

# OPTN Regional Review

## Community Input | Summer 2020 Public Comment

The OPTN is leading a project to analyze the roles of regions and optimize their effectiveness in organizing governance, processes, and operations of the transplantation network. Before a vendor is selected to conduct the review, community input was collected through a short questionnaire that was available June 29 – Oct. 1, 2020. The questionnaire responses will be informational to the selected vendor.

This report is a summary of the community input questionnaire responses.

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## Summary respondent input by question

### 1. How do you describe the current OPTN regional structure?

#### Effective

26 responses had comments that aligned with this category. Members described the current OPTN regional structure as functional, easy to follow, and logical. Respondents reported that the current structure as an effective way to communicate and solicit feedback from OPTN members. They believed that regions serve an important role in the policy making process and benefit both organ procurement organizations and transplant programs. One member called the OPTN regional structure an “administrative necessity for representation”. Members found the current structure effective for the facilitation of communication between regions. Some members voiced concern over the possibility of changes to the OPTN regional structure.

#### Ineffective

20 responses had comments that aligned with this category. Members described the current OPTN regional structure as arbitrary, random, and fragmented. Respondents reported the current structure is irrelevant from an operational standpoint, as oftentimes regional and OPO boundaries are not aligned. Members believe that differences in region size and representation contribute to its ineffectiveness and would prefer boundaries that account for population shifts. One member said that the geographical boundaries “have no demonstrable reasoning behind them.” A few respondents reported that due to allocation changes, the current structure no longer makes sense and is less impactful as broader sharing practices are promoted. One member expressed concern over transplant centers having more of a voice than OPOs.

#### Outdated

17 responses had comments that aligned with this category. Members described the current OPTN regional structure as archaic, broken, and inconsistent with broader sharing. Respondents reported that the current structure is due for an overhaul, as it is based on geographic boundaries that were significant in the early days of transplantation, but are no longer relevant. Members believe the current structure is outdated and requested a structure that is more optimally suited to reflect demographic/population changes and supports equitable organ distribution. One member would like to see more equal representation of patient, candidate, program, and provider voices across regions. Other members asked that a new system be more patient- focused and better represent minorities.

#### Based on Geographic Boundaries

16 responses had comments that aligned with this category. Members reported that the current OPTN regional structure is the grouping of geographically close states into 11 regions consisting of multiple transplant hospitals, histocompatibility labs, and OPOs. Members believe that this structure encourages transplant professionals to collaborate to enhance organ policy. Some members expressed that while the system is based on geographic boundaries, these boundaries do not represent all populations equally.

#### Ability to Provide Input

10 responses had comments that aligned with this category. Members described the current OPTN regional structure as a method for organizing the nation’s transplant professionals into more manageably sized groups (regions) with the purpose of sharing information and providing feedback on

the OPTN policy development process. These members believe that this framework ensures that each region has proper representation when providing input on proposed changes at the local and national levels.

### Building Relationships

Seven responses had comments that aligned with this category. Members reported that current OPTN regional structure allows members within similar geographic regions to connect, network and collaborate. Members use the current OPTN regional structure to meet with other transplant professionals that are in close proximity that may be experiencing similar issues. One member commented that while they appreciated the opportunity to collaborate with institutions inside their region, they would also like opportunities to connect with programs that are close in proximity to their program, but outside their regional boundaries.

### Based on Historical Collaboration

Seven responses had comments that aligned with this category. Members described the current OPTN regional structure as traditional and historical. Respondents reported that the OPTN regional structure is based on historical partnerships between transplant centers. These areas often had similar demographics and were used for organ allocation and distribution. What separates this theme from the “outdated” theme, is that these members did not express that the structure needed to change, only that it was based on historical collaboration.

## 2. What are the advantages of the current OPTN regional structure?

### Building Relationships

37 responses had comments that aligned with this category. Members reported that the current OPTN regional structure has helped to foster collaboration and partnerships between transplant professionals. Members responded that familiarity with nearby transplant centers and OPOs helps to build trust and that ultimately these connections improve donation and transplantation. Members also believe that the current OPTN regional structure gives transplant professionals the opportunity to network, share information, and discuss best practices.

### Geography

29 responses had comments that aligned with this category. Members reported the geographic boundaries as an advantage of the current OPTN regional structure. Members responded that the current structure provides an opportunity for transplant centers and OPOs with similar demographics, populations, and regional issues, to collaborate to overcome challenges. Other members added that the current OPTN regional structure breaks the nation into smaller and more manageable sized regions for meeting and administrative purposes. One member mentioned that the current structure is advantageous to areas with high donor registrations.

### Logistical & Structural Efficiency

14 responses had comments that aligned with this category. Members felt that the current OPTN regional structure is well established, easy to understand, and organizationally efficient. Members also reported the ease of participation in regional meetings due to short travel times. One member voiced concern that changes to the current structure would “come at significant cost in terms efficiency and ability of stakeholders to meaningfully participate”.

### Representation

11 responses had comments that aligned with this category. Members reported that the current OPTN regional structure ensures participation and equal representation in the policy development process. Members responded that this structure allows regional differences to be represented and ensures voices from all across the country are heard. Some members disagreed and reported that there is a lack of community and patient engagement in the current structure.

### Regional System

Six responses had comments that aligned with this category. Members reported that the regional system itself as an advantage. They explained that it is a consistent system that works similarly in each region and enhances the ability of transplant professionals to organize and vote on potential changes. Members believe that the system's design lends itself to regions being represented and rolled into a broad national view. A member commented on the importance of a strong relationship between members and OPTN/UNOS. Another member said OPO involvement is important and should play a large role.

### None

Five responses had comments that aligned with this category. Members did not see advantages to the current OPTN regional system. One member mentioned that air travel expense for their program had increased exponentially.

## 3. What are the disadvantages of the current OPTN regional structure?

### Impacts of Broader Sharing

22 responses had comments that aligned with this category. Members reported that the impact of broader sharing is a disadvantage to the current OPTN regional structure. These members responded that because the regional boundaries are no longer used for allocation, but are still used for meeting purposes- transplant programs and OPOs will meet with transplant professionals outside of their allocation range. Members reported that the shift to broader sharing allocates organs to more densely populated areas, pulling organs away from the donor's community. Members also pointed out that in some cases transplant programs that are close to the donor hospital are considered national as opposed to regional and that this can increase cold time and overall complications. Members believe that broader sharing leads to competition instead of collaboration between centers in the same region. A smaller group of respondents disagreed and reported that regions and geography should not have been linked to allocation in the first place.

### Regional Differences

14 responses had comments that aligned with this category. Members felt that the disadvantages of the current OPTN regional structure have to do with geographic and administrative differences from region to region. Some members expressed that the geographic (such as rural vs. urban areas), demographic, and political differences in each region produce unique challenges that cannot be solved with a "cookie cutter" solution. Members pointed out that due to these differences, the implementation of OPTN policies have a variety of impacts on patients dependent upon place of residence. Members also reported differences in wait times and OPO practices from region to region as disadvantages.

### Regional Population/Size Variation

14 responses had comments that aligned with this category. Members felt that disadvantages of the current OPTN regional structure are that regions are not based on population and that each region varies in the number of programs/OPOs. They feel that large cities with multiple centers often dominate the OPTN and have a louder voice than smaller areas.

### Regional Limitations

13 responses had comments that aligned with this category. Members found the regional limitations of the current OPTN regional structure to be a disadvantage. They reported that the regional mindset contributes to a limited perspective and the development of silos. This is because transplant professionals often think about what is most beneficial for their region rather than the nation as a whole. Members responded that these limitations do not support national policy discussions or the sharing of best practices on a broad level.

### Regional, Board, & Committee Representation

10 responses had comments that aligned with this category. Members reported the current regional, BOD, and committee representation as a disadvantage. These members responded that patients are underrepresented at the regional level and that this highlights the need for more community engagement. They would like to see greater diversity on the OPTN committees and BOD, including more representation from African-Americans and pediatric specialists. Members would also like to see some uniformity in the committee nomination process, as currently each region's process differs. Members pointed out that many of the same transplant professionals sit on OPTN committees over and over. A member also suggested that there are too many committees and that the OPTN should have fewer committees with more subcommittees.

### Current Regional Boundaries

Eight responses had comments that aligned with this category. Members reported that regional boundaries are a disadvantage of the OPTN regional structure. Members referenced situations in which two transplant programs may be close together, but are in different regions. They responded that situations like these do not make sense and contribute to the inefficiencies of the OPTN. One member suggested the OPTN should add more regions and another suggested the current regions are too large.

### Inefficient

Seven responses had comments that aligned with this category. Members reported the current OPTN regional structure as outdated, arbitrary, and random. A member did not see the value of regions, as they are no longer used for allocation.

### None

Five responses had comments that aligned with this category. Members reported that there are no disadvantages to the current OPTN regional structure. A couple members responded that the system works for all states but New York and California.

#### 4. What are the barriers and challenges that should be considered during the course of this project?

##### Regional Relationship

13 responses had comments that aligned with this category. Members reported that managing interregional relationships should be considered during this project. Some members responded that there is a history of camaraderie should to be considered. These members asked the OPTN to support the long-standing collaborative relationships between transplant centers and OPOs. Other members said that the competitive nature and politics of the transplant system could become more evident during a regional restructure. Members also asked the OPTN not to do away with in- person meetings entirely as this would decrease networking opportunities.

##### Travel & Costs

13 responses had comments that aligned with this category. Members reported travel and cost as a potential challenge. They responded that with dramatic changes there may come significant costs, including travel for meetings. Members asked that the OPTN consider travel “hubs” for future meetings. One member suggested that there should be no more than one in- person regional meeting a year and that all other meetings should be held virtually to decrease travel cost and broaden participation. Other members discussed how the recent allocation changes have called for more air travel and that this has been costly for programs and OPOs. These members mentioned increased cold ischemic time and medical personnel travel as allocation change challenges. They requested that the OPTN seek to understand the impact of these changes on the financial status of OPTN members.

##### National Variation

11 responses had comments that aligned with this category. Members reported that accounting for variation on a national level should be considered. Challenges vary from region to region based on geography and the population the region serves. Members responded that a solution that uses a “one size fits all” model is not likely to meet the needs of every transplant center and OPO. Members pointed out that the needs of patients who live in urban environments are different from those in rural ones.

##### Resistance

Eight responses had comments that aligned with this category. Members reported that the OPTN could face resistance to change throughout the course of the regional restructure. They responded that members may question how and why decisions are made. Members will likely need to forge new relationships and some may be reluctant to do so.

##### Logistics

Eight responses had comments that aligned with this category. Members responded that logistics could be a challenge. Members did not feel this was the right time to consider restructuring regions due to the unknown impacts of COVID 19 and implementation of continuous distribution. One member asked for clarity on what exactly regions would be used for and another member expressed that they needed more information on the goal of the project.

##### Allocation Considerations

Eight responses had comments that aligned with this category. These members suggested that a regional restructure could have an impact on allocation practices. Members reported that one large

challenge could be ensuring that various transplant programs and OPOs are grouped into a “region” that is more aligned to their allocation circles. They expressed that this regional reorganization could be complicated to align with allocation as each organ is distributed using different algorithms. A member reported that the reallocation process has been rather unfair as regions with higher donor rates are now sharing organs with those regions with lower donor rates, and now the high donor rate areas are not receiving offers at the same rate they were before. Members seek a clear structure for the transplant community.

#### Community Buy in & Reaching Consensus

Seven responses had comments that aligned with this category. Members suggested that it will be challenging to reach a consensus on what the regional reorganization should look like. They added that addressing shortcomings in the current system, while maintaining fairness to regions is a challenge for consideration. Members reported that the community will request solid rationale for changes before the OPTN can garner their buy in.

#### Equity in Access to Quality Care

Seven responses had comments that aligned with this category. Members responded that equity in access and quality care are challenges the OPTN should be prioritized. They reported that safety, timeliness, effectiveness, efficiency, patient-centeredness, and equitability as the most important considerations. These members seek decreased variation in wait time for organs.

#### Decision-Making

Six responses had comments that aligned with this category. Members reported concern over the possibility of the OPTN making regional restructuring decisions that are not the consensus of most regions. They referenced broadening liver allocation as an example and explained that they did not feel as though the OPTN had listened to their feedback in this situation. One member asked the OPTN to consider variance and flexibility when restructuring the regional system.

#### Equal Representation

Six responses had comments that aligned with this category. Members reported that ensuring equal representation as an important challenge to anticipate. These members felt that larger programs and regions should not be able to dictate policy and that smaller programs should not be seen as non-influential. Members also responded that the regional restructure should place more focus on increasing African American and patient representation at regional meetings. They also requested the OPTN ensure diverse representation and inclusion

#### Shared Broad Vision

Six responses had comments that aligned with this category. These members responded that the consideration of a shared broad vision for the allocation of organs would be a challenge during this project. They reported that in order to embrace broader sharing members will have to consider the impacts of policies on the nation as a whole. This could be difficult as members have vested interests in driving organs to their centers. One member suggested holding local discussions small enough to support discussion, but large enough for that discussion to be diverse.



### No Need for Change

Three responses had comments that aligned with this category. Members reported that there is no need to restructure the OPTN regions.

### OPO Performance

Three responses had comments that aligned with this category. Members expressed that OPO performance should be considered, as not all OPOs have the same visibility.

## 5. Based on your understanding of the current OPTN regional structure, if you were designing a new approach, what would it look like? What would be added, removed, or changed? And why?

### Restructure for Balanced Representation

18 responses had comments that aligned with this category. Members would design the OPTN regional structure to ensure equal representation by grouping the same number of transplant programs and OPOs in each region. They reported the importance of giving a voice to smaller centers and increasing community representation. Members called for wider representation and suggested that all states should be engaged in the OPTN policy development process. These members reported that balancing the regions to be similar in size would help the OPTN regional structure to be more fair and equitable. One member suggested rotating meeting locations to all states within a region to provide an opportunity for all members of that region to be represented.

### Preserving & Building Relationships

16 responses had comments that aligned with this category. Members are interested in preserving the relationship they have with other transplant programs and OPOs. They responded that a regional structure that preserved the ability to network, attend roundtables, and participate in educational collaborations would be of interest to them. Members also suggested that forging new relationships will be important, as any restructure may require programs and OPOs to work together who haven't before. One member suggested that similar programs (type, size, etc.) should meet to discuss best practices. Another member mentioned a similar idea, in which OPOs would meet and collaborate.

### Fewer Regions/ Broader Sharing

15 responses had comments that aligned with this category. Members see value in having fewer regions in order to embrace broader sharing. They suggested the standardization of processes as the OPTN region structure is redesigned. These members responded that the OPTN should shift towards a national mindset and that having less regions would help the organization share ideas and resolve challenges. Members suggested that broadening regions could optimize efficiency.

### Consider Geographic Differences

14 responses had comments that aligned with this category. Members would like the new OPTN regional structure to consider differences across the country such as geography, population, and demographics. Members believe the consideration of population density will create more balanced regions. They also suggested that a variety of solutions should be considered for geographic areas that are different from one another, especially for those with larger health disparities.

### Allocation & Boundaries

12 responses had comments that aligned with this category. Members gave a variety of allocation and boundary suggestions for the optimization of the regional restructure. Some members suggested that regions should be adjusted to current allocation policies and assessed for distribution patterns in order to determine if the restructure is effective. Other members reported that prior relationships and transplant center locations are the most important considerations when determining regional boundaries. Some members suggested that regions could overlap based on geographic radius and that this could facilitate communication over larger geographic areas. One member suggested considering the simplicity of state lines for boundaries.

### No Change

Nine responses had comments that aligned with this category. Members did not favor change to the OPTN regional structure. A couple of members prefer that the OPTN wait until continuous distribution is implemented.

### Travel Cost & Logistics

Eight responses had comments that aligned with this category. Members valued simplifying the logistics and decreasing costs for any travel required by the OPTN regional restructure. Members suggested selecting major cities in order to create greater access to regional meetings. Other members reported that the OPTN should have realistic expectations when asking members to travel to meetings and that virtual options should be included. They reported that the OPTN should assist with procurement and travel costs.

### Regional & Committee Leadership

Seven responses had comments that aligned with this category. Members felt that adjustments should be made to regional and committee representation structure. Members asked for a more inclusive structure in which more than one representative from each region could sit on committees. Generally, members favored more opportunities to participate on OPTN committees and mentioned that more representation is needed from African Americans. One member suggested the addition of more at-large positions to get more/new voices at the table.

### Additional Regions/Local Sharing

Five responses had comments that aligned with this category. Members favored the addition of regions and more local sharing. They preferred the idea of state transplant policy that would decrease organ travel and lessen broader sharing. One member suggested that a national structure may be too large to administer efficiently.

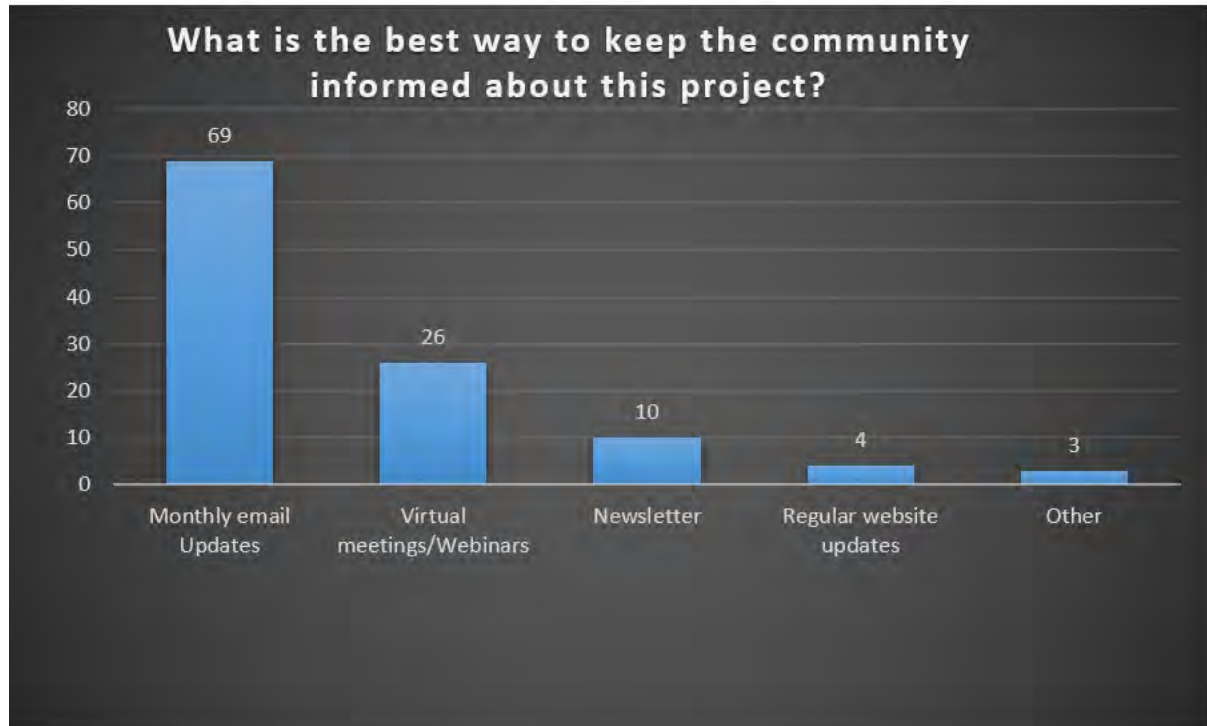
### Performance

Five responses had comments that aligned with this category. Members requested data that would show where transplant hospital and OPOs could improve in terms of performance. Members asked for performance metrics that would hold OPOs accountable.

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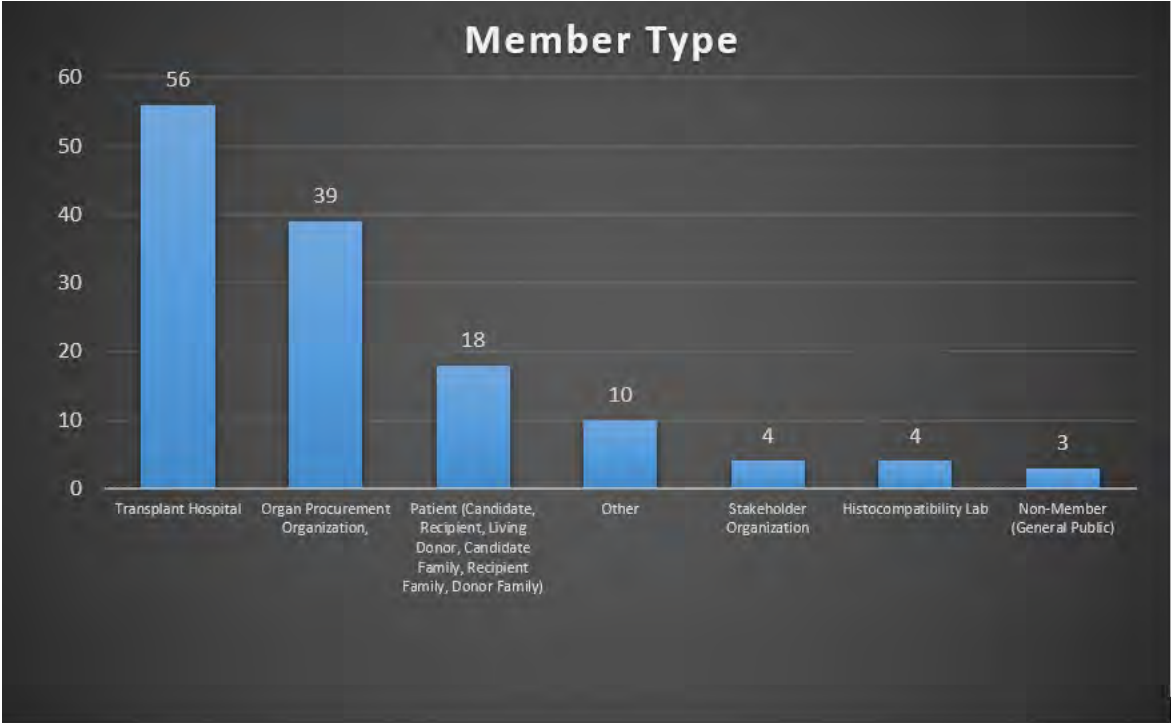
What is the best way to keep the community informed about this project?



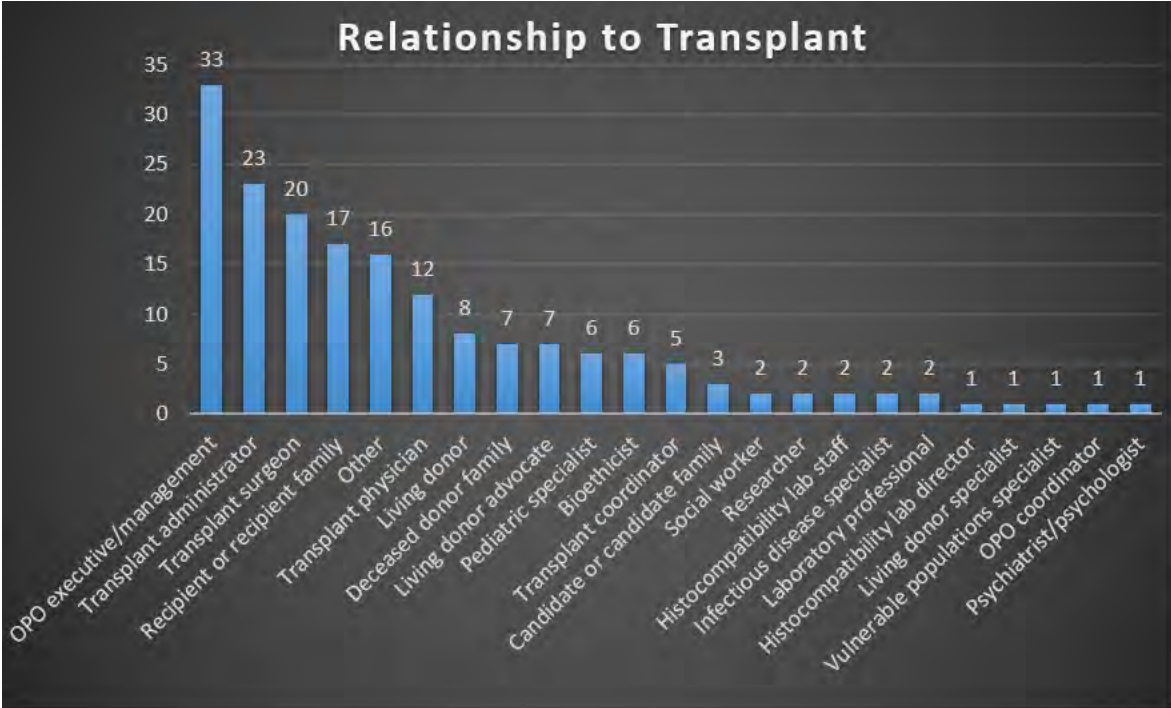
Other please specify

Two responses indicated preference for a multi-faceted approach that combined the above responses.

Member Type



Relationship to Transplant



Other, please specify

Six respondents indicated the following relationships to transplant: Director of adult critical care hospital center, transplant quality, hospitals deceased donor program coordinator, OPO community education coordinator, retired OPO executive, and transplant state policy/donor family.