

**OPTN Data Advisory Committee
Meeting Summary
May 11th, 2020 3:00 PM EST
Conference Call**

**Sandy Feng, M.D., Chair
Rachel Patzer, Ph.D., Vice Chair**

Introduction

The Data Advisory Committee (DAC) met via Citrix GoToMeeting teleconference on 05/11/2020 to discuss the following agenda items:

1. Addressing Medically Urgent Candidates in New Kidney Allocation Policy – Project Check-in
2. Data Collection to Assess Socioeconomic Status & Access to Transplant – Project Check-in
3. Modify Data Collection on Vascularized Composite Allograft (VCA) Living Donors – Project Check-in
4. Wrap-up & Next Steps

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

1. Addressing Medically Urgent Candidates in New Kidney Allocation Policy – Project Check-in

The Kidney Transplantation Committee presented their refined data elements and definitions to the DAC.

Summary of discussion:

A member inquired about whether, previously, there was a narrative surrounding kidney medical urgency and if this policy is replacing it. The Kidney Committee presenter explained that this project is replacing old policy language in order to create a national definition of medical urgency, instead of the definition being inconsistent across donation service areas (DSA).

A member inquired about the current medical urgency documentation. The presenter explained that there isn't documentation, but the discrepancy in the definition of medical urgency was noticed through discussion between members in different DSA's.

A member inquired about whether a patient automatically gets the medically urgent status once their data and lab values are inputted. The presenter confirmed that the patient would automatically receive elevated priority and explained that the review will happen retrospectively.

The DAC agreed that this is a big step forward and that they trust the experts on the Kidney Committee in their push toward a national definition of medical urgency.

2. Data Collection to Assess Socioeconomic Status & Access to Transplant – Project Check-in

The Minority Affairs Committee (MAC) presented post public comment changes regarding the collection Socioeconomic Status (SES) data for the purposes of equitable access to transplants.

Summary of discussion:

The proposed changes based on feedback from Public Comment are:

- Revise annual household income – change to ranges instead of open text
- Remove household size

A member inquired what proportion of transplant centers are already collecting this data. The MAC presenter responded that most centers collect this data but did not have the number. The presenter mentioned that in every region there was a center that expressed this additional data collection would create a burden.

Members understand that patients do not want to report this data due to concerns about misuse. This could lead to incomplete or inaccurate data which could result in more harm than good. The DAC agrees that there is value in collecting SES data. However, the DAC encourages the MAC to consider their approach of removing household size.

Several members expressed concern over the need to protect patients’ trust while they are in this vulnerable situation. A member suggested that the MAC speak with other patient committees for additional feedback.

Next steps:

In light of the value DAC recognized in collecting these data, the DAC encouraged the MAC to rework their proposal and send it out for public comment

3. Modify Data Collection on Vascularized Composite Allografts Living Donors – Project Check-in

A member of the VCA Committee presented an update to require data collection related to living uterus donors and recipients. Currently, data is only submitted voluntarily by uterus transplant programs and the VCA Committee proposes new data collection to determine compliance of institutional members, measure performance, and ensure patient safety. Implementation will require changes in the Transplant Information Electronic Data Interchange (TIEDI) to the Living Donor Registration (LDR) and Living Donor Follow-up (LDF) forms.

Data summary:

Proposed data collections would result in changes made to the Pre-Donation and Post- Donation LDR forms as well as follow up data on the LDF form. Distinctions were made between surgical and clinical proposed data elements.

Summary of discussion:

A member inquired about the reason a person would donate a uterus. The VCA Committee presenter responded that donors are specifically undergoing this surgery with the primary purpose of donation. No questions were posed regarding the proposed data elements.

Next Steps:

VCA will vote on June 10 to send the proposal to public comment in Fall 2020.

4. Wrap-up & Next Steps

NLRB Enhancements, Part 2 from the Liver and Intestinal Organ Transplantation Committee will be sent to the DAC members for review and comment.

Upcoming Meetings

- June 15, 2020 (teleconference)
- July 13, 2020 (teleconference)