

**OPTN/UNOS Minority Affairs Committee  
Meeting Minutes  
March 29, 2019  
Richmond, Virginia**

**Sylvia Rosas, MD, Chair  
Irene Kim, MD, Vice Chair**

**Introduction**

The Minority Affairs Committee (the Committee) met in Richmond, Virginia on 03/29/2019 to discuss the following agenda items:

1. Socio-economic Status (SES) and Access to Transplant
2. Update on Ethics Committee Project on Intellectual Disabilities
3. New Project Ideas
4. Continuous Distribution Presentation

The following is a summary of the Minority Affairs Committee's discussions.

**1. Socio-economic Status (SES) and Access to Transplant**

A member of UNOS staff gave an overview of the results from the socio-economic data, followed by discussion by the Committee.

Summary of discussion:

One member asked if any of the new proposed geography allocation for kidney had been taken into consideration. The UNOS presenter explained that only the Kidney Allocation System (KAS) allocation was taken under consideration. Another UNOS staff member noted that donor service areas (DSA) are going away for allocation policy but will still exist as administrative units for organ procurement organizations (OPOs). A member of the Committee pointed out that it will be important to consider how these proposed allocation systems will impact vulnerable populations.

One member of the Committee noted that a metric used by the data incorporates zip codes which vary by size, population and homogeneity of household income. The Committee discussed the higher cost of living in Puerto Rico compared to cost of living in the United States and the comparative status of Puerto Rico in the percentage of waitlist candidates and living donor recipients by zip code. One member asked for clarification about a map indicating ratio of percent of waitlist candidates to living donor recipients living in low income zip codes by DSA. The UNOS staff presenter explained that the maps were divided by median household income of zip codes and the darker colored the DSA, the fewer candidates that were being transplanted compared to number of candidates. One member noted that the high school graduation age is higher among many Native American populations and therefore could skew data for educational attainment of adults 18+.

One member asked if it was possible for the modeling to analyze multiple variables at once similar to Scientific Registry of Transplant Recipients (SRTR) simulations. The presenter explained that this particular data set was just descriptive and did not analyze multiple variables. A member asked if certain factors were statistically significant. The presenter explained that statistical analysis was not done on this data request. Another member asked for clarification regarding if a metric of individual income was used. The presenter explained that median household income was used and that rather the data pulled from census data and used the metric of median household income per zip code. The presenter explained that while the data

was not granular down to the household, the data still captured trends that might be significant based on the income of a neighborhood/zip code. One member commented that the zip code metric was useful because it captured what general patient population is being served by different programs.

One member asked for clarification on confidence intervals, which the presenter provided. The Chair noted that the waitlist mortality rate confidence interval dropped for all income levels pre-KAS to post-KAS. One member asked for clarification regarding the waitlist mortality metric and whether that accounted solely for candidates that died on the waitlist or also those candidates who were removed for being too sick. The presenter explained that the metric captured the former but not the latter for kidney related data.

One member asked which income subgroup benefited the most in waitlist mortality rate post-KAS. The presenter referred the Committee to the tables in the data results. One member asked if the difference in waitlist mortality rate for adult candidates by educational attainment had shrunk from pre-KAS and post-KAS. The presenter explained the difference is negligible. One member asked if the educational attainment and primary payer metric was also averaged by zip code. The presenter explained that the former two metrics were actually individual to patients and provided by waitlist data.

One member noted that the effects of post-KAS may differ for Puerto Rico due to the increased number of organ exports from that the area. One member commented that the data regarding higher amounts of deceased donor transplants among public payer candidates seems counter-intuitive. The presenter noted that part of the difference may be due to the fact that rates of living donor transplants are higher among private payers. One member asked why there wasn't a graph of all types of donor transplants separated by pay type. A member of UNOS staff explained that it is challenging to present such a graph because of the way that living donor candidates are often listed immediately before receiving a transplant. A Committee member felt that the individual graphs made it difficult to understand the overall trends by pay type because the graphs were separated by donor type.

One member asked if there are potential confounding variables for patients that have multiple insurance types such as both private insurance and Medicare. The presenter explained that is possible as well as potential unseen impact of grouping together both Medicare and Medicaid patients. The Chair asked if there was any data that captured patients who started out on the deceased donor waitlist but then later switched to a living donor transplant. A UNOS staff member explained that those patients are captured as the metrics stand. The staff member clarified that the analysis in general predicts the probability of a certain type of candidate receiving either a living or deceased donor transplant. A Committee member spoke in support of seeing a similar analysis by race in addition to pay type. The Committee in general spoke in concern of the current aesthetics of the graphs that may mislead public members that the high SES group had a disadvantage of receiving a deceased donor transplant. The UNOS staff explained that they could create a different graphic that better represents the various types of odds.

A member of the Committee asked about seeing any graphs with racial metrics. The presenter explained that race was out of the scope of this data request as it specifically requested information on socio-economic status only. One member of the committee expressed that while the graphs may be separate, the overall message was clear that lower income candidates were disadvantaged for receiving a living donor. One member commented on the significance of race and social network in living organ donations and how the health problems of certain races may be an obstacle to living organ donations. The Chair asked if there was data regarding the racial breakdown of the low SES group. Another Committee member spoke in support of seeing more

of this data broken down by race. One committee member commented that it is possible there are additional confounding factors such as within the obese population which tends to have strong SE factors.

One member asked if there was a way to “normalize” the data to create a baseline and then demonstrate proportional representation of the other metrics on the waitlist. Another committee member commented that in the future it is important to separate payer type by more than public and private due to the different populations being treated by Medicare, Medicaid and Veterans Affairs. In addition, the member felt it was incredibly significant to include race in the data. One member commented on how challenging it is to define by race in Puerto Rico. Another Committee member commented that blood type is one of many factors that is significant among race. The presenter explained that one factor of considering race is that it can be a metric that represents a confounding factor as far as certain groups that have been systemically disadvantaged and thus while there may not always be genetic differences, there are often unseen social disadvantages that can be captured by using a racial metric.

## **2. Update on Ethics Committee Project on Intellectual Disabilities**

A Committee member who is also a member of the Intellectual Disabilities Workgroup presented an overview of the workgroup project.

### Summary of discussion:

One member asked if cognitive disabilities fall under the definition of intellectual disabilities in this project. A member of the UNOS staff explained that intellectual disability criteria limit to those who experience developmental issues before the age of 18 and many common cognitive disabilities can develop after due to health issues or life events. One member made a comment on the importance of functional status being weighed into the assessment criteria specifically for patients in vegetative states. The Committee presenter agreed on the importance of assessing functional status and potentially proposing creating regional ethical boards to assess particularly difficult cases. One member spoke of the importance of including patients or patient families on any proposed regional ethics boards. The member also spoke against limiting patients with intellectual disabilities to only living donors.

One member asked if someone who experiences a stroke would be included in this criteria. A member of UNOS staff explained that for the purposes of this paper, intellectual disability is limited to those who experience developmental impairments before the age of 18. One member commented that the range of disabilities is very wide even just when looking at the autism scale. A UNOS staff member acknowledged that while the range varies that the purpose of the paper is to rule out disability as an absolute contraindication. One member commented that the socio-economic factor of the family may have a more significant impact overall than intellectual disability because SES impacts a family’s means to care for a member with intellectual disabilities. The Committee presenter emphasized the difficulty of analyzing these problems without any data.

One member shared that his transplant center does not consider disability as a contraindication and that rather they evaluate support network and ability to care for the transplant. Another member commented that when evaluating transplant candidates it is significant to consider the quality of life years patients will receive from the transplants. Another member noted that it is important to evaluate that quality from a medical standpoint.

### Next steps:

The workgroup plans to have a draft available for this committee and other stakeholder review in May.

### 3. New Project Ideas

The Committee brainstormed new project ideas.

#### Summary of discussion:

Below is a list of proposed projects by the Committee:

- Analysis of the racial makeup of the kidney waiting list. Are minorities proportionally disadvantaged, potentially by multi-organ transplants?
- Analysis of model for end-stage liver disease (MELD) as an indicator of sickness. Is MELD a good indicator of sickness for all racial/ethnic populations or are certain groups not accurately represented by MELD?
  - A UNOS staff member noted that it is possible for research to perform a matched study of patients with similar MELD scores.
- With new geographic changes, are certain rural populations disadvantaged by the potential closing of smaller centers? Those populations may need to travel farther or across state lines.
- Analysis of post-geographic allocation data for lung, liver and kidney, six and one year data.
- Analysis of the stratification of transplants and kidney donor profile index (KDPI) in the elderly population. Do we see worse transplant outcomes among elderly patients especially for deceased donor?
- Shortage of transplant health care officials in Puerto Rico
- A2 subtyping in living donors. How many programs are doing it?
- Review of A<sub>2</sub>B blood typing. Analysis of A<sub>2</sub>B for other organs (heart, lung, etc) and the potential benefits for minority groups.
- Survey on transplant programs practices regarding patients with intellectual disabilities. How do programs help improve support networks for patients with ID to help increase the likelihood of such a patient receiving an organ.
- Open up Sequence C kidneys to pediatric patients. Analysis of pediatric transplant rates pre and post-KAS.
  - A UNOS staff member made note that the Kidney Committee is proposing increasing allocation of pediatric priority in their current modeling for the new geographic allocation system. The staff member also mentioned that such a policy might be best addressed by Pediatric and Kidney committee with the Minority Affairs Committee (MAC) collaborating.
- Analysis of discard rates, decline codes and one-year graft outcomes.
  - The Committee discussed the various practices of programs and surgeons in declining certain organs.

The Committee discussed its role of proposing policy changes in addition to providing guidance.

### 4. Continuous Distribution Presentation

A member of UNOS staff presented the continuous distribution model, followed by Committee discussion.

#### Summary of discussion:

One member asked how the different weights of each metric is determined. The UNOS presenter explained that the weight of metrics will vary by organ, especially considering organ sensitivity to cold ischemic time and therefore travel distance vary. One member asked how one can explain such a complicated allocation system to the average lay person. The UNOS

presenter explained that communication will involve a lot of outreach and collaboration among departments. Several Committee members had questions related to newer geographic polices and continuous distribution. UNOS staff clarified that currently most organ systems are focusing on a establishing a new geographic policy eliminating DSAs as a middle step before creating a continuous distribution model due in part to the intense complexity of the latter. One member commented that MAC should be involved in planning of continuous distribution of various organs.

#### Next Steps

The Committee will be kept up to date about any progress working on continuous distribution.

#### **Upcoming Meetings**

- May 20, 2019 (teleconference)