

**OPTN Ethics Committee
Transparency in Program Selection Workgroup
Meeting Summary
September 27, 2022
Conference Call**

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

Introduction

The Transparency in Program Selection Workgroup met via Citrix GoToMeeting teleconference on 09/27/2022 to discuss the following agenda items:

1. Review Regional Meeting Sentiment and Feedback to Date
2. Discuss Themes in Feedback

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

1. Review Regional Meeting Sentiment and Feedback to Date

The workgroup reviewed the regional meeting sentiment, public comment feedback to date, and the responses to the questions the Committee asked. Regional meetings have concluded but public comment does not end until September 28th, so additional feedback will be submitted for the Committee's review. The purpose of this meeting is to be an initial consumption and discussion of feedback to allow members time to consider how the feedback ought to be implemented.

Data summary:

The sentiment from Regions 1-9 was reviewed and shared. There is overwhelming support for the white paper so far, with over 82.6% of members submitting 'strongly support' or 'support' sentiment. The only opposition to the white paper has come from transplant hospitals.

Summary of discussion:

A member inquired about comments associated with opposition votes submitted at regional meetings. Members are not required to include comments with their opposition sentiment, but staff conducted targeted outreach to the transplant centers that opposed the white paper to gain a better understanding of their stance.

1. Discuss Themes in Feedback

The group reviewed the feedback to the questions they asked during public comment. The primary themes in public comment feedback are: support from patients and for transparency overall, concern for potential unintended consequences, patient access concerns, how to operationalize transparency, and recommendations for next steps. The workgroup will review these themes and determine if they want to modify the white paper to address this feedback. All of the public comment themes and the workgroup's subsequent discussion will be outlined in the briefing paper for the OPTN Board of Directors.

Summary of discussion:

Support from patients and for transparency overall

Members noted the extensive engagement from patients and their support for the white paper. Members shared their experience attending regional meetings and conducting cross-committee presentations and made the point that even the transplant programs that opposed the white paper likely do not oppose the concept of transparency. Members hypothesized that the opposition sentiment was more likely a reflection of how transparency ought to be operationalized than opposition to the concept of transparency.

Concern for potential unintended consequences

A member pushed back on this feedback, specifically referencing the comment that this information could funnel patients away from smaller programs and to larger ones. The member noted that the purpose of this information is to ensure that patients are appropriately matched to the transplant center with the highest likelihood of transplanting them, so directing them to the best-matched center is the intended consequence.

When considering feedback stating this would place a burden on the center, the workgroup disagreed that an added burden would be placed on transplant centers, as the white paper does not urge added responsibilities on behalf of the transplant center. The workgroup was cognizant of not stating how transparency ought to be operationalized or of placing a burden on the transplant centers to change their behaviors.

The members wondered if people did not thoroughly read the white paper and instead assumed there would be unintended consequences without reading the section that addresses unintended consequences. The group highlighted the various points of view that could have voiced concern for unintended consequences and discussed how these perspectives intersect with the ethical principles and argument outlined in the white paper.

Patient access concerns

A member noted that there are instances where a patient is referred to a specific center because of their public insurance and the program opts to transplant patients with private insurance for financial maximization on their end.

How to operationalize transparency

Members emphasized that the purpose of the white paper is to lay the ethical and conceptual foundation for increased transparency and not to establish parameters to operationalize transparency, and as such, this topic will be addressed in the briefing paper and not be highlighted in the white paper.

General discussion

The workgroup discussed the comments associated with opposition feedback. A member noted that relative contraindications could be identified as such to differentiate them from absolute contraindications. The member noted that sharing something as an absolute contraindication and then accepting a patient with that presentation could cause objections from insurance. A member noted that none of the feedback was unexpected or made overwhelming and substantial claims against the white paper. Staff noted that a member did reach out with concern that pediatrics was not explicitly considered in the white paper, but OPTN Pediatric Transplantation Committee did not express concern about this during their cross-committee presentation. It is worth noting that the Ethics Committee has consistently identified pediatrics as an important population with specific needs and protections.

Next steps:

The workgroup will receive an updated document with all of the public comment feedback and a comprehensive public comment analysis. Members are asked to continue to review the public comment feedback and think about which feedback is appropriate to implement in the white paper and how that should be incorporated. Next week's meeting will include a final review of the public comment and sentiment, a determination of how the white paper will be revised, and writing assignments to make those edits.

Upcoming Meetings

- October 6, 2022
- October 21, 2022 – Ethics Committee vote on final white paper

Attendance

- **Workgroup Members**
 - Andy Flescher
 - Earnest Davis
 - Ehab Saad
 - George Bayliss
 - Stephen Gray
- **HRSA Representatives**
 - Jim Bowman
- **SRTR Staff**
 - Bryn Thompson
- **UNOS Staff**
 - Cole Fox
 - Kim Uccellini
 - Kristina Hogan
 - Laura Schmitt