

Meeting Summary

OPTN Policy Oversight Committee

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June 25, 2020

Conference Call

Alexandra Glazier, JD, Chair Nicole Turgeon, MD, Vice Chair

Introduction

The Policy Oversight Committee (POC) met via Citrix GoTo teleconference on 06/25/2020 to discuss the following agenda items:

- 1. Committee Transition
- 2. Data Advisory Committee Late Turndown Project Update
- 3. Case Study: Kidney Medical Urgency

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

1. Committee Transition

The Chair thanked the outgoing members of the POC and welcomed the incoming POC members.

2. Data Advisory Committee Late Turndown Project Update

The Vice Chair (VC) of the Data Advisory Committee (DAC) presented an update on the committee's refusal codes and late turndown project. The purpose of the refusal codes project is to improve OPTN data quality by amending the list of refusal codes. This will help the OPTN to understand why organs are refused in order to improve the efficiency of organ allocation. The POC had asked the DAC to look at improving data collection on late organ offer turndown practices, and the DAC plans to incorporate this effort into the refusal codes project. The DAC may seek participation and input from other committees.

Summary of discussion:

The Chair asked about the timeline of the project. The DAC VC and UNOS staff shared that a lot of foundational work has been done already and the plan is to move forward with this project expeditiously. The Chair said that there is interest from the OPTN Board and the transplant community on this project, and asked to see a project timeline by the next POC call. UNOS staff noted that the project will come forward for POC approval at the next meeting, along with the project timeline.

A member expressed support for this project and said that the refusal code issue needs to be aligned with performance improvement. Community members are concerned that they will be penalized for using accurate refusal codes. The member said this needs to be a joint effort with the Membership and Professional Standards Committee (MPSC) to create an environment where people feel comfortable entering the correct refusal codes. The Chair agreed that the accuracy of this data collection is important to improve performance, noting that this is a foundational step for many other work efforts to increase efficiency and increase transplants, and should not be viewed as a compliance tool.

Another member asked if there has been any consideration of whether this data should be blinded. The DAC VC said they have not discussed that but asked for feedback from the POC. The Chair said the data should not be blinded because organ procurement organizations (OPOs) have worked hard to increase

transparency. A member noted that it might be useful to assess patterns that emerge based on identifiers. The member said they recently had a long conversation with an OPO and their transplant hospital about what refusal code to use in one case, and other transplant programs replicated that decision. The DAC VC said she would bring this feedback to the DAC to discuss further. A member noted that transplant programs will ask why organs were refused previously so it is better to have that information readily available. The UNOS CEO noted that the UNOS Research Department is working on a project to understand how prior decisions of transplant programs impact future decisions of other transplant programs, in order to evaluate how much of that decision-making is based on groupthink instead of the clinical considerations. The UNOS CEO said he will make sure that UNOS research team members meet with the DAC during these conversations.

Next steps:

The DAC will share a timeline for this project during the next POC call on July 29th when the project is presented for POC approval. The DAC VC will share the POC's feedback with the DAC for consideration. UNOS Research staff will participate in upcoming DAC conversations regarding this project.

3. Case Study: Kidney Medical Urgency

The VC of the Kidney Committee and UNOS staff presented a case study to show how to manage a project that has received criticism from the community, and how to navigate those challenges. The case study covered three main themes: (1) distribution of roles, (2) defining vague terms, and (3) Board support and outreach efforts.

Summary of discussion:

The Chair said one of the uniform challenges is ensuring that community members and stakeholders feel heard without promising that the result will be what they are asking for. UNOS staff shared that when conducting outreach, closing the loop with people is important. Even if the end result is not what the stakeholder wanted, it seems to help to share that the committee discussed the issue further, and to share the data and information the committee evaluated to come to their conclusion.

The Chair asked how the Kidney Committee responded when a board member asked for an amendment, and how the Committee moved forward to the resolution. UNOS staff explained that the Committee spent a lot of time reviewing all of the feedback from public comment and from the Board to ensure they had a strong foundation for their decisions prior to the introduction of any amendments. The Committee also held meetings on short notice to consider potential amendments and other concerns from Board members. Committee leadership also made lots of phone calls to board members to help them understand the work that had gone into the proposal and why certain decisions were made.

Upcoming Meetings

- July 29, 2020
- August 12, 2020