OPTN/UNOS Policy Oversight Committee Meeting Minutes April 13, 2018 Conference Call

Chair, Ms. Jennifer Milton Vice Chair, Dr. Elizabeth Pomfret

Introduction

The Policy Oversight Committee met via teleconference on 04/13/2018 to discuss the following agenda items:

- 1. Welcome and Attendance (Ms. Jennifer Milton, POC Chair)
- 2. New Project Review 1 project from Membership and Professional Standards Committee (MPSC) Hospital-Based OPO Voting Rights (Jennifer)
- 3. Minority Affairs Committee (MAC) Checklist (MAC Vice Chair)

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

1. Welcome and Attendance (Ms. Jennifer Milton, POC Chair)

Ms. Jennifer Milton welcomed the meeting attendees and opened the meeting.

2. New Project Review 1 project from Membership and Professional Standards Committee (MPSC) - Hospital-Based OPO Voting Rights (Jennifer)

Summary of discussion:

Someone commented that they often see one person voting for three entities at a regional meeting, which is hard to deal with. Every entity that should be represented needs the representation. If they choose to give the vote to someone else because they can't be there, that is their choice. The OPO is responsible, however, to more than a single hospital in some cases, and they do need to have that in mind.

There was support voiced for splitting the votes up.

With regard to Comment Number 6 and the timeline being perhaps too ambitious, the anticipation was that it would be a minimal impact project.

The MPSC liaison addressed a few questions. They don't anticipate that there would be any significant fiscal impact, but they will continue to analyze it more formally if the project is approved. They also anticipate that it could be done on a pretty quick timeline, which of course could change as they get into the project. They are not going to rush through it, but do hope to get it done as quickly as possible while they have the resources.

The Chair pointed out that there were a lot of comments but no collaborators or stakeholders were identified. Involving the OPO Committee would be key. A committee member suggested that the hospital-based histo labs could potentially use it as a precedent in the future, and she indicated that she didn't know if it would be a good thing or a bad thing. There is potential for it to snowball, and the POC Vice Chair asked what MPSC's thoughts were about the fact that with the OPO thing it would be 6 or 7 but with HLA it would be 97 labs? The majority of the HLA labs represent their own transplant centers, but there are a few that serve smaller transplant centers. It was pointed out that they don't really have any concrete information in terms of how they may have been disadvantaged. It was underscored that the project is the MPSC asking if they can

have the resources to do more work. It's not MPSC asking the Committee to send it out for public comment at this point.

Vote:

Do you recommend the MPSC project "Hospital-based OPO Voting Rights" proceed to ExCom for approval?

64% yes; 29% no; 7% abstained

There was one phone vote that was a yes.

3. Minority Affairs Committee (MAC) Checklist (MAC Vice Chair)

The MAC Vice Chair presented the Minority Affairs Committee current project, which is a checklist for OPTN committee projects. She provided an overview of the problem that started the project, which was that it is often late in the process when the impact to minority and vulnerable populations is examined. The purpose of the checklist is to ensure that committees assess the impact on vulnerable populations earlier in the process and more consistently. The components of the checklist are populations considered by the OPTN and geographic disparities. The toolkit list will bring conformity to when and how committees review the impact a proposal will have on populations. Committees will be asked to use the checklist soon after POC approval of a project, and it is a guide for committees. They should, however, expect MAC to ask questions based on the checklist during public comment or whenever MAC reviews the proposals. There is no requirement for Committees to submit data to MAC, but they are encouraged to share their research or the summaries of their discussions. Sample slides that could be included were shown.

The MAC Vice Chair then showed the draft timeline for the project. It was kicked off in September of 2017, and a full draft was shared at the in-person meeting in March of 2018. It is currently being shared with other Committees that have a particular interest. Early summer 2018, the Committee would like to pilot the checklist on new committee projects.

Questions to ask in reviewing the checklist include: Are the appropriate populations included? Is it logically organized? Would Committees find using the tool beneficial or challenging?

Summary of discussion:

A committee member commented that they may need to add a third bullet where there could be a positive impact, negative impact, or no impact.

A question was raised as to whether the checklist would be a required element of a project form being submitted, and if the POC could ask the proposing Committee whether they had done their due diligence by going through the vulnerable population checklist. It is not meant to be a requirement, it is meant to be a tool. Use of it is, however, encouraged at every implementation of a policy. A member added that they are modifying the project form to make it clear whether there is an impact on minority or vulnerable populations.

The point was raised that Committees sometimes have an agenda, and there should be a process in place to keep looking at it throughout as data become available. In addition, they may need to incorporate some other outside input to encourage other perspectives. Hopefully, it will cause a committee to pause to consider the potential impact on different groups. The Patient Affairs Committee has been spending a great deal of time talking about how to get to patients who have been underserved in the past. One of those groups is non-English-speaking folks, and it impacts a large number of recipients and families. Language disparities aren't currently specifically included, but they will consider whether that should be included.

4. General Feedback

The POC Vice Chair commented that one of the primary issues right now with UNOS and the transplant community is there has been a significant loss of trust.

There was a comment that the POC often doesn't know the context of proposals. They seem to kind of make sense, and most of them get approved by about a 90% vote. It seems like they are really just rubber-stamping stuff without knowing the context. Holding education symposia regarding UNOS at the professional meetings was an idea that was raised and to do so multiple times throughout the year. It is also helpful for Vice Chairs have a specific call when there is a proposal or something that involves significant changes.

Another issue that was raised was considering the lifecycle of a project. There was a comment that the amount of consensus that is needed could be slowing down a project.

A member commented that he is not clear exactly what the designation of a stakeholder results in as far as a dedicated, committed engagement of that stakeholder in policy development. It would be useful to formalize what it means to be identified as a stakeholder and what that stakeholder's responsibility is going forward.

Upcoming Meeting

May 7-8, 2018, Spring in-person meeting, Richmond, VA