

**OPTN Ethics Committee
Meeting Summary
December 21, 2023
Conference Call**

**Andrew Flescher, PhD, Chair
Sanjay Kulkarni, MD, Vice-Chair**

Introduction

The Ethics Committee (“Committee”) met via WebEx teleconference on 12/21/2023 to discuss the following agenda items:

1. Welcome and Announcements
2. Normothermic Regional Perfusion (NRP) Debrief
3. Living Donor Access Project Discussion
4. Public Forum Introduction

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

1. Welcome and Announcements

The Chair and staff welcomed members to the meeting and introduced the agenda.

2. Normothermic Regional Perfusion (NRP) Debrief

The Committee discussed the result of the NRP paper being presented at the OPTN Board of Directors meeting earlier in December. It was approved and is available on the OPTN Website.

Presentation summary:

The NRP paper was presented to the Board of Directors during their December meeting. The ethical analysis in the white paper was approved by the Board of Directors with a vote of 36 to approve, zero decline, and 2 abstain. The Chair recapped some of the discussion and questions from Board members, and noted that the Board appreciated the comprehensiveness and care of the paper.

Summary of discussion:

There were no comments or questions from members.

Next steps:

The paper is available on the OPTN website for community consideration.

3. Living Donor Access Project Discussion

The Committee discussed their new project idea, a white paper on access to living donation, and worked to split into groups by focus area and brainstorm key questions.

Presentation Summary:

The Chair began by recapping the Committee’s charge, the policy development process, timeline and steps for the project, and the goals of today’s meeting. Staff demonstrated tools for the Committee to

use to work collaboratively and compile resources for the project. The goal of collaborative editing is to avoid version control problems, which the Committee has had challenges with previously.

The project idea was approved unanimously by the Policy Oversight Committee (POC) who recommended it for approval by the Executive Committee. Some members of the POC asked questions about the added value of distinguishing between adding incentives and removing disincentives, so the Chair called this out as an area to focus discussion on. Another question that came up at POC was that there seemed to be a lack of understanding of how the Ethics Committee approaches a project from a standpoint of an issue to explore rather than a problem to solve. In the future, more information can be provided about how the Committee approaches a project during the approval process.

The Chair reviewed results of a survey that members filled out in advance of the meeting to indicate which aspects of the project they would be interested in working on. Topic group leaders were then identified.

Summary of discussion:

The Committee workshopped the project idea. Issues surrounding donation from condemned prisoners was debated - some members felt as though it is an important topic to address in this project while others suggested it should be an independent project idea. The Chair explained this will need further discussion and review of prior Committee publications on the topic.

A member brought up that sometimes, living donors come forward for evaluation, but during the evaluation process, significant comorbidities are discovered which necessitate treatment. This member explained that they weren't sure if this would be in scope. A member explained that this happens often and may fit under the equity section because many people have decreased access to living donors based on high comorbidities in people that would typically be their donors.

A member explained that another important topic is what happens to donors who are incompatible with their intended recipient, and whether or not non-directed donation is being presented to them as an option.

Definitions around what constitutes an incentive versus disincentive were highlighted as needing clarification. Variation in assessment processes to prevent incentivization and coercion was also raised as an area to potentially address.

Next steps:

Finalized groupings for topic groups will be sent out via email.

4. Public Forum Introduction

Staff introduced the new aspects of the updated public access plan for Committee meetings, including livestreaming and public forum, which will be a standing agenda item for all OPTN Committees moving forward.

Upcoming Meeting

- January 4, 2024

Attendance

- **Committee Members**
 - Andrew Flescher
 - Lois Shepherd
 - Thao N. Galvan
 - Bob Truog
 - Andrew Courtwright
 - Felicia Wells-Williams
 - Laura Butler
 - Sena A Wilson-Sheehan
 - Megan Urbanski
 - Jen Dillon
 - Keren Ladin
 - Lois Shepherd
 - Laura Jokimaki
 - Ehab R Saad
 - Shelia Nichols Bullock
 - Erica Stohs
 - Lisa Paolillo
 - Carrie Thiessen
- **HRSA Representatives**
 - Jim Bowman
- **SRTR Staff**
 - Bryn Thompson
- **UNOS Staff**
 - Kieran McMahon
 - Cole Fox
 - James Alcorn
 - Kristina Hogan
 - Laura Schmitt
 - Joel Newman
- **Other Attendees**