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Instruction Manual

Transplant Recipient and Organ Donor Information

2004



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Information

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Acknowledgements

The process for revising the Canadian Organ Replacement Register (CORR) reporting forms for transplant and organ donation initiated in the spring of 2000. Working groups were formed to review the donor profile form and each specific organs; kidney, heart, liver, lung/heart-lung. The work of these various groups was refined by a series of consultations with an extended group of people as well as testing of the forms, which was undertaken by transplant centres and organ procurement organizations in the late summer and early fall of 2000. The objective of the revision process was to ensure that the new data standards reflected the information needs of the transplant and organ donation communities.

The Canadian Institute for Health Information (CIHI) wishes to acknowledge the contribution of the following individuals, listed alphabetically, to the revision process:

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CIHI also acknowledges transplant centres and organ procurement organizations from across Canada for their ongoing support of CORR. It is the dedication of these centres to quality health information and outcome data that enable CORR to be a useful epidemiological and clinical resource.

1. Introduction

Purpose of This Manual

This manual has two distinct purposes:

- to provide step-by-step instructions that will assist staff at hospitals providing vital organ transplants and organ procurement organizations to submit data to CORR on organ donors and transplant recipients; and
- to provide the definitions and specification of the data elements used in CORR in order to facilitate an understanding of the database.

Similar information pertaining to chronic renal failure patients on renal replacement therapy is presented in a separate manual.

The definitions and descriptions of data elements in this manual are intended to assist in maintaining and enhancing data consistency and quality, whether data are submitted on the paper forms, electronically, or by computer printouts.

What is CORR?

The Canadian Organ Replacement Register (CORR) is the national information system, which records and analyzes the level of activity and outcome of vital organ transplantation and renal dialysis activities.

The objectives of CORR are to:

- provide a national view on end-stage organ failure statistics, for comparative analyses and research studies;
- increase the availability of comparative material to facilitate better treatment decisions
- provide statistics on long-term trends that can be used for planning and optimizing programs;
- provide a feedback mechanism to centres, a quality assurance function for treatment, and a national standard for comparison; and
- provide statistics to the health care industry, to enhance business decisions.

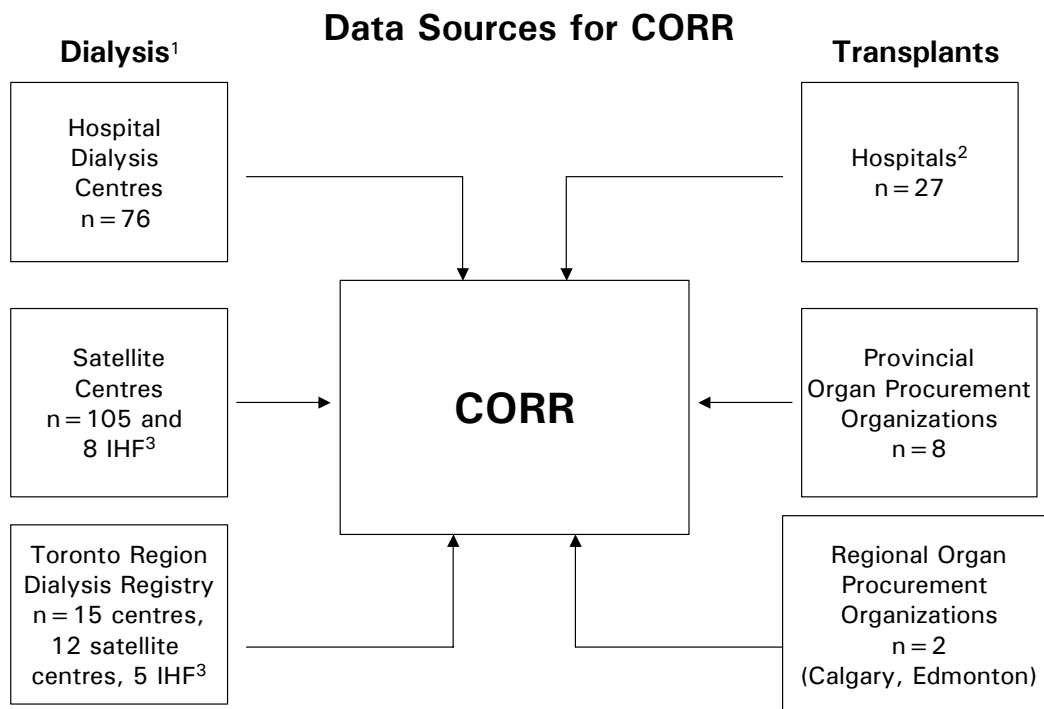
CORR achieves its goals by:

- publishing reports annually on dialysis, organ donation and transplantation;
- providing centre specific reports to participating hospitals;
- responding to ad hoc requests for data and information; and
- continually updating technology, and responding to changing user needs.

As the national database for dialysis and transplantation, CORR reports to its membership, the Canadian Society of Nephrology and the Canadian Society of Transplantation, the results of dialysis and transplantation in Canada. CORR also provides valuable information to a large constituency of health care workers including dialysis and transplant nurses, transplant coordinators, other members of the Canadian Association of Transplantation, Organ Procurement Organizations, hospital administrators, government officials, The Kidney Foundation of Canada and the Canadian Cystic Fibrosis Foundation.

A Brief History of CORR

The Canadian Organ Replacement Register (CORR) incorporates and maintains the Canadian Renal Failure Register, which was operated by Statistics Canada from 1981–1987. In 1987, the Hospital Medical Records Institute won a contract to operate an expanded register, which would include information on all solid organ transplants. The register became known as the Canadian Organ Replacement Register, and was incorporated in 1990 and overseen by a Board of Directors. In 1994, responsibility for the functions, assets and liabilities of the Hospital Medical Records Institute and the MIS Group were assumed by a new organization, the Canadian Institute for Health Information (CIHI). The CIHI also assumed some functions and resources of Health Canada’s Health Information Division and selected activities of Statistics Canada were taken over according to an agreed upon schedule.



¹ Total number of dialysis centres = 91; total number of satellite centres = 117; total number of IHF = 13.

² Provinces reporting include: Nova Scotia, Quebec, Ontario, Manitoba, Saskatchewan, Alberta and British Columbia.

³IHF = Independent Health Facility

Data on Organ Donors and Transplant Recipients

Patient-specific questionnaires are used to gather information on multi-organ transplantation and donors. These are: Heart Recipient, Lung/Heart-Lung Recipient, Liver Recipient, Kidney Recipient, and Pancreas Recipient Registration forms, and the Donor Profile form.

CORR data are patient-oriented. That is, a patient's treatment is followed from the time of the patient's first transplant until the patient dies or is lost to follow-up. Information on all non-renal transplants in Canada has been captured, and on renal transplants occurring since 1981. The capture of more detailed information on donors and recipients began in the early 1990's.

The patient information is collected from individual transplant centres, or from provincial organ procurement organizations (OPO's) with centralized records. Data may be submitted annually, or at more frequent intervals throughout the year. It is hoped that eventually all transplant and donor data will be transmitted to CORR using electronic data files, from locally maintained databases or through web-based interfaces.

When a patient is first entered into the CORR computer, a patient identification number is assigned which will remain with the patient throughout his other course of treatment. 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 is limited to date and cause of graft failure, and date and cause of death for all transplants except Liver. Follow-up information is processed annually or at more frequent intervals. It is captured in one of the following ways:

- Section D on the Recipient Registration forms
- Computer listings distributed by CORR to each centre for updating
- Updated computer files obtained from the programs

Starting in 2001, liver transplant recipients diagnosed with Hepatitis B, Hepatitis C or liver tumours are followed annually in order to track recurrence of disease.

Follow-up records are added and linked to existing records using the patient's identification number, which is located using patient name and date of birth. All follow-up treatments must adhere to strict edit checks. For example, a patient cannot have a second heart transplant while the first heart is still listed as functioning.

CORR staff works closely with hospital and OPO to ensure completeness and accuracy of data.

Key Definitions

Prior to completing the forms, it is important that the following key definitions are understood:

Referral: Consultation communication to a donor program about a patient who may be an organ donor. This patient will be assigned a unique identification number, and this patient will become a **potential** donor only when brain death has been confirmed and consent obtained.

Potential Donor: A referral who has fulfilled the general acceptance criteria for organ donation.

Donor Acceptance Criteria

1. No active systemic infection
2. No malignancy (except primary brain tumour)
3. No indication of HIV

Cadaveric Actual Donor: A potential organ donor who has had at least one retrieved organ transplanted.

Retrieval Donor: A potential donor who has been declared brain dead and consent for organ donation has been obtained. Organ retrieval may occur, but the patient is considered an **actual** donor only if at least one organ is transplanted.

Non-Heart Beating Donor: A patient in which brain death was not determined and death was attributed to cardiac arrest. This patient may or may not have been intubated.

New Patients: Any patient who initiated dialysis or had an organ transplantation for the first time in the calendar year.

Paediatric Patients: Patients who are less than eighteen years of age during the year of study, or at the time of initial treatment/transplant.

Registered Patients: Those patients who commenced their treatment (dialysis or transplantation) for the first time in 1981 or thereafter. These patients have been registered in CORR and their progress is monitored each year.

For More Information

If you would like to receive more information or if you have comments regarding the format, contents, and usefulness of this instruction manual, please forward them to the staff of CORR at the CIHI office in Toronto. Your feedback is appreciated.

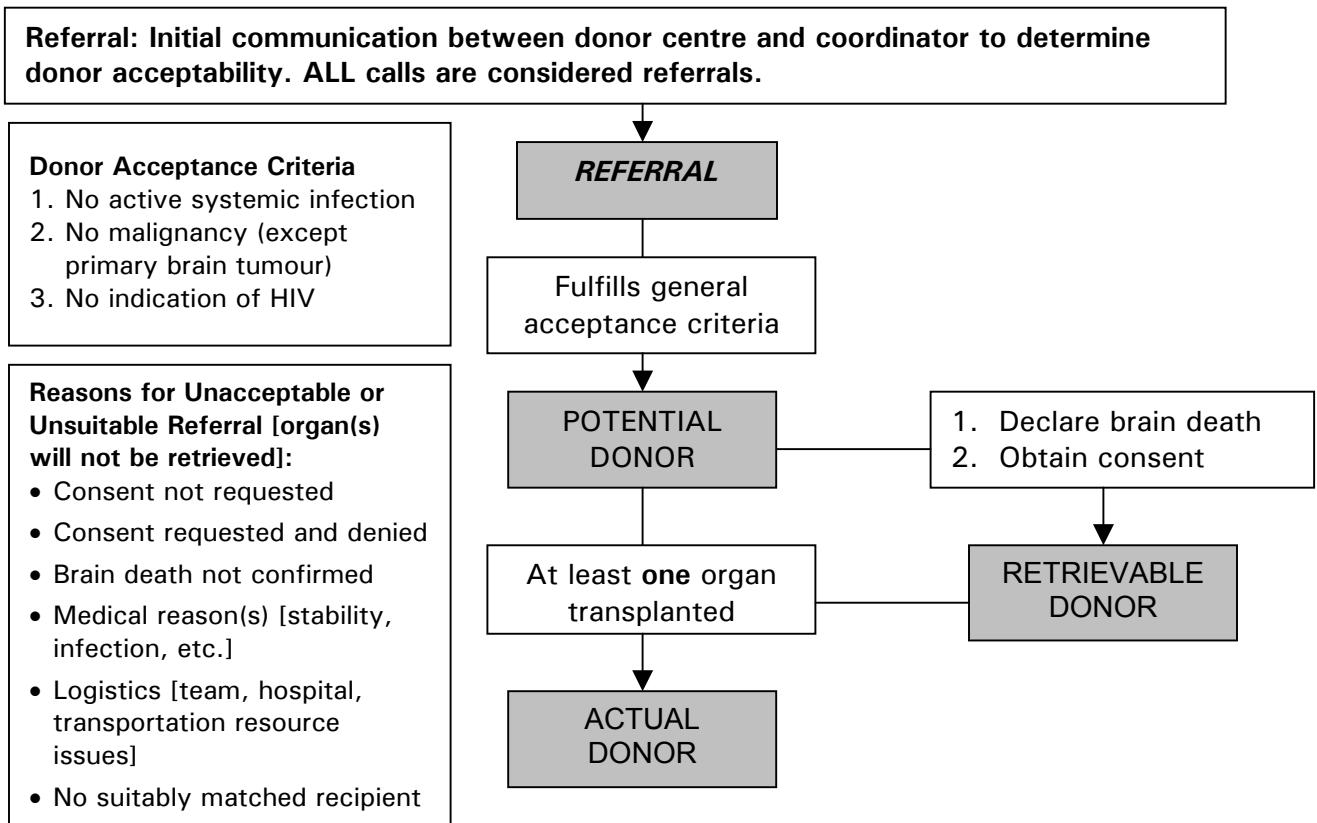
You may contact the Canadian Organ Replacement Register (CORR) at the following address:

Canadian Institute for Health Information
Canadian Organ Replacement Register
90 Eglinton Avenue East
Suite 300
Toronto, Ontario
M4P 2Y3
Tel: (416) 481-2002
Fax: (416) 481-2950
E-mail: corr@cihi.ca

2. Cadaveric Organ Donor Profile

Explanation of Organ Donor Definition Codes

For purposes of maintaining consistency and accuracy in data collection it has been proposed that all Canadian donor programs utilize a common set of standard definitions for organ donation. There are four basic terms to be used—the **referral**, the **potential donor**, the **retrievable donor** and the **actual donor**. Their respective definitions are based on chronology of events as well as a number of basic criteria (see following flow chart). Although there may be inter-program differences in the interpretation of one or more of these terms, it is suggested that the definitions described here be adopted for the purpose of national consistency.



Referral: Consultation/communication to a donor program about a patient who **may** be an organ donor. This patient will be assigned a unique identification number, and this patient will become a **potential donor** only when brain death has been confirmed and consent obtained.

Potential Donor: A referral who has fulfilled the general acceptance criteria for organ donation.

Retrieval Donor: A potential donor who has been declared brain dead and consent for organ donation has been obtained. Organ retrieval may occur, but the patient is considered an **actual donor** only if at least one organ is transplanted.

Actual Donor: A potential organ donor who has had at least one retrieved organ transplanted.

Non-Heart Beating Donor: A patient in which brain death was not determined and death was attributed to cardiac arrest. Also referred to as a possible **tissue donor**. This patient may or may not have been intubated.

Completing the Cadaveric Organ Donor Profile Form

One Cadaveric Organ Donor Profile form is to be completed for every referral donors. This includes all actual and potential donors.

Definitions

Referral: Initial communication between donor centre and coordinator to determine donor acceptability. All calls are considered referrals.

Potential Donor: A referral who has fulfilled the general acceptance criteria for organ donation or for whom organ retrieval may occur but organs are not transplanted.

Actual Donor: A potential organ donor who has had at least one retrieved organ transplanted.

Section A—Referral/Donor Information

Program Organizing Organ Retrieval

- Enter the name of the organ procurement organization responsible for organizing the retrieval of organs from this donor (i.e. where the donor originated).
- For out-of-country donors, the name of the country is sufficient (e.g. USA).
- The program name is converted to a numeric code by the CORR staff.
- Acceptable values:

Codes—Program Organizing Organ Retrieval	
10	St. John's, NL
09	St. John, NB
01	Halifax, NS
07	Montréal, QC
13	Quebec, QC
15	Kingston, ON
11	Ottawa, ON
16	Toronto, ON
02	Hamilton, ON
05	London, ON
06	Winnipeg, MB
14	Saskatoon, SK
17	Regina, SK
03	Calgary, AB
04	Edmonton, AB
12	Vancouver, BC
98	Unknown/not available
99	Other, please specify country

Retrieval Program Donor Number

- Enter the local identification number used for this donor by the identifying organ retrieval program. This number is used when linking recipient information to donor profile information, and also when requesting clarification of information from the local centre (e.g. if organ used was from another province, original retrieval program donor number **must** be used).

Surname Stem

- Enter the first three letters of the surname of the donor. Confidentiality issues, which may be encountered if using the full name, are avoided.
- The surname stem allows this recipient record to be accurately linked with the correct donor profile record, especially in the case of out-of-province donors.

Province or State of Residence

- Enter the province, which is the usual province or state of residence for this donor at the time of death.
- Acceptable values: see codes below – Province or State of Death.

<i>Codes – Province or State of Death</i>	
Code	Province – Canada
AB	Alberta
BC	British Columbia
MB	Manitoba
NB	New Brunswick
NL	Newfoundland and Labrador
NS	Nova Scotia
NT	Northwest Territories
NU	Nunavut
ON	Ontario
PE	Prince Edward Island
QC	Quebec
SK	Saskatchewan
YT	Yukon
	State – United States
AL	Alabama
AK	Alaska
AS	American Samoa
AZ	Arizona
AR	Arkansas
CA	California
CO	Colorado
CT	Connecticut
DE	Delaware
DC	District of Columbia
FL	Florida
GA	Georgia

Codes—Province or State of Death	
GU	Guam
HI	Hawaii
NE	Nebraska
NV	Nevada
NH	New Hampshire
NJ	New Jersey
NM	New Mexico
NY	New York
NC	North Carolina
ND	North Dakota
OH	Ohio
OK	Oklahoma
PA	Pennsylvania
PR	Puerto Rico
RI	Rhode Island
SC	South Carolina
ID	Idaho
IL	Illinois
IN	Indiana
IA	Iowa
KS	Kansas
KY	Kentucky
LA	Louisiana
ME	Maine
MD	Maryland
MA	Massachusetts
MI	Michigan
MN	Minnesota
MS	Mississippi
MO	Missouri
MT	Montana
SD	South Dakota
TN	Tennessee
TX	Texas
UT	Utah
VT	Vermont
VI	Virgin Islands
VA	Virginia
WA	Washington
WV	West Virginia
WI	Wisconsin
WY	Wyoming
XX	If country other than Canada or United States
ZZ	Unknown

Country of Residence

- Enter the country of residence, which is the usual country for this donor at the time of death.
- Acceptable values: see codes below – Country of Death.

Codes – Country of Death	
AUS	Australia
AUT	Austria
BEL	Belgium
CAN	Canada
CZE	Czechoslovakia
DNK	Denmark
DEU	Germany
GBR	United Kingdom
FRA	France
ISR	Israel
ITA	Italy
JPN	Japan
MEX	Mexico
ESP	Spain
SWE	Sweden
USA	United States

Referral accepted

- Indicate if the donor was accepted.
- Acceptable values:
 - Y = Yes
 - N = No

Reason Donor or Organs Not Used

- If the referral was not accepted, indicate the reason.
- Acceptable values:

Codes – Reasons Donor or Organs Not Used	
03	Team/hospital logistics (team, hospital, transplantation resource issues)
04	Medical reasons (stability, infection, etc.)
07	Consent not requested
08	Brain death not confirmed
09	Refusal by medical examiner
10	Consent requested and denied
98	Unknown/not available
99	Other reason; specify

Family Consent Obtained

- Indicate if the consent was obtained.
- Acceptable values:
 - Y = Yes
 - N = No

Declared Brain Dead

- Indicate if the donor was declared brain dead. *Brain Death is the total brain function for 24 hours as manifested by absence of spontaneous movement, absence of spontaneous respiration, and absence of all brainstem reflexes.*
- Acceptable values:
 - Y = Yes
 - N = No

Non-Heart Beating

- Indicate if the donor is non-heart beating.
- *Non-heart beating donor is a patient in which brain death was not determined and death was attributed to cardiac arrest. This patient may or may not have been intubated.*
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Age of Donor

- Enter the age of the donor.
- Acceptable range:
 - Age in **Years** for those patients two or more years of age (002 to 130)
 - Age in **Months** for those patients less than 24 months of age (001 to 023)
 - Age in **Days** for those patients less than 30 days of age (001 to 030)
 - Newborns = 000

Province or State of Death

- Enter the province or States in which this donor died.
- If the donor died outside of Canada or United States, enter the country (e.g. Mexico)—see the data element **Country of Death** below.
- Acceptable values: see codes above—Province or State of Death.

Country of Death

- Enter the country of death.
- Acceptable values: see codes above—Country of Death.

Donor Sex

- Enter the biological sex of the donor. Only one response can be checked.
- Acceptable values:
 - M = Male
 - F = Female
 - O = Other (transsexual, hermaphrodite)

Donor Blood Type

- Enter the blood type of the donor.
- Acceptable values:
 - A
 - B
 - AB
 - O
 - U (Unknown/missing response)

Donor's Race

- Enter the code for the donor's race.
- Only one response can be checked.
- If "Other/Multiracial", record the race.
- Acceptable values:

Codes – Race		
Code	Description	
01	Caucasian (White)	e.g. French Canadians and other peoples of European, Australian or Russian ancestry
02	Asian	e.g. Chinese, Japanese, Vietnamese, Korean, Taiwanese
03	Black	e.g. African, Caribbean, South American, Cuban
05	Indian Sub-continent	India, Pakistan, Bangladesh
08	Pacific Islander	e.g. Filipino
09	Aboriginal	North American Indian, Métis, Inuit
10	Middle Eastern/Arabian	e.g. Saudi Arabia, Iran, Iraq, Jordan, Syria, Armenia, Algeria
98	Unknown	
99	Other/multiracial	

<u>Codes effective Jan. 1, 2001</u>			<u>Former codes</u>	
Caucasian/white	01	→	Caucasian	01
Asian	02	→	Oriental	02
Black	03	→	Black	03
Indian Sub-continent	05	→	Asian Indian	05
Pacific Islander	08	→	Filipino	08
Aboriginal	09	→	North American Indian & Inuit	04 & 07
Mid East/Arabia	10			
Unknown	98	→	Unknown	98
Other/Multiracial	99	→	Other	99

Donor Height

- Enter the height of the donor in centimeters at the time of death.
- Acceptable values: cm (conversion factor: 1 inch = 2.54 cm or 0.39 inch = 1cm).

Donor Weight

- Enter the weight of the donor in kg at the time of death.
- Acceptable values: kg (conversion factor: 1lb = 0.45kg or 2.21 lbs = 1kg).

Cause of Donor Death

- Enter the code representing the cause of death of the donor.
- If the cause of death is code 5 (Overdose), 3 (Trauma), 10 (Intracranial Event), or 99 (Other), provide further details if available (i.e. which drug, what kind of trauma, type of intracranial event (CVA, etc)).
- Acceptable values:

Codes – Causes of Death	
Code	Description
01	Anoxia/Hypoxia
02	C.V.A. (Stroke)
03	Trauma (not MVC) – Describe
04	Motor Vehicle Collision
05	Overdose – Describe
06	Primary CNS Tumour
07	Ruptured Cerebral Aneurysm
08	Spontaneous Intracranial Haemorrhage
09	Gunshot
10	Intracranial Event – Describe
11	CNS infection
12	Carbon Monoxide Poisoning
13	Cerebral Oedema
14	Asthma, unspecified
15	Sudden Infant Deaths (SIDS)
98	Unknown
99	Other – Describe

Section B—Hospital Information

Identifying Hospital

- Enter the full name and location of the hospital where this donor was identified.
- This information is converted to a 5-digit code by CORR staff.

Date of Admission

- Enter the date the patient was admitted to the original admitting hospital for acute treatment prior to being identified as a donor.
- Format: DD/MON/YYYY

Date of Brain Death

- Enter the date when the patient was declared brain dead. *Brain death is the total cessation of brain function for 24 hours as manifested by absence of spontaneous movement, absence of spontaneous respiration, and absence of all brainstem reflexes.*
- Format: DD/MON/YYYY

Time of Brain Death

- Enter the time when the patient was declared brain dead.
- Format: HH/MM

Retrieval Hospital

- Enter the name and location of the hospital where the organs were retrieved.
- This information is converted to a 5-digit code by CORR staff.

Date of Cross Clamp

- Enter the date when the organs were retrieved and flushed with a specially prepared, ice-cold solution. Cross clamp date is the same as the date of organ retrieval.
- Format: DD/MON/YYYY

Cross Clamp Time

- Enter the time when the organ is retrieved and flushed with a specially prepared, ice-cold solution.
- Format: HH/MM

Section C—Donor Serology and Risk Factors (for actual donors only)

Donor Serology Status

Hepatitis BsAg

- Indicate if the donor has the hepatitis B antigen (hepatitis BsAg) at the time of donation.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

Hepatitis BcAb

- Indicate if the donor tested positive for hepatitis B antibody at the time of donation.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

Hepatitis C

- Indicate if the donor has hepatitis C antibody present at the time of donation.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

Epstein Barr

- Indicate if the patient has Epstein Barr virus antibody present at the time of donation.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

HIV

- Indicate if the donor has HIV antigen present at the time of donation.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

CMV

- Indicate if the patient has cytomegalovirus antibody present at the time of donation.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

HTLV (Human T Cell Lymphotropic Virus type-I, II)

- Indicate if the patient has HTLV virus antibody present at the time of donation.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

Donor HLA

HLA = Human lymphocyte antigen, used in determining compatibility between donors and recipients for some transplants. Please record information for the following markers:

Donor HLA A

- Enter the donor’s HLA A1 and A2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).
- Acceptable values:

Codes—HLA A Codes	
Codes	Description
0001	A1
0002	A2
0203	A203
0210	A210
0003	A3
0009	A9
0010	A10
0011	A11
0019	A19
0023	A23(9)
0024	A24(9)
2403	A2403
0025	A25(10)
0026	A26(10)
0028	A28
0029	A29(19)
0030	A30(19)

Codes—HLA A Codes	
Codes	Description
0031	A31(19)
0032	A32(19)
0033	A33(19)
0034	A34(10)
0036	A36
0043	A43
0066	A66(10)
0068	A68(28)
0069	A69(28)
0074	A74(19)
0080	A80
9997	Typing Done, but no antigen identified
9998	Unknown/Not available/Typing not done
9999	Other—Specify

Donor HLA B

- Enter the donor’s HLA B1 and B2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).
- Acceptable values:

Codes—HLA B Codes	
Codes	Description
0005	B5
0007	B7
0703	B703
0008	B8
0012	B12
0013	B13
0014	B14
0015	B15
0016	B16
0017	B17
0018	B18
0021	B21
0022	B22
0027	B27
2708	B2708
0035	B35
0037	B37
0038	B38(16)
0039	B39(16)
3901	B3901

Codes – HLA B Codes	
Codes	Description
3902	B3902
0040	B40
4005	B4005
0041	B41
0042	B42
0044	B44(12)
0045	B45(12)
0046	B46
0047	B47
0048	B48
0049	B49(21)
0050	B50(21)
0051	B51(5)
5102	B5102
5103	B5103
0052	B52(5)
0053	B53
0054	B54(22)
0055	B55(22)
0056	B56(22)
0057	B57(17)
0058	B58(17)
0059	B59
0060	B60(40)
0061	B61(40)
0062	B62(15)
0063	B63(15)
0064	B64(14)
0065	B65(14)
0067	B67
0070	B70
0071	B71(70)
0072	B72(70)
0073	B73
0075	B75(15)
0076	B76(15)
0077	B77(15)
0078	B78
0081	B81
0004	BW4
0006	BW6
9997	Typing Done, but no antigen identified
9998	Unknown/Not available/Typing not done
9999	Other – Specify

Donor HLA DR

- Enter the donor’s HLA DR1 and DR2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).
- Acceptable values:

Codes—HLA DR Codes	
Codes	Description
0001	DR1
0103	DR103
0002	DR2
0003	DR3
0004	DR4
0005	DR5
0006	DR6
0007	DR7
0008	DR8
0009	DR9
0010	DR10
0011	DR11(5)
0012	DR12(5)
0013	DR13(6)
0014	DR14(6)
1403	DR1403
1404	DR1404
0015	DR15(2)
0016	DR16(2)
0017	DR17(3)
0018	DR18(3)
0051	DR51
0052	DR52
0053	DR53
9997	Typing Done, but no antigen identified
9998	Unknown/Not available/Typing not done
9999	Other—Specify

Donor HLA DQ

- Enter the donor’s HLA DQ1 and DQ2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).
- Acceptable values:

Codes—HLA DQ Codes	
Codes	Description
0001	DQ1
0002	DQ2
0003	DQ3
0004	DQ4
0005	DQ5
0006	DQ6
0007	DQ7
0008	DQ8
0009	DQ9
9997	Typing Done, but no antigen identified
9998	Unknown/Not available/Typing not done
9999	Other – Specify

Donor Risk Factors

Smoker

- Indicate if this donor was a smoker at time of donation (e.g. person who has smoked cigarettes, cigars or a pipe in the last three months).
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Hypertension

- Indicate if this donor was receiving medication such as calcium blocking agents, vasodilators, beta blockers, diuretics, ACE inhibitor (e.g. captopril, enalapril) in order to control hypertension at the time of donation.
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Coronary Artery Disease

- Indicate if this donor was diagnosed with Coronary Artery Disease at the time of donation. Coronary Artery Disease also known as atherosclerosis, is the process by which the coronary arteries become narrowed or completely occluded. Ultimately, this is the underlying cause of heart attack.
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Diabetes

- Indicate if this donor was diagnosed with diabetes type 1 or 2 at the time of donation.
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Hyperlipidemia

- Indicate if this donor had elevated concentrations of any or all of the lipids in the plasma, such as cholesterol, triglycerides and lipoproteins.
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Section D—Additional Organ Information—Heart Donors only, please complete the following:

Inotropes at time of Retrieval

- Check which of the following inotropes being administered to the donor at the time of retrieval: Digoxin; Dobutamine; Dopamine; Amrinone; Milrinone; Epinephrine; Nor-epinephrine; Isoproterenol; Phenylephrine; Vasopressin
- If other, please specify.
- Indicate whether the donor was receiving a high dose for each inotrope administered. Please refer to chart for definitions of high dose.

High Dose—Definitions		
Generic	Tradename	“High Dose”
Vasopressin	Pitressin	> 5 units
Amrinone*	Inocor	> 10 mcg/kg/min
Milrinone	Primacor	> 0.50 mcg/kg/min
Digoxin	Lanoxin	> 10 mcg/kg
Dobutamine	Dobutrex	> 10 mcg/kg/min
Dopamine	Intropin	> 10 mcg/kg/min
Epinephrine	Adrenaline	> 10 mcg/min
Norepinephrine	Levophed	> 10 mcg/min
Isoproterenol	Isoprel	> 10 mcg/min
Phenylephrine	Neosynephrine	> 100 mcg/min

Echo Assessment Results

- Indicate whether an echocardiography was done on this donor and, if done, whether function was normal or abnormal.
- Acceptable values:
 - 0 = Not Done
 - 1 = Done, Normal Function
 - 2 = Done, Abnormal Function
 - 9 = Unknown

ECG Result

- Indicate whether an electrocardiogram (ECG) was done on this donor and, if done, whether function was normal or abnormal.
- Acceptable values:
 - 0 = Not Done
 - 1 = Done, Normal
 - 2 = Done, Abnormal
 - 9 = Unknown

Coronary Angiogram Results

- Indicate whether a coronary angiogram was done on this donor and, if done, whether function was normal or abnormal.
- Acceptable values:
 - 0 = Not Done
 - 1 = Done, Normal
 - 2 = Done, Abnormal
 - 9 = Unknown

Section E—Organ Specific Information

This section captures information on reasons why organs were not retrieved and/or transplanted, and also captures information, which will assist in linking organ recipients to the correct donor profile record. Information must be coded for each of the organs listed below:

- Double Kidney/Enbloc, Right Kidney, Left Kidney
- Heart
- Liver (whole organ), Liver Right lobe, Liver Left lobe, Liver Lateral Segment
- Pancreas—whole, Pancreas—segment, Pancreas—*islet cells*
- Heart-Lung
- Double Lungs/Enbloc, Right Lung, Left Lung
- Bowel
- Cluster (liver, small bowel, pancreas, stomach)
- Other multi-organ enbloc Retrieval (specify organs): _____

Organ(s) Retrieved

- Indicate if organ(s) were retrieved. If no, indicate reason why organ(s) was/were not retrieved. If organ(s) was/were not retrieved, Sections A and B should be completed.
- Acceptable values:
 - Y = Yes
 - N = No

Organ Specific

- For each organ listed, indicate whether or not the organ was retrieved from the donor.
- Acceptable values:
 - Y = Yes
 - N = No

Transplanted

- For each organ listed, indicate whether or not the organ was transplanted.
- Acceptable values:
 - Y = Yes
 - N = No

Reason Not Transplanted

- Enter the code representing the reason each organ was not retrieved and/or transplanted
- Acceptable values:

<i>Codes—Reasons Donor or Organs Not Used</i>	
01	No consent for a particular organ
02	No recipient (no suitability matched recipient)
03	Team/hospital logistics (team, hospital, transplantation resource issues)
04	Medical reasons (stability, infection, etc.)
98	Unknown/not available
99	Other reason—specify

Organ Sent To

- Enter the name and location of the hospital to which this organ was sent.
- This information is used to accurately link recipients of organs to this donor.

Recipient Name

- Enter the name of the recipient of this organ, if known.
- This information is used to accurately link recipients of organs to this donor.

3. Heart Transplant Recipient Registration Form

Section A—Recipient Information

Transplant Hospital Name and City

- Enter the hospital name and city where this transplant occurred. The city is required in order to differentiate hospitals of the same name in different cities.
- This information is converted to a 5-digit code by CIHI. If you know the CIHI code for your hospital, you may enter this on the form instead of the hospital name and city.

Patient Last Name

- Enter the surname or family/last name used by the patient. Do not record titles. A single Hyphen (e.g. SMITH-WATSON), apostrophe (e.g. O'HARA) or blank (e.g. VAN DUSEN) is acceptable.

Patient First and Middle Names

- Enter the first name or given name as well as the middle name, if applicable, used by the patient.
- If the patient often is referred to by nickname, please indicate this in brackets (e.g. William (BILL) Smith).

Patient Former Name

- Enter the maiden (unmarried) name or former surname for any patient that has Undergone a name change (e.g. Elizabeth Smith was formerly Elizabeth Jones so Jones would be recorded).

Sex

- Enter the biological sex of the patient.
- Acceptable values:
 - M = Male
 - F = Female
 - O = Other (transsexual, hermaphrodite)

Blood Type

- Enter the blood type of the patient.
- Acceptable values:
 - A
 - B
 - O
 - AB
 - U (Unknown/missing response)

Patient Race

- Enter the code representing the patient’s race.
- Acceptable values:

Codes—Race		
Code	Description	
1	Caucasian (White)	e.g. French Canadians and other peoples of European, Australian or Russian ancestry
2	Asian	e.g. Chinese, Japanese, Vietnamese, Korean, Taiwanese
3	Black	e.g. African, Caribbean, South American, Cuban
5	Indian Sub-continent	India, Pakistan, Bangladesh
8	Pacific Islander	e.g. Filipino
9	Aboriginal	North American Indian, Métis, Inuit
10	Middle Eastern/Arabian	e.g. Saudi Arabia, Iran, Iraq, Jordan, Syria, Armenia, Algeria
98	Unknown	
99	Other/multiracial (specify)	

<u>Codes effective Jan. 1, 2001</u>		<u>Former codes</u>	
Caucasian/white	01 →	Caucasian	01
Asian	02 →	Oriental	02
Black	03 →	Black	03
Indian Sub-continent	05 →	Asian Indian	05
Pacific Islander	08 →	Filipino	08
Aboriginal	09 →	North American Indian & Inuit	04 & 07
Mid East/Arabia	10		
Unknown	98 →	Unknown	98
Other/Multiracial	99 →	Other	99

Date of Birth

- Enter the date of birth for this patient. Format: DD-MON-YYYY (e.g. 08-APR-1958).
- This field is mandatory for proper patient identification.
- The majority of analyses are carried out according to patient age.

Health Card Number

- Enter the health insurance plan number as indicated on the health card for this patient. Please omit hyphens, blanks, etc. and include version number, if applicable (e.g. 123123123M).
- The health card number aids in the identification of the patient, and in avoiding duplicate patient records.
- For Manitoba residents, please use the Personal Health Information Number (PHIN).

Province of Health Card

- Enter the province that is associated with the health card number provided.
- Acceptable values:

Codes—Province of Health Card	
AB	Alberta
BC	British Columbia
MB	Manitoba
NB	New Brunswick
NL	Newfoundland and Labrador
NS	Nova Scotia
NT	Northwest Territories
NU	Nunavut
ON	Ontario
XX	Other
PE	Prince Edward Island
QC	Quebec
SK	Saskatchewan
YT	Yukon
ZZ	Unknown

Patient Address (City)

- Enter the town or city, which is the usual place of residence for the patient at the time of the transplant. (Do not include a new residence for treatment purposes).
- This city is used for incidence mapping.

Patient Address (Province)

- Enter the province, which is the usual province of residence at the time of the transplant.
- This information is used for incidence mapping.
- Acceptable values: See Province of Health Card above.

Patient Postal Code

- Enter the postal code for the patient's address at the time of the transplant.
- Format: M3C 2T9.
- This information is used for incidence mapping.

Recipient Height

- Enter the height of the patient in centimeters at the time of transplant.
- Acceptable values: cm (conversion factor: 1 inch = 2.54 cm or 0.39 inch = 1 cm).

Recipient Weight

- Enter the weight of the patient in kilograms at the time of transplant.
- Acceptable values: kg (conversion factor: 1lb = 0.45kg or 2.21 lbs. = 1 kg).

Section B—Transplant Information

Waiting List Information

Date Patient First Placed on Wait List

- Enter the date that this patient was first placed on a waiting list for this transplant.
- Format: DD-MON-YYYY (e.g. 12-JAN-2000)

Medical Status at Wait List

- Enter the code for the medical status of the patient at the time they were first placed on the waiting list.
- Acceptable values:

Codes—Medical Status	
08	Status 1 (at home)
04	Status 2 (hospitalized)
13	Status 3A (hospitalized ICU or inotropes or less than 6 mos of age)
14	Status 3B (hospitalized ICU or inotropes or less than 6 mos of age, with rapid deterioration)
06	Status 4 (ICU-mechanical/ventilatory support)
15	In utero

Date Moved to Final List Status

- Indicate if the date for the final list status is not the same as the initial listing status.
- Format: DD-MON-YYY (e.g. 12-JAN-2001)

Medical Status at Time of Transplant

- Enter the code for the medical status of the patient at the time of this transplant.
- Acceptable values:

Codes—Medical Status at Time of Transplant	
08	Status 1 (at home)
04	Status 2 (hospitalized)
13	Status 3A (hospitalized ICU or inotropes or less than 6 mos of age)
14	Status 3B (hospitalized ICU or inotropes or less than 6 mos of age, with rapid deterioration)
06	Status 4 (ICU-mechanical/ventilatory support)

Date of Transplant

- Enter the date this transplant occurred.
- Format: DD-MON-YYYY (e.g. 12-JUN-1995)

Heart Transplant Only Flag

- Check this box if the recipient is only receiving a heart and no other organ at this time. If this is a combination transplant, please check the combination transplant box.

Combination Transplant Flag

- Indicate, by checking the combination transplant box, if more than one organ was transplanted during this operation.

Specify Other Organ(s)

- Enter the other organ(s) transplanted during this combination transplant operation.

Primary Diagnosis

- Enter the code, which represents the primary cause of organ failure. One code only is allowed.
- If there is no diagnosis code that represents the primary cause of organ failure, enter the code 99, and describe the condition.
- If this is a second or subsequent heart transplant, please record the diagnosis associated with this transplant.
- Acceptable values:

Codes – Heart Primary Diagnosis	
32	Cardiomyopathy
29	Dilated Cardiomyopathy
01	Idiopathic Cardiomyopathy
30	Other Dilated Cardiomyopathy (please specify)
33	Metabolic/Genetic Cardiomyopathy
34	Cardiomyopathy related to muscular dystrophy
35	Drug-induced Cardiomyopathy (chemotherapy)
12	Restrictive Cardiomyopathy
31	Hypertrophic Cardiomyopathy
24	Myocarditis
07	Coronary Artery Disease (Ischemic Cardiomyopathy)
04	Valvular Heart Disease
23	Acute Myocardial Infarction
15	Congenital Heart Disease (please specify)
36	Metabolic disorder
37	Cardiac Tumour
38	Refractive arrhythmia
39	Muscular Dystrophy
99	Other, Please specify

Re-transplant Flag

- Check this box if this is a re-transplant.

Recipient Serology Status

Hepatitis BsAg

- Indicate if the patient has hepatitis B antigen present at time of transplant.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

Hepatitis BcAb

- Indicate if this patient tested positive for hepatitis B antibody at the time of transplant.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

Hepatitis C

- Indicate if patient has hepatitis C antibody present at the time of transplant.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

Epstein Barr

- Indicate if the patient has Epstein Barr virus antibody present at the time of transplant.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

HIV

- Indicate if the patient has HIV antigen present at the time of transplant.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

CMV

- Indicate if the patient has cytomegalovirus antibody present at the time of transplant.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

Current Cytotoxic Antibody (AB) Level

- Enter the current percentage panel reactive antibody (PRA) at the time of transplant.
- Acceptable range: 0–100%

Peak Cytotoxic Antibody (AB) Level

- Enter the highest percentage panel reactive antibody (PRA) measured for this patient.
- Acceptable range: 0–100%

Pulmonary Vascular Resistance (PVR) Reactivity

- Indicate if this patient has reactive pulmonary vasculature.
- Acceptable values:
 - 0 = Non-reactive
 - 1 = Reactive

Pulmonary Vascular Resistance

- Indicate the pulmonary resistance of this patient at time of transplant.
- Measured in Woods units.
- Acceptable values:
 - 1 = <4 woods units
 - 2 = 4–6 woods units
 - 3 = >6 woods units
 - 8 = Not done
 - 9 = Unknown/missing response

Standard Crossmatch Test Result

- Indicate if the standard cross match test on T-lymphocytes or peripheral blood lymphocytes (PBL) is positive or negative at 22°C or 37°C.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

Recipient HLA

HLA = human lymphocyte antigen (antigenic markers used in determining compatibility between donors and recipients for some transplants).

Recipient HLA A

- Enter the patient's HLA A1 and A2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).
- Acceptable values:

Codes – HLA A Codes	
Codes	Description
0001	A1
0002	A2
0203	A203
0210	A210
0003	A3
0009	A9
0010	A10
0011	A11
0019	A19
0023	A23(9)
0024	A24(9)
2403	A2403
0025	A25(10)
0026	A26(10)
0028	A28
0029	A29(19)
0030	A30(19)
0031	A31(19)
0032	A32(19)
0033	A33(19)
0034	A34(10)
0036	A36
0043	A43
0066	A66(10)
0068	A68(28)
0069	A69(28)
0074	A74(19)
0080	A80
9997	Typing Done, but no antigen identified
9998	Unknown/Not available/Typing not done
9999	Other – Specify

Recipient HLA B

- Enter the patient’s HLA B1 and B2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).
- Acceptable values:

Codes – HLA B Codes	
Codes	Description
0005	B5
0007	B7
0703	B703
0008	B8
0012	B12
0013	B13
0014	B14
0015	B15
0016	B16
0017	B17
0018	B18
0021	B21
0022	B22
0027	B27
2708	B2708
0035	B35
0037	B37
0038	B38(16)
0039	B39(16)
3901	B3901
3902	B3902
0040	B40
4005	B4005
0041	B41
0042	B42
0044	B44(12)
0045	B45(12)
0046	B46
0047	B47
0048	B48
0049	B49(21)
0050	B50(21)
0051	B51(5)
5102	B5102
5103	B5103
0052	B52(5)
0053	B53
0054	B54(22)
0055	B55(22)

Codes—HLA B Codes	
Codes	Description
0056	B56(22)
0057	B57(17)
0058	B58(17)
0059	B59
0060	B60(40)
0061	B61(40)
0062	B62(15)
0063	B63(15)
0064	B64(14)
0065	B65(14)
0067	B67
0070	B70
0071	B71(70)
0072	B72(70)
0073	B73
0075	B75(15)
0076	B76(15)
0077	B77(15)
0078	B78
0081	B81
0004	BW4
0006	BW6
9997	Typing Done, but no antigen identified
9998	Unknown/Not available/Typing not done
9999	Other—Specify

Recipient HLA DR

- Enter the patient’s HLA DR1 and DR2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).
- Acceptable values:

Codes—HLA DR Codes	
Codes	Description
0001	DR1
0103	DR103
0002	DR2
0003	DR3
0004	DR4
0005	DR5
0006	DR6
0007	DR7
0008	DR8
0009	DR9

Codes—HLA DR Codes	
Codes	Description
0010	DR10
0011	DR11(5)
0012	DR12(5)
0013	DR13(6)
0014	DR14(6)
1403	DR1403
1404	DR1404
0015	DR15(2)
0016	DR16(2)
0017	DR17(3)
0018	DR18(3)
0051	DR51
0052	DR52
0053	DR53
9997	Typing Done, but no antigen identified
9998	Unknown/Not available/Typing not done
9999	Other—Specify

Recipient HLA DQ

- Enter the patient’s HLA DQ1 and DQ2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).
- Acceptable values:

Codes—HLA DQ Codes	
Codes	Description
0001	DQ1
0002	DQ2
0003	DQ3
0004	DQ4
0005	DQ5
0006	DQ6
0007	DQ7
0008	DQ8
0009	DQ9
9997	Typing Done, but no antigen identified
9998	Unknown/Not available/Typing not done
9999	Other—Specify

Graft Number

- Indicate the sequential transplant number for this patient (e.g. one, two, three, etc. heart transplant operation(s) this patient has had).
- Most actuarial survival analyses are based on the transplant number, for example, graft survival of first heart graft.

Heterotopic Transplant Flag

- Indicate by checking the box if this is a heterotopic heart transplant (i.e. the native heart is left in place and the transplanted heart is added to the circuit).

Risk Factors

Renal Dysfunction

- Indicate if this patient had renal dysfunction at time of transplant.
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Liver Dysfunction

- Indicate if this patient had liver dysfunction at time of transplant.
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Diabetes Type 1

- Indicate if this patient was diagnosed with diabetes type 1 at the time of transplant.
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Type 1 Diabetes: *Occurs when the pancreas no longer produces any or very little insulin. Usually develops in childhood or adolescence and affects about 10% of the people with diabetes (Canadian Diabetes Association).*

Diabetes Type 2

- Indicate if this patient was diagnosed with diabetes type 2 at the time of transplant.
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Type 2 Diabetes: *Occurs when the pancreas does not produce enough insulin to meet the body's needs or the insulin is not metabolized effectively. Usually occurs later in life and affects 90% of the people with diabetes (Canadian Diabetes Association).*

Hypertension

- Indicate if this patient was receiving medication such as calcium blocking agents, vasodilators, beta blockers, diuretics, ACE inhibitors (e.g. captopril, enalapril) in order to control hypertension at time of transplant.
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Smoker

- Indicate if this recipient was smoking at time of transplant (e.g. person who has smoked cigarettes, cigars or a pipe in the last three months).
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Hypercholesterolaemia

- Indicate if this recipient had hypercholesterolaemia, abnormally high concentrations of cholesterol present in the bloodstream, at time of transplant.
- Means that Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Inotropic Support

- Indicate if this patient was receiving inotropes at the time of transplant.
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Previous Cardiac Surgery

- Indicate if this patient had cardiac surgery prior to this transplant. This does not include a previous heart transplant.
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Prior Defibrillator

- Indicate if this patient had an implanted defibrillator or pacemaker prior to this transplant.
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

On Anticoagulants

- Indicate if this patient was receiving anticoagulant therapy at the time of transplant (e.g. coumadin, heparin).
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Mechanical Ventilation

- Indicate if this patient was mechanically ventilated (on a respirator) at time of transplant.
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Type of Mechanical Circulatory Support Devices

If the patient was on a mechanical circulatory support device, indicate the device(s) being used.

Intra-aortic Balloon Flag

- Indicate whether the patient was on an intra-aortic balloon prior to transplant. This is a mechanical device placed to reduce the workload of the heart and to improve flow of blood to coronary arteries.
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

ECMO (Extracorporeal Membrane Oxygenation) Flag

- Indicate whether the patient was on extracorporeal membrane oxygenation prior to transplant. This is a form of artificial organ support for children suffering from temporary, reversible lung failure or heart failure. During the ECMO procedure, catheters are placed in large blood vessels and used to simultaneously drain blood from the body, oxygenate and warm it, and then return it to the heart through another cannula.
- Acceptables values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Ventricular Assist Device (VAD) Flag

- Indicate whether the patient was on a ventricular assist device prior to transplant. This is a support method used for patients with single ventricle dysfunction without pulmonary dysfunction.
- Acceptables values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Total Artificial Heart Flag

- Indicate whether the patient was on full circulatory support (artificial heart) prior to transplant.
- Acceptables values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Total Ischaemic Time

- Record in minutes the duration of time the ascending aorta is totally cross-clamped. Do not include the duration of partial aortic cross-clamp used for sewing the proximal anastomoses. Zero is an acceptable answer for those performed off bypass.

Section C—Donor Information

Information on surname stem, donor type, age and sex is used to accurately link the recipient information to the donor profile information as provided by the organ procurement organization. Only these fields need to be completed on the transplant forms for locally transplanted donors, as the complete information is provided on the donor profile forms.

Donor Type

- Enter the code representing the type of donor for this transplant.
- Acceptable values:

Codes—Donor Type	
01	Cadaver Donor
12	Domino Donor

Program Organizing Organ Retrieval

- Enter the name of the organ procurement organization responsible for organizing the retrieval of organs from this donor (i.e. where the donor originated).
- For out-of-country donors, the name of the country is sufficient (e.g. USA).
- The program name is converted to a numeric code by the CORR staff.

Retrieval Program Donor Number

- Enter the local identification number used for this donor by the identifying organ retrieval program. This number is used when linking recipient information to donor profile information, and also when requesting clarification of information from the local centre (e.g. if organ used was from another province, original retrieval program donor number **must** be used).

Surname Stem

- Enter the first three letters of the surname of the donor. In this way, confidentiality issues, which may be encountered if using the full name, are avoided.
- The surname stem allows this recipient record to be accurately linked with the correct donor profile record, especially in the case of out of province donors.

Age of Donor

- Enter the age of the donor.
- Acceptable range:
 - Age in **Years** for those patients two or more years of age (002 to 130)
 - Age in **Months** for those patients less than 24 months of age (001 to 023)
 - Age in **Days** for those patients less than 30 days of age (001 to 030)
 - Newborns = 000

Donor Sex

- Enter the biological sex of the donor.
- Acceptable values:
 - M = Male
 - F = Female
 - O = Other (transsexual, hermaphrodite)

Donor HLA

HLA = Human lymphocyte antigen, used in determining compatibility between donors and recipients for some transplants. Please record information for the following markers:

Donor HLA A

- Enter the donor's HLA A1 and A2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).
- Acceptable values: see Recipient HLA A codes above.

Donor HLA B

- Enter the donor's HLA B1 and B2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).
- Acceptable values: see Recipient HLA B codes above.

Donor HLA DR

- Enter the donor's HLA DR1 and DR2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).
- Acceptable values: see Recipient HLA DR codes above.

Donor HLA DQ

- Enter the donor's HLA DQ1 and DQ2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).
- Acceptable values: see Recipient HLA DQ codes above.

Section D—Recipient Outcome

This section collects recipient follow-up information, which may be available at the same time that the transplant is registered.

Updates on patient status with respect to transplant failures and deaths, as well as patient transfers, will be collected annually, or at intervals throughout the year, using computer listings on which to record the updates.

Alternatively, the centre may provide computer printouts of all failures and deaths and the associated causes, as well as information on patient transfers, to the CORR office at specified intervals. CORR data specifications must be used in this case.

Hospital Followed At

- Enter the name of the hospital where the patient is receiving transplant follow-up, if different from the transplant hospital.
- Provide the date associated with the transfer (Date of Event).
- This alerts the CORR staff to send all future requests for information on this patient to the follow-up hospital, and allows accurate tracking of this patient throughout the course of his/her treatment.

Patient Status

- Indicate whether the patient is Alive, Dead, or Lost to Follow-up.
- Provide the date associated with the event indicated (alive as of what date, etc).
- Format: DD/MON/YYYY

If Recipient is Deceased

Cause of Death

- Indicate if this patient died and enter the code for the cause of death (e.g. code 31 for bacterial pneumonia).
- For heart transplant recipients, please enter up to four causes of death.
- Acceptable values:

Codes—Causes of Death	
<i>Generic</i>	
00	Cause of death, uncertain, not determined
<i>Cardiac</i>	
11	Myocardial ischemia and infarction
12	Hyperkalaemia
13	Hemorrhagic pericarditis
14	Other causes of cardiac failure
15	Cardiac arrest, cause unknown
16	Hypertensive cardiac failure
17	Hypokalaemia

Codes – Causes of Death	
18	Fluid overload
<i>Vascular</i>	
21	Pulmonary Embolus
22	Cerebro-vascular Accident
24	Haemorrhage from graft site – specify
26	Ruptured vascular aneurysm (not codes 22–23)
27	Haemorrhage from surgery (not code 23–26) – specify
28	Other haemorrhage (not codes 23–27)
55	Vascular Thrombosis
56	Pulmonary Vein Stenosis
57	Stent/balloon Complication
<i>Infection</i>	
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 41–42)
35	Septicemia/Sepsis – specify source
36	Tuberculosis (Lung)
37	Tuberculosis (elsewhere)
38	Generalized viral infection – specify viral agent
39	Peritonitis (not code 70)
<i>Liver Disease</i>	
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
<i>Gastro-Intestinal</i>	
02	Gastro-intestinal tumour with or without perforation
20	Acute gastroenteritis with dehydration
23	Gastro-intestinal Haemorrhage
29	Mesenteric Infarction
62	Pancreatitis
68	Perforation of peptic ulcer
70	Sclerosing (or adhesive) Peritoneal disease
72	Perforation of colon

Codes – Causes of Death	
<i>Social</i>	
50	Drug Abuse (exclude alcohol abuse)
51	Patient refused further treatment
52	Suicide
53	Therapy ceased for any other reason
54	Alcohol abuse
<i>Accident</i>	
81	Accident related to treatment
82	Accident unrelated to treatment
<i>Miscellaneous</i>	
30	Hypertension
40	Diabetic keto acidosis (DKA)
64	Cachexia
66	Malignant disease possibly induced by immunosuppressive— specify primary site
67	Malignant disease except those of 66—specify primary source
69	Dementia
90	Multi-system failure
99	Other identified causes of death—specify
<i>Respiratory</i>	
19	Acute respiratory distress syndrome
31	Pulmonary infection (bacterial)
32	Pulmonary infection (viral)
33	Pulmonary Infection (fungal)
49	Bronchiolitis obliterans
<i>Renal Disease</i>	
47	Acute Renal Failure
48	Chronic Renal Failure
61	Uraemia caused by kidney transplant failure
<i>Metabolic</i>	
59	Drug-related toxicity—specify drug
<i>Hematologic</i>	
63	Bone Marrow Depression
71	Thrombocytopenia
73	Thrombosis—specify
<i>Neurologic</i>	
75	Drug Neurotoxicity—specify drug
76	Status Epilepticus
77	Neurologic Infection—specify infectious agent

Died Due to Graft Failure

- If this patient's death can be attributed to failure of the transplant (e.g. rejection), complete the date, cause of graft failure fields and enter the code for the cause of death.

Date of Graft Failure

- Enter the date the transplanted organ ceased to function adequately.
- Format: DD-MON-YYYY (e.g. 26-JAN-1996).
- Failure date must be equal to or greater than the transplant date.

Cause of Graft Failure

- Check the code representing the cause of graft failure (e.g. code 64 for chronic rejection).
- Acceptable values:

Codes – Causes of Graft Failure	
00	Uncertain/unknown
01	Hyperacute rejection
63	Acute rejection
64	Chronic rejection
66	Rejection Secondary to non-compliance
30	Rejection after stopping Immunosuppressive drugs
67	Recurrent primary disease
68	Infection and rejection
69	Infection of graft
11	Primary non-function
23	Vascular thrombosis (graft)
28	Surgical complication – not specified
25	Pulmonary Hypertension/Cor pulmonale
19	Graft Coronary Artery Disease
71	Electrolyte disturbance (Please specify)
72	Pericarditis
73	Pericardial Effusion
70	Systemic Hypertension
99	Other cause of graft failure (describe)

4. Kidney Transplant Recipient Registration Form

Section A – Recipient Information

Transplant Hospital Name and City

- Enter the hospital name and city where this transplant occurred. The city is required in order to differentiate hospitals of the same name in different cities.
- This information is converted to a 5-digit code by CIHI. If you know the CIHI code for your hospital, you may enter this on the form instead of the hospital name and city.

Patient Last Name

- Enter the surname or family/last name used by the patient. Do not record titles.
- A single Hyphen (e.g. SMITH-WATSON), apostrophe (e.g. O'HARA) or blank (e.g. VAN DUSEN) is acceptable.

Patient First and Middle Names

- Enter the first name or given name as well as the middle name, if applicable, used by the patient.
- If the patient often is referred to by nickname, please indicate this in brackets (e.g. William (BILL) Smith).

Patient Former Name

- Enter the maiden (unmarried) name or former surname for any patient that has undergone a name change (e.g. Elizabeth Smith was formerly Elizabeth Jones so Jones would be recorded).

Sex

- Enter the biological sex of the patient.
- Acceptable values:
 - M = Male
 - F = Female
 - O = Other (transsexual, hermaphrodite)

Blood Type

- Enter the blood type of the patient.
- Acceptable values:
 - A
 - B
 - O
 - AB
 - U (Unknown/missing response)

Patient Race

- Enter the code representing the patient’s race.
- Acceptable values:

Codes—Race		
Code	Description	
01	Caucasian (White)	e.g. French Canadians and other peoples of European, Australian or Russian ancestry
02	Asian	e.g. Chinese, Japanese, Vietnamese, Korean, Taiwanese
03	Black	e.g. African, Caribbean, South American, Cuban
05	Indian Sub-continent	India, Pakistan, Bangladesh
08	Pacific Islander	e.g. Filipino
09	Aboriginal	North American Indian, Métis, Inuit
10	Middle Eastern/Arabian	e.g. Saudi Arabia, Iran, Iraq, Jordan, Syria, Armenia, Algeria
98	Unknown	
99	Other/multiracial	

<u>Codes effective Jan. 1, 2001</u>		<u>Former codes</u>	
Caucasian/white	01	→	Caucasian 01
Asian	02	→	Oriental 02
Black	03	→	Black 03
Indian Sub-continent	05	→	Asian Indian 05
Pacific Islander	08	→	Filipino 08
Aboriginal	09	→	North American Indian & Inuit 04 & 07
Mid East/Arabia	10		
Unknown	98	→	Unknown 98
Other/Multiracial	99	→	Other

Date of Birth

- Enter the date of birth for this patient. Format: DD-MON-YYYY (e.g. 08-APR-1958).
- This field is mandatory for proper patient identification.
- The majority of analyses are carried out according to patient age.

Health Card Number

- Enter the health insurance plan number as indicated on the health card for this patient. Please omit hyphens, blanks, etc. and include version number, if applicable (e.g. 123123123M).
- The health card number aids in the identification of the patient, and in avoiding duplicate patient records.
- For Manitoba residents, please use the Personal Health Information Number (PHIN).

Province of Health Card

- Enter the province that is associated with the health card number provided.
- Acceptable values:

Codes – Province of Health Card	
Code	Province
AB	Alberta
BC	British Columbia
MB	Manitoba
NB	New Brunswick
NL	Newfoundland and Labrador
NS	Nova Scotia
NT	Northwest Territories
NU	Nunavut
ON	Ontario
XX	Other
PE	Prince Edward Island
QC	Quebec
SK	Saskatchewan
YT	Yukon
ZZ	Unknown

Patient Address (City)

- Enter the town or city, which is the usual place of residence for the patient at the time of the transplant. (Do not include a new residence for treatment purposes).
- This city is used for incidence mapping.

Patient Address (Province)

- Enter the province, which is the usual province of residence at the time of the transplant.
- This information is used for incidence mapping.
- Acceptable values: see Province of Health Card codes.

Patient Postal Code

- Enter the postal code for the patient's address at the time of the transplant.
- Format: M3C 2T9.
- This information is used for incidence mapping.

Section B—Transplant Information

Waiting List Information

Date Patient First Placed on Waiting List

- Enter the date that this patient was first placed on a waiting list for this transplant.
- Format: DD-MON-YYYY (e.g. 12-JAN-1996).

Date of Transplant

- Enter the date this transplant occurred.
- Format: DD-MON-YYYY (e.g. 12-JUN-1995).

Graft Number

- Indicate the sequential transplant number for this patient (e.g. one, two, three, etc. kidney transplant operation(s) this patient has had).
- Most actuarial survival analyses are based on the transplant number, for example, graft survival of first renal cadaveric grafts.

Kidney Transplant Only Flag

- Check this box if the recipient is only receiving a kidney and no other organ at this time. If this is a combination transplant, please check the combination transplant box.

Double Kidney/Enbloc Flag

- Indicate, by checking the double kidney/enbloc box, if two kidneys from the same donor were transplanted during this operation.

Combination Transplant Flag

- Indicate, by checking the combination transplant box, if more than one organ was transplanted during this operation.

Specify Other Organ(s)

- Enter the other organ(s) transplanted during this combination transplant operation.

Recipient Serology Status

Hepatitis BsAg

- Indicate if the patient has hepatitis B antigen present at time of transplant.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

Hepatitis BcAb

- Indicate if this patient tested positive for hepatitis B antibody at the time of transplant.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

Hepatitis C

- Indicate if patient has hepatitis C antibody present at the time of transplant.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

Epstein Barr

- Indicate if the patient has Epstein Barr virus antibody present at the time of transplant.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

HIV

- Indicate if the patient has HIV antigen present at the time of transplant.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

CMV

- Indicate if the patient has cytomegalovirus antibody present at the time of transplant.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

Current Cytotoxic Antibody (AB) Level

- Enter the current percentage panel reactive antibody (PRA) at the time of transplant.
- Acceptable range: 0–100%.

Peak Cytotoxic Antibody (AB) Level

- Enter the highest percentage panel reactive antibody (PRA) measured for this patient.
- Acceptable range: 0–100%.

Recipient HLA

HLA = human lymphocyte antigen (antigenic markers used in determining compatibility between donors and recipients for some transplants). Please record information for the following markers:

Recipient HLA A

- Enter the patient’s HLA A1 and A2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).
- Acceptable values:

Codes—HLA A Codes	
Codes	Description
0001	A1
0002	A2
0203	A203
0210	A210
0003	A3
0009	A9
0010	A10
0011	A11
0019	A19
0023	A23(9)
0024	A24(9)
2403	A2403
0025	A25(10)
0026	A26(10)
0028	A28
0029	A29(19)
0030	A30(19)
0031	A31(19)
0032	A32(19)
0033	A33(19)
0034	A34(10)
0036	A36
0043	A43
0066	A66(10)
0068	A68(28)
0069	A69(28)
0074	A74(19)
0080	A80
9997	Typing Done, but no antigen identified

Codes – HLA A Codes	
Codes	Description
9998	Unknown/Not available/Typing not done
9999	Other – Specify

Recipient HLA B

- Enter the patient’s HLA B1 and B2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).
- Acceptable values:

Codes – HLA B Codes	
Codes	Description
0005	B5
0007	B7
0703	B703
0008	B8
0012	B12
0013	B13
0014	B14
0015	B15
0016	B16
0017	B17
0018	B18
0021	B21
0022	B22
0027	B27
2708	B2708
0035	B35
0037	B37
0038	B38(16)
0039	B39(16)
3901	B3901
3902	B3902
0040	B40
4005	B4005
0041	B41
0042	B42
0044	B44(12)
0045	B45(12)
0046	B46
0047	B47
0048	B48
0049	B49(21)
0050	B50(21)
0051	B51(5)
5102	B5102

Codes—HLA B Codes	
Codes	Description
5103	B5103
0052	B52(5)
0053	B53
0054	B54(22)
0055	B55(22)
0056	B56(22)
0057	B57(17)
0058	B58(17)
0059	B59
0060	B60(40)
0061	B61(40)
0062	B62(15)
0063	B63(15)
0064	B64(14)
0065	B65(14)
0067	B67
0070	B70
0071	B71(70)
0072	B72(70)
0073	B73
0075	B75(15)
0076	B76(15)
0077	B77(15)
0078	B78
0081	B81
0004	BW4
0006	BW6
9997	Typing Done, but no antigen identified
9998	Unknown/Not available/Typing not done
9999	Other—Specify

Recipient HLA DR

- Enter the patient’s HLA DR1 and DR2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).
- Acceptable values:

Codes—HLA DR Codes	
Codes	Description
0001	DR1
0103	DR103
0002	DR2
0003	DR3
0004	DR4
0005	DR5

Codes – HLA DR Codes	
Codes	Description
0006	DR6
0007	DR7
0008	DR8
0009	DR9
0010	DR10
0011	DR11(5)
0012	DR12(5)
0013	DR13(6)
0014	DR14(6)
1403	DR1403
1404	DR1404
0015	DR15(2)
0016	DR16(2)
0017	DR17(3)
0018	DR18(3)
0051	DR51
0052	DR52
0053	DR53
9997	Typing Done, but no antigen identified
9998	Unknown/Not available/Typing not done
9999	Other – Specify

Recipient HLA DQ

- Enter the patient’s HLA DQ1 and DQ2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).
- Acceptable values:

Codes – HLA DQ Codes	
Codes	Description
0001	DQ1
0002	DQ2
0003	DQ3
0004	DQ4
0005	DQ5
0006	DQ6
0007	DQ7
0008	DQ8
0009	DQ9
9997	Typing Done, but no antigen identified
9998	Unknown/Not available/Typing not done
9999	Other – Specify

Primary Diagnosis

- Enter the code from the diagnosis code table, which represents the primary cause of organ failure. Only one code only is allowed.
- If there is no diagnosis code, which represents the primary cause of organ failure, enter the code 99, and describe the condition.
- Acceptable values:

Codes—Primary Renal Diagnosis	
<i>Generic</i>	
98	Unknown/missing response
00	Chronic renal failure— aetiology uncertain
<i>Glomerulonephritis/Autoimmune Diseases</i>	
05	Mesangial proliferative glomerulonephritis
06	Minimal lesion glomerulonephritis
07	Post-strep glomerulonephritis
08	Rapidly progressive glomerulonephritis
09	Focal glomerulosclerosis— adults
10	Glomerulonephritis, histologically NOT examined
11	Severe nephrotic syndrome with focal sclerosis (paediatric patients)
12	IgA nephropathy— proven by immunofluorescence (not code 85)
13	Dense deposit disease— proven by immunofluorescence and/or electron microscopy (MPGN type II)
14	Membranous nephropathy
15	Membranoproliferative mesangiocapillary glomerulonephritis (MPGN type I)
16	Idiopathic crescentic glomerulonephritis (diffuse proliferative)
17	Congenital nephrosis or congenital nephrotic syndrome (paediatric only)
19	Glomerulonephritis, histologically examined— specify
73	Polyarteritis
74	Wegener’s granulomatosis
84	Lupus erythematosus
85	Henoch-Schonlein purpura
86	Goodpasture’s syndrome
87	Scleroderma
88	Haemolytic Uraemic Syndrome
<i>Nephropathy, Drug Induced</i>	
30	Nephropathy caused by drugs or nephrotoxic agents, cause not specified
31	Nephropathy due to analgesic drugs
32	Nephropathy due to cisplatin
33	Nephropathy due to Cyclosporin A
39	Nephropathy caused by other specific drug— specify
<i>Polycystic Kidney</i>	
41	Polycystic kidneys, adult type (dominant)
42	Polycystic kidneys, infantile and juvenile types (recessive)

Codes – Primary Renal Diagnosis	
<i>Congenital/Hereditary Renal Diseases</i>	
21	Pyelonephritis/Interstitial nephritis associated with neurogenic bladder
22	Pyelonephritis/Interstitial nephritis due to congenital obstructive uropathy with or without vesico-ureteric reflux
24	Pyelonephritis/Interstitial nephritis due to vesico-ureteric reflux without obstruction
40	Cystic kidney disease – type unspecified
41	Polycystic kidneys, adult type (dominant)
42	Polycystic kidneys, infantile and juvenile types (recessive)
43	Medullary cystic disease, including nephronophthisis
49	Cystic kidney disease, other type – specify
50	Hereditary Familial nephropathy, type unspecified
51	Hereditary nephritis with nerve deafness (Alport's Syndrome)
52	Cystinosis
53	Primary Oxalosis
54	Fabry's disease
55	DRASH Syndrome
58	Posterior Urethral Valves
59	Hereditary nephropathy, other – specify
60	Congenital renal hypoplasia – specify
61	Oligomeganephronic hypoplasia
62	Segmental renal hypoplasia (ask-upmark kidney)
63	Congenital renal dysplasia with or without urinary tract malformation
66	Syndrome of agenesis of abdominal muscles (Prune Belly Syndrome)
<i>Diabetes</i>	
80	Diabetic nephropathy associated with Type 1
81	Diabetic nephropathy associated with Type 2
<i>Renal Vascular Disease</i>	
70	Renal vascular disease, type unspecified
71	Malignant hypertension (no primary renal disease)
72	Renal vascular disease due to hypertension (no primary renal disease)
73	Polyarteritis Nodosa
78	Atheroembolic Renal Disease
79	Renal vascular disease, classified
<i>Other</i>	
20	Pyelonephritis/Interstitial nephritis, cause not specified
23	Pyelonephritis/Interstitial nephritis due to acquired obstructive uropathy – specify
25	Pyelonephritis/Interstitial nephritis due to urolithiasis
29	Pyelonephritis, other causes
56	Sickle Cell Nephropathy
57	Wilms' tumour
82	Multiple Myeloma
83	Amyloid
89	Multi-system disease, other – specify

Codes—Primary Renal Diagnosis	
90	Cortical or acute tubular necrosis
91	Tuberculosis
92	Gout
93	Nephrocalcinosis and hypercalcaemic nephropathy
94	Balkan nephropathy
95	Kidney tumour
96	Traumatic or surgical loss of kidney
97	HIV Nephropathy
99	Other identified renal disorders—specify

Re-transplant Flag

- Check this box if this is a re-transplant.

Diagnosis at Time of First Transplant

- Enter the code from the diagnosis code table, which represents the diagnosis at time of the first kidney transplant. Only one code only is allowed.
- If there is no diagnosis code, which represents the primary cause of organ failure, enter the code 99, and describe the condition.
- Acceptable values: See above primary renal diagnosis codes.

Organ Laterality of Donor Organ Kidney

- Indicate whether the right or left kidney was used.
- Not applicable if enbloc, double kidney transplant was performed.

Laparoscopic nephrectomy

- Indicate if laparoscopic nephrectomy was used. Laparoscopic nephrectomy is a minimally invasive surgical procedure used to harvest a donor kidney for transplantation.
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Recipient Height

- Enter the actual height of the patient in centimeters at the time of transplant.
- Acceptable values: cm (conversion factor: 1 inch = 2.54 cm or 0.39 inch = 1 cm).

Recipient Weight

- Enter the weight of the patient in kilograms at the time of transplant.
- Acceptable values: kg (conversion factor: 1lb = 0.45kg or 2.21 lbs = 1kg).

Dialysis Pre-transplant Flag

- Indicate if the patient was receiving dialysis treatments prior to this kidney transplant operation. This alerts CORR staff to the fact that the transplant is NOT their first treatment.
- The answer will be No if this is a pre-emptive transplant (prior to any dialysis).
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Delayed Graft Function

- Indicate if this patient had delayed graft function (no spontaneous decrease in creatinine in 48hrs).
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Dialysis Treatment Within the First Week of Transplantation

- Indicate if this patient received dialysis treatment within the first week of transplantation.
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Risk Factors – Kidney

Angina

- Indicate if this patient suffered from angina at the time of this transplant.
- Angina is defined as: ischaemic cardiac pain either at rest or on exercise, requiring medical treatment with anti-anginal medication such as nitrates, calcium blockers (nifedipine, diltiazem).
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown missing response

Peripheral Vascular Disease

- Indicate if this patient has been described as having intermittent claudication at rest or on exercise; or has had aortal-femoral bypass surgery; or amputation of toes, lower legs, etc., prior to this transplant.
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Malignancy

- Indicate if this patient has a malignancy, which existed prior to receiving this transplant.
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Previous Myocardial Infarction

- Indicate if this patient has a confirmed myocardial infarct on the basis of EKG, cardiac enzymes, echocardiogram, or thallium scans, prior to receiving this kidney transplant.
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Pulmonary Edema

- Indicate if this patient has a recent history of pulmonary edema prior to this transplant.
- Pulmonary edema is defined as an episode of severe shortness of breath requiring treatment with diuretics such as furosemide (lasix) or emergency dialysis. Also, the patient may have been described as having congestive heart failure or severe fluid overload.
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Chronic Obstructive Lung Disease

- Indicate if this patient has clinically significant chronic chest disease requiring medical management prior to receiving this transplant.
- This will usually be described as chronic obstructive lung disease, chronic bronchitis, or emphysema. Patient may be on oral bronchodilators (e.g. choledyl), or inhalation drugs (e.g. ventolin).
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Diabetes Type 1

- Indicate if this patient was diagnosed with diabetes Type 1 prior to this transplant. Type 1 diabetes usually develops in childhood or adolescence.
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Type 1 Diabetes: *Occurs when the pancreas no longer produces any or very little insulin. Usually develops in childhood or adolescence and affects about 10% of the people with diabetes (Canadian Diabetes Association).*

Diabetes Type 2

- Indicate if this patient was diagnosed with diabetes Type 2 at time of transplant. Type II usually occurs later in life.
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Type 2 Diabetes: *Occurs when the pancreas does not produce enough insulin to meet the body's needs or the insulin is not metabolized effectively. Usually occurs later in life and affects 90% of the people with diabetes (Canadian Diabetes Association).*

Hypertension

- Indicate if this patient was receiving medication such as calcium blocking agents, vasodilators, beta blockers, diuretics, ACE inhibitors (e.g. captopril, enalapril) in order to control hypertension at the time of this transplant.
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Previous Cerebrovascular Accident

- Indicate if this patient has had a cerebro-vascular event such as transient ischaemic attack, cerebral infarct, cerebral haemorrhage, stroke, CVA prior to this transplant.
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Cold Ischaemic Time

- Enter the time in minutes from initiation of cooling (including in-situ cooling) and removal of the organ from cold storage.
- Acceptable range: Kidney: 0–18 hrs/0–1080 minutes.

Section C—Donor Information

Information on surname stem, donor type, age and sex is used to accurately link the recipient information to the donor profile information as provided by the organ procurement organization. Only these fields need to be completed on the transplant forms for locally transplanted donors, as the complete information is provided on the Cadaveric Donor Profile.

In the case of live donor transplants, please check the living donor flag and complete a Living Donor Profile. This profile should be attached to the transplant recipient registration form for submission to CORR.

Donor Type

- Enter the code representing the type of donor for this transplant.
- Acceptable values:

<i>Codes—Donor Type</i>	
01	Cadaver Donor
12	Domino Donor

Program Organizing Organ Retrieval

- Enter the name of the organ procurement organization responsible for organizing the retrieval of organs from this donor (i.e. where the donor originated).
- For out-of-country donors, the name of the country is sufficient (e.g. USA).
- The program name is converted to a numeric code by the CORR staff.

Retrieval Program Donor Number

- Enter the local identification number used for this donor by the identifying organ retrieval program. This number is used when linking recipient information to donor profile information, and also when requesting clarification of information from the local centre (e.g. if organ used was from another province, original retrieval program donor number **must** be used).

Surname Stem

- Enter the first three letters of the surname of the donor. In this way, confidentiality issues, which may be encountered if using the full name, are avoided.
- The surname stem allows this recipient record to be accurately linked with the correct donor profile record, especially in the case of out- of- province donors.

Age of Donor

- Enter the age of the donor.
- Acceptable range:
 - Age in **Years** for those patients two or more years of age (002 to 130)
 - Age in **Months** for those patients less than 24 months of age (001 to 023)
 - Age in **Days** for those patients less than 30 days of age (001 to 030)
 - Newborns = 000

Donor Sex

- Enter the gender of the donor.
- Acceptable values:
 - M = Male
 - F = Female
 - O = Other (transsexual, hermaphrodite)

Donor HLA

HLA = Human lymphocyte antigen, used in determining compatibility between donors and recipients for some transplants. Please record information for the following markers:

Donor HLA A

- Enter the donor's HLA A1 and A2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).
- Acceptable values: see Recipient HLA A codes above.

Donor HLA B

- Enter the donor's HLA B1 and B2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).
- Acceptable values: see Recipient HLA B codes above.

Donor HLA DR

- Enter the donor's HLA DR1 and DR2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).
- Acceptable values: see Recipient HLA DR codes above.

Donor HLA DQ

- Enter the donor's HLA DQ1 and DQ2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).
- Acceptable values: see Recipient HLA DQ codes above.

Section D—Recipient Outcome

This section collects recipient follow-up information, which may be available at the same time that the transplant is registered.

Updates on patient status with respect to transplant failures and deaths, as well as patient transfers, will be collected annually, or at intervals throughout the year, using computer listings on which to record the updates.

Alternatively, the centre may provide computer printouts of all failures and deaths and the associated causes, as well as information on patient transfers, to the CORR office at specified intervals. CORR data specifications must be used in this case.

Hospital Followed At

- Enter the name of the hospital where the patient is receiving transplant follow-up, if different from the transplant hospital.
- Provide the date associated with the transfer (Date of Event).
- This alerts the CORR staff to send all future requests for information on this patient to the follow-up hospital, and allows accurate tracking of this patient throughout the course of his/her treatment.

Patient Status

- Indicate whether the patient is Alive, Dead, or Lost to Follow-up.
- Provide the date associated with the event indicated (alive as of what date, etc).
Format: DD/MON/YYYY

If Recipient is Deceased

Cause of Death

- Please enter date and cause of death for the recipient.
- Acceptable values:

Codes – Causes of Death	
<i>Generic</i>	
98	Unknown/Missing Response
00	Cause of death uncertain/Not determined
<i>Cardiac</i>	
11	Myocardial ischemia and infarction
12	Hyperkalaemia
13	Haemorrhagic pericarditis
14	Other causes of cardiac failure
15	Cardiac arrest, cause unknown
16	Hypertensive cardiac failure
17	Hypokalaemia
18	Fluid overload
<i>Vascular</i>	
21	Pulmonary embolus
22	Cerebrovascular accident
24	Haemorrhage from graft site
25	Haemorrhage from vascular access or dialysis circuit
26	Haemorrhage from ruptured vascular aneurysm (not codes 22-23)
27	Haemorrhage from surgery (not codes 23-26)
28	Other haemorrhage (not codes 23–27) – specify
55	Vascular thrombosis
56	Pulmonary vein stenosis
57	Stent/balloon complication
<i>Infection</i>	
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	Infection elsewhere (except viral hepatitis codes 41–42)
35	Septicemia/Sepsis – specify source
36	Tuberculosis (Lung)

Codes— Causes of Death	
37	Tuberculosis (elsewhere)
38	Generalized viral infection— specify viral agent
39	Peritonitis (not code 70)
<i>Liver Disease</i>	
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
<i>Gastro-Intestinal</i>	
20	Acute Gastroenteritis with dehydration
02	Gastro-intestinal tumour with or without perforation
23	Gastro-intestinal hemorrhage
29	Mesenteric infarction
62	Pancreatitis
68	Perforation of peptic ulcer
70	Sclerosing (or adhesive) peritoneal disease
72	Perforation of colon
<i>Social</i>	
50	Drug Abuse (excludes alcohol abuse)
51	Patient refused further treatment
52	Suicide
53	Therapy ceased for any reason
54	Alcohol abuse
<i>Accident</i>	
81	Accident related to treatment
82	Accident unrelated to treatment
<i>Miscellaneous</i>	
30	Hypertension
40	Diabetic keto acidosis (DKA)
64	Cachexia
66	Malignant disease possibly induced by immunosuppressive therapy— specify primary site
67	Malignant disease except those of 66—specify primary source
69	Dementia
90	Multi-system failure
99	Other identified causes of death, please specify
<i>Respiratory</i>	
19	Acute Respiratory Distress Syndrome
31	Pulmonary infection (bacterial)
32	Pulmonary infection (viral)
33	Pulmonary Infection (fungal)
49	Bronchiolitis obliterans
<i>Metabolic</i>	
59	Drug-related toxicity— specify drug

Codes – Causes of Death	
<i>Hematologic</i>	
63	Bone Marrow Depression
71	Thrombocytopenia
73	Thrombosis – specify
<i>Renal Disease</i>	
47	Acute renal failure (non-renal patients)
48	Chronic renal failure (non-renal patients)
61	Uraemia caused by kidney transplant
<i>Neurologic</i>	
75	Drug Neurotoxicity
76	Status Epilepticus
77	Neurologic Infection – specify infectious agent

Died Due to Graft Failure

- If this patient's death can be attributed to failure of the transplant (e.g. rejection), and complete the date and cause of graft failure fields.
- Enter the date and the cause of death for this patient. See codes above.

Date of Graft Failure

- Enter the date the transplanted organ ceased to function adequately.
- Format: DD-MON-YYYY (e.g. 26-JAN-1996).
- Failure date must be equal to or greater than the transplant date.
- For Kidney patients, the date of failure is considered to be the date the patient returns to dialysis, or the date the kidney is removed and no longer provides adequate function.

Cause of Graft Failure

- Check code representing the cause of graft failure (e.g. code 64 for chronic rejection).
- Acceptable values:

Codes – Causes of Graft Failure	
00	Uncertain/unknown
01	Hyperacute rejection
63	Acute rejection
64	Chronic rejection
30	Rejection after stopping Immunosuppressive drugs
67	Recurrent disease
68	Infection and rejection
36	Cyclosporin Toxicity
69	Infection of graft
11	Primary non-function
18	De Novo Malignancy (graft)
23	Vascular thrombosis (graft)
26	Vascular operative problems
27	Ureteric operative problems
28	Surgical complication – not specified
99	Other cause of graft failure (describe)

Renal Transplant Facility Profile

This form is completed by each renal transplant facility on December 31st of the current reporting year. It captures summary statistics for the reporting year, which are used to validate the individual patient records for that same year.

Name and City of Hospital

- Enter the name of the hospital and city which the patient had a renal transplant.

Hospital Number

- Completed by CORR, each hospital reporting to CORR is assigned a unique identifier.

Number of Kidney Transplants that were Performed at the Hospital During the Reporting Year (as of December 31st)

Adult Patients: Patients who eighteen years of age or older at the time of transplant.

Pediatric Patients: Patients who are less than eighteen years of age at the time of transplant.

- **Cadaveric Donor—Adult:** Enter the number of adult cadaveric kidney transplants performed at the centre during the reporting year, including combination transplants, but excluding paediatric transplants.
- **Cadaveric Donor—Paediatric:** Enter the number of paediatric cadaveric kidney transplants performed at the centre during the reporting year, including combination transplants.
- **Living Related Donor—Adult:** Enter the number of adult living related kidney transplants performed at the centre including combination transplants, but excluding paediatric transplants.
- **Living Related Donor—Paediatric:** Enter the number of pediatric living related kidney transplants performed at the centre during the reporting year, including combination transplants.
- **Living Unrelated Donor—Adult:** Enter the number of adult living unrelated kidney transplants performed at the centre during the reporting year, including combination transplants, but excluding paediatric transplants.
- **Living Unrelated Donor—Paediatric:** Enter the number of pediatric living unrelated kidney transplants performed at the centre during the reporting year, including combination transplants.

Number of Kidney Combination Transplants Performed at the Hospital During the Reporting Year (as of December 31st)

- **Kidney Combination Transplants—Adult:** Enter the number of adult kidney combination transplants performed at the centre during the reporting year.
- **Kidney Combination Transplants—Paediatric:** Enter the number of paediatric kidney combination transplants performed at the centre identified during the reporting year.

Number of Living Patients with a Functioning Kidney Transplant on December 31st of the Reporting Year

- Enter the number of patients with a functioning kidney transplant being followed at the hospital, regardless of where they were initially transplanted, at year-end of the reporting year. Include patients who may be followed at another centre if your centre continues to be the PRIMARY follow-up centre.
- The number of patients reported should be greater than or equal to the number reported in the previous year. A lower number requires an explanation.

Number of Transplant Patients Who Have Returned to Dialysis

- Enter the number of patients being followed at the hospital who have returned to dialysis following the failure of a kidney transplant during the current reporting year.

Number of Transplant Patients Being Followed at the Hospital Who Died with a Functioning Graft During the Reporting Year

- Enter the number of patients being followed at the hospital who died during the reporting year with a functioning kidney transplant.

Number of Transplant Patients Being Followed at the Hospital Who Died with a Failed Graft During the Reporting Year

- Enter the number of patients who died during the reporting year because of a failed kidney transplant (i.e. did not return to dialysis).

5. Liver Transplant Recipient Registration Form

Section A – Recipient Information

Transplant Hospital Name and City

- Enter the hospital name and city where this transplant occurred. The city is required in order to differentiate hospitals of the same name in different cities.
- This information is converted to a 5-digit code by CIHI. If you know the CIHI code for your hospital, you may enter this on the form instead of the hospital name and city.

Patient Last Name

- Enter the surname or family/last name used by the patient. Do not record titles. A single hyphen (e.g. SMITH-WATSON), apostrophe (e.g. O'HARA) or blank (e.g. VAN DUSEN) is acceptable.

Patient First and Middle Names

- Enter the first name or given name as well as the middle name, if applicable, used by the patient.
- If the patient often is referred to by nickname, please indicate this in brackets (e.g. William (BILL) Smith).

Patient Former Name

- Enter the maiden (unmarried) name, or former surname for any patient that has undergone a name change (e.g. Elizabeth Smith was formerly Elizabeth Jones so Jones would be recorded).

Sex

- Enter the biological sex of the patient.
- Acceptable values:
 - M = Male
 - F = Female
 - O = Other (transsexual, hermaphrodite)

Blood Type

- Enter the blood type of the patient.
- Acceptable values:
 - A
 - B
 - AB
 - O
 - U (Unknown/missing response)

Race

- Indicate the patient’s race.
- Only one response can be checked
- If “Other/Multiracial”, record the race.
- Acceptable values:

Codes—Ethnic Origin/Race		
Code	Description	
01	Caucasian (White)	e.g. French Canadians and other peoples of European, Australian or Russian ancestry
02	Asian	e.g. Chinese, Japanese, Vietnamese, Korean, Taiwanese
03	Black	e.g. African, Caribbean, South American, Cuban
05	Indian Sub-continent	India, Pakistan, Bangladesh
08	Pacific Islander	e.g. Filipino
09	Aboriginal	North American Indian, Métis, Inuit
10	Middle Eastern/Arabian	e.g. Saudi Arabia, Iran, Iraq, Jordan, Syria, Armenia, Algeria
98	Unknown	
99	Other/multiracial	

<u>Codes effective Jan. 1, 2001</u>		<u>Former codes</u>	
Caucasian/white	01 →	Caucasian	01
Asian	02 →	Oriental	02
Black	03 →	Black	03
Indian Sub-continent	05 →	Asian Indian	05
Pacific Islander	08 →	Filipino	08
Aboriginal	09 →	North American Indian & Inuit	04 & 07
Mid East/Arabia	10		
Unknown	98 →	Unknown	98
Other/Multiracial	99 →	Other	

Date of Birth

- Enter the date of birth for this patient.
- Format: DD-MON-YYYY (e.g. 08-APR-1958).
- As most analyses are carried out according to patient age, this is a very important data element.

Health Card Number

- Enter the health insurance plan number as indicated on the health card for this patient. Please omit hyphens, blanks, etc. and include version number, if applicable (e.g. 123123123M).
- The health card number aids in the identification of the patient, and in avoiding duplicate patient records.
- For Manitoba residents, please use the Personal Health Information Number (PHIN).

Province of Health Card

- Enter the province, which is associated with the health care insurance plan number provided on the patient's health card.
- Acceptable values:

AB	=	Alberta
BC	=	British Columbia
MB	=	Manitoba
NB	=	New Brunswick
NL	=	Newfoundland and Labrador
NS	=	Nova Scotia
NT	=	Northwest Territories
NU	=	Nunavut
ON	=	Ontario
PE	=	Prince Edward Island
QC	=	Quebec
SK	=	Saskatchewan
YT	=	Yukon
XX	=	Other
ZZ	=	Unknown

Patient Address (City)

- Enter the town or city, which is the usual place of residence for the patient at the time of transplant.
- This city is used for incidence mapping.

Patient Address (Province)

- Enter the province, which is the usual province of residence at the time renal replacement therapy is initiated or at first transplant.
- This information is used for incidence mapping.
- Acceptable values: see Province codes above.

Patient Postal Code

- Enter the postal code for the patient's usual address at the time of transplant.
- Format: M3C 2T9.
- This information is used for incidence mapping.

Recipient Height

- Enter the actual height of the patient in centimeters at the time of transplant.
- Acceptable values: cm (conversion factor: 1 inch = 2.54 cm or 0.39 inch = 1 cm).

Recipient Weight

- Enter the weight of the patient in kilograms at the time of transplant.
- Acceptable values: kg (conversion factor: 1lb = 0.45kg or 2.21 lbs = 1 kg).

Section B—Transplant Information

Waiting List Information

Date Patient First Placed on Wait List

- Enter the date that this patient was first placed on a waiting list for this transplant.
- Format: DD-MON-YYYY (e.g. 12-JAN-1996).

Medical Status at Wait List

- Enter the code for the medical status of the patient at the time he/she was first placed on the waiting list. (Medical status at time of transplant is also recorded. See Section B.)
- Acceptable values:

Codes—Medical Status	
08	Status 1—At Home
16	Status 1T—Tumour patients
04	Status 2—Hospitalized
05	Status 3—Hospitalized ICU
11	Status 3F—Fulminant
06	Status 4—ICU incubated and ventilated
12	Status 4F—Fulminant

Date Moved to Final List Status

- Indicate if the date for the final list status is not the same as the initial listing status.
- Format: DD-MON-YYYY (e.g. 12-JAN-2001).

Medical Status at Time of Transplant

- Enter the code for the medical status of the patient at the time of this transplant.
- Acceptable values:

<i>Codes – Medical Status</i>	
08	Status 1 – At Home
16	Status 1T – Tumour patients
04	Status 2 – Hospitalized
05	Status 3 – Hospitalized ICU
11	Status 3F – Fulminant
06	Status 4 – ICU incubated and ventilated
12	Status 4F – Fulminant

Date of Transplant

- Enter the date this transplant occurred.
- Format: DD-MON-YYYY (e.g. 12-JUN-1995).

Liver Transplant Only Flag

- Check box if recipient is only receiving a liver transplant and no other organ at this time. If this is a combination transplant, please check the combination transplant box.

Combination Transplant Flag

- Indicate, by checking the combination transplant box, if more than one organ was transplanted during this operation.

Specify Other Organ(s)

- Where applicable, enter the other organ(s) transplanted during this combination transplant operation. Please note that Section B on Recipient Registration Forms for the other organs should also be completed as part of this patient's registration.

Primary Diagnoses

- Enter the codes that represent the primary causes of organ failure. Up to **four diagnoses** may be coded. Note that this can include retrospective/incidental diagnoses.
- If there is no diagnosis code that represents the primary cause of organ failure, enter the code 99, and describe the condition.
- Acceptable values:

Codes—Primary Liver Diagnosis	
<i>Acute Hepatic Failure (Fulminant)</i>	
01	Hepatitis—Type A
02	Hepatitis—Type B
61	Hepatitis—Type C
58	Hepatitis—Type Non A,B,C
35	Hepatitis with Delta
05	Toxic
04	Drug Induced—Other
56	Drug Induced—Acetaminophen
47	Other/Fulminant Hepatic Failure (including Budd Chiari and Wilson’s Disease)
<i>Chronic Hepatic Failure</i>	
12	Budd-Chiari
36	Byler’s Disease (Intra-Hepatic Cholestasis)
09	Cirrhosis—Alcoholic
10	Cirrhosis—Other
08	Cryptogenic Cirrhosis
49	Post-necrotic Cirrhosis
07	Primary Biliary Cirrhosis
14	Secondary Biliary Cirrhosis
45	Drug Induced—Other
42	Hepatitis—Type A
43	Hepatitis—Type B
60	Hepatitis—Type C
59	Hepatitis—Type Non A,B,C
51	Neonatal Hepatitis
06	Autoimmune Chronic Active Hepatitis
13	Primary Biliary Atresia
11	Sclerosing Cholangitis
46	Toxic
15	Watson-Alagille Disease = Arterio-Hepatic Dysplasia
62	Polycystic—Liver Disease
64	Non-alcoholic steatohepatitis (NASH)
<i>Hepatic Tumours</i>	
50	Angiosarcoma
17	Cholangiocarcinoma
18	Fibrolamellar Hepatoma
16	Hepatocellular Carcinoma
19	Metastatic Tumour
53	Hepatic Tumour—Other
<i>Metabolic Disorders</i>	
20	Alpha I Anti-Trypsin Deficiency
28	Crigler-Najjar Syndrome
21	Glycogen Storage Disease
23	Haemochromatosis
27	Hyperlipoproteinemia Type 2
24	Niemann-Pick
26	Phenylketonuria

Codes – Primary Liver Diagnosis	
25	Protoporphyrinemia
29	Tyrosinemia
22	Wilson’s Disease
34	Metabolic Disorder – Other
<i>Other Primary Diagnosis</i>	
30	Congenital Hepatic Fibrosis
31	Caroli’s Disease
32	Cystic Disorders
52	Thrombosed Hepatic Artery
98	Unknown/Missing
99	Other

Re-transplant Flag

- Check this box if this is a re-transplant.

Recipient Serology Status

Hepatitis B

Hepatitis Bs Ag

- Indicate if the patient has hepatitis BsAg antigen present at time of transplant.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

Hepatitis BcAb

- Indicate if this patient tested positive for hepatitis BcAb antibody at the time of transplant.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

Hepatitis B DNA

- Indicate if hepatitis B DNA was present at the time of transplant.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response
- If positive, provide the measurement in pg/ml.
- Acceptable range: 0–100 pg/ml.

Hepatitis B Treatment at Time of Transplant

- Indicate if the patient was receiving treatment at the time of transplant.
- Acceptable values:
 - 0 = No
 - 1 = Yes, Interferon
 - 2 = Yes, Lamivudine
 - 3 = Other—specify
 - 9 = Unknown/missing response

Hepatitis C

- Indicate if patient has hepatitis C antibody present at the time of transplant.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

RNA detectable

- If Hepatitis C positive, indicate if RNA is detectable.
- Acceptable values:
 - N = No
 - Y = Yes—specify method and result (million copies/mL)
 - X = Not collected

Genotype

- Indicate the patient's genotype.
- Acceptable values:
 - 1
 - 2
 - 3
 - 4
 - 5
 - 6
 - 9 = Unknown

Hepatitis C Treatment at Time of Transplant

- Indicate treatment at time of transplant for Hepatitis C.
- Acceptable values:
 - 1 = Interferon
 - 2 = Rivavirin
 - 3 = Both Interferon and Ribvavirin
 - 9 = Unknown/missing response

Epstein Barr

- Indicate if the patient has Epstein Barr virus antibody present at the time of transplant.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

CMV

- Indicate if the patient has cytomegalovirus antibody present at the time of transplant.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

HIV

- Indicate if the patient has HIV antigen present at the time of transplant.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

Current Cytotoxic Antibody (AB) Level

- Enter the current percentage panel reactive antibody (PRA) at the time of transplant.
- Acceptable range: 0–100%.

Peak Cytotoxic Antibody (AB) Level

- Enter the highest percentage panel reactive antibody (PRA) measured for this patient.
- Acceptable range: 0–100%

Standard Crossmatch Test Result

- Indicate if the standard cross match test on T-lymphocytes or peripheral blood lymphocytes (PBL) is positive or negative at 22°C or 37°C.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

Recipient HLA

HLA = human lymphocyte antigen (antigenic markers used in determining compatibility between donors and recipients for some transplants). Please record information for the following markers:

Recipient HLA A

- Enter the patient's HLA A1 and A2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).
- Acceptable values:

Codes—HLA A Codes	
Codes	Description
0001	A1
0002	A2
0203	A203
0210	A210
0003	A3
0009	A9
0010	A10
0011	A11
0019	A19
0023	A23(9)
0024	A24(9)
2403	A2403
0025	A25(10)
0026	A26(10)
0028	A28
0029	A29(19)
0030	A30(19)
0031	A31(19)
0032	A32(19)
0033	A33(19)
0034	A34(10)
0036	A36
0043	A43
0066	A66(10)
0068	A68(28)
0069	A69(28)
0074	A74(19)
0080	A80
9997	Typing Done, but no antigen identified
9998	Unknown/Not available/Typing not done
9999	Other—Specify

Recipient HLA B

- Enter the patient’s HLA B1 and B2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).
- Acceptable values:

Codes – HLA B Codes	
Codes	Description
0005	B5
0007	B7
0703	B703
0008	B8
0012	B12
0013	B13
0014	B14
0015	B15
0016	B16
0017	B17
0018	B18
0021	B21
0022	B22
0027	B27
2708	B2708
0035	B35
0037	B37
0038	B38(16)
0039	B39(16)
3901	B3901
3902	B3902
0040	B40
4005	B4005
0041	B41
0042	B42
0044	B44(12)
0045	B45(12)
0046	B46
0047	B47
0048	B48
0049	B49(21)
0050	B50(21)
0051	B51(5)
5102	B5102
5103	B5103
0052	B52(5)
0053	B53
0054	B54(22)
0055	B55(22)

Codes—HLA B Codes	
Codes	Description
0056	B56(22)
0057	B57(17)
0058	B58(17)
0059	B59
0060	B60(40)
0061	B61(40)
0062	B62(15)
0063	B63(15)
0064	B64(14)
0065	B65(14)
0067	B67
0070	B70
0071	B71(70)
0072	B72(70)
0073	B73
0075	B75(15)
0076	B76(15)
0077	B77(15)
0078	B78
0081	B81
0004	BW4
0006	BW6
9997	Typing Done, but no antigen identified
9998	Unknown/Not available/Typing not done
9999	Other—Specify

Recipient HLA DR

- Enter the patient's HLA DR1 and DR2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).
- Acceptable values:

Codes—HLA DR Codes	
Codes	Description
0001	DR1
0103	DR103
0002	DR2
0003	DR3
0004	DR4
0005	DR5
0006	DR6
0007	DR7
0008	DR8
0009	DR9

Codes – HLA DR Codes	
Codes	Description
0010	DR10
0011	DR11(5)
0012	DR12(5)
0013	DR13(6)
0014	DR14(6)
1403	DR1403
1404	DR1404
0015	DR15(2)
0016	DR16(2)
0017	DR17(3)
0018	DR18(3)
0051	DR51
0052	DR52
0053	DR53
9997	Typing Done, but no antigen identified
9998	Unknown/Not available/Typing not done
9999	Other – Specify

Recipient HLA DQ

- Enter the patient’s HLA DQ1 and DQ2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).
- Acceptable values:

Codes – HLA DQ Codes	
Codes	Description
0001	DQ1
0002	DQ2
0003	DQ3
0004	DQ4
0005	DQ5
0006	DQ6
0007	DQ7
0008	DQ8
0009	DQ9
9997	Typing Done, but no antigen identified
9998	Unknown/Not available/Typing not done
9999	Other – Specify

Graft Number

- Indicate the sequential transplant number for this patient (e.g. one, two, three, etc. liver transplant operation(s) this patient has had).
- Most actuarial survival analyses are based on the transplant number, for example, graft survival of first liver cadaveric grafts.

Child-Pugh Score at Transplant

- Enter the Child-Pugh Score at time of transplantation.
- Acceptable range: 3–15.

Creatinine at Time of Transplant

- Enter the creatinine of the patient at the time of liver transplant.
- Measured in (mol/L).
- Acceptable range: 0–999 (mol/L).

Total Serum Bilirubin at Time of Transplant

- Enter the total serum bilirubin for the patient at the time of liver transplant.
- Measured in $\mu\text{mol/L}$.
- Acceptable range: 0–999.

INR (International Normalized Ratio)

- Enter the INR for the patient at the time of liver transplant.
- INR is defined as the prothrombin time (PT) ratio, which is the patient's PT value divided by the mean of the PT normal range.
- Acceptable range: 0.50–9.99.

Split or Reduction Technique

Liver Reduction

- Indicate if the liver was surgically reduced in size once it was removed from the donor.
- There can be one recipient only.
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Split Liver

- Indicate if the liver was split into two transplantable portions after removal from the donor.
- There can be two potential recipients.
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Technique

- Indicate if the transplantation technique used was as follows: In-situ, Ex-situ or a combination of the two.
- Ex-situ splitting of the liver is performed on the bench after removal from the cadaver. It is usually divided into two grafts: segments 2 and 3 for children, and segments 4 to 8 for adults.
- In-situ liver splitting is accomplished in a manner identical to living donor procurement. Graft splitting is performed in the donor before liver preservation. In-situ splitting results in the same graft types as the ex-situ technique.
- Acceptable values:
 - 1 = In situ
 - 2 = Ex-situ
 - 3 = Combination

Primary and Metastatic Tumours in the Liver

Complete this section on the current liver transplant form or attach copy of the form submitted to the International Registry of Hepatic Tumors in Liver Transplantation (Baylor University Medical Centre). This entire section was added to the reporting requirements on January 1, 2001.

Primary and Metastatic Tumours in the Liver Flag

- Indicate whether the recipient has primary and metastatic tumours in his/her liver.
- If “no”, do not complete the items relating to tumours on the form.
- Acceptable values:
 - Y = Yes
 - N = No

Tumour Markers

Alpha Fetoprotein

- Enter levels of Alpha Fetoprotein (AFP) at the time of transplant.
- Specificity of AFP for malignancy is greatest at levels > 1000 ng/mL.

Chorioembryonic Antigen

- Enter levels of Chorioembryonic Antigen (CEA) at the time of transplant.
- Acceptable reference interval: 0.0–10.0 ng/mL.

Number of Nodules

- Enter the number of nodules or masses found.

Diameter of Largest Nodule

- Indicate the diameter of the largest nodule in centimeters.

Bilobar

- Indicate whether the cancer is in both the right and left lobes of the liver substance and not in the bile ducts or gallbladder.
- Acceptable values:
 - Y = Yes
 - N = No

Tumour Characteristics

- Indicate whether the tumour is multifocal (widely distributed nodules of variable size) or single (unifocal, large mass).
- Acceptable values:
 - 1 = Single
 - 2 = Multifocal

Histologic Grade

- Provide the grade for the patient's tumours.
- If two numbers (e.g. I-II) are used, use the higher number.
- If both grade and grading system are specified (e.g. I/III), code grade only (e.g. I) and not the 3-point grading system.

Histologic Grade Classification System

- Indicate the classification system used to grade the tumours (systems used to grade tumours vary with each type of cancer).

Vascular Involvement

- Indicate whether or not the patient's tumours have vascular involvement.
- Acceptable values:
 - Y = Yes
 - N = No

Spread at Surgery

- Indicate where, if any, the patient's tumours have spread at the time of surgery.
- Acceptable values:
 - 0 = None
 - 1 = Periaortic
 - 2 = Lungs, Mediastinum
 - 3 = Diaphragm
 - 4 = Abdomen, Other
 - 5 = Hilar Nodes

Adjunct Tumor Therapy

Embolization Therapy—Pre-op

- Circle the appropriate response to indicate if the patient has received embolization therapy pre-operatively.
- Acceptable values:
 - Y = Yes
 - N = No

Irradiation Therapy—Pre-op

- Circle the appropriate response to indicate if the patient has received irradiation therapy pre-operatively.
- Acceptable values:
 - Y = Yes
 - N = No

Irradiation Therapy—Intra-Op

- Circle the appropriate response to indicate if the patient has received irradiation therapy intra-operatively.
- Acceptable values:
 - Y = Yes
 - N = No

Irradiation Therapy—Post-op

- Circle the appropriate response to indicate if the patient has received irradiation therapy post-operatively.
- Acceptable values:
 - Y = Yes
 - N = No

Other Tumour Treatment—Pre-Op

- Circle the appropriate response to indicate if the patient has received another form of tumour treatment pre-operatively.
- Specify treatment agent.
- Acceptable values:
 - Y = Yes
 - N = No

Other Tumour Treatment—Intra-Op

- Circle the appropriate response to indicate if the patient has received another form of tumour treatment intra-operatively.
- Specify treatment agent.
- Acceptable values:
 - Y = Yes
 - N = No

Other Tumour Treatment—Post-op

- Circle the appropriate response to indicate if the patient has received another form of tumour treatment post-operatively.
- Specify treatment agent.
- Acceptable values:
 - Y = Yes
 - N = No

Adriamycin (Chemotherapy)—Pre-op

- Circle the appropriate response to indicate if the patient has received Adriamycin treatment pre-operatively.
- Acceptable values:
 - Y = Yes
 - N = No

Adriamycin (Chemotherapy)—Intra-op

- Circle the appropriate response to indicate if the patient has received Adriamycin treatment intra-operatively.
- Acceptable values:
 - Y = Yes
 - N = No

Adriamycin (Chemotherapy) – Post-op

- Circle the appropriate response to indicate if the patient has received Adriamycin treatment post-operatively.
- Acceptable values:
 - Y = Yes
 - N = No

5-FU (Chemotherapy) – Pre-op

- Circle the appropriate response to indicate if the patient has received 5-FU treatment pre-operatively.
- Acceptable values:
 - Y = Yes
 - N = No

5-FU (Chemotherapy) – Intra-op

- Circle the appropriate response to indicate if the patient has received 5-FU treatment intra-operatively.
- Acceptable values:
 - Y = Yes
 - N = No

5-FU (Chemotherapy) – Post-op

- Circle the appropriate response to indicate if the patient has received 5-FU treatment post-operatively.
- Acceptable values:
 - Y = Yes
 - N = No

5-FU DR (Chemotherapy) – Pre-op

- Circle the appropriate response to indicate if the patient has received 5-FU DR treatment pre-operatively.
- Acceptable values:
 - Y = Yes
 - N = No

5-FU DR (Chemotherapy) – Intra-op

- Circle the appropriate response to indicate if the patient has received 5-FU DR treatment intra-operatively.
- Acceptable values:
 - Y = Yes
 - N = No

5-FU DR (Chemotherapy)—Post-op

- Circle the appropriate response to indicate if the patient has received 5-FU DR treatment post-operatively.
- Acceptable values:
 - Y = Yes
 - N = No

Cisplatin (Chemotherapy)—Pre-op

- Circle the appropriate response to indicate if the patient has received Cisplatin treatment pre-operatively.
- Acceptable values:
 - Y = Yes
 - N = No

Cisplatin (Chemotherapy)—Intra-op

- Circle the appropriate response to indicate if the patient has received Cisplatin treatment intra-operatively.
- Acceptable values:
 - Y = Yes
 - N = No

Cisplatin (Chemotherapy)—Post-op

- Circle the appropriate response to indicate if the patient has received Cisplatin treatment post-operatively.
- Acceptable values:
 - Y = Yes
 - N = No

Other Chemotherapy Treatment—Pre-Op

- Circle the appropriate response to indicate if the patient has received another form of chemotherapy treatment pre-operatively.
- Specify treatment agent.
- Acceptable values:
 - Y = Yes
 - N = No

Other Chemotherapy Treatment—Intra-Op

- Circle the appropriate response to indicate if the patient has received another form of chemotherapy treatment intra-operatively.
- Specify treatment agent.
- Acceptable values:
 - Y = Yes
 - N = No

Other Chemotherapy Treatment – Post-op

- Circle the appropriate response to indicate if the patient has received another form of chemotherapy treatment post-operatively.
- Specify treatment agent.
- Acceptable values:
 - Y = Yes
 - N = No

Warm Ischaemic Time

- Enter the time in minutes between clamping of the major vessels (usually the aorta), or the time of cardiac arrest, and the initiation of cold flushing.
- Enter 0 for in situ perfusion.
- Acceptable range: 0–99 minutes.

Cold Ischaemic Time

- Enter the time in minutes from initiation of cooling (including in-situ cooling) and removal of the organ from cold storage.
- Acceptable range: 15min–720min (12 hr).

Re-warm Time

- Enter the time in minutes between removal of the organ from cold storage and until the clamps are released in the recipient allowing blood flow.
- Also known as re-perfusion time or anastomosis time.
- Acceptable range: 15min–90min.

Section C – Donor Information

Information on surname stem, donor type, age and sex is used to accurately link the recipient information to the donor profile information as provided by the organ procurement organization. Only these fields need to be completed on the transplant forms for locally transplanted donors, as the complete information is provided on the donor profile forms.

In the case of live donor transplants, please check the living donor flag and complete a Living Donor Profile. This profile should be attached to the transplant recipient registration form for submission to CORR.

Donor Type

- Enter the code representing the type of donor for this transplant.
- Acceptable values:

<i>Codes – Donor Type</i>	
01	Cadaver Donor
12	Domino Donor

Program Organizing Organ Retrieval

- Enter the name of the organ procurement organization responsible for organizing the retrieval of organs from this donor (i.e. where the donor originated).
- For out-of-country donors, the name of the country is sufficient (e.g. USA).
- The program name is converted to a numeric code by the CORR staff.

Retrieval Program Donor Number

- Enter the local identification number used for this donor by the identifying organ retrieval program. This number is used when linking recipient information to donor profile information, and also when requesting clarification of information from the local centre (e.g. if organ used was from another province, original retrieval program donor number **must** be used).

Surname Stem

- Enter the first three letters of the surname of the donor. In this way, confidentiality issues, which may be encountered if using the full name, are avoided.
- The surname stem allows this recipient record to be accurately linked with the correct donor profile record, especially in the case of out-of-province donors.

Age of Donor

- Enter the age of the donor at the time of the donation.
- Acceptable range:
 - Age in **Years** for those patients two or more years of age (002 to 130)
 - Age in **Months** for those patients less than 24 months of age (001 to 023)
 - Age in **Days** for those patients less than 30 days of age (001 to 030)
 - Newborns = 000

Donor Sex

- Enter the sex of the donor.
- Acceptable values:
 - M = Male
 - F = Female
 - O = Other (transsexual, hermaphrodite)

Donor HLA

HLA = Human lymphocyte antigen, used in determining compatibility between donors and recipients for some transplants. Please record information for the following markers:

Donor HLA A

- Enter the donor's HLA A1 and A2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).
- Acceptable values: see Recipient HLA A codes above.

Donor HLA B

- Enter the donor's HLA B1 and B2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).
- Acceptable values: see Recipient HLA B codes above.

Donor HLA DR

- Enter the donor's HLA DR1 and DR2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).
- Acceptable values: see Recipient HLA DR codes above.

Donor HLA DQ

- Enter the donor's HLA DQ1 and DQ2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).
- Acceptable values: see Recipient HLA DQ codes above.

Section D—Recipient Outcome

This section collects recipient follow-up information, which may be available at the same time that the transplant is registered.

Updates on patient status with respect to transplant failures and deaths, as well as patient transfers, will be collected annually, or at intervals throughout the year, using computer listings on which to record the updates.

Alternatively, the centre may provide computer printouts of all failures and deaths and the associated causes, as well as information on patient transfers, to the CORR office at specified intervals. CORR data specifications must be used in this case.

Hospital Followed At

- Enter in full the name of the hospital where the patient is receiving transplant follow-up only if different from the transplant hospital.
- Provide the date associated with the transfer (Date of Event).
- This alerts the CORR staff to send all future requests for information on this patient to the follow-up hospital, and allows accurate tracking of this patient throughout the course of other treatment.

Patient Status

- Indicate whether the patient is Alive, Dead, or Lost to Follow-up.
- Provide the date associated with the event indicated (alive as of what date, etc).
 Format: DD/MON/YYYY

If Recipient is Deceased

Cause of Death

- Please enter date and cause of death.
- Acceptable values:

Codes – Causes of Death	
<i>Generic</i>	
98	Unknown/Missing Response
00	Cause of death uncertain/Not determined
<i>Accident</i>	
81	Accident related to treatment
82	Accident unrelated to treatment
<i>Cardiac</i>	
11	Myocardial ischemia and infarction
12	Hyperkalaemia
13	Hemorrhagic percarditis
14	Other causes of cardiac failure
15	Cardiac arrest, cause unknown
16	Hypertensive cardiac failure
17	Hypokalaemia
18	Fluid overload
<i>Gastro-Intestinal</i>	
02	Gastro-intestinal tumour with or without perforation
20	Acute gastroenteritis with dehydration
23	Gastro-intestinal hemorrhage
29	Mesenteric infarction
62	Pancreatitis
68	Perforation of peptic ulcer
70	Sclerosing (or adhesive) peritoneal disease
72	Perforation of colon

Codes – Causes of Death	
<i>Hematologic</i>	
63	Bone Marrow Depression
71	Thrombocytopenia
73	Thrombosis
<i>Infection</i>	
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	Infection elsewhere (except hepatitis see 41–42)
35	Septicemia/Sepsis – specify source
36	Tuberculosis (Lung)
37	Tuberculosis (elsewhere)
38	Generalized viral infection – specify viral agent
39	Peritonitis (not code 70)
<i>Metabolic</i>	
59	Drug-related toxicity – specify drug
<i>Neurologic</i>	
75	Drug Neurotoxicity
76	Status Epilepticus
77	Neurologic Infection
<i>Renal Disease</i>	
47	Acute renal failure
48	Chronic renal failure
61	Uraemia caused by kidney transplant failure
<i>Respiratory</i>	
19	Acute Respiratory Distress Syndrome
31	Pulmonary infection (bacterial)
32	Pulmonary infection (viral)
33	Pulmonary Infection (fungal)
49	Bronchiolitis obliterans
<i>Social</i>	
50	Drug abuse (excludes alcohol abuse)
51	Patient refused further treatment
52	Suicide
53	Therapy ceased for any other reason
54	Alcohol abuse
<i>Vascular</i>	
21	Pulmonary embolus
22	Cerebro-vascular accident
24	Haemorrhage from graft site – specify
25	Hemorrhage from vascular access or dialysis circuit
26	Hemorrhage from ruptured vascular aneurysm (not codes 22-23)

Codes— Causes of Death	
27	Hemorrhage from surgery (not codes 23-26)—specify
28	Other hemorrhage (not codes 23–27)
55	Vascular thrombosis
56	Pulmonary vein stenosis
57	Stent/balloon complication
<i>Miscellaneous</i>	
30	Hypertension
40	Diabetic keto acidosis (DKA)
64	Cachexia
66	Malignant disease possibly induced by immunosuppressive therapy
67	Malignant disease except those of 66—specify primary source
69	Dementia
90	Multi system failure
99	Other identified causes of death, please specify

Died Due to Graft Failure

- If this patient’s death can be attributed to failure of the transplant (e.g. rejection), and complete the date and cause of graft failure fields.
- Enter the date and the cause of death for this patient. See codes above.

Date of Graft Failure

- Enter the date the transplanted organ ceased to function adequately.
- Format: DD-MON-YYYY (e.g. 26-Jan-1996).
- Failure date must be equal to or greater than the transplant date.

Cause of Graft Failure

- Check the code representing the cause of graft failure (e.g. code 64 for chronic rejection).
- Acceptable values:

Codes— Causes of Graft Failure	
00	Uncertain/unknown
01	Hyperacute rejection
63	Acute rejection
64	Chronic rejection
30	Rejection after stopping Immunosuppressive drugs
67	Recurrent disease
68	Infection and rejection
69	Infection of graft
11	Primary non-function
14	Graft/Portal Vein thrombosis
15	Graft/Hepatic Vein Thrombosis
16	Biliary Tract Complication
18	De Novo Malignancy (graft)

Codes – Causes of Graft Failure	
22	Arterial Thrombosis
28	Surgical complication – not specified
33	De Novo Hepatitis
99	Other cause of graft failure (describe)

Liver Transplant Follow-up Form

Please complete this form on December 31st of each year or at time of death for transplant patients who have been diagnosed with hepatitis B, hepatitis C or liver tumours (as per primary diagnosis). As an alternative to completing this form, facilities may opt to complete a computer listing of current patients provided by CORR at year-end.

Section A – Recipient Information

Patient label may also be used in lieu of the completion of this section if the same information is captured on this label.

Transplant Hospital Name and City

- Enter the hospital name and city where this transplant occurred. The city is required in order to differentiate hospitals of the same name in different cities.
- This information is converted to a 5-digit code by CIHI. If you know the CIHI code for your hospital, you may enter this on the form instead of the hospital name and city.

Health Card Number

- Enter the health insurance plan number as indicated on the health card for this patient. Please omit hyphens, blanks, etc. and include version number, if applicable (e.g. 123123123M).
- The health card number aids in the identification of the patient, and in avoiding duplicate patient records.
- For Manitoba residents, please use the Personal Health Information Number (PHIN).

Province of Health Card

- Enter the province, which is associated with the health care insurance plan number provided on the patient's health card.
- Acceptable values:

AB	=	Alberta
BC	=	British Columbia
MB	=	Manitoba
NB	=	New Brunswick
NL	=	Newfoundland and Labrador
NS	=	Nova Scotia
NT	=	Northwest Territories
NU	=	Nunavut
ON	=	Ontario
PE	=	Prince Edward Island
QC	=	Quebec
SK	=	Saskatchewan
YT	=	Yukon
XX	=	Other
ZZ	=	Unknown

Patient Last Name

- Enter the surname or family/last name used by the patient. Do not record titles. A single hyphen (e.g. SMITH-WATSON), apostrophe (e.g. O'HARA) or blank (e.g. VAN DUSEN) is acceptable.

Patient First and Middle Names

- Enter the first name or given name as well as the middle name, if applicable, used by the patient.
- If the patient often is referred to by nickname, please indicate this in brackets (e.g. William (BILL) Smith).

Patient Former Name

- Enter the maiden (unmarried) name, or former surname for any patient that has undergone a name change (e.g. Elizabeth Smith was formerly Elizabeth Jones so Jones would be recorded).

Patient Address (City)

- Enter the town or city, which is the usual place of residence for the patient at the time of transplant.
- This city is used for incidence mapping.

Patient Address (Province)

- Enter the province which is the usual province of residence at the time renal replacement therapy is initiated or at first transplant.
- This information is used for incidence mapping.
- Acceptable values: see Province codes above.

Patient Postal Code

- Enter the postal code for the patient's usual address at the time of transplant.
- Format: M3C 2T9.
- This information is used for incidence mapping.

Date of Birth

- Enter the date of birth for this patient.
- Format: DD-MON-YYYY (e.g. 08-APR-1958).
- As most analyses are carried out according to patient age, this is a very important data element.

Section B—Hepatitis B Post-Transplant Information

This section collects recipient follow-up information for transplant patients with a diagnosis of Hepatitis B (as per primary diagnosis). It is to be completed on December 31st of each year or at the time of the patient's death. This section was added to the reporting requirements in 2001.

Recurrent Disease

- Indicate whether the patient has Hepatitis B at year-end.
- Acceptable values:
 - 0 = No
 - 1 = Yes, Mild asymptomatic
 - 2 = Yes, Moderate with symptoms or signs of liver disease (e.g. jaundice)
 - 3 = Yes, Severe graft failure, cirrhosis, fibrosing cholestatic disease, signs of portal hypertension

Date of Recurrence

- Indicate the date at which the patient became positive for Hepatitis B during the reporting year.
- Format: DD/MON/YYYY (e.g. 29-May-2002).

Detectable DNA

- Indicate whether the patient had a detectable HBV DNA.
- Acceptable values:
 - 0 = No
 - 1 = Yes
 - 3 = Not done in calendar year
 - 9 = Unknown/missing response

Current Therapy—Hlg

- Indicate whether the patient is currently on H-Blg.
- Acceptable values:
 - Y = Yes
 - N = No

Current Therapy—Lamivudine

- Indicate whether the patient is currently on Lamivudine.
- Acceptable values:
 - Y = Yes
 - N = No

Current Therapy—Other

- If patient is on another therapy, please specify.

Section C—Hepatitis C Post-Transplant Information

This section collects recipient follow-up information for transplant patients with a diagnosis of Hepatitis C (as per primary diagnosis). It is to be completed on December 31st of each year or at the time of the patient's death. This section was added to the reporting requirements in 2001.

Recurrent Disease

- Indicate whether the patient has Hepatitis C at year-end. Recurrent Hepatitis C must be confirmed by biopsy.
- Disease severity is based on the results of the biopsy.
- Acceptable values:
 - 0 = No
 - 1 = Yes, Mild
 - 2 = Yes, Moderate
 - 3 = Yes, Severe

Date of Recurrence/Biopsy

- Indicate the date at which the patient's biopsy results confirmed recurrent Hepatitis C.
- Format: DD/MON/YYYY (e.g. 29-May-2002).

Receiving Treatment

- Indicate whether the patient received treatment during the calendar year.
- Acceptable values:
 - 0 = No
 - 1 = Yes, for Prophylaxis
 - 2 = Yes, for Recurrence

Section D—Liver Tumour Post-Transplant Information

This section collects recipient follow-up information for transplant patients with a diagnosis of liver tumour (as per primary diagnosis). It is to be completed on December 31st of the reporting year or at the time of the patient's death. Alternately, a copy of the form submitted to the International Registry of Hepatic Tumors in Liver Transplantation (Baylor University Medical Centre) can be submitted to CORR. This section was added to the reporting requirements in 2001.

Current Status of Patient—Recurrence of Tumours

- Indicate whether the patient has had a recurrent tumour.
- Acceptable values:
 - Y = Yes
 - N = No

Date of Recurrence

- Indicate the date when the tumour(s) recurred.
- Format: DD/MON/YYYY (e.g. 15-Sep-2004).

Tumour Markers

Alpha Fetoprotein

- Enter levels of Alpha Fetoprotein (AFP) at the time of transplant.
- Specificity of AFP for malignancy is greatest at levels > 1000 ng/mL.

Chorioembryonic Antigen

- Enter levels of Chorioembryonic Antigen (CEA) at the time of transplant.
- Acceptable reference interval: 0.0-3.0 ng/mL.

First Site of Recurrence

- Indicate the first site where the tumour(s) recurred.
- Acceptable values:
 - 1 = Liver
 - 2 = Mediastinum
 - 3 = Abdomen
 - 4 = Lungs
 - 5 = Adrenal
 - 6 = Biopsy Tract
 - 7 = Bone
 - 8 = Other

Treatment

- Indicate the current treatment that the patient is receiving for the tumour(s).

Re-transplantation Flag

- Indicate if the patient had another liver transplant.
- Acceptable values:
 - Y = Yes
 - N = No

Date of Re-transplantation

- If the patient has had another liver transplant, indicate the date of re-transplantation.
- Format: DD/MON/YYYY (e.g. 09-Nov-2004).

Outcome

- Indicate the patient's outcome.
- Acceptable values:
 - 1 = Alive free of tumour
 - 2 = Alive with tumour
 - 3 = Died free of tumour
 - 4 = Died with tumour

Tumour-related Death

- If the patient died with a tumour, indicate whether the death was tumour-related.
- Acceptable values:
 - N = No, not tumour-related
 - Y = Yes, tumour-related

6. Living Donor Profile

Section A – Donor Information

This form should be completed for all Living Donors. Please attach the relevant Transplant Recipient Form.

Donor Type

- Enter the code representing the type of donor for this transplant.
- Acceptable values:

Code	Description
<i>Living Biologically Related</i>	
02	Parent
03	Sibling
04	Offspring
05	Other Relative (e.g. Mother's sister)
<i>Living Biologically Unrelated</i>	
06	Living Unrelated (e.g. In-law)
07	Spouse

Transplant Program Organizing Organ Retrieval

- Enter the name of the transplant program organizing this living donation.
- The program name is converted to a numeric code by the CORR staff.

Transplant Program Donor Number

- Enter the local identification number used for this donor at the transplant hospital.

Surname Stem

- Enter the first three letters of the surname of the donor. In this way, confidentiality issues, which may be encountered if using the full name, are avoided.

Province or State of Residence

- Enter the province of residence for this donor.
- Acceptable values: see codes below—Province of Residence.

Codes—Province of Residence	
Code	Province—Canada
AB	Alberta
BC	British Columbia
MB	Manitoba
NB	New Brunswick
NL	Newfoundland and Labrador
NS	Nova Scotia
NT	Northwest Territories
NU	Nunavut
ON	Ontario
PE	Prince Edward Island
QC	Quebec
SK	Saskatchewan
YT	Yukon
State—United States	
AL	Alabama
AK	Alaska
AS	American Samoa
AZ	Arizona
AR	Arkansas
CA	California
CO	Colorado
CT	Connecticut
DE	Delaware
DC	District of Columbia
FL	Florida
GA	Georgia
GU	Guam
HI	Hawaii
NE	Nebraska
NV	Nevada
NH	New Hampshire
NJ	New Jersey
NM	New Mexico
NY	New York
NC	North Carolina
ND	North Dakota
OH	Ohio
OK	Oklahoma
PA	Pennsylvania
PR	Puerto Rico
RI	Rhode Island
SC	South Carolina

Codes – Province of Residence	
ID	Idaho
IL	Illinois
IN	Indiana
IA	Iowa
KS	Kansas
KY	Kentucky
LA	Louisiana
ME	Maine
MD	Maryland
MA	Massachusetts
MI	Michigan
MN	Minnesota
MS	Mississippi
MO	Missouri
MT	Montana
SD	South Dakota
TN	Tennessee
TX	Texas
UT	Utah
VT	Vermont
VI	Virgin Islands
VA	Virginia
WA	Washington
WV	West Virginia
WI	Wisconsin
WY	Wyoming
XX	If country other than Canada or United States
ZZ	Unknown

Country of Residence

- Enter the country of residence for this donor.
- Acceptable values: see codes below – Country of Residence.

Codes—Country of Residence	
AUS	Australia
AUT	Austria
BEL	Belgium
CAN	Canada
CZE	Czechoslovakia
DNK	Denmark
DEU	Germany
GBR	United Kingdom
FRA	France
ISR	Israel
ITA	Italy
JPN	Japan
MEX	Mexico
ESP	Spain
SWE	Sweden
USA	United States

Age of Donor

- Enter the age (in years) of the donor at the time of the donation.

Donor Sex

- Enter the biological sex of the donor.
- Acceptable values:
 - M = Male
 - F = Female
 - O = Other (transsexual, hermaphrodite)

Donor's Race

- Enter the code the donor's race.
- Only one response can be checked
- If "Other/Multiracial", record the race

- Acceptable values:

Code	Description	
01	Caucasian (White)	e.g. French Canadians and other peoples of European, Australian or Russian ancestry)
02	Asian	e.g. Chinese, Japanese, Vietnamese, Korean, Taiwanese
03	Black	e.g. African, Caribbean, South American, Cuban
05	Indian Sub-continent	India, Pakistan, Bangladesh
08	Pacific Islander	e.g. Filipino
09	Aboriginal	North American Indian, Métis, Inuit
10	Middle Eastern/Arabian	e.g. Saudi Arabia, Iran, Iraq, Jordan, Syria, Armenia, Algeria
98	Unknown	
99	Other/multiracial	

<u>Codes effective Jan. 1, 2001</u>		<u>Former codes</u>	
Caucasian/white	01	→	Caucasian 01
Asian	02	→	Oriental 02
Black	03	→	Black 03
Indian Sub-continent	05	→	Asian Indian 05
Pacific Islander	08	→	Filipino 08
Aboriginal	09	→	North American Indian & Inuit 04 & 07
Mid East/Arabia	10		
Unknown	98	→	Unknown 98
Other/Multiracial	99	→	Other 99

Donor Height

- Enter the height of the donor in centimeters at the time of transplant.
- Acceptable values: cm (conversion factor: 1 inch = 2.54 cm or 0.39 inch = 1 cm).

Donor Weight

- Enter the weight of the donor in kilograms at the time of transplant.
- Acceptable values: kg (conversion factor: 1lb = 0.45kg or 2.21 lbs = 1 kg).

Section B—Hospital Information

Date of Admission

- Enter the date the donor was admitted to hospital.
- Format: DD/MON/YYYY (e.g. 14-Feb-2001).

Date of Cross Clamp

- Enter the date when the organs were retrieved and flushed with a specially prepared, ice-cold solution. Please note that cross clamp date is the same as the date of organ retrieval.
- Format: DD/MON/YYYY (e.g. 14-Feb-2001).

Cross Clamp Time

- Enter the time when the organ is retrieved and flushed with a specially prepared, ice-cold solution.
- Format: HH/MM

Section C—Donor Serology and Risk Factors

Donor Serology Status

Hepatitis BsAg

- Indicate if the donor has hepatitis B antigen (hepatitis BsAg) present at time of transplant
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

Hepatitis BcAb

- Indicate if the donor tested positive for hepatitis B antibody at the time of donation.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

Hepatitis C

- Indicate if the donor has hepatitis C antibody present at the time of donation.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

Epstein Barr

- Indicate if the donor has Epstein Barr virus antibody present at the time of donation.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

HIV

- Indicate if the donor has HIV antigen present at the time of donation.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

CMV

- Indicate if the donor has cytomegalovirus antibody present at the time of donation.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

HTLV (Human T Cell Lymphotropic Virus type-I,II)

- Indicate if the donor has HTLV virus antibody present at the time of donation.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

Donor HLA

HLA = Human lymphocyte antigen, used in determining compatibility between donors and recipients for some transplants. Please record information for the following markers:

Donor HLA A

- Enter the donor’s HLA A1 and A2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).
- Acceptable values:

Codes: HLA A Codes	
Code	Description
0001	A1
0002	A2
0203	A203
0210	A210
0003	A3
0009	A9
0010	A10
0011	A11
0019	A19
0023	A23(9)

Codes: HLA A Codes	
Code	Description
0024	A24(9)
2403	A2403
0025	A25(10)
0026	A26(10)
0028	A28
0029	A29(19)
0030	A30(19)
0031	A31(19)
0032	A32(19)
0033	A33(19)
0034	A34(10)
0036	A36
0043	A43
0066	A66(10)
0068	A68(28)
0069	A69(28)
0074	A74(19)
0080	A80
0097	Typing Done, but no antigen identified
0098	Unknown/Not available/Typing not done
0099	Other—Specify

Donor HLA B

- Enter the donor’s HLA B1 and B2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).
- Acceptable values:

Codes: HLA B Codes	
Code	Description
0005	B5
0007	B7
0703	B703
0008	B8
0012	B12
0013	B13
0014	B14
0015	B15
0016	B16
0017	B17
0018	B18
0021	B21
0022	B22
0027	B27

Codes: HLA B Codes	
Code	Description
2708	B2708
0035	B35
0037	B37
0038	B38(16)
0039	B39(16)
3901	B3901
3902	B3902
0040	B40
4005	B4005
0041	B41
0042	B42
0044	B44(12)
0045	B45(12)
0046	B46
0047	B47
0048	B48
0049	B49(21)
0050	B50(21)
0051	B51(5)
5102	B5102
5103	B5103
0052	B52(5)
0053	B53
0054	B54(22)
0055	B55(22)
0056	B56(22)
0057	B57(17)
0058	B58(17)
0059	B59
0060	B60(40)
0061	B61(40)
0062	B62(15)
0063	B63(15)
0064	B64(14)
0065	B65(14)
0067	B67
0070	B70
0071	B71(70)
0072	B72(70)
0073	B73
0075	B75(15)
0076	B76(15)
0077	B77(15)
0078	B78
0081	B81
0004	BW4

Codes: HLA B Codes	
Code	Description
0006	BW6
9997	Typing Done, but no antigen identified
9998	Unknown/Not available/Typing not done
9999	Other—Specify

Donor HLA DR

- Enter the donor’s HLA DR1 and DR2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).
- Acceptable values:

Codes: HLA DR Codes	
Code	Description
0001	DR1
0103	DR103
0002	DR2
0003	DR3
0004	DR4
0005	DR5
0006	DR6
0007	DR7
0008	DR8
0009	DR9
0010	DR10
0011	DR11(5)
0012	DR12(5)
0013	DR13(6)
0014	DR14(6)
1403	DR1403
1404	DR1404
0015	DR15(2)
0016	DR16(2)
0017	DR17(3)
0018	DR18(3)
0051	DR51
0052	DR52
0053	DR53
9997	Typing Done, but no antigen identified
9998	Unknown/Not available/Typing not done
9999	Other—Specify

Donor HLA DQ

- Enter the donor’s HLA DQ1 and DQ2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).
- Acceptable values:

Codes: HLA DQ Codes	
Code	Description
0001	DQ1
0002	DQ2
0003	DQ3
0004	DQ4
0005	DQ5
0006	DQ6
0007	DQ7
0008	DQ8
0009	DQ9
9997	Typing Done, but no antigen identified
9998	Unknown/Not available/Typing not done
9999	Other – Specify

Donor Risk Factors

Smoker

- Indicate if this donor was a smoker at time of donation (e.g. person who has smoked cigarettes, cigars or a pipe in the last three months).
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

Diabetes

- Indicate if this donor was diagnosed with diabetes type 1 or 2 at the time of donation.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

Hypertension

- Indicate if this donor was receiving medication such as calcium blocking agents, vasodilators, beta blockers, diuretics, ACE inhibitor (e.g. captopril, enalapril) in order to control hypertension at the time of donation.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

Hyperlipidemia

- Indicate if this donor had elevated concentrations of any or all of the lipids in the plasma, such as cholesterol, triglycerides and lipoproteins.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

Coronary Artery Disease

- Indicate if this donor was diagnosed with Coronary Artery Disease at the time of donation. Coronary Artery Disease, also known as atherosclerosis, is the process by which the coronary arteries become narrowed or completely occluded. Ultimately, this is the underlying cause of a heart attack.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

Section D—Organ Specific Information

This section captures information on organ(s) retrieved. Information must be coded for each of the organs listed below.

Organ Donor

- Enter the code representing the type of donor for this transplant.
- Acceptable values:

<i>Code</i>	<i>Description</i>
11	Kidney left
12	Kidney right
21	Liver left lobe
22	Liver right lobe
23	Liver lateral segment
41	Lung left lobe
42	Lung right lobe

Recipient Information

Recipient Last Name

- Enter the surname or family/last name used by the transplant recipient. Do not record titles. A single Hyphen (e.g. SMITH-WATSON), apostrophe (e.g. O'HARA) or blank (e.g. VAN DUSEN) is acceptable

Recipient Date of Birth

- Enter the date of birth for the transplant recipient. Format: DD-MON-YYYY (e.g. 08-APR-1958).

7. Lung/Heart-lung Transplant Recipient Registration Form

Section A—Recipient Information

Transplant Hospital Name and City

- Enter the hospital name and city where this transplant occurred. The city is required in order to differentiate hospitals of the same name in different cities.
- This information is converted to a 5-digit code by CIHI. If you know the CIHI code for your hospital, you may enter this on the form instead of the hospital name and city.

Patient Last Name

- Enter the surname or family/last name used by the patient. Do not record titles. A single Hyphen (e.g. SMITH-WATSON), apostrophe (e.g. O'HARA) or blank (e.g. VAN DUSEN) is acceptable.

Patient First and Middle Names

- Enter the first name or given name as well as the middle name, if applicable, used by the patient.
- If the patient often is referred to by nickname, please indicate this in brackets (e.g. William (BILL) Smith).

Patient Former Name

- Enter the maiden (unmarried) name or former surname for any patient that has undergone a name change (e.g. Elizabeth Smith was formerly Elizabeth Jones so Jones would be recorded).

Sex

- Enter the biological sex of the patient.
- Acceptable values:
 - M = Male
 - F = Female
 - O = Other (transsexual, hermaphrodite)

Blood Type

- Enter the blood type of the patient.
- Acceptable values:
 - A
 - B
 - O
 - AB
 - U (Unknown/missing response)

Patient Race

- Enter the code representing the patient’s race.
- Acceptable values:

Code	Description	
01	Caucasian (White)	e.g. French Canadians and other peoples of European, Australian or Russian ancestry)
02	Asian	e.g. Chinese, Japanese, Vietnamese, Korean, Taiwanese
03	Black	e.g. African, Caribbean, South American, Cuban
05	Indian Sub-continent	India, Pakistan, Bangladesh
08	Pacific Islander	e.g. Filipino
09	Aboriginal	North American Indian, Métis, Inuit
10	Middle Eastern/Arabian	e.g. Saudi Arabia, Iran, Iraq, Jordan, Syria, Armenia, Algeria
98	Unknown	
99	Other/multiracial	

<u>Codes effective Jan. 1, 2001</u>			<u>Former codes</u>	
Caucasian/white	01	→	Caucasian	01
Asian	02	→	Oriental	02
Black	03	→	Black	03
Indian Sub-continent	05	→	Asian Indian	05
Pacific Islander	08	→	Filipino	08
Aboriginal	09	→	North American Indian & Inuit	04 & 07
Mid East/Arabia	10			
Unknown	98	→	Unknown	98
Other/Multiracial	99	→	Other	99

Date of Birth

- Enter the date of birth for this patient. Format: DD-MON-YYYY (e.g. 08-APR-1958).
- This field is mandatory for proper patient identification.
- The majority of analyses are carried out according to patient age.

Health Card Number

- Enter the health insurance plan number as indicated on the health card for this patient. Please omit hyphens, blanks, etc. and include version number, if applicable (e.g. 123123123M).
- The health card number aids in the identification of the patient, and in avoiding duplicate patient records.
- For Manitoba residents, please use the Personal Health Information Number (PHIN).

Province of Health Card

- Enter the province which is associated with the health card number provided.
- Acceptable values:

Code	Province
AB	Alberta
BC	British Columbia
MB	Manitoba
NB	New Brunswick
NL	Newfoundland and Labrador
NS	Nova Scotia
NT	Northwest Territories
NU	Nunavut
ON	Ontario
XX	Other
PE	Prince Edward Island
QC	Quebec
SK	Saskatchewan
YT	Yukon
ZZ	Unknown

Patient Address (City)

- Enter the town or city which is the usual place of residence for the patient at the time the transplant is performed. (Do not include a new residence for treatment purposes).
- This city is used for incidence mapping.

Patient Address (Province)

- Enter the province which is the usual province of residence at the time renal replacement therapy is initiated.
- This information is used for incidence mapping (location of patients at the time their transplant is performed).
- Acceptable values: see Province codes above.

Patient Postal Code

- Enter the postal code for the patient's address at the time of the transplant.
- Format: M3C 2T9.
- This information is used for incidence mapping.

Recipient Height

- Enter the height of the patient in centimeters at the time of transplant.
- Acceptable values: cm (conversion factor: 1 inch = 2.54 cm or 0.39 inch = 1 cm).

Recipient Weight

- Enter the weight of the patient in kilograms at the time of transplant.
- Acceptable values: kg (conversion factor: 1lb = 0.45kg or 2.21 lbs = 1kg).

Section B—Transplant Information

Waiting List Information

Date Patient First Placed on Wait List

- Enter the date that this patient was first placed on a waiting list for this transplant.
- Format: DD-MON-YYYY (e.g. 12-JAN-1996).
- Specific Cases:
Second Lung Transplant: The patient may go on a waiting list for another organ, while there is still some function of the first transplant. The date the patient is returned to the waiting list is considered to be the failure date (date of chronic rejection) of the first organ.

Medical Status at Wait List

- Enter the code for the medical status of the patient at the time they were first placed on the waiting list. (Medical status at time of transplant is also recorded.)
- Acceptable values:

Code	Description
00	Status 0—On Hold
09	Status 1—Stable and Waiting
10	Status 2—Rapid Decompensation

Date Moved to Final List Status

- Indicate if the date for the final list status is not the same as the initial listing status.
- Format: DD-MON-YYYY (e.g. 12-JAN-2001).

Medical Status at Time of Transplant

- Enter the code for the medical status of the patient at the time of this transplant.
- Acceptable values:

Code	Description
09	Status 1—Stable and Waiting
10	Status 2—Rapid Decompensation

Date of Transplant

- Enter the date this transplant occurred.
- Format: DD-MON-YYYY (e.g. 12-JUN-1995).

Graft Number

- Indicate the sequential transplant number for this patient (e.g. one, two, three, etc. lung transplants this patient has had).
- Most actuarial survival analyses are based on the transplant number, for example, graft survival of first single lung cadaveric graft.

Single Lung/Double Lung/Heart-Lung Flags

- Indicate whether this is a single lung, double lung, or heart-lung transplant.
- A patient receiving two lungs, whether inserted separately or enbloc, is considered to be a double lung recipient (even if each lung originates from a separate donor).

Combination Transplant Flag

- Indicate, by checking the combination transplant box, if more than one organ was transplanted during this operation.

Specify Other Organ(s)

Enter the other organ(s) transplanted during this combination transplant operation.

Primary Diagnosis

- Enter the code from the diagnosis code table that represents the primary cause of organ failure. Only one code only is allowed.
- If there is no diagnosis code that represents the primary cause of organ failure, enter the code 99, and describe the condition.
- Acceptable values:

Code	Primary Diagnosis
06	Drug Toxicity
08	Eisenmenger's Disease
10	Pulmonary Toxins
11	Idiopathic Pulmonary Fibrosis
13	Emphysema
15	Lung Failure due to Congenital Disease
17	Primary Pulmonary Hypertension
18	Chronic Obstructive Lung Disease
19	Alpha I Antitrypsin Deficiency
20	Cystic Fibrosis
22	Bronchiectasis
26	Sarcoid
27	Inhalation
28	Bronchiolitis Obliterans
32	Cardiomyopathy (Unspecified)
99	Other, Please Specify

Re-transplant Flag

- Check this box if this is a re-transplant.

Recipient Serology Status

Hepatitis BsAg

- Indicate if the patient has hepatitis B antigen present at time of transplant
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

Hepatitis BcAb

- Indicate if this patient tested positive for hepatitis B antibody at the time of transplant.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

Hepatitis C

- Indicate if patient has hepatitis C antibody present at the time of transplant.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

Epstein Barr

- Indicate if the patient has Epstein Barr virus antibody present at the time of transplant.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

HIV

- Indicate if the patient has HIV antigen present at the time of transplant.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

CMV

- Indicate if the patient has cytomegalovirus antibody present at the time of transplant.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

Current Cytotoxic Antibody (AB) Level

- Enter the current percentage panel reactive antibody (PRA) at the time of transplant.
- Acceptable range: 0–100%.

Peak Cytotoxic Antibody (AB) Level

- Enter the highest percentage panel reactive antibody (PRA) measured for this patient.
- Acceptable range: 0-100%

Pulmonary Vascular Resistance (PVR) Reactivity

- Indicate if this patient has reactive pulmonary vasculature.
- Acceptable values:
 - 0 = Non-reactive
 - 1 = Reactive

Pulmonary Vascular Resistance (PVR)

- Indicate the pulmonary resistance of this patient at time of transplant.
- Measured in Woods units.
- Acceptable values:
 - 1 = < 4 woods units
 - 2 = 4–6 woods units
 - 3 = > 6 woods units
 - 8 = Not done
 - 9 = unknown/missing response

Standard Crossmatch Test Result

- Indicate if the standard cross match test on T-lymphocytes or peripheral blood lymphocytes (PBL) is positive or negative at 22° C or 37° C.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

Recipient HLA

HLA = human lymphocyte antigen (antigenic markers used in determining compatibility between donors and recipients for some transplants). Please record information for the following markers:

Recipient HLA A

- Enter the patient's HLA A1 and A2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).
- Acceptable values:

Codes: HLA A Codes	
Code	Description
0001	A1
0002	A2
0203	A203
0210	A210
0003	A3
0009	A9
0010	A10
0011	A11
0019	A19
0023	A23(9)
0024	A24(9)
2403	A2403
0025	A25(10)
0026	A26(10)
0028	A28
0029	A29(19)
0030	A30(19)
0031	A31(19)
0032	A32(19)
0033	A33(19)
0034	A34(10)
0036	A36
0043	A43
0066	A66(10)
0068	A68(28)
0069	A69(28)
0074	A74(19)
0080	A80
9997	Typing Done, but no antigen identified
9998	Unknown/Not available/Typing not done
9999	Other—Specify

Recipient HLA B

- Enter the patient’s HLA B1 and B2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).
- Acceptable values:

Codes: HLA B Codes	
Code	Description
0005	B5
0007	B7
0703	B703
0008	B8
0012	B12
0013	B13
0014	B14
0015	B15
0016	B16
0017	B17
0018	B18
0021	B21
0022	B22
0027	B27
2708	B2708
0035	B35
0037	B37
0038	B38(16)
0039	B39(16)
3901	B3901
3902	B3902
0040	B40
4005	B4005
0041	B41
0042	B42
0044	B44(12)
0045	B45(12)
0046	B46
0047	B47
0048	B48
0049	B49(21)
0050	B50(21)
0051	B51(5)
5102	B5102
5103	B5103
0052	B52(5)
0053	B53
0054	B54(22)

Codes: HLA B Codes	
Code	Description
0055	B55(22)
0056	B56(22)
0057	B57(17)
0058	B58(17)
0059	B59
0060	B60(40)
0061	B61(40)
0062	B62(15)
0063	B63(15)
0064	B64(14)
0065	B65(14)
0067	B67
0070	B70
0071	B71(70)
0072	B72(70)
0073	B73
0075	B75(15)
0076	B76(15)
0077	B77(15)
0078	B78
0081	B81
0004	BW4
0006	BW6
9997	Typing Done, but no antigen identified
9998	Unknown/Not available/Typing not done
9999	Other—Specify

Recipient HLA DR

- Enter the patient’s HLA DR1 and DR2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).
- Acceptable values:

Codes: HLA DR Codes	
Code	Description
0001	DR1
0103	DR103
0002	DR2
0003	DR3
0004	DR4
0005	DR5
0006	DR6
0007	DR7
0008	DR8

Codes: HLA DR Codes	
Code	Description
0009	DR9
0010	DR10
0011	DR11(5)
0012	DR12(5)
0013	DR13(6)
0014	DR14(6)
1403	DR1403
1404	DR1404
0015	DR15(2)
0016	DR16(2)
0017	DR17(3)
0018	DR18(3)
0051	DR51
0052	DR52
0053	DR53
9997	Typing Done, but no antigen identified
9998	Unknown/Not available/Typing not done
9999	Other – Specify

Recipient HLA DQ

- Enter the patient’s HLA DQ1 and DQ2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).
- Acceptable values:

Codes: HLA DQ Codes	
Code	Description
0001	DQ1
0002	DQ2
0003	DQ3
0004	DQ4
0005	DQ5
0006	DQ6
0007	DQ7
0008	DQ8
0009	DQ9
9997	Typing Done, but no antigen identified
9998	Unknown/Not available/Typing not done
9999	Other – Specify

Risk Factors—Lung, Heart/Lung

Please check one of the acceptable values of “Y=Yes”, “N=No” or “U=Unknown”.

Renal Dysfunction

- Indicate if this patient had renal dysfunction at time of transplant.
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Liver Dysfunction

- Indicate if this patient had liver dysfunction at time of transplant.
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Diabetes Type 1

- Indicate if this patient was diagnosed with diabetes Type 1 at time of transplant.
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Type 1 Diabetes: *Occurs when the pancreas no longer produces any or very little insulin. Usually develops in childhood or adolescence and affects about 10% of the people with diabetes (Canadian Diabetes Association).*

Diabetes Type 2

- Indicate if this patient was diagnosed with diabetes Type 2 at time of transplant.
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Type 2 Diabetes: *Occurs when the pancreas does not produce enough insulin to meet the body’s needs or the insulin is not metabolized effectively. Usually occurs later in life and affects 90% of the people with diabetes (Canadian Diabetes Association).*

Hypertension

- Indicate if this patient was receiving medication such as calcium blocking agents, vasodilators, beta blockers, diuretics, ACE inhibitors (e.g. captopril, enalapril) in order to control hypertension at time of transplant.
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Mechanical Ventilation

- Indicate if this patient was mechanically ventilated (on a respirator) at time of transplant.
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Non-Ambulatory Status

- Indicate if this patient was confined to bed at time of transplant.
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

On Anticoagulants

- Indicate if this patient was on therapeutic anticoagulants at the time of lung transplant (e.g. coumadin, heparin).
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Other Organ Dysfunction

- Indicate if this patient was suffering from disease in one or more organ other than the lung at the time of transplant.
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Previous Thoracic Surgery

- Indicate if this patient had previous thoracic surgery prior to this lung transplant.
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Multi-Resistant Pathogen

- Indicate if this patient suffered from one or more resistant pathogens at time of transplant (organisms resistant to antibiotics).
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Section C—Donor Information

Information on surname stem, donor type, age and sex is used to accurately link the recipient information to the donor profile information as provided by the organ procurement organization. Only these fields need to be completed on the transplant forms for locally transplanted donors, as the complete information is provided on the donor profile forms.

In the case of live donor transplant, please check the living donor flag and complete a Living Donor Profile. This profile should be attached to the transplant recipient registration form for submission to CORR.

Donor Type

- Enter the code representing the type of donor for this transplant.
- Acceptable values:

<i>Codes—Donor Type</i>	
01	Cadaver Donor
12	Domino Donor

Program Organizing Organ Retrieval

- Enter the name of the organ procurement organization responsible for organizing the retrieval of organs from this donor (i.e. where the donor originated).
- For out-of-country donors, the name of the country is sufficient (e.g. USA).
- The program name is converted to a numeric code by the CORR staff.

Retrieval Program Donor Number

- Enter the local identification number used for this donor by the identifying organ retrieval program. This number is used when linking recipient information to donor profile information, and also when requesting clarification of information from the local centre (e.g. if organ used was from another province, original retrieval program donor number **must** be used).

Donor Organ

- Check whether the donor donated right lung, left lung or heart-lung.

Surname Stem

- Enter the first three letters of the surname of the donor. In this way, confidentiality issues, which may be encountered if using the full name, are avoided.
- The surname stem allows this recipient record to be accurately linked with the correct donor profile record, especially in the case of out-of-province donors.

Age of Donor

- Enter the age of the donor at the time of the donation.
- Acceptable range:
 - Age in **Years** for those patients two or more years of age (002 to 130)
 - Age in **Months** for those patients less than 24 months of age (001 to 023)
 - Age in **Days** for those patients less than 30 days of age (001 to 030)
 - Newborns = 000

Donor Sex

- Enter the biological sex of the donor.
- Acceptable values:
 - M = Male
 - F = Female
 - O = Other (transsexual, hermaphrodite)

Donor HLA

HLA = Human lymphocyte antigen, used in determining compatibility between donors and recipients for some transplants. Please record information for the following markers:

Donor HLA A

- Enter the donor's HLA A1 and A2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).
- Acceptable values: see Recipient HLA A codes above.

Donor HLA B

- Enter the donor's HLA B1 and B2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).
- Acceptable values: see Recipient HLA B codes above.

Donor HLA DR

- Enter the donor's HLA DR1 and DR2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).
- Acceptable values: see Recipient HLA DR codes above.

Donor HLA DQ

- Enter the donor's HLA DQ1 and DQ2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).
- Acceptable values: see Recipient HLA DQ codes above.

Section D—Recipient Outcome

This section collects recipient follow-up information, which may be available at the same time that the transplant is registered.

Updates on patient status with respect to transplant failures and deaths, as well as patient transfers, will be collected annually, or at intervals throughout the year, using computer listings on which to record the updates.

Alternatively, the centre may provide computer printouts of all failures and deaths and the associated causes, as well as information on patient transfers, to the CORR office at specified intervals. CORR data specifications must be used in this case.

Hospital Followed At

- Enter the name of the hospital where the patient is receiving transplant follow-up, if different from the transplant hospital.
- Provide the date associated with the transfer (Date of Event).
- This alerts the CORR staff to send all future requests for information on this patient to the follow-up hospital, and allows accurate tracking of this patient throughout the course of his/her treatment.

Patient Status

- Indicate whether the patient is Alive, Dead, or Lost to Follow-up.
- Provide the date associated with the event indicated (alive as of what date, etc).

If Recipient is Deceased

Cause of Death

- Please enter date and cause of death.
- Acceptable values:

Code	Description
<i>Generic</i>	
98	Unknown/missing response
00	Cause of death, uncertain, not determined
<i>Cardiac</i>	
11	Myocardial ischemia and infarction
12	Hyperkalaemia
13	Hemorrhagic pericarditis
14	Other causes of cardiac failure
15	Cardiac arrest, cause unknown
16	Hypertensive cardiac failure
17	Hypokalaemia
18	Fluid overload
<i>Vascular</i>	
21	Pulmonary Embolus
22	Cerebro-vascular Accident
24	Haemorrhage from graft site
26	Ruptured vascular aneurysm (not codes 22-23)
27	Haemorrhage from surgery (not codes 23-26)
28	Other Haemorrhage (not codes 23-27)
55	Vascular Thrombosis
56	Pulmonary Vein Stenosis
57	Stent/balloon Complication
<i>Infection</i>	
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 see 41-42)
35	Septicemia/Sepsis
36	Tuberculosis (Lung)
37	Tuberculosis (elsewhere)
38	Generalized viral infection
39	Peritonitis (not code 70)

Code	Description
<i>Renal Disease</i>	
47	Acute Renal Failure
48	Chronic Renal Failure
<i>Liver Disease</i>	
41	Liver, due to hepatitis B virus
42	Liver, other viral hepatitis
43	Liver, Drug toxicity
44	Cirrhosis, not viral
45	Cystic Liver disease
46	Liver failure, cause unknown
<i>Gastro-Intestinal</i>	
20	Acute Gastroenteritis with dehydration
02	Gastro-intestinal tumour with or without perforation
23	Gastro-intestinal Haemorrhage
29	Mesenteric Infarction
62	Pancreatitis
68	Perforation of peptic ulcer
70	Sclerosing (or adhesive) Peritoneal disease
72	Perforation of colon
<i>Social</i>	
50	Drug Abuse (exclude alcohol abuse)
51	Patient refused further treatment
52	Suicide
53	Therapy ceased for any other reason
54	Alcohol abuse
<i>Accident</i>	
81	Accident related to treatment
82	Accident unrelated to treatment
<i>Miscellaneous</i>	
30	Hypertension
40	Diabetic keto acidosis (DKA)
64	Cachexia
66	Malignant disease possibly induced by immunosuppressive therapy
67	Malignant disease except those of 66—specify primary source
69	Dementia
90	Multi-system failure
99	Other identified causes of death, please specify
<i>Respiratory</i>	
19	Acute respiratory distress syndrome
31	Pulmonary infection (bacterial)
32	Pulmonary infection (viral)
33	Pulmonary Infection (fungal)
49	Bronchiolitis obliterans

Died Due to Graft Failure

- If this patient's death can be attributed to failure of the transplant (e.g. rejection), and complete the date and cause of graft failure fields.
- Enter the date and the cause of death for this patient. See codes above.

Date of Graft Failure

- Enter the date the transplanted organ ceased to function adequately.
- Format: DD-MON-YYYY (e.g. 26-JAN-2004).
- Failure date must be equal to or greater than the transplant date.

Cause of Graft Failure

- Check the code representing the cause of graft failure (e.g. code 64 for chronic rejection).
- Acceptable values:

Code	Description
00	Uncertain/unknown
01	Hyperacute rejection
11	Primary non-function
18	De Novo Malignancy
19	Graft Coronary Artery Disease
23	Vascular thrombosis (graft)
24	Bronchiolitis Obliterans
25	Pulmonary Hypertension/Cor pulmonale
28	Surgical complication – not specified
29	Large Airway Complications
37	Acute Respiratory Distress Syndrome
63	Acute rejection
64	Chronic rejection
67	Recurrent disease
68	Infection and rejection
69	Infection of graft
99	Other cause of graft failure (describe)

8. Pancreas Transplant Recipient Registration Form

Section A—Recipient Information

Transplant Hospital Name and City

- Enter the hospital name and city where this transplant occurred. The city is required in order to differentiate hospitals of the same name in different cities.
- This information is converted to a 5-digit code by CIHI. If you know the CIHI code for your hospital, you may enter this on the form instead of the hospital name and city.

Patient Last Name

- Enter the surname or family/last name used by the patient. Do not record titles. A single Hyphen (e.g. SMITH-WATSON), apostrophe (e.g. O'HARA) or blank (e.g. VAN DUSEN) is acceptable.

Patient First and Middle Names

- Enter the first name or given name as well as the middle name, if applicable, used by the patient.
- If the patient often is referred to by nickname, please indicate this in brackets (e.g. William (BILL) Smith).

Patient Former Name

- Enter the maiden (unmarried) name or former surname for any patient that has Undergone a name change (e.g. Elizabeth Smith was formerly Elizabeth Jones so Jones would be recorded).

Sex

- Enter the biological sex of the patient.
- Acceptable values:
 - M = Male
 - F = Female
 - O = Other (transsexual, hermaphrodite)

Blood Type

- Enter the blood type of the patient.
- Acceptable values:
 - A
 - B
 - O
 - AB
 - U (Unknown/missing response)

Patient Race

- Enter the code representing the patient’s race.
- Acceptable values:

Code	Description	
01	Caucasian (White)	e.g. French Canadians and other peoples of European, Australian or Russian ancestry
02	Asian	e.g. Chinese, Japanese, Vietnamese, Korean, Taiwanese
03	Black	e.g. African, Caribbean, South American, Cuban
05	Indian Sub-continent	India, Pakistan, Bangladesh
08	Pacific Islander	e.g. Filipino
09	Aboriginal	North American Indian, Métis, Inuit
10	Middle Eastern/Arabian	e.g. Saudi Arabia, Iran, Iraq, Jordan, Syria, Armenia, Algeria
98	Unknown	
99	Other/multiracial	

<u>Codes effective Jan. 1, 2001</u>			<u>Former codes</u>	
Caucasian/white	01	→	Caucasian	01
Asian	02	→	Oriental	02
Black	03	→	Black	03
Indian Sub-continent	05	→	Asian Indian	05
Pacific Islander	08	→	Filipino	08
Aboriginal	09	→	North American Indian & Inuit	04 & 07
Mid East/Arabia	10			
Unknown	98	→	Unknown	98
Other/Multiracial	99	→	Other	

Date of Birth

- Enter the date of birth for this patient. Format: DD-MON-YYYY (e.g. 08-APR-1958).
- This field is mandatory for proper patient identification.
- The majority of analyses are carried out according to patient age.

Health Card Number

- Enter the health insurance plan number as indicated on the health card for this patient. Please omit hyphens, blanks, etc. and include version number, if applicable (e.g. 123123123M).
- The health card number aids in the identification of the patient, and in avoiding duplicate patient records.
- For Manitoba residents, please use the Personal Health Information Number (PHIN).

Province of Health Card

- Enter the province, which is associated with the health card number provided.
- Patient Surname
- Enter the surname or family/last name used by the patient. Enter without titles.
- A single hyphen (e.g. SMITH-WATSON), apostrophe (e.g. O’HARA), or blank (e.g. VAN DUSEN) may be entered.
- Acceptable values:

<i>Code</i>	<i>Province</i>
AB	Alberta
BC	British Columbia
MB	Manitoba
NB	New Brunswick
NL	Newfoundland and Labrador
NS	Nova Scotia
NT	Northwest Territories
NU	Nunavut
ON	Ontario
XX	Other
PE	Prince Edward Island
QC	Quebec
SK	Saskatchewan
YT	Yukon
ZZ	Unknown

Patient Address (City)

- Enter the town or city, which is the usual place of residence for the patient at the time the transplant is performed. (Do not include a new residence for treatment purposes).
- This city is used for incidence mapping.

Patient Address (Province)

- Enter the province, which is the usual province of residence at the time the transplant is performed.
- This information is used for incidence mapping (location of patients at the time their renal failure began).
- Acceptable values: see Province codes above.

Patient Postal Code

- Enter the postal code for the patient’s address at the time of the transplant.
- Format: M3C 2T9.
- This information is used for incidence mapping.

Recipient Height

- Enter the height of the patient in centimeters at the time of transplant.
- Acceptable values: cm (conversion factor: 1 inch = 2.54 cm or 0.39 inch = 1cm).

Recipient Weight

- Enter the weight of the patient in kilograms at the time of transplant.
- Acceptable values: kg (conversion factor: 1lb = 0.45kg or 2.21 lbs = 1kg).

Section B—Transplant Information

Waiting List Information

Date Patient First Placed on Waiting List

- Enter the date that this patient was first placed on a waiting list for this transplant.
- Format: DD-MON-YYYY (e.g. 12-JAN-1996).

Pancreas Transplant Only Flag

- Check this box if the recipient is only receiving a pancreas and no other organ at this time. If this is a combination transplant, please check the combination transplant box.

Combination Transplant Flag

- Indicate, by checking the combination transplant box, if more than one organ was transplanted during this operation.

Specify Other Organ(s)

- Enter the other organ(s) transplanted during this combination transplant operation.

Type of Pancreas

- Enter the code representing the type of pancreas.
- Acceptable values:

<i>Code</i>	<i>Description</i>
50	Whole Pancreas
51	Segmental—No Polymer Occlusion
52	Islet Cells
53	Exocrine Drainage (Enteric)
54	Exocrine Drainage (Urinary)
55	Wirsung Obstruction with Polymer

Primary Diagnosis

- Check the code representing the primary diagnosis, which represents the primary cause of organ failure. One code only is allowed.
- If there is no diagnosis code that represents the primary cause of organ failure, enter the code 99, and describe the condition.
- Acceptable values:

Code	Primary Diagnosis
01	Chronic Pancreatitis
02	Diabetes Type 1
03	Pancreatectomy
04	Cystic Fibrosis
05	Trauma
06	Diabetes Type 2
07	Pancreatic Cancer
08	Bile Duct Cancer
99	Other, Please Specify

Re-transplant

- Check this box if this is a re-transplant.

Recipient Serology Status

Hepatitis BsAg

- Indicate if the patient has hepatitis B antigen(BsAg) present at time of transplant.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

Hepatitis BcAb

- Indicate if the patient tested positive for hepatitis B (BcAb) antibody at the time of donation.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

Hepatitis C

- Indicate if patient has hepatitis C antibody present at the time of transplant.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

Epstein Barr

- Indicate if the patient has Epstein Barr virus antibody present at the time of transplant.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

HIV

- Indicate if the patient has HIV antigen present at the time of transplant.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

CMV

- Indicate if the patient has cytomegalovirus antibody present at the time of transplant.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

Current Cytotoxic Antibody Level

- Enter the current percentage panel reactive antibody (PRA) at the time of transplant.
- Acceptable range: 0–100%.

Peak Cytotoxic Antibody Level

- Enter the highest percentage panel reactive antibody (PRA) measured for this patient.
- Acceptable range: 0–100%

Standard Crossmatch Test Result

- Indicate if the standard cross match test on T-lymphocytes or peripheral blood lymphocytes (PBL) is positive or negative at 22°C or 37°C.
- Acceptable values:
 - P = Positive
 - N = Negative
 - U = Unknown/missing response

Recipient HLA

HLA = human lymphocyte antigen (antigenic markers used in determining compatibility between donors and recipients for some transplants).

Recipient HLA A

- Enter the patient’s HLA A1 and A2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).
- Acceptable values:

Codes: HLA A Codes	
Code	Description
0001	A1
0002	A2
0203	A203
0210	A210
0003	A3
0009	A9
0010	A10
0011	A11
0019	A19
0023	A23(9)
0024	A24(9)
2403	A2403
0025	A25(10)
0026	A26(10)
0028	A28
0029	A29(19)
0030	A30(19)
0031	A31(19)
0032	A32(19)
0033	A33(19)
0034	A34(10)
0036	A36
0043	A43
0066	A66(10)
0068	A68(28)
0069	A69(28)
0074	A74(19)
0080	A80
9997	Typing Done, but no antigen identified
9998	Unknown/Not available/Typing not done
9999	Other – specify

Recipient HLA B

- Enter the patient’s HLA B1 and B2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).

- Acceptable values:

Codes: HLA B Codes	
Code	Description
0005	B5
0007	B7
0703	B703
0008	B8
0012	B12
0013	B13
0014	B14
0015	B15
0016	B16
0017	B17
0018	B18
0021	B21
0022	B22
0027	B27
2708	B2708
0035	B35
0037	B37
0038	B38(16)
0039	B39(16)
3901	B3901
3902	B3902
0040	B40
4005	B4005
0041	B41
0042	B42
0044	B44(12)
0045	B45(12)
0046	B46
0047	B47
0048	B48
0049	B49(21)
0050	B50(21)
0051	B51(5)
5102	B5102
5103	B5103
0052	B52(5)
0053	B53
0054	B54(22)
0055	B55(22)
0056	B56(22)
0057	B57(17)
0058	B58(17)
0059	B59
0060	B60(40)
0061	B61(40)

Codes: HLA B Codes	
Code	Description
0062	B62(15)
0063	B63(15)
0064	B64(14)
0065	B65(14)
0067	B67
0070	B70
0071	B71(70)
0072	B72(70)
0073	B73
0075	B75(15)
0076	B76(15)
0077	B77(15)
0078	B78
0081	B81
0004	BW4
0006	BW6
9997	Typing Done, but no antigen identified
9998	Unknown/Not available/Typing not done
9999	Other – specify

Recipient HLA DR

- Enter the patient’s HLA DR1 and DR2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).
- Acceptable values:

Codes: HLA DR Codes	
Code	Description
0001	DR1
0103	DR103
0002	DR2
0003	DR3
0004	DR4
0005	DR5
0006	DR6
0007	DR7
0008	DR8
0009	DR9
0010	DR10
0011	DR11(5)
0012	DR12(5)
0013	DR13(6)
0014	DR14(6)
1403	DR1403

Codes: HLA DR Codes	
Code	Description
1404	DR1404
0015	DR15(2)
0016	DR16(2)
0017	DR17(3)
0018	DR18(3)
0051	DR51
0052	DR52
0053	DR53
9997	Typing Done, but no antigen identified
9998	Unknown/Not available/Typing not done
9999	Other—specify

Recipient HLA DQ

- Enter the patient’s HLA DQ1 and DQ2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking)
- Acceptable values:

Codes: HLA DQ Codes	
Code	Description
0001	DQ1
0002	DQ2
0003	DQ3
0004	DQ4
0005	DQ5
0006	DQ6
0007	DQ7
0008	DQ8
0009	DQ9
9997	Typing Done, but no antigen identified
9998	Unknown/Not available/Typing not done
9999	Other—specify

Graft Number

- Indicate the sequential transplant number for this patient (e.g. one, two, three, etc. pancreas transplant operations this patient has had).
- Most actuarial survival analyses are based on the transplant number, for example, graft survival of first pancreas cadaveric graft.

Risk Factors—Pancreas

Cardiovascular Disease

- Indicate if this patient suffered from cardiovascular disease at the time of transplant.
- Ischaemic heart disease is the presence of previous myocardial infarction, history of angina or radiological evidence of significant coronary artery disease (shown by 2D echocardiography, thallium scan or coronary angiography).
- Valvular heart disease or other heart disease is the presence of arrhythmia, cardiomyopathy, etc.
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Kidney Failure

- Indicate if this patient suffered from kidney failure at the time of transplant.
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Cerebrovascular Disease

- Indicate if this patient has had a cerebrovascular event such as transient ischaemic attack, cerebral infarct, cerebral haemorrhage, stroke, CVA prior to this transplant.
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Dialysis Required

- Indicate if this patient was on dialysis at the time of transplant.
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Peripheral Vascular Disease

- Indicate if this patient has been described as having intermittent claudication at rest or on exercise, has had aortal-femoral bypass surgery; or amputation of toes, lower legs, etc., prior to this transplant.
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Diabetic Nephropathy

- Indicate if this patient showed signs of diabetic nephropathy at time of transplant.
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Diabetic Retinopathy

- Indicate if this patient suffered from diabetic retinopathy at time of transplant.
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Diabetic Neuropathy

- Indicate if this patient suffered from diabetic neuropathy at time of transplant.
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

Family History of Diabetes

- Indicate if there is a history of diabetes in the family of this patient.
- Acceptable values:
 - Y = Yes
 - N = No
 - U = Unknown/missing response

No. of Years on Insulin

- Enter the number of years that this patient has been receiving insulin prior to this transplant.
- Acceptable values: 0–99, blank

Warm Ischaemic Time

- Enter the time in minutes between clamping of the major vessels (usually the aorta), or the time of cardiac arrest, and the initiation of cold flushing.
- Enter 0 for in situ perfusion.
- Acceptable range: Pancreas: 0–99 minutes.

Re-warm Time

- Enter the time in minutes between removal of the organ from cold storage and until the clamps are released in the recipient allowing blood flow.
- Also known as re-perfusion time or anastomosis time.
- Acceptable range: Pancreas: 15min–60min.

Cold Ischaemic Time

- Enter the time in minutes from initiation of cooling (including in situ cooling) and removal of the organ from cold storage.
- Acceptable range: Pancreas: 15min–720min (12 hr).

Section C – Donor Information

Information on surname stem, donor type, age and sex is used to accurately link the recipient information to the donor profile information as provided by the organ procurement organization. Only these fields need to be completed on the transplant forms for locally transplanted donors, as the complete information is provided on the Cadaveric donor profile forms.

In the case of live donor transplants, please check the living donor flag and complete a Living Donor Profile. This profile should be attached to the transplant recipient registration form for submission to CORR.

Donor Type

- Enter the code representing the type of donor for this transplant.
- Acceptable values:

<i>Code</i>	<i>Description</i>
01	Cadaver Donor
12	Domino Donor

Program Organizing Organ Retrieval

- Enter the name of the organ procurement organization responsible for organizing the retrieval of organs from this donor (i.e. where the donor originated).
- For out-of-country donors, the name of the country is sufficient (e.g. USA).
- The program name is converted to a numeric code by the CORR staff.

Retrieval Program Donor Number

- Enter the local identification number used for this donor by the identifying organ retrieval program. This number is used when linking recipient information to donor profile information, and also when requesting clarification of information from the local centre (e.g. if organ used was from another province, original retrieval program donor number **must** be used).

Surname Stem

- Enter the first three letters of the surname of the donor. In this way, confidentiality issues, which may be encountered if using the full name, are avoided.
- The surname stem allows this recipient record to be accurately linked with the correct donor profile record, especially in the case of out-of-province donors.

Age of Donor

- Enter the age of the donor at the time of the donation.
- Acceptable range:
 - Age in **Years** for those patients two or more years of age (002 to 130)
 - Age in **Months** for those patients less than 24 months of age (001 to 023)
 - Age in **Days** for those patients less than 30 days of age (001 to 030)
 - Newborns = 000

Donor Sex

- Enter the biological sex of the donor.
- Acceptable values:
 - M = Male
 - F = Female
 - 0 = Other (transsexual, hermaphrodite)

Donor HLA

HLA = Human lymphocyte antigen, used in determining compatibility between donors and recipients for some transplants. Please record information for the following markers:

Donor HLA A

- Enter the donor's HLA A1 and A2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).
- Acceptable values: see Recipient HLA A codes above.

Donor HLA B

- Enter the donor's HLA B1 and B2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).
- Acceptable values: see Recipient HLA B codes above.

Donor HLA DR

- Enter the donor's HLA DR1 and DR2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).
- Acceptable values: see Recipient HLA DR codes above.

Donor HLA DQ

- Enter the donor's HLA DQ1 and DQ2 loci.
- If information is available on antigen splits, please use this information.
- Record the lower HLA number first, followed by the higher number (this aids in computer edit checking).
- Acceptable values: see Recipient HLA DQ codes above.

Section D—Recipient Outcome

This section collects recipient follow-up information, which may be available at the same time that the transplant is registered.

Updates on patient status with respect to transplant failures and deaths, as well as patient transfers, will be collected annually, or at intervals throughout the year, using computer listings on which to record the updates.

Alternatively, the centre may provide computer printouts of all failures and deaths and the associated causes, as well as information on patient transfers, to the CORR office at specified intervals. CORR data specifications must be used in this case.

Hospital Followed At

- Enter the name of the hospital where the patient is receiving transplant follow-up, if different from the transplant hospital.
- Provide the date associated with the transfer (Date of Event).
- This alerts the CORR staff to send all future requests for information on this patient to the follow-up hospital, and allows accurate tracking of this patient throughout the course of his/her treatment.

Patient Status

- Indicate whether the patient is Alive, Dead, or Lost to Follow-up.
- Provide the date associated with the event indicated (alive as of what date, etc).
Format: DD/MON/YYYY.

Required Insulin

- Indicate if this patient required insulin after his transplantation.
- Acceptable values:
 - Y = Yes
 - N = No

If Recipient is Deceased

Cause of Death

- Please enter date and cause of death.
- Acceptable values:

Code	Description
<i>Generic</i>	
98	Unknown/Missing Response
00	Cause of death, uncertain, not determined
<i>Cardiac</i>	
11	Myocardial ischemia and infarction
12	Hyperkalaemia
13	Hemorrhagic pericarditis
14	Other causes of cardiac failure
15	Cardiac arrest, cause unknown
16	Hypertensive cardiac failure
17	Hypokalaemia
18	Fluid overload
<i>Vascular</i>	
21	Pulmonary Embolus
22	Cerebro-vascular Accident
24	Haemorrhage from graft site—specify
26	Ruptured vascular aneurysm (not codes 22-23)
27	Haemorrhage from surgery (not codes 23-26)—specify
28	Other Haemorrhage (not codes 23–27)
55	Vascular Thrombosis
56	Pulmonary Vein Stenosis
57	Stent/balloon Complication
<i>Infection</i>	
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 see 41–42)
35	Septicemia/Sepsis—specify source
36	Tuberculosis (Lung)

Code	Description
37	Tuberculosis (elsewhere)
38	Generalized viral infection – specify viral agent
39	Peritonitis (not code 70)
<i>Renal Disease</i>	
47	Acute Renal Failure
48	Chronic Renal Failure
61	Uraemia caused by kidney transplant failure
<i>Liver Disease</i>	
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
<i>Gastro-Intestinal</i>	
02	Gastro-intestinal tumour with or without perforation
20	Acute gastroenteritis with dehydration
23	Gastro-intestinal Haemorrhage
29	Mesenteric Infarction
62	Pancreatitis
68	Perforation of peptic ulcer
70	Sclerosing (or adhesive) Peritoneal disease
72	Perforation of colon
<i>Social</i>	
50	Drug Abuse (exclude alcohol abuse)
51	Patient refused further treatment
52	Suicide
53	Therapy ceased for any other reason
54	Alcohol abuse
<i>Accident</i>	
81	Accident related to treatment
82	Accident unrelated to treatment
<i>Miscellaneous</i>	
30	Hypertension
40	Diabetic keto acidosis (DKA)
64	Cachexia
66	Malignant disease possibly induced by immunosuppressive therapy – specify primary site
67	Malignant disease except those of 66 – specify primary source
69	Dementia
90	Multi system failure
99	Other identified causes of death, please specify
<i>Respiratory</i>	
19	Acute respiratory distress syndrome
31	Pulmonary infection (bacterial)
32	Pulmonary infection (viral)
33	Pulmonary Infection (fungal)

Code	Description
49	Bronchiolitis obliterans
<i>Metabolic</i>	
59	Drug-related toxicity—specify drug
<i>Hematologic</i>	
63	Bone Marrow Depression
71	Thrombocytopenia
73	Thrombosis—specify
<i>Neurologic</i>	
75	Drug Neurotoxicity—specify drug
76	Status Epilepticus
77	Neurologic Infection—specify infectious agent

Died Due to Graft Failure

- If this patient's death can be attributed to failure of the transplant (e.g. rejection), and complete the date and cause of graft failure fields.
- Enter the date and the cause of death for this patient. See codes above.

Date of Graft Failure

- Enter the date that the transplanted organ ceased to function adequately.
- Format: DD-MON-YYYY (e.g. 26-JAN-1996).
- Failure date must be equal to or greater than the transplant date.

Cause of Graft Failure

- Check the code representing the cause of graft failure (e.g. code 64 for chronic rejection).
- Acceptable values:

Code	Description
00	Uncertain/unknown
01	Hyperacute rejection
11	Primary non-function
18	De Novo Malignancy
20	Pancreatitis
23	Vascular thrombosis (graft)
28	Surgical complications—not specified
63	Acute rejection
64	Chronic rejection
67	Recurrent Disease
68	Infection and rejection
69	Infection of graft
99	Other cause of graft failure (describe)

Appendix A

Participating Transplant Hospitals

Symbols

Kid = Kidney Transplants
Liv = Liver Transplants
Hea = Heart Transplants
Ht-Lu = Heart-Lung Transplants
Lun = Lung Transplants
Kid-Pan = Kidney-Pancreas Transplants
Pan = Pancreas Transplants
Bow = Bowel Transplants
Clus = Cluster Transplants

Hosp Code	Institution	Symbol
20085	Queen Elizabeth II Health Sciences Centre 1278 Tower Road, Victoria Building Halifax, NOVA SCOTIA B3H 2Y9	Kid, Hea, Kid-Pan, Pan
20086	IWK Grace Health Centre for Children, Women & Families 5850/5980 University Ave., P.O. Box 3070 Halifax, NOVA SCOTIA B3J 3G9	Kid
40003	Royal Victoria Hospital 687 Pine Avenue West Montréal, QUEBEC H3A 1A1	Kid, Liv, Hea, Ht-Lu, Kid-Pan, Pan
40006	Montréal Children's Hospital 2300 Tupper Street Montréal, QUEBEC H3H 1P3	Kid
40070	C. H. Universitaire de Sherbrooke – Hôpital Fleurimont 3000, 12e avenue nord Fleurimont, QUEBEC J1H 5N4	Kid
40115	Hôpital Laval 2725, chemin Sainte-Foy Sainte-Foy, QUEBEC G1V 4G5	Hea

Hosp Code	Institution	Symbol
40118	Hôpital Maisonneuve-Rosemont 5415, boulevard de l'Assomption Montréal, QUEBEC H1T 2M4	Kid
40120	C.H. de l'université de Montréal- Notre-Dame 1560, rue Sherbrooke est Montréal, QUEBEC H2L 4M1	Kid, Hea, Lun, Ht-Lun, Kid-Pan, Pan
40130	C.H. de l'université de Montréal – St-Luc 1058, rue Saint-Denis Montréal, QUEBEC H2X 3J4	Liv
40135	Hôpital Ste-Justine 3175, chemin Côte Ste-Catherine Montréal, QUEBEC H3T 1C5	Kid, Liv, Hea
40142	C.H. universitaire de Québec Hôtel Dieu de Québec 11, Côte du Palais Québec, QUEBEC G1R 2J6	Kid
40149	Institut de Cardiologie de Montréal 5000, rue Bélanger est Montréal, QUEBEC H1T 1C8	Hea
51100	Kingston General Hospital 76 Stuart Street Kingston, ONTARIO K7M 2V7	Kid
51406	Hospital for Sick Children 555 University Ave. Toronto, ONTARIO M5G 1X8	Kid, Liv, Hea, Lun, Bow, Clus

Hosp Code	Institution	Symbol
51444	St. Michael's Hospital 30 Bond Street Toronto, ONTARIO M5B 1W8	Kid
52003	St. Joseph's Health Care System 50 Charlton Avenue East Hamilton, ONTARIO L8N 4A6	Kid
53850	London Health Sciences Centre- University & Victoria Campuses 339 Windermere Road London, ONTARIO N6A 5A5	Kid, Liv, Hea, Pan, Bow, Clus
53910	Toronto General Hospital - University Health Network 200 Elizabeth Street Toronto, ONTARIO M5G 2C4	Kid, Liv, Hea, Ht-Lu, Lu, Kid-Pan, Clus
54051	The Ottawa Hospital 501 Smyth Rd Ottawa, ONTARIO K1H 8L6	Kid
54164	University of Ottawa Heart Institute 40 Ruskin St Ottawa, ONTARIO K1Y 4W7	Hea
60016	Health Sciences Centre 820 Sherbrook Street Winnipeg, MANITOBA R3A 1R9	Kid, Lun
70141	St. Paul's Hospital 1702 – 20 th Street West Saskatoon, SASKATCHEWAN S7M 0Z9	Kid

Hosp Code	Institution	Symbol
80016	Foothills Medical Centre- Calgary Regional Health Authority 1403 29th Street North West Calgary, ALBERTA T2N 2T9	Kid, Kid-Pan
80044	University of Alberta Hospital - Edmonton Regional Health Authority 8440 – 112 th Street Edmonton, ALBERTA T6G 2B7	Kid, Liv, Hea, Ht-Lu, Lun, Kid-Pan, Pan Islet Cells
90101	Vancouver Hospital and Health Sciences Centre 855 West 12 th Street Vancouver, BRITISH COLUMBIA V5Z 1M9	Kid, Liv, Lun, Kid-Pan Islet Cells
90102	St. Paul's Hospital 1081 Burrard Street Vancouver, BRITISH COLUMBIA V6Z 1Y6	Kid, Hea
90105	BC Children's Hospital 4480 Oak Street Vancouver, BRITISH COLUMBIA V6H 3V4	Kid

Appendix B

Organ Procurement Organizations in Canada

Organ Procurement Organizations in Canada

Newfoundland and Labrador

Organ Procurement and Exchange of Newfoundland and Labrador (O.P.E.N. Program)
Health Sciences Centre
300 Prince Phillip Parkway
St. John's, NEWFOUNDLAND AND LABRADOR
A1B 3V6

New Brunswick

Multiple Organ Retrieval and Exchange Program
Health and Wellness Hospital Services Branch
PO Box 5100
Fredericton, NEW BRUNSWICK
E3B 5G8
<http://www.gnb.ca/0217/organ-e.asp>

Nova Scotia

Multi-Organ Transplant Program
Queen Elizabeth II Health Sciences Centre
Mackenzie Building
5788 University Avenue
Halifax, NOVA SCOTIA
B3H 1V7
<http://www.cdha.nshealth.ca/transplantservices/>

Quebec—Bureau de Montréal

Quebec Transplant
4200, boul. St-Laurent
Montréal, QUEBEC
H2W 2R2
<http://www.quebec-transplant.qc.ca>

Quebec—Bureau du Québec

Quebec Transplant
2601 de la Canardiere
Beauport, QUEBEC
G1J 2G3

Ontario

Trillium Gift of Life Network
155 University Avenue, Suite 1440
Toronto, ONTARIO
M5H 3B7
<http://www.giftoflife.on.ca>

Multi Organ Transplant Program
Kingston General Hospital
76 Stuart Street
Kingston, ONTARIO
K7L 2V7

Multi-Organ Transplant Program
Toronto General Hospital
200 Elizabeth Street
Toronto, ONTARIO
M5G 2C4

Multi-Organ Transplant Program
Hospital for Sick Children
555 University Avenue
Toronto, ONTARIO
M5G 1X8

*Ottawa Hospital Organ and
Tissue Procurement*
Ottawa Hospital
501 Smyth Rd.
Ottawa, ONTARIO
K1H 8L6

Multi-Organ Transplant Program
St. Michael's Hospital
61 Queen Street East
Toronto, ONTARIO
M5C 2T2

Multi-Organ Transplant Program
London Health Sciences Centre
University & South Street Campuses
339 Windermere Rd., P.O Box 5339
London, ONTARIO N6A 5A5

University of Ottawa Heart Institute
40 Ruskin Street
Ottawa, ONTARIO
K1Y 4W7

St. Joseph's Hospital Renal Transplant Program
St. Joseph's Health Care System
50 Charlton Ave East
Hamilton, ONTARIO
L8N 1Y4

Manitoba

Health Sciences Centre
820 Sherbrooke Street, Rm GE441
Winnipeg, MANITOBA
R3A 1R9

Saskatchewan

The Saskatchewan Transplant Program
Royal University Hospital
108 Hospital Drive, P.O. Box 86
Saskatoon, SASKATCHEWAN
S7N 0W8

Alberta

HOPE Program—Calgary

Foothills Medical Centre
1403 29th Street North West
Calgary, ALBERTA
T2N 2T9
<http://www.crha-health.ab.ca/hlthconn/items/orgtiss.htm>

HOPE Program—Edmonton

University of Alberta Hospital
8440-112th St
Edmonton, ALBERTA
T6G 2B7

British Columbia

British Columbia Transplant Society (BCTS)

3rd Floor, West Tower
555 West 12th Avenue
Vancouver, BRITISH COLUMBIA
V5Z 3X7
<http://www.transplant.bc.ca>

Appendix C

Reporting Forms

Canadian Organ Replacement Register Cadaveric Donor Profile

SEND THIS CONFIDENTIAL INFORMATION TO:
 Canadian Organ Replacement Register (CORR)
 Canadian Institute for Health Information
 90 Eglinton Avenue East, Suite 300
 Toronto, ON M4P 2Y3
 Tel: (416) 481-2002 / FAX: (416) 481-2950



Instructions:

To be completed for all referrals, potential and actual donors.

Definitions:

REFERRAL – Initial communication between donor centre and coordinator to determine donor suitability. All calls are considered referrals.

POTENTIAL DONOR – A referral who has fulfilled the general acceptance criteria for organ donation or for whom organ retrieval may occur but organs are not transplanted.
ACTUAL DONOR – A potential organ donor who has had at least one retrieved organ transplanted.

SECTION A—REFERRAL/DONOR INFORMATION

Please provide all available information for referred organ donors.
 Program Organizing Organ Retrieval (**Please check one**)

- | | | |
|--------------------|-------------------|---------------------|
| 01 @ Halifax, NS | 09 @ St. John, NB | 10 @ St. John's, NF |
| 07 @ Montreal, QC | 13 @ Quebec, QC | 02 @ Hamilton, ON |
| 05 @ London, ON | 11 @ Ottawa, ON | 15 @ Kingston, ON |
| 16 @ Toronto, ON | 06 @ Winnipeg, MB | 14 @ Saskatoon, SK |
| 17 @ Regina, SK | 03 @ Calgary, AB | 04 @ Edmonton, AB |
| 12 @ Vancouver, BC | 99 @ Other _____ | |

Retrieval Program Donor Number _____

Surname Stem _____ (Please enter the first 3 letters of the donor surname)

Province or State of Residence _____

Country of Residence _____

Referral accepted Yes @ No @ If no, please complete section A & B only

If no, indicate reason (see codes on right inside) _____

Family Consent Obtained Yes @ No @

Declared Brain Dead Yes @ No @

Non-heart beating Yes @ No @ Unknown @

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

Days: (001–030) _____ Newborn: (000) _____

Province or State of Death _____

Country of Death _____

Sex @ male @ female @ other (transsexual, hermaphrodite)

Blood Type @ A @ B @ AB @ O @ U

Race

01 @ Caucasian 02 @ Asian 03 @ Black 05 @ Indian Sub-continent

08 @ Pacific Islander 09 @ Aboriginal 10 @ Mid East /Arabian

98 @ Unknown 99 @ Other/Multiracial _____

CODES—Reasons Donors or Organs not Used

- | | |
|--|---------------------------------|
| 03 Team/hospital logistics (team, hospital, transplantation resource issues) | 10 Consent requested and denied |
| 04 Medical reasons (stability, infection, etc.) | 98 Unknown/not available |
| 07 Consent not requested | 99 Other reason: specify |
| 08 Brain death not confirmed | |
| 09 Refusal by medical examiner | |

Donor Height and Weight (For actual donors only)

Donor Height @ @ @ • @ @ @ (cm)

Donor Weight @ @ @ • @ @ @ (kg)

Conversion Factors: 1 inch=2.54 cm; 1lb = 0.45 kg)

Cause of Donor Death (for actual donors only)

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

- | | |
|--|--|
| 01 @ Anoxia/Hypoxia | 02 @ C.V.A. (Stroke) |
| 03 @ Trauma (not MVC) Describe: _____ | |
| 04 @ Motor Vehicle Collision | |
| 05 @ Overdose Describe: _____ | |
| 06 @ Primary CNS Tumour | |
| 07 @ Ruptured Cerebral Aneurysm | 08 @ Spontaneous Intracranial Hemorrhage |
| 09 @ Gunshot | |
| 10 @ Intracranial Event Describe _____ | |
| 11 @ CNS infection | 12 @ Carbon Monoxide Poisoning |
| 13 @ Cerebral Oedema | 14 @ Asthma, unspecified |
| 15 @ SIDS (Sudden Infant Death Syndrome) | |
| 99 @ Other Describe _____ | |

SECTION B—HOSPITAL INFORMATION (If referral was not accepted, consent was declined or no organs were retrieved, please complete identifying hospital and date of admission only.)

Identifying Hospital _____ Date of Admission (DD/MON/YYYY) |__|_|/|__|_|/|__|_|_|_|_|

Date of Brain Death (DD/MON/YYYY) |__|_|/|__|_|/|__|_|_|_|_| Time of Brain Death (HH/MM) |__|_|/|__|_|

Retrieval Hospital _____

Date of Cross Clamp (DD/MON/YYYY) |__|_|/|__|_|/|__|_|_|_|_| (Cross clamp date is the same as the date of organ retrieval)

Cross Clamp Time (HH/MM) |__|_|/|__|_|



Donor Number: _____

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 BcAb P @ N @ U @ HIV P @ N @ U @
 Hepatitis C P @ N @ U @ CMV P @ N @ U @
 HTLV type I & II (Human T-Cell Lymphotropic Virus) P @ N @ U @
 Donor HLA A _____ B _____ DR _____ DQ _____

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 @

SECTION D—ADDITIONAL ORGAN INFORMATION – Heart Donors only (please complete the following):

Inotropes at Time of Retrieval (check all that apply and the dosage):

@ Digoxin -> @ High Dose @ Dobutamine -> @ High Dose @ Dopamine -> @ High Dose
 @ Amrinone -> @ High Dose @ Milrinone -> @ High Dose @ Epinephrine -> @ High Dose
 @ Nor-epinephrine--> @ High Dose @ Isoproterenol -> @ High Dose @ Phenylephrine -> @ High Dose
 @ Vasopressin -> @ High Dose @ Other (specify): _____ -> @ High Dose
 Echo Assessment: @ 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.)
 Organ(s) Retrieved @ Yes @ No If no, indicate reason _____

CODES—Reasons Donors or Organs not Used

01 No consent for a particular organ	04 Medical reasons (stability, infection, etc.)
02 No recipient (No suitability matched recipient)	98 Unknown/not available
03 Team/hospital logistics (team, hospital, transplantation resource issues)	99 Other reason: specify _____

Donor Organ	Retrieved	Transplanted	Reason not transplanted (codes above)	Organ sent to: (Indicate hospital or program)	Recipient Name (Indicate if known)
Double Kidney/Enbloc	@ Yes @ No	@ Yes @ No	_____	_____	_____
Kidney Rt.	@ Yes @ No	@ Yes @ No	_____	_____	_____
Kidney Lt.	@ Yes @ No	@ Yes @ No	_____	_____	_____
Heart	@ Yes @ No	@ Yes @ No	_____	_____	_____
Liver (whole organ)	@ Yes @ No	@ Yes @ No	_____	_____	_____
Liver Rt. lobe	@ Yes @ No	@ Yes @ No	_____	_____	_____
Liver Lt. lobe	@ Yes @ No	@ Yes @ No	_____	_____	_____
Liver Lateral Segment	@ Yes @ No	@ Yes @ No	_____	_____	_____
Pancreas—whole	@ Yes @ No	@ Yes @ No	_____	_____	_____
Pancreas—segment	@ Yes @ No	@ Yes @ No	_____	_____	_____
Pancreas—islet cells	@ Yes @ No	@ Yes @ No	_____	_____	_____
Heart-Lung	@ Yes @ No	@ Yes @ No	_____	_____	_____
Double Lungs/Enbloc	@ Yes @ No	@ Yes @ No	_____	_____	_____
Lung Rt.	@ Yes @ No	@ Yes @ No	_____	_____	_____
Lung Lt.	@ Yes @ No	@ Yes @ No	_____	_____	_____
Bowel	@ Yes @ No	@ Yes @ No	_____	_____	_____
Cluster (liver, sm. bowel, pancreas, stomach)	@ Yes @ No	@ Yes @ No	_____	_____	_____
Other multi-organ enbloc Retrieval (specify organs): _____	@ Yes @ No	@ Yes @ No	_____	_____	_____



Canadian Organ Replacement Register Heart Transplant Recipient Registration Form

SEND THIS CONFIDENTIAL INFORMATION TO:
Canadian Organ Replacement Register (CORR)
Canadian Institute for Health Information
90 Eglinton Avenue East, Suite 300
Toronto, ON M4P 2Y3
Tel: (416) 481-2002 / FAX: (416) 481-2950



SECTION A—RECIPIENT INFORMATION

Transplant Hospital _____
NAME AND CITY

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 Sub-continent

08 @ Pacific Islander 09 @ Aboriginal 10 @ Mid East/Arabian

98 @ Unknown 99 @ Other/Multiracial (specify) _____

Date of Birth |__|_|/|__|_|/|__|_| (DD/MON/YYYY)

Health Card Number _____

Prov. of Health Card _____

Address (City) _____

Province _____ Postal Code _____

(At time of transplant)

Recipient Height @ @ @ ● @ @ @ (cm)
(Conversion Factor: 1 inch=2.54 cm)

Recipient Weight @ @ @ ● @ @ @ (kg)
(Conversion Factor: 1lb = 0.45 kg)

SECTION B—TRANSPLANT INFORMATION (CONTINUED)

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)

08 @ Status 1—At Home

04 @ Status 2—Hospitalized

13 @ Status 3A—Hospitalized ICU or inotropes or less than 6 mos of age

14 @ Status 3B—Hospitalized ICU or inotropes or less than 6 mos of age, with rapid deterioration

06 @ Status 4—ICU-mechanical/ventilatory support

Date of Transplant |__|_|/|__|_|/|__|_| (DD/MON/YYYY)

@ Heart Transplant only OR @ Combination Transplant

Specify other organ(s) _____

(Please complete section B of relevant Transplant Recipient Registration Form for other organ(s).)

Primary Diagnosis (check one)

32 @ · Cardiomyopathy

29 @ · Dilated Cardiomyopathy

 01 @ · Idiopathic Cardiomyopathy

 30 @ · Other Dilated (please specify)

 33 @ · Metabolic/Genetic Cardiomyopathy

 34 @ · Cardiomyopathy related to muscular dystrophy

 35 @ · Drug-induced Cardiomyopathy (chemotherapy)

12 @ · Restrictive Cardiomyopathy

31 @ · Hypertrophic Cardiomyopathy

24 @ · Myocarditis

07 @ · Coronary Artery Disease (Ischemic Cardiomyopathy)

04 @ · Valvular Heart Disease

23 @ · Acute Myocardial Infarct

15 @ · Congenital Heart Disease (please specify)

36 @ · Metabolic disorders

37 @ · Cardiac Tumour

38 @ · Refractive arrhythmia

39 @ · Muscular Dystrophy

99 @ · Other (please specify) _____

.....@ · Retransplant

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 mos of age

14 @ Status 3B—Hospitalized ICU or inotropes or less than 6 mos of age, with rapid deterioration

06 @ Status 4—ICU-mechanical/ventilatory support

15 @ In utero



SECTION B—TRANSPLANT INFORMATION (CONTINUED)

Recipient Serology Status
 (Please check one of the acceptable values of "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 @

Current Cytotoxic AB level _____ % Peak Cytotoxic AB level _____ %

PVR: Reactive @ Non Reactive @
 PVR (Woods Units): <4 @ 4-6 @ >6 @ Not done @

Standard Crossmatch Test P @ N @ U @

*Recipient HLA A _____ B _____ DR _____ DQ _____

*Note: CORR enters the lowest haplotype first.

Graft Number: _____ Heterotopic transplant Y @ N @ U @

Risk Factors Existing at Time of Transplant
 (Please check one of the acceptable values of "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 @
 Hypercholesterolaemia 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 device(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 Ischaemic Time (min) _____
 (time between clamp on in donor and clamp off in recipient)

SECTION C—DONOR INFORMATION

12 @ Domino Donor 01 @ Cadaveric Donor

To facilitate matching, please complete the following:
 Program organizing Organ Retrieval: _____
 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 _____ DR _____ DQ _____

*Note: CORR enters the lowest haplotype first.

SECTION D—RECIPIENT OUTCOME

Complete this section at the time this transplant is registered, usually within one month of the transplant date. This section may also be used for follow-up when there is a patient death, graft failure or the patient is being followed at another hospital.

Hospital followed at: _____
 (enter only if different than transplant hospital)

Patient Status (Please check one):
 Patient Alive @ Died @ Lost to follow-up @

Date of death/lost to follow-up/hospital transfer
 |_|_|/|_|_|/|_|_| (DD/MON/YYYY)

If deceased: (Please check one of the following and enter causes of death.)
 @ Died with a functioning graft

OR
 @ Died due to graft failure (Check cause of graft failure below)

Enter cause of death 1° _____ 2° _____ 3° _____ 4° _____
 (code on back of page)
 (secondary causes are co-factors or comorbid complications)

If alive with failed graft or died due to graft failure (date of graft failure is defined as death or date of retransplant)

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

Check cause of graft failure below:

00 @ Uncertain/Unknown	01 @ Hyperacute Rejection
11 @ Primary Non-Function	68 @ Infection and Rejection
19 @ Graft Coronary Artery Disease	30 @ Rejection After Stopping Immunosuppressive Drugs
23 @ Vascular Event (graft)	63 @ Acute Rejection
25 @ Pulmonary Hypertension/Cor pulmonale	64 @ Chronic Rejection
28 @ Surgical Complications	66 @ Rejection Secondary to Non-Compliance
67 @ Recurrent primary disease	69 @ Infection of Graft
70 @ Systemic Hypertension	
71 @ Electrolyte Disturbance (Please specify) _____	
72 @ Pericarditis	
73 @ Pericardial Effusion	
99 @ Other Cause of Graft Failure (describe) _____	

CAUSE OF DEATH/COMORBID COMPLICATION (RECIPIENT)

Generic

00 Cause of death uncertain/not determined

Cardiac

11 Myocardial ischaemia and infarction
12 Hyperkalaemia
13 Haemorrhagic pericarditis
14 Other causes of cardiac failure
15 Cardiac arrest, cause unknown
16 Hypertensive cardiac failure
17 Hypokalaemia
18 Fluid overload

Vascular

21 Pulmonary embolus
22 Cerebrovascular accident
24 Haemorrhage from graft site—specify
25 Haemorrhage from vascular access or dialysis circuit
26 Haemorrhage from ruptured vascular aneurysm (not codes 22–23)
27 Haemorrhage from surgery (not codes 23–26)—specify
28 Other haemorrhage (not codes 23–27)
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 41–42)
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

Gastro-Intestinal

02 Gastro-intestinal tumour with or without perforation
20 Acute gastroenteritis with dehydration
23 Gastro-intestinal haemorrhage
29 Mesenteric infarction
62 Pancreatitis
68 Perforation of peptic ulcer
70 Sclerosing (or adhesive) peritoneal disease
72 Perforation of colon

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
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 Uraemia 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

Canadian Organ Replacement Register Kidney Transplant Recipient Registration Form

SEND THIS CONFIDENTIAL INFORMATION TO:

Canadian Organ Replacement Register (CORR)
Canadian Institute for Health Information
90 Eglinton Avenue East, Suite 300
Toronto, ON M4P 2Y3
Tel: (416) 481-2002 / FAX: (416) 481-2950



SECTION A—RECIPIENT INFORMATION

Transplant Hospital _____
NAME AND CITY

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 Sub-continent
08 Pacific Islander 09 Aboriginal 10 Mid East/Arabian
98 Unknown 99 Other/Multiracial _____

Date of Birth |__|_|/|__|_|/|__|_|_|_| (DD/MON/YYYY)

Health Card Number _____

Prov. of Health Card _____

Address (City) _____

Province _____ 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 of "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

Current Cytotoxic AB level _____% Peak Cytotoxic AB level _____%

*Recipient HLA A _____ B _____ 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) Re-transplant

Describe _____

Diagnosis at time of First Treatment

Code _____ (see codes on back of form)

Describe _____

Donor Organ Kidney Kidney Right Kidney Left

Laparoscopic nephrectomy used? Y N U

(At time of transplant) Recipient Height _____ (cm)
(Conversion Factor: 1 inch = 2.54 cm)

Recipient Weight _____ (kg)
(Conversion Factor: 1 lb=0.45 kg)

Was patient on dialysis 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 of "Y=Yes", "N=No" or "U=Unknown")

Angina	Y <input type="checkbox"/> N <input type="checkbox"/> U <input type="checkbox"/>	Peripheral Vascular Disease	Y <input type="checkbox"/> N <input type="checkbox"/> U <input type="checkbox"/>
Malignancy	Y <input type="checkbox"/> N <input type="checkbox"/> U <input type="checkbox"/>	Previous Myocardial Infarct	Y <input type="checkbox"/> N <input type="checkbox"/> U <input type="checkbox"/>
Pulmonary Edema	Y <input type="checkbox"/> N <input type="checkbox"/> U <input type="checkbox"/>	Chronic Obstr. Lung Disease	Y <input type="checkbox"/> N <input type="checkbox"/> U <input type="checkbox"/>
Diabetes Type 1	Y <input type="checkbox"/> N <input type="checkbox"/> U <input type="checkbox"/>	Diabetes Type 2	Y <input type="checkbox"/> N <input type="checkbox"/> U <input type="checkbox"/>
Hypertension	Y <input type="checkbox"/> N <input type="checkbox"/> U <input type="checkbox"/>	Prev. Cerebrovascular Accident	Y <input type="checkbox"/> N <input type="checkbox"/> U <input type="checkbox"/>

Cold Ischaemic Time _____ (min)

SECTION C—DONOR INFORMATION

Living → Please complete a Living Donor Profile and attach to this form.

12 Domino Donor 01 Cadaveric Donor

To facilitate matching, please complete the following:

Program organizing Organ Retrieval: _____

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 _____ DR _____ DQ _____
*Note: CORR enters the lowest haplotype first.

SECTION D—RECIPIENT OUTCOME

Complete this section at the time this transplant is registered, usually within one month of the transplant date. This section may also be used for follow-up when there is a patient death, graft failure or the patient is being followed at another hospital.

Hospital followed at: _____
(enter only if different than transplant hospital)

Patient Status (Please check one):

Patient Alive Died Lost to follow-up

Date of death/lost to follow-up/hospital transfer:

|_|_|_|/|_|_|_|_|/|_|_|_|_|_| (DD/MON/YYYY)

If deceased:

Died with functioning graft.

OR

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

Enter cause of death _____ (code on back of page)

If alive with failed graft or died due to graft failure (date of graft failure is defined as death or date of retransplant):

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

Check cause of graft failure below:

- | | |
|---|---|
| 00 <input type="checkbox"/> Uncertain/Unknown | 69 <input type="checkbox"/> Infection of Graft |
| 01 <input type="checkbox"/> Hyperacute Rejection | 11 <input type="checkbox"/> Primary Non-Function |
| 63 <input type="checkbox"/> Acute Rejection | 18 <input type="checkbox"/> De Novo Malignancy (graft) |
| 64 <input type="checkbox"/> Chronic Rejection | 23 <input type="checkbox"/> Vascular Thrombosis (graft) |
| 30 <input type="checkbox"/> Rejn after Stopping Drugs | 26 <input type="checkbox"/> Vascular Operative Problems |
| 67 <input type="checkbox"/> Recurrent Disease | 27 <input type="checkbox"/> Ureteric Operative Problems |
| 68 <input type="checkbox"/> Infection and Rejection | 28 <input type="checkbox"/> Surgical Complications |
| 36 <input type="checkbox"/> Cyclosporin Toxicity | 99 <input type="checkbox"/> Other Cause of Graft Failure (describe) |

PRIMARY RENAL DIAGNOSIS

CODE DESCRIPTION

00 Chronic renal failure, aetiology uncertain

Glomerulonephritis/Autoimmune Diseases

- 05 Mesangial proliferative glomerulonephritis
- 06 Minimal lesion glomerulonephritis
- 07 Post-strep glomerulonephritis
- 08 Rapidly progressive glomerulonephritis
- 09 Focal glomerulonephritis—adults
- 10 Glomerulonephritis, histologically not examined
- 11 Severe nephrotic syndrome with focal sclerosis (paediatric patients only)
- 12 IgA nephropathy (proven by immunofluorescence (not code 85)
- 13 Dense deposit disease (proven immunofluorescence and/or electron microscopy) (MPGN type II)
- 14 Membranous nephropathy
- 15 Membranoproliferative glomerulonephritis (MGPn type I)
- 16 Idiopathic crescentic glomerulonephritis (diffuse proliferative)
- 17 Congenital nephrosis or congenital nephrotic syndrome (paediatric only)
- 19 Glomerulonephritis, histologically examined—specify
- 73 Polyarteritis
- 74 Wegener's Granulomatosis
- 84 Lupus Erythematosus
- 85 Henoch-Schonlein Purpura
- 86 Goodpasture's Syndrome
- 87 Scleroderma
- 88 Haemolytic Uraemic Syndrome (Moschowitz Syndrome)

Nephropathy—Drug Induced

- 30 Nephropathy caused by drugs or nephrotoxic agents—cause not specified
- 31 Nephropathy due to analgesic drugs
- 32 Nephropathy due to cisplatin
- 33 Nephropathy due to Cyclosporin A
- 39 Nephropathy caused by other specific drug—specify

Polycystic Kidneys

- 41 Polycystic kidneys, adult type (dominant)
- 42 Polycystic kidneys, infantile and juvenile types (recessive)

Diabetes

- 80 Diabetic nephropathy associated with Type 1
- 81 Diabetic nephropathy associated with Type 2

CODE DESCRIPTION

Congenital/Hereditary Renal Diseases

- 21 Pyelonephritis/Interstitial nephritis associated with neurogenic bladder
- 22 Pyelonephritis/Interstitial nephritis due to congenital obstructive uropathy with or without vesico-ureteric reflux
- 24 Pyelonephritis/Interstitial nephritis due to vesico-ureteric reflux without obstruction
- 40 Cystic kidney disease, type unspecified
- 41 Polycystic kidneys, adult type (dominant)
- 42 Polycystic kidneys, infantile and juvenile type (recessive)
- 43 Medullary cystic disease, including nephronophthisis
- 49 Cystic kidney disease, other specified type—specify
- 50 Hereditary/familial nephropathy—type unspecified
- 51 Hereditary nephritis with nerve deafness (Alport's Syndrome)
- 52 Cystinosis
- 53 Primary Oxalosis
- 54 Fabry's Disease
- 55 Drash Syndrome
- 58 Posterior Urethral Valves
- 59 Hereditary nephropathy, other—specify
- 60 Congenital renal hypoplasia—specify
- 61 Oligomeganephronic hypoplasia
- 62 Segmental renal hypoplasia (Ask-Upmark kidney)
- 63 Congenital renal dysplasia with or without urinary tract malformation
- 66 Syndrome of agenesis of abdominal muscles (Prune Belly Syndrome)

Renal Vascular Disease

- 70 Renal vascular disease—type unspecified
- 71 Malignant hypertension (no primary renal disease)
- 72 Renal vascular disease due to hypertension (no primary renal disease)
- 73 Polyarteritis Nodosa
- 78 Atheroembolic renal disease
- 79 Renal vascular disease, classified

Other

- 20 Pyelonephritis/interstitial nephritis, cause not specified
- 23 Pyelonephritis/interstitial nephritis due to acquired obstructive uropathy—specify
- 25 Pyelonephritis/interstitial nephritis due to urolithiasis
- 29 Pyelonephritis, other causes
- 56 Sickle cell nephropathy
- 57 Wilms' tumour
- 82 Multiple Myeloma
- 83 Amyloid
- 89 Multi-System Disease, other—specify
- 90 Cortical or acute tubular necrosis
- 91 Tuberculosis
- 92 Gout
- 93 Nephrocalcinosis and hypercalcaemic nephropathy
- 94 Balkan nephropathy
- 95 Kidney tumour
- 96 Traumatic or surgical loss of kidney
- 97 HIV Nephropathy
- 99 Other identified renal disorders—specify

CAUSE OF DEATH/COMORBID COMPLICATION (RECIPIENT)

Generic

00 Cause of death uncertain/not determined

Cardiac

11 Myocardial ischaemia and infarction
12 Hyperkalaemia
13 Haemorrhagic pericarditis
14 Other causes of cardiac failure
15 Cardiac arrest, cause unknown
16 Hypertensive cardiac failure
17 Hypokalaemia
18 Fluid overload

Vascular

21 Pulmonary embolus

22 Cerebrovascular accident
24 Haemorrhage from graft site—specify
25 Haemorrhage from vascular access or dialysis circuit
26 Haemorrhage from ruptured vascular aneurysm (not codes 22–23)
27 Haemorrhage from surgery (not codes 23–26)—specify
28 Other haemorrhage (not codes 23–27)
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 41–42)
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

Gastro-Intestinal

02 Gastro-intestinal tumour with or without perforation
20 Acute gastroenteritis with dehydration
23 Gastro-intestinal haemorrhage
29 Mesenteric infarction
62 Pancreatitis
68 Perforation of peptic ulcer
70 Sclerosing (or adhesive) peritoneal disease
72 Perforation of colon

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
31 Pulmonary infection (bacterial)
32 Pulmonary infection (viral)
33 Pulmonary infection (fungal)
49 Bronchiolitis Obliterans

Renal Disease

47 Acute renal failure (non-renal patients)
48 Chronic renal failure (non-renal patients)
61 Uraemia 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



Canadian Organ Replacement Register Renal Transplant Facility Profile



Reporting Year 2004

Please complete this form to reflect the situation in your facility at December 31, 2004. Please keep a copy for your records.

SEND THIS CONFIDENTIAL INFORMATION TO:	Canadian Organ Replacement Register Canadian Institute for Health Information 90 Eglinton Avenue East Suite 300 Toronto, Ontario, M4P 2Y3 Fax : (416) 481-2950 Tel. : (416) 481-2002
---	--

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

A. ANNUAL TRANSPLANTS

1. How many kidney transplants were performed in at your hospital in 2004? <i>(Note: Please include kidney combinations such as kidney-pancreas or kidney-liver transplants.)</i>	Adult Pts (18 +)	Paediatric Pts (Under 18)
a) Cadaveric Donor	_____	_____
b) Living related Donor	_____	_____
c) Living unrelated	_____	_____

2. How many kidney combination transplants were performed at your hospital in 2004?	Adult Pts (18 +)	Paediatric Pts (Under 18)
	_____	_____

B. FOLLOW-UP
(Note please include all patients transplanted during or before 2004.)

3. How many patients alive with a functioning transplant, regardless of where they were transplanted, were being followed at your hospital on December 31 st ? (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 2004?	_____
5. How many transplant patients followed at your hospital died in 2004:	
a) With a functioning graft?	_____
b) With a failed graft (i.e. did not return to dialysis)?	_____

Completed by _____ Date _____

Print Name: _____ Tel.: _____

Name of contact person if different from above _____ Tel.: _____

We thank you for filling out this questionnaire, please take a few minutes and ensure all questions are answered.

Canadian Organ Replacement Register Liver Transplant Recipient Registration Form

SEND THIS CONFIDENTIAL INFORMATION TO:
Canadian Organ Replacement Register (CORR)
Canadian Institute for Health Information
90 Eglinton Avenue East, Suite 300
Toronto, ON M4P 2Y3
Tel: (416) 481-2002 / FAX: (416) 481-2950



SECTION A—RECIPIENT INFORMATION

Transplant Hospital _____
NAME AND CITY

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 Sub-continent
08 @ Pacific Islander 09 @ Aboriginal 10 @ Mid East/Arabian
98 @ Unknown 99 @ Other/Multiracial _____

Date of Birth |__|_|/|__|_|/|__|_| (DD/MON/YYYY)

Health Card Number _____

Prov. of Health Card _____

Address (City) _____

Province _____ Postal Code _____

(At time of transplant)

Recipient Height @ @ @ ● @ @ @ (cm)
(Conversion Factor: 1 inch=2.54 cm)

Recipient Height @ @ @ ● @ @ @ (kg)
(Conversion Factor: 1lb = 0.45 kg)

SECTION B—TRANSPLANT INFORMATION (CONTINUED)

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

08 @ Status 1 (at home) 16 @ Status 1T (tumour patient)
04 @ Status 2 (hospitalized) 05 @ Status 3 (hospitalized ICU)
11 @ Status 3F (fulminant) 06 @ Status 4 (ICU-incubated and ventilated)
12 @ Status 4F (fulminant)

Date of Transplant |_|_|/|_|_|/|_|_| (DD/MON/YYYY)
@ Liver Transplant OR @ Combination Transplant

Specify other organ(s): _____
(Please complete Section B relevant Transplant Registration Form for other organ(s).)

Liver Diagnosis: (see page 3)
1 _____ 2 _____ 3 _____ 4 _____ @ Retransplant

Describe _____

RECIPIENT SEROLOGY
Please check one of the acceptable values of "P=Positive", N="Negative" or U="Unknown"

Hepatitis B

Hepatitis BsAg P @ N @ U @ Hepatitis BcAb P @ N @ U @
Hepatitis B-DNA P @ _____(pg/ml) N @ U @
Treatment at time of transplant N @ Y @ *Check one:*
Interferon @
Lamivudine @
Other (specify): _____

Hepatitis C

Hepatitis C P @ N @ U @ (If "N", skip to Epstein Barr Virus flag below.)
RNA detectable? @ No @ Yes @ *Specify 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 P @ N @ U @
CMV P @ N @ U @
HIV P @ N @ U @
Current Cytotoxic AB level _____% Peak Cytotoxic AB level _____%
Standard Crossmatch Test P @ N @ U @

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

SECTION B—TRANSPLANT 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) 16 @ Status 1T (tumour patient)
04 @ Status 2 (hospitalized) 05 @ Status 3 (hospitalized ICU)
11 @ Status 3F (fulminant) 06 @ Status 4 (ICU-incubated and ventilated)
12 @ Status 4F (fulminant)



SECTION B—TRANSPLANT INFORMATION (CONTINUED)

Graft Number: _____

Child-Pugh Score at transplant: |__|_|_| Creatinine at transplant |__|_|_|_|

Total Serum Bilirubin at transplant (µmol/L): |__|_|_|_| INR at transplant: |__|_|_|_|

Split or Reduction Technique

Liver Reduction (one recipient) Y N U

Split Liver (two recipients) Y N U

Technique: In-situ Ex-situ Combination

Yes (complete shaded section)

Primary and Metastatic Tumours in the Liver?

No (skip shaded section)

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

Tumor Markers (ng/ml); Alpha-fetoprotien: _____

Chorioembryonic Antigen (CEA): _____

Number of Nodules: _____ Diameter of largest (cm): _____

Bilobar: Yes No Characteristics: Multifocal Single

Histologic Grade: _____ System Used: _____

Vascular Involvement: Yes No

Spread at Surgery: None Periaortic Lungs, Mediastinum

Diaphragm Abdomen, Other Hilar Nodes

Adjunct Tumor Therapy

Therapy	Pre-op		Intra-op		Post-op		Specify Agent (where applicable)
Embolization	Y	N					
Irradiation	Y	N	Y	N	Y	N	
Other Treatment	Y	N	Y	N	Y	N	
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	

Warm Ischemic Time (min): |__|_|_|_| Cold Ischemic Time (min): |__|_|_|_|

Rewarm Time (min): |__|_|_|_|

SECTION C—DONOR INFORMATION

Living → Please complete a Living Donor Profile and attach to this form.

12 Domino Donor 01 Cadaveric Donor

To facilitate matching, please complete the following.

Program organizing Organ Retrieval: _____

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 _____ DR _____ DQ _____

*Note: CORR enters the lowest haplotype first.

SECTION D—RECIPIENT OUTCOME

Complete this section at the time this transplant is rejected, usually within one month of the transplant date. This section may also be used for follow-up when there is a patient death, graft failure or the patient is being followed at another hospital.

Hospital followed at: _____

(enter only if different than transplant hospital)

Patient Status (Please check one):

Patient Alive Died Lost to follow-up

Date of death/lost to follow-up/hospital transfer :
|_|_|_|/|_|_|_|/|_|_|_|_|_| (DD/MON/YYYY)

If deceased:

Died with functioning graft

OR

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

Enter cause of death _____ (code on back of page)

If alive with failed graft or died due to graft failure (date of graft failure is defined as death or date of retransplant):

Date of Graft Failure |_|_|_|/|_|_|_|/|_|_|_|_|_| (DD/MON/YYYY)

Codes—Causes of Graft Failure

00 Uncertain/Unknown

01 Hyperacute Rejection

63 Acute Rejection

64 Chronic Rejection

30 Rejection after stopping Immunosuppressive drugs

67 Recurrent Disease

68 Infection and Rejection

69 Infection of Graft

11 Primary non-function

14 Graft/Portal Vein Thrombosis

15 Graft/Hepatic Vein Thrombosis

16 Biliary Tract Complication

18 De Novo Malignancy

22 Arterial Thrombosis

28 Surgical complications—not specified

33 De Novo Hepatitis

99 Other Cause of Graft Failure (describe) _____

Codes—Primary Liver Diagnosis**ACUTE HEPATIC FAILURE (Fulminant)**

- 01 Hepatitis—Type A
- 02 Hepatitis—Type B
- 61 Hepatitis—Type C
- 58 Hepatitis—Type Non A,B,C
- 35 Hepatitis with Delta
- 05 Toxic
- 04 Drug Induced—Other
- 56 Drug Induced—Acetaminophen
- 47 Other/Fulminant Hepatic Failure (Including Budd Chiari and Wilson’s Disease)

CHRONIC HEPATIC FAILURE

- 12 Budd-Chiari
- 36 Byler’s Disease (Intra-Hepatic Cholestasis)
- 09 Cirrhosis—Alcoholic
- 10 Cirrhosis—Other
- 08 Cryptogenic Cirrhosis
- 49 Post-necrotic Cirrhosis
- 07 Primary Biliary Cirrhosis
- 14 Secondary Biliary Cirrhosis
- 45 Drug Induced—Other
- 42 Hepatitis—Type A
- 43 Hepatitis—Type B
- 60 Hepatitis—Type C
- 59 Hepatitis—Type Non A,B,C
- 51 Neonatal Hepatitis
- 06 Autoimmune Chronic Active Hepatitis
- 13 Primary Biliary Atresia
- 11 Sclerosing Cholangitis
- 46 Toxic
- 15 Watson-Alagille Disease (Arterio-Hepatic Dysplasia)
- 62 Polycystic—Liver Disease
- 64 Non-alcoholic steatohepatitis (NASH)

HEPATIC TUMOURS

- 50 Angiosarcoma
- 17 Cholangiocarcinoma
- 18 Fibrolamellar Hepatoma
- 16 Hepatocellular Carcinoma
- 19 Metastatic Tumour
- 53 Hepatic Tumour—Other

METABOLIC DISORDERS

- 20 Alpha I Anti-Trypsin Deficiency
- 28 Crigler-Najjar Syndrome
- 21 Glycogen Storage Disease
- 23 Haemochromatosis
- 27 Hyperlipoproteinemia Type 2
- 24 Niemann-Pick
- 26 Phenylketonuria
- 25 Protoporphyrin
- 29 Tyrosinemia
- 22 Wilson’s Disease
- 34 Metabolic Disorder—Other

OTHER PRIMARY DIAGNOSIS

- 30 Congenital Hepatic Fibrosis
- 31 Caroli’s Disease
- 32 Cystic Disorders
- 52 Thrombosed Hepatic Artery
- 98 Unknown/Missing
- 99 Other (Specify) _____

CAUSE OF DEATH/COMORBID COMPLICATION (RECIPIENT)**GENERIC**

- 00 Chronic renal failure—aetiology uncertain

CARDIAC

- 11 Myocardial ischaemia and infarction
- 12 Hyperkalaemia
- 13 Haemorrhagic pericarditis
- 14 Other causes of cardiac failure
- 15 Cardiac arrest, cause unknown
- 16 Hypertensive cardiac failure
- 17 Hypokalaemia
- 18 Fluid overload

VASCULAR

- 21 Pulmonary embolus
- 22 Cerebrovascular accident
- 24 Haemorrhage from graft site—specify
- 25 Haemorrhage from vascular access or dialysis Circuit
- 26 Haemorrhage from ruptured vascular aneurysm (not codes 22-23)
- 27 Haemorrhage from surgery (not codes 23–26)—specify
- 28 Other haemorrhage (not codes 23–27)
- 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 41–42)
- 35 Septicemia/Sepsis—specify source
- 36 Tuberculosis (Lung)
- 37 Tuberculosis (elsewhere)
- 38 Generalized viral infection—specify viral agent
- 39 Peritonitis (not Code 70)

GASTRO-INTESTINAL

- 02 Gastro-intestinal tumour with or without perforation
- 20 Acute gastroenteritis with dehydration
- 23 Gastro-intestinal haemorrhage
- 29 Mesenteric infarction
- 62 Pancreatitis
- 68 Perforation of peptic ulcer
- 70 Sclerosing (or adhesive) peritoneal disease
- 72 Perforation of colon

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
- 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 Uraemia 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

Canadian Organ Replacement Register Liver Transplant Follow-up Form

SEND THIS CONFIDENTIAL INFORMATION TO:
 Canadian Organ Replacement Register (CORR)
 Canadian Institute for Health Information
 90 Eglinton Avenue East, Suite 300
 Toronto, ON M4P 2Y3
 Tel: (416) 481-2002 / FAX: (416) 481-2950



SECTION A—RECIPIENT INFORMATION

Transplant Hospital _____
NAME AND CITY

Health Card Number _____

Prov. of Health Card _____

Last Name _____ First/Middle Name _____

Former Name _____

Address (City) _____

Province _____ Postal Code _____

Date of Birth |__|__|/|__|__|/|__|__|__|__| (DD/MM/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 31st of each year or at time of death.

Recurrent disease: @ No @ Yes à 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/MM/YYYY)

Detectable HBV DNA: @ Yes @ No @ Not done in calendar year

Current therapy: H-Blg @ 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 31st of each year or at time of death.

Recurrent disease: @ No @ Yes à 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/MM/YYYY)

Receiving treatment during this calendar year: @ No @ Yes à 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 31st of each year or at time of death.

Current Status of patient- recurrence of tumour:

@ No @ Yes à *If yes, please complete the following or send CORR a copy of form from The International Registry of Hepatic Tumours in Liver Transplantation (Baylor University Medical Center).*

Date of Recurrence: |__|__|/|__|__|/|__|__|__|__| (DD/MM/YYYY)

Tumour Markers (at the time of recurrence):

@ Alpha-fetoprotein _____ ng/ml

@ Chorioembryonic Antigen _____ ng/ml

First Site of Recurrence:

@ Liver @ Mediastinum @ Abdomen @ Lungs

@ Adrenal @ Biopsy Tract @ Bone @ Other

Treatment: _____

Retransplantation:

@ No @ Yes à Date |__|__|/|__|__|/|__|__|__|__| (DD/MM/YYYY)

Outcome:

@ Alive free of tumour @ Alive with tumour

@ Died free of tumour @ Died with tumour à Was death tumour related?

@ No

@ Yes

Canadian Organ Replacement Register Living Donor Profile

SEND THIS CONFIDENTIAL INFORMATION TO:
 Canadian Organ Replacement Register (CORR)
 Canadian Institute for Health Information
 90 Eglinton Avenue East, Suite 300
 Toronto, ON M4P 2Y3
 Tel: (416) 481-2002 FAX: (416) 481-2950



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

SECTION A—DONOR INFORMATION

Donor type:

Living Biologically Related

03 sibling 05 other relative (e.g. mother's sister)

02 parent 04 offspring

Living Biologically Unrelated

07 spouse 06 other living unrelated (e.g. in-law), anonymous
 specify: _____

Transplant Program: _____

Program's donor code: _____

Donor last name stem: _____

Province/State of Residence: _____

If not from Canada, country of residence: _____

Age: _____ Years

Sex: male female other

Race

01 Caucasian 02 Asian 03 Black 05 Indian Sub-continent

08 Pacific Islander 09 Aboriginal 10 Mid East /Arabian

98 Unknown 99 Other/Multiracial _____

Height • (cm)
 (Conversion Factor: 1 inch = 2.54 cm)

Weight • (kg)
 (Conversion Factor: 1 lb=0.45 kg)

SECTION B—HOSPITAL INFORMATION

Date of admission |__|_|/|__|_|/|__|_|_|_|_| (DD/MON/YYYY)

Date of cross clamp |__|_|/|__|_|_|_|_|_|_|_|_| (DD/MON/YYYY)

Time of cross clamp |__|_|/|__|_| (HH/MM)

SECTION C—DONOR SEROLOGY & RISK FACTORS

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 BcAb P N U HIV P N U

Hepatitis C P N U CMV P N U

HTLV type I & II (Human T-Cell Lymphotropic Virus) P N U

*Donor HLA A _____ B _____ DR _____ DQ _____

*Note: CORR enters the lowest haplotype first.

Donor Risk Factors:

(Check those that apply by answering: 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 Retrieved

Donor Organ

11 Kidney left 23 Liver lateral segment

12 Kidney right 41 Lung left lobe

21 Liver left lobe 42 Lung right lobe

22 Liver right lobe

Recipient Last Name _____

Recipient Date of Birth |__|_|/|__|_|/|__|_|_|_|_| (DD/MON/YYYY)

Canadian Organ Replacement Register Lung/Heart-Lung Transplant Recipient Registration Form

SEND THIS CONFIDENTIAL INFORMATION TO:
Canadian Organ Replacement Register (CORR)
Canadian Institute for Health Information
90 Eglinton Avenue East, Suite 300
Toronto, ON M4P 2Y3
Tel: (416) 481-2002 / FAX: (416) 481-2950



SECTION A—RECIPIENT INFORMATION

Transplant Hospital _____
NAME AND CITY

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 Sub-continent
08 @ Pacific Islander 09 @ Aboriginal 10 @ Mid East/Arabian
98 @ Unknown 99 @ Other/Multiracial _____

Date of Birth |__|_|/|__|_|/|__|_| (DD/MON/YYYY)

Health Card Number _____

Prov. of Health Card _____

Address (City) _____

Province _____ Postal Code _____

(At time of transplant)

Recipient Height @ @ @ .@ @ @ (cm)
(Conversion Factor: 1 inch=2.54 cm)

Recipient Weight @ @ @ .@ @ @ (kg)
(Conversion Factor: 1lb = 0.45 kg)

SECTION B—TRANSPLANT INFORMATION (CONTINUED)

Date of Transplant |__|_|/|__|_|/|__|_| (DD/MON/YYYY)

Graft Number: _____

@ Single Lung OR @ Double Lung OR @ Heart-Lung

@ Other combination transplant

Specify other organs(s) _____

(Please complete section B of relevant Transplant Recipient Registration Form for other organs.)

Primary Diagnosis (check one)

08 @ Eisenmenger's Disease
11 @ Idiopathic Pulmonary Fibrosis
19 @ Alpha I Antitrypsin Deficiency
26 @ Sarcoid
13 @ Emphysema
20 @ Cystic Fibrosis
27 @ Inhalation
17 @ Primary Pulmonary Hypertension
22 @ Bronchiectasis
18 @ Chronic Obstructive Lung Disease
28 @ Bronchiolitis Obliterans
06 @ Drug Toxicity
10 @ Pulmonary Toxins
32 @ Cardiomyopathy (unspecified)
15 @ Lung failure due to congenital disease
99 @ Other (please specify) _____
.....@ Retransplant

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

Recipient Serology Status
(Please check one of the acceptable values of "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 @

Current Cytotoxic AB level _____% Peak Cytotoxic AB level _____%

PVR:
Reactive @ Non Reactive @ PVR (Woods Units): <4 @ 4-6 @ >6 @ Not done @

Standard Crossmatch Test P @ N @ U @

*Recipient HLA: A _____ B _____ 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 of "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 @	Mechanical Ventilation	Y @	N @	U @
Non-Ambulatory Status	Y @	N @	U @	On Anticoagulants	Y @	N @	U @
Other Organ Dysfunction	Y @	N @	U @	Previous Thoracic Surgery	Y @	N @	U @
Multi-Resistant Pathogen	Y @	N @	U @				

SECTION C—DONOR INFORMATION

@ Living ½ Please complete a Living Donor Profile and attach to this form.

12 @ Domino Donor 01 @ Cadaveric Donor

To facilitate matching, please complete the following:

Program organizing Organ Retrieval: _____

Originating OPO Donor Number: _____

Donor @ Rt. Lung @ Lt. Lung @ Heart-lung

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 _____ DR _____ DQ _____

*Note: CORR enters the lowest haplotype first.

SECTION D—RECIPIENT OUTCOME

Complete this section at the time this transplant is registered, usually within one month of the transplant date. This section may also be used for follow-up when there is a patient death, graft failure or the patient is being followed at another hospital.

Hospital followed at: _____

(enter only if different than transplant hospital)

Patient Status (Please check one):

Patient Alive @ Died @ Lost to follow-up @

Date of death/lost to follow-up/hospital transfer

|_|_|/|_|_|/|_|_| (DD/MON/YYYY)

If deceased:

@ Died with a functioning graft.

OR

@ Died due to graft failure (Check cause of graft failure below)

_____ Enter cause of death _____ (see codes on back of page)

SECTION D—RECIPIENT OUTCOME (CONTINUED)**If alive with failed graft or died due to graft failure (date of graft failure is defined as death or date of retransplant)**

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

Check cause of graft failure below:

00 @	Uncertain/Unknown	01 @	Hyperacute Rejection
29 @	Large Airway Complications	18 @	De Novo Malignancy
23 @	Vascular Thrombosis (graft)	63 @	Acute Rejection
24 @	Bronchiolitis Obliterans	25 @	Pulmonary Hypertension/ Cor pulmonale
28 @	Surgical Complication—not specified	11 @	Primary Non-Function/ Reperfusion injury
67 @	Recurrent Disease	68 @	Infection and Rejection
69 @	Infection of Graft	19 @	Graft Coronary Artery Disease
37 @	Acute Respiratory Distress Syndrome	64 @	Chronic Rejection
99 @	Other Cause of Graft Failure (describe) _____		

CAUSE OF DEATH/COMORBID COMPLICATION (RECIPIENT)

Generic

00 Cause of death uncertain/not determined

Cardiac

11 Myocardial ischaemia and infarction
12 Hyperkalaemia
13 Haemorrhagic pericarditis
16 Hypertensive cardiac failure
17 Hypokalaemia
18 Fluid overload

Vascular

21 Pulmonary embolus
22 Cerebrovascular accident
25 Haemorrhage from vascular access or dialysis Circuit
26 Haemorrhage from ruptured vascular aneurysm (not codes 22–23)
27 Haemorrhage from surgery (not codes 23–26)—specify
28 Other haemorrhage (not codes 23–27)
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 41–42)
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

Gastro-Intestinal

02 Gastro-intestinal tumour with or without perforation
20 Acute gastroenteritis with dehydration
23 Gastro-intestinal haemorrhage
29 Mesenteric infarction
62 Pancreatitis
68 Perforation of peptic ulcer
70 Sclerosing (or adhesive) peritoneal disease
72 Perforation of colon

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
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 Uraemia 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

Canadian Organ Replacement Register Pancreas Transplant Recipient Registration Form

SEND THIS CONFIDENTIAL INFORMATION TO:
Canadian Organ Replacement Register (CORR)
Canadian Institute for Health Information
90 Eglinton Avenue East, Suite 300
Toronto, ON M4P 2Y3
Tel: (416) 481-2002 / FAX: (416) 481-2950



SECTION A—RECIPIENT INFORMATION

Transplant Hospital _____
NAME AND CITY

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 Sub-continent
08 @ 'Pacific Islander 09 @ 'Aboriginal 10 @ 'Mid East/Arabian
98 @ 'Unknown 99 @ 'Other/Multiracial _____

Date of Birth |__|__|/|__|__|/|__|__|__|__| (DD/MM/YYYY)

Health Card Number _____

Prov. of Health Card _____

Address (City) _____

Province _____ Postal Code _____

(At time of transplant)
Recipient Height @ @ @ • @ @ @ (cm)
(Conversion Factors: 1 inch=2.54 cm)
Recipient Weight @ @ @ • @ @ @ (kg)
(Conversion Factors: 1lb = 0.45 kg)

SECTION B—TRANSPLANT INFORMATION

Waiting List Information:
Date Patient First Placed on Waiting List
(for this transplant): |__|__|/|__|__|/|__|__|__|__| (DD/MM/YYYY)

Date of Transplant |__|__|/|__|__|/|__|__|__|__| (DD/MM/YYYY)

@ 'Pancreas Transplant Only OR @ 'Combination Transplant

Specify other organ(s) _____

(Please complete Section B of relevant Transplant Recipient Registration Form for other organ(s).)

SECTION B—TRANSPLANT INFORMATION (CONTINUED)

Type of Pancreas

50 @ 'Whole Pancreas 53 @ 'Exocrine Drainage (Enteric)
51 @ 'Segmental—No Polymer Occlusion 54 @ 'Exocrine Drainage (Urinary)
52 @ 'Islet Cells 55 @ 'Wirsung Obstruction with Polymer

Primary Diagnosis for Pancreas Failure (check one)

04 @ 'Cystic Fibrosis 01 @ 'Chronic Pancreatitis 05 @ 'Trauma
02 @ 'Diabetes Type I 06 @ 'Diabetes Type 2
07 @ 'Pancreatic Cancer 08 @ 'Bile Duct Cancer
03 @ 'Pancreatectomy 99 @ 'Other (describe) _____
.....@ Retransplant

Recipient Serology Status at Time of Transplant
(Please check one of the acceptable values of "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 @ '

Current Cytotoxic Antibody Level ____% Peak Cytotoxic Antibody Level ____%

Standard Crossmatch Test P @ ' N @ ' U @ '

*Recipient HLA A _____ B _____ DR _____ DQ _____

*Note: CORR enters the lowest haplotype first

Graft Number: _____

Risk Factors Existing at Time of Transplant:
(Please check one of the acceptable values of "Y=Yes", N=No or "U =Unknown")

Cardiovascular Disease Y @ N @ U @ Has Kidney Failed Y @ N @ U @
Cerebrovascular Disease Y @ N @ U @ Was Dialysis Required Y @ N @ U @
Peripheral Vascular Disease Y @ N @ U @ Diabetic Nephropathy Y @ N @ U @
Diabetic Retinopathy Y @ N @ U @ Diabetic Neuropathy Y @ N @ U @
Family History of Diabetes Y @ N @ U @
No. of Years on Insulin _____
Warm Ischemic Time (min): |__|__|__| Cold Ischemic Time (min): |__|__|__|
Rewarm Time (min): |__|__|__|



SECTION C—DONOR INFORMATION

@ Living è Please complete a Living Donor Profile and attach to this form

12 @ Domino Donor 01 @ Cadaveric Donor

To facilitate matching, please complete the following:

Program organizing Organ Retrieval: _____

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 _____ DR _____ DQ _____

*Note: CORR enters the lowest haplotype first

SECTION D—RECIPIENT OUTCOME

Complete this section at the time this transplant is registered, usually within one month of the transplant date. This section may also be used for follow-up when there is a patient death, graft failure or the patient is being followed at another hospital.

Hospital followed at: _____
(enter only if different than transplant hospital)

Patient Status (Please check one):

Requires Insulin @ Yes @ No

Patient Alive @ Died @ Lost to follow-up @

Date of death/lost to follow-up/hospital transfer |__|_|_|/|__|_|_|/|__|_|_|_|_| (DD/MM/YYYY)

If deceased:

@ Died with functioning graft.

OR

@ Died due to graft failure (Check cause of graft failure below)

Enter cause of death _____ (code on back of page)

If alive with failed graft or died due to graft failure (date of graft failure is defined as death or date of retransplant):

Date of graft failure |__|_|_|/|__|_|_|/|__|_|_|_|_| (DD/MM/YYYY)

Check cause of graft failure below:

- | | |
|--|---|
| 00 @ Uncertain/Unknown | 28 @ Surgical Complications—not specified |
| 01 @ Hyperacute Rejection | 20 @ Pancreatitis |
| 63 @ Acute Rejection | 68 @ Infection and Rejection |
| 64 @ Chronic Rejection | 69 @ Infection of Graft |
| 23 @ Vascular Thrombosis (graft) | 18 @ De Novo Malignancy |
| 67 @ Recurrent Disease | 11 @ Primary Non-Function |
| 99 @ Other Cause of Graft Failure (describe) _____ | |

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 Haemorrhage from graft site—specify
25 Haemorrhage from vascular Access or Dialysis Circuit
26 Haemorrhage from ruptured vascular aneurysm (not code 22–23)
27 Haemorrhage from surgery (not codes 23 or 26)—specify
28 Other haemorrhage (not codes 23–27)
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 41–42)
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

Gastro-Intestinal

02 Gastro-intestinal tumour with or without perforation
20 Acute Gastroenteritis with dehydration
23 Gastro-intestinal haemorrhage
29 Mesenteric infarction
62 Pancreatitis
68 Perforation of peptic ulcer
70 Sclerosing (or adhesive) peritoneal disease
72 Perforation of colon

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
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 Uraemia 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

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