

**OPTN Ethics Committee  
Transparency in Program Selection Workgroup  
Meeting Summary  
October 28, 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 10/28/2021 to discuss the following agenda items:

1. Section updates
2. Review and discuss Section 3 – *Future state: What should be available?*

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

### **1. Section Updates**

The Chairs provided brief status updates on each section of the project.

#### Data summary:

- Section 1: Ethical justifications for transparency – Andy/Carrie
- Section 2: Current/existing data on what patients want – Ehab/Carrie
- Section 3: Future state: What should be available? – George/Earnest
- Section 4: Future state: How data should be accessed and understood? – Colleen/Earnest

#### Next steps:

The Co-Chair, Carrie, is developing an End Note library with the resources from the literature review.

### **2. Review and discuss Section 3 – *Future state: What should be available?***

The section authors reviewed the exemplars they developed to inform this section. They used examples that would cover thoracic transplant, abdominal transplant, and living donor experiences.

#### Summary of discussion:

When examining the examples to be used, a member inquired about the inclusion of sensitization at the pretransplant level. The section authors explained that the goal of this section was to provide a range of examples that could cover every organ type in order to be applicable across transplant programs. The authors included sensitization because if a patient is highly sensitized then a Kidney Paired Donation program might be a better option and it is important to know if a transplant center participates in that program. A member added that the patient will know that they will need to be a match to their living donor and a patient's sensitization would fall under that.

Members discussed the possibility of framing the language in this example to reflect if the patient is highly sensitized and not make the assumption that they are or are not. A member added that patients who have been previously transplanted would know if they are highly sensitized, but a member countered that the Committee should use examples that could apply to a majority of patients. UNOS

staff identified that living donors who have been pregnant before could be an indicator of sensitization, so it is possible for the group to identify potential indicators to inform patients of at the pretransplant level. Members also identified that patients may have been evaluated at another center but denied or being listed at multiple centers.

Members discussed concern about finding the balance between informing and enabling or overwhelming patients. Members recognized that the range in health literacy will be discussed in section 1, Ethical justifications for transparency, and section 4, Future state: How should data be accessed and understood? Members also discussed where different metrics would be categorized and identified sections 2 and 3.

Next steps:

The co-chairs will communicate with members offline ahead of the Committee's next meeting.

**Upcoming Meetings**

- November 23, 2021
- January 27, 2022
- February 24, 2022
- March 24, 2022

## Attendance

- **Workgroup Members**
  - Amy Friedman
  - Andy Flescher
  - Carrie Thiessen
  - Colleen Reed
  - Earnest Davis
  - Ehab Saad
  - George Bayliss
- **HRSA Representatives**
  - Jim Bowman
  - Marilyn Levi
- **SRTR Staff**
  - Bryn Thompson
- **UNOS Staff**
  - Abby Fox
  - Laura Schmitt
  - Susan Tlusty