



Patient engagement in a Canadian consensus forum for heart donation after circulatory determination of death

Implication des patients dans un forum de consensus canadien pour le don du cœur après un décès circulatoire

Andrew Healey, MD · Amanda van Beinum, MSc · Laura Hornby, MSc ·
Lindsay C. Wilson, MHA · Sylvain Bédard · Heather Berrigan · Diana Brodrecht ·
Clay Gillrie, MSN · Thomas Shing · Jonathan Towers · Everad Tilokee ·
Sam D. Shemie, MD

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Abstract

Purpose Heart donation and transplantation following circulatory determination of death has yet to be performed in Canada. A consensus forum was held to provide expert guidance to inform policy with a comprehensive patient partner strategy. This paper describes the process used to create fulsome patient partner engagement resulting in mutually beneficial policy development in this complex area.

Methods A wide-ranging process for involving patient partners in this area included pre-meeting education, in-meeting expert support, full participation and permission

to step back if desired, and post-meeting debriefing. Following the meeting, a questionnaire was used to guide a debrief discussion with patient partners and steering committee members who co-authored this paper.

Results Five key themes arose that echoed the sentiments and contributions made by patient partners, including: 1) a strong desire to improve the system, 2) gratitude and honour, 3) expert support and process, 4) simplification of complex concepts, and 5) mutual benefit expressed by patient partners and healthcare professionals.

Conclusion Despite the complexity of the content and the emotionally sensitive nature of discussions around deceased organ donation, a well-planned strategy to involve patient partners is important, impactful, and central to the process. This suggests a broad interprofessional audience can engage with properly

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A. Healey, MD (✉)
Division of Emergency Medicine, Department of Medicine,
McMaster University, Hamilton, ON, Canada
e-mail: ahealeymd@gmail.com

Trillium Gift of Life Network, Toronto, ON, Canada

A. van Beinum, MSc
Department of Sociology & Anthropology, Carleton University,
Ottawa, ON, Canada

Children's Hospital of Eastern Ontario Research Institute,
Ottawa, ON, Canada

L. Hornby, MSc
Children's Hospital of Eastern Ontario Research Institute,
Ottawa, ON, Canada

Canadian Blood Services, Ottawa, ON, Canada

L. C. Wilson, MHA · C. Gillrie, MSN · E. Tilokee
Canadian Blood Services, Ottawa, ON, Canada

S. Bédard
Montreal, QC, Canada

H. Berrigan · J. Towers
Halifax, NS, Canada

D. Brodrecht
Kitchener, ON, Canada

T. Shing
Hertfordshire, England, UK

S. D. Shemie, MD
Canadian Blood Services, Ottawa, ON, Canada

Critical Care, Montreal Children's Hospital, McGill University,
Montreal, QC, Canada

prepared and supported patient partners to strengthen and focus dialogue and outputs in the development of health policy in the donation and transplant sector.

Résumé

Objectif *Le don et la greffe cardiaque à la suite d'un décès circulatoire n'ont encore jamais été réalisés au Canada. Un forum de consensus a été organisé dans le but de formuler des recommandations spécifiques qui guideraient les politiques avec une stratégie globale incluant les patients partenaires. Cet article décrit le processus utilisé pour susciter une implication complète des patients partenaires, avec pour résultat la mise au point de politiques mutuellement bénéfiques dans ce domaine complexe.*

Méthode *Nous avons amorcé un vaste processus pour impliquer les patients partenaires dans ce domaine, processus qui a consisté en une formation préliminaire avant la rencontre, le soutien d'experts pendant la rencontre, la participation complète et la permission de se retirer du processus si désiré, et le débriefing après la rencontre. À la suite de la rencontre, un questionnaire a servi à orienter les discussions de débriefing avec les patients partenaires et les membres du comité directeur ayant collaboré à cet article.*

Résultats *Cinq thèmes clés sont ressortis des discussions, faisant écho aux sentiments et aux contributions des patients partenaires, soit : 1) un profond désir d'améliorer le système, 2) la gratitude et l'honneur, 3) le soutien par un processus d'experts, 4) la simplification des concepts complexes, et 5) les avantages mutuels exprimés par les patients partenaires et les professionnels de la santé.*

Conclusion *Malgré la complexité du contenu et la nature émotionnellement sensible des discussions entourant le don d'organes après décès, une stratégie bien planifiée d'implication des patients partenaires est importante, a un impact et doit être placée au centre du processus. Cela suggère qu'une vaste équipe interprofessionnelle peut s'impliquer auprès de patients partenaires bien préparés et convenablement soutenus; une telle approche permettra de renforcer et de concentrer le dialogue et les résultats lors de la mise au point de politiques de santé dans le secteur du don et de la greffe.*

Keywords patient partner · deceased donation · transplantation · heart

Controlled donation after circulatory determination of death (DCD) is responsible for the largest quantitative increase in deceased donation of all organs in Canada,¹ and has the potential to increase heart transplantation. Two

methods have been developed and used to allow recovery and transplantation of the DCD heart in the United Kingdom (UK),² one of which is also used in Australia.³ The limited international experience reported until 31 March 2019 ($n = 105$ in adults) shows good short-medium-term outcomes for both methods, though long-term outcomes remain unknown. In addition, a number of ethical concerns regarding the definition of death⁴ and the quality of DCD hearts remain regularly debated in the academic literature.²

In October 2018, Canadian Blood Services and Trillium Gift of Life Network partnered to host a consensus-building meeting for DCD heart donation and transplantation, engaging both donation and transplantation professionals to create a medical, legal, and ethical framework for Canadian practice (manuscript in preparation). It was a two-day, face-to-face meeting with a multidisciplinary group of participants. A steering committee (including five authors of this paper: A.H., L.H., L.W., C.G., and S.S.) was formed to lead this meeting.

The process of heart donation and transplantation using DCD is complex as the donor is declared dead by circulatory criteria and resumption of circulation is contemplated.⁵ Examination of the related medical, legal, and ethical issues requires a comprehensive understanding of various stakeholder perspectives. The potential impact on policy and practice requires expert opinions and perspectives of not only the medical, legal, and bioethics communities but also of the individuals most directly impacted by this process: patients and their families. Policy-makers and guideline-developers are increasingly urged by quality standards to include the perspectives of these groups when developing, implementing, and using evidence-informed health advice.^{6–8}

Recent research on the impact of patient engagement on clinical practice guideline development reports that early and continued engagement of patients partners influences guideline development, including the scope, patient-relevant topic inclusion, outcome selection, recommendation development, implementation, and dissemination.⁹ Full engagement of patient partners has positive impacts.¹⁰ Like the practice itself, stakeholder consensus-building on the topic of DCD is continuously developing. We sought with this project to measure and analyze the impact of including patient and family partners in this emergent process.

Specifically, we aim to: 1) provide a detailed description of methods used to create a patient partner strategy with full participation in the consensus-building meeting for the framework of heart donation following DCD, 2) describe how patient partners improved the consensus-building

project, and 3) share lessons learned by both researchers and partners through this process.

It is our hope that in sharing these details we can encourage others planning consensus-building activities around emergent medical practices to consider the benefits of similar engagement.

Methods

The patient engagement process used for this project was based on best practices as described by Rashid *et al.*¹¹ We take the definition of *patients* to refer to people with personal experience of a disease, condition, or service (patients, consumers, or users); their caregivers or family members; and people representing a collective group of patients or caregivers. *Engagement* refers to consultation (gathering information from patients/public through literature, surveys, or qualitative research); participation (two-way information exchange between patients/the public and other experts); or communication (tailoring information to patients/the public).¹²

Data for this project comprised the detailed notes, observations, and reflections made by the steering committee throughout the design and implementation of the patient partnership strategy, audio-recordings, and anonymous written feedback obtained during the consensus-building meeting, and post-meeting written reflections and focus group discussions with patient partners. Patient partners additionally completed a post-meeting questionnaire which was developed in consultation with patient partners from another initiative.¹³ The questionnaire contained eleven questions in total and invited reflections on general impressions (Appendix 1). All study data were made available in qualitative (textual) form and were analyzed by A.H. and A.V.B. using applied thematic coding.^{14,15} Identified themes were reviewed with the patient partners to ensure accuracy.

The William Osler Health Centre Research Ethics Board provided ethical review and approval (6 November 2018) for administration and analysis of the patient partner questionnaire. Approval for use and analysis of anonymous meeting feedback forms and audio-recordings was provided by participant waiver at the meeting.

Results

Building the patient partnership strategy

Methods used to build the patient partnership strategy for this consensus-building meeting included recruitment,

preparation, support, inclusion, and debriefing. Throughout each stage, a single point person (C.G.) maintained primary contact with patient partners.

Recruitment

Patient partners were invited to be involved in the early planning of the consensus-building meeting. A convenience sample of heart transplant recipients and family members who consented to organ or tissue donation by DCD on behalf of their loved one was identified by Canadian Blood Services, Trillium Gift of Life Network, the Canadian Donation and Transplantation Research Program, and local physicians in the UK and Nova Scotia. A member of the Steering Committee (C.G. or L.W.) initiated contact by email or telephone to explain the project and the proposed process.

Patient partners were provided with project details via email and invited to participate in an introductory teleconference (see Appendix 2). Patient partners were provided with choices regarding desired engagement, from emailed or video comments to full meeting attendance. All patient partners who were contacted opted to participate in the meeting in person. Six patient partners attended the consensus-building meeting. The group included three donor family members who had provided consent for DCD on behalf of their loved one who had died (H.B., D.B., J.T.), two heart transplant recipients (S.B., E.T.) who received their hearts from donors following death by neurologic criteria (one of whom was relisted for transplant at the time of the consensus-building process and subsequently received a second transplant), and one heart transplant recipient from the UK who received his heart from a DCD donor (T.S.).

There was a clear understanding from the outset that participation at the meeting might increase access to heart transplantation, improved opportunities for donor families, and ultimately more lives saved. For a transplant recipient supported by the medical community in their difficult journey through end-stage heart failure for over ten years:

“Participating in the meeting provided an opportunity to give back to the community that saved my life.” (E.T., heart transplant recipient, Patient and Family Partner Experience Questionnaire.)

The desire to help was the most motivating factor for patient partner participation.

Preparation prior to consensus-building meeting

Following agreement to participate, patient partners were provided with detailed information about patient partner

engagement (see Appendix 3). A videoconference was scheduled three weeks prior to the consensus meeting to review the agenda and discuss plans for patient partner participation, including as members of an expert panel. Given the sensitive nature of discussions surrounding organ donation after death, the steering committee was concerned about the emotional well-being of the patient partners. Family members who had consented to donation had recently experienced significant loss. During pre-meeting discussions, patient partners and supporting members of the steering committee acknowledged the emotions that may arise throughout discussions about dying and the process of deceased organ donation. This experience was normalized, and full support was ensured throughout. On the eve of the meeting, the patient partners were invited to dinner with a member of the steering committee (C.G.) as an opportunity to build interpersonal relationships and resolve remaining concerns or questions.

Support during consensus-building meeting

All meeting participants were reminded of the diversity of the audience and were asked to avoid colloquial language in their commentary. The two-day consensus-building meeting involved input from a multidisciplinary, sex- and geographic-balanced group of 53 participants, including patient partners, physicians, nurses, surgeons, policy-makers, organ donation and transplantation administrators, international experts, and bioethics and legal representatives. The meeting was organized as a series of plenary discussions, panels, and small-group discussion activities (see eAppendix in the Electronic Supplementary Material). A reception took place at the end of the first day.

In addition to participation in small-group and plenary discussions, patient partners contributed as panel members for a discussion entitled, “Learning from Patients and Families”, during which they described their relevant experiences with organ donation and transplantation and explained why they accepted the invitation to participate in the consensus-building meeting. The floor was then opened to questions from other meeting participants, facilitating a rich discussion.

One patient partner (E.T.), was asked to participate in the “Listening for Research” group given his research background. This group was convened to keep track of potential research ideas arising from the meeting.

At each break and at the end of the first day, a member of the steering committee with education and experience in supporting patient partners and families during emotionally challenging times (C.G.) debriefed with patient partners to offer support and further normalize responses. At the end of the second day, the patient partners were invited to

reflect on their experience at the meeting by sharing their thoughts with the larger group. All patient partners agreed that the expert support offered by the steering committee members (C.G., L.H., L.W.) was essential to ensuring their participation was effective and meaningful. As a direct result of the preparatory work and early engagement, in addition to the ongoing support offered at every juncture, the patient partners felt confident to contribute to even the most complex discussions.

After the consensus-building meeting

Following the meeting, the patient partners participated in a teleconference focus group to describe their learning and reflections, facilitated by their completion of a pre-teleconference questionnaire. In addition, one family partner (D.B.) was also a member of an “Expert Review Group” for the consensus-building meeting and is an author of the manuscript in preparation on DCD heart guidance in Canada.

Impact on consensus-building for heart donation after DCD

The perspectives shared by patient partners throughout the consensus-building meeting were powerful and contributed towards building collective consensus. Inclusion of patient partners led to discussions and interactions that benefitted all meeting participants, including: 1) inclusion of interdisciplinary perspectives, 2) simplification and clarity around complex concepts, and 3) introduction of gratitude and honour as guiding concepts.

Inclusion of interdisciplinary perspectives

Including patient partners in this meeting was part of a strategy to involve a broad range of stakeholders. Many participants felt that interdisciplinary participation and discussion contributed to the success of the meeting:

“Different viewpoints presented, family/patient especially” (Anonymous feedback #12).

“Of course, the active and courageous participation of donor families and transplant recipients enriched our discussions” (Anonymous feedback #32).

“The diversity of professionals and patient/family participants. Having such a diverse group from all stakeholders will help to cover all aspects (pros/cons) of DCD heart donation. I felt it was a well-rounded discussion for both days (including “after hours”)” (Anonymous feedback #9).

Involving patient partners in the diverse group of meeting participants, including the invitation of patient

partners to join discussions “after hours,” contributed to a consensus that is representative of the many, and sometimes conflicting, perspectives involved in heart donation after DCD.

Simplification of complex concepts

“Patients and families [bring] things back to a clear simple focus” (anonymous feedback #15).

Inclusion of patient partners improved all meeting participants’ understanding of topics related to DCD heart donation and greatly enriched the resulting discussions and recommendations. For example, one point raised during discussion was the need to prevent brain reperfusion after death when restarting the heart and circulation in the deceased donor’s body, a process required in one proposed heart donation protocol (normothermic regional perfusion). The rationale and mechanism(s) used for preventing brain reperfusion are complex, and it remains unclear how to confirm the absence of brain reperfusion.⁴ One patient partner (J.T.) was able to draw on his professional experience as an electrician, bringing forward the similarities of blood flow in vascular circuits to the current flow in electrical circuits. J.T. shared an electrician safe-work practice called “lock out tag out”, which is used during construction and maintenance to eliminate potential flow of electricity and isolate electrical hazards so work can proceed in a safe manner. The “lock out tag out” process is followed by the appropriate downstream testing to ensure 100% confidence that all potential electrical flow has been eliminated. J.T.’s analogy offered tremendous clarity to meeting participants, as they immediately aligned the “lock out tag out” principles with protecting the brain from perfusing blood supply during normothermic reperfusion.

Patient partners provided insights on important considerations related to the critical need for clarity in communication surrounding heart donation after DCD. Some clinically trained meeting participants felt that donor families should receive detailed information about the heart recovery process at the bedside, specifically the rationale and mechanism(s) for preventing brain reperfusion. Patient partners, however, felt strongly that this information would likely exceed what the average family would want to or be equipped to comprehend. Patient partners suggested that while bedside care providers must be comfortable explaining all donation-related information, they should tailor what is shared in accordance with the donor family’s preference. This was surprising to many of the other participants without lived experience.

Clarity regarding death determination would not have been possible without patient partners, who confirmed that

making the decision to donate organs signifies acceptance of a loved one’s death. Patient partners informed meeting participants that after the decision to donate has been made, families want to be able to trust the medical system to facilitate the donation and transplantation process to save as many other lives as possible.

“The exact process of how Collin’s organs were going to be retrieved was not explained in detail to me, and I did not need to know this. I trusted the team completely. I actually prayed Collin would pass away quickly after life support was removed to ensure more organs could be retrieved to help more people. I had come to terms with Collin’s death...I never once thought he might come back to me or would miraculously wake up” (D.B., donor family, Patient and Family Partner Experience Questionnaire).

The active involvement of engaged patient partners in the consensus-building meeting facilitated the generation of clarity surrounding otherwise complex and challenging concepts.

Gratitude and honour

The patient partners were consistently clear about the gratitude they felt for being asked to participate and to share their perspectives, which helped to underscore the significance of the consensus-building meeting. Patient partners felt honoured to be part of such a far-reaching healthcare system project. Donor families in particular were grateful for the impact their participation had on their healing process and the opportunity to continue the legacy of their loved ones:

“We knew that consenting to donation was the right thing to do for William and our family, but actually saying the words and making the official decision to donate is hard, regardless of your preconceived feelings on donation. Participating in this consensus forum gave us the opportunity to reflect and confirmed for us that we made the right decision. Having that validation to move forward has been essential for us in our continued journey to heal.” (H.B., donor family, Patient & Family Partner Experience Questionnaire)

“Sharing Collin’s story has helped my kids and I heal from our grief and helped us to keep Collin’s memory alive in our hearts and minds. I want to try to help others...realize that donating their loved one’s organs will help them in their grief and honour their loved one.” (D.B., donor family, Patient & Family Partner Experience Questionnaire)

Heart transplant recipients found it beneficial to meet donor families and express their gratitude. As one transplant recipient articulated,

“This unique experience was likely as close as I will come to meeting my donor family” (E.T., heart transplant recipient, Patient & Family Partner Experience Questionnaire).

One donor family commented on how powerful it was to not only interact with healthy transplant recipients but to receive their appreciation:

“Meeting the heart recipients at this meeting and having them say thank you to me for being a donor family was very emotional for me. I no longer felt the need to hear thank you from Collin’s recipients; I knew they woke up every day appreciating what they were given” (D.B., donor family, Patient & Family Partner Experience Questionnaire).

These moments of sharing between donor families and transplant recipients introduced an element of responsibility to consensus-building proceedings. As one participant included in their anonymous feedback, many felt that it was *“an honour to be involved. Refreshed my passion on the work we do,”* (anonymous feedback #15). Facilitation of difficult and emotional conversations such as donor family–transplant recipient meetings and discussions helped contribute to consensus-building.

Lessons learned from patient partnership

Patient partners agreed that their contributions at the meeting were not only important to the success of the process and critical to re-centering complex discussions regarding DCD heart donors and recipients but were also personally beneficial. Several patient partners were inspired through interactions with others during the meeting to become advocates for donation and transplantation. One patient partner (J.T.) registered his consent to donate all organs and tissues, something he had previously opted out of. Two patient partners went on to join the organ and tissue donation committee at their local hospital (J.T., H.B.), while another has continued to share her donation experience at numerous healthcare professional conferences (D.B.).

Though some patient partners attended the meeting expecting to benefit, others only realized the positive repercussions of personal connection, story sharing, and participation in system improvement during and after the meeting.

In the anonymous post-meeting evaluation, the inclusion of patient/family partners, the diversity of stakeholders and opinions, and the interactive process were most frequently

identified as high value. In fact, 19 out of 40 (48%) respondents indicated the component of the meeting they liked most was the participation and perspectives of the patient partners:

“The donors’ and recipients’ heartfelt stories—the reason why we do this” (Anonymous feedback #14).
“Involving the patient partners was critical to this type of expert guidance workshop” (Anonymous feedback #6).

The perspectives of patient partners informed the acceptable risk of moving forward with DCD heart transplantation in Canada despite limited data on outcomes. Given the uncertainties, there was a discussion about whether transplant surgeons should have the ability to refuse hearts from DCD donors without discussion with heart transplant candidates. The idea that this would occur without consulting the patient was troubling for patient partners:

“I am now 50 years old, I don’t need the best heart possible; I need a better heart than the one failing me. I just want to stay alive and see my sons realize their dreams” (S.B., heart transplant recipient in need of a second transplant, meeting notes).

One patient partner who received a DCD heart transplant explained his reason for agreeing to participate in the new program in the UK:

“If you had two tunnels, and one had a speck of light at the end of it [a DCD heart], and one was completely black [not getting a heart at all], which one would you choose?” (T.S., DCD heart transplant recipient, meeting notes).

Several transplant professionals reflected on how these comments gave them “permission” to accept less than perfect grafts or increased margin of risk when performing DCD heart transplantation.

Although meeting participants were aware that opinions and personal experiences from six patient partners were not representative of the entire donor or recipient position, the presence of interdisciplinary perspectives were instrumental in shaping an initial statement about DCD hearts in Canada. Inclusion of patient partners was found to be mutually beneficial, as patient partners obtained a meaningful channel for advocacy, and surgeons and physicians were able to reaffirm “the reason why we do this.”

Discussion

Our results show a successful collaboration with patient partners to create the medical, legal, and ethical framework for DCD heart donation and transplantation in Canada. The methods used for patient engagement allowed the fostering and sharing of mutual benefits for patient partners and for a strong consensus-building process. The presence of both donation and transplant recipient perspectives led to important discussions about what a recipient might be willing to ask of a donor family, and what a donor family might expect of a recipient. This dynamic was exceptionally powerful and led to a more complete understanding of all perspectives. Our findings suggest that a broad interprofessional audience can engage with properly prepared and supported patient partners to strengthen and focus dialogue throughout an interdisciplinary consensus-building meeting even at very early stages of policy formation.

A systematic review of involving patient partners in the planning and development of healthcare concluded that patients and families have contributed to a wide variety of such initiatives, but that the impact of participation on the quality and effectiveness of services is unknown.¹⁶ Our findings show that the engagement of patient partners led to the inclusion of interdisciplinary perspectives, simplification and clarity of complex concepts, and the introduction of gratitude and honour as guiding principles for a process that was felt to be mutually beneficial for all meeting participants. These results are consistent with the findings of a qualitative systematic review of patient partners' involvement in improvement initiatives¹⁰ and a scoping review of current practice for engaging patient partners as co-researchers in health research.¹⁷ Both studies reported that for maximum benefit of patient engagement, support and training is essential.

Studies of patient engagement in health research have identified a number of potential barriers: length of the process and training, transportation, frequency of meetings, time constraints, and a lack of specific funding for engagement purposes.¹⁸ We overcame these challenges during planning and facilitation of the consensus-building process. The time commitment required of patient partners was significant, but they were able to make an informed decision about their level of engagement. In addition, both patient partners and other meeting participants were motivated to invest time in engagement because of the personal and professional benefits.

Several authors have identified concerns that some forms of patient engagement may appear tokenistic at times and thus portray a false sense of inclusiveness, ultimately devaluing patient contributions.^{17–19} In contrast, our experience shows that patient partners were instrumental

to consensus-building discussions, providing insight and perspectives that resonated with all stakeholders. There may be an increased risk of “tokenism” if the time and effort to engage, educate, and prepare patient partners is not provided.

Similar to the experience of another Canadian initiative that included patient engagement for research in organ donation,¹⁹ grief experienced by family members of deceased donors is an additional challenge for initiatives such as ours. It is not uncommon for family members whose loved one became a deceased donor to experience enduring emotional trauma.²⁰ It is tempting for healthcare professionals to want to protect patients and families. Nevertheless, it is also clear that grief can be jointly managed with patient partners through a patient-centred process of preparation, checking-in, and following-up, as we have shown. The inclusion of not just one but three family members was also an important strategy to further support patient participation in this context.

The lack of inclusion of patient partners and healthcare professionals opposed to organ and tissue donation and transplantation is an important limitation of this initiative. In addition, we included one DCD heart recipient from a UK program but did not have a participant with experience in Australia. All meeting participants, including the patient partners, were generally considered supporters of the current donation and transplantation system, a bias acknowledged at the meeting.

Conclusions

Our analysis and report of patient partner and meeting participant experiences of a consensus-building meeting about planning for DCD heart donation and transplant in Canada shows that patient partner contributions were invaluable. With advanced preparation and both in- and post-meeting support, our process of engagement allowed patient partners to participate effectively and contribute to discussions of complex topics in the realm of organ donation and transplantation. Patient engagement in policy decision-making improves the consensus-building process by ensuring the outputs of these collaborative efforts remain focused on the patients and families they serve.

Author contributions Andrew Healey, Laura Hornby, Lindsay C. Wilson, Sylvain Bédard, Heather Berrigan, Diana Brodrecht, Clay Gilrie, Thomas Shing, Jonathan Towers, Everad Tilokee, and Sam D. Shemie contributed to all aspects of this manuscript, including study conception and design; acquisition, analysis, and interpretation of data; and drafting the article. Amanda van Beinum contributed to the study design, structural revisions to the manuscript, and analysis and interpretation of data.

Dedication This paper is dedicated to the donors represented by their families – William and Collin.

Disclosures None.

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Trillium Gift of Life Network is the Government of Ontario agency responsible for planning, promoting, coordinating and supporting OTDT across Ontario and for continually improving the system so that more lives can be saved.

Editorial responsibility This submission was handled by Dr. Hilary P. Gocott, Editor-in-Chief, *Canadian Journal of Anesthesia*.

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Appendix 1 Patient and family partner experience questionnaire

As part of the initiative: DCD Heart Donation and Transplantation: Expert Guidance from a Canadian Consensus-Building Process, we are seeking your feedback with regards to your experience as our patient or family partner. We are interested in your opinion of the process that you went through to prepare for the meeting and your experience at the meeting itself. This questionnaire contains 11 questions in total, addressing issues broadly related to your impressions of the project.

Your answers will be used to improve our process for engaging patient partners in the future and may be included

in a publication on the topic. Your participation is entirely voluntary. In fact, you will be welcomed as a co-author on the final paper.

This information will be used to gather your viewpoints in order for us to improve our methods for engaging patient partners in our work. It will also be used in preparation of the manuscript (which you will have an opportunity to edit). You have two opportunities to share your thoughts. Once you have completed this questionnaire we would like to organize a telephone interview during which you may elaborate on your written answers. The interview will take approximately 30 minutes to complete.

Questions

1. What were your main reasons for agreeing to be part of this initiative?
2. What expectations, if any, did you have about being part of initiative?
3. What are your views on the methods that were used at the 2-day meeting you attended to have participants explore the possible implementation of DCD Heart Donation and Transplantation in Canada?
4. What are your views on the training provided in the course of your engagement? Did the training you received prepare you adequately for your role as a patient or family partner for this initiative?
5. What, if anything, was done well to support you during your participation in the 2-day DCD Heart Donation and Transplantation meeting?
6. What, if anything, do you feel should be done differently to support patient partners to participate in such initiatives in the future?
7. Do you feel that you had sufficient opportunity to contribute personally to the discussions at the meeting?
8. Do you feel that the inclusion of patient partners as participants at the meeting made a difference to the outcomes of the meeting?
9. What are your overall views on the final version of the meeting report and do you feel that issues that are important to patient families are adequately reflected in it?
10. What is your overall impression of your experience as a patient or family partner for this initiative?
11. Did you feel that you personally benefitted from your participation? Please explain.
12. Additional comments:

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Appendix 2 Patient and patient family involvement: project information

Developing the medical, ethical, and legal framework for heart donation after circulatory determined death in Canada: patient and patient family project information

Background

When possible, the opportunity to donate organs after death is integrated into quality end of life care. In Canada, there are two ways that organ donation after death can occur: 1) after death that is determined by neurologic criteria; or 2) after death that is determined using circulatory criteria.

The first type of donation occurs when someone suffers an irreversible brain injury, loses all brain function and is determined dead by neurologic (brain) criteria. In this case, machines are used to maintain circulation and organ function prior to recovery. A growing number of donations are now resulting from the second method, “donation after circulatory determined death” (DCD). In this type of donation, the patient has an irreversible brain injury or terminal medical condition but does not meet stringent brain function testing to be determined dead by neurologic (brain) criteria. Following a joint decision by the family and medical team, life sustaining therapies are removed, the heart and circulation stop, and after an observational period of 5 minutes, death is determined and the organs are recovered. Because DCD includes a time period when the organs are exposed to a lack of oxygen and nutrients as the patient’s heart and circulation slow down and stop, until recently, the heart of DCD donors could not be recovered and transplanted. Nevertheless, in response to growing wait lists for heart transplantation, innovations have occurred in the techniques to recover and resuscitate the heart. These innovations have resulted in the successful recovery and transplantation of hearts following DCD, primarily in the UK and Australia. Hearts recovered from DCD donors have the potential to eliminate the heart transplant waiting list in Canada. Nevertheless, there remain many ethical, medical, and legal issues that need to be addressed prior to establishing Canadian heart DCD programs.

Planned initiative

Trillium Gift of Life (TGLN) and Canadian Blood Services (CBS) are leading an initiative to address these medical, ethical, and legal issues and develop a framework for heart donation by DCD in Canada. As part of this work, a two-day forum has been planned, whereby a multidisciplinary group of participants will explore the current procedures and transplant outcomes for donating hearts by DCD, taking into consideration whether these procedures are in alignment with current deceased donation guidelines from medical, ethical, and legal standpoints.

Patient engagement

Families of DCD donors and potential recipients of DCD hearts make up clear stakeholder groups that would be directly impacted by the addition of heart transplantation from DCD donors. The inclusion of patients, substitute decision makers, and those with lived experiences of specific medical conditions is becoming increasingly recognized as an important component in the development of the healthcare processes. Such individuals bring unique perspectives to the issues that will be discussed at the two-day forum, ensuring that the process is patient- and family-centred. CBS and TGLN will support the inclusion of both DCD donor family members and transplant recipients who are interested in participating as per the following:

Participant general description

Any substitute decision maker of a patient who donated any organs by DCD and any heart transplant recipient who received a heart by DCD or NDD. Inclusion of two people from each of these categories is preferred.

Participant characteristics

Participants must be fluent in English, articulate, and able to speak comfortably in front of groups of at least 40 people. They must be willing to read the appropriate pre-meeting materials that explain in depth the topics to be discussed and be able to review post-meeting reports for completeness and clarity from a non-scientific perspective.

Participant time commitment

Estimated time commitment is as follows:

- 2–3 x 1-hr teleconferences in July or August and September 2018
- 4–5 hrs for pre-meeting supplemental reading
- Two-day meeting, 15 and 16 October 2018 in Ottawa, ON
- 1–2 x 1-hr teleconference(s) in October or November
- 4–5 hrs for post-meeting report review

Participant reimbursement
Participants will be reimbursed for all travel and hotel expenses to attend the 2-day forum in Ottawa

Appendix 3 Patient and patient family involvement: background information

What is patient and patient family involvement? The five Ws & how

(Based on <https://www.g-i-n.net/document-store/working-groups-documents/g-i-n-public/toolkit/toolkit-2015>)

1. WHO

- People with personal experience of a disease, condition, or service
- Patients, consumers, users
- Caregivers or family members
- People representing a collective group of patients, family members, or caregivers
- Members of society
- Citizens, taxpayers, the public

2. WHAT

Many terms are used interchangeably to describe this process: involvement, engagement, partnership, etc. We will rely on three primary strategies that are based on the flow of information between the organization and the public. It is common to combine different involvement strategies to build more comprehensive patient and patient family involvement interventions.

- Consultation involves the collection of information and can include methods such as surveys, focus groups, individual interviews, online consultation, the use of primary research on patients' and patient families' needs and expectations, or the use of a systematic review of studies on patients' and the public's perspective.
- Participation is a method that involves the exchange of information between health professionals and policy-makers and patients and patient family members. This can be done through participation of patient and patient family members in guideline or policy development groups and other methods. Participation methods are useful to foster deliberation and mutual learning between participants with different expertise and involve two-way information exchange.
- Communication strategies involve tailoring the communication of information to patients, patient family members, and the public to support their individual healthcare decisions and choices. This can include the production of plain language versions of

clinical practice guidelines, policy positions, or the development of patient decision aids or education material.

3. WHEN

Best practice indicates that patient and patient family members should be involved as early as possible and this involvement should be maintained at all key stages of healthcare policy or guideline development.

4. WHERE

Best practice requires transparent and inclusive involvement of patient and patient family members as equal participants within all healthcare policy-making or guideline-development initiatives.

5. WHY

The *experiential knowledge* (of their own body, illness, life, and journey through the healthcare system) of patients and patient family members brings an essential new perspective to policy-making and guideline development initiatives. Research has shown that the inclusion of patients and patient family members results in:

- More patient-centered healthcare provision
- More democratic healthcare policy-making
- Quality improvement of both healthcare and health policy.

6. HOW

We will combine different involvement strategies to build a wide-ranging patient, patient family, and public involvement.

- Before the meeting: A survey of public opinion of DCD heart donation and transplantation has been performed and the results will be presented during the meeting. As well, patient and patient family members will be provided with background information on DCD heart donation and transplantation.
- During the meeting: Patient and patient family members will participate fully in the two-day DCD heart donation and transplantation meeting in Ottawa. They will observe and participate in discussions and will be given specific questions (see below) to consider as they participate. They will report back to plenary regarding their perspectives.
- After the meeting: Patient and patient family members will review all materials produced as a result of the meeting and provide feedback. Further involvement will be co-developed as required.

Panel discussion during the meeting

Introduce yourself

- *What is your name and where are you from?*
- *What is your health condition or the medical situation that you experienced that is related to this meeting?*
- *Why did you accept the invitation to this meeting?*

Potential questions for the panel discussion

- *In your opinion, what are the main issues related to DCD heart donation and transplantation from the scope that patients, patient families, and members of the general public consider important?*
- *Does the practice of DCD heart donation and transplantation involve treatments and care that patients and the public might consider unacceptable? Your comments could take into account, for example, what you know about the potential benefits and disadvantages of DCD heart donation and transplantation*
- *Are there specific needs of different groups of patients (for example, people from specific ethnic groups or cultures or those with specific medical conditions) that should be considered with respect to DCD heart donation and transplantation?*
- *What do you think are the primary patient and public needs for information and support specific to DCD heart donation and transplantation?*

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