



ODT

Canadian Organ Donation and Transplantation Data System Living Donation Minimum Data Set

Version 1.4.1

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Table of contents

Acknowledgements	4
Project overview	4
Development of the minimum data set.....	5
Background	5
Notes	6
Data element change history for version 1.4.1	7
Living Donation MDS v1.4.1.....	9
Appendices	31
Appendix A: Living donation workflow	31
Appendix B: Country codes	33
Appendix C: HLA values.....	40
Appendix D: Post-Donation Cause of Death values	41
Appendix E: Glossary of terms.....	44
Appendix F: Text alternative for figure	45
Bibliography	47

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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 - Living Donation Minimum Data Set (LD 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 transplantation and are available on CIHI's Pan-Canadian Organ Donation and Transplantation (ODT) Data and Performance Reporting System Project web page at cihi.ca/odt.

The LD MDS is intended to support improvements in organ donation and transplantation outcomes by supporting future system-level reporting of 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

- **Donor journey:** The LD MDS is organized according to phases along the living donation journey workflow (see [Appendix A](#)). The major living donor workflow phases include
 1. Living donor referral
 2. Living donor management
 3. Donation surgery
 4. Living donor follow-up
- A given organ and tissue donation program's processes 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 donor journey.

Data element change history for version 1.4.1

The table below lists data elements that have been dropped or added since the Living Donation Minimum Data Set, Version 1.3 (not publicly released). These changes were implemented to support a more streamlined MDS and to reflect activities undertaken with stakeholders to prioritize indicators for the project. In most cases, data element IDs were changed so that all data element IDs are in sequential order in version 1.4.1.

Phase	Data element name	Amendment
Phase 1: Living donor referral	<ul style="list-style-type: none"> • Extended Criteria Donor • Exceptional Distribution Donor • Increased Risk Donor • Date of Medical and/or Social History Questionnaire • Alcohol Use • Drug Use • Smoking History • Smoking Rate • Smoking Duration • History of Marijuana Use • History of Diabetes Mellitus • History of Hypertension • History of Coronary Artery Disease • History of Hyperlipidemia • H/O: Malignancy • History of Myocardial Infarction • HLA A • HLA B • HLA C • HLA DR • HLA DQ • HLA DP 	Dropped

Phase	Data element name	Amendment
Phase 2: Living donor management	<ul style="list-style-type: none"> • Human Immunodeficiency Virus Antigen Test • Measurement of Human T-Lymphotropic Virus 1 Antibody and Human T-Lymphotropic Virus 2 Antibody 	Dropped
	<ul style="list-style-type: none"> • Exceptional Distribution Donor • HLA A • HLA B • HLA C • HLA DR • HLA DQ • HLA DP • Date of Decision to Not Proceed With Recovery Surgery 	Added
Phase 3: Donation surgery	<ul style="list-style-type: none"> • Organ Recovery Start Date • Organ Recovery Start Time • Facility Receiving Organ Transfer • Long-Term Follow-Up Plan Established • CTR Recipient Identifier 	Dropped
	<ul style="list-style-type: none"> • Living Donor Transferred • Living Donation Program Transferred From 	Added

Note

The following data elements were moved from Phase 1 to Phase 2: HLA A, HLA B, HLA C, HLA DR, HLA DQ, HLA DP and Exceptional Distribution Donor.



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Living Donation MDS v1.4.1

Phase 1 Living donor referral

ID	Data element name	Description	Valid values
1.1	Date of Self-Referral to Living Donation Program	The date the donor first self-referred to the living donation program	YYYYMMDD
1.2	Living Donation Program	The living donation program responsible for the donor's case management	Note: Subject to CIHI's Organizational Index.
1.3	Living Donation Program Donor Identifier	The unique local identifier assigned to the donor by the living donation program	Living donation program local naming convention
1.4	Donor Health Care Number	The donor's provincial/territorial health care number (HCN) (required for data linkage purposes)	Donor health care number adhering to the provincial/territorial HCN convention
1.5	Donor Health Care Number Issuer	The province/territory that issued the donor's HCN	<ul style="list-style-type: none"> • 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) <p>Note: The value set codes are sourced from the CIHI Reference Data Model (CRDM).</p>

ID	Data element name	Description	Valid values
1.6	Donor Last Name (Partial)	The first 3 letters of the donor's last name	Text
1.7	Donor Birthdate	The numerical representation of the donor's full date of birth	YYYYMMDD
1.8	Sex at Birth	The category assigned to the donor at birth that is typically based on their reproductive system and other physical characteristics	<ul style="list-style-type: none"> • F: Female • M: Male • I: Intersex • UNK: Unknown <p>Note: The value set codes are sourced from Health Level 7 (HL7), except <i>intersex</i>, which is sourced from CRDM.</p>
1.9	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 donor self-identifies	<ul style="list-style-type: none"> • F: Female • M: Male • X: Another gender • UNK: Unknown • NA: Not applicable <p>Note: The value set codes are sourced from HL7, except <i>another gender</i>, which is sourced from CRDM.</p>

ID	Data element name	Description	Valid values
1.10	Donor Province/Territory of Residence	If the donor lives in Canada, the province/territory associated with the address where the donor lives	<ul style="list-style-type: none"> • 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 <p>Note: The value set codes are sourced from the CRDM; UNK is sourced from HL7.</p>
1.11	Donor Postal Code	If the donor lives in Canada, the full postal code for the address where the donor lives	ANANAN
1.12	Donor Country	Country where the donor lives	<p>See list in Appendix B</p> <p>Additional values:</p> <ul style="list-style-type: none"> • OTH: Other • UNK: Unknown <p>Note: The value set codes are sourced from the International Organization for Standardization (ISO) and HL7.</p>
1.13	Donor Demographic Effective Date	The date associated with the Donor Health Care Number, Donor Health Care Number Issuer, Donor Last Name (Partial), Donor Province/Territory of Residence, Donor Postal Code and/or Donor Country	YYYYMMDD

ID	Data element name	Description	Valid values
1.14	Racialized Group	The patient's racial background (as identified by the patient)	<p>Group (examples)</p> <ul style="list-style-type: none"> • 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 <p>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.</p>

ID	Data element name	Description	Valid values
1.15	Indigenous Identity	The patient's Indigenous identity (i.e., First Nations, Métis and/or Inuk/Inuit), as identified by the patient	<ul style="list-style-type: none"> • 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 <p>Note: The value set is sourced from CRDM, with SNOMED CT Canadian Edition codes. Mixed Indigenous identity will be captured through multi-selection.</p>
1.16	Organ Intended for Donation	The organ that the donor is willing to donate	<ul style="list-style-type: none"> • BOW: Bowel/intestine • KDD: Kidney • LUB: Lung • LVR: Liver • PAN: Pancreas <p>Note: The value set codes are sourced from CRDM.</p>
1.17	Donor Height	Height of donor in centimetres (conversion: 1 in. = 2.54 cm)	<p>0.0 to 300.0 cm</p> <p>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 unit of measure.</p>
1.18	Donor Weight	Weight of donor in kilograms (conversion: 1 lb. = 0.45 kg)	<p>0.0 to 700.0 kg</p> <p>Note: The data element code is sourced from LOINC (Body Weight: 29463-7). UCUM is used for the unit of measure.</p>

ID	Data element name	Description	Valid values
1.19	Donor Blood Type	The confirmed blood type of the donor	<ul style="list-style-type: none"> • 112144000: Blood group A • 112149005: Blood group B • 58460004: Blood group O • 165743006: Blood group AB • UNK: Unknown <p>Note: The value set codes are sourced from SNOMED CT Canadian Edition; UNK is sourced from HL7.</p>
1.20	Date of Decision to Conduct Organ Donation Assessment	The date the decision was made whether to conduct the organ donation assessment on the potential living donor	YYYYMMDD
1.21	Status of Decision to Conduct Organ Donation Assessment	The status of the decision to conduct the organ donation assessment on the potential living donor	<ul style="list-style-type: none"> • Y: Yes (will conduct organ donation assessment) • N: No (will not conduct organ donation assessment) <p>Note: The value set codes are sourced from HL7.</p>

ID	Data element name	Description	Valid values
1.22	Reason for Not Proceeding to Organ Donation Assessment	The main reason the donor will not be proceeding to organ donation assessment	<ul style="list-style-type: none"> • 1: Age • 2: ABO incompatible • 3: Size mismatch • 4: Crossmatch positive • 5: Living donor decision not to proceed • 6: Living donor reluctant • 7: Living donor died • 8: Unable to contact living donor • 9: Living donor transferred to another centre • 10: Another donor chosen • 11: Early referral (recipient has not been referred yet or is not a candidate for transplant yet) • 12: Financial reasons • 13: Unsuitable for donation — Psychosocial • 14: Medical non-compliance • 15: Substance abuse • 16: Tobacco use • 17: BMI • 18: Medically unsuitable for donation — Other reasons • 19: Recipient-related reasons — Other • 20: Chain collapsed • OTH: Other • UNK: Unknown <p>Note: OTH and UNK are sourced from HL7.</p>

Phase 2 Living donor management

ID	Data element name	Description	Valid values
2.1	Donation Type	The type of donation being coordinated	<ul style="list-style-type: none"> • 44861000087105: Living donor — Directed • 44941000087103: Living donor — Non-directed anonymous donor • 44891000087102: Living donor — Paired exchange <p>Note: The value set codes are sourced from SNOMED CT Canadian Edition.</p>
2.2	Exceptional Distribution Donor	Indication in the donor’s medical and/or social behaviour history that they are at increased risk of transmitting a disease to the recipient	<ul style="list-style-type: none"> • Y: Yes • N: No • UNK: Unknown <p>Note: The data element code is sourced from SNOMED CT Canadian Edition (Exceptional Distribution Donor: 34421000087104). The value set codes are sourced from HL7.</p>
2.3	Relationship of Donor to Recipient — Type	Indication of whether the donor and recipient are biologically related	<ul style="list-style-type: none"> • Y: Yes • N: No <p>Note: The value set codes are sourced from HL7.</p>
2.4	Relationship of Donor to Recipient — Biological	The biological relationship of the donor to the recipient	<ul style="list-style-type: none"> • 13646006: Biological parent • 82101005: Biological sibling • 75226009: Biological child • OTH: Other <p>Note: The value set codes are sourced from SNOMED CT Canadian Edition; OTH is sourced from HL7.</p>

ID	Data element name	Description	Valid values
2.5	Relationship of Donor to Recipient — Non-Biological	The non-biological relationship of the donor to the recipient	<ul style="list-style-type: none"> • 262043009: Partner in relationship • 45021000087107: Anonymous living donor • 45031000087109: Domino donor • 45051000087100: Paired donor • OTH: Other <p>Note: The value set codes are sourced from SNOMED CT Canadian Edition; OTH is sourced from HL7.</p>
2.6	Serum Creatinine	The donor's most recent creatinine level (in mg/DL) prior to either the decision not to donate or the donation surgery	<ul style="list-style-type: none"> • 0.00 to ##.## mg/DL <p>Note: The data element code is sourced from LOINC (Creatinine [Mass/Volume] in Serum or Plasma: 2160-0). UCUM is used for the unit of measure.</p>
2.7	Estimated Glomerular Filtration Rate	The donor's most recent estimated glomerular filtration rate prior to either the decision not to donate or the donation surgery	<ul style="list-style-type: none"> • 0 to 120 <p>Note: The data element code is sourced from SNOMED CT Canadian Edition (Estimated Glomerular Filtration Rate: 37571000087106).</p>
2.8	Radiography Interpretation	Indication of the most recent result of whether any radiography (e.g., X-ray) was done on the donor prior to either the decision to donate or the donation surgery and, if done, whether the result was normal or abnormal	<ul style="list-style-type: none"> • 280413001: Normal result • 280415008: Abnormal result • 373121007: Test not done • 373068000: Undetermined <p>Note: The data element code is sourced from SNOMED CT Canadian Edition (Radiography Interpretation: 37351000087108). The value set codes are sourced from SNOMED CT Canadian Edition.</p>

ID	Data element name	Description	Valid values
2.9	Cytomegalovirus Antibody Measurement	Indication of the most recent result of whether the donor tested positive for the cytomegalovirus (CMV) antibody prior to either the decision to donate or the donation surgery	<ul style="list-style-type: none"> • 10828004: Positive • 260385009: Negative • 373121007: Test not done • 373068000: Undetermined <p>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.</p>
2.10	Epstein–Barr Virus Antibody Measurement	Indication of the most recent result of whether the donor tested positive for the Epstein–Barr virus antibody prior to either the decision to donate or the donation surgery	<ul style="list-style-type: none"> • 10828004: Positive • 260385009: Negative • 373121007: Test not done • 373068000: Undetermined <p>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.</p>
2.11	Hepatitis B Surface Antigen Measurement	Indication of the most recent result of whether the donor tested positive for the hepatitis B antigen (hepatitis BsAg) prior to either the decision to donate or the donation surgery	<ul style="list-style-type: none"> • 10828004: Positive • 260385009: Negative • 373121007: Test not done • 373068000: Undetermined <p>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.</p>

ID	Data element name	Description	Valid values
2.12	Hepatitis B Core Antibody Measurement	Indication of the most recent result of whether the donor tested positive for the hepatitis B antibody (hepatitis BcAb) prior to either the decision to donate or the donation surgery	<ul style="list-style-type: none"> • 10828004: Positive • 260385009: Negative • 373121007: Test not done • 373068000: Undetermined <p>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.</p>
2.13	Hepatitis C Antibody Measurement	Indication of the most recent result of whether the donor tested positive for the hepatitis C antibody prior to either the decision to donate or the donation surgery	<ul style="list-style-type: none"> • 10828004: Positive • 260385009: Negative • 373121007: Test not done • 373068000: Undetermined <p>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.</p>
2.14	HLAA	The donor's 2 human leukocyte antigen (HLA) type A antigens	<p>See Appendix C for a list of recognized serological HLA specificities</p> <p>Additional values:</p> <ul style="list-style-type: none"> • 37501000087101: Human leukocyte antigen typing — No antigen identified • UNK: Unknown/not available/typing not done • OTH: Other <p>Note: The data element code is sourced from LOINC (HLA-A Locus [Type]: 38548-4). The value set code is sourced from SNOMED CT Canadian Edition; UNK and OTH are sourced from HL7.</p>

ID	Data element name	Description	Valid values
2.15	HLA B	The donor's 2 HLA B antigens	<p>See Appendix C for a list of recognized serological HLA specificities</p> <p>Additional values:</p> <ul style="list-style-type: none"> • 37501000087101: Human leukocyte antigen typing — No antigen identified • UNK: Unknown/not available/typing not done • OTH: Other <p>Note: The data element code is sourced from LOINC (HLA-B Locus [Type]: 38546-8). The value set code is sourced from SNOMED CT Canadian Edition; UNK and OTH are sourced from HL7.</p>
2.16	HLA C	The donor's 2 HLA C antigens	<p>See Appendix C for a list of recognized serological HLA specificities</p> <p>Additional values:</p> <ul style="list-style-type: none"> • 37501000087101: Human leukocyte antigen typing — No antigen identified • UNK: Unknown/not available/typing not done • OTH: Other <p>Note: The data element code is sourced from LOINC (HLA-C [Type]: 13302-5). The value set code is sourced from SNOMED CT Canadian Edition; UNK and OTH are sourced from HL7.</p>

ID	Data element name	Description	Valid values
2.17	HLA DR	The donor's 2 HLA DR antigens	<p>See Appendix C for a list of recognized serological HLA specificities</p> <p>Additional values:</p> <ul style="list-style-type: none"> • 37501000087101: Human leukocyte antigen typing — No antigen identified • UNK: Unknown/not available/typing not done • OTH: Other <p>Note: The data element code is sourced from LOINC (HLA-DR Locus [Type]: 21341-3). The value set code is sourced from SNOMED CT Canadian Edition; UNK and OTH are sourced from HL7.</p>
2.18	HLA DQ	The donor's 2 HLA DQ antigens	<p>See Appendix C for a list of recognized serological HLA specificities</p> <p>Additional values:</p> <ul style="list-style-type: none"> • 37501000087101: Human leukocyte antigen typing — No antigen identified • UNK: Unknown/not available/typing not done • OTH: Other <p>Note: The data element code is sourced from LOINC (HLA-DQ Locus 2 [Type]: 34143-8). The value set code is sourced from SNOMED CT Canadian Edition; UNK and OTH are sourced from HL7.</p>

ID	Data element name	Description	Valid values
2.19	HLA DP	The donor's 2 HLA DP antigens	See Appendix C for a list of recognized serological HLA specificities Additional values: <ul style="list-style-type: none"> • 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.
2.20	On Hold Date(s)	The date(s) the donor case was put on hold for donation	YYYYMMDD

ID	Data element name	Description	Valid values
2.21	Reason for On Hold	The main reason a status of “on hold” was applied to the donor case	<p>Donor reason</p> <ul style="list-style-type: none"> • 1: Medically unsuitable — Temporary • 2: Psychosocial issue(s) — Temporary • 3: Pending investigations • 4: Potential living donor paired exchange transplant • 5: Potential living donor — Desensitization (ABO or HLA) • 6: Not available (away) • OTH: Other • UNK: Unknown <p>Recipient reason</p> <ul style="list-style-type: none"> • 7: Medically unsuitable — Temporary • 8: Psychosocial issue(s) — Temporary • 9: Pending investigations • 10: Potential living donor paired exchange transplant • 11: Potential living donor — Desensitization (ABO or HLA) • 12: Not available (away) • OTH: Other • UNK: Unknown <p>Note: OTH and UNK are sourced from HL7.</p>
2.22	Off Hold Date(s)	The date(s) a donor case was removed from “on hold” status	YYYYMMDD
2.23	Date of Registration for Kidney Paired Donation Program	The date the donor was registered to the kidney paired donation (KPD) program	YYYYMMDD
2.24	Date of Removal From Kidney Paired Donation Program	The date the donor was removed from the KPD program	YYYYMMDD

ID	Data element name	Description	Valid values
2.25	Decision Regarding Donation	Indication of whether the donor is (medically, physically, psychologically, etc.) cleared by the donor care team to proceed to surgery	<ul style="list-style-type: none"> • Y: Yes • N: No <p>Note: The value set codes are sourced from HL7.</p>
2.26	Date of Decision Regarding Donation	The date the decision was made whether to proceed to organ donation	YYYYMMDD
2.27	Reason for Not Proceeding With Donation	The main reason the donor will no longer be proceeding with donation	<ul style="list-style-type: none"> • 1: Age • 2: ABO incompatible • 3: Size mismatch • 4: Crossmatch positive • 5: Living donor decision not to proceed • 6: Living donor reluctant • 7: Living donor died • 8: Unable to contact living donor • 9: Living donor transferred to another centre • 10: Another donor chosen • 11: Early referral (recipient has not been referred yet or is not a candidate for transplant yet) • 12: Financial reasons • 13: Unsuitable for donation — Psychosocial • 14: Medical non-compliance • 15: Substance abuse • 16: Tobacco use • 17: BMI • 18: Medically unsuitable for donation — Other reasons • 19: Recipient-related reasons — Other • 20: Chain collapsed • OTH: Other • UNK: Unknown <p>Note: OTH and UNK are sourced from HL7.</p>

ID	Data element name	Description	Valid values
2.28	Date of Decision to Not Proceed With Recovery Surgery	The date that a living donor who had previously decided to donate withdrew from the living donation process	YYYYMMDD
2.29	Reason the Recovery Surgery Did Not Occur	For donors who were cleared for donation but did not donate, the reason the recovery surgery did not occur	<ul style="list-style-type: none"> • 1: Living donor withdrew • 2: Living donor died • 3: Unable to contact living donor • 4: Unable to contact recipient • 5: Recipient died • 6: Recipient unsuitable for transplant • 7: Team/hospital logistics (team, hospital, resource issues) • 8: Organ deemed unsuitable for transplantation • OTH: Other • UNK: Unknown <p>Note: OTH and UNK are sourced from HL7.</p>

Phase 3 Donation surgery

ID	Data element name	Description	Valid values
3.1	Living Donor Transferred	Indication of whether the living donor was transferred for organ retrieval surgery after assessment	<ul style="list-style-type: none"> • Y: Yes • N: No Note: The value set codes are sourced from HL7.
3.2	Living Donation Program Transferred From	The transplantation centre where the donor was previously assessed	Note: Subject to CIHI's Organizational Index.
3.3	Date of Admission	The date the donor was admitted to the hospital for the purpose of organ recovery surgery	YYYYMMDD
3.4	Facility of Organ Recovery	The facility where the organ recovery occurred	Note: Subject to CIHI's Organizational Index.
3.7	Donor Cross-Clamp Date	The date of aortic cross-clamping in the donor	YYYYMMDD
3.8	Donor Cross-Clamp Time	The time of day of aortic cross-clamping in the donor	HHMM Note: 24-hour clock
3.9	Type of Surgery	The type of surgery that was performed	<ul style="list-style-type: none"> • 73632009: Laparoscopy • 47021000146101: Laparoscopy with conversion to open approach • 51101000087104: Hand assisted laparoscopic procedure • 51111000087102: Hand assisted laparoscopic procedure converted to open approach • 51121000087105: Mini-incision open surgery • 51131000087107: Subcostal mini-incision open surgery • OTH: Other Note: The value set codes are sourced from SNOMED CT Canadian Edition; OTH is sourced from HL7.
3.10	Organ Recovered Date	The date the organ was recovered for the purpose of transplantation	YYYYMMDD

ID	Data element name	Description	Valid values
3.11	Organ Recovered Time	The time of day the organ was recovered for the purpose of transplantation	HHMM Note: 24-hour clock
3.12	Recovered Organ	The specific organ intended to be recovered from the donor	<ul style="list-style-type: none"> • BOW: Bowel/intestine • KDL: Kidney — Left • KDR: Kidney — 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 • LLL: Liver — Left lobe • LRL: Liver — Right lobe • LLS: Liver — Lateral segment • LMS: Liver — Monosegment • PAI: Pancreas — Islet • PAS: Pancreas — Segment Note: The value set codes are sourced from CRDM.
3.13	Perfusion Device Status	Indication of whether an organ perfusion device was used for the specified organ	<ul style="list-style-type: none"> • Y: Yes • N: No • UNK: Unknown Note: The value set codes are sourced from HL7.
3.14	Perfusion Device Used	The device used for organ perfusion for the specified organ	<ul style="list-style-type: none"> • 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.
3.15	Cold Preservation Start Date	The date that cold preservation was initiated for the specified organ	YYYYMMDD

ID	Data element name	Description	Valid values
3.16	Cold Preservation Start Time	The time of day that cold preservation was initiated for the specified organ	HHMM Note: 24-hour clock
3.17	Surgical Complications	Indication of whether there were surgical complications	<ul style="list-style-type: none"> • Y: Yes • N: No Note: The value set codes are sourced from HL7.
3.18	Clavien–Dindo Classification	The classification of surgical complications using the Clavien–Dindo classification	<ul style="list-style-type: none"> • 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.
3.19	Intraoperative Death	Indication of whether the donor died during the donation surgery	<ul style="list-style-type: none"> • Y: Yes • N: No Note: The value set codes are sourced from HL7.
3.20	Organ Transferred Date	The date the specified organ was transferred to another facility post–organ recovery	YYYYMMDD
3.21	Organ Transferred Time	The time of day the specified organ was transferred to another facility post–organ recovery	HHMM Note: 24-hour clock
3.22	Discharge Date	The date the donor was discharged from the hospital	YYYYMMDD
3.23	Recipient's Transplantation Centre	The transplantation centre responsible for the recipient's case management	Note: Subject to CIHI's Organizational Index.
3.24	Recipient's Health Care Number	The recipient's provincial/territorial HCN (required for data linkage purposes)	Recipient's health care number adhering to the provincial/territorial HCN convention

ID	Data element name	Description	Valid values
3.25	Recipient's Health Care Number Issuer	The province/territory that issued the recipient's HCN	<ul style="list-style-type: none"> • 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) <p>Note: The value set codes are sourced from CRDM.</p>
3.26	TXC Recipient Identifier	The unique local identifier assigned to the recipient's case file by the transplantation centre (TXC)	TXC local naming convention
3.27	Transplanted State	Indication of the outcome for the transplanted organ	<ul style="list-style-type: none"> • Y: Yes • N: No <p>Note: The value set codes are sourced from HL7.</p>
3.28	Not Transplanted Reason	Reason the specified organ was not transplanted into a recipient	<ul style="list-style-type: none"> • 1: Organ deemed not suitable for transplant • 2: Recipient-related issues • 3: Surgical complications (surgical safety event) • OTH: Other • UNK: Unknown <p>Note: OTH and UNK are sourced from HL7.</p>

Phase 4 Living donor follow-up

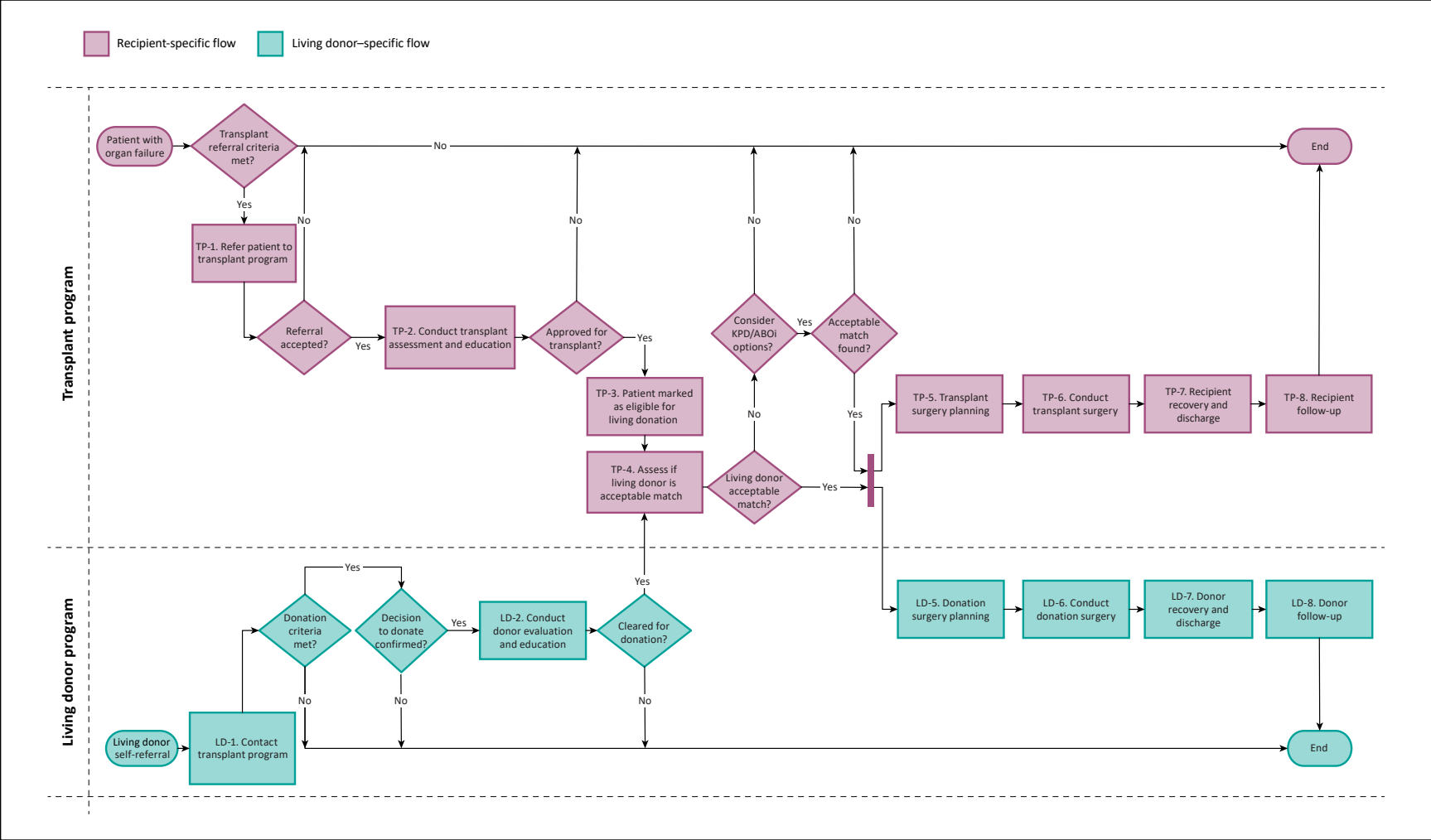
ID	Data element name	Description	Valid values
4.1	Date of Death	The date of declaration of death for the donor	YYYYMMDD
4.2	Post-Donation Cause of Death	The most proximate injury/illness that led to the death of the donor	See list in Appendix D Additional values: <ul style="list-style-type: none"> • OTH: Other • UNK: Unknown Note: OTH and UNK are sourced from HL7.
4.3	Date of Loss of Follow-Up	The date the donor care team lost contact with the donor post-donation	YYYYMMDD
4.4	Route of Loss of Contact	The way in which the contact was lost with the donor	<ul style="list-style-type: none"> • 1: Non-responsive/unwilling to continue follow-up • 184081006: Patient has moved away • 50941000087106: Contact information outdated • 419099009: Deceased • OTH: Other Note: The value set codes 184081006, 50941000087106 and 419099009 are sourced from SNOMED CT Canadian Edition; OTH is sourced from HL7.
4.5	Kidney Failure Start Date	The date the kidney donor developed end-stage kidney failure after donating a kidney (i.e., donor has a glomerular filtration rate of less than 15 mL/min)	YYYYMMDD

Appendices

Appendix A: Living donation workflow

This figure depicts the optimal high-level living donation journey. The workflow has been validated with transplantation centres participating in the CIHI-Infoway ODT Project's Business Data Management Expert Advisory Forum (February 2022).

Figure Living donation workflow



Notes
 ABOi: ABO-incompatible.
 KPD: Kidney paired donation.

Appendix B: Country codes

The following table provides a list of country codes for data element 1.12 (Donor 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 MacDonal, 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: HLA values

The following table provides a list of HLA values for data elements 2.14 to 2.19 (HLA A, B, C, DR, DQ 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 D: Post-Donation Cause of Death values

The following table provides a list of values for data element 4.2 (Post-Donation Cause of Death). These values describe the most proximate injury/illness that led to the death of the donor. These values were adapted from the Canadian Organ Replacement Register (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

Group	Valid values
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
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

Group	Valid values
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 E: Glossary of terms

Term	Description
BMI	Body mass index
CanODT	Canadian Organ Donation and Transplantation Data System
CIHI	Canadian Institute for Health Information
CORR	Canadian Organ Replacement Register
CRDM	CIHI Reference Data Model
DSWG	Data System Working Group
HCN	Health care number
HLA	Human leukocyte antigen
HL7	Health Level Seven
ISO	International Organization for Standardization
KPD	Kidney paired donation
LD	Living donation
LD MDS	Living Donation Minimum Data Set
LOINC	Logical Observation Identifiers Names and Codes
MDS	Minimum data set
ODT	Organ donation and transplantation
ODTC	Organ Donation and Transplantation Collaborative
SNOMED CT	Systematized Nomenclature of Medicine — Clinical Terms
TXC	Transplantation centre
UCUM	Unified Code for Units of Measure

Appendix F: Text alternative for figure

Figure 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.

Bibliography

- BC Transplant. BC Transplant [Living Donation website](#). Accessed August 2021.
- Canadian Blood Services. Deceased Donation Data Working Group Final Report. 2016.
- Canadian Blood Services. Heart Data Working Group Report. 2015.
- Canadian Blood Services. Kidney Data Working Group Report. 2015.
- Canadian Blood Services. Liver Data Working Group Report. 2015.
- Canadian Blood Services. [Living Organ Donation website](#). Accessed August 2021.
- Canadian Blood Services. Lung Data Working Group Report. 2015.
- Canadian Blood Services. Pancreas Data Working Group Report. 2016.
- Canadian Institute for Health Information. [Canadian Organ Replacement Register Instruction Manual, 2021: Transplant Recipient and Organ Donor Information](#). 2021.
- Canadian Institute for Health Information. [CIHI Reference Data Model Toolkit](#). 2022.
- Canadian Institute for Health Information. [Guidance on the Use of Standards for Race-Based and Indigenous Identity Data Collection and Health Reporting in Canada](#). 2022.
- Canadian Society of Transplantation. [Canadian Society of Transplantation website](#). Accessed January 2021.
- Clavien PA, Sanabria JR, Strasberg SM. [Proposed classification of complications of surgery with examples of utility in cholecystectomy](#). Surgery. May 1992.
- DonateLife Network. [Organ and Tissue Authority website](#). Accessed September 2021.
- Health Resources and Services Administration. [Health Resources and Services Administration Organ Donor website](#). Accessed September 2021.
- hla.alleles.org. [HLA antigens](#). Accessed October 2022.
- Marsh SGE, Albert ED, Bodmer WF, et al. [Nomenclature for factors of the HLA system, 2010](#). *Tissue Antigens*. April 2010.
- Multi-Organ Transplant Program of Atlantic Canada (MOTP). [Multi-Organ Transplant Program of Atlantic Canada website](#). Accessed September 2021.

Robinson J, Barker DJ, Georgiou X, Cooper MA, Flicek P, Marsh SGE. [IPD-IMGT/HLA Database](#). *Nucleic Acids Research*. January 2020.

Scientific Registry of Transplant Recipients (SRTR). [About SRTR Reports](#). Accessed November 2020.

Transplant Manitoba. [Living Kidney Donor Guide](#). 2016.

Transplant Québec. [Transplant Quebec website](#). Accessed February 2021.

Trillium Gift of Life Network. [Trillium Gift of Life Network website](#). Accessed March 2021.

United Network for Organ Sharing. [United Network for Organ Sharing website](#). Accessed August 2021.

University Health Network Ajmera Transplant Centre. [Living Donor Program website](#). Accessed September 2021.

U.S. Department of Health and Human Services, Organ Procurement and Transplantation Network. [Organ Procurement and Transplantation Network](#). Accessed February 2021.



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