

OPTN Ethics Committee

Meeting Summary

November 18, 2021

Conference Call

Keren Ladin, PhD, Chair

Andrew Flescher, PhD, Vice Chair

Introduction

The Ethics Committee met via Citrix GoToMeeting teleconference on 11/18/2021 to discuss the following agenda items:

1. New Project: Ethical Evaluation of Multiple Listings
2. New Project: Ethical Considerations of Excluded Living Donors

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

1. New Project: Ethical Evaluation of Multiple Listings

A Committee member submitted this project during the call for project ideas. The Committee voted in favor of pursuing this project. This project would focus on the ethical principles of equity, utility, justice, transparency, and autonomy. This project aligns with Goal 2 of the OPTN Strategic Plan to increase equity in access to transplants. The OPTN Patient Affairs and Minority Affairs Committees are identified as stakeholders for this project.

Summary of discussion:

A member highlighted the potential for this project to intersect with continuous distribution, which is an OPTN policy priority, and considered how multiple listing would occur in a revised allocation framework. UNOS staff noted that while the majority of the patient's Composite Allocation Score (CAS) should remain the same, the points awarded for proximity would change when listed at multiple centers.

A member shared the concern that public or government insurances often only cover one transplant evaluation thus limiting the access for those individuals to listing at multiple centers. Meanwhile, a member expressed concern about how the Committee would handle military members who are listed through both the OPTN and the military. A member suggested that this subset of individuals receive a slight 'bonus' similar to living donors who need a transplant.

A member inquired about data related to the number of patients who are listed at multiple centers and their geographic location. UNOS staff informed the Committee that after the OPTN Policy Oversight Committee (POC) approves the project, the Committee would be able to submit formal data requests to UNOS Research. Members discussed a range of possible data questions they would like and UNOS staff kept a list of these questions for the workgroup to consider when established. Members considered ways in which the data may indicate the reason for multiple listing.

A member also highlighted that the history of multiple listing, and its origin, would be helpful for the Committee when conducting their ethical evaluation. More specifically, members are interested in the requirement that centers inform patients that they can list at multiple centers and what guidelines currently exist on this topic.

Members with patient experience added their perspective of how patients would feel about this policy. A member noted that it is important to increase access and availability for all patients instead of taking away an advantage that reduces everyone's access in order to meet a lower threshold. The Chair countered this point by highlighting concerns over gaming and the difficulty in implementing a way that would allow all patients to level up in their access. Ultimately, a member identified how the landscape of patient access has changed since multiple listings were promoted.

A member asked how one patient listing at multiple centers specifically disadvantages the patient who is only able to list at one center. A member shared research that found kidney transplant patients who were listed at multiple centers were transplanted two and a half years quicker than single listing candidates, providing them with a 42% waitlist advantage.¹

Members highlighted the issue of fairness and how to manage this financial distinction in a system that tries to treat like with like. On the other hand, the Chair asked if the issue of fairness is enough to limit an individual's autonomy. A member questioned if there is a utility benefit to multiple listings that improves the efficiency of the system for all users.

Next steps:

Committee members were encouraged to reach out to UNOS staff if they are interested in participating in this workgroup.

2. New Project: Ethical Considerations of Excluded Living Donors

This project is a combination of ideas submitted by two members, which leadership suggested combining into one project. This project would focus on the ethical principles of equity, utility, transparency, and autonomy. This project aligns with Goal 1, to increase the number of transplants, and Goal 2, to promote living donor and transplant recipient safety, of the OPTN Strategic Plan. The OPTN Living Donor Committee is identified as a stakeholder and collaborator for this project.

Summary of discussion:

Members discussed which living donor populations this paper should address. A member suggested one way to inform the population could be at the time point in which they are included or excluded, for example, if there are populations who are unable to be living donors before even undergoing a medical or psychosocial evaluation – medically healthy individuals who are excluded by their circumstance.

Members noted the tension in autonomy between potential living donors and transplant centers, highlighting the gray zone between the risks of individuals being excluded from living donation and the risk of living donation altogether. A member noted that there is individual variance amongst transplant centers regarding what characteristics they use to exclude living donors outside of the stated contraindications.² A member noted that these variations are even more exacerbated in other countries.

A member suggested three potential approaches to this project:

1. Address the topic broadly to consider risk and center practice for potential living donors in general

¹ Mary A. Decoteau et al., "The Advantage of Multiple Listing Continues in the Kidney Allocation System Era," *Transplant Proceedings* 53, no. 2 (2021): 569-580, <https://doi.org/10.1016/j.transproceed.2020.10.036>.

² More information about living donor exclusion criteria can be found in Policy 14.4.E *Living Donor Exclusion Criteria*, https://optn.transplant.hrsa.gov/media/eavh5bf3/optn_policies.pdf.

2. Focus specifically on categories that are categorically excluded such as inmates
3. Analyze conceptual frameworks that justify risk in living donation

The Chair highlighted the necessity to decide if these categories of living donors overlap enough to be thoroughly considered in a single project or if the Committee should dismantle this into multiple projects.

Next steps:

Committee members were encouraged to reach out to UNOS staff if they are interested in participating in this workgroup.

Upcoming Meetings

- December 16, 2021
- January 20, 2022
- February 17, 2022
- March 17, 2022
- April 21, 2022
- May 19, 2022
- June 16, 2022

Attendance

- **Committee Members**
 - Aaron Wightman
 - Amy Friedman
 - Andrew Flescher
 - Carrie Thiessen
 - Colleen Reed
 - David Bearl
 - Earnest Davis
 - Ehab Saad
 - George Bayliss
 - Glenn Cohen
 - Keren Ladin
 - Lynsey Biondi
 - Melissa Anderson
 - Sanjay Kulkarni
 - Tania Lyons
- **HRSA Representatives**
 - Jim Bowman
 - Marilyn Levi
- **SRTR Staff**
 - Bryn Thompson
- **UNOS Staff**
 - Cole Fox
 - Kristina Hogan
 - Laura Schmitt
 - Lindsay Larkin
 - Meghan McDermott
 - Susan Tlusty