OPTN ORGAN PROCUREMENT AND TRANSPLANTATION NETWORK

OPTN Data Advisory Committee
Meeting Summary
July 11, 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 07/11/2022 to discuss the following agenda items:

1. Welcome Incoming Members
2. Externally Verified Deaths Pt. 1

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

1. Welcome Incoming Members

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

2. Externally Verified Deaths Pt. 1

The Committee reviewed the data request on the externally verified deaths under new process (March 2022) and deaths by source of death information. This presentation was delivered by Research Staff.

Data summary:

- Goal of the data request: Continually increase the quality of OPTN data collected and explore the use of external data to supplement policy-making and research
    - OPTN deaths are externally verified by Kidney Epidemiology and Cost Center (KECC)/Centers for Medicare and Medicaid (CMS), Obituaries, or an external partner
    - OPTN and SRTR datasets are slightly different
    - Current cohort is death dates occurring 1/1/2005 – 12/31/2021
    - Impact of COVID-19 was examined
- Key points:
    - Kidney and Kidney/Pancreas had the lowest rate of member reported deaths
    - Most externally verified and unverified deaths occur 5-20 years post-transplant
    - Large variance in the number of unverified transplant recipient deaths amongst programs
    - Waitlist registration deaths after removal are less likely to be member reported than post-transplant deaths

Summary of discussion:

The Chair inquired whether the 35,000 additional deaths that were added to the verified deaths data set were deaths that were not collected by KECC or CMS, to which staff replied affirmatively that they were not deaths verified through those sources. The Vice-Chair added that this update makes the data set seem quite incomplete, due to the method of collection, and expressed a desire for clearer communications to the transplant research community about the limitations of this data set.

The Chair also added that, when reviewing the percentages of program verified, externally verified, and unverified deaths, the scale for the y-axis is 60,000, so the numbers are of externally verified and unverified deaths are quite large even for programs with low percentages. In addition, because of the variance in how programs are reporting deaths, the quality of the data and the analyses performed are impacted, especially with the range of unverified deaths between programs (.2% to 25% unverified).

A member requested the data be broken down by recipient age at time of death, which staff noted was included in the full report, but not the slide presentation. The member also wondered how programs actually reported recipient death to the OPTN. Staff replied that it was either indicated on the Transplant Recipient Follow-Up form (TRF), or, if they were now a candidate on the waiting list, they would update the candidate registration to be reported directly.

Another member suggested the programs could try to gain access to the CMS database of verified deaths such that they would be altered when a candidate died. Staff noted the OPTN has access to the database through a limited-use data use agreement (DUA), but the boundaries of that DUA are being explored. The Chair and Vice-Chair both reiterated that, in the past, there have been stronger ties between programs and the data they use, and they wondered what it would take to reestablish them to increase the quality of OPTN data. They suggested that the Committee could facilitate this process as the Committee is charged with being stewards of OPTN data.

Finally, the Chair considered that when these sort of large updates are made to the data set, especially when viewed by ethnicity or geography, there is the potential for unintended consequences to be found in past policy work that was impacted by this update. They encouraged the Committee to be considering the ways that the OPTN data set could improve its completeness.

Next steps:

The Committee will continue its review of the data request next meeting.

Upcoming Meeting

- August 8, 2022

Attendance

- **Committee Members**
  - Sumit Mohan
  - Jesse Schold
  - Rebecca Baranoff
  - Elizabeth Boehnlein
  - Jamie Bucio
  - Michael Ison
  - Lauren Kearns
  - Paul MacLennan
  - Krishnaraj Mahendraraj
  - Bilal Mahmood
  - Michael Marvin
  - Christine Maxmeister
  - Jonathan Miller
  - Meghan Muldoon
  - Daniel Stanton
- **HRSA Representatives**
  - Shannon Dunne
  - Adriana Martinez
- **SRTR Staff**
  - Bert Kasiske
  - Jon Snyder
- **UNOS Staff**
  - Matt Belton
  - Brooke Chenault
  - Isaac Hager
  - Nadine Hoffman
  - Courtney Jett
  - Eric Messick
  - Joel Newman
  - Sam Noreen
  - Janis Rosenberg
  - Christopher Sweeny
  - Kim Uccellini
  - Scott Verbeke
  - Anne Zehner