

**OPTN Ethics Committee
Transparency in Program Selection Workgroup
Meeting Summary
October 6, 2022
Conference Call**

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Carrie Thiessen, MD, PhD, Vice Co-Chair**

Introduction

The Transparency in Program Selection Workgroup met via Citrix GoToMeeting teleconference on 10/06/2022 to discuss the following agenda items:

1. Review public comment analysis
2. Discuss considerations for revision and develop plan to address feedback

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

1. Review public comment analysis

The Workgroup reviewed the public comment analysis.

Summary of discussion:

Members discussed the high level of engagement from organ procurement organizations (OPOs) and transplant hospitals, which is likely due to their presence at regional meetings,, but could be due to the concern that these organizations had regarding operationalizing of this white paper. The workgroup emphasized that operationalizing transparency is not the Ethic Committee's purview, rather the purpose of the white paper is to conceptualize transparency. The majority of feedback and sentiment was positive, with the negative feedback coming from transplant hospitals primarily. One member asked whether there was cause to be concerned about transplant hospitals feeling more apprehensive about the paper, the Chair responded that it is consistent with past white papers due to the volume of transplant hospitals. Members agreed that the feedback received was on par with their expectations. A member asked whether an attempt had been made to reach out to those in opposition. Outreach was done to those who did not provide a comment with their opposition sentiment, however, only one submitted a public comment.

2. Discuss considerations for revision and develop plan to address feedback

The Workgroup discussed possible revisions and ways to address public comment feedback in the whitepaper if deemed necessary.

Summary of discussion:

The public comments themes that are not within scope for inclusion in the white paper are: support from patients, conceptualizing versus operationalizing transparency, recommendations for next steps, and community alignment. These topics will be addressed in the briefing paper to the Board of Directors but will not be considered in the white paper. The following topics were ones the Workgroup discussed and agreed would be beneficial additions to the white paper.

Concern for potential unintended consequences

The Workgroup discussed if additional considerations for the potential unintended consequences need to be included, however, the Workgroup felt the concerns from public comment were adequately addressed in the existing text. The only concern about the existing 'complicating questions' section was whether the word paternalism should be replaced, but the Workgroup agreed that paternalism was the most appropriate term for them to use.

Patient access concerns

Members discussed the concern of insurance and geography as limiting factors to patient access and choice. Some feedback addressed the hurdle that insurance might present when trying to "shop around" at different transplant programs, and that increasing transparency would not benefit those who are already limited due to their insurance and socioeconomic status. Members concluded that including access considerations would be appropriate as an additional complicating question, and agreed on a plan for developing this text.

Inclusion of Pediatric Specific Information

The Workgroup discussed whether including an example about pediatric split-liver would address the feedback from the pediatric transplant community. They agreed that developing pediatric specific examples would enhance the paper and provide a more robust consideration of transplant candidates.

Next steps:

The workgroup will revise their assigned sections and send them back to support staff by October 12. Staff will circulate a final draft for the workgroup to review on October 13 and are asked to provide feedback by October 16. The final draft will go to the Ethics Committee for their review on October 17 and the Ethics Committee will vote on the white paper on October 21.

Upcoming Meetings

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

Attendance

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