Potential Organ Donor Identification and System Accountability Workshop

September 20-21, 2016
Ottawa, Ontario

Canadian Blood Services BLOOD PLASMA STEM CELLS ORGANS & TISSUES

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Acknowledgements

This report provides an overview of the Potential Organ Donor Identification and System Accountability workshop and a summary of participant recommendations in response to prescribed questions. The workshop was based on the collaborative wisdom of a broad range of stakeholders, experts and key leaders representing Canadian Blood Services and the Canadian National Transplant Research Program (Refer to *Appendix B: Workshop participants and affiliations*). The Steering Committee would like to collectively thank Canadian Blood Services and the Canadian National Transplant Research Program for their support of this initiative, as well as all participants who helped in the creation of these recommendations. We would also like to acknowledge Ms. Debbie Neville and Mr. Emile Therien, our family representatives, who took the time to share compelling personal experiences which situated participants to the circumstances facing Canadians.

Endorsement

This report is endorsed by the Canadian Critical Care Society.

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Foreword

As Canadians, we are fortunate to live and work in a country where society values the saving and preserving of life, and the alleviation of suffering. Our federal and provincial governments support many initiatives to uphold these values. In the context of devastating and life-threatening illness or injury, the healthcare system aims to prevent death and suffering when avoidable, and accept death once inevitable. These juxtaposed realities are fundamental to the Canadian Organ Donation and Transplantation (ODT) System, which has the following goals:

- serve the needs of potential transplant recipients, by performing as many transplants as possible for this underserviced population;
- serve these needs in an ethical, legal, safe and equitable manner;
- provide the opportunity to donate without compromising the duty of care to the dying patient.

End-stage organ failure and life-sustaining technologies such as kidney dialysis are difficult burdens for patients and families, life-threatening to patients in the absence of transplantation, and expensive to the healthcare system. Compared with dialysis for end-stage renal disease, transplantation is life-preserving and cost effective[1, 2], but limited by an insufficient number of transplantable organs. Countries and jurisdictions have a responsibility to address their domestic availability of transplantable organs in an ethically legitimate manner.[3]

Generally, to become a deceased organ donor, one must die in a hospital, be mechanically ventilated and medically supported. Deceased donors are determined to be dead either by neurological (brain-based) or circulatory (heart-based) criteria. In Canada, the primary source of organs for transplantation are from donors who experience neurological determination of death (NDD), more commonly known as brain death. Donation after circulatory death (DCD) has progressively increased over time and constituted 21 per cent of all Canadian deceased donors in 2015.[4] Deceased donors can provide up to eight transplantable organs (average 2.5 - 4.0 organs/donor) and as many as 50 life-enhancing or life-saving allografts through tissue donation.

Every year there are approximately 250,000 deaths in Canada, of which 120,000 occur in the hospital.[5] The vast majority of those deaths do not fulfill eligibility for organ donation. Of the estimated 2,000 - 4,000 potential donors per year (i.e. those that meet eligibility requirements), approximately 600 individuals become actual donors.[6] Given that donation opportunities occur in low numbers, deceased organ donation may not be seen as a high-priority concern for many hospitals, healthcare professionals (HCPs) and intensive care units (ICUs). Yet a single donor can provide life-saving benefits to multiple transplant recipients. The ODT system in Canada depends heavily on the collaborative efforts of 10 provincial organ donation organizations (ODOs), 80 transplant programs and 286 ICUs to address the needs of 35.5 million Canadians living over 9.7 million square kilometers – an incredible effort and sizable task to coordinate and facilitate the donation and transplant process.

Deceased donation care is complex, difficult, emotionally straining and requires sensitive interplay between the potential deceased donor, their family and HCP. While organ donation should be embedded as a standard component of end-of-life (EOL) care, it hinges on time-sensitive conversations during tragic

circumstances for families. There is a natural discomfort that surrounds the juncture where EOL and donation interface.

Providing optimal donation services and support depends on staff workload, training, qualifications, hospital culture and organizational expectations. Studies demonstrate that providing the opportunity to donate in Canada is dependent on where you die – which city, which hospital, and which department in the hospital – compromising the equity in providing organ donation opportunities during EOL care.[7]

There are a number of critical steps in the donation process, from illness or injury to death, and from donation to surgical retrieval and transplantation. Hospitals and families may not know a patient's wishes regarding donation, families may not be asked about donation, or may be approached in a negative or poorly informed manner. Hospitals may not have a deceased donation program, may not provide DCD services or have access to surgical recovery teams. Physicians may be unaware of best practices for the recognition and clinical management of potential donors. These circumstances may also be influenced by an individual HCP's attitudes and beliefs towards ODT, which may range from active resistance to passive acceptance to active support.

The first and most important step in the donation process is predicated on hospital staff recognizing a potential donor and notifying an ODO in a timely manner. While required referral legislation is in place in most provinces, the issue of failing to identify and refer a potential donor remains problematic. Failure to honour the wishes of potential donors and their families ultimately results in life-threatening consequences for transplant candidates.

The purpose of the Potential Organ Donor Identification and System Accountability workshop was to focus on the identification and referral (ID&R) of potential donors, consistent with existing laws and policy, and to discuss the accountability of the healthcare system in this regard. In question were the elements that constitute a highly reliable ODT system that reduces preventable harm to transplant candidates and the potential mechanisms to advance system and organizational accountability.

We would like to thank our workshop participants, expert speakers, and Steering Committee members, as well as the funding and organizational support provided by Canadian Blood Services and the Canadian National Transplant Research Program.

Dr. Sam D. Shemie *Dr. Jeremy Grimshaw*

Co-chairs

Potential Donor Identification and System Accountability Workshop

Executive summary

Purpose and objectives of the workshop

Canadian Blood Services and the Canadian National Transplant Research Program (CNTRP) collaboratively hosted a Potential Organ Donor Identification and System Accountability Workshop September 20-21, 2016. The workshop objectives were to:

- achieve Canadian agreement on the definition of a potential donor and referral criteria (clinical triggers);
- determine the responsibilities of healthcare professionals for donor identification and referral (ID&R);
- identify barriers and facilitators to donor ID&R;
- create an implementation plan to operationalize clinical processes around donor ID&R;
- initiate the development of accountability strategies; and
- consider whether donor ID&R is a critical healthcare priority with important public health concerns.

Summary of recommendations

Impact of failing to identify and refer a potential organ donor

The following risks and consequences of failure to identify and refer potential donors should be considered in policy and practice:

a. Not respecting the wishes of a potential organ donor who has registered or informed family of their desire to donate

b. Violation of existing laws in provinces with required referral legislation

c. Not providing the family with the potential to help others, including missed opportunity for legacy, potential to provide meaning following the loss of a loved one, and the positive impact this could have on the grieving process

d. Preventable death or disability for transplant candidates

e. Compromised equitable access to transplantation

f. Ongoing costs of dialysis, which exceed the cost of transplantation for end-stage renal disease

g. Economic costs of continued care for end-stage (non-renal) organ failure

h. Loss of economic productivity of those awaiting transplant

i. Perpetuating failure - the acceptance of failure to identify and refer potential donors by HCPs and the healthcare system

j. Erosion of public and professional trust

k. Lost opportunity for increasing public and professional education and awareness through long term donor family engagement – the families of donors have stories to tell

l. Compromising interprofessional trust and accountability among deceased donation and transplant services

Mission statement to guide system accountability for organ donor identification and referral

An accountable system for potential organ donor ID&R should strive to honour patient and family wishes by ensuring the opportunity to donate. HCPs should identify potential donors early, and always refer to ODOs, so that no donation opportunities are missed. Potential donor ID&R practices must be coordinated and collaborative. A successful donor ID&R system is supported by accurate and timely data, has system-level and individual accountability, and incentivizes good performance.

We recommend:

Obligations to potential organ donors and their families

1. HCPs or ODO representatives should consistently initiate conversations around organ donation as an integrated part of EOL care.
2. To avoid any real or perceived conflict of interest, HCPs should separate the discussions regarding withdrawal of life-sustaining treatment (WLST) from donation discussions.
3. The healthcare team be properly educated on how and when to identify and refer potential donors, how to effectively and compassionately discuss donation with family members, and how to provide optimal EOL care whether or not consent for donation is given.
4. From a legal and ethical perspective, it should be assumed and expected that the healthcare team would respect and be accountable to the previously expressed donation wishes made by the dying patient or potential donor.
5. If a dying patient is not eligible to donate, the family should be informed of the reasons why they have not been approached within the limits of respecting patient privacy and confidentiality.

Obligations to potential transplant recipients and their families

6. The deceased organ donation system must be resourced and organized appropriately to ensure all possible donation opportunities are recognized and maximized.
7. A formal accountability framework should be established to ensure any missed donation opportunities (MDOs) are reported and investigated (“zero missed opportunities”).
8. Mandatory training in donor ID&R be implemented to ensure HCPs who intersect with potential organ donors communicate and work collectively, as a well-coordinated multidisciplinary team.
9. Standardized information be provided to transplant candidates and their families, and include:
    a. A description on how the system works, including transplant eligibility criteria.
    b. Local transplant allocation guidelines.
    c. Donor ID&R rates, organ donation rates, and wait times for various organs and regions in Canada.

Defining a potential organ donor

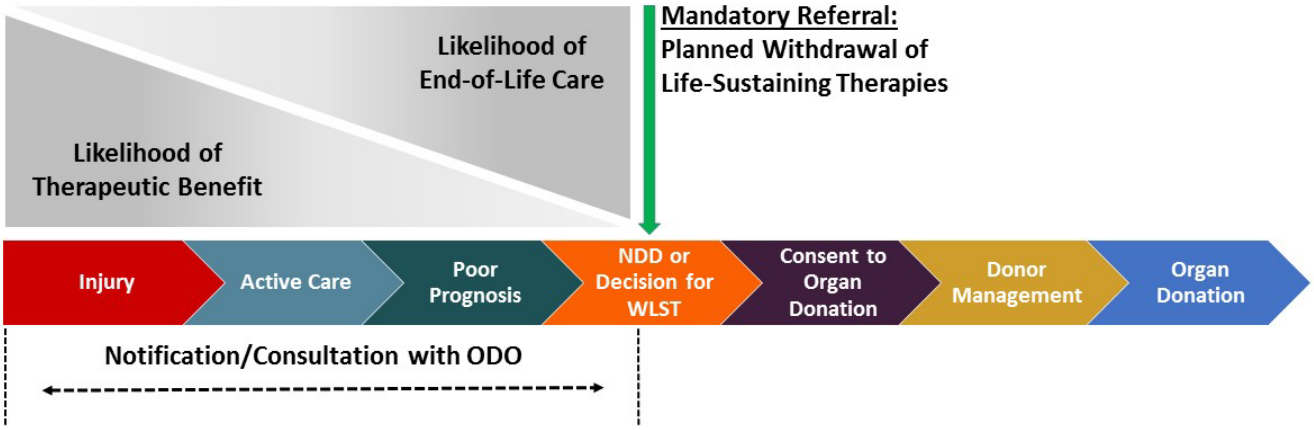
10. Patients who meet <u>all</u> the following criteria (clinical triggers) should be considered a potential organ donor and be referred to the ODO:
    a. Ventilated (invasive [intubated/tracheotomy] or non-invasive [bilevel positive airway pressure/continuous positive airway pressure] ventilation);
    b. Condition with a grave prognosis in which death is imminent; and
    c. Decision to WLST has been made (but not yet acted upon).
11. The above definition of a potential organ donor should be adopted in all Canadian jurisdictions to:
    a. Support consistency in professional education;
    b. Assist HCPs to identify potential organ donors and optimize possible opportunities for donation;
    c. Minimize loss of potential organ donors due to discretionary clinical judgements by individual HCPs; and
    d. Allow for standardized reporting, transparency, and system accountability.

Potential organ donor identification and referral – who and when

12. In donation practice and policy, a clear distinction should be made between "Referral" and "Notification/Consultation" to the ODO.
    a. <u>Referral to ODO</u>:
        - defined as the formal process by which the healthcare team seeks to involve the ODO;
        - based on fulfilling clinical triggers; and
        - should not occur until NDD or after WLST decisions have been made.
    b. <u>ODO Notification/Consultation</u> - refers to a member of the healthcare team advising the ODO of the presence of a potential donor and may be an option prior to meeting referral criteria.
        - Advantages: consultation resource provides specialized knowledge and information, clarifies donor eligibility, initiates early planning and preparations for donation logistics, arranges on-site donor coordinator support when required, provides education, organizes support services, and engages staff and families early, normalizing the integration of donation into EOL care.
        - Concerns: perception of conflict of interest, transparency with families, compromise of family or interprofessional trust, potential for influence on yet-to-be finalized EOL care plan and decisions, higher ODO workload.
        - May also be initiated upon family requests for donation information.
13. The most responsible physician, or their designate, is ultimately accountable for ensuring that referral or notification of a potential donor to the ODO has occurred.
14. All HCPs involved in EOL care can and should ***<u>identify</u>*** potential donors.
15. The most responsible physician should be consulted on process and timing if another HCP involved in EOL care will be referring a potential organ donor to the ODO.

16. The most responsible physician should be consulted on process and timing if another HCP involved in EOL care will be notifying/consulting the ODO about a potential organ donor.

Figure 1: Sequence of care in deceased donation in relation to notification and referral



Early consideration of organ donation: safeguards for patients with devastating injury/illness and their families

17. The following previously agreed upon Canadian guidelines should be strictly followed in the process of organ donor referral:
    a. The decision to WLST should be made prior to any discussion of organ and tissue donation that is initiated by HCPs;
    b. The surgical retrieval/transplant team must not be involved in the decision to WLST.
18. A second opinion regarding prognostication be obtained before proceeding with DCD.

Measurement and reporting

19. A national minimum data set and standards should be developed and implemented for death audits and MDOs should be reported consistently across Canada.
    a. Standardizing death audit methodology and donor referral criteria will improve data quality, allow for comparative measurements, and improve system performance.
    b. A single, electronic, standardized national database and reporting system should be used for all potential donors.

Implementation strategies and professional education

20. Provinces and territories that currently do not have required referral legislation should consider implementing such legal change.

21. Initiatives to ensure compliance with existing required referral legislation and policy for donor ID&R should include:
    a. Local champions (donor coordinators, donation physicians) to ensure implementation of best practices, measurement, advocacy and education;
    b. Embedding donation into EOL care/WLST protocols and checklists that include all professionals involved in EOL care (e.g. respiratory therapists, neuroscience consultants);
    c. Compliance should be monitored and measured through chart reviews and death audits;
    d. Elevating adherence to policy and law within hospital or regional accountability structures; and
    e. Public reporting of donor ID&R compliance rates.
22. Donation activity-based funding that is directed to the unit where donation services are provided.
23. Professional education initiatives that include:
    a. National education toolkit of donor ID&R and clinical trigger strategies for HCPs.
        i. May include clinical trigger cards, posters, simplified messaging (e.g. “Donation Before Extubation”, “Pause Before Withdraws”).
    b. Certification for critical care and emergency medicine staff in partnership with professional associations.
        i. Consider donation as part of hospital or specialty credentialing.
        ii. Consider Royal College or provincial medical college licensure requirements.
    c. Donor ID&R should be covered in medical and nursing school curriculums.

Access of potential organ donors to hospitals with donation services and ICU beds

24. Donor services should be patient/family centric, not hospital centric. While the type of deceased donation (NDD, DCD, or tissue) may have logistic differences, donation services should be offered regardless.
25. Dedicated donor resources may be justified with the understanding that caring for a donor is caring for multiple living recipients.
26. Agreements and collaboration between the emergency room and ICU be established to allow for transfer of potential donors to preserve the opportunity to donate.
27. Transfer of potential donors to hospitals with donation and surgical retrieval capacity:
    a. Criteria for transfer be clear and transparent to HCPs and families;
    b. In cases of DCD potential, priorities of patient care and donor care should be reconciled;
    c. Any decisions regarding relocating potential donors require engagement and discussion with corresponding transplant teams;
    d. Families may suffer stress and hardship if their loved one requires transfer to actualize donation services. Services should be offered to help avoid undue stress, financial and otherwise, on the families of potential donors.

Accountability for potential organ donor identification and referral

28. Potential organ donor ID&R should be considered a Required Organizational Practice, as per Accreditation Canada guidelines.
29. Organ donation should be established as a Program of Distinction, as per Accreditation Canada guidelines.
30. Programs of Patient Engagement should be implemented to provide a voice to donor families and patients on transplant waitlists.
31. Developing a clear accountability structure at the regional, institutional, and individual level would facilitate measurement and improvement, and include:
    a. Harmonization of clinical definitions, roles, and responsibilities; and
    b. Each hospital having designated/assigned responsibility for ID&R.
32. Data-driven assessments with public reporting on deceased donation based on death audits will recognize high performance and drive motivation for improvement. Systems should be developed where potential organ donor ID&R can be accurately tracked and used as an important quality measure and indicator of hospital, ODO, and provincial performance.
    a. Deceased donation balanced scorecards should be part of emergency department and ICU standard reporting to hospital administration, ODOs, and be available to the general public.
33. Donor ID&R should be considered an issue of preventable harm to potential organ donors and transplant candidates.
34. Donor ID&R should be considered an “Always Event” and missed potential organ donor ID&R be considered a “Never Event”.
35. Missing a potential donor referral should be reported as a “Sentinel Event”, such that the risk of adverse outcomes due to recurrence should be recognized as calls for immediate investigation and response.
36. A formal accountability framework should be established to track the utilization and reasons for non-use of all potential organs and organ donors identified, so that any missed opportunities for use of transplantable organs can be investigated and reported upon.
37. Transplant program organ utilization scorecards should be part of standard reporting to hospital administration, ODOs, and be available to the general public.

Workshop overview

Background

In 2016, the Deceased Donation Data Working Group, sponsored by Canadian Blood Services, established a minimum deceased donation data set, consistent with international standards, to compare organ donation performance in Canada. This work also included a definition of potential organ donors.[5]

The CNTRP research team (Project 2), focused on increasing solid organ and hematopoietic stem cell donation, performed a national assessment on the barriers and enablers to DCD implementation in Canada.[8] Knowledge garnered from this investigation can inform theory-based knowledge translation (implementation) interventions to increase the number of DCD donors in Canada. One of the principle findings of this research initiative was the presence of challenges associated with defining, identifying and referring potential DCD organ donors.

Given the focused work of the CNTRP and the core mandate of donation and transplantation at Canadian Blood Services, an opportunity to collaborate in the development of recommendations and educational initiatives to address the ID&R of potential organ donors arose.

Purpose and objectives of the workshop

Canadian Blood Services and the Canadian National Transplant Research Program (CNTRP) collaboratively hosted a Potential Organ Donor Identification and System Accountability Workshop September 20-21, 2016. The workshop objectives were to:

- achieve Canadian agreement on the definition of a potential donor and referral criteria (clinical triggers);
- determine the responsibilities of HCPs for donor ID&R;
- identify barriers and facilitators to ID&R;
- create an implementation plan to operationalize clinical processes around ID&R;
- initiate the development of system accountability strategies; and
- consider whether donor ID&R is a critical healthcare priority with important public health concerns.

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The Steering Committee was convened and met several times throughout the process, providing oversight and insight. Members contributed towards the development of a comprehensive background information package that supported discussion at the workshop which included:

- Process Terms of Reference
- Environmental Scan of ODOs
- Systematic Literature Review of Criteria to Define and Identify Potential Deceased Organ Donors
- National Assessment of the Barriers and Enablers to Increasing Organ DCD in Canada

Workshop process

To support the development of recommendations around potential organ ID&R, the two-day workshop was segmented into four thematic areas:

- Expectations: potential donors, families, and patients on transplant waiting lists
- Donor Identification and Referral - clinical and legal perspectives
- Enhancing Accountability I: Knowledge and action – gaps and solutions
- Enhancing Accountability II: Quality and safety organizations – what they currently do and options for action

Prior to the workshop, all participants received a suggested background reading package and were extended an invitation to examine supplementary material. The workshop involved pan-Canadian representation from critical care, neurocritical care, emergency medicine, donation, transplantation, research, healthcare administration, patient safety and quality organizations, and family partners. To promote interaction and a fulsome discussion, participants were assigned seating to promote interdisciplinary representation at discussion tables.

Each themed segment of the workshop was structured around expert presentations, evidence-based fact sheets and group participation questions designed by the Steering Committee to stimulate discussion and inform deliberations. Presentations and evidence-based fact sheets provided participants, with varying backgrounds, material knowledge to inform recommendations on how the ODT community should proceed.

The workshop was designed to generate expert-derived consensus recommendations for leading practice. Feedback from participant and plenary discussions were collated and summarized by the Steering Committee. This final report containing recommendations from the workshop was drafted by the Steering Committee and confirmed with participants.

Scope

The workshop focused on adult and pediatric deceased organ donation, both NDD and DCD, for any patient in the trajectory from injury or illness to death (an imminently dying patient), with the understanding that organ donor ID&R extends beyond the role of intensive care professionals and includes emergency departments, speciality physicians, donor coordinators and allied health professionals. Living donors, tissue donors who are not eligible for organ donation, and the medical, ethical and legal aspects of initiating ventilation for the sole purpose of organ donation were beyond the scope of this workshop.

Assumptions and key considerations

The following assumptions and key considerations were set by the Steering Committee to situate and provide guidance to the workshop process and development of recommendations:

- Discussions at the workshop would be based on summaries of evidence prepared by the Steering Committee, the experience of practitioners, and Canadian leading practices in data definitions.

- Developing recommendations for organ donor ID&R does not dictate ODT practice, but provides a framework for a more consistent approach, which is also sufficiently flexible to adapt to regional/individual applications; individual ODT professionals would continue to make decisions regarding individual patients and families based on their unique circumstances.
- If a missed donor may result in the harm or death of a patient designated as a transplant candidate and is preventable, missing a donor should be considered a patient safety concern.

The following were considered, as they could have impacted the success of the workshop:

- Leading practice recommendations pertaining to donor ID&R and knowledge translation tools require thoughtful implementation strategies and must recognize the unique needs of different regions, programs and HCPs.
- Existing legal and ethical frameworks in Canada served as a reference for discussions.
- A paradigm and culture shift at multiple levels (HCP, ICUs, hospital administrators, professional societies, patients, the public, patient safety representatives and governments) may be required to achieve consensus in Canada that missing a potential donor should be considered a critical event.

Refer to *Appendix C: Workshop agenda* for details.

A. Expectations: Potential donors, families and patients on transplant waiting lists

Background facts

Canadian organ donation and transplantation system progress report 2006 – 2015[4]

In 2015, 2,559 life-saving or life-enhancing transplants were performed in Canada. Of these, over 57 per cent (1,473) were kidney transplants. At the end of 2015, there were 4,631 individuals on Canada's organ transplant waitlists and 262 patients on waitlists died in 2015 before receiving transplants. Many others who were in advanced stages of their illnesses died without ever making it on to waitlists or after being removed from waitlists, once they were no longer considered suitable for transplant. However, these patients are currently not well tracked in the system. The vast majority of transplants come from deceased organ donors (NDD, DCD). Canada's national deceased donation rate has increased by 29 per cent since 2006 — from 14.1 to 18.2 donor per million population (DPMP) in 2015 but remains well below leading countries (for example, Spain is at 40 DPMP, U.S. is at 29 DPMP).

Current deceased organ donation rates fall well below estimated donor potential in Canada, ranging from as high as 90 DPM[6] to 40 to 50 DPMP[9-11], to as low as 33 DPMP[12], with variance according to study and methodology. Deceased donation performance rates and DCD implementation among Canada's provinces and territories vary significantly and this impacts equitable access to transplantation by province.

Transplantation leads to significant personal benefits for patients and economic benefits for governments

Transplantation is the best therapy for patients with end-stage kidney disease, and the only treatment for patients suffering from end-stage liver, heart or lung disease. Compared with dialysis, a kidney transplant can more than double a patient's life expectancy and is the most cost-effective method of treatment for patients with end-stage kidney disease.[1] Starting in the second year after transplant, the healthcare system avoids between $33,000 and $84,000 per transplant patient per year of dialysis. Returning dialysis patients to work productivity after transplantation contributes to gross domestic product and tax revenue each year.[13] Although all organ transplants are life-saving, economic analyses for non-kidney organs have not been well studied.

Professional and public attitudes

Virtually all HCPs surveyed[14] believe it is important that patients and families be offered the opportunity to donate organs and (or) tissue, yet only 35 per cent report that the opportunity to donate was routinely offered at their hospital. 86 per cent agree (somewhat or strongly) with a required approach to raising organ and tissue donation with the family of an eligible patient whose death is imminent or established. In public surveys[15], there is support for both required and physician-based discretion for initiating donation conversations.

According to the 2015 Canadian Medical Association policy on organ and tissue donation and transplantation[16], Canadians are entitled to timely access, on equitable terms and conditions, to necessary and effective medical treatment. The responsibility to ensure the availability of, and equitable access to medical treatment, including organ and tissue transplantation, is shared among governments, health institutions, HCPs and the general public. Hospitals and healthcare providers have an obligation to provide the opportunity to donate consistent with societal expectations. Adequate resources should be available to support donation, and reasons that donation services are not provided should be explained to families.

Impact on families

Published literature on family impact[17] is related to the entire donation process and is not specific to donor ID&R. Family satisfaction with the organ donation experience refers to the level of emotional comfort or distress felt by the family with respect to the treatment of the family, the treatment of the deceased and the long term satisfaction with the decision to donate or not to donate. Donation appears to offer comfort to some but not all families in the psychological process of bereavement. Factors that increase family satisfaction in the organ donation process include the appropriate timing of the request, trust that medical personnel cared about the deceased patient and provided good quality care for them, adequate information about the patient's status and prognosis, and clear and comprehensible information about organ donation.

Impact of failing to identify and refer a potential organ donor

The following risks and consequences of failure to identify and refer potential donors should be considered in policy and practice:

a. Not respecting the wishes of the potential organ donor who has registered or informed family of their desire to donate

b. Violation of existing laws in provinces with required referral legislation

c. Not providing the family with the potential to help others, including missed opportunity for legacy, potential to provide meaning following the loss of a loved one, and the positive impact this could have on the grieving process

d. Preventable death or disability for transplant candidates

e. Compromised equitable access to transplantation

f. Ongoing costs of dialysis, which exceed the cost of transplantation for end-stage renal disease

g. Economic costs of continued care for end-stage (non-renal) organ failure

h. Loss of economic productivity of those awaiting transplant

i. Perpetuating failure - the acceptance of failure to identify and refer potential donors by HCPs and the healthcare system

j. Erosion of public and professional trust

k. Lost opportunity for increasing public and professional education and awareness through long term donor family engagement – the families of donors have stories to tell

l. Compromising interprofessional trust and accountability among deceased donation and transplant services

Obligations to potential organ donors and their families

We recommend:

1. HCPs or ODO representatives should consistently initiate conversations around organ donation as an integrated part of EOL care.
2. To avoid any real or perceived conflict of interest, HCPs should separate the discussions regarding WLST from donation discussions.
3. The healthcare team be properly educated on how and when to identify and refer potential donors, how to effectively and compassionately discuss donation with family members, and how to provide optimal EOL care whether or not consent for donation is given.
4. From a legal and ethical perspective, it should be assumed and expected that the healthcare team would respect and be accountable to the previously expressed donation wishes made by the dying patient or potential donor.
5. If a dying patient is not eligible to donate, the family should be informed of the reasons why they have not been approached within the limits of respecting patient privacy and confidentiality.

Considerations:

1. While there is an ethical and legal obligation to offer donation as a standard part of EOL care, emphasis was placed on sensitively transitioning from the topic of EOL to donation, to avoid harm to the family.
2. The emotional impact of the tragic loss of a loved one should be at the forefront of EOL discussions and requires sensitivity.
3. During donation discussions, family members expect clear, understandable communication regarding the prognosis of their loved one, the opportunity for donation, and the donation process. These conversations should demonstrate compassion and respect for the patient and their family.
4. When a member of the public registers their wishes, they assume they will be approached at the right time for donation and their registered wishes will be confirmed and acted upon.

Obligations to potential transplant recipients and their families

We recommend:

6. The deceased organ donation system must be resourced and organized appropriately to ensure all possible donation opportunities are recognized and maximized.
7. A formal accountability framework should be established to ensure any missed donation opportunities (MDOs) are reported and investigated (“zero missed opportunities”).
8. Mandatory training in donor ID&R be implemented to ensure HCPs who intersect with potential organ donors communicate and work collectively, as a well-coordinated multidisciplinary team.
9. Standardized information be provided to transplant candidates and their families, and include:
    a. A description on how the system works, including transplant eligibility criteria.
    b. Local transplant allocation guidelines.

c. Donor ID&R rates, organ donation rates, and wait times for various organs and regions in Canada.

Considerations:

1. Jurisdictional variability in donation performance and geography are acknowledged as obstacles to donation and transplant access, but should not be used as an excuse for poor performance.
2. Transplant candidates lack information on the ODT system. Public action through public interest/advocacy groups should be encouraged and may improve ODT system performance.
3. Public access to donor ID&R rates may influence a culture change where donation is valued by the healthcare system and individual hospitals.
4. Successful organ donation efforts should be celebrated.
5. With future development of the Canadian Blood Services' Canadian Transplant Registry (CTR), it may be possible to collect, monitor, and report on national data related to donor potential and MDOs.

Circumstances where identifying or referring a potential donor may be challenging

1. While participants generally felt there were no justifiable circumstances for non-referral, the following circumstances may pose challenges to referral:
   - Conscious patients (e.g. amyotrophic lateral sclerosis, medical assistance in dying)
   - Patients/families with cultural opposition to donation
   - EOL care situations that are contentious, involve compromised trust, or are medico-legally complicated
   - Patient or family has expressed prior opposition to donation
   - Substitute decision maker (SDM) cannot be identified
   - Donation is logistically impossible (e.g. resources/infrastructure not available)
   - Healthcare system under substantial strain (e.g. pandemics, mass casualty)
2. In cases where the family/SDM or patient have indicated a clear opposition to donation, and the healthcare team decides not to formally approach again, this should not be considered a MDO.
3. Donor ID&R is distinct from approaching a patient for donation – medical eligibility to donate (age, underlying disease, organ function) should be established prior to approach.
4. Donor ID&R is distinct from consent discussions with families – medical eligibility to donate should be established prior to consent discussions.

B. Donor Identification and Referral – clinical and legal perspectives

Background facts

The 2011 Canadian Blood Services System Ethics Consultation[18] and 2014 End-of-Life Conversations with Families of Potential Donors[19] recommended the following:

1. Maximizing identification, referral and consent by ensuring the system offers proximate access to provide an opportunity for all types of donation consistent with public policy and broader societal values.
2. Approach the family of every potential donor and offer the opportunity for donation.
3. Notify the ODO as early as possible and before the initial donation conversation with the family.
4. The obligation to inform and disclose appropriate information so that potential donors/surrogates can make an informed decision about donation.
5. The geographic location of a potential donor is appropriate to consider in that it impacts the availability of organ and tissue procurement teams and services may not be available in all communities. It is not mandatory to provide the service in all institutions, if there is proximate access to donation services, and donors or their families are informed of available options.

The Canadian National Transplant Research Program 2016 Systematic Review of Criteria to Identify Potential Deceased Organ Donors[20] found 14 different criteria used to define or identify a potential organ donor, with many of the same criteria used across the different types of donation (i.e. NDD, DCD). The most commonly used criteria across studies were devastating brain injury, brain/brain stem death, medical eligibility for donation, WLST and Glasgow Coma Scale. An environmental scan conducted with organ procurement organizations in Canada (n = 9), the U.S. (n = 5), the U.K. (n = 1) and Australia (n = 1) found that all organizations interviewed had some form of definition and (or) list of clinical triggers to identify potential organ donors. The most commonly used clinical triggers overall, and specifically within Canada, were mechanically ventilated, Glasgow Coma Scale, EOL discussion, devastating brain injury, and GIVE criteria (Glasgow Coma Score, Intubated, Ventilated, EOL care). The systematic review and environmental scan found overlap between the terms used to define or identify a potential organ donor, and having consistently used criteria nationally and internationally could help increase the number of potential donors identified.

The Canadian Blood Services Deceased Donation Data Working Group[5] defined potential donors as persons with a brain injury leading to death, who received mechanical ventilation at or near the time of death. This definition aligns with WHO standards[3] and allows international and interprovincial comparison. However, it was acknowledged that a small percentage of potential donors may not have brain injury and therefore would not be captured by this definition.

A legislative review of provincial tissue gift acts (Refer to *Appendix D: Clinical and legal perspectives supplemental background information*) shows that the provinces of BC, MB, ON, and QC have required referral laws – the ODO must be notified when death is imminent or established. Nova Scotia passed new human tissue gift legislation in 2010, and once proclaimed in force, will include a required referral

provision. Alberta has mandatory consideration after death determination. At the time of this report, SK, NB, PEI and NFLD do not have legislation in this regard.

Recommended safeguards

Canadian DCD guidelines[21] and the Canadian Blood Services – Canadian Medical Association Donation Physician Ethics Guide[18] recommend safeguards for the management of dying patients who may be eligible to donate. These include: ensuring that the dying patient's interests are the first and foremost priority; EOL care should be provided in response to patient needs and applied consistently regardless of the intention or consent to donate; neuroprognostication and EOL decisions should be made prior to and separate from donation considerations and should not be influenced by donation potential; the procurement/transplant team must not be involved in the decision to WLST; supporting the family making decisions on behalf of the patient and providing the opportunity and process to actualize donation if desired by patient or family.

Refer to *Appendix D: Clinical and legal perspectives supplemental background information.*

Defining a potential organ donor

We recommend:

10. Patients who meet all the following criteria (clinical triggers) should be considered a potential organ donor and be referred to the ODO:
    a. Ventilated (invasive [intubated/tracheotomy] or non-invasive [bilevel positive airway pressure/continuous positive airway pressure] ventilation);
    b. Condition with a grave prognosis in which death is imminent; and
    c. Decision to WLST has been made (but not yet acted upon).
11. The above definition of a potential organ donor should be adopted in all Canadian jurisdictions to:
    a. Support consistency in professional education;
    b. Assist HCPs to identify potential organ donors and optimize possible opportunities for donation;
    c. Minimize loss of potential organ donors due to discretionary clinical judgements by individualHCPs; and
    d. Allow for standardized reporting, transparency, and system accountability.

Considerations:

1. A clinical trigger is the criteria defining a potential organ donor that will prompt healthcare teams to initiate case referral to the ODO, and is consistent with practice recommendations and provincial required referral legislation.
2. Participants stressed the importance of ensuring the definition of a potential organ donor be sufficiently permissive and broad to avoid unwarranted exclusions of potential NDD and DCD donors.
3. A permissive definition would likely result in numerous ODO referrals, requiring ODOs to have sufficient capacity with which to respond to the increase in referral requests.

4. Harmonization of commonly used Canadian clinical trigger tools may require provincial support and alignment of provincial protocols.
5. It was acknowledged that there are patients with grave prognosis and imminent death whose lungs are not ventilated as part of their treatment plan. There is diverse opinion as to whether these patients may be considered potential organ donors, as non-therapeutic ventilation of their lungs may be required for organ donation. The ethical, legal and medical framework for this practice has not been addressed in Canada.

Potential organ donor identification and referral – who and when

We recommend:

12. In donation practice and policy, a clear distinction should be made between "Referral" and "Notification/Consultation" to the ODO.

    a. Referral to ODO:

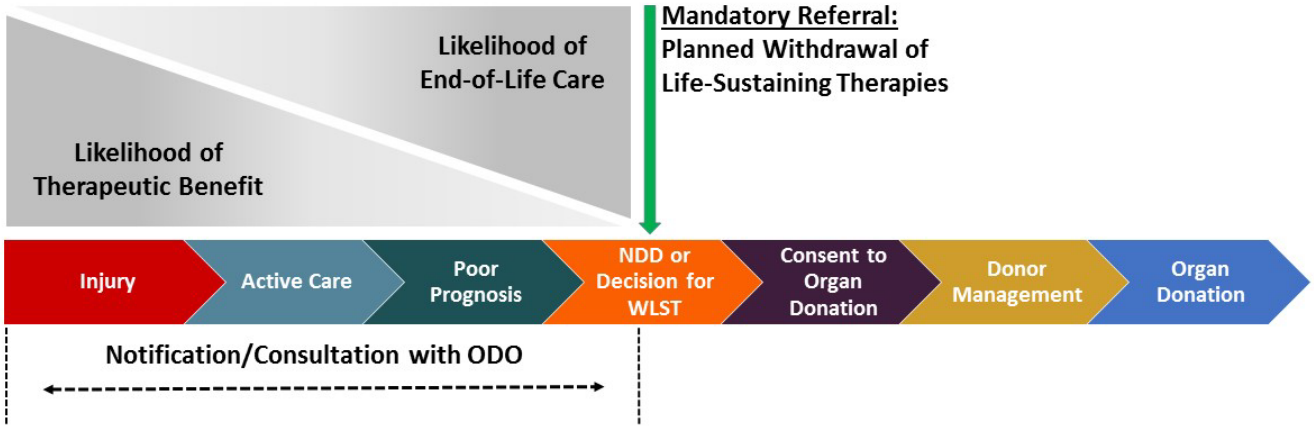
    - defined as the formal process by which the healthcare team seeks to involve the ODO;
    - based on fulfilling clinical triggers; and
    - should not occur until NDD or after WLST decisions have been made.

b. ODO Notification/Consultation - refers to a member of the healthcare team advising the ODO of the presence of a potential donor and may be an option prior to meeting referral criteria.

- Advantages: consultation resource provides specialized knowledge and information, clarifies donor eligibility, initiates early planning and preparations for donation logistics, arranges on-site donor coordinator support when required, provides education, organizes support services, and engages staff and families early, normalizing the integration of donation into EOL care.
- Concerns: perception of conflict of interest, transparency with families, compromise of family or interprofessional trust, potential for influence on yet-to-be finalized EOL care plan and decisions, higher ODO workload.
- May also be initiated upon family requests for donation information.

13. The most responsible physician, or their designate, is ultimately accountable for ensuring that referral or notification of a potential donor to the ODO has occurred.
14. All HCPs involved in EOL care can and should ***identify*** potential donors.
15. The most responsible physician should be consulted on process and timing if another HCP involved in EOL care will be referring a potential organ donor to the ODO.
16. The most responsible physician should be consulted on process and timing if another HCP involved in EOL care will be notifying/consulting the ODO about a potential organ donor.

Figure 1: Sequence of care in deceased donation in relation to notification and referral



Discussion points:

1. These recommendations aim to clarify the nature of contact between the healthcare team and the ODO.
2. Early notification/consultation has advantages in terms of timelines and efficiency of the process. In some cases, if there is no on-site donor coordinator, early notification allows the coordinator to travel to the hospital.
3. The transition between likelihood of therapeutic benefit versus likelihood of EOL care pertaining to donor referral or notification is a similar paradigm to palliative care involvement in injuries or illness with a high risk of mortality.

Early consideration of organ donation: safeguards for patients with devastating injury/illness and their families

We recommend:

17. The following previously agreed upon Canadian guidelines should be strictly followed in the process of organ donor referral:
    a. The decision to WLST should be made prior to any discussion of organ and tissue donation that is initiated by HCPs;
    b. The surgical retrieval/transplant team must not be involved in the decision to WLST.
18. A second opinion regarding prognostication be obtained before proceeding with DCD.

Considerations:

1. While the scope of this workshop was limited to potential organ donor ID&R, it is noteworthy to record that participants felt that increased safeguards for prognostication in potential DCD cases was prudent.
2. It is important to communicate existence of safeguards to HCPs and the public, which includes educating ICU staff on donation and safeguards put in place to protect patients.

3. Where donation physicians are available, they may serve as an expert resource to support families and advocate adherence to safeguards.
4. Participants discussed several means of increasing patient/family confidence through:
    a. communication;
    b. HCP education;
    c. accuracy and checks in prognostication;
    d. quality assurance audits/tools/processes; and
    e. research to demonstrate adherence to best practices.

C. Enhancing Accountability I: Knowledge and action – gaps and solutions

Background facts

Measurement and reporting

The identification of weaknesses within the organ donation process, such as missed donor ID&R, is fundamental to organ donation program assessment and improvement. Successful international organ donation programs perform routine system wide audits of all hospital deaths to evaluate performance. In the Canadian context, while provincial ODOs and hospital-based donation and transplantation programs may perform periodic medical record reviews pertaining to deceased organ donation (so-called death audits), there is lack of clarity on many components of the process and, there are no Canadian national recommendations regarding medical record reviews for deceased organ donation practice, and there are no national accountability processes surrounding MDOs.

Currently, most ODOs perform chart reviews of individuals that died in hospitals, also known as death audits. The objective of these audits is to identify potential MDOs. Canadian ODOs were surveyed by Canadian Blood Service in 2015 regarding practice. For all Canadian ODOs, the objective of their audit is to identify missed potential donors. Methodologies vary in scope in terms of hospitals included, (i.e. major urban hospitals vs. rural/remote), hospital department (critical care and/or emergency department), and criteria deemed to exclude a potential donor (e.g. age, diagnosis, etc.). This makes comparison between jurisdictions of MDOs found in death audits difficult or impossible.

Audits are performed on a variety of time frames (weekly, monthly, annually) at “major hospitals within the ODO referral area”, targeting deaths which occur within critical care and or emergency departments. Most ODOs use a two-step process of screening all deaths, first to exclude those over a certain age or with certain diagnosis and then to perform a complete review of the remaining deaths. There has been no standardization of data elements between jurisdictions. In general data is captured in excel spreadsheets. Results of death audits are most commonly reported to the provincial or local organ donation committees for review and discussion. These audits are usually performed by existing staff with informal training. Although Canadian ODO death audit procedures assess the required components of a death audit process, they do so with great variability across the country.

Currently, there is a lack of data concerning MDOs in Canada, which stems from inconsistency in the frequency, methods, and scope of data collection between jurisdictions. Furthermore, this data is not centrally accessible to researchers, clinicians, administrators, or policy makers. Current Canadian approaches to measurement and reporting of potential donor ID&R are fragmented and lack consistency, timeliness and accessibility of information.

Professional education gaps

A Canadian Blood Services national organ donation professional education needs assessment survey was conducted and has confirmed that donor ID&R is the top educational priority of emergency medicine physicians and nurses, and ICU nurses.[22] A CNTRP qualitative study of Canadian intensivists, nurses and coordinators regarding DCD obstacles identified a lack of knowledge regarding DCD and donor identification as key themes.

Refer to *Appendix E: Enhancing Accountability I supplemental background information.*

Access of potential donors to hospitals with donation services

Access to deceased donation services, such as well-equipped ICUs, operating rooms, and surgical retrieval teams is limited in many places in Canada, depending on where patient is being treated: (1) they are in a hospital that offers donation services but cannot be accommodated due to resource constraints (e.g. ICU bed, operation room time) or (2) they are at a hospital that either does not offer any donation services, lacks access to surgical retrieval teams or cannot accommodate their circumstances, such as the absence of a DCD program. In order to preserve the opportunity to donate, either potential donors would have to be transferred to a hospital that offers donation services or those services would have to come to the donor. Both models are currently in use in limited circumstances in Canada but for regions that don't have agreements and protocols in place, there is no possibility of offering donation.

Donor access to ICU beds

Canadian ICUs often operate at or near capacity and access of potential donors to ICU beds may be compromised. ICU professional surveys[14] reveal mixed opinions in response to questions of priority of access to ICU beds for potential donors: 44 per cent of respondents said that potential donors should receive equivalent priority, 40 per cent stated that patients with the highest chance of survival should receive priority. The most common reasons cited for deciding against admission of potential donors (for confirmation of brain death, or devastating brain injury with poor prognosis) were inappropriate use of resources, lack of physical ICU bed space and a lack of ICU resources such as nursing, medical or support staff.

Refer to *Appendix E: Enhancing Accountability I supplemental background information.*

Measurement and reporting

We recommend:

19. A national minimum data set and standards should be developed and implemented for death audits and MDOs should be reported consistently across Canada.
    a. Standardizing death audit methodology and donor referral criteria will improve data quality, allow for comparative measurements, and improve system performance.
    b. A single, electronic, standardized national database and reporting system should be used for all potential donors.

Considerations:

1. Initiatives to improve data accessibility should be mindful of cost, and wherever feasible, align with existing IT infrastructure (e.g. electronic health records, province specific ODO databases).
2. In the absence of a single electronic national database of all potential organ donors, options to consider may include:
    a. further development of Canadian Blood Services' Canadian Transplant Registry, which is standardized, centralized, and automated.
    b. iTransplant - a Donor Management System (implemented or being considered in some provinces)
        - would require modifications to incorporate death audit data.
        - Canadian Blood Services may have a role in facilitating electronic reporting and data collection from centres who do not use iTransplant.
3. Distinguish between nationally collated and reported data (aggregate) as opposed to locally collected and reported data.

Implementation strategies and professional education

We recommend:

20. Provinces and territories that currently do not have required referral legislation should consider implementing such legal change.
21. Initiatives to ensure compliance with existing required referral legislation and policy for donor ID&R should include:
    a. Local champions (donor coordinators, donation physicians) to ensure implementation of best practices, measurements, advocacy and education;
    b. Embedding donation into EOL care/WLST protocols and checklists that include all professionals involved in EOL care (e.g. respiratory therapists, neuroscience consultants);
    c. Compliance should be measured through chart reviews or death audits;
    d. Elevating adherence to policy and law within hospital or regional accountability structures; and
    e. Public reporting of donor ID&R compliance rates.
22. Donation activity-based funding that is directed to the unit where donation services are provided.
23. Professional education initiatives that include:
    a. National education toolkit of donor ID&R and clinical trigger strategies for HCPs.
        i. May include clinical trigger cards, posters, simplified messaging (e.g. "Donation Before Extubation", "Pause Before Withdraws").
    b. Certification for critical care and emergency medicine staff in partnership with professional associations.
        i. Consider donation as part of hospital or specialty credentialing.

ii. Consider Royal College or provincial medical college licensure requirements.

c. Donor ID&R should be covered in medical and nursing school curriculums.

Considerations:

1. Participants emphasized a need for clarification of who would hold HCPs accountable for compliance to donor ID&R policies.
2. Building measurement and accountability into the system will be critical to increasing equity, reducing MDOs, ensuring compliance with provincial laws and policy, and compiling data on performance and areas for improvement.
3. Because deceased donation is an infrequent event with high impact, it is important to develop methods to enhance and maintain HCPs' competencies.
4. If a province does not have required referral legislation, clarification of provincial laws may be required. Specifically, privacy rules in relation to sharing potential donor information with ODOs need review to ensure disclosure of information is permissible.
5. A common understanding of the term "imminent death", as articulated in provincial donor referral legislation, may need to be established.
6. Patients on transplant waitlists should be engaged as advocates of donor ID&R because patient stories emphasize and humanize the importance of ID&R.

Access of potential organ donors to hospitals with donation services and ICU beds

We recommend:

24. Donor services should be patient/family centric, not hospital centric. While the type of deceased donation (NDD, DCD, or tissue) may have logistic differences, donation services should be offered regardless.
25. Dedicated donor resources may be justified with the understanding that caring for a donor is caring for multiple living recipients.
26. Agreements and collaboration between the emergency room and ICU be established to allow for transfer of potential donors to preserve the opportunity to donate.
27. Transfer of potential donors to hospitals with donation and surgical retrieval capacity:
    a. Criteria for transfer be clear and transparent to HCPs and families;
    b. In cases of DCD potential, priorities of patient care and donor care should be reconciled;
    c. Any decisions regarding relocating potential donors require engagement and discussion with corresponding transplant teams;
    d. Families may suffer stress and hardship if their loved one requires transfer to actualize donation services. Services should be offered to help avoid undue stress, financial and otherwise, on the families of potential donors.

Considerations:

1. ICU/operating room capacity and access of potential donors to ICU beds remains a challenging problem and options for managing access include:
    a. Hospitals instituting dedicated ICU donor beds and agreements around the use of operating rooms for the retrieval of donated organs.
    b. The Ontario model of Criticall was supported as one mechanism to assign ICU beds for province wide triage and access for potential donors
2. On-call management and retrieval teams represent one method of serving rural and remote regions. Consideration should be given to regional and interprovincial agreements such that larger, better resourced provinces could support remote regions of smaller provinces.
3. Resistance may be encountered from critical care staff who may oppose using resources preferentially for donors.
4. In hospital emergency departments and ICUs operating at capacity, there may be natural disincentives to referring potential donors. Managing the donation process increases ICU workload and length of stay of potential donors. In transplant hospitals and ICUs, performing more transplants increases resource consumption, workload, and occupancy.

D. Enhancing Accountability II: Quality and safety organizations – what they currently do and options for action

Background facts

Accountability for donor ID&R is currently challenged by the following realities: fragmentation with lack of harmonization of definitions and measurements; lack of clarity or consistency in current accountability structures, roles and responsibility for deceased donation; enforceability of accreditation standards; significant practice and measurement variability between hospitals such that compliance presents a real challenge. Participants were charged with developing recommendations for changes in accountability structures at the individual and system level.

Refer to *Appendix F: Enhancing Accountability II supplemental background information*, which includes current Accreditation Canada standards and definitions around safety and quality terms.

Note: After presentations by Accreditation Canada, Health Quality Ontario, Canadian Patient Safety Institute, the Public Health Agency of Canada, and the Quality Improvement and Innovation Group under the Centre for Clinical Standards and Quality at the Centers for Medicare & Medicaid Services (US), participants were asked to recommend approaches to donor ID&R as an issue of healthcare quality and safety.

Accountability for potential organ donor identification and referral

We recommend:

28. Potential organ donor ID&R should be considered a Required Organizational Practice, as per Accreditation Canada guidelines.
29. Organ donation should be established as a Program of Distinction, as per Accreditation Canada guidelines.
30. Programs of Patient Engagement should be implemented to provide a voice to donor families and patients on transplant waitlists.
31. Developing a clear accountability structure at the regional, institutional, and individual level would facilitate measurement and improvement, and include:
    a. Harmonization of clinical definitions, roles, and responsibilities; and
    b. Each hospital having designated/assigned responsibility for ID&R.
32. Data-driven assessments with public reporting on deceased donation based on death audits will recognize high performance and drive motivation for improvement. Systems should be developed where potential organ donor ID&R can be accurately tracked and used as an important quality measure and indicator of hospital, ODO, and provincial performance.
    a. Deceased donation balanced scorecards should be part of emergency department and ICU standard reporting to hospital administration, ODOs, and be available to the general public.

33. Donor ID&R should be considered an issue of preventable harm to potential organ donors and transplant candidates.
34. Donor ID&R should be considered an "Always Event" and missed potential organ donor ID&R be considered a "Never Event".
35. Missing a potential donor referral should be reported as a "Sentinel Event", such that the risk of adverse outcomes due to recurrence should be recognized as calls for immediate investigation and response.
36. A formal accountability framework be established to track the utilization and reasons for non-use of all potential organs and organ donors identified, so that any missed opportunities for use of transplantable organs can be investigated and reported upon.
37. Transplant program organ utilization scorecards should be part of standard reporting to hospital administration, ODOs, and be available to the public.

Considerations:

1. System failure for donor ID&R is not clearly defined, identified, or measured.
    a. The degree to which missed donor ID&R contributes to provincial variation in donation performance and consequently, access to transplantation, is not well studied nor reported.
    b. Jurisdictions with low referral rates have the most room for improvement, but have the least data on which to base improvement strategies and inform policy.
2. In the absence of a donation conversation, the death of a potential donor may pass without any recognition by the family, the healthcare team, or the public. The consequences of missing a potential organ donor include failure to respect the wishes of the dying patient, as well as the consequences to those waiting for transplant, and the healthcare system. Missed donors and the loss of available organs for transplant increases mortality, morbidity, and healthcare costs.
3. MDOs in any jurisdiction contributes to inequities in access to transplantation. For patients on transplant waitlists, MDOs represent a significant but often hidden concern. There may be reluctance to communicate the nature and magnitude of this problem to the public or transplant candidates.
4. While MDOs are not routinely measured or publicly reported throughout Canada; Ontario through Trillium Gift of Life Network has initiated public reporting of hospital ID&R rates with a focus on celebrating high performance.
5. There was some disagreement by participants on whether failing to identify and refer a potential donor constituted a Public Health concern. But participants agreed that missing a potential donor has an impact on public health and waitlisted transplant candidates. The public should be aware of missed opportunities and the healthcare system needs to be accountable to the public.
6. Emphasis should be place on sharing patient stories and highlighting benefits to transplant recipients, which may be obscured from those working in critical care, particularly in centres that do not offer transplants.
7. Frame arguments around MDOs as patient related consequences and preventable harm. MDOs result in organs lost and lives lost.

8. While measuring and reporting performance may foster “friendly competition” between units, hospitals, and provinces to improve performance, some participants did not favor public reporting, questioning the effectiveness, and advocating for continuous quality improvement initiatives.
9. Practitioners may respond better to local peer and regional accountability.
10. Consideration should be given around financial incentives for good performance and/or penalties for poor performance related to MDOs. Should there be a greater penalty for missing a donor who had registered their intention to donate?
11. Change behavior and the culture change follows.

Mission statement to guide system accountability for organ donor identification and referral

Note: Workshop participants were challenged with developing a mission statement to guide system accountability and which would reflect the outcome of the workshop.

> An accountable system for potential organ donor ID&R should strive to honour patient and family wishes by ensuring the opportunity to donate. HCPs should identify potential donors early, and always refer to ODOs, so that no donation opportunities are missed. Potential donor ID&R practices must be coordinated and collaborative. A successful donor ID&R system is supported by accurate and timely data, has system-level and individual accountability, and incentivizes good performance.

Research opportunities

Dr. Sonny Dhanani, Dr. Lori West and Mr. David Hartell compiled research opportunities identified throughout the workshop, grouping them under specific themes. Several of the following research questions will be evaluated as part of the ongoing research program within CNTRP and we encourage the broader Canadian research community to take up and address these outstanding questions.

Death audits and donor potential

1. Measurement of the number, type and reasons for missing potential donors.
    a. How do we measure and compare ourselves against US, Spain, UK and other countries around the world?
    b. Can prediction algorithms and big data be used to identify missed donors?
    c. Conduct an audit of potential donors in specific populations e.g. neonatal NDD and DCD donors.
2. A population cohort study on donor potential across Canada (similar methodology to the Redelmeier, Markel and Scales study[7]).
    a. Examine the differences in donor identification rates based on location of death - province, city, urban, rural.
    b. What is the quantitative impact of rural communities on the potential to increase donation? What are the missed opportunities and costs/benefits of improving access from rural communities?
3. Death audits:
    a. How can we measure the effect (before and after) of implementing process improvements in donor ID&R on donation rates?
    b. What is the donor potential in emergency departments across the country?
    c. Potential donor identification after CPR?
    d. Evaluate the impact of donation potential on coronary and cardiac ICUs.
    e. What is the potential of harnessing the wealth of data in death audits for research purposes?
    f. The goal of a system-wide mandatory death audit would be assisted by economic analysis to show cost, effectiveness, and incremental benefit.

Early notification to ODOs

4. What are the benefits, costs and risks of early notification?
    a. Does early notification to an ODO translate into increase in successful donation, improvements in the efficiency of the donation process and/or are families served better?
5. Are there negative consequences that can be measured, for example, increased ODO workload or family consequences?

Transplant outcomes and accountability

6. How do transplant outcomes impact motivation and performance in donor ID&R?
    a. Why are organs not accepted by transplant centers? How does this feedback get back to the ICU physician and does it impact donor ID&R?
    b. Comparison of DCD versus NDD outcomes (e.g. utilization, graft outcomes).
    c. Economic and quality of life analysis for non-renal organs.
7. Improved data on the impact of MDOs on waitlisted transplant candidates:
    a. Accurate number of patients dying on waitlists.
    b. Patients who die after being removed from the waitlists.
    c. Patients who do not get listed, but would benefit from transplantation.

Patient family experience

8. Does the timing of the donation discussion impact the family experience with organ donation (especially DCD)?
9. How does offering the option to donate, or missing the opportunity to donate, impact the grieving process?
10. What are and how do we measure public expectations of the system?
11. What are the ethical implications of offering donation in cases of medical assistance in dying?
12. The impact on family of transferring a potential donor to a donation hospital.

Legal frameworks

13. What is the purpose of the required referral legislation if there are no consequences for non-compliance?
    a. What are the reasons for non-compliance and strategies for improvement?
    b. Are there examples of other Canadian laws that are required but not enforced in the same way?
14. Could waitlisted transplant candidates launch a class action lawsuit against the healthcare system or Canadian government for missing a potential donor and causing a public health risk? Could a patient advocacy group launch this type of lawsuit?

Research: Partnerships

15. Can we measure the impact of targeted strategies to improve awareness about the importance of donor ID&R for patients intersecting with the healthcare system at various points?
    a. After “do not resuscitate” or “EOL care” decisions.
    b. In the family practice office.
    c. With estate or advance directive planning.

16. What can we learn from the palliative care community as to how they shifted the conversation to take place earlier in the EOL care process?
17. Is the neurosurgery community missing from this discussion? What benefits would there be to engage the neurosurgery community?
18. Can we link the Criticall metrics/organ donation prompt with the Trillium Gift of Life Network outcome data? Can we see if the Criticall prompt is helping to identify missed donors?
19. Do existing or future Accreditation Canada standards regarding organ donation make a measurable change in donation practices or rates in participating hospitals?

Research: Education

20. We currently have no quality audit research on the knowledge translation/education initiatives.
21. What educational interventions have been used so far in Canada? What is the most effective educational strategy for academic versus community hospitals?
22. Evaluation of multi-modal, multi-professional donor ID&R education interventions.

Appendix A: Acronyms and definitions (glossary)

Acronyms

CNTRP	Canadian National Transplant Research Program
DCD	Donation after Cardiocirculatory Death
ID&R	Identification and Referral
DPMP	Donor Per Million Population
EOL	End-of-Life
HCP	Healthcare Professional
ICU	Intensive Care Unit
MDO	Missed Donation Opportunity
NDD	Neurological Determination of Death (Brain Death)
ODT	Organ Donation and Transplantation
ODO	Organ Donation Organization
SDM	Substitute Decision Maker
WLST	Withdrawal of Life-Sustaining Treatment

Definitions

Always Event	Best practices that should always occur in the care process.[23]
Never Event	Patient safety incidents that result in serious patient harm or death, and that can be prevented by using organizational checks and balances. Never events are not intended to reflect judgment, blame or provide a guarantee; rather, they represent a call-to-action to prevent their occurrence. [23]
Program of Distinction	Distinction is a rigorous and highly specialized accreditation program from Accreditation Canada based on in-depth clinical performance measures and protocols to recognize clinical excellence and a commitment to innovation and leadership in a specific healthcare field (e.g. stroke or trauma).[24]
Public Health	The organized efforts of society to keep people healthy and prevent injury, illness and premature death and disability, improving health and well-being and reducing inequalities in health. It focuses on preventing disease and optimizing the health of the population rather than the illnesses of individuals.[25]

Required Organizational Practice	Evidence-informed practices addressing high-priority areas that enhance patient safety and minimize risk. They are reviewed and updated regularly.[26]
Sentinel Event	An unexpected occurrence involving death or serious physical or psychological injury, or the risk thereof. Serious injury specifically includes loss of limb or function. The phrase "or the risk thereof" includes any process variation for which a recurrence would carry a significant chance of a serious adverse outcome.[27]

Appendix B: Workshop participants and affiliations

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Appendix C: Workshop agenda

Workshop Agenda for Tuesday September 20, 2016 (Day 1)

Setting the Stage

	Presentation	Presenter(s)
8:30 – 8:45	Welcome from Canadian Blood Services and Canadian National Transplant Research Program	Kimberly Young Dr. Lori West
8:45 – 9:15	Around the Room	Individual Introductions
9:15 – 9:30	Process and Workshop Design	Dr. Sam Shemie Dr. Jeremy Grimshaw
9:30 – 10:15	Challenge Address	Dr. Sam Shemie
10:15 – 10:30	**Break**	

Expectations: Potential Donors, Families & Patients on Transplant Waiting Lists

	Presentation	Presenter(s)
10:30 – 11:00	Organ Transplant Outcomes	Dr. Greg Knoll
11:00 – 11:30	Family Experiences in Organ Donation and Transplantation	Emile Therien Debbie Neville
11:30 – 12:45	**Group Participation Questions**	
12:45 – 13:30	**Lunch**	

Donor Identification and Referral: Clinical and Legal Perspectives

	Presentation	Presenter(s)
13:30 – 13:45	Deceased Donation Process and Data Definitions	Dr. Damon Scales
13:45 – 14:00	Donor Identifications and Clinical Triggers Literature Review	Dr. Michaël Chassé
14:00 – 14:15	Legal Requirements and Privacy Issues	Rosanne Dawson
14:15 – 14:30	Q&A	
14:30 – 14:45	**Break**	
14:45 – 16:15	**Group Participation Questions**	
16:15 – 16:30	Closing Comments	

Workshop Agenda for Wednesday September 21, 2016 (Day 2)

Enhancing Accountability I: Knowledge and Action - Gaps and Solutions

	Presentation	Presenter(s)
8:00 – 8:10	Recap of Day 1 and Introduction to Day 2	
8:10 – 8:25	Measurement and Reporting: Death Audit/Medical Record Review	Karen Hornby
8:25 – 8:40	Canadian Example: Accountability in Ontario	Janice Beitel
8:40 – 8:55	Canadian Example: Accountability in Manitoba	Kim Werestiuk
8:55 – 9:15	ICU Access for Patients with Devastating Brain Injury - Implications for Potential Organ Donors	Dr. Desmond Bohn
9:15 – 9:45	**Open Plenary Discussion**	
9:45 – 10:00	**Break**	

Continued: Knowledge and Action - Gaps and Solutions

	Presentation	Presenter(s)
10:00 – 10:15	National Professional Education Needs Assessment in ICU and Emergency Medicine	Dr. Jennifer Hancock
10:15 – 10:30	DCD Obstacles Study	Dr. Jeremy Grimshaw
10:30 – 12:00	**Group Participation Questions**	
12:00 – 13:00	**Lunch**	

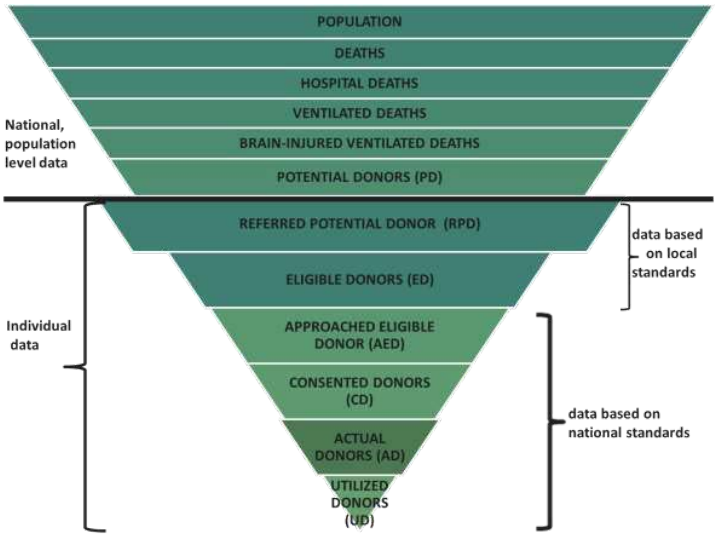
Enhancing Accountability II: Quality and Safety Organizations - What They Currently Do and Options for Action

	Presentation	Presenter(s)
13:00 – 13:10	Facilitator Instructions	
13:10 – 13:40	Evolutionary Thinking About Quality Improvement - US Perspectives on Organ Donation	Dennis Wagner Dr. Paul McGann
13:40 – 13:50	Accreditation Canada	Karen Kieley
13:50 – 14:00	Health Quality Ontario	Dr. Joshua Tepper Angus Steele
14:00 – 14:10	Canadian Patient Safety Institute	Carla Williams
14:10 – 14:20	Public Health Agency of Canada	Cindy Hyson
14:20 – 14:40	**Panel Q&A**	
14:40 – 14:50	**Break**	
14:50 – 16:00	**Group Participation Questions**	
16:00 – 16:15	Research Feedback	Dr. Lori West David Hartell Dr. Sonny Dhanani
16:15 – 16:30	Closing Comments	

Appendix D: Clinical and legal perspectives supplemental background information

Deceased Donation Data Working Group Minimum Data Set[5]

Figure 2: Deceased donation information pyramid



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.
Brain Injured Ventilated Deaths	Deaths of brain injured ventilated patients.
Potential Donors	Persons with a brain injury leading to death, who received mechanical ventilation at or near the time of death.
Referred Potential Donor	A potential donor who was referred to an ODO.

Canadian National Transplant Research Program 2016 Systematic Review of Criteria to Identify Potential Deceased Organ Donors[20]

Table 1: Summary of clinical criteria used to identify potential deceased organ donors

Category	Themes (Clinical Criteria)	Total Articles *n* = 85 (%)	General *n* = 36 (%)	NDD *n* = 46 (%)	cDCD *n* = 29 (%)
Neurological	Devastating Brain Injury	52 (61)	21 (58)	19 (41)	18 (62)
	Brain death or brain stem death	38 (45)	8 (22)	32 (70)	0 (0)
	Glasgow Coma Scale	26 (31)	13 (36)	13 (28)	2 (7)
	Brain stem reflex absence	19 (22)	8 (22)	11 (24)	3 (10)
	Types of Injuries	10 (12)	3 (8)	4 (9)	4 (14)
	Comatose	6 (7)	1 (3)	5 (11)	1 (3)
Medical Decision	Medical Eligibility for Donation	32 (38)	13 (36)	13 (28)	7 (24)
	WLST	29 (34)	10 (28)	3 (7)	18 (62)
	Imminent death	19 (22)	13 (36)	4 (9)	2 (7)
	Poor Prognosis	16 (19)	4 (11)	5 (11)	9 (31)
	End of Life Discussion	4 (5)	0 (0)	1 (2)	3 (10)
Cardio-respiratory	Mechanical Ventilation	25 (29)	9 (25)	11 (24)	10 (34)
	Cardiac Arrest	14 (16)	5 (14)	0 (0)	6 (21)
Administrative	Patient in ICU	5 (6)	1 (3)	2 (4)	2 (7)

Canadian National Transplant Research Program 2016 Environmental Scan of Donor Identification & Clinical Triggers[8]

Table 2: Summary of clinical triggers used in each country to identify potential organ donors

	Australia (*n* = 1)	Canada (*n* = 9)	UK (*n* = 1)	USA (*n* = 5)	Total Use of Clinical Trigger (%)
Mechanically Ventilated	1	8	0	4	13 (81)
Glasgow Coma Scale	1	7	1	3	12 (75)
End of Life Discussion	1	6	0	3	10 (63)
Devastating Brain Injury	0	5	1	3	9 (56)
GIVE criteria	1	4	0	0	5 (31)
Brain Stem Reflex Absence	0	0	1	3	4 (25)
Poor Prognosis	0	2	0	1	3 (19)
WLST	0	0	1	1	2 (13)
Imminent death	0	0	0	2	2 (13)
Devastating illness or injury	0	0	0	2	2 (13)
Family initiated discussion of donation	0	1	0	1	2 (13)
Brain death	0	1	0	0	1 (6)
GIFT Criteria	0	1	0	0	1 (6)
Type of Injury[1]	0	1	0	0	1 (6)
Total Clinical Triggers Used by Each Country	4	10	4	10	

[1]Types of injuries include: aneurysm, anoxic brain injury, cerebral vascular accident, CNS tumor

Table 3: Summary of clinical triggers used in each Canadian province to identify potential organ donors

	BC	AB	SK	MB	ON	QC	NB	NS	NL	Total Use of Clinical Trigger (%)
Glasgow Coma Scale	1	1	1	0	1	1	0	1	1	7 (78)
Mechanically Ventilated	1	1	1	1	0	1	1	1	1	8 (89)
GIVE criteria	1	0	1	0	0	0	0	1	1	3 (33)
Devastating Brain Injury	1	0	1	0	1	1	0	1	0	5 (56)
End of Life Discussion	1	0	1	1	1	0	0	1	1	6 (67)
Brain death	0	0	0	1	0	0	0	0	0	1 (11)
GIFT Criteria	0	0	0	0	1	0	0	0	0	1 (11)
Poor Prognosis	0	0	0	0	1	0	1	0	0	2 (22)
Type of Injury	0	0	0	0	0	0	0	0	1	1 (11)
Family initiated discussion of donation	0	0	0	0	1	0	0	0	0	1 (11)
Total Clinical Triggers Used by Each Province	5	2	5	3	6	3	2	5	5	

Provincial Legislative Review[28]

Table 4: Provincial legislation related to required referral of potential deceased donors to ODOs

	BC	AB	SK	MB	ON	QC	NB	NS	PEI	NL	YK	NWT	NU
Required Referral of Potential Deceased Donor to Organ Donation Agency by Hospital/Physician	Reg 3(1) A facility must notify BC Transplant Society immediately in the event of death or impending death of a patient 75 years or younger in its care. 5(1) If the facility has given a notification under section 3 and has not been advised of a determination of the existence of a medical or other condition that will make the tissue of the patient unsuitable for use in another person, the facility must immediately search the registry to determine whether a decision record exists for that patient.	7(1) When a person dies, the medical practitioner who makes the determination of death must consider and document in the patient record the medical suitability of the deceased person's tissue or organs for transplantation. 7(2) If a medical practitioner determines that a person's tissue or organs may be suitable for transplantation [...], the medical practitioner must notify a donation organization, if any, in a manner satisfactory to the donation organization.	Silent Silent RED Text denotes change in legislation awaiting proclamation	4(1) Subject to the requirements and circumstances established under subsection 4.2(1), a designated facility must notify the required human tissue gift agency when (a) a patient at the facility dies; (b) a physician at the facility advises that the death of a person at the facility is imminent and inevitable; or (c) the facility receives a dead body.	8.1(1) A designated facility shall notify the Network as soon as possible when a patient at the facility has died or a physician is of the opinion that the death of a patient at the facility is imminent by reason of injury or disease. (2) Despite subsection (1), a designated facility is not required to notify the Network if the Network has established requirements that set out circumstances in which notice is not required and those circumstances exist	204.1 When informed of the imminent or recent death of a potential organ or tissue donor, the director of professional services of an institution operating a general and specialized hospital shall diligently (1)verify, with one of the organizations that coordinate organ or tissue donations and are designated by the Minister under section 2.0.11 of the Act respecting the Régie de l'assurance maladie du Québec (chapter R-5), whether the potential donor's consent for the post-mortem removal of organs or tissues is recorded in the consent registries established by the Ordre professionnel des notaires du Québec and the Régie de l'assurance maladie du Québec, in order to determine the donor's last wishes expressed in this regard in accordance with the Civil Code; and (2) send to such an organization, if the consent has been given, any necessary medical information concerning the potential donor and the organs or tissues that may be removed. The director of professional services is informed of the imminent or recent death of a potential organ or tissue donor in accordance with the procedure established by the institution.	Silent	Silent 17(1) Where an individual dies, or in the opinion of a physician death is imminent, in a hospital the hospital shall, as soon as possible, provide [prescribed information] to the organ donation program and, where so prescribed, to the tissue bank. RED Text denotes change in legislation awaiting proclamation	Silent	Silent	Silent	Silent	Silent

Note: The legislation was reviewed in each jurisdiction to determine the requirements for required referral. The chart was prepared September 15, 2016 in preparation for the workshop.

Appendix E: Enhancing Accountability I supplemental background information

Canadian National Transplant Research Program - Organ Donation after Donation after Cardiocirculatory Death (DCD) in Canada[8]

Table 5: Summary of themes and supporting information

Belief Statement	Frequency (%)	Healthcare Professional Group
Knowledge about DCD		
DCD education is needed (Healthcare professional and public)	24 (44)	Intensivists, Nurses, Coordinators
Knowledge of DCD/donation is required to use DCD properly	22 (40)	Intensivists, Nurses, Coordinators
Identification of Potential DCD Donors		
It is difficult to properly decide/assess which patients are viable/a candidate for DCD	15 (27)	Intensivists, Nurses, Coordinators
It is difficult to predict who will die within the required timeframe for DCD	19 (35)	Intensivists, Coordinators
I think about DCD when a suitable patient is dying	16 (29)	Intensivists, Nurses, Coordinators
Potential Donor Referral to Organ Donation Organization (ODO)		
Coordinators only join the DCD process after receiving a referral	7 (13)	Coordinators
Required referral to the ODO would help DCD use	4 (7)	Coordinators
Family Communication		
It is difficult to discuss DCD/donation with families	6 (11)	Nurses
Families influence the use of DCD/donation	36 (65)	Intensivists, Nurses, Coordinators
Separating the decision to withdraw life sustaining therapies (WLST) from the decision to offer DCD		
Decision to WLST and donation/DCD should be kept separate	9 (16)	Intensivists, Coordinators
Separating patient care and donation is difficult	4 (7)	Intensivists, Nurses

Canadian Blood Services National Deceased Donation Professional Education Needs Assessment[22]

Table 6: Background demographics and donation experience

	ICU Nurses	ER Nurses	ER Physicians	ICU Physicians
Response Rate (n)	16.8% (226)	11.4% (214)	12.6% (197)	30.3% (194)
Adult Centre / Pediatric Centre	93% / 7%	95% / 5%	97% / 3%	79% / 19%
Academic Centre / Community Centre	69% / 31%	50% / 50%	46% / 54%	82% / 18%
Transplant center	43%	30%	29%	50%
DCD Center	60%	47%	53%	79%
Donation Experience **>1 NDD/year** **>1 DCD/year**	 54.8% 30.5%	 38.2% 31.8%	 31.5% 25.4%	 87.1% 48.4%

Table 7: Value of donation and benefit of a donation curriculum

	ICU Nurses	ER Nurses	ER Physicians	ICU Physicians
Percentage of respondents who felt donation is of high value	67.3%	72.9%	79.2%	82.5%
Percentage of respondents who felt a donation curriculum would have a moderate-high benefit to their practice	60.4%	67.3%	60.4%	70.1%

Table 8: Curriculum content and delivery

	ICU Nurses	ER Nurses	ER Physicians	ICU Physicians
Requested Instructional Methods	1. Online Module 2. Workshop 3. Video 4. Online Study Guide	1. Online Module 2. Workshop 3. Video 4. Online Study Guide	1. Online Module 2. Online Study Guide 3. Workshop 4. Video	1. Online Module 2. Workshop 3. Video 4. Online Study Guide
Top 5 Educational Sessions	1. I & R 2. Communication 3. Donor Management 4. DCD 5. Transplant Outcome	1. I & R 2. Communication 3. Donor Management 4. Supporting Donation at your Institution 5. Care of the Donor Family	1. I & R 2. Communication 3. Donor Management 4. Supporting Donation at your Institution 5. DCD	1. Donor Management 2. DCD 3. Communication 4. I & R 5. NDD Declaration

Appendix F: Enhancing Accountability II supplemental background information

Accreditation Canada Standards

The purpose of this section is to provide a list of Accreditation Canada standards that pertains to organ donor ID&R.

Organ and Tissue Donation Standards for Deceased Donors[29]

1.8 Goals should include identifying and referring every potential donor.

8.1 The potential donor's wishes and declared intent about donation are respected.

8.3 In organizations that provide DCD, the option to donate is presented after the family has decided to withdraw life-sustaining treatment but before withdrawing life-sustaining treatment.

10.2 Potential donors are screened using organ and tissue-specific exclusionary criteria.

Critical Care[30]

12.0 Potential organ and tissue donors are identified, referred, and managed in a timely and effective manner.

12.1 Clinical referral triggers are established to identify potential organ and tissue donors.

12.2 Training and education on the definition of imminent death, the use of clinical referral triggers, who to contact when potential organ and tissue donation opportunities arise, how to approach the families about donation, and other donation issues is provided to the team.

12.7 The organ procurement organization is notified in a timely manner when death is imminent or established for potential donors.

12.19 Data gathered on all ICU deaths is accessible and there is a process for reviewing that data to identify lost opportunities for donation.

Emergency Department[31]

11.0 Potential organ and tissue donors are identified and referred in a timely manner.

11.3 There is a policy to transfer potential organ donors to another level of care once they have been identified.

11.4 There are established clinical referral triggers to identify potential organ and tissue donors.

11.5 Training and education on organ and tissue donation and the role of the organization and the emergency department is provided to the team.

11.7 When death is imminent or established for potential donors, the organ procurement organization or tissue centre is notified in a timely manner.

List of Quality and Safety Terms

Term	Definition
Adverse Event	Refer to *Patient Safety Incident.*
Always Event	Best practices that should always occur in the care process.[23]
Conditions of Participation and Conditions of Coverage	Health and safety standards that healthcare organizations must meet in order to begin and continue participating in the Medicare and Medicaid programs (US). They form the foundation for improving quality and protecting the health and safety of beneficiaries.[32]
Critical Incident	Refer to *Sentinel Event.*
Effective Care	Providing services based on scientific knowledge to all who could benefit and refraining from providing services to those not likely to benefit (avoiding underuse and misuse, respectively).[33]
Efficient Care	Avoiding waste, including waste of equipment, supplies, ideas, and energy.[33]
Equitable Care	Providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location and socioeconomic status.[33]
Harmful Incident	A patient safety incident that resulted in harm to the patient (replaces "preventable adverse events").[34]
High-Quality Health System	A health system that delivers world-leading safe, effective, patient-centered services, efficiently and in a timely fashion, resulting in optimal health status for all communities.[35] Six aims for the healthcare system identified by Agency for Healthcare Research and Quality are: *safe, effective, patient-centered, timely, efficient and equitable.*[33]
Measures	There are three types of measures to help create targets and achieve aims:[36] *Outcome Measures*: reflect the impact on a patient and demonstrate the end result of doing things (including making changes that you predict will be improvements). Examples are mortality, hospital acquired infection or falls rates. *Process Measures*: reflect the things that you do (processes) and how systems are operating (parts/steps in the process). Commonly process measures show how well (e.g. % compliance with protocol) you are delivering a change that you want to make. Examples are % of hand-washing opportunities taken or % of patients with possible sepsis who received antibiotics within an hour of assessment *Balancing Measures*: show whether unintended consequences have been introduced elsewhere in the system. For example, the aim of an improvement might be to reduce the number of hypoglycaemic episodes in those with diabetes who are inpatients in general surgery. As a balancing measure you might wish to assess whether the number of hyperglycaemic episodes goes up.
Near miss	A patient safety incident that did not reach the patient and therefore no harm resulted.[34]
Never Event	Patient safety incidents that result in serious patient harm or death, and that can be prevented by using organizational checks and balances. Never events are not intended to reflect judgment, blame or provide a guarantee; rather, they represent a call-to-action to prevent their occurrence.[23]

No Harm Incident	A patient safety incident that reached the patient but no discernible harm resulted.[34]
Patient Safety Incident	An event or circumstance that could have or did result in unnecessary harm to the patient and occurs due to the care provided and not the patient's underlying disease. It includes harmful incidents (formerly adverse or sentinel events), no harm incidents (that reach the patient but did not cause harm) and near misses (also known as close calls).[26]
Patient Engagement	In system planning and reporting, patient engagement is carried out by collaborating with patients (and caregivers) to ensure their voices and perspectives are represented, and information meaningful to their care decisions is provided.[35]
Program of Distinction	Distinction is a rigorous and highly specialized accreditation program from Accreditation Canada based on in-depth clinical performance measures and protocols to recognize clinical excellence and a commitment to innovation and leadership in a specific healthcare field (e.g. stroke or trauma).[24]
Public Health	The organized efforts of society to keep people healthy and prevent injury, illness and premature death and disability, improving health and well-being, and reducing inequalities in health. It focuses on preventing disease and optimizing the health of the population rather than the illnesses of individuals.[25]
Required Organizational Practices	Evidence-informed practices addressing high-priority areas that enhance patient safety and minimize risk. They are reviewed and updated regularly.[26]
Sentinel Event	An unexpected occurrence involving death or serious physical or psychological injury, or the risk thereof. Serious injury specifically includes loss of limb or function. The phrase "or the risk thereof" includes any process variation for which a recurrence would carry a significant chance of a serious adverse outcome.[27]

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