

OPTN Data Advisory Committee

Meeting Summary

March 13, 2023

Conference Call

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

Introduction

The Data Advisory Committee (DAC) met via Citrix GoToMeeting teleconference on 03/13/2023 to discuss the following agenda items:

1. Check-in: Living Donor Committee Concept Paper
2. Public Comment Proposal: Optimizing Usage of Kidney Offer Filters
3. Check in: Operations and Safety Committee, Collection Donor CRRT, Dialysis, and ECMO Data
4. Request for DAC Endorsement: MPSC Recommendation to Change OPTN Data Collection in Safety Situations

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

1. Check-in: Living Donor Committee Concept Paper

A representative from the OPTN Living Donor Committee presented two projects that will be combined into a single concept paper to seek community feedback. The two projects are *Granular Review of OPTN Living Donor Collection Forms* and *Collect Living Donor Candidate and Donation Decision Data*. Members of the DAC are currently involved in these projects with representation on an OPTN Living Donor Data Collection Workgroup.

Overview of Proposals:

Granular Review of OPTN Living Donor Collection Forms

Review all data elements on the OPTN living donor data collection forms, and provide recommendations to modify, delete, or add to ensure accurate and relevant data collection on living donors.

Collect Living Donor Candidate and Donation Decision Data

Require the OPTN to collect living donor candidate and donation decision data. This shift in OPTN living donor data collection to more upstream efforts intends to support the SRTR Living Donor Collective to collect long-term follow-up data on living donors.

Summary of discussion:

A SRTR representative stated support for the proposal because it would help reduce burden for transplant programs by shifting the responsibility of long-term follow-up to the SRTR. The SRTR representative stated this proposal would also allow for data collection on a potential control group.

The Chair noted that it is valuable to understand the individuals who are medically eligible to be a living donor, but do not proceed to donation. The Chair noted concern for the data collection burden that is associated with collecting data on every living donor candidate, as a lot of individuals approach transplant programs for interest in living donation. The Living Donor Committee representative stated

that they do not wish to overburden transplant programs, so they are discussing definitions for living donor candidate as well as the amount of data to collect. The Vice Chair stated that the definition for living donor evaluation and living donor candidate must be very clear. The Chair encouraged that pre-transplant definitions, such as evaluation, should align between living donor candidates and transplant candidates.

A SRTR representative stated that the Living Donor Collective defined a living donor candidate as an individual that was seen at a transplant program for evaluation. The Chair stated that the definition of evaluation may vary among transplant programs.

The Vice Chair urged the Living Donor Committee to consider the appropriate key metrics for this proposal to determine success as well as any unintended consequences.

The DAC endorsed the Living Donor Committee's concept paper.

Next steps:

The Living Donor Committee will continue to check-in with the DAC as the projects develop.

2. Public Comment Proposal: Optimizing Usage of Kidney Offer Filters

A representative of the OPTN Operations & Safety Committee presented their public comment proposal, *Optimizing Usage of Offer Filters*.

Summary of discussion:

The Chair asked for more information regarding the specifics of the initial offer filters. The Operations & Safety Committee representative stated that the default filters would be indicated by previous practices of the transplant program, while also allowing the ability for transplant programs to create their own filters and modify the default filters.

The Chair stated that three months is too frequent of a timeframe for re-evaluation of offer filters. The Chair explained that transplant programs may not have the administrative bandwidth to perform a review of offer filters at that frequency. The Chair added that three months may be too short of a time period for smaller transplant programs due to the small amount of data.

The Chair stated that the risk associated with mandatory offer filters could be that it would create a group of conservative transplant programs with very restrictive acceptance practices because the offer filters locked them into those practices. The Chair stated this may be a disservice to patients, particularly in less densely populated areas where there is less access to transplant programs.

The Chair stated that it is difficult to determine what portion of the deceased donors a transplant program is excluding themselves from for any given offer filter, and therefore it may be difficult to determine the impact on access to transplantation for candidates on the waitlist. The Chair added that transplant programs should be transparent in their use of offer filters so that patients can make informed health care decisions. The Operations & Safety Committee representative agreed and added that utilizing offer filters helps increase efficiency in the offer and acceptance processes.

The Vice Chair expressed concerns regarding the iterative nature of default offer filters which may make it difficult for transplant programs to become more aggressive over time. The Vice Chair added that there should be an empirical way to inform how predictive the last several months of organ offer and acceptances may be, and this would be impacted by the volume size.

Next steps:

The DAC's feedback will be summarized and submitted to the Operations & Safety Committee for consideration.

3. Check in: Operations and Safety Committee, Collect Donor CRRT, Dialysis, and ECMO Data

A representative of the OPTN Operations & Safety Committee presented their project, *Collect Donor CRRT, Dialysis, and ECMO Data*.

Overview of Proposal:

To collect data on donor support therapies to promote the efficient review of organ offers from donors on CRRT and ECMO. This data will provide granular information to include in the ongoing offer filters effort. It will also standardize the reporting of these data. There is not another data source for this information, so this will require additional data collection in the OPTN Donor Data and Matching System.

Summary of discussion:

The Chair supported this effort and stated that this data is needed.

The DAC endorsed the Operations & Safety Committee's data collection project.

Next steps:

The Operations & Safety Committee will continue to check-in with the DAC as the project develops.

4. Request for DAC Endorsement: MPSC Recommendation to Change OPTN Data Collection in Safety Situations

The DAC received a presentation on the Membership & Professional Standard's Committee's (MPSC) recommendation to change OPTN data collection in safety situations.

Overview of Proposal:

MPSC is recommending to remove some data fields and sub-category choices to reduce member confusion and data entry burden, and streamline data collection.

Safety Situation Form – five recommended removals

- Type of safety event
- Recipient/candidate social security number
- "did this event involve the entire donor or were only specific organs involved?"
- Organ type
- "Did this safety situation cause or contribute to:"

Living Donor Event Form – two recommended adjustments; keep data fields and remove sub-category selections

- Organ is recovered but not transplanted into any recipient
- Organ is recovered and transplanted into someone other than intended recipient

Summary of discussion:

The Chair expressed concern with removing discrete data fields because then it will be difficult to determine quantifiable and trend-able analyses. Staff clarified that the recommended data removals are collected elsewhere as part of the case review.

The Vice Chair stated that these events are so rare, this should not be a large data burden on transplant programs.

The Vice Chair recommended that the data is synthesized on the backend so that the information is still codified. The Vice Chair explained that the intent needs to be improving the data rather than eliminating the data.

The DAC endorsed MPSC's recommendations with the caveat that the MPSC should ensure the data is codified somewhere other than narratives.

Upcoming Meetings

- April 10, 2023 (teleconference)
- May 8, 2023 (teleconference)

Attendance

- **Committee Members**
 - Sumit Mohan
 - Jesse Schold
 - Rachel Patzer
 - Daniel Stanton
 - Farhan Zafar
 - Jamie Bucio
 - Christine Maxmeister
 - Michael Marvin
 - Rebecca Baranoff
 - Paul MacLennan
 - Meghan Muldoon
 - Michael Ison
- **HRSA Representatives**
 - Adriana Martinez
- **SRTR Staff**
 - Ajay Israni
 - Jon Snyder
- **UNOS Staff**
 - Anne Zehner
 - Brooke Chenault
 - Carlos Martinez
 - Eric Messick
 - Isaac Hager
 - Joann White
 - Joel Newman
 - Kerrie Masten
 - Kim Uccellini
 - Laura Schmitt
 - Lauren Mauk
 - Meghan McDermott
 - Michael Hollister
 - Nadine Hoffman
 - Rebecca Brookman
 - Rob McTier
 - Sevgin Hunt
 - Sharon Shepherd
 - Stryker-Ann Vosteen
 - Suhuan Wang