

OPTN Ethics Committee

Meeting Summary

June 16, 2022

Conference Call

Keren Ladin, PhD, Chair

Andy Flescher, PhD, Vice Chair

Introduction

The Ethics Committee met via Citrix GoToMeeting teleconference on 06/16/2022 to discuss the following agenda items:

1. Committee Updates
2. Discussion and vote on *Transparency in Program Selection* white paper
3. Update on Multiple Listing Project
4. Update on Normothermic Regional Perfusion Project
5. Farewell to Members Rolling Off

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

1. Committee Updates

The OPTN Board of Directors and Committees call for nominations for 2023-2024 is now open. Members are encouraged to update their Volunteer Interest forms and share the Call for Nominations with peers involved in transplant. All new and returning committee members were reminded to complete their education modules in UNOS connect and sign the conflict of interest and confidentiality agreement. Lastly, members will receive emails from Southeastern Institute of Research about completing an anonymous member survey.

2. Discussion and vote on *Transparency in Program Selection* white paper

The Committee reviewed the background, progress, and brief changes made from the Committee's feedback. Members were asked if they had any opposition to sending the white paper, *Transparency in Program Selection*, to the Policy Oversight Committee (POC) to proceed for public comment. No members were in opposition. Members were asked if there were any abstentions from voting. No members abstained from voting. Members were asked if they support sending the white paper, *Transparency in Program Selection*, to the Policy Oversight Committee to proceed for public comment. The Committee unanimously voted in support with 14 votes.

Next steps:

The POC will review the public comment slate during their July meeting and recommend the Executive Committee approve it for public comment. Public comment will occur from August 3rd to September 28th. The workgroup, and subsequently full Committee, will review the public comment feedback and vote on the final version of the white paper. The Board of Directors will review the white paper for approval during their December 5th meeting.

3. Update on Multiple Listing Project

This project is conducting an ethical analysis on multiple listing and the implications of the practice. The Committee received the results from their data request during their May meeting and is planning on submitting another data request to develop a more granular understanding of the impact of multiple listing.

Summary of discussion:

A member inquired about the unexpected demographics depicted in the data request. The Chair clarified that the disparities the report showed were somewhat different from what the members expected. The subcommittee expected there to be larger racial disparities, but the primary racial disparity was for Hispanic and Latino patients in areas with high Latino populations. Multiple listed patients, across all organ types, tended to have private insurance and advanced education, which did not surprise the subcommittee. The subcommittee was also surprised about the relatively close distance between the primary and secondary listing centers.

A member noted that private insurance and advanced education are often proxies for socioeconomic gaps and encouraged the subcommittee to review zip code level data to provide a more granular understanding of the patients pursuing multiple listing. The data request did include zip code level data, which showed similarities in income and poverty percentage across organ types, but there are some challenges in accuracy when using zip code data.

A member inquired about how the data impacts the ethical analysis of multiple listing as a practice. The Chair responded that in order to understand the ethical impact of multiple listing the committee needs to understand if there is any harm done through the practice. A member pushed back that if people who are multiple listed are more likely to get an organ sooner than those who are unable to do that, it creates a difference which is ethically significant. The Chair responded that there are various factors that affect decision-making, such as distance from home, and if there is not a pattern in multiple listing then it could be possible that it is caused by a difference in preference as opposed to a disparity. The purpose of the data request was to better understand if there is a meaningful disparity in access between patients pursuing single listing and multiple listing. A member added that geography has a large impact on access and it is possible that the advantage of multiple listing is correcting a disadvantage caused by another factor. This could be elevating patients to an equal advantage, as opposed to creating a disparity.

Next steps:

The subcommittee is submitting a secondary data request to better understand how localized multiple listing is.

4. Update on Normothermic Regional Perfusion (NRP) Project

The POC approved this project during their June 13th meeting. The project will review the ethical implications of NRP as a surgical technique in deceased donor organ recovery. The project will use the ethical principles of autonomy, transparency, and utility and explore the ethical distinction between killing and letting die. The white paper will consider the potential for NRP to be ethically pursued, and any limitations or objections implied by the ethical principles. The workgroup has an extensive list of stakeholders and includes members from various OPTN Committees.

Summary of discussion:

Leadership noted feedback from the POC, which included concern of public trust and support of the organ donation system, which should be considered within the ethical principle of utility. The POC also

noted that concerns associated with informed consent were outside of the scope of the white paper due to the legal requirements associated with informed consent. However, it is within the scope of the Committee to highlight the areas with which greater legal clarity would be helpful. The Vice-Chair emphasized to the POC that the Ethics Committee is open to this topic and discussion and is not proceeding with this project in a pre-determined trajectory.

A member inquired on the number of organ procurement organizations (OPOs) that are currently participating in NRP. Currently, the OPTN does not collect any data on NRP, but Committee leadership has suggested surveying member organizations to better understand how prolific the practice is. Committee support staff clarified that a survey would not require approval from the Office of Management and Business (OMB) if the goal of the survey is to identify attitudes or beliefs on the practice, but if the survey were to collect information that the OPTN could collect data on in the future then it would require OMB approval. The Committee could tangentially work on a survey while the workgroup works on the white paper, but the Committee needs to deliberately outline how the survey would add to the white paper and its ethical analysis. An incoming member noted that Association of Organ Procurement Organizations (AOPO) might have some data on practice frequency that the Committee could use.

5. Farwell to Members Rolling Off

The Chair acknowledged and thanked the members who are rolling off the Committee on June 30, 2022.

Upcoming Meeting

- July 21, 2022
- August 18, 2022

Attendance

- **Committee Members**
 - Aaron Wightman
 - Andy Flescher
 - Carrie Thiessen
 - Catherine Vascik
 - Colleen Reed
 - David Bearl
 - Earnest Davis
 - Ehab Saad
 - George Bayliss
 - Glenn Cohen
 - Keren Ladin
 - Melissa Anderson
 - Sena Wilson-Sheehan
 - Tania Lyons
- **HRSA Representatives**
 - Jim Bowman
- **SRTR Staff**
 - Bryn Thompson
- **UNOS Staff**
 - Catherine Parton
 - Cole Fox
 - James Alcorn
 - Kim Uccellini
 - Kristina Hogan
 - Laura Schmitt
 - Stryker-Ann Vosteen
- **Other Attendees**
 - Bob Troug
 - Erica Stohs
 - Felicia Wells-Williams
 - Jennifer Dillon
 - Megan Urbanski