

**OPTN/UNOS Pediatric Transplantation Committee**  
**Meeting Minutes**  
**February 21, 2018**  
**Conference Call**

**William Mahle, M.D., Chair**  
**George Mazariegos, M.D., Vice Chair**

**Introduction**

The OPTN/UNOS Pediatric Transplantation Committee met via teleconference on February 21, 2018 to discuss the following agenda items:

1. Public Comment - OPTN Strategic Plan 2018-2021
2. Public Comment - Improving OPTN Committee Structure

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

**1. Public Comment - OPTN Strategic Plan 2018-2021**

UNOS staff shared a presentation of a proposal from the OPTN/UNOS Executive Committee.

Summary of discussion:

UNOS staff were invited to the conference call to present a proposal on the OPTN Strategic Plan 2018-2021. The current OPTN Strategic Plan sunsets on September 30, 2018. The OPTN/UNOS Board of Directors previously met with committee leaders to receive input on what should be included in the 2018-2021 OPTN Strategic Plan. Input was also sought from the Board and an internal group at UNOS. Three key areas for the work of the OPTN were identified; Match, Data and Quality. The goal of developing the new strategic plan was to create a narrative that reflects these three core strengths.

The next three-year plan is structured differently than the last. Two plans (one for UNOS, and one for the OPTN) will no longer exist. One overarching plan is intended that shares, high-level goals, descriptions of core activities, opportunities for growth (new initiatives), and key metrics for assessing success. The intent was to determine metrics under each initiative that would help us assess whether we are successfully meeting our goal and objectives.

The resource allocation benchmarks in the new strategic plan are used as a measure of how to distribute internal resources toward moving each of the strategic goals. It assists in determining how to focus our efforts in policy development, and is considered by the OPTN/UNOS Policy Oversight Committee (POC) and Executive Committee in determining which projects should be pursued, and which should go forward to public comment. Alignment with these benchmarks is reassessed by the Executive Committee at every Board Meeting.

Individuals commenting on the development of the strategic plan agreed that Goal One (Increase the number of transplants) and Goal Two (provide equity in access to transplants) should remain the top two goals. Their respective resource allocation levels of 40% and 30% were maintained from the current strategic plan. However, there was evenly distributed support for the final three goals; Goal Three (promote efficiency in donation and transplant) Goal Four (promote living donor and transplant recipient safety), and Goal Five (improve waitlisted patient, living donor, and transplant recipient outcomes). Based on this feedback, the recommendation was for an even split of the remaining resources to 10% of effort for each of these goals.

UNOS staff then profiled the initiatives under each of the strategic goals:

- Goal One:
  - More dynamic donor/recipient matching
  - Increase transplants arranged through KPD
  - Expand use of collaborative improvement methodologies/models
  - Examine monitoring approaches for transplant programs and OPOs for increased collaboration and performance improvement
  - Promote knowledge of effective donation/procurement practices
  - Improve ability to perform analysis of refusals
- Goal Two:
  - Improve equity in opportunities for multi-organ and single-organ candidates
  - Decrease geographic disparity
  - Increase diversity on Board/Committees to ensure variety of perspectives in policy development
  - Increase opportunities for volunteer engagement and awareness of OPTN/UNOS volunteer opportunities
  - Improve member and public engagement in policy development
  - Develop equity benchmark for each organ
  - Collect additional data on vulnerable populations
- Goal Three:
  - Modularize and simplify UNet<sup>SM</sup> architecture to expedite system changes and improve quality
  - Achieve continuous level of UNet accessibility
  - Improve efficiency in policy development and implementation process
  - Improve volunteer workforce satisfaction and engagement
  - Increase data exchange between members and UNet
- Goal Four:
  - Improve accuracy in HLA reporting
  - Decrease number of safety incidents related to logistics/transport
  - Increase perception of UNOS and MPSC as focused on process improvement
  - Enhance knowledge-sharing about safety events, near misses, and effective practices
  - Enhance system capability for reporting elements of data related to safety
- Goal Five:
  - Improve longevity of organ transplants
  - Evaluate effective methods for assessing living donor outcomes
  - Enhance transplant program tools and education in selection and follow up of living donors
  - Expand use of collaborative improvement models to promote effective donor management practices impacting transplant outcomes
  - Develop transplant program tools to calculate survival benefit

UNOS then highlighted the metrics for each initiative to assess for success in each goal.

The Chair thanked UNOS staff for the presentation and opened the floor for questions. Members shared several points after reading the proposal in detail. Members verbalized mixed sentiments regarding the draft strategic. Some comments were in support of the draft plan for transplantation overall. However, members did feel there was a lack of specificity when it came to pediatric transplantation. For example, data exists for pediatric liver and kidney candidates to show waitlist morbidity and mortality do exist, and there are disparities in transplant access for pediatric candidates. The Committee is hopeful the Executive Committee would amend the Strategic Plan include initiatives to address these needs of the pediatric transplant community.

Two members verbalized the lack of pediatric-specific metrics in the draft plan. One of the metrics in Goal Two alluded to this by examining data on “vulnerable populations”. Measures for transplant equity should assess for disparities across different ages of transplant candidates. Waitlisted outcomes should also be monitored (measures in decreased in waitlist mortality and decrease in re-registration on the waiting list). This latter metric could influence transplant programs to not register transplant candidates that have high waitlist mortality risk. Need to be sure to examine the right metric re: waitlist mortality.

UNOS staff thanked the Committee for their diligent feedback on the draft strategic plan.

#### Next steps:

Committee members were asked to complete an on-line survey for their feedback on the proposal, including a review of a list of initiatives.

UNOS staff will prepare a draft response and share with the Chair and Vice Chair. Once approved, the response will be posted on the OPTN website.

## **2. Public Comment - Improving OPTN Committee Structure**

UNOS staff shared a presentation of a proposal from the OPTN/UNOS Executive Committee.

#### Summary of discussion:

UNOS staff were invited to the conference call to present a concept document to improve OPTN committee structure. The current OPTN committee structure is a “one-sized fits all” approach that limits opportunity for participation, and makes it difficult to incorporate diverse perspectives in the policy development process. This approach, along with how we currently collect public comment from stakeholders (regions, committees, societies, and the public) also doesn’t allow the Board to fully consider the sentiment of those groups when making decisions.

UNOS staff pointed out that the current committee structure is not mandated by the National Organ Transplant Act (NOTA) or the OPTN Final Rule. It has been used over time to provide subject matter expertise, advance diverse perspectives from stakeholders, and generate buy-in on health policy from the transplant community.

The goal is to build a committee structure that achieves several aims:

- Increase opportunities for participation, for example, by adding more spots to be official volunteers for the OPTN (greater than the limited number of committee and Board positions currently available).
- Increase minority representation on the committees, by taking an even more concerted approach to ensuring that the volunteer workforce reflects the system we serve.
- Ensure diversity in perspectives on committees – by amplifying the voices of certain types of members across groups rather than containing them within a group, and by strengthening that individual’s sole contribution to a group discussion by helping them know they have the backing of lots of people from their same perspective.
- Strengthen connections between the Board and committees – by building in Board positions on the committees and expert councils to be the connection between the groups, and to create a better structure for promoting someone through the volunteer lifecycle.

The Executive Committee is proposing a new committee framework in a concept paper to gather early input from the transplant community and other interested individuals. This framework would include:

- Subject Committees present policy proposals to the Board, and leaders are often identified for Board service
- Expert Councils communicate with Subject Committees through their representatives, and Councils are educated on proposal development
- Representatives from the Board sit on Expert Councils providing:
  - Knowledge sharing
  - A direct link to the Board
  - A more established pipeline for succession planning
  - Leaders often identified for Board service

UNOS staff then profiled the tasks and functions that could be assigned to the subject committees and the expert councils.

The Executive Committee carefully considered the form and function of committees and felt there were distinguishing features:

- Subject Committees
  - Single subject
  - Frequently propose specific policies
  - Debate specific policy language – needs smaller working group
  - Send proposals to Board – needs balanced regional representation
- Expert Councils
  - Multiple subjects
  - Weighs in on the work of many others
  - Identifies gaps and opportunities – needs as many participants as possible
  - Comments to Board on current and future issues

With this in mind, the following list was drafted for potential subject committees and expert councils:

- **Subject Committees**
  - Heart
  - Histocompatibility
  - Kidney
  - Liver/Intestine
  - Lung
  - Pancreas
  - Operations
  - Disease Transmission
  - Organ Procurement (or Donation)
  - Quality Improvement (MPSC)
  - VCA
- **Expert Councils**
  - Bioethicists
  - Candidate and Recipient Affairs
  - Deceased Donor Family
  - Living Donors
  - Minority Affairs and Vulnerable Populations
  - OPO Executives
  - Procurement Coordinators
  - Transplant Administrators
  - Transplant Coordinators
  - Transplant Pediatric Specialists

UNOS staff noted that the first ten days of public comment, this concept document struck a chord with many groups who may no longer be considered a subject committee (Pediatrics and Living Donor). With the transition to expert councils, the intent is for more pediatric representatives on committees, organ-specific pediatric work groups for projects, and overall more involvement from the pediatric community.

The Chair thanked UNOS staff for the presentation and opened the floor for questions. Members shared several points after reading the proposal in detail. In principle, the Committee supported the goal of increasing engagement. However, they strongly opposed a transition of the Pediatric Committee to an expert council as proposed in the concept document. Members felt the Committee serves a critical role in discussing, reviewing, and critiquing the policy language that can potentially negatively impact a vulnerable pediatric population. This is a fiduciary responsibility of the Committee due to the unique policy challenges of pediatrics related to ethics, equity, and life span. Members also commented the pediatric perspective is not well represented on organ specific committees and within OPTN Regions. The concept document would reduce this representation, and ask organ specific committees to capture and understand the unique challenges faced by pediatric transplant patients. There was also substantial concern that adult-dominated organ committees will not be receptive to projects that are suggested by a pediatric expert council. With this in mind, the transition from to an expert council would potentially reduce and dilute the voice of pediatric community.

As an alternative to the concept document, members felt:

- The Pediatric Committee should remain a standing committee in order to preserve the ability to develop proposals, solicit public comment, provide subject matter expertise to other OPTN committees, and put forth proposals to the OPTN/UNOS Board of Directors,
- The Committee should expand and nominate at-large representatives to the organ specific committees, and
- Hardwire full Pediatric Committee review of new OPTN policy or bylaw changes to achieve consensus on project goals before consideration by the OPTN/UNOS Policy Oversight Committee.

UNOS staff thanked the Committee for their diligent feedback on the concept document.

#### Next steps:

Committee members were asked to complete an on-line survey for their feedback on the proposal.

UNOS staff will prepare a draft response and share with the Chair and Vice Chair. Once approved, the response will be posted on the OPTN website.

#### **Upcoming Meetings**

- March 21, 2018 4-5 PM Eastern (full committee conference call)
- April 19, 2018 9-3 Central (Chicago, IL)
- May 16, 2018 4-5 PM Eastern (full committee conference call)
- June 20, 2018 4-5 PM Eastern (full committee conference call)

## Attendance

- **Committee Members**
  - William Mahle, M.D. – Chair
  - George Mazariegos, M.D. – Vice Chair
  - Khashayar Vakili, M.D. – Region 1
  - Rachel (Ryan) White, RN, B.S.N., CCTC – Region 2
  - Stephen Gray, M.D. – Region 3
  - Tamir Miloh, M.D. – Region 4
  - Amira Al-Uzri, M.D. – Region 6
  - Andrew Savage, M.D. – Region 11
  - Sharon Bartosh, M.D. – At-large
  - Evelyn Hsu, M.D. – At-large
  - Melissa McQueen – At-large
  - Melissa Nugent, RN, B.S.N., CCRC, CCTC – At-large
  - John Renz, M.D. – At-large
- **HRSA Representatives**
  - Monica Lin
- **SRTR Staff**
  - Katherine Audette
  - Jodi Smith, M.D.
- **OPTN/UNOS Staff**
  - Christopher L. Wholley, M.S.A.
  - James Alcorn, J.D.
  - Amanda Robinson
  - Casey Humphries
  - Kimberli Combs
- **Other Attendees**
  - Kimberly Harbur – Visiting Board member