

**OPTN/UNOS Patient Affairs Committee
Meeting Minutes
January 15, 2019
Conference Call**

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Garrett Erdle, MBA, Vice Chair**

Introduction

The Patient Affairs Constituent Council (PACC) met via Citrix GoTo on 01/15/2019 to discuss the following agenda items:

1. *Education Topic of the Month*: OPTN Policy Development and Public Comment Primer
2. Discussion on Constituent Council Subcommittees

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

1. *Education Topic of the Month*: OPTN Policy Development and Public Comment Primer

UNOS staff presented an overview of the spring 2019 Public Comment cycle, including the timeline for public comment and national webinars. UNOS staff also discussed the Public Comment Primer, including the functions of the OPTN, the policy development process, the various OPTN/UNOS Committees, overview of the Public Comment process and need to include the perspectives of PACC members during this process.

Summary of discussion:

UNOS staff clarified for Committee members that there are two discussion policy webinars, and one non-discussion policy webinar. Committee members requested more information on the webinars, which UNOS staff agreed to disseminate at a later date. UNOS staff also informed the Committee that certain PACC members may have the opportunity to vote on proposals at regional meetings, if they meet criteria as outlined under OPTN Bylaw 9.3 Regional Voting Privileges.

After giving an overview of the public comment process, UNOS staff elicited feedback from Committee members on why the general public does not participate in the OPTN Public Comment Process. The feedback received is as follows:

Barrier	Explanation
Language in Public Comment Proposals	Challenging for those without transplant experience or knowledge of OPTN; very clinical; lack of plain language; acronyms
Patient do not know they can participate in the decision-making process	Lack of information about the policy process and how decisions are made in the OPTN
Patients do not know who the OPTN or UNOS is	General lack of knowledge about the OPTN/UNOS; UNOS does not advertise itself or reach out to the general public as well as it could

Barrier	Explanation
Might know about UNOS but do not know about the policy development process	Patients need to be shown “why” and “how it affects” patients and/or families; What is public comment, when it is open for commentary?
Patients may only know about their own regional organizations or OPOs	Donor families may have limited perspective (e.g. their “transplant universe” may just be their OPO) OPOs have a challenging time in engaging families and patients post-transplant
Many do not realize or understand that their “voice” represents more than themselves	Public comment allows for an individual to amplify their voice when they are representing constituents If people understand this, then they may feel more willing to come forward and comment
No formal education about UNOS with volunteer coordinators or that OPOs give to the general public	OPO volunteer staff do not advertise or speak out UNOS; could leverage OPO staff to help inform about UNOS
General public and patients may not have a desire to comment unless it particularly affects them.	More concern if a policy is going to be immediately take effect or impact their health; may be too busy managing their own healthcare; higher participation rates from transplant hospitals that are either positively or negatively impacted

A few Committee members had suggestions for how the OPTN/UNOS might begin to address the barriers described above, such as creating a one or two page abstract for each policy proposal. Basically, UNOS Communications might disseminate these abstracts to the general public and help to increase the general public’s knowledge of the public comment cycle. Other suggestions included giving literature to the general public, which might also help to improve patient involvement with the OPTN/UNOS. Another member suggested to mobilize the UNOS Ambassadors program to increase the public’s awareness of UNOS and the OPTN. The Committee generally felt that previously, the patient’s “voice” during the public comment process had contributed to changes within policy proposals. There was a noticeable difference that was seen last public comment cycle, and may encourage more people to speak up.

UNOS staff then continued discussion by outlining the responsibilities and guidelines for PACC members during the public comment process, such as the questions that PACC members will be expected to address. The PACC will hear the Thoracic, Kidney/ Pancreas, Disease Transmission Advisory Committee (DTAC) and Ethics public policy proposals at the next in-person meeting on February 25th. Due to time constraints, the Committee was unable to discuss how the OPTN/UNOS could increase patient engagement and participation in public comment. The Committee will move this particular discussion to Basecamp.

Next steps:

UNOS staff will provide more details on the upcoming webinars to the Committee. Furthermore, discussion over how to increase patient engagement and participation during the public comment cycle will occur on Basecamp.

2. Discussion on Constituent Council Subcommittees

UNOS staff presented an overview of the Proof of Concept and the project's next steps. In effect, the Proof of Concept Phase 2 will encompass creating four Subcommittees that will be composed of PACC members.

Summary of Discussion

The four proposed PACC Subcommittees are as follows: Education, Evaluation, Patient Engagement & Communications, Strategy & Process Improvement. The Subcommittees will develop their own scope of work, nominate a leader, and determine how to accomplish their work (e.g. meetings, Basecamp).

An overview of each Subcommittee can be seen below:

Proof of Concept: Phase 2



▪ **Education:**

- Topics or content that would benefit *OPTN patient and donor family member volunteers*
- Enable understanding of OPTN policy, the policy development process, or anything specific to what the OPTN does (e.g. the match, data collection, compliance monitoring, Bylaws).
- Ultimately, this should lead to a more informed, confident patient and donor family member volunteer workforce

▪ **Strategy/Process Improvement**

- Refine Committee report & public comment review processes, including currently available resources and tools

▪ **Evaluation**

- Proof of concept still needs to be assessed on a regular basis.
- How should we continue evaluating?
- What methods, what frequency?
- This group could develop an evaluation plan and help implement.

▪ **Patient Engagement and Communications**

- How to engage patients outside of the OPTN volunteer system

The Chair opined that the focus of the Subcommittees is to form a centralized system for patient-related activities at UNOS. However, the Chair also stated that this process may be lengthy, taking anywhere from 2-4 years. Further recommendations by the Chair included having the Subcommittees focus on areas of improvement, and increasing patient engagement.

One member questioned whether the PACC could produce a one-page summary for the policy proposals written in plain language that UNOS Communications would distribute to the general public. UNOS staff clarified that currently the OPTN/UNOS is more focused on professional support versus patient support. However, there is a chance to formalize engagement with other departments in UNOS, such as with the Ambassador Program. Other Committee members supported the idea that the Subcommittees reach out to the Ambassador Program, which might help engage patients within the processes of the OPTN/UNOS. Another Committee member agreed, but also pointed out that transplant hospitals are required to teach or educate patients on a specific topics (e.g. multi-listing). However, though because there is a barrage of

information, many patients and families do not absorb all of the information or education given to them by transplant hospitals.

Next steps:

UNOS staff will reach out to PACC members who have volunteered for a Subcommittee in order to get their feedback for what they may want to discuss at the in-person meeting in February.

Upcoming Meeting

- February 25