

# **Meeting Summary**

OPTN Ethics Committee Meeting Summary September 26, 2024 Webex Meeting

Andy Flescher, PhD, Chair Sanjay Kulkarni, MD, Vice Chair

#### Introduction

The Ethics Committee ("Committee") met via WebEx teleconference on 09/26/2024 to discuss the following agenda items:

1. Equity in Allocation Out of Sequence (AOOS)

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

1. Equity in Allocation Out of Sequence (AOOS)

#### No decisions were made.

The equity topic group continued discussion for the white paper on AOOS in progress.

#### Presentation Summary:

Equity: Fairness in the pattern of distribution of the benefits and burdens of organ allocation

- Distributive justice: Requires fairness in the distribution of scarce resources so that patients of similar need have an equal opportunity to benefit from transplantation
- Formal equality of opportunity: developing rules and policies that equally apply to all patients
- Fair equality of opportunity: developing rules and policies that each individual has a fair chance to equally exercise opportunity within those rules and policies
- Procedural justice: Upholds a commitment to treating like cases similarly, transparently, and predictably – treating similar people similarly

The National Organ Transplant Act states the importance of "equitable access by patients to organ transplantation and for assuring the equitable allocation of donated organs among transplant centers and among patients medically qualified for an organ transplant."

We are concerned not exclusively with the aggregate amount of medical good that is produced, but also with the way in which that good is distributed among potential beneficiaries. This does not mean treating all patients the same, but it does require giving equal respect and concern to each patient.

The following can be considered possible equity considerations in AOOS:

- Organ Procurement Organization (OPO) Based:
  - Same patient listed at different centers may not have the same access (based on which "aggressive" center the OPO has a relationship with)
  - Should ALL centers get notified of potential expedited offer? Should there be uniform criteria for centers receiving the expedited offer?
- Transplant Center Based:

- Disparities in access to transplantation are potentially exacerbated by homegrown expedited lists maintained by transplant centers
- Consider what criteria and/or biases are impacting center decisions about which patient(s) to select for the expedited offer?
- System/Access Based:
  - Patients able to be listed at large, aggressive centers benefit (impacted by geography, payer)

The presenter also reviewed some summarized data from the prior OPTN data request submitted.

#### Summary of discussion:

Discussion focused on the on equity section of the paper, especially on fairness, distribution of burden, and transparency in organ allocation. The equity group identified three areas of concern related to equity: OPO-based factors, center-based factors, and system issues. Recipients of out of sequence organs are more likely to be male and Caucasian, raising concerns about implicit bias in patient selection. A member raised concerns about the potential inequities in access to organs based on geography and socioeconomic status. The discussion lead acknowledged the existing disparities in access and suggests that these issues are already inherent in the transplant system.

A member asked about the role of the OPTN Expeditious Taskforce and the connection to this paper. The discussion lead explained that a critical comment was received and the work is currently paused but that the ethical analysis of this is still relevant and highly important.

The Chair emphasized the need for reform in the transplant system, even though out of sequence allocation may exacerbate existing inequalities. Members noted that distance, both logistical and travel time, plays a significant role in organ allocation and transplant success. "Marginal" organs can become more marginal over time due to allocation procedures and increased waiting time.

The Committee reached consensus that the issue of promoting equitable access to transplantation, and how AOOS impacts this, needs to be highlighted clearly in the paper.

#### Next steps:

Group leaders will submit their sections of the paper so that the first draft can be compiled.

#### **Upcoming Meeting(s)**

October 16, 2024

## **Attendance**

# • Committee Members

- o Sena Wilson-Sheehan
- o Andy Flescher
- o Laura Jokimaki
- o Lois Shepherd
- o Gloria Chen
- o Laura Madigan-McCown
- o Lisa Paolillo
- o Joel Wu
- o Shelia Bullock
- o Bob Truog

# • HRSA Representatives

- o Jim Bowman
- o Arjun Naik
- o Shannon Dunne

## • SRTR Staff

# UNOS Staff

- o Kieran McMahon
- o Katrina Gauntt
- o Laura Schmitt
- o Kristina Hogan

# Other attendees