



Pan-Canadian Organ Donation and Transplantation Prioritized Indicators

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Executive summary

In 2019, Health Canada approved multi-year funding for the Pan-Canadian Organ Donation and Transplantation (ODT) Data and Performance Reporting System Project, co-executed by the Canadian Institute for Health Information (CIHI) and Canada Health Infoway. This report presents the final indicators and measures prioritized by CIHI, including the rationale behind the prioritization of each one.

A list of proposed indicators was determined using a CIHI-led environmental scan. The proposed indicators were then prioritized using a modified Delphi process (see [Appendix B](#)),¹ which consisted of 2 rounds of prioritization. First, CIHI circulated an online survey to members of the ODT community, and 131 stakeholders responded. Second, CIHI led 12 discussion sessions on 10 topics covering deceased donation, living donation and transplantation from October 2021 to September 2022. These sessions included members of the ODT Data and Performance Reporting System Project's Indicators and Measures Prioritization Expert Advisory Forum (EAF) across the relevant specialties. Participants were asked to review and discuss each of the proposed indicators. After each discussion, members provided their recommendation for or against the inclusion of the indicator in future ODT performance reporting. There was consensus among EAF members to prioritize the reporting of the following 78 indicators over time.

Deceased donation (DD)

Indicator name	Indicator description
People With Registered Intent per Million Population	The number of people with registered intent for organ donation per million adult population
Missed Referral Rate	The percentage of audited deaths meeting referral criteria that are not referred
Approach Rate	The percentage of referred donors eligible for approach whose family/next of kin are approached to discuss donation
Time From Consent to Organ Recovery	The distribution of time between consent for donation and organ recovery, for donors who have at least one organ recovered for transplantation
Consent Rate	The percentage of approached next of kin/substitute decision-makers who consent to organ donation
Family Overturn Rate	The percentage of next of kin/substitute decision-makers for patients with registered consent decisions who overturn the decision to donate
Percentage of Offered Organs Accepted	The percentage of offered organs that are accepted
Percentage of Donors With a Recovered Organ	The percentage of consented donors who have at least one organ recovered for transplantation
Deceased Donors per Million Population	The number of deceased donors who have at least one organ recovered for transplantation per million population
Conversion Rate	The rate of conversion of potential donors into utilized donors
Organ Discard Rate	The percentage of donors who have at least one organ recovered for transplantation who are not utilized donors
Organs Transplanted per Utilized Donor	The number of organs transplanted per utilized donor
Cold Ischemia Time	The median cold ischemia time in hours

Living donation (LD)

Indicator name	Indicator description
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
Percentage of Individuals Registered as a Potential Living Donor Who Donated	The percentage of people registered as living donors who donate
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)
In-Hospital Mortality Rate	The percentage of living donors who die during initial hospitalization for the donation procedure
Length of Stay	The number of days from hospital admission to discharge for the donation procedure
Living Donor Rate	The number of living donors per million population

Indicator name	Indicator description
Percentage of Paired Donation Transplants Proceeding	The percentage of paired donations that proceed to transplantation
Time to Surgery	The number of days from when a person is deemed a suitable donor to donation surgery
30-Day Readmission Rate	The 30-day readmission rate for living donors
Cold Ischemia Time	The median cold ischemia time in hours
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 the follow-up period (time point TBD)
Percentage of Living Kidney Donors Who Develop ESKD	The percentage of living kidney donors who eventually develop end-stage kidney disease (ESKD)
Living Donors With Long-Term Follow-Up Plan	The percentage of living donors with a long-term follow-up plan
Patient-Reported Experience of Medical Care and Donation Process	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)
Patient-Reported Outcomes	The patient-reported outcome measures (PROMs) score. This score 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.

Transplantation (Tx)

Indicator name*	Indicator description
Time Between Referral and Assessment	The number of days between referral and assessment for transplant suitability
Time From Listing to Transplant	The number of days between being added to the wait-list and receiving a transplant, for patients who received a transplant
Wait-List Mortality Rate	The cumulative probability of death by certain amount of time on the wait-list (time points TBD)
Wait-List Volume	The number of people on the wait-list, including new additions, removals (and reason) and those on hold
Wait-Listed Patients per Million Population	The number of patients on the wait-list per million population
Transplant Rate	The number of transplants per million population
In-Hospital Mortality Rate	The proportion of transplant candidates who die while in hospital for the transplant
Length of Stay	The number of days between admission and discharge for the recipient
Primary Graft Dysfunction Rate	The percentage of patients who experience primary graft dysfunction, for organs for which this applies (definition varies by organ)
Surgical Complication Rate	The percentage of transplant recipients with a surgical complication
Warm Ischemia Time	The median time between “out of the cold” and reperfusion
Viral Infection or Reactivation Rate	The cumulative risk of viral infection or reactivation (e.g., cytomegalovirus [CMV], Epstein–Barr virus [EBV]) within a certain time frame after transplantation
Cumulative Incidence of Post-Transplant Dialysis	The cumulative risk of dialysis for a certain time frame after transplant. Excludes kidney transplant (see Graft Survival)

Indicator name*	Indicator description
Graft Survival	The cumulative graft survival at a certain time point. For this indicator, patient death is included as failure. Various time frames for follow-up (e.g., during hospitalization, 30 days, 1 year, 5 years, 10 years)
Patient Survival	The cumulative survival rate. Various time frames for follow-up (e.g., during hospitalization, 30 days, 1 year, 5 years, 10 years)
Percentage With New-Onset Diabetes	The percentage of patients with transplant and no previous diagnosis of diabetes who are afterward diagnosed with new-onset diabetes within a given time period
Post-Transplant Cancer Rate	The cumulative incidence rate of cancer in patients after transplantation
Readmission Rate	The cumulative readmission rate at a certain time point. Various time frames for follow-up (e.g., 30 days, 1 year)
Rejection Rate	The cumulative rate of rejection at a certain time point
Patient-Reported Experience of Medical Care and Donation Process	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)
Patient-Reported Outcomes	The PROMs score. This score 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.

Note

* These indicators apply to all solid organs.

Additionally, CIHI identified a set of 3 transplantation indicators specific to the pediatric population.

Kidney-specific transplantation

Indicator name	Indicator description
Percentage of ESKD Patients Referred	The percentage of patients with ESKD who have been referred for transplant evaluation during a given period of time
Percentage of ESKD Patients Who Have a Documented Discussion About Their Consideration for Transplantation	The percentage of patients with ESKD who have a documented discussion about their consideration for transplantation
Percentage of ESKD Patients Who Have Specifically Discussed Living Donor Transplantation	The percentage of patients with ESKD who have a documented discussion about their consideration for transplantation who are documented to have specifically discussed living donor transplantation
Percentage of Referred ESKD Patients Accepted for Transplantation	The percentage of referred patients with ESKD who are accepted for transplantation
Time Between Dialysis Start and Transplant Referral	The number of days between the start of dialysis and referral for transplant
Delayed Graft Function	The percentage of patients receiving dialysis within the first week post-operatively
Percentage of ESKD Patients Receiving Transplant	The percentage of patients with ESKD who receive a kidney transplant
Pre-Emptive Transplant Rate	The percentage of living donor kidney transplants where the recipient had 2 weeks or less of dialysis before transplantation

Heart-specific transplantation

Indicator name	Indicator description
Percentage With MCS at Listing	The percentage of wait-listed patients who were listed while on mechanical circulatory support (MCS)
MCS Separation	For those patients requiring MCS following transplantation, the percentage who are successfully separated from MCS
Percentage With MCS at Transplant	The percentage of heart transplant patients with MCS at the time of transplant
mTORi Use for Patients With CAV	The percentage of patients with International Society of Heart and Lung Transplantation (ISHLT) cardiac allograft vasculopathy (CAV) of 1 or worse who are receiving mammalian target of rapamycin inhibitors (mTORi)
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)
One-Year CAV Surveillance	The percentage of patients who meet CAV screening guidelines
One-Year Statin Use	The percentage of patients who remain on a statin 1 year post-transplant

Pancreas-specific transplantation

Indicator name	Indicator description
Recipient Is a Type 1 or Type 2 Diabetic	The proportion of pancreas recipients by type of diabetes (i.e., type 1 or type 2 diabetes)
Pancreas Thrombosis Rate	The cumulative incidence of pancreas graft failure due to thrombosis
Graft Function	Description of the graft function post-transplant

Liver-specific transplantation

Indicator name	Indicator description
Primary Non-Function	The percentage of patients for whom transplant does not initially work, leading either to the need for re-transplantation or to death
Hepatic Artery Thrombosis Rate	The cumulative incidence of liver graft failure due to thrombosis of the hepatic artery

Intestine-specific transplantation

Indicator name	Indicator description
Time to Discontinuation	The distribution of time between transplantation and discontinuation of total parenteral nutrition

Lung-specific transplantation

Indicator name	Indicator description
Post-Operative Functional Status	The description of post-operative functional status, as measured by the 6-minute walk test or other functional assessment (TBD), among lung transplant recipients
Best Achieved Lung Function in First Year	Descriptive statistics on best achieved lung function (e.g., best forced expiratory volume in 1 second [FEV1] or forced vital capacity [FVC]) in first year post-operatively
Chronic Lung Allograft Dysfunction Rate	The rate of chronic lung allograft dysfunction
Bridge to Transplant With Extracorporeal Life Support	The percentage of transplant recipients receiving extracorporeal life support (ECLS) at the time of transplant
Post-Operative Extracorporeal Life Support Use	The percentage of transplant recipients requiring extracorporeal life support after transplantation

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. ODT capacity, data, policy and practice vary significantly across the country. 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 the Canadian Institute for Health Information (CIHI) and Canada Health Infoway (Infoway). The project is guided by [Health Canada's ODTC Data System Working Group \(DSWG\)](#), which is co-chaired by Dr. Joseph Kim and Dr. Matthew Weiss.

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

CIHI and Infoway objectives for this 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 (with standards embedded) 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](#) and Infoway's [Organ Donation and Transplantation Data Management web page](#).

Introduction

The Pan-Canadian ODT Data and Performance Reporting System Project aims to address the growing need for life-saving organ transplants that surpasses the availability of donated organs across the country. To understand the scope of this need and provide a significant opportunity for action, it is important to collect, report and monitor ODT indicators.

Across the jurisdictions of Canada, there is wide variation in the reporting of these ODT indicators with each jurisdiction having distinct practices and guidelines. There is also limited reporting of system-level ODT indicators needed for pan-Canadian health system performance monitoring and reporting. The final prioritized indicators listed in this document lay the foundation for the Pan-Canadian ODT Data and Performance Reporting System Project. The project enables the monitoring of and reporting on the progress of the ODT system to support high-quality performance and health system outcomes.

In April 2021, CIHI released the ODT Data and Performance Reporting System indicators and measures short-list for prioritization based on an environmental scan conducted by CIHI. CIHI used a modified Delphi process for the selection of indicators. For the first round of prioritization, CIHI circulated an online survey to stakeholders in the ODT community to obtain feedback on the short-listed indicators. A total of 131 ODT stakeholders responded and provided feedback.

For the second round of prioritization, CIHI hosted and facilitated meetings to prioritize indicators. Patients, families, donors, advocates, clinicians, researchers, and representatives from the government, pan-Canadian organizations and organ donation organizations (ODOs)

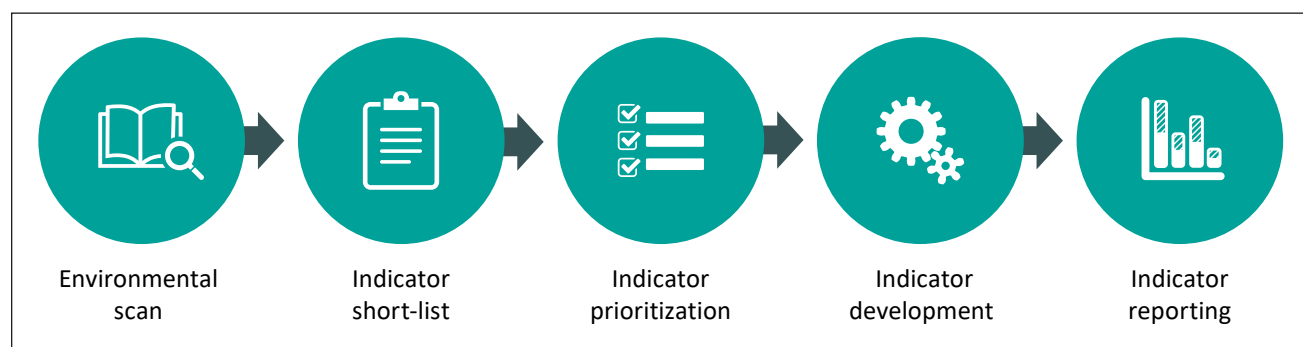
were invited to discuss the survey findings and provide input (see [Appendix A](#)). From October 2021 to September 2022, CIHI hosted 12 forums covering 10 topics on indicator prioritization. Following these forums, 78 indicators were recommended for health system performance reporting for deceased donation, living donation and transplantation. CIHI leveraged previous indicator prioritization sessions conducted by Trillium Gift of Life Network's Ontario Transplant Performance Measurement and Evaluation Executive Committee (TGLN TPEC) for the prioritization of additional organ-specific transplantation indicators.

Figure 1 Indicator development cycle



These 78 prioritized indicators will be developed using a phased approach, based on data availability and feasibility. CIHI is regularly evaluating ODT indicators and determining whether they should be reported, redeveloped or retired. Figure 2 shows the stages of the process of selecting and developing ODT indicators for performance reporting.

Figure 2 Stages of ODT indicator selection and development for performance reporting



Summary of ODT indicator selection process for performance reporting

Stages of indicator selection process		Deceased donation indicators	Living donation indicators	Deceased and living donation indicators*	Transplantation indicators†	Total
Indicators in the CIHI environmental scan		241	50	35	468	794
Unique indicator concepts in the environmental scan		52	24	7	118	201
Indicators considered for prioritization		24	19	3	68	111
Final prioritized indicators‡		13	15	1	50	78
Prioritized indicators categorized by quadrant/performance dimension§	Health system inputs	1	—	—	—	1
	Health system outputs: Access to comprehensive, high-quality health services	1	2	—	11	14
	Health system outputs: Appropriate and effective	1	4	—	24	29
	Health system outputs: Efficiently delivered	7	4	1	—	11
	Health system outputs: Person-centred	2	3	—	3	8
	Health system outputs: Safe	—	2	—	1	3
	Health system outcomes	1	—	—	9	10
	Social determinants of health	—	—	—	2	2

Notes

* These indicators are included in both the deceased and living donations indicator categories.

† Includes organ-specific and pediatric indicators.

‡ Values in subcategories may not sum to the total if indicators are included in more than 1 group.

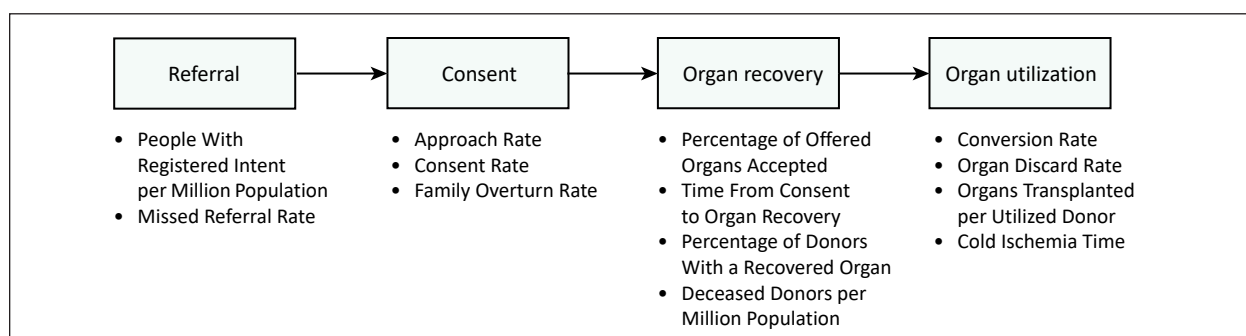
§ See [Appendix C](#) for CIHI's Health System Performance Measurement Framework.²

— Indicator not available for this performance dimension.

Deceased donation (DD)

In October 2021, members of the Deceased Donation Expert Advisory Forum were asked to review and discuss the proposed deceased donation indicators. After each discussion, members provided their recommendation for or against the inclusion of the indicator in future ODT performance reporting. The final list of indicators is organized according to the major workflow phases in the deceased donation pathway (see Figure 3).

Figure 3 Recommended deceased donation indicators for prioritization, by workflow phase



Referral

Indicator name	People With Registered Intent per Million Population
Description	The number of people with registered intent for organ donation per million adult population
Quadrant/performance dimension	Health system inputs
Rationale and comments	<ul style="list-style-type: none"> • This indicator is important for resourcing. For instance, this information could inform how provinces allocate and manage their organ donation and transplantation resources. • This indicator is reported in Ontario at the regional and provincial levels. • Findings from this indicator will be helpful for promotion campaigns by provincial ministries, ODOs and Canadian Blood Services. For instance, this indicator can provide insight into how campaigns are reaching the public and will enable comparisons between provinces to facilitate improvement across Canada.

Indicator name	Missed Referral Rate
Description	The percentage of audited deaths meeting referral criteria that are not referred
Quadrant/performance dimension	Appropriate and effective
Rationale and comments	<ul style="list-style-type: none"> • There was consensus among members that this indicator was important. No further comments were provided.

Consent

Indicator name	Approach Rate
Description	The percentage of referred donors eligible for approach whose family/next of kin are approached to discuss donation
Quadrant/performance dimension	Access to comprehensive, high-quality health services
Rationale and comments	<ul style="list-style-type: none"> • Approach rate is an important indicator to measure, especially for patients in the intensive care unit (ICU). • This is a key indicator to understand how eligible donors' families/next of kin are approached when donation occurs after circulatory death (DCD).

Indicator name	Consent Rate
Description	The percentage of approached next of kin/substitute decision-makers who consent to organ donation
Quadrant/performance dimension	Person-centred
Rationale and comments	<ul style="list-style-type: none"> • This information is essential for hospitals to track the patient donation journey to improve the quality of the process, especially at the consent phase. For example, hospitals can determine where patients drop out in the patient donation journey (e.g., at the consent phase).

Indicator name	Family Overturn Rate
Description	The percentage of next of kin/substitute decision-makers for patients with registered consent decisions who overturn the decision to donate
Quadrant/performance dimension	Person-centred
Rationale and comments	<ul style="list-style-type: none"> • This indicator is important for ODOs to understand missed donations and work with hospitals to improve donation rates (i.e., decrease the Family Overturn Rate). • It is valuable to collect information on why next of kin/substitute decision-makers overturn the decision to donate. This information can help amend legislation and contribute to public reform from a policy and ministry perspective. • This information is being collected in Ontario and appears to be common; however, it is important to collect this information across Canada for comparative purposes. • There was consensus among members that although measuring this indicator is a significant challenge, the ability to action and improve the outcome of this indicator at a pan-Canadian level is significant.

Organ recovery

Indicator name	Percentage of Offered Organs Accepted
Description	The percentage of offered organs that are accepted
Quadrant/performance dimension	Efficiently delivered
Rationale and comments	<ul style="list-style-type: none"> • This indicator is important from a transplant centre perspective as it facilitates comparison between centres regarding the ratio of offered organs accepted and provides an important opportunity for action.

Indicator name	Time From Consent to Organ Recovery
Description	The distribution of time between consent for donation and organ recovery, for donors who have at least one organ recovered for transplantation
Quadrant/performance dimension	Efficiently delivered
Rationale and comments	<ul style="list-style-type: none"> • This indicator provides more information on the bottlenecks and breakdowns in the DD pathway. • It provides ODOs with important information to help them understand how their resources and centres are functioning. • This indicator is currently reported at the ministry and international levels and provides a significant opportunity for action. • The indicator is important for evaluating system efficiency in identifying and addressing the differences in transplant outcomes. • While some factors cannot be controlled clinically for this indicator, this information helps identify and understand these factors.

Indicator name	Percentage of Donors With a Recovered Organ
Description	The percentage of consented donors who have at least one organ recovered for transplantation
Quadrant/performance dimension	Efficiently delivered
Rationale and comments	<ul style="list-style-type: none"> • This indicator is useful for quality improvement initiatives at the ODO level as the management of a deceased donor by the ODO could influence whether an organ is recovered. • This indicator tracks the organ(s) recovered but not used and the reasons for not using the organ(s). This information provides information to better understand the DD pathway.

Indicator name	Deceased Donors per Million Population
Description	The number of deceased donors who have at least one organ recovered for transplantation per million population
Quadrant/performance dimension	Health system outcomes
Rationale and comments	<ul style="list-style-type: none"> • There was consensus among members that this indicator was important as it is the key factor in determining the number of transplantations across the country. • This indicator also allows for comparisons across jurisdictions in Canada.

Organ utilization

Indicator name	Conversion Rate
Description	The rate of conversion of potential donors into utilized donors
Quadrant/performance dimension	Efficiently delivered
Rationale and comments	<ul style="list-style-type: none"> • There was consensus among members that this indicator was important. No further comments were provided.

Indicator name	Organ Discard Rate
Description	The percentage of donors who have at least one organ recovered for transplantation who are not utilized donors
Quadrant/performance dimension	Efficiently delivered
Rationale and comments	<ul style="list-style-type: none"> • This indicator is important to measure from an accountability perspective. For instance, if 1 centre discards organs twice as often as another, then this can be actionable. • This information is helpful as it provides insight into donation or transplant system efficiency by understanding the reason an organ was recovered and why it was or wasn't transplanted. • The organ discard rate indicator is important for public reporting (e.g., reporting at the national and provincial levels).

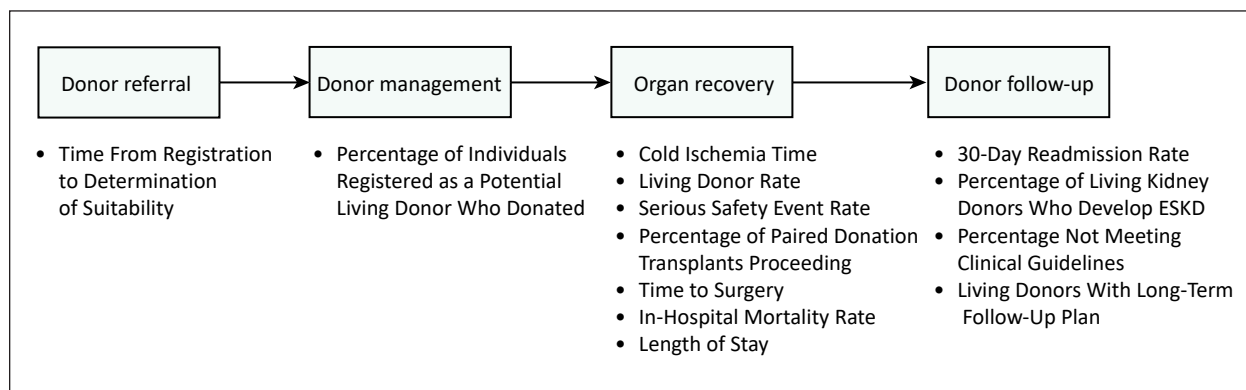
Indicator name	Organs Transplanted per Utilized Donor
Description	The number of organs transplanted per utilized donor
Quadrant/performance dimension	Efficiently delivered
Rationale and comments	<ul style="list-style-type: none"> • Although this indicator needs to be complemented with additional information, it benefits system-level health performance reporting. It can also be leveraged to compare the pan-Canadian ODT system with international systems. • Information on the number of organs transplanted per utilized donor is valuable information for patients on the wait-list.

Indicator name	Cold Ischemia Time
Description	The median cold ischemia time in hours
Quadrant/performance dimension	Efficiently delivered
Rationale and comments	<ul style="list-style-type: none"> • This indicator is important for accountability and actionable as it measures the length of time needed to complete a transplant by respective transplant centres. • The cold ischemia time is impacted by the resources available to the transplant centre (i.e., the length of time needed to move an organ from 1 place to another) and as a result, important to measure.

Living donation (LD)

In November 2021, members of the Living Donation Expert Advisory Forum were asked to review and discuss the proposed living donation indicators. After each discussion, members provided their recommendation for or against the inclusion of the indicator in future ODT performance reporting. The final list of indicators is organized according to the major workflow phases in the living donation pathway (see Figure 4).

Figure 4 Recommended living donation indicators for prioritization, by workflow phase



Note

Additional indicators that were recommended for prioritization include Patient-Reported Experience of Medical Care and Donation Process and Patient-Reported Outcomes (e.g., Health-Related Quality of Life). These indicators cover multiple phases.

Donor referral

Indicator name	Time From Registration to Determination of Suitability
Description	The number of days from when a person registers as a potential living donor to when suitability is determined
Quadrant/performance dimension	Access to comprehensive, high-quality health services
Rationale and comments	<ul style="list-style-type: none"> • This indicator falls under the accountability of the living donation program and can be used to track efficiency. • The time from registration to the determination of suitability demonstrates responsiveness to potential donors. • It provides an understanding of the essential internal process to donors. • It provides a significant opportunity for action. For example, McMaster University and the University of Ottawa have 1-day LD referral programs. The clinic at McMaster has set this target for the past 2 years.

Donor management

Indicator name	Percentage of Individuals Registered as a Potential Living Donor Who Donated
Description	The percentage of people registered as living donors who donate
Quadrant/performance dimension	Efficiently delivered
Rationale and comments	<ul style="list-style-type: none"> • This indicator is helpful to investigate the efficiency of LD programs and identify why potential donors are unable to donate (e.g., found unsuitable at the work-up phase). • This information is important for local transplant centres and may be more suitable for reporting in a secure access environment.

Organ recovery

Indicator name	Cold Ischemia Time
Description	The median cold ischemia time in hours
Quadrant/performance dimension	Efficiently delivered
Rationale and comments	<ul style="list-style-type: none"> • The cold ischemia time varies; local transplants have low ischemia time, and shipped organs have high ischemia time. Due to the increase in the number of shipped kidneys, this indicator is important to measure.

Indicator name	Living Donor Rate
Description	The number of living donors per million population
Quadrant/performance dimension	Access to comprehensive, high-quality health services
Rationale and comments	<ul style="list-style-type: none"> • There was consensus among members that this indicator was important. No further comments were provided.

Indicator name	Serious Safety Event Rate
Description	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)
Quadrant/performance dimension	Safe
Rationale and comments	<ul style="list-style-type: none"> • There was consensus among members that this indicator was important. No further comments were provided.

Indicator name	Percentage of Paired Donation Transplants Proceeding
Description	The percentage of paired donations that proceed to transplantation
Quadrant/performance dimension	Efficiently delivered
Rationale and comments	<ul style="list-style-type: none"> • This is an important metric to capture as some paired donations do not proceed to transplantation. Several programs across Canada are trying to improve this indicator.

Indicator name	Time to Surgery
Description	The number of days from when a person is deemed a suitable donor to donation surgery
Quadrant/performance dimension	Efficiently delivered
Rationale and comments	<ul style="list-style-type: none"> • This indicator is beneficial in advocating for operating room access. • Living donors can find the time before surgery stressful (e.g., worry about getting sick or injured). Therefore, decreasing this length of time is beneficial for living donors.

Indicator name	In-Hospital Mortality Rate
Description	The percentage of living donors who die during initial hospitalization for the donation procedure
Quadrant/performance dimension	Safe
Rationale and comments	<ul style="list-style-type: none"> • This indicator is an accountability measure as any death of a living donor during the donor's hospitalization period should trigger a critical incident review.

Indicator name	Length of Stay
Description	The number of days from hospital admission to discharge for the donation procedure
Quadrant/performance dimension	Appropriate and effective
Rationale and comments	<ul style="list-style-type: none"> • This indicator is important for international comparisons as it measures the efficiency of the living donor pathway. • Length of stay is important to capture because of the low variability in length of stay among living donors. Thus, it is worthwhile to investigate rare cases that have longer stays.

Donor follow-up

Indicator name	30-Day Readmission Rate
Description	The 30-day readmission rate for living donors
Quadrant/performance dimension	Appropriate and effective
Rationale and comments	<ul style="list-style-type: none"> • Readmissions are common in living donors, which is why they are important to measure. • There is a gap in reporting that this indicator fills as there is no specific ODT indicator for readmission.

Indicator name	Percentage of Living Kidney Donors Who Develop ESKD
Description	The percentage of living kidney donors who eventually develop end-stage kidney disease (ESKD)
Quadrant/performance dimension	Appropriate and effective
Rationale and comments	<ul style="list-style-type: none"> • This indicator is important to capture for the living donor community as most living donors have an interest in this information.

Indicator name	Percentage Not Meeting Clinical Guidelines
Description	The percentage of living donors who do not meet clinical guidelines (e.g., for blood pressure, lipids, glycemic control) at the follow-up period (time point TBD)
Quadrant/performance dimension	Appropriate and effective
Rationale and comments	<ul style="list-style-type: none"> • There was consensus among members that this indicator was important. No further comments were provided.

Indicator name	Living Donors With Long-Term Follow-Up Plan
Description	The percentage of living donors with a long-term follow-up plan
Quadrant/performance dimension	Person-centred
Rationale and comments	<ul style="list-style-type: none"> • There was consensus that long-term follow-up for living donors is very important. However, this indicator alone may not capture follow-up accurately, and a more specific indicator (e.g., Percentage of Living Donors with a Serum Creatinine Measurement 1 Year After Donation) may be more appropriate.

Multiple phases

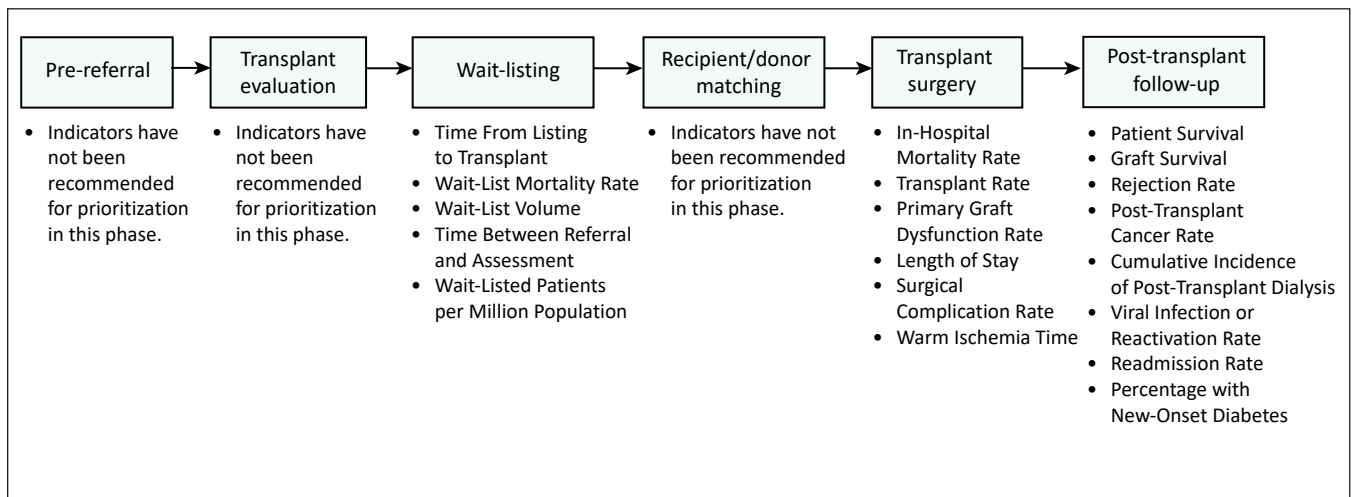
Indicator name	Patient-Reported Experience of Medical Care and Donation Process
Description	The patient-reported experience of medical care and the donation process (e.g., satisfaction with care, communication with health care staff, being well-informed about process/procedure, involvement in decision-making)
Quadrant/performance dimension	Person-centred
Rationale and comments	<ul style="list-style-type: none"> • There was consensus among the group for this indicator to be prioritized. No further comments were provided.

Indicator name	Patient-Reported Outcomes (e.g., Health-Related Quality of Life)
Description	The PROMs score. This score 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.
Quadrant/performance dimension	Person-centred
Rationale and comments	<ul style="list-style-type: none"> • Individuals interested in becoming living donors would be interested in this indicator.

Transplantation (Tx)

In November 2021, members of the Transplantation Expert Advisory Forum were asked to review and discuss the proposed general transplantation indicators. After each discussion, members provided their recommendation for or against the inclusion of the indicator in future ODT performance reporting. Below are the general transplantation indicators. The final list of indicators is organized according to the major workflow phases in the general transplantation pathway (see Figure 5).

Figure 5 Recommended general transplantation indicators for prioritization, by workflow phase



Note

Additional indicators that were recommended for prioritization include Patient-Reported Experience of Medical Care and Donation Process and Patient-Reported Outcomes (e.g., Health-Related Quality of Life). These indicators cover multiple phases.

Wait-listing

Indicator name	Time From Listing to Transplant
Description	The number of days between being added to the wait-list and receiving a transplant, for patients who received a transplant
Quadrant/performance dimension	Access to comprehensive, high-quality health services
Rationale and comments	<ul style="list-style-type: none"> This is a meaningful transplantation indicator as it measures an important time interval in the patient's journey.

Indicator name	Wait-List Mortality Rate
Description	The cumulative probability of death by certain amount of time on the wait-list (time points TBD)
Quadrant/performance dimension	Access to comprehensive, high-quality health services
Rationale and comments	<ul style="list-style-type: none"> • There was consensus among members that this indicator was important. No further comments were provided.

Indicator name	Wait-List Volume
Description	The number of people on the wait-list, including new additions, removals (and reason) and those on hold
Quadrant/performance dimension	Access to comprehensive, high-quality health services
Rationale and comments	<ul style="list-style-type: none"> • This indicator is useful for contextual measure; however, if the appropriate number of donors is known, this indicator might not be useful for performance reporting. • This information is needed to advocate and raise awareness for organ donation and transplantation. • Organizations in Canada such as Transplant Québec collect this information.

Indicator name	Time Between Referral and Assessment
Description	The number of days between referral and assessment for transplant suitability
Quadrant/performance dimension	Access to comprehensive, high-quality health services
Rationale and comments	<ul style="list-style-type: none"> • There may be a huge time variation among patients because some cases may be more complex than others. • Although some of the factors that drive the time can be patient-driven (e.g., patients may take a long time to decide whether they would like to move forward with transplants), it is important to identify and understand these factors for performance reporting.

Indicator name	Wait-Listed Patients per Million Population
Description	The number of patients on the wait-list per million population
Quadrant/performance dimension	Access to comprehensive, high-quality health services
Rationale and comments	<ul style="list-style-type: none"> • There was consensus among the group for this indicator to be prioritized. No further comments were provided.

Transplant surgery

Indicator name	In-Hospital Mortality Rate
Description	The proportion of transplant candidates who die while in hospital for the transplant
Quadrant/performance dimension	Appropriate and effective
Rationale and comments	<ul style="list-style-type: none"> • This indicator is important for reporting as the 30-day mortality rate is part of the Clavien–Dindo score and is reported by most centres.

Indicator name	Transplant Rate
Description	The number of transplants per million population
Quadrant/performance dimension	Health system outcomes
Rationale and comments	<ul style="list-style-type: none"> • There was overall agreement that this is an important indicator that is also reported internationally. • The transplant rate indicator assists in benchmarking and comparing the Canadian ODT system against others. • This indicator helps answer high-level questions (e.g., How is the system supporting the optimized number of transplants?). A high-performing system will support both deceased and living donations. • This indicator aids in understanding whether organs donated are getting transplanted.

Indicator name	Primary Graft Dysfunction Rate
Description	The percentage of patients who experience primary graft dysfunction, for organs for which this applies (definition varies by organ)
Quadrant/performance dimension	Appropriate and effective
Rationale and comments	<ul style="list-style-type: none"> • This is an important outcome and high-level quality indicator. It provides information on issues arising between organ storage and transplantation, which can result in graft dysfunction. • The Primary Graft Dysfunction Rate is a key negative outcome that results from the transplantation of a damaged organ. As a result, this information is useful to assess outcomes of organs considered “marginal.” • For heart transplantation, the International Society of Heart and Lung Transplantation (ISHLT) reports on this indicator. • For kidney transplantation, this indicator is important to measure as it provides information about the extent of injury that occurred with the transplant. This indicator can be defined as primary non-function (i.e., the kidney graft does not function after transplantation) or delayed graft function (i.e., the kidney graft does not function immediately after surgery). • For liver transplantation, primary graft dysfunction is measured by early allograft function. It is important to measure as it could be the reason for re-transplantation.

Indicator name	Length of Stay
Description	The number of days between admission and discharge for the recipient
Quadrant/performance dimension	Appropriate and effective
Rationale and comments	<ul style="list-style-type: none"> • The Length of Stay indicator provides facts on the patient stay at centres, which in turn offers information about resources used during the stay. • It is useful to compare overall length of stay at transplant centres to advocate for resources (e.g., rehabilitation that could have been done at home). However, it is also important to not penalize centres based on length of stay statistics as this would disincentivize taking on high-risk patients. • Long hospitalization after transplantation is sometimes appropriate as the stay at the hospital depends on recipient factors and donor organ quality.

Indicator name	Surgical Complication Rate
Description	The percentage of transplant recipients with a surgical complication
Quadrant/performance dimension	Safe
Rationale and comments	<ul style="list-style-type: none"> • Although there is a wide range of complications that patients may experience and may not be captured by this indicator, it is an important high-level quality indicator. • For lung transplantation, this indicator is important to capture short-term (e.g., 48 to 72 hours post-transplant) and long-term post-operative complications.

Indicator name	Warm Ischemia Time
Description	The median time between “out of the cold” and reperfusion
Quadrant/performance dimension	Appropriate and effective
Rationale and comments	<ul style="list-style-type: none"> • This indicator is important for health system performance reporting as it helps identify long ischemia times in different contexts, which provide a significant opportunity for action.

Post-transplant follow-up

Indicator name	Patient Survival
Description	The cumulative survival rate. Various time frames for follow-up (e.g., during hospitalization, 30 days, 1 year, 5 years, 10 years)
Quadrant/performance dimension	Health system outcomes
Rationale and comments	<ul style="list-style-type: none"> • Reporting this indicator allows for an international comparison of patient survival.

Indicator name	Graft Survival
Description	The cumulative graft survival at a certain time point. For this indicator, patient death is included as failure. Various time frames for follow-up can be considered (e.g., during hospitalization, 30 days, 1 year, 5 years, 10 years)
Quadrant/performance dimension	Health system outcomes
Rationale and comments	<ul style="list-style-type: none"> • There was consensus among the group for this indicator to be prioritized generally, but also specifically for the heart, kidney and pancreas. • The kidney differs from other organs as patients do not depend on a kidney for survival because dialysis can be used to survive. For the kidney, transplant outcomes include death with a functioning graft (i.e., the graft is still functioning when a patient dies) and death post-graft loss (i.e., death when the kidney graft stops functioning, and the patient dies while on dialysis). • For pancreas transplantation, this indicator is important to determine the quality of a pancreas transplant. This indicator is especially important for pancreas transplant recipients who require other medications to keep the graft functioning.

Indicator name	Rejection Rate
Description	The cumulative rate of rejection at a certain time point
Quadrant/performance dimension	Appropriate and effective
Rationale and comments	<ul style="list-style-type: none"> • This indicator is important to measure and can be defined clinically and pathologically. • Rejection can be divided into subtypes (e.g., T-cell-mediated rejection, antibody-mediated rejection) for meaningful reporting. • This indicator is important to measure for the heart, intestine and pancreas as it is internationally reported using grades from ISHLT, the Intestinal Rehabilitation and Transplant Association (IRTA), and the Banff schema for grading pancreas allograft rejection. • For kidney transplantation, this indicator is important to capture because it fosters conversations among experts about band classifications and the distinction between different rejection subtypes. • For liver transplantation, this indicator is important to capture the specific types of rejection in the liver (e.g., ductopenic/chronic rejections).

Indicator name	Post-Transplant Cancer Rate
Description	The cumulative incidence rate of cancer in patients after transplantation
Quadrant/performance dimension	Appropriate and effective
Rationale and comments	<ul style="list-style-type: none"> • Data collected for this indicator can be linked to the data from cancer registries. This is beneficial as it fills the data gap among transplant centres regarding post-transplant cancer. • The post-transplant cancer rate enables the identification and reporting of the various types of cancer across Canada. • For the heart transplant population, this indicator provides information on post-transplant lymphoproliferative disorders (PTLDs) and post-transplant skin cancer.

Indicator name	Cumulative Incidence of Post-Transplant Dialysis
Description	The cumulative risk of dialysis for a certain time frame after transplant. Excludes kidney transplant (see Graft Survival)
Quadrant/performance dimension	Appropriate and effective
Rationale and comments	<ul style="list-style-type: none"> • This indicator is important as it is a proxy for post-transplant kidney trauma and impact. Data collected for this indicator can be used to measure the post-acute impact to the kidney (e.g., drug nephrotoxicity).

Indicator name	Viral Infection or Reactivation Rate
Description	The cumulative risk of viral infection or reactivation (e.g., cytomegalovirus [CMV], Epstein–Barr virus [EBV]) within a certain time frame after transplantation
Quadrant/performance dimension	Appropriate and effective
Rationale and comments	<ul style="list-style-type: none"> • This information is important to help understand the effects of immunosuppression; however, more granular information might be needed for health system performance reporting.

Indicator name	Readmission Rate
Description	The cumulative readmission rate at a certain time point. Various time frames for follow-up (e.g., 30 days, 1 year)
Quadrant/performance dimension	Appropriate and effective
Rationale and comments	<ul style="list-style-type: none"> • There was consensus among the group for this indicator to be prioritized. No further comments were provided.

Indicator name	Percentage With New-Onset Diabetes
Description	The percentage of patients with transplant and no previous diagnosis of diabetes who are afterward diagnosed with new-onset diabetes within a given time period
Quadrant/performance dimension	Appropriate and effective
Rationale and comments	<ul style="list-style-type: none"> • Although it was noted that this process indicator might be too hard to measure, members voted in favour of prioritizing this indicator. • For pancreas transplantation, this indicator is important to measure as patients develop recurrent type 1 or type 2 diabetes after transplantation even with a previous diagnosis of type 1 diabetes.

Multiple phases

Indicator name	Patient-Reported Experience of Medical Care and Donation Process
Description	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)
Quadrant/performance dimension	Person-centred
Rationale and comments	<ul style="list-style-type: none"> • For this indicator, it will be important to develop and validate patient-reported experience measures (PREMs), which is a lengthy process. • PREMs tools specific for transplantation are not currently available. • For pediatric kidney transplantation, existing tools can be leveraged to measure this indicator (e.g., the Pediatric Quality of Life Inventory [PedsQL] Transplant Module) and support health systems performance reporting.

Indicator name	Patient-Reported Outcomes (e.g., Health-Related Quality of Life)
Description	The PROMs score. This score 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.
Quadrant/performance dimension	Health system outcomes
Rationale and comments	<ul style="list-style-type: none"> • Both PREMs and PROMs are very important to patients, caregivers and living donors. • Several initiatives are currently looking at PROMs within organ transplantation, which suggests a pan-Canadian need for this information within the ODT community. • Although this indicator is not measured due to few validated tools, there was consensus among members that it should be measured and reported for the heart, pancreas and intestine. • For liver transplantation, the Patient-Reported Outcomes Measurement Information System (PROMIS) is often used to assess PROMs. • For lung transplantation, PROMs are collected by some transplant centres, but the data collected needs to be more granular.

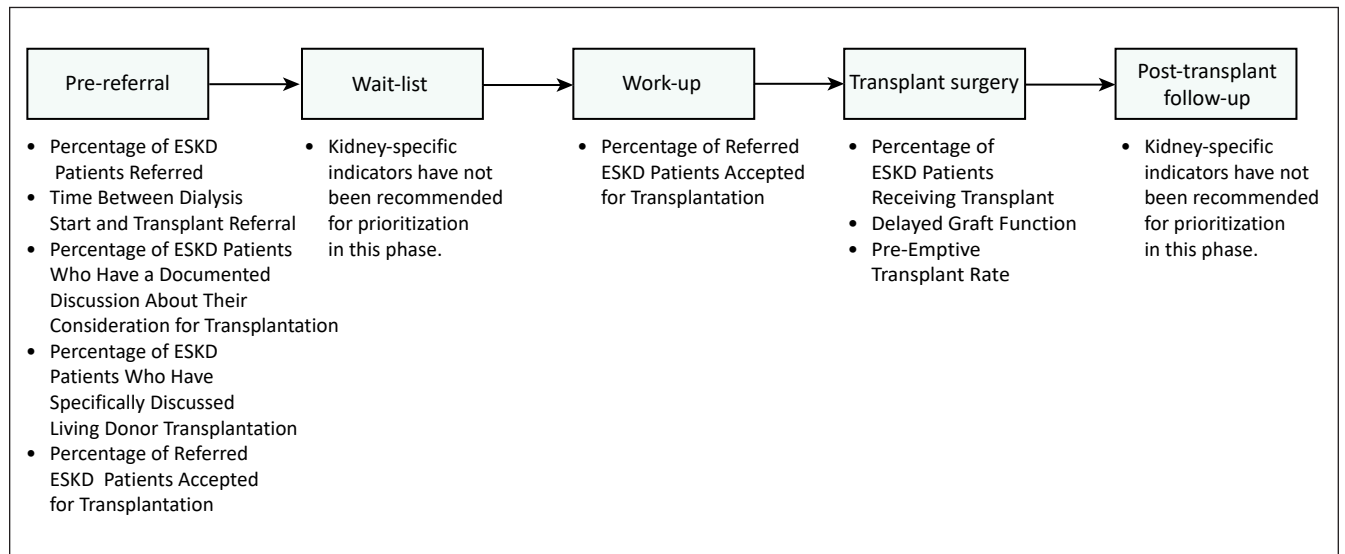
Organ-specific transplantation (Tx)

From January 2022 to September 2022, organ-specific indicator prioritization sessions were held to discuss additional indicators specific to a given organ that were not already included in the general transplantation (Tx) prioritized indicators. Separate expert advisory forums were conducted and attended by members according to expertise for each organ (kidney, heart, pancreas, liver, intestine and lung).

Organ-specific expert advisory forum members were asked to review and discuss the proposed indicators. After each discussion, members provided their recommendation for or against the inclusion of the indicator in future ODT performance reporting. The final lists of indicators are organized according to the major workflow phases in the transplantation pathway (see figures 6 to 11).

Kidney-specific transplantation

Figure 6 Recommended kidney-specific transplantation indicators for prioritization, by workflow phase



Note

While the indicators listed above are specific to kidney transplantation, indicators in the general transplantation (Tx) section are generally applicable to all solid organs including kidney.

Pre-referral

Indicator name	Percentage of End-Stage Kidney Disease (ESKD) Patients Referred
Description	The percentage of patients with ESKD who have been referred for transplant evaluation during a given period of time
Quadrant/performance dimension	Access to comprehensive, high-quality health services
Rationale and comments	<ul style="list-style-type: none"> • This indicator would be important to measure equity and access as it provides a broader system-level view of how patients who need a kidney transplant are progressing through the system. • This indicator is relevant and important to capture patient population characteristics and identify subgroups that may be disadvantaged in getting transplant referrals. • It is important to collect this information as ESKD data could be linked to reasons why patients are not referred for transplants in the future and could inform policy and decision-making.

Indicator name	Time Between Dialysis Start and Transplant Referral
Description	The number of days between the start of dialysis and referral for transplant
Quadrant/performance dimension	Access to comprehensive, high-quality health services
Rationale and comments	<ul style="list-style-type: none"> • Although this indicator would be outside the control of transplant centres, it would be important to track it as a system-level indicator and an important measure of access and equity.

Indicator name	Percentage of ESKD Patients Who Have a Documented Discussion About Their Consideration for Transplantation
Description	The percentage of patients with ESKD who have a documented discussion about their consideration for transplantation
Quadrant/performance dimension	Person-centred
Rationale and comments	<ul style="list-style-type: none"> • This indicator is important to determine equity and person-centred care for transplant recipients. • Reporting this indicator could help to identify barriers that patients encounter when having discussions with their care providers about their consideration for transplantation. As a result, this indicator could provide a significant opportunity for action to mitigate those barriers.

Indicator name	Percentage of ESKD Patients Who Have Specifically Discussed Living Donor Transplantation
Description	The percentage of patients with ESKD who have a documented discussion about their consideration for transplantation who are documented to have specifically discussed living donor transplantation
Quadrant/performance dimension	Person-centred
Rationale and comments	<ul style="list-style-type: none"> • This indicator is important as it is often the timelier option for some patients, such as in scenarios where the deceased donation wait-list is long.

Work-up

Indicator name	Percentage of Referred ESKD Patients Accepted for Transplantation
Description	The percentage of referred patients with ESKD who are accepted for transplantation
Quadrant/performance dimension	Access to comprehensive, high-quality health services
Rationale and comments	<ul style="list-style-type: none"> • There was consensus among members that this indicator was important. No further comments were provided.

Transplant surgery

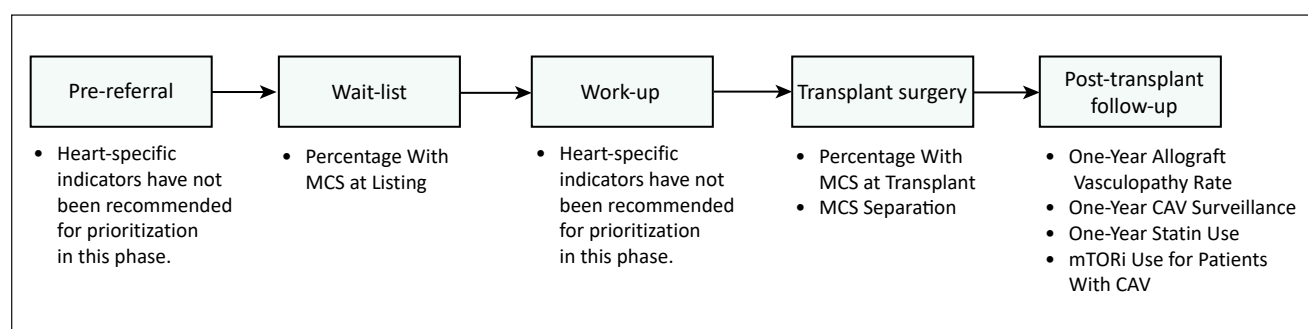
Indicator name	Percentage of ESKD Patients Receiving Transplant
Description	The percentage of patients with ESKD who receive a kidney transplant
Quadrant/performance dimension	Access to comprehensive, high-quality health services
Rationale and comments	<ul style="list-style-type: none"> • There was consensus among members that this indicator was important. No further comments were provided

Indicator name	Delayed Graft Function
Description	The percentage of patients receiving dialysis within the first week post-operatively
Quadrant/performance dimension	Appropriate and effective
Rationale and comments	<ul style="list-style-type: none"> • Delayed Graft Function is a strong predictor of all-cause graft loss and consequently health outcomes. This delay in function could be due to factors such as the frailty of the recipient of the transplant or the quality of the donated organ. Thus, this is an important indicator for health system reporting. • This indicator has been reported on a smaller scale in other studies (e.g., cohort analysis).

Indicator name	Pre-Emptive Transplant Rate
Description	The percentage of living donor kidney transplants where the recipient had 2 weeks or less of dialysis before transplantation
Quadrant/performance dimension	Access to comprehensive, high-quality health services
Rationale and comments	<ul style="list-style-type: none"> • There was consensus among members that this indicator was important. No further comments were provided.

Heart-specific transplantation

Figure 7 Recommended heart-specific transplantation indicators for prioritization, by workflow phase



Note

While the indicators listed above are specific to heart transplantation, indicators in the general transplantation (Tx) section are generally applicable to all solid organs including heart.

Wait-list

Indicator name	Percentage With Mechanical Circulatory Support (MCS) at Listing
Description	The percentage of wait-listed patients who were listed while on MCS
Quadrant/performance dimension	Social determinants of health
Rationale and comments	<ul style="list-style-type: none"> • This is an important wait-list indicator as it measures the wait time for a heart transplant. It also identifies whether the patients on the wait-list are bridged with a durable device before transplant. • It is important to capture this indicator across Canada as it shows variability in practice and provides a significant opportunity for action at the program level and provincial level. • The percentage with MCS at listing indicator influences a wide range of indicators (e.g., repeat hospital stay and length of stay); therefore, it is important to report. • Although patients are referred to left ventricular assist devices (LVADs) regardless of the wait-list status, this indicator provides more information on the acute need for transplant by patients on temporary devices.

Transplant surgery

Indicator name	Percentage With MCS at Transplant
Description	The percentage of heart transplant patients with MCS at the time of transplant
Quadrant/performance dimension	Appropriate and effective
Rationale and comments	<ul style="list-style-type: none"> • This indicator helps to understand the number of people on MCS who got a heart transplant. • This indicator is important to measure as the health outcomes are better for patients who undergo transplants compared to those who are later separated from MCS devices. • This indicator could inform post-transplant outcomes and could indicate how sick patients are when undergoing transplants.

Indicator name	MCS Separation
Description	For those patients requiring MCS following transplantation, the percentage who are successfully separated from MCS
Quadrant/performance dimension	Appropriate and effective
Rationale and comments	<ul style="list-style-type: none"> • This indicator is important because it measures the need for re-transplantation if patients are not successfully separated from MCS.

Post-transplant follow-up

Indicator name	One-Year Allograft Vasculopathy Rate
Description	The cumulative rate of allograft vasculopathy, defined as an ISHLT cardiac allograft vasculopathy (CAV) of 1 or worse, at various time frames (e.g., 1 year, 5 years, 10 years)
Quadrant/performance dimension	Appropriate and effective
Rationale and comments	<ul style="list-style-type: none"> • This indicator is important for health system performance reporting because this measure can be used to advocate for resources and funding from the government.

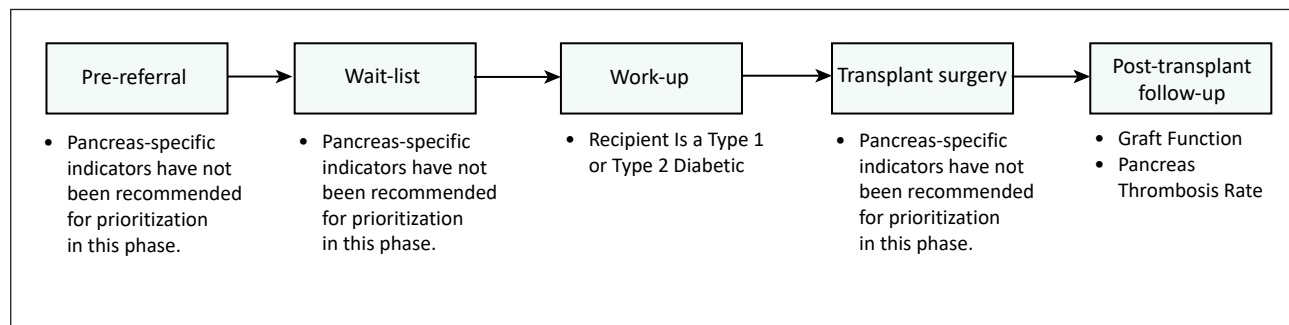
Indicator name	One-Year Cardiac Allograft Vasculopathy (CAV) Surveillance
Description	The percentage of patients meeting CAV screening guidelines
Quadrant/performance dimension	Appropriate and effective
Rationale and comments	<ul style="list-style-type: none"> • This indicator is an important health outcome measure as it informs standards of care and identifies which centres in Canada are conducting screening and monitoring CAV. • One-Year CAV Surveillance is an important quality indicator as it can provide information on the prime opportunity to intervene and adjust treatment. • Findings from this indicator can inform organ donation and transplantation research (e.g., research into the prevalence of CAV). • It is important to capture this indicator because there is variability in CAV surveillance across practices in Canada. For example, some centres use computed tomography (CT) and angiography tests while others use mammalian target of rapamycin inhibitors (mTORi) and intravascular ultrasound (IVUS). These differences could potentially affect the quality of care and thus, it is important to capture.

Indicator name	One-Year Statin Use
Description	The percentage of patients who remain on a statin 1 year post-transplant
Quadrant/performance dimension	Appropriate and effective
Rationale and comments	<ul style="list-style-type: none"> • One-Year Statin Use by transplant recipients could be correlated with CAV-related outcomes (e.g., death). As a result, reporting this indicator could provide a significant opportunity for action as it captures the number of patients who remain on statin and identifies where numbers are low.

Indicator name	Mammalian Target of Rapamycin Inhibitors (mTORi) Use for Patients With CAV
Description	The percentage of patients with ISHLT CAV of 1 or worse who are receiving mTORi
Quadrant/performance dimension	Appropriate and effective
Rationale and comments	<ul style="list-style-type: none"> • This indicator is relevant to measure across Canada because there is variation in the access to and availability of mTORi for transplant patients, which may impact health outcomes. • It is important to collect data to understand why a patient who has CAV is not on mTORi. For example, it's important to understand if the reason is due to access, adverse effects or other factors.

Pancreas-specific transplantation

Figure 8 Recommended pancreas-specific transplantation indicators for prioritization, by workflow phase



Note

While the indicators listed above are specific to pancreas transplantation, indicators in the general transplantation (Tx) section are generally applicable to all solid organs including pancreas.

Work-up

Indicator name	Recipient Is a Type 1 or Type 2 Diabetic
Description	The proportion of pancreas recipients by type of diabetes (i.e., type 1 or type 2 diabetes)
Quadrant/performance dimension	Social determinants of health
Rationale and comments	<ul style="list-style-type: none"> This indicator is an important quality of care measure because it provides insight into the number of patients referred for pancreas transplants who had diabetes (e.g., the percentage of patients who get pancreas transplants among those who have type 1 diabetes).

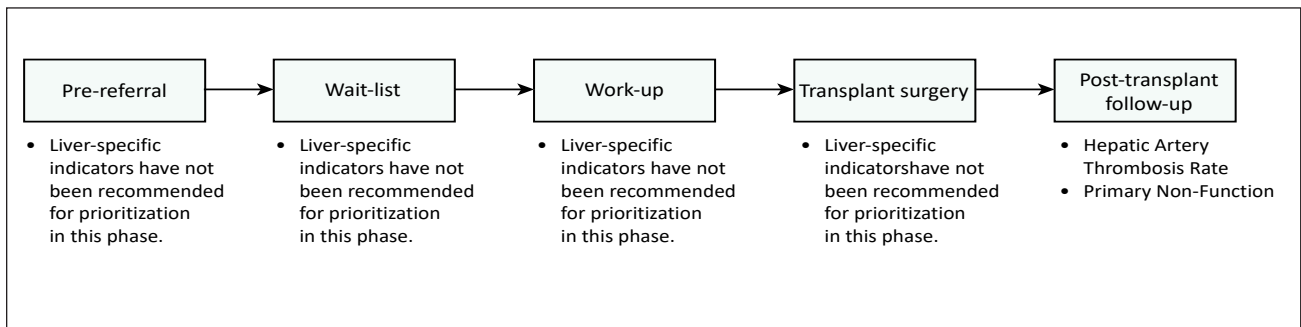
Post-transplant follow-up

Indicator name	Graft Function
Description	Description of the graft function post-transplant
Quadrant/performance dimension	Appropriate and effective
Rationale and comments	<ul style="list-style-type: none"> There was consensus among members that this indicator was important. No further comments were provided.

Indicator name	Pancreas Thrombosis Rate
Description	Rate of graft pancreas thrombosis
Quadrant/performance dimension	Appropriate and effective
Rationale and comments	<ul style="list-style-type: none"> • This indicator is a good quality improvement indicator and can enable the identification of best practices across transplant centres (e.g., measuring the rate of pancreas thrombosis across transplant centres). • This indicator enables comparison between the 2 types of pancreas thrombosis (i.e., arterial and venous).

Liver-specific transplantation

Figure 9 Recommended liver-specific transplantation indicators for prioritization, by workflow phase



Note

While the indicators listed above are specific to liver transplantation, indicators in the general transplantation (Tx) section are generally applicable to all solid organs including liver.

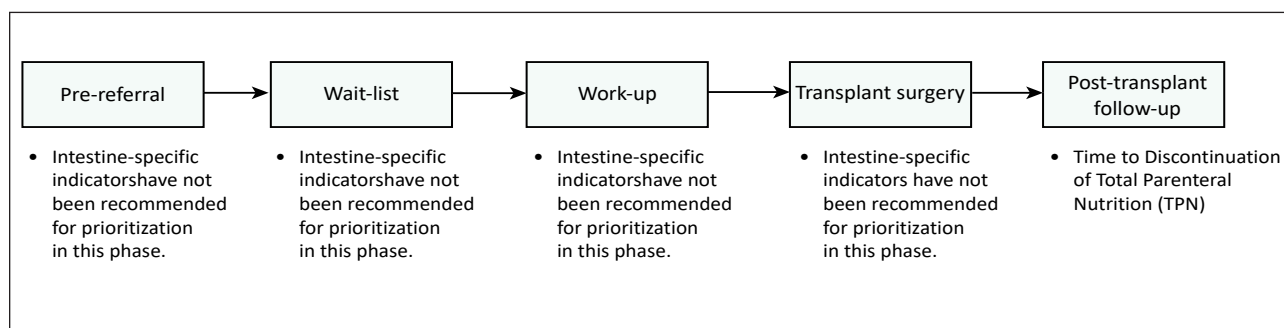
Post-transplant follow-up

Indicator name	Hepatic Artery Thrombosis Rate
Description	The cumulative incidence of liver graft failure due to thrombosis of the hepatic artery
Quadrant/performance dimension	Appropriate and effective
Rationale and comments	<ul style="list-style-type: none"> • This indicator is important to report separately from other graft failure reasons because it is graft failure specific to liver transplantation.

Indicator name	Primary Non-Function
Description	Percentage of patients for whom transplant does not initially work, leading either to the need for re-transplantation or to death
Quadrant/performance dimension	Appropriate and effective
Rationale and comments	<ul style="list-style-type: none"> • This indicator is important to report separately from other graft failure reasons because it is specific to liver transplantation. • This indicator highlights issues related to matching donors and recipients as well as other surgical and technical issues, which should be captured.

Intestine-specific transplantation

Figure 10 Recommended intestine-specific transplantation indicators for prioritization, by workflow phase



Note

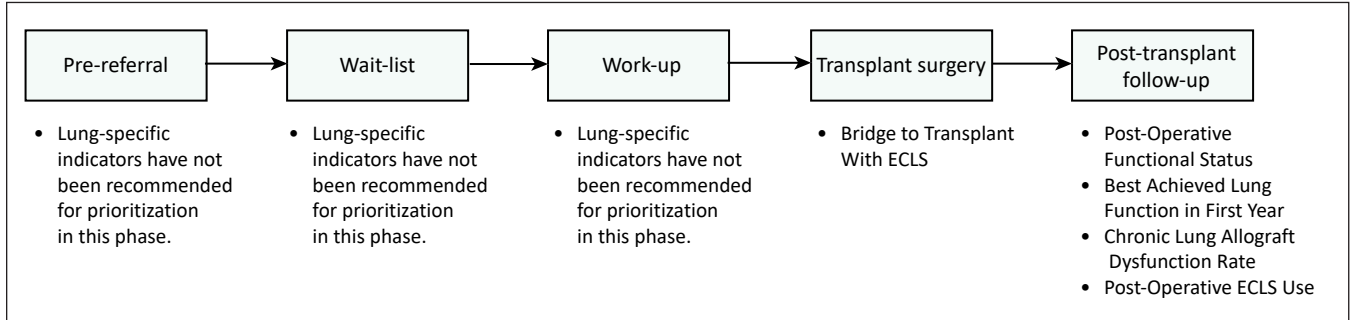
While the indicators listed above are specific to intestine transplantation, indicators in the general transplantation (Tx) section are generally applicable to all solid organs including intestine.

Post-transplant follow-up

Indicator name	Time to Discontinuation of Total Parenteral Nutrition (TPN)
Description	The distribution of time between intestine transplantation and discontinuation of total parenteral nutrition
Quadrant/performance dimension	Appropriate and effective
Rationale and comments	<ul style="list-style-type: none"> • This indicator should be reported because the main health outcome for patients who undergo intestine transplantation is TPN independence. The time it takes to be TPN independent after transplantation varies (e.g., 3 to 6 months) because it takes a long time for an intestine graft to function at full capacity, compared to other organs. Thus, it's important to track this information and measure the variability for intestine transplantations. • There was consensus among members that this is an important and effective quality indicator as it can reveal the success of a transplant.

Lung-specific transplantation

Figure 11 Recommended lung-specific transplantation indicators for prioritization, by workflow phase



Note

While the indicators listed above are specific to lung transplantation, indicators in the general transplantation (Tx) section are generally applicable to all solid organs including lung.

Transplant surgery

Indicator name	Bridge to Transplant With Extracorporeal Life Support (ECLS)
Description	Percentage of transplant recipients receiving extracorporeal life support (ECLS) at the time of transplant
Quadrant/performance dimension	Access to comprehensive, high-quality health services
Rationale and comments	<ul style="list-style-type: none"> This indicator is important to report because it demonstrates whether patients are getting timely access to transplant referrals and transplants. This indicator is important to identify and understand the resource capacities of transplant programs and their ability to adequately support a transplant candidate. Bridge to transplant with ECLS should be reported because it consists of various modifiable factors. These modifiable factors provide significant opportunity for action.

Post-transplant follow-up

Indicator name	Post-Operative Functional Status
Description	Description of post-operative functional status, as measured by the 6-minute walk test or other functional assessment (TBD), among lung transplant recipients
Quadrant/performance dimension	Health system outcomes
Rationale and comments	<ul style="list-style-type: none"> • Post-operative functional status is significantly important to understand rehabilitation and post-operative rehabilitation outcomes. • The indicator is a good quality improvement indicator that is both important to transplant recipients and reported by most transplant programs. • This indicator is important to measure and report as it is a key post-operative outcome.

Indicator name	Best Achieved Lung Function in First Year
Description	Descriptive statistics on best achieved lung function (e.g., best forced expiratory volume in 1 second [FEV1] or forced vital capacity [FVC]) in first year post-operatively
Quadrant/performance dimension	Health system outcomes
Rationale and comments	<ul style="list-style-type: none"> • Best achieved lung function in first year is an important outcome and key quality indicator for lung transplantation. • Reporting this indicator would provide a significant opportunity for action, as the inability to achieve normal lung function is associated with worse health outcomes. • The reporting of this indicator enables comparisons at the hospital, provincial and population levels.

Indicator name	Chronic Lung Allograft Dysfunction (CLAD) Rate
Description	The rate of chronic lung allograft dysfunction
Quadrant/performance dimension	Appropriate and effective
Rationale and comments	<ul style="list-style-type: none"> • The Chronic Lung Allograft Dysfunction Rate should be reported because it impacts health care utilization (e.g., readmission rates). • This indicator provides an opportunity for improvement and action in the lung transplant community, as modifying CLAD rates can be challenging.

Indicator name	Post-Operative Extracorporeal Life Support (ECLS) Use
Description	Percentage of transplant recipients requiring extracorporeal life support after transplantation
Quadrant/performance dimension	Appropriate and effective
Rationale and comments	<ul style="list-style-type: none"> • This indicator is an important quality of care indicator as it speaks to the treatment of primary graft dysfunction (PGD), severe graft failure and hyperacute rejection post-transplant. These complications would affect the long-term health outcomes of the transplant recipients. • Post-Operative ECLS Use is important to measure and understand for health system performance reporting because there is great variability in the use of ECLS across transplant centres.

Pediatric indicators

During the environmental scan phase of the project, it was identified that while a considerable number of indicators have pediatric-transplant considerations, there were few indicators specific to the pediatric transplant population. In December 2021, CIHI gathered input from pediatric transplant clinicians through CIHI-led multi-jurisdictional discussions to identify and explore relevant pediatric indicators.

These discussions revealed common key concepts that were recommended to be reported for pediatric transplant health system performance reporting. As a result, CIHI developed a set of indicators based on these concepts and gaps. CIHI then consulted with pediatric transplant clinicians to confirm the set of proposed indicators for ODT reporting. Based on this consultation, CIHI recommends that the following pediatric-specific transplant indicators be tracked over time:

- Percentage of Pediatric Transplant Recipients With Cognitive Delay or Disability Post-Transplant
- Percentage of School-Age Transplant Recipients at Grade Level
- Percentage of Pediatric Transplant Recipients Who Have Low Length-for-Age

In later phases of the ODT project, additional indicators may be considered and added.

Appendices

Appendix A: Pan-Canadian ODT Data and Performance Reporting System Project's Indicators and Measures Prioritization Expert Advisory Forum

Representative for . . .	Name	Primary organization
Newfoundland and Labrador	Seamus Breen	Newfoundland and Labrador Department of Health and Community Services
	Daphne Osborne	Newfoundland and Labrador Department of Health and Community Services
Prince Edward Island	Angela Carpenter	Prince Edward Island Department of Health and Wellness
	Shaun MacNeil	Prince Edward Island Department of Health and Wellness
Nova Scotia	Philip Acott	Dalhousie University
	Kim Anderson	Queen Elizabeth II Health Sciences Centre
	Katherine Connell	Queen Elizabeth II Health Sciences Centre
	Lisa A. Dillman	Nova Scotia Department of Health and Wellness
	Christine Dipchand	Queen Elizabeth II Health Sciences Centre
	Salah Hussini	Legacy of Life
	Cynthia Isenor	Legacy of Life
	Shelby Kennedy	Queen Elizabeth II Health Sciences Centre
	Amy Laybolt	Legacy of Life
	Nancy MacLeod	Nova Scotia Department of Health and Wellness
	Mirosław Rajda	Queen Elizabeth II Health Sciences Centre
	Amanda Vinson	Queen Elizabeth II Health Sciences Centre
New Brunswick	Tracey Newton	New Brunswick Department of Health
	Nadya Savoie	New Brunswick Organ and Tissue Donation Program

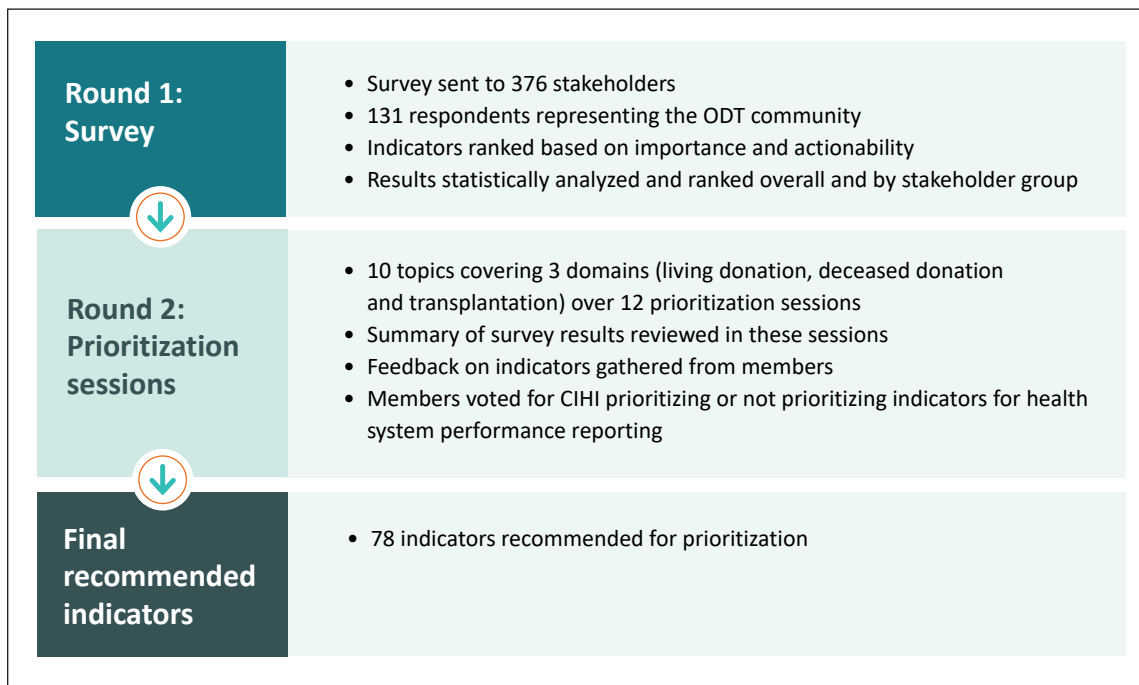
Representative for . . .	Name	Primary organization
Quebec	Jeffrey Barkun	McGill University Health Centre
	Louis Beaulieu	Transplant Québec
	Chantal Bilodeau	Ministère de la Santé et des Services sociaux
	Héloïse Cardinal	Centre hospitalier de l'Université de Montréal
	Brigitte Côté	Institut national d'excellence en santé et en services sociaux
	Pier-Olivier Fortin	Ministère du Travail
	Beth Foster	McGill University Health Centre
	Nadia Giannetti	McGill University Health Centre
	Sylvain Lavigne	Transplant Québec
	Basil Nasir	Centre hospitalier de l'Université de Montréal
	Nasim Saberi	McGill University Health Centre
	Sam Shemie	Montreal Children's Hospital and Canadian Blood Services
	Jean Tchervenkov	McGill University Health Centre
	Matthew Weiss	Centre hospitalier universitaire de Québec — Centre mère-enfant Soleil
Ontario	Samantha Anthony	The Hospital for Sick Children
	Yaron Avitzur	The Hospital for Sick Children
	Mamatha Bhat	University Health Network — Toronto General Hospital
	Sharon Chih	University of Ottawa Heart Institute
	Rebecca Cooper	Trillium Gift of Life Network
	Wendy DeMarco	Ontario Ministry of Health
	Sonny Dhanani	Children's Hospital of Eastern Ontario
	Juan Duero Posada	University Health Network — Toronto General Hospital
	Andrew Healey	William Osler Health System
	Jane Ip	Trillium Gift of Life Network
	Ryan Kalladeen	Ontario Health
	Joseph Kim	University Health Network — Toronto General Hospital
	Greg Knoll	The Ottawa Hospital
	Adriana Luk	University Health Network — Toronto General Hospital
	Dave Nagpal	London Health Sciences Centre — University Hospital
	Trevor Reichman	University Health Network — Toronto General Hospital
	Christine Ribic	McMaster University
	Damon Scales	Sunnybrook Health Sciences Centre
	Jeffery Schiff	University Health Network — Toronto General Hospital
	Markus Selzner	University Health Network — Toronto General Hospital
	Alp Sener	London Health Sciences Centre
	Aman Sidhu	University Health Network — Toronto General Hospital
	Stuart Smith	London Health Sciences Centre
	Melinda Solomon	The Hospital for Sick Children
	Amanda Stypulkowski	McMaster University
	Chia Wei Teoh	The Hospital for Sick Children
	Abby Williams	Ontario Ministry of Health

Representative for . . .	Name	Primary organization
Manitoba	Melanie Ching	Government of Manitoba
	Aviva Goldberg	Transplant Manitoba
	Amelia LaTouche	Manitoba Health, Seniors and Active Living
	Laura Morrison	Manitoba Health, Seniors and Active Living
	Peter Nickerson	Transplant Manitoba — Gift of Life
	Kim Werestiuk	Transplant Manitoba — Gift of Life
Saskatchewan	Jessica Jackson	Saskatchewan Ministry of Health
	Rahul Mainra	St. Paul's Hospital, Saskatchewan Transplant Program
	David Scheurwater	Saskatchewan Ministry of Health
	Caroline Tait	University of Saskatchewan
Alberta	Vince Bain	University of Alberta Hospital (Edmonton)
	David Bigam	University of Alberta Hospital (Edmonton)
	Brian Clarke	Foothills Medical Centre
	Laura Grantham	Alberta Ministry of Health
	Lorraine Hamiwka	Alberta Children's Hospital
	Alim Hirji	University of Alberta Hospital
	Norm Kneteman	University of Alberta Hospital
	Glenna Laing	Alberta Ministry of Health
	Aldo Montano-Loza	University of Alberta Hospital
British Columbia	Parvesh Angrula	BC Transplant
	Tom Blydt-Hansen	BC Children's Hospital
	Jennifer Brooke	British Columbia Ministry of Health
	Heidi Butler	BC Transplant
	Wynne Chiu	University of British Columbia
	Kristi Coldwell	Transplant Research Foundation of British Columbia
	Heather Davidson	British Columbia Ministry of Health
	Parvind Grewal	BC Transplant
	Sean Keenan	BC Transplant
	Hilary Lam	BC Public Service
	Kim Savory	BC Transplant
Northwest Territories	David MacDonald	Northwest Territories Department of Health and Social Services
Nunavut	Susan Anderson	Nunavut Ministry of Health

Representative for . . .	Name	Primary organization
Pan-Canadian organizations	Catherine Butler	Canadian Blood Services
	Sylvie Charbonneau	Kidney Foundation of Canada
	Rosanne Dawson	Canadian Blood Services
	Mélanie Dieudé	Héma-Québec
	Laura Etherden	Health Canada
	Clay Gillrie	Canadian Blood Services
	David Hartell	Canadian Blood Services
	Sasha Hayse	Eastern Health
	Sandra Holdsworth	Canadian Transplant Association — Ontario Division
	Lee James	Canadian Blood Services
	Nick Lahaie	Canadian Blood Services
	Lydia Lauder	Kidney Foundation of Canada
	Margaret Miller	Health Canada
	Cindy Moriarty	Health Canada
	Clare Payne	Trillium Gift of Life Network — Ontario Health
	Roxanne Poirier	Health Canada
	Matthew Rankin	Health Canada
	Lindsay Wilson	Canadian Blood Services
Jun Wu	Public Health Agency of Canada	

Appendix B: Modified Delphi process

Figure B1 Modified Delphi process for ODT indicator selection



Background

This section summarizes the modified Delphi process that CIHI leveraged to determine the recommended ODT indicators for pan-Canadian ODT performance reporting. A modified Delphi process was used to develop consensus among experts. The indicator prioritization process was held from June 2021 to September 2022 and involved ODT stakeholders across Canada.

Environmental scan

CIHI conducted an environmental scan to determine key indicators for deceased donation, living donation, transplantation, and kidney- and heart-specific transplantation. CIHI reviewed indicators that were reported in the literature, focusing on studies that reported multiple sources and on indicators that were recognized by ODT groups within Canada and internationally. CIHI released the finalized list of indicators in the report, Pan-Canadian Organ Donation and Transplantation Data and Performance Reporting System: Indicators and Measures Short-List for Prioritization.

The list of ODT indicators underwent 2 rounds of prioritization. First, an online survey was sent to stakeholders to assess and vote on the indicators based on their importance and actionability. Second, 12 meetings were held to discuss the survey results and prioritize the health system performance indicators. A summary of the prioritization process is provided below.

Round 1: Modified Delphi survey

The survey had broad representation of the ODT stakeholder community. There were 131 respondents from the ODT community, including patients, families, donors, advocates, clinicians, researchers, and representatives from the government, pan-Canadian organizations and ODOs. The survey ratings were made individually in this round, with no interaction among participants.

First, respondents completed the part(s) of the survey based on their expertise (i.e., DD, LD, Tx). Second, for each section the respondents chose to complete, they were presented with a list of indicators. Finally, participants ranked the indicators for each section according to their importance and actionability on a scale from 1 to 9, where 1 to 3 is low, 4 to 6 is medium, and 7 to 9 is high. Respondents could also choose to skip indicators if they wished.

The ODT team divided the survey respondents into subgroups (e.g., ODOs, transplant centres) to understand the variation in responses among respondents. The team ranked the indicators by the sum of the median importance and actionability scores. If there was a tie, indicators were then ranked by median importance and then percent agreement (i.e., an indicator with or above 60% agreement) for importance. If a tie remained, indicators were then ranked by the percent agreement for actionability and median actionability. CIHI presented only the aggregated and anonymized results to stakeholders.

Round 2: Modified Delphi prioritization discussions

In the second round of prioritization, CIHI hosted 12 ODT indicator prioritization meetings on 10 topics covering living donation, deceased donation and transplantation. These meetings were attended by participants from various stakeholder groups across Canada with a range of expertise. The sessions introduced CIHI's indicator prioritization process, oriented EAF members to the indicator results from round 1 of the prioritization process and gathered recommendations from members on the subset of indicators that ODT health system performance reporting should prioritize.

During the meetings, members discussed the ODT indicators and voted on whether CIHI should prioritize them for health system performance reporting. The final list of indicators was based on the voting results from the indicator prioritization process (i.e., 50% of participants or more voted that the indicator should be prioritized) and data feasibility.

Organ-specific transplantation discussion

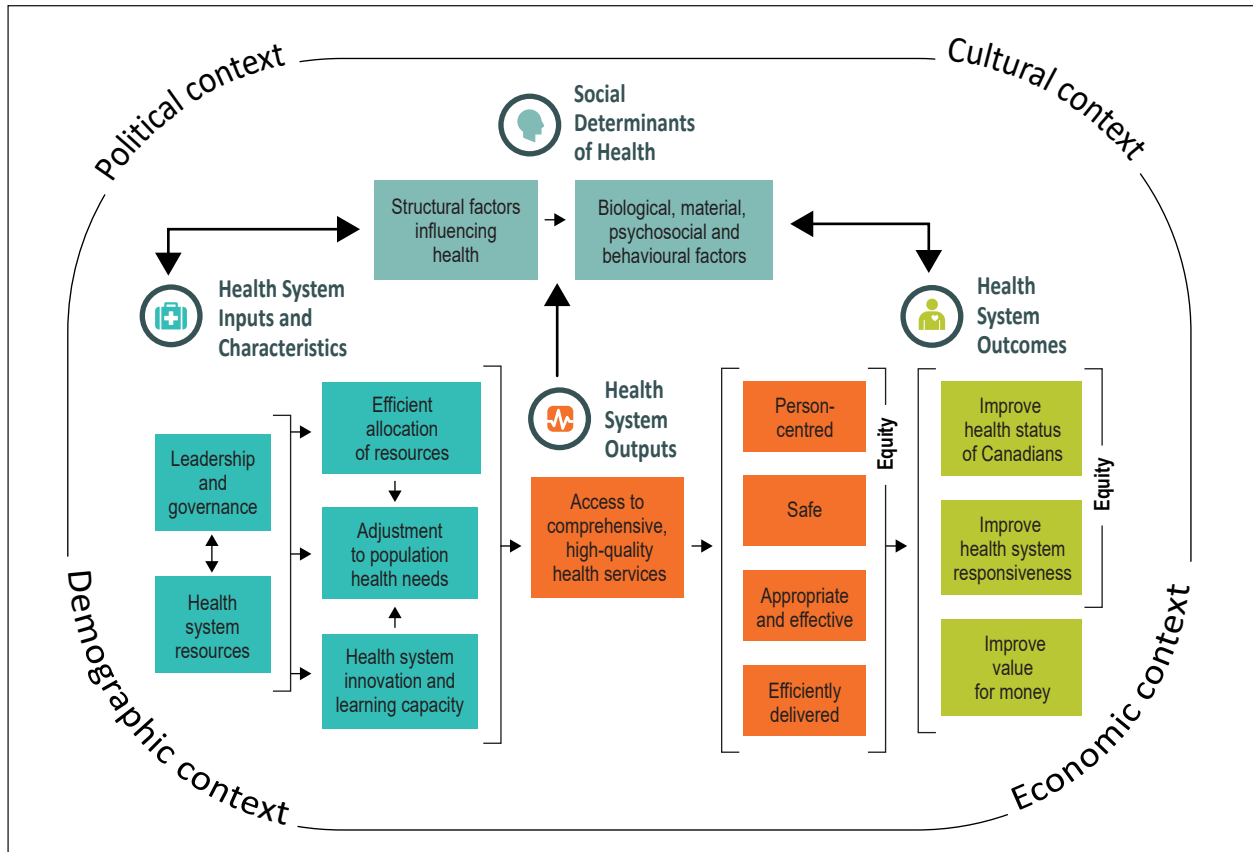
During the environmental scan for ODT indicators, there were not enough organ-specific indicators publicly reported for pancreas, liver, intestine and lung to be suitable for assessment through the modified Delphi process. Therefore, the proposed organ-specific transplantation indicators were developed by CIHI in collaboration with TGLN TPEC groups. During this collaboration, TLGN TPEC indicators were mapped to CIHI's ODT general transplantation indicators, and additional unique organ-specific indicators were identified. CIHI then presented a list of organ-specific transplantation indicators to the stakeholders during the prioritization discussion in round 2 for voting and feedback.

Conclusion

CIHI used the modified Delphi process to prioritize 78 ODT indicators for pan-Canadian ODT performance reporting. Moving forward, CIHI will develop the prioritized indicators based on feasibility and methodological complexity.

Appendix C: CIHI's Health System Performance Measurement Framework

Figure C1 CIHI's Health System Performance Measurement Framework



Appendix D: Other considered indicators

From October 2021 to September 2022, EAF members across the relevant specialties were asked to review and discuss the proposed indicators. After each discussion, members provided their recommendation for or against the inclusion of the indicator in future ODT performance reporting.

The following indicators were also considered for inclusion in ODT performance reporting but did not achieve broad consensus among EAF members. While these indicators have not been prioritized for further development, CIHI may revisit them in the future.

Deceased donation (DD)

Indicator name	Indicator description
Donation Specialist Availability	The number of donation specialists (e.g., coordinators, physicians) per million population
Organ Recovery Rate per Donor	The average number of recovered organs per donor who had at least one organ recovered
Time From Withdrawal of Life-Sustaining Treatment to Organ Recovery	The distribution of time between the withdrawal of life-sustaining treatment and organ recovery, for DCD donors who had at least one organ recovered
Increased-Risk Donors	The percentage of donors who had at least one organ recovered who are considered increased-risk donors (e.g., donors with human immunodeficiency virus [HIV+], donors with hepatitis B virus [HBV+], donors with hepatitis C virus [HCV+], donors with certain lifestyle behaviours that carry increased risk of transmission of infectious disease to transplant recipients)
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
Time Between Referral and Approach	The distribution of time between referral to approach by an ODO
Time From Consent to Withdrawal of Life-Sustaining Treatment	The distribution of time between consent and withdrawal of life-sustaining treatment for DCD donors
Time From NDD to Organ Recovery	The distribution of time between neurologically determined death (NDD) and organ recovery, for NDD donors who had at least one organ recovered
Potential Donor Rate	The number of potential donors per million population (e.g., estimated from existing CIHI clinical administrative hospital databases). Proxy for true potential donor rate where donor audits are unavailable
Donor/Organ Discard Rate	The percentage of referred potential donors registered to be organ donors
Combined Living and Deceased Donor Rate	The number of living and deceased donors who had at least one organ recovered per million population

Living donation (LD)

Indicator name	Indicator description
Complication Rate	The cumulative risk of complications (definition TBD) in a given time frame
Cost of Hospital Stay	The cost of the hospitalization for living donation
Combined Living and Deceased Donor Rate	The number of living and deceased donors who had at least one organ recovered per million population
Donation Specialist Availability	The number of donation specialists (e.g., coordinators, physicians) per million population

Transplantation (Tx)

Indicator name*	Indicator description
Time Between Patient Evaluation (Assessment) and Determination of Suitability	The number of days between patient evaluation and determination of suitability for transplant
Percentage of Referrals With Consultation Performed	The percentage of transplant candidate referrals where the consultation was performed
Transplant Rate at Given Wait-List Time Point	The cumulative probability of transplant by certain amount of time on the wait-list (time points TBD)
Cost of Hospital Stay	The cost of the hospitalization for transplantation
Complication Rate	The cumulative risk of complication (definition TBD) for a certain time frame after transplant
Renal Dysfunction Rate	The cumulative rate of stage 3 or more severe kidney disease after transplantation, at various time frames (e.g., 1 year, 5 years, 10 years)
Percentage With Appropriate Screening and Surveillance	The percentage of patients with appropriate screening and surveillance (varies by organ) at 1 year, 5 years and 10 years post-transplant
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 (time point TBD)
Percentage of Consultations Accepted	The percentage of consultations where the patient was accepted for transplant

Note

* These indicators apply to all solid organs.

Kidney-specific transplantation

Indicator name	Indicator description
ESKD Incidence Rate	The number of incident ESKD patients who began renal replacement therapy per million population
Population Prevalence of Diabetes	The proportion of the population with diabetes at a given time point

Heart-specific transplantation

Indicator name	Indicator description
Percentage Prescribed Statin	The percentage of transplant patients who have been prescribed a statin at discharge from transplant hospitalization
MCS Time	For those patients requiring short-term MCS following transplantation, the number of days spent on MCS
Percentage Undersized Heart	The proportion of transplanted patients with an undersized donor heart
Percentage High-Risk	The percentage of cardiac transplant patients who are considered high-risk (definitions TBD)
Percentage Bicaval Anastomosis	The percentage of transplantations where a bicaval anastomosis was used

Pancreas-specific transplantation

Indicator name	Indicator description
Anastomosis Type	Statistics on the type of anastomosis used for pancreas transplantation

Liver-specific transplantation

Indicator name	Indicator description
MELD Score Documentation Rate	Percentage of transplant evaluations with at least one documented Model for End-Stage Liver Disease (MELD) score in a clinical note by a hepatologist

Intestine-specific transplantation

Indicator name	Indicator description
Primary Non-Function	The percentage of patients whose transplant does not initially work, leading either to the need for re-transplantation or to death
Time for Central Line Removal	The distribution of time between intestine transplantation and central line removal
Time to Ileostomy Closure	The distribution of time between intestine transplantation and ileostomy closure

Appendix E: Acronyms

CAV	cardiac allograft vasculopathy
CIHI	Canadian Institute for Health Information
CLAD	chronic lung allograft dysfunction
CMV	cytomegalovirus
DCD	donation after circulatory death
DD	deceased donation
EBV	Epstein–Barr virus
ECLS	extracorporeal life support
ESKD	end-stage kidney disease
FEV	forced expiratory volume
FVC	forced vital capacity
ISHLT	International Society of Heart and Lung Transplantation
LD	living donation
MCS	mechanical circulatory support
mTORi	mammalian target of rapamycin inhibitors
NDD	neurologically determined death
ODO	organ donation organization
ODT	organ donation and transplantation
ODTC	Organ Donation and Transplantation Collaborative
PREMs	patient-reported experience measures
PROMs	patient-reported outcome measures
TPEC	Transplant Performance Measurement and Evaluation Executive Committee (led by TGLN)
Tx	transplantation

Appendix F: Text alternative for figures

Figure 1 Indicator development cycle

Indicators are developed in 4 stages at CIHI. This diagram represents the stages of the indicator development cycle after an information need or knowledge gap has been identified.

In stage 1, an idea undergoes initial investigations and scoping, including literature reviews, environmental scans and consultations with experts and potential users to clarify what needs to be measured, why and how often.

In the second stage, indicator methodology is developed and iteratively refined based on input from experts and in-depth analyses, including data quality assessments. This stage is essential to develop reliable and comparable indicators that support sound decision-making.

In the third stage, results are prepared. Standard and repeatable approaches to calculations are developed, and specific checks are completed to ensure the accuracy of results.

In the final stage, indicator results are released according to agreed-upon specifications.

After an indicator has been released, CIHI continues the indicator development cycle by returning to stage 1 and evaluating the indicator. Indicators are evaluated on a regular basis to determine what we should keep reporting, what we should re-develop and what we should retire.

Figure 2 Stages of ODT indicator selection and development for performance reporting

The main stages are environmental scan, indicator short-list, indicator prioritization, indicator development and indicator reporting.

Figure 3 Recommended deceased donation indicators for prioritization, by workflow phase

The prioritized deceased donation indicators are listed by the major workflow phases in the deceased donation pathway.

The first phase of the pathway is referral. The indicators for this phase are People With Registered Intent per Million Population and Missed Referral Rate.

The second phase of the pathway is consent. The indicators for this phase are Consent Rate, Approach Rate and Family Overturn Rate.

The third phase of the pathway is organ recovery. The indicators for this phase are Percentage of Offered Organs Accepted, Time From Consent to Organ Recovery, Percentage of Donors With a Recovered Organ and Deceased Donors per Million Population.

The last phase of the pathway is organ utilization. The indicators for this phase are Conversion Rate, Organ Discard Rate, Organs Transplanted per Utilized Donor and Cold Ischemia Time.

Figure 4 Recommended living donation indicators for prioritization, by workflow phase

The prioritized living donation indicators are listed by the major workflow phases in the living donation pathway.

The first phase of the pathway is donor referral. The indicator for this phase is Time From Registration to Determination of Suitability.

The second phase of the pathway is donor management. The indicator for this phase is Percentage of Individuals Registered as a Potential Living Donor Who Donated.

The third phase of the pathway is organ recovery. The indicators for this phase are Cold Ischemia Time, Living Donor Rate, Serious Safety Event Rate, Percentage of Paired Donation Transplants Proceeding, Time to Surgery, In-Hospital Mortality Rate and Length of Stay.

The last phase of the pathway is donor follow-up. The indicators for this phase are 30-Day Readmission Rate, Percentage of Living Kidney Donors Who Develop ESKD, Percentage Not Meeting Clinical Guidelines and Living Donors With Long-Term Follow-Up Plan.

Note

Additional indicators that were recommended for prioritization include Patient-Reported Experience of Medical Care and Donation Process and Patient-Reported Outcomes (e.g., Health-Related Quality of Life). These indicators cover multiple phases.

Figure 5 Recommended general transplantation indicators for prioritization, by workflow phase

The prioritized transplantation indicators are listed by the major workflow phases in the transplantation pathway.

The first phase of the pathway is pre-referral, and the second phase of the pathway is transplant evaluation. There were no indicators recommended for prioritization for these phases.

The third phase of the pathway is wait-listing. The indicators for this phase are Time From Listing to Transplant, Wait-List Mortality Rate, Wait-List Volume, Time Between Referral and Assessment and Wait-Listed Patients per Million Population.

The fourth phase of the pathway is recipient/donor matching. There were no indicators recommended for prioritization for this phase.

The fifth phase of the pathway is transplant surgery. The indicators for this phase are In-Hospital Mortality Rate, Transplant Rate, Primary Graft Dysfunction Rate, Length of Stay, Surgical Complication Rate and Warm Ischemia Time.

The final phase of the pathway is post-transplant follow-up. The indicators for this phase are Patient Survival, Graft Survival, Rejection Rate, Post-Transplant Cancer Rate, Cumulative Incidence of Post-Transplant Dialysis, Viral Infection or Reactivation Rate, Readmission Rate and Percentage With New-Onset Diabetes.

Note

Additional indicators that were recommended for prioritization include Patient-Reported Experience of Medical Care and Donation Process and Patient-Reported Outcomes (e.g., Health-Related Quality of Life). These indicators cover multiple phases.

Figure 6 Recommended kidney-specific transplantation indicators for prioritization, by workflow phase

The prioritized kidney-specific transplantation indicators are listed by the major workflow phases in the transplantation pathway.

The first phase of the pathway is pre-referral. The indicators for this phase are Percentage of ESKD Patients Referred, Time Between Dialysis Start and Transplant Referral, Percentage of ESKD Patients Who Have a Documented Discussion About Their Consideration for Transplantation, Percentage of ESKD Patients Who Have Specifically Discussed Living Donor Transplantation, and Percentage of Referred ESKD Patients Accepted for Transplantation.

The second phase of the pathway is wait-list. There were no kidney-specific indicators recommended for prioritization for this phase.

The third phase of the pathway is work-up. The indicator prioritized for this phase is Percentage of Referred ESKD Patients Accepted for Transplantation.

The fourth phase of the pathway is transplant surgery. The indicators for this phase are Percentage of ESKD Patients Receiving a Transplant, Delayed Graft Function and Pre-Emptive Transplant Rate.

The last phase of the pathway is post-transplant follow-up. There were no kidney-specific indicators recommended for prioritization for this phase.

Note

While the indicators listed above are specific to kidney transplantation, indicators in the general transplantation (Tx) section are generally applicable to all solid organs including kidney.

Figure 7 Recommended heart-specific transplantation indicators for prioritization, by workflow phase

The prioritized heart-specific transplantation indicators are listed by the major workflow phases in the transplantation pathway.

The first phase of the pathway is pre-referral. There are no heart-specific indicators recommended for prioritization for this phase.

The second phase of the pathway is wait-list. The indicator for this phase is the Percentage With MCS at Listing.

The third phase of the pathway is work-up. There are no heart-specific indicators recommended for prioritization for this phase.

The fourth phase of the pathway is transplant surgery. The indicators for this phase are Percentage With MCS at Transplant and MCS Separation.

The last phase of the pathway is post-transplant follow-up. The indicators for this phase are One-Year Allograft Vasculopathy Rate, One-Year CAV Surveillance, One-Year Statin Use and mTORi Use for Patients With CAV.

Note

While the indicators listed above are specific to heart transplantation, indicators in the general transplantation (Tx) section are generally applicable to all solid organs including heart.

Figure 8 Recommended pancreas-specific transplantation indicators for prioritization, by workflow phase

The prioritized pancreas-specific transplantation indicators are listed by the major workflow phases in the transplantation pathway.

The first phase is pre-referral, and the second phase of the pathway is wait-list. There are no pancreas-specific indicators recommended for prioritization for these phases.

The third phase of the pathway is work-up. The indicator recommended for this phase is Recipient Is a Type 1 or Type 2 Diabetic.

The fourth phase of the pathway is transplant surgery. There are no pancreas-specific indicators recommended for prioritization for this phase.

The last phase of the pathway is post-transplant follow-up. The indicators for this phase are Graft Function and Pancreas Thrombosis Rate.

Note

While the indicators listed above are specific to pancreas transplantation, indicators in the general transplantation (Tx) section are generally applicable to all solid organs including pancreas.

Figure 9 Recommended liver-specific transplantation indicators for prioritization, by workflow phase

The prioritized liver-specific transplantation indicators are listed by the major workflow phases in the transplantation pathway.

Phases 1 to 4 of the pathway are pre-referral, wait-list, work-up and transplant surgery. There are no liver-specific indicators recommended for prioritization for these phases.

The last phase of the pathway is post-transplant follow-up. The indicators for this phase are Hepatic Artery Thrombosis Rate and Primary Non-Function.

Note

While the indicators listed above are specific to liver transplantation, indicators in the general transplantation (Tx) section are generally applicable to all solid organs including liver.

Figure 10 Recommended intestine-specific transplantation indicators for prioritization, by workflow phase

The prioritized intestine-specific transplantation indicators are listed by the major workflow phases in the transplantation pathway.

Phases 1 to 4 of the pathway are pre-referral, wait-list, work-up and transplant surgery. There are no intestine-specific indicators recommended for prioritization for these phases.

The last phase of the pathway is post-transplant follow-up. The indicator for this phase is Time to Discontinuation of Total Parenteral Nutrition (TPN).

Note

While the indicators listed above are specific to intestine transplantation, indicators in the general transplantation (Tx) section are generally applicable to all solid organs including intestine.

Figure 11 Recommended lung-specific transplantation indicators for prioritization, by workflow phase

The prioritized lung-specific transplantation indicators are listed by the major workflow phases in the transplantation pathway.

Phases 1 to 3 of the pathway are pre-referral, wait-list and work-up. There are no lung-specific indicators recommended for prioritization for these phases.

The fourth phase of the pathway is transplant surgery. The indicator recommended for this phase is Bridge to Transplant With ECLS.

The last phase of the pathway is post-transplant follow-up. The indicators for this phase are Post-Operative Functional Status, Best Achieved Lung Function in First Year, Chronic Lung Allograft Dysfunction Rate, and Post-Operative ECLS Use.

Note

While the indicators listed above are specific to lung transplantation, indicators in the general transplantation (Tx) section are generally applicable to all solid organs including lung.

Figure B1 Modified Delphi process for ODT indicator selection

This diagram represents the main stages of the modified Delphi process. Round 1 of the process involved sending a survey sent to 376 ODT stakeholders. There were 131 respondents from the ODT community. The indicators were ranked by respondents based on importance and actionability. The results of these rankings were then statistically analyzed and assessed overall by stakeholder groups.

Round 2 of the modified Delphi process consisted of a series of prioritization sessions. There were 12 prioritization sessions held with EAF members, which covered 10 ODT topics. In these sessions, the summary of the survey results was reviewed and discussed by members to build consensus on the prioritization of indicators for health system performance reporting.

As a result of this process, 78 indicators were recommended for prioritization.

Figure C1 CIHI's Health System Performance Measurement Framework

CIHI's Health System Performance Management Framework consists of 4 quadrants: Health System Outcomes, Social Determinants of Health, Health System Outputs, and Health System Inputs and Characteristics. These quadrants are linked together to form a dynamic framework in an expected causal chain. Here is an overview of the quadrants, followed by examples of measures for each of the Health System Output dimensions. The examples were found during the environmental scan.

The first quadrant, Health System Outcomes, consists of 3 dimensions: Improve health status of Canadians, Improve health responsiveness and Improve value for money. The first 2 of these dimensions encompass equity to reflect the overarching goal of equitable distribution. Quadrant 3, Health System Outputs, has 1 dimension (Access to comprehensive, high-quality health services) with 4 quality attributes of the health services delivered (attributes are Person-centred, Safe, Appropriate and effective, and Efficiently delivered), and these impact the 3 dimensions in Quadrant 1. Quadrant 1 and Quadrant 2 (Social Determinants of Health) influence each other.

The second quadrant, Social Determinants of Health, consists of 2 dimensions: Structural factors influencing health, and Biological, material, psychosocial and behavioural factors. The first dimension influences the second dimension. Quadrants 1 and 2 influence each other. Quadrant 4 (Health System Inputs and Characteristics) and Quadrant 2 also influence each other. Quadrant 2 is also influenced by Quadrant 3 (Health System Outputs).

The third quadrant, Health System Outputs, consists of 1 dimension, Access to comprehensive, high-quality health services, and 4 quality attributes: Person-centred, Safe, Appropriate and effective, and Efficiently delivered. These quality attribute dimensions also encompass equity. Access to comprehensive high-quality health services is influenced jointly by the dimensions in the fourth quadrant: Efficient allocation of resources, Adjustment to population health needs, and Health system innovation and learning capacity. Quadrant 3 influences Quadrant 2.

The fourth quadrant, Health System Inputs and Characteristics, consists of 5 dimensions: Leadership and governance, Health system resources, Efficient allocation of resources, Adjustment to population health needs, and Health system innovation and learning capacity. This quadrant comprises 2 foundational dimensions that influence the capacity of the system to improve: Leadership and governance, and Health system resources. These foundational dimensions influence one another as well as the other inputs and characteristic dimensions in this quadrant. The dimensions Efficient allocation of resources, Adjustment to population health needs, and Health system innovation and learning capacity influence each other. Quadrants 4 and 2 influence each other.

4 contextual elements — Cultural context, Economic context, Demographic context and Political context — surround the quadrants in the framework.

References

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