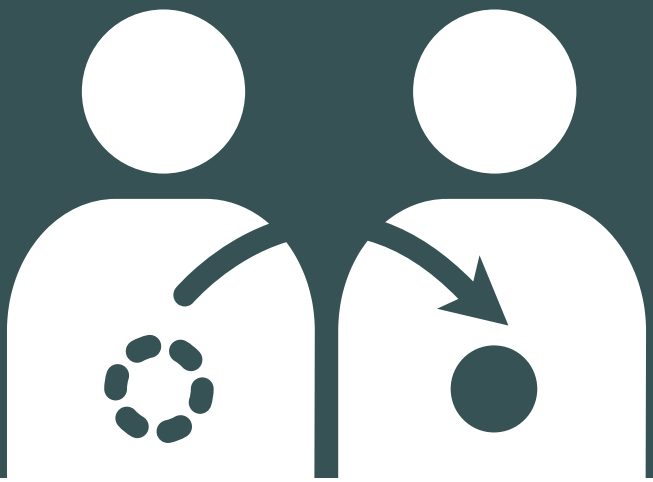

CanODT

Canadian Organ Donation and Transplantation Data System (CanODT)

Transplantation Minimum Data Set

Version 1.3

September 2023

Canadian Institute for Health Information
Institut canadien d'information sur la santé

Production of this document is made possible by financial contributions from Health Canada and provincial and territorial governments. The views expressed herein do not necessarily represent the views of Health Canada or any provincial or territorial government.

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How to cite this document:
Canadian Institute for Health Information. *Canadian Organ Donation and Transplantation Data System (CanODT): Transplantation Minimum Data Set, Version 1.3*. Ottawa, ON: CIHI; 2023.

Cette publication est aussi disponible en français sous le titre *Système canadien de données sur les dons d'organes et les transplantations (CanDOT) : fichier minimal sur les transplantations, version 1.3.*

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Acknowledgements

The Canadian Institute for Health Information (CIHI) wishes to acknowledge and thank members of the Pan-Canadian Organ Donation and Transplantation Data and Performance Reporting System Project's Data Standards Clinical Expert Advisory Forum and Business Data Management Expert Advisory Forum for their input and feedback on the development of this document.

CIHI wishes to acknowledge the following individuals for their contribution to the development of this document: Richard Lam, Erik Markhauser, Ryan Metcalfe, Ahmad Mobin, Jennifer Bucek, Tammy Lau, Nilpa Patel, Sunita Karmakar-Hore, Julia Di Bella, Finnie Flores, Rachel McGihon, Michelle Policarpio, Nicole de Guia, Greg Webster and Juliana Wu.

CIHI also wishes to acknowledge and thank Health Canada as the funder for this project.

Project overview

Despite significant advances in organ donation and transplantation (ODT) practices in Canada, the need for life-saving organ transplants continues to grow and exceed the availability of donated organs across the country — with high variability in capacity, data, policy and practice across the country in both donation and transplantation. System leaders, including the Organ Donation and Transplantation Collaborative (ODTC) led by Health Canada, identified the need for a consolidated and modernized pan-Canadian data repository with system performance indicators to inform improvements in access, efficiency, quality and outcomes across the ODT continuum of care.

In 2019, Health Canada approved multi-year funding for the Pan-Canadian ODT Data and Performance Reporting System Project, co-executed by CIHI and Canada Health Infoway (Infoway). The project is guided by Health Canada's ODTC Data System Working Group (DSWG), which is co-chaired by Dr. Joseph Kim and Dr. Matthew Weiss.

Through collaborations with provincial and territorial ministries of health, health organizations, clinicians, researchers, patients and the ODT community, this project aims to support improvements in ODT access, care and outcomes across Canada through the deployment of technology solutions, system integrations and pan-Canadian data and system-level performance reporting. The CIHI–Infoway Pan-Canadian ODT Data and Performance Reporting System Project builds on existing foundational ODT work, such as initiatives led by the provinces and territories, and those led by Canadian Blood Services and its ODT Expert Advisory Committee, where applicable.

CIHI and Infoway objectives for this 5-year ODT project include the following:

- Development of national minimum data sets and data standards for deceased donation, living donation and transplantation (CIHI);
- Procurement of data management systems to support point-of-care workflows (Infoway);
- Design, build and deployment of a pan-Canadian data repository (CIHI);
- Development and reporting of performance indicators and measures (CIHI);
- Development of data access capability and services for decision-making, policy development, research and innovation (CIHI);
- Stakeholder engagement and management (CIHI and Infoway); and
- Project management and operational planning (CIHI and Infoway).

For more information on the project, please visit CIHI's Pan-Canadian ODT Data and Performance Reporting System Project web page at cihi.ca/odt or Infoway's Organ Donation and Transplantation Data Management web page.

Development of the minimum data set

Background

This document presents CIHI's Transplantation Minimum Data Set (TX MDS), one of the deliverables of the Health Canada–funded Pan-Canadian ODT Data and Performance Reporting System Project. Additional minimum data sets were developed for deceased donation and living donation and are available on CIHI's Pan-Canadian ODT Data and Performance Reporting System Project web page at cihi.ca/odt.

The TX MDS is intended to support improvements in organ donation and transplantation outcomes by supporting future system-level reporting on ODT performance indicators and measures. It will be used to inform the organ donation technology enhancement and investment activities (e.g., transplantation/living donation management systems) led by Infoway for the project. Stakeholders who provided input into this MDS include members of the ODT clinical and business expert advisory forums and other project-specific working groups, the ODTC Data System Working Group, and others. A list of members is provided on CIHI's ODT project external advisory groups web page.

Notes

- **Recipient journey:** The TX MDS is organized according to phases along the transplantation journey workflow (see Appendix A). The major recipient workflow phases include
  1. Recipient referral
  2. Transplant evaluation
  3. Wait-listing
  4. Recipient/donor matching
  5. Transplant surgery
  6. Post-transplant follow-up
- A given organ and tissue transplantation program's process may vary from the generic workflow provided, resulting in the capture of MDS elements in a different order than presented.
- **Organ activity:** CIHI plans to capture activity at the organ level at each phase of the transplant recipient journey.

Data element change history for version 1.3

The table below lists data elements that have been dropped or added since publication of the *Transplantation Minimum Data Set, Preliminary Version 1.2*. These changes were implemented to support a more streamlined MDS and to reflect activities undertaken with stakeholders to prioritize indicators for the project. Where applicable, the original data element IDs were preserved, which resulted in some data element IDs being skipped or incremented in version 1.3.

Phase	Data element name	Amendment
Phase 1: Recipient referral	• Recipient Height • Recipient Weight	Dropped
	• Recipient First Name (Partial) • Date of Death • Recipient Demographic Effective Date	Added
Phase 2: Transplant evaluation	• Academic Activity Level (Pediatric patients only) • Current Class I PRA • Peak Class I PRA Level • Current Class II PRA Level • Peak Class II PRA Level • Method Used to Identify PRA Level	Dropped
	• Previous Transplant(s) — Country • Previous Transplant(s) — Province/Territory • Previous Transplant(s) — Donor Type • Recipient Height • Recipient Weight • Previous Medical Procedures • Learning Difference or Disability (Pediatric patients only) • Learning Difference or Disability Type (Pediatric patients only) • Congenital Cognitive Impairment (Pediatric patients only) • Peak Calculated Panel Reactive Antibody	Added
Phase 3: Wait-listing	• Recipient Transplantation Centre • Medical Status Date • CPALS Score (Pediatric liver transplants only) • CPALS Exception Type (Pediatric liver transplants only)	Dropped
	• Deceased Donor Wait-List Type • Medical Status — Organ	Added

Phase	Data element name	Amendment
Phase 4: Recipient/ donor matching	• Donor Type	Dropped
	• HLA DP • Virtual Crossmatch Test Result • Donor Last Name (Partial) • Donor Birthdate • Donor Age Code at Time of Death • Donor Age Unit at Time of Death • Living Donation Program • Living Donation Program Donor Identifier	Added
Phase 5: Transplant surgery	• Death in Hospital	Dropped
	• Time of Admission to Hospital • Transplantation Start Time • Transplantation End Time • Donor Cross-Clamp Time • Cold Preservation Start Time • Cold Preservation End Time • Reperfusion Time • Cold Ischemia Time • Surgical Complications • Provider of Follow-Up Care	Added
Phase 6: Post-transplant follow-up	• Follow-Up Care Provided By • Re-Transplantation Date • Pancreas Graft Failure Date (Pancreas transplants only) • Graft Removal Date (Intestine, kidney and pancreas transplants only) • Date of Death	Dropped
	• Date of Annual Follow-Up Visit (Pediatric patients only) • Follow-Up Care — Facility Transferred To • Follow-Up Care — Facility Transferred From • Date Follow-Up Care Transfer Received • Date of 1-Year Heart Transplant Follow-Up (Heart transplants only) • Virus Source • Date of 1-Year Lung Transplant Follow-Up (Lung transplants only) • Graft Rejection — Organ • Graft Failure — Organ • Date of Graft Failure	Added

Notes
Recipient Height was moved from Phase 1 to Phase 2.
Recipient Weight was moved from Phase 1 to Phase 2.
Date of Death was moved from Phase 6 to Phase 1.

Contact: odt@cihi.ca

Transplantation MDS v1.3

Phase 1 Recipient referral

ID	Data element name	Description	Valid values
1.1	Recipient's Health Care Number	The recipient's provincial/territorial health care number (HCN) (required for data linkage purposes)	Recipient's health care number adhering to the provincial/territorial HCN convention
1.2	Recipient Health Care Number Issuer	The province/territory that issued the recipient's HCN	• 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 • CA: Canada (penitentiary inmates, Indigenous Services Canada, Veterans Affairs Canada) **Note:** The value set codes are sourced from the CIHI Reference Data Model (CRDM).
1.3	Recipient Last Name (Partial)	The first 3 letters of the recipient's last name	Text
1.3.1	Recipient First Name (Partial)	The first 3 letters of the recipient's first name	Text

ID	Data element name	Description	Valid values
1.4	Transplant Program's Recipient Identifier	The unique local identifier assigned to the recipient by the transplant program	Transplant program local naming convention
1.5	Recipient Birthdate	The numerical representation of the recipient's full date of birth	YYYYMMDD
1.6	Recipient Province/Territory of Residence	If the recipient lives in Canada, the province/territory associated with the address where the recipient lives	• 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 • UNK: Unknown **Note:** The value set codes are sourced from CRDM; UNK is sourced from HL7.
1.7	Recipient Postal Code	If the recipient lives in Canada, the full postal code for the address where the recipient lives	ANANAN

ID	Data element name	Description	Valid values
1.8	Recipient Country of Residence	Country where the recipient lives	See list in Appendix B Additional values: • OTH: Other • UNK: Unknown **Note:** The value set codes are sourced from the International Organization for Standardization (ISO) and HL7.
1.9	Transplant Referral Date	The date the referral was received by the transplant program	YYYYMMDD
1.10	Transplantation Centre	The transplantation centre responsible for recipient case management	**Note:** Subject to CIHI's Organizational Index.
1.11	Organ(s) Requested	Organ(s) requested for transplant at the time of referral (a patient can have multiple requests over time)	• BOW: Bowel/intestine • HRT: Heart • KDD: Kidneys/dialysis (includes en bloc transplants) • LUB: Lung — Bilateral/en bloc • LVR: Liver — Whole • PAN: Pancreas — Whole • PAI: Pancreas — Islet **Note:** The value set codes are sourced from CRDM.
1.12	Previous Discussion about Living Donor Transplantation (Kidney and liver transplants only)	Indication of whether the patient had discussed living donor transplantation with a health care provider before referral	• Y: Yes • N: No • UNK: Unknown **Note:** The value set codes are sourced from HL7.
1.13	Sex at Birth	The category assigned to the recipient at birth that is typically based on their reproductive system and other physical characteristics	• F: Female • M: Male • I: Intersex • UNK: Unknown **Note:** The value set codes are sourced from HL7, except *intersex*, which is sourced from CRDM.

ID	Data element name	Description	Valid values
1.14	Gender Identity	The socially constructed roles, behaviours, identities and expressions of girls, women, boys, men and gender diverse people by a given society, by which the recipient self-identifies at the time of referral	• F: Female • M: Male • X: Another gender • UNK: Unknown • NA: Not applicable **Note:** The value set codes are sourced from HL7, except *another gender*, which is sourced from CRDM.

ID	Data element name	Description	Valid values
1.15	Racialized Group	The recipient's racial background (as identified by the recipient)	Group (examples) • 413464008: Black (African, African Canadian, Afro-Caribbean descent) • 26621000087107: East Asian (Chinese, Japanese, Korean, Taiwanese descent) • 26631000087109: Indigenous (First Nations, Inuk/Inuit, Métis descent) • 26641000087103: Latin American (Hispanic or Latin American descent) • 26651000087100: Middle Eastern (Arab, Persian, West Asian descent [e.g., Afghan, Egyptian, Iranian, Kurdish, Lebanese, Turkish]) • 28291000087106: South Asian (South Asian descent [e.g., Bangladeshi, Indian, Indo-Caribbean, Pakistani, Sri Lankan]) • 26661000087102: Southeast Asian (Cambodian, Filipino, Indonesian, Thai, Vietnamese or other Southeast Asian descent) • 413773004: White (European descent) • OTH: Another race category (includes values not described above) • ASKD: Prefer not to answer (refused to answer) • ASKU: Do not know (person is not aware of their race) • NASK: Not asked **Note:** The value set is sourced from CRDM, with Systematized Nomenclature of Medicine — Clinical Terms (SNOMED CT) Canadian Edition codes. Mixed racial group will be captured through multi-selection.

ID	Data element name	Description	Valid values
1.16	Indigenous Identity	The recipient's Indigenous identity (i.e., First Nations, Métis and/or Inuk/Inuit), as identified by the recipient	• 29921000087109: First Nations • 29931000087106: Inuk/Inuit • 29941000087100: Métis • N: No (do not identify as First Nations, Métis and/or Inuk/Inuit) • ASKD: Prefer not to answer (refused to answer) • ASKU: Do not know (person is not aware of their Indigenous identity) • NASK: Not asked **Note:** The value set is sourced from CRDM, with SNOMED CT Canadian Edition codes. Mixed Indigenous identity will be captured through multi-selection.
1.19	Recipient Blood Type	The confirmed blood type of the recipient	• 112144000: Blood group A • 112149005: Blood group B • 58460004: Blood group O • 165743006: Blood group AB • UNK: Unknown **Note:** The value set codes are sourced from SNOMED CT Canadian Edition; UNK is sourced from HL7.
1.20	Highest Education Level	The highest level of education completed by the recipient	• 1: Less than secondary (high) school graduation • 2: Secondary (high) school diploma or equivalent • 3: Some post-secondary education • 4: Bachelor's degree completion • 5: Post-secondary school completion above bachelor's degree

ID	Data element name	Description	Valid values
1.21	Decision Regarding Referral	The decision regarding the referral and whether the patient can proceed to transplant evaluation	• 1: Deferred • 385645004: Accepted • 443390004: Declined **Note:** The value set codes 385645004 and 443390004 are sourced from SNOMED CT Canadian Edition.
1.22	Date of Decision Regarding Referral	The date of decision regarding the referral and whether the patient can proceed to transplant evaluation	YYYYMMDD
1.23	Date of Death	The date of the declaration of death at any period of the patient's transplantation journey	YYYYMMDD
1.24	Recipient Demographic Effective Date	The date associated with the Recipient First Name (Partial), Recipient Last Name (Partial), Recipient's Health Care Number, Recipient Health Care Number Issuer, Recipient Province/Territory of Residence, Recipient Country of Residence and/or Recipient Postal Code	YYYYMMDD

Phase 2 Transplant evaluation

ID	Data element name	Description	Valid values
2.1	Organ Diagnosis — Primary	The primary cause of organ failure leading to indication for transplantation	See list in Appendix C
2.2	Organ Diagnosis — Secondary	Secondary diagnoses that may have contributed to the organ failure but were not the primary cause of organ failure	See list in Appendix C
2.3	Previous Transplant(s) — Date(s)	The date(s) the recipient received previous organ transplant(s)	YYYYMMDD
2.3.1.1	Previous Transplant(s) — Country	The country (or countries) where the recipient received previous organ transplant(s)	See list in Appendix B Additional values: • OTH: Other • UNK: Unknown **Note:** The value set codes are sourced from the ISO and HL7.

ID	Data element name	Description	Valid values
2.3.1	Previous Transplant(s) — Province/Territory	If the recipient lived in Canada, the province/territory (or provinces/territories) where the recipient received previous organ transplant(s)	• 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 • UNK: Unknown **Note:** The value set codes are sourced from CRDM; UNK is sourced from HL7.

ID	Data element name	Description	Valid values
2.4	Previous Transplant(s) — Specific Organ(s)	The specific organ(s) that were previously transplanted into the recipient	• BOW: Bowel/intestine • HRT: Heart • HLC: Heart–lung combination • KDT: Kidney — Double/en bloc • KDL: Kidney — Left • KDR: Kidney — Right • LUB: Lung — Bilateral/en bloc • LUL: Lung — Left • LUR: Lung — Right • LBL: Lung — Left lung lower lobe • LLU: Lung — Left lung upper lobe • RLL: Lung — Right lung lower lobe • RML: Lung — Right lung middle lobe • RUL: Lung — Right lung upper lobe • LVR: Liver — Whole • LLL: Liver — Left lobe • LRL: Liver — Right lobe • LLS: Liver — Lateral segment • LMS: Liver — Monosegment • PAN: Pancreas — Whole • PAI: Pancreas — Islet • PAS: Pancreas — Segment **Note:** The value set codes are sourced from CRDM.

ID	Data element name	Description	Valid values
2.4.1	Previous Transplant(s) — Donor Type	The type of donor for the previous organ transplant(s)	• 105456007: Living donor • 1187236000: Donor after neurological determination of death • 1187235001: Donor after circulatory death • UNK: Unknown **Note:** The value set codes are sourced from SNOMED CT Canadian Edition; UNK is sourced from HL7.
2.5	Date of First Visit with Transplant Specialist	The date of the first discussion between a transplant specialist and a patient about the transplant procedure	YYYYMMDD
2.5.1	Recipient Height	The height of the recipient in centimetres (conversion: 1 in. = 2.54 cm) **Pediatric patients:** At the time of listing, transplant surgery and annually post-transplant until loss to follow-up or transfer to adult transplant program **Adult patients:** At the time of listing	0.0 to 300.0 cm **Note:** The data element code is sourced from Logical Observation Identifiers Names and Codes (LOINC) (Body Height: 8302-2). The Unified Code for Units of Measure (UCUM) is used for the unit of measure.
2.5.2	Recipient Weight	The weight of the recipient in kilograms (conversion: 1 lb. = 0.45 kg) **Pediatric patients:** At the time of listing, transplant surgery and annually post-transplant until loss to follow-up or transfer to adult transplant program **Adult patients:** At the time of listing and transplant surgery	0.0 to 700.0 kg **Note:** The data element code is sourced from LOINC (Body Weight: 29463-7). UCUM is used for the unit of measure.
2.6	Patient on Chronic Dialysis	Indication of whether the patient is on chronic dialysis at the time of listing and transplant	• Y: Yes • N: No • UNK: Unknown **Note:** The value set codes are sourced from HL7.
2.7	Date of Most Recent Start of Chronic Dialysis	The date of the patient's most recent start of chronic dialysis treatment	YYYYMMDD

ID	Data element name	Description	Valid values
2.8	Medical History — Comorbidities	Indication of the patient's medical condition history	• 194828000: Angina • 62914000: Cerebrovascular disease • 13645005: Chronic obstructive pulmonary disease • 105969002: Connective tissue disease • 46635009: Diabetes type 1 • 44054006: Diabetes type 2 • 698247007: Cardiac arrhythmia • 86406008: Human immunodeficiency virus • 13644009: Hypercholesterolemia • 38341003: Hypertension • 414545008: Ischemic heart disease • 235856003: Liver disease • 45461000087109: Liver dysfunction • 363346000: Malignant neoplastic disease • 22298006: Myocardial infarction • 400047006: Peripheral vascular disease • 19242006: Pulmonary edema • 236423003: Renal dysfunction • 234467004: Thrombophilia • 368009: Valvular heart disease **Note:** The value set codes are sourced from SNOMED CT Canadian Edition.
2.8.1	Previous Medical Procedures	Indication of the patient's previous medical procedures	• 161625008: History of cardiac surgery • 405741001: History of percutaneous coronary intervention • 161664006: History of blood transfusion **Note:** The value set codes are sourced from SNOMED CT Canadian Edition.

ID	Data element name	Description	Valid values
2.9	Cytomegalovirus Antibody Measurement	Indication of the most recent result of whether the recipient tested positive for the cytomegalovirus (CMV) antibody at the time of listing	• 10828004: Positive • 260385009: Negative • 373121007: Test not done • 373068000: Undetermined **Note:** The data element code is sourced from SNOMED CT Canadian Edition (Cytomegalovirus Antibody Measurement: 30200007). The value set codes are sourced from SNOMED CT Canadian Edition.
2.10	Epstein–Barr Virus Antibody Measurement	Indication of the most recent result of whether the recipient tested positive for the Epstein–Barr virus antibody at the time of listing	• 10828004: Positive • 260385009: Negative • 373121007: Test not done • 373068000: Undetermined **Note:** The data element code is sourced from SNOMED CT Canadian Edition (Epstein–Barr Virus Antibody Measurement: 408219003). The value set codes are sourced from SNOMED CT Canadian Edition.
2.11	Hepatitis B Core Antibody Measurement	Indication of the most recent result of whether the recipient tested positive for the hepatitis B antibody (hepatitis BcAb) at the time of listing	• 10828004: Positive • 260385009: Negative • 373121007: Test not done • 373068000: Undetermined **Note:** The data element code is sourced from SNOMED CT Canadian Edition (Hepatitis B Core Antibody Measurement: 59582004). The value set codes are sourced from SNOMED CT Canadian Edition.

ID	Data element name	Description	Valid values
2.12	Hepatitis B Surface Antigen Measurement	Indication of the most recent result of whether the recipient tested positive for the hepatitis B antigen (hepatitis BsAg) at the time of listing	• 10828004: Positive • 260385009: Negative • 373121007: Test not done • 373068000: Undetermined **Note:** The data element code is sourced from SNOMED CT Canadian Edition (Hepatitis B Surface Antigen Measurement: 47758006). The value set codes are sourced from SNOMED CT Canadian Edition.
2.13	Hepatitis C Antibody Measurement	Indication of the most recent result of whether the recipient tested positive for the hepatitis C antibody at the time of listing	• 10828004: Positive • 260385009: Negative • 373121007: Test not done • 373068000: Undetermined **Note:** The data element code is sourced from SNOMED CT Canadian Edition (Hepatitis C Antibody Measurement: 64411004). The value set codes are sourced from SNOMED CT Canadian Edition.
2.14	HBV DNA (Liver transplants only)	Indication of the most recent result of whether the recipient tested positive for the hepatitis B virus (HBV) DNA at the time of listing	• 10828004: Positive • 260385009: Negative • 373121007: Test not done • 373068000: Undetermined **Note:** The value set codes are sourced from SNOMED CT Canadian Edition.

ID	Data element name	Description	Valid values
2.15	Human Immunodeficiency Virus Antigen Test	Indication of the most recent result of whether the recipient tested positive for the HIV antigen at the time of listing	• 10828004: Positive • 260385009: Negative • 373121007: Test not done • 373068000: Undetermined **Note:** The data element code is sourced from SNOMED CT Canadian Edition (Human Immunodeficiency Virus Antigen Test: 31676001). The value set codes are sourced from SNOMED CT Canadian Edition.
2.16	Measurement of Human T-Lymphotropic Virus 1 Antibody and Human T-Lymphotropic Virus 2 Antibody	Indication of the most recent result of whether the recipient tested positive for the human T-cell lymphotropic virus (HTLV) type I or type II antibody at the time of listing	• 10828004: Positive • 260385009: Negative • 373121007: Test not done • 373068000: Undetermined **Note:** The data element code is sourced from SNOMED CT Canadian Edition (Measurement of Human T-Lymphotropic Virus 1 Antibody and Human T-Lymphotropic Virus 2 Antibody: 117754000). The value set codes are sourced from SNOMED CT Canadian Edition.
2.17	SARS-CoV-2	Indication of whether the recipient tested positive for SARS-CoV-2 at the time of transplant	• 10828004: Positive • 260385009: Negative • 373121007: Test not done • 373068000: Undetermined **Note:** The value set codes are sourced from SNOMED CT Canadian Edition.
2.18	Date of SARS-CoV-2 Test	The date that the patient was tested for SARS-CoV-2	YYYYMMDD
2.19	Hematology — International Normalized Ratio (Liver transplants only)	The patient's most recent international normalized ratio at the time of listing and transplant	0.0 to 99.9

ID	Data element name	Description	Valid values
2.20	Hemodynamics — Pulmonary Artery Pressure Systolic (Heart and lung transplants only)	The patient's most recent systolic pulmonary artery pressure at the time of listing and transplant, in mmHg	# **Note:** UCUM is used for the unit of measure.
2.21	Hemodynamics — Pulmonary Artery Pressure Diastolic (Heart and lung transplants only)	The patient's most recent diastolic pulmonary artery pressure at the time of transplant, in mmHg	# **Note:** UCUM is used for the unit of measure.
2.22	Hemodynamics — Mean Pulmonary Artery Pressure (Heart and lung transplants only)	The patient's most recent mean pulmonary artery pressure at the time of transplant, in mmHg	# **Note:** UCUM is used for the unit of measure.
2.23	Hemodynamics — Mean Pulmonary Capillary Wedge Pressure (Heart and lung transplants only)	The patient's most recent mean pulmonary capillary wedge pressure at the time of listing and transplant, in mmHg	# **Note:** UCUM is used for the unit of measure.
2.24	Hemodynamics — Cardiac Index (Lung transplants only)	The patient's most recent cardiac index at the time of transplant, in $L/min/m^2$	# **Note:** UCUM is used for the unit of measure.
2.25	Hemodynamics — Cardiac Output (Heart and lung transplants only)	The patient's most recent cardiac output at the time of listing (heart and lung transplants) and transplant (lung transplants only), in L/min	# **Note:** UCUM is used for the unit of measure.
2.26	Hemodynamics — Pulmonary Vascular Resistance (Heart and lung transplants only)	The patient's most recent pulmonary vascular resistance at the time of transplant, in Wood units	# **Note:** UCUM is used for the unit of measure.
2.27	Hemodynamics — Pulmonary Vascular Resistance Reactivity (Heart and lung transplants only)	The patient's most recent pulmonary vascular resistance reactivity at the time of transplant	• 11214006: Reactive • 131194007: Non-reactive • 373121007: Test not done • UNK: Unknown **Note:** The value set codes are sourced from SNOMED CT Canadian Edition; UNK is sourced from HL7.
2.28	Chemistry — Serum Albumin (Kidney, liver and pancreas transplants only)	The patient's most recent level of serum albumin at the time of listing and transplant, in g/L	# **Note:** UCUM is used for the unit of measure.

ID	Data element name	Description	Valid values
2.29	Chemistry — Total Bilirubin (Heart, intestine, liver and lung transplants only)	The patient's most recent level of total bilirubin at the time of listing and transplant, in mol/L	# **Note:** UCUM is used for the unit of measure.
2.30	Chemistry — Creatinine (Heart, liver and lung transplants only)	The patient's most recent level of creatinine at the time of listing and transplant, in mol/L	# **Note:** UCUM is used for the unit of measure.
2.31	Chemistry — Alpha Fetoprotein (Liver transplants only)	The patient's most recent level of alpha fetoprotein at the time of transplant, in ng/mL	# **Note:** UCUM is used for the unit of measure.
2.32	Chemistry — C-Peptide (Non-Fasting) (Pancreas transplants only)	The patient's most recent level of C-peptide (non-fasting) at the time of transplant, in nmol/L	# **Note:** UCUM is used for the unit of measure.
2.33	Electrolytes — Serum Sodium (Liver transplants only)	The patient's most recent level of sodium at the time of listing and transplant, in mmol/L	# **Note:** UCUM is used for the unit of measure.
2.34	Blood Gases — Partial Pressure of Carbon Dioxide (Lung transplants only)	The patient's most recent partial pressure of carbon dioxide at the time of listing and transplant, in kPa	# **Note:** UCUM is used for the unit of measure.
2.35	Blood Gases — Oxygen Requirement at Rest (Lung transplants only)	The patient's most recent oxygen requirement at rest at the time of listing	0 to 100%
2.36	Cardiothoracic Profile — 6-Minute Walk Distance (Lung transplants only)	The patient's most recent 6-minute walk distance at the time of listing and transplant, in metres	# **Note:** UCUM is used for the unit of measure.
2.37	Cardiothoracic Profile — Forced Vital Capacity Percentage Predicted (Lung transplants only)	The patient's most recent forced vital capacity percentage predicted at the time of listing and transplant	0 to 100%
2.38	Cardiothoracic Profile — Forced Expiratory Volume in 1 Second Percentage Predicted (Lung transplants only)	The patient's most recent forced expiratory volume in 1 second percentage predicted at the time of transplant	0 to 100%

ID	Data element name	Description	Valid values
2.39	Alcohol Use	Indication of whether the patient has a history of alcohol use that poses a potential risk	• Y: Yes • N: No • UNK: Unknown **Note:** The data element code is sourced from LOINC (History of Alcohol Use: 11331-6). The value set codes are sourced from HL7.
2.40	Smoking History	Indication of whether the patient is a smoker (i.e., smoked cigarettes, cigars or a pipe in the last 6 months)	• Y: Yes • N: No • UNK: Unknown **Note:** The data element code is sourced from LOINC (Tobacco Smoking Status: 72166-2). The value set codes are sourced from HL7.
2.41	Smoking Rate	If the patient is a smoker (Smoking History = *yes*), the number of packs the recipient smoked per day	• # packs per day **Note:** The data element code is sourced from LOINC (Tobacco Amount Per Day: 96103-7).
2.42	Smoking Duration	If the patient is a smoker (Smoking History = *yes*), the number of years the recipient was a smoker	• # years **Note:** The data element code is sourced from LOINC (Smoking Tobacco Use Duration: 67741-9).
2.43	History of Marijuana Use	Indication of whether the patient has a history of marijuana use	• Y: Yes • N: No • UNK: Unknown **Note:** The data element code is sourced from SNOMED CT Canadian Edition (History of Marijuana Use: 37601000087102). The value set codes are sourced from HL7.

ID	Data element name	Description	Valid values
2.44	Drug Use	Indication of whether the patient has a history of non-medical or recreational drug use that poses a potential risk (not including smoking and marijuana use). Examples of non-medical or recreational drugs include hash, LSD, cocaine, heroin, crack, crystal meth, amphetamines (bennies), stimulants (uppers), benzodiazepines/barbiturates (downers), speed, ecstasy, anabolic steroids and methadone.	• Y: Yes • N: No • UNK: Unknown **Note:** The data element code is sourced from LOINC (History of Other Nonmedical Drug Use: 11343-1). The value set codes are sourced from HL7.
2.45	Academic Grade Level (Pediatric patients only)	The pediatric patient's academic grade level relative to that of their peers at the time of listing, transplant and annually post-transplant until loss to follow-up or transfer to adult transplant program. If measured during the summer, indicate the academic grade level during the previous academic year.	• 1: Completing standard or higher grade level academic curriculum • 2: At grade level but completing an adapted curriculum that is simplified from the standard curriculum • 3: Attending school at a lower grade level • 4: Not attending school • UNK: Unknown **Note:** UNK is sourced from HL7.
2.45.1	Learning Difference or Disability (Pediatric patients only)	Indication of whether the pediatric patient has an active, current diagnosis of a learning difference or disability at the time of listing, transplant and annually post-transplant until loss to follow-up or transfer to adult transplant program	• Y: Yes • N: No • UNK: Unknown **Note:** The value set codes are sourced from HL7.

ID	Data element name	Description	Valid values
2.45.2	Learning Difference or Disability Type (Pediatric patients only)	The type of learning difference or disability the pediatric patient has at the time of listing, transplant and annually post-transplant until loss to follow-up or transfer to adult transplant program	• 35253001: Attention deficit disorder • 406506008: Attention deficit hyperactivity disorder • 229752008: Auditory processing disorder • 55640002: Dyscalculia • 88278002: Dysgraphia • 59770006: Dyslexia • 62305002: Language processing disorder • 443735008: Nonverbal learning disability • 45501000087109: Visual perceptual and visual motor deficit • OTH: Other • UNK: Unknown **Note**: The value set codes are sourced from SNOMED CT Canadian Edition; OTH and UNK are sourced from HL7.
2.47	Cognitive Development Delay or Impairment (Pediatric patients only)	Indication of whether the pediatric patient has a cognitive delay or impairment below the normal range of cognitive functioning at the time of listing, transplant and annually post-transplant until loss to follow-up or transfer to adult transplant program	• Y: Yes • N: No • UNK: Unknown **Note:** The value set codes are sourced from HL7.
2.47.1	Congenital Cognitive Impairment (Pediatric patients only)	Indication of whether the pediatric patient has a congenital syndrome or genetic diagnosis associated with cognitive impairment or delay	• Y: Yes • N: No • UNK: Unknown **Note:** The value set codes are sourced from HL7.
2.48	Total Parenteral Nutrition (Intestine transplants only)	Indication of whether the patient was on total parenteral nutrition at the time of transplant	• Y: Yes • N: No • UNK: Unknown **Note:** The value set codes are sourced from HL7.

ID	Data element name	Description	Valid values
2.49	Insulin Dependent (Pancreas and islet transplants only)	Indication of whether the patient requires insulin at the time of listing	• Y: Yes • N: No • UNK: Unknown **Note:** The value set codes are sourced from HL7.
2.50	Previous Cardiac Surgery (Heart transplants only)	Indication of whether the patient had a previous cardiac surgery	• Y: Yes • N: No • UNK: Unknown **Note:** The value set codes are sourced from HL7.
2.51	Prior CRT-D, CRT or ICD (Heart transplants only)	Indication of whether the patient had prior use of a cardiac resynchronization therapy defibrillator (CRT-D), cardiac resynchronization therapy (CRT) or an implantable cardioverter defibrillator (ICD)	• Y: Yes • N: No • UNK: Unknown **Note:** The value set codes are sourced from HL7.
2.52	Inotropic Support (Heart transplants only)	Indication of whether the patient was receiving inotropes at the time of transplant	• Y: Yes • N: No • UNK: Unknown **Note:** The value set codes are sourced from HL7.
2.53	MCS/ECLS — Device Used (Heart and lung transplants only)	Indication of whether a mechanical circulatory support (MCS) or extracorporeal life support (ECLS) device was used at the time of listing and transplant	• Y: Yes • N: No • UNK: Unknown **Note:** The value set codes are sourced from HL7.

ID	Data element name	Description	Valid values
2.54	MCS/ECLS — Type (Heart and lung transplants only)	The MCS or ECLS device that was used at the time of listing and transplant	• 129113006: Intra-aortic balloon pump • 360066001: Left ventricular assist device • 360065002: Right ventricular assist device • 361158001: Artificial heart • 45001000087101: Venoarterial extracorporeal membrane oxygenation system • 45011000087104: Venovenous extracorporeal membrane oxygenation system • OTH: Other • UNK: Unknown **Note:** The value set codes are sourced from SNOMED CT Canadian Edition; OTH and UNK are sourced from HL7.
2.55	Anticoagulants (Heart and lung transplants only)	Indication of whether the patient was receiving anticoagulant therapy at the time of transplant (e.g., Coumadin or heparin)	• Y: Yes • N: No • UNK: Unknown **Note:** The value set codes are sourced from HL7.
2.56	Previous Thoracic Surgery (Lung transplants only)	Indication of whether the patient had a previous thoracic surgery	• Y: Yes • N: No • UNK: Unknown **Note:** The value set codes are sourced from HL7.
2.57	Hospitalization Status	Indication of whether the patient was admitted to the hospital at the time of listing	• Y: Yes • N: No • UNK: Unknown **Note:** The value set codes are sourced from HL7.

ID	Data element name	Description	Valid values
2.58	ICU Status	Indication of whether the patient was admitted to the intensive care unit (ICU) at the time of listing	• Y: Yes • N: No • UNK: Unknown **Note:** The value set codes are sourced from HL7.
2.59	Mechanical Ventilation Status	Indication of whether the patient was mechanically ventilated at the time of listing and transplant	• Y: Yes • N: No • UNK: Unknown **Note:** The value set codes are sourced from HL7.
2.60	Highly Sensitized Patient	Indication of whether the patient is a highly sensitized patient (based on their transplant program's definition or eligibility criteria) at the time of listing	• Y: Yes • N: No • UNK: Unknown **Note:** The value set codes are sourced from HL7.
2.65	Calculated Panel Reactive Antibody	The calculated panel reactive antibody (cPRA) measured for the patient at the time of listing and transplant	0 to 100%
2.65.1	Peak Calculated Panel Reactive Antibody	The highest cPRA measured for the patient at the time of transplant	0 to 100%

Phase 3 Wait-listing

ID	Data element name	Description	Valid values
3.2	Date of Decision Regarding Wait-List	The date the patient's suitability for the transplant wait-list was determined	YYYYMMDD
3.2.1	Deceased Donor Wait-List Type	The type of deceased donation wait-list that the patient was put on at the time of wait-list activation	• 1: Standard deceased-donor wait-list • 2: Expanded-criteria deceased-donor (or similar) wait-list • 3: Hepatitis C deceased-donor wait-list • 4: National highly sensitized deceased-donor wait-list • 5: Kidney–pancreas deceased-donor wait-list

ID	Data element name	Description	Valid values
3.3	Reason for Non-Activation for Deceased Donor Wait-List	The main reason for non-activation for deceased donor wait-list	• 1: Active substance use • 2: Active/untreated infection • 3: Destination ventricular assist device • 4: Excessive risk of recurrent disease • 5: Extrahepatic hepatocellular carcinoma • 6: High-risk cardiovascular disease • 7: History of poor medical adherence • 8: Patient deceased while waiting • 9: Patient declined or family choice • 10: Patient has compatible living donor • 11: Patient has incompatible living donor — planned for desensitization and/or paired exchange • 12: Patient left country • 13: Patient left for another program • 14: Patient's condition deteriorated — too sick for transplantation • 15: Patient's condition improved to the point that transplant not required • 16: Poor life expectancy • 17: Recent/metastatic malignancy • 18: Risks outweighs benefits of transplant • 19: Test outdated • 20: Unable to contact patient • 21: Unstable/untreated psychiatric illness • 22: Unsuitable anatomy or weight issues • 23: Ventricular assist device: Bridge to recovery • OTH: Other • UNK: Unknown **Note:** OTH and UNK are sourced from HL7.

ID	Data element name	Description	Valid values
3.4	Wait-List Activation Date(s)	The date(s) the patient was activated/re-activated to the wait-list	YYYYMMDD
3.5	Date Patient Removed From Wait-List	The date the patient was permanently removed from the wait-list	YYYYMMDD
3.6	Reason Patient Removed From Wait-List	The main reason the patient was removed from the wait-list	• 1: Active malignancy • 2: Active/untreated infection • 3: Acute myocardial infarction • 4: Death • 5: Deconditioning • 6: Identified living donor • 7: Investigation for malignancy • 8: Major cardiac surgery • 9: Major non-cardiac surgery (including vascular) • 10: Moved out of area and/or onto new wait-list • 11: Other cardiovascular disease • 12: Patient preference or family choice • 13: Recovery to the point that transplant not required • 14: Stroke • 15: Test outdated • OTH: Other • UNK: Unknown **Note:** OTH and UNK are sourced from HL7.
3.7	Wait-List On Hold Date(s)	The date(s) the patient was placed on hold from the wait-list	YYYYMMDD

ID	Data element name	Description	Valid values
3.8	Reason for Being Put on Hold	The reason the patient was placed on hold from the wait-list	• 1: Medically unsuitable — Temporary • 2: Not available (away) • 3: Pending investigations • 4: Potential living donor — Desensitization (ABO or HLA) • 5: Potential living donor paired exchange transplant • 6: Psychological issue(s) — Temporary • OTH: Other • UNK: Unknown **Note:** OTH and UNK are sourced from HL7.
3.9	Date of Registration for Kidney Paired Donation Program (Kidney transplants only)	The date the patient was registered to the kidney paired donation (KPD) program	YYYYMMDD
3.10	Date of Removal From Kidney Paired Donation Program (Kidney transplants only)	The date the patient was removed from the KPD program	YYYYMMDD
3.11	Medical Status	The medical status of the patient with respect to the organ requested at the time of listing and transplant	See list in Appendix D
3.12	Medical Status — Organ	The organ associated with the medical status of the patient at the time of listing and transplant	• BOW: Bowel/intestine • HRT: Heart • KDD: Kidneys/dialysis (includes en bloc transplants) • LUB: Lung — Bilateral/en bloc • LVR: Liver — Whole **Note:** The value set codes are sourced from CRDM.
3.13	MELD-Na (Liver transplants only)	The patient's model for end-stage liver disease — sodium (MELD-Na) score at the time of listing and transplant	6.0 to 40.0
3.14	MELD-Na — Peak (Liver transplants only)	The patient's highest MELD-Na score at the time of transplant	6.0 to 40.0

ID	Data element name	Description	Valid values
3.15	MELD Exception (Liver transplants only)	The condition for which the patient was assigned a MELD exception score at the time of listing and transplant	• 190905008: Cystic fibrosis • 42295001: Familial amyloid polyneuropathy • 83940008: Hepatic artery thrombosis • 109841003: Hepatocellular carcinoma • 371067004: Hepatopulmonary syndrome • 253017000: Hilar cholangiocarcinoma • 445237003: Portopulmonary hypertension • 17901006: Primary hyperoxaluria • OTH: Other **Note:** The value set codes are sourced from SNOMED CT Canadian Edition; OTH is sourced from HL7.
3.18	Hepatitis BcAb Positive Donor Accepted	Indication of whether the transplant team is willing to accept a potential donor who is hepatitis BcAb positive	• Y: Yes • N: No **Note:** The value set codes are sourced from HL7.

Phase 4 Recipient/donor matching

ID	Data element name	Description	Valid values
4.1	HLA A	The recipient's 2 human leukocyte antigen (HLA) type A antigens	See Appendix E for a list of recognized serological HLA specificities Additional values: • 37501000087101: Human leukocyte antigen typing — No antigen identified • UNK: Unknown/not available/typing not done • OTH: Other **Note:** The data element code is sourced from LOINC (HLA-A Locus [Type]: 38548-4). UNK and OTH are sourced from HL7.
4.2	HLA B	The recipient's 2 HLA B antigens	See Appendix E for a list of recognized serological HLA specificities Additional values: • 37501000087101: Human leukocyte antigen typing — No antigen identified • UNK: Unknown/not available/typing not done • OTH: Other **Note:** The data element code is sourced from LOINC (HLA-B Locus [Type]: 38546-8). UNK and OTH are sourced from HL7.

ID	Data element name	Description	Valid values
4.3	HLA C	The recipient's 2 HLA C antigens	See Appendix E for a list of recognized serological HLA specificities Additional values: • 37501000087101: Human leukocyte antigen typing — No antigen identified • UNK: Unknown/not available/typing not done • OTH: Other **Note:** The data element code is sourced from LOINC (HLA-C [Type]: 13302-5). UNK and OTH are sourced from HL7.
4.4	HLA DR	The recipient's 2 HLA DR antigens	See Appendix E for a list of recognized serological HLA specificities Additional values: • 37501000087101: Human leukocyte antigen typing — No antigen identified • UNK: Unknown/not available/typing not done • OTH: Other **Note:** The data element code is sourced from LOINC (HLA-DR Locus [Type]: 21341-3). UNK and OTH are sourced from HL7.
4.5	HLA DQ	The recipient's 2 HLA DQ antigens	See Appendix E for a list of recognized serological HLA specificities Additional values: • 37501000087101: Human leukocyte antigen typing — No antigen identified • UNK: Unknown/not available/typing not done • OTH: Other **Note:** The data element code is sourced from LOINC (HLA-DQ Locus 2 [Type]: 34143-8). UNK and OTH are sourced from HL7.

ID	Data element name	Description	Valid values
4.5.1	HLA DP	The recipient's 2 HLA DP antigens	See Appendix E for a list of recognized serological HLA specificities Additional values: • 37501000087101: Human leukocyte antigen typing — No antigen identified • UNK: Unknown/not available/typing not done • OTH: Other **Note:** The data element code is sourced from LOINC (HLA-DP [Type]: 12285-3). The value set code is sourced from SNOMED CT Canadian Edition; UNK and OTH are sourced from HL7.
4.6	Standard Crossmatch Test Result	Indication of whether the standard crossmatch test on T-lymphocytes or peripheral blood lymphocytes was positive or negative at 22°C or 37°C	• 10828004: Positive • 260385009: Negative • 373121007: Test not done • UNK: Unknown **Note:** The value set codes are sourced from SNOMED CT Canadian Edition; UNK is sourced from HL7.
4.6.1	Virtual Crossmatch Test Result	Indication of whether the virtual crossmatch test result was positive	• 10828004: Positive • 260385009: Negative • 373121007: Test not done • UNK: Unknown **Note:** The value set codes are sourced from SNOMED CT Canadian Edition; UNK is sourced from HL7.
4.7	Donor Health Care Number	The donor's provincial/territorial HCN at the time of donation (required for data linkage purposes)	Donor health care number adhering to the provincial/territorial HCN convention

ID	Data element name	Description	Valid values
4.8	Donor Health Care Number Issuer	The province/territory that issued the donor's health care number at the time of donation	• 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 • CA: Canada (penitentiary inmates, Indigenous Services Canada, Veterans Affairs Canada) **Note:** The value set codes are sourced from CRDM.
4.10	Organ Donation Organization	The organ donation organization (ODO) responsible for the donor case management	**Note:** Subject to CIHI's Organizational Index.
4.11	ODO Donor Identifier	The unique local identifier assigned to the donor organ/case file by the ODO	ODO local naming convention
4.12	Donor Last Name (Partial)	The first 3 letters of the donor's last name	Text
4.13	Donor Birthdate	The numerical representation of the living donor's full date of birth	YYYYMMDD
4.13.1	Donor Age Code at Time of Death	The age code (value that denotes how age is measured) of the donor at the time of death	• Y: Year • M: Month • D: Day • B: Newborn

ID	Data element name	Description	Valid values
4.13.2	Donor Age Unit at Time of Death	The age unit (numeric value that measures the specified age code) of the donor at the time of death	• Age in years for donors 2 or more years of age: 2 to 130 • Age in months for donors younger than 24 months of age: 1 to 23 • Age in days for donors younger than 31 days of age: 1 to 30 • Newborns: 0
4.14	Living Donation Program	The living donation program responsible for intake of the donor's referral	**Note:** Subject to CIHI's Organizational Index.
4.15	Living Donation Program Donor Identifier	The unique ID assigned to the donor by the living donation program	Living donation program local naming convention

Phase 5 Transplant surgery

ID	Data element name	Description	Valid values
5.1	Specific Organ(s) Being Transplanted	The specific organ(s) that are being transplanted into the recipient	• BOW: Bowel/intestine • HRT: Heart • HLC: Heart–lung combination • KDT: Kidney — Double/en bloc • KDL: Kidney — Left • KDR: Kidney — Right • LUB: Lung — Bilateral/en bloc • LUL: Lung — Left • LUR: Lung — Right • LBL: Lung — Left lung lower lobe • LLU: Lung — Left lung upper lobe • RLL: Lung — Right lung lower lobe • RML: Lung — Right lung middle lobe • RUL: Lung — Right lung upper lobe • LVR: Liver — Whole • LLL: Liver — Left lobe • LRL: Liver — Right lobe • LLS: Liver — Lateral segment • LMS: Liver — Monosegment • PAN: Pancreas — Whole • PAI: Pancreas — Islet • PAS: Pancreas — Segment **Note:** The value set codes are sourced from CRDM.

ID	Data element name	Description	Valid values
5.2	Organ Source	Identifies the source of the transplanted organ	• 1187236000: Donor after neurological determination of death • 1187235001: Donor after circulatory death • 44861000087105: Living donor — Directed • 44941000087103: Living donor — Non-directed anonymous donor • 44891000087102: Living donor — Paired exchange • 44931000087109: Living donor — N-way kidney exchange or closed chain • 44951000087100: Living donor — Non-directed anonymous donor-initiated domino chain • UNK: Unknown **Note:** The value set codes are sourced from SNOMED CT Canadian Edition; UNK is sourced from HL7.
5.3	Date of Admission to Hospital	The date the patient was admitted to hospital for transplant	YYYYMMDD
5.3.1	Time of Admission to Hospital	The time of day the patient was admitted to hospital for transplant	HHMM **Note:** 24-hour clock
5.4	Transplantation Start Date	The start date of the recipient's surgery for transplantation of the specified organ(s), regardless of the outcome	YYYYMMDD
5.4.1	Transplantation Start Time	The start time of the recipient's surgery for transplantation of the specified organ(s), regardless of the outcome	HHMM **Note:** 24-hour clock.
5.5	Transplantation End Date	The end date of the recipient's surgery for transplantation of the specified organ(s), regardless of the outcome	YYYYMMDD
5.5.1	Transplantation End Time	The end time of the recipient's surgery for transplantation of the specified organ(s), regardless of the outcome	HHMM **Note:** 24-hour clock.

ID	Data element name	Description	Valid values
5.6	Donor Cross-Clamp Date	The date of aortic cross-clamping in deceased donor	YYYYMMDD
5.6.1	Donor Cross-Clamp Time	The time of day of aortic cross-clamping in deceased donor	HHMM **Note:** 24-hour clock.
5.7	Perfusion Device Status	Indication of whether an organ perfusion device was used for the specified organ(s)	• Y: Yes • N: No • UNK: Unknown **Note:** The value set codes are sourced from HL7.
5.8	Perfusion Device Used	The device used for organ perfusion for the specified organ(s)	• 37451000087104: Kidney perfusion pump • 37441000087102: Ex vivo pump • UNK: Unknown **Note:** The value set codes are sourced from SNOMED CT Canadian Edition; UNK is sourced from HL7.
5.9	Cold Preservation Start Date	The date that cold preservation was initiated for the specified organ(s)	YYYYMMDD
5.9.1	Cold Preservation Start Time	The time of day that cold preservation was initiated for the specified organ(s)	HHMM **Note:** 24-hour clock.
5.10	Cold Preservation End Date	The date that cold preservation ended for the specified organ(s)	YYYYMMDD
5.10.1	Cold Preservation End Time	The time of day that cold preservation ended for the specified organ(s)	HHMM **Note:** 24-hour clock.
5.11	Reperfusion Date	The date the vascular clamp is released after anastomosis in the recipient	YYYYMMDD
5.11.1	Reperfusion Time	The time of day the vascular clamp is released after anastomosis in the recipient	HHMM **Note:** 24-hour clock.
5.11.2	Cold Ischemia Time	The time elapsed (in minutes) between the start and end of cold preservation for the specified organ(s)	0000 to 4320 minutes (i.e., 0 to 72 hours) **Note:** UCUM is used for the unit of measure.

ID	Data element name	Description	Valid values
5.12	Procedure Type (Heart and pancreas transplants only)	The type of surgical procedure used for transplant	Heart: • 1: Biatrial • 2: Bicaval • OTH: Other • UNK: Unknown Pancreas: • 3: Enteric exocrine drainage • 4: Urinary exocrine drainage • 5: Systemic venous drainage • 6: Portal venous drainage • OTH: Other • UNK: Unknown **Note:** OTH and UNK are sourced from HL7.
5.13	Pre-Emptive Kidney Transplant (Kidney transplants only)	A kidney transplant that was done where the recipient had 2 or fewer weeks of dialysis before transplantation	• Y: Yes • N: No • UNK: Unknown **Note:** The value set codes are sourced from HL7.
5.14	Organ Transplanted	Indication of whether the transplant surgery was successfully completed (i.e., the donor's organ was transplanted into the recipient)	• Y: Yes • N: No **Note:** The value set codes are sourced from HL7.
5.15	Not Transplanted Reason	Reason the specified organ was not transplanted into a recipient	• 1: Organ deemed not suitable for transplant • 2: Recipient-related issues • 3: Surgical complications (surgical safety event) • OTH: Other • UNK: Unknown **Note:** OTH and UNK are sourced from HL7.

ID	Data element name	Description	Valid values
5.16	Primary Graft Dysfunction (Heart and lung transplants only)	Indication of whether the recipient had a primary graft dysfunction (PGD) **Lung transplants**: Lung PGD is diagnosed within 72 hours of the completion of the surgery.	• Y: Yes • N: No • UNK: Unknown **Note:** The value set codes are sourced from HL7.
5.17	Primary Graft Dysfunction Grade (Heart and lung transplants only)	Indication of the grade of the PGD **Heart transplants:** Heart PGD grade is submitted if the recipient experienced moderate PGD-left ventricle, severe PGD-left ventricle or PGD-right ventricle. **Lung transplants:** Lung PGD grade is submitted if the recipient experienced PGD grade 1, 2 or 3.	• 44921000087107: Heart moderate PGD (primary graft dysfunction) — Left ventricle • 44991000087105: Heart severe PGD (primary graft dysfunction) — Left ventricle • 44981000087108: Heart PGD (primary graft dysfunction) — Right ventricle • 1: Lung PGD (primary graft dysfunction) grade 1 • 44901000087101: Lung PGD (primary graft dysfunction) grade 2 • 44911000087104: Lung PGD (primary graft dysfunction) grade 3 **Note:** The value set codes 44921000087107, 44991000087105, 44981000087108, 44901000087101 and 44911000087104 are sourced from SNOMED CT Canadian Edition.
5.17.1	Surgical Complications	Indication of whether there were surgical complications	• Y: Yes • N: No **Note:** The value set codes are sourced from HL7.

ID	Data element name	Description	Valid values
5.18	Clavien–Dindo Classification	The classification of surgical complications using the Clavien–Dindo classification system	• 258351006: Grade I • 258352004: Grade II • 307203009: Grade IIIa • 307204003: Grade IIIb • 307206001: Grade IVa • 307207005: Grade IVb • 258355002: Grade V **Note:** The value set codes are sourced from SNOMED CT Canadian Edition.
5.19	Intra-Operative Death	Indication of whether the recipient died during the transplant surgery	• Y: Yes • N: No **Note:** The value set codes are sourced from HL7.
5.20	Delayed Graft Function (Kidney transplants only)	Indication of whether the recipient had delayed graft function (requires dialysis within the first week post-operatively)	• Y: Yes • N: No • UNK: Unknown **Note:** The value set codes are sourced from HL7.
5.21	Post-Transplant Dialysis (Kidney transplants only)	The number of dialysis sessions the recipient underwent within the first week post-operatively	#
5.22	MCS/ECLS — Post-Operative Device Used (Heart and lung transplants only)	Indication of whether an MCS or ECLS device was used post-operatively	• Y: Yes • N: No • UNK: Unknown **Note:** The value set codes are sourced from HL7.

ID	Data element name	Description	Valid values
5.23	MCS/ECLS — Post-Operative Type (Heart and lung transplants only)	The MCS or ECLS device that was used post-operatively	• 129113006: Intra-aortic balloon pump • 360066001: Left ventricular assist device • 360065002: Right ventricular assist device • 361158001: Artificial heart • 45001000087101: Venoarterial extracorporeal membrane oxygenation system • 45011000087104: Venovenous extracorporeal membrane oxygenation system • OTH: Other • UNK: Unknown **Note:** The value set codes are sourced from SNOMED CT Canadian Edition; OTH and UNK are sourced from HL7.
5.24	MCS/ECLS — Separation Date (Heart and lung transplants only)	The date of MCS or ECLS separation post-operatively	YYYYMMDD
5.26	Date of Hospital Discharge	The date the recipient was discharged from the hospital or the date of death in hospital	YYYYMMDD
5.27	Provider of Follow-Up Care	The health care team providing transplant follow-up care to the recipient, as determined at the time of discharge	• 1: Non-transplantation centre clinic • 2: Transplantation centre • 702855004: Family medicine clinic • OTH: Other • UNK: Unknown **Note:** The value set code 702855004 is sourced from SNOMED CT Canadian Edition; OTH and UNK are sourced from HL7.

Phase 6 Post-transplant follow-up

ID	Data element name	Description	Valid values
6.1.1.1	Date of Annual Follow-Up Visit (Pediatric patients only)	The date the annual follow-up visit occurred for pediatric patients (i.e., for Recipient Height, Recipient Weight, Academic Grade Level, Learning Difference or Disability, Learning Difference or Disability Type, and Cognitive Development Delay or Impairment)	YYYYMMDD
6.1.1	Route of Loss of Contact	The reason or method through which contact was lost with the recipient	• 1: Changed transplantation centre • 2: Transferred to non-transplantation centre clinic • 3: Contact information outdated • 4: Death • 5: Moved • 6: Non-responsive/unwilling to continue follow-up • OTH: Other **Note:** OTH is sourced from HL7.
6.1.2	Date of Loss of Follow-Up	The date the recipient care team lost contact with the recipient post-transplant or the date follow-up care was transferred	YYYYMMDD
6.1.3	Follow-Up Care — Facility Transferred To	If the recipient was transferred during their post-transplant follow-up care, the facility they were transferred to	**Note:** Subject to CIHI's Organization Index.
6.1.4	Follow-Up Care — Facility Transferred From	If the recipient was transferred during their post-transplant follow-up care, the facility they were transferred from	**Note:** Subject to CIHI's Organization Index.
6.1.5	Date Follow-Up Care Transfer Received	The date the transfer of follow-up care was received by the facility the recipient is transferring to	YYYYMMDD
6.2	Malignancy Diagnosis Date	The date of each post-transplant malignancy diagnosis	YYYYMMDD

ID	Data element name	Description	Valid values
6.3	Type of Malignancy	The type of malignancy that the recipient was diagnosed with post-transplant	• 399326009: Bladder cancer • 254837009: Breast cancer • 363354003: Cervical cancer • 372062007: Malignant neoplasm of central nervous system • 781382000: Colorectal cancer • 363349007: Gastric cancer • 271468000: Malignant neoplasm of genitourinary organ • 363402007: Esophageal cancer • 109841003: Hepatocellular carcinoma • 93143009: Leukemia • 93870000: Liver cancer • 363358000: Lung cancer • 118600007: Lymphoma • 109989006: Multiple myeloma • 363392002: Cancer of oropharynx • 254290004: Post-transplant lymphoproliferative disorder • 399068003: Cancer of prostate • 702391001: Renal cell carcinoma • 424413001: Sarcoma • 93655004: Melanoma of skin • 1418361000168101: Non-melanoma skin cancer • 363449006: Malignant tumor of testis • 363478007: Thyroid cancer • OTH: Other • UNK: Unknown **Note:** The value set codes are sourced from SNOMED CT Canadian Edition; OTH and UNK are sourced from HL7.

ID	Data element name	Description	Valid values
6.3.1	Date of 1-Year Heart Transplant Follow-Up (Heart transplants only)	The date the recipient received their 1-year heart post-transplant follow-up	YYYYMMDD
6.4	Statin Use at 1-Year Follow-Up (Heart transplants only)	Indication of whether the recipient was prescribed and remained on a statin 1-year post-transplant	• Y: Yes • N: No • UNK: Unknown **Note:** The value set codes are sourced from HL7.
6.5	CAV — Screening Date (Heart transplants only)	The date the recipient was screened for cardiac allograft vasculopathy (CAV)	YYYYMMDD
6.6	CAV — Screening Methodology (Heart transplants only)	The method used for the screening and diagnosis of CAV	• 77343006: Angiography • 703338002: Stress echocardiography using dobutamine • 241466007: Intravascular ultrasonography of blood vessel **Note:** The value set codes are sourced from SNOMED CT Canadian Edition.
6.7	CAV — Diagnosis (Heart transplants only)	The results of the CAV screening and indication of whether the recipient was diagnosed with CAV	• 10828004: Positive • 260385009: Negative • 373068000: Undetermined **Note:** The value set codes are sourced from SNOMED CT Canadian Edition.

ID	Data element name	Description	Valid values
6.8	CAV — Grade (Heart transplants only)	The CAV grade, per Pollack A, et al. Detection and imaging of cardiac allograft vasculopathy. *JACC: Cardiovascular Imaging*. 2013	• 45581000087102: CAV (cardiac allograft vasculopathy) 0 • 45561000087108: CAV (cardiac allograft vasculopathy) 1 • 45571000087104: CAV (cardiac allograft vasculopathy) 2 • 45591000087100: CAV (cardiac allograft vasculopathy) 3 • UNK: Unknown **Note:** CAV grades obtained from Pollack A, et al. Detection and imaging of cardiac allograft vasculopathy. *JACC: Cardiovascular Imaging*. 2013. The value set codes are sourced from SNOMED CT Canadian Edition; UNK is sourced from HL7.
6.9	CAV — mTORi Prescribed (Heart transplants only)	Indication of whether the recipient was prescribed mammalian target of rapamycin inhibitors (mTORi) when they were diagnosed with CAV	• Y: Yes • N: No • UNK: Unknown **Note:** The value set codes are sourced from HL7.
6.10	Infection Type	The type of infection acquired by the recipient	• 87628006: Bacterial infection • 3218000: Fungal infection • 34014006: Viral infection • UNK: Unknown **Note:** The value set codes are sourced from SNOMED CT Canadian Edition; UNK is sourced from HL7.
6.11	Date(s) Infection Identified	The date(s) of infection or reactivation requiring treatment or adjustment of immunosuppression medication	YYYYMMDD

ID	Data element name	Description	Valid values
6.11.1	Virus Source	The source of the virus that caused the infection or reactivation	• 44881000087104: Reactivation of latent infection • 44871000087101: Donor-derived infection • 255219008: Newly acquired infection • UNK: Unknown **Note:** The value set codes are sourced from SNOMED CT Canadian Edition; UNK is sourced from HL7.
6.12	Virus That Caused the Infection or Reactivation	The virus that caused the infection or reactivation (e.g., cytomegalovirus [CMV], Epstein–Barr virus [EBV])	• 83397001: BK virus • 407444007: Cytomegalovirus • 40168006: Epstein–Barr virus • 81665004: Hepatitis B virus • 62944002: Hepatitis C virus • 78475006: Hepatitis E virus • 19965007: Herpes simplex virus • 19030005: Human immunodeficiency virus • 36319009: JC virus • 19551004: Varicella-zoster virus • 57311007: West Nile virus • OTH: Other • UNK: Unknown **Note:** The value set codes are sourced from SNOMED CT Canadian Edition; OTH and UNK are sourced from HL7.
6.13	Date of Diabetes New-Onset Post-Transplant	The date of diagnosis for new-onset diabetes	YYYYMMDD
6.14	Date of Post-Transplant Chronic Dialysis	The date the recipient began chronic dialysis after transplant	YYYYMMDD
6.15	End of Total Parenteral Nutrition Date (Intestine transplants only)	The date the recipient discontinued total parenteral nutrition post-transplant surgery	YYYYMMDD

ID	Data element name	Description	Valid values
6.15.1	Date of 1-Year Lung Transplant Follow-Up (Lung transplants only)	The date the recipient received their 1-year lung post-transplant follow-up	YYYYMMDD
6.16	Best Percentage Predicted Forced Expiratory Volume in 1 Second (Lung transplants only)	The average of the 2 best measures of the forced expiratory volume in 1 second percentage predicted that were taken at least 3 weeks apart in the first year post-operatively	0% to 100%
6.17	CLAD — Diagnosis Date (Lung transplants only)	The date of diagnosis for definite chronic lung allograft dysfunction (CLAD)	YYYYMMDD
6.18	CLAD — Stage (Lung transplants only)	The stage of the CLAD at the time of diagnosis	• 45521000087103: CLAD (chronic lung allograft dysfunction) 1 • 45531000087101: CLAD (chronic lung allograft dysfunction) 2 • 45541000087107: CLAD (chronic lung allograft dysfunction) 3 • 45551000087105: CLAD (chronic lung allograft dysfunction) 4 **Note:** The value set codes are sourced from SNOMED CT Canadian Edition
6.19	CLAD — Phenotype (Lung transplants only)	The phenotype of the diagnosed CLAD	• 762618008: Bronchiolitis obliterans syndrome due to and after lung transplantation • 45481000087103: Restrictive allograft syndrome • 45471000087100: Mixed CLAD (chronic lung allograft dysfunction) phenotype • 45491000087101: Undefined CLAD (chronic lung allograft dysfunction) phenotype **Note:** The value set codes are sourced from SNOMED CT Canadian Edition
6.20	Graft Rejection Date	The start date(s) of the graft rejection episode(s)	YYYYMMDD

ID	Data element name	Description	Valid values
6.20.1	Graft Rejection — Organ	The organ associated with the graft rejection	• BOW: Bowel/intestine • HRT: Heart • KDD: Kidneys/dialysis (includes en bloc transplants) • LUB: Lung — Bilateral/en bloc • LVR: Liver — Whole • PAN: Pancreas — Whole **Note:** The value set codes are sourced from CRDM.
6.21	Graft Rejection Category	Identifies the grade, type or diagnosis of the graft rejection with respect to the transplanted organ	See list in Appendix F
6.22	Donor-Specific Antibody	The type of donor-specific antibody (DSA) at the time of graft rejection	• 2667000: Absent • 44961000087102: Present de novo • 44971000087106: Present pre-existing • 373121007: Test not done • 373068000: Undetermined **Note:** The value set codes are sourced from SNOMED CT Canadian Edition.
6.22.1	Graft Failure — Organ	The organ associated with the graft failure	• BOW: Bowel/intestine • HRT: Heart • KDD: Kidneys/dialysis (includes en bloc transplants) • LUB: Lung — Bilateral/en bloc • LVR: Liver — Whole • PAN: Pancreas — Whole **Note:** The value set codes are sourced from CRDM.
6.22.2	Date of Graft Failure	The date the transplanted organ ceased to function adequately **Pancreas transplants:** Pancreatic graft failure is measured at the date of restarting insulin after transplantation.	YYYYMMDD
6.23	Reason for Graft Failure	The reason the transplanted organ ceased to function adequately	See list in Appendix G

ID	Data element name	Description	Valid values
6.29	Post-Transplant Cause of Death	The most proximate injury/illness that led to the death of the recipient	See list in Appendix H Additional values: • OTH: Other • UNK: Unknown **Note:** OTH and UNK are sourced from HL7.
6.31	Recipient Died With a Functioning Graft	Indication of whether the recipient died with a functioning graft	• Y: Yes • N: No • UNK: Unknown **Note:** The value set codes are sourced from HL7.

Appendices

Appendix A: Transplantation workflow

The 2 figures below depict the optimal high-level transplantation journeys. The workflows have been validated with transplantation centres participating in the CIHI–Infoway ODT Project's Business Data Management Expert Advisory Forum (February 2022).

Figure A1 Transplant following living donation workflow

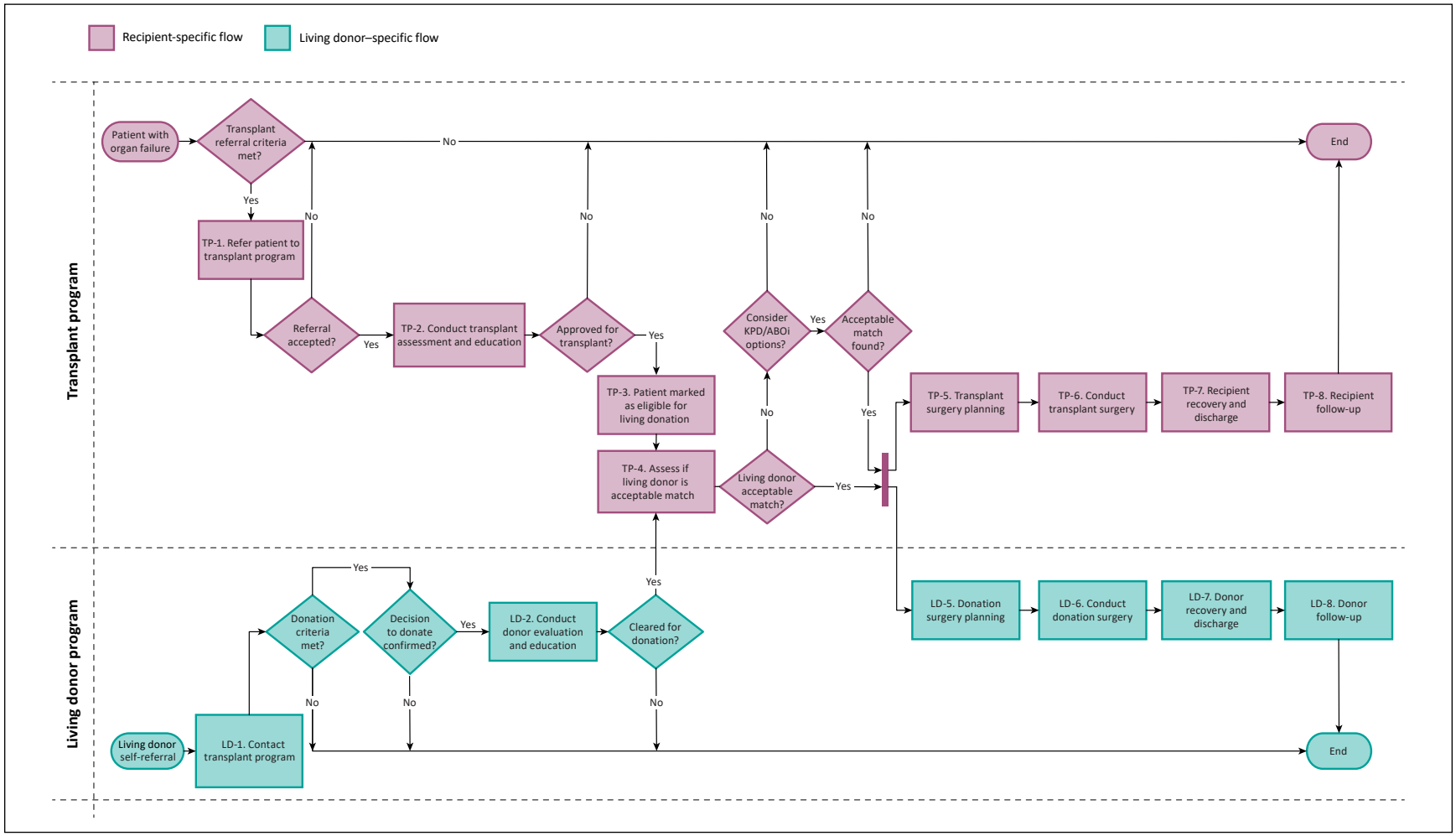
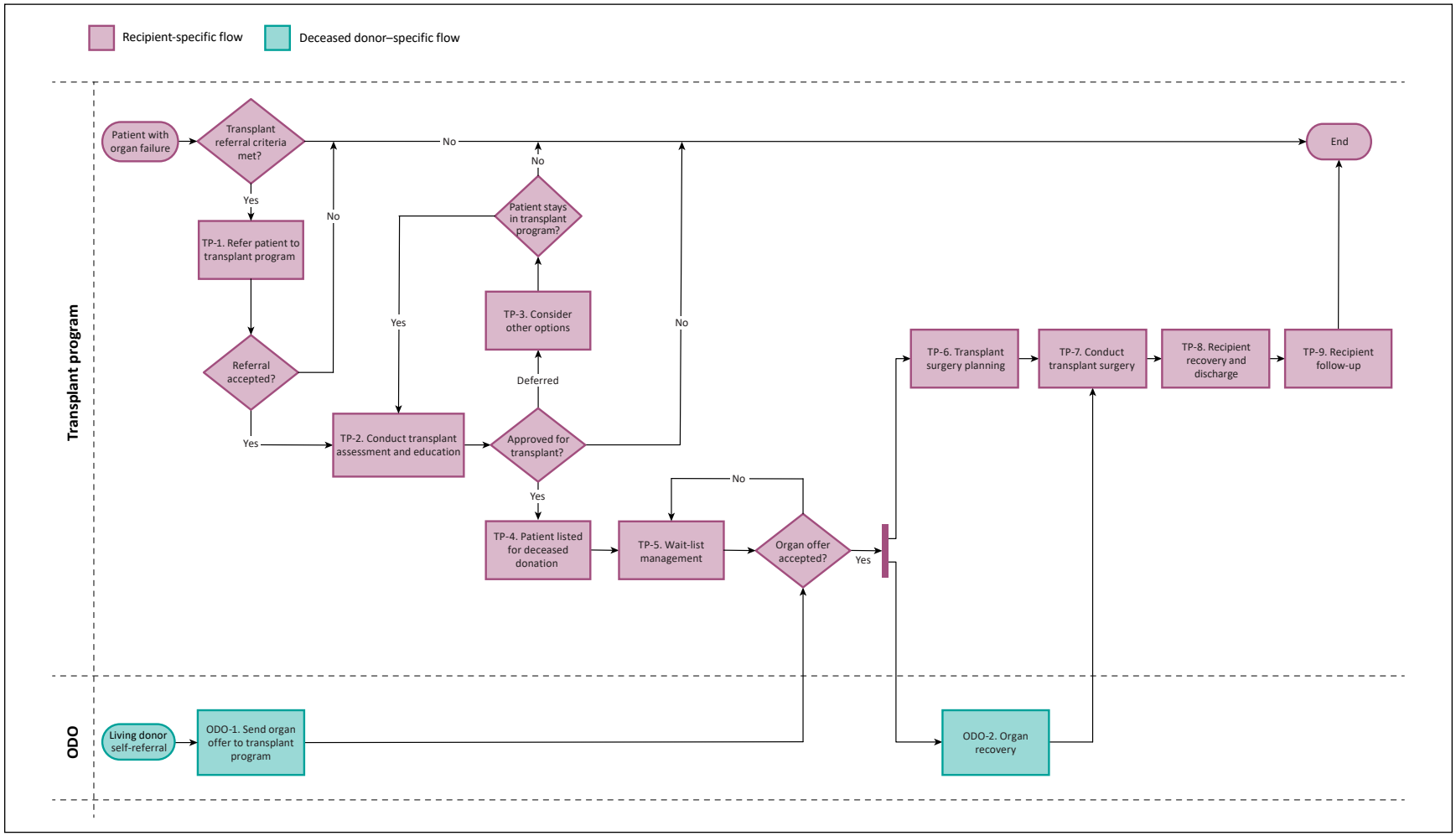


Figure A2 Transplant following deceased donation workflow



Appendix B: Country codes

The following table provides a list of country codes for data elements 1.8 (Recipient Country of Residence) and 2.3.1.1 (Previous Transplant(s) — Country). This CIHI standard country code pick-list is a subset of the current ISO 3166-1 standard. It includes 249 unique country codes that are relevant to Canada, including 2 additional countries from Statistics Canada — Kosovo (XKO) and Sark (XSQ) — that are not part of ISO 3166-1. Note that for a number of countries, the short name from Statistics Canada is used rather than what is provided in ISO 3166-1.

Alpha-3 code	English short name	French short name
AFG	Afghanistan	Afghanistan
ALA	Åland Islands	Åland, Îles
ALB	Albania	Albanie
DZA	Algeria	Algérie
ASM	American Samoa	Samoa américaines
AND	Andorra	Andorre
AGO	Angola	Angola
AIA	Anguilla	Anguilla
ATA	Antarctica	Antarctique
ATG	Antigua and Barbuda	Antigua-et-Barbuda
ARG	Argentina	Argentine
ARM	Armenia	Arménie
ABW	Aruba	Aruba
AUS	Australia	Australie
AUT	Austria	Autriche
AZE	Azerbaijan	Azerbaïdjan
BHS	Bahamas	Bahamas
BHR	Bahrain	Bahreïn
BGD	Bangladesh	Bangladesh
BRB	Barbados	Barbade
BLR	Belarus	Bélarus
BEL	Belgium	Belgique
BLZ	Belize	Belize
BEN	Benin	Bénin
BMU	Bermuda	Bermudes
BTN	Bhutan	Bhoutan
BOL	Bolivia	Bolivie
BES	Bonaire, Sint Eustatius and Saba	Bonaire, Saint-Eustache et Saba
BIH	Bosnia and Herzegovina	Bosnie-Herzégovine

Alpha-3 code	English short name	French short name
BWA	Botswana	Botswana
BVT	Bouvet Island	Bouvet, Île
BRA	Brazil	Brésil
IOT	British Indian Ocean Territory	Territoire britannique de l'océan Indien
BRN	Brunei Darussalam	Brunéi Darussalam
BGR	Bulgaria	Bulgarie
BFA	Burkina Faso	Burkina Faso
MMR	Burma (Myanmar)	Birmanie (Myanmar)
BDI	Burundi	Burundi
CPV	Cabo Verde	Cabo Verde
KHM	Cambodia	Cambodge
CMR	Cameroon	Cameroun
CAN	Canada	Canada
CYM	Cayman Islands	Caïmans, Îles
CAF	Central African Republic	Centrafricaine, République
TCD	Chad	Tchad
CHL	Chile	Chili
CHN	China	Chine
CXR	Christmas Island	Christmas, Île
CCK	Cocos (Keeling) Islands	Cocos (Keeling), Îles
COL	Colombia	Colombie
COM	Comoros	Comores
COD	Congo, Democratic Republic of the	Congo, République démocratique du
COG	Congo, Republic of the	Congo, République du
COK	Cook Islands	Cook, Îles
CRI	Costa Rica	Costa Rica
CIV	Côte d'Ivoire	Côte d'Ivoire
HRV	Croatia	Croatie
CUB	Cuba	Cuba
CUW	Curaçao	Curaçao
CYP	Cyprus	Chypre
CZE	Czechia	Tchéquie
DNK	Denmark	Danemark
DJI	Djibouti	Djibouti
DMA	Dominica	Dominique
DOM	Dominican Republic	Dominicaine, République
ECU	Ecuador	Équateur
EGY	Egypt	Égypte

Alpha-3 code	English short name	French short name
SLV	El Salvador	El Salvador
GNQ	Equatorial Guinea	Guinée équatoriale
ERI	Eritrea	Érythrée
EST	Estonia	Estonie
ETH	Ethiopia	Éthiopie
FLK	Falkland Islands (Malvinas)	Falkland, Îles (Malvinas)
FRO	Faroe Islands	Féroé, Îles
FJI	Fiji	Fidji
FIN	Finland	Finlande
FRA	France	France
GUF	French Guiana	Guyane française
PYF	French Polynesia	Polynésie française
ATF	French Southern Territories	Terres australes françaises
GAB	Gabon	Gabon
GMB	Gambia	Gambie
GEO	Georgia	Géorgie
DEU	Germany	Allemagne
GHA	Ghana	Ghana
GIB	Gibraltar	Gibraltar
GRC	Greece	Grèce
GRL	Greenland	Groenland
GRD	Grenada	Grenade
GLP	Guadeloupe	Guadeloupe
GUM	Guam	Guam
GTM	Guatemala	Guatemala
GGY	Guernsey	Guernesey
GIN	Guinea	Guinée
GNB	Guinea-Bissau	Guinée-Bissau
GUY	Guyana	Guyana
HTI	Haiti	Haïti
HMD	Heard Island and McDonald Islands	Heard-et-Îles MacDonald, Île
VAT	Holy See (Vatican City State)	Saint-Siège (État de la Cité du Vatican)
HND	Honduras	Honduras
HKG	Hong Kong	Hong Kong
HUN	Hungary	Hongrie
ISL	Iceland	Islande
IND	India	Inde
IDN	Indonesia	Indonésie

Alpha-3 code	English short name	French short name
IRN	Iran	Iran
IRQ	Iraq	Iraq
IRL	Ireland	Irlande
IMN	Isle of Man	Île de Man
ISR	Israel	Israël
ITA	Italy	Italie
JAM	Jamaica	Jamaïque
JPN	Japan	Japon
JEY	Jersey	Jersey
JOR	Jordan	Jordanie
KAZ	Kazakhstan	Kazakhstan
KEN	Kenya	Kenya
KIR	Kiribati	Kiribati
PRK	Korea, North	Corée du Nord
KOR	Korea, South	Corée du Sud
XKO	Kosovo	Kosovo
KWT	Kuwait	Koweït
KGZ	Kyrgyzstan	Kirghizistan
LAO	Laos	Laos
LVA	Latvia	Lettonie
LBN	Lebanon	Liban
LSO	Lesotho	Lesotho
LBR	Liberia	Libéria
LBY	Libya	Libye
LIE	Liechtenstein	Liechtenstein
LTU	Lithuania	Lituanie
LUX	Luxembourg	Luxembourg
MAC	Macao	Macao
MKD	Macedonia, Republic of	Macédoine, République de
MDG	Madagascar	Madagascar
MWI	Malawi	Malawi
MYS	Malaysia	Malaisie
MDV	Maldives	Maldives
MLI	Mali	Mali
MLT	Malta	Malte
MHL	Marshall Islands	Marshall, Îles
MTQ	Martinique	Martinique
MRT	Mauritania	Mauritanie

Alpha-3 code	English short name	French short name
MUS	Mauritius	Maurice
MYT	Mayotte	Mayotte
MEX	Mexico	Mexique
FSM	Micronesia, Federated States of	Micronésie, États fédérés de
MDA	Moldova	Moldova
MCO	Monaco	Monaco
MNG	Mongolia	Mongolie
MNE	Montenegro	Monténégro
MSR	Montserrat	Montserrat
MAR	Morocco	Maroc
MOZ	Mozambique	Mozambique
NAM	Namibia	Namibie
NRU	Nauru	Nauru
NPL	Nepal	Népal
NLD	Netherlands	Pays-Bas
NCL	New Caledonia	Nouvelle-Calédonie
NZL	New Zealand	Nouvelle-Zélande
NIC	Nicaragua	Nicaragua
NER	Niger	Niger
NGA	Nigeria	Nigéria
NIU	Niue	Niue
NFK	Norfolk Island	Norfolk, Île
MNP	Northern Mariana Islands	Mariannes du Nord, Îles
NOR	Norway	Norvège
OMN	Oman	Oman
PAK	Pakistan	Pakistan
PLW	Palau	Palaos
PAN	Panama	Panama
PNG	Papua New Guinea	Papouasie-Nouvelle-Guinée
PRY	Paraguay	Paraguay
PER	Peru	Pérou
PHL	Philippines	Philippines
PCN	Pitcairn	Pitcairn
POL	Poland	Pologne
PRT	Portugal	Portugal
PRI	Puerto Rico	Porto Rico
QAT	Qatar	Qatar
REU	Réunion	Réunion

Alpha-3 code	English short name	French short name
ROU	Romania	Roumanie
RUS	Russian Federation	Russie, Fédération de
RWA	Rwanda	Rwanda
BLM	Saint Barthélemy	Saint-Barthélemy
SHN	Saint Helena	Sainte-Hélène
KNA	Saint Kitts and Nevis	Saint-Kitts-et-Nevis
LCA	Saint Lucia	Sainte-Lucie
MAF	Saint Martin (French part)	Saint-Martin (partie française)
SPM	Saint Pierre and Miquelon	Saint-Pierre-et-Miquelon
VCT	Saint Vincent and the Grenadines	Saint-Vincent-et-les Grenadines
WSM	Samoa	Samoa
SMR	San Marino	Saint-Marin
STP	Sao Tome and Principe	Sao Tomé-et-Principe
XSQ	Sark	Sercq
SAU	Saudi Arabia	Arabie saoudite
SEN	Senegal	Sénégal
SRB	Serbia	Serbie
SYC	Seychelles	Seychelles
SLE	Sierra Leone	Sierra Leone
SGP	Singapore	Singapour
SXM	Sint Maarten (Dutch part)	Saint-Martin (partie néerlandaise)
SVK	Slovakia	Slovaquie
SVN	Slovenia	Slovénie
SLB	Solomon Islands	Salomon, Îles
SOM	Somalia	Somalie
ZAF	South Africa, Republic of	Afrique du Sud, République d’
SGS	South Georgia and the South Sandwich Islands	Géorgie du Sud-et-les Îles Sandwich du Sud
SSD	South Sudan	Soudan du Sud
ESP	Spain	Espagne
LKA	Sri Lanka	Sri Lanka
SDN	Sudan	Soudan
SUR	Suriname	Suriname
SJM	Svalbard and Jan Mayen	Svalbard et l’Île Jan Mayen
SWZ	Swaziland	Swaziland
SWE	Sweden	Suède
CHE	Switzerland	Suisse
SYR	Syria	Syrie
TWN	Taiwan	Taïwan

Alpha-3 code	English short name	French short name
TJK	Tajikistan	Tadjikistan
TZA	Tanzania	Tanzanie
THA	Thailand	Thaïlande
TLS	Timor-Leste	Timor-Leste
TGO	Togo	Togo
TKL	Tokelau	Tokélaou
TON	Tonga	Tonga
TTO	Trinidad and Tobago	Trinité-et-Tobago
TUN	Tunisia	Tunisie
TUR	Turkey	Turquie
TKM	Turkmenistan	Turkménistan
TCA	Turks and Caicos Islands	Turks-et-Caïcos, Îles
TUV	Tuvalu	Tuvalu
UGA	Uganda	Ouganda
UKR	Ukraine	Ukraine
ARE	United Arab Emirates	Émirats arabes unis
GBR	United Kingdom	Royaume-Uni
USA	United States	États-Unis
UMI	United States Minor Outlying Islands	Îles mineures éloignées des États-Unis
URY	Uruguay	Uruguay
UZB	Uzbekistan	Ouzbékistan
VUT	Vanuatu	Vanuatu
VEN	Venezuela	Venezuela
VNM	Viet Nam	Viet Nam
VGB	Virgin Islands, British	Vierges britanniques, Îles
VIR	Virgin Islands, United States	Vierges des États-Unis, Îles
WLF	Wallis and Futuna	Wallis-et-Futuna
PSE	West Bank and Gaza Strip (Palestine)	Cisjordanie et bande de Gaza (Palestine)
ESH	Western Sahara*	Sahara occidental*
YEM	Yemen	Yémen
ZMB	Zambia	Zambie
ZWE	Zimbabwe	Zimbabwe

Note

***** Provisional name / Nom provisoire.

Source

Canadian Institute for Health Information. *Country Codes*. 2020.

Appendix C: Organ Diagnosis values

The following table provides a list of values for data elements 2.1 (Organ Diagnosis — Primary) and 2.2 (Organ Diagnosis — Secondary). These values were adapted from CIHI's Canadian Organ Replacement Register (CORR) and the International Intestine Transplant Registry (IITR).

Organ	Valid values
Intestine	Short gut: 1: Crohn's disease 2: Gastroschisis 3: Intestinal atresia 4: Intestinal ischemia 5: Necrotising enterocolitis 6: Trauma 7: Volvulus OTH: Other Motility disorder: 8: Aganglionosis/Hirschsprung disease 9: Chronic intestinal pseudo-obstruction (CIPO) 10: Dysmotility NYD OTH: Other Mucosal enteropathies: 11: Autoimmune enteritis 12: Microvillus inclusion disease 13: Protein-losing enteropathy 14: Tufting enteropathy OTH: Other Tumour/cancer: 15: Desmoid 16: Gardner syndrome/familial polyposis OTH: Other Vascular: 17: Diffuse portomesenteric thrombosis Re-transplant: 18: Retransplant

Organ	Valid values
Heart	19: Acute myocardial infarction 20: Cardiac tumour 21: Congenital heart disease 22: Coronary artery disease 23: Dilated cardiomyopathy 24: Hypertrophic cardiomyopathy 25: Metabolic disorder 26: Muscular dystrophy 27: Myocarditis 28: Refractive arrhythmia 29: Restrictive cardiomyopathy 30: Valvular heart disease OTH: Other UNK: Unknown
Kidney	31: Congenital renal disease 32: Diabetes 33: Drug-induced nephropathy 34: Glomerulonephritis/autoimmune diseases 35: Polycystic kidney 36: Renal vasculopathy OTH: Other UNK: Unknown
Liver	25: Metabolic disorder 37: Acute hepatic failure 38: Alcoholic liver disease 39: Hepatic tumour 40: Hepatitis B or C 41: Nonalcoholic steatohepatitis OTH: Other UNK: Unknown
Lung	42: Alpha I antitrypsin deficiency 43: Asbestosis 44: Bronchiectasis 45: Bronchiolitis obliterans 46: Cardiomyopathy 47: Chronic lung allograft dysfunction 48: Chronic obstructive lung disease 49: Congenital lung disease 50: Cystic fibrosis 51: Eisenmenger syndrome 52: Emphysema 53: Idiopathic pulmonary fibrosis 54: Primary pulmonary hypertension 55: Sarcoidosis OTH: Other UNK: Unknown

Organ	Valid values
Pancreas	6: Trauma 50: Cystic fibrosis 56: Bile duct cancer 57: Chronic pancreatitis 58: Diabetes type 1 59: Diabetes type 2 60: Pancreatectomy 61: Pancreatic cancer OTH: Other UNK: Unknown

Note
OTH and UNK are sourced from HL7.

Appendix D: Medical Status values

The following table provides a list of values for data element 3.11 (Medical Status). They describe the medical status of transplant candidates.

Organ	Valid values
Intestine	1: Status 1: Candidate is waiting at home 2: Status 2: Candidate is hospitalized for related disease 3: Status 3: Candidate is in ICU or step-down unit for complication of bowel disease
Heart	4: Status 1 5: Status 1S 6: Status 2 7: Status 2S 8: Status 3 9: Status 3S 10: Status 3.5 11: Status 3.5S 12: Status 4
Kidney	13: Normal priority 14: High priority (medically urgent)
Liver	15: Status 1: At home 16: Status 2: Hospitalized 17: Status 3: Hospitalized in ICU but not intubated 18: Status 3F: Hospitalized in ICU but not intubated; fulminant hepatic failure (FHF) 19: Status 4: Hospitalized in ICU and intubated 20: Status 4F: Hospitalized in ICU and intubated; fulminant hepatic failure (FHF)
Lung	21: Status 1: Stable and waiting 22: Status 2: Decompensation 23: Status 3: Heart–lung or rapidly deteriorating

Source
Canadian Cardiac Transplant Network. *Heart Status Listing Revision November 9 2021.* 2021.

Appendix E: HLA values

The following table provides a list of HLA values for data elements 4.1 to 4.5.1 (HLA A, B, C, DQ, DR and DP, respectively). These HLA values come from the Immuno Polymorphism Database–ImMunoGeneTics/Human Leukocyte Antigen (IPD-IMGT/HLA) Database.

HLA group	Valid values
HLA A	A1, A2, A203, A210, A3, A9, A10, A11, A19, A23(9), A24(9), A2403, A25(10), A26(10), A28, A29(19), A30(19), A31(19), A32(19), A33(19), A34(10), A36, A43, A66(10), A68(28), A69(28), A74(19), A80
HLA B	B5, B7, B703, B8, B12, B13, B14, B15, B16, B17, B18, B21, B22, B27, B2708, B35, B37, B38(16), B39(16), B3901, B3902, B40, B4005, B41, B42, B44(12), B45(12), B46, B47, B48, B49(21), B50(21), B51(5), B5102, B5103, B52(5), B53, B54(22), B55(22), B56(22), B57(17), B58(17), B59, B60(40), B61(40), B62(15), B63(15), B64(14), B65(14), B67, B70, B71(70), B72(70), B73, B75(15), B76(15), B77(15), B78, B81, B82, Bw4, Bw6
HLA C	Cw1, Cw2, Cw3, Cw4, Cw5, Cw6, Cw7, Cw8, Cw9(w3), Cw10(w3)
HLA DR	DR1, DR103, DR2, DR3, DR4, DR5, DR6, DR7, DR8, DR9, DR10, DR11(5), DR12(5), DR13(6), DR14(6), DR1403, DR1404, DR15(2), DR16(2), DR17(3), DR18(3), DR51, DR52, DR53
HLA DQ	DQ1, DQ2, DQ3, DQ4, DQ5(1), DQ6(1), DQ7(3), DQ8(3), DQ9(3)
HLA DP	DPw1, DPw2, DPw3, DPw4, DPw5, DPw6

Sources

Marsh SGE, et al. Nomenclature for factors of the HLA system, 2010. *Tissue Antigens.* 2010.
Robinson J, et al. IPD-IMGT/HLA Database. *Nucleic Acids Research.* 2020.

Appendix F: Graft Rejection Category values

The following table provides a list of values for data element 6.21 (Graft Rejection Category). They identify the grade, type or diagnosis of the graft rejection with respect to the transplanted organ.

Organ	Valid values
Intestine	1: Mixed rejection 2: Suspected symptomatic rejection, biopsy not performed 3: Acute cellular rejection, grade 2 (moderate) 4: Acute cellular rejection, grade 3 (severe) 5: Antibody-mediated rejection 6: Antibody-mediated rejection with c4d positivity 7: Chronic antibody-mediated rejection 8: Chronic T cell-mediated rejection
Heart	1: Mixed rejection 2: Suspected symptomatic rejection, biopsy not performed 9: Acute cellular rejection grade 2R (moderate) 10: Acute cellular rejection grade 3R (severe) 11: Antibody-mediated rejection grade 2 (pathological antibody-mediated rejection) 12: Antibody-mediated rejection grade 3 (severe pathological antibody-mediated rejection)
Kidney	1: Mixed rejection 2: Suspected symptomatic rejection, biopsy not performed Banff diagnoses: 13: Acute antibody-mediated rejection 14: Chronic active antibody-mediated rejection 15: Chronic (inactive) antibody-mediated rejection 16: Borderline (suspicious) for acute T cell-mediated rejection 17: Acute T cell-mediated rejection, grade IA 18: Acute T cell-mediated rejection, grade IB 19: Acute T cell-mediated rejection, grade IIA 20: Acute T cell-mediated rejection, grade IIB 21: Acute T cell-mediated rejection, grade III 22: Chronic active T cell-mediated rejection, grade IA 23: Chronic active T cell-mediated rejection, grade IB 24: Chronic active T cell-mediated rejection, grade II

Organ	Valid values
Liver	1: Mixed rejection 2: Suspected symptomatic rejection, biopsy not performed Banff diagnoses: 25: T cell-mediated rejection, moderate 26: T cell-mediated rejection, severe 27: Early chronic rejection 28: Late chronic rejection 29: Plasma cell-rich rejection 30: Definite acute/active antibody-mediated rejection 31: Suspicious acute/active antibody-mediated rejection 32: Probable chronic active antibody-mediated rejection 33: Possible chronic active antibody-mediated rejection
Lung	1: Mixed rejection 2: Suspected symptomatic rejection, biopsy not performed 34: Acute rejection grade A1 (minimal) 35: Acute rejection grade A2 (mild) 36: Acute rejection grade A3 (moderate) 37: Acute rejection grade A4 (severe) 38: Definite clinical antibody-mediated rejection 39: Probable clinical antibody-mediated rejection 40: Possible clinical antibody-mediated rejection
Pancreas	1: Mixed rejection 2: Suspected symptomatic rejection, biopsy not performed Banff diagnoses: 14: Chronic active antibody-mediated rejection 41: Chronic allograft arteriopathy 42: Chronic allograft rejection/graft fibrosis: Stage II (moderate graft fibrosis) 43: Chronic allograft rejection/graft fibrosis: Stage III (severe graft fibrosis) 44: Grade II/Moderate acute T cell-mediated rejection 45: Grade III/Severe acute T cell-mediated rejection 46: Grade II/Moderate acute antibody-mediated rejection 47: Grade III/Severe acute antibody-mediated rejection

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Appendix G: Reason for Graft Failure values

The following table provides a list of values for data element 6.23 (Reason for Graft Failure) and indicates whether the value applies for each of the 6 organs. These values were adapted from CORR.

Valid values	Intestine	Heart	Kidney	Liver	Lung	Pancreas
1: Acute rejection	Y	Y	Y	Y	Y	Y
2: Antibody-mediated rejection	Y	N	N	N	N	N
3: Arterial thrombosis	Y	N	N	Y	N	Y
4: Biliary tract complications	N	N	N	Y	N	N
5: Bronchiolitis obliterans	N	N	N	N	Y	N
6: Cardiac allograft vasculopathy	N	Y	N	N	N	N
7: Chronic rejection	Y	Y	Y	Y	Y	Y
8: Coronary artery disease	N	Y	N	N	N	N
9: Cyclosporin toxicity	N	N	Y	N	N	N
10: De novo hepatitis	N	N	N	Y	N	N
11: Graft/hepatic vein thrombosis	N	N	N	Y	N	N
12: Graft/portal vein thrombosis	N	N	N	Y	N	N
13: Hyperacute rejection	Y	Y	Y	Y	Y	Y
14: Infection (coronavirus)	N	Y	Y	Y	N	Y
15: Infection of graft	Y	Y	Y	Y	Y	Y
16: Large airway complications	N	N	N	Y	N	N
17: Mix of rejection and infection	y	Y	Y	Y	Y	Y
18: Newly diagnosed malignancy in graft	y	N	Y	Y	Y	Y
19: Pancreatitis	N	N	N	N	N	Y
20: Post-transplant lymphoproliferative disorder	Y	Y	Y	Y	Y	N
21: Primary graft dysfunction	N	N	N	N	Y	N
22: Primary non-function	Y	Y	Y	Y	N	Y
23: Pulmonary hypertension	N	Y	N	N	Y	N
24: Recurrence of original disease	Y	Y	Y	Y	Y	N
25: Rejection after stopping immunosuppression	Y	Y	Y	Y	N	N
26: Rejection secondary to noncompliance	N	Y	N	N	Y	N
27: Surgical complication: Bowel perforation	Y	N	N	N	N	N
28: Surgical complication: Not specified	Y	Y	Y	Y	Y	Y
29: Surgical complication: Other	Y	N	N	N	N	N
30: Surgical complication: Vascular	Y	N	N	N	N	N
31: Ureteric operative problems	N	N	Y	N	N	N

Valid values	Intestine	Heart	Kidney	Liver	Lung	Pancreas
32: Vascular event in graft	N	Y	Y	N	Y	N
33: Venous thrombosis	N	N	N	N	N	Y
OTH: Other	Y	Y	Y	Y	Y	Y
UNK: Unknown	Y	Y	Y	Y	Y	Y

Notes
Y: Yes, value applies.
N: No, value does not apply.
OTH and UNK are sourced from HL7.

Appendix H: Post-Transplant Cause of Death values

The following tables provides a list of values for data element 6.29 (Post-Transplant Cause of Death). They describe the most proximate injury/illness that led to the death of the recipient. These values were adapted from CORR.

Group	Valid values
Accident	1: Accident related to treatment 2: Accident unrelated to treatment
Cardiac	3: Cardiac arrest, cause unknown 4: Fluid overload 5: Hemorrhagic pericarditis 6: Hyperkalemia 7: Hypertensive cardiac failure 8: Hypokalemia 9: Myocardial ischemia and infarction 10: Other causes of cardiac failure
Gastrointestinal	11: Acute gastroenteritis with dehydration 12: Gastrointestinal hemorrhage 13: Gastrointestinal tumour with or without perforation 14: Mesenteric infarction 15: Pancreatitis 16: Perforation of colon/small bowel 17: Perforation of peptic ulcer 18: Sclerosing (or adhesive) peritoneal disease
Hematologic	19: Bone marrow depression 20: Thrombocytopenia 21: Thrombosis
Infection	22: Infection (coronavirus) 23: Cytomegalovirus 24: Epstein–Barr virus 25: Generalized viral infection 26: Infection (fungal) 27: Infection (viral) 28: Infection (bacterial) 29: Infections elsewhere (excluding viral hepatitis) 30: Peritonitis (not sclerosing [or adhesive] peritoneal disease) 31: Pneumocystic carinii pneumonia 32: Protozoal/parasitic infection (includes toxoplasmosis) 33: Pulmonary infection (bacterial) 34: Pulmonary Infection (fungal) 35: Pulmonary infection (viral) 36: Septicemia/sepsis 37: Tuberculosis (elsewhere) 38: Tuberculosis (lung) 39: Wound infection

Group	Valid values
Liver disease	40: Cirrhosis, not viral 41: Cystic liver disease 42: Liver failure, cause unknown 43: Liver, drug toxicity 44: Liver, due to hepatitis B virus 45: Liver, due to hepatitis C virus 46: Liver, other viral hepatitis
Metabolic	47: Drug-related toxicity
Miscellaneous	48: Cachexia 49: Dementia 50: Diabetic ketoacidosis 51: Graft failure 52: Hypertension 53: Malignant disease 54: Multi system failure 55: Recurrence of primary disease
Neurologic	56: Drug neurotoxicity 57: Neurologic infection 58: Status epilepticus
Renal disease	59: Acute renal failure 60: Chronic renal failure 61: Uremia caused by kidney transplant failure
Respiratory	62: Acute respiratory distress syndrome 63: Bronchiolitis obliterans
Social	64: Alcohol abuse 65: Drug abuse (exclude alcohol abuse) 66: Patient refused further treatment 67: Suicide 68: Therapy ceased for any other reason
Vascular	69: Cerebrovascular accident 70: Hemorrhage from graft site 71: Hemorrhage from surgery 72: Hemorrhage from vascular access or dialysis circuit 73: Other hemorrhage (not elsewhere specified) 74: Pulmonary embolus 75: Pulmonary vein stenosis 76: Ruptured vascular aneurysm (not cerebrovascular accident and gastrointestinal hemorrhage) 77: Stent/balloon complication 78: Vascular thrombosis

Appendix I: Glossary of terms

Term	Description
CanODT	Canadian Organ Donation and Transplantation Data System
CAV	cardiac allograft vasculopathy
CIHI	Canadian Institute for Health Information
CLAD	chronic lung allograft dysfunction
CMV	cytomegalovirus
CORR	Canadian Organ Replacement Register
cPRA	calculated panel reactive antibody
CRDM	CIHI Reference Data Model
CRT	cardiac resynchronization therapy
CRT-D	cardiac resynchronization therapy defibrillator
EBV	Epstein–Barr virus
ECLS	extracorporeal life support
FHF	fulminant hepatic failure
HCN	health care number
HL7	Health Level Seven
HIV	human immunodeficiency virus
HBV	hepatitis B virus
HLA	human leukocyte antigen
HSV	herpes simplex virus
HTLV	human T-cell lymphotropic virus
ICD	implantable cardioverter defibrillator
ICU	intensive care unit
ISO	International Organization for Standardization
KPD	kidney paired donation
LOINC	Logical Observation Identifiers Names and Codes
MDS	minimum data set
MCS	mechanical circulatory support
MELD-Na	Model for End-Stage Liver Disease — Sodium
mTORi	mammalian target of rapamycin inhibitors
ODO	organ donation organization
ODT	organ donation and transplantation
ODTC	Organ Donation and Transplantation Collaborative
PGD	primary graft dysfunction
SNOMED CT	Systematized Nomenclature of Medicine — Clinical Terms
TX MDS	Transplantation Minimum Data Set
UCUM	Unified Code for Units of Measure

Appendix J: Text alternative for figures

Figure A1 Transplant following living donation workflow

This figure captures at the highest level the most important tasks that are being performed during the transplantation and living donation process.

The diagram includes 2 “swim lanes.” The first swim lane represents a transplant program, and the second swim lane represents a living donor program.

For the transplant recipient, the journey begins when a patient with organ failure is referred to a transplant program if they meet the transplant referral criteria.

Transplant program staff conduct transplant assessment and provide education to all patients whose referrals are accepted by the transplant program.

Once the patient is approved for transplant, they are marked as eligible to receive an organ from a living donor.

Transplant program staff review information about the recipient and living donor to assess whether the living donor is an acceptable match with the recipient.

If the living donor is not an acceptable match, other options may be considered (e.g., kidney paired donation program, ABO-incompatible).

If the living donor is an acceptable match or if an acceptable match is found through other options (e.g., kidney paired donation program, ABO-incompatible), the transplant surgery is planned (e.g., surgery is scheduled, operating room is booked, patient is admitted, etc.).

Once transplant surgery planning is completed, transplant surgery is conducted.

Once transplant surgery is conducted, the recipient is provided with post-operative care and recovery, after which they are discharged.

Once the recipient is discharged, the recipient will receive post-transplant and long-term follow-up care.

For the living donor, the journey begins when they self-refer to the transplant program by contacting the transplant program to express their desire to donate their organ.

Transplant program staff conduct a donor assessment and provide education to all potential donors who meet the donation criteria and whose decision to donate is confirmed.

If the donor is cleared for donation surgery and they are an acceptable match with the recipient, the donation surgery is planned (e.g., surgery is scheduled, operating room is booked, donor is admitted, etc.).

Once donation surgery planning is completed, donation surgery is conducted to retrieve the organ.

Once donation surgery is conducted, the donor is provided with post-operative care and recovery, after which they are discharged.

Once the donor is discharged, the donor will receive post-operative and long-term follow-up care.

Figure A2 Transplant following deceased donation workflow

This figure captures at the highest level the most important tasks that are being performed during the transplantation and deceased donation process.

The diagram includes 2 “swim lanes.” The first swim lane represents a transplant program, and the second swim lane represents an organ donation organization (ODO).

For the transplant recipient, the journey begins when a patient with organ failure is referred to a transplant program if they meet the transplant referral criteria.

Transplant program staff conduct a transplant assessment and provide information to all patients whose referrals are accepted by the transplant program.

Once the patient is approved for transplant, they are marked as eligible to receive an organ from a deceased donor.

Transplant program staff review information about the recipient and deceased donor to assess whether the deceased donor is an acceptable match with the recipient.

If the deceased donor is not an acceptable march, other options may be considered (e.g., Kidney Paired Donation program, ABO-incompatible).

If the deceased donor is an acceptable match or if an acceptable match is found through other options (e.g., Kidney Paired Donation program, ABO-incompatible), the transplant surgery is planned (e.g., surgery is scheduled, operating room is booked, patient is admitted, etc.).

Once transplant surgery planning is completed, transplant surgery is conducted.

Once transplant surgery is conducted, the recipient is provided with post-operative care and recovery, after which they are discharged.

Once the recipient is discharged, the recipient will receive post-transplant and long-term follow-up care.

For the deceased donor, the journey begins when they are matched with a recipient. The ODO sends an organ offer to the transplant program, after which the transplant program decides whether they want to accept the received offer and proceed with transplantation.

If the transplant program accepts organ offers from the ODO, the ODO is responsible for planning and executing all activities related to organ recovery and transportation.

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