

**OPTN Patient Affairs Committee
Meeting Summary
March 3, 2021
Conference Call**

**Darnell Waun, M.S.N., Chair
Garrett Erdle, M.B.A., Vice Chair**

Introduction

The Patient Affairs Committee (PAC) met via Citrix GoToMeeting teleconference on 03/03/2021 to discuss the following agenda items:

1. Welcome and Introductions
2. Presentation and Discussion: *Revise General Considerations in Assessment for Transplant Candidacy*
3. Presentation and Discussion: *2021-2024 OPTN Strategic Plan*
4. Closing Remarks

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

1. Welcome and Introductions

The Committee Chair introduced the incoming Vice Chair and a new regional representative. The Committee members introduced themselves and their backgrounds.

2. Presentation and Discussion: *Revise General Considerations in Assessment for Transplant Candidacy*

The OPTN Ethics Committee Vice Chair presented *Revise General Considerations in Assessment for Transplant Candidacy* which is currently out for public comment. Prior to the presentation, the Committee members were split into two groups to analyze each presentation and a member presented the consolidated feedback to initiate the conversation.

Summary of discussion:

The Ethics Vice Chair informed the members the purpose of the White Paper serves to inform practitioners as opposed to creating policy.

PAC members came to the consensus that there is agreement with the premise of the paper, but recommend including more and go into more depth on the current contents to achieve its goal. The Ethics Committee Vice Chair informed the members that was a very prominent debate within the Committee.

PAC members recommended adding language for additional protections for individuals with cognitive disabilities. The Ethics Committee Vice Chair informed members the Ethics Committee is working on a paper on this topic.

A PAC member suggested specific groups that need additional psychosocial considerations and protections. A member suggested the Ethics Committee consider including the challenges associated with a language barrier and how this could create an unconscious bias or impact accessibility. Members also suggested addressing incarcerated individuals and individuals who live in nursing homes.

Multiple members expressed concern about adherence and the importance of a support system following transplant. Members further explained support networks can often be unfairly distributed across the country and it's the responsibility of the transplant center to build an ongoing network of support for patients. Members called for an increase need for patient education which would result in greater adherence and increase the life of the transplant. In terms of patient education, the Ethics Committee Vice Chair agreed on the need for this but suggested that Patient Affairs Committee would be more appropriate to address this need.

The Chair recommended these guidelines be built into actual policy to have a greater impact and be implemented at transplant centers. Overall, the PAC is supportive of this white paper and is eager to continue ethical conversations throughout the OPTN.

3. Presentation and Discussion: 2021-2024 OPTN Strategic Plan

UNOS Staff presented the Executive Committee's 2021-2021 OPTN Strategic Plan proposal which is currently out for public comment. A member initiated the conversation by providing the group's consolidated feedback on the Strategic Plan as a whole.

Summary of discussion:

Overall, Members support the proposed plan but provided guidance in ways that it could be made more patient centric. Members suggested that the Strategic Plan could easily be made more patient friendly by using less acronyms and adding a glossary.

One primary concern that arose was the manner in which outcomes and metrics are calculated. Members encouraged the inclusion of qualitative metrics, such as quality of life after transplantation, in Goal 4. Additionally, the group encouraged that outcomes begin to be tracked once a patient has their initial visit to the transplant center, not just following transplantation. Members commented the duty to the patient by the transplant center needs to be emphasized earlier in the transplantation process. Members believe that Goal 3 does not need 10% devoted to it because there is only one initiative housed within the goal. Members suggested reallocating from Goal 3 to Goal 4.

The group recommended another step towards a more patient centric Strategic Plan would be increasing patient involvement in policy development. Members specifically suggested adding an initiative to Goal 2 "to produce policies that are equitable to all patient populations." Additionally, Members identified the Minority Affairs Committee and Living Donor Committee as 'patient centric' Committees and encouraged increasing the number of patient representatives. Members commented these 'patient centric' Committees, PAC included, should have a membership make up that mirrors the characteristics of the organ waitlist.

The discussion transitioned to transparency as members suggested the inclusion of a data transparency initiative under Goal 1. However, data transparency is not the singular transparency concern of the PAC as major barriers persist caused by patient literacy and patient education. A member suggested providing information that is targeted toward young pediatric patients to help them develop an understanding of what is going on and allow them to play a part in their care as they age. There is a strong desire among members to better mobilize the existing patient tools and develop consistent education tools for providers. Members expressed concern about health literacy as a whole, but specifically within populations where English is not their primary language.

Members also discussed whether or not the OPTN should be a more outward and patient facing organization. This conversation stemmed primarily from where patient education resources could be better housed. There was a general viewpoint that patients were not familiar with the OPTN but the ultimate question that remained was whether or not patients should be familiar with the organization.

Overall, there was consensus that patient education should come from surgeons, coordinators, or other medical providers because those are the providers that patients listen to the most.

Members expressed concern about accomplishing Goal 1 while patients are not being informed when their treatment team receives and organ offer. There seemed to be conflict between increasing the number of transplants while not providing the opportunity to accept organ offers.

Additionally, a member shared their concerns with how overwhelming the start to the transplant process is, especially coming into the transplant center for the first time and meeting their entire transplant team at once. However, other members countered that lower income or rural patients often do not have the luxury to have appointments spread out over multiple days especially if their state has very few transplant centers.

4. Closing Remarks

Official PAC feedback for *Revise General Considerations in Assessment for Transplant Candidacy* and *2021-2024 OPTN Strategic Plan* will be composed and posted on the respective OPTN Public Comment webpages. PAC members are encouraged to post individual public comments as well.

Upcoming Meetings

- March 16, 2021
- April 15, 2021
- May 13, 2021
- June 10, 2021

Attendance

- **Patient Affairs Committee Members**
 - Darnell Waun, Chair
 - Garrett Erdle, Vice Chair
 - Anita Patel
 - David Skinner
 - Diego Acero
 - Earl Lovell
 - Eric Tanis
 - James Sharrock
 - Julie Siegel
 - Kenny Laferriere
 - Molly McCarthy
 - Phil Williams
 - Sarah Koohmarie
 - Stephanie Little
 - Julie Ice
- **HRSA Representatives**
 - Jim Bowman
 - Lauren Darensbourg
 - Raelene Skerda
- **SRTR Staff**
 - Katie Audette
- **UNOS Staff**
 - Abby Fox
 - Brian Shepard
 - Chelsea Haynes
 - Eric Messick
 - Julia Chipko
 - Laura Schmitt
 - Lindsay Larkin
 - Roger Brown
 - Ross Walton
 - Sara Rose Wells
 - Susan Tlusty
 - Tina Rhoades
- **Other Attendees**
 - Andrew Flescher
 - Julie Spear