

**OPTN Ethics Committee  
Transparency in Program Selection Workgroup  
Meeting Summary  
April 29, 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 04/29/2022 to discuss the following agenda items:

1. Introductions and Background
2. Feedback on memo
3. White paper draft review

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

### **1. Introductions and Background**

The Chair began the meeting by reviewing the agenda and welcoming a new member to the workgroup from the Data Advisory Committee (DAC), Minority Affairs Committee (MAC), and Patient Affairs Committee (PAC). UNOS staff provided an overview of the memo that the Committee sent to DAC, MAC, and PAC in February 2022. The white paper builds on the memo by diving deeper into the ethical implications of availability of information and providing experiential examples of transparency. The white paper will also be an outward facing document to be a resource for the transplant community. The white paper is slated to go out for public comment in August 2022 and to the Board of Directors for approval in December 2022.

### **2. Feedback on memo**

Members were asked to provide feedback on the memo and discussed the goals and implications of the white paper proceeding to public comment.

#### Summary of discussion:

A member shared their personal experience as a transplant clinician at a transplant hospital. The member inquired with their finance department if the financial guidelines (money needed to support ongoing medication, impact of being out of work, etc.) were shared with patients, whether that be before or during the evaluation process. The response the member received was 'no, this information is not shared with patients and would require conversations with compliance, legal, marketing, and leadership before engaging in a time intensive project to share that information.' The member shared this experience to provide context on how transplant hospitals may receive and respond to this white paper during public comment.

A member responded that the group has been very cautious to not dictate requirements to transplant programs, but emphasized the value that experience provides to better understand how centers could respond to requests to share more information publicly. A member inquired where this sentiment was mostly likely to arise from, whether that be clinicians, administrators, or legal representatives from

transplant programs? The member responded that clinicians tend to be very supportive of sharing as much information with their patients to aid in their decision-making process and their experience depicted that the concern was from an administrative perspective. The member was surprised their center would be reluctant to share the financial requirements a patient must meet to be listed for transplant and the extensive review that would be required to disclose that information.

A member emphasized the importance of developing an ethical framework for increased transparency and accessibility for information for patients. The DAC has begun discussing how increased transparency at the pre-waitlist stage could be provided and they are likely to hear those administrative concerns when discussing operationalizing this.

A member inquired if it would be advantageous to insert disclaimer language that these suggestions in this paper are not dictating practice or requirements for transplant centers. Members provided mixed feedback on whether this language would address any potential concerns in public comments or undermine its goals. A representative from the Health Resources and Services Administration (HRSA) suggested including language that affirms that the recommendations in this white paper are not policy or bylaw requirements. Members agreed that language should be included in the white paper and background section.

### **3. White paper draft review**

UNOS staff reviewed the feedback that the Ethics Committee provided during their full Committee meeting on April 21 and posed a few outstanding questions for the workgroup to provide feedback on.

#### Summary of discussion:

The group discussed the inclusion of references to the Scientific Registry of Transplant Recipients (SRTR) in the white paper. A representative from the SRTR was not concerned that the mentions in the white paper would cause it to be outdated when changes are made and emphasized the importance of the ethical framework that supports their current initiatives. The group discussed a reference to the Program Specific Reports (PSR) in the alcohol use example and an SRTR hotline in the data accessibility section. A member expressed concern about going beyond the scope of the Ethics Committee, but suggested using the SRTR as an example in the 'Reliance on Internet for Data Accessibility' section, noting that the concern was rooted in equity for the patient. Members agreed with changing the wording but keeping the sentiment.

The group discussed the frailty section and how better to define frailty from the outset. A member sent edits in the previous evening that are being implemented into this draft and will be sent out after the meeting. Another attendee suggested literature that could provide additional clarifying language for the section.

A member inquired about the ethical principles and if the length of the sections ought to reflect how heavily the ethical analysis relied on them. A member responded that the lengths are sufficient in addressing the ethical principles which is the most important component. A member inquired if the 'complicating questions' were too thorough and undermine the content of the white paper. A member responded that this section balances the perspectives of the paper and show that the Committee has considered how complex the issues at hand are.

#### **Upcoming Meetings**

- May 26, 2022

## Attendance

- **Workgroup Members**
  - Andy Flescher
  - Earnest Davis
  - Ehab Saad
  - George Bayliss
  - Rachel Patzer
  - Sejal Patel
  - Stephen Gray
- **HRSA Representatives**
  - Jim Bowman
  - Marilyn Levi
- **SRTR Staff**
  - Allyson Hart
  - Bryn Thompson
- **UNOS Staff**
  - Cole Fox
  - Kaitlin Swanner
  - Kim Uccellini
  - Kristina Hogan
  - Laura Schmitt