

OPTN Ethics Committee

Meeting Summary

May 21, 2020

Conference Call

Elisa Gordon, PhD, MPH, Chair

Keren Ladin, PhD, Vice Chair

Introduction

The Committee met via Citrix GoTo teleconference on 05/21/2020 to discuss the following agenda items:

1. Article Review
2. Facilitating Patient Navigation Update
3. CAT Rewrite Project Update

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

1. Article Review

The Committee discussed *The Morally Complex Mix of Euthanasia and Organ Donation* from the Scientific American Journal.

Summary of discussion:

One member commented that this topic may require guidance in the future but that presently US laws would need to change in order to allow doctor assisted euthanasia and gave an example of an ALS patient in Wisconsin. Another member commented on the challenge in separating the intent to end life and organ donation. The member noted that there is nuance to these cases and that an ALS patient on perpetual ventilation could request surgeons take all their organs and then allow the patient to die on the operating room as opposed to a scenario where the patient donates as much as possible before returning to the intensive care unit. Another member noted that they had seen three similar cases, one which did include an ALS patient and the scenario is not unlikely. Another member noted the current ethics of organ procurement would not allow for intentional death by organ procurement. Members also commented that if the patient doesn't want to live any longer and requests withdrawal of support than it could be considered a DCD.

Next steps:

Committee leadership will discuss the topic further and the potential for a project.

2. Facilitating Patient Navigation Update

The Committee discussed the current status of the workgroup and the next steps.

Data summary:

The Committee began the discussion by reviewing the results of a survey regarding the details of the project. 63% of the Committee responded. The most popular options for deliverable number one were a guidance document or a white paper. The most popular options for deliverable number two were a video or a webpage.

Summary of discussion:

A member of UNOS staff explained the difference between a guidance document, white paper and educational materials while providing a few examples. The member of staff explained that it is important for the Committee to justify the form of deliverable within the context of the purpose of the project and the charge of the Committee. A member of the committee commented that it is important to have a clear rationale when considering approval from the Policy Oversight Committee (POC). A couple of members of the committee agreed that a strong rationale is needed and expressed support for a guidance document in lieu of a white paper for deliverable number one. Another member spoke in support of pursuing a white paper. Another member wondered if the committee needed some hybrid approach. A member of UNOS staff noted that completing an outline may help clarify the preferable deliverable format. A member commented that the committee must address the problem before they can come up with the solution.

Another member asked how this project would differ from the CMS guidelines that transplant centers must follow. A member shared that the workgroup chair had a great explanation of the purpose and goals of the project.

Next steps:

The workgroup will review the feedback from the full committee.

3. CAT Rewrite Project Update

The Committee discussed the current status of the subcommittee and the next steps.

Summary of discussion:

The subcommittee leader provided an overview of the recent project discussions. One member suggested replacing the individual sections focusing on vulnerable populations with a general statement recognizing potential concerns for vulnerable populations such as financial, intellectual, immigration status. Another member agreed that the subcommittee could try to define a vulnerable population rather than listing them individually. Another member noted that the term vulnerable population has already been defined in literature.

One member suggested a statement that status as a vulnerable population should not solely exclude a patient from listing. Two other members agreed that the paper should comment on the present of these vulnerabilities in the context of access to transplant and that patients may need extra support in these situations.

Upcoming Meetings

- June 18, 2020 – Full Committee Call