OPTN Data Advisory Committee Meeting Summary December 13, 2023 Conference Call

Sumit Mohan, MD, MPH, Chair Jesse Schold, PhD, M.Stat, M.Ed, Vice Chair

Introduction

The Data Advisory Committee ("Committee") met via WebEx teleconference on 12/13/2023 to discuss the following agenda items:

- 1. Promote Efficiency of Lung Allocation
- 2. Help Text Updates
- 3. Revise Donor and Recipient Histocompatibility Forms
- 4. Membership and Professional Services Committee (MPSC) Concept Paper Overview: OPO Performance Monitoring Metrics
- 5. Pre-Waitlist Data Collection Workgroup

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

1. Promote Efficiency of Lung Allocation

The Chair of the Lung Transplantation Network (OPTN) Committee shared the progress made to promote lung allocation, including proposing adding history of anaphylaxis to peanut and trees as well as sternotomies. The following proposed elements were reviewed against the Data Element Standard of Review Checklist.

Summary of discussion:

The Chair of the DAC asked how the offer filters will work. In response, the Chair of the Lung Committee noted that they have a plan to monitor offer filters as they progress. Another committee member asked how the Lung Committee plans on educating the community about the proposed changes. The Lung Committee Chair noted that there will be educational content going out to the Organ Procurement Organizations (OPOs). An additional member asked whether there will be material on the differences between allergy versus anaphylaxis. The Lung Chair noted that they will investigate adding that into their education content. Finally, support staff asked for an endorsement of the project. The DAC endorsed the Lung Committee's proposals.

Next steps:

This proposal will go to public comment from January to March 2024 and may appear for an additional check-in before the DAC during Spring 2024. In June 2024 the Board will review the measure.

2. Help Text Updates

The United Network for Organ Sharing (UNOS) Enterprise Data Management (EDM) Data Quality Lead introduced help text updates to the lung composite allocation score (CAS) calculator. The help text updates included clarified blood sources above the calculator.

Summary of discussion:

The Chair asked whether the proposed change was strictly for the language or the calculation. The Lung Chair responded by saying that the changes are strictly for language. Support staff called for any objections to the proposed changes and the Committee voted unanimously in support of changes to the help text.

Next steps:

The Data Quality Lead of EDM will work to move the changes to production.

3. Revise Donor and Recipient Histocompatibility Forms

Summary of discussion:

The Chair of the DAC asked about the severity of the discrepancies described and support staff answered that while they do not have all the variables that go into the discrepancies, the Histocompatibility Committee is working on it. Another member noted that the reliability of the data is additionally important to consider and that the OPTN should investigate where these errors are occurring and why. A support staff member of the DAC requested a call for endorsement, which was unanimous.

Next steps:

The proposal made by the Histocompatibility Committee will be moved to public comment.

4. Membership and Professional Standards Committee (MPSC) Concept Paper Overview: OPO Performance Monitoring Metrics

The MPSC Lead provided the DAC with an update on the OPO performance monitoring workgroup where the workgroup is looking to develop a concept paper to go out for Winter 2024 public comment from January to March. – how to standardize data collection.

Summary of discussion:

A member of the Committee noted that they support this and would like to also note that they should pinpoint ethical barriers for the proposed tool as well. They also mentioned that they should be cognizant of data burden and the knowledge for implementation. Another committee member provided their strong support for this proposed measure. The Vice Chair asked if the MPSC had any contact with donor hospitals or Centers for Medicare and Medicaid Services (CMS). The Data Advisory Committee (DAC) chair responded that the MPSC will plan to relay information to CMS, but that no specific conversations had occurred yet. Support staff for the DAC asked for endorsement of this proposal and it was endorsed.

Next steps:

The proposal will be taken to public comment from January to March 2024.

5. Pre-Waitlist Data Collection Workgroup

A support staff of the DAC provided an update on the pre-waitlist data collection workgroup and the HRSA directive. The pre-waitlist data collection workgroup worked to enhance data collection forms, and analyze the required elements for referral and evaluation.

Summary of discussion:

A member of the Committee asked how the data will be transferred and a support staff member noted that solutions and options will be discovered through the working group.

Next steps:

The pre-waitlist data collection workgroup will work to enhance data collection efforts and will meet in person in January 2024 to discuss potential ideas.

Upcoming Meeting

• January 8, 2024

Attendance

Workgroup Members

- o Sumit Mohan
- o Jesse Schold
- o Rebecca Baranoff
- o Jamie Bucio
- o Kate Giles
- o Dustin Goad
- o Michael Ison
- o Paul MacLennan
- o Michael Marvin
- o Christine Maxmeister
- o Meghan Muldoon
- Hellen Oduor
- o Jennifer Peattie
- o Julie Prigoff
- o Alicia Skeen
- o Allen Wagner

• HRSA Representatives

- o Adrienne Goodrich-Doctor
- o Chris McLaughlin
- o Daniel Thompson

• SRTR Staff

- o Avery Cook
- o Ryu Hirose
- o Jon Snyder

• UNOS Staff

- o Asma Ali
- o Brooke Chenault
- o Jonathan Chiep
- o Kevin Daub
- o Cole Fox
- o Richard Hennings
- Gabrielle Hibbert
- o Nadine Hoffman
- Houlder Hudgins
- o Sevgin Hunt
- o Courtney Jett
- o Beth Kalman
- o Sara Langham
- o Eric Messick
- o Lauren Mooney
- o Joel Newman
- o Leah Nunez
- o Kelley Poff
- o Sharon Shepherd
- o Holly Sobczak

- o Kaitlin Swanner
- o Susan Tlusty
- o Kim Uccellini
- o Roger Vacovsky
- o Joe Watson
- o Divya Yalgoori
- o Anne Zehner
- Other Attendees
 - o Marie Budev
 - o Rachel Patzer