Canadian Blood Services
Société canadienne du sang

Kidney Data Working Group Report

September 29, 2015

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Letter of Introduction

One of the strategic objectives of Canadian Blood Services is to leverage the organization's services, tools, expertise and knowledge in, support of the national effort to improve patient outcomes. In alignment with this objective is the effort undertaken by the Organ Donation and Transplantation (ODT) Data Working Groups to build on a vision, defined by the Canadian Council for Donation and Transplantation (CCDT) in collaboration with the ODT community, for an integrated information system where, *"Every Canadian who needs a transplant has equitable and timely access to safe tissues and organs, and every Canadian who wishes to donate is optimally supported so donation is compassionate, safe and efficient."* (Information Management Blueprint, CCDT April 25, 2007).

Accurate, relevant and timely data is a critical enabler of a better information management system and Canadian Blood Services is proud to work with its national and provincial partners to continue evolving the CCDT vision, a vision that was further articulated at the June 2013 ODT Data, Analytics and Reporting System Workshop. Through the contributions made by the (ODT) Data Working Groups, we are steps closer to achieving the strategic imperative for improved, fair and transparent information management. The data identified will provide clarity for listing and allocation, organ-specific criteria which will in turn inform the evolving shared programs in the Canadian Transplant Registry (CTR).

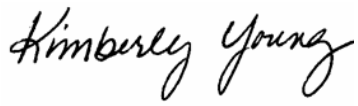
On behalf of Canadian Blood Services, we would like to thank the Kidney Data Working Group (KDWG) members for their participation. This effort represents an important step in building a national data system that will serve the needs of clinicians and researchers by facilitating clinical practice decision-making, developing standards, and informing outcomes reporting for Kidney transplantation in Canada. It builds on work done previously by the CCDT, which included forums to consult with health professionals and other stakeholders on best practices in listing and allocation of organs.

The report begins with a description of the objectives of the KDWG, including the scope, guiding principles, key considerations and the process followed by the group to arrive at a minimum data set. Chapter Seven of the report provides a summary of the recommendations and emerging issues that will be forwarded to the Kidney Transplant Advisory Committee (KTAC). Subsequent chapters, still in development, will be released in the coming months and will outline how the data identified in the minimum data set will be collected, validated, measured, accessed, and audited.

Future work involves laying the fundamental building blocks of the new data system. Using this report, and the final reports of all ODT Data Working Groups, the following initiatives will be undertaken:

- communication of the report contents with ODT Operational groups and committees
- consolidation of the minimum data sets from all data working groups
- enhancement of the CTR to include the new data
- modification of existing data feeds, the development of new feeds or the implementation of CTR links with other data repositories
- implementation of data collection projects
- creation/revision of inter-provincial organ-sharing policies
- development of a process for accessing the CTR data system for research purposes
- implementation of standard data reviews
- establishment of regular performance and audit measures

Our work has just begun. We look forward to the opportunity to continue working together in key stakeholder groups to further advance this important initiative.



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Donation and Transplantation

Kathryn Tinckam, Medical Advisor,
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September 29, 2015

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1. Acronyms

CCDT	**Canadian Council for Donation and Transplantation**
CIHI	**Canadian Institute for Health Information**
CoReTRIS	**Comprehensive Renal Transplant Research and Information System**
CORR	**Canadian Organ Replacement Register**
CNTRP	**Canadian National Transplant Research Program**
CTR	**Canadian Transplant Registry**
DAAC	**Data Analytics Advisory Committee**
DAD	**Discharge Abstract Database**
DDDWG	**Deceased Donor Data Working Group**
ISAC	**Information Strategy Advisory Committee**
KDWG	**Kidney Data Working Group**
KTAC	**Kidney Transplant Advisory Committee**
NHSBT	**National Health Services Blood and Transplant**
NKRAC	**National Kidney Registry Advisory Committee**
ODT	**Organ Donation Transplantation**
SRTR	**Scientific Registry of Transplant Recipients**
TGH	**Toronto General Hospital**

2. Background

The Kidney Data Working Group (KDWG) was convened by Canadian Blood Services in November 2013 to develop a kidney transplant data set that will facilitate clinical practice decision-making, develop standards, and inform outcomes reporting for kidney transplantation in Canada. Canadian Blood Services is responding to the vision articulated in 2007 – and revisited at the June 2013 Organ Donation and Transplantation (ODT) Data, Analytics and Reporting System Workshop – to build a world-leading data system that provides timely access to high quality ODT information for patient care, system management, transplant measurement, outcome reporting, and accountability.

The provincial and territorial governments have funded Canadian Blood Services to continue to lead the development and operation of the Canadian Transplant Registry (CTR). The national registry system includes a data warehouse with business intelligence tools that provide accurate, timely, and comprehensive data to support research, measurement, and the modeling and analytical needs of the Canadian organ donation and transplantation community.

The KDWG had the following objectives:

1. Provide expert advice on data that will support inter-provincial and national operational and clinical policies, standards of practice, and evidence-based practice with respect to kidney listing and allocation;
2. Develop a kidney transplant data set to facilitate clinical practice decision-making, develop practice standards, inform outcome reporting, and advance the science of kidney transplantation; and
3. Develop a framework for the creation and application of kidney transplant performance measures to track the quality and outcomes of care across the country.

The report recommends a national kidney data set to be incorporated in a pan-Canadian organ donation and transplantation system, and advises on the development of data, analytics, and reporting for kidney transplantation in Canada. In addition, it summarizes key considerations and activities of KDWG. The report will be presented and discussed at the Kidney Transplant Advisory Committee (KTAC), formerly known as the National Kidney Registries Advisory Committee (NKRAC), and at the Information Strategy Advisory Committee (ISAC). This will be followed by further discussions with key stakeholder groups.

3. Scope of the Data Working Group

KDWG's scope encompasses matters related to inter-provincial kidney transplant practices, including listing and allocation practices and kidney transplant outcomes in support of the CTR. To contribute to the data needs that will inform clinical decisions with respect to kidney transplantation and outcomes reporting, KDWG will:

1. Identify data points along the kidney donation, allocation, and transplantation critical path that are important to characterize and evaluate the journey of patients through the kidney transplantation process;
2. Identify the availability and gaps in current data for living and deceased kidney donors and recipients, and the comparability of data amongst kidney transplant programs;
3. Develop a minimum data set for kidney transplantation with regards to wait-listing, events after wait-listing, the kidney transplant procedure, and both short- and long-term outcomes;
4. Advise on the scope of kidney data to improve health information management, and recommend a quality control strategy to assess the quality and completeness of data submissions to the registry; and
5. Produce a report that includes a proposal for a minimum data set for kidney transplantation; the data points that should be captured along the kidney donation, allocation, and transplantation critical path; recommendations for a quality strategy; and opportunities for data collection that support innovation and scientific advancement in the field of kidney transplantation.

4. Principles

Building on the vision developed by CCDT in collaboration with the ODT community for better information management across Canada's OTDT System, Canadian Blood Services, in support of its role to lead the development and operation of the CTR and its shared programs, is committed to re-affirming the direction set for this vision, and to continuing to evolve a national information management network. This vision was further articulated at the June 2013 ODT Data, Analytics and Reporting System Workshop, at which a set of guiding principles for data was proposed that will promote accurate, timely and valid data that will move us closer to greater transparency in information management. The KDWG focused on these principles to guide it through the development of a national data set and assist it with the recommendations presented in this report. The principles are as follows:

1. Primarily, adopt the eight guiding principles for national organ transplant and donation data management as recommended by the participants of the June 2013 Data Analytics and Reporting System Workshop. The guiding principles focus on:
    a. Governance
    b. Data Scope
    c. Data Compliance
    d. Data Standardization
    e. Data Quality
    f. Data Stewardship
    g. Data Accessibility
    h. System Efficiency

In addition to the guiding principles listed above, the KDWG expanded its list of guiding principles to encompass elements specific to its scope of developing a national minimum data set for kidney transplantation:

2. Data collection will be instrumental in advancing scientific, evidence-based healthcare.

3. Data chosen for the national data set is meaningful, comparable, measurable and unambiguous, making data collection easy for data collectors.

4. The national data set will provide guidance on data definitions and interpretations where national data standardization is required. It will serve as a national minimal data platform, while provincial data sets can include additional data.

5. KDWG will ensure that the national data set lends itself to national and international benchmarking by kidney transplant programs.

5. Key Considerations

During the development of the national minimum data set, KDWG made the following considerations:

1. The changes required as a result of the recommended national data set will impact kidney transplant program data collection and reporting processes.

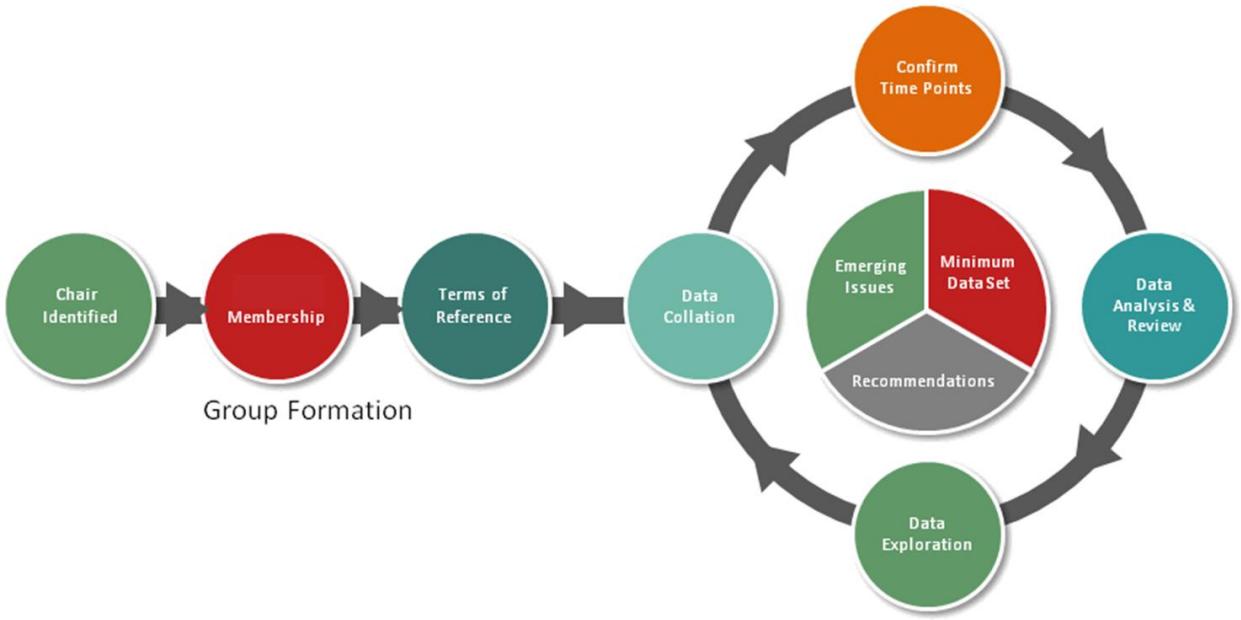
2. There is a definite financial impact to stakeholders due to the need for increased resources, infrastructure, and the development of the requirements necessary to support the recommended data collection and data linkages between systems.

3. The data set considers national practices and the data needs of all health care professionals involved on the patient critical pathway.

4. The transplant and donation community is working towards a national data, analytics, and reporting system that will benefit kidney transplantation in Canada.

6. Process

The diagram below outlines the basic process methodolgy adopted by the group.



6.1 Group Formation

The Chair of the KDWG was appointed by Canadian Blood Services and KTAC. Canadian Blood Services met with the Chair to discuss the objectives and scope of the KDWG. Once members of the KDWG were identified, an initial face-to-face meeting was convened to agree on terms of reference and the approach which KDWG would take to achieve its objectives. The KDWG informed Canadian Blood Services regarding the data sources they would analyze and review. Monthly teleconference meetings were set up in collaboration with Canadian Blood Services to discuss emerging issues, develop recommendations and gain expertise from other knowledge areas.

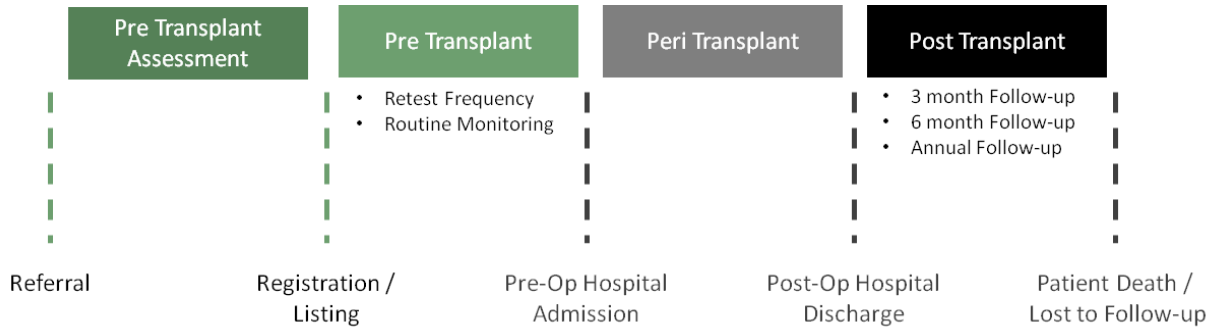
6.2 Data Collation

In order to best inform kidney transplant reporting practices, an assessment of other transplant registries from the international community was produced by Canadian Blood Services. The outcome of this assessment was an environmental scan, containing data elements captured in CTR and other transplant registries. This would provide the group with perspective on what mature registries are collecting and would help inform what elements might be missing from the CTR. Secondly, there are some organ-specific organizations that perform detailed data collection that might be facilitated by the CTR in the future, and this review process presented an excellent opportunity to capture these data needs as well. The following sources were utilized as comparators by the KDWG:

1. Canadian Organ Replacement Register (CORR) – Canada
2. Scientific Registry of Transplant Recipients (SRTR) – United States of America
3. Toronto General Hospital (TGH) data Scan of the Comprehensive Renal Transplant Research Information System (CoReTRIS) – Canada
4. National Health Services Blood and Transplant (NHSBT) Registry – Great Britain

6.3 Time Point Definition

In the interest of consistency and thoroughness, a detailed timeline was necessary in order to ensure that all major events and data were captured at the appropriate point along the patient's critical pathway. The KDWG agreed on five specific reference points and four time periods in order to inform clinical practices and improve patient care through the transplant process. The major time points/periods are as follows:



Defining these different reference points is necessary in order to gain a clear understanding of the impact on both users and data systems.

Time Point	Definition	Rationale for Collection
Referral	Time when patient is first referred to kidney transplant program	Monitors initial time point when patient becomes known to the transplant centre.
Registration / Listing	Time when patient is activated on the kidney transplant waiting list or activated for living donor transplant	Provides a snapshot of patient information at the time of wait-listing for deceased donor kidney, or at time of suitability for living donor transplant.
Pre-Transplant	From the time of registration/listing up to pre-op hospital admission	This time range results from routine monitoring and testing that may occur while the patient is waiting for a transplant.
Peri- Transplant	From pre-op admission date to post-op hospital discharge, including the transplant surgery	This time range includes all surgical detail and complications as well as early graft function and treatment details up to the time of discharge from hospital after the kidney transplant procedure.
Post-Transplant	From hospital discharge to graft failure, death, or lost to follow-up	This time range includes regular follow-up/updates at three months, six months, twelve months and annually thereafter as long as the allograft is functioning.

6.4 Data Analysis and Review

The KDWG was responsible for highlighting potential data gaps and determining what elements are required to reconcile these disparities. To accommodate the identification of data gaps, the environmental scan was organized along two axes: data category and time point (chronology). This set up provided the KDWG with a detailed understanding of what elements are currently collected in the CTR for different data categories (see Appendix B for details) at each major time point from referral through to follow-up. This framework, coupled with indicators of what other major international registries and pertinent kidney community organizations are collecting, provided the KDWG with the means to perform a detailed scan of the various data areas and bolster the data element list where needed.

The identification of data gaps, while not formally documented, is indicated in the environmental scan, where new data fields were added, modified, or expanded.

The KDWG employed an iterative review approach in order to refine the data set and ensure that all aspects of the recipient's critical path were captured with the appropriate level of detail.

As part of the analysis process, specific sub-areas of interest were assigned to individual members for further independent exploration. The results of these analyses were presented to the larger group for discussion, modification, approval, and inclusion into the final data set.

7. Recommendations

7.1 Minimum Data Set

The national kidney data set is detailed in Appendix B and contains a detailed description of the data set. It presents the data element and description grouped by the defined time points.

As part of the minimum data set, the group developed a proposal for Kidney Transplant Biopsy Data Collection, as follows:

1. Data will be collected at the transplant centre on all kidney transplant biopsies (both for surveillance and cause) in all kidney transplant recipients prospectively registered in CTR.

2. Designate at transplant centre will complete collection of all data elements in "Recipient Kidney Transplant Biopsy Data Collection Form".

3. Designate at transplant centre will scan and upload original kidney transplant biopsy report to CTR. This will allow for access to the source documents and extraction of additional data from the reports by Canadian Blood Services at a future date.

Additionally, recommendations were made for a more useful comorbidity data set. The group agreed that the Charlson Comorbidity Index would be best suited for use as the adult comorbidity data set (excluding metastatic disease). Comorbidity would be captured at time of listing, transplant and one year post-transplant. These data elements have been included in the minimum data set. It was agreed that the adult comorbidity data set is not very useful for the pediatric community, and there is no official comorbidity data for pediatrics. After some investigations, the group recommends using the data set being defined by the Canadian National Transplant Research Program's (CNTRP) Project 6 Group. This recommendation will be taken to the data advisory committee, where it will be discussed with all pediatric organ representatives.

7.2 Deceased Donor Data

The KDWG made a recommendation on deceased donor data that should be mandatory from the perspective of the kidney community. This recommendation will be taken to the Deceased Donor Data Working Group (DDDWG) and will be considered as part of the development of the deceased donor minimum data set. The recommended data is presented in Appendix C – Deceased Donor Data for Kidney Community.

7.3 Time Points

The KDWG identified several key time points along a patient's critical path, and recommended that certain elements be collected at predetermined points along this timeline (See Appendix B). It is the recommendation of the KDWG that these time points and related data gathering practices be adopted nationally for kidney transplant patient data.

7.4 Quality Control Strategy

Part of the KDWG's scope was to develop a data control strategy by which the quality, completeness, and accuracy of data submissions would be assessed and measured. To help inform the group's strategy recommendations, the KDWG reviewed the outcomes of the Data, Analytics and Reporting Systems Workshop, at which the ISAC outlined a national guiding principle for data quality:

> *High data quality (accurate, reliable, complete, and timely) is paramount to achieving a trusted system from informed decision making. Data should be validated at multiple levels to ensure quality (e.g., audits, cross-validation through existing data-sets, checks when entering data, essential data quality recognized at data entry).*

Furthermore, the KDWG was presented with the Data Quality Framework, as developed by the CORR:

> *Canadian Institute for Health Information's (CIHI) Data Quality Framework (2009) sets out an approach to systematically assess, document and improve data quality for all of our data holdings. This framework is based on the five dimensions of quality and helps us identify both strengths and limitations in our data. After the assessment, we identify how to improve the data, and we provide documentation to help users determine whether the data meets their needs and, if so, how to use it appropriately.*
>
> *CIHI uses five dimensions to define data and information quality:*
>
> i. *Accuracy—How well information from a data holding reflects the reality it was designed to measure*
> ii. *Timeliness—How current the data is at the time of release*
> iii. *Comparability—The extent to which a data holding is consistent over time and collects data in a way similar to other data holdings*
> iv. *Usability—The ease with which data can be accessed and understood*
> v. *Relevance—The degree to which a data holding meets users' current and potential future needs*[1]

[1] **Source:** CIHI.ca [online], Health Care Data Quality and Information Quality, available at: http://www.cihi.ca/CIHI-ext-portal/internet/en/tabbedcontent/standards+and+data+submission/data+quality/cihi021513#_Data_Quality_Framework [Accessed 20 Aug 2013]

It is the recommendation of the KDWG that the KTAC and the ISAC endorse the CORR-CIHI Data Quality Framework as a starting philosophy for data quality management. In addition to the CORR-CIHI Data Quality Framework, other issues to be considered in the realm of data quality include:

1. Mandatory reporting to ensure compliance with data submissions and maximize data completeness
2. Data capture/management tool that is secure, efficient, user-friendly, and easily accessible (e.g., electronic data capture via the internet)
3. Explore automated/algorithmic internal data validation approaches (e.g., semantic web technologies)
4. Evaluate data linkage opportunities with CIHI's Discharge Abstract Database (DAD), national vital status registry, and other national/regional data source
5. Periodic data audits at the transplant centres

7.5 Emerging Issues

The KDWG identified several issues that they felt were important and should be brought to the attention of the ISAC as items with relevance across all organ groups which will require further discussion and development within the CTR. These emerging issues are as follows:

Emerging Issues	Comment	Recommendation
Data Burdens	Pilot study should be launched on data burdens – what are they, options/recommendations for addressing them	Take to ISAC
Adult Comorbidities	Best approach and time points to capture comorbid disease burden of transplant candidates/recipients	Take to ISAC
Pediatric Comorbidities	A broader discussion is required with other organ groups on pediatric comorbidity data	Take to ISAC
Combined organ transplantation	Need a national strategy for combined organ transplantation	Take to ISAC
Serology	Need a national strategy for a serology data set for all organs	Take to ISAC
Pregnancies	Data related to pregnancies should be consistent across all organs	Take to ISAC
Cancer	Potential for linkage to the national cancer registry	Take to ISAC
PTLD	Approach to data capture should be standardized across all organ groups	Take to ISAC
Cold Ischemia Time	Definition of ischemic times should be consistent across all organs	Take to ISAC
Referral Centre	Definition of Referral Centre should be consistent across all organ groups	Take to ISAC
Perfusion pumps	Should pump parameters be included in the data set?	Take to ISAC
Cause of death	A broader discussion is required with other organ groups	Take to ISAC

Appendix A – Kidney Data Working Group Membership

S. Joseph Kim, MD, PhD, MHS, FRCPC (Chair)	Transplant Nephrologist and Epidemiologist, Toronto General Hospital, University Health Network Assistant Professor, Department of Medicine, University of Toronto Co-Director, Kidney Transplant Program, University Health Network Toronto
John Gill, MD, MS, FRCPC	Transplant Nephrologist, St Paul's Hospital Associate Professor, Transplant Fellowship Director, Nephrology, University of British Columbia Vancouver
Martin Karpinski, MD, FRCPC	Transplant Nephrologist, Winnipeg Health Sciences Centre Assistant Professor, Internal Medicine, Faculty of Medicine, University of Manitoba Winnipeg
Kathryn Tinckam, MD, MMSc, FRCPC	Transplant Nephrologist, Toronto General Hospital, University Health Network Assistant Professor, Department of Medicine, University of Toronto Co-Director, HLA Laboratory, University Health Network Toronto
Susan Samuel, MD, MSc, FRCPC	Pediatric Nephrologist and Clinician-Scientist, Alberta Children's Hospital Assistant Professor, University of Calgary Calgary
Sean Delaney	Associate Director, Listing and Allocation Canadian Blood Services
JoAnne Lussier-True	Sr. Program Manager, Listing and Allocation Canadian Blood Services
Machi Danha	Program Manager, Listing and Allocation Canadian Blood Services
Nick Lahaie	Data Analyst, CODTN Data, Analytics & System Reporting Canadian Blood Services

Appendix B –Kidney National Data Set

The KDWG is recommending a national data set of 158 mandatory fields (70 new), 39 optional fields (14 new) and 52 calculated fields (3 new) for a total of 252 distinct data elements.

Kidney Data Working Group Data Set Recommendation Summary

	Total	● New Fields	● Modified	● No Change
All Fields	**249**	**87**	**39**	**123**
Mandatory	**158**	70	30	58
Calculated	**52**	3	5	44
Optional	**39**	14	4	21

Appendix B lists the recommended data elements being proposed by the KDWG, grouped for the critical path time points outlined in the Process section of this document:

1. Referral (R)
2. Registration / Listing (L)
3. Pre-Transplant (PR)
4. Peri-transplant (PE)
5. Post-transplant (PO)

Beside each element is a letter (M, O or C). These letters indicate whether KDWG is proposing the element as Mandatory (M), Optional (O) or Calculated (C). Where necessary a brief description of the element is included below the element name in italics. Each element is listed with a colour indicator. These indicators help demonstrate potential resource impact, both from system design and maintenance perspective as well as a data collection requirement.

● indicates existing mandatory, optional or calculated data elements that will require no change to system function or data collection requirements.

● indicates existing mandatory, optional or calculated data elements that will require some change to system function or data collection requirements. Typically these indicate fields that have shifted from optional collection to mandatory collection. Though they will have minor impact on system design, the majority of the impact will be on the data collection resources required to collect this data.

● indicates new mandatory, optional or calculated elements that will have both system design impact as well as data collection implications.

Name	Description	Values	Data Rules	R	L	PR	PE	PO
Registration								
Transplant Referral Information								
Date of Transplant Referral		Date	≤ current date	M				
Was the patient on chronic dialysis at the time of transplant referral?		Yes No	If yes then date of initial dialysis treatment for ESRD required. If no then most recent serum creatinine level required.	M				
Date of initial dialysis treatment for ESRD		Date	≤ current date	M				
Transplant Consultation Information								
Was patient seen by a transplant nephrologist/surgeon?		Yes No	If yes then date of first visit with transplant nephrologist/surgeon required.	M				
Date of first visit with transplant nephrologist/surgeon		Date	≤ current date	M				
Patient died before wait-listing or final disposition		Yes No	n/a	M				
Date of final disposition regarding wait list activation		Date	≤ current date	M				
Was the patient on chronic dialysis at the time of final disposition?		Yes No	If yes then date of initial dialysis treatment required (if not already entered). If no then most recent serum creatinine level required.	M				
Decision regarding final disposition		Activate to deceased donor waiting list Do not activate to deceased donor waiting list	Single selection list. If activate is selected then specify type (s) of deceased donor waiting lists and specify main reason (s).	M				

Name	Description	Values	Data Rules	R	L	PR	PE	PO
Type of deceased donor waiting list		Standard deceased donor waiting list Expanded criteria deceased (or similar) waiting list Hepatitis C deceased donor waiting list National highly sensitized deceased donor waiting list Kidney-pancreas deceased donor waiting list	Multiple selection list	M				
Main reason for activation to deceased donor waiting list		Patient does not have an identified living donor Patient had a living donor-donor declined for medical or other reason Patient had a living donor but cross-match positive Patient had a living donor-ABO incompatible	Multiple selection list	M				
Main reason for non-activation to deceased donor waiting list		Patient has compatible living donor Patient has incompatible living donor – planned for desensitization and/ or paired exchange High-risk cardiovascular disease Recent/metastatic malignancy Active/untreated infection Unstable/untreated psychiatric illness Current drug abuse Poor life expectancy History of poor medical adherence Patient left for another program Patient left country Patient declined Other reason – please specify	Multiple selection list	M				

	Name	Description	Values	Data Rules	R	L	PR	PE	PO
Identifying Information									
●	Date of Birth	Date of birth of patient.	Date	≤ current date	M	M			
●	First Name	First name of patient.	Name	≤ 50 characters	M	M			
●	Middle Name	Middle name of patient.	Name	≤ 50 characters	O	O			
●	Last Name	Last name of patient.	Name	≤ 50 characters	M	M			
●	Former Last Name	Former last name of patient.	Name	≤ 50 characters	O	O			
●	Local Recipient ID	Unique local identifier provided by local Transplant Program.	Identifier	≤ 50 characters	O	O			
●	National Recipient ID	Unique national identifier created by the Canadian Transplant Registry.	Identifier	n/a	C	C	C	C	C
●	PHN	Provincial health number of patient.	Identifier	≤ 50 characters If patient has a PHN then PHN and PHN Province are required.	M	M			
●	PHN/Home/Listing Province	Province associated to PHN or Home or Listing province of patient.	Alberta British Columbia Manitoba New Brunswick, Newfoundland & Labrador Northwest Territories Nova Scotia Nunavut Ontario Prince Edward Island Quebec, Saskatchewan Yukon	If patient has a PHN then PHN and PHN province are required. If patient does not have a PHN then another government health identifier and Home province are required. If patient's home is out of country then Listing province is required.	M	M			

Name	Description	Values	Data Rules	R	L	PR	PE	PO
Contact Information								
Contact Relationship	Contact's relationship to patient.	Spouse Relative Friend	Single selection list		O			
Address	Address where patient can be contacted by Transplant Program This could be a temporary address.	Address line 1 and 2	≤ 70 characters		O			
City	City associated to patient's address where they can be contacted.	City	≤ 70 characters	M	M			
Email	Email address used to contact patient.	Text	≤ 50 characters		O			
Postal Code	Postal code associated to patient's address where they can be contacted.	Postal code	Format must be X9X 9X9	M	M			
Province	Province associated to patient's address where they can be contacted.	Alberta British Columbia Manitoba New Brunswick, Newfoundland & Labrador Northwest Territories Nova Scotia Nunavut Ontario Prince Edward Island Quebec, Saskatchewan Yukon Not Applicable	Single selection list	M	M			
Telephone-Home	Telephone-Home used to contact patient.	Phone number	Format must be masked		O			
Telephone-Mobile	Telephone-Mobile used to contact patient.	Phone number	Format must be masked		O			
Telephone-Work	Telephone-Work used to contact patient.	Phone number	Format must be masked		O			

Name	Description	Values	Data Rules	R	L	PR	PE	PO
Demographics								
Body Metrics								
Age	Age of patient.	Age in years, months, weeks	Calculated by the system based on Date of Birth.	C	C			
Sex	Biological sex of patient.	Male Female Other	Single selection list	M	M			
Height	Height of patient.	cm	If in-utero=no then this field must be 0.0 to 300.0. Else if in-utero=yes then this field is not required to be entered (it may be null).		M	M	M	M
Weight	Weight of patient.	kg	If in-utero=no then this field must be 0.0 to 700.0. Else if in-utero=yes then this field is not required to be entered (it may be null).		M	M	M	M
BMI	Body mass index of patient.	Numeric	BMI = weight(kg)/ (height(m) * height(m))		C	C	C	C
Growth Hormone Used	Flag indicating if growth hormone was used.	Yes No	Pediatric patient only. Collect data pre-transplant, 6 months post-transplant and then yearly follow-up.		M	M		M
ABO	Blood group of patient.	A B AB O unknown	Initially ABO may be unknown.		M			
Confirm ABO	Confirm blood group of patient.	Free text entry	≤ 4 characters		M			
RH	RH of patient.	+ -	Single selection list		M			
Confirm RH	Confirm RH of patient.	Free text entry	≤ 4 characters		O			

Name	Description	Values	Data Rules	R	L	PR	PE	PO
In-utero	Flag indicating if patient is not yet born.	Yes No	n/a		O			
Social Details								
Citizenship	Citizenship of patient.	List of countries	Multiple selection list		M		M	
Immigration Status	Immigration status of patient.	Citizen Permanent Resident Study Visa Work Visa Visitor Visa	Single selection list		M		M	
Country of Residence	Country of Residence of patient.	List of countries	Single selection list		M			
Ethnicity	Ethnicity of patient.	Aboriginal Black Caucasian Indian subcontinent Latin American Middle Eastern/Arabian Pacific Islander Other/Multicultural Unknown	Single selection list	M	M			
Highest Educational Level	Highest educational level of primary care giver and patient.	None Grade 1-6 Grade 7-12 High School Diploma University Undergraduate Degree University Graduate Degree Community College or Vocational Program	Single selection list		O			
Academic Activity Level	Pediatric patient's academic activity level.	Full Academic Load Reduced Academic Load Unable to Participate in Academic due to Disease or Condition Not Applicable < 5 Years Old / High School Graduate or GED Status Unknown	Single selection list. Pediatric patients only.		O			

Name	Description	Values	Data Rules	R	L	PR	PE	PO
Academic Progress	Pediatric patient's academic progress.	Within One Grade Level of Peers Delayed Grade Level Special Education Not Applicable < 5 Years Old / High School Graduate / GED Status Unknown	Single selection list. Pediatric patient only.		O			
Working for Income	Working for income of primary care giver and patient.	<20,000/year 20-50,000/year 50-100,000/year >100,000/year Not working Unknown	Single selection list		M		M	M
Reason Not Working For Income	Reason not working for income for patient.	Disability Inability to Find Work Patient Choice Unknown	Required if patient is not working for income.		O		O	O
Treating Facilities								
Transplant Centre	Centre responsible for providing transplant surgery.	List of Transplant Centres	Single selection list	M	M		M	
Referral Centre	Centre that assesses/monitors patients before transplant, but does not perform the transplant for the specific organ request (e.g. St John's, Regina). A Transplant Centre may be a Referral Centre for patients of organs for which it does not perform transplants.	List of Transplant Centres and Referral Centres	Single selection list	M	M			
Dialysis Centre	Centre responsible for patient's dialysis.	CORR List of dialysis centres	If patient is ESRD then dialysis centre is required.	M	M			
Follow Up Centre	Centre where primary post - transplant follow up takes place. These are centres responsible for pre-transplant and post-transplant care but the actual transplant is	List of Transplant and Referral Centres	Single selection list		M			

Name	Description	Values	Data Rules	R	L	PR	PE	PO
	carried out by a Transplant Centre.							
Follow-Up Care Provided By	Physician or health care team providing regular outpatient kidney transplant are to the patient.	Transplant Centre Non Transplant Centre Specialty Physician Primary Care Physician Other Specify	If other selected then specify.		M			
HLA Lab	HLA Lab responsible for providing HLA Typing and Antibody Screening results on patient.	List of HLA Labs	Derived by system based on associated Transplant Centre.		M			
ODO	Organ Donation Organization associated to patient's Transplant Centre.	List of ODOs	Derived by system based on associated Transplant Centre.		M			
Consent								
Consent to be in Registry	Date consent to be in CBS registry obtained. If this date is not entered then identifiable patient information must not be shared.	Date	≤ current date Entered by Canadian Blood Services Customer Solutions only. Conditional mandatory – patients can be listed before written consent received by Canadian Blood Services.		O			
Consent Received by CBS	Consent Form has been received by CBS.	Yes No	Entered by Canadian Blood Services Customer Solutions only. Conditional mandatory – patients can be listed before written consent received by Canadian Blood Services.		O			
Consent for Research	Date consent for research obtained.	Date	≤ current date		O			
Registry Entry Date/Time	Date and time patient record created in registry.	Date and time	n/a		C			
Withdrew Consent	Date and time patient has withdrawn consent to be in the registry.	Date and time	If consent is withdrawn then patient record is locked.		O			

Name	Description	Values	Data Rules	R	L	PR	PE	PO
Registered Pair								
Relationship of living donor to recipient		Anonymous Aunt Boyfriend Brother Brother-in-law Common-law Cousin Daughter Daughter-in-law Father Father in-law Friend Girlfriend Grandfather Grandmother Husband Mother Mother-in-law Nephew Niece Partner Sister Sister in-law Son Son-in-law Uncle Wife	Single selection list		M			
Organ Request								
Organ Requested	Organ requested for transplant (single or multiple) at time of registration. A patient can have multiple organ requests over time, .i.e., one in 1970 and another in 1990.	Heart Lung Liver Pancreas Kidney Small Bowel	Multiple selection list		M			

	Name	Description	Values	Data Rules	R	L	PR	PE	PO
			Stomach						
●	Organ Request State	State of patient's readiness to accept an offer of an organ.	New File Active On Hold Off List	For each organ requested one state is required.		M			
●	Organ Request State Reason	Reason for recipient organ request being changed to a specific state.	<u>On Hold Reasons:</u> Medical Issue(s) Not Available (away) Pending Investigations Potential LDPE Transplant Psychosocial Issue (s) Other <u>Off List Reasons:</u> Improved Patient Choice Unsuitable for Transplant – medical reasons Unsuitable for Transplant – psychosocial reasons Deceased Withdrew Consent Duplicate Cancelled Unlocked Created in Error Other	For each organ requested, one reason is required if state = On Hold or Off List.		O			
●	Organ Request State Change Date/Time	Date and Time Organ Request State is updated in registry.	Date and time	Single selection list		C			
●	List Date/Time	Date and time patient is listed.	Date and time	≤ current date/time. ≥ (date of birth - 1 year).		M			
●	Wait Time	Time on dialysis based on most recent dialysis.	Days	n/a		C			
●	Date patient removed from waiting list		Date	≤ current date/time		M			

	Name	Description	Values	Data Rules	R	L	PR	PE	PO
●	Main reason patient was removed		Identified living donor Acute myocardial infarction Stroke Other cardiovascular disease Major cardiac surgery Major non-cardiac surgery (including vascular) Active malignancy Investigation for malignancy Active/untreated infection Patient preference Moved out of area and/or onto new waiting list Other reason – please specify	Single selection list		M			
●	Was the removal from the waiting list permanent		Yes No Unknown	n/a		M			
●	Date patient was reactivated to the waiting list		Date	≤ current date/time		M			
●	Organ Medical Status	Medical status of patient with respect to organ requested.	Kidney Medical Status 2MU = national medical urgency 1 = normal 0 = on hold	Single selection Used by HSP Program		M			
●	Medical Status Change Date/Time	Date and time medical status is updated in the registry.	Date and time	n/a		C			
●	Urgent/Not Urgent Status	Urgency of medical status.	Urgent Non Urgent	The following are urgent statuses: Heart Medical Status: 4, 4S Liver Medical Status: 4F, 3F		C			
●	Transplant Type	The type of transplant requested i.e. Kidney, combined Kidney-Other.	Single Multiple Same Donor Multiple	Single selection list		O			

Name	Description	Values	Data Rules	R	L	PR	PE	PO
Medical History								
Past Medical History								
Patient on Dialysis	Flag indicating if patient is on dialysis during pre-transplant period.	Yes No	Single selection list. Initially derived from Date of initial dialysis treatment for ESRD.		M	M		
Most Recent Chronic Dialysis Start Date	Patient's most recent chronic dialysis start date.	Date	≤ current date. If patient on dialysis = yes then date is required.		M	M		
Time on Dialysis (days)	Duration of time from most recent chronic dialysis initiation to transplantation.	Days	Calculated into days based on Most Recent Dialysis Start Date.		C	C		
Previous Transplant								
Has recipient donated a kidney?	Flag indicating if patient has donated a kidney in the past.	Yes No	Required by national HSP Kidney Allocation Algorithm.		M			
Date of previous transplant		Date	≤ current date. Previous transplant can be manually entered into CTR or when transplant recorded in registry then this is derived by registry. Multiple dates can be provided for each patient. For combined transplants a date of previous transplant will be derived for each organ transplanted.		M			
Organ Previously Transplanted		Heart Lung Liver Pancreas Kidney Small Bowel Stomach	Single selection list		M			

	Name	Description	Values	Data Rules	R	L	PR	PE	PO
	Organ Type of Previous Transplant		Right Lung Left Lung Double Lung Whole Liver Left Lobe Liver Right Lobe Liver Whole Pancreas Islets Segment 1 Segment 2 Right Kidney Left Kidney En Bloc Kidney Double Kidney	Single selection list		M			
	Transplant Centre of Previous Transplant		List of transplant centres	Single selection list		O			
	Number of Previous Transplants		Numeric	Calculation of previous transplants by system. Transplants that took place before CTR can be added and included in the calculation.		C			
Diagnoses									
	Biopsy Proven ESRD	Flag indicating if patient has biopsy proven ESRD.	Yes No Unknown	Not required if patient has poly-cystic kidney disease.		M			
	Organ Primary Diagnosis	The diagnosis that is chiefly responsible for ESRD.	Acute cortical necrosis Acute rejection (antibody-mediated) Acute rejection (mixed T cell and antibody) Acute rejection (T cell-mediated) Acute tubular necrosis Amyloid Anti-glomerular basement membrane (GBM) antibody disease Anti-phospholipid antibody syndrome Aplastic/hypoplastic/dysplastic	Single selection list		M			

Name	Description	Values	Data Rules	R	L	PR	PE	PO
		kidney Atheroembolic renal disease Balkan nephropathy BK virus nephropathy Branchio-oto-renal syndrome (Melnick-Fraser syndrome) C3 glomerulopathy Churg-Strauss syndrome Congenital anomaly of the urinary system Congenital nephrotic syndrome Congenital renal dysplasia with or without urinary tract malformation Congenital ureterovesical obstruction Cryoglobulinemia Cystic kidney disease, other type - specify Cystic kidney disease, type unspecified Cystinosis Dense deposit disease (MPGN type II) Diabetic nephropathy (type 1 diabetes mellitus) Diabetic nephropathy (type 2 diabetes mellitus) Drash syndrome End-stage renal disease - etiology uncertain Essential hypertension Fabry disease Fanconi syndrome Fibrillary glomerulonephritis Fibronectin glomerulopathy Focal segmental glomerulosclerosis (adults) Focal segmental glomerulosclerosis (pediatric) Glomerulonephritis (not otherwise						

Name	Description	Values	Data Rules	R	L	PR	PE	PO
		specified) Glomerulonephritis (not otherwise specified) Goodpasture's Syndrome Granulomatosis with polyangiitis (Wegener's granulomatosis) Hemolytic uremic syndrome (Moschcowitz syndrome) Henoch-Schonlein purpura Hereditary nephritis (Alport syndrome) Hereditary nephritis (not otherwise specified) Hereditary nephritis, other - specify Horseshoe kidney Human Immunodeficiency Virus (HIV) nephropathy Hydronephrosis Idiopathic crescentic glomerulonephritis (diffuse proliferative) IgA nephropathy IgM nephropathy Immune complex glomerulonephritis Interstitial fibosis and tubular atrophy (not otherwise specified) Interstitial nephritis, cause unknown Interstitial nephritis, drug-induced Interstititat nephritis, other causes Kidney allograft failure (not otherwise specified) Kidney tumour (other than RCC) Light chain nephropathy Lithium nephropathy Malignant hypertension (no primary renal disease) Malignant hypertensive renal disease Medullary cystic disease, including						

Name	Description	Values	Data Rules	R	L	PR	PE	PO
		nephronophthisis Membranoproliferative mesangiocapillary glomerulonephritis (MPGN type I) Membranous nephropathy Meningococcemia Mesangial proliferative glomerulonephritis Methylmalonic acidemia Microscopic polyangiitis Minimal lesion glomerulonephritis Multiple myeloma Multi-system disease, other - specify Nephrocalcinosis (hypercalcemic nephropathy) Nephrolithiasis Nephropathy due to analgesic drugs Nephropathy due to calcineurin inhibitors Nephropathy due to cisplatin Nephropathy due to drugs or nephrotoxic agents, cause not specified Nephropathy due to other specific drug - specify Nephropathy due to uric acid Neurogenic bladder Obstructive uropathy Oligomeganephronic hypoplasia Other identified renal disorder - specify Oxalosis Pauci-immune glomerulonephritis Polyarteritis nodosa Polycystic kidney disease - adult type (dominant) Polycystic kidney disease - infantile/juvenile type (recessive)						

Name	Description	Values	Data Rules	R	L	PR	PE	PO
		Posterior urethral valves Post-infectious glomerulonephritis Primary non-function of kidney transplant Prior living kidney donor Pyelonephritis Rapidly progressive glomerulonephritis Recurrent glomerulonephritis Reflux nephropathy Renal agenesis Renal artery thrombosis Renal cell carcinoma Renal disease in pregnancy - pre-eclampsia/eclampsia Renal dysplasia Renal medullary necrosis unspecified Renal papillary necrosis Renal vascular disease due to hypertension (no primary renal disease) Renal vascular disease, classified (nephrosclerosis, renal vascular thrombosis) Renal vascular disease, type unspecified Renal vein thrombosis Retroperitoneal fibrosis Scleroderma Segmental renal hypoplasia (Ask-Upmark kidney) Sickle cell nephropathy Syndrome of agenesis of abdominal muscles (Prune belly syndrome) Systemic lupus erythematosus Thin basement membrane disease Transplant glomerulopathy Traumatic or surgical loss of kidney						

Name	Description	Values	Data Rules	R	L	PR	PE	PO
		Tuberculosis Tubulointerstitial disease Urethral stricture Urinary tract obstruction Urolithiasis von Willebrand's disease Wilms' tumour						
Organ Secondary Diagnosis	A secondary diagnosis that may have contributed to the organ failure but was not the primary cause of organ failure (e.g., membranous nephropathy as primary and diabetes as secondary).	Acute cortical necrosis Acute rejection (antibody-mediated) Acute rejection (mixed T cell and antibody) Acute rejection (T cell-mediated) Acute tubular necrosis Amyloid Anti-glomerular basement membrane (GBM) antibody disease Anti-phospholipid antibody syndrome Aplastic/hypoplastic/dysplastic kidney Atheroembolic renal disease Balkan nephropathy BK virus nephropathy Branchio-oto-renal syndrome (Melnick-Fraser syndrome) C3 glomerulopathy Churg-Strauss syndrome Congenital anomaly of the urinary system Congenital nephrotic syndrome Congenital renal dysplasia with or without urinary tract malformation Congenital ureterovesical obstruction Cryoglobulinemia Cystic kidney disease, other type - specify Cystic kidney disease, type unspecified	Single selection list		O			

Name	Description	Values	Data Rules	R	L	PR	PE	PO
		Cystinosis						
		Dense deposit disease (MPGN type II)						
		Diabetic nephropathy (type 1 diabetes mellitus)						
		Diabetic nephropathy (type 2 diabetes mellitus)						
		Drash syndrome						
		End-stage renal disease - etiology uncertain						
		Essential hypertension						
		Fabry disease						
		Fanconi syndrome						
		Fibrillary glomerulonephritis						
		Fibronectin glomerulopathy						
		Focal segmental glomerulosclerosis (adults)						
		Focal segmental glomerulosclerosis (pediatric)						
		Glomerulonephritis (not otherwise specified)						
		Glomerulonephritis (not otherwise specified)						
		Goodpasture's Syndrome						
		Granulomatosis with polyangiitis (Wegener''s granulomatosis)						
		Hemolytic uremic syndrome (Moschcowitz syndrome)						
		Henoch-Schonlein purpura						
		Hereditary nephritis (Alport syndrome)						
		Hereditary nephritis (not otherwise specified)						
		Hereditary nephritis, other - specify						
		Horseshoe kidney						
		Human Immunodeficiency Virus (HIV) nephropathy						
		Hydronephrosis						
		Idiopathic crescentic						

Name	Description	Values	Data Rules	R	L	PR	PE	PO
		glomerulonephritis (diffuse proliferative) IgA nephropathy IgM nephropathy Immune complex glomerulonephritis Interstitial fibosis and tubular atrophy (not otherwise specified) Interstitial nephritis, cause unknown Interstitial nephritis, drug-induced Interstititat nephritis, other causes Kidney allograft failure (not otherwise specified) Kidney tumour (other than RCC) Light chain nephropathy Lithium nephropathy Malignant hypertension (no primary renal disease) Malignant hypertensive renal disease Medullary cystic disease, including nephronophthisis Membranoproliferative mesangiocapillary glomerulonephritis (MPGN type I) Membranous nephropathy Meningococcemia Mesangial proliferative glomerulonephritis Methylmalonic acidemia Microscopic polyangiitis Minimal lesion glomerulonephritis Multiple myeloma Multi-system disease, other - specify Nephrocalcinosis (hypercalcemic nephropathy) Nephrolithiasis Nephropathy due to analgesic drugs Nephropathy due to calcineurin inhibitors						

Name	Description	Values	Data Rules	R	L	PR	PE	PO
		Nephropathy due to cisplatin Nephropathy due to drugs or nephrotoxic agents, cause not specified Nephropathy due to other specific drug - specify Nephropathy due to uric acid Neurogenic bladder Obstructive uropathy Oligomeganephronic hypoplasia Other identified renal disorder - specify Oxalosis Pauci-immune glomerulonephritis Polyarteritis nodosa Polycystic kidney disease - adult type (dominant) Polycystic kidney disease - infantile/juvenile type (recessive) Posterior urethral valves Post-infectious glomerulonephritis Primary non-function of kidney transplant Prior living kidney donor Pyelonephritis Rapidly progressive glomerulonephritis Recurrent glomerulonephritis Reflux nephropathy Renal agenesis Renal artery thrombosis Renal cell carcinoma Renal disease in pregnancy - pre-eclampsia/eclampsia Renal dysplasia Renal medullary necrosis unspecified Renal papillary necrosis Renal vascular disease due to						

Name	Description	Values	Data Rules	R	L	PR	PE	PO
		hypertension (no primary renal disease) Renal vascular disease, classified (nephrosclerosis, renal vascular thrombosis) Renal vascular disease, type unspecified Renal vein thrombosis Retroperitoneal fibrosis Scleroderma Segmental renal hypoplasia (Ask-Upmark kidney) Sickle cell nephropathy Syndrome of agenesis of abdominal muscles (Prune belly syndrome) Systemic lupus erythematosus Thin basement membrane disease Transplant glomerulopathy Traumatic or surgical loss of kidney Tuberculosis Tubulointerstitial disease Urethral stricture Urinary tract obstruction Urolithiasis von Willebrand's disease Wilms' tumour					
Organ Tertiary Diagnosis	The diagnosis for organ failure that coexists with the primary diagnosis but likely did not contribute to organ failure.	Acute cortical necrosis Acute rejection (antibody-mediated) Acute rejection (mixed T cell and antibody) Acute rejection (T cell-mediated) Acute tubular necrosis Amyloid Anti-glomerular basement membrane (GBM) antibody disease Anti-phospholipid antibody syndrome Aplastic/hypoplastic/dysplastic	Single selection list		O			

Name	Description	Values	Data Rules	R	L	PR	PE	PO
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Name	Description	Values	Data Rules	R	L	PR	PE	PO
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Name	Description	Values	Data Rules	R	L	PR	PE	PO
		Posterior urethral valves Post-infectious glomerulonephritis Primary non-function of kidney transplant Prior living kidney donor Pyelonephritis Rapidly progressive glomerulonephritis Recurrent glomerulonephritis Reflux nephropathy Renal agenesis Renal artery thrombosis Renal cell carcinoma Renal disease in pregnancy - pre-eclampsia/eclampsia Renal dysplasia Renal medullary necrosis unspecified Renal papillary necrosis Renal vascular disease due to hypertension (no primary renal disease) Renal vascular disease, classified (nephrosclerosis, renal vascular thrombosis) Renal vascular disease, type unspecified Renal vein thrombosis Retroperitoneal fibrosis Scleroderma Segmental renal hypoplasia (Ask-Upmark kidney) Sickle cell nephropathy Syndrome of agenesis of abdominal muscles (Prune belly syndrome) Systemic lupus erythematosus Thin basement membrane disease Transplant glomerulopathy Traumatic or surgical loss of kidney						

Name	Description	Values	Data Rules	R	L	PR	PE	PO
		Tuberculosis Tubulointerstitial disease Urethral stricture Urinary tract obstruction Urolithiasis von Willebrand's disease Wilms' tumour						
Comorbidities – For each comorbidity - multiple time points can be captured - required at time of listing, transplant and 1 year post transplant - initial result must be carried forward								
Myocardial Infarction	Flag indicating if patient has myocardial infarction.	Yes No	n/a		M		M	M
Congestive Heart Failure	Flag indicating if patient has congestive heart failure.	Yes No	n/a		M		M	M
Peripheral vascular disease	Flag indicating if patient has peripheral vascular disease.	Yes No	n/a		M		M	M
Cerebral vascular disease	Flag indicating if patient has cerebral vascular disease.	Yes No	n/a		M		M	M
Dementia	Flag indicating if patient has dementia.	Yes No	n/a		M		M	M
Chronic lung disease	Flag indicating if patient has chronic lung disease.	Yes No	n/a		M		M	M
Rheumatological	Flag indicating if patient is rheumatological.	Yes No	n/a		M		M	M
Peptic ulcer disease	Flag indicating if patient has peptic ulcer disease.	Yes No	n/a		M		M	M
Liver Disease	Flag indicating if patient has liver disease.	Yes No	If yes then specify if: Mild Moderate Severe		M		M	M
Diabetes without complications	Flag indicating if patient has diabetes without complications.	Yes No	n/a		M		M	M

	Name	Description	Values	Data Rules	R	L	PR	PE	PO
●	Neoplasia	Flag indicating if patient has neoplasia.	Yes No	n/a		M		M	M
●	Leukemia	Flag indicating if patient has leukemia.	Yes No	n/a		M		M	M
●	Lymphoma	Flag indicating if patient has lymphoma.	Yes No	n/a		M		M	M
●	Human immunodeficiency virus	Flag indicating if patient has human immunodeficiency virus.	Yes No	n/a		M		M	M
Malignancies									
●	Malignancy	Flag indicating if patient has malignancy and type of malignancy.	Yes No Unknown	If yes then specify all that apply: Skin Melanoma Skin Non-Melanoma CNS Tumour Genitourinary Breast Thyroid Tongue/Throat/Larynx Lung Leukemia/Lymphoma Liver Hepatocellular Carcinoma – Liver only Other please specify		M			
Laboratory / Diagnostics									
Serology – For each serology - multiple time points can be captured - a test type must be recorded for each serology result - sample drawn date/time recorded for each result									
●	CMV	CMV result based on IgG test.	Positive Negative Indeterminate Not Tested	Single selection list		M		M	

Name	Description	Values	Data Rules	R	L	PR	PE	PO
EBV	EBV result based on the following tests: IgG (VCA) or IgG (EBNA), NAT.	Positive Negative Indeterminate Not Tested	Single selection list Antibody testing used pre-transplant. NAT testing used post-transplant for surveillance.		O		O	
Hepatitis B Core Antibody	HBV result based on Anti-HBc (HBcAb) test.	Positive Negative Indeterminate Not Tested	Single selection list		M		M	
Hepatitis B Surface Antibody	HBV result based on Anti-HBs (HBsAb) test.	Positive Negative Indeterminate Not Tested	Single selection list		M		M	
Hepatitis B Surface Antigen	HBV result based on the following test: HBsAG test, NAT.	Positive Negative Indeterminate Not Tested	Single selection list		M		M	
Hepatitis C Antibody	HCV result based on IgG test.	Positive Negative Indeterminate Not Tested			M		M	
Hepatitis C NAT	HCV result based on the following tests: HCV RNA NAT, Double NAT (HIV, HCV), Triple NAT (HIV, HCV, HBV).	Positive Negative Not Tested	Single selection list. Double NAT and Triple NAT cannot be Indeterminate. If HCV RNA NAT positive then provide viral load.		O		O	
HIV I and II Antibody	HIV I and II result based on any of the following tests: IgG, Antibody/p24antigen.	Positive Negative Indeterminate Not Tested			M		M	
HIV I and II NAT	HIV I and II result based on any of the following tests: HIV NAT (HIV DNA, HIV Single NAT), Double NAT (HIV, HCV), and Triple NAT (HIV, HCV, and HBV).	Positive Negative Not Tested	Single selection list. Double NAT and Triple NAT cannot be Indeterminate. If HIV NAT positive then provide viral load.		O		O	

	Name	Description	Values	Data Rules	R	L	PR	PE	PO
	HTLV I and II	HTLV I and II result based on IgG test.	Positive Negative Indeterminate Not Tested	Single selection list		M		M	
	Syphilis	Syphilis result based on the following tests: EIA, RPR, VDRL, FTA-ABS.	Positive Negative Indeterminate Not Tested	Single selection list		M		M	
	West Nile	West Nile result based on IgG, IgM, NAT.	Positive Negative Indeterminate Not Tested	Single selection list		M		M	
Chemistry – For each chemistry - multiple time points can be captured - collection date/time recorded for each result									
	Serum Albumin		g/L	≥ 0 and ≤ 99. Required at time of discharge.		M	M	M	M
	Most Recent Serum Creatinine Level		µmol/L	≥ 0 and ≤ 9999. Required at time of referral, consultation and final disposition and at discharge.	M	M		M	
Renal Profile									
	CrCl Cockroft Gault	Estimated Glomerular Filtration Rate based on Creatinine Clearance.	ml/min/1.73m2	Creatinine Clearance = ((140- Recipient Age at Collection Date) * Weight * constant)/serum creatinine Constant is 1.23 for men and 1.04 for women. Required at time of discharge and post-transplant.				C	C

Name	Description	Values	Data Rules	R	L	PR	PE	PO
eGFR-MDRD	Estimated Glomerular Filtration Rate based on MDRD methodology.	ml/min/1.73m2	MDRD = 32788 * Serum Creatinine$^{-1.154}$ * Age at Collection Date$^{-0.203}$ * (1.212 if Black) * (0.741 if female). Note: Creatinine levels in µmol/L can be converted to mg/dL by dividing them by 88.4. The 32788 number above is equal to 186 * 88.4-$^{1.154}$ Required at time of discharge and post-transplant.				C	C
eGFR-Schwartz	Estimated Glomerular Filtration Rate based on Schwartz methodology.	ml/min/1.73m2	Pediatric patients only Schwartz = (constant * height)/ serum creatinine Constant is 36.5 = (0.413 * 88.4) Required at time of discharge and post-transplant.				C	C
Pre-implantation Kidney Biopsy Performed at Transplant Centre	Was pre-implantation kidney biopsy performed at the Transplant Centre?	Yes No	Single selection list				M	
HLA Typing – Conditional mandatory rules - Required for virtual cross match								
A_1	HLA typing of patient.	Molecular allele	≤ 20 characters		M			
A_2	HLA typing of patient.	Molecular allele	≤ 20 characters		M			
B_1	HLA typing of patient.	Molecular allele	≤ 20 characters		M			

Name	Description	Values	Data Rules	R	L	PR	PE	PO
B_2	HLA typing of patient.	Molecular allele	≤ 20 characters		M			
C_1	HLA typing of patient.	Molecular allele	≤ 20 characters		M			
C_2	HLA typing of patient.	Molecular allele	≤ 20 characters		M			
DRB1_1	HLA typing of patient.	Molecular allele	≤ 20 characters		M			
DRB1_2	HLA typing of patient.	Molecular allele	≤ 20 characters		M			
DRB3_1	HLA typing of patient.	Molecular allele	≤ 20 characters Of the six text-entry fields which are available for the locus DRB3, DRB4, and DRB5, a maximum of two values may be entered, and a minimum of one value must be entered.		M			
DRB3_2	HLA typing of patient.	Molecular allele	≤ 20 characters		M			
DRB4_1	HLA typing of patient.	Molecular allele	≤ 20 characters		M			
DRB4_2	HLA typing of patient.	Molecular allele	≤ 20 characters		M			
DRB5_1	HLA typing of patient.	Molecular allele	≤ 20 characters		M			
DRB5_2	HLA typing of patient.	Molecular allele	≤ 20 characters		M			
DRB 3/4/5 Tested, but not present	Flag indicating if DRB3, DRB4 and DRB5 tested but not present.	Yes No	When no values are entered for DRB3, DRB4, and DRB5, and the HLA typing is to be considered complete, then indicate that DRB3, DRB4, and DRB5		M			

Name	Description	Values	Data Rules	R	L	PR	PE	PO
			were “Tested, but not present”.					
DPA1_1	HLA typing of patient.	Molecular allele	≤ 20 characters		M			
DPA1_2	HLA typing of patient.	Molecular allele	≤ 20 characters		M			
DPB1_1	HLA typing of patient.	Molecular allele	≤ 20 characters		M			
DPB1_2	HLA typing of patient.	Molecular allele	≤ 20 characters		M			
DQA1_1	HLA typing of patient.	Molecular allele	≤ 20 characters		M			
DQA1_2	HLA typing of patient.	Molecular allele	≤ 20 characters		M			
DQB1_1	HLA typing of patient.	Molecular allele	≤ 20 characters		M			
DQB1_2	HLA typing of patient.	Molecular allele	≤ 20 characters		M			
HLA Typing Confirmed	User confirms HLA Typing.	Yes No	Default = blank		M			
HLA Typing Confirmed By	User who confirmed HLA Typing along with date/time of confirmation.	Date/Time of Confirmation and User Name	n/a		C			
HLA Typing Complete	System verifies HLA Typing complete based on organ specific rules.	Yes No	n/a		C			
HLA Typing Last Updated By	User who last updated HLA Typing along with date/time of update.	Date/Time of Update and User Name	n/a		C			
HLA Comments	General HLA comments.	Free text comments	≤ 1024 characters		O			
A_1	HLA typing of patient.	Serological equivalent	Calculated serological equivalent derived from National Canadian HLA Dictionary.		C			

Name	Description	Values	Data Rules	R	L	PR	PE	PO
A_2	HLA typing of patient.	Serological equivalent	See rules in A_1 serological equivalent.		C			
B_1	HLA typing of patient.	Serological equivalent	See rules in A_1 serological equivalent.		C			
B_2	HLA typing of patient.	Serological equivalent	See rules in A_1 serological equivalent.		C			
Bw4	HLA typing of patient.	Serological equivalent	Defaulted to a derived value from National Canadian HLA Dictionary User can modify the suggested value.		M			
Bw6	HLA typing of patient.	Serological equivalent	Defaulted to a derived value from National Canadian HLA Dictionary User can modify the suggested value.		M			
Cw_1	HLA typing of patient.	Serological equivalent	See rules in A_1 serological equivalent.		C			
Cw_2	HLA typing of patient.	Serological equivalent	See rules in A_1 serological equivalent.		C			
DR_1	HLA typing of patient.	Serological equivalent	See rules in A_1 serological equivalent.		C			
DR_2	HLA typing of patient.	Serological equivalent	See rules in A_1 serological equivalent.		C			
DR52	HLA typing of patient.	Serological equivalent	See rules in A_1 serological equivalent.		C			
DR53	HLA typing of patient.	Serological equivalent	See rules in A_1 serological equivalent.		C			
DR51	HLA typing of patient.	Serological equivalent	See rules in A_1 serological equivalent.		C			
DPA_1	HLA typing of patient.	Serological equivalent	See rules in A_1 serological equivalent.		C			
DPA_2	HLA typing of patient.	Serological equivalent	See rules in A_1 serological equivalent.		C			

Name	Description	Values	Data Rules	R	L	PR	PE	PO
DPB_1	HLA typing of patient.	Serological equivalent	See rules in A_1 serological equivalent.		C			
DPB_2	HLA typing of patient.	Serological equivalent	See rules in A_1 serological equivalent.		C			
DQA_1	HLA typing of patient.	Serological equivalent	See rules in A_1 serological equivalent.		C			
DQA_2	HLA typing of patient.	Serological equivalent	See rules in A_1 serological equivalent.		C			
DQB_1	HLA typing of patient.	Serological equivalent	See rules in A_1 serological equivalent.		C			
DQB_2	HLA typing of patient.	Serological equivalent	See rules in A_1 serological equivalent.		C			
Antibody Testing – Conditional mandatory rules - Required for calculated PRA and virtual cross matching								
Serum Collection Date	Date serum collected for antibody screening.	Date	≤ current date. Required for every antibody screening result provided At least one set of results is required for VXM.	M	M	M		M
Antibody Testing Method		CDC ELISA Flow Luminex Other	Single selection list	M	M	M		M
Acceptable Antibody Results	HLA serum results of patient.	Acceptable antigens	Cumulative and current are captured.	M	M	M		M
Unacceptable Antibody Results	HLA serum results of patient.	Unacceptable antigens	Cumulative and current are captured. Need ability to define unacceptable DQA and DQB combinations.	M	M	M		M
Indeterminate Antibody Results	HLA serum results of patient.	Indeterminate antigens	Cumulative and current are captured.	M	M	M		M
Not Tested Antibody Results	HLA serum results of patient.	Not tested antigens	Cumulative and current are captured.	M	M	M		M

	Name	Description	Values	Data Rules	R	L	PR	PE	PO
	Allele-Specific Antibody Results	HLA serum results of patient.	Allele specific antigens	Cumulative and current are captured. For every antigen selected as allele specific then the unacceptable molecular allele (s) can be defined.	M	M	M		M
	Willing to Cross	Antibodies that recipient's HLA Lab is willing to ignore if found in the donor during virtual cross matching.	Any antigen in the National Canadian HLA dictionary	Need ability for each organ to have a list of willing to cross.	O	O	O		
	Antibodies Confirmed	User confirms antibody test results.	Yes No	Default = blank	M	M	M		M
	Antibodies Confirmed By	User who confirmed HLA Typing along with date/time of confirmation.	Date and time of Confirmation and User Name	n/a	C	C	C		C
	PRA Results Calculation Date	Date of calculation by CTR and there could be many things to trigger an update.	Date	n/a	C	C	C		C
	Cumulative PRA	Cumulative Class I and II calculated PRA.	%	n/a	C	C	C		C
	Cumulative PRA Class I	Cumulative Class I calculated PRA.	%	n/a	C	C	C		C
	Cumulative PRA Class II	Cumulative Class II calculated PRA.	%	n/a	C	C	C		C
	Current PRA	Current Class I and II calculated PRA.	%	n/a	C	C	C		C
	Current PRA Class I	Current Class I calculated PRA.	%	n/a	C	C	C		C
	Current PRA Class II	Current Class II calculated PRA.	%	n/a	C	C	C		C
	HSP	Flag indicating patient is HSP patient is >95% PRA.	Yes No	n/a	C	C	C		C
Matching									
Donor Acceptance Criteria									

Name	Description	Values	Data Rules	R	L	PR	PE	PO
Accept DCD	Flag indicating transplant team is willing to accept DCD donor.	Yes No	Default = Yes. Used in HSP Kidney Matching Algorithm.		O	O		
Min Age	The minimum age that transplant team is willing to accept of a donor.	years	0.0 to 150.0. Used in HSP Kidney Matching Algorithm and LDPE Matching Algorithm.		O	O		
Max Age	The maximum age that transplant team is willing to accept of a donor.	years	0.0 to 150.0. Used in HSP Kidney Matching Algorithm.		O	O		
Accept Hepatitis B Core Antibody Positive	Flag indicating transplant team is willing to accept a Hepatitis B Core Antibody Positive donor.	Yes No	Default = No. Used in HSP Kidney Matching Algorithm and LDPE Matching Algorithm.		O	O		
Accept Hepatitis C Antibody Positive	Flag indicating transplant team is willing to accept a Hepatitis C Antibody Positive donor.	Yes No	Default = No. Used in HSP Kidney Matching Algorithm and LDPE Matching Algorithm.		O	O		
Min BMI	The minimum BMI that transplant team is willing to accept of a donor.	years	0.0 to 150.0. Used in LDPE Matching Algorithm.		O	O		
Max BMI	The maximum BMI that transplant team is willing to accept of a donor.	years	0.0 to 150.0. Used in LDPE Matching Algorithm.		O	O		
Accept EBV Positive	Flag indicating transplant team is willing to accept EBV Positive donor.	Yes No	Used in LDPE Matching Algorithm.		O	O		

Name	Description	Values	Data Rules	R	L	PR	PE	PO
Virtual Cross Match								
ABO Match Result	Blood group compatibility test between a donor and list of recipients.	Yes No	If virtual cross match run and patient's blood group exists then ABO match result provided based on the following rules: - O donor can match to an O, A, B, or AB recipient - A donor can match to an A or AB recipient - B donor can match to a B or AB recipient - AB donor can match to an AB recipient			C		
VXM Result	HLA compatibility test between a donor and list of recipients.	Positive Negative	If virtual cross match run and patient's antibody results exist then VXM result provided based on the following rules: Donor-recipient matches are positive when the donor has HLA antigens that have been listed in the recipient's record as being unacceptable.			C		
HLA B Mismatch		0 1 2	Single selection list				M	
HLA DR Mismatch		0 1 2	Single selection list				M	
Surgical								
Surgical Details								

Name	Description	Values	Data Rules	R	L	PR	PE	PO
Date/Time of Admission to Hospital	Date and time of admission to hospital for transplant.	Date	≤ Current Date. Used to calculate days in hospital.				M	
Received on Pump	Flag indicating if kidney was received on pump.	Yes No	Single selection list				M	
Perfusion Device Used	Specify perfusion device used.	Perfusion Pump Ex-Vivo Pump None	Single selection list				M	
Surgical Procedure	Kidney transplant surgical procedure type.	Transabdominal Flank (retroperitoneal) Laparoscopic Not Hand-assisted Laparoscopic Hand-assisted	Single selection list				M	
Graft weight	Weight of graft. Typically 120 – 170 g.	g	≥ 0 and ≤ 500				O	
Number of arteries in donor kidney	Number of renal arteries connected to donor aorta.	Numeric	Single selection list				M	
Number of veins in donor kidney	Number of renal veins connected to donor IVC.	Numeric	Single selection list				M	
Type of kidney being transplanted	Sidedness and number of kidneys transplanted.	Right Left Dual (both same side) Dual (one each side) En bloc	Single selection list				M	
Transplant Date/Time	Date and time of transplant. AKA Recipient Vascular Clamp Release or Clamp Off Time or End Cold Time or Reperfusion Time.	Date	≤ current date. ≥ Donor Cross Clamp Date/Time.				M	
Donor Cross Clamp Date/ Time	Date/Time of aortic cross clamping in deceased donor.	Time	Hr:mm (24 hour time). ≤ current date.				M	
Preservation start time	Time when kidney placed in preservation fluid or connected to perfusion pump.	Time	Hr:mm (24 hour time). ≤ current date. > Cross clamp time.				M	
Preservation end time	Time when kidney removed from preservation fluid or perfusion pump.	Time	Hr:mm (24 hour time). ≤ current date. > Preservation start time.				M	

	Name	Description	Values	Data Rules	R	L	PR	PE	PO
	Reperfusion time	Time of vascular clamp release after renal vessels anastomosis in recipient.	Time	Hr:mm (24 hour time). ≤ current date. > Preservation end time.				M	
	Cold Ischemia Time	Time from start to end of preservation.	Duration (hours)	Preservation end time minus start time.				C	
	Warm Ischemia Time	Time from end of preservation to reperfusion in recipient.	Duration (minutes)	Reperfusion time minus preservation end time.				C	
	Total Ischemia Time	Time from donor aortic cross clamp to kidney reperfusion in recipient.	Duration (hours)	Preservation end time minus cross clamp time.				C	
	Organ Transplanted	Transplant state of donor's organ after organ recovery	Transplanted Not Transplanted	When transplant date/time recorded then data derived by Registry.				M	
	Reason organ not transplanted	Reason organ not transplanted.	Recipient died Recipient medically unsuitable Storage and preservation problems Transportation logistics	If not transplanted is selected then reason required.				M	
	Recipient Intended	Flag indicating if recipient was the intended.	Yes No	Single selection list				M	
	Recipient Not Intended Reason	Reason not intended recipient received organ.	Recipient medically unsuitable Recipient died Positive actual cross match result Recipient unable to travel Recipient refused Organ not as described, Organ test results unacceptable	If not intended recipient then reason required.				M	
	Transplant Centre at Time of Transplant	Transplant Centre where transplant took place.	List of Transplant Centres	Single selection list				C	
	Surgical Complications								
	Major Bleeding	Post-operative bleeding around the kidney transplant requiring transfusion or surgical re-exploration.	Yes No	Required at time of discharge.				M	
	Surgical Re-exploration	Need to take patient back to OR to explore kidney transplant at any	Yes No	Single selection list				M	

Name	Description	Values	Data Rules	R	L	PR	PE	PO
	time during transplant admission.							
Outcome								
Graft Function								
SCr Decline by 25% or More in First 24 Hours on 2 Separate Samples	Ratio of SCr closest to 24 hours after transplant to SCr just prior to transplant.	Yes No Unknown	Single selection list				M	
How many sessions of dialysis did the patient undergo within the FIRST WEEK after kidney transplantation?		0 1 > 1	Single selection list				M	M
Serum creatinine concentration just prior to kidney transplantation (at time of hospital admission)	Post-operative day zero serum creatinine (SCr [POD0]).	µmol/L	≥ 0 and ≤ 9999				M	
Serum creatinine concentration 24 hours after kidney transplantation	Post-operative day one serum creatinine value (SCr [POD1]).	µmol/L	≥ 0 and ≤ 9999				M	
Serum creatinine concentration 48 hours after kidney transplantation	Post-operative day two serum creatinine value (SCr [POD2]).	µmol/L	≥ 0 and ≤ 9999				M	
Creatinine Reduction Ratio at 24 hours	Percentage reduction of SCr comparing 24 hours after transplant to pre-operatively.	%	CRR = {SCr[POD0] – SCr[POD24]}/SCr[POD0]				C	
Creatinine Reduction Ratio at 48 hours	Percentage reduction of SCr comparing 48 hours after transplant to pre-operatively.	%	CRR = {SCr[POD0] – SCr[POD48]}/SCr[POD0]				C	
Post-Transplant Complications								
Kidney Allograft Thrombosis	Development of thrombus in kidney allograft artery and/or vein.	None Venous Arterial Both	Required at time of discharge.					M
Graft Rejection								

Name	Description	Values	Data Rules	R	L	PR	PE	PO
Date of biopsy		Date	≤ current date				M	M
Biopsy test number	ID number used for biopsies at centre where biopsy was taken.	Identifier	n/a				M	M
Biopsy Result	Overview of biopsy result.	Normal ATN (Acute tubular necrosis) Borderline changes Antibody-mediated rejection – specify: C4d positive or C4d negative Acute T-cell mediated rejection – specify type: IA, IB, IIA, IIB, III Polyma nephropathy Glomerulonephritis – specify type Chronic active T-cell mediated rejection Chronic allograft arteriopathy Transplant glomerulopathy Thrombotic microangiopathy Calcineurin toxicity Interstitial fibrosis and tubular atrophy – no evidence of specific etiology – if yes, please specify: Mild interstitial fibrosis and/or tubular atrophy Moderate interstitial fibrosis and/or tubular atrophy Severe interstitial fibrosis and/or tubular atrophy Other specify	Multiple selection list				M	M
Recipient Kidney Transplant Biopsy Data Collection Form	For each biopsy recorded an attachment of biopsy data.	Attachment document	For each date of biopsy entered an attachment is required.				M	M

	Name	Description	Values	Data Rules	R	L	PR	PE	PO
●	Acute Rejection Therapy	Type of treatment(s) patient received for the acute rejection episode.	Corticosteroids Rabbit anti-thymocyte globulin (rATG) Intravenous immunoglobulin (IVIg) Anti-CD20 antibody (e.g., rituximab) Proteosome inhibitor (e.g., bortezomib) C5 inhibitor (e.g., eculizumab) Plasmapheresis (PLEX) Cyclophosphamide OKT3 (i.e., Muromonab) Equine anti-thymocyte globulin (eATG or ATGAM) Immunoabsorption (e.g., Glycosorb column) Photopheresis Total lymphoid irradiation	Multiple selection list If applicable, record at time of discharge.				M	M
	Graft Failure								
●	Graft Failure Cause	Cause of graft failure.	Uncertain/unknown Primary non-function Graft vascular thrombosis Surgical complications – not specified Hyperacute rejection Acute rejection Chronic rejection Transplant glomerulopathy Recurrent primary disease BK virus nephropathy Sepsis/infection of graft Other cause of graft failure	If applicable, record at time of discharge				M	M
●	Graft Failure Date		Date	≤ current date If applicable, record at time of discharge.				M	M
●	Date Graft Removed		Date	≤ current date If applicable, record at time				M	M

Name	Description	Values	Data Rules	R	L	PR	PE	PO
			of discharge.					
Patient Nephrectomy at Graft Failure	Surgical removal of the graft at the time of graft failure.	Yes No	If applicable, record at time of discharge.				M	M
Immunological Regimen								
Immunosuppressive Medication - Induction	Induction immunosuppressive regimen patient has been prescribed at discharge and post-transplant follow-up.	Interleukin-2 receptor blocker (e.g., Simulect) Corticosteroids (relevant for rapid corticosteroid withdrawal protocols) Rabbit anti-thymocyte globulin (rATG) Intravenous immunoglobulin (IVIg) Anti-CD20 antibody (e.g., rituximab) Proteosome inhibitor (e.g., bortezomib) C5 inhibitor (e.g., eculizumab) Plasmapheresis (PLEX) Cyclophosphamide OKT3 (i.e., Muromonab) Equine anti-thymocyte globulin (eATG or ATGAM) Immunoabsorption (e.g., Glycosorb column) Alemtuzumab (i.e., Campath)	Multiple selection list. If applicable, record at time of discharge and post-transplant follow-up. Require ability to capture multiple time points over time.				M	M
Immunosuppressive Medication – Maintenance at discharge	Maintenance immunosuppressive regimen patient has been prescribed at discharge and post-transplant follow-up.	Prograf Advagraf Tacrolimus immediate-release (generic) Tacrolimus extended-release (generic) Neoral Cyclosporine (generic) Sirolimus Everolimus mTOR inhibitor (generic) Cellcept Mycophenolate mofetil (generic)	Multiple selection list. If applicable, record at time of discharge and post-transplant follow-up. Require ability to capture multiple time points over time.				M	M

Name	Description	Values	Data Rules	R	L	PR	PE	PO
		Myfortic Mycophenolate sodium (generic) Azathioprine Oral corticosteroids Leflunomide CTLA-4 costimulation blocker (e.g., belatacept)						
Discharge								
Date of hospital discharge		Date	≤ current date. Used to calculate days in hospital..					M
Days in Hospital	Number of days a patient in the hospital for transplant (from time of admission to discharge).	Number	Calculated based on date of hospital discharge and date of hospital admission for transplant.					C
Lost to Follow-up Date		Date	≤ current date. ≥ Transplant Date.					O
Death								
Date of Death		Date	≤ current date. ≥ Date of Birth.			M	M	M
Cause of Death	Primary cause of death.	Accident related to treatment Accident unrelated to treatment Myocardial ischemia and infarction Hyperkalaemia Hemorrhagic pericarditis Other causes of cardiac failure Cardiac arrest, cause unknown Hypertensive cardiac failure Hypokalaemia Fluid overload Gastro-intestinal tumour with or without perforation Acute gastroenteritis with dehydration Gastro-intestinal hemorrhage Mesenteric infarction	Single selection list			O	O	M

Name	Description	Values	Data Rules	R	L	PR	PE	PO
		Pancreatitis						
		Perforation of peptic ulcer						
		Sclerosing (or adhesive) peritoneal disease						
		Perforation of colon/small bowel						
		Cause of death, uncertain, not determined						
		Bone marrow depression						
		Thrombocytopenia						
		Thrombosis—specify						
		Infection (bacterial)—specify site						
		Infection (viral)—specify site						
		Infection (fungal)—specify site						
		Cytomegalovirus						
		Epstein Barr virus						
		Pneumocystic carinii pneumonia (PCP)						
		Protozoal/parasitic infection (includes toxoplasmosis)						
		Wound infection—specify site						
		Infections elsewhere (except viral hepatitis)						
		Septicemia/sepsis—specify source						
		Tuberculosis (lung)						
		Tuberculosis (elsewhere)						
		Generalized viral infection—specify viral agent						
		Peritonitis (not sclerosing or adhesive peritoneal disease)						
		Liver, due to hepatitis B virus						
		Liver, other viral hepatitis						
		Liver, drug toxicity—specify drug						
		Cirrhosis, not viral						
		Cystic liver disease						
		Liver failure, cause unknown						
		Liver, due to hepatitis C virus						
		Drug-related toxicity—specify drug						
		Hypertension						

Name	Description	Values	Data Rules	R	L	PR	PE	PO
		Diabetic keto acidosis (DKA) Cachexia Malignant disease possibly induced by immunosuppressive—specify primary site Malignant disease except malignant disease possibly induced by immunosuppressive therapy—specify primary source Dementia Multi-system failure Other identified causes of death—specify Drug neurotoxicity—specify drug Status epilepticus Neurologic infection—specify infectious agent Acute renal failure Chronic renal failure Uraemia caused by kidney transplant failure Acute respiratory distress syndrome (ARDS) Pulmonary infection (bacterial) Pulmonary infection (viral) Pulmonary infection (fungal) Bronchiolitis obliterans Drug abuse (excludes alcohol abuse) Patient refused further treatment Suicide Therapy ceased for any other reason Alcohol abuse Pulmonary embolus Cerebro/vascular accident Hemorrhage from graft site—specify Hemorrhage from vascular access or dialysis circuit Ruptured vascular aneurysm (not							

Name	Description	Values	Data Rules	R	L	PR	PE	PO
		cerebrovascular accident) Hemorrhage from surgery (not hemorrhage from graft site or vascular access or dialysis) —specify Other hemorrhage Vascular thrombosis Pulmonary vein stenosis Stent/balloon complication						

Appendix C – Deceased Donor Data for Kidney Community

	Name	Description	Values	Data Rules	Mandatory
	Registration				
	Identifiers				
●	National Donor ID	National donor identifier generated by registry.	Identifier	Calculated by system when record created.	Required to create record
●	Local Donor ID	Local donor identifier entered by OPO.	Identifier	≤ 50 characters	Required to create record
●	Date of Birth	Date of birth of donor.	YYYY-MM-DD	≤ current date	Required to create record
	Donor Case Status				
●	Donor Type	Flag indicating type of donor.	Deceased Living	Defaulted to Deceased	Required to create record
●	Donor Case	State of donor case e.g. open or closed.	Open Closed	Defaulted to Open	Required to create record
	Demographics				
●	Gender	Gender of donor.	Male Female Other Unknown	Single selection list	Required to create record
●	Height (cm)	Height of donor in cm.	cm	≥ 0.0 and ≤ 300.0	Required to create record
●	Weight (kg)	Weight of donor in kg.	kg	≥ 0.0 and ≤ 700.0	Required to create record
●	ABO	Blood type of donor.	A B O AB unknown	Single selection list	Required for VXM and offer
●	Confirm ABO	Confirm blood group by re-entering blood group.	Free-text	≤ 4 characters	Required for VXM and offer

	Name	Description	Values	Data Rules	Mandatory
	Ethnicity	Ethnicity of donor.	Aboriginal Asian Black Caucasian Indian subcontinent Latin American Middle Eastern/Arabian Pacific Islander Other/Multicultural	Single selection list	Required for VXM and offer
	Facility				
	OPO	Organ Procurement Organization responsible for donor.	Abbreviated and full name of OPO	Single selection list	Required to create record
	HLA lab	HLA lab responsible for providing HLA typing.	Abbreviated and full name of HLA	Derived by system based on associated Transplant Centre.	Required to create record
	Referral Hospital	Hospital where potential deceased donor is identified.	Hospital name with city	n/a	Required to create record
	Retrieval Hospital	Hospital where the deceased donor organ procurement surgery takes place.	Hospital name with city	Single selection list	Required to close donor case
	Consent				
	Kidney Consent State	Consent state of kidney.	Consented Not Consented Not Participating	Single selection list	Required for VXM and offer
	Declaration of Death				
	Death				
	Type of Declaration of Death	Declaration of death could be neurological determination of death (NDD) or donor after cardio circulatory death (DCD).	NDD DCD	Single selection list	Required for VXM and offer
	Cause of Death	Deceased donor cause of death.	Encephalitis Ancephaly Anoxia/Hypoxia Arteriovenous malformation Cerebral abscess	Single selection list	Required for VXM and offer

Name	Description	Values	Data Rules	Mandatory
		Cerebral oedema Cerebrovascular accident (stroke) Diabetic ketoacidosis Drug Overdose-Barbiturate Drug Overdose-Benzodiazepine Drug Overdose-Carbon monoxide Drug Overdose-Opiate Fall Gunshot Hepatic failure Hydrocephalus Hyponatremia Inborn error of metabolism Meningitis Motor vehicle collision Primary CNS tumour Ruptured cerebral aneurysm Subarachnoid hemorrhage Unknown Other-comment required		
Country of Death	Country where deceased donor was declared dead.	Canada United States Australia Austria Belgium Czechoslovakia Denmark France Germany Israel Italy Japan Mexico Spain Sweden United Kingdom	Single selection list	Required for VXM and offer

	Name	Description	Values	Data Rules	Mandatory
●	Province/State of Death	Province or state where donor was declared dead.	Canadian provinces and territories US states	Single selection list	Required for VXM and offer
	NDD				
●	First Brain Death Date/ Time	First brain death date/time for NDD.	Date and time	≤ current date/time and ≥ date of birth of donor. ≤ cross clamp date/time. Mandatory for NDD only.	Required for VXM and offer
	DCD				
●	Withdrawal of Life Support Date/Time	Date/Time life support was withdrawn.	Date and time	≤ current date/time and ≥ date of birth of donor. Mandatory for DCD only.	Required to close donor case
●	DCD Declaration Start Date/Time	Start of lack of spontaneous circulation.	Date and time	≤ current date/time and ≥ withdrawal of life support date/time. ≤ DCD Declaration End Date/Time. Mandatory for DCD only.	Required to close donor case
●	DCD Declaration End Date/Time	Confirmation of lack of spontaneous circulation and actual death date/time.	Date and time	≤ current date/time and ≥ withdrawal of life support date/time. ≥ DCD Declaration Start Date/Time. Mandatory for DCD only.	Required to close donor case
	Assessment				
	Medical/Social History				
●	Breast Fed	Flag indicating if the deceased donor has been breast fed in past 12 months.	Yes No Unknown	Single selection list	Required for VXM and offer
●	Drug Use	Flag indicating if patient has a history of drug use.	Yes No Unknown	Single selection list	Required for offer
●	Drug Use Details	Specify details of drug use.	Details	≤ 2000 characters	Required for offer
●	High Risk Sexual Activity	Flag indicating if patient has high risk of sexual activity.	Yes No Unknown	Single selection list	Required for offer

Name	Description	Values	Data Rules	Mandatory
Alcohol History	Flag indicating if patient has alcohol history.	Yes No Unknown	Single selection list. If yes then specify the intensity.	Required for offer
Smoking History	Flag indicating if patient has a history of smoking.	Yes No Unknown	Single selection list If yes specify one of the following: Current Former Never	Required for offer
Cancer History	Flag indicating if patient has history of cancer.	Yes No Unknown	Single selection list If yes then specify all that apply: Skin Melanoma Skin Non-Melanoma CNS Tumour Genitourinary Breast Thyroid Tongue/Throat/Larynx Lung Leukemia/Lymphoma Liver Hepatocellular Carcinoma – Liver only Other please specify	Required for offer
Cancer Free Interval	Time period in years from diagnosis to donation.	Integer representing number of years.	n/a	Required for offer
Hypertension	Flag indicating if patient has hypertension.	Yes No Unknown	Single selection list	Required for offer
Hyperlipidemia	Flag indicating if patient had elevated concentrations of any or all lipids in plasma, such as cholesterol, triglycerides and lipoproteins.	Yes No Unknown	Single selection list	Required for offer

Name	Description	Values	Data Rules	Mandatory
Heart Disease	Flag indicating if patient has heart disease.	Yes No Unknown	Single selection list	Required for offer
Coronary Artery Disease	Flag indicating if patient has coronary artery disease.	Yes No Unknown	Single selection list	Required for offer
History of previous MI	Flag indicating if patient has a history of previous myocardial infraction.	Yes No Unknown	Single selection list	Required for offer
Pulmonary Disease	Flag indicating if patient has pulmonary disease.	Yes No Unknown	Single selection list	Required for offer
Kidney Disease	Flag indicating if patient has kidney disease.	Yes No Unknown	Single selection list	Required for offer
Diabetes History	Flag indicating if patient has a history of diabetes.	Yes No Unknown	Single selection list	Required for offer
Liver Disease	Flag indicating if patient has liver disease.	Yes No Unknown	Single selection list	Required for offer
Cardio Respiratory Arrest	Flag indicating if patient had cardio respiratory arrest.	Yes No Unknown	Single selection list	Required for offer
Cardio Respiratory Arrest Duration (min)	Duration of cardio respiratory arrest.	Minutes	≥ 0 minutes	Required if Cardio Respiratory Arrest = Yes
Trauma History	Flag indicating if patient has a history of trauma.	Yes No Unknown	Single selection list	Required for offer
Previous Surgeries	Flag indicating if patient had previous surgeries.	Yes No Unknown	Single selection list	Required for offer
Travel History	Flag indicating if patient has a history of travel.	Yes No Unknown	Single selection list	Required for offer

	Name	Description	Values	Data Rules	Mandatory
	Tattoos	Flag indicating if patient has tattoos.	Yes No Unknown	Single selection list	Required for offer
	Other Risks	Flag indicating if patient has other risks.	Yes No Unknown	Single selection list	Required for offer
	Other Risk Details		Details	≤ 2000 characters	Required if Other Risks = Yes or Unknown
	Exceptional Distribution				
	Exceptional Distribution	Flag indicating if donor is exceptional distribution.	Yes No	Single selection list	Required for offer
	Exceptional Distribution flags	Selectable list of exceptional distribution reasons.	List of exceptional distribution reasons	Multiple selection list	Select reason if Exceptional Distribution = Yes
	Exceptional Distribution Comments	Comments related to exceptional distribution.	Details	≤ 1024 characters for each comment added	Optional
	HLA				
	A_1	HLA typing of donor.	Molecular allele	≤ 20 characters	Required for VXM and offer
	A_2	HLA typing of donor.	Molecular allele	See rules in A_1 molecular allele.	Required for VXM and offer
	B_1	HLA typing of donor.	Molecular allele	See rules in A_1 molecular allele.	Required for VXM and offer
	B_2	HLA typing of donor.	Molecular allele	See rules in A_1 molecular allele.	Required for VXM and offer
	C_1	HLA typing of donor.	Molecular allele	See rules in A_1 molecular allele.	Required for VXM and offer
	C_2	HLA typing of donor.	Molecular allele	See rules in A_1 molecular allele.	Required for VXM and offer
	DRB1_1	HLA typing of donor.	Molecular allele	See rules in A_1 molecular allele.	Required for VXM and offer

Name	Description	Values	Data Rules	Mandatory
DRB1_2	HLA typing of donor.	Molecular allele	See rules in A_1 molecular allele.	Required for VXM and offer
DRB3_1	HLA typing of donor.	Molecular allele	See rules in A_1 molecular. Of the six text-entry fields which are available for the locus DRB3, DRB4, and DRB5, a maximum of two values may be entered, and a minimum of one value must be entered.	Required for VXM and offer
DRB3_2	HLA typing of donor.	Molecular allele	See rules in A_1 molecular allele.	Required for VXM and offer
DRB4_1	HLA typing of donor.	Molecular allele	See rules in A_1 molecular allele.	Required for VXM and offer
DRB4_2	HLA typing of donor.	Molecular allele	See rules in A_1 molecular allele.	Required for VXM and offer
DRB5_1	HLA typing of donor.	Molecular allele	See rules in A_1 molecular allele.	Required for VXM and offer
DRB5_2	HLA typing of donor.	Molecular allele	See rules in A_1 molecular allele.	Required for VXM and offer
DRB 3/4/5 Tested, but not present	Flag indicating if DRB3, DRB4 and DRB5 tested but not present.	Yes No	When no values are entered for DRB3, DRB4, and DRB5, and the HLA typing is to be considered complete, then indicate that DRB3, DRB4, and DRB5 were “Tested, but not present”.	Required for VXM and offer
DPA1_1	HLA typing of donor.	Molecular allele	See rules in A_1 molecular allele.	Required for VXM and offer
DPA1_2	HLA typing of donor.	Molecular allele	See rules in A_1 molecular allele.	Required for VXM and offer
DPB1_1	HLA typing of donor.	Molecular allele	See rules in A_1 molecular allele.	Required for VXM and offer

Name	Description	Values	Data Rules	Mandatory
DPB1_2	HLA typing of donor.	Molecular allele	See rules in A_1 molecular allele.	Required for VXM and offer
DQA1_1	HLA typing of donor.	Molecular allele	See rules in A_1 molecular allele.	Required for VXM and offer
DQA1_2	HLA typing of donor.	Molecular allele	See rules in A_1 molecular allele.	Required for VXM and offer
DQB1_1	HLA typing of donor.	Molecular allele	See rules in A_1 molecular allele.	Required for VXM and offer
DQB1_2	HLA typing of donor.	Molecular allele	See rules in A_1 molecular allele.	Required for VXM and offer
HLA Typing Confirmed	User confirms HLA Typing.	Yes No	Default = blank	Required for VXM and offer
Serology – For each serology - multiple time points can be captured - a test type must be recorded for each serology result - sample drawn date/time recorded for each result				
Sample Drawn Date/Time	Date/Time serology (blood) sample is drawn.	Date and time	≤ current date/time and Must be greater than date of birth of donor. Required for any serology test result entered in registry.	Required for any serology test result entered in registry
Sample Dilution	Flag indicating if serology sample is diluted or undiluted.	Diluted Undiluted	n/a	Required for any serology test result entered in the registry
Serology Source	Flag indicating source of serology sample drawn.	Mother Donor	Defaulted to Donor	Required for any serology test result entered in the registry
CMV	CMV result based on IgG test.	Positive Negative Pending Not Tested Indeterminate	At least one result is required.	Required for VXM and offer

Name	Description	Values	Data Rules	Mandatory
EBV	EBV result based on any of the following tests: IgG (VCA) or IgG (EBNA), IgM.	Positive Negative Pending Not Tested Indeterminate	At least one result is required.	Required for VXM and offer
Hepatitis B Core Antibody	HBV result based on Anti-HBc (HBcAb) test.	Positive Negative Pending Not Tested Indeterminate	At least one result is required.	Required for VXM and offer
Hepatitis B Surface Antibody	HBV result based on Anti-HBs (HBsAb) test.	Positive Negative Pending Not Tested Indeterminate	At least one result is required	Required for VXM and offer
Hepatitis B Surface Antigen	HBV result based on the following test; HBsAG test, NAT.	Positive Negative Pending Not Tested Indeterminate	At least one result is required.	Required for VXM and offer
Hepatitis B NAT	Hepatitis B NAT test result.	Positive Negative Pending Not Tested	At least one result is required.	Required for offer
Hepatitis C Antibody	HCV result based on IgG test.	Positive Negative Pending Not Tested Indeterminate	At least one result is required.	Required for VXM and offer
Hepatitis C NAT	HCV result based on the following tests: HCV RNA NAT, Double NAT (HIV, HCV), Triple NAT (HIV, HCV, HBV).	Positive Negative Pending Not Tested	At least one result is required.	Required for VXM and offer

	Name	Description	Values	Data Rules	Mandatory
	HIV I and II Antibody	HIV I and II result based on any of the following tests: IgG, Antibody/ p24antigen.	Positive Negative Pending Not Tested Indeterminate	At least one result is required.	Required for VXM and offer
	HIV I and II NAT	HIV I and II result based on any of the following tests: HIV NAT (HIV DNA, HIV Single NAT), Double NAT (HIV, HCV), and Triple NAT (HIV, HCV, and HBV).	Positive Negative Pending Not Tested	At least one result is required.	Required for VXM and offer
	HTLV I and II	HTLV I and II result based on IgG test.	Positive Negative Pending Not Tested Indeterminate	At least one result is required.	Required for offer
	Syphilis	Syphilis result based on the following tests: EIA, RPR, VDRL, FTA-ABS.	Positive Negative Pending Not Tested Indeterminate	At least one result is required.	Required for offer
	West Nile	West Nile result based on IgG, IgM, NAT.	Positive Negative Pending Not Tested Indeterminate	At least one result is required.	Required for offer
	VZV		Positive Negative Indeterminate Not Tested	At least one result is required.	Required for offer
	Electrolytes– For each electrolyte - multiple time points can be captured - for living donor mandatory pre-operative - for deceased donor mandatory pre-terminal				
	Date/Time of Collection		Date and time	≤ current date/time and must be greater than date	Required for any Chemistry entered in

Name	Description	Values	Data Rules	Mandatory
			of birth of donor.	the registry
Creatinine (mmol/L)	Serum Creatinine	Numeric	≥ 0 and ≤ 9999	Required for offer
Recovery				
Disposition				
Cross Clamp Date/ Time	Date and time organs were recovered and flushed with a specially prepared, ice-cold solution.	Date and time	≤ current date/time and Must be greater than first brain death date/time for NDD Donor or DCD Declaration End Date/Time for DCD Donor If organ recovered for transplant then cross clamp date/time required	Required to close donor case
Perfusion	Organ device used to perfuse organ.	Kidney Perfusion Pump Exvivo Pump None	Single selection list	Required to close donor case
Kidney Recovered State	Recovered state of organ.	Recovered Not recovered	If organ consented then recovery details required.	Required to close donor case
Not Recovered Reason	Not recovered reason for each organ.	Coroner / medical examiner decline No suitable recipient (size/ABO) Storage and preservation problems No recipient located No recovery team available Medically unsuitable pre OR Medically unsuitable intra OR Unable to maintain donor pre OR Technical problem in OR Transportation logistics Problem with recipient All offers declined DCD did not die within acceptable time High inotrope requirement Inadequate perfusion of organ (thrombosis) Infection/sepsis	Single selection list	Required if not recovered selected

Name	Description	Values	Data Rules	Mandatory
		Organ damaged during recovery Unable to maintain donor intra OR		
Recovered For Reason	Recovered for a specific medical use, for each organ.	Transplant Research Medical Education Tissue Not Used Not Applicable Pathology	Single selection list	Required if recovered selected
Kidney Transplanted State	Transplanted state of organ.	Transplanted Not Transplanted	If organ consented then transplant details required.	Required to close donor case
Not Transplanted Reason	Not transplanted reason for each organ.	Cold Ischemia Time Lack of recipient hospital resources No suitable recipient Organ no longer transplantable Recipient died Recipient medically unsuitable Storage and preservation problems Technical problem in OR Transportation logistics Warm Ischemia Time	Single selection list	Required if not transplanted selected
Not Transplanted Disposition	Specify disposition of not transplanted organ.	Medical Education Not Used Pathology Research Tissue	Single selection list	Required if not transplanted selected

Appendix D – Sample Data Scan

Data Element	HDWG ..	HDWG R	HDWG Pr	HDWG Pe	HDWG Po	CORR H	UNOS H	NHSBT H	ISHLT	IMACS
Registration	**14**	**4**	**4**	**0**	**0**	**16**	**19**	**29**	**6**	
Identifying Information	2	0	2	0	0	3	3	5	2	
Date of Birth						M	M	M	M	●
First Name						M	M	M	O	●
Middle Name									O	●
Last Name						M	M	M	O	●
Former Last Name										
LDPE ID										
Local Recipient ID									M	
National Recipient ID								M		
Provincial Health Number (PHN)	M		M			O	O	M		
PHN/Home Prov	M		M			O				
Registered On LDPE										
Contact Information	2	0	2	0	0	3	2	4	0	
Contact Relationship										
Order of contact										
Address								M		
City						M				
Email										
Postal Code	M		M			M	M	M		
Province	M		M			M	M	M		
Telephone-Home								M		
Telephone-Mobile										
Telephone-Work										
Patient Waiting in Permanent ZIP Code							O			
Demographics	5	4	0	0	0	5	8	9	3	
Body Metrics	3	4	0	0	0	4	3	6	3	
Age									M	
Advanced Age										●
Gender	M					M	M	M	M	●
Height (cm)	M					M	M	M	O	●
Weight (kg)	M					M	M	M	O	●
BMI							C			
Body Surface Area (Peds)		C						M		
ABO		M				M	O	M	M	●
Confirm ABO		M								
RH		M						M		
Confirm RH		M								
In-utero										

Appendix E – Terms of Reference

Organ Donation and Transplantation

Kidney Data Working Group

Terms of Reference

Objectives

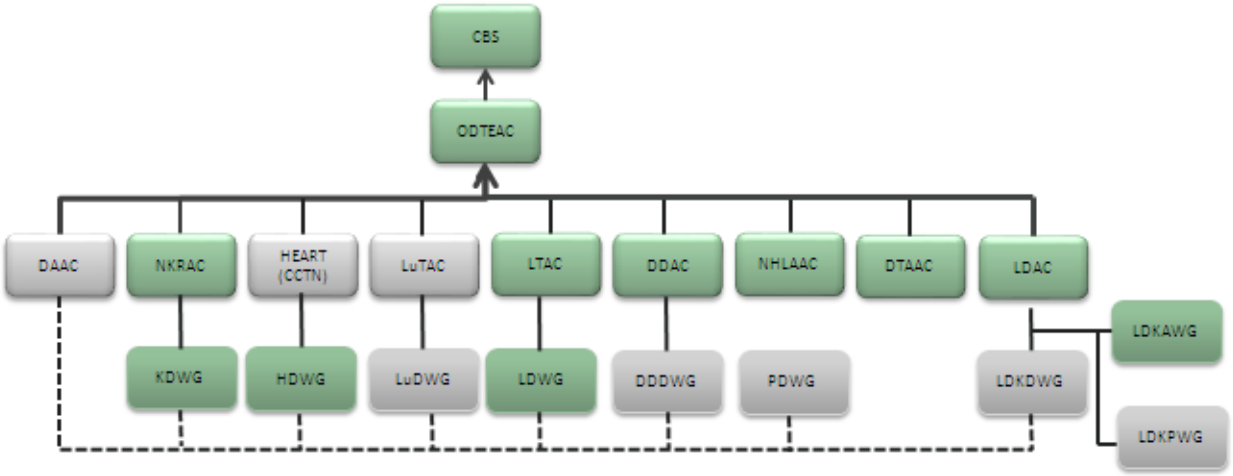
The provincial and territorial governments have funded Canadian Blood Services to develop and operate the CTR. The national registry system includes a data warehouse with business intelligence tools that provide accurate, timely and comprehensive data to support research, national and provincial measurement, and the modelling and analytical needs of the Canadian organ donation and transplantation community.

Building on the CTR data warehouse, Canadian Blood Services is responding to the vision articulated at the June 2013 ODT Data, Analytics and Reporting System Workshop, to build a world-leading data system that provides timely access to high quality ODT information for patient care, system management and accountability. One of the supporting activities to enhancing the ODT Data System is to convene organ and donation-specific data working groups to develop transplant measures and identify a transplant data set to facilitate clinical practice decision making, development of practice standards and inform outcomes reporting for transplantation in Canada.

KDWG will serve to:

- Provide expert advice on *data* that will support inter-provincial operational and clinical policies, standards of practice and evidence-based practice with respect to kidney listing and allocation.
- Develop a kidney transplant data set to facilitate clinical practice decision making, development of practice standards, inform outcomes reporting, and advance the science of kidney transplantation.
- Develop a framework for the creation and application of kidney transplant performance measures to track the quality and outcomes of care across the country.

Organ Donation & Transplantation Committees



CBS: Canadian Blood Services

ODTEAC: Organ Donation & Transplantation Expert Advisory Committee

DAAC: Data & Analytics Advisory Committee (In development)

NKRAC: National Kidney Registries Advisory Committee

CCTN: Canadian Cardiac Transplantation Network

LuTAC: Lung Transplant Advisory Committee (TBD)

LTAC: Liver Transplant Advisory Committee

DDAC: Deceased Donation Advisory Committee

NHLAAC: National Human Leukocyte Antigen Advisory Committee

DTAAC: Donation and Transplant Administrators Advisory Committee

LDAC: Living Donation Advisory Committee

KDWG: Kidney Data Working Group

HDWG: Heart Data Working Group

LuDWG: Lung Data Working Group (In development)

LDWG: Liver Data Working Group

DDDWG: Deceased Donation Data Working Group

PDWG: Pancreas Data Working Group (In development)

LDKDWG: Living Donation Kidney Data Working Group (In development)

LDKAWG: Living Donation Kidney Administrators Working Group

LDKPWG: Living Donation Kidney Protocols Working Group

Scope

The Working Group's scope encompasses matters related to inter-provincial kidney transplant practices, including listing and allocation practices, and kidney transplant outcomes in support of the CTR. To contribute to the data needs that will inform clinical decisions with respect to kidney transplantation and outcomes reporting, the Working Group will:

- Identify data points along the kidney donation, allocation, and transplantation critical path that are important to characterize and evaluate the journey of donors and patients through the kidney transplantation process
- Identify the availability and gaps in current data for living and deceased kidney donors and recipients, and the comparability of data amongst kidney transplant programs
- Develop a minimum data set for kidney transplantation with regards to wait-listing, events after wait-listing, the kidney transplant procedure, and both short- and long-term outcomes
- Advise on the scope of kidney data to improve health information management and recommend a quality control strategy to assess the quality and completeness of data submissions to the registry
- Produce a report that includes a proposal for a minimum data set for kidney transplantation; the data points that should be captured along the kidney donation, allocation, and transplantation critical path; recommendations for a quality strategy; and opportunities for data collection that support innovation and scientific advancement in the field of kidney transplantation

Authority

The KWDG shall function under the current scope and authority of Canadian Blood Services until such time that a formal governance and accountability structure is approved by the Federal Provincial Territorial Deputy Ministers of Health. The KWDG will report to the NKRAC, the kidney representative for the Canadian Blood Services collaborative endeavour in the continued development of the CTR. The Chair of the Working Group committee shall be appointed by Canadian Blood Services and the NKRAC.

Reporting

KWDG will report to the NKRAC, DAAC and to the ODTEAC. Activities may also be reported to an interprovincial government committee, the Provincial and Territorial Blood Liaison Committee, as part of the performance reporting requirements for Canadian Blood Services as set out by governments.

Composition of the Kidney Data Working Group

Membership in KDWG will include five to eight individuals with relevant professional knowledge and experience in kidney transplantation. Members will also have a deep appreciation and interest in the use of kidney data to advance kidney donation and transplantation in Canada.

Canadian Blood Services, with the concurrence of the Chair, has the ability to request the appointment of new members as the need is identified.

Membership will balance and encompass representation from kidney transplantation programs across Canada. Subject matter experts may be invited to attend specific Working Group meetings as required. Absence from more than two meetings in a 12 month period may result in revocation of membership.

Chair

The Chair of the Committee shall be appointed by Canadian Blood Services and NKRAC and shall serve a two year term. Upon completion of this term Canadian Blood Services may extend the appointment. The Chair of the Committee is responsible for ensuring that the Committee functions within these Terms of Reference and will provide regular updates to the DAAC and NKRAC on the activities of KDWG.

Processes and Timeframes

- The day and time for teleconferences will be set based on agreed membership preference
- Materials will be circulated to members five business days in advance of the teleconference

Quorum

- A majority of the voting members of the Committee shall constitute a quorum.
- Ordinarily, decisions and recommendations of the Committee will be achieved by consensus.

Meetings

- CBS will provide the Secretariat to the Committee meetings.
- Meetings will be held monthly, or at the call of the Chair.
- Members shall not send delegates to meetings, unless approved by the Chair.

Confidentiality

All materials used in support of committee business must be treated as confidential Kidney Data Working Group business and should not be distributed without the approval of CBS.

Evaluation

Prior to the final teleconference of the Kidney Data Working Group an evaluation of the performance of the working group will be undertaken and the results will be shared with members.