

Data Collection to Assess Socioeconomic Status (SES) & Access to Transplant

OPTN Minority Affairs Committee

Socioeconomic Status (SES)

- Definition: Social standing or class of an individual or group, often measure by a combination of education, income, and occupation
- Individuals and households are grouped into high, medium, or low SES
- Examination of SES can show disparities in access to resources
- SES is a key determinant of health outcomes

Purpose

- Current SES data collection is not adequate
- Data currently collected are:
 - Primary source of payment
 - Highest level of education
 - Working for income
- The collection of better patient-level data would provide a more holistic understanding of how SES factors impact transplant candidate access

Proposal

- Addition of two data fields to the Transplant Candidate Registration (TCR)
 - Annual household income
 - Household size
- Better analysis on the potential impact of SES on access to transplant
- Does not propose the removal of any elements from the TCR

Two New Data Elements

Annual Household Income:

- Monitor policy impacts on disadvantaged populations and address potential inequity in:
 - Outcomes
 - Annual household income impacts access to health care services and health outcomes

Household Size:

- Clarify how many individuals in the household depend upon the household income reported

Rationale for Annual Household Income & Household Size

- Calculation of household poverty
- Use data to monitor potential policy impacts on disadvantaged populations and better address inequity in outcomes

Stakeholder Collaboration

- Upon proposing these potential new data fields, MAC solicited feedback from:
 - Transplant Administrators Committee
 - Transplant Coordinators Committee
 - Data Advisory Committee
 - Society of Transplant Social Workers
- Considerations:
 - Sensitivity of data
 - Accuracy of data
 - Use of median ZIP Code data
 - Education for transplant hospital staff

Member Implementation

This proposal would impact all transplant hospitals that register candidates on the waiting list:

- Transplant hospitals are required to submit additional data for each candidate registered to the transplant waiting list
- Collection of each transplant candidate's annual household income and household size

Request for Specific Input:

- Are annual household income and household size the best data elements to collect to measure SES?
- What barriers might there be to collecting and reporting these data?
- Are there other data related to SES the OPTN should collect?

Discussion

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- Require members to collect two new data fields; annual household income and household size before submission of the TCR
- Gather greater understanding of the potential relationship between candidate SES and access to transplant

Extra Slides

Other Fields Considered to Measure SES

- Expanded “Working for Income” Options like Living Donor Registration (LDR)
 - Does not produce quantitative or comparable data
- Access to Transportation
 - No standardized definition
- Individual Patient Income
 - May not reflect actual monetary support a patient is receiving