

OPTN Organ Procurement Organization (OPO) Committee Donation after Circulatory Death (DCD) Policy Review Subcommittee Meeting Minutes August 26, 2019 Teleconference

Julie Kemink, RN, MBA, BA, Subcommittee Chair

Introduction

The Donation after Circulatory Death (DCD) Policy Review Subcommittee met via teleconference on August 26, 2019 to discuss the following agenda items:

- 1. Introductions
- 2. Background
- 3. Previous Review
- 4. Next Steps

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

1. Introductions

UNOS staff welcomed subcommittee members and began the discussion by providing an overview of the subcommittee's previous work and next steps in moving forward with the Donation after Circulatory Death (DCD) Policy Review project.

2. Background

UNOS staff began by providing the subcommittee background information of the DCD Policy Review project.

Summary of discussion:

About a year and a half ago, OPO Committee Leadership received an email from a member who raised concern about *OPTN Policy 2.16: Requirements for Controlled Donation after Circulatory Death (DCD) Protocols* and requested that the OPO Committee review the policy. The focus of the policy review is the language addressing the timing of the initiation of DCD donation discussions.

A subcommittee was developed and an initial review of the policy was conducted. The project was set to be reviewed by the Policy Oversight Committee (POC), but the project was then put on hold due to allocation policy changes to eliminate the use of donation service areas (DSAs) and regions.

UNOS staff reviewed a revised timeline of the project with members as follows:

- August 2019: Subcommittee regroup
- September October 2019: Policy review and discussions
- September November 2019: Revise policy language, collaboration/outreach
- December 2019: Finalize proposal
- January March 2020: Public Comment
- June 2020: Board of Directors review

There is an opportunity for the subcommittee to collaborate with not only the OPO community, but also the transplant community to help in the review of the policy. Previously, there was a lot of concern raised from various organizations in the community. There will be outreach done to ensure that whatever policy language is being proposed is favorable before the Spring 2020 public comment cycle begins. This is not a policy change that would require any programming and would be something that would be implemented not too soon after the Board meeting in June 2020.

3. Previous Review

The Subcommittee Chair led the discussion on the focus of the DCD policy review as the work resumes on the project.

Summary of discussion:

The Subcommittee Chair began by stating that the revisions to this policy will help with guide donation conversations earlier in the process which could potentially increase the availability of organs. Previously, the subcommittee made a list of groups and stakeholders the subcommittee should reach out to for input. Members were encouraged to think about additional outreach that may be needed. There was also discussion on making this policy change as uncontroversial as possible and developing language that would be sensitive to the subject matter and being accepted during the public comment cycle.

The Subcommittee Chair continued by stating that the subcommittee had previously discussed developing language addressing "discussions with the legal next-of-kin about organ donation" which may be better stated by saying "next-of-kin is making end-of-life decisions." The Chair asked members for their thoughts and discussion on this approach.

A member stated that this project is very important and that end of life decision-making, regardless of the outcome, needs to happen earlier. There is some stigma bringing donation up prior to the process, which would require some educational efforts to help with this process.

Another member asked if there should be any inclusion of determination of how this process is approached depending on whether the potential donor is on the registry. Would this dictate a better approach? The Subcommittee Chair stated that this could be part of the conversation and background information that is discussed with the community. The member continued by asking if there should be a guidance included with the policy revisions. The Chair stated that there may be some opportunity to provide some guidance.

A member stated that there are many times when the patient has an advanced directive. This provides patients who cannot speak for themselves the opportunity to have their wishes granted. Language should include that the advanced directive be used as a guideline in helping to have that conversation.

Another member stated that using a resource that can easily be referred to and provides an understanding of the DCD process would be helpful. The biggest problem is the misconception about the process. An advanced directive can help with the families but for other constituents to fully understand the process, there should be one standardized answer that could be provided.

Another member asked for more information on what concerns were voiced of the religious and other organizations on the review of the DCD policy. A member stated that these groups voiced concern that the policy would influence the decision to end life for organ donation. The member continued that the intent of organ donation is to promote life. There is a need to educate and provide the best explanation possible to help the community understand this process better.

A member stated that another component would be to speak with family representatives within the Committee to get their perspective of the process. From previous discussions, there were comments about how the conversation happened too late in the process.

A member stated that from experience and perspective, the later the conversation occurs, the harder the decision is for the families. From the donor perspective, bringing up the topic earlier gives families time to process the information and make decisions.

4. Next Steps

UNOS staff discussed next steps for the DCD Policy Review with subcommittee members.

Summary of discussion:

UNOS staff reviewed the meeting materials with the subcommittee members that included the sections of the policies and recommendations from the previous reviewers. UNOS staff suggested that the subcommittee review the policy again and provide any additional thoughts and comments for each section of the policy. Members were also encouraged to send any additional resources that could help support the proposal. UNOS staff continued by stating that the concerns voiced previously by organizations would be sent for members to review. There will be efforts to reach out to those groups to get more information on their concerns/perspectives.

Another conference call will be held in September to prepare for the OPO Committee's in-person meeting on October 10, 2019.

Next Steps:

- UNOS staff will schedule a follow up subcommittee meeting
- UNOS staff will send out meeting materials for the subcommittee to review and provide their feedback.

Upcoming Meeting

• TBD