

OPTN/UNOS Patient Affairs Committee
Meeting Minutes
February 25, 2019
Chicago, Illinois

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Introduction

The Patient Affairs Committee (PAC) met in Chicago, Illinois on 02/25/2019 to discuss the following agenda items:

1. Spring 2019 Public Comment Proposal Review
2. UNOS Ambassador Program
3. Constituent Council Discussion

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

1. Spring 2019 Public Comment Proposal Review

Summary of discussion:

The Committee provided feedback regarding the following public comment proposals.

Modify HOPE Act Variance to Include Other Organs

The PAC noted the following:

- All candidates stand to benefit from this proposal. Those eligible to receive an organ from a donor with HIV will likely experience decreased waiting time; particularly significant because people with HIV are often from underserved and vulnerable populations.
- Expanding the pool of available organs decreases waiting time for all recipients. Although the full scope of impact is unknown as data is not currently collected, more HIV-positive recipients will have the opportunity to realize the gift of life and the proposal would allow OPTN/UNOS to identify trends across varied research studies and identify potential patient safety factors.
- There was no specific language in the proposal that addresses HIV-positive living donors and it was unclear whether living donors were included in the original 2015 HOPE Act variance language.
- Family members of candidates may experience a decreased caregiver burden if their loved experiences a shorter waiting time to transplant and improved quality of life. Indirectly, families of donors with HIV may benefit from increased hope and purpose to their desire to donate. Honoring each gift regardless of HIV status increases equity for these families and allows them to share equally from the opportunity to donate organs.
- There is a long list of acronyms that should be explained for the general patient population in more detail, rather than just simply spelling them out once. The PAC recommends footnoting ALL of these acronyms along with brief explanations of what these organizations do. The general public cannot be expected to understand the proposal without defining these acronyms and clarification on why they are in the proposal to begin with. Additionally, a lay public audience will be confused without clearly defined terminology for words such as "vessels" & "en-bloc", as well as by referrals to established policy without direct links to the referred policy.

The PAC commends the DTAC for professional society outreach and noted that those numerous stakeholder organizations supported the proposal. However, it does not appear the DTAC collaborated with or reached out to any specific patient advocacy groups, although the impetus for this proposal did originate from the HIV+ community to expand the current variance.

The PAC asked the following questions, which were answered by the sponsoring committee's presenter to the satisfaction of the Committee:

Q: Why pediatric populations weren't considered within the HOPE Act; will these patients also be able to benefit from this proposal?

A: The speaker theorized that the NIH document excluded references to HIV positive pediatric transplants due to a lack of experience in current HIV pediatric recipients receiving HIV negative pediatric donor organs. The speaker agreed to provide further details to Committee members as to why the public comment proposal did not reference pediatric candidates at a later date.

Q: Why was living donation not referenced in the proposed policy language?

A: The public comment proposal intentionally excluded language regarding living donation because there was a sense from the Ethics Committee that living donors would be willing to come forward and donate to HIV positive candidates. The only obvious limitation for living donors would be that except for liver and kidneys, there are few other organs that could be livingly donated.

Q: What is the future viability of the current HOPE Act variance if approved after 2020?

A: The speaker highlighted that comparative outcomes data from HIV negative and HIV positive donors will be presented to the HHS Secretary. From there, the Secretary would have authority as to whether the HOPE Act remains a research initiative or becomes a new standard of care (similar to Hepatitis C transplantation now). However, there is a lack of knowledge on the measurements that will be used to judge the HOPE Act as a program worth continuing in the future.

Q: How will OPTN members achieve transparent reporting of HOPE Act outcomes & research back to the community, patients and donor families?

A: There are two pathways in which this may be accomplished: transplant programs presenting outcomes data through public forums (such as symposiums) and the OPTN releasing their own data (such as research abstracts). The speaker noted that a lack of transparency with the public and OPTN community was a fair criticism, and that transplant programs should foster more robust reporting mechanisms in the transplant community.

Q: What procedures are in place to not only notify and consent candidates beyond acceptance of an HIV-positive organ, but also acknowledge of continued participation as a research subject with full knowledge of patient rights in participating in an IRB sanctioned study?

A: To be approved for the HOPE Act, the candidate needs to have met the requirements set forth by the research institution. For example, once a research institution's IRB has approved participation within the HOPE Act, then that institution will analyze the consent process and institute their own research guidelines. The speaker did not necessarily think that the OPTN needed to become involved in the process of research consent.

Q: Identification credentials were undefined for the second person to verify the candidate's willingness to accept an HIV positive organ. Is this a verified family member, patient advocate, or a medical transplant center professional as witness?

A: Currently, there is a lack of standardization with verification amongst transplant centers participating in the HOPE Act. The only stipulation made by the NIH is that the second person verifying must have experience and understanding of HIV transplant and not be on the study team. For example, the presenter's center employs an independent HIV advocate separate from the living donor team. However, the speaker acknowledged that the strict standards for second person verification may result in few qualified people.

Q: Will there be any special organ labeling and handling that OPOs must do? Is there a benefit to having special packaging and labeling of HIV positive organs?

A: Part of the NIH guidelines specify that OPOs must have their own protocols and operation manuals in place (such as for needle-stick injuries). In theory there should be specific labels for HIV positive organs, but the OPTN already has policies in place dealing with disease transmission and organ handling (such as with Hepatitis C organs). Furthermore, since the transplantation of HIV positive organs is so rare, there is heightened awareness in the handling of these organs when such a transplant does occur. However, if these organ transplants increase in the future, then speaker noted that the OPTN should consider how safety precautions can be maintained.

Q: Living Donors should be considered as human participants during these research trials. As such, are there any special requirements for them in the HOPE Act?

A: The speaker agreed that living donors are human participants during research trials, and that transplant centers have independent consents stating such. Furthermore, built into the original NIH guidelines are clear pre-transplant and post-transplant follow-up protocols for living donors. The speaker went on to note that there have been no living donor HIV positive transplants that occurred in the U.S. and only one in South Africa.

Q: Are HOPE Act programs informing the community (both living donors and those potential recipients) that there are different strains of HIV?

A: Transplant centers do inform living donors and recipients on receiving an HIV positive organ during the informed consent process, however more focus is placed on which HIV medications the donor and recipient are on. The reasoning behind this is that viruses may have different antibiotic resistance, though the research behind which resistance pattern takes precedence is still being researched. Lastly, it was noted that the HIV 2 strain is rare in the U.S.

Q: How do patients know which centers have better outcomes under the HOPE Act? What is the transparency level for each center participating?

A: The speaker responded that outcomes data for HIV positive organ transplantation is difficult to ascertain because the sample size is too small per center. It would be a challenge for patients to find center-specific data, and the outcomes for each center.

Q: What patient population would benefit from this policy proposal, specifically in regards to Waitlist?

A: The speaker did not specifically know the benefits, because there is no current Waitlist for HIV positive candidates and they are not required to report their HIV status when registering for an organ.

In Summary,

- The appropriate measurements are in place to guide the evaluation of this policy
- Candidates maintain the option to opt in or refrain from participating
- It could decrease the waitlist for all candidates
- May allow some recipients & their caregivers to attain a higher-level quality of life

For these reasons, the PAC unanimously supported this proposal as it creates a valuable new source of organs and can save lives. It prevents the discard of HIV false-positive organs and provides increased opportunity to candidate populations who are typically underserved.

Elimination of Donation Service Area (DSA) from Thoracic Distribution

The PAC complimented the Thoracic Committee with regards to the way the proposal was written; most felt it was written in a way that members of the general public would understand. The Executive Summary was especially straightforward and easy to follow. The PAC also noted the Thoracic Committee avoided proposing a distance that essentially mimics the status quo.

The PAC asked the following questions, which were answered by the sponsoring committee's presenter to the satisfaction of the Committee:

Q: Although there isn't a formal definition of a "sensitized candidate", the PAC asked what some characteristics are of a "sensitized" heart candidate, and recommended including a detailing of how these patients are currently handled would be helpful.

A: There is ongoing discussions within the OPTN Thoracic Committee on the definition and details regarding "sensitized candidates". The current challenge is that many transplant centers do not report unacceptable antigens for heart candidates. As such, without at least a years' worth of data reporting to inform an evidence-based policy, the Thoracic Committee opted to address this issue in a separate project.

Q: There was much discussion and debate amongst the proposal review group about access to mode of transport and what happens at the 251st NM. How will OPTN/UNOS monitor impacts when lack of transport impacts the successful implementation of this policy, or, if it isn't monitored, why is that the case? What happens beyond the edge of the 250NM cliff?

A: The speaker affirmed that during the Thoracic Committee's discussions, there was concern about an increase in travel costs, specifically air transportation. For example, flying to procure an organ costs more than traveling by car. Furthermore, if an organ recovery team were to fly and decide not to procure the heart, then the transplant program will be forced to absorb the transportation costs. In terms of concentric circles, the "cliffs" of this distribution system may impact a candidate's access to organs. Due to this concern, the Thoracic Committee is interested in pursuing a continuous distribution framework, lung being the first organ to start transitioning. It would take more effort to convert the heart distribution system to a continuous framework.

Q: With this proposed policy change, the costs associated with the recovery event itself may increase, but a broader definition of cost (to include hospital stay, operations, procedures, devices, and medicines), may well see lower utilization, and lower total cost, because the allocation area expanded to a 250NM radius around the donor hospital.

A: It is possible that the new allocation system may lead to a decrease in hospital-stay time, however if the heart has more ischemic time, then the opposite may occur whereby the patient must stay in the hospital for a longer period of time and may experience graft

failure. Also, some transplant programs might shut down if they cannot absorb increased costs, however short-term.

Q: Would less populated, western states be disadvantage if this proposal?

A: The Thoracic Committee analyzed the difference across a variety of metrics for centers east and west of the Mississippi, but overall there were negligible differences. It was noted that transplant centers may have to export more hearts to other states. The speaker cited a recent article that concluded population density may not have a huge impact on the allocation of organs. Due to these concerns, the Thoracic Committee will continue to assess any future impacts stemming from this allocation change.

Q: What is the preliminary feedback so far from the OPTN Regional Meetings regarding this proposal?

A: So far there has been general support from the community for 250NM. Region 8 was more split in their favor for this proposal, however they still agreed to adopt the 250NM concentric circle.

Q: Has there been any specific feedback from pediatric transplant centers regarding the potential impact on pediatric candidates?

A: The presenter shared he had presented to the OPTN Pediatric Committee last week, and overall, the changes implemented to the adult heart allocation system in October 2018 had resulted in increased access for pediatric candidates. Under the new allocation system, pediatric candidates are on par with Status 1 adult heart candidates. The TSAM modeling did not show that 250 NM would negatively impact pediatric candidates, though both 500 NM distances might further advantage them. Also, the sickest pediatric candidates are already offered hearts from 500 NM.

Q: Did the Thoracic Committee take into account U.S. military veterans, specifically those veterans whom may be dependent on a limited number of VA hospitals that have heart transplant programs?

A: The Thoracic Committee did not specifically look at this metric. Overall in the U.S. there are a limited number of heart transplant programs. The presenter did not think that any of the areas with high numbers of U.S. veterans would be disadvantaged, however agreed that the Thoracic Committee may consider looking at the potential impact post-public comment.

Q: What effect will this new heart allocation system have on multi-organ transplants?

A: The presenter acknowledged that multi-organ policy was beyond the scope of this project, and that only a minor clarification to multi-organ policy was included in this proposal. Broader distribution may further complicate allocation.

The PAC supported the Thoracic Committee's proposal to replace DSA with 250NM radius around the donor hospitals as the overall unit for distribution. The Thoracic Committee presented a compelling case that this distance is the best option due to their consideration of Final Rule requirements and neutral impact to wait list mortality.

Ethical Implications of Multi-Organ Transplants

The PAC noted the following:

- Inclusion of an appendix, glossary or footnotes which explain the ethical constructs and terminologies used throughout the document is necessary. As it is now, there are ethical terms used in the document that may be harder for an average patient to understand.

- The definition of utility should be clarified to state that each non-directed donated organ goes to the person whom is a match and most in need of an organ.
- The recommendation for more robust data reporting and closer monitoring of outcomes was supported
- A similar document focused on pediatric SOT vs. MOT should be composed

The PAC asked the following questions, which were answered by the sponsoring committee's presenter to the satisfaction of the Committee:

Q: How are the new changes to geographic distribution (e.g. concentric circles) going to affect MOT allocation?

A: The Ethics Committee acknowledges that the impact of geography on MOT allocation should be better understood. The organ-specific committees are will eventually consider this issue.

Q: There was a general lack of understanding around when multi-organ transplant would be appropriate or necessary, versus single organ transplant. Are there any specific examples that could be cited to explain the differences in MOT and SOT allocation?

A: The purpose of the document was to focus on clarifying how the current MOT system is determining the prioritization of candidates. However, the Ethics Committee did agree that more data collection on MOT allocation was warranted.

Q: What are the next steps for this guidance document post-Board consideration?

A: The Ethics Committee does not generally write policy proposals. The Committees mainly use ethical white papers to help inform future policy proposals. It should be noted that this white paper is merely the beginning of solving issues stemming from MOT policies. A larger, joint-committee workgroup should form to tackle the issues surrounding MOT policies.

The PAC supported the Ethic Committee's white paper on MOT. Although specific concerns were raised that were beyond the scope of the white paper, and the speaker suggested were more appropriate for the organ-specific committees.

Removal of DSA and Region from Kidney and Pancreas Distribution (Concept Paper)

The PAC considered two main questions:

1. Is there one of the five frameworks that impacts equity and outcomes in kidney and pancreas distribution better than the other four or was there an additional framework variation that should be considered and why?
2. Should this distribution framework combine or separate kidney and pancreas allocation policy and why?

The PAC generally supported an allocation policy that optimizes equity in access and maximizes recipient and organ outcomes. Overall, PAC members had difficulty recommending a specific framework due to the complexity of the supporting documentation but did lean towards the hybrid model.

In regards to separating the kidney and pancreas allocation systems, it appears that cold ischemic times may be the main factor to consider for recipient and organ outcomes. As such,

more modeling will most likely be required based on the allocation models selected for the policy proposal.

The PAC noted the following:

- Avoid the term “cadaveric”, and consider using “deceased” when referring to deceased donor and organs. This verbiage change should occur in all transplant discussions as it is more descriptive and more sensitive to the donor family members.
- For the same reasons, the PAC also recommends changing terminology from national “resource” to “life source”.
- While the concept paper’s “Executive Summary” does a nice job describing how this paper was developed and identifying the recommended “options” under consideration, the potential impact of these options is not written in a language that the general public would understand. This can hinder the general public in making a valid argument for one framework over the other.
- If the OPTN wants to seriously include patients (including recipients, donors, and family members) throughout the policy discussion process, then the PAC continues to recommend stronger patient presence and participation in Committee work (or workgroups) and a “Layman’s Abstract” for all policy proposals.

The PAC asked the following questions, which were answered by the sponsoring committee’s presenter to the satisfaction of the Committee:

Q: Is there any utility of standardizing all organ distribution frameworks into one instead of separate frameworks for each organ system? Is it clinically feasible?

A: The KP Workgroup did not consider standardizing all the organ specific allocation systems because organs have different ischemic times and scoring systems. This question is more appropriately answered by the OPTN.

Q: Additionally, is the timeline for implementation, particularly with the hybrid models, realistic or is the OPTN going to settle on the “fastest” model for implementation in light of the highly-charged environment pertaining to DSAs and Regions in OPTN allocation policy? What impact would this have on the recipients and outcomes from organs subjected to this model?

A: The KP Workgroup is currently working on new modeling with the SRTR that would focus on separate models for kidneys and pancreas. The Workgroup plans on continue modeling a variety of different models, and assessing the outcomes This modeling should be available for the PAC to review in future public comment cycles.

Q: If the kidney can tolerate a longer cold ischemic time than the pancreas due to technology options available for recovered kidneys, how will this impact recipient and organ outcomes?

A: Currently, the pancreas has a tighter threshold in terms of ischemic time, and cannot travel as far distances as kidneys. Because of this, the KP Workgroup is looking at separating kidney and pancreas allocation. In future models showing this allocation separation, the Workgroup will assess the impact on recipients and on organ outcomes.

Q: Is the KP Workgroup working towards a continuous distribution model for both kidneys and pancreas?

A: Currently, the concept paper only reflects the SRTR modeling done in fall 2018. At the time, the BOD did not mandate the KP Workgroup model continuous distribution for kidneys or pancreases. However, in the December 2018 BOD meeting, the Workgroup became committed to moving towards a continuous distribution system. It was noted that it is important for the Workgroup to weigh decisions carefully, and are currently working closely with the SRTR on a plan to proceed with continuous distribution modeling. For now though, the Workgroup is focused on removing the term DSA and region from kidney allocation policy. It is the Workgroup's hope that a new model can be implemented while the OPTN works towards a continuous distribution framework. The reasoning behind this is that there are many limitations of the KSAM modeling which may result in unintended consequences if modeling pushed too quickly. Implementing a continuous distribution system too early may disadvantage certain groups, such as pediatric candidates.

Q: Is the KP Workgroup concerned that waiting times for donor families may increase with increased travel distances?

A: The KP Workgroup has discussed the increase in waiting time for donor families, because there is a longer time period between brain death declaration and recovery which may result in organ damage. Unfortunately, this factor cannot be modeled in the KSAM, but should be taken into consideration. In the speaker's opinion, any broader distribution system may negatively impact donor family waiting time. Compared to 20 years ago, the waiting time is much longer due to logistics.

Q: (In regards to costs) How long before budgets and contracts are renegotiated?

A: The speaker acknowledged that insurance companies and other payers need to be brought into the discussion, especially in regards to an OPO's average monthly expense report.

Overall, about half of PAC members did not feel comfortable choosing one proposed framework over another (hybrid versus circles, 250NM versus 500NM), because the data presented was difficult to comprehend and showed a decrease in organ transplantation rates. The PAC members that did vote supported the hybrid model, with a 250 NM circle size. A majority of PAC supported a separate distribution system for kidney and pancreas. All PAC members abstained from voting on proximity points.

Next steps:

UNOS staff will summarize the Committee's discussions, and post the summaries to the OPTN website.

2. UNOS Ambassador Program

UNOS staff presented an update of the UNOS Ambassador program, including current initiatives and future projects. PAC members discussed how the program is operationalized, along with how the Committee can support the program in the future.

Summary of discussion:

To being discussion, PAC members were concerned with community members gaining "easy entry", which could lead to misinformation and a lack of knowledge relating to OPTN processes. UNOS staff acknowledged that this was a barrier, and that they strive to ensure everyone is on par when they come into the program (e.g. minimum standards).

Another PAC member inquired as to the program's hierarchy. Specifically, could people become "organizers" as they progress? UNOS staff clarified that they had previously considered elevating outstanding members to the position of "super Ambassador" but decided not to implement this right now.

PAC members asked what onboarding Ambassadors receive. UNOS staff responded that new volunteers should have a step-by-step guide when entering the program. Essentially, this guide is a checklist to complete for the ambassador program. However, PAC members were concerned that the on-boarding videos UNOS currently offer are too high level. A suggestion was put forth to post recordings of in-person trainings so that this becomes another resource for ambassadors outside of the Virginia area. Furthermore, the program should be providing materials or toolkits in order to ensure a consistent message.

Another suggestion from PAC members was to require that Ambassadors present a certain number of times a year. These presentations could be facilitated by either the local OPO or UNOS. UNOS staff clarified that the program has not requested that members do a certain number of presentations, but will take this under consideration.

3. Constituent Council Discussion

In the latter half of the meeting, PAC members divided into four Subcommittees: Patient Engagement and Communication, Evaluation, Education, and Process Improvement and Strategy to continue facilitating the efforts of the constituent council proof of concept.

Summary of discussion:

Below is a summary of each Subcommittee's feedback discussed during the breakout sessions.

Patient Engagement and Communication

In order to increase engagement with the transplant community, PAC members have suggested in the past creating a one-page document that explains each public comment proposal (written at a 3rd or 5th grade level), so this group was tasked with starting a draft. The Subcommittee opined that there should be a collaborative team that is tasked with developing these abstracts comprised of UNOS staff and OPTN members not affiliated with the sponsoring committee. This document would be posted to the OPTN site with a corresponding public comment proposal, and help make the proposals more accessible to the public. However, in order to help communicate these new documents to the public, the Subcommittee suggested that every quarter, UNOS would release a newsletter to the OPTN community prior to the BOD meetings and before public comment. PAC members suggested every public comment proposal should have glossary at the end, which would help the community engage better with the policy proposals.

When asked whether the Subcommittee had discussed which parts of the policy proposals should be in the layman's abstract, the Subcommittee was unable to discuss such details in the time allotted. However, one PAC member mentioned that they already had a document format or template that they could forward to UNOS staff. However, it was reiterated that someone with expertise in health care should write these abstracts.

The Subcommittee requested also that instead of merely having glossaries, the OPTN should have appendixes for the trainings. Perhaps the Subcommittee can determine what other institutions are already working or doing to educate patients on medical terminology. However,

this brought up the point on how the PAC can interact with other organizations (e.g. HRSA, NATCO etc.). This is especially important if you want the PAC to participate in social media polls or quarterly newsletters. Furthermore, the PAC would need to consider how to amplify their message to the community and leverage their relationships with other organizations. The Subcommittee did agree that patient representatives should be on workgroups within their respective Committees. Currently, most OPTN Committees have a patient representative, but not all (it is not mandated, merely a strong suggestion to do so). However, UNOS staff reiterated that a goal of their organization is to make sure that there is fair and equal representation on OPTN Committees.

Education

The task for the Education Subcommittee was to determine topics or content that would benefit volunteers. The Subcommittee reviewed educational topics that PACC has covered so far (see below for examples):

- OPTN Final Rule
- How does matching work? Organ distribution?
- How does the Waitlist work?

The Subcommittee was tasked with generating topics that could be potentially covered in the coming year. One question UNOS staff posed was whether there were certain topics that should be recycled on a regular (e.g. annual) basis or can they be integrated as part of the onboarding process? Should educational topics move from the basics to more complex (e.g. having education that can be built on one another)? Most Subcommittee members agreed that the PAC orientation should start off at a high level, with education focused on NOTA and the OPTN Final Rule. For now, the PAC will have an educational presentation over healthcare finance in March 2019.

The Education Subcommittee members suggested structuring educational content for patient and donor family volunteers in the following way:

- Foundation (explaining the OPTN, OPO, transplant centers)
- What is the function of each?
- What are their domains?
- How do they relate?

In this way, educating the community can start from the ground up. If UNOS does not start with the basics, PAC members were concerned that patient volunteers will not understand more complex issues.

Another topic of discussion was that donor families don't receive documents except for a letter from their local OPO in the mail. As such, members suggested that the OPTN should release a document that outlines the next steps (e.g. presenting, sitting on an OPTN Committee, writing a letter). UNOS staff clarified that not all OPOs reach out to the donor families because each OPO operates differently.

Another PAC member asked that when UNOS speaks to perspective volunteers, that staff makes sure to include success stories. For example, "this policy would not have been

developed unless this had happened...” By using success stories, the OPTN will make sure that volunteers know they are having an impact.

Process Improvement & Strategy

This Subcommittee focused on analyzing the public comment review process and tool to the PAC uses to evaluate public comment proposals. The Subcommittee was concerned that the document merely takes members through the policy but does not help stimulate their own thought processes.

The Subcommittee suggested that the PAC have executive summaries beforehand, along with establishing a pathway of self-questions. These questions would be tailored for each members’ role (such as a candidate, donor family, and recipient). These questions would be more in-line with prompts, which could help PAC members articulate their unique perspective. In effect, the questions or prompts would be similar to decision trees and may be generic or more specific depending on the policy proposal.

Another Subcommittee member suggested that the sponsoring committee’s patient representative could present an overview of the policy proposal to the general PAC (for example, patient representative on the Kidney Committee). By having these particular members present the policy information, other PAC members may better understand the policy proposals, because they would be conveyed in a more accessible, plain language way. This then would necessitate that patient representative have a solid understanding of the proposal, which is not currently always the case.

A member asked if PAC could sponsor a policy project. UNOS staff clarified that the PAC can create sponsor policy projects and in fact did so several years ago. UNOS staff encouraged PAC members to read OPTN policies. UNOS staff also asked whether there be a checklist enacted when creating policy proposals. PAC members supported UNOS leadership looking into this further. Lastly, UNOS staff reiterated that they will assist the PAC in gaining support for any of their future policy proposals.

Evaluation

The Evaluation Subcommittee was tasked with developing recommendations or a plan to continue evaluating the constituent council proof of concept. For example, the Subcommittee members suggested that the PAC consult with the UNOS policy analysts, and policy associates on how they perceived the impact of the constituent council within other OPTN Committees. Furthermore, Subcommittee members agreed to continue evaluating via surveys, though with more thorough questions. These surveys could then be sent to participating constituent council members for feedback, along with UNOS staff members.

Due to a robust discussion, the Subcommittee was unable to talk about how best to evaluate the involvement of patient representatives on OPTN Committees (e.g. surveying them on how their input is being received in their respective committees) or about who should be included within the PAC.

Next steps:

UNOS staff will collect and compile the feedback from each of the Subcommittees. This information will inform each Subcommittee’s next steps, including potential new initiatives.

Upcoming Meeting

- March 19, 2019