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
Data Collection to Assess Socioeconomic Status & Access to Transplant

- 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