

**OPTN/UNOS Living Donor Committee
Meeting Minutes
March 14, 2018
Teleconference**

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Introduction

The Living Donor Committee met via teleconference on March 14, 2018, to discuss the following agenda items:

1. Review Public Comment Proposal Presentation: OPTN Strategic Plan
2. Projects Update
3. Discussion: "Maintenance Dialysis" references in OPTN Policy 18

1. Review Public Comment Proposal Presentation: OPTN Strategic Plan

The liaison to the Board of Directors, presented the proposed 2018-2021 OPTN/UNOS Strategic Plan. The plan began with a strategic planning session with the committee chairs and board members at the June 2017 board meeting. The feedback was then taken to an internal strategic planning group to integrate internal department goals into the ideas that were brought forward at the planning session.

UNOS has been continually reviewing its processes and work for continuous improvement by going through the Baldrige framework. Part of that process has been determining UNOS's strengths, which include match, data, and quality improvement.

The goal in developing the 2018-2021 Strategic Plan was to create a narrative that reflects the three core strengths, and the three-year plan is structured differently from the last one. Previously, there were two separate plans, one for the corporate side, UNOS, and one for the OPTN. This time there is one overarching plan that has shared high-level goals. There's also a description of the core activities and new initiatives, along with key metrics, which is a key enhancement from the previous strategic goal. Metrics were determined under each initiative that would help them successfully meet goals and objectives. It's also something that OPTN/UNOS could be held accountable to by the community.

The mission statement, vision statement and values from the Strategic Plan were shared and feedback was requested. The mission is to advance organ availability and transplantation by uniting and supporting our communities for the benefit of patients through education, technology, and policy development. The vision therein is to promote long, healthy, and productive lives for people with organ failure by promoting maximized organ supply, effective and safe care, and equitable organ allocation and access to transplantation. UNOS's five core values are stewardship, unity, trust, excellence, and accountability.

The Board liaison shared goals and resource allocation benchmarks for the current Strategic Plan. The benchmarks are used as a measure of how to distribute internal resources for moving each of the strategic goals. They assist in determining how to focus efforts in policy development, and alignment with benchmarks is re-assessed by the executive committee at every board meeting. The Board was given the opportunity to weigh in on five goals and the top initiatives under them in order to determine new benchmarks. The fifth goal was changed to "promote efficiency in donation and transplant," because the title of the goal wasn't really reflective of the initiatives that were underneath it. The two top goals remain the same along

with their respective resource allocations. Support was then evenly distributed for the final three goals at 10% each. The final three goals were reordered. The efficiency goal was moved to the third position instead of the fifth position.

Increasing the Number of Transplants

In the initiative for increasing the number of transplants, the goal is to have more dynamic donor/recipient matching, increase the number of transplants arranged through kidney-paired donation, expand use of collaborative improvement methodologies/models, examine monitoring approaches for transplant programs/OPOs for increased collaboration and performance improvement, promote knowledge of effective donation/procurement practices, and improve ability to perform analysis of refusals.

Promoting Equity

Promoting equity includes improving the equity and opportunities for multi-organ and single-organ candidates, decreasing geographic disparity, and increasing diversity on the board and committees to ensure that a variety of perspectives are involved in the policy development process. It also includes increasing the opportunity for volunteer engagement and the awareness of volunteer opportunities in the community, improving member and public engagement in policy development, developing equity benchmarks for each organ, and collecting additional data on vulnerable populations.

Promoting Efficiency

Under the initiative of promoting efficiency, the goals include modularizing and simplifying UNet architecture to expedite system changes and improve quality, achieving continuous levels of UNet accessibility, improving efficiency in the policy development and implementation process, improving volunteer workforce satisfaction and engagement, and seamless data exchange between members and UNet.

Promoting Safety

Under promoting safety, the goal is to improve accuracy in HLAA reporting, decrease the number of safety incidents that are related to logistics and transport, increase the perception of UNOS and the MPSC as focused on process improvement, enhance knowledge-sharing about safety events, near misses, and effective practices, and enhance system capability for reporting elements of data related to safety.

Improve Outcomes

Finally, the initiative to improve outcomes includes improving longevity of organ transplants, evaluating effective methods for assessing living donor outcomes, enhancing transplant program tools and education in selection and follow up of living donors, expanding use of collaborative improvement models to promote effective donor management practices impacting transplant outcomes, and developing transplant program tools to calculate survival benefit.

Feedback was requested with the following questions:

1. What is your opinion of the Strategic Plan overall?
2. Do you think the OPTN strategic plan contains the right measures to assess progress on the strategic goals?

Questions/Discussion

Public comment will end March 23rd.

In the vision statement there was focus on improving the lives for persons with organ failure, and there was a suggestion that it include a statement about protecting and ensuring the health

of living donors as well. With regard to increasing the number of transplants, there could perhaps be a statement related to removing barriers to living donation and other things that UNOS can do regarding education and improving inefficiency.

One of the objectives was to improve the metric of living donors, or measuring the outcomes of living donors. A question was asked as to what the Board had in mind when considering that enhanced proposal. The Board liaison responded that they are in the process of determining how they measure each of the metrics internally. They are working on developing benchmark committees for further discussion after public comment to fine-tune the metrics for the community.

The Committee Vice Chair commented that the Strategic Plan has significant impact upon their committee work because it provides the foundation whereby any project that is put forward by a committee is gauged in terms of its relevance to the overall goals of UNOS and the OPTN. He highlighted the importance of living donors having an independent voice with regards to policy development. While promoting transplants in patients with organ failure is a primary goal, one shouldn't lose sight of the responsibility to living donors as an independent population. He also encouraged everyone to read through the proposal on the website. He would like for them to craft a brief public comment, but there would be a relatively short amount time to do that.

A committee member asked for clarification on the first initiative, pursue policies and system tools for more dynamic donor recipient matching. Work is being done on enhancements to the system to find better ways to match the gifts that are given with people who are going to accept the organ. If filters could be expanded, there would be ability to get a better organ to a recipient quicker, and the organs that don't match the filters could be moved on to somebody else who would accept them.

A question was raised regarding whether the living donor collective would be included, and OPTN/UNOS does typically collaborate with the SRTR to a degree. The Committee has been receiving regular updates from SRTR on the living donor collective and will receive another one at the April meeting. The SRTR liaison commented that follow-up data that is being collected during the pilot phase of the project is a little bit different than what OPTN requires. Once the pilot has been rolled out a little bit further, they will be looking at ways to streamline.

Action Step

The committee liaison will draft a Committee public comment, and it will then be passed through leadership and members for approval.

2. Projects Update

The committee Vice Chair provided a project update on the social media project and the possibility of a donor self-assessment screening tool. Those projects will not go forward to the Policy Oversight Committee (POC) at the moment. Part of it is due to the sorting out of resource allocation, and the other part is UNOS is developing its understanding of exactly what the goals of the projects are long-term.

As initially presented, the social media projects have two components, a patient resource on how to wisely utilize social media and a resource document for transplant professionals on how to address social media issues with their patients and potentially how to utilize social media as a center. The resource document changes the project from a patient education process to a more formal project that requires POC approval. The patient education piece can definitely move forward.

The Vice Chair reminded the participants to take any ideas they have that might be of interest to the committee to them, even if it is rudimentary.

3. Discussion: "Maintenance Dialysis" references in OPTN Policy 18

Some questions have come in from members with regard to clarifying references to "maintenance" or "chronic dialysis" in living donors. It is referenced in at least two places in Policy 18. A donor having dialysis is a reportable event, and according to staff the question of what that means has come up a number of times over the years.

The question at hand is the older references to the term "maintenance dialysis" as a required follow-up issue and what defines maintenance dialysis. A question was raised as to definitions in dialysis literature about what chronic dialysis is, and CMS has a definition. It's 90 days. There was a suggestion that people who have acute dialysis may need to stay as a reportable event because if the patient has been dialyzed to the point of acute kidney injury, it results in a chronic kidney disease state down the road. That carries long-term cardiovascular implications. They could go with maintenance and not consider acute kidney injury as a problem. Both maintenance and chronic dialysis are important. Any dialysis should be documented, and there could be a separate category for maintenance. A committee member suggested they should capture AKI as an outcome, but he suggested just eliminating the word "maintenance" and have dialysis stand on its own capturing all types of reasons. There was concern whether they were trying to clarify and adhere to what the initial intent was or make a change. What people are reporting is what they consider an organ failure event. It was suggested that the committee member's suggestion would be a change because the original intent was end stage renal disease. It would likely be more of a clarification. It was also suggested that taking out "maintenance" would cause them to lose some specificity in the reporting and discrimination between acute injury and end-stage disease. If maintenance dialysis is going to be 90 days, that should be included.

It was also suggested "transient kidney complications" or "transient renal insufficiency" and instead of maintenance dialysis, perhaps "development of end-stage renal disease" requiring maintenance dialysis. That being said, it was suggested that transient renal insufficiency would not be appropriate to put in because everyone experiences it to some degree.

The committee liaison will check to see what the process would be depending on what they wanted to change and how they wanted to change it. The issue will be revisited at the in-person meeting.

Upcoming Meetings

- April 11, 2018 Conference Call
- April 23, 2018 UNOS (Richmond, VA)