

**OPTN Data Advisory Committee  
Meeting Summary  
February 14, 2022  
Conference Call**

**Rachel Patzer, Ph.D, Chair  
Sumit Mohan, M.D., M.P.H., Vice Chair**

## **Introduction**

The Data Advisory Committee (the Committee) met via Citrix GoToMeeting teleconference on 02/14/2022 to discuss the following agenda items:

1. Holistic Approach to Data Collection – Review of SRTR Report
2. Data Definitions Review

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

### **1. Holistic Approach to Data Collection – Review of SRTR Report**

Given the significant time period since the last review of data elements collected by the Organ Procurement and Transplant Network (OPTN), the Committee identified ways to create a systematic review process that will continuously evaluate the creation of new data elements and the use of existing ones. The Scientific Registry of Transplant Recipients (SRTR) had recently produced a report on Kidney-specific organ forms in order to assess the data elements, which the Committee reviewed.

#### Data summary:

The Chair restated their overarching goal of creating a plan for a data element review process that could be brought to the Policy Oversight Committee (POC) for approval. This process would be cyclical and would incorporate feedback from subject matter experts from OPTN Committees.

The SRTR report was a review of data collection forms for kidney candidates, recipients, and living kidney donors. The report proposed recommendations from SRTR senior staff and highlights were data collection could be improved. Furthermore, it identified areas where risk factors not currently collected by OPTN could be included.

#### Summary of discussion:

The Chair posed three questions to a member involved in the SRTR review:

- 1) What was the process for the review, and how were subject matter experts engaged?
- 2) How often is this review expected to be performed?
- 3) How can the DAC collaborate with SRTR to perform this review?

The member responded that SRTR was charged, in their 2015-2020 contract, to review the risk adjustment models used for program evaluation purposes. During this review, a list of potential changes to data collection approaches was informally collected; this list then was formalized as a special study in the most recent contract cycle, and SRTR began investigating the data collection instruments at the OPTN. The intent behind the investigation was to create a useful document that reflected the opinions of SRTR which could be delivered to the Data Advisory, Kidney, and Living Donor committees.

The document was created from a team of SRTR statistician and epidemiology staff and their senior staff, in this case nephrologists that perform kidney transplantation or living kidney donor procedures. Each member of the team could submit comments on any data element under review, which culminated in a review of all of the comments. This final review informed the recommendations put forth. The approach was similar to a report performed by an external program, which specifically focused on the additional data elements that could improve risk stratification evaluation for programs. However, the SRTR report also addressed each data element already captured by the OPTN and provided recommendations.

The Chair inquired how much time the entire process took, as well as how resource-intensive was it? They added that they'd be curious to know if this was a short-term undertaking by SRTR, or whether the Committee should be considering how best to work with SRTR on similar reviews. The member replied that it was done in a nine month timeframe, and that in theory this report will be done on all organ types. Currently SRTR has not started the next organ to review, and would likely appreciate collaboration with the Committee.

A member also asked whether the SRTR review process assessed continued relevancy for collection. The SRTR member noted that in a number of places, the report suggests the relevancy of a data element should be reevaluated. The Chair added that the DAC could also provide feedback in conjunction with SRTR's feedback, and then provide both to organ-specific committees to consider.

The Vice Chair wondered if there were actions the Committee could take that would not duplicate SRTR's work, but rather complement it. It was suggested that the Committee could consider starting with another organ rather than working on the same one as SRTR. Furthermore, another suggestion was to have the Committee form a subcommittee with SRTR, Kidney Committee, and Living Donor Committee representation to develop concrete recommendations for the data elements to take to the POC. The Chair contributed that there should be both front-end and back-end users of the data on the workgroup, to encompass those entering data as well as those using the data. They also asked Staff present if data element recommendations would have to go through Office of Management and Budget (OMB) approval as well as public comment. Staff noted that any revisions to OPTN forms would have to go through OMB approval and public comment.

The Chair also reiterated that the Committee was developing essentially two projects simultaneously – the first is the development of a continuous review process which occurs a set number of years, and the second is any outcomes stemming from that review, which include possible additions, removals, or revisions. A member added that the two should be linked; for example, for every project that comes under review by the Committee, there should be a uniform set of questions that need to be asked. Staff also emphasized that if a regular review process were to exist, it almost certainly would have to be codified as a policy or bylaw change to ensure that resources would be available for proposed changes.

A member commented that some of the data elements collected may be used outside of risk adjustment and program specific reports, so the Committee would have to be careful to assess every use of collected data. Additionally, they also wondered if there were opportunities to combine collected data elements, where data is collected across forms, thereby lowering the data burden by eliminating redundant fields.

Next steps:

The Committee will consider what the charge of a project to create a systematic data review process should be.

## **2. Data Definitions Review**

The Committee had previously given feedback on the proposed updates to data definitions in their December 2021 meeting, and they were given the opportunity to review the definitions updated to include their feedback.

### Summary of discussion:

#### *Date: Last Seen, Retransplanted or Death – Recipient*

- The Chair ensured that any other areas that collected date last seen now also included virtual visits. Staff noted that they had reviewed those areas.
- The Vice Chair inquired whether routine testing constituted being “seen”, or whether the language could be changed to “last visit” or “patient encounter”.
  - It was noted that if the title of the field were to be changed, it would have to be added to the IT queue for production.

#### *Working for Income – Living Donor*

- A member mentioned that they had received questions from programs as to how veterans and active duty military should be reported in this status. Staff noted that they could add that for review on this data element. The Chair suggested reviewing how veteran status is recorded on other OPTN forms or outside of transplant, and if that could be used as guidance.

### **Upcoming Meeting**

- March 7, 2022

## Attendance

- **Committee Members**
  - Rachel Patzer
  - Sumit Mohan
  - Elizabeth Boehnlein
  - Kristine Browning
  - Jamie Bucio
  - Colleen O'Donnell Flores
  - Heather Hickland
  - Krishnaraj Mahendraraj
  - Melissa McQueen
  - Anna Mello
  - Alicia Redden
  - Jesse Schold
  - Daniel Stanton
  - Maryam Valapour
- **HRSA Representatives**
  - Adriana Martinez
- **SRTR Staff**
  - Bertram Kasiske
  - Jon Snyder
- **UNOS Staff**
  - Sally Aungier
  - Brooke Chenault
  - Cole Fox
  - Isaac Hager
  - Nadine Hoffman
  - Olga Kosachevsky
  - Samantha Noreen
  - Sharon Shepherd
  - Leah Slife
  - Susan Tlusty
  - Kimberly Uccellini