Measuring Quality in Kidney Transplantation: Canadian Consensus Workshop

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Toronto, Ontario, Canada

The Ottawa Hospital
L'Hôpital d'Ottawa

Canadian Blood Services
BLOOD
PLASMA
STEM CELLS
ORGANS
& TISSUES

The Canadian
DONATION and
TRANSPLANTATION
Research Program

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INTRODUCTION

Canada requires more than the traditional one-year survival indicator for measuring quality in kidney transplantation. Potential additional quality indicators include domains of: accessibility, effectiveness, safety, patient-centred care, equity and efficiency.[1] Existing data gaps include sharing of data, reporting of centre-specific data to patients or the public, information on living donors after they donate, and what transplant groups do/could do with this information. Although Canada has multiple standards dedicated to quality measurement in transplantation and living kidney donation,[2] there are no specific requirements for what indicators to collect, how to define the indicators, how to collect the data or how to establish benchmarks. While countries like the United States and Germany may offer examples of measurement with formal and mandatory reporting structures, they come with inherent challenges, including that data used for regulatory purposes has the potential to lead to risk avoidance, limitations on data regarding access to transplant and or population. [3,4]

Through a collaborative initiative between the Ottawa Hospital Research Institute (OHRI), Canadian Blood Services (CBS) and the Canadian Donation and Transplantation Research Program (CDTRP), *The Measuring Quality in Kidney Transplantation* workshop was held in November 2019. Over 80 participants from various stakeholder groups (Appendix 1) were brought together to: (i) develop a pan-Canadian consensus on quality indicators for kidney transplantation and living kidney donation in Canada, and (ii) eventually contribute to quality standards for both these areas. The scope of this process was defined by the patient’s clinical journey (e.g. from wait-listing to long-term post-transplant follow-up care).

Specific workshop objectives included the gathering of professional and patient-level input on important items to measure with respect to kidney transplantation and living kidney donation quality; determination of the best ways to collect data and who should collect it; and the initiation of an implementation plan. Details of the expected outputs and outcomes of each objective are included in Table 1. Of note, the results of this workshop were intended as the basis for a new system at national and local levels, not as an add-on to what currently exists.

Table 1: Conference Focus – Objectives, Outputs and Outcomes

Objective	**Output**	**Outcome**
Gather professional and patient-level input	A precise set of agreed-upon quality indicators segmented by domains of care (e.g. accessible, safe, effective etc.) and based on a clinical timeline (e.g., pre-transplant, transplant, post-transplant) - i.e., a quality standard for both kidney transplantation and living kidney donation.	Patients and their families know what to ask for regarding their care; clinicians and organizations have a better understanding of the indicators for high-quality health care based on the best available evidence; a quality standard for kidney transplantation and living kidney donation is in place and monitored.
Determine the best ways to collect data and who to collect it.	A minimum data set of quality indicators, including recommendations related to efficient and effective data	Rigorous data on quality indicators is available in appropriate language and context to all stakeholders.

	collection. Regular monitoring to accommodate new developments.	
Develop an implementation plan	Initiate the development of an implementation plan at the local/provincial/pan-Canadian levels and a focus on accountability for effecting behavior change.	Enhanced care; strengthened relationships among donation/transplantation professionals in support of quality indicators and their potential impacts

METHODS/PARTICIPANTS

A Steering Committee (Appendix 2) was established to determine the process and methodology for achieving workshop objectives. Committee members agreed on the scope, objectives and outcomes to develop a pan-Canadian consensus on quality indicators for kidney transplantation and living kidney donation in Canada.

Prior to the workshop, a step-wise, evidence-based approach to develop and implement patient-centered kidney transplant/living kidney donation quality indicators to accurately measure and promote improvements in health outcomes was initiated:

Step 1: Systematic Review
Step 2: Qualitative Interviews
Step 3: Delphi Survey
Step 4: Consensus Workshop
Step 5: Pilot Study of Quality Indicators

Based on a systematic review (Step 1), 114 unique and adequately described indicators were selected.[5] Each quality indicator was linked to a quality domain (access, effectiveness, efficiency, patient-centred, safety and equitable) and period of care (referral and wait-listing, in-patient transplant surgery, short-term follow up, long-term follow up and program). The quality indicators exhibited inconsistent definitions, limited evaluation of indicators in the delivery of clinical care, a vital focus on safety and effectiveness, and very few on equity or patient-centred items, illustrating the potential benefit of a consensus workshop.

Qualitative interviews (Step 2) were conducted that included 20 patients, 17 physicians and 11 program administrators who offered perspectives on quality care.[6] Eight themes emerged from these interviews including: access to treatment, accessibility of services, program resources, communication, attitude of care providers, health outcomes, patient satisfaction and safety. Interviewees expressed the importance of timely and convenient care (quality standards and benchmarks for access to care), interpersonal interactions (patient-reported experience measures (PREM)), availability of resources (structure and process metrics) and quality of life (patient-reported outcome measures (PROM)).

Surveys considering quality indicators using the Delphi method (Step 3) were completed by health care professionals, patients and caregivers through two rounds. Participants considered quality indicators and rated them on a Likert scale to determine inclusion. Results were helpful in forecasting potential expectations of the in-person consensus workshop and to identify the importance of specific indicators to different stakeholders. The Steering Committee worked with an objective process consultant to determine the overall process, assumptions, considerations (Table 2) and agenda for the workshop (Step 4). They also participated in the workshop tasks, which required participants to review the compiled quality indicators and suggest additional indicators (Appendix 3).

Table 2: Conference Assumptions and Considerations

Core Assumptions
The effective use of appropriate quality indicators will improve kidney transplantation/living donation performance and be a benefit to Canadians and the Canadian health care system. While there is no official pan-Canadian program at this time, there is a plan and funding to support this work. The results of this process will be formative in this area.
Access to care must not be limited by geography, socioeconomic status, sex, gender identity, or race/ethnicity.
Canadians have the right to know about the measurement of kidney transplant/living donation outcomes and whether this procedure is working optimally.
Canada's transplantation system serves the entire population and aims to be inclusive and fair, based on transparency and accountability.
The focus of this workshop is on the processes/outcomes/experiences of chronic kidney disease patients potentially eligible for transplantation, kidney transplant recipients and living kidney donors.
This process focuses on adult kidney transplantation/living donation. Other organs, combined transplants and pediatric perspectives are not included but may be the focus of future workshops.
While the focus throughout this process is on implementation of the results, decision-making around funding allocation of meeting outputs and outcomes is at the discretion of local/provincial/territorial/federal governments and local health care organizations.
Key Considerations
The Canadian data landscape for kidney transplantation/living donation is evolving. It is important to map and take into consideration relationships among organizations with a commitment to quality indicators.
Debriefing the results of this workshop and the process involved may benefit the development of quality indicators for other organ groups in Canada and may contribute to related initiatives in other countries.

Workshop Process

The consensus workshop included both didactic and interactive components. The didactic components included invited speakers to set the stage for group discussions. Speakers provided a range of perspectives and contributed to educational benefit and guidance. Prior to the workshop, participants were provided with a reading list of studies.[7-11] Selected studies were discussed during the session to highlight evidence critical to the process and to ensure groups had access to evidence during their deliberations on individual quality indicators.

An objective, external facilitator with extensive experience in organ donation and transplantation designed and facilitated the overall process and workshop.

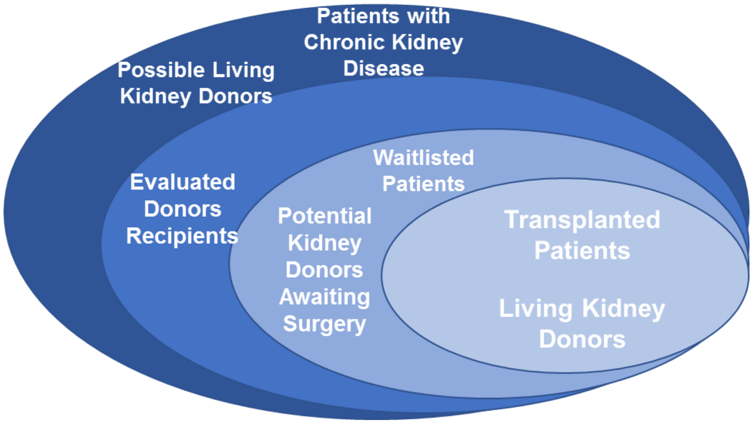
Speakers

Greg Knoll
Head, Division of Nephrology, The Ottawa Hospital

Dr. Knoll presented the Challenge Address to workshop participants including national and international background on the status of measuring quality indicators for kidney transplantation.

As part of providing direction for participants, Dr. Knoll described the patient population: transplanted patients, living kidney donors, wait-listed patients, potential kidney donors awaiting surgery, evaluated donor recipients, patients with chronic kidney disease, and possible living kidney donors (Figure 1).

Figure 1: Population of Patients Included



Based on this foundation, he offered a vision for participants in relation to the workshop aims:

- Develop a core set of quality indicators
    - Kidney Transplantation
    - Living Kidney Donation
- Determine the best way to collect quality indicator data
- Initiate the development of a Quality Implementation Plan

Dr. Knoll encouraged participants to keep this vision in mind throughout the consensus building process, and to learn from acknowledged high-performers in this area in support of the ultimate goal, i.e., to improve patient outcomes, patient experience and system performance.

Hans Vorster
Patient Partner, Can-SOLVE CKD

Mr. Vorster provided participants with a patient's perspective, focusing on chronic kidney disease and transplantation. As a patient living with chronic kidney disease for 25 years, Mr. Vorster experienced five years of home hemodialysis before receiving a deceased donor kidney transplant in March 2018. He introduced the concept of fully inclusive patient-centred care and the importance of patients as full partners in the care team. Detailing how and where patients can be included in health care decision-making, Mr. Vorster outlined the critical perspectives that patients provide and their roles as a source of important data. He emphasized the relevance of patients influencing quality measures in support of successful outcomes.

Irfan Dhalla
(Former) Vice President, Evidence Development and Standards, Health Quality Ontario
Vice President, Physician Quality, Unity Health

Dr. Dhalla discussed the importance of how the purpose of measurement should influence how it is collected. He explained the six dimensions of quality (safe, effective, patient-centred, timely, efficient, and equitable) and the purposes of measurement in health care (research, improvement, accountability). He offered a three-point framework[12] (Donabedian) for quality indicators that includes structure (what needs to be in place), process (active steps that lead to timely reassessment) and outcomes (patient health).

Dr. Dhalla cautioned participants to reflect on how reporting on indicators happens so as not to inadvertently introduce unintended barriers. He stressed that the importance of quality indicators is a focus on improvement priorities, not just the record itself. In discussing quality metrics, Dr. Dhalla presented the "Quadruple Aim" to build on Donabedian's initial framework which adds health care provider wellness to enhancing patient experience, improving population health, and reducing costs. [13]

S. Joseph Kim
Co-Director, Kidney Transplant Program, Toronto General Hospital

Dr. Kim provided participants with an update on Canadian data collection at local, provincial/territorial and national levels regarding quality measurement in kidney transplantation. He detailed what is presently available and encouraged the group to consider efficiencies and to leverage data already available. The vision for Canadian organ donation and transplantation data and reporting system is to be as aspirational as possible from a world-class data system perspective.

Dr. Kim discussed the current role of key organizations such as the Canadian Institute for Health Information, Canada Health Infoway, Canadian Blood Services, organ donation organizations, and professional societies. He indicated that a significant investment from Health Canada is supporting the development of this data-driven system for organ donation and transplantation. He suggested that a successful system requires a culture that values and implements quality improvement initiatives and applies important local considerations regarding data collection, management, and analytics.

Mr. Greg Webster, Director of Acute and Ambulatory Care at the Canadian Institute for Health Information (CIHI), expanded on Dr. Kim's presentation with a brief description as to how CIHI contributes to data collection and analysis in Canada. Mr. Webster provided detail on CIHI databases and information sources that support the work of quality improvement.

Jeremy Grimshaw
Senior Scientist, Ottawa Hospital Research Institute

Dr. Grimshaw offered an overview on strategies for achieving behaviour change based on data. He emphasized the need to ensure that data is used for improvement and to focus on using quality indicators as a stimulus to improve the care provided. Dr. Grimshaw demonstrated that all indicators are not the same, or for the same purpose through the faces of performance measurement (Figure 2).[14] Quality indicators may contribute to performance measurement research, performance improvement and accountability.

Figure 2: The three faces of performance measurement[9]

Dr. Grimshaw also discussed Brehaut's 15 suggestions for optimizing effectiveness (of implementation) from among the themes of: nature of desired action, data available, display of data/results and delivery of interventions as a guide for effective implementation.[15]

Interactive Group Work

Participants were organized into groups to support a range of perspectives in discussion and decision-making. Significant time was allotted to review preliminary kidney transplant recipient quality indicators (n=59) and offer additional or missing indicators. Each group worked through selection criteria including: relevance, measurability, data quality, actionable, feasible, evidence-based, interpretable, as well as unintended consequences to reach a group recommendation for each indicator, i.e., whether it is essential, optional, or should be excluded. The same process was used to review living kidney donation quality indicators (n=19) and to offer additional options. Results from the quality indicator review were then discussed by the full group.

Implementation issues and recommendations were discussed and developed by mixed groups focusing on (i) systems for quality indicator collection and (ii) using quality measurement to effect behaviour and system change.

SUMMARY OF WORKSHOP RESULTS

Indicator Selection

Recipient focused indicators

Participants reviewed 59 indicators and reached consensus on 33. Specifically, 24 indicators were deemed essential, 2 were rated as optional and 7 were excluded. The remaining 26 indicators – where consensus was not reached – were reviewed by the Steering Committee along with key discussion points. As a result, an additional 14 indicators were added to the essentials list resulting in a total of 38 indicators in the final set. Overall, effectiveness measures, such as patient and graft survival, remained important and were the most frequently represented domain of quality. Several quality indicators in the domains of equity, timeliness, and patient-centeredness were also deemed essential. Many of the proposed quality indicators focused on access to transplantation which has previously been identified as a crucial aspect of care by patients.[16] Both participants and the Steering Committee agreed on the importance of patients' support throughout this journey as well as their satisfaction with the process.

Living donation indicators

All groups reviewed the 19 living donation indicators. Consensus was reached for a subset of five indicators; all were rated as essential indicators. The remaining indicators and related discussion points where consensus was not reached were reviewed by the Steering Committee, whose members included an additional 11 indicators in the final set. Overall, the 16 quality indicators deemed essential for living kidney donation were well balanced across the six domains of quality

Tables 3 and 4 present recipient and living donor indicators that reached consensus.

Table 3: Recipient Focus Indicators with Consensus

Equitable	
Percentage of CKD/dialysis patients who have a documented discussion about their consideration for transplantation.	**Denominator**: total number of CKD/dialysis patients **Numerator:** number of people in the denominator who have a documented discussion about their consideration for transplantation **Points to consider for implementation**: consideration for transplantation can denote whether patient would or would not be a candidate for transplantation
Percentage of CKD/dialysis patients who have a documented discussion about the option or possibility of receiving a living donor transplant.	**Denominator**: total number of CKD/dialysis patients who have a documented discussion about their consideration for transplantation **Numerator:** number of people in the denominator who have a documented discussion about the option or possibility of receiving a living donor transplant
Percentage of CKD/dialysis patients who are referred for transplant evaluation	**Denominator:** total number of CKD/dialysis patients **Numerator:** number of people in the denominator who are referred for transplant evaluation (i.e. to determine transplantation suitability) **Points to consider for implementation:** (1) CKD program and dialysis unit will be calculated separately; (2) consider measuring by sociodemographic or disease subgroups
Percentage of CKD/dialysis patients referred for evaluation who are accepted for transplantation	**Denominator**: total number of CKD/dialysis patients who are referred for transplant evaluation **Numerator**: number of people in the denominator who are accepted for transplantation **Points to consider for implementation**: (1) separate measure can be calculated for transplant program, CKD program and dialysis unit; (2) consider measuring by sociodemographic or disease subgroups
Percentage of deceased donor kidney offers that are accepted by the transplant program	**Denominator:** total number of deceased donor kidney offers **Numerator**: number of offers in the denominator that are accepted by the transplant program **Points to consider for implementation**: (1) consider measuring percentage of refused deceased donor kidney offers that are transplanted at another transplant program; (2) Separate measure can be calculated for individual physicians as well as entire transplant program
Number of kidney transplants performed	**Calculation**: can be measured as mean, or median of the number of transplants (living and deceased donor) performed annually over a certain period (e.g. 5-years).

	Points to consider for implementation: stratify by demographic and risk factor categories (e.g. number of females transplanted, number patients >65 years transplanted etc)
Percentage of CKD/dialysis patients who receive a kidney transplant	**Denominator**: total number of CKD/dialysis patients **Numerator**: number of people in the denominator who receive a kidney transplant **Points to consider for implementation**: (1) Separate measure can be calculated for CKD program and dialysis unit; (2) Need to include pre-emptive transplants in numerator and denominator
Timely	
Number of days from when patient starts dialysis to when the transplant referral is made	**Calculation**: can be measured as mean, median, or distribution of wait times (in days) from when patient starts dialysis to when they are referred for transplant evaluation
Number of days from when the referral is made to when the patient is seen for transplant evaluation	**Calculation:** can be measured as mean, median, or distribution of wait times (in days) from when patients are referred for transplant evaluation to when they are seen by the transplant program
Number of days from when patient starts evaluation to when suitability for kidney transplantation is determined	**Calculation**: can be measured as mean, median, or distribution of wait times (in days) from when patient starts the transplant evaluation to when patient suitability for kidney transplantation is determined.
Effective	
Percentage of CKD/dialysis patients on the wait list who die before receiving a kidney transplant	**Denominator**: total number of CKD/dialysis patients on the kidney transplant wait list **Numerator**: number of people in the denominator who die before receiving a kidney transplant **Points to consider for implementation**: include patients who die while active on the wait list as well as those who die within 12-months after removal from the wait list
Percentage of CKD patients who receive a living donor kidney transplant before starting dialysis	**Denominator**: total number of CKD patients who have not started dialysis **Numerator**: number of people in the denominator who receive a living donor kidney transplant
Percentage of transplant recipients who receive a living donor kidney transplant before starting dialysis	**Denominator**: total number of transplant recipients **Numerator**: number of people in the denominator who receive a living donor transplant before starting dialysis
Percentage of patients who receive dialysis in the first week following kidney transplantation	**Denominator**: total number of kidney transplant patients **Numerator:** number of people in the denominator who receive dialysis in the first week following kidney transplantation

	Points to consider for implementation: stratification by donor (ECD or high KDPI, DCD, living)
Percentage of patients who have a complication during the first 30 days following kidney transplantation	**Denominator**: total number of kidney transplant patients **Numerator**: number of people in the denominator who have a complication during the first 30 days following kidney transplantation **Note**: a complication can be an **infection** (pneumonia, urinary tract infection, bacteremia, surgical site infection); **cardiovascular** (myocardial infarction, cardiac arrest, DVT/PE, stroke); **blood transfusion**; or need for an **unplanned operation** **Points to consider for implementation**: (1) Overall measure of 30-day complication rate as well as separate measures for infection, cardiovascular, transfusion and unplanned operation; (2) Consider incorporating NSQIP Transplant
Percentage of patients with an unplanned readmission to any hospital within 30 days of discharge after kidney transplantation	**Denominator**: total number of kidney transplant recipients discharged from hospital **Numerator**: number of people in the denominator who have an unplanned readmission to any hospital within 30 days of discharge after kidney transplantation
Percentage of patients who have a complication from Day 31 to Day 365 following kidney transplantation	**Denominator**: total number of kidney transplant patients **Numerator**: number of people in the denominator who have a complication from Day 31 to Day 365 following kidney transplantation **Note**: a complication can be an **infection** (CMV, BK, pneumonia, urinary tract infection, bacteremia, surgical site infection); or **cardiovascular** (myocardial infarction, cardiac arrest, DVT/PE, stroke) **Points to consider for implementation**: overall measure of 30-day complication rate as well as separate measures for infection and cardiovascular
Percentage of patients with an unplanned readmission to any hospital within 31 to 365 days of discharge after kidney transplantation	**Denominator**: total number of kidney transplant recipients discharged from hospital **Numerator**: number of people in the denominator who have an unplanned readmission to any hospital within 31 to 365 days of discharge after kidney transplantation
Percentage of patients who have a rejection following kidney transplantation	**Denominator:** total number of kidney transplant recipients **Numerator:** number of people in the denominator who have a rejection of their kidney transplant **Points to consider for implementation**: (1) Overall measure as well cellular and antibody-mediated rejection rate are options; (2) Time period will need to be determined – i.e. percentage rejection at 6 months, 12-months or some other time point post-transplantation

Percentage of patients diagnosed with cancer after kidney transplantation	**Denominator:** total number of kidney transplant recipients **Numerator:** number of people in the denominator who are newly diagnosed with cancer **Note:** cancers of interest would be those most associated with transplantation such as PTLD, non-melanoma skin cancer, lip cancer, melanoma, kidney cancer and ano- genital cancers. **Points to consider for implementation**: Time period will need to be determined (i.e. total number of patients transplanted over 1-year, 5-years etc) for correct calculation of incidence
Percentage of patients who are alive following kidney transplantation	**Denominator:** total number of kidney transplant recipients **Numerator:** number of people in the denominator who are alive **Points to consider for implementation**: Time period will need to be determined – i.e. percentage alive at 1-year, 5-years or some other time point post-transplantation
Percentage of patients who have a functioning kidney transplant	**Denominator**: total number of kidney transplant recipients **Numerator:** number of people in the denominator who have a functioning kidney transplant **Points to consider for implementation**: Time period will need to be determined – i.e. percentage with functioning transplant at 1-year, 5-years or some other time point post-transplantation
Percentage of non-diabetic patients screened for diabetes following kidney transplantation	**Denominator**: total number of non-diabetic kidney transplant recipients **Numerator:** number of people in the denominator who are screened for diabetes **Points to consider for implementation**: (1) KDIGO Transplant Recipient guideline recommends screening for diabetes weekly x 4, then q3month for the first year and then annually thereafter; (1) Successful screening will need to be determined – do you need to be screened eight times in the first year or is once acceptable?
Percentage of patients who are diagnosed with new onset diabetes following kidney transplantation	**Denominator**: total number of non-diabetic kidney transplant recipients **Numerator:** number of people in the denominator who are diagnosed with new onset diabetes **Points to consider for implementation**: (1) Time period will need to be determined – i.e. percentage with new onset diabetes at 1-year, 3-years or some other time point post-transplantation; (2) consider alternate denominator of number of non-diabetic kidney transplant recipients screened for diabetes
Percentage of diabetic kidney transplant recipients who meet current treatment targets for glycemic control	**Denominator:** total number of kidney transplant recipients with diabetes **Numerator:** number of people in the denominator who meet current treatment targets for glycemic control

Percentage of kidney transplant recipients who had their blood lipid profile measured at least once in the past year	**Denominator**: total number of patients who are at least 1-year post-transplant **Numerator:** number of people in the denominator who had a blood lipid profile measured **Points to consider for implementation**: KDIGO Transplant Recipient guideline recommends screening for dyslipidemia at 3 months post-transplant and then annually thereafter
Percentage of kidney transplant recipients who meet current guidelines for lipid management	**Denominator**: total number of patients who are at least 1-year post-transplant **Numerator:** number of people in the denominator who meet current guidelines for lipid management **Points to consider for implementation**: Guidelines evolving but may indicate a specific treatment target (e.g. LDL < 2.0 mmol/L) or that a treatment is given (e.g. patient on a statin)
Percentage of kidney transplant recipients who meet current guidelines for blood pressure management	**Denominator**: total number of patients who are at least 6-months post-transplant **Numerator**: number of people in the denominator who meet current guidelines for blood pressure management **Points to consider for implementation**: (1) Assumes BP is measured at each clinic visit; (2) Blood pressure guidelines evolving so exact BP target not indicated for this metric; (3) Will need to decide which BP value to use (i.e. last recorded BP, average of last 3 visits etc).
Efficient	
Number of days from admission to discharge following kidney transplantation (length of stay)	**Calculation**: can be measured as mean, median, or distribution of length of stay (in days) from time patient admitted until discharged following kidney transplantation
Safe	
Percentage of patients who die during the initial hospitalization for kidney transplantation	**Denominator**: total number of kidney transplant patients **Numerator:** number of people in the denominator who die during the initial hospitalization for kidney transplantation
Percentage of patients who experience a serious safety event during the initial hospitalization for kidney transplantation	**Denominator:** total number of kidney transplant patients **Numerator:** number of people in the denominator who have a serious safety event during the initial hospitalization for kidney transplantation **Note:** a serious safety event can be an erroneous/incompatible blood transfusion, major medication error, retained foreign body, pressure ulcer, fracture, falls

Patient-Centered	
Percentage of patients evaluated for kidney transplantation who report a high-level of satisfaction with the educational resources provided	**Denominator**: total number of patients being evaluated for kidney transplantation **Numerator:** number of people in the denominator who report a high-level of satisfaction with the educational resources provided **Note:** Educational resources (e.g. information sessions, videos, handouts) may be provided by CKD program, dialysis unit or transplant program **Points to consider for implementation**: (1) Separate measure can be calculated for transplant program, CKD program, and dialysis unit; (2) Questionnaire will need to be developed
Percentage of patients undergoing evaluation who consider themselves to have a good understanding of the kidney transplant process	**Denominator**: total number of patients evaluated for kidney transplantation **Numerator:** number of people in the denominator who consider themselves to have a good understanding of the kidney transplant process **Note**: this is a self-assessment done by the patient **Points to consider for implementation**: (1) Measure soon after evaluation process completed; (2) Questionnaire will need to be developed
Percentage of kidney transplant patients who felt they were well-informed about the procedure	**Denominator**: total number of kidney transplant patients **Numerator:** number of people in the denominator who felt they were well-informed about the procedure **Note**: this is a self-assessment done by the patient **Points to consider for implementation**: (1) Measure near the day of discharge from hospital; (2) Questionnaire will need to be developed
Percentage of patients who report a high level of satisfaction with the care received during the pre-transplant evaluation process	**Denominator**: total number of patients being evaluated for transplantation **Numerator:** number of people in the denominator who report a high level of satisfaction with the care received **Points to consider for implementation**: Questionnaire will need to be developed
Percentage of patients who report a high level of satisfaction with the care received during the transplant hospitalization	**Denominator**: total number of kidney transplant patients **Numerator:** number of people in the denominator who report a high level of satisfaction with the care received during the hospitalization **Points to consider for implementation**: Questionnaire will need to be developed
Percentage of patients who report a high level of satisfaction with the care received in the post-transplant clinic	**Denominator**: total number of kidney transplant patients discharged from hospital **Numerator:** number of people in the denominator who report a high level of satisfaction with the care received in post-transplant clinic

	Points to consider for implementation: Questionnaire will need to be developed
Percentage of patients who report excellent health-related quality of life (HRQOL) following kidney transplantation	**Denominator**: total number of kidney transplant patients discharged from hospital **Numerator:** number of people in the denominator who report excellent HRQOL **Note**: ICHOM recommends six domains of QOL be measured: general HRQOL, pain, fatigue, physical function, daily activity, and depression **Points to consider for implementation**: (1) Measurement tool(s) will need to be selected; (2) ICHOM recommends generic tools (SF-36, RAND-36, PROMIS Global Health, PROMIS-29) rather than disease-specific tools

Table 4: Living Donor Focus Indicators with Consensus

Equitable	
Percentage of individuals registered as a potential living kidney donor who are deemed suitable to donate	**Denominator:** Total number of individuals registered as a potential living donor **Numerator**: number of people in the denominator who are deemed suitable to donate **Points to consider for implementation:** (1) consider measuring percentage who are deemed suitable to donate after passing initial medical/social questionnaire; (2) do not include potential donors who withdraw from the process; (3) stratify by demographic and risk factor categories (e.g. race, female donors, donors >60 years, number with treated hypertension etc)
Number of living donor kidney transplants performed	**Calculation**: can be measured as mean, or median of the number of living transplants performed annually over a certain period (e.g. 5-years). **Points to consider for implementation:** stratify by demographic and risk factor categories (e.g. race, female donors, donors >60 years, number with treated hypertension etc)
Timeliness	
Number of days from when person registers as a potential living kidney donor to when suitability is determined	**Calculation**: can be measured as mean, median, or distribution of wait times (in days) from when the individual registers as a potential living donor to when suitability is determined **Points to consider for implementation**: consider measuring percentage who complete the evaluation within set times (e.g. 3 months, 6 months)
Number of days from when person deemed a suitable living kidney donor to donation surgery	**Calculation**: can be measured as mean, median, or distribution of wait times (in days) from when person deemed suitable living donor to donation surgery
Efficiency	
Number of days from admission to discharge following living kidney donation (length of stay)	**Calculation:** can be measured as mean, median, or distribution of length of stay (in days) from time patient admitted until discharged following living kidney donation
Safety	
Percentage of living kidney donors who develop end-stage kidney disease	**Denominator:** Total number of living kidney donors

	Numerator: number of people in the denominator who develop end-stage kidney disease defined as needing dialysis, receiving a kidney transplant or receiving conservative care
Percentage of living kidney donors who die during the initial hospitalization for donation	**Denominator**: Total number of living kidney donors **Numerator:** number of people in the denominator who die during the initial hospitalization for donation
Percentage of living kidney donors who experience a serious safety event during the initial hospitalization for donation	**Denominator:** Total number of living kidney donors **Numerator:** number of people in the denominator who have a serious safety event during the initial hospitalization for donation **Note:** a serious safety event can be an erroneous/incompatible blood transfusion, major medication error, retained foreign body, pressure ulcer, fracture, falls
Effective	
Percentage of living kidney donors who have a complication during the first 30 days following donation surgery	**Denominator**: Total number of living kidney donors **Numerator**: number of people in the denominator who have a complication during the first 30 days following donation surgery **Note**: a complication can be an **infection** (pneumonia, urinary tract infection, bacteremia, surgical site infection); **cardiovascular** (myocardial infarction, cardiac arrest, DVT/PE, stroke); **blood transfusion**; or need for an **unplanned operation** **Points to consider for implementation**: Overall measure of 30-day complication rate as well as separate measures for infection, cardiovascular, transfusion and unplanned operation.
Percentage of living kidney donors with an unplanned readmission to any hospital within 30 days of discharge after donation surgery	**Denominator**: Total number of living kidney donors discharged from hospital **Numerator**: number of people in the denominator who have an unplanned readmission to any hospital within 30 days of discharge after donation surgery
Percentage of living kidney donors with a long-term follow-up plan	**Denominator**: Total number of living kidney donors discharged from hospital **Numerator**: number of people in the denominator who have a long-term follow-up plan **Points to consider for implementation**: (1) Measure at time of early post-operative follow-up visit; (2) follow-up can be with primary care provider or living kidney donor program, as long as plan is documented
Patient-Centered	
Percentage of potential living kidney donors who report a high-	**Denominator**: total number of individuals registered as a potential living donor

level of satisfaction with the educational resources provided	**Numerator:** number of people in the denominator who report a high-level of satisfaction with the educational resources provided **Note:** Educational resources (e.g. information sessions, videos, handouts) provided by the living kidney donor team **Points to consider for implementation**: (1) Questionnaire will need to be developed; (2) consider separate measures for those who proceeded with donation vs those who did not
Percentage of potential living kidney donors who report a high level of satisfaction with the care received during the pre-donation evaluation process	**Denominator**: total number of individuals registered as a potential living donor **Numerator:** number of people in the denominator who report a high level of satisfaction with the care received **Points to consider for implementation**: (1) Questionnaire will need to be developed; (2) consider separate measures for those who proceeded with donation vs those who did not
Percentage of living kidney donors who report a high level of satisfaction with the care received during the donation hospitalization	**Denominator**: total number of living kidney donors **Numerator:** number of people in the denominator who report a high level of satisfaction with the care received during the hospitalization **Points to consider for implementation**: Questionnaire will need to be developed
Percentage of living kidney donors who report a high level of satisfaction with the care received in the post-donation clinic	**Denominator**: total number of living kidney donors **Numerator:** number of people in the denominator who report a high level of satisfaction with the care received in post-donation clinic **Points to consider for implementation**: Questionnaire will need to be developed
Percentage of living kidney donors who report excellent health-related quality of life (HRQOL) following donation	**Denominator**: total number of living kidney donors **Numerator:** number of people in the denominator who report excellent HRQOL **Note**: ICHOM recommends six domains of QOL be measured: general HRQOL, pain, fatigue, physical function, daily activity, and depression **Points to consider for implementation**: (1) Measurement tool(s) will need to be selected; (2) ICHOM recommends generic tools (SF-36, RAND-36, PROMIS Global Health, PROMIS-29) rather than disease-specific tools for CKD patients – not clear if same tools applicable to living kidney donors

Data Collection and Implementation

Systems for Quality Indicator Collection

Participants provided details as to current availability of support to implement a system for the collection of transplantation quality indicators. Most indicated that there are some basic databases available, however each of these had significant limitations including manual entry and a clinically-based approach, even though research focused. Some comments were offered on the Canadian Blood Services CTR system, and specific locations that had supportive resources.

When identifying additional supports required in programs/jurisdictions to implement a system, comments largely focused on resource requirements including staff, infrastructure, interconnection of systems, training and funding. National data standards including well-defined measures on what is to be collected, access to data and national program comparatives were mentioned frequently.

Participants offered a vision for the next two years that included clarity regarding the quality indicators to be collected and methods for collection, sharing of data between jurisdictions and national entities, as well as an inclusive approach to governance. The vision at five years expanded beyond preliminary implementation to reporting, anchored feedback mechanisms and assessments of improvements. Visions articulated for both two and five years included defined funding models.

Actions identified by participants as having the highest priority in the development of a pan-Canadian system for the collection of transplant quality indicators involved consultation on jurisdictional barriers and consensus on data sharing (i.e. public vs internal only). Process elements including reporting, feedback, technology and review were offered as important actions. Resources, education and communication were also highlighted by participants.

Using Quality Measurement to Effect Behaviour and System Change

Workshop participants listed structures and processes that need to be in place to ensure that a set of quality indicators can enable measurable improvements in patient care. Most groups indicated that engagement and education at all levels are required in tandem with appropriate resources. Participants suggested that a process for reporting, feedback and re-evaluation needs to be in place with incentives for participation. Funding mechanisms were offered by most groups as well as a requirement for understanding the benefits and potential impacts of mandatory reporting.

In order to implement a set of quality indicators, participants itemized the first steps required in their program or jurisdiction. Most suggested that resources must be in place together with a strategy and process focused on full buy-in from all involved in implementation. Some participants suggested that training must be completed for data entry and must include a comprehensive understanding of the purpose and benefits of quality indicators.

Transparency, public trust, awareness and incentives for improvement and data quality were all mentioned by participants as potential benefits of public reporting of quality indicators. Some also mentioned fundraising benefits and potentially increased organ donation due to improved awareness.

Risks of public reporting of quality indicators offered by participants included misinterpretation of data, increased risk avoidance, funding challenges, erosion of trust, and the potential curbing of innovation.

The results of these discussions have been outlined in a suggested road map in four phases, similar to what the International Consortium for Health Outcomes Measurement group has proposed (Figure 3).[8]

Figure 3: Data Collection and Implementation

Phase One

Determine Vision

- Increased Number of Transplants and Improved Health Outcomes for those Transplanted
- High Quality Data
- Quality Improvement Processes Fully Integrated into Daily Workflow
- Sharing of Best Practices and Data for Quality Improvement
    - Regional
    - National
    - International
- Transparency and Trust

Phase Two

Preparation

- Identify Clinical Champions at Each Program
- Engagement of Patients, Staff and Clinicians
- Education Regarding Clarity of Purpose and Desired Outcomes
- Understand Current Data Measurement, Additional Data Collection Needs and Barriers
- Establish Standardized, Efficient and Effective Data Acquisition Processes

Phase Three

Pilot

- Train Staff and Clinicians
- Test Data Capture on a Small Cohort of Patients
- Clinicians to Verify Data Accuracy
- Refine Set of Quality Indicators
- Establish Benchmarks
- Develop and Disseminate Quality Scorecards

Phase Four

Roll Out and Sustain Quality Improvement

- Full Rollout of Quality Indicator Measurement
- Establish Collaboratives to Share Data and Best Practices
- Communicate Findings to Relevant Stakeholders
- Monitor, Refine Indicators and Reevaluate Processes
- Selection of Appropriate Indicators for Public Reporting

DISCUSSION AND FUTURE DIRECTION

The process used to reach consensus among patients, donors, clinicians, researchers and administrators was successful in achieving the first objective: a core set of quality indicators for kidney transplantation and living kidney donation. It is important to note that the inclusive makeup of the Steering Committee was critical to the finalization of the core set of quality indicators. Consultation among Steering Committee post-workshop involved a close review of both types of quality indicators, i.e., those that reached consensus and those that did not during the workshop. Their review and discussion determined the final set of indicators.

Conference participants contributed foundational information to determine the best way to collect indicator data (second objective) and offered direction that this objective needs a collaborative and ongoing refinement process. Key elements offered by participants through the conference will contribute to the Quality Implementation Plan (third objective) with a better understanding of priorities, vision and purpose from among stakeholders.

Post meeting commitments aim to initiate actions including data collection of the agreed-upon indicators, verification of data quality and a refinement (ongoing) of the collection processes, an establishment of benchmarks for each indicator, the development of collaborative approaches including a Best Practices group and an efficient mechanism for continual feedback for all involved.

This workshop has initiated a significant change for all stakeholders involved in the measuring of quality in kidney transplantation. Change and culture management practices need to be part of implementation and communications initiatives. Conference participants should consider themselves as champions of this change and will be relied upon to contribute to sharing messaging and an understanding of where and why individuals fit into the process.

CONCLUSION

Consensus was achieved on 38 quality indicators for kidney transplant recipients and 16 quality indicators for living kidney donation. These quality indicators will form the basis for a new measurement system at national and local level.

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APPENDICES

APPENDIX 1

Participating Organizations

- British Columbia Patient Safety and Quality Council
- Canadian Blood Services
- Canadian Donation and Transplantation Research Program
- Canadian Institute for Health Information
- Chronic Kidney Disease Patients/Transplant Recipients/Living Donors and their Families
- Canadian Kidney Transplant Programs/Hospitals
  - Administrators
  - Health Professionals (e.g. physicians, surgeons, nurses, researchers)
- Canadian Patient Safety Network
- Canadian Society of Nephrology
- Canadian Society of Transplantation
- Canadian Transplant Association
- Health Quality Ontario
- Ottawa Hospital Research Institute
- Provincial Organ Donation and Transplant Organizations (i.e. Transplant Manitoba, BC Transplant, Saskatchewan Transplant Program, Trillium Gift of Life Network, Transplant Quebec)
- Public Health Agency of Canada
- The Kidney Foundation of Canada

Workshop Participants

Type	Organization	Participant
Clinicians	St Paul's Hospital (Vancouver)	• Jagbir Gill • John Gill • Mike Eng
	Vancouver General Hospital	• Olwyn Johnston • Jessie Rodrigue
	Northern Health Authority (British Columbia)	• Anurag Singh
	University of Calgary	• Ngan Lam
	University of Alberta	• Kevin Wen
	St Paul's Hospital (Saskatoon)	• Ahmed Shoker
	Health Sciences Centre Winnipeg	• Julie Ho • Leroy Storsley
	Kingston General Hospital	• Khaled Shamseddin • Thomas McGregor
	London Health Sciences Centre	• Anthony Jevnikar • Lakshman Gunaratnam • Amit Garg • Alp Sener • Sherry Szucsko-Bedard • Corinne Weernink
	The Ottawa Hospital	• Stephanie Hoar • Ann Bugeja • Greg Knoll
	St Joseph's Healthcare	• Darin Treleaven • Matthew Miller • Sarah Parfeniuk
	Toronto General Hospital	• Joseph Kim • Anand Ghanekar
	Centre Hospitalier de l'Université de Montréal	• Marie-Chantal Fortin • Catherine Girardin • Michel Pâquet

	Hôtel-Dieu de Québec	• Julie Lesage
	Hôpital Maisonneuve-Rosemont	• Caroline Lamarche
	McGill University Health Centre	• Shaifali Sandal • Jean Tchervenkov • Steven Paraskevas
	Queen Elizabeth II Health Sciences Centre	• Christine Dipchand • Amanda Vinson • Thomas Skinner
Patient Partners	Can-Solve CKD	• Hans Vorster
		• Mary Beaucage • Glynis Sharpe • Elizabeth Ingram • Todd Hauptman • Bet Tuason • Greg Wilkinson • Gord Cade • Frank Broeders • Katrina McAndrew • Linda Willis • Sherri Yazdahi • Louise Schwartz • Bob Mcrae • Freddie Marsh • Tim Slater
Organ Donation and Transplant Organizations	Transplant Manitoba	• Kim Werestiuk
	BC Transplant	• Ed Ferre
	Saskatchewan Transplant Program	• Erin Schimpf
	Trillium Gift of Life Network	• Ronnie Gavsie • Clare Payne
	Transplant Quebec	• Sylvain Lavigne
Health Quality and Safety Organizations	Canadian Patient Safety Network	• Virginia Flintoft
	British Columbia Patient Safety and Quality Council	• Benjamin Ridout

	Health Quality Ontario	• Irfan Dhalla • Shirley Chen
Data Organizations	Canadian Institute for Health Information	• Sunita Karmakar-Hore • Greg Webster
Other Organizations	Ottawa Hospital Research Institute	• Jeremy Grimshaw
	Canadian Donation and Transplantation Research Program	• Leanne Stalker • David Hartell
	Canadian Blood Services	• Christina Parsons • Amber Appleby • Kathy Yetzer • Nick Lahaie
	The Kidney Foundation of Canada	• Lydia Lauder
	Canadian Society of Nephrology	• Deborah Zimmerman
	Canadian Society of Transplantation	• Joseph Kim
	The Canadian Transplant Association	• Brenda Brown
	Public Health Agency of Canada (Surveillance and Epidemiology Division)	• Chris Archibald

APPENDIX 2

Steering Committee Members

Greg Knoll, MD, MSc, FRCPC (Chair)
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Janet Crain, BA, Principal, KTE Bridge Consultants
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Priscilla Karnabi, MSc, Ottawa Hospital Research Institute
Project Management and Research Support

Dorothy Strachan, MA, Process Consultant and Facilitator
Partner, Strachan-Tomlinson and Associates

Topic: Kidney Transplantation Quality Indicators: Recipient Focus

Table #_______ **Note-taker:** ________________________ **Facilitator**: ______________________

APPENDIX 3

Clinical Period: Referral and Waitlisting
Domain of Quality: Access (defined as the perceptions and experiences of people as to their ease in reaching health services or health facilities in terms of location, time, and ease of approach)

Indicator	Definition	Criteria	Strongly Agree	Agree	Neutral	Disagree	Strongly disagree
% kidney transplant discussion	Percentage of CKD/dialysis patients with a documented discussion in their medical chart about the possibility of kidney transplantation.	Important/Relevant?	1	2	3	4	5
		Measurable?	1	2	3	4	5
		Data Quality (accurate & valid)?	1	2	3	4	5
		Actionable?	1	2	3	4	5
		Feasible?	1	2	3	4	5
		Evidence-based?	1	2	3	4	5
		Interpretable?	1	2	3	4	5
		Are there potential unintended negative consequences if used? *If so, provide examples below*	1	2	3	4	5
		Final Recommendation A= Essential (need to have) B= Optional (nice to have) C= Exclude	A		B		C
Key discussion points, e.g., rationale for rating:							