

## **OPTN Policy Oversight Committee**

### **Meeting Summary**

**March 9, 2022**

**Conference Call**

**Nicole Turgeon, MD, FACS, Chair**

**Jennifer Prinz, RN, BSN, MPH, CPTC, Vice Chair**

### **Introduction**

The Policy Oversight Committee (the Committee) met via teleconference on 03/09/2022 to discuss the following agenda items:

1. Project Benefit Scoring
2. New Project Review

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

#### **1. Project Benefit Scoring**

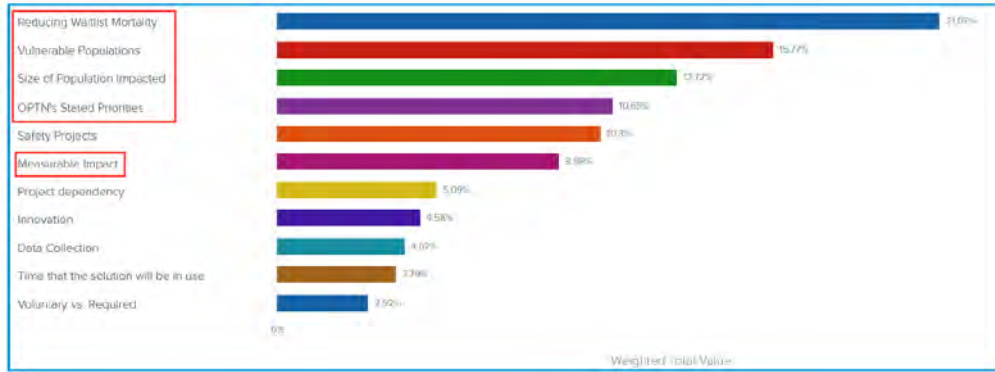
The Committee is in the process of identifying which attributes are most useful as components of a benefit score to aid the Committee in evaluating proposed new projects, and how much relative weight each should have. The goal of the project is create a tool that can reliably assist the Committee in the benefit scoring of projects.

#### Data summary:

The Committee grounded their discussion in three projects. Two were previously approved projects with which the Committee was already familiar, and the other was a project planned for review in the same meeting.

- **DonorNet<sup>SM</sup> Clinical Data Collection**
  - Intends to improve data available at the time of organ offer to increase allocation efficiency.
- **Pediatric ABOi Transplants**
  - Intends to increase the availability of ABO incompatible transplants to medically urgent pediatric patients and decrease waiting list mortality.
- **VCA Living Donor Uterus Data Collection**
  - Intends to increase data collection on living uterus donors to avoid long term safety events.

The results of the Committee AHP exercise were also shown, identifying the highlighted attributes as most valuable. The Committee agreed that whether a project was a Safety Project was already outlined already in the strategic priorities for the Committee, as well as the OPTN as a whole, and therefore it was excluded.



Each category has a tiered structure rating a project’s projected impact as “High”, “Medium”, “Low”, or “None”. These tiers have specific definitions depending on their category.

Summary of discussion:

The Vascularized Composite Allograft (VCA) Committee Vice-Chair commented that some necessary proposals may not score well on reducing waitlist mortality. The Chair responded by noting that the goal is to create a composite score that accurately reflects the benefit of the project; if the project does not score well for that attribute, it should consequently have a greater impact than other projects in a different area. Additionally, the composite score is intended to be a tool, rather than the metric off of which the Committee bases their decision.

The VCA Vice-Chair added that the VCA field is not as large as others, and therefore may not have the ability to impact as large a population as other organs. Furthermore, VCA transplants are frequently quality of life improvements and likely won’t significantly reduce any waitlist mortality. The Chair replied that this is absolutely something the Committee should consider in developing the framework. While the proposed metrics include overall numbers of patients impacted, they also include a measure of the portion of the relevant group; for that measure, a project that affected all VCA candidates would have the same score as a project that would affect all kidney candidates.

The Liver & Intestine Committee Vice-Chair suggested that the “Reducing Waitlist Mortality” could be renamed as it includes projects that increase the longevity of graft survival. This was supported by a number of Committee members. The Operations and Safety Committee (OSC) Vice-Chair contributed that while it is useful that the goal of this project is to assign points to an otherwise qualitative measure, it does feel somewhat “forced”. They expressed concern that committees submitting projects to the Committee will adapt to the scoring system to achieve the highest score possible for their project. The Chair acknowledged this is a valid concern, but the Committee needs to start approaching project review from a standardized perspective. In addition, this review process may not be what the Committee ultimately decides on, but it can serve as a mechanism for discussion for what is needed in a standardized review tool. The Living Donor Vice-Chair also expressed concern that an unintended consequence of the review system may be programs listing fewer candidates in order to increase the percentage of patients impacted by policy proposals. This was position was furthered by the Data Advisory Committee (DAC) Vice-Chair who noted that waitlist mortality is a very easily manipulated values through a number of levers. The Chair then posed the question of whether the Committee should reconsider reducing waitlist mortality as a metric in their evaluation. This was supported by the OSC and DAC Vice-Chairs, but the Liver & Intestine Vice-Chair resisted striking the category entirely, noting that the category encompasses waitlist mortality, graft survival, and access to transplant, all of which are very present in patients’ minds. An attendee from the Scientific Registry of Transplant Recipients (SRTR) also supported a reimagining of the category, rather than an altogether removal, as reducing transplant

mortality is and should be a “laudable goal”. The Ad Hoc Multi-Organ Transplantation (MOT) Committee Vice-Chair also added that removing waitlist mortality could impact low socioeconomic transplant candidates by encouraging programs to be more selective.

In a brief review, to ensure there were no similar objections, the Committee voiced support for maintaining vulnerable populations, size of population impacted, OPTN’s stated priorities, and measurable impact in their evaluation. The Living-Donor Vice-Chair stated that living donors should be added to the vulnerable populations list, which the Chair agreed with.

UNOS Staff then distributed the Committee’s test use of the tool for scoring the projects DonorNet Clinical Data Collection, Pediatric ABOi Transplants, VCA Living Donor Uterus Data Collection.

The Chair noted that when reviewing projects, some did not identify size beyond specific populations (i.e. “the pediatric heart population”) which does not provide a scale for population impacted. Staff responded that they would be updating the project forms to ensure that all elements necessary for review would be available.

Next steps:

The Committee will continue their review, as well as the results of the tool, in a following meeting.

## **2. New Project Review**

The Committee reviewed proposed new projects seeking approval from the Committee.

Data summary:

- **Enhancements to DonorNet Clinical Data Collection (OPO Committee)**
  - Intends to update clinical data reported in DonorNet to better capture information used by transplant hospitals during donor and organ evaluation
- **Update OPTN Kidney Paired Donation (KPD) Policy (Kidney Committee)**
  - Intends to review existing KPD policies and proposes minor modifications for efficiency and alignment with other OPTN policies.
- **Transparency in Transplant Program Selection, White Paper (Ethics Committee)**
  - Intends to conduct an ethical analysis of the need for transparent, accessible, patient-centered data to increase patient autonomy when selecting a transplant program to pursue listing. This white paper focuses on the ethical foundations of increasing access to data to improve shared decision-making between transplant programs and candidates seeking waitlisting.

Summary of discussion:

The discussion lead noted that the Enhancements to DonorNet Clinical Data Collection project may require additional input from committees to determine where system burden may occur. With no further discussion, the Committee approved the project.

The Immediate Prior Chair for the Committee contributed that, when the original project for Transparency in Transplant Program Selection was approved by the Committee, the goal was to create a tool for the Data Advisory, Minority Affairs, and Patient Affairs Committees (PAC). Now that the project is in stage two, the Immediate Prior Chair suggested it may be more appropriate to approach the proposal as a project rather than a white paper, adding that the goal of increasing transparency for those committees may not be well attuned to the design of an outward facing white paper, but emphasized continued support for overall goal of the Ethics Committee.

The Vice-Chair of the Ethics Committee responded that part of the goal with a white paper is not just to advise the identified committees, but also to demonstrate to the transplant community at large that there is a commitment to transparency and equity. The Ethics Vice-Chair also stressed that, within the white paper, the Ethics Committee is not attempting to dictate what data transplant programs should gather; instead, they are creating recommendations for how and what data should be available for patients.

A member replied that even recommendations can influence program behavior. The white paper may unintentionally reduce organ offers for candidates if programs change their behavior based off of any proposed metrics. The Ethics Vice-Chair stated that they only want to increase data availability for patients, rather than judge that data through any metrics, but will return to their committee with the question of whether there is a point of too much information availability. The DAC Vice-Chair supported the Ethics Vice-Chair's point that a public facing white paper will raise visibility for the issue and that fostering a conversation was the place to start. The PAC Chair and Vice-Chair also supported the white paper as it would give the PAC a foundation upon which they could begin discussing what information should be available to patients. The Committee voted to approve the project.

Next steps:

The sponsoring committees will review the Committee's feedback from approval.

**Upcoming Meetings**

- March 28, 2022
- April 11, 2022

## Attendance

- **Committee Members**
  - Nicole Turgeon
  - Jennifer Prinz
  - Sandra Amaral
  - Scott Biggins
  - Marie Budev
  - Richard Daly
  - Lara Danziger-Isakov
  - Alden Doyle
  - Nahel Elias
  - Garrett Erdle
  - Andrew Flescher
  - PJ Geraghty
  - Alexandra Glazier
  - Jim Kim
  - John Lunz
  - Molly McCarthy
  - Sumit Mohan
  - Oyedolamu Olaitan
  - Nataile Santiago Blackwell
  - Susan Zylicz
- **HRSA Representatives**
  - James Bowman
  - Marilyn Levi
- **SRTR Staff**
  - Ryutaro Hirose
  - Jon Snyder
- **UNOS Staff**
  - James Alcorn
  - Sally Aungier
  - Nicole Benjamin
  - Rebecca Brookman
  - Roger Brown
  - Matt Cafarella
  - Cole Fox
  - Amber Fritz
  - Betsy Ganz
  - Chelsea Haynes
  - Kristina Hogan
  - Robert Hunter
  - Courtney Jett
  - Lindsay Larkin
  - Krissy Laurie
  - Lauren Mauk
  - Meghan McDermott
  - Elizabeth Miller

- Rebecca Murdock
- Kelley Poff
- Amy Putnam
- Tina Rhoades
- Liz Robbins
- Janis Rosenberg
- Laura Schmitt
- Brian Shepard
- Sharon Shepherd
- Kristen Sisaithong
- Leah Slife
- Susie Sprinson
- Kaitlin Swanner
- Kayla Temple
- Susan Tlusty
- Kimberly Uccellini
- Joann White