

**OPTN Minority Affairs Committee Socio-Economic Status (SES) Work Group
Meeting Minutes
May 6, 2019
Conference Call**

**Sylvia Rosas, MD, Chair
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Introduction

The Socio-Economic Work Group (the Work Group) met via Citrix GoToMeeting teleconference on 05/06/2019 to discuss the following agenda items:

1. Socio-Economic Status (SES) Project

The following is a summary of the Work Group's discussions.

1. Socio-Economic Status (SES) Project

The Work Group reviewed a presentation by UNOS research staff following up on a presentation to the full Minority Affairs Committee at its in-person meeting on March 29th.

Data summary:

UNOS staff gave background on the data analysis addendum being presented:

- Findings presented in March 29, 2019 in-person meeting prompted discussion about apparent disparity in probability of deceased donor kidney transplant by SES
- Higher probability of deceased donor kidney transplant among low SES patients was unexpected
- Redrafted analysis of five-year probability of kidney transplant by SES factor, with living and deceased donor stacked in same cumulative incidence plots

UNOS staff also presented the key takeaways of the modified graphs shown to the Work Group:

- Five-year probability of kidney transplant is consistently higher for high SES patients
- High SES patients are more likely to be transplanted earlier in their waitlist tenure
- These differences are largely driven by increased likelihood that high SES patients will secure living donor transplants

This presentation does not reflect an additional analysis but certain graphs reformatted to better convey the competing risk analyses for SES candidate probability of transplant. Overall, the data showed at 5 years a greater probability of high SES candidates being transplanted through either deceased or living donation, when compared to low SES candidates.

Summary of discussion:

Work Group members expressed satisfaction with the reformatted data and found the takeaway points clearer. A member asked whether the analysis included time on dialysis – specifically, whether implementation of the kidney allocation system (KAS) may have resulted in an influx of candidates being transplanted that had long dialysis times before KAS. Such an anomaly was not seen in the data. Another member questioned why the data analysis went back to December 2010 – this was to account for the KAS changes in 2014 and to allow for review of changes that KAS incurred.

Members discussed if a publication in a relevant journal or an OPTN product such as a white paper or guidance document would be an appropriate path forward to highlight the results of the analysis and its implications. Specifically, a member suggested a publication or white paper could help increase the access of low SES candidates to living donation. The Work Group expressed support for pursuing an OPTN product and a concurrent publication to provide the community with guidance on the status of low SES candidates and access to transplant, particularly from living donors. The Work Group considered but dismissed the option to pursue a survey on transplant program practices, because:

- Response rate could be low
- It may be difficult to generalize statements based on the results of the survey
- Developing surveys take significant time and effort
- Identifying actionable items from the survey may be difficult

The Work Group reiterated the interest in a white paper/guidance document and publication to show the disparity that exists and how the community could move forward. The OPTN document could highlight that there is an issue in low SES access to living donation, identify the scope of the impact, and discuss what factors may contribute to the discrepancy in access to transplant or inequities that result. The document could also provide recommendations on potential changes to policy, best practices for the community, or additional data that may be helpful to collect to identify the true scope of the impact.

While the Work Group is clearly interested in pursuing both OPTN guidance and a publication, UNOS staff emphasized that the Work Group should focus on the OPTN deliverables as the focus going forward. UNOS staff will follow up with the Committee on what the steps would be to pursue a publication in addition to an OPTN product. Staff will also provide alternative timelines for the Work Group to consider whether to go out for Spring or Fall 2020 public comment. The Work Group will also look into collaboration with relevant committees in its review of potential timelines to ensure stakeholder feedback is gained.

Next steps:

UNOS staff will follow up on the process for pursuing a publication and also on alternate timelines for a public comment proposal. Staff will send out a poll and schedule monthly SES Work Group meetings.

Upcoming Meetings

- TBD (being scheduled)