

# Ethics Guide for Donation Physicians

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Recommendations developed through a national collaboration among Canadian deceased donation experts and bioethicists, and endorsed by the Canadian Medical Association

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*Released November 2015*

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Production of this report has been made possible through a financial contribution from Health Canada, and the Provinces and Territories (excluding Quebec). The views expressed herein do not necessarily represent the views of the Federal, Provincial or Territorial governments.

Electronic versions of this report and background documents can be found under the Leading Practices section at [organsandtissues.ca](http://organsandtissues.ca).

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## Report Summary

In Canada, there is a wide disparity between the demand for transplants and organ availability, and access to transplantation differs significantly between provinces. To improve this situation, in 2011, Canadian Blood Services submitted recommendations on behalf of the ODT community that included the implementation of “donation physician specialists.”<sup>1,2</sup> Donation physicians are specialists with a focus and enhanced expertise in organ and tissue donation. They work with nurse donor coordinators, hospital administrators, organ donation committees and organ donation organizations. Their role can include direct donor care, program administration, education, training, donation performance measures, quality improvement and advocacy. The donation physician role has been recognized internationally as a key contributor to improving organ and tissue donation rates.

Since 2011, donation physician programs have been introduced in Ontario, British Columbia, Nova Scotia and Manitoba and plans for implementation are being considered by Quebec. Though their exact roles vary from region to region, these physicians are involved with promotion, education, and facilitation of organ and tissue donation. In some cases, they act as local champions for organ and tissue donation. In others, they are directly involved in the care of potential organ and tissue donors. Because these professionals, who are generally intensive care physicians, must manage the dual obligation of caring for dying patients and their families while providing donation services, a need was identified to develop national guidelines on ethical practices to manage these challenges. To this end, a forum was held February 23-24, 2015 in Whistler, British Columbia.

The purpose of the forum was to develop an ethics guide that would support donation physicians in managing issues of actual, potential or perceived conflicts of interest, and in protecting the interests of dying patients who might become organ/tissue donors.

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<sup>1</sup> Shemie, S., & MacDonald, S. (2014). Improving the process of deceased organ and tissue donation: A role for donation physicians as specialists. *CMAJ: Canadian Medical Association Journal= Journal De L'Association Médicale Canadienne*, 186 (2), 95-96.

<sup>2</sup> Report on the Consultation “Donation Physicians in a Coordinated OTDT System” (2011)  
[www.organsandtissues.ca/s/wp-content/uploads/2011/11/Donation\\_Physician\\_Report\\_Final.pdf](http://www.organsandtissues.ca/s/wp-content/uploads/2011/11/Donation_Physician_Report_Final.pdf)

The forum was attended by ethicists and clinicians (including practicing donation physicians) and representatives of professional associations, including the Canadian Critical Care Society and the Canadian Medical Association. Areas of focus for discussion included: communication with families, inter-professional conflicts, donation-specific clinical practices, and performance metrics, resources and remuneration. After the forum, the discussions and recommendations were collated and summarized, reflecting the consensus view of the group. The report was reviewed by participants and finalized by the forum Steering Committee.

### **Overarching Principles**

The following principles emerged from discussions at the forum. They form the basis to the recommendations and guide deceased donation practices.

- The donation physician should seek to maintain patient, family, and public trust while facilitating the opportunity to donate.
- Notwithstanding the donation physician’s multiple roles, the primary duty is for the treatment and high quality end-of-life care of the patient.
- End-of-life care should be provided in response to patient needs and applied consistently regardless of the intention or consent to donate.
- End-of-life care must not be compromised for the purpose of enhancing the likelihood of actualizing donation.
- The ‘dead donor rule’ applies to all forms of deceased donation: non-paired vital organs can be retrieved only from patients who are dead.
- Health care professionals and related health care system policies and practices should respect the wishes of those patients who want to donate organs after their deaths.
- Those donation physicians who are involved with organ allocation decisions or transplant procedures should distance themselves from donation proceedings and donation discussion with families.

### **Benefits of the Donation Physician Role**

While the specific responsibilities of the donation physician would depend on the Province or Territory where the physician was practicing, participants identified common key benefits that may improve donation practices and the ethical aspects of donor care:

1. Normalization of the donation process within hospitals
2. Enhanced separation between end-of-life decision-making and deceased donation
3. Support for other health care professionals involved in donation
4. Improved compliance with leading practices
5. Quality improvement and minimization of errors in the process of donation
6. Improved communication between families and health care professionals
7. Enhancement of the actualization of donor potential and intention
8. Participation in donation medicine research

## **Recommendations**

### ***Communication with Families – Role Disclosure***

The circumstances leading up to a decision concerning donation often involve traumatic injury or sudden onset of tragic illness. Given extremes of emotional distress, the capacity of families for rational decision-making during this period may be compromised. As such, communication with families during end-of-life care must be undertaken sensitively and ethically, according to leading practices<sup>3</sup>.

### ***Recommendations***

1. Actual, potential or perceived conflicts of interest that arise in the course of the donation physician's professional duties and activities should be identified, disclosed and resolved in the best interest of the patient.
2. Disclosure of roles is context specific and depends on the donation physician's role, the circumstances, and the relationship with the patient and family. Disclosure is not necessary if it has no bearing on the situation or the relationship with the family.
  - If the physician, as most responsible physician, has been treating the patient, he/she should disclose his/her role as a donation physician once donation conversations begin with the family. The disclosure should be made regardless of whether the donation physician role is clinical or administrative.

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<sup>3</sup> Canadian Blood Services. (2014). End-of-life conversations with families of potential donors: Leading practices in offering the opportunity for donation. [www.organsandtissues.ca/s/wp-content/uploads/2011/11/Leading-Practices-in-Offering-the-Opportunity-for-Donation\\_Feb-2014-workshop-report.pdf](http://www.organsandtissues.ca/s/wp-content/uploads/2011/11/Leading-Practices-in-Offering-the-Opportunity-for-Donation_Feb-2014-workshop-report.pdf)

3. During disclosure conversations, the donation physician should explain:
  - Why the disclosure is being made
  - Why the system exists as it is (separation of roles)
  - How both roles (intensivist/donation physician) are complementary
  - Which role the disclosing physician is playing now and what their involvement would be in future, irrespective of donation preference.
4. Institutions are encouraged to develop policies concerning when and how disclosure should be conducted.

### ***Communication with Families – Consent for Donation***

As part of their role, donation physicians will be involved, either directly or indirectly, in conversations with families about donation. Ethical challenges emerge when there are conflicts between (i) patient wishes and family wishes and (ii) family wishes/staff sensitivities and societal need (i.e., the need for organs). Canadian leading practice guidelines for approaching the family for donation conversations have been developed<sup>4</sup> and provide guidance for navigating these situations. The key goal is to ensure that the family has an opportunity to make an informed decision that would be comparable to one made if they were not in a crisis and that they would not regret at a later date.

### ***Recommendations***

5. The donation physician, in collaboration and consultation with the donor coordinator and hospital staff, should ensure that families have the opportunity to make informed decisions. If the patient has previously expressed the intention to donate by registration or other means, those wishes should be honoured. Reasons for family reluctance to donate can be explored and medical, religious, or cultural misinformation or misconceptions should be addressed.
6. In cases of initial refusal, it is acceptable to re-approach for donation if the patient has previously registered intent to donate, if new information becomes available, if the family misunderstands the information, or if there have been previous conversations by untrained staff that have provided incorrect information.
7. If re-approaching is warranted, the donation physician should communicate with health care professionals involved in the patient's care to make sure the reason for re-approaching the family is understood.

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<sup>4</sup> Canadian Blood Services. (2014). End-of-life conversations with families of potential donors: Leading practices in offering the opportunity for donation.

8. The donation physician should facilitate the re-approach with an emphasis on gaining clarity and ensuring informed decision-making rather than reversing the initial decision. Any revisiting of the subject of donation with a family should focus on the quality of the process rather than the outcome.
9. In cases where consent is withdrawn, the donation physician should debrief with the donor coordinator and staff to identify the underlying causes, work to improve processes and communication, and remove barriers for future opportunities.

### ***Inter-Professional Conflicts – Challenges to Dual Roles***

Issues of actual, potential or perceived conflicts of interest may arise with physicians who have dual responsibility for patients (both potential donors as well as patients on the transplant wait list who are admitted to the ICU) and for supporting donation. Other health care professionals may perceive this as unethical because of the lack of separation between patient care and donation, i.e., that donation physicians may be putting donation ahead of patient care. Donation physicians must work to reassure staff that these actual, potential or perceived conflicts are being managed appropriately, in the interest of the patient, family and integrity of the health care team.

### ***Recommendations***

10. Donation physicians should build institutional trust by openly engaging with staff about their role. The donation physician should be transparent about actual, potential or perceived conflicts of interest and discuss with staff their strategy for addressing these conflicts. Objectivity, transparency, and open communication will help reduce perception of conflict of interest and mitigate the effects of conflict of interest with respect to the dual roles of donation physician and most responsible physician.
11. If concerns of bias persist, the donation physician should seek a collaborative solution. This should involve consensus-building with the health care team based on a discussion of the facts of each case, the published literature, and hospital policies. If the donation physician is the most responsible physician, when a conflict of interest is present, he or she should seek a second opinion or transfer care to another physician. If a potential donor and recipient are receiving care in the same unit (potentially with the same most responsible physician), every effort should be made to separate responsibility and accountability to avoid any conflicts of interest.

12. A system should be implemented to provide ongoing quality assurance and to mediate in cases of conflict. This system may include:
  - A regular review of cases in coordination with the Organ Donation Organization (ODO)
  - Debriefs of staff and physicians to learn from conflicts and improve practice
  - An independent body or ombudsman appointed to mediate conflicts and adjudicate in cases of complaints
  - A timely escalation process to resolve cases, so that patient care is not jeopardized and donation opportunities are not lost

### ***Inter-Professional Conflicts – Conscientious Objection***

Some health care professionals may conscientiously object to certain practices or types of donation. The donation physician must balance the benefit of providing the opportunity of donation for patients with the individual rights of health care professionals not to participate directly in the donation process.

### ***Recommendations***

13. The donation physician should work to remove barriers to donation. In cases of conscientious objection to DCD or NDD, the donation physician should:
  - Offer respectful and sensitive education on the national, ethical, legal and professional framework that donation operates within to allay concerns if possible.
  - Where conscientious objection remains, ensure alternative access to donation services such that family and patient wishes are not compromised
14. Hospitals should have a plan or process for addressing conscientious objection. This may involve:
  - Transfer of care to another physician
  - Transfer of the patient to another facility that will offer donation services
15. When a conscious patient with terminal disease and unbearable burden (e.g. ALS) is able to give informed consent for withdrawal of life sustaining therapies and consent to donation directly, without requiring a substitute decision maker, the health care system and professionals should honour the patient's right to autonomy, while preserving the integrity of the process. This may involve:
  - Discussing with other health care providers the difference between active euthanasia and withdrawal of life sustaining therapies (the latter of which is

currently standard practice in the ICU at the end-of-life). Ethics consultation may also be helpful.

- With patient's permission provided, discussing the patient's wishes with the family, to support them in being comfortable with the patient's decision
- In cases of disagreement between the most responsible physician of the potential donor and the transplant team (who have no role in the management of the potential donor), the donation physician should help facilitate communication and education to address disagreements in order to fulfill the donor's wishes.

### ***Donation-Specific Clinical Practices – Minimizing Errors in Donation Practices***

The donation physician has an important role as a steward of the donation process, ensuring that the process by which donation occurs reflects evidence-based leading practices. Donation physicians must be seen as a trusted resource on the topic of donation care and protocols, and a clinical expert in end-of-life care.

### ***Recommendations***

16. Institutions would benefit from policies that clearly delineate which physicians should be permitted to make determinations of death. These policies should consider:
  - The relationship of the physician with potential recipients
  - Hospital hierarchy (i.e., resident acting as second for his/her attending)
  - Availability of staff
  - Expertise of available staff
17. If the donation physician is acting as most responsible physician for the patient, it is acceptable to perform the first examination for a determination of death. Any risk of bias is mitigated by the requirement for the second physician confirming determination as required by law.
18. The donation physician can assist and advise during end-of-life care, including acting as the second physician in the determination of death. The benefits brought by the expertise of the donation physician are felt to outweigh the risk of perceived conflict of interest. Further, the perceived conflict of interest in these situations can also be managed through transparency and formal policies that outline role expectations.
19. If concerns of bias are expressed by other health care professionals, the donation physician should seek the opinion and involvement of a third party.

20. If the donation physician has responsibilities regarding allocation of organs for transplantation or a direct leadership role in transplantation, he/she must not be involved in making end-of-life care decisions or death determinations of potential donors.
21. The donation physician should use instances of disagreement or misalignment of views as learning opportunities to enhance health care professionals' knowledge and improve the quality of the process around end-of-life care and donation.
22. In the case of errors associated with the donation process, the donation physician should facilitate debriefing of the team and perform a root cause analysis of the error. The goal should be education and quality improvement without focusing on blame.
23. There is a duty to report errors in the donation process or death determination to the family. The donation physician should contact the initial physician and coordinate with the health care team to plan the disclosure to the family. The most appropriate person to make the disclosure depends on the specific context, such as who the current most responsible physician is, what the prognosis upon re-evaluation is, and what the next steps in the patient's care are.

***Donation-Specific Clinical Practices – Neuroprognostication and Decisions on WLST***

Neuroprognostication and decisions to withdraw life-sustaining therapy may result in potential for disagreement among the care team. Disagreements or differing perspectives on prognosis are not uncommon and are not specific to donation. If the donation physician is the most responsible physician and involved in decision-making, it is possible that other health care professionals may perceive that the donation physician is placing donation interests ahead of those of the patient.

***Recommendations***

24. Neuroprognostication and end-of-life decisions should be made prior to and separate from donation considerations.
25. If the most responsible physician is also a donation physician, and if the clinical decision making is called into question, the donation physician should discuss with colleagues and call for another medical opinion.
26. Until a consensus decision has been made, it may be beneficial for the donation physician and/or organ donation coordinator to not be involved in the process.

27. If consensus on prognosis or course of action cannot be achieved among the medical team, the donation physician should advocate for a waiting period (24-72 hours) to confirm diagnostics and prognosis.
28. The hospital should have policies on end-of-life prognostication and withdrawal of life-sustaining therapies. These policies should clearly outline the role of the donation physician by:
  - Acknowledging and supporting the donation physician as a trusted advisor with expertise in prognostication, process, and procedures
  - Providing clarity on the role the donation physician plays in the process, thereby reducing the potential for perceived bias
  - Assisting with culture change in the organization to normalize the role of the donation physician
29. The donation physician should be aware of early considerations for donation prior to the point when neuroprognostication decisions have been made. Early referral may optimize the opportunity for fulfilling a potential donor's wishes. The role of the donation physician should be to reiterate appropriate timing of donation considerations and temper enthusiasm of other less experienced practitioners to help minimize any potential conflicts of interest and/or confusion about patient end-of-life care.

***Donation-Specific Clinical Practices – Provision of End-of-Life and Comfort Care for DCD***

During end-of-life care, physicians may be subject to pressure from family or other health care professionals concerning the type and extent of comfort care a dying patient receives. These pressures may include the family's desire to relieve suffering, hasten death or actualize donation in a scenario that is not suitable, or it may result from frustration and impatience from the transplant-procurement team if the patient does not progress to donation.

***Recommendations***

30. The donation physician should act in an advisory capacity to the most responsible physician and should not direct or interfere with management decisions concerning end-of-life care. If the most responsible physician is acting as the donation physician at the same time, role disclosure should be ensured and/or second opinions should be considered (see also recommendation 11).
31. The donation physician must be aware of the potential for overt and covert pressures from family members and staff. The donation physician should support

other health care professionals in acknowledging these pressures and adhering to leading practices.

32. The donation physician or most responsible physician should not engage in, or condone, the following practices:
  - Withholding appropriate analgesia/sedation for fear of perceptions about expediting death
  - Providing analgesia/sedation that may expedite death as its primary aim (notwithstanding impending legislation on physician assisted death)
  - Providing analgesia/sedation intended to hasten death in order to ensure the patient's/family's wishes for donation are realized.
33. The donation physician should seek congruence among the family, the most responsible physician, and others involved in the patient's care concerning the goals of treatment and symptom control.
34. The donation physician should act as an intermediary between the transplant team and most responsible physician to help protect the most responsible physician from pressure that may influence end-of-life care.
35. Institutions, as well as patients and family, will benefit from policies and protocols around end-of-life care and withdrawal of life-sustaining therapies, to be used in all situations, not just for patients who may be involved in donation.

#### ***Donation-Specific Clinical Practices – Preserving the Opportunity to Donate***

Performing medically non-beneficial treatments to patients to preserve the opportunity to donate presents many ethical challenges and questions. If the donor has expressed their wish to be a donor, and medical treatment will not save their life, then their best interests are served by fulfilling their wishes. Where interventions may potentially cause harm, then risks and benefits need to be discussed between the most responsible physician, the treating team and the family. The donation physician's role should be in engaging the two sides to explore solutions that avoid or minimize harm to the patient while preserving the opportunity to donate.

#### ***Recommendations***

36. Where donation wishes have been expressed directly by the patient or through the family, interventions to preserve the opportunity to donate and enhance graft and recipient outcomes should be considered to be in the best interest of the patient.

37. Pre-mortem interventions should be discussed with family and the health care team, indicating the purpose, benefits, and risks.
38. The transplant team can only advise on the implications of any donor management decision, not seek to alter that decision. In situations of disagreement between the transplant team and the donor care team, the donation physician should liaise between the two groups to clarify facts, discuss risks and benefits, and propose alternatives to try to come to a mutually beneficial solution that honours the intention to donate.

### ***Performance Metrics, Resources and Remuneration – Funding of Donation Physicians***

Measuring the success of donation physician programs, as well as the competence of individual donation physicians, presents several challenges. Poorly designed or implemented compensation and measurement strategies carry a risk of unintended consequences. For example, rewarding based on consent rate or absolute donor number may incentivize physicians to push donation in inappropriate cases. It is, therefore, important that the remuneration and measurement structure is designed such that it favours the ethical conduct of donation physicians.

### ***Recommendations***

39. Compensation for donation physicians should not be predicated on donation rate or donor numbers; rather, measurement should focus on:
  - Reduction of missed donation opportunities through appropriate donor identification, referrals, family approaches and conversations
  - Improved quality of donation related processes including local policy and procedures
  - Improved family and health care professional satisfaction with the donation process
  - Education, training, and research activities
  - Identification and resolution of local barriers to donation

### ***Performance Metrics, Resources and Remuneration – Conflict of Interest***

Donation physicians, as experts in organ donation, have a role in sharing their expertise through research, knowledge translation, and education. They also can offer a valuable perspective to transplant societies or corporations working in the donation and transplantation field. However, in some cases, this may present actual, potential or

perceived conflicts of interest related to personal advancement or financial gain, or result in bias in professional decision-making.

### ***Recommendations***

40. Guidelines exist for the medical profession in managing conflicts of interest related to education and research, and should be followed by donation physicians<sup>5</sup>.
41. Donation physicians can participate in committees/societies/boards dealing with transplantation as they can bring valuable insight from the clinical/donation perspective.
42. Donation physicians should be transparent and disclose any relevant conflicts related to research and educational activities.
43. Honoraria, when they exist, should be modest and proportional to the work being performed.
44. The donation physician has an important role in developing new knowledge to advance understanding in donation and transplantation. The sponsoring organization should support the academic freedom of the role. Opinions and research data should not be suppressed even when contrary to the prevailing views and processes of the organization.
45. The donation physicians should present a balanced view based on evidence-based leading practices. It is permissible to present a challenging, innovative, or controversial view to generate discussion and provoke thought but these should be clearly defined as such.

### ***Performance Metrics, Resources and Remuneration – Access to ICU and OR***

While acknowledging the requirement of the hospital to manage many priorities and patients, participants felt that the donation physician could advocate for increased access for potential donors. Patients waiting for organs are less visible to front line ICU hospital staff but the health care system should strive to fulfil their needs. Recognizing and minimizing “moral distance” through awareness and education can be part of the donation physician’s responsibilities.

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<sup>5</sup> CMA Policy: Guidelines for Physicians in Interactions with Industry, Canadian Medical Association, 2007.  
[www.cma.ca](http://www.cma.ca)

### ***Recommendations***

46. The donation physician should advocate on behalf of donation and explore options to improve access to ICU and OR.

### **Future Discussion Topics**

Throughout the meeting, participants provided questions and outlined areas where research and further information would benefit future discussions. The number and diversity of ethics questions presented will necessitate continued dialogue as the donation community seeks to advance deceased donation practices in a responsible and ethical manne

## Forum Participants

### Steering Committee

Dr. Sam D. Shemie (Chair)	Division of Critical Care, Montreal Children’s Hospital, McGill University Health Centre, Professor of Pediatrics, McGill University Medical Director, Donation, Canadian Blood Services
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Ms. Judie Leach-Bennett	Director, Centre for Innovation, Ottawa, Ontario

## Chair's Message

The donation physician role has been recognized internationally as a key contributor to improving organ and tissue donation rates. In 2011, Canadian Blood Services in collaboration with the Canadian Critical Care Society explored the role of donation physicians during a forum of key stakeholders.<sup>6,7</sup> The consensus at this forum was that donation physician programs should be introduced in Canada. During the forum there were also preliminary discussions about some of the anticipated ethical challenges that donation physicians would likely encounter and the attendees identified the need to develop national guidelines on ethical practices specifically for donation physicians. These ethical challenges have also been identified in response to the publication of the report proceedings<sup>6</sup> and by physicians in the field.

Since that forum, several jurisdictions in Canada have begun the implementation of donation physician programs. Though their exact roles vary from region to region, these physicians are involved with promotion, education, and facilitation of organ and tissue donation. In some cases, they act as local champions for organ and tissue donation. In others, they are directly involved in the care of potential organ and tissue donors. These professionals, who are generally intensive care physicians, must manage the dual obligation of caring for dying patients and their families, while providing donation services. This situation gives rise to inevitable ethical challenges, including several related to conflicts of interest. It is recognized that conflicts of interest are not implicitly unethical, but that ethics should inform their management.

This highlights the need for an ethics guide to support hospital leaders and donation physicians in preserving their duty of care, protecting the interests of dying patients, and fulfilling best practices for organ and tissue donation. While this report is intended to inform donation physician practices, it is recognized that the recommendations may have applicability to end-of-life care and deceased donation practices in general.

On behalf of Canadian Blood Services, we appreciate and would like to acknowledge the time, effort and wise counsel provided by our Steering Committee. We would also like

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<sup>6</sup> Shemie, S., & MacDonald, S. (2014). Improving the process of deceased organ and tissue donation: A role for donation physicians as specialists. *CMAJ: Canadian Medical Association Journal= Journal De L'Association Médicale Canadienne*, 186 (2), 95-96.

<sup>7</sup> Report on the Consultation "Donation Physicians in a Coordinated OTDT System" (2011)  
[www.organsandtissues.ca/s/wp-content/uploads/2011/11/Donation\\_Physician\\_Report\\_Final.pdf](http://www.organsandtissues.ca/s/wp-content/uploads/2011/11/Donation_Physician_Report_Final.pdf)

to thank the meeting participants who participated in rich discussions in order to shape and inform these recommendations. Finally, we would like to recognize the commitment and dedication of donation physicians in enhancing best practices at the complex and challenging intersection of end-of-life care and deceased donation.

A handwritten signature in blue ink, appearing to read 'S. Shemie', with a long horizontal flourish extending to the right.

Sam D. Shemie, Forum Chair

## Introduction

An ethics guide for donation physicians provides a framework to promote ethical decision-making in situations where a single, unifying recommendation is not possible. While many guidelines for donation systems include some guidance for donation physicians, these documents generally focus on broader ethical issues within organ donation. Donation physicians (predominantly intensivists) are likely to face unique ethical issues stemming from their dual roles in donation and as physicians who are responsible for clinical care of dying patients who may become donors.

The purpose of this initiative was to develop an ethics guide that would support donation physicians in managing issues of actual, potential and perceived conflicts of interest, including related ethics issues, and in protecting the interests of dying patients who might become organ/tissue donors. The intent was not to dictate organ donation and transplantation practice for donation physicians but to provide a more consistent approach, recognizing the need for flexibility to adapt to regional and individual circumstances. It was also recognized that, while the forum focused on donation physicians, the recommendations could have applicability to others in health care settings in similar situations (e.g., physicians in intensive care, emergency medicine, neurology, neurosurgery, pulmonology) who may also participate in the care of potential donors in emergency medicine and ICU settings.

To this end, a forum was held February 23-24 2015 in Whistler, British Columbia according to the process developed by the Steering Committee.

## Forum Process

To provide leadership and management for development of the forum, the Steering Committee met regularly for eight months prior to develop the agenda, the process, and the supportive background documents for the workshop. The Steering Committee also set the parameters within which the forum would be conducted.

### ***Objectives***

- Review leading practices related to donation physician ethics in Canada and internationally;
- Explore sources of actual, potential and perceived conflicts of interest for donation physicians in Canada and internationally, and advise on mechanisms to mitigate conflicts that may arise;
- Discuss the real and potential benefits of the donation physician role in mitigating ethical challenges that arise at the intersection of end-of-life care and organ and tissue donation;
- Develop recommendations for an ethics guide for donation physicians;
- Advise on the development of knowledge translation strategies, including the identification of potential barriers to change and the provision of leadership and advocacy in areas specific to the adoption of the ethics guide in Canadian programs.

### ***Assumptions***

- Discussions throughout this process would be based on the best evidence available and the experience of donation practitioners;
- This process would be based on consensus definitions;
- The ethics guide for donation physicians would not dictate ODT practice; rather, it would serve as a guide for ethical conduct facilitating consistency while allowing for regional and individual flexibility; individual ODT professionals would continue to make decisions regarding individual patients and families;
- Discussions throughout this process would be focused on the deceased donation process (independent of the ethics of transplantation);

- Ethical practices were understood to be situated within the current Canadian legal standard (e.g., for death determination, the role of the donation physician and the roles of transplant team members must be separate);
- The physician’s involvement in the management of potential organ donors, including the medical management of death for the purpose of organ donation, is clearly distinct and separate from any future involvement in the clinical practice of assisted dying requested by a patient.
  - It was recognized by the Steering Committee that once clarity of law and practice are established, the potential for intersection with deceased donation should be evaluated in a separate, future project.

### ***Key Considerations***

The following important circumstances, facts, data, and concerns were taken into account due to their potential impact on the success of this initiative:

- Input from both ethicists and health care professionals would be critical to ensure appropriate development of an ethics guide;
- A guide on ethics will need to accommodate the unique needs of regions, programs and health care professionals;
- While the complete separation of roles related to donation is preferable, this may not always be possible due to variations in the donation physician role based on geographical location, resources, specialist scheduling, etc.

### ***In-Scope***

- Roles and activities of designated donation physician specialists and others in this role:
  - Hospital- and region-based donation leads
  - Organ donation organization (ODO) medical directors
  - Senior ODO administrators (e.g., CEO) who may hold a dual role and continue to provide patient care in the ICU
- The focus in this process was on the previous three physician groups while at the same time recognizing that this work may well have an impact on the roles of other physicians, including:

- Physician specialists (e.g., ICU, neurosurgeons, neurologists, emergency medicine specialists, pulmonologists) who may be involved in donor care
- Physicians who may care for donors and potential transplant patients (e.g., a respirologist caring for a patient in ICU with cystic fibrosis who is on a lung transplant waiting list)
- All streams of deceased donation are covered by these guidelines, including:
  - Pediatric and adult
  - Organs and tissues
  - Neurological determination of death (NDD) and donation after circulatory death (DCD)

***Out of scope:***

- Roles and activities of donor coordinators, critical care nurses, other health care staff, transplant physicians and surgeons
- Physicians who may play a role in patient care and donor management but are not affiliated with, or do not represent a donation program
- Processes related to the care of the body after donation
- The ethics of deceased donation practices themselves, including:
  - Death determination
  - NDD
  - DCD
  - Implementation of donation-focused personnel

Background documents were provided to participants ahead of the meeting and included:

- A literature review and environmental scan on practices related to donation physicians (Attachment A)
- A document describing the roles and responsibilities of donation physicians in Canada and the status of implementation in the various provinces
- A terminology document with standardized language to ensure a shared understanding of terms and acronyms during discussions (Attachment B)

The forum was attended by ethicists, clinicians and representatives of professional associations, including the Canadian Critical Care Society and the Canadian Medical

Association. Participants were chosen by the Steering Committee based on medical leadership within the organ donation organizations, practicing donation physicians and ethicists with experience in organ donation and transplantation. The forum started with several presentations to set context and provide information. This was followed by a discussion of the benefits of donation physicians and the value they provide to patients, families, health care professionals, and the health care system. The participants then began in-depth discussions structured around a set of scenarios related to four broad and inter-related themes:

- A. Communication with families
- B. Inter-professional conflicts
- C. Donation-specific clinical practices
- D. Performance metrics, resources and remuneration

Discussions were thoughtful, dynamic, and respectful, as participants focused on building consensus around challenging questions and scenarios.

After the forum, the discussions and recommendations were collated and summarized, reflecting the consensus view of the group. A draft report was developed from this material which was reviewed and edited by the Steering Committee. The report was revised based on this review and subsequently distributed to the forum participants for comment and to confirm faithfulness to the forum process. The final report was approved by the Steering Committee.

## Forum Outputs

### Speaker Presentations

#### ***Challenge Address: Dr. Sam Shemie***

Dr. Shemie formally opened the forum with a challenge address that reviewed the context for the development of an ethics guide for donation physicians within a long-term strategy of leading practice development for deceased donation in Canada. He outlined the donation physician model, describing its progressive implementation that has resulted in an enhanced community of experts focused on donation medicine.

After summarizing the results of the 2011 Canadian Blood Services/Canadian Critical Care Society consultation on donation physicians, Dr. Shemie outlined preliminary ethical guidance developed at that time including: (i) disclosure of roles and responsibilities, (ii) separation of EOL care decisions from donation decisions, and (iii) providing the opportunity to donate without determining remuneration of donation physicians based on donor numbers or organ yield.

Dr. Shemie emphasized the purpose of this forum: to provide *practical* guidance to donation physicians and the organizations that sponsor them on how to manage the complex tensions at the intersection of dying, death, and organ donation. In closing, he acknowledged the importance of this original work for Canada and internationally, given the limited published experience to inform the donation physician role. This forum outcome will derive from the surfacing and description of expressed clinical issues, and the assembly of expert experience to develop a consensus-based ethics guide.

#### ***The UK Experience – Donation Physicians and Ethical Perspectives: How Organ Donation Has Taught UK Intensivists Better Ethics: Dr. Dale Gardiner***

Dr. Dale Gardiner shared insights from his experience implementing a donation physician program in the UK. This program derived from recommendations of the 2008 UK Organ Donation Taskforce, which called for resolution of ethical and legal obstacles to organ donation and changes to hospital roles pertaining to donation (clinical leads/donation physicians, embedded nurse coordinators, donation committees).

These recommendations comprise part of a program of culture change whereby donation becomes accepted as a fundamental component of end-of-life care rather than something inflicted on patients and their families.

At the front lines of this initiative are donation physician champions, termed “clinical leads for organ donation,” or CLOD – the UK’s equivalent of the Canadian donation physician. Dr. Gardiner reported that, although consent rates have remained unchanged, the key component of donation improvement is the greater identification of potential donors and the more frequent approach of their families. This has resulted in deceased donation rates increasing 28% for NDD and 170% for DCD over the last six years to a total of 20 donors per million population. Thus, the significant increase in donation is a result of the efforts of the CLODs and their colleagues in providing more donation opportunities for families.

Dr. Gardiner emphasized that consultation and engagement with various aspects of the UK health service were key to building a robust framework of practice with high ethical, legal, and professional standards. He provided dynamic practice examples to support his assertion that the changes made to underpin the donation physician ethics program in the UK have taught better end-of-life care ethics to UK intensivists in general and that these same ethics guidelines apply to all patients, not just organ donors.

***Ethics at the CMA - General Approach and Relationship to Organ and Tissue Donation and Transplantation: Dr. Jeff Blackmer***

Dr. Jeff Blackmer, Executive Director, Office of Ethics, Professionalism and International Affairs, of the Canadian Medical Association (CMA), brought the perspective of practicing physicians to participants. He emphasized the importance of developing an ethics guide that is grounded in the realities of physician day-to-day practice and takes a pragmatic approach to support decision-making.

Dr. Blackmer referred to the foundational Canadian physician reference document – the CMA Code of Ethics that provides guidance to 80,000 Canadian physicians in regards to directions for clinical practice. Additional topics for guidance include privacy and confidentiality codes, physician-industry relationships, pandemics and ethics, care at the EOL, and OTDT ethics (last revision 2014). He also described how the CMA Office of Ethics activities intersect with legal and international affairs, and

have ties to the CMA ‘Standing Committee on Ethics’ and the World Medical Association.

Dr. Blackmer described the CMA policy development approach and how the organization’s advocacy and communication strategy supports implementation. Policies must be reviewed and approved by the CMA Board and general membership. They are then used to set professional standards for accreditation, and, although not regulatory, are considered by the courts and regulatory authorities when determining policy. He closed by reasserting the position of the CMA: that the ethics guide should be a practical document for use by all physicians.

### **Overarching Principles**

During the forum discussions, several guiding principles emerged, which formed a common basis for many of the recommendations. The forum participants felt these principles should inform all areas of donation physician practice.

- The donation physician should seek to maintain patient, family, and public trust while facilitating the opportunity to donate.
- Notwithstanding the donation physician’s multiple roles, the primary duty is for the treatment and high quality end-of-life care of the patient.
- End-of-life care should be provided in response to patient needs and applied consistently regardless of the intention or consent to donate.
- End-of-life care must not be compromised for the purpose of enhancing the likelihood of actualizing donation.
- The ‘dead donor rule’ applies to all forms of deceased donation: non-paired vital organs can be retrieved only from patients who are dead.
- Health care professionals and related health care system policies and practices should respect the wishes of patients who want to donate organs after their deaths.
- Those donation physicians who are involved with organ allocation decisions or transplant procedures should distance themselves from donation proceedings and donation discussion with families.

### **Benefits of the Donation Physician Role**

Participants were asked for input on how the role of the donation physician could benefit the ethical practice of deceased donation in Canada. While the specific

responsibilities of the donation physician would depend on the Province or Territory where the physician was practicing, there were common key benefits, which are identified below:

1. Normalization of the donation process within hospitals
2. Enhanced separation between end-of-life decision-making and deceased donation
3. Support for other health care professionals involved in donation
4. Improved compliance with leading practices
5. Quality improvement and minimization of errors in the process of donation
6. Improved communication between families and health care professionals
7. Enhancement of the actualization of donor potential and intention
8. Participation in donation medicine research

It was acknowledged that the work of the donation physician must be done in close collaboration with donor coordinators. While roles and responsibilities will vary between ODO and region, both the donation physician and donor coordinator have roles in enhancing the actualization of donation by identifying and addressing hospital policies, behaviours and/or biases that may present barriers to donation. This includes facilitating and implementing change within the existing administrative structure of the hospital as needed. The donation physician and donor coordinator partnership supports improved clinical practice, professional education, communication, and the ethical conduct of practices.

### ***Benefits***

#### ***1. Normalization of the donation process within hospitals***

Although deceased organ donation is a relatively rare process in most hospitals, participants expressed the hope that it would become a normal and expected part of advanced care planning and end-of-life care. The donation physician can facilitate this normalization in several ways, e.g., by professional education of other health care professionals, developing guidelines and policies within their institutions, building awareness and ensuring processes to confirm that all potential donors are offered the opportunity to donate.

## **2. *Enhanced separation between end-of-life decision-making and deceased donation***

A common fear expressed by some members of the public is that life-saving care or end-of-life care for a patient may be compromised in favour of promoting donation. In the absence of a separation of these responsibilities, it might fall to the most responsible physician to offer the opportunity for donation and manage the process. Participants reported that such situations could contribute to a perception that the actualization of donation was being prioritized over patient care. The existence of a donation physician enables the most responsible physician to focus on patient care and avoid this perception of conflict. Participants felt that separation was more important for DCD cases than for NDD cases as, in DCD, the option of donation arises before death and the most responsible physician might be perceived as hastening death to enable donation.

However, it was also suggested that too great a degree of separation between end-of-life care and deceased donation might be a barrier to the normalization of offering the opportunity to donate as a predictable part of end-of-life care. It was thought that families might be adversely affected if the most responsible physician was reluctant to engage in discussions about donation.

## **3. *Support for other health care professionals involved in donation***

Donation physicians have the potential to support other health care professionals by serving as trusted resources with special expertise and focus on deceased donation medicine in relation to:

- Evidence-based leading practice for all aspects of deceased donation
- Communicating accurately and effectively with families, whether or not donation is actualized
- Implementing standards and procedures for donation procedures
- Providing guidance on clinical donation processes, such as death determination

Donation physicians also have a role in the mediation of conflicts with other health care professionals involved with donation by:

- Brokering discussions between parties such as ICU and transplant specialists

- Building consensus among various health care professionals
- Working collaboratively with donation coordinators to address issues
- Providing support and guidance in times of moral distress or uncertainty

#### **4. *Improved compliance with leading practices***

Donation physicians can improve compliance with leading practices in a variety of ways, depending on the nature of the role. A donation physician who has clinical responsibilities may assist with death determination, donor management, and provide advice during end-of-life care. A donation physician whose role is primarily administrative may assist with developing, implementing, and reviewing policies based on available evidence with the aim of improving quality of care.

Donation physicians may also contribute to education and knowledge transfer by advocating for and facilitating the inclusion of donation leading practices in educational programs.

#### **5. *Quality improvement and minimization of errors in the process of donation***

Donation physicians can provide guidance and mentor team members to help ensure policies and procedures are followed correctly. This could include potentially challenging areas such as donor identification (inclusion and exclusion criteria), consent, donor management, and death determination. Depending on the nature of the donation physician role, this may happen in several ways, e.g., by directly intervening in complex clinical situations, coaching less experienced clinicians, education, and/or by developing cognitive aids or checklists to support other health care professionals.

#### **6. *Improved communication between families and health care professionals***

The donation physician can serve as a trusted, reliable resource to address questions and concerns of both families and health care professionals, including:

- ICU physicians and nurses
- Chaplaincy, social work, and psychology staff
- Non-ICU physicians who may be involved in the donation process

- Surgeons or transplant team members who might otherwise be uncomfortable reaching out to those who care for potential donors

Donation physicians also have an important role in providing education to health care professionals on leading practices for donation conversations with families. It is important that families and staff understand the donation process and have realistic expectations of what is to occur, including:

- Timelines and activities before and after withdrawal of life-sustaining therapy
- Clinical and logistical processes for donation
- Risks of delays and/or failure to actualize donation

### **7. *Enhancement of the actualization of donor potential and intention***

In Canada, donation rates fall well below the donation potential that exists in the country. To improve this, donation physicians can seek to preserve the opportunity to donate by advocating for the accommodation of potential donors in the ICU and by facilitating the transfer of patients from hospitals unable or unwilling to offer donation services to hospitals where donation can be offered.

Donation physicians have a role in identifying and addressing hospital policies, behaviours and/or biases that may present barriers to donation. This includes influencing change within the existing administrative structure of the hospital.

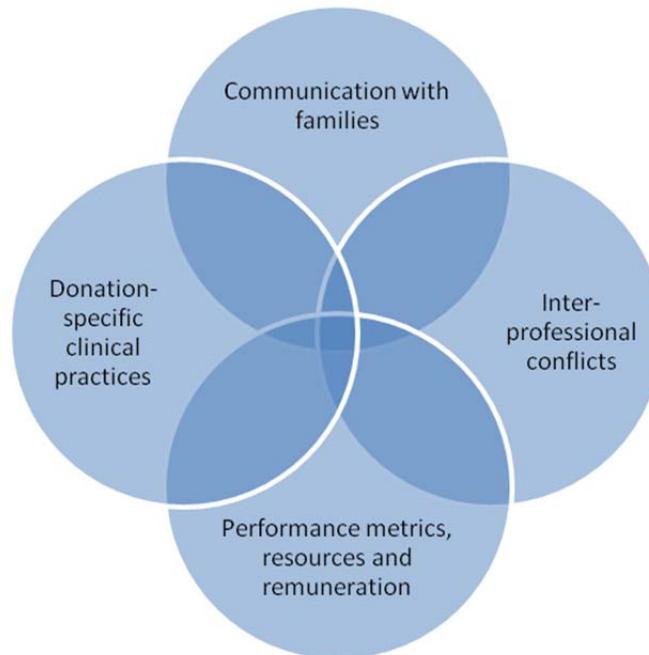
### **8. *Participation in donation medicine research***

Given the historical challenges in studying death, the dying process, and deceased donation, the scientific evidence for deceased donation is still at an early stage. The donation physician role is pivotal for initiating and participating in single-centre and multi-centre studies to advance scientific knowledge concerning organ and tissue donation.

## Recommendations

Forum discussions focused on the development of ethics guidelines through the analysis of illustrative scenarios designed to provoke discussion in four theme areas:

- A. Communication with families
- B. Inter-professional conflicts
- C. Donation-specific clinical practices
- D. Performance metrics, resources and remuneration



The illustrative scenarios presented at the forum are included below. The outcomes of the discussions are summarized for each theme area by:

- a) Considerations – key points of discussion from the forum that qualify or influence interpretation of the recommendations, including special cases or patient groups
- b) Recommendations – specific recommendations to guide practice for donation physicians and other health care professionals
- c) Questions – any queries requiring additional information or where there was not complete agreement

## Theme A: Communication with Families

Communication with families is a critical and sensitive part of the donation process. Regardless of a patient's registered intent to donate, consent for donation of organs is frequently sought from a substitute decision maker, usually a close family member. The circumstances leading up to a decision concerning donation often involve traumatic injury or sudden onset of tragic illness. Given extremes of emotional distress, the capacity of families for rational decision-making during this period may be compromised. As such, communication with families during end-of-life care must be undertaken sensitively, ethically, and according to leading practices<sup>8</sup>. Specific ethics issues related to this theme are donation physician role disclosure and consent for donation.

### A.1 Role Disclosure

#### ***Scenario A1***

The family of a patient with a catastrophic brain injury has agreed to withdraw life-sustaining treatments. A family meeting with the bedside nurse, most responsible physician, donor coordinator and chaplain is held and consent for DCD is provided. The most responsible physician (attending ICU physician) also holds an administrative position as a regional donation physician. After the meeting, the chaplain asks why the most responsible physician did not disclose his/her role as regional donation physician.

#### ***Considerations***

Donation physicians have an obligation to disclose their dual roles to patients and families to manage actual, potential or perceived conflicts of interest and to build trust; however, disclosure must take into account the context of the situation and the nature of the physician's relationship with the patient, and the goals of the patient's care:

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<sup>8</sup> Canadian Blood Services. (2014). End-of-life conversations with families of potential donors: Leading practices in offering the opportunity for donation.

- Is the patient's condition survivable?
- Is the patient a candidate for donation?
- Has an NDD declaration or WLST decision been made?
- What is the donation physician role in care for this patient?

Decisions about when to disclose involvement and expertise in donation should weigh the risks and benefits. The objective of disclosing is not to absolve physicians of responsibility at the expense of potential or actual harm to the family.

Participants concluded that there was a distinction between automatic disclosures for professional protection vs. disclosure to mitigate actual, potential or perceived conflicts of interest. Clinical donation physicians who have a role in providing advice and support for end-of-life care and making death determinations for potential donors are more likely to be in a position of real or perceived conflict than administrative donation physicians.

The risks of disclosing include:

- Potential erosion of trust by the family as the physician may be seen to have his or her focus pulled away from patient care to donation
- Putting the onus on the family to determine whether there is a conflict of interest and whether they should be concerned about this

Potential benefits of disclosing include:

- Establishment of trust based on transparency and openness
- Communicating with families that the most responsible physician has additional expertise
- Avoiding the perception of hidden conflict if families discover the dual role via another means (e.g., web search or news media) that the most responsible physician is also a donation physician
- Building trust among other health care professionals by demonstrating transparency and openness to families
- Contributing to culture change and the normalization of donation by making donation an integral part of end-of-life discussions

### **Recommendations**

1. Actual, potential or perceived conflicts of interest that arise in the course of the donation physician's professional duties and activities should be identified, disclosed and resolved in the best interest of the patient.
2. Disclosure of roles is context specific and depends on the donation physician's role, the circumstances, and the relationship with the patient and family. Disclosure is not necessary if it has no bearing on the situation or the relationship with the family.
  - If the physician, as most responsible physician, has been treating the patient, he/she should disclose his/her role as a donation physician once donation conversations begin with the family. The disclosure should be made regardless of whether the donation physician role is clinical or administrative.
3. During disclosure conversations, the donation physician should explain:
  - Why the disclosure is being made
  - Why the system exists as it is (separation of roles)
  - How both roles (intensivist/donation physician) are complementary
  - Which role the disclosing physician is playing now and what their involvement would be in future, irrespective of donation preference.
4. Institutions are encouraged to develop policies concerning when and how disclosure should be conducted.

### **A.2 Consent for Donation**

#### **Scenario A2**

A notification has been made to an ODO after the first NDD declaration in a patient after catastrophic brain injury.

- The most responsible physician states that the family, whose first language is neither French nor English, has refused organ donation after being offered the opportunity to donate by a resident at the bedside. The most responsible physician wants to stop mechanical ventilation. The donation physician and donor coordinator wish to speak to the family directly through a translator but are accused of not being sensitive to the family tragedy and only being interested in retrieving organs.

- The patient had previously registered on the provincial donor registry but the family has refused the opportunity to donate after an initial meeting with the donor coordinator.

### **Scenario A3**

Parents and a young child have been involved in a car accident. The parents suffered minor injuries. The child suffered a catastrophic traumatic brain injury and, despite neurocritical care and neurosurgical intervention, has progressed to brain death on day 3 of ICU stay. Both parents are health care providers and want to donate their child's organs. After a sleepless night during which preparations for donation and procurement are in process, the parents cannot stand to wait in the ICU any longer and withdraw their consent. The donor coordinator and donation physician wish to speak with the family.

### **Considerations**

As part of their role, donation physicians will be involved, either directly or indirectly, in conversations with families about donation. Ethical challenges emerge when there are conflicts between (i) patient wishes and family wishes and (ii) family wishes/staff sensitivities and societal need (i.e., the need for organs). These deal with different perceptions regarding:

- Potential effects on bereaved families in offering the opportunity for donation – this consideration may be amplified when children are involved
- Respecting a potential donor's expressed desire to donate
- Timing of donation discussions
- Re-visiting the opportunity for donation after initial refusal
- Managing withdrawal of consent

Canadian leading practice guidelines for approaching the family for donation conversations have been developed<sup>9</sup> and provide guidance for navigating these situations. The key goal is to ensure that the family has an opportunity to make a

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<sup>9</sup> Canadian Blood Services. (2014). "End-of-life conversations with families of potential donors: Leading practices in offering the opportunity for donation."

decision that would be comparable to one made if they were not in a crisis and that they would not regret at a later date.

If the family of a potential donor refuses the initial request, national guidelines recommend re-approaching the family if that request was flawed. Re-approaching is supported by research that shows:

- That non-donors families are more likely to regret their decisions than donor families<sup>10,11,12</sup>;
- Highly stressed families might refuse donation even though they would have given consent in different circumstances<sup>13</sup>.

The revisiting of an initial refusal after a flawed request is analogous to disclosing a medical error. If the refusal was based on incorrect or incomplete information, there is an obligation to address this so that an appropriate decision can be made.

A decision of a family to override the documented wishes of a potential donor remains a challenging issue. While legal interpretations of provincial tissue gift acts provide authorization to proceed with retrieval of organs regardless of family refusal (unless evidence is provided by family of a retraction of consent by the donor), health care professionals still turn to next-of-kin for consent.

Even when consent for donation has been given, families that are already suffering the acute crisis of the death of their loved one may grow impatient or frustrated if the donation process is beset with delays or if donation is not actualized.

Early referral has the potential to benefit patients and families by reducing delays and removing barriers to donation. It preserves the donation opportunity if the donor is unstable. It also helps to identify unsuitable donors, thus avoiding unnecessary interventions. However, some health care professionals may see early

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<sup>10</sup> Rodrigue, James R., Danielle L. Cornell, and Richard J. Howard. "The Instability of Organ Donation Decisions by Next-of-Kin and Factors That Predict It." *American Journal of Transplantation* 8.12 (2008): 2661-2667.

<sup>11</sup> Jacoby, Liva, and James Jaccard. "Perceived support among families deciding about organ donation for their loved ones: donor vs nondonor next of kin." *American Journal of Critical Care* 19.5 (2010): e52-e61.

<sup>12</sup> Manzari, Zahra Sadat, et al. "Exploring families' experiences of an organ donation request after brain death." *Nursing ethics* 19.5 (2012): 654-665.

<sup>13</sup> Whyte, Kyle Powys, et al. "Nudge, nudge or shove, shove—The right way for nudges to increase the supply of donated cadaver organs." *The American Journal of Bioethics* 12.2 (2012): 32-39.

referral as unethical, as it creates the perception that the focus has turned prematurely from patient care to procurement of organs, or the early involvement of the donor coordinator will cause additional distress for the family if they become aware of the referral. This can be mitigated by:

- Acting with transparency and openness, and explaining the rationale for early referral to those health care professionals concerned and asserting that referral does not mean family approach, but rather notification of the ODO
- Working with ODOs in communicating with health care teams and educating them on leading practices and related policies
- Building institutional trust and confidence over the long-term

Families of critically ill patients may raise the topic of donation prior to a determination of neurological death or a decision to withdraw life-sustaining treatment. It is important in these instances to understand why the question is being asked: Is there confusion about the goals of treatment or survivability of the patient's condition? Are families seeking specific information? Families may fear missing the opportunity to donate and may benefit from reassurance that these decisions can be made later when indicated and appropriate.

Families may also benefit from institutional policies that:

- Minimize delays from the time of consent to procurement
- Enable optimal prognostication of likelihood of donation
- Provide adequate emotional support for families

Families are unlikely to understand the process by which organ donation occurs and appropriate emotional support and sensitivity must be provided to the patient's family, as well as the health care professionals involved in their care. The donation physician can contribute to this by supporting donor coordinators, educating staff, advocating for the adoption of policy and guidelines, and by intervening directly in complex situations or where other supports are not available.

### ***Recommendations***

5. The donation physician, in collaboration and consultation with the donor coordinator and hospital staff, should ensure that families have the opportunity to make informed decisions. If the patient has previously

expressed the intention to donate by registration or other means, those wishes should be honoured. Reasons for family reluctance to donate can be explored and medical, religious, or cultural misinformation or misconceptions should be addressed.

6. In cases of initial refusal, it is acceptable to re-approach for donation if the patient has previously registered intent to donate, if new information becomes available, if the family misunderstands the information, or if there have been previous conversations by untrained staff that have provided incorrect information.
7. If re-approaching is warranted, the donation physician should communicate with health care professionals involved in the patient's care to make sure the reason for re-approaching the family is understood.
8. The donation physician should facilitate the re-approach with an emphasis on gaining clarity and ensuring informed decision-making rather than reversing the initial decision. Any revisiting of the subject of donation with a family should focus on the quality of the process rather than the outcome.
9. In cases where consent is withdrawn, the donation physician should debrief with the donor coordinator and staff to identify the underlying causes, work to improve processes and communication, and remove barriers for future opportunities.

### Questions

- Is there an obligation (as opposed to a justification) to revisit refusal after a flawed request?

## Theme B: Inter-professional Conflicts

The diversity of experience, knowledge, and perspectives among health care professionals in relation to deceased donation may lead to disagreements concerning the best course of action and tensions among members of the hospital staff. Donation physicians may find themselves involved in these conflicts and may be required to play a mediating role to help resolve these situations.

### B.1 Challenges Related to Dual Roles

#### ***Scenario B1***

Hospital A is a donation and transplant hospital and has recently implemented a donation physician program to support all aspects of organ and tissue donation. Patient H is admitted to the ICU on Thursday with massive brain hemorrhage and high likelihood of death. Dr. Q is the most responsible physician until Friday, after which she begins her shift as the regional donation physician for the weekend. The attending neurosurgeon, who was previously unaware of the donation physician program, expresses surprise and concern that the donation physician appears to be more concerned about retrieving organs than doing what is best for the patient.

#### ***Considerations***

Issues of actual, potential or perceived conflicts of interest may arise with physicians who have dual responsibility for patients (both potential donors as well as patients on the transplant wait list who are admitted to the ICU) and for supporting donation. Other health care professionals may perceive this as unethical because of the lack of separation between patient care and donation, i.e., that donation physicians may be putting donation ahead of patient care. Donation physicians must work to reassure staff that these real or perceived conflicts are being managed appropriately, in the interest of the patient, family and integrity of the health care team.

Conflicts of interest may arise from the dual roles of most responsible physician and donation physician during a variety of situations; however, conflicts are likely to be the most acute in the following situations:

- Making decisions about the care or treatment of patients who may become potential donors, e.g., making decisions about withdrawal of life-sustaining treatment or death determination
- Considering interventions whose purpose is to improve the likelihood of donation but is not medically beneficial to the patient (e.g., pre-mortem heparin)

Perceived conflicts should be kept in perspective – donation physicians cannot “unknow” what they know about organ donation while they are acting as most responsible physician. Irrespective of whether they are on shift as donation physicians or ICU intensivists, they are experts and advocates for donation and bring this expertise to bear in clinical practice. The benefits of their additional expertise will arguably outweigh the risks of perceived conflict.

In reality, when caring for a patient on the transplant waitlist and potential donor in the same ICU, the most responsible physician is not responsible for organ allocation and will not have decision making authority related to whom the organs will be allocated. This separation must be made clear to the staff. In the event that a donation physician does have a role in organ allocation or transplant procedures, he or she should not engage in donation procedures or discussions with families.

The perception of bias is likely to decrease as the donation physician role becomes established and donation practices become normalized. During this transition, it is essential for the donation physician to build rapport with other health care professionals and to educate hospital staff and the public on the nature of the donation physician role and the policies that guide this position.

### ***Recommendations***

10. Donation physicians should build institutional trust by openly engaging with staff about their role. The donation physician should be transparent about actual, potential or perceived conflicts of interest and discuss with staff their strategy for addressing these conflicts. Objectivity, transparency, and open communication will help reduce perception of conflict of interest and mitigate the effects of actual conflicts of interest with respect to the dual roles of donation physician and most responsible physician.
11. If concerns of bias persist, the donation physician should seek a collaborative solution. This should involve consensus-building with the health care team based on a discussion of the facts of each case, the published literature, and

hospital policies. If the donation physician is the most responsible physician, when a conflict of interest is present, he or she should seek a second opinion or transfer care to another physician. If a potential donor and recipient are receiving care in the same unit (potentially with the same most responsible physician), every effort should be made to separate responsibility and accountability to avoid any conflicts of interest.

12. A system should be implemented to provide ongoing quality assurance and to mediate in cases of conflict. This system may include:
  - A regular review of cases in coordination with the ODO
  - Debriefs of staff and physicians to learn from conflicts and improve practice
  - An independent body or ombudsman appointed to mediate conflicts and adjudicate in cases of complaints
  - A timely escalation process to resolve cases, so that patient care is not jeopardized and donation opportunities are not lost

## **B.2 Donation Options and Implications of Conscientious Objection**

### ***Scenario B2***

ICU physicians have ethical concerns regarding DCD and have chosen not to implement a DCD program based on conscientious objection. The option for DCD organ donation is not discussed with a potential donor's family. The question of organ donation has been brought up by families on previous occasions. The Organ Foundation of Canada, an interest group representing patients with end stage organ failure, has asked a provincial donation physician to address the hospital's reluctance to implement DCD.

### ***Scenario B3***

A 60 year-old patient with amyotrophic lateral sclerosis (ALS) is completely bedridden and dependent for all activities of daily living. He has been receiving chronic mechanical ventilation and has requested withdrawal of life support and palliative care. His family is fully supportive. He also requests to become an organ donor after his death. The donor coordinator and donation physician confirm his competence/capacity for informed consent and prepare for controlled DCD. The procuring transplant surgical team refuses to participate and accuses the donation physician of euthanasia.

### ***Considerations***

Support for conscientious objection based on moral or religious beliefs may be found in law and the policies of the Canadian Colleges of Physicians and Surgeons and the Canadian Medical Association. One risk of allowing conscientious objection to donation at an institutional level is that patients may receive a different standard of care at one hospital compared with another.

Donation physicians must balance the benefit of providing the opportunity for patients to donate organs with the individual rights of health care professionals not to participate directly in the donation process. However, as an advocate for donation, the donation physician should explore the rationale for conscientious objection. Conscientious objection may manifest as non-participation and/or as obstruction. In some situations, education may clarify the benefits of donation and also dispel myths. The donation physician may play a role in this regard by advocating directly to physicians or to the boards of hospitals where conscientious objection is taking place.

Donation physicians may also work to give patients the opportunity to donate by facilitating transfers from hospitals that do not offer donation to those that will offer it. Some hospitals have duplicate call systems in place to offer donation care while accommodating conscientious objection. However, it must be acknowledged that there are logistical and practical limits to the implementation of these strategies.

### ***Recommendations***

13. The donation physician should work to remove barriers to donation. In cases of conscientious objection to DCD or NDD, the donation physician should:
  - Offer respectful and sensitive education on the national, ethical, legal and professional framework that donation operates within to allay concerns if possible.
  - Where conscientious objection remains, ensure alternative access to donation services such that family and patient wishes are not compromised
14. Hospitals should have a plan or process for addressing conscientious objection. This may involve:
  - Transfer of care to another physician
  - Transfer of the patient to another facility that will offer donation services

15. When a conscious patient with terminal disease and unbearable burden (e.g. ALS) is able to give informed consent for withdrawal of life sustaining therapies and consent to donation directly, without requiring a substitute decision maker, the health care system and professionals should honour the patient's right to autonomy, while preserving the integrity of the process. This may involve:
- Discussing with other health care providers the difference between active euthanasia and withdrawal of life sustaining therapies (the latter of which is currently standard practice in the ICU at the end-of-life). Ethics consultation may also be helpful.
  - With patient's permission provided, discussing the patient's wishes with the family, to support them in being comfortable with the patient's decision
  - In cases of disagreement between the most responsible physician of the potential donor and the transplant team (who have no role in the management of the potential donor), the donation physician should help facilitate communication and education to address disagreements in order to fulfill the donor's wishes.

### Questions

- Provincial and territorial law forbids death determination by physicians who have any association with the proposed recipient that might influence the medical practitioner's judgment or are participating in transplantation – how do we define “association with the recipient that might influence judgment” and “participation” in transplantation? What is it that we are protecting against?
- Should donation (now an option that is offered) be a medical standard/duty of care for end-of-life care?
- Does failure to offer DCD fall below the medical standard of care?
- Is there a moral duty for physicians to give information and access to donation?
- Does donation introduce risk of errors around withdrawal of life-sustaining treatment or does donation elevate the standard of end-of-life decision-making?
- Does DCD compromise the use of pharmacologic symptom management and sedation for intractable symptoms at the end-of-life?

- In the future, further clarity may be required on the ethics, process and procedures:
  - to manage organ donation requests by conscious patients who will die consequent to withdrawal of life sustaining treatment
  - the impact of impending physician assisted dying legislation on deceased organ donation

## Theme C: Donation-Specific Clinical Practices

The implementation of specialist donation physicians has introduced an additional source of expertise as well as a potential source of perceived or real bias. Potential clinical impacts of donation physicians include:

- Quality improvement of donation practices and end-of-life care
- Offering of expertise and advice in the determination of neurological death
- Improving processes for withdrawal of life-sustaining treatment with or without DCD

### C.1 Adherence to Leading Practices and Minimizing Errors in the Donation Process

#### ***Scenario C1***

An ICU physician, who is also medical director of the ODO, is asked to perform the second examination to determine death in a case of:

- NDD – there are differing perspectives on confounding conditions
- DCD – the arterial line stops working and the detection of circulation is based on palpable pulses while the EKG shows sinus bradycardia.

In both cases, the ICU staff suggests that a medical director of the ODO would be biased and should not participate in death determination for donation.

#### ***Scenario C2***

A 65 year old patient falls down the stairs of his apartment building. On the arrival of paramedics, he has signs of skull trauma and is not breathing. He is intubated and transferred to the local emergency department. Initial evaluation documents a deep unresponsive coma, fixed dilated pupils and the absence of a cough, gag and cold calorics reflexes and no signs of spontaneous breathing. The emergency department physician tells the family that the patient is brain dead. After referral to the ODO and confirmation of registration on the intent to donate registry, the family agrees to transfer the patient to the referral hospital for organ procurement. On arrival at the ICU, he is evaluated by the donation physician and the patient is noted to have wax in the ears. Upon removal of the wax by curette, the patient demonstrates an

extraocular response to cold caloric testing and is not brain dead. Many people are upset.

### ***Considerations***

The donation physician has an important role as a steward of the donation process, ensuring that the process by which donation occurs reflects evidence-based leading practices. As such, donation physicians must be seen as a trusted resource on the topic of donation care and protocols and a clinical expert in end-of-life care. In practice, the donation physician may be involved in:

- Development and implementation of related policies and protocols based on leading practices
- Providing advice in individual cases
- Being responsible for conducting death determination examinations
- Conducting reviews and debriefs with teams in cases of medical errors regarding end-of-life care and donation
- Disclosure of errors around donation to the family

### ***Recommendations***

16. Institutions would benefit from policies that clearly delineate which physicians should be permitted to make determinations of death. These policies should consider:
  - The relationship of the physician with potential recipients
  - Hospital hierarchy (i.e., resident acting as second for his/her attending)
  - Availability of staff
  - Expertise of available staff
17. If the donation physician is acting as most responsible physician for the patient, it is acceptable to perform the first examination for a determination of death. Any risk of bias is mitigated by the requirement for the second physician confirming determination as required by law.
18. The donation physician can assist and advise during end-of-life care, including acting as the second physician in the determination of death. The benefits brought by the expertise of the donation physician are felt to outweigh the risk of perceived conflict of interest. Further, the perceived conflict of interest in

these situations can also be managed through transparency and formal policies that outline role expectations.

19. If concerns of bias are expressed by other health care professionals, the donation physician should seek the opinion and involvement of a third party.
20. If the donation physician has responsibilities regarding allocation of organs for transplantation or a direct leadership role in transplantation, he/she must not be involved in making end-of-life care decisions or death determinations of potential donors.
21. The donation physician should use instances of disagreement or misalignment of views as learning opportunities to enhance health care professionals' knowledge and improve the quality of the process around end-of-life care and donation.
22. In the case of errors associated with the donation process, the donation physician should facilitate debriefing of the team and perform a root cause analysis of the error. The goal should be education and quality improvement without focusing on blame.
23. There is a duty to report errors in the donation process or death determination to the family. The donation physician should contact the initial physician and coordinate with the health care team to plan the disclosure to the family. The most appropriate person to make the disclosure depends on the specific context, such as who the current most responsible physician is, what the prognosis upon re-evaluation is, and what the next steps in the patient's care are.

## **C.2 Neuroprognostication and the Decision to Withdraw Life-Sustaining Therapy**

### ***Scenario C3***

The donation physician is the most responsible physician in an ICU caring for an 18 year old patient with anoxic brain injury after resuscitated cardiac arrest. The patient has registered his wish to be an organ donor. Two situations:

- 24 hours post-arrest the Glasgow Coma Scale (GCS) is 4 (deeply comatose, not brain dead). The neurologist recommends WLST but the most responsible physician wishes to wait until 72 hours to confirm prognosis. The most responsible physician /donation physician is accused of non-therapeutic intent to allow evolution to brain death.

- 24 hours post-arrest the GCS is 4 (deeply comatose, not brain dead). The most responsible physician / donation physician recommends WLST but the neurologist wishes to wait until 72 hours to confirm prognosis. The neurologist accuses the most responsible physician / donation physician of premature neuroprognostication in order to perform DCD.

### ***Considerations***

Neuroprognostication and decisions to withdraw life-sustaining therapy may sometimes lead to disagreement among the care team. Disagreements or differing perspectives on prognosis are not uncommon and are not specific to donation. If the donation physician is the most responsible physician and involved in decision-making, it is possible that other health care professionals may perceive that the donation physician is placing donation interests ahead of those of the patient.

It is important that consensus is established in cases of disagreement. This is true irrespective of donation. If consensus cannot be reached, the opinion of a third party should be sought. Donation need not be discussed until the decision is made regarding withdrawal of life-sustaining therapies. The hospital or regional health authority can support donation physicians by acknowledging their expertise and formalizing their clinical authority and roles in hospital policies.

Delaying withdrawal of life-sustaining therapies allows for the patient to be reassessed for further deterioration, to confirm results of examinations and testing, and to monitor for signs of recovery. It may also preserve the opportunity for the patient to become an organ donor.

While there may be cases when the donation physician, who is also most responsible physician, will decide to distance themselves from the decision making process to mitigate perceived conflict, this must be weighed against the cost of transferring or deferring care. Patients and their families may typically benefit from the continuity of the relationship with the most responsible physician and many families may see the dual roles of most responsible physician and donation physician as complimentary during end-of-life care.

### **Recommendations**

24. Neuroprognostication and end-of-life decisions should be made prior to and separate from donation considerations.
25. If the most responsible physician is also a donation physician, and if the clinical decision making is called into question, the donation physician should discuss with colleagues and call for another medical opinion.
26. Until a consensus decision has been made, it may be beneficial for the donation physician and/or organ donation coordinator to not be involved in the process.
27. If consensus on prognosis or course of action cannot be achieved among the medical team, the donation physician should advocate for a waiting period (24-72 hours) to confirm diagnostics and prognosis.
28. The hospital should have policies on end-of-life prognostication and withdrawal of life-sustaining therapies. These policies should clearly outline the role of the donation physician by:
  - Acknowledging and supporting the donation physician as a trusted advisor with expertise in prognostication, process, and procedures
  - Providing clarity on the role the donation physician plays in the process, thereby reducing the potential for perceived bias
  - Assisting with culture change in the organization to normalize the role of the donation physician
29. The donation physician should be aware of early considerations for donation prior to the point when neuroprognostication decisions have been made. Early referral may optimize the opportunity for fulfilling a potential donor's wishes. The role of the donation physician should be to reiterate appropriate timing of donation considerations and temper enthusiasm of other less experienced practitioners to help minimize any potential conflicts of interest and/or confusion about patient end-of-life care.

### **C.3 Process of WLST and Provision of End-of-Life and Comfort Care (DCD)**

#### **Scenario C4**

The ICU most responsible physician and a donation physician are preparing to WLST in a catastrophically brain-injured and comatose patient whose family has consented to DCD. Based on predictive tools, the patient has a moderate chance of dying

within the time limits required for donation. It is 10 p.m. and the transplant surgical procurement team is on standby in an adjacent operating room. After extubation, the patient struggles to breathe with upper airway obstruction. There is minimal response to escalating doses of morphine. The family around the bedside is visibly upset, feels the patient is suffering, and asks the doctor to help their loved one. Two situations:

- The most responsible physician gives further doses of morphine without effect, and the patient dies four hours later when donation is no longer possible. The family is visibly upset about perceived suffering and failure to donate.
- The most responsible physician gives propofol to manage palliation, the patient immediately stops breathing, dies and proceeds to donate three organs. The family is relieved and is appreciative of actualizing organ donation. The bedside nurse is visibly upset.

### ***Considerations***

During end-of-life care, the most responsible physicians may be subject to pressure from family or other health care professionals concerning the type and extent of comfort care a dying patient receives. These pressures may include the family's desire to relieve suffering, hasten death or actualize donation in a scenario that is not suitable. Pressure may also result from frustration and impatience expressed by the transplant-procurement team if the patient does not progress to donation.

While the donation physician should seek to maximize opportunities to donate, some patients will not progress to death in the time limits required for DCD. As discussed in Theme A, effective communication with families should set expectations concerning the dying process, which may reduce pressure on the most responsible physician to intervene.

Clear, evidence-based guidelines around end-of-life care and terminal sedation will help to protect the most responsible physician from pressures related to managing suffering and the dying process after withdrawal of life-sustaining treatment. These guidelines may include comfort care scales and sedation protocols titrated to comfort, as are in use in some hospitals

### **Recommendations**

30. The donation physician should act in an advisory capacity to the most responsible physician and should not direct or interfere with management decisions concerning end-of-life care. If the most responsible physician is acting as the donation physician at the same time, role disclosure should be ensured and/or second opinions should be considered (see also recommendation 11).
31. The donation physician must be aware of the potential for overt and covert pressures from family members and staff. The donation physician should support other health care professionals in acknowledging these pressures and adhering to leading practices.
32. The donation physician or most responsible physician should not engage in, or condone, the following practices:
  - Withholding appropriate analgesia/sedation for fear of perceptions about expediting death
  - Providing analgesia/sedation that may expedite death as its primary aim (notwithstanding impending legislation on physician assisted death)
  - Providing analgesia/sedation intended to hasten death in order to ensure the patient's/family's wishes for donation are realized.
33. The donation physician should seek congruence among the family, the most responsible physician, and others involved in the patient's care concerning the goals of treatment and symptom control.
34. The donation physician should act as an intermediary between the transplant team and most responsible physician to help protect the most responsible physician from pressure that may influence end-of-life care.
35. Institutions, as well as patients and family, will benefit from policies and protocols around end-of-life care and withdrawal of life-sustaining therapies, to be used in all situations, not just for patients who may be involved in donation.

## **C.4 Preserving the Opportunity to Donate**

### **Scenario C5**

After a consensual decision to WLST, and a very motivated family who have consented to organ donation, the ICU most responsible physician refuses to give

heparin to a potential DCD patient with a subarachnoid hemorrhage. The transplant program will not proceed without heparin. The donation physician is asked to advise.

### **Scenario C6**

Working in a province with mandatory referral, the regional donation physician receives a call from an enthusiastic ED physician who asks for guidance regarding a 65 year old male with a massive stroke, comatose but breathing without assistance. Neurology and neurosurgical consultation confirm a dismal neuroprognosis with no effective treatments available and no indication for ICU admission. The patient's son is a transplant recipient and insists his father wanted to be an organ donor. The ED physician is asking if she should intubate the patient for organ donation and transfer to the ICU. The donation physician is also the most responsible physician on service in the ICU.

### **Considerations**

Performing medically non-beneficial treatments to patients to preserve the opportunity to donate presents many ethical challenges and questions:

- Should physicians proceed with interventions that provide no medical benefit but may fulfill the patient's wishes for donation?
  - How do we define 'best interests' for the patient? What is the limit on supporting the wishes of the family or potential donor?
  - Are these interventions still legitimate or appropriate when there may be potential harm to the patient, e.g., heparin, and there may or may not be evidence of their benefit in donation?
  - Are interventions legitimate if the wishes of the patient are unknown and the family is unavailable?
- Does the interpretation change if we consider an escalation of therapy versus maintenance of therapy, e.g., non-therapeutic ventilation?
  - What is the role of CPR for organ preservation after death has been declared in NDD?

Best interests must be judged in the context of the particular patient. It can be argued that decision makers must look beyond what is medically beneficial to the patient and consider their ethical, social, moral, spiritual, and religious values. The

views and values of the patient, if known, must be taken into account and, if not known, explored through a timely discussion with the patient's family and friends.

If the donor has expressed their wish to be a donor, and medical treatment will not save their life, then their best interests may be served by fulfilling their wishes regarding donation. Interventions that contribute to this can be argued to be in the patient's best interests.

Where interventions may potentially cause harm, then risks and benefits need to be discussed between the most responsible physician, the treating team, and the family/substitute decision maker. In some cases, there may be disagreement regarding treatment options between the most responsible physician and the transplant team. The donation physician's role should be in engaging the two sides to explore solutions that avoid or minimize harm to the patient while preserving the opportunity to donate.

Regardless, all pre-mortem therapeutic options should be explained to the family, including risks and benefits and purpose (if strictly for donation). In addition to facilitating communication among various departments within the hospital, the donation physician can provide factual information and advise on evidence-based leading practices on what interventions are appropriate for patients during the end-of-life care process. Where the donation physician is the most responsible physician, then there should be transparency and disclosure to the family about his/her dual role as part of the discussion about pre-mortem therapeutic options.

### ***Recommendations***

36. Where donation wishes have been expressed by the patient directly or through the family, interventions to preserve the opportunity to donate and enhance graft and recipient outcomes should be considered to be in the best interest of the patient.
37. Pre-mortem interventions should be discussed with family and the health care team, indicating the purpose, benefits, and risks.
38. The transplant team can only advise on the implications of any donor management decision, not seek to alter that decision. In situations of disagreement between the transplant team and the donor care team, the donation physician should liaise between the two groups to clarify facts,

discuss risks and benefits, and propose alternatives to try to come to a mutually beneficial solution that honours the intention to donate.

### **Non-Therapeutic Ventilation**

An emerging issue in donation is the request for intubation to preserve the opportunity for donation in patients who are not expected to survive their injuries but were not initially intubated for treatment purposes. There is a distinction between continuing ventilation (done frequently) and initiating ventilation after recognition that it will not contribute to saving the patient's life (non-therapeutic ventilation).

There were differing perspectives on this at the meeting:

- Some felt that the legitimacy of this practice was dependent on whether the patient's intent to donate was known. Others felt that intubation was an appropriate step in the care of this patient regardless of any discussion of donation, as this would enable proper prognostication and care of the patient, i.e., this should be standard of care regardless of any potential donation opportunity.
- Because this intervention could lead to disability as an outcome instead of death, there was concern that the risk of harm could outweigh the potential benefits in some circumstances. This would need to be taken into account as part of the decision-making. Possible outcomes including the potential for long-term ventilation/tracheotomy and long term care would need to be discussed with the family.

There was consensus that family and health care professionals involved in the patient's care need to be comfortable with and support non-therapeutic ventilation in a specific patient care situation in order to move forward with this, recognizing the above points for consideration. Further exploration of this area is required.

### **Questions**

- Regarding transfer policy from non-tertiary sites, should NDD declarations be accepted upon transfer or should there be a policy of re-evaluation?
  - What about DCD, i.e., should there be a re-evaluation of neuroprognosis or EOL decisions?

- Should DCD be offered after a wrong diagnosis of NDD?  
Should a guiding document be developed as a reference for donation physicians on when they should and should not be involved (e.g., administering sedatives/analgesics)?
- Is non-therapeutic ventilation unethical if you are honouring the wishes of the donor?
- When families are unavailable, are there situations where pre-mortem interventions to preserve the donation option are permissible until consent can be provided? If so, what are these situations?

## Theme D: Performance Metrics, Resources and Remuneration

Measuring the success of donation physician programs, as well as the competence of individual donation physicians, presents several challenges. In a 2011 report jointly produced by Canadian Blood Services and the Canadian Critical Care Society<sup>14</sup>, a distinction was made between system performance measures (e.g., number of donors, transplants) and donation physician performance measures (e.g., peer evaluations, education/training activity). The report concluded that funding mechanisms for donation physicians should support giving patients the opportunity to donate without creating incentives to increase the number of organ donors through undue pressure.

This report also concluded that measurements should be standardized by benchmarks that must be sensitive to regional and community diversity. Performance should be measured relative to the patient population and underlying improvements, not by absolute numbers.

Poorly designed or implemented compensation and measurement strategies carry a risk of unintended consequences. For example, rewarding based on consent rate or absolute donor number may incentivize physicians to push donation in inappropriate cases or seek a positive consent at the expense of providing the information and support for families to make a decision that they will not regret at a later date. Further, many anticipated benefits of the donation physician role, such as improving communication, building trust, and enhancing collaboration, are difficult to measure quantitatively.

It is, therefore, important that the remuneration and measurement structure is designed such that it favours the ethical conduct of donation physicians.

### D.1 Funding of Donation Physician Programs and Performance Metrics for Donation

#### **Scenario D1**

The ODO responsible for donation and transplantation identifies consistently low donor numbers in region B despite the implementation of a donation physician program.

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<sup>14</sup> Report on the Consultation “Donation Physicians in a Coordinated OTDT System”. Canadian Blood Services. Ottawa. 2011.

- There is a consideration to withdraw funding based on poor donor rates.
- There is a consideration to replace the donation physician based on low donor rates.

### ***Considerations***

Measurement of donation physician performance presents challenges both in terms of achieving fair and accurate assessments of individual physicians as well as avoiding the creation of and minimizing any potential conflicts of interest.

Performance based on donation rates may be seen to put donation goals above patient care goals. As well, many of the quantitative measures, such as consent rate, number of organ and tissue donors, and number of transplantable organs and tissues per donor, cannot distinguish between individual and system accountabilities and may not accurately reflect the performance of the donation physician.

Qualitative measures related to quality of donation processes, and family and health care professional satisfaction with donation processes, may present less risk of conflict. Research and educational activities can also be measured by number of peer-reviewed publications and frequency of training sessions, respectively. There may also be changes that can be measured before and after implementation of the donation physician role, such as knowledge of policies around donation and end-of-life, and awareness of the donation physician role.

The ideal remuneration and measurement strategy will depend on the nature of the donation physician role. Remuneration should also take into account workload, which may vary between regions.

### ***Recommendations***

39. Compensation for donation physicians should not be predicated on donation rate or donor numbers; rather, measurement should focus on:
  - Reduction of missed donation opportunities through appropriate donor identification, referrals, family approaches and conversations
  - Improved quality of donation related processes including local policy and procedures
  - Improved family and health care professional satisfaction with the donation process
  - Education, training, and research activities

- Identification and resolution of local barriers to donation

## **D.2 Paid Work, Funding, and Conflict of Interest**

### ***Scenario D2***

A donation physician is requested to sit on the Board of Directors (as the donation representative) of a transplant society. An honorarium is provided for this role. The donation physician has expressed that this may be seen as a conflict of interest by his or her peers in the ICU community and therefore this may affect his or her credibility.

### ***Scenario D3***

A donation physician research network receives an offer from a transplant pharmaceutical company, Organs-R-Us, to support an interventional study of donor management in NDD donors with a view to improving transplant graft outcomes.

### ***Scenario D4***

A donation physician gives a lecture on the ‘future of brain death’ to an ICU conference. During the lecture, he/she questions the necessity of a second examination for the neurological determination of death based on existing evidence. He/she is accused of trying to expedite the determination of death to facilitate organ donation at the expense of safe practice.

### ***Considerations***

Donation physicians, as experts in organ donation, have a role in sharing their expertise through research, knowledge translation, and education. They also can offer a valuable perspective to transplant societies or corporations working in the donation and transplantation field. However, in some cases, this may present actual, potential or perceived conflicts of interest related to personal advancement or financial gain, or result in bias in professional decision-making.

These situations can arise in the normal activities of the donation physician:

- Receiving funding from transplant (medical devices) or pharmaceutical companies for training sessions or conference presentations

- Receiving honoraria for sitting on boards or committees
- Sitting on boards or committees of transplant organizations to provide the donation perspective

Because of the link between donation and transplant, participants felt that direct funding from the transplant industry introduces a risk of conflict of interest.

Appropriate sources of funding could include:

- Professional societies involved in donation
- Not-for-profit or government organizations interested in promoting or increasing donation
- Research networks, which may receive funding from industry (indirect funding)

For a number of participants, the latter group was considered acceptable only if they had clearly defined rules about the degree of autonomy in regards to the funding, i.e., funds should not be directed and/or restricted.

### ***Recommendations***

40. Guidelines exist for the medical profession in managing conflicts of interest related to education and research, and should be followed by donation physicians<sup>15</sup>.
41. Donation physicians can participate in committees/societies/boards dealing with transplantation as they can bring valuable insight from the clinical/donation perspective.
42. Donation physicians should be transparent and disclose any relevant conflicts related to research and educational activities.
43. Honoraria, when they exist, should be modest and proportional to the work being performed.
44. The donation physician has an important role in developing new knowledge to advance understanding in donation and transplantation. The sponsoring organization should support the academic freedom of the role. Opinions and research data should not be suppressed even when contrary to the prevailing views and processes of the organization.

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<sup>15</sup> CMA Policy: Guidelines for Physicians in Interactions with Industry, Canadian Medical Association, 2007.  
[www.cma.ca](http://www.cma.ca)

45. The donation physicians should present a balanced view based on evidence-based leading practices. It is permissible to present a challenging, innovative, or controversial view to generate discussion and provoke thought but these should be clearly defined as such.

### **D.3 Competition for Intensive Care Unit or Operating Room Access**

#### ***Scenario D5***

Dr. W is the ICU most responsible physician and donation physician on call. There is a patient in the ICU (currently on the transplant waiting list) with fulminant hepatic failure and risk of imminent death. The ICU is at full capacity and high-risk surgeries are being cancelled. There is a request for transfer of a suspected brain dead person from a referral hospital for donation and procurement.

#### ***Considerations***

Providing the opportunity to donate requires specialized care at end-of-life including an ICU bed, mechanical ventilation, and operating room availability. Access to these resources may be limited and priority may be given to “living patients” as opposed to those who have been declared dead through neurological criteria or whose prognosis is poor and death is expected.

In some cases, when capacity is restricted, access may depend on whether the hospital has a transplant program, the patient’s declared intent to donate, or if there is a transplant waitlist recipient in the unit. Hospitals that are designated or funded as donation referral or transplant centres may have a particular obligation or incentive to admit potential donors.

How does one weigh the cost and benefit of admitting a potential donor when they may occupy a bed that might otherwise be used by another patient? If potential donors are to be admitted, what threshold of confidence of actualization of donation must be met? Prognostication in determining time from withdrawal of life-sustaining therapies to death is not an accurate science and many potential DCD donors do not progress to donation within the recommended time limits. In these situations, there may be a sense that resources are wasted as surgeons and operating rooms are booked but go unused. This may put pressure on organ

donation organizations to be more selective about DCD patients, thus reducing the potential donor pool.

While acknowledging the requirement of the hospital to manage many priorities and patients, participants felt that the donation physician could advocate for increased access for potential donors. Patients waiting for organs are less visible than patients who are right in front of hospital staff, but the health care system has obligations to fulfil their health care needs. Recognizing and minimizing “moral distance” through awareness and education can be part of the donation physician’s responsibilities.

### ***Recommendations***

46. The donation physician should advocate on behalf of donation and explore options to improve access to ICU and OR.

### **Questions**

- Instead of honoraria, can the donation physician receive compensation directly from the employer/ organization to participate on boards and committees to reduce perceived conflict associated with honoraria?
- How should potential donors be prioritized against other patients who perhaps do not ‘need’ to be in the ICU?
- Should there be implications on funding if a hospital repeatedly refuses to admit potential donors?
- Can the donation physician work at the regional/provincial level on bed mapping to accommodate potential donors? How would this work?
- What is the effect of funded ICU donation beds on decision-making and should this be a standard?
- Does it present a conflict if the most responsible physician in the ICU is also a donation physician?

## Future Research Topics

Throughout the meeting, participants provided several areas where research would benefit future discussions in this area. These topics include:

- a) Communication and mediation strategies
  - i. With families
  - ii. With and among donation teams and health care professionals
- b) Satisfaction:
  - i. Families that consent to donation as well as those that refuse
  - ii. Health care professionals involved in donation or transplant
- c) Donor care:
  - i. Neuroprognostication
  - ii. Analgesia/sedation as part of end-of-life care and donor management
  - iii. Time-to-death prediction after withdrawal of life-sustaining therapies
  - iv. Safety and efficacy of pre-mortem interventions that increase organ quality
  - v. Donor interventions that improve graft quality and outcome
- d) Behaviour/culture change:
  - i. Conscientious objection
  - ii. Awareness of donation policies
- e) Institutional/public support for donation.
- f) Future assisted dying practice.

## Framework for Ethics Decision Making

In addition to providing specific recommendations for practice, this document provides a decision-making framework designed to result in decisions that are consistent with the values and principles that guide ethical donation practices. This tool can be adapted and used by individuals and/or groups and teams to work through an ethics issue.

The following questions help guide conversations and reflection related to an issue. Feel free to move back and forth through the tool; the numbering is for ease of reference rather than being prescriptive in terms of steps. Some questions may be more relevant for particular issues than others. Not all questions may need to be answered. Seeking out additional information and/or coming back to the discussion and analysis at another time may also be beneficial.

### 1. Identify your biases and intuitions.

- What are your gut feelings about the situation? What are the sources of your intuitions (i.e., your training, professional norms, personal history, social position, religious beliefs, relationships with the people involved, etc.)?
- What “story lines” (based on previous cases, situations, experience) are running through your head?
- What is your role or position in this situation?

### 2. Clarify the question(s).

- What is the specific issue that needs to be addressed? Can you describe it in a single sentence?
- Do/would others involved see the issue the same way? Why or why not?
- Is there a decision to be made? If so, what is its scope? How urgent is it?

### 3. Who needs to be involved and what are their perspectives?

- Who is accountable for making the decision(s), i.e., who is the legitimate decision maker? What are his/her needs and concerns?
- Who else should be part of the discussion and decision-making process? What are their values and interests?

- Who needs support and how could they be best supported? Are there other supports (such as ethics consultation, legal/risk management, etc.) that would be helpful?

4. What is known about this issue/situation?

- What medical information is required to inform decisions?
- Are there relevant policies, guidelines, recommendations, etc.?
- Are there contextual, organizational or interpersonal issues contributing to or complicating the case? Who has “power” in this situation? Is this a relevant consideration for this situation?
- Are there crucial unanswered questions or ambiguities?
- What resources, if any, could be mobilized to ease the situation?

5. What values are involved and/or in conflict?

- What key principles and values (personal, professional and organizational) are involved?
  - Remember to consider your own values as well as those of others
- Which values are the most important or seem most relevant to this situation? Which values are in conflict?
- How much weight should each value should carry relative to the others (this will help prioritize the relevant values for this situation)?
- Is there agreement (by all or most) about which values are most important and how they should be weighted? If not, is there something that still needs to be discussed or considered?

6. Reflect and contemplate the results of the previous queries.

- What are the similarities and differences between the perspectives of those involved in the situation?
- How do these perspectives influence and shape what you think?
- What are the possible approaches to this situation? Describe each approach and evaluate all approaches in light of the values, and their relative weighting, identified in the previous step.
  - Remember to include “doing nothing or maintaining the status quo” as one of the approaches to assess.

- What are the likely outcomes of each approach? What are the possible benefits and burdens? How are these distributed?
- How does this issue compare to others you have experienced or heard of? Is there any relevant ethics, medical, etc. literature that would enhance your understanding?

6. Choose an approach/Make a decision.

- Why is this approach the best or most appropriate one? Can you explain it to others? Does it accord with the values that were identified as being most important?
- Is it something that you “can live with”, all things considered? Is it reasonable?
- Is there a way of minimizing any potential burdens?
- Is this decision setting a precedent or establishing a change in practice?
- Who is accountable for this decision?

7. Moving forward.

- Who needs to hear the decision(s)? Who will communicate them and how?
- Is there a plan for evaluating and following up on the outcome of the decision?
- Is there any “residue” from this situation that needs to be considered or acted upon?
- Were any broader policy or organizational issues raised which warrant further investigation or need to be shared with others?
- Is there anything you want to retain or change based on this process for next time?

For additional information about how to identify and weigh values, please see - Bashir Jiwani. 2013. *Ethics-Based Decision Process: An Evidence- and Values-Based Process for Working Through Specific Issues*. Surrey, BC: Fraser Health.

<http://www.incorporatingethics.ca/resources/Ethics-Based%20Decision%20Process%20.pdf>