

**OPTN Patient Affairs Committee  
Meeting Summary  
June 20, 2023  
Conference Call**

**Garrett Erdle, MBA, Chair  
Molly McCarthy, Vice Chair**

## **Introduction**

The Patient Affairs Committee (Committee) met via WebEx teleconference on 06/20/2023 to discuss the following agenda items:

1. Welcome and announcements
2. Moment of silence: remembering Julie Ice
3. Vote: Patient Information Letter
4. Recognition of outgoing and incoming members
5. OPTN Membership and Professional Standards Committee (MPSC) Organ Procurement Organization (OPO) Performance Enhancement Monitoring Project

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

### **1. Welcome and announcements**

Staff provided an update on the inactive status project. A Workgroup is being set up to refine research questions and any further data requests, and a call for volunteers to participate was made.

### **2. Moment of silence: remembering Julie Ice**

The Committee held a moment of silence to honor the life of former Committee member Julie Ice.

### **3. Vote: Patient Information Letter**

The Committee discussed and voted on the updated patient information letter.

#### Summary of discussion:

**Decision 1:** The Committee voted unanimously to approve the patient information letter with the minor changes suggested by members.

**Decision 1:** The Committee voted unanimously to approve the patient information letter with the minor changes suggested by members.

A few members had suggested minor grammatical and language changes to the information letter, which the Committee reviewed. A member stated that it is important to consider that patients may have questions about organ procurement organizations, so this was added to the letter. A member asked what specifically the patient services team is able to provide. Staff answered that the team can help answer questions about their transplant journey, refer them to other departments or organizations for a more specific answer, and provide a space to listen to concerns. Staff noted that one thing the Committee can consider developing is a resource specific to donor families, since this letter is not intended for donors.

The Vice-Chair stated that the Committee should not let perfection be the enemy of progress and asked for members' positions on either re-working the letter or putting it into practice. A member stated that it makes sense to move the letter forward.

The Committee held a vote, and all members were in favor of moving the letter forward and sending it to the OPTN Executive Committee.

Next steps:

The letter will go to the OPTN Executive Committee for approval.

#### **4. Recognition of outgoing and incoming members**

Outgoing members were recognized and had an opportunity to share advice and words of wisdom to the incoming members and feedback about their terms.

Summary of discussion:

An outgoing member suggested having a more extensive training and orientation course to better help new members understand how the OPTN works and the role of the Patient Affairs Committee (PAC). Another outgoing member suggested leveraging the patient experiences on PAC to serve on cross-committee workgroups to improve processes such as evaluation to listing and listing to transplant.

#### **5. OPTN Membership and Professional Standards Committee (MPSC) Organ Procurement Organization (OPO) Performance Enhancement Monitoring Project**

A member of the MPSC shared information about their OPO performance enhancement monitoring report project. The Committee then discussed the presentation and asked questions.

Presentation summary:

The MPSC is the OPTN committee charged with ensuring OPTN members comply with OPTN obligations, including Policies and Bylaws. There are 38 voting members: 11 elected regional reps and 27 at large members. The non-voting members include Health Resources and Services Administration (HRSA) representatives and OPTN Board of Directors Vice President.

The MPSC is representative of the transplant community and is comprised of OPO, histocompatibility laboratory, and transplant program representation, as well as surgeons, physicians, administrators, and patient and/or donor family representatives.

The responsibilities of the MPSC include:

- Monitoring member compliance with OPTN obligations, including applicable provisions of the OPTN Final Rule
- Supporting member improvement through feedback and recommendations
- Identifying opportunities for education and systematic improvements
- Developing bylaw and policies related to membership criteria and MPSC charge that align with and support the OPTN mission

The MPSC reviews OPOs in a variety of ways, including site surveying, investigations of complaints, review of allocations, and performance reviews, which are the focus of today's presentation. The MPSC is evaluating potential changes to the OPTN OPO performance monitoring. So far, the MPSC has discussed:

- Defined the goal as comprehensive "monitoring enhancements" not simply new metrics

- Received updates from the Scientific Registry of Transplant Recipients (SRTR) on current state and suggestions to consider
- Learned more about Centers for Medicare and Medicaid Services (CMS) OPO performance measures
- Considering combining project to revise allocation deviation review process
- Defining scope of the project and metrics to evaluate the success of the project

The desired OPO performance metrics will be metrics that:

- measure OPO activities that are clearly within OPTN authority
- the OPO can impact
- the OPO is responsible for
- have a clearly desired outcome
- are risk adjusted
- incentivizes behavior that will increase transplantation
- do not require collection of new data or development of a new metrics

However, new data collection is clearly necessary. The MPSC does not currently have access to in-hospital death data to calculate donor potential and evaluate OPO performance. Also, inconsistency in existing data definitions makes it hard to select a metric and thresholds for performance monitoring purposes are best established after the metrics that will be evaluated are defined and selected. The MPSC collaborated with CMS in the development of this project. CMS is looking at donation rate (the number of donors as a percentage of the donor potential) and transplantation rate (number of organs transplanted from donors in the donation service area (DSA) as a percentage of the donor potential). The donor potential is defined as total inpatient deaths in the DSA among patients 75 years of age or younger with a primary cause of death consistent with organ donation. A donor is defined as having one organ transplanted or one pancreas recovered for research. CMS uses the data collected two years prior to evaluate OPO performance.

The MPSC has been having the following discussions related to this project:

- What differentiates an OPO that performs well from an OPO that does not?
- What parts of the donation process are the responsibility of OPOs, can OPOs impact, and/or have wide variation across OPOs?
- MPSC feels OPTN needs separate metrics from CMS but acknowledges metrics should be complimentary
- The Committee acknowledges the importance of improved offer acceptance rates by transplant programs to increase the CMS transplantation rate
- Increased data collection is required to proactively monitor and understand member behavior and influence change
- OPOs collect a lot of data that can be shared with the OPTN and analyzed if standardized – consider requiring OPOs to report some of this data to the OPTN

Next steps for the project include:

- Update and discussions with OPTN Board of Directors
- Forming a workgroup with representatives from multiple OPTN Committees and will begin in July
- Engaging stakeholders and the public via presentations at regional meetings and to other OPTN Committees, calls with representatives of associations and societies, and webinars for the general public

### Summary of discussion:

The Chair thanked the presenter for their work in their own OPO and shared how important monitoring OPO performance is from a patient perspective. A member volunteered to serve on the workgroup. A member asked about the process of making changes to CMS data, explaining that changes to data are always necessary. A member answered that CMS goes through a development process including a public comment period, and that the entire process takes about one to two years.

A member asked about out of sequence allocations and the impact on transplant centers affiliated with OPOs. The member asserted that OPOs should function independently from transplant centers to ensure fairness, and suggested adding this as an evaluation metric. The presenter answered that the MPSC is evaluating the increase in out of sequence allocation and is trying to determine causes and explained personal experience with out of sequence allocation. The MPSC is also looking in to how to promote growth of transplant centers so that they can accept more offers and transplant more people. A member explained that it seemed that the OPO is also inadvertently being evaluated on the behavior and performance of the programs to which it is making offers to. This member also expressed concern about including pancreata recovered for research in the metrics. The presenter explained that this is a good point, and that the MPSC is considering some way of taking into account organs that were recovered but ultimately not transplanted, as well as donors for whom no transplantable organs were recovered from.

The Vice-Chair asked if the presenter had any ideas for what the Committee should be thinking about in considering this data that may not have occurred to members. The presenter answered that this is a complex topic, but explained that offering donation to every family (where circumstances allow) is a huge consideration.

A member explained that the most recent CMS data showed a concerning future where there may be scenarios where OPOs are in competition with one another, but this is not adequately prepared for, especially considering that some OPOs will lose certification with these new metrics. The presenter agreed with this concern, stating that there is a lot of room for improvement and consolidation, but there should be a plan for it.

The Chair explained that PAC has been discussing how to involve the patient in organ offer acceptance, such as for accepting different kidney donor profile index (KDPI), and asked how this might impact organ acceptance. The presenter answered that although it might slow organ offers and acceptance, in the long run, it may prove extremely beneficial because candidates often do not know the number of offers the program actually receives for them.

### Next steps:

The MPSC will update the Committee on this project at regular intervals.

### **Upcoming Meeting**

- July 18, 2023

## Attendance

- **Committee Members**
  - Garrett Erdle
  - Molly McCarthy
  - Anita Patel
  - Eric Tanis
  - Justin Wilkerson
  - Kenney Laferriere
  - Kristen Ramsay
  - Lorrinda Gray-Davis
  - Sejal Patel
  - Steve Weitzen
  - Julie Spear
  - Calvin Henry
  - Tonya Gomez
  - Dana Hong
- **HRSA Representatives**
  - Marilyn Levi
  - Jim Bowman
  - Mesmin Germain
- **SRTR Staff**
  - Katie Audette
- **UNOS Staff**
  - Alex Carmack
  - Bridgette Huff
  - Sharon Shepherd
  - Roger Brown
  - Sally Aungier
  - Desiree Tenenbaum
  - Kaitlin Swanner
  - Kieran McMahon
  - Lauren Mauk
  - Laura Schmitt
  - Sara Rose Wells
- **Other Attendees**
  - Kyle Herber