



# End-of-Life Conversations with Families of Potential Donors: Leading Practices in Offering the Opportunity for Donation

August 2014

## Contents

Summary of Recommendations .....	4
1. Introduction .....	7
2. Leading Practice Development Process .....	9
3. Leading Practice Recommendations .....	14
3.1 Effective Conversations with Families .....	14
3.2 Approaching Families Regarding the Opportunity for Donation .....	17
3.3 Elements in the Pre-approach Team Planning Meeting .....	18
3.4 Information Provided to the Family .....	28
3.5 Communicating Information to Families .....	30
3.6 Legal Standing on Family Override of Patient Consent.....	38
3.7 Supporting Families During and After Donation .....	40
3.8 Skills and Individual Characteristics Essential to Donation Discussions .....	43
3.9 Metrics to Measure Effective Donation Conversations .....	48
4. Research Agenda .....	49
5. System Initiatives.....	52
6. In Conclusion .....	53
Appendix A: List of Participants .....	54

### Attachments:

- A. Literature Review
- B. Environmental Scan
- C. Terminology

© Canadian Blood Services, 2014. All Rights Reserved.

Extracts of the information may be reviewed, reproduced or translated for educational purposes, research or private study but not for sale or for use in conjunction with commercial purposes. Any use of the information should be accompanied by an acknowledgement of Canadian Blood Services as the source. Any other use of this publication is strictly prohibited without prior permission from Canadian Blood Services.

Canadian Blood Services assumes no responsibility or liability for any consequences, losses or injuries, foreseen or unforeseen, whatsoever or howsoever occurring, which might result from the implementation, use or misuse of any information or recommendations in this report. This report contains recommendations that must be assessed in the context of a full review of applicable medical, legal and ethical requirements in any individual case.

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.

Canadian Blood Services  
1800 Alta Vista Drive  
Ottawa, Ontario K1G 4J5  
Canada  
613-739-2300  
Email: [info@blood.ca](mailto:info@blood.ca)

## Summary of Recommendations

### Recommendation 1

Effective conversations with families of potential donors are collaborative, compassionate and supportive, providing meaningful information regarding donation and its value. This supports families in reaching an optimal and enduring decision that is also respectful of the wishes of the potential donor.

### Recommendation 2

Approach the family of every potential donor and offer the opportunity for donation. Notify the Organ Donation Organization as early as possible and before the initial donation conversation with the family.

### Recommendation 3

Convene a team huddle with the Organ Donation Organization donor coordinator and key members of the health care team prior to discussions with families. At a minimum, include the donor coordinator, most responsible treating physician and primary bedside nurse(s) in the team huddle.

### Recommendation 4

To ensure a well-planned approach, include the following topics in the team huddle discussions:

- Review information about the patient, including medical status, eligibility and prior donor registration/expressed intent to donate, if available,
- Identify family members and related issues or conflicts that may impact decision-making,
- Determine when and where the initial conversation will take place,
- Determine who will lead the initial conversation with the family, who else will be in the room and what their roles will be.

### Recommendation 5

Communicate the determination of death or grave prognosis to the family in a conversation that is prior to and separate from conversations about donation.

- In the case of neurological determination of death (NDD), ensure that the family has a clear understanding of neurological death and has accepted the death before discussing donation.
- In the case of donation after circulatory death (DCD), hold the donation discussion after the consensual decision to withdraw life-sustaining therapies has been made.

- In the case of DCD, where donation conversations are conducted prior to death, it is essential to avoid perceived or real conflicts of interest. This can be achieved by having conversations led by personnel who are separate from the treating team responsible for withdrawal of life sustaining therapies and palliation. When this is not possible (due to logistics or other reasons) identify and be transparent about the roles and responsibilities of health care team members.

### **Recommendation 6**

Provide the family with sufficient information, in clear and comprehensible language, to make an informed decision:

- Be transparent about roles and responsibilities,
- Describe the value of donation,
- Review the patient's registry information or donation intentions, if available,
- Describe the process, medical/clinical considerations, and probability of donation,
- Describe any impact on funeral arrangements.

### **Recommendation 7**

When communicating with the family, demonstrate sensitive, compassionate and caring behaviour with a focus on family well-being.

- Use a confident and positive approach, rather than a guarded or apologetic approach.
- Do not use aggressive or coercive language, or strategies that polarize families.

### **Recommendation 8**

Explore family reluctance to donate by sensitively discussing reasons, addressing medical, religious or cultural misinformation or misconceptions, and dispelling myths.

- In cases of initial refusal, it is acceptable to re-ask 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 (pre-mentions) that have provided incorrect information.

### **Recommendation 9**

Support the family during and after donation discussions, regardless of whether they consent to donation.

- Provide a dedicated, trained health care organ donation professional who focuses on family support throughout and after the process for the duration of the family's stay at the hospital.

- Provide post-donation grief support/follow-up services and donor recognition.

### **Recommendation 10**

The following skills and traits are essential in leading donation conversations with families:

- A good communicator, listener, and facilitator with high emotional and cultural intelligence,
- Open, honest, collaborative, and patient,
- Self-aware, non-judgemental,
- Comfortable in dealing with families in crisis,
- Trained and experienced in dealing with conflict,
- Compassionate,
- Passionate and knowledgeable about organ donation,
- Confident in their ability to be successful,
- Able to work well with a variety of personalities.

Provide structured, formal training and competency assessment for individuals leading donation conversations, regardless of background, profession or specialty.

### **Recommendation 11**

Build a strong and trusting relationship between the Organ Donation Organization and the donation hospital and establish an effective donation environment in the hospital:

- Create a culture of organ donation within the hospital – donation should be viewed as an integral part of quality end-of-life care, where not providing the option to donate is considered a medical error,
- Engage emergency departments as well as intensive care units,
- Make early referral the norm,
- Provide health care professionals with continuing education,
- Ensure evidence-based policies for donation exist at the hospital.

### **Recommendation 12**

Use the consent rate (the percentage of number of consents over the number of family approaches) as a metric for measuring the effectiveness of donation discussions with families.

- Recognizing the limitations of the consent rate as a measure of family satisfaction and well-being, a survey index should be developed to assess the impact of support provided to the family.

## 1. Introduction

Canadian public and health care professionals strongly support the idea of organ and tissue donation. However, Canada's deceased donation rate is less than half that of the best performing countries, with variable family consent rates across the country. It is recognized that presenting the opportunity for donation to families who are in a stressful, traumatic situation is difficult and must be done with sensitivity to their unique situations, values and beliefs. At the same time, international, national, and local leaders in this area have demonstrated that conversations with families can be done in a way that leads to improved and well informed decision making and support, and can have a positive impact on donation rates.

In February 2014, Canadian Blood Services sponsored an invitational forum in Montreal for the development of leading practices related to effective requesting in deceased donation. This event focused on adult and pediatric NDD and DCD organ donors (who could also be tissue donors) and had the following objectives:

- Review current donation discussion practices in Canada and internationally,
- Develop a common Canadian understanding of what “effective” means,
- Develop leading practice recommendations,
- Initiate the development of knowledge translation (KT) tools for health care professionals.

At this meeting, there were forty-four participants from a broad range of organizations, professions and perspectives: critical care, organ and tissue donation, social work, legal, chaplaincy, ethics, health care administration, donor family and aboriginal representation and international experts. Participants reviewed and discussed issues in a variety of areas: working with families in crisis, ethnic and cultural considerations and challenges, legal requirements, characteristics and skills of effective requesters, training programs, and relevant evidence. The conversations were set in a Canadian context and took into account variations among existing practices across the country. Group members also explored potential research topics and system-wide issues at provincial, regional and/or national levels, reaching agreement in a number of areas.

Meeting discussions were supported by a literature review as well as presentations made by national and international subject matter experts. The conclusions from these discussions and relevant findings from the literature review are presented here as proposed national leading

practice guidelines. While some of these leading practices may take time to implement because of logistical, geographical or funding issues, planning committee members hope that Canadian health care professions and organizations involved with potential organ and tissues donors find this guidance useful in supporting families and improving donation conversations.

## **Planning Committee**

### ***Dr. Adrian Robertson (Chair)***

Medical Director, Intermediate Intensive Care  
Health Sciences Centre, Winnipeg  
Medical Director, Manitoba Organ Donation  
Organization-Gift of Life  
Medical Director, Clinical Ethics Consult Service  
Health Sciences Centre, Winnipeg

### ***Ms. Janice Beitel***

Director, Hospital Programs, Education and  
Professional Practice, Trillium Gift of Life  
Network (ON)

### ***Ms. Janet Evans***

Organ and Tissue Donation Resource Nurse,  
Cape Breton District Health Authority (NS)

### ***Ms. Sophie Gravel***

Program Manager, Deceased Donation and  
Transplantation, Canadian Blood Services

### ***Ms. Dorothy Strachan***

Process Consultant, Strachan-Tomlinson Inc.

### ***Dr. Sam Shemie (Co-Chair)***

Division of Critical Care, Montreal Children's  
Hospital  
Loeb Chair and Research Consortium in  
Organ and Tissue Donation, University of  
Ottawa  
Medical Advisor (Donation), Canadian Blood  
Services

### ***Ms. Jennifer Chandler***

Associate Professor, Faculty of Law,  
University of Ottawa

### ***Mr. Ed Ferre***

Director, Program Development and  
External Relations, BC Transplant

### ***Mr. Mathias Haun***

Director, Strategic Planning, Tissues,  
Canadian Blood Services

### ***Ms. Sylvia Torrance***

Associate Director, Deceased Donation and  
Transplantation, Canadian Blood Services



## 2. Leading Practice Development Process

This workshop brought together a group of national and international subject matter experts and representatives from professional organizations and programs to build a consensus on Canadian recommendations for offering the opportunity for donation to families of potential donors. To provide leadership and management for development of the workshop, the Planning Committee met regularly for nine months prior to the workshop to develop the agenda, the process, the supportive background documents, and to manage the logistics.

In preparation for the workshop:

- A comprehensive background package was provided to participants in advance of the workshop. This included a literature review and an environmental scan on practices related to effective requesting (Attachments A and B).
- A pre-workshop survey on attitudes and current practices was distributed to participants. A report on the results of the survey was presented at the workshop.
- A terminology document was developed to standardize language and ensure a shared understanding of terms and acronyms during discussions (Attachment C).

The objectives, assumptions and key considerations for the meeting (outlined below) were provided beforehand and confirmed at the start of the meeting.

### Objectives:

- Review current donation discussion practices in Canada and internationally.
- Develop a common understanding of what “effective” means.
- Develop leading practice recommendations.
- Initiate the development of knowledge translation (KT) tools for effective requesting.

### Core Assumptions Related to Donation:

- The health care system should strive to fulfill a patient’s stated wishes regarding events upon death.
- Compassion and respect for patients and their families is paramount.
- Organ and tissue donation benefit society.
- Offering organ and tissue donation is an obligation of the system and should be presented at every appropriate opportunity.
- Efforts to increase organ donation should not compromise public or family trust or well-being.

Core Assumptions Related to Leading Practice Development:

- Discussions throughout this process will be based on the best evidence available and the experience of practitioners.
- Developing a leading practice on effective requesting does not dictate organ donation and transplantation (ODT) practice, but provides a framework for a more consistent approach, one which is sufficiently flexible to adapt to regional/individual applications. Individual ODT professionals will continue to make decisions regarding specific patients and families.
- In scope for this initiative are all potential adult and pediatric NDD and DCD organ and tissue donors.
- Out of scope for this initiative are:
  - Resources, i.e., type required, availability and allocation,
  - Living donation,
  - While the impact of donor wishes as identified through intent-to-donate registries is in scope, the actual structure and processes of intent-to-donate registries is out of scope,
  - Tissue donation independent of organ donation.
- The existing legislative context and laws in Canada will serve as a guide for discussions.

Key Considerations:

- One important outcome is agreement among workshop participants regarding what defines an effective request in the Canadian context.
- Questions to form leading practice guidelines should keep the following in mind:
  - Which activities build vs. damage trust?
  - How does the health care team avoid perceived or real conflict of interest between care of the patient and donation?
  - Is there a difference in approach between NDD and DCD?
  - Is there a difference in approach between pediatric and adult donors?
- A leading practice on effective requesting and KT tools will require thoughtful implementation strategies, recognizing the unique needs of regions, programs and health care professionals.
- It will likely take a cultural shift in Canada for health care professionals to assume that offering donation is an essential part of end-of-life care.

Expert presentations provided historical information, a review of baseline knowledge, and a range of perspectives on current issues and controversies as follows.

**Ms. Kimberly Young, Director, Donation and Transplantation, Canadian Blood Services**

*Welcome and Background*

Ms. Young provided a brief overview of work by Canadian Blood Services and the former Canadian Council for Donation and Transplantation (CCDT) in collaboration with Canadian and international ODT communities in the development of OTDT leading practices. She noted the international recognition that improving consent practices increases donation, and that Canadian stakeholders (including the Deceased Donation Advisory Committee) consider this a priority for Canada as well.

**Dr. Adrian Robertson, Planning Committee Chair**

*Challenge Address*

Dr. Robertson shared his experiences and spoke to the opportunity for all involved to contribute to enhanced discussions with families about donation. He outlined the purpose of the workshop and the questions that would be addressed throughout the meeting. Dr. Robertson concluded by encouraging participants to keep in mind the improvements within reach – higher donation rates, better family satisfaction, and a reduction in people dying while waiting for a transplant.

**Mr. Marcel Pincince, Manager, Donor Family and Advocate Services, Donor Network of Arizona**

*Helping Families Make Their Best Decision in Their Worst Moment*

Mr. Pincince described his experience in supporting and holding end-of-life conversations with families of potential donors. He commented that the goal of these interactions was a meaningful conversation with families rather than a process centred on organ procurement. Mr. Pincince described the emotional state of families in crisis and some of the physiological processes that impact their decision-making abilities. He emphasized the importance of innate skills in staff engaged in these conversations as well as the training that can enhance these skills.

**Mr. Tom Mone, CEO, OneLegacy, California**

*Donor Authorization in a Community of Immigrants: A Continuing Experiment at OneLegacy in Los Angeles*

Mr. Mone provided extensive data on the demographics in the Los Angeles area and described three critical success factors that have led to 10 years of rising donation and consent rates: understanding and inspiring communities, collaborating with hospitals, and caring for families. Throughout the presentation, Mr. Mone demonstrated that demographics matter and need to be considered when engaging with families in end-of-life and donation conversations.

**Mr. Richard D. Hasz, Vice President of Clinical Services, Gift of Life Donor Program, Gift of Life Institute, Pennsylvania**

*Designing an Effective Requesting Program – The Philadelphia Experience*

Mr. Hasz provided an overview of the Gift of Life Institute's successful training program for staff engaged with families of potential donors. He stressed the importance, not only of staff training but early referrals, team huddles, trained requesters, hospital support and buy-in and family follow-up. Mr. Hasz noted that once a supportive donation culture is in place, requesters can focus on communicating effectively with families to help them make the decision that is best for them.

**Dr. Heather Traino, Assistant Professor, Department of Social & Behavioral Health, School of Medicine, Virginia Commonwealth University**

*Effective Requests for Organ Donation: The Evidence Base*

Professor Traino presented key research findings for offering the opportunity to donate: donation culture in hospitals makes donation happen; hospital staff need to be trained to support donation; the best requesters are those with specialized training. She also mentioned that while the characteristics of effective conversations in the intensive care unit (ICU) seem almost identical to the characteristics of a good request, intensive care professionals do not always translate those skills to requesting. Time, training and volume of exposure may be key factors.

**Professor Tim Caulfield, Faculty of Law and School of Public Health, University of Alberta**

*Fast Facts Legal Review*

Professor Caulfield's presentation reviewed the laws governing consent to donation. He noted that in almost every Canadian province, if an individual has consented to

donation in advance, this is considered a legally binding decision. Despite that, healthcare professionals will often treat the next of kin as the definitive authority. Complicating factors include the fact that liability rests with the living, as well as the requirement to ensure that the deceased had not changed their mind since consenting. Professor Caulfield also highlighted key differences in the authorization laws between Canada and the United States.

After presentations, participants were provided reference sheets (condensed summaries of existing evidence) and then were divided into groups where extensive discussions focused on challenge questions. Group results were presented in plenary sessions, with outputs being discussed and areas of consensus noted.

There were also two “listening posts” within the meeting – small groups of designated participants who gathered and synthesized ideas on specific areas and reported back at the end of the meeting:

- Research Listening Post: to identify areas of potential research topics in relation to effective requesting – Prof. Jennifer Chandler (Lead), Prof. Tim Caulfield, Dr. Adrian Robertson, Dr. Sam Shemie.
- Systems Implementation Listening Post: to note areas where recommendations may have implications at a system level (provincial/territorial, national, regional, etc.) – Ms. Kimberly Young (Lead), Ms. Janet Evans, Mr. Ed Ferre, Mr. Mathias Haun.

The meeting results were then taken to the Planning Committee in the form of a draft report on proposed leading practices. Further discussion and decision-making by the Committee resulted in this report.

### 3. Leading Practice Recommendations

#### 3.1 Effective Conversations with Families

##### **Recommendation 1**

Effective conversations with families of potential donors are collaborative, compassionate and supportive, providing meaningful information regarding donation and its value. This supports families in reaching an optimal and enduring decision that is also respectful of the wishes of the potential donor.

##### **Practice Guidelines**

Conversations with families of potential donors regarding organ and tissue donation can have several objectives. The goal may be to maximize donation, or it may be to support families in reaching an optimal decision for their psychological well-being. It may also be to ensure that the law is followed and that the patient's wishes regarding donation are respected. The question of the ultimate goal of offering the opportunity for donation is complicated by the fact that goals are inter-related and may overlap or conflict in some cases.

Set in a Canadian context, meeting participants agreed that an effective discussion with families:

- Is collaborative – the shared effort of a multidisciplinary health care team that is involved with the patient and the family,
- Is compassionate and supportive – in recognition of the emotional stress of the situation and a response that must be sensitive and understanding,
- Provides meaningful information on the positive value and impact of donation so that an informed decision can be made,
- Results in an optimal and enduring decision so that the family reaches a decision that would be comparable to one made if they were not in crisis – a decision that will not be regretted at a later date,
- Is respectful of the donor's wishes, recognizing that those wishes are paramount and should not be disregarded by families.

Meeting participants also agreed that the term “effective requesting” was a misnomer and that the scope of the conversations with family is broader than simply a request for consent to donation. It includes the provision of family support, information, and the opportunity for donation in a positive and sensitive manner. If this conversation is appropriate, ethical, and in alignment with leading practices, the objectives of family well-being and increased consent rates are compatible and not in conflict.

### **Summary of Relevant Evidence and Current Practice**

This section provides a condensed summary of the literature review and environmental scan provided to participants to inform workshop discussions and decision-making. The complete literature review and environmental scan are provided as an attachment to this report.

#### **Lowest Regret:**

- Most families do not regret their decisions, whether consenting or refusing donation. However, research repeatedly shows that non-donors are more likely to regret their decisions than donors (Rodrigue et al, 2008; Jacoby and Jaccard, 2010; Manzari et al, 2012).
- Whyte et al (2012) propose that highly stressed families might refuse donation even though they would have given consent in different circumstances. Therefore, requesters should “nudge” these families if the stress of the situation is preventing them from giving consent.
- Truog (2012), in a direct response to Whyte et al (2012) argues that it is dishonest and deteriorates public confidence if requesters are not “open and honest with families” about their intentions. If the goal is to maximize donation, the requester must make this clear.

#### **Maximize Donation:**

- At a 2003 consensus conference of transplant professionals held in the USA, it was concluded that the main goal of ODOs is to increase consent rates, and that ODOs should adopt a more affirmative approach to donation (Metzger et al, 2005).
- Streat (2004) argues that the presumption that there is a moral or social duty for requesters to maximize donation rates is harmful. It undermines the moral validity of family objections to donation. A requester should hold a neutral position because it ensures that the process is performed to the highest standards, and it more accurately reflects the social acceptability of donation, even if it does not produce more donors.

- Williams et al (2003) argue it is unethical for consent to be the main goal of the donation process. If it were the primary objective of the request, family needs may be overlooked and there would be an increased risk of actual or perceived conflicts of interest (e.g., between obtaining organs and providing optimal end of life care for patients).

**Legal Considerations:**

- If consent has been previously given by the donor and as long as there is nothing to indicate that the donor has withdrawn consent, was coerced into donating, or that consent is invalid for any other reason, then the consent is valid and the law does not require that consent be obtained from any other person. (Canada, CNTRP, Fast Facts Consent, 2013).
- A recent initiative in the United States has been the enactment of “first-person authorization laws,” which make it clear that the deceased’s registered consent is legally sufficient and allow donation to proceed without family consent. All 50 states and the District of Columbia in the U.S. now have “first-person authorization laws” (Siminoff et al, 2013).
  - Verble and Worth (2012) are critical of aggressive approaches (based on first-person authorization) that declare to families that organs will be taken against their wishes. They argue that it has “created anti-donation sentiment in families who feel devalued.”



## 3.2 Approaching Families Regarding the Opportunity for Donation

### **Recommendation 2**

Approach the family of every potential donor and offer the opportunity for donation. Notify the Organ Donation Organization as early as possible and before the initial donation conversation with the family.

### **Practice Guidelines**

Existing literature identifies many factors that impact donation discussions and consent, e.g., families who do not accept brain death declaration or grave prognosis, specific religions or those with specific cultural beliefs, uncertainty whether donation can be offered, or when the patient has previously documented not wanting to donate. However, while these factors should be addressed in preparations for discussion with families, they should not preclude providing the offer of donation in all circumstances.

Identifying and referring all potential donors to the designated Organ Donation Organization as early as possible is key to achieving the optimal conversation regarding donation. Referral to the ODO should take place *before* donation conversations are initiated with families. Many ODOs have defined clinical triggers which identify when potential donors should be referred. In general, these triggers relate to patients who are mechanically ventilated, and are deeply comatose after catastrophic brain injury with the intention to withdraw life-sustaining treatment which is expected to result in death.

### 3.3 Elements in the Pre-approach Team Planning Meeting

#### **Recommendation 3**

Convene a team huddle with the Organ Donation Organization donor coordinator and key members of the health care team prior to discussions with families. At a minimum, include the donor coordinator, most responsible treating physician and primary bedside nurse(s) in the team huddle.

#### **Practice Guidelines**

There are a number of health care professionals who may be involved in end-of-life care, including the ICU attending physician, ICU trainee, ICU nursing staff, psychologist, donor coordinator, donation physician specialist, family doctor, faith representation, cultural representation, social worker and others. Members of the multidisciplinary health care team who have been involved with patient care and the family should be involved in the planning of donation discussions.

Conducting a team huddle prior to discussions with family is effective in shaping an approach that meets the family's needs. Health care team members can provide valuable information to inform discussions. The team huddle supports communication among the team members and helps to clarify facts and roles for the ensuing family donation conversations.

At a minimum, include the following people in the team huddle:

- Donor coordinator,
- Primary bedside nurse(s),
- Most responsible treating physician.

Consider involving the nurse-in-charge and physician trainee. If social workers and spiritual care representatives are already involved in family care, include them as well. Depending on the situation and where appropriate, cultural representatives, family physician, and respiratory therapist may also participate in the team huddle.

#### **Recommendation 4**

To ensure a well-planned approach, include the following topics in the team huddle discussions:

- Review information about the patient, including medical status, eligibility and prior donor registration/expressed intent to donate, if available,
- Identify family members and related issues or conflicts that may impact decision-making,
- Determine when and where the initial conversation will take place,
- Determine who will lead the initial conversation with the family, who else will be in the room and what their roles will be.

#### **Practice Guidelines**

##### **Patient Medical Status and Eligibility:**

- Based on the patient's condition, the timing of the family conversation may need to occur sooner than expected or may necessitate a discussion on suitability for DCD or NDD.

##### **Prior Registration of Intent-to-Donate:**

- As part of the discussion, inform families whether the patient has previously registered his/her consent for donation. If he/she has, and unless there are objections, the conversations with the family can focus on discussing how the patient's wishes for donation will be carried out.

##### **Family Considerations:**

- There may be many family members wanting to be involved in the decisions around end-of-life care. It is important to understand not only who can provide legal consent but who are the family decision-makers or influencers. Each patient and family has their own unique set of circumstances, personality, faith and culture. Respecting this and personalizing the discussion to the needs of each family can be done while ensuring standard elements are addressed as required.
- There may not always be agreement among family members on end-of-life care for their loved one. It is important to be aware of potential conflicts and disagreements and to discuss how this will be handled.

### Appropriate Timing:

- Families who feel pressured and rushed toward a decision are less likely to consent to donation. The feeling of pressure may be conveyed in many ways, including through the pace and tone used by the health care professional talking to the family, and is not necessarily linked to the amount of time given to reach a decision.
- It may be helpful to stage the discussion into smaller discussions, i.e., “chunking”, taking into account what the family is able to absorb and decide at a given time.
- There is evidence that daytime discussions are preferable to discussions at night when fatigue may be worse. Practically, an optimal approach time depends on a number of factors including family availability, patient medical stability, death declaration time, staff availability and unit logistics.
- Hold discussions with families in a private, comfortable and quiet location, close to the patient but not in the same room. Choose a room that is large enough to accommodate all family members participating in the conversation. As conversations may occur over an extended period, ensure that family members are comfortable, with no pressure to leave and with amenities such as a phone, water, and food.

## Summary of Relevant Evidence and Current Practice

### What To Discuss in the Team Huddle:

- Marks et al (2006) explain that in the United States, the family approach has developed into a shared responsibility of ODO staff, hospital staff and clergy. The group meets in a “team huddle” to share information and determine the strategy that best meets the needs of the family and is most likely to encourage consent.
- Frutos et al (2002) recommend careful preparation for each particular family donation discussion, with attention to the quality of information available from ICU doctors, the presence of the main family decision makers, and the use of requesters who are prepared in interview techniques.
- TGLN (Ontario) and NHS (UK) recommend that a multidisciplinary health care team, along with an OPO coordinator (TGLN) or nurse specialized in organ donation (NHS), establish a strategy from the beginning, taking into consideration when brain death testing will be complete, the patient’s donor registration status, as well as family dynamics and available support. The strategy should outline when the family will be introduced to the team and who will lead the donation discussion.
- LifeChoice (US) advocates a staff “huddle” to establish a collaborative plan, which will vary depending on the state of the potential donor. The staff answer the question,

“Who are our customers, what are their needs, and how can we conduct an approach that is sensitive to their needs?”

- The ONT (Spain) guidelines indicate that the family interview should be planned as much as possible, including obtaining information on the family, determining if cultural “cooperators and/or translators” are needed, planning the site for the interview, and determining how death will be communicated.

**Prior Registration of Intent-to-Donate:**

- Dodd-McCue et al (2006) examined 569 surveys from donor families collected between 1999 and 2004 from one U.S. OPO (response rate 22%). They found that 75% of the families found the information that their loved one was a designated donor was helpful, with some expressing relief that the decision had been made for them. However, 7% found the donor designation was both helpful and stressful, and 3% found it neither helpful nor stressful.
  - Christmas et al (2008) also examined the effect of asking families to honor the decedent’s wishes rather than asking them for permission to donate. They looked at consent rates for one U.S. OPO in a 15-month period 2006-2007, with the switch in approach occurring in about the middle of the period. They found that before the change, 20/24 (83%) of the families of registered donors consented and 23/42 (55%) of the families of unregistered donors consented, while after the change of approach 19/19 (100%) of families of registered donors consented and 23/52 (44%) of families of unregistered donors consented. The authors note that some OPOs continue to struggle with how to implement first-person authorization laws, and suggest that their modification may be a useful way to facilitate familial adherence to the decedent’s wishes and to give them comfort as they honour those wishes.
- If a patient’s intent-to-donate wishes are known, TGLN, Legacy of Life, and NHS recommend that the ODO coordinator provide this information to the family, and state that he or she is going to work closely with the health care team to honour the donor’s wishes. The NHS warns professionals to avoid any suggestion that the family needs to give permission, and to simply describe what is needed of the family in order to respect the deceased’s wishes.
- Australasian Transplant Coordinators Association (ATCA) adopts the approach of asking the family whether they know if the potential donor has registered. The donor coordinator only checks the registry if the family does not know the registration status. ATCA states that where the deceased has expressed a prior wish to donate, the

conversation with the next of kin “is a formality acknowledging that, in these circumstances the person’s last wish can be carried out.” Nevertheless, ATCA states that although every effort is made to carry out the deceased’s prior wishes, the family’s sincere objection should be respected.

#### **Who Can Represent the Family:**

- Canadian law allows consent for post mortem donation to be given by:
  - the person’s spouse, any one of the person’s adult children,
  - either one of the person’s parents, any one of the person’s brothers or sisters,
  - any other of the person’s adult next of kin,
  - the person lawfully in possession of the body (e.g. executor of the will or administrator of the estate) with the exception of persons such as a funeral director or the administrative head of the hospital.
- No province allows consent to be given by anyone if there is any reason to believe the donor would not have consented on their own behalf.
- No province allows minors (or those below the age specified in the legislation) to consent to organ donation.
- Frutos et al (2002) recommend the presence of the main family decision makers. Rather than beginning with those immediately involved and present, requesters should wait for the presence of members considered by the family to be the main decision-makers. In their sample, they found the principal decision maker was lacking in only 5.4% of consenting families, but was absent in 28.1% of refusing families, and 15.7% of undecided families.

#### **Special Considerations Based on Faith/Culture:**

- One suggestion to address the lower rates of consent amongst minority ethnicities has been to match the ethnicity of requester and family.
  - Baughn et al (2010) studied 33 simulated donation interviews between OPO coordinators and actors portraying potential donor families. They found some evidence for the “matching effect.”
  - Traino and Siminoff (2013) found that within a large sample (N=1087) of families who had been approached regarding donation of a relative’s organs, only 9% agreed with the statement: “I would be more comfortable discussing donation with someone of my own race or ethnic background.” The percentage was similar for consenting families and refusing families (10.4% vs. 10.7%), and lower for families of designated donors (4.0%).

- Ashkenazi and Klein (2012) warn against devising a pre-approach strategy based solely on the demographic profile of the family, and suggest that religious and cultural factors should be used in an enlightened manner to prepare for the meeting with the family and produce more effective and meaningful interactions.
- AHS (Alberta) also recommends considering the cultural and religious needs of the patient's family and determining whether there is a need for an interpreter.

**Location:**

- Jacoby et al (2005) conducted focus group interviews with 11 family members. Privacy during the donation discussion was nearly universally considered critically important. Many families found the locations in which they had their discussions to be unsuitable. Complaints about lack of privacy were also raised in other studies (Stouder et al, 2009).
- Several literature reviews mention the need for a private, calm location for families to discuss donation. West and Burr (2002) propose that quiet, private, and comfortable settings are more likely to generate consent. Aldridge and Guy (2008) suggest that neither the bedside of the deceased loved one nor a public waiting area is suitable for a donation request. Instead, a separate, quiet area with privacy and separation from the hospital environment is required.
- Ebadat et al (2014) found that independent predictors of consent to donation included female OPO representative, discussion initiated by OPO representative, and longer conversations with families. The independent predictor of declined donation was the use of a translator. They also found consent rate was dependent on time of day the approach occurred: 6:00 am to noon (56%), noon to 6:00 pm (67%), 6:00 pm to midnight (68%), and midnight to 6:00 am (45%)
- TGLN, Transplant Quebec, and ATCA each advise that donation discussions take place in a quiet, private setting. ONT (Spain) suggests that the location should have resources to meet the family's basic needs (water, some food, telephone, handkerchiefs etc.)
- ONT also suggests that requests not be made at night, as families are usually better rested and more receptive during the day.

### **Recommendation 5**

Communicate the determination of death or grave prognosis to the family in a conversation that is prior to and separate from conversations about donation.

- In the case of neurological determination of death (NDD), ensure that the family has a clear understanding of neurological death and has accepted the death before discussing donation.
- In the case of donation after circulatory death (DCD), hold the donation discussion after the consensual decision to withdraw life-sustaining therapies has been made.
- In the case of DCD, where donation conversations are conducted prior to death, it is essential to avoid perceived or real conflicts of interest. This can be achieved by having conversations led by personnel who are separate from the treating team responsible for withdrawal of life sustaining therapies and palliation. When this is not possible (due to logistics or other reasons) identify and be transparent about the roles and responsibilities of health care team members.

### **Practice Guidelines**

A standard approach in donation is decoupling, i.e., offering the opportunity to donate takes place separately from (and after) the declaration of death. While evidence is inconsistent, this approach appears to help in avoiding perceptions that physicians have given up on patients prematurely or that physicians have a conflict of interest. It also gives families time to adjust to the shock of the death before considering donation.

#### Neurological Determination of Death (NDD):

- In the case of NDD, offer the opportunity to donate separate from and after the declaration of death, unless there is a compelling reason (e.g., clinical complication) not to do so.
- Ensure that families understand and accept the fact of death. Address potential confusion and misunderstanding about brain death, taking the necessary time required with the family. It is important to ensure that families are saying 'no to donation' rather than 'no to my loved one dying'.



#### Donation after Circulatory Death (DCD):

- In the case of DCD, the donation discussion will necessarily occur before death, but it must not occur until a decision to withdraw life sustaining therapies has been made.
- In order to avoid any perceived or real conflict of interest, in Canada there is required separation between those involved in the declaration of death and those involved in donation and transplantation. At question is whether health care providers involved in the patient's care should be the ones who lead the discussions on donation. The potential for conflict of interest is less of a concern for NDD where the donation discussion occurs after death has been determined. However, for DCD, where donation discussions are conducted prior to death, to avoid perceived or real conflict of interest, donation discussions should be led by personnel separate from the treating team responsible for withdrawal of life sustaining therapies and palliation.

#### Summary of Relevant Evidence and Current Practice

- Decoupling avoids perceptions that physicians have given up on patients prematurely or that physicians have a conflict of interest. It also gives families time to adjust to the shock of the death before considering donation. (Marks et al, 2006; West and Burr, 2002).
- Helms et al (2004) report that a move toward a decoupled approach in which an OPO coordinator requests donation and the treating physician is not involved led to higher consent rates. They speculate that this is because it avoids perceived conflict of interest.
- Some evidence suggests that donation rates may not be significantly different as a function of whether donation is raised before or after the notification of death. In fact, several studies failed to find a significant improvement in consent rates with decoupling (Martinez et al, 2001; Exley et al, 2002; Rodrigue et al, 2006; Rodrigue et al, 2008a; Siminoff et al, 2001b; Siminoff et al, 2002).
- ONT (Spain), TGLN (Ontario), Transplant Quebec, Legacy of Life (Nova Scotia), NHS (UK), and ATCA (Australasia) all explicitly recommend a decoupled approach, with separate conversations for notification of death and the donation discussion.
  - NHS, TGLN, Transplant Quebec acknowledge that conversations may take place earlier if the family initiates discussion regarding organ donation.
  - ATCA suggests that when a family raises the donation issue first, a health care professional should acknowledge them and make it clear that this will be discussed at a more appropriate time.

- There is evidence that families who are dissatisfied with the timing of the request are less likely to donate (Marks et al, 2006). Rodrigue et al (2006) found that families who thought the timing was appropriate consented 68.4% of the time, while families who thought the timing was poor consented 17.9% of the time.
- Some studies report on families who were offended or suffered greater anxiety when the request was made before the declaration of brain death (Haddow et al, 2004; Moraes and Massarollo, 2008). Bogan (2000) suggests that requesters should not request donation until they have determined that the family understands and accepts that the patient is dead. Aldridge and Guy (2008) argue that it is unnecessarily traumatic and unethical to raise donation prior to the declaration of death.
- Siminoff et al (2013) suggest that OPO personnel should approach families early as this allows them the time needed to establish relationships with families and to then judge the best moment to broach the topic of donation.
- Families who are surprised by the request are less likely to donate (Rodriguez-Villar et al, 2012; Siminoff et al, 2001b; Siminoff et al, 2010). It appears to be more effective if the subject of organ donation is introduced sometime before a request is made to the family. Kesselring et al (2007) found that when the request was anticipated, it was felt to be more acceptable than when it was unexpected. Perhaps forewarning may serve to reduce the surprise and give the families some time to prepare themselves for the discussion (Bellali and Papadatou, 2007). The value of forewarning seems to extend to telephone calls for tissue donation as well (Long-Sutehall et al, 2012; Siminoff et al, 2010).
- The time between admission to hospital and brain death testing may also influence donation rates. Vane et al (2001) examined a series of 33 pediatric trauma cases in the United States between 1993 and 1999. The time between admission and initiation of brain death testing was higher in consenting cases (mean 15.5 hours) than in non-consenting cases (mean 7.0 hours). The authors speculate that delay allows parents time to deal with the shock, accept the death, and consider the benefits of donating organs.
- Several guidelines differentiate brain death from cardiac death in their explanations of best practices for timing. TGLN and Legacy of Life advise that in order to be satisfied that a decision maker understands a loved one is brain dead, he or she must have been notified of the death, as well as provided with a time of death to signal finality. For cardiac death, the donation discussion should occur only after the decision maker has decided to withdraw life support. However, the discussion must occur before life support is actually withdrawn.

**Families Who Do Not Accept Brain Death:**

- Smudla et al (2012) studied 29 Hungarian families who had consented to donation. They found that 41.4% of the families remained uncertain that the brain death diagnosis was reliable. Families with less confidence in the brain death diagnosis had more intense grief reactions, and more serious depressive symptoms.
- Manzari et al (2012) noted that some of the consenting families who did not understand brain death suffered uncertainty, guilt and shame for possibly having given up too early or allowed harm to their loved ones.

### 3.4 Information Provided to the Family

#### **Recommendation 6**

Provide the family with sufficient information, in clear and comprehensible language, to make an informed decision:

- Be transparent about roles and responsibilities,
- Describe the value of donation,
- Review the patient's registry information or donation intentions, if available,
- Describe the process, medical/clinical considerations, and probability of donation,
- Describe any impact on funeral arrangements.

#### **Practice Guidelines**

Provide information in clear and comprehensible language - avoid complex medical or technical terms when communicating with families.

As part of the discussion, inform families whether the patient has previously registered his/her consent for donation. If he/she has, and unless there are objections, focus the discussions on how the patient's wishes for donation will be carried out. In cases where the patient's wishes were not previously expressed, it may be helpful to discuss the values and beliefs of the patient. For example, families sometimes refer to the fact that the loved one would have wanted to donate because he/she was a caring person committed to helping others.

Provide information about the benefits of donation and how it helps donor families and recipients. Benefits include honouring the patient's wishes, honouring the patient's life, helping the recipient who receives the transplant and providing some comfort in an otherwise senseless situation. Numerical facts such as donation rates, transplant rates, consent rates, deaths on waiting lists etc. may appear cold or coercive. Emphasize the value of donation in non-numerical terms and more specifically, focus on the rare opportunity to save a life.

Explain the following to the family:

- Donation process: medical-social assessment, testing requirements, logistics (movement of patient/body), timelines, impact on funeral arrangements,
- That donation incurs no financial cost to the family,

- Any additional donation-specific treatments, such as pre-mortem interventions in DCD
- That the donation process may not always result in transplantation for a number of reasons:
  - The patient may not meet testing and assessment criteria,
  - For DCD, the patient may not die within the required time period,
  - Organs may not be viable.

### **Summary of Relevant Evidence and Current Practice**

- According to Jacoby et al's (2005) focus group interviews, families want prompt, accurate, in-depth and consistent information about their loved one's condition. Providing families with factual and procedural information (including frequent medical updates) functions as a form of emotional support.
- Blok (2005) found the clarity and sensitivity of the death declaration and explanation to be important to the overall satisfaction of his sample of Dutch consenting families. He also suggests that satisfaction may also be due to more information, honesty and clarity in the time before the death as relatives who have been kept well informed are better prepared for the bad news.
- Anker and Feeley (2010) found that a common barrier to consent expressed by 64% of the 102 organ procurement coordinators in their sample was families' lack of understanding of brain death, and the fact that families may think that their brain dead loved one may still recover or is in some way still alive.
  - Jacoby and Jaccard (2010) interviewed 199 U.S. families finding that donors were more likely than non-donors to find information about brain death understandable (79.2% vs. 57.8%).
  - Rodrigue et al (2006) found that families' understanding of brain death was significantly associated with consent (71% of those with adequate understanding consented, but only 29% of those with inadequate understanding consented). Note that this factor was not retained in the multivariate analysis, suggesting that understanding of brain death may not be as significant in the decision-making model as other variables.

### 3.5 Communicating Information to Families

#### **Recommendation 7**

When communicating with the family, demonstrate sensitive, compassionate and caring behaviour with a focus on family well-being.

- Use a confident and positive approach, rather than a guarded or apologetic approach.
- Do not use aggressive or coercive language, or strategies that polarize families.

#### **Practice Guidelines**

Families considering donation are in a vulnerable and emotional crisis state during which decision-making can be difficult. As a result, problems with decision-making, attention span, concentrating and remembering information are common. The attitude, manner and language used by health care professionals involved have been shown to have a significant impact on how families experience and react to the opportunity for donation.

#### Empathy:

- Sensitive, compassionate and caring behaviour (with both family and patient) is conducive to family satisfaction, absence of later regret, and to consent for donation. This includes following the principles of effective communication in crisis situations, i.e., appropriate eye contact and modulation of tone. Avoid impersonal or casual behaviour.

#### Perception of Organ Procurement Focus:

- When families perceive medical staff and donor coordinators to be focused primarily on obtaining organs rather than on care for their loved one and on the families' well-being, they may lose trust and become less inclined to donate. Furthermore, there is evidence that when healthcare personnel are perceived to be procurement focused, the risk of psychological harm to families increases.

#### Confident Approach:

- A confident approach is associated with higher family consent, while nervous, guarded or apologetic approaches tend to reduce consent. Those who indicate they are legally required to ask for donation also tend to have lower consent rates. Avoid saying things like ““Sorry I have to ask you about this...” or “I have to do this by law...”

- While various aggressive communication strategies may increase consent rates, there are ethical concerns about this behaviour as they may raise the risk of harm to families. Unacceptable strategies include the use of guilt, shame, deception, manipulation, and omission of truth.

#### Attitudes to Donation:

- The attitudes of health care professionals towards donation also influence the consent rates achieved. Positive attitudes are associated with higher consent rates than neutral or negative attitudes.

### **Summary of Relevant Evidence and Current Practice**

- Several articles report associations between (i) families' perceptions that healthcare providers and donation requesters are empathetic, sensitive, compassionate or caring and (ii) increased rates of donation (Rodrigue et al, 2003; Rodrigue et al, 2006; Siminoff et al, 2001b; Shih et al, 2001a; Siminoff et al, 2010; Rodrigue et al, 2008a).
- Jacoby et al (2005) found that donors and non-donors alike wanted their loved one to be treated compassionately, and with dignity and respect. Nearly all wanted the health care team to speak of the patient as if he/she were alive and conscious, as a mark of respect for the person.
- Apologetic approaches, or approaches in which requesters say that they are legally required to ask, tend to reduce willingness to consent (Siminoff et al, 2001a; Siminoff et al, 2001b).
- Nervous, anxious or guarded approaches, as well as neutral or ambivalent approaches reduce consent rates (Sanner et al, 2007). Where healthcare personnel reported a general lack of confidence in the willingness of families to donate, their requests were more likely to evoke a response of indecision from families (Siminoff et al, 2001a), and the average level of comfort in asking families reported by healthcare personnel is higher in the group of consenting families than refusing families (Siminoff et al, 2002).
- Siminoff et al (2001a) speculate that the self-confidence of requesters in their ability to obtain consent may affect their approach, with less confident requesters taking a more apologetic or tentative approach and more confident requesters transmitting a more positive attitude in non-verbal ways.
- Weathersbee and Maynard (2009) conducted a conversation analysis of recorded tissue donation requests. Their study suggests that tissue telephone requesters adopt a cautious approach that may suggest to families that the call is thought to be an

unwelcome imposition, and that donation is thought to be a non-preferred action. They also point out that solicitations are often introduced tacitly in terms that may invite a negative response (“had you ever discussed donation with the deceased?”).

- Joule et al (2010) varied the script of telephone requests for cornea donation in a study in France to determine the effects on consent rates. They found that consent rates increased if an offer of assistance with funeral arrangements was made before asking for donation (a strategy they refer to as an appeal to the norm of reciprocity) and the requester also first established credibility through stating credentials. Another effective technique was to inform families that a series of simple questions usually enables families to determine what the deceased would have wanted.
- Siminoff et al (2011) studied 1016 recorded requests for tissue donation in the U.S. to study the frequency of various persuasive communications strategies, and to assess their effectiveness. They found that the most common persuasive tactics were the “credibility strategy” (opening the discussion by establishing credibility and suggesting the family wanted or expected to be contacted about donation) (49.3%), referring to the altruistic nature of donation (26.6%), arguing for donation using factual information (10.6%) or refuting incorrect information (10.5%), the “foot-in-the-door tactic” (asking for a specific type of tissue or tissue for a specific use following a much larger request) (8.5%), evoking feelings of guilt (5.9%), evoking feelings of positive self- esteem (1.7%). Certain persuasive tactics were significantly associated with consent (the “foot-in-the-door” strategy, and to a lesser extent, appeals to credibility of the requester and altruism).
- The “Organ Donation Breakthrough Collaborative” (an American national quality improvement effort), encouraged aggressive pursuit of donation opportunities, “including re-approaching refusing families.” (Siminoff et al, 2013).
  - Rady et al (2010) are concerned that the Organ Donation Breakthrough Collaborative’s primary goal to increase donation rates has created changes that risk interference with end of life care decisions for critically ill patients or their families in ways that may not be beneficial to them.
- Zink and Wertlieb (2006) advocate for a “presumptive approach” where requesters play a strong donation advocacy role and make use of persuasive techniques, such as avoiding questions that may elicit negative responses.
  - Siminoff et al (2011) also analyze persuasive strategies in the context of tissue donation. They address the ethical component of persuasion, and note that it includes using emotion and appeals to reason, and need not be manipulative,



referring to Beauchamp and Childress' renowned biomedical ethics text. They also note that persuasive tactics may backfire if used incorrectly.

- NHS (UK) states that the language regarding donation should, at all times, be positive, emphasizing the potential benefits for recipients, their families and society in general. Known benefits to donor families in the long term should be mentioned, and “the use of negative or apologetic language – such as “I’m sorry to bring this up, but...” or “you understand that it is hospital policy that we always ask...” should always be avoided.”
- TGLN states that the goal is ensure that families are given adequate time, support, and information to make an informed decision. The ODO coordinator is trained to have a positive attitude about donation and to never assume that a family will not donate.
- Legacy of Life adopts a “dual-advocacy approach”, which considers both the need of the potential donor and his or her family and also the potential recipient. The requester respects the family’s right to make an informed decision and shows empathy and interest in the deceased. He or she also advocates for donation, explaining the opportunity to save lives and the need.
- Transplant Quebec focuses on honouring the deceased’s wishes, or what they would wish for if they had a choice. The person offering the opportunity to donate is trained to ask the decision maker to imagine “If your (brother, wife, son) could speak right now, knowing what we know, would he/she be in favour of organ donation?”
- NHS takes a somewhat similar approach to Transplant Quebec, i.e., if the decision maker is unable to determine what the deceased would want, the requester asks open-ended questions about the personality of the deceased to help the family member make a decision. These questions are general, such as whether the deceased liked to help others.
- LifeChoice is committed to being a “family first” organization, meaning that those offering donation are encouraged to consider support for the potential donor’s family as the top priority. LifeChoice teaches requesters the presumptive approach, dual advocacy, and the family-centered approach, but does not mandate the use of any particular approach.

### **Recommendation 8**

Explore family reluctance to donate by sensitively discussing reasons, addressing medical, religious or cultural misinformation or misconceptions, and dispelling myths.

- In cases of initial refusal, it is acceptable to re-ask 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 (pre-mentions) that have provided incorrect information.

### **Practice Guidelines**

Not all families or family members are receptive to donation. In this situation, encourage families to elaborate on their reasons for reluctance. To the extent they are based on misinformation, it may be possible to address them. However, not all negative beliefs are likely to be easily dispelled (such as those related to mistrust).

Obstacles or reasons for refusal include:

- The hope for recovery and difficulty in accepting brain death,
- Reluctance to modify or desecrate the body,
- Concern that donation will damage the relationship between the deceased and the family,
- Concern that donation will interfere with reincarnation, resurrection or the afterlife
- Desire to protect the loved one from further suffering and indignity,
- Concern that the funeral will be delayed or the patient will be unable to have an open casket,
- Cost of donation,
- Mistrust of the medical system,
- Mistrust of organ allocation system, i.e., it is unfair, favours the rich,
- A belief that donation goes against what the patient would have wanted,
- A belief that doctors will make less effort to save the life of a donor, or death will be hastened to obtain organs,
- Belief that the patient is ineligible to donate.

Minority ethnicity is associated with reduced family consent rates. This may be related to the degree of inclusion, trust or solidarity felt with the broader society. In addition, minority

ethnicities may have distinct cultural or religious traditions that are poorly understood within a medical system that reflects the majority culture. The positions of major religious traditions on organ donation are complex, and sub-groups within a major tradition may be reluctant to donate for various reasons. As a result, typical statements such as “all the major world religions approve of donation” may be correct but still fail to capture a complex range of religion-based obstacles to donation.

There have been attempts in the US to address this situation by matching the ethnicity of requester and family. Evidence from U.S. studies indicates that this may affect a small proportion of families. Others suggest that the best way to engage these groups is to identify, engage and inspire community, cultural, religious, and ethnic group leaders as part of ongoing public awareness and education.

In some cases there may be conflict and disagreement within the family in terms of end-of-life care and/or donation decisions. This can be a difficult situation to deal with and requires training in conflict management and negotiation. If there is a disagreement about donation, it may be useful to identify key people and decision makers and enlist their assistance in coming to a decision. If available, the registered consent decision may help for proceeding with the legal next of kin. Communicating that all should work towards fulfilling the wishes of the patient may also help. Each case is individual and may require additional support from social work or spiritual advisors.

## **Summary of Relevant Evidence and Current Practice**

### **Religious and Cultural Beliefs:**

- Several review articles outline possible religious convictions contributing to reluctance to donate. In particular, within several traditions one can find:
  - Discomfort with or rejection of the concept of brain death (Judaism, Islam, Buddhism,)
  - Reluctance to desecrate or modify the body by removing organs in some cases because it is considered to be a gift or trust from God or ancestors (Confucianism, Judaism , Islam),
  - Concern that donation will injure the relationship between the decedent and the bereaved (Shinto, Confucianism),
  - Concern that donation will interfere with reincarnation, resurrection or the afterlife (Buddhism, Judaism, Hinduism, Taoism),

- Concern that donation will interfere with religious practices such as funerary rites and the requirement for prompt burial (Judaism, Islam, Hinduism, Buddhism, Christianity).
- Randhawa (2012) notes that it is not clear “whether the families have an informed view of their faith’s position regarding organ donation based upon extensive debate and thought with their faith mentor, or whether they are expressing an intuitive view based upon their personal interpretation.”
- In Lesoeurs et al’s (2009) study of obstacles to donation by migrant families in France, their perception was that religion was often invoked to justify refusals, something that coordinators felt was “a practical cover for [a family’s] inability to decide or to disguise their personal opposition.”
- In the United States, Anker and Feeley (2010) found that half of the OPOs interviewed noted difficulties with donation related to ethnicity and religion, with families stating that their racial, religious or cultural group does not support donation. Families were unwilling to accept OPC assurances that there is general religious and cultural support for donation.
- In Israel, Ashkenazi and Klein (2012) found religion to be the most significant predictor of the decision to donate. Donation rates were 68% for Christians, 56% for Jews and 22% for Muslims. However, the authors note studies that suggest that it is religiousness rather than the religious affiliation that affects willingness to donate. They cite Ashkenazi’s 2010 PhD dissertation on parental consent to donation for a deceased child in a sample 216 Israeli parents, which found that a higher degree of religiousness reduced willingness to donate.
- Singh et al’s (2004) study of North Indian families found that both religious traditions and the joint family system in India discourage donation. The authors observe that religion is a very important factor in the Indian context, where beliefs in rebirth and release from rebirth as well as concern not to disrupt traditional religious funeral rites may dissuade people from donating. Furthermore, the joint family system is important, and it is difficult to obtain timely consent in the large group.
- Tandon et al (2004) also studied family consent in India in the context of eye donation at a forensic medical facility. In this study, only 5 of the 76 refusing families cited religious beliefs and the desire not to interfere with rebirth and reincarnation. Many refusing families (n=42) refused to discuss the issue stating the request was inappropriate at the time of family crisis.

**Reasons for Refusal:**

- Donation will delay the funeral (Verble et al, 2002; Rodrigue et al, 2003),
- The donor will be unable to have an open casket (Verble et al, 2002),
- Donation will be costly for the family (Verble et al, 2002; Anker and Feeley, 2010),
- Mistrust of the medical system (Morais et al, 2012; Siminoff et al, 2007),
  - Non-White American families show higher levels of medical mistrust than White families (Siminoff et al, 2003; Siminoff and Mercer, 2001c),
- Doctors will try less hard to save the life of a donor, or death will be hastened to obtain organs (Anker and Feeley, 2010),
- The allocation of organs is unfair, e.g., it favours the rich and famous (Siminoff and Mercer, 2001c; Anker and Feeley, 2010),
- Belief that the decedent is ineligible to donate (Siminoff et al, 2007; Rodrigue et al, 2003),
- Protection of the loved one from further suffering (Moraes and Massarollo, 2008; Bellali and Papadatou, 2007; Anker and Feeley, 2010; Siminoff et al, 2007; Kesselring et al, 2007; Rodrigue et al, 2003),
- Protection of the loved one from indignity or use as a “spare parts repository” (Kesselring et al, 2007),
- The desire to maintain bodily integrity, or to avoid mutilation or disfigurement (Bellali and Papadatou, 2007; Rodriguez-Villar et al, 2012; Morais et al, 2012; Verble et al, 2002; Anker and Feeley, 2010; Siminoff et al, 2007; Rodrigue et al, 2003),
- The hope for recovery (Moraes and Massarollo, 2008; Morais et al, 2012),
- Difficulty in accepting brain death in a patient who still looks alive,
- Fear that consenting to donation will constitute killing the patient or denying him or her a possible recovery (Bellali and Papadatou, 2007),
- Squeamishness (Siminoff et al, 2010).

### 3.6 Legal Standing on Family Override of Patient Consent

Family override of patient consent/intent to donate remains a challenging issue but of unclear quantitative impact. There was no recommendation on this issue.

Occasionally, families refuse donation where the deceased has made an explicit and legal declaration to donate (e.g. through a registry).

- Some argue that, in this situation, the dominant consideration is to give effect to the deceased's wishes, which also coincide with societal interests in increasing donation rates.
- Others point out countervailing concerns that the removal of organs against the wishes of grieving families will cause undue suffering to the family and also may risk a public backlash against the organ procurement system.
- Another issue is that "informed consent" is needed for any interventions that take place before death (in the context of DCD). Prior donation registration is unlikely to constitute "informed consent" to pre-mortem interventions and some families may refuse consent for them despite the patient's wish to donate.
- Finally, the deceased may have withdrawn consent, or expressed doubts or concerns to the family that call the earlier consent into question.

Meeting participants heard from experts on the laws related to consent-to-treatment (before death) and consent to donation (after death) legislation in Canada as follows:

- The decision to donate is governed by tissue gift acts and provides authorization to proceed with retrieval of the organs.
- The term "informed consent" is used in the context of interventions with living patients, and is required under consent-to-treatment legislation. This informed consent standard is not required for post mortem donation under tissue gift acts, which provide that authorization rather than "informed consent" is sufficient to proceed with retrieval of the organs. (There are distinct considerations in DCD, where informed consent may be required for any pre-mortem donor interventions.)

Despite this binding authorization, health care professionals still turn to next-of-kin as the authority, generally due to respect for the family and fear of consequences, media attention or litigation. It was suggested that clarity on the binding nature of this authorization warrants further investigation. It may be helpful to provide legal clarity on several points for health care professionals, e.g. the donor's prior authorization is sufficient to proceed with donation despite

family disinclination to donate, but that evidence provided by the family of a retraction of consent by the donor would need to be respected.

### **Summary of Relevant Evidence and Current Practice**

- If consent has been previously given by the donor – and as long as there is nothing to indicate that the donor has withdrawn consent, was coerced into donating, or that consent is invalid for any other reason – then the consent is valid and the law does not require that consent be obtained from any other person. (CNTRP, Fast Facts Consent, 2013).
- A recent initiative in the United States has been the enactment of “first-person authorization laws,” which make it clear that the deceased’s registered consent is legally sufficient and allows donation to proceed without family consent. All 50 states and the District of Columbia in the U.S. now have “first-person authorization laws” (Siminoff et al, 2013).

### 3.7 Supporting Families During and After Donation

#### **Recommendation 9**

Support the family during and after donation discussions, regardless of whether they consent to donation.

- Provide a dedicated, trained health care organ donation professional who focuses on family support throughout and after the process for the duration of the family's stay at the hospital.
- Provide post-donation grief support/follow-up services and donor recognition.

#### **Practice Guidelines**

Families in the ICU experience a great deal of stress and anxiety. Stressful aspects include fear of losing a loved one, feeling lost or unsupported, confirmation of a brain death, adjusting to loss, and shock or surprise in being asked to donate. Many factors have been identified that can mitigate a family's stress:

- Support of family and friends,
- Being able to spend time with the patient,
- Receiving information and emotional support,
- Having adequate time to understand the patient's condition,
- Preparation to hear the organ donation request,
- Displays of empathy,
- Quality of communication and care.

Donor coordinators/health care providers can support a family during donation discussions by:

- Addressing whatever is most important to the family in that moment, even if it is not directly related to donation,
- Showing compassion, listening actively, advocating for the family,
- Giving them as much time as is possible to make a decision,
- Sharing information and bridging the gaps between the family and the clinical care team – families greatly appreciate ongoing, timely, and consistent information about the patient's status and prognosis.

After the decision has been made for or against donation, continue with empathetic attention both as a matter of good care to ensure family well-being, and also to avoid leaving the



impression that families matter only for the purpose of organ procurement. There is also a need for follow-up communication with families, who may be left with unanswered questions about the death and the donation. Many families also express a need for psychological support and counselling in the early phases of bereavement, and this may be advisable for both refusing and donating families in order to avoid the psychological risks of decision regret. Many families wish to know about the transplantation outcome, although news of an unsuccessful outcome may be very disappointing to them.

To address the requirements of the family, some organizations in the US are introducing a “companion” role. This is a trained health care organ donation professional who focuses on family support throughout and after the process. For post- donation support, most ODOs have programs for post-donation family support and recognition. These programs vary according to jurisdiction but may include: grief support, condolence cards, letters from the recipient families, annual follow-up, memory boxes, a spiritual ceremony, referral for counselling and donor recognition services.

### **Summary of Relevant Evidence and Current Practice**

- After families decide against donation, they often feel neglected and hurried away without a chance to finish saying goodbye (Aldridge & Guy (2008)). Similarly, in a Greek study it was noted that many parents felt unsupported and without guidance after consenting to organ donation. These parents were left with questions for some time after the death, and desired follow-up communications from health professionals (Bellali et al (2007)).
- Many families need psychological support both at the time of death and in the early stages of bereavement (Bellali et al (2007); Thomas et al (2009)).
- Rodrigue et al (2008a) argue that there is a need for follow-up care in order to minimize the risk of decision regret. Where follow-up care is offered, it appears to be welcomed (Wilson et al (2006)).
- Kesselring et al (2007) note that some families who remained and witnessed donor preparation procedures were troubled by the disturbances to the body and second guessed their decision. However, some family members returned after the donation and were relieved to finally say goodbye (which they had found difficult while the patient was ventilated.)

- Studies show that most families would like to receive information about the transplant outcome, and if the transplant was successful, many families wish to contact the recipient. However, according to Bellali et al. (2007), news of an unsuccessful transplantation can be deeply upsetting to the family of the donor.
- Many guidelines refer to follow-up communications, such as expressing thanks and notifying families of transplant outcomes. ATCA (Australasia) notes that in Australia and New Zealand, families who are approached about donating are offered support, including a bereavement aftercare program. TLGN (Ontario) describes a donor aftercare program.

### 3.8 Skills and Individual Characteristics Essential to Donation Discussions

#### **Recommendation 10**

The following skills and traits are essential in leading donation conversations with families:

- A good communicator, listener, and facilitator with high emotional and cultural intelligence,
- Open, honest, collaborative, and patient,
- Self-aware, non-judgemental,
- Comfortable in dealing with families in crisis,
- Trained and experienced in dealing with conflict,
- Compassionate,
- Passionate and knowledgeable about organ donation,
- Confident in their ability to be successful,
- Able to work well with a variety of personalities.

Provide structured, formal training and competency assessment for individuals leading donation conversations, regardless of background, profession or specialty.

#### **Practice Guidelines**

There is considerable debate on who should approach families, and more specifically whether the offer should be made by a member of the healthcare team, by a dedicated organ donation expert or in partnership. There is considerable variation in approach among countries and organizations. Evidence varies on whether consent rates are higher when healthcare personnel request donation versus when organ donation coordinator personnel do so.

It appears that the job title is less critical than the personality, training and skills of the person leading the discussion. This individual requires both a particular type of personality as well as training in a number of different areas, including conflict resolution and working with people in crisis. Regardless of whether the individual is with the ODO or the hospital, the collaborative involvement of the health care team and ODO donor coordinator in all cases should be routine and established during the pre-approach team huddle.

While some of the required personality traits are innate, others are amenable to training, which appears to positively affect the knowledge, confidence and self-efficacy and donation-related

attitudes of those offering donation. Training should include theoretical and practical content as well as experiential learning opportunities such as role playing and feedback.

The system should evolve to a model where only trained and competent personnel lead donation discussions. The development of a certification program would add credibility in the health care world and with the public.

### **Summary of Relevant Evidence and Current Practice**

#### **Personality Characteristics:**

- Several articles report an association between families' perception that healthcare providers and donation requesters are empathetic, sensitive, compassionate or caring and increased rates of donation (Rodrigue et al, 2003; Rodrigue et al, 2006; Siminoff et al, 2001b; Shih et al, 2001a; Siminoff et al, 2010; Rodrigue et al, 2008a).
- Jacoby et al (2005) found that donors and non-donors alike wanted their loved one to be treated compassionately, and with dignity and respect. Nearly all wanted the health care team to speak of the patient as if he/she were alive and conscious, as a mark of respect for the person.

#### **Training:**

- Siminoff et al (2013) note that OPOs which have actively developed sophisticated training and communication practices have had notable success in obtaining consent to donation (i.e. Gift of Life Donor Program in Pennsylvania and University of Wisconsin Hospital and Clinics).
- Maloney and Altmaier (2003) examined self-efficacy amongst donation requesters, finding that there was an increase in procedural self-efficacy (ability to handle the procedural aspects associated with the donation request process) and affective self-efficacy (ability to handle emotional aspects of the donation request process) after a designated requester workshop involving seven 4-hour guided sessions organized by an ODO.
- Jansen et al (2011) have found that "trained donation practitioners" are more effective at obtaining consent than unspecialized hospital staff and hospital 'hostesses'. The trained donation practitioners obtained a 57.6% consent rate, while the control hospitals only obtained 34.6% and 39.4% respectively.
- Siminoff et al (2009) examined the effects of an educational program for organ procurement coordinators, which covered relational and affective communication

techniques using a day-long interactive workshop and a series of simulated donation scenarios with feedback. The consent rates increased from 46.3% to 55.5% after the intervention.

### **Recommendation 11**

Build a strong and trusting relationship between the Organ Donation Organization and the donation hospital and establish an effective donation environment in the hospital:

- Create a culture of organ donation within the hospital - donation should be viewed as an integral part of quality end-of-life care, where not providing the option to donate is considered a medical error,
- Engage emergency departments as well as intensive care units,
- Make early referral the norm,
- Provide health care professionals with continuing education,
- Ensure evidence-based policies for donation exist at the hospital.

### **Practice Guidelines**

Multiple studies suggest that a family's satisfaction with the care received by their loved one is associated with increased consent. The whole context of care provided to the patient and to the family throughout their hospital encounter affects family perception and willingness to donate. As a result, the trust built with the health care team through caring and competent medical treatment, as well as the sensitivity and compassion shown to the patient and the family are important in inclining families to consent.

Create a climate of continuous quality improvement in which ODOs and hospital staff work together to develop and maintain strong, positive hospital-ODO relationships. Hospital leadership should visibly support organ donation and related activities and integrate donation into the hospital culture. Hospital staff should demonstrate positive attitudes to donation and be familiar with donation procedures, including how to identify potential donors, and when and how to contact the ODO.

### **Summary of Relevant Evidence and Current Practice**

- In addition to the quality of the care provided to the patient, families also reacted positively to the degree of compassion and respect shown their loved one (Jacoby and Jaccard, 2010; Rodrigue et al, 2008a). Haddow (2004) emphasizes the importance of the family's trust in the healthcare team, as this will reassure them that their loved one will be treated with respect and dignity, and also helps them to overcome

discomfort related to the lack of a traditional and recognizable “death moment” (cardio-respiratory failure) in brain-dead patients. Vane et al (2001) examined a series of 33 pediatric trauma cases in the U.S. (1993-1999) finding that the level of involvement of the attending surgeon in the care of the child affected consent rates (85% where the surgeon was involved and 23% when they were not). Involvement was deduced from surgeon and/or nursing notes on the patient charts.

- Families are also more inclined to donate when they feel that the family has been well-treated by health care personnel. Anker and Feeley (2010) interviewed 102 organ procurement coordinators recruited from 16 US OPOs to explore their perceptions of barriers to family consent. A quarter of OPCs reported that problems in the relationship between hospital staff and potential donor families could impair future relations between the OPC and families.
- Cleiren and Van Zoelen (2012) found an association between psychological disturbances (depression, complicated bereavement) and moderate or severe dissatisfaction with the hospital’s care for the family, in the small group of donating families who expressed discontent.
- Others may also be affected by their perceptions of how bereaved families are treated. The demonstration of continuing empathetic care for refusing families may also reassure others about the humanity of the organ procurement system. Shih et al (2001a) report one interesting story of a father who donated in part because of witnessing the handling of another bereaved family who happened to be present at the same time. The father referred to the caring and respectful treatment of the deceased boy and the humane approach by the medical staff with the boy’s father who initially consented but then changed his mind and refused donation.

### 3.9 Metrics to Measure Effective Donation Conversations

#### **Recommendation 12**

Use the consent rate (the percentage of number of consents over the number of family approaches) as a metric for measuring the effectiveness of donation discussions with families.

- Recognizing the limitations of the consent rate as a measure of family satisfaction and well-being, a survey index should be developed to assess the impact of support provided to the family.

#### **Practice Guidelines**

Measures provide a mechanism for monitoring progress within an organization. Standardized measures are also useful in comparative studies across organizations, to determine which strategies are most effective and should be adopted more broadly. Consent rate is a measure that is currently being used by most ODOs. It is relatively easy to determine and makes a useful standard for comparative studies.

There are a number of potential measures of the effectiveness of the donation conversation with families. These include:

- Proportion of families approached who agreed to donation ( $\#consents/\#approached$ ),
- Proportion of families approached who agreed to donation in response to a trained vs. untrained health care professional,
- Proportion of families who over-ride the patient's wishes regarding donation,
- Proportion of families who, 6 – 12 months later, regret the donation decision they made,
- Donor rate per million,
- Donor rate per million adjusted by age and cause-specific mortality.

Given that the goal of an effective discussion is also to support families and enable an enduring decision, it is recommended that a measure be developed to rate family satisfaction, both at the time of donation and at a later date, while recognizing that this may be difficult data to collect.



## 4. Research Agenda

The following ideas were generated during the workshop as potential research activities that would further knowledge and address information gaps in this area.

1. *Framing of the request – effects on requester*
  - How does the framing of the request affect the requester? Does it significantly change their comfort with the process or their behaviour if the request is called a “request” for consent to donation or an “offer” of an opportunity to donate?
  - Is there a better way to capture the pros and cons of using the “request” versus the “offer” frame for interacting with families?
  
2. *How do we measure family well-being and satisfaction?*
  - Performance metrics focus on consent rates. These are easier to measure than family satisfaction and well-being. Yet, performance metrics have a habit of changing the practice to match the metrics. To balance consent rate metrics, should there be a measure of family well-being and satisfaction?
  - Should this be inferred from the presence or absence of later regret, or the stability and enduring quality of the decision, or should this capture family satisfaction closer to the time of the decision? Would this be practical to measure?
  
3. *What is the value-add for certain types of investment in the organ donation system in Canada? Should there be focused public outreach campaigns for certain groups?*
  - It was suggested that public outreach is relatively less effective in increasing donation than hospital development or improving donation discussions with families.
  - Does this hold true in Canada?
  - Does this hold true for certain types of communities in Canada rather than for others? Is a targeted form of public outreach in certain communities, such as the Aboriginal community, worthwhile?
  - What messages should be communicated in those communities, e.g. higher need for organs in some communities, HLA matching?

4. *In which Canadian jurisdictions would it be worthwhile to adopt an approach of matching demographic characteristics of requester and family?*
  - Would the matching approach be worthwhile in Canada? If so, in which jurisdictions should it be used? This may depend upon the size of the demographic group in the jurisdiction. In addition, the benefit of a matching approach may vary by particular demographic group.
  - Should some regions analyze their urban residential distribution demographically as was done in Southern California to help support this?
  - What demographic and social characteristics should be explored – culture, religion, language, race/ethnicity, socioeconomic, education?
  
5. *Should Canada move to a more aggressive first person authorization approach, and what legislative changes (if any) would be needed for this?*
  - Does the current legislative set-up already allow for first person authorization (no family override permitted)?
  - How do requesters find out if there is any reason to suspect that the decedent changed his/her mind without asking the family?
  - Is it necessary to proactively inquire whether the registration represents the unchanged intent of the decedent?
  
6. *Can we treat registration to donate as authorization of DCD as well as NDD?*
  - Does the public know enough about what is involved in DCD (or even NDD) to treat registration as valid?
  - What is the public messaging around the details of pre-mortem intervention for DCD (or perhaps NDD) to ensure that registration is sufficiently informed to not be vulnerable to challenge?
  
7. *Should Canadian legislation adopt the term “authorization” in organ donation legislation rather than consent?*
  - Would this help to clarify the distinction between permission in the organ donation context and the “informed consent” to treatment in the context of a living person who may run risks to health?
  - What other effects would this shift in language have from the psychological or legal perspective?

8. *What grounds are sufficient to override a prior registered wish to donate (i.e. when are advance directives appropriately disregarded or overridden)?*
  - What level of change in circumstances (calling into question applicability of the initial consent) or level of evidence of change in decedent's wishes is enough to set aside the prior registered wish?
  - Is it enough for a family to assert their belief the decedent changed his/her mind, or do they need to provide the basis for this?
  - Does any of this matter – will practitioners err on the side of disregarding the prior registered wish in the face of family opposition? Should they?
  
9. *Does the public really overwhelmingly support donation when it applies to themselves and their families rather than as a remote hypothetical possibility? Why is the public support not reflected in the donation rate?*
  - One of the justifications for saying we should increase organ donation is that the public is overwhelmingly in support (as shown by surveys etc.). However, these surveys ask people about a remote hypothetical possibility – does this really translate to their real feelings? Furthermore, what is the impact of social desirability bias in their responses?
  - Another justification for saying we should increase organ donation is that consent rates in the “highest consent rate” jurisdictions approximate the high approvals shown in surveys, and there is not significant evidence that there are traumatized families in those jurisdictions – therefore the high public approval rates are real. Is this true? To what extent are these jurisdictions reflective of certain demographic populations that might not be generalizable to others?

## 5. System Initiatives

The following were generated during the workshop as areas with potential system impacts, at national, provincial/territorial, or regional levels and that warrant further investigation and consideration.

### Training:

- Identification of skills and knowledge that can be taught to improve donation conversations (e.g. neuroscience, behavioural science, communication skills, etc.),
- Development of training programs and tools ,
- Methods for evaluation of competence,
- Staff development planning,
- Exploration and evaluation of multiple approaches to donation conversations with families, i.e., donor coordinators, intensivists, hybrid approach,
- Measurement of consent rates and trends,
- Measurement of family experience and satisfaction during and after donation.

### Hospital Culture:

- Methods to increase hospital buy-in and partnership in donation process,
- Incorporate donation as part of quality end-of-life care,
- Increased training and awareness for hospital staff,
- Missed donation opportunities should be seen as a medical error.

### Public Awareness:

- Development of tools to address cultural perceptions and perceived barriers to donation,
- Demographic mapping – identification of ethnic populations and leaders within those communities,
- Improvement in registries and websites.

### Resourcing:

- With the lower population density and fewer resources in Canada, how can we develop an approach that accomplishes the same outcomes as seen in the US?

## 6. In Conclusion

In participants' feedback about this process, they mentioned their appreciation for the "thought provoking perspectives," the "respectful and focused conversations", and the opportunity to contribute to national leading practice guidelines designed to enhance donation conversations with families.

When asked at the end of the workshop how they would take action individually and organizationally, participants made commitments to a wide range of follow-up activities such as being an advocate for organ and tissue donation; debriefing cases with greater care; enabling increased collaboration with colleagues; exploring new ways to offer the opportunity for donation; paying greater attention to language; and increasing training and development for those engaged in conversations with families.

The evidence supporting this process clearly indicates that it is possible to strengthen family care and support, while simultaneously improving consent rates. As the co-chairs of this initiative, we look forward to our ongoing collaboration with Canada's donation community in further enhancing how the opportunity to donate is offered to all Canadians. We recommend that provincial ODOs, national organizations and other stakeholders develop working groups to share experience, knowledge, educational opportunities, and successes across the country.

Dr. Adrian Robertson and Dr. Sam Shemie

## Appendix A: List of Participants

### Planning Committee:

Dr. Adrian Robertson (Chair)	Intensivist/Ethicist Assistant Professor, University of Manitoba Medical Director, Intermediate Intensive Care HSC Medical Director, Total Parenteral Nutrition Service HSC Medical Director, Manitoba Organ Donation Organization- Gift of Life Medical Director, Clinical Ethics Consult Service HSC
Dr. Sam Shemie (Co-Chair)	Professor of Pediatrics, McGill University Division of Critical Care, Montreal Children's Hospital Loeb Chair and Research Consortium in Organ and Tissue Donation, University of Ottawa Medical Advisor (Donation), Canadian Blood Services
Ms. Janice Beitel	Director, Hospital Programs, Education and Professional Practice, Trillium Gift of Life Network (ON)
Ms. Jennifer Chandler	Associate Professor, Faculty of Law, University of Ottawa
Ms. Janet Evans	Organ and Tissue Donation Resource Nurse, Cape Breton District Health Authority (NS)
Mr. Ed Ferre	Director, Program Development and External Relations, BC Transplant
Ms. Sophie Gravel	Program Manager, Deceased Donation & Transplantation, Canadian Blood Services
Mr. Mathias Haun	Director, Strategic Planning, Tissues, Canadian Blood Services
Ms. Dorothy Strachan	Process Consultant, Strachan-Tomlinson Inc.
Ms. Sylvia Torrance	Associate Director, Deceased Donation & Transplantation, Canadian Blood Services

### Speakers:

Mr. Timothy Caulfield	Professor, Canada Research Chair in Health Law & Policy Health Senior Scholar, Alberta Heritage Foundation for Medical Research Research Director, Health Law Institute
Mr. Richard Hasz	Vice President of Clinical Services for Gift of Life Donor Program Gift of Life Institute (Pennsylvania)
Mr. Tom Mone	Chief Operating Officer, OneLegacy (California)
Mr. Marcel Pincince	Manager, Donor Family and Advocate Services, Donor Network of Arizona
Ms. Heather Traino	Assistant Professor, Department of Social & Behavioral Health School of Medicine, Virginia Commonwealth University (Virginia)
Ms. Kimberly Young	Director, Donation & Transplantation, Canadian Blood Services

## Participants:

Dr. Stephen Beed	Medical Director , Critical Care Organ Donation Program, Capital District Health Authority ( NS)
Mr. Matthew Connors	Law Student, Faculty of Law, University of Ottawa
Ms. Theresa Daly	Director, Gift of Life Institute (Pennsylvania)
Dr. Saneef (Sonny) Dhanani	Chief Medical Officer, Trillium Gift of Life Network Medical Lead, Pediatric Cardiac Intensive Care Children’s Hospital of Eastern Ontario
Mr. Eugene Dufour	Bereavement and Trauma Specialist, Hospice Palliative Care Consultant, STAR Family Health Team (ON)
Ms. Christine Echegaray-Benites	Critical Care Nurse Clinician, McGill University Health Centre Co-President of the Montreal Chapter- Canadian Association of Critical Care Nurses
Ms. Mary Gatien	Director, Horizon Health Network (NB)
Father Paul Geraghty	Spiritual Leader, Professional Coordinator, The Montreal Children’s Hospital , MUHC
Ms. Julie Gratton	Renal Transplant Coordinator, Transplant Manitoba
Mr. Rob Hadley	Donor Coordinator , Hope Program, Transplant Services, Alberta Health Services
Dr. Jennifer Hancock	Associate Professor, Critical Care Medicine Assistant Program Director of Dalhousie’s Royal College Training Program in Adult Critical Care Medicine (NS)
Ms. Fjola Hart Wasekeesikaw	Executive Director, Aboriginal Nurses Association of Canada
Dr. George Isac	Clinical Assistant Professor Anesthesia Program Director, Critical Care Medicine, University of British Columbia Attending Anesthesiologist, Vancouver Coastal Health (BC)
Dr. Constantine (Dean) Karvellas	Assistant Professor of Medicine Intensivist and Hepatologist Division of Gastroenterology (Liver Unit) Division of Critical Care Medicine, University of Alberta
Ms. Denice Klavano	Patient Advocate (NS)
Dr. Andreas Kramer	Medical Lead, Southern Alberta Organ Donation Program Clinical Assistant Professor, Foothills Medical Center Departments of Critical Care Medicine & Clinical Neurosciences (AB)
Dr. Jean-François Lizé	Assistant Medical Director, Transplant Québec Director, Intensive Care, Notre Dame Hospital, Centre hospitalier de l’université de Montréal (QC)
Dr. Shavaun MacDonald	Emergency Medicine and Adult Critical Care, University of Alberta

Ms. Susan Manitowabi	Assistant Professor, School of Native Human Services, Laurentian University (ON)
Ms. Rhianna Matschke-Neufeld	Living Donor Coordinator, Saskatchewan Transplant Program
Ms. Tami Murphy	Critical Care Organ Donation Coordinator, Legacy of Life (NS)
Dr. Mary O'Brien	Adult Intensivist, Eastern Health, Organ Procurement and Exchange (NL)
Ms. Vasuki Paramalingam	Organ and Tissue Donation Coordinator, Trillium Gift of Life Network (ON)
Ms. Kim Parsons	Nurse Coordinator, NL Provincial Organ/Tissue Donor Program
Mr. Craig Schmidt	Living Donor/ Organ Donor Coordinator, Saskatchewan Transplant Program
Ms. Tina Shaver	Donor Coordinator/ Instructor , Southern Alberta Organ & Tissue Donation Program
Mr. Hugues Villeneuve	Manager, Hospital Program Development and Education, Transplant Québec
Ms. Rachel Ward	Law Student, Legal Division, Canadian Blood Services
Ms. Kim Werestiuk	Manager, GD4 /Transplant Clinic/ Adult Kidney Transplant Program Gift of Life, Transplant Manitoba
Ms. Linda Wright	Director of Bioethics and Director of Palliative Care, Assistant Professor in the Department of Surgery, Faculty of Medicine, University Health Network (ON)