

OPTN Ethics Committee

Meeting Summary

January 4th, 2024

Conference Call

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

Introduction

The Ethics Committee (“Committee”) met via WebEx teleconference on 01/04/2024 to discuss the following agenda items:

1. Living Donor Access White Paper: Timelines
2. NOTA Introduction
3. Living Donor Access White Paper: Workshop on Incentives/Disincentives

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

1. Living Donor Access White Paper: Timelines

Staff reminded the Committee of the timelines required for the white paper.

Summary of discussion:

There was no discussion surrounding this item.

2. NOTA Introduction

The Chair highlighted the National Organ Transplant Act (NOTA) of 1984 and reminded the Committee of its implications for living donation.

Data summary:

NOTA states, “It shall be unlawful for any person to knowingly acquire, receive, or otherwise transfer any human organ for valuable consideration for use in human transplantation”.¹

This does not apply to paired organ donation, which is further clarified in 42 U.S. Code § 274e.

The OPTN authority to regulate living donation is found in the Federal Register Notice published January 23, 2006.²

State laws surrounding living donation are not unified, and provide differing amounts of donor leave, donor protection, assistance, tax deductions, and credits.

Summary of discussion:

There was no discussion on this item.

¹ 42 U.S. Code § 274e

² 71 FR 34946

3. Living Donor Access white Paper: Workshop on Incentives/Disincentives

The Committee discussed the difference between providing incentives and removing disincentives to living donation, informed by the previous introduction to NOTA.

Summary of discussion:

The Committee considered equity barriers hindering individuals from becoming living donors. The term "privilege" was introduced in the context of the identity formation of potential donors. However, a member expressed misgivings about this language, noting it may carry connotations not related to living donation. They suggested a need for a more in-depth discussion and expanded upon their point to explore the perceived implications and nuances associated with such terminology, with a particular focus on the identity formation of potential donors. For example, they felt that "opportunity" and "access" were more aligned with the intent of the paper, rather than privilege. The Chair clarified that, in their experience, most living donors they had talked to felt gratified that they had been in such a position to be able to be a living donor, which implies an amount of privilege. They restated the overarching goal of the white paper: to remove barriers to becoming a living donor, ensuring that the privilege of giving the gift of life is maximally accessible. The intention is to achieve neutrality, considering not only financial costs but all potential barriers. A member noted that the term "privilege" speaks to the education required to understand living donation, the time availability, and the health required, to name a few.

The conversation then shifted to identifying barriers to living donation. One member mentioned the onerous evaluation process, particularly the psychosocial assessment, which varies across transplant centers and may not have strong evidence supporting its effectiveness. Another barrier discussed was the time involved in the evaluation process, and efforts to streamline it, such as a single-day living donor evaluation.

A suggestion was made to include a summary paragraph in the paper, providing background information on existing barriers and efforts to address them. The Committee acknowledged the need to distinguish between removing disincentives and actively offering incentives while adhering to ethical guidelines.

The Committee discussed the aspects of respect for persons related to living organ donation, emphasizing the importance of ensuring free and informed consent while preserving the opportunity for individuals to give the gift of organs. The term "valuable consideration" was noted, and there was a suggestion to explore the meaning of this term further. The discussion then shifted to potential barriers to living donation, including immigration status, healthcare benefits, and medical criteria such as comorbidities. Disparities in access to information and resources for potential donors were highlighted, and the Committee expressed the need to address issues like smoking cessation programs and mental health barriers. The importance of equity in addressing barriers was emphasized, and the Committee discussed variations in center-specific practices and the need for standardization. A member considered standard education as an area for significant improvement, as the amount of information provided varies between programs. The meeting concluded with a plan to delve deeper into these topics in future sessions, with a focus on removing barriers to living organ donation while considering ethical guidelines.

Next steps:

The Committee will continue to refine their approach to addressing incentives and disincentives in their upcoming white paper.

Upcoming Meeting

- January 18, 2024

Attendance

- **Committee Members**
 - Felicia Wells-Williams
 - Bob Truog
 - Megan Urbanski
 - Lois Shepherd
 - Andrew Flescher
 - Ehab Saad
 - Keren Ladin
 - Shelia Nichols-Bullock
 - Sena Wilson-Sheehan
 - Laura Jokimaki
 - Jen Dillon
 - Carrie Thiessen
- **HRSA Representatives**
 - Jim Bowman
 - Marilyn Levi
- **SRTR Staff**
 - Bryn Thompson
- **UNOS Staff**
 - Kieran McMahon
 - Cole Fox
 - Joel Newman
- **Other Attendees**
 - Laura Butler