OPTN Data Advisory Committee
Meeting Summary
January 10, 2022
Conference Call

Rachel Patzer, MD, PhD, Chair
Sumit Mohan, MD, MPH, Vice-Chair

Introduction

The Data Advisory Committee (the Committee) met via Citrix GoToMeeting teleconference on 01/10/2022 to discuss the following agenda items:

1. Holistic Approach to Data Collection
2. VCA Graft Failure – Checkpoint #2

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

1. Holistic Approach to Data Collection

One of the charges of the Data Advisory Committee is to evaluate and improve the performance of the OPTN, using objective measures. This encompasses recommendations to improve completeness and accuracy of data.

Holistic Review:

The Committee should consider approaching the review process systematically, rather than addressing isolated elements. The Chair proposed that the Committee should start brainstorming how often this review should occur, what organ-specific Committees are required for the review, how relevant the collected data is, and how standardized the reporting for the data is.

Summary of discussion:

A Committee member suggested that, when a data quality report is presented to a transplant program, it may be beneficial to show them how they compare against the other regional or national members. This would allow them to understand how they are performing in a larger context. Additionally, they suggested that a form of a data quality report could be presented at regional meetings, again to provider a larger context for data accountability to programs. The Chair did note that in the Data Services Portal, within the Data Lock Policy tools, programs can create a data report that reviews their performance compared to national performance. A second member added that it may be useful for programs to provide feedback about which data points are the most difficult, or the least useful, to collect. This would provide the Committee with a starting point for where data review may be necessary. The Chair stressed that if they were performing this, the Committee would need to ensure that this feedback had representation from a variety of places. Another member offered that the Committee could collaborate with education and outreach to create an orientation plan for data coordinators, which would both give more standardization and visibility to data quality.

It was suggested that, similar to the data report that was delivered to administrators on the data amnesty policy usage in 2020, a bi-annual report could be distributed with data quality statistics. The Committee agreed that the more frequently reminded programs are, or the more visible data quality is, the more likely it is to be considered.

A member also inquired whether the Committee should consider a "data governance workbook" which would detail where data elements are being used and possibly show which elements were being used less frequently. The member, as well as the Chair, both agreed that the Scientific Registry of Transplant Recipients (SRTR) should be included whenever the Committee was reviewing data elements. A representative from SRTR noted that SRTR had recently undergone a review of kidney and living donor collection forms and had submitted to the Health Resource and Services Administration (HRSA) a list of recommendations for possible improvement. These had been centralized around the questions of which data are still current, what data are missing, and what data could be used in different ways. The Chair was wholly in favor of the Committee and SRTR aligning these efforts as they would be mutually beneficial, and suggested that, if this project were to move forward, the Committee should also consider the Kidney forms alongside SRTR.

It was also suggested that, during the OPTN site audits, a program could be held to highlight data reports that could be useful. In this way, programs could learn to monitor their own data compliance, as well as understand the review process better.

The question was also posed that, when presented with the choice to begin the data review process in tandem with SRTR or on the OPTN forms with the most missing data, the Chair felt that the Committee should work alongside SRTR. This would help inform both the OPTN and SRTR as to changes being made and would set the framework for a joint review process. In addition, the data review process is not just addressing missing data, so there is still potential for improvement beyond reducing missing data.

The Chair then added that review of the data was only half of the process, as the use of data (i.e training staff members, disseminating at meetings, distributing to relevant committees, etc.) would also need to be considered. To conclude, they stressed that the DAC should prioritize the holistic data review project for 2022 and should establish a routine system of review for the future.

Next steps:

The Committee will consider drafting a template by which to review data elements for the Policy Oversight Committee. The Committee will also review the process used by SRTR to help inform any review practices started by the OPTN.

2. VCA Graft Failure – Checkpoint #2

The Committee heard a presentation from the Vice-Chair of the Vascularized Composite Allograft (VCA) Committee covering their proposal, Modify Graft Failure Definition for VCA. This is the second checkpoint in the Committee's review of the data elements impacted.

Data Summary:

The purpose of the proposal is to update the definition of graft failure to exclude the planned removal of temporary VCA transplants. This is anticipated to impact data elements that collect data surrounding graft failure and VCA outcomes.

The VCA Vice-Chair detailed to the Committee the Transplant Information Electronic Data Exchange (TIEDI) fields that would be updated with the proposal with each of their proposed changes. Changes would be made to the VCA Transplant Recipient Registration (TRR) form and VCA Transplant Recipient Follow-Up (TRF) form.

Summary of discussion:

The Committee reviewed and had no further discussion.

Next steps:

The VCA Committee will continue to keep the DAC informed of proposed changes.

Upcoming Meeting

- February 14, 2022

Attendance

- **Committee Members**
  - Rachel Patzer
  - Sumit Mohan
  - Kristine Browning
  - Jamie Bucio
  - Colleen Flores
  - Heather Hickland
  - Macey Levan
  - Krishnaraj Mahendraraj
  - Bilal Mahmood
  - Anna Mello
  - Alicia Redden
  - Benjamin Schleich
- **HRSA Representatives**
  - Adriana Martinez
  - Chris McLaughlin
- **SRTR Staff**
  - Ajay Israni
  - Bertram Kasiske
  - Jon Snyder
- **UNOS Staff**
  - James Alcorn
  - Roger Brown
  - Brooke Chenault
  - Cole Fox
  - Isaac Hager
  - Nadine Hoffman
  - Olga Kosachevsky
  - Krissy Laurie
  - Samantha Noreen
  - Sharon Shepherd
  - Leah Slife
  - Kaitlin Swanner
  - Susan Tlusty
- **Other Attendees**
  - Sandra Amaral