

**OPTN Minority Affairs Committee  
Meeting Minutes  
October 21, 2019  
Conference Call**

**Irene Kim, Chair, MD  
Paulo Martins, Vice Chair, MD**

## **Introduction**

The OPTN Minority Affairs Committee (the Committee) met by teleconference on October 21, 2019 to discuss the following agenda items:

1. Brief Overview of Socio- economic Status (SES) Project
2. Update on Decisions Made at In- Person
3. Feedback from DAC
4. Discussion on Potential Data Elements

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

### **1. Brief Overview of SES Project**

UNOS staff reviewed the current status of the SES project.

#### Summary of discussion:

None.

#### Next Steps:

The committee moved on to an update from their in- person meeting.

### **2. Update on Decisions Made at In- Person**

The MAC selected two fields to add to the Transplant Candidate Registry (TCR) form.

1. Household Income
2. Household Size

#### Summary of discussion:

None.

#### Next steps:

The MAC then heard from a stakeholder from the Data Advisory Committee (DAC).

### **3. Feedback from DAC**

A representative from the DAC gave their feedback on household size and household income as new data fields.

#### Summary of discussion:

The member of DAC gave the following feedback:

- These data are sensitive and can be challenging to obtain from vulnerable populations.
- Asked the Committee if the proposed data are collected elsewhere and if transplant staff will be expected to collect this information if it is not.
- Reported that it is important to frame why the data is being collected and the impact it will have.
- Suggested to the Committee that as new fields are proposed and added to forms, old data fields should be retired to decrease the data burden for transplant administrators.
- Asked how the Committee planned to ensure the validity of collected data.
- Advised the Committee that the data collected can be used for more than stating if a transplant candidate is above or below the federal poverty Guideline (FPG).
- Asked for detailed examples of how the data would be used.

Next steps:

The Committee will consider this feedback and seek answers to these questions.

**4. Discussion on Potential Data Elements**

The MAC also heard from stakeholders from the Transplant Administrators Committee (TAC) and the Association of Transplant Social Workers (STSW).

Summary of discussion:

These stakeholders gave the following feedback:

- Reported that income can change overtime and as a list patient becomes more ill.
- Asked if the committee would account for multiple generations residing in one household.
- Advised that candidates might be weary of how their information is being used.
- Suggested the development of a training on how to obtain this information and explain its importance.
- Reported that the Committee would likely hear about data burden from other stakeholders

Next steps:

The Committee will consider this feedback and seek answers to these questions.

**Upcoming Meeting(s)**

- November 18, 2019 (teleconference)
- December 16, 2019 (teleconference)
- January 20, 2019 (teleconference)

**Attendance**

- **Committee Members**
  - Vonzie Barnett
  - Amishi Desai
  - Okechukwu Ojogho
  - Oyedolamu Olaitan
  - Tahuanty Pena
  - Tanjala Purnell
  - Sylvia Rosas
  - Richard Ruiz
  - Oscar Serrano

- Christopher Jones
- Paulo Martins
- William Freeman
  
- **HRSA Representatives**
  - Emily Anozie
  - Janet Kuramoto- Crawford
- **UNOS Staff**
  - Darren Di Battista
  - Kelley Poff
  - Kim Uccellini
  - Ross Walton
  - Anne Zehner
  - Sarah Moriarty
- **Other Attendees**
  - Molly Dugan
  - Jason Huff
  - Jesse Schold