



Pan-Canadian Organ Donation and Transplantation Data and Performance Reporting System

Indicators and Measures Short-List for Prioritization

April 2021



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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 to 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 for system performance indicators that 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, co-chaired by Dr. Joseph Kim and Dr. Matthew Weiss. (See [Appendix A](#) for a list of members.)

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 project include the following:

- Development of minimum data sets and data standards for deceased donation, living donation and transplantation (CIHI);
- Procurement of data management systems and integration solutions (Infoway);
- Design, build and deployment of 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).

Development of short-list for prioritization

This document presents a short-list of indicators and measures for prioritization to support the Health Canada–funded Pan-Canadian ODT Data and Performance Reporting System Project co-led by CIHI and Infoway. Developed by CIHI with input from ODT expert advisory members, the list covers deceased donation, living donation and transplantation. For transplantation, the list includes all-organ indicators/measures plus kidney- and heart-specific indicators. Additional processes will develop and prioritize liver, lung, pancreas, intestine and pediatric-specific transplantation indicators.

This list will be included as part of a broad modified Delphi prioritization exercise starting with a survey planned for spring 2021, with round 2 discussions taking place once results have been compiled and analyzed by CIHI. Development of indicators and measures will follow for prioritized and feasible ones, in a phased manner, for future inclusion in the ODT Data and Performance Reporting System to be managed by CIHI.



In terms of CIHI's approach to the development of this document, CIHI conducted an environmental scan of indicators, which involved looking at over 13 international and national organizations that report ODT data, as well as key articles from the literature. The scan included a review of priority lists from existing Canadian groups such as those previously developed by Canadian Blood Services and Trillium Gift of Life Network's Ontario Transplant Performance Measurement and Evaluation Executive Committee (TPEC) Quality Indicator groups. The following principles were used in the approach:

- Include measures commonly reported by organizations.
- Leverage existing literature and prioritization work to fill priority gaps.
- Include the full care continuum for deceased donation, living donation and transplantation for all solid organs and performance domains.
- Categorize indicators according to the performance dimensions in CIHI's [Health System Performance Measurement Framework](#) (2013) and Donabedian et al.'s (1988) quality framework.

Indicator summary table

Indicator type		Deceased donation	Living donation	All donations*	Transplantation†	Total
Number of indicators in environmental scan		241	50	35	468	794
Number of unique indicator concepts in environmental scan		52	24	7	118	201
Number of indicators in short-list for prioritization		21	16	3	52	92
Short-listed indicators by performance dimension	Access	8	3	0	12	23
	Appropriate and effective	5	5	1	24	35
	Efficient	7	2	0	2	11
	Person-centred	0	3	0	2	5
	Safe	0	5	0	9	14
	Health system inputs	0	0	1	1	2
	Health system outcomes	1	1	1	2	5
	Social determinants of health	1	0	0	3	4
Short-listed indicators by quality framework	Process	15	4	1	15	35
	Outcome	4	10	1	26	41
	Structure	2	1	1	10	14
	Financial	0	1	0	1	2

Notes

* Includes both deceased and living donations.

† Includes organ-specific indicators.

Values in subcategories may not sum to the total if indicators are included in more than one group.

Final short-list of indicators and measures for prioritization

Notes

- **Included metrics:** For example, *numerator*, *denominator*, *rate* and other metric types. Certain indicators may be risk-adjusted to ensure comparability; in these cases, specific metrics will be available for all indicators but are not listed in the table, including *crude rate*, *risk-adjusted rate*, *observed value*, *expected value* and *observed-over-expected ratio*.
- **Stratifications and disaggregations:** Indicators/measures will be stratified by **age** (adult/pediatric), **organ**, **time** (e.g., fiscal year, month) and **geography** (e.g., province/region of residence or treatment, organ donation organization, transplant centre) **as appropriate**. Certain disaggregations will also be available for all indicators as appropriate; these include **age**, **sex**, **comorbidities** (e.g., malignancy, diabetes, renal disease), **diagnosis** and **ethnicity** (as available). These stratifications and disaggregations are not listed in the table. Disaggregations may be applicable only to specific organs; those with small cell counts may be available only in private reporting tools.
- **Reporting organizations and citations:** These include sources that have reported the indicator or a related metric (e.g., volume, rate, other similar measure) or sources where such measures were described but not reported.
- **Preliminary indicator/measure descriptions:** Methodology will be further refined during the indicator development process, which will occur in a phased manner starting in 2022.

Deceased donation (DD)

Note: A flowchart with populations used in deceased donation indicators/measures can be found in [Appendix B](#). See [Appendix C](#) for a list of acronyms.

Number	Phase	Indicator/measure	Description	Included metrics	Potential disaggregations	Performance dimension	Quality framework	Reporting organizations/citations (* denotes indicator was identified as a priority)
DD1	Intent to donate	People with registered intent per million population	The number of people with registered intent for organ donation per million adult population	<ul style="list-style-type: none"> Number of people registered to be an organ donor/not to be an organ donor 	Numerator: registered intent yes versus no (interpretation may differ across jurisdictions depending on legislation)	Biological/material/psychosocial/behavioural factors	Structure	<ul style="list-style-type: none"> BC Transplant Donate Life America Donate Life Australia NHS TGLN U.S. Department of Health and Human Services
DD2	Intent to donate	Registration rate (among referrals)	The percentage of referred potential donors registered to be organ donors	<ul style="list-style-type: none"> Number of referred potential donors Number registered 	—	Efficiency	Process	<ul style="list-style-type: none"> Donate Life Australia TGLN
DD3	Referral	Potential donor rate	<p>The number of potential donors per million population (e.g., estimated from existing CIHI clinical administrative hospital databases)</p> <p>This may be a proxy for true potential donor rate, where donor audits are unavailable</p>	<ul style="list-style-type: none"> Estimated number of potential donors 	<p>Numerator:</p> <ul style="list-style-type: none"> NDD/DCD For DCD: controlled, uncontrolled Extended criteria donor 	Efficiency/Access (Equitable)	Process	<ul style="list-style-type: none"> BC Transplant* CBS* CIHI Donate Life Australia NHS SRTR

Number	Phase	Indicator/measure	Description	Included metrics	Potential disaggregations	Performance dimension	Quality framework	Reporting organizations/citations (* denotes indicator was identified as a priority)
DD4	Referral	Estimated referral rate	The number of referred potential donors divided by the estimated number of potential donors (e.g., from existing CIHI clinical administrative hospital databases) Proxy for true referral rate/ missed referrals, where donor audits are unavailable	<ul style="list-style-type: none"> • Number of referred potential donors • Estimated number of potential donors 	<ul style="list-style-type: none"> • NDD/DCD • For DCD: controlled, uncontrolled, NPOD (lungs) • Extended criteria donor • Medical suitability for donation (numerator only) 	Efficiency/ Appropriateness and effectiveness	Process	<ul style="list-style-type: none"> • BC Transplant* • CBS* • Matesanz et al., 2012 • NBOTP* • NHS • ODEQUS • TGLN* • Transplant Québec*
DD5	Referral	Missed referral rate	The percentage of audited deaths meeting referral criteria that were not referred	<ul style="list-style-type: none"> • Audited deaths meeting referral criteria • Audited deaths meeting referral criteria that were referred/not referred 	<ul style="list-style-type: none"> • NDD/DCD • For DCD: controlled, uncontrolled, NPOD (lungs) • Extended criteria donor 	Appropriateness and effectiveness	Process	<ul style="list-style-type: none"> • BC Transplant* • CBS* • NBOTP* • NHS
DD6	Approach	Approach rate	The percentage of referred donors eligible for approach whose family/next of kin were approached to discuss donation <i>Exact methodology TBD</i>	<ul style="list-style-type: none"> • Number of referred donors eligible for approach • Number of approached/not approached families 	<ul style="list-style-type: none"> • NDD/DCD • MAID • For DCD: controlled, uncontrolled, NPOD (lungs) • Extended criteria donor 	Efficiency	Process	<ul style="list-style-type: none"> • BC Transplant* • CBS* • NHS • TGLN*
DD7	Donation management timelines	Time between referral and approach	The distribution of time between referral to approach by ODO	• Mean, median, percentiles (TBD)	NDD/DCD	Access	Process	—
DD8	Donation management timelines	Time from consent to withdrawal of life-sustaining treatment	The distribution of time between consent and withdrawal of life-sustaining treatment for DCD donors	• Mean, median, percentiles (TBD)	—	Access	Process	NHS

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Number	Phase	Indicator/measure	Description	Included metrics	Potential disaggregations	Performance dimension	Quality framework	Reporting organizations/citations (* denotes indicator was identified as a priority)
DD9	Donation management timelines	Time from consent to organ recovery	The distribution of time between consent for donation and organ recovery, for donors where at least one organ is recovered	<ul style="list-style-type: none"> • Mean, median, percentiles (TBD) 	<ul style="list-style-type: none"> • NDD/DCD • MAID For DCD: controlled, uncontrolled, NPOD (lungs)	Access	Process	NHS
DD10	Donation management timelines	Time from NDD to organ recovery	The distribution of time between NDD and organ recovery, for NDD donors where at least one organ is recovered	<ul style="list-style-type: none"> • Mean, median, percentiles (TBD) 	—	Access	Process	Australia and New Zealand Organ Donation Registry
DD11	Donation management timelines	Time from withdrawal of life-sustaining treatment to organ recovery	The distribution of time between withdrawal of life-sustaining treatment and organ recovery, for DCD donors where at least one organ is recovered	<ul style="list-style-type: none"> • Mean, median, percentiles (TBD) • Time from withdrawal to DCD; time from DCD to donation 	—	Access	Process	Australia and New Zealand Organ Donation Registry

Number	Phase	Indicator/measure	Description	Included metrics	Potential disaggregations	Performance dimension	Quality framework	Reporting organizations/citations (* denotes indicator was identified as a priority)
DD12	Consent	Consent rate	The percentage of approached next of kin/substitute decision-makers who consented to organ donation	<ul style="list-style-type: none"> • Number of approached next of kin/substitute decision-makers • Number of next of kin/substitute decision-makers who consented/did not consent to organ donation 	<ul style="list-style-type: none"> • Donor's registered intent • NDD/DCD • For DCD: controlled, uncontrolled, NPOD (lungs) • Approached/supported by donation specialist versus hospital staff • Extended criteria donor 	Appropriateness and effectiveness	Outcome	<ul style="list-style-type: none"> • Australia and New Zealand Donation Registry • BC Transplant* • CBS* • Donate Life Australia* • Matesanz et al., 2012 • NBOTP* • NHS* • ODEQUS • SRTR • Transplant Québec* • TGLN
DD13	Consent	Family overturn rate	The percentage of next of kin/substitute decision-makers for patients with registered consent decisions who overturned the decision	<ul style="list-style-type: none"> • Number of donors with registered consent decision • Number of those where next of kin/substitute decision-makers overturned the decision/did not overturn 	<ul style="list-style-type: none"> • Reason for overturn • NDD/DCD • MAID • For DCD: controlled, uncontrolled, NPOD (lungs) • Supported/not supported by donation specialist • Extended criteria donor 	Appropriateness and effectiveness	Outcome	<ul style="list-style-type: none"> • NHS • TGLN

Number	Phase	Indicator/measure	Description	Included metrics	Potential disaggregations	Performance dimension	Quality framework	Reporting organizations/citations (* denotes indicator was identified as a priority)
DD14	Offer	Percentage of offered organs accepted	The percentage of offered organs that are accepted	<ul style="list-style-type: none"> • Number of offered organs • Number of accepted organs • Number/percentage of rejected organs 	<p>Numerator:</p> <ul style="list-style-type: none"> • Recipient facility • Recipient region of residence • Reason for non-acceptance <p>Denominator:</p> <ul style="list-style-type: none"> • Location of donor (facility or ODO) • NDD/DCD • MAID • For DCD: controlled, uncontrolled, NPOD (lungs) • Donor risk category • Interprovincial offer • Acceptance at first offer versus acceptance after rejection from another program 	Access (Equitable)	Structure	<ul style="list-style-type: none"> • Brett et al., 2018 • Knoll et al., 2020 • NHS • SRTR • TGLN • TPEC, kidney group* (preliminary) • Transplant Québec
DD15	Organ recovery	Percentage of donors with a recovered organ	The percentage of consented donors where at least one organ was recovered	<ul style="list-style-type: none"> • Number of consented donors • Number of donors for which 1 organ was recovered/not recovered 	—	Efficiency	Process	<ul style="list-style-type: none"> • BC Transplant • NBOTP*

Number	Phase	Indicator/measure	Description	Included metrics	Potential disaggregations	Performance dimension	Quality framework	Reporting organizations/citations (* denotes indicator was identified as a priority)
DD16	Organ recovery	Deceased donors per million population	The number of deceased donors where at least one organ was recovered per million population	<ul style="list-style-type: none"> Number of deceased donors where at least one organ was recovered for the purpose of transplantation 	Numerator: <ul style="list-style-type: none"> NDD/DCD MAID For DCD: controlled, uncontrolled, NPOD (lungs); ischemia times (e.g., warm, functional) Cause of death BMI Blood type Extended criteria donor Ex vivo perfusion used Whether or not donor was transferred for donation 	Efficiency/Health system outcomes: Improve health status of Canadians	Outcome	<ul style="list-style-type: none"> Australia and New Zealand Organ Donation Registry BC Transplant CBS CORR Donate Life America Donate Life Australia* NBOTP* NHS* SRTR TGLN* Transplant Québec UNOS U.S. Department of Health and Human Services Note: Some organizations report utilized donors; others report donors where at least one organ was recovered.

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Number	Phase	Indicator/measure	Description	Included metrics	Potential disaggregations	Performance dimension	Quality framework	Reporting organizations/citations (* denotes indicator was identified as a priority)
DD17	Organ recovery	Increased-risk donors	The percentage of donors for which at least one organ was recovered who are considered increased-risk donors (e.g., HIV+, HBV+, HCV+, those with certain lifestyle behaviours with increased risk of transmission of infectious disease to transplant recipients) (definition TBD)	<ul style="list-style-type: none"> • Number of donors from whom at least one organ was recovered • Number with/without increased risk 	Numerator: <ul style="list-style-type: none"> • Risk type Denominator: <ul style="list-style-type: none"> • NDD/DCD • MAID • For DCD: controlled, uncontrolled, NPOD • Organ yield 	Access	Process	<ul style="list-style-type: none"> • TGLN • TPEC, heart • SRTR
DD18	Organ recovery	Organ recovery rate per donor	The average number of recovered organs per donor where at least one organ was recovered	<ul style="list-style-type: none"> • Number of donors where at least one organ was recovered • Number of recovered organs 	<ul style="list-style-type: none"> • NDD/DCD • MAID • For DCD: controlled, uncontrolled, NPOD (lungs) 	Efficiency	Process	<ul style="list-style-type: none"> • NBOTP* • NHS • SRTR

Number	Phase	Indicator/measure	Description	Included metrics	Potential disaggregations	Performance dimension	Quality framework	Reporting organizations/citations (* denotes indicator was identified as a priority)
DD19	Organ utilization	Conversion rate	<p>This indicator reflects the successful conversion of potential donors into utilized donors. For example,</p> <ul style="list-style-type: none"> • Percentage of potential donors where at least one organ was transplanted (overall measure). <p>Several sub-indicators may be included, such as</p> <ul style="list-style-type: none"> • Percentage of referred/approached donors from whom at least one organ was recovered • Percentage of referred/approached donors where at least one organ was transplanted • Percentage of consented donors where at least one organ was transplanted <p>As such, these may be reported as several cascading indicators showing where patients leave the donation pathway (exact methodology TBD).</p>	<ul style="list-style-type: none"> • Number of potential donors • Number of referred/not referred donors • Number of approached/not approached donors • Number of consented/not consented donors • Number of donors where at least one organ was/was not recovered • Number of donors where at least one organ was/was not transplanted 	<ul style="list-style-type: none"> • NDD/DCD • MAID • For DCD: controlled, uncontrolled, NPOD (lungs) • Extended criteria donor • Increased-risk donor 	Efficiency/ Appropriateness and effectiveness	Outcome	<ul style="list-style-type: none"> • BC Transplant* • CIHI • CBS* • Donate Life Australia* • NBOTP • NHS* • ODEQUS • TGLN • (Definitions vary)

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Number	Phase	Indicator/measure	Description	Included metrics	Potential disaggregations	Performance dimension	Quality framework	Reporting organizations/citations (* denotes indicator was identified as a priority)
DD20	Organ utilization	Donor discard rate	The percentage of donors where at least one organ was recovered who are not utilized donors	<ul style="list-style-type: none"> • Number of donors where at least one organ was recovered • Number of utilized donors • Number of non-utilized donors 	<ul style="list-style-type: none"> • NDD/DCD • MAID • For DCD: controlled, uncontrolled, NPOD (lungs) • Extended criteria donor 	Efficiency	Process	<ul style="list-style-type: none"> • SRTR • TGLN
DD21	Organ utilization	Organs transplanted per utilized donor (i.e., organ utilization rate)	The number of organs transplanted per utilized donor	<ul style="list-style-type: none"> • Mean, median, percentiles (TBD) 	<ul style="list-style-type: none"> • NDD/DCD • MAID • For DCD: controlled, uncontrolled, NPOD (lungs) • Extended criteria donor • Increased-risk donor 	Appropriateness and effectiveness	Process	<ul style="list-style-type: none"> • Australia and New Zealand Organ Donation Registry • BC Transplant* • CBS* • CORR • NBOTP* • NHS • SRTR* • TGLN* • Transplant Québec* • U.S. Department of Health and Human Services

Note

— Not applicable.

Living donation (LD)

Number	Phase	Indicator/measure	Description	Included metrics	Potential disaggregations	Performance dimension	Quality framework	Reporting organizations/citations (* denotes indicator was identified as a priority)
LD1	Self-referral	Time from registration to determination of suitability	The number of days from when a person registers as a potential living donor to when suitability is determined	<ul style="list-style-type: none"> • Mean, median, percentiles (TBD) 	—	Access	Process	<ul style="list-style-type: none"> • Knoll et al., 2020
LD2	Work-up	Percentage of individuals registered as a potential living donor who donated	The percentage of people registered as a living donor who donated	<ul style="list-style-type: none"> • Number of people registered as a living donor • Number of those who did/did not donate 	Numerator: <ul style="list-style-type: none"> • Paired donation • Reason for not donating 	Access (Equitable)	Structure	<ul style="list-style-type: none"> • BC Transplant • National Senior Renal Leaders Forum • Knoll et al., 2020
LD3	Surgery	Serious safety event rate	The percentage of living donors who experience a complication during initial hospitalization for donation Various time frames for follow-up (e.g., during hospitalization, 30 days)	<ul style="list-style-type: none"> • Number of living donors • Number with a complication 	Safety event type	Safety	Outcome	<ul style="list-style-type: none"> • Knoll et al., 2020 • CIHI (Hospital Harm, not ODT-specific)
LD4	Surgery	Cost of hospital stay	The cost of the hospitalization for living donation	<ul style="list-style-type: none"> • Mean, median, percentiles (TBD) 	—	Efficiency	Financial	<ul style="list-style-type: none"> • CIHI (not ODT-specific)
LD5	Surgery	In-hospital mortality rate	The percentage of living donors who die during initial hospitalization for donation procedure	<ul style="list-style-type: none"> • Number of living donors • Number who die during donation hospitalization 	—	Safety/ Appropriateness and effectiveness	Outcome	<ul style="list-style-type: none"> • Knoll et al., 2020 • CIHI (not ODT-specific)
LD6	Surgery	Length of stay	The number of days from hospital admission to discharge for donation procedure	<ul style="list-style-type: none"> • Mean, median, percentiles (TBD) 	—	Appropriateness and effectiveness	Outcome	<ul style="list-style-type: none"> • BC Transplant • CIHI (not ODT-specific) • Knoll et al., 2020

Number	Phase	Indicator/measure	Description	Included metrics	Potential disaggregations	Performance dimension	Quality framework	Reporting organizations/citations (* denotes indicator was identified as a priority)
LD7	Surgery	Living donor rate	The number of living donors per million population	<ul style="list-style-type: none"> • Number of living donors 	Numerator: <ul style="list-style-type: none"> • Relationship of donor to recipient • Altruistic donor • Blood type • BMI 	Health system outcomes: Improve health status of Canadians	Outcome	<ul style="list-style-type: none"> • BC Transplant • CBS • CORR • Donate Life Australia • National Senior Renal Leaders* (preliminary) • NHS* • SRTR • TGLN • Transplant Québec • UNOS • U.S. Department of Health and Human Services
LD8	Surgery	Percentage of paired donation transplants proceeding	The percentage of paired donations that proceeded	<ul style="list-style-type: none"> • Number of paired donations that proceeded • Number that did not proceed • Number that are yet to proceed 	Number of patients in matching run	Efficiency	Process	<ul style="list-style-type: none"> • NHS
LD9	Surgery	Time to surgery	The number of days from when a person is deemed a suitable donor to donation surgery	<ul style="list-style-type: none"> • Mean, median, percentiles (TBD) 	Paired donation versus not paired	Access	Process	<ul style="list-style-type: none"> • Knoll et al., 2020
LD10	Follow-up and outcomes	30-day readmission rate	The 30-day readmission rate for living donors	<ul style="list-style-type: none"> • Number of living donors • Number of donors with readmission within 30 days 	Readmission diagnosis	Safety/ Appropriateness and effectiveness	Outcome	<ul style="list-style-type: none"> • CIHI (not ODT-specific) • Knoll et al., 2020

Number	Phase	Indicator/measure	Description	Included metrics	Potential disaggregations	Performance dimension	Quality framework	Reporting organizations/citations (* denotes indicator was identified as a priority)
LD11	Follow-up and outcomes	Complication rate	The cumulative risk of complications (definition TBD) in a given time frame	<ul style="list-style-type: none"> Number of living donors with given follow-up Number with complication within follow-up 	Numerator: complication type (e.g., vascular, infection); methodology TBD	Safety	Outcome	<ul style="list-style-type: none"> Knoll et al., 2020
LD12	Follow-up and outcomes	Percentage not meeting clinical guidelines	The percentage of living donors who do not meet clinical guidelines (e.g., for blood pressure, lipids, glycemic control) at follow-up period (time point TBD)	<ul style="list-style-type: none"> Number of living donors with given follow-up Number not meeting clinical guideline 	Outcome type (e.g., blood pressure, lipids, glycemic control, creatinine); may vary by organ	Appropriateness and effectiveness	Outcome	—
LD13	Follow-up and outcomes	Percentage of living kidney donors who develop ESKD	The percentage of living kidney donors who eventually develop ESKD	<ul style="list-style-type: none"> Living kidney donors Living kidney donors who develop ESKD 	—	Safety	Outcome	<ul style="list-style-type: none"> Knoll et al., 2020
LD14	Follow-up and outcomes	Living donors with long-term follow-up plan	The percentage of living donors with a long-term follow-up plan	<ul style="list-style-type: none"> Number of living donors Number of living donors with long-term follow-up plan 	—	Appropriateness and effectiveness/ Person-centred	Process	<ul style="list-style-type: none"> Knoll et al., 2020 ODEQUS
LD15	Various phases	Patient-reported experience of medical care and donation process	<p>The patient-reported experience of medical care and the donation process (e.g., satisfaction with care; communication with health care staff; being well-informed about process/procedure; involvement in decision-making)</p> <p>Further development work required, including optimal time points for survey collection</p>	<ul style="list-style-type: none"> TBD (e.g., number of living donors satisfied/dissatisfied) 	—	Person-centred	Outcome	<ul style="list-style-type: none"> CIHI (not ODT-specific) Knoll et al., 2020

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Number	Phase	Indicator/measure	Description	Included metrics	Potential disaggregations	Performance dimension	Quality framework	Reporting organizations/citations (* denotes indicator was identified as a priority)
LD16	Various phases	Patient-reported outcomes (e.g., health-related quality of life)	<p>The patient-reported outcome measure (PROM) score</p> <p>This is a measure of patient perception of health status. Dimensions typically include pain, mobility, mental health, self-care and ability to participate in regular activities of daily living.</p> <p>Further development work required, including optimal time points for survey collection, which instruments to use and appropriate thresholds for “good” score (tools may vary depending on organ and age group)</p>	<ul style="list-style-type: none"> • Mean, median, percentiles, percentage above threshold “good” score, pre–post change in score (TBD) 	—	Person-centred	Outcome	<ul style="list-style-type: none"> • Knoll et al., 2020

Note

— Not applicable.

All donations (AD)

Number	Phase	Indicator/measure	Description	Included metrics	Potential disaggregations	Performance dimension	Quality framework	Reporting organizations/citations (* denotes indicator was identified as a priority)
AD1	Organ recovery	Cold ischemia time	The median cold ischemia time in hours	—	• Donor type	Appropriateness and effectiveness	Process	<ul style="list-style-type: none"> • Brett et al., 2018 • NHS • SRTR • TGLN
AD2	Organ recovery	Combined living and deceased donor rate	The number of living or deceased donors where at least one organ was recovered per million population	<ul style="list-style-type: none"> • Number of living donors • Number of deceased donors 	Numerator: <ul style="list-style-type: none"> • Donor type • BMI • Blood type 	Health system outcomes: Improve health status of Canadians	Outcome	<ul style="list-style-type: none"> • CBS • TGLN • Transplant Québec • UNOS • U.S. Department of Health and Human Services
AD3	Approach/recovery	Donation specialist availability	The number of donation specialists (e.g., coordinator, physicians) per million population	• Number of donation specialists	• Specialist type	Health system resources	Structure	<ul style="list-style-type: none"> • CBS

Note

— Not applicable.

Transplantation (TR)

All organs

Number	Phase	Indicator/measure	Description	Included metrics	Potential disaggregations	Performance dimension	Quality framework	Reporting organizations/citations (* denotes indicator was identified as a priority)
TR1	Work-up	Percentage of referrals with consultation performed	The percentage of transplant candidate referrals where the consultation was performed	<ul style="list-style-type: none"> • Number of transplant candidate referrals • Number where consultation performed/deferred 	<ul style="list-style-type: none"> • Reason for decline of consultation 	Efficiency	Process	TGLN
TR2	Work-up	Percentage of consultations accepted	The percentage of consultations where the patient was accepted for transplant	<ul style="list-style-type: none"> • Number of consultations • Number where patient accepted/not accepted for transplantation 	<ul style="list-style-type: none"> • Reason for decline of transplant 	Appropriateness and effectiveness	Process	<ul style="list-style-type: none"> • BC Transplant • Knoll et al., 2020 • TGLN
TR3	Work-up	Time between patient evaluation to determination of suitability	The number of days between patient evaluation and determination of suitability for transplant	<ul style="list-style-type: none"> • Mean, median, percentiles (TBD) 	—	Access	Process	<ul style="list-style-type: none"> • Brett et al., 2018 • Knoll et al., 2020 • TGLN • TPEC, heart
TR4	Wait-list	Time between referral and assessment	The number of days between referral and assessment for transplant suitability	<ul style="list-style-type: none"> • Mean, median, percentiles (TBD) 	—	Access	Structure	<ul style="list-style-type: none"> • BC Transplant • Brett et al., 2018 • Knoll et al., 2020 • TGLN • TPEC, heart

Number	Phase	Indicator/measure	Description	Included metrics	Potential disaggregations	Performance dimension	Quality framework	Reporting organizations/citations (* denotes indicator was identified as a priority)
TR5	Wait-list	Time from listing to transplant	The number of days between being added to the wait-list and receiving transplant, for patients who received a transplant	<ul style="list-style-type: none"> • Mean, median, percentiles (TBD) 	<ul style="list-style-type: none"> • Blood type • BMI • Donor type • Highly sensitized patient/high status • Extended criteria donor 	Access	Structure	<ul style="list-style-type: none"> • BC Transplant • Brett et al., 2018 • NHS • SRTR • Transplant Québec • TGLN • TPEC, heart • UNOS
TR6	Wait-list	Transplant rate at given wait-list time point	The cumulative probability of transplant by certain amount of time on wait-list (time points TBD)	<ul style="list-style-type: none"> • Number with certain amount of follow-up • Number who received/did not receive transplant by that time point • Transplants per person-year 	<ul style="list-style-type: none"> • Blood type • Highly sensitized/high status patient 	Access	Outcome	<ul style="list-style-type: none"> • BC Transplant • SRTR • TGLN
TR7	Wait-list	Wait-list mortality rate	The cumulative probability of death by certain amount of time on wait-list (time points TBD)	<ul style="list-style-type: none"> • Number with certain amount of follow-up • Number who died/survived by that time point • Deaths per person-year • Mean, median (TBD) time to death 	<ul style="list-style-type: none"> • Blood type • Highly sensitized/high status patient 	Access	Outcome	<ul style="list-style-type: none"> • BC Transplant • Brett et al., 2018 • CBS • CORR • Knoll et al., 2020 • NHS • SRTR* • TPEC, heart • Transplant Québec • (Methodology varies)

Pan-Canadian Organ Donation and Transplantation Data and Performance Reporting System:
Indicators and Measures Short-List for Prioritization, April 2021

Number	Phase	Indicator/measure	Description	Included metrics	Potential disaggregations	Performance dimension	Quality framework	Reporting organizations/citations (* denotes indicator was identified as a priority)
TR8	Wait-list	Wait-list volume	The number of people on the wait-list, including new additions, removals (and reason) and those on hold	<ul style="list-style-type: none"> • Number on wait-list • Number added • Number removed (received transplant, removed without transplant, died) • Number on hold • Growth rate 	<ul style="list-style-type: none"> • Blood type • Highly sensitized/high status patient • Reason for removal or on hold 	Access	Structure	<ul style="list-style-type: none"> • Australia and New Zealand Organ Donation Registry • BC Transplant • CORR • NHS • SRTR • TGLN • TPEC, heart • UNOS
TR9	Wait-list	Wait-listed patients per million population	The number of patients on a wait-list per million population	<ul style="list-style-type: none"> • Number of patients on wait-list 	Numerator: <ul style="list-style-type: none"> • Blood type • Highly sensitized/high status patient • Medical status 	Access	Structure	<ul style="list-style-type: none"> • Australia and New Zealand Organ Donation Registry • BC Transplant • Brett et al., 2018 • CBS • CORR • Knoll et al., 2020 • NHS • SRTR • TGLN • Transplant Québec • U.S. Department of Health and Human Services

Number	Phase	Indicator/measure	Description	Included metrics	Potential disaggregations	Performance dimension	Quality framework	Reporting organizations/citations (* denotes indicator was identified as a priority)
TR10	Surgery	Transplant rate	The number of transplants per million population	<ul style="list-style-type: none"> Number of transplant recipients 	Numerator: <ul style="list-style-type: none"> Life support at time of surgery Procedure type Blood type BMI Cold ischemia time Single/combination transplants Diabetes Donor geography Donor type Donor/recipient age group (e.g., adult donor, pediatric recipient) Extended criteria donation First transplant/retransplant For living donor: relationship Graft number Highly sensitized/high status patient HLA mismatch Medical status 	Access/Health system resources	Structure	<ul style="list-style-type: none"> Australia and New Zealand Organ Donation Registry BC Transplant CBS CORR Donate Life America Donate Life Australia* Knoll et al., 2020 National Senior Renal Leaders (preliminary)* NHS* SRTR* TGLN TPEC, heart Transplant Québec U.S. Department of Health and Human Services
TR11	Surgery	Cost of hospital stay	The cost of the hospitalization for transplantation	<ul style="list-style-type: none"> Mean, median, percentiles (TBD) 	—	Efficiency	Financial	<ul style="list-style-type: none"> CIHI (not ODT-specific) NHS

Number	Phase	Indicator/measure	Description	Included metrics	Potential disaggregations	Performance dimension	Quality framework	Reporting organizations/citations (* denotes indicator was identified as a priority)
TR12	Surgery	In-hospital mortality rate	The proportion of transplant candidates who die while in hospital for the transplant	<ul style="list-style-type: none"> • Number of transplant candidates in hospital for transplant procedure • Number who die/survive 	Numerator: <ul style="list-style-type: none"> • Cause of death Denominator: <ul style="list-style-type: none"> • Blood type • Cold ischemia time • Donor type • Diagnosis • Donor age • Extended criteria donor • Highly sensitized/high status patient • HLA mismatch • Medical status at time of transplantation 	Safety/ Appropriateness and effectiveness	Outcome	<ul style="list-style-type: none"> • CIHI (not ODT-specific) • Knoll et al., 2020 • NHS
TR13	Surgery	Length of stay <ul style="list-style-type: none"> • Admission to discharge • Transplant to discharge 	The number of days between admission and discharge for the recipient	<ul style="list-style-type: none"> • Mean, median, percentiles (TBD) 	<ul style="list-style-type: none"> • Donor age • Donor type • Extended criteria donor • By unit (e.g., ICU) 	Appropriateness and effectiveness	Outcome	<ul style="list-style-type: none"> • BC Transplant • CIHI (not ODT-specific) • Knoll et al., 2020 • SRTR • TPEC, heart
TR14	Surgery	Primary graft dysfunction rate	The percentage of patients who experience primary graft dysfunction, for organs for which this applies (definition varies by organ)	<ul style="list-style-type: none"> • Number of transplant recipients • Number with/without primary graft dysfunction 	<ul style="list-style-type: none"> • Severity 	Appropriateness and effectiveness	Outcome	<ul style="list-style-type: none"> • TPEC, heart

Number	Phase	Indicator/measure	Description	Included metrics	Potential disaggregations	Performance dimension	Quality framework	Reporting organizations/citations (* denotes indicator was identified as a priority)
TR15	Surgery	Surgical complication rate	The percentage of transplant recipients with a surgical complication	<ul style="list-style-type: none"> • Number of transplant recipients • Number with surgical complication 	<ul style="list-style-type: none"> • Complication type • Blood type • BMI • Cold ischemia time • Donor age • Donor sex • Donor type • Extended criteria donor • Highly sensitized/high status patient • HLA mismatch • Medical status at transplant 	Safety	Outcome	<ul style="list-style-type: none"> • BC Transplant • Brett et al., 2018 • CIHI (not ODT-specific) • Knoll et al., 2020 • NHS • TPEC, heart
TR16	Surgery	Warm ischemia time	The median time between “out of the cold” and reperfusion	—	Donor type	Appropriateness and effectiveness	Process	<ul style="list-style-type: none"> • Brett et al., 2018
TR17	Follow-up and outcomes	Viral infection or reactivation rate	The cumulative risk of viral infection or reactivation (e.g., CMV, EBV) in a certain time frame after transplant	<ul style="list-style-type: none"> • Number of transplant recipients with follow-up • Number with viral infection or reactivation within follow-up period 	<ul style="list-style-type: none"> • Induction type • Virus (e.g., CMV, EBV, BK) 	Appropriateness and effectiveness	Outcome	<ul style="list-style-type: none"> • BC Transplant • TPEC, heart

Number	Phase	Indicator/measure	Description	Included metrics	Potential disaggregations	Performance dimension	Quality framework	Reporting organizations/citations (* denotes indicator was identified as a priority)
TR18	Follow-up and outcomes	Complication rate	The cumulative risk of complication (definition TBD) for a certain time frame after organ transplant	<ul style="list-style-type: none"> • Number of transplant recipients with follow-up • Number with complication within follow-up period 	<ul style="list-style-type: none"> • Complication type (e.g., infectious, cardiovascular, unplanned operation) • Blood type • BMI • Cold ischemia time • Donor age • Donor sex • Donor type • Extended criteria donor • Highly sensitized/high status patient • HLA mismatch • Medical status at transplant • Procedure type 	Safety	Outcome	<ul style="list-style-type: none"> • Brett et al., 2018 • Knoll et al., 2020 • TPEC, heart
TR19	Follow-up and outcomes	Cumulative incidence of post-transplant dialysis	The cumulative risk of dialysis for a certain time frame after organ transplant Excludes kidney transplant (see TR20 graft survival)	<ul style="list-style-type: none"> • Number of transplant recipients with follow-up, excluding non-renal transplant recipients who were on dialysis at time of transplant • Number who did/did not begin dialysis by end of follow-up period (excluding delayed kidney graft function) 	—	Appropriateness and effectiveness	Outcome	<ul style="list-style-type: none"> • SRTR • TPEC, heart

Number	Phase	Indicator/measure	Description	Included metrics	Potential disaggregations	Performance dimension	Quality framework	Reporting organizations/citations (* denotes indicator was identified as a priority)
TR20	Follow-up and outcomes	Graft survival	<p>The cumulative graft survival at a certain time point</p> <p>For this indicator, patient death is included as failure.</p> <p>Various time frames for follow-up (e.g., during hospitalization, 30 days, 1 year, 5 years, 10 years)</p>	<ul style="list-style-type: none"> • Number of recipients with follow-up • Number of recipients with/without graft survival at end of follow-up period • Number of recipients lost to follow-up 	<ul style="list-style-type: none"> • Numerator: Reason for graft failure • Blood type • BMI • Cold ischemia time • Diagnosis • Donor age • Donor sex • Donor type • Extended criteria donor • Highly sensitized/high status patient • HLA mismatch • Medical status at transplant • Procedure type 	Appropriateness and effectiveness	Outcome	<ul style="list-style-type: none"> • BC Transplant • CORR • Knoll et al., 2020 • NHS • SRTR • TGLN • TPEC, kidney (preliminary)* • UNOS

Number	Phase	Indicator/measure	Description	Included metrics	Potential disaggregations	Performance dimension	Quality framework	Reporting organizations/citations (* denotes indicator was identified as a priority)
TR21	Follow-up and outcomes	Patient survival	The cumulative survival rate Various time frames for follow-up (e.g., during hospitalization, 30 days, 1 year, 5 years, 10 years)	<ul style="list-style-type: none"> • Number of recipients with follow-up • Number of recipients who died/survived within the follow-up period • Number of recipients lost to follow-up 	Numerator: <ul style="list-style-type: none"> • Cause of death Denominator: <ul style="list-style-type: none"> • Blood type • BMI • Cold ischemia time • Diagnosis • Donor age • Donor sex • Donor type • Extended criteria donor • Highly sensitized/high status patient • HLA mismatch • Medical status at transplant 	Safety	Outcome	<ul style="list-style-type: none"> • BC Transplant • Brett et al., 2018 • CORR • Knoll et al., 2020 • NHS • SRTR • TGLN • TPEC, kidney (preliminary)* • TPEC, heart (preliminary) • UNOS
TR22	Follow-up and outcomes	Percentage with appropriate screening and surveillance	The percentage of patients with appropriate screening and surveillance (varies by organ) at 1, 5 and 10 years post-transplant	<ul style="list-style-type: none"> • Number of transplant recipients with given follow-up • Number screened/not screened for metabolic complications 	Screening type (e.g., blood pressure, lipids, sugars, other metabolites); varies by organ	Appropriateness and effectiveness	Process	<ul style="list-style-type: none"> • Knoll et al., 2020 • TPEC, heart
TR23	Follow-up and outcomes	Percentage not meeting clinical guidelines	The percentage of patients who do not meet clinical guidelines (e.g., for blood pressure, lipids, glycemic control) at follow-up period (time point TBD)	<ul style="list-style-type: none"> • Number of patients with given follow-up • Number not meeting clinical guideline 	Outcome type (e.g., blood pressure, lipids, glycemic control, creatinine); may vary by organ	Appropriateness and effectiveness	Outcome	<ul style="list-style-type: none"> • Knoll et al., 2020 • SRTR

Number	Phase	Indicator/measure	Description	Included metrics	Potential disaggregations	Performance dimension	Quality framework	Reporting organizations/citations (* denotes indicator was identified as a priority)
TR24	Follow-up and outcomes	Percentage with new-onset diabetes	The percentage of patients with transplant and no previous diagnosis of diabetes who are afterwards diagnosed with new-onset diabetes within a given time period	<ul style="list-style-type: none"> • Patients with transplant and no pre-operative diabetes diagnosis, with given follow-up • Patients who receive/do not receive new diabetes diagnosis during follow-up period 	<ul style="list-style-type: none"> • Blood type • BMI • Cold ischemia time • Diagnosis • Donor age • Donor sex • Donor type • Extended criteria donor • Highly sensitized/high status patient • HLA mismatch • Medical status at transplant 	Appropriateness and effectiveness	Outcome	<ul style="list-style-type: none"> • Knoll et al., 2020 • TPEC, heart
TR25	Follow-up and outcomes	Post-transplant cancer rate	The cumulative incidence rate of cancer in patients after transplant	<ul style="list-style-type: none"> • Number of patients with 1 year of follow-up • Number of patients with/without incident cancer 	<p>Numerator:</p> <ul style="list-style-type: none"> • Cancer type (e.g., PTLD) <p>Denominator:</p> <ul style="list-style-type: none"> • Blood type • BMI • Cold ischemia time • Diagnosis • Donor age • Donor sex • Donor type • Extended criteria donor • Highly sensitized/high status patient • HLA mismatch • Medical status at transplant 	Appropriateness and effectiveness	Outcome	<ul style="list-style-type: none"> • BC Transplant • Knoll et al., 2020 • TPEC, heart

Number	Phase	Indicator/measure	Description	Included metrics	Potential disaggregations	Performance dimension	Quality framework	Reporting organizations/citations (* denotes indicator was identified as a priority)
TR26	Follow-up and outcomes	Readmission rate	The cumulative readmission rate at a certain time point Various time frames for follow-up (e.g., 30 days, 1 year)	<ul style="list-style-type: none"> • Number of recipients with certain follow-up • Number of recipients with readmission to hospital within follow-up period 	Numerator: <ul style="list-style-type: none"> • Readmission diagnosis • Transplant hospital/other hospital Denominator: <ul style="list-style-type: none"> • Blood type • BMI • Cold ischemia time • Diagnosis • Donor age • Donor sex • Donor type • Extended criteria donor • Highly sensitized/high status patient • HLA mismatch • Medical status at transplant 	Safety/ Appropriateness and effectiveness	Outcome	<ul style="list-style-type: none"> • BC Transplant • CIHI (not ODT-specific) • Knoll et al., 2020 • TPEC, heart

Number	Phase	Indicator/measure	Description	Included metrics	Potential disaggregations	Performance dimension	Quality framework	Reporting organizations/citations (* denotes indicator was identified as a priority)
TR27	Follow-up and outcomes	Rejection rate	The cumulative rate of rejection at a certain time point	<ul style="list-style-type: none"> • Number of recipients with certain follow-up • Number of recipients who experienced graft rejection within the follow-up period 	<p>Numerator:</p> <ul style="list-style-type: none"> • Cellular versus antibody-mediated rejection • For antibody-mediated rejection: donor-specific antibody absent/present (pre-existing)/present (de novo) • Hyperacute versus acute versus chronic • Grade/severity <p>Denominator:</p> <ul style="list-style-type: none"> • Blood type • BMI • Cold ischemia time • Diagnosis • Donor age • Donor sex • Donor type • Extended criteria donor • Highly sensitized/high status patient • HLA mismatch • Medical status at transplant 	Safety	Outcome	<ul style="list-style-type: none"> • BC Transplant • Brett et al., 2018 • Knoll et al., 2020 • TPEC, heart

Number	Phase	Indicator/measure	Description	Included metrics	Potential disaggregations	Performance dimension	Quality framework	Reporting organizations/citations (* denotes indicator was identified as a priority)
TR28	Follow-up and outcomes	Renal dysfunction rate	The cumulative rate of stage 3 or more severe kidney disease after transplant, at various time frames (e.g., 1 year, 5 years, 10 years)	<ul style="list-style-type: none"> • Number of transplant recipients who did not previously have renal dysfunction, with certain amount of follow-up • Number experiencing stage 3 or more severe kidney disease during follow-up period 	<ul style="list-style-type: none"> • Donor age • Extended criteria donor • HLA mismatch • Medical status 	Appropriateness and effectiveness	Outcome	<ul style="list-style-type: none"> • TPEC, heart
TR29	Various phases	Patient-reported experience of medical care and transplant process	<p>The patient-reported experience of medical care and the transplant process (e.g., satisfaction with care; communication with health care staff; being well-informed about process/procedure; involvement in decision-making)</p> <p>Further development work required, including optimal time points for survey collection</p>	<ul style="list-style-type: none"> • TBD (e.g., number reporting being satisfied/not satisfied) 	—	Patient-centred	Outcome	<ul style="list-style-type: none"> • CIHI (not ODT-specific) • Knoll et al., 2020 • TPEC, kidney (preliminary)*

Number	Phase	Indicator/measure	Description	Included metrics	Potential disaggregations	Performance dimension	Quality framework	Reporting organizations/citations (* denotes indicator was identified as a priority)
TR30	Various phases	Patient-reported outcomes (e.g., health-related quality of life)	<p>The patient-reported outcome measure (PROM) score</p> <p>This is a measure of patient perception of health status. Generic dimensions typically include pain, mobility, mental health, self care and return to regular activities of daily living such as work or school.</p> <p>Further development work required, including optimal time points for survey collection, which instruments/questions to include and appropriate thresholds for “good” score (tools may vary depending on organ and age group)</p>	<ul style="list-style-type: none"> • Mean, median, percentiles, percentage above threshold “good” score, pre–post change in score (TBD) 	<ul style="list-style-type: none"> • Blood type • BMI • Cold ischemia time • Donor age • Donor sex • Donor type • Extended criteria donor • Highly sensitized/high status patient • HLA mismatch • Medical status at transplant 	Person-centred	Outcome	<ul style="list-style-type: none"> • Knoll et al., 2020 • TPEC, kidney (preliminary)*

Note

— Not applicable.

Kidney (K)

Number	Phase	Indicator/measure	Description	Included metrics	Potential disaggregations	Performance dimension	Quality framework	Reporting organizations/citations (* denotes indicator was identified as a priority)
K1	Pre-referral	ESKD incidence rate	The number of incident ESKD patients who began renal replacement therapy per million population	<ul style="list-style-type: none"> Number of incident ESKD patients 	Numerator: <ul style="list-style-type: none"> Diagnosis Treatment modality 	Health system outcomes: Improve health status of Canadians	Structure	<ul style="list-style-type: none"> CORR
K2	Pre-referral	Percentage of ESKD patients referred	The percentage of ESKD patients who have been referred for transplant evaluation during a given time window	<ul style="list-style-type: none"> ESKD patients ESKD patients referred/not referred for transplant evaluation 	—	Access (Equitable)	Process	<ul style="list-style-type: none"> Knoll et al., 2020 TPEC, kidney (preliminary)*
K3	Pre-referral	Percentage of ESKD patients who have a documented discussion about their consideration for transplantation	The percentage of ESKD patients who have a documented discussion about their consideration for transplantation	<ul style="list-style-type: none"> ESKD patients ESKD patients with/without documented discussion about transplantation 	—	Access (Equitable)	Process	<ul style="list-style-type: none"> Knoll et al., 2020
K4	Pre-referral	Percentage of ESKD patients who have specifically discussed living donor transplantation	The percentage of ESKD patients with a documented discussion about consideration for transplantation who are documented to have specifically discussed living donor transplantation	<ul style="list-style-type: none"> ESKD patients with documented discussion about transplantation ESKD patients with/without documented discussion about living donor transplantation 	—	Access (Equitable)	Process	<ul style="list-style-type: none"> Knoll et al., 2020
K5	Pre-referral	Population prevalence of diabetes	The population prevalence of diabetes	<ul style="list-style-type: none"> Number of people with diabetes 	—	Biological/material/psychosocial/behavioural factors	Structure	<ul style="list-style-type: none"> CIHI

Number	Phase	Indicator/measure	Description	Included metrics	Potential disaggregations	Performance dimension	Quality framework	Reporting organizations/citations (* denotes indicator was identified as a priority)
K6	Work-up	Percentage of referred ESKD patients accepted for transplantation	The percentage of referred ESKD patients who are accepted for transplantation	<ul style="list-style-type: none"> Referred ESKD patients Referred ESKD patients accepted/not accepted for transplantation 	—	Access (Equitable)	Process	<ul style="list-style-type: none"> Knoll et al., 2020 TPEC, kidney (preliminary)*
K7	Wait-list	Time between dialysis start and transplant referral	The number of days between the start of dialysis and referral for transplant	<ul style="list-style-type: none"> Mean, median, percentiles (TBD) 	<ul style="list-style-type: none"> Highly sensitized patient 	Access	Structure	<ul style="list-style-type: none"> BC Transplant Knoll et al., 2020
K8	Surgery	Delayed graft function	The percentage of patients receiving dialysis within the first week post-operatively	<ul style="list-style-type: none"> Patients with kidney transplant and 1-week follow-up Patients with kidney transplant receiving dialysis within first week post-operatively 	<ul style="list-style-type: none"> Numerator: number of dialysis sessions in transplant hospitalization Donor age Donor type Extended criteria donor Highly sensitized patient HLA mismatch 	Safety	Outcome	<ul style="list-style-type: none"> BC Transplant CORR Knoll et al., 2020 SRTR
K9	Surgery	Percentage of ESKD patients receiving transplant	The percentage of ESKD patients who receive a kidney transplant	<ul style="list-style-type: none"> ESKD patients ESKD patients who receive/do not receive a kidney transplant 	<ul style="list-style-type: none"> Numerator: pre-emptive transplant Highly sensitized patient 	Health system outcomes: Improve health status of Canadians	Outcome	<ul style="list-style-type: none"> CORR Knoll et al., 2020 National Senior Renal Leaders (preliminary)*
K10	Surgery	Pre-emptive transplant rate	The percentage of live donor kidney transplants that were done where the recipient had 2 or fewer weeks of dialysis before transplantation	<ul style="list-style-type: none"> Number of patients with live donor kidney transplant Number receiving transplant having undergone 2 or fewer weeks of dialysis 	—	Appropriateness and effectiveness	Structure	<ul style="list-style-type: none"> BC Transplant Brett et al., 2018 CORR Knoll et al., 2020 NHS TPEC, kidney (preliminary)* National Senior Renal Leaders (preliminary)*

Note

— Not applicable.

Heart (H)

Number	Phase	Indicator/measure	Description	Included metrics	Potential disaggregations	Performance dimension	Quality framework	Reporting organizations/citations (* denotes indicator was identified as a priority)
H1	Wait-list	Percentage with MCS at listing	The percentage of wait-listed patients who were listed while on MCS	<ul style="list-style-type: none"> • Number of patients wait-listed • Number with/without MCS 	—	Biological/ material/ psychosocial/ behavioural factors	Structure	<ul style="list-style-type: none"> • SRTR
H2	Surgery	MCS separation	For those patients requiring MCS following transplant, the percentage who are successfully separated from MCS	<ul style="list-style-type: none"> • Number of cardiac transplantations where MCS needed • Number successfully/not successfully separated from MCS 	<ul style="list-style-type: none"> • Donor age • Extended criteria donor • High status heart • HLA mismatch 	Appropriateness and effectiveness	Outcome	<ul style="list-style-type: none"> • TPEC, heart
H3	Surgery	MCS time	For those patients requiring short-term MCS following transplant, the number of days spent on MCS	Mean, median, percentiles (TBD)	<ul style="list-style-type: none"> • Donor age • Extended criteria donor • High status heart • HLA mismatch 	Safety	Outcome	<ul style="list-style-type: none"> • TPEC, heart
H4	Surgery	Percentage bicaval anastomosis	The percentage of transplantations where a bicaval anastomosis was used	<ul style="list-style-type: none"> • Number of cardiac transplantations • Number where a bicaval atrial anastomosis used 	—	Appropriateness and effectiveness	Process	<ul style="list-style-type: none"> • Brett et al., 2018 • TPEC, heart
H5	Surgery	Percentage high-risk	The percentage of cardiac transplant patients who are considered high risk (definition TBD)	<ul style="list-style-type: none"> • Number of cardiac transplantations • Number who are/are not high risk 	—	Biological/ material/ psychosocial/ behavioural factors	Process	<ul style="list-style-type: none"> • TPEC, heart

Number	Phase	Indicator/measure	Description	Included metrics	Potential disaggregations	Performance dimension	Quality framework	Reporting organizations/citations (* denotes indicator was identified as a priority)
H6	Surgery	Percentage prescribed statin	The percentage of transplant patients who are prescribed a statin at discharge from transplant hospitalization	<ul style="list-style-type: none"> Number of cardiac transplant patients discharged after transplantation Number prescribed/not prescribed statin 	—	Appropriateness and effectiveness	Process	• TPEC, heart
H7	Surgery	Percentage undersized heart	The proportion of transplanted patients with an undersized donor heart	<ul style="list-style-type: none"> Number of heart transplant patients Number with/without undersized heart 	—	Appropriateness and effectiveness	Process	• TPEC, heart
H8	Surgery	Percentage with MCS at transplant	The percentage of heart transplant patients with MCS at the time of transplant	<ul style="list-style-type: none"> Number of heart transplant patients Number with/without MCS at time of surgery 	MCS type	Appropriateness and effectiveness	Process	• TPEC, heart
H9	Follow-up and outcomes	mTORi use for patients with CAV	The percentage of patients with ISHLT CAV of 1 or worse who are receiving mTORi	<ul style="list-style-type: none"> Number of post-transplant patients with allograft vasculopathy Number receiving/not receiving mTORi 	—	Appropriateness and effectiveness	Process	• TPEC, heart
H10	Follow-up and outcomes	One-year allograft vasculopathy rate	The cumulative rate of allograft vasculopathy, defined as an ISHLT CAV of 1 or worse, at various time frames (e.g., 1 year, 5 years, 10 years)	<ul style="list-style-type: none"> Number of cardiac transplant recipients with certain amount of follow-up Number with/without allograft vasculopathy at follow-up 	<ul style="list-style-type: none"> Donor age Extended criteria donor High status heart HLA mismatch 	Appropriateness and effectiveness	Outcome	• TPEC, heart

Number	Phase	Indicator/measure	Description	Included metrics	Potential disaggregations	Performance dimension	Quality framework	Reporting organizations/citations (* denotes indicator was identified as a priority)
H11	Follow-up and outcomes	One-year CAV surveillance	The percentage of patients meeting CAV screening guidelines	<ul style="list-style-type: none"> • Number of cardiac transplant recipients • Number meeting CAV screening guidelines 	—	Appropriateness and effectiveness	Process	<ul style="list-style-type: none"> • TPEC, heart
H12	Follow-up and outcomes	One-year statin use	The percentage of patients who remain on a statin 1 year post-transplant	<ul style="list-style-type: none"> • Number of cardiac transplant recipients • Number using/not using statin at 1 year post-transplant 	—	Appropriateness and effectiveness	Outcome	<ul style="list-style-type: none"> • TPEC, heart

Note

— Not applicable.

Other organ-specific and pediatric transplantation indicators

Organ-specific indicators (for liver, lung, pancreas and intestine) and pediatric-specific indicators will be short-listed and prioritized through separate processes.

Email odt@cihi.ca for more information.

Appendices

Appendix A: Working group and expert advisory forum membership

ODTC Data System Working Group

Representative for . . .	Name	Organization
Nova Scotia	Cynthia Isenor	Legacy of Life, Nova Scotia Health Authority
	Amy Laybolt	Legacy of Life, Nova Scotia Health Authority
New Brunswick	Nadya Savoie	New Brunswick Organ and Tissue Program
Quebec	Prosanto Chaudhury	McGill University Health Centre, Royal Victoria Hospital
	Matthew Weiss	CHU de Québec, Centre Mère-Enfant Soleil; Transplant Québec
	Samara Zavalkoff	Montreal Children's Hospital; McGill University Health Centre
Ontario	Joseph Kim	University Health Network, Toronto General Hospital
	Greg Knoll	The Ottawa Hospital
	Clare Payne	Trillium Gift of Life Network (Ontario Health)
	Thomas Smith	Ontario Ministry of Health and Long-Term Care
Manitoba	Peter Nickerson	Transplant Manitoba; Canadian Blood Services
Saskatchewan	Luke Jackiw	Saskatchewan Ministry of Health
Alberta	Michelle Bonnier	Southern Alberta Organ and Tissue Donation Programs
	Brian Clarke	Calgary Foothills Medical Centre Hospital
British Columbia	Tom Blydt-Hansen	BC Transplant
	Edward Ferre	BC Transplant
	Jagbir Gill	University of British Columbia; CIHI's Canadian Organ Replacement Registry Board of Directors
	John S. Gill	University of British Columbia Division of Nephrology; American Society of Transplantation
Pan-Canadian organizations	Catherine Butler	Canadian Blood Services
	Sylvie Charbonneau	Kidney Foundation of Canada
	Rosanne Dawson	Canadian Blood Services
	Nicole de Guia	CIHI
	Mélanie Diéudé	Canadian Donation and Transplantation Research Program
	Clay Gillrie	Canadian Blood Services
	Jeff Green	Canada Health Infoway
	David Hartell	Canadian Blood Services
	Sandra Holdsworth	Canadian Transplant Association
	Peggy John	Canadian Blood Services
	Margaret Miller	Health Canada
	Mark Nenadovic	Canada Health Infoway
	Greg Webster	CIHI
Jun Wu	Public Health Agency of Canada	

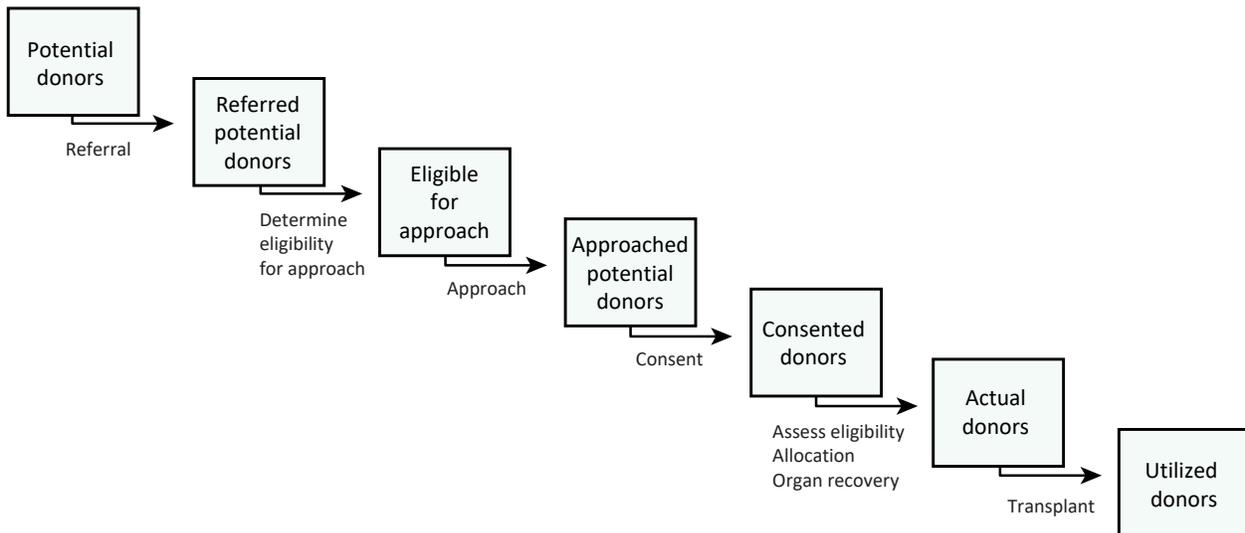
ODT Project Indicators and Measures Prioritization Expert Advisory Forum

Representative for . . .	Name	Organization
Newfoundland and Labrador	Daphne Osborne	Newfoundland and Labrador Department of Health and Community Services
Nova Scotia	Cynthia Isenor	Legacy of Life, Nova Scotia Health Authority
	Nancy MacLeod	Nova Scotia Department of Health and Wellness
New Brunswick	Tracey Newton	New Brunswick Department of Health, Acute Care
	Nadya Savoie	New Brunswick Organ and Tissue Program
Quebec	Jeffrey Barkun	McGill University Health Centre
	Louis Beaulieu	Transplant Québec
	Brigitte Côté (observer)	Institut national d'excellence en santé et en services sociaux
	Sam Shemie	Montreal Children's Hospital; Canadian Blood Services
	Marie-Josée Simard	Transplant Québec
	Matthew Weiss	CHU de Québec, Centre Mère-Enfant Soleil; Transplant Québec
Ontario	Juan Duero Posada	University Health Network
	Greg Knoll	The Ottawa Hospital
	Clare Payne	Trillium Gift of Life Network (Ontario Health)
	Jeffrey Schiff	University Health Network, Toronto General Hospital
	Chia Wei Teoh	The Hospital for Sick Children
Manitoba	Amelia LaTouche (observer)	Manitoba Health, Seniors and Active Living
	Peter Nickerson	Transplant Manitoba; Canadian Blood Services
Saskatchewan	Jessica Jackson	Saskatchewan Ministry of Health
	Rahul Mainra	University of Saskatchewan
Alberta	Brian Clarke	Calgary Foothills Medical Centre Hospital
	Lorraine Hamiwka	Alberta Children's Hospital
	Alim Hirji	University of Alberta Hospital
	Norm Kneteman	Northern Alberta Renal Program and Transplant
	Glenna Laing	Alberta Ministry of Health
British Columbia	Jennifer Brooke	B.C. Ministry of Health
	Heather Davidson	B.C. Ministry of Health
Northwest Territories	David MacDonald	Northwest Territories Department of Health and Social Services
Nunavut	Sonia Marchand (observer)	Nunavut Department of Health

Representative for . . .	Name	Organization
Pan-Canadian organizations	Sylvie Charbonneau	Kidney Foundation of Canada
	Nicole de Guia	CIHI
	Clay Gillrie	Canadian Blood Services
	Jeff Green	Canada Health Infoway
	David Hartell	Canadian Blood Services
	Sandra Holdsworth	Canadian Transplant Association
	Sunita Karmakar-Hore	CIHI
	Roxanne Poirier	Health Canada
	Greg Webster	CIHI

Appendix B: Deceased donor pathway

The following deceased donor pathway shows the populations used for deceased donor indicators/measures. Some organ donation organizations (ODOs) may follow a slightly different pathway. This pathway was developed in consultation with ODOs as part of the CIHI-Infoway ODT project’s Business Expert Advisory Forum.



This image shows the deceased donor pathway. Potential donors who are referred to the organ donation organization are called “referred potential donors.” Afterward, they are assessed to determine whether they are eligible for approach for consent; those who are eligible are referred to as “eligible for approach.” Those whose next of kin or substitute decision-makers are approached for consent become “approached potential donors.” Those for whom consent is obtained become “consented donors.” Afterward, eligibility for donation is assessed and organs are allocated. Those from whom organs are recovered are called “actual donors.” After the organ is transplanted, the donor is called a “utilized donor.”

Appendix C: Acronyms

CAV	Cardiac allograft vasculopathy
CBS	Canada Blood Services
CIHI	Canadian Institute for Health Information
CORR	Canadian Organ Replacement Register (CIHI)
DCD	Donation after circulatory death
ESKD	End-stage kidney disease
HLA	Human leukocyte antigen
ISHLT	International Society of Heart and Lung Transplantation
MAID	Medical assistance in dying
MCS	Mechanical circulatory support
MELD	Model for end-stage liver disease
mTORi	Mammalian target of rapamycin (mTOR) inhibitors
NBOTP	New Brunswick Organ and Tissue Program
NDD	Neurologically determined death
NHS	National Health Service (U.K.)
NPOD	Non-perfused organ donation
ODEQUS	Organ Donation European Quality System
ODO	Organ donation organization
PTLD	Post-transplant lymphoproliferative disorder
SRTR	Scientific Registry of Transplant Recipients
TGLN	Trillium Gift of Life Network
TPEC	Transplant Performance Measurement and Evaluation Executive Committee (led by TGLN)
UNOS	United Network for Organ Sharing

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