

# **Meeting Summary**

# OPTN Patient Affairs Committee Meeting Summary March 10, 2022 Conference Call

# Garrett Erdle, M.B.A, Chair Molly McCarthy, Vice Chair

#### Introduction

The Patient Affairs Committee (the Committee) met via Citrix GoToMeeting teleconference on 03/10/2022 to discuss the following agenda items:

1. Public Comment Presentation, Redesign Map of OPTN Regions, and Discussion

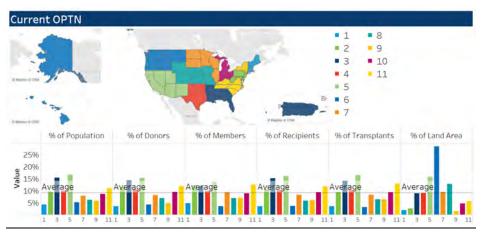
The following is a summary of the Committee's discussions.

## 1. Public Comment Presentation, Redesign Map of OPTN Regions, and Discussion

The Committee reviewed the OPTN Executive Committee's request for feedback Redesign Map of OPTN Regions. The purpose of this proposal is to gather community feedback on the options for updating the map of OPTN regions, with the potential to inform a future proposal.

#### Data summary:

The OPTN Executive Director presented on the Executive Committee's request for feedback. An examination of the existing Organ Procurement and Transplant Network (OPTN) regions was identified as a contract item by the Health Resources and Human Services Administration (HRSA), but does not necessitate a restructuring. At present, the regions serve as a basis for populating the board of directors and committees with regional representation. The rationale for this examination is that the OPTN regions have not been restructured since their inception approximately 35 years ago, organ donation and allocation practices have undergone significant changes, and that the current regions do not provide equitable Board of Directors representation. After partnering with an external contractor, the following maps were produced; the maps below do not reflect all the options, and are included as examples of those that can be found in the full proposal.



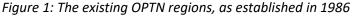
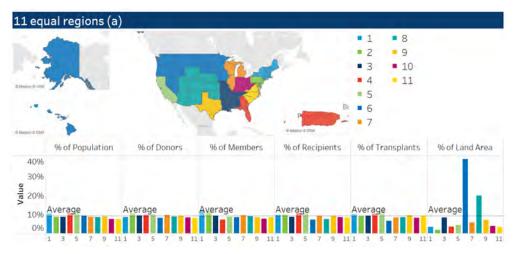




Figure 2: Existing Health and Human Services (HHS) regions

Figure 3: A division of the OPTN regions into 11 equal regions







The full concept paper, as well as the public comments to date, can be found on the OPTN website.

#### Summary of discussion:

A member expressed concern that there were maps in which a single state would comprise an entire region. They felt that this would reinforce regional isolation within those specific regions and would hinder the network overall. They cautioned, however, that there should also be a maximum size for each region, as they noted it did not make sense to them to include Oklahoma in the same region as Washington, such as in *Figure 4*. A second member inquired what data supported restructuring the regions, and it was noted that, since regions no longer use their boundaries for allocation, they have become much more of a tool for education and representation. The Executive Director presenting also clarified to a member that the percentage of total transplants performed in each proposed region was tracked under the "% of Transplants" graph, and did roughly track the other graphs. The member then proposed a scale to view the success rate of transplantations within that region, adding that some regions in a redesign may end up with all "tier two" or "tier three" programs. This consideration would ensure that candidates have access to the same quality level of programs across each region. A fourth member added that there are close working relationships between some Organ Procurement Organizations (OPOs) and the transplant programs with whom they frequently work; by taking this into account, there may not be as significant a change in working relationships. They added that by having larger regions with this taken into account, it could encourage further collaboration between OPOs and new transplant programs. Finally, they speculated that, based on their experience, some OPOs may consider merging on the basis of "increased efficiencies, increased collaboration, and increased outcomes" with the shift in regions as a catalyst.

The Vice-Chair commented that this appears like a large investment for the OPTN and may not be worth it if it is taking away resources from other proposals that could increase the number of transplants or improve patient outcomes. A member further contributed that this could a premature action in the context of continuous distribution; as allocation changes in the upcoming years, there may be new metrics that should be considered because of the new framework for allocation. Additionally, they inquired whether, prior to this request for feedback, there had been concerns voiced from some regions that they felt underrepresented. The presenter replied that there had been some concerns, both supported by data and noted anecdotally by members. The presenter further clarified that the regional redesign was not being driven by organ allocation; it is primarily focused on representation and education.

The Chair also questioned whether this process should be repeated on a routine basis. The Executive Director responded that this was something that could be considered, as it came down to the question of whether historical interactions and relationship were more important than strict regional balance.

Another question posed was whether making the regions geographically larger would be an impediment to patient and donor participation in a regional meeting. A member felt that there may be a benefit to having more people in attendance at a regional meeting, as it would ensure the topics are more generally graspable, rather than specific to a smaller group of people. The Executive Director also contributed that, with the past two years of virtual meetings, attendance was actually higher than in previous years, so there were plans to continue to have a virtual option available even as they returned to in-person. Additionally, the Executive Director stressed that these meetings were vital forums, and they would continue to assess how best to engage the most number of participants.

A member followed up on the point of community engagement, and asked what reducing the regions would mean for regional representation; for example, if the regions were reduced from eleven to eight, would the board of directors shrink, or would those three seats remain with new requirements? From a

personal standpoint, the Executive Director said they felt that there was a point at which committees could get too large, but they didn't believe any committees were at that point, nor was there any reason to shrink a committee's size due to regional representation requirements shrinking. However, they concluded that this had not been fully discussed, and would be considered further by the Executive Committee should the committee opt to develop a public comment proposal.

## Next steps:

The Executive Committee will consider the feedback of the Patient Affairs Committee.

## **Upcoming Meetings**

- March 11, 2022
- March 30, 2022

#### Attendance

# • Committee Members

- o Garrett Erdle
- Molly McCarthy
- o Diego Acero
- o Julie Ice
- o Sarah Koohmaraie
- o Katie Laferriere
- o Earl Lovell
- o Anita Patel
- o Sejal Patel
- o Kristin Ramsay
- o James Sharrock
- o Julie Spear
- o Eric Tanis
- o Justine Van Der Pool
- o Justin Wilkerson
- Christopher Woody

# • HRSA Representatives

- o James Bowman
- o Raelene Skerda
- SRTR Staff
  - o Katie Audette
- UNOS Staff
  - o Roger Brown
  - o Chelsea Haynes
  - o Lindsay Larkin
  - o Meghan McDermott
  - o Lauren Motley
  - o Rebecca Murdock
  - o Erin Parkhurst
  - o Tina Rhoades
  - o Brian Shepard
  - o Katilin Swanner
  - o Susan Tlusty
  - o Sara Rose Wells
- Other Attendees
  - o Mary Beth Murphy