

**OPTN Ethics Committee
Transparency in Program Selection Workgroup
Meeting Summary
April 1, 2022
Conference Call**

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

Introduction

The Transparency in Program Selection Workgroup met via Citrix GoToMeeting teleconference on 04/01/2022 to discuss the following agenda items:

1. Welcome and Introductions
2. Background and Timeline
3. In-Person Meeting Recap
4. Draft Review
5. Next Steps and Concluding Remarks

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

1. Welcome and Introductions

The co-chairs began the meeting by reviewing the agenda and welcoming a new member to the workgroup from the Data Advisory Committee (DAC).

2. Background and Timeline

UNOS staff provided a brief overview of the differences between the memo and white paper and outlined how the white paper builds off the memo. The workgroup reviewed the timeline for the project, emphasizing that the full Ethics Committee needed to vote on the final version of the white paper on June 16 for it to go out to public comment in August.

3. In-Person Meeting Recap

The workgroup met during the full Committee's in-person meeting in Chicago on March 17th. During this meeting, the workgroup discussed feedback the Vice-Chair received when presenting the project for approval to the Policy Oversight Committee (POC). The group also discussed the difference and implications of using 'metrics' throughout the paper, and has since replaced that language with information or data. Lastly, the members discussed how to improve the structure of the future state section.

Summary of discussion:

A member emphasized the importance of tone and having a consistent voice throughout the white paper, noting the difference between the ethical principles and experiential examples section. The Vice Chair has volunteered to work through the tone and cohesion of the language as part of the final review of the white paper.

Members discussed the literature review, which has been part of the outline but is still in progress. Some outstanding references still need to be included in the draft and members were asked to send the

sources they have. A member expressed concern about the length of the document, but the consensus was that if a systematic literature review needs to be in the document then the document length should not be a deterrent.

Members discussed the necessity of including the literature review and reviewed the timeline for doing so. The Chair noted that the role of this white paper is to establish the ethical foundations for increasing transparency and highlighted how that will play into future work taken on by other OPTN Committees. Since the literature review is near completion, it would be beneficial to strengthen the document. Members confirmed that the literature review could be completed in early May. The Chair suggested, as a backup option, some of the information from the literature review could be housed in the background section, as opposed to the body, of the white paper.

4. Draft Review

The workgroup reviewed the updated draft, with a focus on the restructuring of the experiential examples. This section was restructured following the workgroup's last meeting.

Summary of discussion:

The members provided feedback on if the examples made sense for the ethical principles they referenced. A member noted that autonomy is characterized in a different way for a transplant center than for a patient. It was suggested that to strengthen the argument for the patient perspective, it may be worth considering the alternative point of view of the transplant center. A member suggested to include this information so that the paper is balanced and to consider the ethical principles from multiple perspectives. A member noted the chasm between a transplant center wanting an organ to succeed and a patient wanting an organ to succeed for them. A member suggested adding language on the benefit to the transplant program when a patient is able to make a more informed decision.

The workgroup also discussed the examples with respect to the information being specific to each example and population versus its relevance to the transplant system as a whole. A member added that when restructuring the section, they placed the general transplant information into the examples that were the most appropriate for each one.

5. Next Steps and Concluding Remarks

UNOS staff assigned sections to workgroup members to review and revise. The revisions are due back to UNOS staff on April 11 for the full committee's review.

Upcoming Meetings

- April 28, 2022
- May 26, 2022

Attendance

- **Workgroup Members**
 - Anna Mello
 - Carrie Thiessen
 - Earnest Davis
 - Ehab Saad
 - George Bayliss
 - Keren Ladin
- **HRSA Representatives**
 - Marilyn Levi
- **SRTR Staff**
 - Allyson Hart
- **UNOS Staff**
 - Cole Fox
 - Kristina Hogan
 - Laura Schmitt
 - Meghan McDermott
 - Susan Tlusty