

**OPTN Organ Procurement Organization (OPO) Committee
Donation after Circulatory Death (DCD) Policy Review Subcommittee
Meeting Minutes
November 25, 2019
Teleconference**

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Introduction

The Donation after Circulatory Death (DCD) Policy Review Subcommittee met via teleconference on November 25, 2019 to discuss the following agenda items:

1. Centers for Medicare and Medicaid Services (CMS) Regulation Language
2. Collaboration and Outreach Plan
3. Next Steps

The following is a summary of the Subcommittee's discussions.

1. Centers for the Medicare and Medicaid Services (CMS) Regulation Language

The Subcommittee reviewed additional resources regarding DCD and provided clarification on those topics.

Summary of discussion:

During the October 10, 2019, OPO Committee meeting, there was discussion about using the current CMS regulations as a starting point for modifications to the OPTN policies. The Subcommittee reviewed both the current CMS policy and the OPTN policy language. The Subcommittee Chair commented that both policies are similar except the CMS policy is more general and allows each OPO to develop individual protocols. The OPTN policy has more detailed requirements, which includes OPOs confirming that the legal next of kin has elected to withdraw life sustaining medical treatment before initiating donation discussions. Additionally, the timing of this would have to be coordinated with the OPO and the healthcare team.

UNOS staff provided additional information about the previous work done addressing the DCD policy. When the DCD Policy was previously changed, there were concerns voiced around the policy not having a safeguard around discussions. The language is not complicated to change, but one of the processes in developing policy is to collect evidence. The Subcommittee reviewed some of the available literature that provides some evidence:

- The American Society of Anesthesiologists published a statement in 2017 on Controlled Organ Donation after Circulatory Death. One of the recommendations included in the statement was that the decision to withdraw life-sustaining therapies "must happen prior to and independent of any discussions about DCD."
- 2012 OPTN Ethics Committee Memo – The OPTN Ethics Committee provided information to the OPO Committee in response to some of the organizations that commented on the policy proposal. The memo provided general support but also opined that families should "generally be approached" about organ donation after the evaluation and decision to withdraw support. In response to the renewed work on this project, the Ethics Committee voiced interest in the

project and have volunteered to participate in the development of this policy. The Subcommittee agreed with this.

- The National Council on Disability (NCD) developed and submitted a report to the leadership of Health Resources and Services Administration (HRSA) and the OPTN/UNOS in September 2019. One of the recommendations in the report is that the OPTN should “ensure that individuals and families are able to make informed decisions about the withdrawal of life sustaining treatment prior to and independent from any contacts from organ procurement organizations (OPOs).”

The Subcommittee Chair noted that it is clear that concerns are still prevalent and will need to be addressed when moving forward with this project.

2. Collaboration and Outreach Plan

The Subcommittee discussed outreach strategies that would help moving forward with the DCD Policy Review.

Summary of discussion:

The Subcommittee Chair asked members for their thoughts on how to garner support from the community on this project. A member stated that Donor Advisory Committees might be able to provide a valuable perspective on this issue. It is believed that this community would be willing to provide some examples of what families have experienced.

Another member stated that from an OPO standpoint, this would be a good idea. There are many instances when a donor family is not approached soon enough and then come back later stating if they had known about the DCD option, they would have considered it. The member continued that there could be some outreach to groups where families share their stories and perspective of the process.

A member asked if there were any historical data to demonstrate whether a patient would have been a candidate for DCD donation if not for the timing of the conversation with the family. The Subcommittee Chair stated that OPOs most likely track this information differently. She also noted that there is some sensitivity about making this data public due to the subject matter. A member noted that OPOs continually work on hospital development plans to help their teams understand how important and helpful this particular communication is with families.

A member asked if there is a way to make a recommendation to the upcoming Collaborative Improvement Initiative addressing DCD transplants. UNOS staff noted that this effort is currently on hold until potential collaborative efforts based on the Executive Order on Advancing American Kidney Health¹ has been identified.

The Subcommittee Chair asked if there were certain organizations and advocacy groups that the Subcommittee could contact as part of this effort. Another member asked what the sentiment might be from the palliative care groups on a proposed change to the policy. The member replied that it is believed there would be support for this change. For hospital systems that have palliative care, it would be beneficial for those systems to utilize their palliative care team to have donation discussions with the families. The Subcommittee Chair asked if there were any concerns about reaching out to these organizations. UNOS staff stated that there should not be concerns and that it would be helpful to get additional information and perspectives from these groups. The Subcommittee Chair stated getting a statement from these groups is not an effort to change practice, but instead to gain their support for moving forward with changes to improve end of life care. UNOS staff asked the HRSA representatives if,

¹ <https://www.whitehouse.gov/presidential-actions/executive-order-advancing-american-kidney-health/>

the approach to reach out to organizations was acceptable. A HRSA Representative stated that outreach to all of these organizations would be acceptable.

Another member stated that there might be a few families willing to share their stories and advocate these efforts. A member suggested performing outreach to critical care societies and volunteered to ask their critical care representative within their organization on their perspective.

The Subcommittee discussed the possibility of developing a survey to send to OPOs in order to get additional information about their processes. The Subcommittee Chair asked if there was any value in sending out a survey. UNOS Research staff stated that it would be a good opportunity to quantify how big an issue this is among OPOs and noted that it can be done in a confidential manner.

UNOS Staff asked if there were any initial thoughts on survey questions. The Subcommittee Chair stated that there should be high-level questions such as:

- Does the current language impeded your ability to increase donation in your OPO?
- What is the biggest barrier?
- What do you think is the overall impact from a volume perspective?

The Subcommittee Chair commented that if data from a survey would have more weight than simply hearing from several members of the community about the current policy language, then the survey should be done. UNOS research staff stated that a survey could be helpful in determining the extent of the problem. Subcommittee members were asked to think about what they would like to get out of the survey. The next Subcommittee call would be around the development and questions of the survey.

3. Next Steps

- The Subcommittee members will identify potential collaborating organizations. Once the list is compiled, the Subcommittee will then discuss an outreach plan.
- The Subcommittee will provide an outline of the goal of collecting data from a survey and provide possible questions to include in the survey.

Upcoming Meeting

- TBD