

OPTN Minority Affairs Committee (MAC)

Meeting Summary

September 27, 2021

Conference Call

Paulo Martins, MD, PhD, Committee Chair

Alejandro Diez, Committee Vice Chair

Introduction

The Minority Affairs Committee (MAC) met via Citrix GoToMeeting teleconference on 9/27/2021 to discuss the following agenda items:

1. Public Comment Update: Reassess Race in eGFR Calculation Request for Feedback
2. Guidance for Data Collection regarding Classification of Citizenship Status
3. Project Update: Improving the MELD Calculation
4. Update on Continuous Distribution of Kidneys and Pancreata
5. Ethical Considerations of Continuous Distribution in Organ Allocation
6. Project Update: Social Determinants of Health
7. Establish Continuous Distribution of Lungs

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

1. Public Comment Update: Reassess Race in eGFR Calculation Request for Feedback

The Committee was provided an update on the feedback received on the Reassess Race in eGFR Calculation Request for feedback during the Summer 2021 Public Comment period.

Summary of discussion:

Overall, there has been general support for the proposed changes in the eGFR calculation. There has been questions regarding which formula should be used and it was clarified that there is not a mandate on what equation to be used.

Another comment that was brought up was regarding the fact that there are other formulas the Committee should consider in the future to address (ex. KDPI, pulmonary function). A member stated that there is a major difference when using race as a coefficient. The Committee Chair agreed with this and stated that the community is attempting to eliminate all race based calculations. Although not all calculations can be tackled at the same time, this is something the Committee could consider working on over time.

A subject matter expert (SME) provided some findings from the Task Force Report, *New Creatinine- and Cystatin C-Based Equations to Estimate GFR without Race*. The SME summarized the report as follows: A 2021 CPAD epi equation was created that went back to the original data; directly measured GFRs were included in this study. The 2021 epi equation only has age and sex while the 2009 epi equation included age, sex, and race. It was found that the 2021 equation was fairly accurate. Overall, the conclusion was that the 2021 equation is the preferred calculation to use and that it is closely accurate to the 2009 equation. The recommendation is for immediate implementation of the new equation.

The SME continued by stating that the challenge that is posed is how to provide education on this information. The National Kidney Foundation has taken the lead to help with educating clinicians and

patients. In the upcoming weeks, there is a plan for materials to be available for health systems to begin educating their clinicians and patients on these changes and what it means for patients.

The Committee Vice Chair stated that there should be a push for this and suggested that if there was language stating that the equations should not be race-based, it would allow others to use whatever equation they would like. The SME agreed with this and stated that there may be more equations forthcoming that do not include race. It is reasonable to not be too prescriptive on the type of equation to use as there is a lot of variability among equations.

A member asked if there were any considerations given to those individuals with high GFRs. Is this formula positively or negatively affecting donation? The SME stated that during the Workgroup calls, there was discussion around this and did not see any impact on donation; it is understood that patients are not listed based on GFR.

The SME stated that the UK announced they would remove race from their equations. Additionally some programs in Belgium stated they are trying to make this push as well. The change is being seen among countries, especially since the release of the report.

Next Steps:

- October 5, 2021 – Reassess Race in eGFR Workgroup Meeting
- October 7, 2021 – Post Public Comment Board of Directors Meeting
- October 18, 2021 – MAC Meeting: Vote on policy language

2. Guidance for Data Collection regarding Classification of Citizenship Status

The Committee heard and provided feedback on public comment item, *Guidance for Data Collection regarding Classification of Citizenship Status* from the OPTN Ad Hoc International Relations Committee.

Summary of discussion:

A member advised that individuals who are not citizens may be reluctant to disclose their citizenship status. The Committee was generally supportive of the guidance.

Next Steps:

UNOS staff will use Committee feedback to draft and post a comment on the OPTN public comment website on the MAC's behalf.

3. Project Update: Improving the MELD Calculation

The Committee heard an update on the Improving the Model for End-Stage Liver Disease (MELD) Calculation from the OPTN Liver and Intestinal Organ Transplantation Committee.

Summary of discussion:

A member expressed their support for the project and agreed that it will be difficult to define sex for transgender patients when calculating their MELD scores. The presenter responded that the decision on sex may be delegated to a patient's medical team, as they know the patient and their case the best. A member asked if the inclusion of albumin in the MELD formula would be a disincentive for treatment. The presenter responded that albumin has the greatest impact at low MELD scores and as the patient's MELD increases, the impact of albumin decreases. A member asked if organ size would be included in the new MELD score. The presenter responded that while it will not be included in the new MELD score, it will be included in the continuous distribution framework.

Next Steps:

As this project becomes further developed, there will be more updates to the Committee.

4. Update on Continuous Distribution of Kidneys and Pancreata

The Committee heard and provided feedback on public comment item *Update on Continuous Distribution of Kidneys and Pancreata* from the OPTN Kidney Transplantation and Pancreas Transplantation Committees.

Summary of discussion:

A member clarified that the efficient management for organ placement refers to operationalizing kidney offers from an allocation standpoint and that this aims to decrease cold ischemic time. A member suggested that longevity matching should play a larger role in the continuous distribution model. A member asked the sponsoring committees to consider the geographic difference of Puerto Rico and Hawaii as they develop the model, given that they are non-contiguous areas which may have geographic and organ allocation considerations. Another member confirmed the Living Donor Committees' involvement with this project and highlighted the importance of prioritization for prior living donors.

Next Steps:

UNOS staff will use Committee feedback to draft and post a comment on the OPTN public comment website on the MAC's behalf.

5. Ethical Considerations of Continuous Distribution in Organ Allocation

The Committee heard and provided feedback on public comment item *Ethical Considerations of Continuous Distribution in Organ Allocation* from the OPTN Ethics Committee.

Summary of discussion:

A member recommended that the sponsoring committee should monitor the amount of organs imported to and exported from various locations across the country vis-à-vis the rates of organ donation in affected regions. Another member agreed and suggested that OPTN Committees should be provided with monitoring reports on the Continuous Distribution model. Another member asked the sponsoring committee to consider that some minority groups may not be as involved or aware of the shift to continuous distribution and that this could disadvantage those patients.

Next Steps:

UNOS staff will use Committee feedback to draft and post a comment on the OPTN public comment website on the MAC's behalf.

6. Project Update: Social Determinants of Health

The Committee heard an update on the Social Determinants of Health project from UNOS Research.

Summary of discussion:

The Committee Chair voiced concern on utilizing third party vendors. They explained that there is selection bias as underprivileged populations would be missing from this data base. The Committee Chair asked the position of the Data Advisory Committee's (DAC) on this effort.

UNOS staff stated that there is a 100% access rate and are able to developed complete profiles even for those individuals who are under banked and may not have access to the credit they need. While the data comes from a number of these credit agencies, these agencies do have additional information to complete profiles. There is always some discrepancy of access to particular data which is a challenge.

There is awareness that this data set will not have everything but in this research effort and this awareness, the goal will be to use the data that is accessible to gain as much information as possible.

UNOS staff continued by stating that the data would be available for future Committee projects. A UNOS researcher would have to be a part of these efforts based on the agreements of this study. There is an understanding that there are research needs to this data and the aim is to be as transparent as possible with this information.

In regards to the DAC's position on this effort, the DAC is in support of this effort and has been discussing how this data can be accessible and used by OPTN Committees. A plan on how OPTN Committees would work and access this data is still under discussion and more information is forthcoming.

A member asked about linking the first two questions posed on communities with the diversity index. UNOS staff stated that over the next year as the project becomes more developed, there will be more details that will be presented to the Committee. A member stated that it would be valuable to keep track of the time points. Changes observed among communities over time can provide insight into social determinants of health.

Next Steps:

As this project becomes further developed, there will be more updates to the Committee.

7. Establish Continuous Distribution of Lungs

The Committee heard and provided feedback on public comment item *Establish Continuous Distribution of Lungs* from the OPTN Lung Transplantation Committee.

Summary of discussion:

A member voiced agreement in this proposal and stated that the changes being proposed are well overdue. The Lung Committee representative asked the Committee if the 1:1 waiting was appropriate. The member voiced agreement with this change and stated that this was reasonable. By making this change, it would be giving more time for post-transplant survival.

Another member asked for the average time a patient is on the waitlist. The Lung Committee representative stated that there is variation in this and can depend on a number of variables. The median survival after lung transplantation is about 6.3 years. The member asked if the proposal aligns with proper utility and good stewardship.

A member stated that five days is sufficient time for reviewers to review and make a decision on exception applications. The member continued by stating not seeing there being any disadvantages present for minority populations.

Next Steps:

UNOS staff will use Committee feedback to draft and post a comment on the OPTN public comment website on the MAC's behalf.

Upcoming Meetings

- October 18, 2021 (Teleconference)

Attendance

- **Committee Members**
 - Adrian Lawrence
 - Irene Kim
 - Amaka Eneanya
 - Paulo Martins
 - Alejandro Diez
 - Okechukwu Ojogho
 - Pono Shim
 - Wayne Tsuang
 - Christine Hwang
 - Jason Narverud
 - Joey Nuqui
 - Juan del Rio Martin
 - Manuel Rodriguez- Davalos
 - Oscar Serrano
 - Reynold Lopez- Soler
 - Stephen Grey
- **HRSA Representatives**
 - Jim Bowman
 - Edna Dumas
- **SRTR Staff**
 - Bryn Thompson
- **UNOS Staff**
 - Abigail Fox
 - Kelley Poff
 - Anne McPherson
 - Joann White
 - Elizabeth Miller
 - Matt Prentice
 - Anne Zehner
 - Alex Garza
 - Meghan McDermott
 - Kelsi Lindblad
 - Krissy Laurie
 - Kristina Hogan
 - Laura Cartwright
 - Lindsay Larkin
 - Matt Cafarella
 - Ross Walton
 - Sara Moriarty
 - Sara Rose Wells
- **Guests**
 - Barry Friedman
 - Martha Pavlakis
 - Andrew Flescher
 - Marie Budev

- James Pomposelli