Canadian Blood Services
Société canadienne du sang

Lung 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).

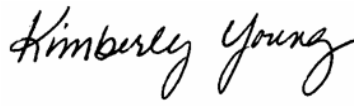
On behalf of Canadian Blood Services, we would like to thank the Lung Data Working Group (LuDWG) members for their participation. This effort represents an important step in building a national data system that will serve the needs of clinicians and researchers by facilitating clinical practice decision-making, developing standards, and informing outcomes reporting for Lung 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 LuDWG, 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 Lung Transplant Advisory Committee (LuTAC). 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.



Kimberly Young, Director,
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1. Acronyms

CTR	Canadian Transplant Registry
CORR	Canadian Organ Replacement Register
DAAC	Data & Analytics Advisory Committee
DDAC	Deceased Donation Advisory Committee
DDDWG	Deceased Donor Data Working Group
DTAAC	Donation and Transplant Administrators Advisory Committee
ISAC	Information Strategy Advisory Committee
ISHLT	International Society of Heart and Lung Transplantation
LuDWG	Lung Data Working Group
LuTAC	Lung Transplant Advisory Committee
NHSBT	National Health Services Blood and Transplant
ODT	Organ Donation Transplantation
ODTEAC	Organ Donation & Transplantation Expert Advisory Committee

2. Background

The Lung Data Working Group (LuDWG) was convened by Canadian Blood Services in November 2013 to develop a lung transplant data set that will facilitate clinical practice decision-making, the development of standards, and the informing of outcomes reporting for lung 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 LuDWG had the following objectives:

1. Develop a lung transplant data set to inform outcome reporting, facilitate clinical practice decision-making, develop practice standards and advance the science of lung transplantation.

2. Provide expert advice on data that will support inter-provincial operational and clinical policies, standards of practice, and evidence-based practice with respect to lung listing and allocation.

3. Develop a framework for the creation and application of lung transplant performance measures to track the quality and outcomes of care across the country.

The report recommends a national lung 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 lung transplantation in Canada. In addition, it summarizes key considerations and activities of the LuDWG. The report will be presented and discussed at the Lung Transplant Advisory Committee (LuTAC) and the Information Strategy Advisory Committee (ISAC). This will be followed by further discussions with key stakeholder groups.

3. Scope of the Data Working group

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

1. Develop a minimum data set for lung transplantation to support clinical decisions and research, with regards to lung waitlist outcomes, lung transplant activity, lung transplant outcomes, and mechanical circulatory support use and outcomes.

2. Identify data collection points along the lung donation, allocation and transplant critical path.

3. Develop a quality control strategy to assess the quality and completeness of data submissions to the registry.

4. Identify the availability, gaps, and comparability of current data systems amongst lung transplant programs and work to assess the feasibility of the implementation of a national data collection collaborative initiative.

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 continue to evolve a national information management network. This vision was further articulated at the June 2013 ODT Data, Analytics and Reporting System Workshop, where a set of guiding principles for data was proposed that will promote accurate, timely and valid data which will move us closer to greater transparency in information management. The LuDWG 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 LuDWG expanded their list of guiding principles to encompass elements specific to their scope of developing a national minimum data set for lung 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 minimum data set will support data sharing and satisfy international data registry contribution requirements.

5. 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.

6. LuDWG will ensure that the national data set lends itself to national and international benchmarking by Transplant Programs.

5. Key Considerations

During the development of the national minimum data set, LuDWG recognized the following considerations:

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

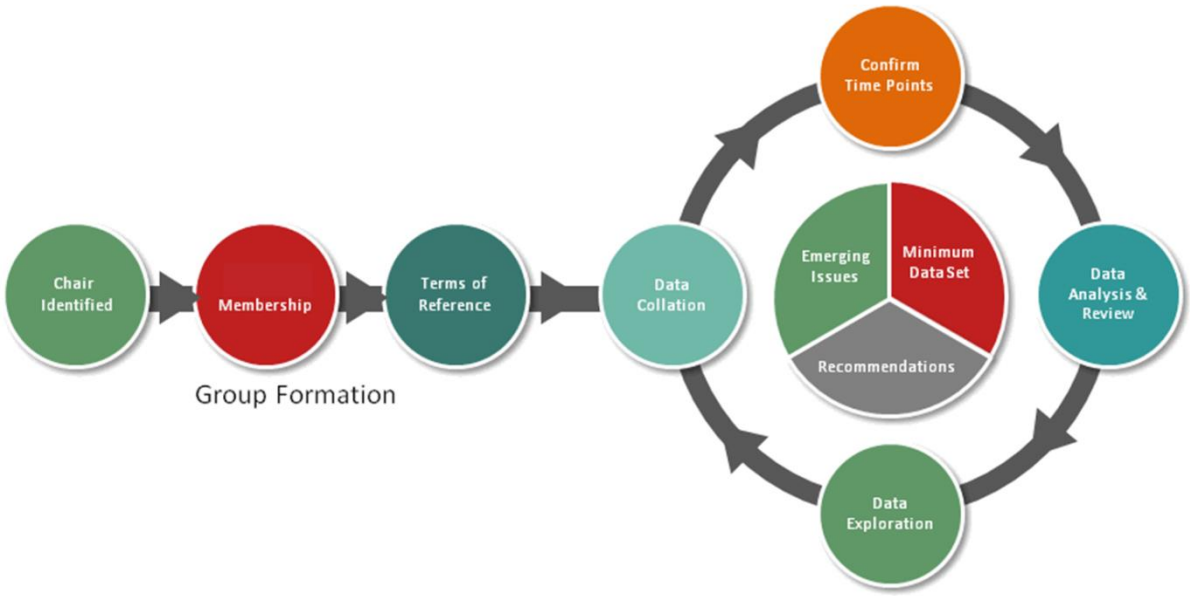
2. There is a definite financial impact to stakeholders due to the need for increased resources, infrastructure, and the development of the requirements necessary to support the recommended data collection and data linkages between systems.

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 lung transplantation in Canada.

6. Process

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



6.1 Group Formation

The Chair of the LuDWG was appointed by Canadian Blood Services and LuTAC. Canadian Blood Services met with the Chair to discuss the objectives and scope of LuDWG. Members of the LuDWG were identified at an initial face-to-face meeting at which an agreement was made on terms of reference and the approach which the working group would take to achieve its scope. The LuDWG informed Canadian Blood Services regarding the data sources they would analyze and review. Monthly teleconference meetings were set up between Canadian Blood Services and the LuDWG Chair to discuss emerging issues, develop recommendations and gain expertise from other knowledge areas.

6.2 Data Collation

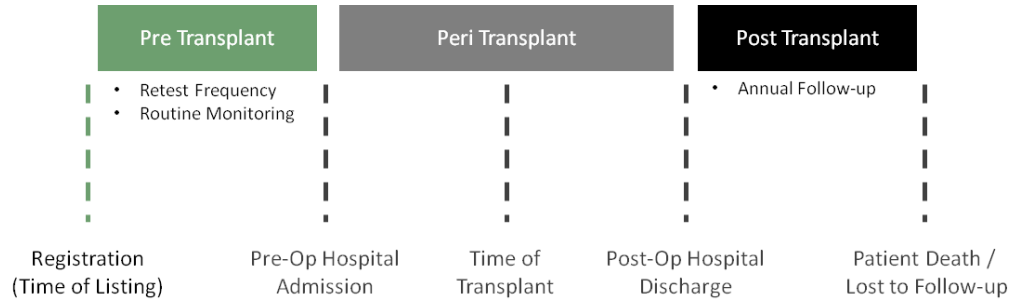
In order to best inform lung transplant reporting practices, an assessment of other transplant registries from the international community was produced by Canadian Blood Services. The outcome of this assessment was an environmental scan containing data elements captured in CTR and other transplant registries. This provided the group with perspective on what mature registries are collecting and helped 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 LuDWG:

1. Canadian Organ Replacement Register (CORR) – Canada
2. Scientific Registry of Transplant Recipients (SRTR) – United States of America
3. National Health Services Blood and Transplant (NHSBT) Registry – Great Britain
4. International Society of Heart and Lung Transplantation (ISHLT) Registry

Furthermore, Minimum Data Sets already developed by previous Data Working Groups (specifically Heart) were assessed for Canadian-specific parameters and for guidance on appropriate mandatory and optional variables.

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 LuDWG agreed on four specific reference points, and four time periods, 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
At time of listing	Time when patient is activated on the lung transplant waiting list or activated for living donor transplant	Provides detailed information of the patient at the time of listing
At time of transplant	From time of listing to time transplant is completed, including the details of the transplant surgery	This time range includes all changes in clinical status from time of listing to time of transplant, and also includes surgical detail of both donor and graft.
At first transplant follow-up or death	From time of completion of transplant, through hospital discharge, to graft failure, death, or lost to follow-up	All details of post-operative hospital stay, until first visit to clinic post-discharge.
Annual follow up, death or lost to follow Up	From post-op hospital discharge to patient graft failure, patient loss to follow-up or death	Includes details of all clinically significant occurrences in the past year, between regular annual follow-ups.

6.4 Data Analysis and Review

The LuDWG 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 LuDWG 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 lung community organizations are collecting, provided the LuDWG 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 LuDWG 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.

7. Recommendations

7.1 Minimum Data Set

The national lung 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 Lung Transplant Data Collection, as follows:

1. Designate at transplant center will complete collection of all data elements in "Recipient Lung Transplant Data Collection Form".

2. Designate at transplant center will scan and upload original lung transplant 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.

7.2 Deceased Donor Data

The LuDWG made a recommendation on deceased donor data that should be mandatory from the perspective of the lung 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 Lung Community.

7.3 Time Points

The LuDWG 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 LuDWG that these time points and related data gathering practices be adopted nationally for lung transplant patient data.

7.4 Quality Control Strategy

Part of the LuDWG'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 LuDWG reviewed the outcomes of the Data, Analytics and Reporting Systems Workshop where 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 LuDWG 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]

It is the recommendation of the LuDWG that the LuTAC and 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 sources, including organ procurement organizations, where they exist; and
5. Periodic data audits at the transplant centres.

[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]

7.5 Emerging Issues

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

Emerging Issues	Comment	Recommendation
Composite Scores	The calculation of composite scores such as the Lung Allocation Score for objective assessment of severity of disease across centers	Take to LuTAC
Data Linkages	The automated process of forwarding inputted data to international registries (namely the ISHLT registry), in order to allow Canada to be an actively participating nation	Take to ISAC
Lung HLA Post Transplant	Accessing the HLA databases in order to follow cases of Virtual Cross Match positive transplants and to follow their outcomes	Take to NHLAAC
Donor Data	Documenting donor lung availability and tracking acceptance rates and use of EVLP	Take to DDDWG

Appendix A – Lung Data Working Group Membership

Dr. Alim Hirji (Chair)	Respirologist, Alberta Lung Transplant Program University of Alberta Hospital Edmonton, Alberta
Dr. Robert Levy	Medical Director, Lung Transplant Program Vancouver General Hospital Vancouver, British Columbia
Dr. Dale C. Lien	Medical Director, Lung Transplant Program University of Alberta Hospital Edmonton, Alberta
Dr. Nancy Porhownik	Respirologist Health Sciences Centre Winnipeg, Manitoba
Dr. Lianne G. Singer	Medical Director, Toronto Lung Transplant Program Toronto General Hospital Toronto, Ontario
Dr. Kathryn Tinckam	Co-director, Histocompatibility Laboratory Laboratory Medicine Program University Health Network Toronto, Ontario
Dr. Charles D. Poirier	Medical Director, Program of Lung Transplantation Centre Hospitalier de L'Universite de Montréal Montreal, Quebec
Sean Delaney	Associate Director, CTR 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 – Lung National Data Set

The LuDWG is recommending a national data set of 98 mandatory fields (39 new), 165 optional fields (107 new) and 40 calculated fields (1 new) for a total of 303 distinct data elements.

Lung Data Working Group Data Set Recommendation Summary

	Total	● New Fields	● Modified	● No Change
All Fields	**332**	**177**	**19**	**136**
Mandatory	**99**	40	18	41
Calculated	**40**	1	1	38
Optional	**193**	136	0	57

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

- At Time of Listing (L)
- At Time of Transplant (T)
- At Time of the First Follow up (FF)
- Annual Follow up (AF)

Beside each element is a letter (M, O or C). These letters indicate whether LuDWG 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	L	T	FF	AF
	Registration							
	Identifying Information							
●	Date of Birth	Date of birth of patient.	Date	≤ current date	M			
●	First Name	First name of patient.	Name	≤ 50 characters	M			
●	Middle Name	Middle name of patient.	Name	≤ 50 characters	O			
●	Last Name	Last name of patient.	Name	≤ 50 characters	M			
●	Former Last Name	Former last name of patient.	Name	≤ 50 characters	O			
●	Local Recipient ID	Unique local identifier provided by local Transplant Program.	Identifier	≤ 50 characters	M			
●	National Patient ID	Unique national patient identifier created by Registry.	Identifier	n/a	C	C	C	C
●	PHN	Provincial health number of patient.	Identifier	≤ 50 characters	M			
●	PHN/Home/Listing Province	Province associated to PHN or Home or Listing province of patient.	Alberta British Columbia Manitoba New Brunswick Newfoundland and Labrador Northwest Territories Nova Scotia Nunavut Ontario Prince Edward Island Quebec Saskatchewan Yukon Not Applicable	Single selection list. If patient has a PHN then PHN province is 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			

	Name	Description	Values	Data Rules	L	T	FF	AF
	Contact Information							
●	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			
●	Postal Code	Postal code associated to patient's address where they can be contacted	Postal code	≤ 10 characters Format must be X9X 9X9	M			
●	Province	Province associated to patient's address where they can be contacted.	Alberta British Columbia Manitoba New Brunswick Newfoundland and Labrador Northwest Territories Nova Scotia Nunavut Ontario Prince Edward Island Quebec Saskatchewan Yukon Not Applicable	Single selection list	M			
	Demographics							
	Body Metrics							
●	Age	Age of patient.	Age in years, months, weeks	Calculated by the system based on Date of Birth. Require ability to derive age at transplant.	C	C	C	C
●	Sex	Sex of patient.	Male Female Other Unknown	Single selection list	M			

	Name	Description	Values	Data Rules	L	T	FF	AF
●	Height	Height of patient.	cm	0.0 to 300.0.	M	C	C	
●	Weight	Weight of patient.	kg	0.0 to 700.0.	M	M	M	
●	BMI	Body mass index of patient.	Numeric	BMI = weight (kg)/ (height (m) * height (m)).	C	C	C	C
●	ABO	Blood group of patient.	A B AB O unknown	Initially ABO may be unknown.	M			
●	RH	RH of patient.	+ -	Single selection list	M			
	Social Details							
●	Country of Residence	Country where patient is currently living.	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			
●	Academic Activity Level	Pediatric patient's academic activity level	Full Academic Load Reduced Academic Load Unable to Participate in Academic due to Disease/Condition Not Applicable < 5 Years Old/High School Graduate/GED Status Unknown	Single selection list. Required for pediatric patient only.	O			

	Name	Description	Values	Data Rules	L	T	FF	AF
●	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 Required for pediatric patients only.	O			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	O			O
●	Alcohol Use	Flag indicating if patient has current or past history of alcohol use.	Yes No Unknown	Single selection list	O			O
●	Current or Past Alcohol Use	Patient has consumed alcohol in last 6 months will be considered an active drinker	Active Past	Single selection list. If alcohol use = yes then specify whether patient has current or past alcohol use.	O			O
●	Current Alcohol Use	Alcohol consumption in past 6 months.	Heavy/Problem Drinking (2+ drinks/day) Minimal/ Social	Single selection list. If active drinker then specify current alcohol use.	O			O
●	Past Alcohol Use	Alcohol consumption greater than 6 months ago.	Heavy/Problem Drinking (2+ drinks/day) Minimal/ Social	If past drinker then specify past alcohol use.	O			O
●	Abstinence Duration	Duration since last alcohol drink	Number of months	< 300. If past drinker then specify abstinence duration.	O			O
●	Smoking history	Flag indicating if patient is a current or previous smoker	Yes No Unknown	Single selection list	O			O
●	Active or Past Smoker	Patient smoking in past 6 months.	Active Past	Single selection list. If smoking history = yes then specify whether patient is active or past smoker.	O			O

	Name	Description	Values	Data Rules	L	T	FF	AF
●	Pack Year History of Smoking	Number of years smoking x average number of packs per day.	Number	If active or past smoker then specify pack year history of smoking.	O			O
●	Year Quit Smoking	Year of last cigarette.	Year	<= current year. If past smoker then specify year quit smoking.	O			O
●	Drug Use	History of drug use.	Yes No Unknown	Single selection list	O			O
●	Current or Past Drug Use	Drug use in the past 6 months.	Active Past	Single selection list. If drug use = yes then specify whether patient has active or past drug use.	O			O
●	Current Drug Use	Drug use within past 6 months.	Identified Drug Abuse Social use	If active drug use then specify current drug use and list of drugs.	O			O
●	Past Drug Use	Drug use greater than 6 months ago.	History of Drug Abuse Social use	If past drug use then specify past drug use and list of drugs.	O			O

	Name	Description	Values	Data Rules	L	T	FF	AF
●	Drugs	Drugs used by patient.	Opium Morphine Codeine Heroin Methadone Fentanyl Cocaine/Crack MDMA Cannabis Ritalin Talwin Barbiturate – please specify Non Barbiturate Depressant – please specify Benzodiazepine – please specify Hallucinogen – please specify Prescription Drug – please specify Other – please specify	Multiple selection list. When current or past drug use specified then list of drugs required.	O			O
●	Abstinence Duration	Duration since last drug use.	Number of months	< 300 If past drug use then specify abstinence duration.	O			O
●	Current Mental Illness Therapy	Patient currently treated for a mental illness.	No Depression Bipolar Disorder Generalized Anxiety Disorder Schizophrenia Delusional Disorder Attention-Deficit Disorder Obsessive Compulsive Disorder Anorexia Nervosa Bulimia Nervosa Other – free-text	Multiple selection list	O	O		O
	Treatment Facilities							
●	Transplant Centre	Centre responsible for providing transplant surgery.	List of Transplant Centres	Single selection list	M			

	Name	Description	Values	Data Rules	L	T	FF	AF
	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			
	HLA Lab	HLA Lab responsible for providing HLA Typing and Antibody Screening results on patient.	List of HLA Labs	Selection list. Derived by system based on associated Transplant Centre.	M			
	ODO	Organ Donation Organization associated to patient's Transplant Centre.	List of ODOs	Single selection list. Derived by system based on associated Transplant Centre.	M			
	Follow Up Centre	Centre where primary post - transplant follow up takes place. These are centres which are responsible for pre-transplant and post-transplant care but actual transplant is carried out by a Transplant Centre.	List of Follow-Up Centres	Single selection list	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.	M			

	Name	Description	Values	Data Rules	L	T	FF	AF
●	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.	M			
●	Registry Entry Date	Date and time patient record created in registry.	Date and time	n/a	C			
●	Withdrawn Consent	Date and time patient has withdrawn consent to be in the registry.	Date and time	≤ current date. If consent is withdrawn then patient information must not be shared.	O			
	Living Donor and Recipient Pair							
●	Relationship of living donor to recipient	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	Single selection list	O	O		

	Name	Description	Values	Data Rules	L	T	FF	AF
			Partner Sister Sister-in-law Son Son-in-law Uncle Wife					
	Organ Request							
●	Date of Transplant Referral	Date of Referral for transplantation to transplant center.	Date	≤ current date	O			
●	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 Stomach	Multiple selection list	M			
●	Organ Type Requested	Organ type requested for transplant.	Right Lung Left Lung Bilateral Lung Lobar Lung Whole Liver Left Lobe Liver Right Lobe Liver Whole Pancreas Islets Head Tail Right Kidney Left Kidney En Bloc Kidney Dual Kidney	Multiple selection list	M			

	Name	Description	Values	Data Rules	L	T	FF	AF
●	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 Moved away Deceased Withdrew Consent 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	≤ current date/time	C			
●	List Date/Time	Date and time patient is listed.	Data and time	≤ current date/time. ≥ (date of birth - 1 year).	M			
●	Wait Time	Time patient on waitlist (in days) starting from first date with a status of "1" or higher.	Days	System derived If recipient organ state <> Off List then Wait time = Current Date - Organ List Date - [elapsed days Organ state=Off List] If recipient organ state = Off	C			

	Name	Description	Values	Data Rules	L	T	FF	AF
				List and date of death is not entered, then Wait time = Latest Off List Date/time - Organ List Date - [elapsed days Organ state=Off List prior to latest Off List Date/Time]. If recipient organ state = Off List and date of death is entered, then Wait time = Date of Death - Organ List Date - [elapsed days Organ state=Off List prior to latest Off List Date/Time].				
●	Organ Medical Status	Medical status of patient with respect to organ requested. 0=patient on HOLD	Lung Medical Status : 3 2 1 0	Multiple selection list	M	M		
●	Medical Status Change Rationale	Reason for change in medical status.	Text	<50 characters	O	O		
●	Medical Status Change Date/Time	Date and time medical status is updated in the registry.	Date and time	≤ current date/time	M	M		
●	Functional Status		Performs activities of daily living with NO assistance Performs activities of daily living with SOME assistance Performs activities of daily living with TOTAL assistance	Single selection list	M	M		

	Name	Description	Values	Data Rules	L	T	FF	AF
	Transplant Type	The type of transplant requested i.e. Heart, combined Heart-Other.	Single Multiple Same Donor Multiple	Single selection list. Default = Single. When multiple organs requested then transplant type must be Multiple - Same Donor or Multiple.	O			
	Medical History							
	Past Medical History							
	Patient On Dialysis	Flag indicating if patient is on dialysis.	Yes No	n/a	M	M	M	M
	Diabetes	Flag indicating if patient has diabetes	Yes No Unknown	Single selection list	M	O	O	O
	Diabetes Type	Type of diabetes	Type 1 Type 2 – on oral hypoglycemic Type 2 – on insulin Unknown	Single selection list	M	O	O	O
	Previous Cardiac Surgery	Flag indicating if patient has previous cardiac surgery.	Yes No Unknown	Single selection list	O			
	Type of Previous Cardiac Surgery		CABG Valve Replacement/Repair Congenital Left Ventricular Remodeling Other	Multiple selection list. If previous cardiac surgery = yes then specify type of previous cardiac surgery.	O			
	Other Previous Cardiac Surgery		Free-Text	<100 characters. Required if other type of previous cardiac surgery selected.	O			
	Previous Congenital Cardiac Surgery	Flag indicating if patient has previous congenital cardiac surgery.	Yes No Unknown	Single selection list	O			

	Name	Description	Values	Data Rules	L	T	FF	AF
●	Previous Congenital Cardiac Surgery Details	Details of pervious congenital cardiac surgery	Free-Text	<100 characters. If patient has previous congenital cardiac surgery then details are required.	O			
●	Previous Thoracic Surgery	Flag indicating if patient had previous thoracic surgery	Yes No Unknown	Single selection list	O			
●	Type of Previous Thoracic Surgery	Flag indicating if patient has previous congenital thoracic surgery.	Lung Volume Reduction Surgery VATS biopsy Bullectomy Pleurectomy Decortication Wedge resection Lobar resection Pneumonectomy Nissen's Fundoplication Other – Free-Text	Multiple selection list. If previous thoracic surgery = yes then specify type of previous thoracic surgery.	O			
●	Previous pleurodesis	Flag indicating if patient had previous pleurodesis	Yes No Unknown	Single selection list	O			
●	Renal Dysfunction	Flag indicating if patient has renal dysfunction.	Yes No Unknown	Single selection list	O	O	O	O
●	Coronary Artery Disease	Flag indicating if patient has coronary artery disease. Defined as a patient having previous MI or coronary artery by-pass grafting or stenting.	Yes No Unknown	Single selection list	O	O	O	O
●	Cerebrovascular Disease	Flag indicating if patient has cerebrovascular disease, defined as a previous TIA or stroke.	Yes No Unknown	Single selection list	O	O	O	O
●	Congenital Disease	Flag indicating if patient has congenital disease.	Yes No Unknown	Single selection list	O			

	Name	Description	Values	Data Rules	L	T	FF	AF
●	Chest Drain > 2 weeks	Flag indicating if patient had chest drain >2 weeks	Yes No Unknown	Single selection list	O		O	
●	Hyperlipidemia	Flag indicating if patient has hyperlipidemia.	Yes No Unknown	Single selection list	O	O	O	O
●	Hypertension	Flag indicating if patient has hypertension.	Yes No Unknown	Single selection list	O	O	O	O
●	Pulmonary Embolism	Flag indicating if patient has had pulmonary embolism.	Yes No Unknown	Single selection list	O	O	O	O
●	Burkholderia cenocepacia-pulmonary disease	Flag indicating if patient has of burkholderia cenocepacia-pulmonary disease.	Yes No Unknown	Single selection list	O	O	O	O
●	Burkholderia cenocepacia-pulmonary colonization	Flag indicating if patient burkholderia cenocepacia-pulmonary colonization.	Yes No Unknown	Single selection list	O	O	O	O
●	Aspergillus pulmonary disease	Flag indicating if patient has aspergillus pulmonary disease.	Yes No Unknown	Single selection list	O	O	O	O
●	Aspergillus pulmonary colonization	Flag indicating if patient aspergillus pulmonary colonization.	Yes No Unknown	Single selection list	O	O	O	O
●	Nontuberculous mycobacterial pulmonary disease	Flag indicating if patient has nontuberculous mycobacterial pulmonary disease.	Yes No Unknown	Single selection list	O	O	O	O
●	Nontuberculous mycobacterial pulmonary colonization	Flag indicating if patient nontuberculous mycobacterial pulmonary colonization.	Yes No Unknown	Single selection list	O	O	O	O

	Name	Description	Values	Data Rules	L	T	FF	AF
●	DVT	Flag indicating if patient has history of DVT.	Yes No Unknown	Single selection list	O	O	O	O
	Comorbidities							
●	Congestive Heart Failure	Flag indicating if patient has congestive heart failure.	Yes No	n/a	O	O	O	O
●	Peripheral Vascular Disease	Flag indicating if patient has peripheral vascular disease.	Yes No	n/a	O	O	O	O
●	Dementia	Flag indicating if patient has dementia.	Yes No	If yes then Mini-Mental Status Exam (MMSE) score is required.	O	O	O	O
●	Rheumatologic/Connective Tissue Disease	Flag indicating if patient has rheumatologic or connective tissue disease.	Yes No	n/a	O	O		
●	Liver Disease	Flag indicating if patient has liver disease.	Yes No	n/a	O	O	O	O
	Diagnoses							
●	Organ Primary Diagnosis	The diagnosis that is chiefly responsible for cause of organ failure	ABCA3 Transporter Mutation Allergic Bronchopulmonary Aspergillosis Alpha – 1 – Antitrypsin Deficiency Alveolar Proteinosis Amyloidosis ARDS/Pneumonia Bronchiectasis Bronchioloalveolar Carcinoma (BAC) Bronchopulmonary Dysplasia Cardinoid Tumorlets Chronic Pneumonitis of Infancy Common Variable Immune Deficiency Congenital Malformation Constrictive Bronchiolitis COPD/Emphysema CREST – Pulmonary Hypertension	Single selection list	M			

Name	Description	Values	Data Rules	L	T	FF	AF
		CREST – Restrictive Cystic Fibrosis Ehlers-Danlos Syndrome Eisenmenger's Syn: Atrial Septal Defect Eisenmenger's Syn : Multi Congenital Anomalies Eisenmenger's Syn : Other Specify Eisenmenger's Syn: PDA Eisenmenger's Syn: VSD Eosinophilic Granuloma Fibrocavitary Lung Disease Fibrosing Mediastinitis Graft – VS – Host Disease (GVHD) Granulomatous Lung Disease Hermansky Pudlak Syndrome Hypersensitivity Pneumonitis Hypogammaglobulinemia Idiopathic pulmonary hemosiderosis IIP: Acute Interstitial Pneumonia IIP: BOOP/COP IIP: Desquama Interstitial Pneumonia IIP: Idiopathic Pulmonary Fibrosis (IPF) IIP: Lymphocytic Interstitial Pneumonia (LIP) IIP: Respiratory Bronchiolitis Inhalation Burns/Trauma Kartagener's Syndrome Lung Re – TX/GF: Acute Rejection Lung Re – TX/GF: Non-Specific Lung Re – TX/GF: Obliterative Bronchiolitis-Obstructive Lung Re – TX/GF: Obliterative Bronchiolitis-Restrictive Lung Re – TX/GF: Obstructive Lung Re – TX/GF: Other Specify					

Name	Description	Values	Data Rules	L	T	FF	AF
		Lung Re – TX/GF: Primary Graft Failure					
		Lung Re – TX/GF: Restrictive					
		Lupus					
		Lymphangioleiomyomatosis					
		Mixed Connective Tissue Disease					
		Oliterative Bronchiolitis (Non-Retransplant)					
		Obstructive Lung Disease					
		Occupational Lung Disease Other Specify					
		Paraneoplastic Pemphigus Associated					
		Castleman's Disease					
		Polymyositis					
		Portopulmonary Hypertension					
		Primary Ciliary Dyskinesia					
		Pulmonary Caplillary Hemangiomatosis					
		Pulmonary Fibrosis Other Specify Cause					
		Pulmonary Hyalinizing Granuloma					
		Pulmonary Hypertension/Pulmonary Arterial Hypertension					
		Pulmonary Lymphangiectasia (PL)					
		Pulmonary Telangiectasia – Pulmonary Hypertension					
		Pulmonary Telangiectasia – Restrictive					
		Pulmonary Thromboembolic Disease					
		Pulmonary Vascular Disease					
		Pulmonary Veno-Occlusive Disease					
		Pulmonic Stenosis					
		Rheumatoid Disease					
		Right Hypoplastic Lung					
		Sarcoidosis					
		Schwackman-Diamond Syndrome					
		Scleroderma – Pulmonary Hypertension					
		Scleroderma – Restrictive					
		Secondary Pulmonary Fibrosis (specify cause)					
		Secondary Pulmonary Hypertension					

	Name	Description	Values	Data Rules	L	T	FF	AF
			Silicosis Sjogren's Syndrome Surfactant Protein B Deficiency Surfactant Protein C Deficiency Teratoma Thromboembolic Pulmonary Hypertension Tuerous Sclerosis Wegner's Granuloma – Bronchiectasis Wegner's Granuloma - Restrictive					
●	Organ Secondary Diagnosis	The diagnosis that coexists with the primary diagnosis	ABCA3 Transporter Mutation Allergic Bronchopulmonary Aspergillosis Alpha – 1 – Antitrypsin Deficiency Alveolar Proteinosis Amyloidosis ARDS/Pneumonia Bronchiectasis Bronchioloalveolar Carcinoma (BAC) Bronchopulmonary Dysplasia Cardinoid Tumorlets Chronic Pneumonitis of Infancy Common Variable Immune Deficiency Congenital Malformation Constrictive Bronchiolitis COPD/Emphysema CREST – Pulmonary Hypertension CREST – Restrictive Cystic Fibrosis Ehlers-Danlos Syndrome Eisenmenger's Syn: Atrial Septal Defect Eisenmenger's Syn : Multi Congenital Anomalies Eisenmenger's Syn : Other Specify Eisenmenger's Syn: PDA Eisenmenger's Syn: VSD	Single selection list	O			

Name	Description	Values	Data Rules	L	T	FF	AF
		Eosinophilic Granuloma					
		Fibrocavitary Lung Disease					
		Fibrosing Mediastinitis					
		Graft – VS – Host Disease (GVHD)					
		Granulomatous Lung Disease					
		Hermansky Pudlak Syndrome					
		Hypersensitivity Pneumonitis					
		Hypogammaglobulinemia					
		Idiopathic pulmonary hemosiderosis					
		IIP: Acute Interstitial Pneumonia					
		IIP: BOOP/COP					
		IIP: Desquama Interstitial Pneumonia					
		IIP: Idiopathic Pulmonary Fibrosis (IPF)					
		IIP: Lymphocytic Interstitial Pneumonia (LIP)					
		IIP: Respiratory Bronchiolitis					
		Inhalation Burns/Trauma					
		Kartagener's Syndrome					
		Lung Re – TX/GF: Acute Rejection					
		Lung Re – TX/GF: Non-Specific					
		Lung Re – TX/GF: Obliterative Bronchiolitis-Obstructive					
		Lung Re – TX/GF: Obliterative Bronchiolitis-Restrictive					
		Lung Re – TX/GF: Obstructive					
		Lung Re – TX/GF: Other Specify					
		Lung Re – TX/GF: Primary Graft Failure					
		Lung Re – TX/GF: Restrictive					
		Lupus					
		Lymphangioleiomyomatosis					
		Mixed Connective Tissue Disease					
		Oliterative Bronchiolitis (Non-Retransplant)					
		Obstructive Lung Disease					
		Occupational Lung Disease Other Specify					
		Paraneoplastic Pemphigus Associated					

Name	Description	Values	Data Rules	L	T	FF	AF
		Castleman's Disease					
		Polymyositis					
		Portopulmonary Hypertension					
		Primary Ciliary Dyskinesia					
		Pulmonary Caplillary Hemangiomatosis					
		Pulmonary Fibrosis Other Specify Cause					
		Pulmonary Hyalinizing Granuloma					
		Pulmonary Hypertension/Pulmonary Arterial Hypertension					
		Pulmonary Lymphangiectasia (PL)					
		Pulmonary Telangiectasia – Pulmonary Hypertension					
		Pulmonary Telangiectasia – Restrictive					
		Pulmonary Thromboembolic Disease					
		Pulmonary Vascular Disease					
		Pulmonary Veno-Occlusive Disease					
		Pulmonic Stenosis					
		Rheumatoid Disease					
		Right Hypoplastic Lung					
		Sarcoidosis					
		Schwackman-Diamond Syndrome					
		Scleroderma – Pulmonary Hypertension					
		Scleroderma – Restrictive					
		Secondary Pulmonary Fibrosis (specify cause)					
		Secondary Pulmonary Hypertension					
		Silicosis					
		Sjogren's Syndrome					
		Surfactant Protein B Deficiency					
		Surfactant Protein C Deficiency					
		Teratoma					
		Thromboembolic Pulmonary Hypertension					
		Tuerous Sclerosis					
		Wegner's Granuloma – Bronchiectasis					
		Wegner's Granuloma - Restrictive					

	Name	Description	Values	Data Rules	L	T	FF	AF
●	Organ Tertiary Diagnosis	The diagnosis that coexists with the primary diagnosis	ABCA3 Transporter Mutation Allergic Bronchopulmonary Aspergillosis Alpha – 1 – Antitrypsin Deficiency Alveolar Proteinosis Amyloidosis ARDS/Pneumonia Bronchiectasis Bronchioloalveolar Carcinoma (BAC) Bronchopulmonary Dysplasia Cardinoid Tumorlets Chronic Pneumonitis of Infancy Common Variable Immune Deficiency Congenital Malformation Constrictive Bronchiolitis COPD/Emphysema CREST – Pulmonary Hypertension CREST – Restrictive Cystic Fibrosis Ehlers-Danlos Syndrome Eisenmenger's Syn: Atrial Septal Defect Eisenmenger's Syn : Multi Congenital Anomalies Eisenmenger's Syn : Other Specify Eisenmenger's Syn: PDA Eisenmenger's Syn: VSD Eosinophilic Granuloma Fibrocavitary Lung Disease Fibrosing Mediastinitis Graft – VS – Host Disease (GVHD) Granulomatous Lung Disease Hermansky Pudlak Syndrome Hypersensitivity Pneumonitis Hypogammaglobulinemia Idiopathic pulmonary hemosiderosis	Single selection list	O			

Name	Description	Values	Data Rules	L	T	FF	AF
		IIP: Acute Interstitial Pneumonia IIP: BOOP/COP IIP: Desquama Interstitial Pneumonia IIP: Idiopathic Pulmonary Fibrosis (IPF) IIP: Lymphocytic Interstitial Pneumonia (LIP) IIP: Respiratory Bronchiolitis Inhalation Burns/Trauma Kartagener's Syndrome Lung Re – TX/GF: Acute Rejection Lung Re – TX/GF: Non-Specific Lung Re – TX/GF: Obliterative Bronchiolitis-Obstructive Lung Re – TX/GF: Obliterative Bronchiolitis-Restrictive Lung Re – TX/GF: Obstructive Lung Re – TX/GF: Other Specify Lung Re – TX/GF: Primary Graft Failure Lung Re – TX/GF: Restrictive Lupus Lymphangioleiomyomatosis Mixed Connective Tissue Disease Oliterative Bronchiolitis (Non-Retransplant) Obstructive Lung Disease Occupational Lung Disease Other Specify Paraneoplastic Pemphigus Associated Castleman's Disease Polymyositis Portopulmonary Hypertension Primary Ciliary Dyskinesia Pulmonary Caplillary Hemangiomatosis Pulmonary Fibrosis Other Specify Cause Pulmonary Hyalinizing Granuloma Pulmonary Hypertension/Pulmonary Arterial Hypertension				

	Name	Description	Values	Data Rules	L	T	FF	AF
			Pulmonary Lymphangiectasia (PL) Pulmonary Telangiectasia – Pulmonary Hypertension Pulmonary Telangiectasia – Restrictive Pulmonary Thromboembolic Disease Pulmonary Vascular Disease Pulmonary Veno-Occlusive Disease Pulmonic Stenosis Rheumatoid Disease Right Hypoplastic Lung Sarcoidosis Schwackman-Diamond Syndrome Scleroderma – Pulmonary Hypertension Scleroderma – Restrictive Secondary Pulmonary Fibrosis (specify cause) Secondary Pulmonary Hypertension Silicosis Sjogren's Syndrome Surfactant Protein B Deficiency Surfactant Protein C Deficiency Teratoma Thromboembolic Pulmonary Hypertension Tuerous Sclerosis Wegner's Granuloma – Bronchiectasis Wegner's Granuloma - Restrictive				
	Previous Transplant							
●	Date of previous transplant		Date	≤ current date. When transplant recorded in registry then this is derived by registry. Allow for multiple dates to be provided for each patient.	M			

	Name	Description	Values	Data Rules	L	T	FF	AF
●	Organ Previously Transplanted		Heart Lung Liver Pancreas Kidney Small Bowel Stomach	Multiple selection list	M			
●	Organ Type of Previous Transplant		Right Lung, Left Lung, Bilateral Lung, Lobar Lung, Whole Liver, Left Lobe Liver, Right Lobe Liver, Whole Pancreas, Islets, Head, Tail, Right Kidney, Left Kidney, En Bloc Kidney, Dual Kidney	Multiple selection list	M			
●	Transplant Centre of Previous Transplant		List of Transplant Centers	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			
	Malignancies							
●	Malignancy	Flag indicating if patient has an existing or past malignancy.	Yes No Unknown	Single selection list	O	O	O	O
●	Malignancy Diagnosis Date	Date of each malignancy diagnosis specified.	Date	≤ current date. If malignancy = yes then for each malignancy diagnosis specify date.	O	O	O	O

	Name	Description	Values	Data Rules	L	T	FF	AF
●	Malignancy Type	Type of each malignancy diagnosis specified.	Skin Melanoma Skin Non-Melanoma CNS Tumour Genitourinary Breast Thyroid Tongue Throat Larynx Lung Leukemia Lymphoma Liver Hepatocellular Carcinoma Other	Multiple selection list. If malignancy = yes then specify each malignancy diagnosis.	O	O	O	O
●	Other Malignancy Type	Name of other malignancy diagnosis.	Free-Text	If Other is selected for malignancy type then specific name of malignancy.	O	O	O	O
●	Malignancy De Novo Tumour	Flag indicating patient has Malignancy De Novo Tumour.	Yes No Unknown	Single selection list			O	O
●	Malignancy, Recurrence of Pre-Transplant Tumour	Flag indicating patient has Malignancy, Recurrence of Pre-Transplant Tumour.	Yes No Unknown	Single selection list			O	O
	Infections							
●	Multi drug resistant infection	Infected with an organism resistant to multiple antibiotics.	Yes No Unknown	Single selection list	O	O	O	O
●	Infection Requiring IV Therapy, organism		Yes No Unknown	Single selection list	O	O	O	O

	Name	Description	Values	Data Rules	L	T	FF	AF
●	Organism		Free-text	<100 characters. If multi drug resistant infection = yes then organism required. If infection requiring IV Therapy = yes then organism required.	O	O	O	O
	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			
●	EBV	EBV result based on the IgG test.	Positive Negative Indeterminate Not Tested	Single selection list	M			
●	Hepatitis B Core Antibody	HBV result based on Anti-HBc (HBcAb) test.	Positive Negative Indeterminate Not Tested	Single selection list	M			
●	Hepatitis B Surface Antibody	HBV result based on Anti-HBs (HBsAb) test.	Positive Negative Indeterminate Not Tested	Single selection list	M			
●	Hepatitis B Surface Antigen	HBV result based on the following test: HBsAG test, NAT.	Positive Negative Indeterminate Not Tested	Single selection list	M			

	Name	Description	Values	Data Rules	L	T	FF	AF
	Hepatitis C	HCV result based on the Ab test.	Positive Negative Indeterminate Not Tested	Single selection list	M			
	HIV I and II	HIV I and II result based on the Antibody test.	Positive Negative Indeterminate Not Tested	Single selection list	M			
	Varicella (VZV)	VZV test result based on IgG test.	Positive Negative Indeterminate Not Tested	Single selection list	M			
	HSV	HSV test result based on IgG test.	Positive Negative Indeterminate Not Tested	Single selection list	O			
	HTLV I and II	HTLV I and II result based on IgG test.	Positive Negative Indeterminate Not Tested	Single selection list	O			
	Syphilis	Syphilis result based on the following tests: EIA, RPR, VDRL, FTA-ABS.	Positive Negative Indeterminate Not Tested	Single selection list	O			
	West Nile	West Nile result based on IgG, IgM, NAT.	Positive Negative Indeterminate Not Tested	Single selection list	O			

	Name	Description	Values	Data Rules	L	T	FF	AF
	Hemodynamics – For each hemodynamic - multiple time points can be captured - collection date/time recorded for each result							
●	PA Systolic	Pulmonary Artery Pressure Systolic	mmHg	≥ 0 and ≤ 99 Conditional mandatory - only required if cardiac catheterization was performed.	M			
●	PA Diastolic	Pulmonary Artery Pressure Diastolic.	mmHg	≥ 0 and ≤ 99	O			
●	PAP Mean	Mean Pulmonary Artery Pressure	mmHg	≥ 0 and ≤ 99 Conditional mandatory - only required if cardiac catheterization was performed.	M			
●	PCWP	Pulmonary Capillary Wedge Pressure	mmHg	≥ 0.0 and ≤ 40.0 Conditional Mandatory - only required if cardiac catheterization was performed.	M			
●	Right atrial pressure	Right Atrial Pressure	mmHg	≥ 0 and ≤ 99	O			
●	Date of Cardiac Catheterization		Date	<= current date	O			
●	Cardiac Index	Cardiac Index	L/min/m2	≥ 0.0 and ≤ 20.0	O			
●	Cardiac Output	Cardiac Output	L/min	≥ 0 and ≤ 40	O			

	Name	Description	Values	Data Rules	L	T	FF	AF
	Chemistry – For each chemistry - multiple time points can be captured - collection date/time recorded for each result							
●	C-Reactive Protein (CRP)	C-Reactive Protein	U/L	≥ 0 and ≤ 99999	O	O	O	O
●	Albumin	Serum Albumin	g/L	≥ 0 and ≤ 99	O	O	O	O
	Blood Gases							
●	PO_2		Kpa		O	O	O	O
●	Listing pCO_2		pCO2/PaCO2 (mmHg)		M	M		
●	Highest pCO_2		pCO2/PaCO2 (mmHg)		O	O	O	O
●	O2 Requirement at Rest		%	≥ 0.00 and ≤ 100.00	M	M	M	M
	Electrolytes – For each electrolyte - multiple time points can be captured - collection date/time recorded for each result							
●	Cr	Serum Creatinine	mmol/L	≥ 0 and ≤ 9999	M	M	M	M
	Cardiothoracic Profile							
●	Ejection Fraction	Left Ventricular Ejection Fraction.	%	≥ 0 and ≤ 99	O		O	O
●	Right Ventricular Systolic Pressure		mmHg	≥ 0 and ≤ 99	O		O	O

	Name	Description	Values	Data Rules	L	T	FF	AF
●	Right Ventricular Function		Normal Mild impairment Moderate impairment Severe impairment	Single selection list	O			O
●	Right ventricle size		Normal Mild enlargement Moderate enlargement Severe enlargement	Single selection list	O			O
●	6MWD	6 Minute Walk Distance.	Meters	At time of transplant most recent result. At time of post-transplant follow up first result. At time of annual post-transplant follow up annual result.	M	M	M	M
●	Cardio Pulmonary Stress Test	VO2 max aka Exercise Oxygen Consumption.	ml/kg/min	≥ 0 and ≤ 99	O			
●	FEV1/FVC ratio	Ratio of Forced Expiratory Volume in 1 second to Forced Vital Capacity.	%	≥ 0 and ≤ 99	M	M	M	M
●	FVC	Forced Vital Capacity.	Litres	At time of listing annual result. At time of first post-transplant follow up first result. At time of annual post-transplant follow up annual result.	M	M	M	M

	Name	Description	Values	Data Rules	L	T	FF	AF
●	FVC % predicted	Forced Vital Capacity % predicted.	%	At time of listing annual result. At time of transplant most recent result. At time of first post-transplant follow up first result. At time of annual post-transplant follow up annual result.	M	M	M	M
●	FEV1	Forced Expiratory Volume in 1 second.	Litres	At time of listing annual result At time of first post-transplant follow up first result At time of annual post-transplant follow up annual result.	M	M	M	M
●	Date of Peak FEV1	Date of Peak Forced Expiry in one second.	Date	<= current date			M	M
●	Peak FEV1	Greatest value of Forced Expiry in one second since transplant.	Litres				M	M
●	Date of First FEV1 Post Transplant	Date of First Forced Expiry in one second, post-transplant.	Date	<= current date			M	
●	FEV1% predicted	Forced Expiratory Volume in 1 second % predicted.	%	At time of listing annual result. At time of post-transplant follow up first result. At time of annual post-transplant follow up annual result.	M	M	M	M

	Name	Description	Values	Data Rules	L	T	FF	AF
●	TLC	Total lung capacity.	Litres	At time of listing annual result. At time of post-transplant follow up first result. At time of annual post-transplant follow up annual result. Conditional mandatory post transplant	M	M	M	M
●	TLC % predicted	Total lung capacity % predicted.	%	At time of listing annual result. At time of post-transplant follow up first result. At time of annual post-transplant follow up annual result. Conditional mandatory post transplant	M	M	M	M
●	DLCO	Diffusing capacity of the lung for carbon monoxide.	ml/min/mmHg	At time of listing annual result. At time of post-transplant follow up first result. At time of annual post-transplant follow up annual result. Conditional mandatory post transplant	M	M	M	M

	Name	Description	Values	Data Rules	L	T	FF	AF
	DLCO % predicted	Diffusing capacity of lung for carbon monoxide % predicted.	%	At time of listing annual result. At time of post-transplant follow up first result. At time of annual post-transplant follow up annual result. Conditional mandatory post transplant	M	M	M	M
	Renal Profile							
	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	C	C	C	C
	HLA Typing – Conditional mandatory rules - Optional for all other lung listings but required for virtual cross match							
	A_1	HLA typing of patient.	Molecular allele	≤ 20 characters	O			
	A_2	HLA typing of patient.	Molecular allele	See rules in A_1 molecular allele.	O			
	B_1	HLA typing of patient.	Molecular allele	See rules in A_1 molecular allele.	O			
	B_2	HLA typing of patient.	Molecular allele	See rules in A_1 molecular allele.	O			
	C_1	HLA typing of patient.	Molecular allele	See rules in A_1 molecular allele.	O			

Name	Description	Values	Data Rules	L	T	FF	AF
C_2	HLA typing of patient.	Molecular allele	See rules in A_1 molecular allele.	O			
DRB1_1	HLA typing of patient.	Molecular allele	See rules in A_1 molecular allele.	O			
DRB1_2	HLA typing of patient.	Molecular allele	See rules in A_1 molecular allele.	O			
DRB3_1	HLA typing of patient.	Molecular allele	See rules in A_1 molecular allele. 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.	O			
DRB3_2	HLA typing of patient.	Molecular allele	See rules in A_1 molecular allele.	O			
DRB4_1	HLA typing of patient.	Molecular allele	See rules in A_1 molecular allele.	O			
DRB4_2	HLA typing of patient.	Molecular allele	See rules in A_1 molecular allele.	O			
DRB5_1	HLA typing of patient.	Molecular allele	See rules in A_1 molecular allele.	O			
DRB5_2	HLA typing of patient.	Molecular allele	See rules in A_1 molecular allele.	O			

Name	Description	Values	Data Rules	L	T	FF	AF
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”.	O			
DPA1_1	HLA typing of patient.	Molecular allele	See rules in A_1 molecular allele.	O			
DPA1_2	HLA typing of patient.	Molecular allele	See rules in A_1 molecular allele.	O			
DPB1_1	HLA typing of patient.	Molecular allele	See rules in A_1 molecular allele.	O			
DPB1_2	HLA typing of patient.	Molecular allele	See rules in A_1 molecular allele.	O			
DQA1_1	HLA typing of patient.	Molecular allele	See rules in A_1 molecular allele.	O			
DQA1_2	HLA typing of patient.	Molecular allele	See rules in A_1 molecular allele.	O			
DQB1_1	HLA typing of patient.	Molecular allele	See rules in A_1 molecular allele.	O			
DQB1_2	HLA typing of patient.	Molecular allele	See rules in A_1 molecular allele.	O			
HLA Typing Confirmed	User confirms HLA Typing.	Yes No	Default = blank	O			
HLA Typing Confirmed By	User who confirmed HLA Typing along with date/time of confirmation.	Date/Time and User Name	n/a	C			
HLA Typing Complete Class I	System verifies HLA Typing complete for class I based on organ specific rules.	Yes No	n/a	C			

Name	Description	Values	Data Rules	L	T	FF	AF
HLA Typing Complete Class II	System verifies HLA Typing complete for Class II 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			
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	See rules in A_1 serological equivalent.	C			
Bw6	HLA typing of patient.	Serological equivalent	See rules in A_1 serological equivalent.	C			
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			

Name	Description	Values	Data Rules	L	T	FF	AF
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			
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	O	O	O	O
Acceptable Antibody Results	HLA Serum results.	Acceptable antigens	Cumulative and current are captured.	O	O	O	O

Name	Description	Values	Data Rules	L	T	FF	AF
Unacceptable Antibody Results	HLA Serum results.	Unacceptable antigens	Cumulative and current are captured.	O	O	O	O
Indeterminate Antibody Results	HLA Serum results.	Indeterminate antigens	Cumulative and current are captured.	O	O	O	O
Not Tested Antibody Results	HLA Serum results.	Not tested antigens	Cumulative and current are captured.	O	O	O	O
Allele-Specific Antibody Results	HLA Serum results.	Allele specific antigens	Cumulative and current are captured.	O	O	O	O
Antibodies Confirmed	User confirms antibody test results.	Yes No	Default = blank	O	O	O	O
Antibodies Confirmed By	User who confirmed HLA Typing along with date/time of confirmation.	Date/Time of Confirmation and User Name	n/a	C	C	C	C
Test Date	Date of test.	Date	<= current date	O	O	O	
Antibodies Last updated by	User who updated antibody results.		n/a	C	C	C	
Serum Test Comments		Text	<=1084 characters	O	O	O	
PRA Results Calculation Date	Date of PRA calculation by Registry.	Date	n/a	C	C	C	
Cumulative PRA	Cumulative Class I and II calculated PRA.	Whole number percentage	n/a	C	C	C	
Cumulative PRA Class I	Cumulative Class I calculated PRA.	Whole number percentage	n/a	C	C	C	
Cumulative PRA Class I	Cumulative Class II calculated PRA.	Whole number percentage	n/a	C	C	C	
Treatment							
Mechanical Interventions							
Ventilated pre-transplant	Flag indicating if patient ventilated pre-transplant	Yes No		M	M		

Name	Description	Values	Data Rules	L	T	FF	AF
Ventilated post-transplant	Flag indicating if patient ventilated post-transplant	Yes No				O	O
Type of ventilation	Ventilation type.	CPAP Bi-level PAP Tracheostomy with chronic home ventilation Acute mechanical ventilation	Single selection list. If pre-transplant ventilated = yes then specify type of ventilation used pre-transplant. If post-transplant ventilated = yes then specify type of ventilation used post-transplant.	M	M	O	O
Total days ventilated	Total number of days patient is ventilated.The number of days should include any complete or partial day.	Days	≤ 365. If pre-transplant ventilated = yes then specify total days ventilated pre-transplant. If post-transplant ventilated = yes then specify total number of days ventilated post-transplant. If assisted ventilation is less than 24 hours then total days ventilated = 1.	O	O	O	O
Number of intubations		Number	≤100. If pre-transplant ventilated = yes then specify number of intubations pre-transplant. If post-transplant ventilated = yes then specify number of intubations post-transplant.	O	O	O	O

	Name	Description	Values	Data Rules	L	T	FF	AF
	Medications							
	Pre-Transplant Therapies							
●	Pre-Transplant Anticoagulation	Flag indicating if patient is using anticoagulation, pre-transplant.	Yes No	n/a	O	O		
●	Pre-Transplant Azithromycin	Flag indicating if patient is using Azithromycin, pre-transplant.	Yes No	n/a	O	O		
●	Pre-Transplant Immunomodulator Therapies	Flag indicating if patient is using Immunomodulator Therapies pre-transplant.	Yes No	n/a	O	O		
●	Specific Pre-Transplant Immunomodulator Therapies Used	Immunomodulator Therapies used pre-transplant.	Chronic Prednisone Sirolimus Azathioprine Mycophenolate Cyclosporine Tacrolimus Cyclophosphamide Rituximab	Multiple selection list	O	O		
●	Pre-Transplant Pulmonary Fibrosis Therapies	Flag indicating if patient is using Pulmonary Fibrosis Therapies, pre-transplant.	Yes No	n/a	O	O		
●	Specific Pre-Transplant Pulmonary Fibrosis Therapies Used	Pulmonary Fibrosis Therapies used pre-transplant.	Pirfenidone Nintedanib N-Acetyl Cysteine	Multiple selection list	O	O		
●	Pre-Transplant Pulmonary Hypertension Therapies	Flag indicating if patient is using Pulmonary Hypertension Therapies, pre-transplant.	Yes No	n/a	O	O		
●	Specific Pre-Transplant Pulmonary	Pulmonary Hypertension Therapies used pre-transplant.	Sildenafil Tadalafil	Multiple selection list	O	O		

	Name	Description	Values	Data Rules	L	T	FF	AF
	Hypertension Therapies Used		Bosentan Ambrisentan Macitentan Intravenous epoprostenol Subcutaneous treprostinil Intravenous treprostinil Inhaled iloprost Riociguat					
	Post-Transplant Therapies							
●	Post-Transplant Anticoagulation	Flag indicating if patient is using anticoagulation, post-transplant.	Yes No	n/a			O	O
●	Post-Transplant Azithromycin	Flag indicating if patient is using Azithromycin, post-transplant.	Yes No	n/a			O	O
●	Post-Transplant Immunomodulator Therapies	Flag indicating if patient is using Immunomodulator Therapies post-transplant.	Yes No	n/a			O	O
●	Specific Post-Transplant Immunomodulator Therapies Used	Immunomodulator Therapies used post-transplant.	Pulse steroids Plasmapheresis IVIG Basiliximab Rituximab Anti-Thymocyte Globulin Bortezomib Tacrolimus Cyclosporine Sirolimus Prednisone Myfortic CellCept Azathioprine	Multiple selection list			O	O
●	Post-Transplant Anti-Viral Therapy	Flag indicating if patient is using Anti-Viral Therapies post-transplant.	Yes No	n/a			O	O

Name	Description	Values	Data Rules	L	T	FF	AF
Specific Post-Transplant Anti-Viral Therapies Used	Anti-Viral Therapies used post-transplant.	Acyclovir Ganciclovir Valacyclovir Valganciclovir Chronic CMV prophylaxisFoscarnet Leflunomide Nelfinavir CidofovirCytomegalovirus Immune Globulin	Multiple selection list			O	O
Post-Transplant Anti-Fungal Therapies	Flag indicating if patient is using Anti-Fungal Therapies post-transplant.	Yes No	n/a			O	O
Specific Post-Transplant Anti-Fungal Therapies Used	Anti-Fungal Therapies used post-transplant.	Aerosolized antifungal therapy Systemic antifungal therapy Fluconazole Itraconazole Voriconazole Amphoterocin Posaconazole Caspofungin Micafungin Other	Multiple selection list. If other systemic antifungal therapy selected then specify name.			O	O
Post-Transplant Pulmonary Non-Tuberculous Mycobacterial Treatment	Flag indicating if patient is using Pulmonary Non-Tuberculous Mycobacterial Treatment, post-transplant.	Yes No	Single selection list			O	O
Post-Transplant Septra Prophylaxis	Flag indicating if patient is using Septra prophylaxis post-transplant	Yes No	Single selection list			O	O

Name	Description	Values	Data Rules	L	T	FF	AF
Matching							
Donor Acceptance Criteria							
Accept Incompatible ABO	Flag indicating transplant team is willing to accept an incompatible ABO donor.	Yes No	Default = No		O		
Accept VXM ABC Positive	Flag indicating transplant team is willing to accept positive VXM ABC.	Yes No	Default = No	O			
Accept VXM DRDQb	Flag indicating transplant team is willing to accept positive VXM DRDQb.	Yes No	Default = No	O			
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			

Name	Description	Values	Data Rules	L	T	FF	AF
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			
Actual Cross Match							
HLA Lab who performed actual xm		List of HLA Labs	System derived when offer recorded.		C		
Organ associated to actual xm		Heart Lung Liver Pancreas Kidney Small Bowel Stomach	System derived when offer recorded.		C		
Recipient ID associated to Actual XM		Identifier	System derived when offer recorded.		C		
Donor ID associated to Actual XM		Identifier	System derived when offer recorded.		C		
Overall Actual XM Result		Negative Positive due to HLA antibody Positive due to non-HLA antibody Positive due to auto antibody Positive due to allo antibody Invalid	Single selection list. Required if XM data entered.		M		

Name	Description	Values	Data Rules	L	T	FF	AF
Overall Actual XM Date		Date	<= current date		M		
Epitope Analysis		Positive Negative	Single selection list. Required if XM data entered.		M		
Auto XM Serum Date		Date	<= current date. Require ability to enter multiple auto xm serum dates.		O		
Auto T Cell XM		Invalid Negative Weak Positive Positive	Single selection list. Required for each auto xm serum date entered.		O		
Auto B Cell XM		Invalid Negative Weak Positive Positive	Single selection list Required for each auto xm serum date entered.		O		
Allo XM Serum Date		Date	<= current date. Require ability to enter multiple allo xm serum dates.		O		
Allo T Cell		Invalid Negative Weak Positive Positive	Single selection list Required for each allo xm serum date entered.		O		
Allo B Cell		Invalid Negative Weak Positive Positive	Single selection list Required for each allo xm serum date entered.		O		
Pronase		Yes No	n/a Required for each auto or allo xm serum date entered.		M		

Name	Description	Values	Data Rules	L	T	FF	AF
Serum Treated		Yes No	n/a Required for each auto or allo xm serum date entered.		M		
Serum Treatment		DTT Heat EDTA Other	Single selection list. Required if serum treated = yes.		O		
DSA in Sera		Yes No Predicted (No) Predicted (Yes) Incomplete	Single selection list. Required for each auto or allo xm serum date entered. If DSA in Sera = yes or predicted (yes) then specify DSA details.		M	O	O
XM Method		Flow Luminex	Single selection list		M		
Surgical							
Admissions							
Date / Time of Admission to Hospital (Hospital admission pre-transplant)	Date and time of admission to hospital for transplant.	Date	≤ Current Date		M		
Required ECLS	Patient bridged to transplant on extra-corporeal life support, (e.g. ECMO, Novalung).	Yes No Unknown	n/a	M	M	O	
ECLS Mode	Type of extra-corporeal life support received.	Veno-Venous ECMO Veno-Arterial ECMO NovaLung A-lung	Single selection list. Required if ECLS = Yes.	M	M	O	
ECLS Duration	Number of days on ECLS prior to transplant.	Days	Required if ECLS = Yes.	M	M	O	

	Name	Description	Values	Data Rules	L	T	FF	AF
	Surgical Details							
●	Procedure type	Type of transplant performed.	Single Bilateral Living Donor Lobar Heart Lung	Single selection list		M		
●	Anatomical reduction	Graft lungs reduced in size for appropriate size-matching.	Yes No Unknown	Single selection list		M		
●	Estimated Blood Loss		Litres			O		
●	Quantity of Blood Given Intra-Operatively		Units of packed red blood cells			O		
●	EVLP	Ex-Vivo Lung Perfusion used.	Yes No	Single selection list		M		
●	Cold flush solution		Perfadex Euro-Collins Papworth University of Wisconsin Celsior	Single selection list		M		
●	Transplant Date and Time	Transplant Date and Time.	Date	<= current date/time		M		
●	Cold Ischemia Time #1 L and R lung	Length of time of cold preservation, from time of donor cross clamp to insertion into recipient chest.	Duration	Transplant Date/Time - Donor Cross Clamp Date/Time. If EVLP Yes, will need Cold ischemic time #2 for L and R lung, which will be from time removed from EVLP to time of insertion into recipient chest.		M		

	Name	Description	Values	Data Rules	L	T	FF	AF
●	Warm ischemic time L and R lung	Length of time of warm ischemia of left lung, from time of insertion into recipient chest to time of reperfusion. Length of time of warm ischemia of right lung, from time of insertion into recipient chest to time of reperfusion.	duration	Only make an option if that lung was transplanted (see procedure type) Hh:mm.		M		
●	Total preservation time	Total duration of both warm and cold preservation time, from donor cross clamp until reperfusion.	duration	Hh:mm		M		
●	TXC at time of transplant	Transplant Centre at time of transplant.				C		
●	EVLP time	Length of time on ex-vivo lung perfusion.	Duration	Hh:mm		M		
●	Ex-Vivo Device Used	Flag indicating if Ex-Vivo device used.	Yes No	n/a		O		
	Surgical Complications							
●	Inotropic Support		Yes No Unknown	Single selection list If yes specify details			O	
●	Vasocontrictor Support		Yes No Unknown	Single selection list If yes specify details			O	
●	Major Bleeding	>3 units of PRBC transfusion post-transplant.	Yes No Unknown	Single selection list			O	
●	Return to Theatre	Flag indicating patient returned to theatre.	Yes No	Single selection list. If yes then specify a date and reason why.			O	
●	Prolonged ventilation > 5 days		Yes No Unknown	Single selection list. If yes, enter duration in days.			O	

Name	Description	Values	Data Rules	L	T	FF	AF
Re-intubation		Yes No	Single selection list			O	
PGD at 72 hours	Evidence of Primary Lung Graft Dysfunction 72 hours post-transplant.	Yes No Unknown	Single selection list			O	
PGD Grade at 72 hours	Severity of Primary Lung Graft Dysfunction 72 hours post-transplant.	PGD 1 PGD 2 PGD 3	Single selection list If yes for PGD at 72 hours.			O	
Anastomotic complications	Complication at graft anastomosis.	Yes No Unknown	Single selection list If yes, then specify type of anastomotic complication.			O	
Type of Anastomotic Complication		Dehiscence Infection Stenosis.	Single selection list. Required if anastomotic complications = yes.			O	
Tracheostomy	Patient underwent tracheostomy.	Yes No Unknown	Single selection list			O	
Intra-operative Death		Yes No	n/a			O	
Pathology							
Explant Pathology Diagnosis		Free-text entry	≤ 500 characters			O	
Incidental Tumour Found at Time of Transplant	Flag indicating incidental tumour found at time of transplant with details on tumour.	Yes No Unknown	Single selection list			O	
Incidental Tumour Details		Free-text entry	≤ 500 characters. Required if incidental tumour found at time of transplant = yes.			O	
Abnormal BAL Cytology		Yes No Unknown	Single selection list			O	
Outcome							

Name	Description	Values	Data Rules	L	T	FF	AF
Post-Transplant Complications							
PTLD	Post-Transplant Lymphoproliferative Disorder.	Yes No	n/a			O	O
Acute coronary syndrome	Acute coronary syndrome.	Yes No	n/a			O	O
CMV infection	Cytomegalovirus infection.	Yes No	n/a			O	O
CMV disease and organ	Cytomegalovirus disease diagnosed via biopsy.	Yes No	If yes, specify: Lung Liver Gastrointestinal Ocular Other – free-text			O	O
Invasive fungal infection, organism	Patient treated for invasive fungal infection.	Yes No	If yes, specify site and organism: Aspergillus Mucor Scedosporium Candida Other-free-text			O	O
Non-compliance	Patient non-compliant with medical advice and/or therapy.	Yes No	n/a	O	O	O	O
Post-transplant alcohol abuse	Consumption of >2 drinks per day.	Yes No	n/a				O
Chronic pain requiring treatment	Chronic pain requiring prolonged analgesic treatment.	Yes No	n/a				O
Graft Rejection							
Acute Cellular Rejection		Yes No	n/a			O	O
Acute Cellular Rejection Date		Date	If Acute Cellular Rejection = yes then date required.			O	O

Name	Description	Values	Data Rules	L	T	FF	AF
Grade of Acute Cellular Rejection	Severity of Cellular Rejection based on pathology.	Clinical Diagnosis A1 A2 A3 A4	If Acute Cellular Rejection = yes then grade required.			O	O
Antibody Mediated Rejection Requiring intervention	Clinical diagnosis of Antibody mediated rejection treated with immunomodulation therapy.	Yes No Unknown	n/a			O	O
Antibody Mediated Rejection Date		Date	If Antibody Mediated Rejection Requiring Intervention = yes then date required.			O	O
Biopsy consistent with AMR	Biopsy result is positive.	Yes No Not done	If Antibody Medicated Rejection Requiring Intervention = yes then biopsy outcome required (biopsy consistent with AMR = yes/no)			O	O
c4d positive		Yes No Unknown	n/a			O	O
Development of CLAD	Patient diagnosed with chronic lung allograft dysfunction.	Yes No	n/a				O
CLAD type	Type of chronic lung allograft dysfunction.	Bronchiolitis Obliterans Syndrome Restrictive Allograft Syndrome	Single selection list If Yes to Development of CLAD.				O
Date of CLAD	Date diagnosed with chronic lung allograft dysfunction.	Date	<= current date				O
CLAD Grade	Grade of chronic lung allograft dysfunction.	BOS 0-p BOS 1 BOS 2 BOS 3	Single selection list If BOS selected in CLAD type.				O

Name	Description	Values	Data Rules	L	T	FF	AF
Discharge							
Days in ICU	Number of days in ICU / LOS in ICU	Numeric	≤ 999			M	
Days in Hospital	Number of days a patient in the hospital for transplant (from time of admission to discharge) / LOS in hospital	Numeric	≤ 999			M	
Discharge destination	Destination to which patient is discharged from hospital for peri-operative admission.	Home Rehab inpatient Rehab outpatient Chronic Complex Care Death	Single selection list			O	
Patient Status		Living Dead Lost to Follow-up	Calculated by system based on Lost to Follow-up Date and Date of Death.	M		M	M
Lost to Follow-up Date		Date	≤ current date ≥ Transplant Date				M
Lost to follow up Reason		Text	<150 characters				M
Death							
Date of Death		Date	≤ current date. ≥ Date of Birth. Conditional mandatory – Only required if patient death occurs.	M		M	M
Cause of Death	Primary cause of death	Unknown Other Specify Graft Failure: Primary Failure Graft Failure: Rejection- Hyperacute Graft Failure: Rejection- Acute Graft Failure: Rejection- Chronic Graft Failure: Technical Graft Failure: Graft Infection	Conditional mandatory – Only required if patient death occurs.	M		M	M

Name	Description	Values	Data Rules	L	T	FF	AF
		Graft Failure: Recurrent Disease Graft Failure: Non-Specific Infection: Bacterial Septicemia Infection: Bacterial Pneumonia Infection: Bacterial- Other Specify Infection: Viral- Cytomegalovirus (Cmv) Infection: Viral- Hepatitis Infection: Viral-Septicemia Infection: Viral- Other Specify Infection: Fungal- Aspergillus Infection: Fungal- Other Specify Infection: Protozoal Infection: Mixed Other Specify Infection: Other Specify Cardiovascular: Myocardial Infarction Cardiovascular: Cardiac Arrest Cardiovascular: Arterial Embolism Cardiovascular: Ventricular Failure Cardiovascular: Coronary Artery Disease Cardiovascular: Atherosclerosis Cardiovascular: Rhythm Disorder Cardiovascular: Carditis Cardiovascular: Aortic Aneurysm Cardiovascular: Cardiogenic Shock Cardiovascular: Other Specify Pulm: Dehiscencepulm: Bronchiolitis Pulm: Primary Pulmonary Hypertension Pulm: Pulmonary Embolismpulm: Respiratory Failure Pulm: Acute Respiratory Distress Disease Pulm: Other Specify Cerebrovascular: Stroke Cerebrovascular: Hemorrhage (Non-Stroke) Cerebrovascular: Brain Anoxia				

Name	Description	Values	Data Rules	L	T	FF	AF
		Cerebrovascular: Degenerative Brain Disease Cerebrovascular: Other Specify Hemorrhage: Gastrointestinal Hemorrhage: Intraoperative Hemorrhage: Disseminated Intravas Coagulation Hemorrhage: Post-Operative Hemorrhage: Respiratory Hemorrhage: Other Specify Malig: Metastatic Other Specify Malig: Primary Other Specify Malig: Post-Tx Lymphoproliferative Disorder Malig: Lymphoma Malig: Skinmalig: Other Specify Diabetes Mellitus Intraop: Not Hemorrhage - Other Specify Pancreatitisrenal Failure Liver Failure Multiple Organ Failure Fluid/Electrolyte Disorder Acid/Base Disorder Amyloidosis Hematologic Other Specify Immunosuppressive Drug Related - Hematologic Immunosuppressive Drug Related - Non-Hematologic Non-Immuno Drug Related - Hematologic Non-Immuno - Non-Hematologic, Specify Drug Motor Vehicle Accident Suicide Non-Compliance Trauma Other Specify					

Appendix C – Deceased Donor Data

	Name	Description	Values	Data Rules	Mandatory
	Registration				
	Identifiers				
●	Local Donor ID	Local donor identifier entered by OPO.	Identifier	≤ 50 characters	Required to create record
●	Date of Birth	Date of birth.	YYYY-MM-DD	≤ current date	Required to create record and at time of transplant
	Donor Case Status				
●	Donor Type	Flag indicating type of donor.	Deceased Living Lobar	Defaulted to Deceased	Required to create record and at time of transplant
●	Donor Case	State of donor case e.g. open or closed.	Open Closed	Defaulted to Closed	Required to create record
	Demographics				
●	Country of Residence	Donor country of residence.	List of countries	Single selection list	Optional
●	Gender	Gender of patient.	Male Female Other Unknown	n/a	Required to create record and at time of transplant
●	Height (cm)	Height of patient in cm.	cm	≥ 0.0 and ≤ 300.0	Required to create record and at time of transplant

	Name	Description	Values	Data Rules	Mandatory
●	Weight (kg)	Weight of patient in kg.	kg	≥ 0.0 and ≤ 700.0	Required to create record
●	ABO	Blood type of patient.	A B O AB unknown	n/a	Required to create record
●	Confirm ABO	Confirm blood group by re-entering blood group.	blood types e.g. A, B, O	≤ 4 characters	Required to create record
●	RH	RH of patient.	+ -	n/a	Optional
	Facility				
●	OPO	Organ Procurement Organization responsible for donor.	Abbreviated and full name of OPO	n/a	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
●	Care Hospital	Hospital where deceased donor care takes place.	Hospital name with city	n/a	Required to close donor case
●	Retrieval Hospital	Hospital where the deceased donor organ procurement surgery takes place.	Hospital name with city	n/a	Required to close donor case
	Consent				
●	Lung Consent State	Consent state of lung.	Consented Not Consented Not Participating	n/a	Required for VXM and offer

	Name	Description	Values	Data Rules	Mandatory
	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	n/a	Required for VXM and offer and at time of transplant
●	Cause of Death	Deceased donor cause of death.	Ancephalitis Encephalitis Ancephaly Anoxia/Hypoxia Arteriovenous malformation Cerebral abscess Cerebral oedema Cerebrovascular accident (stroke) – embolic Cerebrovascular accident (stroke) – hemorrhagic Cerebrovascular accident (stroke) - ischemic Diabetic ketoacidosis Drug Overdose-Barbiturate Drug Overdose-Benzodiazepine Drug Overdose-Carbon monoxide Drug Overdose-Opiate Drug Overdose-Other Fall Gunshot Hepatic failure Hydrocephalus Hyponatremia Inborn error of metabolism Meningitis Motor vehicle collision Primary CNS tumour Ruptured cerebral aneurysm Subarachnoid hemorrhage Non-Accidental Injury Trauma – specify	Must be single selection	Required for VXM and offer

	Name	Description	Values	Data Rules	Mandatory
			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	n/a	Required for VXM and offer
●	Province/State of Death	Province or state where donor was declared dead.	Canadian provinces and territories US states	n/a	Required for VXM and offer
	NDD				
●	First Brain Death Date/ Time	First brain death date/time for NDD.	YYYY-MM-DD HH:MM	≤ current date/time and ≥ date of birth of donor ≤ cross clamp date/time Required for NDD only	Required for VXM and offer
●	Declaration of NDD	Method used for Declaration of NDD performed by physician e.g. Ancillary or Clinical Exam	Ancillary - 4 Vessel Cerebral Angiogram CLINICAL EXAM Ancillary - Radionuclide Testing Ancillary - CT Angiogram Ancillary - MRI Angiography Other	Must be multiple selection	Required for VXM and offer

	Name	Description	Values	Data Rules	Mandatory
	Assessment				
	Medical/Social History				
●	Alcohol Abuse	Flag indicating if patient has a history of alcohol abuse.	Yes No Unknown	n/a	Required for offer
●	Alcohol Abuse Details	Specific details on patient's alcohol abuse.	Details	≤ 2000 characters	Required if Alcohol History = Yes or Unknown
●	Smoking History	Flag indicating if patient has a history of smoking.	Yes No Unknown	n/a	Required for offer and at time of transplant
●	Smoking History Details	A specific detail on patient's smoking history.	Details	≤ 2000 characters	Required if Smoking History = Yes or Unknown and at time of transplant
●	Cancer History	Flag indicating if patient has history of cancer.	Yes No Unknown	n/a	Required for offer
●	Cancer History Details	Specific details on patient's cancer history.	Details	≤ 2000 characters	Required if Cancer History = Yes or Unknown
●	Hypertension	Flag indicating if patient has hypertension.	Yes No Unknown	n/a	Required for offer
●	Hypertension Details	Specific details on patient's hypertension.	Details	≤ 2000 characters	Required if Hypertension = Yes or Unknown
●	Heart Disease	Flag indicating if patient has heart disease.	Yes No Unknown	n/a	Required for offer
●	Heart Disease Details	Specific details on patient's heart disease.	Details	≤ 2000 characters	Required if Heart Disease = Yes or Unknown

Name	Description	Values	Data Rules	Mandatory
Pulmonary Disease	Flag indicating if patient has pulmonary disease.	Yes No Unknown	n/a	Required for offer
Pulmonary Disease Details	Specific details on patient's pulmonary disease.	Details	≤ 2000 characters	Required if Pulmonary Disease = Yes or Unknown
Kidney Disease	Flag indicating if patient has kidney disease.	Yes No Unknown	n/a	Required for offer
Kidney Disease Details	Specific details on patient's kidney disease.	Details	≤ 2000 characters	Required if Kidney Disease = Yes or Unknown
Diabetes History	Flag indicating if patient has a history of diabetes.	Yes No Unknown	n/a	Required for offer
Diabetes History Details	Specific details on patient's diabetes history.	Details	≤ 2000 characters	Required if Diabetes = Yes or Unknown
Liver Disease	Flag indicating if patient has liver disease.	Yes No Unknown	n/a	Required for offer
Liver Disease Details	Specific details on patient's liver disease.	Details	≤ 2000 characters	Required if Liver Disease = Yes or Unknown
Cardio Respiratory Arrest	Flag indicating if patient had cardio respiratory arrest.	Yes No Unknown	n/a	Required for offer
Cardio Respiratory Arrest Details	Specific details on cardio respiratory arrest details.	Details	≤ 2000 characters	Required if Cardio Respiratory Arrest = Yes or Unknown

Name	Description	Values	Data Rules	Mandatory
Cardio Respiratory Arrest Duration (min)	Duration of cardio respiratory arrest.	Minutes	≥ 0 minutes	Required if Cardio Respiratory Arrest = Yes
Blood Gases – For each blood gases - multiple time points can be captured - collection date/time recorded for each result				
Date/Time	Collection date and time.	Date and Time	≤ current date/time and must be greater than date of birth of donor.	Required for any Blood Gas entered in the registry
PaO2	Measured Partial pressure of Oxygen during oxygen challenge.	mmHg	≥ 0 and ≤ 999. Capture multiple time points.	Optional for offer
Lung Profile				
Date/Time	Collection date and time.	Date and Time	≤ current date/time and must be greater than date of birth of donor.	Required for any Lung Profile entered in the registry
Predicted Total Lung Capacity	Calculated adult total lung capacity	L	If Male & Age >= 18 Then Total Lung Capacity = (0.09 * Height (cm)) - 8.618 If Female & Age >= 18 Then Total Lung Capacity = (0.071 * Height (cm)) – (0.007 * Age) - 5.965 If donor age < 18 THEN there will be no calculation	Optional for offer
Pediatric Total Lung Capacity		L	≥ 0 and ≤ 99999.999	Optional for offer

Name	Description	Values	Data Rules	Mandatory
HLA Typing – Conditional mandatory rules - Required for virtual cross match				
A_1	HLA typing of patient.	Molecular allele	≤ 20 characters.	Required for VXM and offer
A_2	HLA typing of patient.	Molecular allele	See rules in A_1 molecular allele.	Required for VXM and offer
B_1	HLA typing of patient.	Molecular allele	See rules in A_1 molecular allele.	Required for VXM and offer
B_2	HLA typing of patient.	Molecular allele	See rules in A_1 molecular allele.	Required for VXM and offer
C_1	HLA typing of patient.	Molecular allele	See rules in A_1 molecular allele.	Required for VXM and offer
C_2	HLA typing of patient.	Molecular allele	See rules in A_1 molecular allele.	Required for VXM and offer
DRB1_1	HLA typing of patient.	Molecular allele	See rules in A_1 molecular allele.	Required for VXM and offer
DRB1_2	HLA typing of patient.	Molecular allele	See rules in A_1 molecular allele.	Required for VXM and offer
DRB3_1	HLA typing of patient.	Molecular allele	See rules in A_1 molecular allele. 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 patient.	Molecular allele	See rules in A_1 molecular allele.	Required for VXM and offer
DRB4_1	HLA typing of patient.	Molecular allele	See rules in A_1 molecular allele.	Required for VXM and offer

Name	Description	Values	Data Rules	Mandatory
DRB4_2	HLA typing of patient.	Molecular allele	See rules in A_1 molecular allele.	Required for VXM and offer
DRB5_1	HLA typing of patient.	Molecular allele	See rules in A_1 molecular allele.	Required for VXM and offer
DRB5_2	HLA typing of patient.	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 patient.	Molecular allele	See rules in A_1 molecular allele.	Required for VXM and offer
DPA1_2	HLA typing of patient.	Molecular allele	See rules in A_1 molecular allele.	Required for VXM and offer
DPB1_1	HLA typing of patient.	Molecular allele	See rules in A_1 molecular allele.	Required for VXM and offer
DPB1_2	HLA typing of patient.	Molecular allele	See rules in A_1 molecular allele.	Required for VXM and offer
DQA1_1	HLA typing of patient.	Molecular allele	See rules in A_1 molecular allele.	Required for VXM and offer
DQA1_2	HLA typing of patient.	Molecular allele	See rules in A_1 molecular allele.	Required for VXM and offer
DQB1_1	HLA typing of patient.	Molecular allele	See rules in A_1 molecular allele.	Required for VXM and offer
DQB1_2	HLA typing of patient.	Molecular allele	See rules in A_1 molecular allele.	Required for VXM and offer

	Name	Description	Values	Data Rules	Mandatory
●	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 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 registry
●	Serology Source	Flag indicating source of serology sample drawn	Mother Donor	Defaulted to Donor	Required for any serology test result entered in registry
●	CMV	CMV result based on IgG test.	Positive Negative Pending Not Tested Indeterminate	At least one result is required.	Required for offer
●	HIV I and II	HIV I and II result based on any of the following tests: IgG, Antibody/p24 antigen, HIV NAT (HIV DNA, HIV Singe NAT), Double NAT (HIV, HCV), and Triple NAT (HIV, HCV, and HBV)	Positive Negative Pending Not Tested Indeterminate	At least one result is required	Required for offer

Name	Description	Values	Data Rules	Mandatory
EBV	EBV result based on the following tests: IgG (VCA) or IgG (EBNA)	Positive Negative Pending Not Tested Indeterminate	At least one result is required	Required for 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 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 offer
Hepatitis B Surface Antigen	HBV result based on HBsAG test.	Positive Negative Pending Not Tested Indeterminate	At least one result is required	Required for offer
Hepatitis C	HCV result based on IgG test.	Positive Negative Pending Not Tested Indeterminate	At least one result is required	Required for offer
Offer Acceptance				
Organ Offered	For each organ offer, name of organ being offered	Heart Lung Liver Pancreas Kidney Small Bowel Stomach	Set by system upon selection of transplant candidate on waitlist.	Required for offer

Name	Description	Values	Data Rules	Mandatory
Organ Type Offered	For each organ offer, name of organ type being offered	Left Right Double	Single selection list.	Required for offer
Offer Sate	For each organ offer, state of organ being offered	Proposed Accepted Declined Withdrawn Cancelled Acceptance	Single selection list	Required for offer
Offer State Reason	For each organ offer that was declined, withdrawn or cancelled acceptance, the reason for the decline.	CTR reason list	Multiple selection list	Required for offer
ODO Offering	For each organ offer, ODO associated with the donor involved in the offer	CTR ODO list	Set by system upon selection of transplant candidate on waitlist.	Required for offer
ODO Receiving	For each organ offer, ODO associated with recipient involved in the offer	CTR ODO list	Set by system upon selection of transplant candidate on waitlist.	Required for offer
Transplant Centre	For each organ offer, Transplant Centre associated to recipient involved in the offer	CTR Transplant Centre list	Set by system upon selection of transplant candidate on waitlist.	Required for offer
National Recipient ID	For each organ offer, national recipient id associated to recipient involved in the offer	Unique identifier	Set by system upon selection of transplant candidate on waitlist.	Required for offer
National Donor ID	For each organ offer, national donor id associated to donor involved in the offer	Unique identifier	Set by system upon selection of transplant candidate on waitlist.	Required for offer

Name	Description	Values	Data Rules	Mandatory
Disposition				
Lung Recovered State	Recovered state of organs.	Recovered Not Recovered	If lungs consented then recovery details required. This pertains to recovery state of right, left or double lungs.	Required to close donor case
Not Recovered Reason	Not recovered reason for organ(s).	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 Organ damaged during recovery Unable to maintain donor intra OR	Single selection list.	Required if not recovered selected.
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

Name	Description	Values	Data Rules	Mandatory
Lung Transplanted State	Transplanted state of organ(s).	Transplanted Not Transplanted	If organ consented then transplant details required. This pertains to transplant state of right, left or double lungs.	Required to close donor case
Recipient ODO	For each organ transplanted, ODO of recipient who received the organ.	CTR ODO list	Set by system when transplant recorded	Required to close donor case
Recipient TXC	For each organ transplanted, Transplant Centre of recipient who received the organ.	CTR Transplant Centre list	Set by system when transplant recorded.	Required to close donor case
National Recipient ID	For each organ offer, national recipient id associated to recipient involved in the offer	Unique identifier	Set by system upon selection of transplant candidate on waitlist.	Required for offer
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(s).	Medical Education Not Used Pathology Research Tissue	Single selection list	Required if not transplanted selected

Appendix D – Terms of Reference

Lung Data Working Group
Terms of Reference

Objectives

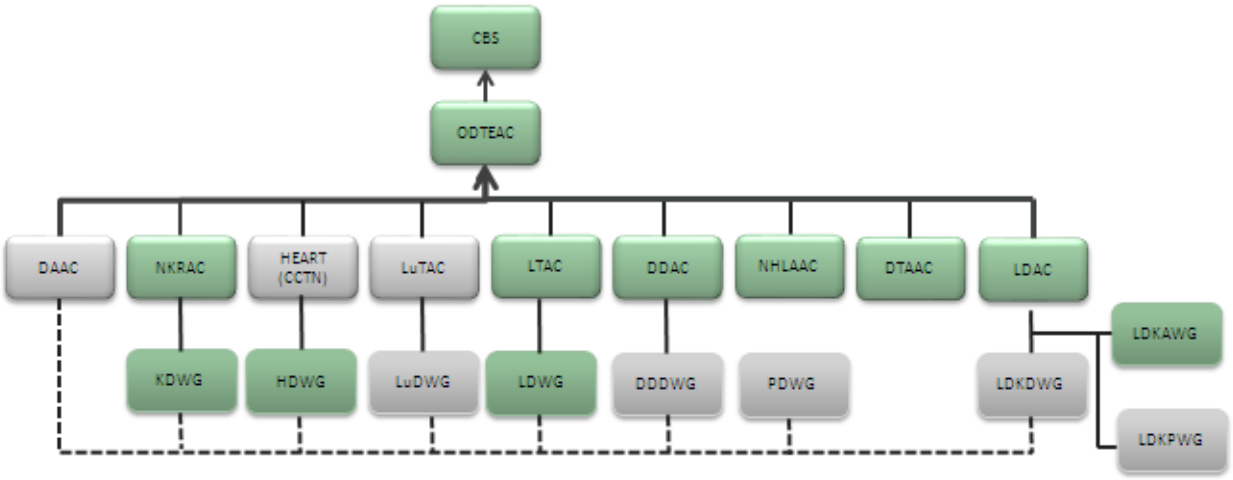
The provincial and territorial governments have funded Canadian Blood Services to develop and operate the Canadian Transplant Registry (CTR). The national registry system includes a data warehouse with business intelligence tools that provide accurate, timely and comprehensive data to support research, 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 (Organ Donation and Transplantation) 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.

The Lung Data Working Group will serve to:

- Develop lung transplant measures to form a lung transplant data set that will:
    - Facilitate clinical practice decision making
    - Aid in the development of practice standards
    - Inform outcomes reporting
    - Support clinical research
    - Provide data to support interprovincial operational and clinical policies, standards of practice and evidence-based practice with respect to lung listing and allocation
    - Relay national data to international registries in order to participate in global data collection efforts

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
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 lung transplant practices, including documentation of listing and allocation practices, donor and recipient information, and lung transplant outcomes in support of the CTR. To contribute to the data needs

that will inform clinical decisions and support clinical research with respect to lung transplantation and outcomes reporting, the Working Group will:

- identify data points along the lung donation, allocation and transplant critical path
- identify the availability and gaps in current data and the comparability of data amongst lung transplant programs
- develop a minimum data set for lung transplantation with regards to lung waitlist outcomes, lung transplant activity and lung transplant outcomes to support clinical decisions and research
- recommend a quality control strategy to assess the quality and completeness of data submissions to the registry

Authority

The Lung Data Working Group 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 FPT Deputy Ministers of Health. The Chair of the Working Group committee shall be appointed by Canadian Blood Services.

Reporting

The Lung Data Working Group will report to the Data and Analytics Advisory Committee (DAAC) and the Organ Donation and Transplantation Expert Advisory Committee (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 Lung Data Working Group

Membership in the Lung Data Working Group will include when possible, a minimum of one person representing each of the Canadian Lung Transplant Centres who have relevant professional knowledge and experience in lung transplantation. Members will also have a deep appreciation and interest in the use of lung data to advance lung donation and transplantation in Canada.

Membership will balance and encompass representation from lung transplantation programs across Canada. Subject matter experts may be invited to attend specific Working Group meetings as required. Membership participation is required at two out of every three meetings scheduled.

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

Chair

The Chair of the Committee shall be appointed by Canadian Blood Services, 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 on the activities of the Lung Data Working Group.

Processes and Timeframes

- The day and time for teleconferences will be set based on agreed membership preference
- Materials will be circulated to members 5 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

- Canadian Blood Services will provide the Secretariat to the Committee meetings.
- Attendance is expected at 2 of every 3 meetings.

Confidentiality

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

Evaluation

The Chair will report monthly to CBS on the deliverables assigned to the LuDWG.

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