

OPTN Data Advisory Committee

Meeting Summary

July 10, 2023

Conference Call

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

Introduction

The Data Advisory Committee met via Citrix GoTo teleconference on 07/10/2023 to discuss the following agenda items:

1. Check-in 2: Ops and Safety, Collect CCRT, Dialysis, and ECMO Interventions Data; *Deceased Donor Support Therapy Data Collection*
2. Welcome to new Committee members
3. Review of materials on Sharepoint and OPTN website
4. Ways to submit new project ideas

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

1. Check-in 2: Ops and Safety, Collect CCRT, Dialysis, and ECMO Interventions Data; *Deceased Donor Support Therapy Data Collection*

A committee member representing the Operations and Safety Committee (henceforth the OSC), introduced the topic of the deceased donor support therapy data and shared the purpose of the presentation – to update the Data Advisory Committee (henceforth the DAC) on the progress of the proposal, review progress around evaluating proposed elements against the Data Element Standard of Review Checklist, and obtain feedback from the DAC.

Summary of discussion:

Decision #1: The DAC members endorsed the data collection changes proposed by the OPTN Operations and Safety Committee.

The OSC committee member presented the proposal's key points, beginning with the rationale behind collecting more detailed information on deceased donors, especially regarding support therapies in donor evaluation, noting the current data is incomplete. The proposed information to be collected will provide granular information to include the ongoing offer filters effort, standardize the reporting of data, and allow for the evaluation of post-transplant outcomes. The flexibility of the proposed system to adapt to evolving support therapy methods was emphasized. It was noted the data collection would focus on post-transplant outcomes and required new fields in the OPTN Donor Data and Matching System.

The proposal aims to introduce seven new fields related to support therapy, with cascading options for more detailed data based on a 'Yes' response. It was noted that as donors' situations evolve, the data would remain dynamic. The information collected would be in the OPTN Donor Data and Matching System and populated into the OPTN Data System. They emphasized the requirement of a 'Yes' or 'No' response in the parent field, which would trigger the cascade of additional information.

A mock-up of the data entry system was presented, illustrating the parent field and the cascading options upon selecting 'Yes.' The OSC committee member highlighted the need for more comprehensive support therapy data due to advancements in the field and suggested removing redundant information spots to align with the proposed standardized approach. This was done by using the current collection process for Extracorporeal Membrane Oxygenation (ECMO) as an example. In the new proposal, this field would be removed, and the same information would be collected in another field aligning with the way other support data is being collected.

The OSC committee member proceeded to discuss the alignment of data collection principles with the Final Rule and how this would enhance efficiency of organ offers and safe transplantation. Examples were provided of parent fields and their cascading responses, highlighting the importance of capturing when therapies were initiated. The new data collection process was designed to mimic the way information is presented in an electronic medical record (EMR) for a more intuitive and recognizable experience for coordinators, ensuring a higher level of data quality.

Another OSC committee member reaffirmed the importance of standardized support therapy information and the lack of its current availability in electronic health records (EHR). They emphasized the collaborative nature of discussions with various committee representations and the consensus on the significance of this data and its need for standardization.

The OSC committee member continued, providing the next steps for this proposal will be submitting it for public comment during the Fall 2023 public comment period. The Data Advisory Committee will be updated should the feedback received during public comment impact the data collection. They then requested feedback from the DAC committee members regarding the proposed 'Yes' 'No' parent field requirement.

A DAC committee member recommended presenting the mock-up to the individuals who would be entering this data to triage questions, identify potential entry issues, and gain knowledge on potential snags the proposal implementation would create. They also inquired about the potential incorporation of changes related to procurement types and normothermic regional perfusion (NRP) given there might be some overlap in different changes in donor procurements.

The OSC committee member responded by noting the rapidly changing field and their idea to remedy this by possibly building in a basic process which could be adapted as things change. They provided an example of this by citing discussions about types of dialysis and the need to avoid hyper-specificity as there are different ways in which continuous dialysis can be administered. They again highlighted the need for the collection processes in this proposal to be flexible and be capable of keeping up with the rapidly evolving support therapy technology and protocols.

It was posited there is limited value in the optional fields in the current collection forms as people regularly opt not to enter in that information creating systematic differences when others do enter the optional information. This sentiment was echoed by another DAC committee member.

Another DAC committee member suggested visual examples of the drop-down fields once 'Yes' is selected as the number of supportive therapies is quite large which can create a potential downfall of the proposed data collection process. If too many options are available for the OPOs to enter, and the variable nature of support therapies regarding medication dose management and medication changes, this would create a burden for the OPOs to keep up with and necessitate a large time commitment for data entry. They noted more visual examples would be good for the public comment period as comments like this would be proactively eliminated.

The OSC committee member acknowledged the feedback and indicated that the proposed categories aimed to capture broad support therapy types. The DAC was assured that this information was intended to alert coordinators and clinicians to specific therapies without delving into detailed dosages. A chart was provided to show the DAC committee member proposed examples of these broader delineation of support therapies. They noted the importance of the feedback and suggestions provided and assured the DAC that they were being considered in refining the proposal.

Support staff requested any objections to endorsing the OSC proposal. No objections were voiced by the DAC.

2. Welcome to new Committee members

The Committee took a moment to welcome the new members to the Data Advisory Committee.

3. Review of materials on Sharepoint and OPTN website

The Committee provided the new members with a refresher on the Committee materials on Sharepoint and information found on the OPTN website.

4. Ways to submit new project ideas

The Committee instructed new members how to submit new project ideas.

Upcoming Meetings

- August 14, 2023
- September 11, 2023
- September 28, 2023 (in-person)

Attendance

- **Committee Members**
 - Sumit Mohan
 - Jesse Schold
 - Rebecca Baranoff
 - Alicia Biscoe
 - Kate Giles
 - Dustin Goad
 - Michael Marvin
 - Meghan Muldoon
 - Hellen Oduor
 - Jennifer Peattie
 - Julie Prigoff
 - Allen Wagner
- **HRSA Representatives**
 - Adriana Martinez
- **SRTR Staff**
 - Ajay Israni
- **UNOS Staff**
 - Brooke Chenault
 - Kevin Daub
 - Nadine Hoffman
 - Michael Hollister
 - Gene Khabinsky
 - Krissy Laurie
 - Elena Liberatore
 - Kerrie Masten
 - Meghan McDermott
 - Lauren Mooney
 - Janis Rosenberg
 - Laura Schmitt
 - Kim Uccellini
 - Deb Vicars
 - Joe Watson
 - Joann White
 - Divya Yalgoori
 - Anne Zehner
- **Other**
 - Alden Doyle