

**OPTN/UNOS Patient Affairs Committee  
Meeting Minutes  
November 20, 2018  
Conference Call**

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## **Introduction**

The Patient Affairs Committee met via Citrix GoTo teleconference on 11/20/2018 to discuss the following agenda items:

1. Proof of Concept Debrief
2. Review Results from Final Survey

### **1. Proof of Concept Debrief**

The goal of the Proof of Concept was to decrease siloing between Committees and to amplify the voice of the PAC throughout the OPTN/UNOS policy development process. UNOS staff debriefed final survey results to the Committee.

#### Summary of discussion

UNOS staff summarized the goals of the proof of concept, framework/parameters, the prep work Committee leadership had done in advance to prepare and what the actual makeup of the full council was. UNOS staff noted the group is larger than the OPTN Board of Directors. In fact, the PAC was so large, that a general concern received through survey feedback was as to whether the group was too large to allow all voices to be heard or to get anything done.

In terms of evaluation, UNOS staff analyzed response results from three surveys, and through Basecamp participation and dialogue (such as which posted topics elicited the most member dialogue). Feedback from regional and in-person meetings were also documented

### **2. Review Results from Final Survey**

The Constituent Council Proof of Concept was implemented in July 2018 and piloted with two Committees: the Transplant Coordinator Committee and the Patient Affairs Committee (PAC). The Proof of Concept focused on two issues: insufficient diversity in perspectives and insufficient connections between the Board and Committees. Over the course of six months, UNOS staff collected feedback via surveys, debriefs and Basecamp discussions. UNOS staff presented the final survey results.

#### Data summary

UNOS staff informed the Committee that there was a noticeable division amongst the survey responses. The majority of survey responses were grouped either by members that had little to no clinical background, and those members who had a transplant or donation background.

Below is a generalized summary of the feedback received for each goal of the Proof of Concept:

1. *Increased diversity in perspectives on Committees and in policy development*
  - a. The PAC became more diversified
    - i. Additional members added to PAC represented living donors, donor family members, recipient family members, etc.
  - b. PAC feedback more robust and diversified
  - c. Limited opportunity to provide feedback earlier in the policy development process

- i. The pilot was only in effect for six months
2. Small minority of Committees sponsoring public comment proposals during this time frame; those Committees that did have public comment proposals were focused on geography issues *Increased connections between the Board and Committees*
  - a. Consensus that uniting patient/donor families was an improvement over status quo; value add for many members; overall sentiment that this objective achieved some success
  - b. Board members especially receptive and were vocal in Board policy groups
    - i. Board members asked informed questions

Other feedback centered around representativeness of the constituent voice within the policy development process. The member responses to this particular survey question were diverse. However, most member responses fell into one of five categories:

- Yes: the constituency's voice is well-represented in the policy development process, and the patient perspective is valued
  - This group was more likely to respond that the patient and donor family perspective is already valued by the Committees and Board of Directors
- Yes: the constituency's voice is well-represented, but feedback included too late in the process
  - For example, providing patient perspective and feedback during public comment is too late in the process for the sponsoring committee to utilize or incorporate changes, based on that feedback
- Do not know
  - Several respondents indicated they did not know whether the patient voice was represented in the policy development process
- No: the proposals are not accessible to the general public
  - Either the proposals are not written in a way that the general public can understand, or the OPTN/UNOS processes are not transparent
- No: the patient opinion doesn't have any weight, is not valued or does not have an impact
  - There was a theme that generally speaking, the patient perspective is not informed, which is likely indicative why it might not be taken seriously

Patient Committee members valued the education provided during PAC meetings, and desired the OPTN to continue patient education. Furthermore, most PAC members either strongly agreed or agreed that because of the proof of concept, members felt better informed about the constituent's perspective and issues facing the transplant community.

The final survey results identified multiple barriers throughout the pilot project, including a lack of new member expertise, insufficient knowledge of Basecamp, other OPTN/UNOS obligations, and an imbalance between work-life commitments. However, perhaps the most noticeable barrier was Committee size, whereby many respondents stated that the PAC was too large for effective member participation and productivity. UNOS staff opined that the larger sized PAC may have contributed to approximately half of the core PAC members withdrawing or disengaging. In addition, Committee member feedback opined that solely changing the structure of the PAC would not achieve OPTN goals. Lastly, a majority of PAC members that felt that professionally affiliated members viewed Committee issues more from a "professional" perspective rather than a "patient" perspective.

In response to how the OPTN should proceed, eighteen PAC members responded positively, noting that the project should continue in order to allow more time for members to acclimate.

However, sixteen PAC members responded that the OPTN should revise the Proof of Concept, and continue testing ways to increase cross-Committee and Board communication.

#### Summary of discussion:

The Executive Committee (ExCom) is considering either “scaling up”, “scaling back” or “abandoning” the project. The term “scaling up” includes either expanding PAC membership (e.g. alumni or patient representatives), or expanding the project to include other OPTN/UNOS Committees. In terms of “scaling back”, the ExCom may decide to extend piloting the project as it is, or choose to abandon the project.

In the following discussion, Committee leadership expressed concern regarding the on-boarding process for new PAC members. In particular, a Committee member stated that new members came into the process too late in the process, which in itself was overlaid with no particular preparation. As such, there was general concern by many Committee that the PAC members were operating on varying levels of knowledge and lacked “a common language”. Combined with increasing PAC membership, Committee members opined that these variables led to more confusion and general frustration for members. Furthermore, a Committee member noted that the PAC is not composed of the “normal” recipient, family member or living donor in the community. This can create barriers in effectively preparing members from diverse backgrounds.

On the other hand, a minority of Committee members opined that it may be too soon to see the full effects of educating PAC members. For example, a Committee member noted that it takes time to build a knowledge base, and therefore more time before results manifest. There was concern that the OPTN/UNOS had not given the project enough time to see actual results.

A Committee member suggested that UNOS begin the on-boarding process of new PAC members in “tiers”. For example, membership in the UNOS Ambassador program would provide a path of entry into the PAC. Then after serving in the PAC, UNOS would allow PAC members to join other Committees that represented a specific constituency, followed by membership on the Board of Directors (BOD). In this way, the Committee member opined that members would not be going directly from never having engaged with UNOS directly into a role on a Committee or the BOD.

Another PAC member asked for clarification regarding the statement that clinician members were not engaging from a “patient perspective”. One Committee member opined that when they analyze policy development, it is difficult to not think about how a particular policy will impact their own transplant center. In essence, the Committee member opined that it is challenging to strictly analyze policy solely from a “patient perspective”. Another member stated that they could never remove the fact that they are transplant professional and that each member brings their personal life with them when they come to these discussions. However, generally Committee members cited that they do attempt to engage with the PAC from a “patient perspective”.

As discussion continued, one Committee member stated that many times they heard a perspective they hadn’t thought about. As a living donor patient, this Committee member voiced appreciation, and felt that they had enough perspective as a patient to understand and appreciate new opportunities for learning. Another Committee member stated that they appreciated hearing different perspectives as a Board member. In general, most Committee members agreed that the Proof of Concept provided the platform for learning different perspectives and developing respect for diverse opinions. One suggestion was that UNOS include an outcome for how a Committee member’s perspective can impact the learning and understanding of another Committee member (e.g. learning, increased knowledge).

Further discussion focused on the limitations of the PAC, such as a lack of representativeness from patients whom are waiting for an organ transplant. A Committee member stated that they were unaware of UNOS and the OPTN. As such, the Committee member opined that the PAC should work towards including more diverse patient perspectives to inform OPTN policy. UNOS staff informed the Committee that there are currently no organ candidates on any OPTN/UNOS Committee. The reason for this low representation stems from a lack of organ candidate applications and the needs of the OPTN/UNOS Committees.

However, another Committee member pushed back on this perceived limitation, and instead opined that patients awaiting organ transplants may not engage due to a lack of time. For example, a Committee member stated that a liver transplant may be too ill to participate in Committee work. As such, many of these patients use advocacy organizations to work on their behalf. However, the Committee member went on to note that not all patients are too sick to participate, such as kidney candidates. In this way, the Committee member suggested focusing outreach to candidates in certain organ groups. This focused outreach could encompass patient education on OPTN/ UNOS processes or organizational structures. UNOS staff addressed the Committee's concerns and suggested that the UNOS Ambassador program might assist in educating the public. A suggestion was made that UNOS Ambassadors or mentors should include a component whereby a flyer be distributed within transplant centers informing candidates about the OPTN/UNOS organization.

Another Committee member felt that members were appreciated more in the smaller PAC and that there were greater expectations for the Proof of Concept in the larger group. Other members of the Committee, especially those that compose the core PAC, echoed this sentiment. Furthermore, the final survey results reflected this sentiment as seen by half of the core PAC members not engaging post- implementation of the project (though a few core PAC members called in monthly).

Overall, there was general consensus amongst Committee members that there needs to be continued discussion on the Proof of Concept processes and operations. As one member put it, "I don't ever want to thwart a patient's voice in any of the processes we are working in". As such, the Committee agreed to focus their efforts on increase accessibility, decreasing the "burden" of the PAC and increasing the patient perspective in order to assure all voices are included.

At the end of the discussion, the Committee voted in two polls. The questions and results are as follows;

1. If the ExCom extends this proof of concept would you continue involvement or opt-out?  
Stay involved: 95%  
Opt-Out: 5%
2. Do you think the individual perspectives should have their own council (what was proposed), versus a merged, diverse group?  
Yes: 50%  
No: 50%

#### Next steps:

The UNOS staff will continue to provide updates to the Committee regarding the next steps for PAC. UNOS staff will compile the feedback from this Committee meeting and provide it to OPTN/UNOS leadership.

#### **Upcoming Meeting**

- December 18, 2018