

# **Meeting Summary**

OPTN Ethics Committee
Transparency in Program Selection Workgroup
Meeting Summary
September 23, 2021
Conference Call

Earnest Davis, MHA, FACHE, Co-Chair Carrie Thiessen, MD, PhD, Co-Chair

#### Introduction

The Transparency in Program Selection Workgroup met via Citrix GoToMeeting teleconference on 09/23/2021 to discuss the following agenda items:

- 1. Section Assignments
- 2. Working Outline and Dsicussion
- 3. Future Meetings

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

# 1. Section Assignments

UNOS staff reviewed which sections were assigned to each workgroup member as per leadership's recommendation.

## 2. Working Outline and Discussion

The workgroup leads discussed their extended outline and discussed.

#### Summary of discussion:

## Ethical justifications for transparency

The outline was introduced and discussed by the workgroup's lead.

#### Current/existing data on what patients want

Members discussed the importance of gaining a better understanding of how patients decide which transplant center to select.

A member shared selection criteria guidelines that have been developed by medical socieites, transplant centers, and insurance providers, as well as international transplant center guidelines. The co-chair clarified that the purpose of this project is not to develop the policy but make the ethical argument for why patient should have access to this type of information to inform their decisions.

#### Future state: What should be available?

Members discussed the importance of including living donor information in the transplant selection criteria to ensure that the potential living donor would be accepted by the transplant center. Member discussed an example of set transplant criteria for Ontario, Canada and how this could be used as an example of what could be available to patients.

#### *Future state: How data should be accessed and understood?*

Members discussed the existing challenge in having information that is accessible and easily understood to every patient, noting the immense physical and psychological toll that transplant takes on an individual. Someone noted that this paper is about the patient finding a transplant center that fits their needs and not a transplant center finding a patient that fits their perameters. Members discussed examples of patient education and accessibility and why this is so important for transplant patients. The co-chair elaborated on the data component, meaning the highest level of BMI for example, and how it's important while not necessarily being a metric.

# Next steps:

The workgroup leads will reach out to each member individual to begin discussing and working on their sections.

### 3. Future Meetings

Due to conflicts with the upcoming holidays, the November and December meetings will be rescheduled. UNOS staff will circulate potential meeting dates and times to the workgroup members.

## **Upcoming Meetings**

• October 23, 2021

# Attendance

- Workgroup Members
  - o Carrie Thiessen
  - o Earnest Davis
  - o Ehab Saad
- HRSA Representatives
  - o Jim Bowman
- SRTR Staff
  - o Bryn Thompson
- UNOS Staff
  - o Abby Fox
  - o Kristina Hogan
  - o Laura Schmitt
  - o Susan Tlusty