven by immunofluorescence) (not code 85)</td>
</tr>
<tr>
<td>13</td>
<td>Dense deposit disease (proven immunofluorescence and/or electron microscopy) (MPGN type II)</td>
</tr>
<tr>
<td>14</td>
<td>Membranous nephropathy</td>
</tr>
<tr>
<td>15</td>
<td>Membranoproliferative glomerulonephritis (MGPN type I)</td>
</tr>
<tr>
<td>16</td>
<td>Idiopathic crescentic glomerulonephritis (diffuse proliferative)</td>
</tr>
<tr>
<td>17</td>
<td>Congenital nephrosis or congenital nephrotic syndrome (pediatric only)</td>
</tr>
<tr>
<td>19</td>
<td>Glomerulonephritis, histologically examined—specify</td>
</tr>
<tr>
<td>73</td>
<td>Polyarteritis</td>
</tr>
<tr>
<td>74</td>
<td>Wegener’s granulomatosis</td>
</tr>
<tr>
<td>84</td>
<td>Lupus erythematosus</td>
</tr>
<tr>
<td>85</td>
<td>Henoch-Schonlein purpura</td>
</tr>
<tr>
<td>86</td>
<td>Goodpasture’s syndrome</td>
</tr>
<tr>
<td>87</td>
<td>Scleroderma</td>
</tr>
<tr>
<td>88</td>
<td>Hemolytic uremic syndrome (Moschowitz syndrome)</td>
</tr>
</tbody>
</table>

**NEPHROPATHY—DRUG INDUCED**

<table>
<thead>
<tr>
<th>CODE</th>
<th>DESCRIPTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>30</td>
<td>Nephropathy caused by drugs or nephrotoxic agents—cause not specified</td>
</tr>
<tr>
<td>31</td>
<td>Nephropathy due to analgesic drugs</td>
</tr>
<tr>
<td>32</td>
<td>Nephropathy due to cisplatin</td>
</tr>
<tr>
<td>33</td>
<td>Nephropathy due to cyclosporin A</td>
</tr>
<tr>
<td>39</td>
<td>Nephropathy caused by other specific drug—specify</td>
</tr>
</tbody>
</table>

**POLYCYSTIC KIDNEYS**

<table>
<thead>
<tr>
<th>CODE</th>
<th>DESCRIPTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>41</td>
<td>Polycystic kidneys, adult type (dominant)</td>
</tr>
<tr>
<td>42</td>
<td>Polycystic kidneys, infantile and juvenile types (recessive)</td>
</tr>
</tbody>
</table>

**DIABETES**

<table>
<thead>
<tr>
<th>CODE</th>
<th>DESCRIPTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>80</td>
<td>Diabetic nephropathy associated with type 1</td>
</tr>
<tr>
<td>81</td>
<td>Diabetic nephropathy associated with type 2</td>
</tr>
</tbody>
</table>

**CONGENITAL/HEREDITARY RENAL DISEASES**

<table>
<thead>
<tr>
<th>CODE</th>
<th>DESCRIPTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>21</td>
<td>Pyelonephritis/interstitial nephritis associated with neurogenic bladder</td>
</tr>
<tr>
<td>22</td>
<td>Pyelonephritis/interstitial nephritis due to congenital obstructive uropathy with or without vesico-ureteric reflux</td>
</tr>
<tr>
<td>24</td>
<td>Pyelonephritis/interstitial nephritis due to vesico-ureteric reflux without obstruction</td>
</tr>
<tr>
<td>40</td>
<td>Cystic kidney disease, type unspecified</td>
</tr>
<tr>
<td>41</td>
<td>Polycystic kidneys, adult type (dominant)</td>
</tr>
<tr>
<td>42</td>
<td>Polycystic kidneys, infantile and juvenile type (recessive)</td>
</tr>
<tr>
<td>43</td>
<td>Medullary cystic disease, including nephronophthisis</td>
</tr>
<tr>
<td>49</td>
<td>Cystic kidney disease, other specified type—specify</td>
</tr>
<tr>
<td>50</td>
<td>Hereditary/familial nephropathy—type unspecified</td>
</tr>
<tr>
<td>51</td>
<td>Hereditary nephritis with nerve deafness (Alport’s syndrome)</td>
</tr>
<tr>
<td>52</td>
<td>Cystinosis</td>
</tr>
<tr>
<td>53</td>
<td>Oxalosis</td>
</tr>
<tr>
<td>54</td>
<td>Fabry’s disease</td>
</tr>
<tr>
<td>55</td>
<td>Drash syndrome</td>
</tr>
<tr>
<td>58</td>
<td>Posterior urethral valves</td>
</tr>
<tr>
<td>59</td>
<td>Hereditary nephropathy, other—specify</td>
</tr>
<tr>
<td>60</td>
<td>Congenital renal hypoplasia—specify</td>
</tr>
<tr>
<td>61</td>
<td>Oligomeganephric hypoplasia</td>
</tr>
<tr>
<td>62</td>
<td>Segmental renal hypoplasia (Ask-Ulmark kidney)</td>
</tr>
<tr>
<td>63</td>
<td>Congenital renal dysplasia with or without urinary tract malformation</td>
</tr>
<tr>
<td>66</td>
<td>Syndrome of agenesis of abdominal muscles (prune belly syndrome)</td>
</tr>
</tbody>
</table>

**RENAL VASCULAR DISEASE**

<table>
<thead>
<tr>
<th>CODE</th>
<th>DESCRIPTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>70</td>
<td>Renal vascular disease—type unspecified</td>
</tr>
<tr>
<td>71</td>
<td>Malignant hypertension (no primary renal disease)</td>
</tr>
<tr>
<td>72</td>
<td>Renal vascular disease due to hypertension (no primary renal disease)</td>
</tr>
<tr>
<td>73</td>
<td>Polyarteritis nodosa</td>
</tr>
<tr>
<td>78</td>
<td>Ateroembolic renal disease</td>
</tr>
<tr>
<td>79</td>
<td>Renal vascular disease, classified (nephrosclerosis, renal vascular thrombosis)</td>
</tr>
</tbody>
</table>

**OTHER**

<table>
<thead>
<tr>
<th>CODE</th>
<th>DESCRIPTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>20</td>
<td>Pyelonephritis/interstitial nephritis, cause not specified</td>
</tr>
<tr>
<td>23</td>
<td>Pyelonephritis/interstitial nephritis due to acquired obstructive uropathy—specify</td>
</tr>
<tr>
<td>25</td>
<td>Pyelonephritis/interstitial nephritis due to urolithiasis</td>
</tr>
<tr>
<td>29</td>
<td>Pyelonephritis, other causes</td>
</tr>
<tr>
<td>56</td>
<td>Sickle cell nephropathy</td>
</tr>
<tr>
<td>57</td>
<td>Wilms’ tumour</td>
</tr>
<tr>
<td>82</td>
<td>Multiple myeloma</td>
</tr>
<tr>
<td>83</td>
<td>Amyloid</td>
</tr>
<tr>
<td>89</td>
<td>Multi-system disease, other—specify</td>
</tr>
<tr>
<td>90</td>
<td>Cortical or acute tubular necrosis</td>
</tr>
<tr>
<td>91</td>
<td>Tuberculosis</td>
</tr>
<tr>
<td>92</td>
<td>Gout</td>
</tr>
<tr>
<td>93</td>
<td>Nephrocalcinosis and hypercalcemic nephropathy</td>
</tr>
<tr>
<td>94</td>
<td>Balkan nephropathy</td>
</tr>
<tr>
<td>95</td>
<td>Kidney tumour</td>
</tr>
<tr>
<td>96</td>
<td>Traumatic or surgical loss of kidney</td>
</tr>
<tr>
<td>97</td>
<td>HIV nephropathy</td>
</tr>
<tr>
<td>99</td>
<td>Other identified renal disorders—specify</td>
</tr>
</tbody>
</table>
Complete this form to reflect the situation at your facility for patient lost to follow death, graft failure, transfer or the patient being followed at another hospital.

SECTION A—RECIPIENT INFORMATION

Transplant hospital ____________________________ (name and city) 

Patient ID ____________________________________

Last name ____________________________

First/middle name ____________________________

Former name ____________________________

Date of birth |___|___|/|___|___|___|/|___|___|___|___| (DD/MON/YYYY)

Health card number ____________________________

Prov. or terr. of health card ____________________________

Address (city) ____________________________________

Province or Territory ____________________________ Postal code ____________________________

Hospital followed at ____________________________________

(Enter only if different than transplant hospital.)

SECTION B—RECIPIENT OUTCOME

Date of Transplant |___|___|/|___|___|___|/|___|___|___|___| (DD/MON/YYYY)

Graft Number __________________________________

Patient Status (Please check one.)

Patient alive ☐ Transfer ☐ Lost to follow-up ☐ Died ☐

Transfer Hospital Name (Please check one of the following:) ☐ To ☐ From ☐

Name of Transfer Hospital: ____________________________

Date of transfer: |___|___|/|___|___|___|/|___|___|___|___| (DD/MON/YYYY)

Date of lost to follow: |___|___|/|___|___|___|/|___|___|___|___| (DD/MON/YYYY)

If deceased (Please check one of the following and enter cause of death.)

☐ Died with a functioning graft

☐ Died due to graft failure (Check cause of graft failure below.)

Enter cause of death _____________ (codes on back of page)

Date of death: |___|___|/|___|___|___|/|___|___|___|___| (DD/MON/YYYY)
# CAUSE OF DEATH/COMORBID COMPLICATION (RECIPIENT)

## GENERIC
- **00** Cause of death uncertain/not determined

## CARDIAC
- **11** Myocardial ischemia and infarction
- **12** Hyperkalemia
- **13** Hemorrhagic pericarditis
- **14** Other causes of cardiac failure
- **15** Cardiac arrest, cause unknown
- **16** Hypertensive cardiac failure
- **17** Hypokalemia
- **18** Fluid overload

## VASCULAR
- **21** Pulmonary embolus
- **22** Cerebrovascular accident
- **24** Hemorrhage from graft site—specify
- **25** Hemorrhage from vascular access or dialysis circuit
- **26** Hemorrhage from ruptured vascular aneurysm (not code 22 or 23)
- **27** Hemorrhage from surgery (not codes 23 to 26)—specify
- **28** Other hemorrhage (not codes 23 to 27)
- **55** Vascular thrombosis
- **56** Pulmonary vein stenosis
- **57** Stent/balloon complication

## INFECTION
- **03** Infection (bacterial)—specify site
- **04** Infection (viral)—specify site
- **05** Infection (fungal)—specify site
- **06** Cytomegalovirus
- **07** Epstein-Barr virus
- **08** Pneumocystic carinii pneumonia (PCP)
- **09** Protozoal/parasitic infection (includes toxoplasmosis)
- **10** Wound infection—specify site
- **34** Infections elsewhere (except viral hepatitis codes 41 and 42)
- **35** Septicemia/sepsis—specify source
- **36** Tuberculosis (lung)
- **37** Tuberculosis (elsewhere)
- **38** Generalized viral infection—specify viral agent
- **39** Peritonitis (not code 70)

## LIVER DISEASE
- **41** Liver, due to hepatitis B virus
- **42** Liver, other viral hepatitis
- **43** Liver, drug toxicity—specify drug
- **44** Cirrhosis, not viral
- **45** Cystic liver disease
- **46** Liver failure, cause unknown
- **74** Liver, due to hepatitis C virus

## GASTROINTESTINAL
- **02** Gastrointestinal tumour with or without perforation
- **20** Acute gastroenteritis with dehydration
- **23** Gastrointestinal hemorrhage
- **29** Mesenteric infarction
- **62** Pancreatitis
- **68** Perforation of peptic ulcer
- **70** Sclerosing (or adhesive) peritoneal disease
- **72** Perforation of colon/small bowel

## SOCIAL
- **50** Drug abuse (excludes alcohol abuse)
- **51** Patient refused further treatment
- **52** Suicide
- **53** Therapy ceased for any other reason
- **54** Alcohol abuse

## ACCIDENT
- **81** Accident related to treatment
- **82** Accident unrelated to treatment

## MISCELLANEOUS
- **30** Hypertension
- **40** Diabetic keto acidosis (DKA)
- **64** Cachexia
- **66** Malignant disease possibly induced by immunosuppressive therapy—specify primary site
- **67** Malignant disease (not code 66)—specify primary site
- **69** Dementia
- **90** Multi-system failure
- **99** Other identified cause of death—specify

## RESPIRATORY
- **19** Acute respiratory distress syndrome (ARDS)
- **31** Pulmonary infection (bacterial)
- **32** Pulmonary infection (viral)
- **33** Pulmonary infection (fungal)
- **49** Bronchiolitis obliterans

## RENAL DISEASE
- **47** Acute renal failure
- **48** Chronic renal failure
- **61** Uremia caused by kidney transplant failure

## METABOLIC
- **59** Drug-related toxicity—specify drug

## HEMATOLOGIC
- **63** Bone marrow depression
- **71** Thrombocytopenia
- **73** Thrombosis—specify

## NEUROLOGIC
- **75** Drug neurotoxicity—specify drug
- **76** Status epilepticus
- **77** Neurologic infection—specify infectious agent
SECTION A—RECIPIENT INFORMATION

Transplant hospital ____________________________________________________________
(name and city)

Patient ID _________________________________________________________________

Last name __________________________________________________________________

First/middle name __________________________________________________________

Former name ______________________________________________________________

Sex   □ Male   □ Female   □ Other

Blood Type   □ A   □ B   □ AB   □ O   □ U

Race

01   □ Caucasian   02   □ Asian   03   □ Black   06   □ Indian subcontinent

08   □ Pacific islander   09   □ Aboriginal   10   □ Mid East/Arabian

11   □ Latin American   98   □ Unknown   99   □ Other/multiracial (specify) ___

Date of birth |___|___|/|___|___|___|/|___|___|___|___| (DD/MON/YYYY)

Health card number _________________________________________________________

Prov. or terr. of health card ______________________

Address (city) ______________________________________________________________

Province or Territory ______________________  Postal code ___________________

(At time of transplant)

Recipient height □□□□•□□□□ (cm)

(Conversion factor: 1 in. = 2.54 cm)

Recipient weight □□□□•□□□□ (kg)

(Conversion factor: 1 lb. = 0.45 kg)

SECTION B—TRANSPLANT INFORMATION

Waiting List Information

Date patient first placed on waiting list (for this transplant)

|___|___|/|___|___|___|/|___|___|___|___| (DD/MON/YYYY)

Medical Status When First Placed on Waiting List (Please check one.)

08   □ Status 1—at home

04   □ Status 2—hospitalized

13   □ Status 3A—hospitalized ICU or inotropes or less than 6 months of age

14   □ Status 3B—hospitalized ICU or inotropes or less than 6 months of age, with
gerapid deterioration

06   □ Status 4—ICU, mechanical/ventilatory support

07   □ Coronary artery disease (ischemic cardiomyopathy)

24   □ Myocarditis

23   □ Acute myocardial infarct

15   □ Congenital heart disease (please specify)

16   □ Congenital heart disease—cyanotic lesions

17   □ Congenital heart disease—cyanotic lesions

36   □ Metabolic disorders

37   □ Cardiac tumour

38   □ Refractive arrhythmia

39   □ Muscular dystrophy

99   □ Other (please specify) ________________________________________________

SEND THIS CONFIDENTIAL INFORMATION TO:
Canadian Organ Replacement Register (CORR)
Canadian Institute for Health Information
4110 Yonge Street, Suite 300
Toronto, ON M2P 2B7
Tel.: 416-481-2002

Please complete section B of relevant transplant recipient registration form for
other organ(s):
Recipient Name ________________________________________________

SECTION B—TRANSPLANT INFORMATION (continued)

Recipient Serology Status at Time of Transplant
(Please check one of the acceptable values: P = positive, N = negative or U = unknown.)

Hepatitis BsAg  P □ N □ U □  Epstein-Barr virus  P □ N □ U □
Hepatitis BcAb P □ N □ U □  HIV P □ N □ U □
Hepatitis C  P □ N □ U □  CMV P □ N □ U □

Living
12  Domino donor

For a living or domino donor, please complete living donor profile.

01  Deceased donor

To facilitate matching, please complete the following:

Program organizing organ recovery _____________________________
Originating OPO donor number _________________________________
Surname stem (first 3 letters of donor surname) __________________

Hepatitis BsAg
P □ N □ U □
Hepatitis BcAb P □ N □ U □
Epstein-Barr virus  P □ N □ U □
HIV P □ N □ U □
CMV P □ N □ U □

Donor specific antibodies Y □ N □
Class I PRA current _____ %  Class I PRA peak _____ %
Class II PRA current _____ %  Class II PRA peak _____ %

* Methods: CDC □ ELISA □ Flow □ Luminex □ Other □
* The most sensitive method should be entered if more than one method is used by the laboratory

PVR: Reactive □ Non reactive □
PVR (Woods units) <4 □ 4–6 □ >6 □ Not done □

Standard crossmatch test  P □ N □ U □

*Recipient HLA  A ____ ____  B ____ ____  C ____ ____  DR ____ ____  DQ ____ ____
*Note: CORR enters the lowest haplotype first.

Heterotopic transplant  Y □ N □ U □

Risk Factors Existing at Time of Transplant
(Please check one of the acceptable values: Y = yes, N = no or U = unknown.)

Renal dysfunction  Y □ N □ U □  Liver dysfunction  Y □ N □ U □
Diabetes type 1  Y □ N □ U □  Diabetes type 2  Y □ N □ U □
Hypertension Y □ N □ U □  Smoker Y □ N □ U □
Hypercholesterolemia Y □ N □ U □  Inotropic support Y □ N □ U □
Previous cardiac surgery Y □ N □ U □  Prior defibrillator Y □ N □ U □
On anticoagulants Y □ N □ U □  Mechanical ventilation Y □ N □ U □

Mechanical Circulatory Support Device
Please indicate the devices(s) being used.

Intra-aortic balloon Y □ N □ U □
ECMO Y □ N □ U □
Ventricular assist device (VAD) Y □ N □ U □
Total artificial heart Y □ N □ U □

Total ischemic time (min) _____________________
(time between clamp on in donor and clamp off in recipient)

SECTION C—DONOR INFORMATION

□ Living  12  Domino donor ➔ For a living or domino donor, please complete living donor profile.

01  Deceased donor

To facilitate matching, please complete the following:

Program organizing organ recovery _____________________________
Originating OPO donor number _________________________________
Surname stem (first 3 letters of donor surname) __________________

Age  Years (002–130) ______  Months (001–023) ______
Days (001–030) ______  Newborn (000) ______

Sex □ Male □ Female □ Other □

*Donor HLA  A ____ ____  B ____ ____  C ____ ____  DR ____ ____  DQ ____ ____
*Note: CORR enters the lowest haplotype first.

Heterotopic transplant  Y □ N □ U □

Mechanical crossmatch test  P □ N □ U □

*Note: CORR enters the lowest haplotype first.

Risk Factors Existing at Time of Transplant
(Please check one of the acceptable values: Y = yes, N = no or U = unknown.)

Renal dysfunction  Y □ N □ U □  Liver dysfunction  Y □ N □ U □
Diabetes type 1  Y □ N □ U □  Diabetes type 2  Y □ N □ U □
Hypertension Y □ N □ U □  Smoker Y □ N □ U □
Hypercholesterolemia Y □ N □ U □  Inotropic support Y □ N □ U □
Previous cardiac surgery Y □ N □ U □  Prior defibrillator Y □ N □ U □
On anticoagulants Y □ N □ U □  Mechanical ventilation Y □ N □ U □

Total ischemic time (min) _____________________
(time between clamp on in donor and clamp off in recipient)
Complete this form to reflect the situation at your facility for patient lost to follow death, graft failure, transfer or the patient being followed at another hospital.

SECTION A—RECIPIENT INFORMATION

Transplant hospital __________________________ (name and city)

Patient ID  ____________________________________________

Last name  ____________________________________________

First/middle name ______________________________________

Former name __________________________________________

Date of birth [___|___|_|/___|___|___|/___|___|___|___| (DD/MON/YYYY)

Health card number _________________________________

Prov. or terr. of health card ____________________________

Address (city) ________________________________________

Province or Territory __________________________ Postal code _________________________

(Enter only if different than transplant hospital.)

SECTION B—RECIPIENT OUTCOME

If alive with failed graft or died due to graft failure, please complete this section.

Date of graft failure [___|___|_|/___|___|___|/___|___|___|___| (DD/MON/YYYY)

Check cause of graft failure below:

- [ ] 00 Uncertain/Unknown
- [ ] 01 Hyperacute rejection
- [ ] 11 Primary non-function
- [ ] 19 Graft coronary artery disease
- [ ] 23 Vascular event (graft)
- [ ] 25 Pulmonary hypertensive/cor pulmonale
- [ ] 28 Surgical complications
- [ ] 30 Rejection after stopping immunosuppressive drugs
- [ ] 63 Acute rejection
- [ ] 64 Chronic rejection
- [ ] 66 Rejection secondary to non-compliance
- [ ] 67 Recurrent primary disease
- [ ] 68 Infection and rejection
- [ ] 69 Infection of the graft
- [ ] 70 Systemic hypertension
- [ ] 71 Electrolyte disturbance (Please specify) __________________________
- [ ] 72 Pericarditis
- [ ] 73 Pericardial effusion
- [ ] 99 Other cause of graft failure (describe) __________________________

If deceased (Please check one of the following and enter cause of death.)

- [ ] Died with a functioning graft

OR

- [ ] Died due to graft failure (Check cause of graft failure below.)

Enter cause of death _____________ (codes on back of page)

Date of Death [___|___|_|/___|___|___|/___|___|___|___| (DD/MON/YYYY)

Transfer Hospital (Please check one of the following:)  □ To OR □ From

Name of Transfer Hospital: ______________________________________

Date of Transfer [___|___|_|/___|___|___|/___|___|___|___| (DD/MON/YYYY)

Date of lost to follow [___|___|_|/___|___|___|/___|___|___|___| (DD/MON/YYYY)
<table>
<thead>
<tr>
<th>CAUSE OF DEATH/COMORBID COMPLICATION (RECIPIENT)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>GENERIC</strong></td>
</tr>
<tr>
<td>00 Cause of death uncertain/not determined</td>
</tr>
<tr>
<td><strong>CARDIAC</strong></td>
</tr>
<tr>
<td>11 Myocardial ischemia and infarction</td>
</tr>
<tr>
<td>12 Hyperkalemia</td>
</tr>
<tr>
<td>13 Hemorrhagic pericarditis</td>
</tr>
<tr>
<td>14 Other causes of cardiac failure</td>
</tr>
<tr>
<td>15 Cardiac arrest, cause unknown</td>
</tr>
<tr>
<td>16 Hypertensive cardiac failure</td>
</tr>
<tr>
<td>17 Hypokalemia</td>
</tr>
<tr>
<td>18 Fluid overload</td>
</tr>
<tr>
<td><strong>VASCULAR</strong></td>
</tr>
<tr>
<td>21 Pulmonary embolus</td>
</tr>
<tr>
<td>22 Cerebrovascular accident</td>
</tr>
<tr>
<td>24 Hemorrhage from graft site—specify</td>
</tr>
<tr>
<td>25 Hemorrhage from vascular access or dialysis circuit</td>
</tr>
<tr>
<td>26 Hemorrhage from ruptured vascular aneurysm (not code 22 or 23)</td>
</tr>
<tr>
<td>27 Hemorrhage from surgery (not codes 23 to 26)—specify</td>
</tr>
<tr>
<td>28 Other hemorrhage (not codes 23 to 27)</td>
</tr>
<tr>
<td>55 Vascular thrombosis</td>
</tr>
<tr>
<td>56 Pulmonary vein stenosis</td>
</tr>
<tr>
<td>57 Stent/balloon complication</td>
</tr>
<tr>
<td><strong>INFECTIONS</strong></td>
</tr>
<tr>
<td>03 Infection (bacterial)—specify site</td>
</tr>
<tr>
<td>04 Infection (viral)—specify site</td>
</tr>
<tr>
<td>05 Infection (fungal)—specify site</td>
</tr>
<tr>
<td>06 Cytomegalovirus</td>
</tr>
<tr>
<td>07 Epstein-Barr virus</td>
</tr>
<tr>
<td>08 Pneumocystic carini pneumonia (PCP)</td>
</tr>
<tr>
<td>09 Protozoal/parasitic infection (includes toxoplasmosis)</td>
</tr>
<tr>
<td>10 Wound infection—specify site</td>
</tr>
<tr>
<td>34 Infections elsewhere (except viral hepatitis codes 41 and 42)</td>
</tr>
<tr>
<td>35 Septicemia/sepsis—specify source</td>
</tr>
<tr>
<td>36 Tuberculosis (lung)</td>
</tr>
<tr>
<td>37 Tuberculosis (elsewhere)</td>
</tr>
<tr>
<td>38 Generalized viral infection—specify viral agent</td>
</tr>
<tr>
<td>39 Peritonitis (not code 70)</td>
</tr>
<tr>
<td><strong>LIVER DISEASE</strong></td>
</tr>
<tr>
<td>41 Liver, due to hepatitis B virus</td>
</tr>
<tr>
<td>42 Liver, other viral hepatitis</td>
</tr>
<tr>
<td>43 Liver, drug toxicity—specify drug</td>
</tr>
<tr>
<td>44 Cirrhosis, not viral</td>
</tr>
<tr>
<td>45 Cystic liver disease</td>
</tr>
<tr>
<td>46 Liver failure, cause unknown</td>
</tr>
<tr>
<td>74 Liver, due to hepatitis C virus</td>
</tr>
<tr>
<td><strong>GASTROINTESTINAL</strong></td>
</tr>
<tr>
<td>02 Gastrointestinal tumour with or without perforation</td>
</tr>
<tr>
<td>20 Acute gastroenteritis with dehydration</td>
</tr>
<tr>
<td>23 Gastrointestinal hemorrhage</td>
</tr>
<tr>
<td>29 Mesenteric infarction</td>
</tr>
<tr>
<td>62 Pancreatitis</td>
</tr>
<tr>
<td>68 Perforation of peptic ulcer</td>
</tr>
<tr>
<td>70 Sclerosing (or adhesive) peritoneal disease</td>
</tr>
<tr>
<td>72 Perforation of colon/small bowel</td>
</tr>
<tr>
<td><strong>SOCIAL</strong></td>
</tr>
<tr>
<td>50 Drug abuse (excludes alcohol abuse)</td>
</tr>
<tr>
<td>51 Patient refused further treatment</td>
</tr>
<tr>
<td>52 Suicide</td>
</tr>
<tr>
<td>53 Therapy ceased for any other reason</td>
</tr>
<tr>
<td>54 Alcohol abuse</td>
</tr>
<tr>
<td><strong>ACCIDENT</strong></td>
</tr>
<tr>
<td>81 Accident related to treatment</td>
</tr>
<tr>
<td>82 Accident unrelated to treatment</td>
</tr>
<tr>
<td><strong>MISCELLANEOUS</strong></td>
</tr>
<tr>
<td>30 Hypertension</td>
</tr>
<tr>
<td>40 Diabetic keto acidosis (DKA)</td>
</tr>
<tr>
<td>64 Cachexia</td>
</tr>
<tr>
<td>66 Malignant disease possibly induced by</td>
</tr>
<tr>
<td>immunosuppressive therapy—specify primary site</td>
</tr>
<tr>
<td>67 Malignant disease (not code 66)—specify primary site</td>
</tr>
<tr>
<td>69 Dementia</td>
</tr>
<tr>
<td>90 Multi-system failure</td>
</tr>
<tr>
<td>99 Other identified cause of death—specify</td>
</tr>
<tr>
<td><strong>RESPIRATORY</strong></td>
</tr>
<tr>
<td>19 Acute respiratory distress syndrome (ARDS)</td>
</tr>
<tr>
<td>31 Pulmonary infection (bacterial)</td>
</tr>
<tr>
<td>32 Pulmonary infection (viral)</td>
</tr>
<tr>
<td>33 Pulmonary infection (fungal)</td>
</tr>
<tr>
<td>49 Bronchiolitis obliterans</td>
</tr>
<tr>
<td><strong>RENALE DISEASE</strong></td>
</tr>
<tr>
<td>47 Acute renal failure</td>
</tr>
<tr>
<td>48 Chronic renal failure</td>
</tr>
<tr>
<td>61 Uremia caused by kidney transplant failure</td>
</tr>
<tr>
<td><strong>METABOLIC</strong></td>
</tr>
<tr>
<td>59 Drug-related toxicity—specify drug</td>
</tr>
<tr>
<td><strong>HEMATOLOGIC</strong></td>
</tr>
<tr>
<td>63 Bone marrow depression</td>
</tr>
<tr>
<td>71 Thrombocytopenia</td>
</tr>
<tr>
<td>73 Thrombosis—specify</td>
</tr>
<tr>
<td><strong>NEUROLOGIC</strong></td>
</tr>
<tr>
<td>75 Drug neurotoxicity—specify drug</td>
</tr>
<tr>
<td>76 Status epilepticus</td>
</tr>
<tr>
<td>77 Neurologic infection—specify infectious agent</td>
</tr>
</tbody>
</table>
**SECTION A—RECIPIENT INFORMATION**

Transplant hospital ___________________________________________ (name and city)

Patient ID __________________________________________________

Last name ______________________ First/middle name ________________

Former name __________________________________________________

Sex  ☐ Male  ☐ Female  ☐ Other

Blood type  ☐ A  ☐ B  ☐ AB  ☐ O  ☐ U

Race  ☐ 01 Caucasian  ☐ 02 Asian  ☐ 03 Black  ☐ 05 Indian subcontinent

08 Pacific islander  ☐ 09 Aboriginal  10 ☐ Mid East/Arabian

11 ☐ Latin American  98 ☐ Unknown  99 ☐ Other/multiracial

Date of birth |___|___|/|___|___|___|/|___|___|___|___| (DD/MON/YYYY)

Health card number __________________________________________

Prov. or terr. of health card __________________________________

Address (city) ______________________________________________

Province or territory ____________________________ Postal code ____________

(At time of transplant)
Recipent height ____________ • ____________ (cm)

(Conversion factor: 1 in. = 2.54 cm)

Recipient weight ____________ • ____________ (kg)

(Conversion factor: 1 lb. = 0.45 kg)

**SECTION B—TRANSPLANT INFORMATION**

**Waiting List Information**

Date patient first placed on waiting list __________________________

(for this transplant) |___|___|/|___|___|___|/|___|___|___|___| (DD/MON/YYYY)

**Medical Status When First Placed on Waiting List** (Please check one.)

00 ☐ Status 0—on hold

09 ☐ Status 1—stable and waiting

10 ☐ Status 2—rapid decompensation

Date moved to final list status |___|___|/|___|___|___|/|___|___|___|___| (DD/MON/YYYY)

(Indicate date if not same as initial listing status.)

**Medical Status at Time of Transplant** (Please check one.)

09 ☐ Status 1—stable and waiting  10 ☐ Status 2—rapid decompensation

Date of transplant |___|___|/|___|___|___|/|___|___|___|___| (DD/MON/YYYY)

Graft number ____________________________________________

☐ Single lung  ☐ Bilateral lung  ☐ Heart lung

☐ Other combination transplant

Specify other organs(s) ______________________________________

Blood type  ☐ A  ☐ B  ☐ AB  ☐ O  ☐ U

(Please complete section B of relevant transplant recipient registration form for other organs.)

**Primary Diagnosis** (Please check one.)

08 ☐ Eisenmenger's syndrome

11 ☐ Idiopathic pulmonary fibrosis

19 ☐ Alpha I antitrypsin deficiency

26 ☐ Sarcoïdosis

13 ☐ Emphysema

20 ☐ Cystic fibrosis

27 ☐ Asbestosis

17 ☐ Primary pulmonary hypertension

22 ☐ Bronchiectasis

18 ☐ Chronic obstructive lung disease

28 ☐ Bronchiolitis obliterans

15 ☐ Lung failure due to congenital disease

99 ☐ Other (please specify) ____________________________

32 ☐ Cardiomyopathy - not specified

98 ☐ Unknown

**Recipient Serology Status at Time of Transplant**

(Please check one of the acceptable values: P = positive, N = negative or U = unknown.)

Hepatitis BsAg  ☐ P  ☐ N  ☐ U  ☐ Epstein-Barr virus  ☐ P  ☐ N  ☐ U

Hepatitis BcAb  ☐ P  ☐ N  ☐ U  ☐ HIV  ☐ P  ☐ N  ☐ U

Hepatitis C  ☐ P  ☐ N  ☐ U  ☐ CMV  ☐ P  ☐ N  ☐ U

Donor specific antibodies ☐ Y ☐ N

Class I PRA current _____ %  Class I PRA peak _____ %

Class II PRA current _____ %  Class II PRA peak _____ %

* Methods: CDC ☐ ELISA ☐ Flow ☐ Luminex ☐ Other ☐

* The most sensitive method should be entered if more than one method is used by the laboratory

PVR:

Reactive ☐ Non reactive ☐ PVR (Woods units): <4 ☐ 4–6 ☐ >6 ☐ Not done ☐

Standard crossmatch test  ☐ P ☐ N ☐ U ☐

*Recipient HLA:  A____ ____  B____ ____  C____ ____  DR____ ____  DQ____ ____

*Note: CORR enters the lowest haplotype first.
SECTION B—TRANSPLANT INFORMATION (continued)

Risk Factors Existing at Time of Transplant

(Please check one of the acceptable values: Y = yes, N = no or U = unknown.)

Renal dysfunction
Diabetes type 1
Hypertension
Non-ambulatory status
Liver dysfunction
Diabetes type 2
Mechanical ventilation
On anticoagulants
Other organ dysfunction
Previous thoracic surgery
Multi-resistant pathogen

SECTION C—DONOR INFORMATION

☐ Living  ☐ Domino donor → For a living or domino donor, please complete a living donor profile and attach to this form.

☐ Deceased donor

To facilitate matching, please complete the following:

Program organizing organ recovery

Originating OPO donor number

Donor
☐ Rt. lung
☐ Lt. lung
☐ Heart lung
☐ Both lungs

Surname stem (first 3 letters of donor surname)

Age
☐ Years (002–130) ______  Months (001–023) ______
☐ Days (001–030) ______  Newborn (000) ______

Sex
☐ Male
☐ Female
☐ Other

*Donor HLA
A____ ____ B____ ____ C____ ____ DR____ ____ DQ____ ____

(Note: CORR enters the lowest haplotype first.

Date of cross clamp (DD/MON/YYYY)
[___|___|/___|___|___|/___|___|___|___|___|]

(Cross clamp date is the same as the date of organ recovery.)

Cross clamp time (HH/MM) [___|___|/___|___|___|]
Complete this form to reflect the situation at your facility for patient lost to follow death, graft failure, transfer or the patient being followed at another hospital.

### SECTION A—RECIPIENT INFORMATION

**Transplant hospital**

(name and city)

Patient ID ________________________________

Last name ________________________________

First/middle name ____________________________

Former name ________________________________

Date of birth |___|___|/|___|___|___|/|___|___|___|___| (DD/MON/YYYY)

Health card number ____________________________

Prov. or terr. of health card ____________________________

Address (city) ________________________________

Province or Territory ____________________________ Postal code ________________

Hospital followed at ________________________________

(Enter only if different than transplant hospital.)

### SECTION B—RECIPIENT OUTCOME

**Date of Transplant** |___|___|/|___|___|___|/|___|___|___|___| (DD/MON/YYYY)

**Graft number**

**Patient Status**

(Please check one.)

Patient alive ☐ Transfer ☐ Lost to follow ☐ Died ☐

**Transfer Hospital**

(Please check one of the following:) ☐ To OR ☐ From

Name of Transfer Hospital: ________________________________

**Date of Transfer** |___|___|/|___|___|___|/|___|___|___|___| (DD/MON/YYYY)

**Date of lost to follow** |___|___|/|___|___|___|/|___|___|___|___| (DD/MON/YYYY)

If deceased (Please check one of the following and enter cause of death.)

☐ Died with a functioning graft

OR

☐ Died due to graft failure (Check cause of graft failure below.)

Enter cause of death ________________ (codes on back of page)

**Date of Death** |___|___|/|___|___|___|/|___|___|___|___| (DD/MON/YYYY)
## CAUSE OF DEATH/COMORBID COMPLICATION (RECIPIENT)

### GENERIC
- **00** Cause of death uncertain/not determined

### CARDIAC
- **11** Myocardial ischemia and infarction
- **12** Hyperkemia
- **13** Hemorrhagic pericarditis
- **14** Other causes of cardiac failure
- **15** Cardiac arrest, cause unknown
- **16** Hypertensive cardiac failure
- **17** Hypokalemia
- **18** Fluid overload

### VASCULAR
- **21** Pulmonary embolus
- **22** Cerebrovascular accident
- **24** Hemorrhage from graft site—specify
- **25** Hemorrhage from vascular access or dialysis circuit
- **26** Hemorrhage from ruptured vascular aneurysm (not code 22 or 23)
- **27** Hemorrhage from surgery (not codes 23 to 26)—specify
- **28** Other hemorrhage (not codes 23 to 27)
- **55** Vascular thrombosis
- **56** Pulmonary vein stenosis
- **57** Stent/balloon complication

### INFECTIONS
- **03** Infection (bacterial)—specify site
- **04** Infection (viral)—specify site
- **05** Infection (fungal)—specify site
- **06** Cytomegalovirus
- **07** Epstein-Barr virus
- **08** Pneumocystic carinii pneumonia (PCP)
- **09** Protozoal/parasitic infection (includes toxoplasmosis)
- **10** Wound infection—specify site
- **34** Infections elsewhere (except viral hepatitis codes 41 and 42)
- **35** Septicemia/sepsis—specify source
- **36** Tuberculosis (lung)
- **37** Tuberculosis (elsewhere)
- **38** Generalized viral infection—specify viral agent
- **39** Peritonitis (not code 70)

### LIVER DISEASE
- **41** Liver, due to hepatitis B virus
- **42** Liver, due to other viral hepatitises
- **43** Liver, drug toxicity—specify drug
- **44** Cirrhosis, not viral
- **45** Cystic liver disease
- **46** Liver failure, cause unknown
- **74** Liver, due to hepatitis C virus

### GASTROINTESTINAL
- **02** Gastrointestinal tumour with or without perforation
- **19** Acute gastroenteritis with dehydration
- **29** Mesenteric infarction
- **62** Pancreatitis
- **68** Perforation of peptic ulcer
- **70** Sclerosing (or adhesive) peritoneal disease
- **72** Perforation of colon/small bowel

### SOCIAL
- **50** Drug abuse (excludes alcohol abuse)
- **51** Patient refused further treatment
- **52** Suicide
- **53** Therapy ceased for any other reason
- **54** Alcohol abuse

### ACCIDENT
- **81** Accident related to treatment
- **82** Accident unrelated to treatment

### MISCELLANEOUS
- **30** Hypertension
- **40** Diabetic keto acidosis (DKA)
- **64** Cachexia
- **66** Malignant disease possibly induced by immunosuppressive therapy—specify primary site
- **67** Malignant disease (not code 66)—specify primary site
- **69** Dementia
- **90** Multi-system failure
- **99** Other identified cause of death—specify

### RESPIRATORY
- **19** Acute respiratory distress syndrome (ARDS)
- **31** Pulmonary infection (bacterial)
- **32** Pulmonary infection (viral)
- **33** Pulmonary infection (fungal)
- **49** Bronchiolitis obliterans

### RENAL DISEASE
- **47** Acute renal failure
- **48** Chronic renal failure
- **61** Uremia caused by kidney transplant failure

### METABOLIC
- **59** Drug-related toxicity—specify drug

### HEMATOLOGIC
- **63** Bone marrow depression
- **71** Thrombocytopenia
- **73** Thrombosis—specify

### NEUROLOGIC
- **75** Drug neurotoxicity—specify drug
- **76** Status epilepticus
- **77** Neurologic infection—specify infectious agent
SECTION A—RECIPIENT INFORMATION

Transplant hospital ____________________________  (name and city)

Date patient first placed on waiting list (for this transplant) ________________ (DD/MON/YYYY)

Patient ID _______________________________________

Last name _______________________________________

First/middle name _______________________________

Former name _____________________________________

Date of birth |___|___|/|___|___|___|/|___|___|___|___| (DD/MON/YYYY)

Sex ☐ Male ☐ Female ☐ Other

Blood Type ☐ A ☐ B ☐ AB ☐ O ☐ U

Race  ☐ Caucasian  ☐ Asian  ☐ Black  ☐ Indian subcontinent

01 ☐ Pacific islander  09 ☐ Aboriginal  10 ☐ Mid East/Arabian

08 ☐ Latin American  98 ☐ Unknown  99 ☐ Other/multiracial

Province or territory _____________________________ Postal code __________

Prov. or terr. of health card _______________________

Address (city) __________________________________

Medical status when first placed on waiting list

☐ Status 1 (at home)  ☐ Status 1T (tumour patient)

☐ Status 2 (hospitalized)  ☐ Status 3 (hospitalized ICU)

☐ Status 3F (fulminant)  ☐ Status 4 (ICU—incubated and ventilated)

Date of transplant |___|___|/|___|___|___|/|___|___|___|___| (DD/MON/YYYY)

☐ Liver transplant  ☐ Combination transplant

Graft number ________________________________

SECTION B—TRANSPLANT INFORMATION

Date moved to the final list status (Indicate date if not same as initial listing status.) |___|___|/|___|___|___|/|___|___|___|___| (DD/MON/YYYY)

Medical status at Time of Transplant

19 ☐ Status 1 (at home)  16 ☐ Status 1T (tumour patient)

17 ☐ Status 2 (hospitalized)  05 ☐ Status 3 (hospitalized ICU)

11 ☐ Status 3F (fulminant)  18 ☐ Status 4 (ICU—incubated and ventilated)

Date of transplant |___|___|/|___|___|___|/|___|___|___|___| (DD/MON/YYYY)

☐ Liver transplant  ☐ Combination transplant

Specify organ(s) ___________________________________________________________________

Recipient Serology Status at Time of Transplant

Hepatitis B

- Hepatitis BsAg ☐ N ☐ U ☐
- Hepatitis BcAb ☐ N ☐ U ☐
- Hepatitis B-DNA ☐ P ☐ N ☐ U ☐

Treatment at time of transplant: ☐ Interferon ☐ Lamivudine ☐

- Other (specify) ________________

Hepatitis C

- Hepatitis C ☐ N ☐ U ☐ (If "N," skip to Epstein-Barr virus flag, below.)

RNA detectable? ☐ No ☐ Yes ⇒ Specifying level _______ ☐ Not collected

Genotype: ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ Unknown

Treatment at time of transplant:

- Interferon ☐ Ribavirin ☐ Both Interferon and Ribavirin

- Epstein-Barr virus ☐ N ☐ U ☐
- CMV ☐ N ☐ U ☐
- HIV ☐ N ☐ U ☐

Recipient specific antibodies ☐ Y ☐ N ☐

- Class I PRA current ______%  Class I PRA peak ______%
- Class II PRA current ______%  Class II PRA peak ______%

* Methods: CDC  ☐ ELISA  ☐ Flow ☐ Luminex  ☐ Other ☐

* The most sensitive method should be entered if more than one method is used by the laboratory.

Standard crossmatch test ☐ P ☐ N ☐ U ☐

*Recipient HLA: A____ ____ B____ ____ C____ ____ DR____ ____ DG____ __

*Note: CORR enters the lowest haplotype first.
**SECTION B—TRANSPLANT INFORMATION (continued)**

Recipient name  _________________________________________________

<table>
<thead>
<tr>
<th>Child-Pugh score at transplant</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th>Creatinine at transplant</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Total serum bilirubin at transplant (μmol/L)</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th>INR at transplant</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Living</th>
<th>Domino donor</th>
<th>For a living or domino donor, please complete a living donor profile and attach to this form.</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
<td>☐</td>
<td></td>
</tr>
</tbody>
</table>

**SECTION C—DONOR INFORMATION**

<table>
<thead>
<tr>
<th>☐ Living</th>
<th>12 ☐ Domino donor</th>
<th>For a living or domino donor, please complete a living donor profile and attach to this form.</th>
</tr>
</thead>
<tbody>
<tr>
<td>01 ☐ Deceased donor</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

To facilitate matching, please complete the following.

<table>
<thead>
<tr>
<th>Program organizing organ recovery</th>
<th></th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Originating OPO donor number</th>
<th></th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Surname stem (first 3 letters of donor surname)</th>
<th></th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Age Years (002–130)</th>
<th>Months (001–023)</th>
<th></th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Days (001–030)</th>
<th>Newborn (000)</th>
<th></th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Sex</th>
<th>Male</th>
<th>Female</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Primary and Metastatic Tumours in the Liver?</th>
<th>Yes</th>
<th>Complete shaded section.</th>
<th>☐ No</th>
<th>Skip shaded section.</th>
</tr>
</thead>
</table>

Complete this section or attach copy of form submitted to the International Registry of Hepatic Tumors in Liver Transplantation (Baylor University Medical Centre).

Tumour markers (ng/ml); alpha-fetoprotein

Chorioembryonic antigen (CEA)

Number of nodules Diameter of largest (cm)

<table>
<thead>
<tr>
<th>Bilobar</th>
<th>Yes</th>
<th>No</th>
<th>Characteristics</th>
<th>Multifocal</th>
<th>Single</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Histologic grade</th>
<th>System used</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Vascular involvement</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Spread at surgery</th>
<th>None</th>
<th>Periaortic</th>
<th>Lungs, mediastinum</th>
<th>Diaphragm</th>
<th>Abdomen, other</th>
<th>Hilar nodes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

**Adjunct Tumour Therapy**

<table>
<thead>
<tr>
<th>Therapy</th>
<th>Pre-op</th>
<th>Intra-op</th>
<th>Post-op</th>
<th>Specify agent (where applicable)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Embolization</td>
<td>Y</td>
<td>N</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Irradiation</td>
<td>Y</td>
<td>N</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Other treatment</td>
<td>Y</td>
<td>N</td>
<td>Y</td>
<td>N</td>
</tr>
</tbody>
</table>

**Chemotherapy**

- Adriamycin | Y | N | Y | N | Y | N |
- 5-Fluorouracil | Y | N | Y | N | Y | N |
- 5-FU DR | Y | N | Y | N | Y | N |
- Cisplatin | Y | N | Y | N | Y | N |
- Other | Y | N | Y | N | Y | N |

<table>
<thead>
<tr>
<th>Warm ischemic time (min)</th>
<th>☐</th>
<th>☐</th>
<th>☐</th>
<th>Cold ischemic time (min)</th>
<th>☐</th>
<th>☐</th>
<th>☐</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rewarm time (min)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
</tbody>
</table>
### Codes—Primary Liver Diagnosis

#### ACUTE HEPATIC FAILURE (Fulminant)
- **01** Hepatitis—type A
- **02** Hepatitis—type B
- **03** Hepatitis—type C
- **04** Hepatitis—type non A, B, C
- **05** Hepatitis with delta
- **06** Toxic
- **07** Drug induced—other
- **08** Drug induced—acetaminophen
- **09** Other/fulminant hepatitic failure (Including Budd-Chiari and Wilson’s disease)

#### CHRONIC HEPATIC FAILURE
- **12** Budd-Chiari
- **13** Byler’s disease (intra-hepatic colestasis)
- **14** Cirrhosis—alcoholic
- **15** Cirrhosis—other
- **16** Cryptogenic cirrhosis
- **17** Post-necrotic cirrhosis
- **18** Primary biliary cirrhosis
- **19** Secondary biliary cirrhosis
- **20** Drug induced—other
- **21** Hepatitis—type A
- **22** Hepatitis—type B
- **23** Hepatitis—type C
- **24** Hepatitis—type non A, B, or C
- **25** Neonatal hepatitis
- **26** Autoimmune chronic active hepatitis
- **27** Primary biliary atresia
- **28** Sclerosing cholangitis
- **29** Toxic
- **30** Watson-Alagille disease (arterio-hepatic dysplasia)
- **31** Polycystic liver disease
- **32** Non-alcoholic steatohepatitis (NASH)

#### HEPATIC TUMOURS
- **50** Angiosarcoma
- **51** Cholangiocarcinoma
- **52** Fibrolamellar hepatoma
- **53** Hepatocellular carcinoma
- **54** Metastatic tumour
- **55** Hepatic tumour—other

#### METABOLIC DISORDERS
- **20** Alpha I anti-trypsin deficiency
- **21** Crigler-Najjar syndrome
- **22** Glycogen storage disease
- **23** Hemochromatosis
- **24** Hyperlipoproteinemia type 2
- **25** Niemann-Pick
- **26** Phenylketonuria
- **27** Protoporphyria
- **28** Tyrosinemia
- **29** Wilson’s disease
- **30** Metabolic disorder—other

#### OTHER PRIMARY DIAGNOSIS
- **30** Congenital hepatic fibrosis
- **31** Caroli's disease
- **32** Cystic disorders
- **33** Thrombosed hepatic artery
- **34** Unknown/missing
- **35** Other (specify)
Canadian Organ Replacement Register
Liver Transplant Follow-up Form

SECTION A—RECIPIENT INFORMATION

Transplant hospital ____________________________________________________________

Patient ID ________________________________

Health card number ________________________________

Prov. or terr. of health card ________________________________

Last name _________________________ First/middle name _________________________

Former name _______________________________________________________________

Address (city) __________________________ Postal code __________________________

Province ____________________________ Date of birth |___|___|/|___|___|___|/|___|___|___|___| (DD/MON/YYYY)

Affix patient label, if available.

SECTION B—HEPATITIS B POST-TRANSPLANT INFORMATION

For transplant patients who have been diagnosed with hepatitis B (as per primary diagnosis), please complete on December 31 of each year, or at time of death.

Transplant date: |___|___|/|___|___|___|/|___|___|___|___| (DD/MON/YYYY)

Recurrent disease: ☐ No ☐ Yes ➔ Please check disease severity:*

☐ Mild

☐ Moderate

☐ Severe

* Mild: asymptomatic

Moderate: with symptoms or signs of liver disease (e.g. jaundice, fatigue)

Severe: graft failure, cirrhosis, fibrosing cholestatic disease, signs of portal hypertension

Date of recurrence |___|___|/|___|___|___|/|___|___|___|___| (DD/MON/YYYY)

Detectable HBV DNA ☐ Yes ☐ No ☐ Not done in calendar year

Current therapy

H-BIG ☐ Yes ☐ No

Lamivudine ☐ Yes ☐ No

Other (specify) __________________________________

SECTION C—HEPATITIS C POST-TRANSPLANT INFORMATION

For transplant patients who have been diagnosed with hepatitis C (as per primary diagnosis), please complete on December 31 of each year, or at time of death.

Transplant date: |___|___|/|___|___|___|/|___|___|___|___| (DD/MON/YYYY)

Recurrent disease: ☐ No ☐ Yes ➔ Please check disease severity:*

☐ Mild

☐ Moderate

☐ Severe

* Recurrent disease and disease severity will be based on the results of a biopsy.

Date of recurrence/biopsy |___|___|/|___|___|___|/|___|___|___|___| (DD/MON/YYYY)

Receiving treatment during this calendar year ☐ No ☐ Yes ➔ Please check one:

☐ Prophylaxis

☐ Recurrence

SECTION D—LIVER TUMOURS POST-TRANSPLANT INFORMATION

For transplant patients who have been diagnosed with liver tumours (as per primary diagnosis), please complete on December 31 of each year, or at time of death.

Transplant date: |___|___|/|___|___|___|/|___|___|___|___| (DD/MON/YYYY)

Outcome

☐ Alive free of tumour

☐ Alive with tumour

☐ Died free of tumour

☐ Died with tumour ➔ Was death tumour-related?

☐ No

☐ Yes
## SECTION A—RECIPIENT INFORMATION

Transplant hospital ________________________________________________________________ (name and city)

Patient ID ________________________________________________________________

Last name ________________________________________________________________

First/middle name ____________________________________________________________

Former name ______________________________________________________________

Date of birth |___|___|/|___|___|___|/|___|___|___|___| (DD/MON/YYYY)

Health card number ____________________________________________________________

Prov. or terr. of health card ____________________________________________________

Address (city) ________________________________________________________________

Province or Territory ______________________  Postal code  ___________________

(Enter only if different than transplant hospital.)

## SECTION B—RECIPIENT OUTCOME

If alive with failed graft or died due to graft failure, please complete this section.

Date of graft failure |___|___|/|___|___|___|/|___|___|___|___| (DD/MON/YYYY)

Check cause of graft failure below:

00  □  Uncertain/Unknown
01  □  Hyperacute rejection
11  □  Primary non-function
14  □  Graft/portal vein thrombosis
15  □  Graft/hepatic vein thrombosis
16  □  Biliary tract complication
18  □  De novo malignancy (graft)
22  □  Arterial thrombosis
28  □  Surgical complications
30  □  Rejection after stopping immunosuppressive drugs
33  □  De nova hepatitis
63  □  Acute rejection
64  □  Chronic rejection
67  □  Recurrent disease
68  □  Infection and rejection
69  □  Infection of the graft
99  □  Other cause of graft failure (describe) ____________________________

Date of Transplant |___|___|/|___|___|___|/|___|___|___|___| (DD/MON/YYYY)

Graft Number __________________________________

Patient Status  (Please check one.)

Patient alive  □  Transfer □  Lost to follow-up □  Died □

Transfer Hospital Name  (Please check one of the following:)  □ To  OR  □ From

Name of Transfer Hospital:_________________________________________________

Date of transfer: |___|___|/|___|___|___|/|___|___|___|___| (DD/MON/YYYY)

Date of lost to follow: |___|___|/|___|___|___|/|___|___|___|___| (DD/MON/YYYY)

If deceased  (Please check one of the following and enter cause of death.)

□ Died with a functioning graft

OR

□ Died due to graft failure  (Check cause of graft failure below.)

Enter cause of death _____________ (codes on back of page)

Date of death: |___|___|/|___|___|___|/|___|___|___|___| (DD/MON/YYYY)
### Cause of Death/Comorbid Complication (Recipient)

<table>
<thead>
<tr>
<th>Category</th>
<th>Codes</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Generic</strong></td>
<td>00</td>
<td>Chronic renal failure—etiology uncertain</td>
</tr>
<tr>
<td><strong>Cardiac</strong></td>
<td>11</td>
<td>Myocardial ischemia and infarction</td>
</tr>
<tr>
<td></td>
<td>12</td>
<td>Hyperkalemia</td>
</tr>
<tr>
<td></td>
<td>13</td>
<td>Hemorrhagic pericarditis</td>
</tr>
<tr>
<td></td>
<td>15</td>
<td>Cardiac arrest, cause unknown</td>
</tr>
<tr>
<td></td>
<td>16</td>
<td>Hypertensive cardiac failure</td>
</tr>
<tr>
<td></td>
<td>17</td>
<td>Hypokalemia</td>
</tr>
<tr>
<td></td>
<td>18</td>
<td>Fluid overload</td>
</tr>
<tr>
<td><strong>Vascular</strong></td>
<td>21</td>
<td>Pulmonary embolus</td>
</tr>
<tr>
<td></td>
<td>22</td>
<td>Cerebrovascular accident</td>
</tr>
<tr>
<td></td>
<td>24</td>
<td>Hemorrhage from graft site—specify</td>
</tr>
<tr>
<td></td>
<td>25</td>
<td>Hemorrhage from vascular access or dialysis circuit</td>
</tr>
<tr>
<td></td>
<td>26</td>
<td>Hemorrhage from ruptured vascular aneurysm (not code 22 or 23)</td>
</tr>
<tr>
<td></td>
<td>27</td>
<td>Hemorrhage from surgery (not codes 23 to 26)—specify</td>
</tr>
<tr>
<td></td>
<td>28</td>
<td>Other hemorrhage (not codes 23 to 27)</td>
</tr>
<tr>
<td></td>
<td>55</td>
<td>Vascular thrombosis</td>
</tr>
<tr>
<td></td>
<td>56</td>
<td>Pulmonary vein stenosis</td>
</tr>
<tr>
<td></td>
<td>57</td>
<td>Stent/balloon complication</td>
</tr>
<tr>
<td><strong>Infection</strong></td>
<td>03</td>
<td>Infection (bacterial)—specify site</td>
</tr>
<tr>
<td></td>
<td>04</td>
<td>Infection (viral)—specify site</td>
</tr>
<tr>
<td></td>
<td>05</td>
<td>Infection (fungal)—specify site</td>
</tr>
<tr>
<td></td>
<td>06</td>
<td>Cytomegalovirus</td>
</tr>
<tr>
<td></td>
<td>07</td>
<td>Epstein-Barr virus</td>
</tr>
<tr>
<td></td>
<td>08</td>
<td>Pneumocystis carinii pneumonia (PCP)</td>
</tr>
<tr>
<td></td>
<td>09</td>
<td>Protozoal/parasitic infection (includes toxoplasmosis)</td>
</tr>
<tr>
<td></td>
<td>10</td>
<td>Wound infection—specify site</td>
</tr>
<tr>
<td></td>
<td>34</td>
<td>Infections elsewhere (except viral hepatitis codes 41 and 42)</td>
</tr>
<tr>
<td></td>
<td>35</td>
<td>Septicemia/sepsis—specify source</td>
</tr>
<tr>
<td></td>
<td>36</td>
<td>Tuberculosis (lung)</td>
</tr>
<tr>
<td></td>
<td>37</td>
<td>Tuberculosis (elsewhere)</td>
</tr>
<tr>
<td></td>
<td>38</td>
<td>Generalized viral infection—specify viral agent</td>
</tr>
<tr>
<td></td>
<td>39</td>
<td>Peritonitis (not code 70)</td>
</tr>
<tr>
<td><strong>Gastrointestinal</strong></td>
<td>02</td>
<td>Gastrointestinal tumour with or without perforation</td>
</tr>
<tr>
<td></td>
<td>20</td>
<td>Acute gastroenteritis with dehydration</td>
</tr>
<tr>
<td></td>
<td>23</td>
<td>Gastrointestinal hemorrhage</td>
</tr>
<tr>
<td></td>
<td>29</td>
<td>Mesenteric infarction</td>
</tr>
<tr>
<td></td>
<td>62</td>
<td>Pancreatitis</td>
</tr>
<tr>
<td></td>
<td>68</td>
<td>Perforation of peptic ulcer</td>
</tr>
<tr>
<td></td>
<td>70</td>
<td>Sclerosing (or adhesive) peritoneal disease</td>
</tr>
<tr>
<td></td>
<td>72</td>
<td>Perforation of colon/small bowel</td>
</tr>
<tr>
<td><strong>Accident</strong></td>
<td>81</td>
<td>Accident related to treatment</td>
</tr>
<tr>
<td></td>
<td>82</td>
<td>Accident unrelated to treatment</td>
</tr>
<tr>
<td><strong>Miscellaneous</strong></td>
<td>30</td>
<td>Hypertension</td>
</tr>
<tr>
<td></td>
<td>40</td>
<td>Diabetic keto acidosis (DKA)</td>
</tr>
<tr>
<td></td>
<td>64</td>
<td>Cachexia</td>
</tr>
<tr>
<td></td>
<td>66</td>
<td>Malignant disease possibly induced by immunosuppressive therapy—specify primary site</td>
</tr>
<tr>
<td></td>
<td>67</td>
<td>Malignant disease (not code 66)—specify primary site</td>
</tr>
<tr>
<td></td>
<td>69</td>
<td>Dementia</td>
</tr>
<tr>
<td></td>
<td>90</td>
<td>Multi-system failure</td>
</tr>
<tr>
<td></td>
<td>99</td>
<td>Other identified cause of death—specify</td>
</tr>
<tr>
<td><strong>Respiratory</strong></td>
<td>19</td>
<td>Acute respiratory distress syndrome (ARDS)</td>
</tr>
<tr>
<td></td>
<td>31</td>
<td>Pulmonary infection (bacterial)</td>
</tr>
<tr>
<td></td>
<td>32</td>
<td>Pulmonary infection (viral)</td>
</tr>
<tr>
<td></td>
<td>33</td>
<td>Pulmonary infection (fungal)</td>
</tr>
<tr>
<td></td>
<td>49</td>
<td>Bronchiolitis obliterans</td>
</tr>
<tr>
<td><strong>Renal Disease</strong></td>
<td>47</td>
<td>Acute renal failure</td>
</tr>
<tr>
<td></td>
<td>48</td>
<td>Chronic renal failure</td>
</tr>
<tr>
<td></td>
<td>61</td>
<td>Uremia caused by kidney transplant failure</td>
</tr>
<tr>
<td><strong>Metabolic</strong></td>
<td>59</td>
<td>Drug-related toxicity—specify drug</td>
</tr>
<tr>
<td><strong>Hematologic</strong></td>
<td>63</td>
<td>Bone marrow depression</td>
</tr>
<tr>
<td></td>
<td>71</td>
<td>Thrombocytopenia</td>
</tr>
<tr>
<td></td>
<td>73</td>
<td>Thrombosis—specify</td>
</tr>
<tr>
<td><strong>Neurologic</strong></td>
<td>75</td>
<td>Drug neurotoxicity—specify drug</td>
</tr>
<tr>
<td></td>
<td>76</td>
<td>Status epilepticus</td>
</tr>
<tr>
<td></td>
<td>77</td>
<td>Neurologic infection—specify infectious agent</td>
</tr>
<tr>
<td><strong>Social</strong></td>
<td>50</td>
<td>Drug abuse (excludes alcohol abuse)</td>
</tr>
<tr>
<td></td>
<td>51</td>
<td>Patient refused further treatment</td>
</tr>
<tr>
<td></td>
<td>52</td>
<td>Suicide</td>
</tr>
<tr>
<td></td>
<td>53</td>
<td>Therapy ceased for any other reason</td>
</tr>
<tr>
<td></td>
<td>54</td>
<td>Alcohol abuse</td>
</tr>
</tbody>
</table>
**SECTION A—RECIPIENT INFORMATION**

<table>
<thead>
<tr>
<th>Transplant hospital</th>
<th>(name and city)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient ID</td>
<td></td>
</tr>
<tr>
<td>Last name</td>
<td>First/middle name</td>
</tr>
<tr>
<td>Former name</td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td>Male</td>
</tr>
<tr>
<td>Blood Type</td>
<td>A</td>
</tr>
<tr>
<td>Race</td>
<td>Caucasian</td>
</tr>
<tr>
<td>Date of Birth</td>
<td></td>
</tr>
<tr>
<td>Health card number</td>
<td></td>
</tr>
<tr>
<td>Prov. or terr. of health card</td>
<td></td>
</tr>
<tr>
<td>Address (city)</td>
<td></td>
</tr>
<tr>
<td>Province or territory</td>
<td>Postal code</td>
</tr>
</tbody>
</table>

**SECTION A—RECIPIENT INFORMATION (continued)**

<table>
<thead>
<tr>
<th>(At time of transplant)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recipient height</td>
</tr>
<tr>
<td>Recipient weight</td>
</tr>
</tbody>
</table>

**SECTION B—TRANSPLANT INFORMATION**

<table>
<thead>
<tr>
<th>Waiting List Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date patient first placed on waiting list</td>
</tr>
<tr>
<td>Date of Transplant</td>
</tr>
<tr>
<td>Graft number</td>
</tr>
<tr>
<td>Pancreas transplant only</td>
</tr>
</tbody>
</table>

**SECTION B—TRANSPLANT INFORMATION (continued)**

<table>
<thead>
<tr>
<th>Type of Pancreas</th>
</tr>
</thead>
<tbody>
<tr>
<td>Whole pancreas</td>
</tr>
<tr>
<td>Segmental—no polymer occlusion</td>
</tr>
<tr>
<td>Islet cells</td>
</tr>
</tbody>
</table>

**Primary Diagnosis for Pancreas Failure (check one)**

<table>
<thead>
<tr>
<th>Type of Failure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cystic fibrosis</td>
</tr>
<tr>
<td>Diabetes type I</td>
</tr>
<tr>
<td>Pancreatic cancer</td>
</tr>
<tr>
<td>Pancreatectomy</td>
</tr>
</tbody>
</table>

**Recipient Serology Status at Time of Transplant**

<table>
<thead>
<tr>
<th>Hepatitis BsAg</th>
<th>BcAb</th>
<th>C</th>
<th>CMV</th>
<th>Epstein-Barr virus</th>
<th>HIV</th>
</tr>
</thead>
<tbody>
<tr>
<td>P</td>
<td>N</td>
<td>U</td>
<td>P</td>
<td>N</td>
<td>U</td>
</tr>
<tr>
<td>P</td>
<td>N</td>
<td>U</td>
<td>P</td>
<td>N</td>
<td>U</td>
</tr>
</tbody>
</table>

**Risk Factors Existing at Time of Transplant**

<table>
<thead>
<tr>
<th>Cardiovascular disease</th>
<th>Cerebrovascular disease</th>
<th>Peripheral vascular disease</th>
<th>Diabetic retinopathy</th>
<th>Diabetic neuropathy</th>
<th>Family history of diabetes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Y</td>
<td>N</td>
<td>U</td>
<td>Y</td>
<td>N</td>
<td>U</td>
</tr>
<tr>
<td>Y</td>
<td>N</td>
<td>U</td>
<td>Y</td>
<td>N</td>
<td>U</td>
</tr>
</tbody>
</table>

**Risk Factors Existing at Time of Transplant (continued)**

<table>
<thead>
<tr>
<th>Warmed ischemic time (min)</th>
<th>Cold ischemic time (min)</th>
<th>Rewarm time (min)</th>
<th>Digestion time (min)</th>
<th>Cold ischemic time (min)</th>
<th>Culture time (hours)</th>
<th>Total ischemic time (min)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Recipient name ________________________________________

**SECTION C—DONOR INFORMATION**

- **Living**
- **Domino donor** ➔ For a living or domino donor, please complete a living donor profile and attach to this form.

- **Autograft (islet)**
- **Fetal tissue (islet cells)**

- **Deceased donor**

To facilitate matching, please complete the following:

Program organizing organ recovery __________________________

Originating OPO donor number ____________________________

Surname stem __________________ (Please enter the first 3 letters of the donor surname.)

**Age**
- Years (002–130) __________________
- Months (001–023) ______________
- Days (001–030) __________________
- Newborn (000) ______________

**Sex**
- Male
- Female
- Other

*Donor HLA A____ ____   B____ ____   C____ ____   DR____ ____   DQ____ ______________

*Note: CORR enters the lowest haplotype first.

Date of cross clamp (DD/MON/YYYY) |___|___|/|___|___|___|/|___|___|___|___|

(Cross-clamp date is the same as the date of organ recovery.)

Cross-clamp time (HH/MM) |___|___|/|___|___|___|
Complete this form to reflect the situation at your facility for patient lost to follow death, graft failure, transfer or the patient being followed at another hospital.

SECTION A—RECIPIENT INFORMATION

Transplant hospital ____________________________ [name and city]

Patient ID __________________________________________

Last name __________________________________________

First/middle name ________________________________

Former name ______________________________________

Date of birth |___|___|_/|___|___|___|_/|___|___|___|___| (DD/MON/YYYY)

Health card number ________________________________

Prov. or terr. of health card _________________________

Address (city) _____________________________________

Province or Territory _____________________________ Postal code __________________

Hospital followed at ________________________________
(Enter only if different than transplant hospital.)

SECTION B—RECIPIENT OUTCOME

If alive with failed graft or died due to graft failure, please complete this section.

Date of transplant |___|___|_/|___|___|___|_/|___|___|___|___| (DD/MON/YYYY)

Graft Number _____________________________________

Patient Status (Please check one.)

Requires insulin ☐ Yes ☐ No

Patient alive ☐ Transfer ☐ Lost to follow-up ☐ Died ☐

Transfer Hospital Name (Please check one of the following): ☐ To ☐ OR ☐ From ☐

Name of Transfer Hospital: __________________________

Date of transfer: |___|___|_/|___|___|___|_/|___|___|___|___| (DD/MON/YYYY)

Date of lost to follow: |___|___|_/|___|___|___|_/|___|___|___|___| (DD/MON/YYYY)

If deceased (Please check one of the following and enter cause of death.)

☐ Died with a functioning graft

☐ Died due to graft failure (Check cause of graft failure below.)

Enter cause of death _____________ (codes on back of page)

Date of death: |___|___|_/|___|___|___|_/|___|___|___|___| (DD/MON/YYYY)
<table>
<thead>
<tr>
<th>CAUSE OF DEATH/COMORBID COMPLICATION (RECIPIENT)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>GENERIC</strong></td>
</tr>
<tr>
<td>00 Cause of death uncertain/not determined</td>
</tr>
<tr>
<td><strong>CARDCAL</strong></td>
</tr>
<tr>
<td>11 Myocardial ischemia and infarction</td>
</tr>
<tr>
<td>12 Hyperkalemia</td>
</tr>
<tr>
<td>13 Hemorrhagic pericarditis</td>
</tr>
<tr>
<td>14 Other causes of cardiac failure</td>
</tr>
<tr>
<td>15 Cardiac arrest, cause unknown</td>
</tr>
<tr>
<td>16 Hypertensive cardiac failure</td>
</tr>
<tr>
<td>17 Hypokalemia</td>
</tr>
<tr>
<td>18 Fluid overload</td>
</tr>
<tr>
<td><strong>VASCULAR</strong></td>
</tr>
<tr>
<td>21 Pulmonary embolus</td>
</tr>
<tr>
<td>22 Cerebrovascular accident</td>
</tr>
<tr>
<td>24 Hemorrhage from graft site—specify</td>
</tr>
<tr>
<td>25 Hemorrhage from vascular access or dialysis circuit</td>
</tr>
<tr>
<td>26 Hemorrhage from ruptured vascular aneurysm (not code 22 or 23)</td>
</tr>
<tr>
<td>27 Hemorrhage from surgery (not codes 23 to 26)—specify</td>
</tr>
<tr>
<td>28 Other hemorrhage (not codes 23 to 27)</td>
</tr>
<tr>
<td>55 Vascular thrombosis</td>
</tr>
<tr>
<td>56 Pulmonary vein stenosis</td>
</tr>
<tr>
<td>57 Stent/balloon complication</td>
</tr>
<tr>
<td><strong>INFECTION</strong></td>
</tr>
<tr>
<td>03 Infection (bacterial)—specify site</td>
</tr>
<tr>
<td>04 Infection (viral)—specify site</td>
</tr>
<tr>
<td>05 Infection (fungal)—specify site</td>
</tr>
<tr>
<td>06 Cytomegalovirus</td>
</tr>
<tr>
<td>07 Epstein-Barr virus</td>
</tr>
<tr>
<td>08 Pneumocystic carinii pneumonia (PCP)</td>
</tr>
<tr>
<td>09 Protozoal/parasitic infection (includes toxoplasmosis)</td>
</tr>
<tr>
<td>10 Wound infection—specify site</td>
</tr>
<tr>
<td>34 Infections elsewhere (except viral hepatitis codes 41 and 42)</td>
</tr>
<tr>
<td>35 Septicemia/sepsis—specify source</td>
</tr>
<tr>
<td>36 Tuberculosis (lung)</td>
</tr>
<tr>
<td>37 Tuberculosis (elsewhere)</td>
</tr>
<tr>
<td>38 Generalized viral infection—specify viral agent</td>
</tr>
<tr>
<td>39 Peritonitis (not code 70)</td>
</tr>
<tr>
<td><strong>LIVER DISEASE</strong></td>
</tr>
<tr>
<td>41 Liver, due to hepatitis B virus</td>
</tr>
<tr>
<td>42 Liver, due to other viral hepatitis</td>
</tr>
<tr>
<td>43 Liver, drug toxicity—specify drug</td>
</tr>
<tr>
<td>44 Cirrhosis, not viral</td>
</tr>
<tr>
<td>45 Cystic liver disease</td>
</tr>
<tr>
<td>46 Liver failure, cause unknown</td>
</tr>
<tr>
<td>74 Liver, due to hepatitis C virus</td>
</tr>
<tr>
<td><strong>GASTROINTESTINAL</strong></td>
</tr>
<tr>
<td>02 Gastrointestinal tumour with or without perforation</td>
</tr>
<tr>
<td>20 Acute gastroenteritis with dehydration</td>
</tr>
<tr>
<td>23 Gastrointestinal hemorrhage</td>
</tr>
<tr>
<td>29 Mesenteric infarction</td>
</tr>
<tr>
<td>62 Pancreatitus</td>
</tr>
<tr>
<td>68 Perforation of peptic ulcer</td>
</tr>
<tr>
<td>70 Sclerosing (or adhesive) peritoneal disease</td>
</tr>
<tr>
<td>72 Perforation of colon/small bowel</td>
</tr>
<tr>
<td><strong>SOCIAL</strong></td>
</tr>
<tr>
<td>50 Drug abuse (excludes alcohol abuse)</td>
</tr>
<tr>
<td>51 Patient refused further treatment</td>
</tr>
<tr>
<td>52 Suicide</td>
</tr>
<tr>
<td>53 Therapy ceased for any other reason</td>
</tr>
<tr>
<td>54 Alcohol abuse</td>
</tr>
<tr>
<td><strong>ACCIDENT</strong></td>
</tr>
<tr>
<td>81 Accident related to treatment</td>
</tr>
<tr>
<td>82 Accident unrelated to treatment</td>
</tr>
<tr>
<td><strong>MISCELLANEOUS</strong></td>
</tr>
<tr>
<td>30 Hypertension</td>
</tr>
<tr>
<td>40 Diabetic keto acidosis (DKA)</td>
</tr>
<tr>
<td>64 Cachexia</td>
</tr>
<tr>
<td>66 Malignant disease possibly induced by immunosuppressive therapy—specify primary site</td>
</tr>
<tr>
<td>67 Malignant disease (not code 66)—specify primary site</td>
</tr>
<tr>
<td>69 Dementia</td>
</tr>
<tr>
<td>90 Multi-system failure</td>
</tr>
<tr>
<td>99 Other identified cause of death—specify</td>
</tr>
<tr>
<td><strong>RESPIRATORY</strong></td>
</tr>
<tr>
<td>19 Acute respiratory distress syndrome (ARDS)</td>
</tr>
<tr>
<td>31 Pulmonary infection (bacterial)</td>
</tr>
<tr>
<td>32 Pulmonary infection (viral)</td>
</tr>
<tr>
<td>33 Pulmonary infection (fungal)</td>
</tr>
<tr>
<td>49 Bronchiolitis obliterans</td>
</tr>
<tr>
<td><strong>RENAL DISEASE</strong></td>
</tr>
<tr>
<td>47 Acute renal failure</td>
</tr>
<tr>
<td>48 Chronic renal failure</td>
</tr>
<tr>
<td>61 Uremia caused by kidney transplant failure</td>
</tr>
<tr>
<td><strong>METABOLIC</strong></td>
</tr>
<tr>
<td>59 Drug-related toxicity—specify drug</td>
</tr>
<tr>
<td><strong>HEMATOLOGIC</strong></td>
</tr>
<tr>
<td>63 Bone marrow depression</td>
</tr>
<tr>
<td>71 Thrombocytopenia</td>
</tr>
<tr>
<td>73 Thrombosis—specify</td>
</tr>
<tr>
<td><strong>NEUROLOGIC</strong></td>
</tr>
<tr>
<td>75 Drug neurotoxicity—specify drug</td>
</tr>
<tr>
<td>76 Status epileptics</td>
</tr>
<tr>
<td>77 Neurologic infection—specify infectious agent</td>
</tr>
</tbody>
</table>
Appendix C—Data Flow Diagram

Dialysis Patient Data Flow to CORR–CIHI

- New Patients on Dialysis
- Treatment Changes and Deaths

CORR–CIHI

- Follow-Up Laboratory
- Facility Profile Data

Provincial Registries

Hospitals

Satellite Centres

Independent Facilities
Transplant and Donor Data Flow at CORR

Not shown is the additional relationship between dialysis and kidney transplants.
Talk to Us

CIHI Ottawa
495 Richmond Road, Suite 600
Ottawa, Ontario K2A 4H6
Phone: 613-241-7860

CIHI Toronto
4110 Yonge Street, Suite 300
Toronto, Ontario M2P 2B7
Phone: 416-481-2002

CIHI Victoria
880 Douglas Street, Suite 600
Victoria, British Columbia V8W 2B7
Phone: 250-220-4100

CIHI Edmonton
10235 101 Street Northwest, Suite 1414
Edmonton, Alberta T5J 3G1
Phone: 780-409-5438

CIHI Montréal
1010 Sherbrooke Street West, Suite 300
Montréal, Quebec H3A 2R7
Phone: 514-842-2226

CIHI St. John’s
140 Water Street, Suite 701
St. John’s, Newfoundland and Labrador A1C 6H6
Phone: 709-576-7006

www.cihi.ca