

**OPTN Socio-economic Status Workgroup
Meeting Minutes
August 5, 2019
Conference Call**

**Amishi Desai, DO, Chair
Sylvia Rosas, MD. MSCE, Co-Chair**

Introduction

The Socio-economic Status Workgroup (the Workgroup) met via teleconference on 08/05/2019 to discuss the following agenda items:

1. Details of Data Proposal
2. Brainstorming

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

1. Details of Data Proposal

A UNOS staff member provided an overview and background of a data collection proposal.

Data summary:

Five Principles for Data Collection:

- Develop transplant, donation and allocation policies
- Determine if institutional members are complying with policy
- Determine member-specific performance
- Ensure patient safety when no alternative sources of data exist
- Fulfill the requirements of the OPTN Final Rule

Data Review Checklist:

- Purpose, population and outcomes
- Data collection principles
- Alternative data sources
- Consistency within system
- Interoperability
- Validity
- Reliability
- Definition
- Usability
- Quality

Summary of discussion:

There was no discussion on this topic

2. Brainstorming

Workgroup members reviewed the Transplant Candidate Registration form and compared to the Living Donor Registration form. Members then brainstormed new fields that could be added to better measure socio-economic status.

Data summary:

The following is a list of currently collected socio-economic data on the Transplant Candidate Registration form (TCR):

- State and ZIP code of residence
- Ethnicity/Race
- Citizenship
- Highest level of education
- Working for income
- Primary source of payment
- Date of birth

Summary of discussion:

One workgroup member commented that the current “Working for Income” field may seem unclear to candidates, particularly if they are working for unreported cash or as caregivers. A UNOS staff member explained that cash payments are still considered a source of income but that uncompensated work as a family caregiver may not be.

One member asked details about how to derive poverty status based on household income and whether the field should have categories or blank field. A UNOS staff member explained that poverty status is best derived from household income and household size as the two are used in federal calculations. The staff member added that the preferable collection field is blank due to the fact that categories don’t provide a flexible option for calculating federal poverty standards which vary from year to year.

A workgroup member asked for clarification on the field “primary source of payment”. A UNOS staff member explained that field referred to different insurance sources and likely the field is not blank but has a set of defined options.

One workgroup member suggested including a field related to gender or self-identified gender. Another member was on the phone and asked for clarification on the information on the screen. A UNOS staff member explained that the slides and forms would all be posted on the OPTN Minority Affairs Committee Sharepoint site.

One member asked why the Living Donor Registration (LDR) form has different options for the “Working for Income” field that are not included on the TCR. A staff member explained that different forms can include different fields and they were not sure the reason for this particular difference. Another member commented that the living donor follow up requires collection of whether or not the donor lost their insurance and this field could relate to understanding any potential losses by donors due to donation. The member noted that this could be a helpful field to also collect on the candidate side through the TCR. Another member spoke up in agreement for expanding this field on the TCR, especially as they could not see a reason why the data collected would be different.

A UNOS staff member reminded the group that any proposed added fields would need to have justifications of their own. One member noted that having more specific and granular data would be helpful in assessing the effects of socio-economic status especially since the current data relies on median household income by zip code. The member noted that this information is commonly covered by transplant programs particularly by social workers, however this data is not currently available by the OPTN. A staff member commented that there may be a skew in the response regarding “Working for Income” as potential candidates may be more likely to be not working due to their health status.

One member commented that candidates working for non-disclosed cash may not mark that they are working for income. A UNOS staff member commented that on the other hand, those candidates may now be marking themselves as working for income but may be more reticent to be specific with expanded options. Another UNOS staff member commented that these candidates are likely already providing that information to transplant programs and that asking at a household level may mask that effect.

A member commented on the significance of having access to transportation and suggested collecting that information. Another member asked if veteran status is currently collected and whether it is a field the workgroup would want to consider. A UNOS staff member responded that they did not believe veteran status is currently collected but that there is an option to list the Veteran Affairs as the primary source of payment.

A UNOS staff member made note that there is a difference between whether an individual collects disability or if they self-identify as disabled. One member asked what the next step is for the workgroup. A UNOS staff member explained that the workgroup should continue brainstorming and the next call would be continuing a more in-depth discussion of some of the options that were discussed.

One member asked for clarification on the process of approval for the Data Collection Proposal. A UNOS staff member explained that the project would be presented and receive provisional approval from the Data Advisory Committee (DAC) followed by project approval by the Policy Oversight Committee (POC). At that point the proposal would go through a public comment period and approval before the board.

Next Steps:

The Committee will continue brainstorming regarding fields to add to the TCR form regarding socio-economic status. There will be a presentation on the workgroup to the DAC on August 12th and to POC on the 22nd.

Upcoming Meetings

- September, 2019 (date TBD)