

**OPTN/UNOS Patient Affairs Committee
Meeting Minutes
December 18, 2018
Conference Call**

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Garret Erdle, MBA, Vice Chair**

Introduction

The Patient Affairs Constituent Council (PACC) met via Citrix GoTo on 12/18/2018 to discuss the following agenda items:

1. Debrief on Board of Directors Meeting
2. Proof of Concept: Next Steps

The following is a summary of the Patient Affairs Constituent Council Committee discussions.

1. Debrief on Board of Directors Meeting

UNOS staff and the Chair of the PACC provided an update on the proceedings and outcomes from the OPTN Board of Directors (BOD) meeting that was held in Dallas, Texas on December 2-3, 2018.

Summary of discussion

UNOS staff began discussion by presenting an overview of the Executive Committee meeting. In particular, the two most pertinent discussion items for the PACC included the OPTN/UNOS Ad Hoc International Relations Committee (whom presented an annual report on Non-U.S. Resident Transplant Activity), and the Constituent Council.

As for the Constituent Council, the OPN President BOD presented analyses from the pilot project conducted between June and December 2018, including final survey respondent's recommendations on how to proceed with the Constituent Council proof of concept. Based on the final survey results, the Executive Committee agreed to proceed with the Proof of Concept solely with the PACC, to eliminate sponsorship by the Executive Committee, to remove further project end dates and to explore areas in which increased engagement was noticed (e.g. Patient and Donors Affairs representatives on the BOD had increased understanding of complex policy proposals due to existing PACC processes). UNOS leadership envisions the PACC to "scale up" within the future, however, UNOS staff advised doing so in a "phased approach" may be prudent, to refine some of the operational challenges and clarify confusion.

Next steps:

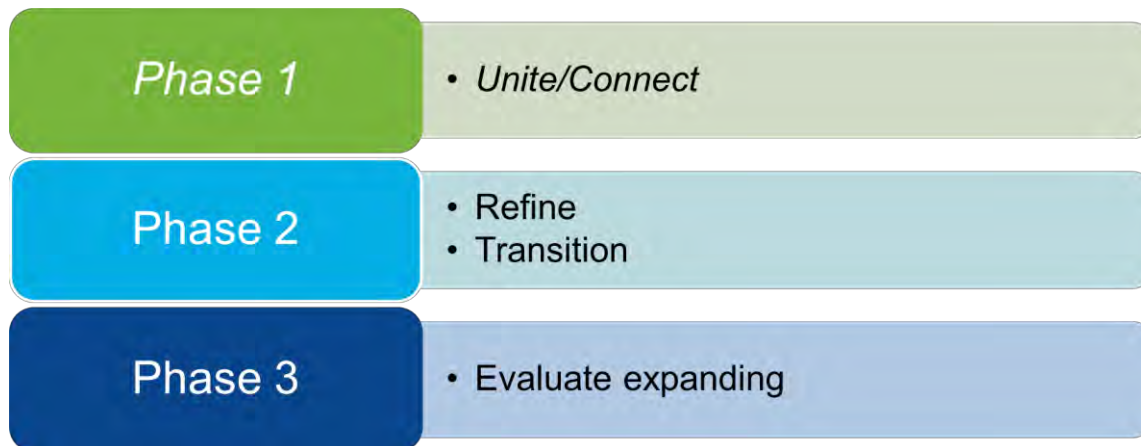
UNOS staff offered to provide any additional information to Committee members if requested.

2. Proof of Concept: Next Steps

In June 2018, the OPTN/ UNOS decided to create a pilot project titled "Improving the OPTN/UNOS Committee Structure through Enhanced Communication and Engagement" (e.g. Proof of Concept). UNOS staff presented possible next steps for the Proof of Concept, including a three phased approach.

Summary of discussion

Below is a proposed outline of a three phased approach to refine the structure, communications and operations of the proof of concept, and transition ownership from UNOS staff to Committee members.



UNOS staff outlined and discussed the three phases shown above. Ideally, phase 2 and phase 3 will be the primary focus of the PACC moving forward. Specifically, phase 2 will encompass refining the PACC processes and then transitioning such processes to PACC members, rather than UNOS staff driving and facilitating the work. The primary purposes of transitioning work is to give PAC members a sense of ownership over the proof of concept, provide members with “projects” to work on, which members indicated would make them more engaged on previous surveys, and to alleviate some of the administrative tasks from UNOS staff. Potentially, phase 3 will include evaluating whether to expand the PACC should the Committee decide that there is value in continuing the project.

There was general consensus amongst Committee members that the initial implementation of this project in June 2018 could have been more appropriately handled. For example, there was concern that UNOS overlaid the project on Committee members whom had previously joined the Committee for different reasons. Ideally, one Committee member noted that this phased project would be developed over the course of three to five years due to a perceived need to change the strategic plan prior to project expansion (this would include deliberation on the continuation of Basecamp). Furthermore, there was concern from Committee members that the PACC needs to be prepared for the influx of new members that will be occurring within the next year.

A Committee member asked for clarification regarding the goals of the PACC Proof of Concept project. UNOS staff informed the Committee that one of the initial goals of the Committee reports was to elicit feedback from the PACC earlier within the policy development process. UNOS staff gave examples of how PACC members presented project updates from other Committees, such as the Ad Hoc Geography Committee and the organ-specific Committees (geography projects). Despite including the PACC earlier in the policy process, there was general agreement that the process in which this is accomplished requires further refinement.

UNOS staff elaborated on what processes needed refinement. First, to solicit PAC feedback earlier in the policy development process, a “Committee report” process was developed. Patient/donor family representatives from the sponsoring Committee (e.g. Kidney) would share an update regarding any project in the “analyzing the problem”, or “evidence-gathering” phase of the policy development process. PACC would have the opportunity to ask questions or provide feedback that the patient/donor family member representative of the sponsoring Committee could then share their Committee. The idea was to provide feedback earlier in the process because Committees are limited to what types of changes they can make post-public comment; they cannot make substantive changes. Another potential process that the PACC

might refine is the public comment proposal process, in particular the form utilized during said process.

Committee members reiterated their feelings that the patient and donor members on the BOD were more informed and vocal than had previously been. In essence, these BOD members continued to bring the patient perspective back to discussion through a constant reinforcement that patients are an integral part to the OPTN policy decision making process. Committee members attributed causes of this increased participation to an increased awareness of the “transplant patient community” as a whole. One particular PACC member commented that through a robust discussion concerning the new Ethics Committee paper, comments and suggestions proposed by patient and donor members at the BOD were incorporated into the paper’s contents. Furthermore, Committee members opined that adding different viewpoints increases the dimensional context of the PACC, and assists in bringing various issues not previously discussed to the policy development process. Likewise, PACC members who identified as professionals with connections to living donors or family members felt more aware as to how patients perceive transplant issues within the broader community.

Lastly, many Committee members noted that the terminology used during the BOD was inappropriate and not respectful to donor families and patients. In particular, due to the verbiage used at the BOD (including “harvest” and “wasted organs”) the Committee would like to focus a workgroup on identifying and distributing information on non-offensive language.

Overall, Committee members were supportive of creating Committee workgroups that would be tasked with developing and managing specific processes. Committee members were supportive of a strategy & process improvement workgroup, evaluation workgroup (to continue assessing the effectiveness of the proof of concept), educational workgroup (e.g. medical or OPTN terminology, OPTN topics), and Basecamp workgroup. One Committee member suggested that a workgroup develop current PACC member’s knowledge of Basecamp in order for those members to then train new members of its functions. Also, the PACC members could develop a governance or structure for how Basecamp is utilized and monitored by the Committee (e.g. how content is posted and shared, comments are grouped etc.). Further suggestions were aligned with creating a Committee workgroup that was focused on developing an education plan for the PACC, along with focusing on OPTN Committee member development. The education plan could encompass identifying educational topics most relevant to the PACC, increasing content, and training for potential PACC members of the OPTN/UNOS leadership.

UNOS staff conducted a poll to determine the likelihood of Committee members to opt out of the PACC if given the option by UNOS. The results are as follows:

1. Very Unlikely (59%)
2. Unlikely (24%)
3. Unsure (14%)
4. Likely (3%)
5. Very Likely (0%)

Next Steps

UNOS staff and the Committee will continue to develop the concept of workgroups.

Upcoming Meeting

- January 15