

**OPTN Ethics Committee  
Transparency in Program Selection Workgroup  
Meeting Summary  
May 26, 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 05/26/2022 to discuss the following agenda items:

1. Final Review and Discussion
2. Next Steps and Public Comment

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

### **1. Final Review and Discussion**

The workgroup reviewed the most recent round of edits on the draft, with a focus on the literature review and experiential examples.

#### Summary of discussion:

##### *Literature Review*

The group discussed including additional tables in the appendix. These tables and graphics are illustrative of the process used in the literature review and its findings. This information will be supplemental to what is included in the text. The Chair noted that while the white paper does not include any discussion or reference to metrics, some of the literature does make recommendations about increasing center metrics.

##### *Procedural Justice*

Member discussed a block quote and whether or not the quote strengthened the point. While the quote references transparency, it is referencing transparency in allocation and not in patient exclusion criteria or information sharing. Alternatively, someone felt that the quote strengthened the paper by linking transparency to another white paper by the Ethics Committee in support of transparency across the transplant system. A member noted that it is essential to note in this section that procedural justices require that processes are consistent across transplant centers, but does not require for practices to be consistent. For example, all centers ought to list their body mass index (BMI) cut off but some centers may accept a higher BMI because of the technology that they use to transplant patients. Members offered ways that the section could be made more clear with the removal of the block quote. It was suggested to add that the Committee is referring to procedural justice in terms of transparency, recognizing that different programs have different selection criteria.

##### *Equity*

An example of the race coefficient used in estimated glomerular filtration rate (eGFR) equations was added to elucidate how an asymmetry of information could negatively impact already marginalized

populations. A member suggested clarifying that this example was an asymmetric information because patients do not know which centers are using eGFR calculations that incorporate race. It was also suggested to add ‘the differential’ use of eGFR or ‘the differential awareness of the use.’ Alternatively, a member suggested changing the example from eGFR to multiple listing and highlighting that not every patient may be aware that they can pursue evaluation at multiple centers. The group decided against using the multiple listing example because OPTN Policy requires transplant programs to inform patients of their option to register at multiple transplant hospitals.<sup>1</sup>

### *Utility*

A member shared that the patient interprets utility as to whether or not they are able to use something, as opposed to the net benefit to the transplant system. This interpretation of utility is more akin to patient autonomy, as opposed to how the OPTN has consistently defined utility. A member suggested adding a reference to the *Ethical Principles in the Allocation of Human Organs* and defining utility to clarify what is meant in this section.<sup>2</sup>

A member noted that this ethical principle was moved to the bottom of the section because it is not carrying the weight of the paper as opposed to equity and autonomy. Members discussed the role of utility in the paper. The group considered ways that the language of this paragraph could be softened to not mislead the reader into thinking that the paper will show that an increase in transparency will lead to an increase of utility. A member opined that by amplifying the other ethical principles there will be an increase in utility. However, a member pushed back that additional empirical data is necessary to prove this.

### *Example 1: Alcohol Use*

The group discussed how to better clarify the inclusion of patients’ insurance will often only cover one transplant evaluation. A member suggested adding language that acknowledged that this challenge was not unique to patients with a history of alcohol use pursuing liver transplant, but that the information transcended examples and needed recognition in the white paper.

### *Example 3: Highly Sensitized Patients*

The group discussed some of the language used in this section and whether it sounded contradictory between paragraphs. The group revised ‘may be unable to access transplantation with potential living donors’ to ‘they have a harder time identifying living donors due to cross-match compatibility.’

### *Reliance on Internet for Data Availability*

The group considered how to strengthen the connection between reliance on the internet to access data and how that impacts health literacy. Members discussed the inconsistent accessibility of internet as well as digital literacy.

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<sup>1</sup> OPTN Policy 3.2, Notifying Patients of Their Options, accessed June 26, 2022, [https://optn.transplant.hrsa.gov/media/eavh5bf3/optn\\_policies.pdf](https://optn.transplant.hrsa.gov/media/eavh5bf3/optn_policies.pdf).

<sup>2</sup> OPTN Ethics Committee, *Ethical Principles in the Allocation of Human Organs*, June 2015, accessed June 26, 2022, <https://optn.transplant.hrsa.gov/professionals/by-topic/ethical-considerations/ethical-principles-in-the-allocation-of-human-organs/>.

### *Accessibility of Information*

A member added language about how patients can access and understand information once it has been located. This includes the ease of navigation and the importance of providing information in a way that is directed at patients as opposed to clinicians.

#### Next steps:

The workgroup will receive the final version of the draft after today's meeting. Members are asked to review and send their final round of comments and feedback.

## **2. Next Steps and Public Comment**

The Ethics Committee will be voting to send the white paper for public comment during their June 16<sup>th</sup> meeting. The community will be able to submit sentiment and comment on the white paper during public comment. Targeted outreach will be conducted to various stakeholder organizations. After public comment, the workgroup will reconvene to consider how they want to incorporate the feedback they received.

### **Upcoming Meetings**

- The workgroup will reconvene after public comment

## Attendance

- **Workgroup Members**
  - Amy Friedman
  - Andy Flescher
  - Anna Mello
  - Carrie Thiessen
  - Earnest Davis
  - Ehab Saad
  - George Bayliss
  - Keren Ladin
  - 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
  - Meghan McDermott
- **Other Attendees**
  - Sena Wilson-Sheehan