OPTN Patient Affairs Committee
Meeting Summary
June 16, 2020
Conference Call

Darnell Waun, R.N., M.S.N., Chair
Garret Erdle, M.B.A., Vice Chair

Introduction

The Patient Affairs Committee (PAC) met via Citrix GoToTraining teleconference on 06/16/2020 to discuss the following agenda items:

1. Board of Directors Meeting Update
2. Continuous Distribution of Lungs – Analytic Hierarchy Process (AHP) Definitions Review and Discussion
3. Cross Committee Work Update

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

1. Board of Directors Meeting Update

The Chair updated the members on the recent Board of Directors meeting. Topics included a COVID-19 update, an update on the nominating committee process, and proposal votes.

2. Continuous Distribution of Lungs – Analytic Hierarchy Process (AHP) Definitions Review and Discussion

The PAC reviewed and discussed the language in the AHP prioritization exercise. This review was to ensure that definitions are easily understood by both professionals and general public in preparation for broad release during summer Public Comment.

Summary of discussion:

A member stated that they find the term "continuous distribution" confusing and did not understand what it means in terms of allocation. The member wondered if there is a more descriptive term. Another member responded that there are concerns about the term "continuous distribution" being linked to geography but they did not see that connection.

Medical Urgency

The Committee had the following observations and recommendations:

- Remove the section regarding Final Rule because it appeared to be implying that medical urgency was the way to "achieve the best use of organs".
- Lung Allocation Score (LAS) should be defined
- There should be educational opportunities depending on the timing of release to the general public
- There is not a broad understanding of the phrase "general ethical utility" or the Final Rule
- In general, the Committee agreed that the definitions are written above the general public's understanding and makes assumptions about an individual's foundational knowledge

Post-transplant Survival

The Committee agreed this explanation is also too complicated for the general public. A member stated that the term "health" should be expanded and defined. Another member asked who the intended target is for the AHP prioritization exercise. The Committee was informed that this is intended to be utilized by everyone. The Committee suggested adding a short definition to the top and have the rest listed under an additional information section.

Patient Access- Pediatric Age Group Priority

A member recommended deleting the sentence "how old the candidate is" from the short definition. as the following sentences define it. Another member stated it is overburdening the public to have to research each acronym.

Biological Disadvantage

Members agreed there are too many medical terms, such as "level of sensitization". A member stated that the general public may not understand what "ethical principle of equity" is. Another member suggested switching "minimize disparities" to "limited number of offers". A member stated that, as a recipient, the term "offers" did not mean much, but the term "match" meant a lot more.

3. Cross Committee Work Update

Summary of discussion:

Committee members serving on cross-committee workgroups updated the Committee on progress.

Provisional Yes Workgroup

The committee representative stated that the early involvement of the PAC is a good sign that other committees are realizing the importance of patient involvement. The representative responded that initially the workgroup was supposed to have a report by June 26 but it has been pushed back to allow for more discussion and research. The Committee was informed the goal of the workgroup is to produce an enhanced provisional yes system that reduces the current inefficiencies. The Committee expressed interest in reviewing workgroup materials once they are available.

Multi-Organ Policy Review Workgroup

The committee representative updated the Committee that the workgroup is still in early stages but there is a goal to have a proposal ready for winter 2021 Public Comment.

Upcoming Meetings

- July 21, 2020 (teleconference)
- August 18, 2020 (teleconference)