Deceased Donation Data Working Group

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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 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 continue to evolve 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 deceased organ donation and transplantation 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 Deceased Donor Data Working Group (DDDWG) members (Appendix A) for their participation and acknowledge the leadership and commitment of the chair of this committee, Dr Damon Scales. 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 deceased donation 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 deceased donation.

The report begins with a description of the objectives of the DDDWG, including its 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 Deceased Donation Advisory Committee, the Donation and Transplantation Administrators Advisory Committee and the Information System Advisory Committee.

Future work that will be guided by the Information System Advisory Committee 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 to ODT Operational groups, committees and other partners
- 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

We look forward to the opportunity to continue working together in key stakeholder groups to further advance this important initiative.

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1. Acronyms

AD	Actual Donor
AED	Approached Eligible Donor
CBS	Canadian Blood Services
CCDT	Canadian Council for Donation and Transplantation
CD	Consented Donor
CIHI	Canadian Institute for Health Information
CTR	Canadian Transplant Registry
DAD	Discharge Abstract Database
DCD	Donation after circulatory death
DDAC	Deceased Donation Advisory Committee
DDDWG	Deceased Donor Data Working Group
DTAAC	Donation and Transplantation Administrators Advisory Committee
DWG	Data Working Group
ED	Eligible Donor or Emergency Department
HMDB	Hospital Morbidity Database
ICU	Intensive Care Unit
ISAC	Information System Advisory Committee
NACRS	National Ambulatory Care Reporting System
NDD	Neurological determination of death
ODO	Organ Donation Organization
ODT	Organ Donation Transplantation
OTDT	Organ and Tissue Donation and Transplantation
PD	Potential Donor
RPD	Referred Potential Donor
TOR	Terms of Reference
UD	Utilized Donor
WLST	Withdrawal of Life Sustaining Therapy

2. Background

The Deceased Donor Data Working Group (DDDWG) was convened by Canadian Blood Services in June 2014 to develop a deceased donation minimum data set that will facilitate clinical practice decision making, develop practice standards and inform outcomes reporting for deceased donation in Canada. Canadian Blood Services is responding to the vision articulated 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 existing Canadian Transplant Registry (CTR). This national registry system includes a data warehouse with business intelligence tools that will 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 DDDWG had the following objectives:

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

The report recommends a national deceased donation minimum 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 deceased donation in Canada. In addition, it summarizes key considerations and activities of the DDDWG. The report will be presented to and discussed at the Deceased Donation Advisory Committee (DDAC), the Donation and Transplantation Administrators Advisory Committee (DTAAC), and the Information System Advisory Committee (ISAC). This will be followed by further discussions with key stakeholder groups.

3. Scope of Data Working Group

DDDWG's scope encompasses matters related to deceased organ donation data, including donors determined dead using neurological or circulatory criteria, operational and performance data, and follows the donor pathway from donation potential to donation and disposition of organs. To contribute to the data needs that will inform clinical decisions and support clinical research with respect to deceased donation and outcomes reporting, DDDWG will:

(1) Develop a minimum data set for deceased donation to support clinical decisions and research.

(2) Identify data collection points along the deceased donation critical path.

(3) Identify the availability, gaps, and comparability of current data systems amongst deceased donation programs and work to assess the feasibility of the implementation of a national minimum data collection collaborative initiative.

4. Principles

Building on the vision developed by the Canadian Council for Donation and Transplantation (CCDT) in collaboration with the ODT community for better information management across Canada's Organ and Tissue Donation and Transplantation (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 DDDWG 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 DDDWG expanded their list of guiding principles to encompass elements specific to their mandate of developing a national minimum data set for deceased donation:

2. Data collection will be instrumental in advancing scientific evidence based healthcare.
3. Data chosen for the national minimum 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 contributions.
5. The minimum data set was defined as containing the elements that the system should aspire to collect
6. The national minimum 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.
7. DDDWG will ensure that the national minimum data set lends itself to national and international benchmarking by Organ Donation Organizations (ODO).
8. The minimum data set is not static. It will need to evolve and be revaluated on a scheduled timeline.
9. The minimum data set should be used for the benefit of donors, families, patients, recipients and Canadians.

5. Key Considerations

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

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

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

3. There is an opportunity to satisfy international data commitments through a consolidated approach to the minimum data set.

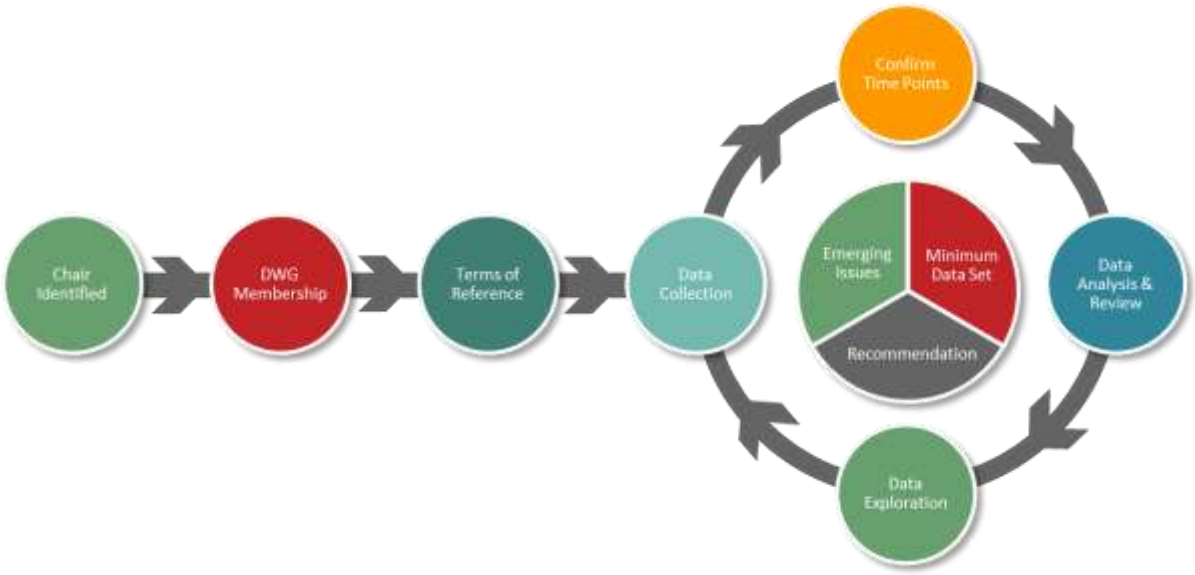
4. The minimum data set considers national practices and the data needs of all health care professionals involved on the deceased donation critical pathway.

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

6. Existing data sets were used as a basis from which to start developing the minimum data set. This involved beginning with CTR data elements and definitions and ensured harmonization with other systems that have been or are being implemented by Provincial organizations.

6. Process

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



6.1 Group Formation

The Chair of the Data Working Group (DWG) was appointed by Canadian Blood Services. Canadian Blood Services met with the Chair to discuss the objectives and mandate of DDDWG. As part of group formation, members were selected based on relevant professional knowledge and experience in deceased donation and in data management. Members had different medical professional backgrounds i.e. ODO co-ordination, nursing, and pediatric. Once members of DDDWG were identified, an initial teleconference call was convened to review the terms of reference (TOR) and agree on the approach DDDWG would take to achieve their mandate. A face-to-face meeting was convened on September 15, 2014 to: approve the TOR; review current data capabilities; discuss principles and key considerations to guide the development of a minimum data set; review the data collation process; and walkthrough the collated data set (data scan) to identify and analyze data for the development of a minimum data set. Following this meeting, regular teleconference meetings were set up in collaboration with Canadian Blood Services to discuss emerging issues, recommendations and gain expertise from other knowledge areas.

6.2 Data Collation

In order to best inform deceased donation reporting practices, it was first required to develop an assessment of other deceased donation registries and data collections from the Canadian and international community. This provided the group with perspective on what deceased donation data elements are being collected and helped inform what elements might be missing from CTR. Data elements from the following sources were captured in an environmental scan and informed the DDDWG:

TABLE 1 – Deceased donation data sources

Canadian ODOs	Responses from all ODOs
Canadian Blood Services	Canadian Transplant Registry Kidney, Heart and Liver Data Working Groups Leading Practices / Guidelines / Breakthrough Collaborative
Canadian ODT Organizations	Accreditation Canada Canadian Institute for Health Information Canadian National Transplant Research Program Canadian Organ Replacement Register Canadian Standards Association Health Canada
International ODT Organizations and Initiatives	**Australia** Australian and New Zealand Organ Donor Registry Australian Organ & Tissue Authority **European Union** The DOPKI project **Spain** Donation & Transplantation Institute Organizacion Nacional de Transplantes **United Kingdom** National Health Service Blood and Transplant **United States** Breakthrough Collaborative Scientific Registry of Transplant Recipients United Network for Organ Sharing **Global** International Registry on Donation and Transplantation International Society for Heart and Lung Transplantation World Health Organization

6.3 Data Collection Considering Time Points

Other DWGs considered clinical trajectories and timelines to ensure all major events and data were captured at the appropriate time point. Given the frequent non-linearity of the deceased donation process, the DDDWG utilized an inverted pyramid framework (adapted from the *Australian Government, Australian Organ and Tissue Donation and Transplantation Authority, Annual Report 2013-2014*, Figure 8: Australia's potential organ donor population) to guide the identification of data elements. This is described in greater detail in section 7.4.

6.4 Data Analysis and Review

The DDDWG was responsible for highlighting existing data gaps and determining what new elements are required to reconcile these disparities. To accommodate the identification of data gaps, the Environmental Scan was organized along two axes: (1) data category (Identification of Opportunity, Referral, Declaration of Death, Family Engagement, Consent, Donor Management, Assessment, Allocation, Offer, International Organ Sharing, Logistics [pre, intra, post], Recovery, Package & Label, Organ Disposition, Post Donation, Reporting & Measurement) and (2) existing data sources. This provided the DDDWG with a detailed understanding of what deceased donation data elements are currently collected by the data sources identified in Table 1. The identified data gaps are outlined in the recommended deceased donation minimum data set (Appendix B), which also describes proposed new data elements.

The DDDWG employed an iterative review approach, in order to refine the minimum data set and ensure all aspects of the deceased donation process were captured with the appropriate level of detail.

As part of the analysis process, specific sub areas of interest were identified and additional information was captured. This information was presented back to the group for further exploration, discussion, modification, approval and inclusion into the final minimum data set.

7. Recommendations

7.1 National Deceased Donation Data Strategy

The DDDWG determined that the most important priority was to ensure the national deceased donor minimum data set is comprehensive, valid, and relevant to stakeholders across Canada. Comparative performance measures can therefore be derived from the minimum data. Accuracy of these performance measures is predicated on numerators and denominators that are well defined and collected using similar approaches across provinces. However, most provincial ODOs in Canada have developed different processes and infrastructure for referring potential donors and subsequent data collection. The DDDWG therefore recognized the importance of using existing population-level data that are collected using similar approaches across regions. The Canadian Institute for Health Information (CIHI) Discharge Abstract Database (DAD) - Hospital Morbidity Database (HMDB) and CTR both have a national scope, and provided a feasible methodology for creating performance measures for deceased donation using common data collection procedures and definitions. The DDDWG recognized that some stakeholders may choose to refine deceased organ donation performance measures by using different denominators (e.g. Per million persons vs. per 1000 hospitalized deaths vs. per 1000 ventilated deaths, etc.). DDDWG considered these issues when creating a framework for data collection and reporting using the newly proposed minimum dataset.

7.2 Minimum Data Set

The recommended national deceased donor minimum data set is presented in Appendix B. All data elements listed should be considered mandatory. It is recommended that minimum data set be maintained by Canadian Blood Services. Population data will be collected by Canadian Blood Services, and the individual donor data will be provided to Canadian Blood Services by the provincial ODOs. The absence of any data element from the minimum data set should not be interpreted by provincial programs as a direction not to capture the data at a local level.

The DDDWG considered the validity of recommending “optional” data elements. It was determined that optional data would be incomplete as not all programs would be collecting the data and conclusions drawn from the data could be invalid. It was therefore agreed that the DDDWG would only make recommendations about mandatory data elements.

The DDDWG considered how donors are reported as either those determined dead using circulatory criteria (DCD) or neurological criteria (NDD) and decided that it was not necessary to categorize all data elements as being associated with either NDD or DCD. However, sufficient details about the deceased donor should be captured to ensure the ability to distinguish between NDD and DCD (e.g., for calculation of metrics such as organs per donor, where rates between NDD and DCD are expected to vary, or conversion rates of eligible donors).

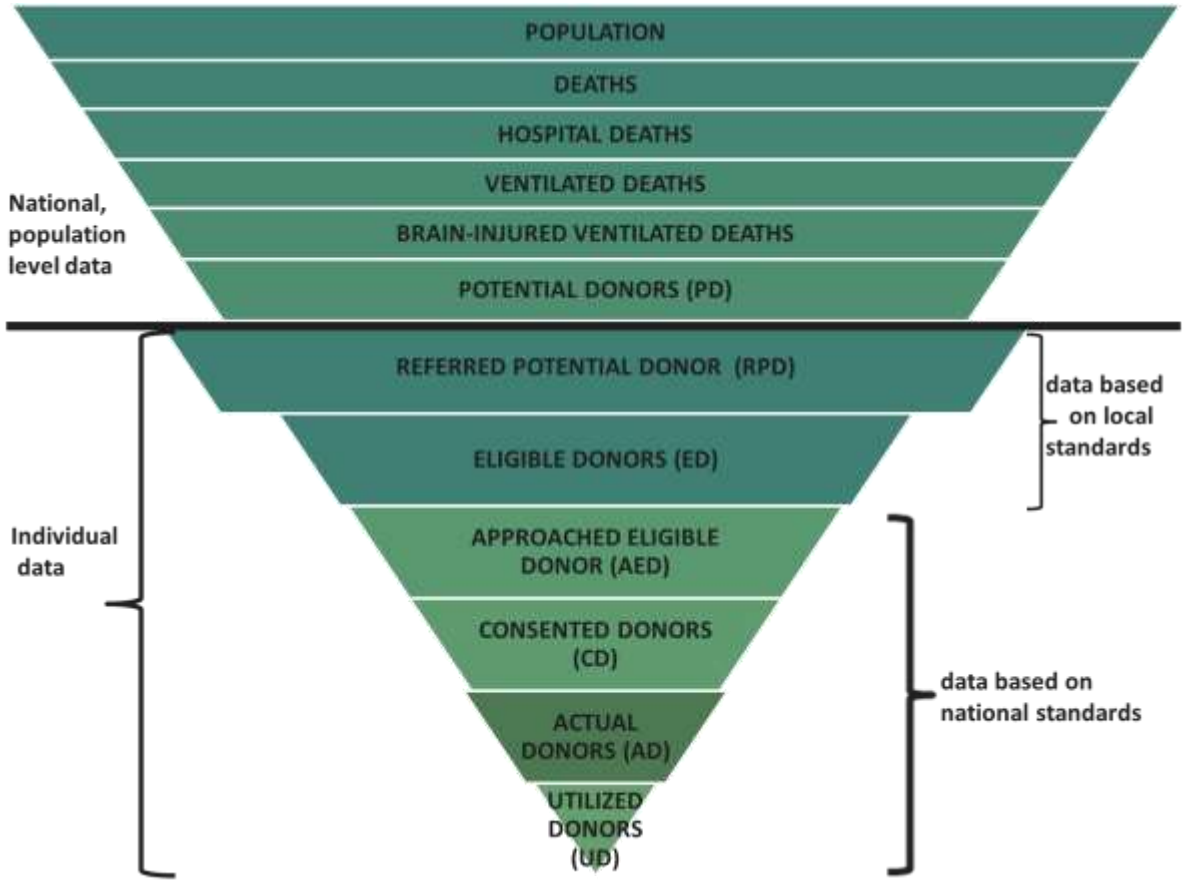
7.3 Deceased donor data elements recommended by organ specific data working groups

The DDDWG also considered and included data that would be required by transplant programs to assess the candidacy of the deceased donor for transplant. It was determined that the organ specific DWGs were better able to determine the organ specific deceased donor data elements (e.g. organ function thresholds, infectious disease status etc.) that would be required by transplant programs; the DDDWG therefore recommends the inclusion of these data elements as identified by the organ specific DWGs. Organ specific deceased donor data elements recommended by the organ specific DWGs that were not included in the DDDWG recommendations are detailed in Appendix C.

7.4 The Data Pyramid

The DDDWG utilized the inverted pyramid framework (Figure 1) to identify deceased donation information and performance measures (Refer to Table 2 and Table 3 for definitions). It is the recommendation of the DDDWG that these concepts, their definitions and data sources be adopted nationally to guide the collection of deceased donation data.

FIGURE 1 – Deceased donation information pyramid*



*adapted from the *Australian Government, Australian Organ and Tissue Donation and Transplantation Authority, Annual Report 2013-2014*, Figure 8: Australia's potential organ donor population.

Each level in the pyramid represents data collection that is required from a specific group or denominator of patients. The pyramid moves from data collection occurring at the level of the entire population, and

becomes more focused with each subsequent level until reaching the apex of utilized donors. More granular data collection is required at each successive (smaller) level of the pyramid. The pyramid is separated into two distinct sections by a bold horizontal line; data collection for patient groups identified above the line will be measured in aggregate using existing data sets: (1) Statistics Canada for population and deaths and; (2) CIHI DAD-HMDB[1] and National Ambulatory Care Reporting System (NACRS) for the remaining Information. Information below the line will be sourced from the provincial ODOs. This framework was developed to maximize efficiency, and to take advantage of existing national data collection systems already in place (i.e. national health administrative databases).

The DDDWG acknowledges that there may be discrepancies between the potential donor numbers identified using administrative data (smallest level above the line) and the referred potential donor numbers (largest level below the line) due to the different approaches used in collecting these data. However, comparison of the number of patients in these levels across regions may provide insights to explain differences in estimates calculated at the national level (e.g. potential donors) and those obtained at the provincial level (e.g. referred potential donors). Notably, there currently exists variability across provinces in the referral process for potential donors (due to differing clinical triggers which define when hospitals need to refer a potential donor) and also for the identification of eligible donors (due to variations in eligibility criteria). This variability reflects differences in local processes and standards, and therefore it is not expected that numbers of potential donors estimated at the national level and numbers of referred potential donors will be the same. (Refer to Section 7.6 Emerging issues for recommended solutions).

The DDDWG also focused on identifying potential donors that had sustained brain injury, since this is the most common condition leading to organ donation. However, the DDDWG acknowledges that there may be cases of organ donation arising from other lethal conditions that are not associated with brain injury (estimate 2 – 3 % of all deceased donors), such as amyotrophic lateral sclerosis. These situations will not be identified using the proposed framework for identifying potential donors using national databases (e.g. CIHI DAD-HDMB/NACRS); however, these cases will still be identified by provincial ODOs. (Refer to Section 7.6 Emerging issues for recommended solutions.)

The following table provides definitions of the recommended deceased donation information described in the pyramid.

TABLE 2 – Deceased donation information and definitions

INFORMATION	DEFINITION*	SOURCE
Population	The population of Canada	Statistics Canada
Deaths	All deaths that occur in Canada. Death refers to the permanent disappearance of all evidence of life at any time after a live birth has taken place. Still births are excluded.	Statistics Canada

[1] Note for the HMDB: all provinces and territories (with the exception of Quebec) submit discharge data to CIHI's Discharge Abstract Database (DAD). Quebec's Ministère de la Santé et des Services sociaux submits a data file to CIHI at the end of the year. This data file is mapped, processed and finally merged with the DAD acute care data to create the national HMDB.

INFORMATION	DEFINITION*	SOURCE
Hospital deaths	Deaths determined in hospital, includes deaths in an acute care facility including emergency departments (ED), intensive care units (ICU), wards, special care units. Excludes long term care facilities, deaths on scene or during transport after failed cardiopulmonary resuscitation.	CIHI-DAD-HMDB & CIHI-NACRS**
Ventilated deaths	Persons that died while on positive pressure ventilation (invasive or non-invasive) at any time during the hospital episode during which the patient died.	CIHI-DAD-HMDB & CIHI-NACRS**
Brain injured ventilated deaths	Deaths of brain injured ventilated patients.	CIHI-DAD-HMDB & CIHI-NACRS**
Potential donors***	Persons with a brain injury leading to death, who received mechanical ventilation at or near the time of death.	CIHI-DAD-HMDB & CIHI-NACRS**
Referred potential donor****	A potential donor who was referred to an ODO	ODOs
Eligible donor	A referred potential donor who is suitable for a consent discussion (to be approached for organ donation)	ODOs
Approached eligible donor	An eligible donor who is approached for donation (a consent discussion is held)	ODOs
Consented donor	A person for whom consent was obtained for organ donation	ODOs
Actual donor	A consented donor from whom at least one organ was recovered for the purpose of transplantation	ODOs
Utilized donor	A consented donor who had at least one organ transplanted	ODOs

*Definitions refer to data in Canada

** NACRS has full data coverage for emergency departments and clinics in Ontario and Alberta, but is less comprehensive for the other provinces. Refer to section 7.6 Emerging issues.

*** Refer to section 7.6 Emerging issues for potential donor definition limitations

* ***For those ODOs who capture “notifications”, referred potential donor numbers should be calculated by subtracting referrals that do not die from the total notifications.

The following table identifies the recommended deceased donation performance measures and their formula.

Table 3 – Deceased donation performance measures

MEASURE	FORMULA
Potential Donor Rate*	Potential Donors (PD)/ Population
Referral Rate	Referred Potential Donors** (RPD) / Potential Donors (PD)
Missed Referrals	Potential Donors (PD) – Referred Potential Donors** (RPD)
Approach Rate	Approached Eligible Donors (AED)/ Eligible Donors*** (ED)
Consent Rate	Consented donors (CD) / Approached Eligible Donors (AED)
Conversion Rate*** *	Utilized Donors (UD) / Approached Eligible Donors (AED) (less medically unsuitable)
Donor Utilization Rate	Utilized Donors (UD) / Consented Donors (CD)
Utilization Rate	Organs Transplanted/Utilized Donors (UD) (Distinct for NDD & DCD)
Non-utilized donor	Actual Donors (AD) - Utilized Donors (UD)

* depending on how potential is being analyzed, a different denominator could be used for the potential donor rate (population, deaths, hospital deaths, ventilated deaths, brain-injured ventilated deaths), and therefore the measure must be clearly identified and defined.
** the number of referred potential donors will depend on clinical triggers in use by each province.
*** the number of eligible donors will depend on eligibility criteria in use by each province.
****depending on which part of the donation process was being analyzed, a different denominator could be used for the conversation rate (potential donor, referred potential donor, eligible donor or approached eligible donor), and therefore the measure must be clearly identified and defined.

7.5 Quality Control Strategy

The DDDWG considered data control strategies by which the quality, completeness, and accuracy of data submissions could be assessed and measured. To help inform the group's strategy recommendations, the DDDWG reviewed the outcomes of the Data, Analytics and Reporting Systems Workshop, which 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 DDDWG reviewed the CIHI Data Quality Framework:

> *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*

It is the recommendation of the DDDWG that Canadian Blood Services endorse the CIHI Data Quality Framework as a starting philosophy for data quality management.

7.6 Emerging Issues

The DDDWG identified several issues that they felt were important and should be brought to the attention of DDAC, DTAAC and ISAC as items that will require further discussion and development within the deceased donation community and the CTR. These emerging issues are as follows:

Emerging Issues	Description	Recommendation
Acquiring Aggregate Data from CIHI.	CIHI is the source of the recommended aggregate data elements: hospital deaths, ventilated deaths, brain injured ventilated deaths, potential donors. Capturing these data presently requires formal requests to CIHI.	Establish process for acquiring CIHI aggregate data on a regular basis.

Emerging Issues	Description	Recommendation
Potential donor: definition limitations	1. It is estimated that up to 10-15% of potential DCD donors (i.e. 2 – 3 % of all deceased donors) would not be captured by the definition of potential donor using existing national CIHI data because the proposed definition is limited to brain injured patients. 2. Depending upon the circumstances of the case, physician-assisted deaths may not be captured as potential donors. 3. Brain injured patients who are never intubated, for example because it is deemed not to be in the best interest of the patient, will not be captured as potential donors.	The impact of these limitations should be monitored and the definition of potential donor should be revisited if there is a substantial increase in these types of cases.
Potential donor: CIHI-DAD measurement limitations	The CIHI-DAD (the national source for potential donor data, except Quebec) only identifies those patients that "ever received mechanical ventilation", and therefore will not actually be able to capture potential donors who require "*mechanical ventilation at or near the time of death".* Until more detailed data on the timing of mechanical ventilation is captured in the CIHI-DAD, only patients who died as a result of a brain injury who ever (yes or no) received mechanical ventilation will be captured as a potential donor. This may overestimate the number of potential donors.	A submission was made to create a new CIHI-DAD variable representing "mechanical ventilation in the 24 hours prior to death" which is either "YES" or "NO" was agreed upon. This submission must be tracked to provide support to CIHI as it moves thorough their change request process.
Potential donor: NACRS measurement limitations	The CIHI NACRS will be used to capture information about deaths in emergency departments NACRS has full emergency department data coverage in Ontario and Alberta, but is less comprehensive for the other provinces. Therefore national estimates of deaths will be underestimated using NACRS.	An initiative to ensure all deaths in emergency departments are captured in the CIHI NACRS is required to ensure national coverage for potential donors in emergency departments.

Emerging Issues	Description	Recommendation
Comprehensive identification of patients who have a determination of neurological death	An ICD-10-CA code exists to identify patients who have a determination of neurological death (G93.81). However, this is an optional code rather than a mandatory data element, and thus it is not reliably collected in the CIHI DAD/NACRS. Consistent use of this code in appropriate cases would allow for discrimination between deaths that occur following a determination of neurological death versus circulatory death.	A submission was made to request that all deaths that are determined using neurologic criteria be identified using the ICD-10-CA code G93.81 (Neurologically determined death) as a mandatory data element. This submission must be tracked to provide support to CIHI as it moves thorough their change request process.
Referred Potential Donors: Clinical triggers standardization	Clinical triggers, which define when hospitals need to notify the ODO of a potential donor, are not standardized. As such, the data element of referred potential donor will be based on local variations in clinical triggers.	A clinical trigger initiative is required to standardize definitions at a national level, to ensure that referred potential donors are consistently defined.
Exclusion criteria for deceased donation standardization	Exclusion criteria, which define which potential donors are eligible, are not standardized. As such, the data element of eligible donor will be based on local variations in exclusion criteria.	An exclusion criteria initiative is required to standardize definitions at a national level, to ensure that eligible donors are consistently defined.
CIHI-DAD cadaveric donor	CIHI-DAD presently captures cadaveric donor (a recoverable donor from whom at least one organ has been procured) information. It is an optional abstract in most provinces and territories and is completed when: (1) A deceased patient is transferred from another facility and is admitted as an inpatient for the purpose of organ procurement; or (2) A deceased patient is transferred from the emergency department, the day surgery unit or ambulatory care setting of the reporting facility for the purpose of organ procurement.	Provide a recommendation to CIHI to abstract information for all “cadaveric donors” and change the terminology to “actual donors”.
Review/alignment of data element values/definitions for Cause of Death, Date & time of WLST, Cross-Clamp date & time	The “value list” for data element Cause of death, and the definitions for Date & time of WLST, Cross-clamp date & time, do not completely align with CTR and other existing data systems.	Further analysis is required to identify the most appropriate value list/definitions for these data elements.

Emerging Issues	Description	Recommendation
Data elements: timeliness, new data requests, performance measures & how they are captured	As deceased donation matures, adjustments to components of the deceased donation minimum data set are anticipated such as sources of potential donors, identification and referrals, donor management etc.	A process is required to ensure the proposed data elements and how they are captured (lists for ethnicity, reasons not recovered, reasons not transplanted) remain up to date/in sync with future changes at the ODO or other levels.
Data quality strategy	A national data quality strategy is required to ensure the comprehensiveness and accuracy of the minimum data set.	Recommend the development of a national quality control strategy.
Death audit development	A leading practice for national medical record reviews for deceased donation (death audits) is required. Data elements essential for these death audits should be identified and standardized.	Death audit data elements and their definitions should align with the relevant DDDWG data elements.

Appendix A – Deceased Donor Data Working Group Membership

CHAIR

Dr. Damon Scales	Intensivist, Sunnybrook Health Sciences Centre Associate Professor, Interdepartmental Division of Critical Care University of Toronto Toronto, Ontario

MEMBERS

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Appendix B – Deceased Donor National Data Set

The DDDWG is recommending two separate national data sets to be collected:

(1) **The Population Level Data Set** (refer to Table B-1)

This data set will be assembled by Canadian Blood Services. All data elements are mandatory and new (not presently collected by Canadian Blood Services).

TABLE B-1 POPULATION DATA SET*

Name	Description	Values	Data Rules
Population	Population of Canada at a specific date	numeric	broken down by age (Q5 years), sex and province of residence
Deaths	The number of deaths that occurred in Canada during a specific period. Death refers to the permanent disappearance of all evidence of life at any time after a live birth has taken place. Still births are excluded.	numeric	broken down by age (Q5 years), sex, province of residence
Hospital deaths	The number of deaths that occurred in Canada in a hospital during a specific period. Deaths determined in hospital, includes deaths in an acute care facility including ED, ICU, wards, special care units. Excludes long term care facilities, deaths on scene or during transport after failed CPR.	numeric	broken down by age (Q5 years), sex, province of residence, postal code, hospital where death occurred, cause of death
Ventilated deaths	The number of deaths in Canada of ventilated patients (on positive pressure ventilation, invasive or non-invasive, at any time during the hospital episode during which the patient died) that occurred in a hospital during a specific period.	numeric	broken down by age (Q5 years), sex, province of residence, postal code, hospital where death occurred, cause of death

Name	Description	Values	Data Rules
Brain injured ventilated deaths	The number of deaths in Canada of ventilated brain-injured patients that occurred in a hospital (including the ED) during a specific period.	numeric	Brain-injured patients are identified by cause of death limited to a specific list of ICD-10-CA codes. broken down by age (Q5 years), sex, province of residence, postal code, hospital where death occurred, cause of death
Potential donors	The number of instances in Canada of a person with a brain injury that lead to death, who received mechanical ventilation at or near the time of death, that occurred in a hospital during a specific period.	numeric	broken down by age (Q5 years), sex, province of residence, postal code, hospital where death occurred, cause of death, criteria used to determine death

*the ability to provide specific numerators will be restricted by privacy regulations.

(2) **The Individual Deceased Donor Data Set** (refer to Table B-2)

This data set will be provided to Canadian Blood Services by the ODOs and stored in the CTR. It consists of 49 mandatory (7 new) and 2 calculated (1 new) fields for a total of 51 distinct data elements. It lists the recommended individual deceased donor data elements being proposed by the DDDWG. These are the descriptive details that need to be captured for each "donor type" defined in table 2.

The last 6 columns in the table indicate whether or not the data element is to be provided for the particular donor types:

- Referred Potential Donor (RPD)
- Eligible Donor (ED)
- Approached Eligible Donor (AED)
- Consented Donor (CD)
- Actual Donor (AD)
- Utilized Donor (UD)

Each element is listed with a color indicator. These indicators help demonstrate potential resource impact; both from system design and maintenance perspective as well as a data collection requirement.

● These are existing mandatory or calculated data elements that will require no change to system function or data collection requirements.

● These are existing mandatory 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. They also include data elements whose definition proposed by DDDWG is different than that currently in the CTR. These differences will be reviewed through consultations with ISAC, DDAC, and DTAAC. 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.

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

Summary

	Total	● New Fields	● Modified	● No Change
All Fields	**51**	**8**	**8**	**35**
Mandatory	**49**	7	8	34
Calculated	**2**	1	0	1

TABLE B-2 INDIVIDUAL DECEASED DONOR DATA SET

Name	Description	Values	Data Rules	RPD	ED	AED	CD	AD	UD
● Date of birth	date of birth	YYYY-MM-DD	≤ current date	x	x	x	x	x	x
● Age	age is **calculated** based on date of birth and declaration of death date	years, weeks, days	n/a	x	x	x	x	x	x
● Sex	sex of person	Male Female	Single selection list	x	x	x	x	x	x
● Height	height of patient in centimeters	in centimeters	≥ 0.0 and ≤ 300.0				x	x	X
● Weight	weight of patient in kilograms	in kilograms	≥ 0.0 and ≤ 700.0				x	x	x
● Province of residence	province associated to person's address where they lived	Alberta British Columbia Manitoba New Brunswick Newfoundland and Labrador Northwest Territories Nova Scotia Nunavut Ontario Prince Edward Island Quebec Saskatchewan Yukon Unknown	Single selection list	x	x	x	x	x	x

Name	Description	Values	Data Rules	RPD	ED	AED	CD	AD	UD
● Postal Code	postal code for the home address of the person	Postal code	≤ 10 characters Format must be X9X 9X9	x	x	x	x	x	x
● Ethnicity	ethnicity of the potential donor	Aboriginal Asian Black Caucasian Indian subcontinent Latin American Middle Eastern/Arabian Pacific Islander Other/Multicultural Unknown	Single selection list			x	x	x	x
● Hospital where death occurred	the hospital where the person died. If patient did not die, hospital where patient was followed	Text		x	x	x	x	x	x
● Date & time of admission to hospital where death occurred	date & time the person was admitted to hospital they died in (If patient did not die, hospital where patient was followed)	yyyy-mm-dd hh:mm	<= current date	x	x	x	x	x	x
● 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.				x	x	x
● DCD Declaration end Date/Time	confirmation of lack of spontaneous circulation and actual death date/time for DCD	yyyy-mm-dd hh:mm	≤ current date/time and ≥ WLST date/time. Required for DCD only.	x	x	x	x	x	x
● Type of declaration of death	Declaration of death could be NDD or DCD.	NDD DCD	Single selection list	x	x	x	x	x	x

Name	Description	Values	Data Rules	RPD	ED	AED	CD	AD	UD
● Location of patient at time of referral	The unit within the hospital that the patient was in at the time of referral	cardiac intensive care unit cardiovascular intensive care unit ED ICU ICU step-down unit Neuro ICU Neonatal ICU Post anesthetic care unit Pediatric ICU Surgical ICU other not documented	Single selection list	x	x	x	x	x	x
● Length of hospital stay	Number of days in hospital **calculation**	numeric	**If the person died:** date & time of death - date & time of admission	x	x	x	x	x	x

Name	Description	Values	Data Rules	RPD	ED	AED	CD	AD	UD
● Cause of death	the injury that lead to the death of the person	Hypoxic-ischemic * respiratory arrest * cardiac arrest of multiple causes * other Cerebrovascular accident * stroke * arteriovenous malformation * aneurysm * venous thrombosis * other Traumatic brain injury * motor vehicle accident * non-motor vehicle accident * other Brain Infection * encephalitis * meningitis * cerebral abcess * other Brain tumor (primary, includes metastatic) Hydrocephalus intracranial hemorrhage * epidural * intracerebral * subarachnoid * subdural * other Metabolic * hyponatremia * hepatic failure * diabetic ketoacidosis * drug overdose * in born errors of metabolism * other Other	Single selection list	x	x	x	x	x	X
● Withdrawal of Life sustaining therapy (WLST)	was life-sustaining therapy withdrawn	Yes No	Single selection list	x	x	x	x	x	X
● date & time of WLST	Date and the time the 1ST treatment was stopped.	yyyy-mm-dd hh:mm	<= current date >=date of admission & date of birth Required only for DCD	x	x	x	x	x	x

Name	Description	Values	Data Rules	RPD	ED	AED	CD	AD	UD
● Mechanical Ventilation within 24 hrs of death	was the person on mechanical ventilation within 24 hrs of death	Yes No	Single selection list	x	x	x	x	x	x
● Heart Consent state	Consent state of heart	Consented Not Consented Not participating					x	x	X
● Lung Consent state	Consent state of lung	Consented Not Consented Not participating					x	x	X
● Liver Consent state	Consent state of liver	Consented Not Consented Not participating					x	x	X
● Small Bowel Consent state	Consent state of small bowel	Consented Not Consented Not participating					x	x	X
● Stomach Consent state	Consent state of stomach	Consented Not Consented Not participating					x	x	X
● Pancreas – whole Consent state	Consent state of whole pancreas	Consented Not Consented Not participating					x	x	X
● Pancreas – islet Consent state	Consent state of islets	Consented Not Consented Not participating					x	x	X
● Kidney Consent state	Consent state of kidney	Consented Not Consented Not participating					x	x	X
● Cross-clamp date & time	date & time organs were recovered	yyyy-mm-dd hh:mm	<= current date >=date of death					x	x
● Retrieval Hospital	Hospital where the deceased donor organ procurement surgery takes place.	Hospital name with city	Single selection list					x	x
● Heart recovered state	recovered state of organ	Not recovered Recovered for	If organ consented then recovery details required					x	X
● Right Lung recovered state	recovered state of organ	Not recovered Recovered for	If organ consented then recovery details required					x	X

Name	Description	Values	Data Rules	RPD	ED	AED	CD	AD	UD
● Left Lung recovered state	recovered state of organ	Not recovered Recovered for	If organ consented then recovery details required					x	X
● Liver recovered state	recovered state of organ	Not recovered Recovered for	If organ consented then recovery details required					x	X
● Small Bowel recovered state	recovered state of organ	Not recovered Recovered for	If organ consented then recovery details required					x	X
● Stomach recovered state	recovered state of organ	Not recovered Recovered for	If organ consented then recovery details required					x	x
● Pancreas – whole recovered state	recovered state of organ	Not recovered Recovered for	If organ consented then recovery details required					x	X
● Right Kidney recovered state	recovered state of organ	Not recovered Recovered for	If organ consented then recovery details required					x	X
● Left Kidney recovered state	recovered state of organ	Not recovered Recovered for	If organ consented then recovery details required					x	X

Name	Description	Values	Data Rules	RPD	ED	AED	CD	AD	UD
● Not Recovered Reason	not recovered reason for each organ	All offers declined Coroner / medical examiner decline DCD did not die within acceptable time High inotrope requirement Inadequate perfusion of organ (thrombosis) Infection/sepsis Medically unsuitable pre OR Medically unsuitable intra OR Not consented for recovery Not participating for recovery No recipient located No suitable recipient (size/ABO) No recovery team available Organ damaged during recovery Problem with recipient Technical problem in donor OR Transportation logistics Unable to maintain donor intra OR Unable to maintain donor pre OR other	If not recovered selected then reason required					x	X
● Recovered For Reason	recovered for a specific medical use, for each organ	Transplant Research Medical Education Tissue Not Used Not Applicable Pathology	If recovered for selected then reason required					x	X
● Heart transplanted state	Transplanted state of organ	Yes No	If organ recovered for transplant then was it transplanted					x	X
● Right Lung transplanted state	Transplanted state of organ	Yes No	If organ recovered for transplant then was it transplanted					x	X
● Left Lung transplanted state	Transplanted state of organ	Yes No	If organ recovered for transplant then was it transplanted					x	X
● Liver transplanted state	Transplanted state of organ	Yes No	If organ recovered for transplant then was it transplanted					x	X
● Small Bowel transplanted state	Transplanted state of organ	Yes No	If organ recovered for transplant then was it transplanted					x	X

Name	Description	Values	Data Rules	RPD	ED	AED	CD	AD	UD
● Stomach transplanted state	Transplanted state of organ	Yes No	If organ recovered for transplant then was it transplanted					x	x
● Pancreas – whole transplanted state	Transplanted state of organ	Yes No	If organ recovered for transplant then was it transplanted					x	X
● Right Kidney transplanted state	Transplanted state of organ	Yes No	If organ recovered for transplant then was it transplanted					x	X
● Left Kidney transplanted state	Transplanted state of organ	Yes No	If organ recovered for transplant then was it transplanted					x	X
● Not transplanted reason	not transplanted reason for each organ	Lack of recipient hospital resources No suitable recipient Not consented for transplant Not participating for transplant Not recovered for transplant Organ medically unsuitable for transplant Other organ type transplanted Prolonged Cold Ischemic Time Prolonged Warm Ischemic Time Recipient died Recipient medically unsuitable Storage and preservation problems Technical problem in OR Transportation logistics other	If transplanted state = NO then reason required					x	X
● Not transplanted disposition	Specify disposition of not transplanted organ(s)	Medical Education Not Used Pathology Research Tissue	If not transplanted selected Single selection list					x	X

Appendix C – Deceased Donor Data – Organ Specific Data Not Incorporated

The DDDWG considered and included data that would be required by transplant programs to assess the candidacy of the deceased donor for transplant. It was determined that the organ specific DWGs were better able to determine the organ specific deceased donor data elements (e.g. organ function thresholds, infectious disease status etc.) that would be required by transplant programs; the DDDWG therefore recommends the inclusion of these data elements as identified by the organ specific DWGs. The remaining (not included in the DDDWG recommendations) organ specific deceased donor data elements recommended by the organ specific DWGs are detailed in Table B-3 below.

TABLE B-3 Organ specific deceased donor data elements recommended by organ specific DWG not included in the DDDWG recommendations

Name	Description	Values	Data Rules	heart	lung	liver	kidney
Country of Residence	Donor country of residence	List of countries	Single selection list **OPTIONAL**	X	X		
ABO	Blood type of patient	A B O AB unknown	Single selection list	X	X		X
Confirm ABO	Confirm blood type by re-entering blood type of patient	A B O AB unknown	Single selection list	X	X		X
RH	RH of patient	+ -	Single selection list **OPTIONAL**	X	X		
OPO	Organ Procurement Organization responsible for donor	Abbreviated and full name of OPO		X	X	X	X
HLA lab	HLA lab responsible for providing HLA typing	Abbreviated and full name of HLA lab	Derived by system based on associated Transplant Centre	X	X		X
Referral Hospital	Hospital where potential deceased donor is identified	Hospital name with city		X	X	X	X
Care Hospital	Hospital where deceased donor care takes place	Hospital name with city		X	X		
Country of Death	Country where donor was declared dead	List of countries	Single selection list	X	X		X
Province/State of Death	Province or state where donor was declared dead	Canadian provinces and territories US states	Single selection list	X	X		X

Name	Description	Values	Data Rules	heart	lung	liver	kidney
Declaration of NDD	Method used for declaration of NDD performed by physician	Ancillary - 4 Vessel Cerebral Angiogram CLINICAL EXAM Ancillary - Radionuclide Testing Ancillary - CT Angiogram Ancillary - MRI Angiography Other	Multiple selection list.	X	X		
DCD Declaration start Date/Time	Start of lack of spontaneous circulation	YYYY-MM-DD HH:MM	≤ current date/time and ≥ WLST date/time. ≤ DCD Declaration End Date/time. Required for DCD only.			x	X
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		X		
Organ Type Offered	For each organ offer, name of organ type being offered	Left Right Double	Single selection list		X		
Offer State	For each organ offer, state of organ being offered	Proposed Accepted Declined Withdrawn Cancelled Acceptance	Single selection list		X		
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		X		
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 waitlist		X		
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 waitlist		X		
Transplant Centre	For each organ offer, Transplant Centre associated to the recipient involved in the offer	CTR Transplant Centre list	Set by system upon selection of transplant candidate waitlist		X		
National recipient ID	For each organ offer, national recipient ID associated to the recipient involved in the offer	Unique identifier	Set by system upon selection of transplant candidate waitlist		X		
National donor ID	For each organ offer, national donor ID associated to the donor involved in the offer	Unique identifier	Set by system upon selection of transplant candidate waitlist		X		x
Partial/Split liver graft		Yes No	Single selection list			x	
Perfusion	Organ device used to perfuse organ	Kidney Perfusion Pump Exvivo Pump None	Single selection list	x		x	X

Name	Description	Values	Data Rules	heart	lung	liver	kidney
Recipient ODO	For each organ transplanted, ODO of recipient who received the organ	CTR ODO list	Set by system when transplant recorded		X		
Recipient TXC	For each organ transplanted, Transplant Centre of recipient who received the organ	CTR Transplant Centre list	Set by system when transplant recorded		X		

Appendix D – Terms of Reference

Deceased Donation Data Working Group

Subcommittee to the Deceased Donation Advisory Committee

Terms of Reference

Objectives

To provide input and advice to Canadian Blood Services, and the Organ Donation and Transplantation (ODT) community, on strategies, policies and practices regarding standardization, collection, analysis and reporting of deceased organ donation data towards the advancement and implementation of initiatives within Canadian Blood Services' existing mandate. The Working Group will operate within the mandate of the Deceased Donation Advisory Committee (DDAC). The mandate of DDAC includes:

- Provide advice on deceased donation clinical policy and practice issues, professional awareness and education; and ODT system performance;
- Define the standard of care through application of evidence-based leading practices;
- Assist in unifying the donation sector and providing an effective link to the transplantation sector;
- Engage key informants in the development of advice on policies and practices;
- Address emerging issues that may arise, as appropriate.

Scope

The Deceased Donation Data Working Group's (the Working Group) scope encompasses matters related to deceased organ donation data, including NDD and DCD donors, operational and performance data, and follows the donor pathway from donation potential to donation and disposition of organs.

Authority

The Working Group shall function under the current mandate and authority of the DDAC and DTAAC as appropriate. The Working Group works in collaboration with other working groups and committees to ensure integrated data across the ODT continuum.

Mandate

- To understand the data needs to inform clinical decisions with respect to deceased donation
- To identify data points along the deceased donation critical path
- To identify the availability and gaps in current data and the comparability of data amongst deceased donation programs

- To understand international standards and definitions
- To develop recommendations for a minimum data set for deceased donation
- To work towards the development of interprovincial agreement on reporting standards
- To provide advice on deceased donation data for operations of the Canadian Transplant Registry
- To develop a quality control strategy to assess the quality and completeness of data submissions to the registry
- To make recommendations regarding leading practices for death audits
- To develop an accurate evaluation of true donor potential
- To address emerging issues that may arise, as appropriate or at the request of the DDAC or DTAAC

Membership

Membership in the Working Group will include individuals with relevant professional knowledge and experience in deceased donation and in data management.

The Working Group will sunset once it has fulfilled its mandate, or when Canadian Blood Services determines otherwise.

Subject matter experts may be invited to attend specific Working Group meetings as required.

Chair

The initial Chair of the Working Group shall be appointed by Canadian Blood Services, and shall serve until completion of the Working Group's mandate. The Chair of the Working Group is responsible for ensuring that the Working Group functions within these Terms of Reference.

Quorum

- A majority of the voting members of the Working Group shall constitute a quorum.
- Ordinarily, decisions and recommendations of the Working Group will be achieved by consensus; where consensus is not requested or cannot be achieved, both assenting and dissenting views are to be presented.
- Absence from more than two meetings may result in revocation of membership.

Meetings

- Canadian Blood Services will provide the secretariat to the Working Group meetings.

- Meetings will be held as often as required, at the discretion of the Chair but will likely include 1-2 face to face meetings per year, and quarterly teleconferences.
- If the Working Group requires a face-to-face meeting, Canadian Blood Services will reimburse travel costs as per Canadian Blood Services travel guidelines.
- Members shall not send delegates to meetings, unless approved by the Chair.