



Canadian Organ Donation and Transplantation Data System (CanODT) Deceased Donation Minimum Data Set

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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 1.8	6
Value set change history for version 1.8	6
Deceased Donation MDS v1.8	7
Appendices	5
Appendix A: Deceased donation workflow	5
Appendix B: Country codes4	6
Appendix C: HLA	3
Appendix D: Glossary of terms5	3
Appendix E: Text alternative for figure5	5
Bibliography	6

# Acknowledgements

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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 <u>Health Canada's ODTC Data System Working Group</u> (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 <u>cihi.ca/odt</u> or Infoway's <u>Organ Donation and Transplantation Data Management web page</u>.

# Development of the minimum data set

### Background

This document presents CIHI's Deceased Donation Minimum Data Set (DD MDS), one of the deliverables of the Health Canada–funded Pan-Canadian ODT Data and Performance Reporting System project co-led by CIHI and Canada Health Infoway. Additional minimum data sets were developed for living donation and transplantation, which are available on CIHI's Pan-Canadian ODT Data and Performance Reporting System Project web page at <u>cihi.ca/odt</u>.

The DD 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., deceased donation management system) led by Infoway for the project. Stakeholders who provided input into this MDS include members of the ODT clinical and business advisory forums and other project-specific working groups, the ODTC Data System Working Group, the Health Canada–funded ODTC Missed Donation Opportunities Project, and others. A list of members is provided on <u>CIHI's ODT project external advisory groups web page</u>.

## Notes

- **Donor journey:** The DD MDS is organized according to categories along the deceased donation journey workflow (see <u>Appendix A</u>). The major deceased donor workflow phases include
  - 1. Referral
  - 2. Consent
  - 3. Donor management
  - 4. Organ retrieval
  - 5. Organ utilization
- 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 1.8

The table below lists data elements that have been dropped or added since publication of the *Deceased Donation Minimum Data Set, Version 1.7.* 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 1.8.

Phase	Data element name	Amendment
Phase 1: Referral	Donor Birthdate	Dropped
	Donor Age Code at Time of Death	Added
	Donor Age Unit at Time of Death	

## Value set change history for version 1.8

The table below lists changes to the data element value sets since the *Deceased Donation Minimum Data Set, Version 1.7.* These changes were implemented to support technical work and development of the data repository.

Phase	Data element name	Amendment
Phase 1: Referral	Donor Province/Territory of Residence	Removed U.S. states and OTH: Other from value set



## Deceased Donation MDS v1.8

#### Phase 1 Referral

ID	Data element name	Description	Valid values
1.1	Donor Health Care Number	The donor's provincial/territorial health care number	Donor health care number adhering to the provincial/
		(HCN) (required for data linkage purposes)	territorial HCN convention
1.2	Donor Health Care	The province/territory that issued the donor's HCN	• AB: Alberta
	Number Issuer		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	Donor Last Name (Partial)	The first 3 letters of the donor's last name	Text
1.4.1	Donor Age Code at Time	The age code (value that denotes how age is measured)	• Y: Year
	of Death	of the donor at the time of death	• M: Month
			• D: Day
			• B: Newborn

ID	Data element name	Description	Valid values
1.4.2	Donor Age Unit at Time of Death	or 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
1.6	Sex at Birth	The category assigned to the donor at birth that is	• F: Female
		typically based on their reproductive system and other	• M: Male
			• I: Intersex
			• UNK: Unknown
			Note: The value set codes are sourced from
			Health Level 7 (HL7), except intersex, which
			is sourced from CRDM.
1.7	Gender Identity		• F: Female
		and expressions of girls, women, boys, men and	• M: Male
		gender diverse people by a given society, by which the donor self-identifies	• X: Another gender
			• UNK: Unknown
			NA: Not applicable
			Note: The value set codes are sourced from HL7,
			except <i>another gender</i> , which is sourced from CRDM.

ID	Data element name	Description	Valid values
1.8	Donor Province/Territory	If the donor lived in Canada, the province/territory	• AB: Alberta
	of Residence	associated with the address where the donor lived	• 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
			<b>Note:</b> The value set codes are sourced from CRDM; UNK is sourced from HL7.
1.9	Donor Postal Code	If the donor lived in Canada, the full postal code for the address where the donor lived	ANANAN
1.10	Donor Country	Country where the donor lived	See list in <u>Appendix B</u>
			Additional values:
			• OTH: Other
			• UNK: Unknown
			<b>Note:</b> The value set codes are sourced from the International Organization for Standardization (ISO) and HL7.

ID	Data element name	Description	Valid values
1.11	Racialized Group	acialized Group The patient's racial background (as identified by the patient)	Group (examples)
			<ul> <li>413464008: Black (African, African Canadian, Afro-Caribbean descent)</li> </ul>
			• 26621000087107: East Asian (Chinese, Japanese, Korean, Taiwanese descent)
			<ul> <li>26631000087109: Indigenous (First Nations, Inuk/ Inuit, Métis descent)</li> </ul>
			• 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])
			<ul> <li>26661000087102: Southeast Asian (Cambodian, Filipino, Indonesian, Thai, Vietnamese or other Southeast Asian descent)</li> </ul>
			• 413773004: White (European descent)
			<ul> <li>OTH: Another race category (includes values not described above)</li> </ul>
			ASKD: Prefer not to answer (refused to answer)
			<ul> <li>ASKU: Do not know (person is not aware of their race)</li> </ul>
			NASK: Not asked
			<b>Note:</b> 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
1.12	Indigenous Identity	The patient's Indigenous identity (i.e., First Nations,	• 29921000087109: First Nations
		Métis and/or Inuk/Inuit), as identified by the patient	• 29931000087106: Inuk/Inuit
			• 29941000087100: Métis
			<ul> <li>N: No (do not identify as First Nations, Métis and/ or Inuk/Inuit)</li> </ul>
			ASKD: Prefer not to answer (refused to answer)
			<ul> <li>ASKU: Do not know (person is not aware of their Indigenous identity)</li> </ul>
			NASK: Not asked
			<b>Note:</b> The value set is sourced from CRDM, with SNOMED CT Canadian Edition codes. Mixed Indigenous identity will be captured through multi-selection.
1.13	Registered Intent to Donate	The donor's registered intent for organ donation with their respective provincial/territorial organ and	• 37431000087108: Organ donation intent — registered yes
		tissue registry	<ul> <li>37421000087106: Organ donation intent — registered no or opt-out</li> </ul>
			<ul> <li>37411000087103: Organ donation intent — not registered or deemed</li> </ul>
			NA: Not applicable (no provincial registry)
			• UNK: Unknown
			<b>Note:</b> The value set codes are sourced from SNOMED CT Canadian Edition; NA and UNK are sourced from HL7.

ID	Data element name	Description	Valid values
1.14	Registered Donor Organ Disposition	The donor's registered organ disposition preference with their respective provincial/territorial organ and tissue registry	<ul> <li>37401000087100: Organ donation for transplant</li> <li>37391000087103: Organ donation for research</li> <li>NA: Not applicable</li> <li>UNK: Unknown</li> <li>Note: The value set codes are sourced from SNOMED CT Canadian Edition; NA and UNK are sourced from HL7.</li> </ul>
1.15	Registered Donor Organs for Donation	The registered organs the donor has specified for donation (i.e., included)	<ul> <li>BOW: Bowel/intestine</li> <li>HRT: Heart</li> <li>KDD: Kidneys/dialysis (includes en bloc transplants)</li> <li>LUB: Lung — Bilateral/en bloc</li> <li>LVR: Liver — Whole</li> <li>PAN: Pancreas — Whole</li> <li>Note: The value set codes are sourced from CRDM.</li> </ul>
1.16	Identifying/Referring Facility	The facility where the donor was identified and/or that referred the donor to the organ donation organization (ODO) for organ donation. For donor organ(s) received from another ODO in Canada, indicate the ODO that the referral was received from.	Note: Subject to CIHI's Organizational Index.
1.22	Donor Was Referred	Indication of whether the potential donor was referred to the ODO for organ donation. This includes referrals received from other ODOs in Canada and from out of country.	<ul> <li>Y: Yes</li> <li>N: No</li> <li>Note: The value set codes are sourced from HL7.</li> </ul>

ID	Data element name	Description	Valid values
L <b>.24</b>	Reason Donor Not Referred	The reason the potential donor was not referred to the	• 1: Missed potential donor
		ODO for organ donation	• 2: Imminent move to comfort care
			• 3: Substitute decision-maker declines approach
			• 4: Unable to locate substitute decision-maker
			<ul> <li>5: Medical/legal conflict with substitute decision-maker</li> </ul>
			• 6: HCP documented substitute decision-maker too emotionally overwhelmed
			• 7: Patient died before referral could be made
			• 704301008: Cultural belief conflict
			• 703474005: Patient unsuitable for procedure due to age
			• 702371008: Patient unsuitable for procedure due to medical condition
			• 161034004: Not willing to be a donor
			• OTH: Other
			• UNK: Unknown
			Notes
			The value set codes 704301008, 703474005,
			702371008 and 161034004 are sourced from SNOMED CT Canadian Edition; OTH and UNK
			are sourced from HL7.
			Values are adapted from the ODTC's Missed Donation Opportunities Project.

ID	Data element name	Description	Valid values
1.24.1	Referral Type	Indication of whether the referral for organ donation was made directly to an ODO, received from another ODO in Canada or received from out of country	<ul> <li>1: Direct referral to ODO responsible for donor case management</li> <li>2: Donor organ(s) received from another ODO in Canada</li> <li>3: Donor organ(s) received from out of country</li> <li>Note: The value set codes are pending; however, they may be sourced from SNOMED CT Canadian Edition.</li> </ul>
1.25	Referral Date	The date the referral was received by the ODO. This includes referrals received from other ODOs in Canada and from out of country.	YYYYMMDD
1.25.1	Referral Time	The time of day the referral was received by the ODO. This includes referrals received from other ODOs in Canada and from out of country.	HHMM Note: 24-hour clock
1.26	Donor ODO	The ODO responsible for donor case management at the time of the referral. For donor organ(s) received from another organization, this represents the ODO that received the referral.	Note: Subject to CIHI's Organizational Index.
1.27	ODO Donor Identifier	The unique local identifier assigned to the donor organ/ case file by the ODO. For donor organ(s) received from another organization, this represents the identifier assigned by the ODO that received the referral.	ODO local naming convention
1.27.1	Originating ODO Donor Identifier	The unique local identifier assigned to the donor organ/ case file by the ODO that the referral was received from. This item is applicable only to referrals received from other ODOs in Canada.	ODO local naming convention

ID	Data element name	Description	Valid values
1.29	Admission Date	The date of the donor's admission to the original referring facility	YYYYMMDD
1.29.1.1	Admission Time	The time of day of the donor's admission to the original referring facility	HHMM Note: 24-hour clock
1.29.1	Type of Donation	The type of donation at the time of referral, classified as after neurological determination of death (NDD) or after circulatory determination of death (DCD)	<ul> <li>1187236000: Donor after neurological determination of death</li> <li>1187235001: Donor after circulatory death</li> <li>Note: The value set codes are sourced from SNOMED CT Canadian Edition.</li> </ul>
1.29.2	MAID Flag	Indication of whether the donation was associated with medical assistance in dying (MAID)	<ul> <li>Y: Yes</li> <li>N: No</li> <li>Note: The value set codes are sourced from HL7.</li> </ul>
1.32	Type of DCD	Indication of whether the donation after circulatory determination of death was controlled (cDCD) or uncontrolled (uDCD)	<ul> <li>37531000087109: cDCD — Controlled donation after circulatory death</li> <li>37561000087102: uDCD — Uncontrolled donation after circulatory death</li> <li>Note: The value set codes are sourced from SNOMED CT Canadian Edition.</li> </ul>

ID	Data element name	Description	Valid values
1.36	Cause of Death	The most proximate injury/illness that led to the death of the donor in relation to donation	80690008: Degenerative disease of the central nervous system
			37521000087107: Anoxia and/or hypoxia of brain without intoxication and/or overdose
			<ul> <li>37511000087104: Anoxia and/or hypoxia of brain with intoxication and/or overdose</li> </ul>
			<ul> <li>37551000087100: Single organ failure without primary brain injury</li> </ul>
			<ul> <li>37541000087103: Multi-system organ failure withou primary brain injury</li> </ul>
			• 422504002: Ischemic stroke
			• 738779002: Spontaneous intracranial hemorrhage
			• 127295002: Traumatic brain injury
			• 126952004: Brain tumour
			• 128117002: Infectious disease of central
			nervous system
			• 50122000: Metabolic encephalopathy
			• OTH: Other
			• UNK: Unknown
			Notes
			The value set codes are sourced from SNOMED CT Canadian Edition; OTH and UNK are sourced from HL7.
			Values are adapted from the ODTC's Missed Donation Opportunities Project.
1.37	Donor Height	Height of donor in centimetres (conversion: 1 in. =	0.0 to 300.0 cm
		2.54 cm)	<b>Note:</b> The data element code is sourced from LOINC (Body Height: 8302-2). The Unified Code for Units of Measure (UCUM) is used for the unit of measure.

ID	Data element name	Description	Valid values
1.38	Donor Weight	Weight of donor in kilograms (conversion: 1 lb. = 0.45 kg)	0.0 to 700.0 kg <b>Note:</b> The data element code is sourced from LOINC (Body Weight: 29463-7). UCUM is used for the unit of measure.
1.40	Donor Blood Type	The confirmed blood type of the donor	<ul> <li>112144000: Blood group A</li> <li>112149005: Blood group B</li> <li>58460004: Blood group O</li> <li>165743006: Blood group AB</li> <li>UNK: Unknown</li> <li>Note: The value set codes are sourced from SNOMED CT Canadian Edition; UNK is sourced from HL7.</li> </ul>

#### Phase 2 Consent

ID	Data element name	Description	Valid values
2.1	Eligible for Formal Consent Discussion	Indication of whether the ODO (based on its own criteria) deemed the donor's substitute decision-maker eligible for a formal consent discussion during referral intake	<ul> <li>Y: Yes</li> <li>N: No</li> </ul>
2.3	Approached for Formal Consent Discussion	Indication of whether the donor's substitute decision-maker (SDM) was approached for a formal consent discussion	<ul> <li>Note: The value set codes are sourced from HL7.</li> <li>Y: Yes</li> <li>N: No</li> <li>Note: The value set codes are sourced from HL7.</li> </ul>

ID	Data element name	Description	Valid values
2.5	Initiator of Approach for Formal Consent	Identifies who initiated the approach and formal consent discussion	37461000087101: Organ donor coordinator/organ donation organization affiliate
			• 37471000087105: Donation physician champion
			• 133932002: Other healthcare provider
			• 34981000087109: Substitute decision-maker
			• UNK: Unknown
			Notes
			The value set codes are sourced from SNOMED CT Canadian Edition; UNK is sourced from HL7.
			Values are adapted from the ODTC's Missed Donation Opportunities Project.
2.5.1	Organ Donation	Indication of whether an ODO-affiliated organ donation	• Y: Yes
	Specialist Involved	specialist (e.g., physician) was involved with the formal	• N: No
		consent discussion	• UNK: Unknown
			<b>Note:</b> The value set codes are sourced from HL7.
2.6	Formal Consent Approach Date	The date the donor's substitute decision-maker was approached for a formal consent discussion	YYYYMMDD
2.6.1	Formal Consent Approach Time	The time of day the donor's substitute decision-maker	ННММ
		was approached for a formal consent discussion	Note: 24-hour clock

ID	Data element name	Description	Valid values
2.7	Reason for No Formal		• 1: Imminent move to comfort care
	Consent Approach		<ul> <li>2: Substitute decision-maker not accepting of prognosis</li> </ul>
			• 3: Substitute decision-maker declines approach
			• 4: Unable to locate substitute decision-maker
			• 5: Most responsible physician prevents approach
			• 6: Medical examiner/coroner refusal
			• 7: No interest from transplant program
			<ul> <li>702371008: Patient unsuitable for procedure due to medical condition</li> </ul>
			• OTH: Other
			• UNK: Unknown
			Notes
		The value set code 702371008 is sourced from SNOMED CT Canadian Edition; OTH and UNK are sourced from HL7.	
			Values are adapted from the ODTC's Missed Donation Opportunities Project.
2.8	Consent for Donation	sent for Donation Indication of whether consent was obtained from the donor's substitute decision-maker for each organ	• Y: Yes
	da		• N: No
			<b>Note:</b> The value set codes are sourced from HL7.

ID	Data element name	Description	Valid values
2.9	Data element name         Description           Reason Consent Was Declined         The reason consent was not given for organ donation	• 1: Lack of confidence in death determination or expressed concern that donation would be the cause of death	
			• 2: SDM unaware of patient's wishes
			• 3: SDM expressed patient had been through too much
			• 4: SDM and family unable to reach consensus
			• 5: SDM did not want patient transferred
			• 6: SDM did not want surgery to the body
			• 7: SDM expressed the organ donation process was too long
			<ul> <li>8: SDM did not want patient to go through additional testing</li> </ul>
			• 9: Worried donation would not actualize
			• 161034004: Not willing to be a donor
			• 704301008: Cultural belief conflict
			304217009: Relatives unwilling to allow organ donation
			• OTH: Other
			• UNK: Unknown
			Notes
			The value set codes 161034004, 704301008 and 304217009 are sourced from SNOMED CT Canadian Edition; OTH and UNK are sourced from HL7.
			Values are adapted from the ODTC's Missed Donation Opportunities Project.

ID	Data element name	Description	Valid values
2.10	Consented Organ	ed Organ Each organ for which consent was legally obtained for	BOW: Bowel/intestine
		organ donation	• 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.
2.11	Consented Date	The date the donor's substitute decision-maker provided	YYYYMMDD
	consent for specified organ(s)	consent for specified organ(s)	<b>Note:</b> In cases where consent is provided for different organs at different time points, record the date of the initial consent.
2.11.1	Consented Time	The time of day the donor's substitute decision-maker provided consent for specified organ(s)	ННММ
			Notes
			24-hour clock
			In cases where consent is provided for different organs at different time points, record the time of the initial consent.
2.12	Consented Donor	The consented organ disposition preference specified	37401000087100: Organ donation for transplant
	Organ Disposition		• 37391000087103: Organ donation for research
			37381000087100: Organ donation for medical education
			<b>Note:</b> The value set codes are sourced from SNOMED CT Canadian Edition.
2.13	Withdrawn Consent	Indication of whether consent to donate was withdrawn	• Y: Yes
			• N: No
			<b>Note:</b> The value set codes are sourced from HL7.

ID	Data element name	Description	Valid values
2.14	Withdrawn Consent Reason	The reason the substitute decision-maker provided for the decision to withdraw consent	• 1: Substitute decision-maker did not want patient transferred
			• 2: Substitute decision-maker expressed the organ donation process was too long
			• OTH: Other
			• UNK: Unknown
			Note: OTH and UNK are sourced from HL7.
2.15	Withdrawn Organ         Each organ for which previously obtained consent was withdrawn	Each organ for which previously obtained consent	BOW: Bowel/intestine
		was withdrawn	• 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.
2.16	Withdrawn Consent Date	The date that consent to donate was withdrawn for the donor or specified organ(s)	YYYYMMDD
2.16.1	Withdrawn Consent Time	The time of day that consent to donate was withdrawn	ННММ
	for the donor or specified organ(s)	for the donor or specified organ(s)	Note: 24-hour clock

#### Note

For MAID donors, approach and consent is conducted with and obtained from the donor, not their SDM.

Phase 3	Donor management
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ID	Data element name	Description	Valid values
3.1	Extended Criteria Donor	Indication of whether the donor is considered an increased risk for organ donation, based on medical conditions/complexities	<ul> <li>Y: Yes</li> <li>N: No</li> <li>UNK: Unknown</li> <li>Note: The data element code is sourced from SNOMED CT Canadian Edition (Extended Criteria Donor: 34431000087102). The value set codes are sourced from HL7.</li> </ul>
3.2	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> <li>Y: Yes</li> <li>N: No</li> <li>UNK: Unknown</li> <li>Note: The data element code is sourced from SNOMED CT Canadian Edition (Exceptional Distribution Donor: 34421000087104). The value set codes are sourced from HL7.</li> </ul>
3.3	Increased Risk Donor	Indication in the donor's medical and/or social behaviour history that they are at increased risk of transmitting hepatitis B, hepatitis C, or HIV (human immunodeficiency virus) to the recipient	<ul> <li>Y: Yes</li> <li>N: No</li> <li>UNK: Unknown</li> <li>Note: The data element code is sourced from SNOMED CT Canadian Edition (Increased Risk Donor: 34461000087109). The value set codes are sourced from HL7.</li> </ul>
3.4	History of Hypertension	Indication of whether the donor was receiving medication at the time of donation to control hypertension, such as calcium-blocking agents, vasodilators, beta-blockers, diuretics or angiotensin- converting enzyme (ACE) inhibitors (e.g., captopril or enalapril)	<ul> <li>Y: Yes</li> <li>N: No</li> <li>UNK: Unknown</li> <li>Note: The data element code is sourced from SNOMED CT Canadian Edition (History of Hypertension: 161501007). The value set codes are sourced from HL7.</li> </ul>

ID	Data element name	Description	Valid values
3.5	History of Coronary Artery Disease	Indication of whether the donor was diagnosed with coronary artery disease at the time of donation. Coronary artery disease, also known as atherosclerosis, is the process by which the coronary arteries become narrowed or completely occluded. Ultimately, this is the underlying cause of heart attack.	<ul> <li>Y: Yes</li> <li>N: No</li> <li>UNK: Unknown</li> <li>Note: The data element code is sourced from SNOMED CT Canadian Edition (History of Coronary Artery Disease: 37581000087108). The value set codes are sourced from HL7.</li> </ul>
3.6	History of Diabetes Mellitus	Indication of whether the donor was diagnosed with type 1 or type 2 diabetes at the time of donation	<ul> <li>46635009: Diabetes mellitus type 1</li> <li>44054006: Diabetes mellitus type 2</li> <li>N: No</li> <li>OTH: Other</li> <li>UNK: Unknown</li> <li>Note: The data element code is sourced from SNOMED CT Canadian Edition (History of Diabetes Mellitus: 161445009). The value set codes are sourced from SNOMED CT Canadian Edition; N, OTH and UNK are sourced from HL7.</li> </ul>
3.7	History of Myocardial Infarction	Indication of whether the donor has a history of myocardial infarction (MI)	<ul> <li>Y: Yes</li> <li>N: No</li> <li>UNK: Unknown</li> <li>Note: The data element code is sourced from SNOMED CT Canadian Edition (History of Myocardial Infarction: 399211009). The value set codes are sourced from HL7.</li> </ul>
3.11	Alcohol Use	Indication of whether the donor has a history of alcohol use that poses a potential risk	<ul> <li>Y: Yes</li> <li>N: No</li> <li>UNK: Unknown</li> <li>Note: The data element code is sourced from LOINC (History of Alcohol Use: 11331-6). The value set codes are sourced from HL7.</li> </ul>

ID	Data element name	Description	Valid values
3.12	Smoking History	Indication of whether the donor was a smoker (i.e., smoked cigarettes, cigars or a pipe in the last 6 months prior to donation)	<ul> <li>Y: Yes</li> <li>N: No</li> <li>UNK: Unknown</li> <li>Note: The data element code is sourced from LOINC (Tobacco Smoking Status: 72166-2). The value set codes are sourced from HL7.</li> </ul>
3.13	Smoking Rate	If the donor was a smoker (Smoking History = <i>yes</i> ), the number of packs the donor smoked per day	<ul> <li># packs per day</li> <li>Note: The data element code is sourced from LOINC (Tobacco Amount Per Day: 96103-7).</li> </ul>
3.14	Smoking Duration	If the donor was a smoker (Smoking History = yes), the number of years the donor was a smoker	# years     Note: The data element code is sourced from LOINC     (Smoking Tobacco Use Duration: 67741-9).
3.14.1	History of Marijuana Use	Indication of whether the donor has a history of marijuana use	<ul> <li>Y: Yes</li> <li>N: No</li> <li>UNK: Unknown</li> <li>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.</li> </ul>
3.15	Drug Use	Indication of whether the donor 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.	<ul> <li>Y: Yes</li> <li>N: No</li> <li>UNK: Unknown</li> <li>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.</li> </ul>

ID	Data element name	Description	Valid values
3.21	H/O: Malignancy	Indication of whether the donor has a history	• Y: Yes
		of malignancy	• N: No
			• UNK: Unknown
			<b>Note:</b> The data element code is sourced from SNOMED CT Canadian Edition (H/O: Malignancy: 266987004). The value set codes are sourced from HL7.
3.22	West Nile Virus	Indication of whether the donor had the West Nile virus	• 10828004: Positive
		(WNV), based on IgG, IgM and/or nucleic acid testing	• 260385009: Negative
		(NAT), at the time of donation	• 373121007: Test not done
			• UNK: Unknown
			<b>Note:</b> The data element code is sourced from SNOMED CT Canadian Edition (West Nile Virus Antibody: 421862008). The value set codes are sourced from SNOMED CT Canadian Edition; UNK is sourced from HL7.
3.23	Rabies	Indication of whether the donor had rabies at the time of donation	• Y: Yes
			• N: No
			• UNK: Unknown
			<b>Note:</b> The data element code is sourced from SNOMED CT Canadian Edition (Rabies: 14168008). The value set codes are sourced from HL7.
3.24	Creutzfeldt–Jakob Disease	Indication of whether the donor was diagnosed with	• Y: Yes
		Creutzfeldt–Jakob disease (CJD or "Mad Cow") at the time of donation	• N: No
			• UNK: Unknown
			<b>Note:</b> The data element code is sourced from SNOMED CT Canadian Edition (Creutzfeldt–Jakob Disease: 792004). The value set codes are sourced from HL7.

ID	Data element name	Description	Valid values
3.25	Prematurity	Indication of whether the donor is considered premature (i.e., less than 36 weeks corrected gestational age)	• Y: Yes
			• N: No
			• UNK: Unknown
			NA: Not applicable
			<b>Note:</b> The data element code is sourced from LOINC (Premature Infant: 76517-2). The value set codes are sourced from HL7.
3.26	History of Hyperlipidemia	Indication of whether the donor had elevated	• Y: Yes
		concentrations of any or all lipids in plasma,	• N: No
		such as cholesterol, triglycerides and lipoproteins	• UNK: Unknown
			<b>Note:</b> The data element code is sourced from SNOMED CT Canadian Edition (History of Hyperlipidemia: 37591000087105). The value set codes are sourced from HL7.
3.27	Terminal Serum Creatinine	The donor's creatinine level at the time of death (in mg/DL)	<ul> <li>0.00 to ##.## mg/DL</li> <li>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.</li> </ul>
3.30	Coronary	Indication of whether a coronary angiogram was done	• 280413001: Normal result
	Angiogram Interpretation	on the donor and, if done, whether the last test's	• 280415008: Abnormal result
		function was normal or abnormal	• 373121007: Test not done
			• 373068000: Undetermined
			<b>Note:</b> The data element code is sourced from SNOMED CT Canadian Edition (Coronary Angiogram Interpretation: 37321000087101). The value set codes are sourced from SNOMED CT Canadian Edition.

ID	Data element name	Description	Valid values
3.31	Radiography Interpretation	Indication of whether any radiography (e.g., X-ray) was	• 280413001: Normal result
		done on the donor and, if done, whether the last results	• 280415008: Abnormal result
		were normal or abnormal	• 373121007: Test not done
			• 373068000: Undetermined
			<b>Note:</b> 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.
3.32	Estimated Glomerular	The donor's estimated glomerular filtration rate (eGFR)	• 0 to 120
	Filtration Rate		<b>Note:</b> The data element code is sourced from SNOMED CT Canadian Edition (Estimated Glomerular Filtration Rate: 37571000087106).
3.33	Kidney Donor Risk Index Score	The donor's kidney donor risk index (KDRI) at the time	• 0.00 to 9.99
		of donation	<b>Note:</b> The data element code is sourced from SNOMED CT Canadian Edition (Kidney Donor Risk Index Score: 37341000087105).
3.36	Hepatitis B Surface	Indication of whether the donor tested positive for	• 10828004: Positive
	Antigen Measurement	the hepatitis B antigen (hepatitis BsAg) at the time	• 260385009: Negative
		of donation	• 373121007: Test not done
			• 373068000: Undetermined
			<b>Note:</b> 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.

ID	Data element name	Description	Valid values
3.37	Hepatitis B Core	Indication of whether the donor tested positive for	• 10828004: Positive
	Antibody Measurement	the hepatitis B antibody (hepatitis BcAb) at the time	• 260385009: Negative
		of donation	• 373121007: Test not done
			• 373068000: Undetermined
			<b>Note:</b> 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.
3.38	Hepatitis C	Indication of whether the donor tested positive for the	• 10828004: Positive
	Antibody Measurement	hepatitis C antibody at the time of donation	• 260385009: Negative
			• 373121007: Test not done
			• 373068000: Undetermined
			<b>Note:</b> 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.
3.39	Epstein–Barr Virus	Indication of whether the donor tested positive for the	• 10828004: Positive
	Antibody Measurement	Epstein–Barr virus antibody at the time of donation	• 260385009: Negative
			• 373121007: Test not done
			• 373068000: Undetermined
			<b>Note:</b> 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.

ID	Data element name	Description	Valid values
3.40	Human Immunodeficiency Virus	Indication of whether the donor tested positive for the	• 10828004: Positive
	Antigen Test	HIV antigen at the time of donation	• 260385009: Negative
			• 373121007: Test not done
			• 373068000: Undetermined
			<b>Note:</b> 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.
3.41	Cytomegalovirus	Indication of whether the donor tested positive for the	• 10828004: Positive
	Antibody Measurement	cytomegalovirus (CMV) antibody at the time of donation	• 260385009: Negative
			• 373121007: Test not done
			• 373068000: Undetermined
			<b>Note:</b> 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.
3.42	Measurement of Human	Indication of whether the donor tested positive for the	• 10828004: Positive
	T-Lymphotropic Virus 1 Antibody and Human T-Lymphotropic Virus 2 Antibody	human T-cell lymphotropic virus (HTLV) type I or type II antibody at the time of donation	• 260385009: Negative
			• 373121007: Test not done
			• 373068000: Undetermined
			<b>Note:</b> 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.

ID	Data element name	Description	Valid values
3.47	HLAA	The donor's 2 human leukocyte antigen (HLA) type A antigens	See <u>Appendix C</u> for a list of recognized serological HLA specificities
			<ul> <li>Additional values:</li> <li>37501000087101: Human leukocyte antigen typing — no antigen identified</li> <li>UNK: Unknown/not available/typing not done</li> <li>OTH: Other</li> <li>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</li> </ul>
3.48	HLA B	The donor's 2 HLA type B antigens	OTH are sourced from HL7. See <u>Appendix C</u> for a list of recognized serological HLA specificities
			<ul> <li>Additional values:</li> <li>37501000087101: Human leukocyte antigen typing — no antigen identified</li> <li>UNK: Unknown/not available/typing not done</li> <li>OTH: Other</li> </ul>
			<b>Note:</b> 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.

ID	Data element name	Description	Valid values
3.49	HLA C	The donor's 2 HLA type C antigens	See <u>Appendix C</u> for a list of recognized serological HLA specificities
			Additional values:
			<ul> <li>37501000087101: Human leukocyte antigen typing — no antigen identified</li> </ul>
			UNK: Unknown/not available/typing not done
			• OTH: Other
			<b>Note:</b> 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.
3.50	HLA DR	The donor's 2 HLA type DR antigens	See <u>Appendix C</u> for a list of recognized serological HLA specificities
			Additional values:
			<ul> <li>37501000087101: Human leukocyte antigen typing — no antigen identified</li> </ul>
			UNK: Unknown/not available/typing not done
			• OTH: Other
			<b>Note:</b> 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.

ID	Data element name	Description	Valid values
3.51	HLA DQ	The donor's 2 HLA type DQ antigens	See <u>Appendix C</u> 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
			<b>Note:</b> 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.
3.51.1	HLA DP	The donor's 2 HLA type DP antigens	See <u>Appendix C</u> for a list of recognized serological HLA specificities
			Additional values:
			<ul> <li>37501000087101: Human leukocyte antigen typing — no antigen identified</li> </ul>
			UNK: Unknown/not available/typing not done
			• OTH: Other
			<b>Note:</b> 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.
3.52	Offer Status	The status of each offer for the specified consented	• 385645004: Accepted
		organ by the ODO, at the time of data submission	• 443390004: Refused
			• 247755007: Withdrawn
			• 89925002: Cancelled
			<b>Note:</b> The value set codes are sourced from SNOMED CT Canadian Edition.

ID	Data element name	Description	Valid values
3.53	Offer Date	For each offer, the date the specified consented organ was offered by the ODO	YYYYMMDD
3.53.1	Offer Time	For each offer, the time of day the specified consented	ННММ
		organ was offered by the ODO	Note: 24-hour clock
3.54	Not Offered Reason	d Reason The reason the organ was not offered to a	• 1: DCD donor
		transplantation centre after consent was obtained	• 2: No suitable recipient (ABO/size/histocompatibility- related issues)
			• 3: Patient did not die in allotted time (DCD)
			• 4: Patient did not progress to NDD and was not a DCD candidate
			• 5: Organ deemed unsuitable (anatomical damage, defect, trauma, etc.)
			• 6: Malignancy or suspected malignancy
			• 7: Prolonged warm or cold ischemia time
			• 8: Positive serology/virology
			• 9: High-risk behaviour
			• 10: Logistical issues
			• 11: Abnormal test result
			• 12: Donor too medically unstable for donation
			• 11761000087106: Patient's age
			• 417662000: Past medical history
			• 165325009: Biopsy result abnormal
			• OTH: Other
			UNK: Unknown
			Notes
			The value set codes 11761000087106, 417662000 and 165325009 are sourced from SNOMED CT Canadian Edition; OTH and UNK are sourced from HL7.
			Values are adapted from the ODTC's Missed Donation Opportunities Project.

ID	Data element name	Description	Valid values
3.55	Offered Organ	The specific consented organ that is intended to be	BOW: Bowel/intestine
		offered, regardless of whether offering actually occurs	• 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
			• 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
3.56	Not Accepted Reason	The reason the organ offered was not accepted/suitable	• 1: DCD donor
			• 2: No suitable recipient (ABO/size/histocompatibility- related issues)
			• 3: Organ deemed unsuitable (anatomical damage, defect, trauma, etc.)
			• 4: Malignancy or suspected malignancy
			• 5: Prolonged warm or cold ischemia time
			• 6: Positive serology/virology
			• 7: High-risk behaviour
			• 8: Logistical issues
			• 9: Recipient-related issues (medically unsuitable, unavailable, refused)
			• 10: Abnormal test result
			• 11: Test result unavailable or not done
			• 12: Donor too medically unstable for donation
			• 11761000087106: Patient's age
			• 417662000: Past medical history
			• 165325009: Biopsy result abnormal
			• 365981007: Smoking
			• 40733004: Infection
			• OTH: Other
			• UNK: Unknown
			Notes
			The value set codes 11761000087106, 417662000, 165325009, 365981007 and 40733004 are sourced from SNOMED CT Canadian Edition; OTH and UNK are sourced from HL7.
			Values are adapted from the ODTC's Missed Donation Opportunities Project.

ID	Data element name	Description	Valid values
3.57	Type of Offer	Indication of whether the offer made was from an ODO to a transplantation centre (TXC) in Canada, was an export from an ODO to another ODO in Canada, or was an export to an organization out of the country (i.e., United Network for Organ Sharing [UNOS])	<ul> <li>37481000087107: Organ offer from organ donation organization to organ donation organization</li> <li>37491000087109: Organ offer from organ donation organization to transplantation centre</li> <li>45041000087103: Organ offer from organ donation organization to out of country organization</li> <li>Note: The value set codes are sourced from SNOMED CT Canadian Edition.</li> </ul>
3.58	ODO Receiving Offer	For the ODO-to-ODO offer, the ODO that received an offer	Note: Subject to CIHI's Organizational Index.
3.59	Receiving ODO Donor Identifier	The unique local identifier that is generated by the receiving ODO	ODO local naming convention
3.61	Recipient TXC	The TXC that received an offer and is responsible for recipient case management	Note: Subject to CIHI's Organizational Index.
3.62	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
3.63	Recipient Health Care	The province/territory that issued the recipient's HCN	• AB: Alberta
	Number Issuer		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.

Canadian Organ Donation and Transplantation Data System (CanODT): Deceased Donation Minimum Data Set, Version 1.8

ID	Data element name	Description	Valid values
3.64	TXC Recipient Identifier	Unique local identifier assigned to the recipient case file by the TXC	TXC local naming convention
3.66	CTR Recipient Identifier	The national recipient identifier assigned by the Canadian Transplant Registry (CTR)	CTR naming convention

## Phase 4 Organ retrieval

ID	Data element name	Description	Valid values
4.2	Withdrawal of Life-Sustaining Therapy (WLST) Performed	Indication of whether withdrawal of life-sustaining therapy (WLST) was performed, regardless of whether the donor proceeded to organ recovery	<ul> <li>Y: Yes</li> <li>N: No</li> <li>UNK: Unknown</li> <li>Note: The data element code is sourced from SNOMED CT Canadian Edition (Withdrawal of Life-Sustaining Therapy [WLST] Performed: 35031000087105).</li> <li>The value set codes are sourced from HL7.</li> </ul>
4.3	WLST Date	The date life-sustaining therapy was withdrawn	YYYYMMDD
4.3.1	WLST Time	The time of day life-sustaining therapy was withdrawn	HHMM Note: 24-hour clock
4.4	Declaration of Death Date	The date of the declaration of death	YYYYMMDD
4.4.1	Declaration of Death Time	The time of day of the declaration of death	HHMM Note: 24-hour clock
4.7	Recovery Facility	Facility where the organ recovery occurred	Note: Subject to CIHI's Organizational Index.

ID	Data element name	Description	Valid values
4.8	Organ Recovery Date	The date that the recovery of the specified organ(s) began in the operating room (i.e., the initial incision on the donor), regardless of whether the organ(s) were actually recovered	YYYYMMDD
4.8.1	Organ Recovery Time	The time of day that the recovery of the specified organ(s) began in the operating room (i.e., the initial incision on the donor), regardless of whether the organ(s) were actually recovered	HHMM Note: 24-hour clock
4.9	Recovered State	Indication of the outcome for the recovered organ	<ul> <li>Y: Yes</li> <li>N: No</li> <li>Note: The value set codes are sourced from HL7.</li> </ul>

ID	Data element name	Description	Valid values
4.10	Not Recovered Reason	Reason the organ was not recovered	<ul> <li>1: Organ deemed unsuitable (anatomical damage, defect, trauma, etc.)</li> </ul>
			• 2: Malignancy or suspected malignancy
			• 3: Prolonged warm or cold ischemia time
			• 4: Positive serology/virology
			• 5: Logistical issues
			• 6: Problem within the operating room
			• 7: Medical examiner/coroner refusal
			• 8: Abnormal test result
			• 9: DCD (did not progress)
			• 10: Donor too medically unstable for donation
			• 165325009: Biopsy result abnormal
			• 40733004: Infection
			• OTH: Other
			• UNK: Unknown
			Notes
			The value set codes 165325009 and 40733004 are sourced from SNOMED CT Canadian Edition; OTH and UNK are sourced from HL7.
			Values are adapted from the ODTC's Missed Donation Opportunities Project.

ID	Data element name	Description	Valid values
4.11	Recovered Organ	Organ The specific organ that is intended to be recovered, regardless of whether recovery actually occurs	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
			• 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
			<b>Note:</b> The value set codes are sourced from CRDM.
4.12	Cross-Clamp Date	The date of the aortic cross-clamping	YYYYMMDD
4.12.1	Cross-Clamp Time	The time of day of the aortic cross-clamping	ННММ
			Note: 24-hour clock

ID	Data element name	Description	Valid values
4.13	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.
4.14	Perfusion Device Used	The device used for organ perfusion for the	37451000087104: Kidney perfusion pump
		specified organ(s)	• 37441000087102: Ex vivo pump
			• UNK: Unknown
			Note: The value set codes are sourced from SNOMED
			CT Canadian Edition; UNK is sourced from HL7.
4.16	Functional Warm Ischemia Time	The time elapsed (in minutes) from donor hypotension/	• 0 to 1440 minutes (i.e., 0 to 24 hours)
		hypoxia to initiation of cold organ preservation	Note: UCUM is used for the units of measure.
4.17	Cold Preservation Start Date	The date that cold preservation was initiated for the specified organ(s)	YYYYMMDD
4.17.1	Cold Preservation Start Time	The time of day that cold preservation was initiated for	ННММ
		the specified organ(s)	Note: 24-hour clock

Phase 5	Organ utilization
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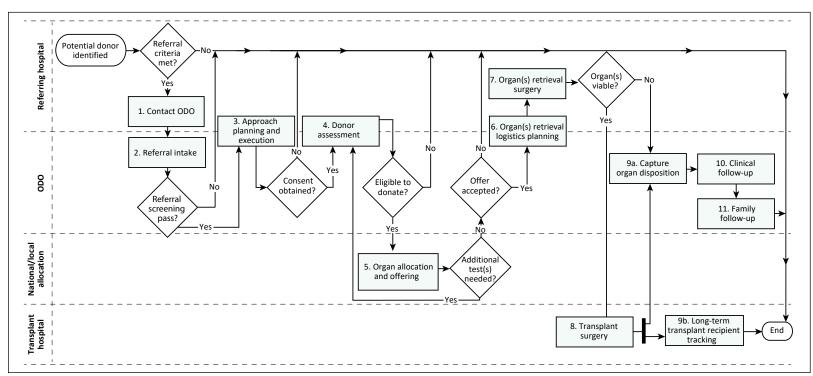
ID	Data element name	Description	Valid values
5.1	Transplanted State	Indication of the outcome for the transplanted organ	Y: Yes     N: No
			Note: The value set codes are sourced from HL7.
5.2	Transplanted Organ	The specific recovered organ that is intended	BOW: Bowel/intestine
		to be transplanted, regardless of whether	HRT: Heart
		transplantation actually occurs	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
			• 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
5.3	Not Transplanted Reason	Reason the specified organ was not	• 1: Organ deemed not suitable for transplant
		transplanted into a recipient	• 2: Recipient-related issues
			• 3: Surgical complication (surgical safety event)
			• 4: Logistic complications (personnel and transport related)
			• OTH: Other
			• UNK: Unknown
			Note: OTH and UNK are sourced from HL7.
			Values are adapted from the ODTC's Missed Donation
			Opportunities Project.
5.9	Not Transplanted	Disposition of the organ that was recovered and	37391000087103: Organ donation for research
	Disposition	not transplanted	• 37381000087100: Organ donation for medical education
			• 37611000087100: Organ submission to pathology service
			• 262009000: Not used
			• UNK: Unknown
			<b>Note:</b> The value set codes are sourced from SNOMED CT Canadian
			Edition; UNK is sourced from HL7.

## **Appendices**

## Appendix A: Deceased donation workflow

This figure depicts the optimal high-level deceased donation journey. The workflow has been validated with ODOs participating in the CIHI–Infoway Pan-Canadian Organ Donation and Transplantation Data and Performance Reporting System Project's Business Data Management Expert Advisory Forum (January 2021).



### Figure Deceased donation workflow

#### Notes

ODO: Organ donation organization.

In certain scenarios, the referring or retrieval hospital may be the same as the transplant hospital. The referring hospital may also be different from the retrieval hospital. Transplant assessment (Step 4) typically involves the transplant hospital as well as the ODO and/or the referring hospital.

## Appendix B: Country codes

The following table provides a list of country codes for data element 1.10 (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. Also included in this list are 2 codes — OTH (other) and UNK (unknown) — that are not in the ISO standard but are a CIHI standard. 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
ΑΤΑ	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

Alpha-3 code	English short name	French short name
BIH	Bosnia and Herzegovina	Bosnie-Herzégovine
BWA	Botswana	Botswana
BVT	Bouvet Island	Bouvet, Île
BRA	Brazil	Brésil
ΙΟΤ	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
КНМ	Cambodia	Cambodge
CMR	Cameroon	Cameroun
CAN	Canada	Canada
СҮМ	Cayman Islands	Caïmans, Îles
CAF	Central African Republic	Centrafricaine, République
TCD	Chad	Tchad
CHL	Chile	Chili
CHN	China	Chine
CXR	Christmas Island	Christmas, Île
ССК	Cocos (Keeling) Islands	Cocos (Keeling), Îles
COL	Colombia	Colombie
СОМ	Comoros	Comores
COD	Congo, Democratic Republic of the	Congo, République démocratique du
COG	Congo, Republic of the	Congo, République du
СОК	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
СҮР	Cyprus	Chypre
CZE	Czechia	Tchéquie
DNK	Denmark	Danemark
IID	Djibouti	Djibouti
DMA	Dominica	Dominique
DOM	Dominican Republic	Dominicaine, République

Alpha-3 code	English short name	French short name	
ECU	Ecuador	Équateur	
EGY	Egypt	jypt Égypte	
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	
НТІ	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	

Alpha-3 code	English short name	French short name	
IND	India	Inde	
IDN	Indonesia Indonésie		
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	
ХКО	Kosovo	Kosovo	
кwт	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	Масао	Масао	
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	

Alpha-3 code	English short name	French short name
ΜΤQ	Martinique	Martinique
MRT	Mauritania Mauritanie	
MUS	Mauritius Maurice	
МҮТ	Mayotte	Mayotte
MEX	Mexico	Mexique
FSM	Micronesia, Federated States of	Micronésie, États fédérés de
MDA	Moldova	Moldova
МСО	Monaco	Monaco
MNG	Mongolia	Mongolie
MNE	Montenegro	Monténégro
MSR	Montserrat	Montserrat
MAR	Могоссо	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

Alpha-3 code	English short name	French short name	
QAT	Qatar	Qatar	
REU	Réunion Réunion		
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	

Alpha-3 code	English short name	French short name	
SYR	Syria	Syrie	
TWN	Taiwan	Taïwan	
тјк	Tajikistan Tadjikistan		
TZA	Tanzania	Tanzanie	
THA	Thailand	Thaïlande	
TLS	Timor-Leste	Timor-Leste	
TGO	Тодо	Тодо	
TKL	Tokelau	Tokélaou	
TON	Tonga	Tonga	
тто	Trinidad and Tobago	Trinité-et-Tobago	
TUN	Tunisia	Tunisie	
TUR	Turkey	Turquie	
ТКМ	Turkmenistan	Turkménistan	
TCA	Turks and Caicos Islands	Turks-et-Caïcos, Îles	
τυν	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 3.47 to 3.51.1 (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

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## Appendix D: Glossary of terms

Term	Description
ACE	Angiotensin-converting enzyme
cDCD	Controlled donation after circulatory death
CanODT	Canadian Organ Donation and Transplantation Data System
СІНІ	Canadian Institute for Health Information
CJD	Creutzfeldt–Jakob disease
CMV	Cytomegalovirus
CORR	Canadian Organ Replacement Register
CRDM	CIHI Reference Data Model
CTR	Canadian Transplant Registry
DCD	Donation after circulatory death
DD	Deceased donation
DD MDS	Deceased Donation Minimum Data Set
DSWG	Data System Working Group
eGFR	Estimated glomerular filtration rate
HCN	Health care number
НСР	Health care provider
HLA	Human leukocyte antigen
HL7	Health Level Seven
HTLV	Human T-cell lymphotropic virus
IPD-IMGT/HLA	Immuno Polymorphism Database–ImMunoGeneTics/Human Leukocyte Antigen
ISO	International Organization for Standardization
KDRI	Kidney donor risk index
LOINC	Logical Observation Identifiers Names and Codes
MAID	Medical assistance in dying
MDS	Minimum data set
MI	Myocardial infarction
NAT	Nucleic acid testing
NDD	Neurological determination of death
ODO	Organ donation organization
ODT	Organ donation and transplantation
ODTC	Organ Donation and Transplantation Collaborative
SDM	Substitute decision-maker
SNOMED CT	Systematized Nomenclature of Medicine — Clinical Terms
ТХС	Transplantation centre
UCUM	Unified Code for Units of Measure
uDCD	Uncontrolled donation after circulatory death
WNV	West Nile virus
WLST	Withdrawal of life-sustaining therapy

## Appendix E: Text alternative for figure

### Figure Deceased donation workflow

This figure shows a high-level deceased donor journey workflow from the procedural perspective. The optimal journey is described, but the workflow also captures situations where the donation case ends because the patient or consented organs are deemed unsuitable to proceed in the process.

The journey begins when a hospital identifies a potential donation candidate and refers them to an organ donation organization (ODO). The ODO intakes, coordinates and manages the donor case going forward.

The ODO conducts a screening process and approaches the patient's next of kin or substitute decision-maker to obtain consent for donation.

Once consent for donation has been obtained, a donor assessment to obtain and evaluate any medical or clinical details related to the donor or consented organs is conducted.

After the donor assessment has been completed, the consented organs are offered and allocated to a suitable transplant recipient.

Upon allocation, the logistics for organ recovery and transplantation surgeries are coordinated and the corresponding surgeries are performed.

A post-surgery follow-up care plan is implemented to assist and monitor the patients and/ or families.

### Notes

In certain scenarios, the referring or retrieval hospital may be the same as the transplant hospital. The referring hospital may also be different from the retrieval hospital.

Transplant assessment (Step 4) typically involves the transplant hospital as well as the ODO and/or the referring hospital.

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