OPTN/UNOS Patient Affairs Committee
Meeting Minutes
August 27, 2018
Chicago, IL

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Introduction

The Patient Affairs Committee met in Chicago, IL on 08/27/2018 to discuss the following agenda items:

1. Policy Oversight Committee Update
2. UNOS CEO Presentation of the Past, Present & Future of Geography in Organ Allocation
3. Fall 2018 Public Comment Proposal Review
4. Improving the OPTN/UNOS Committee Structure through Enhanced Communication and Engagement Proof of Concept

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

1. Policy Oversight Committee Update

The Vice Chair provided an update on recently approved projects and public comment proposals. There were no questions.

2. UNOS CEO Presentation of the Past, Present & Future of Geography in Organ Allocation

The UNOS CEO presented the past, present and future of how geography has been used in organ allocation to provide context and increase knowledge and understanding. The following questions were asked and answered to the PAC's satisfaction:

- **Q:** Has there been any negative patient impact or lessons learned from the geographic changes to lung?
  A: Lungs are traveling a bit further, but not significantly further. There are likely lessons learned about how UNOS communicated with the community, even in spite of the extremely condensed timeline. Finally, the other organ-specific committees will have the time to consider more holistically the impact of removing DSA or region from the entirety of their respective policies, which the Thoracic Committee wasn't able to do in the moment, because of the timeline.
- **Q:** What was meant by the OPO designations would not change?
  A: The donor hospitals served by particular OPOs will not change with these policy changes.
- **Q:** Will the organ-specific geography proposals be under one large proposal, or be separate proposals with similar timeframes? Will they stagger?
  A: Liver will go out for public comment this fall, and the Board will consider the proposal in December. The other organ-specific committee proposals will go out for public comment in the spring, and will go to the Board in June 2019.
- **Q:** Has looking at realistic travel times been considered, versus mileage on the map?
  A: That is a complex problem, one that the OPTN/UNOS is not able to address at this time.

- **Q:** There was a question regarding responsibility for allocating organs if it is distributed to a larger geographic area, and not DSA. Would it be considered national allocation?
  A: OPOs will still be responsible for following the match as they do now, but the geographic units will be different.

One PAC member encouraged UNOS to consider the impact of distributing more broadly to donation and procurement timelines and donor families.

3. Fall 2018 Public Comment Proposal Review

The Committee provided feedback regarding the following public comment proposals.

Pancreas Program Functional Inactivity

The OPTN/UNOS Patient Affairs Committee (PAC) appreciates the Pancreas' Committee's efforts to improve waitlisted patient and transplant recipient outcomes by creating new thresholds for identifying functionally inactive pancreas programs that operate below the level that is adequate for their waitlisted candidates. The PAC acknowledged the proposal may also promote efficiency in the management of the OPTN, and felt that this seemed to be the emphasis of the proposal, eclipsing the primary goal of improving outcomes. Although access to transplant was not cited as a goal this proposal sought to address, the PAC felt that access to pancreas transplants were clearly going to be impacted. The PAC was skeptical the proposed solution would positively impact increasing the number of transplants, as a majority of candidates listed at functionally inactive centers do not end up listing elsewhere.

The PAC felt that for the average candidate on the waiting list, being informed that your pancreas program in functionally inactive may be confusing, psychologically distressing, and burdensome. The proposal equates patient safety and better outcomes with higher-volume programs with shorter waiting lists; these goals are only assured if these patients end up relisting at higher-volume programs.

They were supportive of the patient notification requirement, but acknowledged that may end up being burdensome to the program and not entirely useful to a patient who cannot afford to travel or otherwise relist at a different center. The proposal did not indicate the working group consulted with patients or a patient advocacy group during the development of the proposal. Patients listed at functionally inactive centers would be educated per procedure, but the PAC recommends taking that a step further and require subsequent outreach after X number of months to determine if their patients were able to relist elsewhere, or needed guidance or help doing so. Finally, the PAC offered to assist in developing the patient notification letter.

The PAC asked the following questions:

- **Q:** How the Committee arrived at proposing patients be notified of pancreas programs within a 125 mile radius (in addition to in-state programs) when seeking out alternative programs?
  A: The Pancreas Committee decided to require the patient letter include a more proximate roster of active pancreas programs for practical purposes. Most patients know they can multi-list (the PAC disagreed with this statement, despite there being a policy requirement in place) anywhere but including a list of all active pancreas programs across the country might be counter-productive. The 125 mile radius was informed by the feasibility of estimated travel time (about two hours). The PAC recommended the letter state "125 miles AND in-state or in-US territory" versus "125 miles OR in-state or in-US territory". In addition, there was a suggestion to include a link to the SRTR beta site, or at least when that site goes into production.

- **Q:** Why the proposal does not require functionally inactive programs submit a quality or performance improvement plan?
  A: The Pancreas Committee deferred and acknowledged that would be up to the OPTN/UNOS Membership and Professional Standards Committee (MPSC) to determine. The MPSC has a different process for evaluating transplant program performance in the Bylaws (*Appendix D.11.A*) which depends on a program's graft and patient survival rates. Functional activity is evaluated separately from program performance.
- **Q:** Why aren't patients currently notified of program waiting time? Why does the solution propose notifying patients after the fact?
  A: Many programs do share waiting time information with their patients during evaluation, but that isn't the standard or mandated by UNOS.

Models of Geographic Distribution

The PAC thanks the Ad Hoc Geography Committee for the opportunity to comment on various geographic distribution frameworks to inform future allocation policy more consistent with the OPTN Final Rule.

The PAC applauds OPTN/UNOS' pursuit of standardizing organ distribution and operationalizing a single framework that better meets the needs for equity for transplant candidates. Use of the current arbitrary and outdated DSA and Regional criteria in organ distribution has created the perception of inequity and damaged public trust in the system. While a singular framework for organ distribution will not guarantee equitable distribution in the truest sense of the word, (e.g. health systems that pre-position patients to another same-health system center in a more robust donor area to increase likelihood of their being transplanted), it is likely there will generally be increased equity and access improvements across organ systems. Improving the public perception of equity in access to transplantation for all patients has the potential to improve trust in the system of allocation which is essential in maintaining the support of the donating community.

The Continuous Distribution model is our recommended framework for further development for the following reasons:

1. Provides highest potential level of equity without the geographic "cliffs" of the other frameworks
2. Allows for other variables, such as time, to be considered besides just "distance" alone.
3. Patients may have increased confidence in the non-discriminatory factors that may be seen as influencing their organ offer.

The variables for each framework are well defined but may not be totally inclusive. We suggest the addition of the variable of TIME. While distance can be a proxy for donor organ transportation time it is not constant. Travel time can be influenced by time of year (weather impacts), and method of travel (land, air, etc.). Additionally the impact of candidate travel time is not specified.

Was data showing the number of patients who resort to multi-listing analyzed? The PAC felt this would have been useful information to help assessing the frameworks. It seems that a system that eliminates that advantage, only available to some, may be a good consideration for assessing these distribution models.

The PAC expressed concern about the lack of basic modeling with the organ distribution scenario for the continuous distribution model. This does not mean it should not be considered, but does need to have more modeling, specifically with the organ distribution process, to make sure this option is truly better than another framework for the needs of the transplant community.

While the sponsoring committee reviewed twelve “other distribution frameworks”, (per the webinar on this proposal), it is unclear how diverse those frameworks were. Has the sponsoring committee considered best practices on distribution systems from other industries like Amazon or FEDEX as well as some of the national grocery chains that are developing technology and logistics for driving efficiencies in the delivery models they use?

In various discussions on this proposal in public comment and our review, the responses have run the spectrum from “We need this” to “This is fatally flawed”. As we move toward the selection of a single framework, the proposal is not clear regarding the specific criteria being used by the OPTN/UNOS Board of Directors in the selection process of a single framework.

Finally, the figures used to demonstrate the various models are not intuitive and very hard to extract patient impact implications. These would not be understood by the general transplant patient population.

The PAC asked the following questions:

- **Q:** There was a request to explain the composite scoring in the Continuous Distribution model.
  A: Simply put, allocation would rank candidates by score. The score would have three components: biologic match, proximity to the donor, and medical urgency. Each organ would customize the parameters/variables that make up their organ’s medical urgency score.
- **Q:** Would it be feasible, after a model is adopted and implemented, to show patients, visually, real-time, based on their score, where they are on the list, even if it’s an approximation?
  A: The presenter deferred the question to UNOS staff. UNOS staff advised there might be a way in the future to visually depict to candidates where they are on a match, but more research would be required in how to develop that in a way that is understandable to patients.
- **Q:** How will exceptions and the review board systems impacted by the changes in geographic distribution?
  A: Exception policies that contain references to DSA will be modified. Lung, and liver, imminently, have national review boards. Local geography should matter less with changes to liver exception policies. If broader distribution equalizes access, then gaps in scoring should be smaller and it should matter less if your exception score is attuned to the local geography.
- **Q:** A donor family member asked whether organs could be referred to as a national lifesource, versus resource. “National resource” is comparable to natural gas, versus water, like organs, is a “lifesource”-without it, an individual would die.
  A: The presenter acknowledged that seemed like a reasonable request.

Tracking Pediatric Transplant Outcomes Following Transition to Adult Transplant Programs

The PAC thanks the Pediatric Transplant Committee for the opportunity to provide feedback on their guidance document regarding transitioning and transfer of pediatric recipients to adult care.

The PAC commends the Pediatric Transplant Committee for their outreach efforts to transplant centers to obtain transition and transfer best practices. They questioned why feedback was not solicited from adolescent pediatric patients, former pediatric patients who have successfully (and unsuccessfully) transitioned and the parents or caregivers of pediatric patients who successfully (or unsuccessfully) transitioned? The PAC felt additional perspectives and insight would be valuable to this resource, and suggested the Pediatric Committee conduct additional outreach.

The PAC acknowledged guidance is not policy. Programs may voluntarily implement the recommendations contained within the guidance document, but adoption is not required and thus programs will not be monitored (regarding anything recommended by the guidance document). For these reasons, the PAC felt it may be challenging to evaluate if the document is having any impact on improved data reporting or transplant recipient outcomes. Likewise, it may be challenging to attribute any change to the recommendations outlined in the guidance. They were skeptical whether it will provide any improvement in the status quo. The PAC advocated for a policy solution instead of guidance, as the potential for graft and patient longevity is so great in this population. Similarly, it seems important to improve data collection, especially pertaining to long-term outcomes, to inform future policy.

The PAC asked the following questions:

- **Q:** What data did the Pediatrics Committee analyze to determine there is a correlation between a 'lost to follow up' designation and decreased long term transplant and recipient survival?
  A: The Pediatrics Committee cross-referenced OPTN data sets to rule out patients who were deceased, and patients who were on dialysis to determine the cohort of patients deemed "lost to follow-up".

- **Q:** How did you conclude by decreasing the number of 'lost to follow up' transplant recipients there would be an effect on longer transplant and recipient survival?
  A: They did not have access to graft function data, so they hypothesized that improving follow-up of these patients would lead to better documentation and optimizing care.

- **Q:** The PAC noted there was not a clear communication or education plan to educate the community about this guidance.
  A: The workgroup chair is working on a manuscript to call transplant programs to action regarding this topic. That is beyond the scope of OPTN efforts.

- **Q:** The PAC looked at outcome data several years ago and noted that graft loss was highest for young adult recipients (age ~19-28). Did the Pediatric Committee look at similar data when developing this guidance?
  A: The Pediatric Committee did not view outcome data for recipients, because the scope of the guidance was limited to a cohort that was lost to follow-up. So by definition, the OPTN would not have outcome data on them.

Addressing HLA Typing Errors

The PAC commends the Histocompatibility Committee on their efforts to improve patient safety by proposing data entry safeguards to mitigate human error.

The PAC asked the following questions:

- **Q:** With regard to the setup of HLA data in DonorNet®, where a user can unknowingly change a donor's HLA information prior to the match run, is there a way to "lock" this field so it cannot be edited?
  A: The Histocompatibility Committee is working with UNOS IT on a system enhancement that will lock data fields to prevent mistakes like these. This issue will be addressed.

- **Q:** What is the frequency with which these HLA mismatches occur?
  A: 1-2% critical discrepancies a year over the past several years. But at least 50% of those match runs were repeated with corrected HLA typing. But in the 50% that weren't, the OPTN doesn't have data to ascertain what happened in those cases. Just because typing is incorrect, doesn't necessarily mean there would be an issue, unless the patient doesn't have antibodies against that donor HLA type.

- **Q:** Did the Histocompatibility consider requiring "refresher" education, in addition to any education that will be developed for implementation of these changes?
  A: This could be considered after implementation if the Histocompatibility Committee continues to see these specific reporting errors.

- **Q:** Did the Histocompatibility Committee consider programming that would record the error (on a field-level) real-time for data collection purposes, and then incorporate pop-up warnings or messages to notify the user incorrect data was entered?
  A: The Histocompatibility Committees reviews errors retrospectively on a quarterly basis. The presenter wasn't sure if there were ways for UNOS to visually customize fields identified as problematic. The Histocompatibility Committee does review the data for patterns.

- **Q:** Is there a way to have the raw patient data running in the background and "prompting" a user when they enter the wrong data?
  A: The raw patient information is uploaded to UNet, not entered manually, nor does the testing instrumentation communicate with UNet. There is no link between the raw data and UNet itself.

From a patient perspective, the proposal was very technical and challenging to understand. The average patient would likely support this proposal, however, they are unlikely to understand the content.

Although the proposed improvements may result in additional administrative burden for staff; there seems to be nothing but positive implications for patients. The PAC supports this proposal.

4. Improving the OPTN/UNOS Committee Structure through Enhanced Communication and Engagement Proof of Concept

The PAC discussed the progress of the proof of concept and provided feedback. The PAC is operating under the moniker "Patient Affairs Constituent Council" (PACC) for the duration of the proof of concept.

Data summary:

To assess current engagement levels amongst recipients, living donors, and recipient and donor family members within the OPTN committee system, constituent council members completed a baseline survey. Responses to qualitative questions are captured in **Exhibit A.**

A majority of PACC members are relatively new to OPTN volunteer service, serving for three years or less. Most members devote 2-10 hours a month to the OPTN, and most of that time is spent on conference calls, meeting preparation, research to understand committee work/projects, or communicating with fellow committee members.

On a scale of 0-100, members were asked to rate their engagement level and provide comment explaining their score. Ratings ranged from a low of 31 to a high of 100. Responses to this question can be found in **Exhibit B**.

A majority of members agreed or strongly agreed that UNOS staff and committee leadership make them feel their role is important and valuable. A majority confirmed (agreed or strongly agreed) that they are called upon to offer a patient or donor family perspective during their committee meetings. Not only did a majority agreed or strongly agreed that they feel comfortable speaking up to offer their patient or donor family perspective, but they feel comfortable speaking on behalf of all patients, donor families, etc. Conversely, the group was split when asked about how many times they actually voiced an opinion in their last year of service on a committee(s). More respondents indicated they speak up occasionally, infrequently, or almost never. However, almost an equal number indicated they voice an opinion frequently or often.

A majority agreed or strongly agreed they felt confident in explaining their Committee's projects and policy proposals in layman's terms. However, several members indicated a neutral response, or disagreed with this statement.

Although a majority of survey respondents agreed or strongly agreed that the patient/donor family member voice was well represented in the policy development process, over a third were neutral, disagreed or strongly disagreed. A majority felt patients and donor family members do participate in OPTN policy development.

PAC members provided feedback through an audience engagement polling application, generating a word cloud based on common sentiment. UNOS staff then presented the statement, "This proof of concept is…". The feedback was analyzed and feedback grouped according to whether the feedback was positive, neutral or negative:

Positive	Neutral	Negative
Educational	Transparent	Time-consuming
Exciting	To be evaluated	Unclear expectations
Good idea	A work in progress	Difficult
Good, but needs tweaking	New	Confusing
Innovative	Thought provoking	Not very engaging
Could be good	Ambiguous	Hard to follow
Engaging	Large	Challenging
Has potential	Complex	Over my head
A step in the right direction	Long overdue	Disaster
Sweet		Sloppy
Improving		Unclear
Worthwhile		Intimidating
Collaborative		Cumbersome
Great concept		Not well thought out
Wonderful		
Interesting		

Later in the discussion, members provided feedback on Basecamp, an online team collaboration and communication tool being piloted to serve as a repository for meeting materials and a platform to continue real-time dialogue between meetings. UNOS staff presented the statement, "Basecamp is…". The feedback was analyzed and feedback grouped according to whether the feedback was positive, neutral or negative:

Positive	Neutral	Negative
Great	Networking	Overwhelming
Going to help us collaborate	Like social media	Confusing
Informative	Storage	Spam
Good place to save documents/store info	Work	Overkill
Opened communications	Conversation starter	Difficult
Much better than Sharepoint	Shouldn't be used like texting or direct message	Could be a lot better
Engaging	Better organization	Silly
Fun	New	Frustrating
Easy to use	An email generator	Too much
Entertaining	Participation	Hard to follow threads/conversations
Awesome	Big	Time consuming
		Disorganized
		Not professional
		Overused
		Hard to navigate
		Scary
		Overbearing
		Frustrating
		Too much information
		Annoying
		Disaster
		Awful

Summary of discussion:

The PACC initiated discussion by reviewing baseline survey results (summarized above) and providing initial feedback on the proof of concept and Basecamp. Members elaborated on their feedback via interactive activities and discussion.

Proof of Concept

Leadership posed the following questions to the group:

- What impact has the proof of concept had on communication *within* committees? (i.e. communication between patient/living donor/donor family/family member and their home committee?)
    - Generally positive, several members cited increased engagement with their home committees. Several members shared the experience has increased their knowledge of donation or transplantation generally. A majority felt it was too early to tell.
- What impact has the proof of concept had on communication *between* committees?
    - Many agreed the proof of concept has increased communication between all the patients/living donors/donor and recipient family members across committees. A majority felt this was an improvement over the status quo. A few thought the committee reporting process was confusing, and no one liked the automatic check-in requirement, which would be the catalyst in identifying that another committee had something to share with the PACC. Several felt it was too early to tell.

- What would help you be more engaged in this proof of concept?
    - A majority of members indicated having projects to work on would make them more engaged. In addition, many members cited expectations needed to be clearer, and roles clarified. Several members felt more or better structure was necessary and others though the goals of the proof of concept were too broad. Members noted that more information about Basecamp, and perhaps a robust orientation to the platform would bolster utility. A few members cited time constraints as impacting their engagement level, and a few indicated they were just too new to OPTN committee service.
- What are some unintended consequences you have observed with this proof of concept?
    - The size of the group seems to have affected participation-too many people reduces opportunity to speak on calls. Members opined how to balance between “too big”, “too small” and “just right”. Likewise, a core member of the original PAC noted that other core members stopped speaking up-perhaps they felt “silenced” by the influx of participants, or by louder voices. Several members were surprised by the time demand, especially those who already served on multiple committees. Members expressed that they felt there was more participation. Finally, several members noted it seemed like managing the proof of concept was a significant endeavor for UNOS staff.

Basecamp

Basecamp features members liked included the ability to use the platform to interact real-time with others, the daily digest of activity/updates and the smartphone application. They also liked the “boost” feature because it was a way to communicate agreement and helps boost member confidence. Members indicated frustration regarding the volume of notifications; members acknowledged they could turn off notifications, but they were fearful they might miss something important. Likewise, PACC members shared it was difficult to prioritize what to read or determine what is important. Members indicated it was difficult to find documents or conversation threads; especially the latter. One member noted that people have posted in different areas in the Basecamp site about the same topic; which makes it difficult to follow a conversation. There was some consensus that Basecamp was better than Sharepoint.

The Chair noted that other committees (Histocompatibility and Pancreas) shared during their presentations that they found the dialogue that unfolded within the public comment project sites to be very informative. Another member shared she liked Basecamp because it was a one-stop-shop, and offered transparency. There was consensus that Basecamp seemed useful as a project management tool.

Several members reiterated that it was hard to find documents in Basecamp, and sometimes important information received little or no traction. One member shared that when she reposted something posted elsewhere in the Basecamp site to the “Message Board,” it received a lot of feedback. The member asked UNOS staff if they could repost information and documents to the “Message Board,” since that was clearly a place where members were finding information. UNOS staff told PACC members that they are empowered to share or reshare information in whatever way would resonate with other members; it does not have to be staff only posting things to Basecamp.

Other Feedback

Members offered additional feedback regarding the role of the patient/donor family perspective within the OPTN. They felt that there needs to be increased receptivity and acceptability of the constituent voice. There was consensus that constituent representatives feel the constituent perspective and feedback is not valued by the professionals; they could not recall a time where constituent feedback was actually taken and incorporated into a proposal.

PACC members offered additional feedback about recruiting, orienting and educating patient and donor family representatives. Members asked if the patient recruitment process could be improved. Several members indicated there should be more robust education and orientation for patient volunteers. UNOS staff indicated UNOS provided some patient education, and perhaps there is room for improvement. However, long-term, UNOS staff indicated they wanted to move upstream: how to engage a larger group of patients in the policy-making process. UNOS should be engaging with patients and donor families long before they potentially enter actual volunteer service. If UNOS is educating on the basics and fundamentals at the point in time at which patients and donor family members enter volunteer service, they may be an indicator UNOS has not communicated to the broader general public community nearly enough. That is a symptom that the engagement did not occur on a broader level.

Upcoming Meeting

- September, 2018

Exhibit A

I feel that the patient/donor family is well-represented in the policy development process (please explain):

- I am still not sure of how much the board listens to PAC and we cannot offer up and work on policy
- Transplant center participants completely overshadow other viewpoints just by sheer number
- On some issues and at times depending upon the mix of representatives for assignments, my constituency's voice is weighted less than others depending upon policy being reviewed. Having experienced being strong armed or shut down and replaced with a single personal opinion override rather than having all sides considered with regard to proposed policy that may adversely contradict the Final Rule or undermine untested, yet to be established approved policy. When committee decisions are formally presented with the omission or 'blinding' of opposition research, policy is seriously undermined.
- There should be greater patient advocacy in my committee.
- The views of the donors and recipients of life saving transplantation is a unique perspective that is highly regarded with in the UNOS network.
- I don't feel it is always respected by other Committees.
- As a transplant recipient, I don’t know how much there is to voice...most issues relate to patients who are waiting for transplant or deserve access to organs.
- I believe that each committee does their best to keep the patient/donor family perspective represented but it is hard to generalize that perspective. What works for one patient may not be the best solution for another patient/donor family either due to personal beliefs, geography, etc.
- OPTN/UNOS gives me that impression
- Having only joined the Board as of July 1, I don't have a sufficient basis upon which to answer this question
- The process includes well the voice of constituent who are *UNOS members* - but does not well include voice of the many more constituents who are not in UNOS at all.
- The LDC composition (professionals and donors) results in balanced and considered policy input
- I am new to committee service so I'm not sure yet
- Committee chairman is open to questions at all times. Quick to respond.
- I'm a living donor, and I do feel that the educated patient opinion is present. I struggled early on when I started a professional career in transplantation knowing when it was appropriate to meld my professional and personal opinions. Over time, that has become easier for me. The living donors on the committees are often very different from the average living donor-and I think that is OK. Both as a donor and as a professional, I rather policy decisions (particularly about education and risk in living donation) be driven by evidence and not donor opinion or wants. Donors can speak to the importance of a proposed change, but adding more voices that aren't educated about the specific issues often can cause more harm than good.
- I always think about the donor family and representing them in committee meetings
- I believe that living donors are well represented on this council/committee

- Most transplant recipients don't even know UNOS exists or played a role in their transplant. If they do engage, the policy language is not written at a level where the average American can understand it. UNOS does not 'push' policy to the public, it expects that the public will come to them.
- I think it's natural for many of these policies to be more clinically oriented and the provider/clinician perspective continues to lead such discussions.
- Issues and proposals are presented and each team member has the opportunity to evaluate information and ask questions before making decisions
- Room for improvement, more input earlier
- I need to learn more
- My voice, as the mother of a living donor and wife of a living donation recipient, is highly respected. The more specific question is the impact of this voice. Often, but not always, I see that policy and/or the direction of discussion and project development/design is utilizing this voice.
- I think having a patient representative on my committee makes a difference.
- There is no pancreas recipient on the pancreas committee. I do not know if we have a donor or donor family on the pancreas committee. It seems to be mostly surgeons, physicians, and nurses.
- We are given an opportunity to review proposals once they are close to completion. Wish PAC members were exposed to these potential proposals earlier on in the development process.
- UNOS volunteers, especially the patient and donor family representatives are incredibly passionate and enthusiastic and I think do a good job of being heard and UNOS is very committed to having patient/donor family representation. I sometimes worry about patients and donor families who have needs and opinions but are not in a position or have the personality to be vocal and engaged in policy development and in a similar vein, that in committee meetings, the patient constituency is primarily hearing from vocal professionals who may not represent the concerns and views of less vocal centers and professionals. I'm not sure what there is to do about this except to all try to be good listeners in our local communities and make sure that we represent the members of our constituencies that are different from us.
- From my prior board service, I am aware that they highly regard the patient perspective in considering policy. I have yet to discuss policy and my role in the committee, but I am certain that it will be taken seriously.
- Policy development is often clinically driven. The patient/family recipient constituency voice is encouraged but I would like to see more opportunities for this group to spearhead policy development.
- Could be more for sure
- Numerically well represented, but some public members are intimidated
- The lack of PAC involvement in almost all policy development
- I think as a Donor Mom, I am there as a reminder of what UNOS is doing work for, but not so much called upon for policy development. However, I think that is perfectly fine as others have more knowledge in the transplant world than me.
- It would be helpful if there was more explaining done.
- Sometimes policies are developed, then input is requested.
- So many different people involved

- The comments so far lead me to believe that this group has little understanding about donation and therefore is not equipped to provide an accurate voice
- Always opportunity to express/ask questions
- I believe that the number of living donors on each committee that I serve is sufficient in representing our interests
- Not very many donor families

What is your opinion on the current level of engagement of all constituent perspectives throughout policy development?

- relatively equal
- Not equal - pediatric and all patient viewpoints overshadowed by doctors' prerogatives
- Improvements can be made in transparency, education, layman interpretations of policy, and sincere, respectful encouragement within safe no judgement environments for open communications and sharing of innovative ideas and inclusion of all voices. Having completed my first year with some frustration and to have an insightful chairperson reach out, I am optimistic that with new strategic initiatives, engagement of all constituent perspectives will gain respect and become part of open dialogue for policy development.
- Provider perspective is dominant. Not necessarily inappropriate, but could be better balanced with patient perspective at committee level rather than public comment level.
- I think that is yet to be seen, but so far everything looks positive.
- I like the new idea that there will be more opportunity for input
- I think it can be improved
- I think there is a strong amount of engagement throughout policy development but I may be biased because I am on several committees so the opportunity to be engaged is presented to me on several levels, via committee phone calls, emails, meetings, etc.
- It is good
- High
- The PACC has not yet engaged in substantive policy discussion or feedback on targeted matters under development; to date it's been introductions and emails about miscellaneous issues that are not tied to matters under policy development (most activity is email about whatever might be in someone's mind on any given day.)
- I am new to committee service so I'm not sure yet
- To new for opinion
- I'd like to see more patients and donor families represented in liver committee.
- I think it is challenging to engage all constituent perspectives. I also think that not all constituents are aware of policies implications on operations
- It’s too soon to tell. I've just started with this group.
- Can only speak for my unique constituency. The patient perspective is unique because it does not have a collective arena, like professional committees, for meeting and sharing information about policy issues.
- Not sure. On the Living Donor Committee, often the clinicians are the most vocal; since I've only met everyone in person once I just don't think I've fully assessed level of engagement of others.
- Engagement and participation appears to be high with a genuine desire to make good decisions
- Fair
- 5
- If my only perspective were on committee calls and at committee meetings I would believe that we are missing many vital constituent voices. I know that public comments and member voices are highly valued. I am concerned how we can promote these voices, beyond having interested persons within our meetings.
- Encouraging!

- It is likely that depending on time, and committee composition, certain voices are underrepresented. E.g., the kidney/liver committees have a small peds component and if those people are less 'loud' than the surgeons, their opinions may be 'washed out'
- Opinions are shared by most members. I hope we speak up more often and earlier in the policy development process.
- I can't really say at this point because I haven't dealt with all the perspectives yet.
- Some constituency groups are definitely more vocal than others. This is by the nature of clinical work. Would like to see some of the patient/parent/donor groups be mentored to have a stronger voice in order to help make policy development stronger.
- Balance towards clinicians.
- Professionals representing adults are well represented
- the patient voice seems to always be in last place
- I think the effort is there and working in the right direction to give everyone a voice.
- Good
- unsure
- Good
- It is sought out however feedback can be limited in value based on understanding about the process.
- Very
- I believe all perspectives are adequately represented
- I think ok

Exhibit B

I feel like I am a fully engaged Committee member.

31	Moderate
33	New transplant recipient, want to to give back. Nominated by contacts at the clinic.
39	My life is very busy. I don't always feel I can devote the time needed and I am often last minute on deadlines
49	I always feel I can do more than we are currently doing.
50	There's a lot that I just don't have time to read, follow-up on
55	I fulfill all my committee duties, but there is a lot of additional activity going on that I'm not able to participate in that I think I could contribute to if I had time.
56	I feel engaged, but other participants definitely overshadow the rest.
57	I don't feel like I can provide a lot of medical-based knowledge to many conversations. Many times the conversation gets medical or procedure based and I can't add much to that being a Donor Mom.
60	I served for 3 years on the full board, but just started back with this committee and have not gotten fully engaged in all that is currently going on. My term started this month, with two calls and some emails. I am certain it will pick up.
65	I volunteer for extra subcommittees and try to provide feedback on a regular basis.
65	I participate in as many meetings as my schedule allows, I monitor Basecamp and other Committee communications and engage when I have something to offer. I am looking for more opportunities to be more engaged in UNOS work.
66	I feel like I am still learning. I also just graduated from and RN to BSN program and will have more time to participate than I have in the past 2 years.
69	I feel like it can be hard to be fully engaged. There's so many different things going on in Basecamp that can make it hard to follow. Also, talking during a conference call can be incredibly difficult.
69	It is sometimes difficult for me to understand what is desired by the committee.
70	Would like to have more concentrated time to respond to Basecamp issues being posted by providing additional factual information via research to add for consideration to the conversation and issues being discussed
70	Work restriction
73	My heart transplant. Give back.
73	I feel the need to give something back
73	I am struggling to understand and effectively use Basecamp. I just haven't had the time to get comfortable with it. I've seen the screen shots that others have provided and I can't seem to find those views. I'm wondering if I downloaded the right version!
73	Competing with my day job for time
73	Because I need to learn more
75	Enjoy and benefit from committee work, but other commitments interfere with full participation.
76	I would like to read more to understand more about the topics being addressed.
76	Opportunity to gain knowledge and understanding of the processes, use my years of experience to engage in change.

31	Moderate
78	I participate in many committees at UNOS and usually know what is going on and what steps I need to take to achieve the desired goals and outcomes.
80	I don't always fully understand policy and perspectives.
82	I am engaged both in a committee and 3 subcommittees and fully participate in them
83	I strive to read all the pre-meeting document, attend the calls and meetings, and provide opinions or ask questions.
84	I am encouraged to and have participated as often as needed and have received feedback that tells me my voice is being heard.
85	I feel the communication is great and the expectations are clear so I know I am fulfilling my responsibilities to the committees I serve
86	I am currently on 3 committees and sometimes it's hard to keep up with all of the reading and preparation in addition to my usual work duties.
90	it's useful and rewarding work that result in change and improvements
91	I attend all meetings and keep engaged on a regular basis
91	I participate in all calls, attend face to face meetings, read transplant related articles and periodicals in order to educate myself.
98	Have been eagerly doing all the readings(and extra readings suggested to me by staff members and others); heckling in on Basecamp several times a day; participating in all the calls; etc.
98	Because I am engaged. Do you want a list of everything???
100	Give back to the transplant community
100	I want to help people needing a transplanted organ and people wanting to be donors.
100	I value the opportunity to engage
100	I am excited about being a part of the proof of concept and contributing in a meaningful way