

OPTN Minority Affairs Committee (MAC)

Meeting Minutes

November 18, 2019

Conference Call

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Introduction

The OPTN Minority Affairs Committee (the Committee) met by teleconference on November 18, 2019 to discuss the following agenda items:

1. Feedback from the Transplant Administrators Committee (TAC) & Transplant Coordinators Committee (TCC)
2. Discuss Feedback
3. Data Definitions and Mock up
4. Vote to send Data Collection Proposal to Spring 2020 Public Comment
5. MAC News: SES Article
 - *Development and Validation of a Socioeconomic Kidney Transplant Derailers Index*

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

1. Feedback from the TAC & TCC

The Committee reviewed feedback and discussed how to respond to these comments.

Summary of discussion:

Concerns:

Difficulty obtaining this SES data:

- Patients do not like to share sensitive financial information.
- Some patients may believe that they will not receive as high quality care or be denied for care if they reveal their income.

Response: Much of this data is routinely collected by medical social workers, and asking for these pieces of information (per feedback from the Society of Transplant Social Workers (STSW) representative on the October full committee call) is a normal part of the transplant evaluation process.

Accuracy of data:

- Patients will report inaccurately/inflate their income for fear of not being treated.
- Patients are skeptic of how their information will be used.

Response: Self-report of income data is widely used in public health surveys and regarded to be reliable enough for our purposes.

Increased data burden for transplant hospitals:

- Transplant staff will be tasked with additional fields to fill out before the form can be submitted to UNet.

Response: This concern is fairly normal for any data request, as the addition of any fields to forms will require more staff time to complete.

Alternatives Suggested and Responses:

Use ZIP Code median Income as a Proxy for SES:

Response:

- Many ZIP codes cover large areas and have a wide range of incomes. Using ZIP code median income as a proxy for poverty would require the assumption that the average statistic of that ZIP code accurately represents the patient's environment.

Use whole patient addresses to access their median income census tract data:

Response:

- Storing street addresses and social security numbers meets the definition of "Sensitive Personally Identifiable Information" (PII) from the Department of Health and Human Services (HSS).
- Extra justification and safeguards would be required for collecting this data, as unauthorized access to this information could cause severe damage.
- Large lift from a data validation perspective.
- After collecting this information, the OPTN would still have to assume that the median income of a patient's census tracts is representative of their environment.

Other suggestions:

Framing is important:

- How we explain what we're doing and why matters. Stakeholders suggested providing educational resources for members.

2. Discuss Feedback

The Committee discussed stakeholder feedback and if the new SES data should be mandatory fields on the Transplant Candidate Registration (TCR) data collection instrument.

Summary of discussion:

A transplant social worker supported the idea of developing and releasing educational resources for transplant hospitals as implementation takes place. Other members agreed that this training should highlight the purpose of collecting SES data.

Members came to the consensus that the new data should be mandatory. The Committee reported that if members are given the opportunity to opt-out of this question, the OPTN will not collect an accurate sample of patient SES information. This variance in participation could make the data useless for analysis and defeat the purpose of the data collection itself. A member asked what the transplant center is to do if a patient refuses to answer the annual household income and/or household size questions. Members

decided to ask for feedback during public comment on whether or not there should be a one- year phase in period before these fields become absolutely mandatory.

3. Data Definitions and Mock –up

Summary of discussion:

The Committee reviewed data definitions for annual household income and household size. Committee members approved these definitions and thought they correctly explained data OPTN aims to collect. An updated mock-up showing where and how data will be displayed on the TCR was also presented.

Next Steps:

These data definitions will need to be approved by DAC before they are added to the Transplant Information Electronic data Interchange (TIEDI) Help Documentation.

4. Vote to Send Data Collection Proposal to Spring 2020 Public Comment

Summary of discussion:

The Committee was asked, “Should the MAC SES data collection proposal be sent to Spring 2020 public comment.”

100%- 11 -Yes

0%- 0 - No

Next Steps:

The MAC SES data collection proposal will be sent to Spring 2020 public comment.

5. MAC News: SES Article

The MAC discussed the article: *Development and Validation of a Socioeconomic Kidney Transplant Derailers Index*

Summary of discussion:

A member reported the article highlights the need for such SES data to be collected to see if a disparity exists for patients based on their SES status. By collecting this data nationally, the SES project can then help determine if a problem exists and what solutions would be appropriate if disparities are found.

Upcoming Meeting(s)

- January 13, 2020 (teleconference)
- February 10, 2020 (teleconference)