

**OPTN Ethics Committee
Meeting Summary
December 15, 2022
Conference Call**

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

Introduction

The Ethics Committee met via Citrix GoToMeeting teleconference on 12/15/2022 to discuss the following agenda items:

1. Discuss ethical tradeoffs in kidney and pancreas continuous distribution

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

1. Discuss ethical tradeoffs in kidney and pancreas continuous distribution

The Chair and Vice Chair of the Kidney Transplantation Committee presented to the Committee on the current use of estimated post-transplant survival (EPTS) and kidney donor profile index (KDPI). The presenters shared the results of the first round of Scientific Registry for Transplant Recipients (SRTR) Organ Allocation Simulation (OASim) modeling and requested feedback on how the two calculations could be better utilized for longevity matching in continuous distribution. The presenters asked the following questions for the Committee's feedback:

- What should be the goal of the longevity matching attribute?
- Should any EPTS group have above average access?
- How should longevity matching be considered in comparison to other factors such as waiting time?

Summary of discussion:

A member inquired why there is an emphasis on post-transplant survival as compared to medical urgency. The presenter clarified that in kidney transplant, medical urgency is defined as the loss of access to dialysis and often only applies to a very small population who tend to be patients who have received a kidney transplant as a pediatric patient and no longer have access to dialysis.

The Chair noted the benefit for the youngest group of patients and wondered if the Kidney Committee analyzed how much longer waiting for a higher KDPI kidney resulted in life years post-transplant. For example, if a patient managed to wait four more months for a lower KDPI kidney, would that result in three more years of use for that organ? Staff responded that this information was not included in the initial round of SRTR modeling, but they will likely be able to obtain this type of information through the optimization exercises with Massachusetts Institute of Technology (MIT). The presenter added that there is some literature that support patients over age 50 having a greater benefit by accepting a higher KDPI in order to stop dialysis treatments.

When considering the KDPI groupings, a member questioned the reasoning for a distinction between kidneys with a KDPI under and over 35%. A member felt that this distinction was arbitrary and mirrored the distinction between adults and pediatrics, despite nothing being biologically different between a 17,

18, or 19 year old. The member praised the Kidney Committee for considering such challenging and complex issues, and recommended further work be done to focus on viewing various considerations (such as biological longevity vs age) on a continuum as opposed to absolutes. A member agreed with the desire to view as many attributes on a continuum as possible and commented that the goal of continuous distribution should be to eliminate the hard cut-offs at 20%, 35%, and 85% for EPTS. The presenter responded that the Kidney Committee has focused on translating the existing system into continuous distribution then making modifications. The presenter noted the challenges with both EPTS and KDPI, but commented that the Kidney Committee had not suggested separating the scores into individual components. If done, the Kidney Committee would need to reevaluate each variable, how it is defined, and how it contributes to the score and organ matching.

A member inquired if patient preference of KDPI is taken into consideration when matching EPTS and KDPI for organ offer acceptance. The presenters noted the variability in center practice for this. Currently, transplant teams will make value judgments when determining whether or not to accept an organ offer. The presenters added that there is a lot of education required to understand KDPI and what it means. A member added that there are a litany of factors that go into determining whether or not an organ offer is an appropriate match for a patient. Often times, patients are not privy to these conversations and may not fully understand the challenges associated with determining whether or not to accept an offer.

The conversation shifted to feedback from patients and what has been identified as most important to patients. The presenter noted that patients most often understand the kidney allocation system through the importance of wait time, but the goal of longevity matching in continuous distribution could change how wait time is impacted in allocation. Ultimately, this will require substantial patient education to understand the tradeoffs associated with these changes and decisions. Unfortunately, not many patients participated in the analytical hierarchy process (AHP), clinical experience of the presenters shows that patients most often want to be off dialysis but have adverse opinions about accepting higher KDPI kidneys.

The Chair inquired if the data shared was validated across all EPTS and KDPI groups. Unfortunately, at this time not all of the data is validated. The Kidney Committee had some ethical concerns about prioritizing older donors for higher KDPI kidneys versus if they should remain eligible for low KDPI offers regardless of their EPTS score. With the current impasse the Kidney Committee is at, they plan to proceed with engaging the public in this topic and utilizing the MIT optimization to garner more information about the different ways to utilize longevity matching.

Next steps:

Ethics Committee leadership extended an open invitation for the Kidney Committee to continue to bring any ethical considerations or questions they have to the Ethics Committee for feedback or guidance.

Upcoming Meetings

- January 19, 2023
- February 16, 2023
- March 16, 2023
- March 31, 2023
- April 20, 2023
- May 18, 2023
- June 15, 2023

Attendance

- **Committee Members**
 - Andy Flescher
 - Bob Truog
 - Carrie Thiessen
 - David Bearl
 - Ehab Saad
 - Felicia Wells-Williams
 - Glenn Cohen
 - Jen Dillon
 - Keren Ladin
 - Megan Urbanski
 - Melissa Anderson
 - Sanjay Kulkarni
 - Sena Wilson-Sheehan
 - Thao Galvan
- **HRSA Representatives**
 - Edna Dumas
 - Jim Bowman
 - Marilyn Levi
- **SRTR Representatives**
 - Bryn Thompson
- **UNOS Staff**
 - Catherine Parton
 - Cole Fox
 - Kieran McMahon
 - Kim Uccellini
 - Krissy Laurie
 - Kristina Hogan
 - Laura Schmitt
 - Lindsay Larkin
 - Sarah Booker
 - Stryker-Ann Vosteen
 - Thomas Dolan
- **Other Attendees**
 - Jim Kim
 - Martha Pavlakis