

**OPTN Vascular Composite Allograft Committee: Upper Limb Transplant Outcomes
Workgroup
Meeting Minutes
June 12, 2019
Conference Call**

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Introduction

The OPTN VCA Upper Limb Transplant Outcomes Workgroup (hereafter referred to as the “Workgroup”) met via Citrix GoTo teleconference on 06/12/2019 to discuss the following agenda items:

1. Upper Limb Focused Review of VCA TRR and TRF Forms

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

1. Upper Limb Focused Review of VCA TRR and TRF Forms

Upper limb subject matter experts and externally invited guests discussed and reviewed the transplant recipient follow-up form (TRF) and the transplant recipient registration forms (TRR) in order to suggest possible modifications to both forms.

Summary of discussion:

Workgroups members first reviewed the TRR and TRF data fields to be maintained. There were no proposed changes by the Workgroup members.

Next, the Workgroup members reviewed the fields on the TRR and TRF that are to be stricken from both. The majority of Workgroup members were fine with continuing to enter serum creatinine and then calculating the eGFR afterwards using other data elements. However, Workgroup members stated that there is a need to specify which eGFR formula will be used, and defining each data element that will be included in the formula.

In continuing the discussion, Workgroup members assessed the proposed fields to be added to the TRF form. Workgroup members noted that for the data element “cognitive changes since last patient death”, that there are no standardized definitions for cognitive changes. There was also confusion as to the intent of this question and whether this data element is truly measureable. For example, there may have been permanent or transient changes that occurred, but that such changes may be more applicable to pediatric patients. There was general consensus that the form makes it difficult to interpret the intent, and Workgroup members suggested removing this data element. Workgroup members also discussed the eGFR and joint function measurement data elements to be added. Though members were supportive of including both data elements on the TRF, they suggested that the joint function measurement test be kept more basic (e.g. “Is the patient able to make a fist?”). Workgroup members also asked that more specific questions be added on the TRF to assess the functionality of the hand. For example- can the patient drive? Can the patient comb their hair? Can the patient open a door, write or hold a cup? Along with these questions, members also stated that temporal recording should be added to the TRF data fields.

Next, a Workgroup member stated that they should ensure programs are able to perform upper limb tests specified on both the TRR and TRF forms (such as grip strength and pinch test, cold

intolerance, two-point discrimination test, etc.). Members suggested the need for more operational definitions for each of these tests prior to implementation.

Next steps:

There will be a uterine workgroup call on June 26th. After feedback is received from each workgroup, the data subcommittee will meet on July 10th to review and finalize the TRR and TRF forms.

Upcoming Meetings

- June 26, 2019
- July 10, 2019