# OPTN Ethics Committee Multiple Listing Subcommittee Meeting Summary April 13, 2022 Conference Call

# David Bearl, MD, MA, Subcommittee Chair

### Introduction

The Multiple Listing Subcommittee met via Citrix GoToMeeting teleconference on 05/11/2022 to discuss the following agenda items:

- 1. March Meeting Recap
- 2. Outline Review and Discussion

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

### 1. March Meeting Recap

During the March meeting, the subcommittee finalized the content for the data request, which was submitted to HRSA and UNOS Research has started the analysis. The data report will tentatively be ready for the May subcommittee meeting. If there is further data the subcommittee is interested in, they can submit an additional data request. The subcommittee also decided to push back public comment in order to conduct a more robust data request. The subcommittee reviewed the revised timeline, which features the January to March 2023 public comment cycle and June 2023 Board of Directors meeting.

#### Summary of discussion:

The subcommittee Chair noted that the data from the research request will bolster the existing literature and allow the group to have a more informed ethical analysis of multiple listing. There was also an emphasis on how controversial this topic could be and wanting to do as thorough of work as possible and not rush through the project.

#### 2. Outline Review and Discussion

The Subcommittee Chair presented and discussed the draft outline. The outline is broken out into four main sections: background, ethical considerations for the individual, ethical considerations for transplant centers, and ethical considerations for the healthcare system.

## Summary of discussion:

Members discussed autonomy and beneficence as essential ethical principles for the individual. A member brought up patient activation, which considers how patients self-education and self-promote their healthcare, and how studies have found that it improves their access and outcomes. A member noted that if the opportunity to multiple list is removed, patients may push back on how they ought to be allowed to be proactive in their healthcare. A member shared their clinical experience for multiple listing and opined that the overall benefit of multiple listing for the patient is likely to vary geographically. Members highlighted the discrepancy in center practice can make it more challenging for patients to navigate the system and access multiple listing.

Members also noted that the feasibility for patients is also impacted by the severity of their illness since hospitalized patients awaiting a thoracic organ are unable to multiple list. A member responded with using living donation as an example, stating that just because kidney and liver patients are able to obtain a transplant from a living donor does not mean that it should be removed because it is not available for thoracic patients. Members agreed that it was likely an unequal benefit for the patients who were able to pursue multiple listing due to clinical characteristics, like hospitalization and sensitization. A member added that a transplant center could choose not to list a patient due to a lack of social support, which further disadvantages patients.

Members discussed the ethical implications for transplant centers, noting that programs are required to inform patients about the ability to multiple list but are not required to accept patients who multiple list. A member suggested that the inconsistency of multiple listing practices by transplant centers disadvantages the patient. Members discussed how center practices combined with geographic density can also impact the benefit for a patient, noting that if patients pursue a secondary listing at a center within 250 nautical miles that would have varied benefits and changes in the donor pool in the Northeast versus Southeast.

Members briefly discussed the ethical considerations for the healthcare system. A member suggested including dialysis centers in this section, due to the role they play in kidney transplant. A member noted that the challenges the group has been discussing today are relevant to transplant but also widespread throughout the entire healthcare system.

A member shared that one way to address this issue would be from an egalitarian perspective, where everyone ought to be equal so advantages that exist for some should be removed to make everyone equal. Alternatively, the group could look at advocating for policies that do not negatively impact those who are already disadvantaged. A member added that if the transplant system were able to allocate fairly and equitably then patients would not need to pursue multiple listing. However, due to geographic and socioeconomic disparities, patients attempt to use the tools at their disposal to correct the existing disadvantage. The Subcommittee Chair added that continuous distribution is expected to have the effect of developing a fairer and more equitable allocation system that reduces geographic imbalances. After a fruitful discussion, a member suggested the group ought to refine the focus of the paper on the impact on equity.

## Next steps:

Members identified which sections they would like to work on. Members are asked to work on draft sections for the June meeting. The May meeting will tentatively cover the research request and UNOS staff will circulate that report when it is available.

# **Upcoming Meetings**

- May 11, 2022
- June 8, 2022
- July 13, 2022

## Attendance

# • Subcommittee Members

- o Catherine Vascik
- o David Bearl
- o Keren Ladin
- o Sanjay Kulkarni
- SRTR Staff
  - o Bryn Thompson
- UNOS Staff
  - o Cole Fox
  - o Susan Tlusty