

Public Comment Proposal

Improving the OPTN/UNOS Committee Structure Concept Paper

OPTN/UNOS Executive Committee

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Improving the OPTN/UNOS Committee Structure Concept Paper

Affected Policies: N/A
Sponsoring Committee: Executive Committee
Public Comment Period: January 22, 2018 – March 23, 2018

Executive Summary

In June 2016, the OPTN/UNOS Executive Committee endorsed formation of a two-year workgroup (“committee governance workgroup”) to assess the OPTN/UNOS committee governance structure; possible improvements to committee recruitment, selection, and engagement; and how to improve committee alignment with the Board of Directors. After endorsing several new changes to improve the committee recruitment process, the Executive Committee is considering a new concept recommended by the committee governance workgroup with regard to improving the committee governance structure.

The committee governance workgroup identified the current “one size fits all” structure as needing improvement because it limits opportunity for broader transplant community participation and makes it difficult to incorporate diverse perspectives on committees. In addition, the structure and current methods for collecting public comment from committees, regions, societies, and the general public does not allow the Board of Directors to fully consider the sentiment of particular groups or communities when making policy decisions, as perspectives are offered sporadically throughout the system. In this document, the Executive Committee outlines a proposed new volunteer workforce structure and requests feedback on whether this new concept better incorporates perspectives of different important constituencies (patient, living donor, donor family, transplant professionals), while also maintaining the subject matter expertise.

Is the sponsoring Committee requesting specific feedback or input about the proposal?

1. Does the current committee structure limit participation in the OPTN policy development process?
2. What alternative ideas will increase participation in the OPTN policy development process?

What problem will this proposal address?

The OPTN/UNOS system is currently a “one size fits all” structure that limits opportunity for broader transplant community participation and makes it difficult to incorporate diverse perspectives on committees. In addition, the structure and current methods for collecting public comment from committees, regions, societies, and the general public does not allow the Board of Directors to fully consider the sentiment of particular groups or communities when making policy decisions, as perspectives are offered sporadically throughout the system.

This concept aims to address four different problems with this “one size fits all” approach to committees:

1. Insufficient opportunities for participation
2. Insufficient minority representation on the committees
3. Insufficient diversity in perspectives on committees
4. Insufficient connections between the Board and Committees

Background on Current Committee Structure

The current committee structure consists of two types of committees:

1. Permanent standing committees
2. Ad hoc committees

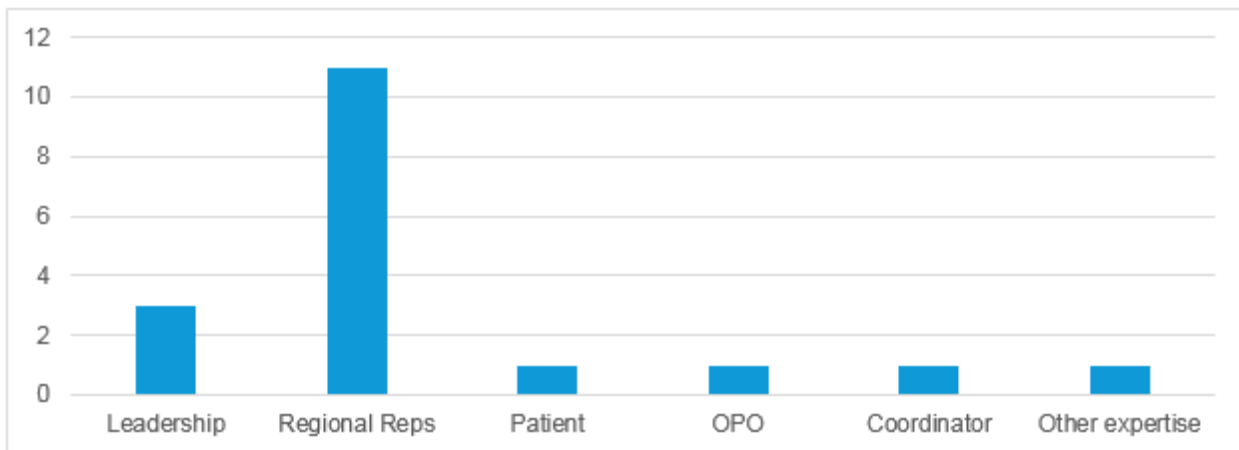
Permanent standing committees

Permanent standing committees are recognized in the OPTN/UNOS Bylaws (Bylaws). There are currently 16 permanent standing committees.¹ The Bylaws require that permanent standing committee composition include the following:

- Committee chair
- Vice-chair
- Past committee chair (for one year)
- A representative from each of the 11 regions
- Transplant hospital representation
- OPO representation
- Transplant coordinator representation
- Representation from transplant candidates, recipients, donors, or their family members

Most committees average 18 members at a time. The structure dictated by the Bylaws emphasizes geographic diversity above all other types of diversity in committee membership. This can be particularly challenging for certain committees which oversee multiple organ systems (ex. thoracic: heart and lung) or desire to have more patient involvement (ex. the Living Donor Committee aims for 1/3 of their membership to be living donors).

Figure 1: Current Required Committee Composition



¹ Ethics, Histocompatibility, Kidney Transplantation, Liver and Intestinal Organ Transplantation, Living Donor, Membership and Professional Standards, Minority Affairs, Operations and Safety, Organ Procurement Organization, Pancreas Transplantation, Patient Affairs, Pediatric Transplantation, Policy Oversight Committee (POC), Thoracic Organ Transplantation, Transplant Administrators, and Transplant Coordinators.

The Policy Oversight Committee is the exception to the Bylaw composition requirements for permanent standing committees. The POC is comprised of all the vice-chairs of the standing committees and is led by a chair and vice-chair not serving in that role.

Ad hoc committees

Ad hoc committees are committees that were created for a particular need, perhaps for particular subject matter expertise or a certain task. Some are named in the current OPTN contract or the OPTN policies. There are currently four ad hoc committees.² Ad hoc committees are not bound by the composition requirements in the Bylaws. The main difference in practice is that ad hoc committees do not have regional representatives.

The permanent standing and ad hoc committees were developed over time and each has an established mission. However, the OPTN/UNOS has not performed a comprehensive review of the committee structure in recent years to ensure that the structure meets the needs of the organization.

1. Opportunities for Participation

The current committee structure allows for approximately 355 volunteers to serve on committees. While this is a large number of committee positions and improvements have been made to increase the number of individuals serving on a committee for the first time, the transplant community consistently requests additional opportunities to participate in the process. Every year, UNOS conducts a member survey. A consistent request from members is for greater participation in the policy development process. Right now, we have roughly two levels of participation:

- First level: participation in public comment or regional meetings
- Second level: board or committee membership

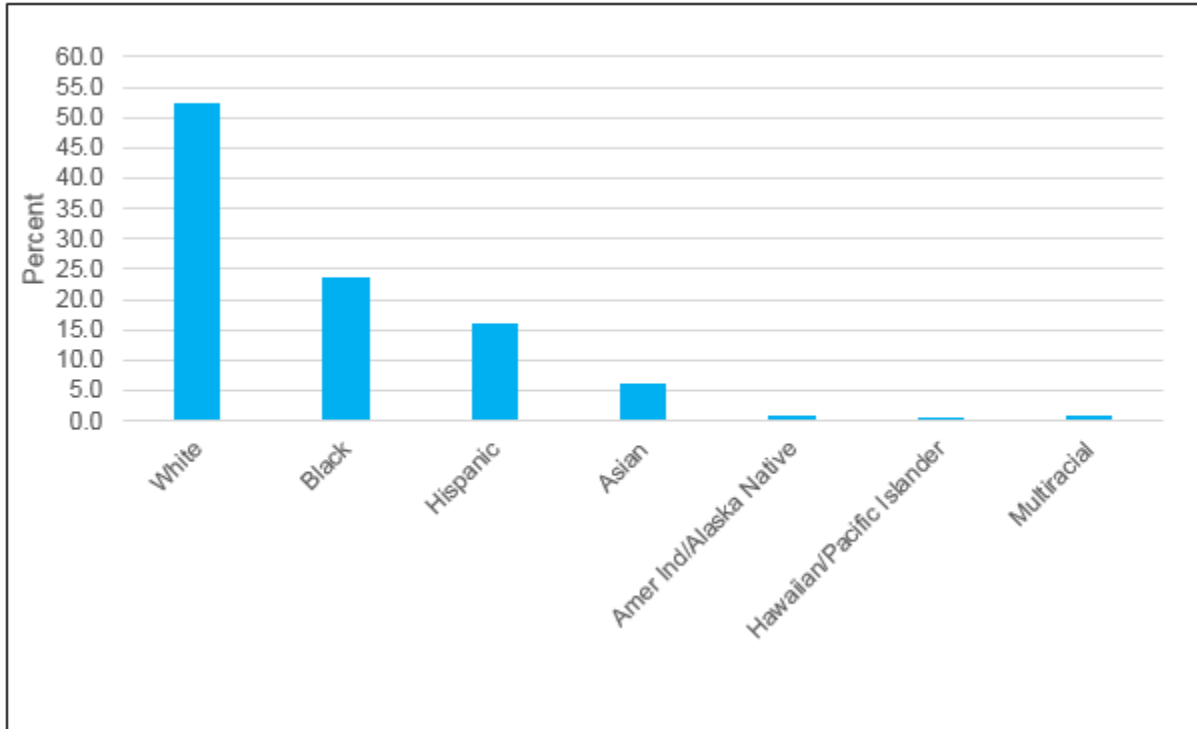
The time commitment between these two tiers is significant. Full committee membership requires time and commitment from members that is not possible for everyone (ex., regular conference calls, assigned reviews and presentations, and travel to committee meetings). There is currently no participation level available for people who would like to participate more than public comment, but less than full committee membership.

2. Minority Representation

The OPTN strives to have a Board and committee system that reflects those we serve. In making decisions about new or revised allocation policies, the Board seeks to understand the impact on minority and other vulnerable populations. The committee governance workgroup reviewed data on waitlisted patients, living donors, and deceased donors in 2015 (the first full year of data preceding the creation of the committee governance workgroup). See Figure 2 below.

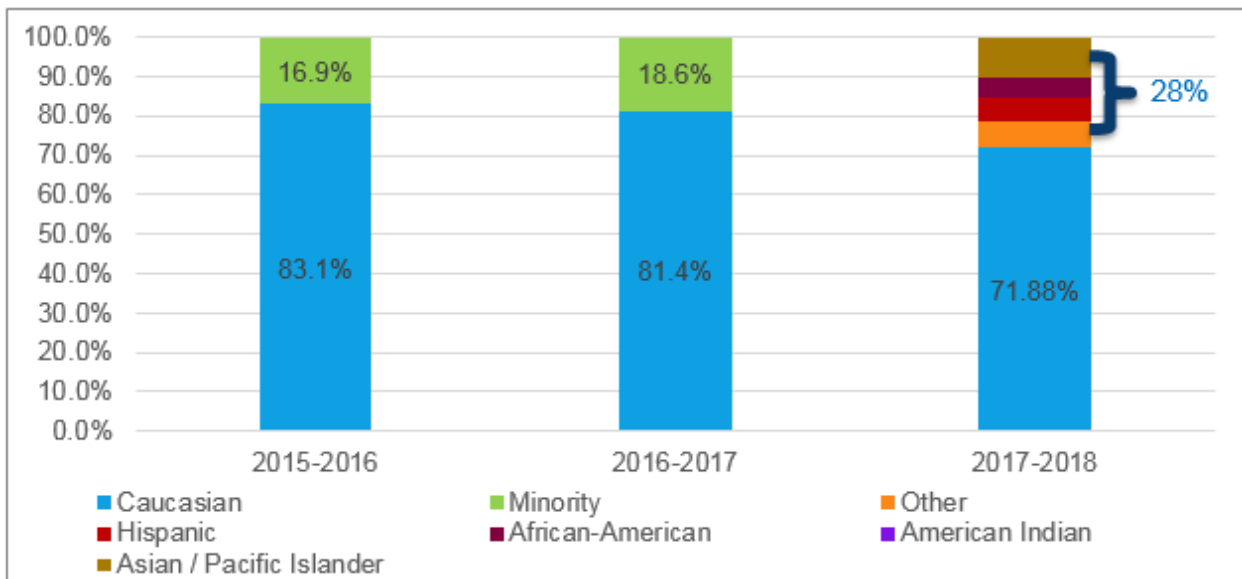
Figure 2: Racial/Ethnic Data for Patients Added to Waitlist (2015)

² Disease Transmission Advisory Committee (DTAC), International Relations Committee (IRC), Data Advisory Committee (DAC), and Vascular Composite Allograft Committee (VCA)



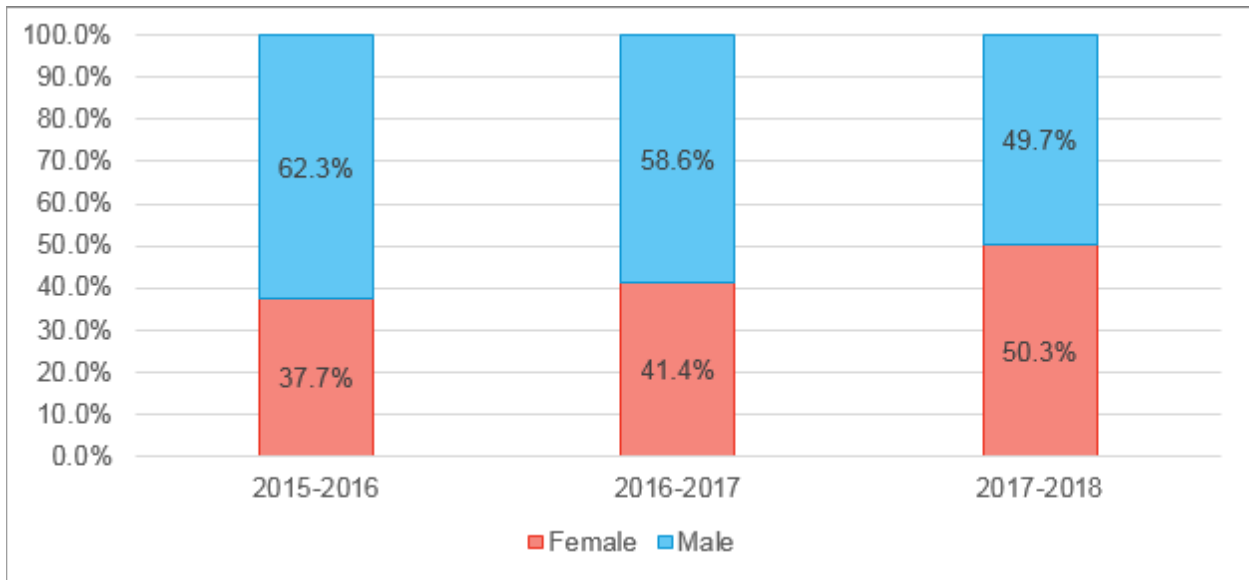
The workgroup then reviewed data on race and ethnicity of individuals serving on committees (Figure 3). As you can see, there are notable gaps in representation of committee members who identify as African American and Hispanic compared to the population of waitlisted patients. The OPTN has made a concerted effort (and incremental progress) to increase the percentage of committee members who identify as African American or Hispanic in order to better reflect those the OPTN serves.

Figure 3: Race/Ethnicity Committee Representation



Similarly, the committee governance workgroup reviewed data on gender representation on the committees. This is an area where the OPTN has seen an increasing in the balance between the percentage of male and female members on the committees.

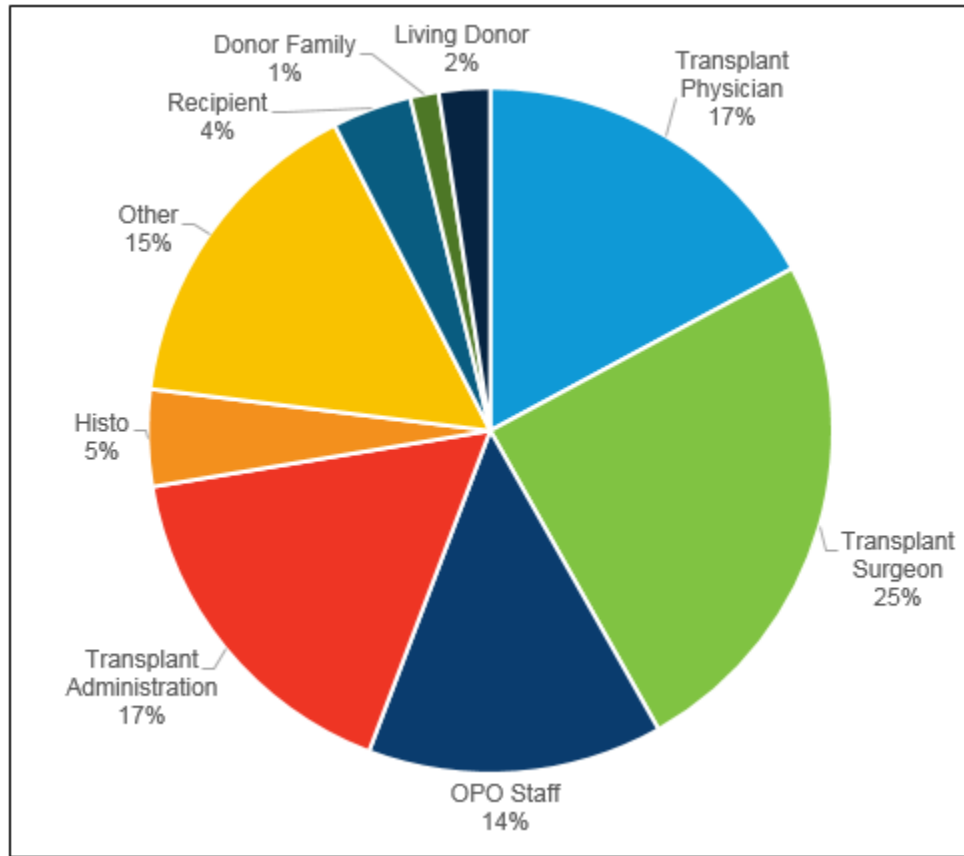
Figure 4: Gender Representation on Committees



3. Diversity in Perspectives

A balance in professional perspectives is also critical in the development of policies. The committee governance workgroup reviewed data regarding the perspectives represented on committees and found that 42% of committee members represent transplant physicians and surgeons, while only 7% represent patient, living donor and donor family perspectives. There was also a comparatively low representation of those in transplant administration and coordination, organ procurement, histocompatibility and other relevant specialties. This reflects the structure outlined in the Bylaws for committees, but does not reflect the breadth of voices needed to create balanced, vetted policies.

Figure 5: Perspectives Represented on Committees (2015-2016)



In observing committee discussions, it is apparent that certain voices and perspectives carry more weight than other voices – even when the individuals carry nearly identical credentials and backgrounds. For example, two surgeons on the same committee might have opposing perspectives but the perspective of the regional representative typically carries more weight. One theory for this is that the regional representative is more typically speaking on behalf of a community (in this case, his/her region) instead of only bringing individual expertise and perspective. This difference can also be seen with members that present the perspective of national societies (ex. AOPO, AST, ASTS, or NATCO).

This difference is most noticeable for members that do not have a mechanism to organize the collective expertise of their representative community (ex. patients or transplant administrators). While appointing isolated members to each committee to represent different communities carries symbolic weight, the policy development process would benefit from increasing their participation.

4. Connection between Board and Committees

The OPTN/UNOS is governed by a Board of Directors. Most of the policy development work occurs within the committee structure. There are some structural connections between the two groups (ex., the Executive Committee approves new projects and the release of public comment proposals from the committees). However, many Board members do not regularly interact with the committees. This can create a disconnect regarding Board members’ understanding of the history of policy projects and proposals.

Furthermore, there are opportunities to improve how we progress volunteers through our Board and Committee system. In the Board recruitment process, committee service is heavily valued because experienced committee members are familiar with the OPTN policy development process and have a demonstrated commitment to the organization. In addition to increasing minority representation and diverse perspectives on the committees, the OPTN is making a concerted effort to do the same with the

Board of Directors. To achieve these goals for the Board of Directors, however, will require a pool of experienced committee volunteers that reflect these communities and perspectives.

What is the Concept that is being considered?

The proposed concept seeks to achieve the following objectives:

- 1) Increased opportunities for participation
- 2) Increased minority representation on the committees
- 3) Ensured diversity in perspectives on committees
- 4) Increased connections between the Board and Committees

Under the new concept, the Executive Committee would ask the Board to revise the Bylaws to remove the prescription of specific committees. Instead, the Bylaws would describe broadly that the OPTN will have a volunteer workforce structure to achieve certain objectives. The Bylaws would continue to contain requirements outlining the process that must be followed when proposing new or revised policies.

Based on current need, the Executive Committee endorsed initially revising the current structure into two types of groups:

1. Subject committees: defined as organ-specific or other groups where broad policy development is required. These groups will be tasked with developing organ-specific policies, policies that span across organs, and/or those that cannot be accomplished through the work of another group.
2. Expert councils: defined as groups with a perspective that is needed on three or more subject committees.

The below table outlines the similarities and differences of both groups.

Subject Committees	Expert Councils
Chair and Vice-Chair (will serve a two-year term)	Chair and Vice-Chair (will serve a three-year term)
Chairs attend Board meetings	Chairs attend Board meetings
Vice-chair serves on POC	Vice-chair serves on POC
Suggests project ideas to POC/Executive Committee	Suggests project ideas to POC/Executive Committee
Assist in UNOS educational, IT, and communication projects	Assist in UNOS educational, IT, or communication projects
Leaders are identified for Board service	Leaders are identified for Board service
With the exception of MPSC, members will serve a three-year term	Members will serve a three-year term
Will have assigned UNOS staff	Will have assigned UNOS staff
Has regional representatives	Does not have regional representatives
Members are appointed by OPTN president	“Core council” (those serving as cross-representatives on a subject matter committee) appointed by OPTN president

Subject Committees	Expert Councils
	Board members representing expert council perspective will serve ex-officio
Sponsor public comment and Board proposals	Provide perspectives on public comment and Board proposals Use tools to perform outreach to larger community with that perspective in order to provide broad perspective of that constituent group
Chairs present proposals to the Board	Expert council chairs and Board members serving on the respective expert councils will provide Board with perspective during Board discussion on new or revised policies
Meet in-person and online	Core council would meet online and possibly in-person Larger expert council group would meet online pre-public comment and during public comment and possibly in-person at professional conferences or other events

With these criteria, the committee governance workgroup proposed the below expert councils and subject committees based on current needs. The committee workgroup emphasized that this list could be modified over time with changing organization and community needs.

Subject Committees	Expert Councils
Heart Transplantation Committee	Bioethicists Council
Histocompatibility Committee	Candidate and Recipient Affairs Council
Kidney Transplantation Committee	Donor Family Council
Liver and Intestine Transplantation Committee	Living Donor Council
Lung Transplantation Committee	Minority Affairs and Vulnerable Populations Council
Operations Committee (includes disease transmission)	OPO Executives Council
Organ Donation and Procurement Committee	Pediatric Transplant Specialists Council
Pancreas Transplantation Committee	Procurement Coordinators Council
Transplant Program Operations Committee	Transplant Administrators Council
Quality Improvement Committee	Transplant Coordinators Council
Vascular Composite Allograft Committee	

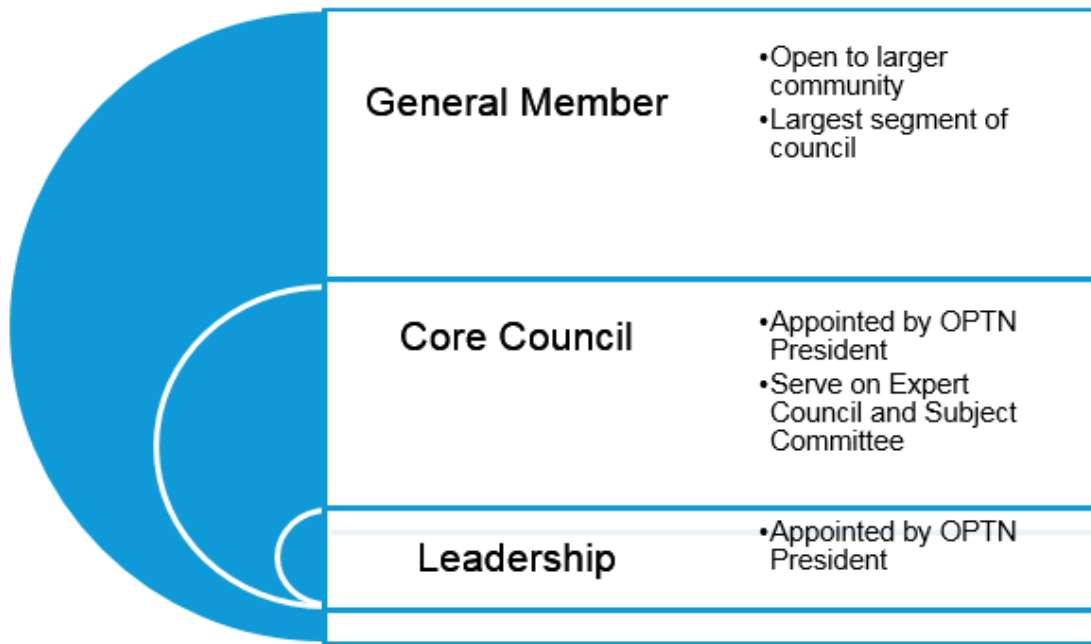
Increased opportunities for participation

One of the first goals of this concept is to increase opportunities for participation. This new concept will achieve this goal through two approaches.

First, the subject committees will be larger than our current committees. The current committees currently average around 18 members. The proposed committees will have more flexibility in their size and will, on average, be larger than 18 members. While there will be less total committees in this new structure, we anticipate that the total number of formal volunteer positions will remain roughly the same.

Second, the expert councils create a new and larger opportunity for community participation. In addition to the core council, the expert council will include a larger group of individuals who will participate in the policy development process before, during, and after public comment. Some expert council members will serve in leadership or on subject committees (i.e., the core council). The general membership of these expert councils will not be limited in size. Participation will be open to any individual who can provide the particular perspective (ex. living donor). For more information on the tools and changes the OPTN will utilize to support the expert councils, see Section “How will the OPTN implement this concept?” below.

Figure 6: Expert Council Composition



Specific question for feedback:

- 1) Will the proposed change in OPTN committee structure allow for greater opportunity for participation by the transplant community?

Increases minority representation on the committees

The new concept would retain the ability of regions to nominate their regional representatives and for the incoming OPTN President to make the final appointment. The OPTN President would then also appoint the core council, along with any at-large positions the subject committees need for additional expertise for projects. This allows for a much larger number of appointed positions that will be made with considerations of the organization’s goals of increasing minority representation and diversity in perspectives. By centralizing more of the committee appointments, we will be able to adjust appointments

in order to achieve appropriate representation across all of the committees. In addition, the expanded opportunity to serve on an expert council is expected to greatly increase overall diversity in the OPTN volunteer workforce.

Ensure diversity in perspectives on committees

The new expert council structure will increase the number of individuals representing diverse perspectives in the policy development process. Core council members will act as liaisons between their constituency and the subject committees, weighing in on new or proposed policies before, during, and after public comment.

With this concept, the OPTN seeks to enhance the voices and influence of constituent groups like transplant patients, living donors, and donor and recipient family members, along with other professional and special interest groups in the policy development process. For example, the stated mission of the current Patient Affairs Committee (PAC) is “to advise the Board of Directors about patient and donor family perspectives on OPTN policies and initiatives that originate in other committees.” However, the current PAC is comprised of five transplant recipients and one donor family member. There are three recipient family members, but the remaining members of the committee are OPO professionals, transplant physicians or surgeons, etc. (in accordance with the Bylaws). If the Kidney Transplantation Committee develops a proposal and seeks to get feedback from transplant patients and donor families, it currently seeks the opinion of the PAC. However, the comments provided by the PAC do not necessarily provide the Kidney Transplantation Committee (or later in the process, the Board of Directors) the patient or donor family perspective on a proposed policy. They include the perspectives of the other transplant professionals on the Committee. In addition, the PAC provides feedback during the formal public comment period, but typically not in the pre-public comment development phase.

As the new concept is proposed, the Candidate and Recipient Council would be comprised exclusively of transplant candidates and recipients. The core council (appointed by the OPTN President) would serve on subject matter committees and, therefore, would provide a global patient perspective before, during, and after public comment. In addition, the expert council would host an online forum for seeking feedback from a larger group of transplant candidates and recipients. As a result, when the Kidney Transplantation Committee presents a final proposal to the Board of Directors, the committee chair will be able to report to the Board the sentiment of different councils (patients, living donors, donor families, transplant coordinators, etc.).

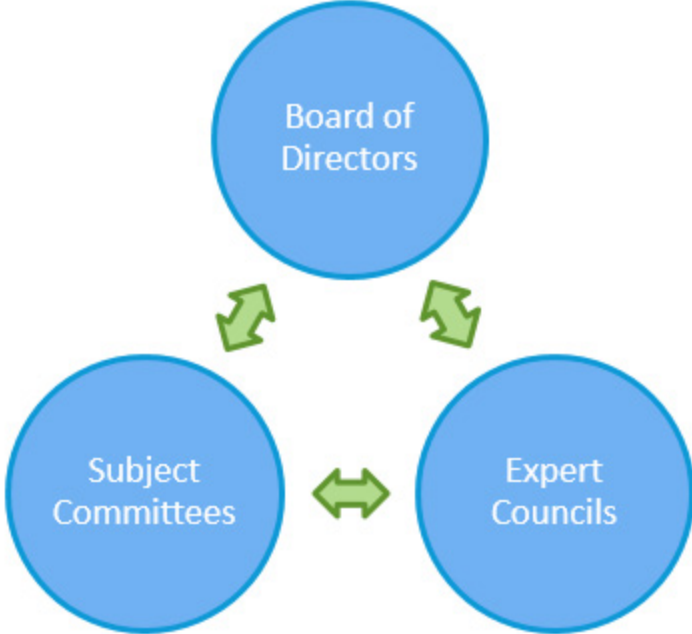
Specific question for feedback:

- 2) Will the proposed change in OPTN committee strengthen your voice in the policy making process? (In answering this question, please consider what perspective or community you might represent in the policy making process.)
- 3) Do the proposed expert councils and subject committees capture all perspectives needed in the policy making process?

Increases Connection between the Board and Committees

This new concept will increase the Board of Director’s ability to successfully transition committee leaders to service on the Board, while also achieving the goals of increasing minority representation and diversity in perspectives in its composition. The leaders of the subject committees and expert councils will often be identified for Board service.

In addition, the expert council structure will allow the Board to be more informed of the sentiment of different stakeholders when considering new or revised policies. The Board members serving ex-officio on the expert council will also be at the table during the decision-making process.



How was this proposal developed?

In June 2016, the OPTN/UNOS Executive Committee endorsed formation of the committee governance workgroup to assess the OPTN/UNOS committee governance structure, possible improvements to committee recruitment, selection, and engagement, as well as how to improve committee alignment with the Board of Directors. The committee governance workgroup contained current or recent Board members, committee Chairs, and community leaders.

The committee governance workgroup spent the first year reviewing the process for committee recruitment, selection, and engagement. That review resulted in the committee governance workgroup recommending (and the Executive Committee endorsing) two process changes:

1. The Executive Committee's Board Governance subcommittee will perform an annual committee needs assessment prior to committee recruitment. The needs assessment will include the skills and subject matter expertise needed for the organization, along with consideration for gaps in representation (i.e. regional and professional).
2. All potential committee members will be presented with a committee job description, outlining expectations and commitment that accompany service on an OPTN/UNOS committee prior to being considered as a nominee.

Once these changes were endorsed and implemented in early 2017, the committee governance workgroup shifted its focus to review of the organization's committee structure.

The committee governance workgroup considered two possible approaches to this review: 1) review the mission and recent work of each current committee and determine whether to continue each; or 2) conduct a strategic organizational review beginning with assessing the purpose and value of committees and conceptualize what a structure would be if the OPTN/UNOS were to build it from scratch today. The committee governance workgroup chose the latter.

The committee governance workgroup determined that, although neither the National Organ Transplant Act nor the Final Rule mandate a committee system, the committees greatly strengthen the organization by helping achieve its mission and strategic goals. This is accomplished by providing advice to the Board and each other in the policy development process and through completion of certain tasks. The committees accomplish this by providing subject matter expertise, advancing diverse perspectives from transplant and donation professionals and patients and donors, and by getting transplant community buy-in through regional meetings and other forms of collaboration.

The current structure serves the OPTN well in terms of providing organ-specific and other specialty expertise. However, it does not allow for the flexibility to ensure diverse perspectives from different types of transplant and donation professionals or from the patient and donor population. The committee governance workgroup determined that a structure with greater flexibility would allow for more diverse perspectives and, along with a new way of collecting public comment, would allow the Board of Directors to understand and consider the sentiment and level of buy-in from different stakeholders.

How does this proposal impact the OPTN Strategic Plan?

1. *Increase the number of transplants:* No impact to this goal.
2. *Improve equity in access to transplants:* It can be argued that increasing diversity in perspectives in the policy development process could enhance fairness in allocation policy. It will ensure that unintended consequences (like those that may disproportionately impact minority or vulnerable patient populations, for instance) are considered and discussed prior to approval of a new or revised policy.

3. *Improve waitlisted patient, living donor, and transplant recipient outcomes:* No impact to this goal.
4. *Promote living donor and transplant recipient safety:* No impact to this goal.
5. *Promote the efficient management of the OPTN:* The 2015-2018 OPTN strategic goal has a stated initiative, “consider reducing the number of committees.” The committee governance workgroup decided to approach this review differently than reducing the number of committees. When reviewing the efficiency of the committee system, the group concluded that a new structure that provides greater flexibility to meet the organization’s needs is a more productive and efficient solution.

How will the OPTN implement this proposal?

Full implementation of this concept would require changes to the Bylaws. It will also require the OPTN/UNOS to utilize new tools and approaches for subject committee and expert council collaboration. Most committee work now occurs in meetings: in-person and through teleconferences. These similar tools will remain effective for subject committees. We expect that the expert councils will be significantly larger in population than the subject committees; therefore, they will require different approaches and tools to be effective. These new tools include listservs, webinars, message boards, online focus groups, and moderated chat rooms. UNOS staff have begun using these tools with committee volunteers. This work will continue through 2018 in preparation of a potential 2019 implementation of this proposal.

The OPTN will also look at ways to better capture sentiment in the public comment phase. Instead of collecting one comment per committee or region, the staff will collect comment at the individual level. This will allow committees and the Board to understand the sentiment from different demographic groups (ex. Member type, patients, geography, etc.).

The Executive Committee plans to incorporate feedback from the spring 2018 regional meeting and public comment cycle and finalize a proposal for formal public comment for fall 2018. If public comment is favorable, the Executive Committee will ask the Board to approve changes to the Bylaws creating greater flexibility in the structure. If approved at the December 2018 Board meeting, the structural changes will go into effect on July 1, 2019. This will coincide with the annual turnover in Board and Committee appointments.

How will members implement this proposal?

Members would not be required to take any new action under this proposal. However, members will see a change in the number of opportunities that exist to serve as part of the OPTN volunteer workforce and policy development process.

How will the sponsoring Committee evaluate whether this proposal was successful post implementation?

The committee has already begun discussions about how to monitor the success of any changes to the committee structure.

- Increase opportunities for participation
 - Whether there is an increase in the number of positions available for community participation
 - Whether there is an increase in the amount of community volunteers
- Minority representation on the committees
 - Whether there is an increase in diversity regarding committee representation

- Whether there is an increase in diversity in in public comment
- Ensures diversity in perspectives on committees
 - Whether Expert Council perspectives are heard and acted upon by Subject Committees and the Board
- Strengthens connections between the Board and committees
 - Whether there is an increase in the percentage of proposals on the consent agenda at the Board meeting
 - Whether Board engagement levels increase
 - Whether there is an increase in the percentage of new Board members who rise from committee service.
- Other
 - Whether there is an increase in volunteer workforce satisfaction