

**OPTN VCA Transplant Outcomes Subcommittee
Meeting Minutes
May 22, 2019
Conference Call**

Bo Pomahac, M.D., Chair

Introduction

The OPTN VCA Transplant Outcomes Subcommittee met via Citrix GoTo teleconference on 05/22/2019 to discuss the following agenda items:

1. Project Discussion: Update to VCA Transplant Outcome's Data Collection

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

1. Project Discussion: Update to VCA Transplant Outcomes Data Collection

The Subcommittee will review:

- Work plan
- The baseline data set collected on all VCA transplants to ensure 1) relevancy, and 2) applicability for developing VCA transplants
- Transplant Recipient Follow up (TRF) Form

Data summary:

A. Recent Work

- a. At the VCA committee in-person meeting earlier this year, members broke into breakout groups by VCA type and discussed potential improvements to the TRR (Transplant Recipient Registration) and TRF (Transplant Recipient Follow up) forms.
- b. A matrix of all the proposed changes was circulated and reviewed.
- c. The VCA Committee reviewed the TRR form on a previous call.

B. Work Plan for the development of this project.

- a. Review any corrections/modifications
- b. Outreach to VCA transplant community
 - i. Contacting OPTN approved VCA transplant programs and asking for their feedback.
- c. Bring the feedback back to the VCA Transplant Outcomes Subcommittee.
- d. Engage with stakeholder OPTN committees

C. Project Timeline

- a. May/June 2019: Engage VCA community for feedback
- b. August/ September 2019: Engage with other OPTN committees
- c. October 2019: Committee Vote
- d. January 2020: Go out for Public Comment
- e. June 2020: OPTN Board of Directors.

Summary of discussion:

The Committee reviewed a majority of all the data fields in the VCA TRF form. Members were asked to keep in mind 1) What should be collected on all VCA transplants regardless of type 2) Review the content in the forms and what changes are needed 3) Will these data fields work for future VCA types.

Below are what sections members propose changing in the TRF Form:

- Cognitive and Motor Development
- SF-36 Score
- Carroll Test
- In the craniofacial section:
 - Olfactory function
 - 2 point discrimination
 - Decannulation
 - Feeding tube removal
 - Speech intelligibility tests
- The use of Functioning and Failed in the Graft Status section.
- Definition of failure in terms of VCA.
- Need to add a measure of good/limited functional outcome of grafts.
- Rearrange the sequence of graft status to put it earlier in the form.
- Hemoglobin A1c%
- Serum creatinine
 - Add GFR
 - GFR needs to have the ability to adjust for amputees
 - Members wanted to ask the OPTN Kidney Committee what the best long-term measure of kidney function.

Members did not finish reviewing the TRF form during this call and agreed to review and give feedback to UNOS staff offline.

Next steps:

- Committee members will finish reviewing the TRF offline and will give their feedback to UNOS staff.
- UNOS staff will:
 - Create a summary of all the proposed changes and will contact VCA Program Directors and other key stakeholders for their feedback.
 - Schedule calls with subcommittee members and other key stakeholders from the VCA community.

2. Upcoming Meeting(s)

- June 12, 2019, Upper Limb Work group
- June 26, 2019, Uterus Work group

Attendance

- **Subcommittee Members**
 - Bo Pomahac
 - Sandra Amaral
 - Linda Irwin
 - Shelia Jowsey-Gregoire
 - Linda Cendales
- **UNOS Staff**
 - Sakshi Thassu
 - Chris Wholley
 - Hannah Byford
 - Paula Dehetre
 - Jen Wainright