

**OPTN Ethics Committee  
Meeting Summary  
December 16, 2021  
Conference Call**

**Keren Ladin, PhD, Chair  
Andrew Flescher, PhD, Vice Chair**

## **Introduction**

The Ethics Committee met via Citrix GoToMeeting teleconference on 12/16/2021 to discuss the following agenda items:

1. POC Assessment Criteria Ranking
2. Transparency in Program Selection Project Update and Discussion

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

### **1. POC Assessment Criteria Ranking**

The Vice Chair provided an overview of a criteria-ranking exercise that the members of the Policy Oversight Committee (POC) participated in to identify the most important considerations when approving a project. This information is useful to the Ethics Committee when considering how their project idea will be evaluated by the POC when they are seeking project approval.

#### Summary of discussion:

The Chair inquired how these fit into the priorities set out in the Strategic Plan and identified overlap between the two. UNOS staff that supports the POC let the Committee know that this exercise is still in progress and the goal of the POC is to refine this list down to five or six criteria. A member inquired about 'project dependency,' which was clarified to mean that one project that is under progress may impact an area that is addressed either by that Committee or another Committee. The Vice Chair also highlighted 'voluntary vs. required' and noted that "required" refers to projects that are policy changes whereas "voluntary" refers to projects that are guidance documents or white papers.

#### Next steps:

Once the POC has finalized this criteria exercise, the Vice Chair will present the final results to the Committee. If members have any questions about the POC or the OPTN's Committee structure, please reach out to UNOS staff.

### **2. Transparency in Program Selection Project Update and Discussion**

The co-chairs of the Transparency in Program Selection workgroup reviewed the document's outline and presented two sections of the first draft for feedback.

#### Summary of discussion:

#### *Ethical Justifications for Transparency*

A member suggested including literature about the impact of 'cherry picking' data and provided a few specific examples to consider analyzing. Members noted that most space ought to be devoted to this section of the analysis. A member noted the importance of this document lies within what is best for

patient transparency and perspectives of providers should be secondary. A member shared that while very few studies have been conducted about what patients want, one that has been done showed that patients selected centers based on the best possible outcomes for themselves. A member asked for more detail on the balancing transparency and shared decision-making with confidentiality and protecting patients' identity. The presenter noted that for smaller centers, it would be necessary to institute a minimum sample size before the metric can be shared in order to reduce the chance of a patient being identified.

### *Complicating Questions*

A member suggested if the organization and flow of the paper may make more sense if the complicating questions were coupled with the data that was most pertinent to that issue. The member noted that the second and third questions were harder to fully comprehend without specific data examples. Members noted that there could be concerns about education, both the patient's level of education and the importance of educating the patient on the implications of data. A workgroup member noted that patient education will be discussed during the second future state section.

### *Future state: What should be available?*

A member shared that if the future state is to be representative of what the system should look like then the examples should reflect what is ideal instead of what is currently stigmatized and discretionary. The member suggested either using different examples that take a stronger stance on the role of center practices, other than just disclosure, or selecting examples that are not tied to social stigmas. A member countered that there is a difference between the future state and the ideal state. Continuing that the future state reflects what is possible in the current system, while ideal state reflects what should be available regardless of any practical limitations.

The Committee was asked if this section should connect the metrics more strongly to the ethical principles or to provide examples of the information that should be available. Members shared perspectives from the transplant center, first being that many other factors can influence these metrics. One example shared was that other factors aside from efficiency on behalf of the transplant center could impact if a referred patient is evaluated within 30 days. A member noted that clear definitions for each metric would be essential to provide consistent and accurate information to patients. The member cautioned that without explicit definitions patients could receive extremely skewed data that could negatively influence their decision in selecting a transplant center. A member countered that this section is geared toward what the metric could do for the patient as opposed to how to operationalize the metric within the transplant center.

### Next steps:

If members have additional comments, please send them to UNOS staff or leadership.

### **Upcoming Meetings**

- January 20, 2022
- February 17, 2022
- March 17, 2022
- April 21, 2022
- May 19, 2022
- June 16, 2022

## Attendance

- **Committee Members**
  - Aaron Wightman
  - Amy Friedman
  - Andy Flescher
  - Carrie Thiessen
  - Catherine Vascik
  - Colleen Reed
  - David Bearl
  - Earnest Davis
  - Ehad Saad
  - George Bayliss
  - Glenn Cohen
  - Keren Ladin
  - Lynsey Biondi
  - Roshan George
  - Sanjay Kulkarni
  - Sena Wilson-Sheehan
  - Tania Lyons
  - Thao Galvan
- **HRSA Representatives**
  - Jim Bowman
  - Marilyn Levi
- **SRTR Staff**
  - Bryn Thompson
- **UNOS Staff**
  - Cole Fox
  - Kristina Hogan
  - Laura Schmitt
  - Susan Tlusty