

OPTN Data Advisory Committee

Meeting Summary

October 3, 2022

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 10/03/2022 to discuss the following agenda items:

1. Post-public comment updates
2. Endorsement of consent materials
3. Notice about HRSA directive on race and ethnicity data collection

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

1. Post-public comment updates

Representatives from the OPTN Organ Procurement Organization (OPO) and Lung Transplantation Committees provided an update on the data collection components of their proposals, following feedback received during public comment. The update is part of the check-in process to ensure a consistent, systematic approach to assessing data and data collection instruments.

Summary of discussion:

OPO Committee – Enhancements to OPTN Donor Data and Matching System Clinical Data Collection

A member inquired about the implementation timeline. Pending Board approval in December 2022, the usual implementation timeline is 12 months; however, DonorNet data collection forms are in the process of undergoing OMB approval so the implementation timeline will likely be closer to 18 months or more. All OPTN data is currently in a transition plan to receive OMB approval.

Lung Committee – Update Data Collection for Lung Mortality Models

A member inquired how some of this data collection could be utilized, where appropriate, for other relevant organ types from a more holistic perspective. Enterprise Data Management staff added that DAC's Holistic Data Review Workgroup is developing a framework for reviewing and revising data from a holistic perspective to make modifications, like suggested, however, in the interim committees, are utilizing the DAC check-in process to ensure consistency. A member suggested that an interim step could potentially be taken to ensure consistency while the framework is being developed by the workgroup. The Chair suggested developing a list of these data as they arise in discussion and identify them as a priority for review once the framework is developed. A member added that in instances like this, where the same data is collected across organs, having consistent definitions is essential for ease and accuracy of use by those inputting the data.

A member noted that 'prior surgeries' felt fairly vague and more detail could improve that data collection field. The presenter responded that the Lung Committee was trying to balance collecting information that would improve mortality predictions without being too burdensome. A member also

suggested ensuring that the terms used for ‘sources of oxygen supply’ are consistently understood by both a clinician and the individual inputting data. The Chair also recommended making the data required, as opposed to optional, to ensure that data is not cherry-picked to influence outcomes. A representative from the Scientific Registration of Transplant Recipients (SRTR) echoed this sentiment, noting the role that this data plays in the Program Specific Reports (PSRs). The SRTR representative recommended a pilot study to better understand the role of this data as an interim step to determining if it should be a required data field.

2. Endorsement of Consent Agenda Items

Enterprise Data Management staff presented the consent agenda for Committee approval. The purpose of this consent agenda is to allow members to review and provide feedback on the data definitions sent via email prior to the meeting in order to expedite the vote.

Data summary:

The definition for ‘Working for Income’ is being revised on the following TEIDI forms:

- Living Donor Registration (LDR)
- Living Donor Follow-Up (LDF)
- Transplant Candidate Registration – Adult (TCR)
- Transplant Recipient Registration – Adult (TRR)
- Transplant Recipient Follow-Up – Adult (TRF)

The definition for ‘Date Last Seen or Death’ is being revised on the following TEIDI forms:

- Living Donor Registration (LDR)
- the Transplant Recipient Registration – All Organs Adult/Peds (TRR)
- Transplant Recipient Follow-Up – All Organs Adult/Peds (TRF)

The definition for ‘HBV Vaccination Status’ is being revised on the TEIDI Transplant Recipient Registration – All Organs Adult/Peds (TRR).

The definition for ‘Data Lock – Unlocking a Form’ is being revised for eight forms in TIEDI.

Summary of discussion:

A member inquired about the ‘last date seen’ definition and noted that it did not include if the transplant center communicated with the patient over the phone or if the patient had been seen at a community physician’s office. The member suggested the Holistic Data Review Workgroup consider revising this definition to be a data field that captures whether or not, and how, the patient is being followed up with. The Chair suggested specifically identifying Committee members with a particular expertise and ensuring they have provided input to the definition.

For the HBV Vaccination status definition, an attendee felt that completion and immunity were not fully answered in this data definition and warned that the modified definition was still insufficient. The Chair suggested that the clinical norm was the standard that the Committee used for the definition.

Ultimately, the group elected to withdraw the HBV Vaccination status from the consent agenda for the current vote. There was a motion and a second to call a vote. A voice vote was conducted and members were asked ‘*Is there anyone opposed to endorsing the data definition clarifications?*’ Without any opposition, there was unanimous support to pass the revised consent agenda.

Next steps:

Enterprise Data Management staff will follow up with the OPTN Ad Hoc Disease Transmission Advisory Committee (DTAC) to revise the HBV Vaccination Status definition for the DAC’s consideration.

3. Notice about HRSA directive on race and ethnicity data collection

Enterprise Data Management staff discussed the directive from the Secretary of the Health and Human Services (HHS) to separate race and ethnicity in OPTN data collection. The purpose of this separation is to better align OPTN data sets with public data sources.

Summary of discussion:

A member inquired if there is a multiple selection process to self-identify, which the presenter confirmed. A member inquired if this data is currently labeled as self-identified and recommended that this be highlighted or bolded to ensure accuracy and consistency in data collection. A member inquired if there has been consideration to have an open text field available under 'other' to gather more granular data. The Chair echoed this recommendation and suggested widespread communication to educate the community about this change.

Upcoming Meetings

- November 7, 2022
- December 12, 2022
- January 9, 2023

Attendance

- **Committee Members**
 - Daniel Stanton
 - Jamie Buccio
 - Jesse Schold
 - Lauren Kearns
 - Michael Ison
 - Megan Muldoon
 - Paul MacLennan
 - Rachel Patzer
 - Sumit Mohan
- **HRSA Representatives**
 - Adriana Martinez
- **SRTR Staff**
 - Ajay Israni
 - Jon Snyder
- **UNOS Staff**
 - Amber Fritz
 - Anne Zehner
 - Brooke Chenault
 - Eric Messick
 - Kim Uccellini
 - Krissy Laurie
 - Laura Schmitt
 - Matt Belton
 - Nadine Hoffman
 - Robert Hunter
 - Serena Straub
 - Sharon Shepherd
 - Suhuan Wang
 - Susan Tlusty
 - Taylor Livelli
- **Other Attendees**
 - Christine Maxmeister
 - Cynthia Gries
 - Kurt Shutterly