

OPTN Data Advisory Committee

Meeting Summary

August 8, 2022

Conference Call

Sumit Mohan, MD, MPH, Chair

Jesse Schold, PhD, M.Stat., M.Ed., Vice-Chair

Introduction

The Data Advisory Committee (the Committee) met via Citrix GoToMeeting teleconference on 08/08/2022 to discuss the following agenda items:

1. Externally Verified Deaths Report
2. Updates

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

1. Externally Verified Deaths Report

The Committee continued their discussion on the verified deaths report delivered by research staff.

Data summary:

Summary of report:

- Sources of death data are variable by hospital
- Post-waitlist removal deaths are less likely to be member reported than post-transplant deaths
 - The majority of member reported post-waitlist deaths are due to the candidate being removed due to death
- There are higher proportions of Hispanic/Latino patients in the unverified deaths group both between post-waitlist removal and post-transplant
- Larger proportions of post-transplant externally verified and unverified deaths occurred after graft failure or lost to follow up compared to member reported deaths
- Higher rates of unverified deaths come from patients who were at a program have had their membership withdrawn

Summary of discussion:

The Vice-Chair commented that the proportion of unverified deaths would likely be higher than what was shown, as it was being delivered as a proportion of all deaths since 2005, but unverified deaths were not considered until 2013. The ex-officio indicated interest in seeing the data broken out into different time periods to see the impact at different times.

The Chair inquired how gaps in the dataset are remedied, or have been remedied in the past. Staff noted that there are not policy requirements for much of the reporting that informs the dataset, so there is not a route to address those quality concerns. They added that if the Committee wanted to pursue that, it would need to be through the development of a policy proposal. The Chair requested more information surrounding data discrepancies, and staff responded that they would inquire with member quality staff.

The Vice-Chair wondered how many of the patients were reported dead after being reported as lost to follow up versus those that had been considered still followed by the transplant program. They considered that this could reveal a lot about centers' practices surrounding follow-up care.

The Vice-Chair also asked if the proportion of programs that have had their membership withdrawn compared to those still active could be shared in a subsequent meeting. They emphasized that the newly added data is systematically different by a number of factors, noting race, listing center, and membership status.

The Chair noted that nearly half of the liver and heart patients at time of reporting in the new data set were considered lost to follow up; they were surprised at this, as they considered there were not the same community support services for liver and heart patients as there were for kidney patients. Staff also speculated this may be influenced by the COVID-19 pandemic, which the Chair resisted, considering that many of these patients came to their transplant program seeking advice regarding the pandemic.

It was asked what lengths programs go to for follow up with their patients. A member replied that they are very active in attempting lifetime follow-up, adding that their center does a lot of research informed by that data. The ex-officio wondered if this process would be feasible for smaller centers, and how the Committee could encourage this kind of behavior.

The Vice-Chair asked if programs were able to see their own data through the data services portal in a more in-depth format than the standard transplant analysis and research (STAR) file. Staff replied that some information may be available (dialysis restart dates, graft failure dates), but likely not to the level of detail that a program would be looking for. The Vice-Chair proposed an idea in which programs are notified when a patient may be dead, and the program can do their own verification on the death to report it.

The Chair, the Vice-Chair, and multiple members of the Committee agreed that, from a data standpoint, much of the removal reasons for the candidates in the deaths dataset being other was functionally useless. The Chair added that, because this will soon be a regulatory measure, the removal codes need more clarity for their reasons.

A member inquired what the requirement was for a program to delist a patient when they became too sick to transplant. Staff responded that there was no requirement, and it was determinant on center-specific practices to evaluate and delist.

Next steps:

Research staff will deliver the final elements of the data request at the following meeting. Policy and Community Relations Staff will request Member Quality report on data quality compliance.

2. Updates

The Committee has their in-person meeting on September 7, 2022.

The Data Lock Policy will go into effect on August 30, 2022.

Upcoming Meeting

- September 7, 2022

Attendance

- **Committee Members**
 - Sumit Mohan
 - Jesse Schold
 - Rebecca Baranoff
 - Elizabeth Boehnlein
 - Jamie Bucio
 - Earnest Davis
 - Michael Ison
 - Macey Levan
 - Paul MacLennan
 - Krishnaraj Mahendraraj
 - Bilal Mahmood
 - Michael Marvin
 - Meghan Muldoon
 - Rachel Patzer
 - Benjamin Schleich
 - Daniel Stanton
- **HRSA Representatives**
 - Shannon Dunne
 - Adriana Martinez
 - Chris McLaughlin
- **SRTR Staff**
 - Ajay Israni
 - Bert Kasiske
 - Jonathan Miller
 - Bryn Thompson
- **UNOS Staff**
 - Sally Aungier
 - Matt Belton
 - Brooke Chenault
 - Isaac Hager
 - Nadine Hoffman
 - Courtney Jett
 - Krissy Laurie
 - Eric Messick
 - Joel Newman
 - Samantha Noreen
 - Janis Rosenberg
 - Sharon Shepherd
 - Christopher Sweeny
 - Kimberly Uccellini
 - Anne Zehner
- **Other Attendees**
 - Christine Maxemeister