

**OPTN Data Advisory Committee
Meeting Minutes
September 16, 2019
Conference Call**

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Introduction

The OPTN Data Advisory Committee (DAC) met via teleconference on 09/16/2019 to discuss the following agenda items:

1. Re-orient to scope of work
2. Kidney Update – Medical Urgency
3. VCA Committee – Modifications to TRR and TRF
4. Public Comment Update
5. Data Definition Review

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

1. Re-orient to scope of work

The DAC heard a presentation outlining their role under the new OPTN contract.

Summary of discussion:

Under the new OPTN contract, the DAC is taking on an expanded role in OPTN Data Governance. The DAC received information on what their new role will be and the resources available to help them execute their new responsibilities.

DAC members had no additional comments.

Next steps:

The DAC will learn more about their new role and scope of work at a subsequent meeting.

2. Kidney Update – Medical Urgency

The OPTN Kidney Transplantation Committee currently has a proposal out for public comment to remove the use of DSA and region from kidney allocation policy. The proposal may include adding new data collection fields as part of the medical urgency solution.

Summary of discussion:

In order for a kidney candidate to qualify for medical urgency, all kidney programs in the candidate's DSA must agree that the candidate meets medically-urgent criteria. However, the Kidney Committee's current proposal will remove the use of DSA from kidney allocation and as such, the Kidney Committee is proposing alternatives to the current practice for listing medically-urgent candidates. The current proposed solution would include the addition of two new data collection fields – loss of vascular access and inability to be on dialysis.

The Chair asked how the new fields would be collected in the proposed solution. The Chair asked if there would also be a narrative field included as many of the other review boards have narratives. The

Kidney Committee representative commented that they are considering the amount of administrative burden the additional data collection would put on transplant programs. The Kidney Committee representative also noted that they might solicit additional feedback on the medical urgency solution with another round of public comment. An SRTR representative commented that the data should be collected in such a way that it is clear when the candidate's status is changed to medically urgent. It should not appear as if the candidate was medically urgent since the time they were listed. The Chair commented that the information sent to the group that will review the medically urgent status requests must be standardized. The DAC agreed that the Kidney Committee was going in the right direction with their proposed data collection.

Next steps:

The Kidney Committee will continue to provide updates to the DAC on their proposed data collection.

3. VCA Committee – Modifications to TRR and TRF

The OPTN VCA Committee is working on a project to update the Transplant Recipient Registration (TRR) and Transplant Recipient Follow-up (TRF) forms for VCA transplant recipients.

Summary of discussion:

The VCA Committee is planning on sponsoring a project to update the TRR and TRF for VCA transplant recipients during the upcoming public comment cycle. The VCA Committee Chair presented the work that the VCA Committee has done thus far on the project. The VCA Committee Chair noted that they are also working on a project to collect data on children born to uterus transplant recipients.

For the TRR and TRF project, the DAC Chair commented that the VCA Committee is the subject matter expert on this topic and it seemed like they were going in the right direction. The DAC Chair asked if there would be different individuals responsible to submitting the forms for the different types of VCA transplantation at each program. The VCA Chair stated that there would likely be one person responsible for each VCA-related organ at each program. The DAC Chair noted that the VCA Committee should consider ways to make sure that the different individuals responsible for data entry at each program all submit accurate and consistent data. The DAC also recommended that the VCA Committee consider the operational impact of the new data collection and what information will be gleaned from the new forms. The VCA Committee should also start to draft data definitions for each data collection field. The DAC also recommended that the VCA Committee explore the Transplant Registry International for insight into data collected on children born to transplant recipients.

The DAC had no concerns with the work of the VCA Committee and agreed that they should proceed with their project to modify the TRR and TRF.

Next steps:

The VCA Committee will continue to provide updates to the DAC on the TRR and TRF project.

4. Public Comment Update

The DAC discussed the public comment feedback submitted to date on the DAC's proposal to modify data submission policies.

Summary of discussion:

The DAC agreed with the public comments asking for more education for individuals submitting data but acknowledged that it would be difficult to provide education for each form. The DAC also discussed the data review period and if there would be a way to highlight the fields in outcomes models in monthly data quality reports.

Next steps:

The DAC will discuss the public comment proposal at their next meeting.

5. Data Definition Review

The DAC discussed four data definitions as part of their fourth quarter data definition review.

Summary of discussion:

The DAC agreed with the proposed definitions for the first three data elements. The DAC will discuss the biopsy definition during an upcoming meeting.

Next steps:

The DAC will discuss the biopsy definition during an upcoming meeting.

Upcoming Meetings

- October 10, 2019 – Chicago, Illinois
- November 18, 2019 - Teleconference